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FINDING COMMON GROUND: PATIENT-CENTERED CARE AND SELF-MANAGEMENT SUPPORT OF MULTIMORBIDITY IN PRIMARY HEALTH CARE

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FINDING COMMON GROUND: PATIENT-CENTERED CARE AND SELF-MANAGEMENT SUPPORT OF MULTIMORBIDITY IN PRIMARY HEALTH CARE

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By

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“If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there.”

Sören Kierkegaard

“In a truly shared decision, physicians and patients mutually influence each other, each potentially ending up in a place different from where they began, with different understandings than either would have reached alone.”

From: Hanson JL. Shared Decision Making: Have We Missed the Obvious? Arch Intern Med. 2008;168(13):1368–1370

ABSTRACT

Background: Patient-centered care is associated with improved health outcomes and increased care satisfaction and is a target for health care internationally. An important component of patient-centered care is patient-centered communication, which aims to involve patients in their care. Nevertheless, recent national and international surveys have found shortcomings in involving patients in their care. This is especially true for older patients with chronic diseases.

As populations age, an increasing number of patients have multimorbidity (i.e., two or more chronic diseases). However, health care is still organized around single diseases. Self-management can be burdensome for these patients because of functional impairment, polypharmacy, and contradictory information from multiple health care professionals. There is evidence that self-management support improves outcomes for patients with single chronic diseases, but such evidence is lacking for patients with multimorbidity.

The aim of this licentiate thesis was to explore perceptions of professional-patient interactions and perspectives on how to improve self-management support for patients with multimorbidity in primary health care.

Methods: Exploratory designs were used to investigate health care professionals', patients', and family caregivers' perspectives on patient-provider interactions and self-management support. Study I was a cross-sectional questionnaire study about patient-centeredness in primary health care consultations in northern Stockholm. The study included 596 participants: 298 pairs of patients and health care professionals (physicians, registered nurses, and physiotherapists). Study II was a mixed-method qualitative study about self-management support for patients with multimorbidity that included 42 participants. It used focus groups and in-depth interviews with health care professionals and patients in central Sweden. It also included in-depth interviews with registered nurses, patients, and family caregivers from a rural region in southern Sweden where telemedicine was used to support patients. The results were analyzed with content analysis.

Results: The main finding of the two studies was that the perspectives of both health care professionals and patients need to be acknowledged to find common ground in primary health care consultations. Study I showed that most patients had expressed their own ideas in consultations, but only a minority had expressed their concerns. Although patients were satisfied with the consultations overall, the health care professionals tended to believe that patients were less satisfied than the patients reported they were. In Study II, the main theme that emerged was "Standing on common ground enables individualized support." This theme was supported by four categories.

Conclusions: The main conclusion of this thesis was that it is important to find common ground between the patients' and health care professionals' agendas and goals in consultations. Finding common ground through patient-centered communication could

reduce misperceptions of patients' experiences (Study I) and enable individualized support for self-management (Study II). A trustful relationship between the health care professional and patient could facilitate patient-centered communication.

Keywords: Primary health care, multimorbidity, patient-centered care, self-care, self-management, telemedicine

LIST OF SCIENTIFIC PAPERS

- I. Freilich J, Wiking E, Nilsson GH, Olsson C. Patients' ideas, concerns, expectations and satisfaction in primary health care - a questionnaire study of patients and health care professionals' perspectives. *Scandinavian Journal of Primary Health Care*. 2019 Dec;37(4):468-475.
- II. Freilich, J, Nilsson, GH, Ekstedt, M, Flink, M. "Standing on common ground" - a qualitative study of self-management support for patients with multimorbidity in primary health care. *BMC Family Practice*. 21, 233 (2020)

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LIST OF ABBREVIATIONS

| | |
|------|--|
| CCM | Chronic care model |
| COPD | Chronic obstructive pulmonary disease |
| FC | Family caregiver |
| HCP | Health care professional |
| ICAN | Instrument for patient capacity assessment |
| ICE | Ideas, concerns, and expectations |
| IOM | Institute of medicine |
| MDM | Minimally disruptive medicine |
| PCC | Patient-centered care |
| PHC | Primary health care |
| RCT | Randomized controlled trial |
| RN | Registered nurse |
| PT | Physiotherapist |
| SDM | Shared decision-making |

1 INTRODUCTION

There is a focus internationally on patient-centered care (PCC) as a target for health care. Such care is characterized by taking the patients' needs, preferences and resources into account (1). PCC is associated with increased patient satisfaction (2,3), better adherence to treatment (4,5), less need for investigations and fewer prescriptions (6–8), fewer referrals (8,9), better health outcomes (5) and less health care utilization (9–12).

In Swedish patient law it is stated that health care should be performed in coalition with the patient, and that health care should take into account the patients' expectations and capacities (13). Patients' experiences of health care in the OECD-countries are yearly evaluated in the International Health Policy Survey (IHP) organized by the Commonwealth Fund. In the recent survey Sweden showed improvements in involving patients in their hospital care compared to earlier surveys (14). However, only around 50 % of patients with chronic diseases in Sweden reported that they had set shared health goals with their health care professionals (HCP)(14). Also, around 50% reported they had been given information about treatment options and possible side effects of treatments. Moreover, the 2017 survey that focused on patients older than 65 years showed lower figures, and compared to other countries, patients in Sweden were receiving less information and shared less in decision-making (15).

Multimorbidity is present in the majority of patients older than 65 years (16). It is defined as living with more than two chronic diseases, with no priority (17), and is correlated with higher age (16). Multimorbidity is further associated with decreased quality of life, functional decline and increased health care use (18). Low socioeconomic status predicts an earlier debut of multimorbidity by 10–15 years (19). Living with multimorbidity could lead to challenges for the individual, who needs to manage multiple self-care activities (20). Also, medical decision-making is complicated by multimorbidity. Guidelines are still based on single diseases, and there has been a lack of guidelines for multimorbidity (21–23). The guidelines for each single disease within an individual could potentially conflict with each other (22). Multimorbidity is further associated with increased health care consumption in primary health care (PHC), emergency care and specialized care (18).

Patients in PHC spend on average 66 minutes per year with their physician, corresponding to 0.01% of their time (24,25). Though this figure is higher for patients with multimorbidity, they usually monitor and manage their diseases themselves, supported by their family caregivers (FC). These activities are referred to as self-management, “an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (26). Literature suggests that self-management approaches are effective in improving patients' knowledge, behaviors, self-efficacy (confidence to carry out a behavior necessary to reach a desired goal) and well-being in the short term (26). However, most studies have focused on diagnosis-specific self-management approaches, and have not targeted individuals with more than one chronic

condition (26). Thus, there is a lack of evidence on how to implement self-management support in PHC for patients with multimorbidity (27).

There is evidence that PCC is effective in achieving time- and cost-effective care with positive effects on outcomes and satisfaction among patients (1–12). Nevertheless, recent international and national surveys have shown shortcomings in involving patients in their care (14,15). Further, there is evidence on effects of self-management support for patients with chronic diseases (26). However, there is a lack of evidence on how to implement self-management support in PHC for patients with multimorbidity (27). The two studies in this licentiate thesis aimed to fill gaps of knowledge on how to improve professional-patient interactions and self-management support for patients with multimorbidity.

While most studies have focused on patients' experiences from consultations, it is also important to gain insight into the experiences of the HCPs, since concordance is a central part of patient-centered communication. Both studies therefore included both perspectives, and Study II also encompassed the perspective of FCs.

2 RESEARCH AIMS

2.1 OVERALL AIM

The overall aim in this licentiate thesis was to explore perceptions of professional-patient interactions in PHC.

2.2 SPECIFIC AIMS OF THE STUDIES

Study I: To explore the perceptions of patients and HCPs of the patient's agenda and satisfaction in consultations in PHC.

Study II: To explore professionals', patients', and FCs' perspectives on how HCPs should support self-management in patients with multimorbidity.

3 BACKGROUND

3.1 MANAGEMENT OF MULTIMORBIDITY

Management of multimorbidity refers to the tasks of HCPs when treating and supporting their multimorbid patients. In recent years, recommendations and guidelines for managing multimorbidity have started to be developed. An international consensus symposium on multimorbidity concluded that its management should focus on PCC “that takes into account the individual patient from a comprehensive and multi-dimensional perspective and acknowledges the complexity and dynamics of older adults’ health” (28). Older adults with multimorbidity need help with prioritizing among treatments to optimize daily function and quality of life (28). In British guidelines for patients with multimorbidity, it is emphasized that patients’ preferences should be taken into account (29). A scoping review of patient-centered interventions has further shown that self-management interventions and training of HCPs in patient-centeredness has the potential to affect health-related outcomes among patients with multimorbidity (30).

A key to reaching high-quality PCC for patients with multimorbidity is to involve them in shared decision-making (SDM)(31). Earlier studies have shown that older adults might want the physician to make medical decisions (32). However, they want to be involved in trusting relationships, feel respected, have sufficient time during consultations and receive information (33). A more recent study also found that feeling trust in a physician was associated with the wish for a more active role in SDM (34). Nevertheless, older adults with multimorbidity are less involved in SDM than younger and healthier people (35,36). Even though SDM is regarded as a tool to improve health care for patients with multimorbidity, it is seldom measured as part of interventions. No randomized controlled trial (RCT) has measured SDM in PHC among older adults with multimorbidity. Therefore, there is a discrepancy between guidelines for multimorbidity and current evidence, especially for older adults with multimorbidity in PHC (31).

3.1.1 Models for managing multimorbidity

In Sweden, there is no general model for managing multimorbidity. Nevertheless, there are regional initiatives that target this group of patients. Most known of these is “Borgholmsmodellen” which aims for a seamless team care of older frail patients, including easy access to a designated and named physician in PHC (37,38). Internationally, the chronic care model (CCM) is one of the most known models developed to target patients with chronic diseases. In recent years, the minimally disruptive medicine (MDM) model has been developed from CCM in order to target multimorbidity. These two models are described below.

3.1.1.1 Chronic care model (CCM)

The chronic care model was developed during the 1990s in order to reform health care for patients with chronic diseases, from reactive to proactive (39,40). The goal was that informed

and activated patients should interact with proactive health care teams, which would result in high-quality meetings and improved health outcomes (41). Collaborative care is central in the CCM, meaning that health care should be a partnership between two experts: the doctor, an expert on diseases, and the patient, an expert on their own life (42).

Studies have shown that CCM interventions improve health care quality and health outcomes for single chronic diseases (43). Nevertheless, interventions with the CCM have not shown convincing cost efficiency (44). Nor have interventions decreased patient burdens. While the interventions have led to an increase of patient knowledge, they seldom contributed actual practical help for the patients (44). Further, few interventions have aimed to improve physical status or quality of life, and few have addressed patients with low socioeconomic status (44).

