

Self-management in hypertension care

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*To my family
Martin, Emil and Nike,
Always feel your capacities*

ABSTRACT

Despite effective treatment strategies for hypertension, many persons with hypertension still fail to reach recommended blood pressure targets. As hypertension is a significant risk factor for cardiovascular disease, measures are needed to decrease the mortality attributed to this condition and to facilitate an optimization of hypertension management. One way to do this may be to support persons with hypertension in better understanding the condition and its treatment in relation to everyday life. The overall aim of this thesis was, from a person-centered perspective, to design, develop and evaluate an interactive mobile phone-based system to support the self-management of hypertension.

A combined methods approach was used to collect and analyze data. Study I used focus group interviews with patients (n=15) and health care professionals (n=12) to explore and describe relevant aspects of hypertension and hypertension treatment, for use in the development of a self-management support system. A further aim was to elicit suggestions for what clinical measures, lifestyle measures, symptoms and side-effects of treatment would be meaningful to include in the system. Data in Study I were analyzed through thematic analysis. In Study II, the content validity of items and usability of the self-management support system were assessed iteratively in four rounds of cognitive interviews, with 21 patients and four health care professionals. Reliability of items was examined using a test-retest. Study III evaluated the effect of the daily use of the self-management support system on reducing blood pressure among 50 primary care patients with hypertension over eight weeks. Descriptive statistics, before-after analysis through paired samples t-test, and latent class growth models (LCGM) were used to analyze data. Study IV aimed at exploring follow-up consultations held at the end of the eight weeks of reporting through the self-management support system. Twenty consultations were audio or video recorded and examined through interaction analysis.

Information gleaned from the interviews with persons with hypertension and health care professionals served to define essential components of the self-management support system and to guide its design and development. The subsequently developed system was shown to capture relevant information for patients' self-management of hypertension, and further, to be reliable and usable. Blood pressure decreased significantly during use of the system (systolic blood pressure -7 mmHg, diastolic blood pressure -4.9 mmHg) between baseline and Week 8, with daily improvements levelling off as the study progressed. Finally, Study IV displayed how patients actively contributed to the follow-up consultations through initiating new topics, equal to the health care professionals, and through contextualizing their blood pressure values, which served to explain and interpret the values in collaboration with the health care professionals.

In conclusion, this thesis describes a collaborative, participatory and structured approach to the design and development of an interactive self-management support system for hypertension care. Use of the system was associated with significant reductions in blood pressure levels; however, the sustainability, scalability and mechanisms behind these results need to be studied further. Importantly, the system served as a mediator in patient-health care professional consultations, enabling patients to contribute and discuss structured, patient-generated information relevant to the management of their condition. Hence, the system may be seen as supporting patient participation and a person-centered approach in hypertension care.

Key words: adherence, blood pressure, cellular phone, communication, health information technology, hypertension, person-centered care, person-centred care, self-management

LIST OF PAPERS

This thesis is based on the following papers, referred to in the text by their Roman numerals I-IV.

- I Bengtsson U, Kasperowski D, Ring L, Kjellgren K. Developing an interactive mobile phone self-report system for self-management of hypertension. Part 1: Patient and professional perspectives. *Blood Pressure*. 2014;23:288-95.
- II Bengtsson U, Kjellgren K, Höfer S, Taft C, Ring L. Developing an interactive mobile phone self-report system for self-management of hypertension. Part 2: Content validity and usability. *Blood Pressure*. 2014;23:296-06.
- III Bengtsson U, Kjellgren K, Hallberg I, Lindwall M, Taft C. Improved blood pressure control using an interactive mobile phone support system. *The Journal of Clinical Hypertension*, 2015. Doi 10.1111/jch.12682
- IV Bengtsson U, Kjellgren K, Hallberg I, Lundin M, Mäkitalo Å. Contextualizing blood pressure: Self-reporting as a basis for patient contributions in hypertension consultations. *Submitted*.

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ABBREVIATIONS

DBP	Diastolic blood pressure
FDA	US Food and Drug Administration
HBPM	Home blood-pressure monitoring
HIT	Health information technology
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
ITM	Item Tracking Matrix
LCGM	Latent Class Growth Models
NPR	National Prescription Repository
SBP	Systolic blood pressure
SSL	Secure Sockets Layer

INTRODUCTION

At the beginning and now the continuation of the 21st century, global and national health care is consistently challenged by rapid demographic and subsequently epidemiological transitions. As the medical and health and care sciences continue to progress alongside economic growth, a rising welfare sector and a growth of knowledge and technologies, people are living longer. Besides the advantages of living a longer life, prolonged old age brings on multiple morbidity and a chronic disease profile [1]. Together with an increase in lifestyle-attributed health problems such as hypertension, diabetes and obesity, this development places new demands on society and health care, which have been highlighted on global as well as national levels [2, 3]. The increased demands on health care in relation to cost constraints have set the focus on rethinking health care, to be fit for the purpose of managing chronicity on an organizational and individual level [1, 4]. The notion of decentralizing health care has been asserted [5], by which managing health will be an increased individual responsibility, i.e. self-management of a condition and participation in one's own care. In other words, the new demands on society will imply new demands on patients, which in turn call for health care to provide support to help patients meet these demands.

In conjunction with these transitions in demography, epidemiology and health care, patient-centered [6] and person-centered care [7] have developed as concepts, perspectives and pragmatic ways of delivering health care, determined and constituted by the participation and capabilities of the patient. In Sweden, the incentives for this development have been strong since Swedish health care has long failed to live up to rules and regulations [8, 9] regarding strengthening the position of patients [10]. Among 11 countries surveyed in 2011, Swedish patients were the least likely to be engaged as partners in their care and treatment decisions [11].

Digital technology is increasingly used in the communication between experts and laypeople, and in the case of this thesis between health care professionals and their patients. E-health, including Internet, e-mail and mobile phone applications [12], has allegedly emerged as an arena for new forms of participation, knowledge building and self-management. Possibly, this new arena of e-health has the potential to challenge a traditional patient-health care professional relationship and facilitate a person-centered approach in chronic disease management, which allows patients to develop self-management skills by receiving support from their health care professionals [13]. However, whether – and under what circumstances – this might be the case is a question that needs to be more thoroughly empirically investigated.

The United Nations and the World Health Organization have focused particular attention on four non-communicable¹ disease groups (cardiovascular diseases², cancer, diabetes and chronic pulmonary diseases), which caused 36 million deaths in the world in 2008 and among which cardiovascular diseases were attributable to 48% of the cases [4, 14]. Hypertension remains one of the most important global risk factors for cardiovascular disease and mortality, and in 2010 was even reported as the largest one [15, 16]. Hypertension management consists of medical treatment in conjunction with lifestyle adjustment, whereby lifestyle adjustment is the preventive cornerstone but has also been proven to contribute to blood pressure reduction among those already receiving medical treatment [17]. Although there are efficient antihypertensive medications with clear benefits for blood pressure control, and despite updated guidelines and education, only a quarter to a third of people treated for hypertension get their blood pressure well under control, a situation that has remained unchanged over the last 40 years [18-20]. One explanation for this is the low adherence to hypertension treatment. No more than 30-50% of those receiving treatment for hypertension adhere to it; thus non-adherence becomes a significant barrier to successful hypertension management [18, 21].

Hypertension is surrounded by people's own understandings about cause and effect – i.e. what comes out of what concerning symptoms, side effects, well-being and lifestyle [22, 23] – which is difficult to grasp and make sense of, and may at times become a problem in its own right. This, in conjunction with the preventive rather than curative focus of hypertension management, makes hypertension treatment and medical treatment as well as lifestyle adjustments a hard case. There is a need for applied research that acknowledges both cornerstones of treatment and that facilitates their optimal effect on blood pressure. It is equally important that this research be planned and conducted in acknowledgement of the currently increasing demands on health care to facilitate a change of the role afforded to patients; from being treated as passive (or reluctant) receivers to being invited to be partners, capable and willing to manage their own condition. This changed relationship requires tools for supporting patients in self-managing their hypertension, as well as health care professionals in providing hypertension treatment in partnership with their patients. Driven by the incentives presented here, the main intention of this thesis is to develop and evaluate a mobile phone support system for the self-management of hypertension, in close collaboration with patients and professionals caring for patients with hypertension.

¹Non-communicable disease is referred to as a non-infectious disease, and is used in parallel with the terms chronic disease and long-term condition. The term chronic condition is used in this thesis, with the exception of when the reference cited uses either non-communicable disease or long-term condition.

²Cardiovascular diseases are a group of disorders affecting the heart and the blood vessels that may cause heart failure, myocardial infarction, stroke, and renal disease.

The thesis is structured as follows: the background provides an introduction to hypertension and hypertension treatment. Further, what living with hypertension may imply is approached, and thereafter self-management. The next section discusses the clinical consultation and, lastly, how technology may play a role in self-management is discussed. The theoretical framework will attend to personalism, person-centeredness and person-centered care in relation to the context of this thesis. Hereafter, a rationale will be presented for the studies conducted, followed by aim, methods, results, discussion and conclusions.

BACKGROUND

Hypertension framed by definition, cause and prevalence

Blood pressure emerges from the force in the movement of blood pushing the blood vessel walls as it is pumped by the heart. Blood pressure is measured in millimeters of mercury (mmHg) and reports two measures, e.g. 120/70 mmHg. Normal blood pressure for adults is defined as 120/80 mmHg, even though normal levels may be extended to lower systolic levels (105 mmHg) and diastolic levels (60 mmHg) because of cardiovascular benefits. Normal blood pressure is important for vital organs, such as the heart, brain and kidneys, to function efficiently. Hypertension (high blood pressure) is defined as a systolic blood pressure (SBP) equal to or above 140 mmHg and a diastolic blood pressure (DBP) equal to or above 90 mmHg; thus, the goal of treatment is a blood-pressure value below 140/90 mmHg. For those at a particular high risk of developing cardiovascular disease, the target is lower: 130/80 mmHg. Among these are people already diagnosed with cardiovascular disease, those with renal disorder, and those with diabetes mellitus [17, 24].

Hypertension is a metabolic risk factor for cardiovascular disease. There are several factors that contribute to the development of hypertension and subsequently its complications: a) social determinants such as globalization, urbanization, aging, income, education and housing, which drive b) behavioral risk factors: stress, physical inactivity, unhealthy diet, tobacco use and harmful use of alcohol, which in turn affect c) metabolic risk factors: hypertension, obesity, diabetes and raised blood lipids. Added to these factors are cases in which there is no specific cause of the hypertension, whereby genetic factors or secondary causes (renal disease, endocrine disease or malformation of blood vessels) need to be excluded [25]. In combination, we are presented with a complex area where target interventions are needed on societal and institutional as well as individual levels.

The immense impact hypertension has on global public health is illustrated by its prevalence: 22% of the world's population aged 18 years or over in 2014 [3]. There has been a slight decrease in the proportion of the world's population with high blood pressure over the last 30 years; however, two remarks need to be made about this: because of population growth and aging, the numbers of people with hypertension have instead actually risen, and in low- and middle-income countries the prevalence has increased [3]. While there is an inequity between high- and low-income countries to be aware of, there is equity between genders as the proportion of men and women with hypertension is equal. At the time of the report by Kahan in 2007, there were 1.8 million people diagnosed with hypertension in Sweden [24]. The prevalence increases with age, and at around 65 years of age more than every second man or woman in Sweden has hypertension [24].

Hypertension treatment

By the beginning of the 20th century the measurement of blood pressure had enabled an emergence of new knowledge, and epidemiologic researchers could report on associations between hypertension and heart failure, stroke and renal failure, albeit still unaware of whether hypertension was the cause. After experimental efforts to treat hypertension, such as cutting nerves to blood vessels or inducing high fever through bacterial infusions (pyrogen therapy) during the 1930s and 1940s, drug treatment started in the 1940s and 1950s. The therapeutic effect on the blood pressure was good, but the side effects were nearly intolerable [26, 27]. Another issue at this time was that the knowledge of whom to treat was limited, so that many patients who today would be treated immediately went untreated. Over time new antihypertensive drugs became available, with oral diuretics almost revolutionizing hypertension drug treatment by the end of the 1950s. Thereafter a whole range of antihypertensive drugs were introduced (calcium-channel blockers, beta-blockers, angiotensin-converting enzyme and angiotensin-receptor antagonists), together contributing to advances in hypertension management [28].

In 1996, when Dustan, Roccella and Garrison concluded (p. 1934) that “If we are to eliminate hypertension as a cause of cardiovascular disease and death, we must have greater understanding of high blood pressure to develop cures and new preventive therapies. Only research can provide the knowledge necessary to provide these goals” [28], they had witnessed some 50 years of vast biomedical development within the area. Since 1996 the focus has increasingly been on prevention rather than curing, and from the historical perspective provided here, hypertensive treatment has developed according to the transformation of the clinical notion of hypertension: from being viewed as a serious illness in the early days to a cardiovascular risk factor today.

The strongest evidence base for blood pressure control today lies within a combination of pharmaceutical treatment and lifestyle modifications [17, 24, 29]. From the perspective of preventing hypertension and cardiovascular risk, a healthy lifestyle implies a healthy, low-sodium diet, physical activity, stress reduction, avoiding smoking and restricting alcohol consumption [2, 17]. Further, alternative approaches beyond medication and diet are suggested. In 2013, The American Heart Association (AHA) published a scientific statement based on a review examining the effectiveness of behavioral strategies (meditation, bio-feedback, yoga and relaxation techniques), non-invasive procedures and devices (acupuncture and device-guided slow breathing) and exercise-based regimens (dynamic aerobic exercise, dynamic resistance and isometric resistance exercise) in lowering blood pressure [30]. The AHA’s review found that aerobic and/or dynamic resistance exercise had the strongest evidence of being effective in adjuvant hypertension treatment [30]. Another review, by Diaz and Shimbo [31], also concluded

that physical exercise was effective in the prevention of hypertension; however, they called for more evidence regarding what type of physical exercise has the strongest evidence on effect.

Despite the profound evidence-based knowledge on how to manage hypertension, the problem of poor blood pressure control remains. As I concluded earlier, hypertension management is a complex task in which efforts need to target not only the individual but also the context in which the individual exists, for example social/psychosocial, cultural and societal contexts, when determining the person's capacities and support needs [25]. Non-adherence to treatment³, one of the principal reasons for poor blood pressure control, is a problem that well reflects this complexity [18], which despite having been thoroughly explored in research for decades has not yet found a solution. For the last 50 years, research on adherence relating to hypertension, mainly coinciding with adherence research in general [18], has foremost been engaged in descriptive and survey studies focusing on mapping, describing and discussing the problem [32], for example in terms of incidence rates and barriers to adherence [23, 33, 34], while there has been less engagement in applied research in order to address the problem. Thus, efforts to improve adherence to antihypertensive treatment have focused on support to remove these barriers, such as amending forgetfulness with reminders but also controlling medication intake, for example through pill counting [35]. Thus non-adherence has become rather technically targeted, which in turn suggests that a behavioristic perspective has been taken as a premise for accomplishing change.

