

A Conceptual Framework of Digital Empowerment of Informal Carers: An Expert Elicitation Study

Completed Research Paper

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Abstract

Many studies on online health communities (OHCs) have focused on patients' well-being. The capabilities of OHCs to effect other psychosocial states like empowerment have been under-explored. Additionally, the study of empowerment of other healthcare stakeholders, specifically informal carers, has not attracted much study. This is despite evidence that carers use OHCs as an information and self-care resource in dealing with the stress and strain of caregiving. It is not clear how moderator support may influence carer empowerment. We propose a conceptual model to explore how moderated OHCs may influence empowerment of carers. In order to assess the model and support its robustness, this paper uses expert interviews of academics and industry professionals, with the view to focusing the research as well as operationalise the model. Results suggest a favourable acceptance of the model by experts, and thematic analysis of their conversations generated an additional construct.

Keywords: Digital empowerment, online health communities, informal carer, moderator support, peer-to-peer networks

Introduction

The growing use of online health communities (OHCs) confirms the assertion made by Weiss et al. (2013, p. 970) that “online social support for patients and families will be an essential comprehensive approach to health care” that also enables self-care in users. This technology-enabled approach to coping with health-related challenges allows lay people to take charge of their lives, in what can be termed ‘digital empowerment’ of users (Mäkinen 2006). In this environment, users can participate in a varied and extended networks, which permit more enriching interactions than getting one person’s opinion. The interactions can be anonymous, thus allowing more users to participate freely. They also provide social support in a way that is different from off-line approaches, and users can exchange information at their own time (Erfani and Abedin 2018).

Users of OHCs include families and friends of care recipients who volunteer their care services and as such are called informal carers. An informal carer is one who gives personal care and help to a loved one who needs help due to some condition they have, someone who shares the care recipient’s ailment experiences and manages their emotions (Grande et al. 2009). In the process of helping their loved one, they get strained by the daily responsibilities of caring, as well as isolation from family and friends since they spend all their time caring (Petty 2015).

As a result, many informal carers use OHCs to find social support and gather the knowledge they need to tackle carer burden. Inevitably, increased levels of stress lower decision-making self-efficacy (Dionne-Odom et al. 2017), hence we explore how OHC use can enable empowerment of informal carers to reduce stress and improve their decision-making capacity. In fact, Hu et al. (2015) state that as a support approach, empowerment is more preventive than remedial, making it an attractive option to carer support. We present that in the context of this study, empowerment is “the process of increasing the capacity of individuals to make choices and to transform those choices into desired actions and outcomes” (Baba et al. 2017, p. 1621). It means, therefore, empowered carers will be able to make decisions/choices better and master issues that concern them. This ability is crucial to an informal carer as making personal and health decisions is part of their daily routine – for themselves as well as for care recipients. Through the lens of the empowerment theory, we propose that the *action* of informal carers on a moderated online forum (*environment*) using appropriate *resources* may enhance their empowerment, so as to make decisions better.

This study contributes to digital empowerment literature, OHC use literature and e-Health literature, by providing empirical evidence from industry and academic experts to validate a conceptual model. This will endorse and legitimise the model, thereby situating the research in information systems (IS) literature. We also study the costs and benefits of OHC use, in that way separating resources into enablers and inhibitors. To the e-Health literature, we bring a different set of stakeholders for study in online environments – informal carers; this group has been less studied in favour of patients. Finally, the study brings to fore an exploration of how moderator support in OHCs can contribute to the empowerment of informal carers.

In light of the foregoing, the aim of our research is to identify and validate constructs of the proposed conceptual model. The model was constructed from reviewed literature, and variables that should be considered within digital empowerment identified. In confirming or refuting the validity of these constructs, experts in the field of IS and carers’ forums shared their perceptions about relevance of the variables to digital empowerment.

The paper is organised in this manner. Following the introduction is an overview of digital empowerment of informal carers, followed by a discussion of expert interviews as used in the study. Findings are then presented, followed by discussion and conclusion.

