



## Review

# Health care consumers' experiences of information communication technology—A summary of literature

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## ABSTRACT

**Background:** There is an increasing interest in reaching consumers directly through the Internet and different telecommunication systems. The most important contacts in health care will always be the face-to-face meetings, but the tools of health informatics can be seen as a means to an end, which is to provide the best possible health care. A variety of applications have been described in different references. To our knowledge there has been no review of a research-based state of the art in the field of consumers' experiences in using different applications in health informatics. According to the benefits in using information communication technology (ICT) as being cost-effective and timesaving it is of great importance to focus on and examine consumers' experiences. It is important that it is user friendly and regarded as valuable and useful.

**Aim:** The aim of this study was to describe consumers' subjective experiences of using electronic resources with reference to health and illness.

**Design and/or method:** A systematic literature search was performed in databases CINAHL, Medline and Cochrane, as well as a manual search. Retrieved references ( $n=14$ ) were appraised according to their scientific structure and quality. A broad search was performed in order to find as many different applications as possible. Our primary intention was to identify existing references describing consumers' experiences with ICT.

**Results:** In spite of this broad search few references were found. Twelve references remained and three themes were identified: support and help, education and information, and telecommunication instead of on-site visiting. Consumers felt more confident and empowered, their knowledge increased and their health status improved due to the ICT resources. Lack of face-to-face meetings or privacy did not appear to be a problem.

**Conclusion:** ICT can improve the nurse–patient relationship and augment well-being for consumers. More research is needed to measure consumers' experiences and factors that influence it.

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## 1. Introduction

There is an increasing interest in connecting with consumers, i.e. patients and other interested groups directly through the Internet and different telecommunication systems. Several terms referring to telecommunication have been used during the years as the technology and applications have developed. Some examples are Medical Informatics, Nursing Informatics, Telemedicine, Telehealth, Telecare, Information Communication Technology (ICT), Consumer Health Informatics and e-Health. When referring to the various references in this study the corresponding term for telecommunication found in each particular reference will be used.

ICT is paving the way for health care in the information age [1]. The tools of medical informatics can be seen as a means to an end, which is to provide the best possible health care. The tools can be anything from telephones, computers or other electronic resources used to access information or communication systems over the Internet. Informatics has grown significantly as a medical discipline in recent years and has fundamentally changed the ability to develop communication systems to support the process of health care [2].

Earlier discharge of patients elevates the demands for home health care. Another demand is maintaining the quality of health care using limited resources. Telemedicine technology may help to close the gap between demand and accessibility of home care, while opening new opportunities for the nursing profession. It can be seen as a complement to the existing health care services, making services available to persons who otherwise might not receive care [2]. Consumer health informatics (CHI) has possibilities to be a complement in nursing, possibly improving nursing care. By using innovative possibilities to acquire support, information and knowledge consumers can experience improved health [3].

The Swedish Federation of County Councils [4] states that the most important contacts in health care will always be the face-to-face meetings. However, with the help of interactive tools on the Internet patients can strengthen their influence on health care by getting both general and specific information. Health care accessibility increases when patients can contact health care professionals at any hour or are able to retrieve information and leave messages by the same media.

Today, patients require not only influence but also active participation in their care and treatment. Positive results indicate on the whole, that the patients' position will be strongly strengthened with the help of e-communication (*ibid.*).

In the beginning of 2000 about 65% of the Swedish people, aged 16–64, had access to the Internet in their homes. In the age range of 16–44 years, 75% had access. Among those age 55–64 years less than 50% had access [5]. Another survey in Sweden from the same review stated that, among people between 65 and 74 years of age, only 12% of the men and 4% of the women had Internet access. Among those between 75 and 85 years old only 4% of the men and none of the women had Internet access. This shows that youths and middle aged persons are the most frequent users of the Internet. Many people ask for direct communication with their physician, and the health care authorities should accommodate to this new pattern and demands from the society [5].

In a study consisting of three interview surveys in USA the aim was to find out who uses the Internet to gain information about health and diseases. Three groups of people using the Internet to gain information were found: (1) the first group included well people aiming to gain health related information, (2) the second group consisted of chronically ill people and their informal caregivers and (3) the third group included newly diagnosed people searching for information about their disease. These three groups were looking for different kinds of information. Among the whole population searching information on the web, 22% had been looking for information regarding mental health [6].

