

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

Complete Research Paper

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Abstract

Many studies on online health communities (OHCs) have focused on patients' well-being. Their capabilities to effect other psychosocial states like empowerment have not been much 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 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) is in tandem with a suggestion by Weiss et al. (2013, p. 970) that “online social support for patients and families will be an essential comprehensive approach to health care”, enabling self-care in users of the community. Online communities provide social support in a way that is different from off-line approaches, since its users can exchange information at their own time, interaction can be anonymous (Erfani and Abedin, 2018). Moreover, this interaction is between a varied and extended network of peers – which may be more enriching than getting one person’s opinion (Mehta and Atreja 2015).

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 feel stressed and strained by the daily responsibilities of caring, as well as isolation from family and friends because they spend all their time caring (Petty 2015).

As a result, many 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 the study of how OHC use can enable carer empowerment to reduce stress and improve decision-making. 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. Providing empirical evidence from professional and academic experts to assess and validate a conceptual model will endorse, legitimise and operationalise the model. This will situate it in IS literature. We also study the costs and benefits of OHC use, in that way separating resources into those 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.

Given the foregoing, the aim of our research is to explore how moderated peer-to-peer online interactions influence the empowerment of informal carers. Specifically, in this part of the research, we purpose to determine the perceptions and experiences of experts in the field of peer-to-peer online health communities for informal carers, to make sense of constructs identified (from literature) in the relationship between OHC use and informal carer empowerment. In confirming or refuting the validity of these constructs, the experts shared their experiences.

The paper is organised in this manner. Following this introduction is the section that gives a brief review of literature on OHC use by carers, empowerment in healthcare, the part played by moderator support and how all these interconnect to address our aim. It ends with a visual conceptual model. The next section details how the expert interviews were carried out, followed by findings of the same. A modified conceptual model is presented after the findings, and the paper concludes with contributions of this work to research.

Carer empowerment through online health communities

In this section, we overview prior work on carer support, empowerment in OHCs as well as the effect of intervention in online communities as we identify the variables in the relationship between OHC use and carer empowerment. The conceptual model (Fig. 1) proposes that the use of online health communities has both benefits and costs (Yan et al. 2016). As much as OHCs permit knowledge creation and exchange (Yan et al. 2016), and social support (Johnston et al. 2013), which are enabling resources, it also yields social overload (Maier et al. 2015) as an inhibiting effect on carer empowerment. It further proposes that the support of a moderator may facilitate carer empowerment, and this support provides an environment over which interaction occurs (Atanasova et al. 2017). Through the lens of empowerment theory (Zimmerman 1995), we suggest that moderator support in an online health community provides the environment that is needed for empowerment to take place, while the needed action is the use of OHC and the necessary resources are social support, knowledge exchange, social overload and emotional contagion.

A literature review was conducted, from which we identified predictor constructs of a conceptual model. The model proposes that the use of a moderated online health community facilitates empowerment of informal carers through social support and knowledge creation and exchange. This happens amidst the possibility that users may experience social overload. The need to validate this conceptual model is supported by the fact that the study has no theoretical basis due to paucity of research in studies relating to online carer empowerment in moderated OHCs (Kaltenbauch 2015). At this stage, the experts' input will contribute to its correctness and ensure that the model is adequate for what it is intended to do. The assessment and input of experts will contribute to show how robust the proposed model is. Therefore, this study set out to establish the preliminary validity of constructs in a conceptual model. The next section discusses the different constructs of the conceptual model as identified in literature.

OHC Use

Online health communities have flattened the structures of communication, knowledge sharing and support between participating stakeholders. Rather than being a 'client', 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). As suggested by Strobel et al. (2014), the principle of peer networks lies in one's willingness to take part in online interactions. In fact, 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 been 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). The sharing of information converts explicit knowledge to tacit knowledge and vice versa, thereby creating knowledge which enables one to cope with challenges they may be facing, and empowering them to improve their decision-making to take appropriate action (Taştan 2013). So the sharing of one's experiences with caring may enable empowerment of the forum 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, which 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 exchange, 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 discussions 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.

With this background, we present the conceptual model in Fig.1 below:

