Developing an interactive mobile phone self-report system for self-management of hypertension. Part 1: Patient and professional perspectives

Ulrika Bengtsson, Dick Kasperowski, Lena Ring and Karin Kjellgren

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Developing an interactive mobile phone self-report system for self-management of hypertension. Part 1: Patient and professional perspectives

Ulrika Bengtsson[1, 6], Dick Kasperowski[2], Lena Ring [3,4], Karin Kjellgren[1, 5, 6]

1. Institute of Health and Care Science, Sahlgrenska Academy, University of Gothenburg, Sweden
2. Department of Philosophy, Linguistics and Theory of Science, University of Gothenburg, Sweden
3. Centre for Research Ethics & Bioethics, Uppsala University, Uppsala, Sweden
4. Medical Products Agency, Uppsala, Sweden*
5. Department of Medical and Health Sciences, Linköping University, Linköping, Sweden
6. University of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Box 457, 405 30 Gothenburg, Sweden

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Corresponding author:

Ulrika Bengtsson
University of Gothenburg
Institute of Health and Care Sciences
Box 457, 405 30 Göteborg
e-mail: ulrika.bengtsson@gu.se
phone: +46.31.7866105
mobile phone: +46.739.624684

Abstract

Low adherence remains a struggle in hypertension management, despite improvement efforts. Presuming that increased patient participation is a possible approach, we collaborated with patients and health care professionals to design a self-report system to support self-management. The study aimed to explore and describe relevant aspects of hypertension and hypertension treatment, for use in the development of an interactive mobile phone self-report system. It further aimed to suggest which clinical measures, lifestyle measures, symptoms and side-effects of treatment would be meaningful to include in such a system. Five focus group interviews were performed with 15 patients and 12 health care professionals, and data were analysed using thematic analysis. Patients suggested trust, a good relationship with caregivers, and well-being as important aspects of hypertension self-management. Further, they regarded blood pressure, dizziness, stress, headache and tiredness as important outcomes to include. Patients sought to understand interconnections between symptoms and variations in blood pressure, whilst health care professionals doubted patients' ability to do so. Health care professionals emphasized accessibility, clear and consistent counselling, complication prevention and educational efforts. The study presents aspects of importance for follow-up to understand the interplay between blood pressure and daily life experiences for patients with hypertension.

Keywords: blood pressure, focus group, hypertension, medication adherence, self-care, person-centred care

Introduction

No more than 25-30% of people receiving treatment for hypertension get their blood pressure well under control. With a percentage of only 30-50% adhering to hypertension treatment, low adherence remains a struggle in hypertension management, and is thus an important issue to consider in efforts to decrease the risk of cardiovascular disease [1, 2]. Adherence-related research has focussed on reasons for low adherence, manifested for example as barriers [3-5]. In the past decade the importance of patients' common-sense beliefs, or lay perceptions, about their illness and treatment as determinants of adherence has been increasingly recognized, and may be important to acknowledge when addressing the question of adherence [1, 5-8]. The common-sense model [9-11] describes beliefs about illness with the assumption that patients act upon their health or health risks guided by subjective or common-sense perceptions of the health threat. In a review by Marshall et al. [12] patients expressed their own understanding of hypertension, one important example being the belief that hypertension is mainly caused by stress and produces symptoms. When not feeling stressed or when not experiencing symptoms, treatment was not perceived to be needed. The effects of previous studies focussing on intervening to improve adherence have been inconsistent from one study to another, and require further development towards more applied research to help patients maintain long-term treatment [13]. The self-management of hypertension via self-monitoring, educational efforts and nurse- or pharmacist-led interventions alone showed low to moderate effects on systolic blood pressure in a Cochrane review by Glynn et al. [14]. To our knowledge, 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. With the enabling of self-management and participation with the aim of helping patients understand the complex relationships of cause, symptoms, side-effects of treatment, the impact of medication and their own lifestyle, their adherence and subsequently their blood pressure may improve.

This study is part of a research programme aiming to evaluate the effectiveness of an interactive mobile phone self-report system in improving self-management of hypertension.

To design such a system for use in collaboration between patients and health care professionals, we need to understand how hypertension and its treatment are perceived by patients as well as health care professionals. The aim of this study was 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.

Materials and Methods

The study was conducted within an interdisciplinary group of researchers and had a participatory orientation [15], cooperating with persons with hypertension and health care professionals.

