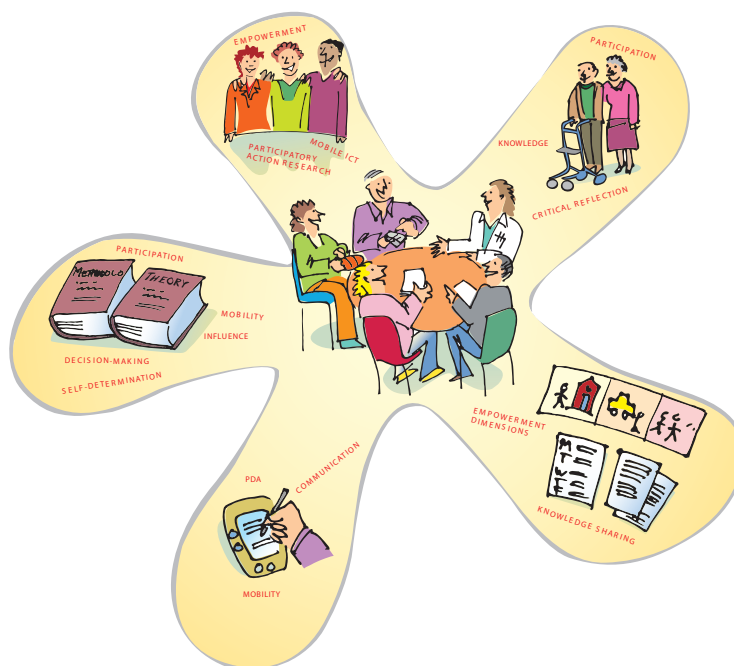


Ageing well

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



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To Lisa and Johan

But there's no yes in yesterday
And who knows what tomorrow brings, or takes away
As long as I'm still in the game, I want to play
For laughs, for life, for love

So here's to life
And every joy it brings
Here's to life
To dreamers and their dreams
May all your storms be weathered
And all that's good get better

Phyllis Molinary

ABSTRACT

The ageing 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. Ageing well is a frequently used concept, describing the objectives of future elderly care and rehabilitation. Enabling elderly people to live longer and independently in their homes is one goal for society as a whole. 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. There is an assumption that Information and Communication Technologies (ICT) will enhance quality of life. Additionally "electronic accessibility" is one of the goals for the European Information Society to support and enable self-determination and mobility. 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 an empowerment methodology for elderly persons in home health care, and if ICT was a useful tool in this process. A multi-method approach was used that included interviews with patients with experience of rehabilitation, interviews with elderly persons with homecare and safety alarms, exploring their needs in relation to empowerment dimensions such as autonomy, self-determination, participation and mobility, an intervention where a mobile safety alarm was tested by elderly individuals and reflective learning workshops with front line staff in home care. Different methods of analysis were used, including Grounded Theory, Latent Content analysis and Constructivist Grounded Theory together with reflections.

One of the overall findings was that all patients/clients that participated in these studies had not reflected upon whether it would be possible or not, to influence care and rehabilitation. The results indicate low patient participation in and influence on, the rehabilitation process. Elderly people perceived freedom of movement as a prerequisite for participation and in one of the studies the elderly participants felt that they could influence care and be participating in one aspect, but they still wanted more support with, for example, being more physically active, like walking out doors. The overall findings show a genuine patient/client desire, but limited possibilities to influence care and rehabilitation. Put another way, patients/clients want to have influence and participate authentically, but they do not exactly know how to achieve this. All patients/clients were positive towards the professionals in care and rehabilitation. They were really grateful and admired the professionals and also identified themselves with how stressed and how overloaded with work the professionals were. This might mean that the

concept interdependency is looked upon as more important than real autonomy. The patients/clients tried to be compliant and this can be understood as “learning unpretentiousness”. After reflecting upon their situation they were more able to articulate their needs that were not responded to or taken care of. When ICT, as an empowering tool, was implemented, findings showed that elderly people experienced the use of a mobile safety alarm as empowering. The mobile safety alarm gave them the freedom of movement needed to be physically 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. The 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 and shift the focus away from ‘what’s life like?’ and ‘what should life be like?’, towards the explicit action question, *‘what needs to be done to make life as good as it can be?’* Real improvement is more likely to be sustained with some changes in accountability.

Keywords: Ageing well, Appreciative Inquiry, Empowerment, E-health, Information and Communication Technology (ICT), Mobility, Participation, Participatory Action Research, Self-determination

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ORIGINAL PAPERS

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

- I Melander Wikman, A. & Fältholm, Y. (2006) Patient empowerment and rehabilitation: "Somebody told me to get rehabilitated". *Adv. of Phys. Ther.*, 8, 23-32.
- II Melander Wikman, A., Fältholm, Y. & Ghaye, T. Ageing well or Learning Unpretentiousness? - Elderly person's living experiences of homecare and safety alarms. (Submitted to The International Journal of Qualitative Studies on Health and Well-being).
- III Melander Wikman, A Fältholm, Y. & Gard, G. (2008) Safety vs. Privacy: elderly persons' experiences of a mobile safety alarm. *Health and Social Care in the Community*, 16(4) 337-346.
- IV Melander Wikman, A., Jansson, M. & Ghaye, T. (2006) Reflections on an appreciative approach to empowering elderly people, in home healthcare. *Reflective Practice*, 7 (4) 423-443.

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ABBREVIATIONS

AI Appreciative Inquiry

AR Action Research

eHHC The e-Home Health Care @ North Calotte project

EBD Experienced Based Design

GPS Global Positioning System

GPRS General Packet Radio Services

GSM Global System for Mobile communication

GT Grounded Theory

ICT Information and Communication Technology

IST Information in Society

mICT mobile Information and Communication Technology

MTL Mobila Trygghets Larmet (Mobile Safety Alarm Project)

PAR Participatory Action Research

PAAR Participatory and Appreciative Action Research

PD Participatory Design

PCC Patient-centred care

PCR Patient-centred rehabilitation

QoL Quality of Life

UMTS Universal Mobile Telecommunications System

WP Work Package

INTRODUCTION

This Doctoral thesis is about ageing well by the means of mobile Information and Communication Technology (ICT) as a tool for this process in home health care and rehabilitation. This tool should be supporting elderly persons in dimensions of empowerment, like autonomy, self-determination, decision-making, participation and freedom of mobility. 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 the theoretical framework is described together with my own subjectivity. The methodology is described and discussed in the following chapters. Thereafter the findings are presented. In the last chapter they are discussed together with insights and theories in the literature as my lessons learned from a methodological, ethical, theoretical and a practical perspective.

It is well-known that the population of Europe is ageing. The ageing 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. Ageing well is a concept frequently used in order to show the ambitions in developing an inclusive elderly care and service with the objective of increasing independent living. Building an inclusive society and improving quality of life (QoL) of Europe's increasingly elderly population by applying technology that meets the needs of older people is a key strategy for EU (EC, 2007). Old people are not a homogeneous group and we must find solutions that take into account the diversities and respect the wishes from individuals (*ibid.*). But how can this challenge be met, and how can Information and Communication Technology (ICT) support this process of ageing well?

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 be met in practice and what constitutes effective practice with high quality from a patient/client perspective?

Introducing the stakeholders and e-health projects in this thesis

This research is guided by a participatory research design. Therefore it is appropriate that I begin by introducing the participants in the research enterprise. As much of the action within my research has been conducted within a 'project' frame, what follows on is a brief description of relevant e-health projects.

Meet the research persons

In the first study (Paper I), six persons with a long experience of rehabilitation, after different types of functional limitations as a result of neurological, circulatory and/or orthopaedic diseases were interviewed. They were four women and two men, aged between 35 and 58 years. The interviews were about experiences of participation and influence in the rehabilitation process. In the second study (Paper II) ten elderly persons living in their homes with homecare and safety alarms were the research persons. Nine women and one man between 63 and 89 years (more than half the group were over 80 years old) were interviewed about their needs in relation to participation, self-determination and mobility. Eight of the participants were living alone, most of them as widows and others as singles. The other two had a spouse with dementia which was also described as being alone.

In order to study if mobile ICT can be a tool for empowerment, in the third study (Paper III), nine elderly persons participated in an intervention with a mobile safety alarm. Four healthy elderly persons, two women and two men, without functional limitations and five elderly persons with functional limitations, one man and four women participated in the testing and were later interviewed. Ages varied between 60 and 84 years 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. In the last study (Paper IV), 35 frontline home care staff (handling officers and work leaders in homecare) at the city of Luleå, all women, participated in a reflective learning workshop. In the workshop the participants reflected on the collective concern about developing and sustaining ways that might enable elderly people to feel more empowered to exercise their right of self-determination.

E-health projects

Three of the studies have been conducted within two different projects on e-health. The second and last studies (Paper II and IV) comprise living data drawn from The e-Home HealthCare@NorthCalotte (eHHC) Project of 2003–2005. The eHHC project aimed at enhancing quality and precision of information exchange in homecare services by introducing mobile ICT equipment to the professional health workers. The project was organized as coordinated trials in five municipalities of northern Finland, northern Norway and northern Sweden. The purpose of the project was to offer customer-oriented empowerment-focused quality service provision in the right place at the right time, which includes competence-building and empowerment. The common basis of the trials was to solve the problems of getting updated information on the present situation of the care of home healthcare clients, services and security situations in the right place and at the right time. Enhanced patient or client empowerment was an expected outcome of the project. By mapping the needs of elderly persons living at home and by developing and testing the solutions of mobile information exchange in the North Calotte region, the trials were aimed at giving home healthcare professionals, patients and clients and their immediate family members empowerment and competence.

The third study (Paper III) was conducted within The Mobile Safety Alarm (MTL) Project of 2005–2006. This was a multidisciplinary research project with researchers from the Department of Computer Science and Electrical Engineering at Luleå University of Technology (LTU). The aim of The Mobile Safety Alarm Project was to develop and test a mobile safety alarm with a fall sensor. These two projects will be described in more depth later in this thesis.

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 experiences come 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).

The aim of the research and my research questions

When I was offered the opportunity 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 believed 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. Later in my work with this thesis, my grounded understandings lead to the idea that if patients/clients could not just be engaged and participating in rehabilitation, but also in the development and design of services that were meant to improve care and rehabilitation, it would be even better. The challenge would then be what methodology that would best support this.

The overall aim of this doctoral thesis is to explore different dimensions of empowerment and empowerment methodology for elderly persons in home health care and rehabilitation and how mobile ICT can support this.

The 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 are the needs of elderly people in relation to empowerment dimensions like participation, self-determination, autonomy and mobility?
- What methodology can be used to empower elderly people in home health care and rehabilitation?
- How far is mobile ICT a useful tool for empowering elderly people in home health care and rehabilitation?

The specific aims of the different studies were:

- To explore patients' experiences of influence and participation in the rehabilitation process (Paper I).
- To explore and understand elderly people's needs in relation to empowerment dimensions such as self-determination, participation, autonomy and mobility (Paper II).
- To describe elderly people's experiences of testing a mobile safety alarm and their reasoning about safety, privacy and mobility (Paper III).

- 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 and rehabilitation (Paper IV).

THE 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. Just as Misco (2007) describes it, I “produced Grounded Understandings” that facilitated my own process of learning. Paper I (Melander Wikman & Fältholm, 2006) was written parallel to my first studies in empowerment and patient-centred care and rehabilitation. Papers III (Melander Wikman, Fältholm & Gard, 2008) and IV (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. Paper II was written parallel to working in an e-health project eHome HealthCare@NorthCalotte (Melander Wikman, Fältholm & Ghaye, in manuscript) and learning more about Appreciative Inquiry (AI) and Experienced Based Design (EBD). I have used a qualitative approach in this doctoral 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 critiqued and judged are related to society and its individuals. Arguably 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.) (See more about my own search for subjectivity and validity in section “In search

of subjectivity”). Through the research I have learned that research is about understanding and being able to explain and justify knowledge creation processes. 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? Who benefits? From who’s perspective? I see this thesis as an example of a multi-vocal account where different voices can be heard but where my own voice and those of ‘users’ are the dominant ones. As my focus is on the empowerment of the elderly 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 doctoral 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. We also hope 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? I agree with Richardson (1999a) that a well-developed view of our professional identity

will guide the continuing development of the profession through the constant and significant changes in health care. The changes of policies and practices in health care have led to a focus on client-centred care and rehabilitation and health promotion with the aim to empower patients/clients to manage their own health needs (Richardson, 1999b). Lindquist (2006) showed that different learning pathways can lead to different professional identities and the physiotherapy students experienced three identities when leaving university; the Treater, the Educator and the Empowerer. 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 styles for clinicians concerned with improving the quality of patient care (Meyer, 2000). This gave me tools (in the form of principles and processes) to combine my interest in the empowerment of elderly 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. In the last part of my doctoral studies PAR developed to PAAR (Participatory and Appreciative Action Research), adding the notion of appreciative inquiry, which will be explained later in the chapter Research Approach.

Further 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 (Burr, 1995; Börjesson, 2003). Key concepts that guide my inquiry or emerge from reflecting on the process are the theories about empowerment (see section Empowerment in Theory) and theories trying to explain the concept of Ageing well (see section Ageing well) presented below. I also think it is important to have a pragmatic approach where reality is characterised by indeterminacy and fluidity and as open to multiple interpretations. As pragmatism presumes that people are active and creative and meaning comes through practical actions to solve problems, this approach is, from my point of view, suitable to

physiotherapy where action is natural and communication is essential. The Habermasian (1995) theory about communication as an action has been helpful for my understanding, as he means that a coordinated system formed by “the” external world, one’s “own” internal world and “our” shared social life-world is the infrastructure of speech and this involves recognizing and positively embracing the issue of “validity claims”. 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, by reflecting in action and on 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[reflective practice] 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).

Ageing well

Reflecting on practice and my work with rehabilitation with elderly patients/clients made me interested in the concept of ageing well. I found that “Ageing well” is a concept frequently used in order to show the ambitions in developing an inclusive elderly care and service with the objective of increasing independent living. My own grounded understandings from practice were that old people are not a homogeneous group and that we must find solutions that take into account the diversities and respect the wishes from individuals. With the concern of enabling elderly person to maintain independence and to add quality to years of life my interest was put on what is “a good life”.

There are a wide range of definitions connected to the concept of “ageing well or “successful ageing”. Bowlin (2007) means that these definitions represents the investigators own academic discipline and values. Psychical and mental functions are empathised as important to a successful ageing by researchers driven by a bio-medical model, social functioning, psychological functioning and life satisfaction are looked upon as important by researchers from disciplines were the socio-psychology models are vital (ibid.). “Successful ageing” was conceptualised by Rowe & Kahn (1987, 1997) with the objective to create a more positive view upon ageing in order to help

individuals to accomplish and maintain higher functions as they grow older (Minkler & Faden, 2002). Successful ageing means: avoidance of disease and disability, maintenance of high cognitive and physical capacity, and engagement in life. Ageing well is connected to aspects of health and focuses on health prevention and health promotion. Important factors in Rowe & Kahns (1997) conceptualisation of successful aging were to continue being involved in activities that are decisive and meaningful and maintain a close relationship to others. Critique against this positive view upon ageing is that negative aspects that accompany higher age such as disability, decline and illness are somewhat disregarded and that elderly people might feel a pressure to live up to the picture of being healthy and fit and this in turn causes a fear to getting older, declined or not to be able to take care of your self, being dependant (Minkler & Faden, 2002). Another critical point is highlighted by Angus & Reeve (2006) who mean that “ageing well”, “health ageing”, “positive ageing”, “successful ageing” and “resourceful ageing” are the new mantras of the 21st century and that these expressions are used unreflectively by society to find ways to reduce age-related losses. I will in this thesis just outline the concept of ageing well, meaning the ambitions in developing an inclusive elderly care and service, with the objective of increasing independent living.

Ageing well is, as already mentioned, connected to aspects of health. The well known definition of health from 1948 by WHO, as “*a state of complete physical, mental and social wellbeing and not merely the absence of disease and infirmity*”, is the starting point for a number of the health-related definitions. Related concepts are Quality of Life and this concept also means different things to different people and different disciplines and social groups of people give their own explanations (Bowlin & Windsor, 2001). Closely related concepts like happiness, well-being and “good-life” draw on as much theoretical confusions (ibid.). Subjective wellbeing can be defined as people’s positive evaluation of their lives including pleasant emotions, fulfilment and satisfaction (Diener & Biswas-Diener, 2005). Psychological empowerment represents one facet of subjective well-being and is referring to people’s belief that they have resources, energy and competence to accomplish important goals and positive moods can lead to psychological empowerment (ibid.). But what are the needs of elderly persons in relation to Quality of Life and well-being?

Quality of Life (QoL) is like the concept of ageing well, a complex, multi-dimensional, holistic agreement based on different scientific models and perspectives. WHO (World Health Organisation) defines QoL as: “*The individuals perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the person’s physical health,*

physiological state, level of independence, social relationships and their relationship to salient features of the environment” (WHO, 1999). This definition shows that QoL is a subjective experience in a socio-cultural context (Bond & Corner, 2004). Subjective wellbeing is one aspect of QoL, but not another term for QoL (Power, 2003). Health related and non-health related aspects of QoL should also be included. There is an emerging consensus that physical, mental and social aspects are to be included in QoL and there is now also a recognition that spiritual aspects needs to be included (ibid.). It has become standard to distinguish theories of well-being as either hedonist theories, desire theories, or objective list theories. Well-being can be seen as the only value according to the view known as welfarism. In ethics the question of how a person's moral character relates to their well-being is important (Brülde, 2003). Self efficacy beliefs, meaning the ability to believe in your own capacity to take control over your life, are important to maintaining and achieving well-being (Bandura, 1977; 1997).

Definitions of QoL in the literature are in line with how elderly persons themselves define QoL (Bond & Corner, 2004). The most important areas of life, self nominated by elderly persons were: 1) their own health 2) family relationships 3) health of close person 4) standard of living 5) social activities 6) spirituality or religion 7) other relationships 8) environment (ibid.). Quality of life also refers to the possibility and the right to be active, to participate, to belong and to be treated as an equal (Renblad, 2003).

Since the mid 1970s it has been more common to use more subjective measures of QoL, such as satisfaction and perception in research (Kitchen & Muhajarine, 2008). More perceptual methods to intercede the potential weakness associated with using stringent objective indicators of QoL should be developed. There is a need for deepening the understanding of multiple indicators of QoL such as accessibility, quality of housing and access to a wide range of services or even sense of belonging to a group of people (ibid.)

In the research by Bowlin & Windsor (2001) individuals' judgment/self rated objective and subjective components and predictors of the overall quality of life, including priorities and their own values were explored. When listening to elderly persons' accounts, you understand that ageing well and related concepts as Life Satisfaction and Quality of Life means different things to different people. Bowlin & Windsor (2001) means that different people, different disciplines and social groups of people give their own explanations and that other close related concepts like happiness, well-being and “good-life” also draw on as much theoretical confusions (ibid.). Bowlin's (2007) research indicates that “there is a need to move beyond the common emphasis on health and functioning, which is prevalent in much of the QoL literature

(p.24)”. A broader and multidimensional perspective of QoL is needed to get a better understanding of the QoL in later life. It is also important to base concepts and measurements of QoL on elderly people experiences and opinions and not just of experts’ in order to cover elderly people’s values and perceptions (ibid.). QoL could be defined as the final value that life has for the person her/him self (Brülde, 2003). This means that we have to understand what situations that have a final value to the elderly person. According to hedonist theory it should only be experiences and feelings of wellbeing that are counted and according to desire theories, only things that should matter is if the elderly person get all her/his desires, needs and wishes fulfilled. We can also see multiple objective reasons or facts that have a final value for all of us like close relations to others, personal development or freedom (ibid.). I agree with Brülde (2003) and his conceptualisation of QoL is combining elements from all three above mentioned theories creating a mixed theory with a happiness character, meaning that a person’s QoL is dependant on how satisfied s(he) is with her/his life in relation to some objectively important dimensions, but only if this sense of satisfaction is real and not just illusionary. Shortly, having a good life is, being happy because of the proper reason (ibid.).

To understand the accounts from elderly, besides different theories about QoL, there is a need to get into the different models of explanation and theoretical frameworks about ageing. There are especially five theories among the socio-psychological models that are referred to when trying to understand ageing; The Activity theory, Disengagement Theory, Continuity Theory, Erikson’s psychodynamic theory of human growth and Thornstam’s Theory of Gero-transcendence. All these theories include assumptions about what successful ageing means (Wadensten, 2006). In Sweden Activity theory influences care of older people and in this theory there is an assumption that elderly people remaining active through later life will be more satisfied (ibid.). The Disengagement theory means that elderly people get more self-centred and will withdraw from social activities and other people, and that this withdrawal is initiated by the individual her/himself and not by others in the social system (Cumming, 1963; 2000). The Continuity theory means that internal and external continuity is important to the identity of being old, meaning that you preserve and maintain existing structures in the basic life and adapt to your individual ageing by making adapted choices (Atchley, 1989; 2000). In Erikson’s psychodynamic theory of human growth you are in a constant personal development all through the lifecycle, which follows eight stages. Each stage has its own crisis and the strategies used to solve these crises, together with experiences, are transformed into the next stage (Erikson, 2004). Elderly people develop toward being less self-centred and get increased well-being by being less materialistic and more interested in spiritual and

meditative activities according to Thornstam's theory of Gero-transcendence (Thornstam, 1997; 1999).

Like many social theories in the early sixties, according to Atchley (1989; 2000) the Activity theory was an equilibrium model that assumed that when changes occurred, a strive for homeostasis was the response to this. But changes due to ageing are hard to manage since it is not possible to go back to prior state (ibid.). In Continuity theory continuity does not mean static, or sameness or lack of change. It is more about coherence or consistency of patterns over time and not an opposite of change (Atchley, 1989; 2000). This means that continuity is a subjective perception which is in shape and linked with the individual's own history. Internal continuity acts as a foundation for daily decisions and an important part of the competence of the individual and a prerequisite for mastery. External continuity is what is expected from others and is tied to earlier role performances in life. Both internal and external continuity can be helpful to individuals in focusing on their strengths and to reduce the effects of deficit in normal ageing (ibid.).

It is important to be conscious about the phenomenon ageism that is embedded in taken-for granted assumptions about older people (Angus & Reeve, 2006). The way knowledge of aging, based on tacit assumptions about what it is like to be old, is created and reproduced for and behalf of older people must be critically examined. Negative images of aging, myths and stereotypes, are perceptions that have not changed significantly although the society has an increased number of elderly (Thornstam, 1992). Fear of aging and prejudices towards older people make false images and beliefs like progressive physical and mental decline, social isolation and economical and familial burden spread (Thornton, 2002). The lifestyle for elderly people has changed throughout the twentieth century towards increased social activity (Bond & Corner, 2004). Social activity is seen as a prerequisite for quality of life and although this engagement reduces slightly with age because of illness, impairment and disability, the changing lifestyle shows a diversity of activity. The factors that older people highlight as important are the same as other groups; own health, independence, mobility, emotional wellbeing, material circumstances, their home environment, social contacts, religion/spirituality, leisure activities and relationship with family and friends (ibid.). Concepts that are important in giving people a positive view of themselves as self-esteem, sense of self and identity, a sense of self-control and spiritual well-being. This has an impact on the relationship with family and friends and their activities and helps in managing life and adapt to changes as well as seeing the meaning in their lives (ibid.). Keeping the ability to be physical active will influence your likelihood to stay healthy. There are many potentially positive effects of participation in physical activity on the aging process in literature (Fiatarone

Singh, 2004). Research shows that regular physical activity can minimize the physiologic changes that aging leads to, give psychological health and well-being, increase life length and decrease the risk of several of the most common chronic diseases, treatment for many chronic diseases and a prevention and treatment of disability (ibid.).

In definitions of rehabilitation where the objectives are bringing individuals with functional limitations from positions of dependency in their community towards independency and own decision making values of helping, choice and independence are highlighted (Curtis, 1998). Lack of knowledge about the benefits on health of physical activity might lead to inactivity in later life. Frändin (1995) showed in her longitudinal study of physical activity and functional performance in a population from 70 to 76 years of age, that lifestyle patterns in early life reflects the degree of activity in later life. If you are active in young age the possibility that you will keep on being active is strong. Physical activities after 50 years of age have the greatest influence on physical performance in later life (ibid.). Also very old persons, using a walker or a wheelchair and dependant in activities of daily living, showed positive long term effects in balance, gait ability and lower limb strength after a high intensity functional exercise program (Rosendahl et al, 2006).

