Like an extended family: Relationships that emerge when older caregivers use written messages to communicate in an ICT-based health care service

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Abstract:

Objective: To explore the relationships that emerge amongst caregivers of persons with dementia and stroke when caregivers use written messages as their communication tool in a closed information and communication technology (ICT)-based support group. **Methods:** An explorative design with a qualitative approach was used that applied systematic text condensation (STC) to analyse 173 written messages extracted from a web

Results: Empathetic, empowering and familiar relationships emerged amongst peers of older caregivers when the caregivers used written messages as their communication tool. The empathetic relationship was characterised by sincerity and openness when the caregivers shared emotions related to caregiving. The empowering relationship reflected a fellowship based on solidarity influenced by a sense of optimism and a willingness to share knowledge to support one another in overcoming challenges. In the familiar relationship, the caregivers were thoughtful and good-humoured with one another and displayed an attitude of consideration towards one another, as in an extended family.

Practice implication: The use of computer-mediated communication in health care service will change the context of establishing and maintaining interpersonal relationships. Therefore, greater knowledge regarding how the peers of caregivers interact with one another is vital so nurses may better support and educate ICT-based support groups.

Keywords: support group, web forum, caregivers, peers, relationship

INTRODUCTION

Family caregivers comprise an important component of the health care system in the Western world [1-3]. The role of a family caregiver may often last for years, and the pressure and demands of care may become a threat to the caregivers' health and well-being. Studies have described caregivers as always feeling tired [4, 5], being isolated in their homes [6], suffering in silence and putting their own needs aside [7], feeling lonely [8] and experiencing physical and mental stress [9], fatigue and depression [10]. Both internationally [2] and in Norway [11-13], attention has been directed to the caregivers' need for support. Information and communication technology (ICT) is expected to provide supportive information, education and communication to ease informal caregivers' everyday lives and to enable their social contacts to be maintained more easily [3, 12, 13]. On the Internet, different types of support groups have evolved in either open or closed networks. In open networks, the participants are often anonymous, and the written messages are visible to any people or peers who log onto the web page [14, 15]. Closed networks are often run by an organisation or the public health care system and often utilise a professional to moderate the communication amongst the participants and between the professionals and the participants [16]. Communication amongst peers has been deemed important [12, 17, 18]

and involves types of support, information and knowledge that differ from what the caregivers receive from health care providers. Because they are in the same situation, peers often have similar experiences and therefore have the ability to help one another. This supportive perspective was reported in a review exploring the interactions of informal caregivers in online support groups [19]. In this review, tailored information from peers directed at their own situation was deemed valuable. The caregivers appreciated having the ability to communicate with a group of people who had similar experiences and concerns regarding changes in their situation. Stoltz, Udén and Willman [20] reported that informal family caregivers wanted to network with peers to avoid isolation and to satisfy learning needs. Studies of online support groups for caregivers have generally focused on evaluating the service, the impacts caregivers have on the service [21-23] and how the participants have used the network [24]. The majority of online support groups for informal caregivers focus on the patient. Communication within these groups occurs between the caregivers and the health care provider to improve communication and improve the care of the care recipient [25-27]. The groups of caregivers generally comprise persons who have different relationships with the care recipient and live separately [28]. There seems to be a paucity of studies focusing on older, spousal, informal caregivers living in the same household as the person receiving the care [28].

Few studies have focused on the experiences peers of caregivers have shared in written messages in a closed, supportive web forum. However, the ComputerLink Network for caregivers of persons with Alzheimer's disease has been the subject of various studies [29-31]. In this network, caregivers use the public bulletin board to request information regarding how their peers master their everyday lives with their respective care recipients. Caregivers vent their frustrations and communicate about how caring influences their own lives. The peers of caregivers provide support, suggestions or acknowledgment to one another [29, 30]. Gallienne et al. [31] observed that caregivers provide instrumental, emotional and spiritual support in their messages. Instrumental support is related to information regarding practical concerns and assistance. Spiritual support comprises offering Scripture, prayer and inspiration. Emotional support comprises expressions of sympathy, understanding and a sense of community when sharing intimate feelings and problems [31].

The studies cited above did not specifically focus on the relationship the caregivers developed in their network. However, Brennan et al. [29] stated that the messages caregivers posted indicate that they have a sense of being part of a group. Brennan et al. [30] also noted that caregivers appreciate having a place to express their feelings to peers. Gallienne et al. [31] focused on the sharing of spiritual support amongst the peers of caregivers and described caregiver interactions to be influenced by closeness, trust and confidence. These studies, with a somewhat different perspective from relationships developed in online networks, indicate that new and additional research on this subject is required. The objective of this study was to explore the relationships that emerge amongst caregivers of persons with dementia and stroke in the context of a closed, ICT-based support group. Therefore, our research question was as follows: What types of relationships emerge when caregivers and their peers use written messages in an online forum as their communication tool?