3.1.1.2 Minimally disruptive medicine (MDM)

Minimally disruptive medicine (MDM) was developed to meet the increasingly growing group of patients with multimorbidity, and focused on a whole-person perspective in PHC. This model takes into account patients' disease and treatment burden that result from having multiple diseases (44). MDM is a patient-centered method that acknowledges patients' own health goals and goals for life quality, and targets the lowest possible disease burden for the individual (45,46). MDM is further designed to identify the most useful and necessary health care for the patient in each health care consultation and to prioritize feasibility. The motto is rather the use of little "appropriate care" than no care at all. MDM build on relationships between HCPs and patients (46).

A large multinational study divided burden of treatment into three components: 1. the tasks that patients are given from HCPs (e.g. to make life style changes, to follow drug prescriptions and to come to follow-up visits); 2. structural (e.g. accessibility to health care, coordination between health care givers), personal, situational and financial factors that negatively affect disease burden; and 3. patient reported consequences (e.g. poor compliance to treatment, financial burdens, effects on the social life) (47).

Thus, in order for PHC professionals to help patients to self-manage multimorbidity, this should include helping them to make life style changes; helping them formulate what is most important to them; and finding ways to incorporate self-management in the daily life. This is achieved by creating relationships with the patient and having feasible treatment plans (48).

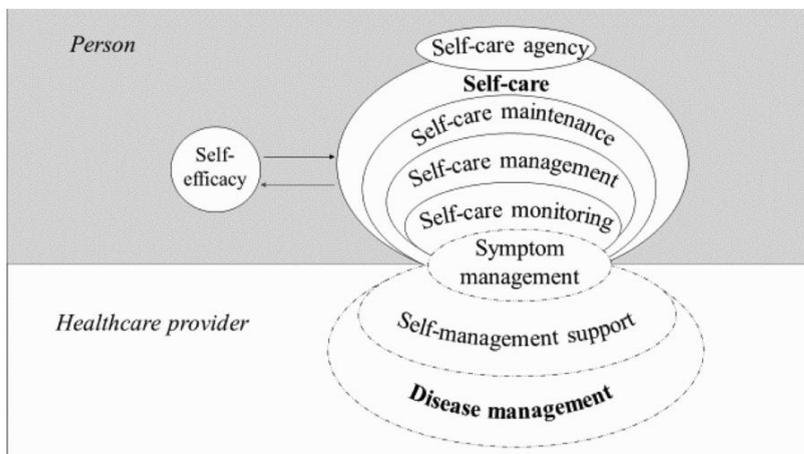
3.2 SELF-CARE AND SELF-MANAGEMENT

As mentioned above, patients mostly monitor and manage diseases themselves, supported by their caregivers. These activities, together with health-promoting and preventive measures, are referred to as self-care. However, there is no consistent definition of self-care (49). Goodfrey et al. in a review found 139 different definitions of self-care (50). In the Middle Range Theory of Self-Care of Chronic Illness "self-care is defined as a process of

maintaining health through health promoting practices and managing illness” (49). Self-care can be seen as a broad concept that includes related concepts. It entails “capacities, activities, and processes directed toward maintaining health, preserving life, and monitoring and managing acute and chronic conditions” (49). In a healthy individual, self-care is about maintaining health. Self-care ability (self-care agency) predicts if patients reach their health goals (self-efficacy, i.e., their confidence to carry out a behavior necessary to reach a desired goal) (Figure 1) (49).

When a person becomes acutely or chronically ill, they will continue to focus on preventive activities, but also do things to maintain a stable disease (self-care maintenance) and control symptoms and signs of disease using self-care monitoring. Further, the person will carry out self-selected activities, or activities chosen in consultation with health care, to manage the disease (self-care management) (49). For chronic diseases, the term self-management is often used (26). In Study II, self-management was used to describe the daily care activities and complex regimens that patients with multimorbidity struggle with. Self-management support thus “encompasses collaborative approaches directed at improving chronic illness outcomes with the involvement of healthcare professionals and healthcare organizations together with the patients: patients make decisions and perform behaviors to improve their health; healthcare professionals provide support to help patients understand their role in managing the disease, making informed decisions about care and engaging in wellness-oriented behaviors; and healthcare organizations provide the infrastructure and resources needed for the patient to self-manage the disease” (49).

Figure 1. Model of self-care and related concepts (49).



Effects of self-care/self-management include improved wellbeing, decreased illness and mortality, and decreased health care costs (49). There are, however, many challenges for people to carry out self-care, including difficulties in changing behaviors and barriers linked to illness. Other life events, cultural impact and psychiatric diseases also affect self-care

abilities, as well as the support from others (partners, family, peers and HCPs) (51). For patients with multimorbidity, self-management is especially challenging, as mentioned earlier (19). Challenges include poor accessibility, fragmented health care, polypharmacy, physical and psychological barriers, complex lifestyle changes and difficulties to integrate self-management advice that may conflict and increase the burden for the individual. Symptoms from different diseases could occur at the same time, which makes disease monitoring and interpretation of symptoms hard (51). When self-management advice increases in complexity, self-efficacy decreases. PHC has an important function in giving self-management support. This opportunity is often missed (69).

3.3 PREREQUISITES FOR PRIMARY HEALTH CARE TO PROVIDE PATIENT CENTERED CARE

In Sweden, recent and proposed changes in legislation have emphasized that PHC needs to take the lead in coordinating care for people with multimorbidity (52,53). PHC is uniquely positioned in health care to provide the holistic and coordinated care recommended for this group of patients (18,23,54). PHC is defined as the “care which provides integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community” (55). The Nordic Federation of General Practice has further underlined patient-centeredness as one of the principles of PHC (56).

A prerequisite for providing qualitative PCC to patients in PHC is personal continuity. However, there are large differences between Sweden and other countries in access to a designated and named physician or registered nurse (RN) in PHC. In Sweden, 35% report they had a designated and named HCP in PHC, compared with an average of 84% in other countries (14). In a Swedish report from 2021, only 26% reported they had a designated and named physician in PHC (57). Another recent reported stated there was a lack of 1,200–1,500 physicians working full-time in PHC in Sweden (58). The lack of physicians implies that Swedish PHC is dependent on temporary solutions such as rental doctors, which impairs personal continuity of care.

3.4 PATIENT-CENTERED CARE (PCC)

3.4.1 Patient-centered care in a historical perspective

In the following sections, I have reviewed the literature on PCC and patient-centered communication. I have also included a section on SDM, which is a central concept in PCC.

Historically, the concept of patient-centeredness has been used in the Anglo-American world, and is based on the biopsychological view that was developed in the 1950s. The concept was originally connected to general practice, but later spread to other medical specialties. The

concept of person-centered care, on the other hand, was developed in the beginning of the 21st century, and is more common in nursing literature (59). In a report from the Swedish Agency for Health and Care Services Analysis from 2018, person-centered care was described as a concept focusing on patient-provider interactions in clinical encounters, taking into account the whole person's perspective and how they experience life with their disease (60). In a review article about the differences between the two concepts, the authors concluded that, while the goal for PCC is a functional life for the patient, person-centered care aims to achieve a meaningful life for the patient (61). Though there are some differences between the two concepts, they overlap to a great extent, and PCC does take a whole-person perspective. In this thesis, I have chosen to use the concept of patient-centeredness, as the main focus of my work has been to investigate what happens in the interaction between HCPs and patients.

3.4.2 The evolution of patient-centered care

Today's focus on PCC has its origin in Breuer's and Freud's psychoanalytical and psychosocial theories from the end of the 19th century (62,63). In contrast to the strictly paternalistic approach that dominated the physician-patient relationship before then, the patient began to be seen as an active party in the relationship. Balint, Szasz and Hollender developed this thinking, and emphasized the participation of both parties (64,65). Balint also expanded the concept of illness into a psychosocial phenomenon, as much as a biological one. He saw the relationship between the physician and the patient as important per se, to both diagnosis and treatment of the patient (64). McWhinney further developed these thoughts twenty years later when he wrote: "The physician tries to enter the patient's world, to see the illness through the patient's eyes" (66).

In 1995, the first extensive definition of PCC was developed, with six components. PCC was characterized by: 1. *exploring both the disease and the illness experience*, 2. *understanding the whole person*, 3. *finding common ground regarding management*, 4. *incorporating prevention and health promotion*, 5. *enhancing the doctor-patient relationship*, 6. *'being realistic' about personal limitations and issues such as the availability of time and resources* (67). Laine and Davidoff further contributed to the concept by adding that PCC "is closely congruent with, and responsive to patients' wants, needs and preferences" (68).

In the 21st century, the definition of PCC was further developed. Mead and Bower made a literature review, and found five cornerstones for PCC (69): 1. *The biopsychosocial perspective*, where the strictly biomedical view is replaced by three perspectives that reflect the patient's illness: the biological, the psychological and the social (70). 2. *Patient-as-person* takes into account each person's experience of their illness, which can differ depending on the person's living situation. "A compound leg fracture will not be experienced in the same way by two different patients; it may cause far less distress to the office worker than the professional athlete" (69). 3. *Sharing power and responsibility* means that the patient needs to get sufficient information and encouragement to be involved in decision-making together with the physician. This is meant to lead to better adherence and better treatment results. 4. *The therapeutic alliance* between the patient and the physician is pointed out as important.

Through empathy, they reach concordance and can set shared goals. The relationship is seen as valuable in itself for successful treatment. 5. *Doctor-as-person* is about the physician's need to be aware of him- or herself being a tool in the consultation. By being aware of the emotions that evolve within themselves, both their own and those transferred from the patient, physicians can get clues to the consultation (71).

More recently, Langberg et al. made another systematic review of the concept, and found another dimension of patient-centeredness that had evolved, namely coordination of care (72). The need for coordination of care was seen as a result of the increasing fragmentation of health care. Further, they found new concepts that had developed and could be connected to Mead and Bower's category "sharing power and responsibility." Those concepts were "common ground," "empowerment" and "shared decision-making". In their review, they found a decreasing amount of new literature on "doctor-as-person," and they removed that dimension, defining instead three new dimensions of PCC: 1) *the patient* (biopsychosocial and patient-as-person); 2) *the doctor-patient relationship* (sharing power and responsibility; therapeutic alliance); and 3) *the coherence of treatment in the health care system* (coordination of care).

While Mead and Bower – and, later, Langberg et al. – described the physician's view of patient-centeredness, the US Institute of Medicine (IOM) in 2001 formulated a definition of PCC that was intended to be more operational and also involved the support of family and friends in caring for the patient (73): "1. *Respectfulness to patients' values, preferences, and expressed needs* implies helping the caregiver to meet the individual patient with a holistic approach rather than standard treatments to 'standard patients.' 2. *Coordinated and integrated care* is considered especially important for vulnerable patients or those too ill to coordinate care sufficiently for themselves. 3. Through *providing information, communication, and education* patients should be properly equipped to take part in medical decisions. Information about diagnosis, prognosis and treatment plans should be shared with patients in non-technical language. 4. *Ensuring physical comfort* stresses the importance of correct management of pain and other discomforts for patients to achieve physical comfort. 5. *Providing emotional support*, relieving fear and anxiety caused by overwhelming emotional stress from fear or uncertainty as patients go through treatment. 6. The IOM recommends *involving family and friends* because close family and trusted friends can prove beneficial during medical decision-making and can offer overall patient support."

