Parental involvement in children's healthcare decisions at the hospital

A health-promoting perspective

by

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Summary

Background: In many Western countries, parents have a legal right to be involved and influence children's healthcare decisions, ensuring that children's healthcare is shaped and customised as far as possible to meet the children's and their families' needs and preferences. It is expected that this kind of parental involvement increases patient safety and quality of care. Parental involvement in children's healthcare decisions has been an important area of health services in several countries for many years; however, it has not been sufficiently implemented in clinical practice.

Aim: This thesis' overall aim was to gain insight, from a health-promoting perspective, into parental involvement in decision-making about shaping and customising children's healthcare in an interprofessional hospital environment. The purpose was to enhance the knowledge on parental involvement in these decision-making processes and to identify areas for improvement. The research aims were as following:

1) To describe and establish a synthesis of previous research on parents' perceptions of their participation in decision-making and the challenges they face in healthcare services for children. (Paper I)
2) To explore parents' experiences on parental involvement in decision-making about their child's healthcare at the hospital and to identify how health professionals can improve parental involvement. (Paper II)
3) To explore and describe parents' experiences of how health professionals facilitate parental involvement in decision-making surrounding children's healthcare and to identify how health professionals can improve parental involvement in the hospital. (Paper III)
4) To explore health professionals' construction of the phenomenon parental involvement in decision-making about children's healthcare at

the hospital and identify how parental involvement can be improved. (Paper IV)

Methodology: This thesis uses an explorative, sequential, descriptive, qualitative design; is situated within a constructivist research paradigm; and involves four sub-studies (Paper I-IV). Sub-study 1 is a systematic integrated review on literature, published from January 2000 to February 2011, concerning research aim 1). This review was conducted according to Whittemore and Knafl's framework. Sub-studies 2 through 4 are explorative, descriptive, qualitative studies involving individual semi-structured interviews. Sub-studies 2 and 3 comprise a purposive sample of 12 parents. Qualitative content analysis was performed according to Graneheim, Lindgren and Lundman. Sub-study 4 recruited 12 health professionals using a purposive selection procedure. The construction of the phenomenon in the interviews was analysed according to Silverman. The cultural stories were then interpreted and organised using Graneheim et al.'s qualitative content analysis.

Findings: This thesis contributes new insights into parents' and health professionals' roles during decision-making about shaping and customising children's healthcare at hospital. Parents' personal factors seemed to influence their involvement; however, health professionals' individually tailored facilitation of parental involvement appeared to empower the parents and increase active engagement. The health professionals' attitudes and competencies seemed to influence how they involved the parents. Important elements that seem to improve parental involvement included empathetic communication, confidence in the health professional-parent relationship, high-quality intra- and interprofessional collaboration and adequate organisational resources.

Conclusion: This thesis highlights the complexity of shared decision-making about children's healthcare, including parents' and health professionals' essential, demanding roles. These roles need to be

supported according to family-centred care, the World Health Organisation's health promotion strategy and the biopsychosocial theory. The foremost responsibility of healthcare managers is to facilitate health professionals' parental involvement and arrange for adequate organisational resources. Furthermore, this thesis provides new knowledge of how health professionals' practice of shared decision-making in paediatric clinical settings influences parents' ability to cope with their parental role and the quality of their children's healthcare. Increased understanding of involving both the paediatric patient and parents in these decision-making processes is required to safeguard the paediatric patients a technical, safe and justifiable healthcare that is in keeping governmental directives, evidence-based practice and the biopsychosocial theory.

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List of abbreviations

DM = decision-making
FCC = family-centred care
GRR = generalised resistance resources
SOC = Sense of coherence
WHO = World Health Organisation

1 Introduction

This thesis, taking a health-promoting perspective, explores parental involvement in decision-making (DM) over how to shape and customise children's healthcare in hospital. In many Western countries, parents have a legal right to be involved and influence their children's healthcare decisions (Edwards, Davies, & Edwards, 2009; Smith, Swallow, & Coyne, 2015). It ensures that children's healthcare is shaped and customised as far as possible to meet the children's and their families' needs and preferences (Shields, 2010). This kind of parental involvement is intended to increase patient safety and quality of care (Elwyn, Frosch, & Kobrin, 2016; Khan et al., 2017). It is in accordance with patient-centred care, family-centred care (FCC) and patient involvement in healthcare decisions (Edwards et al., 2009; Elwyn et al., 2014; Smith et al., 2015). Though parental involvement in children's healthcare decisions has been an important area in health services in Western countries for many years, it was reported that such parental involvement was not sufficiently implemented in clinical practice (Espezel & Canam, 2003; Hallström, Runeson, & Elander, 2002; Jolly & Shields, 2009).

Before I began planning this research programme, I worked as a paediatric physiotherapist at a university hospital for many years. During my clinical practice, I experienced that parents, who participated actively in shaping their child's physiotherapy programme, also more actively assisted the performance of the programme. In addition, they seemed more satisfied with the physiotherapy programme, and the collaboration with them was enhanced. However, parental involvement in these DM processes was often more demanding when the parents were emotionally distressed. Furthermore, parental involvement in intra- and interprofessional settings was a challenging task when my colleagues practiced parental involvement differently than I did. The challenges especially concerned how and when parents should be involved in DM. Over the last few decades, the Norwegian government has increased their

emphasis on patient- and next-of-kin's involvement in healthcare decision-making together with evidence-based practice, patient safety and high-quality care in healthcare services. Based on my experiences, as paediatric physiotherapist, and according to government directives, I was highly motivated to find out how health professionals can improve parental involvement in children's healthcare decisions at hospital. Another contributing factor was the limited knowledge on this topic when I began my doctorate program in health and medicine.

1.1 Background

Since the 1970s, health-related DM has become more complex because of the introduction of biopsychosocial theories, evidence-based practice, patient involvement in healthcare decisions, increased specialisation, interprofessional practice, and advanced treatment methods in healthcare services (Lipstein, Brinkman, & Britto, 2012; Ofstad, Frich, Schei, Frankel, & Gulbrandsen, 2014; Solomons & Spross, 2011; Taylor, 2006; Wirtz, Cribb, & Barber, 2006). These changes have altered the roles of health professionals, patients and their close relatives in healthcare settings (Coyne & Cowley, 2007; Power & Franck, 2008).

Parents have become important partners in the shaping and implementation of children's healthcare in line with FCC (Harrison, 2010; Shields, 2010). As their children's user-representatives, they are responsible for consenting to health and medical examinations and treatments (Kon, 2010; Lipstein et al., 2012). They also have a right to be involved in decisions that concerns shaping and customising their children's healthcare until their children can fully represent themselves. In addition, they have an especially important role in implementing and continuing their children's healthcare, including taking care of their children's psychosocial needs (Harrison, 2010; Shields, 2010). Thus, it is of uttermost importance that parents cope with their parental role during their children's hospitalisation (Thallon, Kendall, & Snider, 2015b). This thesis focuses, therefore, on parental involvement in

children's healthcare decisions as viewed from a health-promoting perspective. This approach is in accordance with the World Health Organisation's (WHO) health promotion strategy, which recommends providing supportive environments in all sectors of society to promote people's coping and health (WHO, 2009).

Moreover, children have a right to be involved in their healthcare decisions, depending on and adjusted to their age and maturity (Coyne, Hallström, & Söderbäck, 2016). Although children's involvement is a significant matter, the focus of this thesis is limited to parental involvement in DM. Research on both parents' and children's involvement would have become too broad and complex to handle in a thesis due to scarcity of knowledge on the already complicated health professional-child-parent triad.

Health professionals are responsible for involving parents in children's healthcare decisions, no matter their cultural backgrounds, health literacy levels or socioeconomic statuses (Lown et al., 2011). However, DM processes are often complex in healthcare institutions with extensive intra- and interprofessional collaborations, such as in hospital paediatric wards (Lipstein et al., 2012; Ofstad et al., 2014). Health professionals must deal with multiple challenges and decisions simultaneously, and each DM may involve several professionals. Therefore, the DM process can take a long time (Elwyn et al., 2016; Ofstad et al., 2014), and the challenges can include organisational shortcomings, limited resources and ethical dilemmas (Bærøe, 2009; Légaré, Ratte', Gravel, & Graham, 2008). Furthermore, DM in the paediatric field differs from DM in adult healthcare due to children's growth, development and dependence on adults (Park & Choe, 2018). Accordingly, parental involvement in children's healthcare decisions at hospital may be particularly challenging for health professionals.

In Norway, patient-centred care and patient involvement in healthcare decisions have been an important area of interest nationally for many

years, and there are several governmental directives (The Norwegian Directorate of Social and Health, 2005; The Norwegian Ministry of Health and Care Services, 2011, 2012, 2014; The Norwegian Ministry of Social and Health Services, 1999). In National health and hospital plan (2015), patient involvement in healthcare decisions is placed great significance on achieving 'the patients' health service' and improving patient safety and quality of care. Accordingly, children's and parents' perspective, needs and user-involvement in DM must be addressed (Patients' Right Act, 1999; Regulations of children's hospitalisation, 2000). Therefore, health professionals in Norway are responsible for incorporating the preferences and qualifications of the parents and their children in healthcare decisions.

In this thesis, parental involvement in DM concerning children's healthcare refers to involvement of parents in shared DM as it pertains to shaping and individually customising their children's examinations, treatments and care. This process entails DM on how each examination and treatment should be performed on a specific child. These decisions are made when making the initial healthcare plan as well as considering adjustments. The decisions may concern special considerations for the child and the family, whether and how the parents will assist in implementing the healthcare procedures, whether and how to use coercion if the child opposes important examinations and treatments, scheduling healthcare appointments and implementing interprofessional healthcare plans. Such decisions may be particularly important for the child and the family (Elwyn et al., 2017).

A review of the previous literature on parental involvement in DM at hospitals revealed lack of knowledge on parental and health professionals' roles in DM (Fiks & Jimenez, 2010; Hallström & Elander, 2004; Lipstein et al., 2012; Shields et al., 2012). There was very little research on parental involvement from a health-promoting perspective and in an interprofessional context. Therefore, a deeper understanding of parental and health professionals' roles in children's healthcare DM at

hospital from a health-promoting perspective may provide important knowledge and implications for clinical practice that will strengthen the parents' involvement in DM and the quality of children's healthcare.

1.2 Research aim

The overall aim of this thesis was to gain insight, from a health-promoting perspective, into parental involvement in DM about shaping and customising children's healthcare in an interprofessional hospital environment. The purpose was to enhance the knowledge on parental involvement in these decision-making processes and to identify areas for improvement.

Four sub-studies, each with its own research aim, were designed to achieve the overall aim. They resulted in four papers that are labelled Papers I-IV and included in Part II of this thesis. The research aims were as follow:

1) To describe and establish a synthesis of previous research on parents' perceptions of their participation in DM and the challenges they face in healthcare services for children. (Paper I)
2) To explore parents' experiences on parental involvement in DM about their child's healthcare at the hospital and to identify how health professionals can improve parental involvement. (Paper II)
3) To explore and describe parents' experiences of how health professionals facilitate parental involvement in DM surrounding children's healthcare and to identify how health professionals can improve parental involvement in the hospital. (Paper III)
4) To explore health professionals' construction of the phenomenon parental involvement in DM about children's healthcare at the hospital and identify how parental involvement can be improved. (Paper IV)

1.3 Structure of the thesis

This thesis consists of two parts and is an article-based thesis with four papers. Part I contains six chapters. Chapter 1 offers the introduction, background, previous international research, description of the research aim and structure of the thesis. Chapter 2 presents key theoretical perspectives and relevant research. Chapter 3 describes the scientific theoretical approach, methodology and justifications for the chosen research design. Furthermore, the research context, ethical considerations and performance of the four sub-studies are included as well as a reflection on how to evaluate the research quality of the research programme. Chapter 4 follows with a presentation of the thesis' findings. In Chapter 5, the main findings and methodological considerations are discussed, followed by a discussion of the implications for clinical practice and future research. Finally, a conclusion is presented in Chapter 6. Part II contains the four research papers.

2 Theoretical Framework

This chapter presents the theoretical approaches used in the thesis to describe and understand parental involvement in children's healthcare decisions, including theory about patient involvement in healthcare decisions, interprofessional collaboration, FCC, health promotion, salutogenesis, sense of coherence, and biopsychosocial approach. Relevant international research literature is also included.

2.1 Patient involvement in healthcare decisions

Patient involvement in healthcare decisions has evolved since the 1970s, along with changes in health services practice and perceptions of health, disease and healthcare decisions (Charles, Gafni, & Whelan, 1997; Taylor, 2006). In health services practice, there has been a shift in dominance from 'acute care with one best treatment alternative' to a focus on 'long-term chronic care and mastery of illnesses' (Charles et al., 1997). In addition, the number of treatment alternatives has increased, and, thus, there has been a growing need to discuss with patients the benefits and risks of treatment alternatives (Charles, Gafni, & Whelan, 1999). Furthermore, the emphasis has changed from being on biomedical theories and paternalistic DM to biopsychosocial theories, patient-centred care and co-production of healthcare (Barry & Edgman-Levitan, 1998; Ostrom, 1996; Taylor, 2006). Consequently, the relationship between health professionals and patients has changed, and the healthcare DM processes have become more complex (Charavel, Bremond, Moumjid-Ferdiaoui, Mignotte, & Carrere 2001; Charles et al., 1999). Meanwhile, a consumer rights movement developed, which advocated patient autonomy and control as well as decrease in professionals' authority (Charles et al., 1997). Furthermore, evidence-based practice, which evolved from evidence-based medicine at The Cochrane Collaboration in the 1990s, has been included in all types of healthcare services and health professions (Kristiansen & Mooney,

2004). Evidence-based practice is clinical practice based on current research evidence, clinical expertise and practice, as well as patients' needs and preferences (Burns & Grove, 2011; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Accordingly, patients need to be involved in DM about shaping their healthcare, informing health professionals of their needs, values and preferences (Burns & Grove, 2011).

2.1.1 Decision-making models

Several treatment DM models have been developed, which focused on physician-patient interactions, information exchange and patient influence and power (Charavel et al., 2001; Wirtz et al., 2006). The models are grounded on different views of health professionals' obligations, ideals of professional behaviour, patient-professional relationships and frames of each roles' power and accountability (Wirtz et al., 2006). Well-known DM models include the paternalistic DM model, shared DM model and informed DM model (Thompson, 2007). The models' main differences concern how and the extent to which a patient is involved in the DM process.

In the paternalistic DM model, patients have little power and influence on the decisions made about their healthcare (Wirtz et al., 2006). They provide information about their health problem, and the professional takes the decision after carefully judging the information received from the patient, as well as after considering treatment alternatives and possible outcomes (Wirtz et al., 2006). In the shared DM model, the patient has moderate DM power and influence. Both the patient and the professional take active roles in sharing information, reaching consensus and taking the decision (Charles et al., 1997). This model is used when the patient is involved in medical decisions where there is more than one option (Elwyn et al., 2012). In addition, this model is relevant when involving patients in decisions about shaping their healthcare. However, Makoul and Clayman (2006) have presented eight communication themes that are key to achieving shared DM. The themes are

communication about the health problem, treatment option alternatives, the patient's values and preferences, the patient's coping abilities, the patient's understanding of option alternatives and outcomes, and making a shared decision. In contrast, in the informed DM model the patient is fully empowered to make the decision after he/she has received information about the options. It is presumed that the patient knows his/her values and preferences (Charavel et al., 2001). This model is often used when patients provide informed consent to medical examinations and treatments.

There are different challenges to implementing these DM models, which have been discussed for many years. Examples include: problems with balancing the professional's and patient's values, the influence of the professional's competencies on the DM process as well as how and when the patient should decide his/her degree of involvement in DM (Charavel et al., 2001; Légaré et al., 2008; Wirtz et al., 2006).

2.1.2 The concept of patient involvement in healthcare decisions

Through the years, patient involvement in healthcare decisions has become a broad, complex and dynamic concept (Entwistle & Watt, 2006; Thompson, 2007). Today, this topic includes several types of healthcare decisions, health professions and healthcare settings (Elwyn et al., 2017; Légaré et al., 2018; Ofstad et al., 2014). It is not limited to medical treatment decisions in a physician-patient encounter. Furthermore, the concept includes a broader set of factors, which influence patients' involvement in healthcare decisions (Edwards et al., 2009; Entwistle & Watt, 2006). Therefore, several models have been proposed that focus on different aspects of patient involvement in healthcare decisions.

Thompson's model of patient involvement in DM

Thompson (2007) presented a model combining patient-desired involvement in DM with a professional-determined level of

involvement. The model is based on Charles et al.'s (1997) models of patient involvement in DM and Arnstein's (1969) ladder of citizen participation with a power continuum. At one end of the continuum the patient has a high level of power and influence in DM, such as in the informed DM model. In contrast, at the other end of the continuum, the patient has little power and influence, such as in the paternalistic DM model. In between there is the shared DM model, in which the patient and the health professional have varying degrees of power and influence on DM. According to Thompson's model (2007), patient involvement in healthcare decisions is co-determined by the patient and health professional; it is influenced by the patient's preferences and characteristics, type and seriousness of illness, and relationship with the health professional. The co-determination of patient involvement occurs in the dialogue between the professional and patient as they share DM.

Research prior to this thesis reported that many parents preferred shared DM over providing consent for healthcare treatment and actions (e.g., immunisation) (Jackson, Cheater, & Reid, 2008; Lipstein et al., 2012), because they needed to choose their preferred level of participation in their children's healthcare decisions (Jackson et al., 2008). Parents' preferences for involvement seemed to depend on their demographic characteristics, emotional condition and competencies (Jackson et al., 2008; Lipstein et al., 2012). The type of health problem and parents' prior health service experiences were other influencing factors (Lipstein et al., 2012).

Edwards, Davies and Edwards' model of shared DM

Edwards et al. (2009) presented a model of how external factors influence information exchange and patient empowerment in shared healthcare DM processes. The model outlines several factors that hinder or facilitate the use of information and support in shared DM, depending on the patient's and professional's characteristics.

Health professionals are influenced by their technical competencies and professional attitudes. Furthermore, health literacy significantly influences patients' participation in DM. Health literacy is defined as the cognitive and social skills patients use when acquiring knowledge and information to make healthcare decisions (Nutbeam, 2009). Thus, health literacy is essential to patients' capacity to acquire knowledge and critically judge received information about the given topic of the DM (Edwards et al., 2009). Therefore, a patient's health literacy is a central influencing factor on how information is used in the DM context. Poor health literacy reduces patients' motivation to be active in healthcare DM, their understanding of received information, and their communication in DM. Consequently, some patients become 'informed patients' while others become 'non-users of information', depending on their health literacy. This implies that language barriers and cultural differences can influence the DM process.

This model describes how information use and exchange influence a patient's empowerment. An 'informed patient' usually holds increased power and control in shared DM, and, thereby, is empowered by the process; however, some patients chose to be 'non-empowered'. In other instances, health professionals 'disempower' patients by reducing their active involvement in DM. According to this model, health professionals greatly influence how active parents can become in their children's healthcare DM.

Several interventions, including DM aids, have been developed to assist health professionals as they try to improve patient involvement in shared DM. However, it is uncertain whether these interventions improve shared DM because there is little documented evidence (Légaré et al., 2018). Most of them focus on the health professional-patient dyad (Diouf, Menear, Robitaille, Guèrard, & Lègarè, 2016).

2.1.3 Interprofessional collaboration and shared decision-making

Parental involvement in children's healthcare decisions in paediatric wards at hospitals is often complex because of the extensive intra- and interprofessional collaborative practice (Lipstein et al., 2012; Ofstad et al., 2014). Intra- and interprofessional collaborative practice utilises collaborative processes to construct collective actions to meet the complexity of paediatric patients needs and build efficient teamwork (D'Amour, Ferrada-Videla, San Martin-Rodriguez, & Beaulieu, 2005). Interprofessional collaboration is defined as a process where different healthcare professionals work together to provide a qualitatively higher healthcare plan of action (Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017). The term interprofessional means involving different professions, whereas intra-professional refers to the fact that the team members come from the same profession. Interprofessional practice is influenced by organisational and interactional factors (San Martin-Rodriquez, Beaulieu, D'Amour, & Ferrada-Videla, 2005). Organisational factors include organisational structure, resources and leadership. Interactional factors involve interpersonal processes, such as trust, mutual respect and efficient communication. Regular interaction and negotiation between the involved professionals are required, where the expertise and contributions of the various professionals are respected and valued (Reeves et al., 2017). Furthermore, in clinical practice, healthcare teams may be constituted on an ad hoc basis, which increases the flexibility of the services (Bleakley, 2013). However, this practice increases the complexity of collaboration in clinical practices.

Interprofessional models to shared decision-making

In the literature, several interprofessional, shared DM models have been proposed. Some models focus on the interaction during shared DM, such as Elwyn et al.'s (2017) 'The three-talk model for shared DM'. The model presents a multistage consultation process with three different stages of talk: 'team talk', 'option talk' and 'decision talk'. Collaboration

and deliberation are emphasised during this consultation process. During 'team talk' the main task for health professionals is to elicit the patients' preferences and goals as they guide and support them. Regarding paediatric patient DM, these are parents' preferences, goals and perceptions of their child's preferences and goals. During 'option talk', the alternatives are compared, using risk communication principles. The last stage is 'decision talk', where the decisions that reflects the parents' informed preferences are made.

Other models focus more on factors that influence shared DM in interprofessional collaborative practice. Légaré et al.'s (2011) interprofessional model to shared DM consist of three levels: an individual (micro) level, an interprofessional healthcare team (meso) level and a higher healthcare system (macro) level. At the individual level, the patient or, in this context, the parent, and at least two healthcare professionals from different professions should collaborate, concurrently or sequentially, to achieve shared DM. During the DM process, reaching a common understanding of the optional alternatives and the influencing factors is emphasised. Therefore, the quality of collaborative communication during parental involvement in DM is important. Furthermore, the roles of a decision coach and next-of-kin are stressed. At the healthcare team level, emphasis is placed on the quality of the team's collaborative communication and the influence of their roles and organisational routines on an individual level. Thus, the model aims to strengthen parental involvement in DM and heighten the quality of the healthcare decisions by utilising the benefits of interprofessional collaboration (D'Amour et al., 2005). Factors that may negatively impact interprofessional collaboration include little knowledge within the team of different members' professional expertise, roles and responsibilities. Finally, the healthcare system, such as health services' organisation and structure, affects both the individual and the healthcare team.

Research on shared DM published prior to this thesis, mostly concerned the patient-professional dyad, generally overlooking the intra- and interprofessional context (Légaré et al., 2011).

2.1.4 Parental involvement in children's healthcare decisions

Parents are their children's user representatives in their healthcare decisions until the children can fully represent themselves (Lipstein et al., 2012; Patients' Rights Act, 1999). The purpose of this arrangement is to increase parents' influence on their children's healthcare decisions, ensuring that services are provided in accordance with their children's needs. Thus, parents provide consent, on their children's behalf, to health and medical examinations and treatments. Additionally, they are directly involved in shared DM about the shaping and customising of their children's healthcare. It must be ensured that the healthcare plan also fits parents' own capacities and needs since parents take part in the provision of healthcare, giving care and other forms of support to their children during hospitalisation (Regulations of children's hospitalisation, 2000).

Research prior to this thesis, reported that the opportunities vary for parents to be involved in their children's healthcare decisions (Hallström et al., 2002). In Norway, prior reports on user inquiries of parents' experiences, from somatic paediatric departments at hospitals and psychiatric outpatient clinics, showed that parents wanted to participate in their child's healthcare decisions more often than they had the opportunity to do (Bjertnæs et al., 2008; Groven, Danielsen, Holte, & Helgeland, 2006). In addition, they were displeased with the provision of information from their health professionals. These findings supported the necessity to conduct research in a Norwegian context to uncover areas for improvement in parental involvement in children's healthcare decisions.

New research reports that the concept of shared DM in the paediatric field is poorly understood, lacking a generally accepted definition (Park & Cho, 2018). Park and Cho (2018) defines shared DM in the paediatric field "as the active participation of parents, children and health professionals in reaching a compromise via collaborative partnership, with a common goal for child's health" (p. 482). According to their review, there are still few studies on shared DM that include the child, parents and health professionals. Nevertheless, Wyatt et al.'s review (2015) report that intervention strategies, such as 'decision aids' and 'decision coaching' in shared medical decisions with paediatric patients and parents, significantly improved knowledge and decreased decision conflicts. This review recommends using available interventions with caution because of a lack of evidence regarding outcomes.

2.2 Family-centred care (FCC)

Until the 1950s, children were usually hospitalised without their parents, often for long periods (Shields, 2010). Parents' presence, during children's hospitalisation, was regarded negatively in health services, despite younger children being affected by psychological distress and trauma (Davies, 2010). Over the years, the work of John Bowlby, James Robertson and Renee Spitz on the effects of child-parent separation influenced and changed healthcare practice (Jolley & Shields, 2009). Several care models in nursing based on the attachment theory, were developed to include the presence of parents, such as 'parental participation', 'care-by-parent' and 'partnership-in-care' (Jolley & Shields, 2009; Tallon et al., 2015b). These care models were precursors to FCC. Thus, attitudes, practice in healthcare and health policy changed. First, parents were allowed to visit their children at hospital (Coyne, 1996). Gradually they were incorporated in the care of their children. Today, parents are important partners in a partnership with health professionals (Uniacke, Browne, & Shields, 2018).

FCC called particular attention to the influence of stress on families during children's hospitalisation (Power & Franck, 2008). The concept emphasises that a child's healthcare should be planned and customised to fit the whole family (Shields, Pratt, & Hunter, 2006). The following definition of FCC is often mentioned:

> "Family-centered care (FCC) is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients". (Shields et al., 2006, p. 1318).

Thus, FCC emphasises parent-professional collaboration, negotiating parent's role in care and respecting the diversity of families (e.g., ethnic, cultural, socio-economic and coping resources) (Shields, 2010). According to FCC, parents should be involved in shared DM about shaping their child's care and the roles of parents and health professionals in providing that care (Corlett & Twycross, 2006).

Research prior to this research programme, reported that parental involvement in decisions about FCC was implemented insufficient in clinical settings (Corlett & Twycross, 2006; Foster, Whitehead, & Maybee 2010). Many parents perceived their parental role during their children's hospitalisation to be demanding, stressful and burdensome (Foster et al., 2010; Power & Franck, 2008; Shields, 2010). Coyne's (2007) research reported that parents felt that they were expected to participate in care and that the nurses determined how they should participate. However, nurses struggled to implement the principles of FCC because of a lack of resources and competence. Furthermore, the parents in that study were worried about their child's welfare because they were uncertain about how present the nurses would be. They were also concerned about how to provide the required care, because of a lack of guidance from the nurses (Coyne & Cowley, 2007). These findings are consistent with other research articles on FCC (Coyne, 2013; Shields,

2010). Accordingly, the parental role at the hospital had changed greatly from being excluded in the 1950s to being more active now feeling fully responsible for fulfilling children's care needs (Coyne & Cowley, 2007).

2.3 Health Promotion

The World Health Organisation of the United Nations was established in 1948 and was assigned the responsibility of human health issues, including health promotion (Lindström & Eriksson, 2010). Health promotion is, therefore, founded on the Human Rights. The term health promotion has been used since the 1970s, and involves interventions intended to prevent disease, promote health, and improve social and environmental factors affecting people's health (Naidoo & Wills, 2009). Several interventions have been attempted that promote health by fostering healthy lifestyles, facilitating access to services, involvement in health decisions, encouraging healthy choices, and offering health education (Naidoo & Wills, 2009). Most interventions were called health education and preventive medicine until the 1980s. In 1986, the Ottawa Charter defined health promotion as "the process of enabling people to increase control over, and to improve, their health" (WHO, 2009, p. 1). Since then, health has been defined broadly from a psychosocial perspective, so that it has been understood both as a resource and a means to creating conditions for a full life (Lindström, 2018). In addition, health has been viewed as a lifelong process.

Today, the focus is on contributing factors for promoting health across society and over the course of a lifetime (Lindström, 2018). This means promoting and maintaining health processes in all sectors of society by implementing the principles of salutogenesis (Eriksson & Lindström, 2008). That is, the community must take action to provide supportive health environments, facilitate people's efforts to take healthier choices, and empower people through their lives (Eriksson & Lindström, 2008; Naidoo & Wills, 2009). It is recommended that health promotion occur in dialogue between the people taking decisions over their life

circumstances and the professionals supporting them (Eriksson & Lindström, 2008). Accordingly, health professionals should practice health promotion by facilitating parental involvement in children's healthcare decisions. This is presumed to support parents as user-representatives for their children and promote parents' empowerment at hospitals and in their everyday lives.

2.3.1 The Concept of Salutogenesis

In the 1970s, Antonovsky (1996) developed the concept of salutogenesis, which is about generating, improving and maintaining health, in contrast to the pathogenic approach, which emphasises the causes and treatment of disease (Antonovsky, 2012; Lindström, 2018). The concept of salutogenesis focuses on peoples' dispositions and resilience to face life's challenges, and thus, it explores factors that promote health and coping throughout life. Today, the concept is broader and termed 'The salutogenic umbrella' (Lindström & Eriksson, 2010). The concept consists of several theoretical health approaches to understanding elements and resources for health and quality of life, including the Sense of Coherence Theory (Lindström, 2018).

