Patterns in sense making interactions

How people make sense of kidney failure in online renal discussion groups

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Certificate of Authorship / Originality

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the text.

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Abstract

Sense making matters because people make sense to understand situations and decide what to do next. Researchers study sense making to understand why space programs fail, why employees resist change, how doctors make diagnoses and how patients cope with experiences and care for themselves. Yet in Library and Information Studies (LIS), sense making research mainly restricts itself to how people interact with information systems. Sense making is rarely defined in any field, but is generally described as a cognitive activity, ignoring potential emotional or experiential aspects of sense making. My aim with this research is to define sense making and extend LIS conceptions of sense making to include *whatever might be involved,* whether cognitive or not and looking beyond the involvement of information systems.

I examined people making sense of kidney failure, a likely situation in which to perceive physicality and emotions in sense making. This thesis has several methodological components including influences by two major sense making theorists, Brenda Dervin and Karl Weick. Based on their insight, I conceive sense making as social, ongoing, enactive processes. Influenced by ethnomethodological descriptions of how meanings emerge in interactions, I participated in online renal support groups, following interactions *en vivo*. Influenced by practice theory, I view activities as evidence of sense making, and examine discussion posts as written sense making. Therefore I describe external performances of sense making, not internal psychological understandings. The result is a longitudinal, social constructionist investigation of text-based sense making interactions, using content and thematic analyses to attend to collaborative sequences.

I found that people collaborated online by developing and breaking patterns of ideas and emotional tones, requiring repetition and time. They connected discussions to their own lives, interrelating feelings, ideas and experiences. Also, they created customized, personalised understandings, improvising shifting connections which allowed them to respond to complexity.

These findings confirm conceptions both of sense making as located in time, and as embodied, emotional and lived, not only a mental activity. They also contribute to conceptions of knowing as flexible and transient rather than stable and structured. These are shifts from common LIS conceptions of sense making and knowledge. This thesis describes the important practical implications for clinicians and information professionals that follow from these significant conceptual shifts, demonstrating the practical relevance of having looked beyond information-related data to extend LIS conceptions of sense making.

Glossary

Dialysis : Treatment for renal failure in which the blood is cleaned and fluid removed by mechanical means

Dialysor : Term used by some renal patients to replace the term ‘patient’ (Peckham 2008): a person who receives dialysis as a treatment to replace lost kidney function.

ESRD : End Stage Renal Disease, a classification applied to patients who have less than 15% kidney function.

Fistula : an access for haemodialysis, in which an enlarged vein is created by surgically joining a vein and an artery, often in the forearm.

Haemodialysis : A treatment for kidney failure in which the patient’s blood is pumped through special tubing to a haemodialysis machine. The machine acts like a kidney, filtering waste products from the blood before returning it to the patient (Kidney Health Australia 2011b).

HD : See *haemodialysis*

LIS : Library and Information Studies

Lurker : Someone who reads online discussions without writing posts.

Nephrology : The study of renal medicine

Nephrologist : A specialist in renal medicine

PD : See *peritoneal dialysis*

Peritoneal dialysis : A treatment for kidney failure where dialysis fluid is moved in and out of the peritoneal cavity to remove wastes and fluid from the blood (Kidney Health Australia 2011b).

Renal : Relating to the kidneys

Renal replacement therapies : Treatments for kidney failure, either transplant or dialysis

Definition of key terms used in this analysis

Consenses : I describe textual, not cognitive consenses. In so doing, I do not argue that all contributors thought alike or agreed, but that text in a thread contained themes that were repeated and reused in recognisably similar ways. I usually talk about consenses in the plural because a single consensus in a thread was rare.

Repetition : I use the term *repetition* not in the sense of *perfectly repeated experiences*, but as shorthand for reiteration, reuse of themes or ideas, the ways in which people loosely clump similar things together and the familiarity which results from recognising such loosely similar things over and over again.

Sense : Meaning, that is, connections between ideas and/or feelings. Local or improvised knowings manifesting as understandings, theories or explanations.

I sometimes interchangeably use the terms sense, understandings, theories, ‘sense-mades’ and explanations.

Sense making : Making transiently coherent connections; improvising networks of meaningful elements; micro-processes of coherent meaning making with reference to situated reality, including orienting oneself for action.

Tones : The emotions that a reader might imagine the contributor of a post to have been expressing through their text. In this analysis, the tones I describe are manifestations of emotions in messages as they appeared to me as a member-insider. I do not presume to know what emotions were actually felt by contributors.

Chapter One: Introduction

My mother passed away suddenly in 2004 on a working holiday in Northern China. The translation we received of her death certificate said she died of "a stuffing of the heart". My father later worked out this meant that a hole had suddenly opened on her aorta, killing her within minutes, an explanation which did little to help me understand how such a thing could be.

Two years later, I met the Sense-Making theorist Brenda Dervin when she came to Sydney for a conference in 2006. My memories of that time will be a little disjointed in this account: I was sent to walk with her from her hotel to the conference venue at my university, which was mainly a matter of crossing a busy intersection in pouring rain. She was wearing black. In a conversation later that day, I commented that there were some things I couldn't make sense of and told her about my mother. I said to Dervin that my mother's unexpected death was a gap that could not be filled with information. Our conversation ranged around different topics and at one point she gave me some good advice – not to propose theory until I had done a hundred hours of interviewing. I acknowledge to you that these memories don't create a sweeping narrative. They are like a cluster of elements.

Most days since then, when I cross that intersection those elements come to me, one connected to another. As I reach the corner and look at her hotel, I remember Dervin, the huge puddles on the road, the traffic, her black clothes and the unexpected loss of my mother. I gave a talk about sense making at the conference. I haven't seen Dervin since, but my interest in sense making remained and is at the centre of this thesis. Some of my findings are about that gap I couldn't cross with information – and about a conception of sense making that is not about resolving gaps, but is instead about elements that can become connected – like Dervin avoiding puddles at an intersection, a hundred hours of interviewing, black outfits, traffic and unexplained deaths.

My PhD began with that problem of filling gaps with information – acknowledging that Dervin is not necessarily to blame for that idea, as I will describe presently. I ended a fair way from that beginning, incorporating theory from LIS and influences from other disciplines. In this introduction, I provide an overview of the thesis, first establishing my methodological perspectives. I then justify the location of the study, by explaining what kidney failure is and why I chose to study sense making online. Last, I briefly outline the structure of the chapters to come, providing a few words about each one and summarising my findings.

1.1 My approach to the study of sense making

I wanted to investigate whatever it is that people do to make sense, whether information-related or not. So when I state my research question:

> *How do people make sense of kidney failure in online renal discussion groups?*

…the focus of the investigation is sense making, not kidney failure. In a similar vein, this is not phenomenology; I am not going to tell you much about people's experiences or their understanding of situations. It is closer to ethnomethodology, which literally means the *study of peoples' methods* for producing recognizable social orders (Rawls 2002, p. 6).

Ethnomethodological studies examine "the range of procedures and considerations by means of which the ordinary members of society make sense of, find their way about in, and act on the circumstances in which they find themselves" (Heritage 1984). The focus is social: ethnomethodologists explore how people make their activities *visibly rational*, how people make sense of interactions in real time, in publicly accountable ways (Garfinkel [1967] 1984), particularly by focussing on how people repair interactions to keep themselves accountable and intelligible. I am going to examine how understandings of kidney failure were developed in publicly accountable ways in a particular form of writing which has many co-authors and which takes place online over time. This is about collective, not individual sense making, and it is about how sense making manifests publicly, not how it develops somewhere 'inside' individuals. In all these ways, my research is guided by Garfinkel and ethnomethodology. But I do not stop at studying accountability in these online interactions. I use textual analyses to understand sense making, rather than producing an ethnography of interactional repairs. So this research is not ethnomethodology either.

My research question was deliberately broad to allow for unexpected findings. Instead of focussing my efforts by creating a more focussed question or a hypothesis for testing, I specified what I meant by each element of my topic: *how*, *people*, *making sense* and the context of *online discussion groups*.

How

My focus was at the micro-level of people interacting. My goal was to identify what I called ‘elements’ or ‘mechanisms’ for making sense – places in interactions where people may have demonstrated an awareness of what was proper or needed for sense making in an interaction and provided it. More specific questions to access the detail of sense making interactions included questions of content:

- *How do contributors describe their situations, experiences and feelings and how do their descriptions change over time?*
- *How do they attempt to help each other?*

..and questions of sequencing:

- *Is there any significance in the timing or sequence of contributions?*

People

As I explained above, this is an examination of social, public interactions. I did not propose to follow the sense making trajectory of individual participants, perhaps to identify characteristics of individuals, such as psychological profiles for sense making. People may make sense in individual or characteristic ways; I set this question aside for later research. My focus was on the give-and-take of messages in a group setting.

Making sense

By *making sense*, I mean *understanding situations* (Starbuck & Milliken 1988; Weick 1995) *and deciding what to do* (Dervin 1999b; Weick 1995). My interest was in social sense making, to explore the social currency of the meanings used by individuals (Olsson 2005a).

The last element of my topic provided the conditions against which appropriate methods could be chosen:

The context: online renal discussion groups

To study social sense making I needed a location where I could observe everyday social constructions of meaning occurring. Online discussion groups provided data from interactions between peers as they dealt with lived experiences. This was a particular kind of textual data: rich, detailed and at times very personal. I discuss what I gained and lost by studying online interactions in Chapter 3.

Dervin described Sense-Making[1] undertaken by a human (with emotions, spirit and dreams as well as mind) "bumbling" through moments situated in space and time (Dervin 1999b). She posited an ongoing, moment-by-moment need for sense making, a metaphorical walk through an unruly reality at each step of which one is faced with "gaps" – for example, gaps in understanding. She theorised the bridging of gaps in flexible ways, pointing out that we must turn attention "away from information as such to the constant design and redesign of the sense by which humans make and unmake their world" (Dervin 1999a, p. 330). Elfreda Chatman, an influential LIS scholar with sociological interests, similarly commented that "one needs to step back from an examination of the seeking process" (Chatman 2001, p. 13). I was guided by the advice of Dervin and Chatman, to look more broadly at whatever contributes to people's sense making, beyond information and cognitive activities.

* * *

I took an ethnomethodological approach to the problem of studying sense making; therefore, my findings are about how people manifest sense making in public interactions online, not psychological explorations of individual sense making profiles. But I was also guided by Dervin's conceptions of sense making as ongoing, bumbling processes involving emotions, body and spirit as well as heart, and I followed both Dervin and Chatman in my aim to find out *what else is going on* in sense making, beyond seeking and using information.

1.2 Kidney failure as a setting for sense making

When I began this project I had known two people who had experienced dialysis. One was my friend James, who died in 2008. The other is my husband, Gregory, whose kidneys failed when he was 19. He may have been sick since

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[1] Dervin always hyphenates and often uses capitals, a convention I use to refer to her writing.

childhood without a diagnosis. Gregory was on peritoneal dialysis for a year, in-centre haemodialysis for another four years, and received a transplant in 1991. He was told most transplants last about six years; that was 21 years ago. His transplant is failing now.

Post-transplant, Gregory finished highschool, went to university and started working in libraries. I met him six years ago when he was 38, when I went to work at the same library; we met shelving. Every evening Gregory would go walking for an hour, up and down hills and I started going along with him. He is a quiet person but on our walks, he talked and he began to tell me about his experiences of hospitals, surgery and dialysis. He has had 12 operations. My friend James didn't talk about his kidney failure much to me. As a person who had never been a patient in hospital I was astonished by Gregory's stories.

When kidney function reaches below 15%, it is classified as end-stage renal disease (ESRD) and requires renal replacement therapy (Kidney Foundation of Canada 2012b; Kidney Health Australia 2012a). At the end of 2009, one in nine Australians over the age of 25 years had signs of chronic kidney disease and over 18,000 Australians were receiving treatment for ESRD (Kidney Health Australia 2010, 2012e). Approximate comparisons with other nations are shown in Table 1.1 below.

Location	Estimated prevalence of ESRD in 2009 (number of cases)	Estimated prevalence of ESRD treatment in 2009 (per million people)
Japan (highest worldwide prevalence)		2,200 per million
USA	871,000 people	1,800 per million
Canada	38,000 people	1,100 per million
Australia	18,000 people	830 per million
Finland	4,167 people	780 per million
UK, Scotland and Ireland		780 per million

Table 1.1: Comparison of prevalence of ESRD in selected countries
Sources: (Canadian Institute for Health Information 2012; Finnish Registry for Kidney Diseases 2010; Kidney Health Australia 2010; National Kidney and Urologic Diseases Information Clearinghouse 2012; OECD 2011).

When the kidneys inadequately filter the blood, toxins build up in the body. The patient may feel lethargic, nauseous, itchy and forgetful. When the kidneys produce insufficient urine, excess fluid gathers in the tissues. The body swells and fluid on the lungs makes breathing difficult, also putting strain on the heart (Kidney Health Australia 2012e; Marcovitch 2010). When overloaded with fluid, people sometimes report trying to sleep sitting up to cope with the weight of fluid on the lungs.

Without adequate regular treatment, a person with ESRD becomes ill within days, and people who withdraw from treatment generally live for another week or two (Renal Resource Centre 2008, p. 10). Kidney failure is treated by kidney transplant or renal dialysis. There are two kinds of dialysis: *haemodialysis* and *peritoneal dialysis*, in which fluid and toxins are removed from the blood by mechanical means. Peritoneal dialysis is a gentler, continuous treatment via a permanent tube in the belly. It is associated with greater independence for some patients as it can be administered at home by the patient, but it does not work well for everyone and it is associated with painful infections (Kidney Health Australia 2011a). Haemodialysis accesses the blood via two large needles in the arm; treatments typically take 3-5 hours, three times a week and are usually provided in a hospital or dialysis clinic. There is usually a wait for kidney transplants, mostly due to lack of donors, so dialysis is usually undertaken for several years; in Canada the median is about 2-5 years until a transplant can be obtained (Kidney Foundation of Canada 2012a); Australians average a four year wait (Kidney Health Australia 2012c).

Side effects of dialysis can include pain, fatigue, cramping, nausea, vomiting and thirst (Lee et al. 2007; Lindsay Waters 2008; O'Sullivan & McCarthy 2009). Psychological symptoms include anger, grief, anxiety, depression and uncertainty (Bellou et al. 2006; Kring & Crane 2009; Polaschek 2005; Wong et al. 2009). Dialysis also has social effects for example, on family and work (Tong et al. 2009; White, Grenyer & Grenyer 1999). Chronic illness involves a biographical redefinition in that one’s future is changed (Bury 1982), and at times patients must also reconstruct their old identity, incorporating symptoms which were previously unknown or ignored. Patients construct their illness using ‘before and after’ stories (Horton-Salway 2001, p. 161; Tuominen 2004). Renal patients also experience stigma and challenges to their identity due to the medical and technological augmentations visible on their bodies – the tube from the belly attached to a bag of fluid (Braun Curtin, Johnson & Schatell 2004; Cruz & de Aranãjo 2008) or enlarged, knotted veins in their arms (Richard & Engebretson 2010). The point here is that kidney failure and dialysis are intense, ongoing physical and emotional experiences (Polaschek 2003; Tong et al. 2009), with symptoms that require patient-specific care (Davies & Engel 2009; El Nahas & El Kossi 2009). As such, chronic kidney failure is a serious ongoing condition requiring ongoing sense making.

In many countries worldwide, the incidence of ESRD is increasing and treatment for ESRD has more than doubled since 1990 in many cases (OECD 2011). Haemodialysis is usually the most common treatment. It costs roughly $60,000 Canadian dollars per patient per year in Canada, $65,000 Australian dollars in Australia and $80,000 US Dollars in the United States (Canadian Institute for Health Information 2012; Kidney Health Australia 2012b; National Kidney and Urologic Diseases Information Clearinghouse 2012). So the cost of treating ESRD is high; but making sense of illness improves compliance which can slow the onset of ESRD (Hallan & Vikse 2008). Financially as well as ethically, it is worthwhile finding ways to support people who have to make sense of kidney failure.

In the Library and Information Studies (LIS) literature, sense making is usually discussed in terms of people seeking information, but, as with my mother's *stuffing of the heart*, information did not seem to be the point of Gregory's stories. I have explained that I was interested in viewing sense making without reducing it to information transactions, so I was looking for situations in which the need to make sense was ongoing and not easily solved with information. I also needed sense making which would stand out: subtle, everyday sense making could easily be lost in the details of everyday life. I needed something that people *would* talk about and maybe *would have to* talk about. Renal failure seemed like that kind of situation and it resonated with me because of the experiences of those two people I care about.

Description of the discussion groups

There are online sites where people can share their illness stories as complete narratives (International Association of Living Organ Donors 2011), renal question-and-answer style websites (Medical Education Institute 2013) and many renal blogs kept by kidney patients (Collette 2013; Stacy 2012). There are also discussion groups or patient experience websites run by corporations or organisations (Health Experience Research Group 2008; Kidney Health Australia 2008; Medical Education Institute 2013). I did not choose any of these kinds of patient-generated online content for my study. Instead, I chose three online support groups which were started by patients or by carers, in which conversations are perceived to be ‘by and for patients’, as interactions there appeared to be the frank exchanges of people who felt themselves among peers. Moderators in each group were volunteers; they were long term members, whose role was not to filter posts, but to maintain etiquette. Discussion could be stopped by ‘locking’ a thread, and members banned but these measures were rare. They also sometimes moved threads from one section to another to maintain the categories of discussions. Posts made to two of the three groups are accessible to anyone, as described below.

I spent almost two years observing and contributing to discussions in three such online renal discussion groups. Making myself known to the groups both as a researcher and as the wife of a kidney transplant recipient, I aimed to develop my understanding of how people in these communities interacted with each other to make sense of their shared concerns. Though I asked no research questions, my status as a researcher remained visible to members via my signature and profile. I discuss the ethical questions relevant to this project in Chapter 3.

There were hundreds of posts a week in these discussion boards and archives going back to 2005. To create a sample of data with which I could describe the groups, I copied all posts made during a week in May 2011 into a database. Table 1.2 (next page) shows the relative contribution of each group during that week. Consent was obtained to include contributions from 147 people who made 1,193 posts of which 787 contained content written by the contributor about renal failure.

Most contributors were renal patients (74%), or the family or friends of patients (18%). Very small percentages comprised health professionals (2%) or other interested parties (2%) such as a dialysis travel destination. People could fall into more than one of these categories, for instance a couple of patient-contributors cared for other family members with kidney failure, and significantly, two of the three health professionals had renal failure, so they were patients as well as clinicians.

Source	Total Membership since inception[2]	During week in May 2011					
		# Contributors	# Threads	# Posts	# Posts about renal failure[3]		
					Total	Reproduced content	Original content
IHateDialysis	6104	120	170	874	671	22 (3%)	649
Kidney Korner	404	17	40	272	97	5(5%)	92
Australian Dialysis Buddies	72	14	11	47	46	0(0%)	46
Total	6580	147	221	1,193	814	27(3%)	787

Table 1.2: Sources of data

The majority of contributors were female (58%) and the (mean) average reported age was 45 years. Many contributors (40%) did not report their age, but judging by those that did, this population may be younger than the average age on dialysis, which is 60 years in Canada (Kidney Foundation of Canada 2012a).[4]

Contributors' locations were often stated in their profiles, or revealed from their comments. Contributions came from a range of mainly first-world, English speaking nations, particularly from the USA, Australia and the United Kingdom / Ireland. The range of locations of participants is shown at Table 1.2, below.

Location	Number of members			Total (%)
	IHateDialysis	KidneyKorner	Australian Dialysis Buddies	
USA	81	6	1	88 (60%)
Australia	7		11	18 (12%)
Unspecified	11	3	2	16 (11%)
UK/Ireland	11	1		12 (8%)
Canada	4	2		6 (4%)
Europe	3			3 (2%)
New Zealand	1	1		2 (1%)
Caribbean	2			2 (1%)
Total	**120**	**17**	**14**	**147**

Table 1.3: Location of active members during the week in May 2011

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[2] Total Membership does not reflect how many members are active: some read but never post, some will have stopped posting, and some are deceased.

[3] My aim in this research was to explore understandings of renal failure *developed between peers*. Posts reproducing information from other sources without comment (mainly by cutting and pasting from news articles) were excluded from the analysis. Posts which engaged with cut-and-pasted information *were* included in the analysis. Of 814 posts about renal failure, 27 posts (3%) reproduced information from other sources without comment or reply. The use by online groups of reproduced renal information could be analysed in future research.

[4] As a very rough estimate, 5% contributors to the discussions in the sample had not begun dialysis.

However the findings reported here are not based solely on data from that week. To develop familiarity with interactions I read an average of 400 posts per week for two years in 2009-11. I also explored the archives going back to 2005. In line with ethnomethodological approaches to research, in Chapter 4 I use example interactions to demonstrate my findings – interactions which were produced while I was a member but not during May 2011. They are analysed in light of my understandings of the norms of the groups.

Differences between the groups

There were differences between the three discussion groups I studied. Table 1.2 showed differences in the size of groups and frequency of posts, while Table 1.3 showed differences in the dominating nationalities of their contributors. I now briefly describe my perceptions of the qualitative differences between them.

IHateDialysis was the largest group with the biggest rollcall of members and the largest quantity of active members – remembering that people who join may never post or may have stopped posting and therefore may not be 'active'. Most posts made to this group are publically accessible. IHateDialysis was started in 2005 by a patient in the USA on haemodialysis named Epoman. He started the group "to stop having his posts censored or deleted by corporate run or sponsored dialysis sites […] so others could have a voice on the internet free from censorship" (IHateDialysis 2012). Epoman died in 2007 but he is still a strong presence in the group; the most recent post on his tribute thread on the discussion board is dated September 2012[5]. Table 1.3 shows that IHateDialysis has the most cosmopolitan membership, though most members are from the USA. Individuals in other groups have referred to IHateDialysis negatively, criticising the negativity allowed in posts; this fascinating aspect of the relationships between groups was outside the scope of my study.

KidneyKorner is the next largest group. It was begun by Angie, a Canadian renal patient who maintains an internet presence in a variety of forms as well as involvement in offline advocacies of various kinds. She comments, "Here is a place

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[5] As of November 23, 2012.

built out of the desire to bring us all together so we no longer have to feel lost and alone!" (KidneyKorner 2012). KidneyKorner is characterised by cheerful, non-renal talk, such as word games and chit chat. Most posts made to this group are publically accessible.

AustralianDialysisBuddies (2012) is the smallest group, and its posts are visible to members only. Most posts from this community are focussed on renal failure. While the larger groups have a predominance of American contributors, AustralianDialysisBuddies consists mainly of Australians. Moreover, as a mailing list, it has a different mode of delivery from the other two groups, which are discussion boards. As a member of a discussion board, I must visit the group website to read messages. At the website, threads are clustered by subject and laid out post by post in order. As I write a post, the context of the surrounding thread is clearly visible and available to me. By contrast, a message sent to a mailing list like AustralianDialysisBuddies is immediately sent as an email to all members. To reply, I then have two options: I can reply from my own email server, or reply from the list website. Both of these options mean that I write my post in an environment separated from the surrounding thread and must remember the content of previous posts. Watching the threads developing in the mailing list, it appears that while composing a stand-alone email, people tend to change the subject header, which then creates a new 'thread' for their message. Also, having read a sequence of emails to the list, they may reply to only one of them, combining comments addressed to a range of other threads. This means that the threads in the mailing list are not as clearly defined as those on discussion boards: they are both more frequently broken into smaller threads and also can be more diverse in the content of a single message. As I will describe in Chapter 4, I looked for ways in which the sequential differences in threads from AustralianDialysisBuddies changed the way sense was made; for my purposes, it made little difference, as the elements of sense making I was identifying were apparent in both kinds of interaction.

* * *

This project mainly aimed to contribute to theoretical understanding of sense making; but I also hoped to find directly practical outcomes. I wondered if there would be conditions in which sense making is easier or harder. By understanding the processes involved in making sense of kidney failure and dialysis, I hoped that appropriate timing, modes and formats of support for sense making might emerge from this research.

1.3 Overview of the thesis

This thesis has a traditional structure: introduction, literature review, methodology, a chapter containing data analysis and findings, three discussion chapters, an implications chapter and a conclusion. In this section I provide a brief chapter-by-chapter synopsis of the rest of the PhD.

Chapter 2 is a literature review, in which I survey existing perspectives on sense making. Sense making research appeared in disciplinary silos, particularly represented within LIS and organisation studies, with rare cross fertilisation. I found two frequently cited theorists, Brenda Dervin and Karl Weick (e.g. Dervin 1999b; Weick 1995), whose conceptions of sense making were surprisingly consonant. Though discussions of sense making in LIS usually concern themselves with problems of the mind, information and knowledge, between them, Dervin and Weick provide eleven theoretical aspects of sense making: *mind,* ***emotions, body, spirituality****, information / knowledge, social aspects,* ***time****, enactive processes,* ***plausibility****, power* and *identity.* The five listed in bold font have generally not been explored in detail in empirical sense making literature. I also surveyed the illness experience research, where themes were similar to the themes of sense making, but were never theorised in terms of sense making processes. I saw an opportunity to extend both the sense making literature and the illness experience literature, by connecting the themes common in one to the other, using perspectives gained from longitudinal research. In the final chapter, I return to these understandings of sense making, connecting my findings back to the literature and identifying opportunities for further research.

Examining common methods and research approaches, I found that longitudinal research was rare across the sense making literature and that interviews were the dominant method of inquiry, especially in LIS. Research in the illness literature was similarly dominated by one-off interviews, for which longitudinal understandings are out of reach. This presented a clear opportunity to match Dervin's theoretical conception of *ongoing* sense making, with ongoing, longitudinal research.

The analyses described in Chapter 3 included a content analysis, an analysis of interactional norms in the online groups and a sequential analysis of eight threads. The content analysis identified eight themes which frequently manifested in posts: *emotional support*, descriptions of *experience*, *explanations* and use of *humour*, *control*, *emotions*, *physicality* and *normality*. The analysis of interactional norms identified four norms which contributed to the smooth running of the discussion groups: *be renal*, *be community*, join *in* and *be positive*. Last, the longitudinal, sequential analysis of threads brought forward four sequential themes: *repetition, guidance via emotional tones, shifting meanings* and *linking explanations into lived experiences*.

In the three discussion chapters that follow, I weave my findings into descriptions of sense making processes, making use of a range of theorists some of whose work is not normally associated with the field of Information Science. In Chapters 5, 6 and 7, I theorise my findings using Chatman and Dervin from LIS, as well as practice theorists like Silvia Gherardi and the philosophers Michel Foucault, Gilles Deleuze, Michel de Certeau and Bruno Latour. I also used Gabriel Tarde, a 19th century statistician and social theorist, whose writing about imitation and routine I encountered via Latour.

For example, in Chapter 5, I combine the themes of normality, humour, emotional support and control into a description of the need to find patterns and to develop areas of life which are routine and which do not need constant re-examination. I discuss how people need repetition and time for patterns to emerge, theorising these discussions using Chatman, Gherardi, Foucault and Tarde. As discussed in Chapter 5, I use the term *repetition* not in the sense of *perfectly repeated* *experiences*, but as shorthand for reiteration, reuse of themes or ideas, clumping similar things together and the familiarity which results from recognising things over and over again. Chapter 6 extends my examination of repetition and time, this time to an understanding of the need for iterative rounds in which people can hone their theories into workable, authoritative understandings. I use Latour and de Certeau to discuss the resulting interplay between people and things and between experience and understanding, in which sense makers can develop control and also find fun and be playful.

In Chapter 7, I examine the question of gap. Dervin put forward an image of a person crossing gaps as a metaphor for sense making. Using Latour and Deleuze, I describe a conception of sense making not as a person crossing gaps, but of people flexibly improvising networks of coherent connections. I explore the changed implications of this different conception of sense making: when a person has to bridge a gap, it helps to provide them with the right tools for the job, asking their needs and trying to provide for them. By contrast, when a person constantly makes and remakes connections in a changing world, it is more helpful to introduce them to varied fields of options, to increase their vocabulary of connections, supporting them with flexibility rather than accuracy.

I understand sense making as *making transiently coherent connections*. Sense makers improvise networks of meaningful elements, including interwoven ideas, physicalities and emotions. Their connection-makings are honed by dialogic interactions with lived experiences and must be flexible if they are to be useful to people living complex lives. Sense making is social because it makes use of socially available vocabularies of networked ideas, which simplify the sense making task of any individual and helps them to make connections which are recognisable to others; and sense making is individual because it is constantly reworked in response to particular situations. To facilitate this reworking, sense making involves recognition of patterns and repetition over time. Once sense makers develop understandings which generally work, they feel a sense of familiarity and can settle that area of life into a routine. Routines are valuable because they form a background against which life can be lived without infinite re-examinations.

In Chapter 8, I explore implications of my findings for the professional practice of clinicians, counsellors and information professionals, looking for ways to help people find patterns, help people maintain routines, help people test theories, help people develop vocabularies, or help people create customised connections specific to their situations. I explore all of these strategies in the context of emotional and physical sense making as well as sense made using ideas. In this context, I criticise some aspects of existing models of care, but more importantly, I put forward a variety of constructive ways in which support could be reinforced, strengthened or reconceived.

Finally in Chapter 9, I revisit the strengths and gaps in the sense making literature that I found in Chapter 2. I demonstrate my contributions to sense making theory and the illness experiences literature. I also examine the limitations of this project, finding ways it could be improved and potential avenues for further research. Chapter 9 provides a roadmap to show where we are and where we could go to next.

Notes about wording

Throughout this thesis, I often refer to ‘patients and carers’, ‘patients and their family’, or ‘patients and their cohabitants’. The sense making processes I describe are social and renal patients do a lot of their sense making with those closest to them (Ndlovu & Louw 1998; Olausson et al. 2006). I refer to patients and their companions in these various ways to draw attention to the possible presence of family members and friends making sense alongside patients and the potential gains of involving and supporting them as well as patients. However, other patients manage their illness alone, only some of whom are single. One cannot *assume* the existence of willing support for all patients. As it would be unwieldy to fill the discussion to come with references to ‘patients and, possibly, those family or friends who help them manage their illness’, I hope you will remember the possible presence or absence of significant others behind all my mentions of patients.

Secondly, in the discussion to come I make a distinction between sense making and sense-mades. *Sense-mades* is not my neologism; Dervin used the term (e.g. in Dervin 1999b). Sense-mades are the shifting products of sense making:

understandings, theories, explanations and sometimes, knowledge. I also refer to actions as sense-mades, when I am discussing physical sense making. I use all these terms more or less interchangeably.

You may notice occasional use of the terms Sense-Making, which is a term used by Dervin and sensemaking, a term used by Weick. When I am not referring to one of those theorists, I discuss sense making.

All quotes and data in this submission are presented without altering spelling or grammar. Text is the principal manner by which people represent themselves in online spaces. Whether intended or accidental, variations in spelling and grammar contribute to the creation of identity online and affect the sense that others make of messages. The quotes already have a different meaning for you reading them in a thesis than they did for group members in the context of discussions. If I corrected texts it would change their meaning even further.

Each of Chapters 1 through to 8 starts with a quote, mostly taken from the children's classic *Alice in Wonderland* (Carroll [1901] 2004). This is a book which shows the ways in which nonsense could be found to have sense in it, demonstrated by Alice's thoughtful interactions with her strange environment. The quote at Chapter 7 was used by Gilles Deleuze to explain an idea which I relate to Brenda Dervin's gap, so I needed to show it to you; the other quotes are mainly for the sake of whimsy. Eventually I will demonstrate how whimsy and other forms of fun are an essential part of sense making and suggest that sense un-making, of which nonsense could be an example, is not so much an opposite of sense as a corollary to sense making. This is a point which will be more easily explained later.

Conclusion

As a 'renal wife' I am particularly motivated to improve the experiences of kidney patients. Moreover, longitudinal sense making research is relatively rare and understandings of some key aspects of sense making – such as emotions and physicality – remain under explored. This project obtained longitudinal qualitative data to investigate ongoing sense making processes – in this case, the changing ways that renal patients make sense of their experiences. I conceived sense making by carefully incorporating perspectives on sense making from Dervin (1999b) and Weick (1995) with ethnomethodological perspectives on interactions (Garfinkel 1967). Acknowledging that situations and perspectives are not static, I explored how renal patients made sense over time. I used longitudinal data from online discussion groups to investigate ongoing collaborative sense making processes. I examined the micro-level of interactional exchanges, which illuminated the ongoing detail of enactive, collaborative sense making processes. To examine sequences in interactions, I created charts to visually highlight sequences over content and reveal relationships between elements of threads. This means that I still haven’t done much interviewing, despite Dervin’s advice. Nevertheless, my project contributes to the theoretical understanding of sense making and also raises ways to help practitioners provide patients and their families with practical support for sense making.

Chapter Two: What we know about sense making

Review of selected relevant literature

> The King turned pale, and shut his notebook hastily. 'Consider your verdict,' he said to the jury, in a low, trembling voice.
>
> 'There's more evidence to come yet, please your Majesty,' said the White Rabbit, jumping up in a great hurry; 'this paper has just been picked up.'
>
> (Carroll [1901] 2004, p. 165)

You might suppose, given the quantity of sense making studies over the years and the long history of the biomedical sciences, that there would be plenty of research into how people make sense of illness. Yet illness studies explicitly stating that their focus is *sense making* are rare and rarer still are those that present theoretical discussions of what sense making is. This chapter presents a critical overview of sense making publications, which I use to locate a very small body of illness-related sense making studies, surrounded by other pertinent studies and revealing exciting gaps in the literature.

I assembled three collections of papers, which I refer to as the *sense making* literature, the *illness experience* literature and the *online discussion groups* literature. The *sense making* literature reveals an array of disciplinary silos, where researchers have produced complementary understandings in different fields with little cross fertilization. I assemble common themes regarding what sense making is and how it is done. To identify opportunities to contribute to Library and Information Studies (LIS) literature, I critically compare that LIS literature to the wider sense making literature, finding gaps in both. Next, my analysis of the *illness experience* literature identifies a lack of theorised research into making sense of illness, even though comparable themes emerged in the illness experience and sense making literature. In particular, under-theorised themes in the sense making literature, like the role of physicality, were commonly explored in the illness literature. Similarly, I find that literature describing *online discussion groups* rarely addressed sense making, but that themes which were under-theorised in the sense making literature were common activities online – for instance, people discussed physicality in intimate detail. So, online groups emerged as useful locations for sense making research.

Overall, in this chapter I present a situation with potential both to enrich existing sense making theories by lowering disciplinary boundaries and also to extend understandings of sense making into the context of illness, in the location of online discussion groups.

2.1 What is sense making?

A search in EBSCO for papers mentioning *sensemaking* or *sense making*[6] in the title or abstract in peer reviewed journals currently produces over 2,500 results[7]. To obtain an overview of the treatment of sense making in academic literature, I examined the results of such a search in EBSCO, Proquest, Ovid and Scopus, choosing papers which made more than passing use of the term. I also added relevant papers of which I was aware, skewing the collection of reviewed papers toward my interests in LIS and health. Yet the resulting collection of 187 papers remains indicative of the relative incidence of papers across the disciplines. Papers tended to cross reference others in this collection, suggesting that I have examined a representative selection of relevant writing. I classified papers into disciplines based on the discipline of the journal, sometimes clarifying by considering the discipline of authors and article keywords. The resulting spread of papers across the disciplines is shown in Table 2.1 below.

Discipline	**# papers**	**% papers**
LIS	83	44.39%
Organisation Studies	36	19.25%
Health	18	9.63%
Psychology	13	6.95%
IT	10	5.35%
Knowledge Management	7	3.74%
Communication	9	4.81%
Education	4	2.14%
Emergency Management	3	1.60%
Cognitive Science	2	1.07%
Environment and Planning	1	0.53%
Arts	1	0.53%
Total	**187**	

Table 2.1: Disciplines in which papers addressing sense making were found.

There are some under-representations in this collection. For example, psychology researchers examine topics which could be related to sense making, like coping and

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[6] A search also including variants on *making sense* produces hundreds of thousands of hits, but most are anecdotal uses of the term; for example, '*Making sense of glycosphingolipids in epithelial polarity'* (Hyenne & Labouesse 2011). Only 200 papers in Proquest had sense making in the subject headers, but this search missed relevant papers.

[7] As of October 2012.

resilience (Folkman 1984; Lazarus 1966; Luthar, Cicchetti & Becker 2000). Moreover, literature on learning from education is under-represented here. In both cases, this is because relevant papers do not always name sense making. Also missing are publications from within the field of LIS which address related topics like information behaviour or information practice. Again, these were not retrieved if they did not use some variation on the term *sense making* in the title or abstract. Throughout this chapter, I will connect this discussion back to that wider LIS literature, using footnotes so that it is clear when I am discussing the sense making literature and when I am not. However, I believe that this summary is already a fruitful undertaking, demonstrating what could be achieved by a more inclusive review.

The majority of papers included in the review were from LIS and organisation studies, accounting for over 60% of the publications I examined. In both fields, I noticed that some authors grappled with the question of understanding sense making, while others made use of sense making theories as a lens to examine some other topic.

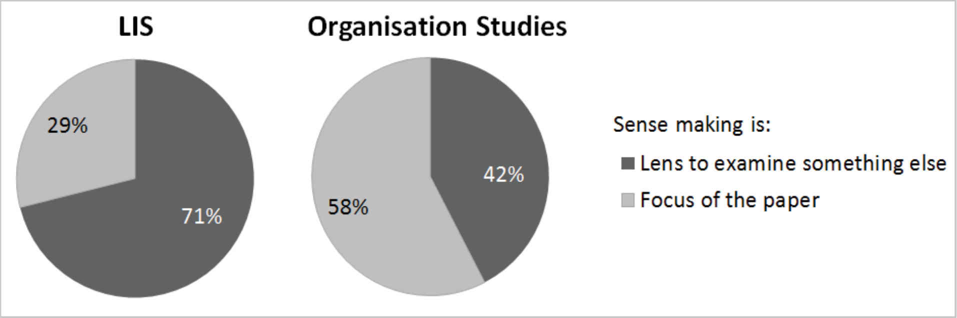

Figure 2.1: Comparative focus of sense making papers in LIS and Organisation studies

Figure 2.1 above depicts the difference in focus between the two fields of LIS and organisation studies: 42% of papers from organisation studies used sense making theories as a lens to investigate another topic, while in LIS, it was 71%.

This means that although LIS appears to be a larger body of papers, proportionately fewer of them undertook to develop the topic of sense making. Moreover, the majority of these LIS papers referred to Sense-Making rather than sense making, a distinction which I will explain shortly. Development of LIS understandings of sense making was represented by only a few authors (Dervin, exemplified by 1999b; Genuis 2010, 2012; Kim 2005; Olsson 2005a, 2005b, 2010b; Savolainen 1993, 2000, 2006a; and probably also Tuominen 1994, though I cannot read his full text in Finnish). In comparison, Organisation Studies and other disciplines are a useful source of critical perspectives and debate about the nature and properties of sense making, as I will discuss presently. I found only seven papers which cite both Dervin and Karl Weick[8], of which most make only passing mentions of one or other author (Dervin 1999b; Hodgson 2007; Klein & Moon 2006; Muhren, van den Eede & van de Walle 2008; Paul & Reddy 2010; Solomon 1997a; Yoo 2011). Of these, only Paul and Reddy (2010) examined theories from both authors carefully. Therefore, the valuable insight on sense making which is available from the various disciplines exists in disciplinary silos. In particular, there is an opportunity for LIS to be enriched by understandings from other disciplines.

Dervin's Sense-Making Theory

> *[Sense-Making] is, first, and foremost, a set of metatheoretic assumptions and propositions about the nature of information, the nature of human use of information, and the nature of human communication.*
>
> *(Dervin 1992, p. 61)*

Dervin has written a lot about a metatheory, methodology or method called Sense-Making. Most of her publications have developed and described that methodology, and most of her research has served to demonstrate and strengthen its usefulness. The Sense-Making methodology is about communication (Dervin 1980, 2010a); it aims to support communication including research as a form of communication (Dervin 1999b), and to improve the design of information systems (Dervin 2010a).

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[8] Almost all the papers examined from LIS cited Dervin, while all Organisation Studies papers cited Weick. This survey does not include publications from this PhD, some of which cite both authors (Godbold 2010, 2012b).

If we interpret Sense-Making as sense making – a problematic interpretation, as I will discuss shortly – then Dervin's writing provides the following perspectives.

First, Dervin specifically describes the individual as more than a mind: they are human with a body, a heart and a spirit, all of which can be involved in making sense of reality (1999b). Hence, Dervin explicitly links Sense-Making to emotions, spirituality and physicality. Second, the individual makes sense within material and temporal reality. This means that sense making is an engagement with context (Dervin 1996) and is subject to change as well as apparent fixedness and solidity. Individual and reality are both "ordered in part, chaotic in part, evolving in part" (Dervin 1999b, p. 730). Manifestations of understanding, such as knowledge, cannot be assumed to remain static. Dervin proposes that "humans are involved in a constant journey through sense-makings and sense-unmakings" (Dervin 1999b, p. 731).

Third, (and because of this constant state of change) Dervin notes a problematic relationship between the individual and "the real", a "never-ending riddle" (Dervin 1999b, p. 730), caused by the appearance of "gaps" in both reality and human perceptions. Such gaps are inevitable when ongoing change manifests in individuals, behaviour, reality and knowledge. Last, since reality is conceived as involved with action and change more often than fixed states, "movement is the one irreducible of the human condition" (Dervin 1999b, p. 731). Hence Dervin focuses attention on verbs and processes rather than on agents, nouns, people or structures which she sees as constantly likely to evolve.

So Dervin describes ongoing epistemological momentum stopped by gap. People are conceived as trying to close the gap, in order to move again. The individual does this by constructing fallible, changing theories about reality.

However, Dervin also makes the point that all the preceding descriptions of Sense-Making are only metaphors, and that "[the] central metaphor of Sense-Making of the sense-maker's moving through time-space is not intended as a description of how an individual faces life." (Dervin 2010b, p. 999). It is "not intended as a literal description of human sense-making (e.g. information seeking and use)" (Dervin

1999b). The metaphors are intended to direct researcher attention, that is, they have a methodological purpose. If one takes the difference between Sense-Making and sense making seriously, her views on sense making are obscured by methodological metaphors, requiring that the reader in search of sense making must look 'between the cracks' of her descriptions, where (relatively) occasional references can be found:

> *The phenomena of interest for Sense-Making is sense-making, which we define broadly in terms of [a] set of assumptions about reality, observing, and power […].*
>
> *(Dervin 1999a, p. 44)*

Here, Dervin points out that sense making is only broadly defined. Meanwhile, her writing is scattered with examples of sense-mades, manifested in lists of verbs made into nouns, such as "comparings, categorizings, likings, dislikings, polarizings, stereotypings, etc […] shoutings, ignorings, agreeings, disagreeings, attendings, listenings, etc" (Dervin 1992, p. 65). The verbs she chooses are usually associated with ideas or understandings and sometimes with emotional responses.

Most simply, sense making may be making sense:

> *Sense-Making focuses on the making and unmaking of sense, the practices and procedures by which individuals and collectives make and unmake their worlds.*
>
> *(Dervin 1999b, p. 736)*

I will return to *sense making as making sense* presently, as it is a description put forward by other writers also.

Sense making in the LIS literature

All but three of the LIS papers I found referred to Dervin's Sense-Making theories (Genuis 2009; Solomon 1997b, 1997c).[9] This indicates how Dervin's work has been

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[9] Dervin was cited in later publications by Genuis (2012) and elsewhere by Solomon (1997a).

useful and relevant to the LIS community. In 1993 however, Savolainen remarked that uptake of Sense-Making in LIS had remained “programmatic” (Savolainen 1993). It appears this trend has continued. Rather than developing understandings of what sense making is, 65% of the papers citing Dervin used her Sense-Making theory or methods as a lens to investigate some other theme of interest. Examples include the health problems of sex workers (Baker, Case & Policicchio 2003); people learning to type (Bergeron & Nilan 1991); improving the usefulness of information systems (Nycyk 2010); students beginning research (Swain 1996); and users’ assessment of video relevance criteria (Yang & Marchionini 2004). So in general, LIS studies referring to sense making did not investigate sense making processes, but rather, made heuristic use of Dervin’s Sense-Making to study perspectives or experiences, or to assess the use of information resources in the information seeking process (e.g. Matsubayashi 1995)[10]. Though their interpretation of information may have become more contextual thanks to Dervin’s influence (Savolainen 2006a, p. 1118), nonetheless most papers I examined focussed on information – either on information behaviour (especially information seeking, e.g. Dervin & Devakos 2010; Kim 2005; Shelby & Capra 2011), information intermediaries and systems (e.g. Behr, Moro & Estabel 2010; Chang & Chang 2010; Jacobson 1991; Lin 2010), or both (e.g. Pettigrew & Durrance 2001; Williams, Nicholas & Huntington 2003). This is not surprising given the field is called ‘information studies’. But there is a tendency for mechanical metaphors in the LIS papers I examined. For example:

> *[Describing a model of sense making] a sense-maker may use the “key item extraction” mechanism to extract […] the basic structure elements to build on. […] All mechanisms (data-driven and structure-driven) may be used in instantiating structure (in the data loop) and building structure (in the structure loop) […] The ultimate product of successful sense-making is an updated knowledge representation […].*
>
> *(Zhang et al. 2008, p. 10)*

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[10] Dervin herself recently noted that her approach has a goal of ‘informing the development of better information and communication systems’ (Naumer, Fisher & Dervin 2008, p. 1; this goal is also expressed in Dervin 2010a, p. 995). That this is one of a range of communication-related goals (Dervin 2010b, p. 999) is not always developed by other writers inspired by her work.

This may be due to the historical connections between LIS and computer science (Olsson 2009). In other disciplines, metaphors of system design were less dominating, allowing consideration of people and understandings without mentioning information.

Treatment of sense making across the disciplines

Outside LIS quite different perspectives on sense making emerge. They often have a focus on people's experiences rather than information and more often attempt to develop and enlarge understandings of what sense making is. I will explore the ways they did this, later in this section. First, given the differences between LIS and other perspectives on sense making, it is important to establish whether the different authors are examining the same topic.

A definition of sense making

Across all the disciplines but particularly in LIS, even when they focus on sense making, many authors use the term anecdotally without ever defining it (Baker 1996; Browning 2012; Cheuk 2008; Jacobson 1991; Kim 2005; Thurlow & Mills 2009; van Vuuren & Elving 2008). Others unhelpfully define sense making as 'making sense' (Dougherty & Drumheller 2006; Hargie, Brataas & Thorsnes 2009; Parris & Vickers 2005; Weick 1995). So to find a definition, I first compare Dervin's approach with that of another sense making theorist, Karl Weick. After that, I will compare the descriptions of sense making as they emerge across the literature, to establish what sense making is seen to be.

Whereas Dervin provides detailed metatheoretical descriptions of a metaphor for sense making, designed to guide researchers, Weick discusses what he calls *properties* of sensemaking. Neither define sense making, a problem to which I will return. Weick's perspective is social constructionist, drawing on ethnomethodology (he cites Czarniawska-Jeorges 1992 and Gephart, 1993 in Weick 1995) and dissonance theory (Chatman, Bell & Staw 1986, cited in Weick 1995 p.13). By describing properties of sense making, he is concerned less with the internal experiences of individuals and more with their relations in the social world, a typically ethnomethodological preoccupation. He pays attention to what is done to make sense – the area that Dervin painted in broad terms as ‘bridge creation’ and exemplified with lists of verbs.

The properties of sense making put forward by Weick involve *identity, retrospect, enactment, social contact, ongoing events, cues* and *plausibility* (1995, p.3). He says that sense makers always develop understandings from the perspective of personal and organisational *identities* and with an eye to how they will look having made sense in particular ways (1995, p.18). They live through situations, and make sense afterwards, or else they consider ways of making sense and imagine what that reveals about their understandings; in these ways, sense making is *retrospective* (1995, p. 24). Sense making is *enactive*, in that one’s perceptions of a situation affect what one does, which affects the situation and one’s further understanding of the situation (1995, p. 32). Sense making is *social*, in that it is influenced by the actual, imagined or implied presence of others and is mediated using language (1995, p. 39). It is *ongoing*, in that existence is “pure duration” in the midst of which we must continually make and remake our understandings (1995 p. 43). And it is based on *cues*, in that, from the infinite data surrounding them every day, people select which things are important or different enough to be cues for sense making (1995, p. 49). Finally, it is “driven by *plausibility* rather than accuracy” (1995, p. 55, emphasis added) in that accuracy takes time to develop and sometimes cannot be achieved; meanwhile, people must respond to situations and by responding quickly, people can shape situations and influence them (1995 p. 57-8)[11].

Similar to Dervin, Weick describes sense making as an ongoing process and reality as “an ongoing accomplishment” (Weick 1995, p. 15). Both recommend attention to verbs, which indicate flow, rather than stable nouns. Dervin has cited Weick to substantiate her discussion of this point (1996, p. 18). Like Dervin, Weick’s sensemaking individual is dynamic and evolving. Another property of Weick’s sensemaking, “plausibility rather than accuracy” is reminiscent of Dervin in that

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[11] It would be fruitful to connect explorations of *plausibility* in sense making with considerations of *enoughness* in LIS, the judgement that one has ‘enough’ information (Berryman 2006, 2008). Meanwhile, some discussions in LIS point to the idea of enactment when they describe the situated development of meaning within interactions (Veinot 2009; Yoon & Nilan 1999).

reality is only partially known. Dervin describes movement through chaos; Weick notes, “people face evolving disorder” (Weick, Sutcliffe & Obstfeld 2005, p. 412). Dervin’s movement metaphor involves “step-takings” (Dervin & Frenette 2003, p. 239); similarly, for Weick, making sense is a prelude to action (Weick, Sutcliffe & Obstfeld 2005).

Though these leading writers describe sense making in comparable terms and are contemporaries, generally they do not cite each other. Dervin commented:

> *There are many uses of the term sense-making as phenomena in the literature (spelled myriad different ways) which have no relationship to the Sense-Making Methodology. For example Weick’s (Weick 1995)* Sensemaking in organizations *proposed looking at organizational life by examining the phenomenon – sensemaking.*
>
> *(Dervin 1999b, p. 729 footnotes)*

Given the similarities in their conceptions, I interpret this as a reference to how Dervin’s aim was to develop a methodology for communicating, more than to investigate sense making. Differentiating her work from that of Weick and others, Dervin described her own approach as the one “most closely tied to specific methodological arguments” (Naumer, Fisher & Dervin 2008, p. 1).

Significantly, both Dervin and Weick are among those who have described sense making as ‘making sense’. For Dervin, as quoted earlier, “Sense-Making focuses on the making and unmaking of sense” (Dervin 1999b, p. 736). Weick places the same idea at the heart of his definition: “The concept of sensemaking is well named because, literally, it means the making of sense” (Weick 1995, p. 4). Neither writer goes on to suggest any technical, specialised or disciplinary specific meaning of the term ‘making sense’.

I have therefore turned to standard dictionary meanings for these terms, using *The Oxford Dictionary of English* (2010). The origins relate to *sense* as in ‘meaning’ and the Latin *senses*, “faculty of feeling, thought, meaning”. *Making sense of* is defined as “find[ing] meaning or coherence in”. Weick chooses the words ‘making sense’ because the process is one of *making* rather than *finding* sense; similarly, Dervin talks about sense as constructed – about people “*making facts*” (Dervin 1999a, p. 41, italics in original). Weick views sense as something both *understood* and *sensed*, that is, it comes from experiences of the real; similarly, Dervin describes knowing as “a product of some inextricable combination of human action, human predisposition, and that elusive thing called reality” (Dervin 1996, p. 17). She notes, “[c]ontext is a necessary source of meaning” (1996 p. 19). Finally, the Oxford Dictionary (2010) notes *sense* as “a property (e.g. direction of motion)”. Combining these levels of meaning, we have a view of sense making as *micro-processes of coherent meaning making, with reference to situated reality, including orienting oneself for action*.

Having established a working definition of sense making emphasising the similarities in the perspectives of these two scholars, I now turn to the sense making papers identified for this review, to identify how the ideas of Dervin and Weick have been interpreted and extended in the represented disciplines.

The faculties involved in sense making

I first demonstrate the variety of ways in which sense making is conceived as being apprehended by humans – the faculties or senses involved in sense making. *With what* do we make sense?

The mind

Across all the literature, sense making was strongly associated with cognitive activities, such as finding or creating meanings (Coburn 2001; De Jaegher & Di Paolo 2007; du Toit 2003; Foreman-Wernet & Dervin 2011; Genuis 2012; Gillies & Neimeyer 2006; Hagar 2010; Holland, Currier & Neimeyer 2006; Murphy 1996; Olsson 2004, 2005b; Pakenham 2008a; Schmidt & Datnow 2005; Solomon 1997a; Tuominen 1994; Volkema, Farquhar & Bergman 1996). A difference is that authors in LIS frequently associated sense making with knowledge or information, turning to the mechanistic metaphors mentioned earlier, while in other disciplines, sense making was associated more generally with understanding or interpreting situations (Blegind Jensen & Aanestad 2007; Brown, Stacey & Nandhakumar 2008; Gioia &

Thomas 1996; Mills 2007; Myers 2007; Olson, Nelson & Parayitam 2005; Paul & Reddy 2010; Rafaeli & Vilnai-Yavetz 2004; Vickers 2002; Wright 2005). This leads to a focus on experiences rather than information-related behaviour.

Outside LIS, sense making is often described in terms of finding patterns or categories (Blatt et al. 2006; Hodgson 2007; Olson, Nelson & Parayitam 2005; Parris & Vickers 2005). For some, the focus was on emplotment, connecting elements of a story in the right order (Wright 2005), or finding reasons for events (this was common in psychological studies – Gillies & Neimeyer 2006; Holland, Currier & Neimeyer 2006; Pakenham 2008a, 2008b, 2008c). For others, pattern making involved deciding what elements are relevant; choosing what to take notice of and filtering out other elements (Starbuck & Milliken 1988)[12]. Mostly likely because of their focus on organisations, many organisational studies writers see sense making as a process of finding and maintaining order (Brown, Stacey & Nandhakumar 2008; Christiansen & Varnes 2009; Gioia & Mehra 1996; Weick 1995).

Moreover, authors often referred to a need for structure (Nathan 2004; Volkema, Farquhar & Bergman 1996) and described understandings as “constructed”. (Cecez-Kecmanovic 2004; Dervin 1992; Zhang et al. 2008). Connected structures show how things meaningfully ‘fit together’. The structure metaphor is a contrast to perceptions of uncertainty and incongruity, seen as the cause for sense making by some (Cramer, van der Heijden & Jonker 2006; Hargie, Brataas & Thorsnes 2009; Mills & Pawson 2006; van Vuuren & Elving 2008). The metaphorical contrast is between order and disorder, coherence and mess.

Emotions

Less frequently, authors connected sense making to emotional faculties, a relatively new development. Dervin instructed researchers to pay attention to the heart (1999b) and in 2005, Weick noted that his treatment of sense making lacked development of the role of emotions (Weick, Sutcliffe & Obstfeld 2005). Occasional authors have

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[12] In LIS, the idea of filtering cues appears in discussion of information searches (Ellis 1989; Kuhlthau 1988) and can also be seen in discussions of monitoring and blunting (Baker 2005) and information avoidance (Case et al. 2005; McKenzie 2003a).

explored roles played by emotions, commonly perceiving them as factors which modify and are modified by sense making of individuals (Bird 2007; Grant, Dutton & Rosso 2008, p. 353; Heldal & Tjora 2009; Myers 2007; van Vuuren & Elving 2008; Volkema, Farquhar & Bergman 1996); from such perspectives, the emotions are separate from the sense making[13].

A contrasting perspective is to view emotions as a component of sense-making (Dervin & Reinhard 2007; Olsson 2010b; Volkema, Farquhar & Bergman 1996). For example, actors use emotions in sense making when they need to know what to feel, or comment on what "feels right" (Kramer 2009; Olsson 2010b). These perspectives draw emotions and information together; emotions are informational, blurring the separation between emotions and cognition (Dougherty & Drumheller 2006). This under-explored perspective may produce useful understandings of emotional aspects of sense making, particularly their involvement in the details of meaning making[14].

The body

In terms of the faculties used for sense making, references to the involvement of physicality in sense making are the least frequent of all. Weick noted the reference to *sensing* implicit in sense making (1995, p. 14). He comments, "[w]e acquire knowledge by acquaintance when we figuratively 'run our hands over the world'" (Weick 2011, p. 16, citing Irwin 1977). Dervin's sense maker was a "body-mind-heart-spirit" (Dervin 1999b, p. 730), bringing attention to physical aspects of sense making. Neither of these authors have presented a detailed analysis of the role of the body in sense making however and relatively few authors have since explored the embodied or physical aspects of sense making. Exceptions are Mills (2002) who noticed how physical environments affected blue collar workers' interpretations of appropriate behaviour; Soneryd (2004) whose participants' sense making involved interaction with the environment such as walking and smelling the air; Waskul and

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[13] Though engagement with emotions is similarly underdeveloped in the wider LIS literature, some authors have explored roles played by *emotions* in information searching processes (Kuhlthau 1985; Mellon 1986; Nahl & Bilal 2007), including by health professionals (Fourie 2009).

[14] In the wider LIS literature, Veinot describes the interplay between information exchange and emotional support (Veinot 2009; Veinot, Kim & Meadowbrooke 2011), while Chatman (2000) describes how feelings of hopelessness or a desire for security may colour an individual's choice of potentially informative sources.

Vannini (2008) who investigated sense making of smells; and finally, Olsson (2010b) and Kramer (2009) who separately described the importance to actors of developing embodied understandings of roles they were to play[15].

Two papers in particular extend and interrelate the ideas of embodiment, cognition, emotion and enactment. They consider making sense as a "whole-organism affair" (Colombetti & Torrance 2009) which they call "participatory sense-making" (Colombetti & Torrance 2009; De Jaegher & Di Paolo 2007) to draw attention to the enactive relations between organisms making sense. An example used to demonstrate the enactive and embodied aspects of participatory sense making is the understanding of a sponge's softness that comes from squeezing it (De Jaegher & Di Paolo 2007, p. 489). For these writers, cognition and emotions are "deeply integrated" and "grounded in biological organisation" (Colombetti & Torrance 2009, p. 507). Cognition is also embodied, with the body as "the autonomous locus and means for significant activity" (De Jaegher & Di Paulo 2007).

Such descriptions of sense making draw attention to elements of sense making processes which occur at the intersection between agents and experience (Colombetti & Torrance 2009). With their enactive perspectives, these accounts evoke Weick, for whom "active agents construct sensible, sensable events" (Weick 1995, p. 4, citing Huber & Daft). He already pointed out that environment is not separate from the individual (Weick 1995, pp. 31-2)[16]; but these cognitive science papers take the idea further and connect it to a fleshed out version of the embodied, affective sense maker suggested by Dervin (1998, 1999b). For them, "researchers […] have not yet gone far enough in taking the interaction process as central" (De Jaegher & Di Paolo 2007, p. 489). Paradoxically, having created an enlarged ecology of sense making, these authors restrict their attention to social interactions between people – leaving

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[15] Also relevant here are Veinot's vault inspector (2007) and Bonner and Lloyd's nurses (2011), who learn from smells and other small sensory changes.

[16] Many but not all LIS researchers view context as separate from the individual but affecting meanings – for example, like a container; see (Courtright 2007) for a comprehensive review of conceptions of context in the information behaviour literature.

open the potential for further exploration of participatory sense making between agents and environments[17].

With or without words?

Dervin differentiates between sense made (nouns, e.g. interpretations) and sense making (verbs, e.g. interpreting) and makes it clear that it is sense making that is her focus (Dervin 1999b, p.736). She suggests a model of human existence as having an unconscious or unarticulated inner being, where sense is made (Dervin 1999b, p. 733). Sense must then be translated to the articulated “at least in part, and often in struggle” (Dervin 1999b, p. 733). Dervin refers to (uncited) psychoanalytic theories as a source of this model. Elsewhere, researchers relate sense making to “the ability to understand what is being experienced” (Stannard 2011, p. 336). This suggests just such a transformation, from located experience into abstractions such as ideas or language. However, looking closely at Dervin’s lists of examples of sense making – the demonstrations of translations from nouns to verbs for which she is renowned – one finds both internal activities (*thinkings, factizings*, etc.) and external activities (*shoutings*) (Dervin 1992, p. 65).

Weick (2011, p. 11) also points to the difference between perception and description and explicitly includes them both as two stages in sense making. Sense making for him involves a movement from knowledge-by-acquaintance to knowledge-by-description, “turning circumstances into a situation that is comprehended explicitly in words.” (Weick, Sutcliffe & Obstfeld 2005, p. 409). Weick’s writing about language and experience depicts tensions between stabilising urges inherent in sense making and the need to be able to deal flexibly with changing realities (Weick 2011). For this, language is both useful and problematic (Dervin 1999b, p. 736): it “pin[s] down experience – to freeze it [and] make it appear immobile for conventional utility” (Purser & Petranker 2005, p. 188). Yet language is also enactive, both enabling social sense making (Olsson 1999) and clarifying one’s experiences into narrative (Kleinman 1988; Weick 1995). Despite these paradoxes, creating descriptions is part

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[17] Within LIS, a comparable perspective is represented by social constructionist perspectives on information, in which people’s understandings are viewed as dialogic processes of informing, where meanings, contexts, knowledges and being informed are interrelated and mutually accomplished (Sundin & Johannisson 2005b; Talja, Keso & Pietiläinen 1999; Tuominen, Talja & Savolainen 2002).

of sense making. The descriptions themselves (sense made) are less interesting as enduring evidence of reality than as fleeting evidence of perceived intersections between aspects of situations. They show what cues were chosen as relevant in the situation (Starbuck & Milliken 1988).

Individual, collaborative and social sense making

Dervin began her discussions of sense making with a focus on the individual (Savolainen 1993). Her subsequent attempts to shift focus to social considerations in sense making (Dervin & Clark 1993) did little to modify enthusiasm in LIS for individually-centred studies using her work. Most of the LIS papers I examined considered the experiences of individuals (e.g. Connaway et al. 2008; Gluck 1996; Gluck 1997).

For most authors outside LIS, sense making is intrinsically social, first in that it is linked to maintaining identity, a process informed by how one imagines others might perceive one's actions (Ashforth, Harrison & Corley 2008; Brown, Stacey & Nandhakumar 2008; Gioia & Thomas 1996; Weick 1995). Second, sense making is social in that it is mediated by language and everyday interaction (Olsson 1999, 2007; Tuominen 1994; Weick 1995, pp. 39-40). People make sense by telling stories (Bird 2007; Brown, Stacey & Nandhakumar 2008), which act as reservoirs of understanding in a vocabulary shared by many individuals. They allow individuals access to the history of a community (Boje 1991). Therefore words are necessarily part of the processes of sense making, being both the attempted expression of sense making and fodder for sense making to come. Often, however, papers addressing these aspects of social sense making do so by exploring the perspectives of individuals as they encounter social meanings or perform social identities (Kim 2005; Olsson 2005a, 2007; Solomon 1997a).

Even when collaborative information behaviour is of interest, in LIS the focus tends to be on individual's experiences as they collaborate with others (e.g. Kim 2005). Differences between individual and collaborative behaviours have been described (Reddy & Jansen 2008) indicating that investigation into collaboration within groups may be fruitful.

Rarely however, consideration is given to sense making within groups rather than by individuals (Chen 2007; Olsson 2004, 2009; Paul & Reddy 2010). Explorations of intergroup or intragroup awareness by LIS authors tend to consider online spaces (Heverin & Zach 2011; Matthews & Stephens 2010; Schaefer & Dervin 2009); I discuss these in Section 2.3. Again, there are more examples of the collective or social focus on sense making in literature drawing on Weick's conception of sense making as social (Coburn 2001; Leykum et al. 2012; Manojlovich 2010; Muhren, van den Eede & van de Walle 2008) Some authors describe collective knowledge (Cecez-Kecmanovic 2004; Merali 2000; Weick & Roberts 1993), viewing organisations as distributed knowledge systems (Tsoukas 1996). This does not imply people having identical ideas nor even shared understandings; the concept usually refers to people "heedfully" communicating interrelating parts of reactive systems (Weick & Roberts 1993, p. 369; Paul & Reddy 2010 paid similar attention to role based distribution of information).

So sense making research can be focused at a variety of levels, ranging from the individual to the social, manifested in discourses or collective interactions; and social sense making is under-explored, particularly by LIS researchers[18].

Power

Savolainen (1993) drew attention to the need for understandings of power in Dervin's Sense-Making theory, suggesting an examination of relations between socio-cultural structures, which are seen to constrain or channel the activities of individuals, and individual agency, seen as the potential to manifest preferences. In the LIS papers I reviewed, discussions of the role of power in sense making mainly came from two authors – Dervin and Olsson (Dervin 1999b, 2010a, 2010b; Foreman-

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[18] Outside sense making, LIS studies examining information practices take social constructionist perspectives on information and meaning making by individuals (McKenzie 2003b; Olsson 2010b; Savolainen 2007b). Some LIS authors have explored the importance of personal networks for information acquisition (Haythornthwaite 1996; Hersberger 2002/3; Veinot 2009, 2010b), while studies of collaborative information behaviour include Hertzum (2008); Neal and McKenzie (2010); Sonnenwald (2006); Talja and Hansen (2006); Veinot (2009); Veinot, Kim and Meadowbrooke (2011). An exploration of group-level collaboration in the wider LIS literature is Sonnenwald and Pierce (2000). Some LIS perspectives have a social focus even beyond the level of groups. Domain analysis (Hjørland 2009) has a social focus on the collected understandings of subject disciplines, while Egan and Shera (according to Fuller 2010) coined the term 'social epistemology', raising social knowledge as a potential focus of research for Library and Information Science.

Wernet & Dervin 2011; Naumer, Fisher & Dervin 2008; Olsson 2004, 2005a, 2005b, 2007, 2011). Occasionally, other LIS authors made passing mention of power in their data (Shelby & Capra 2011). Dervin has mentioned structure at times (Dervin 1991, pp. 63, 5-6; Dervin 1993; Dervin 1999b), noting for example that "[s]tructure is energized by, maintained, reified, changed, and created by individual acts of communicating" (Dervin 1992, p. 67) and that humans sometimes enact structure and sometimes resist or reinvent their worlds (Dervin 1999b, p. 731). But to Dervin, talk of structure versus agency refers to a false dichotomy (Dervin & Schaefer 1999). She passes over the details of how structure and agency interact, stating it is not fixed *a priori* (Dervin & Schaefer 1999, p. 732) and I quite agree with this last point. However, there remain opportunities to explore power dynamics in sense making. Olsson contributes most of the heavy lifting here, exploring social processes involved in construction of authority (Olsson 2003 2005a, 2005b, 2007). Further questions, such as how the resisting, reinventing or enacting mentioned by Dervin (1999b, p.731) might be carried out, remain to be explored[19].

Looking beyond LIS, allusions to power in sense making were more common, but once again, convincing examinations of its workings were rare. Usually, power manifested as attempts to gain or exert control, either by individuals over events, or by organisations over individuals (Ashforth, Harrison & Corley 2008; Gioia & Chittipeddi 1991; Gioia et al. 1994; Hargie, Brataas & Thorsnes 2009; Hodgson 2007; Nathan 2004; Thurlow & Mills 2009; van den Bos 2009; van Vuuren & Elving 2008). An implication of this perspective is that the 'right kind' of sense making is an antidote to trouble, leading to control and good outcomes. A contrasting perspective sees sense making as ongoing reactions to a changing world (Dervin 1999b; Starbuck & Milliken 1988; Weick 2002), in which flexibility should be valued over control (Dervin 1998), and for which multiple understandings are part of a basic toolkit (Starbuck & Milliken 1988). Occasionally authors provided examples of individual agency, such as inexperienced registrars hesitating to report errors (Blatt et al. 2006) or teachers re-interpreting a new curriculum (Coburn 2001).

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[19] In the wider LIS literature, dialogic interrelations between individuals and contexts have been explored for their contribution to reworkings of agency and structure (Sundin & Johannisson 2005a).

A useful contribution to understandings of power lies behind discussions of the sense making process of filtering cues (noted by Starbuck & Milliken 1988; Weick 1995). Sense making enacts a social order (Brown, Stacey & Nandhakumar 2008), bringing together particularly chosen elements which are seen to be meaningful as a result of frames of reference (Klein, Moon & Hoffman 2006; Starbuck & Milliken 1988; van Vuuren & Elving 2008) or which are built into 'schemas' (Balogun & Johnson 2004; Elsbach, Barr & Hargadon 2005; Louis 1980; Merali 2000). When people choose what to attend to, they frame what is important in situations and what can be ignored (Brown, Stacey & Nandhakumar 2008; Salvatore & Venuleo 2008). Hence, sense making is inherently ethical (Colombetti & Torrance 2009), shaping histories and sources of authority (Weick, Sutcliffe & Obstfeld 2005). The political angle of such social order creation is however, rarely noticed or explored.

The start of sense making: gaps, chaos, uncertainty

For Weick, sense making occurs "when the current state of the world is perceived to be different from the expected state of the world, or when there is no obvious way to engage with the world" (2005, p. 409). This is similar to Dervin's metaphor of gap (Dervin 1991, p. 62), used in her methodology to represent a problem needing a solution or bridge. Following Dervin and Weick, researchers conceive of sense making as initiated by or responding to problems or reducing uncertainty. Outside LIS, this was often exemplified by reacting to crises, or noticing clues before a disaster (Blatt et al. 2006; Bloor & Dawson 1994; Weick 1995; Weick 2011; Weick, Sutcliffe & Obstfeld 2005). The focus on problem solving leaves aside more routine processes of life (Gioia & Mehra 1996) of which, presumably, routine sense is made. There is potential here to contribute to understandings of ongoing sense making[20].

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[20] One could do so by connecting to fields in LIS such as everyday life information seeking (Savolainen 2010b) – especially, Savolainen's discussions of habitus and mastery of life (Savolainen 1995, 2008); small worlds (Chatman 1999); information grounds (Pettigrew 1999); Williamson's ecological model for information use (Williamson 1998); and everyday information practices (McKenzie 2003b).

Time

In the organisational studies literature, sense making was viewed as necessarily *retrospective*, relying both on previous experience and ‘what just happened’ (Boland 1984; Weick 1995). People can only see what things meant as they look back on them (Blatt et al. 2006). Weick argued that this is the case even when comprehending things as they occur; he described how understanding must lag slightly behind events (Weick 1995, using Schutz). This appears to ignore the urge to plan and predict (Purser & Petranker 2005). Yet Weick’s conception of sense making also includes how people anticipate and recognise what they are expecting from events, looking for answers to the question ‘what should I do next?’ (Weick, Sutcliffe & Obstfeld 2005, p. 412).

This mixture of retrospect and prospect is also found in Dervin’s metaphor of a person wanting to take the next step, a step which may be a repetition (reuse) of past understanding or based on past experiences. Dervin’s Sense-Making is situated in a “time-space” (1999b) where understandings require constant revisions and reworking due to changes over time. Her Sense-Making interviews trace the story of a progression in time, establishing descriptions of “steps taken” and their perceived outcomes, but the focus is on the progression of “step-takings”; time serves as a background, passing unexamined. The relationships between past and future – how retrospection can become prediction – are not addressed by either writer, though the issue has been noted elsewhere (Purser & Petranker 2005; Wright 2005).

Meanwhile, these are all generally linear conceptions of time (moving from past to future). Less explored are cyclic manifestations of time such as rounds of activity (noted by Solomon 1997a). Weick (1995) described sense making as *iterative* in various ways: in the iterative relationship between sense making and identity and in the enactive relationship between environments and understandings. But he has not explored connections between iterations and cyclic time[21].

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[21] Outside the sense making literature, some LIS authors have developed more sophisticated conceptions of time, including non-linear manifestations, multiple and overlapping timelines (Hartel 2010; McKenzie & Davies 2002; Savolainen 2006b) and the ritual or normative aspects of timing (Widén-Wulff & Davenport 2005). Understandings of sense making could well be enriched with reference to their work.

Connections between sense making and the wider LIS literature

I have noted that Dervin's Sense-Making theory was mostly used in LIS as a lens to examine topics related to information and knowledge. This connects Sense-Making research to literature examining information needs, seeking and use, contributing to the areas of enquiry entitled *information practices* (McKenzie 2003b) and *information behaviour* (Wilson 2000, p. 49). For some, Dervin's Sense-Making is viewed as a subset of information behaviour. Wilson has described it as a model of information seeking (Wilson 1999a, p. 56; Wilson 1999b, p. 252), while Savolainen has aligned sense making with information use (Savolainen 1993, p. 15, 2000, 2006a) and information seeking (Savolainen & Kari 2006). Others have viewed information behaviour as a subset of sense making (Godbold 2006; Solomon 1997b, 1997c). This prevarication is indicative of the co-constitutive relationship between sense making and information.