A variety of applications have been described in different references all over the world for example, a telephone-linked care system (TLC) in USA was used in smoking cessation programs, education and counseling [7]. The use of different telehealth systems for children with special health care needs, for example follow-up visits after in-person treatment and family education and discharge planning have been identified. These references reported that ICT was both cost-effective, timesaving and also improved the medical status from the health care providers' point of view.

Few references refer to consumers' needs or experiences of using the systems [1]. To our knowledge there has been no review of a research-based state of the art in the field of con-

**Table 1 – Databases search result**

	Databases search result		
	Keywords	Results	Rejected
CINAHL	Nursing and support and (patient* experience* or public health or consumer health or patient* satisfaction) and (information communication technology* or ICT or e-health or telemedicine or nursing informatics)	73 (remained = 2)	71 rejected due to not meeting inclusion criterion, duplicates, review articles, low quality, no abstract available, not peer-reviewed
Medline	Nursing and support and (patient* experience* or public health or consumer health or patient* satisfaction) and (information communication technology* or ICT or e-health or telemedicine or nursing informatics)	23 (remained = 6)	17 rejected due to not meeting inclusion criterion, duplicate, anonymous
Cochrane		6 (remained = 0)	6, review articles rejected
Personal contact		10 (remained = 3)	7 rejected (due to not meeting inclusion criterion, duplicates)
Reference lists		1	
Total result		12	101

sumers' experiences in using different applications in health informatics. When considering the benefits of using ICT, for example: (1) ICT as cost-effective and timesaving [8] and (2) decreasing personnel- and economical resources in health care, it is of great importance to focus on and examine consumers' experiences of new techniques. Keeping in mind that the goal with new techniques is to increase consumers' accessibility to health care it is important that it is user friendly and regarded by consumers as valuable and useful.

## 2. Aim

The aim was to describe consumers' subjective experiences of electronic information and communication resources with reference to health and illness.

## 3. Method

A systematic literature search was performed in March 2003 in the electronic databases CINAHL, Medline and Cochrane. Manual search was performed in reference lists in already known references as well as by personal contact with researchers. A second identical search was performed in April 2004 to update the results.

### 3.1. Inclusion criterion

The references (title or abstract) were to have a perspective of consumer health and nursing related to consumer health informatics. Data was limited to care provided in outpatient clinics and hospital discharge. The references should be original studies, peer reviewed and written in English or a Scandinavian language.

### 3.2. Exclusion criterion

References published before 1995 have been excluded since only current state of the art applications were to be included. References referring to ICT applications not provided by health care professionals have also been excluded.

A broad search was performed in order to find as many different applications as possible. In spite of this broad search few references were found. Our primary intention was to identify existing references describing consumers' experiences with ICT. The databases' thesaurus and subject headings were used (Table 1). Four references were found through reference lists (references of references) and through personal contact with researchers.

The search of the literature resulted in an initial set of 93 references. The references that met the inclusion criteria were selected ( $n = 14$ ). After the quality appraisal a total of 12 references remained. The list included seven quantitative references and five qualitative references that reported on consumers' experiences of using ICT. The references have been organized according to their main focus, i.e. support and help, education and information and telecommunication instead of on-site visiting. The references characteristics, quality evaluation and major findings are presented in Table 2.

## 4. Analysis

### 4.1. Quality analysis

The retrieved references were categorized according to their methodological approach, i.e. divided into qualitative and quantitative references. The next step was to perform a crit-

