Quality of Paediatric Hospital Care

Understanding the Perspectives of Children and Families

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Quality of Paediatric Hospital Care
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PINK THE DAY

Content

Account

Chapters 4 to 8 are based on co-authored articles that are published or under review for publication in peer-reviewed journals. I have maintained the we form in co-authored articles.

Chapter 4
I. Schalkers, C.W.M. Dedding, J.F.G. Bunders (2015). '[I would like] a place to be alone, other than the toilet' – Children's perspectives on paediatric hospital care in the Netherlands. *Health Expectations, 18*, 2066-2078. DOI: 10.1111/hex.12174

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Chapter 7
I. Schalkers, H. Rippen, C. Dedding (under review). What patients want you to know about hospital care: exploratory evaluation of narratives of children and parents from the Netherlands. *Patient Education & Counseling*

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Chapter 1

Introduction

In the Netherlands, each year one in three children (0-18 years) visits a hospital for outpatient treatment, day treatment or admission. This concerns about 1.15 million children annually (NPCF, 2013). Children are not just small adults; they need to be diagnosed and treated in the context of their rapid growth and development, a context that has no counterpart in adults. Childhood illnesses, along with environmental circumstances – such as poverty, poor housing and nutrition – have serious implications, and may potentially lead to impaired growth and development (Jameson & Wehr, 1993). Furthermore, there are three other important aspects that need to be taken into consideration. Firstly, children have differential morbidity, meaning that the type of illness, its incidence, expression and severity in children, and their response to (pharmacological) treatment, deviates from that in adults (Jameson & Wehr, 1993; Mangione-Smith & Mcglynn, 1998). Secondly, hospitalization is generally a stressful experience for children, not only due to their medical condition, but also because they are in a completely unfamiliar environment. Major stressors for children in hospitals involve fears of the unknown, medical procedures, operations, pain and discomfort, loss of self-determination, disruption of usual routines and separation from family, friends, home and school (Coyne, 2006a; Ekra & Gjengedal, 2012; Pelander & Leino-Kilpi, 2010; Perry et al., 2012; Wilson et al., 2010). Finally, children depend on their caregivers for access to the medical system and health-related care (Beal et al., 2004). Young people's autonomy develops with age and maturity, but, according to Dutch law, parents need to be involved in the process of consenting to medical treatment until children reach the age of 16. Hence, paediatric healthcare is necessarily grounded in a three-way relationship involving the healthcare professional, the child and the child's parent(s).

These differential characteristics shape the way quality care for children needs to be organized, requiring specialized knowledge and expertise to meet a child's unique physical, mental and developmental needs. The approach that places children and their families at the heart of healthcare practice is considered to be the standard of paediatric healthcare by providers in many countries, including the Netherlands, and is supported by international bodies such as the Institute of Medicine (Institute of Medicine, 2001) and the Council of Europe (Council of Europe, 2011). Different terms have been given to the approach, including *patient- and family-centred* (Institute for Patient-and Family-centred Care), *child-oriented* (Stichting Kind & Ziekenhuis) and *child-friendly* (Council of Europe) healthcare. In essence, it is about recognizing the importance of meeting the psychosocial and developmental needs of children and the role families (and communities) play in promoting the health and well-being of their children. Further, this approach to care recognizes that the perspectives and information provided by children and families are essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health care team (American Academy of Pediatrics, 2012). In this thesis, I use the term *child- and family-centred care*, because it explicitly captures the importance of engaging the patient, in this case the *child*, as well as the *family* as essential members of the healthcare team.

Healthcare professionals are expected to have medical expertise, but children and their families are the ones with direct experience of the disease and its impact on their daily lives (Coulter, 2012; Dunn, 2003; Robertson et al., 2014). Child- and family-centred care demands that patients' experiential knowledge (often implicit) and the professional's medical knowledge are complementary at all levels of decision-making: in consultations between children and clinicians, evaluation and improvement of hospital care and services, and healthcare planning and policy.

Drivers towards increased participation of children

Children have long been denied the right of participation in healthcare due to the cultural belief that they are ignorant, needy, helpless, vulnerable and dependent, and therefore "unable" to participate in decision-making related to their own health (Alderson, 2007; Lenton & Lie, 2014). Consequently, adults with parental or institutional authority have generally defined what is "good" for their children, and societal institutions used by children have been designed by adults. Yet, the notion of children as passive recipients of care has significantly shifted over the last three decades. This movement has been stimulated by three major developments in society: adoption of the children's rights agenda, the reconceptualization of children within the social study of childhood and the growing influence of patients as consumers.

Since the adoption of the United Nations Convention on the Rights of the Child (UNCRC, 1989), ratified by the Netherlands in 1995, children are explicitly recognized as bearers of human rights, including the right to the enjoyment of the highest attainable standard of health, the right to be protected, the right not to be discriminated against and the right to express their views and participate. In particular, articles 12 and 13 of the UNCRC are seen as important drivers for child participation, stating that:

> *"The child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." (Article 12)*

> *"The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice." (Article 13)*

Another important change relates to our understanding of the active role that children can play in shaping their own environment, represented by the concept of children as social actors (Christensen & Prout, 2002; Kirk, 2007). Through the 1990s dominant notions of children as immature and passive objects of socialization were problematized, resulting in a shift from seeing children as immature *becoming's* on their way to adulthood to a focus on children as *beings* and as competent actors with a social agency of their own (Brady et al., 2015; Mayall, 1998). Understanding children as a specific (minority) social group has influenced the way children are heard and taken account of in different social settings, including healthcare. Children are more and more recognized as active agents in managing their own health and stakeholders whose views should be taken into account in the planning, delivery and evaluation of healthcare services. Closely linked to this is our changed understanding of the competence of children, even very young children, to be both commentators on their own lives and to be involved in decision-making processes (Alderson, 1993; Bluebond-Langner, 1978; Dell Clark, 2003).

Moreover, this acceptance of children's participation has been fuelled by the patient participation movement arising from the widespread consumer movement of the 1970s that affirmed the consumer's right to safety, the right to be informed, the right to choose and the right to be heard (Longtin et al., 2010; Sinclair, 2004). Transitions in society, including public accountability and democratisation of science, further stimulated openness towards the patient perspective (Brown & Zavestoski, 2004). The experience with the involvement of adult patients has developed over time and the concept has been successfully applied in various areas of patient care, such as decision-making, the management of chronic diseases and the evaluation of care. The user involvement mandate increasingly stretches beyond the concern of individual patients to challenge more broadly health research systems, policy making processes and care practices. Patients now enter into partnerships with health researchers, contribute to the development of clinical practice guidelines and assess research proposals in the context of grant applications (Pittens, 2013). Despite these developments and many other activities involving patients with the aim to enhance quality and delivery of specific services, such initiatives often face significant challenges in achieving intended results in service organizations or delivery that they seek (Armstrong et al., 2013; Boote et al., 2002; van de Bovenkamp & Trappenburg, 2009).

Increasingly the role of 'user' has extended to include children. If patients, in general, have the right to be involved in healthcare matters affecting them, then why would paediatric patients be denied of this right? The Netherlands is one of the pioneering countries to have recognized the rights of minors to participate in treatment decision-making. The Dutch Medical Treatment Act (WGBO, 1995) states that young people aged 16 or over have the right to make their own treatment decisions, and those between 12 and 15 years are entitled to take decisions with their parents. Nevertheless, there remains a gap between legal regulations on children's rights to participate in healthcare and the actual fulfilment of these rights in practice (Damm et al., 2015; Weil et al., 2015).

The challenge of closing the implementation gap is particularly complex for three reasons. First of all, even though children's willingness and capabilities to have a say in healthcare services have repeatedly been demonstrated, their experiential knowledge generally has a low status compared to that of the parents and physicians. There is still little recognition that children can offer a complementary perspective to that of clinicians and parents, providing unique and valuable insights into their needs and preferences. As a consequence, adults with parental or institutional authority over children generally define what is in the child's best interest, and in the healthcare context, they are the ones to define what constitutes high quality paediatric care. Secondly, the respect for a child's right to participation is largely dependent on the attitudes and approaches of healthcare professionals, but there has been little research on their perspectives on participation. Previous research suggests that professionals might have difficulty in facilitating or supporting child participation, due, among other things, to protective attitudes toward children (Coyne & Harder, 2011; Zwaanswijk et al., 2007), doubts about the competence of children to participate (Alderson, 2007; Dedding, 2009; Mårtenson & Fägerskiöld, 2007) and assumptions about a child's age and maturity (Hemingway & Redsell, 2011; Runeson et al., 2001). Thirdly, there is little experience with *how* to involve children in hospital care, especially how to do so in a way that befits the competences and needs of children and brings about changes that matter to them. While in recent years considerable attention has been paid to enhancing child participation in individual consultations between children and clinicians (Coyne, 2008; Feenstra et al., 2014), more methods and tools are still needed to involve children in the evaluation/improvement of paediatric hospital care and in the policy/planning process for the services they use.

In order to ensure that children and young people can participate more effectively at all levels of healthcare decision-making, research is needed that addresses the challenges mentioned above. As long as those issues will not be tackled, children's universal rights to participation and the best possible healthcare risk being violated. Good quality hospital care for children is only possible if children's views, needs and wishes are structurally taken into account. This will result in much richer perspectives, allow an understanding of how children experience their hospitalization, what they consider important and how to align this with hospital policies and daily care practice, with the ultimate goal of improving health outcomes. The purpose of the thesis research is to understand how participation of children can contribute to strengthening the quality of child- and family-centred care in paediatric hospitals and departments.

Chapter 2

Contextual and theoretical background

In the previous chapter, I have described the importance of children's active participation in the realization of high quality care that fits their unique healthcare needs, and I have introduced the complex context in which participation processes take place. In this chapter, I present the policy frameworks, concepts and theories relevant for this study.

2.1 Policy frameworks on child- and family-centred care

The central question in this thesis is how the participation of children can contribute to strengthening the quality of child- and family-centred care in paediatric hospitals and departments. Several key international organisations – including the World Health Organisation and the Council of Europe – have already addressed the question of what actually constitutes high quality care centred around children's and young people's needs, and they have made recommendations to guide policy-making, planning and delivery of services. These policy frameworks have been developed out of specific needs and perspectives for particular target groups and for use in particular settings, which means that they are partly different and partly overlapping each other. Using these frameworks as a foundation, this present study with its consequent results, aims to complement, adjust, refine and/or operationalize these existing models.

Three frameworks have hereby been identified. The first is the Charter from the European Association for Children in Hospital (EACH), the umbrella organisation for non-governmental, non-profit associations involved in the welfare of children in hospitals. The Charter was adopted in 1988 and sets out ten standards for children's healthcare at times of illness (EACH, 1988). The second model is the World Health Organisation (WHO) framework concerning adolescent friendly healthcare (WHO, 2002). This framework sets out a number of generic characteristics of adolescent friendly healthcare within WHO defined dimensions of quality. Finally and most recently, the Council of Europe drafted and adopted "The Guidelines on Child-Friendly Healthcare" (Council of Europe, 2011). These guidelines propose a human rights-based approach to the delivery of high-quality care that places children's rights, needs and resources at the centre of healthcare activities. Below I provide a description of all three frameworks, followed by a schematic overview of the commonalities and differences (Table 2.1).

EACH Charter for children in hospital

Beginning in the UK in 1961, voluntary, parent-driven associations for the welfare of children in hospitals were set up in many European countries. These associations formed strong lobby groups for improved conditions of care for children. In 1988, twelve of these associations got together in Leiden, The Netherlands, for their first European Conference. At this conference the "Leiden Charter" was drawn up, which described the rights of children (0-18 years) in hospital. The list is now known as the "EACH Charter" and sets out ten standards for children's healthcare with a strong emphasis on the involvement and participation of children and parents (see Table 2.1). For example, the Charter states that children in hospital shall have the right to have their parents or parent substitute with them at all times (article 2), that accommodation should be offered to all parents (article 3), and that children and parents have the right to informed participation in all decisions involving their healthcare (article 5). The Charter has been endorsed by numerous organisation in the Netherlands, including the Dutch Hospital Association (NVZ), the Dutch Association of Paediatrics (NVK) and the Dutch Association of Paediatric Nurses (V&VN Kinderverpleegkunde). The EACH Charter is in line with the United Nations Convention on the Rights of the Child (1989), ratified by the Netherlands in 1995. In 2001, all member organisations agreed to a number of annotations to support the implementation of the EACH Charter. [1]

WHO framework around adolescent friendly healthcare
In 2002 the World Health Organization (WHO) developed a framework around adolescent-friendly healthcare from the perspective of quality. A key reason this framework has been promoted is the gap between the types of services available for young people and those that are needed to address the health issues adolescents[2] experience today. As a result of significant advances in medical care, a great majority of children with complex chronic conditions now survive into adulthood. The WHO framework takes into account the widening scope of paediatric practice that now commonly includes the management of developmental, behavioural and mental disorders (e.g. bullying, eating disorders, obesity, ADHD, depression) as well as risk behaviours (e.g. substance use, unsafe sex) that emerge during the adolescent years (Sawyer, Proimos, & Towns, 2010; WHO, 2002).

The framework sets out a number of generic characteristics of adolescent friendly healthcare within five dimensions of quality – *accessibility, acceptability, appropriateness, equity* and *effectiveness* – with a strong emphasis on primary care in low-income and middle-income countries. There is also a growing appreciation of the framework's potential in promoting quality healthcare to adolescents in high-income countries and within specialist health services (Ambresin et al., 2013). These characteristics are based on the WHO Global Consultation of 2001 and on discussions at the WHO expert advisory group in Geneva in 2002, and build on reviews of scientific evidence (Tylee et al., 2007; WHO, 2001). This detailed list of adolescent-friendly characteristics (see Table

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[1] The Charter with Annotations is available at: http://www.each-for-sick-children.org/each-charter/each-charter-and-annotations.html

[2] The WHO defines adolescence as young people aged 10-19 years; distinguishing between early adolescence (10-13 years), mid-adolescence (14-15 years) and later adolescence (16-19 years).

2.1) can contribute to delivering the quality health services that young people need.
In relation to the list of adolescent-friendly characteristics, the WHO designed two guidebooks as part of a set of tools to standardize and scale up the coverage of quality health services to adolescents. The Quality Assessment Guidebook, published in 2009, was developed for assessing the quality of health services for adolescents, allowing organizations to identify where their services and systems are already "adolescent-friendly" and where and how improvements can be made (WHO, 2009). The second guidebook, published in 2012, was intented to help organisations developing *national* quality standards for adolescent friendly health services, acknowleding that these approaches must be interpreted in a way that befits the cultural, social and economic contexts in which services are delivered. In 2011, the United Kingdom was the first country to publish national quality standards, endorsed by the WHO, for young people friendly services. The "You're Welcome Quality Criteria" points to ten quality criteria that are intended to provide a framework for change in how resources are allocated in order to ensure better health outcomes (Department of Health, 2011).

Council of Europe Guidelines on Child-Friendly Healthcare
In 2011, the Council of Europe (CoE) drafted and adopted the "Guidelines on Child-Friendly Healthcare", endorsed by the ministers of 47 European nations (Lenton & Ehrich, 2015)[3]. The Council of Europe is an international organisation which role is to promote human rights, democracy and the rule of law. The guidelines propose a conceptual and operational framework for delivering high-quality care that places children's rights, needs and resources at the centre of healthcare activities, taking into account their family and social environment (Council of Europe, 2011; Lenton & Lie, 2014). The notion of "child-friendly" thus includes the notion of "family-friendly", facilitating contacts between the child and his or her family and preventing any separation between child and family unless it is in the best interest of the child (Council of Europe, 2011; Lenton & Lie, 2014).

The Guidelines on Child-Friendly Healthcare are explicitly based on children's and young people's rights within the United Nation Convention on the Rights of the Child (1989) and enshrine that all children should have equitable access to quality healthcare services. This includes prevention, promotion, protection and provision of services with the active participation of children (see Table 2.1). A wide range of stakeholders were involved in the development of the guidelines, ranging from parent organizations, professional groups, health

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[3] According to the Council of Europe a "child" means any person under the age of 18.

service managers, civil servants and Council of Europe Experts (Lenton & Ehrich, 2015). Further, the Council of Europe sought to incorporate the views of children and young people. During the drafting of the guidelines, qualitative research identified knowledge gaps in what is known about children's views about healthcare and it was decided to survey children and young people across the Council of Europe on these issues. More than 2000 children from eight European countries completed the survey, providing insight into the healthcare priorities of children and adolescents (Bensted et al., 2015).

Overall, the aim of the guidelines is to improve the quality of healthcare primarily defined by effectiveness, efficiency and equity simultaneously with attention to patient safety and satisfaction/experience. The Guidelines recognize that patient experience is one of the central pillars of healthcare quality and improvement, meaning that:

> *"Children have the right to be informed, consulted and heard, to give their opinions independently from their parents and to have their opinions taken into account. It implies the recognition of children as active stakeholders and describes the process by which they take part in decision making. The level of child participation depends both on his or her age, evolving capacities, maturity and on the importance of the decision to be taken. Parents and families should encourage children to participate in family, community, and society decision making – encouraging increasing independence and reducing their support as the child's capacity for autonomy and independence develops." (Council of Europe, 2011, p. 9)*

According to the guidelines, participation should be exercised at three levels:

I. **Individual decision making**, whether this be lifestyle choices or involvement in medical decision making. Implementation will require accessible information, clinical staff able to communicate with children, and measures for mediation when differences occur;
II. Children should be given the opportunity to **provide feedback** on their experience after they have used services. Implementation will require the development of assessment of both patient-reported outcome and patient-reported experience, and different methods of involving them in the process (individually and with peers);
III. With increasing maturity and capacity, children should be involved in the **policy/planning process** for the services they use. Implementation will require appropriate training/learning opportunities to enable them to partici-

pate in this process, for example understanding priority setting.

Table 2.1 Recommendations from key organizations on quality criteria for child- and family-centred care, showing how they relate to one another

Framework	**World Health Organisation (WHO) framework for adolescent friendly healthcare (WHO, 2002)**	**European Association for Children in Hospital (EACH) Charter (EACH, 1988)**	**Council of Europe (CoE) Guidelines on Child-Friendly Healthcare (Council of Europe, 2011)**
Year	2002	1988, but a number of annotations were added in 2001	2011
Target group	Adolescents 10-19 years	Children 0-18 years	Children 0-18 years
Developed from the perspective of:	WHO experts, building on reviews of scientific evidence, with a strong emphasis on primary care in low-income and middle-income countries.	Voluntary (parent-driven) organisations involved in the welfare of children in hospital.	A wide range of stakeholders, ranging from parent organizations, professional groups, health service managers, civil servants, CoE experts and children.
Quality criteria	Equitable No restriction of services on any terms Health- care providers and support staff treat all clients with equal care and respect		Promotion i. all children ii. vulnerable children iii. children using health services Protection i. all children ii. vulnerable children iii. children using health services
	Accessible Free or affordable services Convenient hours of operation Information about the availability of reproductive health services Community members understand the benefits of and support provision of adolescent health services Community based provision		
	Acceptable Client confidentiality Ensuring privacy Short waiting times Appealing and clean environment Information and	(2) Children in hospital shall have the right to have their parents with them at all times	

	education Adolescents are involved in designing, assessing and providing health services	(3) Accommodation should be offered for all parents (4) Information in a manner appropriate to age and understanding (6) Children shall be cared for together with children who have the same developmental needs and shall not be admitted to adult wards (7) Child-friendly environment with full opportunities for play, recreation and education (9) Continuity of care should be ensured (10) Children shall be treated with tact and understanding and their privacy shall be respected at all times.	
	Appropriate The required package of healthcare is provided to fulfil the needs of all adolescents	(5) Children and parents have the right to informed participation in all decisions involving their healthcare	Participation i. individual decision-making ii. feedback on experiences iii. policy-planning processes
	Effective Health care providers have the required competencies to work with adolescents and to provide them with the required health services Evidence-based care Sufficient time for clients Availability of necessary equipment and supplies	(1) Children are only treated in hospital if the required care cannot be equally well provided at home (8) Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.	**Prevention** i. Primary ii. Secondary iii. Tertiairy **Provision** i. evidence- based ii. delivered by competent practitioners iii. delivered in the right way, in the right place, at the right time

2.2 Relevant concepts

In the previous section I have described a number of recommendations from key organisations on important concepts for child and family-centred care. In most cases, children have not been extensively involved in the drafting of these frameworks. The current study takes the perspective that children need to have a say in what constitutes good quality care and that the participation of children and parents will help to ensure that the goal of child- and family-centred care is being achieved in practice. For example, the *acceptability* of health services (WHO, 2002) – that is how well they meet young people's expectations, as well as the *appropriateness* of services, that is how well they fulfil the needs of adolescents – can only be accomplished by obtaining young people's views and experiences.

Healthcare professionals are expected to have medical expertise, but children and their families are the ones with direct experience of the disease, its treatment and the impact of the condition on their daily lives. Their *experiential knowledge* is reflected in needs, wishes, ideas, expectations and concerns that need to be made explicit in a manner that suit children's and young people's competences and life worlds (Abma & Broerse, 2007). It is often decreed that parents may represent children's perspectives, for example, by participating on their behalf in the evaluation of services. I, however, see the participation of parents as an important addition rather than as a substitute for children's participation. Even though parents can make valuable contributions to improving the quality of paediatric hospital care, their accounts may not always accurately reflect their child's perceptions. In fact, it has been shown that the views of children with long-term illness (such as diabetes or asthma) about their health and illness differ from those of their parents (Curtis-Tyler, 2011). Moreover, Chesney et al. (2005) have found that children rate the quality of received care significantly lower than their parents. These are clear examples that the experiences and perspectives of children and parents can differ and that both perspectives are relevant.

Child- and family-centred care demands that children's and parents' experiential knowledge and professional's medical knowledge are taken into account at all levels of decision-making. Consistent with the "Guidelines on Child-Friendly Healthcare" (Council of Europe, 2011), the scientific literature distinguishes three different levels of service user engagement, that is micro, meso and macro level, often used to demonstrate that participation of service users takes a multitude of different forms and methods (Table 2.2)

Table 2.2 Different types of service user engagement (modified from Bedford Russell, Passant, & Kitt, 2014)

Level	Focus	Examples of methods
Micro (Individual treatment)	Patient information Patient education and patient Involvement in treatment and care decisions Complaint procedures	Doctor or nurse-patient consultations and interactions, patient and parent information leaflets, patient consultation aids, shared-decision making aids, information about patient rights and advocates
Meso (organizational level)	Evaluation of services Sharing information about services Planning changes to local services including resource allocation Local accountability	Patient surveys, study days involving patients/parents as speakers to share their stories, use of websites or social media (e.g. Zorgkaart NL), patient advisory councils
Macro (policy/ planning process)	Influencing national health policy and government agenda; engaging members of parliament	Service users participating in guideline development groups, engagement with and support of national voluntary sector organisations and charities, involvement in research agenda setting, involvement in development of quality standards

2.3 Conceptual framework

For the purpose of this current study, I propose a conceptual framework taking into account that the participation of children (lower circle in Fig. 2.1) is crucial to the realization of high quality care that places children and their families at the centre of healthcare practice (grey box), ultimately benefiting health outcomes (pink box). I will use the distinction between three levels of participation (micro, meso, macro), as described in section 2.2. Furthermore, consistent with the models described in section 2.1, I recognize that the attitudes and practices of healthcare professionals (upper right circle) as well as parents (upper left circle) largely contribute to the delivery of child- and family-centred care. They are the ones to provide children with appropriate care and support, but they also have significant influence in the process of child participation, illustrated by the arrows between the circles in Figure 2.1. As shown in section 2.1, there are many more factors influencing the implementation of child- and family-centred care, such as appealing hospital environments, evidence-based provision, understandable information for patients and the availability of necessary equipment and supplies. In this study, I specifically focus on the question of how the participation of children and parents can contribute to strengthening child- and family-centred hospital care, taking into account that paediatric healthcare is grounded in a triadic relationship, involving the child, the child's parent(s) and the healthcare professional.

In the following section I describe the concepts and the relations between the concepts depicted in Figure 2.1 in more detail and provide further theoretical explorations to reveal why the participation of children and their parents is important at all three levels.

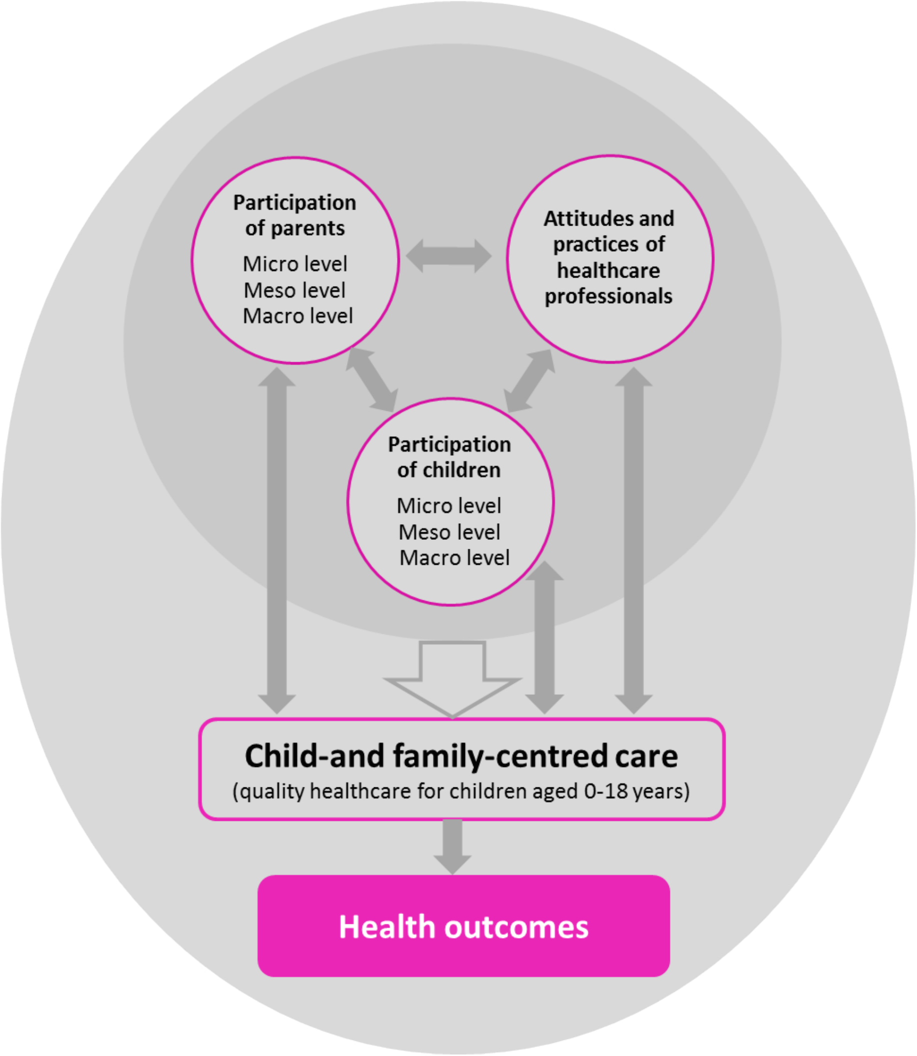


Figure 2.1 Conceptual framework to guide the present study

2.3.1 Participation of children

Evidence supporting the importance of child participation at micro level

It is widely documented that children want information about their treatment, that they want to be heard and have a say in healthcare decisions concerning them, or at least have the choice to do so (Ambresin et al., 2013; Bensted et al., 2015; Coad & Shaw, 2008; Wiering et al., 2016; Zwaanswijk et al., 2007). Research shows that children experience decreased anxiety and an increased sense of value and control when they are included in discussions about their symptoms and treatment (Feenstra et al., 2014; Young et al, 2003). Conversely, exclusion can increase their fear and make them feel angry, confused and upset (Beresford & Sloper, 2003; Coyne, 2006b; Feenstra et al., 2014;Runeson, 2002; Young et al., 2003), which in turn might have a negative impact on the recovery process and wellbeing of the child. Having a say increases children's satisfaction with the decision-making process and increases their adaptation to and understanding of their illness, as well as adherence to prescribed treatments (Donnelly & Kilkelly, 2011; Feenstra et al., 2014). The latter may be explained by the fact that understanding the child's needs, perspectives and values allows the clinician to propose treatment options that are more acceptable to the child (Robinson et al., 2008).

Being involved in decision-making also contributes to children's psychosocial development. It enables them to develop self-esteem and positive self-regard, enhances communication skills and encourages their participation in our wider society as active health consumers (Coyne et al., 2014; Moore & Kirk, 2010). Participation is an important experience that prepares children for more serious decisions in the future, which is particularly important for those with chronic conditions who need to take increasing responsibility for managing symptoms and treatment (Dunst et al., 2007; Jedeloo et al., 2010; Runeson et al., 2002). This implies that the child gradually learns to take conscious decisions about how to deal with the disease and the actions that will be taken with regard to the treatment.

Evidence supporting the importance of child participation at meso level

Since there is no robust work on the benefits of involving children in the evaluation of services (meso level), in this section I will draw on evidence obtained from studies with patients in general, rather than paediatric patients in particular. There is growing evidence supporting the idea that patient experiences are an important component of quality of care evaluation and improvement (Ahmed et al., 2014; Robertson et al., 2014). It is increasingly acknowledged that quality in hospital settings is affected not only by the quality of technical care received, but also by the quality of the interpersonal relationships between patients and hospital staff. Several studies have shown that good communication, partnership and being treated with dignity and respect are important patient needs (Robinson et al., 2008; Sools et al., 2014). Patients are uniquely able to provide feedback on this crucial dimension of quality, which is otherwise difficult to measure (Luxford, 2012; Manary et al., 2013). Robinson et al. (2008) noted that analysis of communication patterns by a third party may indicate the presence of a patient-centred interaction, however, if the patient does not perceive it that way, it really is not patient-centred.

Moreover, there is growing awareness that patient experience should not be looked at in isolation, supported by recent research demonstrating that better patient experience is associated with safer and more effective care (Anhang Price et al., 2014; Doyle et al., 2013; Isaac et al., 2010). Doyle et al. (2013) conclude that this evidence supports the case that the three dimensions of quality – safety, effectiveness and patient experience – should be looked at together, arguing that “clinicians should resist sidelining patient experience as too subjective or mood-oriented, divorced from the ‘real’ clinical work of measuring safety and effectiveness.” (p. 1)

Evidence supporting the importance of child participation at macro level
The participation of children at higher levels of decision-making, including research agenda setting and clinical guideline development, has been endorsed by international bodies like the WHO and UNICEF. Clinical guidelines are important tools for improving patient care. Many organisations and experts recognize patient and public involvement as an important instrument to make guidelines more patient-centred and to enhance their overall quality (Boivin et al., 2010; Légaré et al., 2011; van de Bovenkamp & Trappenburg, 2009). Patients experiential knowledge – acquired by their daily personal experience with the disease – could complement scientific evidence, and thereby increase the rationality of decisions and ultimately, the quality of clinical guidelines. Moreover, the participation of patients could enhance the practical implementation of these guidelines (Pittens et al., 2013). In the Netherlands, facilitating the participation of children and young people in guideline development is an exception, while this is becoming increasingly common for adult patients (van de Bovenkamp & Trappenburg, 2009). In particular, the inclusion of patient representatives in guideline development groups has increased, even though many difficulties with this method of patient involvement have been reported (Eccles et al., 2012; Légaré et al., 2011; van der Ham et al., 2014).

2.3.2 Participation of parents

Evidence supporting the importance of parents' participation at micro level
Historically, hospitalized children in the early half of the 20th century were cared for exclusively by health professionals, and visitation by parents was either extremely restricted or completely prohibited. This was mainly due to fear of cross-infections and beliefs of doctors and nurses that it was in the best interest of children if parents were not present in children's wards. At that time it was thought that a child who became upset when the parent left was experiencing psychological trauma and that it was best if the parents did not visit and the child was left to 'settle in'(Alsop-Shields & Mohay, 2001). Because in these times children were admitted to the hospital for extended periods of time, this meant that some children did not see their parents for weeks, months or even years.

Attitudes and practices began to change in the 1950s and 60s, largely due to the work of Bowlby and Robertson, who demonstrated serious emotional, psychological and developmental consequences of separation between mother and child (Harrison, 2010). The work of Bowlby and Robertson had a major influence on changes to the care of children in hospitals, meaning greater participation of parents in the care of their hospitalized children. Today children's wards admit parents as part of normal routine and the concept of family-centred care has evolved from allowing parents to visit their hospitalized child to welcoming parents as participants in partnership with health professionals.

Several interventions, such as decision-aids and coaching programs, have been developed to support parents in the process of medical decision-making with clinicians. Two recent reviews show that such interventions contribute to improved parent knowledge, increased satisfaction and decreased decisional conflict (measured as perceptions of uncertainty) (Feenstra et al., 2014; Wyatt et al., 2015). Furthermore, parents have significant influence on their child's ability to participate in his/her own care. Parents, for example, may encourage children to speak up or accompany them to talk to the doctor. On the other hand, parents may hamper the child's participation because they have so many questions and concerns of their own, competing for attention. It has also been shown that parents instinctively try to protect their sick child from distressing information and the burden of decision-making (Coyne et al., 2014; Zwaanswijk et al., 2007). Seriously ill children, on the other hand, may deliberately protect their parents by not telling them how much they know or suffer (Bluebond-Langner, 1978).

Evidence supporting the importance of parents' participation at meso level
As mentioned above, it is increasingly acknowledged that the experiences of patients are essential to the evaluation, improvement and patient-centeredness of healthcare. In the absence of systematic and rigorous measures to assess the quality of care from children's perspectives, the views of parents are frequently used as proxies for children (Ammentorp et al., 2005; Solheim & Garratt, 2013; Ygge & Arnetz, 2001). For example, the USA recently developed a paediatric version of the national standard to measure and publically report patient experience in hospitals. This survey – the Child HCAHPS® – is targeted to parents of paediatric patients (<18 years old) rather than to paediatric patients themselves (Toomey et al., 2015). Based on their experiences with the provided care and their knowledge about their child and its disease, parents can make valuable recommendations for delivering and enhancing paediatric healthcare. Assessing the experiences of parents is particularly valuable when children are too young to verbally report on their own experiences of care. However, when children get older, they should be given the opportunity to provide feedback independently from their parents.

Evidence supporting the importance of parents' participation at macro level
As mentioned above, children hardly participate in the planning/policy process for the services they use, including research agenda setting and clinical guideline development. An assessment of existing paediatric guidelines in the Netherlands showed that participation of parents is somewhat more common. Some 15 of the 82 guidelines found cited a method to consult with parents. For example, for the development of the guideline on Inflammatory Bowel Disease (IBD) in children, published in 2008 by the Dutch Association of Pediatrics, parents were invited to participate in the bottleneck analysis. Three focus group discussions with parents had been conducted in order to investigate what problems they encounter in caring for a child with IBD. The problems of both professionals and parents were captured in the formulation of clinical starting questions. For instance, parents indicated that they have many questions about the diet of their child with IBD, even when the disease is in remission. Another problem that parents mentioned was the lack of information on the disease, the medication and the long-term consequences. The final version of the guideline makes recommendations on these topics identified by parents (Nederlandse Vereniging voor Kindergeneeskunde, 2008).

