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In the Proceedings of

ICICTH2009:

7th International Conference on
Information & Communication Technologies in Health,

Samos, July 16-18, 2009

pp. 65-73.

ADAPTING THE STARE-HI GUIDELINES FOR THE EVALUATION OF HOME CARE TELEHEALTH APPLICATIONS: AN INTERPRETIVE APPROACH

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ABSTRACT

An important issue in the advancement and deployment of home care telematic services is their assessment, especially with the goal to improve such services and constitute them easier to integrate into the social and clinical setting. The meaning that researchers apply to assistive environments and telehealth in general (i.e. a medical innovation or a drug that can be prescribed to patients or an information system coming to serve information transmission and processing needs) is critical to the method they select for evaluation. The paper proposes an adapted framework for evaluating home telehealth interventions based on an interpretive evaluation approach, and shows how the STARE-HI statement (2009) on reporting of evaluation studies in Health Informatics can be adapted for the case of home care telematics.

KEYWORDS: home care telehealth, evaluation, interpretive approach, STARE-HI guidelines

INTRODUCTION

Homecare telehealth can be regarded as one of the fastest growing healthcare delivery sectors in the developed world and it is further reinforced as healthcare delivery paradigm is shifting from doctor and hospital-centered towards a new model where the citizen becomes responsible for the personalized management of healthcare, delivered at the point of living whenever possible. An important issue in the advancement and deployment of home care telehealth services is their assessment, especially with the goal to improve such services and constitute them easier to integrate into the social and clinical setting. Reviewing the literature on home telehealth evaluation approaches we came across three different perceptions of telehealth. Each perception leads to the adoption of a different view on the meaning and the aim of the evaluation activity and therefore of a different evaluation technique.

The most dominant perception of home telehealth is that of a ‘drug’ that can be prescribed to patients. Patients are thought to obey to this prescription and use technology in their homes according to the instructions given and in the end an immediate effect in their health condition is expected to be observed. Randomized control trials (RCT) are therefore presented as the most legitimate and credible evaluation technique. Indeed, most of the reviews exclude from their sample studies that do not use RCT [1]. There is a big debate on the appropriateness of such a technique to evaluate telehealth applications. Here we present another deficit of the notion that telehealth and new medicines are equivalent interventions in patients’ lives. In the case of drugs, patients have two options: to obey to the prescription or ignore it. However, in the case of ICT while patients interact with it they ‘enact structures which shape their emerged and situated use of it’ as Orlikowski argues in the structuration theory [2]. Information and communication technology is not a black box that closes after development. An interpretation of this view in our context would suggest that each patient will draw on their skills,

power, knowledge, assumptions, and expectations about the technology when using it at home and therefore enact a distinctive 'technology-in-practice'[2]. RCT focuses only on certain predefined outcomes ignoring this aspect of patients' interaction with ICT which could answer the why of RCT's outcomes.

A slightly more expanded view of telehealth is that of a technical/managerial innovation that will reduce cost of healthcare delivery, will raise physicians' productivity and patients' (seen as 'customers') satisfaction. Following this view, evaluators draw on economic theory to check cost effectiveness and productivity issues of each new innovation. On this category we can place another slightly different view of telehealth that still fits to the notion of telehealth as an innovation. Most telehealth applications today are funded by governmental bodies in order to establish a new modern way of healthcare delivery and bring ICT benefits in the health care sector. This means that telehealth applications are seen as short term projects that have a predetermined end and should be evaluated till the end of the funding. Evaluation is done quickly and by using methods that allow comparison and often serve publication purposes. Whetton points out that although evaluation is conducted on pilot short term telemedicine projects there is a widespread expectation that it assesses the long-term value of telemedicine [3].

