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Harnessing Facilitated Digital Health Communities to Support Empowerment of Informal Carers of People with Mental Illness: Effect of Enablers and Inhibitors

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under the supervision of
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Certificate of original authorship

I, Tsholofelo Jacqueline Sethibe, declare that this thesis submitted in fulfilment of the requirements for the award of Doctor of Philosophy (Information Systems), in the School of Professional Practice and Leadership in the Faculty of Engineering and Information Technology at the University of Technology Sydney.

This thesis is entirely my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Table of Contents

List of Tables

List of Figures

Abstract

The utilisation of digital health communities (DHCs) generates support, advice, and information, which have the potential to empower users – patients or carers, who join a digital health community for support. Empowerment is important because it enhances one's self-directed ability to cope with challenges, make informed decisions and mobilise needed resources to help users to regain a sense of control in their lives. This research contributes to the information systems (IS) body of knowledge by proposing and theorising the concept of empowerment for decision-making in digital health communities.

Despite the potential, it is not clear how digital health communities foster the empowerment of carers. It is also not clear how systematic professional facilitation, which some digital health communities utilise to combat information overload and asymmetry, affects empowerment. To address this lack of understanding, this study aims to investigate what constitutes empowerment, what support exchanges are generated by the digital health community use to empower, and what role is played by facilitator support in the empowerment of users. It draws empirical insights from a less-explored digital health community of informal carers of people with mental illness, based in Australia. It engages a mixed-methods approach (exploratory sequential design) to collect and analyse data from IS experts in interviews, carry out a content analysis on 3000+ messages, and conduct a web-based survey of informal carers. The inquiry is done through the theoretical lens of the empowerment theory.

The key findings of this study are (a). social support and experiential expertise are good predictors of carer empowerment (b). empowerment in a digital health community has an affective dimension in addition to intrapersonal, interactional and behavioural dimensions (c). the type of facilitator presence (collaborative, commanding, motivating) contributes to the carers' ability to make health-related and other decisions (d). facilitator support has a moderating effect on social support and experiential expertise. The findings also provide foundations for further investigation into empowerment, in particular, how to foster it for improved decision-making in digital health communities and other contexts.

Some contributions the study makes include, 1. extending the traditional empowerment theory and its application in the context of the digital health community, enabling theorisation of dual effects. 2. contributing further to understanding empowerment for decision-making. This is because most studies mentioning empowerment in digital health communities are on treatment adherence or doctor-patient relationship (Table 2.2). 3. contributing methodological skill, where the study involved the use of three phases of investigating a sequential, mixed-methods design.

CHAPTER 1: INTRODUCTION

"People on the net are not only solitary information processors but also social beings. They are not only looking for information; they are also looking for affiliation, support, and affirmation" (Sproull & Faraj, 1997, p. 38)

1 Overview

The interface between the internet and various sectors has caused a social revolution in which online social networks have become support tools. In this merger supported by the growing popularity of Web 2.0 technologies, users of online communities generate and exchange content. Digital health communities (DHCs) are a special type of online social networks that are heralded for their ability to empower users. The thesis provides theoretical and empirical evidence for empowerment in digital health communities in the next seven chapters. This chapter lays out the background on the utilisation of digital health communities, research gaps as well as research questions that will be addressed in the thesis.

1.1 Significance of the Study

A digital health community is a collective of geographically dispersed individuals who are brought together by a common interest around health matters and communicate on virtual sites (Mpinganjira, 2018). Most of the time, the individuals do not know each other and a digital health community allows them to form new ties, thereby increasing their knowledge base (Riedl et al., 2013). The communities are mainly text-based information systems that allow users to search and exchange advice, opinions, information, support, and experiences with each other (Erfani & Abedin, 2018; Atanasova & Petric, 2019). By reading others' experiences, advice and opinions, users learn how others cope with a health condition, and can be encouraged to do the same (Chung, 2013). As a complementary information source and provider of social support (Johansson et al., 2021), digital health communities show that mainstream health providers are no longer the sole custodians of health information.

Extant literature has documented a marked increase in the use of digital health communities. For example, a study found that 74% of the population in the US sought information online (Johansson et al., 2021), while another reported more than 50% of adults sought information online in the UK (Zheng et al., 2021). The increase in the uptake of digital health communities has contributed to investigations into how they benefit users. Evidence shows that they contribute to improved well-being (Erfani et al., 2017), resilience (Kamalpour, 2020), and empowerment (Johnston et al., 2013), while others like Hur et al. (2019) contend that there is inadequate evidence relating digital health community use with improved outcomes. These conflicting findings coupled with the fact that widespread use does not equate to a comprehensive understanding of a phenomenon, necessitate an investigation into how the employment of digital health communities benefits users.

Among users of digital health communities are informal carers, who are family and friends that give support, personal care, and help to their loved ones who are unwell. The care recipient may have a disability or chronic illness. Informal carers (hereafter called ‘carers’) usually offer care over a long time, sharing the care recipient’s ailment experiences as well as managing their emotions. This can negatively affect carers (Long et al., 2017). In fact, literature attests that carers of people with mental illness have maladjustments compared to other carers, and are more likely to suffer mental illness themselves as a result of prolonged isolation and stigmatisation of their care recipient’s condition (Onwumere et al., 2018).

To this end, digital health communities have been found to reduce anxiety, stress, and depression (Fortuna et al., 2019), enrich wellbeing (Erfani et al., 2017), lessen social isolation and loneliness (Vaughan et al., 2018), improve coping and enhance empowerment (Atanasova & Petric, 2019). The latter is a necessary and natural reaction to perceived loss of control in one’s life, which happens often when people are faced with some difficult situation (Rappaport, 1995). Hence, a carer can regain control of and manage their situation by being able to make decisions on a daily basis, whether they are health or not health-related (Yan et al., 2017). Decision-making remains fundamental because when one deals with ill-health or some health condition, they easily become despondent due to the seriousness, and sometimes life-threatening nature of health matters (Johnston et al., 2013). This situation is evident in the current Covid-19 era where people must quarantine and isolate, yet they need information about the virus, how it infects and how it can be prevented as well as how to manage the condition once infected. Moreover, the carers need to be socially connected too. Digital health communities are a strong source of reassurance (Zheng et al,. 2021) and a resource that empowers to guide decision-making (Atanasova et al., 2017). The decisions can be related to one's health like progression of the disease, effectiveness of medication, questions to ask doctors, seeking opinions about condition, collaboration among professional service providers, effects of medication, health records, administration of medication (Yan et al., 2015). Other decisions are non-health related, like nutrition, finances, family relationships, personal hygiene, available professional services, upkeep of one's place and so on (Onwumere et al., 2018). Users engage with each other on digital health communities to exchange ideas of how to deal with such challenges.

The conversation of empowerment in digital health communities is less supported by empirical evidence (Atanasova et al., 2017). Some attribute this deficiency to lack of a universal definition of empowerment, which others believe is not necessary (Hur, 2006). Nonetheless, many embrace the definition suggested by Zimmerman (1995), and the thesis builds on it as well because it provides a launchpad for propagation and necessary reflection of the empowerment concept. Hence, empowerment is discussed throughout this work as a contextual process that enables individuals to enthusiastically participate in events that help or support them to have control over and effectively manage their life circumstances, facilitating them to do things they previously found difficult to do (Zimmerman, 1995).

For meaningful empowerment, Hur et al. (2019) propose that digital health communities need to be facilitated (moderated) by health professionals or trained laypeople who are very conversant with the subject matter of discussion. The support, given by human facilitators, provides a safe and amicable environment for user discussions. It does this by focusing discussions, and blocking out malicious attacks on others for the benefit of everyone on the forum (Hur et al., 2019). This creates cordial atmosphere of interaction which can improve confidence of forum members, subsequently influencing empowerment (Li et al. 2017).

The thesis examines how the use of facilitated digital health communities enables empowerment; as Sadovykh et al. (2015) observed, literature lacks empirical evidence on the role of professional facilitator support in enabling empowerment. It also seeks to explore what resources influence empowerment, and how empowerment presents in the context of carers. It employs a pragmatic worldview through the lens of empowerment theory to investigate a digital health community of informal carers of people with mental illness in Australia. Carers as customers of health services have been least studied, because most empowerment studies in digital health communities are on patients (Atanasova et al., 2017; Fan & Lederman, 2018). Patient empowerment has been studied in the context of self-management of illness (Smedley et al., 2015), and improving the patient-doctor relationship (Petrič et al., 2017), and less empirical evidence exists for empowerment that enables decision making, especially in carers.

1.2 Thesis

That the use of facilitated digital health communities enables empowerment for decision-making of informal carers.

1.3 Objectives and research questions

Following the literature's assertion that digital health communities have empowering capabilities, the thesis explores how empowerment happens. It aims to theoretically explain ways in which the utilisation of digital health communities can support carer empowerment. For that reason, it considers the following two main research objectives:
RO1: To examine how the use of digital health communities may enable the empowerment of informal carers.

Under this primary objective, the study establishes how digital health community use enables the empowerment of informal carers of people with mental illness.

RO2: To investigate the effect of professional facilitation on the relationship between digital health communities' use and the empowerment of informal carers.

Under this second primary objective, the study explores the role of a professional facilitator in supporting empowerment over a digital health community for carers of people with mental illness.

To address the research objectives above, the following research questions, with supporting sub-questions, will be answered:

RQ1. How does the use of digital health communities enable the empowerment of informal carers?

RQ2. How does professional facilitator support affect empowerment through digital health community use?

The following sub-questions assist to amplify the main questions:

RQ1.1 What evidence exists for the empowerment of informal carers in digital health communities?

RQ1.2 What is the effect of digital health community use on the empowerment of informal carers?

1.4 Overview of the research design

This thesis employs a pragmatic viewpoint, which accommodates the utilisation of empirical evidence as well as the researcher's interpretation, hence the adoption of an exploratory sequential mixed method (Creswell & Clark, 2018). The adopted research approach furthers the quest for open investigation that accommodates the socio-technical nature of IS. It attends to the need for accommodative approaches that engage various paradigms and philosophical assumptions, which will enable IS to be at the "epicentre of the digital revolution" and contribute to the "challenges of the digital age" (Cecez-Kecmanovic et al., 2020).

The study employs an exploratory, sequential, mixed-methods design, in the order of qual-qual-quant. In general, a qualitative phase allows the study to consider the broad context and multi-dimensional nature of digital health communities, while the quantitative phase explains the relationships between constructs. So, the study uses expert interviews, followed by content analysis and finally a survey. However, before doing the expert interviews (first qualitative phase), the researcher conducted a literature search that revealed aspects of empowerment in digital health community use which merit further exploration. The identified concepts were explored for relevance through interviews with information systems experts and thus were further refined.

The second qualitative phase used an online observation on the refined concepts to find evidence of their existence in digital health community discussions; the online observation employed content analysis. The final quantitative phase used identified variables from the content analysis to build a conceptual model, which was tested empirically to obtain user perceptions on how utilising digital health communities affect their being empowered for decision-making. The expert interviews were transcribed and examined with thematic analysis, the online observation is subjected to a content analysis while the survey results are analysed using structural equation modelling.

1.5 Research Gaps

Empowerment is a contextual, multi-dimensional notion that presents differently in time and space, even within the same population (Zimmerman, 1995). For example, when studied in one digital health community, empowerment cannot give the same outcomes in another, neither can it be affected by the same factors. Considering that exploring empowerment in digital spaces is still nascent (Hur et al., 2019), the study undertakes steps to ascertain concepts that are relevant and make sense to the study of empowerment in digital health communities.

Secondly, the conceptualisation of empowerment in Information Systems is very diverse, so is it in Health as well. The intersection of these two fields has produced even more disparate approaches to conceptualising empowerment. However, its conceptualisation, from Zimmerman (1995) viewpoint, exposes three dimensions – intrapersonal, interactional, and behavioural. For various reasons, various authors treat this multi-dimensional construct differently. Some conceptualise it as a process, and investigate intrapersonal and interactional elements only, (for example, Atanasova et al.

2018), while other researchers explore it as an outcome (Hill et al. 2015). Among those that conceptualise it as a process, most investigate the intrapersonal component (van Uden-Kraan et al., 2008). From these discordant approaches to conceptualising empowerment emerges a need to examine empowerment more closely, to determine what constitutes it.

The third identified gap emanates from the fact that the use of digital health communities has many documented benefits. They include informational, emotional support, and companionship activities (Huang et al., 2019), sharing experiences (Fortuna et al., 2019), social inclusion (Grehling & Maier, 2021), sense of community (Johnston et al., 2013), network support (Sadovykh & Sundaram, 2019b) to mention some. However, the relevance of a system's benefits to a population depends on its needs. Reviewed literature mostly discusses positive and negative benefits separately, with more of the former than the latter. Consideration of both positive and negative benefits of technologies in the same study is encouraged in the current IS literature (Abedin & Qahri-Saremi, 2018).

Finally, the need for professional facilitator support in a digital forum has been pointed out. For instance, Atanasova et al., (2017) argue that the support of a facilitator creates an amicable environment that encourages constructive discussions. This can be achieved by dealing with aggression against norms (Wise et al., 2006), encouraging and promoting cohesion within a community (Barak et al., 2008) as well as providing social support and reliable health information (Atanasova et al., 2018). Therefore, a facilitated forum is likely to have a higher level of usage (Wise et al., 2006), because it nurtures self-confidence and a sense of control; subsequently fostering empowerment in users (Barak et al., 2008). This thesis investigates the role of professional facilitator support on user empowerment because users are beneficiaries of services offered by facilitators. It is a contribution towards heeding a call made by Coulson and Shaw (2013) to study the role of facilitators in the digital space. Moreover, most studies have investigated facilitator support as an outcome. This study applies the empowerment theory to explore how the support of a professional facilitator provides the environment needed for empowerment to eventuate; hence it is considered as a moderator.

1.6 Key Findings and Contributions

The key findings of the study are summarised below:

1. The use of digital health communities displays characteristics of the technology that address the emotions of the user. As a result, the study proposes that in addition to the interactional, intrapersonal, and behavioural dimensions, empowerment in digital health communities has a fourth dimension, being affective empowerment.
2. The study reveals that professional facilitators support carers by using different approaches. They include the commanding, collaborative and motivating approaches. By employing collaborative and motivating approaches, facilitators encourage users and contribute positively to their ability to make decisions. In contrast, the commanding presence has a potential to intimidate and discourage carers, leading to a reduction or complete termination of the use of a digital health community. This action can, in turn, affect empowerment.
3. Communication is an important competence in empowering informal carers for decision-making.
4. Carers experience support overload in the Carer's forum; they reported receiving too much support from others on the forum.
5. Social support and experiential expertise mediate the relationship between the use of digital health communities and empowerment, while self-disclosure, emotional contagion, social network fatigue, and social overload have no mediation effect. Consequently, empowerment is affected by enabling factors, and inhibiting factors have no effect on it.
6. Facilitator support has a moderating effect on the relationship between use of digital health community and social support as well as experiential expertise, but has no moderating effect on the other mediators.
7. Social support and experiential expertise are good predictors of carer empowerment.

1.7 Definition of key terms

In the context of this thesis, the following definitions of key terms are adopted for use.

Digital Health Community: A virtual place that brings together physically dispersed informal carers to share information and personal experiences on caring for people with mental illness. In the process, the carers exchange support and nurture relationships among themselves (Mpinganjira, 2018; Zhang et al., 2018).

Digital Health Community Use: The extent to which an informal carer utilises a digital health community to exchange information and experiences with other carers, for the benefit of all. (Karahanna et al., 2018).

Informal carer: A family member or friend that provides unpaid care to a loved one who is unwell and gets to experience the oscillating and demanding rigours of daily caring. They provide emotional, physical, personal and financial care to their loved one (Boots et al., 2014).

Facilitator Support: Support given by a professional facilitator to ensure a safe and friendly environment for carer interactions, to generate quality information for decision making and ensure adherence to guidelines of the digital health community (Chen et al., 2011; Wise et al., 2006; Atanasova et al., 2017).

Empowerment: Experiencing personal development by strengthening carers' skills, abilities and inherent capacity to cope and make informed decisions on a daily basis, both non-health and health-related decisions (Hur et al. 2019; Liu et al., 2020a).

Support exchanges: Resources generated from using the digital health community; while they benefit carers, they create expected and unexpected consequences that benefit carers. They are determined by the carers’ level of activity and the strength of relationships between them (Chewning & Montemurro, 2016; Kim et al., 2018; Abedin et al., 2020).

1.8 Organisation of the thesis

The thesis follows the structure in Figure 1.1 below:

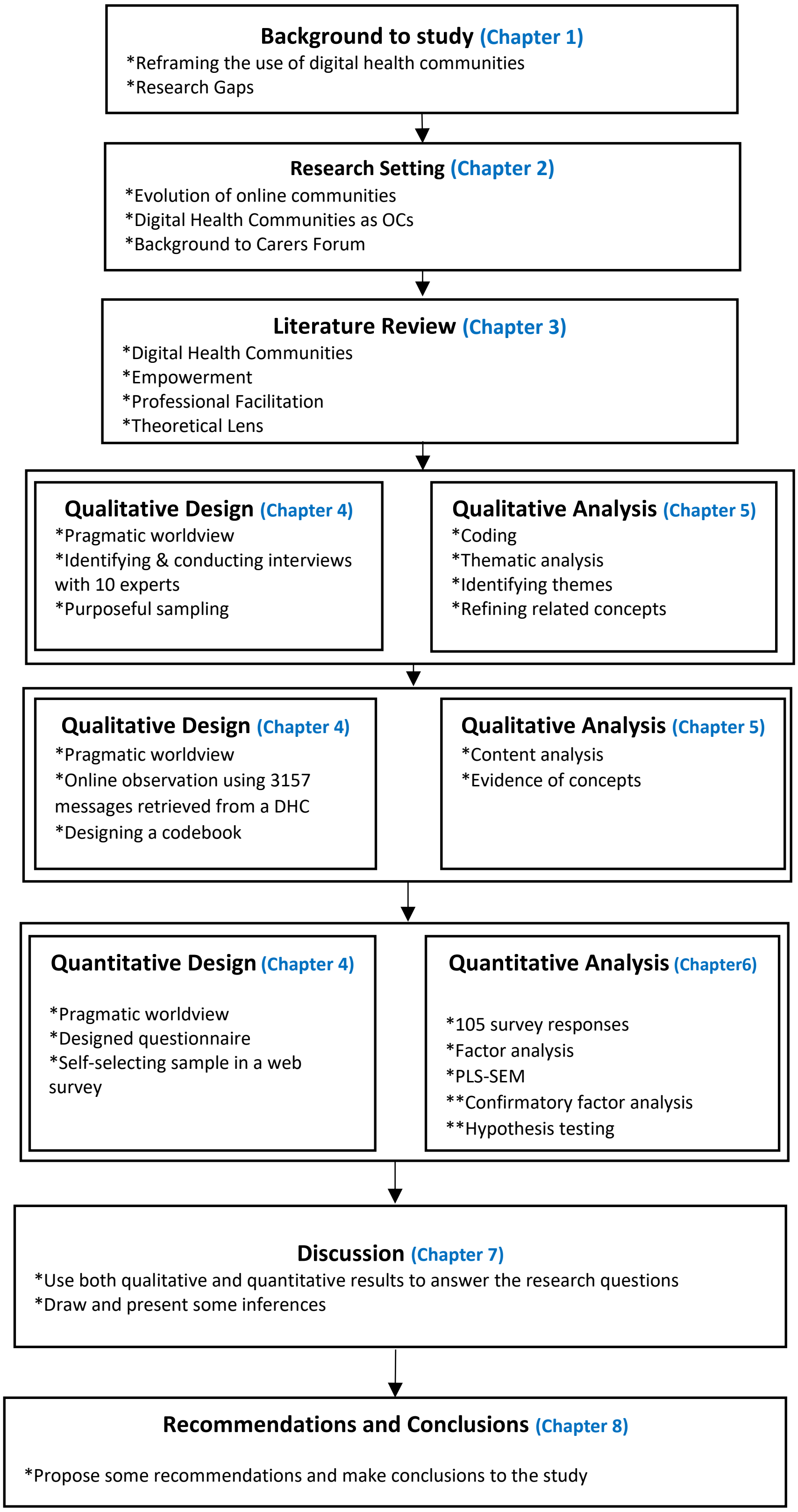


Figure 1.1 The Overview Structure of the Thesis

From this chapter, the rest of the thesis covers the remaining chapters as discussed below.

Chapter 2: Research Setting

The chapter gives a brief of the evolution of online communities and situates digital health communities within the structure. It discusses how online communities can be classified according to the type of host and whether they are facilitated or not. It also details out the SANE Carer's forum as the context of the study.

Chapter 3: Literature Review

The chapter reviews the literature on digital health community, covering what digital health communities are, their benefits, their use, as well as support exchanges found in digital health communities. The description of support exchanges differentiates between enabling and inhibiting exchanges, to capture the effects of technology on the users. The chapter continues to discuss empowerment by describing it within the context of digital health communities and operationalising. It also gives a brief of informal carers' need for digital health communities and concludes with an expatiation of the empowerment theory as the theoretical lens of the study.

Chapter 4: Research Design

This chapter positions the study within the pragmatic worldview and presents how the mixed methods study is conducted. The design used is exploratory and sequential, and the chapter presents the handling of data in this qualitative-qualitative-quantitative study. The chapter ends up with a discussion of the research model and hypotheses.

Chapter 5: Qualitative Analysis

Chapter 5 of the study addresses findings of the qualitative part of the study. It presents the thematic analysis done on expert interviews, as well as the content analysis done on online observations.

Chapter 6: Quantitative Analysis

This chapter presents the results of testing the conceptual model as derived from the qualitative analysis. The quantitative analysis is based on partial least squares structural equation modelling (PLS-SEM).

Chapter 7: Discussion

This chapter discusses findings in the context of pragmatism and also discusses how the research questions are addressed by the study.

Chapter 8: Recommendations and Conclusions

The final chapter discusses contributions the study is making to theory and practice, with recommendations and limitations highlighted.

CHAPTER 2: THE RESEARCH SETTING

2 Overview

To understand the importance and function of digital health communities in empowerment, this chapter discusses the context in which the study is conducted. It begins by detailing how online communities started and their subsequent evolution to different communities that deal with specific fields and areas, including health. Subsequently, a digital health community is defined, followed by how it can be administered, and a description of users of the digital health community in this study.

2.1 Evolution of online communities

Online social networks (also called social networking sites) are described as web-based services which permit users to construct a public profile with photos and information that identify them, showing a list of others who share a connection with them and allowing further connections with friends (Boyd & Ellison, 2008). They allow users to customize their privacy settings in detail, viewing changes in friends' profiles and comments and tagging friends in images (Kwon et al., 2014; Phua et al., 2017). The first well-known example of online social network is SixDegrees.com which was launched in 1997. It was the first platform to combine the creation of a profile, sharing files and photos, and listing friends who are visible to others in your network. Although the site closed down after three years, it set the pace for the further development of online social networks (Boyd & Ellison, 2008).

Over the last twenty-one years, many online social networks have launched, with newer ones improving on the features of the older ones. Some are more popular in certain regions than others e.g. Skyblog is widely used in France, Cyworld in China, Mixi in Japan, but others are universally popular like Facebook and LinkedIn (Boyd & Ellison, 2008). To date, Facebook is the most widely used – with over 1.37 billion active users per month (Sinclair & Grieve, 2017). For instance, 72% of adults who go online use Facebook in the

USA (Phua et al., 2017), 65% in Norway (Lüders & Brandtzæg, 2017), 57% in the UK, and 54% in Sweden (Boulianne, 2015). For a long time, the Internet was considered a space for the young, but evidence now suggests that more older adults are using online social networks than before (Lüders & Brandtzæg, 2017; Sinclair & Grieve, 2017), not only for social purposes but to seek health information as well. Some attribute this to the fact that older adults need information on the health conditions they or their loved ones suffer from due to advanced age (Shang et al., 2020). In addition to those formed in online social networks, other online communities exist outside them but follow the same format using personal profiles. While online communities can be deliberately created, others can emerge spontaneously; some turned out to be highly structured while others were informal, some formed by organisations and others started by individuals (Hara et al., 2009).

Now online communities are popular for disseminating information (Iriberri & Leroy, 2009), facilitating communication (Sadovykh & Sundaram, 2017), enabling collaboration between individuals, agencies, and organisations (Balakrishnan et al., 2017), supporting engagement between users (Wasilewski et al., 2016) to mention a few areas of application. They are used in the public or government sector, as well as in the non-profit sector (Bellström et al. 2016). Within these sectors, they have found relevance in various domains, like education – where they are used for collaboration between learners (Balakrishnan et al. 2017), in advocacy for collective action (Bailo & Vromen, 2017), in finance to share investment information (Sadovykh & Sundaram, 2017), in civic engagement to improve service delivery (Gonçalves et al., 2018), in healthcare to facilitate information exchange between patients and between doctors-patients (Meng et al., 2021), in patient's digital activism to lobby for policy change e.g. HIV advocacy (Petersen et al, 2019).

2.2 Digital Health Communities as Online Communities

The use of online communities for communicating health information and allowing interaction between patients and clinicians dates back to the nineties, with the onset of cancer online discussion groups. One such platform is the Association of Cancer Online

Resources community which was started in 1995 (Young, 2013). Back then, they were utilized mainly to provide information to resolve medical problems (Wentzer & Bygholm, 2013) and were preferred because they contained more up-to-date information to resolve medical problems, compared to printed ones (Matzat & Rooks, 2014). So, in addition to seeking extra information about their new diagnosis and available treatment options, patients would even do online consultations with health professionals (Johnston et al., 2013). Over the years, the internet has become a source of self-management programs and support, as opposed to being just a resource for health information. This explains the surge in the use of digital health communities, whose users have expanded beyond patients.

Although some authors refer to them as ‘virtual’ health communities (Young, 2013), this thesis maintains using the term ‘digital’ health communities in tandem with growing propulsion for digitisation of products and services that recognise digital platforms for their higher networking capacities (Sandberg et al., 2020). These vast capacities enable the convergence of huge numbers of users of digital platforms, an attribute that, when intentionally exploited, is beneficial to users (Hu et al., 2015). Notably, there is an increase in academic discourse about digital technologies in the whole field of information systems (Vial, 2019), as well as healthcare (Hermes et al., 2020). In fact, a review by Stephanie and Sharma (2020) traces the start of e-health in 1998 and its development into 2018 wherein the need for digital health eco-systems grew to accommodate citizens’ avid need for more and better access to health information and services. Further, a steady rise in dialogue within the space of online health communities acknowledges them as a ‘digital space’ (Abedin & Qahri-Saremi, 2018), ‘digital technologies’ in a ‘digital age’ (Onwumere et al., 2018), ‘digital intervention’ (Fortuna et al., 2019), ‘digital destination’ containing ‘digital content’ (Hur et al., 2019). Hence, the study of and reference to digital health communities is opportune as it furthers the discourse.

2.3 Facilitation as a Basis for Nomenclature

Literature recognises two types of digital communities identified according to their origins – those initiated and hosted by organisations and those initiated and hosted by ordinary people or customers of a service in a specific industry like education, health, sport (Teichmann et al., 2015). In strict terms, both types of communities are maintained by facilitators who may be either professional or trained/interested laypeople. Depending on the digital community, the facilitator may be referred to as a ‘community leader’ (Pantelei, 2016; Leong et al., 2019), a ‘moderator’ (Smedley & Coulson, 2017, Perrault & Zhang, 2019), or a ‘community manager’ (Teichmann et al., 2015). Notwithstanding, their core activity is to facilitate discussions and oversee activities of a digital community.

Users consider organisation-hosted communities to be strict and quick to implement guidelines, while customer-hosted ones have no restrictions and yet perform well. A study by Cole et al. (2016) found that a purely customer-based digital health community operated so well that it yielded high-quality information with just collegial interactions and no facilitator. This highlights the contradictory findings of the effect of facilitation in communities. Notwithstanding, facilitated digital health communities continue to be recognised for their contribution to user-professional dialogue, which cannot be conducted in the consulting room (Liu et al., 2020a). Atanasova et al. (2017) note that the effect of digital health communities to empower lies partly in facilitation by professionals. For ease of reference and to focus discussion, the study adopts the idea that organisation-hosted digital health communities are ‘facilitated’ while customer-hosted ones are ‘not-facilitated’ as illustrated by Figure 2.1.

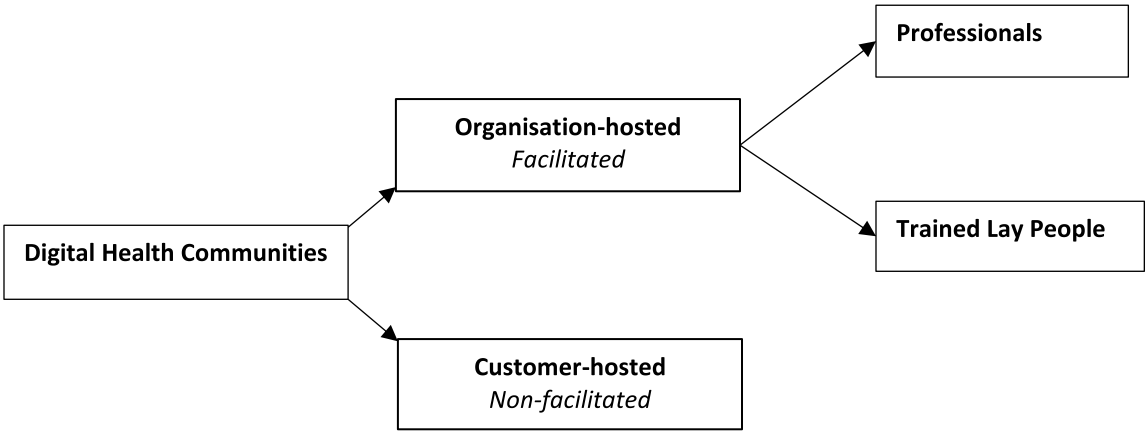


Figure 2.1 Categorisation of Digital Health Communities

With the background of what digital health communities are, and how they are managed, the following section discusses the digital health community investigated in this thesis.

2.4 The Context of this Study – SANE Carers Forum

The choice of a digital health community to use in this study was based on the research questions articulated in Chapter 1 and the discussion so far. Firstly, for a study that investigates *'use',* the digital health community had to be active, whereby users post, comment, like, and reply to each other's posts. Secondly, it had to be facilitated to enable the study to explore the moderating effects of facilitator support on empowerment. This is against the backdrop that facilitation in digital health communities improves the confidence and self-esteem of users, which enables them to have control over their circumstances (Li et al., 2017). As shown in Figure 2.1, facilitated digital communities can be hosted by professionals from organisations, or experienced laypersons to guide and support other users, especially new ones.

The SANE Australia forums are the largest open access, facilitated digital health communities for people with mental illness in Australia. The forums are divided into two: i) the Lived Experience forum for people living with mental illness. Most of its members are care recipients but some are carers who experience mental illness as well; ii) the

Carers forum, which is dedicated to informal carers of the care recipients. This space allows them to share their thoughts, feelings, and experiences of their care journey. The forums are available 24/7.

The Carers forum is a digital health community of about 13,000 registered members. On average, 548 of them visit to share about 590 posts daily, making it a relatively active digital health community (SANE, 2018). It is facilitated by 315 health professionals, trained to support people at risk of suicide, especially in that the forum is a space for people dealing with mental illness in their lives. In the discussions, the facilitators identify either as ‘moderators’ or ‘community managers’ and their role is to monitor conversations and offer advice to carers, maintaining minimal interjections to allow more user interactions. They are also responsible for vetting the carers’ posts, safeguarding against misinformation, and maintaining the integrity of the DHC as well as ensuring adherence to regulations (SANE, 2018). The Carers forum is run as a formal service, not a research intervention.

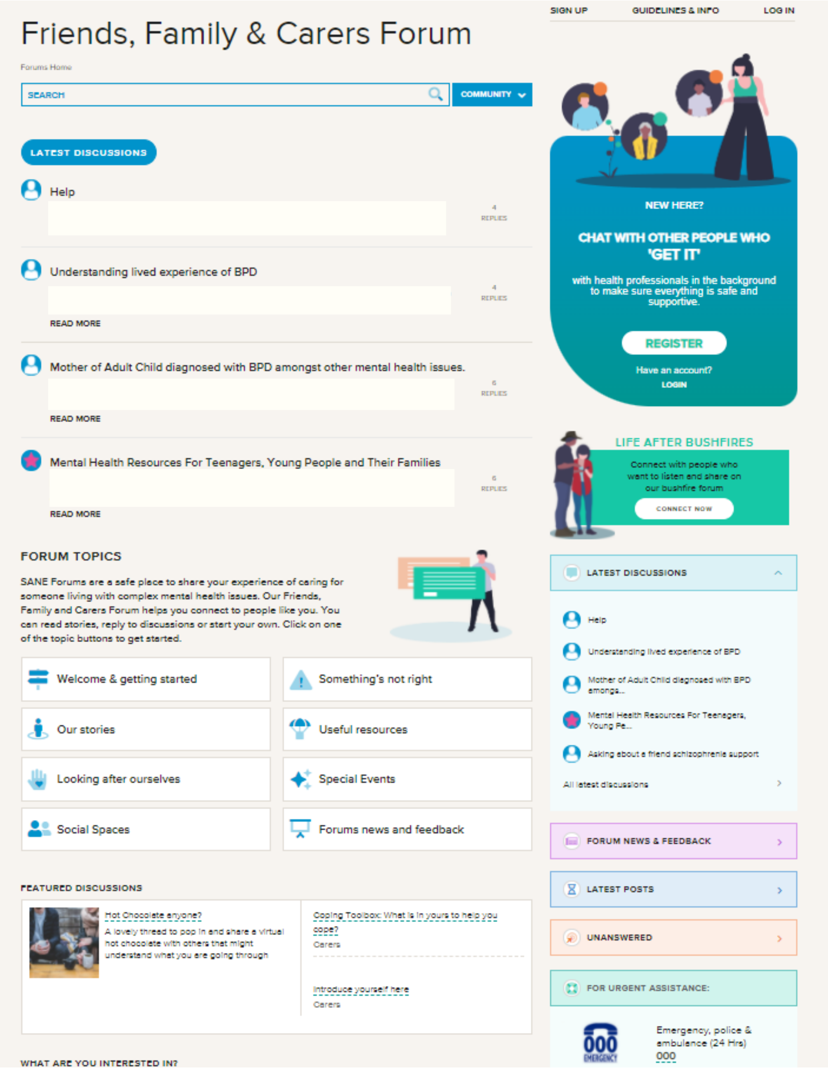
Facilitators work with ‘community guides’ who are volunteers that chaperone other carers and ‘community elders’ who are contributors that have been around the digital health community for many years and are also willing to share information. The digital health community is public, i.e. there is open access to posted messages, but one needs to register as a member to participate in the discussions. Membership is restricted to Australian adult residents (at least 18 years old), but in practice, the digital health community is accessible to people worldwide. They operate under the principles of safety and respect, and contributors are encouraged to communicate content that is helpful and focused on wellbeing, recovery, and help-seeking behaviours (SANE, 2018). Being a peer-to-peer support service, the forum guidelines encourage anonymous sharing of authentic information – either a personal experience or information from trusted sources with links (Smith-Merry et al., 2019). The study uses data from the Carers forum only (referred to as digital health community too), whose homepage is shown below in Figure 2.2.

Discussions on the forum are organised into seven boards or topic categories, which users are at liberty to post to (or search) depending on relevance to their subject matter.

Forum users can write a new post, reply to it, support it, copy the link to a post, mark a post as new or as their favourite, email it to a friend, print a post, or report it. When writing a post, users can share various resources, including web links, graphics, and can use emoticons. This enables them to communicate their ideas and thoughts in visual ways too, not only in text.

As shown in Figure 2.2, the forum also has a ‘search’ facility that allows a carer to type any topic or author name to retrieve previous posts, which one can read as a point of reference at any time. Therefore, shared resources can be managed collaboratively. Users can also employ the @ symbol to tag another and bring an issue that is being discussed to their attention. To guard the confidentiality of carers further, there is a private online chat through which a carer may seek individualised support from the facilitators. They can also call a helpline or communicate by email.

The Carers forum provides data for two phases of this study – the online observation (phase 2) and the survey (phase 3).



Friends, Family & Carers Forum

Help

Understanding lived experience of BPD

Mother of Adult Child diagnosed with BPD amongst other mental health issues.

Mental Health Resources For Teenagers, Young People and Their Families

NEW HERE?

CHAT WITH OTHER PEOPLE WHO 'GET IT'

with health professionals in the background to make sure everything is safe and supportive.

Have an account?

LIFE AFTER BUSHFIRES

Connect with people who want to listen and share on our bushfire forum

FORUM TOPICS

SANE Forums are a safe place to share your experience of caring for someone living with complex mental health issues. Our Friends, Family and Carers Forum helps you connect to people like you. You can read stories, reply to discussions or start your own. Click on one of the topic buttons to get started.

- Welcome & getting started
- Something's not right
- Our stories
- Useful resources
- Looking after ourselves
- Special Events
- Social Spaces
- Forums news and feedback

Help

Understanding lived experience of BPD

Mother of Adult Child diagnosed with BPD amongs...

Mental Health Resources For Teenagers, Young Pe...

Asking about a friend schizophrenia support

Hot Chocolate anyone?
A lovely thread to pop in and share a virtual hot chocolate with others that might understand what you are going through

Coping Toolbox: What is in yours to help you cope?
Carers

Introduce yourself here
Carers

Emergency, police & ambulance (24 Hrs)
000

Figure 2.2 Screenshot of the Carers' forum Homepage

Investigating a digital health community of carers of people with mental illness finds relevance in the assertion that mental health affects a quarter of the world's population – at some point in time, one in four people are affected by some disorder of mental health. Moreover, it is a cause of health-related economic and social burden worldwide (Prakash & Das, 2020). Popular disorders that contribute to this burden include anxiety, depression and post-traumatic stress disorder (PTSD), which continue unabated because of scarce trained mental health workers, social stigma associated with mental illness and inadequate resources to treat mental illness (Prakash & Das, 2020). So, this creates great pressure for informal carers, who are the closest to the care recipients.

2.5 Potential Stakeholders of the Study

The identification of stakeholders is anchored on their contribution to objectives of an undertaking. As such, any individual or group of people who can affect or be affected (Freeman, 1984) by the outcome of this study is among its stakeholders. Compared to traditional organisations, online communities tend to have fluid boundaries of operation but it is still essential to identify those that are beneficial to or derive benefit (Andriof & Waddock, 2017) from studying them.

Considering the focus area and scope of operation, the study has the following stakeholders – carers, health care practitioners, researchers, patients, professional facilitators, forum administrators and health service providers (Atanasova et al., 2017). Carers will gain from identified benefits of digital health community use which can foster their empowerment, while researchers will utilise the derived empirical evidence for empowerment as a base for further investigation into the capabilities of digital health communities. These communities also avail information that can assist forum administrators and facilitators to know what benefits carers derive from utilising them so that they can tailor their forum offerings for maximum benefits to carers. The health service providers and practitioners can utilise outcomes of user behaviours and interactions to support informal carers.

2.6 Chapter Summary

Digital health communities are a special type of online communities which have evolved to provide complementary and supplementary support to their users. They can be professionally facilitated or not. Facilitation is a means of ensuring that the digital health community deals with misinformation, and guides and maintains operations of the community according to the set guidelines. The use of a facilitated digital health community like the SANE Carers forum has many benefits to its users, including fostering empowerment, specifically to carers as this study specifies. The next chapter discusses the reviewed literature relating to the study.

CHAPTER 3: LITERATURE REVIEW

3 Overview

The discussion in this chapter covers a review of literature that presents empirical evidence for utilisation of digital health communities, the dimensions of empowerment and the theoretical perspectives of the empowerment theory which is utilised in this study (Zimmerman, 1995).

3.1 Digital Health Communities

3.1.1 Defining Digital Health Communities

Digital health communities are online communities that allow patients, family and friends as carers, doctors to interact on issues relating to health and social well-being. Although there is no universal meaning of online communities, literature converges on two elements when describing them – members of the community *interact virtually,* and the communities bring together users who share issues of *common interest* (Hara et al., 2009; Iriberri & Leroy, 2009). In the case of digital health communities, Young (2013) adds a third element to the ones mentioned above – that they foster *formation of relationships*. This is possible because, unlike other online communities, digital health communities provide social support, which provides information, communicates sympathy and love that encourages the formation of relationships and emotional bonds (Huang et al., 2019). So, a digital health community can be defined as a virtual space that connects geographically dispersed individuals who share personal experiences and information on some health matters, establishing and nurturing relationships in the process (Mpinganjira, 2018; Zhang et al., 2018).

3.1.2 Benefits of Digital Health Communities

Benefits of digital health communities contribute to their widespread acceptance. The utilisation of these communities yields various support exchanges, like information utility, social support, sense of community, information quality, experiential knowledge (Johnston et al., 2013; Petrič et al., 2017); companionship, empathy, sense of belonging, altruism, connectedness, all of which benefit users (Yan et al., 2017). This section discusses features and attributes of digital health communities that foster user profiting.

The availability of support exchanges in a large network is necessary for continued utilisation of the digital health community. The large network means a user has more resources from a bigger and diverse group; that is, there is a wider variety of opinions, social support and experiences, which offer various and richer viewpoints on issues (Mirzaei & Esmaeilzadeh, 2021). The convenience of accessing these resources any time, from a location convenient and comfortable to the user beyond physical and temporal barriers, also makes the digital health communities attractive to use (Wasilewski et al., 2016; Fortuna et al., 2019). Normally, people would seek medical advice and opinions from friends, family and health personnel off-line; now technology allows them to seek the same support from even physically distant strangers (Fan & Lederman, 2018).

As mentioned in the previous section, digital health communities are focused on some condition, so they tend to have smaller membership compared to social networks, which helps maintain their inherently confidential nature and assists in keeping focus on the core function of exchanging health information (Mirzaei & Esmaeilzadeh, 2021). Their ability to allow for anonymity of users also promotes confidentiality, encourages free expression and discussion of sensitive matters, as well as eliminating discrimination against other users' appearance on how they are addressed (Kirk & Milnes, 2016). On the other hand, their small membership gives users a chance to meet similar others and develop relationships, as well foster togetherness, belongingness and a community spirit (Barak et al., 2008).

Another benefit of digital health communities is their user-centred capability, which has given users the control over what information they can get, and in which form they can package it. These communities have availed concealed and/or otherwise inaccessible information, whose access has been the prerogative of health experts. This challenges the long-held practise of experts monopolising and maintaining autonomy over information flow (Mirzaei & Esmaeilzadeh, 2021). Like other technologies that are ‘demand-driven digital disruptions’, digital health communities have changed the narrative to permit users to generate and distribute content in a multidirectional way; thereby causing ‘a digital disruption’ (Dong, 2019; Hermes et al., 2020). They have also enhanced synergy between users who can now support similar others in their health challenges – hence they are ‘demand-driven’ (Huang et al., 2019). This shift needs health experts and users of digital health communities to alter their attitudes to accommodate change implications for digital transformation to take effect (Hermes et al., 2020).

Other advantages include the asynchronous nature of digital health communities, which affords users time to read and think about the issues discussed, and even to read older posts and ask questions to inform themselves (Zhang et al., 2018). Having had an opportunity to contemplate issues, users have time to write their responses or contribute through new posts. Wasilewski et al. (2016) underscore the psychological and therapeutic effects of writing, that when one writes they let out their feelings and can feel relieved. Kirk and Milnes (2016) credit the digital health communities with inclusivity for people living with disabilities and rare conditions, thereby increasing access.

Table 3.1 gives a summary of other benefits of digital health communities. It also shows disadvantages because technology inevitably has both positives and negatives.