2.3.3 Attitudes and practices of healthcare professionals

As recognized by the frameworks on child- and family-centred care described in section 2.1, children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families. Based on (inter)national agreements that the Netherlands has ratified, paediatric professionals have the duty to facilitate child participation in hospital care. Although most clinicians recognize the need to include children in decision-making, they have varying opinions about when and how to do so (Feenstra et al., 2014). The child's age, clinical condition, previous experiences, behaviour and ability to express oneself are often considered when deciding whether or not to actively involve children in healthcare decisions (Coyne, 2008; Runeson et al., 2001).

2.4 Barriers to child- and family-centred care

Despite the potential benefits of participation outlined above, there remains a gap between legal regulations on children's rights to participate in healthcare and the actual fulfilment of these rights in practice, thereby impeding the delivery of high quality healthcare that is centred around children's needs and preferences (Damm et al., 2015; Weil et al., 2015). Within the complex context in which child participation processes take place, several challenges in closing the implementation gap have been observed.

Firstly, even though children's willingness and capabilities to have a say in healthcare services have repeatedly been demonstrated, children's experiential knowledge generally has a low status compared to that of parents and physicians. There is still little recognition that children can offer a complementary perspective to that of clinicians and parents, providing unique and valuable insights into their needs and preferences. As a result, parents still generally act as children's spokespersons during medical encounters, leaving children in marginalized positions (Cahill & Papageorgiou, 2007; Coyne, 2008; Moore & Kirk, 2010; Tates & Meeuwesen, 2000). Moreover, adults with parental or institutional authority over children generally define what constitutes high quality paediatric care. Secondly, the respect for a child's right to participation is largely dependent on the attitudes and approaches of healthcare professionals, but there has been little research on their perspectives on child participation in consultation and decision-making. Some researchers have suggested that health professionals might have difficulty in facilitating child participation, for instance, due to protective attitudes towards children (Coyne & Harder, 2011), doubts about their competence to participate (Mårtenson & Fägerskiöld, 2007) and assumptions about a child's age and maturity (Dedding, 2009; Runeson et al., 2001). In addition, professionals might find it difficult to share their power and control with children (Coyne, 2006b, 2008).

Children, on the other hand, may not be fully aware of their participation rights and opportunities and may not be used to adults really listening to them and showing genuine interest in their views and perspectives, as many children have experienced in their daily lives (Dedding, 2009). Third, there is little experience with *how* to involve children in hospital care, especially how to do so in a way that fit the competences and needs of children and brings about changes that matter to children. While in recent years considerable attention has been paid to enhancing child participation in individual consultations between children and clinicians (Coyne, 2008; Feenstra et al., 2014), methods and tools are still needed to involve children in the evaluation/improvement of paediatric hospital care (meso level) and in the policy/planning process for the services they use (macro level).

The above highlights the need for gaining an understanding of how children and parents can participate more effectively at all levels of healthcare decision-making, in order to strengthen the quality of child and family-centred care.

Chapter 3

Research design

In this chapter, I present the objectives and main research question. The methodologies used to answer the main research question are described, followed by considerations of validity and research ethics.

3.1 Objectives and main research question

In order to contribute to the realization of high quality paediatric hospital care that meet children's own needs and wishes, this study aims to:

1. Understand what children and parents regard as good quality hospital care and how their perspectives correspond with existing frameworks for child- and family-centred care.
2. Understand health professionals' perspectives on child participation in paediatric hospital care.
3. Understand what methods are appropriate for facilitating meaningful participation of children at different levels of healthcare decision-making (micro, meso, macro)

The following main research question has been formulated:

How can participation of children and their parents contribute to strengthening the quality of child- and family-centred care in paediatric hospitals and departments?

3.2 Research approach

I mainly used a qualitative research approach, combining *participatory data collection methods* and *traditional qualitative research methods*.

Participatory data collection methods have their roots in collaborative or partnership methodologies. Collaborative research adopts an epistemological position that not only acknowledges children's agency, but aims to facilitate their voices being heard in research affecting *their* lives. It appeals for consistent collaboration with children in some or all stages of a research project (Dedding et al., 2013; Jurrius, 2012; Mason & Hood, 2011). Moreover, participatory approaches are usually committed to represent the voices of groups that have been historically excluded from knowledge production, such as women and people of colour, as well as children and young people (Cahill, 2007). By doing so, participatory research methodologies recognize 'that those "studied" harbour critical social knowledge and must be repositioned as subjects and architects of research' (Fine, 2008, p.5). Another important characteristic is that it goes beyond mere data gathering and report writing and uses the acquired knowledge to feed action strategies that promote change in the participants involved, other youth and the broader community. In this study, participatory research methods were used to evaluate the quality of hospital care from children's perspectives and to consider the feasibility of creating healthcare services that more closely meet children's own needs and wishes.

Qualitative research methods are particularly suited to gain insight into the experiences, meanings and views of individuals in relation to the complex circumstances of illness, treatment and hospitalization. Its open and exploratory nature provides room for participants' own words and meanings, allowing new and surprising insights to emerge (Sools et al., 2014). Furthermore, qualitative methods are most often used when few studies are available on a particular topic (Meadows-Oliver, 2009), which was the case in the context of this study.

Study 1 – Children's perspectives on paediatric hospital care

We conducted an exploratory multi-hospital study that aimed to answer the following sub-questions:

- What are children's experiences with and perspectives on the quality of paediatric hospital care?
- What are children's ideas and opinions on improving hospital care and services?
- What is the added value of participatory methods for involving children in healthcare evaluation?

The study was carried out in paediatric departments of eight hospitals in the Netherlands (two teaching and six regional). We used a qualitative study design, incorporating a range of participatory methods, including photovoice, children writing a letter to the chief executive of the hospital, face-to-face interviews using pre-formulated statements and online interviews using MSN Messenger or Facebook. Some 63 children with either acute or chronic conditions, aged 6–18 years (with an average age of 13 years), participated in the study. The vast majority of children were recruited from inpatient departments (n = 58). All data were stored digitally. The written data were analysed collectively using qualitative content analysis. As photographs used in photo-elicitation are not intended to stand alone, the photographs were not analysed in detail themselves. Instead, they were used to generate dialogue on how children give meaning to their hospital experiences. More details on the research methodology can be found in chapter 4.

Study 2 – Health professionals perspectives on children's participation in hospital care

In this sudy we investigated health professionals perspectives on child participation in paediatric hospital care. We posed the following sub-questions:

- How do professionals define the term participation?
- How and to what extent are professionals willing, able and required to commit to child participation?
- What barriers and restrictions for participation do professionals experience?
- What are professionals' opinions on how to strengthen participation practices?

Semi-structured interviews were conducted with healthcare professionals from 10 hospitals that were geographically spread across the Netherlands. Eight of these hospitals had also participated in the first study about children's perspectives on paediatric hospital care. A total of 32 healthcare professionals (4 men/28 women) were interviewed, including the heads of the children's wards (n = 9), paediatricians (n = 7), paediatric nurses (n = 6), hospital play specialists (n = 7), one hospital manager, one communication advisor and one policy advisor. The participants had between 2–35 years of experience working with children 0–18 years of age, which is the general age range for paediatric wards in the Netherlands.

Shier's "Pathways to Participation" model (2001) was used to guide the interviews. The model provides questions for five different participation levels and identifies three degrees of commitment for each level. This makes it a practical tool, with a sequence of 15 questions that help interviewees to critically reflect upon their current ideas and actions, as well as what they consider to be important to move the participation agenda forward. The interviews were audio-recorded and transcribed verbatim for analysis. A summary was sent to the interviewees to confirm that it properly reflected their views and experiences. All transcripts were read in their entirety and analysed using a combination of deductive and inductive content analyses. See for more details on the methodology chapter 5.

Study 3 – Incorporating children's needs and preferences in clinical guidelines

In a subsequent study the importance of incorporating children's needs and perspectives in clinical guideline development were addressed. This project was guided by the following sub-questions:

- What considerations do guideline developers make in deciding when separate guidelines are required for children and how can these insights be translated into a practical tool?
- What are healthcare professionals' experiences with and perspectives

on facilitating children's participation in the process of guideline development?

A sequential multimethod design was used. First, semi-structured interviews were conducted with 12 different stakeholders in the field of guideline development, either from a professional, academic or patient perspective. These sought to explore which criteria might be important in determining when specific guidelines for children are needed and to investigate participants' experiences with and perspectives on facilitating children's participation in guideline development. The interviews were audio recorded and transcribed verbatim for directed qualitative content analysis (Hsieh & Shannon, 2005) using MAXQDA software. Second, a questionnaire was sent out among a larger group of stakeholders (n=60) with the aim of investigating which criteria respondents find most important and of identifying any missing criteria. The respondents were employed at various types of organisations, including professional associations (n=13), patient organisations (n=16), hospitals (n=10), knowledge institutions (n=8), branch associations (n=7) and health funding agencies (n=3). The outcomes of the questionnaire were analysed using the Statistical Package for the Social Sciences (SPSS). Finally, a focus group meeting was organized in order to achieve a consensus about the final list of criteria and the content and format of the tool. The focus group meeting was audio recorded and notes were taken by one of the researchers. A comprehensive report was written and sent to all participants for member check. More details on the methodology are provided in chapter 6.

Study 4 – Narrative evaluation of the hospital-related experiences of children and parents

The Experience Monitor is the first instrument that allows a large number of children and parents to share their experiences of hospital care in the Netherlands. We performed an exploratory evaluation of the lessons that can be learned from these experiences, aiming to contribute to improving the quality of paediatric hospital care in the Netherlands. We were specifically interested in answering the following questions:

- How and by whom has the monitor been used?
- What are the constituent subjects and the nature of the collected experiences?
- What issues dominate participants' stories?
- How can these issues be interpreted and understood?

Narrative catalysis was performed to identify patterns that provide insights into positive and negative hospital experiences, followed by qualitative content analysis, allowing for an in-depth understanding of these experiences. Narrative catalysis is the process of preparing observations and interpretations of collected stories and answers to questions about them (Kurtz, 2014). The data generated by the interpretation questions were analysed and visualized using Tableau software. Subsequently, within these results, patterns were observed, providing insights into (a) aspects of care that contribute to positive experiences, (b) aspects that contribute to negative experiences and (c) themes that prevailed in the experiences of participants. These aspects and themes were then interpreted and analysed in greater detail using qualitative content analysis. See also chapter 7.

Study 5 – Giving voice to children in contexts of poverty and deprivation

In the first study, Photovoice was used as one-off participatory activity to enable children to record and reflect on their hospital experiences, either positive or negative. We were, however, also interested in understanding the added value of engaging children in a photovoice project for a prolonged period of time. For this purpose, an extensive photovoice project that addresses the sensitive topic of poverty was performed. Even in a wealthy country like the Netherlands, poverty is a rising concern that significantly affects children's physical health. There is, for example, a strong relationship between low socio-economic status and the occurrence of paediatric obesity and asthma (Schreier & Chen, 2013).

We involved two groups of children living in contexts of poverty and deprivation in urban areas of the Netherlands, supporting them to record and reflect on their lives and neighbourhoods through photographs. We were particularly interested in answering the following questions:

- What is the potential of Photovoice as a method to make explicit children's narratives about their lives and the problems they face?
- How can Photovoice be used to bring about an effective dialogue between children and policy-makers?

We invited the children to take photographs and tell us about their ideas about what is positive in their lives and neighbourhood and how their lives could be improved. The photographs taken by children formed the basis for individual and group photo elicitation interviews, allowing for an in-depth understanding of children's experiences and needs. Furthermore, we conducted participant observation and informal interviews while working and travelling with the children during work sessions and outings. Though initially the researchers gave direction for the project, the children gradually got more involved as partners, selecting topics for photography and themes to discuss. The children were actively involved in analysing their own data, categorizing the photos and determining which topics might be missing. Parallel to the analysis with the children, detailed interview and group discussion transcripts, field notes and observation reports were written and analysed by the researchers. Inductive content analysis of the raw data was undertaken to identify recurring concepts and themes that were discussed and reflected upon in the research team. This not only fed the analysis with the children, but also augmented our own understanding of their lives and needs. Additionally, it assured that analyses were performed at an academic level, leading to articles for publication in peer reviewed journals. Details on the research methodology are given in chapter 8.

Table 3.1 provides an overview of the research aims and methods, showing in which case study/chapter they are addressed.

Table 3.1 Overview of research aims, methods and corresponding chapters of the thesis

Research aim	**Methods**	**Case study**				
		1	2	3	4	5
		Corresponding chapter				
		4	5	6	7	8
Understanding what children and parents regard as good quality hospital care and how their perspectives correspond with existing quality frameworks for child- and family-centred care.	Participatory data-collection methods	X			X	
Understanding health professionals' perspectives on child participation in paediatric hospital care	Qualitative research methods		X	X		
Understanding what methods are appropriate for facilitating meaningful participation of children at different levels of healthcare decision-making (micro, meso, macro)	Participatory data-collection methods	X			X	X

3.3 Validity

A number of strategies were used to establish the credibility of the study. These comprise:

- Triangulation: different research methods were used in concert, compensating for their individual limitations and exploiting their respective benefits. Another form of triangulation involved the use of a wide range of informants, including children, adolescents, parents and healthcare professionals. This allowed individual viewpoints and experiences to be verified against each other, ultimately leading to a composite picture of needs and perspectives.

- Member checks: where appropriate member checks were used to bolster the study's credibility. Participants were sent a summary of the (group) conversation to confirm that it properly reflected their views and experiences.
- Frequent debriefing sessions: regular meetings were organized with supervisors, co-researchers and project partners to discuss and reflect on results and interpretations, including several feedback rounds on the manuscripts, hereby reducing researcher bias.
- Data management: In all studies, the primary data were extensively documented. Interviews and group discussions were audio-taped and transcribed verbatim for analysis. Detailed field notes were written to document observations and informal interviews.

3.4 Ethical considerations

Given that the research projects described in this thesis did not fall under the Dutch Medical Research Involving Human Subjects Act, it was not necessary to seek official ethical approval from the Review Boards of the hospitals involved. Nevertheless, ethics was at the core of our concerns during the study. All participants (and their parents) received verbal and written information about the goals and procedures of the study. Verbal consent was obtained from participants prior to audio recording of interviews and group discussions. Participants were assured that the information provided would be treated confidentially and would not be linked to their individual identities or to their hospitals. Furthermore, it was emphasized that participation was voluntary, that participants were not obliged to answer questions and that withdrawal was possible at any time. Names of children, employees and hospitals have been removed from the story/interview excerpts to ensure anonymity.

Especially with ill children, and their families, it is important to take into account the strain that participation in such a project can involve. We were therefore concerned not to overburden the children. Researchers drew the interviews to a halt if children's verbal and physical expressions indicated that they needed some rest.

3.5 Outline of the thesis

In chapters 4 to 8 the results of the study are presented. The first case study is described in **Chapter 4**, focusing on children's and young people's experiences with and perspectives on the quality of paediatric hospital care (first research aim). Chapters 5 and 6 focus on the second research objective by analysing health professionals' perspectives on child participation in daily paediatric hospital care (**Chapter 5**) and in the process of clinical guideline development (**Chapter 6**). In **Chapter 7**, the fourth case study is presented, which concerns an exploratory evaluation of narratives written by paediatric patients and their families. **Chapter 8** provides insight into the potential of Photovoice to facilitate an effective dialogue between children and local and policy-makers. In **Chapter 9**, the main research question is answered based on the findings of the five case studies. I close this thesis by suggesting directions for further research.

Chapter 4

‘[I would like] a place to be alone, other than the toilet’ - Children’s perspectives on paediatric hospital care in the Netherlands

Abstract

Background Although it is widely recognized that children are willing, capable and legally entitled to be active participants in their health-care, parents are generally invited to evaluate paediatric hospital care and services rather than children themselves. This is problematic because parents cannot serve as the only spokespersons for the perspectives and experiences of children.

Objective To investigate children's experiences with and perspectives on the quality of hospital care and services in the Netherlands, and how they think care and services could be improved.

Design A qualitative study incorporating different participatory data collection methods, including photovoice and children writing a letter to the chief executive of the hospital.

Setting Paediatric departments of eight hospitals in the Netherlands (two teaching and six regional).

Participants Children and adolescents (n=63) with either acute or chronic disorders, aged between 6 and 18 years.

Results The research results provide insights into children's health and social wellbeing in hospitals. Important aspects of health, like being able to sleep well and nutrition that fits children's preferences, are structurally being neglected.

Conclusion The participatory approach brought children's ideas 'alive' and generated concrete areas for improvement that stimulated hospitals to take action. This demonstrates that participatory methods are not merely tools to gather children's views but can serve as vehicles for creating health care services that more closely meet children's own needs and wishes.

4.1 Introduction

Children and adolescents are significant users of health-care services and it is increasingly accepted that they are not only objects of care but knowledgeable social actors who have their own perspectives on issues that relate to them, including health care (Aynsley-Green et al., 2000; Clavering & McLaughlin, 2010; Hallstrom & Elander, 2003; Lightfoot & Sloper, 2003; Sinclair, 2004).

These changing views of children have led to international reforms in health policies, guidelines and legislation to support or even obligate the involvement of young people in decisions about their health care. For example, in September 2011 the Council of Europe adopted the Guidelines on Child-Friendly Health-Care. These Guidelines aim to integrate already existing international conventions for children's rights with respect to health and health care, including the United Nations Convention on the Rights of the Child (1989), into a practical framework that promotes the delivery of child-oriented health care in the Council of Europe member states. Participation is one of the five main principles of these Guidelines and needs to be applied in individual medical decision making and in the assessment, planning and improvement of health care services (Council of Europe, 2011).

The Netherlands is one of the pioneer countries in recognizing the rights of minors to participate in treatment decision-making. The Dutch Medical Treatment Act (WGBO;1995), states that young people aged 16 or over have the right to make their own treatment decisions, and those between 12 and 15 years are entitled to take decisions with their parents. The Dutch legal system, however, does not require children's participation in health care at the collective level, as service-users or in policy-making processes. Consistent with daily hospital practice in the Netherlands (Dedding, 2009; Tates & Meeuwesen, 2000; van Staa et al., 2010) and elsewhere (Runeson et al., 2002; Vis et al., 2011), children and young people are rarely given opportunities to provide feedback on their experience of hospital care and services. Children's willingness (Carter, 2002; Coyne & Harder, 2011; Coyne, 2006b) and capability (Alderson et al., 2006; Coyne, 2008; Goodenough & Kent, 2003; Moore & Kirk, 2010) to have a say in health-care services and the value of their perspectives for improving child-oriented care (Kilkelly, 2011; van Staa et al., 2011) have repeatedly been demonstrated, but the opinions of parents still generally form the basis for measuring the quality of paediatric hospital care (Ammentorp et al., 2007; Beresford & Sloper, 2003; Homer et al., 2011; Ygge & Arnetz, 2001). This is problematic because the views of parents, although important, do not represent those of children and thus parents alone cannot serve as spokespersons for their children (Christensen & Prout, 2002; Coad & Shaw, 2008; Knopf et al., 2008).

The current paper describes a multi-hospital study that was carried out in eight Dutch hospitals. It is the first comprehensive study of children's and young people's experiences with and perspectives on the quality of paediatric hospital care and services in the Netherlands. It contributes to a growing body of knowledge about how children can play an active role in creating health care practices that better suit their own needs. Furthermore, it provides evidence about the potential of participatory research techniques to invoke change in health care settings. In this paper, we use the term children when referring to our study population (6-18 years old). We distinguish between particular age groups when relevant.

4.2 Methods

Design
We used a qualitative study design incorporating a wide range of participatory data collection methods (Dedding et al., 2012). Photovoice and 'letter to the chief executive' were open to all ages. With adolescents (13-18), online and face-to-face interviews were also used. These methods were chosen because they allow the children to tell their own story instead of making them the object of the researcher's inquiry (Langhout & Thomas, 2010; Lundy & McEvoy, 2011; Mason & Hood, 2011).

Setting
Both in- and outpatient paediatric departments of eight Dutch hospitals participated in the study. Two of the hospitals are teaching hospitals with an associated paediatric hospital. The others are smaller, regional hospitals. In six hospitals one of the four methods was used and in the other hospitals two or three methods were used. The distribution of the methods between the different hospitals depended on their preferences, target group and capacity to facilitate the data collection activities. When more than one method was available, children could choose which method they preferred; only one method per child was used.

Participants
Some 63 children with either acute or chronic conditions, aged 6-18 years, participated in the study (Table 4.1) with an average age of 13 years. The vast majority of children were recruited from inpatient departments (n=58).

Table 4.1 Number of participants for each of the methods used

Method	**# Hospitals involved**	**Girls**	**Boys**	**Total**
Photovoice	3	7	7	14
Letter to the chief executive	1	10	13	23
Online interviews	3	7	6	13
Face-to-face interviews	3	8	5	13
Total		**32**	**31**	**63**

Procedures

Children were invited to participate in the study by hospital play specialists who provided them and their parents with a letter explaining the aims and procedures of the study. We considered that hospital play specialists were the right persons to decide which children might be interested and able to participate. If children agreed to participate, they were approached by one of the researchers from the national patient organisation (Zorgbelang) who planned and carried out the data collection activities. The interviews were audio recorded and transcribed verbatim for analysis.

1) Photovoice

Only children who stayed in hospital for three days or more could be involved in the photovoice activities because they needed to have enough time to take photographs. In addition, a stay of three days or more gave them more experiences on which to draw. Children received an introduction box containing a camera, an information and instruction letter for themselves and their parents, a consent form, and a notebook and pen. Children were asked to make a total of 10-15 photographs, capturing things and places they liked and did not like. Children were given up to one week to take the photographs, depending on the length of their stay. After this, the photos were printed. Then children incorporated their photos with texts, explaining the meaning behind the photos in either a scrapbook or collage. These were used to present the results to the hospital management but also formed the basis for face-to-face discussion of the photos with children, either individually or within a group. During these photo-elicitation interviews, the interviewer asked short questions, such as: What is this? What is happening here? Why did you make this picture? The interviews were generally conducted at a quiet room in the hospital shortly after making the photographs. In two instances, the interview was done at home because the child had already been discharged. As an acknowledgement of their efforts, children received copies of their photographs after the interview.

2) Letter to the chief executive

Children were invited to write their letter through a specially designed format (Figure 4.1), available through a link on the website of the hospital. In this hospital, all children have access to an infotainment system above their bed on which they could fill in the format at a moment that suited them. The letters were automatically saved and copied into a Excel file for analysis.

3) Online interviews using Facebook or MSN Messenger

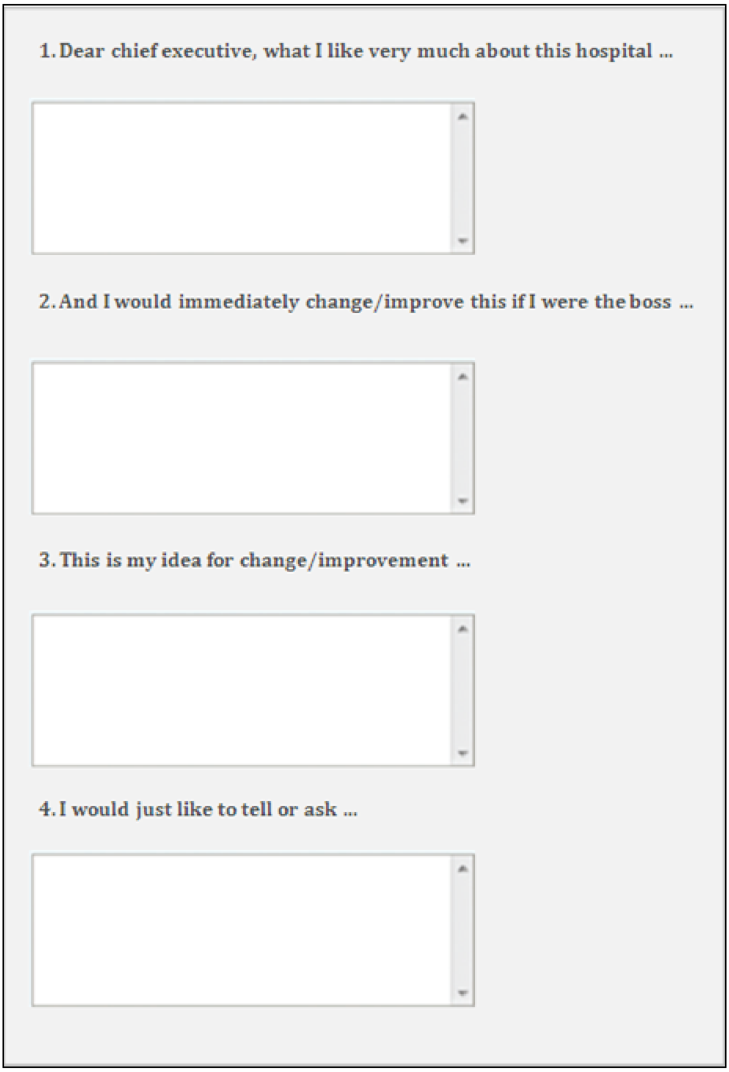
Interview appointments were made on a day and time that suited the participants. More than half of the interviews (n=7) were conducted while children were still hospitalised and these participants were given a laptop or iPad, so they could participate in the interview from their bed. In the other six cases, adolescents participated at home shortly after their discharge from the hospital using their own computer. The interviews were semi-structured; the interviewer opened with some general questions, such as: What was it like to be admitted at the hospital? What went well and what not? If you were the boss of the hospital what would you change? The interviewer asked probing questions to search for depth in the children's stories. The interviews lasted about 30 minutes. Afterwards the transcription of the conversation was copied and saved in a Word file after which the chat history was deleted to guarantee the privacy of the participants.

4) Face-to-face interviews using pre-formulated statements

Children were asked on the spot if they wanted to participate. Children that agreed participated from their own room and were given a box with pre-formulated statements (Table 4.2) that served as starting points for the conversation. Young people were asked to pick statements from the box and to discuss their associations and experiences with them. Moreover participants were explicitly invited to bring up their own topics of discussion. In this way, the dialogue between child and researcher was encouraged without the researcher being dominant.

Table 4.2 Examples of pre-formulated statements

There is too little to do in the hospital for young people my age.
Everyone should have a computer in their room with access to the Internet.
When I need someone in the hospital, they should always come right away.
I do not like that I have to share a room with children that are much younger or much older than me.
I am not afraid to ask the nurse or doctor a question.
It is always asked what I would like and that is being listened to.
They ask my parents more questions and explain more to them than to me.



1. Dear chief executive, what I like very much about this hospital …

2. And I would immediately change/improve this if I were the boss …

3. This is my idea for change/improvement …

4. I would just like to tell or ask …

Figure 4.1 Format ‘letter to the chief’

Ethics

As the research project does not fall under the Dutch Medical Research Involving Human Subjects Act, official ethical approval was not needed. All participants and their parents received verbal and written information about the project and provided written consent. Verbal consent was obtained from children prior to audio recording of interviews. The children were informed that the information provided would not be linked to their individual identities, that participation was voluntary and that withdrawal was possible at any time. For example, two children that had agreed to participate in a face-to-face interview withdrew because they were too ill or too tired on the day of the interview. Four children that participated in the photography activities withdrew from the photo-elicitation interview after they had been discharged because they decided they did not want to be interviewed. The research team was concerned not to over- burden the children. Researchers drew the interviews to a halt if children's verbal and physical expressions indicated that they needed some rest.

Data management and analysis

All data was stored digitally. The written data were analysed together using qualitative content analysis (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). All transcripts were read in their entirety and coded for recurring themes. The codes were then sorted into more abstract (sub)categories. The derived categories were discussed and revised with the project team. As photographs used in photo-elicitation are not intended to stand alone(Carter & Ford, 2013), the photos were not analysed in detail themselves. Instead, they were used to generate dialogue on how children give meaning to their hospital experiences.

4.3 Results

The aim of this study was to explore comprehensively children's experiences with and perspectives on the quality of paediatric hospital care and how this can be improved. By analysing children's positive and negative experiences, five themes were identified: 1) attitudes of health care professionals; 2) communication with staff; 3) contact with peers and family; 4) treatment procedures; and 5) hospital environment and facilities.

Attitudes of health care professionals

Children emphasized that doctors, nurses and other hospital staff needed to have sufficient time and attention for patients, and should be willing to help the patient and to answer questions. They also appreciated personal qualities of staff members, such as sociability, kindness, and amiability:

> *"I believe the nurses are doing a good job. They are kind to me and they are patient." (6-year-old girl)*

These positive experiences, as well as the less positive ones, emphasize the importance of pleasant, open interaction between patients and their care givers. According to children, hastiness and a lack of time among nursing staff, which is unfortunately not uncommon due to the high workload in health-care, does not contribute to such interaction:

> *"Some are very brusque [...] One of them just tosses down the medicines and then walks away quickly. They could at least say something." (14-year-old girl)*

Communication with staff
Children emphasized the importance of effective communication, including being well informed, health care professionals speaking directly to them, consultation between hospital staff, and being listened to.

Accessible and adequate information
Children frequently stressed the importance of being clearly informed about the treatment, planning and procedures. Children also wanted to receive information about details that adults may consider not interesting or too complex for children, such as the type of medication they are receiving. Well informed children are generally very satisfied and describe examples of situations in which they were well prepared and knew what to expect:

> *"They explained everything very well, before I underwent surgery. I was well informed about what they were planning to do and why. I appreciate that very much." (14-year-old girl)*

Poorly informed children, on the other hand, express feelings of discomfort or even anxiety. They articulate a strong desire for appropriate information about the timing, purpose and procedures of medical interventions and the opportunity to ask questions:

> *"There is not enough time to ask questions. I was not well prepared for the surgery. I did not know how long I had to stay here [the hospital], whether or not I could go outside, whether or not I*

> *was allowed to take a shower. I did not have the opportunity to ask those things beforehand. I had to ask all those things yesterday, at the very last moment, in the operating room." (18-year-old girl)*

Direct communication with staff
Children, and in particular adolescents, highly appreciate being directly approached by health professionals, rather than through their parents:

> *"You are kept informed about everything, which is great. They ask you questions, they ask me and my parents. Both, really. That is great. Everything is always clear to me and that is what is most important, as in the end it is about me." (17-year-old girl)*

This does however not mean that parents should be absent or silent during a medical encounter; their involvement is very much appreciated by almost all children. Children considered that parents were able to remember and recall important information, complement children's narratives, introduce things that children had forgotten to say or ask questions that children do not dare to ask themselves. This contrasts with the growing tendency to let children see their medical specialist alone.

Consultation and communication between staff
While children are predominantly positive about communication and relationships with doctors and nursing staff, they express concerns and complain about communication between staff. Problems that were observed include: miscommunication, poor information transfer and conflicting information and advice:

> *"Yesterday all these doctors kept coming up to me and I had to tell all of them the same story over and over again. That is kind of weird. Why don't they write things down?" (12-year-old boy)*

Another girl commented:

> *"I had a conversation with the doctor about being admitted to hospital. No clear agreements were made about what they were going to do. He thought, I expect, that they would explain it here [nursing ward], and here, they thought he had already done it. So that did not go very well. Everyone thought I already knew everything but that was not true at all. I was rather unhappy*

> *about that. It is alright now, because I asked a lot. Everything is clear now. But I was rather unhappy about that.” (15-year-old girl)*

The example illustrates children’s appetite for information but also demonstrates that children are sharp observers rather than passive recipients of care.

Being listened to

Children clearly wish to have a say and to be listened to with regard to both their treatment and the stay in hospital. This was especially the case for chronically ill adolescents who had already been admitted to hospital several times and have extensive knowledge and experience of their condition and treatment. This group of patients specifically want their experience based views to be taken into account but, unfortunately, this was not always the case:

> *“[...] I told them the drip was not set up properly and that I was not feeling well because of it and that the bed needed to be put back. Then they said: ‘Well, the drip is already in and it is done’ but then I fainted anyway. The bed should have been adjusted. At that time, they did not listen.” (17-year-old girl)*

The findings also show that children wish to take part in decision-making processes. For example, some adolescents appreciate being able to choose with whom they share a room or whether they want to be admitted to the children’s ward or the adult department. Smaller children, for instance, like to choose whether the anaesthesia is administered by injection or by means of a cap. However, there are many examples that illustrate that children’s views and wishes are not always taken into account:

> *“[...] the TV is turned off at a certain time. And the nurse comes by to tell you to go to sleep. I find that a bit strange, I can decide that for myself.” (18-year-old girl)*

For participation to be successful, it is important that children’s contributions are taken into account and acted upon. When children feel that they are not being listened to, they are less likely to make an effort to be heard next time.

Participation, furthermore, calls for an atmosphere in which children are aware of their participation rights and opportunities, and feel free to voice their views and preferences and to ask questions:

> *“I dare to ask anything; that’s my nature. But I think that everyone could do that here [children’s ward]. It’s quite open. There’s enough opportunity.” (17-year-old-girl)*

Some children, however, described situations that demonstrate the contrary:

> *“I would enjoy sharing the same room with someone. I would like that. But I think you do not have a choice. You just have to wait and see where you will end up.” (14-year-old boy)*

Another boy commented:

> *“I had to get out of bed for the finger prick. But I wanted to stay in bed a little while longer. And I wanted to say that they should come back later, I would like that better, but I cannot do that. But if I could, I would really like that.” (12-year-old boy)*

These examples illustrate that children are occasionally uncertain about whether they have a choice and that some even keep quiet because they believe they are not allowed to reveal their preferences or think it is inappropriate to do so.

Contact with peers and family

Children wish to have the outside world within reach. It is, therefore, important to them that the right conditions for this are created: access to the Internet, use of mobile phones and unrestricted visiting hours. Children indicate that they do not like to be lonely in hospital and, consequently, express a great desire to be accompanied by familiar people. Children repeatedly mentioned the joy of receiving visits and post cards from family members and friends. Moreover, children very much appreciate their parents having the opportunity to stay overnight.

Modern technologies and social media provide a great opportunity to stay in touch with people at home. Children, for example, mentioned how important it was for them to be able to send text messages to classmates and emails to teachers, and to chat online with friends or parents:

> *“The laptop is important. If you’re missing your parents, you can talk to them on Hyves [a Dutch social media platform] or Facebook.” (9-year-old-boy)*

Children also report enjoying the company of fellow patients. Children consider that playrooms and sitting rooms are a good place to meet others. Furthermore, most children do not mind sharing a room and many even prefer it, preferably if there is someone of their own age to play with or talk to. Some children also stressed that having a roommate reduces the need for parents to stay the night. None of the children disliked the parents of a roommate spending the night in their room because they valued this opportunity themselves and consequently sympathize with children in a similar situation.

Treatment procedures

Children frequently talked about the medical interventions which they undergo. Intrusive procedures which were regarded as unpleasant, frightening and painful were most often mentioned, such as taking blood samples, inserting a drip, receiving injections and inserting stomach tubes. Many children felt that the waiting time before such medical interventions was too long. They felt unhappy about waiting because it makes them even more nervous:

> *"[If I were the boss, I would change this immediately ...] It always annoys me that I have to wait a long time for the epidural. The epidural is always given later than the scheduled time which I really don't like because I'm apprehensive." (6-year-old-girl)*

Children, moreover, highlight the importance of guidance and distraction from hospital play specialists during intrusive procedures. However, according to the children, this is not yet sufficiently done in all hospitals:

> *"I want a lot of distraction when I am being injected because that happens too little. It also helps if you get a small reward after the injection because then the end is a bit more fun." (9-year-old girl)*

The preferred method of distraction differs per child which means that it is important to ask children what they would prefer and to offer them a choice. Some children, for instance, appreciate having their own soft toy with them while others prefer a small reward, like a toy or sticker.

