INTRODUCTION

Patient-centred care has been increasingly adopted as a way to improve the (experienced) quality of care by addressing paternalism in the provision of health care. Following this approach, individual patients’ preferences and needs are the central focus of care services. Various initiatives have been undertaken to include patients’ experiential knowledge in health-related decision-making processes at both an individual and a collective level. Where patient involvement at an ‘individual level’ is focused on patients’ own care, ‘collective involvement’ focuses on care services in general. Studies show, however, variable progress regarding patient involvement and many cases of tokenism in which involvement becomes a box-ticking exercise. Obtaining the successful involvement of patients requires a ‘meaningful’ dialogue between patients and health professionals in which patients act as partners in knowledge co-creation processes. In these processes, different types of knowledge are made explicit (knowledge articulation), integrated (knowledge integration) and implemented in health services and innovations (knowledge embedment). Within the knowledge integration process, stakeholders obtain insight into each other’s perspectives and underlying assumptions. As a result, learning could take place substantially on a topic (single-loop learning), on the underlying norms and values (double-loop learning) and on the learning process itself (triple-loop learning). Through these learnings, a patient-centred approach could be further facilitated, leading to patients’ increased empowerment. Within the scope of this thesis, empowerment is seen as a process of gaining power and capacities to make-informed choices. The empowerment of patients and health professionals is at the same time expected to be helpful in becoming confident in taking up new roles and tasks, necessary for establishing partnerships in which knowledge is co-created.

While the importance and relevance of the concepts of patient-centred care, patient involvement and empowerment have been widely acknowledged, there has been limited theoretical exploration of the relationships between the concepts. In addition, empirical studies tend to focus on one of the relationships. To better understand in which conditions patient involvement – in the form of knowledge co-creation – and empowerment could enhance patient-centred care, insights into the relationships between these concepts are needed. Knowledge about the relations between patient-centred care, patient involvement and empowerment, could improve the quality of these relations, creating a self-reinforcing effect towards patient-centred care. Therefore, this thesis has been guided by the following main research question: How can knowledge co-creation and empowerment processes enhance patient-centred care?
METHODS

This main research question was answered by studying three sub-research questions:

1. How can knowledge co-creation support patient-centred care, and vice versa?
2. How can knowledge co-creation strengthen patient empowerment, and vice versa?
3. How can health care professional empowerment strengthen knowledge co-creation and patient empowerment?

These research questions were studied through a transdisciplinary multiple case study approach. Five cases (described in more detail below) were conducted in the Netherlands. Within the case studies, patients and health professionals were involved in the decision-making processes regarding the research by using the principles of different participatory approaches. To collect the data for the five case studies, primary qualitative research methods were employed. The qualitative data was in some cases complemented with quantitative data when found to be necessary to validate the qualitative findings among a larger patient group.

Overview case studies

The first case study – discussed in Chapter 4 – aimed to obtain insights into the experiences and needs of parents with a child with Congenital Diaphragmatic Hernia (CDH) living in the Netherlands. Through this study insights were obtained into how parents articulated the care needs of their children with CDH and their ideas for improvement. In addition, this study enhanced our understanding on the empowerment of patients’ parents, necessary for ensuring that the care is centred on the needs of their children. The articulated knowledge on patients’ experiences and needs were integrated via discussions with the research team and resulted in recommendations for improvement measures. Attention was given to embedding these measures into clinical guidelines.

The aim of the second case study – described in Chapter 5 – was to provide recommendations on how to better align maternity care services with women’s needs. The perspectives and experiences with maternity care and the level of client-centred care of women who gave birth in the North-West Netherlands were analysed. This study provided insights into what client-centred maternity care means based on clients’ articulated perspectives on good quality care. In addition, clients’ ideas for improvement and about how their empowerment could play a role in ensuring these improvements were highlighted. The articulated knowledge was discussed with a project manager of the Network Birth Care North West Netherlands and presented at a conference to maternal health care professionals in the region.

The third case study – see Chapter 6 – aimed to acquire insights into how patients can be meaningfully involved in Care Pathway Management (CPM) by monitoring and evaluating the implementation of patient involvement in co-creating CPM for the disease types Sarcoma and GIST at Erasmus Cancer Institute in the Netherlands. Throughout the study, reflection was stimulated on both the care pathways and the development process, with a goal of overcoming expected and encountered barriers to involving patients in knowledge co-creation processes. Patients’ articulated
improvements for current care pathways were integrated with health professionals’ perspectives during co-creation sessions and embedded into the CPM process and a grant proposal. In addition, insights were obtained into how patients and health professionals could be empowered to involve patients in co-creating CPM.