Benefits of a Digital Health Community
Social support —Build and maintain social ties with offline friends and those met online —Seek and provide support to the group or the larger community —Opportunity to offer and receive emotional support in a climate of trust and equality —Chance to bond socially and generate social action —Opportunity to offer and receive empathy *Indelible permanence* —Ability to think about and edit responses —Ability to store and retrieve messages —Ability to establish permanent social presence through photographs, textual profiles, and archived messages

—One can control with ease their level of participation in the community, either to be active or passive —Access to research articles and hyperlinks within the community related to the focus of the community
Disadvantages of a Digital Health Community
Addiction —Potentially addictive and may lead to a decrease in face-to-face socialisation *Cyber victimisation* —Chance to have a lower threshold of acceptable behaviour, leading to socially inappropriate and aggressive behaviours and messages *Misinformation* —Potential to receive or send inaccurate and misleading information —Possibility to misinterpret messages because non-verbal elements of communication are absent —Information exchange is not controlled, negative aspects of a health condition can be illuminated more by pessimists *Anxiety* —Asynchronous communication has a time lag before the user receives a response

Table 3.1 Advantages and disadvantages of digital health communities to users

(adopted from Kirk and Milnes, 2016)

3.1.3 Utilisation of Digital Health Communities

Use is described as the degree to which a user may utilise a platform like a digital health community to perform tasks (Karahanna et al., 2018). The last few years have seen a surge in the use of digital health communities due to the increased need for information that complements expert advice (Mirzaei & Esmaeilzadeh, 2021). Literature reports that 94% of Australian adults use the internet, 50% of whom utilise it to retrieve health-related information (Halsam, 2017). More than 50% of United Kingdom adults use online health information sources, while 35% of American adults seek health information online (Zheng et al., 2021). In Europe, 23% of adults use online sources to get medical information, while in China health websites are reportedly visited most frequently compared to social service websites (Yan et al., 2016). Indeed, digital health communities are the most frequently visited online communities by Internet users (Sadovykh & Sundaram, 2017).

Usage determines the performance and existence of a digital health community, and the extent to which users can benefit depends on their usage. An active digital health community is one in which there is a contribution of fresh content for and timely interactions by users; these interactions help users understand each other's expectations (Chen et al., 2018). However, because utilising these communities is voluntary, some users choose to be active while others remain passive (Chen et al., 2014). As a result, most of the digital communities (including those for health) do not achieve the ideal usage environment because users experience the "volunteer's dilemma" – they want to benefit from a resource they are not contributing to, hoping that others will (Gasparini et al., 2020). As a result, digital health communities tend to experience the 1% rule of participation, which explains that 90% of users are inactive (lurkers, who browse the content but rarely contribute), 9% contribute sparingly (contributors) and only 1% contribute frequently (superusers). Most content (70%) is generated by the 1% superusers who are usually long-serving members of the community; their consistent use is borne out of genuine care to assist others (van Mierlo, 2014; Kirchner et al., 2021). Studies have linked active use of a digital health community to positive outcomes (Erfani & Abedin, 2018), connoting that active digital health communities are those that are used.

Research shows that users easily connect with others who have a similar experience as themselves (Huang et al., 2019), and it differentiates between these user types - lurkers and posters or passive and active users, based on their level of activity (Kirchner et al., 2021). Lurkers usually read but seldom post in the community, while posters engage in activities that describe use – reading a post or seeking advice (Karahanna et al., 2018), initiating a thread or posting a message (Li et al., 2019), replying a post or commenting and supporting a post or liking (Chen et al., 2019). Interestingly though, some studies on the empowering effect of digital health communities observe that lurking is as empowering as active use (van Uden-Kraan et al., 2008; Mo & Coulson, 2010). That is, reading and acting on advice from a digital health community has the same effect as the one who reads, replies and acts on advice. In any case, even if they do not post anything, the lurker is part of the audience that posters need and by just reading they are consuming content (Kirchner et al., 2021). It, therefore, suggests that lurkers are more of ‘silent users’ who seek support and information and utilise it in a way that is different from the other group. Information in a digital health community is typically generated by active rather than silent users, so usage is here investigated in the context of those engaged in generating and exchanging information and other supports.

The notion of use has been operationalised in terms of the widely investigated ‘frequency of use’ (Kirchner et al., 2021), together with the duration of use, misuse, use patterns (Jiang & Cameron, 2020), the task of use i.e. what you use the information for (observe, advise or seek) (Dang, 2020) as well as the extent of use (Negoita et al., 2018). The thesis assesses ‘use’ through self-reported measures of the task of use, duration, and frequency of use as well as the reply/post/comment/like activities.

3.1.4 Support Exchanges from Digital Health Community Use

Support exchanges (resources) discussed here were extracted from extant literature and expert interviews reported in a prior paper by Sethibe et al. (2019). They include but not limited to social support (emotional and informational) (Erfani et al., 2017), experiential expertise (Burda et al., 2016), self-disclosure (Zhang et al., 2019), social overload (Maier et al., 2015a), social network fatigue (Zhang et al., 2016), and emotional contagion (Kramer et al., 2014).

The importance of support exchanges in empowerment is highlighted by Nguyen et al. (2020), who mention that when they are shared they enhance interactional empowerment and the feeling of togetherness while at the same time contributing to the pool of resources available to the whole digital health community. Kim et al. (2018) advance an argument which suggests that the movement of resources within a digital community creates expected and unexpected consequences, and as such, the study of any digital technology should consider its dual effects and explore them both (Abedin & Qahri-Saremi, 2018). As a result of this view, it is acknowledged that the resources generated in this digital health community can be categorised into enabling and inhibiting resources (Grehling & Maier, 2021). Enabling resources are represented by social support, experiential expertise and self-disclosure. As intended consequences of digital health community use, they may affect empowerment differently from inhibiting resources. The inhibiting resources are represented by social overload, social network

fatigue and emotional contagion, and are unintended consequences of digital health community use which may affect empowerment differently from enabling resources.
Although digital health community use may directly empower, the contribution of these support exchanges as mediators is documented. The support exchanges serve as resources needed for empowerment (according to the empowerment theory), and are created for the benefit of the entire membership (Abedin et al., 2020). The type of support exchanges accessible in a networked environment and how they flow is determined by users' level of activity, and the strength of the relationships between the users (Chewning & Montemurro, 2016). Employing digital health communities gives users knowledge, which enhances their proficiency and enables them to understand their peers' expectations; consequently, there are better and richer contributions to the support exchanges when users are so equipped (Chen et al., 2018). Furthermore, the networked environment in which the supports are exchanged gives resource durability; that is, even if users were to quit, the resources remain a digital footprint that continues to exist as a reference to whoever searches for them later (Chewning & Montemurro, 2016). Although they are sometimes unsolicited in a public digital health community, resources that are shared benefit all users, strengthen relationships and enhance outcomes (Chewning & Montemurro, 2016).

The obtainability of social support remains fundamental in digital health community utilisation as users depend on it (Mirzaei & Esmaeilzadeh, 2021). Social support defines the sense of recognition, care and assistance given by others within a group. It is especially helpful as it buffers its recipients against stress, isolation, declining mental and physical health, while it contributes positively to their well-being (Erfani et al. 2017). Social support is classified into *emotional support*, which. gives users sympathy, compassion, kindness, comfort and even expressed emotions (e.g. sadness, happiness); it makes users feel less isolated and less lonely (Liu et al., 2020b). Support is also shown through *informational support*, which proffers advice, opinions, propositions, and related knowledge from community members who voluntarily offer it; it helps support seekers to solve challenges a DHC user may be facing (Liu et al., 2020b). Another category of social support is *esteem support*, which provides confidence, motivation and inspiration to boost morale and help someone feel appreciated and valued (Liu et al., 2020b). Support can also be *instrumental support*, in which someone gives something tangible (e.g. financial assistance, services, material goods) or offers to talk to someone who can help (Andalibi et al., 2018). Finally, a digital health community offers *network support*, in which a user communicates being a part of a group of people with experiences that are similar (Andalibi et al., 2018). Social support is a positive predictor of digital empowerment (Petrič et al., 2017), though scantily studied.

As digital health community users interact, they also exchange observed insights from their experiences, and these insights are invaluable to those seeking support as they are shared by ‘people like us’ (Kirk & Milnes, 2016). The recognition of experiences as embedded in the ‘service ecosystem’ is a basis for considering them as affecting outcomes of technology use. This is more so because experiences unfold over time during which DHC users establish strong relationships among themselves that contribute to a sense of community (Gallan et al, 2019). Experiential expertise is the proficiency derived from one’s lived experience with a particular disease or condition, and it explains how carers become ‘experts through experiences’ (Burda et al., 2016). The experiences may include dealing with health care providers, handling social interactions, dealing with medications, and most importantly, coping with a condition and self-caring (Castro et al., 2019). In an empirical study to analyse the concept Castro et al. (2019) reveal that experiential expertise is explicit, therefore it is easily transferrable to other people. That means in a digital health community, it is willingly shared among users (Bødker, 2017). They also confirm that it can facilitate empowerment. While it is established that carers who practice less self-care have lower decision-making self-efficacy, there is little evidence to inform self-care as exchanged over digital health communities, the effects of experiential expertise and its contribution to empowerment. Castro et al. (2019) note the scarcity of such literature and calls for studies that cover ‘friends and relatives’ of patients as well, that is, carers.

The limiting effects of digital health community use, which may lead to unintended outcomes, include social overload and emotional contagion. Upon request, support is usually given by peers to each other, and some users tend to feel obliged to assist. With the perpetual access to digital health communities, requests may inundate users especially that responding to requests may be time-consuming and emotionally exhausting (Yang & Lin, 2018). Once giving support becomes more than what a user can comfortably handle, they experience social overload, which may reduce utilisation of the digital health community (Maier et al., 2015a) and subsequent discontinuance thereby affecting digital empowerment. Utilisation of a digital health community may also result in emotional contagion, a state in which the sentiment of one person may elicit similar reactions in others (Johnson et al., 2016). Users mimic sentiments that they observe in others and may express the same – whether negative or positive (Wang & Lee, 2021). Although the study of emotional contagion is found more in communication literature (Johnson et al., 2016), its application to digital communities gave varying results depending on the size of community, type of digital community, content of messages, and type of emotions (Wang & Lee, 2021), to name a few.

While studies on digital health community use suggest positive effects for outcomes like well-being (Erfani et al., 2017), there is lack of empirical evidence of how the above-discussed support exchanges affect digital empowerment (Petrič et al., 2017). It is also not certain whether support of a facilitator affects digital empowerment or not.

3.2 Empowerment in Digital Health Communities

The interest to explore the potential of digital health communities to improve user outcomes has increased from the time studies on digital health communities emerged in the nineties. A study by Feenberg et al. (1996) is one of the early investigations into empowerment in online health support groups, and it studied how communication flow contributed to patient empowerment. Especially since 2007, there has been growing activity to explore possible benefits of digital health community use for professionals, users, and service providers (Abedin et al., 2020).

3.2.1 What Is Empowerment?

The concept of empowerment lacks a universal definition, which has resulted in difficulty operationalising it (Petrič et al., 2017). It is naturally contextual, across the individual, organisational and community levels it operates at. Consequently, it emerges as a multidimensional notion that is applied across various disciplines (Zimmerman, 2000). Rooted in the ideology of social action of the 1960s and the self-help viewpoints of the 1970s, empowerment is applied in healthcare where it is linked to intervention and prevention, as well as change of power relations between professionals and customers of health services, especially in diabetes and mental health (Cyril et al., 2016). With the digitisation of services across sectors, health included, empowerment takes a different form as technology becomes a medium of support delivery. So, within this context, information systems literature continues to deliberate on the meanings of empowerment, and these are shared in Table 3.2:

Source	**Empowerment definition**
Barak *et.al* 2008	The state of experiencing personal growth from developing skills, abilities, and a positive self-definition, which enables one to cope with challenges and make decisions.
Johnston *et.al* 2013	The degree to which online health community participants develop meaning, competence, self-determination, and impact as benefits gained from participation in the community.
Petrovčič and Petrič 2014	It is people’s strategies, abilities, and actions that allow individuals to more successfully manage their health condition.
Li 2016	A cognitive state characterised by a sense of perceived control, perceptions of competence, and goal internalization.
Petrič, Atanasova & Kamin 2017	The gaining of power within that increases one's personal & professional self-esteem and awareness of his capacity to motivate possible social practices.
Li, Jiang, Fan & Hou 2017	A social process of recognising, promoting, and enhancing people's abilities to meet their own needs, solve their own problems and mobilize the necessary resources to control their lives.
Leong *et.al* 2018	A mechanism through which a community gains mastery over its affairs, and is at the centre of social change.
Hur, Cousins & Stahl 2019	A person’s ability to make independent, informed decisions about his or her health care, showing a self-directed ability to overcome stifling power relationships.
Sharma & Khadka 2019	The process of acquiring confidence and ability to cope with one own’s disease and get a hold of it to better manage it.
Liu et al. 2020a	A person’s discovery and development of their inherent capacity to be responsible for their own life.

Table 3.2 Definitions of Empowerment

The common thread running through these descriptions of empowerment is an individual’s responsibility to develop their inherent capacity to take charge of their life (Oh & Lee, 2012). This is partly because empowerment is not conferred upon someone but is experienced when individuals make conscious choices that they can transform into actions (Zimmerman, 1995). Another idea that is pronounced is the locus of control. Empowerment shifts power relations, advocating for recognition of stakeholders as ‘participants’ and ‘collaborators’, rather than ‘clients’ who need ‘expert’ help; in fact, the participants may end up being experts in their own right. In the same vein, professionals working with stakeholders become ‘facilitators’ not ‘advocates’ (Zimmerman, 2000). Consequently, empowerment in health care gives an alternative to the doctor-centred approach that has been the familiar practice, and advocates for customer-centred approaches, which will assist all health customers to participate in their health (Oh & Lee, 2012). The contribution of digital health communities in aiding this move of power relations is acknowledged in literature (Liu et al., 2020a). The thesis proposes that empowerment due to the use of digital health communities is the mechanism through which a user strengthens their skills and inherent capacity to cope and make informed decisions on a daily basis (Hur et al., 2019; Liu et al., 2020a); the decisions can be health-related or not.

3.2.2 Operationalising Empowerment in Digital Health Communities

Early theorists, specifically Zimmerman (1995), proposed a triad of empowerment components as intrapersonal, interactional, and behavioural, all of which are important in studying empowerment. Most research on empowerment in digital health communities has focused mainly on the intrapersonal dimension, in which the study of empowerment is characterised by control, self-efficacy, and competencies (Petrovčič & Petrič, 2014). These elements explain an individual’s belief in exerting influence in different life spheres, undertaking activities that impact their living conditions, and self-assessing when one carries out a task (Petrovčič & Petrič, 2014). For instance, studies on the intrapersonal dimension showed that users of digital health communities could be empowered to – improve relations with their doctors (Atanasova et al., 2018), improve adherence to treatment (Liu & Kauffman, 2020) as well as manage their illnesses (van Uden-Kraan et al., 2008). This dimension explains one’s capability to make decisions based on how they think about themselves (Amichai-Hamburger et al. 2008), so it is within an individual.

Empowerment can also be studied through the interactional component, which requires an understanding of one's socio-political environment. In this context, a user needs to be involved in the digital health communities and have an understanding of group norms, which will contribute to building their sense of community (Petrovčič & Petrič, 2014). As they interact, users should be able to share perceptions of how they can gain abilities to change their situations, encourage collaboration to improve one's disadvantaged position (Atanasova & Petric, 2019). Users develop a shared sense of community as they exchange support and develop alternative solutions that may enable them to choose the best option for their decision. This sense of togetherness formed by helping others, and regard for adherence to group norms builds community while it demonstrates interactional empowerment (Petrovčič & Petrič, 2014). The few studies on interactional empowerment include Wentzer and Bygholm (2013), which explored how users are empowered for collaboration, and Petrovčič and Petrič (2014) which investigated user empowerment for active participation by emulating others. As users interacted, they shared perceptions of how they can gain abilities to change their situations to a better one. Hence this dimension emphasises community and its interactions (Atanasova & Petric, 2019).

The behavioural dimension of empowerment is concerned with action, involvement, and participating in one's community in a manner that directly influences outcomes (Zimmerman, 1995). It deals with behaviours that assist in adapting to change e.g. managing stress and developing ways of coping. In other ways, the behavioural dimension reflects a user's active contribution to improving the way things are done, by initiating action rather than being forced to act (Sadovykh & Sundaram, 2017). The contribution is self-initiated, so the digital health communities users voluntarily take action (Montani et al., 2015). In that way, the behavioural dimension supports decision-making. Prior literature has covered well empowerment in digital health communities as a consequence of interactional and intrapersonal action (Petrovčič & Petrič, 2014; Sharma & Khadka, 2019), and as such studies on the behavioural component are scant. Commonly, most studies investigate one or two of the three components, and studying the three-factor structure is very rare (van Dop et al., 2016). Therefore, this study concedes to including all the components in its investigations, to recognise the multidimensionality of empowerment, because an empowered individual may hold one or more of these components (Petrič et al. 2015).

For a long time, studying technology use was based on technology as tools utilised to improve effectiveness and efficiency in organisations; however, recent conceptualisations advocate for experiential computing, which recognises users' experiences with the now pervasive technologies (Yoo et al., 2014). The users are a new breed that are natives of the digital world and engage computing in all aspects of their lives (Prensky, 2001). Their computing including the social aspect, hence they are not 'solitary information processors' (Junglas et al., 2013). This notion is expanded by Bødker (2017) as he draws attention to the importance of considering users' emotions and feelings as part of experiential computing. The lack of emotions in IS research had been decried by Ciborra (2006), who suggested that a user has an 'inner life… mind and heart', which are part of their interactions with IS artefacts. As such IS use should be recognised to encompass 'the whole person.' Junglas et al. (2013) also concur that there are sentiments entrenched within technology use, since it has social psychological aspects, and they suggest that consideration for the social aspect of IS use will include the emotions aspect. In the context of information systems, Lu et al. (2019) describe emotions as feelings elicited when somebody utilises an information system, while affect is emotions that are externally induced by interactions with an information system (Bødker 2017).

Given the foregoing discussion that information system artefacts elicit emotions, this thesis proposes that the competences of digital health communities render them experiential computing platforms that enable *affective empowerment*. So, affective empowerment can be explained in terms of the emotional state and sentiments of the user due to competences of the digital health community. This dimension is suggested as an addition to the existing ones discussed above, and addresses an important aspect of information systems use. The thesis further proposes that the *affective* dimension is unique to and identifies empowerment in digital health communities, especially for decision-making. Andrade and Ariely (2009) highlight that decision making needs emotional stability, because big life decisions can be impacted by incidental emotions.

Table 3.3 gives a summary of some of the literature on empowerment in digital health communities, which shows that empowerment in the context of decision making is least studied, and few digital health communities are facilitated. Most of the studies are on empowering patients to improve relationships, self-manage illness, adhere to treatment, activism. So, a study on empowerment for decision-making in a facilitated community will contribute to empowerment literature.

	Source	Target Group	Method	Empowerment context	Is DHC facilitated?
1	Coulson & Shaw 2013	Facilitators	Thematic analysis	Support users	Yes
2	Johnston et.al. 2013	Facilitators & patients	Interview & survey (MM)	Adhere to treatment	Yes
3	Lawlor et.al 2014	Patients	Survey	Have no self-stigma	No
4	Petrovčič and Petrič 2014	Patients	Survey	Improve peer relations	No
5	Wentzer & Bygholm 2013	Patients	Content analysis	Improve patient-doctor relationship	No
6	Smedley et.al 2015	Patients	Content analysis	Self-manage illness	No
7	Atanasova, Kamin & Petrič 2017	Facilitators	Interviews	Service DHC users	No
8	Petrič, Atanasova & Kamin 2017	Patients	Survey	Improve patient-doctor relationship	Yes
9	Li, Jiang, Fan & Hou 2017	Emergency rescuers	Experiment	Tackle role-trauma	No
10	Leong et.al 2018	Citizens	Survey	Digital activism	No
11	Fan & Lederman 2018	Patients	Survey	Build peer relationships	No
12	Petersen, Schermuly & Anderson 2018	Patients	Survey	Patient activism	No
13	Hur, Cousins & Stahl 2019	Mothers	Content analysis	Sensemaking	No
14	Sharma & Khadka 2019	Patients	Survey	OSHG use	No
15	Huang et.al 2019	Patients	Text analysis	Self-manage illness	No
16	Meng, Zhang et.al 2021	Patients	Survey	Participation	No
17	Liu et al. 2020a	Patients Doctors	Experiment	Improve patient-doctor relationship and Patient wellbeing	Yes

Table 3.3 Some of Reviewed Literature on Empowerment in digital health communities

3.2.3 Informal Carers' Needs and the Role of Digital Health Communities

Informal carers (hereafter called carers) are family members and friends who provide unpaid care to their sick loved ones and experience the fluctuating and demanding rigours of caring daily (Boots et al., 2014). As such, they and their patients share the need to know about a patient's health issues, treatment options, available service providers for the management of the condition, feelings and personal experiences of those who have the same condition, and how they cope (Johnston et al., 2013). Apart from health care, carers also provide personal, physical, financial and emotional care to the care recipient, ensuring that they visit health services and have their daily needs met (Hussain et al., 2016).

Carers account for a sizable number of people in communities. For example, they make up approximately 12.5% of the Australian population, providing about 62% of the care needed (Hussain et al., 2016). In Europe, they provide 80% of the needed care, whereas in the USA they make 13.5% (44 million) of the population. In the UK, one in six households has an informal carer, which accounts for about 7 million carers (10% of the population) (Long et al., 2017). Notwithstanding, most carers do not acknowledge their role because they look after someone very close. They ‘drift’ into carer duties, unaware of what the daily responsibilities entail (Long et al., 2017). Over time, they become overwhelmed by the responsibilities of managing symptoms and treatment, dealing with cost implications of caring, the basic routine activities of bathing, feeding, housekeeping for the care recipient, and the perplexing daily decisions they have to make (Onwumere et al., 2018; Sadovykh et al., 2019a). Some carers end up reducing their work days in order to care for someone at home, while other leave their jobs completely (Hussain et al., 2016; Wasilewski et al., 2016). Inadvertently, this may cause mental and physical health challenges on the carers who would typically keep their feelings to themselves. The reason is that for most people, health matters are personal, especially if they involve someone with mental illness since it carries a stigma (Onwumere et al., 2018).

Despite facing these confounding circumstances, carers need to prioritise the care recipient because when they visit a doctor or any health professional, the attention is centred around the care recipient’s welfare and medical needs. The carer’s queries, concerns, and feelings of inadequacies, including how to cope with the change sickness brings, are never part of the discussion in the consultation room (Pope et al., 2017). Moreover, in most cases carers are not able to find help for themselves because they cannot leave care recipients alone, thus increasing their levels of stress (Wasilewski et al., 2016).

Digital health communities provide alternative sources of information and support without leaving home (Onwumere et al., 2018), which usually complement and/or supplement knowledge obtained from off-line networks (Zheng et. al. 2021). They also offer access to very useful resources in the form of experiences (Huang et al., 2019). When all these are exchanged on the digital health communities, interests, skills and common traits emerge, and carers with mutual experiences become an encouragement to others. As a result, the support seeking carers willingly replicate actions that lead to hope and positive feelings which are shared in the forum (Fortuna et al., 2019). Digital health communities also provide motivation and abilities to enrich decision making capabilities. They provide support for improved coping, self-efficacy, general self-management and empowerment (Atanasova & Petric, 2019; Liu et al., 2020a). When empowered, carers can have confidence to deal with stressful situations (Sadovykh & Sundaram, 2017). While the potential of digital health community use in enabling empowerment looks promising, extant literature is inadequate in its representation of whether and how its use empowers for decision-making (Sadovykh & Sundaram, 2017), especially in facilitated environments. Carers are an under-researched group in studies of digital health community use (refer to the 'Target Group' column of Table 3.3), particularly carers of people with mental illness (Smith-Merry et al., 2019).

3.3 Professional Facilitation Providing the Environment

The widespread utilisation of digital health communities has contributed to several challenges for their users. For example, there is peddling of misinformation yet health is a sector that deals with sensitive matters, which sometimes border on life and death (Johnston et al., 2013). In other instances, some users are anti-social and nasty towards others, attacking them and using unacceptable language on the forum (Wise et al., 2006). Users also deal with information overload, which can be attributed to unlimited posts users make. This production of information faster than it can be processed causes an overload, which makes it difficult for users to filter through available options, choose what is useful and make decisions (Hu & Krishen, 2019). The other challenge experienced in digital communities is information asymmetry, where there is uneven distribution and possible shortage of information resources among users of the digital community. This phenomenon tends to permeate health care more due to the sector's high levels of uncertainty, thereby creating power inequalities (Barile et al., 2014). For example, information may be held by some members, while others are less informed. Although there may be guidelines for behaviour and how interactions need to be conducted, some users flout them, hence a need to have a facilitator who oversees activities of the community. Activities include filtering information so that it can be trusted by users and be of a quality that can aid decision-making (Chen et al., 2011); managing interactions so that there is no flaming and the forum is safe for all users to interact, as well as adherence to the set norms of the forum (Wise et al., 2006).

In this study, the empowerment theory explains user behaviour and response to social challenges that affect empowerment. Users are able to choose tasks to do because of the capabilities of the digital health community, which needs to have an amicable and safe environment for interactions. In line with the empowerment theory, Hur et al. (2019) describe an environment as the degree to which the online ecosystem is supportive, and this environment can be altered by the activities of a facilitator. In digital health communities, keeping focused and preventing possible malicious attacks on other users is important because if not checked, attacks and unguided discussions may normalize risky or unhealthy behaviour or even spread misinformation (Milne et al., 2019). Facilitation, therefore, creates a safe and encouraging environment that enables digital health community users to share opinions, interpretations, and insights about issues being discussed, in that way adding value to discussions and providing alternatives for decision-making (Atanasova et al., 2017). This perspective is also shared by facilitators who reported that moderating digital health communities empowered them as much as it empowered users (Coulson & Shaw, 2013).

Literature reports different attributes of facilitation that have been studied, and they are summarised in Table 3.4 below. In one study, Matzat and Rooks (2014) examined styles of moderation, and they established that an indirect, rewarding and positive approach to moderation was more effective against negative behaviours compared to others. It also revealed that moderation improves user outcomes.

Another characteristic studied was the type of host of the forum. The study by Teichman et al. (2015) found that to encourage the contribution of forum members, facilitators should have the buy-in of opinion leaders; they should also encourage an amiable atmosphere which will enable members to be open and express themselves. Company-hosted forums yielded more user participation than user-hosted forums. The finding is corroborated by Stephen et al. (2017) study which explored the usefulness, acceptability and benefit of a moderated forum. They established that a professionally facilitated forum enabled focused and meaningful interactions, which benefitted more users.

Some moderator studies considered the role facilitators play in forum interactions. For instance, Coulson and Shaw (2013)'s study examined these roles from the perspective of the facilitators. Results reveal that facilitators find digital health communities to be empowering for both themselves and other users. They also identified that as facilitators they are nurturers for forum users. Therefore, they need to build trust, show kindness and respect to forum users for (beneficial interactions), as well as create a safe environment. The self-reported findings are similar to those of Windler et al. (2019) whose results also highlighted the importance of creating a safe environment to promote user interactions. They studied moderators of a forum for adolescents with anxiety and depression, who unanimously echoed that meaningful engagement is enhanced by positive encouragement from facilitators.

Another characteristic covered in extant literature is 'presence', which was used to measure the level of engagement in prior studies (Keng & Lin, 2006). Junglas et al. (2013) describe presence as the awareness of the existence of others with the view to engaging with them. For a long time, 'presence' has been known and studied in terms of physical presence, hence face-to-face meetings are still more highly perceived in terms of presence. However, in this era of digital phenomena, there is a growing interest to consider 'digital presence,' using online alternatives to 'presence' like text messaging; as such it is relatively nascent but developing well (Junglas et al., 2013; Panteli, 2016).

For example, a study by Keng and Lin (2006) used the level of presence to categorise online communities into those having a content, personal and social presence. In the context of digital communities therefore, ‘presence’ is the existence of a facilitator in online interactions to exert influence through digital activites (Panteli, 2016), and the thesis explores facilitator support in terms of ‘presence’ in a digital health community. A consequence of digital presence is the far-reaching effect of one’s activities because the digital space has a larger audience. So a facilitator’s presence must be felt if they have to carry out supportive tasks; their visibility and ability to engage users (termed vividness and interactivity by Keng and Lin (2006)) will provide social support and enable experience sharing (Smedley & Coulson, 2017). Influenced by the line of argument taken by Panteli (2016) who articulates presence as interactive, stimulating, instructive and silent, ‘presence’ will be examined in terms of a facilitator’s commanding, collaborative and motivating approaches to giving support.

Feature	Measures	Source
Facilitator role	Empowerment, nurturing, the emergence	Coulson & Shaw 2013
	Enforcing rules, supportive, promoting engagement	Windler et.al 2019
	Supportive, sharing experiences, making announcements, administrative	Smedley & Coulson 2017
Style of facilitation	Direct/indirect; Rewarding/punishing Positive/negative	Matzat & Rooks 2014
Type of host	Company vs consumer hosted	Teichmann et.al 2015
	Therapist-led vs patient-led	Stephen et.al 2017
Facilitator benefits & challenges	Benefits & challenges relative to social support	Atanasova et.al 2018

Table 3.4 Literature on Facilitation

Chen et al. (2011) assert that information systems research has fewer studies on the effect of facilitation, hence the exploration of the role played by facilitation in a digital health community will contribute to such a discussion. The effect of facilitation is even considered as a moderator, studies of which are rare (Dang, 2020).

3.4 Theoretical Viewpoint

Theory is important because it aids researchers to comprehend and predict associations between variables of the concept under study. As Sahu et al. (2020) point out, it permits various measures, definitions, and views to convey a methodical perspective of the notion; it also corroborates its analysis and validation. The study adopts the empowerment theory as the overarching theoretical lens of investigation of empowerment of informal carers in a digital health community.

As a theory that provides framework and principles which can organise knowledge (Zimmerman, 2000), the empowerment theory is based on three assumptions. Firstly, it is contextually embedded; that is, the environment and setting in which people live affects their empowerment. It has an ability to position human dilemmas from a person-in-environment standpoint, suggesting that empowerment has a strong social nature, and its approaches are not universally beneficial. Secondly, the notion of empowerment shifts over time because it is quite a fluid phenomenon. Finally, it takes on multiple forms across different groups of people as it is influenced by the personal characteristics of those in the study (Zimmerman, 1995). In the context of digital health communities, immersing oneself in and getting actively involved in the digital community is essential for its appreciation as an agent of change to life situations (Petrovčič & Petrič, 2014).

Empowerment theory deals with the rationale behind the process and consequence of people’s efforts to have control over their lives. These processes and outcomes greatly differ according to whether they are theorised at the individual, community, or organisational levels (Zimmerman, 1995). Empowering processes are those that need an individual to, as a fundamental principle, have access to resources, understand their environment, and gain control of their circumstances, while empowered outcomes deal with consequences of the empowering process (Zimmerman, 2000). In this thesis, the theory is applied to describe the behaviour, actions and environment of digital health community users relative to the social challenges they face, which necessitate empowerment. The digital health communities provide an environment that users can interact safely in, with flexibility and the necessary support through moderation by human facilitators (Hur et al., 2019).

In the context of this thesis the empowerment theory states that online resources used in a conducive environment can facilitate a carer's empowerment to make daily decisions. The thesis argues that the empowerment theory explains how user behaviour in a digital health community is influenced by differing levels of factors including intrapersonal, interactional, and behavioural drivers. Among the three, behavioural elements encourage active digital health community use for one to be empowered, initiating utilisation to gain skills that enable one to cope and do self-care, as well as make appropriate and informed decisions (Hur et al., 2019). This proactive and participatory approach to digital health community use will help users take charge of their health matters (Zhou et al., 2017).

While the application of empowerment theory to this study will give insights to know the benefits of digital health communities and exploit them fully, it is also an attempt to heed calls to undertake more empirical studies to verify this theory in information systems (Li et al., 2017).

Figure 3.1 below summarises components of the literature as discussed, and how they relate to each other.

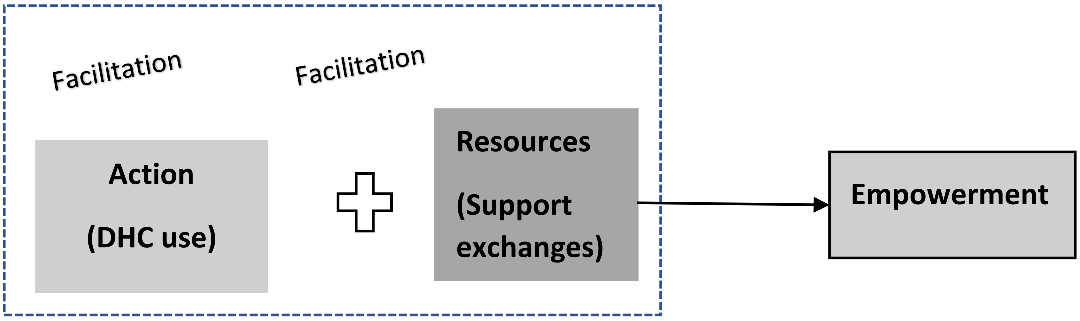


Figure 3.1 Components of the Reviewed Literature

3.5 Chapter Summary

This chapter presents insights from extant literature on the characteristics of the digital health communities, which make them suitable for use by carers. It discusses the elements of empowerment as a notion and the kind of environment provided by professional facilitation. The empowerment theory is discussed as the lens through which digital health community use is investigated, literature suggests a dual effect of information systems use. The next chapter discusses the design used in this research.

CHAPTER 4: RESEARCH DESIGN

4 Overview

Research design details the procedure for collecting, analysing, interpreting, and reporting data in research. This chapter presents the rationale for the approach chosen, the methodology, and the data collection techniques that the research employed (Creswell & Clark, 2011). It concludes by discussing the ethical considerations the researcher made to ensure adherence to regulations.

The aim of the study is to investigate how empowerment for decision-making is affected by the use of facilitated digital communities within the context of a digital health community. Due to the study phenomenon being nascent, its questions do not precisely fit into previous information systems use research (Venkatesh et al., 2013). As a result, the research adopts a sequential exploratory design, which addresses instances where the researcher knows little about an issue (Hair et al., 2015). Hence, the mixed methods approach is employed. The study is carried out in a digital health community of informal carers of people with mental illness in Australia, whose posts are publicly available though only registered members can participate in the discussions.

This chapter is preliminary to chapter 5, which discusses expert opinions obtained through interviews. These provide an initial understanding of the complex environment of empowerment in an explorative and inductive way. Concepts identified from the expert interviews are utilised as broad themes for a content analysis of digital health community user discussions. The content analysis is covered in chapter 5. Its findings were used to design a web-based survey that gathered information on the perceptions of carers on how the digital health community empowers them for decision-making in chapter 5.

4.1 A Pragmatist Philosophical View

Information systems is an interdisciplinary field of study whose origins can be traced to computer science and social science. As such, its theories, methods, and indeed paradigms are from across other disciplines. This interdisciplinary trait continues to make the definition of paradigms in information systems a challenge (Talja et al. 2005; de Albuquerque et al., 2009) although it should not deter researchers from using them since they bring richness and diversity (Venkatesh et al., 2013). Comprehending and situating the nature of reality assumed during the research (ontology), how we know what we know (epistemology), and the process of carrying out the investigation (methodology), all guide the choice of data collection and analyses methods and the overall direction of the research (Creswell & Clark, 2018).

Since a mixed-method study uses both qualitative and quantitative approaches, it cannot employ strictly interpretist or positivist epistemology. Therefore, it adopts a pluralistic philosophical worldview of pragmatism, which sidesteps ontology (Lindberg, 2020) and does not regard knowledge as representing ‘reality’ but rather, as valuable consequences of actions; it also rejects subjective-objective dualism (Bishop, 2015). The approach also uses abduction to explain concepts in terms of effects and consequences (Venkatesh et al., 2013). Abduction is a type of daily reasoning which people generally use in uncertain situations within a particular context, while pluralism is combining methods from differing paradigms (Levallet et al., 2020). Abduction generates reasonable inferences which make sense of available data; it is also wider-encompassing than deductive inference or induction (Lindberg, 2020). Pragmatism is deemed to be the truth for what works, hence its flexibility accommodates the application of mixed methods – both induction (qualitative study) and deduction (quantitative study).

Pragmatism focuses on the action as a source of understanding of the social world, and consequences of action (Lindberg, 2020) like improved quality of life for individual patients. So, each study should be evaluated according to the extent that it achieves its own consequences (Bishop, 2015). It permits the use of multiple methods to investigate a phenomenon to ensure that research questions are adequately addressed. According to this worldview, empirical evidence is important as much as a researcher’s interpretation of observations; reality is constructed by individuals, who, in the process, reconstruct some stable encounters for themselves within their environment (Venkatesh et al., 2013; Creswell & Clark, 2018). Pragmatism also acknowledges that there are social structures, which were established by people who had a role to play in controlling and manipulating the structures through experiences and social interactions. In agreement with the foregoing, Cua and Garrett (2009) point out that the pragmatic worldview portrays reality as formed by a mix of subjective and objective components, which intertwine seamlessly to produce some effect. Its focus on action and its consequences makes it problem-centred, with a tendency to circumvent ontology. Hence pragmatism is suitable for the multidisciplinary field of information systems, especially when mixed methods are used and the study deals with objective and subjective data.

4.2 Applying the Pragmatic Perspective

By adopting a pragmatic perspective, the research intends to capitalise on the acknowledgement that there is no one way of solving any problem, and multiple realities result in various ways of comprehending an issue (Morgan, 2018). This is especially true with the study of information systems like digital health communities whose effect depends on a number of factors. The study utilises the empowerment theory described in detail in section 2.8, which recognises that interactions that empower need resources and a favourable environment. In line with the intention of the study to investigate how utilisation of digital health communities affects empowerment for decision-making, the pragmatic stance encourages the integration of several research methods to examine the ‘how’ and the ‘what’ in sufficient detail.

The usage of both quantitative and qualitative methods in the same study generates a better understanding of the problem from testing of facts and figures, as well as from views of digital health community users who have lived experiences. The latter are generated by people’s actions and cannot be detached from their environment; that is, the usefulness of any action should be interpreted in the social context of their occurrence. Lindberg (2020) has named it ‘the principle of context’. So, the environment shapes the experiences of people, consequently making reality dynamic because of the diversity of experiences (Morgan, 2018). This diversity confers the uniqueness of any particular action in a principle named constitution. Finally, the principle of consequence positions outcomes of actions as having meaning (Lindberg, 2020). Table 4.1 sums up the principles of pragmatism:

Principle	Description	Application
Constitution	While still maintaining engagement with reality, activities become constituted by idiosyncratic action.	Using the digital health community every time constitutes their uniqueness and establishes their capabilities
Context	The efficacy of an action is contextually entrenched and can only be made sense of within that context	The use of digital health communities will produce different effects in different contexts
Consequences	The outcomes of actions are indicators of useful knowledge, as they effectively illustrate the "utility" or "meaning" of an action.	The understanding of digital health communities is closely tied to how we intend to use them.

Table 4.1 A Pragmatist Framework of the Study

[adapted from Lindberg (2020)]

4.3 A Sequential Mixed Methods Approach

Over time, there has been a quest for methodological pluralism to improve inclusivity in research. This has contributed to the pursuit of mixed methods utilisation in IS for the past couple of decades, and has been necessitated by a growing complexity of IS research questions (Levallet et al., 2020), which needed more comprehensive answers within a single research inquiry. This growth of mixed methods use is contributing to a "cure for methodological rigidity found in IS research" (Cecez-Kecmanovic, 2011). Consequently, mixed methods design is esteemed for harnessing strengths that offset weaknesses, and providing and offering insights that go beyond the results of the individual qualitative and quantitative methods (Creswell & Clark, 2018). The approach flaunts "great diversity in the manner in which methods can be mixed" in research, be it by sequencing of the studies, kind of data collected, or ontological positioning (Levallet et al., 2020).

Creswell and Clark (2018) advance three types of mixed-methods designs – convergent (where results of qualitative and quantitative are brought together to be compared or merged), exploratory (qualitative data is used to elaborate or explain quantitative results), and explanatory (use quantitative data to qualitative results). Morgan (2018) proposes similar nomenclature, arguing that 'triangulation' as a term in mixed-methods should be replaced with convergence, complementary, and divergence mixed-methods. According to him, convergence is where the researcher produces nearly identical results using qualitative and quantitative methods. Both studies are independent and complete in themselves, and the results of one do not influence the other; finally, they are integrated. Complementarity is where the investigation tasks are divided among the two methods, to explore different aspects of a topic. Either method achieves what the other cannot. In the end, both results are pieced together to tell one complete story. Finally, Morgan (2018) suggests the divergence approach, where the outcomes from qualitative and quantitative studies are dissimilar, then the contrasting results can be used to create more conversations.

While Creswell and Clark (2018)'s categorisation is concerned with how the collected data are utilised, Morgan (2018)'s classification is based on the method used to produce the results as well as how the results are treated. Therefore, using insights from both researchers' arguments, the current research utilises an exploratory and complementary design, where results of both methods are joined to create a single story (Qual + Quant). It adopts a three-stage QUAL-QUAL-QUAN sequential design, in which results from one stage are a basis for the next stage. That is, findings from expert interviews are used to shape online observations, whose output is integrated into a survey. As Morgan (2018) notes, this approach offers adequate space to move within it during execution, thereby improving chances of meaningful results.

The basis for selecting to start with a qualitative method is that the research is exploring unfamiliar behavioural patterns of digital health community use for the empowerment of carers. Therefore, it is essential to identify relevant attitudes towards these concepts (Ajzen, 1991). The qualitative phase allows the study to consider the broad context and multidimensional nature of digital health communities, while the quantitative phase permits the exploration of relationships between the concepts under study. Hence, the output will be more comprehensive and corroborated (Creswell & Clark, 2018). Before doing the expert interviews, the researcher conducted a review of literature that identified some concepts to consider when studying 'digital health community use' and ‘empowerment’. The identified notions are further explored if they are relevant and make sense by engaging with experts. Ten (10) IS experts from industry and academia were interviewed, which is the minimum number of recommended interviews for experts in literature (Burnham et al., 2008). The interviews are subjected to a thematic analysis, resulting in themes that are used in the subsequent phase of online observation – the second phase. The third phase involved using identified themes to come up with variables for a web-based survey. This sequential mixed method is captured in Figure 4.1.

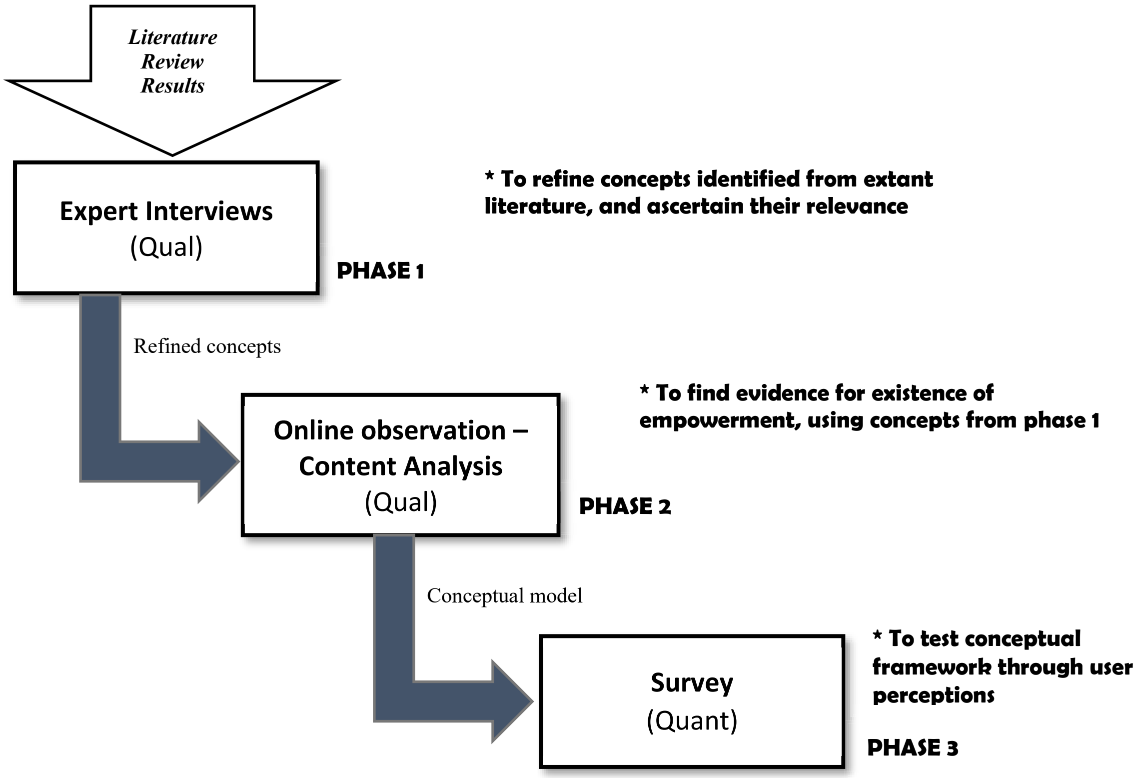


Figure 4.1 Research Design

Mixed methods are advantageous because they illuminate different features of empowerment of informal carers in a digital health community and obtain the integration of qualitative and quantitative results which expands the research. Moreover, the technique is permitted by the epistemological approach of pragmatism which the study has adopted. Pragmatism emphasises choosing the most suitable technique that works, even if it is a combination of methods.