Sense of Coherence Theory

Antonovsky (2012) based this theory on an epidemiological study of women who managed to have full lives, despite having suffered extremely stressful life events, including the Holocaust. Two key items include a 'sense of coherence' (SOC) and 'generalised resistance resources' (GRR). The SOC is a person's ability to use his/her resources as a coping capacity. Three dimensions indicate the extent of a person's orientation towards the world, with a perception of life as meaningful, understandable, and manageable, on a continuum from strong to weak SOC. The stronger the SOC, the more capable a person will be at mastering challengers. For example, under demanding conditions, a person with a strong SOC will be motivated to master the situation and will believe that he/she can understand the challenges and has resources

to meet them. GRR is defined as the resources a person has gained through mastering stressors in life (Antonovsky, 2012). The resources are, for example, a person's attitudes, identities, and knowledge. In addition, they entail the assistance a person may gather from his/her environment, such as social support and cultural and material resources.

Included in this theory is a collective SOC, which indicates how a society supports and promotes each individual's SOC (Lindström, 2018). Accordingly, it is important to create a supportive health environment, which all parts of a society promote life experiences that facilitate a strong SOC (Antonovsky, 2012; Eriksson & Lindström, 2007). Hence, health professionals ought to strengthen parents' sense of coherence by facilitating and supporting them during their involvement in their children's healthcare decisions. It is important to promote parents' meaningfulness, comprehensibility and manageability during the DM process.

This model is claimed to be universal and cross-cultural (Antonovsky, 2012). Furthermore, researchers report that people with strong SOC tend to live longer and have a better quality of life (Lindström, 2018).

2.4 The Biopsychosocial Theory

George Engel (1977) introduced the biopsychosocial theory in 1977. He claimed that health and illness are influenced by biological, psychological, and social factors in a complex, intertwined system. Health and illness are shaped by many factors; therefore, a disease can result in different outcomes. The term illness is understood as a personal experience, which is influenced by psychosocial and biophysical factors (Tyreman, 2015). Accordingly, an individual's health and illness cannot be assessed in an isolated biomedical dimension. Furthermore, Engel (1977) highlighted the importance of the physician-patient relationship during diagnosis and treatment, which affects patient outcome and compliance. The biopsychosocial theory is now generally accepted and associated with the practice of patient-centred care (Cheng, 2018; Wade

& Halligan, 2017). According to the theory, health professionals should consider patient's personal factors, such as their personality, emotional condition, stressful life events, and social and cultural context, during the diagnosis and planning of treatment and care (Karl & Holland, 2015). In addition, they should facilitate open communication and relationships with patients and next-of-kin. In the context of parental involvement in DM concerning children's healthcare at the hospital, health professionals should consider these influencing factors to improve the quality of children's healthcare.

However, the biopsychosocial theory has been criticised for lacking a concise theoretical framework and for being too complicated to apply in clinical settings (Papadimitriou, 2017). These issues may derive from the theory's multifactorial nature and Engel's use of the General Systems Theory (Tyreman, 2015).

3 Methodology

This chapter starts by presenting this thesis' scientific theoretical approach. Then, the description and justifications for the research design follow. Next, the research context, ethical considerations and performance of the sub-studies are described. Finally, a reflection on how to evaluate the quality of this research programme is presented.

3.1 Scientific theoretical approach

This research programme was designed within a qualitative, constructivist research paradigm (Lincoln, Lynham, & Guba, 2013). Qualitative research studies social phenomena in their natural settings with the use of different interpretive practices and research perspectives (Denzin & Lincoln, 2013a). This research approach emphasizes studying quality, processes and meanings of social phenomena (Denzin & Lincoln, 2013a). Accordingly, qualitative research was appropriate for this Ph.D. programme's research aim.

Qualitative research is an interactive process influenced by both the researcher's and participants' backgrounds, perceptions and values and influenced of theory (Denzin & Lincoln, 2013a; Silverman, 2016). It can be categorised into different interpretive paradigms, which differs about their perspective on ontology (e.g., the nature of reality), epistemology (e.g., the process of thinking, the relationship between the researcher and the known) and methodology (e.g., how to gain knowledge) (Denzin & Lincoln, 2013a). These assumptions influence the researcher's view of the world and how he/she performs research.

My epistemological and methodological point of view regarding research on people's experiences and opinions of social phenomena fits within the constructivist paradigm and a subjectivist epistemology. Nevertheless, I have a realist ontological point of view, with which I assume there is a real world, with objects and people, independent of

how researchers study it (Silverman, 2014). People act and interact in this world and co-construct meanings about reality, including phenomena. Their meanings are contextual and partial. Therefore, knowledge, theories, concepts and research findings are based on perspectives and values. Moreover, constructions of reality are ongoing processes influenced of history, culture and values (Denzin & Lincoln, 2013b). Reality is thus multiple and changes in a kind of relativist ontology. Nevertheless, my ontological and epistemological assumptions are very different from a radical constructivist view, which does not believe in the existence of any realities (Altheide & Johnson, 2013).

According to the constructivist paradigm, as applied to this thesis, knowledge is constructed in interactions between people in which meaning-making conversations are central (Denzin & Lincoln, 2013a; Holstein & Gubrium, 2016). Thus, in interviews both interviewer and participants actively construct accounts of the research topic (Silverman, 2014, Chapter 7). The interview accounts can be retrospective, causing participants to explain and justify their actions (Silverman, 2014, Chapter 7). This approach can provide information about participants' understanding and meanings of their experiences, bringing the research topic into focus. Moreover, the ways in which people understand and express their meanings are historically and culturally embedded. Therefore, interview texts can represent reality and provide insight into the interview context (Miller & Glassner, 2016). They can give access to the interactions and the cultural and normative perceptions and versions of reality that the participants use to understand and describe their social worlds (Miller & Glassner, 2016). Accordingly, interview texts show how participants make meanings and attach them to their experiences, statements and accounts of the research topic. Based on these assumptions, interviewing was the chosen data production method in three of this research programme's sub-studies.

Since the participants' meanings are historically and culturally embedded, the meanings they express of the research topic in the interviews reflect relatively lasting and recognisable meaning and opinion forms in the culture (Holstein & Gubrium, 2016).

Interview texts can be analysed through different approaches (Elo & Kyngäs, 2008). An inductive approach is recommended when there are no previous studies on the phenomenon or when knowledge is fragmented. This analysis is data driven, which means the researcher analyses concrete, specific phenomena from the interview text to derive abstract, general understandings, generating a new theoretical understanding of the phenomena (Graneheim, Lindgren, & Lundman, 2017). The inductive approach is useful as a theory and hypothesis-generating process (Alvesson & Sköldberg, 2008). When testing a theory or model in a new context, a deductive approach is applicable (Elo & Kyngäs, 2008). The researchers use the theory or model of a phenomenon during data analysis of new context. The deductive process moves from the general and abstract to the concrete and specific. Combining these analytical approaches is called the abductive approach, which is useful for achieving a more comprehensive understanding of a phenomenon (Alvesson & Sköldberg, 2008; Elo and Kyngäs, 2008). The abductive approach is relevant to this research programme because of scarcity of knowledge on the research topic and the aim of taking a health-promoting perspective. An inductive analytical approach is useful for arriving at a new theoretical understanding of the topic, and it will be followed by a deductive approach to applying the Sense of Coherence Theory in three sub-studies.

3.2 Research design

A review of previous research revealed scarce knowledge on the research topic. Furthermore, the context of the research phenomenon includes two main actors: parents and health professionals. They have different social status and roles and, therefore, different perspectives on the research

topic. Because of these conditions and a complex research topic, an explorative, sequential, descriptive design was chosen for the research project. The design has three phases, as illustrated in figure 1.

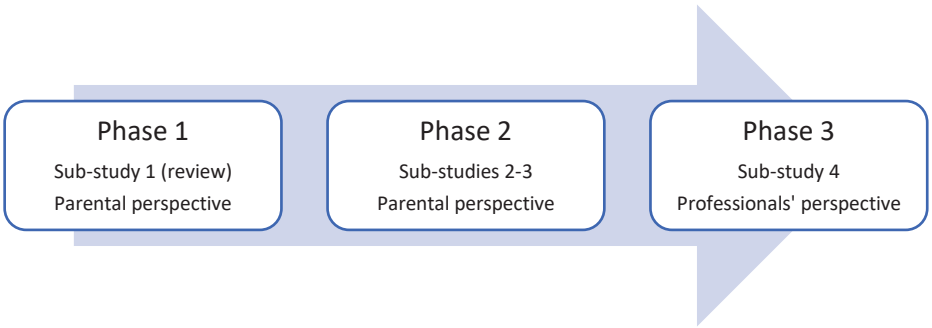

Figure 1. The research phases.

This research programme started with a systematic review (Phase 1) on parental involvement in DM about children's healthcare, from parents' perspective. Parents' perspective was chosen because we thought of parents as vulnerable actors in the context of DM about their children's healthcare in health services. Phase 2 was research on parental involvement in DM about children's healthcare, also from parents' perspective (sub-studies 2-3, Papers II-III). The last phase (Phase 3) was research on parental involvement from health professionals' perspective (sub-study 4, Paper IV); it succeeded sub-studies 2-3. This sequential explorative design should provide new knowledge from each of the main actors in this research context. Accordingly, the sub-studies build on each other, using the findings from the different sub-studies to design the one that follows, as illustrated in figure 2.

Paper I	**Parent participation in decision-making in health-care services for children: an integrative review**
Design	Systematic integrated review.
Aims	To describe and establish a synthesis of previous research on parents' perceptions of their participation in DM, and the challenges they face in healthcare services for children.
Sample	5 studies with quantitative, 8 studies with qualitative and 5 studies with mixed-method design.
Analysis	Identified, selected and synthesised research findings in previous studies according to Whittemore and Knafl's (2005) framework.

Paper II	**Parental involvement in decision-making about their child's healthcare at the hospital**
Design	Qualitative, individual semi-structured interviews.
Aims	To explore parents' experiences on parental involvement in DM about their child's healthcare at the hospital, and to identify how health professionals can improve parental involvement.
Sample	12 interviews, 12 parents with hospitalised children.
Analysis	Qualitative content analysis according to Graneheim et al. (2017).

Paper III	**How health professionals facilitate parents' involvement in decision-making at the hospital: a parental perspective**
Design	Qualitative, individual semi-structured interviews.
Aims	To explore and describe parents' experiences of how health professionals facilitate parental involvement in DM surrounding children's healthcare, and to identify how health professionals can improve parental involvement at the hospital.
Sample	12 interviews, 12 parents with hospitalised children.
Analysis	Qualitative content analysis according to Graneheim et al. (2017).

Paper IV	**Health professionals' involvement of parents in decision-making in interprofessional practice at the hospital**
Design	Qualitative, individual semi-structured interviews.
Aims	To explore health professionals' construction of the phenomenon parental involvement in DM about children's healthcare at the hospital and identify how parental involvement can be improved.
Sample	12 interviews, 12 health professionals with different professions.
Analyses	Analysed the construction of the phenomenon according to Silverman (2014). Organised and analysed the cultural stories with qualitative content analysis (Graneheim et al., 2017).

Figure 2. Sequential, explorative, descriptive design.

The semi-structured interview method with interview guides was chosen to construct the research phenomenon in sub-studies 2-4. The method allows the interviewer to use follow-up questions based on the participant's responses (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). The interviewer can then direct and promote the conversation in a flexible manner. If needed, the interviewer can probe or facilitate the nuancing of statements and in-depth descriptions. Furthermore, the participant has greater opportunities to influence the communication and express views in this style of interview. Thus, this data production method facilitates the interviewer and participant to construct rich, in-depth descriptions and accounts of the research phenomena dialectically.

3.3 Research context

The research context was a paediatric department at a university hospital in Norway. The department offered healthcare to children, from newborn to 16 years of age, during sub-studies 2-3 and up to 18 years of age, during sub-study 4. There was a neonatal ward, an infection ward, a general paediatric ward and an outpatient clinic during sub-study 2-3. Because of a reorganisation, there was a neonatal ward, a general paediatric ward and an outpatient clinic during sub-study 4. Approximately 3,500 children were hospitalised, and 13,000 received outpatient consultations each year. Interprofessional collaboration was emphasised at the department level implying that registered nurses, physicians, physiotherapists and dietitians worked in teams and collaborated on involving parents in DM about children's healthcare. Health professional were also responsible for involving parents in children's healthcare decisions within their respective areas of expertise.

3.4 Ethical considerations

The sub-studies were conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013). Sub-studies 2-4 were approved by The Regional Ethics Committee (2013/1603B) in Norway

and the university hospital's internal commission, the management of The Department of Paediatrics and the Director of research (Nov/Des. 2013).

The participants received both oral and written information about the study (Appendix 1 & 2). That information included the voluntary nature of participation and the ability to withdraw from the studies at any time. In addition, they were guaranteed confidentiality. Written informed consent was provided by all participants.

Participants' anonymity in Paper II-IV was ensured and that was through consideration about how to present the participants in the papers. In this regard, Paper IV was the most challenging. Since some of the professions had only a few positions, participants could be easily recognisable, therefore, little information was given about the participants in the description of the sample and in the findings section.

3.5 Sub-study 1 (Paper I)

A systematic integrated review was performed to establish a synthesis of previous research on parental involvement in DM about children's healthcare from parents' perspective (Burns & Grove, 2011). An integrated review was chosen to provide a comprehensive understanding of the research phenomenon and implications for further research (Whittemore, 2005). When searching the literature on parental involvement in DM about shaping and customising children's healthcare, we found no systematic review on the topic.

Previous independent studies containing diverse methodologies were identified, selected and synthesised, according to Whittemore and Knafl's (2005) framework. The review covered research studies, which include data sources related to parents' participation in DM about their children's healthcare in somatic healthcare services in Western countries from the period January 2000 to February 2011. Studies about informed

consent in terminal and palliative care, resuscitation, acute care, immunisation, and prenatal and natal screening and diagnosis were excluded. The reason was that these studies were about providing consent to healthcare, not about parental involvement in shaping their children's healthcare. There is a wealth of research studies about parental consent in these areas.

A systematic search was performed in several relevant, acknowledged research data bases, some relevant international journals, and the reference lists in relevant articles (Paper I). The included 18 studies were critically appraised, according to the guidelines for quantitative and qualitative research by Burns and Grove (2011, pp. 194-195, 202-203, 419-428, 443-446) (Paper I). Thus, the studies purposes, research themes, literature reviews, methods, results and conclusions were carefully judged using a form.

The analytical process involved data extraction, reduction, comparison and synthesis (Whittemore & Knafl, 2005). First, relevant data from the included studies were extracted, coded and organised into a group classification system with the following themes: 1) parent participation in DM, 2) parents' perceptions of their participation in DM, and 3) factors that may influence parents' role in DM. Second, the coded data were compared to identify patterns, themes and relationships based on three questions: 1) How do parents participate in DM in healthcare services for children? 2) What perceptions do parents have about their participation in DM? 3) Which factors seem to influence parents' participation in DM? This analysis resulted in a meaningful higher-order organisation of the data, such as relational factors, personal factors of parents, health professionals' attitudes, and parents' preferences. Then, the findings were synthesised into an integrative summary with three main themes (Paper I).

Accordingly, there was an abductive analytical process during research, using both inductive and deductive analytical approaches (Elo &

Kyngäs, 2008). The research questions and inclusion- and exclusion criteria were formulated after studying relevant literature on the research topic: a deductive process. The data extraction was also deductive. However, the data reduction, comparison and synthesis of the extracted text from the included studies were data driven, an inductive analytical process, which provided a new theoretical understanding.

Reflexivity on the research process

Preparing a systematic integrated review is a complex process because different research approaches, paradigms, objectives and theoretical perspectives are combined (Whittemore & Knafl, 2005). Systematic mistakes can be made in all phases of preparing the review, such as in the systematic search, inclusion of studies, data extraction and analysis. To counteract such mistakes, I used the strategy of Whittemore & Knafl (2005) in several phases, described below.

In the problem identification phase, the review's research question and inclusion- and exclusion criteria were formulated after a systematic study of relevant literature on the research topic. Well-formulated research questions and aims for the review promote the quality of reviews, especially during the systematic search, selection of studies and data extraction (Dixon-Woods, 2016; Whittemore & Knafl, 2005). In this regard, well-compiled inclusion and exclusion criteria were significant to conducting the research systematically.

In the literature phase, relevant studies were systematically searched and included, according to the inclusion and exclusion criteria. The research topic of the review was relevant to several subject areas: healthcare, medicine, psychology, pedagogic and sociology. Therefore, I performed the systematic search in data bases that contained articles covering all these areas (Paper I). The various databases had very different courses of action for search-delimiting. Thus, it became impossible to put the search findings (hits) from several databases together in new searches. This led to the same search-findings being entered in several data bases.

Consequently, the stated number of findings became large and a bit misleading. At that time, it was difficult to achieve high sensitivity and specificity in database searching (Whittemore & Knafl, 2005). First, the searches resulted in 1503 articles. Then, they were screened for relevance using the inclusion- and exclusion criteria (Paper I). This selection process resulted in 74 studies, then 55 studies, and ultimately in 18 studies.

In the data evaluation phase, the included studies were appraised for quality. The appraisal revealed varying degrees of focus on methodological procedures, limitations and ethical rigour. However, the appraisal of the included studies did not grade or range the findings based on quality demands. This was because we did not find any suitable method for studies with different scientific theoretical approaches and research methods (Whittemore & Knafl, 2005). Moreover, each study's influence on the synthesis was determined in the analytical process by other criteria, such as the study findings' importance for the research question. There is still no consensus on grading and ranging the quality of qualitative research studies (Dixon-Woods, 2016; Knafl & Whittemore, 2017).

The data analysis phase involved data reduction, display and comparison. The 18 included studies had great variation in objectives, variables, contexts and sample populations. During the data extraction phase, well-formulated research questions and review aims were particularly important to facilitating the extraction of relevant data. In the analysis and synthesis process, there were no special challenges to preparing the review and its credibility.

3.6 Sub-studies 2-4 (Papers II-IV)

This section starts with a short presentation of the methodology used in sub-studies 2-4. A comprehensive description follows for the recruitment of participants, sampling procedures, interviewing process and analysis.

3.6.1 Sub-studies 2-3

Two explorative, descriptive, qualitative studies were performed to explore parents' experiences on parental involvement in DM about their child's healthcare at the hospital (sub-study 2) and of how health professionals facilitate parental involvement in DM surrounding children's healthcare (sub-study 3). In addition, it was to identify how health professionals can improve parental involvement. A purposive selection procedure (Silverman, 2014, Chapter 3) resulted in twelve parents; sub-studies 2 and 3 used the same sample data. The parents participated in one individual semi-structured interview (Kallio et al., 2016), which was audio-recorded. In addition, the participants answered a demographic questionnaire to provide information on their backgrounds (Appendix 3). This information was useful when judging whether the inclusion- and exclusion criteria for the sample were met. The interview guide is attached as Appendix 4. The interview data were organised manually using the data management system, NVivo 10 (Bazeley & Jackson, 2013), and were analysed using Graneheim et al.'s (2004, 2017) qualitative content analysis (Paper II-III).

3.6.2 Sub-study 4

An explorative, descriptive, qualitative study was performed to explore health professionals' construction of the phenomenon parental involvement in children's healthcare decisions at the hospital. Another aim of the study was to identify how parental involvement can be improved. My intention was to provide insights into important cultural and normative topics related to parental involvement that may concern health professionals at the hospital. Therefore, I explored how health professionals constructed the phenomenon in interviews and implications for clinical practice. Accordingly, the term 'construct' is used in the research question, as it often is in the constructivist paradigm (Silverman, 2013).

The participants were selected using a purposive selection procedure (Silverman, 2014, Chapter 3). Twelve health professionals from different health professions, participated in an individual semi-structured interview, which was audio-recorded (Kallio et al., 2016). The participants answered a survey with demographic questions to provide information on their backgrounds (Appendix 5). The interview guide is attached (Appendix 6). The analysis of the interviews consists of two main parts. The first part offers an analysis of the construction of the phenomenon in the interviews based on the interactions and construction of accounts (Silverman, 2014, Chapter 15). It is followed by an interpretation of the participants' expressed meanings, conjuring cultural stories of the phenomenon. In the second part, the participants' expressed meanings were organised and analysed according to Graneheim et al. (2017) qualitative content analysis (Paper IV).

3.6.3 Recruitment of participants and sampling

A purposive selection procedure was used to gather participants at a university hospital in Norway for sub-studies 2-4 (Silverman, 2014, Chapter 3). Inclusion and exclusion criteria, (Papers II-IV), were used to ensure that selected participants had relevant experience and knowledge about the research topic and that there would be variation in data.

Recruitment of participants to sub-studies 2-3

Nurses, from the paediatric wards at the hospital, recruited parents who met the inclusion criteria to participate in sub-studies 2-3. Completing participant recruitment was challenging, and it took a relatively long time. According to the nurses and my contact with recruited parents, several parents seemed to be in a demanding situation during their child's hospitalisation and had too little energy and time to participate in an interview. Three parents cancelled the planned interview. One parent informed me that she had to cancel the interview because her child was diagnosed with a serious diagnosis. Another parent had a child who was acute transferred to another hospital. One child was discharged from the

hospital earlier than expected, and the parent could not come for an interview. Some parents forgot their interview appointments and new appointments were made. Finally, the inclusion criteria for the samples were met. However, there were few males, no single parents and no parents with children between 11 and 16 years of age in the sample. The ages of the parents' hospitalised children were not mentioned in the articles to maintain parents' anonymity. However, I can confirm that four parents had infants, five had pre-school children and three had elementary school children.

Recruitment of participants to sub-study 4

The managers of the health professionals from the paediatric wards informed employees who met the inclusion criteria about sub-study 4. Health professionals were also informed in three meetings at hospital. Interested professionals contacted me by SMS, and I made appointments for interviews with them. However, recruiting health professionals took a long time, because several of them had difficulties leaving their clinical work for interviewing.

A purposeful and theoretical sampling in sub-studies 2-4

Participant recruitment and interview conducting continued until the sampling inclusion criteria were met for the sub-studies. In addition, they continued until sufficiently rich data were obtained and that it was clear that no new variation in knowledge would appear during analysis of the interviews (Daly et al., 2007). The following analytical procedure, called purposeful and theoretical sampling, was performed for each sub-study (Tuckett, 2004). First, ten interviews were analysed according to the analytical method used in each sub-study. Second, two other interviews were analysed. Third, the results were interpreted and compared with the results from the first ten interviews. No new knowledge was generated, but the process did support findings from the first ten interviews (Daly et al., 2007).

3.6.4 Conducting interviews

Interview guides

The interview guides were based on the findings from sub-study 1 and the theories of salutogenesis (Antonovsky, 2012; Eriksson & Lindström, 2008) and user involvement (Entwistle & Watt, 2006; Thompson, 2007). Sub-study 4's interview guide was also founded on the findings from sub-studies 2-3. Accordingly, the interview guides were based on acknowledged theories and previous research to ensure quality (Kallio et al., 2016). During development of the interview guides, I aimed to make them user-friendly, balancing the main and follow-up questions and avoiding leading questions. Two researchers agreed on the questions, which is called 'internal testing' (Kallio et al., 2016). However, the interview guides were not 'field-tested' due to issues in recruiting participants. On the other hand, it is of utmost importance to ensure that participants understand the questions in the intended way in order to encourage them to produce data that answer the research questions (Silverman, 2014, Chapter 4). I tried to address this concern by thoroughly informing the participants of the research topic and the meaning of 'parental involvement in DM' and 'user involvement'. In addition, follow-up questions were used to direct and facilitate more nuanced statements and in-depth descriptions, a benefit of semi-structured interviewing (Kallio et al., 2016).

Interviewing

During interviews, the interviewer needs to concentrate entirely on what the participants express, interpreting what and how they say it and their body-language (Silverman, 2014, Chapter 4). That way, he/she can make appropriate responses and follow-up questions. I focused on these elements. With my background in paediatric physiotherapy, I had experience and knowledge on talking to parents and health professionals while assessing their body-language. Nevertheless, some participants were a bit difficult to understand. In brief periods of the interviews with them, I was not sure what they were talking about. In such cases, I let

them talk until they wanted to stop even though the subject of conversation did not seem relevant to the research question. In addition, I asked them follow-up questions on the subject at hand to gather more nuanced statements.

Another important task is to motivate the participant to engage in the co-construction of the phenomenon during the interview since participants' engagement influences the findings (Enosh & Ben-Ari, 2016). I tried to motivate the participants by asking contextualising follow-up questions; for example, to parents I asked, 'how have you been involved in your child's healthcare decisions during this hospitalisation'. The participants' level of engagement differed as they answered questions and expressed their views; however, all the participants were motivated and contributed actively.

In the interviews of sub-studies 2-3, some of the parents were extra vulnerable and appeared emotionally distressed. Therefore, as interviewer, I took extra care with them to avoid adding to their comfort and strain. I let them talk about what was important to them in addition to what was important for the research topic. Children were not present during the interviews to avoid disturbing the parents and to facilitate parents' speaking freely. Ten interviews were carried out while the children were hospitalised and two took place within a week of discharge. The parents who appeared extra vulnerable and emotionally distressed had hospitalised children.

After the interviews about the research topic, I talked to each participant about the interview setting, thus giving them an opportunity to talk about their reactions to it. After the interviews, I made notes on the interview setting, describing the setting, any disturbances and the behaviour of the participants. These notes were helpful during the transcription and analytical processes.

3.6.5 Analysis of interviews

All the interview tapes were carefully and strictly transcribed verbatim according to each participant's dialect and pronunciation since the participants expressed themselves very differently. These measures safeguarded the quality of further interpretations and analysis.

Analysis of interviews in sub-studies 2-3

The transcripts for sub-studies 2-3 were entered into the data management system, NVivo 10 (Bazeley & Jackson, 2013), for manual organisation and coding. Qualitative content analysis was conducted according to Graneheim et al.'s (2017) description. As the main researcher, I performed the initial analyses. First, each transcript was read with the note describing the setting to obtain an impression of the interview and setting. Second, the interpretation of what was expressed by the participants was interpreted and coded. Therefore, the interactions and the participants' expressions were carefully interpreted at the same time. Third, transcript portions that were relevant to the research questions were extracted and divided into meaning units. Further analysis, which is described in Papers II and III, resulted in manifest categories and subcategories and then latent main themes and subthemes. Latent themes reflect the latent content of the transcripts after a higher level of data abstraction and interpretation (Graneheim et al., 2017). Accordingly, the latent themes illustrate a higher-order meaning of what the participants said about the research topic. One of the other researchers contributed to the analysis, and we reached a consensus on the final composite analysis.

Sub-study 2-3 followed an abductive analytical process (Elo & Kyngäs, 2008). The research aims and interview guide were formulated on the basis of relevant findings from sub-study 1 and theory (3.6.5), which is a deductive process. In the initial phase, the analysis of the interview text was data driven, which is considered an inductive analytical process. The findings were analysed using the Sense of Coherence Theory to ensure a

health-promoting perspective. This abductive approach provided a more comprehensive understanding of the research phenomenon.

Analysis of interviews in sub-study 4

The transcripts for sub-study 4 were analysed according to Silverman (2014, Chapter 15). Both the interaction between the interviewer and the participant and what the participant expressed in the interview were analysed. In addition to expressing meanings of the research phenomenon in interviews, as the participants position themselves, they signal identities and norms (Holstein & Gubrium, 2016; Silverman, 2014, Chapter 7). Because of this, it was important to analyse the interactions and construction of the phenomenon in each interview. Uncovering what was going on during the interview improve the quality of the analysis of the participants' meanings of the research phenomenon (Silverman, 2014).

The first part of this analysis started with reading the transcripts. Each transcript was read together with the note describing the interview setting, to get an impression of the interview and setting. The interview text was then divided into construction of meaning accounts. Next, the interactions and the construction of meaning accounts were assessed without paying attention to 'what' the participants expressed about the research phenomenon. The construction activation, positioning of the participant and interviewer, identity work and function of statements and narratives were all analysed and organised in a table. Construction activation concerns when, how and why a construction starts and continues (Holstein & Gubrium, 2016). Positioning of participant and interviewer deals with self-presentation vis-à-vis each other as well as the way they talk about other people during the interview (Silverman, 2014, Chapter 7). Identity work involves assessing who the participants identifies themselves as during the interview; for instance, a mother as 'morally responsible' or 'a well-functioning good mother' and a health professional as 'a health professional who behave the right way and do the right things' according to cultural norms (Silverman, 2014, Chapter

7). In addition, there is the positioning of each other in the interview. The analysis of the interactions indicated that the interviewer was sometimes positioned by the participants as a researcher and other times as a physiotherapist. To strengthen the quality of the analysis it was important to reveal such positioning because it has consequences for the analysis. Function of statements and narratives means assessing what function the participants' statements and narratives have in the interview (Holstein & Gubrium, 2016; Silverman, 2014, Chapter 7). Examples include exploring why they said certain things and what they wanted to achieve. These analyses provided important information about what happened in the interviews, which became a basis for further analysis.

