Empowerment in Living Practice

Mobile ICT as a tool for empowerment of elderly people in home health care

Anita Melander Wikman

Luleå University of Technology
Department of Health Sciences
Division of Physiotherapy
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To Sara Ulrika and Erik Albert

For me there is only the travelling on the paths that have a heart, on any path that may have a heart. There I travel, and the only worthwhile challenge for me is to traverse its full length. And there I travel - looking, looking, breathlessly.

Carlos Castaneda
ABSTRACT
The aging of Europe’s population is a crucial challenge for the 21st century. Today, the mean life expectancy in Sweden is 83 years for women and 78 for men. Providing health care of high quality on equal terms for all citizens is an important political goal in Sweden. It is a great challenge for providers to achieve elderly care of high quality and to develop products, services and technologies that meet the needs of elderly people. Increased use of various forms of Information and Communication Technology (ICT) can enable the citizens to take more active part in their own health care. Dimensions of empowerment such as participation and ability to influence/control one’s life situation imply an approach to health care with the patient/client in focus. The aim of this thesis was to explore different dimensions of empowerment and empowerment methodology for elderly persons in home health care, and if ICT is a useful tool in this process. Methods used included interviews with patients with experience of rehabilitation, reflective learning workshops with first line staff in home care and an intervention where a mobile safety alarm was tested by elderly individuals. Different analysis methods were used, including Grounded Theory, Latent content analysis and constructivist Grounded Theory together with reflections. My findings were that the process of rehabilitation was experienced as a parallel process based on traditional and individual models, implying that a patient copes with a situation by shifting between being compliant and adopting more self-regulatory behaviour. The results indicated low patient participation in and influence on the rehabilitation process in the hospital. When ICT as an empowering tool was implemented, findings showed that elderly people experienced the use of a mobile safety alarm as an empowering tool. The mobile safety alarm gave the freedom of movement needed to be physical active and still feel safe. The positioning device was not experienced as a threat to their integrity. Mobility and safety were experienced as more important than privacy. Freedom of movement and mobility were described as matters of freedom and empowerment. My research findings indicate that in order to improve home health care services from the patient’s/client’s perspective, we need to work with the triads of participation, empowerment and mobile Information and Communication Technology. We need to critically and creatively reflect on what clients say and then try to respond positively to what we learn. Real improvement might only occur when accountability changes.

Keywords: Empowerment, Influence, Information and Communication Technology (ICT), Mobility, Participation, Participatory Action Research, Reflective Practice, Rehabilitation process, Self-determination
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### ACKNOWLEDGMENTS

### REFERENCES
ORIGINAL PAPERS

This licentiate thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


II Melander Wikman, A., Fältholm, Y. & Gard, G. Safety versus Privacy – Elderly person’s experiences of a mobile safety alarm. (Submitted for publication).


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INTRODUCTION

This Licentiate thesis is about empowerment in practice and mobile Information and communication technology (ICT) as a tool for this process in home health care. In the introduction the context of my research is presented, along with the over all aim of my research and my research questions. In the next chapter my theoretical framework is described. The methodology is described and discussed in the following chapters. Thereafter the findings are presented, and in the last chapter they are discussed together with findings and theories in the literature as my lessons learned from both a methodological, theoretical and a practical perspective.

It is well-known that the population of Europe is aging. The aging of Europe’s population is a crucial challenge for the 21st century. The population of Sweden today is 9.09 million, of whom 17% are older than 65, and it is estimated that by 2018 this demographic group will increase to comprise 20% of the population, corresponding to 2 million people (SCB, 2006). Today, mean life expectancy is 83 for women and 78 for men. Providing health care of high quality on equal terms for all citizens, meaning that local health care should be easily accessible and meet patients’/clients’ needs and be provided in accordance with political priorities, is an important political goal in Sweden. According to these priorities, the care provided should result in acceptable and safe living conditions and give the citizens the prerequisites for quality of life (SFS 2001:453). Therefore, it is a great challenge to provide elderly care of high quality and to develop products, services and technologies that meet the needs of elderly people (Norén, 2005). How can this challenge be met in practice and what constitutes effective practice with high quality from a patient/client perspective?
Starting in Practice

I consider this thesis and my postgraduate studies as a learning process where the “road has been created while walking” instead of my knowing exactly which way I was going to go in advance. My most important experience comes from practice, from being a physiotherapist for more than 20 years working with mostly neurological rehabilitation with both adults and elderly people. In my previous work as a physiotherapist and as a supervisor, my interest in continuous improvement of practice was important. During my 20 years in rehabilitation work a great deal has changed and improved. In the early 1970s, patients stayed in hospital for longer periods of time, sometimes months, in order to be sufficiently rehabilitated to be able to get back to work or/and to manage in their own homes. As a result of the Swedish elderly care reform “Ädelreformen” in 1992 more rehabilitation began to be carried out in the person’s homes and the goal was to have the patients stay at hospital as short a time as possible (Prop. 1990/91:14). I had the opportunity to participate in the transformation from “long term care” units to rehabilitation units and to document this transformation in a video film “12:an bra men hemma bäst” (“Ward nr 12 is nice, but home is best.”). I was also involved in developing and starting an outpatient rehabilitation clinic mostly for neurological rehabilitation. This day time rehabilitation work was based on teamwork both among the professionals and with the patients themselves. We found this team-based philosophy, as Ghaye (2005) describes it as a useful and appropriate mechanism for facilitating effective service delivery. We also felt that we, the staff were enabled to be competent and feel confident when working together. Our approach was rehabilitation where the patients were participants instead of passive recipients of care. We as staff knew from
experience that the patients themselves had the solutions to many of their problems if they got enough support and information and knowledge of how to manage. It all has to do with enabling people, which I later learned, was also referred to as empowerment (Rodwell, 1996). For the professionals, empowerment can also be described as an ‘enabling’ process, which is about creating opportunities that will encourage power to be taken. Empowering staff often requires a change in management style (Ghaye, 2005).

When I was offered the possibility of pursuing doctoral studies, I saw a possibility to study patient experiences of influence and participation in care and rehabilitation and empowerment methodology in this context. I believe that this could improve clinical practice in physiotherapy, since the tacit knowledge and my pre-understanding is that if the patient/client were enabled to use his or her self-determination and engage in rehabilitation, the outcomes would be better.

**The aim of the research and my research questions**

The overall aim of this licentiate thesis is to explore different dimensions of empowerment and empowerment methodology for elderly persons in home health care.

My research questions in the thesis are:

- How do patients/clients experience dimensions of empowerment such as participation, opportunity to influence, self-determination and mobility?
- What methodology can be used to empower elderly people in home health care?
- Is mobile ICT a useful tool for empowering elderly people in home health care?
MY THEORETICAL FRAMEWORK

I would like to begin by explaining that my theoretical framework was not there at the start as a basis for developing the research questions. It has, like everything else in this learning process, been developed “while walking” as I proceeded with this study. Paper I (Melander Wikman & Fälthholm, 2006) was written parallel to my first studies in empowerment and patient-centred care and rehabilitation. Papers II (Melander Wikman, Fältholm & Gard, in manuscript) and III (Melander Wikman, Jansson & Ghaye, 2006) were written parallel to reading and learning about both Participatory Action Research, theories gathered under the umbrella “at the mercy of technology” and methodology in different paradigms. I have used a qualitative approach in this licentiate thesis. In qualitative research the researcher has to describe the lens through which (s)he has been looking at reality (Patton, 2002). To make it possible for the reader to understand what I have done and to justify my research I open by describing my view of research. The ontology underpinning my research lies in the following convictions: I believe that reality is very complex and can rarely be explained completely. I also believe that realities exist in the form of multiple mental constructions which are socially and experientially based. Meaning is local and specific and changes from situation to situation even for the same person. The characteristics of development and success and the criteria according to which theories are to be criticized and judged are related to society and its individuals. There is no general and objective knowledge, because all knowledge is developed from a somewhat limited perspective and can therefore only be valid in relation to this perspective. Bergström (1998) states that cultures and groups at different times have different general perspectives on reality and different ways of thinking. One could even say that there is no universal standard of right and wrong. There is no objective
truth. What is considered right for one person in one context might well be seen as wrong for another person in a different context. Knowledge has “local validity” (ibid.). Through my research I have learned that research is about understanding and being able to explain knowledge. Much of my own understanding, developed during a research course: Doing Workplace Research (McGinty, 1996). I learnt that the questions that had to be asked and actions taken were these: What do I want to find out? What are my values and interests? For whom is my research important? If I want to know what people are doing and why – I have to ask them. I have to immerse myself into the world of the researched (interact, hear, listen, see, observe). So, again, what did I want to know? I wanted to know how health and public welfare services can be both improved and sustained so that patients/clients can be empowered, develop self-determination, participate and exert their influence. For whom am I doing my research? As my focus is on the empowerment of the patient/client, I see my research mainly as for them but also for relatives and professionals working in rehabilitation in home health care. As my research subject is physiotherapy, I also hope that physiotherapists will find this licentiate thesis and the description of my learning interesting, and that it will guide their work with rehabilitation and health promotion for elderly people.

In physiotherapy, the ontological questions are assumptions concerning, for example, health, movement ability and the functional activity of a patient/client. It is also hoped to develop knowledge in the discipline of physiotherapy that can be used to improve practice in order to enhance mobility, functional capacity and the well being of patients/clients (Noronen & Wikström-Grotell, 1999). The part of the physiotherapists’ work that involves interaction with the patient/client and understanding the wholeness
of and cooperation with her or him must be emphasised (Lundvik-
Gyllensten, Gard et.al, 2000). The paradigm of physiotherapy is being
developed towards using this holistic and hermeneutic approach. I agree
with Noronen & Wikström-Grotell (1999) that the ontology perspective is a
determining factor when considering the scientific perspective, and that the
target of physiotherapy as a field of science is to develop knowledge which
can be applied in practice. Reflecting on practice and finding theories helps
us understand practice, which helps you to find out ways of improving
practice. Cott, Finch et al. (1995) argue that it is important to integrate
knowledge and theoretical perspectives that are specific to physiotherapy
and to place this knowledge in a theoretical context that highlights the
profession of physiotherapy. But how can we transform values like
participation and empowerment into living practices in physiotherapy?
Through research courses I came in contact with Action Research (AR),
Participatory Action Research (PAR) and Workplace Transformation. A
practitioner-led approach to the research questions was appealing to me.
Single case experimental design studies, reflective case studies and
reflective action research were also described in the literature as ideal
research methods for clinicians concerned with improving the quality of
patient care (Meyer, 2000). This gave me tools to combine my interest in the
empowerment of patients/clients with doing/learning research. These tools
which led to reframing the traditional views of the relationships between
research and practice and, as a consequence, hopefully opening up new
possibilities for understanding how elderly people’s lived experience can be
a positive force for service improvement.

I find the constructivist hermeneutic/dialectic methodology which aims at
the reconstruction of previously held preconceptions useful as a tool for
finding my knowledge. Individual constructions are elicited and refined through dialogue between researchers and the researched to generate constructions about which there is substantial consensus (Patton, 2002). A common criticism of constructivism is: if reality is constructed, will it then turn out exactly as we want it to be? (Börjesson, 2003). The constructivists are said to relate to an alternative reality that is concealed in discursively formed ideas. The basic idea in constructivism is that the researchers (and everyone) construct their versions of the world (ibid.). Key concepts that guide my inquiry or emerge from reflecting on the process are the theories about empowerment presented below (see section Empowerment in Theory). I also think it is important to have a pragmatic approach and this approach is, from my point of view, suitable to physiotherapy where action is natural. According to Chalmers (1982): "It is not the case that any view is as good as any other. If a situation is to be changed in a controlled way, whether the situation involves the state of development of some branch of knowledge or the state of development of some aspects of society, this will best be achieved by way of a grasp of the situation and a mastery of the means available for changing it. This will typically involve co-operative action." (p.170)

In the research course on doing workplace research I came into contact with the naturalistic approach of Lincoln and Guba (1985). It was in line with my own thinking to search for new knowledge through “going out to the field” without a priori theory and seeing if theory could emerge from the inquiry (cf. Lincoln & Guba, 1985). This paradigm, often called “naturalistic inquiry” (also referred to as constructivist inquiry), is based on knowledge that helps human beings maintain cultural life, symbolic communication and meaning (Miller & Crabtree, 1999). In Malterud (1998) I found support for
my approach. According to her there is consensus that all scientific knowledge should be the result of systematic, critical reflection. Data, results and conclusions are expected to be part of a larger context on which the researcher has to take a position. Different kinds of understanding can develop shades and nuances that bring deeper insights into what we want to know (ibid.). In development and improvement of rehabilitation, studies with a qualitative design could be very useful tools (Öhman, 2005). The rehabilitation process itself is based on social interaction, which is based on people’s attitudes, motivation and thoughts (ibid.).

I have an interest in learning, and I view improvement and development of practice as a learning process both for the organisation and for the individual. As a consequence I also view rehabilitation as a learning process. Empowerment and learning are closely associated since empowerment is about consciousness-raising through reflection (Ghaye, 2001). Illeris’ (1999) theory of learning, which gave me a comprehensive understanding of learning, has been valuable for me in writing this thesis. He sees learning as an integrated process comprising a cognitive, a psychodynamic, and a social science dimension (ibid.). As knowledge is created, shared and applied in different ways, I reflected on my long experience as a physiotherapist and thought about how I had been acting and thinking. Reflecting on practice led me to theories about reflection and the work of Donald Schön (1983, 1987). According to Schön (1983), people learn to do something through actually doing it, reflection in action. But there are also limits to learning alone and to solitary reflection (Schön, 1987). Health care development in the twenty-first century requires new and different approaches to learning through reflection, and Ghaye (2005) seeks to establish reflection as a collegial and collective process. In physiotherapy programs a curriculum reform to
promote reflection and professional development was introduced in the early 1990s (Shepard & Jensen, 1990; Jensen et al, 1999; Clouder, 2000). Reflective practice works with concepts such as synthesis, interface and interaction (Ghaye & Lillyman, 2000). Reflective practice is also a continuous learning process because when we reflect on practice we delve below the surface of the practice incident. It involves re-seeing, re-experiencing, re-viewing and re-searching what it is we do in practice in order to develop a more holistic view of care (p.10 Ghaye & Lillyman, 2000). Reflective practice is educative, as reflective practitioners develop themselves and their work systematically and rigorously (Ghaye & Lillyman, 2000). Reflective practice has links to Action Research (AR), described below (see Research Approach).

Empowerment in Theory
In the literature, empowerment is defined and described in different ways: as a term, a construct, concept, a process, etc. Some of the descriptions and interpretations of empowerment are introduced in this chapter, which concludes with a definition of empowerment as used in this licentiate thesis.

Empowerment is a complex concept that refers to individual and social resources, independence, self-determination and choice (Renblad, 2003). It is also a multidimensional concept and has been used in different contexts and formulated differently by different individuals, communities and organisations, from both local and global perspectives (ibid.). There is, in other words, no universally agreed definition of empowerment. It is linked to a number of expressions and ideas (Ghaye et al., 2000). Empowerment can be seen as a discourse (Glenister & Tilley, 1996; Tilley et al, 1999; Ghaye, Gillespie & Lillyman, 2000; Ghaye, 2001). It is possible that the
rehabilitation context can form a community of discourse which shares the values that come with empowerment. Therefore it is important to explore the related values. The concept of empowerment suggests both individual influence over one’s own life and democratic participation in one’s community (Rappaport, 1987). The concept expresses both a psychological sense of personal control or influence and a concern with actual social influence, political power and legal rights. As a multilevel construct it is applicable to the individual, group/team level and at the organisational level, so the context is important when empowerment is studied (ibid.).

**Individual level**

Ultimately, empowerment is unique to each individual (Stuart-Hamilton, 2000). At the individual level it is often referred to as self-empowerment and is linked to ideas of personal control, self-responsibility, self-care and self-determination (Ghaye et.al, 2000). The concept of empowerment can be seen as a confirmation of one’s values, dreams and abilities (Rodwell, 1996). Positive self-esteem is created that give the individual the ability to set and reach goals, a sense of control over life and the ability to change processes, as well as a sense of hope for the future (ibid.). Empowerment is assumed to promote health, in the sense that empowerment is a process through which people gain increased control over the actions and decisions that affect their health (Arneson, 2006). Seeing empowerment as a process, in which a person develops an active approach to problem-solving, increased political insight as well as a greater ability to exercise control over his or her environment seems to be generally accepted (cf. Arneson, 2006). Empowerment can also be described as a broader construct. Zimmerman and Rappaport (1988) suggest that psychological empowerment can be thought of as composed of personality, cognitive and motivational aspects of personal control and competence. They describe psychological
empowerment as “the connection between a sense of personal competence, a desire for, and a willingness to take action in, the public domain.” The individual experience of empowerment includes a combination of self-acceptance and self-confidence, political and social understanding and an ability to play a confident role in controlling resources and decisions in the community you live in, according to Zimmerman and Rappaport (1988). Involvement with others, increased responsibility and organisational problem solving are expected to contribute to the individual’s sense of psychological empowerment (ibid.). Participation is thus a prerequisite for the development of psychological empowerment.

**Group/team level**
Empowerment is a fundamental way of thinking and cannot be seen as a technique (McDougall, 1997). Reflective practices can help a caregiver make decisions together with patients/clients, share and support ideas and views of things and create an identity that strengthen team cohesion (Ghaye, 2005). Structures for empowerment can be developed that support the group/team by creating opportunities for dialogue and for making improvements in practice and policy. According to Ghaye (2005), team empowerment is often experienced in terms of what enables the team to work together with quality relationships between staff members being at the heart of this. It is about creating opportunities that enable and encourage power to be taken and creating an ‘enablement’ process, since empowerment has to do with enabling (Ghaye, 2005; Rodwell, 1996). It is important that members of any work group or team make their view of empowerment explicit. This avoids misunderstandings and provides an opportunity for it to be known and appreciated by colleagues (Ghaye, 2005).
Organisational level
Most research on empowerment has been conducted in business, management and organisational psychology and rather than in health care (Arneson, 2006). Research on empowerment in working life focuses on three perspectives: prerequisites for empowerment at work, psychological experiences of empowerment in working life and a critical perspective questioning if interventions aimed to empower have succeeded (ibid.). It is easy to talk about empowerment but less easy to deliver the key to success of any empowerment strategy or program (Appelbaum et al. 1999). Thatchenkery (2005) sees empowerment as one of the knowledge enablers in an organisation using an appreciative sharing of knowledge. Empowerment can also be defined as the extent to which people are involved in defining the problems and setting the targets that constitute the work (Tilley et al. 1999). Wallcraft (1994) states that: “Power comes from within. You can facilitate it, but you can’t make it happen.” Self-awareness and self-esteem helps people make contact with their strengths and resources (McDougall, 1997). People who have opportunities to develop and grow will also feel more empowered. Having control in the sense that you can fulfil your needs and influence others’ beliefs, thinking and feelings is having power (Renblad, 2003). Power is in itself both positive and negative and can be used either to support people or to oppress them. Empowerment extends a person’s possibility to make choices and to exert influence (Renblad, 2003). It is also a question of democracy and ethics in everyday life and issues like social interaction and communication are important enablers of participation in society (ibid.). In this licentiate thesis empowerment is seen as a process (cf. Rappaport, 1984; 1987; Ghaye, 2005; Arneson, 2006). The focus is on self-determination, ability to influence, participation and mobility as dimensions of empowerment. Self-
determination is defined as the individual’s experience of being in control to initiate and legalize actions (Arneson, 2006). Self-determination includes both the right and the capacity to direct your own life and to exert control over it (Wehmeyer, 2004). Psychological empowerment represents one facet of subjective well-being and refers to people’s belief that they have resources, energy and competence to accomplish important goals and positive moods (Diener & Biswas-Diener, 2005). Psychological empowerment differs from perceived control and according to Zimmerman (1990a; 1990b), psychological empowerment is multidimensional and includes a theoretical link to community involvement. Dimensions of empowerment such as participation and influence lead us to an approach in health care where the patient/client is in focus. This is the objective of Patient-centred care and rehabilitation.

**Patient-Centred Care and Rehabilitation**

Patient-centred care (PCC) is a concept that focuses on improved understanding and incorporation of the patient’s perspective in care delivery (Mark et al. 2002). It is also an approach according to which the patient is seen as an active problem solver and valuable collaborator instead of as a passive recipient of treatment recommendations (Ozer & Kroll, 2002). In Patient-centred rehabilitation (PCR), rehabilitation is a problem solving process where only the patient knows what problems (s)he needs to resolve (Ozer & Kroll, 2002).

The Patient-centred clinical method puts the patient at the centre of both medical care and education and research (Stewart et. al., 2003 s.301). This model reveals the commonalities among all medical disciplines and health professions as well. Stewart et al. (2003) describe six components of the patient-centred clinical method: exploring both the disease and the illness
experience; understanding the whole person; finding common ground; incorporating prevention and health promotion; enhancing the relationship; and being realistic. The first component means that it is important to distinguish between disease and illness and to know that understanding illness requires a different approach. Illness is the patient’s personal and subjective experience: the feelings, thoughts and altered behaviours of someone who feels sick. The patients ‘explanatory model’ is her/his own conceptualisation of the problem, a narrative it is important for health care professionals to listen to. By expanding the focus from simply the disease and including the patient’s experience of illness it is possible to attain a richer and more meaningful and productive outcome for all participants. Stewart et al. (2003) write about the importance of exploring the four dimensions of the patient’s illness experience – feelings, ideas, function and expectations (FIFE). The second component: understanding the whole person – individual and family, means developing an understanding of the social and developmental context in patient’s lives and also being aware of the many layers of contextual nuance in which both patients and clinicians are embedded. Finding a common ground is the third component in the patient-centred clinical method and describes the process through which patient and professional reach a mutual understanding and mutual agreement in defining the problems are in establishing the goals and priorities of treatment and/or management. When finding the common ground, it is also important to define the roles of patient and professional. The fourth component consists both of promoting health and preventing disease. The patient-centred clinical model facilitates health promotion and disease prevention. Stewart et al. (2003) have labelled the fifth component ‘enhancing the patient-doctor relationship’, as their research focus is on this particular relationship. But as mentioned above, they argue that this
component can also be applied to the relationship between the patient and other health care staff. This relationship is accomplished through a sustained partnership with the patient, which should include sharing power, constancy, compassion and healing. The sixth and last component is being realistic. Teamwork and effective team-building contribute to making realistic decisions. Awareness of one’s own abilities and priorities is critical in participating in interdisciplinary teams. Issues of cost-effectiveness and ongoing development of health care will also have their effects. Advances in information and communication technology and evidence-based medicine will also influence the practice of patient-centred care (ibid.).