4.4 Phase I: Expert Interviews

Although expert interviews have been a focus of scholarly research for the past two decades, it is only recently that they came through methodological literature as a distinct type of interview. They have been finding application in various disciplines like science and technology, sociology, political science, and social science (Littig & Pöchhacker, 2014). Also referred to as 'elite' interviews, this approach of eliciting responses from knowledge specialists is defined by the target group (experts), as well as the research technique used – semi-structured interviewing (Burnham et al., 2008), which gives them the liberty to share as much expert knowledge as possible within the guided structure. Hence the technique is described as "a semi-standardized interview with a person ascribed the status of an expert" (Littig & Pöchhacker, 2014).

Expert knowledge typically includes technical or specialist professional knowledge or interpretive knowledge of the field. The intention of the interviewer then is to tap into this knowledge and narrow the knowledge gap between them and the expert, and extract the most knowledge from them (Littig & Pöchhacker, 2014). Expert interviews can reduce the time-consuming processes of producing data, especially that experts as important guardians of 'practical insider knowledge' may give access to information that is typically difficult to obtain (Bogner et al., 2018). The technique can be used to collect high-quality data but is best suited to triangulate a study, rather than using it as a sole method of data collection (Burnham et al., 2008).

In this research, expert interviews are used to narrow the gap between literature and expert knowledge and gain an appreciation of expert perceptions on the use of digital health communities to enable empowerment for decision-making. For that reason, respondents were asked to draw from their experience and make sense of the assumptions underlying the concepts identified in the literature. In the context of this research, expert interviews are used to validate and verify the proposed framework (Hatsu & Ngassam, 2017), which is reasonable to use in assessing the effect of digital forum use on the empowerment of informal carers. The researcher interviews experts to explore their experiences, practices, and attitudes in relation to digital health community use by informal carers, with the intention to utilise their feedback to modify the conceptual model, as well as identify themes around which the carers' survey will be designed. More than that, the use of expert interviews also provides a chance to explore whether the use of social media as perceived by experts is represented convincingly in literature. As advised by Burnham et al. (2008), expert interviews in this study are used for triangulation and not as a principal technique for data collection.

The choice of an exploratory expert interview as one of the techniques with which to gather data is appropriate and efficient because it gives experts an opportunity to share their thoughts, feelings and recount their real-life experiences with digital health communities. The method gives the needed direction and provides a sense of orientation in an area that is less understood (Littig & Pöchhacker, 2014). Bogner et al. (2018) consider expert interviewing to be a "concentrated method of gathering data" that provides objective data quickly compared to other methods like observation. Furthermore, this approach can be used to generate theory from the experts' tacit and specialised knowledge that they have garnered from their professional activities (Littig & Pöchhacker, 2014).

This phase of the study aims to establish the relevance of concepts previously identified from extant literature to the study of digital health community use and its effect on empowering users. Semi-structured interviews were conducted with ten (10) experts. The qualitative method permits the study to consider the wide context and multi-faced nature of the digital health community and offers in-depth analysis from a fairly small sample size. The experts' narrative and insights on the concepts relevant to studying 'digital health community use' and 'empowerment' were significant for an area that little is known on. Using it as an exploratory investigative tool, the technique affords the collection of preliminary data. Table 4.2 presents the process followed to gather data through expert interviews.

Stage	Activities	Interactions with expert
Before interview	Developing items	After drafting the questions, the researcher consulted with academic experts to solicit their opinions on whether the questions were sound.
	Recruiting participants	The interviewees were sent background to the study as well as questions and requested to be interviewed.
During interview	Confirming consent	The interviewer confirmed with each expert if they give consent to participate in the interview.
	Request to record	The interviewer verbally requested permission to record the discussion.
	Conducting the interview	Using the semi-structured guide shared with the interviewees earlier, the interviewer led the discussions.
After interview	Emails	The experts were sent 'thank you' notes via email to show appreciation for their input.

Table 4.2 Procedure of Eliciting Expert Response

4.4.1 Developing Interviews Items

In developing items for the expert interviews, the researcher ensured that questions have content validity – that is, they are relevant and representative of what is being measured. Content validity is done in two stages – developmental and judgement-quantification. The developmental stage comprised identifying the domain, creating items, and forming the instrument.

i) The researcher identified the domain by undertaking a review of the literature and identifying the concepts in the study. A literature review highlights the views of different experts in the field and brings them together, thereby improving the legitimacy of the suggested variables.

ii) Using previous instruments for guidance on the structure of interview questions that confirm a framework, like Hatsu and Ngassam (2017), items themed on the identified concepts were drafted. The questions were open-ended statements that required the interviewee to give a personal opinion on each concept, drawing on their experience and a specific request to elaborate on answers.

iii) The researcher did initial verification of items by going through them with the supervisory team and two peers to remove ambiguity, improve clarity and refine them. The items were then assembled into a usable form, and the questions are in Appendix 1 as the Interview Protocol.

The interview schedule went through the next phase of content validity which requires that the items and the whole interview schedule be validated in a pilot test (Moore & Benbasat, 1991). The interview schedule is piloted with three knowledgeable and experienced academics from three different universities to check if they solicited the necessary information. Some had used online health communities during the time they cared for loved ones, and others were very conversant with research in the IS field. They were interviewed to check the content, clarity, phrasing, and presentation of the items. Revisions were made to some items with the feedback obtained from the professionals. Once the items were content validated, the interviews were administered following these steps – who to interview, gaining access and arranging the interview, preparing and conducting the interview, analysis, and post-interview follow-up (Burnham et al., 2008; Littig & Pöchhacker, 2014).

4.4.2 Participants and Recruitment

Participants were selected using a purposeful and convenience sampling strategy (Creswell & Creswell, 2018) from a population of professional carer organisations, facilitators, and senior academics. The latter were senior teaching staff in IS across three universities in two continents, which the author interacted within academia. They were chosen because they have worked on research projects in a similar field as the current, and/or based on their expertise of IS theories and methods. The other professionals were staff at the management level from carer organisations who have interacted with informal carers, while others were facilitators of digital health communities. The researcher had interacted with some of the industry interviewees during events of Carer Organisations in Sydney, while others were contacted as staff members of the study organization.

4.4.3 Gaining Access and Arranging Interview

Due to their busy schedules, some experts were not readily available for an interview. The postponements and turn downs that a researcher gets typically contribute to the length of time it may take to conduct such interviews. So planning and sticking to the plan of conducting such interviews proved vital to the success of the interview process (Burnham et al., 2008). The prospective interviewees were recruited through an email shown in Appendix 8, with an interview protocol (Appendix 1) attached for their perusal and appreciation. This comprised a research brief explaining the essence of the interview as well as the interview schedule. Following their consent to participate, a follow-up email was sent to request an interview date and time.

4.4.4 Conducting Expert Interviews

All the interviews were conducted by the researcher between 15th November to 17th December 2018. The semi-structured questions allowed the discussion to focus on specified areas while allowing the respondents to narrate further and allowing the interviewer to pose follow-up questions. Where possible, the interviews were conducted in person, while the distant respondents were interviewed virtually over Skype. In both instances, the 20-30 minute interviews were recorded with the permission of the respondents. The interviews were transcribed with the aid of Trint software. After transcription, I tidied up the scripts by matching them with what is on the audio recordings, to ensure correct transcriptions. This improved the readability of scripts and the precision of facts. The interview items were appropriately labelled in all the scripts, and the scripts were uploaded into NVivo 11 for coding.

Post-interview, each interviewee was sent a ‘thank you’ note for taking their time to participate in the interviews.

4.4.5 Thematic analysis

Thematic analysis is a technique “for identifying, analysing and reporting themes within data” and there are two kinds – theoretical and inductive thematic analysis (Braun & Clarke, 2006). As a robust qualitative method, one of its benefits is flexibility, which makes it compatible with any paradigm and worldview. This feature does not remove the need for a structured way of carrying out the analysis, hence thematic analysis operates on guidelines, which facilitate the identification of themes. Themes capture the gist of responses given, to show a pattern of some sort, relative to the research objective or question (Braun & Clarke, 2006).

The study of empowerment from digital health community use is under-researched, hence the main objective of analysing interviews is to refine concepts related to empowerment and digital health community use. Consequently, the thematic analysis is used to provide a rich description of each notion to explore if they make sense and are relevant as characteristics of the concepts under study. It is done based on the phased approach by Braun and Clarke (2006). From the pragmatic stance, thematic analysis allows exploration of multiple views and experiences because of its flexibility, hence it suits the study well.

The thematic analysis follows the steps below –

- familiarising with data: I collected the data and transcribed it, thereby getting a very good feel of the data at hand. Still, the researcher took time to read the transcribed scripts twice before starting the analysis.
- generate initial codes and search for themes: I came up with codes that describe the content of the data e.g. support types, kinds of users; at the same time, I worked on meaning to find themes. The process is iterative with repeat visits to the same data to verify and make sense of the coding.
- review potential themes and name them: for the current research, the two stages were combined, to label the themes.
- producing the ‘report’: although this stage is iterative, in this research it had to be shortened and completed to enable progress to data analysis (Braun & Clarke, 2006). In this case, the thematic analysis is part of a sequential study, so its results were utilised in the next stage of the research.

Extant literature was used to construct and refine themes, as well as understand possible relationships between constructs. The study uses NVivo 11 to code and perform a thematic analysis followed by an online observation, which uses the identified themes from interviews. The observation is a content analysis of forum discussions and is used to find evidence of the existence of these themes in the discussion posts. Using data from secondary sources like digital health communities helps explore real-world problems because the data is collected in a natural setting. It also allows for data to be used in predictive and causal-predictive modelling, even where there is less clearly defined theory (Hair et al., 2017a). The evidence from the online observation identifies variables that are used to build a conceptual model that is then tested in a survey. The survey gathers user perceptions on how digital health community utilisation affects their empowerment to aid decision-making and helps establish relationships between the concepts. Figure 4.1 sums up the exploratory sequential design that the research uses.

4.5 Phase II: Content Analysis

Content analysis is a systematic coding and categorisation approach that works well with large amounts of textual data. Since data used in content analysis is collected without interference from the researcher, it is generated in a near 'natural environment' as much as possible, especially in a digital community where users are anonymous and cannot be identified (Huang et al., 2019). This approach to data analysis is helpful to explore the use of the study community from the users' perspectives, as it enables the researcher to examine characteristics of the content with the view to establishing who says what, to whom, and with what effect (Neuendorf, 2017). Content analysis allows researchers to assess the rich meaning related to the actual thoughts of the author of a message, to get insights into the author's beliefs, intentions, values, and behaviours. From these, more profound insights into the capabilities of digital health communities may be obtained from the analysis of users' actual interaction behaviour (Huang et al., 2019).

4.5.1 Message characteristics and sampling

Using a web crawler, messages covering the period between 01/01/2018 and 01/05/2019 (inclusive) were retrieved from the study forum and used in the content analysis (online observation). Further criteria used for the retrieval were:

- The unit of analysis used is a sentence, which could belong to more than one code and could not be larger than one message. The sentence unit was preferred because it is syntactically defined.
- A complete message could contain several units of analysis belonging to the same code.
- Sample threads could be two (2) messages long and no more than sixty (60) messages (see Figure 5.2), which is the 95th percentile of thread length.
- The messages were extracted from discussions across all seven boards.

Once messages were retrieved, the study adopted a procedure of segmentation for added guidance of effective manual coding (Coursaris & Liu, 2009). The main aim of having a set procedure for segmentation was to ensure consistency when dividing sentences so that they do not lose logic. The segmentation involved the coder reading the whole message to establish the meaning of the post, dividing the message into sentences that shared a common meaning, then checking if the sentence fitted into one code or more.

Although the SANE forums are public, one can only participate in the discussions if they register. Users can register with pseudonyms. So, I also registered as a member – to familiarise myself with the structure and characteristics of the forums. I interacted with the posts as a 'silent' user throughout and got a chance to observe the exchanges.

4.6 Phase III: Survey

From the themes that were identified in Phase II (Content Analysis), the following latent variables were found to be linked. Their association is shown in the conceptual research model (Figure 4.3), which is the basis of this stage of the study. They comprise an independent variable, which is digital health community use; a dependent variable, being empowerment; mediating variables which are social support, social network fatigue, self-disclosure, experiential expertise, emotional contagion, and social overload; and a moderating variable, which is facilitator support. To measure their dimensions, the study utilised a five-point Likert scale ranging from 'strongly disagree' (being 1) to 'strongly agree' (being 5), which assessed how strongly respondents disagree or agree with the given statements.

4.6.1 Population

The target population for this phase was all informal carers that are registered members of the SANE Carers forum. Before completing the questionnaire, respondents are made aware that all identifying data are kept anonymous and confidential. They are also mandated to give consent before continuing with the survey.

4.6.2 Questionnaire Development

A questionnaire that is well-constructed and properly administered gathers data that will enable relationships between variables to be measured (Moore & Benbasat, 1991). The development of such a questionnaire is informed by theory and has to be clear on what it measures. Typically, a questionnaire captures the opinions, views, attitudes, and behaviours of users. The process of designing a questionnaire starts with conceptualising individual constructs by defining them, followed by creating items and testing the instrument (Moore & Benbasat, 1991). Figure 4.2 illustrates the process.

a) *Conceptualisation*: A ‘construct’ is a variable that is latent and abstract. It is constructed from researchers’ thoughts, as such does not exist as a noticeable component of behaviour (Mackenzie et al., 2011). Defining a construct during questionnaire design is important because it delineates the construct from other similar concepts and positions it as a distinct concept. It also specifies the domain of its operation, so that the definition is used within the context of the study. The construct’s referent needs to be clear during conceptualisation, that is, the “general type of property to which the construct refers” – whether it refers to perception, feeling, thought, action, or outcome; as well as the level at which it is being investigated – individual, organisation or community level (Mackenzie et al., 2011).

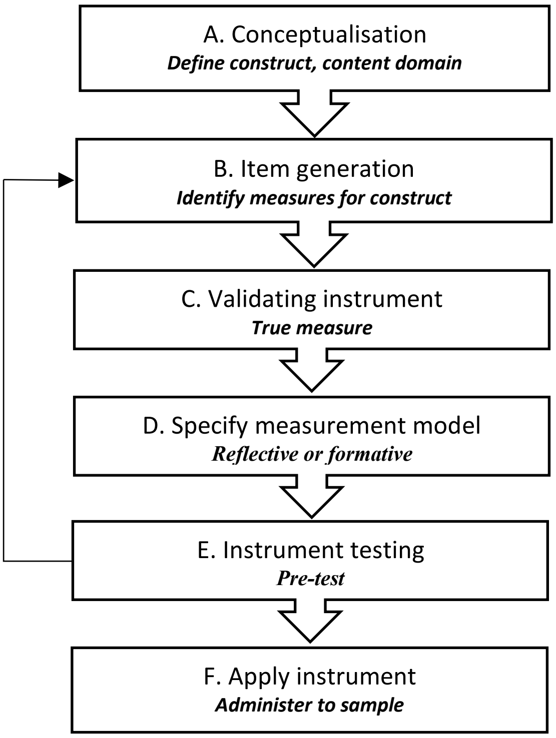


Figure 4.2 The questionnaire development process

One of the sources when defining a construct and identifying the content domain is a literature review. It helps identify how a construct was previously defined, so as to position it within the current research (Moore & Benbasat, 1991). Typically, when a construct has numerous and inconsistent definitions, it shows a lack of conceptual clarity, hence the need to define it and demarcate its content domain. The latter can also be achieved through interviews or content analysis (Schmiedel et al., 2014). For example, definitions of the construct 'empowerment' from extant literature are given in Table 3.2; this study proposes a composite definition derived from previous definitions, and it is presented in Table 4.3. The definition presents empowerment in digital health communities as a mechanism, which occurs at the individual level of a user. Table 4.3 presents definitions of all constructs in the study to provide a context of how they are applied.

Construct	Definition	Source
1. DHC use	The degree to which an informal carer may utilise a digital health community to perform tasks.	Karahanna et al. 2018
2. Empowerment	The mechanism through which a carer strengthens their skills and inherent capacity to cope and make informed decisions (non-health and health-related) on a daily basis.	Hur et al. 2019; Liu et al., 2020a
3. Facilitator support	The action of a facilitator guiding discussions according to given guidelines of SANE forums as a digital health community.	Smedley & Coulson 2017; Hur et al., 2019
4. Emotional contagion	A state in which the sentimental expression of an individual elicits similar sentimental reactions from the receivers, be they positive or negative sentiments.	Park & Conway 2017; Lee & van Dolen 2015
5. Experiential expertise	Knowledge and skills from the carer's life experiences which they share with others, who in turn use it to make decisions on self-caring.	Blume 2017
6. Self-disclosure	A carer's voluntary and intentional reveal about themselves to others on a DHC – including thoughts, feelings, and experiences.	Zhang et al. 2019
7. Social network fatigue	Carers' feelings of exhaustion, anger, annoyance, loss of interest, or reduced motivation due to technology utilisation and interactions.	Ravindran, Kuan & Lian 2014
8. Social overload	A state of being overwhelmed by giving too much support to other carers on the forum.	Maier et.al. 2015a
9. Social support	The support exchanged in the carers' forum to help others going through potentially stressful events, which serves to reduce uncertainty through knowledge sharing (informational) and appreciating others' value, and sharing their feelings (nurturant).	Erfani, Abedin & Blount 2017; Huang et.al 2019

Table 4.3 Definition of constructs

b) *Item generation:* With an understanding of what the construct is and its delimitations in terms of coverage, the generation of items is the next step. The objective of this stage is to come up with items that fully depict all the necessary dimensions of a construct. Items are identified from several sources, including reviewing the literature to find questions from existing instruments (Moore & Benbasat, 1991); inferences from theoretical construct definitions, focus group discussions, or expert suggestions (Mackenzie et al., 2011). This study utilises Google Scholar to search for definitions of constructs as well as look for items from previous questionnaires. The search engine has a wide coverage of grey and academic literature across the internet, retrieving that which is brought up by Web of Science as well. Its query facility enables a search to be refined enough to yield results that have high recall and precision; hence it generates articles that are relevant, most of the time (Ortega & Aguillo, 2014). The advantage of using items from existing instruments is that the questionnaire will have items with a high content validity (Schmiedel et al., 2014).

In addition to using Google Scholar, the researcher identified other papers from references of key articles and used them as well to find items and definitions of constructs (Leidner & Kayworth, 2006). This resulted in more papers to look at. While Mackenzie et al. (2011) advise that items should be written in clear, simple, and precise wording, they underscore the importance of individual items representing a portion of the content domain, and at the same time, all items collectively representing the whole content domain of the construct. This will ensure the content validity of the items. Once the items were put together, they formed an instrument for the survey. The items were arranged in an easy-to-follow format, that has sections as demonstrated in Goode and Gregor (2009). The first section had questions soliciting demographic information from respondents, followed by a few general questions about respondents' care work and their membership of the Carers' forum. The second section is the main survey, with questions on operationalised adaptations of every construct as identified above. To encourage the participation of the carers and increase their response rate, the instrument was limited to two pages because lengthy instruments are likely to be associated with low rates of response (Goode & Gregor, 2009).

In operationalising the constructs, digital health community use is measured using five items adapted from Erfani et al. (2017). Four items on empowerment are adapted from Mo and Coulson (2010), while those from facilitator support are adapted from Coulson and Shaw (2013). The mediator variables include social support, which is captured through eight items from Lin et al. (2015), experiential expertise, measured with four items from Ma and Chan (2014); emotional contagion, which is assessed through four items from Lee and van Dolen (2015); social overload as measured by four items from Maier et al., (2015a); self-disclosure as captured through four items from Zhang et al. (2018) and social network fatigue as measured by four items from Zhang et al. (2016).

c) *Validating instrument:* the questionnaire is validated so that it measures what it intends to, that is, it is analysed to ensure that it is dependable. There are different forms of validation that are employed.

i) Face validation: is the process of reading-through items to check if the language is clear, questions are readable, complete, and understandable, and not leading the respondents to answer in a particular way. It confirms that the format of the instrument and presentation of items are relevant to measure the construct, are unambiguous, and can be answered. It can be conducted with chosen individuals. In this study, the initial set of items are face-validated by the supervisory team, who are IS experts and are conversant with questionnaire development. Their feedback is used to make improvements to the items by removing those that are ambiguous and leading. After face validation, the instrument has to confirm the validity of the content.

ii) Content validation: is the process of ensuring that the contents of the items represent the theoretical constructs under investigation so much that the items mirror the context to which the investigation will be generalised. It is better conducted by experts who have a sound theoretical background and professional experience in the area of study and can check the adequateness of items to measure constructs (Mackenzie et al., 2011). The current study uses two well-published and experienced IS professors from two different Universities, to check if the items are measuring the constructs. Their expert feedback enables the identification of items lacking content validity. Literature is re-visited and used to further improve the items.

To improve the testing or validity of the questionnaire, literature encourages strategies like a consultation with subject area specialists like professors and the use of existing surveys. Survey questions were formulated from a process of identifying areas of relevance through expert interviews, identifying the existence of these areas through content analysis (Saunders et al., 2019). PLS-SEM It was employed to statistically test the hypotheses, evaluate the global model fit and substantiate the suitability of the measurement model, as well as validate the structural model. The Partial Least Squares (PLS) is an exploratory approach that is commonly used in IS research and enables the testing of both structural and measurement models at the same time. It is suitable to use as it permits structural modelling for small- to medium-sized samples, as the reliability and validity of constructs need to be evaluated (Korzynski et al., 2021).

d) *Specify measurement model:* once the items and constructs are validated, the measurement model needs to be specified. This identifies the relationship between the constructs and indicators. Based on the conceptualisation of the construct, indicators can be either reflective or formative. Formative items form or cause the construct while reflective items reflect the measures of a given construct indicating that the construct causes the indicators. It is important to correctly identify indicator relationships with constructs in a model, to guide the choice of analysis approaches because wrong analysis brings bias to results (Hair et al., 2017c).

e) *Instrument Testing:* A pre-test of an instrument can be on a small sample, which can be conveniently selected. The aim of a pre-test is to check the adequacy of compiling the instrument, by soliciting the testers' opinion on the wording and length of the instrument as well. The first survey version is carried out with five peer researchers to check the clarity, efficiency, and completeness of the instrument. Based on the comments and suggestions received, the instrument is further modified to deal with possibly confusing items. The order of items is changed, so items are reworded, some are dropped out of the instrument, all in a bid to improve the flow of questions. This is an iterative process that seeks to refine and produce a good quality instrument (Goode & Gregor, 2009), which is reasonably sized. Moore and Benbasat (1991) caution against very long surveys, and very short surveys. A long survey may discourage participation, while a short one may tamper with content validity.

f) *Apply instrument:* Once the instrument is tested, it is then administered to a sample of the whole population. A sample is a section of a defined population and is selected following stipulated rules; typically, it is representative of the population. While there are various ways of choosing a sample, the study uses a non-probability approach of selecting participants and obtains a convenient, self-selected sample where carers responded to an announcement about this unrestricted survey on the website (Toepoel, 2016). From extant literature, the advantages of web-based surveys are unique and warrant the surveys' extensive use. The advantages include coverage of a wide geographical area in a short time – an online survey easily reaches and is accessed by many people from different locations in a short time. The resulting sample is likely to be more representative of the target population because it reaches everyone. It also has very low costs for the researcher, because they do not have to travel to any place. It lacks researcher intervention because it is self-administered, as such it is less influenced by social desirability bias, that is, socially accepted responses instead of truthful ones. Web-based surveys offer the most anonymity compared to paper-based surveys because respondents do them in their private space, without physically meeting the researcher (Toepoel, 2016; Becker et al., 2019).

To benefit from the discussed advantages, the survey for this study is developed and administered on the web using Qualtrics. After obtaining the necessary permissions from SANE Australia, facilitators assist to administer the survey by posting it on the Carers forum. It runs from 1st January to 28th February 2020, specifically to informal carers of people with mental illness. The forum facilitators periodically bring the survey to the attention of the carers as a reminder for them to complete it. To promote its completion and improve the survey's return rate, retail e-vouchers of $50 each are offered to twenty of those who complete the survey. As literature attests, incentives increase the chance of participation. Monetary incentives especially are known to encourage the less-motivated respondents and increase the enthusiasm of those willing to take the survey. The notion of incentives in a survey is based on reciprocation – respondents complete the survey and the researcher compensates their time and effort, so both parties benefit (Becker et al., 2019).

At the end of the survey, 123 responses were retrieved from Qualtrics, and 105 questionnaires were valid after dealing with missing data and invalid responses. In the survey, respondents were given an option to write their emails if they wanted to be considered for the e-voucher draw; seventy-six (76) respondents had given their emails. They were assigned numbers, which were written on small-rolled pieces of paper and placed in a container. Using simple random selection, twenty beneficiaries were picked from the container by a colleague. Between each pick, the container was shaken to mix up the papers, and each had a chance of being randomly selected. My colleague picked all the twenty numbers in one session, and the researcher recorded them to match them with their emails. The respondents were only identified by emails and all the twenty were sent their e-vouchers by email. As requested, all twenty confirmed receipt of the shopping vouchers. The survey instrument is in Appendix 4.

4.6.3 Data analysis method

Analysis of research data is increasingly harnessing the capabilities of structural equation modelling (SEM), due to its enhanced assessment of validity and reliability of construct measures with multiple items. Validity and reliability are important because they help assess the quality of research. Validity is concerned with the accuracy of items, whether they measure what they are meant to measure, while reliability is about the consistency of a measure so indicator reliability and internal consistency reliability are measured (Hair et al., 2017c).

Structural equation modelling is able to merge structural path analysis and exploratory factor analysis, thereby allowing concurrent valuation of both measurement and structural models found in SEM. The measurement model is the outer one that represents relationships between variables, and the structural model is the inner one that represents structural paths between constructs (Hair et al., 2017c). Structural equation modelling is employed to statistically test hypotheses, and substantiate the suitability of the measurement model, as well as corroborate the structural model (Wong, 2019).

PLS-SEM characteristics

Literature differentiates between two SEM methods that researchers utilise – covariance-based structural equation modelling (CB-SEM) like AMOS and variance-based structural equation modelling like partial least squares (PLS-SEM) like WarpPLS, SmartPLS (Matthews et al., 2018). The former is founded on the common factor model, which bases its analysis on the common variance found in the data (Hair et al., 2017a); as such it is used mainly to confirm theory (Hair et al., 2017c). The latter is built around the composite factor model and is prediction-oriented as it focuses on the explanation of variances; therefore, it is more suited for exploratory studies than confirmatory ones (Hair et al., 2017a). Consequently, it has gained traction in information systems research where it is now a widely accepted method as noted in a literature review done by Urbach and Ahlemann (2010).

The features of PLS-SEM enable it to handle complex models which have many constructs (whether formative or reflective), and many indicators, as well as analyse cause-and-effect relationships that are inadequately investigated (Hair et al., 2017c). PLS-SEM derives determinant latent variable scores, which are usable in subsequent analyses, thereby increasing the depth of its analyses (Hair et al., 2017a; Hair et al., 2019b). Using the guidelines in Table 4.4, PLS-SEM analysis is selected as appropriate to use in this thesis because of its suitability for an exploratory study that needs validation, and its ability to allow the addition of more measures as the study develops (Hair et al., 2017c; Fan & Lederman, 2018). This is an important characteristic because, as established in Chapter 1 of this thesis, the study of empowerment of informal carers from utilising digital health communities is at its nascent stage of development, so it has an exploratory component. PLS-SEM also permits a ‘full-information analysis and interpretation’ of empowerment, because it allows the investigation of empowerment as a process researcher to see changes over time (Markwart et al., 2020).

PLS-SEM is also preferred because it is less demanding on sample size and has the ability to deal with both small and large samples (Matthews et al., 2018), yet producing more accurate results on smaller-sized samples compared to CB-SEM (Han et al., 2019). This is a result of its algorithm’s ability to compute partial regression relationships in both the structural and measurement models separately rather than simultaneously (Hair et al., 2019b; Wong, 2019). The PLS-SEM shows high levels of statistical power in small populations and possesses favourable convergence behaviour in small sample sizes, provided the sample represents the population (Hair et al., 2019a).

Like typical data from a real event, the study data in this thesis are skewed and not normally distributed – and PLS-SEM is credited with being robust enough to handle skewed data since it does not assume a normal distribution (Matthews et al., 2018). The normality test (reported in Section 5.1.3) is utilised to determine the extent to which data are non-normal. Coupled with a small-sized sample, skewed data can cause inflated standard bootstrap mistakes that minimise statistical power, but PLS-SEM can handle both instances (Hair et al., 2017a). Finally, the ability of PLS-SEM to run adequate moderation and mediation analyses makes it an appealing option because the model in this study has both moderation and mediation (Ali et al., 2018).

The thesis also uses PLS-SEM because it seeks to know and appreciate the causal relationships between theoretical concepts. The latter is established by combining the explanatory approach, which focuses on explaining the dependent variable in the structural model using the coefficient of determination (R^2) and the significance of path coefficient estimates, as well as the confirmatory approach, which seeks to corroborate the empowerment theory as the lens through which we expatiate the study (Benitez et al., 2020). The exploratory-causal-predictive data analysis ability of PLS-SEM (Matthews et al., 2018) allows flexibility that is permitted by pragmatism, which is applied in this thesis. It also supports the mixed methods approach applied in the study.

Type of analysis	*Recommendation*	
	PLS-SEM	*CB-SEM*
Objective = prediction	X	
Objective = exploratory research or theory development	X	
Objective = explanation only		X
Objective = explanation and prediction	X	
Measurement philosophy = total variance (composite-based)	X	
Measurement philosophy = common variance (factor-based)		X
Formative measurement model specification	X	
Non-metric data = nominal and ordinal	X	
Smaller sample sizes: n =< 100	X	
Larger sample sizes: n => 100		X
Normally distributed data		X
Non-normally distributed data	X	
Secondary (archival data)	X	
Latent variable scores needed for subsequent analysis	X	

Table 4.4 Guidelines for selecting CB-SEM and PLS-SEM

(adapted from Hair et al., 2017c)

4.6.4 Assessing Measurement Model

The conceptual model in this thesis comprises constructs that are all measured reflectively; therefore, they are assessed through the steps discussed below, using the re-sampling technique of bootstrapping to generate standard error estimates to enable significance testing (Ali et al., 2018). The procedures to evaluate a reflective measurement model include factor loadings, convergent validity, and internal consistency reliability.

a) Loadings and Convergent Validity

Factor loadings for each indicator need to be established so that they provide a guide for item reliability since the latter is a condition for validity. Item reliability is acceptable when loadings are above 0.708 because they suggest that the construct describes more than 50% of the item's variance (Hair et al., 2019b). Once reliability is determined, an assessment of convergent validity has to follow. It is described as the degree to which an indicator associates with others positively within a construct. It is explained by the average variance extracted (AVE) of items in a construct and is calculated by squaring the factor loading of each indicator and computing the mean value. Its acceptable value is at least 0.50, which suggests that the construct describes at least 50% of its indicators' variance (Hair et al., 2017a).

b) Internal Consistency Reliability

The measurement model also considers internal consistency reliability, which assesses Cronbach's alpha, composite reliability, and rho_A. Regarding the internal consistency reliability, the traditional Cronbach's alpha gives an approximation of reliability-centred on interconnections of constructs. However, Cronbach's alpha has been challenged due to its sensitivity to the number of items on the scale, resulting in a tendency to undervalue reliability. It assumes that all indicators taken together are reliable, yet PLS-SEM assumes each indicator is individually reliable; its acceptable value is 0.7 (Hair et al., 2017a). Consequently, to deal with the limitations of Cronbach's alpha, a separate measure of internal consistency reliability is applied, which considers the different outer indicator loadings. This measure, called composite reliability, varies between 0-1 as well and tends to overestimate internal consistency reliability. While values below 0.6

represent a lack of composite reliability, values above 0.9 show that indicators are evaluating the same occurrence, and do not provide a good assessment of the construct. In fact, it concedes content validity. Generally, Cronbach's alpha makes the lower border, and composite reliability makes the upper border of internal consistency reliability, where acceptable values fall within the range of 0.7-0.9 (Hair et al., 2017a).

Thus, we consider alternative measures of internal consistency reliability, including composite reliability and rho_A.

c) Discriminant Validity

Discriminant validity presents the degree to which a construct is empirically unique and distinct from other constructs and many measures have been advanced to assess this distinction. The Fornell-Larcker criterion evaluates only reflective constructs that have multiple items; both the Fornell-Larcker criterion and cross-loadings have been relied on over time. Using the cross-loadings, discriminant validity is achieved when the outer loadings of given constructs are greater than its cross-loadings on other constructs. With the Fornell-Larcker criterion, the square root of the AVE of a construct is compared with its correlation and that of other constructs. This squared correlation between constructs must be less than their AVEs (Hair et al., 2011; Hair et al., 2017a).

However, recent studies have challenged the performance of these two metrics, showing that neither one is adequately consistent in detecting discriminant validity (Henseler et al., 2015). While cross-loadings cannot reveal a lack of discriminant validity, the Fornell-Larcker criterion is considered unsuitable for evaluating and establishing discriminant validity (Hair et al., 2019b). Hence, research has advanced a new measure, which is particularly useful in PLS-SEM, and is inclusive because it covers various ways of detecting discriminant validity. The new criterion proposed by Henseler et al. (2015) – the Heterotrait-Monotrait Ratio (HTMT) – is now utilised to determine the discriminant validity of items. It is described as the mean of correlations of items used to assess the same construct; running bootstrapping helps determine how significantly the HTMT value deviates from 1. A value of 0.90 indicates that constructs are very similar conceptually, and HTMT>0.90 shows the absence of discriminant validity, while a value of 0.85 connotes conceptually dissimilar constructs (Hair et al., 2019b).

4.6.5 Assessing Structural Model

The structural model is assessed on the significance of path coefficients, by reporting the significance and size of *p-values* or *t-values*. The assessment also reports the standardised root mean square residual (SRMR), the predictive capability or coefficient of determination (R^2), the predictive relevance (Q^2), effect sizes (f^2), and the significance and size of beta coefficients (Hair et al., 2017c). The acceptable range of R^2 is 0 to 1, where values closer to 1 show higher levels of predictive accuracy than those closer to 0. For instance, R^2 values of 0.75, 0.50, and 0.25 for endogenous constructs are considered substantial, moderate, and weak (Hair et al., 2017a). The value of R^2 is influenced by the number of predictor constructs – the larger the number of constructs, the higher the value of R^2. So R^2 gives the effect of independent and predictor constructs on the dependent construct.

4.6.6 Mediation Analysis

Mediation is when a third construct comes in between an independent and a dependent construct to explain the type of relationship between them (Danks, 2021). It is analysed by examining if a change in the independent construct will cause the mediator to change, which in turn causes a change in the dependent construct. Mediation analysis assumes a sequence of relationships that considers the effects of an antecedent construct on a mediating construct, which then affects a dependent construct. It reports *total effect,* which is the effect of the independent on the dependent construct without the mediator. It also studies the *direct effect*, which is the effect of the independent on the dependent construct in the presence of the mediating construct. Finally, it considers *indirect effect,* which is the effect of the independent construct on the dependent, through the mediating construct (Hair et al., 2017a).

4.6.7 Using the Sequential Approach

The sequential approach allows the researcher to collect data, analyse it and use the results to develop tools for the next phase. This study uses an exploratory approach; therefore, it starts with a qualitative study. The interviews exploit the expertise of IS professionals to provide insights into what concepts may be related to digital health communities generating user empowerment. The results are employed to carry out a content analysis of discussions on the digital health community. Finally, the results of the latter are utilised to guide the construction of a survey in the last stage of the investigation.

4.7 Research Model and Hypothesis

The proposed model draws from the empowerment theory, using concepts drawn from the qualitative phases of this study. It is featured in Figure 4.3, and shows use and the support exchanges that contribute to empowerment in a digital health community.

4.7.1 Use of Digital Health Communities and Empowerment

Karahanna et al. (2018) define use in the context of digital communities as an actor's utilisation of such a community to perform tasks such as writing, commenting/replying, supporting, reading a post, seeking, or giving advice to others. The use of digital health communities is voluntary, not work-related and informal. As such, reasons for using them vary widely according to personal preferences. The reasons may include loneliness, lack of information, seeking emotional support, need to belong (Han et al., 2019).

This study employs the common measures of use, which are subjective and self-reporting. They include frequency and length of use (Erfani et al., 2017), and the task of use (Dang, 2020) – i.e. whether one uses a digital health community to advise, observe or seek. The survival and sustenance of any digital health community depend on its utilisation; once members stop using it, a digital health community may cease to develop further and its benefit may be limited or cease. The effectiveness of a digital health community largely depends on its ability to keep members together and maintain strong ties of interaction among them (Chewning & Montemurro, 2016; Leong et al., 2018), and in the process change the power dynamics of a group to enable empowerment. A waning membership may reduce the number of resources (support exchanges), which in turn may alter outcomes (Leong et al., 2018). Indeed, as observed by Hur et al. (2019) use has a positive effect on outcomes. Therefore, the first hypothesis proposes:

H1: The use of digital health communities has a positive effect on the empowerment of informal carers of people with mental illness.

4.7.2 The Resources Approach to Digital Health Community Use

4.7.2.1 Social support and Empowerment

Provision of social support is the main benefit of utilising digital health communities, and users mainly participate in the communities for support rather than hedonic rewards (Zhang et al., 2018). Social support offers care, empathy, assistance, encouragement, acknowledgement, recognition by fellow members of the digital health community, and a feeling of belonging to some community. For this reason, it is especially valued for its ability to lower stress levels, encourage positive coping and enhance outcomes like self-efficacy (Liu et al., 2020b). Prior research has found that social support positively improves the well-being of members of a digital health community (Erfani & Abedin, 2018). Further, it provides support for the empowerment of its users, so that they can take actions that will help them cope with ill health. Most of the digital health communities provide mainly informational support, followed by emotional then esteem support (Sharma & Khadka, 2019). Therefore,

H2a: The use of digital health communities has a positive effect on social support.
H2b: Social support has a positive effect on the empowerment of informal carers of people with mental illness.

4.7.2.2 Self-disclosure and Empowerment

The existence of a digital health community is powered by sharing of information, encouragement, and companionship. Part of this is obtained from self-disclosed statements by users of a digital health community (Zhang et al., 2018). The disclosure of one's emotional or informational standing is a conscious decision they make to get help with their concerns and fears. As they share their personal information, others respond in empathy and encouragement or information which will empower them to face their apprehensions and concerns (Yan et al., 2016). Self-disclosure to most is therapeutic because it makes them feel that they belong to this huge network which now knows their vulnerability; this improves their well-being and allows them a feeling of being in control (Zhang et al., 2019). It helps lessen stigmatisation and empower relegated people, which carers are. The study, therefore, proposes:

H3a: The use of digital health communities has a positive effect on self-disclosure.

H3b: Self-disclosure has a positive effect on the empowerment of informal carers of people with mental illness.

4.7.2.3 Experiential expertise and Empowerment

A user who shares their experience is a credible role model that can be copied by others who hear how the user is coping. This is likely to result in positive behaviour in other digital health community users (Blume, 2017). Among these users, carers are noted to experience the most role stress, and therefore sharing experiences allows them to learn from similar peers. Literature attests that individuals are more likely to cherish and embrace advice when they have some commonality with the 'adviser.' This similarity, based on experiences, makes it less cumbersome to explain a possibly unfamiliar idea, and enables effective communication centred on mutual understanding of the basis and beneficiary of the advice (Gómez-Solórzano et al., 2019). Therefore, the hypothesis proposes as follows:

H4a: The use of digital health communities has a positive effect on experiential expertise.

H4b: Experiential expertise has a positive effect on the empowerment of informal carers of people with mental illness.

4.7.2.4 Social overload and Empowerment

The social connectedness created by employing digital health communities, benefits users because they exchange social support, whether solicited or not. With increased activity, as new members join in to increase the number of solicitors for social support, some users may feel exhausted from giving support (Nawaz et al., 2018). Hence, carers may experience social overload (Maier et al., 2015a) from utilising this digital health community. This is especially true because digital networks tend to have fewer active users than should be the case – a notion explained by the 1% rule of participation. It states that only 1% of users are active enough to generate 70% of the content exchanged in the digital network (van Mierlo, 2014). Over time, the active users may tire out because expectations from others exceed what they can offer (Zhang et al., 2019), and they feel that they are giving more social support than they can manage (Maier et al., 2015a). At its worst, social overload results in terminating use, where somebody does not create nor consume the community resources (Ransbotham & Kane, 2011), thereby risking inhibiting empowerment of carers in this digital health community. Therefore, the hypotheses propose that:

H5a: The use of digital health communities has a positive effect on social overload.
H5b: Social overload has a negative effect on the empowerment of informal carers of people with mental illness

4.7.2.5 Social network fatigue and Empowerment

When users excessively utilise and get tired of digital technologies, they are likely to have a higher level of social network fatigue (Nawaz et al., 2018). It is described as a 'negative emotional reaction to social network activities like stress and anxiety' (Zhang et al., 2016). The stress and anxiety may be due to information overload, and is likely to result in decreased use of a digital health community (Nawaz et al., 2018), which negatively affects empowerment. Social network fatigue is a subjective phenomenon that is likely to differ between contexts. However, it is recognised to exist both psychologically and as physical fatigue. The use of a digital health community is likely to exert mental fatigue more than physical, as the former presents as burnout, exhaustion, stress, and even anxiety (Zhang et al., 2016). Consequently, a carer may decrease or completely abandon using the digital health community (Nawaz et al., 2018). Therefore, to test the suggested relationships, the hypotheses propose the following:

H6a: The use of digital health communities has a positive effect on social network fatigue.
H6b: Social network fatigue has a negative effect on the empowerment of informal carers of people with mental illness.

4.7.2.6 Emotional contagion and Empowerment

Emotional contagion explains the sharing of some sentiment over a network; it elicits the same reaction from the next person – whether the sentiment is positive or negative (Kramer et al., 2014). Research has shown that in online forums, negatively written responses may trigger negative replies in the subsequent posts (Lee and van Dolen 2015), thereby causing apprehension and discomfort in other forum members. On the other hand, positive experiences of how others cope may increase the other users' competence and autonomy, which may, in turn, encourage them to be proactive and take charge of their lives as carers (Mo & Coulson, 2014), consequently enhancing their empowerment. Therefore,

H7a: The use of digital health communities has a positive effect on emotional contagion.
H7b: Emotional contagion has a negative effect on the empowerment of informal carers of people with mental illness.

4.7.3 Moderating Effects of Facilitator Support on Empowerment

To amplify the benefits of their use, digital health communities are facilitated, whereby facilitator support is known to increase use, and enhance outcomes for the user (Windler et al., 2019). Facilitator support prevents the spread of untruths by guiding discussions and encouraging problem-solving. The latter aids decision-making.

How they achieve this is explained in part by the kind of support they get from the facilitator, which has been studied in terms of the role of a facilitator in a digital health community (Coulson and Shaw 2013, Windler et al., 2019) as well as the styles of facilitation used. Most studies investigate this phenomenon through content analysis (shown in Table 3.3) of text from digital health communities. Facilitation allows digital health community users to share insights and opinions about issues, adding value to discussions and providing alternatives for decision-making (Atanasova et al., 2017), thereby empowering users.

To maximise benefits from their use, digital communities are facilitated, and literature presents mixed perspectives regarding the effect of facilitation. Some study findings suggest that facilitation in digital health communities makes patients uncooperative with doctors because of the information they gathered from facilitators (Petrič et al. 2017). Still, others found evidence that facilitation enhances user outcomes and increases engagement (Windler et al., 2019) as it averts possible malicious attacks and unguided discussions that may spread untruths. The application of facilitation to deal with information overload and asymmetry in digital communities has been investigated (Bagayogo et al., 2014).

Matzat and Rooks (2014) report that the type of support a facilitator gives their digital community matters. That is, a negative, punitive approach may deter unwanted behaviour but is not effective in engaging people like a positive, rewarding approach (Matzat & Rooks, 2014). The positive approach, in which the facilitator offers gratitude and encouragement, creates a safe and nurturing environment, which allows digital health community users to share insights and opinions about issues; this adds value to discussions and provides alternatives for decision-making (Atanasova et al., 2017). The action of a facilitator may elicit greater user participation in digital health communities and improve chances of getting more emotional support for users, thereby nurturing digital empowerment. This is achieved either by ensuring a safe and conducive environment or providing the actual emotional support that will enhance digital empowerment. Undoubtedly, digital communities have both prosocial and antisocial effects, and it is helpful to understand how to exploit facilitator support to get the best of the prosocial outcomes of digital health community use. A study by Atanasova et al., (2017) affirms that the potential for digital health communities to empower users depends on them being facilitated. Hence the hypotheses propose:

H8a: The positive relationship between digital health community use and social support is stronger at high levels of professional facilitator support.
H8b: The positive relationship between digital health community use and self-disclosure is stronger at high levels of professional facilitator support.
H8c: The positive relationship between digital health community use and experiential expertise is stronger at high levels of professional facilitator support.