Generally, interpersonal relationships are established in face-to-face (FtF) communication [32, 33]. In the current study, however, the communication amongst the caregivers was based on computer-mediated communication (CMC). Social Information Processing (SIP) theory [34, 35] provides a framework for interpreting and understanding

relationships that change when transferring interpersonal communication from FtF to the use of CMC. According to Walther [34], using CMC generates identical or better possibilities to develop and maintain as close a relationship as FtF communication, but relationships may take longer to develop. The absence of the usual nonverbal FtF cues allows users to employ the verbal characteristics in CMC to impart the relational information that normally is expressed through nonverbal cues. Walther observed that the interpersonal FtF relationship might change and evolve into a hyperpersonal relationship amongst the users in CMC. Hyperpersonal communication is more intense and intimate than we tend to experience in parallel FtF interaction. Four relevant media effects render this development possible: 1) the sender, who has the ability to present his or her self in a controlled and socially desirable manner; 2) the receiver, who may idealise the sender because of a lack of contextual cues; 3) the CMC channel, which enables editing, discretion, convenience, no time limit and no distractions; and 4) the feedback loops, which are exaggerated expectations that are confirmed and responded to by mutual interaction between the sender and receiver in the communication process. The relational perspectives described in SIP theory have formed the underlying analytical framework for this study.

METHODS

We applied an explorative design with a qualitative approach to obtain more knowledge regarding our theme [36, 37].

Description of the supportive health care service

The participants were members of a closed, nurse-moderated health care network intended for spousal caregivers of patients suffering from dementia or stroke. The service was a result of co-operation amongst three municipalities in one county in southern Norway and was primarily based on CMC. The service had operated for approximately six years, and its purpose was to support caregivers in their everyday lives and to establish contact amongst the caregivers in the network. The network integrated four services, and the participants were expected to use all of those services when signing up for the network. Three of the services were ICT-based services: a mutual call centre staffed with a nurse, an information platform and a web forum. The fourth service was social FtF meetings, which were organised separately for each of the municipalities. In the present study, the mutual online web forum was the selected area for data collection, and the focus was on the written communication amongst the caregivers without support from the nurse. However, writing anonymously was not an option in this forum because every written message was linked to the name and image of the sender.

Data source and selection of text

Digital texts are one type of data source described in qualitative research [38, 39]. We aimed to explore the types of relationships that appeared when the peers of caregivers communicated online via written messages. We considered that excerpts from the web forum would provide the necessary data. We requested access to the network from the manager of the inter-municipalities organisation of the health care services in the county.

Our application was accepted, and our access to the web forum was obtained through the coordinator of the network.

Approximately 40 caregivers participated in the network, 30 of whom were active members. Their ages ranged from 42 to 92 years, although the majority were over 65; the number of participants was equally divided between men and women. Concerning the data collection, the coordinator was of the opinion that the best way of collecting data from the web forum was to select excerpts from the dialogues over a period, and not take out random prints from distinct days, as we had initially planned. The reason for this was that the content of the forum was organised chronologically, which resulted in different themes emerging interchangeably. One person could post a message, and comments regarding this message could appear days or weeks later. In between these messages, there were numerous messages addressing other topics such as congratulations, information and jokes. The number of daily postings varied considerably.

The research team agreed on this approach and presented the following criteria to the coordinator for selecting messages: images of the contributors were to be removed, names of caregivers and spouses were anonymised [38] and repeated contributions from the same person in one discussion were to be labelled with the same number for each contribution. In the beginning of the data collection, the coordinator extracted all kinds of messages regardless of subject to give the researchers a broad understanding of what kind of subjects the caregivers discussed. During the process, we decided not to collect more messages dealing with congratulations and comments about the weather, but to focus upon subjects related to the caregivers' situations and their roles as caring spouses. Every month we received a document with extracted messages from the coordinator, and we could ask for additional messages if we thought it necessary. The data collection lasted for two years to ensure we received a large and varied selection of written dialogue and themes from the caregivers. Each message varied in length from five to approximately 650 words. Some messages addressed multiple themes in the same message. When this occurred, we accessed the entire message to prevent any discontinuity in the themes and tone of the message. During 2010 to 2012, we received 21 documents of message excerpts containing 476 written messages.

Ethical considerations

All of the participants in the health care service network signed an informed consent indicating acceptance of the possibility that their text on the web forum might be used in research studies. The Regional Committees for Medical Ethics approved the study (Reference number: 5-08733c2008/20175).