**Information and Communication Technology (ICT) in the context of health care and care**

In connection with my interest in empowerment issues, I also developed an interest in the development and impact of Information and Communication Technology (ICT) within health care and care. ICT is described as a future solution implying improvements for all citizens and “reflecting the major concerns of increasing industrial competitiveness and the quality of life for European citizens in a global information society” (IST, 2006). The vision in the EU Information in Society (IST) programme is:

“*The focus of IST in FP6 is on the future generation of technologies in which computers and networks will be integrated into the everyday environment, rendering accessible a multitude of services and applications through easy-to-use human interfaces. This vision of ‘ambient intelligence’ places the user, the individual, at the centre of future developments for an inclusive knowledge-based society for all.*”
ICT will surely influence home health care\(^1\), the way health care services are organised and delivered, as well as relationship between staff and patients/clients\(^2\) and between different staff. My interest in ICT in home health care increased as I participated in application writing for the Fifth Framework Programme project CUORE in 1999 and participated in an industry driven e-health project as part of that Framework Program, The MobiHealth Project 2002-2003 (www.mobihealth.org). Both projects were part of the IST program. The aim of the MobiHealth project was to test the present infrastructure in Europe and its ability to transmit and store medical data. In order to evaluate usability aspects, a questionnaire was also developed in a participatory process, by all the participants in the MobiHealth project (Melander Wikman, Jansson & Gard, 2005). Experiences from working as a researcher in industry driven multidisciplinary e-health projects are described later, in the section Discussion. I have also participated in one additional industry driven EU project on e-health, the e-Home Health Care @ North Calotte project (eHHC) and one multidisciplinary research project with researchers from the Department of Computer Science and Electrical Engineering, The Mobile Safety Alarm project. The aim of both projects was to develop and test ICT solutions in homecare. The projects will be described in more depth elsewhere. Let us now examine what ICT is and how it can be understood in the context of health care and care.

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1. With home health care I include all services provided in the context of a patients/clients home (care and rehabilitation).
2. I prefer to use both patient and client together (patient/client) as I want to see a person as a whole person with or without functional limitations, cared for by staff from either the hospital, primary care centre or home care office.
Can the use of Information and Communication Technology (ICT) be a resource in solving today’s problems with a growing elderly population and fewer employees within elderly home care? Can delegation of decision making to clients make them more empowered and healthy? To answer these questions we must obtain a picture of ICT in the context of health and social care and of how ICT use can be understood in this context. ICT use can be reflected on mainly from two perspectives, technological determinism and social constructivism (Köhler, 2006). If we see ICT as something that cannot be affected by any social influence we have a determinist perspective, believing that individuals, organisations and society have to change in relation to changes in ICT. The determinist view has been criticised for disregarding the specific context and how it influences ICT use. With a social constructive perspective, where the assets of technology are considered to be with human beings and not inherent in the technology, it is people who interpret the technology and who set the limits, not the technology itself (ibid.).

Information and Communication Technology (ICT) is defined as “a broad concept which enables people to communicate, gather communication and interact with distant services faster, more easily and without limits of time and space” (Campell et al, 1999). There are many names for the use of ICT in health care. Telehealth is defined as ‘the delivery of health related services and information via telecommunications technologies. Telehealth is generally used as an umbrella term to describe all the possible variations of health care services using telecommunications’ (www.wikipedia.org). E-Health describes the combined use of electronic communication and information technology in the health care sector: the use of digital data in the health care sector – data transmitted, stored and retrieved electronically – for clinical, educational and administrative purposes, both at the local site
and at a distance (Mitchell, 1999). E-health is described as the overall, umbrella field that encompasses ICT and Telecommunications Technologies (Telehealth) (Mitchell, 1999). See also Fig. 1.

![Diagram of E-health](image)

**Fig 1** Two sets of technologies in e-health

With an ageing population, there is an increased need for rehabilitation and care and a gap between resources and needs. The development and implementation of mobile information and communication technology (mICT) can somewhat balance this gap. Research focusing on ICT solutions for the development of care for elderly people has high priority in Sweden (Proposition 2005/06:115). Mobile telemedical solutions and Internet use have been introduced in home rehabilitation with the aim of increased independence, safety and mobility. Different kinds of technologies are designed to prevent undesirable events related to the mobility of geriatric patients in hospitals and homes, i.e. patient falls, bed-rail entrapment, patient treatment, and wandering (Nelson et al. 2004). There is research ongoing on
the design and development of intelligent assistive technology, such as response systems using image-based sensors and video cameras that detect falls at home (Lee & Mihailidis, 2005). During the mid-1990s, the first project concerning mobile safety alarm was performed, the so-called SAFE-21 (Thie, 1999). An evaluation of SAFE-21 showed that the first safety alarms used were simple, but useful in fulfilling basic user needs. Within the MobiHealth project, part of the EU’s Information Society Technologies (IST) Programme during 2002 and 2003, the aim was to develop new services and applications in the area of mobile health and hence to promote the use and deployment of GPRS and UMTS mobile services and technologies (Melander Wikman, Jansson, et al, 2004). The main task of MobiHealth was to deliver flexible and dynamic service to patients and health care providers with a focus on optimal utility and usability. Nine trials with a participatory approach were performed in health care, i.e. the end-users were involved in the development and testing of the MobiHealth services. For the caregivers, the MobiHealth system served as decision-making support. In one of the trials, elderly people tested a mobile safety alarm (Melander Wikman, Jansson et al, 2007). The result of “Lighthouse Alarm and Locator trial” showed that elderly people that tested the mobile safety alarm thought that this technology was positive for mobility but that more development was needed. The locator function which showed their position was not considered a threat to their integrity. The staff, however, was of a different opinion and found the positioning to be an ethical dilemma (ibid.).
RESEARCH APPROACH

The specific aims of the different studies were:

- To describe patients’ experiences of influence and participation in the rehabilitation process (Paper I).
- To describe elderly people’s experiences of testing a mobile safety alarm and their reasoning about safety, privacy and mobility (Paper II).
- To explore what methodology can be used to enable elderly people to feel more empowered to exercise their rights of self-determination in home health care (Paper III).

I chose a qualitative approach to answer my research questions since qualitative research, as Silverman (2001) for example, describe it, seeks to see things in context. This also makes the qualitative approach suitable in the rehabilitation research (Öhman, 2005). There are different models in the qualitative research paradigm and each model offers a “toolbox”, providing the researcher with a set of concepts and methods to be used when selecting appropriate data and to elucidate the analysis (Silverman, 2001).

**Participatory Action Research as a way for improving practice**

Physiotherapists work with a problem-solving model that includes examination – analysis – planning – intervention – analysis – re-planning – new interventions – and new analysis, and so on (Thyni-Lenné, 1987). I found it very easy to get into “the soul” of action research as a research strategy, since the action research circle closely resembles “the physiotherapy process” described above. As an approach I found, as I have described earlier, Participatory Action Research a good way to get an
answer to my research questions on patients’/clients’ dimensions of empowerment as influence/personal control and participation. Participation is fundamental to action research and it is important that the participants really feel the need for change and are willing to play an active part in the research (Meyer, 2000). In client-centred clinical practice and in rehabilitation research, Participatory Action Research principles can serve as a participatory model for empowerment (Taylor, 2003).

The objectives of the studies described in Papers II and III were to promote changes that improve the human condition, as Hollingsworth (1997) writes about. The aim of Paper II was to test an intervention, a mobile safety alarm, to see how it was experienced by elderly people as influencing mobility and safety. The research question was developed in close cooperation with staff members at elderly home care authorities. The care givers had experience of how the limited range of the safety alarms in present use was problematic both to them and to the clients in their homes (Melander Wikman & Jansson, in manuscript). This resulted in a joint project, The Mobile Safety Alarm project in which homecare staff, researchers from the Department of Computer Science and Electrical Engineering, myself as a PhD student together with my supervisors, the co-authors of Paper II, participated. The way to improve conditions is best decided by the practitioners. Action research is more directly useful for practitioners if it is done by and with them (Whyte, 1991).

The topic for this research project simply seemed to be there (cf. Winter & Munn- Giddings, 2001). Working in a project like eHHC and The Mobile Safety Alarm project, the objectives of the projects were issues important to all participants. The staff members working in elderly care for Luleå
municipality were participants in both projects and this made the research topics very relevant to the ambitions of developing and improving home health care for elderly people in the community. Representatives from several pensioners’ organisations, a reference group at Luleå municipality, were also speaking partners in the research process. A participatory inquiry means that the participants are invited into the processes as people with ideas and views, as reflecting human beings instead of as research objects. In Paper III, the staff members who participated in the workshops were active in the research in that sense that the results were returned to them as feedback and their responses were incorporated as new data in the final paper. This process has been described by Meyer (2000). In this way we, as researchers, strove to include the participants’ perspective. Participatory Action Research (PAR) has been developed in the context of Action Research (AR), which sometimes gives rise to some confusion (Thesen & Kuzel, 1999). Action research seeks to bridge the gap between theory and practice by placing value on the experiential basis for knowledge, with a focus on the practical motivation for developing increased understanding (Winter & Munn-Giddings, 2001). The researcher applies theories and contributes to practice and the practitioners apply practice and contribute to theory (Coghlan & Brannik, 2001). Participatory Action Research can be described as, a research process that embraces an equal commitment to participation and action (for working towards some level of change) (Bhosekar, 2006, p.46) and the core is working towards some kind of improvement for the participants. I agree with Bhosekar (2006) who argues that PAR values and hears voices of others, respects various and diverse realities of the participants and also challenges the domination of the objective and reclaims the subjective nature of inquiry.
The staff members who participated in the workshops in study III reported back to us after the workshop days, that they intended to use the knowledge they had gained from the two days in their daily work. As they were all front line staff in elderly home care they also had the power to formulate and to transfer the description of the process and outcomes of the workshop out to the community. Thesen & Kuzel (1999) write about the importance of this.

In a project aiming to change conditions, the participants have to achieve a critical understanding of the social reality (Winter & Munn-Giddings, 2001). Action research has the potential to close the research-practice gap (Kennedy, 2001). Like Kennedy (2001) I felt that I was able to be both an “insider”, as a physiotherapist, with the same values and beliefs as the practitioners and at the same time an “expert”, facilitating the learning process in the workshops in Paper II together with my fellow researchers (cf. Winter & Munn-Giddings, 2001). I do not think the home care staff viewed me and my colleagues as external researchers. This may have limited the project and some of the staff may have seen this as influencing the validity, reliability and objectivity of the project. However, my opinion is that, as we as researchers were looked upon as “insiders” this made the communication-process more open, compared with if this investigation had been carried out by experts/outsiders. We were, as Winter & Munn-Giddings (2001) describe it, focused on the findings instead of the process. Action research is really about establishing inquiry processes that are specially intended to be “empowering” for those who are involved in the inquiry. In Paper II, elderly people who tested the mobile safety alarm came to reflect upon the importance of mobility as an empowering dimension and as how limited they could experience themselves as being when functional limitations were impeding them in their daily life. They saw the mobile safety alarm as an empowering tool. In Paper III the whole workshop can be
seen as a consciousness-raising process, using an appreciative approach, just as described by Cooperrider & Witney (2005). Appreciation is seen as the “missing link” in facilitating knowledge sharing, according to Thatchenkery (2005).

**Using critical friends**

It is important that the researchers have contact with some “critical friends” who help them change this way of thinking, if necessary.

Winter and Munn-Giddings (2001) write:

> Critical realism asserts that social inquiry is always a part of the social world it describes. (Hence the action research principle of **reflexivity**, which emphasises that the **process** of research is always also a topic for inquiry.) It therefore follows that social inquiry does not have an external ‘platform’ from which researchers can conduct ‘objective’ observations of those being ‘researched’. Hence the significance of the action research ideal of research as a **participatory, collaborative** process, in which participants are encouraged to take **creative** part in **negotiating** the focus and the **conceptual framework for interpreting data** (pp.261-262).

In my research I have had the pleasure of working with many critical friends. Being part of a multidisciplinary research school, Arena Lifestyle, Health and Technology, also makes the idea of critical friends easy to grasp. The research school has been a platform where I have been able to discuss my research questions with my friends and with the different lecturers at the multidisciplinary courses that was the basis of the research school. Working in projects together with others is another given forum for discussions and possibilities for reflection. Paper II was based on the Mobile Safety Alarm Project (MLT). Paper III was based on the e-Home Health Care @North Calotte (eHHC) project. My co-authors in all three papers have all been very good critical friends. Paper III was a particularly collaborative project with
lots of creative discussions and reflections. The writing process was also a collaborative one.

**Grounded Theory approach**
The aim of Paper I was to explore whether the patients experienced themselves as having any influence on their own rehabilitation and whether they had been participants in the planning and performance of the interventions. The method chosen was qualitative and inductive, inspired by Glaser and Strauss’ Grounded Theory (GT), according to which new theory can be generated from the data, produced by the interviews (Glaser & Strauss, 1967). This method embraces all the steps from the collection of data to the final theoretical writing and implies that ideas generated in interviews are organised in a systematic way. Thus in this study, there was constant interaction between data (a description of reality) and generated theory, aiming to identify the main problems and processes. Most themes developed at the outset of the data collection process were kept intact, but new themes and questions also emerged and were developed during the collection of data, as a result of the parallel process of analysis. No new interviews were therefore conducted before those already carried out had been preliminarily analysed (Malterud, 1998). My ambition was to use grounded theory as an influence in the design and conducting of the research project. Afterwards I have learned from Glaser (2001) that it is wrong to be “influenced “ by GT. Either you do GT or you do some other qualitative data analysis. As GT is all about conceptualization and not about description, you must follow the rules of GT strictly (Glaser, 2001). GT is a combination of induction and deduction. This means that preliminary ideas and hypotheses are tested on already collected data and also in the collection of new data (Glaser, 2001). Starrin et al. (1991) calls this abduction. Theory emerges from the researcher's observations and interviews through
systematic comparative analysis, and is grounded in fieldwork. These
theories are used to explain or obtain a better understanding of what has
been observed and at the same time to discover new ideas and theories. A
researcher using GT moves back and forth between induction and deduction,
between experience and reflection on experience and between greater and
lesser degrees of naturalistic inquiry. This leads to discovery and
verification (Patton, 2002). GT is a search for “basic social process” or the
“core category” (Glaser, 2001). GT focuses on the process of generating
theory rather than particular theoretical content. Key concepts in GT are pre-
understanding, theoretical saturation and constant comparison – comparing
research sites, doing theoretical sampling and testing emergent concepts
with additional fieldwork. The objective is to see what is going on that is not
obvious at first glance. The researcher must lift the veils that obscure or hide
what is going on (ibid.). However, these strict rules about how to conduct
GT “the best way” gradually made me feel insecure about how to act, so I
left this approach in Paper II and used Latent Content Analysis instead. This
method is described under section Participants, data collection methods and
methods of analysis. In Paper III, more social constructivist grounded theory
was used, inspired by Charmaz (2000).

**The research context**

For research in a rehabilitation context, I agree with Öhman (2005) that
qualitative methodology is suitable since qualitative research seeks to see
things in context. The first paper in this thesis was written in the context of
rehabilitation in primary care in the north of Sweden (Paper I). Two of my
papers were based on the results of two different e-health projects; The
Mobile Safety Alarm Project (Paper II) and the e-Home Health Care @
North Calotte project (Paper III). In choosing PAR as a research approach
for Papers II and III the context of home care was already there. Staff
members from the municipality’s elderly care system were already partners in the project. This made it easy to gain access to home health care and also to be accepted. The research questions are grounded in practice. It is necessary to explain the potential and problems of doing research in industry driven development projects before discussing the use of Participatory Action Research (PAR) approach. Let us begin with the potential. The research is performed in a team of interdisciplinary people: researchers, technicians and professionals from practice, in this case home care. The project approach was strongly dynamic in itself as the project had a given start and end. The project also has a result-oriented focus, with deadlines for prototype development, so things moved very fast in the project. In such a case, the researcher has to be aware of each phase in the project, otherwise (s)he will not understand the participants’ way of thinking and acting and will be standing alongside as an observer.

The e Home Health Care @ North Calotte project (eHHC) was the context for Paper III. The overall aim of the eHHC project was to provide customer-oriented empowerment-focused quality service provision in the right place at the right time in elderly care in the north of Norway, Finland and Sweden. In eHHC we distinguished between two levels in the reasoning about patient empowerment in ICT-based health services (Holthe, Melander Wikman et al, 2005). The concept of empowerment was initially defined within the project as concerning the clients’ well-being and quality of life, and their position as consumers of health care services. Empowerment at this level is about cooperation and communication between the clients/families and staff as well as among staff members. The aim of empowerment initiatives in the eHHC project was to provide health services that comply with the clients’ needs and priorities (ibid.). Empowerment initiatives in the context of e-
health can strengthen client-client relations as well as client-staff relations through the application of ICT - and involve electronic distribution of relevant health information. Secondly, in the eHHC project, empowerment was about client influence on the shaping and running of e-health services at an organisational level. Representatives of the health care recipients were present at the level of decision making about health care work organisation. Representatives from several pensioners’ organisations, a reference group at Luleå municipality, were speaking partners about how the e-health service developed in the project. Constructive reasoning about empowerment in home care services took place and the individual, the team/group and the organisational level were taken into account in the project (Holthe, Melander Wikman et al, 2005). This means that the eHHC project had an approach by which deep insight into the clients’ needs and preferences in the context of e-health was required. Structured knowledge about patients’ application of ICT and health information was the starting point. The project partners discussed the concept of empowerment and learned about what dimensions of empowerment would be prerequisites for creating “customer-oriented empowerment-focused quality service” in home health care.

Paper III is an example of activities requested by the professionals within homecare at the Swedish site of the eHHC project, in order to understand the concept of empowerment better. In Paper III, two reflective learning workshops with an approach from Appreciative Inquiry (AI) were used as data. The focus was not on problems of how to improve care of elderly people, but on human ideals, achievements and best practice (Cooperrider & Witney, 2005).
In rehabilitation, it is common to think in terms of “building on the strengths” of the patient/clients, so to me it was natural to use AI in the workshops. The traditional focus on problems has a tendency to make the participants blind to potential and strengths (Anderson, Cooperrider et al. 2006). When individuals are valued they are more sensitive to the desires and needs of those for whom they work (ibid.).

PARTICIPANTS, DATA COLLECTION METHODS AND METHODS OF ANALYSIS

Below, a description of the participants, how they were recruited, data collection methods and methods of analysis is given. An overview is shown in Table 1.

Table 1. Overview of participants, data collection methods and methods of analysis

<table>
<thead>
<tr>
<th>Paper No</th>
<th>Participants</th>
<th>Data collection methods</th>
<th>Methods of analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>6 patients</td>
<td>Interviews</td>
<td>Grounded Theory (GT)</td>
</tr>
<tr>
<td>II</td>
<td>9 elderly individuals</td>
<td>Intervention study with interviews</td>
<td>Latent Content Analysis</td>
</tr>
<tr>
<td>III</td>
<td>35 first line staff in home care</td>
<td>Reflective learning workshops</td>
<td>Constructivist GT</td>
</tr>
</tbody>
</table>
Paper I – The interview study
The informants in Paper I were selected by three physiotherapists at three different health care centres in primary care. The participants were chosen by purposeful sampling, i.e. the participants with special knowledge about the phenomenon that was the aim of the study – experience of rehabilitation, were selected. The inclusion criteria were that the informants should be of working age (below 65 years), have experience of a three-month or longer rehabilitation process and still be in rehabilitation. Each potential informant received information on the aim of the study from a physiotherapist at the health care centre, and the informants who chose to participate were informed once again by telephone by one of the authors, after which an agreement was reached about where and when the interview would take place. Four informants chose to be interviewed in a room at the health care centre. The other two interviews took place in the home of the informants. At the time of the interview, each informant signed an informed consent, stating that participation was voluntary and that all data from the interviews would be treated confidentially. The total number of informants was six, two from each health care centre. The informants were four women and two men between 35 and 58 years of age who had impairments and disabilities as a result of neurological, circulatory and/or orthopaedic diseases. The interviews took 1-1½ hours, and each informant was given the opportunity to talk for as long as (s)he wished without time pressure.

Paper II – The intervention study
A purposive sample of nine individuals were selected to be the participants of this study. The participants were from 60 to 84 years of age. They were four healthy elderly people with no functional limitations, and five elderly
people with functional limitations such as balance problems, pain, dizziness after for example, a car accident or stroke and with chronic disease. These five elderly participants already used traditional safety alarms that were not mobile and had a limited range of 10 meters. The participants were recruited by two heads of elderly care. The four “healthy” pensioners were recruited from an advisory board of pensioners’ organisations with which the municipality cooperates on a regular basis.

The safety alarm tested consisted of an alarm with a GPS receiver and a built-in drop sensor. The alarm was triggered either by pressing a button on the mobile safety alarm and locating device or when the drop sensor (based on a mobility sensor) was activated. It was possible for the alarm-bearer to communicate with the staff who answered up on the alarm. The main expected benefit of using the alarm and locating device in this pilot test was that it was to increase mobility and allow elderly people to live a more normal life than before. The alarms were shown on a receiver in form of a handheld device used by the staff. Positioning was done by a GPS receiver that sent the positioning data, and the position was indicated on a map on the receiver used by the staff. It was possible to track elderly people person’s position using a map displayed in the handheld device with regularly updated locations.

The interviews were conducted to explore how the participants had experienced the use of the mobile safety alarm and their reasoning about safety and privacy. Conversation is the most basic form of interaction and communication in an inter-human situation, thus interviews are valuable tools for being familiar with other people’s experiences, knowledge and
feelings about the world they live in. Kvale (1997) writes that a qualitative interview should be both an everyday conversation and a professional conversation at once. Our interviews were narrative and also reflective. Sandelowski (1991) is of the opinion that using narrative models help to obtain a better understanding of how people experience their lives through their stories.