Hospital facilities and environment

Children had much to say about the hospital facilities and environment. Remarks focused specifically on hospital facilities, poor hospital food, the furnishings and decorations of the paediatric department, and lack of privacy.

Hospital facilities
Children appreciate the many entertainment activities facilitated by the hospital, such as watching television, playing computer games and playing with the hospital play specialists, and spending time in the playroom or the teenager's room. Access to and functioning of some equipment was problematic: poorly working computers, slow Internet connections, broken televisions, and fees for television and Internet use. The latter was especially important for children whose parents could not afford to pay these fees. Children also wished for some more activities for patients aged 12 and over, such as organizing a weekly 'fun night' for teenagers that have to stay in hospital for a longer period.

Some adolescents, especially those that stayed in hospital for more than a few days, had concerns about missing lessons and falling behind at school. To maintain schoolwork during hospital admission, children wished for opportunities to go to hospital school, receive individual tuition or to make use of the electronic learning environment offered by many schools, again emphasizing the importance of access to the Internet.

Hospital food
With few exceptions, children had nothing positive to say about hospital food. Several issues were raised repeatedly, including undercooked, unappetizing and non-fresh food, little variation in the menus, and food that does not meet particular cultural or religious dietary requirements:

> *"The main meal of the day should be improved. Often I didn't eat because it doesn't taste nice." (8-year-old-boy)*

Furnishings and decorations
Children attach great value to a colourful decor and furnishing of the rooms and corridors in the children's hospital or department, and they much prefer this to more standard hospital decor:

> *"I once went to a small hospital in Germany. And everything was so sterile and white there. You just felt like: you are alive, but that is all. Compared to that, I like this [hospital] better." (14-year-old boy)*

According to children, bright and colourful settings contribute to a pleasant atmosphere. Although all paediatric departments, to a greater or lesser extent, addressed the 'child-friendly' decoration of their unit, children think this still needs improvement in some hospitals and they made a number of suggestions, like message boards and some extra space to display their mail. Children also frequently mentioned the desire for a private toilet and shower. This arises largely from practical considerations. Children, especially those that are extremely weak and/or attached to a drip stand, experience great difficulties getting to toilets in the corridor.

Some children made comments about doors and windows. For example, in one newly built hospital, transparent doors were problematic because they allowed in too much light (Figure 4.2). This was especially an issue at night because it causes difficulties with sleeping. In another hospital, one girl complained about a window that could not open:

> *"I cannot get any fresh air in my room, and now I have a cloud in my head. I wish the window could open, like in the room I stayed in last time." (15-year-old girl)*

Privacy

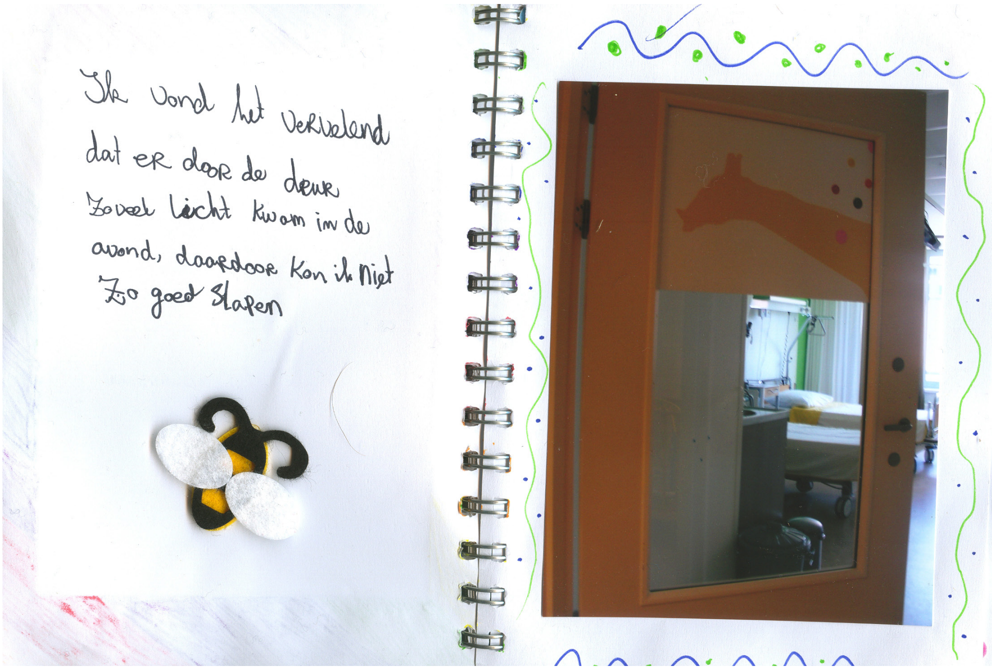
One girl explicitly considered the privacy aspect of private shower and toilet facilities:

> *"Actually, every room should have a private shower and toilet, also with regard to privacy. Because if you return from surgery, you do not have any clothes on, except for a blue gown. And then there are many nurses and there are no curtains. I do not feel comfortable with that." (18-year-old girl)*

The need for more privacy was also articulated in relation to other environmental issues, such as not having a place to be on your own. As one boy aptly put it:

> *"[I would like] a place to be alone, other than the toilet." (9-year-old boy)*

Others experienced the absence of window blinds as a violation of their privacy. One girl, for example, made a photo (Figure 4.3) of the view from her room that shows that the other building is very near and that blinds are absent, making it possible to look inside someone else's room.



Ik Vond het VeRvelend
dat eR door de deuR
Zoveel licht kwam in de
avond, daardoor Kon ik niet
Zo goed Slapen

Figure 4.2 “It bothered me that a lot of light shone through the door at night, I could not sleep very well because of that.” (12-year-old girl)

je kon zo bij iemand naar
binnen kijken

Figure 4.3 “You could easily look into someone else’s room.” (13-year-old girl)

4.4 Discussion

The object of this study was to investigate children's experiences with paediatric hospital care in order to consider the feasibility of creating health care services that more closely meet children's own needs and wishes. Some findings may not seem interesting because they have long been known. Despite this knowledge, major aspects of health and well-being of ill and diseased children, such as nutrition that fits their preferences and being able to sleep well, are structurally being neglected in hospitals. Children's priorities for hospital care and services are well documented but they are often not acted upon. Our study established that participatory methods have the potential to promote direct action and bring about meaningful changes.

Health and social well-being of children in hospital
The importance of a healthy diet and being responsive to children's general sleeping habits may seem self-evident, especially when considering that this directly contributes to the healing process. The need for window blinds so that children can sleep in darkness (Figure 4.1) seems obvious but had been completely overlooked when designing the new children's ward in one of the hospitals in our study.

Other key findings underline the importance of taking into account social aspects that are known to greatly affect children's subjective well-being, including relationships with family, friends and peers (Adamson, 2013; Rees et al., 2012). Children repeatedly mentioned that they were happy when parents could stay the night and when they received visits from family members and friends. This is consistent with the findings of Pelander & Leino-Kilpi (2010) who reported that separation from parents and family, friends, home and school were children's worst experiences during hospitalization. Wilson et al. (2010) made similar observations from research with school-aged children who indicated being alone as a primary fear of hospitalization that makes them feel "scared, mad and sad." This evidence reaffirms the importance of hospital policies, including unrestricted visiting hours and the possibility for parents to room-in with their hospitalized child, that have been introduced over the last 20 years in an attempt to make hospitals more child-friendly places.

Children, and in particular adolescents, also highlighted the need for electronic communication with people outside the hospital using mobile phones and the Internet for both social and educational reasons. This is not surprising given that the popularity and use of such technologies has increased considerably among children over recent years, even faster than among the rest of the population (Kuntsche et al., 2009), and has become an integral part of young people's daily lives, allowing them to maintain relationships with friends and peers (Currie, et al., 2010). Increasing numbers of schools in the Netherlands make use of electronic learning environments which means that it is important that children in hospital, especially those admitted for longer periods of time, have access to a computer with Internet in order to keep up with school.

Children complained about broken computers, slow Internet connections and fees for Internet use, leading us to suggest that some hospitals are lagging behind the rapid technological developments in society. Lambert et al. (2013) drew similar conclusions from research with young children (5-8 years), arguing that health care has been slow in keeping up with global advancements in children's use of social technologies. Hospitals need to consider how to facilitate children's technological connectivity, important for both their social and school lives. This may be even more crucial for adolescents because peers are more important in their lives and play a substantial role in their psycho-social development (Kuntsche et al., 2009). For example, Kendall et al. (2001) suggested that the psychosocial impact of congenital cardiac disease on adolescents, such as disruption of social relationships, may play a greater role in determining self-perceived health than the physical limitations they experience.

Many of the other topics that participants raised support findings from previous studies, such as children's preference for a warm and colourful décor (Kilkelly, 2011), more privacy (Ekra & Gjengedal, 2012; Pelander & Leino-Kilpi, 2004), complaints about poor hospital food (Coyne, 2006a; Curtis et al., 2004), the need for sufficient preparation and guidance during stressful medical interventions (Coyne, 2006a; Wilson et al., 2010) and the importance of good relationships (Curtis et al., 2004; Jackson, 2003; Livesley & Long, 2013) and effective communication (Birks et al., 2007; Lambert et al., 2011; Tates & Meeuwesen, 2001) with hospital staff. Lightfoot and Sloper (2003), for example, showed that young people with a chronic illness or physical disability find staff communication with patients to be of key importance.

Given that these topics have long been recognized and highlighted by a number of authors, no further evidence is required to demonstrate that these are major issues for children. Instead, hospital staff need to acknowledge and act upon them. As Curtis and collegues (2004) point out, practitioners and managers are often poor at acting on such knowledge, although we did not find that in this study.

Methodological strengths

Many of the children's needs and areas for improvement identified during this study were acted upon by the hospitals. Examples include blinding of doors and windows and developing child-friendly menus that have been tasted and assessed by a specially established team. Other action points could not be addressed immediately but are now receiving attention or have been placed high on the agenda. We believe that the participatory approach taken in this study has played an essential role in motivating hospitals to take direct action upon the issues identified by the children. The methodology has a number of strengths which supported implementation of the findings.

First, our approach acknowledged that children are experts about their own lives and we provided them with the opportunity to tell their own stories. Second, it facilitated direct communication between young patients and hospital management, giving children the unusual opportunity to speak up and be heard in their own words, without parents or researchers interpreting their words or acting as their spokespersons. Third, photovoice was able to provide visual metaphors of what the children wanted to tell (Lorenz & Kolb, 2009). Finally, the data produced by children generated concrete points for improvement to which hospital managers were able to respond.

Participatory methods are uncommon and not well accepted in hospital settings (Carter & Ford, 2013) as a result of widespread unfamiliarity with the participatory philosophy and an ideological clash with the medical paradigm. However, in our opinion, participatory methods have greater potential to bring about changes that matter to children than traditional social research methods. For this reason, we recommend that participatory approaches should be employed to evaluate hospital care with children on a structural basis. Hospital managers should be involved from the very start in order to make sure that they fully embrace the initiative. Ultimately, children and young people are dependent on policymakers and hospital managers to implement participant's needs and create more responsive health care services.

4.5 Conclusion

Using a number of participatory research methods children and young people were very eager to share their experiences. The strength of this participatory approach is that it brought children's ideas 'alive' and generated concrete areas for improvement that stimulated hospitals to actually address and act upon the issues raised by children. This demonstrates that participatory methods are not merely tools to gather children’s views but can serve as vehicles for making changes that matter.

v

Chapter 5

Health professionals' perspectives on children's and young people's participation in health care: a qualitative multihospital study

Abstract

Aims and Objectives To investigate healthcare professionals' perspectives on child participation in paediatric hospital care and their opinions on improving participation practices.
Background Some scholars argue that the decision-making capacities of children largely depend on the attitudes of healthcare professionals rather than on the children's own competences. Healthcare professionals' perspectives on children's participation in hospital care remain largely unexplored.
Design Qualitative descriptive design.
Methods Healthcare professionals (n=32) from 10 paediatric wards in the Netherlands participated in semi-structured interviews. Shier's Pathways to Participation model (2001) was used to guide the interviews.
Results Participation is not a term that is frequently used by professionals; however, they feel familiar with the ideas underlying the term, and it is perceived as being at the core of their work. Professionals believe that high levels of participation are possible in basic care for children. Participation in medical decision-making is considered to be more complex and subject to a number of reservations and restrictions. The participants expressed a strong need to enhance child participation in service evaluation and to increase the respect for and understanding of the rights of children to participate outside of the paediatric unit, including in the surgery or emergency departments.
Conclusion Children do not currently participate in the assessment of hospital services. Creative methods that support the role of children in evaluating and improving the quality of paediatric hospital care and services should be developed. Hospital-wide policies could help to promote understanding of child participation among all professionals caring for children in hospitals.
Relevance to clinical practice: Based on international agreements that the Netherlands has ratified, professionals have the duty to facilitate child participation in hospital care. Concrete opportunities and ideas on how to accomplish this goal in practice are provided, and areas for improvement are identified.

5.1 Introduction

The right of children (0-18 years) to express their views and have those views taken into consideration has been officially established for more than 25 years by the United Nations Convention on the Rights of the Child (1989). These rights have been increasingly recognized in national policies in many countries, as has their relevance in healthcare. In the Netherlands, the right of minors to participate in treatment decision-making is enshrined in the Dutch Medical Treatment Act (Wet op de Geneeskundige Behandelingsovereenkomst, 1995). The Act states that young people 16 years of age or over have the right to make their own treatment decisions, and children between 12 and 15 years of age are entitled to make decisions with their parents. According to the European Guidelines on Child-Friendly Health Care, children should also be able to participate in the evaluation, planning and improvement of healthcare services (Council of Europe 2011). However, this right to participate is frequently violated in hospitals (Simonelli & Guerreiro 2010).

5.2 Background

Coyne (2008) reviewed the literature on children's, parents' and healthcare professionals' experiences with child participation in consultations and healthcare decision-making. She observed that children are marginalized during medical consultations, which lead her to suggest that professionals might have difficulty in facilitating or supporting child participation. This finding is problematic because health professionals, together with parents, have significant influence in the process of child participation (Tates & Meeuwesen, 2000; Tates et al., 2002a). Mårtenson and Fägerskiöld (2007), for example, have suggested that the decision-making capacity of children in healthcare primarily depends upon the attitudes of parents and healthcare professionals rather than on children's own competences. Simonelli and Guerreiro (2010) have also noted that respect for a child's right to information and participation is particularly dependent upon the approach of individual professionals.

Documented reasons for not involving children include protective attitudes towards children (Coyne & Harder, 2011), doubts about the competence of children to participate (Dedding, 2009; Mårtenson & Fägerskiöld, 2007), assumptions about a child's age and maturity (Runeson et al., 2001), parental obstruction (Coyne, 2006b), lack of child-friendly communication skills (Coyne, 2008), and organizational constraints, such as a lack of time due to high work pressure (Runeson et al., 2001). In addition, professionals might find it difficult to share their power and control with children. Coyne (2006b, 2008), for example, suggests that professionals might feel threatened by children who are knowledgeable about their care and who might question the views and approaches of professionals. She concludes that more research is needed on healthcare professionals' perspectives on child participation in consultation and decision-making (Coyne, 2008).

This study aimed to bridge this gap by exploring health professionals' experiences with and perspectives on child participation in Dutch paediatric hospital care and by investigating the need to improve their participation practices.

5.3 Methods

Design

A qualitative descriptive design was used. Semi-structured interviews were conducted with healthcare professionals from 10 hospitals that were geographically spread across the Netherlands (two teaching hospitals and eight regional hospitals).

Participants

We contacted the same hospitals that we had worked with in a previous study about children's perspectives on paediatric hospital care (Schalkers et al. 2015). The heads of children's wards were asked to participate in this follow-up study. The aim of the study was to conduct three interviews in each hospital with 1) the head of the paediatric ward, 2) a paediatrician and/or paediatric nurse and 3) a hospital play specialist. In two hospitals, only two interviews were conducted because a hospital play specialist was not available. In the other hospitals, three or more interviews were conducted but, in some cases, with professionals from a field of expertise other than what we had originally intended (e.g., a communication advisor or a hospital manager). These professionals were interviewed because other participants had indicated that they played an important role in facilitating child participation within the hospital. A total of 32 healthcare professionals (4 men/28 women) were interviewed, including the heads of the children's wards (n=9), paediatricians (n=7), paediatric nurses (n=6), hospital play specialists (n=7), one hospital manager, one communication advisor and one policy advisor. The participants had between 2 and 35 years of experience working with children 0 to 18 years of age, which is the general age range for paediatric wards in the Netherlands. Interviews were conducted individually, unless the participants requested to do the interview with a colleague of their own choice, which occurred in 10 cases. This process resulted in lively discussions and the introduction of many concrete examples because the participants stimulated one another to share experiences with us. The interviews lasted for approximately 45 minutes.

Theoretical framework and interview design

Shier's Pathways to Participation model was used to explore the professionals' experiences, ideas and wishes with child participation in decision-making (Shier, 2001). A Dutch translation of the model was already available because one author had used it in interviews for her doctoral research into child participation in diabetes care in the Netherlands (Dedding 2009). The model provides questions for five different participation levels (see Figure 5.1). The main difference with other well-known participation models, such as Hart's ladder of participation (Hart, 1992), is that it identifies three degrees of commitment for each level: 'openings', 'opportunities' and 'obligations.' This distinction makes it a practical tool, with a sequence of 15 questions that help interviewees to critically reflect upon their current ideas and actions, as well as what they consider to be important to move the participation agenda forwards.

Data management and analysis

The interviews were audio-recorded and transcribed verbatim for analysis. A summary was sent to the interviewees to confirm that it properly reflected their views and experiences. All transcripts were read in their entirety and analysed using a combination of deductive and inductive content analyses. We started by grouping the data according to the three overarching concepts of 'openings', 'opportunities' and 'obligations' and the five different levels of participation of the model (deductive). 'Restrictions/barriers to participation', which did not fit within the model, was a recurring theme in the data; it was identified as an additional theme for analysis (inductive).

Ethical considerations

This research project does not fall under the Dutch Medical Research Involving Human Subjects Act (Wet Medisch-Wetenschappelijk Onderzoek met Mensen, 1998); therefore, official ethical approval was not needed. All participants received written information about the goals and procedures of the study, and verbal consent was obtained from them prior to audio-recording the interviews. The participants were not obliged to answer certain questions, and they were able to withdraw from the interview at any time. The professionals were assured that the information provided would be treated confidentially and that it would not be linked to their individual identities or to their hospitals.

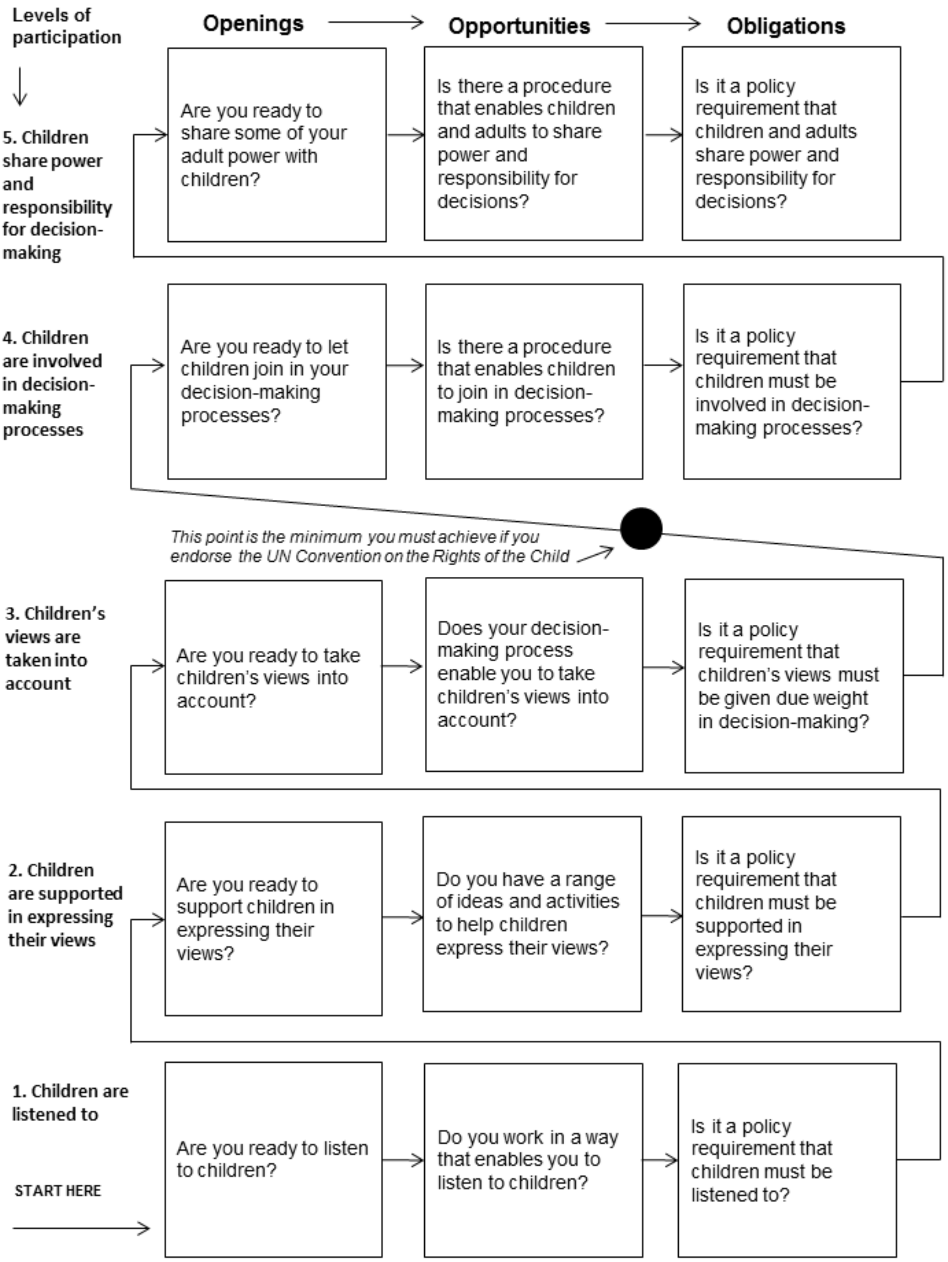


Figure 5.1 'Pathways to participation' (taken from Shier 2001)

5.4 Results

Discussion of Shier's participation model with the interviewees made it possible for us to acquire a comprehensive understanding of how and to what extent healthcare professionals are willing (openings), able (opportunities) and required (obligations) to commit to child participation. These three degrees of commitment were also used to structure the results section. First, we describe how professionals define the term participation.

Definition of participation

The term 'child participation' is not frequently used by professionals: "We don't call it child participation but we've been doing it for years" (Paediatric Nurse). Nevertheless, as this quote illustrates, they feel familiar with the ideas behind participation, and when asked what they understand by participation, they could define it. For interviewees, the essence of child participation is to actively involve children as much as possible in individual decision-making about their treatment and their hospital stays. One department head, for example, described it as follows: "It's important to check that what you think children will prefer is actually what they do prefer. I think participation involves that you check this on a regular basis."

Comparing the descriptions of participation provided by the participants demonstrated that different meanings were given to the term, thereby reflecting different levels of participation. "Listening to children" and "asking their views" were mentioned a few times. The majority of the professionals, however, argued that participation extends beyond listening and that it involves taking children's views into account when making decisions. Some participants took it a step further and defined participation as "children making their own decisions" or "giving children agency and control over their situation"

Comments about children's collective involvement, as service users or in policy-making processes, were scarce. Only one paediatrician mentioned that giving children the opportunity to provide feedback on their hospital experiences is an important aspect of participation, despite the fact that this process is becoming common practice for adult patients.

Openings for participation

Shier (2001) has stated that an opening occurs when a professional makes a personal commitment to facilitate child participation. When interviewees were asked whether they listen to children, the response was unanimously strong: "definitely", "of course", "always", "otherwise I should not work here." Participants actively engage with children because doing so contributes to physical and psychological recovery. Doctors, in particular, regard participation as a means of gaining engagement and cooperation from children in medical treatment. They feel that this engagement benefits recovery, therapy compliance and treatment outcomes. Many professionals believe that participation helps children to cope with their hospital experience in a more positive manner, reduces stress and prevents psychological traumas. As one paediatrician explains: “Because children suffer less stress [when they participate] and it’s actually been proven that children who are less stressed just get better faster.”

Another reason for participation that was regularly mentioned by participants is that gaining insight into children’s experiences and perspectives helps healthcare professionals to provide the best possible care: “We still often think that we know best. While actually parents and children themselves know what is best.” (Head of a Children’s Ward)

Opportunities for participation

According to Shier (2001), an opportunity occurs when the needs (e.g., resources, skills and knowledge) are met that will enable the organization to operate at a certain level in practice. Professionals consider informing children about their treatment (e.g., using child-friendly brochures or educational films) and preparing them for medical procedures (e.g., using booklets or photo albums) to be prerequisites for child participation. Shared decision-making is only possible if children are well informed about their treatments.

Play specialists mentioned several methods of supporting children in expressing their views. These methods varied from asking children general questions, such as “How do you feel today?”, “Is there anything you need?”, and “What would you like to do today?”, to specially designed “pain passports.” In these passports, children can write down personal rituals, special wishes and coping strategies they have developed over time in painful situations (Megens et al., 2008). Children can, for instance, indicate whether they want an anaesthetic pad or not, and who should accompany them during procedures. Children can also make a note of their personal wishes.

> *“Not so long ago, we had a girl here who wanted to have the Koran under her pillow when she was in theatre. She found it difficult to have to ask for this the whole time and that’s one reason for a pain passport [in which she has written this request].” (Communication Advisor)*

Play specialists also reported that they help children to prepare questions to ask the doctor and that they encourage children to speak up, or even accompany them to talk to the doctor:

> *"I always let the child do the talking but when they find this really very difficult I sometimes make the opening gambit 'I think you had a question for your doctor?' " (Play Specialist)*

Interviewees said that they often allow children to have input in how and when particular procedures are carried out. They provide alternative options. For example, whether the child would prefer to be anesthetized using a mask or an injection or the choice between a pill or the liquid form when taking pharmaceuticals. Furthermore, professionals said that they often give children the opportunity to postpone or determine the timing of invasive procedures and, for example, decide who should accompany them.

> *"We sometime have children who are constipated and they need to have an enema every day. [Then, we ask] 'What do you think is the best time of the day to have it?' And then they [the children] generally choose a time of day when the other children are not around [...] They have to have it, that's not up for discussion, but you can ask them 'How shall we do it?' and 'Who do you want to be there?' " (Paediatric Nurse)*

Chronically ill children are often given a high level of responsibility and are encouraged to establish their own treatment goals. In particular, this process is used when treatment largely occurs at home, such as with diabetes or asthma, or when behavioural changes are required, for instance with obesity or constipation.

Professionals have developed several strategies and tools to ensure that children can participate in the clinical encounter, but they still rely on parents for feedback on the quality of paediatric hospital care and services. With two exceptions, interviewees said that they are not accustomed to inviting children to evaluate their hospital stays, nor do they involve them in policymaking processes. However, the adolescent unit of one hospital has a notebook in which patients can write down their experiences. One-and-a-half years after the interviews took place, another hospital has set up a children's council (the second children's hospital in the Netherlands to do so). The council is composed of a group of experienced patients between seven and 18 years old, and it meets four times a year to discuss how things can be improved in the hospital and, subsequently, it communicates their advice to hospital management.

Professionals recognize the lack of specific evaluation strategies for children as a shortcoming because they feel that children often perceive things differently than their parents or focus on other aspects of care. The need for age-appropriate methods for evaluating paediatric hospital care from children's and adolescent's perspectives was repeatedly expressed. Professionals generally express the preference for a questionnaire that could be easily administered to a large group of children at the same time and that would demand little time from staff, in terms of distribution and analysis.

'Yes, but…': restrictions on participation

There were several restrictions on child participation from the perspective of openings and opportunities. The amount of influence that might be given to a child appears to be strongly dependent upon three conditions: (1) the type of decisions being made, (2) the child's medical condition, and (3) the child's age and individual competences.

The type of decisions being made

Professionals agreed that a high level of participation in the child's basic care is possible. Interviewees mentioned examples of children having input in entertainment activities, bedtimes, day programmes, diet and timing of showers. Joint decision-making in medical treatment is considered to be less straightforward and of a different nature: "What's it about? If it's about choosing a toy or entertainment or about going to bed a quarter of an hour later. That's a very different thing than a child having to choose a type of medication" (Head of a Children's Ward).

Professionals argue that involving children in medical decision-making is complex because of the implications of such decisions on the child's health and wellbeing. Acting on the children's wishes is not always considered to be easy or medically justified. Participants described various examples of situations in which children's participation rights might conflict with children's rights to help and protection, as was the case in one new hospital where children were asked what aspects of their care or the hospital environment they liked and disliked.

One girl said she had trouble sleeping because the transparent ward doors allowed in too much light. In reaction, several doors at the department were blinded. One play specialist however explained that this new situation was hardly kept for more than a few hours because it hindered hospital staff from keeping an eye on the children from the hallway.

This incident shows that the perspectives of children and professionals can differ and that both are relevant. At the time of the interview, the hospital was looking for a suitable alternative, such as a camera monitoring system.

The child's medical condition
When the child's medical condition is acute or severe, professionals believe that the appropriate level of participation decreases. Interviewees described examples of acute situations in which decisions are not negotiable because the child's health and wellbeing are at stake:

> *"If they're really poorly, they have to have a drip. And you can't say 'Would you like it now or in half-an-hour?' It just needs to be done right away" (Paediatric Nurse).*

In less critical conditions, professionals are more likely to take the child's views into account. They mentioned examples of skipping a procedure (e.g., taking the child's temperature) because the child did not want it and even the last minute cancelation of non-urgent operations when the child was too anxious or did not want the operation to be performed. Some participants believe that professionals are more likely to take children's preferences into account when children are suffering from chronic conditions. Professionals recognize that such children often have extensive knowledge and experience of their condition and treatment and, as a result, they tend to take these children more seriously. Several times, cancer patients were mentioned as an example.

> *"When a child has, for example, leukaemia, and needs an injection but says 'Please wait a second,' it is probably more likely to be accepted than when a child who has come in for ordinary tests, and it's not obvious what's wrong with them, asks the same. Then, it [the needle] just has to go in because the doctor doesn't have more time... although that child probably needed the time-out just as much." (Paediatric Nurse)*

Age and individual competences
The interviewees consider age and individual competences to be important factors affecting the ability of children to participate in their treatment. Although the Dutch law stipulates that all children have the right to be informed and heard, professionals believe that children should first be able to think abstractly, have a high level of understanding of the issue at stake, must have

good verbal communication skills and must be able to understand the consequences of a particular decision.

> *"A decision often has very diverse implications. Can a child be aware of these? If you give children power and responsibility, and allow them to take certain decisions, what happens afterwards when the decisions prove to be the wrong ones? Do you then say that the child was responsible? I think that's going too far." (Play Specialist)*

Interviewees unanimously believe that the amount of responsibility that can be given to a child gradually increases with age. Professionals are more likely and more accustomed to asking the opinions of older children because communicating with them is 'easier', less complicated and less time consuming. Some professionals specifically referred to respecting the Dutch Medical Treatment Act, in which the increasing influence of children in medical decision-making in line with increasing age is legally established.

One paediatric nurse mentioned an example of a 16-year-old adolescent who was admitted to hospital with suspected appendicitis. This diagnosis could not be confirmed but the doctor wanted him to stay overnight for intravenous rehydration and observation. The parents agreed with the doctor, but the boy did not. He felt much better and insisted on going home. Because the boy was 16 years old, and thus (in the Netherlands) legally entitled to make his own autonomous decisions, the hospital staff had to respect his wishes, and he went home that same day.

Other restrictions/barriers
Other restrictions on participation include time constraints, high staff workloads and organizational barriers, such as the unavailability of play specialists during the night and weekend shifts or the inflexible scheduling of, for example, MRI scans. The professionals mentioned that parents sometimes hamper the child's participation by answering the doctor's questions themselves or by interrupting the child's story, thereby excluding the child as an equal partner in the consultation. Professionals frequently mentioned lack of awareness of child participation within other medical specializations that treat children regularly, such as surgery, anaesthesia, orthopaedics or accident and emergency care. Interviewees referred to specialists rushing procedures instead of taking enough time to prepare and comfort the child; not offering the child the choice of sedation in case of pain or anxiety; and communicating with the parents instead of the child. This less child-centred behaviour was likely due to tighter

scheduling than in the children's department and less experience in working with children. Information on how to facilitate child participation and why this is important must be disseminated within these departments. Employing paediatric nurses outside the children's ward, as one hospital recently did in the accident and emergency department, was mentioned as an effective strategy.

Obligations for participation
According to Shier's model (2001), an obligation is established when a specific level of child participation becomes the agreed policy of the organization. Many interviewees associate the word 'policy' with formal, written documents in which the participation policy of the organization is defined. None of the professionals were aware of such explicit policies within their organizations. The majority of professionals consider participation to be an unwritten policy: "It is done automatically rather than relying on a piece of paper to tell us what to do" (Head of a Children's Ward). Some interviewees believed that it makes no sense to make participation a formal hospital policy because, they argue, participation is a habit that is inextricably linked to the healthcare process. For these participants, a policy paper would make no difference in practice because "It [child participation] is not a protocol but I think we do our very best" (Paediatric Nurse). Others welcomed the idea of a policy document on child participation. They argued that a hospital-wide policy would increase awareness among staff from other medical specializations and among hospital management, obliging them to commit to child participation. They argued that such a policy paper should be as practical and specific as possible. A play specialist provided the following explanation.

> *"The choice between an injection or a mask [for giving the anaesthetic] is a good example. A child is allowed to choose; that's our policy. Most anaesthetists think that that's nonsense. They think that when a child is above a certain age, it should be done by injection. We often clash about this. And if the child wants it to be done differently, the anaesthetist will put forward all sorts of arguments but we say, too bad, it's our policy, and it's in black and white!" (Play Specialist)*

5.5 Discussion

The results show that the type of decisions being made, the child's medical condition and his/her age (with related individual competences) greatly influence the extent to which professionals are willing to actively involve children in healthcare decisions. The finding that professionals are more likely to enable a high level of participation in decisions that have a relatively low impact on the child's health supports the findings of Runeson et al. (2002), which showed that the highest levels of participation were primarily found in decision- making regarding everyday issues, such as how children were going to pass the time or what they were going to eat and drink. This finding implies, as noted by Moore and Kirk (2010), tokenistic forms of participation in which children are viewed as having a say in decisions without having any influence on their medical care and treatment.