Analysis

Systematic text condensation (STC) was conducted using a model described by Malterud [40]. STC was chosen because it is appropriate for organising, interpreting and summarising data from multiple participants [33], such as our data. The analysis was conducted in four steps. First, the first author read and reread the messages to become familiar with the content and identify preliminary themes. We then used qualitative research software QSRNVivo version 10 [41] to organise the data into eight preliminary themes: caring for the patient, knowledge, duration of respite, the weather, social meetings, spare time, family life and their own health. Considering the research question, three of the themes (caring for the

patient, knowledge and duration of respite) were assigned priority for further analysis. Second, each of the messages in the three themes was systematically reviewed line by line to identify meaning units, which were marked with codes. The codes were grouped and organised into categories and sub-categories. Third, every meaning unit within the categories was reviewed, and the content was reduced to a condensed form written in first-person. Fourth, the condensed form was synthesised into an analytical text based on the empirical text. The final component of the analysis encompassed an iterative process in which the story of each category and sub-category was read and re-read several times. The process of moving repeatedly back and forth between the text and the whole guided the interpretation that established the final themes. To assure the quality of the interpretation, the research group discussed the labels, content and quotes in every theme.

FINDINGS

Three types of relationships — empathetic, empowering and familiar — were identified in the analysis of the messages the peers exchanged. These categories reflect different but closely related types of relationships. The empathetic relationship refers to the illness of the caregivers' spouses and how this affected the caregivers' health. An empowering relationship reflects how the caregivers received support from peers to endure in their respective situations. The familiar relationship shows how the caregivers acted towards one another in the peer group.

An empathetic relationship reflects the empathy the caregivers expressed when their peers disclosed their concerns regarding their spouses' declining health. The empathy was visible when a caregiver showed his or her despair according to their own mental and physical strain, which they experienced as a threat to their health. The messages were characterised by sincerity and openness.

In the messages, a number of caregivers expressed constant worry regarding the progression of their spouses' diseases. Caregivers of spouses who had suffered from stroke described their stress related to the dramatic and unpredictable hospitalisations that were often the result of fall injuries. The responses from other caregivers expressed understanding that such incidents affected the caregivers both practically and mentally and that it was impossible to be mentally prepared for such events. A caregiver felt gratitude for the concern her peers expressed: 'Thank you for the good thoughts brought to me by phone and here on our forum. It feels so good when somebody cares'. Other caregivers wrote about their spouses' rapidly declining cognitive function because of dementia. These messages conveyed sadness, despair and helplessness. Replies from peers conveyed empathy in their understanding and compassion for the caregiver, as exemplified in this dialogue:

'The nurse told me that my wife's dementia is rapidly worsening. From week to week, I notice major changes. One problem is, what do I tell her? What have you that have been in the same situation told your spouses?'

'Dear John! It hurts me deeply to read what you are writing now! I am really sympathizing with you! My wife often asks me who I am. Then we look at old photos, which helps to revitalize her memory. Forgive a novice; I'm just trying to say what works for us. Sincerely, Joe.'

Unfortunately, some caregivers' spouses died, and the caregivers announced this either personally or through another caregiver. The peers answered with condolences, sympathy and comfort. Several caregivers wrote that they knew how such an event affected life both now and in the future. The comfort they conveyed in their messages contained advice such as 'Take one day at a time' but also wishes that God would give comfort and strength in the situation. Peers described the importance of having close family around, but also urged the mourners to take comfort in and find support from their relationships on the forum. A response from one caregiver indicated the condolence messages had been significant to her: 'Warm thanks to everyone who sent me words of comfort'.

Around-the-clock caregiving causes mental and physical strain. The messages afforded the caregivers opportunities to spend a little time on themselves. Some caregivers conveyed discouragement, and others conveyed despair and frustration over the situation. One caregiver was exasperated by poor service on their safety alarm, describing how, after a week's reminders, the security alarm was finally repaired, which meant the caregiver could leave his wife for a few hours. Several responses showed that other caregivers rejoiced over this outing and wished the caregiver a good time. Another caregiver, Tom, showed his despair over his situation when he posted this message: 'Nurses are very good at telling me that I have to take good care of myself, but how is it possible to have some privacy? Who is observing the patient?' Tom received a reply from another caregiver expressing respect for Tom's vulnerability and gently gave him advice: 'Forgive me, but I would have chosen to listen to that nurse. Find a safe placement for your wife while you take care of yourself, then you will be able to continue to take good care of her'. The empathetic relationship showed the peers trusted each other when they disclosed their vulnerability and reflected empathy in their consideration for one another.