Informal carers' empowerment in online health communities

Online health communities are a support intervention that allow peer-to-peer connections, which enable users to exchange experiences that are personal. The sharing of these lived experiences provide an understanding and support that healthcare professionals do not necessarily possess (Mo and Coulson 2014). Studies conducted on digital empowerment in healthcare have been mainly on care recipients with differing health conditions – cancer (Gamache-O'Leary and Grant 2017) , HIV/AIDS (Mo and Coulson 2014), arthritis and others. Their results suggest that OHCs have an empowering capability. However, empirical research done with carers is limited (Kaltenbaugh et al. 2015) yet they experience social isolation and emotional distress due to their care work, which OHCs are known to improve (Harris et al. 2015).

From the review of literature on digital empowerment, we propose a conceptual model as shown in Figure 1. It suggests that OHC use is mediated by enabling resources and inhibiting resources (Yan et al. 2016) to facilitate empowerment; moreover, the support of a moderator of an OHC may affect this empowerment. As much as OHCs permit the sharing of experiential knowledge (Yan et al. 2016), and exchange of social support (Johnston et al. 2013), which are enablers, it also may cause social overload (Maier et al. 2015) as an inhibitor of carer empowerment. Using the empowerment theory (Zimmerman 1995), we explain how peer interactions over moderated OHCs may result in the empowerment of informal carers. The theory proposes that participation of OHC users in a conducive environment, with the necessary resources may foster empowerment. We, therefore, identify that moderator support in an OHC provides the environment needed for peer interactions, while the resources are experiential knowledge sharing, social support and social overload.

Due to paucity of research in studies relating to online carer empowerment in moderated OHCs (Kaltenbaugh et al. 2015), we undertook to validate the proposed model in Figure 1 using expert knowledge. Their input will contribute to the model correctness and ensure that it is adequate for what it is intended to do; their assessment will also contribute to show how robust the model is. Therefore, this study set out to establish the preliminary validity of constructs of a conceptual model that proposes a relationship between the use of a moderated OHC and empowerment. The next section discusses these constructs.

OHC Use

Online health communities have flattened the structures of communication, knowledge sharing and support between participating stakeholders. Rather than having 'clients' and 'experts', everyone is a 'participant' (Zimmerman 2000) who contributes and collaborates with others. This interaction continues to benefit participants if they remain active (Teichmann et al. 2015). In fact, the principle of peer networks lies in one's willingness to take part in online interactions. A study of online forum users by Li (2016) confirms a link between active participation and empowerment. It is believed that the use of OHCs can enable empowerment of users, and researchers have encouraged to further investigate potentials of online communities for individual empowerment and development (Abedin and Qahri-Saremi 2018).

Experiential Knowledge

One of the reasons of the existence of an online community is sharing of experiential knowledge, which users may do voluntarily and informally. In their use of OHCs, users share personal information about their feelings and emotions, as well as general information about treatment and options for services (Yan et al. 2016). Knowledge is derived from shared information and enables one to cope with challenges they may be facing, thereby empowering them to improve their decision-making to take appropriate action (Taştan 2013). Specifically, most users find OHCs to be an outlet through which they freely share personal experiences, which peers value as heart-felt, personally relevant, easily understood

and meaningful (Mo and Coulson 2014). So the sharing of one's experiences as a carer may enable empowerment of other users.

Social Support

Social support is the means by which social relationships promote physical functioning (health) and psychosocial well-being and is, therefore, "an integral resource for coping" with challenges (Rains et al. 2015, p. 404). This support is accessible through social ties to other individuals, groups and the community at large (Lin et al. 2016). Previous research confirms the existence of five forms of social support on OHCs namely, emotional, esteem, network, informational and instrumental support (Loane et al. 2015), with informational and emotional support being the commonest forms of support online users get (Rains et al. 2015). Prior information systems research confirms that social support has positive effects such as improving health, reducing stress and strain (Lin et al. 2016), and improving well-being (Erfani et al. 2017). Moreover, literature acknowledges that OHCs offer an important therapeutic element of social support, as they enable users to offer and receive this support (Coulson and Shaw 2013), which boosts feelings of helpfulness and a sense of community that may encourage positivity and foster empowerment in informal carers.