After the analysis of the interaction and the construction of meaning accounts for all the interviews, there is an analysis of these findings. I first analysed the findings from four interviews with different health professions by exploring and comparing data fragments, a kind of analytic induction (Silverman, 2014, Chapter 4). Gradually, I generated a set of categories and found a preliminary pattern of categories, which were tested with data from other interviews. In this way, deviant cases, which is, cases that were different from the rest, challenged the preliminary pattern of categories (Silverman, 2014, Chapter 4). However, these cases also strengthened the analysis. After intense work on the analysis, the preliminary pattern of categories was improved, thereby enhancing its quality (Peräkylä, 2016). Ultimately, I achieved a more comprehensive description of the interactions and the construction of the cultural stories of the phenomenon.

Next, I interpreted what the participants expressed in the interviews based on the results of the interpretation of interactions (Holstein & Gubrium, 2016; Silverman, 2014, Chapter 7). I used a table to carefully consider what was expressed in relation to how it was said. Further, relevant meaning accounts were extracted and entered a new table. They were interpreted and compared according to identifying similarities and differences. The meaning accounts, a collection of assumptions, are the

cultural stories about the phenomenon (Silverman, 2014, Chapter 7); as such, they reflect relatively long-lasting and recognisable meaning- and opinion-forms in the culture (Holstein & Gubrium, 2016).

The second part of this analysis is an organisation of the cultural stories, using qualitative content analysis (Graneheim et al., 2017). The analysis is described in Paper IV, resulting in one main manifest category and three subcategories. These findings illustrate a descriptive version of the cultural stories of the phenomenon from the interviews, based on high abstraction and low interpretation levels (Graneheim et al., 2017). This is consistent with the constructivist approach which is contextually sensitive and descriptive (Silverman, 2014, Chapter 14).

The findings from these two analyses are presented, discussed and summarised in Paper IV. As the main researcher, I performed the analysis of the interviews and cultural stories. The other researchers critically assessed the analyses and agreed on the final composite analysis.

The analytical process used in sub-study 4 was abductive (Elo & Kyngäs, 2008). The research aims and interview guide were formulated on the basis of relevant findings in sub-study 1-3 and theory, making it a deductive process. The analysis of the interactions, the construction of meaning accounts, the 'what' expressed in the interviews and the cultural stories were all analysed using an inductive process, which provided a new theoretical understanding. Thereafter, these findings were analysed in light of the Sense of Coherence Theory to ensure a health-promoting perspective. This abductive approach provided a more comprehensive understanding of the research phenomenon.

3.7 Research quality

There are several opinions about how to evaluate the quality of qualitative research (Altheide & Johnson, 2013; Choen & Crabtree,

2008). The variances in opinion are based on different perspectives on ontology and epistemology, which affect methodological assumptions.

Denzin and Lincoln (2013b, p. 347) report three main positions: the foundationalists' position, the quasi-foundationalists' position, and the non-foundationalists' position. The foundationalists' position is based on the positivist paradigm, assuming there is a single objective reality (Choen & Crabtree, 2008). The position advocates that all research should be evaluated according to a set of standard criteria (e.g., validity, reliability and objectivity) regardless of the study's ontological, epistemological and methodological points of view. The quasi-foundationalists' position is based on ontological neorealism and constructivist epistemology (Denzin & Lincoln, 2013b). This position advocates for a real world of objects and people. Knowledge of this reality is bound to perspectives and theory and is always imperfect. It recommends a set of criteria unique to qualitative research and suggests criteria for generating theories, scientific credibility, transferability of findings, and reflexivity on the researcher's role and the research strategy. In contrast, the non-foundationalists' position, based on interpretivism, assumes a relativist ontology and constructivist epistemology (Denzin & Lincoln, 2013b). Knowledge is socially co-constructed and connected to perspective, theory, values and context. This position emphasises the significance of understanding versus prediction and research from within a moral frame. Because of these assumptions, the criteria for evaluating research is relative, moral and political.

These three basic positions for evaluating qualitative research are in line with Choen and Crabtree's review (2008) about evaluating qualitative studies in health research. They identified a general agreement on four criteria: '(1) carrying out ethical research; (2) importance of the research; (3) clarity and coherence of the research report; (4) use of appropriate and rigorous methods' and essential differences in opinion concerning three criteria: '(5) importance of reflexivity or attending to researcher

bias; (6) importance of establishing validity or credibility; and (7) importance of verification or reliability' (Choen & Crabtree, 2008, p. 333). The differences were based on ontological and epistemological assumptions.

On the basis of these opinions, how should this qualitative research programme be evaluated? The research programme was designed within a constructivist research paradigm, which is an interpretive approach that assumes reality, phenomena and knowledge are constructed intersubjectively in ongoing processes related to a context that is influenced by history, culture and values (Lincoln et al., 2013). This implies that there are multiple, fluid realities. In my opinion, the evaluating criteria should emphasise research that describes multiple, subjective ways of meaning, understanding phenomena and making relative, moral and political evaluations. Furthermore, using verification techniques, such as triangulation and member checking, are inappropriate because of these ontological and epistemological assumptions (Silverman, 2014). However, I think research studies and findings in healthcare research ought to be judged according to appropriate criteria within their theoretical and methodological frameworks as well as their purposes and disciplinary values (Altheide & Johnson, 2013) so that they can become useful for health professionals and politicians. Thus, there is an ethical, pragmatic need to gauge the trustworthiness of the research process and its findings rather than 'truth' and 'validity'. Reflexivity, reflecting critically on the researcher's role and influence on all parts of the research process (Lincoln et al., 2013), is important.

On the basis of these assumptions, the trustworthiness of sub-studies 1-4 ought to be appraised on the performance of all parts of the research process, including the influence of the researchers (Graneheim et al., 2017). The research process is thoroughly described in 3.5 and 3.6, aiming for transparency for the readers. Credibility refers to the research findings' authenticity and plausibility according to the research aim and

the original data (Lincoln et al., 2013). Recruitment of participants with experience of the research phenomenon and the participants' engagement in the construction of the phenomenon are important (Enosh & Ben-Ari, 2016; Graneheim et al., 2017). Another essential element for achieving credibility is gaining enough rich data to cover important variations and diverse descriptions of the phenomenon (Graneheim et al., 2017). This aim is met by providing a manageable sample of active participants with relevant, different backgrounds.

Dependability refers to whether the findings are supported by the data as received from the participants of the study (Graneheim et al., 2017). The analyses and information on the researchers' pre-understandings must be accurate because they influence the research process. The performance of the analyses is described in 3.5, 3.6. and Paper I-IV. Since the main researcher is Norwegian, the interviews and analyses were carried out in Norwegian to increase the quality. Furthermore, examples from the analyses and representative quotations are presented in Paper II-IV to support the confirmability of the research findings (Peräkylä, 2016). Readers can assess the categories and themes based on their logical connections to the aims of the studies in Papers II and III (Graneheim et al., 2017); the goal is to achieve a kind of transparency in terms of analytic claims (Peräkylä, 2016). The quality of analysis in sub-study 4 can be evaluated by comparing parts of the transcripts to the analysis, which is supposed to be based on the interview data. This can be done using techniques such as the transparency of analytic claims and assessment of 'next turn' (Peräkylä, 2016). The readers can assess the degree of apparent logical understanding associated with the claims linked to the quotations in Paper IV. Assessment of 'next turn' involves evaluating how the participants and the interviewer respond to each other's utterances. Their responses are connected to their interpretations of the utterances and can reveal less credible interpretations. The translation of the quotations to English were edited by a bilingual expert and professional English editing services.

My pre-understanding of the research topic was influenced by my experience as paediatric physiotherapist for many years at hospital and in primary healthcare services and as mother and user-representative for my children at different healthcare services. I have a lot of experience in working alone as a professional as well as in different intra- and interprofessional paediatric settings. In addition, my pre-understanding was based on my education in paediatric physiotherapy, health promotion and user-involvement. From a social-constructivist perspective, I believe my pre-understanding influenced the co-production of data in the interviews as well as the entire research process. Furthermore, my familiarity with the included hospital wards influenced my pre-understanding and the interviewing including the interactions, follow-up questions, and construction of the phenomenon. Accordingly, it affected the research process. My supervisors' pre-understandings have also influenced me and the research process, primed as I was by their knowledge and experiences, as a critical care nurse and a paediatric medical physician in hospital settings, and their research backgrounds in health science, leadership and medical settings.

The last search for relevant current research on the research topic was 15.01.2019.

3.7.1 Transferability

Transferability means transferring the use of research findings from one study to similar groups of participants and settings; it is important in health research to improve clinical practice (Polit & Beck, 2010). In qualitative research, it is often the readers who judge whether research findings can be transferred to other settings (Donovan & Sanders, 2007; Polit & Beck, 2010). Thick descriptions and reflexivity about the research process, sample, context and findings are a necessity when considering transferring research findings. Accordingly, the readers of Papers I-IV can judge whether the findings are transferable to similar

contexts such as paediatric wards at hospitals in Norway, other Scandinavian countries, or Western countries.

4 Findings

This chapter presents the sub-studies' findings followed by a summary of the thesis' findings.

4.1 Findings in the sub-studies

4.1.1 Sub-study 1 (Paper I)

This systematic, integrated review provides a synthesis of previous research on parental involvement in decision-making (DM) about children's healthcare from parents' perspective. The results revealed that there was little research from Western countries. We did not find any studies from Norway. Nevertheless, this review provided new insight into parental involvement in children's healthcare decisions. Three themes were identified as important for the parents: 'relational factors and interdependence', 'personal factors and attitudes', and 'organisational factors'.

The findings indicated that parents participated in decisions about their children's healthcare to varying degrees, and they wanted to participate more than they were able to do. Furthermore, health professionals appeared to dominate the DM process due to their authority and power. The parents' involvement in DM seemed to depend on if, how and when the health professionals involved them in DM. This seemed to place the parents in a vulnerable position during their children's healthcare decisions. The health professionals' involvement of parents appeared to depend on their attitudes on the parental role at hospital and competencies of communication and relational skills. In addition, the competencies in question included balancing user-involvement, evidence-based practice and resource allocation, as well as their knowledge of parental involvement in healthcare decisions.

Moreover, parents' personal factors, such as demographic characteristics, life circumstances, attitudes and competencies, seemed to influence their involvement in DM. It was important for the parents to have the opportunity to vary their degree of involvement as they seemed to need to be in control of their preferred role in DM. This appeared to be influenced by the information they could access, their relationship with the health professionals, and their preferred degree of involvement. Furthermore, most of the parents viewed and preferred the DM as a shared process. The parents emphasised mutual trust, respect, and a two-way process of listening, sharing information and making decisions. Challenges arose from asymmetries in authority and power between the parents and the health professionals during DM. Other influencing factors were organisational shortcomings such as available time, resources and routines in healthcare services.

The most important findings for further research were that parental involvement in children's healthcare decisions seemed to be insufficiently implemented and that parents appeared to be vulnerable during DM. Based on these findings, it was necessary to increase knowledge on the roles of parents and health professionals in children's healthcare DM and to identify how parental involvement can be improved. The findings that parents appear to be in a particularly vulnerable situation during children's healthcare DM led to the aims of sub-study 2.

4.1.2 Sub-study 2 (Paper II)

Parents' experiences of involvement in DM about their child's healthcare at hospital were explored in a descriptive qualitative study. In addition, how health professionals can improve parental involvement was identified. The analysis resulted in 'a demanding parental role' as the main theme with two sub-themes: 'parental competence and need for information' and 'parental involvement and control'.

The findings indicated that the parents were highly concerned about their child's healthcare and were in a very challenging and vulnerable situation while being involved in their child's healthcare decisions. The parents' ability to cope in these DM processes seemed to depend on their competencies and their perceptions of their influence and control in DM. Furthermore, the health professionals' facilitation of parents' active involvement in these decisions and their provision of sufficient, consistent information seemed to strengthen parents' sense of coherence (SOC), empowering them and increasing their involvement in DM. The findings indicated that the health professionals' role was essential to facilitating parents' ability to cope with the parental role during children's hospitalisation.

Further research was recommended, such as qualitative research, to improve the understanding of health professionals' role in facilitating parental involvement in children's healthcare decisions. This led to the research aims of both sub-study 3 and 4.

4.1.3 Sub-study 3 (Paper III)

Parents' experiences of health professionals' facilitation of parental involvement in DM surrounding children's healthcare at hospital were explored in a descriptive, qualitative study. In addition, how health professionals can improve parental involvement was identified. The analysis resulted in 'sensitivity in clinical practice' as a main theme with two sub-themes: 'empathy in communication' and 'confidence in the health professional-parent relationship'.

The findings indicated that the health professionals' sensitivity to parents' capacity, resources and needs was essential to facilitating the latter's involvement in children's healthcare decisions. The health professionals' sensitivity seemed to influence the quality of communication and the health professional-parent relationship. Therefore, empathetic communication, confidence in the health

professionals-parent relationship, and continuity of care from the same health professionals appeared to be essential. Moreover, these factors seemed to strengthen parents' SOC, affecting parents' coping ability during their child's hospitalisation. Accordingly, the findings suggested that health professionals' sensitivity to parents' capacities and needs and their communication and relationship with the parents figured significantly in facilitating parental involvement in children's healthcare decisions.

The study provided implications for further qualitative research on increasing knowledge of health professionals' perspectives on their roles in facilitating parental involvement in children's healthcare decisions at hospital. This implication was then operationalised into the research aim for sub-study 4.

4.1.4 Sub-study 4 (Paper IV)

Health professionals' construction of the phenomenon, parental involvement in DM about children's healthcare at hospital, was explored in a descriptive, qualitative study. In addition, how parental involvement can be improved was identified.

The findings indicated that the health professionals were concerned about involving parents in children's healthcare decisions and shaping a technically safe, justifiable healthcare plan for the children. They appeared to face challenges when combining these objectives if the parents preferred a type of healthcare that did not fit with the wards' strictures. Organisational shortcomings at the hospital also reduced the health professionals' opportunities to meet parents' needs. Another challenge was parents' preferences for a type of healthcare that the health professionals could not judge to be technically safe and justifiable. The findings from the cultural stories about the phenomenon were illustrated in one main category: 'facilitating parental involvement', and three sub-categories: 'parental involvement and influence', health professionals'

facilitation of parental involvement', and 'the impact of intra- and interprofessional collaboration'.

The health professionals expressed that they needed information from the parents about the hospitalised children and their families in order to individually customise the healthcare plans. Furthermore, they needed parents' assistance in implementing the healthcare to provide high quality. However, how the health professionals involved parents in their children's healthcare decisions, which appeared to be influenced of their competencies, seemed to affect parental involvement. The quality of the intra- and interprofessional collaboration appeared to influence parental involvement and the quality of healthcare.

4.2 Summary of the thesis' findings

This thesis contributes new insights into parents' and health professionals' roles during DM about shaping and customising children's healthcare at hospital (Papers I-IV). Important findings concerned the insufficiently implementation of parental involvement in children's healthcare decisions and the vulnerability of parents during the demanding situation of DM (Papers I-II). Furthermore, parents' personal factors, such as demographic characteristics, life circumstances, attitudes and competencies, seemed to influence their involvement in DM (Papers I-II). Having the opportunity to vary their degree of involvement appeared to be important as they seemed to need to be in control of their preferred role in DM (Paper I). This need appeared to be influenced by the information they could access, their relationship with the health professionals, and their preferred degree of involvement (Papers I-III). The parents' ability to cope in DM seemed to depend on their competencies and their perceived influence and control in DM (Paper II). Furthermore, individually tailored facilitation of parents' active involvement in DM by the health professionals appeared to empower the parents, increasing their active involvement (Paper II). The parents' ability to cope with the parental role seem to improve along with

strengthening their SOC (meaningfulness, comprehensibility and manageability) during DM (Papers II-IV). Consequently, the findings highlight health professionals' essential role in facilitating parents' active involvement in children's healthcare decisions and in improving parents' ability to cope with their parental role during hospitalisation.

The findings indicate that the parents were dependent on whether, how and when the health professionals involved them in DM (Paper I-III). In addition, the health professionals' competencies and attitudes seemed to influence their involvement of parents (Papers I-IV). The health professionals' sensitivity to parents' capacity and needs and their communication and relationship with the parents appeared to factor greatly into how they facilitated parents' involvement in DM (Paper III). Empathetic communication, confidence in the health professionals-parent relationship and continuity of care from the same health professionals seemed, thus, to be important.

The health professionals were concerned about involving parents in their child's healthcare decisions and in shaping a technically safe and justifiable healthcare plan for the children (Paper IV). They appeared to face challenges in combining these objectives when the parents preferred a type of healthcare that the health professionals regarded as technically unsafe, unjustifiable, or unfeasible in the wards (Paper IV). Organisational shortcomings at the hospital seemed to reduce the health professionals' opportunities to meet parents' needs and preferences. Support from intra- and interprofessional colleagues was particularly important for the health professionals in their more demanding cases. Moreover, the quality of the intra- and interprofessional collaboration also influenced parental involvement in DM and the quality of the provided healthcare (Paper IV).

Figure 3 at page 52 illustrates this thesis' findings in a model. The model shows how health professionals' involvement of parents in DM about children's healthcare influence the ways parents engaged and affected

their ability to cope with the parental role at hospital. Important elements for health professionals' involvement of parents and for parents' involvement in DM are listed in the model. Factors that seemed to influence health professionals' involvement of parents and parents' involvement in DM are also listed.

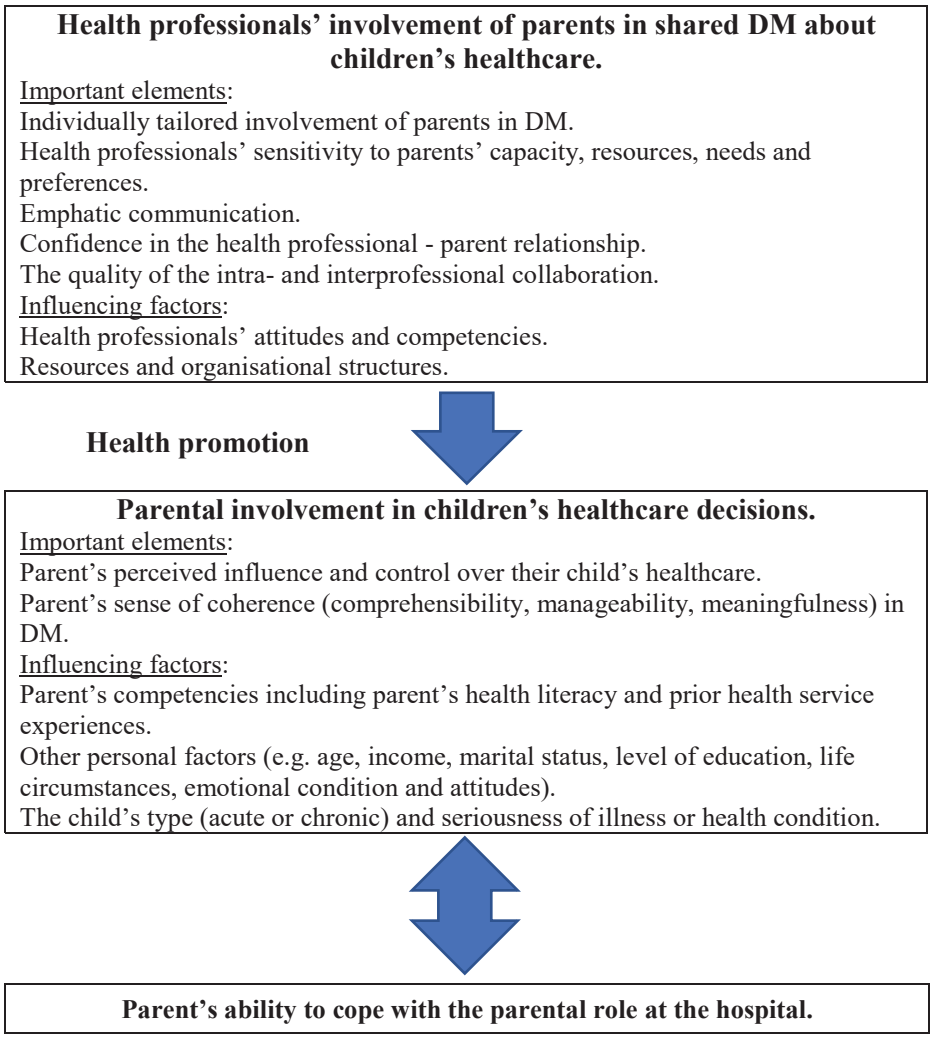

Figure 3. A model about health professionals' involvement of parents in DM about shaping and customising children's healthcare at the hospital.

5 Discussion

This chapter starts with a discussion of the thesis' main findings in light of previous and current research and ends with practical and theoretical implications. Reflections are also offered on methodological considerations about the quality of the research design and the research process. Finally, implications for clinical practice and future research are presented.

The overall aim of this thesis was to increase insight into parental involvement in decision-making (DM) about shaping and customising children's healthcare in interprofessional practice at hospital, from a health-promoting perspective.

5.1 Main findings and its implications

This thesis contributes new important insights into the roles of parents and health professionals in involving parents in children's healthcare decisions at hospital.

5.1.1 Health professionals' involvement of parents

The findings indicate that health professionals' involvement of parents in DM influences parents' participation, which is in accordance with research on patient involvement in healthcare decisions (Edwards et al., 2009; Power, Swartzman, & Robinson, 2011). Health professionals' facilitation of parents' active involvement in children's DM and their provision of sufficient, consistent information both seem to empower parents, increasing their active involvement (Paper II). Research on family-centred care (FCC) supports the importance of parents' receiving sufficient, consistent information from health professionals when negotiating their parental role in care at hospital (Corlett & Twycross, 2006; Foster et al., 2010). In addition, other studies on FCC (Power &

Franck, 2008; Uhl, Fisher, Docherty, & Brandon, 2013) and a systematic review on informed consent (Jackson et al., 2008) report that parents seem to need a lot of information to be able to participate in healthcare DM.

The ways in which health professionals facilitate and involve parents in DM appear to be essential factors for empowering parents in DM (Papers II-III), which is consistent with Edwards et al.'s model of shared DM (2009). It is an important finding that individually tailoring the involvement of parents in DM, conveying health professionals' sensitivity to parents' capacity and needs and cultivating an openly communicative relationship with parents all seem to affect the facilitation of parental involvement in children's healthcare decisions (Paper III). These findings reflect the literature on clinical empathy (Decety, Smith, Norman, & Halpern, 2014). That is conscious use of empathy in clinical practice is expected to improve health professionals' understanding of children's and parents' life circumstances, perspectives and needs (Halpern, 2014). In addition, communication between health professionals and parents is assumed to improve. Accordingly, health professionals should use empathic communication to improve their communications and relationships with parents when facilitating parental involvement in DM.

This suggestion for clinical practice is supported by the thesis' findings, which indicate that health professionals' competencies seem to influence their involvement of parents in children's healthcare decisions (Papers I-IV). Important competencies concern communication, relational and empathic skills, and knowledge about parental involvement in healthcare decisions. These findings are consistent with research on patient involvement in shared DM (Land, Parry, & Seymour, 2017) and FCC (Coyne, 2007). On the basis of these findings, practising optimal parental involvement in DM is a complex endeavour, requiring several, different competencies of health professionals. However, health professionals' individual communication, relational and empathic skills may vary

(Paper II-IV), which is consistent with previous research (Avis & Reardon, 2008; Lown, 2016). Accordingly, optimal parental involvement in DM demands health professionals to be highly competent in communication and relationship-building and to be aware of how they are involving parents in DM.

The findings show that health professionals' awareness of their power positions and their parental involvement practices appear to vary (Paper II-IV), which is consistent with previous research (Smith, Cheater, Bekker, & Chatwin, 2013) and Lègarè et al.'s (2008) systematic review on patient involvement in shared DM. Moreover, parents seem to depend on whether, how and when health professionals involve them in DM (Papers I & III). Evidently, the asymmetry in authority and power between health professionals and parents influences parental involvement in DM. This finding is in line with previous reports on FCC that health professionals tend to define rather than negotiate parents' role in children's care at hospital (Corlett & Twycross, 2006; Coyne, 2013; Foster et al., 2010). This indicates that health professionals still tend to dominate DM related to children's healthcare. One reason might be that parental involvement in shared DM can challenge health professionals' attitudes and routinised thinking on the roles of parents and professional at hospital (Paper I; Entwistle & Watt, 2006). The health professionals' attitudes are influenced by their professional understanding of health, disease causality and evidence-based practice (Whall, Sinclair, & Parahoo, 2006). An increased awareness among health professionals about practicing parental involvement in DM is crucial to counteracting the misuse of authority and ensuring parents' role as user-representatives for their children. Moreover, health managers, whose overall responsibility is to facilitate health professionals' involvement of parents in DM, need to motivate their employees to improve their parental involvement practices.

Paper IV provides new insight into health professionals' challenges when involving parents in DM. The findings indicate that health

professionals find it difficult to combine parental involvement in children's healthcare decisions with co-producing a technically safe, justifiable healthcare plan for the children, especially when parents prefer a type of healthcare that is unfeasible in the wards (because of available resources, room conditions, and ward rules). Such organisational shortcomings reduce health professionals' opportunities to meet parents' needs and preferences causing ethical dilemmas among health professionals. This finding is supported by previous research on FCC (Coyne, 2013; Harrison, 2010; Watts et al., 2014). Evidently, such organisational shortcomings reduce health professionals' options during DM about shaping and customising children's healthcare.

Moreover, the findings indicate that health professionals face a challenge when parents prefer a type of healthcare that they do not judge to be technically safe or justifiable (Paper IV). In such cases, the health professionals spend time in dialogue with the parents, arguing for their opinions about the healthcare plan and trying to come to an agreement. This represents an ethical dilemma because health professionals' most important responsibility is to provide a technically safe, justifiable healthcare to the children (Law of health professionals, 1999, § 4). They cannot compromise on this responsibility. Their practice is appropriate when the parents are involved respectfully and in accordance with the shared DM process for preventing decisional conflicts (Boland, Kryworuchko, Saarimaki, & Lawson, 2017; Chorney et al., 2015). Nevertheless, such cases are complex and can be particularly demanding for health professionals. Support from their intra- and interprofessional colleagues may be required for finding new solutions for influencing and supporting the parents professionally (Paper IV). Accordingly, in such challenging causes, health professionals need to have opportunities to obtain support and guidance from their colleagues. Moreover, health managers are responsible for arranging for such collegiate support and facilitating intra- and interprofessional collaboration.

Furthermore, the thesis contributes new knowledge about how the quality of the intra- and interprofessional collaboration influences parental involvement in DM (Paper IV). The quality of the collaboration seems to influence the collaboration on how to involve parents in DM as well as the quality of the healthcare provided. More efficient intra- and interprofessional collaboration about shaping and implementing children's healthcare is expected to increase continuity of care and promote parents' trust in it. An interprofessional approach is more likely to increase the meeting of parents' preferences. These findings are in accordance with previous research on patient involvement in healthcare decisions (Carman et al., 2013; Körner, Ehrhardt, & Steger, 2013; Légaré et al., 2011). On the basis of these findings, the quality of the intra- and interprofessional collaboration needs to be prioritised and strengthened to facilitate parental involvement in DM.

The findings indicate that complex intra- and interprofessional collaboration practices can be improved by strengthening health professionals' understanding of their roles, the ways they communicate and their relationships among each other (Paper IV). These findings are consistent with previous research on patient involvement in DM (Körner et al., 2013; Légaré et al., 2011). Health professionals' adherence to recommended practices and organisational routines should be improved (Paper IV; Reeves et al., 2017). Poor workforce reduces the intra- and interprofessional collaboration, thereby weakening continuity of healthcare (Paper IV; Körner et al., 2013). On the basis of these findings, it is important to prioritise and strengthen the quality of intra- and interprofessional collaborations in clinical practice to improve parental involvement in DM.

These findings are in accordance with Elwyn et al.'s (2017) three-talk model of shared healthcare DM for adults, which emphasises an efficient interprofessional collaboration during patient involvement. However, a model for shared DM in interprofessional paediatric practices need to be developed in which both parents and paediatric patients are involved.

The thesis' findings describe how parental involvement in shared DM in paediatric interprofessional clinical practices seemed to be affected by several factors at the parent-health professional, intra- and interprofessional, and the healthcare-system levels (Papers I-IV). This is in line with Lègarè et al.'s (2011) model on factors that influence shared DM in interprofessional practice. However, both Elwyn et al.'s (2017) and Lègarè et al.'s (2011) models lack the intra-professional perspective, which must be considered to make improvements.