Emerging from biomedical research, hypertension treatment has long been characterized by a biomedical perspective. It has been argued that its strict focus on the medical diagnosis, as well as the view of sickness and health as dependent on and determined by biomedical signs, has established a paternalistic⁴ patient-health care professional relationship, implying a passive and cooperative (obedient/compliant) patient [36]. According to this view, the success of biomedical research would have a downside that becomes problematic in relation to the current need for health care to encourage and facilitate increased patient engagement and participation in care. Imposed by the epidemic of non-communicable

³The active action of choosing whether or not to take one's medication at a certain point has been denoted in different ways over the years. WHO defines it as: "The extent to which a person's behaviour - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (WHO. Adherence for long-term therapies - Evidence for action, Geneva 2003). Earlier, the term compliance (to comply = abide by, follow) was used. However, the concept of compliance has been criticized for its paternalistic conception of the health care provider-patient relationship, the patient being reduced to a passive and compliant (obedient) recipient of health care. The term adherence can mean affection, loyalty or fidelity, but also has a metaphorical meaning: to adhere = follow through or carry out a plan without deviation. (Swedish: "hålla fast vid"). This meaning implies a decisive action through the predicates "follow through" and "carry out". Based on the metaphorical meaning of the concept, adherence is the preferred term in this thesis because of its more collaborative, participatory and person-centered dimensions (Gould E, Mitty E. Medication adherence is a Partnership, Medication Compliance is not. Geriatric Nursing. 2010;31(4):290-298).

diseases and changes in demography, the biomedical perspective has thus become increasingly challenged. Today an awareness of the importance of including the patient as a partner, and of psychosocial and lifestyle factors as determinants of health, is increasingly common [3]. However, this awareness and slight shift in perspectives away from a biomedical model of care to one of interaction and guidance have not gained momentum in the context of hypertension management. To go from awareness to a set way of working may require facilitation and support.

Hypertension management provided by health care implies blood pressure measurement, judgment of medical treatment, and counselling on lifestyle changes. In Sweden, these services mainly take place in primary care and are generally organized such that patients attend yearly visits with their general practitioner and go to consultations, with a public health care nurse, that include blood pressure control between visits. Counseling on lifestyle changes is an interdisciplinary responsibility, and can be performed both by the general practitioner at the yearly visit and by the public health care nurse at each visit. This counseling includes education about hypertension and the importance of lifestyle adjustments, and motivational support for enacting behavioral changes [37]. Earlier research has shown that many patients are unaware of their target blood pressure, and do not understand the meaning of a certain blood-pressure value or what they themselves can do to improve it and their overall health [38]. More recent research provides a similar picture: health care professionals neither communicated blood pressure targets to patients nor used them as a motivational tool to reach the goal of the target blood pressure [39]. For their part, the patients expressed a sincere wish to understand the interrelationships of blood pressure, perceived symptoms, side effects of medication, lifestyle and well-being. These connections were not clear to them, and they reported struggling to get a grip on the whole picture of blood pressure and how to manage it in everyday life [39].

Living with hypertension

Hypertension is a risk factor for cardiovascular disease and is often a chronic condition that has to be managed by the patient for a long time, sometimes for the rest of his or her life. Being diagnosed with a chronic condition has been described by sociologists as a disrupting life event in which the condition not only affects a person's physical self but also his or her sense of identity; meaning that self-confidence and self-esteem may need rebuilding [40-42]. Added to this are uncertainties regarding how to relate to the new prerequisites in life that a chronic condition may imply, the course and impact of the condition, and how to act in order to manage it.

⁴According to Hellin (2002), paternalism may be seen from the perspective of the Hippocratic ethical requirement of "beneficence"; paternalism is then regarded as a hardline beneficence, similar to the parent-infant relationship in which the infant is totally dependent on the parent for decision-making (Hellin, T. The physician-patient relationship: recent development and changes. *Haemophilia* 2002; 450-454).

For those who wish to understand the meaning of the blood pressure value; the biomedical sign, and how it relates to symptoms, side effects⁵ of treatment and lifestyle, this may be a particular challenge since hypertension has traditionally been communicated to patients as an asymptomatic condition [39, 43, 44]. However, it has been repeatedly shown by previous as well as recent research that patients do ascribe symptoms to their hypertension [22, 44-47]. This mismatch in views becomes problematic for hypertension management; it causes confusion for patients, which may well affect adherence to treatment and self-management actions. It may be stressful knowing hypertension is a serious condition at the same time it is communicated that no symptoms are expected to occur, which is inconsistent with how the person feels.

The sustaining poor adherence rates, possibly due to this complexity for patients in grasping what hypertension is, have made the self-management of hypertension treatment a hard case. It has engaged researchers in understanding how people with hypertension perceive, explain and act upon their high blood pressure and treatment. Hypertension and hypertension treatment are surrounded by lay perceptions about cause, effect and course [22, 38, 48], which has been shown to determine drug-taking behavior and self-management actions [44, 49]. In 2012, Bokhour et al. [49] described this in terms of explanatory models of hypertension (cause, course/timeline of illness, treatment) and daily-lived experience (everyday life factors), which are inextricably intertwined in shaping behavior. One example, consistent in several studies, is course of illness; people with hypertension have expressed the belief that hypertension is intermittent, a condition that comes and goes. This is closely connected to whether or not symptoms are experienced: if an experienced symptom – for example headache – abated, hypertension was perceived as cured or temporarily cured, and medications were omitted [22, 49, 50]. In their systematic review, Marshall et al. showed that these beliefs were not culturally specific but were similar across ethnic and geographical groups [22]. Thus, there is a need for health care to acknowledge that people living with hypertension anchor their understanding of their condition in everyday experiences of tangible bodily symptoms, rather than the abstract information often given from a medical point of view.

In summary, living with hypertension is something that takes place every day, every hour, every minute, while contact with health care professionals is something that occurs only occasionally. This places high demands on people to deal with their condition in daily life themselves. In light of these circumstances, there

⁵Side effects to medications may be of non-serious consequence for the patient, or serious, i.e. harmful and resulting in, for example, hospitalization or life threat. Further, side effects may or may not be confirmed to be causally related to the medication. Adverse events are side effects whereby causality has not been judged, or has not been possible to establish. Adverse reactions, on the other hand, are confirmed to be causally related to the medication (Edwards IR, Aronson JK. Adverse drug reactions: definitions, diagnosis and management. *Lancet*, 2000;356:1255-1259). In this thesis, the term side effect is used as a concept denoting minor undesirable consequences experienced by patients in relation to taking their prescribed medication, such as dryness of the mouth or constipation.

ought to be great potential in supporting those with hypertension to gain a concrete apprehension of how the overall picture relating to their hypertension is connected to their everyday lives, for the possible facilitation of self-managing their health condition.

Self-management

The concept *self-management* has been defined in a number of ways depending on discipline. In an early study of self-management of hypertension, Nakagawa-Kogan et al. [51] chose to define it from a psychological perspective, according to Karoly and Kanfer [52]: a treatment that combines biological, psychological and social intervention techniques with the goal of maximizing functions of regulatory processes. Barlow et al [53] defined it as follows: “Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle inherent in living with a chronic condition” (Barlow et al, 2002,p. 178). They further argued that the abilities to self-monitor one’s condition and to affect cognitive, behavioral and emotional responses needed to maintain quality of life were predictors of effective self-management [53]. Concepts in close relation to self-management are self-monitoring and self-care. In a concept analysis based on a review of qualitative research Wilde and Garvin found that self-care and self-monitoring were used as components of self-management, which was viewed as the broader construct [54]. Common elements, tasks and challenges of chronic disease self-management in physical, psychological and social domains were suggested by Swendeman et al. [55], for example understanding illness and wellness, health-promoting behaviors, adherence to treatment, self-monitoring, self-efficacy, empowerment, cognitive skills of self-management and collaborative relationships with health care professionals.

Although education in key self-management skills like problem-solving, decision-making, finding resources, forming partnerships with health care professionals and taking action [56] is acknowledged in self-management interventions, concerns have been raised that contemporary self-management programs fail to incorporate people’s existing capacities as well as social and everyday life contexts [57]. Lorig and Holman [56], Kendall et al. [57] and Townsend et al. [58], the latter two taking a sociological perspective on self-management, proposed that most people have the desire and skills to stay healthy. Lorig and Holman suggest that all people manage their health in some way, i.e. when someone decides not to engage in a healthy behavior or not to be actively engaged in managing his or her disease, this is a self-management style in its own right. Accordingly, it is a question of *how* to manage [56]. Based on these ideas, Li et al. [59] stated that self-management should be supported rather than taught.

Self-management of hypertension developed with the trend of home blood-pressure monitoring (HBPM). HBPM had beneficial effects on blood pressure, and moving the monitoring out of the office to the home of patients helped decrease the “white coat effect”. HBPM also seemed to reflect true blood-pressure values

more reliably, and was further well accepted by patients [60, 61]. Thus, the self-management of hypertension has mainly consisted of the self-monitoring of a sign, the blood-pressure value. Studies including interventions involving the self-monitoring of hypertension have resulted in significant declines in blood pressure, but results between studies have been inconsistent [62, 63]. Interventions consisting of either elements of self-management or components reinforcing self-management have often included what is referred to as patient education or educational packages on hypertension, adherence, lifestyle and health, for example executed as a lifestyle intervention, individual or group counselling sessions, or instructional individual/group sessions. Most common, it seems, was providing information, either face-to-face or through booklets, DVDs or other written material (unspecified) [62, 64].

Many interventions, however, failed to show a decline in either systolic or diastolic blood pressure, or improved blood pressure control [62, 63]. Common to interventions aiming at the self-management of hypertension thus far is that they often have not taken it any further than the component of self-monitoring or patient education, as defined above. There were functions of reporting blood-pressure values back to health care professionals via telephone and later sending values to a database. If the values were high, either the health care professional would contact the patient or the patient would get an automated message with the advice to contact the caregiver, with no feedback in terms of understanding the value or what had caused it. Educational packages were delivered, but were seldom followed up in terms of the patients' understanding or interpretation of the information given. Exceptions to this were repeated counselling or group sessions directed at changing lifestyle, interventions that showed significant effects on blood pressure [62, 65].

Given this background, there is a lack of interventions recognizing self-management of hypertension as something not to be taught but rather facilitated by supporting understanding and interpretation of self-monitored signs, in relation to perceived symptoms and daily activities of persons living with this condition.

The clinical consultation in light of future demands and increased patient involvement

The consultation is an important cornerstone in the delivery of health care. For the patient it is the arena in which, ideally, questions can be asked, thoughts can be shared and an understanding of the condition, necessary for managing it on a daily basis, can be increased [66, 67]. The consultation, like established health care practices in general, faces the demand of adapting to the demographic and epidemiological changes in society. These changes call for an increased individual responsibility of patients, for example through self-management and increased participation in their own care. The task of health care becomes, as mentioned, to support patients in meeting these new demands. This implies that there is a need

for interactional structures that allow patients to participate and hold their own in the consultation, on equal terms with the health care professional.

At health care appointments a typical interaction order in the communication is usually established, a well-recognized routine that is maintained by both parties [68] and serves the purpose of pursuing the agenda of the meeting. Many studies over the years have shown that communication between patients and health care professionals in the clinical consultation are often asymmetrical and controlled by the professionals [68-70], which according to Maynard [68] can have various reasons, one being communicational structures whereby health care professionals, for example, ask more questions, interrupt more often and control the topical development. Mishler [69] referred to a dialectical struggle between the voice of medicine and the voice of the lifeworld: "The voice of the lifeworld refers to the patient's contextually grounded experiences of events and problems in her life. These are reports and descriptions of the world and everyday life expressed from the perspective of the 'natural attitude'. The timing of events and their significance are dependent on the patients' biographical situation and position in the social world. In contrast, the voice of medicine reflects a technical interest and expresses a 'scientific attitude'. The meaning of events is provided through abstract rules that serve to decontextualize events, to remove them from particular personal and social contexts" (Mishler, 1984, p. 104).

In response to the movement in health care and society towards increased patient involvement, however, the prevailing interaction order in the clinical consultation has been questioned and there has been a shift from what has been referred to as a dominant and paternalistic communication model with a biomedical focus [68] to a pluralistic model that endeavors towards "democratized decision making, shared understanding and empowered individuals" [71], p. 150. Yet, research shows that patient participation in the clinical consultation has remained low [72-76], possibly due to the established interactional structures and routines maintained by both patients and health care professionals. Again, support tools may be needed to change established routines and to encourage patients to take a more active role in the clinical consultation. If we draw upon the perspectives of Mishler, this could imply support by means of encouraging and facilitating a regained attention to the lifeworld, through a narration and contextualization of symptoms, signs and experiences.

Technology as mediational means in self-management of hypertension

With the widespread availability of modern digital technology e-health [12], also referred to as health information technology (HIT) [77], new possibilities have emerged for communication and support between and for patients and health care professionals. This section will address technology as a mediational means [78] in supporting the self-management of hypertension, and what forms of participation such means can possibly support.

In hypertension care, several HIT interventions have been tried. For example, Rinfret et al. [79] reported on self-reports of HBPM in combination with an automated interactive telecommunication system, providing motivational counseling and self-management tips together with a nursing intervention component. Green et al. [80] used self-reports of HBPM in combination with a secure e-mail account where patients could transmit blood-pressure values and pharmacists could make medication changes according to an approved protocol. Further, McManus et al. [81] analyzed the effect of self-reports of HBPM in combination with a program for self-titrating medications. All three examples showed a decrease in blood pressure. However, the improved blood pressure control could not be attributed to increased self-management support; instead, it was argued that intensified antihypertensive treatment was the reason, which seems to be common in similar attempts [82]. Thus, in these examples technology was not used as a means for self-management support. What is lacking in these interventions seems to be some kind of feedback support in the system, for example visualizations of the measured blood-pressure values.

In a Cochrane review from 2005 [83], it was concluded that health information technology increased patients' knowledge of their chronic condition, had positive effects on clinical outcomes, and improved social support when patients were the end users of HIT applications [83]. Importantly, these programs consisted of tools supporting self-management and not only the provision of information. According to Bodenheimer et al. [84], self-management support is part of establishing a partnership between patient and health care professional, whereby patient-defined problems, participatory decision-making, problem-solving skills and self-efficacy are in focus. Bodenheimer et al. further emphasized collaborative care as an important aspect of supporting the self-management of chronic disease [85]. Thus, according to these presented perspectives, health information technology ought to focus on supporting an increased contextual understanding of the chronic condition as well as the communication between patient and health care professional, within the patient-health care professional relationship. An increased understanding of the impact of health information technology on the patient-health care professional relationship was also called for in the 2005 Cochrane review on interactive health communication applications for people with chronic disease [83], which revealed limitations in the scope of the computer applications included. The primary focus was on the patients' interaction with the tool and on the reporting of patient information to the health care professional, but not the other way around. Nor did the system provide feedback to the patients to allow them to follow up the reported data over time [83]. Also, in 2008, a review by Solomon et al. [13] showed a lack of self-management tools supporting collaboration between health care professionals and patients; instead, the focus seemed to be on developing "a more informed health care consumer" (Solomon et al, 2008, p. 396).

Self-reporting may include ways of collecting information that allow the patient to actively contribute to generating the actual data that the care and/or self-management can be based upon. By contributing in this manner, a new premise and foundation is generated for the patient-health care professional consultation; i.e. the meeting is no longer solely based on health care records (conducted or planned investigations, blood samples, tests – all arranged by the health care professional) but rather the patient enters the meeting with data he or she has produced. In the US, the Open Notes project [86] gave 20,000 patients access to their health records through secure health system portals. Despite initial physician reluctance the project was a success, with a high use of the Open Notes and reports on patient activation and empowerment, alongside patients feeling more in control of their care and an increase in adherence to treatment [86]. What is interesting in relation to self-reporting is that patients believed they would be able to comment on notes in their medical records, and many also believed they would be able to approve their doctors' notes, which would imply going beyond access to their notes to *co-authoring* them [77]. Such co-authorship is in play when self-reporting a condition; in fact it goes even further, as it is the patient who is the author of the original notes and the health care provider who contributes to them. Clearly, this self-generation of data, together with the affordances certain technologies potentially offer (self-reporting through mobile devices may serve as an example), may have implications on the possibility to establish a partnership between patients and health care professionals. It may also play a role in supporting patients in how to self-manage their condition.