These definitions of patient-centeredness share some main components: a biopsychosocial health care approach that focuses on the relationship between the professional and the patient with a goal to achieve common ground on management, including preventive measures and coordination of care. In this thesis, I have used a "narrower" definition of the concept in the first study, focusing only on the professional-patient communication. In the second study, a broader definition including multiple HCPs and FCs was used when trying to find ways for professionals to support self-management for patients with multimorbidity.

3.4.3 The evolution of patient-centered communication

Patient-centered communication is a central tool for the professional to provide PCC, and to find the patient's perspective and see the person in his/her psychosocial context. By gaining knowledge of the patient's ideas, concerns, expectations, emotions, needs and preferences, the professional can invite the patient to be involved in his/her own care. The goal for patient-centered communication is shared understanding of the health problems and the treatment (74,75). Studies have shown that when the physician has listened to a patient's concerns and has given emotional reassurance, the patient sees no need to mentioning any new concerns at the end of the consultation (76). When a physician has addressed a patient's concerns or expectations, this has led to fewer prescriptions (7).

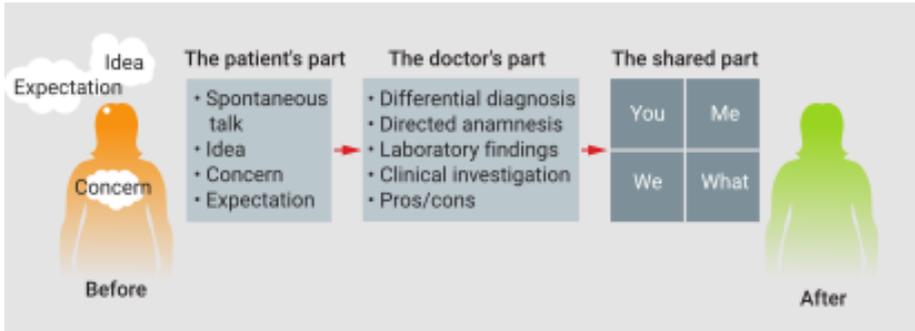
Over the years, different communication models have been developed to achieve a patient-centered approach in consultations. The interest in studying PHC consultations took off after Ballints' conversations with his colleagues about patients who did not fit into the biomechanical model (64). Byrne and Long studied over 2,000 audio-taped patient-physician consultations and found that physicians often misperceived their patients' reasons for the visits (77). Later studies have also found that physicians fail to elicit patients' entire agenda for their visits (78–80) and that patients are interrupted after talking on average 23.1 seconds during consultations (80). Studies have concluded that it does not take more than two to three minutes for patients to tell their story when asked open-ended questions and not being interrupted (81,82).

Based on the findings of Byrne and Long, consultation models started to develop in the 1980s. The anthropologist Helman emphasized the patient's experience of illness in his model. He believed that patients asked themselves several questions before attending an appointment with a physician and that these needed to be answered. They were: What happened?; Why did it happen?; Why to me?; Why now?; What would happen if nothing were done about it?; What should I do about it, or who should I consult for further help? (83). In the beginning of the 1980s, medical students in Maastricht were taught a generic consultation model encompassing three phases. In the first phase, the patient was the expert, in the second phase, the physician was the expert and, in the third phase, both were experts and should negotiate on what needed to be done (84). Later in the 1980s, Pendleton developed the concept "ideas, concerns, and expectations" (ICE) to describe the different parts of the patient's agenda that were to be elicited at the beginning of each consultation (85). The acronym is today commonly used in teaching patient-centered consultation. In Pendleton's model, focus was also on shared understanding of the patient's problem and finding a shared treatment plan. Next, Neighbour developed a model with five checkpoints: *connecting* (establishing rapport with the patient), *summarizing* (in order to gather the patient's agenda), *handing over* (reassurance that there is a concordance between the patient's and the physician's agenda), *safety netting* (making a plan for unexpected outcomes of the consultation) and *housekeeping* (physician's reconciliation with the self in order to be prepared for the next patient) alongside an awareness of "minimal cues" (verbal and non-verbal) to enable discovery of the unspoken agenda (86). Larsen developed his model to

guide the physician: from the patient's preparation prior to the consultation to the physician leaving the consultation and getting ready for the next patient (87). An even more comprehensive model, the Calgary–Cambridge Observation Guide, encompassing no less than 71 points, was developed in 1998 to guide physicians through consultations (88).

Larsen started to give courses together with his Danish colleagues on the Greek island Kalymnos, where family physician residents were taught patient-centered consultations through role plays that were video-taped and discussed in small groups. With the experiences from those courses, they further developed the consultation model. Like the creators of the Maastricht consultation model, they found it facilitating for the physician to view the consultation as having three distinct parts; the patient's part, the doctor's part and the "shared part." After having listened to the patient's story (the patient's part), the physician continues to the doctor's part of the consultation. Here, the physician asks medical questions and examines the patient in order to diagnose and prioritize what needs to be done next. In the third part of the consultation, the shared part, the physician first summarizes the patient's agenda and questions, and then tries to answer those questions, using the findings of the examination. After that, the two parties can negotiate a common agenda regarding what should be done next. When the patient has been able to tell his/her story, this could give the physician an understanding of which questions need to be answered during the consultation. Giving verbal "receipts" (such as "thank you for telling me that – tell me more") can reassure patients that the physician has really been listening to them, and that their emotions have been acknowledged. Together with Neighbour, Larsen wrote about five cards that could enhance the first part of the consultation. They were three "ICE" cards, a "receipt" card and a "summary" card (89). Larsen and colleagues from all the Scandinavian countries developed the "Kalymnos model." This was a pedagogical problem-based model, in which student feedback was given using a window model based on what is already well-functioning, to encourage a learning environment (85,90). This model is under continuous development, and is today taught to medical students as well as family physician residents in Sweden. In recent years, Hedberg has developed the shared part of the consultation, dividing it to four parts: 1) *You* (came here today with these questions and expectations), 2) *I* (asked more questions and examined you), 3) *We* (made sure we understood each other and shared understanding of the problem), and 4) *What* (did you take home from today's consultation?) (Figure 2) (91).

Figure 2. The three-part consultation model, translated from (91). Illustration: Typoform.



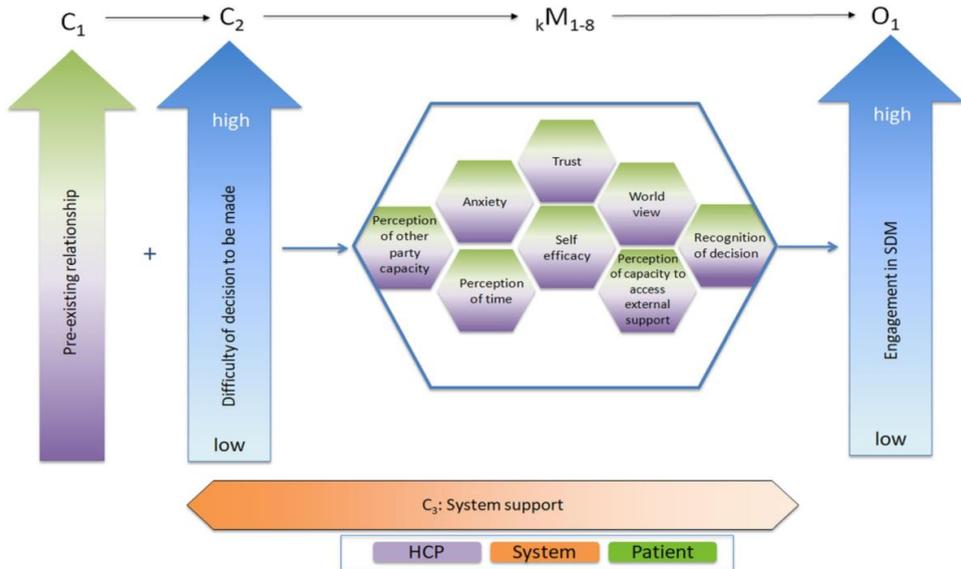
3.4.4 Shared understanding and shared decision-making

Shared decision-making is a central concept of patient-centered communication and involves a shared understanding of the problem (92). The term “compliance” comes from the paternalistic view of the physician who gives orders and the patient who follows them. In the development of PCC, patients are invited to share information, negotiate and are involved in decision-making. Compliance has been replaced by the term “concordance” (93).

Confusingly, the concept of SDM also has many different definitions, and there is no real consensus on its meaning (94,95). One model that is widely used comprises three steps: a) introducing choice, b) describing options, often by integrating the use of patient decision support, and c) helping patients explore preferences and make decisions (96).

In a recently published article, researchers tried to find out how SDM worked, and for whom it worked best, using a realist synthesis (97). They described the complexity of the SDM process, finding three contexts to be important: pre-existing relationship, difficulty of decision and health system support (Figure 3). The key mechanisms for how SDM worked were labeled as: perception of other party capacity, anxiety, perception of time, trust, self-efficacy, world view, perception of capacity to access external support and recognition of decision.

Figure 3. Program theory for shared decision-making (97).



This model, and the three-part consultation model (Figure 2) will be discussed in relation to the results in the discussion section.

4 METHODS

Two studies were performed to fulfill the overall aim of the thesis. As the two studies aimed to explore perceptions of interaction and self-management support, questionnaires and interviews were deemed appropriate. In the analyses, descriptive data were used to reveal patterns in the responses from patients and HCPs in Study I, while content analysis was used in Study II.

4.1 STUDY I

4.1.1 Design

A cross-sectional questionnaire study was used to explore the perspectives of patients and HCPs who took part in planned consultations in PHC.

4.1.2 Setting

The study was conducted at five PHC centers and two rehabilitation centers in northeast Stockholm from 1 February 2015 to 31 July 2015. Ten of the 28 PHC centers in the northeast part of Stockholm were invited to participate in the study. Invitations were made by one of the researchers via telephone and in-person visits. The research team was familiar with the centers in the area, and the 10 PHC centers were chosen because their staff situation was stable and they had shown previous interest in research. Six of the centers agreed to participate in the study, but one dropped out after a few months because of a heavy workload. One of the PHC centers had physicians, RNs and physiotherapists (PTs), and five had physicians and RNs, but no physiotherapists (PTs). Two rehabilitation centers had only PTs. Only fully trained specialist physicians in family medicine were included in the study.

Socioeconomic status is generally high in northeast Stockholm, and Swedish is the most commonly used language. The populations of the three municipalities represented in this study had higher educational levels than those in most other areas in Stockholm and Sweden as a whole.