The findings indicate that organisational shortcomings, such as lack of resources, time constraints and poor room conditions in the wards, negatively affected health professionals' involvement of parents in DM (Papers I & IV). These findings are supported by previous research on parental involvement in shared DM (Smith et al., 2013), informed consent (Jackson et al., 2008) and patient involvement in shared DM (Lègarè et al., 2008). In addition, they support research on FCC, which reports that nurses struggle to implement FCC and involve parents in role negotiations because of poor workforce and ward limitations (Coyne, 2013; Watts et al., 2014). This is a major concern since high workloads and stressful environments can decrease health professionals' sensitivity to parents' capacities and needs and their communication and relationships with the parents (Teng, Chang, & Hsu, 2009). On the basis of these findings, organisational shortcomings seem to reduce health professionals' involvement of parents in DM. Accordingly, optimal parental involvement in children's healthcare decisions requires adequate organisational resources, which is the healthcare managers' responsibility.

5.1.2 Parental involvement in DM

This thesis contributes new knowledge about parent's role as user-representatives for their children in DM. Parents can be in a vulnerable, demanding situation during DM, and they seem to have a special need for dialogue and support from health professionals (Papers I-II). These

findings are consistent with previous research on parents' informed consent (Jackson et al., 2008) and treatment decisions (Massimo, Wiley, & Casari, 2004; Stewart, Pyke-Grimm, & Kelly, 2012). Moreover, research on FCC reports that parents perceive their parental role at hospital to be demanding (Foster et al., 2010; Power & Franck, 2008; Uhl et al., 2013). Based on these findings, this thesis' overall research aim is highly relevant to clinical practice.

The findings indicate that parents are very concerned about their children's healthcare (Paper II), which is consistent with research on FCC (Thallon, Kendall, & Snider, 2015a; Uhl et al., 2013). Furthermore, parents' ability to cope in DM about shaping and customising their children's healthcare appears to depend on their competencies and perceptions of their influence and control in DM (Paper II). Moreover, parents seem to prefer to be involved in a shared DM process (Papers I-II). In addition, they want to be involved according to their preferred role, which may differ from time to time and according to the type of decision being made. Furthermore, parents' personal factors, such as demographic characteristics, life circumstances, health literacy, attitudes and competencies, seem to influence their involvement in DM (Papers I, II & IV). These findings are consistent with Thompson's (2007) and Edwards et al.'s models (2009) of shared DM, both of which show patients' and health professionals' power and influence in DM varying according to the patients' preferences and characteristics, type of illness and the relationship with professionals. The models highlight how the patients' personal factors, clinical factors and health professionals' characteristics influence patients' power and influence in DM. The influence of parents' health literacy is supported in previous research (Jimenez, Barg, Guevara, Gerdes, & Fiks, 2013) and research on the influence of patients' health literacy (Nutbeam, 2009; Sorensen et al., 2015). Research on FCC (Corlett & Twycross, 2006; Foster et al., 2010), informed consent (Jackson et al., 2008; Lipstein et al., 2012) and treatment DM (Stewart, Kimberly, Pyke-Grimm, & Kelly, 2005) support

the notion that parents' personal factors affect their involvement in DM. Accordingly, health professionals need to care about parents' preferred role in DM and be aware of parents' health literacy among other personal factors. They must respect and support parents in their preferred roles in DM in order to promote their ability to cope with DM. This can improve health professionals' individually tailored involvement of parents, thereby increasing parents' active involvement in DM.

The thesis contributes new knowledge about how health professionals' individually tailored facilitation of parental involvement in children's healthcare DM strengthens parents' sense of coherence (SOC) (Papers II-III). Promoting parents' SOC appeared to empower their involvement in DM, thereby increasing their control over their parental role (Eriksson & Lindström, 2008). Therefore, the findings indicate that involvement in DM plays an important part in parents' ability to cope with their parental role at hospital (Paper II). Professionals' can promote parents' SOC by encouraging a perception of life as meaningful, comprehensible and manageable (Antonovsky, 2012). In addition, this is in line with research on FCC, in which health professionals' involvement of parents in their children's healthcare decisions seems to increase their engagement and involvement in care (Uhl et al., 2013). Accordingly, facilitating parental involvement in children's healthcare decisions can potentially increase parents' engagement and involvement in their children's healthcare, improving the quality and safety of the healthcare provided. Health professionals' role in involving parents in DM is essential in facilitating parents' ability to cope with the parental role at hospital. In this regard, the health professionals perform health promotion in paediatric clinical practice at hospital (Eriksson & Lindström, 2008; WHO, 2009). Therefore, health professionals should be aware of their influential role and use it to empower parents in DM processes and encourage their ability to cope with their parental role during their children's hospitalisation.

This thesis supports the purpose and principles of FCC, such as emphasising that children's healthcare should be planned to fit the whole family and thereby reduce parental stress (Shields et al., 2006). The roles should be negotiated between the nurses and parents. How the nurses involve parents in these negotiations will affect parents' ability to cope with their parental role during children's hospitalisation (Paper II-III). The children's and the parents' needs and preferences must be considered as far as it is possible at hospital. The same implications apply to the parents' role in performing other healthcare tasks, such as physiotherapy, at hospital.

Coyne et al. (2016) criticise the practice of FCC for favouring the parents' and health professionals' perspectives at the expense of children's perspective. They argue for practising child-centred care; however, this thesis found a need to consider parents' and children's perspectives. The children need parents who can cope with the demands of the parental role during their hospitalisation. Such parents can better assist examinations and treatments by meeting their children's psychosocial needs and supporting their development. This is in accordance with Tallon et al.' s (2015b) alternative model of FCC, which focuses on supporting the families' psychosocial functioning and promoting the children's health and development. This practice is also consistent with the biopsychosocial theory (Karl & Holland, 2015) and the Norwegian governmental directives (Regulations of children's hospitalisation, 2000).

On the other hand, it is the paediatric patient who is hospitalised, and her/his needs should be given top priority. Therefore, health professionals are responsible for providing a healthcare plan that is technically safe and justifiable for the paediatric patient (Law of health professionals, 1999, § 4). They must promote patient-centred care; in this context that means a child-centred care. This involves shaping and providing a healthcare plan that is individually customised to meet the child's needs and preferences. Therefore, the paediatric patient needs to

be involved in DM about their healthcare adjusted to their maturity, health condition, preferences and competencies. This can strengthen their SOC, thereby increasing their coping abilities at hospital (Eriksson & Lindström, 2008; Kelly, Mowbray, Pyke-Grimm, & Hinds, 2017; Wangmo et al., 2017).

5.1.3 Shared decision-making in paediatric practice

To summarise, a new model is needed for health professionals' involvement of parents and paediatric patients in shared DM about shaping and customising children's healthcare in an intra- and interprofessional collaborative practices at hospital. I have suggested a model (Figure 4) based on my research on page 63. This model illustrates how health professionals' involvement of parents' and their child in DM influences parents' and the child's involvement; it affects their ability to cope with their roles at hospital as well as the quality of the healthcare provided. In addition, this model contains important elements and influencing factors for how health professionals involve parents and the child as well as those affecting parents' and the child's involvement in DM.

This model is in accordance with FCC, patient-centred care, the biopsychosocial theory, evidence-based practice and the WHO's health promotion strategy (Burns & Grove, 2011; Elwyn et al., 2014; Karl & Holland, 2015; Smith et al., 2015; WHO, 2009). In addition, the model is consistent with the Norwegian government's directives for paediatric patients' and parents' right to involvement in healthcare decisions and parents' tasks during hospitalisation (e.g., National health and hospital plan, 2015; Patients' Right Act, 1999; Regulations of children's hospitalisation, 2000).

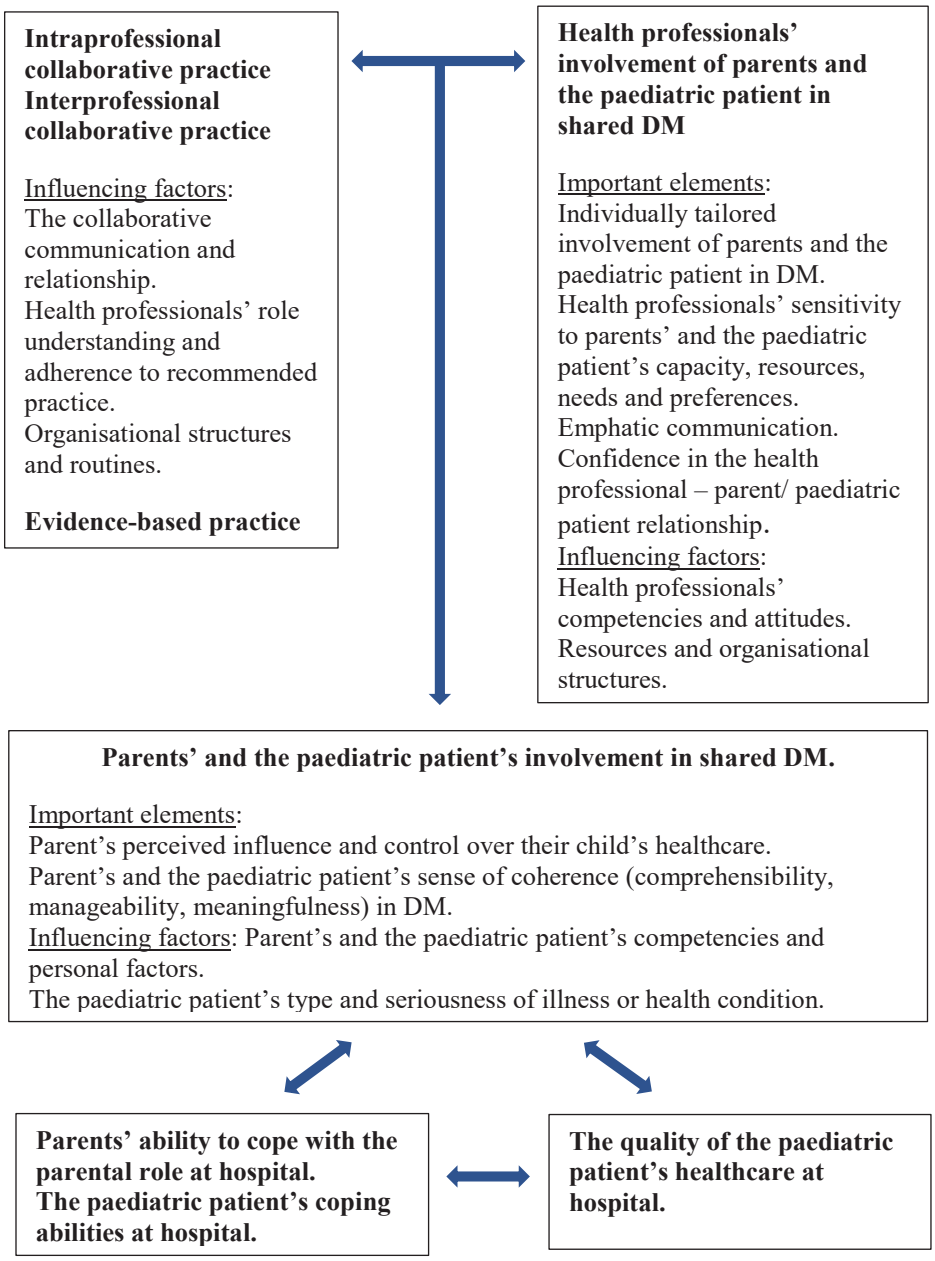

Figure 4. Model about health professionals' involvement of parents and the paediatric patient in DM about shaping and customising children's healthcare at hospital.

This model differs from the one Park and Cho (2018) offers for shared DM in the paediatric field, which also encouraging involving the child, parents and health professionals in a shared DM process. Their model illustrates the relationships between attributes, antecedents and consequences of the process. Antecedents are the existence of DM options with different possible outcomes, a substantial decisional conflict, a recognition of the need for DM about the child's healthcare and the willingness to be involved in DM. The attributes include active involvement of parents, child and health professionals, forming a partnership, coming to a compromise, and mutual goal making for the child's health. The consequences concerns decisional conflicts, joint empowerment, better child health status and increased quality of the child's healthcare.

On the other hand, the thesis' model (Figure 4) emphasises the facilitation of parents and the child in decisions about shaping and customising children's healthcare in an intra- and interprofessional collaborative practice at hospital. Park and Cho's (2018) model seems to emphasise a shared DM process that has several options and potential decisional conflicts in a triad. Both models stress the importance of involving parents, the child and health professionals in DM, good communication and relationships, empowering parents and the child and sharing the aim of deciding how to provide high-quality healthcare to the child. Accordingly, the models complement each other. Nevertheless, there is still lack of knowledge about how to best involve paediatric patients in their healthcare DM and how that might influence parental involvement (Feenstra et al., 2014; Papers I & IV; Park & Cho, 2018).

5.2 Methodological considerations

The quality of the research design and the research process is discussed in this section.

5.2.1 Quality evaluation of the research design

An explorative, sequential, descriptive, qualitative design was appropriate for strengthening the quality of this research programme because of its broad, comprehensive aim and the scarcity of prior knowledge on the research phenomenon. These arguments support the design's three phases, which began with an integrated systematic review that provided an overview of relevant previous research on the research topic and a synthesis of the findings. This sub-study contributed important implications for further research. Furthermore, the strength of a sequential design was that the findings in one sub-study affected the design of the next sub-study. This made the research process more efficient and sounder, providing important elements of knowledge about the research topic, such as parents' perspective on how health professionals facilitate parental involvement in DM as an integrated whole. This amplified the quality of the research programme. Recruiting parents and health professionals to participate was also a strength since their very different perspectives could increase the knowledge on the research phenomenon. Moreover, the sub-studies' research questions were relevant for the research programme's overall aim and theoretical perspectives, leading to a comprehensive understanding of the research field.

However, I had planned to conduct focus-group interviews with the health professionals in sub-study 4. The strength of focus-group interviews is that the method provides knowledge on the participants' attitudes and cultural norms, derived from their discussions of the research topic (Halkier, 2010). I tried to organise focus-groups at the hospital but failed because several health professionals could not leave clinical practice at the same time.

Nevertheless, individual interviews were a good replacement for focus-groups, enabling participants to speak freely, compared to focus-groups in which some participants may be less active (Halkier, 2010).

Furthermore, the analysis according to Silverman (2014, Chapter 14) provided insight into important cultural and normative subjects regarding the research topic. Another strength of this analysis was that it assessed the interactions in the interviews and the interviewers' influence on the construction of the phenomenon. This was important for ensuring the quality of the further analysis in sub-study 4 because of my background as a paediatric physiotherapist at the hospital.

When considering the use of other research methods, focus-group interviews with parents as participants was regarded as inappropriate because they were judged to be too vulnerable as participants. Moreover, prior research findings were too limited to conduct surveys to answer the research questions.

5.2.2 Quality evaluation of the research programme

The topic and purpose of the research programme were important for improving clinical practice since parental involvement in children's healthcare decisions was reported to be insufficiently implemented (Hallström et al., 2002). In addition, there was lack of knowledge about this topic. The thesis' findings confirmed that lack as well as the demands of the parental role during DM about children's healthcare at hospital. Furthermore, the overall aim of the programme was consistent with national and international laws and guidelines (Edwards et al., 2009; National health and hospital plan, 2015; WHO, 2009). We did not find any research studies from Norway, which supported the need for research in a Norwegian context. Based on these arguments, it was important to execute this research programme.

The research programme built on previous research findings and was carried out according to ethical guidelines (World Medical Association, 2013). Relevant, acknowledged theories were used to construct the theoretical framework. Moreover, appropriate, systematic and rigorous methods were applied in the sub-studies that were consistent with the

research questions. Taking an abductive analytical approach to all the sub-studies achieved a comprehensive understanding of the research phenomenon (Alvesson & Sköldberg, 2008; Elo and Kyngäs, 2008), thus strengthening the research process. The findings provided implications for clinical practice and theory. These criteria strengthened the quality of this research programme. Concerning the trustworthiness of the research process, all parts, including reflexivity, are carefully described and explained in section 3.0 (Graneheim et al., 2017; Lincoln et al., 2013).

The strategy of Whittemore & Knafl (2005) was used to counteract mistakes during preparation of the systematic integrated review (sub-study 1). Providing well-formulated research questions, aims and inclusion and exclusion criteria promoted quality in the systematic search, selection of studies and data extraction phase. However, the included studies were not arranged according to quality demands because of lack of a suitable method. The included studies presented parents' perspective and experiences of their participation in their children's healthcare decisions from different perspectives and contexts. These variations can be viewed as a strength in terms of providing a comprehensive understanding of the research topic. However, it can also be regarded as a limitation because of the small number of studies from each context. Another potential limitation is that the systematic review included only English articles, excluding articles published in other languages.

Regarding credibility in sub-studies 2-4, a purposive selection procedure, with inclusion and exclusion criteria, was used to recruit participants who had relevant, varied experience with the research phenomenon. They engaged in constructing the phenomenon in the interviews, which resulted in sufficiently rich data. A purposeful, theoretical sampling (Tuckett, 2004) was practised for securing enough rich data to answer the research questions. The interview guides were based on acknowledged theories and previous research, which increased the quality of data production. However, the interview guides were not

'field-tested' (Kallio et al., 2016) due to difficulties recruiting participants to sub-studies 2-4, which may be a limitation. Nevertheless, the strength of the semi-structured interview method heightened the quality of the conversations. Because of recruitment difficulties in sub-studies 2-3, the sample of participants consist of few men, no single parents and no parents of children aged 11 – 16 years. This is a potential limitation. Several parents seemed to be in a demanding situation during their child's hospitalisation and had little energy and time to participate in an interview. Therefore, parents' life circumstances may have influenced whether they participated or not. This may be why no single parents were recruited. A more heterogenic sample, perhaps, would have added other findings. Parents of children aged 11 – 16 years may have talked about the influence of youths' involvement in DM. Parents in very demanding situations may have talked more about the hardships of the parental role at hospital more than others. Recruiting health professionals to sub-study 4 was also difficult because several had problems leaving clinical work for interviewing. This may have influenced the study's credibility.

The sample sizes of sub-studies 2-4 may not be considered adequate for answering the research questions, judging by the studies' information powers (Malterud, Siersma, & Guassora, 2016). The sub-studies' aims, sample specificity, use of established theory, quality of dialog and analysis strategies have been contemplated. According to the concept of information power, broad research aims, such as these sub-studies', require larger samples. The use of purposive sampling with inclusion criteria facilitated the recruitment of participants with both broad and highly specific experiences and knowledge. However, the characteristics of the participants were not optimally broad, causing the sample of sub-studies 2-3 to have some limitations, as reported. Nevertheless, the sub-studies were supported by established theories, such as patient involvement in healthcare decisions, FCC and salutogenesis. The quality of dialogue in the interviews was good (3.6.4), producing multiple, rich

data. Since the analytical strategies were explorative with in-depth analysis in all the sub-studies, sample sizes were required that were manageable but not too small (Graneheim et al., 2017; Malterud et al., 2016). To summarise, the study aims were broad; the participants were specific considering the research questions, causing some limitations; established theories were used; the interview dialogues were strong; and the analytical strategies required samples that were not too large to handle. The sample sizes for the sub-studies seemed to hold adequate information power to achieve the research aims.

The quality of the analytical processes and the influence of the researchers' pre-understandings affect dependability. A potential limitation to all of the data analyses was that the initial part was performed by one person. On the other hand, that the analysis was done by one person does not mean it is insufficient (Malterud, 2008, p. 181). Moreover, other researchers critically assessed the analyses and agreed on the final composite analysis. Furthermore, the entire research process, including data analyses, are always influenced by the researchers' pre-understandings (3.7), contexts and local cultures (Altheide & Johnson, 2013). As the main researcher, I had a pre-understanding and background as paediatric physiotherapist at the hospital, and those factors probably influenced the research process the most. Knowledge about the culture and institution can be an advantage when asking questions on the research topic that might obtain important information (Miller & Glassner, 2016). Or it may be a disadvantage, because the knowledge can blind someone from other perspectives. The influence of the supervisors' pre-understanding is considered a strength since the research context is interprofessional. However, all findings are based on values and perspectives and are contextual and partial (Altheide & Johnson, 2013). Therefore, other researchers may have arrived at other research findings, which may have provided another understanding and extended the knowledge of the research phenomenon.

There were some ethical considerations during the research process. Some of the participants appeared to be vulnerable and emotionally distressed during the interviews in sub-study 2-3. Extra care was taken with them. My impression was that they did not experience discomfort or extra strain and that they were grateful to have an opportunity to speak about their experiences of being at hospital. All the participants in sub-studies 2-4 had an opportunity to speak about how they perceived the interview setting. No one expressed discomfort or problems. However, it was challenging to secure the anonymity of the participants in Paper II-IV; therefore, I was careful when describing the samples and presenting quotations.

There were two key findings that surprised me: the high vulnerability of parents in DM and the ability to cope with the parental role at hospital in sub-studies II-III. Furthermore, in sub-study IV, I did not expect to find that some health professionals would have so little awareness of parents' rights to be involved in DM about shaping their children's healthcare. These findings helped me realise the importance of this research and motivated me to complete the programme.

5.3 Implications for practice and future research

5.3.1 Implications for practice

The thesis' holds several implications for clinical practice. Health professionals need to increase their awareness of the importance of their role and responsibility in involving parents in children's healthcare decisions. That means learning about the influence of their role in empowering parents in DM processes and encouraging parents' ability to cope with their parental role during children's hospitalisation. Health professionals need to provide individualised, respectful facilitation of parental involvement. They need to care about parents' preferred role in DM and their health literacy among other personal factors. Doing thus

could help promote parents' sense of coherence during involvement in DM and strengthen their ability to cope with the demands of the parental role at hospital. Optimal parental involvement in DM requires high communicative and relational competencies from health professionals. Health professionals should use empathic communication to improve their communication and relationships with parents. Furthermore, an increased awareness among health professionals about how they practise parental involvement in DM is important to counteracting the possible misuse of authority so that parents can act as user-representatives for their children.

However, health professionals also need to be aware of their foremost responsibility, to provide paediatric patients with technically safe, justifiable healthcare plans in accordance with governmental directives and evidence-based practice (Law of health professionals, 1999, § 4). In addition to high communicative and relational competencies, best practice requires high technical competencies, knowledge about evidence-based practice and the capacity to appraise such knowledge (Akerjordet, Lode, & Serverinsson, 2012; Paper I).

To improve FCC, the parents' role in healthcare needs to be decided in a shared DM process. However, when the health professionals involve parents in these DM it is important to promote their ability to cope with their parental role at hospital. That means both the children's and the parents' needs and preferences should to be considered as far as possible according to the hospital's arrangements. Such considerations are expected to improve the quality and safety of children's received healthcare.

The healthcare managers have an essential role in facilitating health professionals' involvement of parents in children's healthcare decisions. In accordance with the thesis' findings, they need to prioritise parental involvement and motivate their employees to improve their practices of parental involvement. The healthcare managers need to strengthen their

health professionals' competencies in clinical empathy, communication, sense of coherence theory, evidence-based practice, appraisal of information and technical knowledge. Furthermore, they need to arrange for health professionals to receive colleagues' support and guidance in challenging cases. The quality of complex intra- and interprofessional collaborations needs to be strengthened by increasing health professionals' understanding of their roles, collaborative communication, and improving their relationships with each other. In addition, adequate organisational resources are required.

5.3.2 Implications for future research

Further research is needed to increase the knowledge on health professionals' involvement of parents and the paediatric patient in DM about children's healthcare in an intra- and interprofessional collaborative practice at hospital. Knowledge is especially lacking about how to best involve the paediatric patient in DM and how that influences parental involvement (Feenstra et al., 2014; Papers I & IV; Park & Cho, 2018). Furthermore, the suggested model (Figure 4) needs to be confirmed and further developed with research on the topic in different national contexts. This can be performed by transferring the projects' findings to similar settings and applying them according to implementation research (Graham et al., 2006; Nilsen, 2015), thus documenting the effects. Quantitative research within a realist paradigm is required to confirm the findings for statistical generalisation using a longitudinal design and multilevel analysis (Polit & Beck, 2010). Moreover, more knowledge is needed from the intra- and interprofessional perspective. Further research is also needed to increase the knowledge on parental involvement in children's healthcare decisions among migrant parents with language and cultural barriers (Papers I & IV).

6 Conclusion

This thesis highlights the complexity of shared DM in children's healthcare decisions, contributing new insights into that field of research. It has generated new knowledge about the parents' and the health professionals' roles in parental involvement in children's healthcare decisions at hospital from a health-promoting perspective. It provides new insight into how practising shared DM in paediatric clinical practices influences parents' ability to cope with the parental role and the quality of children's healthcare. The ways in which parental involvement can be improved have been identified. Accordingly, the overall aim of this thesis has been fulfilled. In addition, the thesis contributes implications for clinical practice and further research.

The findings reveal that parents and health professionals have essential and demanding roles during shared DM about shaping and customising children's healthcare. Health professionals have an influential role in empowering parents in DM processes and thereby affect parents' ability to cope with their parental role during children's hospitalisation. Practising optimal parental involvement in children's healthcare decisions requires that the health professionals have a positive attitude and adequate competencies and organisational resources. Healthcare managers must to facilitate both actors' roles in shared DM to improve parents' ability to cope with their demanding parental role during children's hospitalisation. This is in accordance with FCC and the WHO's health promotion strategy.

This thesis supports the aims and principles of FCC, focusing in particular on meeting the parents' and the children's needs and preferences as far as possible within a given hospital. The children need parents who can cope with a demanding parental role during children's hospitalisation, which is in accordance with the biopsychosocial theory. Increased knowledge about involving the paediatric patient and parents

in DM processes is required to safeguard the paediatric patient by providing a technically safe and justifiable healthcare plan in line with governmental directives, evidence-based practice and the biopsychosocial theory.

References

Akerjordet, K., Lode, K., & Severinsson, E. (2012). Clinical nurses' attitudes towards research, management and organisational resources in a university hospital: part 1. *Journal of Nursing Management*, 20, 814-823.

Altheide, D. L., & Johnson, J. M. (2013). Reflections on Interpretive Adequacy in Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds), *Collecting and Interpreting Qualitative Materials* (pp. 381-412) (4th ed.). California: Sage Publications.

Alvesson, M., & Sköldberg, K. (2008). *Tolkning och reflektion. Vetenskapsfilosofi och kvalitativ metod.* (2nd ed.). Denmark: Studentlitteratur.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, 1(11),11-18.

Antonovsky, A. (2012). *Helsens mysterium. Den salutogene modellen.* Oslo: Gyldendal Akademisk. A Norwegian edition of Unraveling the Mystery of Health. How People Manage Stress and Stay Well (1987). San Francisco: Jossey-Bass Inc., Publishers.

Arnstein, S. R. (1969). A Ladder of Citizen Participation. *Journal of the American Planning Association,* 35(4), 216-224.

Avis, M., & Reardon, R. (2008). Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study. *Journal of Child Health Care*, 12(1), 7-17.

Barry, M. J., & Edgman-Levitan, S. (1998). Shared Decision Making -

The Pinnacle of Patient-Centered Care. Downloaded from nejm.org 14.01.18. *The New English Journal of Medicine*, (2012), march, 780-781.

Bazeley, P., & Jackson, K. (2013). *Qualitative data analysis with NVivo.* London: Sage Publications Ltd.

Bjertnæs, Ø. A., Garratt, A., Helgeland, J., Holmboe, O., Dahle, K. A., Hanssen-Bauer, K., & Røttingen, J. (2008). Foresattes vurdering av barne- og ungdomspsykiatriske poliklinikker. *Tidskrift Norsk Lægeforening, 9*, 1041-1045. (In Norwegian)

Bleakley, A. (2013). Working in "teams" in an era of "liquid" healthcare: What is the use of theory? *Journal of Interprofessional Care*, 27, 18-26.

Boland, L., Kryworuchko, J., Saarimaki, A., & Lawson, M. L. (2017). Parental decision making involvement and decisional conflict: a descriptive study. *BMC Pediatrics*, 17, 146-153.

Burns, N., & Grove, S. K. (2011). *Understanding nursing research. Building an evidence-based practice.* Maryland Heights: Elsevier Saunders.

Bærøe, K. (2009). Priority setting in health care: A framework for reasonable clinical judgements. *Journal of Medical Ethics*, 35, 488-496.

Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and Family Engagement: A Framework for Understanding The Elements And Developing Interventions And Policies. *Health Affairs*, 32, 223–231.

Charavel, M., Bremond, A., Moumjid-Ferdiaoui, N., Mignotte, H., & Carrere, M. O. (2001). Shared decision-making in question. *Pscho-Oncology,* 10, 93-102.

Charles, C., Gafni, A., & Whelan T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes, at least two to tango). *Social Science Medicine*, 44, 681-692.

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science Medicine,* 49, 651-661.

Cheng, J. (2018). My Take on the Biopsychosocial Model of Patient-Centered Care. *Pain Medicine*, 19, 2101-2103.

Choen, D. J., & Crabtree, B. F. (2008). Evaluative Criteria for Qualitative Research in Health Care: Controversies and Recommendations. *Annals of Family Medicine*, 6(4), 331-339.

Chorney, J., Haworth, R., Graham, M. E., Ritchie, K., Curran, J. A., & Hong, P. (2015). Understanding Shared Decision Making in Pediatric Otolaryngology. *Otolaryngology–Head and Neck Surgery*, 152(5), 941-947.