Social Overload

Any online community needs to have fresh content and timely interactions for it to survive (Jiang et al. 2018), and that can be attained by active participation of members. However like most online communities, OHCs have 90% inactive users (lurkers); 9% contribute sparingly (contributors) and only 1% contribute the most (superusers) – they observe the 1% rule. In fact, studies confirm that superusers contribute more than 70% of the content (van Mierlo 2014). Most superusers are long-serving members of the community, and their consistent participation is borne out of a genuine care to assist others. However over time, these users may experience fatigue, a concept referred to as social overload. At its worst, it may result in users stopping to contribute altogether – either producing or consuming information to an OHC (Maier et al. 2015). This non-use will negatively affect social support and knowledge sharing, consequently inhibiting empowerment. This constraint of OHC use has been overlooked previously.

Moderator Support

Moderation is the practice of maintaining deliberations in an online forum and keeping them focused, as well as preventing possible malicious attacks on community participants (Wise et al. 2006). If not checked, attacks and unguided discussions may normalize risky or unhealthy behavior or spread misinformation. Moderation can be done by either a professional who is an expert in a specific field, a trained para-professional or a lay-person who has experiential knowledge (Atanasova, Kamin & Petrič 2017). A moderator's ability to create a conducive environment and engage forum users to work together amicably is the level of support they give forum users (Chewning et.al. 2016). Coulson and Shaw (2013) contend that moderator support may influence empowerment in online communities, improving the members' confidence to access online interactions and make decisions.

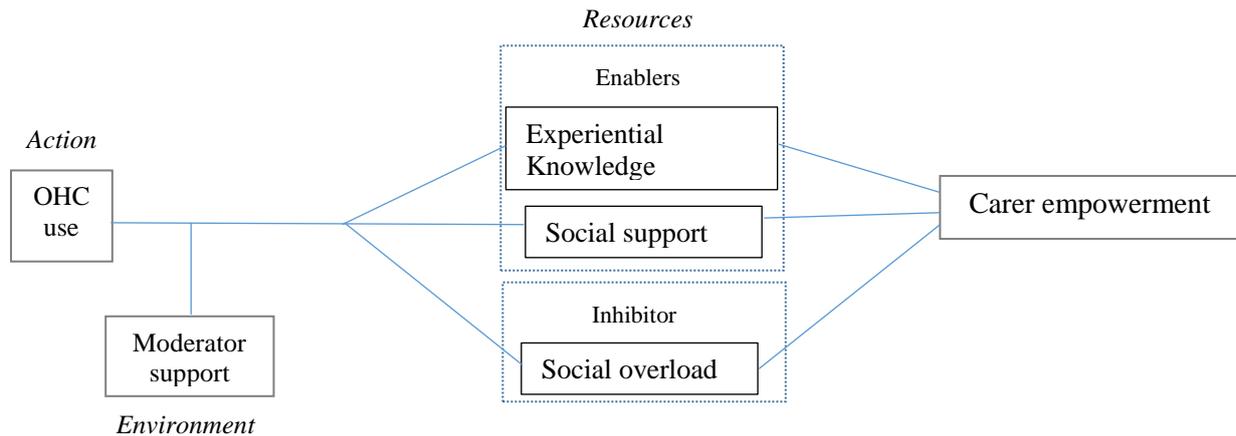


Figure 1. Initial conceptual model of OHC use and carer empowerment

Expert interviews

To explore the perceptions of experts on constructs of online empowerment of informal carers, semi-structured interviews were conducted with eight experts. This qualitative method was appropriate to use as it permits in-depth analysis from a fairly small sample size and puts the research focus on the respondents. Since we wish to obtain narratives and insights of experts' opinions on the relevance of constructs in the online empowerment model in moderated online health communities, this method of investigation was suitable.