**Paper III - The Reflective learning workshops**
The aim of Paper III was to reflect on our collective concern about developing and sustaining ways that might enable elderly people to feel more empowered to exercise their right of self-determination. The work was undertaken in the context of home health care in northern Sweden. In Paper III we put three espoused values ‘under pressure’ from the client, professional (home care staff) and research perspectives. We also explored, in more detail, three aspects of the landscape of homecare: the notions of client participation, empowerment and ICT. The living data for Paper III were drawn from two days of reflective learning workshop activities with 35 home care staff working in the municipality of Luleå, Sweden. The workshops were one outcome of the e-Home Health Care @ North Calotte (eHHC) Project of 2003-5. The participants chose to join the workshop by putting their name on a list of participants. Our ambition was to try to make each day’s workshop an ‘appreciative intervention’ (Bushe, 1998). This meant bringing to each group the most helpful example of an elderly person’s experience that we could find (see Olga’s story in Paper III). This experience would connect with the work of staff from the home care sector. We also wanted to provide plenty of opportunities to collectively explore the discourses associated with client participation, empowerment and the use of ICT. A third aim with Paper III was to give the ‘mind a hand’ by utilising one aspect of visual methodology, namely the use of storyboards, to
understand the social relations, professional interactions and subjective agendas of home care staff. Finally we wanted to focus on the visual and participatory elements of meaning-making in order to better understand how the future (for Olga) unfolds from her present family and professional relationships and patterns of power with home care staff.

As description forms the bedrock of all qualitative reporting a description of the reflective learning workshops is in order here (cf. Patton, 2002). Reflective learning workshops were conducted with first line staff of care assistants in home care, case workers/process officers and supervisors of personal assistants. Workshops are used when the objective is to gather and analyse information about a selected theme (Bødker, Kensing & Simonsen, 2004). The workshop technique aims to create an overview by focusing on an understanding of the entirety as well as on existing aspects of the work practice (ibid). We, the authors, acted as facilitators of the workshops. The reflective learning workshops started with a personal presentation of each participant and exercises to make cooperation visible and to create a good atmosphere in the group, and increase the group cohesion as a basis for the workshop activities (cf. Wibeck, 2000). After these exercises, the group was divided into four smaller groups with 4-5 people in each group. These small groups functioned as focus groups although the aim was not to conduct interviews. The reflective workshop technique resembles focus groups as a valuable technique for collecting qualitative data. As in the focus groups technique the advantage was that we as researchers were able to observe the interaction among the participants on all subjects (cf. Morgan, 1997). As in focus group technique, you have to go beyond attitudes and opinions and instead emphasise learning about the participants’ perspectives and experiences of the research topic (ibid.). Similarities and differences in participants’ opinions and experiences were provided directly in the group
discussions, as in focus group interviews (cf. Morgan, 1997). As in the focus group technique, a great deal of emphasis is placed on the role of the moderator/facilitator of the workshop. The result depends on the styles of moderating (ibid).

A large amount of data was produced during the two days of the reflective workshops, including the individual answers of the participants written on paper, results from their activities in form of consensus reports written on sheets of paper to display to the other group members, researchers’ field notes from the discussions and tape recordings from some of the discussions the different groups had while they were working with the storyboards. Qualitative research often produces a rich amount of data, which needs to be analysed systematically and in a logical fashion (Miles & Huberman, 1994).

To visualize client participation in home care, Olga’s story was presented. Olga’s story was a narrative created by the authors together as stimulus material to generate a basis for discussions and questions in the reflective workshops (cf. Wibeck, 2000). This narrative (Olga’s story) was based upon findings from an interview study with 10 elderly individuals in home care, conducted by one of the authors (Melander Wikman et al., manuscript in progress). Three activities were planned for the workshop under the heading “Promoting Olga’s health, well being and independence”. The first activity was a significant incident analysis using the storyboard technique. In the second activity the storyboard was used for a Gap Analysis and from the Gap Analysis the participants developed a positive improvement plan. A GAP analysis activity allows you to compare current practice and to focus attention on changes that are needed (Wikipedia.com). In the third activity, “Process Mapping” we used the outcomes from activities one and two. Professional practice is a process of problem solving from the perspective of
technical rationality. Problems concerned with choice or taking a decision will be solved by using the available means considered to be the best for the given aims (Stolterman, 1991).

This technical rationality stresses problem solving instead on focusing on problem setting, which is defined by Schön (1983) as the process through which we define decisions taken and the goals to be reached and what means are to be chosen. In reality the problems do not appear to the practitioner as given. They need to be constructed with problematic situation as a basis, situations that are troubling, uncertain and puzzling and according to Schön (1983) it is an interactive process in dialogue with the situation. The storyboards created in the workshops were the result of an interactive process between Olga’s story, which we, the facilitators had given them and their experience from practice and their reflections about it.

**Methods of Analysis**
The methods of analysis are presented separately for each paper.

**Paper I**
Concurrently with the collection of data, the analysis of data in Paper I was carried out until there was enough material and new data were not considered to develop new knowledge, a phenomenon referred to as ”theoretical saturation” by Strauss & Corbin (1990). That is also described by Holloway & Wheeler (1996), who write about it in terms of theoretical sampling. According to them, sampling is guided by ideas that have significance for the emerging theory. The interviews in Paper I were tape-recorded and transcribed verbatim, and the data were then analysed in four steps, without any preconceptions. The first step involved looking for wholeness and patterns, after which the material was coded by open coding
in order to find units with a meaning (Strauss & Corbin, 1990). Malterud (1998) describes the process as choosing text that in some way carries knowledge about one or more themes from the first step of the analysis (decontextualisation). The different stories told by the informants were summarised using different keywords. In the third step, the material was reduced to a sample of collected and meaningful units (condensation) and the main keywords were established (Malterud, 1998). In order to create a comparative analysis, different story maps were formulated, based on each informant’s own story (cf. Miles & Huberman, 1994). The second author and I compared different interpretations. The authors met several times to make comparisons, and the outcome was negotiated. During the fourth step, the material was recontextualised and core categories were identified. In grounded theory, conceptualisation is important. Conceptual grounding is constantly verified such that the voices of the participants are abstracted and constantly compared and modified, and thus built-in and made appropriate (Glaser, 2001). The core category of Paper I was identified as The Parallel Process of Rehabilitation. The findings are presented in next chapter in this thesis.

**Paper II**

In Paper II, the aim was to describe elderly people’s experiences of testing a mobile safety alarm and their reasoning about safety, privacy and mobility. The participants were chosen as a convenient sample to test the mobile safety alarm and all of the participants were interviewed after the testing period. Thus we could not use a grounded theory approach with theoretical sampling to achieve theoretical saturation (cf. Glaser, 2001). The interviews with the participants in Paper II were analysed using Latent Content Analysis (cf. (Downe – Wamboldt, 1992). Content analysis can be conducted at different levels of abstraction. You can either look at the
manifest content that is expressed in the text or you can analyse the latent content and make an interpretation of the underlying meaning of the text. According to Graneheim & Lundman (2004), it is impossible to avoid making some kind of interpretation, although interpretations may be more or less deep. The procedure of analysis was conducted in the following stages (cf. Graneheim & Lundman, 2004):
1. The whole text from the interviews (the unit of analysis) was read several times with the purpose of getting a feeling for the context. 2. After reading the interviews meaning units were identified, with the same purpose in mind, and sorted into groups in relation to the content. 3. The meaning units were condensed in order to shorten the content but still keep the core of the content. 4. The condensed units were coded and grouped into categories that mirrored the central message in the interviews. These categories were then merged into main categories. 5. The theme “Safety and mobility is more important than privacy” emerged as the main theme, and can be seen as the latent content of the interviews. The three authors discussed the codes and categories together to obtain the relevant information.

**Paper III**
The analysis in Paper III was made in a structured reflective process by all three researchers/authors together. After each session in the workshop all three researchers/authors made some collective reflections on what had happened. All the working materials, storyboards, field notes and tape recordings were collected and analysed after the workshops. We concluded each workshop with some collective reflections about (a) The practice of participation (dialogue) and an intention of participation (empowerment) in the context of home care services accelerating change. (b) How to reframe traditional views of the relationships between research and practice and, as a consequence, how to open up new possibilities for understanding how
elderly people’s lived experience can be a positive force for service improvement. (c) The use of storyboards as an appreciative approach to enable frontline staff to reflect on their work, share and learn together. The analysis can be compared with social constructivist grounded theory as described by Charmaz, (2000). We had a constructivist, rather than an objectivist approach to grounded theory (Charmaz, 2006), because, although there are no firm lines between them, an objectivist “…attends to data as real in and of themselves and does not attend to the process of their production” (Charmaz, 2006, p. 131), while a constructivist studies how participants construct meanings and actions in specific settings. This means that not only were our previous personal and professional experience sources of theoretical sensitivity (Strauss & Corbin, 1998), but what happened during the reflective learning workshops also contributed to our ability, in the act of theorizing, to “reach down to fundamentals, up to abstractions, and probe into experience” (Charmaz, 2006, p. 135). It also means that during the interviews the participants and we as researcher/facilitators were engaged in a reflective process.
FINDINGS

The findings are here presented separately for each paper, and the categories and/or themes in each respective paper are italicized.

Paper I

This paper describes how the process of rehabilitation is experienced as a parallel process. This means that the patients coped with the situation by relating to two models of care, “the traditional medical model”, based on experiences of acute care and rehabilitation at the hospital and “the individual model”, based on experience of and attitudes towards rehabilitation in primary care. These two models represent two types of coping and, in reality, the patient shifts between compliant and more self-regulatory behaviour.

The traditional model was described as a rehabilitation process where compliance with the professionals, the “experts” was taken for granted. None of the patients had thought of the possibility of bringing an influence to bear on planning of the rehabilitation at the hospital. The physiotherapists was invisible in the sense that it was hard for the patient to decide what professional category was responsible for the treatment and who belonged to the team at the hospital. In primary care, there was no team and the physiotherapist and the doctor were seen as the main players with responsibility for the rehabilitation. When the informants talked about the rehabilitation process, they did not differentiate between medical treatment and rehabilitation interventions. They saw it all as a complete process from the day they fell ill or were injured until the present day. The reason for being moved from one ward to another during their hospital stay was unclear. One informant described the meeting with the acute hospital care as
“a merry-go-round where you had to keep control so as not to get involved in interventions of which you did not understand the aim”. This subordination was shown as waiting to see what would come out of the stay at the hospital.

The individual model was based on experience of and attitudes towards rehabilitation in primary care, and all the informants talked about the importance of being confirmed, in the sense of being seen and listened to. They appreciated caregivers who could see how they felt without their having to say anything. Support, encouragement and back-up from the physiotherapists were appreciated most of all. They felt it was important to be taken seriously, to be confirmed and not to be seen as crazy. Many of the informants searched for information about their disabilities in books and weekly journals. They also received help from relatives and friends and had information from the Internet sent to them. They would have liked some kind of forum in the health care sector that could inform them about laws and social insurance matters, a forum where they could get support that was not provided by a controlling authority. They received some help from patient organisations, which they felt were on the patient’s side and gave them a feeling that they were not alone with their problems. Piece by piece they integrated information from different sources: professionals, relatives, workmates, friends, and the media. Together with their own experience they interpreted this information and obtained a sense of coherence. The physiotherapist was described as the person who helped them gain control over their bodies and achieve a balance between body and soul. All informants tried to give themselves the power to dare to demand to be treated in the right way. One informant reflected over and regretted that she had not been more clear and demanding. They all gave examples of what
could have been done better. They reflected on patient participation and influence and remembered situations in which they had been disappointed in the way they had been received and treated. Experience acquired over a long period of time in rehabilitation had made the informants conscious of how this process should be organized and they stated that if the same thing would happen to them again, they would be more active and not so compliant. The results showed that the informants were not aware of the possibility of exert influence, and therefore did not participate in or have influence on the rehabilitation process at the hospital. The participants chose to make their own way, supported by their relatives and workmates. It seemed to me that the informants had been part of a parallel process. The informants tried to be compliant with the rehabilitation process offered within the health care system and, at the same time, they got support from family, relatives, colleagues and friends. All informants had many good ideas of their own about their situations, ideas no one from the health care system asked to hear.

**Paper II**

In this paper, findings from elderly people’s experience of using a mobile safety alarm and their reasoning about mobility, safety and privacy are described. The core finding was expressed in the theme: *Safety and mobility are more important than privacy*. The main reason for having a safety alarm was safety. Five participants used traditional – not mobile – safety alarms, and all of them had friends or relatives who were users of the same type of alarm. All of them said that the alarm system was essential to their ability to feel safe and secure, but its limited range was perceived as problematic. All nine participants described the *fear of falling* as one of the main reasons for using a safety alarm, and those with difficulties in moving around feared falling the most. Participants who had difficulties in moving around and
those who were active and mobile thought they needed a safety alarm because of the “increased violence” in the community. This fear of violence was expressed as a fear of being assaulted/attacked and robbed, those with difficulties in moving around thought that a safety alarm could also be used if someone broke into their homes. Fear of falling also contain an element of fear of not being able to take care of oneself and of insecurity about whether anyone would come to the rescue if they fell down and couldn’t get up. This had to do with losing self control. It was not experienced as a good idea to have relatives answer the safety alarm. They knew that their relatives were busy people and thought they should be free from responsibility for their next of kin. Having someone at the other end was important, but opinions varied as to what kind of competence was needed by the people answering the alarms. The participants without functional limitations had higher demands regarding the medical competence of the staff answering the mobile safety alarms than participants with experience of declining physical functions, who thought a “fellow human being” who could decide very fast what to do next and ensure that the best help needed was called for was good enough.

All participants who tested the mobile safety alarm thought that being positioned and supervised was no problem. It was experienced as positive that the alarm could position them and show where they were. Two different opinions emerged: the first was about having nothing to be ashamed of. They saw themselves as ordinary citizens with no secrets to hide, either where they were or who they visited. However, if in the future a camera would be connected to the mobile safety alarm one participant said she would not want to be filmed in her own home. The second opinion was that we are already living in a “society of surveillance” and so using a mobile positioning device made no difference with regard to personal integrity.
The participants were asked to define what mobility and *being mobile* meant to them in relation to *freedom of movement*. This was expressed not just as being well-coordinated and lively and able to move your arms and legs, but as a matter of freedom – To be *able to do what you like* and to be *empowered*. The participants with functional limitations longed for activities where they could be autonomous, like walking on a path, not on crowded streets, alone, taking a trip to the cottage and just staying overnight by oneself, and going and seeing some friends on their own.

The participants *reflected on new technology* and offered ideas on how to improve the safety alarm, and based on what they said, it can be concluded that safety and security were associated with the usability of the technology. They saw themselves as *participating in development and design*. Overall, the participants were positive about the new technology and also showed *acceptance and fascination*. Almost all of them had ICT experience, using mobile phones and some also used computers. This experience was the same in both groups. The participants were also positive about being able to have opinions on the design and contributing their experience to the development process of the safety alarm.

**Paper III**

In this paper, findings from a two-day workshop together with first line staff in home care were described. During the reflective workshops the staff reflected upon how Olga’s (see Olga’s story in Paper III) health, well-being and independence could be promoted. The reflective process was about how staff could live out their espoused values in practice. Values such as a) *being an active listener* and *learning about elderly people’s needs and desires*, b) *how to use this knowledge/insight in practice to improve the care of elderly,*
c) how research and information and communication technology could support the client to participate more and decide more in relation to her/his care. All staff agreed that we all need to reflect more critically and creatively on what clients say and try to respond positively about what we learn. One critical incident chosen by the participants was about a situation where the client had not been a participant in decisions about how home care services should be conducted, what kind of services the client requested her/himself, etc. Another critical incident was about the client’s self-determination. Activities were done that the client had not decided upon, for instance changing the furniture in the client’s home. The third critical incident had to do with the use of technology such as safety alarms without the client understanding how or why to use it. We learned about home care clients accelerating change and the need to be working in the triads of participation, empowerment and information and communication technology.

DISCUSSION
The overall aim of this licentiate thesis was to explore dimensions of empowerment and empowerment methodology for elderly people in home health care. The findings from my three papers together with my experience from participating in research projects and research seminars have led to my learning methodological, ethical, theoretical and practical lessons. In this chapter I discuss the findings and describe the lessons learned from these four perspectives.

Methodological and ethical understanding
To begin with, let us discuss the validity of the findings from Papers II and III, where PAR was the process used. When using PAR it is very important that all participants take part in evaluating, interpreting, and reflecting on the
data generated to get a consensus validation (Whyte, 1991; Argyris & Schön, 1991). In naturalistic epistemology, the concept of internal validity is referred to as “credibility” (Lincoln & Guba, 1987). It has to do with trustworthiness. In Paper II the participants received a written description of the most important findings. The findings were also presented and discussed with Luleå municipality advisory board of representatives from pensioners’ organisation. The participants could have been invited to a more active discussion about the interpretation of the data if we had planned this. PAR is very complex and multifaceted and a very time consuming process/method, and using this approach in projects with a tight time schedule was a challenge. In Paper III the reflective learning workshops functioned as an interactive forum. The participants reflected on our findings and some of the participants gave their reflections by sending an e-mail after the work shops. The study that resulted in Paper III was, as described above, one of many activities in the eHHC project and the whole project used a PAR approach. As both projects (eHHC and Mobile Safety Alarm Project) were industry driven, this created special conditions for doing research. Developing and testing an ICT device is a process where different professionals have different objectives and agendas. The technical staff wants to proceed fast to develop a quick solution to test. The researchers want to plan and discuss design, actions taken and reflect. This can be experienced by the technical staff as the researchers slowing the process down. Involving elderly people in the design process might also be experienced as prolonging the development process.

Credibility can be analysed by taking the interpretation of the data and data itself back to the sources from which they are drawn (Lincoln & Guba, 1987). The descriptions of the experiences and interpretations should be
recognized as the informants’ own (Appleton, 1995). Using field notes after each interview is a way to improve validity (Miles & Huberman, 1994). In Papers I and II a Contact summary sheet (cf. Miles & Huberman, 1994) was used after each interview. The most important findings were noted and also the overall impression. To present the story findings to the informants for a credibility check is totally wrong in Grounded Theory, according to Glaser (2001), because the total analysis is based on all informants’ interview data. GT is not the informants’ voice, it is a generated abstraction from their accomplishments and its meaning which are used as data (ibid.). I agree with Glaser (2001) in this statement and based on these views, there was no member checking in my papers. This is, however, in contradiction with how research should be done according to PAR as described above. We chose other ways to bring the findings back to the participants. The findings from Paper II were presented to the Luleå municipality advisory board of representatives from pensioners’ organisation.

Paper I was inspired by grounded theory (GT) (Glaser & Strauss, 1967) and in Paper III a constructivist mode of grounded theory was used (cf. Charmaz, 2000; 2006). There has been a debate over GT and how it should be performed. The instructions by Glaser (2001) can be understood to mean that the method remains fairly close to traditional positivism with an interactionist perspective. As researchers, we are not always aware of how an epoch is shaping our research practice (Hallberg, 2006). Grounded theory gives the researcher guidelines for building conceptual frameworks and these guidelines should be a flexible tool rather than rigid rules (ibid.). Hallberg (2006) states that the grounded theory method has been modified/renewed towards a constructivist grounded theory because views on reality vary and this influence the modes of GT. In Paper III a
constructivist mode of grounded theory was used (cf. Charmaz, 2000; 2006). This means that data from Paper III was constructed through an ongoing interaction between researchers and participants in the reflective learning workshops. Hallberg (2006) argues that we have to discover what people consider important and be aware that the analysis also reflects the researcher’s understanding of how the participants create their understanding. The analysis reflects both the participants’ and the researcher’s way of thinking (ibid.). Theory that can be generated from data should emphasize understanding rather than explanation (Charmaz, 2000).

In Paper II, Latent content analysis was used. When using interpretive content analysis, it is important to report the method by which coding categories are derived and the coding unit from which they are derived (Baxter, 1994). The systematic process of deriving coding categories should be shown. The coded categories need to be tested during the systematic process of analytic induction (ibid.). In all papers (I-III) the coding and categorizing were based on teamwork carried out by all co-authors together.

Transferability is used instead of generalisation in qualitative research. According to Holloway and Wheeler (1996) this means that findings from one context can be transferred to similar context, situations and participants. There seem to be agreement between findings in Paper II and those in other studies. The participants focused on feeling safe and secure and feared falling and not being able to take care of themselves (Paper I). This is supported by Tischler & Hobson (2005).

In research, ethical considerations are essential. For the studies reported in Papers I and II, written informed consent was obtained. The informants were
informed, (both verbally and in writing), about the objectives of each study, the methodology, the intervention, where the findings would be published and that confidentiality was guaranteed. Informed consent is of particular interest since it was introduced with the aim of increasing the patient’s autonomy and letting her/him have the “last word” when it came to decisions around care (Veatch, 1998). I agree to some extent with Veatch’s (1998) criticism, that it is not easy to know if we can really get true informed consent, since we do not know how our information is interpreted. We are, as researchers, in a special position that my entice patients/clients to participate against their will. This also affects the procedure of selecting informants. People helping researchers gain access to informants might also have a certain position that influences the informants to agree to participate without reflecting on the consequences. In Paper III, a reflective practice workshop with staff was the method chosen. Here informed consent was requested verbally at the start of each workshop. Informed consent in workshops for example, is a very important ethical challenge discussed by Löfman, Pelkonen et al. (2004). They state that in workshops even if the individual’s rights are respected, it is difficult in group discussions to exclude individuals who refuse to give their informed consent (ibid.). We asked the whole group of staff in Paper III for permission to use the information and they all agreed, but it is of course impossible to know if all really did agree.