Corlett, J., & Twycross, A. (2006). Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing*, 15, 1308-1316.

Coyne, I. (2007). Disruption of parent participation: nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing*, 17, 3150-3158.

Coyne, I. (2013). Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expectations*, 18, 796–808.

Coyne, I. T. (1996). Parent participation: a concept analysis. *Journal of Advanced Nursing,* 23(4), 733-740.

Coyne, I., & Cowley, S. (2007). Challenging the philosophy of

partnership with parents: a grounded theory study. *International Journal of Nursing Studies*, 44, 893-904.

Coyne, I., Hallström, I., & Söderbäck, M. (2016). Reframing the focus of family-centred to a child-centred care approach for children's healthcare. *Journal of Child Health Care,* 20(4), 495-502.

Daly, J., Willis, K., Small, R., Green, J., Welch, N., Kealy, M., & Hughes, E. (2007). A hierarchy of evidence for assessing qualitative health research. *Journal of clinical epidemiology*, 60, 43-49.

D'Amour, D., Ferrada-Videla, M., San Martin-Rodriguez, L., & Beaulieu, M-D. (2005). The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks. *Journal of Interprofessional Care*, 19(1), 116-131.

Davies, R. (2010). Marking the 50th anniversary of the Platt Report: from exclusion, to toleration and parental participation in the care of the hospitalized child. *Journal of Child Health Care*, 14(1), 6-23.

Decety, J., Smith, K. E., Norman, G. J., & Halpern, J. (2014). A social neuroscience perspective on clinical empathy. *World Psychiatry*, 13, 233-237.

Denzin, N. K., & Lincoln, Y. S. (2013a). Introduction: The Discipline and Practice of Qualitative Research. In: N. K. Denzin, & Y. S. Lincoln (Eds), *The Landscape of Qualitative Research*. (pp. 1-41) (4th ed.). California: Sage Publications.

Denzin, N. K., & Lincoln, Y. S. (2013b). Part II. The Art and Practices of Interpretation, Evaluation, and Representation. In N. K. Denzin, & Y. S. Lincoln (Eds), *Collecting and Interpreting Qualitative Materials.* (pp. 245-354) (4th ed.). California: Sage Publications.

Diouf, N. T., Menear, M., Robitaille, H., Guèrard, G. P., & Lègarè, F. (2016). Training health professionals in shared decision making: Update of an international environmental scan. *Patient Education and Counseling*, 99, 1753-1758.

Dixon-Woods, M. (2016). Systematic Reviews and Qualitative Studies. In D. Silverman (Ed), *Qualitative research.* (pp. 379-394) (4th ed.). London: Sage Publications.

Donovan, J., & Sanders, C. (2007). Key issues in the analysis of qualitative data in health services research. In A. Bowling, S. Ebrahim (Eds), *Handbook of Health Research Methods: Investigation, Measurement and Analysis.* Berkshire, GB: Open University Press.

Edwards, M., Davies, M., & Edwards, A. (2009). What are the external influences on information exchange and shared decision-making in healthcare consultations: a meta-synthesis of the literature. *Patient Education and Counseling*, 75, 37-52.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115.

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P.J., Berger, Z., … Van der Weijden, T. (2017). A three-talk model for shared decision making: multistage consultation Process. *BMJ*, 359, j4891, 1-7.

Elwyn, G., Frosch, D. L., & Kobrin, S. (2016). Implementing shared decision-making: consider all the consequences. *Implementation Science*, 11,114 (1-10).

Elwyn, G., Lloyd, A., May, C., van der Weijden, T., Stiggelbout, A., Edwards, A., … Epstein, R. (2014). Collaborative deliberation: A model for patient care. *Patient Education and Counseling*, 97, 158-164.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A, Kinnersley, P., … Michael Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of General Internal Medicine*, 27(10), 1361-1367.

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science, 126*, 129-136.

Enosh, G., & Ben-Ari, A. (2016). Reflexivity: The Creation of Liminal Spaces-Researchers, Participants, and Research Encounters. *Qualitative Health Research*, 26(4), 578-584.

Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling*, 63, 268-278.

Eriksson, M., & Lindström, B. (2007). Antonovsky's sense of coherence scale and its relation with quality of life: a systematic review. *Journal of Epidemiol Community Health*, 61, 938-944.

Eriksson, M., & Lindström, B. (2008). A salutogenic interpretation of the Ottawa Charter. *Health Promotion International*, 23, 190-199.

Espezel, H., & Canam, C. J. (2003). Parent-nurse interactions: care of hospitalized children. *Journal of Advanced Nursing,* 44(1), 34-41.

Feenstra, B., Boland, L., Lawson, M. L., Harrison, D., Kryworuchko, J., Leblanc, M., & Stacey, D. (2014). Interventions to support children's engagement in health-related decision: a systematic review. *BMC Pediatrics*, 14, 109-118.

Fiks, A. G., & Jimenez, M. E. (2010). The promise of shared decision-making in paediatrics. *Acta Paediatrica*, 99(10), 1464-1466.

Foster, M., Whitehead, L., & Maybee, P. (2010). Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: A review of the literature. *International Journal of Nursing Studies*, 47(9), 1184-1193.

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in Knowledge Translation: Time for a Map? *The Journal of Continuing Education in the Health Professions*, 26(1), 13-24.

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56, 29-34.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.

Groven, G., Danielsen, K., Holte, T., & Helgeland, J. (2006). Pårørendes erfaringer med somatiske barneavdelinger - hovedresultater fra nasjonal undersøkelse. (Acessed 11.06.10). http://www.kunnskapssenteret.no. (In Norwegian)

Halkier, B. (2010). *Fokusgrupper*. Oslo: Gyldendal Norsk Forlag.

Hallström I., & Elander, G. (2004). Decision-making during hospitalization: parents' and children's involvement. *Journal Clinical Nursing,* 13, 367-375.

Hallström, I., Runeson, I., & Elander, G. (2002). An observational study of the level at which parents participate in decisions during their child's hospitalization. *Nursing Ethics*, 9, 202-214.

Halpern, J. (2014). From idealized clinical empathy to empathic

communication in medical care. *Medicine, Health Care and Philosophy*, 17, 301-311.

Harrison, T. M. (2010). Family-Centered Pediatric Nursing Care: State of the Science. *Journal of Pediatric Nursing*, 25, 335-343.

Holstein, J. A., & Gubrium, J. F. (2016). Narrative Practice and the Active Interview. In D. Silverman (Ed), *Qualitative research.* (pp. 67-82) (4th ed.). London: Sage Publications.

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, 11, 232-251.

Jimenez, M.E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2013). The impact of parental health literacy on the early intervention referal process. *Journal of Health Care for Poor and Underserved*, 24(3), 1053-1062.

Jolly, J., & Shields, L. (2009). The evolution of family-centered care. *Journal of Pediatric Nursing*, 24, 164-170.

Kallio, H., Pietilä, A., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954-2965.

Karl, S. R., & Holland, J. C. B. (2015). The Roots of Psychosomatic Medicine II: George L. Engel. *Psychosomathics*, 56, 630-633.

Kelly, K. P., Mowbray, C., Pyke-Grimm, K., & Hinds, P. S. (2017). Identifying a conceptual shift in child and adolescent-reported treatment decision making: "Having a say, as I need at this time". *Pediatric Blood &Cancer*, 64, 1-8.

Khan, A., Coffey, M., Litterer, K. P., Baird, J. D., Furtak, S. L., Garcia,

B.M., … the Patient and Family Centered I-PASS Study Group. (2017). Families as Partners in Hospital Error and Adverse Event Surveillance. *JAMA Pediatrics*, 171(4), 372-381.

Knafl, K., & Whittemore, R. (2017). Top 10 Tips for Undertaking Synthesis Research. *Reasearch in Nursing* & Health, 40, 189-193.

Kon, A. (2010). The Shared Decision-Making Continuum. *The Journal of the American Medical Association*, 304(8), 903-904.

Körner, M., Ehrhardt, H., & Steger, A-K. (2013). Designing an interprofessional training program for shared decision making. *Journal of Interprofessional Care*, 27, 146-154.

Kristiansen, I. S., & Mooney, G. (2004). *Evidence-Based Medicine. In its Place.* New York: Routledge

Land, V., Parry, R., & Seymour, J. (2017). Communication practices that encourage and constrain shared decision making in health-care encounters: Systematic review of conversation analytic research. *Health Expectations*, 20, 1228-1247.

Law of health professionals (1999). Lov om helsepersonell (helsepersonelloven). (acessed 30.09.18) https://lovdata.no/dokument/NL/lov/1999-07-02-64/%25C2%25A75#%C2%A75 (In Norwegian)

Légaré, F., Adekpedjou, R., Stacey, D., Turcotte, S., Kryworuchko, J., Graham, I.D., … Donner-Banzhoff, N. (2018). Interventions for increasing the use of shared decision making by healthcare professionals (Review). *Cochrane Library. Cochrane Database of Systematic Reviews.*

Légaré, F., Ratte', S., Gravel, K., & Graham, I. D. (2008). Barriers and

facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Education and Counseling,* 73, 526-535.

Légaré, F., Stacey, D., Pouliot, S., Gauvin, F-P., Desroches, S., Kryworuchko, J., …. Graham, I. D. (2011). Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. *Journal of Interprofessional Care*, 25, 18-25.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2013). Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited. In N. K. Denzin, & Lincoln, Y. S. (Eds), *The Landscape of Qualitative Research.* (pp.199-265), (4th ed.). California: Sage Publications.

Lindström, B. (2018). Workshop salutogenesis and the future of health promotion and public Health. *Scandinavian Journal of Public Health*, 46(20), 94–98.

Lindström, B., & Eriksson, M. (2010). *The Hitchhiker's guide to salutogenesis. Salutogenic pathways to health promotion.* Helsinki: Folkhälsan research Center.

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What Is Known about Parents' Treatment Decisions? A Narrative Review of Pediatric Decision Making. *Medical Decision Making*, 32, 246-258.

Lown, B. A. (2016). A social neuroscience-informed model for teaching and practising compassion in health care. *Medical Education*, 50, 332-342.

Lown, B. A., Kryworuchko, J., Bieber, C., Lillie, D. M., Kelly, C., Berger, B., & Loh, A. (2011). Continuing professional development for interprofessional teams supporting patients in

healthcare decision making. *Journal of Interprofessional Care*, 25(6), 401-408.

Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling,* 60, 301-312.

Malterud, K. (2008). *Kvalitative metoder i medisinsk forskning.* Oslo: Universitetsforlaget. (In Norwegian)

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guideed by Information Power. *Qualitative Health Research*, 26(13), 1753-1760.

Massimo, L. M., Wiley, T. J., & Casari, E. F. (2004). From informed consent to shared consent: a developing process in paediatric oncology. *The Lancet Oncology*, 5, 384-387.

Miller, J., & Glassner, B. (2016). The 'Inside' and the 'Outside': Finding Realities in Interviews. In D. Silverman (Ed), *Qualitative research* (pp. 51-66) (4th ed.). London: Sage Publications.

Naidoo, J., & Wills, J. (2009). *Foundations for Health Promotion. Public health and health promotion practice.* (3d ed.). Bailliére Tindall, Elsevier.

National health and hospital plan (2015). Nasjonal helse- og sykehusplan (2016-2019). Meld. St. 11 (2015-2016). (acessed 25.08.17) https://regjeringen.no/no/dokumenter/i-korte-trekk-nasjonal-helse- og sykehusplanny-side/id2462251/ (In Norwegian)

Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation science*, 10, 53.

Nutbeam, D. (2009). Defining and measuring health literacy: what can

we learn from literacy studies? *International Journal of Public Health*, 54, 303-305.

Ofstad, E. H., Frich, J. C., Schei, E., Frankel, R. M., & Gulbrandsen, P. (2014). Temporal characteristics of decisions in hospital encounters: A threshold for shared decision making? A qualitative study. *Patient Education and Counseling*, 97, 216-222.

Ostrom, E. (1996). Crossing the great divide: Coproduction, synergy, and development. *World Development*, 24(6), 1073.

Papadimitriou, G. (2017). The "Biopsychosocial Model": 40 years of application in Psychiatry. *Psychiatriki*, 28(2), 107-110.

Park, E. S., & Choe, I. Y. (2018). Shared decision-making in the paediatric field: a literature review and concept analysis. *Scandinavian Journal of Caring Sciences*, 32, 478-489.

Patients' Rights Act. The Act of 2 July. (1999). No. 63 relating to Patient's Rights. (accessed 20.02.17) http:app.uio.no/ub/ujur/oversatte-lover/data/lov-19990702-063-eng.pdf

Peräkylä, A. (2016). Validity in Qualitative Research. In D. Silverman (Ed), *Qualitative research* (pp. 413-428) (4th ed.). London: Sage Publications.

Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies*, 47, 1451-1458.

Power, N., & Franck, L. (2008). Parent participation in the care of hospitalized children: a systematic review. *Journal of Advanced Nursing*, 62, 622-641.

Power, T. E., Swartzman, L. C., & Robinson, J. W. (2011). Cognitive-emotional decision making (CEDM): a framework of patient medical decision making. *Patient Education and Counseling*, 83, 163-169.

Reeves, S., Pelone, F., Harrison, R., Goldman, J., & Zwarenstein, M. (2017). Interprofessional collaboration to improve professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews*, Issue 6. Art. No.: CD000072.

Regulations of children's hospitalisation (2000). Forskrift om barns opphold i helseinstitusjon. (acessed 01.01.19). https://lovdata.no/dokument/SF/forskrift/2000-12-01-1217?q=forskrift%20om%20barns%20opphold%20i (In Norwegian)

Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M. Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: what it is and what it isn't. *British Medical Journal,* 312, 71-72.

San Martin-Rodriquez, L., Beaulieu, M-D., D'Amour, D., & Ferrada-Videla, M. (2005). The determinants of successful collaboration: A review of theoretical and empirical studies. *Journal of Interprofessional Care*, 19(1), 132-147.

Shields, L. (2010). Models of care. Questioning family-centred care. *Journal of Clinical Nursing*, 19, 2629-2638.

Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: a review of qualitative studies. *Journal of Clinical Nursing*, 15, 1317-1323.

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012). Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database of Systematic Reviews* (10).

Silverman, D. (2013). *Doing qualitative research* (4th ed.). London: Sage Publications.

Silverman, D. (2014). *Interpreting qualitative data* (5th ed.). London: Sage Publications.

Silverman, D. (2016). Introducing Qualitative Research. In D. Silverman (Ed), *Qualitative research.* (pp. 3-14), (4th ed.). London: Sage Publications.

Smith, J., Cheater, F., Bekker, H., & Chatwin, J. (2013). Are parents and professionals making shared decisions about a child's care on presentation of a suspected shunt malfunction: a mixed method study? *Health Expectations*, 18, 1299–1315.

Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition – a concept synthesis of family-centred care and partnership-in-care. *Journal of Pediatric Nursing*, 30, 143-159.

Solomons, N. M., & Spross, J. S. (2011). Evidence-based practice barriers and facilitators from a continuous qualitative improvement perspective: an integrative review. *Journal of Nursing Management, 19,* 109-120.

Sorensen, K., Pelikan, J. M., Rothlin, F., Ganahl, K., Slonska, Z., Doyle, G., ... & Brand, H. (2015). Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *European Journal of Public Health*, 5, 1-6.

Stewart, J. L., Pyke-Grimm, K. A., & Kelly, K. P. (2005). Parental treatment decision making in pediatric oncology. *Seminars in Oncology Nursing,* 21 (2), 89-97.

Stewart, J. L., Pyke-Grimm, K. A., & Kelly, K. P. (2012). Making the

right decision for my child with cancer: the parental imperative. *Cancer Nursing*, 35, 419-428.

Tallon, M. M., Kendall, G. E., & Snider, P. D. (2015a). Development of a measure for maternal confidence in knowledge and understanding and examination of psychosocial influences at the time of a child's heart surgery. *Journal for Specialist in Pediatric Nursing*, 20, 36-48.

Tallon, M. M., Kendall, G. E., & Snider, P. D. (2015b). Rethinking family-centred care for the child and family in hospital. *Journal of Clinical Nursing,* 24, 1426-1435.

Taylor, S. E. (2006). *Health psychology*. Boston: McGraw-Hill.

Teng, C. I., Chang, S. S., & Hsu, K. H. (2009). Emotional stability of nursing: impact on patient safety. *Journal of Advanced Nursing*, 5(10), 2088-2096.

The Norwegian Directorate of Social and Health (2005). Sosial- og helsedirektoratet (2005) .... og bedre skal det bli. Nasjonal strategi for kvalitetsforbedring i Sosial- og Helsetjenesten (2005-2015). (Veileder IS-1162). (In Norwegian)

The Norwegian Ministry of Health and Care Services (2011). Helse- og omsorgsdepartementet (2011). Nasjonal helse- og omsorgsplan (2011-2015). Meld. St. 16 (2010-2011). (In Norwegian)

The Norwegian Ministry of Health and Care Services (2012). Helse- og omsorgsdepartementet (2012). God kvalitet – trygge tjenester. Kvalitet og pasientsikkerhet i helse- og omsorgstjenesten. Meld. St. 10 (2012-2013). (In Norwegian)

The Norwegian Ministry of Health and Care Services (2014). Helse- og omsorgsdepartementet (2014). Kvalitet og pasientsikkerhet

2013. Meld. St. 11 (2014-2015). (In Norwegian)

The Norwegian Ministry of Social and Health Services (1999). Sosial- og helsedepartementet. (1999). Om verdier for den norske helsetjenesten. St.meld. nr. 26 (1999-2000). (In Norwegian)

Thompson, A. G. H. (2007). The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine*, 64, 1297-1310.

Tuckett, A. (2004). Qualitative research sampling: the very real complexities. *Nurse Researcher*, 12(1), 47-60.

Tyreman, S. (2014). Finding the system in the System. *Philosophy, Psychiatry & Psychology*, 21(3), 207-209.

Uhl, T., Fisher, K., Docherty, S. L., & Brandon, D. H. (2013). Insights into Patient and Family-Centered Care Through the Hospital Experiences of Parents. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 42, 121-131.

Uniacke, S., Browne, T. K., & Shields, L. (2018): How should we understand family-centred care? *Journal of Child Health Care*, 22(3), 460–469.

Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: a model whose time has come. *Clinical Rehabilitation*, 31(8), 995 –1004.

Wangmo, T., De Clercq, E., Ruhe, K. M., Beck-Popovic, M., Rischewski, J., Angst, … Elger, B. S. (2017). Better to know than to imagine: Including children in their health care. *AJOB Empirical Bioethics*, 8(1), 11-20.

Watts, R., Huaqiong, Z., Shields, L., Taylor, M., Munns, A., & Ngune, I. (2014). Family-centered care for hospitalized children aged 0-12 years: a systematic review of qualitative studies. *JBI*

Database of Systematic Reviews & Implementation Report, 12(7), 204-283.

Whall, A. L., Sinclair, M., & Parahoo, K. (2006). A philosophic analysis of evidence-based nursing: recurrent themes, metanarratives, and exemplar cases. *Nursing Outlook*, 54, 30-35.

Whittemore, R. (2005). Combining Evidence in Nursing Research Methods and Implications. *Nursing Research*, 54(1), 56-62.

Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553.

Wirtz, V., Cribb, A., & Barber, N. (2006). Patient-doctor decision-making about treatment within the consultation - a critical analysis of models. *Social Science & Medicine*, 62, 116-124.

World Health Organization (2009). Milestones in Health Promotion. Statements from Global Conferences. (accessed 25.07.17) http://www.who.int/healthpromotion/Milestones_Health_Promotion_05022010.pdf

World Medical Association (2013). *Ethical Principles for Medical Research Involving Human Subjects.* (accessed 14.11.17) Available at: wma.net.

Wyatt, K. D., List, B., Brinkman, W.B., Lopez, G. P., Asi, N., Erwin, P., … LeBlanc, A. (2015). Shared Decision Making in Pediatrics: A systematic Review and Meta-analysis. *Academic Pediatrics*, 15, 573-583.

PART II

List of papers

PAPER I

Aarthun, A., & Akerjordet, K. (2014). Parent participation in decision-making in health-care services for children: an integrative review. *Journal of Nursing Management*, 22, 177-191.

PAPER II

Aarthun, A., Øymar, K., & Akerjordet, K. (2019). Parental involvement in decision-making about their child's healthcare at the hospital. *Nursing Open*, 6, 50-58.

PAPER III

Aarthun, A., Øymar, K., & Akerjordet, K. (2018). How health professionals facilitate parents' involvement in decision-making at the hospital: A parental perspective. *Journal of Child Health Care*, 22(1), 108-121.

PAPER IV

Aarthun, A., Øymar, K., & Akerjordet, K. Health professionals' involvement of parents in decision-making in interprofessional practice at the hospital. *Manuscript submitted in Journal of Interprofessional Care 21.08.18.*

Paper I

Aarthun, A., & Akerjordet, K. (2014). Parent participation in decision-making in health-care services for children: an integrative review. *Journal of Nursing Management*, 22, 177-191.

Journal of Nursing Management, 2014, **22**, 177–191

Parent participation in decision-making in health-care services for children: an integrative review

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Parent participation in decision-making in health-care services for children: an integrative review

Aim To describe and synthesize previous research on parents' perceptions of their participation in decision making in child health-care services.
Background Health policy in the area of user involvement emphasizes parent participation in decision-making (DM), thus ensuring that services are provided in accordance with their child's needs and enhancing parents' control over their child's health-care services.
Method A systematic literature search, covering the period January 2000 to February 2011, found 18 studies that met the inclusion criteria. The analysis process involved data extraction, reduction, comparison and synthesizing.
Findings Three themes emerged: (1) relational factors and interdependence, (2) personal factors and attitudes and (3) organisational factors.
Conclusions Parents highlighted the importance of the parent–health professional relationship, professionals' competence and the possibility of varying the degree of participation in decision making. Challenges involved asymmetry in authority and power, professionals' attitudes and competence and organisational shortcomings in health-care services. Health professionals need to become more aware of their critical role and responsibility in involving parents in DM.
Implications for nursing management Health professionals' attitudes and competence can be improved by knowledge of user involvement and research and facilitating the inclusion of parents in decision making by influencing the culture, routines and resources in the health service.

Keywords: decision-making, health-care services, parent participation, parent–health professional relationship, review

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Introduction

This systematic review deals with parent participation in decision-making (DM) and the challenges they face in health-care services for children. In most Western countries, health policy in the area of parent participation has changed to place increased emphasis on the inclusion of parents as partners in child health-care services (Gabe *et al.* 2004, Jackson *et al.* 2008). Since the 1970s, there has been a shift in the perceptions of health, disease and the roles of health professionals and patients, from biomedical to biopsychososial and

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holistic theories (Taylor 2006). At the same time, there has been a shift from a paternalistic DM model, where the professionals make the decisions, to a shared model, in which both parents and health professionals play an active part by sharing information and reaching consensus. In the informed decision-making model, which includes informed consent and choice, parents are expected to make their own decisions after professionals have provided appropriate information about the options (Wirtz *et al.* 2006). This approach is considered an important part of the user involvement paradigm, which is a principle of health policy in many countries. The aim of user involvement is to increase patient influence on treatment and care decisions, thus ensuring that services are provided in accordance with their needs, and to enhance patient control over health care (Ford *et al.* 2003, Bradshaw 2008). Increased patient participation is asserted to favour patient health outcomes and satisfaction (Ford *et al.* 2003, O'Connor *et al.* 2009).

Family-centred care and services are an important part of user involvement and thus designed to ensure that health care can be planned both individually for the child and around the whole family (Franck & Callery 2004, Jolly & Shields 2009). Ongoing role negotiation and open communication with parents are reported to be important elements in family-centred care and services. Today, these elements do not appear to be included sufficiently in clinical settings (Espezel & Canam 2003, Jolly & Shields 2009). Illness, personal and relational factors were found to influence parental DM in paediatric oncology units (Stewart *et al.* 2005). In order to make informed decisions, parents need support in the form of information, talking to others and a sense of control over the process (Jackson *et al.* 2008).

Shared DM has not yet been widely implemented in the health-care services (Elwyn *et al.* 2003, Guimond *et al.* 2003, Légaré *et al.* 2008) and there is a need for increased understanding of factors that affect the implementation process (Légaré *et al.* 2010). For this reason it is essential to obtain a better comprehension of parents' needs and preferences. When perusing the literature, no review on parent participation in shared DM was found. Therefore, it is vital to perform a systematic review on shared DM to determine current knowledge of parent participation. A review may contribute important implications for practice and health management, which can have a significant impact on the quality of children's health-care services. This systematic review may also identify gaps in present knowledge, thus providing suggestions for further research.

Aim

The aim of this review study was to describe and establish a synthesis of previous research on parents' perceptions of their participation in DM and the challenges they face in health-care services for children. The review question was: What is the current knowledge of parent participation in DM and the challenges they face in health-care services for children?

Methods

Design

An integrative review was performed in order to determine current knowledge and establish a synthesis of understanding (Burns & Grove 2011). It involved identifying, selecting and synthesizing previous independent studies containing diverse methodologies and was performed according to Whittemore and Knafl's (2005) framework.

Search methods

A systematic search was conducted in the Academic Search Elite, ERIC, CINAHL and MEDLINE databases, with the following key words in various combinations: decision making, parent, child, healthcare, negotiation, consumer involvement, consumer, decision, parent participation, relationship, informed content and informed choice. The search was limited by the inclusion criteria. 'Decision' and 'parent' were found to be the most sensitive search words. Thus, additional searches were performed with these words in the PsycInfo, AMED, ISI Web of Science, ScienceDirect, PEDro and EMBASE. Moreover, searches in international journals were performed electronically in: 'Social Science & Medicine', 'Health Expectation', 'Medical Informatics and Decision Making' and 'Patient Counseling and Health Education'. Finally, the references in relevant articles were manually scanned for studies that might have been missed by the database searches.

Inclusion and exclusion criteria

The inclusion criteria were:

- peer reviewed articles published in the period January 2000 to February 2011;
- in English;

- studies with quantitative and qualitative design;
- studies that included data related to parents' participation in DM regarding their child's treatment and care in health-care services in Western countries, but not restricted to DM as the main objective of the study;
- studies limited to somatic health-care services, but not restricted to somatic diagnoses.

The exclusion criteria were:

- Studies about informed consent in terminal and palliative care, resuscitation, acute care, immunization, and prenatal and natal screening and diagnosis because of the wealth of research available in these areas;
- studies about outcomes of general parent intervention programmes, DM tools, children's participation in DM and decisions about children's participation in randomized clinical trials;
- studies about parent participation in DM in the mental health services.

Search outcomes

Overall, the systematic searches revealed 1503 articles (Table 1). The titles and, when necessary, the abstracts were reviewed according to the inclusion criteria, after which 74 articles were considered relevant (Figure 1). These were then reviewed in their entirety, after which 55 studies remained. A new systematic assessment of the articles in relation to the inclusion criteria and research question resulted in a final sample of 18 studies. Scanning of the reference lists of the studies included and other relevant articles and reviews failed to add more studies. To ensure transparency, the retrieval and selection processes are presented in Figure 1.

Table 1
The systematic search and outcomes

Databases	*Papers identified in the search*	*Selected papers*
Academic Search Elite, ERIC, CINAHL, MEDLINE		11
'Informed consent' AND parent AND child	137	
Relationship AND child AND healthcare AND parent	129	
'Parent participation' AND child AND healthcare	11	
Involvement AND parent AND child AND healthcare	38	
Decision AND parent AND child	57	
Negotiation AND parent AND child AND decision-making AND healthcare	11	
ISI Web of Science		
Decision AND parent	77	6
PsykInfo		
Decision AND parent	119	3
ScienceDirect		
Decision AND parent	206	16
AMED		
Decision AND parent	123	4
EMBASE		
Decision AND parent	130	3
PEDro		
Decision AND parent	0	0
International journals: Search words: decision AND parent		
Patient Counselling and Health Education	301	16
Social Science & Medicine	127	15
Health Expectation	4	0
Medical Informatics and Decision Making	33	0
Total	1503	74

Quality appraisal

A critical appraisal of the 18 studies was performed according to the guidelines for quantitative and qualitative research by Burns and Grove (2011). This involved a careful examination of all aspects of the studies, including purpose, research problems, literature reviews, methods, results and conclusions in order to judge the studies' strengths, weaknesses, limitations and significance.

Of the 18 studies included, five had a quantitative design, eight had a qualitative design and five had a mixed-method design. Methodological approaches such as descriptive research (Tait *et al.* 2001, Cygan *et al.* 2002, Miceli & Clark 2004, Pyke-Grimm *et al.* 2006, Brotherton *et al.* 2007, Tarini *et al.* 2007, Ellberg *et al.* 2010, McKenna *et al.* 2010), descriptive correlational research (Cox *et al.* 2007), quasi-experimental research (Penticuff & Arheart 2005), ethnographical research (Hallström *et al.* 2002, Hallström & Elander 2004, Alderson *et al.* 2006) and grounded theory research (Kirk 2001, MacKean *et al.* 2005, Fiks *et al.* 2011) were applied. Eleven studies reported the parent perspective and seven reported both the parent and the professional perspectives. The context of the studies varied and included hospital units, primary care, physicians' practice and a physiotherapy practice.