An empowering relationship reflects fellowship and solidarity as a catalyst to empower one's self and peers. The caregivers wrote about the practical challenges of their daily lives, as well as their challenges with the public health care service. This relationship was influenced by a sense of optimism, a willingness to develop the necessary competence to care for their spouses and the strength to continue.

In several messages, the caregivers mentioned their demanding daily lives. In addition to spousal care, these spouses had to manage and perform all of the practicalities of daily life alone. However, several messages showed a positive attitude towards their situation; they did not ask for sympathy or convey negativity, as this dialogue shows:

'Suddenly both my arms became powerless, and we needed help for everything.

Then I came across a link to an agency that could care for my husband and our house, and in addition, they could look after my husband for four hours every fortnight. I write down the phone number, in case some of you are interested.'

'This may be something to think about! Just being able to get some hours off with a good conscience is so valuable. My husband is so shaky that I must be present all the time. Quite tiring ... but one must not complain.'

To empower themselves or one another, several caregivers inspired their peers by writing narratives regarding how they managed their daily lives. One caregiver wrote that openness regarding his and his wife's situation was the easiest way to receive understanding from other people. The caregivers also explained the importance of making plans for when their spouses were away for a brief period of relief. It was important to use this period to restore themselves so they would be able to continue to meet the demands of caring for their spouses. Although the caregivers required some time off, they discussed their feelings of guilt concerning sending their spouses away. One caregiver wrote, 'When I feel longing and guilt in her absence, I try to tell myself that it is a healthy sign of love'. Several caregivers wrote about their joy when their spouse returned after a period away from home. The peers of the caregivers sent their best wishes and showed they shared one another's joy. The peers also wrote about the importance of appreciating the good times the caregivers had with their spouses. The peers knew that changes in their situation could occur abruptly; therefore, it was important not to grieve in advance, although avoiding grief is difficult.

To ease their daily lives, peers shared Internet links regarding dementia, stroke and procedures to access and address public health care tasks. Several caregivers deemed it a great challenge to understand how to manage Internet procedures to fill in public forms. These procedures were too difficult for some caregivers to master, and those caregivers appreciated the peers who provided help. This help empowered the caregivers to manage better on their own.

'I clicked on helfo.no and found links to change GP. I wrote down the procedure in case it could be beneficial to others who experienced the same.'

'I am impressed, Christian. This, I must say, requires its MAN. Why do they make things so difficult for us users that we have to give up? You, however, do not give in, and that's really tough. Good work, I send you a hug!'

Receiving no response to messages posted on the forum seemed to be a catalyst for action for one of the caregivers. Paul experienced discontinuity in the public health care system because of the numerous and different health care professionals caring for his wife. Paul asked his peers on the forum whether any other caregivers had had the same experience. No one responded. Consequently, Paul concluded that his situation was unusual, prompting him to contact the health care service. Later, Paul posted another message regarding the results of the meeting with nurses from the health care service: the health care service was going to provide more continuity in caring for his wife. This time, Paul received more answers to his message. Some caregivers had been wondering about that practice, and some of his peers concluded that caregivers always had to be an advocate for their spouses. Some peers approved of his taking action: 'So good, nice to hear, Paul. Now you know you can just go and visit them if you need to. Sure, you had a good day then'. The significance of sharing messages is thus twofold. First, Paul was empowered by a go-ahead spirit to do something

about his situation after receiving no responses to his first message. Furthermore, his peers may have been inspired to take action later if such situations occurred. Paul's action showed that it was possible to address things that were not working properly with the homecare service.

Experiencing similar challenges with the public health care service appeared to bond the caregivers in solidarity and community, and empower them with a mutual go-ahead spirit to take action. This type of empowerment appeared in two different situations. The first situation concerned a change in the public system for ordering transportation for their spouses. Earlier, their spouses had managed to book transport themselves; however, this new procedure rendered such independence impossible. Consequently, the caregivers had to take charge of this action as well. They discussed the matter, and, as a group, they agreed on the importance of fighting to change the new policy: 'I think this case ought to be written about in the newspaper here or in the capital. I think it's the only way we can get someone to react'. Their mutual challenges inspired these caregivers to do something about their situation. The second situation occurred when a caregiver, Carl, wrote about his involvement in improving public support for caregivers of people with dementia. After reading a government report, this activist requested a caregiver course and dementia team in his municipality. Several responses from caregivers supported this request, and his peers encouraged Carl to exert pressure on the council to cause this change to occur: 'Terrific, Carl, and good luck! Hope you gain a hearing for us who are struggling with this daily. We do not have an 8-hour day, but 24/7'. After working on the project for a year and a half, Carl posted the following message on the forum: 'Now I have been informed that they will carry out a study of the dementia plan and I'm invited to a meeting about this. I need to have some input from you by Thursday. FINALLY, something will happen'. In this case, the peer group encouraged the caregiver, who was empowered to stand up for their mutual good. The feeling of solidarity and community in these situations appeared to empower each of the caregivers and the entire group.