Ethical issues in e-health projects are a topic of growing interest. Guidelines for ethical considerations in development and testing of ICT devices are under development (Magnusson & Hanson, 2003). In Paper II, a positioning device was used to locate the test participants. This was experienced by them as increasing their safety as it made it possible for them to be located
and found in cases of emergency. Those who participated in the test understood that they had to be positioned to be located. They did not think that this kind of surveillance was a threat to their integrity. It might be the case that, to maintain self-determination and empowerment, the individual has to make a “cost-benefit” analysis where privacy is sacrificed in favour of mobility and safety. A relevant ethical consideration in this context is whether it is ethical to let people test technology and possibly find it helpful, and then take away the technology when the test period is over. However I think that the test participants gain from being part of a development process, as they have the possibility to influence future technology.

**Theoretical understanding**

Below I outline my theoretical understanding of the empowerment concept and lessons learned during the process of writing this licentiate thesis. Zimmerman (1990a; 1990b) distinguishes between psychological empowerment and individually orientated conceptions of empowerment. He suggests that an interdisciplinary approach to empowerment research is necessary. It is important for the future to integrate theories from other disciplines to provide a more suitable framework for investigating empowerment, and also to incorporate contextual influences in research. According to Zimmerman & Warschausky (1998) empowerment theory can be a useful framework for attaching rehabilitation research that focuses on control and involvement. They also state that empowerment may not yet fulfil the requirements of a formal theory because empowerment theory is still developing, but however it include definitions, propositions and interrelated constructs that are necessary building blocks for a more formal theory (ibid.). Empowerment is as conceptualised involving both internal psychological as well as social/structural aspects.
In Paper I empowerment was studied on the individual level in line with Zimmerman & Rappaport (1988), Anderson (1995) and Anderson & Funnel (2005). Dimensions such as participation and opportunity to influence in the context of rehabilitation were explored and the findings showed that the participants had not reflected on the opportunity to influence. They instead experienced a parallel rehabilitation process where other aspects such as social support from relatives and friends as well information from different media were experienced as important. Anderson & Funnel (2005) argue that health care professionals with an empowerment approach have a responsibility to support patient-centred collaborative care. On the other hand the acute care paradigm has to be considered, and how it shapes the interaction between professionals and patients. Using reflective practice and a psychological “mirror” might help the shift towards an empowerment paradigm (ibid.). Client centering as a part of an empowerment model in rehabilitation, is supported by Mostrom (1999). A patient must be given the tools to take responsibility for her/his own health (Anderson, 1995). In this context, empowerment can imply that a patient has learnt enough about his/her disease to be able to decide and choose between alternatives. Patient empowerment has changed towards increased independent decision-making (Feste & Anderson, 1995). The concept of “patient power” is used and patient organisations are becoming more involved in health care (Trädgårdh, 1999). This will also change the relationship between professionals and patients to include more exchanges of experience, thoughts and knowledge. When improving empowerment, a focus on the context is important, for example promoting a context that provides access to information, support and an opportunity to learn and develop. I found that the interviews with informants in Paper I functioned as a reflection process on the informants’ own rehabilitation. One informant expressed it like this: “If something like
I believe that empowerment must be understood individually. It has to do with power, and different people define power in different ways. According to Appelbaum (1999), power is not a steady state of equilibrium. I believe that it is important to further develop an empowering philosophy in rehabilitation.

In Paper II, freedom of movement and mobility were expressed as a dimension of empowerment by the elderly test participants. Here empowerment was studied mainly on group level in line with Ghaye (2005) and Rodwell (1996). These findings can be compared with the research of Fairhurst (2005). Her study focused on ‘ordinary’ as opposed to ‘professional’ discourse on aging and showed that aging is associated with matters of health, rather than age and that the link between age and lifestyle has been broken in the existing consumer culture (ibid.). Health was identified as an important condition ensuring the ability to do what you want in old age. Elderly people who did not enjoy ‘good health’ noted that this limited their ability to choose how to live their lives. In theorizing ageing, ‘good health’ was seen as embracing both physical and mental health and could be a result of exercise and ‘not worrying’ (ibid.). The ‘new public health’ embraces a more social model of health and environmental factors, in which active participation in society is central (Fairhurst, 2005). A person’s physical, social, economic and technical resources as well as the structural conditions in the region where she/he lives are prerequisites for outdoor mobility in old age (Mollenkopf et.al, 2004). The importance of outdoor mobility for maintenance of health and independence in old age is stressed. Mobility also promotes “ageing well” and delays onset of disability (ibid.). The participants in Paper II were aware of several risks: they feared
falling, remaining lying unnoticed, and violence in the society. These aspects seem to be more important than the fact that a stranger would have access to information on where they were. The dominant discourse may be a safety culture with increased risk awareness. The mobile safety alarm was experienced as a tool for being active and mobile. To keep self-determination and empowerment the individual has to make a “cost-benefit” analysis in which privacy is sacrificed in favour of mobility and safety.

In Paper III, participation, self-determination and information technology were explored in relation to empowerment in elderly home health care. Empowerment was studied mainly at group and organisational levels, in line with Appelbaum et al, 1999, McDougall, 1997 Duvall (1999), Schön (1983, 1987), Illeris (1999), Cooperrider & Whitney (2005) and Ghaye (2005). The reflective learning workshops described in Paper III are examples of learning activities that can promote a better understanding of clients’ situations and needs. Drugge (2003) argues that learning is a matter of relating to each other, experiencing new things and understanding things differently. Home health care is a context where there is a free zone for such actions. Seeing rehabilitation as a learning process using theories about how knowledge is created, shared and applied. Illeris (1999) theory about learning is based on a constructivist perspective, and he describes learning as an integration of psychological and social processes with interplay between the individual and the context (a social constructivist perspective). In this view learning is dependent on an integrated interplay between two different constructive processes (ibid.). Learning and development are closely related. Through learning, experience develops into knowledge, according to Tiller (1997). He uses the metaphor that you climb up on your own glass roof and look down at what you do. I agree with him.
Empowerment research on working life is also relevant in home health care. Knowledge from organisational psychology shows that formal and informal power, access to information, social support, opportunities and resources can be transformed to home health care and a patient/client perspective (cf. Arneson, 2006). More research however must be conducted to establish whether and if so how these factors have an impact. Action research can be used as a process to ‘generate’ living or practical theory by depicting a specific sequence of events in such a detailed way that others can perceive implications for different contexts (Winter & Munn-Giddings, 2001). In Participatory Action Research the focus is on concerns that have been highlighted by all participants (ibid.). I looked at the core concepts in my studies at three different levels. Those at the individual, group and organisational level. Paper I describes the individual level, Paper II mainly the group level and Paper III mainly the organisational level. Through my papers I have gained a more holistic view of empowerment as a concept. I have also come to realize that empowerment methodology in the context of e-health needs to be more explicit and developed further.

**Practical understanding**

How can we use the knowledge we have gained in practice? I have learned that it is important to develop the rehabilitation context into a learning organisation promoting patient/client empowerment. My findings in all three papers show that *participation is* important and that everyone involved in home health care needs to take participation seriously. In Paper I the results indicate low patient participation in and influence on the rehabilitation process. In Paper II elderly people perceived freedom of movement as a prerequisite for participation. In Paper III the first line staff in home care agreed that the patient/client needs to participate in planning and decision-making processes in home health care. To listen actively to the patient/client
is a ‘positive core’ in home health care, as is to create genuine, co-learning opportunities between staff and patients/clients. How can we increase empowerment in living practice in home health care for the future? In my opinion this can be done by developing patient/client centred care and rehabilitation, with shared responsibility between professionals and patients/clients. The concept of power will still exist even if we talk about shared responsibility. It is a matter of delegating power, to give people the ability to respond to each other. I chose to see power as positive, having ‘power to’ do something, like to get ‘a good job’, instead of having ‘power over’ someone/something (cf. Ghaye, Gillespie & Lillyman, 2000). The findings in Paper I showed that the patients did not have the power to act in the situations at the hospital. The power to act was instead in their own context, together with relatives, colleagues and friends. Appelbaum et al. (1999) discuss power and argue that it is possible that empowerment relations stimulate “a positive sense of self-discipline by transforming individuals into subjects who secure their sense of identity, meaning and reality through participating in (certain) practices.” I believe that no one can develop from the outside, through others and that applies to all of us, patients/clients and professionals. You have to be motivated, and one way to be motivated is to be challenged. A prerequisite for this is that you can understand the core of what has to be done. The findings from Paper I showed that in order to be able to take more responsibility for your own health, you must have information good enough to create support for decision making and clear communication.

The findings in all three papers show that an information age model influences patients’ and clients’ perspectives on the use of ICT in home health care. According to Campell (2002), older care delivery models and
the traditional medical model will be replaced an information age model. This new model will take the form of an inverted pyramid with six layers: 1) individual self-care, 2) friends and family, 3) self-help and community networks, 4) health care professionals as facilitators, 5) health care professionals as partners and 6) health care professionals as authorities (ibid.). New perspectives are developing in the context of e-health. By providing tailored information, guidance and monitoring through ICT, individuals can be empowered and this will have an impact on individual health behaviour (del Hoyo-Barbolla et.al, 2006). It is important, however, to be more explicit about what is meant by empowerment in relation to ICT. What dimensions of empowerment are to be affected? Who is going to be empowered and how? The findings from the interviews and the reasoning about mobile ICT in Paper II showed that elderly people had an interest in new technology and also a fascination with what was supposed to be possible to do using mobile ICT. The mobile safety alarm tested was experienced as a tool for empowerment, as it made it possible to be more mobile and still feel safe. Freedom of movement seems to be a prerequisite for feeling empowered, as it has to do with having control over your life. The mobile safety alarm gave the users the freedom of movement needed to be physically active. It is important to develop mobile ICT that can make it possible to be mobile both at home and outside if needed/wanted. The findings from Paper II give support to the thought that development of mobile ICT might help the client/patient in keeping mobile and still feeling safe. With mICT such as a mobile safety alarm it might be possible for elderly people to maintain independence and control over their lives. Perceiving ICT as a tool for empowerment is supported by the research of Renblad (2003). One question that remained to be answered is: “How can
mobile ICT be a supportive tool for both patients/clients and staff in relation to the patients'/clients’ particular living situations?"

Active reflection and reflective action is, as Ghaye (2001) states: “about becoming more aware of how we learn, how this affects what we think, feel and do and how reflection reveals to us how we construct our own and distort the realities of others.” The findings from the reflective learning workshops, presented in Paper III, indicate that with reflective practices to help, people can make decisions together. With reflective practice the rehabilitation team together with the patients/clients can create an identity that strengthens team cohesion. I believe team cohesion is one of the most important things to create. In cooperation with others you become more creative and can feel the sense of belonging that is a basis for trust and respect. In the spirit of trust and respect, it will be easier to be open-minded and positive to new ideas (Duvall, 1999). Collective empowerment includes qualities like a ‘sense of community’ that help and motivate individuals in their striving to build empowered teams (Ghaye, 2001). It is easy to talk about empowerment but not as easy to deliver the key to success of any empowerment strategy or program (Appelbaum et al. 1999). The findings from the two days of reflective workshops with home care staff described in Paper III showed how collective reflections created motivation for action towards improvements in practice. It is in those self-reflections and discussions together that you can start the empowering process and create an action plan. I believe it is important to work in the triads of participation, empowerment and mobile ICT to improve home health care services for the future. It is important to reflect creatively on what clients say and try to respond positively to it.
Concluding remarks
The aim of this thesis was to explore different dimensions of empowerment and empowerment methodology for elderly persons in home health care, and if ICT is a useful tool in this process. My findings were that the process of rehabilitation was experienced as a parallel process based on traditional and individual models, implying that a patient copes with a situation by shifting between being compliant and adopting more self-regulatory behaviour. The results indicated low patient participation in and influence on the rehabilitation process in the hospital. When ICT as an empowering tool was implemented, findings showed that elderly people experienced the use of a mobile safety alarm as an empowering tool. The mobile safety alarm gave the freedom of movement needed to be physical active and still feel safe. The positioning device was not experienced as a threat to their integrity. Mobility and safety were experienced as more important than privacy. Freedom of movement and mobility were described as matters of freedom and empowerment.

Empowerment is linked to the process of enabling people to increase their control over and improve their health. Empowering relations enable individuals to have a secure and valid sense of identity, meaning and reality. Empowerment as a process has an ethical dimension. The challenge is to create an “appreciative space” where the client feels free to express her needs and wishes. But staff need to listen actively and openly. It is important to enable elderly people to have a positive view of themselves, a sense of self and identity, a good feeling of self-control and spiritual well-being. The ability to be physically active is experienced as important and maintains physical and psychological health and well-being. Mobility is experienced as having freedom of movement, to do what you like – being
empowered. As the feeling of empowerment differs from person to person it is a good idea to consider, for each person, to what extent (s)he feels she/he is mobile, participate or have power and personal control. It could also be valuable to examine what from the individuals’ point of view, would be the best way to gain empowerment. Mobile ICT can be used as one tool, but it is important to explore how it can best be done from a patient’s/client’s perspective. A prerequisite for this is that patients/clients can participate in the design and development of mICT. There is an assumption throughout the literature that empowerment is “a good thing”, that it is better to be empowered than disempowered, and this has to be reflected upon. Is it always the case that everyone wants to be empowered, all the time, in all situations? In some situations it might be necessary to leave the responsibility for decisions to others. But if this is your own decision it might mean that you are still empowered. More research is needed to better understand exactly what elderly people experience as empowering, and if and how ICT can support self-determination, personal control, participation and mobility.
SVENSK SAMMANFATTNING
Empowerment i praktiken – mobil IKT som ett redskap för ökad empowerment av äldre vid rehabilitering i hemmet.

Syftet med denna licentiatuppsats var att undersöka hur äldre patienter/brukare upplever olika dimensioner av empowerment och vilken metodik som kan användas för att äldre skall få ökad empowerment vid rehabilitering i hemmet samt om mobil informations och kommunikationsteknik (mobil IKT) kan vara ett redskap i denna process.


De forskningsfrågor som var utgångspunkt för de olika delstudierna var:

- Hur upplever patienter/brukare dimensioner av empowerment som delaktighet, inflytande, självbestämmande och rörlighet?
- Vilken metodik kan användas för att äldre ska få ökad empowerment vid rehabilitering i hemmet?
• Kan mobil IKT fungera som ett redskap för ökad empowerment av äldre vid rehabilitering i hemmet?


gjordes inom ramen för två olika projekt i e-hälsa, Mobilt trygghetslarm (delstudie II) och eHome HealthCare @North Calotte (delstudie III) och ansatsen var deltagande aktionsforskning (Participatory Action Research). Det betyder att forskningsfrågorna utvecklades tillsammans med alla deltagare i projektet.

Den första delstudien, vars syfte var att studera hur personer med erfarenheter av en längre rehabilitering upplever delaktighet och inflytande i rehabiliteringsprocessen, visade ett lågt inflytande i rehabiliteringen på sjukhuset och att deltagarna inte tänkt på möjligheten att utöva ett inflytande. Två teman framkom; den traditionella medicinska modellen och den individuella modellen. Den traditionella medicinska modellen innehåller kategorierna följsamhet, osynlig sjukgymnast och underordning. Den individuella modellen innehåller kategorierna att bli bekräftad, sökande efter information, en känsla av sammanhang och att våga kräva.

Rehabiliteringsprocessen upplevdes som en parallell process baserad på en traditionell modell och en individuell modell, där patienten hanterar sin situation genom att skiftra mellan att vara följsam till sjukvården och att anta ett självreglerande beteende där stöd och information från familj, anhöriga och vänner var viktiga. Delaktighet, möjlighet att utöva inflytande samt information som underlag för självbestämmande och beslutsfattande var i studien viktiga dimensioner av empowerment. Det är viktigt att reflektera över den medicinska modellen och hur interaktion skapas mellan professionella och patienter. Med hjälp av reflektion över hur vi arbetar i praktiken kan vi arbeta mot ett paradigma i hälso- och sjukvården som leder till ökad empowerment. Förhållandet mellan professionella och patienter/brukare kommer då att innebära ett ökat utbyte av erfarenheter, tankar och kunskap. Patienten/brukaren måste få de redskap som behövs för
att själv kunna ta ansvar över sin hälsa. Patienten behöver stöd, tillgång till rätt information i rätt tid och kunskap för att lättare uppnå eget självbestämmande och beslutsfattande. Det är viktigt att studera på vilket sätt IKT bäst kan vara ett redskap för detta.


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Paper 1
Patient empowerment in rehabilitation: “Somebody told me to get rehabilitated”

ANITA MELANDER WIKMAN & YLVA FÄLTHOLM

Department of Health Science, and Department of Human Work Science, Luleå University of Technology, Boden, Sweden

Abstract

Within healthcare, there is a growing interest in patient influence and participation. The aim of this study is to describe patients' experience of participation in and influence on rehabilitation with the focus on physiotherapy. Interviews with patients from three different primary healthcare centres were conducted. The result indicated low patient participation in and influence on the rehabilitation process within the hospital. The informants trusted the competence of the caregivers and tried to be as compliant as possible. Their experiences were that training must be supported and followed up. Information about rights was requested. The informants felt that they were listened to and confirmed by the physiotherapists. The positive attitude was combined with low demands and a great feeling of gratitude as a matter of course. Using information and support from the physiotherapist, together with friends and next of kin, the informants had learned to cope with the new situation. In this paper, these results are understood and described in terms of the parallel process of rehabilitation, based on traditional and individual models, and implying that the patient copes with the situation by shifting between being compliant and adopting more self-regulatory behaviour, for example. Attitudes are changing in society and this study reflects the patient of today, and is confirmed by recent studies.

Key words: Decision making, empowerment, participation, patient-centred, physiotherapy, rehabilitation process

Introduction

Patient participation and patient influence are concepts that are increasingly becoming a point of focus. The World Health Organisation (WHO) has included participation as a concept in the International Classification of Functioning, Disability and Health (ICF) (1). Within healthcare, there has been a shift in focus from looking at just the illness/disease to looking at the consequences of impairment/disability/health status. In Sweden, a number of reforms inspired by management ideas and practices in the private sector, often labelled “New Public Management” (NPM), were introduced in the general public healthcare sector in the early 1990s (2). NPM created new opportunities for choice and patients were given the chance to choose caregivers (3). Choice can also be seen as a way of extending patient rights. The law controlling healthcare in Sweden (HSL) was changed in order to strengthen the position of the patient (4). Since 1999, patients have had the right to obtain individual information about their health status and, in cases where there is more than one treatment alternative, the patient’s opinion must be taken into account. It should also be possible to get a second opinion from another physician, if needed (4).

Patient-centred care (PCC) is a concept that is used when the focal point is a better understanding and incorporation of the patient’s perspective in care delivery (5). This is also an approach that sees the patient as an active problem solver and valuable collaborator, instead of a passive recipient of treatment recommendations (5). Research focusing on a patient-centred clinical method has literally “exploded” in the last decade (6) The patient-centred clinical method has six components: exploring both the disease and the illness experience; understanding the whole person; finding common ground; incorporating prevention and health promotion; enhancing the relationship; and being realistic (6).
During the last 10 years, researchers in the medical field have been interested in patient empowerment in healthcare (7). This type of care is based on the philosophy of seeing the patient as an equal and autonomous member of the healthcare team, which is a prerequisite for the management of future healthcare. According to Rodwell, the concept of empowerment is a process enabling people to choose to take control over their life and health and make decisions (8).

It is important to take account of the patient’s own opinion of what is needed to get the best results out of the rehabilitation (1). According to Larsson Lund et al., client participation in rehabilitation planning is the ideal method for decision making in healthcare (9). The influence of the patient on the rehabilitation process is a prerequisite when it comes to obtaining a satisfactory solution that functions (9). If practitioners collaborate effectively with their patients, they will value and respect the patient’s knowledge and see it as a resource. This so-called collaborative reasoning will result in better physical therapy (10). Medical treatment processes are often varied and complex, especially for patients with chronic diseases, and this explains why a number of different solutions and decisions are made by the patient as the process continues.

What does the process of rehabilitation look like from the patient’s perspective? Does the patient feel believe that his/her experiences/wishes are considered when plans relating to rehabilitation are drawn up? Does the patient feel that his/her experiences/views/opinions are taken into account in the planning and implementation of the rehabilitation process? Does the patient feel that he/she has the opportunity to influence the planning and implementation of the rehabilitation process? The aim of this qualitative study was to describe the patient’s experiences of influence and participation in the rehabilitation process.

**Method**

In order to understand and describe the experience of patient participation in rehabilitation, a qualitative interview study was conducted. Thematic, in-depth interviews with six participants taking part in rehabilitation at three different healthcare centres were conducted. The method that was chosen was qualitative and inductive, inspired by Glaser & Strauss’ Grounded Theory, by and according to which new theory can be generated from the data produced by the interviews (11). This method embraces all the steps from the collection of the data to the final theoretical writing and means that ideas generated in interviews are organized in a systematic way. It also means that, in this study, there was constant interaction between data (which is a description of reality) and theory generated, aiming to identify the main problems and processes. Most themes developed at the outset of the data collection process were kept intact, but new themes and questions also emerged and were developed during the collection of data, as a result of the parallel process of analysis. This means that no new interviews were conducted before those already carried out had been preliminarily analysed (12). The committee of research ethics at Umeå University (Dnr 99-034) approved the study.

**Informants and data collection**

The informants were selected by three physiotherapists at three different healthcare centres within primary care. The inclusion criteria were that the informants should be of working age (below 65 years), have experience of a 3-month or longer rehabilitation process and still be in rehabilitation. Each potential informant received information about the aim of the study from a physiotherapist at the healthcare centre, and the informants who chose to participate were informed once again by telephone by one of the authors and an agreement was reached about where and when the interview should take place. Four informants chose to be interviewed in a room at the healthcare centre. The other two interviews took place in the home of the informants. At the time of the interview, the informant signed an informed consent, stating that participation was voluntary and that all data from the interviews would be treated confidentially.

The total number of informants was six, two from each healthcare centre. The informants were four women and two men between 35 and 58 years of age who had impairments and disabilities as a result of neurological, circulatory and/or orthopaedic diseases. The interviews took 1–1½ h, which meant that each informant was given the opportunity to talk for as long as he/she wished without being stressed by time.