Two questionnaires were developed: one for patients, which asked about their experiences, and one for HCPs, which asked about patients' experiences (Additional files 1 and 2, questionnaires in Swedish). The questions were based on items in questionnaires used in earlier studies of patient-centeredness. Because none of the previously existing questionnaires addressed all the items that the research team wanted to include in this study, study-specific questionnaires were developed. A group that included physicians, RNs, PTs, and senior researchers revised, translated and adapted the questions to Swedish PHC. The questions addressed background factors and ideas, concerns, expectations, and satisfaction. The questionnaires were tested on pairs of patients and HCPs (3 physicians and 3 patients, 3 RNs and 3 patients, and 3 PTs and 3 patients). The patients and HCPs deemed the questions to be understandable, so no changes were made.

4.1.3 Sampling

The receptionists at the centers consecutively invited Swedish-speaking adult patients to participate. During the study period, they were asked to invite as many patients as possible who were booked for consultations with physicians, RNs and/or PTs and to keep track of the number of patients who declined to participate. Only patients attending planned consultations were invited, not those attending acute care consultations. It was not considered possible to include acute care consultations as such consultations are too short for patients and professionals to provide reflections on patient ICE.

The receptionists provided patients who chose to participate with two anonymous questionnaires with matching codes: one for the HCP and one for the patient. The codes enabled the researchers to match responses from each consultation. Immediately following a consultation, the patient and HCP were to complete their questionnaires separately and return them to the receptionist. The surveys were returned to the receptionist by the patients, either by hand or in a sealed box. The participating centers were of differing sizes and recruited different numbers of participants. The length of time during which questionnaires were distributed and collected also varied by center.

A total of 724 questionnaires were distributed, and 641 were returned by patients and health care professionals and collected from the centers by one of the researchers. These questionnaires included responses from 156 pairs of patients and physicians, 73 pairs of patients and RNs and 69 pairs of patients and PTs (a total of 298 consultations) (Table 1, Study I). Thirty-five patients who were invited declined to participate or returned a blank questionnaire (7 who consulted physicians, 19 who consulted RNs and 9 who consulted PTs). The majority of respondents were women. Most patients who consulted physicians and RNs were ≥ 50 years.

Of the health care professionals, physicians had the most equal gender distribution. On average, PTs were younger than physicians and RNs.

The most common causes of consultations with physicians were musculoskeletal, circulatory and psychological problems. With RNs, they were most often related to wound dressing, blood pressure measurement and medical supplies. With PTs, they were usually musculoskeletal problems.

4.1.4 Analysis

Data were analyzed at the group level to investigate patterns in responses from patients and HCPs.

4.2 STUDY II

4.2.1 Design

Because the study included two sets of data, it was deemed appropriate to use a qualitative mixed-method design (33). Focus groups and in-depth interviews with professionals and patients in central Sweden comprised the core data. Complementary data came from in-depth interviews with RNs, patients, and FCs from a rural region in southern Sweden that used telemedicine to support patients with chronic heart failure.

4.2.2 Setting and sample

The study was carried out between April 2018 and October 2019 in three urban areas in central Sweden, and in a rural area in southern Sweden (Figure 1, Study II). Whereas two of the urban areas were located in suburbs of Stockholm and close to university hospitals, the third was located in a municipality with a population of around 60,000 that has its own hospital. The rural area in southern Sweden has around 10,000 inhabitants and is situated 40 km from the nearest hospital. The recruitment of both urban and rural locations in Sweden contributed to obtaining maximum variation.

A total of 42 participants, including 20 physicians (14 women), 3 RNs (all women), 12 patients (6 women) and 7 FCs (all women), were interviewed in the study (see Tables 2A and 2B for data on patients and HCPs).

4.2.2.1 Health care professionals

All physicians and one RN were recruited from three PHC centers in the urban areas in the capital region. Two RNs were recruited from a PHC center in the rural area of southern Sweden. One was a coordinator for the telemedicine program and the other worked in the municipality's home care unit. The coordinator nurse was one of two at the PHC center, both of whom were asked to participate. Only one of them agreed. Snowball effect was used to include the RN from the home care unit. She was recommended by the coordinator RN. Convenience sampling was used when choosing PHC centers. They had shown earlier interest in participating in research and had a stable staff situation. Fifteen of the physicians were family physicians, and the remaining five were physicians-in-training. The physicians' mean age was 45 years, and the physicians had worked in their profession for a mean of 13 years. The RNs were a mean of 51 years and had worked in their profession for a mean of 15 years.

4.2.2.2 Patients from the urban areas

Patients were selected using purposive criterion sampling. The purpose was to interview patients with complex multimorbidity. Therefore, patients who had been hospitalized for one chronic disease and had at least one additional chronic disease in a different organ system were asked about inclusion. The patients had been part of the control group in an RCT study (35) and had agreed to participate in a qualitative evaluation of their care. JF collaborated

with Carina Brandberg, who had performed the RCT and had knowledge of the patients. Several of the patients on the list were too sick to be interviewed or had died after the previous study had been carried out. People with cognitive impairment were excluded from the study. One patient who was contacted did not have any contact with their physician and was therefore excluded, since the aim of this study was to study PHC. Ultimately, three patients came from urban areas in central Sweden (Patients 1–3, Table 1, Study II). One of these three patients received help with drug administration from a home care unit.

4.2.2.3 Patients and family caregivers from the rural area

Nine patients (Patients 4–12, Table 1, Study II) and seven FCs were recruited from the PHC center in southern Sweden. The patients were involved in the telemedicine program that was part of a regional effort to support patient-centered and seamless care for older patients. The patients were selected using convenience sampling: the two coordinator RNs asked all 19 participants in the telemedicine program about participation, and 9 accepted. The recruitment of patients from this program can be seen as a form of intensity sampling, which is used to investigate a phenomenon of interest; in this case, the experience of using telemedicine. To make sure that this group of patients had multimorbidity, JF double-checked that patients had more than one chronic condition by asking the RNs. The telemedicine program targeted patients with chronic heart failure and/or diabetes, and included registration of health parameters in a tablet computer (blood pressure, weight, temperature, oxygen saturation, and – for those with diabetes – blood sugar). Patients also filled out questionnaires about their health status and symptoms related to chronic heart failure. Two RNs at the PHC center monitored patients' registrations daily. The RNs could react to changes in patients' conditions by contacting them and involving their PHC physician or home care nurse. The patients could also use their tablets for video meetings with the RNs. The frequency of registrations and contacts with the RNs was decided individually by the patient and the RNs. No goal-setting or motivational support was provided as part of the telemedicine program. Patients received supportive care from RNs in the home care unit when needed, but these RNs were not directly involved in the telemedicine program. The inclusion and exclusion criteria were the same as for the patients in urban areas. All FCs except one (a daughter) lived with the respective patient.

The mean age of all participating patients was 80 years. The most frequent diseases were chronic heart failure, chronic obstructive pulmonary disease (COPD), arthritis and diabetes.

4.2.3 Data collection

Data were collected sequentially. The research team developed an initial interview guide for the focus group interviews with professionals. Questions were open-ended and related to 1) how professionals perceived their role in supporting self-management for patients with multimorbidity, and 2) how patient-centered the professionals perceived this support to be. It was considered important to include questions about patient-centeredness because PHC professionals are trained in PCC and earlier studies had suggested that such care is central to

successful self-management support. Questions covered communication, motivational work, coordination of care, continuity of care, shared information and SDM. The research team also developed a patient interview guide with corresponding open-ended questions about what support the patients wished for from PHC.

The decision was made to use focus groups with professionals for practical reasons (convenience sampling): it is challenging to schedule individual interviews with professionals, as they are often pressed for time. Focus group discussions also have qualities of both interviews and discussions and benefit from group dynamics because they stimulate participants to react to, reject or confirm statements from other participants (98). The focus groups were led by two of three researchers (JF, MF, or ME). One of them moderated the discussion and another ensured that all the topics were covered. Participants were asked to keep in mind patients with multimorbidity, whose diseases, including mental disorders, had a major impact on their everyday lives. They were also asked to think of diseases and treatments that were complex for patients and professionals to evaluate because of polypharmacy or overlapping symptoms (e.g., shortness of breath in COPD and chronic heart failure).

Patients and FCs were interviewed using convenience sampling. It was easier to interview patients in their homes because their health conditions often made it difficult for them to participate in group interviews. There were too few RNs to form a focus group. Interviews with patients and FCs were performed by JF and two research assistants. Five of the interviews were with a patient and his or her FC; that is, two people were interviewed at the same time. The two final RN interviews were performed by JF via telephone.

Focus group interviews lasted 40–65 minutes, and individual interviews lasted 20–45 minutes. All interviews were audio-taped and transcribed verbatim.

4.2.4 Analysis

An inductive approach to content analysis was used, as it was deemed appropriate for inductive exploration of a perspective that was not already well-explored (99). After each interview, the transcript was read and analyzed several times by JF, MF and ME. The analyses comprised descriptions of the manifest content, capturing the visible or obvious contents close to the text. Analyses also comprised descriptions of the latent content, capturing the underlying meaning of the content – distant from the text, but still close to the participants' lived experiences (100). Then, text about the topic of the study was divided into meaning units, which were condensed. After all the interviews, the condensed meaning units were abstracted and each labeled with a code. Next, the research team met to compare and organize the condensed meaning units into categories and subcategories (100,101). The categories and subcategories were then presented to and discussed with two groups of researchers not involved in the study. Two final interviews were conducted to check whether any new data emerged; these were the telephone interviews with the two RNs from southern

Sweden. These interviews did not result in any new categories. A main theme emerged from the categories as a result of analyzing latent findings in the data.

4.3 ETHICAL CONSIDERATIONS

Ethical approval was sought for both studies. Both studies were approved by the Regional Ethics Review Board in Stockholm, Sweden: Study I, Dnr 2014/1851-31, and Study II, Dnr 2018/9-31/2.

4.3.1 Informed consent

Participation in the two studies was voluntary and the participants gave informed consent that could be withdrawn at any time.

In Study I, all managers and participating professionals were provided with verbal informed information before the study started. The receptionists also gave patients verbal and written information about the study prior to inclusion, highlighting the voluntary and anonymous nature of participation. Answering the survey was interpreted as consent to participate.

In Study II, HCPs, as well as patients and FCs, were given verbal and written information about the study prior to inclusion.

4.3.2 Privacy and confidentiality

In Study I, questionnaires were coded: one code for the patient and a corresponding code for the HCP. In this way, participants' integrity was protected during and after the study. The receptionist kept the completed questionnaires in sealed boxes until one of the researchers collected them, to further ensure that no one outside the research team could read them. After collection of the questionnaires, they have been kept stored in a locker.

In Study II, care was taken not to reveal information that could be traced back to participants, while still enabling telling of the participants' stories. To protect confidentiality, no private sections from the data that could be traceable were published. Further, since data were collected from a small rural region, a fact that could enable participant identification, the region was not named in the article. To protect the participants' integrity, individual codes have been used instead of names. The European General Data Protection Regulation (GDPR) was observed in all stages of data management, protecting personal data from third parties and ensuring participant privacy.