Study participants

In Sweden the hypertensive patients are mainly treated in primary health care, but also at internal medical clinics. In the study, a strategic selection of participants was used. Patients were recruited from two locations, geographical apart and with a demographic variety: one primary health care centre in a multi-cultural city suburb and one internal medical outpatient clinic at a provincial hospital in a smaller town.

The proportion of women was slightly higher than men, as in the adult hypertensive population [16], and the background data comparable with the general hypertensive population in Sweden [17], Table 1. Patients were asked to participate by an enquiry from their treating nurse or physician based on the inclusion criteria: >30 years of age, currently using hypertension drugs, alert and oriented, able to hear well enough to take part in a focus group discussion, and fluent in Swedish. Following this, 15 patients were recruited to the study. Twelve health care professionals were recruited from the same units as the participating patients and comprised equal numbers of physicians, nurses and pharmacists, Table 1. The inclusion criterion was past and current experience of care for patients with hypertension.

Table 1. Participant demographics

Patients (n=15)	**Women (n = 9)**	**Men (n = 6)**
Age (md)	65	64.5
Range	59 – 81	49 – 82
Years with hypertension (md)	5	12.5
Range	< 1 – 40	< 1 – 30
Health care professionals (n=12)	**Women (n = 10)**	**Men (n = 2)**
Age (md)	44.5	51.5
Range	26 – 63	47 – 56
Years with experience of hypertension care (md)	5	25
Range	1 – 30	20 – 30

Data generation

Data were obtained through focus group interviews [18-20] consisting of three groups of patients and two groups of 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 recruitment was done. The interviews lasted 1.5-2 hours. An experienced focus group moderator led the interviews and two semi-structured interview guides, one for the patient group and one for the health care professional group, were used. Examples of questions to the patients about hypertension are: Do you have any symptoms? What inconvenience do you experience? If you were not to take your medication as prescribed, what would the reason be? Examples of questions to health care professionals are: What are the aims of the pharmacological treatment? Do patients share these aims? How do you motivate patients to adhere to the treatment regimen?

During the interview the patients and health care professionals tested the technique, a communication system for mobile phones, CQ, Circadian Questions, developed by 21st Century Mobile AB (http://www.cqmobil.se), 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 [17].

Data analysis

The focus group interviews were transcribed verbatim in Swedish. The transcripts were coded using NVivo 8 (QSR International, Doncaster, Australia), a qualitative research software program designed to help users organize and analyse non-numerical data.

Thematic analysis is a method for identifying, analysing and reporting patterns or themes within a set of data that allows for working with both a deductive and inductive approach to the data [21]. The inductive approach (i.e., without trying to fit into a predefined coding frame) and the deductive approach (i.e., driven by our analytic interest) were used iteratively, and we worked through the following stages to identify themes:

1. Familiarization with data

To familiarize ourselves with the data, we listened through the recordings several times. We first noted our initial thoughts and observations entirely unreserved and without transcriptions. Second, we listened to the recordings again with the anonymized transcriptions at hand. Third, we read through the transcriptions several times.

2. Generating initial codes

To organize the data systematically we developed a coding framework based on analyses of the transcripts, hypothesized concepts [21] and earlier research [17, 22].

The transcripts from interviews with patients and health care professionals were coded separately by the authors. This coding was then compared by number and concordance of quotes per code. After discussions to reach consensus, inter-rater reliability was measured. The degree of concordance was 78% when comparing the total sum of coverage of all codes measured in one patient focus group session.

3. Searching for themes

An identified theme captures important issues in relation to the aim of the study, and represents a pattern or meaning within the data set. The themes can be organized as overarching themes and sub-themes [21]. When searching for themes, we assembled codes into potential themes and considered how these could be combined as sub-themes from which overarching themes could be derived.

4. Reviewing themes

We reviewed the suggested themes to determine whether they worked in relation to our codes and whether they were valid in relation to the entire data set by reading all assembled quotes/extracts for each theme.

5. Defining and naming categories, sub-themes and overarching themes

Categories were organized into the identified sub-themes from which overarching themes were ultimately derived. To present and visualize the results further, descriptive quotes were identified. The analysis was iterative, and the findings were reviewed and discussed within our interdisciplinary team in order to reach agreement in our understanding of the data.

The study was approved by the Regional Ethics Board in Gothenburg, Sweden (study code 551-09) and was conducted in accordance with the Declaration of Helsinki [23]. All participants were informed about the study both in writing and orally before giving their written informed consent. Transcripts were anonymized, and the participants were ensured confidentiality.

Results

The analysis of the data resulted in two overarching themes: *Framing outcomes in order to self-manage treatment* and *Measuring outcomes in order to self-manage hypertension*. Further, four sub-themes and additional categories were identified (Table 2).