Concurrently with the collection of data, the analysis was carried out until there was enough material and more data were not thought to develop new knowledge, a phenomenon called “theoretical saturation” by Strauss & Corbin (13). This is also described by Holloway & Wheeler, who write about it in terms of theoretical sampling and according to whom sampling is guided by ideas that have significance for the emerging theory (14).
Data analysis

The interviews were taped and transcribed word for word, and the data were then analysed in four steps, without any preconception. The first step involved looking for wholeness and patterns, after which the material was coded by open coding in order to find units with a meaning (14,15). Malterud describes the process as choosing text that in some way carries knowledge about one or more themes from the first step of the analysis (decontextualization) (12). The different stories told by the informants were summarized using different keywords. In the third step, the material was reduced to a sample of collected and meaningful units (condensation) and the main keywords were established (12). In order to create a comparative analysis between the informants, different story maps were formulated, based on each person’s own story (15). Together with the second author, different interpretations were compared. The authors met several times to make comparisons and the outcome was negotiated. During the fourth step, the material was recontextualized and core categories were identified (14).

Results

The analysis resulted in the core category “The parallel process of rehabilitation”, which was derived from the categories labelled “The traditional medical model” and “The individual model”. “The traditional medical model” category was based on the informants’ experiences of acute care and rehabilitation at the hospital, while “The individual model” was based on experiences of and attitudes towards rehabilitation within primary healthcare. The subcategories, categories and core category are summarized in Figure 1. All the informants chose to talk about the rehabilitation process from a time perspective and talked about the medical and rehabilitating interventions they had experienced in chronological order. The informants did not differentiate between medical treatment and rehabilitation interventions but defined everything as rehabilitation. If they had experienced rehabilitation before, they often made comparisons between “then” and “now”. In order to illustrate and strengthen the analysis and/or to show a different opinion, quotes from the interviews are used below.

The traditional medical model

The subcategories “Compliance”, “The invisible physiotherapist” and “Subordination” constitute the main category “The traditional medical model”.

Compliance. The influence of the patient on the rehabilitation process was not something the informants had thought that much about. Instead, they trusted the expertise of the professionals.

... I suppose that, if that’s what they’ve decided, then I have to, I have to trust them. I mean they are supposed to be specialists.

The date of discharge from hospital was decided by the healthcare personnel and this was not something about which the informants had reflected. They had no influence over what would happen at the next visit at the hospital and did not participate in deciding the date of that visit. The doctor alone decided what was going to happen and no alternatives were discussed until afterwards. As far as the informants were concerned, their contacts with the hospital were stressful and they thought that they had better keep out of the decision-making process.

... Well, I thought that this would do, well it has to be... Yes, there were two, there were two different methods, but if they had chosen one then it felt that was the one I would accept, there and then.

At the hospital, the concept of “clinic treatment is completed” was used by the professionals, meaning that the medical treatment was finished. This was experienced as confusing for one informant. Her interpretation of the concept was that there was nothing more to be done. The concept was also interpreted as a way to get a person to take his/her own responsibility for the continuing rehabilitation.

The invisible physiotherapist. It was not clear to the informants in this study whether the responsibility for the rehabilitation was held by a team or by a special caregiver. Some of the informants did not
know which profession they met and regarded the caregivers as just individuals. Often they did not remember the names of the professionals. They said it was much easier to remember the names and the titles of the physicians they met.

There were a lot of women there ... Their names? They told me what kind of education they had, but that I don't remember.

When it came to physiotherapy as an intervention, the informants had no clear picture of what it had been like at the hospital. It was often hard to remember the names of the physiotherapists and sometimes the informants did not differentiate between physiotherapy and occupational therapy. The rehabilitation within primary care was much easier to overview, but the informants did not feel that there was any team that had the responsibility. They saw the physiotherapist and the physician as the main players when it came to the responsibility for the rehabilitation.

Subordination. The patients who were interviewed did not know which physician was in charge of their case and one informant described the meeting with the acute hospital care as “a merry-go-round where you had to keep control so as not to get involved in interventions that you did not understand the aim of”. The informants did not know who was responsible for their next visit, for applying plaster, for following up or for putting them on the sick list. They just waited to see what would come out of the visits. When the informants talked about the rehabilitation process, they did not differentiate between the medical treatment and the rehabilitation interventions. They saw it all as a complete process from the day they became ill or were injured until the present day. The reason for moving from one ward to another during their hospital stay was unclear.

Yes ... I don’t know. I don’t know who decided ... I just was told that I was going to move to the rehab clinic ... I don’t know his name, the one who told me ... I was just moved to the rehab ward.

Or, as another informant put it,

Somebody told me to get rehabilitated.

Some of the informants felt guilty, as they did not follow the advice given by the doctor at the hospital about training at the primary care centre after being discharged from hospital. When it came to planning a return to work, the informants had their own ideas that they did not think were listened to or taken into account. Rules and other restrictions were often seen as a reason for this.

The individual model

The category “The individual model” comes from the subcategories “Being confirmed”, “Searching for information”, “Sense of coherence” and “Daring to demand”.

Being confirmed. All the informants talked about the importance of being seen and listened to. They wanted to be understood, although pain and fatigue sometimes made it difficult for them to describe how they felt. They appreciated caregivers who could see what they felt like without them having to say anything.

I can’t “magic” away my pain. OK I have to live with it and that’s that. So I have it but I have to get an understanding of it, that, yes, that’s the way it is. Just to confirm that it’s not me being a hypochondriac but that it is like this. Then I get this feeling. Then I get the response I want.

All the informants thought that they had been listened to, but at the same time, they were grateful for being so well received and for the fact that their demands were not so high. They all had a wish not to cause inconvenience. Support, encouragement and back-up from the physiotherapist was appreciated most. One informant expressed it like this:

And it turned out ... in a way there were two of us in this and when two people could struggle through it, it turned out to be easier!

In the co-operation between the physiotherapist and the informants, it was important to be capable or “a good girl”, especially when it came to training.

The joy when you hear “Yes, you were good!”. “Yes, sure, I was good!” “Yes, it was ME, I was good!” and this is the way you pep yourself up and the physiotherapist begs you up.

The informants appreciated it when the physiotherapist regarded them as an integration of body and soul. They also appreciated other professionals they met who had listened to their signals and had the strength to take in their feelings. They felt it was important to be taken seriously, to be confirmed and be seen as not being insane.
Searching for information. Many of the informants searched for information about their disabilities in books and weekly magazines. Some informants received help from relatives and friends and two informants had relatives that sent them information from the Internet. They would have liked some forum within healthcare that could inform them about laws, agreements, social insurance matters and rights, a forum where they could get support and not a controlling authority. The informants thought that the doctor’s time was too valuable to be used for questions of these kinds. The information and advice given by the physiotherapist was compared to the knowledge you are given by a teacher, who shows and informs you about the best way to exercise, an expert who knew all about muscles, tendons and so on. They felt trust and respect for all that knowledge.

You felt, when you got to her, that she knows what she’s on about . . .

They received the information they needed to be able to take responsibility and be part of the decision-making process. Sometimes, however, advice from the physiotherapist was perceived as more of an order.

The physiotherapist told me not to go outside if it was colder than minus 15 degrees Celsius . . . And that I should have the right, practical shoes so that I wouldn’t fall again.

To meet the need for information about insurance matters, rights and so on, the informants contacted patient organizations for help and advice, because they did not expect any support on these matters from healthcare. They felt that the patient organizations were on their side and they also gave them the feeling that they were not alone with their problems.

One opinion that was commonly held by the informants was that you have to learn by mistakes and experiences. You need the difficulties in order to learn to know the limits when it comes to ability, pain, fatigue and so on.

I think that even if they had said to me: “Be careful when you get up, you might break something!” I would still have done it because it is the experience that . . .

The informants who had come a long way in their rehabilitation had a feeling of coherence and self-control.

. . . and then you have this feeling after you have done something: “Now, wait, this is not the way to do it. Here is the limit, I can feel it.”

The goal of rehabilitation was described as finding a new balance in life and a balance in training; not too much and not too little.

When describing physiotherapy, the informants focused on limbs and muscles. They talked about their body as: “this leg” or “this spastic muscle”. Training was like a fight with the body to get it integrated with the self and to learn to know the body again.

. . . You have to train the whole body to get wholeness . . . I think you have to build the whole body because I believe that this mental part is the most important one.

The physiotherapist was described by the informants as the person who helped them to get control over their body and a balance between body and soul. The physiotherapy that they asked for was not just training and exercises but also supporting conversations.

The strange thing is that she doesn’t have to do so much. She says: “I have not had the time to do so much for you this time”. And I say: “But, hey, it was my spirit you were taking care of!”

Daring to demand. All the informants tried to give themselves the power to dare to demand, to be treated in the right way or to come to appointments and training at a time that suited them best, for example. One informant regretted that she had not been more clear and demanding.

In that situation, I should also have been stricter and said: “Now you have to be more alert or I will ask for a new physiotherapist”. 

Sense of coherence. Piece by piece, the informants took in the information from the different professionals, relatives, workmates, friends and media. Together with their own experience, they interpreted this information and gradually learned to cope with the new situation and obtained a sense of coherence. Others wanted to get to know themselves from the inside, through their lived experience. After some time, the informants felt that all their knowledge about their body came from themselves and not from the professional caregivers.

I have come to know my limits. I know that I cannot do whatever I like. It is I myself that has learnt to know this body.
The informants said they should have demanded that the physiotherapist gave advice about how to train on your own, e.g. training programmes that you could have at home on the fridge. These training programmes should be followed up by the physiotherapist either at the healthcare centre or at the home of the patients. The informants thought that most support was needed when they were tired of the exercises and wanted to give up. Training together with others in the same situation was perceived as a good way to become motivated. If they had to go to the healthcare centre for training, they wanted to come at times that suited their daily situation or their working hours. At the healthcare centre, they wanted the physiotherapist to be present when they were training and they wanted to be able to discuss the planning and organization of the training. When they had been training according to a certain programme for a while, they wanted to get advice on how to progress with new exercises.

I think it is good because I think it is good if people can choose. And I believe very much in what you yourself believe in. If I believe that . . . it will be better.

Understanding the difficult working conditions of both physiotherapists and physicians, from the perspective of the informants, prevented them from being demanding. They were very conscious about the lack of resources within healthcare.

They have got so much on their plate; they are burning themselves out until they are completely finished.

During the interviews, when the informants reflected on patient participation and influence, they remembered situations in which they had been disappointed at the way they had been met and treated. All these situations had, however, taken place within the hospital.

. . . to decide by yourself. Yes, that was it. I had heard about this law where it states that the patient and the doctor should agree about the treatment and then I felt that we did not agree!

Experiences after a long time in rehabilitation made the informants conscious about how this process should be organized and that, if the same thing were to happen to them again, they would be more active and not so compliant.

. . . then you want to know what they can do and what that person can do and I absolutely think that I will draw up a “specification of demands” for them.

The parallel process of rehabilitation

The informants described their rehabilitation as a process. The hospital was usually the first place where they were treated. Within the first 2–3 days, the patient makes contact with a physiotherapist for consultation and treatment. When the physician that is responsible for the patient feels that the time is right, the patient is moved to a rehabilitation ward, also at the hospital, where the patient is contacted by a rehabilitation team comprising a physiotherapist, occupational therapist, nurses, physician and counsellor. When the condition is regarded as clinically stable and there is no need for the medical care, the patient is discharged from the hospital and receives ambulatory rehabilitation at a healthcare centre within primary care. It is also possible for the patient to be visited by the physiotherapist in his/her home.

The analysis resulted in the core category “The parallel process of rehabilitation”, which was derived from the categories labelled “The traditional medical model” and “The individual model” respectively. The traditional medical model was based on the experiences of acute care and rehabilitation at the hospital, while “The individual model” was based on experiences of and attitudes towards rehabilitation within primary healthcare. The core category “The parallel process of rehabilitation” shows how the patient copes with the situation by relating these two models to one another. This means that the two models represent two extremes or two ideal types and that, in reality, the patient shifts between being compliant and more self-regulatory behaviour.

Discussion

In this study, which aims to describe the way in which patients experience the process of rehabilitation and focuses on patient influence, a method based on Grounded Theory was used. Six patients were interviewed and, despite variations in terms of gender, age, diagnoses and duration of rehabilitation, theoretical saturation was obtained. Based on the data that were collected and the analysis that was carried out, it is possible to describe the ways in which the patients experienced the process of rehabilitation in terms of the parallel process of rehabilitation. As is shown in the paper, this was established as a result of the way the informants described the ways in which they coped during the rehabilitation process by relating to what is labelled the traditional medical model and the individual model respectively. These two models are further
discussed in the following sections, but, before this is done, there is reason to discuss the method from a critical perspective and to do so in terms of validity. First, the selection of interviewees can be seen as problematic. For practical reasons and, as it was not possible to obtain access to a register of possible patients to be interviewed, they were selected by three physiotherapists at three different healthcare centres. This might give rise to the question of whether a special type of informant was selected, for example, those that the physiotherapists knew had either positive or negative experiences of the rehabilitation process, implying that the validity of the study could be questioned. Another issue is the relatively small number of informants, but, in qualitative research in general, and perhaps in research based on a Grounded Theory approach in particular, the number of interviewees should not be confused with the number of samples in quantitative research (12–14). This means that obtaining statistical generalizations from a statistically valid or reliable population was not the purpose of the interviews that were conducted. Instead, the validity of the study was ensured by the manner in which the interviews and the analysis were carried out, which is described above in this paper.

The traditional medical model

The aim of this study was to generate knowledge about and to describe the ways in which patients experience the process of rehabilitation, with special focus on patient influence. The results show that the traditional medical model was employed, especially when it comes to medical care during the hospital stay. The contact with the caregivers at the hospital was described as lacking structure and the rehabilitation planning was described as uncertain. There was no demand for more clarity, as the informants tried to be as compliant as possible with the solutions offered by the caregivers. The medical model is sometimes described as the paradigm that has dominated and influenced the medical education system (16). Anderson illustrates this model with a classical example of the way a patient is treated in acute hospital care. The physician makes a diagnosis and decides whether the patient should be subject to hospital care and then decides on the nature of the care to be given. The patient, on the other hand, decides to put his or her destiny into the hands of the physician, which means he or she will accept the physician’s proposals/decisions. This means that the physician is in charge of and responsible for the treatment of illness. The physician is active, powerful and knowledgeable and controls the care process. The patient is regarded as passive, accepting, compliant and dependent on the physician’s goodwill and competence. Although other professionals are involved in the care of the patients, both inside and outside the hospitals, this traditional medical model has been the predominant paradigm in the healthcare system and has had/still has a huge impact on the organization of healthcare (16). The traditional concept gives the patient a passive role, where the main concern of the patient is to seek competent help and to adapt himself or herself to the will of the healthcare professionals and co-operate with them in order to get well. It is, however, difficult for the hospitals to create an atmosphere of learning and patient influence (17). The caregivers are strangers and not relatives. Care is more important than meeting the demands of the patient. There is a tendency for players within the healthcare system to regard humans as nothing but biological beings. Traditionally, the patient is expected to be motivated to be well and therefore the work of the patient is to seek competent advice from the physician and be compliant with his/her prescriptions (17). This compliance is also described in physiotherapy research (18,19).

The informants in this study remembered the names of the physicians at the hospital much better than the names of the physiotherapists, although the physicians had changed from time to time. The physiotherapists and occupational therapists were referred to as “girls” rather than as representatives of professions. At the healthcare centre, the informants experienced good co-operation between the physicians and the physical therapists, but they also said that there were no organized, effective teams. The invisibility of the physiotherapist as a profession at the hospital may be a result of teamwork. Working with other professions with the same values and the same goals can sometimes prevent professions from focusing on its professional interests (20). However, collaborative interdisciplinary teamwork is described as challenging but vital to the success of PCC, for example, and the active involvement of the patient in all phases of planning and implementing his/her care is vital. The patient should be an equal participant in the team (6).

The results showed that the informants had never thought of questioning their treatment. From the patient’s perspective, the main thing appears to have been that he/she had to get the best rehabilitation, regardless of the profession that gave this best treatment, and this may have been the reason for being compliant and subordinated.

The informants’ experiences of the rehabilitation process differ when they describe experiences of hospital care or the treatment in primary care. This can be understood in terms of the medical model.
“used” as a model for solving problems at the hospital, as it diagnoses, sets goals, plans and conducts follow-ups focusing on the disease, what needs to be repaired and not the patient’s experience of illness. According to Stewart et al., exploring both the disease and the illness experience is an important component in the patient-centred clinical method. It is important to make a distinction between disease and illness and to be aware of that understanding of illness requires a different approach. Illness is the patient’s personal and subjective experience: the feelings, thoughts and altered behaviours of someone who feels sick. The patient’s “explanatory model” is his/her own conceptualization of the problem and it is important for healthcare professionals to listen to this narrative. By expanding the focus from nothing but the disease to include the patient’s experience of illness, it is possible to obtain a richer and more meaningful and productive outcome for all participants (6).

If rehabilitation is looked upon as a dynamic process, this will lead to enhanced quality of life. A human being must be regarded as a social individual functioning in relation to the interplay between physical, physiological and social functions.

The individual model

The result of this study shows that the informants were not demanding consumers of healthcare and rehabilitation. They felt great gratitude and did not impose high demands on healthcare. The study conducted by Larsson Lund et al. showed that client-centred practice can mean different things to different people. Some of the participants in that study did not want to participate in rehabilitation planning, while others were very concerned about being part of the decision-making process (9).

Patients must be given the tools to take responsibility for their own health (16). Empowerment means that the patient has learnt enough about his/her disease to be able to decide and choose between alternatives. Patient empowerment has changed from patient influence to self-control and self-decision making (7). The concept of “patient power” is used and patient organizations are becoming more involved in healthcare (21). This will also change the relationship between professionals and patients to more exchanges of experiences, thoughts and knowledge.

Healthcare must develop a pedagogic role and function as a learning organization that will help the patient to build up self-confidence around her or his own health values, needs and goals. This learning process is an integral part of the rehabilitation process. The informants who told their story in this study showed how their long experience has given them an in-depth knowledge of how they function “in body and mind”. The informants perceived the physiotherapists as guides, offering support and motivation, when a feeling of hopelessness was experienced. This is confirmed in a study by Payton, where a patient saw herself as the boss and the physiotherapists and occupational therapist were her guides in the rehabilitation (22).

The concepts of PCC and patient-centred rehabilitation (PCR) can also be used to describe the parallel process of rehabilitation that the informants in this study were going through (5). In PCR, rehabilitation is a problem-solving process where only the patient knows which problems he/she needs to resolve. A large survey in five countries – Australia, Canada, New Zealand, the United Kingdom and the United States – was conducted to explore the results of the efforts to make primary care more patient centred (23). The study revealed shortcomings in delivering PCC in all five countries, although the performance varied between countries. The lack of PCC extended to those with chronic illness. Some of the findings in the survey of PCC were missed opportunities to identify patients’ preferences or concerns, to communicate well, or to engage patients in care decisions, treatment or care plans. One-third to half the respondents in the five countries answered that their physicians sometimes, rarely or never told them about choices or involved them in care decisions (23).

In the 1980s, at the beginning of the so-called Information Society, patients asked for more information and expected to be informed. The right to information is of the utmost importance for self-decision making and patient empowerment. If interaction between patient and caregiver is to be on equal terms, there must be a dialogue in which the patient has access to information. In this study, the informants were not pleased with information about social insurance and the economic aspects of rehabilitation. This is supported by research in a Finnish survey of patient education at a hospital where some patients indicated that they had not learned enough about the possible side-effects of care, problems associated with care and future care (24). The patients in the Finnish study were not content with the education they received in support of social, experiential, ethical and financial aspects. With access to new information sources, patients will be more engaged and “in charge” of their own care. The degree to which healthcare providers support patients in decision making and incorporate the patient’s values in the treatment choice should also be part of the quality measurement (25). The informants in this study
were content with the information given by the physiotherapist and regarded it as expert knowledge. They searched for most of the information themselves by asking friends and relatives and by looking in books and on the Internet. Patient information on the Internet is the fastest growing source of medical information (26). A Norwegian study showed that almost 90% of adults who search for information online feel that the information makes it easier for them to take care of their personal health needs (27). There is a move towards patient-held electronic health records so that patients can have control over their own medical data (28). This trend calls for a change in the relationship between patients and healthcare personnel. There is a need for “cyber medical skills” and for doctors to prepare for a change in the doctor–patient relationship by integrating this knowledge into medical education (29). The Internet provides a tool for the health consumer to investigate types of medication and treatment that are recommended (30). According to Campbell, this will change older care-delivery models and the traditional model will be replaced by an information age model. This new model will take the form of an inverted pyramid with six layers. From the top to the bottom, you will find individual self-care, friends and family, self-help and community networks, healthcare professionals as facilitators, healthcare professionals as partners and healthcare professionals as authorities (30).

In research into patients coping with illness and being in a rehabilitation process, the discourse of the patient as an active agent in managing illness and healthcare has become very important (31). This can be seen in the significance attached to patient empowerment and participation. However, it should not be taken for granted that the Information Society per se will automatically lead to more empowerment among citizens. To date, technology has been based on a concept that imposes demands on the citizen to be active, motivated and to have a knowledge of technology. The goal must be technology which is user friendly, which will increase the individual’s own control over his/her health. This may involve access to information, but it will also necessitate better communication between patient and healthcare.

The parallel process of rehabilitation

This core category comes from the informants’ way of relating to the individual model and the traditional model. In relation to healthcare and professionals, they behaved in the way they thought was right and proper and tried to be compliant. Parallel to this, the informants used relatives, friends and workmates as social support and information sources. They obtained knowledge and information from sources other than healthcare, like newspapers, books and the Internet. This way of coping with illness is described by Leventhal & Cameron as a self-regulatory model (32). Individuals use their generalized pool of illness information together with their social communication with other people, communication with healthcare professionals and their personal illness experience (33). The self-regulatory model views decisions as being based on intuitions and emotions to motivate health actions (33,34). As mentioned earlier, the patient’s “explanatory model” is his/her own conceptualization of his/her problem and it is important for healthcare professionals to listen to this narrative. Finding a common ground is one component in the patient-centred clinical method and it describes the process through which the patient and healthcare professional reach a mutual understanding and mutual agreement in defining the problems and establishing the goals and priorities of treatment and/or management. When finding this common ground, it is also important to define the roles of patient and professional (6).