Numerous authors and studies in the LIS literature can be seen to connect to sense making studies without referring directly to making sense, for which reason they are missing from the discussion above. For example, Kuhlthau (2004) explored processes of *seeking meaning* with a search-process model incorporating feelings, actions and thoughts, while Chatman investigated "the idea of meaning, or how people use information to reshape, redefine, or reclaim their social reality" (1996, p. 195). These show the limitations of including in this review, only authors who explicitly addressed sense making; the review could be usefully expanded if I had considered Kuhlthau and Chatman as sense making theorists, even though they do not identify as such.

Methods and research perspectives

As shown by Figure 2.2, below, the most popular methods used in the sense making literature were interviews or questionnaires, usually resulting in non-longitudinal studies, especially in LIS.

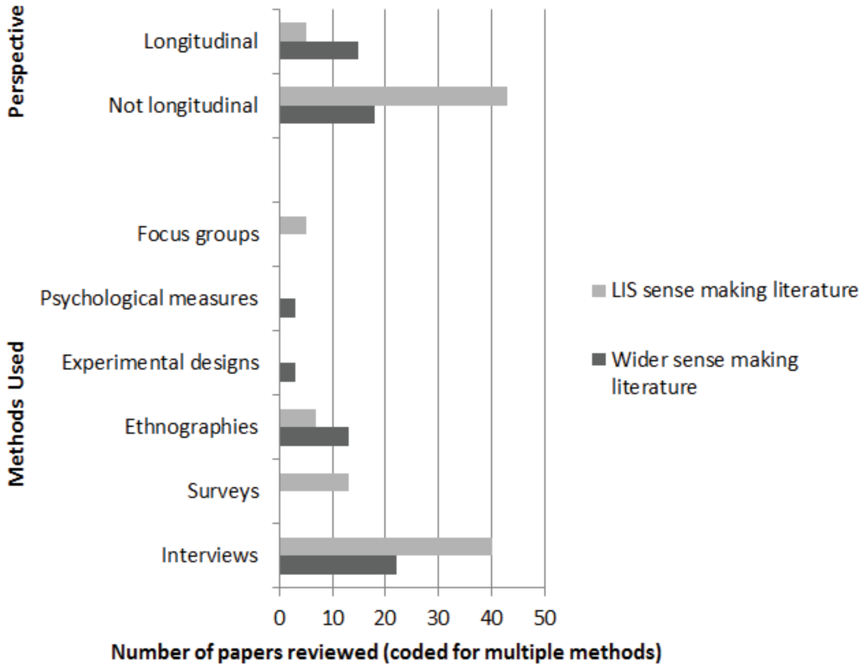

Figure 2.2: Comparative distribution of research perspectives and methods in the sense making literature

Longitudinal methods such as ethnography appear more frequently outside LIS, demonstrating the potential of such approaches to develop different perspectives on sense making.

* * *

Here in Section 2.1, I have reviewed a selection of publications which explicitly addressed sense making – excluding passing mentions or anecdotal uses of the term. LIS was the largest field represented in that collection, and I consistently noted its contributions and shortfalls, noting frequent opportunities to contribute to the field. LIS authors mostly focused on cognitive aspects of individual sense making in relation to information and knowledge. Other theoretical contributions appeared outside LIS, providing broader insight into cognitive aspects such as pattern finding and filtering of cues, and conceptions of social sense making as enacted identity work. The embodied, emotional aspects of sense making, the workings of time, and manifestations of power such as agency, authority or control, generally remain under-developed across the sense making literature.

Meanwhile, there were only 18 papers representing health in the papers reviewed so far, of which none addressed renal failure. In Section 2.2, I examine papers which provide relevant perspectives on the experiences of illness. I will show how this second collection connects to understandings of sense making – albeit usually in untheorised ways.

2.2 Making sense of illness

This is the second of the three reviews in this chapter, for which I bring together a new selection of papers representing what I refer to as the *illness experiences* literature. To do this I performed a wider search than before, including *any passing mention* of *sense making*[22], then limiting results to papers mentioning variations on *patients, kidneys, renal* or *nephrology*. In these results I identified 86 relevant references including six papers relating to renal failure (see Table 2.2 row 1 next page). Since so few papers in the renal literature mentioned sense making, I supplemented them with 22 papers which did not mention sense making but which did explore the experiences of renal failure. I also added papers which explored related topics such as *meaning making* about illness by patients or their families. In total the illness experience literature I collected numbered 125 publications, distributed as shown in Table 2.2 (below).

	Renal	Non renal	Total
Mention Sense making	6	80	86[23]
(Focus on sense making)	(0)	(20)	(20)
Examine illness experience	22	10	32
Explore related topics such as meaning making	-	7	7
	28	87	125

Table 2.2: Papers relating to sense making from the health literature

Twelve out of the 125 publications in this collection of illness experiences literature addressed sense making theoretically. Theories used were (1) narrative theory; (2)

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[22] Any passing mention of sense making: any peer-reviewed paper with *sensemaking* or *sense* in the title or abstract.

[23] These papers included health papers from the sense-making collection examined in Section 2.1.

health-psychology or (3) meaning making, which is theoretically similar to sense making; the next few paragraphs summarise usage of these theoretical approaches.

In Section 2.1, when examining the LIS and organisation studies literature, I found that many papers used sense making theories as a lens to examine other phenomena. Here, similar tendencies appeared in the illness experiences literature, where the theoretical lens frequently used was narrative theory. According to narrative theory, people create stories about their lives to understand their experiences (Czarniawska 2004; Frank 1995; Kleinman 1988). Though they do not directly address sense making, Frank and Kleinmann explore the power of storytelling to heal, to "express[…] the body" and to connect via stories to others' experiences (Frank 1995, p. xii), connecting to sense making perspectives on language both as enactive and as a medium for social understandings. However, the papers I examined citing narrative theory used it as a lens, for example, to explore reflective nursing practice (Bailey 2001; Brown & Addington-Hall 2008; Carlick & Biley 2004; Carolan 2005; Crossley 2003; Macpherson 2008; McCance, McKenna & Boore 2001; McKevitt 2000; Morrissey 2006; Sakalys 2003). Therefore, they contributed little to theoretical understandings of sense making.

Health-psychology authors viewed sense making as "finding reasons" for an event, and compared it to "finding benefits" as two aspects of coming to terms with a challenging event, involving cognitive restructuring and reappraisal (Mock & Boerner 2010). Such studies used surveys to measure if sense making and benefit finding were present or absent for participants, in combination with other variables like depression (Pakenham 2008a, 2008b, 2008c). Thus, they explore relations between a set of variables, without shedding light on the processes by which people make sense.

Lastly, authors theorised *meaning making* in ways which are relevant to sense making (e.g. Chan, Ho & Chan 2007; Dougherty & Drumheller 2006; Fife 1994, p. 309; Pakenham 2008b). These papers cited authors from psychology or health-psychology (Antonovsky 1987; Aronowitz 1998; Radley 1994) to examine ideas comparable with those used to theorise sense making. An implication is that a more thorough examination of meaning making literature may fruitfully expand on the themes contributed by these papers to the discussion begun here.

Most papers in the rest of the illness experiences collection addressed issues other than sense making. For example, a study led by Dunn (2006) theorised the concept of quality of life, then presented findings relating to quality of life for cancer patients. Sense making appeared as one of six core themes in their findings but was not theorised. The illness literature almost never cited sense making theorists such as Weick or Dervin (the two exceptions I found cited Weick: Davidson 2010; Epstein & Street 2011). In particular, the renal papers neither defined sense making nor connected it to a theoretical perspective, even though some expressed intentions to explore sense making. In every case, to *make sense* meant to *describe,* and papers investigating sense making examined how people described experiences (Hagren et al. 2001; Martin-McDonald 2003; Ndlovu & Louw 1998; Reid 2012). The exception is Dervin's (1980) study of people visiting doctors, in which she identified that the questions they asked were correlated to the ways they viewed their sense making momentum: blocked, being dragged down a path and so on. Beyond that study, none of the illness experiences papers explicitly contributed to theoretical understandings of sense making processes. But they did shed light on factors frequently related to sense making, which I now examine.

Sense-making-related themes in the illness literature

Not surprisingly given the context of illness, in this literature the prompt for sense making was associated with loss (Beanlands, McCay & Landeen 2006; Robinson, Clare & Evans 2005; Tijerina 2006) presented in catastrophic terms: "illness and impending loss tears the coherence of the life narrative" (Romanoff & Thompson 2006, p. 310). This contrasts with organisation studies where sense making is perceived as prompted by crises, and LIS where it is conceived in terms of solving problems. Loss is not necessarily a problem that can be solved or a crisis that might be resolved by quick thinking. So while organisation studies considered sense making as a fore-runner to *action* (Wieck 1995), it was associated with *coping* in the illness experience literature (Carlick & Biley 2004; Giske & Gjengedal 2007;

Greenstreet 2006; Holt et al. 2009; King et al. 2002; Nyhlin 1990; Quinn et al. 2008; Witenberg et al. 1983).

The illness experience literature provided descriptions of coping, making sense or adjusting, in which common themes were as follows: *emotions, identity, power, physicality* and *relationships*, including social connections. In the case of emotions, this is significant in itself, because the sense making literature so rarely addressed emotions that one might have wondered if their inclusion as a factor of sense making was romantic thinking on Dervin's part. The need for theoretical attention to emotions is confirmed by the fact that one in five papers in the illness experience literature discussed that topic (e.g. Epstein & Street 2011; Gascoigne & Whitear 1999; Macpherson 2008; McGovern 2011; Nicholas, Picone & Selkirk 2011; Ouellette, Achille & Pâquet 2009; Pakenham 2008a, 2008b, 2008c; Persenius, Hall-Lord & Wilde-Larsson 2009; Richard 2008; Tong et al. 2009). The detail in the discussions of *identity* also confirm its importance in processes of coping with illness (papers contributing to the theme of identity include Beanlands, McCay & Landeen 2006; Hoogerdijk, Runge & Haugboelle 2011; Lee, Chaboyer & Wallis 2010; Robinson, Clare & Evans 2005; Tijerina 2006; Tong et al. 2009). Discussions of relationships in the illness literature brought forward the need of patients for social connections (Mock & Boerner 2010; Olausson et al. 2006; Tong et al. 2009; Veen et al. 2012; Wong et al. 2009) and the benefit of observing peers or hearing about their experiences (McCaughan, Parahoo & Prue 2011; Neal & McKenzie 2010; Ormandy 2008; Ouellette, Achille & Pâquet 2009; Veinot 2009, 2010b; Veinot & Harris 2011; Veinot, Kim & Meadowbrooke 2011; Veinot & Williams 2011).

Meanwhile, the illness experiences literature treated the themes of physicality and power in ways which suggest extensions to existing understanding sense making, as I now describe.

Power(lessness)

As described in the previous section, power is acknowledged as relevant to sense making by only some theorists (e.g. Olsson 2007; Savolainen 1993) and tends to emerge in that literature mainly in terms of control. Similarly, the illness experiences literature raises frequent references to control. But while organisation studies authors consider how organisations might create structural control, in the illness literature, the discussion is more about individual agency and in particular about powerlessness and individual bids for control. Manageability, the ability to manage or control one's circumstances, is seen as one of the three elements required for a coherent worldview (Antonovsky 1987). Patients and their families lose freedoms due to illness, such as via dietary or other restrictions (King et al. 2002; Tong et al. 2009; Veen et al. 2012; Veinot et al. 2010b) or they describe shifting experiences of freedoms and restrictions (Martin-McDonald 2003; Molzahn, Bruce & Sheilds 2008). Taking control has an enabling effect on some patients (McCaughan & McKenna 2007; Veen et al. 2012) reflecting perspectives on control as a buffer against trouble already noted in Section 2.1.

People may find freedoms by developing routines (Polaschek 2003; Veinot et al. 2010b) or by finding pleasurable aspects of restricted activities – thus creating the sense of 'choosing' compliance (Veen et al. 2012). Patients occasionally emerge as developing strategies and practices to better engage with doctors or medical systems, when situations do allow some expressions of agency (Braun Curtin & Mapes 2001; McKenzie 2002a, 2002b; McKenzie & Carey 2000). Also, the personal experiences of patients gives them authority among their peers (McCaughan, Parahoo & Prue 2011; McKenzie & Carey 2000; Neal & McKenzie 2010; Ormandy 2008). But, while aiming for and achieving self-care are noted as important to some patients (Braun Curtin & Mapes 2001; King et al. 2002; Nicholas, Picone & Selkirk 2011), others express anxiety at being responsible for self-care (Wong et al. 2009). Moreover if control is not achievable, attempts to attain it may be associated with depression and lowered compliance in some patients (Witenberg et al. 1983).

So in terms of the implications for individual agency via sense making (Savolainen 1993), the illness experience literature presents a complex picture. Agency, manifesting as control, is not always desired or attainable. Moreover, the forces presented in opposition to agency are not the usual collection of structural forces, such as culture or societal norms, against which one could decide to rebel. In this literature, authority emerged in relation to lived experience and patients' powerlessness emerged in the context of physical imperatives which one's will or preferences cannot directly address. This may explain why the illness experiences literature often raised physicality as a key theme, again one rarely explored in the sense making literature.

Physicality

Physicalities mentioned in the illness literature were often symptoms, such as pain or fatigue, which impede people's ability to maintain normal activities (Ashby et al. 2005; Hagren et al. 2001; Lindsay Waters 2008; Ormandy 2008; Polaschek 2003; Tong et al. 2009) or altered body image, which affects one's sense of identity (Braun Curtin, Johnson & Schatell 2004; Fife 1994; Keeping & English 2001; Ormandy 2008; Richard & Engebretson 2010). Some authors pointed out other relationships between physicality and sense making, starting with measures of correlation between physical health and psychological variables like depression (Chan, Ho & Chan 2007). But physicality was also sometimes described in *interaction* with meaning making. For instance, women diagnosed with osteoporosis downplayed the seriousness of the situation because they felt physically well (Weston, Norris & Clark 2011); and patients found it hard to learn to self-care while already physically ill (Wong et al. 2009). Describing the couple-hood of dementia patients and their care-giving partners, McGovern (2011) drew attention to the embodied activities of caring which both created a sense of shared identity and enabled communicating and shared meaning making, without need for words. These examples partially illuminated physicality and sense making as interwoven trajectories of experience, recalling the inter-processual interactions suggested by participatory sense making theorists (De Jaegher & Di Paolo 2007).

New themes specific to illness

Some aspects of sense making suggested by the illness experiences literature were not explored in the sense making literature. For example, Dervin has raised spirituality as relevant to sense making, but I am not aware of any publications which develop the relevance of spirit in the sense making literature. But in the illness literature, *spirituality* or *religious beliefs* appeared occasionally, both for finding meaning and for maintaining hope (Chan, Ho & Chan 2007; Giske & Gjengedal

2007; Greenstreet 2006; Holt et al. 2009; Lee 2004; Mir & Sheikh 2010; Ndlovu & Louw 1998; Pakenham 2008a; Paun 2004). *Time*-related experiences were frequently referenced in this literature, not only *linear* time, appearing here as changed perspectives on the past or future (Fife 1994; Kilshaw 2004; King et al. 2002; Langner 1995; Olausson et al. 2006; Quinn et al. 2008; Reid 2012), and time taken to adjust to illness (Hoogerdijk, Runge & Haugboelle 2011; McCaughan & McKenna 2007; Reid 2012; Robinson, Clare & Evans 2005; Tong et al. 2009). This literature also referred to *non-linear* time. Perhaps it is lack of control that brings time forward as a protagonist in the illness experience literature; especially time experienced as cyclic or enduring (Hagren et al. 2001; Moss-Morris & Petrie 1994; Polaschek 2003) and time spent waiting (Lee 2004). To quote the title of one paper, "*You can't cure it so you have to endure it*" (King et al. 2002).

Finally, *normality* appears in the health literature via frequent references to normalisation as a tactic for feeling less worried about situations. Symptoms might be explained away as normal to maintain denial of illness (Polaschek 2003; Quinn et al. 2008; Weston, Norris & Clark 2011); normalisation is also a goal of diagnosed patients who want to make their changed lives into a new normal (Tong et al. 2009; Veen et al. 2012). Renal patients lived with troubling tensions between passing as healthy or normal while struggling with abnormal experiences (Martin-McDonald 2003; Molzahn, Bruce & Sheilds 2008). Normality is a theme which appeared only once in the sense making literature I examined (Genuis 2012)[24]. Normality's frequency in the illness experiences literature, where it is linked to the processes of understanding illness, suggested a need to develop its inclusion in theorisations of sense making.

Methods and research perspectives

Most of this research reported interviews with individuals, resulting once again in non-longitudinal perspectives on the experiences of illness (Ashby et al. 2005; Keeping & English 2001; Mock & Boerner 2010; Molzahn, Bruce & Sheilds 2008; Pakenham 2008a; Polaschek 2003; Polaschek 2007; Robinson, Clare & Evans 2005;

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[24] I have discussed *normality* in the context of sense making, in publications from this PhD (Godbold 2010, 2012)

Witenberg et al. 1983). Three ethnographic studies appeared in the renal literature (Bennett 2011; Lindsay Waters 2008; Richard & Engebretson 2010) but none mentioned sense making. I found only two longitudinal studies mentioning sense making (Langner 1995; Martin-McDonald 2003), while several studies commented on the likely benefits of longitudinal research in this area (Chan, Ho & Chan 2007; Hagren et al. 2001; Ouellette, Achille & Pâquet 2009). Therefore, the renal literature and the illness literature in general could benefit by longitudinal research investigating collective rather than individual perspectives and using methods other than interviews. In particular, research which uses qualitative methods to investigate sense making in theorised ways is both necessary and missing from the illness experience literature.

* * *

I examined the illness experience literature with two intentions: to identify what is already known about sense making undertaken by patients and those around them; and to identify the methods with which such phenomena were being studied. Most salient from this review was the opportunity to investigate patient sense making in theorised ways. For instance, sense making theory could be connected to insights from both illness-related narrative theory and meaning-making literature. Such study would have the potential both to contribute to the illness experience literature, and to enrich sense making theory, by following up on themes such as *emotions, physicality, powerlessness, spirituality, normality* and *time*.

2.3 Making sense in online discussion groups

This is the last of the three reviews presented in this chapter. Here, I summarise a representative collection of papers about online discussion groups, particularly those with a health related focus, concentrating on self-formed groups, or those formed to support health or illness. Relatively little of it adds new perspectives on sense making, so my treatment of it here is brief. I found that online discussion groups create content which exemplifies particular aspects of sense making – making them a useful location for sense making research.

Contributions to sense making theory

Searches across EBSCO, Proquest, CINAHL, PubMed and CSA produced only two studies of renal discussion boards (Nicholas et al. 2009; Taylor et al. 2007) of which neither addressed sense making. There is therefore potential to contribute to the literature by discussing sense making in renal discussion groups.

I located three studies exploring sense making in online discussion groups (Bordia & DiFonzo 2004; Heverin & Zach 2011; the third study is reported in three papers: Schaefer 1999; Schaefer & Dervin 2005, 2009). These three studies are interesting not only for their discussion of sense making themes in online settings, but also for their attention to collective or community sense making. Moreover, they demonstrate what can be achieved in terms of clarifying understandings of sense making when one takes a very close look at the level of interactional turns – the micro-level of sense making.

Finally, four other mentions of sense making were incidental or passing (Bresnahan & Murray-Johnson 2002; Emad 2006; Erickson 2010; Fox, Ward & O'Rourke 2005a). Beyond these, I have encountered no other studies of discussion groups which mention sense making at all. Nevertheless, the lively research exploring online discussion groups reveals themes relevant to sense making.

Emotional and Informational support

Analyses of discussions online reported a predominance of emotional support and information sharing (Colineau & Paris 2010; Drentea & Moren-Cross 2005; Eichhorn 2008; Malik & Coulson 2010; McCormack 2010; Rubenstein 2009; Sanders et al. 2011; Savolainen 2011b). These papers were supported by studies which asked contributors why they participate in online groups: emotional or informational support consistently emerged as the major reasons (Armstrong & Powell 2009; Bacon, Condon & Fernsler 2000; Nicholas et al. 2009; Rasmussen, Dunning & O'Connell 2007).

In keeping with this, frequent emotional language or descriptions of emotions are commonly noted by authors (Liu 2002; McCormack 2010; Sanders et al. 2011). Though aggressive, negative interactions or ‘flaming’ are said to occur (Burnett 2000), I found little discussion of it in the online health support group literature, where support tended to be positive (Eichhorn 2008; Savolainen 2010a). Examining an online group for partners of seafarers, Tang (2009) described how feelings of individual contributors could be shaped collectively away from negative feelings and towards positive feelings, supporting contributors though times of loneliness and anxiety.

Given the evident importance of the support available from internet groups, some researchers have explored it in greater detail, describing types of emotional support (Bresnahan & Murray-Johnson 2002), and finding correlations between giving or receiving emotional support and coping with illness (Han et al. 2011; Kim et al. 2011). Chuan and Yang (2010) contradict other papers, by finding that explicit emotional support was rare in alcohol support forums. However, they only coded each message once, for either informational or emotional support, where most other studies reported here used multiple coding for these themes[25].

Other studies have examined the kinds of information appearing online (Burnett 2000; Burnett & Buerkle 2004; Heverin & Zach 2011; Jaloba 2009; Marton 2003; Savolainen 2011a; Wikgren 2003). They found that people tended to post personal stories (Chuang & Yang 2010; Malik & Coulson 2010; McCormack 2010; Rubenstein 2009; Sanders et al. 2011; Savolainen 2011b), creating narratives which could be examined as sense making instances (Brown & Addington-Hall 2008; Crossley 2003; McKevitt 2000; Morrissey 2006; Olausson et al. 2006; Sakalys 2003). People sought opinions or evaluations more than facts (Chuang & Yang 2010; Savolainen 2010 2011b). Motivations to share information online included the enjoyment of helping others (Bacon, Condon & Fernsler 2000; Krasnova et al. 2010), viewing ‘gifting’ as a social activity that communicates regard or esteem (Skågeby 2010). Sometimes patients tried to avoid asking for help from family too frequently

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[25] Chuan and Yang also appear to show that requests for emotional support came from forums more often than the other formats they studied: journals and notes between members.

or at ‘unsociable’ times, like the middle of the night, turning to the understanding of peers online instead (Sanders et al. 2011). Others perceived a combination of intimacy and anonymity in discussion groups which made it easier for them to share personal details online than with close associates or health practitioners (Colineau & Paris 2010; Rasmussen, Dunning & O'Connell 2007; Seale et al. 2010). This included discussion of physicalities and taboo topics like pain, sex, genitalia, “wet fart syndrome”, and diahorrea (Emad 2006; Rasmussen, Dunning & O'Connell 2007; Seale et al. 2010). These examples suggest that online groups are a location in which ideational and emotional interactions abound, as well as discussions of physicality, in a form amenable to research.

Social dynamics

Though online groups may not always be viewed as communities (Blanchard 2008), nonetheless the creation, protection and management of a sense of community was frequently noted across this literature (Armstrong, Koteyko & Powell 2012; Bar-Lev 2008; Bresnahan & Murray-Johnson 2002; Burnett, Besant & Chatman 2001; Burnett & Buerkle 2004; Fayard & DeSanctis 2010; Hampton & Wellman 2003; McCormack 2010; Rosenbaum & Shachaf 2010; Rubenstein 2009; Skågeby 2010; Walker & Wehner 2009)[26]. This is significant given the theoretical importance of social interactions to sense making (Olsson 1999; Weick 1995) and the importance of interactions and relationships for patients and their relatives, identified in Section 2.2. A study of an online forum created to train people with chronic illnesses noted that “participants seemed to colonize this online space as a means of creating collective support that went beyond the formal structures of the course” (Sanders et al. 2011, pp. 144-5). Participants could be relatively isolated in their experience of illness offline (Bacon, Condon & Fernsler 2000; Jaloba 2009; Tang 2009), so the online groups provided opportunities for members to identify normality for their situation (Drentea & Moren-Cross 2005). LIS researchers have considered virtual communities as potential *information grounds* (Counts & Fisher 2010) and *small worlds* (Burnett, Besant & Chatman 2001; Burnett, Jaeger & Thompson 2008).

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[26] Though the format of blogs is different, Savolainen notes similar community development around dietary blogs (Savolainen 2010a, 2010)

Moreover, online communities exhibited norms, rituals and ethics (Blanchard 2008; Radford 2006; Rier 2007; Wikgren 2003), illuminating inter-relations between individual contributions and the identity or culture of groups (Rosenbaum & Shachaf 2010), and revealing how authority can be contested online. Community norms online might reinforce dominant discourses such as biomedical explanations for illness (Barker 2008; Copelton & Valle 2009; Fox, Ward & O'Rourke 2005b) but could also develop and reinforce divergent discourses (Fox, Ward & O'Rourke 2005a; Wojcieszak 2010). Explicit judgements of quality and credibility were found to be frequent in online discussion forums (Savolainen 2011a) with participants evaluating information posted by others, rather than taking solutions directly from online discussions (Armstrong & Powell 2009).

Therefore, online groups provide opportunities to study ways in which people identify normality, react to norms, and negotiate social understandings including constructions and contestations of authority.

Methods and research perspectives

In terms of research methods, the online groups literature emerged with clear differences from the other literature reviewed here. Instead of interviews, most researchers analysed the transcripts of online interactions (e.g. Barker 2008; Burnett et al. 2003; Han et al. 2011; Park 2008a, 2008b; Seale et al. 2010). Their analyses tended to focus less on individual experience, and more on group dynamics (Drentea & Moren-Cross 2005; Emad 2006; Fayard & DeSanctis 2010; Gajjala 2002; Jörgen 2012). Most saliently, the online groups research demonstrated the potential for longitudinal research into everyday sense making, which I will explore further in Chapter 3.

* * *

In section 2.1, I identified sense making processes requiring theoretical attention, including the role of *emotions* and *physicality*, the idea of *normality* and the processes by which *sociality* and *power* are enacted. The online research literature suggests that these themes commonly manifest in interactions online, making them potentially available to research. In the next section I bring together the findings of my literature review from Sections 2.1 to 2.3, identifying how the strengths of the disciplines of LIS, organisation studies and illness-related sense making research complement each other. I identify how, with a cautious eye for the particularities of any community, these potential areas for new research might be well supported in online environments.

2.4 Summary of gaps in the literature

Theoretical treatments of sense making have brought forward eleven theorised themes pertinent to sense making processes: *mind, emotions, body, spirituality, information / knowledge, social aspects, time, enactive processes, plausibility, power*, and *identity*. The illness experiences literature suggested one more theme needing theoretical attention: *normality*.

Theoretically identified themes of sense making	**Theorist**	**Literature source**		
		Sense making (Theorised attention)		**Illness experience *(untheorised mentions)***
		LIS	**Non LIS**	
The mind (including cues)	Dervin, Weick	Common	Common	*Common*
Emotions	Dervin			*Common*
The body	Dervin			*Common*
Spirituality	Dervin			*Occasional*
Information / Knowledge	Dervin	Common		
Social aspects	Weick, Olsson Savolainen		Common	*Common*
Time (retrospective, ongoing)	Dervin Weick			*Common*
Enactive	Weick Dervin		Common	
Power or Control	Savolainen Olsson		Common but problematic	*Common*
Plausibility	Weick			
Identity	Weick		Common	*Common*
Normality	Genuis			*Common*

Table 2.3: Coverage of themes relating to sense making

Most of these factors are not yet explored in LIS sense making literature. Table 2.3, above, shows that Dervin was involved in raising seven of the identified themes. Yet in the LIS literature I surveyed, sense making was generally only presented in relation to *cognitive processes* and the need or use of *information and knowledge*, two of the twelve potential themes. Contributions from the wider sense making literature provide details of other themes, but still leave some gaps. The illness experience literature confirms the frequency of the least explored areas of sense making, without providing theoretical detail. For example, while there were only occasional discussions of emotions or the physical senses in the sense making literature, almost every paper in health referred to these themes – but rarely went further than noting them as important aspects of experience. Much work remains to theorise their relevance to sense making processes by patients. Finally, extensions of theoretical understandings of sense making to include *normality* should incorporate theoretical understandings from the social sciences (such as Durkheim 1982; Foucault 1977; Goffman 1973; Strauss 1967) and connect to Chatman's (1999) work on *small worlds*.

Methods and research perspectives

The majority of studies I examined used sense making perspectives as a lens to investigate other phenomena. Even when research focussed on *what sense making is*, the preference for one-off, retrospective interviews meant that studies identified *factors* associated with sense making. The detailed, enactive *processes* whereby people make sense are typically not made available by interviews. The opportunity emerged to examine how sense making is done at the micro level of "step taking done by individuals" (Dervin & Clark 1993, p. 104). This is particularly so outside LIS, where Dervin's micro-moment interviews are rarely used (a comparable interviewing method is Leung 2010). In Chapter 3 I argue that even Dervin's interviews are not able to provide the detail required to study sense making as it is enacted.

The organisation studies literature demonstrated useful outcomes from longitudinal studies of sense making. Moving away from interviews to examine lived interactions in this way may enable investigation of time in sense making and observation of sense making as enactive processes. Moreover, few authors have examined more ordinary, ongoing or everyday sense making, for which longitudinal studies would be suited.

It can be difficult to obtain data for studying sense making. The review of online groups is valuable here, by demonstrating that the transcripts of online groups contain ample quantities of data exemplifying themes of sense making, in longitudinal form and as social interactions. I argue that it is possible to develop longitudinal, micro-level understandings of enactive social sense making interactions, by the study of online discussions.

Conclusion

To create this review of sense making, I looked beyond LIS literature to theoretical perspectives and debate occurring in other disciplines, particularly organisation studies. Considering the ideas raised by key sense making theorists, I established a working definition of sense making as *micro-processes of cognitive and embodied meaning making, with reference to situated reality, including orienting oneself for action*. According to the sense making theorists I surveyed, sense making combines *mind, emotions, body,* and *spirit*, and involves *identity*, *time*, *power*, *information/knowledge*, and orientation with *social* understandings. It is *enactive*, and aims for *plausibility* more than accuracy. Potentially, understandings of *normality* may also need to be included as having to do with sense making.

I found very few papers about sense making in online groups, and none about renal sense making, indicating the potential to contribute to the literature in these areas. Gaps identified across the literature suggested an opportunity for longitudinal examinations of enacted sense making micro-processes in groups, with an eye for themes other than cognitive uses of information.

I have restricted this review to papers explicitly addressing sense making. Even so, it dramatically widens perspectives on sense making current in LIS, which focus on information related themes. This is not surprising as information provision is their core business; however I argue that LIS could benefit from the wider perspective. In Chapter 8, I will demonstrate that looking beyond information does produce useful insights, including practical opportunities for information professionals.

Chapter Three: Methodology and Methods

Including ethical issues

> All this time the Guard was looking at her, first through a telescope, then through a microscope, and then through an opera-glass. At last he said, 'You're travelling the wrong way,' and shut up the window and went away.
>
> (Carroll [1901] 2004, p. 165)

Though I knew I wanted to investigate how people make sense, it took me some time to find the right approach, or even the right data set. In the end, like the train guard inspecting Alice with a range of lenses, when I found my data I used a variety of ways to interrogate it. However it would be a stretch to get anything practical out of the guard's conclusion. By contrast I wanted to produce practical conclusions with reasonably self-evident utility.

In the previous chapter I described how most of the literature exploring sense making used sense making theories as a lens to study something else. These studies focussed on *what people make sense of*. They often ended up creating maps of common experiences, rather than describing sense making processes. It's a bit like studying how people see by asking them what they saw. I needed to find a way to turn the telescope back onto sense making itself. To do so, I set aside methodologies focussing on experiences – such as phenomenology – and existing recommended methods like Dervin's Sense-Making interviews. It is common for social science methodology and methods to be a *bricolage* (Denzin & Lincoln 2005). In this chapter, I will explain the decisions I made while piecing together mine.

Following the hierarchy for research frameworks outlined by Crotty (1998), my research is theoretically positioned as follows. Of the perspectives gathered here, so far I have only briefly discussed Sense-Making. In this chapter, I will describe the range of other theoretical and practical contributions which influenced the design of this research.

Epistemology: social constructionism;
Theoretical perspectives: ethnomethodology, Weick's sensemaking and Dervin's Sense-Making;
Methodology: hybrid (informed by ethnomethodology, practice theory, conversation analysis and grounded theory);
Methods (data gathering): participant observation in online spaces;
Methods (data analysis): content analysis and thematic analyses.

In this chapter, I first describe my theoretical perspectives, which are based on ethnomethodological understandings of social negotiations of sense described by Harold Garfinkel, combined with a social constructionist reading of Dervin's Sense-Making Theory. In Section 3.2, I discuss the location for this research: online discussion boards. I explore implications of the combination of this particular location with my methodological approach, reflecting on my ethical position and my interactions with the research field. I present my research question at Section 3.3. In Section 3.4, I describe the detail of my methods of analysis, explaining how they stem from the theories used in this project. Section 3.5 is an overview of the limitations and contribution of my methodological approach.

3.1 Theoretical perspective

This study began with Dervin's Sense-Making metatheory (1999b), whose influence remains at a theoretical level. During the three years of this research, I moved toward more explicitly social constructionist perspectives (Charmaz 2006) and eventually found a better theoretical fit in for my project in ethnomethodology (Garfinkel, 1967). Here, I describe key contributing theoretical elements from Dervin and Garfinkel and justify the connections I have made between them.

Sense-Making

Dervin's metatheoretical approach to making sense informs this research at ontological and epistemological levels. Ontologically, I began at her vision of a shifting and partly-comprehensible reality, and of sense making as ongoing bumbling processes whereby humans negotiate living (Dervin 1999b). Epistemologically, Dervin specifically describes the individual sense maker as more than a mind: they are human with a body, heart and spirit, all of which can be involved in making sense of reality (Dervin 1999b, p. 730). Following her directive, I did not restrict attention to cognitive elements of sense making.

To Dervin, humans constantly make sense by constructing theories about reality (1999b, p. 733, 2003). This is not 'grand theory' – these everyday theories might be comments, stories, narratives, explanations, pictures, tunes or actions. Though they make mistakes and change their mind, Dervin's humans are able to express their theories when asked, for example, by a researcher. To this end, Dervin designed a range of Sense-Making interviews by which a researcher and participant can create detailed descriptions of the participants' past sense making (Dervin 1989a).

Dervin has suggested that her perspective on communication does not focus on the individual but *does* draw on their perspective. She noted that "individuals constitute society / culture / institutions and these collective entities have no existence without the energizing behaviours of individuals. Thus, a formulation of communication must account for the individual" (Dervin & Clark 2003, p. 167). However the give and take between individual and collective sense making is not apparent in her interview design. Her interviews are intensive investigations of the perspectives of an individual participant. In most interview-based research the interrelated renegotiations of perspectives between the interviewer and the interviewee(s) is sidelined (Rapley 2004), and Dervin's interviews are no exception.

Moreover, Dervin specifies sense-making as dynamic and ongoing (1999b), which suggests a need for longitudinal observation of changing situations, attitudes, feelings and events. Her interviews are structured to follow sense making processes through time but they do so as recollections created by the participant during one interview. That is, the memories of the sense making are accessed from one perspective in time – the time of the interview.

I therefore had two methodological problems with Dervin's interviews – that they are retrospective and that they have an individual rather than a social focus. So I took Dervin's Sense-Making metatheory as my theoretical starting point, looking elsewhere for ways to explore *social* aspects of *ongoing* sense making processes.

Social sense making

Constructionism is a theoretical viewpoint on meaning and knowledge as constructed by and through human interactions with the world (Crotty 1998). This does not mean that we invent our own realities: "the world and objects in the world […] are our partners in the generation of meaning" (Crotty 1998, p. 44). This makes constructionism neither completely subjective nor completely objective, and connects to Dervin's view of sense making as embodied and involved with physicality. *Social* constructionism is the acknowledgement of the social origin of meanings, institutions and culture, such that individuals do not develop (all of) their own meanings, but inherit meanings from people around them (Berger & Luckmann 1966; Crotty 1998). This realist-and-relativist take on social constructionism will become crucial in Chapter 6, when I explore the interrelations of experiences and understandings.

If humans make sense – or develop meanings – using meanings they inherited from others, then the passing of meaning between humans is crucial, and understanding sense making requires paying attention to the shifting understandings of individuals *in interactions* and to relationships between individual- and group-held understandings. Weick's (1995) conception of sensemaking emphasises the importance of socially negotiated understandings, but he did not recommend methods by which to direct sense making research. He did however base some of his theorising of sensemaking on ethnomethodology.

Ethnomethodology

With its particular emphasis on analysis of interactions, ethnomethodology specifically directs attention to interplays between social and individual. It does so, however, with a focus neither on the individual nor the collective, but rather on the situated production of order in activities (Rawls 2008). Deriving its name from interest in the *methods* by which people (*ethno*) enact socially sanctioned ways of acting and being, ethnomethodology is an approach to social inquiry which began with Harold Garfinkel and colleagues in the 1950s and subsequently influenced practice theory (e.g. Gherardi 2009a) while it was also developed into conversation analysis (e.g. Sacks & Schegloff 1974). It is directly relevant to this study as it is a theoretical approach to studying the sense making processes of people in everyday situations (Heritage 1984; Rawls 2008), by examining how they understand each other, make decisions, account for action and construct rationality (Mullins 1973). Ethnomethodology directs research focus towards the norms and rules of behaviour in groups, as well as the sequence and timing of actions within interactions, observing society as a "system of rule governed activities" (Garfinkel [1967] 1984, p. 74). Theoretical attention is focussed on both societal expectations and the activities of individuals, by considering interactions as the point at which they merge and manifest. Ethnomethodological questions centre around how people maintain those rules and act accountably (Garfinkel 2002; Rawls 2002). I had similar questions about what people do to contribute to *developments of sense* in socially recognisable ways.

Ethnomethodology dovetails well with Dervin's Sense-Making Methodology, a connection noticed by Savolainen (1993). Both approaches reject the model of 'transmission of information', referring instead to methods by which people work towards common understandings (Fox 2008). Dervin's scorn of the transmission metaphor is well established (Dervin 1989a, 1991, 1992; Dervin 1994; Dervin 1999b, 2003; Dervin & Clark 2003; Dervin & Frenette 2003). Furthermore, both Dervin and Garfinkel conceive individuals as actively designing their moves (Dervin 1999b; Rawls 2008). For both, meaning is contextual and developed by participants in ways particular to each unique situation; on that basis Dervin attempts to predict behaviour using "categories of situation-facing" (Dervin 1998, p. 40). Therefore, both require that the researcher pay attention to context and its involvement in people's interpretation of meaning. Dervin's detailed interviewing systems develop exhaustive descriptions of context, while for Garfinkel, ideally the researcher should locate themselves within the fields they are researching, able to observe emerging meanings of events (Fox 2008). Ethnomethodological studies are commonly ethnographic.

Garfinkel is concerned with how situations unfold contextually, in time. Actors must realign themselves and design subsequent acts against changing contexts, moment by moment (Rawls 2008). Therefore, situations should be studied as they unfold, with activities contextualised live (Fox 2008; Heritage 1984; Maynard & Clayman 1991). This is the perspective I was looking for, because it pays attention to the longitudinally unfolding processes of sense making. It calls for live data rather than post-hoc interviews, both for the sake of engagement with context and for the observable presence of relevant actors. At the same time, ethnomethodology directs attention to the interactions of people in shared situations – to collective rather than individual sense making.

Garfinkel's understanding of unfolding interactions is not however, perfectly congruent with Dervin's concept of Sense-Making. For Dervin, sense is constantly made and unmade, a process inherent to living. By contrast, Garfinkel views habits and habitual practices as our first point of contact with the world, a kind of unthinking or habitual *sense*, while sense *making* is secondary, a process of repairs undertaken when things go wrong (Garfinkel [1967] 1984). Garfinkel pays attention to situations and understandings which are taken as given, embedded in habits and manifested in activities which for him provide evidence of *sense*. I follow Dervin by considering all interactional material as *sense making*.

Ethnomethodology is therefore a crucial theoretical influence in this project, the means by which I moved away from Dervin's (interview based) and Weick's (often ethnographic) approaches to the study of making sense. Ethnomethodology is not cognitivist but has a social focus, which suits my interest in how sense making is socially shaped; ethnomethodological research requires attention be paid to sequences during which accountability unfolds. The attention I pay to sequences will be explained in Section 3.4. Ethnomethodological perspectives inform this research by guiding how I thought about methods. However my focus was *sense making*, not *accountabililties*. I study the interactions of three communities and I will discuss their habits and behavioural norms, but these discussions are not the end goal of the research, only a stepping stone. At one point in Chapter Four, I will discuss reactions to broken norms, but again only in order to discuss sense making, not in order to understand these communities' norms. As I will soon describe, I examined sense making processes by examining interactions using thematic and content analyses.

Studying text

One might expect that to understand sense making I would ask people how they made sense. Or I might want to watch people being treated for kidney failure, to understand how they make sense of it. Having chosen to study how people make sense in online discussion boards, I neither interviewed participants nor watched them dialyse. I have already explained why I passed over Dervin's particular interviewing techniques; here I will explain why I decided not to interview at all.

First, as discussed above, I wanted to study sense making *en vivo* rather than retrospectively. I hoped to observe *happenings* in a particular sense making scenario, rather than what people *report happening* (Silverman 2007). Though what might be said in interviews would be interesting and might provide useful perspectives on the experiences of kidney failure, an interview is a piece of social sense making in its own right; trying to use an interview *to examine past sense* *making*, I would not only fail to retrieve those processes from the past, but may also fail to grasp the processes of the interview *as sense making in the present* (Silverman 2006, pp. 44-5; 2007).

Moreover, interviewing implies a conception of sense making as something that happens internally, which must then be externalised to become accessible to the researcher. By contrast, Gergen (1985, p. 270) wrote that “knowledge is not something that people possess in their heads, but rather, something that people do together”. As an alternative to interviewing, I was inspired by a body of theory loosely grouped together and called *practice theory* (Postill 2010). Inspired in part by ethnomethodology, practice theorists abandoned the assumption that knowledge and learning are mainly individual and mental processes, conceiving of them instead as mainly social and cultural phenomena (Brown & Duguid 1991; Cook & Brown 1999; Gherardi & Nicolini 2000; Lave & Wenger 1991; Weick 1995). People make themselves accountable and demonstrate their accountability, in and by their everyday activities (Weick 1995). This means that the things people do and say demonstrate their understandings of what should be done (Garfinkel [1967] 1984; Heller 2001; Heritage 1984). Practice theorists focus on these observable, manifested phenomena: “doings and sayings” (Schatzki 2012) which demonstrate and re-enact knowledge, and make “knowing” accessible to research (Gherardi 2008).

Writing is both doing and saying (Austin 1962). Language makes experiences readily transmittable, and thereby, social (Berger & Luckmann 1966, pp. 68-70); and language is seen as intrinsic to sensemaking (Brown, Stacey & Nandhakumar 2008; Gioia & Mehra 1996; Weick, Sutcliffe & Obstfeld 2005). In fact, some sense making theorists suggest that language generates understanding rather than the other way around: “[Weick sees that] sense is generated by words. […] And it is these inscriptions – not the events themselves – that serve as the stuff of the sense-making process.” (Gioia & Mehra 1996, p. 1228). Berger and Luckmann (1966) used the term “sedimentation” to describe how experiences are developed into recognizable and memorable entities which may enter into the collective stock of knowledge[27].

These remarks may lead you to expect that I undertook some form of discourse analysis. Discourse analysis, in a range of guises, is commonly used to explore how people use language to perform actions including positioning themselves, enacting identity, and co-constructing meaning (Hepburn & Potter 2007; Heritage & Maynard 2006; Paltridge 2006; Potter & Wetherell 1987). This allows one to theorise possible strategies in the timing of appearances of different discourses present in a community and how speakers construct worlds of meaning (Schwandt 2007, p. 73). Discourse is seen as *constructions* of meanings by those involved (Clarke 2005, p. 149) and the practices of discourse are the locale in which individuals enact cultural and social institutions – potentially modifying them in the process (Farnell & Graham, 1998, cited in Clarke 2005, p. 152). Certainly I thought of this kind of discourse analytic perspective during my analyses. However, this study is not a classic example of any of the various forms of discourse analysis. For instance, I identify *control* and *power* as themes in my data, and their relationship to meaning making, knowledge and authority (Fairclough 2001; Olsson 1999), but such questions are not the focus of this thesis. Nor do I reflect on discourse from a societal perspective (Jäger 2001; Van Dijk 2001). I paid attention to interpretive repertoires employed in the data (Potter & Wetherell 1987), but that work is reported separately to this PhD (Godbold 2013). As I will describe presently, the analysis in this thesis pays close attention to structures of interactive turns, following the ideas – but not the methods – of conversation analysts, and shaped by my theoretical interest in ethnomethodology. Detailed explanations of the sequential analysis will come at Section 3.4.

Opening out the research agenda

In previous writing, I have suggested enquiry into information behaviour other than information seeking (Godbold 2006). Individuals may not seek information when, for example, the context involves risk (Chatman 2000; Wilson 1997). For this

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[27] Berger & Luckmann cited Schutz (1962), whose writings also influenced Garfinkel ([1967] 1984) . Schutz’s influence on the writers who have influenced me only became apparent late in the writing of this thesis; it will be interesting to read his work in the future; such reading may well have enriched this project.

project, I therefore wished to locate a context in which people are *likely* to experience significant levels of risk, in case I might observe a wide range of possible sense making activities. Also, I was intrigued by Dervin's references to sense-unmaking, an area less theorised to date. She comments that "humans are involved in a constant journey through sense-makings and sense-unmakings" (Dervin 1999b, p. 731). I wondered how sense *un*-making might manifest.

These problems required fresh perspectives on sense making, for which I was informed by grounded theory (Charmaz 2006; Glaser & Strauss 1967). Although variations of grounded theory exist, a central concept is that of generating new theory 'grounded' by empirical research – that is, in response to data – rather than working with preconceived models or by creating and testing hypotheses (Clarke 2007). However, my study departs from the procedures described by Glaser and Strauss, who charged the researcher to approach data without preconceptions, and who implied that data can be studied objectively to reveal inherent categories for the researcher to discover. The approach I took to theory building was informed by the perspectives of social constructivist grounded theorists (Charmaz & Mitchell 2007; Clarke 2005), who point out that the researcher necessarily produces interpretations: "Meaning is created, not discovered" (Dey 2006, p. 88). My findings represent one of several possible ways to interpret the data. Nor did I follow any of Glaser or Strauss's various detailed programs for coding. Instead, I followed Silverman's description of the constant comparative method for developing and testing provisional hypotheses and actively addressing deviant cases (Silverman 2006).

* * *

At the centre of this research are theoretical conceptions of sense making as ongoing processes of socially constructed meanings. This meant that I needed access to social sense making unfolding step-by-step in interactions. For the purposes of the research, it was possible to take detailed text, such as written interactions, as data[28]. I

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[28] Texts can be conceived widely as 'communicative events' (de Beaugrande & Dressler 1981, cited by Titscher et al. 2000, p. 21), which may include situations, objects and conversations, as well as more traditional written forms such as letters or articles. Moreover, language is not the only carrier of meaning; the range of potential sites for the study of discourses include objects, pictures, movements

was fortunate to find data in *online renal discussion boards* which matched all of these criteria. In the next section I will describe why online renal discussion boards were a good location in which to study ongoing social sense making.

3.2 Locating the research

I have explained in Chapter 1 how, as I was planning this research, I was also newly married. My husband Gregory and I had a routine of walking every night. As we walked and chatted, Gregory often referred to his experiences with kidney failure. I finally made the obvious connection between my need for a research location and the complex, frightening stories he was telling. People with kidney failure and their companions live with the risks inherent in that illness and they undertake ongoing sense making; moreover the difficulties they experience justify investigation and support. By studying renal sense making, my apparently theoretical research question could simultaneously obtain both a tangible location and the possibility of being practical and valuable. In addition, given that I am the wife of a renal patient, I may be described as an 'insider' within that community (Goffman 1968), giving me the potential to learn about their sense making as a participant.

However the context of renal failure opened up its own set of problems. To attempt longitudinal research, data was needed on a frequent and ongoing basis. In addition, quite detailed, intimate data was needed. I needed lived data because of my interest in ongoing sense making rather than retrospective, recreated or idealised data from interviews (Silverman 2006). Yet, particularly when considering the chronically ill, it is preferable to avoid intruding into the lives of research participants more than necessary (Brannen 1988).

Online discussion groups

Online discussion groups are internet forums where people discuss ideas by typing 'posts', usually a paragraph or two long. Posts are gathered into 'threads' which maintain the conversational order in which posts appeared, and keep them on semi-

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and more (Clarke 2005). As it turned out, the data which I found for analysis was written text. Therefore in the discussions to come, when I refer to text I mean written texts.

permanent display. In some groups, new posts are emailed to all members; more commonly members must visit the group website to read posts or add to ongoing discussions.

Online discussion boards can encourage frank, honest and detailed exchanges (Hine 2005, pp. 22-3; Seale et al. 2010). Contributors are reported to benefit by writing out their thoughts (e.g. Frank 1995; McGrath, Reavey & Brown 2008, p. 61) without having to deal with (some) physical issues such as being properly dressed. In particular, internet-based modes of research are well documented as being of value for working with patients or the chronically ill, as it allows patients to participate from home and choose the timing of their contribution (Kivits 2005; Kralik, Koch & Brady 2000, p. 913).

I located three renal discussion groups which focussed on the ongoing lived experiences of chronic kidney failure: they were introduced in Chapter 2. People in these groups described situations they were in, talked each other through problems, compared understandings, discussed test results and so on; plenty of non-medical chat also occurred. Interactions contained detailed, personal accounts of life on dialysis. Some contributors posted frequently, and it was common for people to provide ongoing updates of situations. I realised that if I could study these online interactions, I would have access to rich, ongoing data, appropriate to my research objectives, while minimising intrusion into the lives of contributors because posts are ‘naturally occurring data’ made only when contributors choose to post (Kellehear 1993; Silverman 2005).

I viewed posts in the discussions as instances in which contributors attempted to make sense of situations for other members, using typed narratives (Czarniawska 2004). Furthermore, the discussion group archives preserved linked sequences of text-based social sense making: lasting representations of interactions, of which the interweaving of messages as well as their phrasing remained for analysis. Here was an opportunity to investigate how sense was developed in communities and how individuals drew from and contributed to communal sense making. And I was qualified to join as an insider, as a ‘renal wife’. Such hand rubbing raises ethical questions, which I now address.

Ethical issues

Online ethnographic research presents particular ethical challenges, which were complicated by my decision to work with renal patients, a potentially vulnerable population due to their chronic ill health.

Approaches to ethics in online research

In discussions of ethics for online research three main perspectives emerge. One perspective is that data which people have put online into public view is ‘published’ and in the public domain (Walther 2002). Such bodies of data can therefore be analysed without contacting those who created them. In particular, this approach has been put forward as appropriate for some methodological approaches, such as large scale quantitative analysis and forms of discourse analysis, where individual personalities and circumstances are not presented as data (as for Herring 1993; Walther & D'Addario 2001). Such large scale analyses could not reasonably expect to obtain consent from the thousands of contributors, many of whom may no longer be contactable (Walther 2002).

A contrasting approach is based on ethical guidelines for human research: though data may be publicly available via search engines, participants’ informed consent must still be obtained before research using their contributions can proceed (King 1996). This is because public and private spaces become blurred online, particularly in online discussion forums (Waskul & Douglass 1996). Although contributors may know that an online space is public, discussions can acquire the ‘feel’ of a small group gathered in the corner of a café. They develop a sense of “perceived privacy” (King 1996, pp. 125-6). This complicates our considerations of research ethics, particularly for research concerning the individuality or perspectives of research subjects and even more so for researchers interested in empowering those researched. The emphasis is on respect for individual perceptions of privacy and minimising potential harm to participants (King 1996).

Medical research ethics generally insist on informed consent from individual participants. However, King (1996, p. 126) suggests that support groups for medical conditions constitute communities which are high in perceived privacy, and suggests that nonreactive research methods might be used so that members are not “affronted by the presence of an investigator in their forum” (King, p. 125). Because renal patients are chronically ill, I considered whether to design my research in this way, but conversations with group owners[29] led me to believe that an upfront approach was less likely to affect the perceived safety of the support space.

Finally, a third perspective is that of online content as intellectual property. This approach sees online content as creative output mandating acknowledgement of its creator’s identity (Bassett & O'Riordan 2002; Bruckman 2002). This kind of approach is normally appropriate where people are developing a creative or political presence online, or otherwise trying to present a message in a public space. Even this approach became relevant for this project, because among the goals of the groups I studied was the aim of creating archives of experiential knowledge for other renal patients. Group owners asked me to acknowledge their groups as sources of my research data.

Ethical approach of this project

Guided by the literature and by discussions with owners of the three groups, my approach was based on obtaining individual consent from contributors to use anonymised data, while acknowledging the groups as hosts.

I joined the three discussion groups in early 2010. I had already joined one group before I conceived of the groups as a location of my research. I asked the owner and then the members of that group if I could stay as a researcher and they allowed me to do so. Meanwhile, I approached the owners of the other two groups to discuss this research. They each independently proposed to let members discuss my project and

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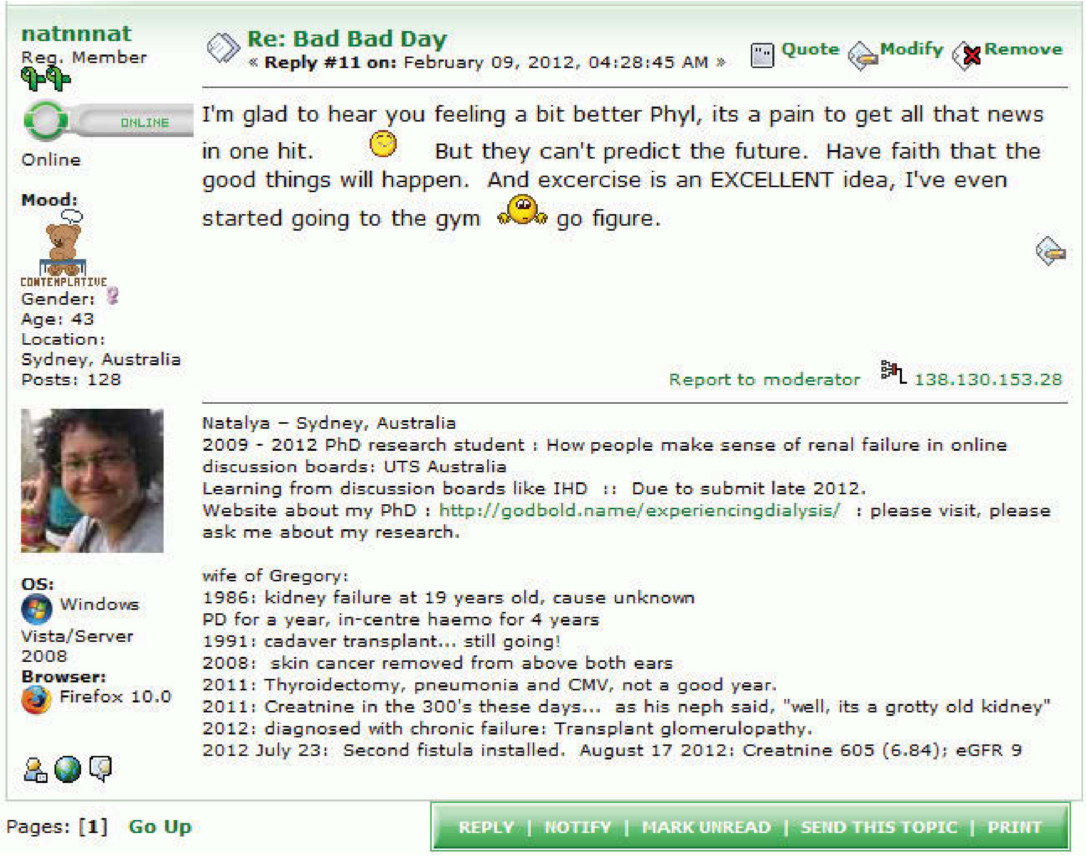
[29] An ‘owner’ of a discussion group is often the founder of the group. Owners set up the conditions for membership and posting, create moderators and exercise discretionary control over activities, for example, by closing down discussions, removing messages or ‘banning’ members.

decide if I was welcome. I was accepted by the communities as a member, as I will describe presently. For two of the groups, at the bottom of every post is a signature and profile information. Mine stated that I am a researcher as well as the wife of a renal patient, and includes a link to my project website, as shown in Figure 3.1.



natnnnat
Reg. Member
Online
Mood:
Gender:
Age: 43
Location:
Sydney, Australia
Posts: 128
OS: Windows Vista/Server 2008
Browser: Firefox 10.0

Re: Bad Bad Day
« **Reply #11 on:** February 09, 2012, 04:28:45 AM »

I'm glad to hear you feeling a bit better Phyl, its a pain to get all that news in one hit. But they can't predict the future. Have faith that the good things will happen. And excercise is an EXCELLENT idea, I've even started going to the gym go figure.

138.130.153.28

Natalya – Sydney, Australia
2009 - 2012 PhD research student : How people make sense of renal failure in online discussion boards: UTS Australia
Learning from discussion boards like IHD :: Due to submit late 2012.
Website about my PhD : http://godbold.name/experiencingdialysis/ : please visit, please ask me about my research.

wife of Gregory:
1986: kidney failure at 19 years old, cause unknown
PD for a year, in-centre haemo for 4 years
1991: cadaver transplant... still going!
2008: skin cancer removed from above both ears
2011: Thyroidectomy, pneumonia and CMV, not a good year.
2011: Creatnine in the 300's these days... as his neph said, "well, its a grotty old kidney"
2012: diagnosed with chronic failure: Transplant glomerulopathy.
2012 July 23: Second fistula installed. August 17 2012: Creatnine 605 (6.84); eGFR 9

Figure 3.1: screen shot of one of my posts, showing my profile information in KidneyKorner

In each group, new members were expected to write a post introducing themselves. As instructed by owners, I used my first post to the new groups to introduce my research as well as my interest in dialysis as the wife of a renal patient. I invited members to discuss what they thought about the idea of the group being researched, and also asked people to let me know if they wished never to be contacted about the project (one person made this request), or to if they wished to provide blanket consent for their contributions to be included in the research (eighty-five people gave this blanket consent).

I obtained individual consent from other members on a case by case basis by sending draft writing to relevant contributors and asking for permission to quote them. This approach was consistent with established online ethnographic research (e.g. Scharf 1999 cited by Elgesem 2002; Orgad 2005; Sundén 2003). Through my ongoing participation, I developed relationships with other members online. I sometimes sent or received private correspondence with individuals and I attended occasional lunch meetings for the Sydney-based Australian Dialysis Buddies. I also posted final drafts of my writing to the discussion boards, inviting comment and feedback. By June 2012 I had sent requests for consent to 169 individuals, removing quotes for which consent was not obtained. This process has allowed me to present at conferences and publish journal articles and book chapters about my research with the informed support of those I have counted or quoted.

Data gathering: Participatory fieldwork

Ethnography is traditionally used to create descriptions of cultural behaviour (Schwandt 2007, p. 96). A recent development is online ethnography (following examples such as Blevins & Holt 2009; Capitulo 2004; Copelton & Valle 2009; Gajjala 2002; Markham 1998). Posts are seen as discursive acts, constituting the bulk of the activity in the text-based environment of the discussion boards. The researcher joins the online community as a member, and participates by making posts or chatting online, to develop understanding of aspects of life online, such as the performance of gender (Sundén 2003), or how people understand illness online (e.g. breast cancer Orgad 2005; irritable bowel Stewart & Williams 2005). Online ethnography produces rich and informative accounts of human interactions online (Hammersley & Atkinson 2007, pp. 137-9). This project is not an example of online ethnography, but I did make use of ethnographic methods to gather my data. I will explain the distinction presently.

I deliberately avoid referring to the online as ‘virtual’ because of the associations of the word ‘virtual’ as somehow less real than offline experience (Markham 1998; Sundén 2003). Rather than being viewed as mere repositories of text, online spaces are viewed as places (Markham 1998) in which culture and society are enacted, activities and events occur, and time passes (Hammersley & Atkinson 2007, pp. 136-7; Sundén 2003). Online spaces involve sound and movement – for example, from videos and animation. Occurrences include the arrival and departure of members, and the progression of key discussions and announcements; and members are affected by technical events like servers crashing or software problems closing chat rooms. Threads occur in time: posts written late at night must wait for day to come for replies, especially as the turning earth rolled daylight around for members in other countries. I missed comments while I was busy, and often found myself pondering the wait between comment and answer, especially after my own posts, as I nervously considered the meaning of a long pause before someone responded.

Because I aimed to learn what it was like to be a member, I attempted to participate as a normal member most of the time, rather than as a researcher. I only once asked a 'research question', and received one reply[30]. Instead, I took part in normal discussions, offering relevant anecdotes from Gregory's experiences, sharing events in our lives, and commiserating or celebrating the news of other members. When Gregory became sick, I asked for help, and received it. I spent almost two years in this way. I did not attempt to become a forgotten "fly on the wall" (Hammersley & Atkinson 1983). As I will discuss presently, in online discussions, if you are silent you disappear completely (Blanchard 2008), and I aimed to be a familiar presence. I hoped that would help other contributors feel comfortable enough with me to allow me to write about their posts (Fetterman 2004).

On the other hand, I was not a normal member, because I was a researcher. I provided drafts of my analyses back to contributors as described in the previous section, and I maintained my introduction thread as an ongoing conduit of my research-related news, so that people could comment on my work and so that they could have a clearer idea of my research activities.

However, although I needed to understand posts in the situated context of the culture of the groups, a description of the culture of online renal discussion groups was not the goal of this project. My research focus was sense making as it occurred in the online space. I make a distinction between the methodological approach called ethnography – of which this project is *not* an example – and ethnographic *methods,*

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[30] Gregory told me he sometimes dreams he is back on dialysis. I described that conversation in a post, and asked "Have you ever dreamed you were on dialysis?"

which I used for data collection and to develop myself as an instrument of analysis (Hammersley & Atkinson 1983). It is common for ethnomethodological research to involve this kind of ethnographic immersion in the field of study, in line with the research goals of being able to recognise norms and memes in the community with an insider's eye (Fox 2008; Maynard & Clayman 1991).

My presence in the field

By November 2010, five months after I joined, my introduction posts to the two larger boards had received a total of 31 responses. Of those 31 responses, I perceived 29 as 'positive', for example:

> *[Welcome emoticon] to [the group]. Your research sounds interesting AND respectful as well as potentially useful.*
>
> *I love being researched. Do I have to take my clothes off? Can I do it anyway? Anything for science!*

The one negative response I received[31] described feeling a sense of safety and privacy in the boards, stating that having a researcher there changed what this person would feel free to say. The person wrote to me privately asking not to be included in the research. They continued to contribute to discussions, and helped me when I needed advice about giving my husband injections.

As described earlier, I had to keep posting in order to maintain a degree of visibility as a familiar presence to other contributors. My being 'in the field' therefore made me accessible and accountable to the communities under study. In particular, showing draft writing to contributors, and then to groups for feedback, enabled personal exchanges with members and offered me some understanding of how I was perceived by others. The potential was also there for contributors to have a voice in the research. On consent forms I included a space for people to give me instructions or make comments. Some comments remarked on uses or relevance of the research, helping me to better conceive its implications. When I posted my first draft paper to

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[31] There was also one 'unclear' response which stopped halfway through the first sentence.

the whole group, a member with a Masters in anthropology sent me pages of feedback and commentary, which I incorporated into the next draft of the paper. In ways like this I learnt from the community, whose members acted as the first round of ‘peer review’ for my findings. The possibility of negative feedback from them kept the voices of contributors in my mind as I wrote – and would have made criticism of the groups, had I so desired, harder to achieve. Yet I remained in control of writing for publications, and the whole project is presented through my perspective; rather than ‘channelling’ participants, I have interpreted them.

Sensitive research

Sensitivity in research is usually directed toward participants, who are seen as vulnerable (Dickson-Swift, James & Liamputtong 2008). In the case of my research, I particularly worried about wrecking the safety and privacy of the space either during my research or due to publications from it. Contributors *are* vulnerable, in that they have a serious, chronic illness. But they were also humorous, educated, and sometimes willing to function as colleagues in the research process. They had opinions and ideas about their illness, and the relevance of this research. Overall, individuals and groups appeared to be robust in their reactions to the research. I do not take this to mean that such groups can or should be researched frequently; rather, their welcome may be due in part to the approach I took, in part due to their interests in improving the experiences of kidney patients, and in part to their not yet having been over-researched (Clark 2008).

However, the threat in sensitive research can also manifest on researchers (Dickson-Swift, James & Liamputtong 2008). I found that my own situation was both more exposed and more robust than I had imagined. Online spaces are all public spaces to some degree; comments are archived, and people can search the content *in perpetuum* (boyd 2010)[32]. I had to think about my husband’s privacy, and about my long term professional identity as well as my private identity as a renal wife or a group participant. Meanwhile I learned that people from the groups were ‘googling’ me and finding other parts of my identity such as emails I have sent to academic

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[32] danah boyd’s name is not capitalised in citations.

mailing lists, and wedding photos posted online by my father. This turned out to have positive effects, for example one of the moderators said to me when she agreed to let me join the boards, "I found [some academic emails] and knew you were genuine."

When I first thought of studying sense making in the context of renal dialysis I blithely thought that I would be an insider. I later felt that I was not really inside, as I had never seen dialysis. All of Gregory's dialysis experience occurred long before we met. At times I was stoic about this feeling, merely commenting in my blog "I wave Gregory in front of me like a white flag" (My blog[33], 15/4/2010). At other times it troubled me. However, my feelings of being an outsider did not appear to translate into comments from others, who manifested acceptance and inclusion. I actually found safety online by posting and being present in the boards, because when I did the community supported me. They sent me messages of warmth and 'electronic' hugs, they wrote in support of my research, of my attempts to support my husband and of our experiences of the medical system. They suggested questions to follow up with our specialists and tips for injecting medications. And as Gregory's transplant began to fail they provided role models and reassurances.

This research space involved difficult content with disturbing descriptions and photos. People suffered, worried and sometimes died. I was very aware that I could not actually help anyone online except by sharing parts of Gregory's experience. I also began to realise that these were often discussions about situations which Gregory had experienced and which he might experience again. I developed a clearer understanding of his past and future, and it scared me sometimes. On the other hand what I learned was helpful. As well as picking up medical understandings, I learned how to 'be' a renal wife without becoming overwhelmed and maybe without being annoying, a common outcome of well-intentioned attempts to help one's ill companions (Veinot, Kim & Meadowbrooke 2011).

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[33] I kept a private blog during my PhD in which I recorded my experiences and feelings about my fieldwork.

* * *

In this section I have described the process of locating my research in online discussion boards, tracing the connections from my theoretical assumptions about sense making to the contingencies of the online groups, and exploring the particularities of that kind of space as a location for research. I have explored relevant ethical problems, first with reference to what the literature suggested as the right way to approach this field and then contextualised in terms of my experiences, beginning with a reflection on my effect on the groups and their effects on me, and ending with a sketch of the effects of the research on my understandings of my husband's illness. In the conclusion to this thesis I will return to my interaction with the data, to reflect briefly on how my own sense making exemplified my findings.

Some research starts with the research question, from which the methodology and method can be derived. In my case, I began with a topic (sense making), chose a theoretical perspective from which to consider it, and looked carefully for a location in which it could be observed. Only then was it practical for me to create a research question, which I now present in Section 3.3, along with some brief clarifying comments. Detailed discussion resumes in Section 3.4 where I describe the methods I chose to address the research question.

3.3 Research question

In this section, I present my research question along with brief explanations of its constituent parts. The research question is:

> *How do people make sense of kidney failure in online renal discussion groups?*

The question has four elements, which I unpacked briefly in the introduction. I provide more detail here.

How

The research focus of the project was at the micro-level of people interacting: how people provided appropriate contributions to discussion threads. I examined descriptions of experiences as *attempts* to make sense (Czarniawska 2004, p. 5; Fisher 1984; Weick 1995), or *demonstrations* of sense made. My goal was to identify what I call 'elements' and 'mechanisms' for making sense – including Garfinkel's "accountabilities" ([1967] 1984) – places where people may have demonstrated an awareness of what was proper or needed for sense making in an interaction and provided it. This formed a connection to my theoretical understanding of sense making as ongoing, socially negotiated, situated yet 'bumbling' processes. More specific questions to access the detail of sense making interactions included questions of content:

- *How do contributors describe their situations, experiences and feelings and how do their descriptions change over time?*
- *How do they attempt to help each other?*

…and questions of sequencing:

- *Is there any significance in the timing or sequence of contributions?*

People

Significantly, I did not propose to follow the sense making trajectory of individual participants, nor did I wish to link sense making activities to the characteristics of individuals. For example, I did not propose to identify psychological profiles related to sense making 'styles'. Though individuals are interesting, I was not interested in the characteristics of individuals, but in social interactions and what they might demonstrate about social sense making. People may make sense in individual or characteristic ways; I set this question aside for later research.

Making sense

My working definition of sense making from Chapter 2 was: *micro-processes of cognitive and embodied meaning making, with reference to situated reality,* *including orienting oneself for action*. My interest was in social sense making. Acknowledging the social origin of the meanings constructed by individuals (Olsson 2005a), my aim was to engage with communally held understandings such as stories (Boje 1991) as they occurred in interactions (De Jaegher & Di Paolo 2007) by studying conversations where everyday social constructions of meaning occur.

These first three parts of the research question created a theoretical and methodological background for the research, but did not suggest methods. It is the last element of the question which provided the conditions against which appropriate methods could be chosen.

The context: online renal discussion groups

The online renal discussion groups I studied provided a particular kind of textual data: rich, detailed, and at times very personal. This data was from interactions between peers who described each other as family, dealing with lived experiences, and there was a great quantity of data.

* * *

I was to examine thematic *dynamics* in interactions online. I wanted to see how *understanding and responding to situations* was demonstrated in the conversations, not because I wanted to learn what individuals were thinking, but because I wanted to see what they chose to show each other as models of sense making.

In the following section, I explain the methods I used, first to obtain an overview of data, and then to develop detailed understandings.

3.4 Methods

In the previous section, I commented that the online discussion groups provided rich, detailed, personal data in great quantities. Posts accrued at a rate of over 150 messages a day. I needed first to obtain an overview before I could develop detailed understandings of what was happening in interactions. In this section I explain the methods I used to achieve those ends.

Data analysis

I had begun reading posts for several months before I joined two of the groups, and I continued to read every day, noting no obvious changes in interactions or group dynamics after I joined. I read an average of 400 posts per week for almost 1.5 years in 2009-10 and approximately 30 per week until May 2012. I also explored the archives going back to 2005. As I read, I copied interesting posts and threads into word documents, some of which were later entered in a database or translated into charts, a process which I will explain presently.

While there may well have been many revisions and deletions before a person ‘published’ a post, it was only the published version of a post that contributed to public sense making in the thread. For that reason I only concerned myself with the text as it was published, leaving aside ruminations about the thought processes that went into creating them. Because of my interest in interplays between individual and group sense making, the unit of analysis shifted between posts and threads.

Analytical focus

As described earlier, to explore unknown aspects of sense making, I wanted to ‘begin from scratch’, though I acknowledge that I could not begin without preconceptions (Charmaz 2006). I devised a layered approach to the data analysis, illustrated in Figure 3.2, on the next page.

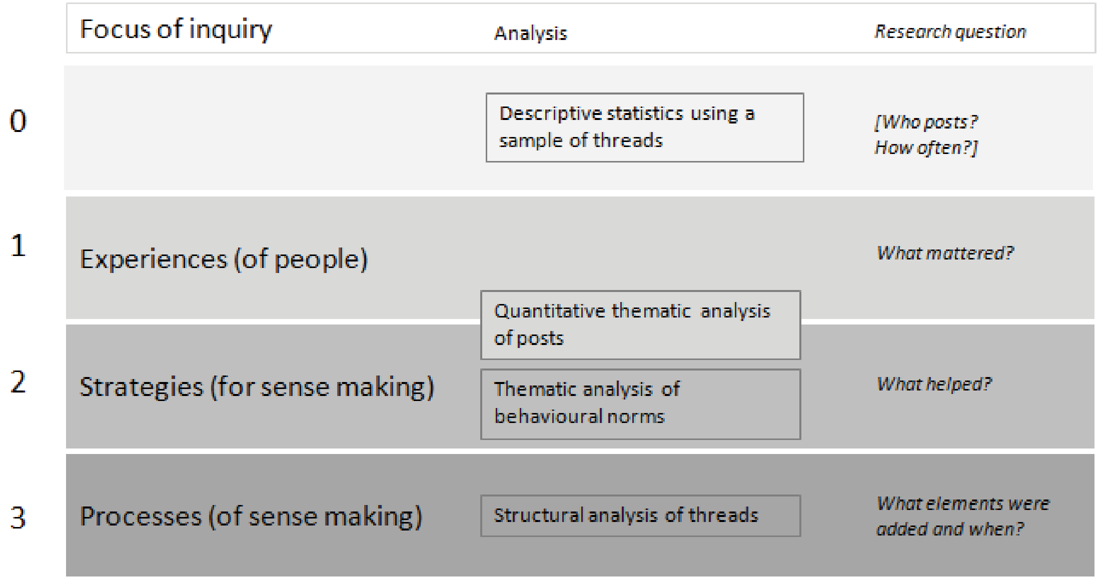

Figure 3.2: Layered approach to the data analysis

The array of analyses I undertook were as follows. First, in May 2011, all posts made during a week of discussions were copied into a database, to create a sample with which to contextualise the study and to describe the population of the three groups. Following this background analysis of who was posting and how often, there were three layers of focus to my inquiry. I call them layers because I felt that they were hierarchical, in that I was drilling down deeper into details with each layer. At times I examined what people described as their *experiences*; I also noted the *strategies* they shared with each other for making sense of situations; and beyond these two levels, I looked for common *processes* in sense making – what tended to be done, and when.

