Online support communities for older people: Characteristics and dynamics of online social support

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Introduction

More and more people aged 60+ are using the internet. In recent years, older people's activities online have expanded from information retrieval to include social and communicative activities as well. While email is currently the most prevalent communication activity of older people online, the use of online communities is also growing within this group (Jones & Fox, 2009). Many older people now use online communities on a regular basis, often to find information and support concerning a specific health problem. Scholars and practitioners in the area of Inclusive Design have done a lot of work towards accessible web design for older people by developing guidelines that assert accessibility standards (e.g. Kurniawan & Zaphiris, 2005). The focus of this work has been mainly on the accessibility of information on the internet. However, the increasing amount of social activities on the internet poses new challenges for Inclusive Design researchers. Ensuring access to information on the internet is no longer sufficient: social aspects of activities on the internet should also be considered (Pfeil & Zaphiris, 2009a).

Jones and Fox (2009) found that around 70% of internet users aged 64+ go to web sites that provide information or support for a specific medical condition or personal situation. In addition, they state that "older internet users are significantly more likely than younger generations to look online for health information. [...]. Researching health information is the third most popular online activity with the most senior age group, after email and online search." (Jones and Fox, 2009, p.3) This figure shows that many older people consider the internet as a source for support concerning health issues. The increase in communication activities of older people online and their interest in exchanging support online suggest that online support communities might be of particular benefit for older people. Thus, research is necessary in order to understand what kind of support older people expect from online support groups and how older people exchange support in these settings. This includes taking into account how older people communicate with each other, how they exchange information and support, and how they form relationships and groups online.

Up to now, research has shown that online communication can enhance older people's quality of life and well-being (Xie, 2007), as it increases social interaction (Bradley & Poppen, 2003), provides the opportunity to connect to like-minded people (McMellon & Schiffman, 2002), and empowers older people to not only receive but also provide support. Especially for older people who suffer from a specific illness and/or are housebound, online support communities give the opportunity to meet people who are in a similar situation and engage in satisfactory social interaction (McMellon & Schiffman, 2002) which can prevent isolation and decrease loneliness (Bradley & Poppen, 2003). Research investigating why older people use CMC found that the opportunity to socially interact with like-minded people and the exchange of social support and companionship

are strong motivators (Kanayama, 2003, Pfeil & Zaphiris, 2007). Several studies have already investigated the content that older people share in online support communities (White, & Dorman, 2000; Wright, 2000; Xie, 2005; Kanayama, 2003). Others have applied query-based techniques to investigate the perception of online social interactions among older people (Wright, 1999; Wright, 2000, McMellon & Schiffman, 2002) or looked at online social networks (Zaphiris & Sarwar, 2006). However, few of these studies investigated social support specifically, and few used multiple methods to conduct their research.

Our work investigates the use of online support communities by older people. In particular, we are interested in the kind of support that older people exchange in online support communities (study I). Furthermore, we analyse in detail the conversational components that compose online supportive interaction (study II). In addition to looking at the content of online supportive interaction of older people, we also investigate how the exchange of different forms of support and other content in these settings facilitate relations between online support community members (study III). These studies provide a comprehensive overview of activities and dynamics in online support communities for older people. In order to investigate how older people perceive the exchange of support in online communities, we conducted interviews with 31 older people with various levels of experience of participating in online support communities (study IV).

In the following, we present a synthesis of our work by summarising our studies. In addition, we will briefly touch on our current study, focusing on social roles of older people in online support communities.

Analysis of online social support for older people

Online support communities offer a place for people who experience a similar life situation to come together to share information and to support each other. Up to now research has mainly investigated online support communities for mainstream users. Little is known about how people with disabilities and older people interact and socialise in these settings. The aim of our research is to fill this current gap and investigate the exchange of support in online support communities for older people.