Conclusions

The results showed that the informants were not aware of the opportunity to exert influence and that they therefore did not participate in or have any influence over the rehabilitation process within the hospital. The participants chose to make their own way, supported by their relatives, friends and workmates. This means that the informants were part of a parallel process and used the self-regulatory model of illness cognition to cope with their situation. At the same time, they tried to be compliant with the rehabilitation process offered by the healthcare system. The informants perceived that they were listened to and reinforced. Through information and support from the physiotherapist, the informants had learned to know themselves in body and mind. This was not, however, due to empowerment and options, but was the result of using a coping strategy that suited the traditional medical model. More research is needed in the area of PCR and the use of the empowerment concept within physiotherapy. It is to be hoped that the emphasis on patient satisfaction, disease prevention and health promotion within future healthcare will facilitate PCR. The development of information and communication technology and the Internet will perhaps encourage patient education and involvement in decision making in rehabilitation and this must also be studied.
References

Paper II
Safety versus Privacy – Elderly Persons’ Experiences of a Mobile Safety Alarm

Melander Wikman A¹, Fältholm, Y ² and Gard G ¹.
¹ Dept. of Health Sciences, Luleå University of Technology
² Dept. of Human Work Sciences, Luleå University of Technology

Correspondence to:
Anita Melander Wikman
Luleå University of Technology
Department of Health Science
SE 971 87 Luleå
Sweden
Phone: +46 920 490000, Fax: +46 920 498350
E-mail: anita.melander-wikman@ltu.se
Safety versus Privacy – Elderly Persons’ Experiences of a Mobile Safety Alarm

Melander Wikman A¹, Fältholm, Y ² and Gard G ¹.
¹ Dept. of Health Sciences, Luleå University of Technology
² Dept. of Human Work Sciences, Luleå University of Technology

Abstract
Future demographic development indicates an increased elderly population in Sweden. One of the greatest challenges for a society with an ageing population is to provide high-quality health and social care. New information and communication technology (ICT) and services can be used to further improve health care. To enable elderly persons to stay at home as long as possible, various kinds of technology, such as safety alarms, are used at home. The aim of this study was to describe the experiences of the elderly persons through testing a mobile safety alarm and their reasoning about safety, privacy and mobility. Five elderly persons with functional limitations and four healthy elderly persons from a pensioner’s organisation tested the alarm. The mobile alarm with a drop sensor and a positioning device was tested for six weeks. This intervention was evaluated with qualitative interviews, and analysed with latent content analysis. The result showed four main categories: feeling safe, being positioned and supervised, being mobile and reflecting on new technology. From these categories, theme emerged; Safety and mobility are more important than privacy. The mobile safety alarm was perceived to offer an increased opportunity for mobility in terms of being more active and as an aid to self-determination. The fact that the participants were located by means of the positioning device was not experienced as violating privacy as long as they could decide how to use the alarm. The mobile safety alarm tested was a prototype in development and the participants were actively contributing to the development process. Conclusions: This mobile safety alarm was experienced as a tool to be active and mobile. As a way to keep self-determination and empowerment, the individual has to make a “cost-benefit” analysis where privacy is sacrificed to the benefit of mobility and safety.

Keywords
Elderly, Information and Communication Technology (ICT), Mobility, Privacy, Safety
Introduction

As a result of demographic change, the percentage of elderly people in Sweden and other similar western countries is increasing. The Swedish population today is 9.09 million, of which 17% are older than 65 years and it is estimated that by 2018, this demographic will grow to 20% of the population, corresponding to 2 million people (SCB, 2006). Today, the mean life expectancy is 83 years for women and 78 for men, but increased life expectancy does not automatically imply better health. Providing health care of high quality on equal terms for all citizens is an important political goal in Sweden, meaning that local health care should be easily accessible and meet the needs of the clients and be provided in accordance with political priorities. According to political goals, social care should provide acceptable and safe living conditions and give prerequisites for quality of life (SFS 2001:453). Therefore, it is a great challenge to provide elderly care of high quality and to develop products, services and technologies that meet the needs of elderly persons (Norén, 2005).

Research shows that already today, many elderly persons stay healthy and live independently with a high quality of life (Bond & Corner, 2004). For the future, it is therefore also important to promote self-determination, personal development and social participation of elderly persons (Persson & Lexén, 2006). Factors such as the availability of social networks and social support from family and friends are not only important for good health, but also safety and privacy. Especially for elderly persons, safety is seen as important. Safety can be viewed as an ongoing individual process that progresses with an increased awareness of risks (Stave, 2005). A safety culture can be looked upon as multifaceted and encompass subjective internal psychological factors (e.g. awareness of and attitudes to safety and safety culture), observable safety-related behaviour and objective situational features like organisational structure and working procedures (Ek, 2006).

An important goal for society is to create conditions for elderly persons to stay healthy and to remain at home. An important factor for health, and possibly a prerequisite for avoiding risks, is the possibility to be active and mobile. Mobility can be defined as “moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation” (ICF, 2006). Measuring where people move or travel, the degree of independence during such movements and consideration of the frequency of movement can help assess mobility (Peel et al., 2005). To make it possible for elderly persons to move freely and to promote their well-being, different kinds of support are needed and a wide range of technologies and services have been developed and implemented. However, new technology is not always adapted to the needs of prospective users in terms of its functionality and usability (Wichansky, 2004).

With an ageing population, an increased need of rehabilitation and care and a gap between resources and needs can be noted. The development and implementation of new information and communication technology (ICT) can somewhat balance this gap. Research focusing on
ICT solutions for the development of elderly care has high priority in Sweden (Proposition 2005/06:115). Mobile telemedical solutions and Internet usage have been introduced in home rehabilitation with the aim to be used for increased independence safety and mobility. Different kinds of new technologies are designed to prevent undesirable events related to the mobility of geriatric patients in hospitals and caring homes, i.e. patient falls, bed-rail entrapment, patient treatment, and wandering (Nelson et al, 2004). Current research focuses on the design and development of intelligent assistive technology, such as response systems using image-based sensors and video cameras that detect falls at home (Lee & Mihailidis, 2005). During the mid-1990s, the first project concerning mobile safety alarms was performed, the so-called SAFE-21 (Thie, 1999). An evaluation of SAFE-21 showed that the first safety alarms used were simple, but useful in fulfilling basic user needs. Within the MobiHealth project, performed within the EU’s Information Society Technologies (IST) Programme during 2002 and 2003, the aim was to develop new services and applications in the area of mobile health and hence to promote the use and deployment of GPRS and UMTS mobile services and technologies (Melander Wikman, Jansson, et.al., 2004). The main task of MobiHealth was to deliver a flexible and dynamic service to patients and health care providers with a focus on optimal utility and usability. Nine trials with a participatory approach were performed within healthcare, i.e. the end-users were involved in the development and testing of the MobiHealth services. For the caregivers the MobiHealth system served as a decision support. One of the trials involved the testing of a mobile safety alarm.

Elderly persons often use safety alarms in the form of care phones as a technology to make staying at home possible. This alarm normally functions by pressing an alarm button that is fixed on a device that resembles a wristwatch or a necklace. Staffs answer via a phone with a loudspeaker in the client’s home. The care phone is connected to the ordinary telephone system. Homecare staffs administrate, answer and act on these alarm calls. The alarm system in current use is limited in terms of range and cannot be used outdoors (Melander Wikman & Gard, 2006). Consequently, the elderly persons’ freedom related to mobility is limited and they may feel trapped in their home. By replacing the fixed alarm system with a mobile system the elderly person is supposed to be able to move freely anywhere. The aim of this study was to describe elderly person’s experiences of testing a mobile safety alarm and their reasoning about safety, privacy and mobility.

Methods

Nine participants were recruited in 2006. Staff from the municipal elderly care organization turned to a reference group of pensioners in the municipality to find participants interested in testing a mobile safety alarm. They also asked a group using a traditional safety alarm, with a range of 10 meters and installed in their respective homes. As a result, four healthy elderly persons with no functional limitations, two men and two women, and five elderly persons with functional limitations, one man and four women, agreed to participate in the testing and to be interviewed. Ages varied between 60 and 84 and their functional limitations were balance problems, pain and dizziness after a car accident, stroke and chronic disease. All nine participants were experienced in using information and communication technology, such as mobile phones, and some also used computers in their daily life.

The tested safety alarm consisted of an alarm with a GPS receiver and an inbuilt drop sensor. The alarm went off either by pressing a button on the mobile safety alarm or by activating a drop sensor by falling. It was possible to communicate with the personnel who answered the alarm (see Fig 1). The alarms were shown on a receiver in the form of a
handheld device used by the personnel. A GPS receiver sent the positioning data, which was shown on a map on the receiver used by the personnel. It was possible to track the elderly person’s position via a visible map in the handheld device with regularly updated locations. Two nurses used the receivers with the map function. Three to four alarms/day were sent to the receiving unit of staff. If the first receiver did not immediately answer an alarm, the alarm automatically went to the second receiver.

**Mobile safety alarm**

The client is out walking  The staff and the client talk to each other

There is a problem and she/he uses the alarm  The staff's phone rings

The Alarm is sent  A new position can be found by pressing a button.

When the call is over  The staff use the map function and start navigating to the place of the alarm

an SMS is sent with the client's position from the alarm phone to the staff's phone.

The mobile safety alarms were tested for three to six weeks between December 2005 and February 2006. Three participants also tested a safety alarm with a drop sensor, i.e. if the person wearing the alarm should fall, an alarm would be sent to the receiver used by the personnel. A manual on how to use the equipment was included. The participants tested the mobile safety alarm in their daily activities during this period. They used the alarm when walking outdoors, e.g. visiting friends, visiting the hospital or taking daily walks.

**Ethical considerations**

The coverage range of the alarm system is a safety factor, meaning that an emergency situation might be undetected. There was an ethical imperative to safeguard against this happening and the participants were informed to not use the mobile alarm in case of emergency. Participants with functional limitations who usually did not leave home on their own were accompanied by others. Vulnerable patients were not asked to participate. Another ethical consideration was that when positioning was used, the participants might have felt that they were being watched and interfered with. These considerations were adequately dealt with.
by, for example, the use of a written consent. The committee of research ethics at Umeå University approved the study (Dnr 04-179M).

**Analysis**

The stories of the participants were analysed by thematic content analysis (cf. Downe – Wamboldt, 1992). Latent content analysis was used for the analysis and interpretation of the underlying meaning of the text (cf. Graneheim & Lundman, 2004). The analysis procedure was conducted in the following stages (ibid.): 1. The whole text from the interviews (the unit of analysis) was read several times with the purpose in mind to get a feeling for the context. 2. After reading the interviews, meaning units were identified to continue getting a feeling for the context and sorted into groups in relation to the content. 3. The meaning units were condensed to shorten the content, but still keep its core. 4. The condensed units were coded and grouped into categories that mirrored the central message in the interviews. These categories were put together into main categories. 5. A theme “Safety and mobility is more important than privacy” emerged as the latent content of the interviews. The three authors discussed the codes and categories together to reach consensus.

**Findings**

The analyses resulted in seven sub categories that were used as a basis for the formulation of the four main categories; feeling safe, being positioned and supervised, being mobile and reflecting on new technology. Based on these four main categories, the theme safety and mobility is more important than privacy emerged.

**Table 1.** Analysed emerging categories from the interviews with the test persons of the mobile alarm.

<table>
<thead>
<tr>
<th>Theme: Safety and mobility is more important than privacy</th>
<th>Sub categories</th>
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<tr>
<td>Main categories</td>
<td></td>
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<tr>
<td>Feeling safe</td>
<td>Fear of falling</td>
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<td></td>
<td>Fear of violence</td>
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<td></td>
<td>Fear of not being capable to take care of one self</td>
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<td></td>
<td>Someone at the other end</td>
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<tr>
<td>Being positioned and supervised</td>
<td>Nothing to be ashamed of</td>
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<td></td>
<td>Living in a “society of surveillance”</td>
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<tr>
<td>Being mobile</td>
<td>Freedom of movement</td>
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<tr>
<td></td>
<td>Able to do what you like-empowered</td>
</tr>
<tr>
<td>Reflecting on new technology</td>
<td>Participating in development and design</td>
</tr>
<tr>
<td></td>
<td>Acceptance and fascination</td>
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</tbody>
</table>
Feeling safe
The main reason to have a safety alarm was safety. Five participants used traditional – not mobile – safety alarms, and all of them had friends or relatives who were users of the same type of alarm. All said that the alarm system was essential to their ability of feeling safe and secure, but its limited range was perceived as problematic. One participant expressed this as: 
*I knew that with the alarm I have, it only works in the apartment, and I also know that there are many other places where there is a greater risk that something can happen...but I like to be in the washing room and it’s hidden the concrete wall in the basement of the house. “*

All participants described the fear of falling as one of the main reasons for using a safety alarm, and those with difficulties in moving around feared falling the most: “*Yes, you’re scared to fall and not be able to get up. I just think about if I go out alone on our terrace, if it’s slippery I can slip. Then I might not be able to get myself up*.”

In this fear of falling, there was also a feeling of insecurity concerning if anyone would come to their rescue in case they would fall and remain lying there. And this had to do with losing self control. One of the participants felt this as a dependency on others and said: “*You have to rely on others, that they will notice your dilemma ... see that you get help*.”

Participants who had difficulties in moving around and those who were active and mobile thought that a safety alarm was needed because of the “increased violence” in the community. As they feared being assaulted/attacked and robbed, those with difficulties in moving around thought that a safety alarm would be a good idea to warn for burglary. This fear was expressed as: “*They can easily get to you when you use a walking aid. I can’t run away from anyone! If it had been before it would have been possible, but now, no. But an alarm brings safety, no doubt*”. This fact made some participants think that a safety alarm could be developed and also used as an alarm against burglars in their homes. Two participants thought that this technology should be integrated into other technologies in the home, such as home alarms and telephone systems. However, there was also this fear that maybe no one would react and do something to help them and one said: “*No, but it is the same thing with those home alarms, if an alarm goes off outside right now, very few will react...that’s the way it is if a car alarm goes off. I give a damn that you could steal that car as easy as that. Nobody would do anything*.”

Having control over the situation was important and the participants feared not having self-control in the future if the physical functions would decline. One participant had prepared her son for this situation and said: “*I use to say to my son that the day you notice that I do not get it, that I do not have any ideas about things, then you have to make sure that I get care. ‘Yes, but what do we do if you say no? Shall we use force?’ Yes, but then you have to take responsibility, because if I cannot take responsibility of myself and if my health and everything fails, we have count on this when I get older*”.

None of the participants thought that it would be a good idea to have relatives that answered the safety alarms. They said that their relatives were always busy and should be free from the responsibility of their next of kin, and one of the participants thought that: “*I don’t think that this responsibility should be put on relatives. They have surely enough*.”
One informant perceived this as connected to the culture you live in and expressed this: “Now you support each other... as least this is what I did it within the family, as they do in the Latin countries. But I believe it is a matter of attitudes”. Not everyone has relatives or next of kin and in these cases it was considered as important that the municipality should provide this service with a safety alarm. “I think a lot is a question of attitudes...not the least that with the family. Some might have it within the family, that you should take care of each other and so on ...I suppose that in Sweden most people are used to buy ourselves free from things”.

Opinions varied on what kind of competence needed for the professionals for answering the alarms. One informant thought that the main thing was a “fellow being” that could decide very fast what to do next and ensure the best help needed was called for. One participant wanted the help to be like this: “You do not have to be an educated doctor for this...a wise fellow being can help you if you have gotten stuck or fallen down and if it looks like I cannot get any air he can put me on my stomach. Not several years of academic studies”. The informant without functional limitations had higher demands on medical competence of the personnel answering the mobile safety alarms than those with experience in declining physical functions and one said: “This particular alarm should be answered by so-called professionals or those who have this as their job. I absolutely believe so”.

**Being positioned and supervised**

All participants who tested the mobile safety alarm thought it only positive that the alarm could position them and indicate their location. Surveillance was not perceived as a problem. Two different opinions emerged. The first was about having nothing to be ashamed of: “But I don’t have such a lifestyle that I need to be afraid that someone can see me, if you understand what I mean. If you have such an alarm, it is a part of the security to track me. This is how it’s supposed to work”. These participants saw themselves as ordinary citizens with no secrets to hide, either where they were located or who they visited. However, if in the future a camera would be connected to the mobile safety alarm, one participant said that she did not want to be filmed inside her own home. The second opinion was that we are already living in a “society of surveillance”: “I do not care in the least! There are so many security-police-things today and they are for my benefit. I mean “Big Brother” is already watching you all over. Think about how many photos are being taken and you can get to know everything about your life”. They answered with an attitude of resignation: “...yes, computers makes it possible, so if someone wants to have control over me they can really map me, what kind of newspaper I read, how long I talk on the phone...all the data...it’s so open...You are already so surveilled...the shops know exactly what you buy and when you pay with credit cards and pay cards and everything they know exactly where to send the advertisements. And the banks know exactly...and more and more cameras are put up on public places”.

There was an understanding that if you should be located by the mobile safety alarm, then you had to be supervised and watched. When questions were raised about how all this information should be stored, some participants thought that this kind of data should only be in “real time” and be deleted and not stored.
Being mobile

The participants were asked to define what mobility meant to them in relation to freedom of movement. This was expressed not just as being smooth and vital and able to move your arms and legs, but as a matter of freedom and empowerment. This was expressed as: “That you can come and go as you like”. The participants with functional limitations longed for activities where they could have autonomy, like walking on a path outside of crowded streets, alone, taking a trip to the cottage and just staying overnight by oneself, and going to see some friends on your own. One participant expressed it like this: “Yes, it is almost the same as doing what you like, go out for a walk, travel around, yes, this is freedom of movement when you don’t need to do more than you want yourself. You decide over your own time”.

One informant with functional limitations thought that a mobile alarm could be used to “test the limits”, but that in his case a mobile alarm would not make him move around more because he does not want to place the responsibility on those answering the alarm: “But we are all different and I am convinced that to some people it would be important to put the responsibility on someone else”.

Reflecting on new technology

The participants offered ideas on how to improve the safety alarm, and based on what they said, it can be concluded that safety and security were connected to the usability of the technology. For example, one of them said: “Well, only if I’m in such a condition that I can use my head, of course I can use the alarm system…Because if I can’t do that, it won’t matter if I have 10 alarm systems, if I don’t know how to handle them”.

Overall, the participants were positive towards the new technology and some also showed fascination. One said: “It’s fantastic. It is so unbelievable that you can’t think it is true, that the technology has improved”. Almost all of the participants had ICT experience, using mobile phones and some also used PCs in their daily life. This experience was the same in both groups. One participant told about how he had tried to teach his father how to use the Internet but he was not interested in learning: “I know that many friends of my generation do not use computers very much. I have had taken a course”. The participants were also positive towards being able to have opinions on the design and to contribute with their experience to the development process of the safety alarm.

Discussion

The participants focused on feeling safe and secure, and feared falling and not being able to take care of themselves. They also feared that no one would notice or care if they had fallen. This fear of falling is a multifaceted and valid experience supported by others (Tischler & Hobson, 2005). It is a concern that the elderly deal with daily, along with the fear of a physical injury, lying a long time without any help, losing independence, being limited to a life in a wheelchair and being institutionalised (Tischler & Hobson, 2005). In this study the participants’ need for autonomy implied risk taking. Taking charge of one’s life implies a risk taking, a confrontation with a diversity of open possibilities (Giddens, 1999). This is supported by research showing that preventive advice on falling can be rejected by the elderly persons, since it can be seen as a potential threat to their identity and autonomy (Yardley et. al., 2006). Living alone with balance problems and trying to be mobile and active may increase their risk for falling. The interviewed also expressed a fear of increasing violence in
society. For example, their usage of a walking aid exposed their fragility and that they felt that they were an easy victim for robbery and assault.

The participants also reasoned about who should be at the other end of the alarm. They all thought that their relatives should not be responsible for answering the alarm calls, because they were too busy and should not be responsible for the safety of the elderly persons. It was also considered a risk, since relatives might forget to bring the alarm receiver or to reload it. They would like a professional from care or health care to answer the alarm. We have already discussed how “the electronic eye” can discipline persons (Foucault, 1977). This discipline can create a feeling of safety. But the fact that one is supervised does not automatically guarantee their safety. It requires someone to be watching on the other side, ready to act in case the person needs help.

None of the participants considered being positioned and located by the mobile safety alarm as a threat to privacy. They found it natural that if they were to be found in an emergency, persons on the other side should get information on their position. This information was essential and not of a sensitive nature. Nissenbaum (1998) reasoned about information that is personal/private, but also public and not of sensitive nature. In a normative discussion, this kind of information is looked upon as harmless, since you cannot expect to stay private in public. If we omit information about ourselves, others can take part of this information, or omit information that does not threaten privacy, then it is not possible to hinder others from taking part of this information about us (ibid.). The critiques state that if we do not make anything to hinder, hide or cover private information about ourselves from public access, you “let the cat out of the bag” (ibid.). Nissenbaum (1998) uses two example to show how through our actions, we throw away our possibilities to continue being private. We put garbage in the container, and then our garbage is public. But if someone examines and analyzes the garbage to get a picture of us as individuals, then the privacy sphere is threatened. It can be compared to if we talk to someone in a public place, we risk being listened to by others.