H8d: The positive relationship between digital health community use and social overload is weaker at high levels of professional facilitator support.

H8e: The positive relationship between digital health community use and social network fatigue is weaker at high levels of professional facilitator support.

H8f: The positive relationship between digital health community use and emotional contagion is weaker at high levels of professional facilitator support.

4.7.4 Control variables

Control variables are user characteristics that are likely to affect the core variables and/or relationships between them. In this thesis, the variables controlled for are age, gender, and years of forum membership (memberYrs). All three are widely used control variables in technology research, with 'years of forum membership' named 'length of experience' (Pan et al., 2017). The study also considered gender because previous research suggests that women find it a bit more challenging to use IS than men (Korzynski et al., 2021). Lastly, we include the length of membership in a digital health community as a control variable since literature suggests that the longer one is a member, the better the outcome – that is, the more empowered they become (Pan et al., 2017). Therefore, the study assumes that users of different ages, gender, and length of digital health community members have diverse empowerment behaviours because they have different personality traits and experiences.

4.7.5 Ethics Consideration

The study involved interviews and surveys, which required contact with people. Therefore, ethics approval was sought and obtained from the University of Technology Sydney Human Research Ethics Committee (UTS-HREC) before data collection. The approval number is UTS HREC REF NO. ETH18-2716, as illustrated in Appendix 2.

4.8 The Conceptual Model

The study uses the foregoing discussions to propose a model for comprehending empowerment through digital health communities. Based on the principles of the pragmatic worldview, the model (Fig 4.3) represents (a) activities users participate in by some unique actions (UOD), (b) the contextual environment within which users act with some efficacy (FAS) and the resources generated by the action (Support exchanges), and (c) the outcome or consequence of actions (EMP), which may explain the usefulness of the unique action taken.

As a standard, rules and resources are needed for any action. The rules are provided by the environment and are necessary to guide and apprise the action. The environment also provides the drive and purpose needed for the action to be carried out. Resources are benefits derived from the said action, and both these are needed for empowerment to be realised.

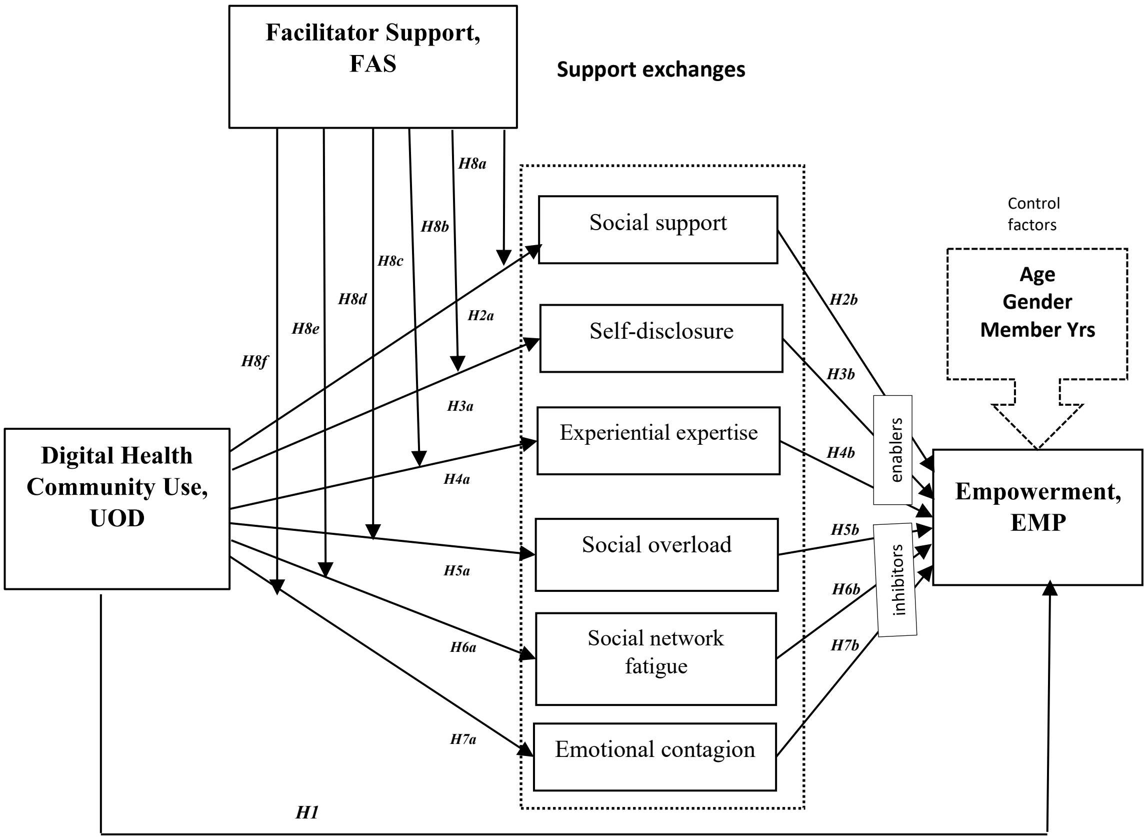


Figure 4.3 Research model and hypotheses

4.9 Chapter Summary

This chapter presents the research design from the pragmatic philosophical point of view. Pragmatism explains the relevance of the exploratory sequential mixed methods used in this study, as well as the exposition of the empowerment phenomenon. The research uses an exploratory, sequential design, which is appropriate as a mixed-method relevant for a nascent concept of digital health community use and empowerment. Each stage uses findings from the previous phase to make further inquiry into the study phenomenon. Expert interviews are used to refine concepts relevant to digital health communities and empowerment. The online observation found evidence for the concepts identified by experts. The concepts are related to each other in a conceptual model, which is tested in a survey. The current chapter is followed by the analysis of qualitative data.

CHAPTER 5: QUALITATIVE DATA ANALYSIS

5 Overview

The chapter presents the results of the qualitative phases of the study, which are expert interviews and content analysis as highlighted in the research design (Chapter 4). The interview schedule was drawn from extant literature, while the content analysis was based on what the experts shared as possible contributors to empowerment.

5.1 Expert Interviews

This section presents findings to questions explored with experts, and it starts with a brief on the demographics of the interviewees. Expert interview questions are obtained from literature search that is conducted to ascertain coverage of concepts relevant to digital health community participation and empowerment. Through the search, the study intends to establish if participation of informal carers in a digital health community has any link to their empowerment. This helps to identify the focus of literature on the concepts. The literature search reveals the following concepts related to digital health community use and empowerment of informal carers: *participation, knowledge exchange, social support, social overload, role of moderator/facilitator*. The study population is informal carers.

5.1.1 Demographics of the Experts

A total of ten (10) experts are interviewed in the first phase of investigation – 40% are from academics and 60% from industry. The sample has a representation of 20% males and 80% females. They are name-coded E1 to E10; with the academic experts coded E3, E5, E8 and E10, while the industrial experts are coded E1, E2, E4, E6, E7, E9.

The expert interviews were carried out to answer the research question:

> **RQ1**. How does the use of digital health communities enable the empowerment of informal carers?

The identified concepts related to digital health community use and empowerment are explored with information systems experts in interviews. The interview schedule is in Appendix 1, while Figure 5.1 summarises the themes that emerged from the interviews.

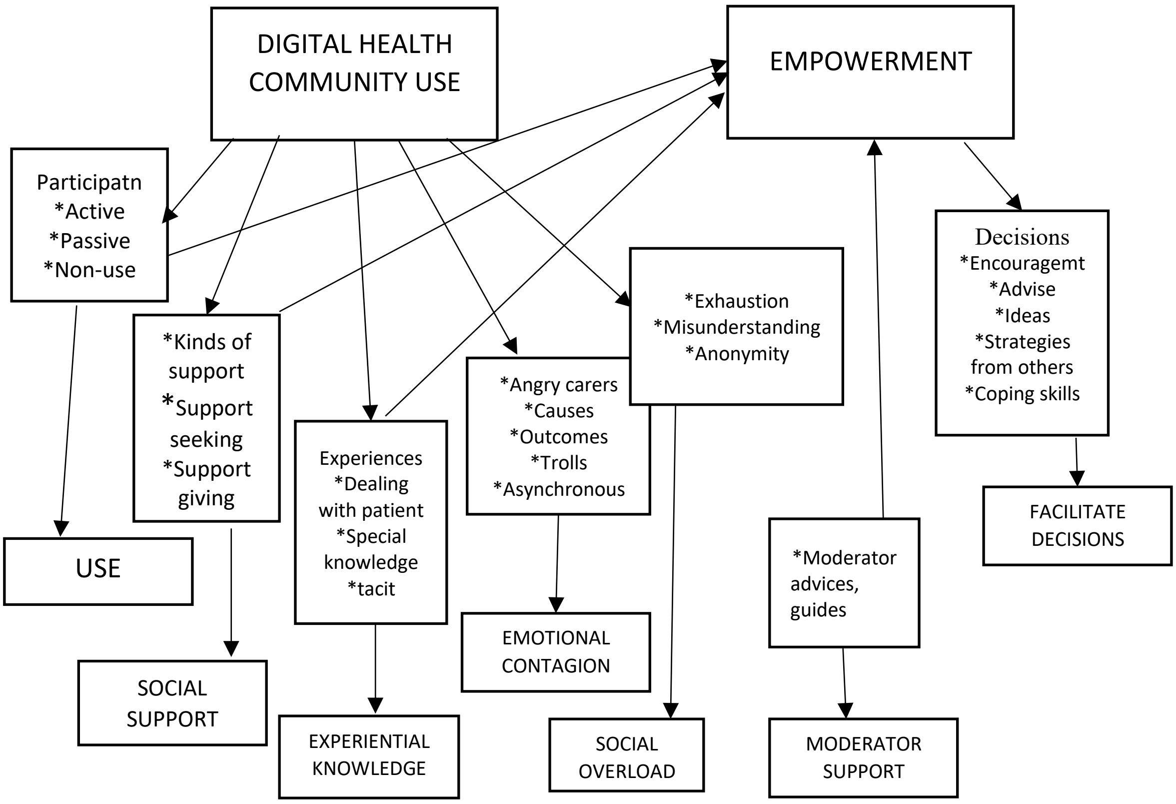


Figure 5.1 Summary of Sub-themes Derived from Interviews

The sub-themes are further discussed below under the two broad concepts of 'digital health community use' and 'empowerment', with examples of their responses.

5.1.2 Use of Digital Health Communities

The experts discuss participation of informal carers in a digital health community in terms of activity level, where they highlighted that some users are active, some are passive, and others are 'non-participating'. All respondents confirm the assumption that using digital health communities empowers carers, since interactions over online forums are *“good for peer-to-peer support… and validation of the struggles that carers have*” (E3). Once they acknowledge their struggles, using the online forum can help the carers overcome them. Like E1 says, *“…. they would be empowered and definitely they should participate.” (E1)*, which is corroborated by E8: *“using online forums get you to feel that sense of empowerment, when you contribute something of yourself – your ideas, your thoughts, your problems.…”*

Using the digital communities also helps most informal carers come to terms with their duties as they learn from others; they become better equipped to do their carer duties. Most of them need validation in their role since they do not consider themselves as carers (E7): “*Because I know a lot of people have trouble defining themselves as that (carer).*” They do their care work out of duty because *“there is that push and motivation to be there for the loved one and one does not think about how they are actually coping and how they are going.”* (E7, E10)

Active and passive use

To maximally benefit from the digital health community, most of the experts encourage that carers must be active rather than passive or lurking participants. For example, their responses include:

“Yeah, I think (participation) is more important in terms of the well-being of carers.” (E3)

“I would definitely say they need to participate in order to make the most of the forums.” (E8)

Even then, other experts believe that lurking is a form of participation too, which needs to be acknowledged:

> *“The people who are just reading do get benefit, various benefits. You do not have to be participating in an active way to get benefits” (E2)*
>
> *“And sometimes just reading others carers’ responses to a problem can be useful to them. So, you know, I guess it can still be a helpful process” (E4)*

> *"It is true that some of the users in online social networks are passive…. But even from just reading communication between other members, one can learn something." (E9)*

Although it is true that lurkers benefit from passive use, they do not produce any content, yet it is content that users need to read. In fact, participation that signifies use means posting, replying, commenting, liking to support other digital health community users. This is vital for the survival and continued existence of an online forum (Atanasova et al., 2017). So, the gain for informal carers is greater and more meaningful, and the existence of the digital health community assured, if members actively take part in the online interactions (Zhang 2016). Therefore, the use of a digital health community is a relevant concept to study in empowerment.

5.1.3 Effects of Digital Health Community use

This part discusses results of digital health community use.

a) Social Support

One of the themes identified from the expert interviews is social support, which some experts identified according to the classification by Loane et al. (2015). Most experts believe that the provision and exchange of social support by carers is the most important thing that happens in an online forum. As attested by expert (E2) and other carers, "it is certainlly very common… and one of the most predominant types of support we see."

"I think that's probably the biggest thing a lot of members get from the forums – just feeling like they have support…" (E10)

"I think that's one of the most important elements" of online communities (E4)

Further categorisation of social support describes:

i) *Informational Support* is support that offers guidance and advice on possible solutions to a challenge. Carers use the forum to gather information on issues they need advice on. Its importance is highlighted by E1, that "*informational support… definitely once we share our information and so we provide advice, we provide guidelines, we provide guidance and we provide feedback as information support." (E1)*

"Some carers will come in looking for information and that's all they want. They'll come in, share their issue or whatever they're dealing with, get information support, and then kind of move on…" (E7)

ii) *Emotional Support* is about being able to turn to others for consolation and encouragement in stressful times, leading to a feeling of being cared for. As one expert noted, carers tend to "invest emotional energy into caring… they often feel depleted" although they are not aware "that they're kind of running out of emotional resources themselves and need some care for themselves" (E4). So, the digital health community is the destination for their emotional support.

On the forum, especially if it is anonymous, they know *"that it is valid for them to feel stressed or upset"(E10).* Most have found a voice to express how they feel, knowing that it is ok to be stressed. As assured by one of the carers: "*…as a carer at any level you can easily feel like you have no right to feel stressed…but you do" (E9).*

Just as importantly, the forum *"provides that space to listen and not necessarily offer any sort of advice... Just letting people know that others are listening. It is priceless" (E2)*.

iii) *Network Support* - The other type of support is the one that builds and fosters togetherness; one that helps you belong and know you are part of a group since you share the same concerns and interests. Network support is essential for carers because most are "quite isolated generally", and have no "positive social network". So they come to the forum, "create friendships" and stay for "social fulfillment" (E7).

Beyond the individual, the online forum provides *"a non-judgemental space where others are going to be able to understand where they are coming from" (E10) " a space that just offers reassurance and validation. It is very important" (E2)*. The digital health community is also credited with long-lasting networks: *"… relationships that people build in the forums are very deep and can last over many years"* because they are *"a very real part of their social network" (E8).*

iv) Esteem Support – seeks to boost another person's self-esteem by giving them positive feedback on what they manage to do e.g. coping with stress. As one expert points out, the importance of the digital health committee as a platform over which users can encourage one another cannot be overlooked: *" be strong and not give up… and take care of your loved one" (E1)*. Indeed, giving positive feedback makes other users feel good about what they achieve, "as they continue to strive to do their best in the situatiion".

v) Instrumental Support – lastly, this type of support deals with giving tangible resources to assist another person to cope in a tough situation. Although it has fewer applications or occurrences in an online forum, it still exists to provide support. One expert used their experience in another forum to show the existence of this support type in online forums – where they arranged on the forum to lend someone books or shared links to e-books and other online sources for information.

Reference to these different forms of support suggests that they have a place in social support of carers, for many of them their "*focus is on the person that they're caring for rather than themselves."* Unfortunately, many of the carers "a*re not really looking out to themselves, and nobody else is looking out for them"* (E3). In most cases, they also feel that they *"have no right to look after (themselves) because it's all about the person you're caring for"* (E7). Thankfully, the provision of social support on the digital community places focus on the carer; their peers *"value them for themselves, not just caring"*. This kind of validation boosts their confidence to make decisions better. Consequently, social support is confirmed to be a necessary construct in studying empowerment in an online model.

b) Negative Outcomes of Digitall Health Community Use

Seven experts agree that exhaustion from offering social support is real, while the remaining three were not sure if they had observed it on forums, and these were academics. From the group that confirms the existence of exhaustion, three of them confirmed that they have counseled fatigued carers on the side, outside the forum. They get carers who feel *"That's it, I'm done. I don't want to be part of this community anymore" (E2)*

This construct is explained further by feeling overwhelmed, gives further insights into the concept of online empowerment – that it can be negatively impacted during the interaction of carers. --- social overload?

Experts attribute the exhaustion experienced in online interactions to several factors:
* the inability of a carer to invest in themselves, because they *“try to be there for so many people”* and extend support to everyone (E4). Also, because of their care duties, getting online *“might not just be a priority for them.”* As a result, they feel *“very frustrated, or very stressed, and they cannot share information.” (E1)*. In that state of fatigue, they feel that they have *“nothing left to give”* (E6).

* asynchronous communication of online forums causes desperation in carers when they cannot get immediate help because sometimes they face very challenging situations:
“..you're delayed in terms of it's not always instant support….You don't get that immediate engagement…...” (E7)
* misunderstandings between carers on the forum
The tone of posts may be construed for something other than what the author means and that may cause arguments on the forum. As E5 notes:
“…it's very difficult to convey emotional tone in this format….it could be different if you could talk to that person if you could find them. But if it's just all online …... it's very difficult to do that in a sensitive way…. somebody else will just respond with… ‘uh, what are you talking about?’ You know, and they will feel upset, insulted” (E5)
* anonymous identities – Some people can be unruly because there are no face-to-face relationships in online interactions, and this can be a stressor to other carers on the forum. *“when I look at that message online – I might feel – I don't know that person” (E6)*
“You may get some troll behaviour, some people who may become abusive…. Similarly also if it's an open forum, there's a risk of somebody else quite maliciously coming in and just being really destructive. And unfortunately, we know that that does happen” (E8)

Whatever the cause of the social overload is, carers threaten to or do quit the forum. Especially because the forums are anonymous, they find it easier to leave. From the viewpoint of E6, *"it doesn't take much for them to not participate anymore",* they just *"won't log in."* For some it is easy to do, for others it is a difficult decision because the forum may be their only emotional outlet. Notwithstanding, literature confirms quitting or suspending information systems use as a way of coping when users feel overwhelmed (Maier et al., 2015b).

c) Experiential Knowledge

Experts perceive the exchange of knowledge as a justified variable when considering online interactions concerning empowerment, largely because most forum users relate better to personal stories rather than hypothetical knowledge. Mostly, the personal stories are based on experiences. For example,

"…they can also share knowledge from their own personal experience…. (which) they can tell other members or other carers about" (E4)

Knowledge shared in these forums is both *"tacit and explicit" (E1).* The tacit knowledge is from their experiences and *"very specific and unique…"* as well as *"deep knowledge… about caring" (E2),* and is *"more personal" (E4)*, having been accumulated over 20-30 years of caring by some forum members(E2). So they surely possess a *"sense of expertise about caring" (E2)* that they willingly share. This makes the knowledge very special and confined to those that are involved with caring as they encourage each other to *"keep trying different strategies and trying a different approach..."(E10)*

Furthermore, experts purport that knowledge exchange informs empowerment:

"definitely I think there is scope for empowerment and self-efficacy to be informed by knowledge transfer" (E5)

"Yeah we definitely see a lot of ….. sharing their stories, how they might have approached a certain issue and …. how that might apply to somebody else's situation. And I think …. that does empower other people" (E3)

Sharing of personal experiences is reported to resonate well with informal carers as it gives them information to think about in their decision-making. Knowing that someone is going through the same experience as themselves makes the carers feel less lonely. Another expert noted that knowledge about self-care is also shared among informal carers out of concern for each other, and that helps them make decisions. So, all the experts subscribe to the importance of knowledge exchange as a valuable construct in online empowerment.

However, with further reflection on their responses, there is evidence of emphasis on carers' experiences and the need for self-care. Consequently, with influence from conceptualisations from Castro et al. (2019) and Burda et al. (2016), the concept is renamed 'experiential expertise', with specific interest on what they share about self-care.

d) Making Decisions

Some experts (four of them) note the online community's abilities to aid decision-making of users. More specifically, E2 contends that *"the way that carers support each other in our online community certainly helps them to make decisions".* The decisions range from how *"they care for their loved one"*, to the different health options available, the types of services available and decisions around self-care of the carer (E10). E9 also acknowledges that even from just reading *"communication between other members, one can learn something…. that can help them make better decisions."*

e) Moderator Support

All experts affirmed the suggestion that facilitated online forums may improve empowerment. Their explanations of how the forums enable empowerment are summarized in Table 5.1 below under five identified functions of facilitator support.

Function	**Sample expert response**
Provides safe environment	*"I think that moderators are needed to create a safe space on that online forum" (E4, E7) A moderator is needed to create a safe space on the online forum (E4)* *"I feel like there'd be more barriers to empowerment if you're in an unsafe environment." (E7) An unsafe environment is likely to pose barriers to empowerment (E10)* A moderator provides a *"bird's eye view of safety of the whole online community"(E3)*
Facilitate discussions	*"…it is important to have somebody who has a high degree of knowledge and facilitative skills to monitor and interject if that's really necessary." (E5)*
Promote self-care	*"to….. ensure that people are focusing on their self care so that they can have longevity in the forums" (E2)*
Ensure factual and correct contributions	*"I think a moderator is really important because they have to be making sure that any advice that's being given is right." (E6)*
Initiate and maintain discussions	*"The role of a moderator is very important they can manage and encourage participation" where carers seem to lack interest in the forum (E1)*

Table 5.1 Benefits of Facilitator Support

There is consensus that moderator support in an online environment contributes to empowerment, so it makes a valuable construct in the conceptual model.

From the foregoing results, the interviewed experts confirm that all the variables identified from the literature are sensible and relevant in the study of empowerment in a moderated environment. Above that, it has emerged from the expert discussions that there is another inhibiting factor to empowerment in a digital health community – 'emotional contagion', which is discussed next.

f) Emotional Contagion

Emotional contagion is a concept that explains how the sentiment of one person may elicit similar reactions in others – whether positive or negative (Kramer et al., 2014). Research has shown that in online forums, negatively written responses trigger negative replies in the subsequent posts (Lee & van Dolen, 2015), thereby causing apprehension and discomfort in other forum members. On the other hand, positive experiences of how others cope may increase the other members' competence and autonomy, which may, in turn, encourage them to be proactive and take charge of their lives as carers (Mo and Coulson 2014). Experts share the same views that online communities tend to permit emotional contagion. For example, E5 notes that a carer may not realise the negative effect their post may have on others:

"… for example, somebody with advanced cancer and early-stage cancer in the same online forum – that can be problematic because the person with early-stage is listening to all these problems; so all these issues, all these fears, these terrible things that are happening for the person with more advanced disease are actually distressing the person who has not got to that part of his journey yet"

"..if you are supporting people who you know there is a lot going on for them and there isn't any easy answers…. that can feel quite disempowering; sometimes when you're seeing a lot of people without a lot of options…. I don't think that necessarily feels great" (E2)

From the interviews, the following is the output. From further literature exploration, slight amendments resulted in:

*concepts refined by experts are social support, digital health community use, social overload.
** knowledge exchange changed to ***experiential expertise***
** role of moderator/facilitator changed to **facilitator support**
** ***emotional contagion*** added

The next phase is an online observation that uses content analysis to find evidence of the concepts in the forum discussions. The discussions involve both facilitators and carers.

5.2 Content Analysis

The content analysis was used to examine forum messages which showed decision-making activities (Smedley & Coulson, 2017). That is, the data are coded into existing categories derived from prior work that identified support exchanges generated by the use of a facilitated digital health community for user empowerment (Sethibe et al., 2019). Based on the interview results and further extant literature, the themes identified are social support, experiential expertise, emotional contagion and social overload, from which categories were determined. Notwithstanding, the researcher remains open to consider any emerging themes as coding continued. These are compiled into a codebook of themes with descriptions (Appendix 3).

The data retrieved comprise 468 threads, out of which 419 threads met additional criteria that messages should contain at least two messages and no more than sixty messages (i.e. the 95th percentile of thread length). Eliminating a couple more threads posted by carers residing outside Australia, the sample became 417 threads, which contain a total of 3157 individual messages that fit the criteria. Figure 5.2 below shows a typical thread. Each thread starts with an initial post (ip), which other forum members – including a facilitator – may respond (r1, r2….). The post originator can also respond to comments in their own thread – self response (sr1, sr2….). In this study, a thread needs to have at least two responses.

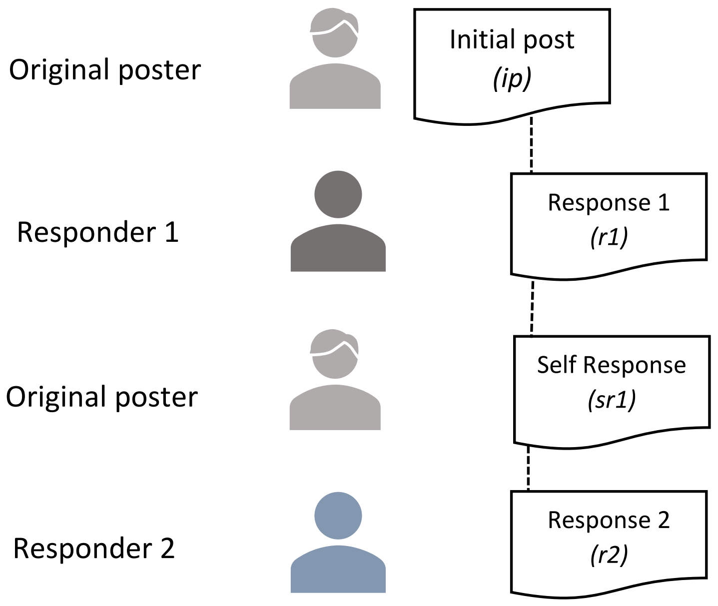


Figure 5.2. Example of a thread

To check the readability and comprehension of the codebook, two peer researchers were requested to check it, and their suggestions were used to modify it. It was then shared with the supervisory team who critiqued it further, resulting in a version that was pilot-tested with 100 messages from the forum. The pilot data was taken from conversations of two years ago on a month corresponding to the last month of the sample study period. Older messages were used because they were not part of the real data used for content analysis. The pilot data was manually coded into NVivo 11 and analysed. The analysis leads to the following observations in Table 5.2:

Concept	**Operationalisation**
Social support	Three common types: informational, emotional and esteem
Digital health community use	The act of posting, replying and liking posts. Frequency and length of use. Assumption : all posts denote use
Moderator support	Presence - denoted by modes of facilitator operation/interaction as they support carers
Experiential expertise	Exchanges of one's experiences in self-care, and acknowledgement of others' expertise by tagging them in a post
Emotional contagion	Almost impossible to know if someone's reaction is due to what was said previously, so EE is not identifiable in text
Social overload	Not detectable. However, there's mention of receiving too much support, which this study labelled '*support overload'*
Empowerment	Soliciting help to make decisions, reporting on decisions made etc

Table 5.2 Initial Operationalisation of Concepts

The results prompted further improvement in the descriptions of the categories. This iterative process is necessary to improve the final product (Neuendorf, 2017). A consensus is finally reached with the supervisory team. As the analysis is ongoing, a few modifications are done to improve the codebook further, specifically reclassifying some ideas to fall under a different theme and acknowledging ideas that come out of the data. The final codebook, in Appendix 3, is used to analyse text messages.

Although carers use pseudo names on the forum, any potentially identifiable information is excluded during analysis, so that data cannot be attributed to a known user. The pseudo names are replaced with codes e.g. FF5. To further ensure confidentiality and anonymity, full quotation of messages is avoided, and participants' thoughts are paraphrased. The data are then re-arranged into a format that can be uploaded into NVivo 11, where the conversations are coded manually.

The coding procedure is guided by research questions, and results in six categories. During analysis, the categories are further clustered into three themes: 1) empowerment constituents, 2) influencers of empowerment, and 3) the role of facilitator presence. The results are structured around these main themes, including the use of digital health communities.

5.2.1 Utilisation of the Digital Health Community

The realisation of empowerment as an outcome depends on the use of the digital health community, which generates the content and facilitates its consumption (Smedley & Coulson 2018). Figure 5.3 below shows the pattern of use of the Carers forum, in terms of the number of messages posted per month, over the sixteen-month period of the study. The highest level of activity is when 303 messages were generated per month, which is above the average of 197 messages/month, and the lowest is 59 messages. The forum is used by 512 unique contributors from across Australia. Figure 5.4 breaks down the activity further to show the number of messages posted by the number of carers. The graph shows that 91% (464) of users posted eight or fewer messages, with 9% (48) of users actively posting and responding to messages. 39% (202) of users posted once and 0.2% (1) user posted 430 messages during the period of study.

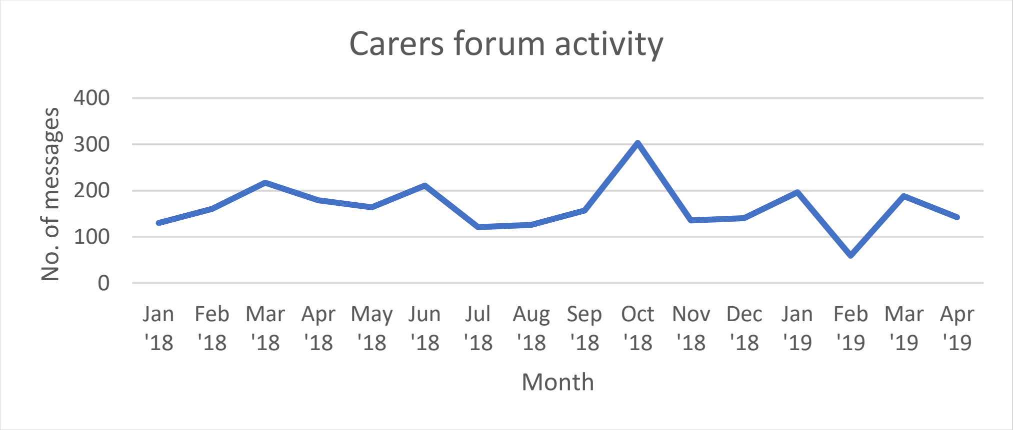


Figure 5.3 Pattern of Use of the Carers’ Forum

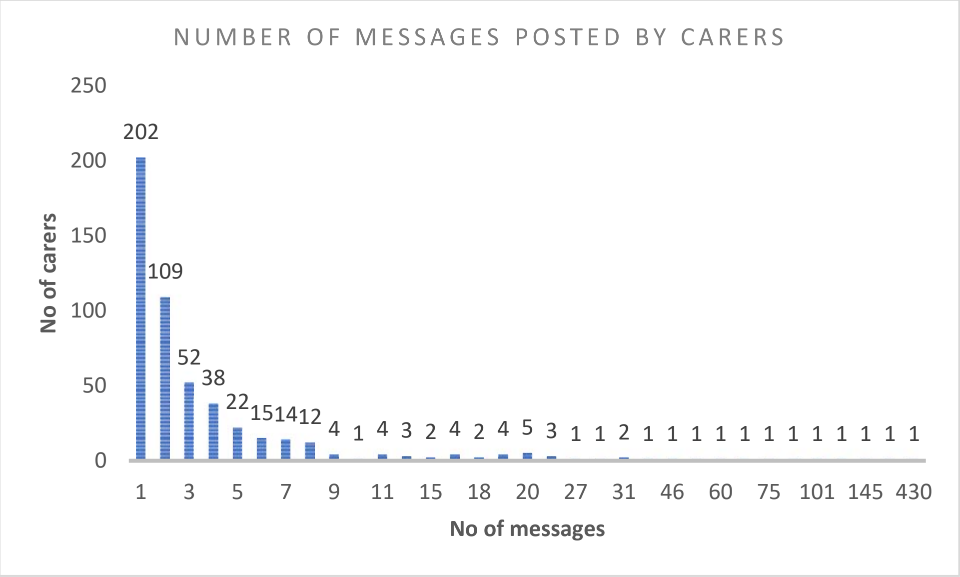


Figure 5.4 Frequency of Use of the Forum

Carers in their responses highlight some of the reasons they use the forum. These include – to find '*support', 'information', 'inspiration', 'help', 'a space for venting', 'a source of courage and strength', 'a place of solidarity and understanding.'* Figure 5.5 shows a word cloud of frequently appearing words, the most common of which are 'find', 'support', 'help', 'advice', 'forum', 'forums', 'need', 'feel', 'supportive', 'talk', 'hope', 'people'

Figure 5.5 A word cloud of reasons for using the forum

Theme/Category	**Sample post**	**Freq**	**%**
A. Elements of empowerment			
i) Intrapersonal Empowerment			
* Identify and show a need to make a decision	** I feel trapped and don't know where to turn to for help as I'm new to caring – I am starting a relationship with someone with paranoid schizophrenia.*	360	11.4
* Competence (communication skills)	** I had a useful chat with my child yesterday, he agreed that we split the images in his imagination into two separate worlds as you suggested.*		
ii) Interactional empowerment		222	7.1
* Collective account and affinity	** It has been helpful to know I am not alone, or abnormal as I read other people's ways of working through these challenges.*		
* Group norms	** Advise to all of us here. Please be careful not to give specifics as you share information, so that you don't get identified*		
iii) Behavioural empowerment		270	8.6
* Coping – adaptive	** When someone criticised me the other day, I calmly refuted their opinions on my caring abilities using the tips I learnt here. I was so proud of myself because I was composed.*		
* Acting on decision taken	** I can proudly raise my hand as the contributor of genes that gave our children mental illness*		
iv) Affective empowerment		269	8.5
* Forum competence	** I am feeling very hopeless now, but am very thankful for your posts* ** Thank you all. This forum stories have given me hope* ** Yesterday I was at my wits' end, but after the discussion I feel a little better, today I am more in control of my emotions.*		
B. Influencers of empowerment			
1 Experiential expertise		555	17.6
• Self-care	** It is ok to reach out for professional help so you can be supported as well; it is also helpful to talk to someone you trust in your social circle.* ** Continue to do things you enjoy like sports, and hobbies you love such as gardening.*		
• Tagging	** There are some great insights in this discussion from @Z12, @FF5, @Z11* ** Hey @E6, please come meet @Q6 who looks after her elderly mum as well.*		
2 Social support			
• Informational	** Please check for help here, they have a very resourceful and comprehensive website and the organisation is in your area.* ** Family support services can help you and your brother cope with your mother's situation.*	1002	31.7
• Emotional	** I hear your hurt and how isolated you feel. You are dealing with a lot of emotions on your own, and you have done well to reach out here for support.* ** There are many carers who are struggling financially to make ends meet, you are not alone.*	1500	47.5
• Esteem	** Without doubt, you are a very strong person. Please take time to recognise that you are persevering, intelligent and tough in your care role.* ** I think you are a saint dealing with what you are at the moment.*	510	16.2
3 Self-disclosure			
• Emotion disclosure	** Well… I am happy today because I achieved a lot with my big lovable bear😆.* ** I am feeling broken at the moment.*	*702*	*22.2*
• Information disclosure	** With no private insurance and free counselling sessions finished, she cannot afford the counselling on her pension.* ** At times, my partner tells me what the voices say but he can also deny hearing voices even if I see him talking to himself.*	*1736*	*55.0*
• Social norms (Appreciations)	** Thank you again for listening to my rants.* ** I am very grateful to you all for reaching out to me.*	*486*	*15.4*
• Social norms (Salutations & Farewells)	**Hi everyone. Thank you @AA9 for introducing yourself and welcome to the forums.* **Hello… my first time posting, looking forward to being part of this community and hearing your stories.*	*455*	*14.4*
4 Support overload	** I appreciate you checking on me but it's a bit too much because it brings back issues I want to leave behind and move on.*	*8*	*0.3*
5 Social network fatigue	** Many of the discussions posted here are lengthy, which can be overwhelming.* ** Engaging with people who are struggling online is very challenging and cumbersome, as it feels like a hefty load on me.*	*10*	*0.3*
C. Facilitator Support	** Hello everyone! We are not allowed to be specific about medication names, can you please modify your post @X10.* ** It's good to see you reaching out and sharing your experiences here, welcome!*	327	10.4

Table 5.3 Results of the Content Analysis

The data analysis identified more categories than the original ones. Sample posts are given for each category, as well as the frequency of occurrence of each category and its corresponding percentage. The posts are paraphrased to protect the respondents' identities, and their names codified into e.g. A3, FF8, using the number of messages analysed *n=3157.*

5.2.2 Evidence for Empowerment

Using the conceptualisation of empowerment by Zimmerman (1995), the carers' responses are categorised into interactional, intrapersonal and behavioural elements, according to the codebook (Appendix 3). The results in Table 5.3 show evidence that carers experience empowerment (35.6% of postings). Operationalised in the context of decision-making, the first dimension of intrapersonal is explained by a carer's expressed need to make a decision, and their communicative competence. The dimension focuses on the individual, whose need is echoed in statements of loss of control and overwhelming feelings in carers, yet needing to make decisions; expressions that signify despondency for example, *'I feel lost, any advice will be appreciated'*. Another admitted *'I feel a little overwhelmed and do not know where to turn' while one said they are 'finding life very stressful and need someone to talk to here.'* The statements usually prompted other carers to respond with advice, which may assist one to make decisions. An intention to *'follow through with your suggestions as they are very helpful and reassuring'* or '*your ideas have a lot of value, I am going to use some'* showed that advice given is favourably considered and that forum users seeking advice intended to improve their proficiencies by adopting other's approaches to solving their problems.

Empowerment is also demonstrated in the interactional dimension (Petrovčič & Petrič, 2014). It is identifiable from expressions showing perception of group norms, sociability and affinity, and is represented in about 6% of conversations. Carers assure each other of togetherness as they face difficulties in their care journey – '*Letting you know you are not alone…. I have found great support here'*. Moreover, this support is available continually, as *'there is always someone there for you on the forum to lend an ear because we are together.'* The acknowledgement that indeed *'supportive comments are* *invaluable as they remind me I'm not alone',* that the community is a caring one *'where we support each other through the good and bad times'* because *'other carers are in this journey with me'*, serves two purposes. It validates the carers giving support and also affirms those receiving support; when they feel they are not alone, it gives credence to belongingness and affinity. As one carer remarked, being *'in a community of people with diverse issues in mental health helps me understand the importance of sticking together and supporting each other through tough times.'* The interactional is also recognised by statements connoting sociability, where carers share jokes, common interests or favourite hobbies. For example, when newcomers joined the forum, they were usually invited to the thread *'used by many of us when we just want some friendly company'*, and to *'social threads where we chat about mutual interests.'* The carers occasionally checked on each other's progress with these therapeutic, companionship activities: *'how far are you with your jigsaw puzzle? I am not able to finish planting my bulbs.'* Some followed classical music as it is *'known to soothe emotions and lifts the mood,'* others preferred *'reading a book because it is relaxing.'* Moreover, carers reminded each other to edit posts that *'mention names of medications'* or that *'give identifiable information*' which is identified as an act of comradery that encourages adherence to forum guidelines for proper use of the forum and attainment of its goals.

Results also showed support for the behavioural component of empowerment that is supported by 5% of instances in the discussions. Behavioural empowerment is the outcomes which when acted upon will improve the way things are done. The behaviours are communicated with statements that depict continuance and discontinuance behaviour. Continuance behaviour is influenced by exchanges of social support, self-disclosure and experiential expertise which are social influencers of empowerment. They were expressed in statements that showed adaptive coping behaviours of hope and positivity in the face of adversity: '*it is easy to feel inundated by caring challenges, but I am hopeful that the clouds will part.'* Other carers shared their resolute spirit to continue caring: '*only time will tell if things will get better or not, but I have chosen to stay and support my spouse.' 'If you are like me, you don't want to give up on your brother and take no for an answer. I am sticking with mine.'*

The carers' statements exhibited support for the affective component of empowerment as well (8.5%). As explained, affective empowerment is due to emotions derived from the capabilities of the Carers forum, most of which are positive. For instance, carers noted that being able to post without identifying oneself gave them freedom to write, with the confidence that their stories are heard by the right people: *'knowing that someone who knows my journey is listening, makes me happily come back to this forum.'* This confirms also that a forum brings together people with a similar interest, in this case, carers of people with mental illness. Other carers highlighted that they loved being able to come back to older posts to either refer to or consult previous discussions. That way they are able to work through issues at their pace. For instance, one carer acknowledged being on the brink of a breakdown but reading past posts of other carers *'brought a smile to my face despite my adversity.'* Users also appreciated that the forum has a facilitator 24/7, who is able to listen to and assist forum members with '*feelings of helplessness at 2am.*' Getting assistance made them *'feel cared for,'* their *'emotional burden lighter'* and encouraged them to support other carers by posting advice and carer tips, which they never did before. In general, the carers expressed appreciation for what the digital health community: *'If it wasn't for this forum, where would I be?*'

Some of the carers' conversations were quite humorous, as they believed that *'having a good laugh at the situation is very therapeutic*.' One carer admitted to being so *'inspired by (another's) humorous take on issues'* that they were going to find a way of adopting it in their family. Others found that '*interacting with faith-based websites'* gave them *'a lot of hope'* that you can survive well with a mental health diagnosis. These positive sentiments encouraged others not to give up, as *'reading other carers' stories gave me hope.'* Discontinuance behaviours were influenced by support overload and social network fatigue expressions, which showed to be personal influencers of empowerment. These highlighted the incorrect use of the forum and unsatisfactory facilitation practices. The proper use of forum, hope, and optimism that users get from others' posts helped them cope with care work and be able to make decisions.

The results also show that among others, a crucial competency for carers is communication, which assists in decision-making. Some carers find it challenging to communicate with their care recipients, and they seek help concerning how they can *'communicate in a way that will bring happiness to both of us.'* As one observed, they seemed to *'spark hysterical anger'* from their care recipient whenever they talked. After advice from the forum, they managed to seek the assistance of a psychologist for purposes of *'learning better tactics to converse and get my point across.'* Carers also have an occasional need to talk with family or friends about their care responsibilities, which also causes discomfort as they are *'protective over (their) loved one.… as people will conclude that she is a bad person.'* It also emerged that they have to communicate with health personnel when they accompany the care recipients to the hospital or other. To avoid possible mistakes leading to crises in their caring, carers note the need to *'maintain clear communication about the condition and treatment'* of their care recipient.

5.2.3 Influencers of empowerment

Results show the following support exchanges as influencers of empowerment:

a) Social support

The social support that is investigated is informational support, expressed by 36% of the posts, emotional support by 46%, and esteem support by 10%. The emotional support type is the most prevalent in the forum. In communicating concern and love, some participants identified with the other's situation in sympathy and empathy towards their circumstances. In supporting each other to persist in facing challenges, carers encouraged others to endure. For example, one carer encouraged another to '*keep getting up when they are knocked down'*, and that they shouldn't give up believing in their loved one. Other messages were well wishes, which gave other participants a feeling that they deserved the best; for instance, one carer wished another one and *'family all the best with everything moving forward.'* Still, other carers inspired their peers with messages of hope that circumstances will improve and there will be a better outcome of situations they may be facing. Others offered sympatry while relating to the situation.

Informal carers often seek information to accomplish one or more empowerment activities. Informational resources can support decision-making thereby reducing carer's uncertainties and strengthening their understanding of carer roles. While some resources are shared as a response to those who need immediate support, some carers recognise the digital health community's knowledge repository aptitude and *'make periodic contributions for myself so I can read it later'* to get the needed support. For instance, one carer sent out a message seeking help on how she can access assistance for her mother, who is off medication and does not want to get medical care yet is very delusional. In response, one carer advised her to find a therapist for support who may help her strategize as well as share insights into available services in her area, which will *'help and empower'* her to support her mother. Another informed her that any of her mother's treatment and care team (either GP or mental health service) should be able to provide a listening ear and guide her on mental illness and its treatment, albeit in general terms. Other informational support types shared by carers included information resources like web links to reading material. For instance, one carer shared a link to another organisation, which has stacks of resources for MI; another shared the book title “Walking on eggshells”, which they found to have very helpful strategies to use in dealing with people with mental illness. Still, another shared a link to a movie called “When the voices fell silent,” a story of hope by a carer and her care recipient who struggled, but recovered, from mental illness.