Experts are 'knowledge specialists' with technical professional knowledge or interpretive knowledge of the field, and they provide high quality data (Burnham et al. 2008). In our research, expert interviews were used to tap knowledge and narrow the gap between expert knowledge and literature (Littig and Pöchlacker 2014). The experts were asked to use their experiential knowledge and practices to elaborate on their responses and share their perceptions on contributors of empowerment in a moderated online health community of informal carers. Their contributions were used to verify the proposed framework, and modify it as necessary. The process followed is summarised in Table 1:

Table 1: Procedure of eliciting expert response

Stage	Activities	Interactions with expert
Before interview	Developing items	The first author drafted the items, then consulted with academic experts to solicit their opinions on whether the questions were sound.
	Recruiting participants	The interviewees were sent a 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 for 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 appreciate their input.

Developing Items

The researcher identified the domain by undertaking a review of literature and identifying variables associated with empowerment of informal carers in online forums, as well as relationships between them. They then used previous instruments for guidance on structure of interview questions that confirm a framework, like Hatsu and Ngassam (2017), and drafted items themed on the identified variables. The questions were open-ended statements that required the interviewee to confirm if the variable is sensible to propose and to support their answer – drawing on their experience. These are presented in Table 2. The co-authors of this paper did the initial verification of the questions to remove ambiguity, improve clarity and refine them to be assembled into a usable form. The items and interview schedule were pre-tested with two knowledgeable and experienced academics – some had used online health communities during the time they cared for loved ones, and others are very conversant with research in the information systems (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. With that process, the items were content validated (Lynn 1986).

Participants and Recruitment

Participants were selected using a purposeful and convenience sampling strategy (Creswell and Creswell 2018) from a population of online community coordinators, academics and moderators. The selected academics are senior teaching staff in Information Systems across three universities in two continents, which the authors have interacted with in 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 online community coordinators are staff at management level from carer organisations who have interacted with informal carers, while the last group comprises moderators of online communities. A total of eight (8) experts were interviewed – four from academics (E1, E5, E6 & E8) and four from industry (two online community coordinators – E2 & E7) and two online moderators (E3 & E4).

Conducting the Interview

Basing on the approval of this research, UTS HREC REF NO. ETH18-2716, the experts were duly requested for interview by email, and the interview protocol attached for their perusal. All the interviews were conducted by the first author between 15th November to 17th December 2018. 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 respondents' permission. The interviews were then transcribed with the aid of Trint software. After transcription, the first author manually tidied up the scripts by listening to the audio recordings and matching with the transcribed file to corroborate what is said with what has been transcribed. This improved readability of scripts and precision of facts. The interview items were appropriately labelled in all the scripts, and the latter uploaded into Nvivo for coding.

Post-interview, each interviewee was sent a 'thank you' note for taking their time to participate in the interviews, with indication that developments of the research project will be shared with them in due time.

Coding

It is the clustering of key issues into themes for analysis. We used Nvivo to code and perform a thematic analysis. Themes were built around the suggested constructs of the conceptual model, with the openness to identify any that may develop from the conversations.

Findings

This section presents findings from interviews with the eight experts. Fig. 2 shows the sub-themes that emerged from interviews