The development of mobile devices in health care

Given the positive results in several of the early HIT interventions, e-health/HIT holds great potential for hypertension and chronic care. However, there are limitations to the use of HIT systems; for example, user acceptance, availability and affordability were major issues at the time of the first of these interventions [87]. For technology to serve as a mediational means that supports people in managing their chronic conditions, these are of course important factors to address. When the use of mobile phones in health care was introduced, availability and affordability were rapidly addressed. Today, access to mobile phones is more or less globally omnipresent, and the use of smartphones soon will be [87-89]. This development may remove disparities in access to HIT programs, and may also extend self-management support to people who were previously more difficult to reach [90]. Accordingly, the explosion of mobile health care devices, software and applications has raised issues of not only usability but also data security and ways of developing tools in a scientific and sound manner. In Sweden, the National eHealth Strategy [91] stated that HIT tools must be easy to use, support the dialogue between patients and health care professionals, and comply with strict demands on “data protection and information security, in order to maintain citi-

zen integrity" [91], p. 16. Some time later the same concerns were raised by the WHO [92], and in 2013 the FDA in the US published an approach to regulating mobile phone medical applications [93]. Accordingly, it is important to ensure the quality of data generated by self-reports; that they are reliable and thereby useful. There is thus, in all, a need to standardize the development of tools – HIT tools/mobile phone tools in general and self-report tools in particular – including a thorough piloting of feasibility and usability, as well as ensuring the validity of items. Including those for whom an HIT tool is intended (for example, patients and health care professionals) in this development process ought to be of great importance.

THEORETICAL FRAMEWORK

This is a thesis in health and care science that relates to the field of person-centered care, a research area that challenges the biomedical paradigm as the only prevailing perspective in health care. In person-centered care the person behind the patient is in focus, and the right to participate in and impact one's own care on equal terms with health care professionals, on own terms, is central [94, 95]. I use the concepts *patient* and *person* interchangeably, depending on the context. While I do not view these terms as contradictory, I feel it is important to distinguish them from one another. In the context of the health care encounter, the concept of patient is a denomination of a person who has entered into an institutional relationship with a health care provider. This kind of relationship is premised on the health care system and its regulations at a societal level, as well as in terms of responsibilities to patients. When using the concept of patient it is important to be aware of this, and not to "objectify and reduce the person to a mere recipient of medical services" [7], p. 249. In the following two sections I will describe the person-centered perspective and person-centered care as I perceive them in relation to the work in this thesis.

Person-centeredness

In a conceptual analysis of the notion of person-centeredness, Leplege et al. concluded that it cannot be reduced to one specific idea but that it is rather a multi-dimensional concept with meanings that may differ in different contexts [94]. However, the person-centered perspective, or person-centered approach, has its roots in the philosophical tradition of personalism, which engages in the person as a concept: what is a person and what is it that constitutes a person? A common denominator within the genre is the view that a person has a will and capabilities, exerts agency in relation to goals and life plans, and may, accordingly, be ascribed responsibility for her⁶ actions. A person is also a narrative being who makes sense of herself and her lifeworld, of which she can create representations in order to interpret and understand. A person accordingly has her own view; rationalities, perceptions and values from which she moves to action in a given situation [96, 97]. Essential to personalism is anti-reductionism, the view that the whole constitutes more than the sum of its parts, and the fundamental role of the other; i.e. a person comes into being in relation to significant others and develops in and through relational contexts [97-99].

In adopting a person-centered perspective that is relevant to the work of this thesis, I have found the perspectives of Charles Taylor and Christian Smith [96, 97] suitable. Their emphasis on representations and interpretations for how man con-

⁶When the words "her", "herself" or "she" appear in the text they are used as generic terms and do not exclude men.

structs personal knowledge of the world becomes relevant if we choose to view a person as interpretive with a clear need to make sense of, understand and explain the world. It also becomes relevant if we believe that a person draws on experiences and synthesizes them into views from which she judges and acts upon situations.

According to Charles Taylor, our understanding or interpretation of an emotion (or in this case, let us use the example of the sensation of dizziness) comes to be co-constitutive of the emotion; that is, the understanding contributes to shaping the emotion [96]. Christian Smith takes this further by stating that it is an “inevitable human need to interpret reality in order to know it”, p. 334. As humans we are aware that there is more than one possible interpretation in order to understand something, which compels us to choose the most suitable explanation, draw conclusions and act accordingly [97]. This is where we stand when a person with hypertension, or any other chronic condition, self-manages the actual condition on an everyday basis.

The foundation for Smith’s notion of personhood is *emergence*. New entities are brought into being through an interactive combination of other, different entities that are needed to create the new entity, but that do not contain the characteristics of the new one [97]. In other words, the evolution of self, or of anything, is determined by emergence through interaction. It could be possible to apply the notion of emergence to the appropriation of new knowledge and of gaining new insights, which in turn may change interpretations and understanding of, for example, dizziness in relation to blood pressure. Within the frame of a relationship, through conversation or dialogue, experiences and interpretations (of dizziness, for instance) may be narrated into being by a person in interaction with a health care professional. Through joint reflection and co-construction, new insights may come out of the interaction. However, in order to interact in such a productive way that an emergence of new insights, knowledge, and ways of being active and participating occur, support for the patient and health care professional may be helpful.

Person-centered care in the context of self-management

Ontologically rooted in personalism and based on a person-centered approach, person-centered care is the doing: the practical application of the delivery of care that is irrefutably focused on the *person* behind the patient and the person’s experiences, perceptions, preferences, values, capacities, barriers and social context [7]. It has been proposed that person-centered care is characterized by three key concepts [7] that may serve to facilitate a practical application of a person-centered approach and of which the partnership, deriving from the relational aspect of personalism, is the most central. All aspects of person-centered care are thought to be realized within an initiated, worked and subsequently safeguarded partnership. The next key concept is the patient narrative – the person’s own account of, for example, the illness and its symptoms and impact on daily life. The

patient narrative serves as the base from which care is conjointly planned. Last, there is the key concept of documentation, which apart from rules and regulations concerning patients' health care actions [100] becomes a way to safeguard the partnership by legitimating the patient perspective forwarded in the narrative [7].

As mentioned earlier, the activity of people's self-management consists of self-monitoring and self-care in collaboration [55] and/or in partnership [56] with health care professionals. So, despite the contradiction of the words, "self-managing" largely implies "participating". Thus, in relation to person-centered care, as realized through supporting patients in self-managing a condition, it is relevant to relate to the concept of patient participation. In 1996, Cahill [101] published a concept analysis of patient participation with regard to meaning and nature within the context of nursing practice; another was likewise pursued in 2008 by Sahlsten et al. [102]. These two agreed that patient participation is determined by three defining attributes: an established patient-health care professional relationship; a surrendering of power or control by the health care professional; and active mutual engagement in care/the planning of care. However, Sahlsten et al. also mention a fourth attribute: shared information and knowledge between the parties. Further, Sahlsten et al. found more emphasis on surrendering power or control to the patient, which may be a result of the norms at the time (2008 compared to 1996). In 1996, Cahill also mentioned three concepts as hierarchically related to patient participation, suggesting that the preceding one needs to be present in order for the next one to be attained: the lower level consists of patient involvement/collaboration, the middle of patient participation, and the top of partnership. Partnership was seen as the ultimate goal, but also more or less unrealizable in practice, since it would imply a total surrender and control of power by the health care professional as well as complete equality and a verbal or written contract/agreement throughout the whole care process rather than only parts of it [101].

In 2008, Thórarinsdóttir and Kristjánsson [103] analyzed the concept of patient participation in health care in relation to person-centeredness from patients' perspectives, through an integrative review of qualitative research findings. The results showed that patients emphasized the human connection (i.e., again the relational aspect) and the moral ideals of respect and equality. Patients wanted to be respected as whole persons with individual strengths and resourcefulness, and desired equality in the interaction with health care professionals. However, even though patients admitted to being participatory, they did not always sense the aspect of respect and equality in the interaction. In such cases the patients felt they had to struggle to be heard, to get information, or to have their expertise acknowledged [103]. Hence, patient participation was not always person-centered but was sometimes constrained. In order for the self-management of a condition, through patient participation, to be operationalized as person-centered care, these barriers need to be acknowledged by supporting structured ways of working these aspects (respect and equality) into the partnership.

When conducting self-management research in which a person manages her body in relation to a condition such as hypertension, expressed as a biomedical sign, if a person-centered perspective is adopted it is relevant to reflect on the concepts *individual* and *person* and how they are approached. From the perspective of person-centeredness these concepts may be seen as contradictory, since the concept of individual from the person-centered perspective implies a discrete, self-contained, autonomous and self-existent self [97]. What is missing is the essential relational aspect, since people are inescapably social, interactive and communicative in their origin and being [97]. The individual emphasizes her uniqueness, what makes her different from others, expresses *how I am*, and is occupied with getting to know herself in this way. The person sees herself in others, sees similarities between herself and others, emphasizing “I am”. Getting to know oneself as a person implies getting to know oneself as one who is always in relation to the other [99]. Do these concepts have to be contradictory? Martin Buber [99] provided us with a way to view this that shows that they do not. He spoke of the dual I: the I-Thou that comes forth as a person in the form of subject and through the relation to others; and the I-It that comes forth as an individual who demarcates herself from others. Buber does not view these two as contradictory but rather as two dimensions of life, one individual and one personal, both necessary for personal development. When self-managing hypertension the individual within a person is encouraged to come forth: get to know your body, in parts and in whole, discover interrelations and strive for an increased understanding of your body and its processes. However, the person would be better not left alone after having been addressed as an individual; she should not be left to interpret or understand everything on her own, and health care should not claim autonomous actions [104] disconnected from the support of a health care professional (fellow man). What can be done, however, is to offer support to facilitate self-management, within the frame of the relation to the health care professional. Through this both the person and the individual will be approached, and self-management can be a part of person-centered care, in accordance with its intrinsic value of the relational.

Common-Sense Model

The Common-Sense Model is a behavioral model that has helped researchers and professionals understand a person’s perception of illness and coping strategies, as it focuses on the person’s beliefs about the health problem, condition or recommended actions [105]. Already in the 80s Meyer, Leventhal and Gutman used the example of hypertension in relation to the Common-Sense Model of illness [106], and in 2012 it was updated in relation to adherence [107]. There are recent examples of using the model in relation to hypertension, for example relating to illness perceptions [23] and symptom representations [44]. During the beginning of the work on this thesis, it was used as a theoretical yet pragmatic framing of the “person” and his/her actions in a certain context. It was not applied methodologically, but rather served as a perspective from which to view self-management

and adherence. Later in the process, that perspective was supplemented with the perspectives of the personalists Christian Smith and Charles Taylor. I would like to point out that the Common-Sense Model is a behavioral model that differs from a person-centered perspective, as it lacks the relational, communicative and interactional aspects between patient and health care professional. However, as mentioned, it has been repeatedly related to the example of hypertension over the years and was an early (and still applied) attempt to structure an understanding of human actions in relation to a condition, for instance hypertension.

RATIONALE

The low number of people who attain a well-controlled blood pressure is in itself a contradiction to the profound knowledge base and the well-developed, effective blood-pressure lowering medications we have. Commonly, and probably rightly, blamed is low adherence to treatment – another problem which we still have not managed to overcome, although it has been well researched over the last four decades. Clearly, new perspectives and approaches are needed.

In parallel with an increased awareness of the need for a novel strategy to embrace the complexity of managing hypertension treatment, society and stakeholders cast light on the management of chronic diseases. Increased patient power and self-management in health care are advocated. Indeed, hypertension is a chronic condition, and thus needs to be viewed and managed accordingly, with the person at the center of attention and point of departure.

Adherence-related research and self-management research have thus far been separated, yet their relationship is close from the perspective of the actual goal: ensuring well-controlled blood pressure in order to prevent cardiovascular complications. If support is offered for patients' self-management by facilitating an understanding of the complex relationships of symptoms, side effects of treatment and the impact of medication and lifestyle, adherence and subsequently blood pressure may improve.

AIM

Overall aim

The aim of the thesis was to, with a person-centered perspective, design, develop and evaluate an interactive mobile phone-based system to support self-management of hypertension.

Specific aims

Study I

To explore and describe relevant aspects of hypertension and hypertension treatment, to be used in the development of an interactive mobile phone self-report system for hypertension self-management. A further aim was to suggest which clinical measures, lifestyle measures, symptoms and side effects of treatment would be meaningful to include in the self-report system.

Study II

To examine comprehension, comprehensiveness and relevance of items and, further to evaluate the usability and reliability of an interactive hypertension-specific mobile phone self-report system.

Study III

To evaluate the general efficacy of an interactive mobile phone self-management support system in reducing blood pressure; to examine blood pressure change trajectories over the course of the 56-day study period; and to identify subsets of patients that benefit most from the self-management support system.

Study IV

To describe the communicative structure of follow-up consultations, and to explore how patients contributed to the consultations after eight weeks of using a mobile phone-based self-management support system.

METHODS

Methodological viewpoints

The work in this thesis may be seen as two-part: firstly, there was a focus on developing a mobile phone support system for the self-management of hypertension that was relevant and meaningful for persons with hypertension; secondly, there was a focus on evaluating the effect of A) the blood pressure and B) the structure, content and patient contributions in follow-up consultations after eight weeks of using the developed self-management support system. Thus, the point of departure was the beliefs, needs, expectations and wishes rooted in the patients' experiences, with input from health care professionals, while the point of arrival needed to offer information on a biomedical sign – the blood pressure – as well as on interactional, communicative aspects between patients and health care professionals. This required the employment of combined methods research [108] through the use of multiple methods [108]. This was done in order to: 1) take departure in the patients' experiences beliefs, needs and wishes when developing the self-management support system; and 2) explore different facets of the effect of the instrument after use in clinical practice. In employing combined methods I do not ascribe this work to one epistemological paradigm; rather, the research questions of each study determined the methodology used. This is a pragmatic way of relating to epistemology when conducting research, and can be referred to as epistemological relativism [108]. However, in adopting the humanistic perspectives of personalism, which has modelled this work, a social science tradition is the foundation of the thesis, and is complemented and enriched by the logical empirical science tradition of Study III.

Research design and setting

The study by Hallberg et al. [109], included as an appendix to the thesis, gives an overview of the design and development of the mobile phone support system for the self-management of hypertension. The research program, planned and carried out by an interdisciplinary group of researchers, presupposed a person-centered perspective and had a participatory orientation, working together in the development process with persons with hypertension and healthcare professionals [110]. In all, the research program comprised five phases from the first step of the development process to evaluations of the system and targeted outcomes:

- Define conceptual framework and delivery of system
- Adjust conceptual framework
- Confirm conceptual framework and delivery of system
- Collect, analyze and interpret data
- Evaluate the self-management support system in clinical practice

A flow chart of the research program is illustrated in Figure 1.

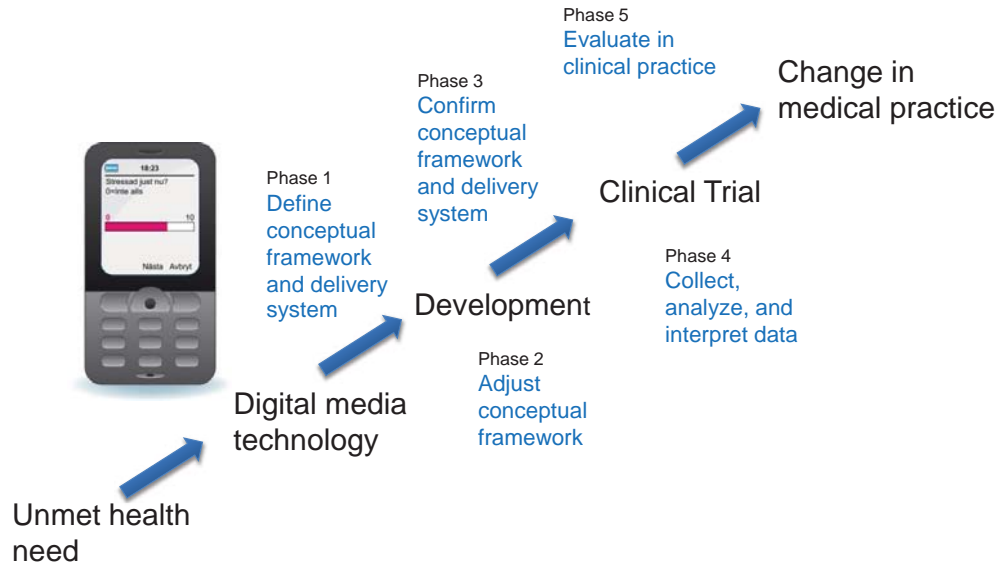


Figure 1. Flow-chart of the research program.