The three levels of analysis shown at Figure 3.2 partly connect to Dervin's methodological perspectives. She conceived of three aspects of sense making, circled by the person making sense: their perception of *gap*, their understanding of the situation (its *"situationality"*) and what they perceived to *help* (Dervin 1980; 1992). I similarly examined people's descriptions of their experiences (*situationality*), and their expressed strategies for sense making, which they often passed to each other as what *helped* them. However, my interest in sequences within threads saw me depart from Dervin's example. Here, I was guided by Garfinkel's (2002) descriptions of people cooperating to create well-functioning, intelligible interactions.

The three levels of my analysis were associated with three partially overlapping methods of analysis. First, themes in discussions were created by constant comparative readings and re-readings of the threads in the sample database (Silverman 2006). Next, given Garfinkel's interest in social mores ([1967] 1984), I studied themes in behavioural norms online. Finally, the placement, timing and context of elements in posts were represented visually using charts, to enable a sequential analysis of threads. In this way I paid attention to content, culture and sequencing, with an eye to how they might affect each other (Weick 1995). The different level of analysis also gave me insight into posts from multiple angles, each of which provided more detailed, contextual insight than the one before – starting from the overviews provided by thematic analysis, and ending with the very contextualised sequential analyses.

Details of each of these approaches were as follows.

Descriptive statistics

I used data from the week in May 2011 to create a set of measures with which to describe the groups and their activities – which I already presented in Chapter 1 when introducing the discussion groups. I obtained measures about the activity of each group, including frequency of posts, lengths of threads, and number of active members. Statistics about groups included where people (said they) were posting from, their ages, and their length of experience with renal failure.

'Content' analysis

Using the data from the week in May 2011, I coded and counted instances of themes in posts, tabulating frequencies of (1) themes in descriptions of experiences – especially, in what people identified as important in the experiences – and (2) themes in people's advice to each other. As the themes were created and refined during iterations of coding (Silverman 2006), this was not classic content analysis which is based on pre-determined categories (Titscher et al. 2000). However, I used the eight most commonly occurring themes to create a coding frame, with which I then re-coded all posts in the data set.

Thematic analysis of behavioural norms

Garfinkel saw interactions as revealing the morals and rules by which people maintain coherent social interchange (Maynard & Clayman 1991). I looked for themes in interactional norms in the three groups such as how people were expected to treat each other. I examined home pages, rule lists and examples of welcome posts to new contributors, reflecting on what they revealed of group expectations (strategies) for supporting member's sense making.

Sequential analysis

I analysed sequences in threads, noting for example, the timing or placement of the appearance of themes from the thematic analyses – as I describe later in the section on sequential charts.

Qualitative researchers commonly stop their analysis when they reach theoretical saturation (Dey 2006; Glaser & Strauss 1967), when no new themes appear to them despite analysis of new data. When I reached theoretical saturation for one level of analysis, I moved the analysis to another level. The analyses still eventually stopped when I felt I had reached theoretical saturation, but the shifts between analyses prolonged and enriched the process. In this way I was later able to notice congruencies between content and sequences. For example, people described situations in which they had become used to experiences as time passed – so time passing appeared as a *theme* in people's descriptions of their experiences; elsewhere, people advised each other that time was needed for them to get used to experiences, presenting 'allowing time to pass' as a sense making *strategy*; meanwhile development of familiarity over time also appeared as a *sequential element* in threads. This does not create the kind of triangulation which might identify 'truths' about sense making, but it did triangulate my understandings – no matter where I looked, I found similar themes.

Most of the methods I used were straightforward: coding themes and counting instances of them. The thematic analyses were useful for demonstrating the frequency which which I was noticing themes in discussions. But being frequency counts, they removed themes from the context in which they appeared, which is inappropriate for a study which assumes a key role for context in situated sense making. The sequential analysis addressed this need for contextualised analysis. It involved creating charts, a process which needs methodological explanation.

Sequential Charts

My goal with the sequential analysis was to explore the contexts and timing with which themes appeared. I also wanted to identify other ways in which posts and interactions were constructed. For instance, Garfinkel conceived social activities as having a “sequential back-and-forth character” in which “each next thing that is done or said is taken in relation to the last” (Rawls 2008, p. 712, describing Garfinkel 2006). I wanted to examine sequentiality in the discussions, in case common elements were used in particular ways at particular times, and to see if themes had particular significance in particular combinations.

Conversation analysis has been said (albeit controversially) to be located at the ‘micro’ level of analysis – compared to ‘macro’ analyses of how discourse shapes and is shaped by society (Van Dijk 2001). The inspiration for conversation analysis was “empirically based, naturalistic, descriptive study of human conduct” (Pomerantz & Fehr 1997, p. 68). It takes a closer look at sequences in conversations, considering turn-taking, the uses made of particular words or silences, as well as how people position themselves with respect to shared understandings and claims of authority or truth (Heritage & Raymond 2005; Heritage & Sorjonen 1994; Sacks, Schegloff & Jefferson 1974). It was developed by Sacks and Scheloff, among others, inspired by Goffman’s interest in ordinary life (Goffman 1963) and Garfinkel’s ([1967] 1984) interest in everyday conduct.

However, conversation analysis is designed for the analysis of spoken interactions, in which timing and overlap play particular roles. By contrast, the development of threads or sequences in online posts is different to the spoken turns in a live conversation: though posts may be written hastily, in general the medium of text allows planning and rewriting of posts compared to the improvisation of speech, and the archival properties of threads allow writers to review earlier posts before or as they compose new ones (Van Dijk 1997). The use of signifiers unique to the online environment, such as animated emoticons and profile information, adds other dimensions which are particular to online interactions. Moreover, I was interested in the development of meanings more than in conversational practices. In these ways, though influenced by conversation analysis, this project is not conversation analytic research.

In the online discussions, people might make use of thousands of possible ideas or themes, so following all possible themes *across* threads or looking for the appearance of particular themes in every thread could only get me so far. Instead I examined individual threads for whatever local themes they contained, charting the re-use of local themes or elements of speech *within* threads. In particular, I wanted to be able to note when and how elements recurred at this local level. In creating the sequential charts, elements of interest to me were primarily:

- content (new ideas, repeating themes; use of vocabulary including metaphors, sayings and cultural references); and
- tones (investigating manifestations of emotions in posts).

In the discussion to come I will talk about 'themes in content' and 'themes in tones', and I will examine sequential developments and interrelations of content and tones. The analysis of tones relates to Dervin's interest in emotional sense making while the examination of locally unfolding intelligibility was inspired by my reading of conversation analysis (Pomerantz & Fehr 1997). However, my analysis was undertaken visually, with charts, rather than using text. My interest was in the turn-by-turn progressions of interactions, interrogating them for how people organised and produced meaningful interactions which made sense (Pomerantz & Fehr 1997). I illustrate the charts and describe their creation in detail in the next chapter.

The sequential charts are therefore not conversation analysis, nor discourse analysis. Though inspired by elements of these two approaches and by ethnomethodological perspectives on the development of interactional sense, the charts are best described simply as a form of visual thematic analysis. They make patterns and sequences visually apparent, highlighting sequences ahead of content. Each chart mapped a different set of speech elements (different metaphors, different ideas and so on), but the charts revealed similar patterns such as how local elements were taken up within a thread, re-used and developed.

* * *

In this section I have drawn connections from my chosen theoretical conceptions about sense making, through to their manifestations in the methods of data analysis I undertook. Next, I summarise my approach, gathering together the methodological strengths and weaknesses of this project.

3.5 Overview of the Methodology

To conclude Chapter 3, I present an overview of the structure of the project, reiterating its key elements. This is followed by discussions of the limitations of the research and its possible methodological contributions.

First, this project explores social sense making by observing interchanges between individuals as they contribute to and gain from collective sense making. This is a perspective noted by Dervin (Dervin & Clark 2003) but which she appears to have rarely enlarged upon except with Schaeffer (Schaefer & Dervin 2005, 2009). It is overtly social constructionist research principally developed using perspectives from ethnomethodology but also springing from my reading of practice theory and conversation analysis. This is appropriate, as practice theory and conversation analysis are themselves related to ethnomethodology.

To study social sense making I chose a location in which people were interacting. For detailed longitudinal perceptions of the development of sense and to observe ongoing sense making, I sought a participant population who were faced with situations likely to require sustained, ongoing sense making, and who might demonstrate 'sense-unmaking' – whatever that might be. I joined them as a fellow-participant, to obtain an insider's understanding of the meanings and contexts of the situations under study. Meanwhile, Dervin's conception of the sense making human as "body-mind-heart-spirit" (1999b, p. 730) enlarged my focus beyond facts, cognitive activity, or language, to include emotions and physicality.

These methodological implications stemming from theoretical perspectives related to sense making are summarised at Table 3.1, below.

Theoretical perspectives	**Methodological implications**
Sense making as social processes (Weick) Accountability in social processes (Garfinkel)	Need participant observation within a social location
Sense making as ongoing processes (Dervin; Weick; also related to ethnomethodology, practice theory)	Detailed longitudinal data needed
Sense making involves emotions and bodies as well as minds (Dervin; practice theory)	Attention paid to emotions and physicalities as well as exchanges of ideas

Table 3.1: Summary of key theoretical perspectives on sense making and implications for research

Methodological Limitations

Limitations of the data

Anyone who has ever read a description of a needle going into an arm knows that the words do not merely describe an image; they conjure an imagined experience of steel in flesh. But descriptions of physicality and manifestations or descriptions of emotions are different to the smell of disinfectant and the sounds of machine alarms. In studying text I chose a set of compromises. People might make sense by thinking, writing, while interacting with other people; via actions such as by testing the body for ability or pain; or by learning a skill; and by many of these combined. Text-based sense making in discussion boards are a different kind of sense making than I might have explored with other methods, such as interviews, video ethnography or regular visits to dialysis wards and homes of patients. Was my move toward text a move toward ideas and away from physicality and emotions and their role in sense making? This raises tantalising questions about when one might feel one had access to ‘real data’, a problem best approached by trying to be as clear as possible about what my data and research focus ‘really were’.

My research focus was not on experiences but on sense making. Given that my data *really were* textual interactions, if I had wanted to study something like *how people feel kidney failure*, then I would have had a problem. Instead, my research focus was sense making, and I viewed the written interactions as rich, accessible examples of active sense making. Having sought data with the potential to match my goals, I also adjusted my goals in line with what could best be learnt from the data. I adjusted my focus to *sense making in the online spaces*. In this way, the data and my research goals became better matched.

Furthermore, by studying social interactions, I studied how people worked together to develop *sense* in sensible interactions, rather than *truth*. I did not take descriptions posted to the forums as direct expressions of experience, nor as perfect expressions of the state of the writer at the time. I did not attempt to perfectly understand another's private perspectives nor how they experienced situations, to discover what people 'really' thought or felt (Heritage 1984, pp. 49, 55, referencing Schutz and Garfinkel). Rather, I viewed posts as *attempts* at sense making, and the analysis focuses on how people made those attempts. So another limitation of the research methodology may be that it focuses on expressions of sense rather than 'inner-felt' sense. However I see this less as a limitation of the research than recognition of what can realistically be studied.

Limitations in the analysis

My inner positivist wants to tell you 'how people make sense', but that would be foolhardy. In its classic form, content analysists attempt to produce *reliable, objective* counts of elements of data (Berelson 1952) – but such a goal is inappropriate for social constructivist research[34]. My interest was in the nuanced inter-relations between members, based on insider-understandings (Rawls 2008) which are necessarily subjective; objectivity is a stance which would render me blind to such details. So the analyses represent only my interpretation of the data. Instead of generalisability and reliability, I aimed for verisimilitude and well documented procedures (Silverman 2006). With the thematic analyses, I quantified some of my subjective impressions, which allows me to say that particular threads were typical of my view of the data.

---

[34] From social constructivist perspectives, objectivity does play a part due to the recognition that people's constructions reflect interactions with reality – though idiosyncratic, they are not 'invented'. Beyond that however, social constructionist research precludes reaching for a single truth applicable across many situations and people (Crotty 1998).

Hence, one limitation of my methods of analysis hinges on whether I recognised conditions for sense making in the online interactions in the way that others would – verisimilitude. A curlier way to state the problem is one commonly raised in criticism of grounded theory. That is, the categories I saw in the data may have sensitized me to continue seeing them, strengthening my sense of familiarity with the findings and my feelings of their "right fit" (Dey 2006). The meanings I was using were not discovered but created (Charmaz 2006; Dey 2006) – though the constructedness of facts and meanings does not necessarily make them untrustworthy (Latour 2005a).

On close inspection, this thesis is circular. In the chapters to come, I will describe findings such as the following: that people made sense by finding patterns and categorising. That they looked for norms and what was normal. Meanwhile this chapter has established my methods of analysis: that I looked for patterns and categorised, identifying what was normal, that is, prevalent or commonly occuring.

A rejoinder comes from Schutz (1962, 1964 as summarised by Heritage 1984). He used *verstehen* to describe how people interprete the social world in terms of social categories and constructs, that is, by reference to common, socially located understandings. Schutz argued that not only are these *verstehende* processes the central procedures through which the world is interpreted by ordinary social participants (Heritage 1984), but also that *verstehen* is "an indispensable method of the social sciences" (Heritage 1984, p. 46; see also p.50). Social scientists interpret and understand the actions of subjects to the same degree of inexactitude as any other social actor, because *verstehen* is social. This is not access to what others experience; rather, it "involves a 'making out' of 'what's going on here'" (Heritage 1984, p. 49) using what is typical or reasonable of a situation. When the social scientist is member enough to interpret shared common understandings of social situations, then they have "intimate access to these common-sense constructs as they are used and acted upon" (Heritage 1984, p. 50). They are an acceptable instrument for the interpretation of *verstehen* in a situation, by their own access to *verstehen. Verstehen* means 'to be able to stand in the place of'. In my case, my account emerges from my experiences of a field of possibilities in interactions as a group member, able to take a place in discussions or to imagine taking the place of other participants.

Perhaps the circularity between my findings and my methodology strengthens the findings. The different levels of the project point to my making of myself a consistent research instrument, finding the same kind of features in the data no matter at what level I examined it. My adequate *verstehen* is confirmed in part by my being included in discussions; the fact that some participants responded to my academic writing and agreed with it is an added extra (Maxwell 1998, p. 78). Furthermore, that my findings about sense making are similar to established processes for making sense of research data may be another form of verisimilitude, though I wonder at my capacity to see otherwise.

Methodological contribution

A final question is whether I have constructed something new, relevant and useful (Silverman 2006), the goal with which I began this chapter. I devote another whole chapter (Implications, Chapter 8) to argue for the utility of my findings to the broader community. They may have already been useful to members of my host groups, who have seen much of my writing about them.

As a piece of research, this project applies ethnomethodological theoretical perspectives to the study of sense making, incorporating perspectives from Sense-Making (Dervin 1999b) and sensemaking (Weick 1995). This combination gave rise to some methodological innovations and resulted in one customised method – sequential charts.

The theoretical focus was not on people’s experiences of something (such as, of renal failure), but on the processes of discussing (making sense of) experiences. This makes it different from most research based on Dervin’s work. It is also different from most LIS studies, where researchers rarely cultivate an ongoing, active participation in the research environment or use naturally occurring longitudinal data. Even among Organisation Science researchers, sense making is more often examined by taking snap shots of participant’s perspectives at a point in time, via interviews.

Sense making research is usually a retrospective look at how sense *was* made, while my approach is a situated look at sense *as it is made*. My approach contributes to the smaller body of research analysing the ongoing inputs of all actors involved in sense making interactions (Heverin & Zach 2011; Matthews & Stephens 2010; Schaefer & Dervin 2009; Sonnenwald & Pierce 2000), constituting an explicitly social, longitudinal focus. Finally, my approach is different from ethnomethodological research which explores how people account for themselves and respond to each other's accounts – but here the difference is subtler. I do explore accountabilities but not to understand the social norms behind them so much as to learn what they show about the social processes of sense making.

This study is not the first to use thematic analyses to explore social norms or the presentations of identities and classifications (Clarke 2005) – but my approach turned theoretical justifications for discourse analysis (such as, that discourses are used to construct local meanings) into methodological tools *to study sense making* (such as, that local meanings might reveal generalisable sense making elements). The same shift occured with my use of ethnomethodology. Ethnomethodologists analyse activities as demonstrating *how people conceive an activity should be done* (Garfinkel [1967] 1984). I made the methodological move of studying interactions to learn *how people conceive sense can sensibly be made*. Rawls points out a similar layering in Garfinkel's work, in that ethnomethodology is both a *theory* of work and a *method* for studying work (Rawls 2008). In my study ethnomethodology manifests both as a *theory of sense making,* and as a *method for studying sense making.*

No doubt this project is a special case, because the subject of the research was sense making. *How do we make sense* is essentially an epistemological question: *what is it to know, how do we know?* So, in choosing an epistemological position for the research, I already proposed an answer to the research question. It could be said that I put forward a hypothesis, that we make sense by social construction, and explored the implications. Perhaps I should have rephrased my research question as follows:

> *Let us assume that people make sense by the processes referred to as 'social construction'. What can I learn about the detail of social construction, if I examine patterns in interactions between people discussing renal failure in online discussion groups?*

So one contribution of this research is that it adds to our understanding of the details of how social constructionism works during interactions.

Another methodological contribution of this study is the development of sequential charts as a visual method of analysis. Inspired by the step-by-step focus of conversation analysis, they facilitate the study of sequence over content, by foregrounding sequential relationships between elements of threads while moving content into the background. In this way, the charts had a kind of wordlessness which I needed to be able to 'see' interactional construction; in so doing, I was able to map the development of emotional tones and ideas, as threads progressed.

Conclusion

To investigate sense making, I analysed text from online discussions. I developed coding frames for content analysis and I also identified emergent themes using less structured thematic analyses; producing both qualitative and quantitative descriptions. This is a very simple set of methods, but sense making is not a simple concept. It needed a carefully thought out approach. The methodological basis for my project draws on elements of Dervin's Sense-making theory, Weick's sensemaking theory, Garfinkel's ethnomethodology, practice theory, grounded theory and conversation analysis – while manifesting none of these kinds of research as they are traditionally known.

Based on insights from Dervin and Weick, I conceive sense making as social, ongoing, enactive processes. Influenced by ethnomethodological descriptions of how meanings emerge in interactions, I participated in online renal support groups, following interactions *en vivo*. Influenced by practice theory, I view activities as evidence of sense making, examining discussion posts as written sense making. Therefore I describe external performances of sense making, not internal psychological understandings. I explored themes suggested by the literature, but to extend understandings of sense making, I also describe themes that I perceived frequently in this naturally occurring data – influenced by my readings of grounded theory. Ethnomethodological and conversation analytical attention to sequences in interactions lead me to look for sequences in my textual data, but sequences in meaning development rather than conversational acts. This is the rich combination of theoretical influences sitting behind my simple methods, a series of content and thematic analyses. The result is a social constructionist approach to social sense making carried out using content analysis and thematic analysis to attend to norms and sequences in textual interactions.

The findings presented in Chapter 4 begin with descriptive statistics and content analyses, followed by broad thematic analyses to present common themes in the content of discussions and the behavioural norms of the three groups. Then I present a sequential analysis of threads best described as a graphical thematic analysis. It involved translating threads into charts depicting the relationship between repeating elements over time, providing detailed views of contextually developing meanings within threads.

Chapter Four: Data Analysis and Findings

Patterns in themes of meaning and in tones: consenses, norms and shifting meaning making

> "If seven maids with seven mops
> Swept it for half a year,
> Do you suppose," the Walrus said,
> "That they could get it clear?"
> "I doubt it," said the Carpenter,
> And shed a bitter tear.
>
> (Carroll [1901] 2004, p. 179)

I have established that my methods were simple applications of textual analysis: content analysis when I used locally pre-defined coding frames, and thematic analysis when I analysed emergent themes as they appeared to me in text. I use these methods to present a combination of thematic and numerical findings.

I analysed the online discussions in three ways. In Section 4.1, a content analysis establishes themes in what people said. In Section 4.2, themes in social norms for interactions online are identified with a thematic analysis. In Section 4.3, an analysis of sequences begins with three threads, producing patterns which I then try to break in Section 4.4 by looking for deviant data in a further four threads. I thereby present a network of mutually reinforcing themes, some of which are recognisable from the literature review at Chapter 2.

The content analysis identifies eight themes in posts: *explicit support*, *explanations*, descriptions of *experience* and use of *humour*, *control*, *emotions*, *physicality* and *normality*. Next, the analysis of interactional norms identifies four themes which are seen as important for the smooth running of the discussion groups. I describe them as *be renal*, *be community*, *join in* and *be positive*. Last, the sequential analysis of threads brings forward four sequential themes: *repetition, guidance via emotional tones, shifting meanings* and *linking explanations into lived experiences*.

In this chapter, I show how I identified these themes, and demonstrate some of the tensions and dynamic relationships between them. I also show how the three approaches to my analysis complement and reinforce each other. But in this chapter, that is as far as I go; the work required to connect these themes into sense making processes takes place later, in Chapters 5, 6 and 7.

4.1 Patterns in content - what people say

Content analysis of posts

The content analysis used representative data to establish a quantitative basis for the eight most frequently occurring themes in discussions.

Data selection

The three groups under study averaged over 150 posts a day between them, with archived messages dating back to 2005. In the introduction, I explained how I created a sample archive by copying all posts made during a week in May 2011 into a custom built FilemakerPro database. During that week there were a couple of people in hospital, no deaths, and no major arguments. As such, based on my understanding of two years of discussions, it was a fairly normal week in terms of content.

Consent was obtained for the use of contributions from 147 people who made 1,193 posts, of which 787 contained content written by the contributor about renal failure. While the data was only intended to be representative, it was drawn from three sources which are different in measures such as rate of posting, activity levels of individual members, and percentage of 'on topic' posts – that is, posts about renal failure - as shown in Table 4.1, below. From this perspective, the relative *similarity* in discussions is a strong finding.

	# contributors	**# posts**	**posts per person**	***on topic* posts per person**	**% *on topic* posts**
IHateDialysis	120	874	7.3	5.41	74.26
KidneyKorner	17	272	16.0	5.41	33.82
Australian DialysisBuddies	14	47	3.4	3.29	97.87
Total	147	1,193	8.1	5.35	65.97

Table 4.1: Comparison of posting activity between the three groups during a week in May 2011

Findings

The content analysis used posts as the unit of analysis. Each post was coded to as many themes as were required to be able to describe and compare them. The codes were not developed prior to analysis, but were chosen to describe what I observed during iterations of coding. The array of codes expanded as my perceptions of repeating themes enlarged. Later, I combined some codes. I continued to re-read and re-code the same 787 posts until the codes had stabilised. In this way, the process of developing codes was an outcome of my meaning making as I read and re-read the data. I then took the eight most frequently appearing themes and re-coded all 787 posts one last time using only these themes.

The coding frame settled into eight themes: *explicit support*, *explanations*, descriptions of *experience* and use of *humour*, *control*, *emotions*, *physicality* and *normality*. Their coding criteria and examples of each are displayed in Table 4.2, below.

Theme	**Coding criterion**	**Example from posts**
Explicit Support	Directly expressing support	"You can do it" "Don't give up" "we're all here for you" "I'm praying for you"; or emoticons[35] depicting hugs, for example.
Explanations	Presenting information or opinions which are not explicitly linked to the contributor's life	"A fistula is created by joining a vein and an artery" "It's not difficult to self cannulate"
Experience	Information or opinions which are linked to the contributor's life	"My fistula is in my forearm"
Humour	Jokes, references to humour	"You have to laugh"; or emoticons depicting laughter.
Control	Being able to affect outcomes (or not)	"No one would listen to me" "I stop drain pain by squatting"
Emotions	References or expressions of emotions	"I was scared" "I'm so delighted" or similar references to emotions / tears including emoticons
Physicality	References to the body, architecture, machines…	"I have terrible cramps and headaches" "I can't find anywhere to put all these boxes"
Normality	Mentions or descriptions of normality	"Is this normal?" "This is how we do it…"

Table 4.2: Eight most frequently coded themes in posts

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[35] Emoticon: a small picture used in online groups. Some are animated.

When coding, I coded each post to as many themes as I saw in evidence. It was possible (but rare) for a thread to have elements of *all* these themes. Thus the coding frame operates not as a set of exclusive categories but as a collection of dimensions which play through one another in posts. To demonstrate coding, I reproduce a post here, showing how themes overlapped. The post is from a thread in which the wife of a patient mentioned her own recent illnesses, and shared the name given by her husband to his new home dialysis machine. A reply from another wife of a patient read as follows.

1. [referring to the wife's illnesses] Stress and tiredness does horrible things, too … don't
2. ever forget that – you are going through a lot.
3. [My husband's dialysis] machine was called "Pammy" after Pamela Anderson because
4. "Pammy" had big bags, too … *sigh* … yes, I know …
5. Big hugs,
6. [name]

This post was coded to five themes as shown in Table 4.3, below.

Theme	Reason for coding to that theme	Lines
Explanations	Information / opinion not connected explicitly to the contributor's own life: "*Stress and tiredness does horrible things, too*"	1
Experience	Referring to her own life: "[*My husband's dialysis] machine was called "Pammy"*"	3
Explicit support	"Big hugs"	5
Physicality	Commenting on the physical effects of stress on the body Commenting on the design of the machine	1-2 4
Humour	*[My husband's dialysis] machine was called "Pammy" after Pamela Anderson because "Pammy" had big bags, too … *sigh* … yes, I know …*	3-4

Table 4.3: Example of multiple coding for a single post

Table 4.3 shows how the various themes overlapped in coding. Sometimes a single comment produced multiple codes, like the coding to *experience* and *humour* in the comment about bags here. Other times, contributors would cover a range of ideas in the course of a post; a reference to *emotions* may only appear at the end of an otherwise calmly worded post. While most codes could overlap, the exception is *explanations-experience*. These two codes differ according to whether the contributor explicitly linked their comments to lived experiences or not. A sentence was coded as *either* explanation or experience. However posts could still be coded to both codes if both kinds of sentence were present, as in the example above (line 1 compared to line 3). This overlapping coding frame allowed me to count how often posts manifested common dimensions without having to reduce posts to one code over another.

The incidence of each theme in posts is shown in Figure 4.1, below. The most frequently coded themes were *experience* (60% of posts) and *control* (51%), while the least frequent of these top eight themes were *explicit support* (25% of posts) and *explanations* (24%). Confirming the review of illness literature, *physicality* and *emotions* were significant themes which each appeared in over a third of posts.

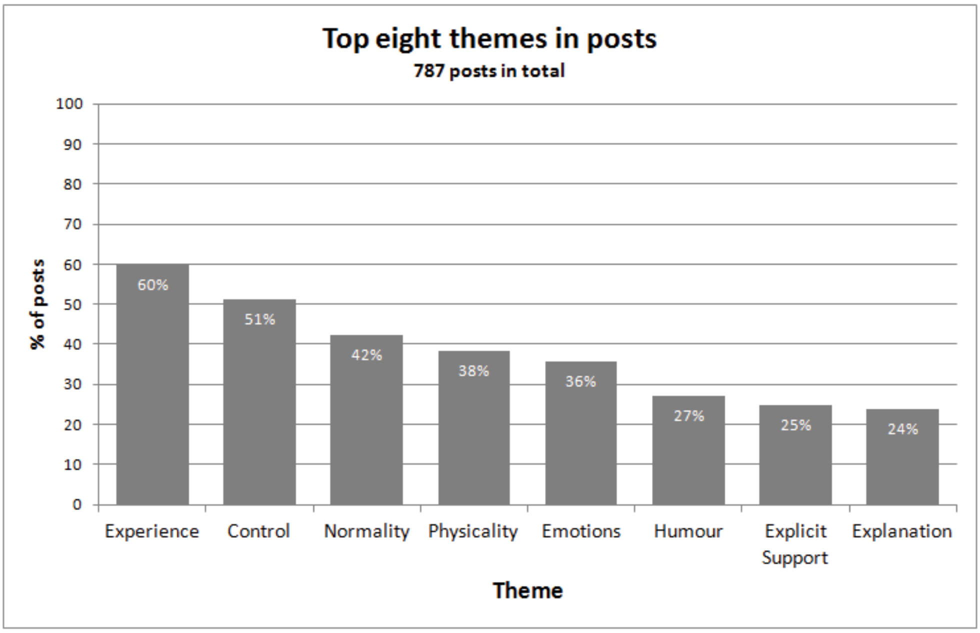

Figure 4.1: Incidence of eight most frequently coded themes in posts

Figure 4.2, below, displays a comparison between the incidences of each theme between the three groups. Despite differences between the groups, the most frequently coded themes remain *experience* and *control* in two of the three groups, while for all three, the least frequent of these top eight themes were *explicit support* and *explanations*.

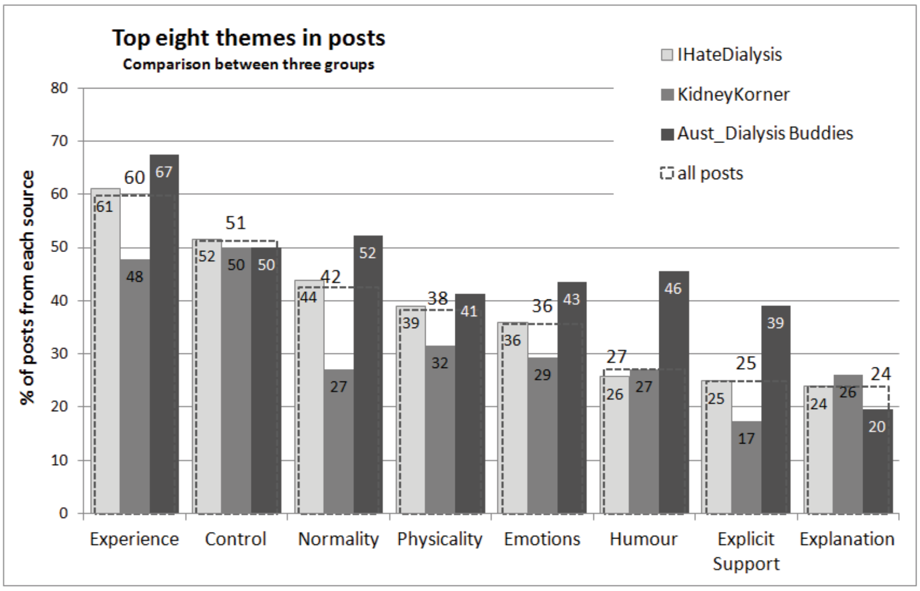

Figure 4.2: Comparative incidence of the eight top themes, between groups

* * *

These graphs show *how often* various themes appeared in discussions, but cannot show *how they were used*. Meanwhile, these results appear to contradict the literature review, in which it was established that the principal reasons why people come to online support groups are for information, and support, which might be expected to correspond to *explanations* and *explicit support*. To understand why *explanations* and *explicit support* were not the most frequently offered elements of posts here, requires more detailed analysis. To start with, the following thematic analysis of social norms sheds some light on how and why of these themes manifested, especially *explicit support* and *experience*.

4.2 Thematic analysis of interactional norms

People in the discussion groups learn implicit and explicit rules which guide interactions online. Ethnomethodological studies pay attention to these behavioural norms for what they reveal of peoples' understandings of functional, comprehensible interactions. I therefore examined references to such interactional norms in the three groups to see how they might support sense making.

My sources of interactional norms included the explicit rules displayed on each group's website or sent regularly to email based groups. In addition, people sometimes revealed behavioural norms in posts, either by mentioning them directly or 'between the lines', for example when people justified their remarks. Such references were especially frequent in posts welcoming newcomers, where people sometimes overtly told newcomers how to conduct themselves and what to expect. The analysis to follow is supported by data sets, consisting of the explicit 'rules of conduct' for each group and a selection of 'welcome posts' (see Appendix A).

I found four themes in the interactional norms: the idea of who should be speaking and listening; the idea of supporting one another; the idea of speaking freely; and having the 'right' positive, determined attitude.

Who can speak and listen (be renal)

Each of the *welcome* pages began by defining who the group was for – generally, "people who are affected by kidney disease" (See Appendix A, lines 8 & 23; see also line 34), in particular, patients and their loved ones but sometimes also people who "work in the dialysis field" (lines 10-11). Though their wording was welcoming and inclusive ("I welcome ANYONE who has a loved one on dialysis or in kidney disease! You are ALL WELCOME HERE!!" lines 80-81), this does imply the exclusion of people who are not "going through or have been through, similar experiences" (lines 39-40). New members were all asked to introduce themselves (lines 18; 52-55), and keep in touch from time to time (lines 21, 95-98). Welcome posts also encouraged active membership with comments such as "Looking forward to hearing more from you" (Example#2, Appendix A). This kind of involvement allowed members to get to know each other (lines 60, 104-107), but also can mean that those who did not have renal experiences to share were weeded out. Sharing experience was seen to be a key activity for members (lines 23-24, 39-40, 43-44, 60). Also significant was that when a person had described a situation, they were encouraged to "report back" so that others could follow how the situation progressed[36].

> *[…] any update you can provide would be very much appreciate it. Everyone has something to contribute. Someone who is still lurking[37] might be in a situation just like yours and may now have a better idea of how to help her husband...or herself.*
>
> *(Patient, IHateDialysis)*

The importance of sharing experiences, and of having members who are experienced enough to do so becomes clear later in the analysis. Even here however, one can see people pointing out how much new members will gain from the experience of other members because they have "in so many ways have 'been there/done that'" (Example#1). These were people who can understand the isolating experiences of renal failure.

Support one another (be community)

Support was a key goal of each group, and each group was described as "community" (lines 6, 22 and 78). Members developed friendships (lines 36, 39, 97). Two of the groups made the point that they aimed to connect people who might otherwise have been very isolated, helping them to feel "that you are not alone" (line 42; see also lines 24-27). Elements of this ethic included not insulting others, not contributing to ongoing arguments (lines 73-76, 82-3, 88, and 99-103) and being courteous and respectful (lines 88, 101-103). Welcome messages to new members predicted that the group would "'lend a hand' in support" and "encouragement" (Example#1 and #2). Posts also *demonstrated* support when they empathised with elements of the biography provided by newcomers. The groups were described as made of "wonderful", "friendly" people (Example#1 and #6), who were "family" (Example#2 and #4). The idea of *family* suggests non-judgemental acceptance, concern for welfare, and being in a place where one belongs: "you'll fit right in here" (Example#3). Family members are glad to see you (as in Example#1, #2, #4

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[36] All quotes and data in this submission are presented without altering spelling or grammar.
[37] 'Lurkers' read discussions without writing posts.

and #5); and they'll back you up: in the family of the renal discussion groups, "You've got someone in your corner" (Line 19).

The importance of supporting one another is noted across the literature dealing with online discussion groups, as has been discussed in Chapter 2. Here, I have established that this was an actively maintained ethic of the groups under study. Later, I will show how supportive and non-supportive tones in threads contributed to the development of consenses[38], and argue that feeling supported and feeling good about one's situation are central to sense making.

Speak freely (join in)

Etiquette at IHateDialysis made it particularly clear that members can and should speak freely in discussions.

> *[...] I started this site so dialysis patients can come and say what they really feel [...] I want people to be able to come here to vent and share their experiences. [...] feel free to ask any questions. [...] don't hold back, speak from your heart.*
>
> *(Epoman, founder of IHateDialysis)*

Though they were less emphatic, the other groups agreed that "[i]t is good to share your thoughts" (lines 41-2; see also 23-24). "KidneyKorner supports free speech" – so long as other rules of etiquette are observed (lines 87-9). By encouraging debate (lines 102) or friendly arguments (line 75) the groups created an atmosphere in which different opinions and perspectives could be shared "free from censorship" (line 4, 23-4, 71). IHateDialysis explicitly encouraged members to "rant and vent their frustrations" (lines 13-14), though fighting and insults were not tolerated by any group (IHateDialysis – lines 73-76; KidneyKorner - lines 82-83; AustralianDialysisBuddies – lines 99-101). In addition to speaking freely about one's experiences and frustrations, asking questions was encouraged, both in the *rules for posting* (line 61, 68) and in posts (Example#4 and #5). Meanwhile, people

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[38] Consenses: plural of consensus.

were to expect the same frankness in answers they receive; at IHateDialysis at least, they must expect “the straight truth” (line 15; see also lines 61-2 and Example#4). In this sense, “realism” could sometimes override the mandate to provide or accept emotional support; in practice, posts which attempted to deliver hard truths had to prepare their readers carefully.[39] Though meta-commentary in IHateDialysis expressly prepared members for this tough love, I saw it in gentler operation in the other groups also.[40]

There was another aspect to this safe space for expression, a norm which says that that it was okay to use humour; that being funny was in fact, good. Sometimes this was expressed by sentiments akin to ‘you have to laugh’[41], but more often than not it was demonstrated by frequent use of humour in posts. Humour appeared frequently as a social norm in the general discussions; it emerged in the content analysis (at Section 2.1) and will presently be noted in the sequential analysis of threads (Section 4.3).

Be positive and determined (don’t give up)

A collection of attitudes were put forward as appropriate or admirable for members to maintain: positive rather than depressed, determined rather than defeated. In the welcome pages and rules, members were “not about being negative” (line 5 and 16) and they were not looking for “a place to feel sorry for yourself” (line 65). They had a “positive attitude” (line 66). Despite their “daily struggles” (line 7) members “come together” (line 26) to “read and learn” from each other (Example#4). Not only that, members were “fighters” (Example#3), who were willing to “let [their] voice be heard” (line 12) with the knowledge that there was now “someone in [their] corner” (line 19). The role model emerging from the meta-commentary was active, positive and determined. That said, other self-presentations – frightened, crushed, isolated, uncertain, silly, angry, bored, and others besides, were also acceptable personae to present in posts – as part of speaking freely. Nor was generic, blind optimism particularly popular in discussions. So rather than being a ‘face’ which

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[39] An example is Appendix B, Thread A, Post#11.

[40] See for example, Appendix B, Thread D, post#8.

[41] Or, “laughter is healthier”, Chapter 5, Thread A, Post#16.

members must always present, the positivity described here was put to certain uses in particular situations.

* * *

This brief discussion covers four key themes common to the interactional norms for each group. Table 4.4 (below) shows how the interactional norms might have contributed to the most frequently coded themes in discussions. For instance, the norm of being positive and helping others to be positive supported the frequent appearance of *explicit support*, (positive) *emotions* and *humour*. The norm that members should join in and speak frankly supplied many instances of *explanations* and descriptions of (positive and negative) *emotions* and *experiences*, which in turn allowed *normalities* to emerge. The ethos of being supportive encouraged *explicit support* and the discussion and sharing of *emotions*; and the need to be renal to contribute meant that *explanations*, *experiences*, *support* and *humour* were all relevant because they were based on firsthand knowledge.

Content analysis	Thematic analysis of interactive norms			
	be renal (right experience)	be community (be supportive)	join in (contribute often)	be positive
experience	X		X	
control				
normality	X		X	
physicality	X			
Emotions		X	X	X
humour	X			X
explicit support	X	X		X
explanations	X		X	

Table 4.4: Connections between interactive norms and frequently occurring themes

However Table 4.4 also raises some questions. The rows are arranged in order of frequency of themes: at the top *experience* was the most frequently coded theme appearing in 60% of posts, while at the bottom *explanation* was the least frequently coded, appearing in only 24% of posts. Table 4.4 suggests that the themes most likely to be supported by the interactional norms are *emotions* and *explicit support* because they connect to three of the four interactive norms. Yet these themes are not at the top of the table. Instead, *control* is the second strongest theme, and it is not directly connected to *any* of the interactional norms. Understanding the interactional norms at play in these groups helped me to analyse interactions in Section 4.3 and also provides a background which supports my other findings – but only in part. Clearly there are other factors at work.

Moreover, in practice there are tensions between these interactional norms which sometimes made their enactment problematic. I have noted already the tension between speaking freely and being positive, which often do not amount to the same thing. In the analysis of interactions which follows, I will demonstrate some of the ways in which people negotiated these tensions, providing examples of how the interactional norms both guide sense making interactions online and contribute to producing good demonstrations of sense making.

4.3 Patterns in sequences – how and when things are said

In this section, I present a detailed sequential analysis of threads, paying attention to the timing and development of local themes as they appeared and developed from post to post. This was undertaken to draw out the interplay between the eight key themes identified in the original content analysis, and to understand how they might contribute to sense making.

This sequential analysis provides the central tenets of the discussions in Chapters 5, 6 and 7, because here I establish the interactive dynamics whereby sense making is mutually coordinated and maintained. I find that

1. *Repetition* (i.e. reuse) of themes across many posts and contributors developed consenses and conceptions of normality;
2. Emotional guidance was provided indirectly by tones; and
3. Meanings were shifted by the introduction of related themes, supported by tones.
4. People embedded their remarks within descriptions of their lived experiences;

Establishing sequential patterns

As this next method of analysis is unusual, it requires careful explanations. I start by concentrating on a single thread which, I propose, displays typical patterns. While examining this thread, I interweave similar results from two more threads. Later, I will introduce another five threads hoping to disrupt the patterns I have been identifying. In this way I end up demonstrating similar patterns in a total of eight closely analysed threads.

The eight threads are not from the week in May 2011. That data produced measures against which I could compare the rest of my findings. I did choose threads written after I began reading the boards in January 2010, so I might have an insider's understanding of the development of meaning in the threads. In line with ethnomethodological approaches to research, I aimed to be able to recognise normal interactions, to be able to see from people's reactions what was judged intelligible or not and to understand nuances of meaning in light of my experiences with the groups and a shared history of interactions.

The eight threads are summarised in Table 4.5, below. The first three (Threads A, B, and C) were chosen as 'typical' threads. I saw these threads as typical because they discuss renal failure, they don't involve arguments; they involve a problem and discussion about how to proceed, which is a classic context of discussion; they deal with common questions posed by contributors, and responses cover the typical answers provided to such questions. They may be of typical length[42].

The last four threads were chosen to explore deviant data, that is, to try and break the patterns suggested by the first three threads: Threads D and E are from an email group rather than a discussion board; as I noted in Chapter 1, this makes the connections between individual posts less clear. Threads F and G are not about renal failure, while H is a very long discussion which developed into disagreement.

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[42] This selection of threads may be of typical i.e. median length. The median number of posts per week in the first three threads was 7.66, and across all eight threads the median was similar. As a comparison, in the content analysis, which covered a week, the median length of a thread was 4 posts, but these tended to be unfinished threads. To understand if the eight threads are of typical length, a large sample of full threads would be required.

	Thread Subject header	# Contributors	# Posts	Duration (time between first and last post)	Source	Topics covered
'Typical' threads						
A.	Enough	19	25	6 days	IHD	Starting dialysis; effect on relationships; effect on life.
B.	I AM BORG	12	23	3 weeks	IHD	Is my fistula developing normally? Dialysis patients as cyborgs
C.	Stint Removal	9	13	12 days	IHD	Facing the prospect of a medical procedure, how can I prepare?
Searching for deviant data						
D.	Using Blunt needles	9	23	9 days	ADB	1. Using blunts for Haemodialysis; 2. Techniques for inserting needles; 3. Using gel to reduce infections; 4. Avoiding having to take off too much fluid in one session
E.	Transplants	4	10	1 day	ADB	How it feels to be the partner of a patient as they receive a transplant
F.	[Problem with rental property]	7	11	3 days	IHD	Problems with proprietor
G.	Major Rant. Do not read if you are in a good mood	24	32	1.5 months	IHD	Television programming
H.	[Argument]	-	>30	months	-	[data missing to de-identify this thread]

Table 4.5: Summary of all threads included in the sequential analysis; IHD = IHateDialysis; ADB = Australian Dialysis Buddies

Charting local thematic patterns

What follows is a very 'close-up' examination of the sequences of themes in threads. I will show how I translated threads into charts to display when different elements appeared in the discussion[43]. Having demonstrated the construction of one chart, I will then discuss common patterns in the three typical threads using their charts to illustrate examples. I refer to the person who commenced a thread by the letter of the thread: Person A began Thread A, Thread B was begun by Person B and so on.

Creating the local thematic charts

Thread A was begun by a relatively young man beginning dialysis[44]. His commencing treatment schedule was three haemodialysis sessions a week, each lasting four hours. He wrote:

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[43] These charts are inspired by charts used by my fellow student Marie Manidis to show sequences of medical encounters in emergency departments (Manidis 2013).

[44] All quotes and data in this submission are presented without altering spelling or grammar.

TOPIC: Enough

Hi all!

I must put out my emotions, otherwise I'll explode. Yesterday, I had my first 4 hours sessions. Afterwards, I was a mess. I cried and said I won't do it anymore. My parents and friends tried to calm me down, but no success. I'm so frustrated to be depended to a machine.

And on top of that, my girlfriend sad to me yesterday, that she doesn't feel that our relationship is the right one and that she needs time to think about us. Between the lines: she wants to go away.

Did I deserve this?

I went to a doctor yesterday and asked, what do I need to sign to get just paliative care. Yes, I want to die.

Sorry for being depressed, but you're the only one, who understand me.
PersonA

The chart at Figure 4.3 (below) represents interactions of local themes in Thread A. While there were many themes included in the analysis of this post, for the purposes of demonstration I start with an excerpt from the full chart. The discussion begins at the left and runs across in chronological order to the right. Hence, the column marked "1" represents the first post in the thread. Themes are listed in the first column at the far left. When a theme appeared in a post, the row is coloured in the column for that post. I thickened the row to indicate posts where the theme is developed in some way. One contributor could not be contacted for consent; the two posts from that person are covered with a pale blank column at post#2 and post#19. Contributions from Person A (Posts 1, 14 and 20) are marked with an A.

As this is not a typical way to produce or display data, on the following pages I will work through some examples to explain how I made decisions to colour squares.

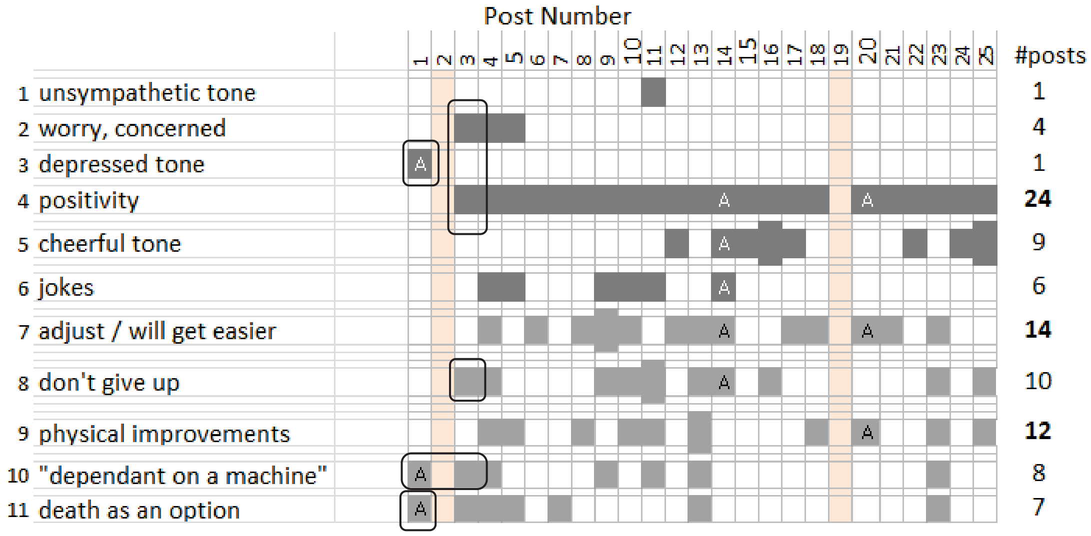


Figure 4.3: Close up from the analysis of Thread A ('Enough')

Post#1 is marked as having a tone which is 'depressed', by the coloured square at row 3, column 1. His depressed tone is stated outright in line 18 ("Sorry for being depressed"), but also demonstrated by the author having cried (line 5), wanting to die (line 16), by the title of the post ("Enough", line 1) and by the question at line 13: "Did I deserve this?"

He says that he is "depended to a machine" (lines 6-7), for which reason I have coloured the cell at row 10, column 1. The idea of death as an option for escape from dialysis is a theme which is taken up by several other posts, PersonA's first mention of it is marked here at row 11.

As noted above, I could not contact the author of the second post for consent, so it is blanked out on charts (column 2, Figure 4.3). The third post read:

20. PersonA, what can I say, you sound so down. Its not going to be a bed of roses, it is a life
21. changing thing, going on to dialysis. I am saddened to here you want to end it all, because
22. basically that is what you are saying. PersonA, even being on dialysis you can have a
23. good life, it is what you make of it. You are only young, you will get the chance of a
24. transplant, a lot of people don't. Everyone experiences depression when they learn that
25. they will have to rely on a machine. Is there a chance you could go onto PD[45] so you could
26. do this at home? I can understand where your girl friend is coming from, she is scared
27. there is so much to learn about dialysis and you are scared as well, it is natural.Please do
28. not give up your life, there must be lots of things you want to achieve and they are
29. achievable if you give your self a chance. Thinking of you and sending you hugs

---

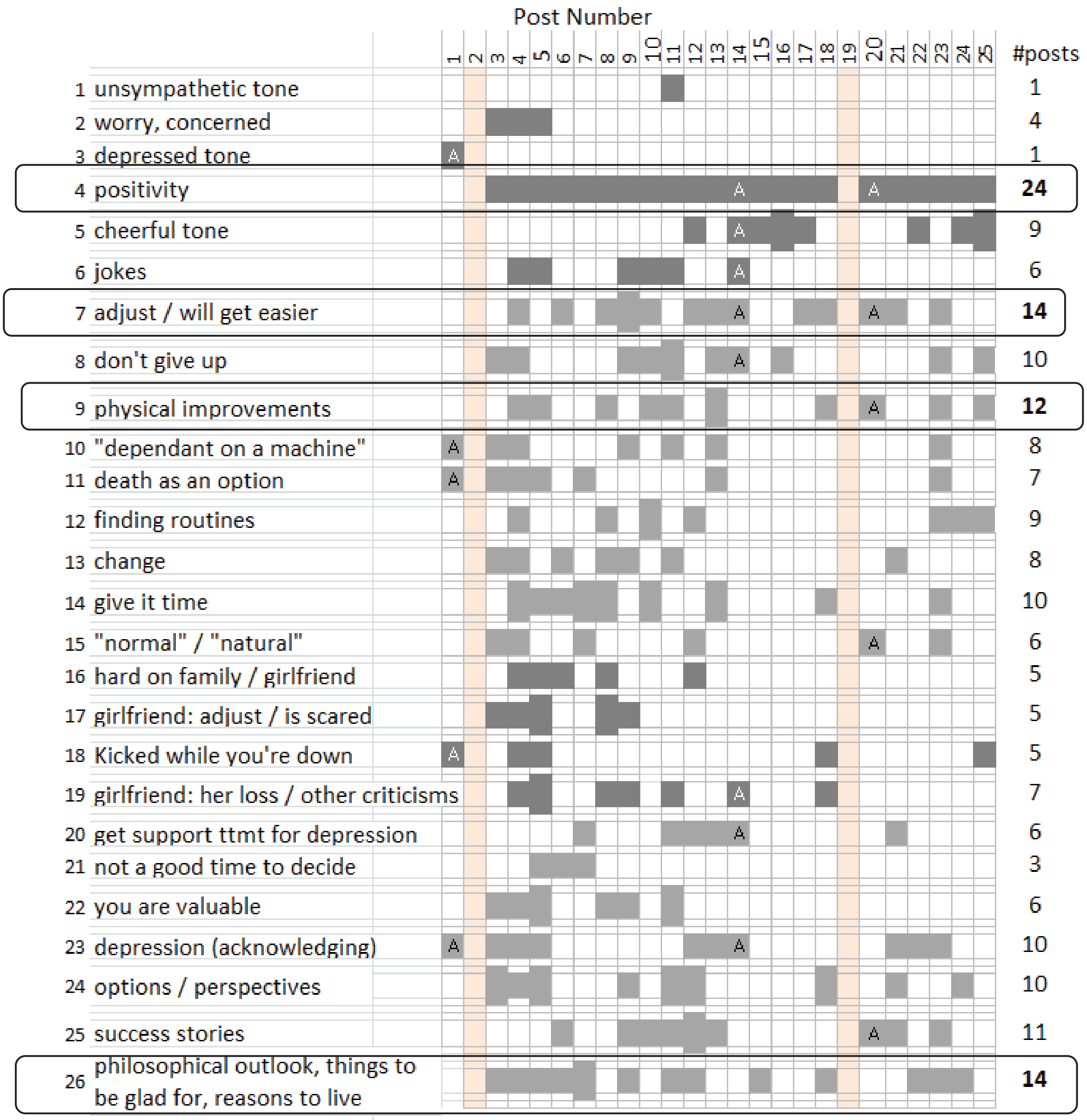
[45] PD = peritoneal dialysis – an alternative dialysis method.

Post#3 begins by addressing the desire to die (lines 21-22) for which row 3 is coloured at row 11. This post is marked as 'worried and concerned' (row 2) based on comments such as "I am saddened to here [sic] you want to end it all" (line 21). I have also marked this post as 'positive' (row 4), because this post puts forward perspectives which suggest improvements to come: the chance of a transplant (line 24), of being able to treat oneself at home (lines 25-26), and the idea of the things possible in life which are "achievable if you give your self a chance" (line 29). There is also a positive spin on the reactions of the girlfriend (lines 26-27).

Looking at row 10, I have marked both Post#1 and Post#3 as referring to being 'dependant on a machine' (Post#1, lines 6-7; Post#3, line 25). In row 8, I marked how Post#3 raised the idea of not giving up (lines 27-28). The pattern of coloured cells in rows 8 and 10 bring forward how this vocabulary was re-used along the thread.

Each post was analysed in a similar way, creating new rows for themes as they became apparent in the thread. Threads were re-read and reanalysed several times, after which the rows were rearranged to position related themes next to each other; themes in tones at the top, and themes related to content underneath.

The full chart for this thread (Figure 4.4, next page) shows how people took up the themes and vocabulary introduced by PersonA, developing them and bringing in related ideas. The numbers down the right hand side of the chart show the frequency of returns to each theme; the most frequently occurring local themes were *positivity*, *adjusting*, *physical improvements*, and *having a philosophical outlook.*



		#posts
1	unsympathetic tone	1
2	worry, concerned	4
3	depressed tone	1
4	positivity	**24**
5	cheerful tone	9
6	jokes	6
7	adjust / will get easier	**14**
8	don't give up	10
9	physical improvements	**12**
10	"dependant on a machine"	8
11	death as an option	7
12	finding routines	9
13	change	8
14	give it time	10
15	"normal" / "natural"	6
16	hard on family / girlfriend	5
17	girlfriend: adjust / is scared	5
18	Kicked while you're down	5
19	girlfriend: her loss / other criticisms	7
20	get support ttmt for depression	6
21	not a good time to decide	3
22	you are valuable	6
23	depression (acknowledging)	10
24	options / perspectives	10
25	success stories	11
26	philosophical outlook, things to be glad for, reasons to live	**14**

Figure 4.4: Overview analysis of Thread A ('Enough')

When I discuss 'tones' I mean manifestations of emotions in the text. These are manifestations as they appeared to me, as an insider to discussions. I do not presume to know what emotions were actually felt by contributors.

In terms of tone, though early replies manifested worried tones (row 2), by the second half of the thread, the consenses are cheerful tones and a sense that the situation will get easier (line 7). In describing these as consenses, I do not assume that contributors thought alike or agreed, but that along the thread, tones or themes were repeated or reused in similar ways. The consenses I allude to are textual, not cognitive.

In terms of content, at first people acknowledged PersonA’s dependency on machinery, depression and desire for death, but the discussion gradually moved away from these themes (rows 10 and 11, and row 23), towards physical improvements (row 9) and the idea that it will get easier to cope with dialysis as time passes (row 7).

I reproduce the same chart in Figure 4.5, below; smaller and without the labels, to show that the details are not required for the patterns to be visible. The repeating elements show how people reused ideas from each other’s posts, reinforcing some while gradually dropping others. The most popular themes are circled showing where consenses emerged in the discussion, while some ideas were more or less abandoned, evidenced by blank space at the right hand side of the chart.

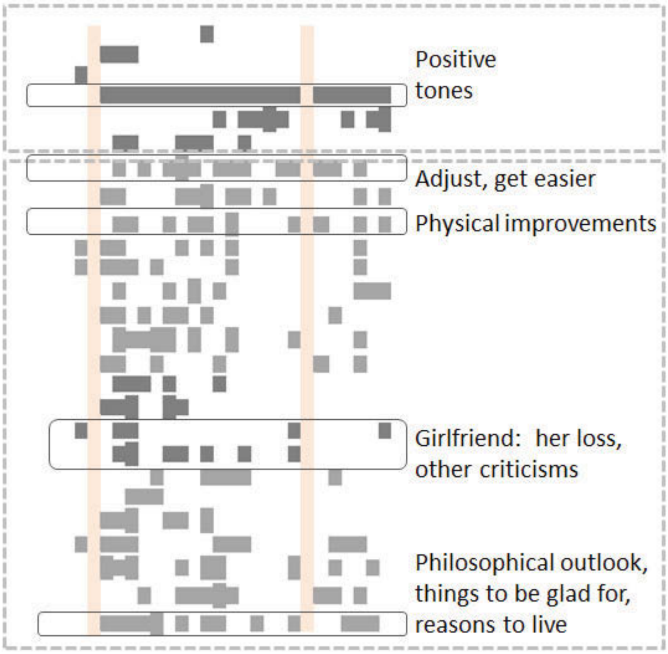


Figure 4.5: Overview of Thread A (‘Enough’)

I mostly use detailed charts to illustrate my findings, but from time to time, I display less detailed overviews like this one, to illustrate the general shape of an entire discussion.

Development of content-related consensus

Thread A ('Enough') began as Person A declared his depression at being *dependant on a machine*. He declares death as a preferable option to dialysis. Other contributors advise him to *give it time* (row 14). Fourteen posts (40% of the thread) suggest that one can adjust to dialysis or that it will *get easier*, which emerges as a consensus in the thread.

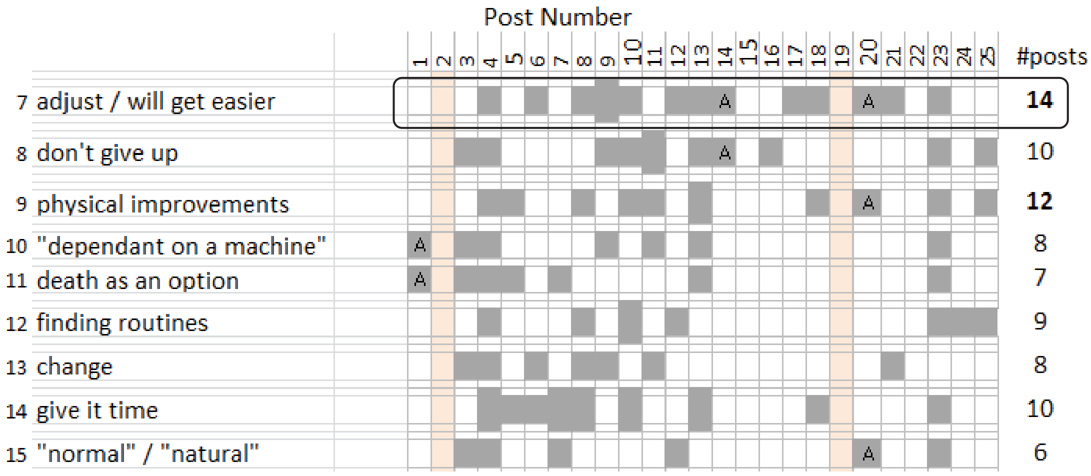


Figure 4.6: Close up from the analysis of Thread A ('Enough'): responses to dependency on a machine.

Persevere (Row 27, Figure 12, below) is a row formed by combining rows related to the themes *it will get easier, don't give up*, *finding routines* and *give it time*. Row 27 shows that almost every post used some combination of these themes.

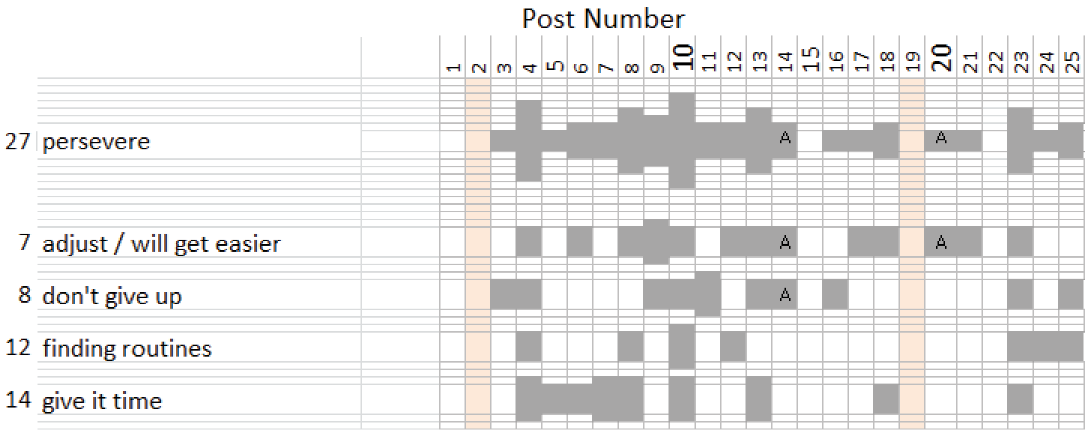


Figure 4.7: Creation of Row 27 from rows related to *giving it time* in Thread A ('Enough')

As visual analyses of sequences, these charts illustrate how consenses emerge through repetition (reuse of similar themes). As noted above, in using the term *consenses* I do not assume that contributors thought alike or agreed, but that along the thread, themes were repeated and reused in similar ways. The consenses I allude to are textual, not cognitive. Meanwhile, it is common in discussions online for contributors to advise others to persevere or ‘give it time’, as they do here. So repetition and the time required for familiarity to develop are principles which operate at two levels: as well as being shared as useful principles, they are also themes in sequences within threads.

Development of emotional consenses

Repetition of themes occurred in *tones* as well as in the *content* of posts.

In Thread A (“Enough”), Person A stated the emotional tone of his first post outright: “Sorry for being depressed”. No other posts matched his *depressed tone* (row 3). Instead, all replies presented *positive* perspectives regarding his situation (row 4), and set to the task of supporting and guiding him away from depression and towards a more optimistic outlook, matching social norms noted in Section 4.2. The ongoing, combined reiteration of positive tones in this thread created an overall positive tone, which can be seen in row 4 in the chart below (Figure 4.8).

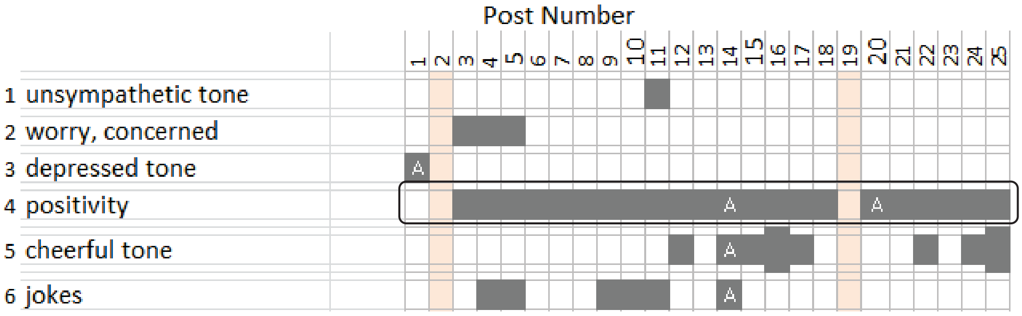


Figure 4.8: Tone from the analysis of Thread A (‘Enough’)

Shifting tones

When he next posted, Person A matched the positivity of other posts, managed some black humour, and injected the beginning of a cheerful tone into his post: “So, let’s go on 🙂” (Post#14). He ‘changed his tune’ to match the emergent consenses. The response to his turnaround was a sequence of cheerful (sometimes, joyous) posts. Without whitewashing the difficult experiences of dialysis, emotional tones in the thread settled on cheerful positivity, aligning with the interactional norm *be positive* identified in Section 4.2.

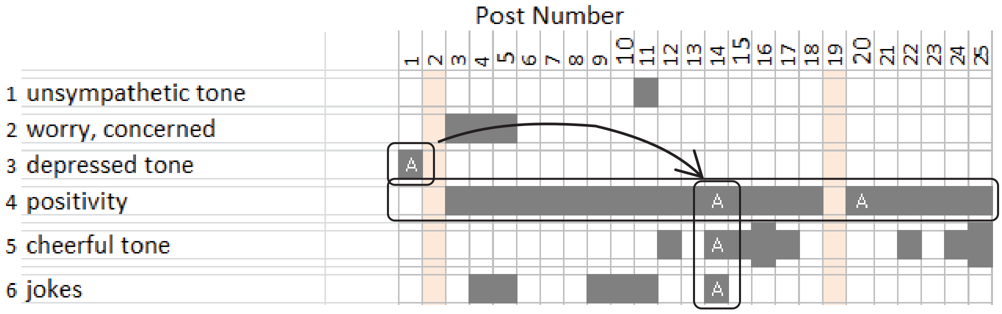


Figure 4.9: Tonal shift in Thread A ('Enough')

Similar patterns appeared in the other threads. For example, Thread B opened with tones which were both *worried* and *playful*: the initiator of the thread was worried about a health issue but presented her worry in a humorous way. Almost no other post echoed worried tones back to her. Most responded with *positivity* (row 1 in Figure 4.10, below) and an *unconcerned tone* in which they made it clear that they were not worried (row 4). PersonB, when she next posted, matched their positive, unconcerned tones.

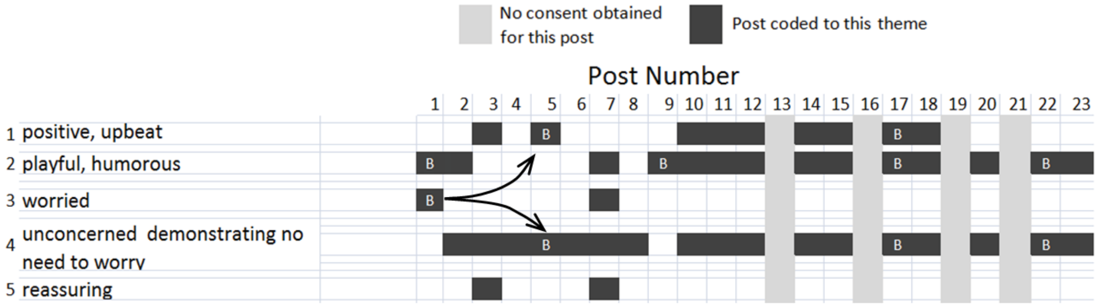


Figure 4.10: Tone from the analysis of Thread B ('I AM BORG')

Joining and shifting consenses

Just as consenses in tone may influence individual contributors to change their own tones, so consenses in themes can shift the focus of discussion. For example in Thread A, as the theme of dialysis *getting easier* developed, contributors left aside the ideas of death or dependency as discussion points. In this way, the consensus shifted away from the original focus of Post#1. These shifts can be seen at Figure 4.11 (below), where I have circled the blank space where people do *not* continue with the themes of death and dependency (rows 10 and 11).

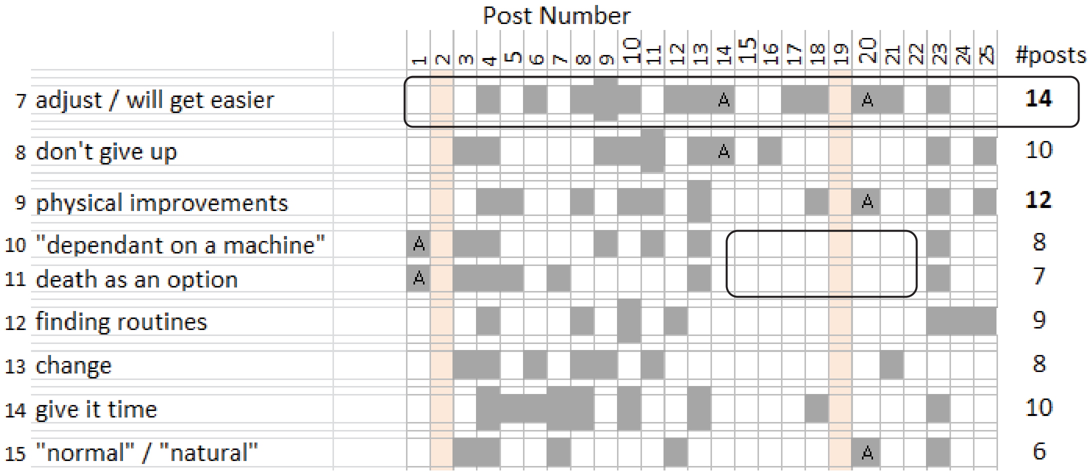


Figure 4.11: Close up from the analysis of Thread A ('Enough'): responses to dependency on a machine

Person A returned to the thread twice with updates, and used ideas from other posts to express his return from the "bottom of my life" (Figure 4.12, post#14): he will *not give up* in the hopes that things will *get easier* (rows 7, 9); he has also taken up the suggestion of *treatment for depression* (row 20). Having read a succession of descriptions of other people's successful adaption to analysis (their 'success stories'), PersonA's final post (Post#20) is a start of his own *success story*, in which he used themes and vocabulary from other posts to report beginning to feel emotionally and physically better (see Figure 4.12, below).

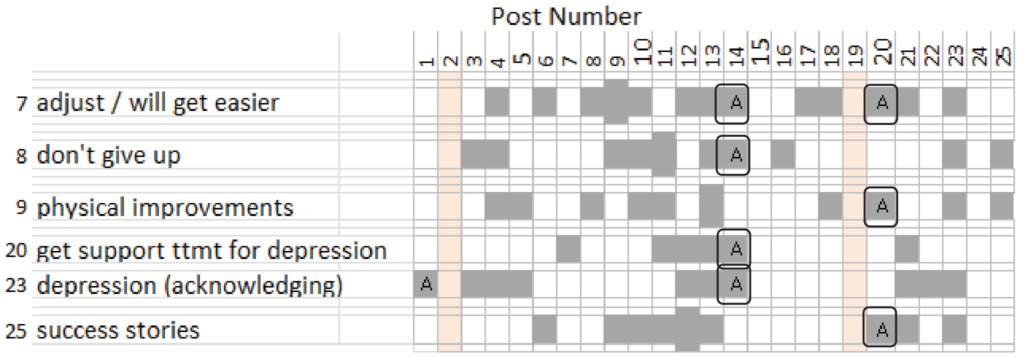


Figure 4.12: Excerpts from the analysis of Thread A ('Enough')

Using tones to select meanings

Commonly, tone was used to support incremental developments in meaning, indicating favour for particular ideas over others.

A good example occurs in Thread B ('I AM BORG'), begun by a woman looking anxiously at changes in her body at the site of her newly installed fistula[46]: she compares herself with a cyborg[47]. In the first half of the thread, cheerful replies supplied reasons why the fistula enlarges after it has been created, and why the fistula is, in general, a good and useful thing. Later, the idea of the fistula as off-putting returned as a contributor described the way her pseudoaneurysm[48] "pulsates"[49].

> Post #6
> Person6
>
> [...] I have one of those lovely psuedoanyerisms near my elbow. From time to time it will pulsate, and I can actually see it pulsate. It freaked me out the first time I saw it, so I kinda did what you did, and went to twitter. Within a few minutes, I was told by several people that it was normal.
>
> Post #8
> PersonB
>
> I think I have a pseudoanuerysm, too...sort of a knot adjacent to my scar that I can see pulsate. Creepy.
>
> Post #9
> Person8
>
> It's always something you can scare kids with, though. 🙂🍺🍺🙂[see footnote[50]]

The conversation quickly moved from fistula-as-good-and-useful, to fistula-as-strange-and-useful – for scaring children. At this point, contributors took up the borg theme. One's identity as dialysis patient was related to one's potential identity as borg, and the borg identity emerged as something desired, something with positive outcomes (jokingly, that one can assimilate doctors, but more valuably, that one can regenerate and be 'one of us'). The playful development of the borg theme was co-developed with the idea of strangeness as good and positive identity as 'other'. In

---

[46] A fistula for renal dialysis is often an enlarged vein created surgically by joining a vein and an artery, and commonly located in the arm. A person may have a fistula 'installed' quite some time before they start dialysis, in order to allow it to develop and mature before use. There is a great deal of variation from person to person, both in functionality and visual appearance. Some fistulas are almost invisible, while others develop into enlarged, lumpy veins, snaking along the arm.