With an occurrence frequency of 10%, esteem support is the lowest. It expresses confidence in and respect for one's abilities. Participants acknowledge the others' efforts in tackling challenges they face and they keep encouraging each other. In welcoming a new carer to the forum, one remarked on the admirable strength and ability they possess in the face of a difficult situation. Another identified one as *'a saint for being able to deal with what you are at the moment.'* This support type encourages others to keep doing their best.

b) Self-disclosure

Results show that disclosure can be either informational or emotional (Huang et al., 2019). Most of the participants on SANE forums also share background stories to explain their situations, ranging from the condition of their care recipient, to how they relate with them, how family relations affect their care work, their experiences with doctors and other health professionals involved in the treatment of their loved one and personal reflections about whether what they are doing is right or not. Some relate their situations in very lengthy write-ups, making informational disclosure to be the most common form of disclosure in this forum.

On the other hand, carers disclose their emotional state to solicit emotional support. They share their thoughts and feelings which cover their emotional journey with mental illness, maybe even before diagnosis, facing and dealing with the stigmatisation of mental illness, lack of emotional support for carers, and the emotional transitioning they have to make in their relationships with their care recipient when on this journey with mental illness. In some posts, the carers express outright exasperation from their care duties.

Another theme categorised under disclosure is *social norms* whose prevalence is at 15%. The category comprises informal rules that emerge out of social interactions and influence the behaviour of forum members (Huang et al., 2019). Social norms tend to encourage and reward desirable behaviour while discouraging unacceptable conduct. In the forum, they were presented as expressions of gratitude, comments, encouraging words, ideas, and experiences of others in the conversation. Being appreciated nurtures caring relationships in a positive way and encourages relatedness, which contributes to better decision-making e.g. '*…yes that makes sense, thanks for explaining that and for your help. I really do appreciate it.'* Another carer remarked *'Your replies have put a smile on my face. Thank you for responding.'* New carers, especially, while introducing themselves seek to connect with other carers straight up: *'hi everyone, I've just recently* *heard of this platform and thought to share with you a small story'* which is a story of their own challenges.

c) Experiential expertise

Experiences of the carers are represented by about 18% of instances of all posts on the forum. The need for support through shared experiences is expressed by several new posters especially, those who would like to hear '*first-hand experiences'* of *'someone who is going through this and knows what this is like'.* Other people's *'own experiences greatly help someone understand and accordingly assist'* their loved one.

Experiential expertise in this digital health community is shown in two ways – statements on self-care by carers and tagging others. Experiences help other carers to self-care regarding their mental health. As one carer put it, it's essential to mind that *'my own mental state may crumble, so I have to be conscious of self-care*.' This statement would highlight the importance of caring for oneself, especially those who are newcomers to the journey. Notably, posts on self-care constitute about 75% of all posts on experiential expertise, and they include sharing about self-care activities that individuals can undertake, e.g. *'seeking professional counselling and therapy', 'getting support from friends and family', 'getting respite or time-out', 'setting clear boundaries around behaviour of the care recipient', 'going out for coffee', 'getting mental health support services', 'regular exercising', 'taking up hobbies,' 'playing games like puzzles.'* The sharing of experiences is one of the principles upon which the forum operates, with an emphasis that exchanges must be kept anonymous, respectful, and the forum safe to use (SANE forums online).

On the carers' forum, the experiences of the experts are also highlighted by tagging using @ symbol. Linking content to another person's profile in this manner causes other users to trust the tagged one, giving them the status of a trusted source of expertise and regarding them as having a wealth of expertise to share (Li et al., 2017). For example, when responding to a plea for help, one carer pointed out that *'some members on the forum who care for their mothers as well may be able to assist @Q6, @E6, @WW2,*

@B10, @H3' and they tagged them since they *'have similar experiences and may be able to share their views*.*'*

d) Social Network Fatigue

Carers in this forum also experience social network fatigue, due to issues discussed being *'too familiar and triggering,'* or *'too challenging to manage'* and it results in some carers discontinuing usage. Some impose *'a self-enforced ban for a while'* and suspend their usage of the digital health community.*'* The tendency to discontinue use has been noted as a typical reaction by users to avoid social network fatigue in previous research on the use of information systems (Zhang et al., 2016). Either quitting or suspending use may negatively affect empowerment since users get empowered from engagement with the digital health community (Chen et al., 2019). Possible ways to mitigate social network fatigue may include the use of a recommender system to filter and personalise messages.

e) Emotional Contagion

Emotional contagion is not detectable in carer conversations. It could not be ascertained that an expressed emotion is a result of the preceding one. Instead, carers expressed 'social network fatigue' which is tiredness from activities related to social network sites (Maier et al., 2015b; Zhang et al., 2016), of which digital health communities are part. Users could be wearied by reading long posts, bickering exchanges between others or finding the discussions too confronting. Some carers intimated that they found 'm*any of the discussions posted here lengthy, which can be overwhelming.'* Others shared that they used the forum excessively, even if they did not want to because it is addictive for them, so they were consciously taking periodic breaks from using it. Therefore, the study proposes that some carers experience "social network fatigue". Social support, experiential expertise and self-disclosure have been identified as social influencers while social network fatigue and support overload were inhibiting resources influencers of empowerment.

f) Support overload

From the content analysed, there is no evidence of social overload, as described by Maier et al. (2015a) – extreme social online engagement with friends and family, whereby one *gives* too much support that it wears them out. Rather, the discussions show some evidence (0.3%) that carers get tired of *receiving* too much support, a phenomenon named “support overload” in this study. It is fashioned around the same notion of too much technology use as discussed by other researchers. Overload refers to someone’s evaluation and perception of the amount of what they can handle, with the view that it is excessive (Zhang et al., 2016), as in information overload (Hur et al., 2019), social overload (Maier et al., 2015a) or communication overload (Zhang et al., 2016). Given that some carers suggest that receiving too much support is exhausting: ‘*I appreciate you checking on me but it’s a bit too much because it brings back issues I want to leave behind and move on,’* the study proposes that they are experiencing support overload. Apart from being exhausted by this *‘kind of excessive’* support, another carer remarks that it does not give someone time to think through others’ suggestions, and pick a viable option. Thus, it affects their decision-making negatively. Rather than being exhausted by giving too much support, carers are drained by receiving too much support.

5.2.4 Facilitator Presence

The presence of facilitators is acknowledged by 10% of forum posts. The activities of facilitators were summed up in what we term collaborative, commanding and motivating presence, depending on the way the facilitator interacts with users on the digital health community. A collaborative presence is identified by facilitator responses that engaged digital health community users in an understanding manner, giving advice and suggestions on user queries (social support), as well as prodding comments from everyone. This promoted warmth, a sense of belonging, and a feeling that someone matters. For instance, facilitators underscored the importance of forum use and participation because ‘*everyone is important and has something important to share’*. In turn, the positivity cultivated trust and formed relationships among users, some who felt *‘isolated, confused and lost’* but now have found *‘similar others to hold your hand* *without judging you, and it is a huge relief.'* The collaborative presence also nurtured users and looked out for first-timers to welcome them and invite them to take part in the deliberations: *'Hi @Z6, welcome to the forums. I believe you will get some good advice and support from fellow members once they read your post; please feel free to participate as well.'* as well as check on the older users: *'Hello @A5, we haven't heard from you in a while. How have you been keeping?'* A facilitator displaying collaborative presence also shared support with digital health community users – both emotional: *'I can hear the anguish in your words, and understand your frustration'* and informational: *'it may be helpful to read this fact sheet by SANE to answer your questions on schizophrenia - https://www.sane.org/mental-health-and-illness/facts-and-guides/schizophrenia'*

Facilitators also show a commanding presence, which ensured that forum guidelines were followed, conflicts were resolved and discussions were respectfully kept on topic, otherwise, the facilitator could modify or delete the post. This tended to promote consistency on the forum, information quality, and forum identity. For example, a user who divulged information that contravened forum guidelines is cautioned *'to be careful not to name hospitals or other facilities when giving advice for certain services',* so as not to mislead others. Another one is reminded that they *'are not permitted to discuss medications'* to avoid misinformation since they have no medical training as laypeople. Instead, everyone on the forum is encouraged to visit a GP for professional medical attention. Facilitators also gave advice to protect carers, where they would caution them to *'be guarded about the information they give'* to maintain their privacy. In the unfortunate event that a forum user did not adhere to a facilitator's advice, their post is taken down. Some such users were very unhappy and stayed off the forums for some time: *'I do not browse much these days due to the extreme political correctness hinders me from expressing my feelings'*. On the whole though, users showed that they are aware of guidelines and the activity of facilitators: *'I really hope my post is ok; facilitators, if not I apologise!'*

Finally, facilitators exhibited a motivating presence as well, which is displayed in a couple of ways. They inspired digital health community users to deliberate on a discussion initiated by the facilitator. Initiating dialogue in such a manner prompted user participation in a specific direction, thereby creating focus in a discussion. This thought is exemplified in the 'Ask us anything – Service Spotlight' program which is conducted on the forum. In the program, an invited service provider talked briefly about their support services for carers, and the carers participated in a follow-up discussion which is open but focused on the presentation. Facilitators also motivated carers to practice self-care a lot. They acknowledged it as an issue because carers *'focus most on their loved ones'* and neglected themselves, so they encouraged them to establish some support system that they can easily access. They motivated them to also engage in some self-care activities like taking respite and doing some hobbies.

Given the above results, we summarise the findings in Figure 5.6 below.

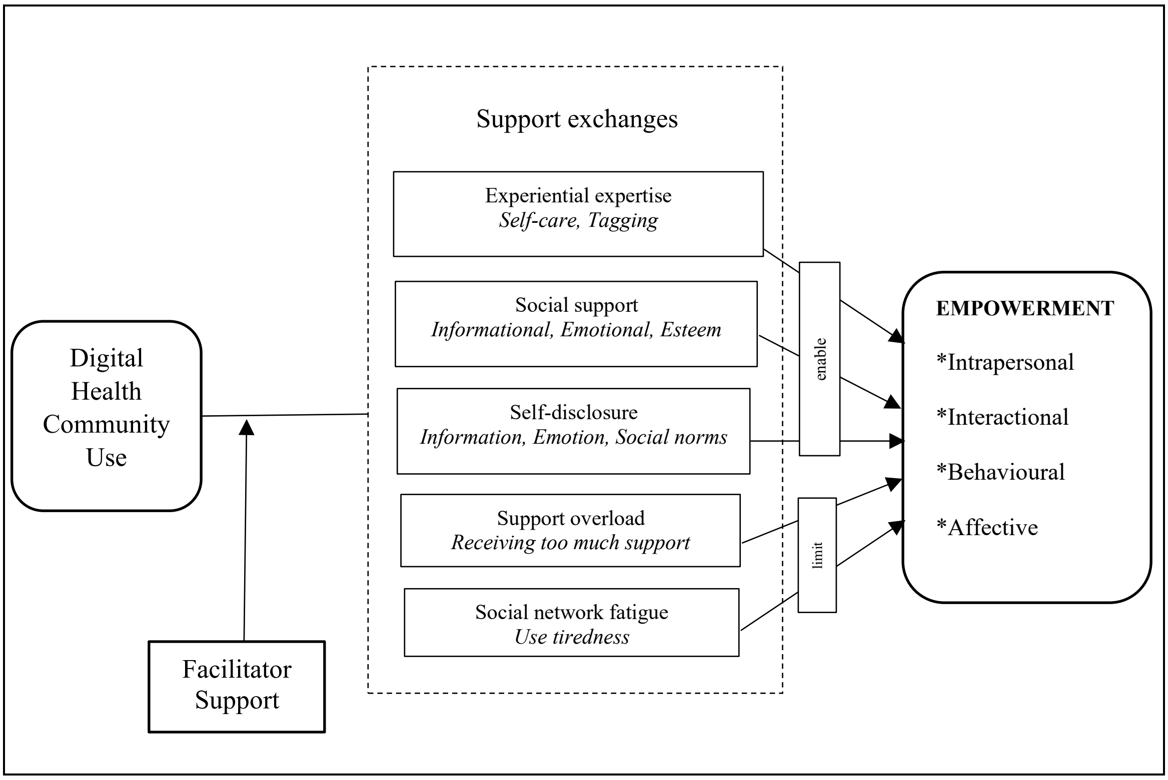


Figure 5.6 Theorising empowerment in a digital health community

Both enabling and inhibiting resources empower users. The social support exchanges empowered users to decide for continuance behaviour, while the personal support exchanges empower users to decide for discontinuance behaviour.

5.3 Chapter Summary

This chapter presents findings from the qualitative phases. Expert interviews conducted with IS professionals show the main finding to be that the proposed concepts are relevant to studying digital health community use and empowerment. They are social support, participation, knowledge exchange (experiential knowledge), social overload, moderator (modified to facilitator support), emotional contagion (additional). Modifications to the concepts were made with more literature searches. The second qualitative phase, an online observation, is carried out using the verified concepts and finds evidence of the concepts in forum conversations. Facilitators on this digital health community carry out support using the three identified approaches, which a facilitator employs depending on the carer's need or the situation at hand. These are collaborative, commanding and motivating approaches to facilitating, Empowerment in digital health communities has an 'affective' dimension, in addition to the conventional three. Results also show that carers need communication as a skill for their empowerment, because they are the liaison between the care recipient and everyone else. Empowerment is influenced by knowledge, social and psychological factors. The next chapter 6 presents quantitative data analysis.

CHAPTER 6: QUANTITATIVE DATA ANALYSIS

6. Overview

This chapter presents findings of the quantitative phase of the study, which follows the qualitative phase according to the research design described in Chapter 4. The cross-sectional survey was administered to informal carers of people with mental illness on the Carers side of SANE forums, and analysis done using PLS-SEM, specifically SmartPLS 3. The chapter reports (i) validation of the measurement model by assessing the factor loadings, as well as evaluating validity and reliability; (ii) confirmation of the structural model by testing hypotheses and relationships between constructs. It also analyses the mediating role of support exchanges yielded by digital health community use, and their effect on carer empowerment. The mediators are social network fatigue, social support, self-disclosure, emotional contagion, experiential expertise, and social overload. The chapter covers an assessment of the moderating role of professional facilitator support on DHC use and the support exchanges. The analyses will help expatiate the hypothesised relationships between the conceptual entities in the model.

6.1 Preliminary analysis

The preliminary analysis section discusses the preliminary general assessment of data, covering the characteristics of survey participants, treatment of missing values, normality tests that assess data distribution, sample size, and convergence check.

6.1.1 Descriptive statistics

Table 6.1 presents results that give a description of the study population. Most of the respondents are women (approximately 83%), compared to 15% that were men; 1% was non-binary, while another 1% preferred not to stipulate their gender. The dominant age group was 46-55 (35.2%) years, followed by 56-65 years (30.5%). The 18-35 age group made 10.5%, while the 66+ category made up 9.6% of the respondents. The results also show that 43.8% of carers are looking after their parent, followed by those who are looking after their spouse at 21% and some number is caring for their children at 15.2%, as well as other relatives (12.4). Most carers in the survey had been caring for 2-5 years (33.3%), and 6-10 years (21%). So, the majority of carers (63.8%) are 0-10 years caring, and the longest-serving are 20+ years in caring – they make up 19% of the respondents. The greatest number of respondents have just joined the SANE forum (41%) and have been 0-1 year as members; followed by the 1-2 years (31.4%). Those that are 1-3 years made up about 83%, this result is presented graphically in Figure 6.1.

The survey respondents reside in all the states of Australia; with most living in NSW (32.4%), followed by VIC (24.8%); the NT has the lowest number of participants in the survey (1%).

Detail	Category	Number	Percentage
Gender	F	87	82.9
	M	16	15.2
	Non-Binary	1	1.0
	Pref not to say	1	1.0
Age	18-25	1	1.0
	26-35	10	9.5
	36-45	15	14.3
	46-55	37	35.2
	56-65	32	30.5
	66-75	9	8.6
	76+	1	1.0
State	ACT	2	1.9
	NSW	34	32.4
	NT	1	1.0
	QLD	21	20.0
	SA	11	10.5
	TAS	2	1.9
	VIC	26	24.8
	WA	8	7.6
No yrs as a carer	0-1	10	9.5
	2-5	35	33.3
	6-10	22	21.0
	11-15	10	9.5
	16-20	8	7.6
	20+	20	19.0
No yrs as a SANE member	0-1	43	41.0
	1-2	33	31.4
	2-3	11	10.5
	3-4	6	5.7
	4-5	7	6.7
	5+	5	4.8
Relation to the care recipient	Spouse	22	21.0
	Partner	7	6.7
	Child	16	15.2
	Parent	46	43.8
	Grandchild	1	1.0
	In-law	0	0.0
	Other	13	12.4

Table 6.1 Profile of Respondents

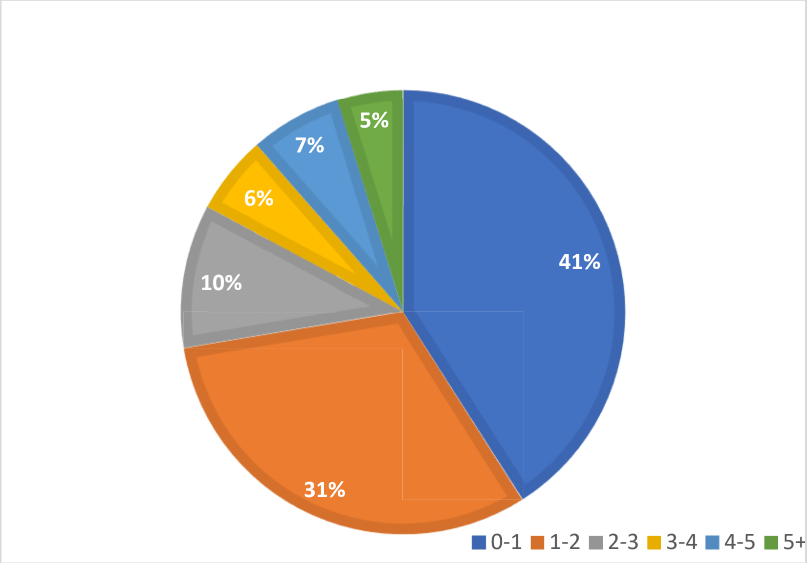


Figure 6.1 Number of Years as Forum Member

6.1.2 Sample size

The minimum size of a sample can be estimated using different methods in PLS-SEM, including the ‘10-times rule’ method widely utilised in IS (Hair et al., 2017a), and the ‘minimum R-squared’ method as an alternative (Wong, 2019). The first method suggests that the size of a sample should be ten times the most number of structural paths pointing to a specific construct in the outer model (Hair et al., 2017a). Using the study’s model with ten structural paths pointing to the empowerment construct, the sample size is estimated to be 10 x 10 = 100.

To corroborate this estimation, the R-squared method uses a power table, which shows that to achieve a statistical power of 80% for detecting R^2 values of at least 0.10 (with a 5% probability error), the study needs a minimum of 80 responses (Wong, 2019). The number of usable responses in the study is 105, which is more than the minimum of 100 and 80 estimated by the two methods respectively. It falls within the acceptable range of 100-200 responses in path modelling (Wong, 2019). The number of responses is also rationalised by the fact that respondents are self-selected in web-based surveys, and the nature of the population and sample selection contribute to the size of the sample. Nevertheless, PLS-SEM is able to achieve favourable convergence for the minimum number of responses (Hair et al., 2019a).

6.1.3 Missing Values

The use of a survey almost always yields missing data. For that reason, a data set is cleaned to ensure that all questions have answers before running analyses. Whether intentionally or inadvertently a respondent may skip and not provide answers to questions because they find them difficult or they have reservations about providing answers. This happens despite the fact that a web-based survey can be set to disallow a respondent to proceed without answering a question. The method to force answers discourages some respondents from continuing and they stop answering the survey. As observed from this study's data set, most of the missing responses are towards the end of the survey (Hair et al., 2017a).

There are three possible ways of dealing with missing values – replacing them with the mean of provided values; removing all observations with missing values in any indicator or using whatever values are available to compute the model parameters. While the first approach is likely to lessen the possibility of finding meaningful relationships, the latter approach can bias results as it uses various samples sizes (Hair et al., 2017a).

The current study employs the second approach mentioned above, that of eliminating questions with missing values – known as casewise deletion. Before it is carried out, the researcher browses through the data set to ensure that the questionnaires to be deleted do not belong to a certain category of respondents, otherwise, results will be biased. They also ensure that the deletion leaves an acceptable number of responses. Therefore, entries that are missing more than 15% of answers are removed from the data set (Hair et al., 2017a). Following this recommendation, out of the 123 questionnaires retrieved from the web-based survey, 18 questionnaires were invalidated and discarded due to missing values. 105 were valid and usable – giving a response rate of 85.4%.

6.1.4 Assessment of Normality and Data Distribution

Standard normality tests like the Kolmogorov-Smirnov test and the Shapiro-Wilk test are used to evaluate the extent to which data are non-normal. They are also used to report kurtosis and skewness measures (Ali et al., 2018). Skewness evaluates the degree to which the distribution of a variable is symmetrical. Responses that are distributed in a manner that forms a tilt to either the left or the right of a distribution curve are labelled as being skewed. When calculated, a Z value of more than +1.96 or lower than -1.96 indicates a skewed distribution. Kurtosis, on the other hand, is a measure of whether the distribution forms a narrow peak with most of the responses in the centre, or the responses spread out to form a flatter peak. A calculated Z value of more than +1.96 denotes a distribution that is too peaked, while a value of less than -1.96 shows a flatter distribution of data (Hair et al., 2017a). Table 6.2 below presents the results of the distribution of data collected in this study, and Appendix 5 gives the details of the output of SPSS Statistics on skewness and kurtosis.

Variable	Mean	SD	Skewness (SE=0-236)	$Z_{skewness}$	Kurtosis (SE=0.467)	$Z_{kurtosis}$
UOD	3.234	0.626	0.601	2.547	0.845	1.809
SSU	2.449	0.733	0.827	3.504	2.076	4.445
EEX	2.660	0.761	1.029	4.360	1.770	3.790
ECO	3.271	0.594	0.235	0.055	0.407	0.872
EMP	2.750	0.812	1.114	4.720	1.390	2.976
FAS	2.536	0.707	0.766	3.246	3.063	6.559
SOV	3.555	0.752	-0.137	-0.581	0.428	0.916
SDI	2.445	0.754	0.722	3.059	1.112	2.381
SNF	3.367	0.842	-0.658	-2.788	0.972	2.081

Table 6.2 Skewness and Kurtosis results of Normality Tests

From the table, most of the values for $Z_{skewness}$ fall out of the acceptable range, with most being greater than +1.96. Only two values for the constructs emotional contagion and social overload are within the range of -1.96 to +1.96. This means that the data distribution is skewed.

In like manner, most of the values for $Z_{kurtosis}$ when considered against the acceptable range, fall outside. Except for three constructs (digital health community use, emotional contagion, and social overload), all others have values of $Z_{kurtosis}$ that are greater than +1.96. This means that the data are mostly in the centre, making the distribution too peaked. The data are non-normal, with a skewed distribution and a narrow peak, and PLS-SEM is able to analyse data that lacks normality (Hair et al., 2019b).

6.1.5 Convergence Check

Before analysing results, it is also important to check if the stop criterion of the PLS algorithm is attained when running it. The number of iterations attained must be less than the maximum number of iterations (Hair et al., 2017a), the latter being 300 in this analysis. Table 6.3 shows part of the table of iterations, displaying that the algorithm converges after iteration 18, which is very less than the maximum number of iterations. This means that the PLS algorithm is attained, and a stable solution is found after iteration 18 showing that the path model estimation converges.

	ECO2	ECO3	ECO4	EEX1	EEX2	EEX3	EMP1	EMP2	EMP3	EMP4	·······
Iteration 0	0.404	0.404	0.404	0.375	0.375	0.375	0.285	0.285	0.285	0.285	·······
Iteration 1	0.388	0.237	0.581	0.365	0.383	0.378	0.269	0.308	0.280	0.284	·······
Iteration 2	0.377	0.299	0.537	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 3	0.387	0.272	0.552	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 4	0.382	0.282	0.547	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 5	0.385	0.278	0.549	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 6	0.384	0.28	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 7	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 8	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 9	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 10	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 11	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 12	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 13	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 14	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 15	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 16	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 17	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······
Iteration 18	0.384	0.279	0.548	0.365	0.381	0.379	0.269	0.308	0.280	0.284	·······

Table 6.3 Stop criterion table

6.1.6 Collinearity Assessment

The intensity of the PLS-SEM analysis depends on the complexity of the research model and the research scope, and a collinearity assessment is often necessary for detailed analysis (Wong, 2019). Collinearity issues can be between indicators of a construct or between constructs in a model; in both cases, they result in biased estimation of structural model relationships. Hence, it is important to resolve them by developing a higher-order construct or either merging or deleting the concerned construct or indicator (Hair et al., 2017a; Wong, 2019). Multicollinearity is the interdependence among predictors, which affects the accuracy of parameter estimates and statistical significance, therefore affecting inferences made on the results (Thompson et al., 2017).

Two types of collinearity are assessed in structural equation modelling – lateral collinearity, which is found in the structural model, and vertical collinearity, which exists in the measurement model. Vertical addresses collinearity between items of predictor constructs, while lateral deals with collinearity between predictor and outcome constructs (Kock & Hadaya, 2018).

The assessment of collinearity is based on the variance inflation factor (VIF) values of constructs. Several rules of thumb for VIF are presented, most commonly that VIF>10 indicates severe multicollinearity and that VIF>4 indicates the presence of multicollinearity. However, these rules alone may not be sufficient to cast doubt on the coefficients. Therefore, multicollinearity has to be assessed in relation to other diagnostics such as the correlation between variables (Thompson et al., 2017). They contend that if the correlation is less than 0.6 then a VIF of less than 3 indicates the absence of collinearity issues in the data. The confidence in the results should also be based upon the *R*-squared, *t*-values, confidence intervals, and sample size (Hair et al. 2019a). The results presented in Table 6.4 below will be considered in the context of Hair et al. (2019a) argument that VIF should be less than 5 to avoid multicollinearity issues; in fact, they advocate for a value close to 3 or less. Collinearity diagnostics for results are provided in Table 6.4 below.

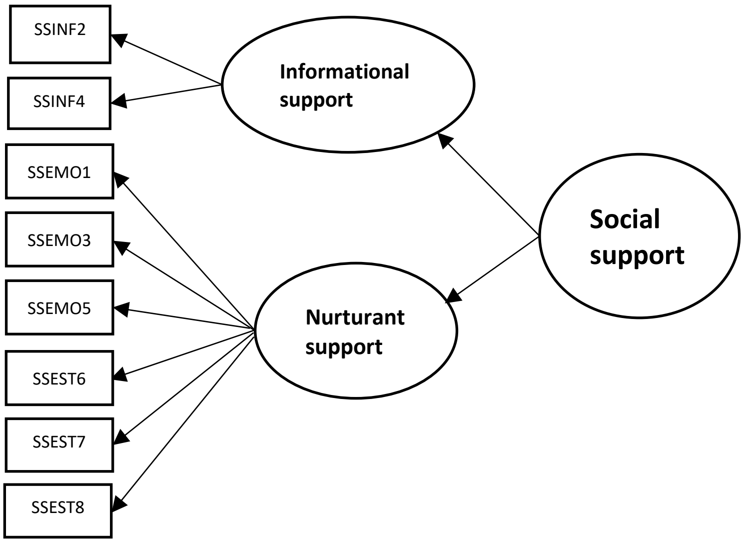
Construct	Inner VIF	Items	Outer VIF1	Outer VIF2
Emotional contagion		ECO1	1.085	
	1.847	ECO2	1.834	
		ECO3	1.850	
		ECO4	1.358	
Experiential Expertise		EEX1	1.895	
	2.347	EEX2	3.058	
		EEX3	2.638	
		EEX4	1.141	
Empowerment	--	EMP1	1.962	
		EMP2	2.341	
		EMP3	3.453	
		EMP4	3.363	
Facilitator support		FAS1	2.801	
	1.593	FAS2	2.418	
		FAS3	2.512	
		FAS4	2.426	
Self-disclosure		SDI1	1.630	
	1.809	SDI2	2.243	
		SDI3	1.980	
		SDI4	1.292	
Social network fatigue		SNF1	1.852	
	1.438	SNF2	2.358	
		SNF3	3.970	
		SNF4	2.886	
Social overload		SOV1	2.412	
	1.544	SOV2	2.507	
		SOV3	2.013	
		SOV4	2.242	
Social support		SSEMO1	1.898	1.879
		SSINF2	1.776	1.776
		SSEMO3	1.898	2.484
	3.575	SSINF4	1.776	1.776
		SSEMO5	5.023	3.529
		SSEST6	3.032	2.800
		SSEST7	5.214	Deleted
		SSEST8	2.973	2.687
Digital health community use		UOD1	1.437	
	2.261	UOD2	1.592	
		UOD3	1.151	
		UOD4	1.458	
		UOD5	1.153	

Table 6.4 Collinearity Statistics (VIF)

As shown in Table 6.4 above, most inner VIF values are less than the thresholds. The VIF<3 for all constructs except social support, which has VIF<5. This result confirms that there is no vertical collinearity threat. However, in the outer VIF, two indicators of emotional support and esteem support (SSEMO5 and SSEST7) have values exceeding the acceptable threshold of VIF<5; they have values of 5.023 and 5.214 respectively. They also have a high correlation, SSEST7-SSEMO5 : 0.857. This contributes to critical issues of multicollinearity, which cause a bias in the estimation of the structural model relationships and could threaten inferences (Hair et al., 2019b). From literature, two approaches to solving the multicollinearity issue are suggested, and the study adopts them:

- Separating indicators and establishing a second-order model as recommended by Hair et al. (2017a). In this study the indicators causing multicollinearity are in the social support construct, which according to literature comprises five types of support (Coursaris & Liu, 2009; Johnston et al., 2013). However, the study operationalises social support in terms of informational, emotional and esteem support due to their prevalence on the digital health community under study, as established in the content analysis (qualitative phase). To separate the indicators, they are grouped into two support types – informational and nurturant (esteem and emotional) support according to literature (Huang et al., 2019). These are treated as lower-order constructs (LOC), which result from splitting the higher-order construct (HOC), social support (Figure 6.2).
- Deleting the indicator with the highest VIF (Hair et al., 2017a). The first step helps to slightly increase the t-value on the social support path but does not eliminate the multicollinearity issue. So, one of the indicators involved in this challenge is deleted, because of its high VIF, and the remaining values are adjusted as shown in the column labelled 'Outer VIF2' in Table 6.4. The VIF value for SSEMO5 is reduced to a lower level of 3.529.

With the preliminary analysis completed, the next step is to assess the measurement model and determine the reliability and validity of items prior to assessing the structural model. These will be done on lower-order constructs first, and then on higher-order constructs because the LOCs are elements of the HOCs' measurement model (Sarstedt et al., 2019). In this study, social support is a higher-order construct that is reflective-reflective (Figure 6.2), and its analysis is achieved with the repeated indicators approach (Sarstedt et al., 2019).



(Sarstedt et al. 2019)

Figure 6.2 Social support as a reflective-reflective HOC

6.2 Measurement Model Analysis

To analyse the measurement model, the following factors are considered. The constructs in the model are operationalised using reflective items, and the analysis technique requires assessment of internal consistency reliability, convergent validity, and discriminant validity (Hair et al., 2017a). This section presents the assessment, starting with lower-order constructs, followed by an assessment to validate the higher-order constructs (Sarstedt et al., 2019).

6.2.1 Reliability

a) Internal Consistency Reliability

A model has acceptable internal consistency reliability when the Cronbach alpha of individual constructs is greater than the threshold of 0.60 – 0.70; values beyond 0.90 show that items are redundant, while those below 0.60 show a lack of reliability (Hair et al., 2019b). This measure was noted to produce conservative values that are low, so composite reliability was brought as an alternative criterion, but it produces overestimated values of internal consistency reliability. As a compromise, both the Cronbach's alpha and composite reliability are applied to find the true value of internal consistency reliability between their values (Hair et al., 2017a).

Dijkstra and Henseler (2015) propose a further compromise that gives a more accurate measure of internal consistency. Rho_A is acknowledged as a modern measure of internal consistency in PLS-SEM studies (Hair et al., 2019a; Wong, 2019) and studies apply it (Chin et al., 2020) to evaluate internal consistency. All three measures are evaluated at a minimum value of 0.7, while a rho_A value of more than 1 should not occur in the model.

Results in Table 6.5 demonstrate that the internal consistency reliability is established:

- The composite reliability values range from 0.840 (for the digital health community use construct) to 0.930 (empowerment), which are all greater than 0.7.
- All values of Cronbach's alpha are within the acceptable range (>0.60), as they vary from 0.651 to 0.901; the lowest is the emotional contagion construct, while the highest value is for nurturant support.
- Additionally, all values of rho_A are above 0.70, with the lowest being 0.725 for the digital health community use construct and the highest being 0.938 for social support.

So, results across the three methods all confirm that the items meet acceptable internal consistency reliability.

Construct	Internal consistency reliability		
	Cronbach's Alpha	rho_A	Composite Reliability
Digital Health Community Use	0.547	0.623	0.732
Emotional Contagion	0.458	0.293	0.685
Empowerment	0.899	0.900	0.930
Experiential Expertise	0.796	0.830	0.918
Facilitator Support	0.899	0.904	0.929
Social Network Fatigue	0.886	0.937	0.920
Self-Disclosure	0.798	0.819	0.867
Social Overload	0.875	0.916	0.912
Informational Support	0.796	0.837	0.906
Nurturant Support	0.901	0.907	0.927

Table 6.5 Item Reliability for the LOCs

b) Indicator Reliability

Indicator reliability demonstrates the degree to which associated indicators have a lot in common that is shown by the latent construct. It is shown by loadings, whose values should preferably be calculated at a significance level of 0.05. So, the outer loadings of all indicators must be significant statistically. As a rule, a construct should account for at least 50% of the variance of each item, so the minimum loading for each item is 0.708 (which gives 0.50 when squared), though 0.70 is commonly accepted (Hair et al., 2017a).

Outer loadings that are lower than the acceptable value of 0.70 may cause the removal of the affected indicator. However, Mackenzie et al. (2011) caution that such deletion should only be done if it improves the composite reliability (reported in Table 6.5) and the average variance extracted of the constructs (reported in Table 6.7). It should also consider how the content validity of the construct will be affected to avoid having a construct that no longer measures what it purports to (Moore & Benbasat, 1991). On the other hand, outer loadings that are higher than the threshold suggest that indicators may be having a lot of commonalities (Hair et al., 2019b).

Table 6.6 presents outer loadings and shows that some values are below 0.70, specifically indicators in digital health community use, emotional contagion and experiential expertise. Using guidance provided by Mackenzie et al. (2011), indicators UOD1, UOD3, ECO1, EEX4 were dropped to improve composite reliability and average variance extracted. The improved values are reported later in section 6.2.3 when validating the higher-order construct.

Constructs	**Items**	**Loadings**
Digital Health Community Use	UOD1	0.701
	UOD2	0.830
	UOD3	0.205
	UOD4	0.644
	UOD5	0.525
Emotional contagion	ECO1	0.425
	ECO2	0.643
	ECO3	0.525
	ECO4	0.763
Empowerment	EMP1	0.824
	EMP2	0.868
	EMP3	0.907
	EMP4	0.905
Experiential expertise	EEX1	0.838
	EEX2	0.899
	EEX3	0.865
	EEX4	0.535
Facilitator Support	FAS1	0.894
	FAS2	0.878
	FAS3	0.867
	FAS4	0.862
Self-Disclosure	SDI1	0.763
	SDI2	0.880
	SDI3	0.786
	SDI4	0.718
Social network fatigue	SNF1	0.759
	SNF2	0.861
	SNF3	0.935
	SNF4	0.890
Social overload	SOV1	0.891
	SOV2	0.878
	SOV3	0.796
	SOV4	0.834
Informational support	SSINF2	0.885
	SSINF4	0.935
Nurturant support	SSEMO1	0.777
	SSEMO3	0.827
	SSEMO5	0.901
	SSEST6	0.875
	SSEST8	0.849

Table 6.6 Indicator Loadings for LOC

c) Convergent Validity

Convergent validity is a type of construct validity that evaluates the extent to which two constructs correlate or are theoretically related to each other. It is assessed by examining the average variance extracted (AVE). Indicators achieve an acceptable convergent validity when the AVE is higher than 0.50, while the outer loadings of indicators are higher than 0.7 (Hair et al., 2011; Hair et al., 2019b).

Except for two constructs (digital health community use and emotional contagion), the AVE values for most are above 0.5 (Table 6.7). So, the AVE values range from 0.363 (emotional contagion) to 0.828 (informational support). Those with low AVE values also have low outer loadings, and do not have good convergent validity. The rest of the constructs have good convergent validity; hence items are reliable. The next section presents the discriminant validity evaluations between constructs.

Construct		**Average Variance Extract (AVE)**
Digital Health Community Use	UOD	0.383
Emotional contagion	ECO	0.363
Empowerment	EMP	0.768
Experiential expertise	EEX	0.637
Facilitator Support	FAS	0.766
Self-Disclosure	SDI	0.623
Social network fatigue	SNF	0.746
Social overload	SOV	0.723
Informational support	SSINF	0.828
Nurturant support	SSNUR	0.717

Table 6.7 Average Variance Extract for LOC

6.2.2 Discriminant Validity Assessment

Discriminant validity is assessed through different approaches, some of which are considered to be conventional while others are contemporary. Henseler et al. (2015) cast doubts on the efficiency of cross-loadings and the Fornell-Larker criterion to establish discriminant validity, but some researchers still report them. Wong (2019) acknowledges them as the ‘classical approach’ to assessing discriminant validity, while the ‘modern approach’ is the use of HTMT, and advocates for the use of all.

In the Fornell-Larker criterion, discriminant validity is established when the correlation of constructs is less than the square root of their AVEs. When applying cross-loadings, the outer loadings of given constructs are greater than the cross-loadings on other constructs for discriminant validity to be realised. On the other hand, HTMT uses thresholds to explain discriminant validity. When HTMT=0.90, constructs are very similar conceptually; if HTMT>0.90, there is no discriminant validity; and when HTMT<=0.85, the constructs are conceptually dissimilar. The Fornell-Larcker criterion operates on the notion that a construct’s variance is explained more by its associated indicators than other constructs (Hair et al., 2019b). To benefit from the classical and modern methods, this section reports and discusses all three approaches as determinants of discriminant validity in PLS-SEM.

a) Cross Loadings

The output of item cross-loadings is presented in Table 6.8. All indicators load higher against their respective constructs compared to others. Moreover, the loading of individual blocks is greater than loadings found in similar columns and rows (Henseler et al., 2015). This result verifies that the measurement model has discriminant validity.

	ECO	EEX	EMP	FAS	SDI	SNF	SOV	SSNUR	SSINF	UOD
ECO1	**0.425**	0.411	0.382	0.285	0.318	-0.131	-0.106	0.372	0.317	0.279
ECO2	**0.643**	0.169	0.154	0.051	0.115	0.106	0.471	0.104	0.065	0.226
ECO3	**0.525**	0.104	0.127	0.022	0.031	0.161	0.476	0.062	0.031	0.158
ECO4	**0.763**	0.372	0.321	0.255	0.239	-0.193	0.322	0.309	0.298	0.388
EEX1	0.389	**0.838**	0.679	0.444	0.358	-0.378	-0.007	0.667	0.728	0.565
EEX2	0.392	**0.899**	0.677	0.494	0.341	-0.276	0.030	0.636	0.599	0.531
EEX3	0.395	**0.865**	0.691	0.447	0.289	-0.279	-0.014	0.530	0.528	0.482
EEX4	0.567	**0.535**	0.448	0.375	0.566	-0.112	0.225	0.570	0.396	0.467
EMP1	0.373	0.634	**0.824**	0.446	0.311	-0.237	0.119	0.611	0.539	0.465
EMP2	0.432	0.746	**0.868**	0.545	0.397	-0.261	0.112	0.621	0.644	0.541
EMP3	0.428	0.680	**0.907**	0.375	0.424	-0.223	0.151	0.568	0.465	0.464
EMP4	0.450	0.711	**0.905**	0.410	0.359	-0.234	0.173	0.564	0.498	0.480
FAS1	0.281	0.477	0.456	**0.894**	0.536	-0.196	0.105	0.650	0.567	0.426
FAS2	0.313	0.592	0.537	**0.878**	0.526	-0.201	0.146	0.691	0.579	0.477
FAS3	0.283	0.452	0.383	**0.867**	0.468	-0.085	0.100	0.562	0.464	0.388
FAS4	0.278	0.397	0.386	**0.862**	0.468	-0.280	0.043	0.582	0.563	0.380
SDI1	0.270	0.292	0.277	0.414	**0.763**	-0.067	0.238	0.498	0.424	0.358
SDI2	0.336	0.487	0.418	0.550	**0.880**	-0.186	0.165	0.576	0.474	0.359
SDI3	0.171	0.208	0.236	0.300	**0.786**	0.020	0.005	0.361	0.345	0.211
SDI4	0.319	0.392	0.362	0.476	**0.718**	-0.114	0.153	0.464	0.360	0.373
SNF1	-0.133	-0.207	-0.159	-0.063	-0.091	**0.759**	0.219	-0.172	-0.056	-0.172
SNF2	-0.048	-0.214	-0.157	-0.201	-0.062	**0.861**	0.244	-0.204	-0.196	-0.201
SNF3	-0.113	-0.370	-0.278	-0.211	-0.089	**0.935**	0.376	-0.330	-0.261	-0.257
SNF4	-0.099	-0.351	-0.317	-0.248	-0.191	**0.890**	0.299	-0.402	-0.334	-0.259
SOV1	0.342	0.115	0.217	0.122	0.213	0.283	**0.891**	0.183	0.042	0.229
SOV2	0.326	0.005	0.139	0.110	0.216	0.336	**0.878**	0.091	0.073	0.138
SOV3	0.241	0.014	0.039	0.064	0.037	0.281	**0.796**	-0.044	-0.049	0.032
SOV4	0.378	0.018	0.095	0.078	0.137	0.240	**0.834**	0.057	-0.056	0.203
SSEMO1	0.388	0.613	0.580	0.466	0.407	-0.327	0.153	**0.777**	0.578	0.556
SSEMO3	0.291	0.530	0.484	0.549	0.520	-0.228	0.055	**0.827**	0.602	0.442
SSEMO5	0.344	0.686	0.615	0.683	0.581	-0.253	0.047	**0.901**	0.690	0.609
SSEST6	0.459	0.645	0.579	0.641	0.544	-0.302	0.154	**0.875**	0.652	0.570
SSEST8	0.363	0.677	0.589	0.660	0.551	-0.304	0.026	**0.849**	0.696	0.540
SSINF2	0.313	0.587	0.457	0.467	0.444	-0.216	-0.059	0.640	**0.885**	0.517
SSINF4	0.373	0.705	0.640	0.648	0.490	-0.256	0.066	0.740	**0.935**	0.609
UOD1	0.360	0.373	0.363	0.214	0.206	-0.293	0.139	0.428	0.326	**0.701**
UOD2	0.374	0.546	0.434	0.357	0.247	-0.187	0.123	0.513	0.489	**0.830**
UOD3	0.058	0.215	0.298	0.170	-0.071	-0.072	0.027	0.034	0.088	**0.205**
UOD4	0.403	0.319	0.303	0.344	0.418	-0.070	0.406	0.393	0.271	**0.644**
UOD5	0.207	0.446	0.349	0.361	0.343	-0.155	-0.132	0.437	0.592	**0.525**

Notes: ECO – Emotional Contagion; EEX – Experiential Expertise; EMP – Empowerment; FAS – Facilitator Support; SDI – Self-disclosure; SNF – Social network fatigue; SOV – Social Overload; SSNUR – Nurturant Support; SSINF – Informational support; UOD – Digital Health Community use

Table 6.8 Discriminant Validity by Cross Loadings in LOCs *b) Fornell-Larcker*

Table 6.9 shows the result of the Fornell-Larcker analysis where the bolded values are the square roots of AVEs and the ones below are the construct correlations. As the results indicate, all square root values are larger, showing that discriminant validity using the Fornell-Larcker criterion is met. Information support (SSINF) has a value of 0.910, which is >0.90 so there is no discriminant validity.

