

The Use of Information and Communication Technology to Meet Chronically Ill Patients' Needs when Living at Home

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Abstract: The aim of the study was to describe influences, benefits, and limitations in using information and communication technology to meet chronically ill patients' needs when living at home. The study is a descriptive, exploratory designed pilot study and the intervention was performed using an electronic communication program enabling communication between ill persons and the district nurse in real time by web cam pictures and sound. The participant used the programme once or twice a week from February to August 2008. Data were collected by means of repeated interviews and logbook notes, and were subjected to qualitative content analysis. The results showed that all participants appreciated being able to communicate regardless of time and place and their experiences of using information and communication technology revealed that it created feelings of safety and security. The information and communication technology became a tool in their communication and improved nursing care among seriously chronically ill persons living at home.

Keywords: Accessibility, chronic illness, communication, information and communication technology, nursing care, pilot study.

INTRODUCTION

It has become a challenge to find new ways to support and care for persons with chronic illness living at home, since they are discharged from hospitals earlier and less well today than has been reported previously [1]. Living with chronic illness changes the lives of those affected. Persons with chronic illness living in their own homes often need support and nursing care from the district nurse [2, 3]. Research [4] has shown that one way to meet this challenge may be through suitable applications of information and communication technology (ICT), offering persons with chronic illness the opportunity to communicate with caregivers, gather information, and interact at a distance.

To date, eHealth research has covered health science-related aspects of ICT usage closely focused on needs, consequences and experiences with respect to professionals, caregivers, patients and relatives. Interest has primarily focused on the care of older and severely ill persons, and software applications have been used in healthcare as a support for ill persons in several areas, e.g., at a hospice, for ill persons' caregivers and as a support for frail elderly persons living at home. It has been found that chronically ill elderly persons living at home are satisfied with the use of ICT applications in providing nursing care at home [5-9].

ICT in the form of video conferencing has also been used as a tool for helping elderly, cognitively impaired persons living in nursing homes to communicate with their family members, leading to greater involvement of family members in the caring process [10-12]. Family carers can help and support their sick relatives by using ICT in the caring

situation and its use has been found to reduce family carer's anxious and isolation, create a presence, and provide easier access to healthcare professionals [13].

Utilizing technology to support persons with chronic illness has proven effective, while pervasive and mobile computing has been found to be central to increasing their quality of life. Communication *via* text messages through ICT improves feelings of security and safety among persons with chronic illness living at home, and they describe how ICT gives them a chance to access support and care from the district nurse [9]. The challenges, however, are twofold: to develop technical solutions that will meet the care needs of the chronically ill that are acceptable to them; and to provide care that is both accessible and of high quality. The aim of the study was therefore to describe influences, benefits, and limitations in using information and communication technology to meet chronically ill patients' needs when living at home.

METHODS

A descriptive, exploratory pilot study design [14] was chosen to test an application for information and communication between chronically ill persons living at home and the district nurse.

This pilot study was conducted within primary healthcare in one of twelve municipalities in the county of Norrbotten in Northern Sweden. The selected municipality was the largest in the county with about 74 000 inhabitants. The healthcare centre was located outside the city and had a mixed age structure population. The pilot study involved a preliminary test of an intervention designed to enable information exchange and communication in the form of synchronous and asynchronous messages. The head of a healthcare centre selected a district nurse for the pilot. Eligibility criteria for study participation included the

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following: That the nurse: 1) possessed a graduate diploma within primary healthcare specialist nursing, 2) was responsible for a sick person's nursing care at home, 3) had an established contact with the sick person, 4) had computer skills. When the district nurse was selected and had consented to participate, she in turn was asked to select chronically ill patients based on the following criteria: That they were: 1) diagnosed with a chronic illness that require nursing care, 2) living at home, 3) computer literate and able to communicate with her using ICT in form of synchronous and asynchronous messages. This selection resulted in a sample comprising two male patient's in the age of 58 and 76 years. One of the patients was diagnosed with multiple sclerosis (MS) and the other with stroke. The patient's daily life was strongly influenced by their illness and they were in need of mobility aids and special equipment. Their life situation required home visits by the district nurse every two weeks and extensive 24 hours care from personal assistants, and for that reason also a relative and the personal assistants were asked to participate in the study. This selection process created a pilot study group with eight participants i.e. one district nurse, two chronically ill persons, one relative and five personal assistants. When all participants had consented to participate they were informed about how to communicate through the ICT application with no limitations to time and place, and were given information about how data would be collected for the study. The study was approved by the Regional Ethical Review Board, Sweden.