[47] The Borg is a fictional, cyborg civilisation depicted in the TV series 'Star Trek'. They are warlike, and actively invade other species. They then 'assimilate' individual members of vanquished species by adding machine parts and connecting their consciousness to 'the collective' Borg mind.

[48] An aneurysm is an abnormal swelling in the wall of an artery; in a pseudoaneurysm the swelling of the artery is contained by clotted blood rather than the artery wall (Martin 2010).

[49] All quotes and data in this submission are presented without altering spelling or grammar.

[50] This animated emoticon makes a 'cheers' motion with the steins.

combination with a cheerful tone, both being cyborg and being an outsider became sources of pride, part of a cheerful dialysis identity.

These exchanges demonstrate how tones have constitutive effects on understandings in threads and how content and tone are interrelated. Emotional tones were used to select particular perspectives or reinforce them – for example, that people were not worried about fistulas which look like hers, and later, enjoyment of the perspective that being a bit alien has advantages.

I have pointed out that when I discuss ‘tones’ I mean manifestations of emotions as they appeared to me, without presuming to know what emotions were actually felt by contributors. I refer to themes of tone but tones are better imagined as *chromatic*, providing colour to messages. The tonal colours of messages affect meanings; emotional elements provide guidance for sense making, in particular signalling urgency and the need to worry, or contentment and no need for alarm. Sense making occurs at this emotional-chromatic level as well as the level of content. Thereby sense making empirically ceases to be a solely cognitive activity.

Meaning building beyond threads

Strongly developed themes and meanings did not only reappear within threads: reuse occurred between threads as well. Ideas and jokes were recycled within the community at large.

For example, in Thread A, Post#17 made it clear that their advice “From what I hear people say on this forum, dialysis does get better with time” is an idea they obtained from the community, not just from this discussion but from elsewhere in other threads. People knew each other and remembered each other’s posts. The phrases and ideas used to make sense online were a circulating stock from which people chose fragments to fit together for each situation as it arises.

Nor were the processes of reiteration restricted to discussions online. In Thread B (‘I AM BORG’), the twelve contributors supplemented their opinions by referring to comments from people offline: health professionals - a vascular nurse and a vascular surgeon - and “several” other people. So the development of ideas in threads involved circulation of ideas and reuse (repetition, expansion, elaboration) of them by people in a range of contexts, both within and across threads, and referring to experiences both on and offline.

Multiple consenses and the link to experience

This is not to suggest that everyone agreed. As people took up content and tone, and moved them in ways relevant to their own experiences, nuances emerged with an accompanying complexity of themes. Even in the relative consensus of Thread A (‘Enough’), one could identify all manner of consenses, such as whether the girlfriend was scared, needed to adjust, was a “sad loss” or someone he was “well rid of”; these options were reworked to different degrees by various contributors. Frequently in threads, as people developed and explored possibly relevant material, consenses which emerged were rooted in people’s different experiences, revealing experience as a kind of bedrock upon which people’s beliefs were founded, or a reef on which ill-founded beliefs came to grief.

A good example of this link between one’s experiences and one’s relationship to consenses appeared in Thread C (‘Stint removal’). Urine passes from the kidneys to the bladder via the ureter. A stint/stent is a thin tube commonly left in the ureter for a short time after kidney operations. Contemplating its removal, Person C began the thread with a *serious* and *worried* tone (rows 3 and 4): “I was told it was not exactly pleasant for the male patients”.

An excerpt from the chart of local themes in Thread C is shown at Figure 4.13, (next page). Replies often *downplayed negative* aspects of the experience (row 8), by saying they were *normal* (row 7) or *easier than they expected* (row 6), cracking jokes about their compromised dignity (row 1). An emerging consensus of tones was of *playful positivity* (rows 1 and 2). In this way, posts may have guided Person C toward a stalwart and humorous way of responding to a difficult experience.

However, of the nine contributors to this thread, three experienced pain or trouble with the removal of their stents: Person C, and the authors of post#4 and post#13.

Looking at posts#4 and #13 in Figure 4.13, observe how their posts had neither jokes nor positive spin.

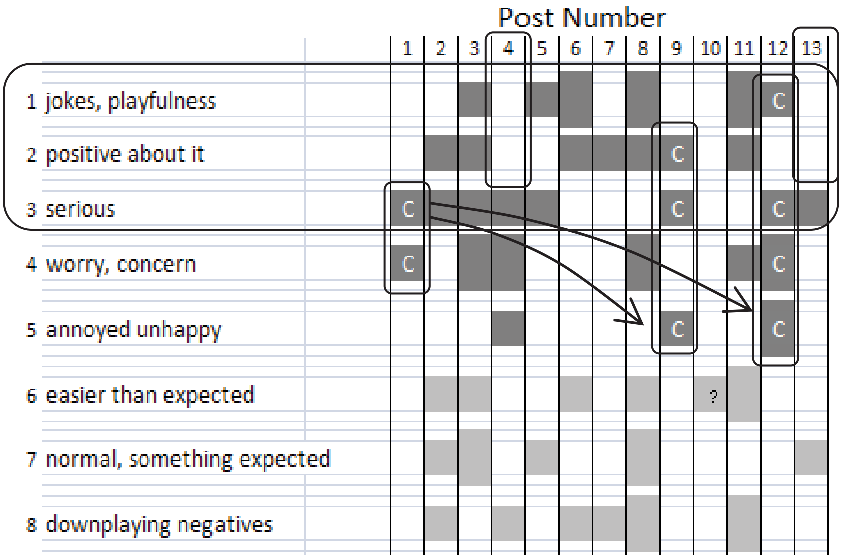


Figure 4.13: Tonal shift in Thread C ('Stint Removal')

Person C changed his tone to partially match that of other contributors, when he included some attempts at positivity in post#9. But he remained unconvinced by the emerging positive tone of the thread, because his experience was not positive. One cannot always put a positive spin on an unappealing procedure. His posts retained a serious, worried tone (Rows 3 and 4, Post#1, 9 and 12).

One can see how regardless of the urge for positivity, perspective interacts with realism. Though they are manifestations of a performed online identity and may express attempts at 'good attitude', emotional tones are also connected to the details of people's experiences, exemplifying tensions between the social norms identified in Section 4.2; here, between the mandate to be positive and the call to be real and to speak honestly.

Overviews of three 'typical' threads

I have found that people constructed messages partly from themes already in the thread, and that consenses emerged in threads as a result of repeated use of similar themes. I also showed how shifts in meanings were usually achieved by variations in ideas supported by tones.

Earlier in the discussion, I produced a simplified version of the full chart of local themes in Thread A, removing most of the labels to make the patterns of consensus formation more apparent. It looked like this:

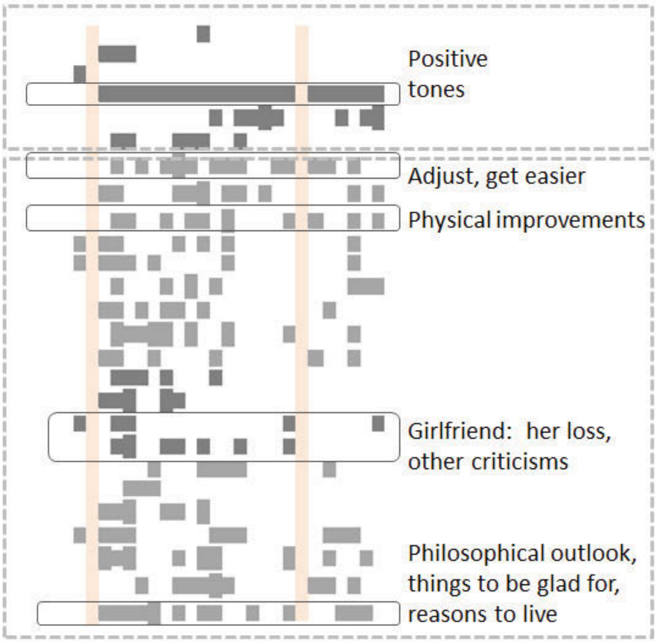


Figure 4.14: Simplified chart of local themes in Thread A ('Enough')

I have reproduced this chart here to remind you of how consenses are visible in the sequences of shapes along the chart: they can be seen without needing the details of all themes and post numbers involved. Similar charts for each of the three typical threads are laid out together (Figure 4.15, next page), forming a 'bird's eye' overview. The overview shows the same kind of repeating elements, with spaces appearing towards the right hand side as some themes fell out of currency. The repeating elements show how in each case, ideas were re-used as contributors developed meanings using themes already in earlier posts. Also, in each chart, one can see more or less continuous bands, where themes were reiterated in successive posts. This view displays at a glance the development of themes and patterns of consenses as they appeared in each thread, including at times, shifts away from particular themes in favour of others.

Thread A: ‘Enough’

Thread B: ‘I AM BORG’

Thread C: ‘Stint Removal’

Figure 4.15: Simplified charts of local themes for Threads A, B and C

Charting patterns in the ‘themes of format’

I now present a different perspective on the same three threads, exploring some of the themes identified in the content analysis at Section 4.1: *explicit support,* descriptions of *experience, explanations*, and use of *humour*. Of the eight themes identified in the content analysis, these four themes had to do with the *kind of content* in messages rather than the *content* of messages. I call them ‘themes of format’[51]. To explore these themes I created new charts concentrating only on those themes in each thread, and depicting the appearance of themes at the level of sentences rather

---

[51] Of the eight themes from the content analysis, there were four themes of format, listed above, three themes relating to content: *control*, *physicality* and *normality* and a final theme, *emotions,* which was sometimes a topic of conversation (content) and sometimes demonstrated by someone expressing emotions in their post. ‘Themes of format’ is a problematic name, as format might suggest differences in media, such as a comparison between text and voice, or between electronic discussions and blog posts. The next best term, ‘themes of genre’ has similar issues but also suggests connections to linguistics which I wish to avoid.

than posts. I made the rows one square thicker whenever a sentence containing that particular theme appeared in a post. This is a more intense degree of coding than in the charts shown so far, where a cell was coloured once for each theme regardless of how many sentences contained that theme.

Experience was marked whenever a sentence described a lived experience (‘Mine is like this...’, ‘I thought this...’, ‘we do it this way’, and the like). *Explanation* shows instances of general information not explicitly embedded in experience (such as, ‘The fistula will enlarge as it matures’, ‘the whole point is to enlarge your veins...’). I examined two forms of emotional support. *Explicit support* was still reserved for sentences which directly expressed understanding or reassurance (‘I feel the same’, ‘don’t worry’). Meanwhile *implicit support* showed where people described having the same experiences or having felt the same way. This is a wide view of support; such mirroring of experiences suggests comprehension of feelings (sympathy) without the use of directly compassionate expression[52]. *Humour* includes jokes, statements marked with ‘laughing’ emoticons, and references to the importance of humour.

For most threads, I also finish the chart with the row representing the consensus tone of the thread, such as ‘positivity’ for Thread A.

As noted earlier, the literature suggests that people frequent online support groups for information and support. When examples of ‘information’ appear in that literature they are often what I would code as *explanations* – generic, often factual information not connected to lived experience. I have explored ‘information’ in two forms, *explanations* and *experiences*. The content analysis was striking because explanations and explicit support appeared at the bottom end of the top eight themes. The charts shown at Figures 4.16 and 4.17 (next two pages) once again reveal how much descriptions of *experience* dominated the discussions – their predominance is even clearer in this sentence -by-sentence view.

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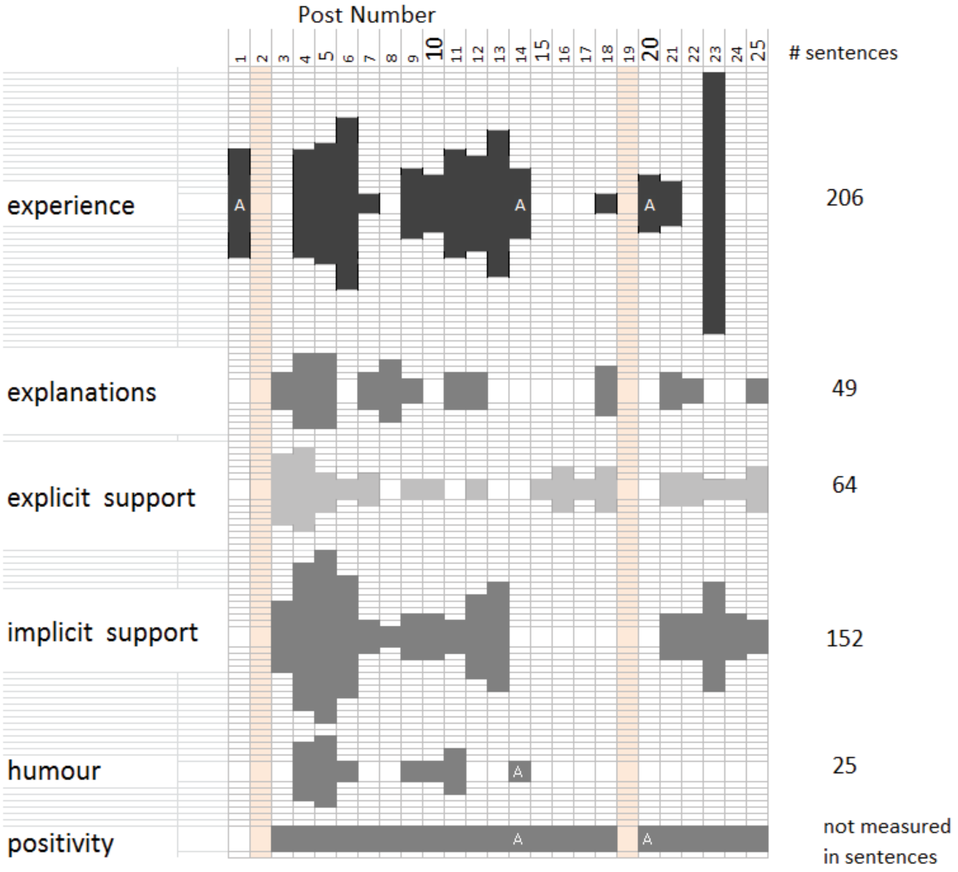
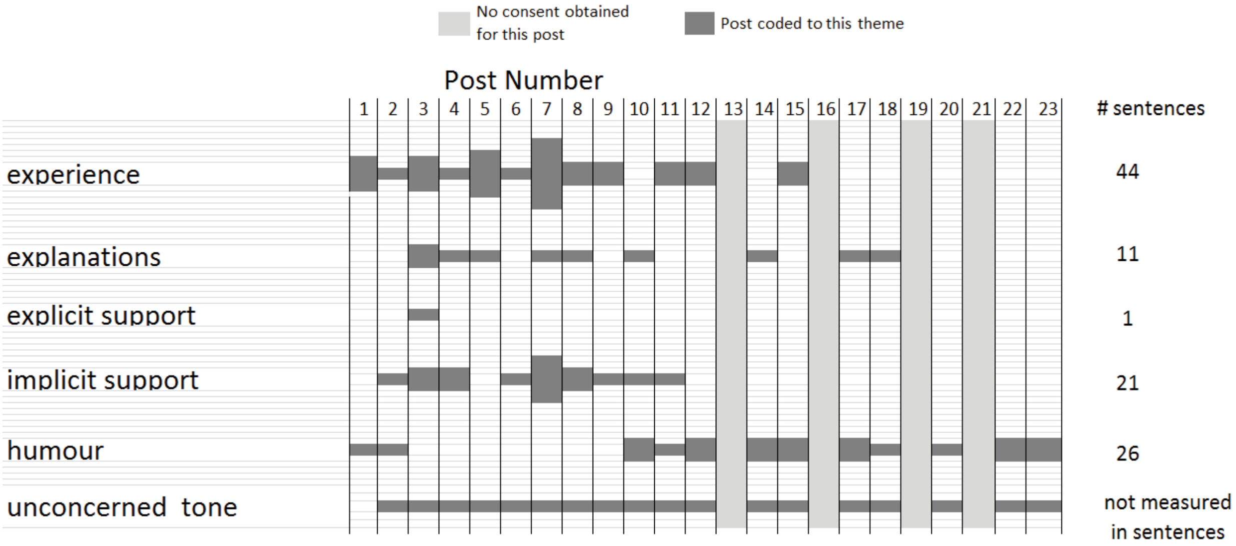
[52] When coding support, each sentence was coded as *either* direct support *or* indirect support.

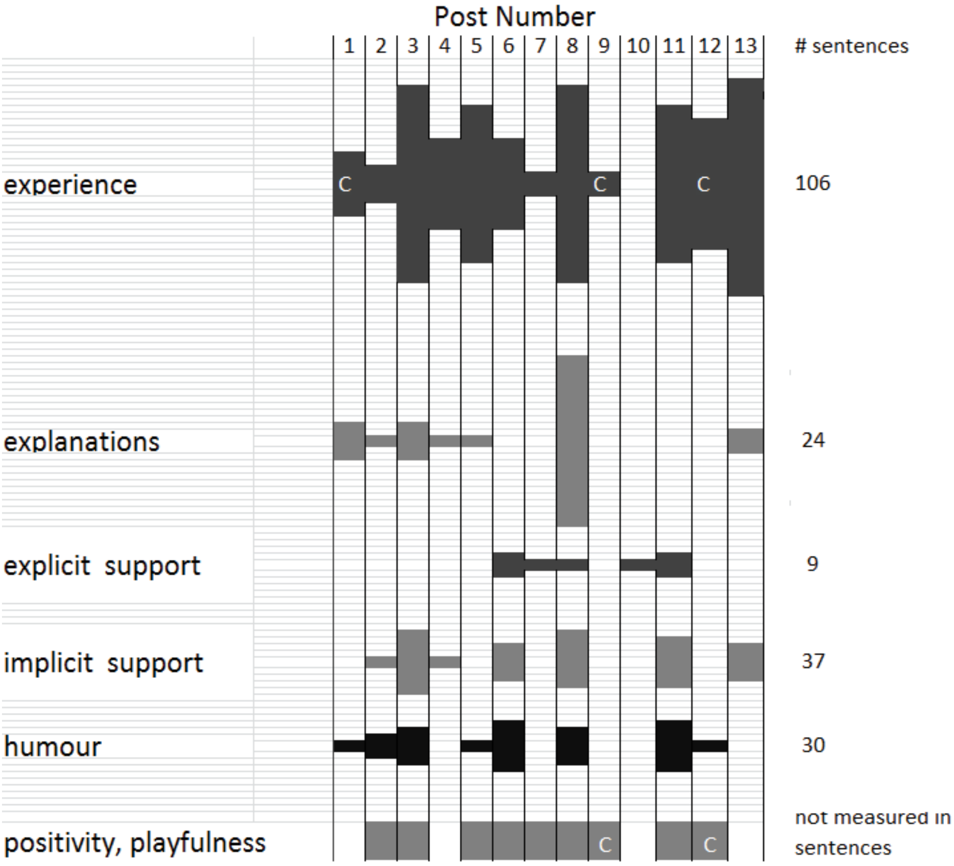


Thread A: 'Enough'



Thread B: 'I AM BORG'

Figure 4.16: Chart showing themes of format for Threads A and B



Thread C: 'Stint Removal'

Figure 4.17: Chart showing themes of format for Thread C

Table 4.6 (below) summarises the incidence of each theme in these threads. Sentences were most frequently marked to *experience* and *implicit support*, while *explanations* and *explicit support* were less frequently coded. The bottom section of Table 4.6 provides a comparison with the incidence of themes from the content analysis.

Thread	Total # sentences	% of sentences marked to each theme			
		experience	implicit support	explanations	explicit support
Enough	272	76%	56%	18%	24%
I AM BORG	69	64%	30%	16%	1%
Stint removal	140	76%	26%	17%	6%
Average	160.3	72%	37%	17%	10%
	% of posts marked to each theme				
Content analysis		60%	-	24%	25%

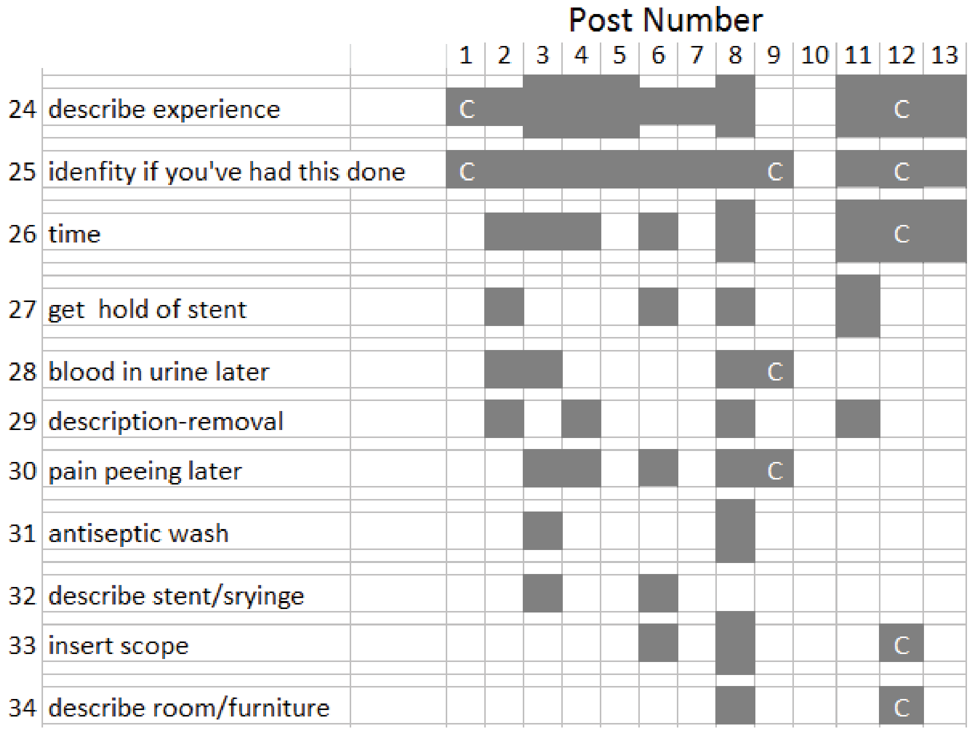
Table 4.6: Comparative incidence of themes of format in Threads A, B and C

The content analysis only counted themes once per post, while the sequential analysis counted themes once per sentence, so they are not the same measure. But it can be seen that they are comparable measures, supporting my suggestion that experiences are generally most frequently put forward, not only in these posts but in many of the posts I read.

Provision of information

Since contributors did not *have* to post experiences and were capable of producing explanations, the predominance of experiential information suggests some utility in providing information in this way, a question to which I return in Chapter 6. Here, I merely demonstrate how people used anecdotes to provide information which, although contextualised in particular experiences, was useful for developing broader understandings.

For example, post by post in Thread C (‘Stint removal’), contributors developed a picture of the procedure by contributing the (similar and different) ways that each of them had experienced it. Returning to the chart of local themes from Thread C at Figure 4.18 below, one can see how elements of each description were developed in different posts.



		Post Number												
		1	2	3	4	5	6	7	8	9	10	11	12	13
24	describe experience	C	▨	▨	▨	▨	▨	▨	▨			▨	C	▨
25	idenfity if you've had this done	C	▨	▨	▨	▨	▨	▨	▨	C		▨	C	▨
26	time		▨	▨	▨		▨		▨			▨	C	▨
27	get hold of stent		▨				▨		▨			▨		
28	blood in urine later		▨	▨					▨	C				
29	description-removal		▨		▨				▨			▨		
30	pain peeing later			▨	▨		▨		▨	C				
31	antiseptic wash			▨					▨					
32	describe stent/sryinge			▨			▨							
33	insert scope						▨		▨				C	
34	describe room/furniture								▨				C	

Figure 4.18: Excerpt from Thread C ('Stint Removal') showing discussion of experiences

Some described the equipment used, others provided detail on after-effects such as blood in the urine; some filled in how the different parts of the procedure are performed or how they negotiated problems they encountered, others even described the room or furniture. The detail of these accounts allows the reader to imagine what a normal stent removal might be like for a patient, including how the procedure is performed and how pain is minimised. Possibilities for control emerged – such as being able to see the doctor's monitoring screen, or knowing to ask for different kinds of pain control. Contributors also highlighted situations where they lacked or wished for control. Though the details differed, an overall description emerged which was both detailed and flexible in that the reader obtained an idea of a range of ways in which the procedure might unfold.

By providing stories from their own experiences, people positioned themselves as having potentially useful perspectives to contribute. Experience had already tested the advice they might offer. At the same time, because anecdotes are limited by their connection to particular contexts, their truth claims are modest, making them less prescriptive, and reducing one's responsibility for being right. In the discussion at Chapter 7, I will explore how the development of situated anecdotes may be a powerful way to negotiate knowing amidst complexity. Meanwhile the informative elements of stories were interwoven with instances of emotional information such as explicit and implicit support and the ongoing supportive tones provided throughout the thread. For example, the following quote combines information embedded in lived experiences, implicit support and the (consensus) positive, humorous perspective:

> *[T]hey had the thing in there for maybe 2-3 minutes (though it did seem longer) while they searched around for the stent, found it, and pulled the bugger out. Injecting the liquid local or whatever it was was unpleasant but I suppose once it kicked in it was mostly OK apart from having some bloke mucking around with you down there in a way you don't want!!!*
>
> *(excerpt from Post#9, Thread C ('Stint Removal')*

Provision of support

Explicit support was consistently among the least frequently coded themes. The workings for provision of support can be seen by inspecting the bottom four rows of each chart (look back at Figures 4.16 and 4.17). *Implicit support* was relatively frequent, and was always underlaid with ongoing emotional guidance as almost every post demonstrated the local consensus tone. Humour usually appeared at points where discussions covered taboo subjects such as urination, genitalia and blood. Via humour, contributors demonstrated ways of dealing positively and cheerfully with difficulties such as stigma and fear of medical complications. For example in Thread B ('I AM BORG'), the humorous turn began with people exploring the negative side of having a fistula: the disturbing look of it "pulsating" and its cyborg symbolism (as shown in Figure 4.19, below). Their humorous perspectives produced the changed meaning of the fistula from a stigmatising identifier to one with positive connotations.

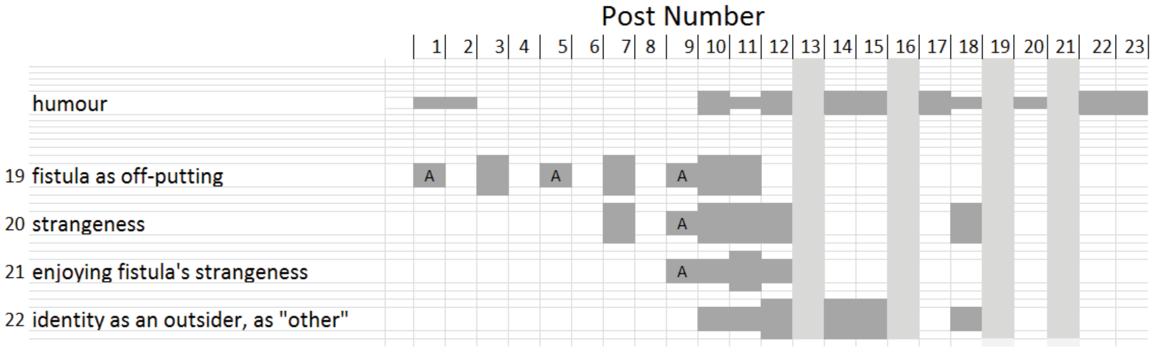


Figure 4.19: Use of humour and exploration of fistulas as strange, in Thread B ('I AM BORG')

* * *

In the discussion so far I have used three threads to demonstrate common patterns in the interactions online. I have shown how people steered each other toward and away from possible perspectives, *repeating* or re-using elements of each other's posts in ways which developed *consenses* of opinion and feelings in threads.

1. *Repetition* of themes across many posts and contributors developed consenses and conceptions of normality;
2. Emotional guidance was provided indirectly by tones; and
3. Meanings were shifted by the introduction of related themes, supported by tones.
4. People embedded their remarks within descriptions of their lived experiences;

By talking about *consenses*, I do not suggest that people necessarily felt or thought the same, but only that opinions or feelings were manifested across many posts – these are textual consenses, not cognitive or psychological consenses.

Descriptions of *experience* had a number of functions in interactions: it brought *authority to respond* and reduced the need for generalisability, by only describing what was true for a person at a particular time. This begins to show a distinction between *explanations* and *experience* which I will develop in Chapter 7: how explanations, which are simple and not connected to particularities, are useful for their simplicity and generalisability; while on the other hand, experience produces specific anecdotes which can connect to particular situations and can allow flexible or dynamic responses to complexity. *Experience* also signified *capacity to understand* and enabled expressions of implicit support, a point to which I return in Chapter 6.

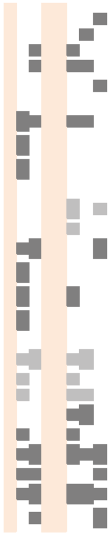
4.4 Examining deviant data

Once particular patterns begin to be identified in data, researchers are encouraged to find deviant cases, which might disprove or develop their emerging theories (Silverman 2006). In my case, I needed to find threads presenting different patterns or which might break the patterns I had found.

As the threads I have presented thus far were all from IHateDialysis, I first examined two threads from a different group, with a different geographic location of contributors and a different format: the electronic mailing list, Australian Dialysis Buddies. Having a different way of presenting and delivering threads, I thought it possible that sequential differences may appear in threads; it was also possible that cultural differences might affect the patterns of emotional tones. Being a mailing list rather than a discussion board meant that messages were not clustered neatly, and people tended to respond to several threads in a single message. The first thread I present from that list (Thread D) was indeed, a mass of jumbled themes. However, as soon as I separated the strands of conversation into four sub-threads, the familiar patterns of element re-use, consensus building and theme development became apparent.

Sub-thread D1:

Using blunt needles



Sub-thread D2:

taking 6 kilos off

Sub-thread D3: Antibacterial cream

Sub-thread D4:

Hubbing

Figure 4.20: Simplified charts for Thread D, split into four subthreads

I have described how emotional tones serve as models for the first contributor in a thread, who can often be seen to shift their tone to match consenses in a thread. I demonstrated with threads in which the first contributor was worried and was reassured by other contributors. In Sub-thread D2 there was an emotional shift the other way: from cheerful to worried. Person D2 did not consent to inclusion in the analysis, so I cannot demonstrate the detail of the shift in tones, other than to remark that the whole sub-thread worked at the level of emotional tone to alert Person D2 to particularities of their situation. The play of tones confirmed the dynamic of shifting emotional tones even in this kind of fragmented discussion.

A detailed example of shifting dynamics in the Australian Dialysis Buddies can be presented with another thread from that group, Thread E. This thread again presents sequences with the familiar patterns of repeating themes, consensus building, and guidance with tones enabling shifts in meaning.

Person E was awaiting ‘the call’ summoning her husband for a transplant. She began the thread asking about other’s feelings when their partner received a transplant.

Figure 4.21 (below) shows how the discussion took a cheerful, positive tone centred on organising and preparing for ‘the call’ from hospital. Simultaneously, contributors made it clear that getting the transplant is often followed by troubles before it begins to work as a surrogate kidney.

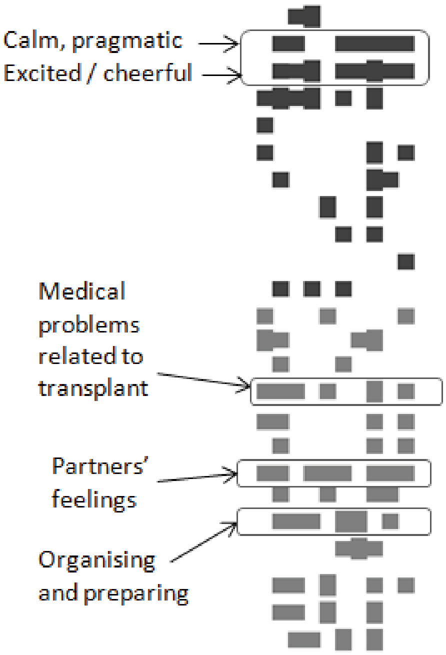


Figure 4.21: Simplified chart for Thread E (‘Transplants’)

Person E began the thread “excited” but also “scared” and tense. As shown in Figure 4.22, her subsequent posts demonstrated a pragmatic, positive approach to her situation – she never manifested fear again, but matched the consensus tones of the thread, confirming the pattern which I described in Section 4.3.

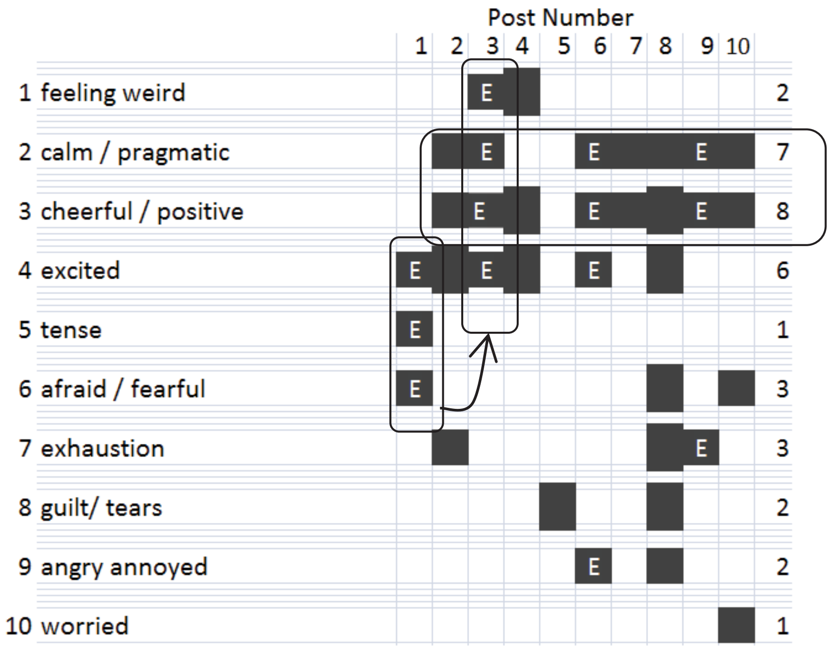


Figure 4.22: Tones from the analysis of Thread E ('Transplants')

However this thread was not an exercise in blinkered positivity. Having established the importance of a pragmatic outlook and celebrating the excitement of the chance of a transplant, Figure 4.22 shows how these renal wives also described exhaustion, fear, guilt, anger and tears. Figure 4.23 (below) shows the juxtaposition of positive tones and negative experiences. Contributors demonstrated calm and positivity *while also* providing descriptions of life-threatening problems after the transplant surgery and their deeply felt guilt and gratitude at the 'gift' from donor families. They positioned pragmatism as a realistic attitude to take *because* of the attendant fears and uncertainties of transplant, not despite it.

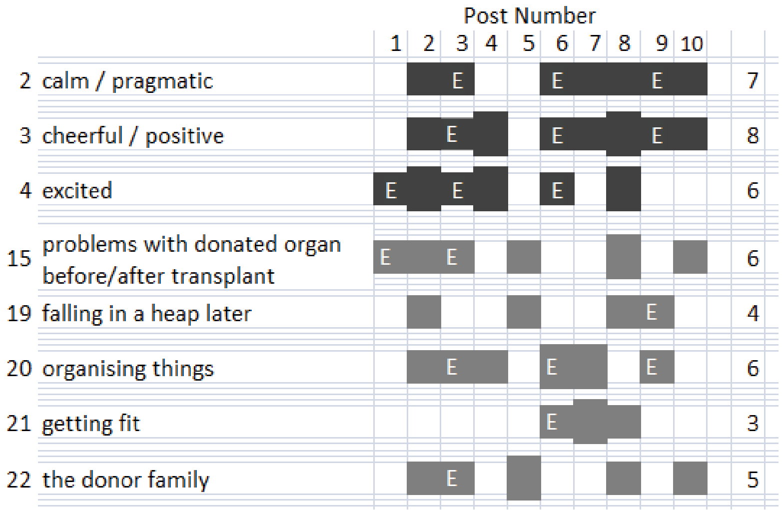
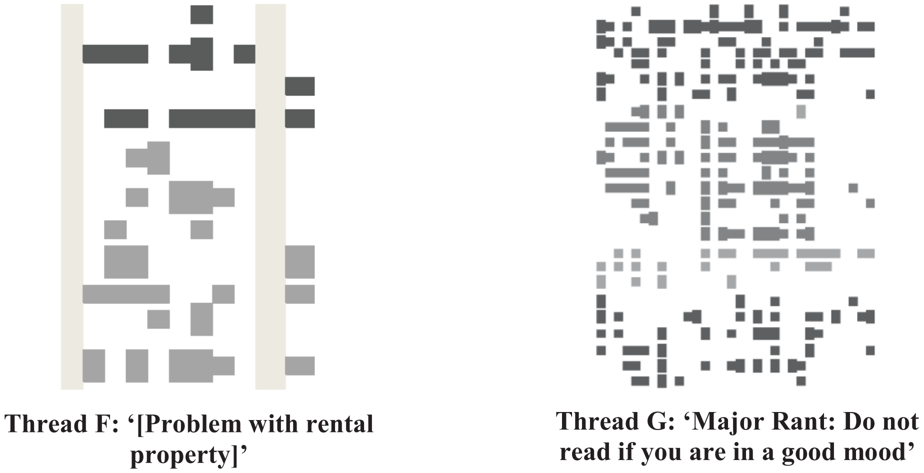


Figure 4.23: Juxtaposition of selected tones and content from the analysis of Thread E ('Transplants')

During the discussion, ‘the call’ shifted from being the culmination of one’s efforts to being only the beginning of a longer process of waiting and coping – anticipated with determined pragmatism rather than dread. These shifts in meaning were attained by a combination of tone and content.

In Section 4.3, I examined long threads with an average of 20 posts and 13 contributors, interacting in a shared space on a website. Threads D and E are from a different group which interacts by emails. Thread E had only 10 posts and 4 contributors. Nonetheless these threads manifested familiar patterns of repeated elements, consensus forming, and tonal guidance supporting shifts in meanings.

Thus far, my search for deviant data had uncovered familiar patterns, confirming the kinds of sequences described in Section 4.3. Next, I examined two threads which did not deal with kidney failure (Threads E and F). I thought perhaps if people were not discussing renal issues, they might interact differently. Instead, Figure 4.24 demonstrates sequences which again matched the patterns I had already found, in which themes were reused and modified, developing consenses.

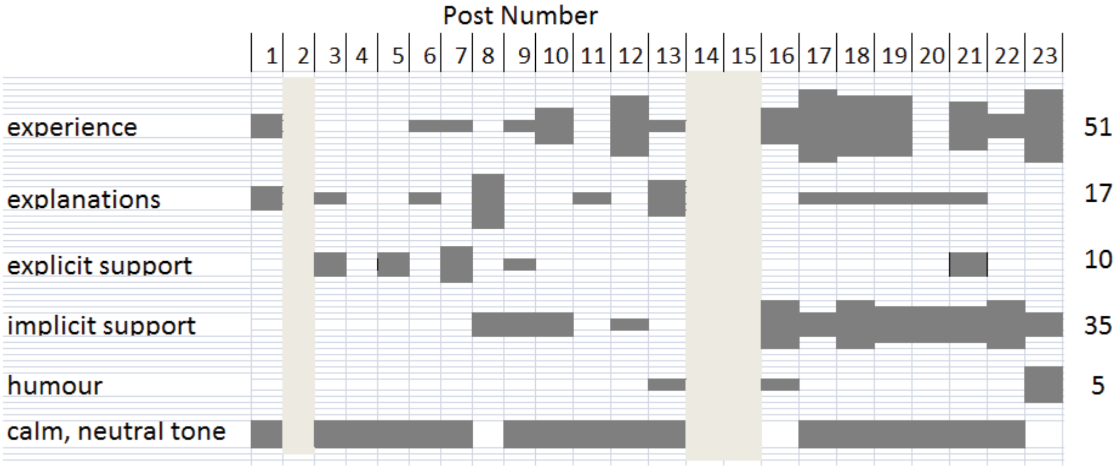


Thread F: ‘[Problem with rental property]’

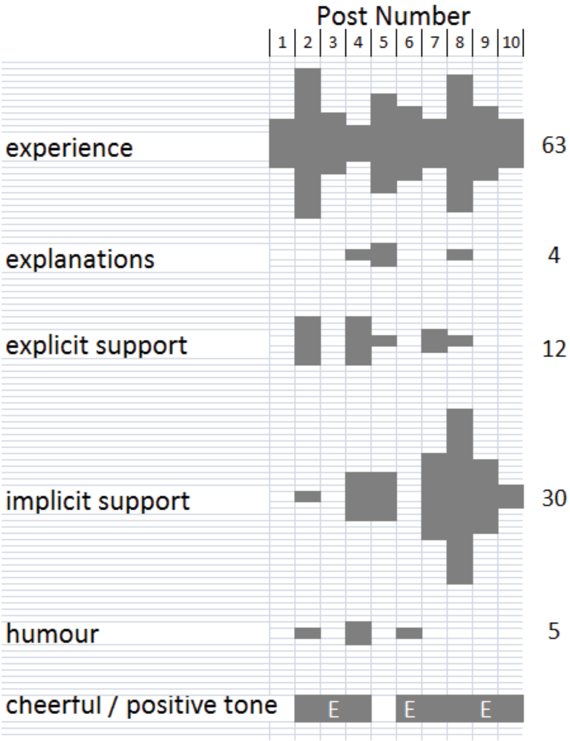
Thread G: ‘Major Rant: Do not read if you are in a good mood’

Figure 4.24: Simplified charts for Threads F and G

Considering patterns of format in sentences, Figure 4.25 (on following pages) shows a recognisable predominance of descriptions of *experience*. Here again, *implicit support* and guidance by tones predominated over displays of *explicit support*.

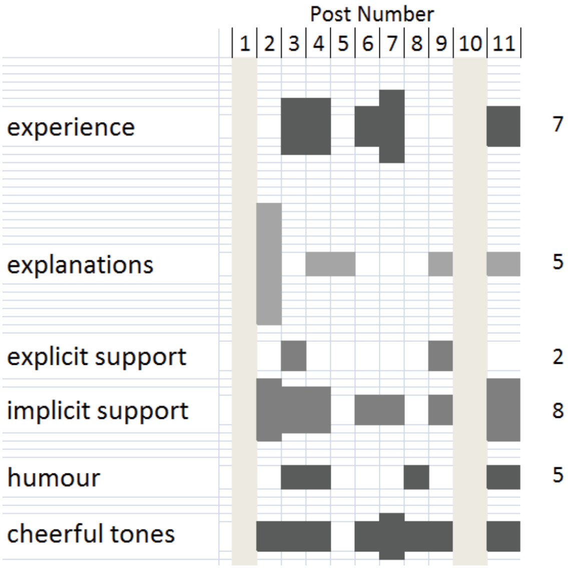


Thread D: ‘Using blunt needles’

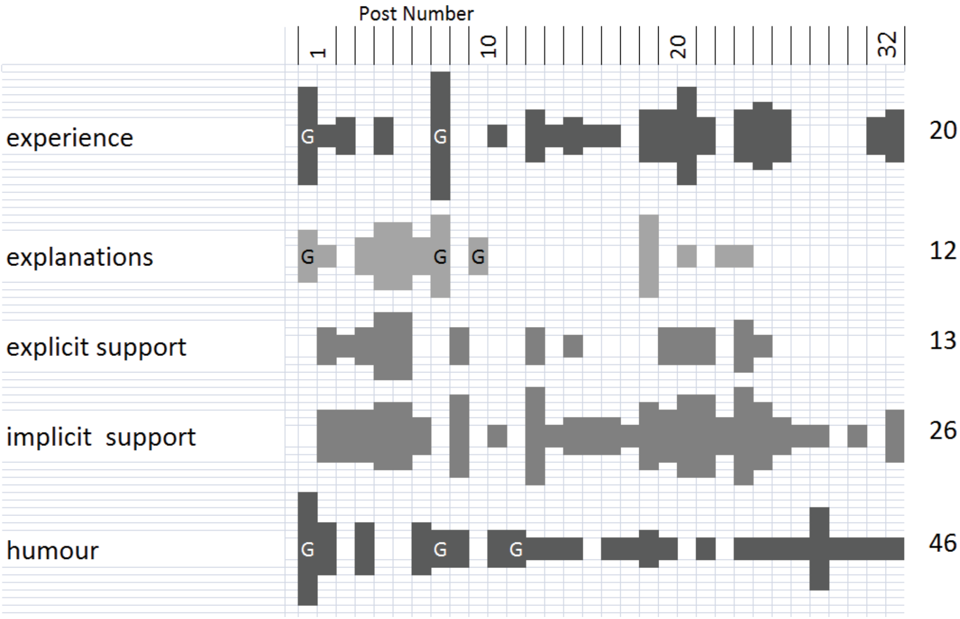


Thread E: Transplants

Figure 4.25a: Thread D and E, showing patterns in themes of format (continued next pages)



Thread F: '[Problem with rental property]'



Thread G: 'Major Rant: Do not read if you are in a good mood'

Figure 4.25b: Threads F and G, showing patterns in themes of format
(Threads D and E shown on previous pages)

Thread G actually contained ironic displays of support. The title of the thread, *Major Rant: Do not read if you are in a good mood*, recalled the titles of threads expressing frustration with the health system, but this one turned out to be about the loss of a favourite TV show. In response, people *performed* explicit support to echo the ironic drama used by Person G. This confirmed two patterns: first, that one should be supportive, and second, the complexity of support: because these ironic displays of explicit support echoed the irony of the title they worked more as *implicit* than explicit support.

Analysis of an argument

So far, I had not found any convincingly deviant data. I next looked for a deviant case in an example of serious disagreement (Thread H). It may be reasonable to expect that this could be a situation where consensus might not be achieved, or where people might not match the patterns of ideas or emotions raised by others.

There are minor disagreements in threads all the time. Some have appeared in the threads already analysed in this chapter, such as the differing perspectives on stent removal in Thread C. Thread H is different because it is an example of an ongoing, troubled disagreement. It involved recurring non-neutral emotional tones, insults and sarcasm. To avoid reigniting the discussion or recalling what may have been a troubling interaction for several of those involved, I present only the barest context of the thread and no identifying detail. In this way, it cannot be identified with certainty even by the members of whichever board it came from. This also may have made it less onerous for contributors to give consent for posts to be included. As you will see, an outcome is that I can tempt the reader with this analysis of an argument, but not provide all the details about it. However, the points I need to make are about sequences within this thread, which can be demonstrated without commenting on the content.

There were other such ongoing, troubled disagreements from time to time, which may lead one to wish I had chosen one for which I could have presented the whole analysis. However, I did not wish to request consent to show the *content* of *any* troubled disagreements, with their insults, sarcasm and emotional upsets – to avoid reigniting the discussion or troubling those involved. Therefore Thread H, for which I obtained consent for the veiled use of most posts, is a good example to use.

The local thematic chart for Thread H is shown at Figure 4.26. The thread had over thirty posts covering a diverse range of issues, so its chart is both long and wide. It shows familiar patterns of repeating tones and content, and of emergent consenses. In these ways, it immediately confirms my main findings about patterns and consenses.

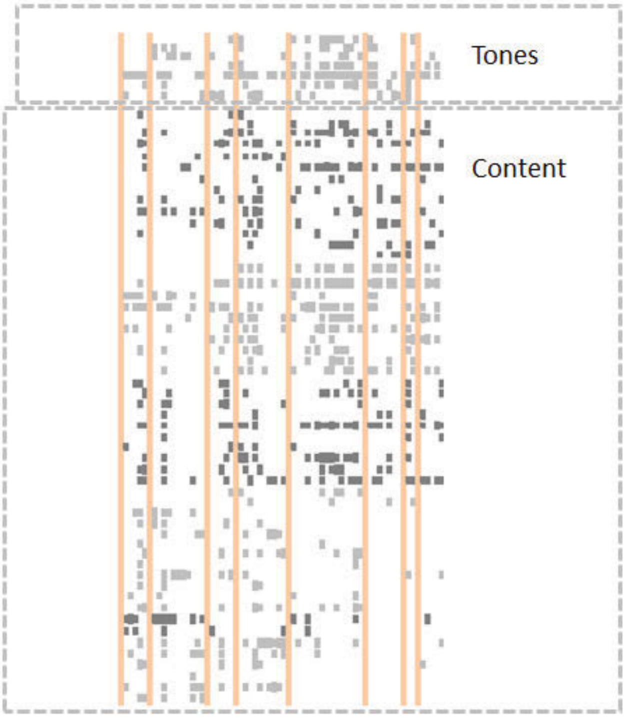


Figure 4.26: Thread H ([argument]) showing repeated themes in tones and content

Patterns in themes of format (displayed at Figure 4.27, below) show a predominance of *experience*-related talk, more implicit than explicit support, and a basic guiding tone underlying most posts.

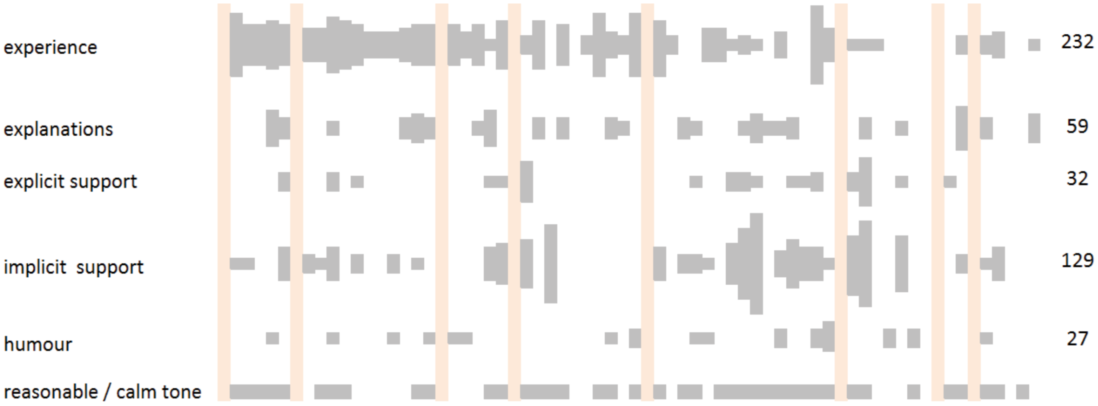


Figure 4.27: Thread H ([argument]): patterns in themes of format

As the chart for Thread H is so long, from here on I present it split into two columns, as shown at Figure 4.28 (next page). Figure 4.28 shows five aspects of the discussion, including tones, and the type of content. This included ongoing comments about ‘appropriate behaviour’ and frequent explicit statements of agreement with other contributors or ideas. While consenses emerged about what should be done (in Figure 4.28, top right hand corner), ideas raised by Person H were rarely examined in the second half of the discussion.

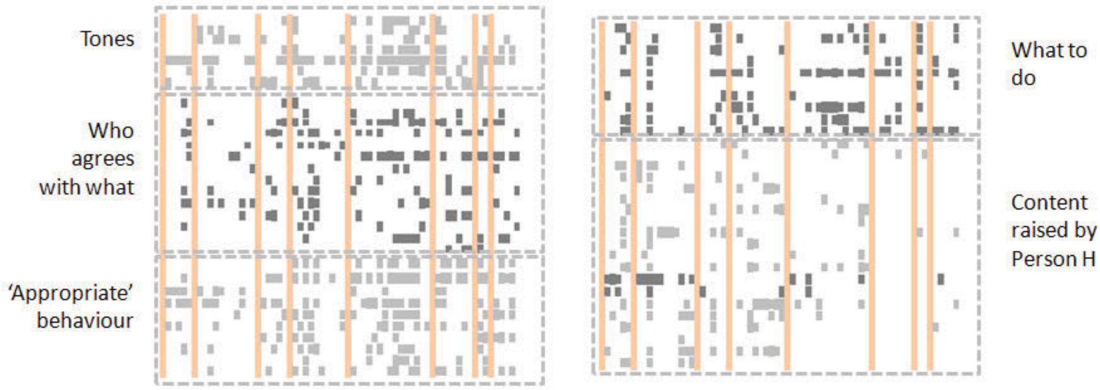


Figure 4.28: Thread H ([argument]): indicating sections of the discussion

Consenses developed on some topics, but significantly, no particular consensus emerged regarding content raised in the first post. Figure 4.29 (below) shows general areas of consenses. Posts commonly manifested what I called a ‘reasonable’ tone; two particular ideas concerning ‘what should be done’ emerged which I have called ‘Idea One’ and ‘Idea Two’. Unusually, the more commonly explored topics in this thread were not problems faced by Person H, but the bounds of appropriate

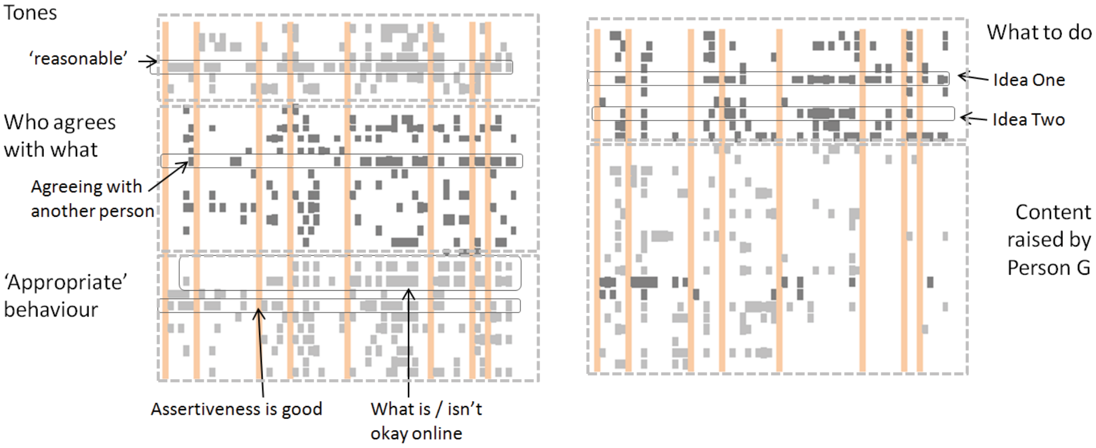


Figure 4.29: Thread H ([argument]) indicating consenses

behaviour in the discussion, especially as people began to argue. Consenses regarding appropriate behaviour included that 'assertiveness is good', an idea which was applied both to behaviour offline and within discussions. Frequent references were made to what was appropriate behaviour in the group: was it 'okay' to question, to attack others, to disagree, to put forward one's own opinion and so on. These areas of consensus are all signposted in Figure 4.29 (above).

Emotional tones

Closer examination reveals that the patterns of emotional tone in this thread were slightly different from those of previous threads examined, in a way which may be relevant to how the discussion broke down into argument.

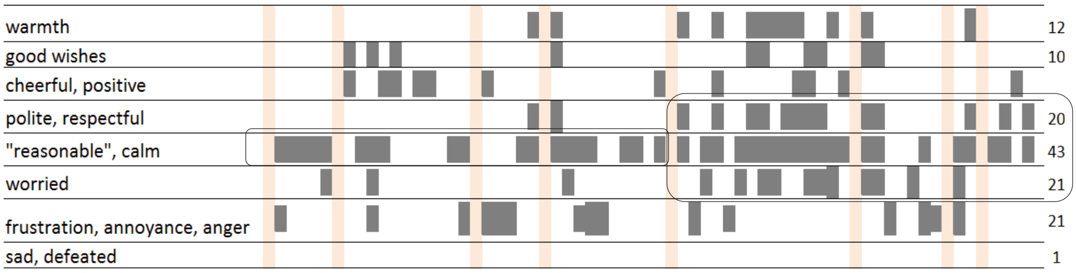


Figure 4.30: Thread H ([argument]): close up of rows showing emotional tones in posts

A consensus of '*reasonable'* tones emerged (Figure 4.30) joined by *polite* and *worried* tones in the second half of the thread. In this aspect, Thread H provided emotional guidance via tones in much the same manner as already discussed. The stage was set to cheer and reassure Person H, putting them on a more positive track. But when Person H made a second contribution, it only partly matched tones of other posts. I cannot however demonstrate how Person H responded. Although none of the contributors know which thread it is or the role they played in it, one of those who withheld consent happens to be Person H.

Previously, in Thread C ('Stint Removal'), Person C only partly matched the positive tone of others, but provided good reasons why: the procedure had turned out to be difficult for him, justifying his worry. Did Person H provide convincing reasons to maintain particular tones? Not all contributors to the thread thought so. Person X was the first to disagree with Person H. I noted where people who agreed with

Person X or criticised Person H at Figure 4.31, below. Disagreement with Person H continued throughout the thread.

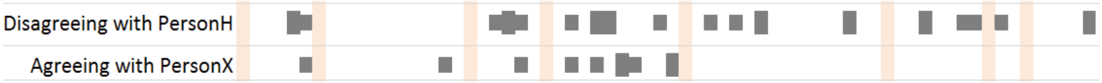


Figure 4.31: Thread H ([argument]): close up of rows showing agreement / disagreement with Person H

Though many posts found ways to empathise with Person H, relatively few defended Person H, and only two posts directly agreed with points Person H made. Throughout the course of the thread, people presented various ways in which events or ideas could be interpreted differently, presenting different perspectives as well as suggesting material which could be used if Person H needed to negotiate outcomes. Even hostile posts demonstrated these patterns.

This reiterates a point made earlier, that emotional tones do not only support contributors, but also contribute to guiding people toward or away from different perspectives. The tonal shifts usually accompany expressed shifts in perspective. In Thread B ('I AM BORG'), Person B began worried, but was reassured *and* echoed the perspective that her fistula is a good and useful thing. In Thread E, Person E began scared, but became pragmatic *and* found ways to organise and prepare for transplantation. Here, Person H only partly matched the tones offered by other contributors, and Person H's original perspectives on the situation remained unchanged.

Given that key sequential patterns were broken in this thread, it is significant that people became frustrated. In his early work demonstrating the importance of behavioural norms for sense making, Garfinkel (1967) devised "breaching experiments" in which people purposefully broke interactional rules. A common response was outrage and anger from the unwitting subjects of the experiments. Garfinkel suggested that people's frustration was a good way to identify the existence of unwritten rules. In the case of Thread H, the frustration manifested by contributors would suggest such problematic breaking of sequential norms. It strengthens my claims that tone matching and recognition of shifts in meaning were the important patterns being broken in the interactions.

Figure 4.32 (below) provides a close up on the dynamics of agreement and disagreement in the thread. Displays of agreement were infrequent in early posts, after which, various 'camps' emerged. One might think these were camps of people, but as noted for other threads, usually neither people nor posts were purely of one opinion to the exclusion of others. Six posts *both supported and criticised* Person H. What is not shown in these charts is how particular contributors criticised someone in one post and later agreed with them on a different issue. So when I say 'camps' emerged, they were camps of ideas.

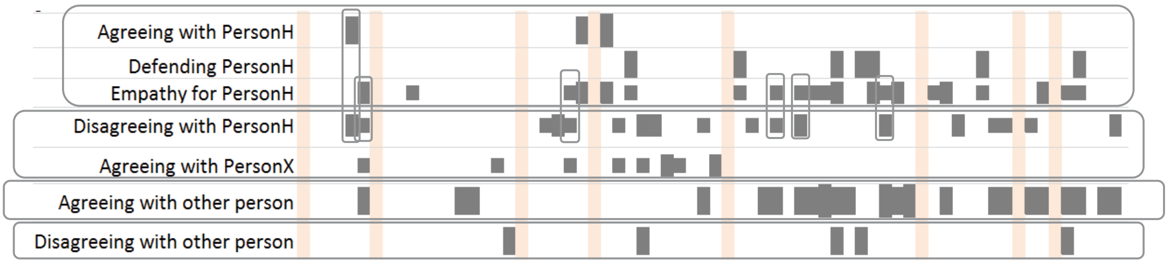


Figure 4.32: Close up from the analysis of Thread H ([argument]) comparing "camps" of supporters or ideas

Rather than examining a thread which would demonstrate a *lack* of consensus, I found myself looking at a *range* of consenses, some contradictory and others complementary with each other.

References to interactional norms in Thread H

Figure 4.33 (next page) shows how engagement with the issues raised by Person H petered out in the second half of the thread. Meanwhile, many posts in the latter part of the thread raised questions about the proper ways for people to interact online.

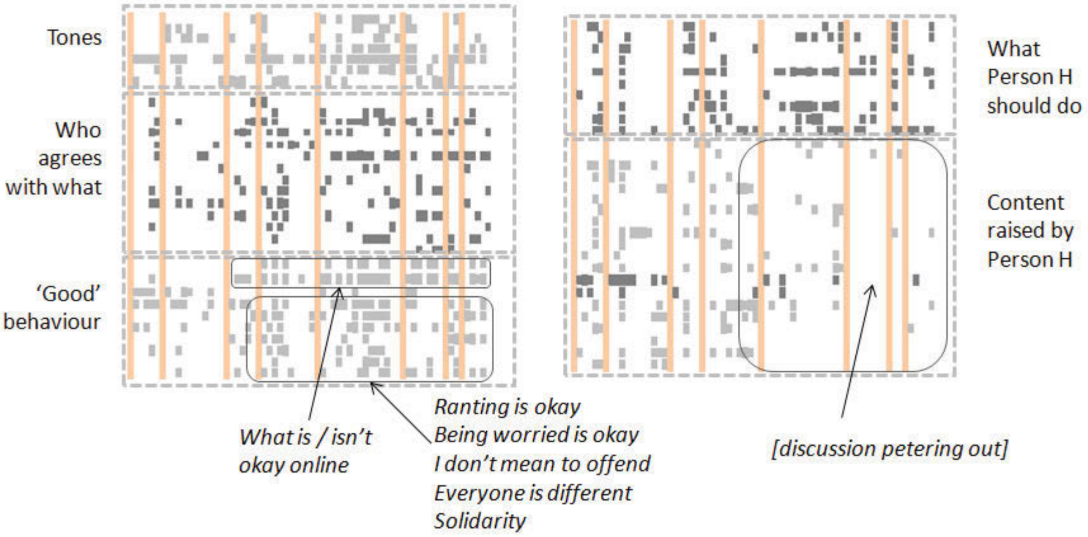


Figure 4.33: Thread H ([argument]): content related themes versus discussion of interactional norms

Such a profusion of direct references to etiquette is unusual, and reflects the breakdown of relations that occurred here. People justified themselves and overtly noted problems with meaning making as they perceived them occurring in the thread. Their remarks were intended to mend or steady the course of the discussion, and so they reveal what a thread is 'supposed' to be able to achieve. Discussions implied that it was proper for people to ask questions and let off steam, that they had a right to speak based on experience and that people should offer support.

Comments appeared along the lines of "We are all trying to help."; "I'm sorry to have upset people."; "I haven't had this exact experience, but I tried to offer my point of view". Such comments imply that it is useful to have access to a range of perspectives, and reinforce that opinions which are grounded in experience give one the right to speak. They also imply that upsetting other contributors was not appropriate. Comments like "this person has been taken apart, we are meant to be supportive" also showed the conflicting ways in which interactional norms can be played, pitting, for example, the right to speak freely against the mandate not to upset others.

I noted earlier that some claims made by Person H were judged to be unlikely. The basis of these judgements revealed the significance that people placed on comparisons of new experiences with familiar patterns of experience, and in particular with one's experience of what was normal for a situation. When making sense of Person H's comments, particularly early in the thread, contributors compared them to their own experiences, pointing out that many issues described by Person H were normal elements of their own experiences, and not a matter of outrage (Figure 4.34).

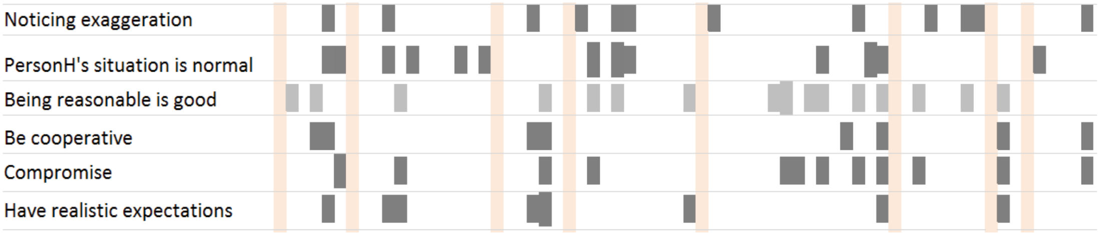


Figure 4.34: Thread H ([argument]): close up of rows related to finding being realistic

Such comparisons contributed an ethic of being reasonable, and of being willing to compromise to fit norms of experience. As shown in Figure 4.34, several contributors directly advised Person H to have reasonable expectations. 'Reasonable expectations' require that one can understand and recognise what might normally be expected to happen, so that one can temper one's expectations accordingly. This requires being willing to *compromise* and *cooperate* when the normal is not what one might wish for.

Meanwhile, there were consistent, intermittent protests against exaggeration (again, see Figure 4.43). The discussions collect experiences which are used as an archived information source by other members. Exaggeration is bad practice in discussion forums because (among other reasons) it may lead to unrealistic expectations. However, I have seen plenty of threads where exaggeration in posts was accepted. Moreover, norms such as the idea that it is "okay for everyone to be different" encourage acceptance of a range of perspectives. Nonetheless Thread H demonstrates that perspectives must be able to weather scrutiny, being tested by comparison with the experience of others.

* * *

Thread H confirmed many of the patterns already described. People took up themes from other posts, repeating (reusing) them or iteratively developing new meanings; in so doing, a range of consenses emerged; people embedded their discussions within their lived experiences. People also used emotional tones from which consenses emerged which might have guided the reader toward particular perspectives. So apparently the patterns I have been describing appeared even in problematic interactions like Thread H.

Meanwhile this analysis casts new light on dynamics between themes. When hostilities broke out, Thread H fruitfully produced a wave of commentary attempting to steer the thread back ‘on track’, confirming the social norms I identified in Section 4.2 while demonstrating tensions between them. Moreover, interactions made it clear that theories and emotional perspectives must stand the test of experience.

4.5 Summary of findings

I have presented three analyses in this chapter. The first two analyses led up to the third, which contains the heart of the matter. The first two analyses described aspects of the environment in which the threads are created. In this summary, I reiterate the findings from each of my three analyses, demonstrating how they support each other.

First analysis: content analysis of posts from a week of data

The content analysis found themes that were involved in sense making, but not how they were involved. Eight themes frequently appeared in posts. First were four themes of format: people frequently presented descriptions of *experience*, use of *humour, explicit support* and *explanations.* Second were four themes of content: people talked about *control*, *normality*, *physicality* and *emotions*. It was surprising that explicit support and explanations were the least frequently occurring of these top eight themes, as other literature suggests that the key reasons why people join online support groups is for emotional support and information (Armstrong & Powell 2009; Bacon, Condon & Fernsler 2000; Nicholas et al. 2009; Rasmussen, Dunning & O'Connell 2007).

Second analysis: thematic analysis of interactional norms

I identified interactional norms which suggest how people were expected to conduct themselves online. They provide clues to what is considered important by these groups for conducting supportive sense making interactions. The interactional norms of these groups included four themes: *be renal*, *be supportive*, *join in*, and *be positive,* which I recognised first by their explicit mentions in welcome posts and group home pages.

One important outcome of my analysis of interactive norms was that it helped me identify problems with sense making associated with broken sequential norms. For instance, when a contributor did not appear to acknowledge emerging consenses in tones and themes, people became frustrated and began quoting interactional norms to each other.

The interactional norms established conditions for discussions, shaping the content and format of messages to an extent; but on their own they cannot reveal the dynamics of sense making in interactions.

Third analysis: sequential analysis of eight threads

My key findings from the sequential analysis were as follows:

1. *Repetition* (reuse, reworking) of themes across many posts and contributors developed consenses and conceptions of normality. Here, by talking about consenses, I do not suggest that people necessarily felt or thought the same, but only that opinions or feelings were manifested across many posts – these are textual consenses, not cognitive or psychological consenses.
2. Emotional guidance was provided indirectly by tones; and
3. Meanings were shifted by the introduction of related themes, supported by tones.
4. People embedded their remarks within descriptions of their lived experiences;

The above findings are at the heart of this thesis. They have been carefully documented in eight threads, and it could be imagined that those threads were special in ways which emphasised the patterns I have described. For that reason, the first two levels of analysis provide evidence of verisimilitude. The interactional norms and prevalent themes suggest a particular kind of interactional environment, a background against which my claims concerning sequences within threads ring true.

Sequential analysis consistent with content analysis

For example, the sequential analysis established that *experiences* were shared more often in threads than other formats of message; this was consistent with the content analysis, in which *experiences* were the most frequently emerging theme. The sequential analysis established that *implicit support* was more frequent than *explicit support*. This is consistent with the content analysis, in which explicit support was relatively infrequent despite reports in the literature of the importance of support. The sequential analysis revealed the missing *implicit support*. Finding implicit support required comparisons between posts in a thread, a perspective which was obscured by the kind of counting involved in a content analysis. In such ways, some findings of the sequential analysis are corroborated by the content analysis.

Moreover, the sequential analysis suggested ways in which common themes might appear. It showed how repetition (reuse) of ideas allowed conceptions of *normality* to emerge. Emotional tones suggested what it may be *normal* to feel. Shifting meanings allowed the development of *explanations* and *support* which were tailor-made to a situation, while they also enabled *humorous* expression. In such ways, the findings of the sequential analysis and the content analysis corroborate each other.

Sequential analysis consistent with interactional norms

The sequential patterns I propose are consistent with the interactional norms of these groups. For example, the norm that people should *contribute often* encourages people to post similar ideas for the sake of contributing, creating a melting pot of repeated *experiences* and *explanations* from which c*onsenses* could emerge. The norm of *being supportive* encourages people to provide *implicit* or *explicit support*. In such ways, the findings of the sequential analysis and the analysis of interactional norms corroborate each other.

In the ways shown above, the sequential analysis produced findings which supported and were supported by the other analyses.

* * *

I have gathered together a set of elements with which to understand the content, the interactional norms and the sequential dynamics of social sense making online. In the next three chapters, I weave these themes into three successive layers of commentary on sense making processes, to show not only how the themes presented here connect to each other, but how they contribute to making sense.

In particular, the sequential themes lie at the heart of my discussions of sense making. In the next three chapters, I will show how these themes – *repetition*, presentations of *experiences*, emotional guidance using tones and the development of slight changes in meaning – reveal tools for sense making. I will address the following three questions in particular:

1. What are the functions of repetition and normality in threads, and how does emotional guidance work the way it does? This will involve a discussion of the importance of patterns for sense making in Chapter 5.
2. What are the outcomes of sharing experiences? This will involve, in Chapter 6, discussions of the importance of experience in sense making.
3. How do comments and tones slightly shift meanings, and what are outcomes and implications of such shifts? This will involve, in Chapter 7, discussions of the need to develop complex, situated understandings. There I will suggest that complexity needs specificity which is achieved incrementally via small shifts in meaning. Although the generality of explanations is useful, they are not sufficient to cope with complex situations.

Chapter Five: Patterns

Orientation via norms and variation (repetition and difference)

> She ate a little bit, and said anxiously to herself, 'Which way? Which way?' holding her hand on the top of her head to feel which way it was growing, and she was quite surprised to find that she remained the same size.
>
> (Carroll [1901] 2004, p. 18)

The quote above is another from *Alice in Wonderland*. Having followed a rabbit down a rabbit-hole into a magical world, Alice has found that whenever she eats or drinks, she rapidly changes size. She now eats *in order to* change size, and is surprised when the new pattern of her experiences is broken. Her situation exemplifies an assertion I explore in this chapter: that people's theories about the world are based on their observations of repeating patterns, and that these theories are constantly being reformulated. As demonstrated by Alice, these theories do not have to be what one might call 'sensible' or 'true', so much as they are based on what has often been encountered. They don't even have to be based on *much* experience, so long as there is some connection to familiarity: Alice had 'only' changed her size a few times when this scene occurred.

Here in Chapter 5, I discuss *patterns* in the form of repetition and difference. In terms of repetition, I will explore how posts repeat themes enough to create familiarity and local conceptions of normality. Understandings of normality are immensely useful, both knowing what is normal for people in general and finding one's own lived normalities. Meanwhile, in terms of difference, the online discussions provide readers with an idea of the range in people's experiences. Such perspectives provide the 'lay of the land' – not just peaks caused by what is often said but also the spread of 'what else is out there'. This larger sense of variety allows one to comprehend obstacles and dangers and plan a path through shifting landscapes. It also enables a process of iterative development of meanings. By noting variety one's perception of norms can drift a little, and by incorporating variety discussions can run along normative lines without demanding absolute conformity.

5.1 Repetition

In the data analysis, I showed that many voices repeated the same idea, or reported having experienced 'the same thing'. I use the term *repetition* not in the sense of *perfectly repeated experiences*, but as shorthand for reiteration, reuse of themes or ideas; as I have noted already, I used the term to refer to the ways in which people loosely clump similar things together and gain familiarity from recognising such loosely similar things over and over again. I have shown how this 'repetition' made certain themes appear more loudly in the data to create consenses. People would add a post simply to agree with someone else or repeat what they said. Sometimes, ideas were explicitly acknowledged to have come from previous threads. Such ideas had been tested both by lived experience and in the context of the groups. Moreover, the development of ideas in threads involved not just repeated *ideas* but repetition from *many people* in a range of contexts. Group understandings were forged and modified by these agreements and rewordings.