A friendly relationship reflects the bonding between the caregivers and their thoughtfulness for one another. The tone in their messages was friendly and humorous when members of the group shared good news and information regarding their situations.

In messages, the group also named certain caregivers who had been inactive on the forum for some time. There were questions regarding how a caregiver's spouse was getting used to a day-care centre and how a caregiver coped with the period when the spouse was on a stay of relief, and there were requests to make contact. The messages showed that the group was thoughtful of and wanted to be there for one another. One caregiver wrote to a peer, 'I know that you're lonely now while your wife is on a stay of relief, but try to relax. Write or call me, I have been a caregiver for a long time, and I want to contribute as much I can to whoever needs it'. Mutual consideration was also seen when a peer was hospitalised, as this message shows: 'Robert suffered a femoral fracture the other day, and he is now hospitalized. I've allowed myself to send him flowers and greetings from all of us'. Other caregivers sent their greetings for a good recovery. Occasionally, some of the caregivers had not been on the forum for some time and sought information regarding what had occurred from certain peers: 'I have not followed so well within the past [weeks], but how is it going with Robert, the poor thing?' Some messages reported that a caregiver would be gone for a

few days, maybe for a vacation or a hospital stay. There were also messages in which a peer called for activity on the forum: 'Sitting here in the early morning and wondering where everyone is?' The tone in this type of message was friendly, thoughtful, kindly and humorous. Caregivers addressed their messages to 'Dear you, send you a hug', and called the peer group their 'extended family' or the 'big family': 'Welcome home! It is so nice to receive good news. We are following our "big family" here on the forum, and we try to put ourselves in your place'. Clearly, some caregivers knew one another quite well; however, some messages also addressed new members of the community: 'Hey Sophie, I do not know you yet, but it seems like you are an early bird, and start your day early in the morning'. Messages such as this indicate that the peer group of caregivers was able to be considerate towards one another and include new members in their community.

DISCUSSION

In the discussion section, we draw on SIP theory to explore the manner in which the four media effects influenced and enabled the different types of relationships described in the results section. The empathetic, empowering and familiar aspects of the relationships will be elaborated upon separately because the media effects appeared in different patterns in each type of relationship.

The empathy in the relationships showed how the caregivers disclosed their feelings to one another. That members disclose feelings in support groups is well-documented in several studies [42], both in open networks [14, 15] and in closed health care networks [30, 31]. In the present study, John and Tom described their feelings regarding their situations. Their messages portrayed their despair, vulnerability, helplessness and, to some degree, desperation. The messages were well-formulated, and both John and Tom requested responses to their situations/feelings. According to SIP theory [43], the media effect of the 'sender' may influence the manner in which the message is formulated. The sender has control of his presentation and can use language to convey the feelings that the sender chooses to disclose. Consequently, in his written messages, the sender can disclose more or fewer emotions than the same sender would have disclosed in FtF communication. The responses to John and Tom from the other members conveyed understanding, humility and sympathy. The tone and formulation of these answers were personal and intimate and were directed to the sender — similar to a feedback-loop. According to SIP [34], the channel used in CMC allows the user to have greater control over message construction than when using FtF communication [43]. The receiver of a message may inflate the perception the receiver forms regarding the sender because of a lack of non-verbal cues. This lack of non-verbal cues, no time span and perceived empathy may lead to an intimate feedback loop from the receiver to the sender, much like the loop described in the present study.

In the present study, John and Tom posted personal and intimate messages that were visible to all caregivers in the network. These senders shared their inner feelings with a number of people who were nearly strangers, and neither John nor Tom knew whether the receivers would care about their despair. In FtF communication, we are likely to choose who we speak to, and typically we know the receiver before we share our inner feelings [33, 44]. When the sender uses a web forum as the channel, that sender has less control of his audience than in FtF communication. On a web forum, one has no information regarding

how the receivers in the network will react to one's disclosure. The receiver, however, has the option to respond specifically to a named person using a feedback loop, although his response is available to the entire peer group. Other studies have also reported on the use of messages directed to a named person on a mutual forum [29-31]. We observed that Joe addressed an answer personally and empathetically to a message John had written to the entire peer group. Using the feedback loop to respond in this manner, Joe indicated to John and the other receivers that Joe had virtually embraced John. Additionally, Joe disclosed his own vulnerable situation. In this manner, the web forum functioned as a communication channel in which the group showed empathy and developed mutual respect for one another.