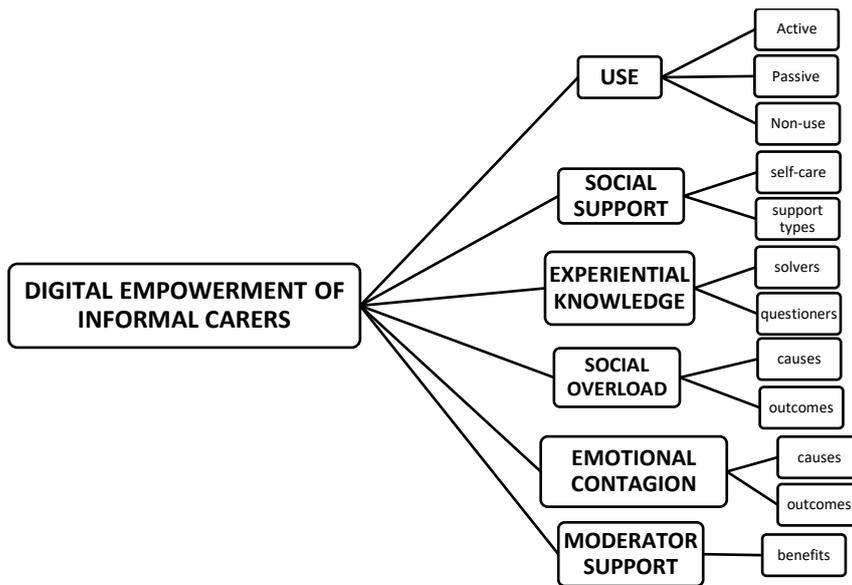


Figure 2. Summary of sub-themes as derived from interviews

These sub-themes emerged from discussions of the questions in Table 2, which summarises them and indicates the percentage of carers supporting it or not.

Table 2. Summary of results of expert interviews

Constructs	Interview question details	Results	
		Yes	No
Use of OHCs	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?	100%	0
Experiential knowledge	We also propose that informal carers create and exchange knowledge in online discussions. Is that a sensible proposition?	100%	0
Social support	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?	100%	0
Social overload	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?	71%	29%
Moderator support	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 moderated environment may improve empowerment of informal carers?	100%	0

OHC Use

All respondents confirmed that the assumption that OHC use empowers carers makes sense because interactions over online forums are “*good for peer-to-peer support... and validation of the struggles that carers have*” (E3). Most informal carers need validation in their role since they don't 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 – *“There's that push and that motivation to be there for the loved one and then they don't tune into how they're actually coping and how they're going”*. As confirmed by E7: *“So I think the big key part of it is finding that validation in other people that have had similar experiences or having similar experiences which definitely empowers them hugely, and being able to hear other people's insights.”*

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 (E2).

Active and passive use

To maximally benefit from the OHC, most of the experts wholly encourage active rather than passive participation or lurking, by carers.

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

“...they would be empowered and definitely they should participate.” (E1)

“I would definitely say that they would need to participate in order to be able to make the most of the forums and to be able to feel that sense of empowerment because I think it's when they contribute something of themselves – their ideas, their thoughts, their problems” (E4)

The others acknowledge that lurking is a form of participation too, with other experts acknowledging that a carer may engage in both forms of participation:

“The people who are just reading do get benefit, various benefits. You don't have to be participating in an active way to get benefit” (E2)

“And sometimes just reading others' responses to that problem can be useful to them. So it's, you know, I guess it can still be a helpful process” (E4)

“I have observed that some of the users in online social networks are passive users.... even though someone may just read communication between other members, they can learn something.... and they can make better decisions.” (E1)

Participation of forum members, which is vital for its survival and continued existence, signifies the use of an online forum (Teichmann et al. 2015). So the gain for informal carers will be great and the meaningful existence of the OHC assured if members actively take part in the online interactions; therefore, use of an OHC is a significant variable in the conceptual model of online empowerment.

Experiential knowledge

Experts perceive exchange of experiential knowledge as a justified variable when considering online interactions in relation to empowerment, largely because most carers relate better to personal stories rather than hypothetical knowledge. For example,

“...they can also share knowledge through their own personal experience and so if they've had an experience and they've learnt something from that, they can tell other members or other carers about that experience.” (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 (E2) by some forum members. 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...” (E3)*

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 that, like sharing their stories, how they might have approached a certain issue and then yeah... telling others what their experience was and how that might apply to somebody else's situation. And I think, yeah, that does empower other people to not give up.” (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 with empathy. So, all the experts subscribe to the importance of experiential knowledge sharing as a valuable construct in online empowerment.