Study I: Aspects of supportive communication

In order to understand the nature of online social support for older people, we investigated the content of an online support community for older people (SeniorNet). Qualitative content analysis of 400 messages from a discussion board about depression was used to determine how social support is expressed and facilitated in online communication. Special emphasis was placed on determining the components of online social support. Based on our analysis, we developed a code scheme that can be used to analyse online supportive communication among older people. This investigation identified different components of social support as well as their frequency and prevalence in supportive communication. In particular, we identified the kinds of communication shown in Table 1 (Pfeil & Zaphiris, 2007):

Table 1: Categories of the code scheme for communication in online support communities

Category	Description	Example

Self disclosure (SD)	Text units in which people post information about themselves. This can be done in several ways (emotional, medical, narrative).	" I want to go to bed. I know you're supposed to get out, but I don't have the energy to do that much."
Community building (CB)	Text units that include people's opinion about the online support community and meta-information about the activity within the online support community.	"Thank God for this board, as I can sit here and cry and rattle on---you are the only ones who understand."
Deep support (DS)	Supporting text units that are often emotional and customised towards the unique situation of the person that the message is written to.	"Words are so hard right now. So I place my hand gently over yours and let love […] flow through to you."
Light support (LS)	Encouraging and uplifting text units. They are usually written in a generic way and can be aimed at individual members or the whole online support community.	"Hang in there" , "I am thinking about you" "Best wishes"
Factual information (IF)	Text units that include factual questions and information about the topic of discussion.	"So in "both cases" situational depression and bipolar depression they alter chemicals in the brain?"
Off topic (OT)	Text units that are not related to the topic of the online support community	"Sorry to hear Iowa's weather yesterday. Minnesota is much too cold and damp."
Technical issues (TI)	Text units that ask technical questions about the use of the online support community and suggestions on how to solve them	"Read in your browser screen and have Notepad or Wordpad minimised…"

By investigating the components of social support, we further clarified the phenomenon and its occurrence online. Our code scheme and its relation to social support go beyond existing research and provide a framework for analysing the nature and degree of social support within an online community (Pfeil & Zaphiris, 2007).

Study II: Interaction patterns of supportive conversation

In addition to the analysis of the content that older people exchange in an online support community, we also investigated the interaction patterns of online supportive conversation. We analysed a data-set of messages posted over the period of six years in an online support community for older people (the same community as in study I) using our code scheme. We studied the content and sequences of messages within this data-set. Our findings showed that the following pairs of content categories occur significantly more frequent in related messages than the random value based on the probability of the individual categories:

- Self disclosure–Self disclosure
- Self disclosure–Deep support
- Deep support–Community building
- Deep support–Self disclosure
- Community building–Community building
- Light support–Light support
- Factual Information–Factual Information
- Off topic–Off topic
- Technical issues–Technical issues

We linked our findings to the level of activity of the online support community over time. We found that certain sequences of messages within the online community are related to the level of activity. For example, we showed that the mutual exchange of personal information and receiving support after talking about personal problems are basic components for the sustainability of the online community, whereas conversations

that go off the topic of the online community seem to be related to a decrease in the level of activity (Pfeil, Zaphiris & Wilson, under review).

In a second part of the investigation of interaction patterns, we focused on different levels of interactivity within the online support community. Namely, we investigated different topologies of message connections: lines (messages only responding to one previous message), triangles (three interconnected messages) and cliques (four or more interconnected messages). Figure 1 shows these topologies.
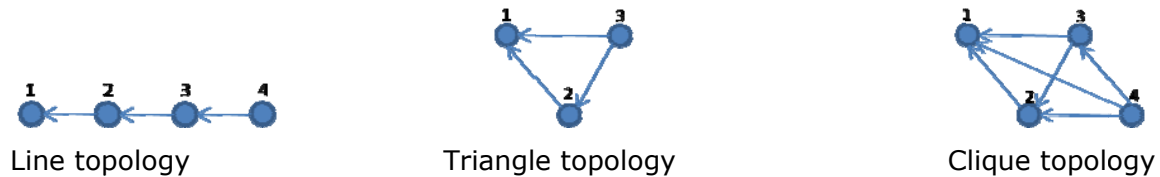

Line topology   Triangle topology   Clique topology

Figure 1: Topologies of message structure

Our findings showed that these three message connection topologies seem to facilitate different kinds of communication processes. Lines seem to support short and general message exchanges in a dialogue-style, containing mainly off-topic conversations. In contrast, triangles seem to be the backbone of supportive communication, as they facilitated the exchange of both emotional as well as informational support and played a major role in sustaining large conversations. Cliques, being the most interactive topology investigated, seem to be associated with the exchange of experiences of online support community members. Rather than being just a conversation between two or three people, cliques were found to form a conversation context that invites other members of the online support community to contribute with their particular viewpoint about the issue under discussion.