Literature reveals that recently several researchers abandon partial views on home telehealth and perceive telehealth as an information system that is embedded in a clinical/social context. All three components of telehealth: technology, people and context are included in the evaluation and the interplay between them is examined in depth. Pragmatic approaches that consider the organizational context are proposed and qualitative evaluation using semi-structured interviews are carried out [4],[5],[6]. However, most of this work does not usually employ any theoretical framework to guide research and draw conclusions [7]. They do not present detailed descriptions of their method of gathering data and therefore their researches are strongly criticised as incredible.

The paper argues that home telehealth interventions more than any other health information systems applications require a holistic, interpretive approach in their evaluation, emphasizing the overall assessment of the telehealth service seen as an information system embedded in a clinical and a social context, rather than seen merely as a technical innovation or a drug. The paper presents an adapted framework for evaluating home telehealth interventions based on an interpretive evaluation approach, and shows how the STARE-HI statement (2009) on reporting of evaluation studies in Health Informatics can be adapted for the case of home care telehealth. This work has been spawned by the need for evaluating a novel telehealth service for the monitoring of peritoneal dialysis at home [8],[9].

INTERPRETIVE EVALUATION OF HOME TELEHEALTH INTERVENTIONS

There is an agreement between authors of home telehealth that the evaluation process is much more complicated than that of the rest telehealth applications [4], which among else include a number of issues related to the nature of stakeholders and the context of home telehealth interventions, and the engagement (or lack of) patients in the design process. Indeed, the most common reason mentioned is the diverse group of stakeholders. Stakeholders come from different parts of the healthcare system with different value systems, different perceptions of risk and different expectations of the home telehealth application. Costs and benefits may fall unequally between the various groups of stakeholders. The second reason that is seen often in literature is the diffused context that home telehealth is applied to. The surrounding context varies (each patient's home) and given the fact that home telehealth applications are few and short (in terms of pilot applications duration) makes it difficult to generate data of sufficient scope and scale for conducting a careful analysis.

These obstacles require careful consideration of the evaluation approach to be used. Another difficulty that should be pointed out is that home telehealth applications are usually designed without the participation of the most important group of stakeholders, the patients. Whole systems are developed without patients to be asked about their needs and preferences. Just like the production of new

pharmaceuticals and therapeutic procedures, patients are more or less forced towards obligatory usage of the home telehealth application after development, while during development their position is expressed mainly by their doctors and nurses. This tactic may preserve physicians' status and power over patients but may result in the development of home telehealth systems that ignore patients' abilities and/or needs.

ADAPTING THE STARE-HI GUIDELINES

In 2004 and during the HISEVAL workshop in Innsbruck, prominent researchers in the field of medical informatics raised the idea for developing a Statement on the Reporting of Evaluation Studies in Medical Informatics (STARE_HI) [10]. As a consequence STARE-HI guidelines were developed and recently published [11]. The STARE-HI guidelines include a comprehensive list of principles relevant for properly describing Health Informatics evaluations, and they recommend a structured list of items that should be included in Health Informatics evaluation reports. These items are organized in various categories: (1) title; (2) abstract; (3) keywords; (4) introduction; (5) study context; (6) methods; (7) results; (8) discussion; (9) conclusion; (10) authors' contribution; (11) competing interests; (12) acknowledgments ; (13) references; and (14) appendices. These primary categories include more detailed items. Considering the above discussion on the special requirements of home care telehealth evaluation under the interpretive approach, we have specialized category #6 of the STARE-HI recommendations as presented in the detailed comments in the following paragraphs.

STARE-HI “6.1.Study design”

Adopting the interpretive approach on home telehealth evaluation involves basing the study mainly on qualitative research. In qualitative research the aim is to get an in-depth understanding of stakeholders' acts and the reasons that are hidden behind these acts. The investigation is focused on the why of stakeholders' actions. In qualitative research small groups are investigated in depth in contrast to quantitative research where the sample is larger. In depth investigation requires the examination of the meanings that stakeholders attach to home telehealth systems and the interpretation of these meanings. Researchers' position is never seen as neutral and objective. Their positions and bias should be taken under consideration when the results of qualitative research are read. Qualitative approach allows adaptation of the research questions and pre-defined issues under investigation during the evaluation process itself letting capture any un-expected event.