**Table 2 – Summary of analysed articles (n = 12)**

Author, year, country and title	Design/quality subjects	Method	Findings
Allen et al. (1996), USA, Home health visits using a cable television network: user satisfaction	DS <sup>a</sup> = II pilot study, small number of study subjects. Two nurses, 3 patients, 181 consultations	Nurse and patients questionnaires. Five point Likert scale	Easy to ask the nurses questions and receive answers. Ninety-one percent felt the nurse was able to assess their condition. Discrepancy in nurse/patient perception of weather on-site visit would have made a difference in the care provided
Edgar et al. (2002), Canada, Providing Internet lessons to oncology patients and family members: a shared project	DS <sup>a</sup> = II, pilot study, only one librarian participated (bias?), no control group. Sixty-nine patients, 15 family members	Open-ended and Likert scale questionnaires at base line, immediately after teaching session and 2–4 months after	All subjects found the information helpful. Patients felt empowered by the new knowledge and being cared for. Decrease in confusion, patients felt greater sense of personal control over the disease. A few met negative response from their physician. One felt no better equipped to cope with problems
Friedman et al. (1996), USA, A telecommunications system for monitoring and counseling patients with hypertension; impact on medication adherence and blood pressure control	RCT <sup>b</sup> = I, 267 patients from 29 communities	Structured interviews. Scales from “short form 36”, questionnaire to evaluate attitudes about computer technology/health care. Structured questions about using TLC. Brief questionnaire to physicians about the use of TLC reports	Significantly reduced diastolic, and possibly lower systolic blood pressure. The majority of the users were satisfied with the system and it made them more aware of their blood pressure and relieved their worries
Glasgow et al. (1997), USA, Long term effects and costs of brief behavioral dietary intervention for patients with diabetes delivered from the medical office	RCT <sup>b</sup> = I, 206 adults	Four-day food record form, background questionnaire. HbA1c, cholesterol blood tests. Crystal food habits questionnaire. Seven-item patients satisfaction questionnaire. Baseline and 12-month scores	Participants showed a reduction in fat intake and decreasing overall caloric consumption after 1 year. Reported higher over all satisfaction with their office visits
Gray et al. (2000), USA, Baby CareLink: using the Internet and telemedicine to improve care for high-risk infants	RCT <sup>b</sup> = II, small number of participants, 56 (26 study and 30 control) very low birth weight (VLBW) infants	Sociodemographic and clinical information collected. The Picker Institutes Neonatal Intensive Care Unit Family Satisfaction Survey (80-item questionnaire)	The subjects reported higher over all quality of care with fewer problems with the care, and greater satisfaction with the departments physical environment and visitation policies. All infants were discharged directly to home
Hanson et al. (2000), England, The role of telematics in assisting family carers and frail older people at home	Q <sup>c</sup> = II, few subjects. Two families	Quality of life interviews, log diaries	Increased confidence, and knowledge. Able to make own decisions. Enjoying talking with other participants or the GP over the videophone. Fear that the video camera would invade the privacy
Lazenbatt et al. (2001), Northern Ireland, Telemedicine as a support system to encourage breast-feeding in Northern Ireland	Q <sup>c</sup> = II, case report, pilot study, few subjects. Two primiparous women	Five months breast-feeding diary	The women felt the system helped them for example when a problem occurred in the middle of the night

**Table 2 (Continued)**

Author, year, country and title	Design/quality subjects	Method	Findings
Lorig et al. (2002), USA, Can a back pain e-mail discussion group improve health status and lower health care costs? A randomized study	RCT <sup>b</sup> = I, 580 subjects in 29 states	Baseline, 6 and 12 months questionnaires	Subjects showed improvements in health status variables (pain, disability, role function, health distress) after 12 months
Magnusson et al. (2002), Sweden, Support for family 674 carers by using ICT in the West of Sweden	Q <sup>c</sup> = I, case study, 4 families, 11 carers	Interviews before and after the intervention period	Increased self-confidence, increased knowledge. Less fear to harm the cared for person. Being able to leave messages to health care professionals at any time. Fear of no privacy in the home. Health care professionals did not always answer calls
Marrero et al. (1995), USA, Using telecommunication technology to manage children with diabetes: the computer-linked outpatient clinic (CLOC) study	RCT <sup>b</sup> = I, 106 subjects study group, n = 52 control group, n = 54	Repeated measure design. Questionnaires: psychological status (OFFER scale), family dynamics “family assessment device” (FAD). Diabetes-specific quality of life, “diabetes quality of life for youth” (DQOLY). Responsibility for diabetes care (the parent-child responsibility scale PCR). Structured interviews. Nursing time-on-task - number of calls and minutes spent on the phone	Decrease in family problem solving, probably due to the nurses rather than the parents discussed problems related to the diabetes
Solberg et al. (2003), Canada, Experiences of rural women with breast cancer receiving social support via audio conferencing	Q <sup>c</sup> = II, 11 women	Interviews	Support groups via audio conferencing permitted women living in rural areas to share experiences and to learn from and teach each other. The use of telephone and audio conferencing facilitated information and support to people in rural settings
Topo et al. (2002), Finland, Can the telephone-using abilities of people with dementia be promoted? An evaluation of a simple-to-use-telephone	Q <sup>c</sup> = I, seven families and carers (one drop-out)	Interviews at four occasions. Questionnaire marked with date was filled in on 10 different days during a two-month period. Clinical dementia rating scale, instrumental daily activities scale	Easier for demented persons to maintain social network, get support and advice when needed. Family carers were able to leave home and could be reached on the cell phone. Poor sight and coordination problems made it difficult to use the phone
I: high quality; II: medium quality. <sup>a</sup> Descriptive study. <sup>b</sup> Randomized controlled study. <sup>c</sup> Qualitative study.			