The Technology

An electronic communication program *via* a computer with an Internet connection was used during the test period together with traditional home visits by the district nurse. This eHealth service was based on the European Pre-standard CEN/TC251 Health Informatics System Architecture (HISA) standard approach [15] aimed to enabling the development modular open systems to support healthcare. The program consisted of virtual rooms that enable the district nurse to communicate with the ill persons in real time by web cam pictures and sound based on a Session Initiation Protocol (SIP) standard. Communication was also supported through recorded messages or text messages from the ill persons to the district nurse, who could receive and replay text messages from anywhere. Communication in real time or in the form of recorded messages was however considered the most suitable mode of communication because the ill persons had difficulty in writing. The program was reputed to be user friendly as the participants were given proper training before the test period started and secure as all participants had a personal log in. The pilot study lasted for six months, from February 2008 to August 2008, and technical support was available to all participants during the test period.

Data Collection

The data were collected through repeated semi-structured interviews [16] before, during and at the end of the test period i.e. the persons with chronic illness, the relative and the district nurse were interviewed three times each and the personal assistant during and at the end of the test period. The interviews were based on an interview guide, which was developed based on previous research [9-11] describing the use of ICT in healthcare. The district nurse was also asked to

make notes in a logbook describing the reasons for contact and communication, and which of the parties initiated contact.

The first interview took place before the test period started and the research question focused on what was expected of the technology. The follow-up interviews during the test period focused on experiences of contact and communication with support of the ICT between the patient and the district nurse. After the test period ended a final interview was performed where the participants were asked about their experiences of what was good or less good, concerning security, difficulties or limitations, with the ICT used during the test period.

The interviews with the district nurse were conducted in her work place, while the interviews with the patients, the relative and the personal assistants were conducted in respective patient's home environment. All interviews was carried out by the first author, lasted for about 30 - 40 minutes, were tape-recorded, and transcribed verbatim.

Data Analysis

Qualitative content analysis was applied to the interview data, as it aims to provide knowledge and understanding of the phenomena under study [17]. This provides a process of organizing and integrating material from written documents and narrative information according to aspects and key concepts into categories. The content aspects deals with descriptions of the visible, obvious components, referred to as the manifest content.

The analysis process was similar for all interviews and to obtain a sense of the whole content, all transcribed interviews were first read several times independently by both authors. The first interviews, from before the test period, were analyzed separately, and the follow-up interviews were analysed together as the content was fairly similar. One of the most basic decisions when using qualitative content analysis is selecting the unit for analysis so the texts was first divided into meaning units, guided by the research question: that is, "What are the influences, benefits, and limitations in using information and communication technology to meet chronically ill patients' needs when living at home?". The selected meaning units were then coded and a pattern of preliminary categories began to emerge. The next step in the process was to re-read all the transcribed interviews and the selected meaning units to gain an understanding of the participants' experiences and thereby develop the categories, by means of which the authors tried to order those experiences. After the categories were established, both authors again coded the data independently to refine the categories until consensus was reached [17].

The logbook notes were analyzed through a systematic organization and synthesis of the content [14]. Reasons for contact *via* ICT were sorted and nine different reasons were identified. The analysis process identified and synthesized the information in the logbooks regarding who was present and who initiated contact for each reason.

RESULTS

For the sake of clarity the findings are presented in three parts. The first part concerns the participants' *Expectations*

of ICT (questions from the first interview). The second part relates to *Reasons for contact via ICT* (based on the district nurse's logbook notes). The final part relates to *Experiences of using ICT* (questions from the follow-up interviews).

Expectations of ICT

'Expectations of ICT' was constructed from three categories: nursing care twenty-four hours a day; direct communication could reduce stress; and the importance of being able to trust on the technology.

Nursing care twenty-four hours a day: The patients', the relative and the assistants' expectations were that accessibility to the district nurse would be increased and nursing care would be available twenty-four hours a day. They explained that by using ICT to contact the district nurse, nursing care could become more accessible irrespective of time or place. The district nurse, on the other hand, was afraid that she would be too accessible to the patients or that the patients would make contact more often than they needed to. However, increased accessibility to nursing care was expected to allow the patients, the relative and assistants to feel more secure.