In these ways, repetition was important at the level of sequencing within discussions. It was also a theme in the content of discussions. People recommended strategies involving repetition: allowing experiences to unfold by reiteration; trying an idea in their lives, then reporting back with news of how it went; letting time pass and routines develop. In addition, people advised that they felt better about a situation as it became familiar due to repetition.

Approximate repetition

Having said that themes repeat in the data, the recurring themes were not actually the same. In particular, the remarks in which they appeared were always different. Each post was unique, just as experiences and situations offline are unique. If people describe the same event, their descriptions will be different; even sources of potentially reliable repetition, like different performances of a play, are different in myriad ways, many of which might easily be apparent to an astute audience member. A photo or a photocopy, may (sometimes) appear indistinguishable from the 'real thing', yet multitudinous hidden differences can be found at the level of construction or the distribution of ink on the page.

The idea of *perfect repetition* is less useful in day to day life than that of *approximate repetition*. Approximation is critical to being able to recognise ‘sameness’, and from there, to identify patterns.

Seeing similarity

Despite differences, we recognise similarity and call it repetition. ‘The same’ is an act of categorisation whereby differences can be glossed over for the sake of workability (Deleuze 2004a; Weick, Sutcliffe & Obstfeld 2005, p. 335) – an act of pattern recognition which forms a basis for the recognition of larger patterns like ‘normal’, which have their own blurry borders (Bowker & Star 1999; Heritage 1984, p. 122).

For example, I state that the ‘same’ themes appeared in posts along a thread. Here is a selection of items I have categorised as ‘the same’:

‘Repetitions’ of the theme ‘dependant on a machine’

Post#1: I'm so frustrated to be **depended to a machine**.
Post#3 Everyone experiences depression when they learn that they will have to **rely on a machine**.
Post#4 It does get easier when you get in a routine, [...] rather than focusing on the bad things like needles, **being tied to the machine** [...]
Post#9 There is more than being **strapped to a machine** out there.

What I coded was not exact repetition: the wording here was different each time. Even if vocabulary was reused, meanings were slightly changed by the surrounding message, or at the very least, by the fact that it was a new message. This is the blurring required to group elements: almost-like goes with almost-like, similar is put with similar, to create workable clusters of ‘repetition’. In this way, as they look for patterns, people blur details, allowing them to find the familiar; but in this same process, they create similarity / familiarity out of what could otherwise be viewed as a teeming sea of unique elements.

Reproducing similarity

Having well-developed capacities to *recognise* similar things, humans also *act* in similar ways, following patterns and routines learned from others. French sociologist Gabriel Tarde (1903) posited imitation as the human solution to pervasive differences and variation. He suggested that humans mostly imitate each other, choosing our self-identified superiors as models – those we believe to be better than us in some relevant way. When they laid out the mechanics of social constructionism, Berger and Luckmann made a similar point: in light of an endlessly complex world, institutionalization, roles and reification are short hand which people have developed to package ideas together and refer to them quickly. Experiences become congealed in recollection as "recognizable and memorable entities" (Berger & Luckmann 1966, p. 67) and form sedimentations which may enter into the collective stock of knowledge. Language makes such experiences readily transmittable. Sedimented meanings are simplified in the processes of entering into a tradition; they are formularised and routinised to make them more memorable (Berger & Luckmann 1966, p.70). For Tarde, though some imitation is deliberate, much of it is unconscious. He described it as "somnambulism" or "hypnotism", a reference to the unthinking, instinctive ways in which many routine activities are carried out (Tarde, 1903, p. 76, 87).

Such imitative or repetitive processes are useful and productive. Pattern-making reduces the cognitive burden on individuals. "All human activity is subject to habitualization. Any action that is repeated frequently becomes cast into a pattern, which can then be reproduced with an economy of effort" (Berger & Luckmann 1966, p. 53). Habitualisation allows humans to reduce the number of decisions they have to make – to the point of unthinking imitation, the "somnambulism" described by Tarde.

As well as reducing the effort inherent in particular activities or decisions, this smoothing by habitualisation creates a larger space of safety within which individuals can live in routine ways: a home-space, including an existing social order which provides "direction and stability for the greater part of human conduct." (Berger & Luckmann 1966, p. 52). At the level of society, shared institutionalisation and habitualisation develop into symbolic universes shared by large subsections of a community. Symbolic universes attempt to explain the entire experience of a person, allowing them to locate themselves with respect to their identity, put "everything in its place" and live correctly (Berger & Luckmann 1966, p. 98). Roles allow people to construct a background of routine which stabilises their everyday activities and interactions. This is the kind of useful orderliness described by Chatman, in the midst of which people can follow routines and live in generally unreflective ways from day to day (Chatman 2000). Such packaging *facilitates* what we do, for example, the shorthand of pre-existing metaphors and phrases facilitates people's capacity to think using complex ideas. However Chatman pointed out that such packaging also *restricts* what we do or think according to the borders inherent in socially refined roles and meanings.

Chatman described a life lived in a "small world", using the sociological theories of Luckmann, Goffman, Schutz and other sociologists of 'everyday life'. This is a life based on routine and predictability, with a collective sense of order and balance, and social norms which tell individuals "what he/she may do and what he/she can expect out of life" (Chatman 2000, p. 8, citing Berger, 1963). Examining these theories from the point of view of information need, Chatman argued that such conditions stifle or reduce information seeking. She said that people will not seek information they need through fear of social censure and other repercussions arising from having revealed aspects of their situation (Chatman 1996, 2000). Chatman's "Theory of Life in the Round" is constituted by six propositional statements:

> Proposition 1: A small world conceptualization is essential to a life in the round because it establishes legitimized others (primarily 'insiders') within that world who set boundaries on behaviour.
>
> Proposition 2: Social norms force private behaviour to undergo public scrutiny. It is this public arena that deems behaviour – including information-seeking behaviour – appropriate or not.
>
> Proposition 3: The result of establishing appropriate behaviour is the creation of a world-view. This world-view includes language, values, meaning, symbols, and a context that holds the worldview within temporal boundaries.

> Proposition 4: For most of us, a world-view is played out as life in the round. Fundamentally, this is a life taken for granted. It works most of the time with enough predictability that, unless a critical problem arises, there is no point in seeking information.
>
> […]
>
> Proposition 6: Individuals will cross information boundaries only to the extent that the following conditions are met: (1) the information is perceived as critical, (2) there is a collective expectation that the information is relevant, and (3) a perception exists that the life lived in the round is no longer functioning.
>
> (Chatman 2000, pp. 9-10)

In fact, the structured routines of "life in the round" as they are described here create good conditions for sense making, because they establish patterns with which new situations can be compared, familiarity against which to ground the new. The usefulness lies not so much in making the world 'smaller' as in making it less detailed – simpler, and less time consuming. Alternative propositional statements could be the following, which highlight the usefulness of norms and socialised institutionalisation of meanings:

> Proposition 1: It is useful when 'insiders' recognise similar meanings;
>
> Proposition 2: Social norms force private behaviour to undergo public scrutiny. It is this public arena that deems behaviour 'familiar' and 'appropriate' or not;
>
> Proposition 3: The result of establishing *routine* behaviour is the creation of a *predictable, familiar* world view, including language, values, meaning, symbols, and a context that holds the worldview within temporal boundaries;
>
> Proposition 4: For most of us, a world-view is played out as life in the round. This is life taken for granted, which works most of the time, with enough predictability that, unless *an unfamiliar situation* arises, *one can proceed confidently with no need to re-analyse everything.*

Normality

As posts are placed together and compared in online discussions, a number of perspectives emerge, including: (a) an idea emerges of what could be normal for experiences in general, and of what the norm is in the cluster of stories presented. Also involved here is each individual's conceptions of where everyone fits in relation to the norms and ideas of what is normal. (b) People develop an idea of what emotions are acceptable in relation to the situation in general, and to the specifics of different people's narratives.

Normality does not only emerge organically by reused elements within threads; it is also directly discussed by contributors. In Thread A, six out of the 25 posts (nearly a quarter of them) referred to what is 'normal' or 'natural' for a person to feel as they start dialysis. When Person B began Thread B, she described changes in her arm and shoulder, and asked "Is this normal?" In Thread C, Person C asked, "What should I prepare for?" People directly ask each other for a conception of normality. So for contributors to the groups, establishing a range for *normality* and having a sense that their experiences fall within that range is an important factor in making sense. This theme connects with the literature review in Chapter 2, where normality was a common theme in illness experience literature (Polaschek 2003; Quinn et al. 2008; Weston, Norris & Clark 2011; Tong et al. 2009; Veen et al. 2012), suggesting its relevance to sense making.

Normality (in the world out there)

Normal, as it is used in the groups, has a range of meanings. One in particular is worth starting with: this is the 'normal' of life outside dialysis: the life lived by healthy people who are even referred to in discussions as *normals*. This is constructed in posts as a life and an ideal quite different to the *normal* of the dialysis experience. People dream of a return to the 'normal's *normal*', either by transplant or as a goal obtainable via a 'good' dialysis routine.

> *I dialyse while I sleep and have a normal life otherwise. I run my household, work out at the gym 4 days a week, I ride and train my*

> *horse, walk and train my dog, work 2 jobs, have a fantastic relationship with my husband and our extended family and friends.*
>
> *(Excerpt from Post#12, Thread A)*

For many, this *normal* is a lost idyll, dependent as it is on a complicated regime of diet restrictions and regular, invasive treatments. Beyond the normal of a healthy body, one looks for 'dialysis *normal'*. Dialysis *normal* appears to be about routine and predictability. It dictates that although an experience is a surprise, it does not signify the start of an emergency. This needs to be accompanied by the establishment of stable physical symptoms within which the individual is relatively safe.

> *I'm doing better now. After my Friday's session, I wasn't tired at all and I could immediately proceed with my usual activities.*
>
> *(Excerpt from Post#20, Thread A)*

An experience can become *normal* if it is accepted as normal by others or commonly reported by others.

> *... particularly on my first day of dialysis, when my lines clotted, and when i blacked out, i didn't freak out, cos through this group i knew that was just a possible outcome, and nothing out of the ordinary.*
>
> *(Patient, AustralianDialysisBuddies)*

Blacking out is not normal for healthy people, but is common on haemodialysis and therefore for this contributor, can be called normal.

Norms

New kidney patients enter a world of hospitals, clinics, medications, and medical procedures, a social milieu in which a "system of intelligibility" prevails (Crotty 1998, p. 54). They must learn how to fit into that system. One way they do that is by watching and listening to others in the community: other patients, doctors, nurses, who indicate by their words and actions, the meanings of objects and ideas.

They pass on understandings, “the truth” of this new milieu (Crotty 1998, p. 59). Online, too, members learn the expectations and norms of the group and gain perspectives on the larger renal community. They acquire information relevant to their needs; in this way the discussions educate members. Individual members contribute to discussions and then take part in developing group norms, a process to which I return in Section 5.2.

Consenses are also built up locally in each thread, such as what patients should and should not worry about, or how contributors to the thread consider a normal fistula should look and feel. Though contributors do not all agree (in fact most point out how they both agree and disagree with others), each contribution adds to the developing stores of opinion. Again, conflicting consenses can co-exist and consenses may sometimes change as a result of repeated or frequent contributions from particular perspectives. Importantly, repetition of ideas can affect consenses, even if (particularly if) they provide ‘redundant’ repetition.

My normal

Every dialysor’s[53] body is different, and learning the experiences of dialysis in one’s own body is a topic I will discuss in Chapter 6. For now, it will suffice to say that people need to understand what their body’s versions of normal are going to be. In terms of this personal understanding, an experience becomes ‘normal’ when it has happened to the individual frequently. As time passes the dialysor finds out the hard way how their body responds to kidney failure. Their repeated exposure to initially shocking experiences means that they may become accustomed to them. A new normal will be attained, within which, it appears, the dialysor will have become ‘used to it.’

> *After you have been on dialysis for awhile you realize that there are some things you can enjoy and you start to accept it. You never get to like it, you just get used to it.*
>
> *(Patient, IHateDialysis)*

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[53] Term used by some kidney patients to replace the term ‘patient’ (Peckham 2008).

> *Please, give it some time. Don't do anything too hasty. Give yourself 2 months. 3 months. See how you feel then. [...] You're only just starting, and I promise you it WILL get easier... the vast majority of my treatments are dead flat BORING.*
>
> *(Excerpt from Post#4, Thread A)*

Comparing oneself to norms and consenses

The philosopher Michel Foucault's work has an historical, macro-sociological focus, but his descriptions of norms and normalising processes offer insight into the micro-sociological context of the discussion groups I studied. Of particular relevance is his writing about normative or disciplinary relations and processes of self-control, which are developed in the context of moral and ethical values and energised by the idea of norms and normality. In this context Foucault views norms as having the potential for repression or prohibition, but he also engages with normality, via discipline, as a productive network (Foucault 1984c, p. 61). On one hand, Foucault describes this productivity as exercising itself by obtaining service from individuals, developing greater efficiency and usefulness from their "acts, attitudes, and modes of everyday behaviour" for social or sovereign ends (Foucault 1984c, pp. 66-7). However, discipline also benefits the individual by their improved access to their own capacities.

In a particularly influential discussion of self-subjectifying control, Foucault examined Bentham's designs for the *panopticon*, a prison tower in which all cells are visible from a single central observation point (Foucault 1977). As prisoners cannot see whether they are being observed or not, they may monitor their own behaviour, controlling *themselves* whether they are being guarded or not.

By writing posts, contributors manifest themselves online. 'Lurkers' can choose to never post at all, instead learning from the posts of others. However, to participate fully by posting and receiving replies, members must show themselves, after which their posts remain on display, fulfilling the discussion boards' secondary goal as archives of experiential knowledge. They become visible to others and allow others to get to know them. Having shown themselves, posts then remain on show, open for perpetual observation. But this is always retrospective observation, looking back on an action without being able to see what a person is doing ‘now’; and unless they post, people are more or less invisible. The discussion boards are at best an incomplete panopticon, allowing only partial observation.

Describing disciplinary mechanisms such as those used to compare student’s grades, Foucault refers to processes whereby individuals are differentiated by noting their particular combination of relations to normality in a variety of measures.

> *[B]y ‘normalization’, Foucault means a system of finely gradated and measurable intervals in which individuals can be distributed around a norm – a norm which both organizes and is the result of this controlled distribution*
>
> *(Rabinow 1984, p. 20).*

Norms are established by the comparison of individuals to each other. In this way an individual (or behaviour) is located with reference to the norm, while simultaneously the norm is clarified. When the range of experiences in a particular domain is visible, it allows the identification of what is common as well as what is different (Foucault 1977, pp. 182-3).

Hierarchical observation refers to a mechanism or apparatus in which all elements of the disciplinary process are visible to each other. Foucault notes that “hierarchized surveillance creates a network of surveillance from top to bottom and from bottom to top, in which all individuals are perpetually supervised by each other and by themselves” (Foucault 1977, pp. 176-7). Power is exercised “through exact observation” (Foucault 1977, p.171) in which every gaze is involved, but not all potential viewers can be seen. That is, people discipline each other. When it allows visibility, architecture operates on its occupants by affecting their conduct and making it possible to know them.

By clustering posts in threads, the discussion websites form a structured apparatus whereby contributors are always (partially and retrospectively) visible to each other.

Manifesting the meticulous attention to detail made possible by their access to many eyes, discussion groups permit ongoing attention to the specifics of behaviour and opinion by contributors. The posts of contributors combine to create "fields of comparison", within which individual contributors can obtain a normalising perspective (Foucault 1977, pp. 182-3). When people ask for or receive descriptions of normality, or when they quietly search the archived discussions looking for such data, they can access a range of experiences and locate themselves within that range. The discussion boards therefore function as normative technology.

Finally, participation is in part, confessional. Sitting in their separate houses, alone before a keyboard, contributors write to unseen readers; they express their motivations, their confusions, their activities, their fights, and the development of their situations and ideas. According to Foucault, the Catholic ritual of confession created the self-disciplining subject, who is individualised in three ways: (1) via moment by moment calculations of merits and faults; (2) by placement in a network in which everyone sees everyone else, rather than a hierarchy; and (3) by production of one's own particular, internal, secret, hidden truth (Foucault [1978] 2007, p. 184). Foucault saw the development of the confessional as aiding in the creation of subjects who are ready for governmentality – who can find norms themselves and compare themselves to them, each of their own accord. In particular, as contributors produce posts, writing up their own 'hidden truth', they compare themselves to norms and expectations, judging the merits of their own stories, and at times, justifying them: the first judgement is *self*-judgement, occurring regardless of whether they hit the 'submit' button for consideration by other readers.

Foucault points out that these kinds of normalisation processes are not necessarily oppressive (Foucault 1984a, p. 205). One may feel pressure to conform, or perceive the condemnation of others for errant behaviour, and this may serve to modify one's behaviour. Conversely, by comparison to the range of others' experiences, one's own experience may become understandable. Dervin described sense making as a process of needing to close gaps, including perceived gaps between one's own situation and that of others. I have suggested in previous writing that people may solve this kind of problem by convincing themselves that there is actually no gap

(Godbold, 2006). Having found norms online, though people may worry when their experiences appear too different, conversely they may be able to comfort themselves when their experiences are similar, reducing their perception of 'gap'. In addition, norms provide a form of guidance, allowing people the happy imitation described by Tarde. Contributors may make of their renal career an ongoing project to improve their health, their ability to cope or their medical compliance. At any rate it is apparent that participants in the discussion groups seek out the advice and opinions of their peers and find them helpful.

> *This site is such a blessing. I often talk about the information it provides. To say it is a great source of information would be an understatement.*
>
> *(Patient, IHateDialysis)*

Right emotions

The volume of data related to emotions and emotional support which emerged in Chapter 4 makes it clear that sense making involves not just getting *ideas* straight 'in your head' but also being able to '*feel* alright' about yourself and your situation. Apparently when things made sense (fitted into familiar patterns), people felt good, and vice versa. However, people also made sense without feeling 'good' when others agreed that their feelings were appropriate. In this 'place for letting off steam', people expressed emotions which were not positive and were met with replies suggesting that others have felt the same. People commented online that they felt better just for knowing that the other contributors understood them. For example, the consensus that a situation was outrageous lent authority to an account in which a person was angry, because being angry about it was a reasonable feeling (and vice versa: more angry stories would add to a consensus that a situation was outrageous). Even though emotions have been considered inherently illogical and irrational it appears that making sense involves developing logical or reasonable perspectives, including reasonable or the 'right' emotions.

Tarde proposed that the basic 'things' that people imitate are beliefs and desires (1903, p. 145). He saw other, more complex 'things' such as activities, politics, aesthetics, and government, as compounded from either beliefs or desires. In so doing, Tarde attributed the basic motivation for much imitation to emotional drives; particularly preference and aversion (1903, p. 189). He also suggested that one imitates what one loves or admires, and described the "love of seeing again" (1903, p. 354), the joy of the familiar.

When Weick outlined the properties of sense making, the first property he described was that sense making is "grounded in identity construction" (1995, p. 17). With an assumption that the individual puts forward identities which are constituted during interactions, he noted, "What the situation will have meant to me is dictated by the identity I adopt in dealing with it. And that choice, in turn, is affected by what I think is occurring" (Weick 1995, p. 24). The identity which is put forward is constantly re-evaluated and reworked in the light of one's self perceptions and one's perceptions of the expectations of others, using the same processes for the subjective appropriation of the identity as for the subjective internalisation of the social world (Berger & Luckmann 1966, p. 132). "People learn about their identities by projecting them into an environment and observing the consequences" (Weick 1995, p. 23). Weick noted but did not explore the role of emotions in sensemaking (Weick, Sutcliffe & Obstfeld 2005) yet they play a key role in these reflexive social-self-evaluative processes of identity construction. Psychologists Haviland-Jones and Kahlbaugh describe emotions as a "glue" for identity (2000, p. 294), drawing the individual towards particular identifications related to familiar positive emotional responses. In this way, identity construction, emotions and sense making operate in concert.

Returning to the data analysis from Chapter 4, just as consenses in ideas emerged via patterns, similarly, emotional support emerged using matching or divergent tones, (patterning in tones) and mirroring (pattern matching) of ideas. Explicit support was important, but it was dwarfed in comparison to these continual fluxes in emotional consenses. People guided each other towards particular feelings about a situation. For example in Thread A, Person A declared:

> *Yesterday, I had my first 4 hours sessions. Afterwards, I was a mess. I cried and said I won't do it anymore.*
>
> *(PersonA, Excerpt from Post#1, Thread A)*

Later in the thread, responding to a wave of positive tones and ideas of other contributors, he returned with the words:

> *Hi everybody!*
> *I've already made some steps. Today, I reached the bottom of my life and now the path can lead me only up. [...]*
> *So, let's go on* 🙂.
>
> *(PersonA, Excerpt from Post#14, Thread A)*

His return is marked by a flicker of the positivity demonstrated to him by other posts.

As well as guiding with tone, posts also demonstrated a *range* of contextualised emotional reactions, showing how other possible emotional reactions to situations might be accepted. In processes parallel to those described for ideas, emotional cues in interactions were a normalizing apparatus, providing confirmation that a person's feelings are 'normal', providing guidance for how a person can reasonably feel, and dampening (or inspiring) displays of inappropriate or socially unfamiliar emotions.

Humour

So far, I have scarcely acknowledged the hardships of dialysis. The reader may have recoiled at some quotes I have included from the data, but the ongoing daily slog faced by patients and their families is difficult to convey. Having read the boards for almost two years, I still sometimes recoil at scenes described. Pain, fear and death are frequently discussed, including the temptation to give up dialysis and die from renal failure. At the same time, the most common thing for me to do while reading the online discussions is to laugh aloud. I find the discussions genuinely funny, and some of the contributors are particularly and consistently droll. The content analysis showed that people drew on humour in almost a third of posts, and in over half of all threads. Considering threads responding to angry, frustrated or frightened first posts, over eighty percent of such threads also contained jokes or references to humour in subsequent posts. Evidently there is much to be said about the role played by humour in these interactions, requiring detailed exploration in future work. I will limit myself to a few comments here.

Most relevant to the present discussion is that humour addresses tensions between two strong interactive norms identified in the data analysis. First, people are willing to describe their negative feelings and experiences online, for interactive norms encourage them to do so. But contrasting interactive norms mandate positivity and support, and as discussed, ‘feeling alright’ helps people to make sense of their experiences. Humour conforms with both of these expectations. Most likely, people genuinely wish to be stay positive and help others feel positive even while being realistic about the gruelling experiences of dialysis.

Freud suggested that humour provides a release for so-called negative feelings such as anger, fear and depression (Freud 1976). It allows people to talk about the unspeakable. In the discussion groups, humour allowed people to criticise their doctors, their loved ones or the medical system and to express their fear and frailty.

> *If there was anything that was actually private [in hospital] , I wouldn't have the very distinct memory of the male patient several beds down yelping, "You have to shave where?!" [...]* 🤣 😆 *too funny*
>
> *(Patient, IHateDialysis)*

Humour allowed people to negotiate the tensions between positivity and speaking freely.

Strangely, it may not be very difficult to be funny about dialysis. According to Freud, a technique for the production of humour is a set up, followed by an inappropriate end: a broken pattern. The ongoing changes experienced by kidney patients mean that they frequently experience broken patterns. Their experiences are naturally humorous in a dark sense of the word. Meanwhile the patterns they become used to are so abnormal compared to the rest of society, that even their expectations are humorous. Finally, the strangeness of the dialysis experience means that their stories may be confusing to 'normals', but are immediately recognisable to other dialysis patients; dialysis stories make other dialysis patients laugh with the laughter of recognising an insider. This is another humorous technique described by Freud (1976), the humour that divides one group from another. For example a contributor posted a URL line to a web page selling the following product – the replies suggest a particular kind of renal humour.

Organ Transport Lunch Cooler

Is that a BLT or a spleen?

- White and Red insulated lunchbox cooler
- Big enough to hold a typical frozen meal, plus a couple of sodas, and / or viscera
- Not fit for actual human organ transport, but are you really gonna do that?
- Read more...

$19.99 ✗ Out of stock *(Est. 3/17)*

This product is not available for purchase at this time.

Many contributors posted in reply saying they loved the lunch box and wanted one. One contributor commented dryly:

> *Gift box for a kidney cake is my first thought.*
>
> *(Patient, IHateDialysis)*

Most jokes fall flat on explanation but I must attempt to convey the humour here. This is particularly 'renal' humour because of the suggestion about kidney cake. A kidney cake is a cake in the shape of a kidney, served to transplant recipients to celebrate the anniversaries of their transplant. The joke combines images some of which are recognisable only to some renal patients, which would create a confusing, confronting and therefore funny series of emotional responses in the recipient of such a container and those watching it being opened – especially the reactions of those unfamiliar with kidney cake.

* * *

I have explored the normalizing processes evident in online discussions, identifying how repetition usefully develops consenses in ideas as well as in emotional tones. The repeated themes that contribute to norms and conceptions of what is ‘normal’ allow people to orient themselves; they allow them to find familiar ground, develop routines and reduce the complexity of their daily experiences. People iteratively develop their own routines and sets of familiar ideas and emotions, which evolve in conjunction with their dialysis identities.

5.2 Difference

As well as locating *repeated themes*, it is also useful for sense makers to have an idea of the *range of difference* in people’s perspectives. For a start, it allows one to see not only what usually seems to happen, but also what may be the worst and best-case scenarios, and how frequently they occur. Contributors point out differences to each other, particularly in respect to changes over time. In addition, the variety of the boards includes and encourages dissonant voices. So in these aspects, the reader is not just taking in the field of others’ experiences but has a “calculating gaze” (Foucault [1963] 2003): estimating the probabilities of different outcomes and balancing preferences for the options presented.

In this section I examine two aspects of difference: the effects of time, and useful variations in perspective represented by dissonant voices.

Time

Deleuze identifies two kinds of time: an ongoing present, which is cyclic – *Chronos*; and a linear time divided between past and future, which stretch endlessly in the two directions – the *Aion* (Deleuze 2004b). As I noted in Chapter 2, most conceptions of time in the sense making literature have been of linear time. LIS researchers focus on the effects of time on information (making it more or less valuable, e.g. Solomon 1997a) or on information seeking – usually by making people stressed, or causing them to curtail full searches (Kuhlthau 2004; Wilson 1997). Time is present but is not discussed, in process-related models of behaviour (for example as sequences of steps taken). McKenzie and Davies (2002) paid careful attention to discursive orientations around linear time, noting time as both a spur (running out of time) and a barrier to information seeking (it is not the right time yet to ask particular questions). Hartel (2010) described a range of temporal experiences, including “careers”, subject related phases and episodes. Careers were long spans of time in which a person gradually becomes expert, by virtue of embedded, cyclical experiences: subject-related phases, where one concentrates on one subject area after another, comprised of episodes, in which one undertakes small, repeated projects.

In line with his interest in everyday life information practices, Savolainen (2006b) paid attention to how cyclic time emerges in Library and Information Science literature in the form of recurrent activities – habits and routines – which affect information seeking, for example by limiting it (Chatman’s “small worlds”: 1999) or by providing time-dependent opportunities (Pettigrew's “information grounds”: 1999). Chatman’s (2000) descriptions of “life in the round” are of ways of living based on routine activities standardised by repeated comparison to social norms. Veinot and her colleagues described such routines among dialysis patients as they attended their thrice weekly treatments, noting that the local, everyday focus “may have soothed the pain of a life limited by renal failure” (Veinot et al. 2010a, p. 3). Solomon (1997a) studied the activities of a planning unit within an organization over three annual cycles, noting how routines were established over time. He made it clear that sense making requires time, a point which appears to have lain fallow since then.

Other references to time in the Library and Information Science literature are less direct. I once made a point of returns in sense making by presenting a model of information behaviour as a cycle (Godbold 2006). Sonnenwald (2005) suggests that information seeking behaviour includes reflective interaction and continuing relations with resources; similarly Bates’ (1989) berrypicking model involves ongoing reflective interactions with a system. However, these are not explicit or direct explorations of cycles, and other writers discount the importance of repeated information, suggesting that it is perceived by sense makers as less useful or relevant (e.g. Veinot, Kim & Meadowbrooke 2011).

However, time, specifically one's momentum through linear time, is a central theme in Dervin's description of sense-making. She describes how change contributes to the epistemological-ontological gap to initiate sense-making, in a set of remarks which cut to the heart of the relationships between time, difference and sense making.

> *[T]he quest of human beings to fix*[54] *the real faces a never-ending riddle. [...] The real is always potentially subject to multiple interpretations, due to changes in reality across space, changes across time, differences in how humans see reality arising from their differing anchorings in time-space; and differences in how humans construct interpretive bridges over a gappy reality.*
>
> *(Dervin 1999b, p.730)*

Dervin draws attention to the effects of time on reality and on understandings, but she is not specific about how time might interact with sense making, though she does observe that sense-makers might base understandings on ideas that worked in the past (Dervin 1999/2003, noted by Savolainen 2006a, p. 1119). Her main concern is that researchers pay attention to shifting meanings and fluidity: "movement through time-space" (1999b, p. 730). She offers this as a contrast against research assumptions of stable conditions with subjects whose reactions and perceptions can be predicted by persistent personality types (Dervin 1989b). For her, time is part of the flux in people and reality which creates the need for sense making. Her perspectives on fluidity and flexibility are explored in Chapter 6. Here, I take a closer look at the dynamics afforded by time in terms of difference and its relationship to change.

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[54] fix – that is, make it fixed, make it stop changing. Alternatively, the sense-maker may need to repair (fix) reality by bridging gaps.

Changing bodies, changing understandings

> *... you'll soon start to see the fuller picture. I say fuller because there is no "full" as such... the picture just keeps changing and we try to keep up as best we can.*
>
> *(Patient, IHateDialysis)*

It is changes in the body that first draw the individual's attention to ill health. Posted descriptions reveal dialysors' ongoing accommodations to changes in their bodies and bodily systems. In particular, as their kidneys fail, contributors appeared to manifest a change in awareness, turning their attention to monitoring the processes once carried out invisibly by the kidneys. They attend to the levels of toxins and fluid in their blood, requiring a detailed knowledge of their body, including the 'feel' of renal failure, from day to day. I have already described the importance for contributors of learning their personal normals.

However, contributors do not merely describe intense change during the onset of various stages of renal failure, but rather attest to experiences of ongoing change. The relative fragility of their health means that change is amplified for renal patients and the implications of change can be serious. Given the kinds of situations and processes with which dialysors learn to live, the multiple other illnesses which often accompany kidney failure, and the vulnerability of the dialysing body, even experienced dialysors post to the group to establish if some new change is normal.

> *I got my central line taken out about a month ago. ... it feels as if the line is still there. ... is this normal, and will it go away with time? or is this something I should tell the dialysis nurses?*
>
> *(Patient, IHateDialysis)*

While the *mechanisms* for establishing and negotiating norms online demonstrate processes described by Foucault, *motivations* for identifying normality are less clear. I argue that contributors' interest in normality is linked to their negotiation of the epistemological-ontological gap described by Dervin, in particular to identifying whether gap is there or not. Regarding 'giving it time', allowing time to pass is a significant strategy because in an environment of ongoing change, time passing may cause the gap to close naturally. When contributors say to each other, “give it time”, the implication is not that this bad situation will repeat, but that this bad situation will change. This is a potentially positive outcome of a reality in constant flux. In this context, though change ‘caused’ the situation requiring sense-making, change may paradoxically also be seen to have ‘ended’ sense making.[55]

I noted in Section 5.1 that experiences become normal when they are repeatedly confirmed to be so by others. Weick’s descriptions of sense making include ongoing feedback processes: “Sensemaking is [...] about continued redrafting of an emerging story” (Weick, Sutcliffe & Obstfeld 2005, p. 415). This is retrospective, as the meanings of events are constructed and reconstructed in hindsight, and the change he describes is in the understandings of a group or in the individual. That a situation is deemed normal may be enough to remove the appearance of gap for the individual. As expressed earlier in a quote from a participant: “I didn’t freak out, cos [...] i knew that was [...] nothing out of the ordinary”.

Meanwhile, a possible reason for gap to ‘close’ may be simple familiarity, due to iteration. As noted already, activities and situations, often repeated, become familiar. Time allows a lived sense of normality to develop. It is as if the individual has to ‘move in’ to a perspective awhile before they feel a sense of ownership of norms obtained from the discussion groups, in the context of their situation. Seen from this perspective, sense making may be about making and remaking a lived normality. This kind of iterated, embodied sense making will be explored in Chapter 6.

But the point here is that normality is not just established once. Bodies, situations and understandings change, and descriptions posted online reveal processes of constant adjustment to new versions of normality. Accompanying the establishment and evolution of what *normal* means in physical terms, a change in attitudes or expectations of dialysors can be observed, leading to radically shifted emotional understandings of normality.

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[55] Although sense making is an ongoing, ‘endless’ process, nonetheless from the perspective of a sense maker, one may feel at a given time that things ‘now’ make sense.

> *We have had some blood geysers at home (oops, forgot to close clamps!). Nothing like having your home look like a scene from CSI!*
> 😆
>
> *(Caregiver, IHateDialysis)*

The online discussions frequently included exchanges of techniques and descriptions of manual skills, such as how to self-cannulate. The practical, technical tone demonstrated a mental and emotional calmness which people not used to hospital procedures may view with incredulity. This ‘matter of fact’ tone and technician’s attention to detail may reflect normalisation.

> *it is not courage when it is happening. It is just doing what you need to do.*
>
> *(Patient, IHateDialysis)*

Like a nurse or surgeon, the dialysis patient has grown accustomed to sights and activities which would disturb the uninitiated. Once again, a link is demonstrated between making sense – achieving normality or familiarity – and feeling emotionally comfortable.

> *Title: You know you love a kidney patient when*
> *...seeing little blood stains on their clothing and bed linens no longer freaks you out*
>
> *(Patient, IHateDialysis)*

> *I’ve been at this unit for almost 2 years, and in that time 3 [patients] have died (that I know of), so it happens. It’s part of life, you have to learn to deal with it.*
>
> *(Patient, IHateDialysis)*

As Dervin points out, reality and understanding are both subject to inevitable evolution, so change will continue to manifest. The processes of re-establishing normality must go on. Therefore people describe an evolving normality as their sense making keeps pace with ongoing changes in their health. This is how ‘renals’ may arrive at that sense of normality far removed from the experiences of ‘normal’ healthy people.

Dissonant voices

Despite concerns that ‘lay experts’ may develop subversive attitudes toward medical expertise or standard medical practices (Kopelson, 2009), discussions in online health communities contest but also perpetuate the centrality of the biomedical paradigm regarding treatments and the relevance of biomedical guidelines for compliance (Barker 2008; Copelton & Valle 2009). The paradox has been noted by other authors, that patient expertise, sometimes viewed as a potential threat to medical authority, is instead a motivator for compliance (Broom & Tovey 2008; Fox, Ward & O'Rourke 2005b; Veinot 2010a). This is the case in the three communities I have described here, where references to alternative medicine are rare and much of the discussions are about how to achieve compliance. Notwithstanding this, attitudes toward the authority of health professionals range from admiration to gratitude to frustration (Godbold 2013; Hor et al. 2013). Though one could say that there are particular, emergent perspectives in the groups, they are contested. Similarly, the active, negotiative processes within threads are not necessarily concordant or harmonious.

For this reason, I have spoken throughout this and the previous chapter about the development of *consenses*; use of the singular *consensus* could imply that everyone ends up agreeing. Counter discourses and cliques develop within threads and may prevail across the community. People contribute to particular threads with ideas from their lives, or ideas which are already in currency in the group (ideas like ‘cyborg is good’ and ‘befriend your fistula’), but always modify them slightly to fit new situations.

Because interactional norms in the boards encourage people to share their experiences, supporting the expression of (some) ‘real’ feelings, and acknowledging the validity of each other’s experience, people may be encouraged to express dissonant voices online, adding to the collected perspectives that one may encounter there. This is subject to the various bounds of what people will say in posts: propriety, the desire of contributors to present themselves as reasonable or likeable, the desire for privacy, or not. Within those parameters, the boards accumulate variety: a range of experiences and reactions, which are valuable for their capacity to show possibilities. One can consider 'what could happen' by reading what did happen to other people. If, as in the case of Thread H, others in the board disagree with what is said, or think it is unlikely, they may argue, providing even more ways for the reader to interpret what they read.

My point here is to present the importance of variety for its place as a contrast to norms, allowing people to comprehend patterns both by what is foregrounded via repetition, as well as by observing outliers and elements of the background. I will spend a great deal more time with the implications of this gathering of experiences, in Chapter 6.

Iterative changes (shifting meanings)

Though I have described repetition as composed of elements which reappear and become familiar, I also showed how the 'repeating' elements actually all contain tiny differences. While some differences are ignored, absorbed into the blurry boundaries of 'the same', at other times, differences which occur during interactions between ideas, or between tones and ideas, enable substantial shifts in meanings.

For example, in Chapter 4 I described how people responded to Person B ("I AM BORG") as she worried about changes in her arm due to a developing fistula. I remarked on how the conversation moved from fistula-as-good-and-useful, to fistula-as-strange-and-useful (for scaring children).

> *Captains Log; Stardate 29th December 2010.*[56] *The collective have decided you cannot be BORG for although you share the group ideal*

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[56] References in this post are to the Star Trek series: narration in the show is accomplished by voice-overs in which the Captain of the "Enterprise" reads from / writes into his log. Star Trek is about the adventures of the crew on the Enterprise, a spaceship. The Klingon are another alien race in this show, who have a humanoid appearance but a large, forehead featuring a row of furrows.

> *you do not have any tubes protruding from any body parts ..LIKE ME ! 🤣 I am therefore BORG but you may be Klingon ? 🤣*[57]
>
> *Post#11, Thread B*

The author of Post#11 was dialysing as she typed, hence, connected by tubes to the (dialysis) machine. Though Person A had had her fistula ‘installed’, she had not started dialysis yet, so had not yet been ‘connected to the machine’. Hence, Person A was not fully borg. Appearing after a build-up of related comments, the dialysis patient identity here became fully related to a potential identity as cyborg, while being cyborg and being an outsider both became interrelated sources of pride. Gradual iterative changes occurring along the thread enabled such shifts in meanings. These were shifts achieved in the shadow of familiar social norms: the use of humour (helping others feel alright), and the authority of renal experience (the perspectives of people in-the-know). In an ongoing give-and-take between repetition (imitation, agreement) and difference (dissent, individuality and innovation), these are the minutiae of norms being reworked in social situations using minor details which make a difference.

As such, each thread is a new negotiation of social norms and locally derived understandings, developed to fit the particularities of the situation at hand by the comparings, arguings, adding-tos and asides of the individuals who took part. People echo the combined sense making of others with modified tones, and re-use of vocabulary; they may also affect consenses in the thread, for example with different tones, as “counter-conduct” (Foucault [1978] 2007). People joke about their situation: they are ‘borg’, they enjoy scaring children, they have “lovely” pseudoaneurisms. This allows them to resist their role of ‘good patient’ by criticising their situation even while they submit to it (Freud 1976; Parkhill et al. 2011). With each post, people identify and contribute to locally produced norms and consenses while pushing against others and maintaining their differentness. As Berger and Luckmann (1966) put it, people do not dumbly take on all the elements of socialization that surround them. “The individual apprehends himself as being both

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[57] This animated emoticon “rolls on floor laughing” whilst slapping the ground.

inside *and* outside society" (1966, p. 1134). They maintain a separation manifested in countless small and occasional large demonstrations of individuality.

> *I was extremley anxious today and when the D tech said to me:"It is not so bad, isn't it" I said to her some rude words.*
>
> *Excerpt from Post#14, Thread A*

In her examinations of normativity, Chatman suggested that people are guided by norms to the extent that they will stop seeking or ignore information, if they feel that it may contravene social expectations (2000). From this perspective, norms could be seen to trap the individual or leave them with restricted options. This is an example of the problem known to social theorists as 'structure versus agency'. 'Structure' is comprised of social rules, cultural norms, the routines of everyday life and other societal boundaries which shape the behaviour of individuals, to the point that their activities may appear pre-determined by duty and social or professional expectations. By contrast, 'agency' is the capacity of the individual to *be* individual, to bend rules, to go against the social contract. Bourdieu used the term 'habitus' to describe social order as it is internalised in the individual, particularly on the body. It is a formation which reflects sequential forces, but is an individual product, and is further individualised by the agent's practice, including their capacity for improvisation (Bourdieu 1990). Giddens presented structure as a duality because it is both "the medium and outcome it recursively organizes" (Giddens 1984, p. 374). He used the term 'structuration' to refer to this recursive process-entity. In so doing, Giddens turned a noun into a verb and back into a noun. The shift from noun to verb is a move endorsed in principle by Dervin because it moves attention from static 'things' to the flexibility and change inherent in processes.

In online interactions, the looseness that allows shifting meanings lies at the heart of people's potential to negotiate between structure and agency: this is a useful messiness in which rich descriptions add to possibilities, reducing the sparse grip of rules or norms of behaviour. Some practice theorists emphasise this kind of ongoing interplay between structure and agency as an essential part of all practices (Gherardi 2009b).

> *We therefore cannot simply equate practice to a set of routines, nor a set of rules. Both routines and rules are constitutive of the dynamics that shape how a practice emerges. The routines within any practice self-organize to create new rules and new routines as a practice co-evolves with other practices.*
>
> *(Antonacopoulou 2008, p.116)*

Gherardi directs attention away from the study of "practice as a recurrent pattern of action" towards "what socially sustains practices and how practices are reproduced and in being reproduced change over time – intentionally and unintentionally" (2009a, p. 124). This includes practices or ideas which are disruptive or contrary, and which may change or contrast with the consensus. Normative strictures are loosened by the range of variations manifested in each post and the space generated by contributors who described their own situations more than they posed opinions. In this sense, norms which may be seen as oppressive (Chatman 2000), or guiding (Foucault [1978] 2007), can also be seen as flexible and re-workable.

Similar feedback processes occur in sense making both at the level of the individual and that of the social. Tarde believed that by repetition – by imitating – we perpetuate society as well as become part of it (1903, p. 165). Berger and Luckmann similarly make clear the reflexive relationship between society and individuals, pointing out that the way people bring society to life is crucial. As they point out, "to be in society is to participate in its dialectic" (Berger & Luckmann 1966, p. 129).

> *"[T]he symmetry between objective and subjective reality is never a static, once-for-all state of affairs. It must always be produced and reproduced in actu. In other words, the relationship between the individual and the objective social world is like an ongoing balancing act."*
>
> *(Berger & Luckmann 1966, p. 134).*

This balancing act makes productive use of dissonance. Small differences make tiny changes, iteratively overcoming the resistance which norms would otherwise, necessarily raise against more obvious forces. In Chapter 6 there will be further opportunity to explore the potential of dissonant acts.

Conclusion

> *Make sense of: to find meaning or coherence*
>
> *(Oxford Dictionary of English 2010)*

The aim of this chapter has been to explore the use of patterns in social sense making processes online. I have explored how people find the coherence referred to in the definition above, in recognisability and familiarity. To do so, I have explored two aspects of patterns: repetition and difference.

Repetition enables the formation of norms and conceptions of normal. It develops familiarity, helping people to feel 'alright' about situations; and repetition of tones across posts provides emotional guidance. Meanwhile, difference emerges as a dynamic partner to repetition: it provides a sense of one's location in the range of possibilities, while it also creates an answer to norms, a counterpoint which opens out spaces in normality within which social understandings can shift and new meanings can develop.

Noticing patterns and deviations from patterns allows people to perceive issues in their own lives as background and foreground, settling the background into routines which don't need to be re-examined. In this way, life can become less detailed. So this exploration of patterns reveals layers in our sense making. Some of what we do is somnambulism (Tarde 1903) or "Life in the Round" (Chatman 2000) – the unreflected part, which we can skip over, save time on, or luxuriate in. Some of what we do is a kind of endurance, 'giving it time'. And some of what we do is dissent, counter conduct (Foucault [1978] 2007) or innovation (Tarde 1903) – the parts where we individuate ourselves, making up new stuff, or at the very least, paying attention.

Chapter Six: Experiential Brutality

Keeping it 'real'

> […] exercise caution with regards to moving the machine with you attached. However I believe that it is possible, given a few precautions to move it whilst you are dialysing. I used to do it all the time.
>
> First - look at the proposed route you plan to take and make sure that it is clear of obstacles like hoses and stuff. Try not to use your fistula arm. I used to stand up - wait a while to make sure I was not going to have to cope with dizziness. Then I would treat my machine like a dance partner. With my right hand I would grasp the saline pole and then I would lean my whole body against the machine, changing direction by adjusting where I pushed and using the saline pole to aid in steering. Ensure that you do not inadvertently push any buttons on the machine. This was always an unhurried, cautious process. It is a bit like a Zen dance (if there is such a thing) where every movement is careful, slow and deliberate. [...]
>
> (Patient, AustralianDialysisBuddies)

This description was posted by a veteran dialysor, in answer to questions from someone just starting home haemodialysis. He later noted ironically, this 'dance' is so slow that by the time he makes it to the living room where the television is, sometimes the show is over and the family gone to bed. His remarks demonstrate a number of the issues which I wish to explore in this chapter. First, they clearly show how physicality (the body, the machine, needles, buttons and poles) complicates the lives of dialysis patients. They *must* allow for experiences of 'reality' as they make sense. It appears that 'reality', especially physicality, can be in charge: this passage shows how the patient's actions and abilities are restricted and reigned in, to the extent that at first, it seems they must obey the interacting demands of their machine and their body.

Second, we see how this gentleman learned, by trial and error, how to move in a particular way, developing new understandings of how to proceed, and testing them against the physicality of his body and his machine. He demonstrates an attitude which accommodates for experiences and finds ways to achieve goals despite limitations. He has developed understandings about his machine and gathered experiences of moving with it, and has now developed a workaround, a way to achieve a goal, refined into familiarity.

Third, he presents his workaround with authority. His remarks came in reply to a previous comment, that one can't move when attached to a dialysis machine. He needs not go to great lengths to say authoritatively that it can be done: the fact that *he does it* and therefore speaks from experience is sufficient right to speak.

I noted in Chapter 4 how posts put forward descriptions of experience with such frequency that there must be some value in doing so. In this Chapter I explore what that value might entail. The crux of this chapter is that one cannot create theories without regard for reality. Instead, authoritative theories are based on and are tested by experience. But what do I mean by 'reality' and what kinds of experience do I propose to examine? Clearly there is a lot of work to do in this chapter.

6.1 Making sense of experience

Dervin theorises reality, not as solid, stable circumstances that one might expect would collide with one's dreams and smash one's theories. She describes reality as "gappy" and subject to unexpected changes (1999b, p. 730). The experiences described by renal patients seem a far cry from such subtlety. Their reality is physical, harsh; it hurts and makes them bleed. Yet it is the same reality: gappy because it is only partly understood, and because it changes unexpectedly - but nonetheless, if one encounters it in certain ways, it is apparently unforgiving and temporarily immovable.

Searle (1995, citing Anscombe 1958) describes "brute facts": requiring no human institutions for their existence, they are "totally independent of any human opinions" (Searle 1995, p. 2). What I like about brute facts is that whether or not we agree on the explanation for it, if I start bleeding, we can't stop the blood coming by arguing about it. Instead we need something to hold against the wound. Searle distinguishes between brute facts, like the distance between the sun and the earth, and institutional facts, like money, government and marriage. For my purposes, individuals experience institutional facts similarly to brute facts, for neither are amenable to what you or I might wish. For example, even if you and I make a private agreement that our money is worth more than its current currency value, or if we decide that a medication should be available to us for free, our agreements would come to naught in the local pharmacy. So when I refer to 'experiential brutality' in the title of this chapter, I am referring to how all experiences can be as intractable as Searle's "brute facts": just as brutish.

I return to the problem of 'reality' in Chapter 7, because Searle's brute facts and Dervin's gaps require more careful reconciliation. Here, I wish to develop understandings of the relationships of people with reality.

Physicality (for example)

Dervin describes sense-making as

> *embodied in materiality […] a body-mind-heart-spirit living in a time-space […] anchored in material conditions […This] mandates simultaneous attention to both the inner and outer worlds of human beings and the ultimate impossibility of separating them.*
>
> *(Dervin 1999b, p.730)*

For her, sense making is unavoidably located in materiality and undertaken by an embodied human. She notes, "The patient who says 'my body told me' is making sense" (Dervin 1999b, p. 739).

Olsson extended Dervin's acknowledgement of the body of the sense-maker by exploring the primacy of the body as a sense-making site. He suggested not only that people use the body to convey meanings which are socially understood – "discourses of the body" (Olsson 2010b, p. 277) but also that comprehension and incorporation of understanding are undertaken via bodily experience and experimentation.

> *[K]nowing can be a matter for bodies, as well as for minds. […W]hile information use implies an interaction between two discrete entities (person and information), embodiment provides a richer understanding of the process by which new sense is incorporated into the participants' practices. […]*
>
> *(Olsson 2010b, p. 278)*

To explore the relations between the sense maker and their experience, I focus on physical experiences, specifically, bodies and equipment. This is appropriate given that 'sense' can mean perception of stimuli, for example by touch, smell or sight according to the Oxford Dictionary of English (2010). Of course 'lived experience' may also involve non-physical experiences such as social acceptance or rejection by others, legal rights, options for treatments and procedures, eligibility for processes or tests, finances and the enormous bureaucracies of national health systems and insurance. I will return to the question of these myriad manifestations of reality later.

The physical experiences of kidney failure

Patients with any physical ailment are confronted by physicality. They have to face physical dysfunction on some level or another, a betrayal of the body. They may experience pain and scarring. They may have to remove their clothes for examination. Their body may be invaded with probes or needles or by scans and tests, and they may experience surgery (Purtilo & Haddad 2007).

When the kidneys inadequately filter the blood, toxins build up in the body. The renal patient may feel lethargic, nauseous, itchy, and out of breath. They may find it hard to think clearly, and their legs may jerk and spasm making it hard to sleep. I have described some of this in the introduction, including how, when the kidneys produce insufficient urine, excess fluid gathers in the tissues. The body swells, and fluid on the lungs makes breathing difficult. When overloaded with fluid, people sometimes report trying to sleep sitting up to cope with the weight of fluid on the lungs. In addition, fluid retention puts a strain on the heart.

Dialysis has the dual function of removing some toxins, and taking fluid out of the body. I have described how dialysis involves connecting the body to technologies, either a haemodialysis machine using needles to access the blood, or via a permanent tube in the belly for peritoneal dialysis. Peritoneal dialysis involves carrying fluid inside the abdomen which can cause great discomfort for new patients until their body stretches to make room. In the gut, the end of the tube can contact with the inside of the abdomen, causing pain, which may be relieved by jumping around, dancing, lying on one’s back, squatting or other physical adjustments. Alternatively haemodialysis channels blood out of the body, through a dialysis machine and back into the body again. Particularly if fluid is removed too quickly, the physical effects on the patient can be harsh, including dizziness, blacking out, heart attack, or painful cramps.

Because their treatments are not continuous and fluid can only be removed at relatively slow speed, restrictions on drinking are an issue for haemodialysors, some of whom are restricted to around two cups of fluid per day including the liquid in food, soups and ice. They are often thirsty. Whatever their treatment modality, dialysors must be aware of fluid retention to some degree and may find themselves retaining fluids, typically manifesting as swollen ankles. Renal patients face complex lifestyle restrictions which reflect the limitations of their impaired physicality. These may include dietary restrictions, being beholden to a schedule of treatments, or being unable to shower or swim. The need for attachments to the patient's body makes sleeves hard to accommodate, leaving renal patients vulnerable to cold in the clinics.

Cyborg body

The attachments and modifications necessary for renal treatments draw attention to the demands of the tools which mediate and modify our experience of life (Latour 2005a). Dialysis machines need clean water and sound loud alarms, waking (and frightening new) patients. Their hoses are short, their plugs need electricity. Their displays communicate in a language of codes, requiring translation via a manual. Peritoneal dialysors protect their abdominal attachments from painful and dangerous infection. When the tube from the gut leading to the bag of dialysate fluid was longer, in the 1980s, my husband once stepped on his tube in the shower, tugging painfully at its attachment in his belly. The technology that crowds around dialysors and supports their vital function is demanding and often noisy. Even the name 'dialysor' is a machinic term similar to 'dialyser', the artificial kidney inside the dialysis machine. It foregrounds the person's intimate relationship with mechanised renal function.

These ideas are applicable in the lives of any 'normal', warmed by their blanket, woken by their alarm in the morning, alerted to their meal by the microwave's chime, and running for the sake of a train with a busy timetable. The difference is one of urgency: a 'normal' who misses their train will not find themselves swelling and gasping from fluid overload.

Experiential brutality

> *Going through life tied to a chair*
>
> *(Quote on a patient's 'profile', IHateDialysis)*

> *[E]xperience, as we know, has ways of boiling over, and making us correct our present formulas.*
>
> *(James 2000, p. 98)*

Consider yourself connected to a dialysis machine with two large needles. If you move in the wrong way, the needles may pierce the vein from within causing sudden swellings or bruising. Once the needles are in, you must try to keep fairly still.

> *[Y]ou will get to know how far, if at all, you can bend your fistula arm at the elbow. I had a number of blows while I figured this out. After months of sitting most cautiously, with my arm supported by pillows and kept straight, I decided that if I needled my venous site away from my elbow and closer to my wrist, I could virtually bend my arm with impunity. I never take that for granted however and still bend my elbow very carefully.*
>
> *(Patient, AustralianDialysisBuddies)*

In a healthy individual, one's body is used variously for different social activities, whereas in the vulnerability of illness one becomes subject to the body (Billig et al. 1988). When ill, even the body at rest demonstrates compelling authority, moving to the foreground of one's attention and making activities premeditated.

Objects and illnesses cannot necessarily *control* humans. Nor however, are we *always* in control, and as Latour points out, the role of non-human actors is often ignored or sidelined (2005a). Latour specifically attacks structures of meaning in which humans have hierarchical precedence over non-humans (1992, p. 232 & 6). He describes how behaviour may be imposed on humans by the objects around them. To him, a person does not use an object so much as an object and the person interact with each other. Returning to the quote with which I opened the chapter, as the dialysor moved from room to room with his machine, the object restricted and guided the human, affecting the human, while the human also affected and guided the object.

Foucault describes "the submission of bodies through control of ideas" (1977, p. 102). Here we see a partial reversal of that situation, in which the body disciplines the dialysor, forcing them to submit to limits. The patient takes themselves to the dialysis chair where they still as if strapped in place; they avoid drinking the water that is available from every tap. The birth of policing was concerned with the micro-management of populations, an involvement in every aspect of activity for the sake of the wellbeing of all, a project which failed for complex reasons (Foucault [1978] 2007). In the body of the patient, however, we see such a level of micromanagement apparently working. Its success lies in the existence of the very 'policeman' imagined by that early system – an agent of regulation ever-present in the form of the body itself. I raised the idea of the panopticon in Chapter 5, and set it aside as an inadequate metaphor, but I return to it here, because at last the analogy may be complete. The unpredictable, hidden gaze of the central observer in the panopticon comes not from regular check-ups by specialists, but from the patient's own body. The patient's body responds to diet, medications and treatment, but not always in predictable ways. Sometimes forgiving, other times not, the patient's body can be imagined as the watcher in the observation tower: the patient never knows if their transgressions or good behaviour will be reflected by the body-as-observer.

Everyone is different

The idea of discovering the *constraints* of one's own body (often by trial and error) appears frequently in discussions, the default reply to a wide variety of questions (*what can I eat, what can I drink, will this hurt?).* Commonly, the first reply to such questions is *everyone is different*. *Proprioception* is the term for knowing one's own body and anticipating problems. Some renal patients online described searching for this kind of awareness. Although anatomical diagrams serve as useful maps, individual bodies are not the same as diagrams. Moreover, just as one face is different to another, so bodies also differ, the organs different sized, the veins deeper in the flesh, or close under the skin, sometimes with stronger walls, faster clotting blood and so on.

Much of a dialysor's knowledge of their body is based on trial and error – people must put their own body 'on the line' to discover its particular limits and capacities, including how it functions as a unique system to manifest kidney failure and respond to treatment. Patients learn how their body-system will react to different foods, how quickly healing occurs, scabs form, swelling comes on, bruising appears and fades, and how the blood levels respond to the changes in the diet.

However, as described in Chapter 5, renal patients don't become used to changes once, learning a single, new, stable normality. Rather, change is ongoing. People have to know their own body before they can recognise changes such as fluid build-up, which often appears at the feet or face but may appear in other odd places:

> *My left boob is my water retainer.*
>
> *(Patient, IHateDialysis)*

In the previous chapter, I described how people find patterns. They do not clump together things that are *literally* identical, because everything is different. Instead, they classify some things as 'the same', put them aside, and focus on the rest. When monitoring their body, patients make the same kind of approximations between same ('normal') and different ('abnormal'). They must learn to separate changes due to new dysfunctionality, from their normal range of bodily changes, and from treatments currently being administered, such as normal damage to the fistula by regular needling. Foucault described the historical development of this kind of medical gaze by doctors ([1963] 2003). However he made no reference to the possibilities of the patient having a medical gaze. In the discussion groups, active patients teach each other to 'see' inside the body by the sensations of a needle going correctly into their vein, or the feelings associated with low blood pressure just before one faints.

Measurements

Patients also described how they learned, like health professionals, to 'see' into the body with measurements. Blood tests and urine analyses are commonly taken once a month. A full set of results covers thirty-six measures. These supplement frequent measurements of weight, temperature and blood pressure. The measurements are used by clinicians: longitudinal data sets can show changes occurring, and help to decide whether a particular measurement lies within a normal range for this body or signifies change. They allow doctors to recognise emergencies and gauge changing treatment needs. Such ongoing tests also operate as a measure of compliance: if patients have been following their renal diet, their labs should be within normal or acceptable ranges. Online, I found patients discussing measurements in much the same ways.

Experiential authority

In face to face conversations, people defer the ‘right to know’ by acknowledging privileged access to one’s own experiences. ‘Having been there’ earns a person the right to speak (Heritage & Raymond 2005). The establishment of authority in the discussion groups appeared to follow the same lines.

Learning from other’s experiences

> *For those who had this done what was their experience and what should I prepare for?*
>
> *(Excerpt from Post#0, Thread C ‘Stint Removal’)*

It was common for people to ask for and learn from the experiences of others in the groups. People imitate where they perceive authority (Tarde 1903, p. 213). As people’s perceptions are idiosyncratic, they may not only perceive authority in traditionally authoritative figures such as doctors. I demonstrated in Chapter 5 that people imitated each other, by reusing each other’s vocabulary and repeating ideas from previous posts. In addition to imitating vocabulary in discussions, people modified their positions online in response to the experiences reported by others, and they said that descriptions of experience were useful. Since people make such use of each other’s stories in the online forums, it was important that members have authentic stories to tell – that their stories were based on lived experience. This may explain the passion with which people attacked exaggeration when they suspected it in Thread H.

In Chapter 4 I showed how the prevalence of experience emerged in all three levels of the data analysis. In the descriptive statistics, most members were renal patients or members of their families; only 2% of participants were medical professionals, two of whom were health professionals *as well as* patients. Not only was renal experience an expectation of the community (as identified in the analysis of interactive norms), people asked for comment *from those with experience*.

Experiential authority in the sequential analysis

The sequential analysis at Chapter 4 revealed the prevalence of descriptions of *experience* in posts. Contributors embedded their comments within descriptions of their own experiences, demonstrating the perceived value of such stories. There was a strong tendency for contributors to match each other's tone, but experiences provided the authority to maintain differing opinion and tones.

Experiential authority in the interactional norms

Several interactional norms attested to the importance of experience. First, participants should, in some way be renal – they should have relevant experience. A related theme, often referred to in discussions, was the idea that 'only renal patients know what it's like' – only 'we' can understand renal failure. This gave patients an authority which was unavailable to health professionals or even carers (Godbold 2013)[58].

The importance of experience for sense making was also demonstrated by interactions in which experiential norms were pitted against other norms. Before questioning another's experiences, contributors first acknowledged and tried to cushion any attendant emotional blow. Such care acknowledged the importance of both norms. Despite the tension between them, the voice of experience prevailed, demonstrating the value of experience to sense makers.

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[58] Delighted with the term 'dialysis practitioner', a contributor began signing her name followed by the letters DP, a reflection on the letters following surgeons' names, affording knowledge or expertise to the person on dialysis.

Experiential authority in the content analysis

In the content analysis, *experience* was the most frequently coded theme, while *control* was the second most frequent. To understand more, I undertook two additional analyses.

Control can manifest actively though being able to do things, or passively through being find help with things. Considering *being able to do things*, I examined manifestations of power and authority in discussions, with a content analysis linking a range of *actors* to *sites of authority*, and *attributions of power*. Following Latour (2005b), I included both human actors and non-human actors. Human actors were *health professionals* and *patients*, and each *discussion group* as a whole, referred to as 'here' in posts – 'you'll get lots of help *here'*. Nonhuman actors included *objects* and *measurements*. I also noted references to contributors' *experience* including physical and non-physical experiences. It could be argued that experience is both human and nonhuman, an outcome of interactions between human(s) and other actor(s). Regardless of that ambiguity, people specifically referred to *having experience* as significant, so I included experiences as an *element of interest* in the analysis. I coded both direct references to having experience and examples of particular experiences in interaction with other themes, such as when a post described obtaining information through experiences: 'I got a terrible cramp and realised I was dialysing too fast'.

When actors were described as able to do something or to stop something from happening, I coded it as an *attribution of power*. Examples included the surgeon who chose where a catheter[59] would be located in the belly; the machine alarms which kept someone awake all night; and the headache which stopped someone from working. *Sites of authority* were instances where a particular actor was confirmed as 'knowing', or where they had the last word: for example consulting measurements such as blood levels to decide if you are well, or being assured about a situation because a doctor said it was alright. I also noted when people cast *doubt* on the authority of an information source.

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[59] A catheter for Peritoneal Dialysis is a semi-permanent tube going into the belly, allowing fluid to be moved in and out of the body.

Looking only at human agents, Figure 6.1 (below) shows what one might expect: *health professionals* were positioned in discussions as powerful and authoritative. However once non-human actors were taken into account, the landscape changed. Objects emerged as powerful – able to make things happen – far more frequently than clinicians.

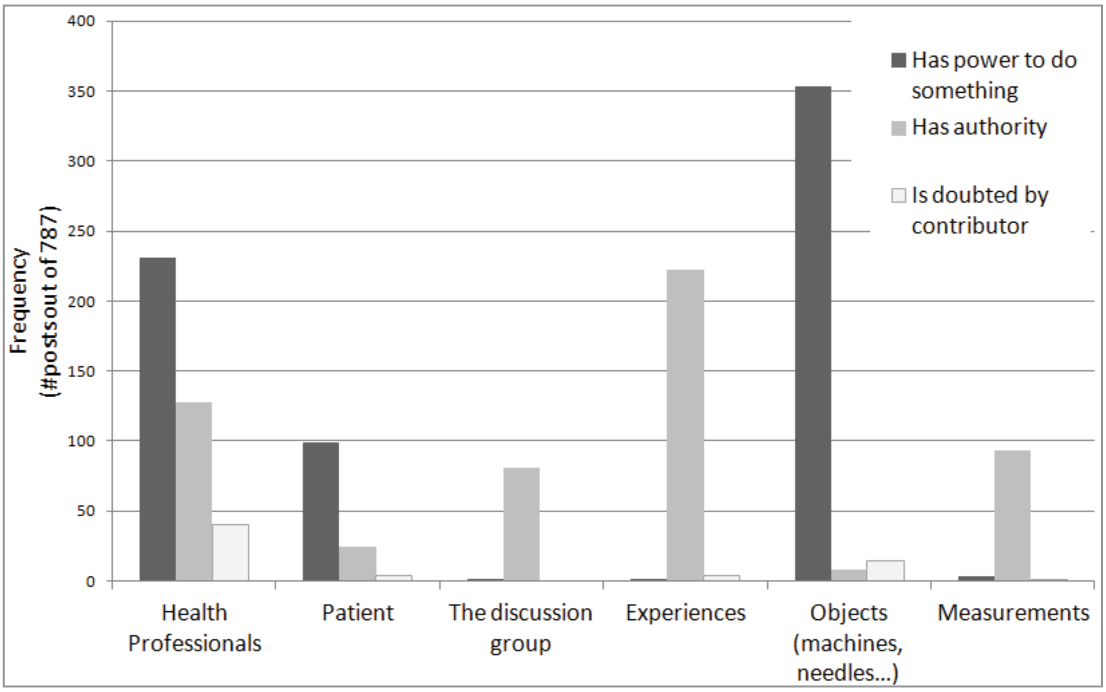

Figure 6.1: Attributions of power / authority in posts

This is unsurprising since they included the unwell bodies of patients as well as needles and medications. I coded posts according to what was said, so if a needle damaged a vein I coded it to the needle unless the patient blamed the nurse using it. *Experiences* were described in authoritative ways more often than *health professionals*. These were situations where contributors reported that they know something worked because they tried it, or they knew there was a problem because of a sensation they noticed.

Practitioners were doubted in posts more than any other actor, for complex reasons which did not eclipse their continued *authority*. Doubting *experience* came about, for example, when people suggested that they might need dialysis less frequently, because they skipped dialysis and ‘felt fine’. At these times, others posted to suggest that the good feeling could not be trusted, because other, unfelt changes were happening in the body. These were times when the authority of *measurements* might come into play. Blood tests could be relied on to demonstrate dangerous changes in the body requiring dialysis to restore relative healthy balance. *Measurements* were least often doubted in posts – perhaps because as Latour remarks, they have the mechanical, objective aura of science, and are an avenue for the otherwise mute voices of the body (Latour 1993).

Dervin conceived of Sense-Making processes as related to sources of *help* (Dervin & Frenette 2003, pp. 242-243). For passive actors, like patients, control may manifest indirectly as being *able to obtain assistance*. In a final content analysis, I therefore coded examples of finding assistance, in terms people finding *help, information* or *support*. I was uncertain of how to tease these elements apart, so I allowed contributors to define them themselves: when they said they found *support*, or where they said *information* could be or was obtained. Sources of *help* included when people said they found something helped, but also when people described having obtained help, such as 'the nurse fixed my dressing' or 'calcium binders help me control my phosphate levels'. The results of this final analysis are displayed at Figure 6.2 (below).

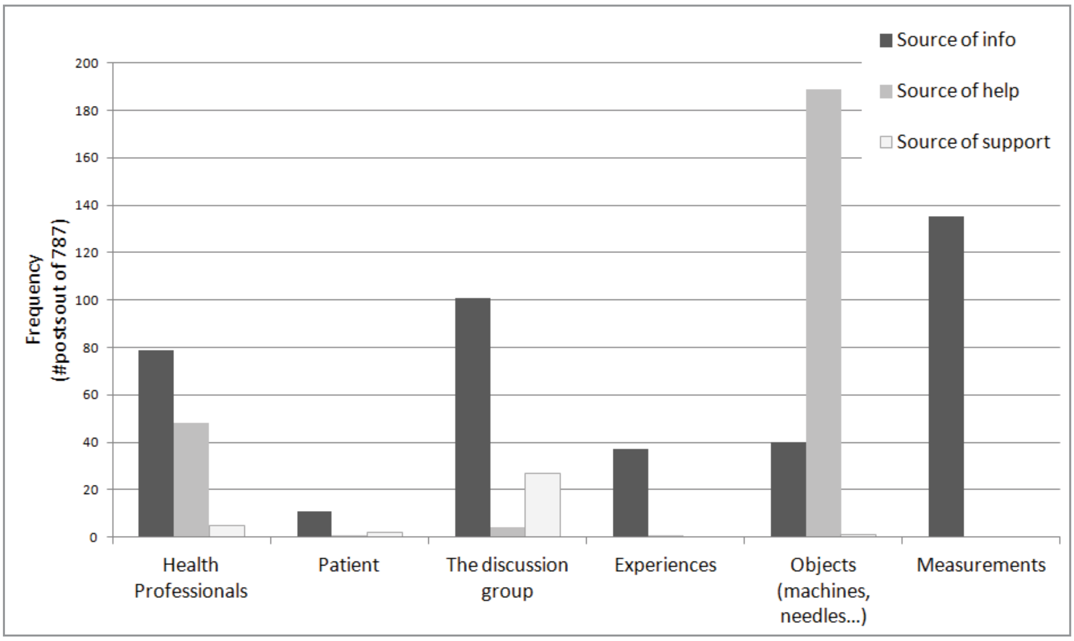

Figure 6.2: Attributions of information / help / support in posts

Help most frequently involved objects, such as medications and tools. This suggests that the objects created to help people live with this chronic illness do often help them outside consultation or clinic hours. Similarly, *information* was obtained from a range of sources. Tellingly, all these aspects of control (power, authority and access to information, help and support) were located in a wide range of sites, rather than people relying on professionals. In particular, experiences and objects manifested as potentially informational, authoritative, powerful and helpful. It could be argued that objects provided by health professionals are an indirect measure of professionals' *help*, but it was not always evident from where particular tools or equipment were obtained. As before, I coded posts according to what was said, counting instances of professional help only when clinicians were mentioned, which brought forward differences between objects and the clinicians who might have provided them. For instance, being available out of hours and having the potential to be used in creative ways are two ways in which objects were characterised differently from clinicians.

Neither information professionals nor clinicians tend to consider experiences or objects (except documents) in their efforts to support patients. This analysis opens up new opportunities for provision of support to renal patients, which I take up in the discussion of Implications in Chapter 8.

* * *

Dialysors located authority in experience, and obtained 'truths' from their experiences. For their faith in experiences, renal patients are well represented by the ancient Greek philosopher Epicurus (341-270 BCE) who was an early proponent of empiricism, seeing experience as the basis of truth (Mitsis 2006). Epicurus is relevant here for a few reasons. Perhaps based on his faith in experience as a guide to truth, Epicurus taught that one should follow pleasure as the source of good. But he explained that the greatest pleasure lies in the lack of pain (Urmson 2005). Critics of Epicurus cite this idea as a weak point in his philosophy (Mitsis 2006). But the ultimate pleasure of being *out of pain* will be familiar to anyone with chronic illness, and it appeared frequently in the discussion groups. Epicurus is said to have lived with the recurring pain of kidney stones, and to have died of kidney failure brought on by kidney stones (O'Keefe 2005). Given his understanding of pain, and his recognition of experience as a source of understanding, Epicurus is the quintessential renal patient's philosopher.

6.2 Iterative rounds

As described in Chapter 5, time passing allows comparisons between theory and experience, and may allow a sense of normality to develop.

By 'theory', I mean the ways that people understand their lives, in the sense that Dervin used the term when she described humans as 'theory-makers'. "[T]heory-making is a mandate of the human condition given pervasive discontinuity" (Dervin 1999b, p. 733). To navigate gap, human's 'moves' are theories: part designed and part unknown. In common English usage, at times 'theory' refers to an idea which hasn't been verified by experience yet, and at others, to an idea which has been proven by testing hypotheses. Both of these aspects of *theory* are relevant to these situations of perpetual testing, where even tried and tested theories will be tested again. Finally, theories may not only be expressed in words: I use the term loosely to include habits and routines – the theoretic or tentative aspects of what we try to do as well as what we say or think.

In this chapter, I have begun to outline how people experience limits, and how they develop ways to comprehend such experiences (with measurements, and by closer attention to sensations). People develop theories based on their experiences – theories which are necessarily tested by new situations. As Wieck described, "actions enable people to assess causal beliefs that subsequently lead to new actions […] as supporting evidence mounts, significant changes in beliefs and actions evolve" (Weick, Sutcliffe & Obstfeld 2005, p. 416). By the ongoing tests of experience, oft-repeated activities and situations become familiar. People begin to compare experiences and refine their conceptions of details. Encountering limits confirms or challenges expectations. Experiences suggest flaws, or reveal ideas and routines which work, developing familiarity and authority.

There are four important aspects of the dynamic between repetition and authority:

- Experiences are needed in order to develop theories; these can be the experiences of others;
- Experiences which break theory allow theories to be refined, by removing 'erroneous' parts;
- Experiences reinforce successful aspects of theories, developing certainty and authority;
- Time is required to allow these iterations and refinements.

In the content analysis I identified common themes, including *explanations* (theories); *emotions*, and *experience*. Their relationship can now be clarified in terms of iterative rounds, illustrated (at Figure 6.3) below.

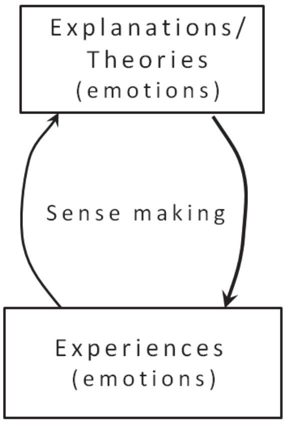

Figure 6.3: Relations driving iterative rounds in sense making

It is important not to overstate or understate the empirical dimension of sense making as it is presented here. Figure 6.3 should not be read as placing explanations above experiences. It does not suggest that experience dictates theory, any more than it suggests that theory dictates experiences; the intention is only to represent constant dynamic interrelations between theories and experiences. This is an important shift because it draws *experience* into hitherto cognitive conceptions of sense making processes. In so doing, I conceive social constructionism as "at once realist and relativist" (following Crotty 1998, p. 63), whereby people draw on interactions with physicality and reality as much as on culture, language and society to construct shared meanings.