The first phase aimed at drafting a conceptual framework for a prototype mobile phone system and, further, to explore possible uses for the system in clinical practice. Theoretically we took on a person-centered perspective, and in practice the notion of participation (ultimately, the partnership), as a cornerstone of person-centered care [7]. Further, the notion that actions taken to reduce health risks are determined by the patient's subjective or common-sense perceptions of the health threat, as explained in the Common-Sense Model [105, 107, 111], was used for guidance in the development process. A literature search was conducted to gather potential concepts of hypertension self-management regarding symptoms of hypertension, side effects of medical treatment, clinical measurements, and examples of lifestyle habits. During this first phase, seven researchers and three technical experts held regularly scheduled meetings to discuss these issues [112]. These steps resulted in a list of pre-defined concepts, i.e. symptoms, clinical measurements and lifestyle habits that would be tested in the continued development process. Study I [39] provides the reader with a closer look at these concepts to be tried, see Table III, paper I.

The communication platform for the delivery of the system was developed by 21st Century Mobile AB (<http://www.cqmobil.se>), and was designed such that daily self-reports are registered by means of the patients' own mobile phones and are then returned to and stored in a database. A login-restricted web-based feed-

back module provides the patients with the opportunity to examine for themselves how their self-reports of drug intake, lifestyle, blood pressure, symptoms and well-being relate to one another. Lifestyle motivational messages (twice a week) are optional, and are chosen based on the patient's preferences. Feedback is provided in the form of graphs, whereby patients can choose which variables or combinations of variables to display. See Figure 2 for an overview of the interactive self-management support system. The next phases in the research program, Phases 2-5 (Figure 1), will be approached more closely through Studies I-IV.

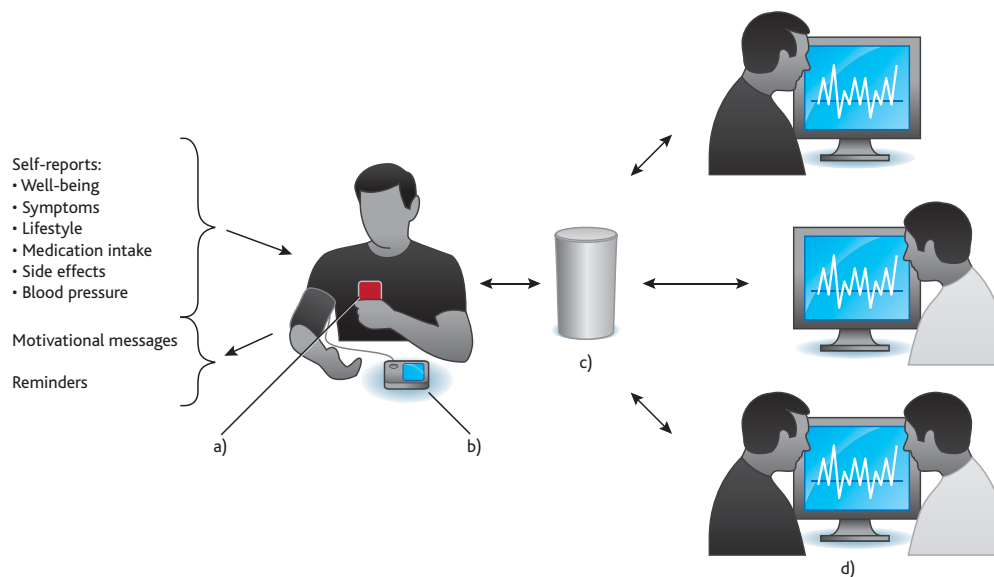


Figure 2. Overview of the interactive self-management support system. The system consists of: (A) Mobile phone-based system for the self-report questions together with optional motivational messages and reminders. (B) blood-pressure device. (C) data-base: real-time registration of the daily self-reports captured from the mobile phone. (D) Web-based platform for real-time visualization of the patients' reported data, available after log-in for the patient and physician/nurse and eg at consultations.

Data for the studies were collected through focus group interviews, individual cognitive interviews, self-reports, self-measurements and video/audio recordings. The data collection for the studies covering the development process (Studies I and II) was guided by the guidelines outlined by the FDA for patient-reported outcomes [113, 114], which emphasize the importance of involving primarily patients, but also experts, in the development process of tools containing patient self-reports. Study II was further guided by the ISPOR task-force reports on good research practice for developing patient-reported outcomes measures [115, 116], which provide a feasible and usable framework for assessing respondents' understanding of items and response options. To evaluate the effect of the self-management support system on blood pressure, a three-month pilot study with two

patients was first conducted, followed by an eight-week longitudinal study. The follow-up consultations at the end of the eight week study period were explored and evaluated through an analysis of video and audio recordings, interactional in nature [117, 118].

The context of the studies comprised three primary care settings located in three Swedish towns, amongst which the city as well as suburbs were represented. Table 1 provides an overview of the studies conducted.

Table 1. Overview of studies

	Study I	Study II	Study III	Study IV
Focus	Development of a mobile phone self-management support system: What is deemed important for the users: patients and health care professionals?	Development of a mobile phone self-management support system: Comprehension, comprehensiveness and relevance of items. Reliability of items. Usability system.	Evaluation after use of mobile phone self-management support system: Effect on blood pressure.	Evaluation after use of mobile phone self-management support system: Effect on structure and interaction in follow-up consultation.
Design	Explorative Cross-sectional	Validation-study	Explorative Longitudinal	Interpretive
Data collection	Focus groups	Cognitive interviews	Mobile phone self-report questions, blood-pressure and pulse measurements	Audio/video recordings of follow-up consultations
Participants	Patients (n=15), professionals (n=12)	Patients (n=21), professionals (n=4)	Patients (n=50), professionals (n=8)	Patients (n=20) and professionals (n=7) in audio – (n=10) and video (n=10) recorded consultations
Setting	1 Health Care Centre 1 internal medicine out patient clinic	2 Health Care Centres	4 Health Care Centres Self-reporting in daily life	4 Health Care Centres
Data analysis	Thematic analysis	Structured iterative analysis Item tracking matrix	Descriptive statistics Analytical statistics: Paired sample t-test Latent class growth modelling	Interaction analysis

Study participants

The participants of the studies were asked to participate by their treating nurse or physician at the health care center (Studies I-IV) and/or at the internal medical outpatient clinic (Studies I, II). Table 2 provides a demographic overview of all study participants. The participating health care professionals in Studies I and IV were recruited from the same units as the participating patients.

Table 2. Demography

	Study I	Study II	Study III	Study IV
Number of patients	15	21	50	20
Females n (%)			24 (48)	11 (55)
Median age (range)	65 (58-88)	66 (49-82)		
Mean age (range)			59.5 (33-81)	56 (43-72)
Median years with hypertension (range)	6 (1-40)	10 (<1-40)	7 (<1 -32)	3,5 (<1 -25)
Mean years with hypertension (range)			8,5 (<1- 32)	6.8 (<1 - 25)
Systolic blood pressure (mmHg) mean (range) STUDY 3			142 (115-195)*	
Diastolic blood pressure (mmHg) mean (range) STUDY 3			84 (61–113)*	
MARITAL STATUS n (%)				
Married		17 (80)	39 (78)	14 (70)
Unmarried		2 (10)	10 (20)	6 (30)
Widow/ widower		2 (10)	1 (2)	
EDUCATION n (%)				
Compulsory school (\leq 9 years)		3 (14)	5 (10)	2 (10)
High school (9-12 years)		10 (48)	22 (44)	8 (40)
University		8 (38)	22 (44)	10 (50)
Missing			1 (2)	
EMPLOYMENT STATUS n (%)				
Employed		7 (33)	28 (56)	11 (55)
Long term sick leave		1 (5)	1 (2)	
Retired		13 (62)	19 (38)	9 (45)
Missing			2 (4)	

*Reported systolic and diastolic blood pressure are means calculated of each patient's four pre-study blood-pressure measurements.

Study I

Fifteen patients were strategically selected based on the inclusion criteria: currently being medically treated for hypertension, over 30 years of age, alert and oriented, hear well enough to take part in a focus group discussion, and able to understand and speak Swedish. To ensure demographic variety, patients were recruited from two geographically distinct locations: one primary health care center in a multi-cultural city suburb, and one internal medical outpatient clinic at a pro-

vincial hospital in a smaller town. Twelve health care professionals, comprising equal numbers of physicians, nurses and pharmacists, were included based on the criterion of past and current experience of caring for patients with hypertension.

Study II

Twenty-one patients were recruited based on the same inclusion criteria as in Study I, for face-to-face cognitive interviews. To enhance the chances of effectively testing item understanding, attempts were made to achieve a sample representative of the topic in focus and with demographic diversity; thereby the recruitment from two geographically separate locations, the same as in Study I.

Study III

For the third study the required sample size was estimated at 50 patients, in order to detect a change of 8 mmHg in SBP and 5 mmHg in DBP with 90% power at 5% level of significance [119]. The systolic and diastolic change thresholds were derived from earlier studies [45, 120]. Seventy-three patients – located at four different primary health care centers and meeting the criteria of currently being medically treated for hypertension, over 30 years of age and able to understand and read Swedish – were asked to participate by their treating health care professional, either through a phone call or at a regularly scheduled consultation. In addition, participants in this study needed to have access to a mobile phone with Internet access, and to agree to allow access to their data at the National Prescription Repository (NPR) to verify medication adherence [121]. A total of 54 patients subsequently agreed to participate, of whom three withdrew before study start. Hence, 51 patients started the study; however, one dropped out halfway through and was not included in the analyses due to sporadic self-reports even before dropout. Thus, 50 patients completed the study.

Study IV

The 20 participating patients in the fourth study were suggested from within the sample of Study III, and hence fulfilled the same inclusion criteria. All 20 patients who were asked to participate agreed to be audio or video recorded during the follow-up consultation with their health care professional. The seven participating health care professionals were those who had been involved in Study III at their respective health care center, and all agreed to be audio and/or video recorded during follow-up consultations.

Focus group interviews: Incorporation of patient and professional perspectives

In Study I, focus group interviews [122] were conducted to collect data on relevant aspects of hypertension and hypertension treatment, from the perspectives of the patients and their health care professionals, and further which clinical mea-

asures, lifestyle measures, symptoms and side effects of treatment would be meaningful to include in a mobile phone-based system to support self-management of hypertension. This interview method, with its origin in social science, has more recently been embraced by market researchers and is today used in a variety of areas [122]. Within the health and care sciences, focus groups have been widely used to explore people's experiences and perceptions of illness as well as attitudes towards care and health services [123]. In being shaped as group discussions, led by a moderator asking open-ended or semi-structured questions on a pre-specified topic [122], the presumption is that the group dynamic and the interaction between participants explicitly promotes insights and the construction of new knowledge [123, 124]. For the purpose of Study I, the interactional characteristic of the method was important: not only are focus groups a pragmatic and feasible way of collecting data within a group instead of performing individual interviews; the group dynamic and interaction between participants offer great potential to gather rich interview data.

Data collection

Five focus group interviews were conducted from June to August 2010. For the principle of homogeneity in focus groups – i.e. being able to benefit from the participants' shared experience [125] – patients and health care professionals were divided into separate groups, three with patients and two with health care professionals. Four groups had six participants each, while a fifth (consisting of patients) had three. Since the fifth interview did not reveal any new relevant information, no further interviews were performed. The 1.5-2-hour interviews were led by an experienced focus group moderator, and semi-structured interview guides were used. Two interview guides, one for the patient group and one for the health care professional group, were developed to provide a structure and some common topics and questions for each interview. Questions to patients referred to, for example, symptoms, inconvenience of hypertension, medication intake and reasons for taking/not taking medication. Questions to health care professionals referred to aspects including aims of pharmaceutical treatment, the health care professionals' perception of patient's knowledge and agreement with those aims, and motivating patients to follow treatment. During the interview, the patients and healthcare professionals tested the communication platform in a test run, answering mock questions on a mobile phone brought by the study team. At the end of the interview, they were further given a list of predefined symptoms, clinical measurements and examples of lifestyle habits, and were asked to number these according to priority of perceived importance to follow-up. The predefined symptoms were based on the results of a Swedish national multicentre study [45].

Data analysis

Data consisted of audio recordings of the focus group interviews, which were subsequently transcribed verbatim in Swedish. Transcriptions and recordings were compared and corrected, re-read and re-listened to continuously throughout the analysis process. The transcripts were coded using NVivo 8 (QSR Interna-

tional, Doncaster, Australia), a qualitative research software program designed to help users organize and analyze non-numerical data.

Data were analyzed using thematic analysis as described by Braun [126], a method for identifying, analyzing and reporting patterns or themes within a set of data, which is independent of theory and epistemology and can thus be used across different theoretical and epistemological approaches. Thematic analysis further allows for working with both an inductive (data-driven or “bottom-up”) and deductive (theory-driven or “top-down”) approach [126]. In Study I the inductive approach (approaching data without trying to fit into a predefined coding frame) and the deductive approach (approaching data driven by our analytic interest) were both used through the stages of 1) familiarizing ourselves with (getting to know) the data, 2) generating initial codes, 3) searching for themes capturing important issues in relation to the aim of the study, 4) reviewing themes, and 5) defining and naming categories, sub-themes and overarching themes. During the coding, discussions were held in order to reach consensus between the authors, followed by a measurement of inter-rater reliability.

Cognitive interviews: Assessment of item content validity and usability

In Study II, individual cognitive interviews [127] were conducted to assess the content validity (comprehension, comprehensiveness, relevance) of items and the usability of the developed prototype of a mobile phone self-management support system. Further, item reliability was evaluated using a test-retest.

The cognitive interviewing methodology is designed to assess the cognitive processes behind respondents’ understanding of items and generation of answers. The intent can be divided in two: one is to determine the respondent’s comprehension of what the item is asking and whether this comprehension is in line with the intended meaning of the item; the other determines what specific phrases and terms mean to respondents and whether this meaning is consistent with the intent of the item [127]. Cognitive interviewing is further a useful methodology for assessing whether the items are perceived as relevant and comprehensive enough for the purpose of, for example, the questionnaire or self-report system. For the purpose of Study II, it was also an advantage that usability could be tested within the frame of the interviews.

Data collection

Based on the intents of cognitive interviewing, determining the understanding and meaning of items and response options, a structured interview guide designed for using probes [128] was developed. Twenty-one face-to-face cognitive interviews were held and audio recorded at the respondents’ health care centers in four rounds during May-November 2011. The interview procedure was set up such that the respondents first received instructions on how to answer to the items in the mobile phone, as well as how to measure their blood pressure with a

home blood-pressure monitor and subsequently enter the answers and values in the mobile phone. Thereafter they performed the entire reporting and measuring procedure themselves, without interruption from the interviewer. Following this, the content validity was assessed through cognitive interviewing. Retrospective probing [128] was used, i.e. the respondents first went through the reporting and measuring procedure without interruption, and directly afterwards were asked about the items. Questions on usability of the mobile phone self-management support system were included, posed at the end of the cognitive interviews. The interviewer took notes while interviewing and observing the respondent going through the reporting and measuring procedure, in a copy of the interview guide assigned to each respondent. For the measurement of blood pressure a home blood-pressure monitor, validated according to the International Protocol of the European Society of Hypertension, was used [129].

Reliability of items was tested using a test-retest whereby 21 participants completed the ten mandatory items of the assessment twice, four hours apart. The clinical measurements, i.e. blood pressure and pulse, are not constant by nature, and the items describing side effects are not to be answered on a daily basis or by all participants; hence, these items were not included in the test.