ical appraisal in accordance to scientific structure. Protocols (Appendices 1 and 2) designed and inspired by The Swedish Council on Technology Assessment in Health Care [9] were used for this purpose. According to these protocols references with a qualitative approach were appraised regarding their well defined question/aim, if there was a relevant and explicit sampling, explicit described data collecting and analyzing method, logically and understandable interpretations and conclusions, ethical discussion, good communicability and news value. References with a quantitative approach were appraised regarding their design and systematics, i.e. randomization, equal groups at start, drop outs, statistical methods, ethical discussion, results and clinical applicability. Only references with high or medium quality have been included for this study. The quality appraisal was validated by the second and third author.

#### 4.2. Content analysis

The references were read and reread with the aim of this study in mind. This was not a linear process, but one that moved back and forth between the references and the researchers' critical thinking. Content analysis provides a systematic approach to make valid inferences from e.g. verbal or written data in order to describe specific phenomena [10]. According to Polit and Hungler [11] the content in the studies is analyzed in order to determine themes or patterns.

Several themes were identified: (1) support and help, (2) education and information, and (3) telecommunication instead of on-site visiting. The theme "support and help" refers to the consumers' perceptions of an emotional or empowering support. The theme "education and information" refers to the consumers' perceptions of education or information provided by health professionals. The theme "telecommunication instead of on-site visiting" refers to applications where the consumers had accessibility to health care independent of time and space. The content analysis was validated by the second and third author.

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## 5. Results

### 5.1. Support and help

Four qualitative studies [12–16] focusing on support and help were included in this category. An easy-to-use-telephone for people with dementia and their informal caregivers [15] was tested as an intervention. The telephone had 12 keys size 3 cm × 4 cm, which had a photograph or other information on it. Telephone numbers could be programmed for each key. Most demented participants benefited from the new telephone by being able to perform a phone call or being part of the call. One man called independently several times with help of the programmed keys and was no longer worried about dialing wrong numbers. The telephone made it easier for him to maintain a social network and get support and advice when needed. Some family carers were able to leave their homes for work or to do errands, and could easily be reached on the cell phone by their demented family member.

In a social support programme that used audio conferencing, the process by which women who survived breast cancer received social support was examined [16]. The process consisted of four distinct and overlapping stages, at first the women had to get connected to the network, then find a voice, connect with the other participants and last, become empowered. The support groups that used audioconferencing transcended the geographical distances and permitted the women in rural areas to share their experiences with each other. They also learned from and taught each other. The use of telephone and audioconferencing technologies was especially beneficial in providing information and support to people living in rural settings.

Baby CareLink was another intervention study [17]. It was an Internet-based telemedicine program that was designed to reduce costs of care and to provide enhanced medical, informational and emotional support to families of very low birth weight (VLBW) infants during and after their neonatal intensive care unit (NICU) stay. The system included a daily clinical report and a message center. Support like answers to common questions and information about the services available was provided in conjunction with links to world wide web-based resources and an on-line library. In the "see your infant" section the family could share photographs of the baby with their relatives and friends. "The kid's corner" provided information and support materials for the older siblings of the patients. A clinical information and care section, and a section focused on preparation for discharge to home described the various stages in an infant's NICU stay. The study group ( $n = 26$ ) reported higher overall quality of care, with significantly fewer problems with the care received by their family. They also reported greater satisfaction with the departments' physical environment and visitation policies, even though the same policies applied to both study and control groups ( $n = 30$ ). All infants in the Baby CareLink group were discharged directly to home, however 20% of the control group were transferred to community hospitals before discharge. The Baby CareLink families also showed a trend toward fewer problems related to receiving practical support from the NICU. The families were enthusiastic about the use of the Baby CareLink system [17].