Direct communication could reduce stress: The possibility of direct communication between the district nurse and the patients was seen as a positive expectation that could reduce stress. For the patients stress was reduced by the feeling that it was safe to stay in the home environment even when care needs increased related to progression of the chronic illness, whilst for the district nurse less travelling time was anticipated to result in reduced stress. The district nurse also thought that ICT could improve her work and referred to the fact that ICT made it possible for information to be received and given directly to the patient with no need for visits to the healthcare centre. The district nurse also expected ICT to increase patient's and the relative's participation in nursing care decisions, which in turn would reduce stress as decisions could be made at once together with the patient.

The importance of being able to trust on the technology: The participants described the importance of being able to trust on the technology, that is, that it would work and that the messages they sent would reach the correct receiver. In their descriptions of their expectations the participants also mentioned that the technology might be difficult to use or too advanced or unsuitable for nursing care.

Reasons for Communicating via ICT

The results from the logbook indicated that ICT increased accessibility to nursing care for persons with chronic illness living at home (see Table 1). ICT was used for various needs and most of the contacts were initiated by the patients and the assistants. The district nurse only initiated contact with the patients to answer questions or give test results.

The content of the communication showed that ICT, in the form of synchronous and asynchronous messages, impacted on the patients taking responsibility for care needs and that ICT was used to obtain answers to practical questions and advice on care. The district nurse had noted in

the logbook that the relative and the assistants were always present when the patient initiated contact and often took over the communication with her. The logbook also showed that the patients, the relative and the assistants contacted the district nurse once or twice a week; about half the contacts occurred during the district nurse's working hours and the rest during evenings or at weekends.

Table 1. Overview of Reasons for Contact and Communication Initiated by the Patients, Relative, Assistants or the District Nurse

Reasons for Contact	Contact Initiated by		
	Patient	Relative/Assistants	District Nurse
Renew prescriptions	x		
Problems with catheter		x	
In need of technical aids		x	
Help with drug dosage	x		
Booking to a pedicure	x		
Ask for test results	x		
Appointment with a dietitian		x	
Give test results			x
Discuss feelings of sickness	x	x	

Experiences of Using ICT

'Experiences of using ICT' was constructed from two categories: Possibilities of ICT and Limitations of ICT.

Possibilities of ICT: All the participants appreciated the possibility of communicating regardless of time and place. The district nurse explained that according to her workload, the ICT allowed her to have contact with the patients even when she was out meeting other patients. She could receive a message from the patients and answer within a short time or at least the same day. This positively affected the quality of care she gave the patients. It was also perceived positively that the technology supported direct communication in real time and the district nurse stated that she could take the patient's nonverbal communication into account by using web cam pictures. This way of communicating and providing care for sick persons was seen as a complementary to higher quality care, increasing accessibility to nursing care at home and creating a trusting relationship.

The patients, the relative and the assistants also pointed out that the use of ICT allowed them to communicate with the district nurse regardless of time and place i.e. outside telephone hours or during evenings or at weekends. The patients explained that when they could send a question to the district nurse, even knowing that she was not at work, created a feeling of freedom, security and participation in the care. This increased access to nursing care also engendered feelings that care was developed according to the personal needs within the relationship.

Limitations of ICT: The participants identified limitations related to the ICT in that it took away opportunities for them to develop relationships and that

technological problems affected the communication. The patients and the assistants saw ICT as offering additional possibilities of establishing relations with the district nurse but it was difficult to actually get into contact in real time every time they used the ICT. The patients had to leave a message about an issue and wait for the district nurse to answer on these occasions.

The district nurse described the limitations of ICT as including a lack of physical meetings even when communication *via* the technology was good. She said that it was difficult to judge the patient's condition *via* ICT and she missed opportunities due to lack of physical contact and face-to-face communication. The district nurse explained that no technological solution could compensate for human touch or a sharing of the same emotional space. Limitations related to ICT also included technological problems in the form of both faulty equipment and problems in managing it. All participants said that the connection was sometimes of low quality.

DISCUSSION

This pilot study show that the use of ICT including web cam pictures and sound in real time increased accessibility to nursing care and that the patients participate to a greater extent in their own healthcare. Opportunities for influence, choice decisions or being responsible are crucial for patient participation and strengthen the patient's own power and control [18]. The fact that the contact with the district nurse was initiated by the patients and the assistants gave the patients opportunities to influence and control their needs. This can accord Sahlsten, Larsson, Lindecróna and Plos [19] lead to a sense of independence and have a positive impact on well-being.

