

Receiving Bad News: A Thematic Analysis of Stroke Survivor Experiences

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Abstract

Background: Breaking bad news to patients may be required in service provision to stroke survivors. While challenging, it may be critical to the retention of optimism and participation in rehabilitation. **Objectives:** To explore the experience of stroke survivors when receiving bad news (RBN) from medical practitioners. **Methods:** Data were obtained via 1:1 interviews conducted at stroke support groups with survivors at least 12 months into recovery and subsequently transcribed for thematic analysis and coded using NVivo. **Results:** Eight of 10 participants experienced RBN, and 2 participants did not. The themes of being “lucky to be alive” and waiting for “delayed information” were expressed by all participants early in the interviews. Three sub-themes emerged and were labelled alliance, dissent, and dissatisfaction, each with a further 3 contextual themes. The perception of RBN was marked amongst the dissent and dissatisfaction groups, with the latter reporting negative implications for their rehabilitation as well as negative emotions, such as anger and anxiety. The perception of a poor-quality relationship with medical practitioners was said to impede rehabilitation and recovery processes. The dissent group was characterized by initial disbelief after RBN and consequently poorer long-term outcomes, whilst the Alliance group experienced very good quality of care due to existing personal knowledge and therefore did not perceive RBN during their early medical meetings. **Conclusions:** In the period soon after their stroke, survivors required their medical practitioners to not only communicate knowledge and information, but also needed validation of their hopes and fears for the future from an empathically attuned clinician.

Keywords

stroke, bad news, communication, qualitative methods

Introduction

After a stroke, patients await their first meeting with medical practitioners to receive information regarding their immediate mortality, prognosis, and likely recovery (1). In these meetings the clinician will deliver news that, while not life threatening for most, may substantially change their expectations for the future. Further such meetings take place as a patient progresses. When breaking bad news (BBN) regarding independence and mobility, for example, skill is required to communicate clear, realistic, and hopeful information (2). Given the uncertain trajectory of stroke recovery, (3,4) BBN can be a challenging and critical task where successfully imparting the key qualities of hope and optimism is likely to motivate survivors toward optimal participation in rehabilitation programs (5).

Research in stroke has shown that some medical practitioners spend very little time with patients discussing psychosocial issues (6) and some nurses find it taxing to discuss emotional matters with patients (7). In their immediate

poststroke confusion and fear, patients may be reluctant to receive bad news (4,8,9) suggesting that both medical practitioners and patients may be motivated to avoid discussion of difficult topics (10). Breaking bad news to stroke survivors can also be complicated by the cognitive and communication impediments caused by stroke (1).

A comprehensive literature search revealed that research into the management of BBN in stroke care has been predominantly quantitative and undertaken from the Clinician’s

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perspective (10,11). A qualitative methodology was used to document a training programme for community health workers when BBN to people with stroke, (1) but there are no studies specifically targeting the experiences of the stroke survivors when receiving news, for example, that they may not walk again or drive a car again. Consequently, the voice of the survivors remains an unexplored dimension in the literature. There is a need for an evidence base for best practice in BBN to survivors which should be informed by the experiences of the survivors and their needs when receiving bad news (RBN) (12,13) as well as how difficulties communicating the news may impact their recovery (1).

The overarching aim of this study was to explore the experiences of survivors when RBN from their medical practitioners. Such experiences were thought likely to illuminate how medical practitioner behaviors promoted or impeded recovery as well as identifying survivor satisfaction with the recovery process.

Methods

The study design was qualitative with an exploratory thematic analysis (TA) methodology (14). Random and representative samples are not a feature of qualitative studies, which are typically conducted on small samples and therefore aim for theoretical rather than empirical generalizability. The analytic approach was influenced by the interpretive principles of interpretive phenomenological analysis; therefore, a-priori hypotheses were not generated (15,16). As participants perceive and interpret their world, they assign meanings to their experiences (17). The researcher identifies patterns and themes from such meanings via a process of developing and rechecking the text (18). Such an interpretive approach to TA allowed a flexible and detailed exploration of the experiences of this particular group (14).