Building an inclusive society where elderly people have a full citizenship is a necessity. Craig (2004) argues that elderly people are denied some of the basics of citizenship that are important for being included in society, namely mobility and independence, maintenance of their own identity and dignity, control and choice and the ability to be fully participating in society on terms of their own choices. Mobility was seen as a civil right because enhanced mobility meant increased social contacts reducing isolation. The reason for decreased mobility was often functional limitations but also less earnings after retiring. Many were unable to purchase key items for reasonable comfortable living and this had an effect on emotional and physical well-being (ibid.).

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 used in this doctoral 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 can also be seen as a fundamental way of thinking and cannot be seen as a technique (McDougall, 1997). Reflective practices can be empowering especially if they help a caregiver make decisions together with patients/clients, share and support ideas and views of things and create an identity that strengthens 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, 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, 2002; 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 doctoral 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-entered care and rehabilitation.

Patient- and Client-Centred Care and Rehabilitation

The term 'client-centred' was first used by Rogers (1951) in the field of psychiatry and referred to 'client-centred' counselling where the client is defined as a person who comes actively and voluntarily and seeks help for her/his problem but is not surrendering her/his own responsibility. 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. Client centred practice (Law et al, 1995) recognises the autonomy of the individual, the clients' choice when it comes to needs of the client, appreciating the strengths of the client when s/he comes to the encounter, appreciating the partnership between the client and therapist and making assure that services fit with the context that the client is living in and that it is accessible. They mean that different levels of client-centeredness should be appropriate (ibid.) Sumsion (1997) empazises the importance of using a 'client-centred language' when communicating in 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).

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. With 'exploring both the disease and the illness experience' is meant, 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 patient's 'explanatory model' is her/his own conceptualisation of the problem, a narrative 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. It is important to explore the four dimensions of the patient's illness experience – feelings, ideas, function and expectations (FIFE) (*ibid.*).

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. A mutual agreement in defining the problems is 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 and client-centred care (ibid.).

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

Building an inclusive society and improving quality of life (QoL) of Europe's increasingly elderly population by applying technology, that meets the needs of older people, is a key strategy for EU (EC, 2007). Old people are not a homogeneous group and we must find solutions that take into account the diversities and respect the wishes from individuals (ibid.).

As communication is primal to self-understanding and understanding is primal for lifeworld-understanding, communicative actions are fundamental for shared and mutual understandings between people (Habermas, 1995). Habermas (1995) means with his Theory of Communicative Action that there's a natural connection between our interest in reaching understanding for the sake of orienting action and the sense of utterances we do. A concern about the interaction between professionals and patients/clients made me interested in the development and impact of Information and Communication Technology (ICT) within health care and care and how especially mobile ICT could support self-understanding and understanding between all stakeholders in health care and rehabilitation. How could mobile ICT serve as a tool for empowerment of elderly people in home healthcare and rehabilitation meaning that the elderly person's voice would be listened to and the process of ageing well would be supported?

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). Two of the initiatives of the i2010 policy framework are:

- ICT tools for sustainable and personalised healthcare ensuring delivery of quality healthcare at affordable costs and contributing to greater efficiency and safety of health systems.
- ICT for independent living, inclusion and participatory governance ensuring that all citizens can benefit from ICT and that ICT helps improve participation in public and active life.

As ageing is already strongly influencing the needs for care and ‘lifelong participation’ in society and the ICT literacy of the above-65 age group will improve significantly in the next decade, service markets for well-being products and services will be created. Citizens have increasing expectations in terms of full inclusion in society and economy, quality of life and exercising of rights. Elderly people and people with functional limitations are increasingly recognised as posing the most challenging requirements also for mainstream usage. Finally, major technological developments drive R&D for e-Inclusion in new directions, characterised by more adaptive and less intrusive and smarter "human-like" solutions (From DRAFT WP of ICT Work programme, April 2008). The work programme suggests that: “Industrial participation is important. Realistic test environments should allow for early user involvement and impact analysis during the RTD phases”.

ICT will surely influence home health care¹, the way health care services are organised and delivered, as well as relationship between staff and patients/clients² and between different staff. My interest in ICT in home health care and rehabilitation increased as I participated in application writing for the Fifth Framework Programme project CUORE in 1999 and as working project participant in an industry driven e-health project as part of that Framework Program, The MobiHealth Project 2002-2003 (Melander Wikman et al, 2004). 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. Let us now examine what ICT is and how it can be understood in the context of health care, care and rehabilitation.

As more and more elderly people stay in their own homes larger efforts on health- and social care is needed. To get better health and elderly care services for the individual and the community the perspective is changing from organisational to a patient perspective. To meet the demands and to maintain an acceptable level of services in health and homecare, implementation and use of ICT as support for caring work, are increasing. The assumption is that

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.

technology will give rise to a large number of improvements, such as effectiveness and ability to follow up and evaluate the performance of the services provided. In the National strategy for e-health in Sweden (2006) it is stated that:

” 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 organisation-based view of efficiency and appropriateness. The new approach, gradually adopted over the last few decades, is based on citizens’ and actual needs and emphasises 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” (2006. p. 7)

There is a gap between the decided service and the service the elderly person actually receives (Wikström, 2005). Critique on the possibility for the client to influence the way the service is conducted was also reported (ibid.) The importance of involving elderly people in specifying their needs of services and also their views on how to remain independent and stay in their homes longer has been stressed (Raynes et al, 2004). The development of the new services in the earlier mentioned eHHC project was interactive; this means that the various experiences of the informants were used by the companies building the service as an ongoing evaluation of the system. Theories of Participatory Action Research (PAR) (Whyte, 1991) were used. PAR is a social process which explores the relationship between the realms of the individual and the social. It is built on participation, which means that all involved must be engaged in examining their knowledge and also reflect critically on how the present knowledge constrains and frames the actions that are taken. This means that personnel, clients and next of kin were not just test persons in the different trials but also participants in constructing the new technology, by sharing their experiences and opinions. Professionals, clients and relatives were involved in different ways at the trial sites. This view, where attention to the concern of all stakeholders, is held when designing and developing services within the area of e-health, is supported by Percival & Hanson (2006). They argue that special attention should be put on elderly peoples’ view upon key issues like individual choice, surveillance, risk-taking and quality of service (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. Telehealth constitutes of Tele-care and Tele-rehabilitation. Tele-care and Tele-rehabilitation provide services directly to the end-users as distinct to telemedicine, which uses ICT systems for diagnosis (c.f. Percival & Hanson, 2006). 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).

There has been a considerable debate on what is and isn't included in the general Telehealth and Telecare definition. Two models are discussed; The Telehealth umbrella model and the Telecare umbrella model (Doughty et al, 2007). In the Telehealth umbrella model, Telehealth is consisting of Telecare (alarms, monitoring, advice/feedback), e-care (mobile care-phones and worn sensors) and telemedicine (real time consulting, online data, image review). In this model Assistive technology with its mechanical devices and electronic systems are not included. In the Telecare umbrella model, the continuum of care technologies are centred on Telecare as a term used for all preventive technologies that involve the use of electronics, telecommunications and information systems. It covers applications from alarms to monitoring of vital signs and activities both when the person is in her/his home or mobile. This means that assistive technologies and telemedicine cover a smaller group of modalities that are associated with housing adaptations and hospital services respectively (Doughty et al, 2007) (see also Figure I below). I agree with Doughty et al. (2007) that terms and definitions are likely to evolve as services based on technology continue to develop and devices are being increasable embedded within items of clothing, furniture etc. and will be able to communicate with each other. They suggest that a new term should be added as umbrella in the future; PROCESS Technologies (PeRsOn-Centred Equipment & Support Services) and that you should separate technology services in four roles; 1) Functional support – which improve an individual's ability to perform activities of daily living. 2) Alerts and alarms – sensors or combination of sensors that defect situations where a person might be at risk. 3) Monitoring – providing an ongoing assessment of a person's physical, medical, well-being and performance state. 4) Interactive and virtual services – systems that are distance-spanning and empowering and enable people to network with each other (Doughty et al, 2007).

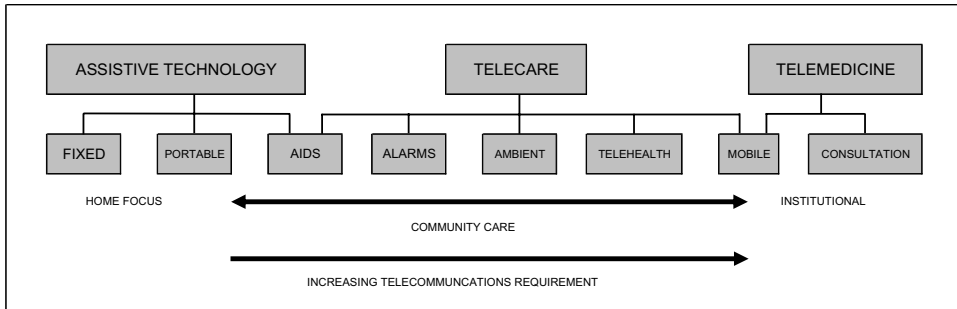


Figure 1. The continuum of care technologies centred on Telecare (Doughty et al, 2007).

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. ICT as technology can enable changes at many different levels; in the artefact itself (both the device and services), on working processes, in communication, coordination, and cooperation, knowledge exchange and concerning scope of action. Needs together with the solutions are deciding which ICT innovation that will be developed and designed in order to empower the user.

Ericson & Ståhlbröst (2006) mean that needs that are difficult to express are situated in the user's context and are experienced by her/him as a perceived lack of satisfying solutions as the solution is not known or understood by the user. They mean that these needs have to be found through a need finding process that is interpretive and the understanding of the needs are a central concern in ICT development. Needs are often mixed up with requirements, wants, desires or experiences in the literature (ibid.). Maslow's need hierarchy with categories listed with the basic organic needs on the lowest level is criticised by Illeris (1999) who means that it is not possible to categorise and quantify because needs are always developed through the interplay between the individual and her/his context. I agree with Illeris.

There is a demand for more research to be concerned with improving Quality of Life for citizens. The EQUAL initiative is a recent programme in United Kingdom, to encourage the embracing of a broader perspective in order to better know the lives and needs of elderly people and trying to extend Quality of Life (Lansley, 2006). The project was interdisciplinary with architects and engineers working with medical, health and social scientists. The project also collaborated with service providers from health and social care. Their focus had a strong user focus with involvement of elderly people in research and one of the aims were to encourage a greater interest in the

needs of elderly people among a broader range of researchers. Their results show that an interdisciplinary approach is required and their research findings have been influencing the development of a national policy (Lansley, 2006).

Another example of research where elderly persons' needs and experiences, in relation to healthcare services, are put in focus is the research of Nolan et al. (2006). In their work on 'relationship-centred care', Nolan et al (2006) highlight that in the best and most enriched care environments, older patients, their relatives and staff all experience what are known as the 'six senses'. These are described as;

- A sense of security – to feel safe and receive or deliver competent and sensitive care.
- A sense of continuity – recognition of biography, using the past to make sense of the present, and help to plan the future; working within a consistent team using an agreed philosophy of care.
- A sense of belonging – having opportunities to form meaningful relationships and to feel part of the community of the home, whether as a resident or staff member.
- A sense of purpose – to have opportunities to engage in purposeful activity, or to have a clear set of goals to aim for.
- A sense of fulfilment – to achieve meaningful or valued goals and to feel satisfied with one's efforts.
- A sense of significance – to feel that you, and what you do, matter, and that you are valued as a person of worth.

(Nolan, Davies & Brown, 2006; Nolan et al, 2006).

Can the use of 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.).

Sweden has a high percentage of technology and computer literacy regardless of age (PTS-ER 2006:1). Among 16- to 75-year-old Swedes, the usage of mobile phones is 92%, 83% are using computers and 75% have access to the Internet. In the ages 61-75, the usage of mobile phones is 19.6%, 13.5% have computers at home and 12 % have access to the Internet. Of these 6.7% use the Internet daily (ibid.). Research focusing on ICT solutions for the development of care and services 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. Numerous studies have reported high rates of satisfaction with telecare, telemonitoring and telephone contacts among elderly participants (Onor et al, 2008; Magnusson et al, 2003; Sävenstedt, 2004). The assistive devices that are already in use or under development range from low-tech devices (e.g. telephone) that assist with daily life tasks to more complex remote control systems and mobility devices.

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, 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 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 persons 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, were of a different opinion and found the positioning to be an ethical dilemma (ibid.).

Design and development of products were parts of the objectives in all e-health projects that I have been participating in. Participatory design methods as Participatory Design (PD) and techniques were used as design approach. In the MobiHealth project the end-users³ were involved in the development and testing of the MobiHealth system and the system also functioned as a decision-support for caregivers (Melander Wikman, Jansson et al, 2007; Jansson, 2007). In the eHHC project enhanced patient or client empowerment was an expected outcome of the project. By mapping the needs of elderly people in the North Calotte region when it comes to home health care and rehabilitation and by developing and testing mobile technical solutions where information could be exchanged, home health care professionals and patients/clients together, with their next of kin, would get more empowered and increased competence (Jansson, 2007). In the Swedish trial different participatory activities were used to map the needs and to make participation from different stakeholders possible; future workshops, reflective learning workshops, focus group interviews, individual interviews and observations (ibid.) The future workshops was conducted together with all care assistants working in the specific district, following the five phases suggested by Bødker, Kensing & Simonsen (2004), 1) preparation 2) critique 3) fantasy 4) implementation and 5) follow-up. The reflective learning workshop (described later in Paper IV) was conducted with handling officers and work leaders in homecare at the city of Luleå.

³ As end-users, both professionals and elderly test persons are included, although my focus in research has been listening to the elderly persons' voice.

RESEARCH APPROACH

In this chapter I will present the participatory style that has been the research approach that I have adopted. The development from Action Research to Participatory and Appreciative Action Research via Participatory Action Research in my different studies will be outlined. Thereafter the use of constructive Grounded Theory as an approach and the search for subjectivity in my research will be described. I end by describing the research context.

I chose a qualitative approach to answer the 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 rehabilitation research (Öhman, 2005). There are different processes in the qualitative research paradigm and each one offers a “toolbox”, providing the researcher with a set of values, concepts and methods to be used when selecting appropriate data and to elucidate the analysis (Silverman, 2001).

Participatory Inquiry

During the work with this thesis, I have had the opportunity to be engaged in several projects within the context of e-health namely the MobiHealth Project, The Mobile Safety Alarm Project, The e-Home Health Care (eHHC) Project and the MyHealth@Age project. All projects had/have the objectives of developing products and improving services built on modern Information and Communication Technology (ICT) within health and home care. All projects were/are examples of applied research and therefore had/have an action research (AR) approach, meaning that the research built on problems/needs that were experienced by staff or elderly persons in elderly homecare (cf. Winter & Munn-Giddings, 2001). This approach also means that the results of research within the projects, were communicated back to staff and technicians, following the action research circle enabling all participants to follow the stages of reflecting, planning, acting and observing, or fact-finding about the result of the action (ibid.). Another way of putting this is making the research process *transparent* to all and upon further reflection, new and improved plans emerge.

The objectives of the studies described in Papers II, III and IV were to promote changes that improve the human condition (as Hollingsworth (1997) writes about). The aim of Paper III 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 municipality's board of elderly representatives was a speaking partner parallel to the project work. 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. 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 III, 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). In the eHHC project focus was on developing, testing, refining and evaluating an automatic planning system and a handheld mobile computer. The integration of the two devices had the objectives of enabling planning of homecare work to be more effective and to reduce travel time for home care assistance and give clients a better service (Jansson, 2007).

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 and rehabilitation 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. Participatory inquiry also has deep roots in education and John Dewey's (1929) ideas on an educational system where teachers and learners collaborate as co-investigators (Thesen & Kuzel, 1999). In Paper IV, the staff members who participated in the workshops were active in the research in the sense that the results were returned to them as feed-back and that 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 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). Lewin (1946; 1948) is often seen as the originator of AR and in his original conception of AR it was a form of collective, self-reflective enquiry, undertaken by participants in social situations in order to improve their own social practice and the situation these practices were carried out. 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.

PAR can be called the 2nd generation action research and takes a participatory worldview (Ghaye, 2008). Both AR and PAR are oriented toward reform rather than just being descriptive or meaning oriented and are examples of critical/ecological inquiry (Crabtree & Miller, 1999). 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. I find approaches with participatory inquiry appropriate in health science work because this research approach is more closely linked to practice and can be readily undertaken by practitioners and service users as it emphasises the value of the experiential knowledge of both groups. With participatory inquiry stakeholders are invited into the process as thinking and feeling human beings with real influence on the process and not only as objects to be studied (c.f. Thesen & Kuzel, 1999).

Participatory and Appreciative 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 find it very easy to get into “the soul” of action research (AR) 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 (PAR) as a good way to get an answer to my research questions on patients’/clients’ dimensions of empowerment as influence, autonomy 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). Later appreciation was added, as knowledge from Appreciative Inquiry (AI) shows that a focus on strengths (which is the core of rehabilitation) is a better way for development and service

improvement, and Participatory and Appreciative Action Research was developed (Ghaye, 2008). This development from AR to PAAR via PAR has to be described here together with the experiences from using this approach in the different papers.

The quality in an action research project is that people that are involved will get empowered and energized by being part of the project. Quality is also if the participants, as a result of growing critical consciousness, can develop new useful reflective insights that can help them in their improvement of their work (Reason & Bradbury, 2001). During the following projects, this approach of AR developed to become more participative, using a Participative Action Research (PAR) approach, meaning that people in the organisation under study actively participate with the professional researchers throughout the research process and also discuss the action implications (cf. Whyte, 1991) and appreciations (cf. Cooperrider & Whitney, 2005). So in the latest two projects (described in Paper II and IV) a Participatory and Appreciative Action Research (PAAR) approach was used meaning that instead of looking for what problems are to be solved, we focused on what we wanted more of. On what strengths and successes we could build. The improvements here required us to have an appreciation of aspects of “the positive present” (cf. Ghaye, 2008). It is the use of appreciative intelligence that distinguishes PAAR from PAR, meaning that is about our ability to reframe a given situation so that we can ‘see’ what the positive parts of the present actually are and to understand how they have come to be that way. This is crucial. If we fail to understand the root causes of success, we may never be able to amplify or repeat success in the future (Ghaye & Melander Wikman, In manuscript). So the essence of the PAAR process is about recognising the positive possibilities embedded in the current situation and taking the necessary action to positively engage with others, so that valued outcomes unfold from the generative aspects of the current situation (ibid.).

Towards a creative synthesis?

Participatory and Appreciative Action Research (PAAR) can be regarded as a kind of 3rd generation of action research and builds on both AR and PAR. Arguably it can be said to be even more appropriate to research in health and social care and rehabilitation (Ghaye, 2007; Ghaye & Melander Wikman in manuscript). In our conception of PAAR there is a focus on ‘we’ and on the idea of relationships and this requires users of PAAR to draw upon their social intelligence. Central are the processes of collective working and appreciative knowledge sharing. In Paper IV an appreciative approach to empowering elderly people in home health care was developed and justified by having a two day workshop with a group of front line staff in elderly care

in northern Sweden. The staff members who participated in the workshops, in the study described in Paper IV, 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 is really about establishing inquiry processes that are specially intended to be “empowering” for those who are involved in the inquiry. In Paper III, 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. The participating elderly persons were engaged in giving their view upon how the design should be to fulfil their needs and were active shapers of knowledge that was used by the technicians, just inline with the ideas of PAAR. In Paper IV 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).

Constructive 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 methodology 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 retains the fluidity and open-ended character of pragmatism and 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. 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 (ibid.). 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 “the basic social process” or the “core category” (Glaser, 2001). The goal is to discover the participants’ main concern and how they are continually working on it (cf. Thulesius, 2003). 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 and the question that you as researcher keep on asking yourself is “*What is going on?*”. The researcher must lift the veils that obscure or hide what is going on (ibid.). However, these strict rules on how to conduct GT “the best way” gradually made me feel insecure about how to act, so I left this approach in Paper III and used Latent Content Analysis instead. This method is described under section Participants, data collection methods and methods of analysis. In Paper II and IV, more social constructivist grounded theory was used, inspired by Charmaz (2000; 2006).

Constructed Grounded Theory takes one step forward from typical Grounded Theory practice and its pragmatic foundation and tries to make “everyone’s vantage points and their implications explicit – yours as well as your various participants” (Charmaz, 2006 p.184). I wanted to learn and interpret nuances of action and meaning and at the same time become aware the interactive and emergent nature of my data and analysis and as Charmaz (2006) describes, be encouraged to construct an *interpretive rendering* of the world I want to study, instead of reporting events and statements from outside. The objectivist grounded theory approach where the researcher takes the role of a neutral observer who remains separate from the research participant was not attractive to me after having learned more about

participatory action research. Therefore Charmaz' (2006) more constructivist grounded theory, with the perspective of constructivism where the researcher together with the research persons construct the realities they participate in, where more appealing and suited my research questions. The constructivist inquiry is starting by experiences and then questioning how all associates are constructing them (cf. Charmaz, 2006). With the interpretivist philosophy it is important to recognize that enquiry always is context bound and that all data should be viewed both as theory- and value laden and that knowledge is seen as actively and socially constructed (Goulding, 1998). This made me reflect on my own personal paradigm or basic belief system. The use of *memo-writing* and *story maps* (based on each research person's own story) as methods in order to early in the research process analyze data and try to develop codes into categories helped me. Memoing helps the process of conceptualizing. I used notebooks to put down thoughts and reflective accounts and later I also used these memos as a way to discover my own subjectivity.

In search of subjectivity

It is a common comprehension that science should, or at least ought to be, objective (Bergström, 1972). Through what looks like data, facts and impressions of "reality" you can get a useful base for conclusions that are based on empery and then further on you can make generalisations and build theory (Alvesson & Sköldberg, 1994). But what does objectivity mean? The critique towards this view upon science is that it is not possible to separate "the knowledge from the knower" (Alvesson & Sköldberg, 1994 citing Steedman 1991:53) and that facts/data are constructions or interpretations. Bergström (1972) discusses eight different terms that can be connected to objectivity; "value freedom", "unprejudiced", "consciousness and openness", "versatility", "value objectivity", "impartiality", "methodological objectivity" and "inter-subjectivity". Bergström (1972) cites Popper who said that "*science and scientific objectivity is not (and can not be) the result of one individual scientist's attempt to be objective, but the cooperation between several scientists*". This means that we are all subjected to our own prejudices.

Alan Peshkin (1988) cites Cheater (1987) who wrote: "*We cannot rid ourselves of this subjectivity, nor should we wish to; but we ought, perhaps to pay it very much more attention.... (p.172)*". With this citation he wants to put our attention on that it is not just enough to acknowledge or assert subjectivity as an invariable component of research (Peshkin, 1988). You must do more than this. You as a researcher have to be aware of *how* your subjectivity is forming the results and the inquiry. This search for subjectivity should, according to Peshkin (1988; 2001), be done all the time, during all stages of the research process and

not only in the end after all data has been collected and analysed. He means that by putting yourself in the centre of attention and observing yourself, you will learn what special personal qualities that the contact with the research phenomena has freed (ibid.). By selecting one category at a time and putting your attention on this as a basis for your perceptions, you can take away focus from other things that are competing for your attention (Peshkin, 2001). He means that the richness of our perceptions expands as the awareness of categories expands. In my research I have become increasingly aware of the importance of understanding my own subjectivity and how this has influenced what I have felt, thought and done.

When it comes to trustworthiness, qualitative studies have to be judged against criteria that are especially developed within the qualitative paradigm (Bradbury-Jones, 2007). This kind of research is common within health research and the qualitative health researchers must find both frameworks for achieving rigour in the research as well as make their own influence on the research process explicit (ibid.). Bradbury-Jones (2007) suggests an approach that will encourage health care researchers' cognisance of their ontological basis of research as well as their particular philosophical position and that this positioning and clarity making is a way to secure and demonstrate rigour.