STARE-HI “6.2. Theoretical background of the study”

Evaluation activity that is based on interpretive methods aims ‘at producing an understanding on the context of the information system, and the process whereby the information system influences and is influenced by its context’ [12]. Two theoretical frameworks can be selected to guide the research: (a) the content, context and process framework [13] serves to present the evaluation activity that was conducted; according to this framework content describes what is to be evaluated, process refers on how the content is evaluated and context includes the social, political and economic environment; and (b) the ‘structure, process and outcome’ framework created by Cornford and Doukidis [14] which derives from information systems literature and precisely from interpretative thinking, but also encompasses medical evaluation literature. The reason for the selection of this evaluation framework is that it serves our view of the evaluation as an attempt to understand the context, and the interplay between technology-people-context and as a ‘continuous learning process rather than a search for ‘judgment’ [15].

Cornford, Doukidis and Forster [14] have proposed an evaluation framework for telemedicine and telehealth interventions that views telehealth effects from three different angles: the structure, the

process and the outcome. These three angles are applied at three levels: the level of the systems functions, the human perspectives and the organizational context.

In the level of systems functions the evaluation of structure involves the assessment of the technical details of the telemedicine application, the examination of the process focuses on the information processing and that of the outcome on whether the system as a technological innovation has relevant, applicable and reliable results. In the human perspective level, all stakeholders and participants in the telemedicine application are included and their acceptability searched. Actors may vary from owners, providers, and consumers of the system. In each case, the changes in their work conditions, or their behavior should be assessed in the structure layer, their view on the changes in the mode of operation and health care experience is to be addressed in the process layer while systems effectiveness through the eyes of the different actors is judged in the outcome layer. The aim is to view the system applying different lenses according to actors' role in it. Finally, at the organizational context which in the case of telemedicine is the health care system in the layer of structure the attention is drawn on systems sustainability assessment, while impact on the delivered quality of health provision and on the health status of the patients is examined in the process and outcome layer respectively.

	Home telehealth functions	Human perspectives			Renal disease clinic context-Patients' home context
		Physicians- Medical personnel	Patients	Administrators	
Structure	Are the hardware and software technical requirements met; does the system work; does it present technical problems?	What are the changes to physicians' and medical personnel's working conditions and practices; do they need to obtain new skills, and abilities?	Are patients required to obtain new skills, and abilities?	Is the system cost-effective?	Could this home telehealth system be sustained and supported within the renal disease clinic context? Could it be accepted within the home context?
Process	Is telehealth service operation correct & valid ? (collection & transfer of biometric data, communication between different units, presentation of telemetry data)	How was the physicians' and medical personnel's mode of operation changed? Are these changes seen as desirable to them?	How is the renal patients' behaviour altered; what are the changes in their everyday practices at home; which are the effects to their families?	Does it imply changes to administrator's working practices?	Could such a system be institutionalised?
Outcome	Are the functions of the telehealth application usable and reliable?	Was their effectiveness within the health care system affected?	Does the use of the system result in changes in the perceived quality of care/life?	Does the system improve specific clinical parameters?	Could such a system improve the health status and quality of life for renal patients?

Figure 1. A detailed adaptation of the Cornford, Doukidis and Forster framework for the specific case of home telehealth.

In our work, we have adopted this model to evaluate home telehealth services [9]. In our adaptation, we have further analyzed the framework in order to account for the special requirements of the home care environment and its actors. Emphasis is given to the human perspective, as in home telehealth applications we encounter the unique setting with the patient/citizen at home (or at their own

environment), secluded from direct contact with the healthcare personnel and/or technical support. The chart in Figure 1 gives the basic questions that have to be tackled for every evaluation angle and every different level. It should be noted that depending on the goal of its evaluation, some or all of the cells in the proposed framework may be tackled. The proposed framework was developed and implemented for the evaluation of PERKA a novel telehealth service that supports peritoneal dialysis at home [8]. The aim was to understand how various users involved in the service interact with it in the particular setting of a pilot implementation. The process of evaluation was viewed as a learning process used as an input for the advancement of the service and the study of the interaction of such a service with its human and organizational environment.