The fourth case study – described in Chapter 7 – aimed to offer insights into the development of an empowering educational intervention. An empowering patient-education intervention for urological (bladder, prostate and kidney) cancer patients in the Netherlands was co-created by patients and health professionals following the principles and guidelines of the participatory approach Interactive Learning and Action. Knowledge was articulated on patients’ and health professionals’ experiences with patient information and their empowerment needs. During co-creation sessions the different types of articulated knowledge were integrated in a blueprint for patient information. Subsequently, the information was embedded nationally via relevant websites, and locally via patient record systems of various Dutch hospitals.

The aim of the fifth case study - described in Chapter 8 - was to explore patients’ and health professionals’ needs to address sexual health in the context of Anorectal Malformations and Hirschsprung disease in the Netherlands. A second goal was to use this understanding to develop a tool that is aligned with patients’ and health professionals’ needs. To develop the tool, in the form of a website, the Participatory Action Research approach was used. The articulated knowledge of patients and health professionals was integrated into an empowerment product – in the form of a website – during co-creation sessions. The website was implemented nationally via the collaborating hospitals and by addressing the topic in the clinical guidelines.

RESULTS

Mutually reinforcing knowledge co-creation and patient-centred care

The case studies highlighted that knowledge co-creation processes led to more patient-centred care by providing services which were responsive to patients’ needs. Being responsive does not mean that the care services fulfil or exceed patients’ expectations, but that there is flexibility to adapt to patients’ individual needs at a particular moment. At an individual level, responsiveness to patients’ needs was realized when health professionals took patients’ background into account, communicated openly, showed a caring attitude, and provided continuous care within a cohesive team. However, in some cases patients felt they did not have a real choice in the care processes, for instance regarding the planning of transfers and treatment options or steps. At a collective level, the integration of patients’ articulated knowledge, enabled among others the formulation of specific improvement measures and empowering interventions that were in line with patients’ needs and therefore patient-centred. The areas of improvement were also used as an input to improve current clinical guidelines and care pathways. Consequently the clinical guidelines and care pathways were more in line with patients’ needs and therefore more patient-centred. These patient-centred guidelines and pathways are expected to improve patients’ empowerment at an individual level by increasing their knowledge and skills and improving their involvement in knowledge co-creation processes on a collective level. Patient involvement at an individual and collective level are
CONCLUSIONS

Thus, knowledge co-creation processes were found to be influenced by the extent to which patients’ needs were placed centrally through their involvement. Patient involvement at an individual level was regularly hindered because communication was lacking, unclear or not provided in a timely fashion. In addition, the difficulty of sharing perspectives or pose questions to health care professionals were described by patients as a barrier to become involved. Even though health professionals assume patients have the opportunity and feel free to ask questions and share their perspectives, stories showed that knowledge co-creation processes were frequently impeded because of limited involvement in care services. The use of questionnaires to evaluate patients’ satisfaction on the care services provided were often experienced by patients as a box-ticking exercise instead of truly listening to their feedback. The collective involvement of patients in the decision-making processes of the research were found to be successful. The facilitators created an atmosphere of trust, enabling patients to share their knowledge and provided time and opportunities to reflect on the articulated knowledge. In this way, facilitators were thus able to adapt to patients’ needs to become involved, thereby improving the knowledge co-creation processes.

Mutually reinforcing knowledge co-creation and patient empowerment

Regarding the second research question, the case studies showed that knowledge co-creation processes stimulated patients’ empowerment state through mutual learning. Patient involvement at an individual level – regarding their own care – increased their knowledge and skills regarding self-management, treatment options or caring tasks in the case of patients’ parents. The improved knowledge of and skills of patients and patients’ parents subsequently contributed to the extent to which they perceived personal control and thus felt empowered. Decision-aids helped patients to become more aware of their own values and needs. However, these aids were not consistently used, in a tokenistic way or only by patients themselves, hindering double- and triple-loop learning and consequently empowerment. The involvement of patients at a collective level - within the decision-making processes of the case studies - did stimulate, however, double- and triple-loop learning. Patients learned about their own and health professionals’ perspectives and assumptions (double-loop learning), enhancing their self-awareness and changing their attitudes. Patients also became more aware of their own knowledge and that their knowledge was additional to that of health professionals (and vice versa). Furthermore, patients learned about how they could be involved in knowledge co-creation and contribute (triple-loop learning). These learnings seemed to enhance patients’ perceived personal control and self-efficacy and thus their empowerment. The extent to which double- and triple-loop learnings took place were however limited compared to single-loop learning, hindering the embedding of the integrated knowledge as well as the structural involvement of patients.