The empowering aspect of the relationships appeared when the caregivers shared messages addressing challenges the peers had also experienced, followed by encouragement to master these situations. More caregivers reported their experiences with the new routine of ordering transportation service, which had resulted in more strain on their daily lives. The community they experienced empowered the group to use the web forum to discuss the case and do something about the problem as a group. Feelings of fellowship in support groups are well known from other studies [45-47]. From the perspective of SIP theory [43], relationships may be hyperpersonal when the users experience fellowship, are physically separated, communicate via a limited channel and have the media effects of being a sender or receiver. CMC affords opportunities to communicate as desired, allowing the users to selectively minimise or maximise the use of interpersonal effects in their messages. The asynchronous communication enables users to respond whenever it is individually convenient [35]. However, when there is no time limit, it is also possible to forget to answer in an appropriate time frame, which may lead to misunderstandings and perhaps disappointment for the sender, as occurred in the present study. Paul experienced no responses to his question regarding the number of health care professionals who generally visited the other caregivers' spouses. If Paul had asked this question FtF, an answer would have been immediate. The CMC channel did not provide the same type of response time, which Paul had expected. Not receiving any answers caused Paul to assume that his situation was unnatural. Consequently, Paul was empowered to take action. In the present study, asynchronous communication demonstrated both pros and cons.

The familiar relationship showed that the group informed one another when a caregiver was going away for some time. The group also asked about caregivers who had been away from the web forum for some time. These peers had obviously bonded, and they were thoughtful of one another despite living in different municipalities. In this context, the hyperpersonal perspective [34] is interesting to consider. Because of the messages the group sent and the peers' feedback, the caregivers began to know one another in a personal manner. Several messages, written by both men and women, reflected despair and grief. Likewise, both men and women responded to and comforted one another. It appeared as if the many feedback loops over time had given the group a sense of togetherness, and a frendship had developed because of their interactions on the web forum. Several studies have recognised that a sense of togetherness is vital for participants of support groups [21, 45, 48, 49]. In a community that provides anonymity for the participants, the hyperpersonal perspective may occur because it is easier for the participants to avoid embarrassment [35].

In the present study, each message was conveyed with an image of the sender; consequently, anonymity was not an option.

METHODOLOGICAL CONSIDERATIONS

The primary strength of this study lies in the fact that the data were collected from a closed online network. The caregivers' messages were displayed with a picture and name; no one could write anonymously. Caregivers could participate in the network for as long as they chose. Consequently, the peers were familiar with each other and were able to follow one another's situations for years. These factors most likely affected the degree of personal openness and engagement among the caregivers, which were evident in the messages the group shared on the web forum.

The weaknesses in the study are linked to data collection: the researcher was not the active party, as described in the section 'Data source and selection of text'. The fact that 'the manager' extracted excerpts from the web forum created a risk that certain themes and discussions may have been overlooked. Discussions that may have continued over time may have been reported in fragments, thus presenting an incomplete picture of the discussion. Data collection occurred over a period of two years to attempt to capture discussions that continued over time. Furthermore, we considered that, by collecting data over such a long period, we could compose a broad picture of the types of experiences the caregivers shared and the types of relationships the caregivers developed using CMC.

CONCLUSION

Our findings showed that empathetic, empowering and familiar relationships developed amongst older caregivers when the group used and exchanged written messages in an online forum. The empathetic relationship was characterised by sincerity and openness when peers shared emotions related to their caregiver role. The empowerment reflected a fellowship that induced a sense of optimism and a willingness to share knowledge to support one another in addressing daily challenges. The familiar relationship was evident in how the group joked with their peers and showed an attitude of thoughtfulness towards one another, as in an extended family. In the discussion section, we drew upon SIP theory. We argued that the media effects described by Walther [34] allowed caregivers to develop their relationships in the manner that appears in their dialogues.

Based on the findings of the present study, the introduction of CMC as a relatively new manner in which to communicate in health care service will change the context of developing interpersonal relationships. In nursing practice, the traditional manner of establishing and maintaining close relationships has occurred through FtF communication with patients and caregivers [33]. From this perspective, it is vital to know more regarding how the peers of caregivers interact with one another so that nurses may better support and educate ICT-based support groups [50].