I find it important to clarify my own subjectivity in the research described in this thesis. A way to capture my subjectivity in the research was to look back at field notes that I collected in close connection to the interviews for Paper I, II and III, so called Contact summary sheet (cf. Miles & Huberman, 1994) and memo-writings in connection to Paper I, II, III and IV (cf. Charmaz, 2006). I also looked back at all kinds of notes that I have been making in relation to my research process, written in notebooks, only used for this purpose. Some notes were dated like journal notes, others were just undated reflections. I also reflected on the research process by reading some of the e-mail correspondence with my supervisors and reflecting upon the content of our face-to-face conversations. All these data made it possible to recall and reflect back upon different stages of the research process. In the analysis and writing of Paper II, the cognisance of my subjectivity has influenced my work and a more reflexive journal has been used as data. I found it important to explain how we make judgments about the quality of our work as researchers in a) our actions and those with others, b) our research into these actions, and c) our communication of what we are doing e.g. research papers.

The research context

Using memo-writing and field notes were particularly important for me as I made my research in the context of several e-health projects. It helped me to

sort things out and to reflect upon the importance of the 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. In choosing PAR, and later PAAR, as a research approach for Papers II, III and IV the context of home care was already there. Staff members from the municipality's elderly care system were already partners in the e-health projects. This made it easy to gain access to home health care and rehabilitation and also to get accepted. The research questions were grounded in practice. It is necessary to explain the potential and problems of doing research in industry driven development projects. Let me begin with the potential. The research was performed in a team of interdisciplinary people: researchers, technicians and professionals from practice, in this case the municipality's elderly care. This is often called an iterative Triple Helix method. The project approach was strongly dynamic in itself as the projects had a given start and end. The projects also had a result-oriented focus, with deadlines for prototype development, so things moved very fast. 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.

In eHHC we distinguished between two levels in the reasoning about patient empowerment in ICT-based health services (Holthe 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 on 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 et al, 2005). This means that the eHHC project had an approach according to 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 and rehabilitation.

The empirical data from Paper II were collected within the eHHC project. It was important to listen to the elderly persons’ own voices on what need and preferences they had concerning services and also how they experienced living at home with homecare and a safety alarm in relation to dimensions like mobility, self-determination, participation, in the society but also in decision-making regarding their own care and rehabilitation. Before the interviews were conducted a questionnaire, created in a participatory and collaborative way by all researchers in the eHHC project, was sent to elderly persons and their next of kin at the different project sites. Unfortunately the response rate was low, but the results from the survey were still used as guidance for the interviews that were conducted later in the project.

Paper IV was 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. 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.).

Using critical friends

It is important that the researchers have contact with some “critical friends” who help them learn through reflection and also with validity claims, if necessary. Winter & 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 (Winter & Munn-Giddings, 2001, 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 e-health projects together with others is another given forum for discussions and possibilities for reflection. My co-authors in all four papers have all been very good critical friends. Paper II and IV were particularly collaborative projects with lots of creative discussions and reflections. The writing process was also a collaborative one.

Another example of an activity using critical friends was a workshop in which senior researchers from different disciplines and subjects were invited to share their experiences and offer their comments on my work with the cover paper of my licentiate thesis (Melander Wikman, 2007). This workshop gave me the knowledge about constructiveness and how a different ontology can give different structure and layout in writing and enabled me to feel free to write a cover paper that illustrated my own research process. The cover paper of this thesis was also “put under pressure” at a seminar at the department of Health Science at Luleå University of Technology, to which I am affiliated, where research students, teachers and senior researchers gave their view and suggestions for improvement. I agree with Kemmis (2008) who argues that enlightenment is best understood as a social process, drawing on the critical capacities of groups. Together people can open up communicative spaces that permit and foster collective reflection. I also learnt that there were some basic inter-personal prerequisites if this kind of appreciative knowledge sharing, amongst ‘critical friends’ was to be an enabling and empowering one. One prerequisite was that those involved could demonstrate active listening. Another was that participants could suspend personal judgement and preference and focus more on listening in order to try to understand why particular research decisions and conclusions were articulated. A fundamental one was some shared understanding of what ‘being critical’ meant. It was important to move past the negative connotations of the word ‘critical’ and towards a re-positioning of the critical within the creative. This of course involves aspects of ‘power’ within the process of ‘empowerment’. This repositioning enables all involved, and especially me, to appreciate that there is always a need to stay open to constructive critique and a need to put my ideas ‘under pressure’. If the

critique is constructive and well meant, then new ideas, options and alternative ways of conducting and writing about research become possible. The challenge is finding good critical friends.

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 I.

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

Paper No	Participants	Data collection methods	Methods of analysis
I	6 patients	Interviews	Grounded Theory(GT)
II	10 elderly individuals	Reflective interviews	Constructivist Grounded Theory
III	9 elderly individuals	Intervention study with interviews	Latent Content Analysis
IV	35 frontline staff in home care	Reflective learning workshops	Constructivist Grounded Theory

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. Each interview 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 Reflective and constructive Interview study

The method of purposive sample was used also in Paper II. Ten individuals were selected to be the participants of this study. The participants were from 63 to 89 years of age. The inclusion criteria were that they should all have homecare services and a safety alarm. Eight of the informants were living alone and the other two were living with their spouse who also needed homecare. Six of the informants were widows and two were divorced. They were all research persons in the eHHC project, described above, and before they had got a questionnaire with questions about how they experienced home healthcare and what needs they had when it came to information and communication from/with health and homecare. This inquiry was part of the need finding process in the eHHC project. Unfortunately the respond rate was to low (11 out of 90) to be representative.

The recruiting and interviews were conducted at two different times, in June and in October 2005. The knowledge from a first analysis of the first interviews was used in the later interviews. Information about the eHHC project and the aim of the interviews were presented at three different situations; 1) by the recruiting social worker 2) in phone calls when the time for the interview was scheduled 3) a written information sheet about the project that I brought to the interviews and left there so that the participants also could show their relatives, children etc. Information was also shared during the interview. All of the participants signed an informed consent document.

The interviews were reflective and constructive in the meaning that the interview was seen as a conversation where I as a researcher was reflecting upon my role and appreciating the interview as a kind of relationship between

me and the participating research persons and as a speech act that could either succeed or fail. Citing Habermas (1976),

“To be understood in a given situation, every utterance must, at least implicitly, establish and bring to expressions ascertain relation between speaker and his counterpart”. “In a certain way, every explicitly performative utterance both establishes and represents an interpersonal relation” (Habermas, 1976, p.34).

Paper III - The intervention study

A purposive sample of nine individuals was 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 the elderly 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 helps to obtain a better understanding of how people experience their lives through their stories.

Paper IV -The Reflective learning workshops

The aim of Paper IV 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 and rehabilitation in northern Sweden. In Paper IV 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 IV were drawn from two days of reflective learning workshop activities with 35 frontline 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 IV). 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 of Paper IV 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 front 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, 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 the first analysed findings from Paper II. 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 (cf. Brown & Swartz, 1989). 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 of 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 the 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 of 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. We 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 addition to concurrent data collection, coding and analysis, one of the major characteristics of grounded theory is hierarchical coding processes, meaning that initial or open coding is followed by focused or selective coding (Hallberg, 2006). As proposed by Charmaz (2006), when there is more than one researcher involved, which was the case in Paper II, they may code data separately and then compare and combine their codes. When engaged in such open coding, this is precisely what we did, and the discussions later formed the basis for the next step; that of focused coding, which means that we used the most significant codes when again returning to data. At this stage, we began to see the contours of a core category as well as a number of possible categories and subcategories (Strauss & Corbin, 1990; 1998). Applying a constructivist approach, at the last stage when looking for relationships between these categories, we all three authors were inspired by the theoretical coding suggested by Charmaz (2006). Additionally, when ordering the data of this study, it became clear that it was necessary to integrate structure and process and in order to code for actions and processes, we were inspired by Charmaz (2006) who writes; “... *I have developed subcategories of a category and showed the links between them as I learned about the experiences the categories represent. The subsequent categories, subcategories, and links reflect how I made sense of the data*” (2006, p. 61). This means that the last coding procedure was inspired by the theoretical coding suggested by Charmaz (2006).

Paper III

In Paper III, 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). Instead the interviews with the participants in Paper III 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 IV

The analysis of Paper IV was made in a structured reflective process by all three researchers/authors together. After each session in the workshop all three researchers/authors co-constructed 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; 2006). 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 workshops the participants and we as researchers 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- Patient empowerment and rehabilitation- a parallel process

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 respectively “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 a 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 were 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 said they 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 on 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 us 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- Ageing well or Learning Unpretentiousness - a living contradiction

The core category of Paper II was identified as *Ageing well or learning unpretentiousness?*, formed in response to structural aspects, such as the fact that the respondents, often as a result of illness or accident become subject to hospital care and later home care. This was experienced with mixed feelings or contradictions: dependence and independence, alone and sometimes lonely,

feeling safe, but also unsafe, all of these ways of coping and adapting to situations connected with growing/being old. It was not experienced as a straight (downhill) road but rather was characterized by strategies employed by the elderly individuals to deal with their situation to, on the one hand, try to remain the same person as before and on the other hand, adjust to the new situation, to ageing and becoming dependent on services and support. This duality or dichotomy of the process of *learning unpretentiousness* was illustrated by the sometimes contradictory elements of categories and subcategories. The core category was constituted by four categories: *Social networking*, *Psychosocial wellbeing*, *Physical capacity* and *Empowerment*. The subcategories show the contradictive experiences; *Being alone/lonely*, *(Dis)connecting*, *Being (in)active*; *Focusing on here and now/the future*, *(Re)constructions of reality*, *Being (dis)content*, *Feeling (un)safe*; *Being (im)mobile*, *Reflecting on/for capability*; *Feeling (in)dependant*, *Being in(out) of control*, *(Dis)using assistant technology* (see Table I in Paper II) . The categories were formed in response to how the participants were experiencing life with more limited functions in strength and balance and being less able to manage their daily activities. The categories were not mutually exclusive nor fully 'saturated'. In formulating the categories we were uplifted by the Heideggerian (1992; 1996) principle of a 'lack in completeness of being'. This is explicated by Schatzki et al (2001) when they talk about objects of knowledge having the capacity of unfolding infinitely. They state that objects of knowledge,

“..... are more like open drawers filled with folders extending indefinitely into the depth of the dark closet. Since epistemic objects are always in the process of being materially defined, they continually acquire new properties and change the ones they have. But this also means that objects of knowledge can never be fully attained, that they are, if you wish, never quite themselves” (Schatzki, 2001 p. 181).

The participants' experiences were not static but situated and important to understand. The elderly participants expressed feelings that could be viewed as *apparent contradictions* and also that the experience of ageing is not homogeneous. Any one participant could express *both positive feelings and anxieties* and describe their current situation in *both a contented way* but also a manner that expressed *a longing for something different* e.g. they were content with being at their home, indoor but at the same time longed for being outdoor walking. The subcategory *Feeling (in)dependant* helped make the notion of inter-dependency more visible. In essence it reveals links between the participants themselves, their care assistants and the nature of services on the one hand, and between personal needs/wants and the working lives of homecare staff, on the other. The elderly participants' strategy was what in Swedish is called, '*Gilla läget*' or *getting the best out of the situation*.

Paper III- Safety and mobility is more important than privacy

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 IV- Appreciating practice and the practical

In this paper, findings from a two-day workshop together with front line staff in home care were described. During the reflective workshops the staff reflected upon how Olga’s (see Olga’s story in Paper IV) 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 significant 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 significant 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 significant 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. We also learned that experiences situated within practice needed to be acknowledged, appreciated and used in a knowledge construction process. The catalyst for this was systematic and collaborative reflection-on-action.

A SUMMARY OF THE MAIN FINDINGS

The findings and understandings are shown in Table II below. One of the overall findings is that all patients/clients that participated in these studies had not reflected upon whether it would be possible or not, to influence care and rehabilitation. In Paper I the results indicate low patient participation in and influence on, the rehabilitation process. In Paper III elderly people perceived freedom of movement as a prerequisite for participation and in Paper II the elderly participants felt that they could influence care and be participating in one aspect but they still wanted more support with, for example, being more physically active, like walking out door. The overall findings show a genuine patient/client desire, but limited possibilities to influence care and rehabilitation. Put another way, patients/clients want to have influence and participate authentically, but they do not exactly know how to achieve this.

All patients/clients were positive towards the professionals in care and rehabilitation. They really were grateful and admired the professionals and also identified themselves with how stressed and how overloaded with work the professionals were. The patients/clients tried to be compliant and in Paper II this is called “learning unpretentiousness”. After reflecting upon their situation they were more able to articulate their needs that were not responded to or taken care of.

Freedom of movement is one essential need that was expressed in Paper I, II and III. Safety and security was also expressed as important. The participants in Paper III 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 one focused upon a safety culture with increased risk awareness (cf. Cooper, 2000).

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. The fear of falling, but also the perceived risk of being attacked, prevents elderly people being mobile and active. They are aware of the relationship between being physically active and muscle strength and fitness, but need to be supported to be more active.

The findings also show that the elderly persons long for more social relations and comfort and they have ideas of their own how these needs could be met or supported. They are both fascinated by and positive towards new technology and think that it can help and at the same time some are sceptical about their ability to handle it or if it will be too expensive. The front line staff that participated in Paper IV showed how important it is to listen to the clients' voices and that they were positive towards clients' participation in decision making. Having expressed this they also said that they felt this might be easier said than done.

Table II. A summary of the main findings presented as categories and major understandings in the four different papers.

	Subcategories	Main categories	Major understandings
I	Compliance Subordinance The invisible physiotherapist Being confirmed Searching for information Sense of coherence Daring to demand	The traditional medical model The individual model	The parallel process of rehabilitation
II	Being alone/lonely (Dis)connecting Being (in)active Focusing on here and now/ the future (Re)constructions of reality Being dis)content Feeling (un)safe Being (in)mobile Reflecting on (in)capability Feeling (in)dependent Being in(out) of control (Dis)using assistant technology	Social networking Psychosocial wellbeing Physical capacity Empowerment	Ageing well or learning unpretentiousness?
III	Fear of falling Fear of violence Fear of not being capable to take care of one self Someone at the other end Freedom of movement Able to do what you like Nothing to be ashamed of Living in a “society of surveillance” Participating in development and design Acceptance and fascination	Feeling safe Being mobile Being positioned and supervised Reflecting on new technology	Safety and mobility is more important than privacy
IV	Reflection 1 ‘Olga did not feel in control of what was happening’ Reflection 2 ‘They said her bed had to go. Olga felt out of control’ Reflection 3 ‘The man came to fit the safety alarm. Olga felt powerless to say no’	Client participation Empowerment The use of ICT	Appreciating practice and the practical

DISCUSSION

The overall aim of this doctoral thesis is to explore different dimensions of empowerment and empowerment methodology for elderly persons in home health care and rehabilitation and how mobile ICT can support this. The findings from the four papers together with my experience from participating in research projects within e-health and research seminars, have led to methodological, ethical, theoretical and practical lessons learned. In this chapter I discuss the lessons learned from these four perspectives.

Perspective 1: Methodological understandings

First I want to start with a discussion of my own subjectivity and how the awareness of my subjectivity has shaped the inquiry process and its outcomes. Thereafter I will present some of my validity claims for example those associated with trustworthiness. I continue by discussing my grounded understandings from working with participatory inquiry methodology which leads to a discussion about how to include both individual and societal dimensions in a conceptualization of quality of life for elderly people.

Discovering and understanding my ‘subjective I’s’

I think that in research of the kind that I have been undertaking, it is imperative that I understand the nature of my own subjectivity. I found Peshkin’s (1988; 2001) arguments with regard to researchers systematically seeking out their own subjectivity, very helpful. As described in the chapter ‘In search of subjectivity’ I have gone back retrospectively to my own diary-notes and field notes from the work with Paper I, III and IV and made reflections upon my own subjectivity. In the work with Paper II, I have been working with my subjectivity while the analysis was actively in progress as Peshkin (1988) actually suggests. From the above mentioned data and reflections I want to discuss four subjective I’s that emerged during the inductive analysis process in which I have been involved (cf. Bradbury-Jones 2007, Peshkin 1988; 2001). The four I’s that emerged were ‘**The Democratic I**’, ‘**The Freedom-loving I**’, ‘**The Open-minded I**’, and ‘**The Emotional I**’. In my categorisation I have connected my subjective I’s to empowerment dimensions like participation, influence, self-determination and freedom of movement, which thread their way through my research. Together they will be discussed with Bergström’s (1972) interpretations of objectivity within research, as an activity, and objectivity within research, as a product.

‘The Democratic I’ vs. participation and influence.

‘The Democratic I’ emerged from the fact that, at the start of the research process, I had already formulated research questions that had to do with influence, participation, information enough for decision making and what needs elderly people have in relation to those dimensions (Paper I, II and IV). According to Pershkin (2001) the research procedure is, and he cites Burgess (1982 p.2) “*always...infused with ideologically resonant assumptions*” and by searching for the subjectivity the researcher can, discover what orientation s(he) will bring to the inquiry. Richard Chambers’ (1997) expression “*putting myself last*” felt natural to me, having the perspective of the patient/client. Freire’s (1972) theories about conscious making have also inspired me in my work with rehabilitation. One’s ideological loyalties always lie somewhere and Pershkin (2001) means that we might not, as researchers, make these explicit for ourselves or to others. In my research I think these loyalties influenced by ‘My Democratic I’, and helped create an atmosphere, in the interview situation based on, that I was on the informant’s side. I felt this enabled them to open up and talk about situations, when they had not been listened to or confirmed by health care professionals. This also might have made the interview situation a kind of conscious making process, because in Paper I, the result showed that the participants would act in a different way when it came to exert influence and participation in the rehabilitation process if something would happen to them again in the future. They had not thought of the right or possibility to exert influence in the rehabilitation process. Did ‘My Democratic I’ bring the informants to this consciousness? Or did ‘My Democratic I’ interpret this result? In this first paper we were inspired by Grounded Theory (Glaser & Strauss, 1967) and we, the authors, in order to be close to the informants’ subjective I’s, questioned ourselves during the analysis “How far are our results grounded in the data?”. Looking upon my research as a product (Bergström, 1972), my own interpretation is that this was their subjective feeling and a result of the reflective way the interviews were conducted. Bergström (1972) also means that results from research within social science, should not be value free, since the aim of this kind of research is to bring solutions to problems that are connected to values. I think this can also be the aim of qualitative research within Health Science that the results do not need to be value free and as so, no criteria for objectivity are required. Looking upon my research as an activity (cf. Bergström, 1972), my ‘Democratic I’ is a result of my values. My actions and judgements in different phases of my research, as well as in my rehabilitation work, are all guided by values and they are indicators of what is held in esteem (cf. Curtis, 1998). Also Bergström (1972) means that the choice of research area can never be value free, that this fact affects all stages in the research process like choice of concepts, definitions, methods etc. and that this is seldom questioned in the

literature of Theory of Sciences. Peshkin (2001) uses the metaphor that our sense of research purpose acts like traffic cops, that tells us to pass right on, stay behind somewhere, call for us to stop or direct us in what way to go. I have learnt that my personal and professional values make me the kind of person that I am. They influence my thinking and my actions. My values act as reasons why I do the things I do. Although my values are sometimes hard to articulate, and at times hard to put into action, for many reasons, they have been, undeniably, a big influence on my inquiry process.

‘The Freedom loving I’ vs. freedom of movement and autonomy.

Once again the research questions mirror this ‘Freedom Loving I’. Empowerment and freedom of movement were connected to each other since my interview guides in Paper II and III had questions like ”How mobile are you?, Can you walk outdoor?, Do you visit friends and family?, Do you travel?, How do you define freedom of movement? This focus on freedom of movement and mobility can be a result from ‘My Freedom Loving I’. It can also be a result of my experience of being a physiotherapist working with rehabilitation for more than 20 years. It is definitely a part of my pre-understanding but does it enable me to give voice to the informants own subjective experience? The result from Paper II shows that the informants longed for being more mobile and having the possibility to move around more, do walks, travel, visit friends and relatives etc. Did I influence them indirectly by my questions around how mobile they were and about how they defined freedom of movement? Looking at my research as a product, I mean that the result is close to empery, it is the informants’ subjective voices. Bergström (1972) states that truth can be defined according to the theory of correspondence and this means that truth is what are corresponding to reality. Bergström (1972) writes about how you as a researcher have to liberate yourself from the prejudices that come from the influence of traditions and environmental factors. He also means that if a researcher would question everything, then it would not be possible to get to any results. Looking at my research as an activity, ‘My Freedom loving I’ and the fact that I have been working as a physiotherapist and with all my knowledge about the importance of being physically active when it comes to health, of course has influenced my research questions and my themes at the interview. As Pershkin (2001) writes, you can choose to take a theme (as in my case Freedom of movement) and “*hold it up, so to speak, before your eyes and ears, and consciously follow the play, the elaboration, the elucidation ...*” (p.246) of the concept because when doing so you deliberately shut off other perceptual possibilities so that you can better concentrate on what could be learned from this special focal point.

‘The Open-minded I’ vs. support for decision making.

This ‘subjective I’, I see as essential when looking for the informants own subjectivities. In all communication I find it important to be open-minded and to listen carefully. This also puts demand on you as a sender of information, to speak out clearly. It is an interactive process. According to Kvale (1997), as a researcher, one has a responsibility to establish a good relationship with the interviewee. I think again that my former experiences and pre-understanding with long experience of working together with people, guiding them in their rehabilitation, I am used to communication and information on different levels and under different circumstances. Working with rehabilitation also puts a demand on you to “read between the lines” and to be able to interpret and ‘read patients. For example, if a therapy is painful although the patient says it is fine. This I think created a trustful atmosphere and made the informants speak but also daring to ask me questions. I tried to be open and sensitive to their needs and open to their questions. In Paper II the informants saw me as someone with knowledge about rehabilitation, information, technology and issues about homecare and therefore asked me questions. I found it ethically right to answer them and inform them about facts that were familiar to me even if this as an activity might have influenced my research. This reminded me very much of the fuzzy boundaries between my different I’s in my research. During the interviews I sought to see to that the informants had got everything right when it came to technology in their home. One example was when I asked a woman, in Paper III, about how she experienced safety. When it came to using her safety alarm, the woman answered that she had not yet tried it outdoors, but she intended to do that the next day. As I then understood that she had got it all wrong and that she did not understand or remember that the safety alarm she was using did not function outdoors, I felt that I had to tell her that so that she did not take any risks. About reading between the lines and perceiving what is there before us as researchers, Pershkin (2001) writes about “*the lens of silence*” that requires us to listen to the silence, the unspoken words, to get to know about both successes and failures.

During one of the interviews in Paper II, I noticed that the informant had problems walking indoors, most of all because she was using her late husband’s rollator that did not fit. I struggled with my two identities, that of the researcher and that of the physiotherapist, and I had to tell her at the end of the interview: “*As I used to work as a physiotherapist, I can not help but noticing that your rollator does not fit. Is it OK with you if I adjust it to the right size?*” Other interview situations, where ‘My Open-minded I’ was engaged, were when the research persons needed my help and asked me to take care of their laundry because the women could not manage by themselves and took the chance to ask me instead. Or the woman who wanted me to post an urgent

letter before we started the interview because it would have taken too long, waiting for the care assistants to come and help her.

Bergström (1972) used the concepts of “consciousness” and “openness”. These are closely linked together. Openness can be taken to mean that you as a researcher should openly account/present what values and prerequisites that are of importance for your research to be understood by others. Looking upon my research as an activity ‘My Open-minded’ I helps me see the importance of this and by accounting all my subjective Is, this is a way to deal with this openness. By consciousness I, as a researcher, am aware of the impact/influence my prerequisites and values have on my research (cf. Bergström, 1972). In all interviews in all papers (Paper I, II, III and IV) I have been open with the fact that I am a physiotherapist and about my function in the e-health projects. This has also made me give the informants information and facts about e.g. technology or about home care services and rehabilitation issues because the informants have asked me questions about this during the interviews. Looking again at my research as an activity, ‘My Open-minded I’ has made me open to working in multidisciplinary settings, research school *Arena Lifestyle, health and technology*, working in multidisciplinary e-health projects and collaborating with researchers from other disciplines. This has also made me open to other research approaches, other theories from other disciplines than my own, to explain my research findings and so also influenced my research as a result. Using Pershkin’s (2001) concept of positionality, ‘My Open-minded I’ hopefully helps me to take the role of others and to observe as though I was such persons.