Data analysis

The audio recordings and notes taken during interviews constituted raw data. After each interview the interviewer listened through the recording, taking thorough notes while listening. These notes built upon those taken during the interviews, and together the two composed a detailed summary synthesis for each respondent. Based on the stringent mode of action for structuring and systematizing the analysis of cognitive interviews suggested by Donald et al. [116], the summary syntheses were utilized in the development of an Item Tracking Matrix (ITM). Until the final item wording and response options had been reached, the ITM tracked the item development item-by-item and round-by-round, with continuous updates through the rounds of interviews. Between rounds, findings were discussed and actions for the next round of interviews determined within the interdisciplinary research team. Through this, the interview process and analysis were iterative. The test-retest reliability was analyzed by calculating the intra-class correlation coefficient (r_{tt}) [130].

Longitudinal self-reported data: Evaluation of effect on blood pressure

The mobile phone self-management support system developed during Studies I and II was initially pilot-tested by two patients for 12 weeks. Patients' experiences from the pilot study led to a decision to decrease the length of the study period. Thereafter we conducted Study III, a longitudinal study lasting eight weeks in which the mobile phone self-management support system was brought into use in the daily life of the study participants as well as in clinical practice. The intent was to evaluate its effectiveness in reducing blood pressure and to examine blood

pressure change trajectories over the study period. It was also of interest to try to identify subsets of patients who would potentially benefit the most from using the self-management support system.

Data collection

A study procedure was established that included help and instructions for health care professionals, in order to start using the system within the database. Following this, start-up meetings for patients were held at which they first met the researcher for individual instructions on how to use the system and the blood-pressure monitor, how to measure their blood pressure according to the European Society of Hypertension's practice guidelines for home blood-pressure monitoring [131], and how to download the software to their mobile phone. They were also shown how to log in to the database and find the graphs, and were allowed to try this themselves. Thereafter, a meeting with their nurse or physician was scheduled. During this meeting the patient and the nurse or physician together tailored the system for the individual needs of the patient by selecting relevant items on drug side effects related to the patient's drug regimen, choosing motivational messages (optional) according to the patient's preferences, and choosing the timing of the daily measurements, self-reports and reminders according to the patient's wishes. Items on side effects and motivational messages occurred in the system twice a week. The research team provided the patients with a home blood-pressure monitor (Microlife BP A200 AFIB), and thereafter the patients used the self-management support system and self-reported via their own mobile phone once a day during the eight-week study period. The patients first answered the items and then measured their blood pressure and pulse, and when these data had been input into the mobile phone they were automatically registered in the database.

Four weeks into the study, the researchers made phone calls to all participating patients to check on their progress and ask if they had any questions or thoughts (usability, feasibility, urgent problems or worries) that needed to be addressed. The self-reports of medication intake – "Taken your antihypertensive medication today?", with response alternatives "yes", "partly" and "no" – were manually checked for consistency with the NPR registry; i.e., to check whether the prescription fill rates corresponded with the reported intake. The study was concluded after eight weeks with a follow-up consultation between the nurse or physician and the patient. Data were collected from February until June 2012.

Data analysis

Comprising 56 consecutive days of blood-pressure assessments, Study III yielded data that offered the opportunity to look at trends of change in blood pressure during the course of the study period. This demanded the selection of an analytical method able to maximally exploit the richness of this data set. As pointed out, we wished to determine first whether the intervention significantly reduced blood pressure in the patient group, but also how the change trajectory would

look over the course of the study period. Further, since heterogeneity in response to treatment is common, we wanted to see if we could identify sub-groups of responders/non-responders who were homogeneous with respect to blood pressure trends and, if so, who would benefit most from the intervention.

As a first step in the analysis, descriptive statistics were used to characterize patient demographics and clinical variables (SPSS, version 19 for Windows, Chicago, IL, USA). For a before-after analysis on a group level, we extracted pre-trial blood-pressure values from the four most recent blood-pressure checkups from the patient health record for each patient. The mean of these four pre-trial measurements was subsequently compared to the mean of those of the last seven days of the study. This was done using a paired samples *t-test* with statistical significance set to *P*-value <0.05.

Latent class growth models (LCGM) [132-134] are a form of Growth Mixture Models [135], used for looking at within-person change and differences in within-person change between individuals. This approach also makes it possible to look for relationships between individuals and to identify homogeneous sub-groups (or classes) of patients. We decided to use LCGM rather than more traditional methods such as repeated measures ANOVA or cluster analysis since LCGMs are more flexible in handling complex longitudinal data, e.g. partially missing data, unequally spaced time points, non-normally distributed or discrete repeated measures, and in dealing with large numbers of measurement points.

The LCGM analyses were based on the first 14 days of measurement, excluding Day 1, in addition to one occasion per week from Day 14 to Day 56; i.e. 19 waves of data. Excluding values from Day 1 is common, and is acknowledged in guidelines for HBPM [131]. Commonly, these values are higher than the patient's normal blood pressure. This was in line with the Day 1 values from Study III, and therefore the decision was made to exclude them from analysis. Weekly instead of daily blood-pressure values were used from Day 14 on, due to analytical and interpretive constraints related to the complexity of models.

Recordings of hypertension consultations: Examination of implications for patient-professional communication

At health care appointments a typical interaction order is usually established in the patient-professional communication, a routine that is maintained by both parties and serves the purpose of an agenda-driven strategy [69, 136]. The fourth study of this thesis intended to examine how the use of a mobile phone self-management support system was taken up in clinical practice, particularly whether and how it altered the ways patients and professionals interacted. It was further of interest to explore what happens when technology enters as a mediating means in the consultation; in what ways it may support or disrupt the agenda of the meeting; and whether it allows patients to become more involved in their care. An important

perspective for this thesis was what it implied when the patients arrived at their follow-up appointment with the experience of having self-reported well-being, symptoms, drug intake, side effects and lifestyle in relation to their hypertension, as well as having performed self-measurements of blood pressure and pulse once daily for eight weeks.

Data collection

Twenty patient-physician/nurse follow-up consultations were documented through audio recording (n=10) or video recording (n=10). The recordings were made in the office of the nurse or physician at the patient's health care center, with no-one present but the patient and the health care professional. Due to use of the self-management support system, the prerequisites for these consultations were new to both the patients and the health care professionals, but since the main interest was how this would have an influence on the consultations, the health care professionals received no instructions for how to structure or perform them. Data were collected May to June 2012.

Data analysis

Data consisted of video and audio recordings, and their verbatim transcripts. The analysis was explorative in nature and was systematically pursued, investigating how the communication between the parties was organized in terms of internal phase structure and activities pursued within each consultation. First, the ten video recordings were analyzed with the aim of getting an overview of the consultations. Also, topic initiations by speaker were marked and counted. A new topic [72] was defined as a change in topic of conversation that did not uphold or support the previous one *or* when a new topic was created by departing from the current one and transferring its content to something new to talk about. To approach this task, six video sessions of collaborative viewing [117, 137] were held within the research group. Before the sessions, each researcher meticulously read the transcript alongside the original data from the specific follow-up consultation to be addressed. During the video session, the follow-up consultation was analyzed by indicating what the parties were doing, or engaging in, during the consultation. Questions of interest in the analysis were how the activity was initiated and by whom. Who initiated new topics of conversation? Who took the responsibility to move the conversation forward? How was it done? By what means was it done (conversational support, follow-ups, summaries)? Who contributed knowledge and by what means? And finally, who made recommendations for future practice? Second, the remaining four video recordings were analyzed in the same way, but now by one of the members of the research team, with support from a mentor from the same team. Through this a structure of 1) phases and 2) activities within phases common to the consultations emerged.

Subsequently, the ten audio recordings were likewise analyzed to investigate whether the emerging structure would be consistent through all consultations.

On the basis of the preliminary analyses, Phase 2 of four was selected for further investigation, as it seemed particularly intense in terms of patient contribution, and it was also in Phase 2 that the self-management support system was commonly drawn on in the consultations. The analysis of Phase 2 was structured in a matrix in terms of timing and a listing of activities engaged in and topics addressed. Finally, we explored how the blood-pressure value was talked about in terms of whether patients' everyday perspectives or institutional perspectives were made salient [69, 136].

ETHICS

The work of this thesis was planned and conducted in accordance with the World Medical Association's Declaration of Helsinki [138], ensuring that the basic ethical principles of research involving human subjects are met: *respect* for the individual (respect for the autonomy and/or protection of those with diminished autonomy), *beneficence* (maximize benefits and minimize harm) and *justice* (distributive justice; i.e. the potential burden due to participation in research should correlate with the expected benefits). *Justice* also refers to *vulnerability*, an incapacity to protect one's own interest. The Belmont Report [139] provided researchers a referral of these theoretical principles to practical applications: the requirement for informed consent, voluntariness (the right to approve, decline or discontinue participation at any time), assessment of risks and benefits for participants, and the (*just*) selection of subjects [139].

The studies in the thesis have been approved by the Regional Ethics Board in Gothenburg, Sweden (study codes 551-09 and T-100-12). The patients and professionals were given both written and oral information that their participation was voluntary, and that their responses would be kept confidential and would only be presented as anonymous quotes in scientific publications. Background data, audio- and video-recorded data and data from the National Prescription Repository were kept in a locked space at the university. All data in the database were coded, and all participants were assigned a code number. The server containing the database is located at a secure location in Sweden, with levels of security comparable to those used within the Internet banking system. Access to the server is limited to authorized personnel, and access is logged. When the database is accessed through the web interface, all data are encrypted with SSL (Secure Sockets Layer).

When starting up the self-management support system, participants were asked for approval of PuL (the Privacy Protection Law) in order to allow data to be sent from their mobile phones to the database and to be stored there. By approving, they also agreed to share their data with their nurse or physician as well as with technical staff from 21st Century Mobile AB. All professionals involved had strict instruction to keep information confidential. The data traffic was de-identified so that the traffic itself cannot be tied to a certain identity. The study was monitored by an independent monitoring board to ensure that data were entered accurately.

Ethical considerations on the individual level are twofold, one being the risk of feeling worry about one's blood-pressure value when measuring blood pressure at home. It is also possible that other questions will arise when new thoughts and insights take form, brought on by the use of the self-management support system. A system to support self-management cannot be left to live its own life; it is crucial that the system be incorporated into the usual care, whereby it is always possible to get in touch with the caregiver if a measurement, or anything

else, cause worry or needs to be discussed. The other aspect is the risk of feeling supervised or controlled; however, the advantages of gaining control over a situation one previously had a poor understanding of and having the chance to feel empowered are likely to compensate for this. On a group level another concern, related to the principle of justice, needs to be addressed. When research with behavioral components is conducted, a common problem is that it is most often the most motivated and health-literate people who are included in the study. This carries the risk that groups who would potentially benefit from an intervention are not included. Through our strive for diversity among participants included in the studies of this thesis this risk is acknowledged, even if not diminished.

RESULTS

The results are presented in two parts, reflecting the design and development phase, and subsequently the evaluation phase, of the self-management support system.

Design and development of an interactive mobile phone-based system to support the self-management of hypertension

The results of Study I presented aspects that patients deemed important for hypertension management, with the aspect of top priority for patients entailing having control over their blood pressure, the biomedical outcome. Further, patients sought to understand the variation of the blood-pressure value in relation to experienced symptoms and lifestyle. Subsequently, the self-monitoring of blood pressure and self-reports of aspects such as dizziness, tiredness and stress were outcomes considered important to include in a self-management support system. The patients felt that keeping a closer watch over their blood pressure and the factors affecting it would make them feel more secure, for instance when starting or changing a medication. Health care professionals emphasized items including accessibility, complication prevention and educational efforts as important aspects of hypertension management, and agreed with patients regarding outcomes to include in a self-management support system. However, there was a discrepancy in how symptoms were perceived by patients and how they were viewed (and hence communicated to patients) by health care professionals, in the respect that health care professionals largely held the view that hypertension is a symptomless condition while patients related symptoms to their hypertension. Another mismatch in views between the patients and the health care professionals concerned the expectations for hypertension treatment. The patients experienced symptoms, and thus their desire and expectation were that the treatment would resolve the symptoms. Patients also wished to feel good in the present, and thus expected the medication to work here and now, as well as prevent future complications. This expectation of treatment did not fit with that of the health care professionals, who mainly emphasized the long-term benefits of preventing future complications and that patients generally could not expect that the treatment would make them feel better in the present.

An important finding of this study was the patients' expressed need for an understanding of blood pressure in relation to perceived symptoms and lifestyle, which indicated the direction for the continuation of the interactive mobile phone system to support the self-management of hypertension. Moreover, an important finding from Study I was the evident discrepancy in views between patients and health care professionals regarding certain aspects in relation to hypertension and its management, most importantly regarding symptoms and expectations of treatment. Health care professionals did not ascribe symptoms to hypertension whereas the patients did, and with regard to pharmaceutical treatment the

patients wished to feel good in the present, while the health care professionals viewed treatment as long-term prevention. This offered evidence of the importance of the person-centered and participatory orientation in the development process.

The findings of Study I provided further guidance for the development process: when to use a self-management support system, and what would be meaningful to include. A draft set of six areas covered by 16 concepts, and beneath them 16 items, was developed for possible inclusion in the self-management support system, intended for use during periods of increased need to monitor blood pressure, for example when starting/changing a medication or when blood pressure is difficult to control. Figure 3 provides a map of the areas, concepts and items.

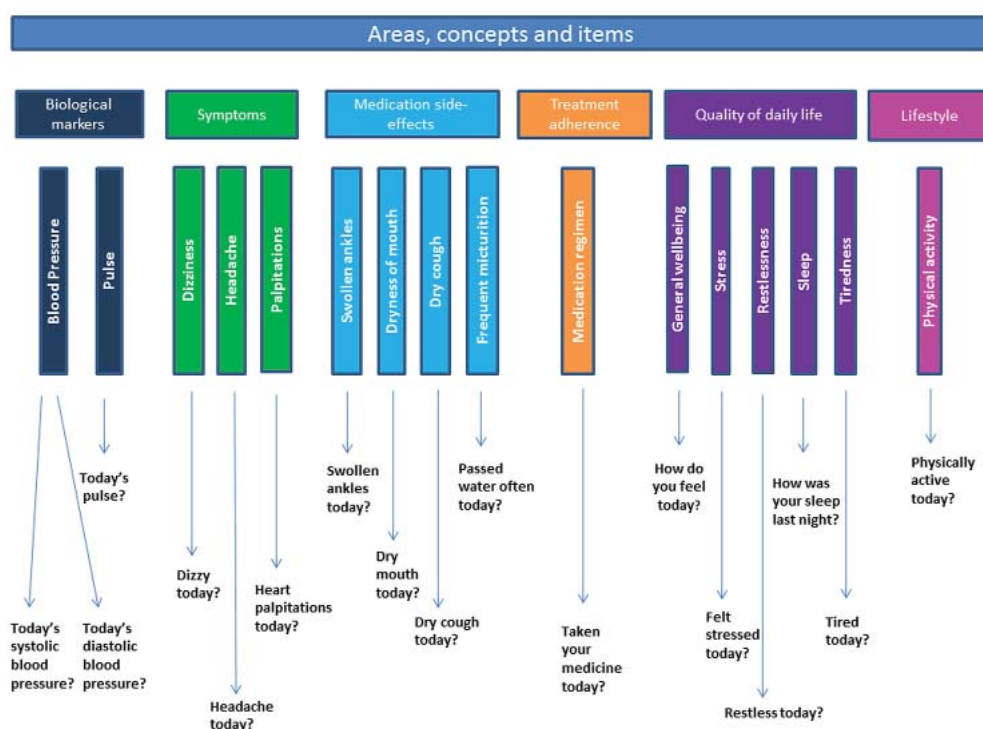


Figure 3. The map organizes the content of the interactive self-report system into six areas, 16 concepts and, subsequently, the final 17 items.