Social Support

Most experts believe that the provision and exchange of social support by carers is the most important thing that happens in an online forum:

It is “one of the most predominant types of support that we see. It's certainly very common.” (E2)

“I think that's probably the biggest thing a lot of members get from the forums – just feeling like they have support...” (E3)

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

In their discussions, some of the experts made reference to the different kinds of social support derived from OHCs, which fell into the following categories as described by Loane et al. (2015):

Informational Support

Offering guidance and advice on possible solutions to a challenge. Carers use the forum to gather information on issues they need advice on.

“So 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 and support and then kind of move on...” (E7)

Emotional Support

Means being able to turn to others for consolation and encouragement in stressful times, leading to a feeling of being cared for. As noted from the discussions, 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 when they need emotional support, they turn to the forum.

On the forum, especially if it is anonymous, they know *“that it is valid for them to feel stressed or upset or you know because as a carer on any level it can be really easy to feel like you have no right to feel stressed...” (E7)*.

At other times, the forum *“provides that space to listen and not necessarily offer any sort of advice... So letting people know that others are listening” (E2)* is important as well.

Network Support

Believing that 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)*.

Also, the online forum provides *“a non-judgemental space where other carers are going to be able to understand where they're coming from and just offer that reassurance and validation. It is really important.”(E2)*. Another expert actually noted that *“..the 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” (E2)*.

Esteem Support

Boosting of someone's self-esteem by giving them positive feedback on what they manage to do e.g. coping with stress.

The carers commend each other's efforts in caring, and are encouraged to hear *“that they are doing their best in the situation”*, as they have *“to be strong and not give up... don't give up, be strong, take care of your mom” (E1)*, in that way giving them positive feedback which makes them feel good about what they achieve.

Instrumental Support

This type of support deals with giving tangible resources to assist another person to cope in a tough situation.

“... for example some patient in the forum that I was using needed some types of books or sometimes types of services or even some types of goods that other patients could provide” (E1) and they got that kind of help on the forum.

Reference to these different forms of support suggest that they have a place in social support of carers, many of whom their *“focus is on the person that they're caring for rather than themselves. Whereas sometimes they'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 OHC places focus on the carer; their peers *“value them for themselves, not just caring”*. That kind of validation boosts their confidence to make decisions better. Consequently, social support is confirmed to be a necessary construct in an online empowerment model.

Social Overload

Six experts agree that exhaustion from offering social support is real, while the remaining two 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 actually have counselled 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 of ‘social overload’, which is explained further by feeling overwhelmed, gives further insights into the concept of online empowerment – that it can be negatively impacted during interaction of carers.

Experts attribute the exhaustion experienced in online interactions to a number of 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 is 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 behavior, 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” (E5)

Whatever the cause of social overload is, carers threaten to or actually 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”*. This tendency of users quitting when overwhelmed in an online environment is confirmed by Maier et al. (2015).

Moderator Support

All experts affirmed the suggestion that moderated online forums may improve empowerment. Their explanations of how the forums enable empowerment are summarized in Table 3 below under five identified functions of moderator support.

Table 3: Benefits of moderator support

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

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 literature are sensible and relevant in the study of digital empowerment in a moderated environment. Above that, it has emerged from the expert discussions that there is another inhibiting factor to empowerment in an OHC – ‘emotional contagion’, which is discussed next.