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REFERENCES

- 1. Penning MJ, Keating NC. Self-, informal and formal care: partnerships in community-based and residential long-term care settings. Canadian Journal on Aging/La Revue canadienne du vieillissement 2000;19(SupplementS1):75-100.
- 2. Rechel B, Doyle Y, Grundy E, McKee M. How can health systems respond to population ageing. Wold Health Organization, on behalf of the European Observatory on Health Systems and Policies 2009: Copenhagen; 2009. p 36
- 3. Koch S. Healthy ageing supported by technology--a cross-disciplinary research challenge. Inform Health Soc Care 2010;35:81-91.
- 4. Gosman-Hedstrom G, Dahlin-Ivanoff S. 'Mastering an unpredictable everyday life after stroke'--older women's experiences of caring and living with their partners. Scand J Caring Sci 2012;26:587-597.
- 5. Leiknes I, Høye S. Family caregivers' experiences of provided home care to persons with Parkinson's disease. Nordisk sygeplejeforskning [Nordic nursing research] 2012; 2:29-44.
- 6. Hogsnes L, Melin-Johansson C, Norbergh KG, Danielson E. The existential life situations of spouses of persons with dementia before and after relocating to a nursing home. Aging Ment Health 2014;18(2):152-160.
- 7. Quinn K, Murray C, Malone C. Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. Disabil Rehabil 2014;36(3):185-198.
- 8. Johansson AK, Sundh V, Wijk H, Grimby A. Anticipatory grief among close relatives of persons with dementia in comparison with close relatives of patients with cancer. Am J Hosp Palliat Care 2013;30(1):29-34.
- 9. Coombs UE. Spousal caregiving for stroke survivors. J Neurosci Nurs 2007;39(2):112-119.
- 10. Teel CS, Duncan P, Lai SM. Caregiving experiences after stroke. Nursing Research 2001;50(1):53-60.
- 11. Report No 10 to the Storting [Meld.St.10] Good quality safe services. Quality and Patient Safety in Health Care Services [God kvalitet trygge tjenester. Kvalitet og pasientsikkerhet i helse- og omsorgstjenesten] Oslo: The Norwegian Ministry of Health and Care Services [Helse- og omsorgsdepartementet] 2012-2013.
- 12. Report No 16 to the Storting [Meld.St.16] National Health- and Care Plan [Nasjonal helse- og omsorgsplan] Oslo: The Norwegian Ministry of Health and Care Services [Helse- og omsorgsdepartementet] 2011-2015.
- 13. Report No 25 to the Storting [St.meld.nr.25] Coping, Opportunities and Meaning: The Future Care Challenges [Mestring, muligheter og mening: Framtidas omsorgsutfordringer] Oslo: The Norwegian Ministry of Health and Care Services [Helse- og omsorgsdepartementet] 2005-2006.
- 14. Finn J. An exploration of helping processes in an online self-help group focusing on issues of disability. Health & Social Work 1999;24(3):220-231.
- 15. Perron B. Online support for caregivers of people with a mental illness. Psychiatr Rehabil J 2002;26(1):70-77.
- 16. Chaparro-Diaz L. ICT as a Social Support Mechanism for Family Caregivers of People with Chronic Illness: a Case Study. Aquichan 2013;13(1):27-40.