Table 2. Categories, sub-themes and overarching themes

Categories	**Sub-themes**	**Overarching themes**
Important for good quality of care *To follow the treatment* *To reach treatment goals*	Communicating and understanding high blood pressure and its treatment	**Framing outcomes in order to self-manage treatment**
Impact on daily life *Perceived symptoms* *Perceived side-effects* *Expectations of treatment*	Perceptions of high blood pressure and its treatment	
Symptoms *Signs* *Habits*	Measurements to be followed	**Measuring outcomes in order to self-manage hypertension**
To be in control of high blood pressure *To see the relationship between blood pressure and symptoms*	Making use of measuring outcomes	

Framing outcomes in order to self-manage treatment

This overarching theme focuses on how high blood pressure and its treatment were framed from a patient and a health care professional perspective.

Communicating and understanding high blood pressure and its treatment

According to health care professionals, concordant counselling and clear communication as well as being accessible to patients were important for good hypertension management. For patients, blood pressure control, a good relationship with the caregiver and trust were most important for good quality of care.

With regard to their own experiences, neither patients nor health care professionals perceived non-adherence a problem. Taking medication was seen as part of a daily routine. However, to prevent it from occurring, health care professionals further emphasized clear communication and working together with patients. This was contradicted in the assertion that treatment goals as such were not communicated to patients. The health care professionals worked according to national guidelines, but did not use them as a tool to set individual goals. Subsequently, the patients had neither a goal to focus on nor an understanding of the actual blood pressure value.

For patients, the main reason for not taking their medicine was forgetting it due to changes in their daily routines. Health care professionals stated that the main reasons for patients not following the treatment plan were inadequate information and poor communication. It was further expressed that the presumed lack of symptoms of hypertension might be another reason.

"Perhaps because high blood pressure often doesn't… have proper symptoms. Many think… 'Oh I'm fine. I don't feel I have problems with that….'"

Health care professional (pharmacist), focus group interview 1.

Perceptions of high blood pressure and its treatment

Patients judged that living with a diagnosis of high blood pressure had little or no impact on their daily life. . Symptoms of high blood pressure and treatment side-effects were discussed. Symptoms were perceived, but there was uncertainty about whether they resulted from high blood pressure, were side-effects of treatment or were due to other diseases.

"I quite often get headaches, but I've no idea if they're linked to the blood pressure."

Patient, focus group interview 2.

The patients felt unsure in their attempt to understand the relationships between symptoms, side-effects to treatment and/or other diseases; they looked for answers about cause and effect but felt they could not find them. Still, they perceived hypertension to be a serious condition. Feeling well and healthy here and now was described as important, at the same time as patients' expectation of the treatment was primarily to help them stay well and healthy, i.e. prevent them from developing cardiovascular complications.

The health care professionals largely agreed with patients' view that hypertension had little or no impact on patients' daily lives. However, when it came to symptoms and side-effects, the views between patients and health care professionals differed. The health care professionals varied in their opinions about how patients' symptoms are related to their hypertension; some felt there was no relationship, others that only a few symptoms were related, and still others that the relationship was diffuse. They felt that the patients related many of their daily difficulties to symptoms of blood pressure or side-effects of treatment, or both.

Consequently, health care professionals asserted that patients who perceive symptoms they believe are due to high blood pressure should not expect to feel better from the treatment. Rather, the treatment should merely serve to prevent these patients from feeling worse; in other words, to prevent them from deteriorating and developing serious complications in the future.

Summary of theme

Patients felt that having control over their blood pressure value was of top priority in good hypertension management. Still, there was a lack of understanding of the meaning of the actual values. Adherence was not considered a problem by any party. Reasons for non-adherence were attributed to either disruption of daily routines, communicative factors or the presumed lack of symptoms of hypertension. Patients and health care professionals agreed on the apprehension that hypertension has little or no impact on daily life. 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. Patients wished to feel good here and now, 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.

Measuring outcomes to self-manage hypertension

This overarching theme describes the factors patients and health care professionals emphasized as important to evaluate and follow up in the self-management of hypertension.