‘My Emotional I’ vs. self-determination

Emotion can be defined as *‘that which sets the mind and judgement in motion’* (Burgi-Golub, 1997) meaning that it is a proper and necessary object for contemporary analysis and methodological enquiry because emotion is the elemental source of ethical judgement (ibid.). Emotions can in this aspect be seen as a dimension of moral motivation (Burgi-Golub, 1997). Compassion is one of the key elements in the philosophy of practice of physiotherapy together with competence and collaboration (Jensen et al, 1999). Compassion and empathy are emotional elements. But what impact can emotions have on research, both as an activity and as a result? Ehn & Löfgren (2004) cite research of Bloch (2002a:44) who interviewed researchers, teachers and doctoral students at different faculties about how they were coping with emotions like pride, joy, anger and shame. She found that emotions should be mastered when you are in the Academia. Here you must not show strong emotions, all you do and say must be carefully reflected upon, or otherwise you will be regarded as non-scholarly, odd or threatening. As a PhD student you have to develop strategies to cope with both shame and pride. You have

to cover the anxiety for failure as well as not be bragging over your successes. Ehn & Löfgren (2004) mean that this fear is destructive in the meaning that it takes away the joy of work and self-esteem and make people not to trust each other, not even yourself. This fear is not nourishing learning and research as an activity and might affect research as a product in the sense that it is hindering creativity and interpretations.

Data analysis in Paper II enabled the core category of “*Learning Unpretentiousness*” to emerge. This meant that elderly persons gave up their self-determination since they did not think they had the possibility to make any demands. Drawing on the concept “learned helplessness” which is connected to disempowerment, we found that we had to re-think the notion of helplessness because the informants did not speak about or show any helplessness. They expressed themselves as “*living contradictions*” saying for example, “*I want to walk. My body itches because I want to move so much*” and some minutes later: “*I am content, I do not need to be out walking. I can have the balcony door open and feel the summer breeze that way.*” Maybe ‘My Emotional I’ made the interpretation of living contradiction possible because I wanted them to protest and speak loudly about how important it was to them to be able to be outdoors, walking but with assistance? As Pershkin (1988) suggests my awareness of ‘My Emotional’ I was a warning to my self, not to get trapped in perceiving things because of my untamed sentiments. Discussions with my supervisors in the analysis work have also been more consciously conducted in Paper II and the hazards of overidentification have been better handled, a result of my intention to act in the informant’s/subject’s best interest at heart (cf. Pershkin, 1988). Another reason for interpreting this longing for being mobile could be my pre-understanding as experienced physiotherapist comparing the results with hundreds and hundreds of meetings with other patients with the same longing to be mobile, together with the knowledge of the importance of being physically active. All practical knowledge that is theorized as Theory of practice in Physiotherapy I find important to inform about as a choice, a solution to the needs and wishes of the informants. The subjectivity in research as an activity has been influenced by ‘My Emotional I’ in the sense that I have been listening to advice and supervision from persons that I trust, choosing to work with people that I feel comfortable with, listening to my “gut feeling” as the source of ethical judgement as far as possible (cf. Burgi-Golub, 1997). Bergström (1972) writes that objectivity can be defined as when a result is tested for inter-subjectivity, which means that the result is tested, confirmed or disconfirmed by other persons. How has this inter-subjectivity been influencing me when I, as a researcher, chose to work with people I feel comfortable with? How has it been influenced by ‘My Emotional I’? I agree with Alvesson & Sköldberg (1994) who argue that what decides the value of qualitative research is not

how different elements of work are handled technicality but the ability to handle the dimensions of interpretation on different levels. *“Good qualitative research is not a technical project, it is an intellectual.....Reflection, not following procedures, is in our meaning characterising the science in social science”* (p.369). I agree with this statement and think it is transferable to Health Science as well.

In the sections above, I have tried to explain the significance of my living and subjective I's in my research. I have also illustrated in Paper II the significance of the 'I' as a living contradiction for elderly people in my research. For me, my different subjective I's have not only served to interpret the worlds of the elderly people who have participated in my research. They have also been used to try to improve these personal worlds. When I use the term 'living contradiction' I am referring to it as embracing two mutually exclusive opposites. The experience of holding particular health care values and the experience of their negation. I can appreciate this now, both as a researcher and from the perspectives of the elderly people in my research. The importance of this is fundamental as health care is a value-laden, practical activity. Arguably we cannot say that a general process such as rehabilitation is in the best interests of the patient/client, without making a value judgement. So this leads me on to another question which is, 'How do we know that what a researcher says is true?' This is a question of validity.

Claiming validity, credibility and transferability

Habermas (1976) writes about four criteria of communicative validity in strengthening the validity and robustness of research and these are 1) the comprehensibility of the account, 2) appropriateness of the evidence that justifies the assertions/claims/conclusions that we make, 3) an explanation of our value based actions with regard to what constitutes an influence in and on a situation and 4) the authenticity of the account in the sense of showing that we are living the values we espouse. Here again I want to 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 IV 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 IV the reflective learning workshops functioned as an interactive forum and followed a PAAR approach. 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 IV was, together with the interviews in Paper II, as described above, two of many activities in the eHHC project and the whole project used a PAR and PAAR 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 wanted to plan and discuss design, actions taken and reflect. This can be experienced by the technical staff as the researchers slowing down the process. Involving elderly people in the design process might also be experienced as prolonging the development process. I agree with Jansson (2007) that in participatory design projects all stakeholders have diverse perspectives on participation and also different goals with participation. All stakeholders’ experiences are not always appreciated

because there are special logics depending on different backgrounds (ibid.). Thesen & Kuzel (1999) suggest six questions as checkpoints for whether or not research is participatory and one of them is (p.288): “*Who has real influence on the process?*” I think that PAAR is a good methodology to be used in research & development projects within the context of e-health where the objectives are to improve services for people. 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 IV 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, usefulness and objectivity of the project. However, my opinion is that, we as researchers were looked upon as “insiders” and this made the communication-process more open, compared with if this investigation had been carried out by outside experts. We were, as Winter & Munn- Giddings (2001) describe it, focused on the process and not just the outcomes.

It is important though that the project leadership is one who is understanding and appreciating the ground principles of PAAR. In Paper II and IV our ambitions to claim validity followed the suggestions by Habermas (1976) and his criteria of communicative validity mentioned above. This means that anyone acting communicatively must, in performing any speech action (i.e. writing a research paper) should a) utter something understandable, b) give (the hearer/reader) something to understand, c) make themselves thereby understandable and d) come to an understanding with another person, or reach an understanding with those (stakeholders) involved e.g. elderly people. In Paper IV we added to Habermas’ (1976) criteria *Appreciative* as described above.

Credibility can be achieved 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 discussed with a reference group of elderly persons and Paper III were presented to the Luleå municipality advisory board of representatives from pensioners' organization. Both actions aimed to search for *resonance*, which means to see if the analysis made sense to people who shared the similar circumstances (cf. Charmaz, 2006).

Paper I was inspired by grounded theory (GT) (Glaser & Strauss, 1967) and in Paper II and IV 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 II and IV a constructivist mode of grounded theory was used (cf. Charmaz, 2000; 2006). This means that data from Paper IV 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 according to Charmaz (2006) and I agree with this view.

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 seems to be agreement between findings in Paper III 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 III). This is supported by Tischler & Hobson (2005). Also the findings in Paper II, that activity and the possibility to be active is important for elderly people's positive self-image, are supported by research by Åberg (2003) According to some GT researchers (i.e. Goulding, 1998) transferability is not considered as

the responsibility of the investigator since the obtained knowledge is most influenced by the life situation and context of the individuals' and it is this variety of constructions of knowledge that the investigator is searching for. Lincoln & Guba (1985) suggest that the reader can make their own judgment of transferability if the research is described in detail and this has been my ambition in this thesis work. I agree with Misco (2007) and his notion 'grounded understandings' as "tentative apprehensions of the importance or significance of phenomena, which conceptualize the point of producing meaning and explanatory power." These grounded understandings can be used as lessons learned to be applied in the future in another context.

Perspective 2: Ethical understandings

In research, as in physiotherapy practices, *ethical considerations* are essential. For the studies reported in Papers I, II and III, 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, 1995). I agree to some extent with Veatch's (1995) 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 may 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 IV, 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 IV for permission to use the information and they all agreed, but it is of course impossible to know if all really did agree.

All papers were approved by the committee of research ethics at Umeå University (Dnr 99-034; Dnr 04-179M). 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 III, 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 this is counteracted by the fact that the test participants gain from being part of a development process, as they have the possibility to influence future technology. In Paper II the intervention in the eHHC-trial (a mobile planning system) was used by the home care staff and the elderly participants did not notice that the staff used new technology because the staff tried to avoid using the handheld device in the elderly participants’ homes because they wanted to be more present in the meeting with the old person (Melander Wikman et al, 2005). Paper II adds to the current ethical debate about public participation in service improvement and re-design and particularly the involvement of some people who may be frail, vulnerable, lonely, who experience loss of mobility, of affection and so on. Three key concerns are, who to involve, how and to what extent? Another is, ‘what is the best we can do with what elderly people tell us?’ What is clear to us is that participatory research into ageing needs to be of some clear benefit to those older people who have taken part. What pretensions can we have in our society when it comes to care? What can we afford? What is ethical? What is good enough? Who should pay for this? I expand this discussion now by referring to both the individual and collective participatory issues.

Including both the Individual and the Societal

I agree with Mollenkopf & Walker (2007) that it is important to engage with elderly people in order to ascertain what they feel are the important experiences that positively contribute to the quality of their lives. In order to do this we have in Paper II been guided by the principles and processes of an approach called ‘experienced based design’ (EBD). This approach encourages elderly people to ‘tell their stories’ of ageing. By drawing upon a constructivist grounded theory approach (Charmaz, 2006) we were able to analyse these stories to pinpoint those experience that appear to most powerfully shape participant views of ageing. I have come to understand that a common feature of almost all quality of life approaches is the conceptualization of quality of life as concerning individual characteristics (Noll, 2007). Dimensions of human welfare related to more societal characteristics and qualities such as participation, empowerment, social cohesion, access,

inclusion, sustainable societal capital, self determination, choice and so on, which affect an individual's experience of ageing have been rather neglected. Methodologically, we tried to overcome this dualism in Paper II, by including both individual and societal elements in a creative way. We include the individual by presenting a summary of the whole data set supported by excerpts of the stories of elderly people. These may be regarded as their subjective experiences of ageing well or learning unpretentiousness. We include the societal in the way the research was undertaken. By that we mean we have positively embraced, and put into practice, such societal values like the positive engagement of elderly people themselves in service improvement, the development of a democratic and reflective discourse and by working with research participants in an egalitarian and collegial way. Also in Paper III this methodology of listening to the elderly participants' own stories and their views upon how technology could support them, was used. I have also come to understand that theory building, using participatory and experienced based design methods, brings with it a range of ethical issues that need to be explicitly considered in order to avoid older people being exploited and misrepresented. I have also come to appreciate that conducting research of the kind I have, brings with it a recognition of our *interdependency* and *interconnectedness*.

Perspective 3: Theoretical understandings

Below I outline my theoretical understandings of the empowerment concept and how it is linked to the concept of ageing well. I looked at the core concepts in my studies at three different levels. Those at the individual, group and organisational level. Paper I and II describe the individual level, Paper III mainly the group level and Paper IV mainly the organisational level. Through the papers I have gained a more holistic view of empowerment as a concept in the context of ageing and rehabilitation. I have also come to realize that empowerment methodology, in the context of e-health, needs to be more explicit and developed further. I also found that empowerment dimensions are closely related to the concept of ageing well and that freedom of movement, one of the dimensions, can be supported by mobile technology if the technology is developed together with elderly people.

Ageing well and having a life as good as it can be

In Paper II, the concept of *Ageing well* in relation to *dimensions of empowerment like self determination, autonomy, participation and freedom of mobility* was put under pressure. The narratives of the elderly people were studied with Habermas' (1995) theories of communicative action in mind in order to better understand the elderly persons' life world. The result showed that the needs of

elderly people are influenced by the possibilities to be fulfilled and responded to by the healthcare providers so that a learned unpretentiousness was developed as a strategy to “age well”. Behind the gratefulness and compliance to the situation the participants showed contradictions as longing for to be more physically active and a need for a social network. Health providers must question their own “common sense” understanding of the lives of older people and the best way to this is by critical self-reflective practice and research (Angus & Reeve, 2006). Angus & Reeve (2006) discuss the new mantras of the 21st century; “ageing well”, “health ageing”, “positive ageing”, “successful ageing” and “resourceful ageing” and how these expressions are used unreflectively by society to find ways to reduce age-related losses. They examine ageism and states that the concept ‘dependency’ is a stereotype that is connected to ageing and that provides a platform to promote a culture of self-reliance. If ageing-well ideas are based on individualism and “self-reliance”, there will be a risk of keeping up existing power relations that continue to inform ageist stereotypes. By critically examining our own tacit assumptions and involve older people as active participants in their own ageing knowledge and experiences a process of change can start. Health providers also must critically reflect over these issues so that they will not spread stereotypic attitudes towards ageing well (Angus & Reeve, 2006). In Paper II some of the participants told about how they felt that their needs were not listened to by the healthcare system and thought that this was a result of their age. Expressions from health care staff like: “*At your age you can not expect to be fully fit*” were experienced as discriminating. This made the participants think about having to reconstruct the image they had of themselves and try to accept that they were older than they often felt inside. Andersson (2008) means that one aspect of ageism is how elderly people look upon themselves and despite of the existing ageist stereotypes, elderly people still have a positive view upon themselves because they do not see themselves as “elderly” in the first place but as a whole lot of other identities, like, grandmother, sailor etc. The view you have upon yourself earlier in life influences the extent to which you have a positive or negative view upon yourself as old and what stereotypes that you will be influenced by (ibid.). Andersson (2008) cites Kalish (1979) who means that researchers and professionals in elderly care and rehabilitation are supporting a new kind of ageism by being too paternalistic, having the attitude that *they* now best how and what is best for elderly people. The findings in Paper II and III are supported by research by Åberg (2003) and Åberg et al. (2005). They found that activity and the possibility to be active provide various role supports for elderly people which in their turn are necessary for maintaining a positive self-image and as so also life-satisfaction (ibid.). Being active is a prerequisite for independence and fear of physical decline and dependence is a common phenomenon in the Western society. Adaptation is a way to cope with dependence, according to Åberg (2003). This could be

compared with our findings of learned unpretentiousness, to 'Gilla läget' (*in Swedish*) or getting the best out of the situation.

My theoretical understanding is that continuing to build a theory about ageing well and learning unpretentiousness needs to be situated within the more general demographic transition processes in Sweden and within the European region, particularly their pace and social impact. Arguably this is a prerequisite to meet particular ageing challenges. In undertaking this research, I have sensed the real need to develop a more holistic theory that makes the links between the processes of 'ageing well' and enhancing older people's quality of life, more explicit. I think one important part of this is to positively engage with particular groups of older people, to appreciatively and authentically deepen our understanding of what they feel, think and what they perceive their needs and wants to be. By 'holistic' theory I mean a theory which acknowledges that ageing is not equal. People age differently. What is needed is a theory which reflects the fact that older people are not a homogeneous group, but groups with different ageing trajectories. They are people who have different views of what quality of life means and life-course perspectives. One challenge is to work out how to generate opportunities for the synergy required, building such a holistic theory. In Paper III the participants showed different views on e.g. safety and how to handle this need according to if they were limited in functions or not. In Paper I, the age of the participants were under 65 and they are the coming 'elderly people' showing a different attitude about being participant than e.g. the participants over 80 in Paper II. In Paper II I believe we have made a contribution to a more holistic theory of the process of ageing well by, not only, exploring notions of ageing well, but by placing this alongside learning unpretentiousness, in an apparently contradictory relationship. In doing so we have taken what Allardt (1981) originally called 'dilemmas' in his classic comparative Scandinavian welfare study and reframed dilemmas as elderly people 'living-with-contradictions.' Burr (1995) refers to Billing et al (1988) who mean that all our thoughts with content and processes are given to us from wider socially shared concepts and issues. These concepts and beliefs of society shape what we see but also what we see as two sides of an argument or issue and this makes thinking itself characterized by a 'dilemmatic' nature – a two sided question to which there is no easy answer (ibid.) By implication, we have reframed Allardt's (1981) original dilemmas which were objective and subjective indicators of quality of life, material needs and social needs and re-casted them within this contradictory frame. In this reframing we have paid particular attention to expanding Allardt's (1981) notions of 'Loving' (experiences of attachment) and 'Being' (social relations). For example that data from the interviews with the elderly participants enabled us to generate the four categories; of *social networking*, *psychosocial wellbeing*, *physical capacity* and *empowerment*. My

grounded understandings from working with this thesis are that in the future the needs of elderly people will be changed in relation to the changes and globalization of society. Care and rehabilitation are only some of these needs together with other needs like i.e.; good housing, nice clothing, nice experiences, good food, travel, social relations and networking and all things that makes a life as good as it can be. Allardt's (1981) third dimension 'Having' (the resources the individual have e.g. health, housing, education etc.), can be helpful in the need finding process. This understanding is important to take into account in improvement of rehabilitation services. This means that elderly people have to be engaged in and participating in the development and design.

An empowering framework in rehabilitation

My grounded understandings come from my experiences in practice together with findings from my research put in the theoretical framework. 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 & Warschusky (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 includes 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). Richardson (1999a; 1999b) means that a client-centred and empowerment approach is essential for professional development in Physiotherapy. A patient must be given the tools to take responsibility for her/his own health (Anderson, 1995). In this context, empowerment might 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 this should happen to me again, I would be more strict and clear over what I would want.”* The participants in Paper I were, as discussed above, all under 65 years old and I do not think that the result would have been different if the participants had been over 65 years. This is grounded on comparisons with the experiences from living data from Paper II.

In Paper II the participants had contradictory expressions of both being content about life as it was and at the same time longing for being more mobile, walking around and do walks outdoor. So how do we listen more carefully to what elderly people say and what do we do with what elderly people tell us? 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. The findings in this thesis show that the self determination and autonomy are steering values among the elderly participants and that they want to be able to stay at home and take care of themselves as long as possible but that they are positive towards help and support. I believe that it is important to further develop an empowering philosophy in rehabilitation to support the elderly persons in these needs.

Rehabilitation as a learning process

In Paper IV, *participation, self- determination and information technology* were explored in relation to empowerment in elderly home health care and rehabilitation. 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 IV 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 constructive 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 and rehabilitation. 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 rehabilitation 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.). Participatory and Appreciative Action Research has the potential to be empowering and generative.

Freedom of movement- a dimension of empowerment

In Paper III, *freedom of movement* and *mobility* were expressed as a dimension of empowerment by elderly people 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 s(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 III 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. Mobile ICT can be a tool for experiencing increased freedom of mobility. I agree with Östlund (1999) that methods for evaluation needs and use of mobile ICT for elderly people must be developed and that both technical and societal knowledge and competence is needed. The theoretical underpinnings are different and should not be underestimated. The user’s perspective should be steering and it is important not to see elderly people as a homogeneous group and to remember that ICT use is no longer related only to working life (ibid.).

Perspective 4: Practical understandings

How can we use the knowledge we have gained in practice? During my thesis work I have learned about which some call the ‘practice turn’ in social theory, meaning that new knowledge seeks its ground in theorizing that what people actually do in actions, e.g. empowering ones, more than beginning with theories that are abstracted from actions. I learned that practice theorists tend to emphasize the importance of not just *what* is done, but also *how* it is done (Schatzki 2001; Whittington 2006). This means that a phenomenological emphasis is put in meanings embedded in linguistic and physical artifacts and focuses on a critical theoretical emphasis and its focus on power relations and on a participatory action research point and its emphasis on participation and inclusivity. So, I see research within this practice turn as a ground for asking questions like, ‘*what constitutes effective practice?*’ and this is in line with all of my grounded understandings from working in practice with rehabilitation.

Participation and listening to the patient/client

I have learned that it is important to develop the rehabilitation context into a learning organisation, promoting patient/client empowerment. My findings in all four papers show that *participation is* important and that everyone involved in home health care and rehabilitation needs to take participation seriously. In Paper I the results indicate low patient participation in and influence on the rehabilitation process, in Paper III elderly people perceived freedom of movement as a prerequisite for participation and in Paper II the elderly participants felt that they could influence care and be participating in one aspect but they still wanted more support with e.g. being more physically active, like walking out door. Cardol et al. (2002) discusses the importance of autonomy and participation in rehabilitation and the need for client centred practices in rehabilitation and that the principle of autonomy, meaning both decisional autonomy (the ability to make decisions without external restraint) and executional autonomy (the ability to act as one wishes) should be guide the development of rehabilitation strategies. But we also have to remember that conceptions of autonomy draw from a group of value laden ideas which differ between cultures, social groups and persons (cf. Cardol et al, 2002; Chan, 2002; Saadah, 2002). I also agree with Cardol et al. (2002) and Clapton & Kendall (2002) that we should regard the concept of *interdependence* as a valuable alternative to autonomy since sometimes autonomy/independence is too much stressed. To view each person's individual needs in the context of their life's narrative is in the ethics of care and rehabilitation (ibid.) In Paper II the elderly participants showed a contradictory view on being (in)dependant of care-assistants help. In a relation where the elderly person thought they helped the care assistants in how to manage and organise their work in the elderly persons' homes, this interdependence was visual. They were learning how to manage their expectations of homecare (Wikström 2005). The Western culture has a focus on self-determination as independence (Renblad, 2003). My grounded understanding is that the concept of *interdependence* is essential in the empowerment discussion. Both professionals and patients/clients are dependant on each other and this is, as I have come to understand it, not in contradiction to 'being empowered'.

So what does meaningful and ethical involvement mean in practice? As a consequence of the methodology used, we more fully appreciate that elderly people have much to say about issues like quality of life, about empowerment, self determination (Carlstedt & Forssén, 1999), influence, autonomy and mobility (Mollenkopf & Walker, 2007) and how their needs could be met. In Paper II the elderly participants were not short of ideas. The participants were no victims. They kept their identity and they had a lot

of self-determination. But interestingly they had little possibility to act and be as they would like to because of several reasons. They adapted to their new situation because they thought this was what they ought to do, should do, because they could no longer manage by themselves. They may be dependent but they were no victims. Sometimes they struggled to find the best possible way to cooperate with homecare, to relate to them in the best possible way. When they reflected upon their situation, it seemed that there were things they could do about ageing like exercising (Rydeskog et al, 2005; Elkjaer et. al, 2006), out-door walking and using assistive technology, but they often did not know exactly how to satisfy these needs. We learned that these elderly people were not necessarily dissatisfied or unhappy but were trying to accept and to adapt to their new life situation (Peel et al, 2007).

In Paper III the participants were content with participating in development of technology with the aim to support them. In Paper IV 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 and rehabilitation. To listen actively to the patient/client is a 'positive core' in home health care and rehabilitation, 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 and rehabilitation 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. Power differences 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 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) practises.*" 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. Working empowering as a physiotherapist is in line with research by Lindqvist's (2006) and Lindqvist et

al. (2006), where one of the professional identities of being a physiotherapist is The Empowerer.

Use of ICT in home health care and rehabilitation

The findings in all four papers show that an information age model influences patients' and clients' perspectives on the use of ICT in home health care and rehabilitation. 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? In Paper II the elderly participants were both fascinated with what help and support modern technology might bring but also frightened as they thought it could be hard to understand how to handle and manage. Assistive technology that they had learned to handle, like the rollator and the safety alarm, was considered as increasing safety. The findings from Paper II also showed that current safety alarms was not enough to give safety outdoor and to remain safe the participants had to stay indoor. The findings from the interviews and the reasoning about mobile ICT in Paper III 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 and mobility and safety was considered as more important than privacy. 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 III 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?" One way to explore this is to enable elderly people to participate in design, development and research of/about mICT after the principles of Experienced based design (EBD) and Participatory and Appreciative Action Research (PAAR).