Knowledge co-creation processes, in turn, were influenced by patients’ empowerment behaviours. Shared decision-making, information and help-seeking behaviour, influenced by patients’ empowerment ‘state’, enhanced their involvement at an individual level. Empowered patients were for instance able to ensure that an equal relationship was established by testing health professionals’ knowledge via other resources. At the same time, patients frequently felt unable to make an informed
decision because they were not sufficiently informed, resulting in a more reactive attitude during the consult. At a collective level, empowered behaviours of both individual patients and patient organizations improved knowledge co-creation processes. Conversational skills, the ability to think at an abstract level, knowledge of medical terms, and an assertive attitude were found to stimulate empowerment behaviours among patients visualized by posing questions, asking for explanations and articulating their knowledge. Conversely, less empowered behaviours, due to a lack of assertiveness or feelings of insecurity, hindered knowledge articulation and integration. Researchers’ facilitation of the process by reiterating knowledge, explicitly allowing patients to speak-up, helped patients to feel respected and to have the skills to play a more active role within the knowledge co-creation process. Patient organizations’ network and tools, such as an online forum through which members’ experiences could be collected, helped the organization to contribute in the knowledge co-creation process. A lack of time to consult grassroots’ support, however, hindered the validation of patients’ input among fellow-sufferers.

Relations between professional empowerment and knowledge co-creation

With regard to the last research question, the case studies highlighted that health professionals need new responsibilities and roles to establish a collaborative interaction (in which knowledge is co-created). In order to take up these responsibilities and roles, health professionals have the following empowerment needs: (1) knowledge; (2) reflection skills; (3) conversational skills; (4) rule orientation skills; (5) extended role perceptions; and (6) time. In relation to these needs, reflection is mentioned as a skill, but also as a desirable outcome reached through achieving some of the other empowerment needs. For example, health professionals need conversational skills and time to be able to have a reflective interaction with patients.

CONCLUSION

This thesis showed that three elements were essential for enhancing patient-centred care through knowledge co-creation and empowerment: (1) responsiveness, (2) mutual learning, and (3) empowerment behaviours. Based on the explored interrelation between patient-centred care, patient involvement (in knowledge co-creation) and empowerment, the Patient-Centred Care Enhancement Cycle (PCCEC) was set up. This model consists of a direct and indirect route to enhance patient-centred care. Following the direct route the empowerment of patients and health professionals could stimulate patient-centred care by introducing a culture in which placing the patient at the centre of care services is valued. Conversely, by placing patients’ needs more centrally, care services will be more empowering. The indirect route demonstrates that patient-centred care stimulates patient involvement in knowledge co-creation, which subsequently leads to more responsiveness towards patients’ needs and therefore patient-centred care. At the same time patient involvement in knowledge co-creation stimulates learning processes which enhance patient and health professional empowerment. Their increased empowerment stimulates empowerment behaviours, improving knowledge co-creation processes. Empowered health professionals could also directly stimulate patient empowerment by for instance providing education for patients. Patient-centred care can thus be enhanced indirectly by improving the quality of the process, serving as a guide for operationalizing the direct route.
To enhance patient-centred care in practice, I recommend that health care organizations empower health professionals to support patients to become involved in knowledge co-creation processes. At an individual level, health care organizations are advised to allocate time for joint decision-making processes, discussing psychosocial aspects of care and having interactive reflections. Health care organizations are also advised to allocate accountability for providing holistic care services and provide professional training on rule flexibility and reflecting on intersubjective dynamics. To involve patients at a collective level, I recommend that health care organizations allocate time for organizing and joining participatory reflections. In addition, professional training for improving conversational and reflection skills should be provided. Formally evaluating these skills could stimulate health professionals’ motivation to change. Patient organizations are advised to articulate patients’ knowledge by collecting their members’ experiences through, for instance, online forums, questionnaires or weblogs and support their members in becoming more empowered, for example by providing sample questions, mentioning possible opportunities and communicating success stories.

Through the research conducted for this thesis, I aimed to contribute to the transformation of the health care system towards patient-centred care. I hope that the insights of this thesis will be an inspiration to anyone who wishes to support the shift from physician-focused towards patient-centred care.