Measurements to be followed

Table 3. Preferences of symptoms, habits and measurements to follow

Preference	**Symptoms**		**Habits**		**Measurements**	
	Health care professionals	*Patients*	*Health care professionals*	*Patients*	*Health care professionals*	*Patients*
1	Dizziness	Dizziness	Smoking	Everyday exercise	Blood pressure	Blood pressure
2	Stress	Heart palpitations	Everyday exercise	Exercise	Weight	Blood glucose
3	Headache	Tiredness	Exercise	Food	Heart rate	Blood lipids
4	Sleeping problems	Headache	Alcohol	Alcohol	Blood sugar	Weight
5	Tiredness	Frequent micturition	Food	Smoking	Blood lipids	Heart rate
6	Swollen ankles	Sleeping problems	Taking snuff	Taking snuff	Waist measurement	Waist measurement
7	Heart palpitations	Stress			Breathing frequency	Breathing frequency
8	Anxiety	Swollen ankles				
9	Depression	Anxiety				
10		Dry mouth				
11		Depression				

Table 3 lists the symptoms, measurements and habits that patients and health care professionals believed were important to follow up. Dizziness, stress, heart palpitations, tiredness and headache were highlighted by both parties. Blood pressure monitoring was considered important, but patients and health care professionals had diverging opinions on how to perform this task. The patients wanted to measure their blood pressure at home, but health care professionals – in this case the nurses – did not feel this was a good idea because they did not believe the patient could understand or interpret the blood pressure values. On the other hand, the physicians saw benefits to monitoring blood pressure at home, one of which was an increased awareness of blood pressure values. Patients expressed interest in and a desire to understand and make sense of their high blood pressure.

Making use of measuring outcomes

During focus group interviews, benefits from measuring outcomes in hypertension self-management were highlighted. Health care professionals stressed the importance of being accessible to the patients and therefore believed that, for example, an interactive self-report system might be of valuable help as a means to increase contact with patients. The patients felt that having closer control of their blood pressure, seeing relationships between symptoms, side-effects and treatment, and further being able to connect this to their own well-being might be positive outcomes. Furthermore, they believed it could help them to feel more secure during periods of increased need to monitor their blood pressure, for example when starting or changing medication.

"Well, the strength is that I have better control [over the blood pressure]. And then that it in collaboration with others [nurse / physician] becomes a good foundation for judging how to plan the treatment."

Patient, focus group interview 3.

The health care professionals mainly viewed an interactive self-report system as a way to improve adherence, and hoped they could subsequently use it as an educational tool to teach patients the importance of taking their medication.

"It should be pedagogical (hmm, yeah), helping the patient see things in 'black and white'. Being able to sit down with patients and show them how things are and how this can be reasonably linked to their adherence."

Health care professional, focus group interview 1 (physician).

Summary of theme

While patients wished to measure their blood pressure at home, there was a hesitation expressed by nurses regarding patients' ability to interpret the blood pressure values measured at home. The benefits of an interactive mobile phone self-report system highlighted by health care professionals included increased contact with patients, but the system was mainly viewed a possible educational tool to improve adherence. Patients liked the idea of a closer control of their blood pressure and the factors affecting it, and thought this could make them feel more secure when starting or changing medication.

Discussion

Patients expressed a need for increased understanding of the complex relationships between hypertension, symptoms, side-effects and treatment. They voiced a wish to learn more and to be in better control over their condition. The health care professionals believed that having a participating and knowledgeable patient was an important factor in achieving successful hypertension management. However, they also doubted the patient's ability to become such a patient.

Patient perspective

Patients stressed several aspects regarding the importance of self-managing their hypertension. Trust, the relationship with health care professionals, feeling well, feeling healthy and preventing future complications were aspects considered important. The outcome measurements prioritized by patients seem to focus on signs, symptoms and causes of hypertension. They wished to understand the impact of hypertension and treatment, as well as other features of their health and daily life. Since this information is not easily accessed by individual patients today, such a lack of knowledge adds to the complexity of the situation for a patient who wants to be in control and understand what affects their hypertension.

The patients felt that they adhered to their treatment, and did not perceive that hypertension caused any difficulties in their daily life. This finding contradicts the known low percentage of adherence [1, 2], and is something that needs to be reflected upon. When recruiting participants to adherence-related research, it is generally hard to reach individuals who are truly non-adherent; instead, we reach the most motivated ones. Intentional non-adherence is in line with what is described in the common-sense model [9-11]; i.e. the action of altering or skipping doses is based on an active and deliberate decision. Individuals in this group are also motivated and may consider themselves adherent even when altering their prescribed medication. The reported good adherence among the participants in this study may further in itself contribute to the conception that hypertension had little or no impact on the participants' daily life.