The quality appraisal of the studies revealed that the research problems and purposes were relevant

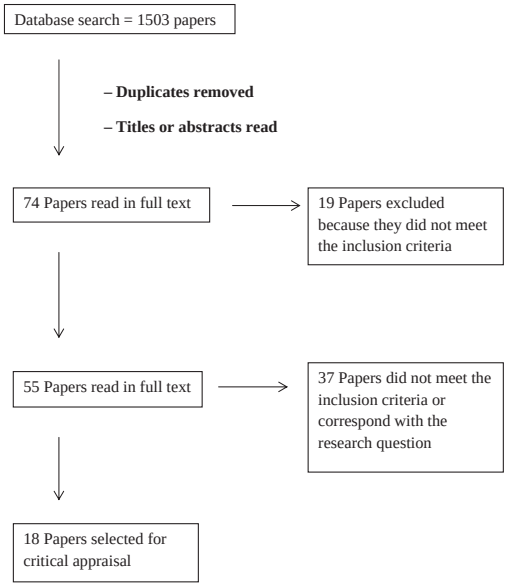

Figure 1
Flow chart of the selection process.

and significant in relation to earlier research. The studies included literature that was relevant to the problem and purpose. Similarly, the methodology of the individual studies seemed to be relevant and appropriate to their purposes (Burns & Grove 2011). The studies had varying degrees of focus on methodological procedures, rigour and bias, limitations and ethical rigour. One study only provided a very brief description of the data analysis process (Miceli & Clark 2004). Six of the 10 studies with a quantitative or a mixed-method design reported the instrument's validity and reliability (Penticuff & Arheart 2005, Pyke-Grimm *et al.* 2006, Brotherton *et al.* 2007, Cox *et al.* 2007, Ellberg *et al.* 2010, McKenna *et al.* 2010). The sample sizes of three of the studies were small (Pyke-Grimm *et al.* 2006, Brotherton *et al.* 2007, Cox *et al.* 2007) and three articles failed to explicitly state the limitations (MacKean *et al.* 2005, Penticuff & Arheart 2005, Young *et al.* 2006). In addition, ethical reflections were only briefly mentioned in two articles (Guerriere *et al.* 2003, Alderson *et al.* 2006) and not mentioned at all in four (Tait *et al.* 2001, Cygan *et al.* 2002, Penticuff & Arheart 2005, Tarini *et al.* 2007). The conclusions of the studies were based on the results. The studies included are presented in Table 2.

Analytical process

The data analysis process involved the following steps:

Data reduction
Relevant primary sources from the studies were organised into a group classification system based on the following themes: (1) parent participation in DM, (2) parents' perceptions of their participation in DM and (3) factors that may influence parents' role in DM. Only data directly related to parent participation in DM were included. Overlapping data on shared and informed DM were included, although there is no universally agreed definition of the DM models (Makoul & Clayman 2006, Wirtz *et al.* 2006). Data were then extracted and coded in the group classification system.

Data display
The coded data were organised in accordance with the group classification system.

Data comparison
The data were compared to identify patterns, themes, and relationships on the basis of the following questions: (1) How do parents participate in DM in healthcare services for children? (2) What perceptions do parents have about their participation in DM? and (3) Which factors seem to influence parents' participation in DM? The data were placed in subgroups and labelled using descriptions such as parents' participation reported by observation, parents' participation reported by parents, parents' ability to be involved in DM, characteristics of parents' influence on their participation in DM and parents' preferences. Meaningful higher-order clusters were then identified, such as relational factors, personal factors pertaining to the parents, health professionals' attitudes and parents' preferences.

Synthesis and verification
Important elements were synthesized into an integrative summary of the topic, after which the main themes were developed. In the verification, the links between the study process, findings and previous studies were examined and conflicting evidence addressed. The two authors reached a consensus on the final composite analysis and synthesis.

Results

The quality of the studies included was generally good with the exception of a few weaknesses arising from varying degrees of focus on methodological rigour and

Table 2
Characteristics of the included studies

Authors and country	*Purpose*	*Design*	*Data collection/sample size*	*Findings which are relevant for the review*
Alderson *et al.* (2006), UK	Are parents informed in detail and asked to consent to procedures in medical care, and do they want to be asked?	Qualitative method. Ethnographic research	Observation, semi-structured interview. 96 parents 40 practitioners	Informed consent tended to be connected to major medical decisions, but these arose relatively rarely in the unit. Parents' viewed two-way decision-making as the 'drawing together' aspect and the need to know. The doctors tended to be concerned with the 'distancing' aspect so as to provide a good service including honest information, warning about and preparing parents for possible problems, preventing dissatisfaction and potential litigation by parents
Brotherton *et al.* (2007), UK	To explore and compare parents' perceptions of home gastrostomy feeding in children following PEG, to those of paediatric outreach nurses and paediatric dietitians	Mixed-method. Comparative descriptive design. Cross-sectional study	Structured interview, questionnaire; 24 parents, 21 dietitians 15 nurses	Parents, nurses and dietitians shared similar perceptions regarding success of feeding, support for gastrostomy reinsertion and the acceptability of the child's quality of life. There were far greater differences in perceptions regarding the parents' involvement in the PEG placement decision-making process and adequacy of the support received from health-care professionals.
Cox *et al.* (2007), USA	To assess the amount of deliberation; the involvement of parents and children in deliberation and how it is associated with child, physician, parent, and visit characteristics	Quantitative method. Descriptive correlational design	Observation, questionnaire; 101 children with parents, 15 physicians	The majority of visits were characterized by passive involvement of parents and children (65%). A substantial proportion of each visit was devoted to deliberation and included consideration of multiple plans. There were considerable variations in deliberation. Longer visits were associated with more plans, longer deliberation and reduced chances of passive parent/child involvement. Shorter deliberations occurred with college-graduate parents
Cygan *et al.* (2002), USA	To examine how parents of children with bleeding disorders describe quality health care and indicators of quality care that are important to them	Mixed-method. Descriptive design	Questionnaire, Quality Health Care Questionnaire; 54 parents	According to the parents, the most important indicators of quality of care were: being included in decisions about their child's care, their child being cared for by nurses and doctors

Table 2
(Continued)

Authors and country	*Purpose*	*Design*	*Data collection/sample size*	*Findings which are relevant for the review*
				who are competent and up-to-date and with whom they can communicate
Ellberg *et al.* (2010), Sweden	To investigate how new parents experience postpartum care	Mixed-method. Descriptive design. Cross-sectional study	Questionnaire; 773 mothers, 701 fathers	There was an asymmetric encounter between parents and staff. Parents were dissatisfied with their possibility to influence care (50%) and actively participate in decision-making (35%). Fathers were significantly more dissatisfied. The close emotional attachment between the parents was not always supported by staff
Fiks *et al.* (2011), USA	To compare how parents and clinicians understand shared decision-making in ADHD	Qualitative method. Grounded theory research	Semi-structured interview; 60 parents, 30 clinicians	Parents described shared decision-making as a partnership between equals. Clinicians understood shared decision-making as a means to encourage families to accept clinicians' recommended treatment. Both groups viewed shared decision-making favourably and were aware of barriers that limit consideration of evidence-based treatments and involvement of key participants
Guerriere *et al.* (2003), Canada	To explore mothers' perceptions of decision uncertainty concerning gastrostomy tube insertion according to O'Connor's four factors: lack of information; unclear value trade-offs; lack of support; social pressure	Qualitative method	Semi-structured interview, O'Connors' 24-item Decisional Conflict Scale; 50 mothers	Mothers indicated that the decision-making was extremely challenging and that several factors contributed to their uncertainty. Half of the mothers reported feeling under pressure during the decision-making process. Most mothers wanted more information; 76% reported that they had received some support during the decision-making process and the rest had received no support
Hallström and Elander (2004) Sweden	To explore what kind of, and how decisions were made during a child's hospitalization	Qualitative method. Ethnographic research	Observation; 25 children, 25 parents	Most decisions were of a medical nature, and usually decisions were made in consultation with those affected. The children and their parents were usually involved in the decision-making process, but made few decisions themselves. Few decisions were reconsidered when they disagreed with the decision made

Table 2
(Continued)

Authors and country	*Purpose*	*Design*	*Data collection/sample size*	*Findings which are relevant for the review*
Hallström *et al.* (2002), Sweden	To investigate the extent to which parents participate in decisions concerning their child's care and to identify the factors that influence a parent's degree of participation	Qualitative method. Ethnographic research	Observation; 25 children, 25 parents	Parents' possibility to be involved in decision making varied. Two factors seemed to influence the level of parent participation: how explicitly parents explained their needs and how sensitive staff members were in identifying parents' needs
Kirk (2001),UK	To assess how transfer of responsibility from professionals to parents was negotiated, the tensions and contradictions that can ensue and the implications for the professional nursing role and relationships with parents	Qualitative method. Grounded theory.	Interview; 33 parents, 44 professionals	From the parents' perspective, their initial assumption of responsibility for the care of their child was not subject to negotiation with professionals before discharge. As parents gained experience in caring for their child and in interacting with professionals, role negotiation appeared to occur. Factors such as professionals' expectations of parental involvement in the care of sick children, parents' feelings of obligation and lack of community services acted as barriers to negotiation
MacKean *et al.* (2005), Canada	To develop a conceptualization of family-centred care grounded in the experiences of families and health-care providers	Qualitative method. Grounded theory	Interview, focus group; 37 parents, 16 professionals	Parents want to work collaboratively with health-care providers in making treatment decisions and implementing a dynamic care plan that will work best for child and family
McKenna *et al.* (2010), UK	To investigate parents' information needs and involvement in decision-making processes that affect the care of children diagnosed with cancer	Mixed-method. Descriptive design	Interview, demographic quest. Decisional Conflict Scale, Responsibility for Treatment Choice Questionnaire (RTCQ); 66 parents	Parents reported that doctors contributed almost twice as much to the decision-making process as they did. Parental satisfaction was positively correlated with the amount of information received before giving informed consent. Satisfaction about their involvement in this process depended upon the level of support received from others. Health professionals' accessibility, support, information and the degree of control afforded to parents had an impact upon parental satisfaction with the decision-making process and their confidence in the decisions made

Table 2
(Continued)

Authors and country	*Purpose*	*Design*	*Data collection/sample size*	*Findings which are relevant for the review*
Miceli and Clark (2004), USA	To obtain information about how to improve the experience of paediatric inpatient care	Quantitative method. Descriptive design. Cross-sectional studies	Questionnaire; 50446 parents	Overall, the parents were satisfied with the paediatric care experience. One of their top priorities was improved staff efforts to include parents in decisions about the child's treatment
Penticuff and Arheart (2005), USA	To test the effect of an intervention to strengthen parent –professional collaboration by increasing the accuracy of parents' understanding of medically relevant information and to increase parents' satisfaction with their input to decisions about their infants' treatment by providing parent–professional infant care-planning meetings	Quantitative method. A quasi-experimental design	Questionnaire; Parents' Understanding of Infant Care and Outcomes Questionnaire, Relationships with Professional and Decision Input Questionnaire, Collaboration and Satisfaction About Care Questionnaire, Decision Conflict Scale, Demographic Data Sheet, Infant Characteristics, Neonatal Therapeutic Intervention Score. Intervention group 77 parents. Control group 77 parents	A statistically significant change was found between the control and the intervention group in collaboration and accuracy of parents' understanding. The intervention group had fewer unrealistic concerns and less uncertainty about infant medical conditions, less decision conflict, more satisfaction with the medical decision-making processes and the amount of decision input they were given, and reported more shared decision-making with professionals. There were no statistically significant differences between the groups in satisfaction with infants' care, relationship with health professionals and the decisions made for their infants' treatment. The intervention was especially effective in improving understanding and collaboration in low-income, young, minority mothers
Pyke-Grimm *et al.* (2006) Canada	To determine the factors that parents identified as influencing their role in treatment decision-making	Mixed-method. Descriptive design	Semi-structured interview, Control Preferences Scale for Paediatrics. The 14-item Sociodemographic, Disease and Treatment Questionnaire; 36 parents	The factors identified were relationship with the physician, nature of communication, trust in the physician, parents' and physician's knowledge and experience, importance of the parental role, and the emotional stress surrounding diagnosis and treatment
Tait *et al.* (2001), USA	To examine parents' preferences for participation in decisions regarding their child's anaesthetic care and to determine whether active participation is associated with greater parental satisfaction	Quantitative method. Descriptive design	Questionnaire, interview; 308 parents	In general, parents reported a preference for shared decision-making with the anaesthetist. Parents preferred to be passive with respect to intraoperative pain management but active with regard to being present when their child woke up; 32% of parents stated that they would have preferred more involvement in decision-making

Table 2
(Continued)

Authors and country	*Purpose*	*Design*	*Data collection/sample size*	*Findings which are relevant for the review*
Tarini *et al.* (2007), USA	To determine parental participation in medical decision-making during hospitalization and its association with parental self-efficacy and to explore other factors associated with participation	Quantitative method. Descriptive design. Cross-sectional study	Questionnaire. The Perceived Efficacy in Patient–Physician Interactions, Marlowe-Crowne 2 scale of Social Desirability; 130 parents	Eighty-six per cent of parents reported that they had participated in medical decisions about their child's care. Parents with scores in the middle and highest self-efficacy tertiles had higher odds of participation in medical decision-making compared with parents in the lowest tertile. Younger parents and parents of previously hospitalised children were more likely to participate. Parents with a high-school education or lower were less likely to participate
Young *et al.* (2006), UK	To explore children's, parents' and practitioners' accounts of shared decision-making in the context of community-based physiotherapy services for children with cerebral palsy	Qualitative method	Semi-structured interview, focus groups; 11 children, 12 parents, 10 physiotherapists	Parents and practitioners were involved in decision-making, but their involvement varied depending on the nature of the issues in question, and decision-making appeared more unilateral than shared. Each party made decisions within particular domains in ways that seemed largely independent of the other. Parents and children appeared to have most involvement in decisions about the acceptability and implementation of interventions. Families and practitioners shared information, including families' experiences of interventions, but the researchers were less certain that they engaged in negotiation in ways that were consistent with shared decision-making

ADHD, attention-deficit hyperactivity disorder; PEG, percutaneous endoscopic gastrostomy.

bias, limitations and ethical rigour. In the verification of the analysis process, no conflicting evidence was found. Three themes emerged from the preliminary synthesis related to DM: (1) relational factors and interdependence, (2) personal factors and attitudes, and (3) organisational factors. In order to provide a comprehensive picture of the research field, each theme is presented below at descriptive level.

Relational factors and interdependence

The findings revealed that parents participated in DM about their child's health care to varying degrees (Kirk 2001, Hallström & Elander 2004, MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, Young *et al.* 2006, Cox *et al.* 2007, Tarini *et al.* 2007, McKenna *et al.* 2010) and that they wanted to participate more than they were able to (Tait *et al.* 2001, MacKean *et al.* 2005, Brotherton *et al.* 2007, Ellberg *et al.* 2010, McKenna *et al.* 2010). However, health professionals were dominant in the DM process (Kirk 2001, Hallström *et al.* 2002, Hallström & Elander 2004, MacKean *et al.* 2005, Young *et al.* 2006, Ellberg *et al.* 2010, McKenna *et al.* 2010). It was evident that the encounter between parents and health professionals was asymmetric and that there was a lack of negotiation (Kirk 2001, Hallström *et al.* 2002, Hallström & Elander 2004, MacKean *et al.* 2005, Ellberg *et al.* 2010). Some parents even felt pressure during DM because of professionals' expectations (Kirk 2001, Guerriere *et al.* 2003, MacKean *et al.* 2005, Fiks *et al.* 2011). Professionals' inclusion of parents in the DM process was found to be important (Miceli & Clark 2004, Alderson *et al.* 2006, Fiks *et al.* 2011). However, parents had various degrees of opportunity to become involved in this process (Kirk 2001, Hallström *et al.* 2002, MacKean *et al.* 2005), which also seemed to be influenced by how explicitly they explained their needs and how sensitive the professionals were in identifying them (Hallström *et al.* 2002).

Parents' level of confidence and participation in DM was affected by the quality of communication with professionals (Hallström *et al.* 2002, MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, McKenna *et al.* 2010). The timing, manner and context of information provided had to match parents' needs and preferences (Guerriere *et al.* 2003, Alderson *et al.* 2006). In addition, professionals who identified and respected parents' preferences and needs positively affected parents' participation in DM (Hallström *et al.* 2002, Miceli & Clark 2004, MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, Brotherton *et al.* 2007, Ellberg *et al.* 2010). The professionals' competence was perceived as important for the quality of the parent–health professional relationship and parents' role in DM (Cygan *et al.* 2002, MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, Fiks *et al.* 2011) and involved communicative, relational and educational knowledge and capability.

Personal factors and attitudes

The findings revealed that parents wanted to participate to varying degrees (Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, Young *et al.* 2006, Fiks *et al.* 2011). Some parents wanted to be included in decisions but wished to be spared the responsibility (Pyke-Grimm *et al.* 2006). Other parents emphasized the authority of the physician and relied on him/her to make the decision. A few parents highlighted their own authority in DM, wanted to remain in control and discharge their responsibilities (Pyke-Grimm *et al.* 2006, Young *et al.* 2006).

Parents emphasized parent–professional relationships characterized by mutual trust and respect, a two-way process of listening and sharing information, with professionals answering their questions (Guerriere *et al.* 2003, Miceli & Clark 2004, MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, McKenna *et al.* 2010, Fiks *et al.* 2011). Support from health professionals and others was also reported to be of significance to parents in the DM process because of the fact that many decisions were extremely difficult in a critical situation (Guerriere *et al.* 2003, Brotherton *et al.* 2007, McKenna *et al.* 2010, Fiks *et al.* 2011). Thus, they perceived professionals' communicative and relational competencies as important factors for good parent–professional relationships (MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006). In addition, parents valued professionals' technical knowledge and experience (Cygan *et al.* 2002, MacKean *et al.* 2005, Pyke-Grimm *et al.* 2006, Fiks *et al.* 2011).

Most parents preferred DM as a shared process, even if it involved informed consent (Tait *et al.* 2001, MacKean *et al.* 2005, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006, Fiks *et al.* 2011). They did not want more autonomy but to work collaboratively with health professionals in making decisions about what services would best meet their child's needs (MacKean *et al.* 2005). They emphasized the 'drawing together' aspect and perceived DM as an

informed agreement between fairly equal partners (Alderson *et al.* 2006). However, the professionals appeared to perceive parental participation differently from the parents themselves, which may influence parents' role in DM (Alderson *et al.* 2006, Fiks *et al.* 2011). The professionals' attitude was 'distancing' and they seemed more concerned with fulfilling the legal provisions than making shared decisions (Alderson *et al.* 2006, Young *et al.* 2006, Fiks *et al.* 2011). Professionals and parents also appeared to have different perspectives and priorities with regard to 'significant' procedures and choices (Alderson *et al.* 2006).

Parents' participation in DM was influenced by professionals' interpretations of and attitudes to parents' role in health care. The findings revealed a tendency for professionals to define parents' role in health care (Kirk 2001, MacKean *et al.* 2005, Alderson *et al.* 2006). However, some professionals struggled to include parents in DM, which seemed to be connected to the norms associated with biomedical theories (Young *et al.* 2006).

Personal factors influenced the parents' participation in DM. This appeared to involve their demographic characteristics, life circumstances, attitudes and competence. Thus, parental level of education, age, income and marital status seemed to play an important role (Penticuff & Arheart 2005, Cox *et al.* 2007, Tarini *et al.* 2007, McKenna *et al.* 2010). Tarini *et al.* (2007) found that parents with lower educational levels were less likely to participate in DM. Mothers with higher levels of education, who were married and had higher incomes tended to be less satisfied with the DM process (Penticuff & Arheart 2005). Low-income, young, less educated, minority mothers experienced far more DM conflicts (Penticuff & Arheart 2005). Parents' degree of knowledge and experience of their child's health problem and their interaction with professionals also affected their involvement (Kirk 2001, Penticuff & Arheart 2005, Pyke-Grimm *et al.* 2006, Tarini *et al.* 2007, McKenna *et al.* 2010). When parents acquired increased knowledge and experience, they participated more actively (Kirk 2001, Penticuff & Arheart 2005, Pyke-Grimm *et al.* 2006, Tarini *et al.* 2007). Parents in temporary emotional distress because of their child's illness situation were less active in DM (Kirk 2001, Guerriere *et al.* 2003, Alderson *et al.* 2006, Pyke-Grimm *et al.* 2006). Parents' expectations of themselves as parents were also a factor contributing to participation in DM (Kirk 2001, Pyke-Grimm *et al.* 2006).

Organisational factors

Organisational shortcomings in the health care services were perceived to affect professionals' opportunities to facilitate parent participation and influenced the parents' preferred role in DM. Parents' level of participation was influenced by available resources, time to include them in and prepare them for the DM process by means of the provision of adequate information, discussion and negotiation (Alderson *et al.* 2006, Young *et al.* 2006, Fiks *et al.* 2011). Parents were more involved in decisions if they had a longer time to consider the options (Alderson *et al.* 2006, McKenna *et al.* 2010). Time constraints and costs limited the involvement of key participants and evidence-based treatments (Fiks *et al.* 2011). Organisational shortcomings such as short hospital stays, lack of routines for including parents in DM and for the provision of information hindered parents' participation in DM (Miceli & Clark 2004, Alderson *et al.* 2006, Ellberg *et al.* 2010). Alderson *et al.* (2006) reported that the more transparent the rules and the greater the access in the units, the more confident parents and staff were to talk and discuss. The lack of acceptable alternatives to parental care in the community acted as a barrier to negotiation about children's care (Kirk 2001).

Discussion

This study provided a synthesis of the research on parents' perceptions of their participation and the challenges they face in DM in health care services for children. To strengthen the quality, the final composite analysis and synthesis were agreed by consensus among the researchers. Nevertheless, it is important to acknowledge that the synthesizing process is influenced by the researchers' perceptions and pre-understanding (Burns & Grove 2011). Moreover, the complexity of knowledge due to substantively different types of knowledge that cannot be easily translated into each other. Thus, other authors with divergent interests may read the studies differently (Reid *et al.* 2009).

The studies reflected parents' perceptions and experiences of their participation in DM from different perspectives and contexts of the child health-care services. This can be regarded as a strength in terms of comprehensive understanding of parent participation in DM. Conversely, it can also be seen as a weakness because of the small number of studies from each context, which can contribute to bias and limit the possibilities for generalization. Moreover, other search words and databases could contribute different findings.

Important aspects of parent participation in DM in health-care services for children that emerged were relational factors and interdependence, personal factors and attitudes and organisational factors. The first theme involved asymmetry in authority and power as well as characteristics of the relationship. The second was linked to parents' perceptions and preferences. The third theme included available resources and organisational structures. Despite a shift from a paternalistic DM model, where professionals make the decisions, to a shared DM model, the relationships and organisational shortcomings were associated with asymmetry in authority and power that counteracted parents' active involvement in DM.

The review revealed that parents wanted to participate more than they were able to and that health professionals were dominant in the DM process. Parents emphasized the parent–health professional relationship, professionals' competence and the opportunity for varying the degree of participation in DM. Most parents viewed DM as a shared process. Thus, they preferred professionals who provided information in accordance with their needs and preferences and having an opportunity to engage in a two-way process of listening, sharing information and making decisions. Making decisions on behalf of a child can be an extremely demanding duty (Massimo *et al.* 2004, Power *et al.* 2011). Parents may be in a state of emotional distress because of their child's health situation, thus the information about his/her medical condition and treatment options can be overwhelming (Just 2005, Stewart *et al.* 2005, Jackson *et al.* 2008). The decisions made can also have serious and long-lasting consequences (Stewart *et al.* 2005, Jackson *et al.* 2008, Légaré *et al.* 2010). The findings indicate that parents are in a particularly vulnerable situation when making decisions and therefore have a special need for dialogue and support from professionals (Massimo *et al.* 2004, Stewart *et al.* 2005, Jackson *et al.* 2008, Power *et al. 2011*). In addition, it appeared that parents needed to be in control of their preferred role in DM, which seems to be influenced by the information they can access, their relationship with the professionals and preferred level of participation (Stewart *et al.* 2005, Jackson *et al.* 2008, Power *et al.* 2011). Parents who had acquired knowledge of their child's diagnosis and health care, and experienced interaction with professionals, participated more actively in DM. This is supported by the research of Stewart *et al.* (2005) and Corlett and Twycross (2006). Parents' individual demographic and personal characteristics also appeared to affect their participation in DM (Stewart *et al.* 2005, Jackson *et al.* 2008, Foster *et al.* 2010). These findings indicate that professionals need to be aware of their essential role in facilitating and supporting parents in the DM process as well as the necessity of acquiring relational and communicative competence (Akerjordet 2009).

Challenges included asymmetry in authority and power, professionals' attitudes and competence as well as organisational shortcomings in health care and services. In this review professionals dominated DM because of their interpretation of and attitudes to parent participation. There appears to be a tendency for professionals to define parents' role in health care and not to negotiate sufficiently with them (Espezel & Canam 2003, Corlett & Twycross 2006, Foster *et al.* 2010). From the outset, the parent–health professional relationship is asymmetric because of health professionals' authority and power. Professionals manage the health service, have the expertise and use their discretion in which decisions to involve parents and when to facilitate parent participation in DM. Professionals' attitudes and perceptions of user involvement, their professional role and the parent role appear to influence whether and how they facilitate parent participation (Légaré *et al.* 2008). Professionals' attitudes to user involvement are influenced by their understanding of health, disease and causality, reflecting the professional paradigm (Whall *et al.* 2006), which has consequences for the DM process. Consequently, many health professionals appear to adhere to biomedical theories, which do not involve the patient in DM (Ford *et al.* 2003, Goldenberg 2006, Whall *et al.* 2006).

The findings indicated that some health professionals struggled to balance user involvement, evidence-based practice and resource allocation (Young *et al.* 2006). The implications of evidence-based practice may not be compatible with parent preferences and it can be difficult to make a shared decision where both parties are in agreement (Makoul & Clayman 2006, Wirtz *et al.* 2006). Professionals may also experience difficulties in relinquishing power in the relationship with parents because of their accountability and routinized thinking. They are responsible for providing health-care services that are technically justifiable and balanced with regard to resource allocation (Bærøe 2009). This may result in ethical dilemmas, which can be played out in the parent–professional relationship, where professionals use their authority and power, thus exhibiting paternalistic behaviour (Wirtz *et al.* 2006). In addition, lack of resources and acceptable alternatives to parental care-giving, together with costs

and organisational shortcomings, act as barriers, which might influence professionals' opportunities to facilitate parent participation in DM and parents' control over the process (Jackson *et al.* 2008). In particular, time constraints can be a major concern (Légaré *et al.* 2008) and may reinforce professionals' ethical dilemmas.

Based on this systematic review, further research is needed. Health and legal provisions about service user involvement and evidence-based practice should be taken into consideration, together with the issue of expert and lay accountability, as well as how these influence parent participation in DM. Future research should also include qualitative studies about parents' perceptions of their vulnerability as well as their own and professionals' accountability in DM in health-care services for children.

The findings also provide implications for clinical practice and health professionals' education. First of all, health professionals need to be more aware of their vital role and responsibility in parent participation in DM and prioritize its facilitation. Professionals also need to emphasize communication and relational competence in clinical settings (Akerjordet 2009). It is therefore significant that the education system focuses on knowledge about user involvement and its importance in evidence-based practice (Solomons & Spross 2011). In addition, students' and health professionals' communicative and relational awareness and competence including research capacity need to be developed (Akerjordet *et al.* 2012).

Conclusion

This review provides an extended perspective on the current knowledge of parents' perceptions of participation in DM, in which health professionals' power, attitudes and competencies are taken into consideration. Further research on DM is necessary, especially qualitative research about parents' perceptions of their vulnerability, as well as their own and professionals' accountability.

In conclusion, different underlying aspects exist with regard to parent participation in DM, including the consequences of parents' vulnerability and causalities of professional dominance. Professionals need to become more aware of their critical role and responsibility in involving parents in DM, in accordance with their preferences and needs, which may empower parents and enhance the quality of children's health care.

Implications for nursing management

Nurse managers have a great responsibility for and an essential role in implementing user involvement in practice. Thus it is imperative to identify new approaches that promote the integration of this paradigm into practice, which requires conscious management strategies and transformative learning to enhance the quality of children's health care. In this regard, emotional intelligence offers potential for health leadership in terms of positive health outcomes, personal growth and professional competence development, demonstrating the significance of leaders' self-awareness, self-management and supervisory skills in creating a favourable work climate to enable shared DM. Improving nurses' and health professionals' abilities to facilitate parent participation in DM requires conscious routines, information and allocation of sufficient organisational resources. Furthermore, every effort must be made to ensure that managers develop educational strategies and an evidence-based research culture for fostering increased knowledge of user involvement and empowering parents in DM. In addition, clear visions and frameworks for collaborative care in the form of multidisciplinary teams characterized by emotional intelligence are vital if health professionals are to adequately meet the needs of parents in DM in health care for their children. In this regard, emotional intelligence is not merely considered an individual attribute, but dependent on the social and cultural context for creating human and professional development.