Data Collection

Following ethical approval by the University of Western Sydney's Ethics Committee, contact was made with a national stroke charity which facilitated contact with 2 stroke support groups in a state capital city in Australia. Group coordinators were sent information sheets and ethics clearance letters for distribution, and arrangements made to address the group and explain the research. Eligibility to participate required survivors to be 18 years or older, have suffered a stroke no less than 12 months ago, and have the desire and capacity to engage meaningfully in an interview. Informed written consent was obtained from all participants. Semistructured interviews allowed the researcher and participant to engage in a dialogue in which 5 open-ended questions and prompts were modified according to participant responses. For 3 interviewees in particular, the researcher had to compensate for speech difficulties. In these instances, the investigator would paraphrase what it was thought a survivor meant, and they would respond "yes" or "no" or

Table 1. Sample Characteristics and Subthemes.

Name	Age	Years Since		Themes	(n)
		Stroke	Living Situation		
Sam	69	14	Spouse carer	Dissatisfaction	5
Lena	73	4	Spouse		
Frank	63	12	Alone		
Charlotte	67	2	Alone		
Anne	65	10	Spouse carer		
Larry	61	2	Spouse	Dissent	3
Ted	74	5	Spouse carer		
David	78	10	Spouse carer		
Charles	84	3	Spouse carer	Alliance	2

"not quite." Suggested responses were generated until participants were satisfied the understanding was correct. Interviews were conducted and recorded at stroke club venues, and field notes were made to capture the immediate impressions of the interviewer. Audio files and field notes along with transcribed interviews were deidentified and imported to qualitative data analysis software (19).

Participants

Table 1 summarizes the sample characteristics using pseudonyms. The sample comprised 3 women and 7 men (aged 35 to 80 years) who either lived alone, with a spouse or a spouse/carers. Time since stroke was between 2 and 14 years.

Data Analysis

Analysis was conducted using computer-assisted qualitative data analysis software (19) applying a layered approach to TA (14). Each interview was read and summarized in detail, resulting in the sample of 10 transcripts being referenced by 53 distinct but related themes. These themes and subthemes were subjected to repeated reading and scrutiny by the authors to ensure the participants' understandings were not lost and their comments faithfully developed. The researchers' own interpretive understandings were then applied, and the data were reduced to 1 overarching theme and 3 subthemes, each with 2 or 3 further subthemes.

Results

Eight of 10 participants provided responses consistent with having RBN in their initial medical meeting; for 3 of these 8 participants, acknowledgement of RBN occurred after leaving hospital. The themes "lucky to be alive" and "waiting for delayed information" were common to all participants (Table 2 below). Beyond these initial experiences, themes varied between being "dissatisfied" with medical care, not heeding medical recommendations (dissent) and alignment with medical care (alliance). Figure 1 is a schematic of these and related contextual themes arising, with Tables 3–5 (below) documenting examples of the 3 themes.

Table 2. Overarching Themes Common to All Participants at First Meetings With Medical Physicians.

Lucky to be alive The sub-theme of feeling lucky to have survived, resulted from survivors having been sharply reminded of their mortality.	<p>“I don’t get upset because I’m lucky to be alive. We all are lucky to be alive . . .”. (Anne)</p> <p>“I could’ve been dead, so any day was a benefit.” (Frank).</p> <p>“I want to live for a lot longer. I’ve got 5 grandsons.” (Charlotte).</p> <p>“I do love gardening and do love activities at home. I’m extremely lucky and go out quite a bit.” (Laurie).</p>
Waiting for things to happen. The discomfort of not knowing. Delayed information The time between the realization of having had a stroke and receiving substantive information about your prognosis.	<p>“You’re lying there waiting and everything is happening around you, but no one actually says, you know, this is what’s going to happen to you, you know, you’re just taken from emergency, put up in the ward and that’s it.” (Frank).</p> <p>“I started to cry because I didn’t know what was going on, and I heard the medical practitioner telling my family that the next 24 hours would be crucial ones . . . [I would have been] a lot less cranky [if I had known].” (Anne)</p> <p>“They didn’t [give me much information] . . . They came in once a day and checked on me, to see how you’re going and you know, and so forth. No [I didn’t feel like I knew what was happening]. I mean, doctors come in, how are you, and they’ve got their medical staff with them, you know, the learners and 5 seconds they’re gone again!”. (Lena)</p>