5 RESULTS

The main finding in both studies was that the perspectives of both HCPs and patients need to be acknowledged in order to reach concordance in PHC consultations. In Study I, it was found that there was a discrepancy between HCPs' and patients' perceptions of the consultations. Study II showed that both parties need to stand on common ground in order for PHC professionals to individually support a patient's self-management.

5.1 RESULTS OF STUDY I

The main findings in Study I were that most patients had expressed their ideas, but fewer had presented their concerns during consultations. A relatively low number expected to receive an explanation for their symptoms, but most felt that their overall expectations had been met (Table 2, Study I). Also, HCPs tended to believe patients were less satisfied than patients reported they were (Table 3, Study I).

5.1.1 Ideas, concerns and expectations

A majority of patients and HCPs reported that patients' thoughts and explanations about their symptoms were expressed during the consultations (60–84%, Table 2, Study I, question 2). Approximately 70% of patients and HCPs reported that patients' questions about health were answered (question 3). In 11–33% of consultations, patients reported that they had expressed their concerns (question 7). The figure was lowest at RN visits and highest at PT visits. About a third of patients consulting physicians (31%) and PTs (32%) expected to receive an explanation for their symptoms. The figure was lower when consulting RNs (12%, question 9).

5.1.2 Questions about satisfaction

A high percentage of patients felt their expectations for the consultation had been fulfilled (84–88%, Table 3, Study I, question 11) and that they were respected and taken seriously (88–98%, question 10). These figures are in line with those of the HCPs. Few patients felt something was missed during their consultation, whereas a higher percentage of HCPs perceived that patients felt this way (question 14).

The majority of patients reported that they were satisfied with the HCP's attitude towards them, with the information and emotional support they received, and with the sharing of decision-making (74–94%, questions 16–19). The highest proportion of satisfied patients was observed in PT consultations. Among HCPs, the percentages reporting that patients were satisfied with the consultations were lower in all groups than they were among patients (questions 16–20).

5.2 RESULTS OF STUDY II

In Study II, the main theme that emerged was “Standing on common ground enables individualized support.” This theme was supported by four categories (Table 2, Study II):

1. Individualized support and patient-professional relationships.
2. Professionals as knowledge translators to help patients learn self-management skills.
3. Managing and coordinating multimorbidity in a system focused on single diseases.
4. Shifting roles and differing views of responsibility for self-management.

Professionals, patients, and FCs thought it was important for the professionals to be accessible and support patient self-management. This was enabled by personal continuity, which facilitated trustful relationships. According to participants, PHC professionals should also function as knowledge translators and should coordinate different levels of care. Two perspectives on responsibility emerged. Professionals, patients, and FCs could consider professionals responsible for managing patients’ diseases or could think that professionals should support patients in taking the lead in self-management. Latent in the findings was the desire for individual support for self-management, and the overall theme that emerged was that standing on common ground would enable such support. In other words, to support patients’ self-management, the professionals must first understand their own perspectives on who is primarily responsible for self-management. They must also understand patients’ and FCs’ preferences, needs and perspectives on self-management and seek common ground with them on the support they need and on the distribution of responsibility.

5.2.1 Individualized support and patient-professional relationships

Patients and professionals said that health care should be individualized by taking a patient’s agenda into account and considering their knowledge about and capacity for self-management. Professionals emphasized the importance of answering patients’ questions before reverting to their own agenda for the visit. One patient said:

“I’m worried about my leg, which goes numb. Instead of investigating it, they gave me a walker and transportation service, but that doesn’t solve the problem.” (Patient 1)

It was seen that patients sought care at other places or trusted what they read in newspapers or what acquaintances said more than health care guidelines when they did not get their questions answered.

Professionals and patients mentioned the importance of patients’ individual goals. When discussing goal-setting, physicians and RNs mostly thought of clinical goals such as blood pressure and blood sugar. Patients, on the other hand, talked about symptom relief and health goals related to things they appreciated in their everyday lives, such as working in the garden

or being with their grandchildren. One patient was clear about not wanting preventive drugs, only drugs that gave symptom relief:

“My goal is not to become 100, but to have pain relief, nothing else.” (Patient 2)

Participants said that a trustful relationship facilitated self-management support. Patients and FCs appreciated encountering professionals they knew and trusted. Though a new professional could read information in the medical record, they preferred to see someone they had known for a long time. They felt that this person cared about and knew them, which meant they did not have to repeat their medical history. PHC physicians thought they had a better opportunity than hospital physicians to see their patients as individuals because they had known the patients for a longer time and were familiar with their family situations. This was something that RNs also mentioned as important.

“Through home visits, I can get another picture of the person and the FC. It’s a whole image that you can’t achieve by reading the medical record” (RN 1).

Several things could negatively influence patient-professional relationships, such as a lack of trust in the professional’s competence. A couple of patients mentioned not trusting their PHC physician’s competence in treating heart disease. Difficulty understanding a physician whose native language was not Swedish could also affect patient trust.

Physicians, patients and FCs talked about support that went beyond information and disease management. Physicians mentioned that patients often wanted to contact them because of anxiety, stress or loneliness, not primarily because of disease. Patients brought up loneliness as something frightening, and one patient had continued to participate in the telemedicine program not for health reasons, but because she wanted the social contact.

5.2.2 Professionals as knowledge translators to help patients learn self-management skills

Physicians and patients reported that knowledge and understanding of their diseases, symptoms and treatments were important for both self-management abilities and reducing anxiety. They thought that PHC had an important role to play as a knowledge translator.

“Patients know their symptoms, but why they have these symptoms and these problems and how they’re correlated with their disease, it’s our role to try to explain it to the patients.”
(Focus group 2)

Patients gave examples of how they had learned to act in response to different symptoms, e.g., increase their dose of medicine to decrease swelling in their feet. Patients also talked about when to initiate contact with the PHC center. Patients reported that it was more frightening to experience symptoms that they could not interpret than to experience those that they understood. Some diseases, such as myocardial infarction, were more frightening than chronic pain they had lived with for a long time, and those that felt threatening made them more prone to make lifestyle changes.

Whereas patients talked about professionals' pedagogical failings, professionals focused on their pedagogical strengths. Examples of pedagogical failings that patients mentioned included not answering patients' questions and not explaining why different health parameters had to be checked (e.g., why patients needed to monitor their oxygen saturation). One patient who smoked said that she was often given admonitions that did not make her more likely to quit. As examples of pedagogical strengths, physicians mentioned that they used analogies and imagery to explain concepts and sometimes printed out patients' medicine lists and wrote clarifying information on them. To confirm that patients had understood them, physicians and RNs used questions that required patients to summarize what they had said.

Physicians, patients, and FCs also talked about self-monitoring of health parameters. Patients sometimes initiated such monitoring on their own and sometimes did so at the request of professionals. Monitoring could help patients better understand their diseases and thus facilitate self-management.

5.2.3 Managing and coordinating multimorbidity in a system focused on single diseases

This category encompassed problems related to a health care system that the professionals and patients both saw as focused on single diseases. This meant that PHC played an important role in coordinating care in a fragmented system. Fragmentation of care forced patients with multimorbidity to visit different specialists every year for their diseases. One physician in Study II said:

"It becomes an involuntary full-time job for the patients; it's their 40-hour week." (Focus group 3)

Care coordination could be a burdensome issue for patients with multimorbidity. Physicians, patients and FCs all gave examples of such problems. Patients mentioned that they did not know whether their PHC physician and hospital specialist communicated or not, and they did not even know if the different professionals at the PHC center communicated with each other. Physicians not only thought that specialized care was fragmented, but also experienced fragmentation at their PHC centers, where RNs have become increasingly specialized in different areas, such as diabetes or COPD. According to physicians, electronic medical records were a technical barrier to coordinated care, as were health apps, both of which they described as being disease-oriented.

On the other hand, there were examples of better care coordination. The RNs talked about their role as coordinators of different caregivers for patients with multimorbidity. FCs, home care providers, care managers, and allied health professionals often played a crucial role for patients with multimorbidity, and the RNs saw themselves as being the people who pulled it all together. Most physicians also saw it as their role to coordinate care and keep medication at a reasonable level for older patients with multimorbidity. Some regarded themselves as their patients' advocate in dealings with other specialists.

Accessibility to health care for patients with multimorbidity was also important for supporting self-management. Physicians wished for more time with these patients so that they could clinically evaluate their complex health problems. Physicians explained that patients with multimorbidity were crowded out because of increased access to PHC visits for people with all sorts of health problems, even problems that had in the past been regarded as manageable at home. Patients also brought up the importance of easy access to PHC.

5.2.4 Shifting roles and differing views of responsibility for self-management

This category describes the shifting roles that PHC professionals took on to support patients' self-management, as well as differing views on who was responsible for self-management.

A professional's role in supporting self-management could vary with each patient. Some patients with multimorbidity coordinated and managed their care independently, whereas others needed more support. Views on responsibility for self-management also differed, not just among professionals, but also among patients and FCs. Some preferred the professional to take a more controlling role; others emphasized the need for the professional to let go of control and empower the patient.

Professionals, patients and FCs could believe that when professionals were in control, patients adhered to treatment better and felt safer and less anxious. One physician who believed it was important for her to maintain control said that she had to schedule regular checkups for patients to prevent their health from deteriorating. Personal continuity could help physicians feel in control, because it was easier to see changes in the clinical status of patients they had met before. Patients appreciated it when professionals had control of patient-related information, both through familiarity with a patient's medical history and through ongoing monitoring. Several patients in the telemedicine program felt secure knowing that someone was keeping track of their health parameters and that the nurse would contact them if there was a change. FCs could also play an important part in helping professionals see changes in a patient's condition. For patients with more severe disabilities, support from a FC was not enough, and they needed extra assistance from home care.

Some professionals regarded it as their role to motivate patients to take more responsibility for self-management. They favored patient empowerment and believed that patients could manage their diseases better with the right knowledge. These professionals were more likely to hand responsibility over to patients after having made sure the patients had such knowledge.

Professionals also described how patients who managed their diseases more independently gave the professionals valuable time to see other patients in need. For most patients and FCs in the telemedicine program, recording the information felt meaningful and became an important daily routine. For others, this shift in responsibility felt challenging at times, and some patients were so weak that their FCs had to record information on their behalf.

Professionals also brought up personal continuity as an important tool to motivate patients in the long term.

“If you want to achieve a goal, it’s much easier to follow up your patient on a regular basis than to say: ‘See you in half a year’.” (Focus group 1)

Professionals could find it challenging to motivate patients to take more responsibility, but it was easier with patients who had a degree of motivation than those who did not. Physicians promoted group activities for patients and collaborated with RNs at the PHC center to talk about lifestyle changes with patients. They thought e-health tools could play a role in motivational work, but could find it challenging to motivate patients to continue using such tools.

Whereas some patients preferred professionals to take a lot of responsibility for managing their diseases and coordinating their care, others preferred to maintain overall control. They contacted the PHC center when they felt they needed to, and some would also independently change their medication regimens after consultation with their physician.