Health care professional perspective

Important aspects of hypertension management from a professional perspective were accessibility, clear communication, concordant counselling within and across professional groups, participating and knowledgeable patients, working pedagogically and preventing future complications. The patients’ wishes and needs were in agreement with what the health care professionals considered important. The professionals further agreed with patients regarding adherence to hypertension treatment, and did not consider this to be a problem among their patients.

Views on hypertension

There were divergent views between patients and health care professionals about hypertension. One important factor was the way health care professionals viewed hypertension as a symptomless condition, and believed that when patients perceived symptoms these had other causes, such as other life events. This finding contradicts the results of a previous multicentre study [17] that showed that 80% of patients on hypertensive treatment and 85% of patients without hypertensive treatment reported symptoms related to current treatment or increased blood pressure. Another aspect was the way health care professionals viewed the goal of treatment; i.e., treatment would not make them feel better but should prevent them from deteriorating. If such information is communicated to patients who do perceive symptoms and, as expressed in this study, expect to feel better from their treatment, they may feel uncertain and frustrated about how to manage their condition. By overemphasizing an asymptomatic view of hypertension, we may create barriers to adherence [5]. Patients may not be able to relate to conditions in general as asymptomatic; if they have experiences of symptomatic conditions they may fail to see the necessity to take medication for an asymptomatic condition [4]; i.e., why follow treatment if it will not make one feel better and if the perceived symptoms are not caused by high blood pressure?

Patients and health care professionals described and discussed high blood pressure differently. The health care professionals' views of patients' desire to learn and obtain deeper knowledge about their condition did not correspond with the patients' descriptions. Rather, the patients expressed a need to see the relationships between symptoms, side-effects, treatment and how these aspects of hypertension effected how they felt. Patients' prime concern was to manage their high blood pressure and its complications. The results of this study stress that health care professionals need to understand each patient's needs and circumstances and that the health care professionals and patients need to agree on treatment and treatment goal. This is in agreement with the predominating view of patient-centredness in Sweden whereby patients will participate more in their own care in the near future [24].

Self-management

Patients believed that the self-measurement of blood pressure was necessary to improve blood pressure control. Without self-measurement, it would not be easy to see the relationship between blood pressure values and the patient's general well-being. All patients clearly expressed the wish to learn more and to be able to actively take control of their condition. Future health care will increasingly acknowledge this desire to self-manage: in Sweden, for example, the national e-health strategy supports it through My Health Account [25], an account that assembles all health-related personal information, owned and controlled by the patient him/herself.

Methodological aspects

Focus group interviews are effective in obtaining data within a participatory orientation; the interaction between participants creates possibilities for richness and depth of the information obtained. To optimise these possibilities and to minimise the risk of sample bias it is of importance to recruit participants as representative for the population of the topic in focus as possible. Looking at the sample of participants in our study it shows they are in line with the Swedish hypertension population in terms of age and gender [17, 26]. With regard to demographic variety we managed to recruit a sample with different education levels, employment and civil statuses. One further intent was to recruit a sample with different ethnical backgrounds, however we only managed to recruit two participants with non-Swedish origin. One explanation to this is the inclusion criterion of being fluent in Swedish, to be able to take an active part in the focus group discussion. This is a limitation to our study. In focus group methodology it is important to relate to the moderator as a part of the process and hence the risk of confirming bias. The experience of the moderator is thus of great importance, being aware of the own person as a part of the process and being able to identify when and how to interfere and take part in the dialogue. Even so, the risk of confirming bias is not possible to control for but something we have be aware of. An important strength of the study is the principle of saturation. Although the sample was small, data were collected until saturation was reached and the last interview did not contribute to any substantially new information.

One advantage of thematic analysis is the method’s flexibility regarding deductive and inductive approaches. The participatory research design framework was suitable for this study, as it was conducted from an interdisciplinary perspective and took into account both patients’ and health care professionals’ perspectives. This way of performing adherence research, from a patient-health care professional perspective, is of value in designing and implementing user-friendly, feasible and valid adherence interventions [26].

Conclusion

This study presents aspects that patients and health care professionals deemed important in the evaluation and follow-up of hypertension. Our findings provide input for future hypertension self-management interventions and suggest what is important to acknowledge when designing them. An important clinical outcome of our study is the the patients' expressed need of an understanding of the blood pressure in relation to perceived symptoms and life-style. The results may increase the understanding of hypertension and its treatment from a person-centred perspective [27]. Health care is heading towards increased patient power and self-management, and hence there is a need for tools supporting this development. Our next step will be to use the study results to develop an interactive mobile phone self-report system to be used as a tool to support hypertension self-management.

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