The cognitive interviews of Study II showed satisfactory item comprehension, relevance and coverage; however, one item (pulse) was added, resulting in a total of 17 items. The mobile phone as an administration mode was perceived as easy to use, with little or no trouble associated with recording answers to items, and the same applied to the self-measurement of blood pressure.

The items of the mobile phone self-management support system were reliable, with correlations of $r_{tt} > 0.90$ for Items 4, 7, 8 and 9, and $r_{tt} > 0.70$ for Items 3 and 6.

Items 1 and 2 were just below the threshold 0.70 (rtt = 0.69) [140]. An example of the development from an initial to a final item as well as wording and response options, presented in a sample version of an ITM, are shown in Table 3. In short, the cognitive interview process, including the analyses, was iterative and any changes or actions decided upon were evaluated in the next round of interviews until no more misinterpretations of an item were detected.

Table 3. Example of development of an item

Item tracking matrix											
Domain	Concept	Definition of concept	Item no	Original item	Original response options	Attribute to measure	Change or actions taken after first round of cognitive interviews	Rationale for change or action	Change or action taken after second round of cognitive interviews	Rationale for change or action	Patient quotations
Side-effects	Swelling of ankles	Swelling of ankles due to hypertension medication	14	Swollen ankles today?	- not at all - slightly - neither nor - severely - extremely	Degree	Explicitly ask what middle is preferred, "neither nor" or "moderately", in the second group of interviews	The research team is not confident that the response option "neither nor" is to be preferred to "moderately"	-Explanation added to the accompanying leaflet: "This item asks if your foot <i>and/ or</i> ankle are swollen" -Change response option "neither nor" to "moderately"	-Respondents could relate to being swollen but how it manifests itself or how ankle was defined varied. -"Moderately" was preferred by patients	"If my body is swollen" "Yes, they mean in the feet, in the ankles" "Swollen foot" "Swollen legs"
Continued:											
Change or action to take after third round of cognitive interviews		None		Final item	Swollen ankles today?		Final explanation of item		Final response option		
None							"This item asks if your foot <i>and/ or</i> ankle are swollen" added to the Information leaflet.		-not at all -slightly -moderately -severely -extremely		

Finally, the included items were developed in a structured manner to ensure content validity, and the usability of the mobile phone as a mode of administration was established. The mobile phone self-report system was reliable, and appeared to efficiently and effectively capture information relevant in patients' self-management of hypertension.

Evaluation of an interactive mobile phone-based system to support self-management of hypertension

The findings from the design and development studies (I and II) signaled that the interactive mobile phone-based system to support the self-management of hypertension was fit for its purpose and ready to be tested in clinical practice. For the comprehensive purpose of this thesis, Studies III and IV examined the effects of using the self-management support system from different perspectives: a biomedical one focusing on the sign (blood pressure), and a communicative one.

Study III reported the effects on blood pressure, and showed that the daily use of the mobile phone-based self-management support system for the self-management of hypertension significantly reduced both SBP and DBP over the course of the eight-week study period. First, the before-after analysis between the mean of the pre-trial blood pressure measurements and the mean of the Week 8 values showed a statistically significant decrease of 7 mmHg in SBP ($p=0.008$) and 4.9 mmHg in DBP ($p=0.002$).

The LCGM analysis supported these findings, also revealing significant reductions in blood pressure on a group level. The average SBP and DBP on the first day of the study were 140.34 (SE=2.16) mmHg and 81.78 mmHg (SE=1.05), respectively. The mean change (average linear slope) was significant and negative for SBP ($M=-0.32$, SE=0.11) and DBP ($M=-0.17$, SE=0.06), indicating that individuals generally lowered their SBP an average of 0.32 mmHg per day and their DBP an average of 0.17 mmHg per day during the course of the study period. Also, the quadratic slope was significant and positive for both SBP and DBP, indicating that the mean decline in blood pressure levelled off as the study progressed. The patterns of trajectories for SBP and DBP are illustrated in Figures 4a and 4b.

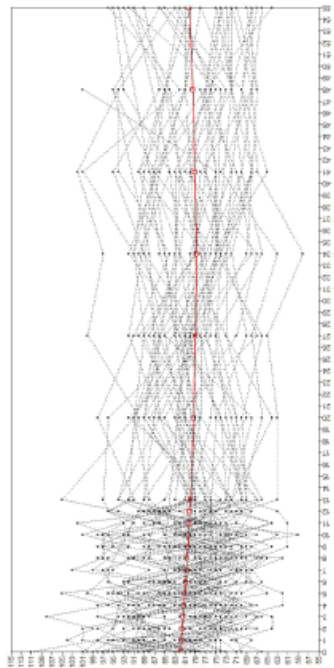
The sub-group analysis identified three subsets of patients who were homogeneous with respect to baseline blood pressure and change trajectories. The first and smallest latent class, consisting of five patients, demonstrated a higher mean SBP at study start (168.81 mmHg). This class had a non-significant decrease (-0.42 mmHg) and a non-significant quadratic effect (0.003), indicating that the trajectory of change remained stable. The second class was the largest, with 30 patients, and had a substantially lower mean SBP (143.4) at study start. For this class the mean decrease (-0.28 mmHg) was significant and the quadratic effect (0.003) was significant and positive, indicating that improvement abated or levelled off during the treatment period. The third class, consisting of 15 patients, had the lowest

mean SBP at study start (124.71 mmHg), which also significantly decreased (-0.46 mmHg). This decrease levelled off, indicated by a positive and significant quadratic slope (0.08). Trajectories for the three groups are shown in Figure 4c.

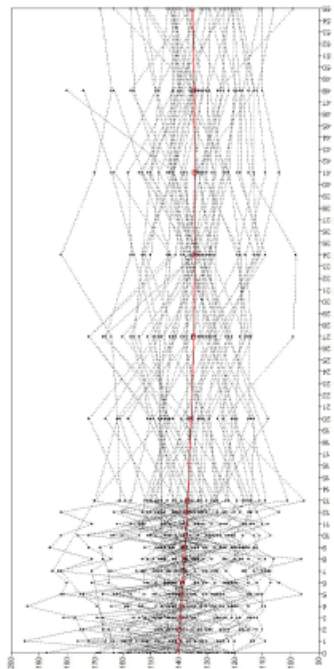
For DBP the first class of 15 patients had a starting DBP of 91.27 mmHg, a significant mean decrease of -0.21mmHg, and a non-significant quadratic effect (0.002). The second class, with 29 patients, showed a starting DBP of 79.33 mmHg, a significant decrease of -0.19 mmHg, and a positive and significant quadratic effect (0.004). Finally, the third class, consisting of six patients, had a lower DBP at the start (71.63 mmHg), a significant decrease (-0.20) and a significant positive quadratic effect (0.003). Trajectories for DBP for the three groups are shown in Figure 4d.

Study IV reported on the impact of the eight-week use of the self-management support system on follow-up consultations in clinical praxis, held by the end of the eight week period. From the person-centered standpoint of this thesis, it was of particular interest to explore patient participation in terms of how patients contributed during consultations, but also to describe the consultations' communicative structure and, further, their content in terms of topics addressed. The study was unique in the new prerequisites for the follow-up consultation it presented; i.e., that the data constituting the foundation of the consultations were generated by the patients themselves in their own contexts, and that the graphs visualizing their self-reported data over time would potentially play a role in the consultations in one way or another. Nonetheless, the overall structure of the consultations remained in a pattern of three main phases (opening, examination and closing), like consultations in the clinical practice of primary care [141]). The new conditions for the consultations thus fit into a familiar frame, but the activities the parties engaged in within Phase 2, with the patient and health care professional exploring the blood-pressure values together by jointly orienting themselves towards the computer screen, were pursued differently. This became salient in different ways during the consultations. One example of this is how the graphs functioned as an explicit mediating tool in the discussion around the blood-pressure values; this was observed, for example, in how the conversation was usually structured according to the sequential order of the items on the screen. This seemed to facilitate elaborations on relevant parameters in relation to blood-pressure values, and the patients and the health care professionals conjointly explored these relationships. In this way, the self-management support system supported the activity by coordinating both parties' perceptions and actions throughout Phase 2 of consultations. It also gave the patients the opportunity to broaden their interaction space and to contribute to the conversation by providing context and their interpretations of the variations in blood pressure.

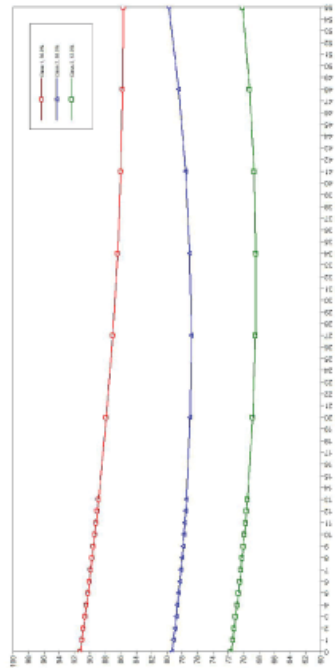
The topics addressed during the consultations were dominated by the blood-pressure value, mainly related to lifestyle factors and everyday life. Through the number of initiated new topics (mean), the results exposed a symmetrical dis-



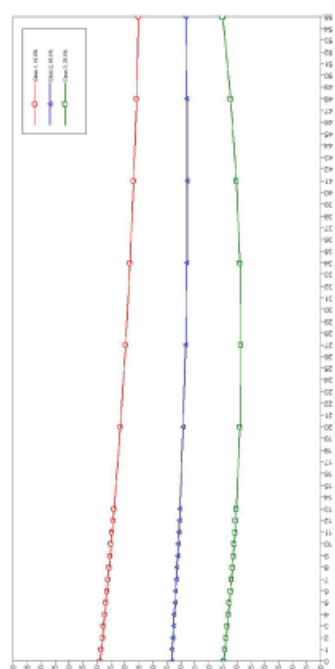
4a



4b



4c



4d

Figure 4. Between-person heterogeneity in systolic (4a) and diastolic (4b) blood pressure for all participants (1-class model) and description of the classes in the best fitting 3-class models for systolic (4c) and diastolic (4d) blood pressure.

tribution between the patients and the health care professionals (patients $m=8$, health care professional $m=7$), which contrasts earlier research that has shown more health care professional dominance during consultations [72, 142].

The most distinct way patients contributed to the discussion and understanding of blood pressure was in the way they contextualized blood-pressure values to specific situations in their everyday life. By remembering a certain occasion, patients could connect the blood-pressure value to what was done, felt or experienced on that particular day. This implies that the blood pressure was approached from a life-world-focused perspective whereby the interconnections between medical signs, perceived symptoms and life could be explored. In this regard, Study IV provides contrast to earlier research that has reported patients remaining relatively passive during clinical consultations in general [143-145], as well as in hypertension care in particular [72, 73, 142]. The self-management support system thus seems to facilitate patient agency, through the reflexivity gained by documenting one's own health during the study.

DISCUSSION

The presented findings provide descriptions of ways to proceed when developing an HIT tool to be used conjointly by patients and health care professionals, from a person-centered perspective, in a participatory and structured manner. In addition, the results showed that patients were capable of handling the interactive mobile phone self-management support system and that effects from using it could be shown; that blood pressure decreased; and that patients rose above their traditional role as patients and showed agency as equal partners in the follow-up consultations.

Methodological considerations

Overall design

As the studies required different methods the thesis was based on research conducted with multiple methods, which implies relating to epistemology in a pragmatic way and letting the research question determine what method to use. This is not to say that one should not be aware of epistemological differences between the qualitative and quantitative research paradigms; however, I would believe that today integrating different methods into research design is more or less uncontroversial, and can be viewed as a strength of the research design. Or, as LJ Philip [146] put it already in 1998: *“employing a range of methodological strategies means that the researcher does not necessarily privilege a particular way of looking at the social world... I would suggest that such [postmodernist] diversity encompasses methodological plurality as well as postmodernism, encouraging different voices to be heard and facilitating the exploration of different truths”*. Spicer [108] asserts that the actual differences between qualitative and quantitative methods are the rationales for combining them at all, as the differences strengthen and complement each other. In Studies I and IV, the combined method approach is integrated within the same study. Study I is particularly interesting in this sense, as this is materialized in both the data collection and the data analysis in different ways; the results from the thematic analysis of the focus group interviews were supplemented with numerically ranked data. The thematic analysis per se was driven by both induction (data-driven analysis) and deduction (theory-driven analysis), which are ways of approaching data that themselves derive from different epistemological assumptions. Accordingly, Study III allowed the nature of the research questions to direct the analysis to LCGM, a relatively new and promising method for analyzing trends and heterogeneity in treatment response in large longitudinal datasets. The FDA model for developing patient-reported outcomes [113] that was used as working tool for developing the self-management support system (Studies I and II) is a model chosen for its pragmatic relevance, in that the FDA standard can be used to design systems containing patient-reported outcomes to be used in clinical practice, according to current regulations. The FDA model contains several methods from both the humanistic as well as the logical, empirical sci-

ence tradition, according to combined methods research [108]. In emphasizing the compulsory aspect of working together with patients and health care professionals in the development process of patient-reported outcomes, the framework fit the theoretical perspectives of personalism that have framed the thesis. The FDA model also provided a feasible and sequential structure that helped ensure rigor and transparency in the development process.

Sample selection and size

An aim of the qualitative research method is to describe and understand meanings of phenomena; in the case of this thesis, perceptions and experiences of hypertension as a condition (Study I). In the recruiting and inclusion of a sample in a qualitative study, participants need to have experience from the studied phenomenon and, further, must be able to share it [147]. In focus groups homogeneity is sought in relation to experience of the studied phenomenon, but diversity in relation to demography, in order to obtain as rich and comprehensive data as possible [122]. The same principles apply when conducting individual cognitive interviews (Study II) to assess the validity of items [127]. Studies I-IV did recruit a demographically diverse and representative sample of the target population in Sweden [45]. However, despite efforts to recruit at primary health care centers that were different in terms of geographic location and patients' ethnic backgrounds, there was a lack of cultural diversity throughout all the studies. In Studies I and II a lack of skill in Swedish was a barrier, which ideally could have been overcome by holding interviews in both Swedish and English, or in some cases using an interpreter. Further, the results of Study I yielded a picture of a more medication-adherent sample than average and Study III had an adherence rate of 80% at outset compared to earlier research on adherence to hypertension medication [18], which implies that the patients we reached were already motivated. Reaching less motivated persons, who would likely benefit from receiving self-management and motivational support, is a challenge that needs to be attended to in future self-management supporting strategies. Accordingly, sample bias has to be considered for all the studies.

In contrast to quantitative research, which seeks to select a sample that will make it possible to achieve statistical validity and to generalize from the results with generally larger sample sizes, qualitative research strives for rich and contextually relevant data. Hence, sample size as such is not the key issue when sampling for a qualitative study, but rather context and the composition of participants [147]. Studies I and II continued the data collection until an interview or round of interviews did not offer any new or substantial information. The participants of Study II were consecutively included until the last round of interviews. The 20 audio- and video-recorded follow-up consultations of Study IV resulted in a large body of interactional data consisting of about ten hours of audio and visual material. The quantitative study of this thesis (Study III) included 51 patients, of whom 50 completed the study, based on a sample size calculation [119], see p. 37. Given the study's 1) design, the daily self-reporting of blood pressure, pulse

and a range of other parameters over eight weeks that provided rich data with a large number of measure points that could show statistically significant improvements in blood pressure, and 2) intent, an exploration of the effect of a newly designed and developed self-management support system, the sample size can be regarded as adequate.

Trustworthiness and validity

A well-known standpoint is that all research should become the subject of critical scrutiny of its quality, and even though the criteria according to which quality should be assessed seem to differ depending on qualitative or quantitative research paradigms, parallels can be drawn between them [148, 149]. In qualitative research one speaks of *trustworthiness*, which includes the intertwined aspects of *credibility, conformability, dependability and transferability* [148, 149].