6 DISCUSSION

This thesis provides insight into how patient-centered communication is delivered in Swedish PHC today. While Study I was performed in an all-population context, Study II focused on interaction with and support of self-management for patients with multimorbidity.

6.1 DISCUSSION OF THE FINDINGS

The main finding in this thesis was the importance for HCPs and patients to find common ground in consultations in order to avoid misperceptions of patients' experiences and to individually support patient self-management. The following discusses the findings related to the three-part consultation model (Figure 2)(91) and the program theory for SDM (Figure 3)(97).

6.1.1 Patient-centered communication

According to the three-part consultation model, the patient's agenda for the visit (their ideas, concerns, and expectations) should be elicited in the first part of the consultation. Study I showed that in most cases, patients expressed their own ideas, whereas a minority of patients expressed concerns and expectations about treatment and investigation. Earlier studies that have investigated the extent to which the patient's agenda has been elicited have been carried out with differing research designs, making it hard to compare the results. Both questionnaires and analyses of audio recordings were used (7,80,81,102,103). In earlier studies, patients' concerns were elicited in about a third of PHC consultations, similar to the figure in Study I (7,80,81). This result could reflect the difficulties in eliciting the most sensitive part of a patient's agenda, but could also reflect shortcomings in patient-centered communication among physicians. One such factor could be interruption of patients, shown in several of the earlier studies (80,81,102). Another factor could be that HCPs did not allow patients to tell their entire agenda by using affirmations or "receipts." Neighbour and Larsen have suggested that using receipts is an effective method to make patients feel trust and to express views that feel significant, strange, embarrassing or worrying (89,104). In Study I, participants were coming to their HCPs for follow-up visits. This could mean that visits were check-ups rather than being related to new concerns. This could be true especially in the case of RN visits that were about blood pressure measurements or wound dressing. The fact that the study investigated follow-up visits could also explain the low number of patients expecting to receive an explanation for the cause of their illness; this might already have been mentioned in earlier visits.

6.1.2 Shared understanding and shared decision-making

As mentioned in the background section, a goal for patient-centered communication is a shared understanding of the problem between the HCP and the patient. When patients have shared their entire agenda, the HCP can get an understanding of which questions need to be answered in the consultation. This enables the HCP to give the patient the information required to take part in SDM. When patients have not shared their entire agenda, there is a

risk that essential parts are missed and that HCPs fail to answer the patients' questions. When patients' questions were not answered (Study II), they sought care from other places or trusted their acquaintances or what they read in the newspapers more than they trusted their HCP.

In Study I, most patients reported that they were satisfied with their experiences of having been listened to and having had their questions answered. They also felt involved in their care. However, there was a discrepancy between patients' and HCPs' answers: HCPs generally underestimated patients' experiences of being listened to, being involved and having had their questions answered. Patients generally answered "yes" to questions about whether they were satisfied, whereas HCP answered "yes, partly" to the corresponding questions. This could indicate shortcomings relating to the very last shared part in the consultations, namely the question: "What do you take home from today's meeting?" Having asked this question, or a similar teach-back question (105), could support the HCP with the information needed to confirm either a satisfied and well-informed patient or the opposite. In Study II, HCPs reported that they used this technique to confirm that patients had understood the information given. The fact that HCPs used "yes, partly" as alternative in Study I could also be due to an end-aversion bias, meaning that the end options are avoided (106). This bias could be assumed to be more likely among HCPs than patients because they do not want to stand out.

Several factors may influence HCP and patient involvement in SDM. In a realist synthesis, a program theory was developed in order to answer how SDM could work when decisions are complex (Figure 3) (97). In the following sections (6.1.2.1–6.1.2.7), I have related the program theory of SDM to the findings in the two studies included in this thesis. I have also compared this model to the management and communication models used when treating multimorbidity, as described in the background section.

6.1.2.1 Recognition of decisions and preferences for shared decision-making

In order for both parties to be involved in SDM, patients must first be invited to take part in that process. *Recognition of decision*, in this model, is when HCPs and patients consciously acknowledge that a decision choice exists. In most consultations, some kind of choice is involved. However, consultations in PHC can be more of a social character than a medical one (e.g., patients who are lonely). Study II showed that some patients wanted to visit their HCPs or be part of the telemedicine program for this reason. In the program theory, the authors suggest that when decisions are more complex, the HCPs are more likely to involve patients in SDM. However, as pointed out in the background, past studies have shown that many older adults are not involved in SDM (35,36). Study II did not specifically examine how involved patients felt in SDM, but patients gave examples of unanswered questions (see example above), which implies that they were not fully involved in SDM. On the contrary, in Study I, patients generally felt highly involved in SDM. This may have been related to the high socioeconomic status of the study area. Previous studies have indicated that high socioeconomic status is linked to a preference for a more active role in SDM (107,108).

6.1.2.2 *Pre-existing relationships and trust*

The authors have suggested that *pre-existing relationships* play an important role in the process of SDM. If the relationship between the HCP and the patient is good, the patient will feel more *trust* in the HCP, who will have more knowledge about the patient's preferred level of engagement, which would lead to better engagement in SDM. In Study II, participants emphasized the importance of a trustful relationship. Patients believed that when a HCP knew them, this meant they would not have to repeat their medical history, and that the HCP cared about them. Another study of older patients has also found that trust highly influences preferences for SDM (34). In Study I, there were no data on pre-existing relationships. However, since the health care centers had a stable staff situation, this could mean that patients met the same HCP as they had met before, which could have increased their involvement in SDM.

6.1.2.3 *Complexity of decisions and anxiety*

Another contextual factor that is included in the program theory is the *complexity of decisions*. Decisions with complex implications (such as a cancer diagnosis) can result in *anxiety*, which can, in turn, decrease involvement in SDM. Study II showed that increasing a patient's knowledge could reduce such anxiety. Thus, HCPs have an important pedagogical task in simplifying and individualizing information to the patients. By letting the patient talk spontaneously during the patient's part of the consultation, the HCP can gain an understanding of the patient's level of health literacy. Further, trustful relationships promote knowledge. Trustful relationship may also decrease a patient's anxiety, which could further increase involvement in SDM. This trust goes both ways; the HCPs, ideally, can trust the patients to adhere to the treatment or be forthcoming about their symptoms and thoughts. On the other hand, Study II showed that anxiety, or rather fear, when diagnosed with a life-threatening disease such as myocardial infarction could make patients prone to be more involved in lifestyle changes suggested by the physician.

6.1.2.4 *System support and consultation times*

The third contextual factor included in the model is *system support*. This could mean decision aids and tools for SDM, but also support at an organizational level. For patients with multimorbidity, there has been a lack of guidelines, both for management of diseases and for self-management support (21–23). HCPs in Study II mentioned the complexity of managing patients with multimorbidity and experienced a lack of support in the form of e-health tools to help manage this complexity. Additionally, fragmentation of health care further obstructs management of multimorbidity (21–23), which makes coordination of care a burdensome task for both HCPs and patients. Involving all HCPs of a patients in the SDM process is suggested to improve care coordination and reduce this fragmentation by helping break down the silos that separate different health professions (109).

When supporting SDM, one consultation model or tool that is suggested to be used for this group of patients is the “Ariadne principle” (110). In this tool, patients' preferences are taken

into account, and mutual goals are set between HCPs and patients. The tool underlines the necessity of reevaluating what is most important for the patients, depending on what diseases or symptoms are dominating at the time, and depending on other life events that could affect patients' priorities (such as their husband or wife becoming sick). The tool also fits well with the three-part consultation model, which focuses on answering patients' questions. Another tool to support SDM for patients with multimorbidity is the Instrument for Patient Capacity Assessment (ICAN) tool (111). This is used in order to prioritize what is most important for the patients, but also takes into account the patients' capacities and treatment burden. Unlike in the three-part consultation model, the conversation starts off with the HCP asking the patient directed questions such as "What are you doing when you're not sitting here with me?" and "Where do you find the most joy in your life?" Though these questions are relevant, this could potentially prevent the patient from tell his/her uninterrupted story during the consultation.

In Study II we found that telemedicine could be used as a tool to make PHC more accessible, but also to help monitor vulnerable patients in order to prevent them from having to be admitted to hospital. However, the monitoring targeted chronic heart failure and no other diseases. A systematic review and meta-analysis of telemedicine interventions for multimorbidity showed only small reductions in hospital admissions (112). We also found that self-monitoring helped some patients experience that they had increased their knowledge. However, the telemedicine program did not include any tools to support SDM and could not be shared with other HCPs; thus, it did not enhance care coordination.

Aside for support tools, sufficient *time* for patients with complex decisions is also suggested to enhance conversations, both in the program theory of SDM and in recommendations for managing patients with multimorbidity (18,23). Further, longer consultation times have been associated with a more comprehensive care (113). Longer consultation times and a higher degree of personal continuity have also resulted in an increased sense of security and better ability to self-manage new symptoms (114). In Sweden, consultation times have generally been longer than in other European countries (115). At the same time, the low numbers of physicians in Sweden make accessibility to care poor, which results in more issues having to be taken care of at each consultation. Bodegård et al. found that patients with more than two reasons for visits felt more interrupted, had fewer of their questions answered, and were less satisfied overall than patients with only one reason for their visit (103). If the physician listens to a patient's entire agenda for the visit and makes a plan with the patient for when to deal with each of the problems, this could help reduce patient disappointment.

6.1.2.5 Self-efficacy and activated patients

Self-efficacy is another factor that is suggested to play a role in the SDM process, here referring to an individual's belief that he or she is able to participate in the SDM process. This could mean both the HCP's perception of being able to share knowledge and expertise with the patient and the patient's perception of his/her capability to perform actions to prevent or treat health conditions. Study II showed that some patients preferred to take a more active

role in self-management and care coordination. They were also positive to self-monitoring of their health parameters and felt this increased their knowledge. Others preferred the HCPs to take overall responsibility. The preference for taking a more active role could be a result of high self-efficacy among some patients. This would be in line with the findings in another study, where the authors found a subgroup of patients with multimorbidity consisting of well-prepared and proactive patients who wanted to be in charge of and coordinate their own care (116).

As mentioned in the background, CCM interventions target well-informed and activated patients who collaborate with their HCPs to improve health outcomes (39,41). Patients with high self-efficacy are favored by such interventions, but as science continues to look at more vulnerable groups of patients with multimorbidity, other interventions are likely to be considered necessary for these groups.

6.1.2.6 Capacity and need of support from others

Related to self-efficacy, involvement in SDM could also be influenced by a patient's *capacities*. The program theory describes the perception of *capacity to access external support* as important in this. Study II showed that patients with functional and/or psychological impairment had difficulties taking part in their self-management and had to rely on FCs or home care for assistance. For them, access to care was very important, and the telemedicine program promoted this, as well as care surveillance. Additionally, low health literacy, low educational levels and low financial means could increase the need for external support (116,117). The program theory could be interpreted to indicate that if these patients believe they have such support, they are more likely to experience reduced anxiety and increased self-efficacy, resulting in high SDM engagement.