With new ICT, it is easier to collect, store, process and analyze data (Nissenbaum, 1998). The use of different expert systems for data both inside and outside institutions can be coordinated. There is no longer any limit for how much data can possibly be handled and stored in a lifetime (ibid.). Information in the public arena can be ordered, systemized and analyzed from aspects other than they were meant for when they were collected. Rights protect the right to privacy because of the special interests it defends (Rachels, 1975). We also act differently in familiar situations when it comes to how we treat information that we find private. A combination of conscious and intended choices protects privacy (Rachels, 1975). ICT changes the view upon what is private and what is public. Information that can be seen as without value to others and not a threat towards privacy can together with other facts suddenly threaten privacy (Nissenbaum, 1998). The individual no longer has control over the total description of herself that is available through all authoritative databases and, for example, via the web (Nissenbaum, 1998). Ström (2003) states that ICT-ethics is an area that needs increased focus. Even if the digital revolution can be very positive, it can also lead to very many undesirable consequences (Ström, 2003). The access to personal, identifiable information is increasing every year and the amount of “electronic footprints” we leave by, e.g. wireless communication, makes it easier to map a person’s life by putting together all these electronic “footprints”. There is a need for ethical guidelines concerning ICT use within home health care (Magnusson & Hanson, 2003).
The use of ICT to control persons is described by, e.g., George Orwell’s fiction novel, 1984, where “tele-screens” in the homes, work places and public places were used to survey citizens (Orwell, 2001). Different kinds of supervision and registration are the modern society’s way of socializing people (Foucault, 1991). The goal is to get control and create conformity. The “surveillance society of today” can be compared to Panopticon described by Foucault (1991). In his book “Discipline and Punish – the birth of the prison” he describes Panopticon as the ideal prison with the aim to get control over and supervise the prisoners without the prisoners’ knowledge. The development of ICT with cameras and positioning systems creates “an electronic eye” that rationalises this. The mobile safety alarm can be seen as a geographical surveillance. It is important to assure that ICT will not socialise persons in the way that no longer lets them decide for themselves what to do and how to act. The individual has to get the power to decide what information should be public and used and who will have access to it.

As mentioned earlier, an important factor for health is the possibility to be active and mobile. The main expected benefit of using the mobile safety alarm and locating device was to increase mobility and allow the living of a more normal life than before. In the end, the participants thought that this new technology would increase the possibility to be active and mobile. When asked to define the meaning of mobility or freedom of movement, they responded as being able to do what they liked to do, and have control over their life. The concept mobility or freedom of movement seemed to involve both self-determination and empowerment. The results also showed that not all individuals wanted to put the responsibility in other hands, even if this would give an increased freedom of movement. Empowerment is organising life in a way that enhances the possibilities to have control over it (Rappaport, 1981). Mobility can be seen as a dimension of empowerment. It is also a prerequisite for the elderly possibilities to participate in society. Empowerment means that you facilitate self-determination and mobility. Participation is involvement in life situations, according to the International Classification of Functioning, Disability and Health (ICF), meaning ‘taking part’, ‘being included’, ‘being accepted’, ‘engaged in an area of life’ and ‘having access to needed resources’ (Molin, 2004). Technical aids like a mobile safety alarm can be seen as a resource that is needed to be more participative in society.

Concerning new technology, the participants were all positive. They all had experiences of using mobile phones and most also used computers (PC) in their daily life, which might be the reason for a positive attitude towards new technology. When the elderly persons acquire technological skills and qualifications, there is shown to be a higher degree of acceptance of ICT and telemedical solutions including the use of Internet (Bratton & Short, 2002). Another reason to accept new technical solutions can, according to Östlund (1995), be that elderly persons have in fact seen much technology come and go and therefore often have a relaxed approach to the possibilities that new technology offers. It is important to reflect upon this positive attitude when developing and testing new ICT. Issues of satisfaction are one of the most researched areas in telemedicine (Mair & Whitten, 2000). The studies are often tests of ICT that is under development and has never been used before. Expressions of satisfaction reveal little about the quality of the actual health care if a patient/client has no experience of that quality (Mair & Whitten, 2000). In this study, six participants already had experience with a traditional safety alarm, which may have made it easier for them to reason how a mobile safety alarm would be experienced in everyday use. This might also explain the participants’ positive attitudes to the positioning by the safety alarm and that this functionality was seen as a prerequisite for mobility. Another explanation could be the fact that they had been selected as participants to test the technology and that their opinions were important in
developing the device. In Swedish society there is also a strong belief that ICT will secure growth and prosperity as a part of a dominant discourse (Mörtberg, 1997). The participants’ positive attitude towards the mobile safety alarm can also be a result of their view upon this mobile technology as a tool for gaining increased safety. Risk perception and self-related behaviour are aspects of a safety culture (Ek, 2006). The participants were aware of several risks; they feared falling, to remain lying unnoticed as well as a fear of violence. These aspects seem to be more important than the fact that someone would have access to information on where they were located. Maybe the dominating discourse is a safety culture with increased risk awareness? This mobile safety alarm was experienced as a tool to be active and mobile. As a way to keep self-determination and empowerment the individual has to make a “cost-benefit” analysis where privacy is sacrificed to the benefit of mobility and safety.

**Acknowledgement**

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References


Paper III
Reflections on an appreciative approach to empowering elderly people, in home healthcare

Anita Melander-Wikman*\(^a\), Maria Jansson\(^a\) and Tony Ghaye\(^b\)
\(^a\)Luleå University of Technology, Sweden; \(^b\)The Institute of Reflective Practice, UK

Figure 1. A pictorial version of our abstract

*Corresponding author. Luleå University of Technology, Department of Health Science, SE 971 87 Luleå, Sweden. Email: Anita.Melander-Wikman@ltu.se

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This is a reflective account of aspects of our collective concern about developing and sustaining ways that might enable elderly people to feel more empowered to exercise their right of self-determination. This work has been undertaken in the context of home healthcare in northern Sweden. In this paper we put three espoused values ‘under pressure’ from client, professional (homecare staff) and research perspectives. We also explore three aspects of the pictorial landscape of homecare (see Figure 1). They are the notions of client participation, empowerment and ICT. The living data for this paper is drawn from two days of workshop activities with 35 homecare staff working in the municipality of Luleå, Sweden. The workshop was one outcome of the e-Home Health Care @ North Calotte (eHHC) Project of 2003–2005. We conclude with some collective reflections about: (a) the practice of participation (dialogue) and an intention of it (empowerment) in the context of clients accelerating service change; (b) how to reframe traditional views of the relationships between research and practice and, as a consequence, open up new possibilities for understanding how elderly people’s lived experiences can be a positive force for service improvement; and (c) the use of storyboards as an appreciative approach to enable frontline staff to reflect on their work, share and learn together.

Workshops for the non-oppressed

We hope Paulo Freire, were he still alive, would not be too disapproving of this term, the ‘non-oppressed’ (we thank Chambers, 2004, for first placing the phrase on the page). We were to work with professionals for two days, not elderly people. So we had an opportunity to invite them to creatively confront and re-examine their current ways of working. In the cooperation that developed during eHHC-project, we were asked by one of the heads of the Homecare Service in Luleå, and the head of case workers/process officers, to plan two days of workshop activities to explore home healthcare practice, with two groups of their staff. Planning took several months. At one meeting, with the writers of this paper, the challenges ahead began to crystallize in this way:

Anita: This is going to be fun, I think. But quite a challenge. The population in Sweden is ageing, so this means that we have to think hard about the quality of life of older people, their well-being, sense of independence. Generally how we support and assist them in their daily living. To do this we need to listen to what they have to say.

Maria: But what do you mean by ‘support and assist’? And who is the ‘we’?

Anita: I think we can understand ‘support and assist’ if we look at them in a broad way and relate them to quality of life. For example like the emotional support older people might need from others, to feeling safe and secure and in touch with their social environment. We also need to think about how older people might be assisted by non-invasive technologies, not threatened by them. What do you think Maria?

Maria: Well I feel there are a lot of assumptions made about the use of technology and the interests it serves. We know the Swedish Government’s ambition is to give elderly people the opportunity to receive care and services in a way that is naturally integrated into their own home and daily living. I know we agree that ICT support is essential within homecare. But we have to make sure that it’s the right kind of technology, doing the most appropriate things for and with elderly people in control, not just technology that does things to them.

Anita: We have to ask them what they want! We have to ask them what they feel their needs are, what they would like and want. What they would wish for even! For me it’s about empowerment. How elderly people become more empowered and
how we, as professionals, health and social care workers, can respond most appropriately to what they say.

Tony: I guess this is fundamentally about daring to ask older people the question ‘what do you feel you want’, isn’t it? So how far do you think we could plan a workshop that embraces all of this given we’ve got a range of homecare staff, two different groups, for two whole days?

Maria: Well what are the key things? Empowerment, client’s being asked, involved. I suppose we could call this participation, client participation, ICT ...

Tony: Decision-making ...

Anita: Values ...

Tony: How homecare staff see their roles and responsibilities maybe?

Maria: So where do we go from here?

Tony: I know you’ve used storyboards before in your research work. Could we possibly think of using this method in our workshops?

After time we framed the challenges ahead of us like this:

1. To try to make each day’s workshop an ‘appreciative intervention’ (Bushe, 1998; Cooperrider & Whitney, 2005). This meant bringing to each group the most helpful example of an elderly person’s experience that we could find (see Olga’s story, Figure 5). An experience which would connect with the work of staff from the homecare sector.

2. To provide plenty of opportunities for teams of homecare staff to collectively reflect (Ghaye, 2005) and explore the discourses associated with client participation, empowerment and the use of ICT.

3. To give the ‘mind a hand’ by utilizing one aspect of visual methodology (Rose, 2001) namely the use of storyboards, to understand the social relations, professional interactions and subjective agendas of homecare staff.

4. To focus on the visual and participatory elements of meaning-making in order to better understand how the future (for Olga) unfolds from present family and professional relationships and patterns of power with homecare staff.

Establishing an appreciative disposition

At the start of each day’s workshop we invited homecare staff, some of whom knew each other well, to engage in two activities in order to acknowledge that an appreciative disposition (Ghaye, in press) towards each other, their clients and their service would be needed throughout the day. The three of us, as facilitators, had known each other for four years. Anita’s field is physiotherapy. Maria’s is information systems and Tony’s is education. We began in a circle inviting homecare staff to get into pairs. We joined in this activity as well. Our invitation was:

Spend five minutes discovering something of the best about your partner. Use the time you have to discover something you most appreciate or admire in them. We will then be inviting you to share this appreciation with others in the room. So please check out with your partner, how far they are OK with what you will say!

This activity was a way of trying to positively frame the whole day. It was a way of (re)grounding relationships (Chaffee, 2005). What was shared was astonishing,
powerful, insightful, believable and humorous. One woman said, ‘I’ve been working with Sonia for 10 years and I still can’t find anything positive to say about her!’ When the slightly nervous laughter died down she said, ‘Seriously. I want to say that Sonia can do things that I can only dream about. She is sensitive, creative and very good at her work’.

The second activity was even more interactive. All staff had to work together to achieve success. Eight string circles, of different sizes, were laid out onto the open floor. Our invitation was, ‘When I say “now”, please choose a circle and go and stand inside it, making sure both feet are inside the circle’. For the first two rounds, there was more circle space than was needed for staff. They were spoilt for choice. Then for the next seven rounds, the instruction was the same, but one string circle was taken away each time. As choice diminished, homecare staff had to make key decisions about where they were going to stand and with whom. They had to be creative in the way they made sure both feet were inside the circle. When there was only one string circle left the instruction was, ‘Now there is no more choice. Come together here, making sure both of your feet are inside the circle’. Some rushed into doing what they had done before. But they soon appreciated that they had to act differently if they were to achieve the task. They had to listen carefully to what was said. There simply was not sufficient room inside the circle for doing things the same way. Creative discussion, active listening, trial-and-error, partnerships were all in evidence. When they solved the problem there was spontaneous applause, a valuing of a ‘job well done’.

Working from the ‘positive present’

We built on from appreciative circle work by encouraging homecare staff to reflect upon their own practice. We provided them with two coloured pieces of paper (see Figure 4). On the blue paper we asked staff to write down how they might improve in their work. On the yellow piece, we asked them to state something that they felt they were very good at, in their daily work. We encouraged them to forget being modest!

- ‘Sad face’ translation: Lowering the demands on myself and listening to my body. Stay at home from work when I am sick. Not do things that are other people’s work. Who owns the problem?
- ‘Happy face’ translation: Listening to and positively affirming staff/client. To be present in meetings with the client.

![Figure 2. Appreciative pairs activity with homecare staff](image-url)
Figure 3. Appreciative circles activity with homecare staff

Sänka kraven på mig själv, lyssna på kroppen. Ex. vara hemma når jag är sjuk. Inte ta på sig saker som är andras jobb. "Vem åger problemet?"

Figure 4. Reflection-on-practice sheets

Lyssna på & bekräfta personal/brukare. Att vara närvarande i mötet m. brukaren
In small groups of four–five people they then discussed what they had written on all the pieces of paper. Each group then brought one blue and yellow piece of paper to the front, something the whole group could relate to, and presented them to others. Table 1 sets out some of their responses. When each group had presented, we were able to ask the question, 'Do any common themes emerge from these reflections?'

So, what did we learn from this activity?

Anita: Working together with people, both clients and staff, seems to demand but also create energy. It is important to create a culture at work that helps in this balance so that staff, in their ambitions to create good homecare services, will not be drained of energy. I learnt that if you listen and learn from others, from what they are good at, this can help you create a positive strategy at work.

Maria: I learnt that we are very good at talking about what we like to improve but not so good at talking about what we are really good at. Therefore, it is important that we can have workshops like this, appreciating each other's knowledge and learning from each other.

Tony: I learnt that we need to develop reflective activities that are uncomplicated and enjoyable for frontline staff to engage with. Activities that are inclusive, participatory and as non-threatening as possible. Ones that don't take too much time to do, but which have the potential for high yield. In other words through dialogue, we amplify, not only what concerns us, but what creates energy and joy in our daily work.

How can we promote Olga's health, well-being and independence?

The rest of the workshop placed the experiences of elderly people, as health homecare clients, front and central. Prior to the workshop, the three of us co-wrote the story of Olga based on our first hand experiences. Olga is 79-years-old. We presented a hard copy of Olga's story to homecare staff. They read through it individually and

<table>
<thead>
<tr>
<th>Table 1. Some reflections on practice by homecare staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Something I feel I can improve in my work (blue sheets)</td>
</tr>
<tr>
<td>.... To stop putting up boundaries in my work and not take over others' responsibility</td>
</tr>
<tr>
<td>Listen to myself, trust my own judgment</td>
</tr>
<tr>
<td>Delegate more</td>
</tr>
<tr>
<td>Structure my work better</td>
</tr>
<tr>
<td>Try to keep better documentation</td>
</tr>
<tr>
<td>I'm not sure!</td>
</tr>
<tr>
<td>Express myself better</td>
</tr>
<tr>
<td>Be able to handle conflict better</td>
</tr>
<tr>
<td>Not rust people too much</td>
</tr>
<tr>
<td>Give feedback</td>
</tr>
<tr>
<td>Be able to plan for better cooperation between different kinds of professionals</td>
</tr>
</tbody>
</table>
privately. We invited each person to try to identify up to eight significant incidents in Olga’s story. In groups of four–five they then discussed their thoughts. All groups spent time discussing the phrase a ‘significant incident’.

Meet Olga

Olga is 79 years old.
She lives in an apartment on the 2nd floor in an old house with no elevator. She has been a widow for 2 years. She misses her husband, Ernst, very much.
Olga has a best friend who lives 1km away.
She enjoys holidays with her friend.
She has one daughter who lives in the South of Sweden.
Olga was a teacher until 1990.
She likes reading and plays the piano.
Normally she is a happy and positive person.
Olga likes to be independent and likes to take pride in how she looks.
She attends church every Sunday.
But now things in her life are changing.

On Friday January 27th Olga slipped while she was shopping with her friend. She hit her head and badly sprained her ankle. She was taken to hospital and treated for cuts and bruises to her head and torn ankle ligaments. She also became confused. Olga cannot remember much about the incident or much about her hospital treatment.

She was sent home by taxi at 6pm. She was discharged so quickly there was no one there to meet her. The driver helped her to climb the stairs to her apartment. Homecare services were not there to assist her because they did not know that she had been discharged from hospital.

Olga spent most of the weekend on her own. She phoned her friend to bring some groceries and to help her wash. Her friend asked why homecare services had not visited yet. Olga’s ankle was very painful.

On Monday morning, at 9.30am, homecare services and a handling officer visited Olga. They discussed her situation and told her what services she could receive. Olga did not really understand what they were talking about. They were giving her a lot of information. Olga had lots of questions to ask them. But they had to leave at 10.30am. Olga really wanted to have a shower. But she was afraid she would slip. She decided to wait until a nurse arrived. But she did not know what time the district nurse would get to her apartment. No one seemed to know.

At 11.00am a physiotherapist and an occupational therapist arrived. Olga did not expect them. They started to move her furniture to make it easier for Olga to get around her flat. They talked to each other while Olga sat in a chair. They were very kind to Olga but she did not feel in control of what was happening to her apartment. She used to know where everything was. It was being moved for her own safety, but not with her consent. She felt out of control. They sold her big bed had to go. This was the bed she and Ernst got as a wedding gift. The therapists stayed with Olga for 2 hours. They helped her to make some lunch before they went.
One hour later the doorbell rang again. Olga was resting. It kept ringing. She opened the door to a strange man. He said that he had come to fit a safety alarm for her. Olga did not recognise him and did not know what to do. But she felt powerless to say 'no' and let him into the apartment. He started work. Olga's daughter had asked the man to install the alarm but had not told Olga about this. He quickly explained how the alarm worked. Olga was not really concentrating.

10 minutes later the district nurse arrived. Olga felt safer now because the nurse was there. She still wanted to have a shower but not when the man was working in her apartment. So she said nothing. The nurse checked her cuts on her head and looked at her ankle. Olga was told to rest her foot and to stay warm inside. She must not go shopping or visit her friend until she was stronger. Olga was now feeling depressed.

At 4.30pm Olga was alone again. The telephone rang. It was Olga's daughter. She asked Olga lots of questions and wanted to know who was taking care of her. But Olga could not remember the names of everyone and got frustrated. Her daughter promised to visit her as soon as possible. But she had to wait for her husband to take time off work to look after the children before she could fly to Norrbotten from Stockholm.

In the evening Olga was visited by 2 friends from the church. They were very comforting and tried to cheer her up. But Olga was now very tired and just wanted to go to bed. She said goodbye to them at 9.30pm. By 9.30pm she was in bed and fast asleep. She did not sleep well.

One Month later

Olga has met many different carers and received lots of advice and information. All the people are very kind but Olga does not always agree with them. Homecare like to organize which days Olga will do her laundry and the best time for her to order groceries. Sometimes Olga feels frustrated because she wants to go to the shops herself and choose her groceries. She also wants to buy some new clothes and visit her hairdresser.

Olga is frustrated because she wants to get outside and have more exercise. She thinks this will help her ankle to get stronger but the nurse is concerned that she may injure herself again. Olga does not want to upset the nurse.

Olga has to see a physiotherapist 3 times a week. She travels by taxi. This is expensive and it is a difficult journey. Sometimes Olga cancels her appointment because she does not want to travel. Her friend visits her and rubs her legs but Olga does not want her friend to feel responsible for her.

Homecare keep Olga's apartment very tidy but sometimes Olga cannot find things. She asks her daughter to put things back, in their old place, when she visits. She hopes homecare will not notice.

Figure 5. Olga's story

The day now took on its own momentum. After much discussion about what the group wanted to regard as incidents in Olga's story that were 'significant' in one way or another, they were invited to:
1. Build a storyboard which showed each of their chosen significant incidents. (We provided staff with a straightforward definition of a storyboard as a series of drawings, showing the sequence of actions/incidents and people involved.) Our storyboard activity was informed by work in the field of visual methodology (Rose, 2001).

2. To name each incident and to do this, clearly and briefly, above each segment of their storyboard. This said something about what the incident was perceived to be about.

3. And below each segment of their storyboard, to label each incident with a dominant emotion. This would be something about how staff thought Olga was feeling as she lived through the incident.

We provided everyone with a range of art and craft materials, of various colours, dimensionality and textures. Paints, colouring pens and crayons were also provided. Each group had the freedom to choose how they wanted to build their storyboard. The last general instruction was, ‘In building your storyboard, please think about clarity and communication. When you have finished, we will invite each group to move around the room to appreciate others’ storyboards. So they need to be self explanatory’.

After the review of others’ storyboards we asked staff two questions.

1. What was the most important thing you learned from looking at other storyboards?

2. Now you have seen other storyboards, is there anything you would want to add or change in your own storyboard?

Interestingly comments fell into two broad categories, deficit-based and strengths-based. The former is about what staff felt was missing in their storyboards. This included comments about less than ‘good’ practice. For example, ‘We forgot to include that the daughter was worried’ and ‘We rumble in. We are so ambitious and we want so much to do a good job that sometimes we forget to take the thoughts and

Figure 6. One group of homecare staff engaging in the storyboarding activity
feelings of the individual into account’. The latter is about what is right, good, appropriate and what staff would want to generate more of. For example, ‘We thought about wholeness. We wanted to know about Olga’s life before, the kind of life she had and to get away from starting with the disease’. As facilitators we learnt a great deal about the challenges of shifting a discussion from evaluation to valuation. We felt that not only does this bring a shift in spirit but also significant increases in more trusting and open relationships amongst staff.

For this paper, we have chosen one storyboard as an illustration of the work completed by one of the groups of homecare staff. This is shown in Figure 7. Underneath this is Table 2, which names each significant incident and how staff thought Olga might be feeling.

In terms of what matters most and to whom, we invited staff later to reflect again on Olga’s story and their storyboards. Specifically how far they felt Olga’s needs were or were not being met. This was the precursor to the development of a positive improvement plan. As facilitators we shared, with staff, 10 of Olga’s ‘wants’. They were:

1. I want to be able to walk.
2. I want to be able to look after myself.
3. I want to be involved in decisions made about me.
4. I want to be safe.
5. I want the help I need at home.