Study III: The development of social networks

In order to investigate the development of older people's relationships within an online support community, we analysed the communication patterns and relationships between members of an online support discussion board (the same data-set that we used for the development of the categories – see study I). Figure 2 shows the sociogram of the communication activities within the online support community. The nodes represent members and the lines represent communication activities among members (e.g. one line from member 41 to member 45 represents member 41 sending a message to member 45).
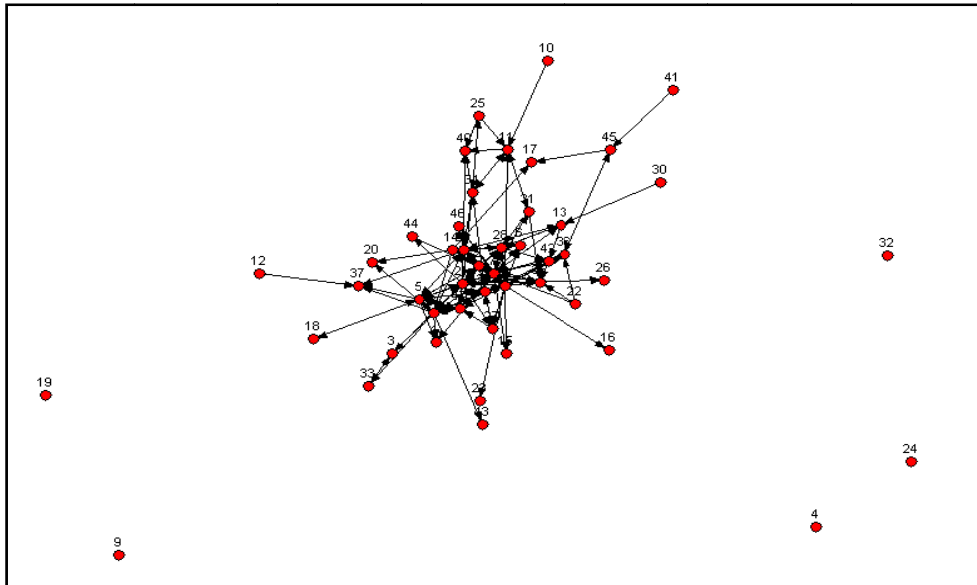
Figure 2: Sociogram of online support community showing the communication activities among online community members

In addition to looking at the structure of the message exchanges within the discussion board as a whole, we also investigated associations between the communication content and the social network patterns. We were interested in whether the exchange of emotional communication content is associated with specific characteristics of the social network structure opposed to factual communication. Investigating the differences and commonalities of the category-specific sub-networks, it was clearly visible that emotional conversation is linked to a different network pattern compared to factual conversation. People were more connected, closer to each other, and included more members in the sub-networks that were built on emotional communication compared to factual communication. This shows that emotional communication is an essential part of the discussion board as it is the emotional part of the conversation within the discussion board that is associated with a strong connection between people.

In addition, we also focused on the differences in the network structure between the two components of seeking and giving support. We found interesting differences between self-disclosing (seeking support) and supportive communication. Self-disclosing messages were often sent to the whole community. In contrast, supportive messages were rather directed to a specific member of the online community than to the whole community. As supportive messages were directed to specific others, they have a very important role in the development of relationships as they connect individual members of the online community. However, self-disclosing messages play also an important role for the development of a social network. The fact that self-disclosing messages were often sent to all members of the community shows that they are very inclusive and act as prompt to trigger responses from members of the whole community. This means that even members that are currently not very active receive self-disclosing messages which could encourage them to reply.

Differences were also found between the category-specific sub-networks of Light support and Deep support. The sub-network that was developed from messages within the category Light support showed a lot of reciprocal links between members of the online community. This means that a lot of the relations that were developed through the exchange of light support were bi-directional and balanced. In contrast, the exchange of deep support was linked to a sub-network-structure that was imbalanced and distinguished more between the role of the support-giver and the support-receiver.

Additionally, the exchange of deep support seemed to happen within cliques within the online community rather than within the online community as one group (Pfeil & Zaphiris, 2009b).