In order to target patients with complex multimorbidity, MDM was developed to take into account a patient's treatment burden, including not only tasks given to the patient by HCPs, but also structural, personal and situational factors (46). MDM aims to target these factors and applies a whole-person perspective. One such intervention is capacity coaching, including use of the ICAN tool, focusing on strengthening the patient's capacity to adapt and thrive despite a chronic illness, with the support of the whole health care team (118). Though these types of interventions seem promising, they are still under development, and need further evaluation prior to implementation in a larger scale.

Another capacity mentioned in the program theory is the perception of *other party capacity*. This refers to the other's ability to successfully meet the expectations placed on their role within the consultation. This could be about the perception the patient has regarding the HCP's knowledge and experience of their disease. In Study II, a couple of patients did not rely on their physician's competence in treating their heart disease, and another had difficulties understanding a physician whose native language was not Swedish. Such experiences could lead to low patient engagement in SDM. Further, the theory suggests that if a patient is displaying high levels of anxiety, the HCP might perceive that they do not have

the capacity to participate in decision-making. This could result in low HCP engagement in SDM.

6.1.2.7 Goal-setting as part of shared decision-making

Goal-setting was not included in early definitions of the concept of SDM (94,96). Goal-setting is, however, an essential aspect of supporting self-management as part of the collaborative care used in the CCM (42). Setting goals has also been suggested to improve care for patients with complex multimorbidity (119–121), with three types being distinguished: fundamental goals (e.g., continue to live at home); functional goals (e.g., better mobility); and disease- or symptom-specific goals (e.g., reduce pain or improve diabetes control). This holistic view of goals is in line with the MDM model and is used in the “Ariadne principle” and the ICAN tool described above. The holistic view of goals also aligns with the program theory, which takes into account the patient’s *world view*, meaning the patient’s beliefs, customs and values, when sharing decisions. Study II showed that HCPs and patients talked about different kinds of goals when asked about goal-setting. While HCPs thought of disease-related goals (e.g., blood pressure or diabetes control), patients talked more about fundamental or functional goals (e.g., being able to work in the garden or be with their grandchildren).

However, conversations on goals did not occur often, especially with home care patients. Other studies have shown similar results: older adults are minimally involved in conversations about goals (122–124). This could be due to goals not being a priority due the limited time available, with visits focusing on symptoms, as well as the mutual perception of disinterest in goal-setting and the presumption that all patients’ goals are the same (123).

6.2 PATIENT AND HEALTH CARE PROFESSIONAL’S SATISFACTION

As mentioned, Study I included questions related to satisfaction with the consultation. Most patients were generally satisfied with the consultations, regardless of what type of HCP they had visited. However, satisfaction was hard to interpret. As discussed in the study, factors other than the actual consultation might affect satisfaction. Such factors could be contextual (e.g., short waiting times and care continuity) (125–127) or correlated with patient characteristics (e.g., age and functional status) (128). Thus, it was not possible to draw conclusions about patients’ satisfaction with the consultation itself.

As mentioned earlier, there was a discrepancy between HCPs’ answers and patients’ answers, with a tendency for HCPs to underestimate how satisfied patients were with consultations. Such a discrepancy might lead to feelings of insufficiency and stress in HCPs. As previously noted, checking at the very end of the consultation what patients will take home could perhaps prevent stress, increase HCP satisfaction with their work, and improve care delivery. A cross-sectional study found that patients of physicians who were happier with their work experienced better communication, continuity, access, and comprehensiveness (113).

6.3 METHODOLOGICAL CONSIDERATIONS

6.3.1 Comments on the statistical analyses

Study I investigated the perceptions of both HCPs and patients. Descriptive rather than analytical statistics were used to report results because of the explorative design of the study. If hypothesis testing had been undertaken, t-tests could have been performed to investigate whether differences between HCPs' and patients' answers differed statistically. Since the variables could be regarded as on an ordinal rather than an interval scale, a Wilcoxon rank-sum test would be the appropriate test. The research team also discussed analyzing potential correlations between eliciting the patient's agenda (i.e., ICE) and the patient's satisfaction with the consultation. Since satisfaction was high overall, it was concluded that such analysis would not be meaningful.

6.3.2 Trustworthiness

Several criteria have been established within both quantitative and qualitative design to judge the trustworthiness of studies (129). For trustworthiness, four questions are to be answered: 1. Have we measured what we set out to measure? (truth value); 2. How applicable are our results to other subjects and contexts? (applicability); 3. Would our findings be repeated if our research were replicated in the same context with the same subjects? (consistency); and 4. To what extent are our findings affected by personal interests and bias? (neutrality).

Internal validity is used as the criterion for truth value in quantitative research, whereas *credibility* is used in qualitative research. In Study I, the questionnaires were tested on nine pairs of HCPs and patients to check face validity. Face validity is the weakest form of validity test, measuring only that the questions "look valid" to the test persons (130). To more deeply validate if the questions reflected the constructs of ICE and patient-centeredness, psychometric testing of content validity could have been used (130). Further, the sampling method could have resulted in selection bias, further weakening internal validity. Receptionists at the different centers were given the instruction to invite as many participants as possible. There was no randomization, meaning that the receptionists could have chosen people who seemed more willing to participate, potentially those with a more positive view of their care. In Study II, credibility was ensured by including researchers from different disciplines (family medicine, nursing, social work and health care research) which ensured triangulation when developing the interview guides and analyzing data. Also, all researchers in the group had worked with patients with multimorbidity, and two of the researchers (ME and MF) also had studied this group of patients. This prolonged engagement further increased credibility. To separate our own experiences from those of the study participants, we performed peer-debriefing with two other groups of researchers (one in health care implementation and one in multimorbidity), who gave their comments on the results. On the other hand, no participants in the study were asked to give feedback on the results. Such

feedback would have increased the certainty that the analyses had captured what the participants really meant.

Applicability is evaluated through *external validity* or *generalizability* in quantitative research, and through *transferability* in qualitative research. In Study I, all centers included in the study were situated in an area of Stockholm with high socioeconomic levels, making external validity weak. As discussed, the high level of perceived SDM could be a result of this factor. Study II focused on patients with multimorbidity and complex needs. To achieve transferability, patients who had recently been hospitalized for their diseases or were included in a telemedicine program were included in the study. On the other hand, the frailest patients, those with cognitive impairment and dementia, were not included, nor were patients living in nursing homes. Interviews with the participants in urban areas raised questions about the use of e-health to support self-management. Therefore, a mixed qualitative method that made it possible to supplement with data from the rural area was used (131). To further increase transferability, the different settings were described in as much detail as possible.

Reliability is the measure of consistency in quantitative design. Again, if the questionnaires had been psychometrically validated, reliability (if repeated measurements had given the same results) could also have been increased. In qualitative design, the term *dependability* is used for consistency. This refers to the ability to account for the changing conditions of the phenomenon studied, and also for the research process. Through the use of memos that were discussed within the research team, the dependability in Study II was increased. Everyone in the team could follow each other's thoughts throughout the process.

Last, but no less important for trustworthiness, is neutrality. In quantitative research, this is measured through *objectivity*, whereas *confirmability* is the qualitative measure. Confirmability refers to the neutrality of data, and not that of the researcher who interacts with the participants. Conclusions drawn from a study must be based on the data. As I am a physician using and teaching the consultation method investigated in Study I, who works with patients with multimorbidity, neutrality was of particular importance. In both studies, researchers came from different disciplines which ensured that more than one perspective was applied when discussing the findings. In Study II, when qualitative data were analyzed, triangulation was essential for confirmability.

7 CONCLUSIONS

The overall conclusion of this thesis was that HCPs and patients need to find common ground in consultations. Finding common ground could reduce misperceptions of patients' experiences (Study I) and enable individualized support for self-management (Study II). Patient-centered communication that takes the patient's entire agenda into account could enable HCPs and patients to find this common ground because it can give the HCP an understanding of the patient's concerns, capacities, needs, and preferences. A trustful HCP-patient relationship facilitated patient-centered communication. Individualized consultation time could also help, as some patients needed more time than others. Additionally, the finding that HCPs and patients could have different health-related goals underscores the importance of goal-setting that takes both clinical goals and the patient's own goals into account.

Additionally, the findings of Study II suggest that to support patients' self-management, HCPs should be aware of their own and patients' preferences and views of responsibility for self-management, as these may vary. Patients' self-management abilities are also individual. For patients with higher abilities, HCPs may be able to play a less controlling role and empower patient self-management. For patients with lower self-management abilities, HCPs may need to take more responsibility, for example, in symptom monitoring. These patients may also need more support from their FCs and other caregivers.

8 IMPLICATIONS FOR HEALTH CARE AND FOR FUTURE RESEARCH

The findings of this thesis indicate a need for ongoing training in patient-centered communication and SDM. This training should be provided to all HCPs and should give them skills that support their abilities to achieve shared understanding with patients. The training should also help them educate patients, including assessing what patients are taking home from the consultation. Earlier studies have shown that using teach-back questions may increase patient satisfaction, knowledge, and self-efficacy (132,133). Future studies could focus on the effects of teach-back questions on concordance and HCP satisfaction with consultations.

Priority should be placed on developing guidelines for managing multimorbidity and supporting self-management in patients with multimorbidity. The guidelines should focus on personal continuity, individualized consultation length, and multidisciplinary care. PHC should take the lead in providing patient-centered care to this group of patients, and to do so, needs to be provided with the prerequisites to deliver such care. One such prerequisite is recruiting more physicians to work in PHC to provide care for the growing number of older patients. Another is to organize care in multidisciplinary teams.

Although data on telemedicine were limited in this thesis, the findings suggest that telemedicine tools have the potential to support patient self-management. Future work could focus on tailoring these tools to better meet the individual needs of patients with multimorbidity. The tools could add functions for setting joint goals and giving feedback to patients to strengthen their self-management. Information sharing and care coordination could be enhanced with a built-in ability to include multiple caregivers. Future research could provide more information on how to best use telemedicine tools to support patients with multimorbidity.

Future multimorbidity research could focus on how patients' experiences of living with multimorbidity are affected by self-management interventions. These studies could include quantitative data on how much time patients spend on self-management. They could also provide qualitative data on how much attention patients focus on their diseases and how their treatment burden is affected by such interventions.

9 SAMMANFATTNING PÅ SVENSKA

Trots att många studier visar kostnadseffektivitet och positiva hälsoutfall av patientcentrerad vård, tyder enkäter på att det är långt kvar till att nå målet med att involvera patienter i sin vård. Detta gäller särskilt vården av äldre personer med kroniska sjukdomar. Det finns i Sverige också ett mål om fast vårdkontakt i primärvården. Samtidigt visar en nyligen utkommen rapport att endast 35 procent av Sveriges invånare uppger sig ha en fast vårdkontakt i primärvården.

Resultatet i det här licentiatarbetet lyfter just vikten av långvariga tillitsfulla relationer för äldre personer för att möjliggöra patientcentrerad vård.