Second, our results align with those of other studies that found that older children are more actively involved than younger children (Cahill & Papageorgiou, 2007; Tates et al., 2002a; 2002b). However, as Hemingway and Redsell (2011) argue, "age is related to health professionals' assumptions about cognitive ability, and as such is not a reliable indicator of the extent to which a child or young person might want to be involved" (p.194). Young et al. (2003), who interviewed young people (8-17 years) with cancer about their views on communication about their illness, found, for example, that some of the youngest children wanted detailed information, while one of the oldest children only wanted "the basics", indicating that the relation between children's ages and their preferences for participation is not straightforward. Alderson (2007) has noted that competence mainly develops through experience and not through age. Her work shows that children with long-term conditions, even as young as two years old, know far more about their conditions than people with acute or emergency conditions.

Third, the views and preferences of chronically ill children are more likely to be taken into account than those of children with acute conditions. Although Hemingway and Redsell (2011) have observed that child participation in the emergency care environment might be more complex due to anxiety, professional time pressure and the severity of the child's illness or injury, these factors should not be used as reasons not to facilitate child participation. Even in these cases, children could be asked, for example, from which arm they would prefer the professional to take blood from, whether they want their parents nearby, and how they want to be prepared and distracted. For child participation in decision-making, we argue for a situational approach that considers each child's own contributions in each specific situation. Their competence and preferences will, amongst other things, depend on previous experiences and specific circumstances. Coyne and Harder (2011, p. 316) have argued that "the situational position recognizes children's right to have a say, without necessarily having full control over decision-making [...] This will allow a balance between protection and shared decision-making, as it enables children's voices and preferences to be heard." Finding the right balance is rarely a subject of reflection among professionals in hospitals, and it could substantially improve child participation.

The facilitation of children's collective participation in service assessment lags behind the implementation of activities involving children at the individual level, despite the European Guidelines on Child-Friendly Health-Care (Council of Europe 2011), which explicitly state that "children should be given the opportunity to provide feedback on their experience after they have used services" (item 42.2). Implementation will require assessments of patient-reported outcomes and patient-reported experiences, as well as different methods of involving children in the process (item 42.2). The participants of this study wanted a collective evaluation questionnaire because it could be easily administered and because they are acquainted with such an approach. We plea for more creative methods to ensure that children can express their views in a manner that suits their capabilities and preferences and that assists them in telling their stories from their own perspective, instead of having to answer predefined questions (Schalkers et al., 2015).

Finally, the participants expressed the need for hospital-wide policies on child participation to convince other departments to develop more child-centred practices. Although policies in isolation do not necessarily change practices, this step could be important to address the ambiguous understanding of participation, thereby providing clear goals for all persons involved in the care for children.

Strengths, limitations and further research

Shier's model proved to be a valuable tool for structuring the interviews and for reflecting on professionals' experiences, ideas and wishes. However, while the professionals expressed their views on child participation, it does not necessarily mean that they act accordingly in practice. Research using a combination of interviews and participatory observation provides more in-depth knowledge about participation in practice; such research has been performed by Dedding (2009) in a study of the care of children with diabetes. However, this approach could not be undertaken in a study of 10 hospitals.

Certain situations described by professionals might be perceived and experienced differently by children and their parents. Do professionals, children and parents have a common understanding of participation and how best to facilitate it? Do they have shared ideas about the decisions in which children should participate? There is a dearth of studies comparing children's, parents' and professionals' perspectives on child participation, which is unfortunate because divergent perspectives between children, parents and professionals about the purpose, meaning and execution of participation could be an important barrier in implementing and improving participation practices. More research is needed to identify the situations in which the child's wishes conflict with what adults, both professionals and parents, consider to be in the child's best interests because professionals clearly experience difficulties with these tensions. This research will help to provide a more complete picture of how participation is being put into practice, provide insights into what considerations and actions can be taken to alleviate or address conflicts between health professionals, children and parents and, finally, ensure that initiatives for improving participation reflect the needs of children, parents and health professionals.

5.6 Conclusion

This research shows that considerable attention has been paid to child participation in clinical encounters. However, methods and tools are still needed to provide children with a voice in terms of evaluating and improving the quality of paediatric hospital care and services. Hospital-wide policies could help to promote an understanding of child participation for all persons involved in the care of children.

5.7 Relevance for clinical practice

First, healthcare professionals have a duty to facilitate the individual and collective participation of children in hospital care; however, in practice, they struggle to fulfil this duty, particularly when they consider that a child's right to participate conflicts with the child's right to protection. Shier's Pathways to Participation model proved to be a useful framework to facilitate professional discussion and reflection on these tensions. Second, our findings highlight the need to develop and implement age-appropriate methods of evaluating the quality of paediatric hospital care from the perspectives of children and adolescent to ensure that evaluations are not solely based on the views of their parents. Finally, hospitals should be aware that respect for children's right to participate extends beyond the children's ward because children are also significant users of other healthcare departments.

Chapter 6

When to invest in clinical guidelines for children? A practice oriented tool to facilitate decision-making

Abstract

Rationale, aims and objectives Children are not just small adults; they need to be diagnosed and treated in the context of their rapid growth and development. However, in guideline development, children's needs and interests are still overlooked. This study aims 1) to develop a tool that could stimulate guideline developers to take children into account on a more structural basis and 2) to explore how to facilitate children's participation in the process of guideline development.

Methods Three-phase multimethod sequential design. Professionals involved in guideline development participated in interviews (n=12), filled in a questionnaire (n=60) and/or participated in the focus group meeting (n=11).

Results A comprehensive understanding of the considerations that professionals take into account when deciding whether guidelines need to apply to children specifically. This resulted in a tool that assists guideline developers to make this assessment more accurately. It takes the form of a flowchart that guides users through a series of critical questions.

Conclusion The flowchart reminds guideline developers to consider children as a particular patient population when prioritising and demarcating new guideline topics. It will help to ensure that clinical guidelines address children's unique healthcare needs and perspectives. Facilitating children's and parents' participation in the process of guideline development is perceived as challenging; nevertheless it should be the next step in making paediatric guidelines more child-and family-centred.

6.1 Introduction

Clinical practice guidelines form the cornerstone of quality policy in the Dutch healthcare system and in many other western countries. Guidelines have their intellectual roots in evidence- based medicine, relying on randomised clinical trials as the ‘golden standard’ for finding evidence for the most adequate treatments (Bensing, 2000). However, clinical guidelines are usually based on evidence from highly selected populations who may not be typical of the actual population with the disease (Bensing, 2000; Hughes et al., 2013). This means that guidelines are often poorly applicable to special interest groups, such as children. This situation is slowly changing as the need for clinical trials on children is increasingly recognised by the scientific community and broader public (Caldwell et al., 2004; Kaplan et al., 2013; Klassen et al., 2008).

In some cases, a separate guideline or addendum for the care of children has been developed, for example for diabetes (Foundation, 2003) and obesity (Seidell et al., 2008). In the last 10 years, the Dutch Association of Paediatrics has developed approximately three paediatric guidelines each year in the Netherlands, while other medical societies, such as the Dutch Society of Otolaryngology Head and Neck Surgery and the Dutch Society for Psychiatry, have occasionally developed specific guidelines for children. However, many guidelines do not pay attention to issues specifically related to children, showing that the recognition of children as a special interest group in guideline development is still relatively limited in practice.

The fact that children are included in clinical guidelines sporadically is problematic because children (0-18 years) are significant users of health care with the right to high quality care that fits their specific needs (Convention on the Rights of the Child, article 24). Jameson and Wehr (1993) point out that ‘using single standards for differentially situated groups disadvantages one group (children, in this case) by failing to adjust for their relevant differences from the other group’ (p. 153). There are three important differences between children and adult patients. Firstly, children need to be diagnosed and treated in the context of their rapid growth and development; a context that has no counterpart in adult patients (Jameson & Wehr, 1993; Mangione-Smith & Mcglynn, 1998). Secondly, children have differential morbidity, meaning that types, incidence, expression and severity of illness in children, and their response to treatment, deviates from that in adults (Kain et al., 2006; Stephenson, 2005). Third, more so than for adults, medical treatment and hospitalisation is a stressful experience for children that may have serious emotional and psychological consequences (Lerwick, 2013; Pelander et al., 2009; Spijkerboer et al., 2008). Therefore, it is generally accepted that the organisation of paediatric healthcare needs to be “child-friendly”, with particular attention to the provision of age-appropriate information, sufficient preparation, stress-reducing interventions, parental presence and paediatric-trained staff (Coyne, 2006a; Grootens-Wiegers et al., 2015; Pelander et al., 2009).

Patient and public involvement is widely recognised as an important instrument to make guidelines more patient-centred and to enhance the quality of the guidelines (Légaré et al., 2011; van de Bovenkamp & Trappenburg, 2009). The Dutch Assessment framework for health quality standards specifically emphasizes that the experiential knowledge of care users should be incorporated in the guideline (Zorginstituut Nederland, 2014). Experiential knowledge refers to the specific knowledge that patients acquire based on their daily experience with their body, the disease and the healthcare system (Abma & Broerse, 2007; Caron-Flinterman et al., 2005). It can be challenging to include experiential knowledge in the process of guideline development, because experiential knowledge is often considered to be “too subjective” (Doyle et al., 2013) or “inferior” to scientific knowledge (Abma et al., 2009). However, from a pragmatist perspective, incorporating patients’ experiential knowledge in clinical guidelines can contribute to recommendations that will improve the quality of healthcare and its responsiveness to patients’ needs and preferences (Boivin et al., 2010; Caron-Flinterman et al., 2005). Moreover, the participation of patients could enhance the practical implementation of clinical guidelines (Pittens et al., 2013).

In the Netherlands, facilitating the participation of children and young people in guideline development is still in its infancy, although it is becoming increasingly common for adult patients (van de Bovenkamp & Trappenburg, 2009). Children are knowledgeable social actors with their own unique perspectives on their illness and its treatment. While these perspectives remain unknown, services cannot respond to children’s specific needs (Dedding, 2009; Hart & Chesson, 1998). Furthermore, children have the right to participate in health care matters that affect them (Convention on the Rights of the Child, article 12), which implies that it is the healthcare professional’s duty to facilitate this. Finally, in the context of under investment in paediatric clinical trials, guidelines for children might need to draw on different types of knowledge, including the experiential knowledge of children and parents.

It can be concluded that children’s needs, interests and perspectives are often overlooked in clinical guideline development, thereby violating their right to participation and the best possible health care. In the field of guideline development, much is still to be done to improve the quality of care for children. Ideally, a separate guideline or chapter about children should be made available for every disorder that occurs in children. However, given that time and resources are often limited, choices need to be made. Therefore, the aims of this research, commissioned by the Dutch Child and Hospital Foundation, were: 1) to develop a tool that assists guideline developers to explicitly assess when specific guidelines for children are needed, and to incorporate this tool into existing quality registers; and 2) to explore how to facilitate children's participation in the process of guideline development.

6.2 Methods

Design

In order to achieve the first research aim, a three-phase multi-method sequential design was adopted, combining qualitative and quantitative research methods (Creswell & Plano Clark, 2011). For the first phase of data-collection, 12 semi-structured interviews were conducted with different stakeholders in the field of guideline development. These sought to explore which criteria might be important in determining when specific guidelines for children are needed. Informed by the results of the interviews, a questionnaire was developed that was sent to a larger group of stakeholders (n=60) with the aim of investigating which criteria the respondents find most important, and identifying any missing criteria (second phase). In the final phase of the study, a focus group meeting was organised in order to achieve a consensus about the final list of criteria and the content and format of the tool.

The second research aim was addressed only during the first, qualitative phase of the study. Interviews were considered to be particularly suited to gain insight into experiences and perspectives of health professionals' in relation to the complex question of how to facilitate children's participation in the process of guideline development.

Participants and procedures

Interviews

Participants were selected from organisations that are engaged in guideline development in the Netherlands, either from a professional or patient perspective. Details of the participants can be found in Table 6.1. All accepted an invitation by email to participate in a face-to-face interview. This email provided participants with information about the aims and procedures of the study. We used a semi-structured interview guideline containing open-ended questions. The interview guideline covered the following topics: 1) the current position of children in guidelines, 2) criteria for specific children's guidelines and 3) children's expertise and experiences as input for guidelines.

Table 6.1 Interview participants

Stakeholder	Organisation type	Function of participant(s)
1. Dutch Association of Paediatrics (NVK)	Professional association	1. Paediatrician
2. The Dutch College of General Practitioners (NHG)	Professional association	1. Senior scientific employee and General Practitioner
3. Knowledge Institute of Medical Specialists (KiMS)	Professional association	1. Senior advisor 2. Director
4. Foundation for Paediatric Oncology in the Netherlands (SKION)	Professional association	1. Director
5. Association for Collaborating Parent- and Patient Unions (VSOP)	Patient organisation	1. Policy Officer
6. Crohn's and Colitis Ulcerosa Association Netherlands (CCUVN)	Patient organisation	1. Director
7. Association for People with Physical Disabilities (BOSK)	Patient organisation	1. Policy coordinator
8. Lung Foundation Netherlands (Longfonds)	Patient organisation	1. Project manager Quality of care
9. Netherlands Organisation for Applied Scientific Research (TNO)	Research institute	1. Youth healthcare physician and scientific researcher
10. Netherlands institute for health services research (nivel)	Research institute	1. Senior researcher Quality of care
11. The Netherlands Organisation for Health Research and Development (ZonMw)	Funding agency	1. Program Manager youth

12. Dutch Centre for Youth health care (NCJ)	Knowledge centre	1. Senior advisor

Questionnaire

The questionnaire was developed based on the themes derived from our analysis of the qualitative interviews. The questionnaire was tested among key stakeholders from the Dutch Association of Paediatrics prior to data collection in order to improve the content, structure and wording of questions. An email invitation for the online questionnaire (using Spidox software) was sent to 100 people who have an interest in guideline development. Participants who did not respond to the initial email invitation received a reminder after eight days. Some 45% of the invitees (45 individuals) have completed the questionnaire. The snowball method was used to recruit more respondents, setting the total number of completed questionnaires at 60. The respondents were employed by various types of organisations (see Table 6.2 for details).

Table 6.2 Questionnaire respondents

Organisation type	n=
Professional associations	13
Patient organisations	16
Hospitals	10
Knowledge institutions	8
Branch associations	7
Health funding agencies	3
Others	3
Total	60

Respondents were asked to rate each criterion derived from the interviews on its importance (on a nominal scale of 0 – 4, where 0 is ‘very unimportant and 4 is ‘very important’) in determining when specific guidelines for children are needed. They were also given the opportunity to add any criteria that they thought were missing. Moreover, additional interval scale questions were asked, concerning the need for guidelines specifically focused on children, and future prospects and wishes regarding guideline development for children. Respondents were invited to explain their answers by using the questionnaire’s field for comments.

Focus group discussion

Some 18 professionals from various organisations were invited to participate in the focus group discussion (FGD). Eleven professionals accepted the invitation. Four of them had also participated in an interview. More details of the participants can be found in Table 6.3.

The FGD lasted two hours and was conducted according to a detailed scenario that was divided into three rounds. After a short introductory round, one of the researchers (IS) presented the preliminary results and conclusions derived from the interviews and questionnaires (first round). The second round consisted of a group discussion, facilitated by another researcher from our team (CD). In this phase, the participants were divided into three smaller groups and invited to deliberately decide which five criteria they thought were most important in determining when specific guidelines for children are needed. Then, each group presented their outcomes to the other participants. These short presentations were followed by an in-depth group discussion about the commonalities and differences. Ideas, opportunities and challenges regarding the implementation of the criteria set were discussed in the third round.

Table 6.3 Focus Group participants

Stakeholder	Organisation	Function of participant
1. Dutch Association of Paediatrics (NVK)	Professional association	Paediatrician
2. Dutch Association of Paediatrics (NVK)	Professional association	Policy Officer
3. The Dutch College of General Practitioners (NHG)	Professional association	Senior scientific employee and General Practitioner
4. Dutch Association of Paediatric Nurses (V&VN Kinderverpleegkunde)	Professional association	Board Member
5. Knowledge Institute of Medical Specialists (KiMS)	Knowledge Centre	Advisor
6. Dutch institute for health care improvement CBO	Knowledge Centre	Senior Advisor
7. Dutch Knowledge Centre for Pharmacotherapy in Children (NKFK)	Knowledge Centre	Coordinator
8. Association of parents of premature children (VOC)	Patient organisation	Director
9. Association for Collaborating Parent- and Patient Unions (VSOP)	Patient organisation	Policy Officer Rare Disorders
10. Lung Foundation Netherlands (Longfonds)	Patient organisation	Project manager Quality of care
11. In Home Child Care (Kinderthuiszorg)	Healthcare organisation	Director

Data management and analysis

Interviews

The interviews were audio recorded and transcribed verbatim for qualitative analysis. A summary was sent to the interviewees to confirm that it properly reflected their views and experiences. All transcripts were read in their entirety and analysed using a combination of deductive and inductive content analyses (Hsieh & Shannon, 2005). We started by coding the data for the main themes that were informed by the topics in the interview guideline (deductive). Within these themes, several sub-themes were identified. 'Self-management and empowerment' and 'transition from paediatric to adult care' were identified as additional themes for analysis (inductive). The derived themes were discussed and revised with the research team.

Questionnaire

The outcomes of the questionnaire were analysed using the Statistical Package for the Social Sciences (SPSS). Using descriptive statistics, a mean score was calculated for each criterion.

Focus group discussion

The focus group meeting was audio recorded and notes were taken by one of the researchers. A comprehensive report was written and sent to all participants for a member check.

Ethical considerations

This research project does not fall under the Dutch Medical Research Involving Human Subjects Act (Wet Medisch-Wetenschappelijk Onderzoek met Mensen, 1998); therefore, official ethical approval was not needed. All participants received written information about the goals and procedures of the study and verbal consent was obtained from them prior to the audio recording of interviews and the focus group discussion. Professionals were assured that the information provided would be treated anonymously and would not be linked to their individual identities.

6.3 Results

The study allowed us to gain a comprehensive understanding of the considerations that professionals find important in determining when guidelines specifically for children are needed, as will be described in the first two paragraphs of this section. Subsequently we present the tool that was developed based on these findings. The tool takes the form of a flowchart (Figure 6.3) that guides users through a series of critical questions in order to assist them to explicitly assess the need for particular guidelines for children. It has a guiding text about the reason, importance and practical use of the tool. Finally, we describe participants' experiences with and perspectives on facilitating children's participation in the process of guideline development.

When to invest in clinical guidelines for children?

When interviewees were asked to identify important criteria for the development of a guideline particularly for children, one answer stood out: *"When the disease occurs in children, a guideline specifically focused on children is required. No discussion."(paediatrician, professional association, interview)* This finding is supported by the results of the questionnaire. Some 48 respondents (80%) agreed with the following statement: "When the disease occurs in children, a guideline specifically focused on children is required" (Figure 6.1). The main reason given for this opinion is that children are not perceived to be small adults but are still in growth and development, reacting differently to medical treatments than adults, both physically and mentally. Participants mentioned examples of children experiencing different side-effects from medication, having different recovery periods, and emphasised the need for a more child-oriented organisation of care.

Questionnaire respondents frequently commented that when the disease progression, treatment and evidence for recommendations do not differ extensively from adults, an addendum or separate chapter might be sufficient to cover children. Participants think this approach is most efficient in terms of time and money.

> *"In any case, a separate guideline is needed when the treatment is completely different for children. In other cases, a separate section on children is probably sufficient. In all guideline development, attention should be paid to the question of whether a section on children is enough or whether a separate guideline would be better." (paediatric surgeon, questionnaire)*

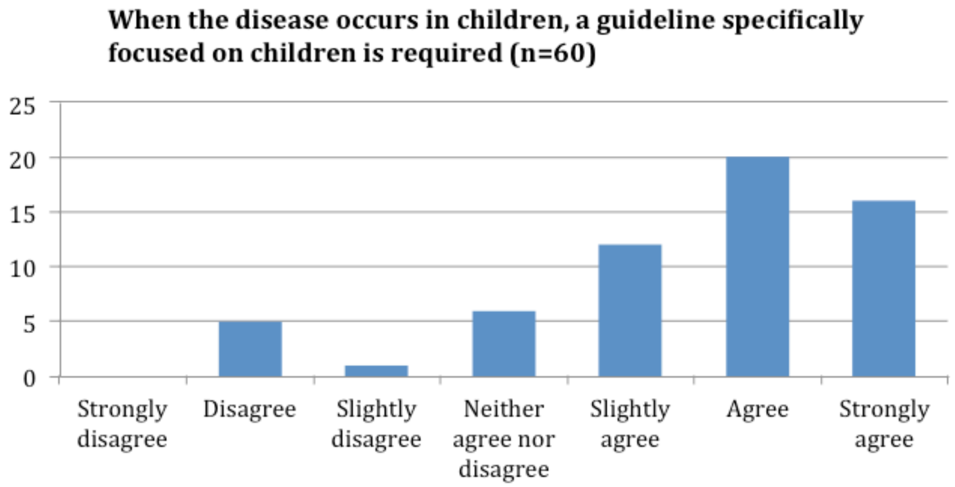


Figure 6.1 Need for guidelines designed particularly for children

When do specific guidelines for children have priority?
In principle, both interviewees and questionnaire respondents considered that a separate guideline for children or an addendum is always necessary when the disease occurs among children. However, guideline development is labour-intensive, time and money are limited, and a lot needs to be done. Therefore, the question remains, when do specific guidelines for children have priority?

Interview participants suggested various criteria that could be helpful in determining in what cases a specific guideline for children is particularly important. For example, when the disease is highly prevalent among children or when there is controversy between professionals about the treatment. The total list of 14 criteria derived from the interviews and a short description per criterion are presented in Table 6.4. These criteria were subsequently rated on importance in the questionnaire. Figure 6.2 displays the mean score for each criterion. According to respondents, the three most important criteria for specific guidelines are ‘clearly expected health gains among children’, ‘need for guidelines identified by professionals’ and ‘controversy between professionals’. The criteria ‘disease with high healthcare costs’, ‘availability of scientific evidence’, and ‘pharmacological treatment’ are considered least important.

Four criteria were added by respondents. A few mentioned that an important criterion to add (if not the most important) is whether the treatment for children is different from that for adults. One respondent mentioned that it is important to develop guidelines for rare diseases because often little is known about such diseases. Finally, respondents suggested two further criteria: the need for guidelines identified by patient organisations; and the extent to which a guideline can contribute to improving the quality of life of children. As Figure 6.2 shows, there is little differentiation between criteria (only five score lower than 3), meaning that many criteria are perceived as relevant. In the subsequent focus group discussion, it was suggested that a hierarchy-tree was needed in order to make choices manageable. Therefore, a flowchart was agreed upon to guide decision-making.

Table 6.4 Longlist of criteria

Criterion and description	
1	**Clearly expected health gains among children** The extent to which a guideline about the topic can contribute to improving the health of children.
2	**Need for guidelines among professionals** The need for a guideline on the topic that exist among health care professionals because it is unclear what is the best way to deal with the topic.
3	**Controversy between professionals** The extent to which unwanted heterogeneity in the care provided between regions, hospitals and practitioners exists. Unwanted practice variation relates to variation which has a negative effect on the quality of care and/or its costs.
4	**Severity of the disease** The extent to which the topic causes damage in the individual, in the form of sickness, disability, mortality, inability to work or attend school, absenteeism or otherwise loss of quality of life.
5	**Chronic disease** In general, chronic diseases are defined as irreversible disorders without the prospect of complete recovery. In children, a disease is considered chronic if the disease is not (yet) curable and lasts more than three months, or has occurred more than three times in the past year and is likely to occur again.
6	**Need for guidelines among children/parents** The need for a guideline from the perspective of the patient (in this case children and/or parents)
7	**High prevalence/incidence** The prevalence or incidence of the topic in the child population.

8	**Congenital disorder** Disorders that arose before birth by inherited or spontaneous genetic defects or during pregnancy.
9	**Feasibility of guideline development and implementation** The feasibility of the development and implementation of a guideline on the topic given the context of health care, politics and society. Are the parties involved ready to address the problem and incorporate the guideline into policy?
10	**Invasive treatment** Treatment procedure in which one penetrates with equipment, or otherwise, in the body to be treated or examined.
11	**High level of self-management** Chronic disease where self-management is high on the agenda. Self-management is the extent to which a child and its parents take responsibility for the treatment. With good self-management the child and its parents are able to take conscious decisions about how to deal with the disease and the actions that will be taken with regard to the treatment.
12	**Pharmacological treatment** Treatment with prescription of medicines. Included as separate criterion as drug use in children is usually different compared to adults.
13	**Availability of scientific evidence** The extent to which there is sufficient (new) evidence of sufficient quality available.
14	**Disease with high healthcare costs** The costs of the health care budget on the topic/health care problem. Health costs refer to costs related to diagnosis, treatment, or follow-up and the costs regarding possible absenteeism or inability to work.

Descriptions were partly adapted from: Regieraad Kwaliteit van Zorg (2012). Prioriteren onderwerpen voor richtlijnontwikkeling in Nederland [prioritising topics for guideline development in the Netherlands]. The Hague: Regieraad.

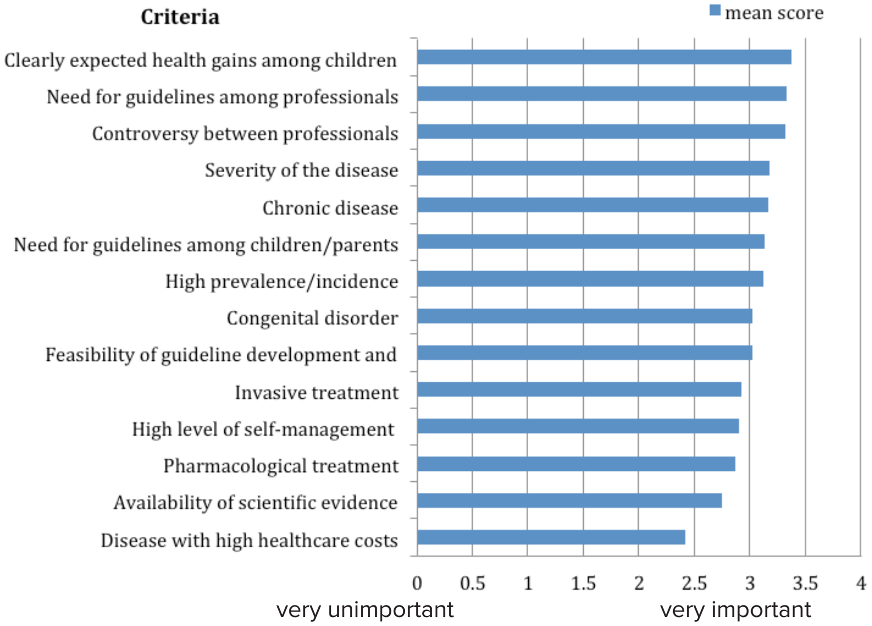


Figure 6.2 Prioritization of criteria

Flowchart

The focus group participants indicated that the first stage of the flowchart (Figure 6.3) should consist of general criteria for the prioritisation of guideline topics. According to them, the most important ones which scored high in the questionnaire (Figure 6.2) and also appear in several existing prioritisation lists, are: 'need for guidelines identified by professionals', 'controversy between professionals', 'severity of the disease' and 'high prevalence/incidence'. 'Need for guidelines identified by patient (organisations)'did not appear in existing prioritisation lists but was considered to be an important addition. 'Clearly expected health gains among children' scored a first place in the questionnaire (Figure 6.2) but was not included in the list since the overall aim of guidelines is to contribute to better care for all. The criterion, 'chronic disease' scored just as high as 'severity of the disease', but has not been included separately because focus group participants considered that a chronic disease can be classified as a severe disease.

In the second stage of the flowchart, the central question is whether the disorder that was highly prioritised in the first stage also occurs in children. If not, specific attention for children in the guideline is not required. Participants agreed that subsequently the question would be whether the disease progression in children differs from that in adults and whether the treatment and care in children is different from adults. In accordance with the questionnaire respondents, the FGD participants indicated that when this is not the case, an addendum or separate chapter might be sufficient to cover children. When there are significant differences, it can be concluded that an evidence-based guideline specifically about children is necessary. Furthermore, it was decided that gaps regarding knowledge/evidence about children and children's perspectives need to be clearly visible in the guideline.

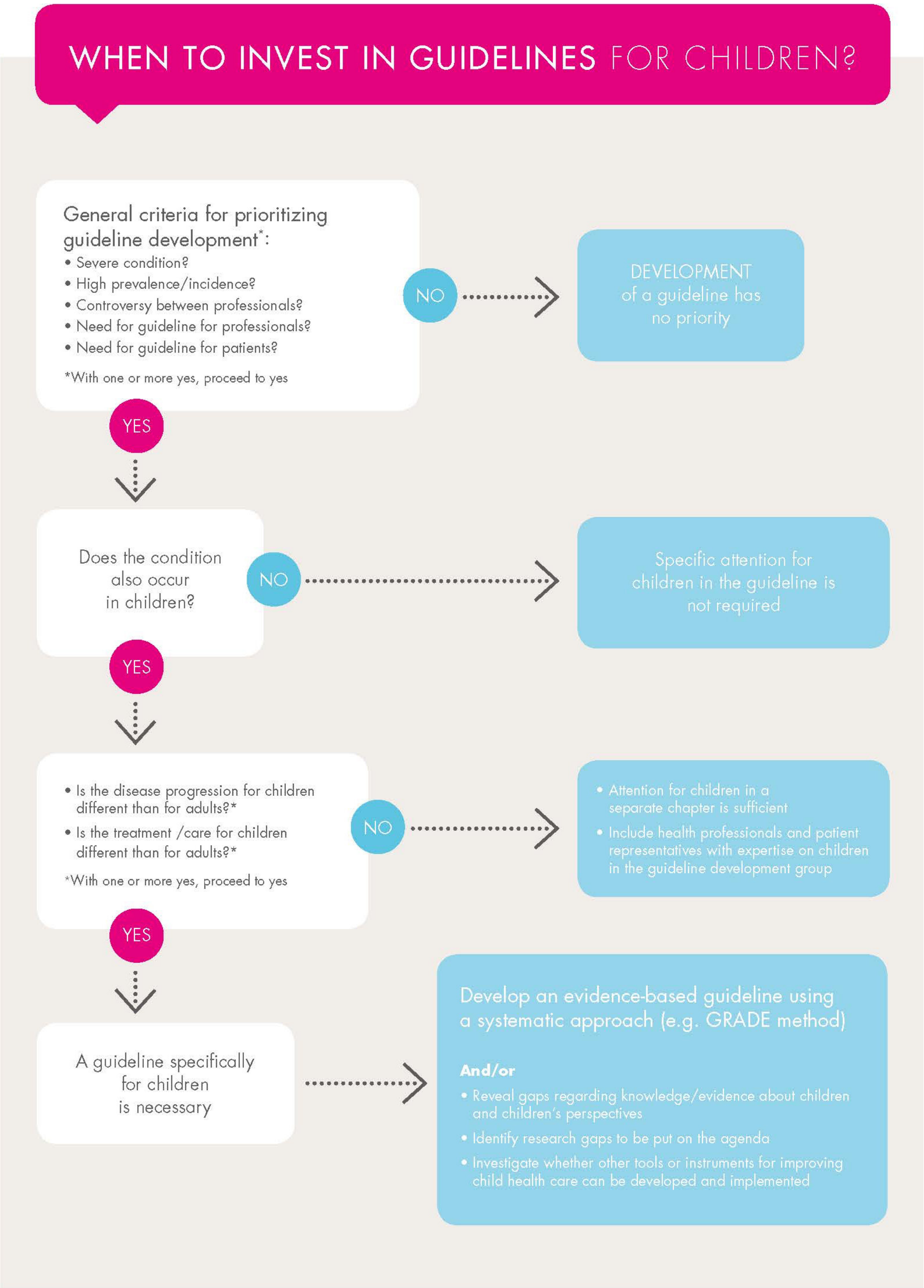
Recommendations regarding guidelines for children

Three themes were repeatedly mentioned during the FGD and have been included as important recommendations in the text accompanying the tool. The first concerns the transition from paediatric to adult care. Since there are large differences in the care of children and adults with a chronic condition, participants argued that it is important that clinical guidelines explicitly address how to bridge the gap between paediatric and adult health care practice in order to ensure the continuity of care. For example, the Guideline on Inflammatory Bowel Disease, published in 2008 by the Dutch Association of Paediatrics, specified that the transition process should already be discussed with parents and children from the age of 12, that this process should be guided by a transition protocol and that optimal continuity is ensured by means of a transition clinic where the paediatrician and the gastroenterologist hold a joint consultation.

Second, participants recommended that the guideline should pay attention to the self-management and empowerment of children and their parents. This is of particular importance because care tasks and responsibilities are increasingly transferred to parents in the home situation, as one FGD participant explained:

> *"Guidelines are written for professionals but, in this process, no attention is paid to the role of children and parents in the treatment. Care of sick children is increasingly being undertaken by parents at home but there are often no clear guidelines or handbooks for this." (board member, professional association, FGD).*

Third, it was recommended that attention be given to shared decision-making in children's health care process because this is legally regulated differently than for adults and depends on the age of the child. In the Netherlands, the increasing influence of children in medical decision-making in line with increasing age is established in the Dutch Medical Treatment Act (WGBO; 1995). It states that young people aged 16 or over have the right to make their own treatment decisions, and those between 12 and 15 years are entitled to take decisions with their parents.



WHEN TO INVEST IN GUIDELINES FOR CHILDREN?

General criteria for prioritizing guideline development*:
- Severe condition?
- High prevalence/incidence?
- Controversy between professionals?
- Need for guideline for professionals?
- Need for guideline for patients?

*With one or more yes, proceed to yes

DEVELOPMENT of a guideline has no priority

Does the condition also occur in children?

Specific attention for children in the guideline is not required

- Is the disease progression for children different than for adults?*
- Is the treatment /care for children different than for adults?*

*With one or more yes, proceed to yes

- Attention for children in a separate chapter is sufficient
- Include health professionals and patient representatives with expertise on children in the guideline development group

A guideline specifically for children is necessary

Develop an evidence-based guideline using a systematic approach (e.g. GRADE method)

And/or
- Reveal gaps regarding knowledge/evidence about children and children's perspectives
- Identify research gaps to be put on the agenda
- Investigate whether other tools or instruments for improving child health care can be developed and implemented

Figure 6.3 Flowchart 'when to invest in guidelines for children'

How to involve children in the process of guideline development?

Interviewees acknowledged that there is little attention paid to the inclusion of children's perspectives in current guidelines. Professionals mentioned several reasons for this. First, they are not used to it; it is not in their way of working and clear requirements to give children a voice in the process of guideline development do not exist. Second, several participants believed that it is due to the hierarchical health care system in which the medical knowledge of professionals is considered as superior to experiential knowledge of patients, and that this might be even more the case with children than with adults:

> *"I think that you really don't fully acknowledge the child as a participant in such a process." (general practitioner, professional association, interview)*

Third, interviewees frequently literally said that involving children in the process of guideline development is difficult. The question is whether children are able and willing to contribute to the complicated and scientific matter of guideline development:

> *"It is difficult enough for guideline developers to consider how you should involve adults. So I think that it is even more difficult for them as far as children are concerned." (project manager, patient organisation, interview)*

Many substantial and practical questions were raised, such as: Do children have the right skills to participate? From what age can they be involved? Is it not too demanding for them? How to organise it? Which children are going to be consulted or involved? These questions have not yet been solved for adults but are paramount for facilitating children's participation. Apart from the question of what is the best way to involve children, interviewees mentioned that participation is time consuming and that often no budget is available for it.