Study IV: Older people's perception of online support

After investigating older people's behaviour in online support communities, we studied older people's needs and preferences concerning online social support. We focused our analysis on the seven different aspects of online support already mentioned above: Self disclosure, Community building, Light support, Deep support, Factual Information, Off topic, and Technical issues. For each aspect we were interested in how older adults perceive this aspect of support, what they think are the similarities and differences of this aspect of support in online settings vs offline settings, and what they perceive are the advantages and disadvantages of communicating this aspect of support online. We did this by conducting detailed interviews with three groups of older adults (31 people in total) with different levels of expertise in using the internet and online communication (older adults who do not use the internet, older adults who use only email, and older adults who participate in online support communities). Interviews were transcribed verbatim and analyzed. Our findings describe older adults' perception of different aspects of support and identify their motivation for turning to online support and the reasons for any reluctance to do so. Thus, our findings give insight into how online support communities could best be utilized to improve older people's experience with online support (Pfeil, Zaphiris, & Wilson, 2009).

Our participants reported that they enjoyed using online communication to exchange light support and information in a similar way to younger people. But they also mentioned feeling uneasy when it comes to building trust with people that they don't know, talking about personal issues and exchanging emotional support online. Our study showed that even people who generally have a positive attitude towards online support communities do not easily trust others online. In contrast to younger users, our participants felt that online communication is a skill that they have to learn and communicating via email or in online communities is not something that comes naturally to them. Some participants considered the internet a communication device only for the younger generation. They argued that online communication requires being able to speak a 'specific language' which is harder for them to learn, because they have not grown up with it. Also, older adults in our study mentioned that online communication is not very useful for them as most of their friends do not communicate online either.

In our study, most of these inhibitions towards participating in online support communities seemed to be rooted in a mistrust and suspicion towards people who participate in online support communities. Our findings show that some older adults still have a strong tendency to stigmatise people who participate in online support communities as sad and insincere. In addition, some of our participants mentioned that they had been warned of harmful consequences of disclosing personal information online which made them anxious about becoming a victim of fraud and misbehaviour. They focussed on this warning and had the impression that online communication is very dangerous as there are others 'out there' that will intercept their messages and steal their personal information and identity or harm them in some other way. Also, older adults mentioned that they do not feel as internet-literate as they would wish to and this results in an insecurity that prevents many of them from using online support communities. Although they generally do not have any problems using the computer, they feel that in times of distress it still poses an extra burden to them and in these situations, they would rather seek support through other communication channels (eg. face-to-face meetings or phone conversations).

Our findings clearly show that there are still barriers for older adults to participate in online support community settings. By investigating older people's motivations to exchange support in online settings and their reasons for being reluctant to do so, we help better understand how online support communities could best be utilized to improve older people's experience with online support (Pfeil, Zaphiris, & Wilson, 2009).

<u>Current study</u>

As a follow-up to our previous studies, we focus our current research activities on social roles that older people take on when communicating in online support communities. Based on their communication activities and relations to other members in the online community, members of the online support community are characterised by their communication activity. And it is through these characteristics that older people take on certain roles in the online community. Similar studies in online communities for different target populations have shown that people take on roles, like the "questioner" (coming to the online community to ask questions only), the "answer-person" (answering other people's questions), the "troll" (starting provocative conversations) etc. (Turner et al., 2005). The aim of our studies is to investigate the nature of the roles that older people take on in online support communities and investigate to what extent this differs from roles in other online communities for different target populations.

Conclusion

We believe that the outcome of our studies is of use for both researchers and practitioners in the area of HCI/CMC as it sheds light on an area about which relatively little is known. Our research shows the characteristics of online social support as exchanged in online support communities for older people. By investigating in detail the components and dynamics of social support, our research helps clarify how online support communities are currently facilitated and used by older people. In addition, our categories provide a useful tool for investigating online social support. Furthermore, we go beyond the mere investigation of user behaviour, but our interview results also give insight into how this behaviour is perceived by older people.

Findings from the studies and the description of social interactions in online support communities for older people can help better understand how older users interact with each other in online support groups. If we understand the aspects of online social support and how it is exchanged by older people in online communications, we can also find ways to nurture it and design online communities to better facilitate supportive communication.

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