The third intervention study is the European ACTION project (assisting carers using telematic interventions to meet older person's needs) [12,13]. Telematics were used in assisting informal carers and frail older people in their homes. The overall aim of the project was to maintain the autonomy, independence and quality of life of frail older people and their informal carers. Technology was used within the informal carers' homes in order to meet their key needs. The system consisted of the informal carers' own television and remote control with additional technologies such as multimedia PC and CD ROM, a videophone and a camera. Multimedia programs regarding Caring in daily life (i.e. transferring technique, emergency situations, nutrition and incontinence), financial information, coping, respite care and planning ahead were provided. In Sweden 11 informal carers within four families used the ACTION-system [12]. The programs about transferring technique, emergency situations and economical rights were most useful. One informal carer described how she felt more confident and she was now able

to make her own decisions due to an increased knowledge of her husband's illness and eating problems. She also experienced less fear of harming her husband or herself. Care planning with the hospital at discharge also worked out very well. Another informal carer, an 80 years old man caring for his wife who had suffered from a stroke, used the videophone to get in contact with other participants in the project and this was very valuable. He also found out the possibilities of sending e-mail to get in contact with his daughter on a daily basis. Neither did he have to leave his wife to go to the bank as he was paying his bills via the Internet. Yet another informal carer had the expectation that the system would make it easier to get in contact with the health care staff, but these expectations were not met. Another man found it useful to be able to leave messages for health care professionals at any time, not having to keep up with telephone- or office schedules [12].

Another part of the ACTION project included three families in England [13]. From the first family one woman withdrew from the project because of worrying about the invasion of privacy in her own home and did not believe in the information that was provided. She had to be "on call" 24 h a day caring for her father who was 90 years old. The second family found the ACTION service a marvelous thing, especially for people who are housebound. The wife, 73 years of age and caring for her husband diagnosed with Parkinson's disease, felt so confident in using the new technique that she was considering buying a video recorder [13]. In the third family the husband who was in his late eighties and caring for his wife, who suffered from dementia, used the services to talk to his general practitioner, and also enjoyed talking with the other participants in the study over the videophone.

## 5.2. Education and information

Four references, (two RCT's, one descriptive study and one qualitative study), were sorted into this intervention category which focused on education and information.

The feasibility and outcomes of presenting one-to-one Internet training sessions to patients with cancer and family members were examined [18]. Forty subjects filled in a questionnaire on computer use. Twenty-eight subjects requested and completed an individual teaching session with a librarian in order to find quality health information on the web. This teaching session consisted of three parts. At the first session a booklet of how to find quality health information, cancer related web sites, multimedia sites and university sites on the web was presented. The second session included a hands on presentation by the librarian demonstrating search techniques. During the third session, specific information searches was performed. All the participants found the information helpful. The majority felt empowered by the knowledge they received from the web. Some of the patients had metastatic cancer and yet found that the intervention gave them a sense of being cared for. Positive benefits that patients mentioned were: (1) a decrease in confusion, (2) a greater sense of personal control over the disease and (3) being more focused and better able to formulate questions to the physician. All but one patient felt better equipped to cope with problems and all of the participants were able to evaluate the information they

found on the web. The information received would be shared with the physician by 82% of the patients. A few patients met a negative response from their physician, as he was "not interested" or "not receptive at all" to the information.

In the second study, 580 subjects with chronic back pain participated in a randomized controlled trial in 49 states in the US. The treatment group was randomized to a closed, moderated e-mail discussion group, and also received a book and a videotape about back pain. After 1-year the subjects demonstrated significant improvements in all four of the health status variables, i.e. pain, disability, role function and health distress. During the 12-month study, 2399 e-mails were sent and 41% of the participants read most or all of the e-mails. The results show that this intervention may be useful in the treatment of chronic back pain and that e-mail discussion groups can positively affect health status [19].

The third reference, a case study dealt with establishing a telemedicine link in the homes of women who had decided to breast-feed [14]. Bottle-feeding is common in Northern Ireland and mothers claim that they might have breast-fed for a longer time, if they had received more support and advice from health care professionals. The authors wanted to examine the feasibility of using a system with analogue videoconferencing equipment in order to provide informational, emotional and instrumental support from midwives in the hospital. Two primiparous mothers participated and used the telemedicine link on eight and five occasions, respectively, calls ranging from 5 to 35 min. The health care professionals showed the mothers how to position their baby correctly and offered practical and emotional support. Even though the mothers reporting having an excellent support system from their partners, family and community midwives they felt the system helped them; for example with problems occurred in the middle of the night.

The last study in this category evaluated a 12-month follow-up study of results of a personalized medical office-based intervention focused on behavioral issues related to dietary self-management [20]. Adults with diabetes ( $n=206$ ) were randomized to either traditional care or participation in an intervention group. The single session intervention involved a 5–10 min touch screen computer-assisted assessment providing immediate feedback on key barriers to dietary self-management, goal-setting and problem-solving counseling. The materials were coordinated to produce an individualized goal setting plan to lower fat intake based on the patients eating patterns. One year after beginning the program, the participants were showing a reduction in fat intake, and also decreasing overall caloric consumption. The intervention group reported significantly higher overall satisfaction with their office visit than the control group.