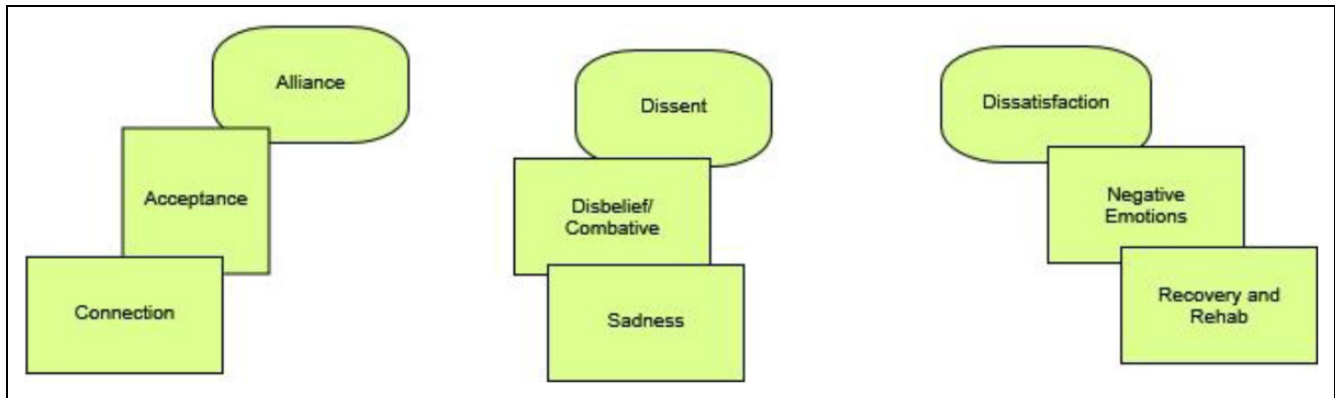


Figure 1. Alliance, dissent, and dissatisfaction with supporting context.

Table 3. Subtheme Alliance.

<p>Alliance (n = 2)</p> <p>Comments indicating the information provided at first meeting was congruent with survivors’ understanding of stroke outcomes and survivors were accepting of advice.</p>	<p>“My medical son is a professor of medicine at [a] University, so the doctors immediately sort of associated with that and I think the general feeling that they don’t want anything to happen to me on their watch. I looked to [my son] for the most information.” (Charles)</p> <p>“I had been working in . . . nursing for 47 years . . . largely because I’d been a nurse for so many years, I could comprehend what they said.” (Laurie)</p>
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Overarching Themes

Lucky to be alive. As can be seen in Table 2, the overarching-theme of feeling “*lucky to be alive*,” resulted from survivors having received a sharp reminder of their mortality. Such was the context in which their recovery issues were recalled and discussed. Feeling lucky to have survived inspired survivors to make the most of life, but was never said to erase the earlier effects of poorly delivered bad news.

Waiting for things to happen. The “*lucky to be alive*” theme was tempered by the quality of the relationships with medical practitioners and in particular perceived delays in receiving practical assistance, medication, and rehabilitation information. The perception of just “*waiting for things to*

happen” was common throughout. When medical practitioners were late or had little time to spend with the survivor, there was a sense that their manner did not invite questions and as a result information was not provided/received soon enough, allowing survivors’ negative thoughts and emotions to grow. Survivors wanted information, explanations, and encouragement to relieve them from their worrisome thoughts—even if they did RBN, it was said to be better than not knowing.

Subthemes

Alliance. A sense of alliance with the medical practitioner existed when survivors described themselves as having

Table 4. Subtheme Dissent.