	UOD	ECO	EMP	EEX	FAS	SSINF	SSNUR	SDI	SNF	SOV
UOD	**0.618**									
ECO	0.488	**0.602**								
EMP	0.558	0.481	**0.877**							
EEX	0.639	0.525	0.792	**0.798**						
FAS	0.480	0.331	0.508	0.553	**0.875**					
SSINF	0.624	0.380	0.614	0.716	0.624	**0.910**				
SSNUR	0.645	0.437	0.675	0.748	0.714	0.763	**0.847**			
SDI	0.425	0.362	0.426	0.462	0.573	0.517	0.617	**0.789**		
SNF	-0.262	-0.112	-0.273	-0.340	-0.220	-0.268	-0.334	-0.129	**0.864**	
SOV	0.186	0.379	0.158	0.054	0.115	0.019	0.101	0.189	0.336	**0.851**

Notes: UOD – Digital Health Community use; ECO – Emotional Contagion; EMP – Empowerment; EEX – Experiential Expertise; FAS – Facilitator Support; SSINF – Informational Support; SSNUR – Nurturant Support; SDI – Self-disclosure; SNF – Social Network Fatigue; SOV – Social Overload; SSU – Social Support

Table 6.9 Fornell-Larcker Criterion Analysis in LOCs

This table also shows that experiential expertise has a high, positive correlation with empowerment while informal support and nurturant support have a moderate, positive correlation with empowerment. The correlation with empowerment further reduces in self-disclosure (low and positive), then social overload which has a very low and positive correlation. Social network fatigue has a negligible, negative correlation with empowerment.

c) HTMT values

The bias-corrected and accelerated (BCa) confidence interval method derived from complete bootstrapping comprises the limit that HTMT<0.90, and therefore it is regarded as the appropriate indicator of discriminant validity (Henseler et al., 2015). As

Table 6.10 shows, most of the constructs exhibit conceptual dissimilarity, as they have HTMT<=0.85. Even though experiential expertise and nurturant support constructs have values above 0.85, they are still below the required threshold of 0.90, and are, therefore, conceptually dissimilar. However, there is no discriminant validity between experiential expertise and empowerment as well as digital health community use, as their values are 0.961 and 0.935 respectively.

	UOD	ECO	EMP	EEX	FAS	SSINF	SSNUR	SDI	SNF	SOV
UOD										
ECO	0.583									
EMP	0.765	0.441								
EEX	0.961	0.532	0.935							
FAS	0.630	0.290	0.558	0.654						
SSINF	0.838	0.341	0.710	0.890	0.719					
SSNUR	0.820	0.379	0.748	0.897	0.783	0.892				
SDI	0.620	0.353	0.482	0.589	0.648	0.635	0.707			
SNF	0.354	0.267	0.296	0.394	0.233	0.289	0.360	0.177		
SOV	0.376	0.627	0.163	0.135	0.122	0.090	0.132	0.221	0.372	

Notes: UOD – Digital Health Community use; ECO – Emotional Contagion; EMP – Empowerment; EEX – Experiential Expertise; FAS – Facilitator Support; SSINF – Informational Support; SSNUR – Nurturant Support; SDI – Self-disclosure; SNF – Social Network Fatigue; SOV – Social Overload

Table 6.10 Discriminant Validity using HTMT in LOCs

Having established the reliability and validity of the lower-order constructs, the next section considers how to validate the higher-order construct, which is social support.

6.2.3 Validating Higher-Order Construct

Social support is assessed for reliability and convergent validity, which are reported in Table 6.11, Table 6.12 and Table 6.13. It is also assessed and evaluated for discriminant validity, which, according to Sarstedt et al. (2019), is overlooked by most researchers when evaluating higher-order constructs. Therefore, Tables 6.14, 6.15 and 6.16 report the outcome of the assessment using cross-loadings, Fornell-Larcker, and HTMT.

i) Reliability

a) Internal Consistency Reliability

Construct	Internal consistency reliability		
	Cronbach's Alpha	rho_A	Composite Reliability
Social Support	0.865	0.874	0.937

Table 6.11 Reliability with internal consistency reliability – HOC

With reliability values above 0.70, the social support construct has good reliability.

b) Indicator Reliability

Construct	**Items**	**Loadings**
Social Support	SSINF	0.931
	SSNUR	0.946

Table 6.12 Reliability with indicator reliability – HOC

The loadings values show good indicator reliability.

c) Convergent Validity

Construct		**AVE**
Social Support	SSU	0.881

Table 6.13 Reliability with convergent validity – HOC

Since the AVE is higher than 0.50, the items measuring social support converge very well.

ii) Discriminant Validity

The discriminant validity of social support is established through the use of the Fornell-Larcker criterion (Table 6.14), cross-loadings (Table 6.15) and HTMT values (Table 6.16).

a) Fornell-Larcker Criterion

	UOD	ECO	EMP	EEX	FAS	SDI	SNF	SOV	SSU
UOD	**0.797**								
ECO	0.393	**0.856**							
EMP	0.465	0.295	**0.876**						
EEX	0.452	0.269	0.769	**0.889**					
FAS	0.385	0.203	0.510	0.520	**0.875**				
SDI	0.360	0.220	0.428	0.373	0.575	**0.788**			
SNF	-0.230	-0.089	-0.280	-0.354	-0.226	-0.135	**0.862**		
SOV	0.280	0.439	0.161	0.004	0.115	0.213	0.334	**0.849**	
SSU	0.550	0.269	0.689	0.735	0.715	0.607	-0.329	0.066	**0.939**

Table 6.14 Discriminant Validity with Fornell-Larcker

For all constructs in Table 6.14, the highlighted value (the square root of AVEs) is greater than the correlations with other constructs. So, the higher-order construct has good discriminant validity.

b) Cross Loadings

	ECO	EEX	EMP	FAS	SDI	SNF	SOV	SSU	UOD
ECO2	**0.787**	0.116	0.154	0.051	0.115	0.105	0.476	0.091	0.290
ECO4	**0.920**	0.308	0.322	0.256	0.239	-0.193	0.321	0.323	0.374
EEX1	0.247	**0.848**	0.680	0.444	0.360	-0.382	-0.005	0.741	0.396
EEX2	0.279	**0.920**	0.677	0.494	0.343	-0.282	0.029	0.658	0.426
EEX3	0.191	**0.896**	0.692	0.447	0.292	-0.283	-0.014	0.564	0.382
EMP1	0.240	0.598	**0.822**	0.446	0.312	-0.244	0.125	0.615	0.411
EMP2	0.273	0.745	**0.871**	0.545	0.398	-0.270	0.114	0.672	0.412
EMP3	0.238	0.654	**0.906**	0.375	0.425	-0.230	0.155	0.553	0.378
EMP4	0.281	0.685	**0.904**	0.410	0.361	-0.236	0.173	0.568	0.429
FAS1	0.216	0.442	0.457	**0.895**	0.537	-0.203	0.103	0.651	0.336
FAS2	0.169	0.554	0.538	**0.877**	0.527	-0.207	0.150	0.679	0.418
FAS3	0.128	0.425	0.384	**0.866**	0.470	-0.087	0.098	0.549	0.327
FAS4	0.192	0.384	0.387	**0.862**	0.470	-0.284	0.043	0.610	0.256
SDI1	0.179	0.176	0.277	0.414	**0.758**	-0.073	0.246	0.493	0.308
SDI2	0.266	0.413	0.419	0.550	**0.882**	-0.191	0.163	0.562	0.306
SDI3	0.099	0.137	0.235	0.300	**0.783**	0.009	0.004	0.376	0.151
SDI4	0.113	0.356	0.362	0.476	**0.722**	-0.109	0.159	0.442	0.325
SNF1	-0.059	-0.195	-0.159	-0.063	-0.093	**0.739**	0.212	-0.125	-0.216
SNF2	-0.052	-0.248	-0.157	-0.202	-0.063	**0.853**	0.241	-0.213	-0.163
SNF3	-0.105	-0.382	-0.278	-0.211	-0.091	**0.936**	0.372	-0.317	-0.206
SNF4	-0.082	-0.345	-0.317	-0.249	-0.191	**0.906**	0.297	-0.394	-0.216
SOV1	0.352	0.066	0.217	0.122	0.213	0.284	**0.898**	0.124	0.309
SOV2	0.404	-0.046	0.139	0.111	0.216	0.337	**0.867**	0.088	0.206
SOV3	0.338	-0.001	0.039	0.064	0.038	0.284	**0.775**	-0.049	0.086
SOV4	0.413	-0.034	0.095	0.078	0.138	0.245	**0.853**	0.004	0.284
SSINF	0.239	0.695	0.615	0.624	0.515	-0.271	0.011	**0.931**	0.464
SSNUR	0.264	0.687	0.675	0.714	0.618	-0.343	0.107	**0.946**	0.562
UOD1	0.327	0.311	0.364	0.214	0.206	-0.293	0.146	0.405	**0.792**
UOD2	0.324	0.516	0.434	0.357	0.247	-0.187	0.135	0.534	**0.828**
UOD4	0.289	0.220	0.303	0.343	0.419	-0.069	0.412	0.357	**0.770**

Table 6.15 Discriminant Validity with Crossloadings

Results in Table 6.15 show that items measuring a specific construct loads better for the same construct than others, which means that the discriminant validity of the higher-order construct, social support, is established.

c) HTMT Values

	UOD	ECO	EMP	EEX	FAS	SDI	SNF	SOV	SSU
UOD									
ECO	0.566								
EMP	0.573	0.360							
EEX	0.556	0.328	0.869						
FAS	0.472	0.231	0.558	0.584					
SDI	0.463	0.269	0.482	0.413	0.648				
SNF	0.291	0.228	0.296	0.388	0.233	0.177			
SOV	0.347	0.613	0.163	0.060	0.122	0.221	0.372		
SSU	0.685	0.320	0.778	0.852	0.804	0.710	0.345	0.107	

Table 6.16 Discriminant Validity with HTMT – HOC

The HTMT is based on correlations as well, where its value should be less than 0.90 (Henseler et al., 2015). Results on Table 6.16 show that the discriminant validity is established for all constructs, as the HTMT values are all less than the threshold.

The foregoing analyses establish that the measurement model has acceptable reliability and validity. The next section briefly describes the significance of a model's predictive features, which contribute to the discussion of the structural model that follows.

6.3 Structural Model Analysis

A structural PLS-SEM analysis follows four critical steps (Hair et al., 2019a), which include determining a research aim (as specified in Chapter 1), specifying the structural model, specifying the measurement model, and estimating the model, and evaluating the results.

The structural model analysis is based on evaluation and interpretion of hypotheses results based on the path coefficients and their significance, as well as the predictive capabilities as explained by effect size (f^2), the predictive relevance (Q^2), and the coefficient of determination (R^2). It also evaluates the Standard Root Mean Square Residual (SRMR) which is used to ascertain a measure of fit, and the importance-performance matrix analysis (IPMA) which gives performance of critical factors in empowering informal carers.

6.3.1 Predictive Capabilities of the Model

a) *Coefficient of Determination (R^2)*

A model is assessed based on the coefficient of determination (R^2) of a dependent variable, which is a gauge of a model's predictive power. A model's goodness is decided by how strong each structural psrath is, shown by this coefficient, where $R^2 >= 0.1$ (Hair et al., 2017a). A high value of R^2 explains the variance of the endogenous variable well, as it improves the predictive capacity of the structural model. The output of analysis presented in Figure 6.3, shows that the use of digital health communities in the presence of facilitator support explains 65.7 percent of the variance in social support, 36.3 percent in self-disclosure, 48.1 percent of the variance in experiential expertise, 11.0 percent of the variance in social overload, 12.2 percent of the variance in social network fatigue and 17.2 percent of the variance in emotional contagion. All the above-mentioned mediators and the independent variable combine to explain 66.6 percent of the variance in empowerment. The R^2 values are summarised in Table 6.17.

Since all the R^2 values are over 0.1, the model has a good predictive capability. The enablers (those theorised to contribute positively to empowerment) have higher R^2 values that are moderate and above, while the inhibitors (theorised to impact empowerment negatively) have lower R^2 values that are weak (Hair et al., 2017a).

b) *Effect Size (f^2)*

The study also considers the f^2 value to quantify the effects observed. The f^2 values show the substantive impact on the outcome variable (empowerment) when a specified exogenous variable is omitted from the model (Hair et al., 2017a). According to Cohen (1988), f^2 values of 0.02, 0.15, and 0.35 represent small, medium, and large effect; and an effect size of less than 0.02 shows no effect. In cases where the effect sizes may be too small to negligible, there is advocacy for use of a standard which proposes more realistic, lower values - 0.005, 0.01, and 0.025 to represent small, medium, and large effect sizes respectively (Ramayah et al., 2018). This study employs Cohen's (1988) standard.

c) *Predictive Relevance (Q^2)*

The predictive relevance of the model is assessed by employing the blindfolding procedure in SmartPLS 3, which gives Stone-Geisser's Q^2 value (Hair et al., 2019b). Blindfolding is done at a specified omission distance, *D,* which should preferably be between 5 and 10. A Q^2 value that is higher than 0 suggests that the model has predictive relevance for the examined variables (Hair et al., 2017a). Using an omission distance of 8, the Q^2 values in the model are as displayed in Table 6.17 below. Therefore, the model has predictive relevance.

	R^2	Q^2
Emotional Contagion	0.172	0.033
Empowerment	0.666	0.481
Experiential Expertise	0.481	0.347
Self-Disclosure	0.363	0.190
Social Network Fatigue	0.122	0.050
Social Overload	0.110	0.057
Social Support	0.657	0.429

Table 6.17 The R^2 and Q^2 values

d) *Standardised Root Mean Square Residual (SRMR)*

The Standardised Root Mean Square Residual is also utilised to ascertain a measure of fit. A good fit is a value less than 0.10, and the employment of bootstrap-based tests indicates that the SRMR values do not exceed 0.08 ($SRMR<0.08$). The SRMR for the model in this study is 0.078, which is below the value of 0.10. The result indicates that the model has a good and acceptable fit (Hair et al., 2017a).

6.3.2 Path Coefficients

As further assessment of the goodness of fit, hypotheses are tested to establish the significance of relationships in the model. The structural model path coefficients represent route location and size of hypothesised relationships between constructs. Their value usually ranges from -1 to +1, with larger values signifying strong, positive relationships and smaller values representing weak relationships. The significance of a coefficient, or its lack, depends on standard error, which is found by applying bootstrapping procedures (Hair et al., 2017b). They enable the computation of *p*-values and *t*-values for all path coefficients.

A *t*-value that is greater than the critical value indicates a statistically significant coefficient at a specified significance level. The output in this study is calculated with a *one-tailed* test at a significance level of 5%, and the associated critical value is 1.65, so any t-value lower than that connotes a statistically non-significant coefficient. The *p*-value can also be utilised to evaluate the significance level, and it is described as the probability that one can assume the path coefficient to be significant when it is not. So, with a significance level of 5% that is used in this study, the *p*-values must be less than 0.05 for the relationship to be considered significant (Hair et al., 2017a).

6.3.2.1 Hypotheses Testing

The effect of DHC use on empowerment is tested directly (H1), and through mediators (H2-H7). The relationships between the independent variable and mediators are studied through hypotheses labelled 'a' and those between the mediators and the dependent variable are explored through hypotheses labelled 'b'. Figure 6.3 shows the path relationships obtained when testing these hypotheses. The relationships are also shown in structural model SmartPLS 3 diagrams in appendix 6 and appendix 7.

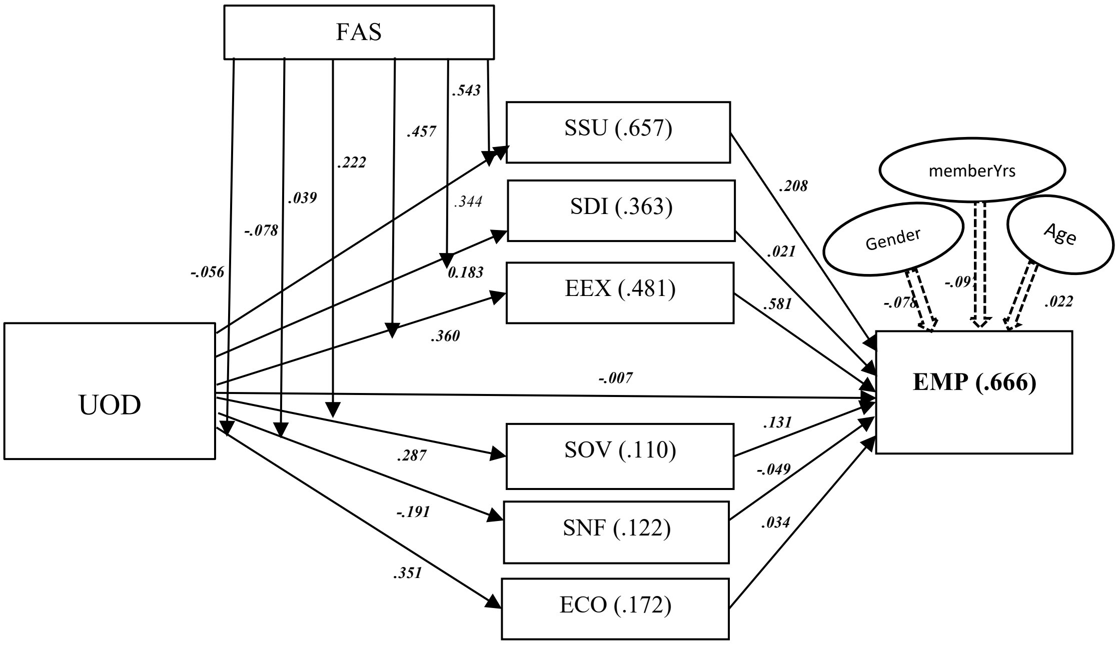


Figure 6.3 The Effect of Digital Health Community Use on Empowerment

H1: *The use of digital health communities has a positive effect on the empowerment of informal carers of people with mental illness.*

H1 evaluates whether digital health community use has a positive effect on the empowerment of carers or not. The results show that using digital health communities among informal carers has a negative effect, which is not significant, on their empowerment (β= -0.007, t= 0.101, p=0.460), f^2 = 0.000. Hence H1 is not supported.

First Set (H2a-H7a):

H2a: *The use of digital health communities has a positive effect on social support.*

H2a evaluates whether digital health community use has a significant effect on social support. The results show that utilising digital health communities by carers has a significant positive effect on their empowerment (β= 0.344, t= 5.756, p=0.000), f^2 = 0.287; H2a is supported.

H3a: *The use of digital health communities has a positive effect on self-disclosure.*

H3a evaluates whether digital health community use has a significant effect on self-disclosure. The results show that the use of digital health communities by carers has a significant positive effect on their empowerment (β= 0.183, t= 2.374, p=0.009), f^2 = 0.043; H3a is supported.

H4a: *The use of digital health communities has a positive effect on experiential expertise.*

H4a evaluates whether digital health community use has a significant and positive effect on experiential expertise. The results show that utilising digital health communities by carers has a significant positive effect on their empowerment (β= 0.360, t= 5.213, p=0.000), f^2 = 0.207. Therefore, H4a is supported.

H5a: *The use of digital health communities has a positive effect on social overload.*

H5a evaluates whether digital health community use has a significant effect on social overload. The results show that utilising digital health communities by carers has a significant positive effect on social overload (β= 0.287, t= 2.665, p=0.004), f^2 = 0.076. H5a is supported.

H6a: *The use of digital health communities has a positive effect on social network fatigue.*

H6a evaluates whether digital health community use has a significant and positive effect on social network fatigue. The results show that utilising digital health communities by carers has a significant and negative effect on their empowerment (β= -0.191, t= 1.732, p=0.042), f^2 = 0.035. H6a is, therefore, supported.

H7a: *The use of digital health communities has a negative effect on emotional contagion.*

H7a evaluates whether digital health community use has a significant and positive effect on emotional contagion. The results show that utilising digital health communities by carers has a positive and significant effect on their empowerment (β= 0.351, t= 3.419, p=0.000), f^2 = 0.126. Hence H7a is supported.

Second Set (H2b-H7b):

H2b: *Social support has a positive effect on the empowerment of informal carers of people with mental illness.*

H2b evaluates whether social support has a positive and significant effect on empowerment. The results show that social support, as information and nurturant support, has a positive effect on their empowerment (β= 0.208, t= 1.840, p=0.033), f^2 = 0.036; H2b is supported.

H3b: *Self-disclosure has a positive effect on the empowerment of informal carers of people with mental illness.*

H3b evaluates whether self-disclosure has a positive and significant effect on empowerment. The results show that self-disclosure has a positive but non-significant effect on their empowerment (β= 0.021 t=0.254, p=0.400), f^2 = 0.001; H3b is not supported.

H4b: *Experiential expertise has a positive effect on the empowerment of informal carers of people with mental illness.*

H4b evaluates whether experiential expertise has a positive and significant effect on empowerment. The results show that experiential expertise has a positive effect on their empowerment (β= 0.581 t= 6.179, p=0.000), f^2 = 0.431; H4b is supported.

H5b: *Social overload has a negative effect on the empowerment of informal carers of people with mental illness.*

H5b evaluates whether social overload has a negative and significant effect on empowerment. The results show that social overload has a positive and significant effect on their empowerment (β= 0.131, t= 1.725, p=0.043), f^2 = 0.028; H5b is not supported.

H6b: *Social network fatigue has a negative effect on the empowerment of informal carers of people with mental illness.*

H6b evaluates whether social network fatigue has a negative and significant effect on empowerment. The results show that social network fatigue has a negative, and non-significant effect on their empowerment (β= -0.049, t= 0.685, p=0.247), f^2 = 0.005; H6b is not supported.

H7b: *Emotional contagion has a negative effect on the empowerment of informal carers of people with mental illness.*

H7b evaluates whether emotional contagion has a negative and significant effect on empowerment. The results show that emotional contagion has a positive effect, which is significant on their empowerment (β= 0.034, t= 0.396, p=0.346), f^2 = 0.002; H7b is not supported.

The study controls for the effects of age, gender, and a carer's years of membership in the Carers' digital health community. All three factors have no significant effect on the empowerment of carers due to digital health communities'use.

6.3.2.2 Moderation Analysis

A moderator is a construct that can alter a relationship between an independent and a dependent construct, and its impact varies according to the level of the moderator (Ramayah et al., 2018). It interacts in a manner that enables it to have an impact on the level of the dependent construct, stipulating the terms under which an effect takes place. Moderation analysis investigates how a relationship between a dependent and an independent construct can be altered by a moderator, establishing the conditions in which the strength of an effect differs (Ramayah et al., 2018). In PLS-SEM, moderation analysis entails the use of interaction terms, which can be studied using three different approaches – product-indicator, two-stage and orthogonalzing. This study utilises the product-indicator approach, which multiplies each indicator of the independent construct by individual indicators of the moderator. The approach has a higher prediction accuracy than the other two approaches, and is most suitable for a study with reflective constructs (Chin et al., 2003).

In the analysis of moderation, the change in R^2 is important. Table 6.18 below shows the change in R^2 when the model is run without the interaction term, UOD*FAS, (R^2 excluded), and when it is run with the interaction term (R^2 included), showing the interaction effect. This change gives the effect size of moderation, which is an estimate of a manually calculated f^2 using the formula:

$$f^2 = \frac{R^2 \text{ included} - R^2 \text{ excluded}}{1 - R^2 \text{included}}$$

(Ramayah et al. 2018)

The significance of the interaction effect is determined by running a bootstrapping procedure and noting the t-values at a significance level of 5% (1.645). Table 6.18 displays the resulting R^2, f^2 and t-values.

	R^2, excluded	R^2, included	f^2	Effect size	t-value
UOD*FAS-ECO	0.137	0.172	0.050	Small	0.947
UOD*FAS-EEX	0.345	0.481	0.265	Medium	5.125
UOD*FAS-SDI	0.283	0.363	0.017	Small	1.036
UOD*FAS-SNF	0.078	0.122	0.055	Small	0.586
UOD*FAS-SOV	0.095	0.110	0.016	Small	0.462
UOD*FAS-SSU	0.638	0.657	0.060	Small	1.800

Table 6.18 The effect size of moderation

The effect sizes are assessed using the ranking suggested by Cohen (1988), which stipulates that an effect of 0.02 is small, 0.15 is medium, and 0.35 is large; at less than 0.02, there is no effect. Most of the effect sizes in this study are low (see Table 6.18), but it does not mean that the effects are negligible. In fact, Chin et al. (2003) propose that if the resultant beta coefficients are significant, so can moderation effects. For example, social support has a small effect and t-value=1.800, while experiential expertise has a medium effect and t-value=5.125; both effects are significant since their t-values>1.645.

To further expound the moderation analysis, interaction graphs are plotted showing two-way interaction effects for standardised constructs. The standardised beta coefficients approach is chosen because professional facilitator support (moderator) is a continuous measurement. The interpretation of each graph (for hypothesis H8a to H8f) is based on the gradient of the slope and significant result of the t-value (Ramayah et al., 2018).

H8a: *The positive relationship between digital health community use and social support is stronger at high levels of professional facilitator support.*

The hypothesis seeks to establish the moderating role of professional facilitator support between digital health community use and social support. The outcome indicates that facilitator support positively moderates the relationship between use and social support (β=0.146, t=1.800, p=0.036). In high levels of facilitator support, social support increases much more with increased digital health community use. At low levels, the graph is flatter, showing that the relationship is weakened (Figure 6.4). Therefore, professional facilitator support strengthens the positive relationship between digital health community use and social support; hence, H8a is supported.

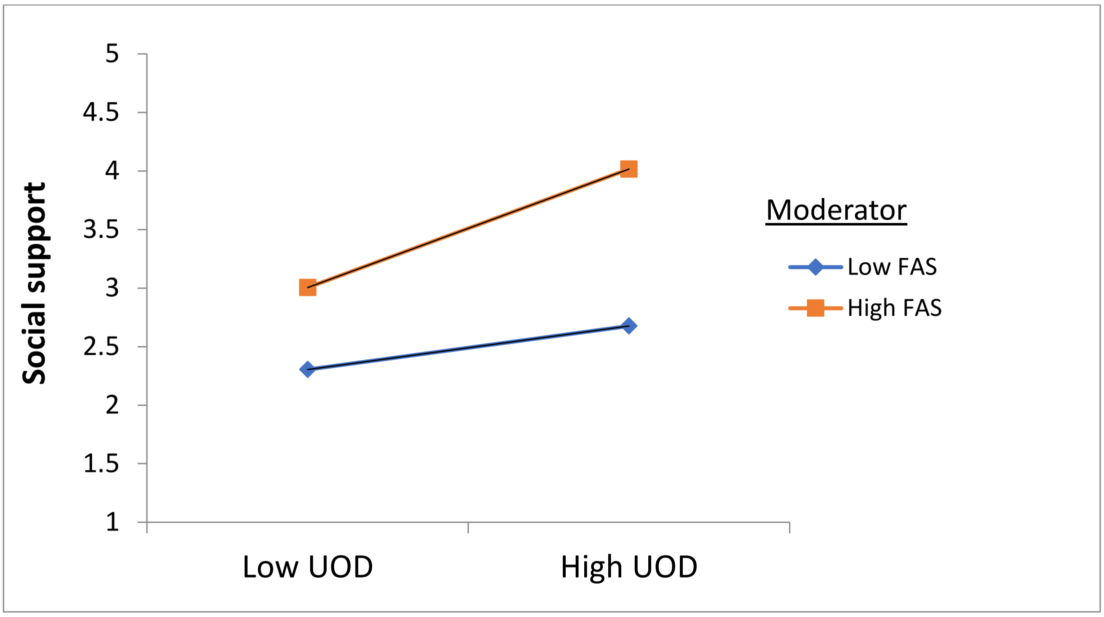


Figure 6.4 Moderating effect of facilitator support on social support

H8b: *The positive relationship between digital health community use and self-disclosure is stronger at high levels of professional facilitator support.*

The hypothesis seeks to establish the moderating role of facilitator support between digital health community use and self-disclosure. The outcome indicates that facilitator support positively moderates the relationship between use and self-disclosure, and the relationship is stronger at high levels of facilitation. In low facilitator support, self-disclosure increases minimally with increasing digital health community use, but at higher levels of facilitator support, the increase is steeper (Figure 6.5). Since the t-value is less than 1.645, the moderation effect is not significant (β=0.106, t=1.036, p=0.150), so H8b is not supported.

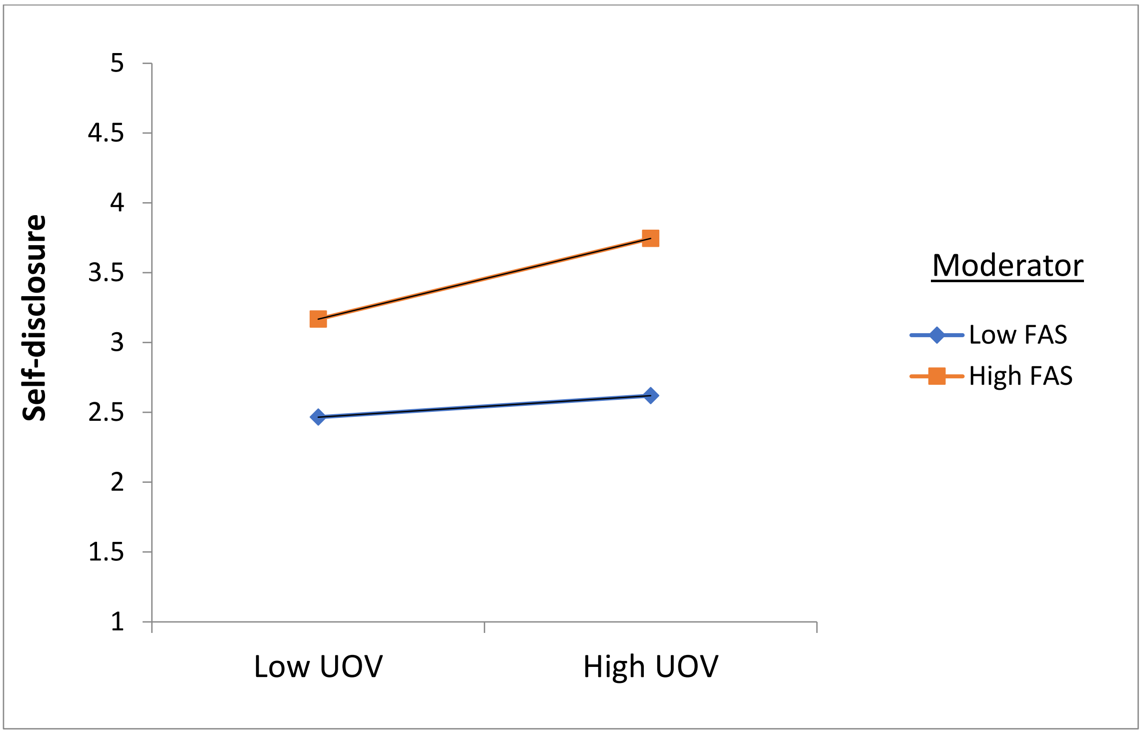


Figure 6.5 Moderating effect of facilitator support on self-disclosure

H8c: *The positive relationship between digital health community use and experiential expertise is stronger at high levels of professional facilitator support.*

The hypothesis seeks to establish the moderating role of facilitator support between digital health community use and experiential expertise. The outcome indicates that facilitator support moderates the relationship between use and experiential expertise (β=0.369, t=5.125, p=0.000). From Figure 6.6, experiential expertise increases with intensifying digital health community use at high levels of professional facilitator support. At lower levels of facilitator support, increasing digital health community use has no impact on experiential expertise. It can be concluded that facilitator support strengthens the positive relationship between digital health community use and experiential expertise. Since t-value>1.645, H8c is supported.

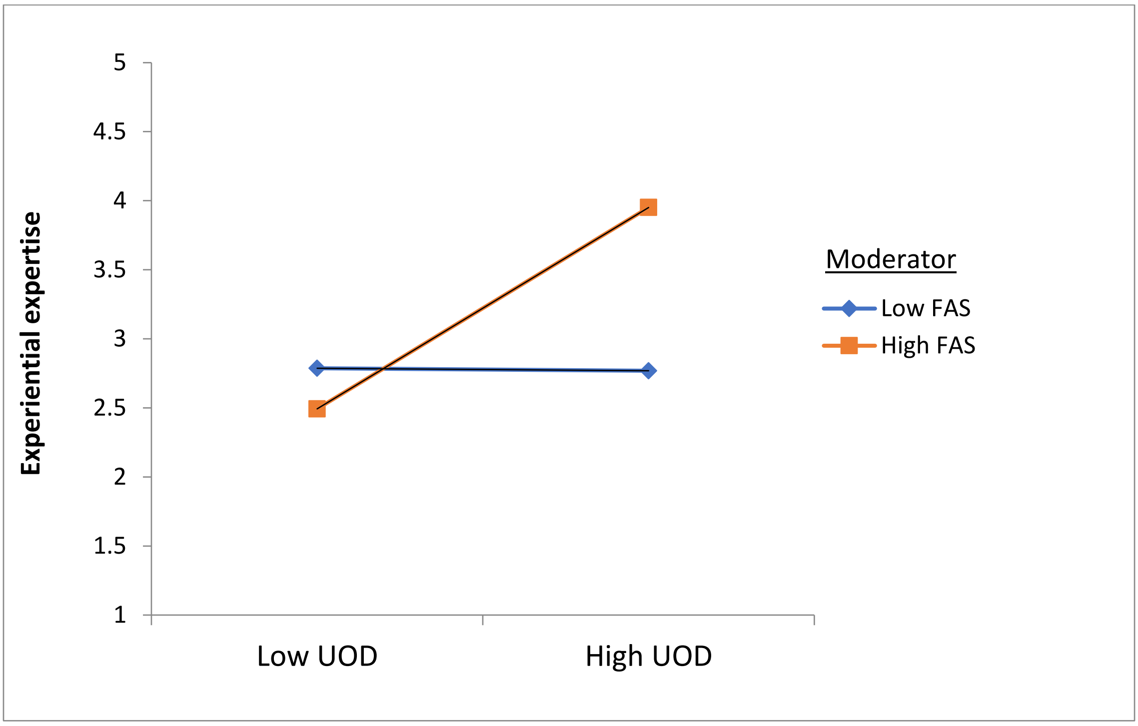


Figure 6.6 Moderating effect of facilitator support on experiential expertise

H8d: *The positive relationship between digital health community use and social overload is weaker at high levels of professional facilitator support.*

The hypothesis seeks to establish the moderating role of facilitator support between digital health community use and social overload. The outcome reveals that facilitator support moderates the relationship between use and social overload (β=-0.103, t=0.462, p=0.322). Figure 6.7 shows a steeper graph at lower than higher facilitator support. Therefore, facilitator support dampens the positive relationship between digital health community use and social overload; but since t<1.645, H8d is not supported.

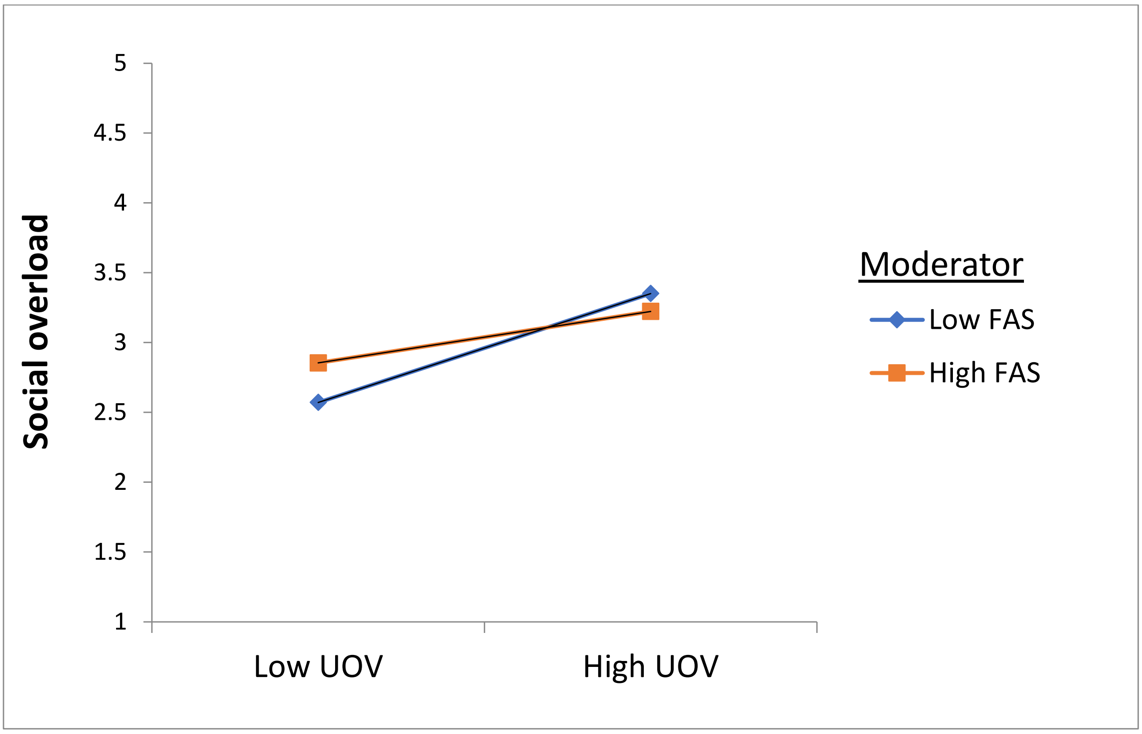


Figure 6.7 Moderating effect of facilitator support on social overload

H8e: *The positive relationship between digital health community use and social network fatigue is weaker at high levels of professional facilitator support.*

The hypothesis seeks to establish the moderating role of facilitator support between digital health community use and social network fatigue. The outcome indicates that this relationship is negative and is moderated by high levels of facilitator support (β=-0.191, t=0.586, p=0.279). The moderation is shown by the steep graph, while in low support the graph is constant because social network fatigue is not affected by increased use of digital health community (Figure 6.8). Facilitator support strengthens the negative relationship between digital health community use and social network fatigue, and with t-value<1.645 also, H8e is not supported.

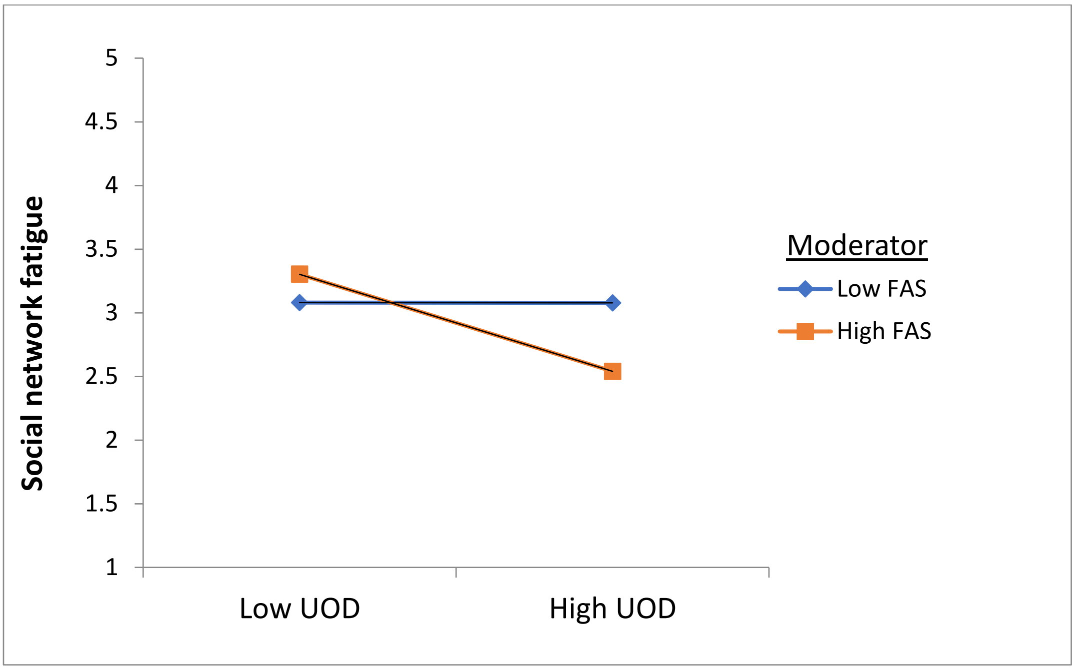


Figure 6.8 Moderating effect of facilitator support on social networking fatigue

H8f: *The positive relationship between digital health community use and emotional contagion is weaker at high levels of professional facilitator support.*

The hypothesis seeks to establish the moderating role of facilitator support between digital health community use and emotional contagion. The outcome reveals that the positive relationship between use and emotional contagion is strengthened by moderation (β=0.225, t=0.947, p=0.172). Figure 6.9 shows a steep gradient in high facilitator support; hence it reinforces the relationship rather than weaken it as hypothesised. As a result, H8f is not supported.

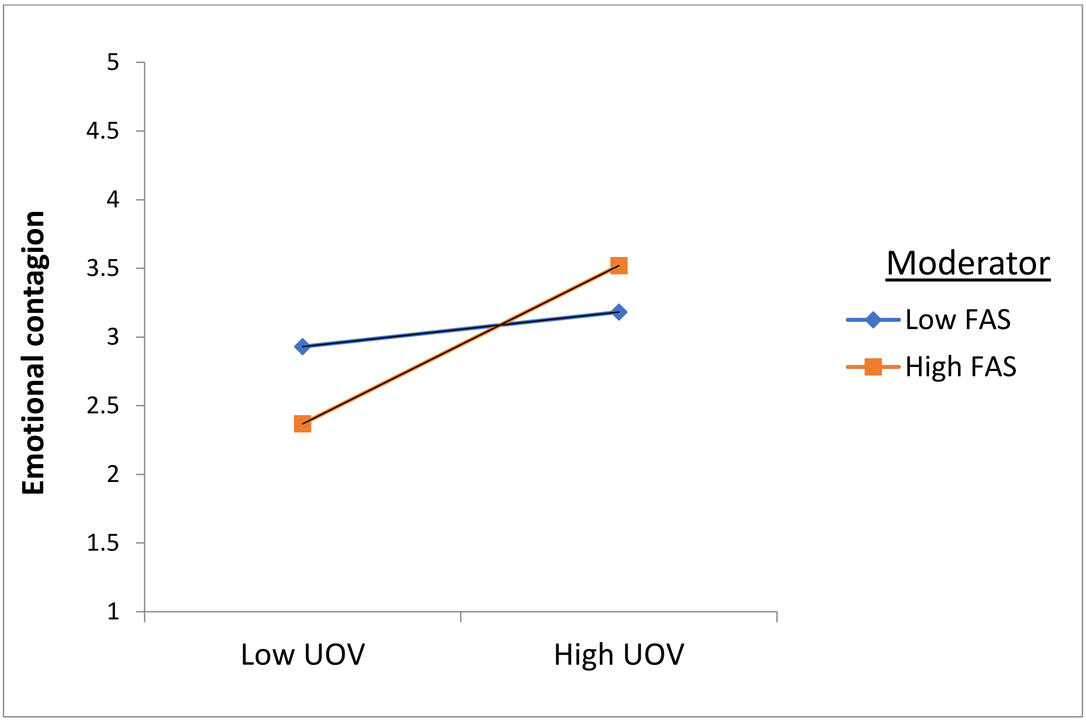


Figure 6.9 Moderating effect of facilitator support on emotional contagion

Table 6.19 below gives a summary of the path relationships, with an indication of whether the hypotheses are supported or not. From the foregoing presentation of results, H8a and H8c are the only supported hypotheses. That is, professional facilitator support only moderates the relationships between digital health community use and social support and experiential expertise. The three control variables have no impact on empowerment.