Despite all the questions and difficulties, participants do see the benefits of children's involvement and welcome further exploration of its possibility in guideline development:

> *"I think that it is really good that more attention will be paid to children. And I think it is also very useful. Because we have seen ourselves that children see things differently and you miss that if you don't involve them"(senior researcher quality of care, re-*

search institute, interview)

6.4 Discussion

Professionals acknowledged that despite its importance, the recognition of children's needs and perspectives in clinical guideline development is limited. Our results indicate that professionals are not accustomed to consider children as a special sub-group from the start of developing guidelines. Moreover, existing tools for developing guidelines (e.g. the GRADE method (Guyatt et al., 2011)) and for assessing the quality of guidelines (e.g. the AGREE instrument (Brouwers et al., 2010)) do not pay specific attention to children. This underlines the need for a tool for guideline developers to be alert to children's unique health care needs. The flowchart developed here could remind guideline developers to always consider children as a particular patient population from the start, when prioritising and demarcating new guideline topics. The tool is available for guideline developers in the register ('kennisbank') of the Dutch National Health Care Institute. [4]

Most of the prioritisation criteria in the first stage of the flowchart correspond to criteria from existing prioritisation lists used by professional associations in the Netherlands (e.g. NVK, KiMS, ZonMw), and to criteria that are mentioned in the scientific literature (Eccles et al., 2012; Reveiz et al., 2010). However, different organisations place different emphases on the various criteria, as did our participants. In 2012, the Dutch Council

for Quality of Healthcare (Regieraad Kwaliteit van Zorg) commissioned
a study to develop a set of prioritisation criteria that would be broadly supported by stakeholders from various health care sectors in the Netherlands (Regieraad Kwaliteit van Zorg, 2012). This resulted in an outlining of the top 5 criteria for the prioritisation of guideline topics: 1) need among professionals; 2) severity of the topic; 3) promoting quality of care; 4) patient safety and 5) disease burden. Three criteria from the first stage of the flowchart correspond to criteria from this list: severity of the disease, prevalence (disease burden) and need among professionals. Controversy between professionals, which is included in our list, finished in 6th place in the research of the Council for Quality of Healthcare. The need for guidelines among patients scored low (10th place), indicating that this criterion had relatively low relevance for professionals. The

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[4] Available at https://www.zorginzicht.nl/kennisbank/Paginas/Kwaliteitsstandaarden-specifiek-voor-kinderen.aspx

participants in our study, however, thought that the need for guidelines identified by patients was an important criterion to add.

An outstanding challenge is to make sure that children's and parents' perspectives become part of guideline development. After all, it is widely recognised that though clinical guidelines should be based on systematic review of scientific evidence, they must be complemented with expertise and experience of health care professionals and *health care users* (Sackett et al., 1996). Facilitating children's involvement in the process of guideline development is still in its infancy. However, over the last 20 years, much experience has been gained with participation of adult patients in guideline development. The inclusion of patient representatives in guideline development groups has become increasingly common (van de Bovenkamp & Trappenburg, 2009), even though many difficulties with this method of patient involvement have been reported (Légaré et al., 2011; van de Bovenkamp & Zuiderent-Jerak, 2015). These include how to deal with discrepancy between the views of patients and experts, challenges of recruitment, obtaining representative input, consumers' lack of familiarity with technical issues and the degree of work/time involved (Eccles et al., 2012; Légaré et al., 2011; van der Ham et al., 2014). Moreover, there is a lack of evidence to demonstrate that patient participation in guideline development leads to guidelines of higher quality and legitimacy (van de Bovenkamp & Trappenburg, 2009).

When facilitating participation of adult patients is already experienced as hard, the question is how to do this for children? Interviewees clearly found this a difficult issue. Many perceived children's participation in guideline development as a challenge and had doubts and questions about children's abilities to participate. However, children's willingness and capability to share their health-related experiences with professionals, researchers or policymakers and the value of their perspectives for improving child-oriented healthcare, have been demonstrated repeatedly (Alderson, 2007; Aynsley-Green et al., 2000; Schalkers et al., 2014; Wilson et al., 2010). Keeping this in mind, there are several ways to make sure that the experience and expertise of paediatric patients is collected and incorporated in the guideline.

One option is to systematically seek and integrate published evidence on children's health-related experiences, preferences and priorities (Chong et al., 2009). This may include studies of children's attitudes towards treatment, studies on preferences for information and shared-decision making, and research into children's preferences for health outcomes. Since children are increasingly recognised as knowledgeable social actors who have their own unique perspective on their illness and treatment, the body of knowledge from which to draw is steadily growing.

Another option is to directly involve children in the development of clinical practice guidelines. Experience of the National Institute for Health and Care Excellence (NICE), UK, demonstrates that carrying out consultations with children – in the form of questionnaires and group discussions – to identify diagnosis and treatment issues that are most important to children themselves, yields valuable insights into children's daily realities of living with a condition. For example, children involved in the development of the childhood constipation guideline emphasised the impact of the condition on their social life. The prevention of unintentional stool loss appeared to be a major concern for school-going children. One of the participants described: 'I don't want to do a poo in my pants. How do I stop it happening?' This illustrated that children can bring a unique window of experience and address important issues that adults might not have thought of. Children's responses were used to inform discussions in the guideline development group and, where appropriate, were recorded in the interpretations of evidence (National Collaborating Centre for Women's and Children's Health, 2010).

Even for adult patients, it might be good to look for an alternative to involving them in guideline development groups. Van de Bovenkamp and Zuiderent-Jerak (2015) argue that we need to reject the idea that involving patient representatives in guideline development groups is by definition the best achievable level of patient participation, especially considering the many problems that have been reported. The key is to consider in what stages of guideline development, patients, in this case children, can meaningfully participate and how to facilitate this in a manner that their input can make a valuable contribution to the quality of the guideline, ultimately benefiting clinical practice.

It is often considered that parents may represent children's perspectives, for example by participating on their behalf in a guideline development group. We, however, see the participation of parents as an important addition rather than as a substitute for children's participation. After all, parents play a very important role during a child's treatment and/or hospitalisation. Based on their experiences with the provided care and their knowledge about their child and its disease, parents can make valuable recommendations for delivering and enhancing paediatric health care. However, the views and experiences of parents and children can differ and both perspectives are relevant. Thus, if we want to know what children consider important regarding their illness and treatment, we need to directly ask children as well as their parents.

Chapter 7

What patients want you to know about hospital care: exploratory evaluation of narratives of children and parents from the Netherlands

Abstract

Objective The Experience Monitor is the first instrument that allows large numbers of children and parents to share their experiences of hospital care in the Netherlands. This study distilled lessons from these experiences to contribute to improving the quality of hospital care.

Methods Narrative catalysis was performed to identify patterns that provide insights into positive and negative hospital experiences, followed by qualitative content analysis allowing for an in-depth understanding of these experiences.

Results Some 1747 individuals shared a story over a period of 21 months. The majority of the stories were positive in nature. Respondents expressed their discontent about situations in which they felt that the staff barely paid attention to them and did not take their wants, needs and experiential knowledge into account.

Conclusions The monitor is a promising method for gaining an understanding of what contributes to positive and negative experiences; it generates concrete starting points for improving the quality of care from patients' perspectives. Further refinement of the way the inquiry is facilitated in practice is needed.

Practice implications This evaluation stresses the need for the provision of child-centered care in the children's ward and beyond. Improvements are particularly needed in surgical and Accident & Emergency departments.

7.1 Introduction

It is increasingly recognized that patient experiences are essential to the monitoring, quality improvement (Ahmed et al., 2014; Coulter, 2012) and patient-centeredness of healthcare (Heerings et al., 2014). Patients are able to provide feedback on patient-provider interactions – an important dimension of quality that is otherwise difficult to measure (Manary et al., 2013). Moreover, patient experience is positively associated with two other important quality dimensions, namely safety and effectiveness, supporting the case of the inclusion of patient experience as one of the central pillars of quality in healthcare (Doyle et al., 2013). Patient Reported Experience Measures (PREMs) are being widely used to investigate, analyze and publically report patients'experiences with healthcare. Such measures can be an effective way to stimulate competition and quality improvement (Black & Jenkinson, 2009). However, a recent, large international study demonstrates that there is often no link between patient experience and hospital quality management strategies (Groene et al., 2015). One explanation for this apparent contradiction is that PREMs might not influence hospital quality strategies because such strategies do not match with what patients consider good quality care. Indeed, Groene et al. (2015) indicate that direct personal interactions of patients with hospital staff are powerful predictors of patient experience. In addition, PREMs have been criticized in terms of interpretation of the numerical scales. Some commentators argue that numerical scales do not adequately reflect the complex reality, making it difficult to give meaning to the outcomes of the PREMS (Black & Jenkinson, 2009) and to translate the outcomes to concrete opportunities for improvement (Gerding, 2013).

While PREMs are increasingly being used to research the experiences of adult patients, pediatric quality measurement is still young (Schuster, 2015). There are few child-oriented measures of health care quality based on self-reporting (Ambresin et al., 2013), despite European Guidelines on Child-Friendly Health-Care which explicitly state that “children should be given the opportunity to provide feedback on their experience after they have used services” (item 42.2) (Council of Europe, 2011). Even though it has repeatedly been demonstrated that children have their own unique perspective on treatment and hospitalization (Dickinson et al., 2014; Donnelly & Kilkelly, 2011), evaluations of hospital care are generally based on the opinions of parents. In addition, such measurements are not routine in daily pediatric health care practices (Schuster, 2015).

In this context, novel methods are needed to evaluate structurally the quality of pediatric hospital care from the perspectives of both children and parents, taking into account the fact that quality of care cannot be measured by numbers alone and needs to reflect actual experiences. The Child and Hospital Foundation (Stichting Kind en Ziekenhuis 2015 - www.kindenziekenhuis.nl), the Netherlands, together with StoryConnect (www.storyconnect.nl), has developed one such novel method, namely the Experience Monitor (Ervaringsmonitor). The Monitor is a web-based instrument which compiles children's (0-18) and parents' stories of pediatric hospital care. It has become a central part of the Smiley quality evaluations which focus on child- and family centeredness of hospital care, making it possible for parents to make informed choices between individual hospitals. The 11 hospitals that currently hold the highest achievable quality mark, the Golden Smiley, are required to record the experiences of children and parents using the Monitor. These hospitals receive reports with hospital-specific results twice a year to help them identify patterns over time, and to support decision-making and intervention design. Furthermore, they receive an annual benchmark report which compares their results with those of other hospitals, stimulating competition on quality.

A scientific assessment of the outcomes and practical value of the Experience Monitor that stretches beyond individual hospitals has not yet been performed. Therefore, this study performs an exploratory evaluation of the lessons that can be learned from the Experience Monitor, aiming to contribute to improving the quality of pediatric hospital care in the Netherlands. We specifically address 1) by whom and how the monitor has been used, 2) the nature and subjects of the collected experiences, 3) the issues that dominate the stories and 4) how these issues can be interpreted and understood. Finally, since the Experience Monitor is a novel method, this study represents a first academic reflection on its practical value.

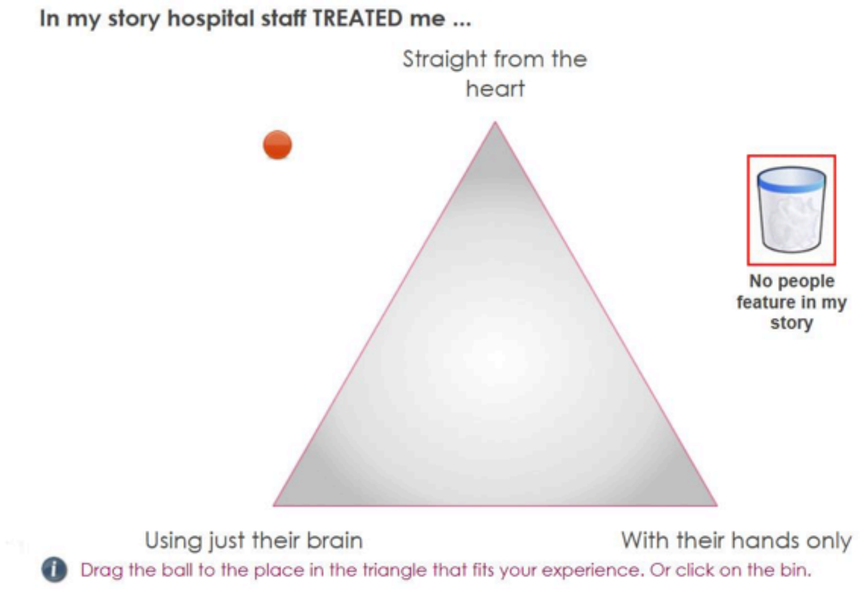
7.1.1. Background: short description of the Experience Monitor

The Experience Monitor is a narrative survey that is based on the method of Participatory Narrative Inquiry (PNI), using insights from the field of psychology, anthropology and complexity science. Kurtz (2014) defines PNI as:

"An approach in which groups of people participate in gathering and working with raw stories of personal experience in order to make sense of complex situations for better decision making. PNI focuses on the profound consideration of *values, beliefs, feelings, and perspectives* through the recounting and interpretation of lived experience." (p.85)

The Experience Monitor is available on the website of the Child and Hospital Foundation (www.kindenziekenhuis.nl/ervaring) making it possible for parents and children to share their hospital-related experience at their convenience, no matter which hospital they visited. The 11 Golden Smiley hospitals are keen to bring the survey to the attention of their patients, particularly given that this is a requirement of the Golden Smiley quality mark (Kind & Ziekenhuis, 2015). Three versions of the survey are available: for children (0-11 years), adolescents (12-18 years) and parents. The versions differ from each other in terms of formulation of questions, although the type and content of questions are the same.

The Experience Monitor starts by inviting respondents to share a story about an event in the hospital that most *stands out* in their mind and they are asked to give it a title which fits. Example questions are used as prompts, such as “If family or friends ask you about your experiences with your child in the hospital (positive or negative), what story do you tell?” Subsequently, questions are asked about the story, stimulating participants to consider and interpret their stories. The content of these questions was based on earlier research performed by the Child and Hospital Foundation which focused on what children and parents find important in hospital care. Interpretation questions cover the nature of the experience (good vs bad), how it made them feel (emotions), which themes were most important, and how hospital staff behaved. For example, participants are asked to drag a red ball to the place in a triangle that fits their experience, as shown in Figure 7.1.



In my story hospital staff TREATED me ...

Drag the ball to the place in the triangle that fits your experience. Or click on the bin.

Figure 7.1 Example of an interpretive question

7.2 Methods

We used narrative catalysis to identify patterns in the stories and answers to questions about them (Kurtz, 2014), followed by directed qualitative content analysis (Hsieh & Shannon, 2005) to contextualize and to add depth to the results of the narrative catalysis.

7.2.1. Narrative catalysis

Narrative catalysis is the process of preparing observations and interpretations of collected stories and answers to questions about them (Kurtz, 2014). First, the data generated by the interpretation questions were analyzed and visualized using Tableau software. Subsequently, within these results, patterns were observed, providing insights into (a) aspects of care that contribute to positive experiences, (b) aspects that contribute to negative experiences and (c) themes that prevailed in the experiences of participants. These aspects and themes were then interpreted and analyzed in more detail using qualitative content analysis.

7.2.2. Qualitative content analysis

The collected stories were imported into MAXQDA software, read in their entirety and coded based on the 10 thematic categories in the Experience Monitor. Respondents could chose up to three categories per story. The categories comprises: attention for children and parents; how you [parents and children] were treated; medical treatment and examinations; play/distraction; food and beverages; procedures; information; building/facilities; other staff[5]. Subsequently, the four most popular categories were analyzed to gain an in-depth understanding of participants' experiences. For each main category, sub-categories were identified based on participants' experiences. These sub-categories were discussed with the research team and revised. For example, within the category 'attention for children and parents', we identified 'being listened to', 'being taken seriously', 'attention for feelings/emotions', 'involvement in decision-making', and 'staff commitment' as important sub-categories. The story excerpts used to illustrate our findings in this article were translated from Dutch to English by a bilingual editor.

7.2.3. Ethical considerations

Names of children, employees and hospitals have been removed from the story excerpts to ensure anonymity.

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[5] Some of these categories have been translated differently in the English version of the Experience Monitor available online. We have chosen an English translation which fully reflects the meaning of the Dutch categories.

7.3 Results

By analyzing the positive and negative hospital experiences of children and parents, we identified three topics that dominated the stories and which will be described in more detail: 1) attention for children and their parents, 2) attitudes of hospital staff and 3) medical treatment and examinations. First, we describe the characteristics of the respondents.

7.3.1. Respondents

Some 1747 individuals posted a story on the website over a period of 21 months from December 2013 to August 2015. Most of the respondents were parents, followed by adolescents and children (Table 7.1). The majority of responses came from hospitals with a golden Smiley quality mark (n=1491) and the remainder from hospitals with a silver (n=38) or bronze Smiley (n=150), and from hospitals without a Smiley quality mark (n=68). For parents, the highest response came from those with children aged 0 to 2 years (n=371), followed by those with children aged 2 to 7 years (n=482). For parents with older children, the response was relatively low, possibly because older children can fill out the survey themselves. However, sometimes parents assisted children filling out the survey, evident from adult language use or statements like 'my daughter said that...'

Table 7.1 number of participants

	Male	**Female**	**Gender unknown**	**Total**
Parents	658	523	7	1188
Adolescents	122	200	0	322
Children	115	121	1	237
Total	892	844	8	1747

7.3.2. Nature and subject of the experience

Most stories were concerned with the 'pediatric ward' (51%), followed by 'day admission' (36%). The response was low for Accident & Emergency (A&E) (4.9%), Outpatients (2.7%) and Intensive Care (1.0%) departments, possibly because of the more acute nature of such care or because of the shorter timeframe. Another explanation is the lack of a Smiley quality mark for these departments, giving them little incentive to bring the Experience Monitor to the attention of their patients.

The stories ranged in length from a single sentence to 600 words. Children's and parents' experiences were much more frequently reported as good than as bad (Figure 7.2). On average, the stories labelled as 'bad' are substantially longer than 'good' stories. 'Bad' stories do not necessarily reflect on the actions of hospital staff: a hospital visit can be labeled as a bad experience, even though patient felt that they received good care as the following story illustrates:

> 14-year-old boy / day admission / nature of experience: very bad (number 1 in figure 7.4)
> **Title: Serious illness but receive the best care that I could imagine**
> *"I received the diagnosis of acute leukemia but they saw me straightaway at the hospital. ...You can ask the nurses and doctors questions about anything you want and they were really helpful. I'm now in the hospital every week for day admissions and I'm very positive about the cooperation that I get here."*

Figure 7.2 shows the categories that respondents chose as most applicable to their story. Interpersonal aspects of care, including 'attention for children and parents', 'how we [children and parents] were treated' and 'nursing care' prevailed in the stories. In addition, 'medical treatment/examination' was a common topic that applied to the stories. These main four topics have been analysed in detail and will be described below. Since the topics 'how we [children and parents] were treated' and 'nursing care' had much in common, we decided to merge this theme into 'attitudes of hospital staff'.

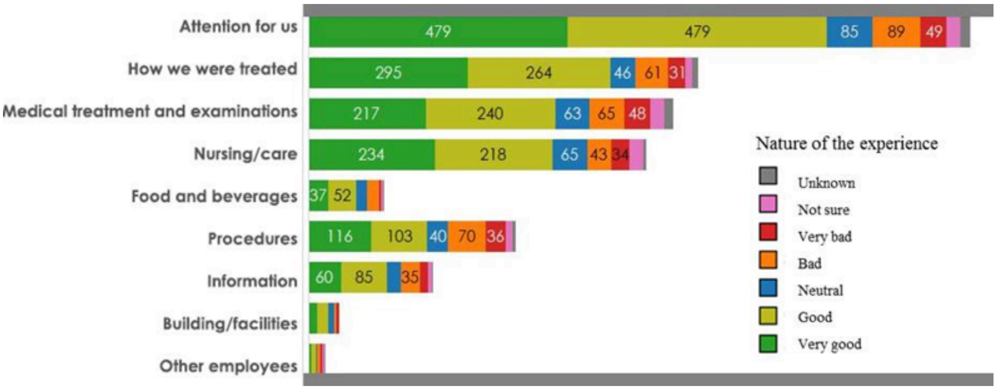


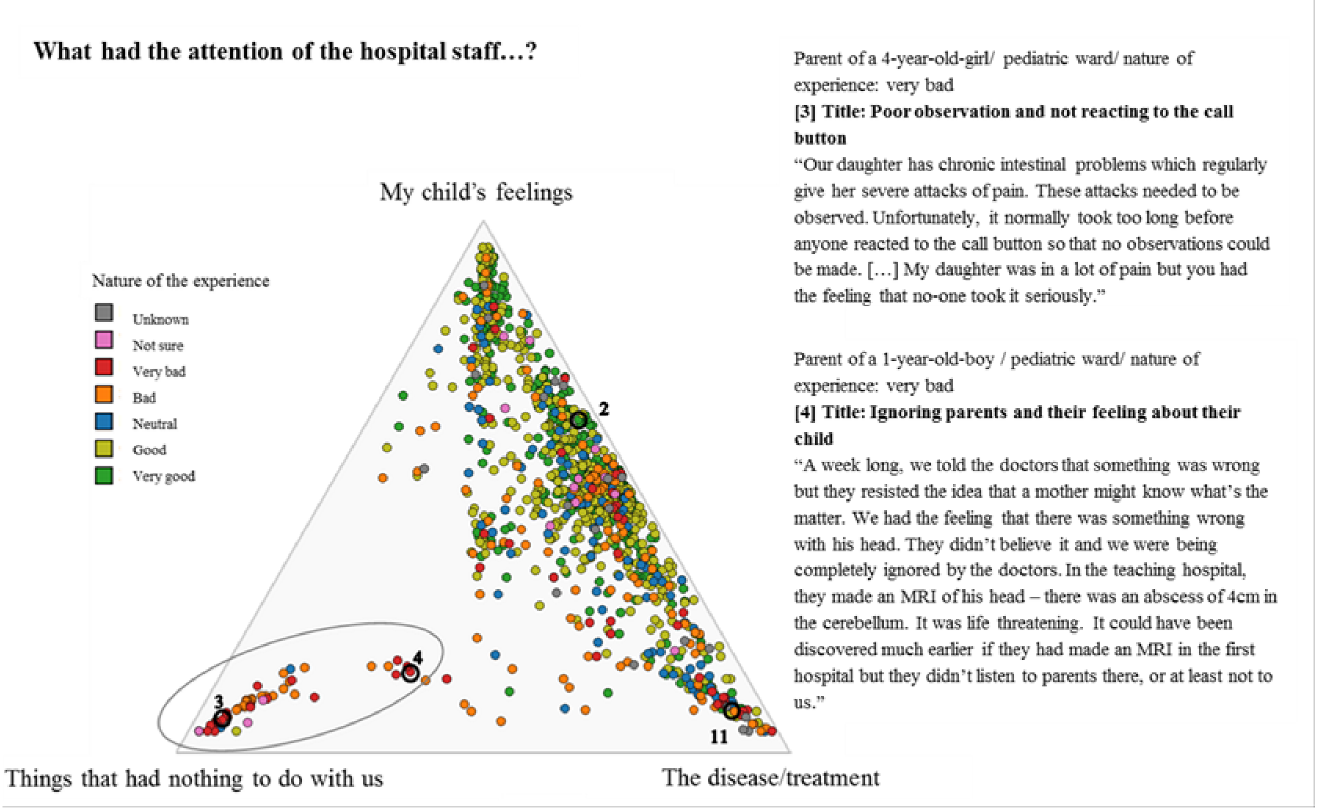
Figure 7.2 Themes chosen by children (0-18) and parents as applicable to their story

7.3.2.1. Attention for children and parents

Children and parents predominantly shared positive stories about the attention they received. This included recognizing and responding to specific needs of children and parents, and interaction of staff with the family: listening to children and parents, taking their ideas and wishes into account, giving the opportunity to ask questions, and paying particular attention to their feelings and emotions:

> Parent of a 4-year-old girl / pediatric ward / nature of experience: very good (number 2 in figure 7.3)
> **Title: Taking parents seriously**
> *"In the hospital, after the operating theatre, my daughter spent some time in intensive care. When she was there, the staff explicitly asked about my opinion and my feelings as a mother. In all the months before, this had never happended! When important decisions were being taken, they really asked me what I thought and if I was in agreement. In the beginning, I had been a lonely voice calling in the wilderness but this made me a proper mother again. Because of this, the treatment became clear, understandable and … bearable."*

Figure 7.3 shows how attention from hospital staff was perceived by parents. The figure displays a substantial spread in the results, indicating that attention is paid to the illness/treatment as well as to the feelings of the child. Remarkable is a small cluster in the lower left corner concerning "things that had nothing to do with us", demonstrating that patients did not always receive the attention they wanted, as illustrated by the story excerpts in Figure 7.3.


What had the attention of the hospital staff…?

Parent of a 4-year-old-girl/ pediatric ward/ nature of experience: very bad

[3] Title: Poor observation and not reacting to the call button

"Our daughter has chronic intestinal problems which regularly give her severe attacks of pain. These attacks needed to be observed. Unfortunately, it normally took too long before anyone reacted to the call button so that no observations could be made. […] My daughter was in a lot of pain but you had the feeling that no-one took it seriously."

Parent of a 1-year-old-boy / pediatric ward/ nature of experience: very bad

[4] Title: Ignoring parents and their feeling about their child

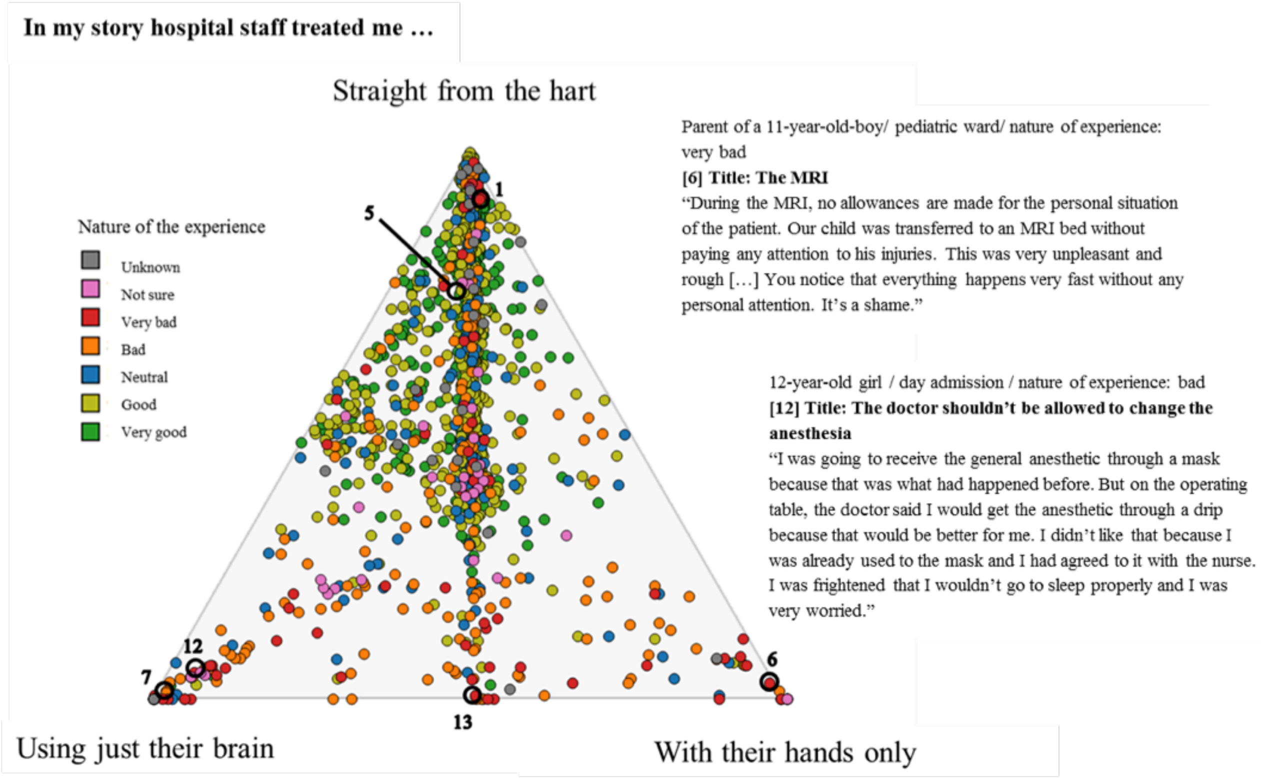
"A week long, we told the doctors that something was wrong but they resisted the idea that a mother might know what's the matter. We had the feeling that there was something wrong with his head. They didn't believe it and we were being completely ignored by the doctors. In the teaching hospital, they made an MRI of his head – there was an abscess of 4cm in the cerebellum. It was life threatening. It could have been discovered much earlier if they had made an MRI in the first hospital but they didn't listen to parents there, or at least not to us."

Figure 7.3 Health professionals' attention as perceived by parents

Pediatric nurses, in particular, receive much praise. They are described as kind, loving, emphatic, helpful, caring, child-friendly and successful at putting children and parents at ease. Figures 7.4 and 7.5 show that respondents indicated that they felt that hospital staff treated them mainly from the heart. The experiences run as a line from ‘straight from the heart’ towards the center of the triangle. Such a pattern is an indication of balance between ‘heart, head and hands’; showing expertise and professionalism without losing sight of the humanity of nursing:

> 17-year-old boy / pediatric ward / nature of experience: very good (number 5 in figure 7.4)
> **Title: Good suggestion on an unpleasant day**
> *“I was in the hospital with acute appendicitis. In the beginning, everything was very serious, straight to the point. Fine to be taken seriously and to have the feeling that a whole team is working on you, pulling out all the stops. Just before the operation, the atmosphere was relaxed and warm. The nurses were chatting, joking around, and it was almost fun to be in hospital. This continued until I was waved goodbye by the nurses when I was allowed to go home.”*

When this balance is missing, experiences are mainly negative, reflected by the orange and red dots in the lower corners of figures 7.4 and 7.5. In such cases, professionals showed little empathy, did not listen to the opinions of parents, took decisions without consulting parents, acted hurried or carelessly and failed to apologize for their mistakes, as illustrated by the story excerpts in figures 7.4 and 7.5.



Parent of a 11-year-old-boy/ pediatric ward/ nature of experience: very bad

[6] Title: The MRI

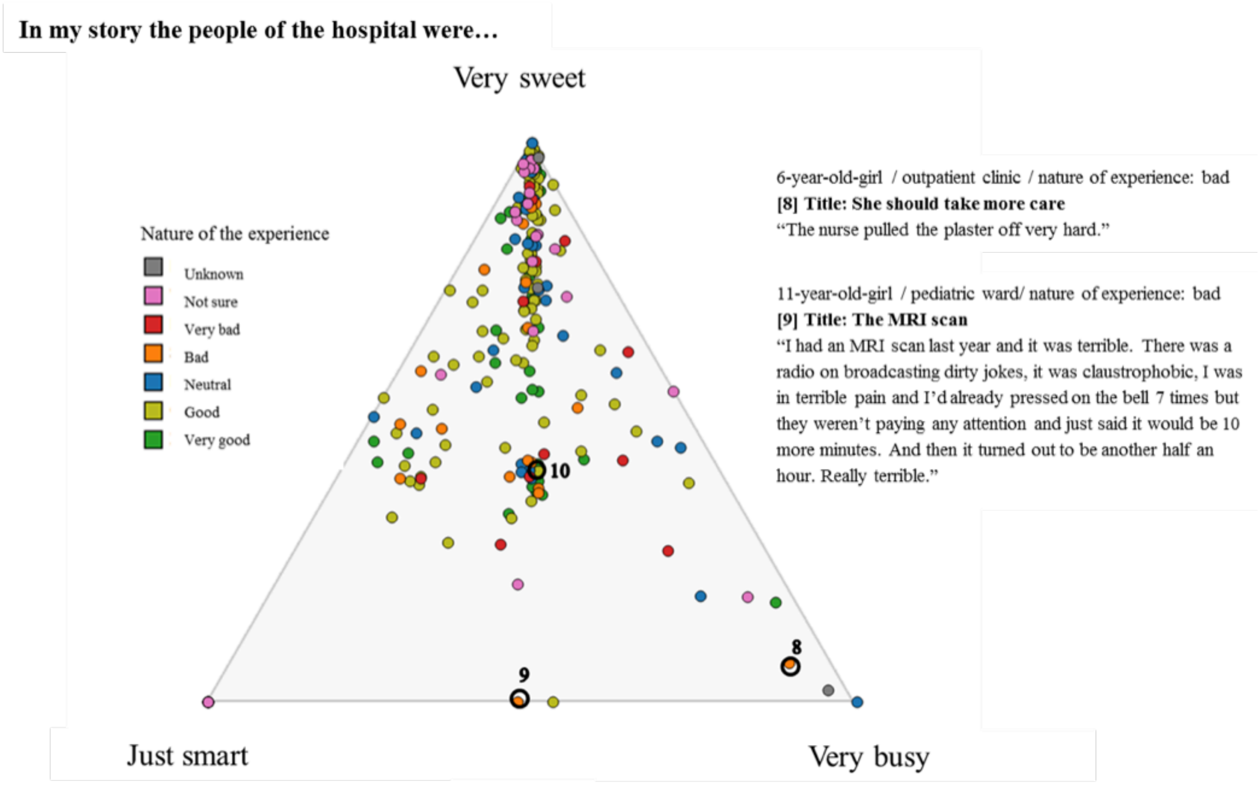
"During the MRI, no allowances are made for the personal situation of the patient. Our child was transferred to an MRI bed without paying any attention to his injuries. This was very unpleasant and rough […] You notice that everything happens very fast without any personal attention. It's a shame."

12-year-old girl / day admission / nature of experience: bad

[12] Title: The doctor shouldn't be allowed to change the anesthesia

"I was going to receive the general anesthetic through a mask because that was what had happened before. But on the operating table, the doctor said I would get the anesthetic through a drip because that would be better for me. I didn't like that because I was already used to the mask and I had agreed to it with the nurse. I was frightened that I wouldn't go to sleep properly and I was very worried."

Figure 7.4 The perception of adolescents (12-18) and parents on how they were treated by hospital staff



6-year-old-girl / outpatient clinic / nature of experience: bad
[8] Title: She should take more care
"The nurse pulled the plaster off very hard."

11-year-old-girl / pediatric ward/ nature of experience: bad
[9] Title: The MRI scan
"I had an MRI scan last year and it was terrible. There was a radio on broadcasting dirty jokes, it was claustrophobic, I was in terrible pain and I'd already pressed on the bell 7 times but they weren't paying any attention and just said it would be 10 more minutes. And then it turned out to be another half an hour. Really terrible."