Credibility refers to confidence in the authenticity of the data and the interpretation of them; i.e. "truth value" [150]. According to Lincoln and Guba [148], this involves conducting the study so that the credibility of the findings is enhanced, and clearly demonstrating this. Graneheim and Lundman [151] asserted that questions concerning credibility arise already when determining the study's focus, selection of context, participants (representative but diverse) and approach to gathering data (most appropriate method for data collection, collecting the right amount of data). The parallel concept for credibility in quantitative research would be *internal validity* [149].

In Studies I-IV, the sample and contexts were strategically selected and thoroughly described. In striving for credibility of the interviews in Study I (focus groups) and Study II (cognitive interviews), the semi-structured (focus groups) and structured (cognitive interviews) interview guides were designed with follow-up questions in the focus groups and probes in the cognitive interviews. In Study I, the interpretation of the focus group data was based on the interview audio recordings and verbatim transcripts that could be checked for consistency against each other. The themes and sub-themes were illustrated through exemplifying quotations. The credibility of Study IV was strengthened through source data consisting of audio and video recordings of authentic clinical consultations with the self-management support system in place. The audio and video observations provide ecologically valid data, necessary in order to analyze the interaction and the local use of the self-management support system. Such data can be scrutinized through repeated listening/viewing, in detail, and the results can be scrutinized and qualified by several researches, supported by verbatim transcripts. The main findings were substantiated by longer quotations from the communication during the follow-up consultations, and variations in the material were also brought to the fore in reporting the results. In Study II, *validity of items* was secured through the cognitive interviews. This kind of validity, referred to as *content validity*, is an important quality measure in the development of patient-reported outcomes

[115, 116, 152] and encompasses the comprehension, comprehensiveness and relevance of the developed items. In Study III, *internal validity* was strengthened by the study's context in terms of a careful selection of participants and sites and further, sample size. A point worth making in relation to Study III, although it is not a threat to internal validity, is the rationale for using LCGM, which enabled the analysis of large numbers of measure points, which encompassed 55 days. But these analyses in fact comprised 19 measurement points (13 of the 14 in the first two weeks, plus Day 1 of each of the following six weeks) due to analytical and interpretive constraints related to the complexity of models.

Conformability relates to objectivity; i.e., whether there is congruity between observers concerning the accuracy of the data with regard to meaning and relevance. Conformability was established in Study I through the participation of all authors in the coding and analyzing process, in addition to a measure of inter-rater reliability. In Studies II and IV the author group was extended to the whole interdisciplinary research group taking part in design meetings on item development through the data collection and analysis process (Study II) [112, 140] and video data sessions of follow-up consultations (Study IV).

Dependability relates to the stability of data over time; i.e., what would happen to results if the study were replicated in a similar context by the same researcher [147]. The related concept in quantitative research is *reliability*. Study II added a reliability measure of the developed items to the structured item development through a test-retest [140].

Transferability refers to the extent to which the findings can be transferred to other settings and groups. To facilitate transferability, the research should be thoroughly described in a way that allows the reader to judge its applicability to other contexts. The results of the developmental steps taken in Studies I and II are most likely to be transferable to other contexts and situations of developing HIT tools. Some of the descriptive results from Study I could probably be possible to apply to the self-management of other chronic conditions. The results of Study IV show the potential of self-reporting for patient participation and how the self-management system, when used in the consultations, served its purpose of aiding in understanding and interpreting signs, symptoms and lifestyle parameters. This potential is likely transferable to any chronic condition in which these interrelations are hard to grasp, and for which a visualization tool with similar functions is developed to guide clinical consultations. The related concept in quantitative research is *external validity*, which deals with the extent to which the research can be generalized to other people and other situations. Due to its explorative design the results of Study III cannot be generalized to a larger population, but the carefully selected sample, may represent a larger group of persons with hypertension.

Finally, for an overall outline of the project an overview paper of its work has been published, and is included as an appendix to this thesis [109].

Reflections on the findings

With a background of the public health issue of the present and future care for chronic conditions in general and hypertension in particular, the work of this thesis attempted to respond to the need to provide self-management support to patients in an era in which an increased individual responsibility for one's own health and care is demanded. Societal aspects to acknowledge in relation to this attempt are an increase in the number of people requiring health care services, fewer people at the age of being able to provide this service and, in parallel to the challenge of caring for the long-term conditions, a more specialized care. These aspects place new and increased demands on patients that they have knowledge about their own condition, but also imply changed demands on health care and health care professionals. In order to support patients in self-management, health care needs to acknowledge the person with the condition, which in turn implies a need to change old routines and establish new ways of organizing and pursuing care [153]. The results illuminate how an HIT tool has the potential to support patients as well as health care professionals in this transition. This and more will be discussed in the following.

Person-centered care has come to be increasingly forwarded and endorsed, often as the approach in care that will answer to the needs of change in the thus far predominant biomedical model of care. But no model of care will serve its purpose if it neither works nor is feasible in clinical practice. Research has thus looked at the fact that, even though it is strongly advocated, person-centered care does not seem to be widely used, and that implementing the approach, as with all major changes to organizations, entails barriers [153, 154]. Leyshon and McAdam [155] recently emphasized the importance of taking an overall systems approach to person-centered care, Eaton [153] promotes practical support, and in his thesis Alharbi [156] concluded that *"The level of success of the actors' involvement in the implementation of a new care model can be measured by their level of involvement in the design of the model rather than their participation in a model designed for them"*, p. 49.

Consequently, the person-centered approach not only applies to the person with a condition, but also to those providing the care; and not only through providing a new and set approach of care, or support system to be used, but by involving both patients and health care professionals in its design and development. When developing the interactive mobile phone-based system for supporting self-management of hypertension, this was taken into account. In Study I health care professionals raised concerns regarding the use of a self-management support system. Would this mean worry for the patients? Would it imply a greater workload for health care? How would all the blood pressure data be meaningful to health care and patients? Later, after their continued participation in the development process, these concerns had faded. Study II approached the persons in a more structured way to validate items for understanding, coverage and relevance, and further, the usability of answering items with the restrictions imposed by the mobile phone as a physical object, i.e. the size of the screen. The health care

professionals were also consulted in this step. After the (simultaneous) closing of Studies III and IV, with 50 of 51 participants completing study III and having self-reported every day for eight weeks, interviews were held⁷ with the patients [157] and health care professionals (manuscript under preparation), respectively. The experiences were unilaterally positive regarding usability, feasibility and gained insights and knowledge. The reluctance from health care professionals at the beginning of the project had turned into a desire to continue using the system at their clinics. If we relate to Alharbi's conclusion above [156], it is confirmed by this thesis in the clinical practice of hypertension care. The results of Studies III and IV, as well as the post-study interviews⁸ with patients and health care professionals, further reflect that successful outcomes from working according to a new approach, method or support system depend on its acceptance by users, and that a way to gain acceptance is to involve the main parties in the design and development, while also ensuring validity and usability. This thesis relates to a person-centered approach, and to allow this to pervade all steps in the design- and development of research, be it a support system, an intervention or implementation (and also in research and development in general), may be fruitful. Working in a participatory manner, as in Study I and II, is a way to translate a person-centered approach to a practical realization in a design- and development process.

The results of Study III showed significant decreases in blood pressure over the eight-week study period. The results raise interest regarding the reasons for the improved blood-pressure values among participants, who were already taking their medications at baseline and did not alter their hypertension medication to any great extent. Further, all three sub-groups improved their blood pressure, regardless of its value at study start. This study thus differs from previous self-management HIT interventions for persons with hypertension, in which the reason for blood pressure decrease has been attributed to intensified medication schemes [79-82]. How the documentation of blood pressure, pulse and self-reports over time allowed the patients to follow the course of the blood-pressure values, and how it showed variation in relation to other self-reported parameters, could be one possible aspect to consider when deliberating on the results of Study III. The follow-up consultations of Study IV clearly showed that the patients had taken on an interpretive approach, relating their daily life to the blood-pressure value.

In a paper by Hallberg et al. [157] reporting on patients' experiences from using the self-management support system and taking part in the follow-up consultations, patients reported an increased motivation with regard to medication intake and lifestyle changes, and some also said they had made lifestyle modifications during the study. Another aspect to consider is how the patients actively participated in, and contributed to, the follow-up consultations of Study IV and how they showed agency in relation to their blood-pressure values, by sharing insights

⁷The post-study interviews held with patients and health care professionals by the end of the eight-week period were performed within the project but is not a part of this thesis.

⁸See footnote 7

and interpretations with the health care professional. A third aspect is how the patients in Study I clearly voiced a wish to learn more and to be in control of their condition, which the patients in Studies III and IV are shown to have gained. Might this feeling of control in itself have had an effect on the blood pressure in its own right? This would be an intriguing question to explore further. In addition to the mechanisms behind the blood pressure decrease reported in Study III the sustainability, and also the scalability [158] of these results would be opportune to study further.

Given the results of previous research [79-82], e-health in general holds great potential for hypertension and chronic care. Studies III and IV of this thesis showed how e-health, through self-reporting and self-measurement may serve as basis for decisions in care, and the results of care have the potential to improve through patients' increased knowledge and understanding, as shown in Study IV. Inherent to this potential are: firstly, the self-management support systems' specific content and functions that were developed in collaboration with the patients and health care professionals; secondly, how it was used by the patients themselves under specific conditions; thirdly, the use of the system being followed up and incorporated in an institutional activity; and fourthly, an activity in which the patients become responsible for the groundwork that the conversation was expected to build upon. Important aspects of HIT tools are that they are cost-effective; Stoddart et al. recommended a long-term modeling of costs to examine the cost-effectiveness implications of, in their case, telemonitoring in hypertension care [159]. Further, they should be easy to use in everyday life. Study II showed that the self-management support system was easy to use and well accepted, as indicated by the low attrition rate in Study III. However, post-study interviews with patients revealed the need for a mobile-adapted website for viewing graphs directly in the mobile phones immediately after sending the day's data off to the database [157]. Today this is made possible after log in, it is however limited by the size of the patient's mobile phone display. While a cost-effectiveness analysis has not been performed, the cost for the individual is known and it is very low: for the individual patient the cost is a maximum of approximately 0.5 cent (EUR) for sending a set of answers daily, plus 10 cents at start-up for downloading a mobile phone client. This indicates that the self-management support system is potentially cost-effective. The need for a home blood pressure monitor also needs mentioning, however in clinical practice it may be that a monitor can be provided as a loan by the health care centre. The cost for the individual is of importance from a justice perspective: even though the possession of for example a mobile phone is almost globally omnipresent, high costs involved with using a system may exclude people.

In the view of the widely endorsed benefits of e-health by several stakeholders (authorities, health care, health care providers, insurance companies and patients) its potential downsides and risks also need to be addressed. McKoy et al. [160] reported on blurred roles of health care settings and health care professionals that could affect the liability of health care professionals who use telehealth in hyper-

tension care, and further that legal and ethical guidance regarding privacy and security issues as a support for health care professionals was lacking. Another issue with regard to physical safety is what happens if, for example, a mobile app does not work as intended. Several of these aspects have been attended to in policy documents and guidelines in Sweden as well as globally [91-93]. Technically, the developed self-management support system (Studies I and II) works through a platform that is connected to a login-restricted database. Access to the server is limited to authorized personnel with strict instructions to keep information confidential, and whose access is logged. When the database is accessed through the web, all data are encrypted with SSL. Given these technical conditions the self-management support system is safe, which is however not to say that the organizational aspects reported by McKoy et al do not need attention in future use in clinical practice. These aspects are part of the routines that need to be established in order for the implementation of a new way to work.

Another potential risk with self-reporting and self-measuring can be a feeling of being supervised or constrained. In Study I some patients said they did not want to be disturbed too often, which seemed to display a concern over being monitored as well as disrupted in their daily life activities. This risk is present in all kinds of self-management of care at a distance, and in the development of the present system it was balanced against the benefits of what the self-monitoring and self-reporting could imply. It was thus important to take into account relevance and ease of use when validating the items and the use of the mobile phone platform in Study II, in order to make the self-management support system as meaningful and non-intrusive as possible for each user. Further, another aspect that is highlighted rather seldom in the eagerness to endorse the self-management of chronic conditions is the question of integrity when care moves from the institution to the home of the patient. Langstrup [161] provides this perspective, discussing an ambivalence towards the home as the preferable site of treatment of chronic conditions. For example, some patients saw treatment as belonging in the clinic, and when it moved into their own home it had implications on their identity formation and the disease became a more salient part of their self. Furthermore, the home was reconfigured to fit the needs for care in the home, which sometimes collided with the fact that the home exists as a virtual community where spouses, parents, children and siblings share the collective space. In the post-study interviews [157], positive experiences in relation to self-management and self-reporting from home were reported. This may be afforded to the small amount of space and time that was required in order to use the self-management support system, why it may have had no more than a minor impact on the home environment as a collective space. Negative identity formation, identifying oneself with the condition, is more likely if the condition is serious and may be a life threat on a daily basis. Hypertension may lead to life-threatening diseases, but does not pose an immediate threat in the lives of patients; thus, relating to one's own blood pressure becomes the first step on the path towards a better understanding and, subsequently, self-management. Nevertheless, in the broader area of chronic care in the future, self-management also needs to be seen from the per-

spective of integrity, which needs to be forwarded when planning and designing support systems and models of care.

Generally, by adding a self-management support system through which self-reporting is made an important part, continuity in patient-health care professional discussions about care may be grounded in the mutually shared patient-generated data that are stored, but also facilitated by the visualization of data over time, allowing for patterns in the variations of different parameters to be explored and followed up. With this data available, consultations in the health care encounter may become more relevantly and meaningfully related to the person with the condition, which in turn facilitates interpretation and understanding. More specifically, the results of Study IV revealed how technology and the self-generation of data showed potential to impact possibilities for patients' and health care professionals' partnership and the patients' overall, more concrete understanding of their blood pressure. The notions of Taylor (interpretation and understanding) [96] and Smith (interpretation, understanding and emergence) [97] became visible in the interactions during the follow-up consultations of Study IV. Through the way patients connected their blood pressure to other parameters and to specific points in time of their everyday life in interaction with, and within the relationship to, their health care professional, utterly new knowledge and insights emerged. I argue that this was facilitated by the self-management support system through the possibility to turn to the screen and consult the graphs of the system together, and to share experience and knowledge, leading to the creation of new insights in collaboration.

Self-management, in the context of person-centered care, may need to be addressed a bit further. There is a tension between the two such that much of the policy on self-management is driven by an institutional agenda and pays less attention to patients' goals. The same critique could be applied to the notion of participation, as described by Thórarinsdóttir and Kristjánsson [103]: patient participation could be perceived as non-person-centered (but constrained) when there was an imbalance in the human connection (the relation), often expressed as a lack of respect and equality in the interaction. So, when and how are self-management support and participation in fact person-centered? I believe the answer to this question lies in the term *support* and how this support is designed, developed and finally pursued. Applying a participatory-oriented design and development process, involving those for whom the self-management support is intended (be it a mobile phone platform or web-based support) is a crucial first step (Studies I and II.) However, Sparud-Lundin et al. [162] rightly point out that this does not guarantee a person-centered support system; instead, the actual methods used in order to apply a participatory approach (for example, focus group or semi-structured face-to-face interviews) to reach the persons views, wishes and goals are determinative. And, importantly, to self-manage (with a support system) in a personal context cannot mean to *self-manage*, as in managing something alone. It has to be pursued within the frame of the patient-professional relationship. The actual support needs to be materialized through the follow-up of for example

self-reports by discussing and supporting interpretations of self-reported parameters in relation to the condition (Study IV). As shown by the previously discussed results of Study IV, but also in the paper by Hallberg et al. [157], not only active engagement and contribution but also positive experiences from this were at play. During the follow-up consultations the self-management support system, through its visualizing graphs, mediated patient narratives, connecting the blood pressure to the wider context of the person. This supported interpretations (Study IV), an increased understanding of the blood pressure (Hallberg et al.) [157], active *mutual* engagement during the consultation (Cahill) [101], a sharing of information and knowledge (Sahlsten) [102], and respect and equality in the interaction (Thórarinsdóttir and Kristjánsson) [103]. I argue that herein, within the design, development and way of use of the self-management support system, lies the potential of the results of this thesis, to support self-management in line with the philosophical and practical principles of person-centered care.