Reflect and learn together

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 IV, 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). At the workshop with personnel from homecare sector, the care-workers got the opportunity to discuss and reflect upon their own thoughts around ageing and through the storyboard with Olga they tried to get an understanding of what needs she wanted to express. Our attitudes about elderly persons are grounded in our conception about ageing, conceptions that are based upon either positive or negative feelings about ageing as a process. Our conceptions and feelings will influence our meeting with elderly persons. If we think that elderly persons are dependent and not capable or willing to be involved in decision making regarding their own matters, then we might think that the best way is to take over and make decisions in their place. I have come to understand that, as society is changing, so are elderly peoples' needs, values and behaviours that are the result of their values. Following Habermas' (1976) idea of communicative rationality, meaning that people's behavior or thinking becomes guided by criticizable validity claims and not behaving as you are told by unquestionable sacred authority and that means that there are potential for rational, communicative actions.

The findings from the two days of reflective workshops with home care staff described in Paper IV 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 and rehabilitation services for the future. It is important to reflect creatively on what patients/clients say and try to respond positively to it.

Concluding reflections and grounded understandings

In my research my grounded understandings have led to these questions: How can Information and Communication Technology (ICT) support the process of ageing well? How can this be met in practice and what constitutes effective practice with high quality from a patient/client perspective?

In the end I will conclude by reflecting on my research, drawing on Alvesson & Sköldbberg (1994) ideas of reflective research. They suggest that a researcher should reflect upon four things; 1) Methodology that shows systematics and rigour. 2) Clarity in how the interpretation is made and where hermeneutics is an important form of reflection. 3) Consciousness of the political/ideological character of research. 4) Reflection in relation to representation/authority problems. All data are always interpreted and always constructed in relation to the personal, cultural and ideological frames of references we all are carrying within our selves (*ibid*). Good qualitative research is characterised by a systematic and transparent methodology where interpretation is lifted up and reflected upon. I suggest that by using Participatory Research approaches together with Appreciative Inquiry and using PAAR in my research as an activity I have followed the kind of methodology suggested by Alvesson & Sköldbberg (1994). They suggest that you have to interpret your own interpretations, put your own perspective in a perspective and critically explore your own authority as interpreter and author in research (*ibid.*). In this thesis, I have searched for my own subjective I's and four I's emerged, 'My Democratic I', 'My Open-minded I', 'My Freedom loving I' and 'My Emotional I', all of them to be looked upon as lenses to use in a way to enhance the efficacy of my perception (cf. Peshkin, 2001). Peshkin (1988) suggests that you should be aware of your own subjective Is and see their enabling as well as their disabling potentials during the whole research process, while data is still gathered and not only afterwards. I have been searching for my subjectivity by recalling back to research already made (Paper I, III and IV) except for Paper II that was my last written paper. Searching for my subjectivity has given me a better awareness in the analysis and in the writing of Paper II. I think this is in line with Alvesson & Sköldbberg's (1994) idea of being clear with your interpretation and the inductive work. I think I have followed the hermeneutic circle, meaning that I have tried to understand the wholeness by going back and forth between the parts and the whole in order to secure the

scientific inquiry from the things itself (“Vorhabe”, “Vorsicht” and “Vorgriff” (Gadamer, 1980 p. 330)).

Alvesson & Sköldbberg (1994) also suggest that you, as a researcher, have to show consciousness of the political/ideological character of your research. By choosing Participatory and Appreciative Action Research (PAAR) as my research approach I put my intentions with my research in the open. This kind of research involves actions together with others so that valued outcomes unfold from the generative aspects of the current situation (Ghaye & Melander Wikman, in manuscript). It is about having the skills to see, to make sense of and to interpret things in different ways in order to make improvements in society. By using empowered participation through deliberative democracy, PAAR creates a sense of ownership and responsibility in generating and using knowledge (ibid.). This is in accordance with Alvesson & Sköldbberg’s (1994) ideas about reflection in relation to representation/authority problems. In qualitative research that is built on empery in the form of texts that are “processed” by the researcher, meaning condensed and interpreted in order to make the informant’s subjective voice to speak, these interpretations can be seen in relation to power (ibid.). They mean that you as a researcher not only should rely on interviews as a method, but also do observations (ethnographic methods) although observations in a naturalistic context are as well influenced by the indeterminability of the language. It is important to explain though when working in the spirit of participation with PAAR, not to see ‘we’ as the centre and everything else is defined in terms of ‘not-we’. I found that by integrating Constructed Grounded theory and Participatory and Appreciative Action Research in order to claim validity was a helpful way to respond positively to my questions. Teram et al. (2005) have the same experience of integrating GT and PAR in research in physiotherapy, although the two methodologies seem to be based upon different views upon how research persons should be included in research. The differences in the methodology complement (not compete with) each other and make an effective process for amplifying the voices of patients/clients in a way that is acceptable to health professionals within an environment dominated by evidence-based practice (ibid.)

I agree with Bradbury-Jones (2007) that the search for my own subjectivity in my research is not an egocentric fascination with my own position as a researcher, but a way to demonstrate how the process of reflexivity and the developing consciousness of my subjectivity formed the research and facilitated the ambition to give voice to the informants in the different studies. I think this approach, although it might be experienced as an omission and perhaps showing your vulnerability, is enhancing the rigour of qualitative research. A prerequisite for reflection in the interplay between empirical data

and interpretations of it, is a broadness and variation in the interpretation repertoire (Alvesson & Sköldbberg, 1994). By illuminating my subjective I's, I have made my perceptions visible, increased my self-awareness and improved my interpretation repertoire. In PAAR work we need to appreciate that the creation of knowledge requires an active and subjective knower who makes a personal commitment to reflect on the influence of her/his actions on the situation they are researching. This created knowledge is potentially transformational and developmental in its nature and the use of this knowledge is to enable both the 'I' and the 'we' to implement creative thinking, positive engagement in and improvement of what we want to develop/improve. The PAAR epistemology contains a theory of knowledge creation which guides you as a researcher in making claims about the validity/robustness/trustworthiness of the research accounts as described in the discussion about methodological understandings. During my thesis work I have been inspired by research in social work and I have discovered that methods of science have moved on, as have their forms of inquiry and models of expressions. PAAR is one example of a research methodology that can be fruitful in research in healthcare and rehabilitation and particularly in research into ageing well. As researcher, I think it is of great importance to be able to use more expressive forms to show the reality of lived experiences when we report research. Feelings, subjectivity and multiple kinds of language can be used when communicating this complex transformative experience of living in order not to lose some important aspects, to show how existence might be understood and expressed at the level of lived experience.

The aim of this thesis was to explore different dimensions of empowerment and empowerment methodology for elderly persons in home health care and rehabilitation and rehabilitation, and if ICT is a useful tool in this process. My findings are 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. In future research it would be interesting to conduct the same kind of research with elderly persons (over 65 years). Findings from interviews with elderly participants showed contradictory experiences of e.g. being both active and inactive, being both dependant and independent, and both mobile and still in many aspects immobile. The findings also show *interdependence* as something to be appreciated since it includes social interaction. Friends, relatives, homecare staff and patients/clients all rely on each other and this inter-dependence supports social interaction. Elderly people in this thesis want to be part of social networking and freedom of mobility and ICT can support this. 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. Freedom of movement is one important dimension of empowerment. In Paper III the possibility to be active and mobile and still feel safe was seen as more important than privacy.

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 s(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. In development of technology for elderly people, it is important to have their perspective and the user engaged in the development process. Without their knowledge there is a risk that technology will be developed that will isolate and exclude elderly people instead of including and empowering (cf. Essén, 2003). With increased technological skills and qualifications, a higher degree of acceptance of ICT and telemedical solutions has been shown (Bratton & Short, 2002). Focus must not just be on the technical possibilities but rather on what needs to be done to make life good enough (cf. Essén & Conrick, 2008).

I found the ‘need-finding process’ essential in IT development but also in physiotherapy practice and there is a need to know more how to understand and better interpret needs of elderly people. I have earlier described that I agree with both Illeris (1999) and Allardt (1977) about needs being difficult to

categorise and quantify as in Maslow's hierarchy. Bridges (2008) found that older people can delay seeking help and often need help deciding what to do. Older people may also feel they do not matter. This diminished sense of significance appeared to constrain some older people in expressing their needs.

All of the 'six senses', mentioned earlier, (Nolan et al 2006), can be interpreted as needs of elderly people; *needs of security, needs of continuity, need of belonging, need of purpose, need of fulfilment and need of significance*. One of these findings of Nolan et al. (2006) that is particularly relevant to my research and issues around empowerment and learning unpretentiousness, is concerned with a '*sense of significance*'. In other words, a sense that one matters as a person, regardless of age. Arguably a sense that one may not matter in older age, seems to underlie some older patients'/clients' reluctance to ask for help or advice and to undermine their feelings that they can indeed, influence care. It may also contribute to feelings of disempowerment, learned helplessness and learning unpretentiousness. I suggest this might be a fruitful area for further research.

I think that there is a friction between what professionals think and feel is 'right' and in their patients/clients best interest, and what patients/clients feel are their needs and wants. This could be emphasised when users are democratically and authentically involved in shaping the services from below. This puts a challenge on other stakeholders, like professionals, in care and rehabilitation, technicians and researchers to focus on putting the patients/clients first and themselves last. This has implications for the language we use to describe user involvement. For example my research suggests that it may no longer be appropriate, by those who develop modern assistive technologies for example, to refer to patients/clients in the traditional or conventional way as 'end-users'. In the spirit of democratizing innovation processes (von Hippel, 2005) and participatory research methodologies, there is an argument for referring to patients/clients as '*lead-users*'. There is also an assumption throughout the literature that empowerment is 'a good thing', that it is better to be empowered than disempowered. 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.

In this thesis most of the research persons were women, reflecting the existing gender distribution among elderly in Sweden. Gender issues have not been explored in this thesis and more research is needed to understand elderly peoples' experiences of empowerment dimensions from a gender

perspective. The *concept of inter-dependence* should also be lifted up and explored more deeply in relation to empowerment. Furthermore, there is a need for research on the experience of inter-dependence from both professionals and patients/clients points of view. More research is also needed to better understand exactly what elderly people mean by ageing well and what they experience as empowering, and if and how ICT can support self-determination, autonomy, participation and mobility. It would also be of interest to understand better how elderly peoples' lived experiences can influence the health and care system's responsiveness. Fundamentally I have learned that empowerment is about finding a voice and acquiring visibility.

I suggest that in order to understand ageing well and learning unpretentiousness, we need a more holistic theory of what constitutes a 'good life'. To achieve this I suggest we need a participatory and appreciative methodology which sincerely values the experiences of elderly people and which respects the integrity of what they say. Finally I suggest that to build an even better future for both the younger and older groups within the elderly, we need to further develop our current understandings of ageing well. This thesis has subscribed to the view that we can build a better future, for elderly people in the society, from aspects of the positive present. In order to do this we might usefully go on and ask elderly people three fundamental and appreciative questions; 1) What contributes to life being 'as good as it can be'? 2) So what do we need more of? 3) What do we need to do more of? If we change the questions we ask elderly people, we have a chance to change the conversation. If we change this, we create an opportunity to change the action. These three questions hold some promise to do this as they shift the focus away from 'what's life like?' and 'what should life be like?', towards the explicit action question, '*what needs to be done to make life as good as it can be?*'

SVENSK SAMMANFATTNING

Det goda åldrandet – mobil IKT som ett redskap för ökad empowerment av äldre vid omsorg och rehabilitering i hemmet.

Det övergripande syftet med denna doktorsavhandling var att undersöka olika dimensioner av empowerment och en 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 stöd i denna process.

Europas åldrande befolkning är en utmaning i det tjugonde århundradet. Idag är medellivslängden i Sverige 83 år när det gäller kvinnor och 78 år för män. Ett viktigt politiskt mål i Sverige är att förse befolkningen med hälso- och sjukvård av hög kvalitet och på lika villkor. Det betyder att vården skall vara lättillgänglig och bygga på patientens/brukarens behov. Dimensioner av empowerment, som delaktighet, självbestämmande och inflytande över sin livssituation, leder oss till ett koncept där patienten/brukaren är i fokus. Konceptet patient- och klientcentrerad vård och rehabilitering används med målet att få en ökad förståelse för och inkludering av patientens/brukarens perspektiv i vård och rehabilitering. En ökad användning av informations och kommunikationsteknik (IKT) i rehabiliteringen av äldre kan sannolikt medföra att äldre får en ökad möjlighet att aktivt påverka sin egen hälsa och livskvalitet.

De forskningsfrågor som var utgångspunkt för de olika delstudierna är:

- Hur upplever patienter/brukare dimensioner av empowerment som delaktighet, inflytande, självbestämmande och rörlighet?
- Vilka behov har äldre personer i relation till dimensioner av empowerment som delaktighet, 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?

I den första delstudien intervjuades sex personer med lång erfarenhet av rehabilitering efter olika typer av funktionshinder; fyra kvinnor och två män. Dessa intervjuer handlade om erfarenheter av delaktighet och inflytande i rehabiliteringsprocessen. Med syftet att undersöka vilka behov äldre har när det gäller delaktighet, självbestämmande och rörlighet gjordes inom ramen för delstudie två djupintervjuer med tio äldre med hemtjänst och trygghetslarm. Nio kvinnor samt en man mellan 63 och 88 år intervjuades

och mer än halva gruppen var äldre än 80 år. För att studera om IKT kan vara ett redskap för ökad empowerment gjordes i delstudie tre en intervention där nio äldre personer testade ett mobilt trygghetslarm med positioneringsfunktion under 6 veckor. Efter testperiodens slut intervjuades testpersonerna och resultatet presenteras i delstudie tre. Fem av testpersonerna hade funktionshinder som t.ex. yrsel, balansproblem, smärta efter t.ex. trafikolycka eller stroke. Dessa personer hade erfarenhet av ett traditionellt trygghetslarm med en begränsad räckvidd på 10 meter. Fyra av testpersonerna hade inga funktionshinder och levde ett aktivt liv. Den fjärde delstudien baseras på data från reflekterande workshops med 35 arbetsledare inom hemtjänst. Under dessa workshops reflekterade deltagarna över hur hemtjänst och rehabilitering i hemmet kunde upplevas ur ett brukarperspektiv, när det gällde delaktighet och självbestämmande.

Alla fyra delstudier har en kvalitativ ansats. Första delstudien var inspirerad av Grounded Theory enligt vilken teorier genereras på empirisk grund. Efter varje intervju gjordes en analys som sedan låg till grund för nästa intervju. Vid den andra och fjärde delstudien användes en reflekterande analys metod som inspirerats av konstruktivistisk Grounded Theory. Det betyder att i delstudie två reflekterade forskarna tillsammans under analysen. I delstudie fyra, reflekterade deltagare och forskare tillsammans under analysen av workshoppen där forskarna fungerade som moderatorer. I den tredje delstudien analyserades intervjuerna med hjälp av latent innehållsanalys. Den andra, tredje och fjärde delstudien gjordes inom ramen för två olika projekt i e-hälsa, Mobilt trygghetslarm (delstudie III) och eHome HealthCare @North Calotte (delstudie II och IV) och ansatsen var deltagande aktionsforskning (Participatory Action Research). Det betyder att forskningsfrågorna utvecklades tillsammans med alla deltagare i projektet. I delstudie IV användes deltagande och uppskattande aktionsforskning (Participatory and Appreciative Action Research) vilket betyder att man fokuserade på det som fungerat bra och som man ville utveckla, istället för att fokusera på problemen.

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 under sjukhusvistelsen och att deltagarna inte tänkt på möjligheten att utöva ett inflytande. Två teman framkom; *den traditionella medicinska modellen* respektive *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 skifta mellan att vara följsam i relation 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. Studien visar att 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 förhållningssätt 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.

Den andra delstudien skedde inom ramen för projektet eHome Health Care@North Calotte där projektets syfte var att utveckla ett mobilt planerings och informationsstöd för personal inom hemtjänst. Intervjuerna med de äldre personerna handlade om vilka behov äldre personer har i relation till delaktighet, självbestämmande och rörlighet för att leva ett gott liv i trygghet och säkerhet. Resultatet visade att för att leva ett liv som äldre i sitt eget hem krävs att man lär sig att *leva med minskade anspråk*. Kategorier som *socialt nätverk*, *psykosocialt välbefinnande*, *fysisk kapacitet* och *empowerment* formades av underkategorier som visade på en dikotomi av upplevelser och erfarenheter av att vara både *oberoende* och *beroende*, vara *ensam* och samtidigt *ha nära relationer*, känna sig *rörlig* på ett plan men samtidigt vara *utan rörelsefrihet*. *Tekniska hjälpmedel* som t.ex. rollator och trygghetslarm hade en *stor funktion för att öka rörelsefrihet och trygghet*. Ny modern teknik som t.ex. mobila trygghetslarm, bildtelefoner och datorer för kommunikation upplevdes som *onödiga*, *kanske dyra och skrämmande* av vissa och som en *intressant utveckling* men svår att sätta sig in i och förstå av andra. Den sammanfattande förståelsen var att äldre personer försöker göra sig själva och sina behov förstådda genom att anpassa sig till den nya situationen som beroende av de olika systemen inom vård, omsorg och rehabilitering. För att integreras med sin identitet som äldre lärde de sig att bli mer anspråkslösa än de varit tidigare i livet och detta förde med sig många delade och motsägelsefulla ställningstaganden. Resultaten analyserades med hjälp av teorier om kommunikativt handlande (Habermas, 1976; 1995). När vi konstruerar vår livsvärld är vi alla levande motsättningar och konstruktionen sker genom kommunikation med andra. Studien visar att vid utvecklandet av ny IKT är det viktigt att vara medveten om denna anspråkslöshet hos äldre

personer så att deras verkliga behov tas tillvara tillfullo. Det betyder att äldre personer bör vara aktiva deltagare vid design och utveckling av ny IKT som har syftet att stötta äldre.

I den tredje delstudien testades mobil informations och kommunikationsteknik i form av ett mobilt trygghetslarm och syftet var att studera hur äldre personer upplevde användningen ur ett rörlighets-, säkerhets- och integritetsperspektiv. Resultatet visade att testpersonerna *upplevde det mobila larmet som ett redskap för ökad empowerment genom att rörelsefriheten ökade samtidigt som de kände sig säkra*. Att larmet hade en positioneringsfunktion upplevdes inte som integritetskränkande. Testpersonerna var positiva till att använda mobil informations- och kommunikationsteknik och även fascinerade av teknikens möjligheter. *Det upplevdes även positivt att vara delaktig i utveckling och design av ny teknik*. Vi lever i en säkerhetskultur där människan är beredd att ge avkall på privatliv och integritet för att behålla sin rörelsefrihet och samtidigt känna sig säker. *Rörelsefrihet är en dimension av empowerment*. Fynden analyserades med hjälp av teorier om empowerment av bl.a. Rodwell (1996) och Ghaye (2005). Forskning om hur äldre upplever åldrandet visar att hälsa handlar om att ha möjlighet att göra vad man vill trots att hög ålder och begränsad hälsa begränsar denna möjlighet. God hälsa har både en fysisk och en psykisk dimension som påverkas av fysisk träning och ett obekymrat förhållningssätt. Med mobil IKT kan möjligheten till ett aktivt liv öka och därigenom även till god hälsa. Det är viktigt att studera hur ett sådant mobilt trygghetslarm bäst skall vara utformat för att passa äldres behov och önskningar.

I den fjärde delstudien, vars syfte var att undersöka hur arbetsledande personal inom hemtjänst reflekterar över hur hälsa, välbefinnande och självständighet kan förbättras hos äldre, visar resultaten att *personalen måste lyssna aktivt till äldres behov och även lära sig att förstå äldres behov och önskningar*. Personalen måste även lära sig hur man använder denna kunskap/insikt i praktiken för att förbättra äldreomsorgen mot ökad empowerment för äldre. *Forskning och informations och kommunikationsteknik kan vara ett stöd för brukaren när det gäller att kunna vara mer delaktig och öka sitt medbestämmande*. För att förbättra äldreomsorgen mot ökat självbestämmande för äldre måste rehabiliteringspersonalen *arbeta i en triad av delaktighet, empowerment och IKT*. Fynden tolkades med hjälp av teorier om lärande, reflektivt lärande (Schön, 1983, 1987; Cooperrider & Whitney, 2003; Ghaye, 2005) och empowerment (Appelbaum et. al, 1999; McDoughall, 1997; Duvall, 1999).

I denna avhandling ses empowerment som ett begrepp som innefattar både individens inflytande över sitt eget liv och delaktighet i samhället. Det betyder att begreppet uttrycker både en psykologisk dimension i form av

egenkontroll och inflytande samt en social dimension som handlar om socialt och politiskt inflytande. Empowerment kan också ses som en diskurs. Det är möjligt att den kontext i vilken rehabilitering bedrivs kan forma en diskurs som delar de värderingar som hör ihop med empowerment; delaktighet, möjlighet att utöva inflytande, självbestämmande och rörelsefrihet. Att professionella, äldre, anhöriga och vänner är ömsesidigt beroende av varandra för att skapa ett gott åldrande behöver lyftas fram. Med hjälp av mobil IKT kan den traditionella modellen inom hälso- och sjukvård och rehabilitering att bytas ut mot en modell som hör ihop med informationssamhället och där hälsofrågor löses genom kunskap, hjälp till självhjälp, familj samt vänner och där professionella inom hälso- och sjukvården ses som partners och möjliggörare istället för auktoriteter. Utmaningen ligger i att skapa ett utrymme för uppskattning ("*appreciative space*") som gör att patient/brukare upplever det möjligt att fritt uttrycka sina behov och önskningar och att de professionella verkligen lyssnar. Det är viktigt att möjliggöra för äldre att ha en positiv syn på sig själva, eget självbestämmande och välbefinnande. Möjligheten att vara fysiskt aktiv är en förutsättning för detta och rörelsefrihet upplevs som en dimension av empowerment – att vara fri att göra det man vill och på det sätt man vill. Det är viktigt att ytterligare studera om, hur och på vilket sätt IKT kan vara ett stöd för både professionella och patienter/brukare i förbättringen av vård och rehabilitering ur ett empowermentperspektiv. Den fråga som kan ställas är: "Vad *behöver göras för att göra livet så gott som det kan bli?*"

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Paper 1

ORIGINAL ARTICLE

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

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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).

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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 she/he 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 sub-categories, 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

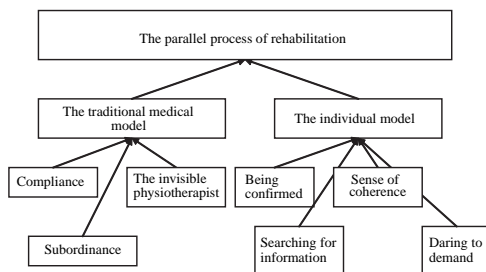


Figure 1. The rehabilitation process as experienced by the informants.

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.

I've read somewhere that if your "clinical treatment is completed", that's what they say when they want you to be in charge of yourself.

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 peps 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.

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.

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".

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. Cure 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 supports 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.

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Paper II

Ageing well or learning unpretentiousness? – Elderly persons' living experiences of homecare and safety alarms.

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Abstract

Ageing well and maintaining a good quality of life, is one general societal goal. Another, from the European Information Society, is to support and enable self-determination and mobility through the use of information and communication technologies. Taken together, and within the context of experienced-based service design, this study aimed to understand what ageing well meant for a group of elderly people. Methodologically a constructivist grounded theory approach was used to analyse ten in-depth interviews with elderly people living at home with homecare and safety alarms. Hierarchical coding procedures enabled us to develop the core category of *ageing well or learning unpretentiousness*. This is made up of four categories namely *social networking*, *psychosocial wellbeing*, *physical capacity* and *empowerment*. Data suggests that ageing well was linked with elderly people learning to get more unpretentious as they get older. In developing new information and communication technologies for ageing well, it is important to take this learned unpretentiousness among elderly people into account, so that their needs can be fully appreciated. One consequence of this is that elderly people need to have the opportunity, and be sufficiently empowered, to actively participate in the development of ICT systems that are designed to meet their needs.

Keywords: Ageing well, elderly people, empowerment, information and communication technology, learning unpretentiousness, quality of life

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Introduction

One story of ageing well?