STARE-HI “6.3. Participants”

Interpretive evaluation examines and reports on all groups of stakeholders: patients, physicians- nursing staff, technicians, and administrators. Focus is placed on their interaction with one another and their interaction with the technology. Especially in the stage of evaluation during design a challenging activity in home telehealth service development is the involvement of patients in the design of the system and the evaluation of their interaction with the system. The level of users participation during the development of an information system is seen as a determinant of users’ commitment to the project and therefore to their perceived understanding of the usefulness of it and their satisfaction with it [16],[17],[18]. Patients’ side being expressed by their physicians is not enough to get a clear specification of their requirements and trigger their active participation and engagement in the later stages of service deployment. In the case of home telehealth although patients are the key stakeholders they cannot easily participate in the development process for two basic reasons. First of all their health condition doesn’t allow participation in long meetings between system developers and users and second getting involved in the development process would require familiarizing with information technology terminology that could bring them confusion and stress. Involving patients in the life cycle model at the stages of requirements specification would pose an unrealistic demand.

To overcome this distinctiveness that patients as users have, we have opted for the use of prototyping in order to evaluate patients’ contribution during design [19]. Once a first service prototype reaches maturity, it is used in a controlled environment by a number of representative patients. The key issue here is the proper selection of the controlled environment. In our case, we have chosen the one-day or out-patient clinic, where the renal patient on peritoneal dialysis and their kin often spend several hours, in order to re-adjust treatment and get a personal re-training on peritoneal dialysis. Introducing the service during such sessions within the hospital/clinic helps patients easily grasp the concept of the service, and do this without any technology related anxiety that may arise when at alone at home. During such pilot uses/demonstration of service prototypes, patients have the opportunity to express requirements in terms of tangible features rather than abstract concepts. Additionally, their needs are captured while in the same time they acquire confidence on the usage of the prospective service.

STARE-HI “6.4. Study flow”

Evaluation is considered as an activity during all stages from design and development (as presented in the previous paragraph) to implementation and deployment of the technology. It is seen by interpretive researchers as a life long learning process that can contribute to the understanding of any deficits early enough to make improvements

STARE-HI “6.5. Outcome measures”

The evaluation report should identify the key themes under research that are presented on the adapted framework (Figure 1) and provide a detailed description.

STARE-HI “6.6. Methods for data acquisition and measurement”

Qualitative researchers may use different approaches in collecting data, such as the grounded theory practice, narratology, storytelling, classical ethnography, or shadowing, etc. The techniques employed are observation of the different stakeholders groups, unstructured and semi-structured interviews, documentation review and researchers’ interaction with the technology used.

Interviews could be conducted using the following model. Arrange at least one meeting with patients preferably on the day that the intervention is introduced to them. Issues on this first meeting could be the identification of their technological competence, their introduction to the new system and to its usefulness. After a week of usage a telephone interview can be conducted on issues such as: ease of use, user satisfaction, fit of the system to the users’ needs, changes in their practices and ways of communication of users with technicians, physicians, expectations. Once a month new telephone interviews can be arranged. Telephone interviews may be substituted with home visits, according to patients’ health condition and preferences. In a similar manner, medical personnel and administrators’ interviews can be conducted, but on site. Questionnaires can also be used for the identification of points of opposition.