In Figure 6.3, I haven't separated emotions into their own place, but left them mixed up with explanations and experiences, as I found them in the data. Explanations and experiences also appeared combined in the data, but I have separated them to demonstrate the action of iterative rounds in sense making. Iterative rounds involve three-way tests between explanations, emotions and experience, as people decide whether the theory works or not, in terms of how they feel about the theory and their experiences with it.

For example, consider the progression evidenced by the following four comments, written during the course of a month of home dialysis training:

> *[…] finally got all set up, put needles in ok. venous*[60] *one hurt a bit when i pushed down on the syringe, but i thought i would leave it and see if it went away. started the pump as usual on 100 mls/min, and almost straight away, i felt pressure growing on the inside of my arm, and i quickly looked, and it looked like someone was blowing up a small sausage balloon inside my arm! stopped the pump straight away, had this huge lump in my arm! i sort of freaked out, […It was] a blow out […]*
>
> *(Patient, AustralianDialysisBuddies, July 6)*

This patient is learning how to put her own needles in. In this experience, the tip of the needle has apparently gone through the wall of the vein. She will learn from this to be wary if the venous 'hurts a bit' in future.

> *[…] i have to learn what different pains mean! it's ok to get pain, cos it means in one way that something isn't right, but it's hard when you don't know what's not right! […]*
>
> *(Patient, AustralianDialysisBuddies, July 12)*

The dialysor, still having trouble with experiences, also doesn't feel confident: she "freaked out", and finds it "hard".

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[60] Venous: the needle and tube which will carry blood from the machine to her body. Blood is carried to the machine via the arterial needle.

> *[I] put needles in while sitting on the edge of the bed. arterial to my huge relief was fine! venous, needle went in ok, pulled on syringe, all good. but when i pushed back, got a bit of a swelling and it hurt a bit. so i figured i possibly had put the tip of the needle through the other side, so pulled the needle back a little bit, and then there was no probs.*
>
> *(Patient, AustralianDialysisBuddies, July 28)*

By now, this dialysor has a better sense of the inner topology of her arm, and can read the signals she receives via sensations such as pain. But, as she points out in this final quote, there appear to be subtle changes from day to day.

> *my arterial gives me the most problems too, so i know when it's kicking up a stick just for the hell of it, i just have to move it into the spot that it feels like that day! it's a bit like a crabby baby! gotta burp it the right way! haha!*
>
> *(Patient, AustralianDialysisBuddies, July 31)*

She uses a cheerful metaphor to conceptualise the activity of cannulation, and feels good about the procedure. Over the month, she developed embodied understandings of sensations, specific to her body. Her understanding has been refined by repeated attempts to self cannulate[61]. With each attempt, her understandings were re-enacted and modified by the presence or absence of pain or injury. Painful sensations taught her to recognise when she had pushed the needle in too far. When she responded to pain by pulling back slightly, the success of avoiding injury reinforced her understanding of the meaning of pain, and led to her more confident attitude: the authority of a mother with her baby.

Practice theorists interpret such situations in terms of "affordance": "a three-way relationship between the environment, the organisms and an activity" (Antonacopoulou 2008, p. 120, citing Gibson 1979). First and most directly, it was

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[61] Cannulate: (in this case) to put the cannula (needle) into the fistula. The cannula makes the connection from the fistula vein to the tubes leading into the dialysis machine.

sensation that taught this dialysor to feel the invisible topology of her arm (Strati 2007). But this was not only an interaction between the girl and her arm. The actors involved (needles, arm, person, machine) and the environment (including location and time of day) came together in an activity ostensibly undertaken by an individual dialysor, but which connected to socially acquired expertise and practices, re-interpreted in each dialysis session. The practice of self-cannulating "is continually reproduced and negotiated, and hence it is always dynamic and provisional" (Gherardi & Nicolini 2000, p. 330).

Iterative rounds use experiences to grind theories. Pickering (1993) describes the "mangle of practice", whereby people's theories about situations, their goals and the things they do are changed (pushed and squeezed) by the materiality they have to work with, which is in turn shaped and changed by what people do. By these "dialectics of resistance and accommodation" (Pickering 1993, p. 567), the understandings (explanations, routines) of an experienced dialysor become like glass on a beach – not new, broken shards, but the old pieces, smooth and rounded as pebbles. Yet as Pickering points out, their experiences, for example, their bodies are also made more amenable in the process. For example, by being needled, fistulas become more easily needled. Epicurus' philosophy could have been shaped by his chronic illness, the perfect example of the iterative rounds of the mangle of practice – the body of the philosopher shaping the philosopher's philosophy.

The mangle of all kinds of experience

To demonstrate how people's experiences impact their sense making, I have focussed on physical experiences. I have analysed relationships between sequences and content in people's remarks, looking for relationships between experiences and sense making.

Renal patients do not have privileged access to the real, but they do inhabit fragile physical systems which manifest immediate and serious implications, making it easier to notice the dynamic tension between theories and physicality. It is therefore hard to avoid the impact of physicality on sense making in this renal data. But discussions online also showed me how people make sense of other kinds of experiences –like legal rights, treatment choices, standards and bureaucracies – with similar iterative rounds. I argue that theories are honed and refined by experiences, whatever their experiences may be.[62]

For example, a patient realises that the nurse who ignores his dialysis machine's alarm will answer the clinic phone, so rings the clinic from his dialysis chair when he needs help – until he notices the mounting annoyance of nurses summoned in this way. A patient's wife describes to a nephrologist her exhaustion and misery from juggling long waits for other specialists who cancel at the last minute; she is offered a form of respite by having her husband dialyse in centre one day a week, instead of at home, freeing her to attend tasks in town. She tries the new arrangement, and begins to feel more positive about the future, basing new plans on the possibility of ongoing access to in-clinic dialysis. Logistical issues affect situations in terms of how people might manage their lives in order to cope adequately. People's theories are hemmed in by realities of different kinds, yet are also be modified, extending towards new possibilities when opportunities present themselves or are quashed by new limitations.

* * *

People in renal discussion boards referred to experiences as they made sense of the realities in which they found themselves. To demonstrate this, I have mainly used physical realities as examples, because physicalities for renal patients are so striking. People learned to 'read' experience by attending to detail, and by separating normal from abnormal – that is, using processes of pattern recognition described in Chapter 5. Sense making was based on iterative rounds as theories were refined in the

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[62] That said, it is tricky to separate physicality from other levels of experience. Physicality has direct political and economic implications in ways which demonstrate the densely woven networks in which dialysis patients find themselves. For example, the fear of illness and death necessarily involves dialysors in politics of treatment choice and economics of health and medical insurance. The relations I describe in this chapter between patients and physical agents such as bodies and equipment are social and political as well as physical relations (Latour 1993). Latour describes how actors (human and non-human) interact with each other, so that attempting to make persistent attributions of cause and effect are not as relevant as observation of an ongoing network of effects and interactions. He sees actors as enmeshed in a relational structure, which is also the dynamic by which power differentials emerge between people (Foucault 1984b).

mangle of practice (Pickering 1993). Iterative rounds revealed both weaknesses and strengths in theories; showing up ill-advised theories and helping to develop confidence and authority when people started to ‘get it right’.

In terms of sense making, the key function of experience is as a basis for authority. The iterations allow people to develop theories with which they can feel familiar and secure, allowing them to develop confidence in routines and perceptions of normality. And because experiences carry such authority in sense making, therefore people with experience gain authority.

6.3 Taking and losing control

Once they have begun to ‘get used to it’, developed a sense of normality and found the limits afforded by their bodies, dialysors may begin to construct a sense of control over their situation. Control could be seen as a reflection of the successful inter-relation of experience and explanation – if you are able to control your experiences then the particular explanations and mental models you are using may be ‘right’. Control provides advantage on two levels. First, it slows the rate of change, so that people don’t have to work so hard, so often, to make sense. Second, feeling that they can affect outcomes is sometimes reflected in emotions: anger and depression over powerlessness; feeling good or confident over successful control. One’s ability to control lends one authority in the eyes of others, increasing the good feelings associated with understanding one’s world. And having authority afforded to one increases one’s control in some situations.

Taking control

Control is enabled by knowing about situations, and made stronger when one knows how to do things in situations. In particular, control manifests as people find workarounds, and as they develop flexibilities.

Knowing *about*

People report ‘using knowledge’ to make better decisions, avert dangerous practices, and recognise when things are going wrong. This includes theoretical knowledge about kidney function, the implications of measurements, and how dialysis machines work; I have already described the usefulness of knowing what is normal for others, as well as the importance of specific knowledge of one's own body; people also develop observer's knowledge of practices such as how to use needles, and prepare machines.

> *it is important to know what the best practices are so that you can [...] protect your fistula.*
>
> *(Patient, IHateDialysis)*

This quote refers to recommended guidelines for health professionals, relating to sterilization techniques, and use of the right size of needles. Safe practices contribute significantly to protecting a person's fistula over the long term, making knowledge of such guidelines well worthwhile. People may seek out guidelines, standards and tips, hoping to find a sense of stability or control by adhering to norms or standards which tend to work for the general population. Guidelines are again seen as positive, and control is a creative act laying down foundations for freedom when the chaotic storms of the unwell body have quietened. In this sense, discipline is reinforced by the dialysor's desire for freedom from uncertainty and danger (Foucault 1990).

Longitudinal and specific knowings

Patients are uniquely positioned to know the details and history of their own medical case, and to understand the particular symbiosis of their body with their equipment – including allergies to different bandages or medications, hairiness interfering with dressings, and personal susceptibility to inflammation. They are intimately motivated to focus on their single case. An outcome is that people begin to recognise more of the complexity of situations, a recognition that may or may not be accompanied by confidence or interest. Some contributors begin to feel safer away from hospitals, feeling that the care provided there is 'one size fits all', and ignores the particularities of each case (Neal & McKenzie 2010). By contrast, realising the complexity of their care, other contributors attest to a greater feeling of safety dialysing in a renal clinic, where there are staff to help when things go wrong.[63]

> *I have seen a lot of "things" happen in-centre with people "crashing"[64] - low BP[65], very high pulse, bleeding not stopping, chest pains and lots more. [...] What if you fainted or something?*
>
> *(Caregiver, IHateDialysis)*

Workarounds

The idea that everyone is different may dismay beginner dialysors, yet it is in their differences that dialysors may find freedom within the dialysis lifestyle. Contributors seem to learn the play inherent in their situation, which they use to their advantage. This links knowledge to control and power, bearing in mind the range of meanings of the French term Foucault used: *pouvoir* is a noun, *power*, but also a verb, *to be able to*, *to have the capacity*[66]. People start to find agency – ways to experience choice and variety, reclaiming small freedoms, and having fun. This is significant because it restores the sense of 'feeling alright' identified as important for making sense. People learn to work around their limitations, to 'make do'. Workarounds are locally devised tactics for achieving goals despite limitations, such as eating banned foods the day after monthly blood tests. People playfully use all kinds of 'things' as tools. To increase how much you can drink, sweat more by driving with the windows up in summer. To get the attention of clinic staff, make your dialysis machine alarm by kinking the blood lines. To get a second opinion from a different nephrologist, go to emergency instead of your regular clinic. By exchanging helpful ideas, online interactions bring forward tactics such as 'renal friendly' recipes, or tricks for drinking less.

> *If you haven't already, I'd recommend buying small glasses. Helped me cut down on my fluid intake at home.*
>
> *(Excerpt from Post#16, Thread D)*

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[63] In an online poll on one forum, 44.7% or 17 of 38 respondents reported self cannulating. While the results are problematic, they do imply that only some dialysors acquire the manual skills related to dialysis.

[64] Crashing = passing out.

[65] BP = blood pressure

[66] Michael Olsson remarks on this in lectures at UTS.

Many renal patients sleep during treatments – an escape from the location of the clinic as well as from time (Veinot et al. 2010b). While sleeping, patients find freedom in an otherwise structured environment; other patients describe watching movies, reading or doing crafts. Dialysis patients require one-handed activities.

De Certeau describes how people develop *tactics*, or *ways of operating* within the boundaries placed upon them, “knowing how to get away with things” which allow “victories of the weak” over the “strong” (de Certeau 1984, p. xix). Online discussions include frequent references to such small but significant victories. As de Certeau points out, mutations and reworkings make the guidelines and limitations of the dialysis world “habitable, like a rented apartment” (1984, p.xxi) – poetic, and possible to enjoy; limitations are decorated by the variations in ways people adhere to them. The familiarity by which people attain this kind of playfulness allows them to feel at home in temporary hospital spaces where they learn how to ‘make do’. Making ‘sense’ has a tentative aspect as one ‘senses’ possibilities, while ‘making do’ is active. One ‘does’ with familiarity, finding ways to control doing and feeling good about it.

Knowing *how*

Preparing and using dialysis machinery requires familiarity and technical skills which some patients acquire. They may also take their own blood pressure, give themselves injections and put their own dialysis needles in. Not all patients learn every skill, and many prefer to leave operating machines to health professionals, but some take whatever they can learn very seriously.

> *[T]he control and the peace of mind, the elimination of the anxiety associated with the crap shoot of who gets to stick you and the certainty that you can do right by your own arm and care properly for the fistula, make it most worthwhile in my opinion.*
>
> *(Patient, IHateDialysis)*

For some patients, the goal is minimisation of harm due to error or accident. For others, the goal is maximised health achieved by close attention to the body through self-surveillance – a far closer scrutiny than health professionals can normally provide over the long term.

Flexibility

The tactics of ‘making do’ described by de Certeau are operations of the weak in spaces governed by the strong, always taking place in full view. It is not until a person can withdraw to their own private space that they establish control over being seen (de Certeau 1984). The greatest potential for freedom opens up with home dialysis (peritoneal or home haemodialysis). Contributors who feel that they can care for themselves may choose the greater freedom and comfort of home based care. Taking dialysis away from the scrutiny of clinics lays it open to all manner of possibilities – people report having sex on dialysis. One must however remain aware of that unseen policeman, the body, which remains on humourless vigil.

By this stage, knowledge and control are not only used by patients to have fun. Some patients who pay careful attention to their experiences conclude that responsive treatments result in better health. They may begin to attempt more refined treatments; closer yet more flexible forms of adherence. They may realise that they need less fluid removed one day, more another, or that they need a slower, gentler treatment. They may delay or reduce treatments to rest a swollen belly or an injured fistula. Dialysors with a detailed understanding of their body may avoid cramping by adjusting dialysis speeds and fluid removal – a degree of control not always available to in-centre dialysis patients where dialysis speeds are set by policy and constrained by patient rosters. In-centre dialysors who are able to negotiate changes with their nurses are ones who report trusting relationships in which nursing staff recognise the patients’ authority – their knowledge of dialysis and their familiarity with their body’s needs.

The picture at Figure 6.4 (next page) shows a portable home dialysis machine being taken on a three night white water rafting trip by a couple of dialysors. It is an example of what can be achieved by some home dialysors, under some conditions. It is a far cry from the energy levels of many patients, and from normal treatment plans prescribed in clinics, as well as a departure from recommended operating and care instructions laid out by machine manufacturers. It is a fine example of workarounds, and the potential offered by gaining ‘control over’ illness.

Figure 6.4: IHateDialysis patient contributor taking his portable dialysis machine rafting

Losing control

This is not a simple story about discipline and control. Because bodies change, because people frequently experience more than just renal failure, because people need, want or cannot help change and fluctuations in their daily lives, therefore control is not absolute. Some bodies seem easier to ‘dialyse in’ than others, but all people appear to experience change, even if they have excellent self awareness: they cramp, they faint, their blood results spike.

I have arrived at this kind of pattern twice already now. In Chapter 5 I described how sense makers find their ‘normal’, which evolves in response to ongoing changes. In this chapter I have described how sense makers get to know their body, where changes necessitate continuous monitoring. Now we see how sense makers attain control but lose it again because of change. In fact these are examples of the same principles: the changing body is a system of changing normals; meanwhile control is a changing relationship between changing understandings and changing systems.

The limits of controllability

With their potential for particularised, experiential, bio-medically informed and longitudinal knowledge, patients have a different perspective on illness than practitioners. Meanwhile practitioners' knowledge of renal failure varies: general practitioners and emergency room staff infrequently encounter renal patients; casual or new staff members may lack experience, while nephrologists and renal nurses may not recall relevant details of a particular patient's history. The decisions of such professionals may not be as close to renal best-practice as those of experienced patients who know their own care. So sometimes, compliance with health professionals and compliance with one's health are contradictory. But patient knowledge is rarely accompanied by the authority to act or make decisions.[67] The politically contested borders of knowledge, authority and practice give rise to a range of tactics by patients, but their workarounds must often be invisible victories, hidden from medical authority. Non-compliant patients face serious repercussions such as being taken off the transplant list, as well as the day-to-day disadvantages they might expect if they are seen to be 'difficult' or 'bad' patients (Jeffery 1979; Stockwell 1984; Werner & Malterud 2003). Patients aim to maintain safety without disturbing the appearance of proper hierarchies of care (de Certeau 1984).

Meanwhile, control cannot be obtained which transcends physicality. The following description of the effects of skipping dialysis is in stark contrast with the dialysor's dreams of freedom via control. It is a description of a person who had not dialysed for about four days.

> *He is very sick as the day goes on. He's been vomiting all morning/day so far, diarrhea (had to put on [one] of the diaper things on for that [...)] sweating heavily, lying in the bed, and he must be cold because he has a blanket over him.*
>
> *(Caregiver, IHateDialysis)*

Dialysors rarely attain the freedom to do as they want. Faced with experiences as brutal as this, we cannot forget that in direct confrontation, experience usually beats theory.

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[67] I have explored a range of implications for authority, compliance and safety in separate publications (Godbold 2013; Hor et al. 2013)

Accommodation: a constantly renegotiated peace

Some dialysors describe being able to judge their dialysis needs. Having this close understanding of their body allows patients to respond to changing situations. As another of the gentlemen in the raft (Figure 6.4) remarked,

> *[T]he trick is learning to accommodate dialysis.*
>
> *(Dialysor[68], IHateDialysis)*

Accommodating dialysis is an interesting approach to take. Accommodating suggests on the one hand, that the person recognises that dialysis has needs or requirements and that those requirements might be met. So people cannot just ignore the limits of their bodies but must learn to actually live within those limits. It also implies that the person who is being accommodating has important needs of their own, which may be being set aside in a dignified manner. Another angle is that the person who accommodates is not a person overcome by dialysis; an accommodator is the host of the house, the accommodated is the guest. So there is an implication not just of being proactive, but of actually being in control. Finally, accommodating is a word which also implies a certain distance in the relationship: a cordial, possibly pleasant relationship, not overly close nor necessarily warm.

I commented at the start of this chapter that institutional facts like money and government are just as brutish as Searle's 'brute facts' (1995). It turns out to be only a potential brutishness, as people do have some room to manoeuvre. A person can be hit by a bus, or if they wait a little longer, they may ride on it. An application can be refused by a bureaucracy, only to be accepted later if one finds the right ways to fill out the forms. By learning to accommodate dialysis one may be able to control change to some degree and maintain freedom within the small space of a temporary normality.

I began this chapter with a description by a patient of moving from room to room while attached to his haemodialysis machine, using careful manoeuvres "a bit like a

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[68] This contributor prefers to be called a dialysor than a patient.

Zen dance". It is a classic demonstration of the inventiveness and determination of an experienced dialysor who wishes to accommodate dialysis. He allows for the needs of the machine and the demands of the needles in his arm, yet he keeps his own goals in mind and co-ordinates the machinery that forms his 'extended self', as if it were another entity, a partner. Significantly, he cannot do as he pleases. He misses the television show, and his family have gone to bed. He finds small freedoms but he cannot transcend the limits of his situation. Yet this whole scenario of moving the machine is, in another context, an unheard of liberty. In some dialysis clinics, patients are not allowed even to turn their machine to face them so that they can read it, effectively removing their ability to monitor their own treatments. Dancing with his machine at home, this gentleman can monitor the whole of his treatment, and choose its timing and frequency. Or he can 'plank' on it[69].

Figure 6.5: AustralianDialysisBuddies patient-contributor 'planking' on his home dialysis machine

Conclusion

> *Men have dreamed of liberating machines. But there are no machines of freedom, by definition.*
>
> *(Foucault 1984b, p. 247)*

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[69] 'Planking': a short lived internet fad, in which people took photographs of themselves pretending to be a plank of wood. Instances in which the person 'planking' was balanced in a dangerous or inappropriate place were prized.

When Foucault made the above comment, he was not talking about the impossibility of freedom. Rather, he was describing how power and control are manifestations of relations between people, a remark which is easily extended to include relations with machines (and other non-human actors). His point was that liberty must be exercised, not legislated for; no system is perfectly oppressive, nor is anything intrinsically liberating. “Liberty is a *practice*” (Foucault 1984b, p. 245, emphasis in the original).

In this chapter I have explored sense making encounters with what I called ‘brutal’ experience, to emphasise how experience has the authoritative ‘last word’ in sense making and is in fact, a key source of authority, certainty, and truth. I used physicality as a working example, as I searched for patterns in how sense makers respond to and incorporate experience into their understandings. Experiences could be seen to modify theory: ideas which left people vulnerable to negative experiences were identified as ‘wrong’ and modified; ideas which appeared to lead to positive experiences were seen as ‘right’ or true. The repeated modification of theories in response to experience led me to describe iterative rounds in which experiences of reality chipped away at theories and formed understandings which were both authoritative and familiar. Seen in this light, experiential brutality emerged as an example of the processes of pattern finding already described in Chapter 5. But experiences are a special case, because they are the source of authority. They confirm or break the theories from which individual and collective norms can be made.

Strangely however, the end of this chapter began to reveal a softer side to experience. As people developed detailed understandings of situations, via iterated experimentation, they found ‘the play in the system’ and began to identify workarounds and flexibilities. Brutal Experience, that arbiter of truth, may be only a public face. Having discovered how details and familiarity served to soften experience, I wonder what further potential there is in porousness, accommodation, flexibility, and complexity?

Chapter Seven: Complexity

Putting blurry spaces to use.

> The shop seemed to be full of all manner of curious things – but the oddest part of it all was, that whenever she looked hard at any shelf, to make out exactly what it had on it, that particular shelf was always quite empty: though the others round it were crowded as full as they could hold.
>
> (Carroll [1901] 2004, p. 198)

Deleuze (2004b) uses this moment from Carroll's 'Alice's Adventures through the Looking Glass' to exemplify a basic problem of sense making: a kind of eternal blind spot, which lies at the heart of this chapter. In the following discussion, I make clear that theories about sense making may refer to experience, to understanding, to descriptions, or to something between all these things. This 'something between' could be one way to explain the blind spot or empty space described by Deleuze. It is one of several perspectives from which I propose to explore complexity in sense making. In addition, I explore the usefulness of the rich, complex explanations found in posts, and examine the processes that 'complex knowing' may involve.

This chapter is not always based directly on the analysis of threads from Chapter 4. Parts of the discussion are instead based on the last two chapters. It is a second layer of discussion at a more abstract, theoretical level. Later, I will demonstrate why this abstraction has practical outcomes, and therefore, why it is an important discussion to have.

Based on the discussion in Chapter 5 and 6, I put forward sense making processes as necessarily embedded in complexity. However this is not a chapter devoted to complexity theory (as described for example, by Gell-Mann 1994; or Kauffman 1995). Instead, following Annemarie Mol and John Law (Mol & Law 2002), I use the term in its ordinary English sense, for a situation which is complex – the Oxford English Dictionary (2011) describes complexity as having a "composite nature or structure […] interconnected parts or involved particulars". Complexity refers to interweavings or interconnections which resist being simplified to generalities. I will describe how people sometimes make sense *while leaving complexity complex*, that is, without reducing the complex to simplicity.

This may seem to contradict my discussion of pattern recognition in Chapter 5. There, I said that the urge is to find sameness, to recognise similarity, and pack as much as possible into that which need not be examined, in order to proceed with one's routines. Here, I say that life is complex, and people use complexity to make sense. In fact I do more than that. In this chapter I will appear to take sense making apart. I will seek out gaps at all levels of sense making, and in the process, seemingly destroy the chance of anyone *ever* being able to make sense of *anything*. The blank spot described by Deleuze will permeate the middle of this chapter. I do that so that we can 'see' sense making despite the blind spot, and see if we can 'get to the bottom of it' despite its infinite depths. And (luckily), I will show that people *do* make sense anyway – good enough sense, which gets us all by from day to day, and which is sometimes better than being accurate. They make sense which is flexible and sensitive, *because* of its lack of specificity.

7.1 Living in ecologies of meaning

In Chapter 4, the theme of 'experience' emerged at every level of the data analysis. In the sequential analysis, I found that people were likely to embed explanations (theories, facts, and information) within descriptions of their own lived experience. Sharing one's experiences also emerged as an expectation of the groups – one of the strong interactive norms.

So while people talked about patterns in the data, such as what was normal, they did not necessarily give simple answers. Rather, they made connections from patterns back to their lives, adding details. In this section I will show how, rather than coping with complexity by developing *simplifications*, with their stories and anecdotes people maintained or *added complexity*. They created an expanded field of possibilities and left the reader to pick through variations on the theme. I will also describe how flexible meanings are made by drawing together familiar ideas into arrangements which are custom-made for new situations.

The garden of possibilities

Messages to the groups are archived, so any member can return to old threads for as long as the archive persists (Thomsen, Straubhaar & Bolyard 1998). This puts members in contact with wide ranging experience from people in distant physical locations. The discussion groups enable the accumulation of a range of options and perspectives, while their archives make visible what may otherwise only remain in memories: an enduring collection of possibilities.

Describing 'information grounds' where people gather for a purpose, and exchange information on other topics, Pettigrew used Granovetter to point out the advantage of obtaining information from 'weak ties' – people who are not part of one's everyday networks (Pettigrew 1999). As Pettigrew conceived them, a condition for the development of information grounds is that people gather for a purpose *other than* information sharing or provision. The discussion groups are not strictly 'information grounds' in that their stated purpose is precisely to share information and support about renal failure and dialysis. However it could be argued that after a while, some contributors come to the boards[70] just to see what is happening (Thomsen, Straubhaar & Bolyard 1998), which fits their use as a "great good place" (Savolainen 2009 citing Oldenburg 1999); this is similar to the approach taken by Fleming-May & Miller (2010), discussing blogs as information grounds. Reading messages, people obtain access to a range of perspectives on their situation, from people outside their normal network who therefore may have useful new ideas to contribute.

Posts supply options for actions and for emotional responses. They show how contributors' experiences match normality and how they differ. During the course of this research, my husband began to have trouble with his kidney transplant and I turned to the discussion groups for advice, experience and support. They told stories about similar transplant problems. Among their replies, I found ideas I could use including strategies for talking to my husband and hospital staff. Their ideas and vocabulary formed a collection of possibilities, some from posts written to me, some from posts written long ago and archived. I have already described, in Chapter 5, how this spread of possibilities creates the potential for people to negotiate between structure and agency: the range of descriptions add to possibilities, building a messiness which reduces the imperative of rules or norms. The archives, or perhaps my memories of having read the archives, became for me like a garden of possibilities, from which I could gather useful snippets as I needed.

An important outcome of engaging with a range of possibilities is that they support individuals' abilities to make complex connections, on the run, while working through the moment-by-moment sense making required of them in their everyday life. Each time a person needs to describe an idea (to make a request, to defend a decision, to contribute to a discussion group, to respond to a researcher and so forth), they may be able to do so with greater flexibility and in more various ways than they could before, because they have access to more options from the open field of detailed possibilities they have encountered both on- and offline.

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[70] Boards: online websites which archive posts in easily browsed displays.

New sense from old

Sense is not created out of a void but uses pre-existing understandings (Deleuze 2004b). In the construction of new sense, having access to many similar stories is an advantage. It provides a great range of possible elements from which to make new sense. Old descriptions and explanations are reworked for each new post, incorporating changes to suit the situation, making them new. Beyond that, from access to old threads one also has access to *how others threaded sense together*: combinations which resonated for some people and which were received with enthusiasm or uncertainty by others. The discussion archives provide a ready-made sounding board for the normalisation of theories.

Casting nets to catch sense: sense-mades as improvised networks of meaning

> *It's nice to talk like everybody else, to say the sun rises, when everyone knows it's only a manner of speaking.*
>
> *(Deleuze & Guattari 1987, p. 3)*

It is especially when sense making uses language segments for building blocks that we see the use of repetition – the rearranging of recurring elements, the strings of meaning, fractured, shuffled and re-pieced together. In this way making explanations requires "...an endless tracing of established concepts and words" (Deleuze & Guattari 1987, p. 24). Sense making is associated with knowledge constructions, which are traditionally viewed as stable and well-structured. But here, the elements used for such constructions appear a little second hand and improvised. Rather than stable, semi-permanent edifices of knowledge, Montuori suggests an "ecology of knowledge" (1998, p. 33) filled with many small narratives. There, people are creatively implicated in their knowings because they have to pull them together themselves: a "participant epistemology" rather than the usual "bystander epistemology". This is a perspective of improvisation: a fluid, active, shifting version of sense making.

Actor Network Theory refers to collectivities in which human and non-human actors are progressively connected and enrolled in relations of meaning or activity (Callon

1986; Latour 1987). Interactional strategies maintain or change the nature of such networks, which are created by processes of translation in which actors construct common meanings, define representativities, and co-opt each other in the pursuit of individual and collective objectives. This perspective can be used to describe how meanings are made by pulling together fragments of language into networks (Gherardi & Nicolini 2000; Thrift 1999). Sense making networks for dialysis patients include bodies, doctors, the discipline of western medicine, current experiences and memories of experiences, posts made to discussion boards, things said to friends, needles and machines, as well as language – words and phrases – all of which acquire meanings via their changing positions in shifting networks. Each new theory, with its rearrangement of elements and emphases, entangles new networked arrangements of meanings. As we create explanations or focus on particular parts of experience (making sense), we produce an order from a selection of the available elements, pushing other elements into marginality (Mol & Law 2002).

For example, in Chapter 4, Thread B was initiated by a person who had not begun dialysis, but who did have a new fistula installed and who had noticed that she could see her veins beginning to enlarge all the way up onto her chest. She asked, ‘is this normal?’ Her first post described the physical look of her fistula. The first half of the thread addressed the physicalities she raised with assurances they were normal. The sixth reply included a description of a ‘pulsating pseudoaneurism’, while the eighth reply pointed out this could be used ‘to scare kids with’. I have pointed out already how at that point the discussion shifted to fistulas as a symbol of cyborg-dialysis identity. Physical deformities changed their meaning from signs of medical problems to signs of elite membership. This example demonstrates how, as meanings evolve in a conversation, some elements are brought forward as active, constituent parts of a particular meaning network. By so doing, other elements move into the background, or “disappear” (Law 2004). Here, elements relating fistulas to elite membership were brought forward while elements relating fistulas to physical or medical problems were backgrounded.

The garden of possibilities functions as an active ecology of knowledge (Montuori 1998) – in which various visions of worlds co-exist, compete, overlap, reinforce and negate each other. This is one of the contradictions inherent in ‘common sense’ assumptions about knowledge: meanings are co-opted transiently, but people look for discrete structures – and assume they are relatively stable, so ignore the “crossings, movement, [and] travel” inherent in their emergence. Such turbulence and rearrangements are a crucial dimension for Actor Network theory (Thrift 1999, p. 38). Under this interpretation of sense making and sense made, any particular enunciation of sense-made becomes a “power takeover [...] within a political multiplicity” (Deleuze & Guattari 1987, p. 7) as people pull together shifting assemblages of meanings. These are a similar politics to that described by Latour and Woolgar in the development of the shifting collectivities they refer to as “actor networks”, whose connections are held by processes of *intéressement* and conscription, always renegotiating and likely to dissolve (Latour & Woolgar 1986).

The expected order of things is reversed here. Rather than sense making as a process which supports the construction of edifices of sense made, sense-mades such as explanations emerge as tools for sense making. Provisional, useful for a task at hand, sense-mades are constructed to order but are made of pre-existing chunks taken from the communal toolbag. I conceive sense mades – explanations, theories, statements – as assemblages of moving components (Deleuze & Guattari 1987). Something can be sense and at the same time an affordance for new sense (new sense from old) because complex sense is made by shuffling and assembling existing elements. Rather than asking what an expression means, Deleuze and Guattari (1987) might instruct us to observe what it connects to, relates to, interferes with, what makes it change, or with what elements it is (temporarily) interlocked.

Knowing is created in company

Sense making is revealed here as an activity which is both individual and social. While an individual sense maker pulls together a collection of meanings into a sense made, they do not create the meanings and will rarely be the first to bring them together. When PersonB, looking at her new fistula, called herself *Borg*, she was not the first person to make that analogy. She connected to ongoing references to being cyborg in all three groups. She also connected to the meanings about being cyborg created by the Star Trek series. Sense making no longer originates from the sense maker, who might be better called a sense assembler. Nor is it created for individual ears: sense mades have a trajectory from the social to the social. The multiple perspectives from which new knowings are made and confirmed are extra-individual.

Moreover, the social confirmation of theories is carried out in the society of objects or experiences as well as humans (Latour 1993): *will this theory allow me to safely insert this needle into this arm*. The previous chapter described how objects and experiences form part of the relations within which sense is made and provisionally confirmed. The communication involved in constructions of the informative can be between human and non-human actors, such as the pain of a needle going too far into a vein.

Because of these various social origins of many of the elements from which sense is made, individual and social divisions break down. The sense maker, pulling together a collection of connections, creates turbulence (O'Sullivan 2002), a threshold or event of gathering which simultaneously communicates and contributes to social collections of meanings.

Connecting from generalities to specifics

Generalised information is designed to be true for most people; examples are scientific and medical knowledge as well as understandings of what is normal in a situation. Such explanations are prized for being ‘realistic’ – grounded in rigorous scientific empiricism, for example, or verified by lived experience. In Chapter 5, I described how people ask for and provide such explanations. But I also described a tension between such generalised information and specific meaning making by individuals.

In Chapters 5 and 6 we saw how patients, presented with medical descriptions, must learn to translate generalities into particularities and vice versa: to understand how their system manifests renal failure, and rework maps of veins and fistulas into their specific topology. Such understandings need to be flexible enough to change as one's situation changes. Individuals take medical understanding into account, as well as population norms, generally reported experience and their own lived norms of experience, forging links from them into the complexity of their situation. Posts often demonstrated such links with which explanations were contextualised. Explanations did not remain general for long but were rapidly embedded in the particular.

> *[Fistulas] get more pronounced since they are rerouting the blood due to the fistula creation. The main fistula vein will develop even more as it is used* ***and mine is quite large****.*
>
> *(emphasis added, excerpt from Post#3, Thread B ('I AM BORG')*

> *Yup, normal.* ***I've still got a place below my collarbone on the left side that everyone things is bruised since there are so many extra veins just below the surface.***
>
> *(emphasis added, Post#4, Thread B ('I AM BORG')*

In addition to finding connections from generalities to specifics, people also work the other way: having developed understandings specific to their situation, people then look for ways to generalise their experience. In Chapter 5, I described how people try to develop understandings of what is normal for them – localised normality. We saw the troubles people go through to develop such understandings and the authority with which experienced dialysors are able to discuss what is and is not normal. These trials by fire forge authoritative 'localised generalisations' of the form 'this is how I do it'. I have already shown you the following quote:

> *My left boob is my water retainer.*
>
> *Patient, IHateDialysis*

When her "left boob" swells, this lady recognises it as a sign of fluid retention and has normalised ways to respond, for instance by drinking less.

* * *

Being able to generalise means that you are also able to work within generalised patterns and have a sense of the give-and-take of your situation. Posts which described ‘how they normally do things’ were accompanied by a calm or positive tone, suggesting that good feelings accompany one’s ability to state one’s personalised general-case. This may be the ‘feeling alright’ that comes when things make sense – that comes from finding patterns, knowing what is normal and possibly beginning to be able to control situations.

7.2 Finding gaps

In Chapter 3 I explored Dervin’s ontological-epistemological conception of reality and the humans who try to theorise sense of it. She describes a literal movement through time and space, accompanied by a metaphorical movement in the form of the ongoing narratives of sense making. In both the literal and metaphorical trajectories, one encounters and manufactures change as well as fixedness. Individual and reality are both “ordered in part, chaotic in part, evolving in part” (Dervin 1999b, p. 730). Therefore, at conjectured points of comparison (between people’s ideas, between a person and their experiences, between what a person thinks now and what they think later) one may encounter gaps, which are caused by the various changings and fixednesses of reality and humans. People are conceived as trying to close gaps, in order to be able to move again – particularly, to know what to do next, and regain their sense making momentum.

In Chapter 6, I presented the following representation of iterative relations between experiences and explanation during sense making.

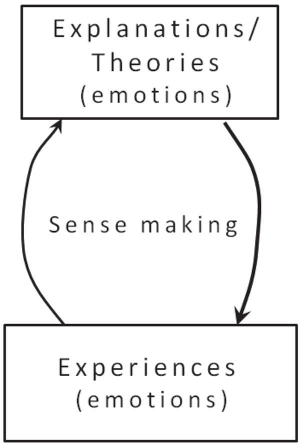

Figure 7.1: Relations driving iterative rounds in sense making

It represents how experience and explanations affect each other in iterative sense making rounds. A goal of sense making is to produce explanations which describe experience as closely as possible. In Chapter 6, I explained how, by encounters with experience, sense making theories (explanations, routines) are refined and smoothed, theoretically improving the match between them until one arrives at 'the truth'. Truth is often a goal of sense makers. In this section, I aim to explain why this goal cannot be achieved, because of persistent gap between understanding and experience. I examine a range of places in which philosophers have established the persistence of gap, most of which are also explicitly described in Dervin's writing. Since the idea of gap as an impetus to sense making is so important in Dervin's writing, I spend some time on it in this section. The point of this exercise is to find if there are limits to gap – places where gap *is not*, and where, perhaps, sense making is not required. Instead of finding such refuges from gap, I will explain how there are not only gaps between things, but even gaps within things.

Gaps 'between'

In her writing about gaps, Dervin most frequently describes gaps or discontinuities as located *between* – between entities (living and otherwise, including institutions, nations and structures), between perspectives, cultures, contexts and circumstances, and what is seen as true including between different times or across space (Dervin 1991, 1999b; Dervin & Frenette 2003). She occasionally mentions two more kinds of gaps which are worth more attention: gaps between experiences and explanation, and gaps between explanation and understanding.

Gaps between experience and explanation

Gaps are evident between experience and explanation in a number of ways. First, sense making occurs retrospectively (Weick 1995), ensuring a time-lag-gap as explanation trails behind experience. Next, given that sense making constantly changes, descriptions are also (always already) only traces of that process; evidence, leftovers, attempts which always miss an ever shifting ‘truth’. Moreover, due to specialisation, individuals do not know the full range of knowledges available in their society (Berger & Luckmann 1966). And as theories are expressed and expression always involves a context, a perspective and description, therefore expressions will not adequately describe experience from multiple perspectives, even for the same person (with their collections of identities: Weick 1995).

Next, even though people may aim to develop specific and accurate descriptions, they can only get so far because language turns out to be a blunt tool. Words notoriously fail to describe love, pain or even the taste of chicken.

> *The pain is really more of a "pang", if that makes sense. It comes and goes and doesn’t feel like stomach pain so much as an isolated pain, like nerve or muscle. It’s hard to explain. The only thing I’m sure of is that it’s new. It’s not scream out pain or bend over clutching your side pain, but it’s something different.*
>
> *(Patient, IHateDialysis)*

The absolute individuality of individual experience is inexpressible because to express it one can only use language, and language necessarily approximates with similes and stock phrases. Included in her lists of gaps, Dervin described these gaps between “the sense of an experience physically and the articulation of it verbally” (Dervin & Frenette 2003, p. 237) – gaps “between mind and tongue, between tongue and message created, between message created and channel” (Dervin 1991, p. 62).

Considering descriptions of experience, Deleuze builds on semiotics (e.g. Barthes 1970, de Saussure 2006) to describe four sources of gap: three to do with the descriptions themselves, and one which, he says, hovers around the attempt to describe.[71] The first three are denotation, manifestation and signification.

(1) **Denotation** is the difference between a situation, which is individuated and particular, and the words I choose to describe it. "Denotation functions through the association of the words themselves with *particular* images *which ought to* 'represent' the state of affairs" (Deleuze 2004b, p. 16). If I wanted to tell you the colour of my cat, I could choose the word 'black'. But anyone who specialises with colour will know that 'black' is used to represent an enormous range of shades or tints. The word 'black' gestures toward that cluster of colours, generalising the particular colour I have before me to a more widely representative word.

Next, a person has desires and beliefs about the situation they are describing. Deleuze points to (2) the difference between those desires and beliefs of the person who speaks, and what they say, a difference which he calls **manifestation** (Deleuze 2004b, p. 17). I could say that I love my black cat, a comment which does not include the various ways in which I might have been prompted to make the remark – laughing as I watch him chase dream-rats in his sleep, sadly, as I observe his continued weight loss, proudly, as I admire his thick, shiny coat. (3) A third gap lies in **signification**, the connections made by those who hear a proposition back to general ideas or universal meanings.[72] Not unreasonably, you may have decided that my cat is black; but between my denotation (choosing the word black) and your signification (choosing some shade of blackness in which to imagine a generic cat) we have lost the range of blacks, browns and greys with which his coat reflects the light. Also, I doubt you imagined his nose as marvellously lion-like as it really is.

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[71] I could compare Deleuze's treatment of these sources of gap to those of Barthes (1970), Foucault (1972), Derrida (1990) or de Saussure (2006) but the point here is mainly, that gaps exist not just between expressions and experience, but within expressions. For my purpose, Deleuze's version will suffice.

[72] This conception only refers to explanations or theories which are manifested in words, and ignores physical or embodied theories such as routines, physical ways of doing (Bourdieu's 'way of walking' 1990), or mechanisations such as the coordination of trains or the movements inside an analogue watch (Latour 1992). As my data is all text, all written explanations, I am able neither to fill in the blanks here nor do more than point to the continued theoretical lack (the continued othering of physicality - Law 2004).

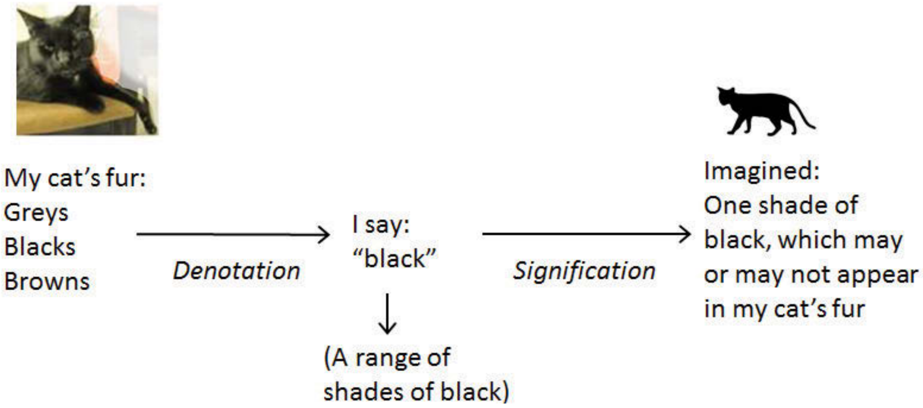

Figure 7.2: Gaps (loss of specificity) during denotation and signification

Thus, gaps necessarily inhere not only between experience and what can be said about it, but also, as my last example demonstrates, between what may be said and what is understood.

Gaps between explanation and understanding

The fourth source of gap identified by Deleuze is **sense**, which hovers between explanations and experience. Wavering between propositions and things, sense is both expressed by the proposition and an attribute of some situation.

> *The duality in the proposition is [...] between the denotation of things and the expression of sense. It is like the two sides of a mirror, only what is on one side has no resemblance to what is on the other.*
>
> *(Deleuze 2004b, p. 31)*

Deleuze is suggesting sense as some quality which manifests as I describe my cat, yet which is neither expressed by my remarks, nor inherent in my cat. Given these manifold failures of words to express meaning, we find we cannot say what we mean. What is more, having said something, because of the gap between what one says and what one means, one can always clarify what one means, which clarification can also then be clarified and so on, an infinite regress. (Deleuze 2004b, pp. 44-50).

Meanwhile, sense making does not occur in isolated instances, but enactively, in series' of related moments. Series can emerge chronologically or achronologically. Chronologically, for example, may be the pair of simultaneous series which emerge as a person goes to a hospital appointment: driving and parking their car, navigating hospital corridors, and so forth. As the series of the experience unfolds (a series of scenes and situations), there is a simultaneous series of the sense made by the person of the series of experiences. Suppose the person describes their journey to a friend, turning the series of experiences into a related series of descriptions. The descriptions, the experiences, and the sense making are three cogenerating series which are related to each other but which never fully overlap, that is, which never properly and fully represent each other. [73] There are gaps between each.

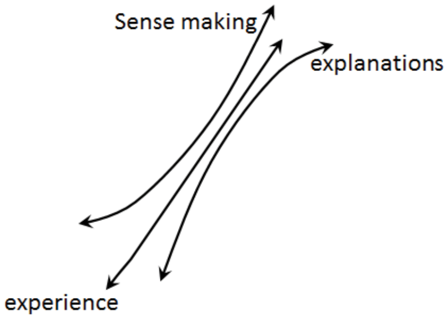

Figure 7.3: The co-related series of experience, description and sense, based on descriptions by Deleuze (2004b)

One also encounters "achronological series": for example, experiences relating to just the moments of dialysis sessions, or just those of driving to and from dialysis. The disjoint events (one dialysis session each day or two), are joined together into 'dialysis sessions' or 'driving to and from dialysis', creating a series of experiences of 'dialysis sessions' in which particular sessions are joined to each other. One is 'back on dialysis', returning to the endless space in which one is and always has been on dialysis.

There is an ongoing gap between the three series, a moving empty space which can never be properly filled by intersection. Deleuze describes something which moves between any pair of series, a "paradoxical entity" which circulates in both. He calls

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[73] The discussion boards are such a series: a series of observations on an ongoing experience. They create yet another series, the series of experiences writing and reading posts.

it the occupant without a place, linked to a place without an occupant (Deleuze 2004b, pp. 48-9). Leaning on the counter in the sheep's shop, Alice tried to fasten on such a shifting object which always seemed to be on a shelf near where she was looking, but moved every time she looked directly towards it. Foucault refers to a similar emptiness within language, which is "hollowed by absence" (1972, p. 111) and Derrida describes something similar with his *différence* (1990).

Gaps 'within'

I promised to look for places without gaps; one reason is in order to understand how bridging gaps might work by examining such places. But so far I have found only inherent gaps *between* entities. Next I show that gaps are also inherent *within* entities, finishing the search for gaps by finding gaps everywhere.

Gaps within knowing

In Section 7.1, I described how people pull together theories and explanations *ad hoc*. This is a conception of knowledge as various temporary states, better described as knowings. Gherardi & Nicolini use "knowings" to make the point that knowledge is necessarily always in process (2000). Knowings are expressed using attempts at coherent, sequential, logical statements which are derived from fields of possibilities. They can be applied in context to situations, but may have only temporary relevance because of unpredictable shifts in experience and understanding.

Since knowing-assemblages are improvised rather than static, they are necessarily, potentially unstable. Knowings are subject to iterative reformative processes by which they are reinforced or modified (Gherardi 2008) and are constantly being reworked in ways which cover and create new gaps. Knowing as a practice is affected by routines, habits, teleoaffective momentums (Schatzki 2012), and other situational forces like urgency, playfulness, and (especially) who is listening, co-creating the knowing. Knowings are structured, in that we make meanings out of patterns and fit them into other patterns, following patterns encountered previously (Garfinkel [1967] 1984). They are improvised in that we rework meanings a little bit every instant.

Gaps within experience

Gaps manifest in experience because of shifts in focus. I pay attention to the restless group of travellers nearby me on the train, then return to my writing, only to find myself staring blankly out the window. I fall asleep and wake up later. My moment by moment comprehension of experience is shifting and can be disjointed. On the other hand, I stitch together asynchronous events into a continuum of experiences, as I described earlier with the help of Deleuze.

Gaps within reality

The only problems Deleuze seems to raise with reality's continuity have to do with our ability to see or describe it. But for Dervin, "gappiness applies to […] ontological conditions (i.e., the nature of reality)" (Dervin & Frenette 2003, p. 239).

Physics currently posits that physical reality is full of gaps between subatomic particles. But questions of gaps in reality go back to the ancients. Born around 460 BCE, Democritus (or his teacher, Leucippus), pointed out a gap between perception and reality (Berryman 2010 , citing Diels & Kranz 1951). Democritus' work is relevant because he is also credited as the first Greek philosopher to suggest the existence of void in the universe, necessary to allow movement (Berryman 2010). He argued that if the universe is full then there would be no space left for objects to move into – and proposed an early theory of atoms.[74] According to Democritus, "Void does not impede the motion of atoms because [its] essential quality is that of 'yielding,' in contrast to the mutual resistance of atoms" (Berryman 2010), a reference to a potential usefulness in gap to which we will return presently. For the time being, the point here is to establish a vision of persistent and ubiquitous gap, of gap which is pervasive throughout human experience even at the level of what reality is 'made of'.

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[74] Aristotle countered that the substance of the air moves aside to make space for objects; therefore, the universe is full.

Sense unmaking

I take a moment for what might seem like a detour. A question remains about sense-*unmaking*, an idea raised by Dervin (e.g. 1999b).

> *[I]t is assumed that humans are involved in a constant journey through sense-makings and sense-unmakings.*
>
> *(Dervin 1999b, p. 731)*

One could try to imagine what sense unmaking or loss of sense might look or feel like, and look for examples of it to contrast with sense making. If one assumes an epistemology such as Brookes' knowledge structures (1980) then sense-unmaking might be gap creation, including loss of structure or content. The implied permanence of knowledge structures makes contradictions or gaps appear dangerous. In Dervinian terms, sense-making is undertaken to close epistemological-ontological gaps in an evolving reality. Sense *making* implies that when sense is *made*, gaps become closed. Yet we have just established that gaps are ubiquitous and most cannot be closed.

I may be being too critical of the gap-metaphor because it has led to useful research exploring sense making. However, I think that in practice, the bridge-gap metaphor has maintained images of stability, and I believe it is deeply problematic to consider sense, understanding and knowledge as stable structures. By looking for what is stable and enduring about knowledge, we fail to support what is flexible and complex about knowing, and we try to defend ideas in situations and times for which they were not designed.

Gaps are less problematic in a system where transient sense-made-assemblages interrelate with experience, forming only momentary structures. As discussed in this section so far, gaps permeate every layer of sense making more or less all the time, a permanent feature of the human condition (Dervin 1991), which only manifests as a 'problem' for sense makers when they become aware of it (Godbold 2006). Earlier, I described explanations in terms of networks which bring together selections of elements relevant to a situation, a process in which other elements are silenced, erased or cleared away (Law 2004). Expressions which fit one perspective necessarily preclude others. Rather than ‘discovering’ or ‘removing’ gaps, sense making therefore involves relocations of sense making elements, including gaps.

Instead of worrying about bridges, structures and gaps, it may be more productive to consider emotional strata of sense, asking for example, where one feels unhappy about a situation. In Chapter 6, I linked knowing to having theories about which one feels secure: authoritative theories. Epicurus and the practice theorists point out that knowing manifests in and emerges from experience, the ‘school of hard knocks’ from which people emerge with greater confidence in their theories because they have stood the test of time (or else not). In such an environment, problems with knowing are related to uncertainty. This is a return to the question of feeling ‘alright’ when things make sense, and feeling troubled when they do not.

From this perspective, knowing (having trustworthy theories) and making sense are related to changes in feelings of certainty and authority. I ‘know’ when I feel good about my theories, and I ‘don’t know’ when my feelings are troubled or unsure. From this perspective, sense *unmaking* does not necessarily signify *gaps* such as missing information, and is heralded by experiences of troubling feelings.

* * *

I have spent some time in this section discussing gaps because they are so important in Dervin’s conception of Sense-Making. If we make sense by bridging gaps, there must be locations where gaps are, at least sometimes, bridged. So I have searched for limits to gap, but I have not found them. I have found gap between and within many of the layers of existence: understanding, experience and even reality all have gaps. In fact I have located a perpetual blind spot, Deleuze’s ‘paradoxical entity’, which ensures gap *wherever we look*. This may seem to make the idea of bridging gap into a pointless exercise, and render sense making impossible. Clearly people do, however, make some kind of sense. In the next section, I explore how this may be done.

7.3 Structure verses flux

Knowledge is traditionally conceived using structural metaphors: we ‘build’ on knowledge; we want it to be ‘sound’ and reject knowledge that does not ‘fit’. Cognitivists explicitly try to ‘map knowledge structures’ (Todd 1999). In Chapter 6, I described how dialysors appear to construct stable knowledge about a solid (and hurtful) reality, adding facts to solidify their understandings of the truth, which they strengthen further by the discussions in the group, creating common agreements about their shared experiences.[75] ‘Fact’ comes from the Latin, *facio*, to do or make. *Factum* is the past tense, done: it was made, and now, is solid. Facts are hard, solid and reliable. “Truth is a fixèd star” (Griffiin & O'Daly 1919). The trouble with this beautiful image is that there are no unmoving stars, not according to current astrophysical models. They move, and so do we.

An alternative theoretical conception of knowing is as rhizomal (Deleuze & Guattari 1987). Rhizomes (like ginger, grass, potatoes) are multipliticities which can be extended from any point into any direction, and which have neither single origin nor hierarchical structure. Connections can be made into any medium and broken without catastrophe.

Dervin (199b, p. 731) described a “constant journey through sense-makings and sense-unmakings” (Dervin 1999b, p. 731). With the ontological shift suggested by Deleuze and Guattari’s rhizomic visions, the momentum of the sense maker as far as Dervin imagined it is changed. The rhizomal sense maker undergoes experiences, and may simultaneously create multiple, distinct, coherent, transient descriptions (sense-made-assemblages). Instead of a sense of coherent forward progression, we have oscillations among versions of sense made, a campfire of rhizomal sense making from which sense-mades rise like flames: “a model that is perpetually in construction or collapsing, and of a process that is perpetually prolonging itself,

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[75] Back in Chapter 6 I always used quotation marks around the ‘truth’ to avoid any claim to singular or fixed truth, though I do ‘believe in reality’ (Latour 1999). In Chapter 6, the experiences of contributors pointed to constant change and modifications. Via the processes I called ‘experiential brutality’, people constructed their understandings in concert with their experiences of situations and things. So while in Chapter 5, I described how people construct reality in social interactions with other people, in Chapter 6, objects and situations were part of the networks of socialising agents (Latour 2005a) contributing to the development of understandings.

breaking off and starting up again" (Deleuze & Guattari 1987, p. 20). 'Being' and sense making are rhizomal multidirectional multiplicities, while the explanations created to fit them are linear, structured and univocal.

Unstructured structures

So sense makers attempt to find patterns, but reality and understanding are not necessarily structured; moreover they problematise description by changing. To compensate, people develop many versions of understandings of situations and systems, some of which are varied at an ontological level, and conceive of the same artefacts or processes using contrasting metaphors (Mol & Law 2004). They strengthen their field of possibilities with a variety of possible points of view, couched as individually coherent (structured) theories, without their needing to be combined into a meta-structure (such as Belkin's 1980 knowledge structures). These are the useful multiple understandings mentioned by Starbuck and Milliken (1988).

For example, in the mixture of interactions online, contributors support contrasting perspectives on the body. They refer to bodies as simultaneously healthy (e.g., able to work) and unwell (needing dialysis). They visualise them in terms of medical diagrams and biomedical function, which can be known by measurements (the body-we-have), but also as felt, lived-in environments which are known by the sensations of inhabiting them and by their capabilities for action (the body-we-are; Mol & Law 2004). These views on the body are not just interesting varieties of metaphors; at times they are contradictory metaphors. Moreover, contributors must inhabit their bodies as patients, but also as parents or people with jobs – teachers, fire fighters and truck drivers. Sometimes these roles can be kept separate, but sometimes they overlap (the teacher who needs to avoid the germs of the schoolyard; the pet owner whose cat wants to warm itself on his dialysis bags). These are roles with contradictory needs, which must be accommodated by the same body. In the discussion groups, contributors apparently do so without manifesting epistemological crises. Mol and Law describe this drawing-together of ways of knowing as "the body-we-do".

> *So long as it does not disintegrate, the body-we-do hangs together. It is full of tensions, however. There are tensions between the interests of its various organs; tensions between taking control and being erratic; tensions, too, between the exigencies of dealing with [illness] and other demands and desires. In the day-to-day practice of doing bodies such tensions cannot be avoided.*
>
> *(Mol & Law 2004, p. 57)*

I have described how people draw from whatever fields of possibilities are available to them, to improvise explanations 'on the run', and how their access to options and variations allow flexibility in their ability to improvise. As people's conceptions or models of situations are not necessarily stable or fixed ways of knowing. They can be flexible in response to situations. Explanations will often be structured in-the-moment because people find coherence by seeing patterns. For instance explanations may have a narrative sequence, but not a fixed sequence: elements can be rearranged. This is a conceptualisation of sense-made not as a single, stable structure (which might often be described in more or less the same way) nor even as a stable set of connections, but as many, mini-structures (Montuori's ecology of knowings) – improvised assemblages, able to be re-designed sometimes, or which might 'come tumbling out differently' at other times.

Remember Person B considering her new fistula, which made her 'BORG'. Before it was installed, she had written:

> *Having a fistula created represents the crossing of the Rubicon in my mind. Up to now, I have not seen the physical effects of my disease. Having a fistula changes that. I don't care what it looks like to other people. [...] But it is a physical manifestation of my disease and of my frightening future. It is a symbol of my worst nightmare coming true. I know I need to make that phone call to make an appointment, but I just can't. I just can't, I just can't. I can't even think clearly. All I can see is my arm being butchered without any guarantee whatsoever that it will serve a useful purpose.*

Years later, encouraging others to face their first fistula surgery, she wrote: ‘I have a marvellous fistula that is a year old and that I haven't had to use yet. I get it checked regularly and everyone says it is just wonderful.’ ‘Still haven't used it, but I'm told it's fab. But it still feels alien.’ To downplay surgery, she wrote ‘My fistula surgery was no big deal.’ Meanwhile to acknowledge fears, she has written ‘The day I got my fistula was probably THE WORST day of my life; it's when I had to admit the inevitable. But the day after, I felt a strange sense of relief’. Elsewhere, she has written, ‘I am sick of this damn thing in my damn arm, damn it.’ These statements are only contradictory if one expects all true statements to combine into a stable, mutually confirming structure. Instead, people use statements rhetorically to make points and position themselves. Sometimes, Person B expressed the horror her fistula represented to her; sometimes, she emphasised its usefulness or her recovery from fear. What she can say is flexible.

This conception aligns with Dervin’s descriptions of “the constant design and redesign of the sense by which humans make and unmake their worlds” (1999a, p. 330): “continued sense-making” in a reality in constant flux (p.332). But it extends the concept away from necessarily coherent, interlocking designs, and weakens implications of progression in an ongoing sense making journey. Importantly, the capacity for flexible meaning making strengthens a person’s capacity for complex, situated sense making.

Useful looseness

The idea that looseness is useful has been a recurring theme in the past few chapters. In Chapter 5, I described how people look for patterns against which to make sense. I pointed out that the patterns are found not by *identifying exact* sameness, but by *designating* sameness. Patterns emerged thanks to the natural looseness of classifications. In Chapter 6, I described how people’s theories are tested by experience – but how, in their deepening understandings of their situations, people find looseness there too, give and take which not only allows them to develop some degree of control with experiences, but also provides the elements from which fun could be had.

Here again, we have found ourselves in loosened spaces. People variously pull forward assemblages of ideas into theories, drawing their elements from the possibilities of which they are aware. The ‘fields of possibilities’ are not completely unstructured – elements of meaning are always already in multiple simultaneously remembered structures. It is by their being multiple, their overlap, their redundancy in meanings and the inclusion of possible alternatives for saying almost the same thing or for saying quite different things – that they are useful. Contradictions allow yet more opportunities for meaning making, by providing ways to argue or compare, or ways to defend (Olsson 2010b). As people gather together collections of elements of meaning, they take advantage of the flexibilities and spontaneities made possible by gaps between structures, places where structure is weakened or lacking, or where choices lie between possible ways of theorising. As Democritus may have put it, it is the spaces between ideas – their looseness – which allow them to be shifted around. And people take advantage of *expectations* of structure, using commonalities to create familiar theories in which they feel secure and which are recognised and accepted by others. Because people construct sense together in interactions, explanations and actions are designed to fit the patterns anticipated by others, to make them mutually recognisable and coherent.

As well as putting forward contrasting positions about situations, contributors to the discussions were at times vague or equivocal, particularly in situations involving the provision of advice. Rather than specifying what another person would experience, they described their own experience using linguistic devices which allowed them to suggest an idea without precluding other possibilities. Such tactics create looseness which allows for variation. For example, in Thread C (‘Stint Removal’), a range of attitudes toward the procedure emerged, ranging from people who encouraged Person C ‘not to worry’, through to others who experienced pain. Each post in Thread C negotiated a space between reassurance and negativity. To be positive about the experience, negatives were expressed but played down: it was “a tad uncomfortable”; there were “a few drops of blood”; “I felt everything […but…] survived”. Those who presented the experience in a negative light did so by modifying positives: it was “none too pleasant”; it was “not fun for me”. Such modifications created space for variations in accounts and variability in experience.[76]

This allows the reader to draw their own conclusions regarding what is and is not useful. Hence, I have described the collection of possibilities as an open field: it is usually not prescriptive (beyond the expectations of cultural and societal norms). People can make use of fragments of ideas and use them in ways suited to their own purposes (subject to norms and expectations, to varying extents). This is the kind of useful vagueness described by Star and Griesemer in their discussion of boundary objects (1989, p. 393). Boundary objects were put forward as objects which are meaningful in different social worlds, by being plastic enough to adapt to local needs, while remaining recognisable and useful in different localities. Here, the recognisability of elements of other people’s narratives makes them useful, so long as a certain amount of uncertainty or vagueness remains in play. Similarly, people estimate their proximity to metaphors, norms and normalities with the same need for ease of fit. In all these situations, the boundary object (norm, metaphor, narrative description) is recognisable in a general way, vague enough to fit many situations and flexible enough to remain recognisable to other participants. In this way, the usefully loose meanings of metaphors allow ideas to travel (Thrift 1999)[77].

But all of language has this quality. Language forces me to use approximation for my expression – representations which are necessarily inexact. Rather than confounding communication, the looseness inherent in language *enables* communication. I can relate my unique experiences to others, by ‘typifying’, subsuming the specific into general categories to which others can relate (Berger & Luckmann 1966, pp. 38-9). By translating my ideas loosely into words which then loosely refer to mutually recognisable ideas, I can describe the detailed particularities of my situation to you. Sort of. But if the looseness in meanings was not there, if

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[76] They also made use of positivity as a ‘way of looking at it’, an attitude which diminishes negatives. The interactions enabled ongoing feedback loops between social expectations and norms on the one hand – for example, to be positive – and individual opinions, preferences and situations on the other – that it was not a fun experience.

[77] ‘Useful looseness’ is similar to Garfinkel’s ([1967] 1984), p.21) discussion of ‘ad hocing’ procedures. Strong connections to Garfinkel’s (2008) discussion of information could also be explored, a task to which I will return in later publications.

words did not *create* an overlap between what I experienced and what you recognise, we would not be able to talk about it because our experiences are not the same. With the looseness of language, I can describe *something*, and you will then have *something* to work with in reply. Watching conversations from this close-up, every word is a boundary object (Star & Griesemer 1989), succeeding (and failing) to deliver meaning because of their capacities to blur and approximate.

This kind of useful looseness appears in routines and practices as well as language. Chatman described a normative life in the round which, in Chapter 5, I showed to have a stabilizing, reassuring effect on everyday life. On close inspection, Chatman's description of life in the round is of a paradoxical balance. Though it is a structured, routine, predictable life, yet it is filled with "an enormous degree of imprecision", with "accepted […] uncertainty" and "tolerable […] inexactitude" (Chatman 2000, p. 9). Gaps such as those between description and experiences allow one to recognise (more or less) sameness and use that familiarity to recognise what to do next. People recognise and are then able to work with loose rules, so long as they are not spelled out completely or fully (Garfinkel [1967] 1984, p. 2, quoting Helmer & Rescher(n.d.)).

More than that however, Deleuze and Guattari describe "lines of flight", points of rapid modulation from one manifestation of a situation to others. Such access points allow the possibility of rapid or gradual change. These may allow simple escape (the dialysor sleeping through treatment:Veinot et al. 2010b) or they could allow shifts in meaning: humour, genius, poetry, connections by which one might experience pleasure in the midst of discipline. It is the points of flexibility as well as established meanings possible with practices and language that allow the kinds of subtle plays of meaning required for "lines of flight". When people make playful or creative connections to established meanings – whether it be with language, objects or practices, then variation and movement result, creating the poetry that makes the disciplined life worth living (O'Sullivan 2002).

Improvised knowings

In Chapter 6, I differentiated between sense making, the process of understanding or comprehending experience, and sense-mades, the explanations one might produce. Sense-mades might be expected to be expressions of cognitive processes, words which express ideas. However, they need not take that form. Sense-mades may be a way of saying something, or they can be a way of doing something, so long as they are coherent. Like walking, or tango. A classic Argentinian dance form, tango is not performed in a set sequence, but is the result of the music as it is played by the musicians, and the dancers, signalling to each other the commencement of brief sequences. Tango is a combination of communication, interpretation, co-production, and performance. It is an example of physical sense making, an ongoing recursively formed *doing* in response to prevailing situations. Walking too – each step is a solution of particular problems between foot and ground, another improvisation (Mitchell 2011) .

So the idea of knowledge as a single, coherent, stable (or slowly changing), well-structured conglomerate, 'out there' for us to find and know, is a dream of pattern-seeking sense makers. Instead, imagine knowings improvised by people in iterative rounds (Barlow 1994), called on to fulfil some tasks and left in the background at other times. Sense-mades involve assembling coherent ideas, which sometimes – but not always – may appear as the 'structures' of knowledge suggested by cognitivist thinkers such as Brookes (1980).

Beyond that, however, such structures and coherences are not permanent edifices. They are transitional – impermanent not in a long-term sense that they must one day inevitably change as context and experiences change, but impermanent in an immediate sense that they are made and remade differently all the time (Orlikowski 2002). Their apparent permanence is misleading. People will often re-use existing patterns, making recurring structures which *look* permanent. Sense-mades could be imagined as provisional theatrics, raised and enacted, then dismantled. If a particular pattern is often enacted, this is not because it is permanent so much as because it is popular. Patterns may be re-enacted, or replaced. They reflect structures, but as transient instances, like snowflakes. Sense making, even of familiar territory, is always improvised, drawn together, and subject to changes and rearrangements.

Learning to live with gap

At the start of Section 7.2, I promised to show why ‘truth’ is a goal of sense makers which cannot be achieved. Here, I explain why this is not necessarily a problem.

Much of my effort in this chapter has been to show that gap is everywhere. This is not an epistemological disaster, because people ‘smooth over it’. When making sense, people aim for “plausibility rather than accuracy” (Weick 1995, p. 55). Returning to a process I described in Chapter 5, people dismiss differences inherent to situations, in order to create patterns and make sense. They call gaps “good enough” (Chatman 1999), delegating differences to categories in which they are perceived as ‘the same’ – not different at all.[78] They bridge the gap. This is about perception: perception that there is no gap; perception of familiarity or safety; perception of sameness. Dervin once criticised how “assumptions about reality are reduced to an impossibly simple choice – either reality is orderly or it is inaccessible and chaotic” (Dervin 1999a, p. 328). As a solution, she proposed that we learn to make sense of a reality which is sometimes chaotic and sometimes orderly. Similarly, assumptions about humans are often reduced to a dichotomy: either we can accurately perceive reality or we cannot. I propose a solution which has the same kind of self-evident pragmatism as Dervin’s: *We perceive reality accurately enough to get by.*

As described in Chapter 6, recursive connections between experiences and descriptions operate as a *mangle of practice* (Pickering 1993), in which one’s experiences modify one’s theories, and vice versa. Dervin describes a “dialectic dance” (1999b, p. 735) – “not a single explanation but a series of explanations

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[78] A key distinction between ‘gap’ and ‘difference’ however, is that gap might be bridged, but it is not always so practical to try to ‘bridge’ differences between things. Dervin points explicitly to gaps for which information or messages can serve as the answer: “gaps regarding the characteristics, aspects, or dimensions of self, others, objects, events, timing, spacing, causes, consequences, and what-ifs” (Dervin 1989b, p. 225). For such situations, bridging is a useful metaphor for sense making. It is harder to see how (or why) one would ‘bridge’ differences between my cat before (awake) and my cat now (asleep).

anchored in a series of dialectical considerations focusing on commonnesses and contests" (Dervin 1999b, p. 736). With such comments, however, Dervin appears to be thinking mainly of series of interpretations *from multiple perspectives*, that is from various people considering a situation; she comments that these series could converge, but that divergence between people's perspectives is not necessarily error. By contrast, Deleuze points out that one's own sense making and experiences are series which orbit each other but never converge. For renal patients, the mangle of practice as I described it in Chapter 6, offers hope that one gradually approaches truth.

Dervin and Frenette suggested that "[s]ense-making is gap-bridging" (2003, p. 239). We have already established that gap is inevitable and that sense making may have more to do with 'feeling alright' – on familiar ground, relatively sure of what to do or say. Physical matter, seen at the level of atoms, appears more as space than material. Similarly, oft-used meaning-networks are operationally stable at our level of magnification. That is the 'stability' of familiar sense making. Although people sometimes 'need information', the metaphysical / ontological / epistemological and linguistic gaps surrounding us cause little trouble. Everyday life is lived at a level of magnitude (if you like) where they are not even apparent.

> *Gap is not some earth-shattering event, rather an everyday occurrence - an axiomatic mandate. [...] gappiness is an assumed 'constant' of the human condition.*
>
> *(Dervin 1991, p. 62)*

Conclusion

The ideas explored in this chapter form a second layer of discussion building on Chapters 5 and 6. In Chapter 8 I will demonstrate why the theoretical abstractions presented here have very practical outcomes.

In various ways throughout this chapter, I have described tensions between specificity and looseness. To start with, I explored how, although (loose) generic information is valued, explanations in the discussion groups were almost always embedded in detailed descriptions of particular lived experiences (specifics). Meanwhile, such narratives contributed to a rich collection of details whose variety created looseness again, and whose complexity could enable creative, situated sense making. I called the collections*, fields (or gardens) of possibilities*. They enable the interplay between individual and social sense making, where having access to widely varied possibilities via social interactions improves possibilities for flexible sense making by individuals, and for mutual recognisability of meanings between people. Making sense using elements of meaning from such social sources involves drawing together transient networks of pre-existing meanings, choosing[79] which elements to bring forward according to the situation. For their use of familiar elements or patterns, theories created in this way are recognisable to others as meaningful, yet may be conservative or innovative depending on how constituent meanings are combined.

Contributors to online discussions moved explanations from generic to specific, in order to understand their own situations, but also from specific to what I called 'localised generalisations', as they became able to make use of whatever 'play' they were able to find in their own situations – and thus became able to contribute to group understandings of the range of normalities experienced by group members.

A dynamic emerged between being able to describe situations in *specific* ways, paying attention to the details of a particular case, and being able to describe situations more *broadly*. This is a dynamic which permeated the analysis through to the level of language, in which specificity is useful to describe the particular, while vague, transferable meanings allow people to communicate with each other, albeit with necessarily imperfect understandings. Sense makers strike compromises between perfect understanding and workable understandings.

Since gap is a central metaphor for Dervin's descriptions of Sense-Making, I spent some time exploring all the levels at which understandings could be 'spoilt' by gaps: words falling short, reality shifting, up to and including the edifices of knowledge becoming at close view, squirming masses of viewpoints and options. I argue that

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[79] Sometimes such 'choices' may be forced by structuring relations such as convention.

since gaps are ubiquitous, sense making cannot be dependent on their removal. I explained in Chapter 5 how, if we look closely at anything, differences emerge; in Chapter 6 I demonstrated how people discover the differences and details of their situation (and begin to make use of them in workarounds). In this chapter, we have looked very closely at understandings and descriptions, and it is no surprise to again find teeming variation with great chasms separating differences. Not to worry: physics has shown us that solids hang together very nicely, despite the gaps which we 'know' to be there.

Instead of ordered, stable edifices of knowledge, I have described knowings as assemblages or transiently gathered networks. Order may sometimes be inherent in reality, but more clearly, order is inherent in people because we look for patterns, create patterns, make sense with patterns, and do all we can to find patterns. Meanwhile, looseness and flexibility are useful. They allow us to move meanings around and create new theories. They allow us to communicate with each other. And they allow us to make jokes and have some fun; as you might have gathered by now, some dialysis patients place great value on jokes and fun.