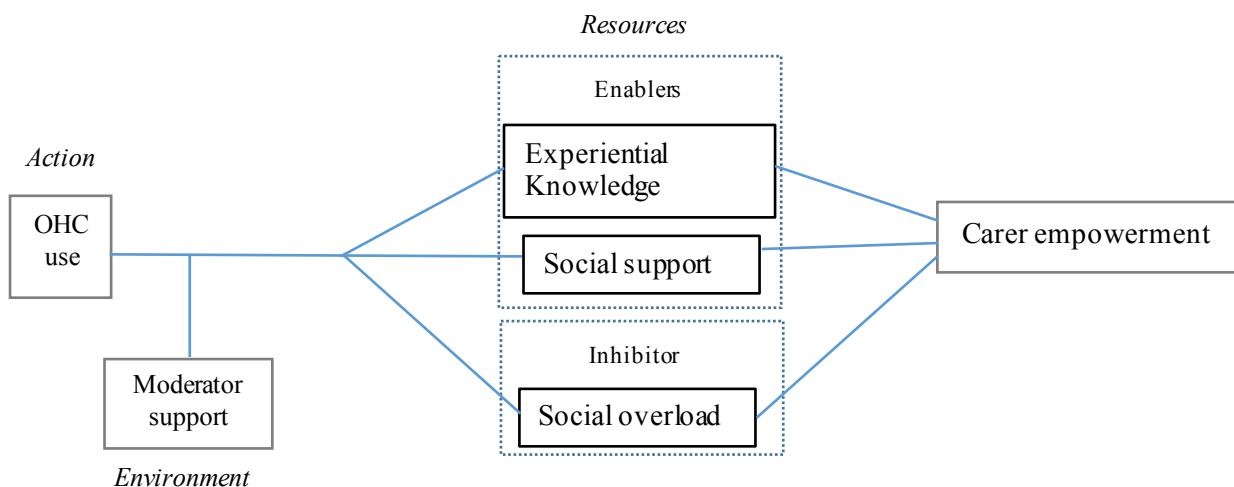


Figure 1. Initial conceptual model of OHC use and carer empowerment**Expert interviews**

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 (OHCs), this method of investigation was suitable. Although it is not the primary method of data collection, this technique of interview has been employed as an exploratory investigation to collect preliminary data.

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 Pöchhacker 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 described in Table 1:

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.

Table 1: Procedure of eliciting expert response

a). Developing the 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).

b). 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), and these are named E1 to E8 in the discussion below. This research has been approved by UTS HREC REF NO. ETH18-2716

c). Conducting the interview: 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.

d). Coding: It is the clustering of key issues into themes for analysis. We used Nvivo to code and perform a thematic analysis. Themes were formulated from the text as the coding took place, as opposed to being formulated before.

Findings

This section presents findings from interviews with the eight experts. Fig. 2 shows the sub-themes that emerged from interviews, while Table 2 gives a summary of the interview responses.

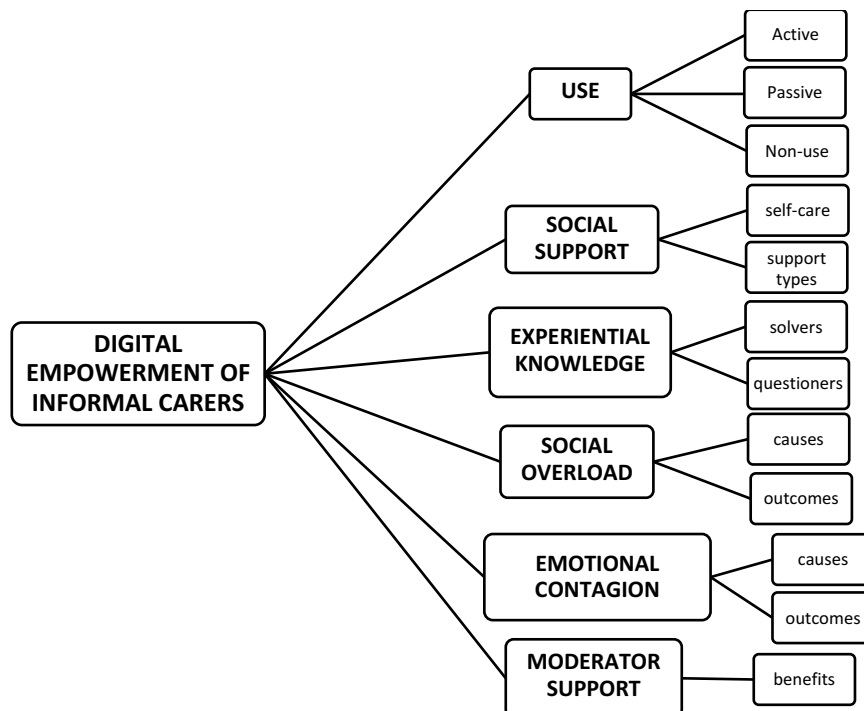


Figure 2. Summary of sub-themes as they came from interviews

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

Table 2. Summary of results of expert interviews***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), thereby empowering them. 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 – that's the point where others can actually support

them because if they don't know what that person is going through, you don't really know what kind of support they're needing... I think, you know, contributing is very important to receiving the support you need..... if you really want the response or the support to be very idiosyncratic and very addressed to you as an individual, that contribution, that participation is needed from you.” (E4)

The others acknowledges 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, they can be informed and they can make a better decision.” (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 creation and exchange of knowledge as a justified variable when considering online interactions in relation to empowerment, largely because most carers relate better to experiential 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*”, the “*kind of tacit knowledge that came from their experience and they share it,*” as well as “*explicit knowledge which is written there, you know, that can be transferred through let's say, writing to others...*” (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 has 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.