Figure 7. One group’s storyboard
Table 2. What the storyboard in Figure Figure 5 says

<table>
<thead>
<tr>
<th>Picture number</th>
<th>Our name for the incident</th>
<th>How we thought Olga might have felt</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Olga's life before the incident</td>
<td>Olga is content and feels good</td>
</tr>
<tr>
<td>2</td>
<td>Olga slips</td>
<td>Olga is lonely and in pain</td>
</tr>
<tr>
<td>3</td>
<td>Olga is taken care of</td>
<td>Olga is dejected and thoughtful</td>
</tr>
<tr>
<td>4</td>
<td>Olga's home is refurbished by the staff who have ideas of what is best for her</td>
<td>Olga has no control</td>
</tr>
<tr>
<td>5</td>
<td>Many want to talk</td>
<td>Olga is tired</td>
</tr>
<tr>
<td>6</td>
<td>Many want to decide</td>
<td>Olga feels trapped and does not want to trouble anyone</td>
</tr>
<tr>
<td>7</td>
<td>Olga wants to decide</td>
<td>Towards freedom and independence?</td>
</tr>
<tr>
<td>8</td>
<td>'The well-being of Olga'</td>
<td></td>
</tr>
</tbody>
</table>

6. I want the best support I can get at home.
7. I want to feel free and be able to go outside, if I want to.
8. I want my family and friends to come and see me.
9. I don’t want to be in pain.
10. I don’t want to fall again.

In envisioning a better future, comments principally centred around participation, self-determination, empowerment, coordination of services, the role of ICT and active listening. For example:

We need to make sure that Olga feels like a real participant in the care chain (cooperation, compassion, being looked at, taking part in, etc) and respected. If we really respected her she would have had the opportunity to participate in her discharge from hospital (she was discharged so quickly there was no one at home to meet her) and about her pain. She should have been listened to. She, herself, should have had the opportunity to say how she was feeling. Someone needed to have asked her what she wanted or needed.

**Putting our espoused values ‘under pressure’**

Olga’s experience and the reflective learning workshop process gave us much to reflect upon. For example, how far staff felt able to live out, in their practice, three of their espoused values. These were:

1. To actively listen to and learn more about who we work with and care for, by systematically, collectively and publicly reflecting on our practice.
2. To utilize knowledge and insight, derived from such listening, to strive to improve the quality of life of elderly people in the north of Sweden.
3. To weave together, for the benefit of homecare clients, research and modern information and communications technologies so that they may actively participate in and manage their own care.
At the end of each day’s workshop we asked ourselves, ‘What have we learnt today?’ We reflected together for a couple of hours. We also asked staff to write down their responses to the following statements and to leave them with us. The first was about usefulness and was action-oriented. ‘As a result of today, the most important thing I am going to do now is …’ The second was about enjoyment. ‘How far have you enjoyed today?’ So what did we learn? What appreciations have been deepened, challenged?

**Mapping the ‘rough ground’ of home healthcare**

In his book *Educating the reflective practitioner* Schön (1987) uses the metaphor of the swamp and the high ground. ‘On the high ground, manageable problems lend themselves to solution through the application of research-based theory and technique. In the swampy lowland, messy, confusing problems defy technical solution’ (p. 3). Without doubt life in the swamp, with the ‘messy and confusing problems of practice’ can lead to powerful opportunities for learning. But we have a choice. To climb and stay on the high ground or to descend into the swamp. In the context of homecare in the north of Sweden we came to appreciate that there may be a more appropriate metaphor to illuminate what it was we were trying to achieve with homecare staff in order to further improve services for older people. It was Wittgenstein’s metaphor of ‘rough ground’, captured in the Derek Jarman film (1993) of the Viennese-born, Cambridge-educated philosopher Ludwig Wittgenstein (1889–1951). In essence the metaphor is all about ‘friction’. When we try to walk on slippery ice, where there is no friction, we are unable to do so. We fall over. If we want to walk, we need an amount of friction. In the film, Wittgenstein’s image of the ‘crystalline purity of logic’ is set in contrast with the ‘rough ground’ of what we actually say and do. As the film unfolds, a young man dreams of reducing the world to pure logic. It’s a dream of a world purged of imperfection and Schön-like indeterminacy. The world becomes a landscape of gleaming ice. But this world, perfect though it might appear to be, is uninhabitable because it is a landscape without friction. As an older person, the man begins to appreciate that roughness, ambiguity, error and indeterminacy are not imperfections. They are an important part of what actually makes things work! He begins to dig up the ice to uncover the rough ground. But he can’t sustain this. He yearns for the ice where everything appears radiant and absolute. Unable to live on the rough ground he ends up marooned between earth and ice, at home in neither! We learned that empowering elderly people in home healthcare meant that all involved had to discover and know what constituted the ‘rough ground of practice’. In the spirit of learning through reflection, we needed to confront the question, ‘How can we (the professionals) walk alongside older people, on this rough ground?’

So how far were homecare staff prepared to discover more of the ‘rough ground’ of their own practice? These were some of their written comments left with us.

We want to continue to understand the clients with their needs, *ask questions*, and have a sensitive ear for their needs. Discuss at the workplace that the client always should be in centre.
I will try to have a sensitive ear and focus on the human being.

In my daily work with clients and personnel/staff, comment upon and listen to what clients really want, ask him/her in more detail about what s/he means.

**Homecare clients accelerating change**

So how can client experiences, like Olga’s, help create changes in homecare services that matter to older people? We learned that we needed to critically and creatively reflect on what clients say and then try to respond positively to what we come to know. But we appreciate that this might sound like a seductive rhetoric. Too much ice and not sufficient roughness! Simply changing administrative procedures, in themselves, did not seem to be enough to improve the service. Similarly simply asking staff to work together, in even better ways, seemed not to tackle some of the underlying issues in Olga’s story. We began to sense that real improvement might only occur when accountabilities changed. So we began to think, ‘To whom do individual homecare staff feel accountable? To their clients, their profession, team leader or head of service? Some of these. All of them? To others? In what order?’

We came to more fully appreciate that much depended upon working with the triad of participation, empowerment and modern technologies.

**Reflection 1. ‘Olga did not feel in control of what was happening’**

Here we reflect briefly upon some aspects of client participation that arose in the workshops. It is a phenomenon that is multifaceted and includes experiences of participation as well as goal-oriented actions (Almqvist et al., 2004). Participation is influenced by many factors, particularly the interplay between the individual and the context in which the individual is embedded. To improve homecare services, it was felt that everyone involved needed to take participation seriously. In discussions, staff talked about loss of control as a significant incident in Olga’s story. The reason for Olga’s loss of control was explained by homecare staff as Olga’s lack of participation in the planning and decision-making processes of her homecare. One of the suggestions to solve the problem was that Olga ought to be participating in the process from the start. For example, when she was discharged from the hospital. One of the staff wrote down on a note, ‘I think Olga’s experience would improve if she felt that she was met as the leading character’.

Staff agreed that if Olga was listened to, she could tell staff how she wanted her care to be and what she needed. The challenge would then be to coordinate all involved in co-constructing, managing and delivering her care plan. The importance of actively listening to the client, when planning services, developed as the ‘positive core’ (Cooperrider & Whitney, 2003) of good homecare practice. But what does it mean to be a participant in shaping the service you receive from society? Does it mean that you can have your voice heard, that you are asked, or something different? During the workshop, participation became closely aligned with notions of how homecare services were actually experienced. About how the service was made understandable to clients
which was linked with how homecare services were organized (Larsson, 2004). So much discussion revolved around how best to enable clients to exercise their right to participate individually in the planning and implementation of their healthcare. Also how improvement in homecare services could best address real client needs, taking into account, through a genuinely open and democratic process, their expectations about health and health care. A power-related issue was how the client’s voice and choice could decisively influence the way in which home health services were designed, managed and implemented.

Participants in the workshops came to a consensus around the importance of being active listeners to the clients’ needs and wishes and to see each as an individual. In the discussions the question ‘Who should be listened to?’ was brought up. ‘The relatives are steering. They want certain things very much. So whose needs should we listen to?’ The participants expressed a fear of being used or perhaps manipulated by clients’ relatives. Participation is not just a question of our right to something that is already there (the service) but also a question about who we want to be and how we want to create our own (future) identity (Larsson, 2004). Our post-workshop reflections were forward looking, focusing on ways of increasing the capacity of staff to continually listen to clients and how to create genuine, co-learning opportunities with them.

*Reflection 2. ‘They said her bed had to go. Olga felt out of control’*

Here we reflect briefly on the notion of empowerment (Rodwell, 1996; Duvall, 1997; McDougall, 1997) and the ways it is used in healthcare. Why? Because it is linked with the process of enabling people to increase their control over and improve their health. In this paper we are making an assumption that empowerment is ‘good’ and ‘desirable’. Having said this, we are aware that not everyone wants to be empowered and that the process of empowerment can be distorted by vested interests and different value systems.

In the section above we described one process that might enable Olga to gain more control over her situation. Appelbaum *et al.* (1999) suggest that relations that are empowering are relations that enable individuals to have a secure and valid sense of identity, meaning and reality. Additionally empowerment, as a process, not a commodity, has an ethical dimension (Stainer & Stainer, 2000) in this paper, because it embraces what’s right and best for Olga. In the workshop, the staff agreed that it was not ethical to take away Olga’s bed, although this was meant to give both her and the staff better space, while moving around in her home. Olga’s big bed was intimately connected with her emotional needs and her identity. So this issue is also related to self determination and autonomy and more generally related to social participation (Renblad, 2003). Self-determination and autonomy, as dimensions of empowerment, are ways clients can retain some sense of control over their lives. In ‘a helping partnership’, people are enabled to choose, to take control over, and make decisions about, their lives (Rodwell, 1996). This process values all those who are involved. In discussions at the workshops, staff said that clients do not necessarily express their wishes. ‘Few say: “I want...”. You have to create a dialogue and read between the
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lines’. This was also found in the research by Wikström (2005). Many clients have wishes and needs that they never bring forward to staff. The client–career situation often quietened them. Sometimes quietness has to do with a lack of knowledge of what services are available. Olga has to make her needs and wishes explicit and staff have to make their homecare services understandable. The challenge is to create an appreciative space where Olga feels free to express her needs and wishes and staff listen openly. In building their storyboards, staff learned from each other that you have to look for wholeness and learn about the kind of person Olga was before the accident. ‘We want to add the loss of her husband. Her independence before the accident. She wanted to take a walk. Her own wishes’. The past is clearly not irrelevant.

In many first world nations, lifestyles and opportunities for elderly people are continually changing and expanding (Bond & Corner, 2004). Social activity is seen as a prerequisite for quality of life, even though this reduces with age because of illness, impairment and disability. Quality of life can be defined in many ways. One way of defining it is that it refers to the possibility and the right to be active, to participate, to belong and to be treated as an equal (Renblad, 2003). The factors that older people highlight as important are the same as other groups; their own health, independence, mobility, emotional wellbeing, material circumstances, their home environment, social contacts, religion/spirituality, leisure activities and their relationships with family and friends (Bond & Corner, 2004). Arguably it is very important to enable older adults to have a positive view of themselves, sense of self and identity, a good feeling of self-control and spiritual well-being. These impact on relationships with family and friends. Keeping the ability to be physically active influences our likelihood to stay healthy (Fiatarone Singh, 2004). Research shows that regular physical activity can minimize the physiological changes that aging leads to, maintains psychological health and well-being, increases life length and decreases the risk of several of the most common chronic diseases (Fiatarone Singh, 2004). We collectively reflected on better ways of listening to Olga’s wish to be more active and mobile and together with her, construct services that promote this. One way to support the process of empowerment is the use of information and communication technology (ICT). Arguably the right to information about the nature of available services, is of the utmost importance for self decision-making and supports the principle of more empowered individuals.

Reflection 3. ‘The man came to fit the safety alarm. Olga felt powerless to say no’

Here we reflect briefly on the notion of the roles of modern technologies. Information and communication technology (ICT) is often at the centre of today’s workplace transformation (Bjører et al., 2003). The use of ICT in healthcare, and homecare specifically, is seen as a way of improving care. Using ICT in this context has a potential to provide care at a lower cost and, at the same time, enhance the quality of care for people with illness and disability, in their home, in the future. The claim about more cost effective care is still to be proven (Proposition 2004/05:175). Through an increased use of forms of ICT, it is expected that people will have more possibilities to take an active part in their own healthcare. In the context of living in the north of
Sweden, technology-supported, distance-spanning home healthcare is obviously very important. Many see this new technology as a tool for empowering elderly people. The general line of thinking is that with better communication with the care givers, and more and better information about their own condition/s, it will be more possible for older people to stay at home and retain a good quality of life.

Different assistive technologies (ATs) that clients use in their homes already exist (Miskelly, 2001). The safety alarm that was installed in Olga’s home is an example of a common assistive technology in elderly care. Olga was upset because she had not been participating in the decision to install it. Instead it was her daughter that wanted it and ordered it, maybe for her own safety (cf. Melander-Wikman & Jansson, 2006). There are several projects where ICT has been used to provide older people, their family and carers, with information, education and support in relation to their caring situation, particularly to improve client independence and autonomy (Magnusson & Hanson, 2003; Sävenstedt, 2004). A key question is, ‘In what ways could ICT most usefully support Olga and her daughter?’

In the near future many professionals in Swedish homecare will reach retirement age and new staff must be recruited. To meet service demands, the implementation and use of ICT, as a support for caring work, is increasing (National strategy for e-health: Swedish Government Offices, 2006). The government in Sweden therefore hopes that new technology will make work in homecare more attractive and efficient. Until now, due to long traveling distances and the nature of the work, contacts and information flows between different caregivers has been problematic. ICT might be the solution to these challenges. It is regarded as a necessity by many (Bjørner et al., 2003). In the workshops, staff talked about a need for ‘care planning. Co-operation between actors around services. … Follow up of services …’. and so on. If homecare staff had been able to use ICT in their work more effectively, the coordination of services for Olga, might have been better. Staff felt there was room for improvement around the sharing of information, by different occupational groups and that this should also have involved Olga.

In Sweden there is an increasing emphasis on client-centred elderly care services. Within this, there is an implicit assumption that technology will be supportive of this. In the National strategy for e-health in Sweden (Swedish Government Offices, 2006) things are joined up thus:

A feature of ongoing development work is the gradual transformation of the system’s relationship to patients. In the past, the emphasis has been on improving and enhancing the efficiency of care services on the basis of assessment by care professionals of how an efficient operation should be run, and on an organization-based view of efficiency and appropriateness. The new approach, gradually adopted over the last few decades, is based on citizens’ and patients’ actual needs and emphasizes the value of active patient participation. Development and reform measures must first of all be assessed on the basis of whether and how they help improve conditions for those affected by them. (Swedish Government Offices, 2006. p. 7)

An unfinished question in the workshop was, ‘How can ICT’ be used by clients and staff in a way that best supports them both and in relation to the client’s particular
living situation? Since the late 1990s increased emphasis on client participation can be seen as a means of modernizing services, at least in the case of the Nordic countries. Governments are committed to create public services that are coherent, accessible and responsive, rather than organized for the provider’s convenience. The emphasis on client participation, means that clients need to know their rights and their responsibilities and feel secure in front of authority, in the form of healthcare workers. Clearly much more work needs to be done to see how client participation, empowerment strategies and ICT can be woven together in the pursuit of service excellence. So what else were we learning? At least two fundamental things. First, that improving home healthcare services might depend upon the quality of the interaction between research and practice. An openness to the potential for research to inform and transform practice, and vice versa. The issue is not simply one of research utilization. Secondly, clients accelerating change may depend upon the sincere, genuine and sustained use of the ‘four practices of open space’ (Owen, 1997). In summary these are:

1. The practice of opening. This is about opening hearts. About creating opportunities to really listen to and learn from client experiences. A willingness to be open to the possibility that ‘we’ don’t always know best!

2. The practice of inviting. This is about inviting connection. About creating spaces to explore how client experiences help achieve a vision of high quality homecare services.

3. The practice of holding. This is about supporting collaboration. About how we work together to support desirable change and improvement. Providing space and time, maybe for further workshops, where clients and professionals can work and learn together.

4. The practice of practice. This is about making a difference. About moving from rhetoric to action. About seeing things through, sustaining, realizing and making talk of better services, real. What is crucial in this practice is that those who can, acknowledge and reward those who are working towards building a better service.

So what did homecare staff feel about taking action? What were some of their responses to, ‘As a result of today, the most important thing I am going to do now is …?’

I will take with me the experience about the equal importance of the team’s different components and also try to listen even better to the clients I meet in order to try to understand the actual need and be able to do an even better job.

I hope that I will be able to pass the whole day on to my staff. I wish that they also could have a day like this. I hope that I won’t forget to see the “whole person.”

I will talk with my two co-workers and prepare us for the project Client Participation in Homecare Service.

System thinkers in action

During each workshop there was much talk about connecting, integrating and joining up homecare practices for the benefit of clients. Olga’s experiences generated a lively
debate about how best to co-ordinate services around her needs. Also discussions about the content of the storyboards revealed how we sometimes tend to focus on ‘our bit of a bigger process’. Collectively we learnt that if we want to improve services for homecare clients we have to improve our understanding of homecare, not just as a service, but as a system. Since a system consists of parts that are related to each other, if one part in the homecare system changes, the whole system will be influenced by the change (cf. Checkland and Scholes, 1990). We realized that improvements in services might require systems solutions (NHS, 2005).

Soft Systems Thinking is essentially the science of how things are connected. It is a way to deal with a world that is complex and constantly changing (Checkland & Scholes, 1990). A soft systems approach gives a holistic perspective that cannot be defined simply in terms of its parts. Often we have to look ‘upstream’ and across the different elements of a service to understand the ‘problem’ in a specific part of it. Further, in soft systems thinking, system models are regarded as models relevant to explore what we, as people, perceive as reality, not abstract models of the world (Checkland & Holwell, 1998). Thus, soft systems thinking is based on interpretative principles. They take into consideration that people have various perspectives on the world. Moreover, in a soft systems approach, design of ICT is seen as a learning process, where various individual perspectives are formulated and organized into systems. These perspectives are then debated, communicated and negotiated with the purpose of reaching a common understanding, as well as a shared interest for change. These changes should be both feasible and culturally desirable (Checkland & Scholes, 1990).

If we want to design ICT that supports homecare staff and their clients, we must find out the meanings they attribute to their perceptions of the world. Then we can understand which action or actions they regard as reasonable and purposeful. To support homecare staff and clients with technology and to create information systems that serves their actions, we must first define the system of homecare together.

Senge (1990) popularized the notion of systems thinking in bringing about effective change in organizations. More recently the work of Fullan (2004) draws our attention to the possibility that, despite what Senge claims, ‘we have made no gains in conceptualizing, let alone promoting, systems thinking on the ground’ (p. 8). Fullan believes that little has been done to promote the ‘in action’ part. He goes on to assert that what is needed is ‘systems thinkers in action’ (p. 15). Essentially these are people who can see and promote the interconnectedness of practice. So we began to formulate this question: ‘How can we enable homecare staff to develop a “literacy of the system”?’ One possible way to do this we felt was to create opportunities for work-based learning where staff interacted with others, beyond their own immediate work situation.

Appreciating practice and the practical

The reflective learning process embedded in the workshops was about and for the improvement of practice. Practice as a fascinating, sometimes frustrating, complex
lived reality for homecare staff. The centrality of storyboarding engaged their perceptiveness, passion and eloquence. It also developed their relational knowledge as staff co-operatively worked to relate Olga’s experiences to their own working practices. In this way the workshop aligned itself with Dewey’s (1933) position of philosophical pragmatism and his concern with interaction, reflection, experience and interest in community and democracy. More specifically with his view that experience is what knowledge starts from.

We feel we could do more to make our workshops a better form of appreciative inquiry (Cooperrider & Whitney, 2005). In other words we don’t begin the day by asking staff, ‘What’s the problem?’ If we do, we simply focus our energy on what we want less of and work (like car mechanics) to ‘fix’ things. Rather we have learnt that if we begin by trying to focus on what we want more of, even if it currently only exists in small quantities, then we create opportunities for different kinds of conversation. In turn these open up new possibilities for action. Moral courage (Kidder, 2005), leadership, commitment and persistence are all required, together with learning through reflection. An appreciative approach to empowering elderly people in home healthcare needs all those involved to be able to stand back occasionally from the busyness of daily life and enrich their understanding of health and well-being. Enrichment is about attending to how we feel just as much as to what we do. Without this kind of consciousness and the courage to talk about it (maybe through workshops of the kind described in this paper) the practices of staff, and the experiences of clients, run the risk of being misunderstood. Or worse they are regarded as trivial and of little consequence. Almost: meaningless. It would be like reading Shakespeare’s Hamlet without the Prince of Denmark ever uttering a line!

One final thought. We now understand more richly that all learning through reflection is not fun! But trying to have fun is important. As Paul Everett (2006) says:

Fun creates Enjoyment.
Enjoyment invites Participation.
Participation focuses Attention.
Attention expands Awareness.
Awareness promotes Insight.
Insight generates Knowledge.
Knowledge facilitates Action.
Action yields Results.
(Therefore, Fun is results-producing)

**Consent**

Our intention to place our experiences of facilitating the workshops, in the public domain, was discussed with homecare staff. Informed consent was given orally, by all participants, to use the material produced during the workshop. This provided us with the ethical approval to cite from their individual notes, group discussions and the storyboards they created.
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Notes on contributors

Anita Melander-Wikman has an M.Sc. in physiotherapy and is a Ph.D. student at Luleå University of Technology. Her research interests lie within the field of the empowerment of elderly people and rehabilitation. The focus of her research is to explore how elderly people experience self-determination and participation in relation to rehabilitation and how mobile ICT can support them. Anita’s intention is to foreground the client’s perspective. She has experience in physiotherapy practice, working in neurological rehabilitation, and has been working at Luleå University as a lecturer in physiotherapy since 1997.

Maria Jansson is a licentiate of philosophy and Ph.D. student in informatics. Her research interest lies within the development and implementation of ICT for the homecare sector. The focus of Maria’s research is exploring the expectations, needs, dreams and notions that care assistants have regarding ICT and homecare work. With participatory design principles as the base, her intention is to foreground the care assistant’s perspective. She has been working at Luleå University as a lecturer since 2000.

Tony Ghaye achieved the title of Professor in Educare in 2000 after studying and working at the Universities of London and Worcester. He is the first Chief Executive of the international Institute of Reflective Practice-UK and Visiting Professor at Luleå University. Tony has worked extensively at the interface between health, social care and education, in both developing and developed countries. He specialises in workplace culture development, service and organisational improvement issues. He has chaired national and international conferences and reported to Government departments in the UK, the Middle East and Australia, and is currently involved in building reflective teams and organizations that act ethically and with moral courage.

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