Figure 7.5 The perception of children on how they were treated by hospital staff

7.3.2.2. Medical treatment and examinations
Children and adolescents, approximately twice as often as parents, reported feelings of stress, nervousness and fear, particularly with respect to operations under general anesthesia. The stories indicate that pediatric nurses and hospital play specialists generally respond well to children's tension by preparing and supporting them and their parents during such procedures. Participants mentioned that hospital play specialists prepare children for medical procedures in a playful way, they distract children when necessary, they accompany/ guide children into the operating theatre, and care for the parents once the child is under anesthetic. Parents said that this approach reassures both children and parents, underlining the importance of hospital play specialists in the children's ward.

> 10-year-old girl / pediatric ward / nature of experience: good (number 10 in figure 7.5)
> **Title: Everything is going well**
> *"Dear Hospital Director, The hospital play specialists really need to stay. They keep you company and then everything is fine. You can always ask questions. And you can tell them what's bothering you. While the hospital play specialist is there, you don't feel sick and you don't feel pain."*

The results indicate that in acute situations, particularly in A&E, age-appropriate information and preparation is not as extensive as parents would like, possible due to the high pressure on these departments and/or the severity of the child's illness or injury. Although the response for A&E departments was relatively low, this is a signal that cannot be ignored because hospital related-stress and anxiety can have a major impact on the recovery and wellbeing of the child.

> Parent of a 1-year-old boy/ pediatric ward / nature of experience: bad (number 11 in figure 7.3)
> **Title: Let the child see what is going to happen and then it's not so bad**
> *"I came to the hospital with my little boy via the Accident & Emergency department. I understand that it was busy and that it was necessary to get to work. But I found it really a shame – despite the fact that my son is very young, only a year and a half – that no-one took the time to explain things to him. From his perspective, he suddenly had a mask put on his face, despite the fact that he didn't want to be touched on his face because he was*

> *short of breath. A small amount of explanation – or a demonstration with a doll or a toy bear – would have really helped him to understand. [...] I'm convinced that if there had been more attention to explain things to him right at the start that he would have found everything easier to accept. That would have saved us - him, me and the kind nurses on the ward who did their best – a lot of stress. It was a missed chance."*

Furthermore, parents often mentioned that introduction of general anesthesia often happened in a hurried, overwhelming way with little sympathy for the feelings and needs of children and parents. Examples were mentioned of negative interactions with personnel, disagreement about how the anesthesia would be administered (injection or mask), being overwhelmed by the large number of professionals in the room, and being called too late to the recovery room with a child awaking in panic.

> Parent of a 7-year-old boy / pediatric ward / nature of experience: very bad (number 13 in figure 7.4)
> **Title: Working with people**
> *"When I arrived with my little boy at the operating theatre it was very busy – logical but impressive. A number of people were talking to my son and, at the same time, they were busy with applying stickers for the heart monitor, the little lamp on his finger, and talking to him about the anesthetic mask. My child (and I) were completely overwhelmed by the fact that many things were being asked at once. At that moment, someone suddenly appeared from behind my son with the mask. Without any warning, she set the mask on his face. He was surprised and pushed her hand away. The mask was put right back on and luckily he accepted that. After the results, he said straightaway that he found this the most unpleasant of the hospital stay. There had been a prior understanding that my son could put the mask on his face himself [....] You should be able to expect a bit more empathy in such a place, certainly when there is a child involved. I understand that work needs to be done but they are working with people."*

Children, just as parents, mentioned examples of situations in which they felt scared and overwhelmed by the number of people in the operating theatre and also confusion about the induction of general anesthesia:

> 12-year-old girl / day admission / nature of experience: bad (number 12 in figure 7.4)
> **Title: The doctor shouldn't be allowed to change the anesthesia**
> *"I was going to receive the general anesthetic through a mask because that was what had happened before. But on the operating table, the doctor said I would get the anesthetic through a drip because that would be better for me. I didn't like that because I was already used to the mask and I had agreed to it with the nurse. I was frightened that I wouldn't go to sleep properly and I was very worried."*

Furthermore, children mentioned being upset by the bad smell of the anesthetic gas in the mask.

7.4 Discussion and conclusion

7.4.1. Discussion

The Experience Monitor is a novel method to perform large-scale evaluations of the quality of pediatric hospital care from the perspectives of children and parents. Inviting children and their parents to share a story, the focus is not on what the researchers want to know but what children and parents want to tell. As recognized by other researchers (Heerings et al., 2014; Tsianakas et al., 2012), narratives elicit the crucial moments that shape an individual patient's overall experience. The large number of stories collected with the Experience Monitor demonstrates the willingness of people to share their experiences. Here we discuss the lessons we distilled from these experiences to contribute to improving the quality of pediatric hospital care. In addition, we reflect on the limitations of our study and ways to further refine and implement the method of the Experience Monitor.

7.4.1.2. Lessons learned for improving the quality of child-centered hospital care

The experiences shared were more frequently 'good' than 'bad', demonstrating that the Experience Monitor is not only an invitation to complain. Children and parents have shared positive experiences, providing a wealth of information about what constitutes good quality pediatric care from patients' perspectives. One of the major lessons is that patients want to be cared for by skilled and experienced professionals with the ability to empathize, respect the preferences of children and parents and take their experiential knowledge into account, reflecting the desire of being treated as a human being rather than as an object of disease. Though not a new lesson, it shows that continuous efforts are needed to make this happen.

Age-appropriate information for children and participation in medical decision-making are widely recognized as key components of child-centered healthcare (Council of Europe, 2011; EACH, 1988). Our results demonstrate that this is not always being achieved in practice, particularly not in surgery and A&E departments. This finding is consistent with a previous study in which child health professionals frequently mention the lack of awareness on children's rights to participation among other specializations that treat children regularly, such as emergency care, anesthesia and surgery (Schalkers et al., 2015).

Children's needs should be particularly investigated and respected in surgery departments because this is the department when they undergo serious, sometimes unexpected operations that are an evident source of stress and anxiety (Ahmed et al., 2011; Capurso & Ragni, 2015; Lerwick, 2013). Dreger and Tremback (2006) suggest that 60% of children experience significant anxiety before general anesthesia and surgery. The introduction of the anesthesia mask is possibly the most stressful procedure for a child during the peri-operative period (Perry et al., 2012). This evidence reaffirms the importance of pre-operative preparation programs for children. However, as the narratives show, good preparation in the children's ward and clear agreements about the administration of the anesthesia will not yield benefits to children when these are being flouted in theatre. We therefore conclude that more child-friendly approaches need to be promoted in surgery in order to prevent or reduce negative outcomes associated with pre-operative anxiety in children, such as increased post-operative pain, analgesic consumption and negative behavioral change, including separation anxiety, apathy and withdrawal, and sleep and eating disturbances (Ahmed et al., 2011; Kain et al., 2006; Perry et al., 2012).

Our results suggest that more child-centered approaches are also necessary at A&E departments. This finding aligns with those of other studies emphasizing the need for emergency facilities that are well equipped to handle children's unique physiological and emotional needs (Athey et al., 2001; Eikendal, 2012). This is particularly important when children account for approximately 20% of all A&E patients. Separate treatment areas for children that have the necessary equipment, staff and policies to provide high-quality care for children, as promoted by the recently developed Smiley quality mark for A&E departments (Kind & Ziekenhuis, 2015b), is a favorable development. Several pilots in the Netherlands have shown that this has many benefits for children, including that they suffer less from stress and pain and have to spend less time in the hospital (Eikendal, 2012; OLVG, 2013). These positive results support implementation in more hospitals.

7.4.1.2. Strengths and limitations of the study

The combination of narrative catalysis and qualitative content analysis allowed for an in-depth and contextualized understanding of what contributes to positive and negative hospital experiences and generated concrete starting points for improving the quality of care from patients' perspectives. There is a broad range of opportunities for further investigations, such as examination of differences in patient experiences between hospitals and between groups of respondents but this was not feasible within the scope of this exploratory study.

Our study has several other limitations. The first is that the stories occasionally lack richness as some of them only consist of short phrases or remarks, particularly those of children. This makes it hard to fully understand and contextualize them. In addition, the response in children and adolescents was relatively low compared to adults. This requires further investigation: should the survey be better promoted among children? Or should the survey be better adapted to fit the preferences and competences of children? Finding answers to these questions is necessary in order to increase children's responses, which is important to make sure that initiatives for improving family-centered care truly reflect the needs of children as well as parents.

Based on this first exploratory study, we recommend that children and young people should be invited to share their experiences on the basis of prompting questions. As demonstrated by Hosli (1998), the verbal and reflexive ability of children is less developed than that of adults, and they therefore need cues to access their memory. Furthermore, we suggest that face-to-face meetings between children and someone administering the survey would support sense-making, as described by Kurtz (2014), and would make it possible to interpret better children's experiences and to explore possible actions for addressing the issues identified by children.

Finally, asking patients to indicate whether the events in the hospital were 'good' or 'bad' makes it possible to distinguish between positive and negative experiences but, unintentionally, ignores the fact some experiences may be more ambivalent. Providing more opportunity for the expression of ambivalence, for example by distinguishing between overall feelings of being in the hospital and feelings related to the actions of hospital staff, might improve our understanding of what has happened and how it has been experienced.

7.4.2 Conclusion

Based on this first investigation, we conclude that the Experience Monitor is a promising method for large scale evaluations of pediatric hospital care from the perspectives of children, adolescents and parents. It yields valuable insights into what is needed to make hospital care more child and family-centered. Further investigations are needed in order to understand the full potential of this methodology.

7.4.3 Practice implications

The Experience Monitor supports critical reflection on what needs to be improved in order to meet the specific standards of children's healthcare, as developed by the European Association for Children in Hospital (EACH) Charter (1988), and as included in the European framework for the delivery of child-friendly healthcare (Council of Europe, 2011). These improvements include reducing the emotional (pre-operative) stress of children, children's participation in all decisions involving their healthcare, and children's healthcare being undertaken by staff with specific pediatric education, knowledge and experience.

Chapter 8

Around the table with policymakers: giving voice to children in contexts of poverty and deprivation

Abstract

Increasingly children are seen as social actors who are knowledgeable about issues that concern their lives, both in research and policymaking. However, this is not without challenges, particularly in relation to sensitive topics like poverty. The question is how to involve children effectively, that is in a way that thteir stories are actually listened to and acted upon by policymakers. This article reflects on the potential of Photovoice as a method to make explicit children's narrative about their lives and to inform policymakers of children's perspectives. We involved two groups of children living in contexts of poverty and deprivation in urban areas of the Netherlands, supporting them to refine their narrative and presentation through photography. The children were brought into contact with policymakers after they had gained experience as photographers and experiential experts. The policymakers found their narratives compelling and there is evidence that the children's perspectives were taken on board in local government. Exhibition of the photographs using a specially designed table was also found to be an effective addition to the Photovoice method. We conclude that Photovoice can be successfully used to facilitate dialogue between children and policymakers, but it requires time, creativity and reflexivity.

8.1 Introduction

Taking children seriously as partners in research has gained ground. In childhood studies children are increasingly seen as social actors, that is as active participants in societal life, and addressed accordingly as participants and co-researchers in order to reveal issues and concerns that they themselves identify as important (Christensen & Prout, 2002). Much effort is being made to develop research methods that support children so that they can contribute to our understanding of their living environment. This ranges from consulting children to actively involving them in designing and carrying out research projects themselves (Kellet, 2004; Vis et al., 2011; Dedding et al., 2013).

Not only social scientists, but also local governments increasingly acknowledge the importance of taking children's views into account to develop policies that fit their needs and daily reality, with regard to such diverse issues as tackling domestic violence (Jurrius, Havinga, Sarti, & Stapel, 2006), debt problems among youth (Noorda & Pehlivan, 2009), and quality of health care (Rutjes & Sarti, 2012). As in other European countries, in the Netherlands local councils have become increasingly responsible for youth policy (Timmerman, 2009). The law requires that local councils not only strengthen the development of children, through families, neighbourhoods, schools and youth work, but also invest in strengthening the 'pedagogical civil society' and in giving children and youngsters a voice ("Coalition Agreement VVD-PvdA", 2012). The local councils have considerable freedom in the way they interpret and carry out this obligation, leaving many of them struggling with the question of how to do this properly. Initiatives like youth councils are seldom potent, often failing to represent groups of children or to bring their issues to the policymaking table effectively, especially since they are often initiated and led by adults and depend on formal adult-oriented systems and communication styles (Wyness, 2009). For example, Matthews (2001) found that youth involved in UK based youth councils named 'it does not represent the views of people like me' as a major weakness.

One promising method to achieve youth participation in research and policymaking is Photovoice. Photovoice is a participatory action research method that can be used to give voice to vulnerable groups, by engaging them through photography to act as researchers and potential catalysts for change in their own communities (Wang & Burris, 1997). Photovoice can serve three goals: 1. help people to record and reflect on their community's strengths and concerns; 2. promote critical dialogue and knowledge about important community issues through large and small group discussions of photographs; and

3. reach out to policymakers (Wang, 2006; Wang 2000; Wang & Burris, 1997). Although Photovoice can serve these goals, action is not guaranteed. If not executed well Photovoice can raise false hopes, failing to inform policy or rally public concern, and leaving participants feeling less empowered than before (Strack et al., 2004). Especially children's stories are often not translated into change because, even more than adults, they are dependent on researchers and policymakers to take the needed measures (Strack et al., 2004; Catalani & Minkler, 2010).

In this article, we consider how Photovoice can be used to bring about an effective dialogue between children and policymakers, focusing on how children growing up in contexts of poverty can express themselves on issues which are relevant to them. In addition to the intrinsic advantages of Photovoice described above, we opted for Photovoice to cope with the methodological difficulties of discussing the subject of poverty with children. Poverty can set children apart, particularly if it is not addressed sensitively (Holloway et al., 2014). Poverty and being poor is surrounded with taboos because it can generate shame in both children and adults in a wealthy country like the Netherlands. Children who face deprivation tend to avoid using labels as 'poverty' and 'poor' and sometimes get angry or upset when others, like researchers, use these terms (Sime, 2008; Sarti et al., 2015). Moreover, due to the image of children as vulnerable and to the notion of childhood as an ideally carefree and joyful period in life (Sandbaek,1999; Sorin, 2005), researchers feel restrained in discussing what is seen as a painful and confrontational topic, while gatekeepers may express objections to such discussion as well (Sandbaek,1999; Cree, Kay, & Tisdall, 2002).

Giving children the opportunity to photograph their lives and neighbourhoods allows them to address topics in a comfortable way because they can tell their story in their own words and at their own pace, without much intervention from adults. In our study, we aimed to bring children and policymakers together, and arouse genuine interest and foster understanding of children's daily lives among the policymakers in order to invoke a sense of urgency to act upon the expressed needs of children. Furthermore, we were interested in answering the question whether Photovoice, as is originally designed by Wang (2002, 2006), is suitable for reaching these aims or whether special adjustments or refinements are needed.

8.2 Methodology

Our study was designed as a participatory action research (PAR) project. The PAR-approach entails data collection, reflection, and involving the people in taking action to bring about public improvements (Baum, MacDoigall, & Smith, 2006). Photovoice was used as the central method, which meant that children were involved in recording and reflecting on their lives and neighbourhoods through photos. Although researchers initially directed the project, children gradually became more involved as partners, deciding on topics for photography and themes to discuss. In individual and group photo elicitation interviews (Epstein, Stevens, Mc Keever, & Baruchel, 2008; Harper, 2002), understanding of children's experiences and needs was gained. Furthermore, we conducted participant observation and informal interviews while working and travelling with the children during work sessions and outings.

In order to enhance the quality of our research, provisions were made to ensure credibility. Among others, the following measures were taken: 1. Different methods, such as photovoice, individual and group discussions, and observation, were used in concert, compensating for their individual limitations and exploiting their respective benefits (triangulation) (Denzin, 2009; Shenton, 2004); 2. The adoption and adaptation of such a well-established method as photovoice allowed for us to obtain a more complete picture of children's lives (Shenton, 2004); 3. All the researchers had many years of experience in the field of child participation and qualitative research; 4. Frequent debriefing sessions, including regular meetings, were organized with the project leader, researchers and project partners to discuss and reflect on results and interpretations, reducing researcher bias (Shenton, 2004).

The project was presented to the children as 'a photo project on children's lives and neighbourhoods.' A total of 29 children living in impoverished areas of the Dutch provincial town of Hoorn and the capital city of Amsterdam, participated in the project. The Hoorn group was recruited by local youth workers. This group consisted of five boys and ten girls, aged 8-12 years. The Amsterdam group was recruited via three local schools and consisted of nine boys and five girls, aged 10-14 years. The children of the Hoorn and Amsterdam groups were all born and raised in the Netherlands, but have diverse ethnic backgrounds: Dutch (n= 15), Moroccan (n= 7), Chinese (n= 2), Turkish (n=1), Iranian (n= 1), Surinamese (n=1), Iraqi (n=1) and Afghan (n= 1). We met the Amsterdam children once a week for two hours, over a period of one year. We organised weekly meetings with the children from Hoorn as well, but due to practical reasons only for a period of six months. The Amsterdam group was involved in a dialogue with policymakers and the local community. Due to organisational challenges in the welfare organisation in Hoorn, they could not provide sufficient support to extend the project with a dialogue. For reasons of coherence, the findings of this article predominantly relate to our work with the Amsterdam children, validated by encounters with the Hoorn children.

The researchers developed relationships of trust with the children by walking them from school to the project location and to their homes afterwards, by organising recreational outings and by having casual conversations with them. This helped to establish high levels of rapport with the children and contributed to the researchers' in-depth insights into the children's lives. The children were intrigued by the fact that one of the researchers has the same ethnic and religious background as some of them, contributing to an atmosphere of trust and open-heartedness. The second researcher has a native, secular background and contributed a candid and inquisitive attitude, preventing researcher bias. However, in spite of the differences in researchers' backgrounds, there were also many common characteristics that distinguished them from the children: both researchers are older than the children and highly educated. Both are interested in and have much experience in working with the theme of child poverty in the Netherlands but are not poor themselves. This did not seem to pose an obstacle in connecting with the children, especially since poverty and being poor was not at the centre of discussions with children. Instead, the focus was on their neighbourhood with which the researchers were not familiar. The children appreciated adult attention and thrived on having someone to talk to and someone to listen to their stories, illustrated, for example, by them showing us their report cards or texting us during their holidays.

Given the sensitivity of the issue of child poverty, we chose to involve children as co-researchers and facilitate them in giving direction to the course of the project. We approached informed consent as a process rather than assuming it throughout on the basis of initial consent (cf Heath et al., 2007). This meant that consent was negotiated as an ongoing concern. We kept the parents and young people informed at all stages of the research. To ensure that we only involved children who were genuinely interested in taking part, we emphasised the voluntary nature of their participation and the opportunity to withdraw from the project whenever they wished, and without any consequences. In order to ensure anonymity and confidentiality, aliases were chosen for use in publications, like the article in hand.

Throughout the project expert research knowledge and local knowledge were combined and children were involved in the interpretation of the material in order to increase validity of the results (Brydon-Miller et al., 2003). After initial basic training on how to use a camera provided by a well-known news photographer, the children took a first set of pictures. These were discussed among themselves and with the researchers. After these first photographs were categorised and initial themes were established, the researchers together with the children studied the results and determined which topics could be missing. Increasingly the children got more say in operation procedures and, on the basis of identified lacunae, new ideas for photography were discussed with the children in order to further deepen the understanding of their lives and needs. Children were not just involved in analysis once, after finishing data collection, but were involved throughout in a responsive dialogue. The researchers facilitated the process by doing small exercises, such as a candy sorting game (Foster-Fishman et al., 2010) and ranking exercises, to make the children familiar with the process of qualitative analysis. Parallel to the analysis with the children, detailed interview and focus group discussion transcripts, field notes and observation reports were written and analysed by the researchers. Inductive content analysis of the raw data was undertaken to identify recurring concepts and themes that were discussed and reflected upon in the research team. This fed the analysis with the children but also our own understanding of their lives and needs, and assured that analyses were performed at an academic level, leading to articles for publication in peer reviewed journals.

8.3 Findings: connecting children with policymakers through Photovoice

In the first part of the findings, we focus on how Photovoice contributed to dealing with the difficulty of discussing the sensitive topic of poverty with children in a non-offensive manner. In the second part, we describe how we engaged policymakers in a dialogue with children about their concerns and needs.

Addressing child poverty with the help of Photovoice
We developed a varied programme to guide the maturation of the children's story and that children would find enjoyable to spend their time on. The programme was not fixed, we were always open to adjust and adapt to the unexpected, for example when children needed more time to get acquainted with each other and the researcher, when they had better ideas on activities or when they appeared to be bored.

The first meeting was dedicated to explaining the goals and procedures of the photo project. We explained to the children that we were interested in their stories and lives, and that they have a right to have their voices heard in matters that concern their lives. We asked them to take photographs and tell us about their ideas about what is positive in their lives and neighbourhood and how their lives could be improved. We further explained we wanted to generate attention to their lives and needs via these photographs. We explained that we wanted to set up a photography exhibition and that they could invite whomever they wanted, but that we thought it was beneficial to invite policymakers because they have the power to bring about change. In order to manage participant expectations, we informed the children that policymakers were not involved initially and that their involvement later on was not yet decided. We explained that we would fully commit ourselves to getting policymakers to listen to children's stories. The children reacted enthusiastically but were also sceptical about the idea that they would discuss their lives and needs with policymakers, not expecting them to be interested. The researchers explained that they would help the children where needed, for example in getting in touch with policymakers and focusing attention on their story.

During the photographer's first encounter with the children, he explained basic mechanical aspects of camera use, like operating the camera when taking pictures, and close-ups and angles. Matters of ethical conduct, such as asking permission from subjects, were also discussed. Subsequently, the children were accompanied by the photographer on guided tours through their neighbourhood, appealing to children's experiential knowledge. The children made photographs of places and things they liked or did not like. For example, Jamey made a picture of litter in his neighbourhood. For him, this is a significant problem because litter hinders him and his friends when playing outside (see Figure 8.1).

Figure 8.1 A walk through the neighbourhood with the photographer: capturing litter

In addition to group trips through the neighbourhood, the children took the cameras home to capture different aspects of their day-to-day lives. The children expressed that they were excited about bringing the brand new camera to their homes since many of them had never owned a camera. We invited them to take 10 to 15 photographs of anything that says something about their lives, whether positive or negative. These pictures were used as a starting point for an individual interview, offering children the opportunity to bond with the researcher and to share things they might be less willing to talk about in a group setting. Some children preferred to do this interview together with their friend(s). The children were in charge of which photos to discuss and in which order. The researcher asked short, open-ended questions, such as: What is this? What is happening here? Why did you take this picture? This provided insights into how children perceived their lives and neighbourhood, and which themes were important to them.

As the project progressed, we carefully encouraged children to take photos of domains in their lives that were still underrepresented in their photo series. For example, we noticed that children mainly took photos of the outside environment, such as streets and playgrounds, their friends and school life, but very few of their home environment. Hence, we invited them to take some photos inside, for example to take a picture of their favourite spot in the house.

Moreover, in order to shape their own stories and for us to gain a better understanding of their personal lives, we invited them to make their own photograph series about a topic of their interest. Three children decided to take this opportunity. Interestingly, these individual series yielded more photographs of children's intimate home environment. This provided an opening to discuss why they initially were not very willing to take such pictures. Children told us that this had to do with privacy aspects as their parents do not want them to take pictures of the interior and only family and really good friends are allowed to see their house. Furthermore, this individual approach strengthened our relationship of trust with the children. New and sensitive topics that previously had not been explicitly addressed came to the fore, also during group discussions. For example, Ebru's series concerning 'things I hold dear and would not want to miss for the world' included a picture of her mother's wallet because, as she shortly explained, 'money is important.' This was an opening for Brittany to share that her mother has financial problems: 'Sometimes we have no money. Mum sometimes wants to cook a particular dish and we're really looking forward to it but we can't buy the ingredients.' The girls mentioned that they also know other people in the neighbourhood with little money, and they indicated that it is a topic that is not openly talked about. The conversation continued about why, according to children, being labelled as poor is such a bad thing. They associated being poor with scarcity and limitations in taking part in activities such as sports, things they don't want to be identified with. As children explained, referring to someone as poor is 'a bit like gossiping' and only happens when people want to speak ill of a person. Therefore, when it affects you, you only want your nearest friends and people you trust to know about it. Brittany explained in response to a question as to why she is now talking about being poor:

> *It is really terrible if it's said about you [that you are poor]. But this is about me, this is not gossip. This is not terrible because it's only you [the researcher] and my girlfriends that are hearing it. That is safe but if you say it in public, then people will know and they will talk about you.*

Successful elements of the photo project. Three main elements were identified that contributed to enabling a discussion about poverty with children and gaining in depth insights into their personal lives and needs. First, children were in charge of presenting their own story. Second, they were encouraged to show rather than tell their stories and third, the method appealed to children´s sense of pride.

Children in charge of their own story. Giving children a photo camera put them in charge and let them influence themes of subsequent conversations and what they would disclose and when. The children gradually grew in their role as of photographers and 'experts on their neighbourhood', growing increasingly comfortable in discussing their lives and neighbourhood. Working in a group for a prolonged period of time contributed to children's skills in expressing their own opinions and listening to others. In addition, children increasingly felt comfortable enough to speak up in order to really make their voices heard. Tarik explained: 'For example, you don't want to talk, you're afraid or something, maybe you're shy. But then you are not shy anymore because the others talk and then you join them in the conversation. That's good.'

Show rather than tell. Photovoice offered the children an opportunity to show rather than 'tell' aspects of their lives and identities that might have otherwise remained unknown, as it does not depend solely on their oral competencies. Besides, children believed that only talking is 'boring'. At the same time, the verbal accounts elicited, supported and contextualised the visual images. For example, children took pictures of playgrounds, explaining that playgrounds mainly address the needs of small children and that they never change, which makes them boring (Figure 8.2). As Omar said: 'Nobody goes to the playgrounds. There is no adventure at all!'

Figure 8.2 Children take pictures of playgrounds

By discussing the photos of inadequate playgrounds, we realized how these are especially problematic for children living in impoverished areas. Cramped living arrangements often mean that children have little space at home to play, and joining clubs and formal activities is impeded as well due to scarce financial resources. Ebru commented:

> *I play outside every day. I play more outside than inside. Outside you can play with your friends. Inside you can't do that. There's not much room inside: we've only got the rooms. We don't have a garden. We would play at home more often if we had a garden.*

Appeal to pride. Photography was found to have a positive impact on children's sense of pride and feelings of self-worth. For children living in poverty, taking photos is not a common past-time and they enjoyed having a camera in their possession. In addition to using photographs as a way of expressing their needs, we invited children to take photographs of positive issues too. On a regular basis, they received prints of their photographs which were proudly put in a special place in their rooms or homes:

> *I just can't believe that I am in the photo project and that I make all these beautiful pictures [...] I have placed the card with my photograph on it on my closet. I look at it every day (Sahar).*

The fact that children increasingly had the opportunity to articulate and execute their own projects added to their sense of accomplishment.

Preparing for a dialogue with policymakers

Initially, children and policymakers were not enthusiastic about having a dialogue. Children stated that they were worried about whether policymakers would be genuinely interested in their photo exhibition and related stories. Policymakers saw practical barriers. For example, they commented that exhibition spaces had been already booked for the coming year. Nevertheless, seven months after the start of the project, we visited the council office with seven children for a meeting with the local councillor, a policy advisor and a communication officer. The children were quickly at ease, talking about the photo collages (Figure 8.3) they had brought to the meeting, reflecting different themes that needed attention in their opinion, such as the importance of adequate playgrounds, the handling of litter and feelings of unsafety in their neighbourhood.

Figure 8.3 Preparing collages for the meeting with the local councillor

The local councillor promised the children that their photos could be displayed at the council office notwithstanding earlier expressed practical objections, but nothing concrete was agreed upon concerning time and occasion.

In the meanwhile, we went to a photography museum with the children because we learned that none of the children had ever been to a formal exhibition. They enjoyed the outing but came to the conclusion that a conventional photo exhibition, as the researchers had planned, was boring. Based on the criticism of the children on the idea of having a ‘boring’ exhibition and a lack of space on the wall at the council office, the project leader came up with an innovative way to present the data, namely a photo stories table, and the researchers proposed the idea of using the table to the children. Using the photo stories table bypassed the argument of not having space on the walls for an exhibition, and offered more opportunities for creativity and for doing things differently. Together with an empathic co-designer, a special table was created with seven different styles of legs, chosen by the children and representing their individual identities. The table had a glass top layer under which a selection of photographs was displayed. Some of the photo material was highly sensitive, calling for careful deliberation on what to exhibit. For example, children did not want to exhibit photos of their bedrooms. Children gave permission for the exhibition of other intimate photographs, such as photos of their homes and relatives, with the restriction that these photos would be less visible. This led to the idea of drawers for more intimate material, some of which could be opened and others not.

The advantage of the table is that it naturally facilitates a dialogue, since people literally gather around it. Due to its form, it has the ability to assert its presence and claim people's attention. Two months after the meeting at the council office the table was proudly presented by the children to local policy-makers and the general public at the annual open evening for citizens (Figure 8.4). Parents stated that they were surprised and impressed that their children were having a public conversation with the local councillor and the general public. Adults seemed moved emotionally by the stories of the children and they were also impressed by the children's skills as storytellers of their lives and as knowledgeable conversation partners. People spontaneously started to talk to the children and each other. The local press was present to generate a number of items in local newspapers and a magazine. This contributed to the children's sense of accomplishment and empowerment:

> *Researcher: What did you find most special about the photo project?*
> *Omar: Well when we were at the council office, right guys?! [directed at the other children]*
> *Researcher: The other evening?*
> *Jasim: Yes, then we were famous!*

Figure 8.4 Gathering around the photo stories table at the council office

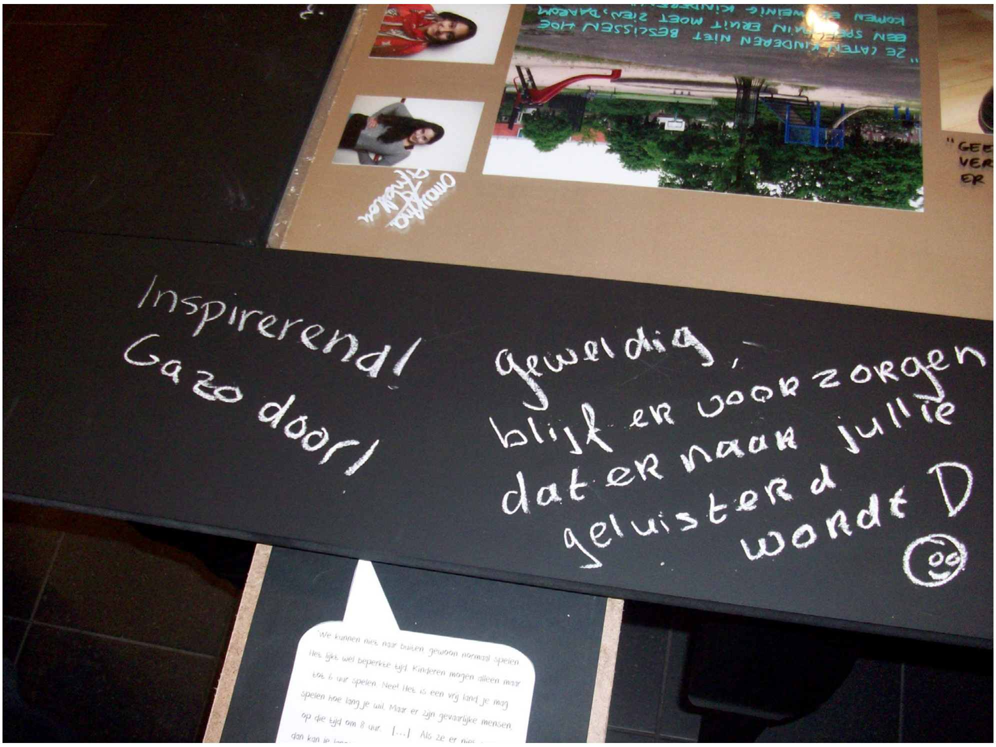


Figure 8.5 Reactions on the blackboard: 'Inspiring! Keep it up' (left) and 'Amazing, keep making sure people listen to your stories!' (right)

The photo stories table stayed in the council office for a week for everyone to see and reflect on the photographs and the children's stories. During this time, people could share their thoughts on a blackboard on the side of the table (see Figure 8.5). Subsequently the table was also exhibited at two schools and at a local library. At these locations, the children had the opportunity to discuss their photographs with their peers. Furthermore, it provided them with the opportunity to communicate the results to their own communities and to influence local professionals. For instance, a head teacher said that he intended to involve children in the design of the school playground in the future.

The project stimulated local policymakers to further discuss the issue of youth poverty, taking children's perspectives into account. For many policymakers, it was the first time they had actively communicated with children in their work and it gave them new insights. They became very enthusiastic about the potential of the method to address and prioritise the issues and needs identified by children. They stated that they wanted to continue with such a consultation process because it is consistent with current developments in the direction of citizen consultation (*burgerraadpleging*). Furthermore, the enthusiasm of the officials of the local council spread to the city of Amsterdam at large. A strategy meeting was organised in which the future policy for children living in poverty was discussed. The children's table held centre stage at this meeting and was used to reflect on existing and future policies for children living in poverty.

Figure 8.6 Outlining policy for children living in poverty with the help of the photo stories table

8.4 Discussion and conclusion

This study demonstrates how Photovoice can be used to empower children who grow up in contexts of poverty and can be instrumental in bringing about an effective dialogue between children and policymakers. Photovoice facilitates this process by its focus on images that tell the children's own stories and generate more empathy than words alone. More than other methods, Photovoice makes it possible for children to take charge of conversations, putting the image in the forefront and offering children the opportunity to clarify their stories verbally. Furthermore, a few additional aspects contributed to the success of the project. First, using Photovoice, we were able to maintain contact with the children over a long period. This meant that there was enough time for the children's stories about their lives and poverty to mature in a positive way giving, as is suggested by Wang and Burris (1997), children the opportunity to depict their own and their neighbourhood's needs as well as assets. Furthermore, by giving children much time and opportunity to practice with discussion and presentation, children's confidence was strengthened. Second, rather than starting out by connecting with and mobilising policymakers as is suggested by Wang (2006), we deliberately chose to start by forming a bond with children, empowering them to build their own narrative about their lives and neighbourhood. This turned out to be an effective way of getting heard by policymakers who initially did not have a clear vision on child participation and how to execute it in their municipality. We argue that confronting policymakers with an ongoing process and the first results was more powerful than asking them to join an indeterminate participatory action research process with unclear added value. Third, the use of the photo stories table as a means for communicating children's stories turned out to be extremely powerful tool in facilitating dialogue. The children had the opportunity to literally gather round the table with policymakers, show them their photographs and tell their stories. This caused a change in the mind-set of individual policymakers who were drawn into children's stories and felt the urgency for action. This led them to evaluate their own policies critically and define a new strategy for the future better fitting the daily realities of children.