<p>Dissent (n = 3)</p> <p>The dissent theme embodied disbelief, and faulty thinking with disregard for medical advice.</p>	<p>“I just thought, I’ll be all right, I’ll be all right. . . . the people told me that you will get aphasia and that you’re going to have that for the rest of your life and I thought, yeah, I’ll be over that in a couple of weeks’ time, and never did [get over it].” (Ray)</p> <p>“I only had a stroke, I have no problems at all. As far as I [was] concerned, I [had] no problems, but I had a problem [later].” (Richard)</p> <p>“if you’re positive in your mind, you’ll do it [make a good recovery] . . . Well, I was always positive, that I was going to do things, you know . . . now I have problems with my foot, I’ve got sores on my toes, my toes are turning black. I’m still on antidepressant tablets now, because if I think about it too much it upsets me.” (Harry)</p>
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Table 5. Subtheme Dissatisfaction.

<p>Dissatisfaction (n = 5)</p> <p>Comments from survivors first meetings with medical professionals indicating levels of dissatisfaction.</p>	<p>“No real discussion, not that I recall, just a matter of negativity, Frank won’t make it, improve any further than what he has. He’ll never live, never live independently.” (Frank)</p> <p>“John finally had a word with him and he said, was his wife . . . going to [get] better because I had no speech, my arm was paralyzed and the attitude was, he said, “what you see, you’re going to get.” That’s not nice, that was a specialist . . .” (Anne)</p> <p>“Yeah, and you know, he was negative . . . I was so frightened about what [he was] going to say and what [he was] going to tell me. And I didn’t like him . . .” (Charlotte)</p>
<p>In the days following the stroke, dissatisfied survivors experienced a range of negative emotions: distress, fear, and anger as a result of experiences with their medical practitioners.</p>	<p>“Terrible, [the news] really frightened me, I was, you know, I was really frightened and I think I was crying, you know, and they said that they’d have to watch me [inaudible 08:05] and my son stayed with me that night, and yeah.” (Charlotte)</p> <p>“the neurologist came around and she said, ‘we don’t think F can go any further than what he’s got, can he come and live with you in Queensland? He’ll never live independently. . . . So from thereon, she just stopped all rehab, like I was a dead-end. I was just angry. What kind of a person is she? . . . it is devastating.” (Frank)</p> <p>“. . . put my back up . . . yeah, I’m going to show him”. (Anne)</p>
<p>Survivors unanimously said they would have been better if their recovery was supported by positive and motivating comments from their initial medical practitioner. Their dissatisfaction regarding the less than optimal experience had a strong impact on recovery trajectory.</p>	<p>“. . . I would be better, I could talk better . . . I think it would be a hundred per cent better . . . in my mood . . . he was being rude and it put my back up and I’m going to prove him a liar, and that motivated me.” (Anne)</p> <p>“You need encouragement, yeah”. (Lena)</p> <p>“Well, more understanding of the patient to what they go through, because when you’ve had a stroke, it’s devastating. Because you think your life’s over really, because you think well, you can’t do things, you know, you can’t go here, you can’t go there.” (Lena)</p> <p>“I think they need to be more in empathy with the patient rather than just a number.” (Frank).</p> <p>“Yes, just to be able to sit down and say, you know, are you experiencing this, do you have, is it just me, you know, and you know, to come to someplace where everybody is the same.” (Charlotte).</p>

positive attitudes, social support, and having been happy with their medical treatment. Most important for them was feeling able to question their medical practitioner and receive satisfactory responses. Initial comments about their medical practitioners suggested that they did not experience any difficulties around receiving their prognosis and that their interactions with their medical practitioners were generally positive.

This group ($n = 2$) was familiar with medical terminology and accepting of expert knowledge so they did not report the experience of RBN.