“For me it started at the hospital and I had hurt myself. I had fallen in the shower and I hit my head and it was bleeding all over. I stayed there (*at the hospital*) for fifteen days and the doctor asked me, “How are you coping at home?” “Yes, I am fine”. “Are you many?” “I am alone”. “Do you have any relatives?” “No, I have not”. And then he phoned the home-care group. // I had been trying to be as I used to be, going out in town, shopping, and I fainted once in a shop and then once more at another shop. So they had to drive me to the hospital. Then some time passed and I was content with home care, absolutely content, but I could not go out for walking alone. And then I broke my leg. I fainted and broke my leg and had another visit to the hospital. And there they had a conference and a women, I think she came from elderly care, arranged so that I got homecare three times a day....But I thought: Three times a day! No, I do not want a person coming here three times, what can I do? I can only talk. I asked if I could get just two times a day, morning and evening. I am very content. It works very well. But they have a low status. They are nice all of them but I do not think they are longing for their work. // I try to do the washing-up but I can not stand up straight for so long because I might faint. It must have to do with the balance system, I am sure of that. I got this “pensioners-food” for a year but I got tired of it, because the potatoes are not possible to eat...I always throw the potatoes in the garbage and cook my own. But then I thought, why pay for this? So then I ended this. Now I do the cooking myself. I have this distribution of groceries and that is fine. You just order from a list...I have not been out shopping at all this year. But I think I was out once in December when an acquaintance came and picked me up by car and drove me back again. After this I have not been outdoors. // I have a relative but I have not had so much to do with him. He also has heart illness and I do not want to disturb him....With a rollator I should be able to walk outdoor if someone accompanies me, because I used to walk here, indoors, by myself. I guess they (*care assistants*) could accompany me but what help does that make? They don’t have any time! No, this does not belong to their work. But things like dish washing, making the bed and maybe cooking porridge in the morning, as many do. No, they are not allowed to do such things. They take my mail and post it, I have a mailbox just nearby. And take out the garbage and so. // But without homecare I could not manage. I do not have the strength. Many of them (*care assistants*) have invited me for a walk around the block but I have declined, I do not want to. I do not know, I get shy from going out. It is five years now.I used to be out before, I often traveled abroad and I traveled to my cousin and to old friends but they are all gone. There is no one left. So it is. I used to know a lady upstairs and we used to visit each other and I helped her. We were very good friends....But this summer I will go out when my relative comes for a visit. This will be nice. // I love to read. I hope my eyes will last long. It is most difficult for me to read the paper. Books are better, but the paper...but I don’t need to know what’s in the paper. At least not all of it.”

This story is a fragment of the living experiences, from one of the elderly people that participated in this research. Within this story we can find experiences to do with functional limitation, activity restriction, unmet need, physical dependency, some loss of autonomy and social networking and therefore a changed quality of life. So what can we learn from this and other accounts gathered in this study about the quality of life of the elderly, about

conceptualizing ageing, understanding the ageing experiences from elderly people themselves and about developing services that really meet the needs of an increasing number of elderly people in today's society? We begin to 'frame' this paper by situating the experiences of the participants within the notions of ageing well and quality of life.

Ageing well and Quality of Life

Ageing well and maintaining a good quality of life, is one general societal goal. Ageing well is a concept frequently used in order to show the ambitions in developing inclusive elderly care and services with the objective of increasing independent living. Building an inclusive society and improving quality of life (QoL) of Europe's increasingly elderly population by applying technology that meets the needs of older people, is a key strategy for the EU (EC, 2007). Older people are not a homogeneous group and we must find solutions that take into account the diversities and respect the wishes from individuals (ibid.). But how can this challenge be met, and how can Information and Communication Technology (ICT) support this process of ageing well?

The concern of enabling elderly people to maintain independence and to add quality to years of life puts an interest on what is "a good life". There are a wide range of definitions connected to the concept of ageing well or successful ageing. Bowlin (2007) suggests that these definitions represents the investigators own academic discipline and values. Psychical and mental functions are emphasised as important to successful ageing by researchers driven by a bio-medical model. Social and psychological functioning and life satisfaction are looked upon as important by researchers from disciplines were the psycho-social models are vital (ibid.). The concept of "successful ageing" was conceptualised by Rowe & Kahn (1987, 1997) with the objective to create a more positive view upon ageing in order to help individuals to accomplish and maintain higher functions as they grow older (Minkler & Faden, 2002). Successful ageing means avoidance of disease and disability, maintenance of high cognitive and physical capacity and engagement in life. Ageing well is connected to aspects of health and puts a focus on health prevention and health promotion. Important factors in Rowe & Kahn's (1997) conceptualisation of successful ageing were to continue being involved in activities that are decisive and meaningful and to maintain a close relationship to others. There is research to suggest that elderly people might feel a pressure to live up to the picture of being healthy and fit and this in turn causes a fear of getting older and not being able to take care of ones self. In other words, of being dependant (Minkler & Faden 2002).

When listening to elderly people's accounts about ageing well and related concepts such as Life Satisfaction and Quality of Life it is common to deduce that they mean different things to different people. Bowlin & Windsor (2001) express this diversity in relation to concepts like happiness, well-being and 'a good-life.' Bowlin's (2007) research indicates that "there is a need to move beyond the common emphasis on health and functioning, which is prevalent in much of the QoL literature" (p.24). A broader and multidimensional perspective of QoL is needed to get a better understanding of QoL in later life. It is also important to base concepts and measurements of QoL on elderly people experiences and opinions and not just of 'experts' in order to cover elderly people's values and perceptions (ibid.). QoL could be defined as the final value that life has for the person her/him self and it has become standard to distinguish theories of QoL as hedonist theories, desire theories, or objective list theories (Brülde, 2003). This means that we have to understand what situations that have a final value to the elderly person. According to hedonist theory it should only be experices and feelings of

wellbeing that are counted. According to desire theories, only things that matter to older people are of consequence and how their needs and wishes are fulfilled. Many other things constitute a final value like close relations to others, personal development or freedom (ibid.). Brülde's (2003) own conceptualisation of QoL is a synthetic one and is dependant on how satisfied older people are with their life. In this paper we align ourself with the concept of Ageing well rather than successful ageing.

We have already mentioned that to create an inclusive society we must find solutions that take into account that people age differently. We also suggest that the wishes of elderly people themselves need to be factored-in to our ambition to improve elderly care and rehabilitation. The central challenge is how can we create a good life for elderly people?

Definitions of QoL in the literature are in line with how elderly persons themselves define QoL according to Bond & Corner (2004). The most self nominated important areas of life, listed by the elderly persons were their own health. The second are was family relationships, third was health of close person followed by standard of living like concerns about money. Social activities were listed as number five and thereafter spirituality or religion. As number seven other relationships was important and the environment was listed last (ibid.). In Renblad's (2003) research QoL was referred to as the possibility and the right to be active, to participate, to belong and to be treated as an equal.

To understand the accounts from our elderly participants in this study we need, besides different theories about QoL, to get into the different models of explanation and theoretical frameworks about ageing.

There are especially five theories among the socio-psychological models that are referred to when trying to understand ageing; The Activity theory, Disengagement Theory, Continuity Theory, Erikson's psychodynamic theory of human growth and Thornstam's Theory of Gero-transcendence. All these theories have assumptions about what it means with successful ageing (Wadensten, 2006). In Sweden Activity theory is influencing care of older people and in this theory there is an assumption that elderly people that remain active through later life will be more satisfied (ibid.). The Disengagement theory means that elderly people get more self-centred and will withdraw from social activities and other people, and that this withdrawal is initiated by the individual her/himself and not by others in the social system (Cumming, 1963; 2000). The Continuity theory means that internal and external continuity is important to the identity as old, meaning that you preserve and maintain existing structures in the basic life and adapt to your individual ageing by making adapted choices (Atchley, 1989; 2000). In Erikson's psychodynamic theory of human growth you are in a constant personal development all through the lifecycle that follows eight stages. Each stage has its own crisis and strategies used to solve these crises and experiences are transformed into the next stage (Erikson, 2004). Elderly people develop toward being less self-centred and get increased well-being by being less materialistic and more interested in spiritual and meditative activities according to Thornstam's theory of Gero-transcendence (Thornstam, 1997; 1999).

Like many social theories in the early sixties, according to Atchley (1989; 2000) the Activity theory was an equilibrium model that assumed that when changes occurred a strive for homeostasis was the response to this. But changes due to ageing are hard to manage since it is not possible to go back to prior state (ibid.). In Continuity theory continuity does not mean static, or sameness or lack of change. It is more about coherence or consistency of patterns over time and not an opposite of change (Atchley, 1989:2000). This means that continuity is a

subjective perception which is in shape and linked with the individual's own history. Internal continuity acts as a foundation for daily decisions and an important part of the competence of the individual and a prerequisite for mastery. External continuity is what is expected from others and is tied to earlier role performances in life. Both internal and external continuity can be helpful to individuals in focusing on their strengths and to reduce the effects of deficit in normal ageing (ibid.).

In definitions of rehabilitation where the objectives are bringing individuals with functional limitations from positions of dependency in their community towards independency and own decision making values of helping, choice and independence are highlighted (Curtis, 1998).

Elderly, mobility and physical activity

The lifestyle for elderly people has changed throughout the twentieth century towards increased social activity (Bond & Corner, 2004). Social activity is seen as a prerequisite for quality of life and although this engagement reduces slightly with age because of illness, impairment and disability, the changing lifestyle shows a diversity of activity. The factors that older people highlight as important are the same as other groups; own health, independence, mobility, emotional wellbeing, material circumstances, their home environment, social contacts, religion/spirituality, leisure activities and relationship with family and friends (ibid.). Concepts those are important in giving people a positive view of themselves as self-esteem, sense of self and identity, a sense of self-control and spiritual well-being. This impact on the relationship with family and friends and their activities and helps in managing life and adapt to changes as well as seeing the meaning in their lives (ibid.). Keeping the ability to be physical active will influence your likelihood to stay healthy. There are many potentially positive effects of participation in physical activity on the ageing process in literature (Fiatarone Singh, 2004). Research shows that regular physical activity can minimize the physiologic changes that ageing leads to, give psychological health and well-being, increase life length and decrease the risk of several of the most common chronic diseases, treatment for many chronic diseases and a prevention and treatment of disability (ibid.).

Lack of knowledge about the benefits on health of physical activity might lead to inactivity in later life. Frändin (1995) showed in her longitudinal study of physical activity and functional performance in a population from 70 to 76 years of age, that lifestyle patterns in early life reflects the degree of activity in later life. If you are active in young age the possibility that you will keep on being active is strong. Physical activities after 50 years old have the greatest influence on physical performance in later life (ibid.). Also very old persons, using a walker or a wheelchair and dependant in activities of daily living, showed positive long term effects in balance, gait ability and lower limb strength after a high intensity functional exercise program (Rosendahl et al, 2006).

Building an inclusive society where elderly people have a full citizenship is a necessity. Craig (2004) argues that elderly people are denied some of the basics of citizenship that they are important for being included in society, namely mobility and independence, maintenance of their own identity and dignity, control and choice and the ability to be fully participating in society on terms of their own choices. Mobility was seen as a civil right because enhanced mobility meant increased social contacts reducing isolation. The reason for decreased mobility was often functional limitations but also less earnings after retiring. Many were unable to purchase key items for reasonable comfortable living and this had an effect on emotional and physical well-being (ibid.).

Information and Communication Technology that will meet the needs of elderly people

To get better health and elderly care services for the individual and the community the perspective is changing from organisational to a client perspective. The assumption is that technology will give rise to a large number of improvements, such as effectiveness and ability to follow up and evaluate the performance of the services provided. In the National strategy for e-health in Sweden (2006 p.7) a new approach is gradually adopted that is based on citizens' and patients' actual needs and an active client/patient participation is emphasised.

The use of ICT in health care and homecare is seen as an improvement of care. Home healthcare when using ICT has a potential to provide care at a lower cost and in the same time obtain quality care for people with illness and disability in their home in the future, but will probably become more cost effective when widely implemented and practised (Prop. 2004/05:175). Through an increased use of ICT it is expected that the citizens will have more possibilities to take an active part in their own health care. A deeper knowledge about diseases, diagnostics and a better overview over different care givers are expected by the use of ICT, both for clients and for relatives. With ICT-based care and technology that supports, distance-spanning home healthcare will develop. Many see this new technology as a tool for empowering elderly persons. With better communication with the care givers and more and better information about their own conditions it will be more possible to stay at home and keep a high quality of life. There already exist different assistive technologies (AT) that clients use in their homes (Miskelly, 2001). There are several projects in Sweden where ICT has been used to provide older people, their family carers and relatives with information, education and support in relation to their caring situation, in order to improve independence and autonomy (Magnusson & Hanson, 2003; Sävenstedt, 2004).

The concept empowerment meaning that elderly persons should be able to exert influence and use their self determination when it comes to services from the home health care system is widely accepted as a concept worth striving for and is shown both in research, laws and regulations. Research shows though that there is a gap between the intentions and praxis (Wikström, 2005). As the ambitions with the concept "Ageing well" is to promote an inclusive information society it is important to explore how this development best could be met by starting from a positive present. We have to stand back occasionally from the busyness of daily life and enrich the elderly persons understanding of health and wellbeing (Melander Wikman et al, 2006). What are elderly persons' needs in relation to empowerment dimensions like self determination, influence, autonomy and mobility and how could they be met?

Method

Participants and procedure

The e-Home Health Care @ North Calotte (eHHC) project, carried out between 2003 and 2005, aimed at providing customer-oriented quality service provision in elderly care in the north of Norway, Finland and Sweden. By the application of ICT and by the intended influence of elderly on the development of e-health services, it also aimed at enhancing empowerment among the elderly. As part of the project, in order to find out about the needs of the clients, a survey was distributed to 90 elderly that were subject to home care. However, for various reasons, merely 12 of them completed the questionnaire. Later, in order to gain a deeper understanding of different aspects of empowerment of elderly, in relation to ICT, ten elderly people (one man and nine women), aged between 63 and 89 (more than half of the group were more than 80 years old), were selected and interviewed in their homes. All of them had received the questionnaire, but many of them had failed to complete it, because of difficulties to understand the questions or because of forgetting about it. The interviews, upon which the results of this article are based, lasted from one and a half to three hours. All of them were audio taped, transcribed, and coded for tentative categories during initial coding, which began already during the collection of data in accordance with a grounded theory approach (Glaser & Strauss, 1967).

Anita Melander Wikman, who is a physiotherapist, and who interviewed the participants is well experienced in meeting different kinds of patients in various situations, and in using a language easy to understand. She made an effort to keep the participants informed throughout the process. Information was given at three times: Firstly, all participants were informed by the head of the care assistants, who also recruited the participants. The participants signed a paper saying they agreed to be phoned by the first author, who then informed them about the project and the interviews, both verbally and in writing. Finally, all participants signed an informed consent. The study was approved by the committee of research ethics at Umeå University (Dnr 04-179M).

In-depth interviews

In the process of interviewing the elderly and when analyzing their stories, results other than the ones that we were initially looking for were generated. These results were not only found in *what* was said, but also in *how* it was said, indicating that we apply a *constructivist*, rather than an objectivist approach to grounded theory (Charmaz, 2006). This means that unlike objectivists, who assume that the data already exist in the world based upon which the researcher discovers theory, we believe that the resulting theory is an interpretation (Charmaz, 2006). It also means that the interviews were reflective (Thomasson, 2002) in the sense that they aimed to create a meeting between the researcher and the researched. Not only were our previous personal and professional experiences sources of theoretical sensitivity (Strauss & Corbin, 1998), but what happened during the interviews and when later analyzing the data together also contributed to our ability to develop theory. All of the interviews were carried out in a relaxed atmosphere in the homes of the elderly people, to which Anita felt very welcomed. This might reflect the fact that the participants were so used to be visited by new home-care assistants and that they therefore treated her like one of them. It might also reflect the fact that the interviewer was used to doing home visits and therefore perhaps acted in a non-threatening and perhaps professional manner. Her pre-understanding from working with rehabilitation for many years, together with values, such as the conception that the

participants should be put first and the researcher last (cf. Chambers, 1997) probably also had a positive impact on the interview situation and opened up for a constructive conversation. For example, when Anita interviewed the elderly, knowing that she is a physiotherapist or, more often, believing that she represented the home care system, the participants asked her about how to handle the safety alarm or about how to adjust the walking frame. In her turn, based on her professional background, she volunteered with advice or asked questions on the rehabilitation of the participants. Additionally, she helped the participants with practical matters. One participant asked her to post a letter that was urgent; another wanted her to help taking care of the laundry before they started the interview. Almost everybody offered her coffee. To the extent that these types of occurrences were visible in the transcripts or remembered and retold by the interviewer, they were discussed with the co-authors and integrated in the analysis of the interviews, and were thus not looked upon as redundant, but as part of the empirical findings.

Data analysis

In addition to concurrent data collection, coding and analysis, one of the major characteristics of grounded theory is hierarchical coding processes, meaning that initial or open coding is followed by focused or selective coding (Hallberg, 2006). As proposed by Charmaz (2006), when there is more than one researcher involved, which was the case here, they may code data separately and then compare and combine their codes. When engaged in such open coding, this is precisely what we did, and the discussions later formed the basis for the next step; that of focused coding, which means that we used the most significant codes when again returning to data. At this stage, we began to see the contours of a core category as well as a number of possible categories and subcategories (Strauss & Corbin, 1990; 1998). Applying a constructivist approach, at the last stage when looking for relationships between these categories, we were inspired by the theoretical coding suggested by Charmaz (2006).

As a result, the core category *ageing well or learning unpretentiousness*, as well as its categories and subcategories were constructed inductively from the interviews. For example, throughout the process, memo-writing and constant comparisons were carried out. In accordance with the use of literature put forward by Strauss and Corbin (1990; 1998), the initial interview schedule, based on a literature review contained issues like the use of ICT, empowerment, theories of ageing, homecare organisation and elderly rehabilitation practices. As a result of initial coding, a framework containing concepts like ageing well, disempowerment, dependency/autonomy, role of being old, physical capacity, and psychosocial wellbeing emerged, reflecting the stories of the elderly. This framework was then later used in the more focused coding. This means that the literature review presented in the introduction was not merely the result of studies of extant research carried out before the collection of data. Instead, it was driven by and evolved from the analysis of the interviews, in accordance with the lines between a literature review and a theoretical framework (Charmaz, 2006), the introduction above includes both a literature review and a presentation of theoretical concepts that are later used in the analysis. Although the analysis was not checked with the participants later, so called *member-checking*, it was discussed with other groups of elderly persons and representatives from pensioners' organisations. Additionally during the time of the eHHC project the analysis was also discussed with the Board of seniors at the municipality.

Understandings

The core category of this study is *ageing well or learning unpretentiousness*? It comprises four categories namely social networking, psychosocial well-being, physical capacity and empowerment. Each of these categories has sub-categories (see Table I). The categories were formed in response to how the participants were experiencing life with more limited functions in strength and balance and being less able to manage their daily activities. As a result of this, they were experiencing home care and had become users of safety alarms. The categories in Table I are not mutually exclusive. Neither are they fully 'saturated'. In formulating the categories we were uplifted by the Heideggerian (1996) principle of a 'lack in completeness of being'. This is explicated by Schatzki et al (2001) when they talk about objects of knowledge having the capacity of unfolding infinitely. They state that objects of knowledge,

"..... are more like open drawers filled with folders extending indefinitely into the depth of the dark closet. Since epistemic objects are always in the process of being materially defined, they continually acquire new properties and change the ones they have. But this also means that objects of knowledge can never be fully attained, that they are, if you wish, never quite themselves" (Schatzki, 2001 p. 181).

The formulation of the categories in Table I was also guided by the principles of experienced-based design (EBD) (Bate & Robert, 2006; Pickles et al, 2008). What is special about EBD, for ageing research, is that it focuses on capturing and understanding elderly people's personal experiences. One important way it does this is by encouraging them to 'tell their stories' (ibid.). EBD then goes one step further and requires the active participation of elderly people, as co-designers of an improved service (this is the focus of another paper).

Knowledge of the experience of ageing, held by elderly people themselves, is unique and precious. In this section of the paper we begin to move away from the traditional view of elderly people as passive recipients of homecare services and users of ICT, to the new view of elderly people as integral to the improvement and innovation process. Understanding their experiences is an important early step to make. In analysing the data it became clear to us that the participants' experiences were not static, but changing, and mixed with contradiction. For example with feelings of dependence and independence, feeling alone but not lonely, feeling safe but also unsafe, being both in control and experiencing a loss of control. These are situated experiences and important to understand. The individual stories of growing older, reflected strategies, employed by the elderly, to deal with their situation. For example on the one hand trying to remain the same person as before and yet on the other hand, to adjust to new life situations and to ageing. So the process of *ageing well or learning unpretentiousness* is a tensioned one, often evidencing itself in the data as elderly people 'living-with-contradictions' (Ghaye 2008). By this we mean that elderly people expressed feelings that could be viewed as apparent contradictions. Just as it is unwise to view older people as a homogeneous group, it is also unwise to think that older people experience ageing in the same way. Our data shows that the experience of ageing, both within and between individuals, was also not homogeneous. Any one participant could express both positive feelings and anxieties. Describe their current situation in both a contented way but also a manner that expressed a longing for something different. In communicating what Heidegger (1996) called 'being-in-the-world', these living contradictions (or tensions) are illuminated in Table I. Parts of this Table I are then illustrated with selected excerpts from the interview data.

Table I. Understanding ageing well or learning unpretentiousness?

Core category			
Ageing well or learning unpretentiousness?			
Categories			
Social networking	Psychosocial wellbeing	Physical capacity	Empowerment
Sub- categories			
Being alone/lonely	Focusing on here and now/ the future	Being (im)mobile	Feeling (in)dependent
(Dis)connecting	(Re)constructions of reality	Reflecting on (in)capability	Being in(out) of control
Being (in)active	Being (dis)content Feeling (un)safe		(Dis)using assistant technology

Category: Social networking

This category comprises the contradictory sub-categories *Being alone/lonely*, *(Dis)connecting* and *Being (in)active*. The feeling of *being alone* meant that many were living alone since their husband had died and also because many had children living far away, in another part of the country. Eight of the participants were living *alone*, most of them as widows and others as singles. The other two had a spouse with dementia which was also described as being alone. For the participants with a big social network, with many of their next of kin, still alive and children living close, being alone was not experienced so much. Many of the participants showed photos of their next of kin. This stimulated storytelling. They kept contact with relatives and friends by phoning each other and the telephone was experienced as something they could not live without. The *loneliness* was expressed as a longing for company. This was tinged with feelings of tentativeness, whether they could bother others with their loneliness. A way to cope with *loneliness* was visiting their neighbours and old friends, reading and watching television. One participant said: “*I am rather alone, but I watch TV extremely much.*” Being alone was at the same time looked upon as natural and something to try to adapt to and learn to live with. The reduced social network was described like this by one participant. “*I could take the bus. But there is not a need so much to visit old people because there are not so many left. They leave one after the other.*” Participants were aware of being in a situation where they were losing their social network. But there were different ways to adapt to this *disconnecting* situation. One way was to make friends with the care assistants. *Connecting* with new persons in this way was seen as a positive thing. They could become real friends.

So for some elderly people, it was important to have the same care-assistants coming into their home. For example,

“Yes, it is so fantastic, and I have heard others saying the same, that they also look upon homecare assistants that are coming as their personal friends. That is how it turns out to be. Really, if you have some problems of a kind that you cannot keep to yourself, I always talk to the girls. And there are some boys as well.....because they are so extremely kind. There are no bogymen working as care assistants. They are kind persons, very kind and they are exactly like any good friend of yours.”

Some of the participants appreciated meeting places where they could meet and talk, have a cup of coffee, maybe do some knitting and socialise. To *be active* as they used to be before, when their husbands were alive or when they were at work. They tried to encourage themselves to be as active as possible although they had limitations in strength and balance. One participant said, *“It is like this Finnish saying: ‘No one is lifting the tail of the cat. He has to do that himself’. You have to activate yourself. And keep going.”* There was a big consciousness among all participants that they had to *be active*, both as a way to keep their physical functions, but also as a way to get more strength and keep fit. One of the elderly people said,

“It is so that I have to try to get out for a walk in order to be able to handle this and gradually manage in the daytime as well. If I only could get the help to be out door for half an hour for a walk. Because it is important that you keep active. ..It is good if I walk outdoor because it is a big difference if you e.g. walk outdoor or just stay some meters indoor in the flat. Then you have to try to exercise your muscles and keep your body fit.”