Path Relationship		Path Coeff.	*t*-stat.	P Value	effect size (f^2)	Path significant?
H1	DHC use → empowerment	-0.007	0.101	0.460	0.000	No
H2a	DHC use → social support	0.344	5.756	0.000	0.287	Yes
H2b	Social support → empowerment	0.208	1.840	0.033	0.036	Yes
H3a	DHC use → self-disclosure	0.183	2.374	0.009	0.043	Yes
H3b	Self-disclosure → empowerment	0.021	0.254	0.400	0.001	No
H4a	DHC use → experiential expertise	0.360	5.213	0.000	0.207	Yes
H4b	Experiential expertise → empowerment	0.581	6.179	0.000	0.431	Yes
H5a	DHC use → social overload	0.287	2.665	0.004	0.076	Yes
H5b	Social overload → empowerment	0.131	1.725	0.043	0.028	No
H6a	DHC use → social network fatigue	-0.191	1.732	0.042	0.035	Yes
H6b	Social network fatigue → empowerment	-0.049	0.685	0.247	0.005	No
H7a	DHC use → emotional contagion	0.351	3.419	0.000	0.126	Yes
H7b	Emotional contagion → empowerment	0.034	0.396	0.346	0.002	No
H8a	UOD*FAS → social support	0.146	1.800	0.036	0.060	Yes
H8b	UOD*FAS → self-disclosure	0.106	1.036	0.150	0.017	No
H8c	UOD*FAS → experiential expertise	0.369	5.125	0.000	0.265	Yes
H8d	UOD*FAS → social overload	-0.103	0.462	0.322	0.016	No
H8e	UOD*FAS → social network fatigue	-0.191	0.586	0.279	0.055	No
H8f	UOD*FAS → emotional contagion	0.225	0.947	0.172	0.050	No
Control Variables						
Age → empowerment		0.022	0.292	0.385	0.001	n.s
Gender → empowerment		-0.078	1.303	0.097	0.016	n.s
Member Yrs → empowerment		-0.097	1.535	0.063	0.023	n.s
Notes: ** p<0.01 * p<0.05 n.s – not significant UOD (Digital Health Community Use) * FAS (Facilitator support) is labelled as the interaction variable showing a moderating effect in the structural model in Figure 6.3						

Table 6.19 Results showing path relationships, p-values and f^2 (H1-H8)

Summary of hypotheses:

The hypotheses of the study are summarised in Table 6.20, with and indication of whether they are supported or not:

	Hypothesis	**Supported?**
H1	The use of digital health communities has a positive effect on the empowerment of informal carers of people with mental illness.	No
H2a	The use of digital health communities has a positive effect on social support.	Yes
H2b	Social support has a positive effect on the empowerment of informal carers of people with mental illness.	Yes
H3a	The use of digital health communities has a positive effect on self-disclosure.	Yes
H3b	Self-disclosure has a positive effect on the empowerment of informal carers of people with mental illness.	No
H4a	The use of digital health communities has a positive effect on experiential expertise.	Yes
H4b	Experiential expertise has a positive effect on the empowerment of informal carers of people with mental illness.	Yes
H5a	The use of digital health communities has a positive effect on social overload.	Yes
H5b	Social overload has a negative effect on the empowerment of informal carers of people with mental illness.	No
H6a	The use of digital health communities has a positive effect on social network fatigue.	Yes
H6b	Social network fatigue has a negative effect on the empowerment of informal carers of people with mental illness.	No
H7a	The use of digital health communities has a positive effect on emotional contagion.	Yes
H7b	Emotional contagion has a negative effect on the empowerment of informal carers of people with mental illness.	No
H8a	The positive relationship between digital health community use and social support is stronger at high levels of professional facilitator support.	Yes
H8b	The positive relationship between digital health community use and self-disclosure is stronger at high levels of professional facilitator support.	No
H8c	The positive relationship between digital health community use and experiential expertise is stronger at high levels of professional facilitator support.	Yes
H8d	The positive relationship between digital health community use and social overload is weaker at high levels of professional facilitator support.	No
H8e	The positive relationship between digital health community use and social network fatigue is weaker at high levels of professional facilitator support.	No
H8f	The positive relationship between digital health community use and emotional contagion is weaker at high levels of professional facilitator support.	No

Table 6.20 Summary of hypotheses

6.4 Post-hoc Analysis

In addition to assessing the measurement and structural models, SmartPLS 3 has some features which go beyond reporting the path coefficient estimates discussed in section 6.3.2 above. This section considers two such features – multiple mediation analyses (because the study model has many mediators) and Importance-Performance Matrix Analysis (IPMA).

6.4.1 Multiple Mediation Analyses

The analysis of mediation explains the relationship between an independent and a dependent variable through another variable (Wong, 2019). That is, it explains the mechanism by which a mediator affects an indirect relationship, thereby causing an indirect effect. The indirect effect, together with the direct effect, make up the total effect (Wong, 2019). As portrayed by Figure 6.3, the model in this study has mediators, so mediation analysis is an essential part of the report as it will assist to evaluate their mediating role. Additionally, the model has several mediators, so a multiple mediation analysis has to be conducted (Hair et al., 2017a).

The analysis of mediation always starts with testing indirect effects, which can be computed using this approach:

$$\text{indirect effect } (a.b) = \text{total effect}(c)\text{-direct effect } (c')$$

where *c* is the total effect, as opposed to the mediated effect. A PLS model allows computation of the effects of all mediators at the same time because it can handle the effects of mediators on each other. So it is not necessary to test a separate model to get the total effect *c* (Nitzl et al., 2016). Table 6.21 below presents the significance analysis of both direct and indirect effects, as obtained from bootstrapping. The type of mediation was determined by the use of a decision tree depicted in Figure 6.10, and is adopted from Hair et al. (2017a).

Path Rel	Indirect effect	*t*-stat	p value	Signf	Direct effect	*t*-stat	P	Signf	a*b*c	Mediation type
SSU -> EMP	0.064	1.652	0.045	Yes	0.184	1.653	0.049	Yes	0.012	Complementary (partial med)
SDI -> EMP	0.007	0.459	0.323	No	0.034	0.492	0.311	No	0.000	No effect (No mediation)
SOV -> EMP	0.036	1.386	0.083	No	0.131	1.795	0.037	Yes	0.005	Direct only (no mediation)
EEX -> EMP	0.211	4.081	0.000	Yes	0.581	0.585	0.000	Yes	0.123	Complementary (partial med)
SNF -> EMP	0.010	0.700	0.242	No	-0.052	0.783	0.217	No	-0.001	No effect (No mediation)
ECO -> EMP	0.011	0.354	0.362	No	0.030	0.377	0.353	No	0.000	No effect (No mediation)

Table 6.21 Significance Analysis of Mediation Effects

The social support to empowerment path relationship is moderate and statistically significant (t=1.840; p=0.033). Using the mediation analysis in Figure 6.10, we deduce that social support and experiential expertise partially mediate their relationship with empowerment. Self-disclosure, social network fatigue, and emotional contagion have no mediation effects at all; while social overload has a direct effect only, and no mediation.

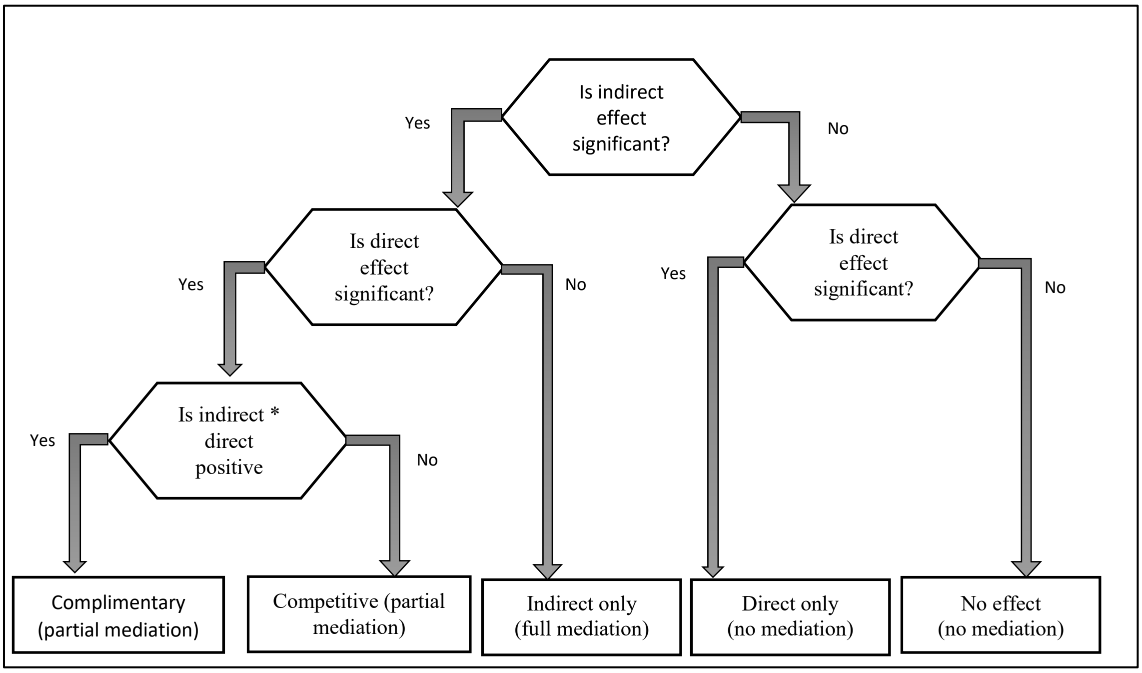


Figure 6.10 Mediation Analysis Procedure

Adopted from Hair et al., (2017a)

6.4.2 Importance-Performance Matrix Analysis (IPMA)

The IPMA compares the total effects (importance) of variables with the average values of latent variables (performance). This way, the IPMA helps identify predecessor variables that have a high importance for the outcome variable (Hair et al., 2017a). Precisely, the IPMA compares the total effects of the structural model on empowerment with the scores of the mediator variables. Table 6.22 and Figure 6.11 show that the most important constructs influencing empowerment are experiential expertise followed by digital health community use, social support and social overload. The effect of the other constructs on empowerment are negligible. Furthermore, the effects of social network fatigue on empowerment are indirect. The effects of experiential expertise, social support and digital health community use are direct and positive, meaning that an increase in any of these constructs leads to an increase in empowerment.

Particularly, this analysis shows the importance and performance of digital health community use and specific support exchanges that shape carer empowerment. The technique allows us to identify key areas of improvement that an organisation such as SANE can address or use to guide decision-making in developing and managing digital health communities. The IPMA results are reported in Table 6.22 and presented in Figure 6.11.

Predecessor Construct	**Direct Effects on empowerment**	**Indirect Effects on empowerment**	**Importance (Total Effects)**	**Performances**	**Priority**
Digital Health Community Use	0.341	0.344	0.336	67	Low
Emotional contagion	0.034	-	0.034	61	very low
Experiential expertise	0.584	-	0.584	38	High
Self-disclosure	0.038	-	0.038	36	very low
Social network fatigue	-0.049	-	-0.049	60	very low
Social support	0.208	-	0.208	36	Low
Social overload	0.131	-	0.131	64	Low
Facilitator support	-	0.262	0.262	38	Low

Table 6.22 IPMA Analysis for Empowerment

The predecessor factors in Table 6.22 together with the control factors (age, gender, memberYrs) are plotted in the importance-performance map below (Figure 6.11).

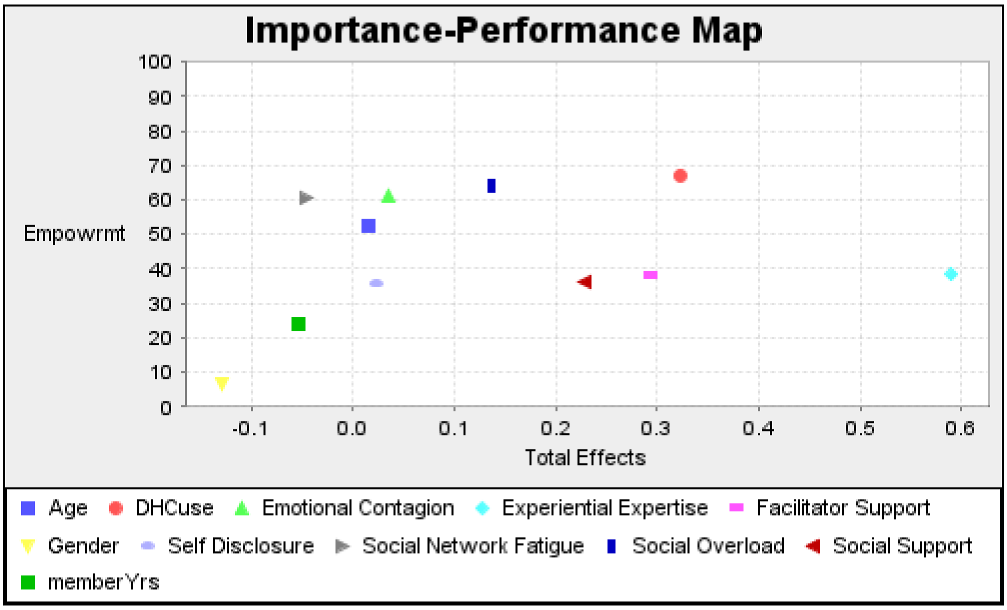


Figure 6.11 The Importance-Performance Map for Empowerment

As shown in Table 6.22, experiential expertise is a priority factor that platform managers need to consider. This predecessor has high importance (i.e., high total effects) of 0.584 although it has a relatively low performance in enabling carer empowerment. Therefore, a one-unit increase in experiential expertise from 38 to 39 would increase the performance of carer empowerment by 0.57 points from 43.34 to 43.91. Other predecessors are considered a low priority because increasing their performance will not yield a substantial increase in the performance of carer empowerment.

6.5 Chapter Summary

This chapter presents the analysis of quantitative data. All constructs have good convergent validity, all items meet acceptable internal consistency reliability, all indicators are reliable, all constructs are empirically distinct and conceptually similar, with good discriminant validity. Findings show that experiential expertise and social support are strong predictors of empowerment of carers. They also show a partial mediation of the same constructs. Social overload does not inhibit empowerment as predicted, and although it has no mediation effect on the use-empowerment relationship, it has a direct effect. While digital health community use has a significant and positive effect on all mediator constructs except social network fatigue, the moderation analysis shows that facilitator support moderates social support and experiential expertise.

The results also show that all the three control variables have no significant effect on carer empowerment. A Q^2 value of 0.481 suggests that the model has predictive relevance, and the effect of experiential expertise on empowerment is large, while that of social support is medium. Experiential expertise and social support both have a significant positive effect on carer empowerment. The results are discussed in detail in the next Chapter 7.

CHAPTER 7: DISCUSSION

7 Overview

The aim of this study is to investigate how the use of digital health technologies enables the empowerment of carers to make decisions, specifically when the digital health communities are facilitated. It investigates twenty hypotheses, most of which are supported. The results show that usage of digital health communities by carers enables their empowerment. This chapter interprets the findings presented in the previous Chapters 5 and 6 and integrates them to give context while answering the research questions presented in Chapter 1. It concludes with a suggestion of the theoretical and practical implications of the findings.

Employing mixed methods with a quantitative approach alongside qualitative output gives a deep understanding of empowerment from numerous angles. The combining of methods allows the study to find similarities and compare differences in digital health communities as utilised by informal carers. The use of quantitative methods complements qualitative results, and this triangulation augments information quality and offers confirmation. Therefore, qualitative research emphasises cause-effect association to reveal the intricate interrelationships of a phenomenon like empowerment. It also aids the build-up of arguments within a context like digital health communities, consequently extending knowledge about them using a real-life context of the Carers forum of SANE Australia, without applying any controls on the setting. Notwithstanding, the outcome from the two approaches may not validate each other but they may highlight new insights into the concept of digital health communities' use.

Given the setting of a study population that is scattered around Australia, the researcher is not able to study the entire population but has depended on a self-selecting group of respondents to the survey. They acted as the study sample that represents the target group. In the case of the qualitative part of the study, online observation requires a researcher to be immersed in the study context, therefore the researcher registered as a member of the forum to have an opportunity to observe interactions over the Carers forum. The study subjects, informal carers, provide a relevant case for empowerment because of their need for information about the condition of their care recipients and how to manage it; as mentioned, they end up suffering from role stress and are socially isolated as they are with their care recipients all the time, which affects their decision-making. This section, therefore, discusses answers to the two main research questions:

> **RQ1**. How does the use of digital health communities enable the empowerment of informal carers?
>
> **RQ2**. How does professional facilitator support affect empowerment through digital health community use?

Table 7.1 below shows how the research concepts developed through the different phases of the exploratory, complementary method, and the research questions they covered.

Review of extant literature	**Qualitative Results**		**Quantitative Results**
	Expert Interviews (RQ1.1)	*Content analysis (RQ1.1 & RQ2)*	*Survey (RQ1.2 & RQ2)*
Participation in OHCs	VHC use	DHC use	DHC use
Knowledge creation & exchange	Experiential knowledge	Experiential expertise	Experiential expertise
Social support	Social support	Social support	Social support
Social overload	Social overload	Self-disclosure	Social overload
Moderator/Facilitator	Emotional contagion	Support overload	Emotional contagion
	Moderator support	Facilitator support	Facilitator support
		Social network fatigue	Social network fatigue
			Self-disclosure

Table 7.1. Development of the concepts across the qual-quant phases

7.1 Evidence for Empowerment in Digital Health Communities

This section answers the first part of question 1.

> **RQ1**. How does the use of digital health communities enable the empowerment of informal carers?
>
> > RQ1.1 What evidence exists for the empowerment of informal carers in digital health communities?

To establish what empowerment means, the question is tackled by firstly using extant literature to identify concepts that relate to digital health community use and empowerment. The concepts are then explored with IS experts in interviews, to establish if they make sense in the study of empowerment in digital health communities. This search for concept relevance is encouraged, especially when investigating unfamiliar user behaviours (Ajzen, 1991) like empowerment. The identified concepts include social support, digital health community use, the role of moderator, social overload and experiential expertise, emotional contagion. In the next phase of the sequential study (content analysis), some concepts are dropped from the investigation, as it is permissible to pick what aspects of the results to use in a sequential study (Creswell & Clark, 2018). The final list of concepts investigated in the content analysis includes social support, which has been identified by much research like Hill et al. (2015) digital health community use, which has also been studied by Johnston et al. (2013) and Grehling and Maier (2021); experiential expertise, which Shepherd et al. (2018) discussed in a position paper, and has been least studied as an outcome of systems use. The notion of self-disclosure was also identified as relevant to study empowerment in digital health communities; this is line with works of researchers like Huang (2016) who studied self-disclosure in the context of informational disclosure. These three are identified as enabling resources. The next three concepts are identified as inhibiting resources: support overload [constructed from social overload by (Maier et al., 2015a)], emotional contagion (Coviello et al., 2014), and social network fatigue (Zhang et al., 2016).

To further address this question, the thesis conceptualises empowerment in digital health communities by exploring its components, using the qualitative approach of content analysis. Results show evidence of more intrapersonal empowerment, followed by behavioural, affective, and interactional empowerment in that order (Table 7.2).

Component	Intrapersonal	Interactional	Behavioural	Affective
Percentage	11.4%	7.1%	8.6%	8.4%
Sample post	*It must be schizo - how do I get an adult person help if he refuses?*	*I am feeling less alone in this caring and supportive community*	*For me, it's about living well despite the diagnosis, rather than focusing on the diagnosis.*	*Grateful for this forum, I couldn't tell this to anyone. Happy to type.*

Table 7.2 Occurrence of empowerment across its dimensions and sample posts

The prevalence of intrapersonal empowerment in digital health communities is evidenced by previous research done applying the concept. As highlighted by van Dop et al., (2016), a search of extant literature shows that there is more research done applying intrapersonal empowerment followed by interactional empowerment (van Dop et al., 2016) which is about the level to which carers believe in their abilities, competencies and control and motivation to influence their situations research.

It emerges that in addition to the known intrapersonal, interactional, and behavioural dimensions of empowerment, digital health communities possess functional attributes which facilitate empowerment that addresses users' emotions, giving them the confidence to make decisions and carry out tasks. For instance, carers assert:

> *"The posts on this forum have given me hope, I am now able to help my son."*
>
> *"I was an emotional wreck before I came here, and used to find it hard to decide for my health."*

By their own admission, carers confirm that the emotional support offered by the forum functionalities boosted their moods and changed their trajectory of decision-making. This function of the digital health community to address the carers' emotions is not captured in empowerment literature, yet it addresses an important perspective of technology use. Bødker (2017) contends that exploring utilisation of technology should incorporate users' experienced truths and emotions, otherwise it would be irrelevant technology. The idea finds relevance in the technologies we use on a daily basis, which have become an essential component of everyday life. Sadovykh et al. (2015) have also echoed the need to find a link between emotional support to daily activities like decision-making and technology, arguing that technology is now more social than technical.

The additional dimension gives empowerment a wholesome and holistic view, enabled by voluminous resources which are not available in offline empowerment; it also acknowledges the contribution of digital health communities to decision-making. Moreover, it gives IS researchers a reason to examine the notion further, and how it relates to existing empowerment dimensions.

Findings also highlight the behavioural dimension of empowerment, which has evidence in this study although it is generally sparsely explored (Petrič et al., 2015). It is explained by the confirmation of carers to have made a decision after some forum interactions. This dimension is explained by coping of carers, both adaptive and maladaptive. A carer shows adaptive coping when they display behaviour or act in a way that shows they have accepted their situation of caring, when they joke about their caring duties and circumstances, if they engage in some hobby or sport or go on a holiday to do some fun and relaxing activities, or intentionally seeking emotional support (even from professionals) (Lin et al., 2021). On the other hand, maladaptive coping is when a carer adopts approaches that are 'not-so-useful' towards their situation; for example, ignoring their worries and not doing anything, blaming themselves for the situation, venting all the time, and discontinuing use (Lin et al., 2021).

As an example of adaptive coping, some carers in the forum usually share their family situation in a very humorous way. They cause such a positive ambiance with their post that every subsequent responder is amused about and comments on the funny remark more than its content, which lightens the mood of the discussion. For example, one carer shared:

> *"I can proudly raise my hand as the contributor of genes that gave our children MI."*

This finding confirms the different ways of coping that carers on the forum can benefit from, which others can emulate. Exposure to more adaptive than maladaptive coping approaches (described by Lin et al., 2021), can help carers to be positive in their care journey.

In the quantitative phase of the study, the empowerment variable was treated and analysed as a unidimensional construct, as an aggregate, rather than having the elements as indicators. Furthermore, this study specified empowerment as a reflective model, following the approach used by Miguel et.al (2015). However, Markwart et al. (2020) suggest using a formative model in their study of empowerment in adolescents.

7.2 How Use Enables Empowerment of Carers

This section answers the second part of question 1, which considers the effect of digital health community use on empowerment, having established what empowerment is in this digital health community.

The discussion draws from the earlier operationalisation of support exchanges as enabling and inhibiting resources (as discussed in Chapter 3), which are necessary for empowerment according to the empowerment theory. It presents how utilisation enables empowerment, and the contribution of resources to empowerment of carers.

> **RQ1**. How does the use of digital health communities enable the empowerment of informal carers?
>
> > RQ1.2 What is the effect of digital health community use on the empowerment of informal carers?

Results indicate that the direct relationship between digital health community use and empowerment has a negative effect. That is, carers do not get empowered by the use of the digital health community. This finding is supported by literature which submits that expected outcomes are compelling predictors of user actions (Mirzaei & Esmaeilzadeh, 2021), like digital health community use. Moreover, the result gives more evidence that carers expect to utilise the information from the digital health community to solve problems and make decisions, cope with care and have confidence in themselves as espoused in carer empowerment (Lin & Chang, 2018).

The next section details how the mediators and moderator contributed to care empowerment. As theorised in Chapter 3, and basing on the empowerment theory, digital health community use generates enabling and inhibiting resources, under the assumption that they are all generated at the same time. All the hypotheses predict a positive relationship between digital health community use and the resources, so we assume that an increase in one causes an increase in the other. Nevertheless, the study acknowledges that some are intended or desired consequences of digital health community use (enabling resources), while others are unintended consequences of digital health community use (inhibiting resources).

7.2.1 Enabling resources

a) Social support

From the qualitative findings, empowerment in the Carers' forum is shaped by social support, experiential expertise, self-disclosure, support overload, and social network fatigue. The findings show that more emotional support exists in this community than informational support, and esteem is the least prevalent support type in the Carers' forum. Notably, informational and emotional support are mostly solicited, but esteem support is given without solicitation from the one who receives it. The finding of more emotional support is corroborated by quantitative findings which show that social support has a significant and positive effect on empowerment. Further analysis operationalised social support as a higher-order construct, with informational and nurturant support as lower order constructs. Some extant literature actually categorises them the same way – where esteem and emotional support are recognised for their nurturing disposition and informational support provides information (Lin et al., 2015; Huang et al., 2019; Sharma & Khadka, 2019).

The social support generated by using the digital health community is strengthened by facilitator support, and in turn, social support enables empowerment. This partial mediation of social support on the DHC use -- empowerment relationship, confirms that social support is needed for carers empowerment, especially nurturant support, which has a larger and stronger effect on empowerment than informational support. Comparing t-values and path coefficients shows that, in general, nurturant support plays a more significant and important role in empowerment outcomes when compared to informational support. This provides important lessons for a self-help system that is used by carers dealing with mental illness – emotional support is more critical than just providing information to users (Li, Juang et.al 2017).

Apart from Huang et al. (2019) who obtained similar results as this study, most authors in IS literature emphasise that digital health communities are dominated by the exchange of informational support, especially patients in health communities (Sharma & Khadka, 2019). However, carers use the digital health community to escape social isolation and share their joys and tears; in the process, they get comfort and sympathy, which makes them come back for more. Emotional support may also be prevalent in this digital health community because carers need to manage their feelings because of role stress, but doctors are usually too busy for supportive conversations; they only have time to attend to the care recipient. So, carers rely largely on the digital health community for emotional support (Liu et al., 2020b).

b) Self-disclosure

One of the enabling resources of empowerment in this study is self-disclosure, which carers do willingly. From what they share about themselves, both information and emotions, it is evident that carers experience stressful events in their caring journey, and they reach out for help by disclosing their thoughts, feelings and opinions (Zhang et al., 2019). The content analysis confirms a heavy presence of self-disclosure in the conversations, which also include the social norms of thanking others for their support as well as courtesies of greeting others and/or bidding them farewell (Abedin et al., 2020).

Thread-starting posts (*ip* in Figure 5.2, Chapter 5) contain higher levels of self-disclosure, as observed also by Andalibi et al. (2018). Most carers disclose their caring journey challenges immediately after a diagnosis, sharing their perplexities about what to expect and how to deal with the condition of mental illness. Carers use the self-expression facility of self-disclosure to release the tension inside them and disclose their feelings and thoughts; in the process they receive social support from other carers (Zhang et al., 2019). The emotional disclosure they make mostly solicits emotional support and the informational disclosure contributes informational support, which enable carer empowerment. Moreover, as highlighted by Makri and Turner (2020), gratitude and social norms contribute positively to emotional support and encourage continued use of the digital community. As stated earlier, this Carers' forum has more emotional than informational support, which is explained also by self-disclosure. When people are appreciative, others are encouraged to continue contributing and others are encouraged to keep coming back to the digital health community for more support (Huang et al., 2019). This thesis has so far established that continued utilisation contributes more to empowerment than non-use.

Although facilitator support strengthens the ability of carers to disclose their feelings and opinions; statistically the effect of their self-disclosure on empowerment is not significant, although it is positive. This contrasts the theorisation that it significantly affects carer empowerment. A possible explanation to this deviation is that negative responses to disclosure harm the well-being of the discloser (Andalibi & Forte, 2018) and since the questions did not establish whether the carer gets negative responses to their disclosures, there is no evidence that they are not affected. The lack of significance may be due to the negative responses that affected the carers, who then feel out of control of the situation. There is also the possibility that there is a mismatch between support people seek, what they receive (Andalibi & Forte, 2018) and the effectiveness of the support; especially that the survey did not establish effectiveness of support. The questions did not have anything to do with evaluating the support received – whether it was relevant and supportive or not; the questions were on whether someone discloses. Further investigation will minimise options and hopefully establish explanations.

Considering an observation made by Andalibi and Forte (2018) that self-disclosure itself does not improve well-being (and by extrapolation, does not improve empowerment), it is noted that it is rather the social support other people get as a result of self-disclosing, which benefits the carers. Maybe there is no direct link with empowerment, it has to go through social support. One of the modern ways of communicating when one writes a text message, is by the use of emojis and emoticons, which carers also used in their self-disclosure posts as well as in regular support seeking or giving. They tend to communicate the same message as intended but graphically – in a shorter and quicker way. At this stage, the study did not do an analysis of the emojis and emoticons which were used in self-disclosure statements; therefore, some factors contributing to disclosure may have been overlooked.

c) Experiential expertise

The need for support from others with similar experiences highlights the importance of experiential expertise in aiding other carers' decision-making. Although the concept of sharing personal experiences has been in use for a long time, there is a notable absence of theoretical and conceptual clarity (Castro et al., 2019), more so in empowerment. Yet, it has significant promise for carers' participation in their empowerment.

**Digital validation :* One of the findings of the content analysis is that carers tag each other and facilitators tag carers to alert the one who is being tagged that there is someone who needs support – either informational or nurturant. The tagging (using @ before a name) is based solely on the fact that the one being tagged has a similar experience as the one seeking help. This endorsement gives credence to the support given by the tagged carer, making them credible and trustworthy experts in the matter at hand. Research suggests that an individual who has very similar experiences to the one seeking support tends to offer specialised help (LaValley et al. 2015), so tagging them increases their accessibility and visibility. This ensures that the right expert is brought on board to share their expertise on a discussion point, or a user needing support is called to the attention of the same. Another validation indicator is the up-vote or ‘like’ to show appreciation of the content. We posit that the self-care experiences as shared by individuals and other carers (by tagging) make a contribution to empowerment.

From the quantitative results, experiential expertise is the most effective social resource of carer empowerment. Evidently, sharing of experiences from others with similar issues or circumstances is highly esteemed. With the positive and significant effect of experiential expertise on empowerment, which is strengthened by facilitator support, it shows that the advice empowers more. The outcome is as expected because the experiences of other carers give those seeking support the confidence that they can also manage the challenges just like their peers, contributing to adaptive coping (Lin et al., 2021).

7.2.2 Inhibiting resources

d) Emotional contagion

Emotional contagion was not detectable in content analysis so the results discussed here are from the quantitative phase of the study. Digital health community use is associated with emotional contagion, which leads to a positive and non-significant effect on empowerment. With a weak effect of f^2 =0.002, emotional contagion is negligible. Possibly there are other inhibiting resources that may affect this digital health community than emotional contagion. The moderation analysis (β=0.005, t=0.041, p<0.001) shows a non-significant, positive moderating effect with very low t-value and p-value. One of the reasons for this outcome may have to do with the type of messages – some diffuse faster within a digital health community than others. Most of the time, carers exchange positive supportive messages, especially encouraging and nurturing ones, which do not invoke controversy. If, for some reason, someone expresses negative emotions, they are countered with social support. This observation contradicts a suggestion by Myrick et.al (2016) that negative messages move faster than positive ones; while it is echoed by Wang and Lee (2021). Wang and Lee (2021) propose that the diffusion of messages in a forum is also dependent on the way recipients receive the message being shared – if they liked it enough to share it, they pass it on, if not then it is not shared.

e) *Social Overload*

The content analysis of the Carers' forum discussions did not detect social overload, which, according to Maier et al. (2015a), is *giving* too much social support to others in the forum. Instead, the carers mention discomfort at *receiving* too much social support. Although carers come to the forum in search of social support, anything in excess causes an overload (Nawaz et al., 2018). Hence the suggestion that this is *support overload*. The occurrence may be explained by the fact that the Carers' forum provides more emotional than informational support, and unintentionally some carers 'care too much.'

From the quantitative results, social overload has a positive, significant effect on empowerment, contrary to the expectation that it has a negative effect as conceptualised in the study model. It is presented as a negative consequence of technology use (Maier et al. 2015b) and a personal resource of carer empowerment. Some possible reasons to explain the result include the fact that social overload triggers adaptive coping (Lin et al., 2021), and users are able to control it. They use the available resources in the forum to plan how to tackle the stressor (social overload), so it ends up having no effect on them.

Another possible explanation is that even if they report exhaustion and tiredness from role stress, carers also report contentment from caring – they report feeling rewarded, experiencing a sense of personal growth and satisfaction (Hawken et al., 2018). So, in the same way, they may be able to continue using the Carers' forum with the same positive mentality, resulting in negative effect to social overload. This possibility is strengthened by research findings which report that people continue to use social network sites even if they have negative emotional consequence from them (Sagioglou & Gretemeyer 2014).

Literature also suggests that older people have more experience in dealing with adverse stimuli (Ragu-Nathan et.al 2011), so even if they give a lot of support, they are still able to be positive about it. More than 60% of the study population are 46 years old and above, so they may be the population that is able to handle negative stimuli. In addition, the older forum members have more experience and have learnt some coping strategies in their caring journey, so they offer advice on the everyday challenges a carer is likely to face.

Finally, the outcome for social overload confirms that context matters. It is possible that there is need to re-consider the conceptualisation of 'social overload' within the context of digital health communities. The current approach of conceptualising it, is tailored for social networking sites (which was the platform studied by Maier et al. (2015a), and is not fitting the core function of a digital health community. In social networking sites, people meet for socialisation with friends and acquaintances (Chen et al., 2014), while digital health communities bring together complete strangers whose commonality is the health condition they are dealing with. So, they meet to interact about their health challenges, even though they may socialise a bit. These findings corroborate the qualitative results, strongly suggesting that social overload in digital health communities is a misfit of its goals and context.

f) *Social Network Fatigue*

Social network fatigue was observed from carers discussions when conducting online observations through content analysis. Most carers who expressed fatigue were exhausted by excessive use as well as inability to balance their duties and caring for themselves. Users experiencing social network fatigue perceive that the absence of facilitator support exerts a more positive effect on digital health community use. In other words, facilitator support is causing *less effect on the use of* digital health communities; as a result, the users *do not use the* digital health community, and do not *seek support.* One possible explanation is that users with no social network fatigue are more likely to use. Individuals affected with social network fatigue are likely to avoid that which is triggering them and so will not engage in using digital health communities if they are the source of the trigger [avoidance or maladaptive coping] (Lin et al., 2021). When someone's expectations are not met, their anxiety increases and social network fatigue results (Ravindran et al., 2014). This is likely in an asynchronous community where responses are typically delayed. Others are triggered by uninteresting discussions, excessive use of the digital health community and lack of interest in digital health community life (Ravindran et al., 2014). The latter explains the levels of use observed in a digital health community life cycle shown in Figure 3.1, Chapter 3). Findings showing negative effect imply that carers are able to find ways of dealing with social network fatigue.

Through the qualitative research, it emerged that carers' most needed competence is communication skills, as they have families and friends, health services providers, doctors, professional services providers, and the care recipient themselves to communicate with, specifically about the welfare of the care recipient. As observed in the carers' discussions, miscommunication has soured relations and made caring and acquiring services difficult (Li et al., 2019). It has also emerged that carers need support in one of their important daily tasks – decision-making, for and with the care recipients and for themselves. Possible empowerment for decision-making is not made easy by digital health communities which have challenges of information overload (Sadovykh et al., 2019a). Therefore, findings from this study may be a basis for further inquiry into decision-making in digital health communities.

7.3 Support of Professional Facilitator

RQ2: *How does the support of a professional facilitator affect empowerment through the use of digital health communities?*

Insights drawn from both qualitative and quantitative approaches indicate that professional facilitation does affect empowerment. Qualitative findings indicate that facilitators showed their presence in three modes – collaborative, commanding, and motivating. At any one time, depending on the needs of digital health community users, a facilitator exhibited presence in one or more approaches. For instance, they motivated carers to intentionally engage in self-care activities and prompted active participation when there is slack in forum activities, thereby using a motivating approach. When they advised on ways to communicate with care recipients or health care providers, they displayed a collaborative presence. These approaches were appreciated by most forum users for nurturing informative peer discussions and contributing to the success of and a positive culture within this digital health community. From these findings, we suggest that the collaborative and motivating approaches of facilitation contribute more to enabling resources, i.e. experiential expertise, self-disclosure, and social support.

The commanding presence, however, brought discontent to some forum users, especially those who were forced to either edit or remove inappropriate posts because they felt bridled from telling things as they are. As a result, some of the carers left the forum to use social media platforms which allowed *'more freedom'*, others took a protracted leave, while others took a temporary break from all digital forums. Although the facilitator could be correct in their decisions, the perceived political correctness may impede iteration for problem-solving and natural dialogue thereby resulting in discontinuance behaviour, which will negatively affect empowerment. Despite this possibility, we suggest that having fewer numbers of complaining carers may signal the effectiveness of rules and prove the necessity for professional facilitator support in minimising unhealthy information-seeking behaviours and promoting decision-making.

Results also demonstrate that facilitator support has a negative moderation effect on social network fatigue (Figure 6.8 in Chapter 6). This is contrary to expectations, because the hypothesis pre-empted increasing social network fatigue when one increases use. A possible explanation to this result is that social network fatigue triggers adaptive coping in carers, and its effect becomes negligible. As a result, carers will continue to use the digital health community because they perceive that facilitator support will improve their continued use of the digital health community.

Supported hypotheses:

H2a The use of digital health communities has a positive effect on social support.
H3a The use of digital health communities has a positive effect on self-disclosure
H4a The use of digital health communities has a positive effect on experiential expertise.
H5a The use of digital health communities has a positive effect on social overload.
H6a The use of digital health communities has a positive effect on social network fatigue.
H7a The use of digital health communities has a positive effect on emotional contagion.

H8a The positive relationship between digital health community use and social support is stronger at high levels of professional facilitator support.

H2b Social support has a positive effect on the empowerment of informal carers of people with mental illness.

H4b Experiential expertise has a positive effect on the empowerment of informal carers of people with mental illness.

H8c The positive relationship between digital health community use and experiential expertise is stronger at high levels of professional facilitator support.

Figure 7.1 below depicts the proposed empowerment framework in digital health communities derived from the study. The results presented in chapter 6 and the discussion in this chapter 7, indicate that social support and experiential expertise both show a positive and strong relationship when moderated and as mediators. Moreover, both experiential expertise and social support emerged as key priority factors that shape carer empowerment when evaluated with the IPMA. This means that a carer who utilises digital health communities will get social support and experiential expertise which can assist them in making decisions daily.

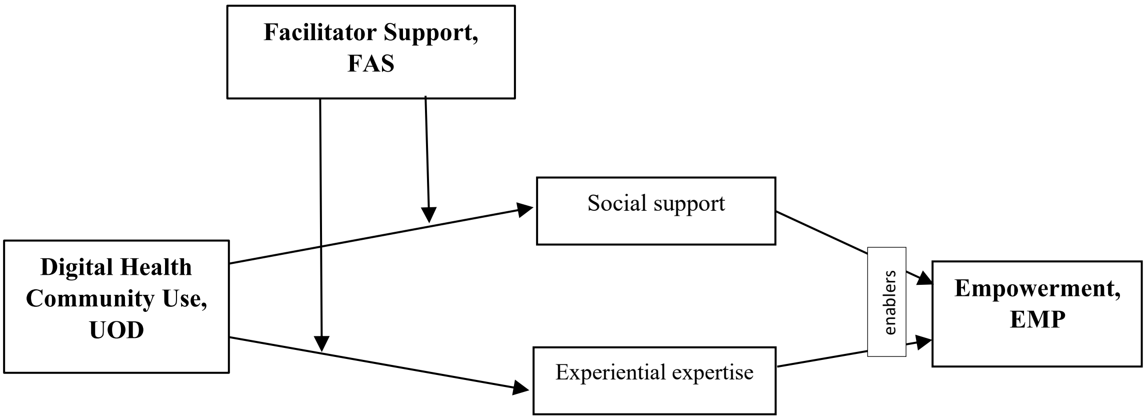


Figure 7.1 The Proposed IS-enabled Empowerment Framework

7.4 Theoretical and Practical Implications

7.4.1 Theoretical Implications

First, it adds to empowerment literature by highlighting the role of information systems in empowerment, especially that it has been only nominally covered in the past (Sadovykh & Sundaram, 2017). Several models of empowerment have been suggested in the literature (Oh & Lee, 2012; Johnston et al., 2013) and we build onto them to propose an information systems-enabled empowerment framework to explain the role of digital health communities in empowerment activities of informal carers. This study presents empirical evidence for digital health communities as an exceptional source of implicit knowledge that extends prescribed information resources for daily decision-making of carers of people with mental illness.

The study also adds to the operationalisation of the concept of empowerment. In addition to the existing intrapersonal, interactional and behavioural dimensions by Zimmerman (2000), empowerment in digital health communities has an *affective* dimension due to the functional properties of the technologies that attend to users' emotions. With advocacy for experiential computing where users' emotions need to be catered for by technology use (Bødker, 2017) in an era where people's online and off-line lives are intertwined (Boyd & Ellison, 2008), and subsequent acknowledgement of emotions in empowerment of technology users, including digital health communities (Yoo et al., 2014), the influence of this digital health community to users' positive emotions suggests the affective dimension of empowerment. This study results show a stronger effect of nurturant support on empowerment, compared to informational support. Hence, the contribution of emotions to empowerment backs the proposal for the affective dimension in empowerment.

The study empirically positions the carers' context of empowerment from their conversations, and the outcome fortifies the assertion that empowerment takes different forms for various people and contexts (Zimmerman, 2000; Hur et al., 2019). The social support types generated by this DHC were identified through the qualitative phase – emotional, esteem and informational support, and the experiential expertise shared in the digital health community both have a strong effect on empowerment of an under-researched cohort of stakeholders in healthcare – informal carers.

Finally, this study also extends the empowerment theory by categorising resources into personal and social, as a result of the dual effects of digital technologies as advocated by Abedin and Qahri-Saremi (2018). Inhibiting resources of digital health communities use have unintended consequences, while enabling resources have intended consequences on empowerment; the study's findings help explain how they each affect empowerment.

7.4.2 Practical Implications

The findings of this study have valuable, practical implications for stakeholders of digital health community use. Firstly, community administrators can highlight the benefits of the health communities to users, possibly by administrators may have a flashing notice on the website to catch the carers' attention when they visit the health community. Even before they read posts, newcomers would be assured that this digital health community is worth their time. This is important because for users to realise benefits of the digital health community, they must spend time on it and interact; so there has to be a catch to make them stay longer.

The results also show the importance of empowerment in carers through sharing experiences and social support. This finding provides a reason for facilitators of digital health communities to provide trustworthy, positive and beneficial information that emphasises nurturing and informing support. This may be attained by deliberately improving the available information to be exhaustive, accessible, of excellent quality, and available in formats that are attractive and easy-to-use. Attractive systems are likely to sustain and ensure continued use by carers, which positively affects empowerment. Administrators can also leverage the digital health communities to maximise exchange of experiential expertise, by developing the tagging system further. Tagging prompts carers with similar circumstances to respond to a query. The system can be improved to provide individualised assistance, especially to new carers, by assigning them an online buddy who can immediately assist the newcomer. This will improve response times for newcomers' queries because most come to the digital health community when they have a pressing need for assistance. Hopefully, it can also increase peer interactions for sharing of experiences and enhancing empowerment.

The study findings also give administrators a base for considering ways of encouraging sustained use, which will prolong interactions and consequent empowerment. For instance, when carers give feedback on the digital health community, administrators can improve their offerings. In this community, the system allows for up-votes only, there is no similar quick option to give other feedback, as such feedback may be currently one-sided. Permitting alternatives to up-votes may relieve facilitators, as carers will flag inapt posts, thereby reducing the time other carers can be subjected to potentially damaging content. Another option can be for posts to be rated by the carers, where they indicate how useful the post is. This will improve further the efficiency of information retrieval because highly rated posts will come up top during a search, making it easier for a carer to quickly evaluate the post and decide whether it is relevant or not. The search facility on the Carer's forum can also be improved to have suggested alternative terms to the seeker's search term. This also helps to quicken the search and make it more specific, which will aid informational support necessary for empowerment. Administrators may also have to consider having complementary applications which members of the forum can use on the go. This will improve access to the forum, improve interactions as well as provide support quickly for empowerment and quicker decision-making.

The outcomes are also useful as a source of evidence for relevant facilitator training. The study established that facilitators have to switch between different approaches to assist carers. Depending on the carer's query, they have to engage in a collaborative, commanding, or motivating manner. This places expectations on facilitators to be versatile enough to switch between any of the modes of operation within a short time. The finding also has important practical implications for the training of facilitators; the instant switching from one mode to another is a skill that needs tact, patience, sensitivity and skill for continued relations within the forum. Therefore, training of facilitators needs to factor in this important attribute.

The empirical evidence also confirms the practical applications and importance of digital health communities in empowering carers to get through their daily duties. This is a useful finding for government and policy makers because it can be the bases upon which they enhance their policies to increase access to infrastructure that can enable carers to use digital health communities, even in the remote parts of the country. With the finding that facilitators are essential in digital health communities for empowerment of carers, government may also put strategies in place to extend support to more organisations that run digital health communities and assist with acquiring professionals to facilitate such communities. In addition, advocacy for and strengthening of digital health communities can be best achieved by appropriate policies of both health organisations and government as important players in the use of digital health communities. Both can be involved in publicising and advertising services of these communities to all stakeholders within their sphere of influence. As noted, digital health communities for carers supplement and complement services given at hospitals, and their ability to provide support carers through experiences, information, esteem and emotional support is an encouragement for them to continue utilising them.