## 5.3. Telecommunications instead of onsite visiting

Three references, two RCT [21,22] and one descriptive study [23] were sorted into this interventional category focusing on telecommunication instead of on-site visiting.

The first study, a telephone-linked computer system (TLC) regarding routine, weekly, monitoring of patients with hypertension was described [21]. TLC is an interactive telecommunication system that converses with the patients in their

homes. The system speaks to patients over the telephone using a computer-controlled speech; the patient communicates using the touch-tone keypad on their telephone. TLC asks questions and gives feedback to promote adherence to the treatment regimen. The mean age of the participants ( $n=267$ ) was 76.0 years, and 77% were women. The system was thought to improve health outcomes and reduce health services utilization and costs. The TLC users demonstrated an overall satisfaction with the system. By scoring a 100 point VAS scale on which 0=very dissatisfied and 100=very satisfied, 69% scored in the upper quartile, 54% scored a similar scale for health benefit of TLC use, 5% and 6% respectively scored in the lower quartile. Patients who were nonadherent with their medication at baseline were most affected by the intervention. The authors suggest the system can be used to monitor patients with hypertension or other chronic diseases.

In the second study, a cable-TV-mediated interactive video system was used to deliver home health care at a retirement home [23]. Three homebound patients, who so far had been followed by on-site visiting nurses, were now followed by televideo-mediated nursing visits. A 13-in. monitor and camera was placed in each patient's home, usually in the largest room. After the patients' completed 183 video consultations, 60% strongly agreed and 39% agreed it was easy to ask the nurse questions and receive answers via video transmission. Almost every one, i.e. 91% felt that the nurse was sufficiently able to assess their condition. The investigators' concerns about the lack of personal contact or possible lack of privacy did not prove to be warranted. Three patients with multiple diseases participated together with two nurses in the same study. The interactions concerned emotional support (78%) medication check (93%), mental status check (17%), blood pressure check (1%), blood sugar check (18%), neurological check (1%), weight and oedema check (19%), respiratory assessment (17%), and dizziness (3%). Of the consultations, 85% were scheduled. Both patients and nurse satisfaction with the tele-video system was very encouraging. Although the results were positive, an important finding was the discrepancy seen in satisfaction in the differing nurse and patient perceptions of whether an on-site visit would have made a difference in the care provided. Nearly 40% of the patients thought it would have made a difference if the nurse had been present. None of the nurses suggested that that would have been the case [23].

In the third study a telecommunication system to assist in the outpatient management of pediatric patients with insulin dependent diabetes was evaluated [22]. In the computer-linked outpatient clinic (CLOC) study, 106 families with children with diabetes participated. The control group ( $n=54$ ) received standard care. The study group children ( $n=52$ , mean age 13.3 years) were using the technology to manage their diabetes. They transmitted self-monitored blood glucose data by modem to the hospital every 2 weeks. A nurse practitioner phoned back in order to discuss the data and regimen adjustments. Metabolic control, patients' psychosocial status, family functioning, perceived quality of life, patterns of parental/child responsibility for daily diabetes maintenance and nursing time-on-task were also evaluated. No negative effects on patients who are monitored in this more intensive manner were found. Neither were any negative psychological

consequences or changes in family functioning reported. Subjects in the study group reported a decrease in solving family problems over time. According to the authors, this finding may reflect the increased frequency of the nurses rather than the parents discussing problems pertaining to regimen adjustments. Nurses may have assumed a greater part of what had been the parents' role in helping the children figure out how to respond to problems with daily diabetes control.

## 6. Discussion

A summary of literature was chosen in order to get a broad view of consumers' own experiences of ICT. The research area of information communication technology is a relatively new field and uses several different terms for ICT, as it is developed and expanded over time. This limits the possibilities in finding relevant references. Another limitation was that few references matched the search words and inclusion criteria and actually showed the consumers experience with different applications. Most telemedicine research seem to focus on for example treatment results, costs, personnel matters, technical possibilities and documentation [7,24]. However, this literature search focused on results regarding consumers' own experiences, although methods used for assessing consumers experience or satisfaction were not clearly specified in most of the references. Another limitation was that several references were pilot studies with few subjects which could have affected the findings in the performed references [14,18,23]. They did however meet the medium quality criterion.

The literature search has been performed according to scientific praxis and with the help of a librarian. The first and third author each performed the quality appraisal individually in order to strengthen the results. All authors discussed and agreed to the quality appraisal.