CONCLUSIONS

Conclusions that may be drawn from the studies are:

- Persons with hypertension have a need and wish to gain an understanding of blood pressure in relation to perceived symptoms, side effects, medication intake and lifestyle, which points to what aspects of hypertension and hypertension care are meaningful to include in a support system facilitating self-management.
- Divergent views are in play regarding hypertension and hypertension treatment between persons with hypertension and health care professionals, especially with regard to communication and perception of symptoms, which may cause confusion for those with hypertension who do experience symptoms. The interactive mobile phone self-management support system developed in this project was found to be reliable and usable, and to efficiently and effectively capture information relevant in patients' self-management of hypertension.
- The effect on blood pressure after eight weeks of daily use of the interactive mobile phone support system was promising: blood pressure significantly decreased, and optimal effects appeared to occur after a quite short period of using the system. Those who benefited the most were those with moderate to high blood pressure at the start of the study.
- After the eight weeks of using the interactive mobile phone self-management support system, patients and health care professionals contributed evenly to the follow-up consultations, in terms of the initiation of new topics. The way patients contributed to the follow-up consultations, through contextualizations of the blood-pressure values to specific situations in their own lives, may imply a shift from a medical perspective only to a focus on the patient as a person living with a chronic condition. The system thus seems to have the potential to support patient participation and person-centeredness in medical and health consultations within hypertension care.

IMPLICATIONS

When the patient becomes an active and empowered partner in care, this brings about needs to induce new mindsets and ways of offering care. Thus far we have seen that the self-management support system can work as a mediator of patient involvement, but also as support for the health care professional, by facilitating to work practically according to a person-centered approach, in the clinical practice of hypertension care. A long-term implementation in clinical practice requires sustainability of the system and some flexibility for both health care professionals and patients to be actively involved in modifying relevant parts of the system to their needs. Further, careful consideration is needed regarding what facilitators as well as barriers may be in play in an implementation process.

We have seen that the self-management support system holds great potential of benefit for not only the person with hypertension but also for health care. Such potential should be implemented in a considerate and goal-oriented manner, in order for this benefit to be drawn by society, health care and, primarily, the patient. The self-management support system, and the way it was developed, could further act as a model for the development of self-management support tools within other areas of care and health prevention.

FUTURE PERSPECTIVES

Further, in going beyond the care of hypertension and chronic conditions, self-reporting of data will likely provide research groundwork from a broader perspective in the future. For example, crowdsourcing has emerged as collective collaborations, by groups of people with varying backgrounds and knowledge, in voluntary engagement in the performance of a task or as a solution to a problem. Making use of/analyzing large data sets is one area where crowdsourcing has been active, a movement of action that further blurs the boundaries of the relationships and responsibilities of experts and laypeople. As we have seen, technology, by means of mobile phone applications used for self-management through self-reporting and self-monitoring is increasing; not only in health care, but also on the free market. This development has encouraged people to monitor personal metrics to obtain knowledge of how lifestyle influences not only their symptoms and health prevention but also their physical athletic performance. The communities *Quantified Self* and *Cure Together* are outcomes of these movements in society.

Deborah Lupton [163] refers to the discourse of “Healthism”, that put emphasis on the potential of self-tracking technologies for empowerment of lay persons but also on the importance of “taking responsibility” of one’s own health. Important to put forward in relation to a discourse like healthism is that it tends to be a privilege of those that are socio-economically privileged; those who have the economic and educational resources to engage in taking charge of the own health. Health care need to be aware of this discourse so that it does not value persons who take such responsibilities as “ideal citizens” [163], and align interventions and care approaches to it, something which would not be in line with the ethics of person-centeredness in care. However, with the need for awareness being stated, these movements in society are expressions of self-management in different ways, by quantification of the body through metrics but also by increased insights of links between lifestyle and symptoms, signs and wellbeing. Therefore, a “self-tracking future” might hold potential for better supporting persons in their self-management efforts.

SVENSK SAMMANFATTNING

Bättre levnadsförhållanden och medicinska framsteg gör att fler människor lever allt längre i Sverige. Samtidigt blir hälso- och sjukvården bättre på att upptäcka och behandla sjukdom. Denna positiva utveckling medför en förändring i sjukdomspanoramata. En ökad andel äldre i befolkningen medför att fler utvecklar åldersrelaterade sjukdomar. I kombination med att fler överlever akut eller smittsam sjukdom, samt goda levnadsförhållanden, leder den här utvecklingen till att fler kommer att leva med kroniska och livsstilsrelaterade sjukdomstillstånd i framtiden. Utvecklingen i demografi och sjukdomsbild innebär en utmaning för hälso- och sjukvården att tillgodose ett ökat behov av vård och omsorg. Aktiv delaktighet i den egna vården är en rättighet för patienten, men blir nu, på grund av utmaningen att möta vårdbehov för kroniska sjukdomstillstånd, också efterfrågat av fler aktörer. Parallellt har personcentrerad vård utvecklats som ett sätt att förhålla sig till patienten som en person i ett livssammanhang där fokus riktas mot personens självuttryckta kapacitet och behov, samt mot delaktighet i den egna vården - i partnerskap med vårdgivaren.

Högt blodtryck är ett exempel på ett långvarigt tillstånd som ställer krav på personen att förstå samband mellan blodtrycksvärdet och det dagliga livet. Trots väletablerad kunskap om god effekt av blodtrycksmedicin i kombination med livsstilsförändring är det få personer som når ett välkontrollerat blodtryck. Det finns ett behov av insatser som förbättrar förutsättningarna för behandling av högt blodtryck, så att fler patienter når ett blodtryck som minskar risken för hjärtkärlkomplikationer. Ett sätt kan vara att ge stöd åt personer med högt blodtryck att själva hantera tillståndet i sin vardag; bland annat genom att få hjälp att förstå betydelsen av hur livsstilen påverkar blodtrycksvärdet. Det övergripande syftet med denna avhandling var därför att, ur ett personcentrerat perspektiv, utveckla och utvärdera ett interaktivt system via den egna mobiltelefonen, som stöd i personers egen hantering och vid behandling av högt blodtryck.

Avhandlingen omfattar fyra studier där *Studie I* syftade till att ge kunskap om högt blodtryck och dess behandling; ur främst patientens - men också ur hälso- och sjukvårdsprofessionens - perspektiv. Ett ytterligare syfte var att få kunskap om både patienters och personals behov, önskemål och förväntningar på ett system för självrapportering som stöd i personers egen hantering, samt vid behandling av högt blodtryck. Resultatet från *Studie I* användes i framtagning av systemets innehåll, bland annat av de frågor som skulle besvaras i den egna mobiltelefonen. *Studie II* beskriver denna utvecklingsprocess samt tillvägagångssätt för att säkra frågornas kvalitet med avseende på förståelse och relevans. Hur väl svaren på frågorna överensstämde om man svarade på dem upprepade gånger inom ett visst tidsintervall, bedömdes också. Slutligen utvärderade *Studie II* användarvänligheten i systemet; det vill säga om det upplevdes lätt eller var förknippat med svårigheter att mäta blodtrycket och mata in blodtrycksvärdet och svaren på frågorna i mobiltelefonen. För en översikt av systemet hänvisas till Figur 2 på

sid 34 i avhandlingens ramberättelse. I korthet omfattar systemet moduler för a) självrapportering av blodtryck, puls, läkemedelsintag, livsstil, symtom och välbefinnande; b) påminnelser och individuella livsstilsrelaterade uppmuntrande meddelanden och c) grafisk feedback av självrapporteringen. Patienten kan välja att titta på blodtrycksvärdet i relation till övriga variabler, antingen på en specifik dag, eller över tid. I *Studie III* prövades systemet för stöd i behandling och personers egen hantering av högt blodtryck i klinisk praxis. 50 patienter rapporterade dagligen i mobiltelefon under åtta veckor varpå användningen av systemet utvärderades med avseende på effekt på blodtrycket. *Studie IV* syftade till att undersöka vilken påverkan patientens självrapportering under åtta veckor kunde ha på struktur, innehåll och interaktion i uppföljningssamtal mellan patient och läkare/sjuksköterska i slutet av åtta-veckorsperioden. Av särskilt intresse var hur man talade om blodtrycket och på vilket sätt patienten bidrog till förståelsen och tolkningen av blodtrycksvärdet. Det faktum att patienten själv samlat sina egna data, det vill säga underlaget för samtalet, var en helt ny förutsättning för ett samtal mellan patient och vårdgivare i hälso- och sjukvård.

I avhandlingen har en kombination av olika metoder använts i de olika studierna. Forskningsfrågan har fått avgöra vilken metod, eller kombination av metoder, som passar bäst. I *Studie I* genomfördes fem fokusgruppsintervjuer; tre stycken med patienter och två stycken med hälso- och sjukvårdspersonal. Data från dessa analyserades med hjälp av tematisk analys; en kvalitativ, tolkande metod. I *Studie II* genomfördes 21 individuella intervjuer med patienter, vilka kompletterades med fyra intervjuer riktade till hälso- och sjukvårdspersonal. Analysen genomfördes med hjälp av ett system för strukturerad kvalitativ analys, ett så kallat Item Tracking Matrix. Tillförlitligheten i frågorna (reliabilitet) beräknades med test-retest intra-class korrelation koefficient. *Studie III* inkluderade 50 patienter med högt blodtryck i en studie där två olika statistiska metoder beräknade effekten på blodtryck på gruppnivå, före jämfört med efter studien, samt effekten på blodtryck över tid på gruppnivå. *Studie IV* innefattade 20 stycken video- respektive ljudinspelade uppföljningssamtal som analyserades med interaktionsanalys; en metod för samtalsanalys.

Ett viktigt resultat från *Studie I* var att patienterna uttryckte ett behov av att förstå sambandet mellan blodtrycksvärden, symtom, effekter av blodtrycksmediciner och livsstilsfaktorer. För att kunna ta ett ökat ansvar för behandlingen av sitt höga blodtryck var denna förståelse nödvändig enligt patienterna. Den kunskapen fick utgöra en grund för den fortsatta utvecklingen av systemet för uppföljning, så att det skulle bli relevant och meningsfullt för patienten. *Studie II* visade att frågorna var lätta att förstå, var relevanta och täckte områden av betydelse för högt blodtryck. Det var enkelt att använda mobiltelefonen för att svara på frågorna och frågornas reliabilitet var fullgod. *Studie III* kunde visa en statistiskt och kliniskt signifikant sänkning av blodtrycket mellan utgångsvärdet och värdet vid slutet av studien (vecka åtta); systoliskt blodtryck sänktes i medeltal med 7 mmHg och diastoliskt blodtryck sänktes i medeltal med 4.9 mmHg. Sänkningen tenderade att ske främst under de första veckornas användning av systemet för att sedan

stabiliseras; vilket kan betyda att så mycket som åtta veckors användning inte var nödvändigt. Vidare var trenden för blodtryckssänkningen relativt likartad - oavsett initial blodtrycksnivå. Detta kan innebära att det finns ett potentiellt värde i att använda systemet för personer med högt blodtryck - oberoende av blodtrycksnivå. *Studie IV* visade hur patienterna aktivt bidrog i uppföljningssamtalen genom att initiera nya samtalsämnen; i samma utsträckning som vårdgivaren. Samtalen handlade framförallt om hur blodtrycket påverkades av det dagliga livet. Patienterna kunde beskriva hur blodtrycksvärdet en specifik dag kunde relateras till vad som hade hänt, upplevts eller hur man hade mått under just den dagen. På det sättet fick både patient och vårdgivare något konkret att relatera blodtrycksvärdet till. Detta använde man sig av när man gemensamt gick igenom de olika variablerna i systemet i relation till blodtrycket. I avhandlingen benämns detta fenomen kontextualisering av blodtrycksvärdet.

Avhandlingen ger beskrivning av ett arbetssätt som inkluderar framförallt personer med högt blodtryck men även hälso- och sjukvårdspersonal, i egenskap av framtida användare, som partners i designen och utvecklingen av ett interaktivt system för stöd i personers egen hantering och vid behandling av högt blodtryck. Genom detta sätt att arbeta kan ett personcentrerat synsätt utvecklas vidare, från ett förhållningssätt i ett möte med en person, till att genomsyra även en utvecklingsprocess, stödd av mobiltelefon-teknologi. Användningen av systemet resulterade i sänkning av blodtrycket. Effekt över längre tid och med fler deltagare, samt mekanismerna bakom effekten på blodtrycket behöver dock studeras ytterligare. Slutligen, att patienterna var aktiva partners i uppföljningssamtalet och det sätt de kopplade blodtrycket till specifika situationer i sina liv, vittnar om att systemet med hjälp av patientrapporterad data kan stödja ett personcentrerat förhållningssätt vid behandling av högt blodtryck.

EPILOGUE

My personal educational background includes studies in social work as well as health and care science, while professionally I have worked with caring for other people for 14 years (the first nine during summers, caring for the elderly, and the last five as a registered nurse caring for persons with renal disease). During an interim period of seven years I safeguarded patients through working with a drug safety profile with regard to side effects, in the pharmaceutical industry. Thereafter I went on to graduate as a public health nurse, and following this I started my doctoral studies. My conviction was that in order to support a person in self-management we had to start right there, with the person and his or her perceptions of and beliefs about the condition, and thereafter to never let go of that perspective. My life as a whole, my personal background as a patient since childhood, and my professional background caring for others has given me a vast opportunity to reflect upon the importance of being acknowledged as a person with a condition, with inherent capacities, integrity, strengths and weaknesses, and as someone who is living a life in the broader bio-psychosocial context. As a child and teenager this was hard for me to put into words, but my complete revolution against whatever a physician told me (as an example, I was strongly advised not to become a nurse) witnesses that something in the relationship between me and health care was very wrong. As an adult I now know I was a fighter when I was young, not giving up “me” as a person for anyone, and also that by saying *NO* I wanted to be seen and heard, something that didn’t succeed very well. Now, if health care had been less caught in an old structure with its paternalistic stance towards the person being cared for, the outcome of my interactions with my caregivers could have been different. Now that I’m an adult patient, are things better or worse?

On one occasion I had an x-ray appointment. Presently, with my life experience from the last 25 years including education, working, working abroad, PhD studies, being the mother of two, sadness, joy and an image of myself as someone filled with a great deal of integrity and an expectation of respect, for me as a person. I was the only person sitting in the waiting room and sat gazing towards the door, which was opposite me, as it opened and someone shouted something: “Bengtsson!” The voice filled the whole room, travelled along the walls, jumped up and down the floor to the ceiling, and back again. I didn’t react right away; of course I know my name, but I was completely confused by the shouting out loud of my surname in an empty, soulless room. “Bengtsson!” My name was shouted out again, even louder and more firmly this time. They’re referring to me, I thought. Now something happened inside me: the old feeling of being reduced and depersonalized awoke from an inner hiding place and all of me, just like in my younger years, filled with protest. I stood up and walked to the person standing at the door. “I guess that must be me”, I said. “I’m sorry, but I don’t relate to myself by my surname; but Hi, I’m Ulrika, are you the one who’s going to help me today?” By the cold look I received from the person in front of me, followed

by silence, I understood that 2013 was not much different from 1988 when it came to acknowledging patients as persons in the health care encounter, and that there was still work to be done. In 2015 we know that change has been on its way for quite a while and that, for example, the University of Gothenburg Centre for Person-Centred Care has developed a new model for providing care in which the person is placed at the center of attention. Through the work of this thesis I hope I've contributed to this challenge for health care, by providing a support system for the facilitation of the self-management of hypertension, within the context of a person-centered approach, theoretically as well as practically.

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