An interpretive evaluation approach includes and should report on issues such as:

- the researcher should be present on site in order to get understanding on and grasp the context, of stakeholders’ acts and to interpret the meaning which they give to their interactions;
- the researcher can be biased, thus any competing interests and/or personal predispositions should be taken into account and reported;
- in the case of an external researcher, it is important to clarify his/her position to the stakeholders, to be experienced in order to become accepted by stakeholders, to show confidentiality, to let actors being expressed anonymously, to spend time within the organization in order to integrate within it and to make a detailed investigation of stakeholders acts and meanings;
- in the case of internal researcher, there is the inherent drawback that he/she cannot being seen far from the status that he/she is assigned within the organization, while there is always employers’ fear of punishment in case of being expressed freely.

Data collection involves the following issues that have to be accounted for and discussed: semi-structured interviews to be conducted with key stakeholders; interviewees being expressed freely guided by the researchers themes; researchers themes being based on the literature review and on the adapted evaluation framework proposed.

STARE-HI “6.7. Methods for data analysis”

Arrangement of the empirical data can be done so as to reveal the relations between actual subjective events and the interpretation of the reality as observed in the field. Some indicative steps to follow: identification of themes based on the research question, classification of the information gathered from the interviews based on these themes, identification of the importance and value of each theme, the relationship between them, and the reasons that causes them. Each event should be analyzed and its connection with the research question should be examined in order to construct a logical chain of causes and effects.

DISCUSSION

In home telehealth interventions, the surrounding context varies as patients are alone at their home trying to cope with the information technology that was given to them. Analysing patients' behaviour, reactions and resistances to home telehealth should be a major part of the evaluation activity since patients are the most important stakeholders and the less expressed ones. Emphasis on patients' side during evaluation could provide several answers to a number of questions on the development, training and implementation issues as well as the outcome of home telehealth. Here we list some of these issues that worth further exploration and analysis:

- How do we select patients to use the proposed home telehealth application in cases of pilot/prototype evaluation within a controlled environment?
- Should home telehealth be considered for 'mandatory' or voluntarily usage? Can patients be offered the opportunity to choose?
- Can patients be included during the planning stage?
- What should we know about each prospective patient user before introducing them to home telehealth?
- In general, telehealth aims to broaden the provision of healthcare services irrespective of distance to the healthcare center, thus bringing down the distance and the place barrier. However, is it the case that home telehealth may be creating a new distinction between patients, excluding from advanced care digitally illiterate patients?

Evaluation of pilot projects can produce valuable insights on some of the above issues. It can be the starting point of discussions on issues of approaching, training, involving patients and getting their commitment on home telehealth applications. Studying the influence of patients' cognition, personality, ideologies, knowledge, and social situation on home telehealth usage could offer answers on both development and implementation issues. Evaluation should aim to identify which factors do really affect patients' acceptance on home telehealth. Is it their technological ability, their confidence or anxiety about inability to use and control technology or is it their fear of not obeying to their physicians' recommendation. Patients are not a common group of ICT users since their life is very much dependent on their physicians.

Home telehealth interventions more than any other health information systems applications require a holistic, interpretive approach in their evaluation, emphasizing the overall assessment of the telehealth service seen as an information system embedded in a clinical and a social context, rather than seen merely as a technical innovation or a drug. To conduct such evaluation a formal framework should be described and adopted. Such an example has been presented in this paper, where the general "structure-process-outcome" health informatics evaluation framework has been adapted for the special case of home telehealth. Special issues pertaining to evaluating of home telehealth interventions include patients' participation in the design phase as well as taking into account the varying context and related ethical issues. This interpretive approach for telehealth evaluation imposes also certain requirements for the reporting of the study and its results. Following the STARE-HI guidelines, one should especially take into account certain recommendations when reporting on the evaluation method.

ACKNOWLEDGEMENT

This work was supported in part by a Regional Operational Programme, East Macedonia and Thrace, Ministry of Development, Greece fund under the project: "PERKA – Supporting Peritoneal Dialysis at Home", and is currently supported in part by the project "Novel System for Monitoring Renal Failure", within the program DESMI 2008, co-funded by the Republic of Cyprus and the European Regional Development Fund.

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