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References

Akerjordet K. (2009) *An Inquiry Concerning Emotional Intelligence and Its Empirical Significance*. Doctoral Thesis, Depart-

ment of Health Studies, Faculty of Social Sciences, University of Stavanger, Norway.

Akerjordet K., Lode K. & Severinsson E. (2012) Clinical nurses' attitudes towards research, management and the hospitals' organisational resources: part 1. *Journal of Nursing Management* **20**, 814–823.

Alderson P., Hawthorne H. & Killen M. (2006) Parents' experiences of sharing neonatal information and decisions: consent, cost and risk. *Social Science & Medicine* **62**, 1319–1329.

Bærøe K. (2009) Priority setting in health care: a framework for reasonable clinical judgements. *Journal of Medical Ethics* **35**, 488–496.

Bradshaw P.L. (2008) Service user involvement in the NHS in England: genuine user participation or a dogma-driven folly? *Journal of Nursing Management* **16**, 673–681.

Brotherton A., Abbott J., Hurley M. & Aggett P.J. (2007) Home enteral tube feeding in children following percutaneous endoscopic gastrostomy: perceptions of parents, paediatric dietitians and paediatric nurses. *Journal Human Nutrient Dietitian* **20**, 431–439.

Burns N. & Grove S.K. (2011) *Understanding Nursing Research. Building an Evidence-Based Practice*, 5th edn. Elsevier Saunders, Maryland Heights, MO.

Corlett J. & Twycross A. (2006) Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing* **15**, 1308–1316.

Cox E.D., Smith M.A. & Brown R.L. (2007) Evaluating deliberation in pediatric primary care. *Pediatrics* **120**, 68–77.

Cygan M.L., Oermann M.H. & Templin T. (2002) Perceptions of quality health care among parents of children with bleeding disorders. *Journal of Pediatrics Health Care* **16**, 125–130.

Ellberg L., Högberg U. & Lindh V. (2010) 'We feel like one, they see us as two': new parents' discontent with postnatal care. *Midwifery* **26**, 463–468.

Elwyn G., Edwards A., Wensing M., Hood K., Atwell C. & Grol R. (2003) Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality of Safety in Health Care* **12** (2), 93–99.

Espezel H. & Canam C.J. (2003) Parent–nurse interactions: care of hospitalized children. *Journal of Advanced Nursing* **44**, 34–41.

Fiks A.G., Hughes C.C., Gafen A., Guevara J.P. & Barg F.K. (2011) Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. *Pediatrics* **127** (1), 188–196.

Ford S., Schofield T. & Hope T. (2003) What are the ingredients for a successful evidence-based patient choice consultation?: a qualitative study. *Social Science Medicine* **56**, 589–602.

Foster M., Whitehead L. & Maybee P. (2010) Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: a review of the literature. *International Journal of Nursing Studies* **47**, 1184–1193.

Franck L.S. & Callery P. (2004) Re-thinking family-centred care across the continuum of children's healthcare. *Child: Care, Health & Development* **30** (3), 265–277.

Gabe J., Olumide G. & Bury M. (2004) 'It takes three to tango': a framework for understanding patient partnership in paediatric clinics. *Social Science & Medicine* **59**, 1071–1079.

Goldenberg M.J. (2006) On evidence and evidence-based medicine: lessons from the philosophy of science. *Social Science & Medicine* **62**, 2621–2632.

Guerriere D.N., McKeever P., Llewellyn-Thomas H. & Berall G. (2003) Mothers' decisions about gastrostomy tube insertion in children: factors contributing to uncertainty. *Developmental Medicine & Child Neurology* **45**, 470–476.

Guimond P., Bunn H., O'Connor A.M. *et al.* (2003) Validation of a tool to assess health practitioners' decision support and communication skills. *Patient Education and Counseling* **50** (3), 235–245.

Hallström I. & Elander G. (2004) Decision-making during hospitalization: parents' and children's involvement. *Journal of Clinical Nursing* **13**, 367–375.

Hallström I., Runeson I. & Elander G. (2002) An observational study of the level at which parents participate in decisions during their child's hospitalization. *Nursing Ethics* **9** (2), 202–214.

Jackson C., Cheater F.M. & Reid I. (2008) A systematic review of decision support needs of parents making child health decisions. *Health Expectations* **11**, 232–251.

Jolly J. & Shields L. (2009) The evolution of family-centered care. *Journal of Pediatric Nursing* **24** (2), 164–170.

Just A.C. (2005) Parent participation in care: bridging the gap in the pediatric ICU. *Newborn and Infant Nursing Review* **5** (4), 179–187.

Kirk S. (2001) Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of Advanced Nursing* **34**, 593–602.

Légaré F., Ratté S., Gravel K. & Graham I.D. (2008) Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Education and Counseling* **73**, 526–535.

Légaré F., Ratté S., Stacey D. *et al.* (2010) Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systemic reviews* **5**, 1–45.

MacKean G.L., Thurston W.E. & Scott C.M. (2005) Bridging the divide between families and health professionals' perspectives on family-centered care. *Health Expectations* **8**, 74–85.

Makoul G. & Clayman M.L. (2006) An integrative model of shared decision making in medical encounters. *Patient Education and Counseling* **60**, 301–312.

Massimo L.M., Wiley T.J. & Casari E.F. (2004) From informed consent to shared consent: a developing process in paediatric oncology. *Lancet Oncology* **5**, 384–387.

McKenna K., Collier J., Hewitt M. & Blake H. (2010) Parental involvement in paediatric cancer treatment decisions. *European Journal of Cancer Care* **19**, 621–630.

Miceli P.J. & Clark P.A. (2004) Your patient – my Child. Seven priorities for improving pediatric care from the parent's perspective. *Journal of Nursing Care Quality* **20**, 43–53.

O'Connor A.M., Bennett C.L., Stacey D. *et al.* (2009) Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systemic reviews* **3**, 1–116.

Penticuff J.H. & Arheart K.L. (2005) Effectiveness of an intervention to improve parent–professional collaboration in neonatal intensive care. *Journal of Perinatal & Neonatal Nursing* **19**, 187–202.

Power T.E., Swartzman L.C. & Robinson J.W. (2011) Cognitive-emotional decision making (CEDM): a framework of patient medical decision making. *Patient Education and Counseling* **83**, 163–169.

Pyke-Grimm K.A., Stewart J.L., Kelly K.P. & Degner L.F. (2006) Parents of children with cancer: factors influencing their treatment decision making roles. *Journal of Pediatric Nursing* **21** (5), 350–361.

Reid B., Sinclair M., Barr O., Dobbs F. & Crealey G. (2009) A meta-synthesis of pregnant women's decision-making processes with regard to antenatal screening for down syndrome. *Social Science & Medicine* **69**, 1561–1573.

Solomons N.M. & Spross J.S. (2011) Evidence-based practice barriers and facilitators from a continuous qualitative improvement perspective: an integrative review. *Journal of Nursing Management* **19**, 109–120.

Stewart J.L., Pyke-Grimm K.A. & Kelly K.P. (2005) Parental treatment decision making in pediatric oncology. *Seminars in Oncology Nursing* **21** (2), 89–97.

Tait A.R., Voepel-Lewis T., Munro H.M. & Malviya S. (2001) Parents' preferences for participation in decisions made regarding their child's anaesthetic care. *Paediatric Anaesthesia* **11**, 283–290.

Tarini B.A., Christakis D.A. & Lozano P. (2007) Toward family-centered inpatient medical care: the role of parents as participants in medical decisions. *Journal of Pediatrics* **151**, 690–695.

Taylor S.E. (2006) *Health Psychology*. McGraw-Hill, Boston, MA.

Whall A.L., Sinclair M. & Parahoo K. (2006) A philosophic analysis of evidence-based nursing: recurrent themes, metanarratives, and exemplar cases. *Nursing Outlook* **54**, 30–35.

Whittemore R. & Knafl K. (2005) The integrative review: updated methodology. *Journal of Advanced Nursing* **52** (5), 546–553.

Wirtz V., Crib A., & Barber N. (2006) Patient–doctor decision-making about treatment within the consultation – a critical analysis of models. *Social Science & Medicine* **62**, 116–124.

Young B., Moffett J.K., Jackson D. & McNulty A. (2006) Decision-making in community-based paediatric physiotherapy: a qualitative study of children, parents and practitioners. *Health Social Care in the Community* **14** (2), 116–124.

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RESEARCH ARTICLE

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Parental involvement in decision-making about their child's health care at the hospital

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Abstract

Aim: To explore parents' experiences on parental involvement in decision-making about their child's health care at the hospital and to identify how health professionals can improve parental involvement.

Design: An explorative descriptive qualitative study within a constructivist research paradigm.

Methods: Individual semistructured interviews were conducted with a purposive sample of 12 parents. Qualitative content analysis was performed.

Results: This study gives unique insight into how parental involvement in children's healthcare decisions influence parents' ability to cope with the parental role at the hospital. The results showed that parents' competence and perceived influence and control over their child's health care appeared to affect how they mastered their role of involvement in decision-making. Individually tailored and respectful facilitation of parental involvement in these decisions by health professionals seemed to improve parents' influence, control and ability to cope with the parental role. Nurses should thus strengthen parents' sense of coherence enhancing the quality of health care.

KEYWORDS
coping, decision-making, health promotion, paediatric, parent involvement, parent role

1 | INTRODUCTION

In many Western countries parents have a legal right to participate in decision-making (DM) about their child's health care to ensure that health care is provided in accordance with the children's and the families' needs and preferences (Entwistle & Watt, 2006; Thompson, 2007). From a health promotion perspective, this provides parents the opportunity to improve their personal control over their child's health care and their own life circumstances (Eriksson & Lindström, 2008). This is in line with the World Health Organization's (WHO) health promotion strategy, which recommends supportive environments and implementation of salutogenesis in societies (Eriksson & Lindström, 2008; WHO, 2009). The theory of salutogenesis is about peoples' dispositions and resilience to face life and its challenges (Antonovsky, 2012). Salutogenesis focuses on factors that promote health and the ability to cope by facilitating people's sense of coherence; enhancing their perception of life as meaningful, comprehensible and manageable. According to this strategy health professionals (HPs) can strengthen parents' sense of coherence when involving parents in children's healthcare decisions by that is, clarifying their legal rights, treatment options and daily caring routines.

In Norway as in most Western countries, parents are user representatives of their children until their children can fully represent themselves (Patients' Rights Act, 1999). As the main guiding principle, parents are responsible of giving consent to health and medical examinations and treatments on behalf of their child until they are 16 years old. In addition, parents have a legal right to participate in DM to customize their child's health care. This implies that parents have the opportunity to be involved in and influence the DM concerning individual modifications to their child's care, examinations

and treatments. This is in line with family-centred care approaches, which expect parents to participate in partnership with HPs in the co-production of children's health care (Smith, Swallow, & Coyne, 2015). Parents have valuable knowledge about their child and are important helpers in implementing their children's health care (Harrison, 2010; Watts et al., 2014). Increased parental involvement in DM about children's health care is expected to increase the individual customization of children's health care and thereby improve the quality of care and safety (Ministry of Health & Care services, 2009).

Although parental involvement in decisions about their child's health care is widely acknowledged, parents do not participate as much as they would like to (Aarthun & Akerjordet, 2014; Foster, Whitehead, & Maybee, 2010). In addition, they seem to be in a particularly vulnerable situation when participating in these DM processes. Moreover, this new conceptualization of parental involvement has led to significant changes in the role of both HPs and parents (Aarthun & Akerjordet, 2014), which may be challenging to implement in clinical settings. There is thus a need to explore current practice on parental involvement in DM to gain increased knowledge about parents' role as user representatives of their children.

1.1 | Background

Patient involvement in health services-related DM is a complex concept and includes several approaches (Entwistle & Watt, 2006; Thompson, 2007). One main approach focuses on the patient-professional interaction and patients' degree of involvement and influence during the DM process (Wirtz, Cribb, & Barber, 2006). The shared DM model is a part of this approach were the parents and the HPs are expected to share information and reach consensus (Kon, 2010). This model is relevant when parents participate in DM concerning the customizing and preparation of their child's health care. However, the parents' influence is restricted by HPs' responsibility of giving a health care that is justifiable and within the hospital's framework (Patients' Rights Act, 1999). Another DM approach focus on parents' cognitive and emotional information processing, where psychosocial factors and health literacy are important aspects (Edwards, Davies, & Edwards, 2009; Entwistle & Watt, 2006). Health literacy refers to the essential cognitive and social skills parents need when acquiring knowledge and using information to make decisions about their child's health and health care (Nutbeam, 2009).

Previous studies report that parents want to be involved in decisions about their child's health care to varying forms and degrees of involvement and this desire may change over time (Aarthun & Akerjordet, 2014). Their preference of involvement seems to depend on factors such as parents' demographic characteristics (e.g., age, level of education, income and marital status), emotional condition and competence (Aarthun & Akerjordet, 2014; Jackson, Cheater, & Reid, 2008; Lipstein, Brinkman, & Britto, 2012). Other influencing factors are type of illness, whether the illness is acute or chronic, the seriousness of the condition and parents' prior experiences with health service (Lipstein et al., 2012). Health-related decisions have, however, become more complex because of enhanced multidisciplinary practice and increased advanced treatment methods (Lipstein et al., 2012; Ofstad, Frich, Schei, Frankel, & Gulbrandsen, 2014). Many parents have limited understanding of illness, treatment and how health services function (Corlett & Twycross, 2006). Moreover, several parents experience emotional distress because of their child's health condition, which may hinder their involvement (Jackson et al., 2008; Tallon, Kendall, & Snider, 2015). Accordingly, parents seem to be in a particularly vulnerable situation in their role as user representatives of their children. Mainly, having a need for support from professionals when being involved in their child's healthcare decisions (Aarthun & Akerjordet, 2014). However, it varies whether and how HPs involve parents in these decisions (Aarthun & Akerjordet, 2014).

There is scarce knowledge about parents' role and needs in terms of their involvement in DM about preparing children's health care in hospitals (Aarthun & Akerjordet, 2014; Lipstein et al., 2012; Shields et al., 2012). In our research, this is considered as an interdependent process, which includes information exchange, discussions, deliberations and reaching consensus using the shared DM model. An increased understanding of the challenges and needs of parents concerning their involvement in their child's healthcare decisions has the potential to give important knowledge and implications for clinical practice.

1.2 | Objective

The objectives of this study were to explore parents' experiences on parental involvement in DM about their child's health care at the hospital and to identify how HPs can improve parental involvement.

2 | THE STUDY

2.1 | Design

This study used an exploratory descriptive qualitative design within a constructivism research paradigm, an interpretive approach (Lincoln, Lynham, & Guba, 2013). Semistructured interviews were used to generate data about the informants' descriptions of their experiences (Peräkylä & Ruusuvuori, 2013). According to the research paradigm, interviews are considered complex social performances where both the interviewer and the informants are active contributors in coconstructing the informants' account of their experiences (Silverman, 2011).

2.2 | Method

2.2.1 | Selection of informants

A purposive selection procedure was applied to select informants at the Department of Paediatrics of a university hospital in Norway (Silverman, 2013). New informants were included up to saturation (N + 1), meaning that when sufficient data had been obtained and no new variations in knowledge appeared, only one more interview was performed (Daly et al., 2007). This resulted in 12 informants. The inclusion criteria were individuals with parental responsibility for a child

who was staying or had stayed in a paediatric ward at the hospital in the last 3 months. The parents also needed to have sufficient fluency in Norwegian to participate in the interview. In In addition, the sample should represent parents of both genders, parents of children ranging in age from newborn to 16 years and parents who had been admitted to different paediatric wards within the hospital. Clinical nurses at the three different paediatric inpatient wards recruited the informants.

2.2.2 | Data collection and setting

The interviews were conducted from February to September 2014. The data were collected in one individual semistructured interview per informant that was audio recorded (Ryan, Coughlan, & Cronin, 2009). The interview guide was based on a systematic review (Aarthun & Akerjordet, 2014) and the theory of salutogenesis (Antonovsky, 2012) and user involvement (Entwistle & Watt, 2006; Thompson, 2007). Two of the authors agreed on the included questions. Typical questions to the informants were: "Please tell me about your child's last admission to the hospital" and "How were you involved in DM about preparing your child's healthcare?" Ten informants were interviewed during their child's hospitalization, one was interviewed 4 days later at the hospital and the other 7 days later at the informant's workplace. The interviews lasted between 35 and 90 min. After the interviews, the informants answered a survey with demographic questions that gave information on their background (Table 2). In addition, the interviewer made notes about the interview setting. The recorded interviews were transcribed verbatim, with the exception of identifying details, which were anonymized or removed.

The department of paediatrics offered health care to children from the ages of 0–16 years and has a neonatal ward, an infection ward and a general medical ward. Approximately 3,500 children are hospitalized annually and 13,000 receive outpatient consultations each year. Interprofessional cooperation is emphasized at the department level, meaning that individuals in different health professions, such as registered nurses, physicians, physiotherapists and dietitians, work closely in teams. They collaborate in the DM regarding the children's health care. In addition, individuals in each profession are responsible for involving parents in the aspects of the children's care plan that fall in their subject area.

2.3 | Analysis

To facilitate the organization of data, the transcripts were entered into the data management system NVivio 10 for manual coding (Bazeley & Jackson, 2013). Two of the authors (AA and KA) performed the analysis according to the qualitative content analysis described by Graneheim, Lindgren, and Lundman (2017), Graneheim and Lundman (2004). Initial coding and the identification of preliminary categories was performed by AA. Further analysis was discussed with KA and the authors reached a consensus on the final composite analysis. First, the transcripts were read several times to give an impression of the parents' experiences of the parental role and involvement in DM about their child's health care in the hospital. Second, relevant transcripts were extracted and divided into meaning units which are sentences that contain a central meaning related to the context (Graneheim & Lundman, 2004). The condensed meaning units were then coded and compared to examine similarities and differences. This manifest content analysis resulted in a set of subcategories and categories. Third, after comparison and interpretation of the manifest categories, one main theme and two subthemes were identified that reflected the latent content of the transcripts; a higher level of data interpretation. Table 1 gives information from the analysis process.

2.3.1 | Methodological considerations

The researchers conducted this qualitative study according to the constructive research paradigm aiming scientific rigour and trustworthiness (Carter & Little, 2007; Graneheim et al., 2017). This was influenced by the researchers preunderstanding and context, culture and time (Altheide

TABLE 1 Examples from the analysis based on Graneheim and Lundman (2004)

Meaning unit	Condensed meaning unit	Category	Subtheme	Main theme
"Sometimes it's difficult to judge a recommendation because you think you are not competent. Then, you think they (health professionals) are so competent and have done it before."	The parent thought that he sometimes did not have enough competence to be active involved in decision-making and that the health professionals were so competent.	Parental competence and understanding.	Parental competence and need for information.	A demanding parental role.
"You become involved and informed and you can calm yourself because you understand that they are doing what is best for your child."	Parental involvement in decision-making increase parents' sense of security and control of their child's health care.	Parental involvement. Parental influence and control.	Parental involvement and control.	

& Johnson, 2013). All authors had a professional preunderstanding as experienced clinicians in various fields such as paediatric physiotherapy, critical care nursing and paediatric medical practice in hospital settings.

The interviewer was a paediatric physiotherapist who was familiar with the hospital wards, which increased the understanding of the informants' descriptions of the context (Silverman, 2011). The notes describing the interview settings gave valuable additional information about the informants' role and the context during the interviews. The applied research paradigm assume that the findings are a product of the researchers' interpretations of the informants' accounts of their experiences as situated in time (Allen & Cloyes, 2013; Choen & Crabtree, 2008), accordingly the informants were not asked to confirm the findings.

2.4 | Ethics

The study adhered to the general ethical principles outlined in the Declaration of Helsinki (World Medical Association, 2013). All informants received both oral and written information about the study. They were also informed about the voluntary nature of participation and the ability to withdraw from the study at any time and were guaranteed confidentiality. The informants gave written informed consent to participate in the study.

3 | RESULTS

3.1 | The sample

The demographics of the informants are presented in Table 2. The sample consisted of four parents from each of the three paediatric wards. One parent was nonnative Norwegian and one was married to a nonnative. The informants' children were aged from being newborn to 11 years old, with various healthcare needs.

3.2 | Identified themes

The main theme, "a demanding parental role", was identified with two subthemes: "parental competence and need for information" and "parental involvement and control". The parents were highly concerned about their child's health care and perceived their parental role as user representatives of their child in the hospital to be demanding. This was particularly when the parents felt lack of continuing of health care, which led to increased stress, concern and insecurity. Mastery of involvement in decisions about their child's health care, seemed to depend on parental competence and how parents perceived their influence and control in DM. HPs' facilitation of parental involvement in DM and provision of sufficient and consistent information appeared to be of great importance. This indicate that the HP's role was essential in facilitating parents' ability to cope with the parental role during children's hospitalization by promoting parents' ability to perceive their role as meaningful, comprehensible and manageable. The subthemes are presented below and describe the parents' challenges, needs and preferences in mastering the parental role of involvement in DM about their child's health care at the hospital.

3.2.1 | Parental competence and need for information

Lack of parental competence and insufficient information from the HPs appeared to make the parental role of involvement in DM demanding.

TABLE 2 The demographics of the informants

Nr.	Gender	Age	Diagnosis of child	Number of children	Number of child's hospitalization	Education level
1	Female	36	Cancer	3	>5	Upper secondary education
2	Female	39	Premature	2	1	College/university (1–4 years)
3	Male	35	Lung disease	2	>5	Upper secondary education
4	Male	41	Lung disease	2	2	College/university (5 years or more)
5	Female	47	Evaluation process for diagnosis	3	1	College/university (1–4 years)
6	Female	35	Premature	1	1	Upper secondary education
7	Female	41	Evaluation process for diagnosis	2	3	College/university (5 years or more)
8	Female	40	Heart failure	2	4	College/university (5 years or more)
9	Female	35	Immune deficit	3	>5	Upper secondary education
10	Female	28	Premature	1	1	College/university (1–4 years)
11	Female	32	Evaluation process for diagnosis	1	1	College/university (1–4 years)
12	Female	24	Premature	1	1	College/university (1–4 years)

This was related to the parents' knowledge and understanding of their child's health condition, needs and health care, which depended on their previous experiences, perceived stress and respect for the HPs' competence. In addition, some parents' lack of knowledge about the Norwegian health services and culture seemed to negatively influence their involvement in their child's healthcare decisions.

Generally, parents stated that they had little healthcare knowledge even if the HPs had provided a substantial amount of information. This made it difficult for the parents to participate in decisions about their child's health care, particularly in decisions about the individual preparing of medical examinations and treatments. One mother said the following:

> We think that you ought to have so much information, but at the same time, you know so little. Thus, as parents, we have to trust that the HPs know what they do and believe that they do what's best for the child. (8)

Several parents experienced a lack of knowledge about their child's health condition, disease and needs, which affected their ability to participate in influencing their child's health care. They needed to receive much more information from HPs before they could actively participate in DM. Thus, lack of knowledge influenced their comprehensibility and manageability. In the initial stages of their hospital stay, parents therefore preferred for the HPs to give clear recommendations about their child's health care. However, when the parents acquired more knowledge of their child's special needs and increased their own experiences in assisting with different healthcare settings, they became more capable of participating in determining their child's health care. They then took a greater role in discussions about their child's health care. The parents also perceived receiving different options about their child's health care more positively because they were better able to judge the various possibilities. One mother expressed the following:

> It's nice to hear different perspectives, but it can also be very confusing. It can be a bit frustrating and stressful when a HP says, e.g., using breastplates doesn't influence the child's suckling, while others say you will affect ordinary breastfeeding because it presents another technique. In the beginning, you get frustrated, but as time goes by, you have to decide yourself .... (10)

Parents with long-term ill children who had acquired a substantial amount of experience and knowledge about their child's condition, needs and health care expressed this notion in particular. These parents were more actively involved in DM about preparing their child's health care. Other parents emphasized the fact that despite the availability of good information, they did not achieve sufficient understanding of their child's condition to participate in DM due to a high degree of distress. In particular, this was difficult for parents with critically ill children. One mother said the following:

> You get a depressing message and it worsens over a period of time when you feel broken. You're not capable of participating in DM. (1)

Some parents received incomplete, incomprehensible or inconsistent information about their child's health condition, needs and health care from the HPs, especially when parents felt lack of continuity and coordinated health care. Thus, they became confused, frustrated and insecure, not knowing which of the professionals they should listen to. This made it difficult to achieve sufficient insight and comprehensibility of their child's condition and needs and thus too demanding to take an active role in determining their child's healthcare plans. An example which illustrates this was one mother who expressed:

> When you have a new (nurse) in the morning, a new one in the afternoon and a new in the evening, so there are three persons during 24 hours and when there are three new nurses the next day and three after that... you get confused about who is who and who has said what and who you should listen to because the nine persons are very different and have their own opinions about different things. (12)

Moreover, some parents seemed to have a limited knowledge and understanding of the Norwegian healthcare services, for example, some parents experienced that they did not behave according to HPs' expectations when implementing their child's care. Cultural differences and lack of information from the HPs seemed to lead to misunderstandings in the communication with HPs reducing parents' comprehension of their child's healthcare services. This negatively affecting the parents' involvement in DMs and thereby their manageability of the parental role.

3.2.2 | Parental involvement and control

There was considerable variation in how and the extent to which the parents perceived they were involved in decisions about their child's health care. Several parents perceived a lack of influence and control in their child's health care, making the parental role as user representative demanding. Furthermore, HPs' facilitation of parental involvement in DM seemed to influence how the parents perceived their level of control, influence in decisions and empowerment. This indicates that HPs' facilitation of parental involvement influenced parents' manageability of the parental role. One mother described her opportunity to be involved in DM about her child's care as the following:

> How much parents are involved in DM about their participation in care is often dependent on the nurse. Some ask you what you want to do today to care for the child. Do you want to do this or this? Have you thought about this? Do you want to try this? Maybe

> we ought to do this some days? However, some nurses don't involve you and just administer the care of the child. (12)

Some parents experienced lack of being involved in decisions or a sense of not being listened to by HPs, which led to powerlessness, insecurity and little self-confidence when they sought health care for their child. One mother expressed it as such:

> One of the worst things you can experience as a mother is having to explain the same things several times and not being listened to. You sit there and feel so powerless. (7)

To enhance parental influence and control on their child's health care, it was thus of utmost importance that HPs promoted parents' involvement in DM about their children's health care. This required HPs to provide parents with improved opportunities to gain an understanding of their child's health condition, needs and health care through sufficient, consistent and individual tailored information. As a result, parents became convinced that their child was receiving the right form of health care which improved their sense of security and control of the situation. In addition, they became more active involved in the DM process. One father stated the following:

> Being involved obviously makes us feel certain about what's happening. We can understand it better when we participate and discuss the progress. Is it becoming worse? Is it getting better? Should we do things differently? (3)

Furthermore, parents who received support about the importance of their knowledge and opinions were of significance felt that they influenced their child's health care. This positive experience facilitated an active seeking of information and parental involvement in DM, enhancing their empowerment. One father expressed this as follows:

> If you receive support about the importance of your point of view, it can be an incentive that helps you become more active and further investigate the situation. When HPs involve you in preparing your child's health care and give you information, they are providing an opportunity to participate more actively. Parents then feel more empowered. (4)

This indicates that HPs' facilitating of parental involvement in DM's promoted parents' manageability and comprehensibility of their child's health care. The opportunity to be involved in preparing their child's health care was especially important to parents of long-term seriously ill children. Although it was both demanding and informative, the parents needed support from the HPs on their opinions about their child's health care and their performance of the parental role. This helped the parents take responsibility and manage severe stress over time.

However, several parents who were involved in preparing their child's health care struggled to ask for help to address their own needs, wishes and preferences. In these circumstances, it was easier for the parents to express their own needs and opinions when they had regular conversations with the HPs, particularly when the professionals showed genuine concern for the parents' situation. This indicated that the parents preferred being involved in preparing their child's health care through regular conversations with well-known HPs. One mother expressed this as follows:

> Take us out of the ward to discuss what we think about our child's health care, what has happened, what we're wondering and ask us if there is something we need or would prefer. Just as an evaluation of the hospital stay. Then, they'll get to know what we're dissatisfied with or very pleased about and then they can carry that information on to the other HPs. (10)

4 | DISCUSSION

The findings indicate that parents were highly concerned about their child's health care and were in a very challenging and vulnerable situation during involvement in decisions about their child's health care. Parents' ability to cope in these DM seemed to depend on their competence and how they perceived their influence and control in DM. However, HPs' facilitation of parents' active involvement in these decisions and provision of sufficient and consistent information seemed to empower the parents and increase their active involvement in DM. Accordingly, the parents' ability to cope with the parental role in the hospital appeared to be strengthened by promoting their perception of life as meaningful, comprehensible and manageable; their sense of coherence, when involving parents in children's healthcare decisions.