Dissent. The dissent theme was characterized by shock and disbelief following RBN in the first meeting with their physicians. The news was countered by a combative element in which survivors ($n = 3$) made light of their diagnosis and

thought they would be all right within a few weeks. The adage “she’ll be right mate”¹ sustained the belief they would improve upon returning home. Realizations occurred after leaving hospital when the full impact of their loss of function became apparent. A sense of sadness emerged along with the realization that activities they had been passionate about, such as fishing, golf, and bushwalking, were now beyond them. Within the dissent theme, the impact of RBN unravelled slowly, and as much as 2 years after leaving hospital, survivors had not come to terms with their changed physical abilities. One participant remained on antidepressants and each discussed chronic symptoms of grief and depression.

Dissatisfaction. Receiving bad news at a time when survivors were hopeful of improvement and needing motivation to maintain their efforts was a dissatisfying experience for 5

survivors. The sense of dissatisfaction came from a view that the medical practitioner's skill in BBN to them did not generally provide hope and encouragement. On the contrary, at times they felt patronized, rushed, or disrespected by medical practitioners. Such events gave rise to negative emotional responses such as anger and anxiety during early meetings, and these were carried over to subsequent meetings. There was dissatisfaction with receiving information reportedly due to an ineffective means of conveying information to them and a sense that greater skill and empathy in BBN would have alleviated their harrowing experiences. There was complexity within this theme with survivors expressing combative behaviors, which were ironically helpful.

Survivors were motivated by their anger at their medical practitioners' negative prognoses, and manifested a strong desire to prove the prognoses wrong. Their negative emotions were perceived as a barrier; survivors had first to deal with their anger and anxiety about the medical practitioner before starting their recovery journey. RBN in a less than optimal manner was said to have had a strong impact on their recovery trajectory, and survivors would have much preferred positive encouragement from an empathic medical practitioner. This rehabilitation and recovery based theme was frequently expressed as "I would have been better if . . ."

Survivors unanimously said they needed a closer relationship with their medical practitioner to feel comfortable asking questions. Much emphasis was placed on the desire for their medical practitioner to simply listen to them, understand their individual circumstances, and respond empathically with motivating and hopeful comments. Survivors required patience in the face of their slow progress, and a realistic but hopeful appraisal of their disabilities. In this study, the extent of the medical practitioner's medical knowledge and skill was never questioned. Survivors accepted the medical practitioners as experts, and it was therefore meaningful to receive reassurance, positivity, hope, and encouragement from them.

Discussion

The great good fortune for most stroke survivors is that having faced the possibility of death, initially at least, each day holds the potential for improvement. Their desire to regain function and achieve better outcomes challenges medical practitioners who are expected to be pivotal in their recovery process. A medical practitioner's expert knowledge of their condition was a source of comfort, and RBN was reported to shape the behaviors and attitudes of survivors in ways that supported or undermined recovery.

The 3 different experiences of the survivors are to some extent explained by psychosocial factors such as employment (alliance) and health beliefs (dissent). Living situation, whether alone, with partner or with carer, did not appear to discriminate the experience (Table 1). All survivors' expectations of their practitioners being medically knowledgeable were met, but the dissatisfied group was shocked, angered,

and upset by receiving minimal time and empathy from them. These survivors believed their own emotional responses to interactions with medical practitioners directly impeded their rehabilitation progress because they had to deal with their negative affect before fully engaging in their recovery process. The dissatisfied group of survivors considered that due to information delays and discouraging and rude experiences with medical practitioners, there were lost opportunities for rehabilitation. They believed their outcomes would have been enhanced if the medical practitioners BBN skills had been better.

Issues around timing identified several unmet needs and gaps in resources (20,21). As recipients of good, or bad, news survivors expected to spend sufficient time with their medical practitioner to air their worries and concerns. Rushed and seemingly dispassionate medical practitioners were perceived as "rude" and disinterested in the patient and their recovery. A second aspect of timing related to problematic delays in information (13,22). In the period between the stroke event and meetings with medical practitioners, survivors reported feelings of uncertainty about their prognosis (8,10). A perceived delay in RBN was anxiety provoking for survivors wanting to learn their prognosis. Early and honest transfer of information appeared to reduce much of the preoccupation and worry arising from mortality fears and allowed survivors to develop realistic hopes and expectations that led to the timely commencement of rehabilitation.