For the reasons advanced, all the experts subscribe to the importance of knowledge creation and exchange 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)

They continued to discuss 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 is 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

Emotional Support - being able to turn to others for consolation and encouragement in stressful times, leading to a feeling of being cared for.

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)

Network Support - believing that you are part of a group since you share the same concerns and interests.

Most carers are “quite isolated generally”, and have no “positive social network”. So they come to the forum, “create friendships” and stay for “social fulfillment” (E7)

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)

“..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 care about each other, and commend each other's efforts in caring, “that they are doing their best in that situation”, encouraging them “to be strong for example, say ‘don't... 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 - 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.

For most informal carers, “the 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) yourself because it's all about the person you're caring for” (E7); but thankfully, the provision of social support places focus on the carer. In the forum, other carers “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 fatigued and 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 unless you're on an online chat which is not something we have.” (E7)

“sometimes people... who are very frustrated, or very stressed, they cannot share information.” (E1)

- * 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. As E6 views the issue, *“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.

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>
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/facilitator 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>

Table 3: Benefits of moderator support

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

Given the foregoing, the general outcome of the interviews confirms that all the variables identified in literature are actually sensible and relevant to study in online empowerment in a moderated environment. Notwithstanding, it has emerged from these results that there is another inhibiting factor to empowerment in an OHC, that is ‘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. Experts shared the same views, that online communities tend to permit emotional contagion. For example, someone who posts negative emotions with the intention to get them off their chest, would not realize the negative effect this is having on other carers:

“... 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” (E5)

“...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)

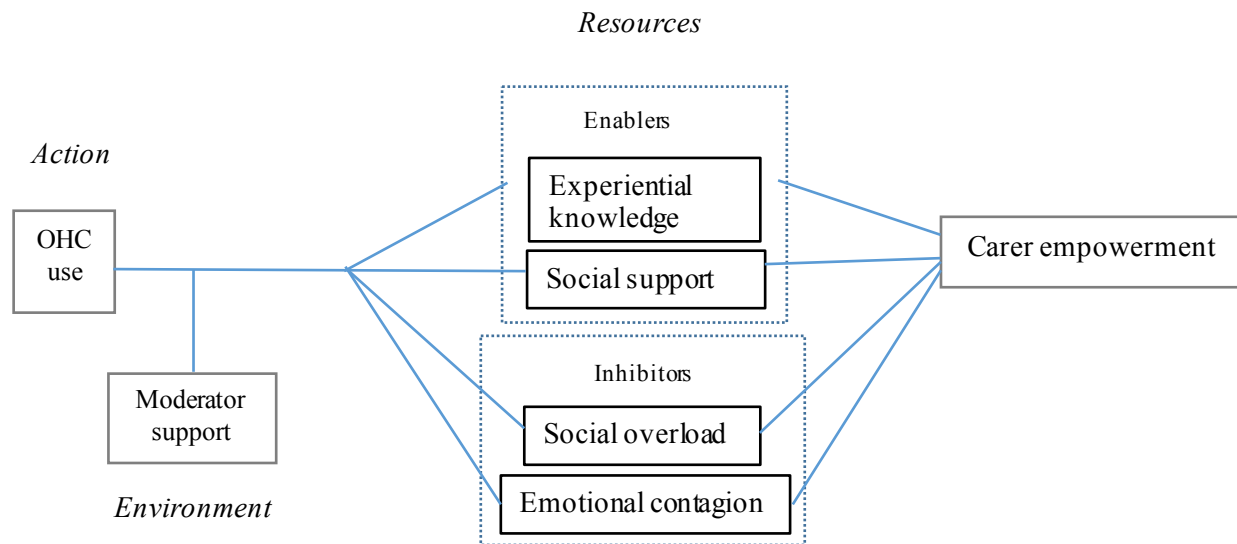


Fig. 3: Modified conceptual model of OHC use and carer empowerment.

Discussion, contributions & further work

The primary aim of this study was to verify the conceptual model of digital empowerment of informal carers in OHCs. Through an exploratory expert interview, the validity of all the proposed constructs in the model was confirmed. An additional construct emerged from the experts' conversations – emotional contagion). Most experts confirmed that the constructs made sense in exploring digital empowerment of informal carers, specifically in moderated environments. Therefore, this outcome adds to our understanding of digital empowerment of informal carers in online health communities.

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 – health workers 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. 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 aspect of online forums' use (Erfani and Abedin, 2018). 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'. That construct emerged from the interviews.

Expert interviews are normally used to triangulate studies, and so it is with this study. The authors intend to proceed with content analysis of informal carers' and moderators' discussions from an OHC, which will confirm if the discussions conform to the proposed conceptual model. The analysis of these

studies will further inform the carer's survey, which will solicit their perceptions on online empowerment and effect of moderator support.

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