The findings extend previous research on parental involvement in DM concerning children's health care from a health promotion perspective. The findings, that is, a demanding parental role, the significance of parental competence and understanding and the importance of receiving consistent and sufficient information from HPs, confirm previous research (Aarthun & Akerjordet, 2014; Corlett & Twycross, 2006; Foster et al., 2010). However, this study contributes new insight into parents' role as user representative of their children which seems to be an important aspect of parents' ability to cope with the parental role in the hospital (Antonovsky, 2012). The findings also highlight HPs' essential role in both facilitating parents' active involvement in children's healthcare decisions and in improving parents' ability to cope with their parental role during hospitalization. In this regard, HPs are important contributors to the provision of health promotion, which should be more emphasized in this context.

In line with previous research, our study shows that parents need a substantial amount of information about their child's health

condition, disease and the healthcare system to be able to participate in decisions related to their child's health care (Jackson et al., 2008; Power & Franck, 2008; Uhl, Fisher, Docherty, & Brandon, 2013). Parents with more experience from their child's hospitalization had a good understanding of their child's condition and the healthcare system and were more actively involved in preparing their child's health care (Lipstein et al., 2012). Nonetheless, it was still difficult for them to participate in decisions about the medical component of health care due to a lack of knowledge (Power & Franck, 2008; Uhl et al., 2013). Furthermore, parents with a limited knowledge of the Norwegian health services and culture appeared to have more difficulty communicating and cooperating with the HPs. These factors are reported in the literature on patient's health literacy, which also seems to be an important factor affecting parental knowledge and understanding of their child's condition and health care (Nutbeam, 2009; Sorensen et al., 2015). HPs should therefore become more aware of parents' health literacy and need of individual facilitation when involving parents in their child's healthcare decisions.

Nevertheless, our results indicate that parents are dependent on *if*, *how* and *when* HPs involve them in DM about their child's health care, as supported by the literature (Aarthun & Akerjordet, 2014). This reflects the asymmetry in authority and power between HPs and parents. Moreover, how HPs' involve parents in DM is dependent on many factors such as lack of resources, time constraints and organizational shortcomings as well as HP's attitudes and routinized thinking towards the parental role and their professional role at the hospital (Aarthun & Akerjordet, 2014). There was a considerable variation in the extent to which parents were involved and able to influence their child's health care. Some parents were not involved or listened to and thus felt powerless and uncertain about their child's health care. This seemed to heighten these parents' stress in an already demanding situation and can limit their coping with the parental role in the hospital (Edwards et al., 2009; Tallon et al., 2015). On the other hand, our findings support the notion that HPs' active involvement of parents in their child's healthcare decisions increases parents' competence and engagement in preparing their child's health care (Aarthun & Akerjordet, 2014; Uhl et al., 2013). These findings imply that active involvement and support from HPs enhance parents' influence and control over their child's health care. In addition, the findings indicate that inter- and intraprofessional coordination of children's health care is of significance to achieve consistent information to parents. Thus, HPs should become more conscious about how they convey information and involve parents in children's healthcare decisions as a healthcare team. Several parents reported that they preferred to be involved in decisions about their child's health care through regularly appointed conversations with known HPs (Coyne & Cowley, 2007; Roets, Rowe-Rowe, & Nel, 2012). This gives parents an opportunity to give feedback about their child's health care and their hospital stay. Furthermore, parents who were extremely distressed because of their child's health condition seemed to have unique needs, such as individually tailored facilitation of their involvement in DM concerning their child's health care (Edwards et al., 2009; Power, Swartzman, & Robinson, 2011). This requires HPs to have a high degree of empathy to actively listen to the parents' thoughts, opinions and preferences to improve their involvement and ability to cope with their parental role (Eriksson & Lindström, 2008; Halpern, 2014).

4.1 | Limitations and further research

The study's inclusion criteria were met. The sample, however, consisted of few males and no single parents, which is a potential limitation. Nevertheless, quantitative studies are required to confirm the results (Polit & Beck, 2010). Qualitative research is needed to improve the understanding of HPs' role in facilitating parental involvement in DM. Further, more research is required to explore how children are integrated in healthcare DM (e.g., their thoughts, wishes and opinions) and how this influence parental involvement during hospitalization. Finally, further knowledge is needed on the parental involvement in DM amongst migrant parents with language and cultural barriers.

5 | CONCLUSION

This study gives unique insight into parents' perspectives on their parental role as user representative of their children at the hospital primarily from a health promotion perspective. In particular, it expands on the literature on how parental involvement in children's healthcare decisions influence parents' ability to cope with the parental role at the hospital.

Nurses and other HPs should thus safeguard individualized and respectful facilitation of parental involvement in preparing children's health care to strengthen parent's sense of coherence. In addition, to ensure the quality and provision of family-centred care during children's hospitalization.

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CONFLICT OF INTEREST

The authors declare no potential conflicts of interest with respect to the research, authorship and publication of this article.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (https://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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REFERENCES

Aarthun, A., & Akerjordet, K. (2014). Parent participation in decision-making in health-care services for children: An integrative review. *Journal of Nursing Management*, *22*, 177–191. https://doi.org/10.1111/j.1365-2834.2012.01457.x

Allen, D., & Cloyes, K. (2005). The language of 'experience' in nursing research. *Nursing Inquiry*, *12*, 98–105. https://doi.org/10.1111/j.1440-1800.2005.00259.x

Altheide, D. L., & Johnson, J. M. (2013). Reflections on interpretive adequacy in qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Collecting and Interpreting Qualitative Materials*, 4th ed. (pp. 381–411). Thousand Oaks, California: Sage Publications.

Antonovsky, A. (2012). *Helsens mysterium. Den salutogene modellen*. Oslo: Gyldendal Akademisk. A Norwegian edition of Unraveling the Mystery of Health. How People Manage Stress and Stay Well (1987).

Bazeley, P., & Jackson, K. (2013). *Qualitative data analysis with NVivo*. London, UK: Sage Publications Ltd.

Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies and methods in qualitative research. *Qualitative Health Research*, *17*, 1316–1328. https://doi.org/10.1177/1049732307306927

Choen, D. J., & Crabtree, B. F. (2008). Evaluative criteria for qualitative research in health care: controversies and recommendations. *Annals of Family Medicine*, *6*, 331–339. https://doi.org/10.1370/afm.818

Corlett, J., & Twycross, A. (2006). Negotiation of parental roles within family-centred care: A review of the research. *Journal of Clinical Nursing*, *15*,1308–1316.https://doi.org/10.1111/j.1365-2702.2006.01407.x

Coyne, I., & Cowley, S. (2007). Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies*, *44*, 893–904. https://doi.org/10.1016/j.ijnurstu.2006.03.002

Daly, J., Willis, K., Small, R., Green, J., Welch, N., Kealy, M., & Hughes, E. (2007). A hierarchy of evidence for assessing qualitative health research. *Journal of Clinical Epidemiology*, *60*, 43–49. https://doi.org/10.1016/j.jclinepi.2006.03.014

Edwards, M., Davies, M., & Edwards, A. (2009). What are the external influences on information exchange and shared decision-making in healthcare consultations: A meta-synthesis of the literature. *Patient Education and Counseling*, *75*, 37–52. https://doi.org/10.1016/j.pec.2008.09.025

Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling*, *63*, 268–278. https://doi.org/10.1016/j.pec.2006.05.002

Eriksson, M., & Lindström, B. (2008). A salutogenic interpretation of the Ottawa Charter. *Health Promotion International*, *23*, 190–199. https://doi.org/10.1093/heapro/dan014

Foster, M., Whitehead, L., & Maybee, P. (2010). Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: A review of the literature. *International Journal of Nursing Studies*, *47*, 1184–1193. https://doi.org/10.1016/j.ijnurstu.2010.05.005

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, *56*, 29–34. org/10.1016/j.nedt.2017.06.002

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*, 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Halpern, J. (2014). From idealized clinical empathy to empathic communication in medical care. *Medicine, Health Care and Philosophy*, *17*, 301–311. https://doi.org/10.1007/s11019-013-9510-4

Harrison, T. M. (2010). Family-Centered Pediatric Nursing Care: State of the Science. *Journal of Pediatric Nursing*, *25*, 335–343. https://doi.org/10.1016/j.pedn.2009.01.006

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, *11*, 232–251. https://doi.org/10.1111/j.1369-7625.2008.00496.x

Kon, A. (2010). The shared decision-making continuum. *JAMA*, *304*, 903–904. https://doi.org/10.1001/jama.2010.1208

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2013). Paradigmatic Controversies, Contradictions and Emerging Confluences, Revisited. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The Landscape of Qualitative Research*, 4th ed. (pp. 199–265). Thousand Oaks, CA: Sage Publications.

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? a narrative review of pediatric decision making. *Medical Decision Making*, *32*, 246–258. https://doi.org/10.1177/0272989X11421528

Ministry of Health & Care services (2009). Report No. 47 to the Storting (2008–2009). The Coordination Reform – Proper treatment – at the right place and right time. https://www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/2008-2009/stmeld-nr-47-2008-2009-.html?xml:id=567201

Nutbeam, D. (2009). Defining and measuring health literacy: What can we learn from literacy studies? *International Journal of Public Health*, *54*, 303–305. https://doi.org/10.1007/s00038-009-0050-x

Ofstad, E. H., Frich, J. C., Schei, E., Frankel, R. M., & Gulbrandsen, P. (2014). Temporal characteristics of decisions in hospital encounters: A threshold for shared decision making? A qualitative study. *Patient Education Counseling*, *97*, 216–222. https://doi.org/10.1016/j.pec.2014.08.005

Patients' Rights Act. 1999. The Act of 2 July 1999 No. 63 relating to Patient's Rights. http:app.uio.no/ub/ujur/oversatte-lover/data/lov-19990702-063-eng.pdf

Peräkylä, A., & Ruusuvuori, J. (2013). Analyzing talk and text. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Collecting and Interpreting Qualitative Materials*, 4th ed. (pp. 277–307). Thousand Oaks, CA: Sage Publications.

Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies*, *47*, 1451–1458. https://doi.org/10.1016/j.ijnurstu.2010.06.004

Power, N., & Franck, L. (2008). Parent participation in the care of hospitalized children: A systematic review. *Journal of Advanced Nursing*, *62*, 622–641. https://doi.org/10.1111/j.13652648.2008.04643.x

Power, T. E., Swartzman, L. C., & Robinson, J. W. (2011). Cognitive-emotional decision making (CEDM): A framework of patient medical decision making. *Patient Education and Counseling*, *83*, 163–169. https://doi.org/10.1016/j.pec.2010.05.021.

Roets, L., Rowe-Rowe, N., & Nel, R. (2012). Family-centred care in the paediatric intensive care unit. *Journal of Nursing Management*, *20*, 624–630. https://doi.org/10.1111/j.13652834.2012.01365.x

Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one- to-one interview. *International Journal of Therapy and Rehabilitation*, *16*, 309–314. https://doi.org/10.12968/ijtr.2009.16.6.42433

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012). Family-centred care for hospitalised children aged 0–12 years. *Cochrane Database of Systematic Reviews*. *10*, 0–12. doi:10.1002/14651858.CD004811.pub3

Silverman, D. (2011). *Interpreting qualitative data*, 4th ed. London, UK: Sage Publications Ltd.

Silverman, D. (2013). *Doing qualitative research*, 4th ed. London, UK: Sage Publications Ltd.

Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition – A concept synthesis of family-centred care and partnership-in-care. *Journal of Pediatric Nursing*, *30*, 143–159.

Sorensen, K., Pelikan, J. M., Rothlin, F., Ganahl, K., Slonska, Z., & Doyle, ... H. (2015). Health literacy in Europe: Comparative results of the European health literacy survey (HLS-EU). *European Journal of Public Health*, *5*, 1–6. https://doi.org/10.1093/eurpub/ckv043

Tallon, M. M., Kendall, G. E., & Snider, P. D. (2015). Development of a measure for maternal confidence in knowledge and understanding and examination of psychosocial influences at the time of a child's heart surgery. *Journal for Specialist in Pediatric Nursing*, *20*, 36–48. https://doi.org/10.1111/jspn.12096

Thompson, A. G. H. (2007). The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine*, *64*, 1297–1310. https://doi.org/10.1016/j.socscimed.2006.11.002

Uhl, T., Fisher, K., Docherty, S. L., & Brandon, D. H. (2013). Insights into patient and family-centered care through the hospital experiences of parents. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, *42*, 121–131. https://doi.org/10.1111/1552-6909.12001

Watts, R., Huaqiong, Z., Shields, L., Taylor, M., Munns, A., & Ngune, I. (2014). Family- centered care for hospitalized children aged 0–12 years: A systematic review of qualitative studies. *JBI Database of Systematic Reviews & Implementation Report*, *12*, 204–283. https://doi.org/10.11124/jbisrir-2014-1683

Wirtz, V., Cribb, A., & Barber, N. (2006). Patient-doctor decision-making about treatment within the consultation - a critical analysis of models. *Social Science & Medicine*, *62*, 116–124. https://doi.org/10.1016/j.socscimed.2005.05.017

World Health Organization (2009). Milestones in health promotion. Statements from global conferences. Retrieved from https://www.who.int/healthpromotion

World Medical Association (2013). Ethical principles for medical research involving human subjects. Retrieved from wma.net

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Paper III

Aarthun, A., Øymar, K., & Akerjordet, K. (2018). How health professionals facilitate parents' involvement in decision-making at the hospital: A parental perspective. *Journal of Child Health Care*, 22(1), 108-121.

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Paper IV

Aarthun, A., Øymar, K., & Akerjordet, K. Health professionals' involvement of parents in decision-making in interprofessional practice at the hospital. *Manuscript accepted by Journal of Interprofessional Care 21.08.18.*

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Appendices

Appendix 1: Inquiry about participation in sub-studies 2-3.

Appendix 2: Inquiry about participation in sub-study 4.

Appendix 3: Survey with demographic questions for sub-study 2-3.

Appendix 4: Sub-study 2 and 3's interview guide.

Appendix 5: Survey with demographic questions for sub-study 4.

Appendix 6: Sub-study 4's interview guide.

Appendix 1: Inquiry about participation in sub-studies 2-3.

Forespørsel om deltakelse i forskningsstudien

Foreldres erfaringer fra medvirkning i utformingen av barns helsetilbud på sykehus.

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie som har som formål å undersøke foreldres erfaringer fra medvirkning i utformingen av barns helsetilbud på somatiske barneavdelinger. Du er blitt forespurt om å delta i studien da ditt barn får eller har fått helsetilbud på barneklinikken, X sykehus. Deltakerne i studien er foreldre til barn som får eller har fått helsetilbud på barneklinikken i løpet av de siste 3 månedene. For å kunne delta i studien må du ha tilstrekkelige norskkunnskaper til å kunne uttrykke deg godt i et intervju. I tillegg kreves det at ditt barn ikke har fått helsehjelp fra prosjektleder og fysioterapeut Antje Aarthun.

Målet med studien er å få økt kunnskap om hvordan helsepersonell tilrettelegger for foreldres medvirkning i beslutningene om barns helsetilbud på sykehus. I følge helselovgivningen skal foreldre vanligvis gi samtykke til helsehjelp til sitt barn. I tillegg har foreldre rett til å medvirke i utformingen av sitt barns helsetilbud som når det skal tas valg om *hva* som skal gjøres og på *hvilken måte* ved undersøkelser og behandling. Foreldres medvirkningsrett sikrer at de kan ivareta sitt barns behov og interesser og bidrar til at helsetilbudet tilpasses barnet.

Undersøkelsen inngår i et større forskningsprosjekt som undersøker helsepersonells tilrettelegging for foreldres brukermedvirkning på somatiske barneavdelinger med tanke på å fremme foreldres brukermedvirkning på barns helsetilbud. Det inngår fire delstudier som bygger på hverandre. I denne delstudien (delstudie 1) inngår foreldre som deltakere. Forskningsprosjektet forventes å gi ny kunnskap som kan gi føringer for klinisk praksis på barneavdelinger og medisinsk og helsefaglig utdanning med tanke på å bedre

kvaliteten barns helsetilbud og foreldres rolle som pårørende. I tillegg forventes det å gi føringer for videre forskning.

Forskningsprosjektet er et doktorgradsprosjekt som er finansiert av X med en stipendiatstilling og driftsstipend. Prosjektleder er ph.d.- kandidat Antje Aarthun som er tilknyttet Forskningsavdelingen, X og Institutt for helsefag, Det samfunnsvitenskaplige fakultet, Universitetet i Stavanger. Hun har lang erfaring som barnefysioterapeut. Andre medvirkende er førsteamanuensis Kristin Akerjordet, Institutt for helsefag, Det samfunnsvitenskaplige fakultet, Universitetet i Stavanger og forskningsleder Knut Øymar, Forsknings-avdelingen, X.

Hva innebærer studien?
For deg innebærer undersøkelsen å delta i et intervju og fylle ut et kort spørreskjema om din bakgrunn. I intervjuet blir du spurt om å fortelle om dine erfaringer fra et opphold på barneklinikken og hvordan du medvirket i utformingen av ditt barns helsetilbud. Du vil bli bedt om å fylle ut spørreskjemaet i etterkant av intervjuet. Intervjuet varer i opptil 1 1/2 time. Det vil bli tatt opp på digital lydopptaker og i etterkant transkribert (skrevet) og analysert. En får ikke dekket utgifter i forbindelse med deltakelse i intervjuet.

Hva skjer med informasjonen om meg?
Informasjonen som registreres om deg, skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det betyr at opplysningene er avidentifisert. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og lydfilene og som kan finne tilbake til deg. Tidspunkt for sletting av informasjonen er satt til 01.07.2018. Det vil så langt som mulig søkes å publisere resultatene av studien slik at identiteten til inkluderte ikke kommer frem.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektleder Antje Aarthun på tlf. X eller e-mailadresse X.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om delstudien og prosjektet og er villig til å delta

_____

_____

(Signert av prosjektdeltaker, dato)

Appendix 2: Inquiry about participation in sub-study 4.

Forespørsel om deltakelse i forskningsstudien

Helsepersonells perspektiv på foreldres medvirkning i utformingen av barns helsetilbud på sykehus

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie som har som formål å undersøke helsepersonells oppfatninger om temaet foreldres brukermedvirkning og deres erfaringer fra tilretteleggingen for foreldres brukermedvirkning på somatiske barneavdelinger. Du er blitt forespurt om å delta i studien siden du er helsepersonell tilknyttet barne- og ungdomsklinikken, X. Deltakerne i studien er helsepersonell med ulik fagprofesjon som sykepleiere, hjelpepleiere, leger, fysioterapeuter og ernæringsfysiologer.

Undersøkelsen inngår i et større forskningsprosjekt som undersøker foreldres brukermedvirkning på somatiske barneavdelinger. Det inngår fire delstudier som bygger på hverandre. I denne studien benyttes både fokusgruppeintervju og individuelle intervju til å samle inn data. Studien forventes å gi ny kunnskap som kan nyttes til å bedre foreldres brukermedvirkning, kvaliteten på barns helsetilbud og foreldres rolle som pårørende på sykehus.

Forskningsprosjektet er et doktorgradsprosjekt som er finansiert av X. Prosjektleder er PhD-kandidat Antje Aarthun som er tilknyttet Forskningsavdelingen, X og Institutt for Helsefag, Det Samfunnsvitenskaplige fakultet, Universitetet i Stavanger. Andre medvirkende er professor Kristin Akerjordet, Institutt for helsefag, Det Samfunnsvitenskaplige fakultet, Universitetet i Stavanger og forskningsleder/professor Knut Øymar, Forskningsavdelingen, X.

Hva innebærer studien?

For deg innebærer undersøkelsen å delta i ett intervju med varighet opptil en time og fylle ut et kort spørreskjema om din bakgrunn. I intervjuet vil

du blir spurt om å fortelle om (1) dine oppfatninger om temaet foreldres medvirkning i utformingen av barns helsetilbud og egen rolle i tilretteleggingen for foreldres brukermedvirkning, (2) dine erfaringer fra tilretteleggingen og (3) dine oppfatninger om hva som kan bedre tilretteleggingen på somatiske barneavdelinger. Intervjuene vil bli tatt opp på digital lydopptaker og i etterkant transkribert (skrevet) og analysert. En vil ikke få dekket utgifter i forbindelse med deltakelse i intervjuene.

Hva skjer med informasjonen om meg?
Informasjonen som registreres om deg, skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det betyr at opplysningene er avidentifisert. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og lydfilene og som kan finne tilbake til deg.

Tidspunkt for sletting av informasjonen er satt til 01.07.2019. Det vil så langt som mulig søkes å publisere resultatene av studien slik at identiteten til inkluderte ikke kommer frem, eks. ved bruk av anonymisering.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektleder Antje Aarthun på tlf. X eller e-mailadresse X.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om delstudien og prosjektet og er villig til å delta

_____

_____

(Signert av prosjektdeltaker, dato)

Appendix 3: Survey with demographic questions for sub-study 2-3.

BAKGRUNNSSPØRSMÅL

1) Kvinne: __ Mann: __

2) Alder: __

3) Sivilstatus: Gift/samboer: __ Enslig: __ Skilt/eks.samboer: __

4) Hva er din høyeste fullførte utdanning?

Grunnskole	Videregående skole	Høyskole/universitet 1-4 år	Høyskole/universitet 5 år eller mer

5) Hva er ditt nåværende arbeidsforhold?

Yrkesaktiv fulltid	Yrkesaktiv deltid	Sykemeldt/ uføretrygd	Under utdanning	Hjemme-arbeidende	Barselpermisjon	Annet

6) Hvor mange barn har du? __

7) Hvor mange ganger har barna dine vært innlagt på barneklinikken?
___

8) Hva tid var den siste innnleggelsen på barneklinikken? _____

9) Hvor mange ganger har barna dine vært til poliklinisk time på barneklinikken? _____

Appendix 4: Sub-study 2 and 3 's interview guide.

Intervjuspørsmål:

Fortell om den siste innleggelsen ditt barn hadde på barneklinikken. Hvordan medvirket du i utformingen av barnets helsetilbud?

Hvordan involverte helsepersonellet deg i utformingen og beslutningene om ditt barns helsetilbud? (1)

Hvordan var ditt forhold og samarbeid med helsepersonellet? (2) Hvordan snakket helsepersonellet til deg? (2)

Hvordan var helsepersonellets faglig kompetanse ?

Hvordan opplevde du at din situasjon var under oppholdet? (3)

Fikk du god informasjon og den informasjonen som du hadde behov for? (4)

I hvor stor grad deltok du i utformingen og beslutningene om ditt barns helsetilbud? (5)

I hvor stor grad ønsket du å medvirke i utformingen og beslutningene om ditt barns helsetilbud? (6)

Hva betydning hadde det for deg at du kunne medvirke i utformingen og beslutningene om ditt barns helsetilbud på barneklinikken?

Hvordan synes du foreldres medvirkning i utformingen og beslutningene om barns helsetilbud bør være på barneklinikken?

Når foreldre medvirker i stor grad, hvor stort ansvar har helsepersonell for beslutningene som tas om barns helsetilbud?

Hva synes du kan gjøres for å bedre foreldres medvirkning og medbestemmelse i utformingen av helsetilbudet til barn på barneklinikken?

Hva kan helsepersonell gjøre bedre i tilretteleggingen for foreldres medvirkning?

Hvor stor betydning hadde organisatoriske forhold som tilgjengelig tid og rutiner i avdelingen, for din medvirkning i utformingen av ditt barns helsetilbud?

Har du mer du ønsker å si før vi avslutter intervjuet?

Tilleggsspørsmål – etter behov.
1) Ble du tatt med i en diskusjon om valg av undersøkelser, tiltak og behandlingsopplegg?
2) Ble du møtt med høflighet og respekt av personalet?
Skapte de tillit og trygge forhold?
Opplevde du at personalet hadde omtanke og omsorg for deg?
Ble du spurt om barnets symptomer, problemer og situasjon?
Lyttet de og viste interesse for det som du informerte dem om?
Snakket personalet til deg på en måte som du forstod?
Var de lydhør for dine preferanser og verdier?
Opplevde du at personalet forstod din situasjon som foresatt?
3) Hvordan hadde du det følelsesmessig sett?
4) Fikk du tilstrekkelig informasjon om barnets helse- og utviklingstilstand / hvordan undersøkelser og tester skulle foregå / resultatene fra undersøkelsene / hvilke behandlingsmuligheter som var aktuelle for barnet / hvordan behandlingen skulle utføres?
Fikk du anledning til å stille spørsmål til personalet?
Ble dine spørsmål besvart tilstrekkelig?
5) Fikk du innflytelse på valg av undersøkelser, tiltak og behandlingsopplegg?
Fikk du delta i en form for overveielsesfase der du fikk stilt spørsmål og diskutert med helsepersonellet?
Hvor stor påvirkningsmulighet synes du at du fikk?
Ble dine synspunkt hørt og tatt til følge?
6) Fikk du anledning til å medvirke i utformingen av ditt barns helsetilbud i så stor grad som du ønsket?

Appendix 5: Survey with demographic questions for sub-study 4.

BAKGRUNNSSPØRSMÅL

1) Kvinne: __ Mann: __

2) Alder: __

3) Hvilken yrkesprofesjon tilhører du?

sykepleier	hjelpepleier	lege	fysioterapeut	ernæringsfysiolog	andre

4) Hva er din høyeste fullførte utdanning utover profesjonsutdanningen?

Videre- og etterutdannelse tilsvarende minst ett år	Fullført klinisk spesialisering	Mastergrad	Ph.D

5) Hvor mange år har du arbeidet på barne- og ungdomsklinikken, X?
_____

6) Hvilke barneavdelinger/poster er du tilknyttet? _____

7) Hvor mange år har du arbeidet med pasientgruppen barn? _____

8) Hvor mange års yrkeserfaring har du totalt? _____

Appendix 6: Sub-study 4's interview guide.

Vi ønsker at du skal si din mening og fortelle om dine erfaringer fra temaene: foreldres medvirkning i utformingen av barns helsetilbud, helsepersonells tilrettelegging for foreldres medvirkning og tiltak som kan fremme helsepersonells tilrettelegging for foreldres medvirkning på barne- og ungdomsklinikken (BUK).

1. tema: Foreldres medvirkning i utformingen av barns helsetilbud på BUK.
Innledningsspørsmål: Hvordan medvirker foreldre i utformingen av helsetilbudet til sitt barn på BUK?

Oppfølgingsspørsmål:

- Hvilke beslutninger medvirker foreldre i ved utformingen av helsetilbudet til sitt barn på BUK?
- Ønsker foreldrene å delta i beslutningene om helsetilbudet til sitt barn?
- Har foreldrenes kompetanse og utdannelse noe å si for deres medvirkning?
- Hvilke beslutninger synes du at foreldre skal medvirke i?
- Hvor stor innflytelse får foreldre i beslutningsprosessene om sitt barns helsetilbud?
- Hvor stor innflytelse synes du at foreldre bør ha i beslutningene om helsetilbudet til sitt barn?
- Hva betydning har det for foreldre at de får medvirke i beslutningene om sitt barns helsetilbud?

2. tema: Helsepersonells tilrettelegging for foreldres medvirkning på BUK.
Innledningsspørsmål: Fortell om dine erfaringer fra tilretteleggingen for foreldres brukermedvirkning på BUK? Vær vennlig å bruk eksempler fra ulike settinger for å få frem erfaringene.

Oppfølgingsspørsmål:

- Hvilken rolle har du i tilretteleggingen for foreldres brukermedvirkning på BUK?
- Hva legger du vekt på i samarbeidet og relasjonen med foreldre i tilrettelegging for foreldres medvirkning og medbestemmelse i utformingen av helsetilbudet til barn?
- Hva legger du vekt på i kommunikasjonen med foreldre?
- Hva legger du vekt på i informasjonsformidlingen?
- Hvilke utfordringer har du møtt i tilretteleggingen for foreldres brukermedvirkning på BUK?
- Har dere prosedyrer og rutiner for tilretteleggingen for foreldres brukermedvirkning på BUK?
- Hva har du gjort når du ikke kommer til enighet med foreldrene om utformingen av deres barns helsetilbudet?
- Hvor langt er det rimelig at helsepersonell strekke seg for å imøtekomme foreldrenes preferanser?
- Hvordan tror du asymmetrien i maktforholdet mellom foreldre og helsepersonell virker inn på foreldres brukermedvirkning?
- Hvordan foregår dette i en tverrfaglig setting?

3. tema: Tiltak som kan fremme helsepersonells tilrettelegging for foreldres medvirkning i utformingen av helsetilbudet på BUK.
Innledningsspørsmål: Hva/ hvilke tiltak kan fremme helsepersonells tilrettelegging for foreldres brukermedvirkning på BUK?

- Organisering? Intraprofesjonellt vs tverrfaglig.
- Prosedyrer?
- Bevisstgjøring og opplæring av helsepersonell?