The studies revealed that healthcare delivery via telemedicine is acceptable to patients in many different contexts. However few references actually reported the consumers' opinion of the intervention itself. Interventions that have had positive changes in well-being, perceived quality of life, health distress, role or family function, etc. have been considered positive to consumers [19,20,22]. In most of the reviewed references there were no practical difficulties regarding use of the technique among the elderly, people suffering from light dementia, children or lower educated people. Two references suggest that contextual factors, for example patient location, education, and quality of verbal communication must be considered to understand the communicative implications of patient experiences with telemedicine [20,25].

ICT can facilitate interaction with other persons in the same situation, which was seen as valuable in the reviewed references. Support and information from other patients and relatives were in some references found to be more helpful than support from the health care staff [12,13,16,26]. This is likely to not only relieve the pressure on health care staff, but also to confirm patients and their families as experts of the experiences related to their illness and disease [27]. Increased attention and emotional support from staff and researchers during the survey period could have influ-



enced the results in the reviewed studies in a positive way [12,19,20,22]. This phenomenon is also mentioned by other researchers [25]. This increased attention could probably be perceived by the consumer as a affirmation of their situation. Affirmation strengthen the capacity of the consumer for self-determination and this leads to a choice of further challenging tasks [28].

Empowerment by retrieving information from the web is a process that encourages active participation, and may foster autonomy and lead to more satisfaction with the medical system. The satisfaction may also lead to other helpful behaviors that are linked to an increased sense of personal control [18]. A successful completion in challenging tasks results in skill acquisition. In the references reviewed there were examples of persons who were encouraged and empowered to challenge their earlier behavior and use other technical equipment in the future [16]. Some patients became more focused and better able to formulate questions to the physician, they felt decreased confusion and a greater sense of personal control over the disease [18]. Perceived higher overall quality and fewer problems with the received care, as well as greater satisfaction with the hospitals' physical environment and visitation policies, and higher overall satisfaction with the office visit was also stated [17,20], and can also be related to a sense of coherence [29] and feelings of affirmation [28].

As for telecommunication instead of onsite visiting, some women, most of them in their seventies reported improved health outcome, reduced health services utilization, and increased adherence to the treatment regimen in monitoring blood-pressure by using the touch-tone keypad on the telephone, with answers from a computer-controlled speech [21]. This procedure could be considered distant and impersonal, this raises questions such as; how come the women found this improving their health? Maybe they felt that this procedure contributed by helping them to manage their condition. Sense of coherence [29], i.e. a feeling that life is comprehensible, manageable, and meaningful has been shown to have a mediating effect on an individual's ability to manage stressful life events. The sense of manageability describes a person's conviction that difficulties are soluble, and that there are resources at your disposal which can meet your demands. It also fit into the belief that someone will help one to overcome difficulties.

To be able to reach health care professionals at any time also gives the consumer a feeling of managing the situation. However, the professionals did not always meet this possibility [12]. It must be taken into consideration that when the consumers' demands increase, the pressure on the health care providers' also increases. To what extent are health care professionals supposed to be online and provide information? Probably there is a need to find a balance in the amount of accessibility and information provided by health authorities.

To be "on ones own turf" leads to a greater satisfaction and personal empowerment [8]. The interaction with family, friends and health care providers contributes to quality of life. To be able to receive care in ones home facilitates this interaction. To what extent this interaction with family and friends contributes to quality of life needs to be further investigated

[30]. Another study [8] suggests that a higher degree of consumer satisfaction with ICT also could be due to cost saving for consumers, i.e., saving travel time and money. These results illuminates that the experience of well-being and quality of life to a great extent is influenced by a variety of phenomena, not only the medical care. The consumers stated this as increased independence, possibilities to maintain a social network, and informal carers who became more confident [15,16] and experienced less fear, due to increased knowledge [12]. In a study of health promotion, consumers' participation affects health in a curvilinear way [31]. Very intensive participation and non-participation are related to negative health effects, thus moderate levels of participation can lead to increased competence with positive health effects.

## 7. Conclusions

This study illuminates the field of consumers' experiences of a variety of applications in the field of ICT and elucidate that nursing needs ICT as one mean to provide good quality care. In the future the patients' position will grow stronger with the help of e-communication [4,18]. It is clear that ICT applications can enhance the nurse-patient relationship, but it can never replace it [13,18]. The technical interventions were seen to give support, help and knowledge, which empowered the users. Some applications were relatively simple and user friendly, for example the adjusted keypad telephone and they provided valuable support in various ways. Likewise monitoring blood-pressure by using a touch-tone keypad on the telephone and the management of pediatric patients with insulin dependent diabetes by using the technology to transmit self-monitored blood glucose data to the hospital were found very useful.