At the same time they were experiencing *being inactive* and living more of their lives indoors. Interestingly, *“I do not miss anything”* was an expression to show that it was ok to be alone and not engaged in any activity outside the home. Although many elderly people longed for the summer when relatives visited during their holiday and when they could all go out for shopping and to cafes, they were, at the same time, acknowledging that much more of their life was indoors and that this was an adjustment that had to be made.

Category: Psychosocial wellbeing

This category comprises the contradictory subcategories *Focusing on here and now/the future*, *(Re)constructions of reality*, *Being (dis)content* and *Feeling (un)safe*. The participants were *focusing on here and now* when they said things like, *“You must live a life that you can get as much out of as possible.”* Expressions about *the future* were often about how they might be able to stay at home as long as possible and having to stay at an elderly home. This was looked upon as scary. One participant said, *“It is a black ghost for me when I think of this. That I should not be able to live at home.”* Another said: *“You don’t care until you are there.”*

Another expression which *focused on here and now* came from one participant who had just had a stroke. She described her situation, *“And I have never before been eating any medicine, so this is all new for me. But I have been able to live for 86 years so I must be grateful.”*

The participants were aware of their present situation and focused on how they should act in order to adapt to it. This was expressed by one participant like this:

“It is a question of being able to speak on behalf of yourself to hold one’s own.....When you come in this situation you get to see how important this is. Of course I have to say that it is exceptional how much help you can give persons like this. I am very grateful for everything.”

Growing older and being old were described with the consciousness of not being treated or met as before, when they were younger and more active. This was a fact they had to accept as a *construction of reality*. They felt they had to learn to live with this. One participant compared how she had been met in her working life and how she experienced it now.

“It is mainly young people that are promoted and that you read about in the press. I do not exist..... Well I must not care about this.....I am very much against this segregation.....after a certain age you ought to die. Or are you supposed to live? You are supposed to be a pensioner, a happy pensioner, but not supposed to do something.”

This way of being met was sometimes experienced when visiting a doctor and being told, “*At your age you can not expect to be fully fit*”. This made the participants think about having to *reconstruct* the image they had of themselves and try to accept that they were older than they often felt inside. That this could be different from others’ perceptions of them. At the same time as the participants described themselves as dependant on help from others and being less capable of managing activities of daily life, they also talked about their concern about others, as old and fragile and what it would be like to have dementia. *Reconstructing reality* was expressed by one participant in this way.

“There are those who have certain severe illnesses, those you cannot speak with. But we can speak to each other without any problems. It must be a tremendous difference, this not being able to stay in your own home, it must be terrible. So I hope that I never will experience this because the atmosphere at those kinds of elderly homes can be so different. Those, what do they call them? ...demented persons, they can be very hard to handle, I believe, for those who are taking care of them.”

Reconstructing reality often involved the process of reframing, or seeing things from a different angle. One participant said:

“I am optimistic. So I use in fact to look upon everything from the bright side. Or everything.., most things. So I get very happy when people tell me “Oh what a difference it is now compared to when you got home! You walk so much better and at the start we had to take you in the wheelchair and now you can walk by yourself with the rollator!”

All the participants expressed that they were *being content* with homecare services. *Being content* or *discontent* differed both within the same person and between the different participants. Sometimes *being content* was expressed as being able to exert a positive influence over the kind of homecare they felt they needed. A measure of *discontent* was expressed when participants realized that it was not possible to some of the things they felt they wanted, like an outdoor walk, a visit to the shops or training to get better strength in their legs.

The participants expressed an empathic understanding about the care assistants’ work, about their limited time and limited resources within the service. They also thought that the occupation had a bad status. They admired the care-assistants for being so nice and patient and for their own sake they were afraid to be bothering or taking too much time because they moved and acted so slowly. Interestingly, this made the matter of *being content* or *discontent* a tensioned experience. For example,

“I have been healthy in all my times and suddenly you get stricken by a thing like this and get dependant by others. Not being able to take care of yourself and being dependent on others, that I will not be able to take care of myself and when you thought of this before

you thought: "Oh how terrible to be dependant on other people, then I will rather leave everything." But as homecare is functioning here, I cannot praise them enough and the system itself. It functions so well.....One has heard so much about having homecare, that there are so many different people that are coming. And so it is, many are coming, one after the other. But I feel it is so nice to meet with different people, different people that are coming. I mean, one is saying this and one is saying that, but I do not experience this as negative but on the contrary. And I use to think like this: "Yes, I wonder who will be coming tomorrow? I wonder who will be coming tonight? And it is not so that I dread this, but on the contrary, as I said, I experience all of them (care assistants) so positive and nice."

The sub-category *feeling (un)safe* is full of apparent contradictions in the way we have explained them. For example all the participants had a safety alarm installed, often after advice from a doctor at the hospital or because their children thought it would be safer for their parent to have one. Some of the participants had used the alarm in connection with some incidents of insecurity or after falling. Knowing how and where to get help, made them *feel safe*. Some of the participants had not used the alarm, but *felt safe* just to know they had one, just in case something happened to them in the night. At the same time as they feared falling, they described how they were quite used to falling since they had experienced falling so many times. One participant described it like this:

"I have fallen so many times. Here outside I have fallen, beside the shop I fell because the sliding doors closed in front of me and I have fallen with my rollator. It was a guy that pushed me so I fell. I have fallen at the house we used to live in before and the dog made me stumble and fall because of the lead. And in the bathroom here and there."

The fact that a safety alarm did not function outdoors and not all the participants realized this, added to the tensions within this sub-category. For example, *"If I fall and get one of these attacks of fainting, I count on the fact that there will be people around me that can call for help.* Safety was an important issue for the care assistants and one participant that used to fall a lot said: *"They say to me that you must not walk alone, you have to tell us. And I tell them but they forget about it because they have so much to do these girls, far too much."*

Another reason for *feeling unsafe* was associated with a fear of violence. This was mentioned as one reason for not going out in the evening. One participant said, *"Freedom of movement is that I can choose to go where ever I like. But now this violence on the streets and markets has increased. You never know when you might be effected your self."* Feeling unsafe was also connected to balance problems, fainting or other functional limitations while walking outdoors.

Category: Physical capacity

This comprises the contradictory subcategories *Being (im)mobile* and *Reflecting on (in)capability*. There was a consciousness about the importance of *being mobile* and physically active and to keep on being as active as they could in relation to their functional limitations. As one of the participants put it,

"I have promised myself that I will go outdoors every day....Sometimes I just walk around the house, but I usually walk with my rollator for shopping a couple of times a week and it is not so easy as you may believe." Another elderly person said, *"It is a big difference with the freedom of mobility if you compare before and now, because I am like reduced to these four walls when I am in-doors...compared to before."*

With the help of the care assistants many of the participants took the chance to take a walk indoors as exercise. This was planned for particular days. For example, *“I think it is written in that book about walking-exercises. So it is always when they (care assistants) are here, then I walk around, all the time. Because I am in some way more safe if someone more than me is here. But it happens that I walk alone also. But I am not that safe. Because I mean I can slip.”* This help with walking was experienced as very important and all participants that had this service thought that once a week, on a certain day, was not enough as exercise. The contradiction between the need for exercise and not wanting to walk alone was expressed like this.

“It is training that I need but the girls say that “you must not walk alone!”. But I don’t think that I get any training just walking with my rollator indoors. I have to walk and hold on to somebody, and then I will get more strength in my legs.”

Many longed to be more mobile and active but they were not aware of how to fulfill this need. If they asked the care assistants for this kind of help they were afraid that this would be rejected. One participant said,

“I have never asked if they could do that (accompany for a walk). I walk so slowly so that would not be much fun for them. No, I have not asked them for this. But I have adjusted myself to this and...I stay inside in my home and I always have something to do and to be interested in, as long as I can sit here and.....I never, never have a boring time. I don’t have that. It is so fine.”

This longing for being mobile was expressed by one participant as like *“an itching in my body.”* Two of the participants had been active when they were younger and saw exercise and training as a way of keeping fit. They found it hard to not being capable to exercise alone without support or help any more. One participant answered the question about what was her greatest wish: *“Well the only thing would be, I wish that I would be able to walk out-doors more than just once a week. Just for a short time!”*

Experiences of *being immobile* and dependant on assistive technology and taxi services for the disabled were narrated in many of their stories. The rollator was impossible to use when the roads were full of snow. Also the taxi service was not always reliable. One participant told about how she had missed her friend’s funeral and came just to see her coffin being carried out from church, because she had to wait for the taxi-service for the disabled although she had ordered it beforehand. She compared this with the taxi service to the airport that she thought never would let any businessmen come too late to their flight. Another told her story about standing out-doors in winter in minus twenty degrees waiting half an hour for the taxi. One of the participants described the experience of taxi-service like this:

“It functions badly because in this last week we had foot-care at 16.15 and I called at 15.00 and ordered the taxi service to come at 16.00. But it did not show up. So I had to call the foot-care and tell them that we were late. It was just lucky that they could serve us later. But this is not encouraging. But on the other hand you must understand the taxi drivers as well. It was rainy that day and it was a lot of people that was calling. So it worked. We got our foot-care.”

Participants reflected on their (in)capability and compared this with how they used to be. For example,

"You can not move around as much as you used to do before and look around.... ...before we used to go to the mountains, but now I cannot manage this walking around....."

Another said, *"When I sometimes ask them (care assistants) to take out a pot that is furthest away, down in the cupboard. When I remember to ask, they will do it for sure. But that is when I remember to ask. But there are so many times that you have to give up because you can not manage. I must give up because I cannot make it."*

None of the participants had any training or physical therapy at home. One of them said that she had got a home training program but that she forgot to do the exercises. She received instructions about how to do these exercises at the health care centre but it was not possible to do the same kind of training at home. Three of the participants used to go to the physiotherapist at the health care centre. To travel there was both tiresome and costly. But they felt that the exercises gave them increased capability.

"Yes I now know that I am capable of rising up from the floor because we have been training to do this. The physiotherapist has been very precise with that you must practice how to raise in case of a fall and to walk the stairs almost already from the start."

They reflected on their incapability and how many activities they would like to do in their mind that was not possible to do because of functional limitations. They gave a picture of themselves, how they had lived their life before, as active, taking long walks, every day no matter what the weather looked like. A time when they went for shopping without any problem and visited friends. But this was less possible now. One elderly person said,

"I have sometimes had the thought that....would I dare to go out-doors by myself with the rollator? Because it was one day when I forgot to buy something, when we had been out shopping, and I forgot this and it was....It was important in the sense thatit was important for me. And I thought: Imagine if I should dare to go out! No, I didn't. I thought that I shall not take the risk. Yes, it was something I forgot, I thought of buying some sweets for coffee, so it was. But I didn't because I am not that secure so I know that I would manage."

Category: Empowerment

This comprises the contradictory subcategories **Feeling (in)dependant**, **Being in(out) of control** and **(Dis)using assistive technology**. After an incident like falling or a hospital visit because of heart problems, stroke or some physical weakness, they participants gradually became aware that they could no longer manage at home by themselves. This was expressed like, *"At the start I felt like I wanted as little help as possible. I wanted to feel like I could do something by myself, but they have managed to persuade me to take more service than I had thought from the beginning."* This feeling of dependence was often actualised by their children who, as many were afraid some new incident could happen, advised them to get a safety alarm or get in contact with homecare services. As one of the participants said,

"Yes my next of kin, my son, that is not living in this city, he saw to it that his mother could not go home from the hospital after six months without homecare being involved in one way or another. And most of all because I should not fall.....So this was the case and I realized that I could not manage in my flat without a support of some kind, that was given."

Being in control was strongly connected to being independent and it was described as a struggle with themselves when they had to cope with others helping them with activities of daily life. For example with regard to how the porridge was cooked, how the laundry and cleaning was done and how much food they should eat. The elderly people were aware that they needed help and ought to be happy at receiving this, but at the same time it was experienced as *being out of control* and also tiring. One person expressed *being dependant* in terms of someone else taking control over matters they thought they should manage by themselves. This added to a sense of *being out of control*. *“It was so super tasty when you could cook yourself. This is the kind of food you long for. I used to like to cook once. But now I have given it up.”* Additionally one participant described her relationship with the care assistants like this,

“I have a dishwashing machine, but they like to wash by hands. I ask them ‘Why don’t you use the machine? You just have to press the button?’..... But I have noticed that you have to let them do it, because they like to do it.”

With regard to being tired, a meeting where homecare services were decided was described in this way by one participant: *“It was so much when I came home. They should explore and explore and explore. And people came all the time. It was very tiring (fatiguing?).”*

Losing control was a strong and persistent theme in the data. For example it was experienced as not to be the one to decide upon your own health, such as if and when they could take a sleeping pill. One participant said, *“I thought I was free to do what I wanted.”* Another example was about when and how to take their insulin. One participant expressed it like this. *“I was insisting since I had been doing it for 25 years so I could keep on doing it. But they wanted it to be the homecare that took the insulin-responsibility”*. Alternatively *being in control* of their health could also be saying ‘no’ to suggested treatments as for example surgery, because they did not know if it would succeed or not. One participant told how she had opposed the recommendation to have an operation:

“One of my hips is extremely bad, but I do not want to have the operation, because I am very sceptical when it comes to surgery. I do not think that it will be better. And as long as I don’t have extreme pains...”

A way to *be in control* was to have a strategy about how to act to reduce the risk that something would happen. For example to take away all carpets so that they would not slip. Have a telephone in close reach to the bed and learn how to get up from the floor in case of a fall. One participant expressed her strategy as, *“You see to that you make friends with the neighbors next door so that you dare to ask them for help as well.”* Another strategy to *take control* was to act as a kind of ‘supervisor’ to the care assistants. One person described this activity thus.

“And, I got pretty tired of having to explain every time there was someone new, what and how to do, so I took a large paper and wrote down, item by item what there was to be done, from making the bed etc.. And when their boss heard about this she found it very good. “This ought to be done by many...”

As already mentioned, the participants in this study were all users of a safety alarm. Often this *use of assistive technology* was initiated by their children. Some elderly people had experiences of using the alarm in cases of emergency, after a fall and were pleased to know that someone was coming for help, very fast. Others had never used it. It was just there for their safety, lying on their night table, just in case.

“Because when I got ill, I fell here in the hall and my next of kin were very anxious that I should have a safety alarm and so did the physiotherapist. But I have not been using it for myself. I had it always on my arm and you should have it on in the shower and so and I have not been wearing it now but I have it on my bedside table.”

The participants in the study had all used *using assistive technology* for quite long time. The most often used assistive technology was a rollator which was praised as the best assistive technology they could think of. One participant expressed this as: *“It is a very practical invention, the rollator, and the one who invented it ought to get the Nobel Prize. It has served humanity so terribly much. It is fantastic.”* Another said, *“I used to say ‘This is my pal!’ ...Yes, without it I would not even be able to move around in my flat.”* Less pleasingly, many of the participants described how other *assistive technologies*, such as the safety alarm was installed in their home without any discussions in beforehand. This made these elderly people look upon the technology as something they were not owner of, control or understand fully. They had the same attitude toward an electric door opener or a hall telephone. One participant described how she got some technology. *“They just came here with that apparatusso I was reacting against that...I already had one thing that took space on the hall table and so they came with this other thing...I thought that it is a must with this one also.”* With regard to influencing what assistive technology they would like to have, one participant answered,

“But I don’t know if I am particularly interested in that either. In all cases I am 87 years old. So that means that I am pretty old, so I don’t have the strength to be so much on the go. Possibly be walking down to the shop...”

New mobile technology was discussed in each interview. The elderly people were informed about different forms of ICT. There were discussions about its future use like a mobile safety alarm with positioning, the internet as information support and the use of e-mails in communications between health, homecare and rehabilitation centres were all discussed. Elderly people reacted differently to the different uses of assistive technology. One participant said that if she had not had difficulties in sitting, she would have got herself a computer. Others said that as their late husbands were against computers, they were also against them. Some had difficulty in thinking about how it would be like and others thought it would be fantastic and that it was fascinating, what technology could do. Comments were,

“Yes, it sounds unbelievable, but it sure must cost a fortune”, “It sure must be facilitating a lot, but it must not be too costly” and “Well, from my point of view I do not think that I would need something like this. No, I don’t think so.”

Another participant saw the possibility of using a mobile alarm. She then speculated about daring to walk a longer distance. The fact that a mobile safety alarm had a positioning function was not experienced as a threat to people’s integrity. One said:

I think it is such verbiage with personal integrity! I think it is quite ridiculous. Because it is all about helping the person in question. This is about supervision... We are supervised all the time! Where ever we go. And I do not think about it. So I think this is verbiage. It is just for us, that we should get this help.”

Discussion

In this section we reflect upon both our methodology and the understandings derived from it. In doing so, we essentially address the knowledge question, “What have we learned about ageing well and learning unpretentiousness?” We suggest that the data points to three kinds of understanding. They are to do with theory building, methodological development and service improvement.

Theory building

First, we have come to understand that continuing to build a theory about ageing well and learning unpretentiousness, needs to be situated within the more general demographic transition processes in Sweden and within the European region, particularly their pace and social impact. Arguably this is a prerequisite to meet particular ageing challenges. Secondly, in undertaking this research, we have sensed the real need to develop a more holistic theory that makes the links between the processes of ‘ageing well’ and enhancing older people’s quality of life, more explicit. We suggest that one important part of this is to positively engage with particular groups of older people, to appreciatively and authentically deepen our understanding of what they feel, think and what they perceive their needs and wants to be. By ‘holistic’ we mean a theory which acknowledges that ageing is not equal. People age differently. We are therefore suggesting that what is needed is a theory which reflects the fact that older people are not a homogeneous group, but groups with different ageing trajectories. They are people who have different views of what quality of life means and life-course perspectives. One challenge is to work out how to generate opportunities for the synergy required to build such a holistic theory. In this paper we believe we have made a contribution to this by, not only, exploring notions of ageing well, but by placing this alongside learning unpretentiousness, in an apparently contradictory relationship. In doing so we have taken what Allardt (1981) originally called ‘dilemmas’ in his classic comparative Scandinavian welfare study and reframed dilemmas as elderly people ‘living-with-contradictions.’ By implication, we have reframed Allardt’s (1981) original dilemmas which were objective and subjective indicators of quality of life, material needs and social needs and re-cast them within this contradictory frame. In this reframing we have paid particular attention to expanding Allardt’s (1981) notions of ‘Loving’ (experiences of attachment) and ‘Being’ (social relations). For example Table I shows that our data has enabled us to generate the four categories of social networking, psychosocial wellbeing, physical capacity and empowerment. Taken together these categories comprise a further twelve sub-categories. We have not addressed Allardt’s (1981) ‘Having’ notion (material conditions) because our research emphasises the active role of elderly people’s experience and their physical capacities and capabilities in determining the quality of their lives. This is what Lane (1996) called the ‘*quality of persons*’ in determining people’s quality of life.

Methodological development

First, we agree with Mollenkopf & Walker (2007) that it is important to engage with elderly people in order to ascertain what they feel are the important experiences that positively contribute to the quality of their lives. In order to do this we have been guided by the principles and processes of an approach called ‘experienced based design’ (EBD) (Bate & Robert, 2006; Pickles et al, 2008). This approach encourages elderly people to ‘tell their stories’ of ageing (ibid.). By drawing upon a constructivist grounded theory approach (Charmaz 2006) we were able to analyse these stories to pinpoint those experience that appear to most powerfully shape participant views of ageing. Secondly we have come to understand

that a common feature of almost all quality of life approaches is the conceptualization of quality of life as concerning *individual* characteristics (Noll, 2007). Dimensions of human welfare related to more *societal* characteristics and qualities such as participation, empowerment, social cohesion, access, inclusion, sustainable societal capital, self determination, choice and so on, which affect an individual's experience of ageing have been rather neglected. Methodologically, we have tried to overcome this dualism in this paper, by including both individual and societal elements in a creative way. We include the individual by presenting a summary of the whole data set in Table I, supported by excerpts of the stories of elderly people. These may be regarded as their subjective experiences of ageing well or learning unpretentiousness. We include the societal in the way we have undertaken this research. By that we mean we have positively embraced, and put into practice, such societal values like the positive engagement of elderly people themselves in service improvement, the development of a democratic and reflective discourse and by working with research participants in an egalitarian and collegial way. Thirdly we have come to understand that theory building, using participatory and experienced based design methods, brings with it a range of ethical issues that need to be explicitly considered in order to avoid older people being exploited and misrepresented. This paper adds to the current ethical debate about public participation in service improvement and re-design and particularly the involvement of some people who may be frail, vulnerable, lonely, who experience loss of mobility, of affection and so on. Three key concerns are, who to involve, how and to what extent? Another is, 'what is the best we can do with what elderly people tell us?' What is clear to us is that participatory research into ageing needs to be of some clear benefit to those older people who have taken part. So what does meaningful and ethical involvement mean in practice? Fourthly, and as a consequence of this methodology, we more fully appreciate that elderly people have much to say about issues like quality of life, about empowerment, self determination (Carlstedt & Forssén 1999), influence, autonomy and mobility (Mollenkopf & Walker, 2007) and how their needs could be met? They were not short of ideas. The participants were no victims. They kept their identity and they had a lot of self-determination. But interestingly they had little possibility to act and be as they would like to because of several reasons. They adapted to their new situation because they thought this was what they ought to do, should do, because they could no longer manage by themselves. They may be dependent but they were no victims. Sometimes they struggled to find the best possible way to cooperate with homecare, to relate to them in the best possible way. When they reflected upon their situation, they seemed that there were things they could do about ageing like training (Rydeskog et al, 2005, Elkjaer et. al, 2006), out-door walking and using assistive technology, but they often did not know exactly how to satisfy these needs. We learned that these elderly people were not necessarily dissatisfied or unhappy but were trying to accept and to adapt to their new life situation (Peel et al, 2007). They were also learning how to manage their expectations of homecare (Wikström 2005). In Swedish it is called, 'Gilla läget' or getting the best out of the situation. In this paper we have called this 'learning unpretentiousness'. What pretensions can we have in our society when it comes to care? What can we afford? What is ethical? What is good enough? Who should pay for this?

Service improvement

First, we suggest that this paper contributes to a knowledge base for the management and delivery of services. It has tried to achieve this by valuing the contributions of elderly people to service improvement and by listening and responding to what they say. This paper has focused on the first part of 'listening to'. It has listened to elderly people's experiences of ageing. In this paper, we have moved away from the traditional view of the elderly person as a passive recipient of homecare. This has given way to the new view of elderly people as

integral to the improvement and innovation process. The paper is therefore located within the wider '*practice turn*' in social theory and healthcare management research more generally. Secondly, practice theorists tend to emphasise the importance of not just *what* is done, but also *how* it is done (Schatzki, 2001; Whittington, 2006). They make an important distinction between 'practices' and 'what happens in practice'. In this paper we have tried to demonstrate that what needs to 'happen in practice', to further improve policy and homecare practices, is the development of service strategies that actualize the authentic and positive engagement of elderly people.

We suggest that in order to understand ageing well and learning unpretentiousness, we need a more holistic theory of what constitutes a 'good life'. To achieve this we suggest we need a participatory and appreciative methodology which sincerely values the experiences of elderly people and which respects the integrity of what they say. Finally we suggest that to build an even better future for both the younger and older groups within the elderly, we need to further develop our current understandings of ageing well. This paper has subscribed to the view that we can build a better future, for the elderly in society, from aspects of the positive present. In order to do this we suggest we might usefully go on and ask elderly people three fundamental and appreciative questions;

- (1) What contributes to life being 'as good as it can be'?
- (2) So what do we need more of?
- (3) What do we need to do more of?

If we change the questions we ask elderly people, we have a chance to change the conversation. If we change this, we create an opportunity to change the action. These three questions hold some promise to do this as they shift the focus away from 'what's life like?' and 'what should life be like?', towards the explicit action question, 'what needs to be done to make life as good as it can be?'