Nevertheless, as is the case for other Photovoice projects, our project was subject to pitfalls and limitations, and new questions arose. First, involving the most vulnerable children is a challenge. In our project, the choice to use Photovoice was rooted in the ambition to give children the opportunity to develop the story of their lives and neighbourhood at their own pace, giving their own interpretation of the role poverty does or does not play. For this reason, rather than making a strict selection based on adult definitions of who is poor and not, participation was open to all children in neighbourhoods that are known to be deprived. We wanted to engage children of all segments in the neighbourhoods, including children with less aptitude for concentration, by incorporating many informal events and outings. Children who found it difficult to engage in photography were still welcome to the meetings, and able to make a contribution to the conversations. However, we may have missed some of the most marginalized children that we ideally would have wanted to include, because they did not feel welcome or comfortable or were not allowed to come by their parents. This corresponds with Wang's suggestion that 'it may be that the people who have the most difficult lives find the method impractical, unappealing or inaccessible' (2000, p. 191).

Secondly, using Photovoice can intrude into children's private space (Wang & Redwood-Jones, 2001; Prins, 2010), a challenge that becomes the more pressing with a sensitive topic like poverty. Given the intensive nature of the cooperation between the researchers and the children and because we continuously worked on developing a relationship of trust, we saw that the children increasingly felt at ease with sharing their experiences with us. Painful and difficult issues such as poverty were discussed openly. Children played a crucial role in co-selecting and co-interpreting material (Newkirk, 1996). Although careful attention was paid to gaining and on regular basis renewing informed consent, we realize that children might not at all times have been sufficiently aware of the full meaning of their research involvement, as is reflected in Brittany's statement that it is not bad to disclose being poor since it is only shared with the researcher and her friends. We carefully deliberated on what to include in public publications, such as this article. Given the importance of sharing children's intimate experiences and the precautionary principles of anonymity being upheld, we decided to disseminate such processes and experiences. A related question that arises when working with Photovoice is how photo material can be used and how not. In our study, the sensitivity of some of the photo material meant that careful deliberation on whether to exhibit it was needed, and opportunities to exhibit some aesthetically beautiful photo material was lost.

Thirdly, taking a participatory approach, children's interests directed the photography and determined the course of the discussions. We employed creative methods and games to empower children and give them space to explore and develop their ideas. Though initially hesitant, looking to the researchers for guidance, gradually children felt more in charge and took more initiative. Researchers' ideas were always explained to the children so that children were able to object or bring forward other ideas. This also meant that we were confronted with children's limits and taboos. In particular, photographing and discussing the private home environment turned out to be problematic. This means that this area is relatively underexposed. More time would be needed to involve parents, creating the opportunity to learn more about children's private lives inside the home and about interactions between children and parents.

Finally we would like to make some suggestions for how to use Photovoice to its best advantage. As we have experienced in our project, it is essential to take enough time for the children to gradually get used to each other, the researchers and the photographer, and their roles as experiential experts. Employing Photovoice once and briefly could lead to insufficient depth and false insights and interpretations. Although the literature considers the need for enough photos to reach saturation (Nykiforuk et al., 2011; Strack et al., 2010), less consideration is given to the importance of taking enough time for a cyclic process in which new ideas for photography arise and are executed. In our project, children first took ‘safe’ photographs, showing things they were proud of and could show and discuss easily. It took time and encouragement to get the children to shift their focus to include more problematic parts of their life worlds as well. Moreover, it is important to come full circle by preparing a dialogue with relevant stakeholders in order to have children’s stories heard in such a way that it leads to change. This starts with giving children the opportunity to speak up in a way that fits their competences and interests, and choose a mode of presenting that they are comfortable with and moves policymakers to action.

Chapter 9

Discussion and Conclusion

In this chapter I present the conclusions of my study, which was guided by the following research question:

How can participation of children and their parents contribute to strengthening the quality of child- and family-centred care in paediatric hospitals and departments?

The research question will be answered by summarizing and discussing the main findings per research objective outlined in chapter 3:

1. To understand what children and parents regard as good quality hospital care and how their perspectives correspond with existing frameworks for child- and family-centred care.
2. To understand health professionals' perspectives on child participation in paediatric hospital care.
3. To understand what methods are appropriate for facilitating meaningful participation of children at different levels of healthcare decision-making (micro, meso, macro).

Subsequently, I discuss the implications of our findings for daily paediatric practice and for policy frameworks followed by a discussion of the strengths and limitations of the study. The chapter concludes with mapping directions for future research.

9.1 Children's and parents' perspectives on quality hospital care

By focusing on what children and parents have to say instead of solely what researchers want to know, this study has identified those aspects of hospital care that are most important to children, young people and their families. The results from chapters 4 and 7 point to six domains that stand out as central to children's and parents' experience of health care. These reflect: (1) attitudes of hospital staff; (2) communication with staff and between staff; (3) support and distraction during medical procedures; (4) child-friendly hospital environments; (5) contact with parents, family and peers and (6) being listened to and having a say in healthcare. In this section I will summarize the key findings per domain, and identify areas for improvement.

(1) Attitudes of hospital staff

The prevailing attitudes of healthcare professionals are central to hospital-related experiences of children, young people and parents. One of the major lessons to be learned from these experiences is that doctors, nurses and other hospital staff need to show technical expertise and professionalism without losing sight of the humanity of healthcare. Children and their parents want to be respected, meaning that hospital staff need to pay sufficient time and attention to the child's medical condition, as well as to the child's psychosocial wellbeing. This finding is consistent with a systematic review by Ambresin et al. (2013) on indicators for youth-friendly healthcare drawn from young people's perspectives (10-24 years), showing that they want to be treated by healthcare providers who have accurate knowledge and can provide holistic care. In the current study, paediatric nurses, in particular, receive much praise. They are described as kind, loving, empathic, helpful, caring, child-friendly and successful at putting children and parents at ease. When the balance between 'heart, head and hands' is missing, experiences are mainly negative. In such cases, professionals displayed little empathy for patients' feelings, took decisions without consulting children and families, did not listen to their opinions, and acted hurried or carelessly. These negative experiences, as well as the more positive ones, demonstrate that continuous efforts are needed to invest in friendly and compassionate relationships between paediatric patients, families and healthcare providers.

(2) Communication with staff and between staff

The children in this study emphasized the importance of effective communication, including being well- informed and being spoken to directly by healthcare professionals. Children's appetite for accessible and adequate information, and the opportunity to ask questions, is well-documented (Coyne et al., 2014b; Lightfoot & Sloper, 2003), but our findings demonstrate that their desire for information is sometimes being underestimated in practice. Children, for example, wanted to receive information about details that adults may consider not interesting or too complex for children, such as the type of medication they are receiving. Children, and in particular adolescents, highly appreciate being directly approached by health professionals, rather than through their parents. Moreover, children emphasized the need of collaboration and good communication between all people involved in their care and treatment, including professionals outside of the paediatric unit, such as anaesthesiologists, surgeons and emergency physicians. This was considered important because it may prevent problems of miscommunications and conflicting agreements, for example about anaesthesia administration.

(3) Support and distraction during medical procedures

Children in this study frequently talked about intrusive procedures that were regarded as unpleasant, frightening, and painful, such as taking a blood sample, inserting a drip, receiving injections and induction of general anaesthesia. In this regard it was noted that hospital play specialists generally respond well to children's tension by preparing, supporting and distracting them during medical procedures. The results indicate that this approach is reassuring for both children and parents, and underline the importance of hospital play specialists in the children's ward. The findings, however, show that outside of the children's ward, including in the surgery and Accident & Emergency (A&E) department, preparation and support are not as extensive as patients would prefer. Participants referred to specialists rushing procedures instead of taking enough time to prepare and comfort the child; not explaining to the child what is going to happen and not taking the preferences of children and their families into account. For example, parents frequently mentioned that the general anaesthesia is administered in a hurried, overwhelming way with little sympathy for the needs of children and parents. This less child-centred behaviour is likely due to the severity of the child's illness, and healthcare being undertaken by staff without specific paediatric education, knowledge and experience and probably a tighter scheduling than in the children's department. Information on how to prepare and support children for medical procedures that are a source of stress and anxiety (Ahmed et al., 2011; Capurso & Ragni, 2015) could be more disseminated within these departments. Employing paediatric nurses outside of the children's ward, as one hospital did in the A&E department, might be an effective strategy as well.

(4) Child-friendly hospital environments

In recent decades, paediatric hospital environments, décor and furnishing have improved in such a way that patients and staff at other departments are occasionally envious of the warm, entertaining and welcoming atmosphere of the children's ward. Children in our study attach great value to a colourful décor and furnishing of the rooms and corridors, and they much prefer this over standard hospital décor (sterile and white). Children also appreciate the many play and recreational activities facilitated by the hospital, such as watching television, playing computer games, playing with the hospital play specialists and spending time in the playroom or teenagers room. Furthermore, children and adolescents emphasized the need for privacy and personal retreat, a concern that has been found in previous studies (Ekra & Gjengedal, 2012; Pelander et al., 2009). Ekra and Gjengedal (2012), for example, found that children (aged between 7 and 12 years) want to have a private space where they are not being disturbed by fellow patients. Children and adolescents in the current study experienced that their privacy was violated in relation to other environmental issues as well, such as the absence of window and door blinds and shared toilet/shower facilities. Based on these findings I suggest that hospitals need to consider how children's and young people's need for more privacy can be met. As shown in chapter 4, sometimes simple solutions, like blinding windows or ward doors, can make a big difference for children.

(5) Contact with parents, family and peers

As outlined in chapter 2, current quality standards for child- and family-centred care enshrine that hospitals should admit parents as part of normal routine. They are encouraged to participate in basic child care activities and accompany their children at all times, also during invasive procedures and anaesthesia induction, unless it is in the best interest of the child. Our findings suggest that these standards are generally well respected in the hospitals researched in this study. Children indicated that they do not like to be lonely in the hospital and they repeatedly mentioned that they were happy when parents could stay the night and when they received visits from family members and peers. These findings are consistent with previous studies that found that separation from parents and family, friends, home and school were children's worst experiences during hospitalization (Pelander et al., 2009; Wilson et al., 2010). In the current study, children, and in particular adolescents, also highlighted the need for electronic communication with people outside the hospital using mobile phones and the Internet. This is not surprising given that the popularity and use of such technologies has increased considerably among children over recent years, even faster than among the rest of the population (Kuntsche et al., 2009), and has become an integral part of young people's daily lives. Despite this importance, healthcare has been slow in keeping up with global advancements in children's use of social technologies. I therefore suggest that hospitals need to consider how to better facilitate children's technological connectivity, significant for both their social and school lives.

(6) Being listened to and having a say in healthcare

Children repeatedly stressed the desire to be heard and to have their views taken into account when making decisions about their treatment and stay in the hospital. The finding that this is a major concern for children is not new. Children's desire to have a say in healthcare decisions affecting their bodies and personal lives, arises in many (qualitative) studies (e.g. Coyne, 2008; Gibson et al., 2010; Kuo et al., 2012). A recent large-scale (quantitative) study across eight European countries by Bensted et al. (2015), found that being listened to was rated the most important healthcare priority by children (up to 12 years), early adolescents (13-15) and older adolescents (16-18 years), ahead of understanding what the doctor is saying, not feeling scared, the presence of parents/family, and five other aspects of patient experience. As described in chapter 2, the principle of listening to and engaging children and parents is highly supported by current policy frameworks on child- and family-centred care. Nevertheless the findings from this study show that children did not always have the influence they wanted or receive the recognition they felt they deserved as knowledgeable actors. Children, as well as parents, frequently expressed the wish that their experiential knowledge – acquired through their daily personal experience with the condition and the healthcare system – should be more valued and taken into account by healthcare professionals, claiming that nobody knows about the issues of hospitalized children better than the children and parents themselves.

9.2 Health professionals' perspectives on child participation in paediatric hospital care

It is known that child healthcare professionals have a significant influence in the process of child participation, but there has been little research into their perspectives on such participation. The studies described in chapters 5 and 6 aimed to bridge this gap by understanding health professionals' perspectives on child participation in daily paediatric hospital care (chapter 5) and in the process of clinical guideline development (chapter 6).

Health professionals' perspectives on child participation in daily paediatric hospital care

When participants were asked to define the term participation, it appeared that it is not a term that is frequently used by child health professionals. Nevertheless, they feel familiar with the ideas underlying the term, and it is perceived as being at the core of their work. For interviewees, the essence of child participation is to actively involve children as much as possible in individual decision-making about their treatment and their hospital stays. The majority of the professionals agreed that participation extends beyond listening to children and that it involves taking children's views into account when making decisions. The results show that the amount of influence that might be given to a child is strongly dependent on the child's medical condition, the type of decisions being made and the child's age and individual competences.

Some participants believe that professionals are more likely to take children's views and preferences into account when children are suffering from chronic conditions. Interviewees recognise that children with chronic conditions often have extensive knowledge and experience of their condition and treatment, and as a result, they tend to take these children more seriously. Child participation in acute hospital settings, including in the emergency care environment, may be more complex due to child and parental anxiety, professional time pressure and the severity of the child's illness or injury (Hemingway & Redsell, 2011). In addition, Dudley et al. (2015) have noted that delivering child- and family-centred care in the emergency department is challenging due to the lack of a previous relationship between the patient/family and health professionals. Moreover, children and families visiting the emergency department may be unaware of their role as partners in care. These factors, however, should not be used as reasons not to facilitate child participation. Even in these cases, children could be asked, for example, from which arm they would prefer the professional to take blood from, whether they want their parents nearby, and how they want to be prepared and distracted. There is an increasing body of research on how to strengthen the participation of children with chronic conditions (e.g. Curtis-Tyler, 2011; Dedding et al., 2014; Knopf et al., 2008; van Staa et al., 2011), but remarkably few studies into children's participation in Accident and Emergency (A&E) settings. Given that children account for approximately 20% of all A&E attendances, more studies are needed to explore the opportunities for facilitating child participation in these departments, as I will further explain in section 9.7.

Moreover, our results indicate that professionals are more likely to enable a high level of participation in 'minor' decisions that have a relatively low impact on the child's health, including decisions about the child's basic care (showers, bedtimes, diets) and choices about care delivery. Health professionals indicated that they often allow children and young people to have input in how and when particular (invasive) procedures are carried out, with the purpose of gaining their cooperation, giving back a sense of control and helping them to cope with their hospital experience in a more positive way. Even though involvement in such decisions is beneficial for children, this finding implies, as noted by Moore and Kirk (2010), tokenistic forms of participation in which children are viewed as having a say in decisions without having any influence on their medical care and treatment.

Children's willingness and competences to have a say in their own healthcare have repeatedly been demonstrated and will, amongst other things, depend on their age, previous experiences and the specific circumstances. Children as young as 2 years have been shown to know the names and purpose of their cancer drugs (Alderson, 2007), children in oncology wards have deliberately protected their parents by not telling them how much they knew or suffered (Bluebond-Langner, 1978). More recently, Hein (2015) has demonstrated that children from the age of about 11 years are able to meaningfully decide on clinical research participation. Nevertheless, the findings from our study demonstrate that healthcare professionals have reservations/concerns about involving children in complex medical decision-making, because of the implications of such decisions on the child's health and well-being. Although the Dutch law stipulates that all children have the right to be informed and heard, professionals believe that children should first be able to think abstractly, have a high level of understanding of the issue at stake, have good verbal communication skills, and be able to understand the consequences of a particular decision. Given that children's competences to understand medical information and be an active participant in their treatment have long been recognized and confirmed in the present study, no further evidence is required to demonstrate that they are willing and able to become more involved in 'major' decisions about their care and treatment. Instead, it is time to challenge professional mind-sets about the capability of children to participate. For child participation in decision-making, I argue for a situational approach that considers each child's contribution in each specific situation. Coyne and Harder (2011, p.316) have reasoned that 'the situational position recognizes children's right to have a say, without necessarily having full control over decision-making [...] This will allow a balance between protection and shared decision- making, as it enables children's voices and preferences to be heard.' Finding the right balance is rarely a subject of reflection among professionals in hospitals, and it could substantially improve child participation. Shiers's Pathways to Participation (Shier, 2001) can provide a useful framework to facilitate professional discussion and reflection on the apparent tensions between protection and shared decision-making.

While previous studies into health professionals' perspectives on child participation particularly focused on participation in consultations and individual decision-making (Coyne & Harder, 2011; Mårtenson & Fägerskiöld, 2007; Runeson et al., 2001), health professionals in the current study explicitly articulated the need to enhance child participation in service evaluation and improvement (meso level). With two exceptions, interviewees said that they are not accustomed to inviting children to evaluate their hospital stays, nor do they involve them in policy-making processes. The adolescent unit of one hospital has a notebook in which patients can write down their experiences. One-and-a-half years after the interviews took place, another hospital has set up a children's advisory council. Professionals recognize the lack of specific evaluation strategies for children as a shortcoming because they have experienced how children often perceive things differently than their parents or focus on other aspects of care. The need for age-appropriate methods for evaluating paediatric hospital care from children's and adolescent's perspectives was repeatedly expressed. Professionals generally articulate the preference for a questionnaire because it could be easily administered and because they are acquainted with such an approach. I argue that participatory methods can be more accurate, as will be discussed in section 9.3 of this chapter.

Health professionals' perspectives on child participation in guideline development

Health professionals (chapter 6) acknowledged that despite its importance, the recognition of children's unique healthcare needs and interests in clinical guideline development is limited. Professionals are not accustomed to consider children as a special sub-group from the start of developing guidelines. Moreover, existing tools for developing guidelines – e.g. the GRADE method (Guyatt et al., 2011) – and for assessing the quality of guidelines – e.g. the AGREE instrument (Brouwers et al., 2010) – do not pay specific attention to children. This underlines the need for a tool for guideline developers to be alert to children's unique health care needs. The flowchart that we have developed together with the Child and Hospital Foundation (Stichting Kind en Ziekenhuis), helps guideline developers to always consider children as a particular patient population from the start, when prioritising and demarcating new guideline topics. The tool is available for guideline developers in the register ('kennisbank') of the Dutch National Health Care Institute[6].

While patient and public involvement in guideline development is becoming increasingly common for adult patients (Boivin et al., 2010; van de Bovenkamp & Trappenburg, 2009), facilitating the participation of children and young people in guideline development is still in its infancy. The research described in chapter 6 is, to our knowledge, the first study of health professionals' perspectives on child participation in clinical guideline development. Interviewees acknowledged that in current paediatric guidelines there is hardly any attention paid to the inclusion of children's perspectives. They mentioned that this is due to the low status of children's experiential knowledge and the absence of clear requirements to give children a voice in the process of guideline development, while this is increasingly the case for adult patients. For example, in the Netherlands, the participation of patients is becoming an increasingly important requirement to get funding for guideline development (e.g. at ZonMw).

Professionals wondered how to actually involve children, bearing in mind that it is difficult enough for guideline developers to consider how to involve adult patients. Many substantial and practical questions were raised, such as: Do children have the right skills to participate in the scientific matter of guideline

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[6] https://www.zorginzicht.nl/kennisbank/Paginas/Kwaliteitsstandaarden-specifiek-voor-kinderen.aspx

development? Is it not too demanding for them? How to organize it? Which children are going to be consulted or involved? In section 9.3, I will make a first step towards answering these questions on the basis of my own experiences with researching children and the (limited) available literature on this topic. As will be described in the final section of this chapter, further empirical research is needed to understand in what stages of guideline development children can meaningfully participate and how to facilitate this in a sense that their inputs can actually make a valuable contribution to the quality of the guideline.

9.3 Methods for facilitating meaningful participation of children at different levels of healthcare decision-making (micro, meso, macro)

Based on (inter)national agreements that the Netherlands has ratified, including the United Nations Convention on the Rights of the Child and the Council of Europe Guidelines on Child-Friendly Healthcare, professionals have the duty to facilitate child participation in hospital care. This study generated knowledge of appropriate methods for accomplishing this goal in practice at different levels of healthcare decision-making: micro, meso and macro level.

Micro level
The study described in chapter 6, not only identified health professionals' ideas and perspectives on child participation, but unlike other studies, also a number of concrete strategies and tools that doctors, nurses and hospital play specialists have developed to ensure that children can participate in the clinical encounter. Professionals consider informing children about their treatment (e.g., using child-friendly brochures or educational films) and preparing them for medical procedures (e.g., using booklets of phot albums) to be prerequisite for child participation. Shared decision-making is only possible if children are well informed about their treatments. Play specialists mentioned several methods to support children in expressing their views. These methods varied from asking general questions, such as 'How do you feel today?', 'Is there anything you need?', to specially designed 'pain passports', in which children can write down personal rituals, special wishes and coping strategies they have developed over time in painful situations (Megens, Van Der Werff, & Knape, 2008). Play specialists also reported that they help children to prepare questions to ask the doctor and that they encourage children to speak up, or even accompany them to talk to the doctor. As mentioned above, interviewees indicated that they often allow children to have input in how and when particular procedures are carried out. They provide alternative options, for example, whether the child would prefer to be anesthetized using a mask or an injection and

they often give children the opportunity to postpone or determine the timing of invasive procedures and, for example, decide who should accompany them.

Meso level

It is surprising how few measures of healthcare quality, satisfaction or experience of care are based on child self-report (Ambresin et al., 2013). As a result, the opinions of parents still generally form the basis for measuring the quality of paediatric hospital care (e.g. see Ammentorp et al., 2007; Homer et al., 2011; Toomey, 2015). Recently, Schuster (2015) has argued that an important challenge in measuring paediatric quality that has contributed to a lag in developing measures – including patient experience measures – is that such measures need to be age-specific and developmentally appropriate. This means that measures need to be designed for children and cover issues that paediatric patients and families care about. This thesis research has contributed to solving this challenge by aiming to understand what methods/instruments are appropriate for gaining meaningful feedback from children and parents on their experiences of hospitalization.

Traditionally, questionnaires have been the golden standard for obtaining feedback from healthcare users. A common argument for the use of questionnaires is the provision of objective and comparable data on patient experiences and the opportunity to monitor changes over time. However, the use of such standardized methods is increasingly being criticized, because they do not adequately grasp the multi-layered texture and complexity of experience in hospitals and they do not provide sufficient detail of what to do to improve experiences (Goodrich & Cornwell, 2008; Sools et al., 2014; Tsianakas et al., 2012). Moreover, when patients act as respondents to surveys, questions and answers are predefined by the investigators; leaving hardly any room for patients to convey what really matters to them (Abma et al., 2009). I have shown that the use of participatory and qualitative research methods can overcome many of these drawbacks.

A range of participatory methods were used for one-off consultations with children and parents and included Photovoice, online/face-to-face interviews, children writing a letter to the chief executive of the hospital (chapter 4) and the Experience Monitor (chapter 7). Furthermore, a long term, in-depth Photovoice project has been conducted (chapter 8). Except for the Experience Monitor, the knowledge and experience gained with these methods have been made available in a practical handbook for healthcare practitioners and researchers

(Dedding et al., 2013).[7] The methods studied have in common that they enable children to express their views in a manner that suits their capabilities and preferences, and assist them in telling their stories from their own perspectives. However, in terms of outcomes, they differ in the degree to which in-depth and contextualized insights into children's lifeworld's were obtained, the extent to which the process contributed to the empowerment of children and the extent to which children's ideas were acted upon.

Photovoice

The outcomes that Photovoice might bring have been comprehensively summarised in two reviews of the methodology (Catalani & Minkler, 2010; Hergenrather et al. 2009) and overall reflect: 1) improved understanding of community needs and assets within a community itself as well as among influential advocates; 2) increased individual empowerment and 3) development of plans of action based on community concerns (Janes et al., 2015). The present study further supports and complements this evidence, though, the reported outcomes were strongly associated with the duration of the project and the level of participation achieved.

Better understanding of children's everyday lives and experiences

Engaging with Photovoice increased awareness and understanding of children's experiences and needs among researchers, service providers, managers, local policy makers and the broader community. It opened professionals' eyes to children's unique perspectives as they were literally confronted with issues that they themselves were not aware of or had different opinions about. Moreover, the photographs were successful in generating dialogue between children and researchers, allowing for an in-depth understanding of how children give meaning to their experiences. Individual photo-elicitation interviews offered children the opportunity to bond with the researcher and to share things that they might be less willing to talk about in a group setting. Group discussions, however, have the advantage that they invite children to engage in conversations with each other. This gives them the opportunity to reflect on their own experiences and that of others, to complement and reinforce each other's stories and to learn from one another.

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[7] The handbook "Children's Participation in Hospitals- a short introduction to the theory and practice of involving children in improving the quality of care" can be downloaded for free. Dutch version is available at: https://www.kindenziekenhuis.nl/storage_common/Handboek/Handboek%20Kinderparticipatie%20in%20het%20Ziekenhuis.pdf English version at : http://www.each-for-sick-children.org/best-practices/children-s-participation.html

Empowerment of children

Engaging with Photovoice significantly contributed to children's sense of empowerment. This already starts with inviting children to have a say in matters affecting them, meaning recognition of their knowledge, experiences and capacities. The results of this study support previous evidence suggesting that the level of empowerment is related to the duration of the project (Catalani & Minkler, 2010; Kirby & Bryson, 2002). The long-term project in Amsterdam (chapter 8) allowed children plenty of time to consider their own living environment, to reflect on their own experiences and that of others, to collaborate with other children in the same situation, and to take initiative. This ensured that children gradually learned to stand up for their opinions and interests and they got more and more confident that their views and opinions matter. However, it should be noted that the extent to which participatory projects bring about change is just as important. Short-term and one-off participation activities that succeed to bring about meaningful changes (see chapter 4) may contribute more positively to children's sense of empowerment than long-term projects that fail to do so. When children experience that their ideas are not acted upon this negatively impacts on their self-esteem and confidence and on their desire to get involved in future projects because of their discouragement that so little had been achieved.

Photovoice as vehicle for change

More than traditional social research methods, Photovoice invokes a sense of urgency to act upon the expressed needs of children. We observed that the use of photographs played an essential role in motivating hospitals to take direct action upon the issues identified by children (chapter 4). The photographs provided visual metaphors of what children wanted to tell, brought their ideas 'alive' and generated empathy for children's daily realities. Many of the children's needs and areas for improvement were acted upon by hospitals; one example being blinding of doors and windows so that children had more privacy and could sleep in darkness. Other action points could not be addressed immediately but had been placed high on the agenda, demonstrating that the data produced by children generated concrete points for improvement to which hospital managers were willing and/or actually able to respond. In the project described in chapter 8, children had the unique ofpportunity to literally gather round the table with policymakers, causing a change in the mind-set of individual policymakers who were drawn into children's stories and felt the need for action. This led them to evaluate their own policies critically and define new strategies for the future. Consistent with current developments in the direction of citizen consultation, they stated that they wanted to continue with such consultation processes, making sure that new policies better fit children's needs and priorities.

Photovoice works best when the group of participants is kept small, but has the limitation that feedback obtained from a small group of highly-engaged children may not represent the needs and perspectives of the larger population of paediatric patients. This underlines the need for having a broader range of evaluation methods available, including instruments that allow large numbers of children to structurally share their hospital-related experiences, as will be discussed in the next section.

‘Letter to the chief’ and the Experience Monitor

Making use of survey open comments can be an effective way to overcome some major drawbacks of questionnaires mentioned above, as we have shown when inviting children to write a letter to the chief executive of the hospital though a digital format (chapter 4). Despite the success of the ‘letter to the chief’, we decided to not further investigate the possibility of widespread implementation of this method, because meanwhile the Child and Hospital Foundation, together with StoryConnect, had already started with the development of a novel method with similar features; the Experience Monitor (Ervaringsmonitor). This is the first web-based instrument that allows large numbers of children and parents to share their experiernces of hospital care in the Netherlands. The Experience Monitor is based on the method of participatory narrative inquiry (Kurtz, 2014), taking into account the fact that quality of care cannot be measured by numbers alone, and needs to reflect actual experiences.

When children and parents are invited to share a story, the focus is not on what researchers want to know but what children and parents want to tell. Asking childern and parents to consider and interpret their stories, patterns can be identified that provide quick insight in positive and negative hospital experiences, without having to read all the stories in first instance. In the phase of interpreting remarkeble patterns, stories can be read in their entirity and analysed by means of qualitative content analysis, allowing for an in-depth understanding of patients’ experiences. If one would decide to not read the stories (or parts thereof), then a lot of valuable, contextualized information and richness would be lost. I argue that the strenghth of this narrative approach is that you do justice to the richness and uniqueness of personal experiences, while simultanously drawing conclusions that stretch beyond single stories in order to identify points for improving the quality of care from patients’ perspectives.

Based on this first exploratory study, the Experience Monitor is considered a promising method for large scale evaluations of hospital care from the perspectives of children, adolescents and parents. It generates concrete starting points to improve the quality of child-and family centered care, and its continous character enables hospitals to monitor the effects of the actions that were taken upon issues identified by children and their families.

However, further refinement of the way the inquiry is facilitated in practice is needed. Since the response in children and adolescents was relatively low compared to adults and their stories occasionally lacked richness, it is particularly necessary to investigate how the survey can be better adapted to fit the preferences and competences of children. I recommend that children and young people should be invited to share their experiences on the basis of prompting questions. As demonstrated by Hosli (1998), the verbal and reflexive ability of children is less developed than that of adults, and they therefore need cues to access their memory. Inviting children to answer simple and short questions, such as, 'what I like very much about this hospital…' and 'I would immediately change/improve this If I were the boss…' may be an effective strategy (see letter to the chief).

Macro level
Healthcare professionals and patient representatives recognize the importance and benefits of involving children in guideline development and they welcome further exploration of the possibilities to accomplish this goal in practice. The key is to consider in what stages of guideline development children can meaningfully participate and how to facilitate this in a way that their input actually can make a valuable contribution to the quality of the guideline. It was beyond the scope of the present study to undertake an empirical study to inform our understanding of how and when to involve children in paediatric guideline development. Instead, on the basis of my own experiences with researching children and the (limited) available literature on this topic, I make a number of suggestions. One option is to systematically seek and integrate published evidence on children's health-related experiences, preferences and priorities, as suggested by Chong et al. (2009) in relation to clinical practice guidelines for adult populations. Another option is to directly consult children and/or parents during the process of developing guidelines. The key is to approach children as experts about their life and disease and that methods are used that suit children's age, maturity and daily living environment. The methods presented in this thesis and the larger body of knowledge on how to actively involve children in research might provide an important source for guideline developers who want to increase the inclusion of children's perspectives in clinical guidelines (Christensen & James, 2000; Dedding et al., 2013; Lundy & McEvoy, 2011; Pridmore & Stephens, 2000). Experience of the

National Institute for Health and Care Excellence (NICE), UK, demonstrates that carrying out consultations with children – in the form of questionnaires and group discussions – to identify diagnosis and treatment issues that are most important to children themselves, yields valuable insights into children's daily realities of living with the condition. For instance, the children involved in the development of the childhood constipation guideline, emphasised the impact of the condition on their social life. School-going children, for example, mentioned the prevention of unintentional stool loss as a major concern. Children's responses were used to inform discussions in the guideline development group and, where appropriate, were recorded in the interpretations of evidence (National Collaborating Centre for Women's and Children's Health, 2010). Currently, NICE is planning a similar initiative in the development of a guideline on child abuse and neglect (NICE, 2015).

9.4 Implications and recommendations for practice

The finding of six domains that stood out as central to participants' experiences of child- and family-centred care are immediately relevant to clinical practice. Some of the domains identified by children and parents support current good practices, such as unrestricted visiting hours at the children's ward, the possibility for parents to room-in and the crucial work done by hospital play specialists. The finding that children and adolescents want to be treated with respect for their personal preferences and experiential knowledge, could be incorporated within teaching and training initiatives about child- and family-centred care. Some other quality indicators recognized by the participants in this study are applicable to interventions that better orient hospital care to children's and young people's needs. Paediatric wards, for example, need to consider how children's and young people's needs for privacy and electronic communication with people outside the hospital can be met better. The need for more child-centred A&E departments that have the necessary equipment, staff and policies to provide high-quality care for children, might require more drastic measures, such as redesigning the A&E physical plant to ensure that emergency care for children is, as much as possible, separated from emergency care of other patients (Dudley et al., 2015). However these investments are likely to pay off in the end, considering that child- and family-centred care is associated with improved health outcomes, therapy compliance, satisfaction, self-management and more efficient use of services (Dunst et al., 2007; Feenstra et al., 2014; Kuhlthau et al., 2011). Several pilots with child-friendly A&E departments have shown that children suffer less from stress and pain and have to spend less time in the hospital (Eikendal, 2012; OLVG 2013). These positive results encourage implementation in more hospitals.

The quality of paediatric healthcare may substantially be improved by adopting participatory evaluation methods, either as primary evidence of children's most significant needs and issues, or as complementary data for triangulation with survey data. Statistical data – gathered through more traditional means – may convince policy makers of the benefits of addressing a particular problem. I have shown that participant-generated data in turn might have greater potential to stimulate policy maker action in order to bring about meaningful changes. Structural and widespread implementation of participatory methods in paediatric hospital care will require a cultural shift as they challenge institutional norms and philosophies. Participatory methods are uncommon and not well accepted in hospital settings as a result of widespread unfamiliarity with the participatory philosophy and an ideological clash with the medical paradigm. One step towards the enhanced embedding of participatory methods is making the added value and benefits of these methods explicit and visible, as has been done in this study.

9.5 Implications for policy frameworks on child- and family-centred care.

Children's and parents' perceptions of quality healthcare can complement existing policy standards and frameworks (see chapter 2). A few of the criteria identified by the participants of this study, point to domains that are absent in some or all of the existing standards that were described as theoretical context for the current study. The CoE Guidelines on Child-Friendly Healthcare, for example, do not include a criterion about privacy, while the children in this study frequently stressed the need for privacy and a place to be alone. Similarly, the importance of support and distraction during invasive medical procedures was repeatedly mentioned by both children and parents, but this quality criterion is not explicitly captured in any of the three frameworks. In addition, children's perceptions of quality healthcare are helpful in refining and operationalizing existing quality standards and frameworks. For instance, where it is generally accepted that paediatric patients deserve “child-friendly” hospital environments, children and young people in this study specified that this implies colourful rooms and corridors, a range of recreational activities and being able to sleep well. Similarly, where it is commonly established that children are allowed to receive unrestricted visits of parents and other family members, the participants from this study added the significance of maintaining contact with peers. Table 9.1 provides an overview of how the domains from this study complement/refine the quality criteria on child- and family-centred care identified by the WHO, the EACH and the Council of Europe.

Furthermore, children's and parents' perceptions of 'good care' highly support the recognition of the inclusion of patient experiences as one of the central pillars of quality in healthcare. Except for 'hospital environments' the domains that children and parents identified as central to the delivery of good hospital care, typically relate to 'relational' aspects of care (e.g. attitudes of hospital staff and communication with staff), rather than 'functional' aspects such as continuity, accessibility and evidence-based care. Accepting that good quality care is more than just technical care, supports broader definitions (and measures) of quality, acknowledging that nobody can judge the quality of relational aspects better than the patients themselves.