More complicated technical equipment were not shown to have any practical implications [8,17,18].

Education and information, and telecommunication instead of on site visiting were the fields most commonly reported in the reviewed references. The new technique undoubtedly has great possibilities to improve nursing care and augment well being regarding for example consumers with chronic diseases or disabled people and their informal carers. Consumers living in remote areas can attain a higher accessibility to health care, at the same time as saving travel time and money and they can improve their accessibility by not having to depend on office or telephone hours. This coincides with economizing with health care resources. Consumers can also easily access other persons' experiences of the situation they are facing with illness and disease in the family [16].

The results from the present review implicate the need for further research of consumers own experiences of ICT and the factors that influence consumers' satisfaction, for example by randomized controlled studies. One of the revised studies reported discrepancies in the evaluations of satisfaction between the consumers and the nurses of whether an on-site visit would have made a difference in the care provided. In a review of references on patient satisfaction with telemedicine it was found that only 33% of the references included a measure of preference between telemedicine and face-to-face consultation [32]. It is important that different professions

in software engineering and nursing work together to create useful applications for health care.

### Summary points

What was known about this topic before our study

- Consumer health informatics has possibilities to open new opportunities in nursing and improve nursing.
- Consumer health informatics can improve consumers' experiences of health.

### What this paper has added to our knowledge

- No difficulties regarding the use of the technique among different consumers were found.
- The cooperation between professions in nursing and software engineering is important to create useful applications for consumers in health care.

## Acknowledgements

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## Appendix A

### Protocol quality criteria, quantitative studies

Author: .....

Title: .....

Design: ☐ RCT ☐ CCT ☐ DS ☐ Pilot study

☐ Multi centre, numbers: .....

Aim: .....

Instruments: .....

Intervention:

..... Study period:

Sample characteristics?

Numbers; .....

Age: .....

Men/Women .....

Is the method of selection described?

☐ Yes ☐ No ☐ Partly

Is the sample selection representative?

☐ Yes ☐ No ☐ Partly

Is the method of randomising described?

☐ Yes ☐ No ☐ Partly

Equal groups at start?

☐ Yes ☐ No ☐ Partly

Analyzed in the randomized groups or not?

☐ Yes ☐ No ☐ Partly

Is the dropout described?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is the dropout analyzed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is there an ethical discussion?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly

Is the statistical method adequate?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the instruments valid?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the instruments reliable?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the findings general?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the findings reliable?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is there a critical discussion?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the findings clinically useful?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly

Principal findings (magnitude of the effect, how was it calculated, NNT, statistic significance, power analyze)

.....  
 .....  
 .....

Summarized quality assessment:

☐ High (minimum 12 “yes”)   ☐ Medium (minimum 9 “yes”)   ☐ Low

Comments:

Protocols designed and inspired by The Swedish Council on Technology Assessment in Health Care. (1999) Evidensbaserad omvårdnad vid behandling av personer med depressionssjukdomar [Evidenced based nursing - treatment of persons in state of depression]. Stockholm: SBU. (Authors' own translation).

## Appendix B

Protocol quality criteria, qualitative studies

Author: .....

Title: .....

Aim: .....

What are the results? .....

.....  
 .....

Study period: .....

Subjects characteristics?	Numbers;	.....
	Age:	.....
	Men/Women	.....

Explicit definition/problem?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is the method of sample selection described?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Explicit inclusion-/exclusion criteria?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is the sample selection relevant?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is the sample strategic?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is the context described?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is there an ethical discussion?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Description of data collection?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Description of data analysis?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the findings clearly displayed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Are the findings logic, understandable?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is there a new value?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is there a discussion of the findings?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly
Is there a discussion of the method?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Partly

Principal findings: .....

.....  
 .....  
 .....

Summarized quality assessment

☐ High (minimum 10 “yes”)    ☐ Medium (minimum 8 “yes”)    ☐ Low

Comments:

Protocols designed and inspired by The Swedish Council on Technology Assessment in Health Care. (1999)  
 Evidensbaserad omvårdnad vid behandling av personer med depressionssjukdomar [Evidenced based nursing -  
 treatment of persons in state of depression]. Stockholm: SBU. (Authors' own translation).

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