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Paper III

Safety vs. privacy: elderly persons' experiences of a mobile safety alarm

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Abstract

The demographic development indicates an increased elderly population in Sweden in the future. 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 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 elderly persons through testing a mobile safety alarm and their reasoning about safety, privacy and mobility. The mobile safety alarm tested was a prototype in development. 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 6 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, the overarching category 'Safety and mobility are more important than privacy' emerged. The mobile safety alarm was perceived to offer an increased opportunity for mobility in terms of being more active and as an aid for self-determination. The fact that the informants 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. It was concluded that 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. The participants were actively contributing to the development process.

Keywords: elderly, information and communication technology, mobility, privacy, safety

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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 (Statistics Sweden 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 healthcare services should be easily accessible, meet client's needs and be provided in accordance with political priorities. Social care should provide acceptable and safe living conditions and give prerequisites for quality of life (Swedish Codes of Statutes 2001:453). Therefore, it is a great challenge to provide elderly care of high quality, to promote self-determination, personal development and social participation of elderly persons, and to

develop products, services and technologies that meet their needs (Bond & Corner 2004, Norén 2005, Persson & Lexén 2006). Health factors are important to promote, such as the availability of social networks and social support and safety and privacy. Additionally, safety is important for elderly people and can be seen as an ongoing individual process that progresses with the increased awareness of risks (Stave 2005). A safety culture can be 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. To obtain this and to avoid risks, it is important that elderly people are 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' (International Classification of Functioning, Disability and Health 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). Sweden has a high percentage of technology and computer literacy regardless of age (PTS-ER 2006:1). Among 16- to 75-year-old Swedes, the usage of mobile phones is 92%, 83% are using computers and 78% have access to the Internet. In the ages 61–75, the usage of mobile phones is 19.6%, 13.5% have computers at home and 12% have access to the Internet. Of these 6.7% use the Internet daily. Mobile telemedical solutions and Internet usage have been introduced in home rehabilitation aiming at increasing independence, safety and mobility. Different kinds of new technologies are designed to prevent undesirable events related to the mobility of elderly patients in hospitals and nursing homes, i.e. patient falls, bed-rail entrapment, patient

treatment and wandering (Miskelly 2001, Essén 2003, 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 conducted, the so-called SAFE-21 (Tie 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 European Union's Information Society Technologies 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 the General Packet Radio Service and Universal Mobile Telecommunications System mobile services and technologies (Melander-Wikman *et al.* 2004). The main task of MobiHealth was to deliver a flexible and dynamic service to patients and healthcare providers with a focus on optimal utility and usability. Nine trials with a participatory approach were performed within 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 a decision support. One of the trials involved the testing of a mobile safety alarm (Melander-Wikman *et al.* 2007). Results from this trial showed that the care assistants felt that using a positioning device to track someone was an ethical dilemma, but this was not experienced by the elderly test-persons.

Elderly persons often use safety alarms in the form of care phones as a technology to make staying at home possible (Essén 2003). This alarm normally functions by pressing an alarm button that is fixed on a device that resembles a wristwatch or a necklace. Members of the staff answer via a phone with a loudspeaker in the client's home. The care phone is connected to the ordinary telephone system. Homecare staff 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 homes. 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 persons' experiences of testing a mobile safety alarm and their reasoning about safety, privacy and mobility.

Methods

A purposive sample of nine informants were recruited in 2005. Staff from the municipal elderly care organisation

Mobile safety alarm

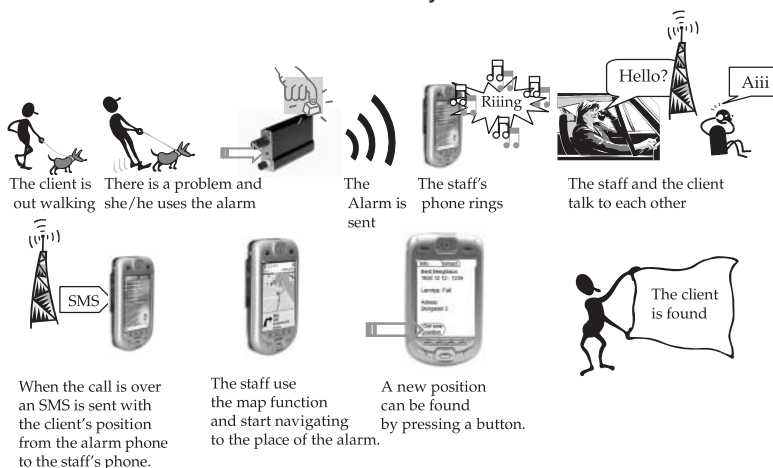


Figure 1 Function of mobile safety alarm (used here with permission from Hallberg, personal communication, 11 July 2005).

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. 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. The latter group of informants were users of traditional – not mobile – safety alarms with a range of 10 metres and installed in their respective homes. 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 informants were experienced in using information and communication technology, such as mobile phones, and some also used computers in their daily life.

The intervention

The tested safety alarm consisted of an alarm with a global positioning system (GPS) receiver and an inbuilt drop sensor. The mobile safety alarm tested was a prototype in development within the Mobile Safety Alarm Project, a collaborative research project carried out by researchers from the Departments of Computer Science, Electrical Engineering, and Health Sciences at Luleå University of Technology together with staff from the municipality's elderly care. 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 Figure 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 per 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.

The mobile safety alarms were tested for 3–6 weeks between December 2005 and February 2006. Three informants also tested a safety alarm with a drop sensor. 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 informants tested the mobile safety alarm in their daily activities during this period and used the alarm when walking outdoors, e.g. visiting friends, visiting the hospital or taking daily walks.

Data collection and data analysis

To explore how the informants had experienced the use of the mobile safety alarm and their reasoning about safety and privacy, interviews were conducted after the test period. Kvale (1996) argues that the qualitative interviews should be an everyday conversation that is at the same time a professional conversation. The

Table 1 Quotations, codes and categories from the categorisation procedures

Examples of quotations	Examples of condensed codes	Subcategory	Main category
But suppose if I pass out ... what will happened? Then none will send an alarm. This is again about integrity, as you have to relay on that other people see your dilemma and ... see to that you get help. (Fp8)	She is afraid that she might faint and fall and then she has to relay on others – that they will see to that she gets help.	Fear of falling	Feeling safe
I walk beside someone and have a living support which means that I hold on to somebody when I am walking and then it goes well, because I never walk alone outdoor. And this has partly to do with that I am somewhat anxious to fall. (Fp7)	Due to the fear of falling she doesn't walk by herself outdoor.	Fear of falling	Feeling safe
Today it unfortunately happens many unfortunate incidents and many are sadly elderly people and when they see 'this person cannot run so fast, let's snatch her bag', this have made me leave my bag at home. I cannot run away from anybody! If it had been in former times it had been different, but now we are in presence. But an alarm is safety, without a doubt. (Fp5)	She is afraid of being robbed and that she would not be able to run away anymore. But an alarm would give safety.	Fear of violence	Feeling safe

Table 2 Analysed emerging categories from the interviews with the test persons of the mobile alarm

Overarching category: safety and mobility is more important than privacy

Main categories	Subcategories
Feeling safe	Fear of falling Fear of violence Fear of not being capable to take care of oneself Someone at the other end
Being mobile	Freedom of movement Able to do what you like
Being positioned and supervised	Nothing to be ashamed of Living in a 'society of surveillance'
Reflecting on new technology	Participating in development and design Acceptance and fascination

conducted interviews were narrative but also reflective. The understanding of how people experience their lives may improve through their stories (cf. Sandelowski 1991). The interviews were conducted by the first author, took 1–1.5 hours, and were tape recorded and transcribed verbatim. Each informant was given the opportunity to talk for as long as he or she wished without time pressure. All interviews took place in the informants' homes and covered topics like experiences of safety alarms, both traditional and the tested mobile safety alarm, mobility and freedom of movement, and the meaning of being active in old age. Theories and dimensions of empowerment were the basis for the framework that guided the interviews.

The stories of the informants were analysed by latent content analysis (cf. Downe-Wamboldt 1992, Graneheim & Lundman 2004). In latent content analysis the underlying meaning of the text is interpreted (Graneheim & Lundman

2004). The analysis procedure was conducted in the following stages: The whole text of the interviews (*the unit of analysis*) was read several times. After reading the interviews, *meaning units* were identified and sorted into groups and condensed to shorten the content but keep the core. The meaning units were then condensed to shorten the content, but still keep its core. Finally, 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 (see Table 1). An overarching category *safety and mobility is more important than privacy* emerged as the latent content of the interviews (see Table 2). The three authors discussed the codes and categories together to reach consensus.

Ethical considerations

The coverage range of the alarm system was a safety factor, meaning that an emergency situation might be undetected. There was an ethical imperative to safeguard against this happening and the informants were informed not to use the mobile alarm in case of emergency. Informants with functional limitations who usually did not leave their home on their own were accompanied by others. Vulnerable patients were not asked to participate. When positioning was used, the informants 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).

Findings

The analysis resulted in seven subcategories 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.

Feeling safe

In the view of the informants, the main reason for having a safety alarm was safety. Five informants 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. As put by one of the interviewed:

I know 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 by the concrete wall in the basement of the house. (P1)

All informants 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. (P7)

In this fear of falling, there was also a feeling of insecurity concerning whether anyone would come to their rescue in case they would fall and remain lying there. And this had to do with the fear of losing control. One of the informants viewed this as an unwelcome dependency on others and said:

You have to rely on others, that they will notice your dilemma ... see that you get help. (P4)

Informants 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 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. (P5)

Some informants thought that a safety alarm could be developed and also used as an alarm against burglars in their homes. Two informants thought that this technology should be integrated into other technologies in the home, such as home alarms and telephone systems. The

informants feared 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 swear that you could steal that car as easy as that. Nobody would do anything. (P2)

Having control over the situation was perceived as important and the informants feared not having self-control in the future if the physical functions would decline. One informant had prepared her son for this situation and said:

I often 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. (P7)

None of the informants felt 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. Not everyone had relatives or next of kins and in these cases it was considered as important that the municipality should provide this service with a safety alarm. Opinions varied on what kind of professional competencies were needed for the professionals for answering the alarms. The main thing was a 'fellow being' that could decide very fast what to do next and ensure that the best help needed was called for. The informants without functional limitations wanted staff with medical competence at the other end of the alarm:

This particular alarm should be answered by so-called professionals or those who have this as their job. I absolutely believe so. (P9)

Being mobile

When the informants 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 expressed as: 'That you can come and go as you like' (P6).

The informants 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 informant 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. (P1)

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 did 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. (P2)

Being positioned and supervised

All informants 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. (P5)

These informants 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 informant 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 that are taken and you can get to know everything about your life. (P1)

To the question about if the locator was experienced as a threat to privacy the informants answered with an attitude of resignation:

.... yes, computers make 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. (P6)

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 informants thought that this kind of data should only be in 'real time' and be deleted and not stored. The overall

opinion was that it was of high importance that they could decide themselves when and how to use the mobile safety alarm.

Reflecting on new technology

The informants 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. (P8)

Overall, the informants 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. (P8)

Almost all of the informants had ICT experience, using mobile phones and some also used personal computers in their daily life. This experience was the same in both groups. One informant 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. (P2)

The informants 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

Some methodological considerations

In a qualitative study it is important to discuss issues of trustworthiness and how credibility, transferability and conformability can be analysed (Lincoln & Guba 1987). Credibility can be analysed by taking the interpretation of the data and data itself back to the sources from which they are drawn. In this study this was attained by presenting the results and discussing them with the municipality's reference group of pensioners from which four of the informants were recruited. The informants were recruited aiming at obtaining a purposive sample, including informants that represented both healthy active pensioners as well as elderly persons with experiences of functional limitations after, for example, stroke. This design was meant to achieve credible findings.

The fact that the informants were recruited by staff from the municipal elderly care organisation may have influenced the trustworthiness of the selection of informants, as this might give rise to the question whether special types of informants were selected, for example, those that the staff knew had a very positive attitude to new technology. The relatively small number of informants is first of all due to the design of the tests and the availability of technical devices. But the aim of this study was to describe not only elderly people's experiences of a mobile safety alarm, but also their reasoning about safety, privacy and mobility. This should be seen against the conception that obtaining statistical generalisations are not the purpose in a qualitative study but to get a deeper understanding of a new phenomenon.

Discussion of the findings

The overarching category showed that *safety and mobility were experienced as more important than privacy*. The informants focused on feeling safe and secure, feared falling and not being noticed and *not being able to take care of themselves*. Living alone with balance problems and trying to be mobile and active may increase the risk for falling, which also has been shown in previous research (Tischler & Hobson 2005). Fear of falling is a multifaceted and valid everyday experience among elderly which may include fear of a physical injury, fear of lying a long time without help, losing independence, being limited to a life in a wheelchair and being institutionalised. In this study, the informants' need for autonomy implied risk taking, leading to avoidance of activity and restriction in mobility. This is a well-known phenomenon, described by other researchers (Vellas *et al.* 1997, Zijlstra *et al.* 2007). Although risk prevention is needed, preventive advice on falling has been seen as a potential threat to identity and autonomy and, therefore, has been rejected (Yardley *et al.* 2006). The interviewed also expressed a *fear of increasing violence* in society. For example, as their usage of a walking aid exposed their fragility, they felt that they were potential victims of robbery and assault.

The results showed that the mobile safety alarm was experienced as a tool to be active and mobile, *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 most important expected benefits of using the mobile safety alarm and locating device were increased mobility and possibility of living a more normal life than before. According to previous research, empowerment organises life in a way that enhances self-control and self-determination (Rappaport 1981). Based on the results of this study, it might be concluded that mobility,

which can be seen as prerequisite for participation in society, is a dimension of empowerment. Furthermore, a mobile safety alarm can be seen as a resource needed to participate in society. Participation is defined as involvement in life situations, according to the International Classification of Functioning, Disability and Health, involving 'taking part', 'being included', 'being accepted', 'engaged in an area of life' and 'having access to needed resources' (Molin 2004). Not all informants wanted to put the responsibility to the hands of other people, even if this would increase freedom of movement. Furthermore, the informants reasoned about who should be *at the other end of the alarm*, and were all of the opinion that it should not be their relatives, as they were too busy. It was also considered a risk, since relatives might forget to bring the alarm receiver or to reload it. Instead, the interviewees said they would like a professional from the healthcare services to answer the alarm. This way of relying on professionals when it comes to telehealth and telecare services has also been found in other studies (Magnusson *et al.* 2004).

None of the informants experienced that being positioned by the mobile safety alarm was a threat to privacy. Why was the threat to integrity not seen as important by the informants? One reason was that the information was perceived as essential and not of a sensitive nature, which was expressed as having 'no secrets to hide'. Trust and privacy are reliant on our perceptions of these concepts (Adams & Blandford 2005). Nissenbaum (1998) argued that information that is personal/private is at the same time is public. He also argued that, in a normative discussion, information may be harmless, but 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'. Furthermore, there is a risk that we throw away our possibilities to continue being private, which might be compared to the fact that if we talk to someone in a public place, we risk being listened to by others. Seeing themselves as *living in a 'society of surveillance'*, the experiences of the informants were those of resignation. This should be seen against the fact that, with new ICT, it is easier to collect, store, process and analyse data (cf. Nissenbaum 1998) and that information in the public arena can be ordered, systemised and analysed from aspects other than they were meant for when they were collected. ICT use changes the view upon what is private and what is public, meaning that the individual no longer has control over the total description of him- or herself available through authoritative databases and, for example, via the Web (Nissenbaum 1998). Ström (2003) stated that ICT ethics is an area that needs increased focus and that although the digital revolution might be regarded as positive, it might also lead to very

many undesirable consequences. The access to personal, identifiable information increases every year and so does the amount of 'electronic footprints', e.g. wireless communication. The fact that actions of staff might also be traced in the surveillance and monitoring data of new positioning systems is highlighted by, for example, Roback & Herzog (2003). All these circumstances point to the need for ethical guidelines concerning ICT use within home health care (Magnusson & Hanson 2003).

When reflecting on new technology, the informants were positive, all of them having had experiences of using mobile phones and most of them of using personal computers in their daily life, which might be the reason for their positive attitude. Elderly persons have experiences of different technologies and therefore often have a relaxed approach to the possibilities that new technology offers (Östlund 1995). In this study, the reflections of the informants on new technology can be summarised as *acceptance together with fascination*. Magnusson *et al.* (2004) highlighted that it is a myth that elderly people have negative attitudes towards computer technology and that positive attitudes are strongly linked to personal usefulness of information technology. Issues of satisfaction are one of the most researched areas in telemedicine (Mair & Whitten 2000). The studies are often pilot tests of ICT. Expressions of satisfaction reveal little about the quality of the actual health care if a patient/client has no experience of that quality. In this study, six informants already had earlier safety alarm experiences, where mobility was restricted, and could see the possibilities with a mobile safety alarm. This may explain their positive attitudes to the positioning of the safety alarm and the fact 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. The positive attitude to *participating in development and design* of new technology among the informants in this study can be understood by the fact that, in Sweden, a dominant discourse is that ICT is supposed to secure growth and prosperity (Mörtberg 1997). The development of technology for elderly people should be based on the perspective of the users, who should be engaged in all parts of the process. Without their knowledge, there is a risk that technology will be developed that will isolate and exclude elderly people instead of including and empowering them (cf. Essén 2003). Previous research shows that, with increased technological skills and qualifications, there is a higher degree of acceptance of ICT and telemedical solutions (Bratton & Short 2002).

The main findings indicate that the fact that the informants were located by means of the positioning device was not experienced as a threat to privacy, as

long as they could decide how to use the alarm. The steering motive for using the safety alarm was the awareness of different risk factors in their environment/context. Risk perception and self-related behaviour are aspects of a safety culture (Ek 2006). The informants' view upon safety vs. privacy might be related to Cooper's (2000) reciprocal safety culture model, which is based on Bandura's model of reciprocal determinism. In Cooper's model, the internal psychological factors of an individual, together with the environment/context he or she is in and the way he or she acts, all operate as interacting determinants, influencing each other (Cooper 2000). The informants of this study were aware of several risks; they feared falling, to remain lying unnoticed and feared violence which can be referred to as the *safety climate* of the individual. The possibility to use the services provided by a mobile safety alarm with professionals answering the alarm can be referred to as the situation and its *safety management system*. Feeling safe and being mobile seem to be more important than the fact that someone would have access to information on the location of the individual, explaining the *safety behaviour* of the individual. The risk awareness of the informants motivated them to use new technology (cf. Stave 2005). Based on the results of this study, an interesting question is whether the current discourse might be that of a safety culture involving increased risk awareness. In this study, the mobile safety alarm was experienced as a tool to be active and mobile. In order to keep self-determination and obtain empowerment, the individual has to make a 'cost-benefit' analysis, where privacy is sacrificed for the sake of mobility and safety, although only as long as he or she can decide how to use the alarm. Additionally, as argued above, this study shows that mobility/freedom of movement are dimensions of empowerment.

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Paper IV

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

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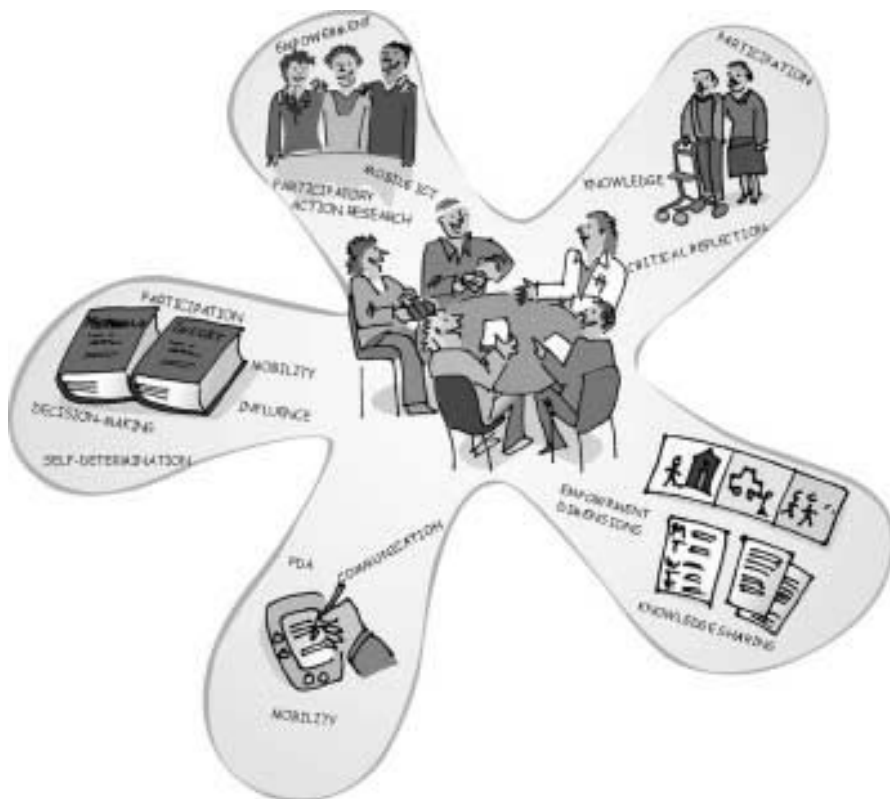


Figure 1. A pictorial version of our abstract

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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 educare. 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 spoiled 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



Figure 3. Appreciative circles activity with homecare staff

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



BLUE SHEET

Lyssna på & bekräfta personal/brukare. Att vara närvarande i mötet m. brukaren



YELLOW SHEET

Figure 4. Reflection-on-practice sheets

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 1. Some reflections on practice by homecare staff

Something I feel I can <i>improve</i> in my work (blue sheets)	Something I feel I am very <i>good</i> at in my work (yellow sheets)
.... To stop putting up boundaries in my work and not take over others’ responsibility	I am good at listening to my colleagues
Listen to myself, trust my own judgment	I am good at listening to people having a hard time
Delegate more	To listen! Reach out to people
Structure my work better	Empathy
Try to keep better documentation To create a good atmosphere and be encouraging
I’m not sure!	I am good at organising my work
Express myself better	I am good at finding solutions to problems
Be able to handle conflict better	Planning & structuring
Not <i>trust</i> people too much	Do not know!
Give feedback	I have patience in my work
Be able to plan for better cooperation between different kinds of professionals	I am able to stay calm in different situations

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 said 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 9.00pm. 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.

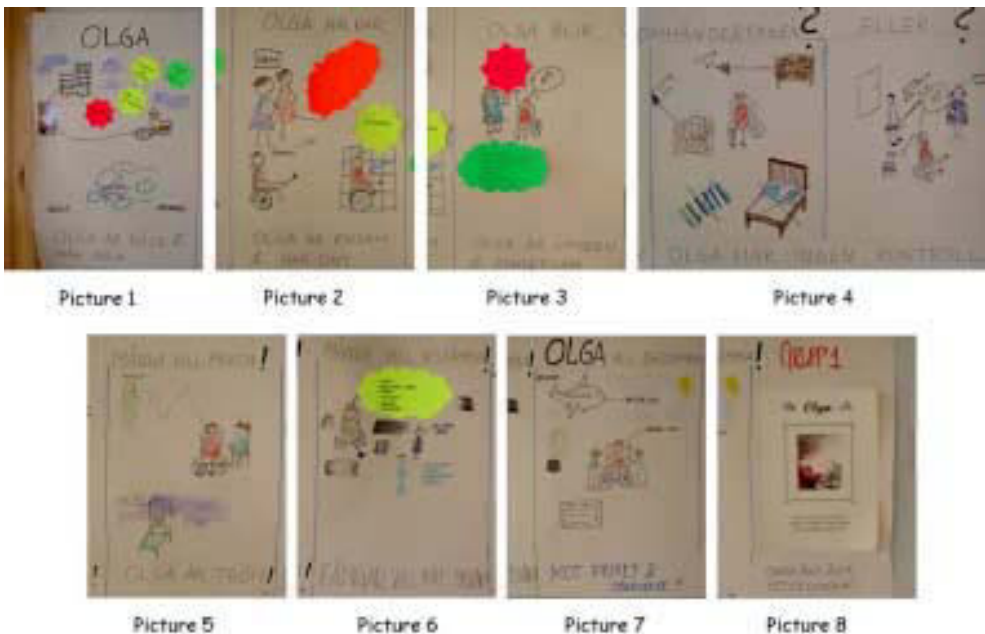


Figure 7. One group's storyboard

Table 2. What the storyboard in Figure Figure 5 says

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

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

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-carer 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.

Systems 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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