- 17. Namkoong K, DuBenske LL, Shaw BR, Gustafson DH, Hawkins RP, Shah DV, Cleary JF. Creating a bond between caregivers online: effect on caregivers' coping strategies. J Health Commun 2012;17(2):125-140.
- 18. Marziali E, Donahue P, Crossin G. Caring for Others: Internet Health Care Support Intervention for Family Caregivers of Persons With Alzheimer's, Stroke, or Parkinson's Disease. Families in Society 2005;86(3):375-383.
- 19. Kinnane NA, Milne DJ. The role of the Internet in supporting and informing carers of people with cancer: a literature review. Support Care Cancer 2010;18(9):1123-1136.
- 20. Stoltz P, Udén G, Willman A. Support for family carers who care for an elderly person at home a systematic literature review. Scandinavian Journal of Caring Sciences 2004;18(2):111-119.
- 21. Torp S, Hanson E, Hauge S, Ulstein I, Magnusson L. A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. Health Social Care in the Community 2008;16(1):75-85.
- 22. Glueckauf RL, Ketterson TU, Loomis JS, Dages P. Online support and education for dementia caregivers: overview, utilization, and initial program evaluation. Telemed J E Health 2004;10(2):223-232.
- 23. Pierce LL, Steiner V, Govoni AL. In-home online support for caregivers of survivors of stroke: a feasibility study. Computers, informatics, nursing: CIN 2002;20(4):157-164.
- 24. Armstrong NN, Koteyko N, Powell J. 'Oh dear, should I really be saying that on here?': issues of identity and authority in an online diabetes community. Health (London) 2012;16(4):347-365.
- 25. Barrera-Ortiz L, Carrillo-Gonzalez GM, Chaparro-Diaz L, Afanador NP, Sanchez-Herrera B. Social support through using ICT for family caregivers regarding people suffering chronic disease. Rev Salud Publica (Bogota) 2011;13 (3):446-457.
- 26. Taylor LA, Bahreman N, Hayat MJ, Hoey F, Rajasekaran G, Segev DL. Living kidney donors and their family caregivers: developing an evidence-based educational and social support website. Prog Transplant 2012;22(2):119-128.
- 27. Gane LW, Iosif AM, Flynn-Wilson L, Venturino M, Hagerman RJ, Seritan AL. Assessment of patient and caregiver needs in fragile X-associated tremor/ataxia syndrome by utilizing Q-sort methodology. Aging Ment Health 2010;14(8):1000-1007.
- 28. McKechnie V, Barker C, Stott J. The effectiveness of an Internet support forum for carers of people with dementia: a pre-post cohort study. J Med Internet Res 2014;16(2):e68. Doi:10.2196/jmir.316
- 29. Brennan PF, Moore SM, Smyth KA. ComputerLink: electronic support for the home caregiver. ANS Adv Nurs Sci 1991;13(4):14-27.
- 30. Brennan PF, Moore SM, Smyth KA. Alzheimer's disease caregivers' uses of a computer network. West Journal of Nursing Research 1992;14(5):662-673.
- 31. Gallienne RL, Moore SM, Brennan PF. Alzheimer's caregivers. Psychosocial support via computer networks. Journal of Gerontological Nursing 1993;19(12):15-22.
- 32. Watzlawick P, Jackson DD. On Human Communication (1964). Journal of Systemic Therapies 1964;29(2):53-68.
- 33. Travelbee J. Interpersonal aspects of nursing. Philadelphia: FA Davis Co 1966. p xii-235.
- 34. Walther JB. Selective self-presentation in computer-mediated communication: Hyperpersonal dimensions of technology, language, and cognition. Computers in Human Behavior 2007;23(5):2538-2557.

- 35. Walther JB, Parks MR. Cues filtered out, cues filtered in: Computer-mediated communication and relationships. In: Knapp ML, Daly JA, editors. Handbook of interpersonal communication. Thousand Oaks, CA: Sage Publications; 2002 p 529 563.
- 36. Polit DF, Beck CT. Nursing research. Philadelphia, Pa.: Wolters Kluwer Health; 2012. P XIV- 802.
- 37. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet 2001; 358(9280):483-488.
- 38. Creswell JW. Qualitative inquiry & research design: Choosing among five approaches. 2 ed. Thousand Oaks, California: Sage; 2007. p XVII- 395.
- 39. Beals DE. Computer-networks as a new data-base. Journal of Educational Computing Research 1992; 8(3):327-345.
- 40. Malterud K. Systematic text condensation: A strategy for qualitative analysis. Scandinavian Journal of Public Health. 2012;40(8):795-805.
- 41. NVivo qualitative data analysis software [computer program] Version 10: QRS International Pty. Ltd.
- 42. Wood AF, Smith MJ. Online communication: linking technology, identity, and culture. Mahwah, N.J.: Lawrence Erlbaum Associates; 2005. p xviii- 245.
- 43. Walther JB. Computer-mediated communication: Impersonal, interpersonal and hyperpersonal interaction. Communication Research 1996;23(1):3-43.
- 44. Watzlawick P, Bavelas JB, Jackson DD. Pragmatics of human communication: a study of interactional patterns, pathologies, and paradoxes. New York: Norton;1967. P 294 s.:ill.
- 45. Barak A, Boniel-Nissim M, Suler J. Fostering empowerment in online support groups. Computers in Human Behavior 2008;24(5):1867-1883.
- 46. Sullivan CE. Cybersupport: empowering asthma caregivers. Pediatr Nurs 2008; 34(3):217-224.
- 47. Diefenbeck CA, Klemm PR, Hayes ER. Emergence of Yalom's therapeutic factors in a peer-led, asynchronous, online support group for family caregivers. Issues Ment Health Nurs 2014;35(1):21-32.
- 48. Brennan PF, Moore SM, Smyth KA. The effects of a special computer network on caregivers of persons with Alzheimer's disease. Nurs Res 1995;44(3):166-172.
- 49. Torp S, Bing-Jonsson PC, Hanson E. Experiences with using information and communication technology to build a multi-municipal support network for informal carers. Informatics for Health and Social Care 2012; Early Online:1-15.
- 50. Orem DE, Taylor SG, Renpenning KM. Nursing: concepts of practice. 6th ed. St. Louis: Mosby; 2001. P XVIII-542.