7.5 Chapter Summary

This chapter discusses results of the study as presented in Chapter 6. The output of the QUAL-QUAL-QUAN sequential study is put together to answer the two research questions. The discussion shows evidence of empowerment, which has four elements in digital health communities. Results show that sharing of experiences is a very significant outcome of using the Carer’s forum, which contributes to carer empowerment. It is followed by social support which is provided as nurturant and informational support. The theoretical implications of the findings include modification to the empowerment theory to include enabling and inhibiting resources, in recognition of the fact that information systems use has intended and unintended consequences, which affect empowerment. Chapter 8 discusses recommendations and conclusions of the study.

CHAPTER 8: CONCLUSIONS & RECOMMENDATIONS

8 Summary of the Study

Extant literature supports and encourages the use of digital health communities for the benefits discussed in the earlier chapters. However, the results show that some of the variables that are applicable to online social networks, are not observed in digital health communities. Sadovykh & Sundaram (2017) suggest that the differences can be attributed to the goals of the various forums.

This thesis applied the empowerment theory as its theoretical lens. It employed a sequential mixed methods approach, with a QUAL-QUAL-QUAN chronology to investigate data from a digital health community of carers. While the qualitative expert interviews were analysed thematically, the quantitative data were analysed using PLS-SEM.

8.1 Limitations and Future Work

Basing on the discussions and results presented in the preceding chapters, this section considers recommendations, suggestions for further studies and a conclusion to the thesis. The following limitations warrant further consideration.

The way ‘use’ has been conceptualised may have had an effect on the outcome of the investigation. It is proposed that use in digital health communities may be different from other online communities, based on their core mandates. This study observes that people use the digital health community for the period they need to, and they move on when life circumstances change – much like a hospitalised patient who at one point gets discharged. The coming and going out of the digital health communities happens especially for chronic conditions and is evident in this forum that deals with mental health, in which someone can relapse. Unlike social forums, users of digital health communities meet over emotionally draining circumstances of sickness, so they would not want to extend the emotional drain beyond what they can take. Seeing that use in digital health communities is characterised by brevity, maybe we need a different definition and conceptualisation of ‘use’, where frequency of use is not a measure. This study proposes that when one stops using digital health communities, they may have achieved their goals. Maybe they got the help they need or maybe they have learnt skills to cope, so getting weaned off the digital health communities is an achievement. The study observes also that there is a group of carers who joined the digital health community, thinking they will be staying for a short time but find themselves still in the community after many years. They may have stayed due to valuable relationships they formed over years or due to a drive to support new members. Or maybe they are unable to sever ties because they have developed a dependence? This warrants further investigation.

The use of digital health communities complements and/or supplements face-to-face support that health customers get from service providers. With the COVID-19 pandemic, life activities have been significantly reduced to virtual; any support given is virtual. It remains to be seen with time whether digital health communities will still serve the purpose of complementing support, or they will now have to step up to be the main source of support.

Empowerment is a context-specific concept, as mentioned in the earlier sections. The study focuses on the compelling needs of informal carers for people with mental illness. Future studies can consider other users, like carers of people with different medical conditions. It will also be worthwhile to investigate the same user group in a different country to establish possible differences or similarities in empowerment due to cultural settings. There is a growing interest to digitise technologies, including their outcomes. Literature is already addressing the notion of ‘digital empowerment’, so expansion of this thesis to theorise and conceptualise the concept would make a necessary contribution to information systems literature.

The study also investigates empowerment within a limited period, while digital health community use is a continuum and a long-term journey for a user. Future investigations can consider the different levels of a user's caring journey (new or long-term member), especially that they join specifically to be supported with a health-related challenge. Some carers drop out of the forum once their loved ones *"get out of the woods"* or when they separate (in the case of partners) or when the care recipient passes away. Often when one joins a digital health community they are quite active but may slow down and disengage as time goes on (Leong et al., 2018), for different valid reasons. Typically, their activity has a peak and a decline. The study assumes peak activity at all times and does not account for the period of reduced activity. So, an improved study can consider both points of activity.

The study is carried out on one digital health community; possible future studies can include more than one digital health community at the same time to determine its applicability and generalizability. One of the main findings from the qualitative analysis is that empowerment in a digital health community has a fourth 'affective' dimension in addition to the interactional, behavioural and intrapersonal dimensions. It is proposed that this dimension is exclusive to empowerment in digital health communities. To advance it, future research could operationalise it and develop a measurement instrument to test it.

Prior research that utilised the empowerment theory has not considered the dual effects of resources. Since this is a study of technology, the dual effects cannot be ignored because technology use yields intended and unintended consequences, which may affect empowerment differently, hence both need to be studied (Abedin & Qahri-Saremi, 2018). However, results reported here show that intended outcomes (enablers) overpowered the effect of unintended outcomes (inhibitors). However, it is possible that the investigated inhibiting factors may be relevant to social networks, and not relevant to digital health communities. Therefore, there is need to further probe this split approach, and explore both enablers and inhibitors of digital health community use.

While this study utilises a reflective measurement perspective, other researchers like Peterson (2014) propose that empowerment can be studied using a formative measurement approach, wherein they conceptualise empowerment as a high order multidimensional construct. These differences in treating the empowerment construct and its output are evidence that more research on the theory is needed to develop the construct further. In addition, the empowerment construct in the current study may benefit from having specific relationships established for each dimension and tested separately.

There are divergent views on self-disclosure. While it is true that reading bad experiences of others can help a carer be better prepared for similar eventualities, it can also scare them and result in pessimism and reduced confidence (Malik & Coulson, 2010). More work needs to be done to establish the authenticity and effects of these variations on empowerment in digital health communities. Further, Coyle and Carmichael (2019) point out the contribution of emojis and emoticons in expressing oneself, which this study did not consider. More work is necessary to explore this contemporary way of self-disclosing one's feelings.

Despite it being a possible variable in carer empowerment according to expert interviews, emotional contagion was not observed in both content analysis and the survey. As explained in the previous sections, it could be because the abundant emotional support shared on the forum overshadows possible emotional contagion, suggesting that it has no place in a digital health community because it provides social support. It could also be explained by the way carers receive messages being shared (Wang & Lee, 2021). The inconclusive results call for more investigations. Therefore, the outcome of this study serves as a base for undertaking further research on emotional contagion specifically in digital health communities, considering that past studies were in general social network sites (Wang & Lee, 2021).

One of the observations from the content analysis is that carers *receive* rather than give too much support [social overload as discussed by Maier et al., 2015a)]. The concept of worrying about *receiving* too much support, which this study discusses as *support overload*, is yet to be expanded. Further work can develop and operationalise the notion of 'support overload', to establish its effect (mediating or causal) on empowerment and determine how it interacts with other support exchanges.

As shown by both qualitative and quantitative findings, this Carers' forum has more emotional than informational support. However, emotions cannot be observed directly but sentiments (which reflect emotions) can be determined. Results of sentiment analysis to further explore the contribution of emotional support for empowerment will extend the study. In the same vein, studying self-disclosure from a valence perspective may help establish negative and positive self-disclosure, analysis of which may help bolster provision of emotional support. The proposed theoretical model of empowerment can be tested and further refined in other domains and contexts, such as online learning.

Although carers experienced overload of support, they reported challenges from *'receiving'* too much support, rather than *'giving'* too much support (described as social overload by Maier et al. 2015a). This may be attributed to the fact that the existence of digital health communities is anchored on encouraging formation of relationships among users (Young, 2013), as such carers tend to give lots of support. Therefore, 'social overload' may be a misfit to the goals and context of digital health communities, hence the proposal that carers experience *'support overload'* instead of social overload. The proposed phenomenon merits further investigation.

8.2 Conclusion

The extensive utilisation of digital health communities continues to pose a need for more investigation into how they can benefit users. This thesis reports on an investigation of how one digital health community of informal carers of people with mental illness enables empowerment of its users to make daily decisions. Although empowerment in the IS field is starting to gain traction, little work has been done previously to conceptualise empowerment of users. In addition, there is a lack of understanding which factors may influence it. The study draws upon and extends the empowerment theory and finds that a proactive and participatory approach of an empowered carer helps them take charge of their decision-making and coping matters.

The findings presented here can help users to cope with the challenging job of caring for others and to make appropriate and informed decisions that benefit themselves and the care recipient (Hur et al., 2019). The study also examines the moderating effect of facilitator support on the empowerment of users. It finds that the support of facilitators strengthens the empowerment of carers while using the forum. When some factors are present, the strength of facilitation varies between the factors. This outcome suggests that facilitation supports and strengthens carer empowerment within the context of the different factors While theoretically the use of technologies has negatives and positives, which may diminish or augment empowerment, results show that only enablers have an effect on empowerment, and inhibitors have no effect. These findings encourage and pave the way for future research on empowerment in other digital health communities, and more broadly, different types of online communities and contexts.

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Appendix 1: The Interview Protocol

UNIVERSITY OF
TECHNOLOGY SYDNEY

Empowerment of informal carers through peer-to-peer interactions in online communities: The role of facilitator support

Interview protocol

Online communities are modern technologies that have dramatically changed the way we communicate and share information in the form of text, pictures and even videos. The field of healthcare is one of those that have experienced wide use of online communities where people, be they patients or their carers (e.g. family members, friends), or health professionals discuss health issues and share health information. Just as in physical support group meetings, online communities have facilitators that offer expert advice and/or facilitate online discussions to help patients and their carers to make better decisions.

This study particularly focuses on empowering informal carers in online communities. In doing so, the researcher has conceptualized a framework and identified a number of variables that can influence carers' empowerment in the online space. Thus, at this early stage of this research, we seek professionals' expert insights and feedback on:

Whether our proposed framework is relevant to the informal carers? Are the relationships being suggested valid and do they make sense?

Please note:

** The interviewee will give consent to being interviewed.*

** The interviewee may stop the interview at any time if they don't want to continue with it.*

** They have a right to see the questions before the interview.*

Thank you for your time.

By Tsholofelo Sethibe

PhD candidate

Supervised by Drs Babak Abedin, Olivera Marjanovic & David Milne

Interview questions

1. I am interested in studying empowerment of informal carers, from the perspective of them being able to make better decisions in caring for others as well as for themselves.

We assume that the use of online forums, such as SANE Australia's Carers forum, can equip them to make better and informed decisions. Do you think that assumption makes sense? Can you please elaborate, basing on your experience?

2. In this research, we propose that informal carers' participation in online forums may contribute to their empowerment.

Do you consider this statement to be sensible? Please explain further.

3. We also propose that informal carers create and exchange knowledge in online discussions. Is that a sensible proposition? Kindly elaborate.

4. We further suggest that informal carers provide and exchange social support in their online interactions. Support could include comfort and encouragement to others, sharing same concerns and experiences, sharing suggestions of what to do in a situation as well as assuring others that they will manage the tough situation they face.

Do you think that makes sense? Would you consider exchange of support in an online forum empowering? Please discuss further.

5. Do you believe that giving other carers support online can be overwhelming? That is, can giving support be too much and exhausting to those who give it? Kindly explain more.

6. In some forums, like SANE Australia's Carers forum, the online environment is managed by a facilitator or moderator. Do you consider it sensible to assume that a facilitated environment may improve empowerment of informal carers? Please explain further.

7. Would you have any other comments?

Thank you very much for your time and input. After the interviews, we hope to analyse the data we have collected and use the results to inform the next phase of the research project, especially the carers survey. We are happy to share the analysis of the interviews with you, if you would like.

Appendix 2: Letter of Ethics Approval

-----Original Message-----
From: research.ethics@uts.edu.au <research.ethics@uts.edu.au> Sent: Sunday, 28 October 2018 9:46 PM
To: <TsholofeloJacqueline.Sethibe@student.uts.edu.au>; <Babak.Abedin@uts.edu.au>
Subject: Your ethics application has been approved as low risk - ETH18-2716

Dear Applicant
Your local research office has reviewed your application titled, "Empowerment of informal carers through peer-to-peer interactions in online social networks: The moderating role of facilitator-engagement level.", and agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application, subject to any conditions detailed in this document.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

Your approval number is UTS HREC REF NO. ETH18-2716.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:
- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.
- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat (Research.Ethics@uts.edu.au).
- The Principal Investigator will notify the UTS HREC of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions can be found at https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/Post-approval/post-approval.aspx#tab2.
- The Principal Investigator will promptly report adverse events to the Ethics Secretariat (Research.Ethics@uts.edu.au). An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.
- The Principal Investigator will report to the UTS HREC annually and notify the HREC when the project is completed at all sites. The Principal Investigator will notify the UTS HREC of any plan to extend the duration of the project past the approval period listed above through the progress report.
- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).
- The Principal Investigator will notify the UTS HREC of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

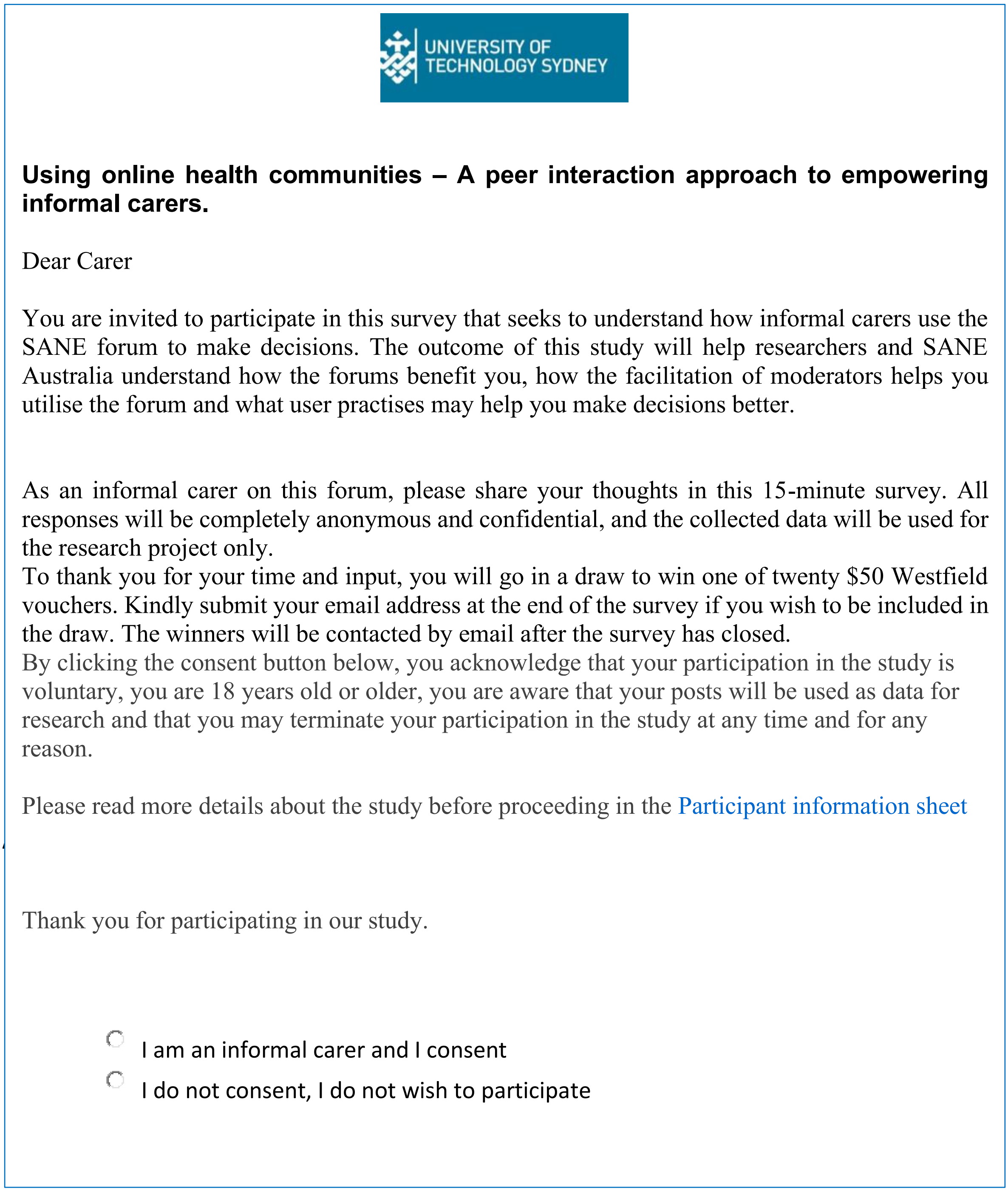
We also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval.
If you have any queries about this approval, or require any amendments to your approval in future, please do not hesitate to contact your local research office or Research.Ethics@uts.edu.au.

Appendix 3: The codebook for content analysis

Category	Description	Source
1. VHC use	An actor's utilisation of a VHC to perform tasks like reading, replying, supporting, initiating a post, seeking or giving advice to others	Karahanna et.al 2018
2. Experiential expertise	Knowledge, skills, problem-solving ability that one possesses from life experience, which they use to solve problems.	Castro et al. 2019
• *Self-care*	Advice on how to look after yourself to cope with care work (doing hobby; using humour; holidaying, religion; managing care work by accepting to live with your situation.	Pope et al. 2017; Burda et al. 2016
3. Social support	The support received or given by a network of connections to an individual who goes through potentially stressful events.	Lin et al. 2015;
• *Informational*	Support sought or given to a carer in response to their request. It reduces uncertainty through knowledge sharing – where to get services, handling symptoms, sharing a link or book. Advice, facts and feedback.	Erfani, Abedin & Blount 2017; Huang et.al 2019
• *Emotional*	Support sought or given to a carer in response to their request. It helps them persist in challenges, it conveys condolences; expresses understanding and shares others' feelings; provides hope; expresses togetherness and teamwork, all to restore emotional stability. Use of emojis and emoticons showing the same feelings.	Erfani, Abedin & Blount 2017; Huang et.al 2019
• *Esteem*	Support given to appreciate someone's intrinsic value, skills, abilities and accomplishments; minimising someone's guilty feelings about their situation; complimenting others and agreeing with their viewpoint.	Oh & Lee 2012
4. Facilitator support		
• *Presence*	The availability and action of a facilitator on a digital health community to engage with users according to given forum guidelines	Panteli, 2016; Junglas et.al 2013
5. Carer empowerment		
• *Intrapersonal*	Identifying the need to make a decision, and expressing communicative skills.	Petrovčič & Petrič 2014
• *Interactional*	Expressing collective action and account, community spirit, affinity and togetherness, and articulating group norms.	Wentzer & Bygholm 2013; Petrovčič & Petrič 2017
• *Behavioural*	Sharing adaptive coping strategies, acting on a decision made.	Petrič et.al 2017
6. Social overload	Expressing feelings of being overwhelmed by giving too much support to other users; they do it out of sense of duty to help.	Maier et.al. 2015a; Zhang et.al. 2016
7. Emotional contagion	A state in which the sentimental expression of an individual elicits similar sentimental reactions from the receivers, be they positive or negative sentiments.	Park & Conway 2017; Lee & van Dolen 2015
8. Self-disclosure		
** Appreciations*	Recognising encouraging words, ideas, comments, and experiences of others.	Zhang, Kwok et al. 2019
** Introductions and goodbyes*	Greetings, welcomes, self-introductions and bidding farewell.	Zhang, Kwok et al. 2019
** Information disclosure*	Carer explaining their situation and challenges they face, as well as sharing news.	Zhang et.al 2019, Posey et.al 2010
** Emotional disclosure*	Carer sharing details of their feelings and thoughts about their situation, both positive and negative.	Zhang et.al 2019, Posey et.al 2010

Appendix 4: Questionnaire



Using online health communities – A peer interaction approach to empowering informal carers.

Dear Carer

You are invited to participate in this survey that seeks to understand how informal carers use the SANE forum to make decisions. The outcome of this study will help researchers and SANE Australia understand how the forums benefit you, how the facilitation of moderators helps you utilise the forum and what user practises may help you make decisions better.

As an informal carer on this forum, please share your thoughts in this 15-minute survey. All responses will be completely anonymous and confidential, and the collected data will be used for the research project only.
To thank you for your time and input, you will go in a draw to win one of twenty $50 Westfield vouchers. Kindly submit your email address at the end of the survey if you wish to be included in the draw. The winners will be contacted by email after the survey has closed.
By clicking the consent button below, you acknowledge that your participation in the study is voluntary, you are 18 years old or older, you are aware that your posts will be used as data for research and that you may terminate your participation in the study at any time and for any reason.

Please read more details about the study before proceeding in the Participant information sheet

Thank you for participating in our study.

○ I am an informal carer and I consent
○ I do not consent, I do not wish to participate

<u>Section A</u>

1. What is your age?

- ☐ *18-25*
- ☐ *26-35*
- ☐ *36-45*
- ☐ *46-55*
- ☐ *56-65*
- ☐ *66-75*
- ☐ *76+*

2. What is your gender?

- ☐ *Female*
- ☐ *Male*
- ☐ *Non-binary*
- ☐ *Prefer not to say*
- ☐ *None of these options describe me*

3. Please indicate your state/territory

- ☐ *NSW*
- ☐ *WA*
- ☐ *QLD*
- ☐ *SA*
- ☐ *TAS*
- ☐ *VIC*
- ☐ *NT*
- ☐ *ACT*

4. How are you related to the care recipient?

- ☐ *spouse*
- ☐ *partner*
- ☐ *child*
- ☐ *parent*
- ☐ *grandchild*
- ☐ *in-law*
- ☐ *other*

5. How long have you been a carer?

- ☐ *0-1 year*
- ☐ *2-5 years*
- ☐ *6-10 years*
- ☐ *11-15 years*
- ☐ *16-20 years*
- ☐ *20+ years*

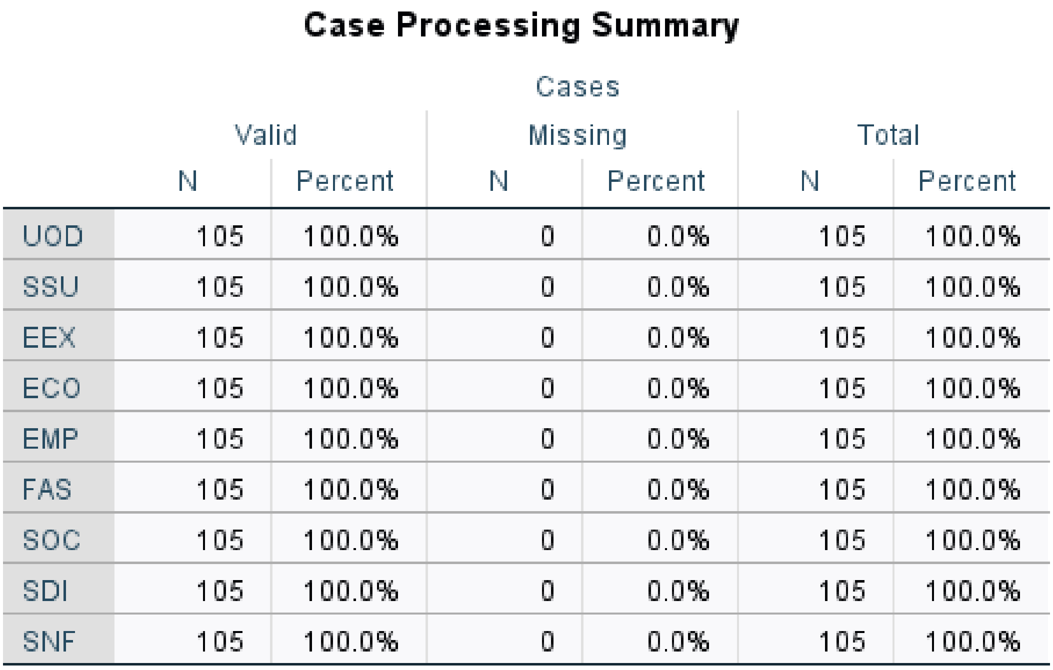
6. How long have you been a member of SANE Australia Carers' forum?

- ☐ *0-1 year*
- ☐ *1-2 years*
- ☐ *2-3 years*
- ☐ *3-4 years*
- ☐ *4-5 years*
- ☐ *5+ years*

Section B: Please indicate how much you agree or disagree with each of the following statements

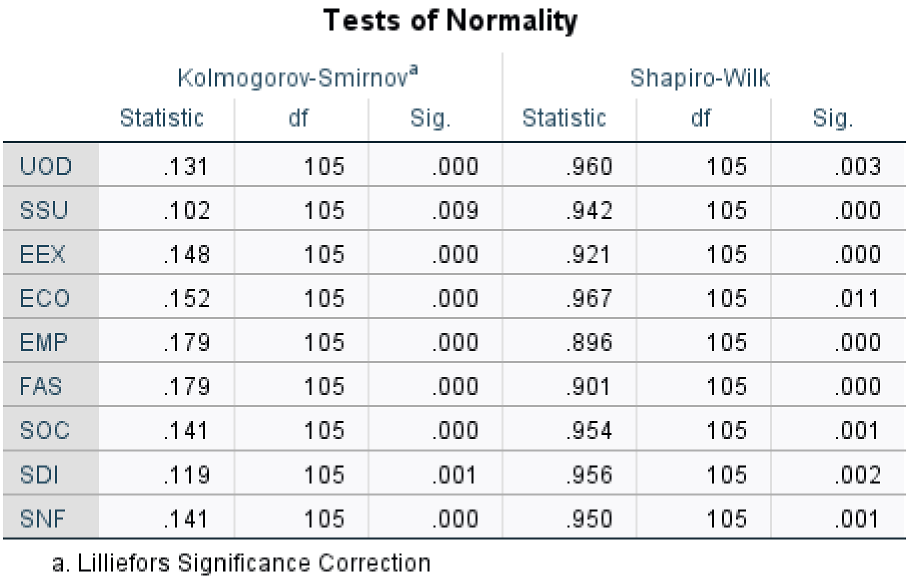
Construct	Code	Item
DHC Use (UOD)	UOD1	On average, I use the Carers forum every day
	UOD2	When I log in for a session, I use the Carers forum for a long time
	UOD3	I use the Carers forum to observe discussions but not ask questions or post advice
	UOD4	I use the Carers forum to give advice
	UOD5	I use the Carers forum to seek information
Social support (SSU)	SSEMO1	Members of the Carers forum can distract me from my worries when I feel under stress
	SSINF2	Members of the Carers forum make me feel that they care about me
	SSEMO3	Members of the Carers forum care about my feelings and health condition
	SSINF4	Members of the Carers forum tell me what they did in a situation similar to mine
	SSEMO5	Members of the Carers forum share information useful to my care responsibilities
	SSEST6	Members of the Carers forum congratulate and compliment my ability to deal with challenges
	SSEST7	Members of the Carers forum respect my opinion and perceive me positively
	SSEST8	Members of the Carers forum give constructive comments on my abilities to deal with challenges
Experiential expertise (EEX)	EEX1	The experience of other members of the Carers forum has increased my understanding of my care recipient's condition
	EEX2	The experience of other members of the Carers forum helps me to care for myself
	EEX3	The experience of other members of the Carers forum helps me to complete similar tasks more efficiently
	EEX4	I usually actively share my experiences with others on the Carers forum
Emotional contagion (ECO)	ECO1	I am able to remain calm even though other carers on the forum are very worried
	ECO2	I get upset just because a friend on the forum is upset
	ECO3	I become nervous if others on the forum seem to be nervous
	ECO4	My friends around me on the forum have a great influence on my moods
Empowerment (EMP)	EMP1	The carers forum encourages me to spend quality time with people I care about
	EMP2	The carers forum helps me to think of different ways to solve challenging situations
	EMP3	The Carers forum helps me to be actively involved in life despite my carer challenges
	EMP4	The Carers forum helps me to have confidence to do interesting things in my life despite my carer challenges
Facilitator Support (FAS)	FAS1	The moderator answers questions directed to them
	FAS2	The moderator returns answers to my requests quickly
	FAS3	The moderator calms an angry forum member before a discussion gets nasty
	FAS4	The moderator keeps discussions informative
Social overload (SOV)	SOV1	I take too much care of other carers' well-being in the forum
	SOV2	I deal too much with problems of other carers in the forum.
	SOV3	I often feel too responsible to care for other carers in the forum.
	SOV4	I pay too much attention to posts of other carers in the forum.
Social Network Fatigue (SNF)	SNF1	I feel drained from activities that require me to use the Carers forum
	SNF2	I feel tired from my activities on the Carers forum
	SNF3	Using the Carers forum is a strain for me
	SNF4	I feel burned out from my activities on the Carers forum
Self-disclosure (SDI)	SDI1	I do reveal my carer experiences on the Carers forum
	SDI2	I always feel completely sincere when I reveal my own feelings and experiences on the Carers forum
	SDI3	When I reveal my feelings about myself on Carers forum, I consciously intend to do so
	SDI4	On the whole, my disclosures about myself on the Carers forum are more positive than negative

Appendix 5: SPSS Output for Normality Test



Case Processing Summary

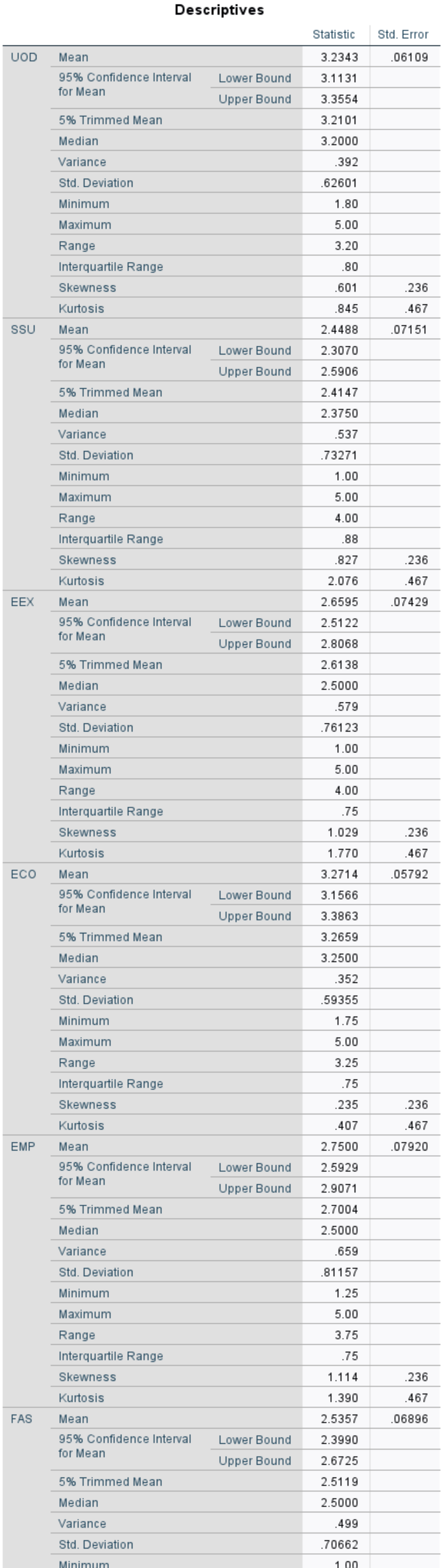
	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
UOD	105	100.0%	0	0.0%	105	100.0%
SSU	105	100.0%	0	0.0%	105	100.0%
EEX	105	100.0%	0	0.0%	105	100.0%
ECO	105	100.0%	0	0.0%	105	100.0%
EMP	105	100.0%	0	0.0%	105	100.0%
FAS	105	100.0%	0	0.0%	105	100.0%
SOC	105	100.0%	0	0.0%	105	100.0%
SDI	105	100.0%	0	0.0%	105	100.0%
SNF	105	100.0%	0	0.0%	105	100.0%



Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
UOD	.131	105	.000	.960	105	.003
SSU	.102	105	.009	.942	105	.000
EEX	.148	105	.000	.921	105	.000
ECO	.152	105	.000	.967	105	.011
EMP	.179	105	.000	.896	105	.000
FAS	.179	105	.000	.901	105	.000
SOC	.141	105	.000	.954	105	.001
SDI	.119	105	.001	.956	105	.002
SNF	.141	105	.000	.950	105	.001

a. Lilliefors Significance Correction

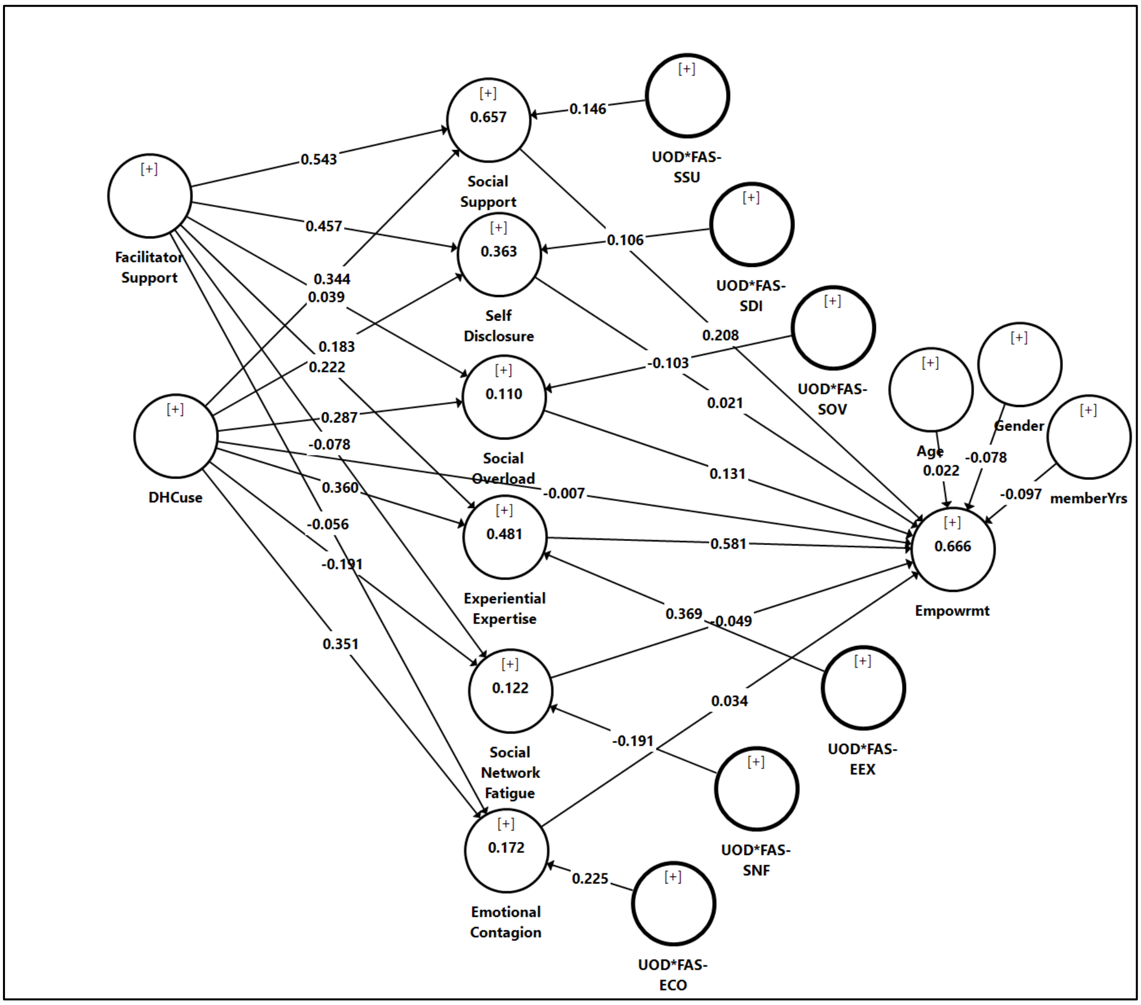


Descriptives

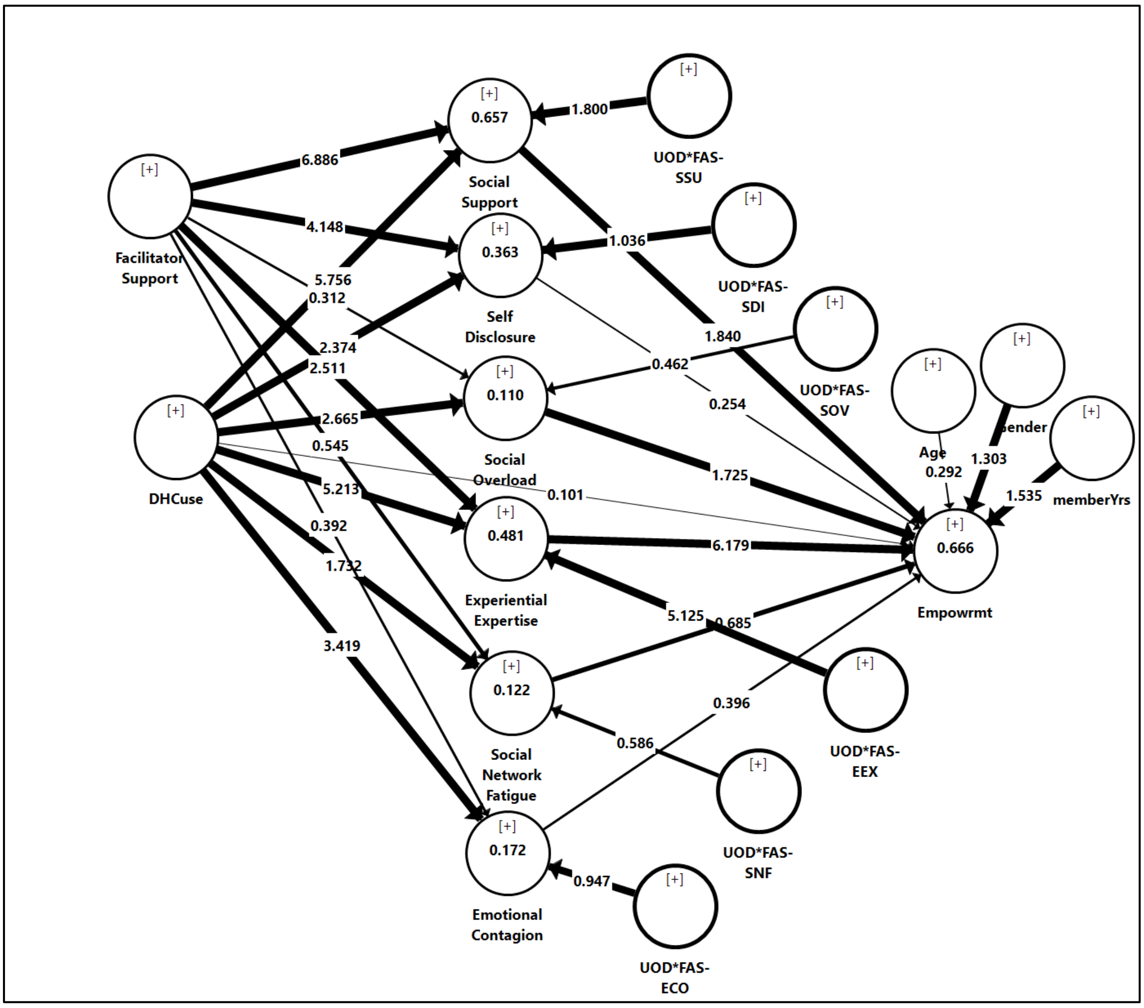
			Statistic	Std. Error
UOD	Mean		3.2343	.06109
	95% Confidence Interval for Mean	Lower Bound	3.1131	
		Upper Bound	3.3554	
	5% Trimmed Mean		3.2101	
	Median		3.2000	
	Variance		.392	
	Std. Deviation		.62601	
	Minimum		1.80	
	Maximum		5.00	
	Range		3.20	
	Interquartile Range		.80	
	Skewness		.601	.236
	Kurtosis		.845	.467
SSU	Mean		2.4488	.07151
	95% Confidence Interval for Mean	Lower Bound	2.3070	
		Upper Bound	2.5906	
	5% Trimmed Mean		2.4147	
	Median		2.3750	
	Variance		.537	
	Std. Deviation		.73271	
	Minimum		1.00	
	Maximum		5.00	
	Range		4.00	
	Interquartile Range		.88	
	Skewness		.827	.236
	Kurtosis		2.076	.467
EEX	Mean		2.6595	.07429
	95% Confidence Interval for Mean	Lower Bound	2.5122	
		Upper Bound	2.8068	
	5% Trimmed Mean		2.6138	
	Median		2.5000	
	Variance		.579	
	Std. Deviation		.76123	
	Minimum		1.00	
	Maximum		5.00	
	Range		4.00	
	Interquartile Range		.75	
	Skewness		1.029	.236
	Kurtosis		1.770	.467
ECO	Mean		3.2714	.05792
	95% Confidence Interval for Mean	Lower Bound	3.1566	
		Upper Bound	3.3863	
	5% Trimmed Mean		3.2659	
	Median		3.2500	
	Variance		.352	
	Std. Deviation		.59355	
	Minimum		1.75	
	Maximum		5.00	
	Range		3.25	
	Interquartile Range		.75	
	Skewness		.235	.236
	Kurtosis		.407	.467
EMP	Mean		2.7500	.07920
	95% Confidence Interval for Mean	Lower Bound	2.5929	
		Upper Bound	2.9071	
	5% Trimmed Mean		2.7004	
	Median		2.5000	
	Variance		.659	
	Std. Deviation		.81157	
	Minimum		1.25	
	Maximum		5.00	
	Range		3.75	
	Interquartile Range		.75	
	Skewness		1.114	.236
	Kurtosis		1.390	.467
FAS	Mean		2.5357	.06896
	95% Confidence Interval for Mean	Lower Bound	2.3990	
		Upper Bound	2.6725	
	5% Trimmed Mean		2.5119	
	Median		2.5000	
	Variance		.499	
	Std. Deviation		.70662	
	Minimum		1.00	

0

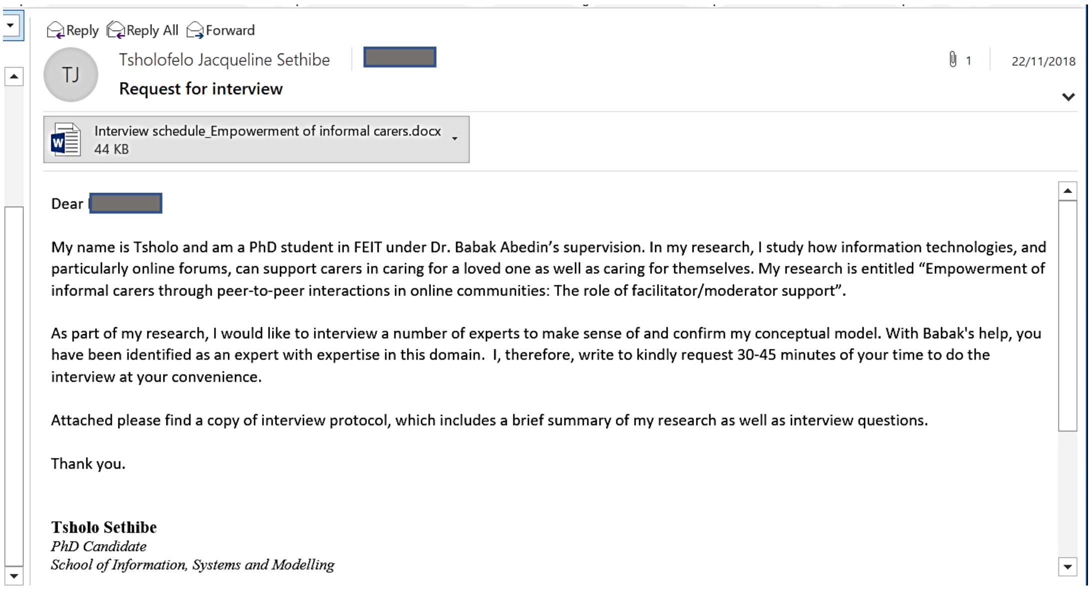
Appendix 6: Overall Structural Model with Factor Loadings (SMARTPLS 3)



Appendix 7: Overall Structural Model of t-values with highlighted paths (SMARTPLS)



Appendix 8: A Screenshot of the Recruiting E-Mail



Tsholofelo Jacqueline Sethibe [redacted]

22/11/2018

Request for interview

Interview schedule_Empowerment of informal carers.docx
44 KB

Dear [redacted]

My name is Tsholo and am a PhD student in FEIT under Dr. Babak Abedin's supervision. In my research, I study how information technologies, and particularly online forums, can support carers in caring for a loved one as well as caring for themselves. My research is entitled "Empowerment of informal carers through peer-to-peer interactions in online communities: The role of facilitator/moderator support".

As part of my research, I would like to interview a number of experts to make sense of and confirm my conceptual model. With Babak's help, you have been identified as an expert with expertise in this domain. I, therefore, write to kindly request 30-45 minutes of your time to do the interview at your convenience.

Attached please find a copy of interview protocol, which includes a brief summary of my research as well as interview questions.

Thank you.

Tsholo Sethibe
PhD Candidate
School of Information, Systems and Modelling