Chapter Eight: Implications

for research and professional practice

So what?

(Silverman 2005, p. 70)

The discussion so far has become increasingly philosophical. I now aim to show how these philosophical issues affect practicalities. For each of the three aspects of sense making that I have described in the last three chapters, I will first explain theoretical implications for research, then practical implications for patients and health practitioners. Finally, I discuss possibilities for patient training and opportunities for LIS professionals.

In so doing, I emphasise that training matters, but that the key to situated sense making is enactment, which requires commitment to ongoing support of the enactive relations of care between patients, clinicians and family members, even for so called passive patients. I bring forward three main reasons why patients' sense making matters: compliance, safety, and happiness.

8.1 The implications of pattern making

In Chapter 5, I discussed *patterns* in the form of repetition and difference. In threads, repetition enabled the formation of norms and conceptions of normal. It allowed people to identify what was normal for others, while repetition of tones across posts provided emotional guidance. Repeated contact with ideas and experiences developed familiarity, helping people to feel ‘alright’ about situations. Meanwhile, difference emerged as a dynamic partner to repetition, indicating one’s location in the range of possibilities. Difference also opened out spaces in normality where social understandings could shift and new meanings could develop.

Pattern recognition in sense making allowed people to perceive issues in their own lives as either background or foreground, settling the background into routines which do not need to be re-examined. In this way, life could become less detailed.

Implications of pattern making for researchers

When he described pattern finding processes as filtering or recognising cues, Weick drew attention to foregrounded problems. I view construction of background as similarly important for sense making. *Backgrounding,* involving repetition over time to create familiarity, enables parts of life to pass unexamined. This raises repetition and time as subjects for continued research which may make new contributions to understanding everyday life (Savolainen 2010b).

The role of emotions in sense making

In the analysis of patterns, emotion emerged as intrinsic to sense making. In her own work Dervin explicitly positioned emotions as “information bearers in a confluence of sense-making elements” (Dervin & Reinhard 2007, p. 79). This is a contrast to perceptions of emotions as something which *accompanies* stages of information behaviour processes (Kuhlthau 1985; Mellon 1986; Nahl & Bilal 2007), which hinders information seeking or upsets ‘information processing’ (Kim et al. 2007; Kuhlthau 2004; Mellon 1986; Nahl 2005; Savolainen 1995) or which might prompt or support particular activities or goals (Kuhlthau, 2004; Nahl, 2005; Savolainen, 1995). I described this conceptual shift in Chapter 2 when I reviewed literature on sense making. There, I commented that it was relatively rare for authors to examine emotions as informational or intrinsic to sense making (exceptions were Dervin & Reinhard 2007; Dougherty & Drumheller 2006; Kramer 2009; Olsson 2010b; Veinot 2009; Veinot, Kim & Meadowbrooke 2011). My research provides some details about how emotions are 'informational', demonstrating the potential for continued research in this area.

Implications of pattern making for clinicians

Patients, their companions, and health professionals all need to be able to find relevant patterns, theories, and norms, including about how to feel. But patterns cannot emerge until a person has access to a *collection* of data, allowing comparison – this means that the word of a specialist might not be enough, not because it is not authoritative, but simply because more voices are needed. Finding similar advice from other sources builds a sense of coherence and credibility (Genuis 2012 called this *source complementarity*). Access to the experiences of peers helps patients to normalize their own experiences and adherence to treatment (Hughes, Wood & Smith 2009), as I will explore presently. Meanwhile, the patterns which clinicians need are those specific to particular patients. To this end, patients could be taught to keep records of their measurements and symptoms, and encouraged to discuss them with clinicians (Street & Haidet 2010).

Time and repetition

Familiarity and consenses require repetition to develop. My research underscores that people need time for such repetition to occur. Moreover, networks of meaning – connections between ideas – are strengthened by repetition as people successfully draw ideas together and see them drawn together by others. In particular, problems of information overload experienced by new patients (Bawden & Robinson 2009; Savolainen 2007a) may be allayed by waiting for elements to repeat.

Information provision in single, typically rushed appointments with a doctor or specialist, does not allow for this kind of time to pass nor facilitate much repetition. Researchers estimate that patients remember about half the facts communicated by physicians (Roter & Hall 1989, p. 167). In important interactions, it would be useful to create back-ups of key information. Professionals could, for example, automatically provide people with copies of their blood results and other tests, and make clear written copies of instructions (Smith & Shuchman 2005; Wibe et al. 2011). Patients could expect to take notes, and professionals could help them to do so.

Professionals could expect to have to repeat themselves, and could do so by offering second appointments a day or two later. Alternatively, patients may benefit from the ability to ask questions of known clinicians from home, such as via email (Andreassen 2011; Leong et al. 2005; Neinstein 2000; Neville et al. 2004b; Sondrup et al. 2011) or phone (Partridge 2004). This might allow patients and carers time to reflect and realise what questions they have (Andreassen 2011; Neinstein 2000). Email saved physicians' and patients' time in some studies (Leong et al. 2005; Neville et al. 2004a; Sittig 2003). These are solutions which would require support for clinicians, and attention must also be paid to those patients who are not online (Hatcher 2001; Virji et al. 2006) or not partial to written exchange, for whom the assumption that email interactions could supplement face-to-face discussion might create inequity. Expanding patient-practitioner interactions by email could give health professionals an additional role as tutors who can contribute to patients' learning how to self-care. This is a non-traditional role for health professionals which I will explore presently.

Most people need time to practise being able to express new ideas. It is reasonable to expect trial and error while learning skills or techniques, but unusual to imagine the importance of trial and error while learning how to talk about situations and while working out how one feels. However, people's attempts to pull together theories start off hesitant and uncertain, particularly about a field as complex as renal failure; it also takes time to develop skills for practical tasks, and time even to react to diagnoses. To achieve practical and communicative skills, patients and carers need to allow for their experiences to develop over time – their knowledge of illness and the ill body in question, their understanding of what is normal; and their capacity to theorise about them must develop over time also.

Help with developing emotional patterns

Complex understandings take time to form. People may need cues about how to feel, emotional information about the gravity or urgency of the situation. I have explained how, similar to consenses of ideas, emotional consenses emerged over time, with repetition and reinforcement of tones. Health professionals could be aware of this need for emotional information as well as facts. Nephrologists[80] play a key role in diagnosis, and therefore also in early patient orientation, providing hope (Latos & Schatell 2003). But *telling* a patient how to feel – 'don't worry' is a classic example – may not be as effective as discussions of clinical details *accompanied by cues and tones* which indicate calm or urgency. Attempts to 'give' emotional information mirror the difficulties inherent with all attempts at information provision: that information operates as a construct whose components must form *in situ*, rather than an object which can be provided.

The need for emotional cues may suggest problems with professional distance if such cues are suppressed. Studies find that clinicians miss most opportunities to respond empathetically to patient emotion (Hsu et al. 2012). Veinot called for basic counselling training as part of development of the reference interview by librarians; something similar for health professionals may support emotional information-sharing by developing skills such as "active listening, paraphrasing, and reflection of feelings" (Veinot 2009, p. 2328, citing Nelson-Jones 2007). However, health professionals already experience tension between professionalism, authority and emotional burnout (Hochschild 1979; McKnight 2007; O'Brien 2011).

The perspective of clinician-as-counsellor may over-estimate the importance of practitioners' provision of support, when it is fellow patients who can more authoritatively understand the feelings and describe the experiences of being a patient. The stories and emotional reactions of fellow patients can serve as models for sense making by newer patients. Health professionals could encourage or facilitate ongoing connections between people in similar experiences. Such connections side-step problems of professional distance for clinicians, while patients

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[80] Nephrologist = specialist in renal medicine

and carers provide the authentic emotional cues of those who know by experience "how it feels" (Hughes, Wood & Smith 2009). I will return the potentials of peer support later.

Frequent comments in the groups I studied suggest low morale is an issue in some dialysis clinics (Allen, Wainwright & Hutchinson 2011). Patient morale matters, first because the capacity to 'feel alright' about dialysis has been identified here as an intrinsic aspect of sense making, and also because of the tendency demonstrated in Chapter 4 for people to pick up on each other's feelings. Clinicians need to be aware of morale in clinics in general and in particular need to avoid the placement of relatively healthy patients in sessions populated by the very ill.

Discontinuity in care

The importance of patterns for people maintaining sense suggests problems with medical environments characterised by discontinuity (Olson 2009; Parliament of Australia Senate & Marshall 2005; Tong et al. 2009). People need time to develop links and make sense of the spaces and equipment around them, especially in the alien surroundings of hospitals and dialysis clinics (Purtilo & Haddad 2007). Once established, these connections would ideally be maintained to minimise the constant sense-making required of ill people. Soltner and colleagues (2011) reported better patient satisfaction and reduced anxiety from continuity of care by anaesthetists. Planned continuity of care would need to be supported at the level of policy and funding (Dunston et al. 2009), and runs counter to trends in modern health systems planning. Hospitals could provide a form of continuity via a coordination service in which a single staff member oversees a patient's care trajectory[81], or provide more care in patients' homes.

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[81] Discontinuity is a problem for staff as well as patients (Manidis 2013). Practitioners are frequently interrupted and may see hundreds of patients a week, raising a discussion beyond the scope of this study.

The strategies I have presented here to support pattern recognition involve producing repetition over time, providing models, and reducing discontinuity. Repetition over time allows people to develop familiarity. Models show patients and their companions what patterns to look for and how to interpret them. They can include providing a sense of what normally happens in particular situations and enabling access to authentic cues, such as from experienced peers. Reducing discontinuity in care may protect familiarity, maintaining elements backgrounded by patients, about which they don't have to worry; these are familiarities which patients may have struggled to achieve.

8.2 The implications of experiential brutality

In Chapter 6, I explored how people develop 'true' understandings via rounds of experience, which I called 'brutal' to emphasise that the process can be uncomfortable or even painful. In iterative rounds, experiences turned theories into well-honed, useful and familiar understandings. In this way, experience is a key source of authority and certainty. People brought together various kinds of informative elements like measurements and sensations to understand situations. This allowed them control over their situations – to a degree. An example was of a contributor learning the location of her veins and the feeling of infiltrating herself by putting the needle in too far. I also described how, as people developed detailed understandings of situations, they found 'the play in the system' and began to identify opportunities for flexibility and fun.

Implications of experiential brutality for researchers

Iterative rounds expressly involve physicality within sense making, providing the detail alluded to by Dervin's mention of the sense maker having a body. But they involve more than bodies; experiences which refine and modify understanding could include situational factors such as space/place, equipment, time, and the reactions of other people. Importantly, researchers should note that iterative rounds do not reduce sense making to problems involving information.

Terms like ‘information needs’, ‘information sources’ and ‘information seeking’ have a tendency to isolate parts of sense making scenarios, while silencing others. Researchers often investigate information needs in one study, leaving information seeking to another, and ignoring the interweaving of available information sources. Using the term *information* belies the richness of situations, where remarks, pains, and realisations are interwoven with people’s determination, curiosity, aversion and surprises – affecting and being affected by each other in real-time. When one is putting in a needle, the dialogic aspects of sense making come to the fore: experiences, emotions and understandings are entwined in the situation as it unfolds. The implication for research is a need for researchers to continue to look for how people make sense, sometimes involving information-as-event(s), but perhaps without talking about information at all (Solomon 1997b).

Implications of experiential brutality for clinicians

Experience as teacher

> *When [...] patients can notice and verbalize body experience, the health-related teaching they receive is usually less nuanced than their own embodied awareness.*
>
> *(Swartz 2012, p. 15)*

I described how through trial and error, people learn ways to express experiences. Evidently, trial and error are also needed for patients and carers to develop technical or manual abilities. Therefore, patients should be encouraged to *expect* a need for trial and error to allow physical, emotional and cognitive understandings to develop; more basic than that, they need to expect a need for time, and should be encouraged to pay attention to their experience. Through trial and error, patients and carers may develop more control over their experiences, as they learn how their body responds to foods, medications and treatments (Kralik et al. 2004). By understanding the symbiosis between their body and their illness, and learning how to communicate about it, they may also develop authority, and may take on an active role in their own care.

Experience as enforcer

In Chapter 6, the exploration of interactions between realities and theories revealed the importance of having a sense of control, and beyond that, finding looseness within which people could have fun or play. Having fun or finding areas of control in some way balanced patients' experiences of being controlled by pain, physicality, doctors, dietary regimes and schedules of medications and treatments. Meanwhile being able to 'feel alright' emerged as integral to feeling that things made sense. Therefore there is a value in helping patients find the spaces available to them within compliance, requiring a tolerant view of non-compliant episodes. Though non-compliance can lead to feeling ill rather than 'alright' and more depressed than before, non-compliant episodes already punish the patient by making them feel the brunt of renal failure, "a feeling like no other" as my husband Gregory describes it. Non-compliant episodes may allow the patient to develop their own experiential authority concerning where and why they do not have freedoms as well as where they do.

> *When I got back to the states [after traveling four days without dialysis] I was really feeling like needed dialysis - but it was worth it. That experience also showed me/convinced me that I really did need dialysis, at the time that is something I hadn't come completely to grips with.*
>
> *(Dialysor[82], IHateDialysis)*

Patient as an information source

> *Discussion between doctors and patients has long been regarded as the vehicle by which much of the curing and caring of medicine is conveyed.*
>
> *(Roter & Hall 1989, p. 163)*

The expectation expressed in this quote from Roter and Hall appears reasonable until you consider that health practitioners see patients for only a fraction of the hours in

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[82] This contributor prefers to be called a dialysor than a patient.

the week. During all the rest of the time chronically ill people continue to deal with their illness (Department of Health 2004). In Chapter 6, I identified a range of information sources other than practitioners, including information obtained from lived experiences, from bodies or from the machinery used to tend to patients' health, as well as information related to changes over time. Sources of authority included physicalities such as pain, medical alarms and equipment, which also demonstrated power to constrain or enforce patients' compliance to medical advice. This is a healthy situation, as it suggests that medical equipment is useful to patients, that patients are not constantly dependant on clinicians during day-to-day life, and that to a certain extent, patients can develop their capacities to interpret the sensory information of their own bodies.

Peer guidance

One response to complex situations is to attempt to limit informal communication and control access only to formal information (van Vuuren & Elving 2008). But other authors recognise the value of people talking things through with their peers (Coburn 2001; Volkema, Farquhar & Bergman 1996). Access to experienced peers is of ongoing importance to renal patients (Hughes, Wood & Smith 2009; Sondrup et al. 2011; Veinot et al. 2010a). Hearing the experiences of peers helps them to normalize their own experiences (Hughes, Wood & Smith 2009); and peers are able to present advice with the understanding of personal experience (Ljungdalh & Møller 2012). Peers are authoritative specifically because they have lived through brutal experience. They have more to offer than that however, so I will discuss them again in the next section.

Patient as collaborator

All kidney patients are expected to accept some responsibility for their care including adhering to treatment plans and accurately reporting symptoms (Latos & Schatell 2003). This is crucial because changes in the health of renal patients are ongoing (Godbold 2010; Purcell et al. 2004) as is the need to adjust treatment. Information related to changes is required by both health professionals and patients. A patient's ability to communicate their experiences and preferences helps practitioners to deliver care (Street & Haidet 2010), but potentially, patients could play more than this passive role. The experiential information available to patients due to their position of simultaneously *knowing about* and *being* the body in question (Mol & Law 2004) raises possibilities to support patients who wish to develop their understanding of their situation and their ability to communicate with health professionals to enable active collaboration in their care.

By virtue of being embedded in context, some patients or their family members can operate as an information locus: able to oversee information such as measures of weight and blood pressure, able to generate information related to the patient's sensations (Mol & Law 2004), able to summarise information about the trajectory of their illness (Olson 2009), and able to remember what medications or treatment settings they should receive. Patients are intimately motivated to focus on their single case, and this kind of patient collaboration can improve compliance (Smith & Shuchman 2005). Given changing staffing and the segmented disciplines involved in renal care, patients and their partners repeatedly reported finding themselves uniquely positioned to know the details and history of their own medical case. Patients and their companions can be involved in the enactment of safe care, by monitoring continuity of care, and getting to know good practice (Godbold 2013; Hor et al. 2013; Saibu et al. 2011).

This echoes comments by Julien (1999) and Dervin (1992) concerning recognition of the expertise of the "user", but self-evidently, it is a different case to the relationship between librarians and library users. The inherently uneven power dynamics between patients and clinicians (Lupton 2003; Måseide 1991; Silverman 1987) have greater consequences than those between librarians and library users (Radford & Radford 2001). Not all patients can successfully undertake all aspects of collaboration, which include being able to learn, remember, record, and explain. Being sick makes it harder to learn (Wong et al. 2009), and renal failure in particular affects clear thinking (Bass et al. 1999). Many renal patients are elderly and therefore presently of a generation expected to fill the role of the passive patient (Parsons 1951a, 1951b). Meanwhile, some clinicians dislike active patients (Stacey et al. 2009) who can be misled or wrong (Broom 2005) and ask annoying questions (Kopelson 2009; Wright & Morgan 1990), while some clinicians and academics are suspicious of ever ascribing 'expertise' to patients (Prior 2003; Wilcox 2010). So the potential to become an actively collaborating patient, with its associated sense making benefits to clinicians in terms of improved clinical outcomes, and to patients in terms of safety, compliance, control and assertion of individuality and identity, is for the time being, a fragile proposition.

* * *

The fundamental connection from experience to authority is valuable to renal patients and their companions, because over time, they may develop their own authority. This can be supported by encouraging contact with experienced peers, taking a tolerant view of some non-compliance, and particularly, by encouraging patients and carers to view their experiences as informational. In Section 8.4, I will develop opportunities for clinicians and information professionals to support patients in their contingent, responsive relationship with real-time information relating to their treatments.

8.3 The implications of complexity

> *Improvisation suggests a process of continuous change that is realized through ongoing variations that emerge frequently, sometimes even imperceptibly in the slippages and improvisation of everyday activity, that involve simultaneous composition and execution or repeated acts of learning that enlarge, strengthen, or shrink the repertoire of responses.*
>
> *(Purser & Petranker 2005, p. 186)*

In Chapter 7, I explored what I called 'complex knowing'. I put forward sense making processes as necessarily embedded in complexity, using the term in the sense described by the Oxford English Dictionary (2011), a situation which has "interconnected parts or involved particulars" . I described how, despite our preferences for simple, ordered sense, fitting accurately into patterns, people make sense *while leaving complexity complex*; 'good enough' sense, which is sometimes better than being accurate. This kind of sense can be flexible and responsive *because* of its lack of specificity.

I described three sets of tensions between specificity and looseness. First, loose, generic information was valued, but people then wove it into specific descriptions of particular lived experiences – they moved explanations from generic to specific. Second, people moved from specifics back to localised generalisations as they became able to describe their own normals – and made use of the looseness or 'play' inherent in their own situation. Meanwhile, individual stories contributed to a rich collection of details whose variety created looseness again, and whose complexity could enable creative, situated sense making. I called the collections*, gardens of possibilities*, which expose people to variations, improving their possibility for flexible sense making, and for mutual recognisability of meanings between people.

What this means is that pattern-finding on its own is a restrictive kind of sense making. Because reality is complex and evolving, we need multiple and sometimes contradictory understandings, to enable looseness and flexibility. Looseness and flexibility are useful because they allow us to move meanings around and create new theories. They allow us to communicate with each other, to make jokes and have fun, and to comprehend complexity.

Implications of complexity for researchers

Most important to researchers is the centrality of *socially repeated connections* replacing *fixed facts* as the basis for lasting knowledge. This kind of knowing can be accessed for research because such connections are manifested externally in observable connections – for example, in speech and in writing (Gherardi 2008).

Because connection making is improvised, researchers must exercise caution if they wish to establish bodies of stable knowledge structures. Although instances of knowing may make use of familiar and pre-existing networked elements, this by no means implies that they are used in stable ways, nor that the cultural store of such knowledge collections is stable or enduring. Examples of knowledge are not so much selected from a knowledge-library as invoked[83]. Searches for structure should be tempered with understanding of the constant changes inherent in knowledge connections. To be able to theorise about relatively longer lasting sets of connections (structures) one would have to look for repeated manifestations of connections which might suggest longer-lasting patterns. When structures appear to change, this may not demonstrate a change in practices so much as the flexibilities inherent in complex, multiple knowings.

It is common for researchers to investigate demographic or situational variables which may allow one to predict or explain situations. However, the elements which people weave into situated explanations are not predictive in the sense that particular variables might be said to be present or absent and therefore likely to affect sense making or not. Rather, contextual elements depend on being noticed by the sense maker and then incorporated into the conversation; they need to *cue* in order to become *cues* for sense making[84]. What may be more predictable is that people re-use the structure-arrangements with which they are familiar, using the vocabulary of words and activities at their disposal, and are less likely to invent new ones. This means that norms and habits are on the research agenda, as are the structural influences previously eschewed by Dervin (1989b) in relation to the information practices of individuals. But these are still only relevant as elements of interest, rather than predictive variables. Dervin found that structural influences might be transcended by individuals at any moment, which is quite true; nonetheless, they may also be appropriated at any time, or (and these may be more likely) included without being noticed, found to be natural, or found to be irresistible. Instead of trying to predict what particular sense might be made, researchers should attempt to understand the environments and timeframes conducive to sense making and the range of information content people might need.

Finally, the preceding discussion highlights problems inherent in conceiving a sense maker in isolation from their social systems. Though a patient makes sense

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[83] This is similar to Schutz's view of cultural knowledge as constantly renewed by and dependant on enactments (Heritage 1984, p. 56).

[84] Harold Blumer (1969, p. 16) makes a similar point about interpretative process people use in dealing with the things they encounter. I read Blumer just after submitting this thesis and noticed strong connections to his work which I will need to explore in future writing.

individually by drawing together networks of meaning, the meanings they draw on hang in a communicative system involving patient, family, friends, fellow patients, colleagues and health care professionals (Collier 2012). To understand patients' sense making, researchers and practitioners must pay attention to these communicative systems.

Practice theory

LIS writing concerning *information practices* did not originally refer to practice theory (Anderson 2007; Folb et al. 2010; Haider 2011; McKenzie 2003b; Olsson 2010a). Instead, the term *information practices* emerged to develop social constructionist alternatives to *information behaviour* (Savolainen 2007b). Only recently have the ideas common to the literature of practice theory begun to appear in LIS information studies (Cox 2012; Talja 2010) in connection with information practice (Bonner & Lloyd 2011; Cox 2013; Haider 2011; Lloyd 2009; Pilerot & Limberg 2011; Savolainen 1995, 2008; Veinot 2007). Less common are LIS uses of practice theory in connection with information literacy (Lloyd 2007, 2010, 2012), or with connections to the concept of communities of practice (Cox 2012, 2013; Talja 2010). This thesis is the first connection I know of between sense making and practice theoretic perspectives on knowing.

Though there is variation between writers associated with practice theory, commonly *knowing* is connected with *doing*; knowing and doing arise from practices and reiteratively rebuild practices from moment to moment. Practices are conceived as in-between habit and action (Gherardi, 2008). Practice theorists like Silvia Gherardi (Gherardi 2000, 2008, 2009a, 2009b; Gherardi & Nicolini 2000; Gherardi & Nicolini 2002) and Theodore Schatzki (Schatzki 2001, 2012; Schatzki, Knorr-Cetina & Savigny 2001) therefore move the iterative processes that build and rebuild *knowing* from minds to bodies and beyond, including but not limited to language, movements, sensations, expectations, and so on. For emphasising verbing over nouns they can be connected to Dervin (1999b); but where Dervin indicated that the mind was not the only faculty of sense making, practice theoretic approaches successfully induce their followers to develop understandings of embodiment and action. My research contributes to demonstrations of the utility of this important shift from *static knowledge* in the mind to enactive, embodied *processes of knowing and feeling*.

Implications of complexity for clinicians

From generics to specifics

> *[T)herapists working with clients struggling to find sense in loss would be well advised to [...] help the bereaved integrate their experiences into a purposeful and coherent life narrative.*
>
> *(Holland, Currier & Neimeyer 2006, p. 186)*

To become useful, information often needs to be connected into the specifics of one's situation. It must be contextualised by processes including trial and error, discussion and argument (Solomon 1997b, p. 1125). This study echoes Dervin's (2003) suggestion that it is these links and connections that lead to our being informed. In my sequential analysis of threads I showed how often people embedded their ideas within descriptions of lived experience. They provided the "situated links" (Dervin 2003, p. 305) that allowed their ideas to be understood by others, later and elsewhere. Such informational links may be few, such as when we first read a description of the function of the kidneys and connect the generic sentences to our everyday experiences of urination, and a vague location in the abdomen. A renal patient becomes aware of complex relations between diet, fluids and their kidney function, drawing connections to particular foods they eat and sensations or blood results. Renal surgeons develop detailed connections between medical diagrams and physical topographies of bodies opened for surgery. So people develop informational connections according to their experiences and needs.

Patients and carers are often provided with general information during medical appointments, including statistics, medical explanations and brochures. These are invaluable, particularly for helping people to understand *why* things might be happening; but people also need to know *how to proceed*. If I develop renal failure, this will mean creating complex, changing links from generic explanations of how kidneys function and how renal medicine works, to implications for me in my body, in my life, at my work, with my family and my pets and my house and my government's health system. This is work which must be done by me and my family either with help or on our own.

This is especially important for the chronically ill who must develop a lifestyle of compliance to medical advice. Compliance involves taking medications, accepting treatments, conforming to diets or exercise regimes, attending appointments and submitting to tests (Smith & Shuchman 2005). Compliance is a matter of concern in medical literature because of the correlation between non-compliance and patient morbidity or mortality (Denhaerynck et al. 2007; McCarthy, Shaban & Fairweather 2010). Patients must also be compliant to qualify for some treatments, such as for transplants. The medical literature usually looks to patients for the reasons for non-compliance (Trostle 1988) proposing factors such as psychological reasons, sociological issues to do with identity, and problems with literacy or information provision (Cukor et al. 2009; McCarthy, Shaban & Fairweather 2010; Smith & Shuchman 2005) – imagining that non-compliant patients 'must be crazy, troubled, or stupid'. Compliance is viewed as a default state that normal people could maintain easily. I argue that for renal patients, compliance is complicated and requires ongoing maintenance to constantly renew translations from generic guidelines into specific enactments in the face of the potential for slight or significant change.[85]

Statistics and brochures provide useful standardised descriptions using generic illustrations and examples. They are useful because they express normalities. But they are limited for the same reason – because they lack particularised connections to the specific case of the reader. People consider the relevance of generalised information for their particular situations, and judge its legitimacy (Veinot 2009, p. 2325). As their need for detail develops, people find less use for generic information which they dismiss as 'one size fits all' (Godbold 2013; Neal & McKenzie 2010). Clinicians assist patients in making the complex connections from general into the specifics of patients' lives (Costantini 2006; Sondrup et al. 2011) by giving specific

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[85] As well as *being* compliant, patients must *perform* compliance to maintain the faith of clinicians despite the vagaries of living, begging further study.

rather than general instructions (Roter & Hall 1989, 168) *when the specific instructions work*. For this, clinicians need understandings of patients in the context of their families, peers, preferences and feelings (Smith & Shuchman (2005). As I will discuss later in this section, peers can help each other to develop individualised solutions to problems (Huh & Ackerman 2012), and importantly, experienced peers demonstrate by their example that these connections from generic explanation to complex, lived, changing specificities *can be made* (Ouellette, Achille & Pâquet 2009). Patients and their families also need to allow time for trial and error, as they hone ideas and suggestions into something that works for them; and they need practical advice on how to achieve behavioural changes in their daily life (Seligman et al. 2007).

An example once again involves my cat. When he was diagnosed as diabetic, I was shown how to use prick test equipment to obtain a reading of his blood glucose levels. I was 'informed' with a great deal of what appeared to be specific information. On trying it at home however, I had to work out how to hold the pricking equipment, reassure my cat, and find the 'sweet spot' on his ear from which blood could be easily obtained. These are specifics of my own hands, capabilities and bodily topology, and those of a struggling cat. They are personal connections some of which still need to be made each time I attempt a blood test, though gradually it has become an everyday part of our shared routines.

This process of personalisation needs time and experimentation; it is not the work of moments, achieved in a single session of information provision, but calls for building and testing of specific solutions. As I tried different approaches with my cat, I turned for advice to the 24 hour online communities for feline diabetes. In the case of renal patients, the need to create and test specific links suggests the importance of opportunities to workshop solutions with clinical staff or peers.

Enlarging the field of possibilities

I have described how people make sense by forming assemblages of meaning, drawn from the possibilities with which they are familiar. These 'fields of possible meanings' contain fragments of ideas, phrases, vocabulary, and whole stories told them by others, which may be remembered as they become relevant to the person's experiences. Variations in expressing existing ideas increase people's ability to be flexible in their discussions. Sometimes this may enable people to find new perspectives, but more importantly for patients, this may allow them more capacity to express preferences and negotiate their treatment. It may also help them to respond to changes.

Sources for the field of possibilities

Renal patients obtain much authoritative information from clinicians, but patients only see clinicians for a tiny percentage of their everyday life (Schatell & Witten 2006 suggest 8% of an average week, for in-centre dialysis patients). This research has demonstrated the importance of contact with many perspectives. Here, I identify a range of possible sources for new perspectives.

Peers

Ongoing connections with peers and information from print, online and other media sources are all valuable supplements to clinicians' advice, for the potential to find different ideas but even more importantly, in order to find congruent messages across different sources (Chiu 2011; Genuis 2012).

The benefits of speaking with peers emerged in the sense making literature (Coburn 2001; Glanz 2003), while the benefits of peer-mentors to patients are also noted in the illness literature (Armstrong & Powell 2009; Colineau & Paris 2010), and specifically in the renal literature (Morton et al. 2010; Veinot et al. 2010a). I have already discussed how patients value the exchange of descriptions of experiences (Armstrong & Powell 2009; Kivits 2009; McCaughan, Parahoo & Prue 2011; Ormandy 2008; Tong et al. 2009), and benefit from information which emerges during general conversation (Pettigrew 1999; Wong et al. 2009). Sense making in communities can encourage people to "question their assumptions, challenge their frames, and continue to improve their practices over time" (Coburn 2001, p. 163). Patients have a different kind of authority to that of clinicians (Hartzler & Pratt 2011; Wilcox 2010), partly because experienced patients know 'how it feels', but significantly because patients know how to make the shift from generic information to specific enactments of compliance, which clinicians have generally not had to do. By workshopping the enactment of care, peers can teach them how to survive, like Chatman's "lifers" (Chatman 1999). Information shared between peers may not always be medically accurate, and the norms that patients learn from peers may not reflect clinical ideals, questions begging further research. Yet, in contrast with fears that patients may go renegade with self-sourced information (Broom 2005), the online communities I studied maintained dominant biomedical perspectives on treatment (similarly noted by Copelton & Valle 2009) and the ultimate authority and power of trusted clinicians. Importantly, patients can and do help each other to make sense, which involves establishing patterns, creating links from general ideas to lived specifics, and developing a sense of normality with which they feel satisfied.

Peers online

Online health support groups have characteristics which make them ideal for such peer networking, and have been found to have beneficial effects on participant self-care and wellbeing (Kim et al. 2011; Leung, Joyce Ma & Russell 2012). Large enough groups offer support at all hours, for people to access in their own time. Members can go online from home rather than having to travel to a support group location (Colineau & Paris 2010). Online peer groups allow people to ask questions and discuss issues as they become relevant, and to encounter anecdotes by chance. This flexibility is ideal for people who may often feel fatigued or ill and who already use up a lot of their time with treatments (Polaschek 2003).

Large online groups offer a wide range of perspectives and advice, increasing the likelihood of finding people with relevant experiences, including rare diagnoses or co-morbidities. They can provide access to peer mentors, as well as the examples of other 'newbie' dialysors as they learn the ropes, and they allow people to compare experiences in different clinics or health systems. They function like information grounds (Pettigrew 1999) where advantageous information might be obtained because of the presence of "weak ties" – people who are not part of one's everyday networks and therefore might have access to information other than that already known to one's everyday contacts. (Pettigrew 1999 citing Granovetter's 1973 Theory of the Strength of Weak Ties). People know enough of each other to be able to offer partially contextualised ideas, having deduced relevant factors by understanding aspects of each other's circumstances.

In terms of providing access to repetition and time, a person may spend hours reading the archives of discussions and can pose questions after they have had time to think about ideas, compared to the brevity of a medical appointment. The archives provide annotated scenarios through the unfolding of contributors' described experiences, accompanied by the commentary of the group (Wright 2005). In Chapter 2, I described the beneficial anonymity of online groups, and the generally supportive behavioural norms in health support groups online, meaning that people can discuss intimate and stigmatising issues with a level of candour unlikely in face to face support groups (Colineau & Paris 2010; Rasmussen, Dunning & O'Connell 2007; Seale et al. 2010). Dialysis clinics already bring peers together, but the need to maintain ongoing relationships may restrict people's willingness to express negative emotions or perspectives (Goffman 1963). A patient online could be describing problems with their bowels or their sex lives or criticising their care providers and receiving suggestions and support, without threatening their day-to-day relations with family members, fellow patients and clinic staff (Goffman 1963).

It may be tempting for practitioners to join online groups themselves or to set up a local group; such efforts may be counter-productive, if they reduce patients' feelings of talking frankly in a safe space away from medical surveillance; moreover, it misses the point that clinicians are not able to provide the same kind of assistance as peers. Instead, practitioners could direct patients to existing online groups; further research to ascertain the quality of information provision and support online may reassure clinicians of their value, bearing in mind that sharing stories and viewpoints may be useful despite the objective accuracy of particular messages, if on the whole, the thread provides feedback on what is useful or accurate in others' remarks.

Household members

Understandings are built out of regular, repeating ideas. Co-habitation represents a likely environment in which ideas may be echoed and reworked between cohabitants. In particular, partners (married or otherwise) may "share a sense of identity, commitment, and purpose […m]eaning-making and couplehood are thus closely linked" (McGovern 2011, p. 680). When a doctor discusses a diagnosis, or explains how to care for a wound, or when nurses do handovers, it makes sense to include patients' companions in the discussion, where appropriate (Smith & Shuchman 2005). This aligns with other research findings that accompanied patients are likely to benefit from the extra information that their companions remember (Jansen et al. 2009); that the needs and influence of household members can affect patient compliance (Fix & Bokhour 2012; Smith & Shuchman 2005; Tijerina 2009) and that patients' companions such as their partners wish to be kept informed by doctors but have trouble being included in consultations (Olson 2009). Consideration of caregivers' roles is relatively rare to date, especially in the renal literature (Gayomali, Sutherland & Finkelstein 2008), and tends to focus on caregiver burden and their need for informational, emotional and substantive support (Beanlands et al. 2005; Gayomali, Sutherland & Finkelstein 2008; Olson 2012 ; Quinan 2005). In terms of their contribution to sense making, only the part they play by seeking and filtering information for the patient has been noted (Brashers 2001; McKenzie 2001; Veinot, Kim & Meadowbrooke 2011).

Clinicians who speak to patients and their companions together create circumstances in which cohabitants might have similar or complementary understandings of what doctors may have said to them. It is advantageous if a family member expresses opposition to plans or treatments directly to clinicians, especially if they are expressed to clinical decision makers, so that opposition or confusion within the family group is known; it will otherwise be likely to manifest at home where adjustments to care or treatments cannot be negotiated with clinicians, and may be negotiated without them. Training may be appropriate for health professionals to develop their ability to interact with family groups and cope with the strengthened dynamics involved.

* * *

Renal patients need to form situated links with enough flexibility for complex knowing. Situated links enable people to manage the complex compliance demanded of renal patients, whereby knowing is linked to safety. Moreover, the capacity for flexibility creates opportunities for patients and their families to find fun despite the inherent discipline of renal life. I have suggested strategies which might support them to do so. By hearing how others make meaningful connections, people can develop a vocabulary of connection making which they might use as situations demand. I have also suggested a range of situations in which clinicians or experienced peers can act as mentors to help with the development of links particular to their particular situations, so that patients and their families are not left to make these essential connections on their own.

In the last section, I will explore how existing training and support programs might be extended to enhance renal patients' capacities for flexible, situated sense making. However, I argue that the key element for drawing out potentials for improved safety and clinical outcomes in health care is ongoing support of patients' involvement in collaborative care, regardless of how well-trained or 'active' they are.

As I have described, the classification of end-stage renal disease is applied when a person has less than 15% kidney function (Kidney Foundation of Canada 2012b; Kidney Health Australia 2012a). At this point, patients need treatment to survive. But when you get to 15% function, you find that the decision to dialyse is more complicated than that. Bodies are complex and people are individual. My husband's transplant is failing, and his kidney function has been under 15% for six months. Yet he is still working in the library and manifests few symptoms of renal failure. He is not a medical miracle, but an everyday example of the need for individual comprehension of illness. Our nephrologists have explained that at present, Gregory's moderate need for treatment is overshadowed by the loss of quality of life represented by haemodialysis.

This is a balance which is renegotiated with his doctors every fortnight. To make these negotiations requires attention and collaboration from us all, as Gregory and I describe his symptoms from the fortnight and what he wants to do, and one or two doctors collaborate with us about whether to start dialysis. One of my contentions in this thesis is that patients and their partners *are necessarily* always involved in such decisions, even if they take a passive stance, because only they know how the illness is manifesting and communicate it to doctors. I believe that supporting the sense making of patients and their companions will not only sometimes help them to be compliant with medications and treatments, but that it may also help them to understand and describe symptoms, and so improve their care.

8.4 Patient training

Wieck, Sutcliffe and Obstfeld (2005, p. 419) talk about sense making as a skill which can be developed. Fully supporting sense making by patients with chronic illness means developing their sense making skills, a worthwhile exercise because renal patients are ultimately the ones whose actions can most readily affect long and short term clinical outcomes (Lidz, Meisel & Munetz 1985). In Chapter 1, I already pointed out the cost of treating kidney failure; a report published by Kidney Health Australia in 2010 estimated that increasing the use of Home Dialysis over 10 years might lead to net savings of between $378 and $430 million for the health system (Cass et al. 2010). Policies and programs which improve patient's ability to self-care are financially important in this context.

Discussion of patient training has become more prevalent in the renal literature in the past decade (Deeg 1980; Fox & Kohn 2008; Iles-Smith 2005; King et al. 2008; Prescott 2004; Tsay 2003; Tsay & Lee 2005; Wong et al. 2009). Advocates of 'empowered' or 'active' patients include national health departments in the UK, US and Australia (Commonwealth of Australia 2010; Department of Health 2001; Hartkopf Smith 2009). Renal patient training has been found to improve patient outcomes such as mental wellbeing, blood test results and slowing of kidney failure prior to dialysis (Bergstrom, Barany & Holm 1999; Binik et al. 1993; Caldeira et al. 2011; Curcani & Tan 2011; Karley, Mantulak & Parsons 1998; Lingerfelt & Thornton 2011; Tsay 2003; Tsay & Lee 2005). Hence, active patients are seen to be safer (Hartkopf Smith 2009) and healthier (Costantini et al. 2007; Department of Health 2001). Moreover, patient training programs have been correlated with reduced frequency and duration of hospitalisation for new dialysis patients (Inaguma et al. 2006) and with prolonged survival pre-dialysis (Binik et al. 1993), both of which represent substantial financial savings for health care systems.

My findings suggest that induction programs for new renal patients should include more than physical skills or factual information such as common symptoms. Patients also need sense making skills and an understanding of sense making processes. Training with the aim of assisting sense making appears in the sense making literature (Louis 1980; Wright 2005). Such training for patients might include developing the perspectives common among experienced patients: that it will take time to develop understandings and gain experience; that ongoing change is normal, and to be prepared for trial and error. Patients need to learn about experiential information, like the feel of a needle properly placed (Swartz 2012). Patients can be trained to take notice of their body and surroundings in order to identify their own conditions for safety (Jirkovská 2008; Swartz 2012). Most patients are taught about norms for their illness and generalised experiences (people tend to do this, they tend to find that); patients and their companions also need to be able to distinguish between themselves and the norms (you have a particular system and you will manifest renal failure in your own way).

Becoming the kind of patient collaborator I described earlier is not something that a patient can do alone: “the active patient is an emergent relationship [between patient and practitioners]” (Heldal & Tjora 2009, p. 1). Active patients who are able to self-care are not created by training so much as sustained by ongoing collaborative relations with practitioners (Mol 2002). Such communication must be approached carefully: pervasive power differentials exist between patients and clinicians, and patients are strategic in their interactions (Chiu 2011; Curtin & Mapes 2001) to avoid becoming known as ‘difficult’ (Hor et al. 2013; Stockwell 1984; Werner & Malterud 2003). Clinicians need particular skills and kinds of awareness if they are to successfully encourage patient-collaborators, which may necessitate training for clinicians (Libert et al. 2007) and cultural change in some hospitals or clinics (Dunston et al. 2009). Beyond that, induction programs might show patients how to work with health professionals, establishing the benefits to patients of being active in their own care (Lidz et al. 1985) covering how to talk with practitioners (keeping notes, making lists) and how to maintain records of symptoms.

In existing renal patient training literature, training is often conceived as short-duration classes (Binik et al. 1993), with allocated training professionals (Department of Health 2001). Other authors discuss the preparation of training materials like DVDs or print materials (Chiou & Chung 2012; Koh & Koo 2007; Robinson et al. 2011). Allocated class times are a good idea, because they can be used to orient patients, and because at the beginning of sense making, people often look for relevant generic information like ‘what normally happens’.

Ongoing or repeated training has been suggested (e.g. every six months, Yen, Huang & Teng 2008) to make up for patients’ reduced “knowledge measures” over time (Yen, Huang & Teng 2008, p. 2927). Beyond forgetfulness, my research shows that the constant change experienced by kidney patients requires ongoing sense making. DVDs, brochures and online training materials are useful here, but such resources are not usually specific. Particularly once they have mastered the basics, renal patients need ongoing access to learning opportunities (Lingerfelt & Thornton 2011), which are responsive to the particularities of their circumstances, and support longitudinal adaptation to change; that this allows repetition of ideas and development of deeper familiarity is an added benefit. Moreover, slow paced, ongoing training could ease the need for rushed induction programs, and counteract problems of information overload (Bawden & Robinson 2009; Savolainen 2007a) experienced by newly diagnosed patients.

Rather than conceiving training as separate from clinical care, clinicians need to be ready to provide everyday training during normal clinical interactions, subject to a patient’s capacities or interest to learn. Ordinary exchanges with health practitioners are opportunities to develop the patient’s understandings and sense that they have a role in understanding their care (Kralik et al. 2004; Smith & Shuchman 2005). In this way, patient learning may be specific, ongoing, and consistent with their clinician’s goals and perspectives (Lingerfelt & Thornton 2011). Kidney Health Australia suggests that nephrologists have limited time for one-on-one education

(Kidney Health Australia 2012d, p. 23) but ongoing training which is woven into normal interactions need not be time consuming. Clinicians could ask for patients' opinions on their own blood results (why has potassium gone up) or what a machine alarm means as it goes off, briefly but constantly workshopping understandings and management techniques (building on suggestions by Costantini 2006). Patients and carers need to see health professionals as resources to help them develop medical understandings in combination with personalised physical understandings. Professionals would need to be willing to be involved in this training capacity. As I mentioned earlier, the literature suggests that many clinicians, like some patients, are uncomfortable with patient involvement in diagnosis and treatment decisions (Broom 2005; Kopelson 2009; Wright & Morgan 1990).

Most sense making occurs away from hospitals and clinics, especially when a patient tries techniques or treatments at home. To support situated sense making in the home, the final session of clinical training for home dialysis patients could occur in their homes (Keeping & English 2001). Alternatively, patients may benefit from the ability to ask questions of known clinicians from home, such as via phone or email, as discussed earlier. Email is preferable, as it allows interlocutors time to consider their remarks, and is delivered in an enduring format allowing repeated reading. One implication of this is again, a place for always-available systems like online discussion groups.

Limitations of training

The discussion in this section is consistent with patient-empowerment literature in which the doctor-patient relationship is re-imagined from that of a passive patient and authoritative clinician (Parsons 1951a, 1951b) to an active, co-production of health care involving both patients and clinicians. But renal medical knowledge is complicated; patients who question their treatments can annoy clinicians (Broom 2005) and can be wrong (Kopelson 2009); learning about medicine frightens some patients (Tuominen 2004) and can be hard for renal patients when they are ill and fatigued (Wong et al. 2009). Moreover, the recent shift towards patient self-care (Department of Health 2001) involves a flawed neo-liberal rhetoric of the patient-consumer taking individual control and responsibility for their care (Godbold 2012a;

Lupton, Donaldson & Lloyd 1991; Veinot 2010a; Veitch 2010). “The new [patient-]consumer is consistently described as competent, as knowledgeable, as expert, and as able to make a critical and necessary contribution at all levels and in all areas of health system development and functioning” (Dunston et al. 2009, p. 45). Patients are not all competent, knowledgeable, expert, critical and able to contribute – nor interested in doing so (Lupton 1997). They are not necessarily motivated or able to be the informational locus I have described. I believe the kind of training and support described here is important, as it was a goal of many contributors to my research, and I will want it, when I become sick. Nonetheless it only serves as an exploration of how sense making might be supported for some people, rather than for all.

Implications for Information professionals

Opportunities exist for information professionals to support the sense making needs of renal patients.

First, are questions related to information provision. Information needs and practices of renal patients have been explored only by a few authors (Bonner & Lloyd 2012; Ormandy 2008). Potentially, particular kinds of manuals and informational resources could be usefully developed and put online or provided to patients in hardcopy – raising opportunities for LIS professionals to create and maintain relevant collections. In particular, I observed young renal patients expressing a wish for information relevant to their age group.

This is the traditional role of information professionals, to archive and provide access to information (Davis & Shaw 2011), in particular, by developing and working with information systems or within “memory institutions [… such as libraries, archives and museums, which] organise and provide access to our cultural records” (Davis & Shaw 2011, p. 207, quoting Hjerppe 1994). We think of our role as providing access to *information* or *knowledge* rather than providing access to *experience* or *skills*. Yet in terms of sense making, experience has a key function as a basis for authority. Experience allows people to develop theories with which they can feel familiar and secure, and experiential authority accords a person the “right to speak” (Heritage &

Raymond 2005). Meanwhile web 2.0 style self-publishing, including blogs and peer networks or online discussion groups, allow people to share experiences, workshop ideas, and post videos in which they demonstrate skills.

Sense making might be supported by actively curating collections of peer experiences which connect people with the experience of their peers, and by directing people to existing online sites. Information professionals could create archives of links to them; help people to set them up, or teach people how to participate in them. Information professionals could also provide a reference support role to discussion groups, for example by developing wikis of frequently asked questions, hot topics, and popular resources.

There are also opportunities to improve existing interfaces or to develop or exploit new technologies and formats to connect people to people. Given the need for variations on a theme, good design might support users' need for vocabularies of sense making: systems might offer 'similar variants', much like digital dictionaries which currently offer links to thesaurus entries, encyclopaedias with their 'see also' suggestions, and online sales databases with their 'people who bought that also bought' lists. Along similar lines, a system might connect a new question with other similarly worded posts, automatically identify useful or popular discussions as they occur in discussion boards, and potentially, connect new questions with these existing relevant discussions (Huh & Ackerman 2012).

Eighty per cent of internet users in the US look for health information online (Fox 2011)[86]. It is impractical to try to reduce patients' uncontrolled information access. Instead patients could be taught to be able to recognise quality, to be able to discuss meanings and to be able to workshop responses. Moreover, much medical literacy training could be *provided* online, either as online tutorials or as online classes similar to Kidney School (Freier et al. 2010; Schatell 2002). Kidney School provides

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[86] Australian figures are not available; however, the two top reported activities by Australians and US adults using the internet at home are comparable: for Australians in the period 2010-11, they were *emailing* (91%) and *general browsing* (87%) (Australian Bureau of Statistics 2011), while in the US they were *emailing* (94%), followed by *using search engines* (87%) (Fox 2011). The third most popular activity in the US was not measured in the Australian census: it is *looking for health information* (80%).

general knowledge about kidney failure as well as techniques for self-care; such resources could go further by moving beyond provision of general information toward development of patients' abilities to tailor their understandings.

Alongside patient training by clinicians, health librarians could provide complementary support and training, such as how to read medical statistics and blood results (Kamal & Burkell 2011), strategies for the management of medical paperwork and schedules (Olson 2009), how to find and interpret medical information, including medication labels and how to interpret them in the context of one's own situation (Connor 2009). The goal is to develop patients' or caregivers' capacities to take part as collaborators in the epistemic work of clinicians, for which any training by information professionals must be provided in the context of ongoing training with clinicians, and working together with clinicians – viewing information literacy as a located, enactive socio-cultural practice. (Lloyd 2010, 2012; Tuominen, Savolainen & Talja 2005).

Lastly, user-friendly medical equipment is needed for use by patients who want to home test or monitor their treatments in-clinic. A useful example of information management technologies which support the complex needs of people with chronic illnesses are newly emergent phone applications which keep track of complicated medication schedules and provide reminders to users (OnTimeRx 2012). A second example is the recent rise in self-measurement devices like blood glucose meters, pedometers, exercise trackers and electronic personal calorie counters. Renal patients may benefit from self-measurement of changes in the blood measurements by which they judge their health, and of dietary food databases allowing people to track their dietary intake of elements like potassium. Such tools may allow more flexible and responsive understandings of dietary and treatment needs. Systems designers could be involved in the design of such renal self-monitoring devices, and patient literacy training could include training in their use.

* * *

Much of the discussion of training in this section has been based on the finding that having a sense of control is integral to sense making (Antonovsky 1987; Kralik et al. 2004; Kralik, Price & Telford 2010), which must be considered in tandem with the insight that solutions to complex needs must involve flexibility. So rather than providing patients with recipes which might control outcomes, people need to develop skills and vocabularies with which to react adaptively to contexts and even work proactively in flexible ways. The recommendations explored here make use of people's abilities to know what should be done, using humans for what they are good at: making finely tuned judgements of situations in context. For the potential to improve clinical outcomes for renal patients, such opportunities are worth exploring – both in terms of how to deliver support and in terms of equity issues for people who are not well placed for this kind of active role in their care.

Conclusion

At the heart of my findings is a metaphor of sense making as improvising networks of meaningful elements. Such assemblages include interwoven ideas, physicalities and emotions, which are constantly reworked in dialogic interactions with lived experiences.

In light of this, I have devoted this chapter to considering ways in which health professionals, LIS professionals and peers might support the sense making of patients and their companions. Three reasons emerged concerning why their sense making matters: compliance, safety, and happiness. Compliance matters because it keeps patients healthier, and in the case of renal patients, it can keep them alive; I have explained how complex compliance requirements require ongoing, flexible sense making of links from generic instructions to personal situations, which can be assisted by workshopping solutions with clinicians and with peers, and by acceptance of the need for trial and error by clinicians, patients and family members.

Safety for patients involves more than just compliance; it extends to recognising change and communicating changed needs. In medical scenarios, timely recognition of change *matters* – and for their central position in the context of care, patients and their companions can be a key 'information locus'. For this, patients need to be understood as central actors in care. I have described ways in which patients' and clinicians' sense making can be supported by patients' abilities to look for, recognise and describe changed symptoms, by their self-interested monitoring of procedures and activities related to their care, and, if they wish to go this far, by their active involvement as collaborators in their own care. But while many contributors to the online discussions were actively trying to engage in their care, not all patients could or wanted to successfully negotiate the barriers to active collaboration, which include being able to learn, record, explain and argue. Nonetheless patient and clinicians always already collaborate, in ways which sometimes necessitate that patients pretend they have nothing to contribute. Therefore, training patients to be active is useful but only to *improve* collaboration between patients and clinicians – to *draw it out*, not to create it. Also important are policies and processes of care which support patient-clinician collaborations in whatever form they take. Ongoing, active patient-clinician collaboration is for the time being, a fragile, worthwhile, yet potentially inequitable enterprise.

Finally, patient sense making must be supported with the goal of their happiness. I have shown how tones can be seen as chromatic, providing colour to messages and providing guidance, in particular signalling urgency and the need to worry, or contentment and no need for alarm. The sense making that occurs at this chromatic level requires attention to emotional tones used by patients and their families. For many patients, feeling alright is connected to having a sense of control, which can be supported by training which helps them understand and direct their experiences. For most, feeling alright may also accompany a sense of security and familiarity, which can be supported by reducing discontinuity, establishing normality, and providing examples of appropriate emotional, physical and cognitive understandings. Lastly, feeling alright is connected to having routines and a sense of continuity and familiarity.

Chapter Nine: Conclusion

In Library and Information Studies, discussions of sense making are often about information and knowledge structures. For example, as they worked towards a model of sense making processes, Zhang and her colleagues described the following steps in every-day sense making.

- *recognize a knowledge gap;*
- *possibly generate an initial structure or model of the knowledge needed to complete the task — concepts, relationships, and hypotheses;*
- *search for information;*
- *analyze and synthesize information to create an understanding; and possibly*
- *create a task product based on this understanding in the form of a report, decision, or problem solution.*

(Zhang et al. 2008, p. 2, using Pirolli & Card, 2005; Stefik et al., 1999)

This is a useful paper, as it incorporates learning theory to produce a model on the basis of which information-delivery systems might be better designed. With *knowledge gaps* and information *seeking* at the centre of this conception of sense making, it is not surprising that having a good retrieval system becomes a key issue. There are similarities between the vision of sense making presented here and the one I have described in this thesis: they both involve ongoing iterative processes, in which relationships between elements are important. But it is also easy to see how differently I have framed sense making.

I understand sense making as *making transiently coherent connections*. Sense makers improvise networks of meaningful elements, including interwoven ideas, physicalities and emotions. Their connection-makings are honed by dialogic interactions with lived experiences, and must be flexible if they are to be useful in complex lives. Sense making is social because it makes use of socially available vocabularies of networked ideas, which simplify the sense making task of any individual and helps them to make connections which are recognisable to others. It is also social because sense is developed responsively, in adaptive communication with other people and environments. Nonetheless, sense making is also individual because it is constantly reworked in response to particular situations. To facilitate this reworking, sense making involves recognition of patterns and differences, and repetition over time. Once sense makers develop tested understandings, they feel a sense of familiarity and can settle that area of life into a routine. Routines are valuable because they form a background against which life can be lived without infinite re-examinations.

In this chapter I summarise the important differences between my approach and existing perspectives, demonstrating my contributions to LIS and the wider sense making literature. In particular, I examine my contribution to sense making theory. Finally, I contemplate the limitations of this study, and how it could be extended or reworked. My goal with this final chapter is to provide a roadmap of what has been covered so far, and where we could go with future research.

9.1 Contributions to research

This project is theoretically based on an application of ethnomethodology to sense making, incorporating perspectives from Sense-Making (Dervin 1999b) and sensemaking (Weick 1995). These influences occurred at a theoretical level however, while my methods manifested simply as content and thematic analyses. This is the first influence on LIS from ethnomethodology of which I am aware (though Thomsen, Straubhaar & Bolyard 1998 discussed its potential utility to the field).

Acknowledging that situations and perspectives are not static, this thesis explored how renal patients make sense over time. I used longitudinal data from online discussion groups to investigate ongoing collaborative sense making processes. This is rare in communities of the chronically ill, who are difficult to access using traditional methods. Unlike most Sense-Making studies in the LIS literature, my theoretical focus was squarely on the ongoing processes of sense making in order to develop understanding of those processes, rather than using sense making as a lens to investigate other phenomenon. I examined interactional exchanges at a micro-level, using textual analyses to illuminate the ongoing detail of enactive, collaborative sense making processes. I also created charts to visually highlight sequences over content and reveal relationships between elements of threads, a novel form of analysis. All the above aspects of this study contribute to LIS by enriching the range of ways in which sense making, knowing or information might be researched.

Contributions to sense making theory

Sense making research currently appears in disciplinary silos, particularly represented within LIS and organisation studies, with rare cross fertilisation. I found two frequently cited theorists, Brenda Dervin and Karl Weick (e.g. Dervin 1999b; Weick 1995), whose conceptions of sense making were relatively consonant. Between them, Dervin and Weick provide eleven theoretical aspects of sense making, of which five have generally not been explored in detail. In Chapter 2, Table 2.3, I laid out the relative gaps in LIS and outside it. Table 9.1 (next page) extends Table 2.3 with a new column showing how I have been able to contribute to understandings of sense making.

Theoretically identified themes of sense making	**Theorist**	**Sense making (Theorised attention)**		**My contribution**
		LIS	**Non LIS**	
The mind	Dervin	Common	Common	Connections between pattern-recognition and routine-making
Emotions	Dervin			The roles of ***emotions***, ***physicality*** and experience in sense making
The body	Dervin			
Spirituality	Dervin			
Information / Knowledge	Dervin	Common		Sense making and knowing are usefully understood in terms of ***relations*** and connection-making
Social aspects	Weick, Olsson Savolainen		Common	Developing social conceptions of sense making in LIS
Time (retrospective, ongoing)	Dervin Weick			Repetition over time is required to test theories and develop routines.
Enactive	Weick Dervin		Common	Re-enactment of norms maintains or loosens structures; Relationships between experience and authority
Power or Control	Savolainen Olsson		Common but problematic	
Plausibility	Weick			Connections between plausibility and backgrounding / routine
Identity	Weick		Common	
Normality	Genuis			***Normality*** serves as a fundamental pattern used for orientation

Table 9.1: My contribution to themes relating to sense making

These contributions connect to existing work in LIS as follows:

- The roles of ***emotions*** and ***physicality*** in sense making. (connects to Bonner & Lloyd 2011; Dervin & Reinhard 2007; Kuhlthau 1985; Lloyd 2007; Mellon 1986; Nahl & Bilal 2007; Olsson 2009, 2010b; Veinot 2007, 2009; Veinot, Kim & Meadowbrooke 2011)

- Sense making and knowing are usefully understood in terms of ***relations***; (connects to Egan & Shera 1952; Hjørland 2007; Karamuftuoglu 2009; Sundin & Johannisson 2005b)

- Sense making is usefully conceived as ***social***; and (connects to Hertzum 2008; Neal & McKenzie 2010; Olsson 1999, 2003 2005a, 2010b; Sonnenwald 2006; Talja & Hansen 2006; Veinot 2009; Veinot, Kim & Meadowbrooke 2011)

- The role of ***time*** in sense making; I have explored repetition as one aspect of this. (connects to Hartel 2010; McKenzie & Davies 2002; Savolainen 2006b; Widén-Wulff & Davenport 2005)

I also argue that

- ***Normality*** serves as a fundamental pattern used by sense makers for orientation. (connects to Genuis 2012)

Therefore this thesis contributes to both LIS and the wider sense making literature by investigating aspects of sense making, most of which were already theorised to be there. Sometimes, I have developed ideas which were left fallow in the literature, like the role of physicality. But I have also contributed to understandings of more commonly explored ideas. I describe these contributions first.

Patterns and structures

Sense making is often described by researchers in terms of people finding patterns into which to fit new ideas (Hodgson 2007; Olson, Nelson & Parayitam 2005), and of noticing or ignoring things which don't fit patterns – filtering (Starbuck & Milliken 1988). Similarly, I describe sense making in terms of people finding patterns, extending the idea by positioning *normality* as a special kind of pattern. I have also described how people use their knowledge of patterns to attempt to control situations, particularly to slow change, and thus maintain the usefulness of currently understood patterns. Finally, I have explored connections between patterns and routine making.

Multiple understandings

When I summarised sense making literature in Chapter 2, I pointed out a common conception of sense making as making coherent connections between ideas, creating cognitive structures. In this thesis I have developed this idea of connections into assemblages, which are less fixed than structures and located in actions rather than hidden in the mind – therefore, more flexible and amenable to future research. Starbuck and Milliken (1988) remarked that multiple understandings are part of a basic sense making toolkit. I extend their idea of how multiple understandings, especially those with slight variations, contribute to flexible sense making of complex experience.

Socially enacted authority-making

Meanwhile, disciplines outside LIS provided rich understandings of *social* and *enacted* aspects of sense making and the role of *power* in sense making. My research has provided detail on the interplay between these themes.

In online interactions, I found that norms were both enacted and loosened by the range of variations manifested in each post. The useful messiness in rich descriptions added to possibilities, reducing the sparse grip of rules or norms of behaviour. Looseness allowing shifting meanings lies at the heart of people's potential to negotiate between structure and agency, and is an essential part of all practices (Gherardi 2009b). People drew from social knowledge but did so purposefully, making small differences which led to tiny changes, re-enacting or working around the structural resistance represented by norms and cultural conventions, or being guided by the useful framework they provided. In this sense, norms which may have been seen as oppressive (Chatman 2000), and could also be seen as guiding (Foucault [1978] 2007), can here be seen as flexible and re-workable (Gherardi 2009b).

This enactive perspective on the social construction of structure and agency connects with the resisting and reinventing described so briefly by Dervin (1999b), providing some detail of the processes involved and furnishing empirical examples. Practice theory has begun to emerge in LIS mainly in the past five years (Cox 2012, 2013; Haider 2011; Lloyd 2007, 2009, 2010, 2012; Pilerot & Limberg 2011; Savolainen 1995, 2008; Talja 2010; Veinot 2007), to which I contribute this direct connection between *sense making* and practice theoretic perspectives on knowing. I made use of metaphors from practice theory to describe the moment by moment re-enactment of norms, whereby these same norms are constantly being corrupted and shifted slightly during individual enactments; an example of dialogic interactions between sense makers and their environments.

These are aspects of sense making which are actively developed by the sense making literature, to which I have contributed with small additions and connections. Sense making theory has proposed other aspects of sense making which remain relatively unexplored by empirical investigation. My findings contribute there too, as I now describe.

Emotions and physicality

Dervin proposed that sense making involves *emotions*, *spirit* and *physicality* as well as *mind*, but in LIS, only Olsson (2010b) has explored the role played in sense making by emotions and physicality. He is joined by a small collection of similar voices from the wider sense making community (Dougherty & Drumheller 2006; Kramer 2009; Mills 2002; Soneryd 2004; Volkema, Farquhar & Bergman 1996; Waskul and Vannini 2008). Meanwhile, literature describing common experiences of renal failure and chronic illness are filled with themes associated with sense making theory, in particular emotions and physicality. This reinforces the need to understand emotional and physical aspects of sense making, opening an unusual opportunity to contribute to sense making theory both inside LIS and in the wider disciplines. My findings contribute descriptions of informational aspects of emotions and physicality.

Physicality appeared within the processes I described as *experiential brutality*, in which experiences, like pain, taught patients what they could and could not do. In a show down between theories and experience, experience has the ‘last word’ in sense making, and is a source of authority and truth. The repeated modification of theories in response to experience led me to describe iterative rounds which form familiar, workable understandings. Experience was a special case of pattern finding, because experiences are a source of authority, confirming or breaking the theories from which individual and collective norms can be made. Yet a contrasting, softer side of experience emerged in which, by learning the range of possibilities open to a person in a given situation, people were able to find a bit of freedom and make choices. Sometimes people used this looseness for control, to make slight changes; at other times people put together outrageous contrasts for the sake of fun.

Emotions became informational when patterns of emotional cues appeared to provide emotional models within interactions, which were then echoed by other contributors. Emotional cues seemed to show people how to feel; and emotions were a matter of interest to contributors, who expressed relief at being understood and being able to vent their emotions. Emotions warrant more attention by researchers, as I believe that ‘feeling alright’ is inherent in feeling that things make sense.

It is significant that ideas, emotions and physicality did not necessarily emerge as isolated elements of sense making; they often appeared intermingled. Speaking, feeling and doing activated and affected each other (Colombetti & Torrance 2009; De Jaegher & Di Paolo 2007; Olsson 2010b). My consideration of interrelated cognitive, emotional and embodied sense making connects to understandings of participatory sense making (Colombetti & Torrance 2009; De Jaegher & Di Paolo 2007) extending them towards consideration of non-human actors. Though participatory sense making has previously only been used to explore interactions between people, it has direct relevance to ways that people interact enactively with objects and situations.

Time

In my literature review, time emerged as relevant to sense making – but it was a linear time concerning one’s orientation to the past and the future. I have found significance in what could be called cyclical time, with repetition as a driving force. People moved from general (normal) to specific (my situation) and then back again (my normal), a process which required time for iterations, and required lived experience for adjustments. Though changes were inevitable in linear time, reiteration and constant modification in cyclic time allowed sense making to keep pace with situations. Moreover, repetition developed familiarity, allowing the identification of workable patterns to develop into routine.

Retrospection versus planning

In particular, I have begun to flesh out understandings of the interactions between retrospective sense making (Weick 1995) and forward-facing sense making plans – partly represented by Dervin’s step-takings (Dervin 1999b). Common in the organisational studies literature is a view of sense making as always retrospective, relying both on previous experience and ‘what just happened’ (Boland 1984; Weick 1995). People can only see what things meant as they look back on them (Blatt et al.

2006). This is a perspective which appears to ignore one's need to plan and predict (Purser & Petranker 2005), and is oblivious to the image of a person attempting to cross a gap, presumably with some future-facing goal in mind (Dervin 1999b). The problem is addressed by the sense making predilection for finding patterns. While particular patterns are established, they transcend or fill time, becoming 'sensible' for past events and creating expectations for the same patterns to reappear in the future. By looking back, one finds patterns, patterns which we (erroneously sometimes) assume will continue, creating the imagined conditions in which plans are made.

Normality

My analysis of the illness experience literature suggested a role played by *normality* in people's sense making experiences. I have also identified the role of normality in the sense making processes I studied, which I began to theorise in Chapter 5. Normality appears as a particularly useful manifestation of pattern making, an indicator of what generally occurs (normal for patients, normal for *normals* who are not ill) and of individualised understandings (my normal). Foucault points out that normalisation processes are not necessarily oppressive (Foucault 1984a, p. 205). Understanding what is normal may serve to modify one's behaviour, or may help to make one's experiences understandable. This may not always be uplifting, when normality is as regimented as the dialysis lifestyle, with its high mortality rates. But knowing norms provides a form of guidance, allowing people the happy imitation described by Tarde (1903), and may provide milestones for an ongoing project by patients to improve their health, their ability to cope, or their medical compliance (Foucault 1977).

Shifting from Gap to connections

Dervin's descriptions of morphing, ongoing sense making in an environment of constant change is an important element of my theorisation of sense making. However, central to her perspective is the human sense-maker stopped by a gap, which they consider from a situated perspective, with various potential 'helps' in mind. She directs attention to the triad of gap-situation-helps (Dervin 1992), a focus which I have set to one side. Dervin's alternative expression for gap illuminates its more interesting aspects, as an "ontological-epistemological divide" (1999b, p. 730).

This is a reference to the continual misfit between experience and understanding, between understanding and expression, and between expression and experience. These form three convergent series which can never properly overlap (Deleuze 2004b). This is the ongoing paradox of sense-making and sense-mades. However, as gap is inevitable and persistent, it ceases to be the emergency that made it theoretically interesting for Dervin, or rather, the interest is that sense making occurs *whether gap is apparent or not*.

This thesis represents a shift from Dervin's interest in movement and gaps to an interest in networked elements – a shift from stalled momentum, to working assemblages. Conceiving sense making as connection making instead of bridge building changes the relationship between the sense maker and gap. Rather than being a block to sense making, gaps inhere in all connections as the differences between connected elements. They are not effaced by sense making, but are restructured as networks are restructured, not filled but re-positioned as a normal part of understanding. Dervin acknowledged the inevitability of gaps when she remarked that "reality is such that the gaps can never be completely bridged" (Dervin & Huesca 2003, p. 318). She meant not only that understanding is always inexact, but also that people can never fully share the same understanding.

This is a problem when one focuses on the problem of individual minds which have their own individual ways of knowing. My argument is that ways of knowing – ways of connecting elements – have social origins and must remain socially recognisable to be of use to individuals for communication. Therefore, minds can meet, by their mutually recognisable use of socially sourced patterns. Minds meet *approximately enough* for approximate mutual understanding; this is an outcome of the *approximate* sense making I described in Chapter 7 and the *plausibility* described by Weick (1995). Theoretical attention moves from gaps and bridges to patterns – the patterns people are likely to use to make sense – either by recognising familiar elements of situations, or by putting together familiar (to them) collections of socially familiar meanings. What we call knowledge lasts not because it is fixed, but because it is repeated. This is a theoretical perspective which again brings *repetition* to the fore, since *socially repeated connections* replace *fixed facts* as the basis for lasting knowledge.

Sense making assemblages may not manifest as narratives.

There is a perception in organisation and nursing literature, noted briefly during the literature review at Chapter 2, in which narratives are viewed as the fundamental medium for sense making.

> *It is only through constructing narratives can [sic] the complexities, subtleties, nuances, debates and dramas of organizational life be made meaningful. Narratives also provide a common language through which the ambiguities and equivocalities of everyday life are shared and collectively made sense of. It is through narratives that happenings are assigned meaning and structure, and through emplotment these events are given both a linear and spatial dimension.*
>
> *(Wright, 2005 p. 92)*

This literature uses narratives to design support for sense making by patients and also to support reflective nursing practice (Bailey 2001; Brown & Addington-Hall 2008; Carlick & Biley 2004; Carolan 2005; Crossley 2003; Macpherson 2008; McCance, McKenna & Boore 2001; McKevitt 2000; Morrissey 2006; Sakalys 2003). Narratives are seen as a key to sense making and in particular, a key to reimagining futures, and affecting how people make sense. I agree that sense making can manifest as narratives, including variations or concatenations of particular stories (terse storytelling; Boje 1991), but I also propose that it can manifest as bricolages of even smaller units: fragments, sequences, turns of phrase and tones. They could be as simple as a metaphor (not that metaphors lack complexity; Lakoff & Johnson 1980) or the sequences of common interactions: ‘how are you? Good thanks’. Sense-making assemblages could be loose and appear incomplete. It may be a useful contribution to nursing literature to make that difference between fully formed narratives, and the improvised sets of connections which I have found ‘do the job’.

Everyday sense making cues and plausibility

Rather than sense making in response to a problem, loss or crisis, this project has investigated the relatively ordinary sense making undertaken in conversations – though these were *often* prompted by loss, problems or crises, they were not *always* so. Moreover, as sense making is not a binary choice between success and failure, interest lies in how particular constructions worked or not, in particular situations. The idea of losing sense, or sense-un-making, which may be a reference to being confused or confounded, is reconceptualised with a metaphor of network making. Confusion may relate to having too many potential connections, or to having made connections which do not fit with the expectations of one's companions. Being confounded may relate to having too few connections one can make, finally bringing us to a situation comparable to Dervin's unbridged gap.

I have described how the construction of background using familiarity and routines raises the roles of repetition and the involvement of time in sense making as subjects for future research. Familiarity and routine create understandings which temporarily need no re-examination; this is a judgement call which people make on the fly, judging situations as 'familiar enough'. This is a *good enough fit*, a judgement of plausible familiarity, providing a new perspective on Weick's discussion of the topic of plausibility in sense making. It casts light on the processes by which people stop making sense and move on – because their understandings have become workable and can be backgrounded temporarily.

A difference between Chatman's work and this project, is that Chatman studied the recurring and controlled aspects of routines which were guarded by the norms of inward-looking communities, whereas I have studied international gatherings of people with only weak ties between them (Granovetter 1973). Renal patients live the dual lives of the chronically ill, who are both well and unwell (Bury 1982) and whose lives are paused as they await transplant (Lee 2004; Noble 2000; Sloan & Gittings 1999; Weems & Patterson 1989). Perceptions of living in limbo and a sense of isolation from the normality of the lives of their family and friends are commonly expressed (Keeping & English 2001; Martin-McDonald 2003; Molzahn, Bruce & Sheilds 2008; Nicholas, Picone & Selkirk 2011; Russ, Shim & Kaufman 2005; Sloan

& Gittings 1999; Tong et al. 2009). This means that like Chatman's old ladies (1999) my patients' routines are fragile, but unlike Chatman's populations, my patients reached beyond their everyday community for understanding and support.

No predictive variables

Dervin and Garfinkel both rejected the use of demographics as predictive variables (Dervin 1989b; Rawls 2008). Dervin put forward an alternative set of "situation-states" which she proposed might more successfully predict the sense making needs of individuals (Dervin 1980, [1984] 2003). I make no attempt to isolate any kind of content-related variables which could be used to predict future sense making, neither to predict what people might make sense *of*, nor to suggest what people might *do* to make sense (such as information seeking tactics). Instead, I have simply watched and taken part in interactions. My findings are useful, not for predicting or designing sense making outcomes (which are always contingent) but for understanding the flexible, adaptive elements which may come into play and the ways in which people might use them, and for creating environments which, by containing those elements, might be conducive to sense making.

9.2 Limitations of the study

Several factors limit the claims that can be made from this research, raising areas for further study.

For instance, sense making interactions may be different online than in other locations. In Chapter 1, I described differences between the groups in terms of how messages were delivered; two of the groups required the reader to visit a URL and read messages *in situ* while the third sent new messages as emails to all members. Evidently a conversation in real life is different again to one online: spoken comments 'disappear' rather than remaining archived as text, while one can usually see the body and expressions of face-to-face interlocutors. The patterns I discuss here, of repeating ideas and developing loose consenses, or making slight shifts in meaning, were apparent in all three groups despite the differences in their delivery of messages. I suspect that may be because people are reusing patterns from face to face interactions; that is, I suspect that the patterns would also occur in face to face interactions, but this is a matter for further research.