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 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 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 shared 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)

With the addition of another inhibiting factor, the conceptual model is now modified as shown in Figure 3:

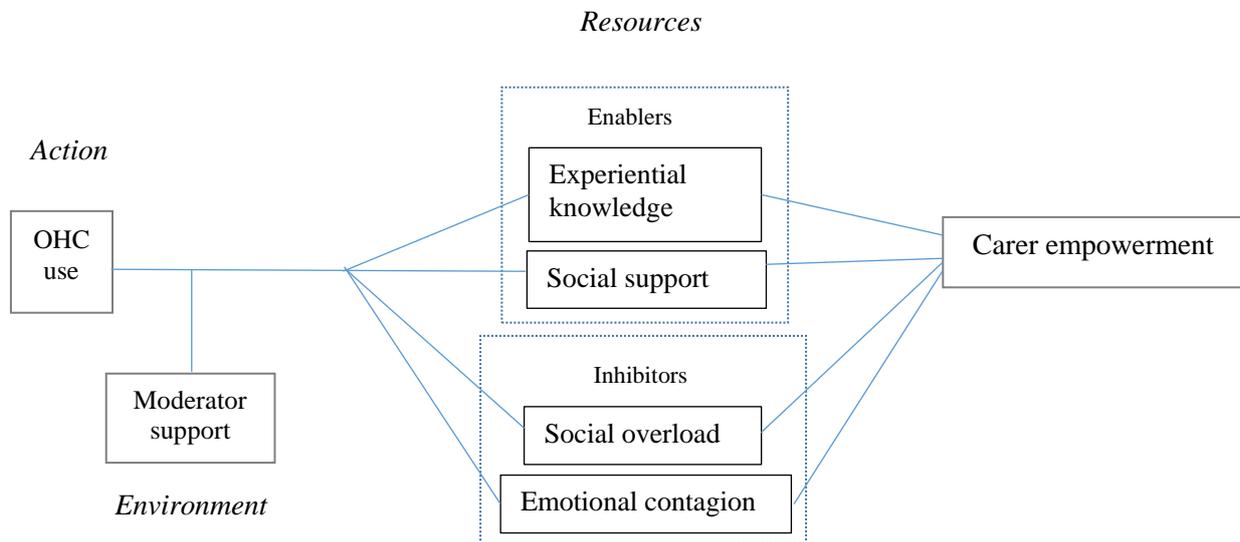


Figure 3: Modified conceptual model of OHC use and carer empowerment.

Discussion

The primary aim of this study was to verify the theoretically derived conceptual model of digital empowerment of informal carers in OHCs. It was necessary to determine constructs more reliably through expert interviews because an exclusively theoretical model would risk being irrelevant to practice and real life circumstances (Magenheim et al. 2010). In the model, we identified enablers and inhibitors in the study of online environments, as advised by Abedin and Qahri-Saremi (2018) who contend that researchers need to consider positive and negative aspects of technology-enabled social interactions. This approach will give a practical and balanced view of the use of OHCs. In their study of OHC use by HIV/AIDS patients, Mo and Coulson (2014) adopt the same approach of studying both empowering and disempowering outcomes of OHCs.

Our study contributes to IS literature in a number of ways and builds on prior research with practical implications. First, it brings empirical evidence from experts – industry professionals and information systems (IS) academics – on what variables can be investigated in the study of digital empowerment. Such evidence from qualitative approaches is not common in IS, as highlighted by Malinen (2015) in their systematic literature review; the use of expert interviews specifically in this field of study is even less common (Malinen 2015).

Secondly, we propose a wider view of resources in the empowerment theory to include enablers and inhibitors (Hahn et al. 2014). Mostly, discussions focus on the positive aspects of online forums' use. Our approach highlights both the negatives and positives of OHC use. Finally, we propose a modified conceptual model of OHC use for informal carer empowerment, which includes 'emotional contagion' alongside 'social overload' as inhibitors of empowerment, when initially we only had 'social overload'. The 'emotional contagion' construct emerged from the interviews. This study outcome may have been limited by the disparate length of time using an OHC by different experts – some participants may have not provided as rich a description of their experiences as others.

Conclusion

From reviewed literature, we identified constructs that formed a conceptual model which depicts digital empowerment of informal carers. Expert opinions on the validity of these constructs was sought through interviews. A thematic analysis of these interviews confirmed the constructs and added another construct. Finally, the proposed constructs in the model were endorsed – with most experts confirming that the constructs made sense to investigate digital empowerment of informal carers, specifically in moderated environments.

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