Furthermore, the pilot study indicates that using ICT increased the possibility of reaching the district nurse and assisted direct communication, and saved time for both the patients and the district nurse. All participants felt this was positive and provided increased knowledge of and control over the sick person's health through a trusting relationship. The fact that the relative and the personal assistants always were present when the patients initiated contact with the district nurse demonstrates that relatives and assistants are often key persons in persons with chronic illness lives. Relatives and personal assistants represent continuity for persons with chronic illness and might provide a sense of trust [20]. Relatives' and personal assistants' experiences with and attitudes about interventions are therefore crucial because they serve as the primary carer for persons with chronic illness living at home. Demiris [21] found that when healthcare personnel and other end-users, such as relatives or personal assistants together with persons with chronic illness, are included in implementation of ICT solutions their levels of satisfaction with the technology increase. However, trust in the relationship between patients and healthcare providers have the same importance when ICT is used as it has in physical meetings [22]. In telehome care, nurses have no direct physical contact with the patient and building a trusting relationship in such a setting requires different strategies [23]. In the same way as district nurses welcome the way assistants develop relationships and become familiar with needs among patients in palliative care [24], personal

assistants could support the care needs for persons with chronic illness in a way that could contribute to good quality nursing care when using ICT.

The participants in this pilot also felt secure about using ICT because the need for accessibility to care increases in relation to the progression of the patient's condition in the case of chronic illness. This is in line with previous research [15] that demonstrates that the use of ICT increased access to care and the district nurse. The use of ICT seemed to improve everyday life for persons with chronic illness living at home. Patient communication with the nurse *via* ICT also improved the patient's feeling of security [25]. Allen *et al.* [6] state that nurses who use virtual visits in the course of telecare feel that the quality of care is equal to that provided in physical meetings. Johnston *et al.* [25] described that remote video technology in a home healthcare setting is effective and well received by those who are ill and enables high quality of care to be maintained.

The pilot also shows that the participants experiences limitations using ICT in the form of fewer possibilities to develop relationships. The district nurse pointed out the importance of learning to know the sick person in order to be confident when individual care was provided; otherwise it was difficult to judge the patient's condition *via* ICT despite having both web cam pictures and sound. Whitten, Collins and Mair [26] describe how nurses perceive a difference between using traditional home nursing and telehome care as a result of the lack of physical contact with the patient. However, telenursing does not always have negative consequences; instead, it can enhance the frequency of contacts in the nurse-patient interaction, but this too could be seen as a limitation because it replaces physical contact with the sick person. Physical touch is an important form of nonverbal communication in nursing care and is an important issue in nursing [27]. Nilsson, Skär and Söderberg [10] state that limitations in transferring communication cues can be overcome when a web camera is used, which was evident in this pilot when the district nurse's possibilities of understanding the patient's nonverbal communication increased by using ICT.

Methodological Considerations

The strength of this pilot is that it offers insights from different perspectives that help in understanding the complexity of the research question [14]. The repeated interviews and the logbook notes served to enhance the understanding of the study under investigation and provide for a broader interpretation. It is important to be aware that the data collection during 2008 describes a situation three years ago, however care for persons with chronic illness living at home are still the same. Furthermore are studies describing the use of ICT to meet chronically ill patients' needs when living at home not common compared to studies testing ICT in various areas within healthcare. Therefore, this study can, although this limitation, contribute valuable knowledge about technical solutions that will meet the care needs of chronically ill that are acceptable to them. To enhance trustworthiness and improve credibility [cf.17], the authors had a constant dialogue during the analysis process together and with the district nurse throughout the study.

Although this pilot is small scale and exploratory, we consider our sample is typical for primary healthcare.

CONCLUSION

In conclusion, the pilot shows that by using ICT as a tool for increasing accessibility to nursing care allow persons with chronic illness living at home to participate to a greater extent in their own healthcare. Possibilities for persons with chronic illness to communicate with the district nurse regardless of time and place could therefore be one solution to meet chronically ill patients' needs. The pilot shows, however, a limited communication due to technological problems despite available technical support during the test period. Also fewer opportunities to develop a relationship between the patient and the district nurse were reported, although it must be noted that this method of communicating and providing care cannot replace a physical presence and that the district nurse performed traditional home visits during the pilot. To meet the requirements from patients', relatives' and healthcare personnels' perspectives, the perceived needs must be understood and factors influencing accessibility and acceptability must be examined. Therefore, longer and larger studies are necessary including larger numbers of participants, patients who lived alone without relatives or personal assistants, to elucidate possibilities to increase accessibility to nursing care.

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CONFLICT OF INTEREST:

None Declared.

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