Similarly, this self-selected, online population of English speakers may not be representative of the larger population of renal patients. They may be more actively motivated or empowered than others. Moreover, because contributors to the discussion boards I studied are from a range of countries, they describe a range of health systems and significantly, health care funding arrangements. But it is unlikely that the different medical systems experienced by my participants would affect my results, because I have focused on sense making processes rather than on the content of discussions. I perceive that international differences in care provision augment my understanding by making the connection between experiences and sense making clearer.

As was evident in Chapter 4, my approach to consent created holes in my reportable data wherever a contributor was unavailable or withheld consent. If one imagines research to be a process of reporting truths about a situation, then this is a weakness inherent in my approach to consent, for there are findings I cannot present. Instead, I approached research as a process of learning about a situation and interacting within it. The consent I obtained from members and moderators at the start of the project was only consent *to be present*. Because I did not attempt to obtain pre-emptive consent to write whatever I liked about any post, I was indeed vulnerable to people withholding consent after the analysis. I could suggest that I was vulnerable to disappointment, just as they were vulnerable to being analysed. Had I been less cautious with consent I may not have been allowed to research the discussions at all. By being present, I was able to learn from all discussions – including arguments. Though I cannot write about all that I learnt, my findings are richer for being based on my understandings as a kind of insider. I accepted a trade-off: my insider status allowed access to interactions; it was forged by my being present during interactions, and it remains dependant on my respect for other members and for the groups.

I did not systematically investigate the accuracy of information exchanged in online forums, though this has been explored elsewhere (Savolainen 2011a; Marton 2003).

I did observe people refer to medical websites, newspaper and journal articles, and quote clinicians, and I observed how contributors, some with decades of experience with renal failure including of all kinds of procedures, clinicians and modes of treatment, *afforded each other* authority in medical questions. But my research addresses online groups as locations for sense making, which has more to do with being able to live life than being perfectly right. Nevertheless, accuracy is important in the light of my recommendations in Chapter 8 to increase peer-to-peer sense making; I explore how this could done in the next section.

When I described my methodology in Chapter 3, I made it clear that I was not following individuals' sense making activities. This is not a psychological exploration, delving deeply into the internal processes of individuals. Rather, I have investigated the detailed layers of processes occurring during social, collaborative sense making. For this reason I cannot comment on the potential relationships between personality types and particular sense making profiles, and I cannot theorise about the 'internal' sense making trajectories of any individual contributor. I also remain unaware of the disadvantages of online groups – how people might not find them friendly or accessible, and the isolating aspects of community dynamics. A future project could investigate how online groups reject or suppress ideas, or exclude individuals.

Given the size of the sense making literature, I limited the scope of my literature review by differentiating sense making studies from the rest of the LIS research into information practices and behaviour. This is an artificial distinction which removed some of the better research available in LIS. In future research, perhaps I would not make this distinction so sharply, especially as I believe that sense making is manifested all kinds of information practices.

9.3 Future research

At the start of this project, I hoped to observe people making sense of kidney failure 'in the flesh' using ethnographic methods; but the logistics and ethical problems involved in trying to observe people dealing with kidney failure made it hard for me to find a location in which I could access detailed ongoing data. Studying written interactions about kidney failure was a compromise, which shifted the object of my research from ‘how do people make sense of renal failure’ to ‘how do people make sense of renal failure as they write and interact in online discussion boards’. Since then, I have begun to develop academic relationships with practitioners in Australian hospitals and kidney research centres. Such relationships may open opportunities which were not available to me as a fledgling PhD student in the social sciences, with no connections to clinicians or medical schools. In future research, I may be able to undertake face-to-face ethnography, for example, in dialysis clinics or by video ethnography, giving people video cameras to use as video journals when they begin to dialyse at home (Carroll, Iedema & Kerridge 2008; Iedema et al. 2006; Iedema et al. 2009).

Meanwhile, this research has mainly investigated the *advantages* of sense making online. There is a need to understand the disadvantages and shortfalls of online discussion groups for renal patients. For example, as discussed in the previous section, how medically reliable are the online discussions – how often do people give each other ‘wrong’ information, and how do participants respond to incorrect information. Interviewing contributors and non-contributors might help to understand how they perceive online groups. Are there common negative experiences, for example, which might make participation risky for some patients? Interviews may also help to explore how people perceive the accuracy of interactions and the authority of contributors (Savolainen 2011a), as well as when and how contributors might read discussions critically.

In light of the discussions in Chapter 8 about patient-clinician collaboration, further research must also explore how patients’ or carers’ monitoring of care affects patient safety or the quality of patient-practitioner relationships (following Davis et al. 2012). Patient-clinician interactions could be examined in clinics or hospital wards, to learn how safety is successfully co-produced; learning from strengths in what people already do. A key question is how medical staff might encourage patients and carers to remain or become interested in knowing about their care – to *not* discourage them, *not* view them as a nuisance. When they can be involved, such patients and carers could be a resource for vigilance over safe practice. But just as urgent are understandings of how patients are affected by discouragement – and whether such collaborations improve clinical outcomes and patient happiness or not. Patient happiness matters, because some renal patients get so depressed that they want to end dialysis (Noble et al. 2008; Noble et al. 2009; White & Fitzpatrick 2006). This is a problem, as ending dialysis causes death. I will return to this point in a moment.

There are other ways these online groups could have been analysed. Network analyses of interactions (Haythornthwaite 1996; Veinot 2010b) would show whether comments came from a range of locations and perspectives. By examining nexes in interactional networks, it may be possible to consider the difference between 'noisy' contributors and those who post rarely, or to identify sub-groups (like the Americans, the nXstage[87] users) and consider their effects on group dynamics.

Finally, there are sense making themes identified in theory which still haven't been explored by researchers. I have not explored *spirituality*, though I saw it in my data. Reconsidering Dervin's comments about spiritually now, I wonder what could be learned from a focused exploration of spirituality in this data. Connected to this use of faith to maintain good spirits and positivity, it would be useful to investigate the use of humour by patients, by returning to the online groups, but also by watching the use of humour in clinical settings (connecting to Parkhill et al. 2011; Tanay, Roberts & Ream 2012). There are likely to be important connections to be made between faith or humour and optimism in sense making.

* * *

I noted earlier that depression is an issue for renal patients. When we were first warned that his transplant was failing, Gregory told me of his long standing resolve that this would be his only transplant and that he wouldn't go back on dialysis. Though I had not yet read the renal literature about depression and the choice to die, I was able to recognise what he meant because these questions had been discussed online. I listened quietly to his remarks and had a vocabulary with which to respond.

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[87] nXstage = a brand of home haemodialysis machine

Having vocabulary for sense making is an idea which appears in my findings. Since then his attitude has changed and he is preparing for dialysis. Time has passed and our perspectives have changed as we have become used to our changed future. These are also themes which appear in my findings. Ethnomethodologists recommend that researchers should develop insider understandings of the contexts of their study. I found this enriched not only my understanding as a researcher, but also as the wife of a renal patient; the two aspects of my developing understandings complemented each other.

Conclusion

I began this thesis with an example of networked ideas: Dervin, rain, interviewing, and stuffing of the heart. I pointed out it was not a grand narrative, but a collection of elements, elements which you hopefully remember and recognise now with only the barest detail required. It was an example of flexible connection-making, which for me, still contains emotional elements and physical cues which I pass each morning and afternoon. It is my attempted demonstration of some of the collection of contributions I have assembled here: sense making's flexibility, its emotional-physical-ideational interrelationships, the detail of its specific, particularising links, and yet how detailed accuracy is not always needed.

My contributions connect into LIS and the wider sense making literature, as well as into the illness experience literature. They include developments of our theoretical understandings of the role in sense making of emotions, physicality, enactment, social relations, power, time and normality. I have presented these themes in the context of theoretical discussions, and also in the context of practical ways in which people can help each other to make sense. I am already looking for ways to express these opportunities in the clinical literature, and to develop collaborations with clinicians in order to make some of these opportunities happen.

Appendix A: Data for analysis of interactional norms

As with other quotes presented in this submission, I present the following extracts without altering spelling or grammar. Text is the principal manner by which people represent themselves in online spaces. Whether intended or accidental, variations in spelling and grammar contribute to the creation of identity online, and affect the sense that others make of messages. If I 'corrected' texts, it would change their meaning.

Selections from *Welcome* pages at group websites

IHateDialysis

The following text appears the home page for IHateDialysis, which similarly contains links to the home page for the discussion forums.

1. A Site For Patients By Patients
2. Welcome to a site for patients by patients. Epoman started ihatedialysis.com to stop
3. having his posts censored or deleted by corporate run or sponsored dialysis sites. He
4. created the site so others could have a voice on the internet free from censorship. Do
5. not let the sites name fool you, we are not about being negative, we just hate dialysis.
6. We are a community that is very supportive of each other and we help new patients
7. and veterans of this disease cope with the daily struggles of living with kidney disease.
8. If you are affected by kidney disease you are welcome here, that includes all types of
9. dialysis Hemo, PD, Home, or maybe you will soon be starting dialysis. If you are a
10. spouse, relative, friend, or a loved one you are also welcomed here. Also if you work
11. in the dialysis field you too are welcome here on this site.
12. Let Your Voice Be Heard!

Near the top of the home page for the IHD discussion forums, a banner scrolls through a succession of messages. A selection of these messages follow:

13. Welcome to ihatedialysis.com – a meeting place for people on dialysis to rant and vent
14. their frustrations with living on dialysis
15. No holds barred, the straight truth from fellow people who hate living on dialysis
16. We are not being negative, we just hate dialysis.
17. We are a site FOR patients BY patients
18. Welcome to all new members: please post an introduction.

KidneyKorner

The following text appears at the home page for AngiesKidney.com. Links from here lead to the home page for the KidneyKorner discussion forum, which bears the slogan,

19. "You've got someone in your corner"
20.
21. AngiesKidney.com
22. A Community Striving for Unity
23. This is a "Community Striving for Unity" as our slogan goes. What that means is
24. that everyone effected by Kidney Disease coming together to share their views
25. and experiences to help us grow as a community. A lot of patients feel alone
26. when they first discover their kidneys are failing and there is no saving them.
27. […] Here is a place built out of the desire to brings us all together so we no longer

28. have to feel lost and alone! Be it if you or someone you care about is on Dialysis, or
29. just discovered they have Renal Failure, or have had a Kidney transplant! You are all
30. welcome here!
31. Our Purpose:
32. The purpose of this site originally was for support of every renal patient who
33. grew up sick such as I did […]

Australian Dialysis Buddies (ADB)

The following text appears the home page for the ADB message board.

34. Hi there and welcome,
35. We are an Australian based online support group for those with an interest in dialysis.
36. Any Haemo and Peritoneal dialysis consumers, their partners,friends or family
37. members who would like to join us for support and friendship are most welcome,even
38. if you are are from overseas with a dialysis connection. Also, those who haven't yet
39. started dialysis but know they may be heading in that direction in the future, this is
40. somewhere to come, chat, and build friendships and learn from others who are going
41. through or have been through, similar experiences to you.
42. It can be lonely and frightening dealing with kidney disease at times. It is good to
43. share your thoughts and know that you are not alone. Here you will find a place to talk
44. and gather general information by hearing the personal experiences of those who are
45. on or have been on dialysis or their family members.
46. We are not doctors so we can not offer medical advice, just support on what we have
47. experienced and learned during our time with dialysis. So, if you are interested, COME
48. JOIN UP and become a Dialysis_Buddie. :)
49. Disclaimer
50. All information provided is not intended as medical Advice, but is a source for
51. information purpose only. If you need medical information please consult your health
52. care provider.

Selections from *rules for posting* threads

IHateDialysis –forum entitled "Introduction - PLEASE READ THIS SECTION FIRST"

Excerpts from "SITE RULES All Members/New Members MUST read!"

53. Please make your FIRST post an Introducing myself post in the "Introduce Yourself"
54. section. This is very important as we will get to know you as a person and not just as
55. another dialysis patient. This is a requirement, you must post an introduction thread
56. introducing yourself.
57. […] Obviously spammers are not allowed. […] You will not be given a warning, you will
58. be banned.

Excerpts from: "Why I started this site, and what this site is all about. READ HERE FIRST"

59. […] I started this site so dialysis patients can come and say what they really feel. "I
60. hate dialysis, yeah it keeps me alive but I still despise it". I want people to be able to
61. come here to vent and share their experiences. If you or someone you know are about
62. to begin dialysis feel free to ask any questions. However be prepared, you will get the
63. truth and sometimes the truth is hard.
64. […] I will not edit posts like some dialysis boards do. If you become a member
65. and post don't hold back, speak from your heart.
66. […]This site it not a place to feel sorry for yourself, It's a place to
67. come to vent and rant because you have accepted your fate and try to keep a positive
68. attitude but you still hate dialysis. […]
69. [..] There is also an Off-Topic section so if you have a question or want to make a
70. comment about something else other than dialysis feel free to.
71. Also this site is not in any way funded or supported by any medical affiliation. This site
72. is also for family or friends of someone on dialysis. Feel free to share your story or ask
73. questions that concern you[…]
74. […] I will ban any member on the spot who is blatantly trying to cause problems by
75. starting a topic or replying to a post that can be insulting or distasteful to another
76. member this is NOT a forum for verbally fighting with each other, A friendly argument
77. is OK once in a while but don't push your luck. […]

KidneyKorner

Excerpts from “The Rules of Posting (READ FIRST)”

Don't spam

This is a support community. Be nice and supportive of each other. And respect the rules and the host (me).

I welcome ANYONE who has a loved one on dialysis or in kidney disease! You are ALL WELCOME HERE!!

Insults directed toward other forum members (like name calling for instance) will not be tolerated!

[…]

NO advertising of any drugs, porn, selling of organs, etc.

[…]

Kidney Korner Supports Free Speech

But that doesn't mean we allow bashing of our members.

"You are only entitled to free speech in public places - your forum is a private place which has its own rules."

AustralianDialysisBuddies

Excerpts from an email sent regularly to all members, entitled “File - group guidelines”

Hello and Welcome to Australian_Dialysis_Buddies group.

We would appreciate it if you could take the time to read the rules of the group. There are not many and most are just common courtesy.

All new members messages will be moderated for a short period of time to keep the dynamics of the group talking about dialysis.

It is nice to hear from our members on a regular basis, even if it is just a hi so we can see that you are well and it is nice to keep in touch. The more you are active, the better you get to know everyone and therefore have a closer friendship within the group.

[…] Please 'no flaming', this will not be tolerated as it is not appropriate in a group like this. If you are not happy with something that someone has written, you can debate it, but do not insult anyone. […]

Common courtesy must be used with all posts. Treat people the way you would like to be treated and there should be no problems :)

Examples of *Welcome* posts.

The quotes that follow are responses to posts from new members introducing themselves.

Example#1

[…] Glad you found this great place. It looks like you've already figured out that there are lots of wonderful people 'round here who in so many ways have 'been there/done that', and are also ready to 'lend a hand' in support.

Example#2

A belated welcome, [name]! I love de-lurkers[88]!! It means that you have checked us out and are thoroughly convinced that this is the best place for information, support and encouragement. Delurking means that you are now part of the IHD family […] Looking forward to hearing more from you.

Example#3

You will fit right in here, you are a fighter.”

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[88] A ‘lurker’ is someone who reads a discussion group without posting. The person being address explained they lurked for some time before deciding to introduce themselves and join the discussions. ‘De-lurkers’ is not a commonly used term however.

Example#4

Welcome aboard [name]! We are family here and glad you joined! Lots here that know what you are going through. Excellent source of support!

Example#5

Hi [name] and welcome to IHD. I'm so glad you found us. Really, you have done the best thing you could do at this point and that is to read and learn from this site. Ask questions. You will get the truth here. You will do fine.
Thanks for joining.

[name] Welcome

Example#6

WELCOME [name]! […] You came to the right boards, there are many friendly people here who can help answer any questions and concerns you may have! 👍

Appendix B: Confidential Data for Sequential analysis of threads

All quotes and data in this submission are presented without altering spelling or grammar. Text is the principal manner by which people represent themselves in online spaces. Whether intended or accidental, variations in spelling and grammar contribute to the creation of identity online and affect the sense that others make of messages. If I 'corrected' texts, it would change their meaning.

Thread A: Enough

This thread was begun by a relatively young man beginning dialysis. He describes haemodialysis; his treatment schedule appears to be sessions lasting four hour, three days a week.

Topic: Enough

Post#1
PersonA

Hi all!

I must put out my emotions, otherwise I'll explode. Yesterday, I had my first 4 hours sessions. Afterwards, I was a mess. I cried and said I won't do it anymore. My parents and friends tried to calm me down, but no success. I'm so frustrated to be depended to a machine.

And on top of that, my girlfriend sad to me yesterday, that she doesn't feel that our relationship is the right one and that she needs time to think about us. Between the lines: she wants to go away.

Did I deserve this?

I went to a doctor yesterday and asked, what do I need to sign to get just paliative care. Yes, I want to die.

Sorry for being depressed, but you're the only one, who understand me.

PersonA

Post#2
Person2

[consent not obtained to include this post]

Post#3
Person3

PersonA, what can I say, you sound so down. Its not going to be a bed of roses, it is a life changing thing, going on to dialysis. I am saddened to here you want to end it all, because basically that is what you are saying. PersonA, even being on dialysis you can have a good life, it is what you make of it. You are only young, you will get the chance of a transplant, a lot of people don't. Everyone experiences depression when they learn that they will have to rely on a machine. Is there a chance you could go onto PD so you could do this at home? I can understand where your girl friend is coming from, she is scared there is so much to learn about dialysis and you are scared as well, it is natural.Please do not give up your life, there must be lots of things you want to achieve and they are achievable if you give your self a chance. Thinking of you and sending you hugs.

Post#4
Person4

Gee mate, even I'm finding it hard to know what to say reading this. I share your pain in that regard, though I've never actually had a woman tell me, right when I'm dealing with starting D, that the relationship wasn't right and all that - talk about kicking a bloke when he's down - I don't think that one would have been right for you anyway with an attitude like that.

What can I say? It does get easier when you get in a routine, and start to feel the positive effects of dialysis rather than focusing on the bad things like needles, being tied to the machine, and all of that stuff that we all know so well.

I think you are adjusting to a big change in life and to be upset about it, angry, frustrated and all that is pretty normal. There's times I feel like that too (and no, I'm not just saying that).

It's normal and healthy to let these feelings and emotions out - come here, vent, yell at something... (I used to play mindless video games where I could blow up stuff!). The thing I want you to do is NOT pack it in!!! Yes, it seems dire now, I absolutely understand that... but you DO have so much to live for, and dialysis, as horrid as it is, lets you do that. Your family and friends who care about you certainly don't want you ending it all.. they want you to hang around for as long as you can - and so do we.

As for your girlfriend... remember it's also a big change for her to get used to and maybe, just maybe, she's having to deal with this stuff in her own way - how she cares for you, how it must feel to see someone you love going through this and feeling helpless etc. Now if she wants to run off because she can't handle it, well that's her (poor) call. but you can't let that stop you. You're better than that!!!

Please, give it some time. Don't do anything too hasty. Give yourself 2 months. 3 months. See how you feel then. If you really feel that God awful and that it's just not helping you and it's not for you then you need to have long and frank discussions with your family, friends, doctors. You're only just starting, and I promise you it WILL get easier... the vast majority of my treatments are dead flat BORING. I was trying to explain that too two very attractive pharmacy students they brought in to see me today... but then my pulse went high and I got all embarassed.....

Just don't do anything too rash, OK? You need time to adjust, as does everyone around you.

Hang in there, OK?!

PS: I'd love to only be doing 4 hours!!!!

Post#5
Person5

PersonA, this was a heartbreaking read. First rule of life, do not make any important decisions when you are depressed or your thinking is otherwise cloudy. Whether to live or die is arguably the most important decision any of us can make. Please give dialysis a chance to clean the toxins out - those poisons really affect your thinking.

I know you mentioned that your parents offered to donate, but that your father was not in the best health, and that you did not want to 'butcher' your mother. Let me speak as a mom to two boys for a moment. If one of my kids came to me 30 years from now and said "I am considering two options: asking you to undergo an operation that will leave you with a few scars and maybe some pain for several weeks, or.... I could kill myself" you would hear the peal of rubber against road as I raced to hospital to get this operation. I doubt I would even bother asking what the procedure was or what the risks are. If dialysis is that bad, please look into this option.

About the butchering: My husband donated to me. He has two oval-shaped scars on his abdomen that we call his 'walrus bites' [this is a joke to do with the recent BP oil spill] and a short, linear scar below the bikini line. (You'll be happy to hear my husband does not actually wear bikinis.) PersonA, he is so proud of himself!!! My first donor was, too. They want to tell everyone about it. My first donor even went on to donate bone marrow twenty years later, THAT is how much he got out of the donation experience.

As for the girlfriend, I think Person4 has the right idea. It could be fear, or it could be that she cannot handle this. If it's fear, hopefully she will return to you when she takes time to sort herself out. If it's the latter, well, she is not as great as we all once hoped. I picture you laughing about this with your future girlfriend (or wife) because, come on, dropping someone just as they start dialysis will be a classic "worst day ever" story in time. Please give yourself the chance to get to that point.

We're here for you, PersonA. Keep coming back and telling us how you are managing.

Post#6
Person6

My DH[89] and I had been dating about a year when he was diagnosed. (He had been getting progressively more ill for weeks.) Shortly after that, he broke up with me. It was a terrible blow with everything going on, but I told myself that everything was up in the air and we both needed time to figure out what the hell was going on. A couple weeks later, he went on a date with a dialysis tech. (How do I know? I was spying on him, of course!) The day after the date, I went to his house and said look, whatever happens happens but I think we're old enough to be honest about what's going on. I was incredibly calm about everything (despite being devastated) and assured him that I wasn't angry about the date. Was there anything he wanted to talk about? Could we be honest about our conflicted feelings?

After many minutes of him reassuring himself that I really wasn't going to go ballistic about him seeing someone else, it all came pouring out. With great relief, he told me how it was possibly the worst date of his life and they had had nothing to talk about, and nothing in common. He told me some stories, and we had a good laugh.

It wasn't a magical fix for our relationship, but we went on from there and there was a bit less worry about things being blown out of proportion, a bit more confidence that we could communicate.

That was about sixteen years ago...

This is a horrible time for you, and a horrible time for those around you. But it doesn't have to be the end. Dialysis is not a death sentence. People change their minds. New people come into your life. Now is not a good time to be making long-term decisions.....give it some time for things to settle out.
- Person6

Post#7
Person7

you need more than 1 treatment to make such a decision

---

[89] DH = dear husband

ther should be a light in the distance that should be your reason for getting up each day, mine is my wife and child.

don't be too hard on your girlfriend,when people get sick, how do people treat them usually not as a normal person and that all the sick really want

you ned to give it at least a month then reassess and make the decision thats right for you.

is there anyone in your home town that will predominantly listen and offer bits of advice occassionally.

good luck with it all 👍

Post#8
Person8

I agree with everyone here. Give it at least a couple of weeks. Once you're feeling better, and into a bit of a routine, you may see things differently

When it comes to your girlfriend, she may, like you, need time to deal with all the changes. There's a lot to go through in the beginning, not just for you, but for your family members as well. There's a lot of fear of the unknown, and once you've been doing it for a while, and there is so much less of the unknown there, she may come around. If she doesn't, that's her loss.

Post#9
Person9

Something I always tell my new patients is that it does get better. I have seen people brought in on stretchers and 6 months later they are planning family vacations again. It is a long, hard road but it is worth it. I won't ever say I know what you are going through because I don't. I do see all the struggles all my patients go through. I try to give encouraging words. Don't give up so soon. There is more than being strapped to a machine out there. Thinks of dialysis as time for you to socialize with other patients. That's what I tell my patients, I don't work there I only come in to socialize with everyone. 🙂🍺 🍺🙂
As far as your girlfriend goes, if she wants to leave her lose. there are others that are out there that could understand you better and what you are going through or she just needs time to deal in her own way.

Everything happens for a reason, good and bad. If she leaves then maybe there is someone better, if she takes time away maybe she will realize how much she really loves you. AS far as dialysis goes maybe you can learn something from the people there. Everything in life is a lesson whether it be to you or for someone else. Good luck with all.

Post#10
Person10

PersonA, I felt exactly the same way after my first few sesions. It's absolutely shattering, isn't it? BUT, and it's a bloody big BUT, my perspective and attitude changed as I started to feel better and started acceepting the routine. As far as I am concerned I have a 3 days a week part time unpaid job that makes me feel healthier.
Hang in there, buddy. Give it a 3 month trial and then re-assess.

Post#11
Person11

PersonA ..im not going to give you the softly softly approach ..its not my style! Yeah you are depressed, firstly see your neph get something for it . Secondly the girlfriend ..forget her, shes not for you ..her loss ! Why are you ready to give up ? after just one session as well ..thats nothing . Some of us have been doing it for years , some of us have no hope of a transplant. If you have chance of a transplant , then how are you going to do that if you give up?

and imagine how you will feel in the future if you get a transplant , that the thought of giving up crossed your mind? Yes life changes,its now a rollcoaster. Ive had just about everything go wrong , everything thrown at me BUT i wont give up and believe me , ive felt just like you ! Whats the point , why do it . Its a big shock to the system, but there is still quality of life . Its a machine , its 4 hours out of your day but that 4 hours gives you LIFE . Alright it might be crappy at the moment , but it wont always be like that . Roll with the bad times , enjoy the good times , they will come. But get help for your depression firstly 👍😁👍

PS ;and looking at your avatar[90] wow ! I'll be your cougar[91] .. 😀

Post#12
Person12

PersonA, I'm so sorry to hear you're down but I think that's part of be ill. We all get down sometimes but luckily it's not too often. I've been on some form of dialysis for 13 yrs and I've made an educated decision that being on home nocturnal hemo is the best program available next to transplant. As my neph puts it "my body doesn't even realize my kidneys aren't working". Yes, home hemo is alot of work, but I dialyse while I sleep and have a normal life otherwise. I run my household, work out at the gym 4 days a week, I ride and train my horse, walk and train my dog, work 2 jobs, have a fantastic relationship with my husband and our extended family and friends. If this program is available to you, pls check it out!! It will help in every single way!! But in the meantime, look at all the beautiful and wonderul things and people in your life. Don't let the disease take over - there's so much more out there!! Seek out some counsel with your depression - most of have therapists, as do our support givers. It's not the end, it's just a lifestyle adjustment! 😀

Post#13
Person13

Just a few short weeks ago I was feeling a lot like you. For me it took two months on dialysis to get adjusted and to notice an improvement in my health. People here told me to wait it out, because it would get better. I didn't believe any of it. Every day I continued to feel miserable. I connected to a machine 4 times a day 7 days a week. I just didn't see the point in all of it. I was tired of all the pain and worry. Now the treatments are working. I actually feel like I am going to have a life again. It has been hell getting here, but I am glad I held on. I say, talk to your doctor get some meds to to deal with your emotions and any other problems you are having. Then give it two months and if you still believe it isn't worth staying a live then...

Post#14
PersonA

Hi everybody!

I've already made some steps. Today, I reached the bottom of my life and now the path can lead me only up. I was extremley anxious today and when the D tech said to me:"It is not so bad, isn't it" I said to her some rude words.

I saw that I'm really depressed so I searched for help. Been at psychiatrist and got some meds. Hoping, they will work. The doctor was extremly nice and cheered me up.

So, let's go on 🙂. And yes, my ex has a BIIIIIGGGGGGGG loss.
PersonA

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[90] Each member's avatar or profile picture is an image that appears next to every post by that member.

[91] Cougar: an older woman who dates a younger man (slang).

Post#15
Person11

Glad to hear it , now just take it a day at a time .. 👍😁👍

Post#16
Person12

👍👍:thumbup;Great news!! Onward and Upward I say!!

Post#17
Person3

I am so glad you are feeling more positive, it will get better.

Post#18
Person15

Think long term, because the dialysis will make you feel better in the long run, though it may be difficult at first.
As for your girlfriend, I can understand your feelings of devastation upon having her call it quits when you need her support most. That must really hurt. Maybe consider a way to get the word out that you are in need of a transplant and that dialysis is difficult for you. Hold out hope for a living donor and make sure you are activated on the cadaver transplant list. From what I hear people say on this forum, dialysis does get better with time and hopefully you will start feeling better too.

Post#19
Person2

[consent not obtained to include this post]

Post#20
PersonA

Person2, I'm doing better now. After my Friday's session, I wasn't tired at all and I could immediately proceed with my usual activities. Apparently my great phisicall condition contributes to good mood after session.

I can see that D at the moment will not be a major obstacle in my life, cause the break up bothers me much more. But I think I will manage them both.

Thanks for asking,
take care,
PersonA

Post#21
Person16

[Quoting Post#12]

My husband has been on dialysis for 13 years as well, and for the last 4 years nocturnal home hemo as well. If it is available to you, and you are able it is definitely the way to go next to a transplant!! My husband is very active as well. The depression does get better with treatment. It is normal to go through a proces similar to greiving when you lose your kidney function. Take care!! 😁😁

Post#22
Person17 (me)

PersonA - this is great news to hear you sounding more resilient. 😁👍
I guess there's going to be more ups and downs, but you are a strong healthy fellow and looks like that will stand you in good stead!
👍👍👍
We are all right here with you whatever happens next.
🙂

Post#23
Person18

PersonA
When I started dialysis I thought my life was over. I had no concept of what dialysis was; I thought it was like an iron lung where you were hooked up to the machine 24/7 and never got to go out or anything. When I did start and saw how it was, I was still grumpy and didn't have much to say to my fellow patient sitting next to me. I still thought it was a death sentence. As time went on it became easier and easier. i opened up to my fellow patients and to my nurses and PSWs. I advocated kidney groups and got involved with the local chapter of the Kidney Foundation. I eventually returned to work full-time and have resumed as normal a life as I can. Nowadays I feel so good that I don't feel sick or weak anytime. I just treat dialysis like an extended doctor's appointment three times a week. Just as something else that I have to do.

I'm glad you've chosen to continue your treatments. I had one dialysis friend who needed heart surgery for calcification of the heart. He didn't want the surgery and also decided to quit hemo altogether. The nurses told me of his situation and wanted me to talk to him. They wheeled him over to me and we talked for two or three hours while I was on. After that he asked the nurses to hook him up. His nurse came over to me afterwards and thanked me for talking to him. Unfortunately he never made it to the surgery. He was a good friend and I will miss him dearly.

It seems bad and there will be times it seems totally overwhelming. Life is so precious. Fight onwards. Embrace life.

Post#24
Person4

PERSON A - great to read that you are feeling more positive about how you can live with dialysis. This is really good to read. Life isn't about Dialysis. Dialysis is about Life.

Post#25
Person19

deep sigh here.. I can just say im Soooooooooo glad things are a bit better for you.. Lots of life is tough, and you sure got punched at a horrable time, but im just glad your a 'stick it out' kind of guy, and life will once again become what you want it to be. This 'D' stuff,,,, minor INconvience once you feel the effects.. And heck, ya always got us here to come to Hope you even better today :-)

Thread B: I AM BORG

Thread B, titled “I AM BORG”, is a discussion about the normal development of a fistula for renal dialysis, which is often an enlarged vein created surgically by joining a vein and an artery. Commonly located in the arm, Figure 10.1 (next page) shows an example of a fistula though there is a great deal of variation from person to person. A person may have a fistula "installed" quite some time before they start dialysis, in order to allow it to develop and mature before use.

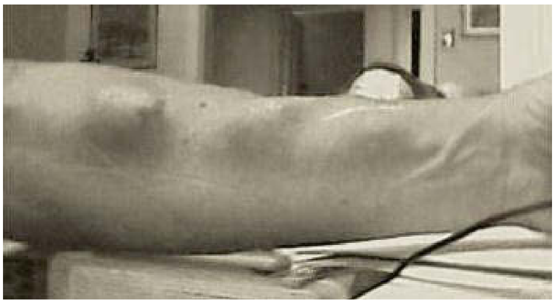

Figure B.1: A fistula (the three lumps running along the length of the arm)

Thread B is initiated by a person has not begun dialysis, has a relatively new fistula and has noticed that she can see her veins beginning to enlarge, all the way up onto her chest. She asks, "Is this normal?"

Topic: I AM BORG![92]

Post #1
PersonB
> Just a quick question as I need a bit of reassurance. I just got out of the shower, and I happened to notice how pronounced my veins are in my left arm and up into my shoulder and onto my chest. My fistula is in my upper left arm. It looks as if someone has taken a thin paint brush and has painted light blue lines all up my arm, AND the lines are in 3D. Is this normal?

Post #2
Person2
> First, make sure you don't have two pairs of glasses on. My veins are definitely more pronounced on my fistula arm.

Post #3
Person3
> It is totally normal [nickname]. They get more pronounced since they are rerouting the blood due to the fistula creation. The main fistula vein will develop even more as it is used and mine is quite large. As hard as it is to do, I try to befriend it and view it as my lifeline which of course it is when we're on D[93]. Mine shows no sign of going anywhere despite transplant almost two years ago. 🤗 [see footnote[94]]

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[92] The "Borg" is an alien civilisation depicted in the TV series "Star Trek". They are warlike, and actively invade other species. They then "assimilate" individual members of vanquished species by adding machine parts (including a robotic eye) and connecting their conciousness to "the collective" borg mind. Then the knowledge of the individual is shared with the collective knowledge, to which the individual also gains ongoing, reciprocal access. In this way, the Borg are seen as "one".

[93] D = dialysis

[94] This animated emoticon "hugs" the recipient.

Post #4
Person4

Yup, normal. I've still got a place below my collarbone on the left side that everyone thinks is bruised since there are so many extra veins just below the surface.

Post #5
PersonB

Thanks so much for the reassurance! I figured it was normal...it makes sense that if the whole point is to enlarge your veins to make access to the bloodsteam easier, then that blood path is going to be enlarged. But I'm still relatively new at all this, and the occasional word of reassurance means a lot.

I don't really care how it looks. My mother's fistula got enormous, and it looked particularly big since she was a very tiny woman. I know she was bothered by how it looked, but for me, I don't care...I just want it to work.

Again, thanks.

Post #6
Person5

> *Quote from Post#1:*
> *First, make sure you don't have two pairs of glasses on. My veins are definitely more pronounced on my fistula arm.*

Same here and hospitals would love to use that arm till they find out that there is a fistula and a graft.

Post #7
Person6

yeah, it's normal. I have a spot in my upper arm, close to my shoulder, where the vein is rather close to the surface, and it looks like it's bruised. It hasn't been needled yet, but I'm sure that when it is, it will be one heck of an access point.

I have one of those lovely psuedoanyerisms near my elbow. From time to time it will pulsate, and I can actually see it pulsate. It freaked me out the first time I saw it, so I kinda did what you did, and went to twitter. Within a few minutes, I was told by several people that it was normal.

Post #8
Person7

Yes, this is normal. I have an upper arm A/V[95] graft and I have three or four big, blue raised veins going from my chest to the front of my shoulder. Our vascular nurse said they were big enough to needle if need be.

Post #9
PersonB

> *Quote from Post #6*
> *I have one of those lovely psuedoanyerisms near my elbow. From time to time it will pulsate, and I can actually see it pulsate. It freaked me out the first time I saw it, so I kinda did what you did, and went to twitter. Within a few minutes, I was told by several people that it was normal.*

I think I have a pseudoanuerysm, too...sort of a knot adjacent to my scar that I can see pulsate. Creepy.

Post #10

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[95] A/V = *arteriovenous, referring to the joining of an artery and a vein. An AV graft is like a fistula, but the connection is made with synthetic material.*

Person8

It's always something you can scare kids with, though. [see footnote[96]]

Post #11
Person 6

> *Quote from Post #9*
> *It's always something you can scare kids with, though.*

When I was a kid, I used to have line ups of kids wanting to feel my fistula.. they thought it was the coolest thing.. *L*[97]

Post #12
Person9

Captains Log; Stardate 29th December 2010.[98] The collective have decided you cannot be BORG for although you share the group ideal you do not have any tubes protruding from any body parts ..LIKE ME ! I am therefore BORG but you may be Klingon ? [see footnote[99]]

Post #13
Person10

[consent not obtained to use this post]

Post #14
Person6

Hey Person9.. I think we still qualify as Borg with just a fistula.. we still need to regenerate at regular intervals....

Post #15
Person9

I am sending this communication as a direct download as we speak. I am in my station re-charging ..

Post #16
Person11

[consent not obtained to use this post]

Post #17
PersonB

Laughter is healthier!

Post #18
Person9

Nah Assimilate him !

Post #19
Person12

[consent not obtained to use this post]

Post #20

---

[96] this animated emoticon makes a "cheers" motion with the steiners

[97] *L* = laugh

[98] References in this post are to the Star Trek series: narration in the show is accomplished by voice-overs in which the Captain of the "Enterprise" reads from / writes into his log. Star Trek is about the adventures of the crew on the Enterprise, a spaceship. The Klingon are another alien race in this show, who have a humanoid appearance but a large, forehead featuring a row of furrows.

[99] This animated emoticon "rolls on floor laughing" whilst slapping the ground.

Person9
Make it so ....[100]

Post #21
Person12
[consent not obtained to use this post]

Post #22
PersonB
I suppose Resistance is Futile. 😕

Post #23
Person6
Quote from Post #20
Quote from Post #19
Make it so ....
ok it will be no tribble at all
NO TRIBBLE!! NO! cute, fuzzy, nasty beings... although, when my cat lays the right way, he looks like a large, orange tribble

Thread C: Stint Removal

The third thread presented here concerns the removal of a "stint", most likely a Ureteric Stent, a hollow flexible plastic tube which is used to relieve obstruction in the ureter, between the kidney and the bladder. Patients who have received transplants may have a stent placed to support the connection of the new kidney to the patient's existing bladder. The first contributor to the thread, who I refer to as Person C, is a recent transplant recipient.

Topic: Stint Removal

Post#1
PersonC
In a little over a week I am suppose to have the stint removed after I had my transplant over a month ago. For those who had this done what was their experience and what should I prepare for? I would hope to be put under. Should I worry or is it nothing to be concerned about? I was told it was not exactly pleasant for the male patients.
PersonC

Post #2
Person2
For me ,the event was much easier than I expected. Some pressure going in, but once they get ahold of it, the stint comes out like a strand of spagetti in about 2 seconds and that it. I think I had a couple of drops of blood in my urine

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[100] An encountered Star Trek character is called "Q", who is known for saying "Make it so".

over the next 24 hours but that is expected.
Person2

Post #3
Person3

I had mine out 5 days ago. Being female, my experience was significantly different from what yours will be, I am sure. I had myself so worked up about the stent removal that I couldn't think about anything else for weeks  [see footnote [101]]

The whole procedure itself was over in less than a minute. I was able to watch the removal on the same monitor as the urologist. Oddly, I had to request the numbing gel placed beforehand because apparently my urologist's office had stopped using the gel because it interferes with lab results (I told the nurse that I wasn't having anything done for the lab, so give me the numbing gel!!!) and I can honestly say the anticipation was worse than the actual removal. No pain other than having my dignity hurt by having to bare my bottom, have my privates washed in antiseptic, having the gel placed and then the actual procedure. Again, being male, your experience will obviously be different than mine because of the extra plumbing involved.

To be blunt and truthful, the stent was not at all what I expected... It looked like a plastic coated electrical (small gauge) wire w/o the metal wire inside the plastic - the urine flows through the center and it was curled at the ends to keep it in place. Mine was about 4 inches long. I was expecting something that looked more like a heart stent not something I would find in an electrical gadget or my toolbox.

I did not have any bleeding or discomfort after the removal. I drove the 75 miles home and had a relaxing rest of the day because I no longer had to think about the dreaded stent removal  [102] Talk with your doctor about the least stressful way to have the stent removed - the gel was enough for me, but perhaps not for a guy.

Post #4
Person4

I tried to find the thread that had this discussion before, but did not find it.

Well for me it was nerve wracking and slightly painful. One, I didn't know what to expect, this was not discussed in pre transplant seminars or during hospital stay till release. Second, it is like getting a urinary cath stuck in and then taken out that is taking longer than usual, numbing cream did not help one bit, had a female nurse watching (not comfortable about that part), burned to urinate after procedure for a bit. It was not fun for me.

Post #5
Person3

Person4- I encountered the same thing... Nobody said anything about a stent placement. I found out about it here and asked about it. I also requested that a stent not be placed if at all possible. Apparently not all surgeons use them. When I had an ultrasound done two days post-tranplant, I asked the tech to look for a stent, she said she didn't find one, but that didn't mean I didn't have one. Since nobody said anything about a stent placement post-transplant and the tech didn't see one, I thought I was off the hook. Then I received a letter from a urologist's office at the hospital telling me they had scheduled an appointment to remove the stent...  [103] I called my coordinator

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[101] Tears roll down the face of this emoticon

[102] These animated emoticons raise and lower themselves in a bow.

[103] I have shown three shots of this single animated emoticon to demonstrate how it becomes nauseous and vomits a green puddle.

and asked her to look in the actual surgery notes to make sure one was placed because I didn't want the urologist to get in there and not find anything to remove.

A foley catheter placement would be a good description of the procedure, but the scope was much narrower in diameter and the numbing gel worked for me. I have had caths placed before, but I was always under anesthesia so I didn't feel a thing and wasn't even embarassed, lol.

Post #6
Person5

wasn't as bad as i was making it out to be...whole procedure from start to finish lasted less than 10 mins...male nurse used a syringe (without a needle) to shoot some type numbing medicine down pee pee hole which numbed me instantly.I watched the same monitor as the Dr did as he inserted a "scope" in me and inserted some type of grabber to get a hold of it and pull it out.Not to be dreaded!! wouldn't wanted done everyday but been through worse..Hope this will easy your mind. God Bless!! [Person5] BTW[104] little burning afterwards but no biggie 🙂🍺🍺🙂

Post #7
Person6

My experience, as a woman, wasn't bad at all. A tad uncomfortable, but no pain. Good Luck.

Post #8
Person7

I had it done last October. They get you into a standard room with a special chair. First a nurse will come in the tell you to put on a gown, and NOTHING underneath. She will explain everything to you. You sit on the chair and raise your gown up and expose yourself (yeehaw !).

Nurse will wipe betadine all over your genital area. Then she puts some numbing cream inside your urethra. Puts some cloth around the penis leaving it exposed for the doctor.

Doctor uses a cystoscope (flexible tube with camera at the end). It's small so it fits in the urethra. They have saline flowing out of the cystoscope so it can travel up the urethra easier.

I had the exact same concerns you have. I was like, "You're gonna go up !@#! and pull what out of my @#$! ? But it's not bad. There was a point where the pressure got slightly too much and I had to pinch my "butt-hole" muscle (sorry but that's the best way I can say it), but it was like a brief second.

Once the doctor grabs the stent, it comes out in one nice fluid motion. The sensation is like when you go pee.

All in all, the cystocope was in and out in less than a minute. It goes by realy quick. Before you can start complaining of any pain or un-easiness, it's over.

You may have to pee right after, because the saline they have running goes into your bladder and you automatically get the "pee" sensation.

It's normal to have slight stinging sensation when urinating afterwards. Mine went away the next day. Maybe a little blood. All normal. The relief you have afterwards is awesome. You'll find that all the anxiety over it was unecessary.

I don't know about you, but when I got my transplant, they had a cath placed in my urethra for urine. If you had that already, then this should be nothing new to you.

---

[104] BTW = by the way

Post #9
PersonC

I had the stint removed that was placed in me after they transplanted the kidney via cystoscopy which is a procedure that was none too pleasant. However it is over with and with some discomfort, some bleeding and burns when I urinate. I guess no pain no gain. Hopefully after this it is smooth sailing.

Post #10
Person3

Glad to hear you made it through relatively unscathed. Was it as bad as you anticipated?

Post #11
Person8

Sorry that I missed this thread before the event PersonC - glad to read it is over and done with without too many problems.

Just for completeness I'll recount my experience because it seems everyone (and I am going to focus on the males here since it's quite different for the genders) has a different one.

For me, it was almost comical in a way. I was dreading it, like most males, and having a female doc tell me it was "nothing" didn't help. lol

Anyway I came in and they basically said get on the couch, PULL YOUR JEANS AND UNDERWEAR DOWN (don't bother taking it off!! No serious!!) like back and think of England (glad I didn't think about Kate Middleton[105]).

The whole thing was done in under 10 minutes. Yes, it's embarassing with these nurses wandering around while your junk's out in the limelight(as it were) and yeah I think the thought of what is actually going on is more scary/painful than the act. I would say the actual pain/discomort level is up there with having a catheter removed - it's not fun but it' over with relatively quickly. I think in sum total they had the thing in there for maybe 2-3 minutes (though it did seem longer) while they searched around for the stent, found it, and pulled the bugger out. Injecting the liquid local or whatever it was was unpleasant but I suppose once it kicked in it was mostly OK apart from having some bloke mucking around with you down there in a way you don't want!!!

Really though it was a relief to have done, but I would agree with everyone else that says it's almost like the bark is worse than the bite.

Post #12
PersonC

Person8, I am not sure if there was not a bite. The nurse I had was good. She put in the numbing cream which I supposed helped and the second woman was just assisting because she was new and wanted to know if this was going to be her next career move. I was put on a table told to remove everything except my shirt and they gave me a hospital gown. It was when the doctor came in and he put the probe in was when I felt everything. He said there was a possibility my prostate was enlarged and I think that was most of the problem. Felt like it took longer than it really was. I survived and I still wish I had been put under. I did not sleep all night and with all that has gone on in the last six weeks including the transplant...this seemed the most stressful.
I know that is silly, but glad it is over.

Post #13
Person9

I know you already had the stint removed, but I want to give my take on it

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[105] In 2011, Kate Middleton married Prince William, heir to the English throne.

hoping my experience could help someone out. Here is a good rule of thumb as to whether or not you should be put under to have the stint removed. If you felt tremendous and I do mean tremendous pain when they removed your catheter after the transplant make sure you call the Urologist and request to be put under. I had a major surgery twenty years ago and I was still in recovery and I had just opened my eyes when a nurse said we are going to remove your catheter and next thing I know I experience the worst quick burst of pain I ever had in my whole life. Jump ahead to my transplant and all four days I had the catheter in I had several occurrences with urine backing up from the long drain hose and it hurt really bad and every time the different nurses looked at me like I was nuts. When they took out the catheter I started screaming so loud a nurse came flying up the hall to see what was going on. Just like twenty years ago when I had the catheter out it was a pain that was off the charts. I went to see the Urologist to have the stint out and it is a very large practice with a ton of elderly patients, so this doc is a real pro at it and he has probably done a ton of them over the years. The nurse puts in the numbing gel and I thought it was just a saline rinse because I was in a ton of pain as she was putting the numbing gel in. The doc comes in and he spends literally three seconds in me and he stops because I jumped twice and he could see I was in a ton of pain. He stopped and said we get one or two a year that we have to put under because of the pain. He was real cool and he said the procedure barely lasts a minute, but you can't do it awake. After he left the room the nurse tells me I made her jump because I was bouncing around so much, I said to her I thought they give you some kind of numbing gel for this and she said I already did earlier. I was shocked because I could not imagine what it would have felt like without the numbing gel.

I know I am in the minority because the nurse at the hospital who took out the catheter remarked she never witnessed a reaction like I had from removing a catheter. If anyone reading this had a ton of pain getting the catheter out I would see if they would agree to knock you out for the stint removal because the catheter is out in say three to five seconds, now imagine that same pain for fifty to sixty seconds.

Thread D: Using Blunt needles

In this thread, the first person to post (Person D1) had relatively recently begun dialysis at home and was getting used to the techniques for putting the needles into her arm herself, unsupervised. She sends a message to the group to clarify needling placement techniques. She refers to a ‘blunt’, which is a kind of needle. Other contributors are pleased to hear that she is using ‘blunts’ as this implies that she is attempting to develop ‘buttonholes’, permanent locations in the fistula where blunt (rather than sharp) needles can be inserted. ‘Buttonholes’ are regarded as easier to use and more durable over the long term use but are not always easy to develop. The next (unrelated) post in the thread is about fluid removal, which is one of the purposes of renal dialysis: to remove fluid and toxins from the body, replacing the function of healthy kidneys. The ‘right’ amount of fluid must be removed: if not enough is removed, it is hard to breathe and swelling appears in places like the hands and feet; remove too much fluid and the patient becomes dehydrated. Beyond this, if fluid is removed too quickly, or too much fluid is removed in one quick burst, then the body experiences too much change at once. Usual symptoms related to rapid fluid removal are cramping, headaches, dizziness, passing out, or (as pointed out in this thread) more dangerous effects on the heart.

Thread D: Using Blunt needles

Post#1
PersonD1
Hi All, I have just started using blunts after my recent blowout i thought it was time to give them another go. After inserting the needle i turn it so the eye faces downwards. Just have to twist the canula.
Do i need to turn the needle back before i remove it after dialysis. ??
Or can i just pull it out in that position. Thanks.
PersonD1

Post#2
PersonD2
[consent not obtained to include this post]

Post#3
PersonD3
Just a quick reply.....You can just pull it out PersonD1:) good to hear your giving blunts another try.

I will catch up with emails tonight, sorry guys.
Cheers PersonD3.

Post#4
PersonD1
Thanks PersonD3, it was just one of those little things that just crop up from time to time. Not sure if i was doing it right or not.
PersonD1

Post#5
PersonD3
We all have those moments PersonD1.... 🙂
I was wondering if everyone who are doing their dialysis at home, use a antibacterial cream on your buttonholes after you have finished dialysis at the bleeding has stopped?
cheers PersonD3.

Post#6
Person4
Hi PersonD1
I had really limited success with blunts but i think the principles would be the same for both blunts and sharps. I see no reason why one would have to rotate the needle back before removal after dialysis.
cheers
Person4

Post#7

Person5

Hi PersonD1
I was definitely a 'blunt gal' and used to rotate to help the flow (worked much better particularly with the arterial) and no, you don't need to turn the cannula back for removal.
Look after yourself PersonD1, you have come a long way!
Love Person5 XX

Post#8
PersonD4

Hi PersonD2,
PersonD2, What does the nursing staff say adout 6kg to take off?
You are doing much damage to your heart dy getting such a big fluid intake. Over a period of around 5 hours of dialysis your blood level is about halved and your heart will get very "soft" and not be able to function if you keep doing this. If you want to stay healthy, cut back on your fluids now. This is important!!!!!
Regards, PersonD4.

Post#9
PersonD4

Hello PersonD1, Glad you are trying dull needles again. I don't rotate my needles, it doe not seem to acheic=ve any thing. But if you do, there is no need to rerotate them to pull them out.
PersonD4

Post#10
PersonD4

Hello PersonD3. We use an alchol wipe supplied in the kit when we are coming off. The wipe is put under the gauze before the needle is removed and kept in place untill the bleeding has stopped, then discarded with the gauze, then a pressure bandaid is applied.,
regards, PersonD4.

Post#11
Person7 (me)

Hi PersonD3, your question reminded me of a discussion I took part in on another dialysis message board. A person there who is a doctor of some kind and also is on dialysis, and who uses blunts and buttonholes, posted a detailed description of his sterilisation techniques.

[URL]

Post#12
Person8

Hi PersonD2,
I'm assuming they tell you how much fluid you can drink/intake between dialysis sessions? The MOTH[106] is limited to very little (not sure how it has settled but think it is around 500ml per day). He is very very strict with this, and they are only taking off small amounts (1kg give or take) each session even though over the weekend he doesn't have dialysis for 2 days. How much do they tell you to limit yourself to? (if you don't mind me asking)

Just curious.........Person8

Post#13
PersonD4

[consent not obtained to include this post]

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[106] Man of the House

Post#14
PersonD2
[consent not obtained to include this post]

Post#15
PersonD2
[consent not obtained to include this post]

Post#16
PersonD1
Thanks Person5, I am doing quite well on blunts, don't want to jinx myself by bragging lol. But i do feel allot safer. After reading an article that i think PersonD4 put on the site i am now being careful about (hubbing) pushing the needle in too far. Think i have been doing that. So much to learn so short on time. I WANT some life back. Still getting there slowly
PersonD1

Post#17
Person9
Have you considered doing overnight, nocturnal dialysis?

I do dialysis 3 times a week for 8 hours each time and never feel washed out, work full time, etc. I take off 3kg each time maximum.

If you haven't already, I'd recommend buying small glasses. Helped me cut down on my fluid intake at home.

Post#18
PersonD1
PersonD4 i found this article very useful, as i think i push the needle in to far. You certainly do have to push harder with the blunts and the skin does tend to bunch up, for want of a better word. There are so many different techniques but all this info does help.

I only use gauze after pulling the needle out, dry gauze. Does anyone put alcohol on. I don't have alcohol wipes as we don't get individual packs.
PersonD3 i don't use antiseptic cream, should i be using it ???
PersonD1

Post#19
PersonD3
Hi PersonD4,
Thanks for the reply. It is funny how different centres do different things. We don't use any antibacterial cream at the moment, but our home training nurse told us they are now doing it that way to help with infection. [Husband] and I were just wondering how many other centres are doing the same. We really don't have a problem with infection but that isn't to say it 'couldn't' happen.
I guess it is better to prevent than to treat. 🙂
cheers PersonD3.

> *Quoting Post#9*
> *Hello PersonD3. We use an alchol wipe supplied in the kit when we are coming off. The wipe is put under the gauze before the needle is removed and kept in place untill the bleeding has stopped, then discarded with the gauze, then a pressure bandaid is applied.,*
> *regards, PersonD4.*

Post#20
PersonD3

HI Nat,
Thanks for sharing that with us. I had a good read. It is an interesting topic. Personally, I think it is the cleanliness that is the issue, not how long the needles are in the arm for.
cheers PersonD3.

> *Quoting Post#10*
> *Hi PersonD3, your question reminded me of a discussion I took part in on another dialysis message board. A person there who is a doctor of some kind and also is on dialysis, and who uses blunts and butttonholes, posted a detailed description of his sterilisation techniques.*
> *[URL]*

Post#21
PersonD3

HI Person8,
that's a very low restriction, poor MOTH. I think if [Husband] had to go back to day time dialysis with shorter hours he would find it very hard to deal with. He has no food or fluid restriction on him.
At the very most he removes 2.3kgs. On average he removes 1.4kgs over an eight hour period.

cheers PersonD3.

> *Quoting Post#11*
> *Hi PersonD2,*
> *I'm assuming they tell you how much fluid you can drink/intake between dialysis sessions? The MOTH is limited to very little (not sure how it has settled but think it is around 500ml per day). He is very very strict with this, and they are only taking off small amounts (1kg give or take) each session even though over the weekend he doesn't have dialysis for 2 days. How much do they tell you to limit yourself to? (if you don't mind me asking)*
>
> *Just curious.........Person8*

Post#22
PersonD3

Hi PersonD4,
very interesting indeed. [Husband] does have alittle hubbing I feel on his arterial line. We will remember to not push the needles all the way in. We actually thought we were doing a good thing by making sure it was all the way inserted, but this article really does make a lot of sense.
thanks for sharing it.
PersonD3

> *Quoting Post#12*
> *I found this article about hubbing. I was tought to push the needle in until it was competely hidden, now I am wondering if this is good.*
> *http://www.nwrenalnetwork.org/Fist1st/Hubbing.pdf*

Post#23
Person8

Hi PersonD3,

Just asked the MOTH and he says he can have 750ml "give or take" now. I think perhaps the 500ml limit was when they weren't sure where his dry weight was going to settle. Still a meagre amount though! Got him a free drink one night when my son & I told the bar man to make his drink right as he had saved up to have a special drink that night! Bar man said "geez if that's all I could drink it would kill me - can't charge a man for that"! He he - gotta be some compensations I suppose............Person8

Thread E: Transplants [Text not included]

Thread F: [Text not included]

Thread G: Major Rant. Do not read if you are in a good mood

This thread was also posted in the 'off topic' section of a discussion board. One way that a person can read this discussion board is by looking at the list of 'recent posts'. Therefore, during the time that this discussion was ongoing, a person could come across it in the 'recent posts' list and not realise that it is 'off topic'. They would then be likely to expect that the promised 'Major Rant' is on a renal topic, most likely therefore, a problem with care: bad doctors, medical errors, outrageous behaviour of staff, terrible dialysis clinics or the like. Such an expectation would heighten the humour of the first post and subsequent replies.

Thread G

Topic: Major Rant. Do not read if you are in a good mood

Post#1
PersonG

Well, it's official.

I am old and no one gives a XXXX.

ABC cancelled the soap opera All My Children; it's last airing will be in September. "Big flippin' deal!", you may say, and it's true...it's only a TV show just like all of the other tv shows on the telly today. But I've been watching it since it started in 1970. It's the only soap I've ever watched. I have a history with this show, and I am furious that it is being taken off the air because most of its viewers are female and are my age and are considered virtually invisible.

You know what they are putting in its place? A cooking show with Mario Batali. Did you know that according to a study that came out yesterday, Americans spend less time cooking than any other nation on earth, yet we have more cookery programs than you can shake a stick at. Mario Batali? I'm sorry, but I can't spend an hour looking Mario Batali doing anything, much less cook Italian food. For God's sakes, I live in effing Chicago in which there is no dearth of pasta.

Now, I don't consider myself an old fogey. My son calls me from London to give me some music recommendations for my MP3 player, and I have some pretty "out there" stuff. I'm cool. I watch SNL and Colbert and Jon Stewart like a lot of cool people do, not because I want to be cool but because I find them clever and amusing. And I don't think I am a prude, but I challenge all of you to sit down and watch one of these shows and count how many times they talk about pen*ses. Since when did male genitalia become the greatest comedic gag of all time? It's not just sex that is the topic of laughter, it's MALE sexuality and the adolescent nature of it, and it is so pervasive that it just astonishes me. Do you men really find your dangly bits so damn funny? I'm not offended, but I am massively BORED TO BITS WITH YOUR BITS!!

OK, so soap operas are not high browed viewing. But neither are the gazillion "reality" shows, especially that one where contestants are in those puffy suits and try to get through bizarre obstacle courses. Geez, we're getting our TV ideas from the Japanese! At least soaps have a history of starting important social conversations. The only conversations these days on TV are about MEN'S BITS!!

I'm not of the sought-after demographic anymore. That has been made abundantly clear. I don't identify with men who somehow lose all intelligent thought when they have access to beer or some new-fangled fried food item with a billion calories. Why do men make these sorts of commercials about other (usually young) men? I would be insulted if I were a young man. But I'm an old lady, and I've been thoroughly reminded by TV executives that I don't count and that I am invisible.

Have a nice day.

Post#2
Person1

I'm sorry. I don't watch soaps, but after so many years, I think it'd be like losing a friend.

Post#3
Person2

Sorry. I actually watched this show in college. I rented an apartment with 3 girls and got caught up in it. David Canary, who played Adam & Stuart hung out at the local saloon in my home town on many occasions.

Post#4
Person3

Change is hard.

And losing something dear and familiar is even harder.
So sorry.

Person3

Post#5
Person4

I am in a good mood PF[107] and I just have to tell you that you made me laugh out loud. Not at you of course but at how you describe things in this little rant. Change is unsettling and even more so when we don't feel well and something is part of a routine that helps to pass time. and sorry you're losing your show and for the little giggle. I don't like Mario either btw...whatever he's eating I want to stay away from on health grounds.

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[107] The usual nickname for Person F is based on initials, so I have substituted with initials of 'Person F': 'PF'

Post#6
Person5

Rant away! I can totally relate to the frustration that comes when things familiar and comforting are taken away! We've lost so much already, these "little" losses are BIG because they are added to an already full load of loses!!!!!
so sorry!

Post#7
Person6

Wow, just picturing the collection of boxed sets of seasons for that! And most TV shows sell a single season for $30 to $50. $2,000 for the complete set! Can you imagine?

I bet they do it! Just think, PF - you could start over and see it from the beginning!

Post#8
PersonG

Quite a few soaps have been cancelled recently, and there have been no boxed sets or anything because you'd probably have to have a separate house in which to store them. But I do have a DVR machine, so I might record the final episodes for posterity. The writers have plenty of time to wrap up lots of storylines, so I'm hoping that most characters will get their happily ever afters.

I guess TPTB[108] have decided that all viewers are happy watching cheap crap on TV. You have to pay for actors, writers and crew in a soap, but if you just stick Mario Batali in front of an oven for an hour, that doesn't cost much, so that's what we get. Another soap is being replaced by yet another "makeover" type of show. Doesn't that sound like compelling viewing? And they wonder why ratings are going down for all shows across the board. One show is just like the next.

Do any of you remember back when dirt was new that a series would start in September, run through the new year and then have repeats until the summer? Year after year, this is the way it worked. But now you never know when a network is going to show a new episode of any given series. I do like some of the half hour comedies...Modern Family, The Middle, The Office...but they'll show repeats for weeks on end for no discernable reason. I guess it's another money saving measure.

There are just so many memories attached to All My Children; it was the only link I still had to my past. My parents are both dead now, and I'm having to sell the house I grew up in. My dad used to tape the show, and we'd watch it in the evenings together. My autistic son would even watch it with us, and when he is here from London, he will gradually get pulled into it again. I know this sounds silly, but All My Children was instrumental in my son's social development. Autistic children have real problems understanding social relationships and reading non-verbal cues. They have trouble with empathy and "theory of mind". So I would often use All My Children as a teaching tool and have discussions with my son about who was feeling what and why. I would ask him to guess what might happen next; it helped him to anticipate characters' reactions and made him think about how someone's actions could impact another person. The acting style of these types of shows were somewhat exaggerated which made reading non-verbal cues a lot easier for someone like my son.

I've got so many other stories about this show, but it makes me terribly sad to think about them so I won't go into it; you all can breathe a sigh of relief. When I moved back to the US from the UK back in 2003, the one thing that settled me down the most was the fact that I'd get to see All My Children every day, something I had not been able to do since I left the US back in 1985. Chicagoland is still foreign territory to me, and now yet another lifebuoy has

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[108] TPTB = the powers that be

been shattered. I am completely and totally bereft, and it feels like such a huge loss. I'm sure I don't have to explain that it is not so much the show itself as it is what it has represented to me for all these years.

Oh, and to add insult to injury, I find it to be particularly galling that they are replacing my show with a FOOD PROGRAM which is undoubtedly going to feature food that I CAN'T EAT BECAUSE KIDNEY PATIENTS CAN'T EVEN DRINK WATER WITHOUT RISK OF DEATH. Do you think Mario Batali et al would ever even *consider* devoting an episode to renal-friendly food? I so totally think NOT. 🙄🙄🙄🙄🙄🙄🙄🙄🙄🙄🙄🙄

Post#9
Person2

I am at a loss. I feel so bad for you. 🫂 🫂 🫂 🫂 🫂

Post#10
PersonG

> *Quote from: Person2*
> *I am at a loss. I feel so bad for you.* 🫂 🫂 🫂 🫂 🫂

I know it is so so so so so so stupid in the grand scheme of things, and I will live and get on with life. But I feel really sad about this silly thing, and I'm not gonna apologize for it. Sometimes you spend so much emotional energy in coping with the big stuff...death, dialysis, CKD[109]...that there's nothing left, and a small loss just sends you over the edge.

You're so sweet. Thank you. 😕

Post#11
Person7

I don't regard my dangly bits as being at all funny!

Post#12
PersonG

> *Quote from: Person7*
> *I don't regard my dangly bits as being at all funny!*

Well, it seems that most of America would find them to be hysterical and would want to feature them in every TV show on the air...at least on the cable networks. 😛

Post#13
Person8

I understand your pain, PG; I imagine this is how I'll feel when the BBC cancel EastEnders. I remember watching the first episode in 1985 (I was 10) and I've watched every episode since (minus a few.) I can't even stand people criticising it, and despite everybody else finding it devoid of humour and completely miserable, I notice all the funny-ness that is subtley worked in by clever writer people.

😁

Perhaps if enough people kick up a fuss another channel/network/company/whatever will take it on. It's happened before; it can happen again.

huggles

Post#14

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[109] Chronic Kidney Disease

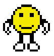
Person9

Quote from: Person7
I don't regard my dangly bits as being at all funny!

well you made me laugh out loud this morning with that comment!! SO i guss I find them funny... hahahaha 

Post#15
Person10

I understand your pain PG.

I felt the same way when they took the Kroft Supestars off the air.  [110]

Post#16
Person11

I just said that my husband as I read it this morning. "They're putting some stupid cooking show in it's place?" I yelled out. It's like the end of an era.

Post#17
Person12

My husband's grandmother said, "They discontinued my shade of lipstick and my favorite shampoo. They no longer have the shows i like on TV and my hairdresser has retried. Pretty soon I will be discontinued!" (She was 92 at the time.)

Post#18
Person13

Quote from: Person7
I don't regard my dangly bits as being at all funny!

I think I would find them funny. Heads up all who would find Person7's dangly bits funy? 

Post#19
Person14

I was already in a rotten mood, so this was a good post for me to read. 

When you've been watching a show for a long time, it's hard to say goodbye. I remember how bad I felt in my youth when long-running shows, like Candid Camera, finally came to an end.

But the main reason that soap operas are dwindling is that fewer women are home to watch them anymore. The original demographic for soap operas was stay-at-home moms, maids, and housekeepers. And there just aren't enough of them anymore.

Today's young women aren't even watching as much broadcast TV (any genre) as their parents did; they've got iPods and iPads and the Internet for entertainment. I can remember when a hit prime-time TV show could command at least one-third of all the viewers in America. Today, no show can do that because the viewing audience has become so fragmented.

Time moves on.

As far as food programs are concerned: I imagine it's a question of image. Many viewers who can barely microwave a TV dinner watch the Food Channel to give them the feeling that they themselves are gourmets and world-class cooks. The same way that TV commercials of SUVs[111] often show them off-road in rugged terrain and wilderness--while most purchasers of SUVs are suburban women who only drive them back and forth to supermarkets and

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[110] This animated emoticon waves happily at the viewer
[111] SUV = sport utility vehicle

shopping malls. Such a woman can imagine herself as a frontierswoman in a wagon train crossing the Plains, as she cruises around looking for a parking space.

Post#20
Person15

I can totally relate!!

Today while I was riding in the car to work I heard on the radio that AMC[112] was going to be over 😢I am 31 years old and I have watched that show my entire life and to be honest IDK[113] what i am going to do when its over

I feel your pain deeply, and I am effected by this profoundly 😕

🤗

Post#21
Person16

I've never been a soap watcher, but, I do remember when AMC first aired. It was much more "modern" that the other old soaps. My sister was in college at the time and she watched it every day. Then she studied on "Semester at Sea" and wanted me to watch it every day and once a week write to here! She was in Africa, India or where ever and when they docked, she went straight for her mail.

Now, neither of my daughters have ever seen a soap. My oldest girl is the Regional Ex. Director for MDA and the other for Methodist Childrens Home and even with DVR's they never watch daytime tv. It is a whole new generation. I know how my Mom must have felt when tv invaded our homes - she must have thought the world was changing too fast for her. This generation is so busy, they never seem to have any down time. I am attached to some night time series and everytime one ends, I tell myself not to get involved with a new one. I don't like change. And I like control --- so I understand your frustration and sadness. I miss the old movies that use to be on every afternoon (3pm). And watching a DVD isn't the same. Take care, PF

Post#22
Person17

oh my gosh im cracking up here!!! for being such a sad posting (really it is! i lost my "monk" show which was probably the only show i [😖]really realated to and that was just a short run of time, so i do feel for ya PF, espacially as it's part of your past!) , the other parts are making my innerds laugh... Bunches of whats said just hit different funny bones 🤣Just the word "bits" is hysterical!! and I gotta tell ya Person14, i cant even explain how funny that hits me on your SUV comment you added. I think it's RIGHT ON target!! 🤣

Post#23
Person18

tv just ain't worth watching anymore, it deff ain't what it use to be.

Post#24
Person19

PF, I think in another post, we discussed how the smallest things can bring your life to a screaming halt. Getting hit however, by the loss of your favorite show and having ESRD[114] is a bit much for any one. You do have a great and open way of discussing your feelings and made a lot of us laugh. This comes from the woman who would literally murder her husband if he tried to watch something other than Grays Anatomy or Desperate Housewives. But, I do feel for you and appreciate your reaction. You will be okay, as you always are, as

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[112] AMC = All My Children

[113] IDK = I don't know

[114] ESRD = End stage renal disease

time goes on.

Post#24
Person20

I know how you feel. I felt the same way when Another World was cancelled. It was something that I watched, even when I didn't realize I was watching it. I always thought it funny, how quickly children grow up soaps. I was the same age as Amanda Cory, but she was an adult well before I was.. *L*[115]

My grandmother watches One Life to Live, which is also being cancelled. I'm betting that she's not amused.

I have to wonder.. what will Susan Lucci do now?? I always loved Erica Kane...

Post#26
Person21

My mom has watched one life to live since way before I was born. Interesting to see how character's lives go faster (I was born the same year a character on the show was...she's in her 30s now, I'm 24). I still bet dollars to doughnuts the "world" is gonna explode when the last episode airs.

Post#27
Person6

> *Quote from: Person21*
> *My mom has watched one life to live since way before I was born. Interesting to see how character's lives go faster (I was born the same year a character on the show was...she's in her 30s now, I'm 24). I still bet dollars to doughnuts the "world" is gonna explode when the last episode airs.*

They'll be the only ones to see the Rapture that Camping guy predicted! 😁

Post#28
Person22

I am puzzled as to why people watch soapies (see, I'm not being sexist) but I fail to see why women can't be more like a man (guess which show) and watch the footie like I do.
PS I got some beaut new boots but my wife didn't notice them so I took off all my clothes (except my new boots)went in and confronted her. She still didn't notice them so I said "look at what my dangly bits are pointing at"....she said "you should have got a new hat".

Post#29
Person23

Person22 that is so funny. I wish I could have been there to see it.

Post#30
Person24

> *Quote from: Person12*
> *My husband's grandmother said, "They discontinued my shade of lipstick and my favorite shampoo. They no longer have the shows i like on TV and my hairdresser has retried. Pretty soon I will be discontinued!" (She was 92 at the time.)*

Aw I love older folks like this! Sounds like someone with a great sense of humor!!

Post#31
PersonG

Person22, we don't have "footie" here, but I park my lady bee-hind on the couch every Sunday during the NFL season. My years in the UK taught me the glories of football and Formula 1 (which, unfortunately, is on TV here in the US at very inconvenient times). I've been a baseball fan since I was 8. I'm currently watching the NBA finals. I've discovered a real appreciation for ice hockey. I love my sports, but I want my soap back, too. 😟

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[115] *L* = laughs

Post#32
Person6

> *Quote from: Person22*
> *I am puzzled as to why people watch soapies (see, I'm not being sexist) but I fail to see why women can't be more like a man (guess which show) and watch the footie like I do.*

The biggest, most-crazed fan group of soap watchers I've ever met were all guys from my college dorm. They all watched "Days"[116] every day and got mad if anyone called or interrupted them during the show! Not that they didn't watch sports, too - but that soap ruled their schedules.

Thread H: [Text not included]

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[116] "Days" = "Days of Our Lives", a soapie

Appendix C: Coding frames

Criteria for top eight themes

Theme	**Coding criterion**	**Example from posts**
Explicit Support	Directly expressing support	“You can do it” “Don’t give up” “we’re all here for you” “I’m praying for you”; or emoticons[117] depicting hugs, for example.
Explanations	Presenting information or opinions which are not explicitly linked to the contributor’s life	“A fistula is created by joining a vein and an artery” “It’s not difficult to self cannulate”
Experience	Information or opinions which are linked to the contributor’s life	“My fistula is in my forearm”
Humour	Jokes, references to humour	“You have to laugh”; or emoticons depicting laughter.
Control	Being able to affect outcomes (or not)	“No one would listen to me” “I stop drain pain by squatting”
Emotions	References or expressions of emotions	“I was scared” “I’m so delighted” or similar references to emotions / tears including emoticons
Physicality	References to the body, architecture, machines…	“I have terrible cramps and headaches” “I can’t find anywhere to put all these boxes”
Normality	Mentions or descriptions of normality	“Is this normal?” “This is how we do it…”

Coding themes related to control:

being able to affect outcomes / obtaining help or learning to help oneself		
Power	Able to do something or stop something from happening.	Surgeon choosing where to place a catheter in the belly; machine alarms waking a patient; headache stopping them from working
Authority	Confirmed as “knowing”, or had the last word	Consulting measurements to decide if you are well; being assured because a doctor said it was alright.
Doubt	Doubting the authority of a source	Doctor may not have got it right; machine sounding a false alarm
Help	Where positive, practical changes were obtained	“Thanks for your *help*!” ; “The nurse fixed my dressing” ; “Calcium binders help me control my phosphate levels”
Information	As identified by contributors	“Ask your doctor for *information* about peritoneal dialysis”
Support		“Thanks for that *support*”

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[117] Emoticon: a small picture used in online groups. Some are animated.

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[118] [note: boyd's name is not capitalised in publications]

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