Patientcentrerad vård utgår från patienternas perspektiv och tar hänsyn till deras individuella förutsättningar, behov och önskemål. Med en åldrande befolkning lever allt fler personer med mer än en kronisk sjukdom. Benämningen för att ha mer än en kronisk sjukdom är multisjuklighet. Trots att multisjuklighet ökar i vår del av världen är vårdriktlinjer fortfarande utformade för att hantera enskilda sjukdomar. Om vårdgivare följer var och en av de enskilda riktlinjer som finns för varje kronisk sjukdom en patient har, riskerar dessa riktlinjer att motverka varandra. Det kan innebära mediciner som krockar med varandra eller egenvårdsråd som blir motsägelsefulla och ibland övermäktiga för patienter, särskilt när de är äldre och sköra.

Målet med det här licentiatarbetet var att utforska hur kommunikationen mellan vårdgivare och patienter ser ut i primärvården idag och hur vårdgivare kan ge egenvårdsråd på ett bättre sätt till äldre personer med multisjuklighet. Vi har för det ändamålet genomfört två studier i primärvården. I bägge studierna har vi valt att ha med både vårdgivare och patient för att fånga respektives perspektiv av kommunikationen, och i studie två har vi också tagit med anhöriga.

Den första studien var en enkätstudie som genomfördes i norra Stockholm med 596 deltagare. I studien ingick allmänläkare, distriktssköterskor, sjukgymnaster och patienter i vuxen ålder. Efter att patienter besökt någon av dessa vårdgivare fick både patient och vårdgivare svara på enkäter som handlade om huruvida patientens egna tankar, önskemål och eventuella oro kom fram vid besöken, samt hur patientens upplevelse av besöken var. I den andra studien ingick 42 deltagare. Studien handlade om erfarenheter av egenvårdsråd till multisjuka och genomfördes i form av en intervjustudie. Både fokusgrupper med läkare och individuella intervjuer med sjuksköterskor, patienter och anhöriga användes i studien. Den utfördes i både storstad och på landsbygd. Vi analyserade studien med innehållsanalys.

Huvudfyndet i de två studierna var att både vårdgivares och patientens perspektiv behövs för att uppnå samstämmighet vid primärvårdsbesök. I den första studien fann vi att huvudparten av patienterna upplevde att de fick uttrycka sina tankar om orsaken till sina besvär, medan bara en minoritet uttryckte oro vid besöken. Även om patienterna överlag var nöjda med besöken, fann vi en skillnad mellan vårdgivares och patients svar i enkäterna; vårdgivare

underskattade överlag patientens nöjdhet. I studie två av multisjuka fann vi att när vårdgivaren kände till patientens önskemål, kunskapsnivå och kapacitet kunde egenvårdsstödet individualiseras. Kännedom om patienten underlättades av patientcentrerad kommunikation och tillitsfulla relationer. Utifrån synen på ansvar, förmågan att ta ansvar och önskemål från patienten, kunde stödet individualiseras. I vissa fall behövde vårdgivaren ta huvudansvaret att hjälpa patienten att ta hand om sina sjukdomar, medan de i andra fall kunde lämna över till patienten själv att ta huvudansvaret.

Sammanfattningsvis fann vi att när vårdgivare och patienter når samstämmighet i möten minskar det risken för missförstånd och ökar chansen för vårdgivare att ge ett individanpassat egenvårdsstöd. Samstämmighet nås genom patientcentrerad kommunikation som tar hänsyn till hela patientens agenda vid besöken. Det möjliggör en gemensam förståelse för problemen och därmed ett delat beslutsfattande. Genom tillitsfulla relationer ökas möjligheten för patienter att involveras i sin vård.

Fyndet i den här licentiatavhandlingen ger stöd för målen om patientcentrering och om fast vårdkontakt i primärvården, särskilt till äldre multisjuka. En annan slutsats var att det finns ett behov av att ytterligare träna vårdgivare i patientcentrerad kommunikation för att uppnå delat beslutsfattande med patienter.

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12 ADDITIONAL FILES

Additional file 1. Patient version of questionnaire in Swedish, Study I.

FÖRESTÄLLNINGAR, FARHÅGOR OCH FÖRVÄNTNINGAR

KONSULTATIONENS HÖRNSTENAR

- en kvantitativ och kvalitativ studie i primärvården i Sverige

| | | | |
|-------------|--------------------------|--------------------------|--------------------------|
| Kön | <input type="checkbox"/> | <input type="checkbox"/> | |
| | man | kvinna | |
| Ålder | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | 20-49 år | 50-70 år | över 70 år |
| Modersmål | <input type="checkbox"/> | <input type="checkbox"/> | |
| | svenska | annat språk: | |
| Besöksorsak | | | |

FÖRESTÄLLNINGAR

1. Vad har du för tankar och förklaringar kring vad Dina symtom kan bero på och hur det kan behandlas?

.....
...
.....
...

2. Kom Dina egna tankar och förklaringar kring Dina symtom fram vid besöket?
(- ringa in ett av nedanstående alternativ)

Ja Delvis Nej Vet ej

3. Fick Du svar på Dina frågor om Ditt hälsotillstånd?

Ja Delvis Nej Vet ej

4. Var har Du hämtat information kring Dina föreställningar vad besvären beror på?
(- flera alternativ kan fyllas i)

1. Internet
2. Litteratur
3. Andra personers uppfattning

4. I sjukvården
5. Övrigt.....

FARHÅGOR

5. Finns det något Du är rädd för som Du tror kan orsaka Dina symtom/besvär?

Ja Delvis Nej Vet ej

- och i så fall vad?

.....
...

6. Är det något kring utredning eller behandling som Du känner oro/rädsla inför?

Ja Delvis Nej Vet ej

- och i så fall vad?

.....
...
.....
...

7. Har Du uttryckt Din oro/rädsla vid besöket?

Ja Delvis Nej Vet ej

8. Är det något speciellt du oroat dig för i övrigt och som du ville ha svar på vid besöket?

Ja Delvis Nej Vet ej

- och i så fall vad?

.....
....
.....
....

FÖRVÄNTNINGAR

9. Hade Du några förväntningar angående besked om orsak/förklaring till Dina symtom?

Ja Delvis Nej Vet ej

- och i så fall vilken/vilka förväntningar?

.....

...

.....

...

10. Kände Du Dig respekterad och tagen på allvar för Dina symtom/besvär?

Ja Delvis Nej Vet ej

11. Har Dina förväntningar på besöket uppfyllts?

Ja Delvis Nej Vet ej

12. Markera på skalan nedan i vilken grad Dina förväntningar uppfyllts vid besöket
(-ringa in en siffra där 0 betyder inte alls och 10 helt och hållet)

0 1 2 3 4 5 6 7 8 9 10

13. Fick Du hjälp med det Du förväntade Dig vid dagens besök?

Ja Delvis Nej Vet ej

14. Är det något särskilt du saknat som Du tänkt skulle göras vid besöket idag?

Ja Delvis Nej Vet ej

- och i så fall vad?

.....

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.....

...

15. Vad har Du för förväntningar på den fortsatta vården och omhändertagandet?

.....

...

.....
...

NÖJDHET

16. Är Du nöjd med bemötandet vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

17. Fick Du tillräcklig information vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

18. Kände Du Dig delaktig i de beslut kring eventuell utredning och behandling som togs vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

19. Fick Du tillräckligt känslomässigt stöd vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

20. Är Du nöjd med besöket som helhet?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

21. Markera på skalan nedan hur nöjd Du är med besöket som helhet.

(-ringa in en siffra där 0 betyder inte alls och 10 helt och hållet)

0 1 2 3 4 5 6 7 8 9 10

22. Är Du nöjd med omhändertagandet i övrigt på vårdcentralen?

- 1. Ja, helt
- 2. Ja, delvis
- 3. Nej, bara delvis
- 4. Nej, inte alls
- 5. Vet inte

Övriga synpunkter och förslag till förbättring av vården:

.....

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Tack för Ditt bidrag!
141204

Eivor Wiking

5. Upplever Du att patienten känt/känner oro/rädsla kring tänkbar orsak till besvären?

Ja Delvis Nej Vet ej

6. Upplever Du att patienten känt/känner oro/rädsla inför eventuell utredning eller behandling?

Ja Delvis Nej Vet ej

7. Har patienten uttryckt sin rädsla vid besöket?

Ja Delvis Nej Vet ej

8. Har det framkommit något speciellt patienten oroat sig för i övrigt och som han/hon vill ha svar på?

Ja Delvis Nej Vet ej

FÖRVÄNTNINGAR

9. Har patienten uttryckt förväntningar angående besked om orsak/förklaring till sina symtom?

Ja Delvis Nej Vet ej

10. Upplever Du att patienten kände sig respekterad och tagen på allvar för sina symtom/besvär?

Ja Delvis Nej Vet ej

11. Tror Du att patientens förväntningar på besöket uppfyllts?

Ja Delvis Nej Vet ej

12. Markera på skalan nedan i vilken grad Du tror att patientens förväntningar uppfyllts vid besöket

(-ringa in en siffra där 0 betyder inte alls och 10 helt och hållet)

0 1 2 3 4 5 6 7 8 9 10

13. Tror Du att patienten fick hjälp med det han/hon förväntade sig av dagens besök?

Ja Delvis Nej Vet ej

14. Har patienten uttryckt något särskilt i övrigt som han/hon tänkt skulle göras vid besöket idag?

Ja Delvis Nej Vet ej

- i så fall vad?

.....
.....
...

15. Har det framkommit vad patienten har för förväntningar på den fortsatta vården och omhändertagandet?

Ja Delvis Nej Vet ej

- i så fall angående vad?

.....
.....
.....

NÖJDHET

16. Är Du nöjd med Ditt eget bemötande vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

17. Gav Du tillräcklig information vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

18. Kände Du att patienten var delaktig i de beslut som togs vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

19. Upplevde Du att Du gav tillräckligt känslomässigt stöd vid besöket?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls
5. Vet inte

20. Tror Du att patienten är nöjd med besöket som helhet?

1. Ja, helt
2. Ja, delvis
3. Nej, bara delvis
4. Nej, inte alls

5. Vet inte

21. Markera på skalan nedan hur nöjd Du tror att patienten är med besöket som helhet.

(-ringa in en siffra där 0 betyder inte alls och 10 helt och hållet)

0 1 2 3 4 5 6 7 8 9 10

22. Är DU nöjd med besöket som helhet?

- 1. Ja, helt
- 2. Ja, delvis
- 3. Nej, bara delvis
- 4. Nej, inte alls
- 5. Vet inte

23. Markera på skalan nedan hur nöjd Du är med besöket som helhet.

(-ringa in en siffra där 0 betyder inte alls och 10 helt och hållet)

0 1 2 3 4 5 6 7 8 9 10

Övriga synpunkter och förslag till förbättring av vården:

.....
...
.....
...
.....
...

Tack för Ditt bidrag!

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