Delays in communication were troublesome for most survivors, however, may have been judged to be appropriate by the medical practitioner. It is expected medical practitioners can correctly judge the best time to provide information (8,23) based on the survivor's readiness to receive and comprehend it (22). This study suggests this may be incorrect in half of cases.

Consistent with previous findings, absent, avoidant, hasty, or overly busy medical practitioners were considered to impact the recovery process (24,25). Survivors wanted medical practitioners who had the ability to understand their particular psychosocial circumstances and could adapt their communications appropriately, as well as having empathic qualities to address and encourage their questions. Positive comments from the medical practitioner, or lack of them, were highly implicated in recovery motivation and the survivor's ability to manage negative affect. Importantly, while some depressive symptoms were evident amongst survivors, they reported being more upset by medical practitioners' poor BBN skills than depressed by RBN itself. This has implications for preventing and treating poststroke depression, which is commonly experienced.

One of the puzzling circumstances about RBN was that negative affect arising from the survivor-medical practitioner interaction motivated survivors initially to prove the practitioner's prognosis wrong. However ongoing dislike of the medical practitioner and her/his methods caused substantial emotional upset which was said to impede and delay recovery. Survivors had to deal with the upset of the

experience as well as find the motivation to sustain their rehabilitation. Such psychosocial barriers to motivation and related emotional and psychological factors appear to be receiving limited attention in the literature (20,26). Having been used as an indicator of likelihood of return to work in a young survivor population, they may hold the key to greater understanding of the necessary psychosocial transitions following a stroke (4,21) and individual recovery needs. Further work in this area and the provision of early assessment of psychosocial factors could be incorporated into early training for medical practitioners (20).

The use of a qualitative methodology identified a “*lucky to be alive*” context that predisposed stroke survivors to overestimate their satisfaction with life (10). When personal circumstances impacting recovery are identified in a respectful interaction with a medical practitioner, as advocated by person-centred approaches, (23,27) they have been shown to be important to survivors (23). For example, sharing information with patients, exploring their perspectives and values around health beliefs, and behavioral change (21,23) potentially improves the RBN experience. These findings support those from the broader patient-centred literature identifying elements such as personal support (28,29) as necessary to motivate survivors’ engagement in rehabilitation (23,27,30). Potentially, poststroke recovery and successful adaptation to changed life circumstances can be influenced by incorporating these qualities into the BBN/RBN interaction.

Limitations

To participate in this study, stroke survivors required sufficient communication skills to engage with the open-ended questions required by the methodology. The sample was therefore limited to those with better cognitive outcomes. Nonetheless as with any study with a sample who may have cognitive impairment, specific details, such as dates were at times vague. Despite this, it was rarely the case that perceptions of their experiences as a whole were unclear; quite the contrary.

Conclusions and Practice Implications

From this research, we know that survivors want poststroke information transmission, including RBN, to be extensive and occur early so as to minimize the uncertainty caused by delays. Most important is to RBN in a way that promotes motivation for sustaining rehabilitation. We know that early affective states in hospital, such as disbelief regarding prognosis, need to be identified and managed as indicators of potential depression (21,30,31). It is also evident that a sense of being well-cared for occurs when people feel connected to and have confidence in the medical system and understand the information being communicated to them. The absence of conflict in relationships with medical practitioners appears to coexist with positive and sustained recovery motivation.

Tensions remain between the professional’s responsibilities to provide realistic expectations to survivors while sensitively promoting the hope which appears crucial to facilitate rehabilitation. Early assessment of emotional states (32) and provision of appropriate services including supporting and clarifying bad news might be useful. Considering BBN in the training of stroke medical practitioners is also recommended (1) and future qualitative studies of carers’ perceptions would be a way to overcome the language constraints of some survivors while continuing to integrate survivor perspectives into stroke research.

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Note

1. A common use idiom in New Zealand and Australian culture that expresses the view that “a wrong will right itself over time.”

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