The six domains as identified by children, young people and parents could inform the development of a national quality standard to guide policy-making, planning and delivery of child- and family-centred hospital care. Drafting a national quality standard is necessary as the analysis showed that current quality standards have a number of shortcomings. Neither the EACH Charter nor the CoE guidelines have a sound scientific foundation, but are mainly developed from the perspective of parent organizations and professional experts. The CoE also sought to incorporate the views of children and young people. As described in chapter 2, the WHO model is more scientifically underpinned, but children and young people have not been involved in the development of the model. Moreover, the WHO model is particularly focused on adolescents (and not on children <10 years) and had originally been developed for use in low-income and middle-income countries, meaning that it is not completely applicable to the Dutch cultural, social and economic context. Taking into account these considerations, I suggest that there is a particular need for developing a quality standard that combines domains of *children's experiences of care* with domains of *evidence informed care*, with particular emphasis on hospital settings. This model should focus on children as well as adolescents, taking into account their distinct healthcare needs and priorities. Subsequently this quality standard can provide clarity about what domains and indicators should be included in instruments that measure the child-and family-centeredness of hospital care and services.

Table 9.1 Recommendations from key organizations on quality criteria for child- and family-centred care, showing how they relate to the domains from this study

Framework	**World Health Organisation (WHO) framework for adolescent friendly healthcare (WHO, 2002)**	**European Association for Children in Hospital (EACH) Charter (EACH, 1988)**	**Council of Europe (CoE) Guidelines on Child-Friendly Healthcare (Council of Europe, 2011)**	**The present PhD study**
Year	2002	1988, but a number of annotations were added in 2001	2011	2016
Target group	Adolescents 10-19 years	Children 0-18 years	Children 0-18 years	Children 0-18 years
Developed from the perspective of:	WHO experts, building on reviews of scientific evidence, with a strong emphasis on primary care in low-income and middle-income countries.	Voluntary (parent-driven) organisations involved in the welfare of children in hospital.	A wide range of stakeholders, ranging from parent organizations, professional groups, health service managers, civil servants, CoE experts and children.	Paediatric patients and their families in Dutch hospital care
Quality criteria	**Equitable** No restriction of services on any terms Health- care providers and support staff treat all clients with equal care and respect		**Promotion** i. all children ii. vulnerable children iii. children using health services **Protection** i. all children ii. vulnerable children iii. children using health services	
	Accessible Free or affordable services Convenient hours of operation Information about the availability of reproductive health services Community members understand the benefits of and support provision of adolescent health services Community based provision			(1) Attitudes of hospital staff (2) Communication with staff and between staff (4) Child-friendly hospital environments (5) Contact with parents, family and peers

	Acceptable Client confidentiality Ensuring privacy Short waiting times Appealing and clean environment Information and education Adolescents are involved in designing, assessing and providing health services	(2) Children in hospital shall have the right to have their parents with them at all times (3) Accommodation should be offered for all parents (4) Information in a manner appropriate to age and understanding (6) Children shall be cared for together with children who have the same developmental needs and shall not be admitted to adult wards (7) Child-friendly environment with full opportunities for play, recreation and education (9) Continuity of care should be ensured (10) Children shall be treated with tact and understanding and their privacy shall be respected at all times.		
	Appropriate The required package of healthcare is provided to fulfil the needs of all adolescents	(5) Children and parents have the right to informed participation in all decisions involving their healthcare	**Participation** i. individual decision-making ii. feedback on experiences iii. policy-planning processes	(6) being listened to and having a say in healthcare
	Effective Health care providers have the required competencies to work with adolescents and to provide them with the required health services Evidence-based care Sufficient time for clients Availability of necessary equipment and supplies	(1) Children are only treated in hospital if the required care cannot be equally well provided at home (8) Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.	**Prevention** i. Primary ii. Secondary iii. Tertiairy **Provision** i. evidence- based ii. delivered by competent practitioners iii. delivered in the right way, in the right place, at the right time	(3) Support and distraction during medical procedures

9.6 Research strengths and limitations

With regard to the internal validity, one strength of this study is the inclusion of a wide range of stakeholders, including children, adolescents, parents/families and various types of healthcare practitioners (paediatricians, paediatric nurses, hospital play specialists, healthcare managers, guideline developers, policy-makers). This allowed individual viewpoints and experiences to be verified against each other, which ultimately lead to a broad picture of experiences, ideas and wishes. Another form of triangulation involved the use of a combination of different research methods, compensating for their individual limitations and exploiting their respective benefits. The current study has the limitation that, except for thev project described in chapter 8, observational techniques were not used. Thus, these studies (chapters 4-7) are dependent upon participants' accounts of their experiences and not on what they actually do in practice.

Some strategies were used to minimise researcher bias, including audio-recording of interviews and group discussions, transcribing research data verbatim, keeping field logbooks and using qualitative data analysis software for content analyses. Furthermore, summaries of (group) conversations were sent to participants to confirm that it properly reflected their views and experiences. Finally, frequent debriefing sessions were organized with supervisors, co-researchers and project partners to discuss and reflect on the results and its interpretations.

The inclusion of multiple hospitals (both teaching and regional), geographically spread across the Netherlands has contributed to establishing trustworthiness of the study, reducing the effect of particular local factors. It should, however, be noted that the data for the evaluation of the Experience Monitor (chapter 7) were largely obtained from hospitals that hold a Golden Smiley quality mark. Hospitals with such a quality mark positively distinguishes themselves from competitors in terms of the child-and family-centeredness of their care. This means that the results from our explorative evaluation are not representative for children's hospitals and departments in general.

The research team aimed, as much as possible, for saturation of data within the employment of the research methods. However, I am aware that some important quality indicators may have been missed, because they were not brought to the fore by the participants. When children and parents have been silent on a particular topic, it does not necessarily mean that the topic is not important to them. Structural and long-term participation projects have greater potential in reaching data saturation, because they allow for a reflective process in which new themes for discussion can arise. Such research has been performed in the project described in chapter 8. However, this approach could not be undertaken in the study of 10 hospitals (chapter 4).

Almost all studies included in this thesis have been conducted in paediatric hospital settings, but some major findings may have wider applicability in the rest of the hospital. Child-friendly hospital policies, such as unrestricted visiting hours and the possibility for parents to room-in, that have been introduced in an attempt to reduce hospital-related stress and trauma in children, could be a good example for adult departments. Why would rooming-in exclusively be allowed in the children's ward? Why would a daughter, for example, not be allowed to stay with her elderly mother? It is quite often assumed that hospitalisation is not that problematic for an adult and that he or she will be able to adapt easily. Vingerhoets (2000) however argues that being separated from their homes and families are major stressors for adult in-patient, implying that adult wards might learn a great deal from the advances made in paediatric hospitals and departments over the last 30 years.

9.7 Directions for future research

In the previous sections I have briefly mentioned a number of recommendations for follow-up research. In this closing section, some final recommendations are made for further research that could contribute to strengthening the participation of children, young people and parents in the paediatric ward and beyond, with the ultimate goal of improving the quality of care. I propose that progress in the future will depend on participation becoming a routine part of the culture of paediatric hospital care at all levels of decision-making: from the level of individual consultations between children and clinicians (micro), development and evaluation of hospital care and services (meso), and the level of healthcare planning and policy (macro). This requires investigations of current practices as well as the development and evaluation of emerging and new initiatives.

Firstly, at the micro level, there is a need for studies comparing children's, parents' and professionals' perspectives on child participation, and their ideas on how to best facilitate it. The present study generated knowledge of concrete ideas and opportunities for facilitating child participation in daily paediatric practice from the perspective of health care professionals. Furthermore, it highlighted what professionals consider to be important to move the participation agenda forward. However, certain situations described by professionals might be perceived and experienced differently by children and their parents. Similarly, children's and parents' ideas and wishes for improving participation practices may differ from those of healthcare professionals. In particular, research is needed to identify the situations in which the child's wishes conflict with what adults, both professionals and parents, consider to be in the child's best interests. This research will help to provide a more complete picture of how participation is being put into practice, provide insights into what considerations and actions can be taken to alleviate or address conflicts between health professionals, children and parents and, finally, ensure that initiatives for improving participation do justice to the experiences and needs of children, parents and health professionals.

Based on the results from this study, I made a number of suggestions for increasing the respect of children's right to participate in healthcare consultations in the surgery and A&E department. However, as mentioned before, these departments have different settings and face particular challenges, meaning that good practices found in the children's ward might not unambiguously be translated to other departments. Further research is required to understand how the provision of child- and family-centred care in the surgery and A&E department might be improved. This should include the monitoring and evaluation of emerging initiatives, such as separate A&E treatment areas that have the necessary equipment, staff and policies to provide high-quality care for children, as promoted by the recently developed Smiley quality mark for A&E departments (Stichting Kind en Ziekenhuis, 2015a). Research is needed to examine the impact of child-centred A&E departments on patient experiences and clinical outcomes. In addition, medical specialists' (e.g. surgeons, anaesthetists, emergency physicians) experiences with and perspectives on children's and young people's participation need to be investigated, as this was beyond the scope of the current study.

At the meso level, follow-up research is needed to understand how the insights gained from the present study can be used to ensure that children enter into dialogue with professionals/policy makers about healthcare quality improvement on a structural basis. In this respect, the installation of a Children's Advisory Council (KinderAdviesRaad) in two paediatric hospitals in the Netherlands, is a promising development. The Children's Advisory Council in one of these hospitals has realized a number of significant actions that reflect the needs and experiences of paediatric patients, including the abolishment of television fees, opportunities for children to spend time with their pets, and the blinding of ward doors in such a way that people passing by can less easily look inside (Cnossen, 2015). By now, several more Children's Councils are under formation, demonstrating hospitals' commitment to child- and family-centred care (Stichting Kind en Ziekenhuis & Radboudumc, 2015). Future studies are needed to investigate the impact of such councils on the quality and improvement of services. In addition, barriers to young people's voices being heard need to be investigated.

Just like the Photovoice method, Children's Advisory Councils have the disadvantage that feedback obtained from a small group of highly-engaged children may not provide a representative overview of the needs and perspectives of the diverse paediatric patient population. For this reason, future research should also focus on developing/improving instruments to perform large-scale evaluations of the quality of paediatric hospital care from the perspectives of children, adolescents and parents, and how these methods can be effectively applied in concert with more participatory methods.

Finally, at the macro level, much work is to be done to provide children and young people with a voice in the policy and planning process for the services they use. As mentioned in section 9.3, there is hardly any experience with children's and young people's involvement in clinical guideline development, thereby violating their right to participation and the best possible healthcare. Following the example of the National Institute for Health and Care Excellence in the UK, the time has come to recognize the importance and benefits of involving children and families in guideline development. A pilot project could be undertaken to inform the development of a particular paediatric guideline and our understanding of how and when children can meaningfully participate in such a process.

Summary

Samenvatting

Dankwoord

References

Summary

Introduction

In the Netherlands, each year more than one million children (0-18 years) visit a hospital for outpatient treatment, day treatment or admission. Children are not just small adults; they need to be diagnosed and treated in the context of their rapid growth and development, a context that has no counterpart in adults. Other important differences between children and adults as patients include children's dependence on adults for access to the medical system, their different types, expression and severity of illnesses and their different responses to treatment. Furthermore, hospitalization is generally a stressful experience for children, not only due to their medical condition, but also because they are in a completely unfamiliar environment.

These differential characteristics shape the way quality care for children needs to be organized. The approach of *child and family-centred care* is considered to be the standard of paediatric healthcare by providers in many countries, including the Netherlands. This approach to healthcare recognizes the importance of meeting the child's unique physical, mental and developmental needs. Furthermore, it recognises that patients and family are integral partners with the healthcare team, demanding that children's and parents' experiential knowledge – acquired though their daily personal experience with the condition and the healthcare system – and the professional's medical knowledge are complementary at all levels of decision-making. The increasing recognition that children are not only objects of care but knowledgeable social actors who have their own unique perspectives on issues that affect them, has been stimulated by the adoption of the children's rights agenda, the reconceptualization of children within the social study of childhood and the growing influence of patients as consumers. Nonetheless, there remains a gap between legal regulations on children's rights to participate in healthcare and the actual fulfilment of these rights in practice.

The challenge of closing the implementation gap is particularly complex for a number of reasons, including that children's experiential knowledge generally has a low status compared to that of the parents and physicians, and that there is little experience with how to involve children in hospital care, especially how to do so in a way that befits the competences and needs of children, and brings about changes that matter to them. Further, the respect for a child's right to participation is largely dependent on the attitudes and approaches of healthcare professionals, but their perspectives on children's participation in hospital care remain largely unexplored. Previous research suggests that professionals might have difficulty in facilitating or supporting child participation, due, among other things, to protective attitudes toward children, doubts about the competence of children to participate and assumptions about a child's age and maturity.

This thesis research addresses the challenges mentioned above, in order to ensure that children and young people can participate more effectively at all levels of healthcare decision-making. Good quality hospital care for children is only possible if children's views, needs and wishes are structurally taken into account. This will result in much richer perspectives, allow an understanding of how children experience their hospitalization, what they consider important and how to align this with hospital policies and daily care practice, with the ultimate goal of improving health outcomes.

Theoretical background and study objectives

Several key international organisations, including the World Health Organisation (WHO), the Council of Europe (CoE) and the European Association for Children in Hospital (EACH) have already addressed the question of what actually constitutes high quality care centred around children's and young people's needs, and they have made recommendations to guide policy-making, planning and delivery of services. Relevant concepts from these policy frameworks are brought together in a conceptual framework that takes into account that the participation of children is crucial to the realization of high quality care that places children and their families at the centre of healthcare practice. Three levels of participation are distinguished:

- *Micro level:* participation in individual decision-making, whether this be lifestyle choices or involvement in medical decision-making.
- *Meso level:* children should be given the opportunity to provide feedback on their experience after they have used services.
- *Macro level:* with increasing maturity and capacity, children should be involved in the policy/planning process for the services they use.

Furthermore, the conceptual framework recognizes that the attitudes and practices of healthcare professionals as well as parents largely contribute to the delivery of child- and family-centred care. They are the ones to provide children with appropriate care and support, but they also have significant influence in the process of child participation. Obviously, there are many more factors influencing the implementation of child- and family-centred care, such as appealing hospital environments, understandable information for patients and the availability of necessary equipment and supplies. In this study, I specifically focus on the question of *how* the participation of children and parents can contribute to strengthening the quality of child- and family-centred hospital care, taking into account that paediatric healthcare is grounded in a three-way relationship, involving the child, the child's parent(s) and the healthcare professional. Three study objectives have been formulated:

1. To understand what children and parents regard as good-quality hospital care and how their perspectives correspond with existing policy frameworks for child- and family-centred care.
2. To understand health professionals' perspectives on child participation in paediatric hospital care.
3. To understand what methods are appropriate for facilitating meaningful participation of children at different levels of healthcare decision-making (micro, meso, macro).

Methodology

I mainly used a qualitative research approach, combining *participatory data collection methods* and *traditional qualitative research methods*. Participatory data collection methods have their roots in collaborative or partnership methodologies. Collaborative research adopts an epistemological position that not only acknowledges children's agency, but aims to facilitate their voices being heard in research affecting *their* lives. It appeals for consistent collaboration with children in some or all stages of a research project. In this study, participatory research methods were used to evaluate the quality of hospital care from children's perspectives (first research objective) and to consider the appropriateness of such methods for facilitating meaningful participation of children at different levels of healthcare decisions-making (third research objective). Qualitative research methods, including semi-structured interviews and focus group discussions, were used to address the second aim of this study because these methods are particularly suited to gain insight into the experiences, meanings and views of individuals in relation to the complex circumstances of illness, treatment and hospitalization.

Results

Children's and parents' perspectives on quality hospital care

By focusing on what children and parents have to say instead of solely what researchers want to know, this study has identified those aspects of hospital care that are most important to children, young people and their families. We identified **six domains** that stand out as central to children's and parents' experience of healthcare. The **first** domain reflects hospital staff's attitudes, such as respect, attention and friendliness. Participants emphasized that doctors, nurses and other hospital staff need to show technical expertise and professionalism without losing sight of the humanity of healthcare. When the balance between ‘heart, head and hands’ is missing, experiences are mainly negative. In such cases, professionals displayed little empathy for patients’ feelings, took decisions without consulting children and families, did not listen to their opinions and acted hurried or carelessly. The **second** domain reflects children’s desire for effective communication, including being well-informed, healthcare professionals speaking directly to children, and good collaboration and communication between all persons involved in the care of children, including professionals outside of the paediatric unit, such as anaesthesiologists, surgeons and emergency physicians. The **third** domain relates to children’s need for support and distraction provided by nurses and hospital play specialists during stressful medical procedures, such as taking a blood sample, inserting a drip, receiving injections and induction of general anaesthesia. Particularly outside of the children’s ward, including in the surgery and Accident & Emergency (A&E) department, preparation and support are not as extensive as patients would prefer. The **fourth** domain reflects child-friendly hospital environments. Participants’ comments focused specifically on recreational facilities, poor hospital food, the furnishings and decorations of the paediatric department, and lack of privacy. The **fifth** domain is about maintaining contacts with parents, family and friends. Children frequently mentioned that they were happy when parents could stay the night and when they received visits from family members and peers. Adolescents, in particular, also highlighted the need for electronic communication with people outside the hospital using mobile phones and the Internet. The **sixth** domain, being listened to and having a say in healthcare, touches upon the core objective of this thesis. Even though the principle of listening to and engaging children and parents is highly supported by current policy framework on child- and family-centred care, in this study, children, as well as parents, frequently expressed the wish that their experiential knowledge should be more valued and taken into account by healthcare professionals, claiming that nobody knows about the issues of hospitalized children better than the children and parents themselves.

Health professionals’ perspectives on child participation in paediatric hospital care

Health professionals, together with parents, have significant influence in the process of child participation. Our results demonstrate that participation is not a term that is frequently used by professionals; however, they feel familiar with the ideas underlying the term, and it is perceived as being at the core of their work. For interviewees, the essence of child participation is to actively involve children as much as possible in individual decision-making about their treatment and their hospital stays. Professionals believe that high levels of participation are possible in ‘minor’ decisions that have a relatively low impact on the child’s health, including decisions about the child’s basic care and choices about care delivery (micro level). Participation in medical decision-making is considered to be more complex and subject to a number of reservations and restrictions because of the implications of such decisions on the child’s health and wellbeing.

With two exceptions, professionals said that they are not accustomed to inviting children to evaluate their hospital stays (meso level), nor do they involve them in policy-making processes (macro level). Professionals recognize the lack of specific evaluation strategies for children as a shortcoming because they feel that children often perceive things differently than their parents or focus on other aspects of care. The participants expressed a strong need for age-appropriate methods for evaluating paediatric hospital care from children’s and adolescents’ perspectives. Furthermore, they voiced the need to increase the respect for and understanding of the rights of children to participate outside of the paediatric unit, including in the surgery and emergency departments.

Methods for facilitating meaningful participation of children

This study generated knowledge of appropriate methods for facilitating child participation at different levels of healthcare decision-making (micro, meso, macro). We identified a number of strategies and tools that doctors, nurses and hospital play specialists have developed to ensure that children can participate in the clinical encounter (*micro level*). Play specialists mentioned several methods of supporting children in expressing their views. These methods varied from asking children general questions, such as “Is there anything you need?”, to specially designed “pain passports”, in which children can write down personal rituals, special wishes and coping strategies they have developed over time in painful situations. Interviewees said that they often allow children to have input in how and when particular procedures are carried out. They provide alternative options, for example, whether the child would prefer to be anaesthetized using a mask or injection, and they often give children the opportunity to postpone or determine the timing of invasive procedures, and for example, decide who should accompany them.

Professionals indicated that they still rely on parents for feedback on the quality of paediatric hospital care and services (*meso level*). This study identified a number of methods/instruments that are appropriate for gaining meaningful feedback from children (and parents) on their experiences of hospitalization. These methods include Photovoice, online/face-to-face interviews, children writing a letter to the chief executive of the hospital and the Experience Monitor. The methods studied have in common that they enable children to express their views in a manner that suits their capabilities and preferences, and assists them in telling their stories from their own perspectives. In addition, Photovoice is able to provide visual metaphors of what the children want to tell; hereby generating more empathy than words alone. However, in terms of outcomes, the methods differ in the degree to which in-depth and contextualized insights into children's lifeworlds were obtained, the extent to which the process contributed to the empowerment of children and the extent to which children's ideas were acted upon.

The participation of children at higher levels of decision-making, including research agenda setting and clinical guideline development (*macro level*), has been endorsed by international bodies like the WHO and UNICEF. However, our findings indicate that in practice children hardly participate in the planning/policy process for the services they use. For example, in the Netherlands, facilitating the participation of children and young people in guideline development is still in its infancy, although it is becoming increasingly common for adult patients. Many guideline developers perceived children's participation in guideline development as a challenge, and had doubts and questions about children's abilities to participate, such as: Do children have the right skills to participate? From what age can they be involved? Is it not too demanding for them? How to organise it? These questions have not yet been solved for adults but are paramount for facilitating children's participation. Despite all the questions and difficulties, participants recognized the importance and benefits of children's involvement and welcome further exploration of its possibility in guideline development.

Discussion and Conclusion

Over the last three decades is has been increasingly accepted that paediatric patients are not only objects of care, but knowledgeable social actors who should be enabled to have a say in healthcare decisions that relate to them. However, facilitating meaningful participation of children and adolescents in daily paediatric practice is complex. The present study aimed to better understand how participation of children and their parents can contribute to strengthening the quality of child- and family-centred hospital care.

Evaluating the quality of paediatric hospital care from the perspectives of children and families increases awareness and understanding of their daily realities and experiences. The lessons that we distilled from these experiences are immediately relevant to clinical practice. Some of the domains identified by children and parents support current good practices, such as unrestricted visiting hours, the possibility for parents to room-in and the crucial work done by hospital play specialists. Some other quality indicators recognized by the participants in this study are applicable to interventions that better orient hospital care to children's and young people's needs. Many of the areas for improvement identified during this study were acted upon by the hospitals. Examples include blinding of doors and windows so that children have more privacy, and developing child-friendly menus that have been tasted and assessed by a specially established team. Other action points could not be addressed immediately but are now receiving attention or have been placed high on the agenda. This demonstrates that participatory methods are not merely tools to gather children's views but can serve as vehicles for making changes that matter.

From a theoretical point of view, children's and parents' perceptions of quality healthcare can complement existing policy standards and frameworks. A few of the criteria identified by the participants of this study point to domains that are absent in some or all of the existing standards that were described as theoretical context for the current study. For example, the importance of support and distraction during invasive medical procedures was repeatedly mentioned by both children and parents, but this quality criterion is not explicitly captured in any of the three frameworks. In addition, children's perceptions of quality healthcare are helpful in refining and operationalizing existing quality standards and frameworks. For instance, where it is generally accepted that paediatric patients deserve 'child-friendly' hospital environments, children and young people in this study specified that this implies colourful rooms and corridors, a range of recreational activities and being able to sleep well.

Finally, children's and parents' perceptions of 'good care' highly support the recognition of the inclusion of patient experiences as one of the central pillars of quality in healthcare. Except for 'hospital environments' the domains that children and parents identified as central to the delivery of good hospital care, typically relate to 'relational' aspects of care (e.g. attitudes of hospital staff and communication with staff), rather than 'functional' aspects such as continuity, accessibility and evidence-based care. Accepting that good quality care is more than just technical care supports broader definitions and measures of quality, acknowledging that nobody can judge the quality of relational aspects better than the patients themselves. In this context, the quality of paediatric hospital care may be substantially improved by adopting participatory evaluation measures, taking into account the fact that quality of care cannot be measured by numbers alone and needs to reflect actual experiences.

Samenvatting

Introductie
In Nederland komt jaarlijks één op de drie kinderen (0-18 jaar) in het ziekenhuis voor een poliklinische behandeling, dagopname of (langdurige) opname. Kinderen zijn echter geen kleine volwassenen; zij moeten worden gediagnosticeerd en behandeld in het licht van hun snelle groei en ontwikkeling. Er zijn een aantal andere belangrijke punten waarop kinderen verschillen van volwassen patiënten. Ten eerste zijn kinderen voor toegang tot de gezondheidszorg afhankelijk van volwassenen. Ten tweede presenteren zij zich vaak met andere klachten en aandoeningen en reageren zij anders op medische behandelingen dan volwassenen. Tot slot is een ziekenhuisopname doorgaans een stressvolle ervaring voor kinderen, niet alleen vanwege hun medische conditie, maar ook omdat ze in een voor hen volledig onbekende omgeving zijn.

Deze verschillen bepalen grotendeels hoe kwalitatief hoogwaardige ziekenhuiszorg voor kinderen georganiseerd moet worden. In veel landen, waaronder Nederland, wordt kind- en gezinsgerichte zorg als de standaard beschouwd. Deze benadering van zorg erkent dat het van groot belang is om rekening te houden met de fysieke-, mentale- en ontwikkelingsbehoeften van het kind. Bovendien erkent deze aanpak dat kinderen en hun familieleden integraal deel uitmaken van het gezondheidsteam. Hierbij wordt ervan uitgegaan dat de ervaringskennis van kinderen en ouders – die zij hebben verworven door hun persoonlijke ervaring met de aandoening en het gezondheidszorgsysteem – een belangrijke aanvulling vormt op de kennis en ervaring van medisch professionals. Het groeiende besef dat kinderen niet enkel objecten zijn van zorg, maar goed geïnformeerde maatschappelijke actoren met hun eigen unieke perspectieven over zaken die hen aangaan, is gestimuleerd door de invoering van de kinderrechtenagenda (1989), de herconceptualisering van kinderen binnen de sociale studie van de kindertijd en de toenemende invloed van patiënten als consumenten. Er bestaat echter nog steeds een kloof tussen de wettelijke voorschriften inzake de rechten van kinderen om te participeren in de gezondheidszorg en de daadwerkelijke uitvoering van deze rechten in de praktijk.

Het dichten van deze implementatiekloof is een complexe uitdaging. Ten eerste omdat de aan de ervaringskennis van kinderen over het algemeen een lagere status wordt toegekend dan aan die van ouders en professionals. Ten tweede is er weinig kennis over *hoe* kinderen het beste betrokken kunnen worden bij de ziekenhuiszorg en in het bijzonder over de vraag hoe dit gedaan kan worden op een manier die past bij de behoeften en competenties van kinderen en die veranderingen teweegbrengen waar kinderen van profiteren. Tenslotte is de mate waarin het recht op kinderparticipatie in de praktijk gerespecteerd wordt grotendeels afhankelijk van de houding en aanpak van medische professionals. Er is echter zeer weinig onderzoek gedaan naar hun perspectieven op kinderparticipatie in de gezondheidszorg. Voorgaand onderzoek suggereert dat professionals moeite hebben met het faciliteren en ondersteunen van kinderparticipatie, onder andere vanwege hun beschermende houding ten opzichte van kinderen, hun twijfels over de bekwaamheid van kinderen om te participeren en veronderstellingen over de leeftijd en rijpheid van een kind.

Dit proefschrift adresseert bovengenoemde uitdagingen, met als doel dat kinderen en jongeren effectiever kunnen participeren op verschillende niveaus van medische besluitvorming. Goede kwaliteit van kindergeneeskunde is immers alleen mogelijk als er structureel rekening wordt gehouden met de opvattingen, wensen en behoeften van kinderen. Dit zal resulteren in rijkere perspectieven en het verschaft inzicht in hoe kinderen hun ziekenhuisopname ervaren, wat zij belangrijk vinden en hoe dit afgestemd kan worden op de dagelijkse zorgpraktijk en het ziekenhuisbeleid, met het uiteindelijke doel de gezondheidssituatie van kinderen te verbeteren.

Theoretische achtergrond en doelstellingen

Een aantal belangrijke internationale organisaties, waaronder de World Health Organisation (WHO), de Raad van Europa (RvE) en de European Association for Children in Hospital (EACH) hebben zich reeds gebogen over de vraag hoe goede kindgerichte zorg eruit zou moeten zien en zij hebben aanbevelingen gedaan die richtinggevend zijn voor beleid en de dagelijkse zorgpraktijk. Relevante concepten uit deze beleidskaders zijn samengebracht in een conceptueel kader dat ervan uitgaat dat de participatie van kinderen cruciaal is voor het realiseren van kwalitatief hoogwaardige zorg waarbij het kind en zijn/haar familie centraal staat. Er worden drie niveaus van participatie onderscheiden:

- *Microniveau*: deelname aan individuele besluitvorming. Dit kan bijvoorbeeld gaan om keuzes rondom leefstijl maar ook om betrokkenheid bij medische besluitvorming
- *Mesoniveau*: kinderen moeten de kans krijgen om aan de hand van hun ervaringen feedback te geven op de zorg
- *Macroniveau*: afhankelijk van hun leeftijd en capaciteiten moeten kinderen betrokken worden bij planning en beleid van de diensten die zij gebruiken.

Daarnaast gaat het conceptuele kader ervan uit dat de opvattingen en gewoonten van zorgprofessionals en ouders van grote invloed zijn op het realiseren van kind- en gezinsgerichte zorg. In de eerste plaats zijn zij degenen die kinderen adequate zorg en steun geven, maar zij hebben ook een belangrijke rol in het participatieproces. Vanzelfsprekend zijn er nog veel meer factoren van invloed op het realiseren van kindgerichte zorg. In de huidige studie richt ik mij specifiek op de vraag hoe de participatie van kinderen en ouders kan bijdragen aan het optimaliseren van de kwaliteit van kindgerichte ziekenhuiszorg, in aanmerking nemend dat de kindergeneeskunde per definitie gegrond is in een driehoeksrelatie tussen kind, ouder(s) en zorgverlener. Er zijn drie studiedoelstellingen geformuleerd:

1. Begrijpen wat kinderen en ouders verstaan onder goede kwaliteit van ziekenhuiszorg en hoe hun perspectieven overeen komen met bestaande beleidskaders voor kind- en gezinsgerichte zorg.
2. De perspectieven van gezondheidszorgprofessionals op kinderparticipatie in het ziekenhuis begrijpen.
3. Begrijpen welke methoden geschikt zijn voor het faciliteren van betekenisvolle participatie van kinderen op verschillende niveaus van besluitvorming in de gezondheidszorg (micro, meso, macro)

Methodologie

Ik heb voornamelijk een kwalitatieve onderzoeksopzet gevolgd waarbij ik gebruik heb gemaakt van participatieve onderzoeksmethoden alsmede traditionele kwalitatieve dataverzamelingsmethoden. Participatieve methoden vinden hun oorsprong in collaboratieve en partnerschap methodieken. Collaboratief onderzoek gaat uit van een epistemologische positie die niet alleen het agentschap van kinderen erkent, maar ook beoogt dat kinderen een stem moeten hebben in onderzoek dat hen aangaat. Het pleit voor een consistente samenwerking met kinderen in sommige of alle fasen van een onderzoeksproject. In deze studie werden participatieve onderzoeksmethoden gebruikt om de kwaliteit van ziekenhuiszorg te evalueren vanuit het perspectief van het kind (eerste studiedoel). Daarnaast werd onderzocht in hoeverre dergelijke methodieken geschikt zijn om zinvolle participatie van kinderen op verschillende niveaus van besluitvorming te faciliteren (derde studiedoel). Kwalitatieve onderzoeksmethoden, waaronder semigestructureerde interviews en focusgroep discussies, werden gebruikt om het tweede doel van de studie te adresseren. Deze methoden zijn in het bijzonder geschikt om inzicht te krijgen in de ervaringen, betekenissen en standpunten van individuen met betrekking tot complexe omstandigheden zoals ziekte, behandeling en ziekenhuisopname.

Resultaten

Perspectieven van kinderen en ouders op de kwaliteit van ziekenhuiszorg

Door te focussen op wat kinderen en ouders te zeggen hebben in plaats van enkel op wat de onderzoekers willen weten, heeft deze studie díe aspecten van zorg geïdentificeerd die het meest belangrijk zijn voor kinderen, jongeren en hun families. Er zijn **zes domeinen** die eruit springen. Het **eerste** domein gaat over de attitudes van ziekenhuisstaf, zoals respect, aandacht en vriendelijkheid. De deelnemers benadrukten dat artsen, verpleegkundigen en ander personeel deskundig en professioneel moeten handelen, zonder daarbij de menselijke kant van de zorg uit het oog te verliezen. Wanneer er geen balans is tussen 'hart, hoofd en handen' zijn de ervaringen van kinderen en ouders voornamelijk negatief. In dergelijke situaties toonden professionals weinig empathie voor de gevoelens van patiënten, werden er beslissingen genomen zonder met kinderen en ouders te overleggen, werd er niet naar hun meningen geluisterd en werd er haastig of onzorgvuldig gehandeld. Het **tweede** domein weerspiegelt de wens van kinderen voor effectieve communicatie. Voor kinderen betekent dit goed geïnformeerd zijn, rechtstreeks aangesproken worden door zorgverleners en een goede samenwerking en communicatie tussen verschillende professionals, onder wie professionals van andere afdelingen, zoals anesthesiologen, chirurgen en spoedeisende hulp (SEH) artsen. Het **derde** domein heeft betrekking op de behoefte van kinderen om ondersteund en afgeleid te worden door pedagogisch medewerkers tijdens medische procedures, zoals bloedprikken, het inbrengen van een infuus en het toedienen van injecties en algehele narcose. Vooral buiten de kinderafdeling, bijvoorbeeld op de chirurgie en SEH, kan de voorbereiding en begeleiding wat kinderen betreft een stuk uitgebreider. Het **vierde** domein gaat over een kindvriendelijke ziekenhuisomgeving. De opmerkingen van kinderen hadden specifiek betrekking op de recreatieve voorzieningen, het slechte ziekenhuiseten, de inrichting en decoratie van de kinderafdeling en het gebrek aan privacy. Het **vijfde** domein betreft het onderhouden van contacten met ouders, familie en vrienden. Kinderen vertelden dikwijls dat ze blij waren wanneer hun vader of moeder mocht blijven slapen en wanneer ze bezoek kregen van vriendjes en leeftijdsgenootjes. Adolescenten benadrukten tevens de noodzaak om gebruik te kunnen maken van hun mobiele telefoon en het internet om te communiceren met mensen buiten het ziekenhuis. Het **zesde** domein – gehoord worden en een stem hebben in de zorg – raakt aan het kerndoel van dit proefschrift. Hoewel het principe van kinderparticipatie in hoge mate wordt ondersteund door bestaande beleidskaders voor kindgerichte zorg, hebben zowel kinderen als ouders in deze studie regelmatig naar voren gebracht dat hun ervaringskennis meer gewaardeerd en in aanmerking genomen zou mogen worden door medisch professionals. Niemand weet immers beter hoe het is om als kind in het ziekenhuis te liggen dan kinderen zelf.

Perspectieven van professionals op kinderparticipatie in het ziekenhuis
Professionals in de gezondheidszorg hebben een aanzienlijke invloed op het proces van kinderparticipatie. Onze bevindingen laten echter zien dat de term 'kinderparticipatie' door professionals amper gebruikt wordt. Toch voelen ze zich vertrouwd met de ideeën die aan het concept ten grondslag liggen en zij beschouwen het als de kern van hun werk. Volgens de geïnterviewden is de essentie van kinderparticipatie om kinderen zoveel mogelijk actief te betrekken bij de individuele besluitvorming over de behandeling en hun verblijf in het ziekenhuis. Professionals zijn van mening dat een hoge mate van participatie mogelijk is bij eenvoudige beslissingen die relatief weinig gevolgen hebben voor de gezondheid van het kind, waaronder beslissingen over de basiszorg en keuzes over de zorgverlening (microniveau). Deelname aan medische besluitvorming wordt als meer complex beschouwd en professionals plaatsen hier serieuze restricties en kanttekeningen bij vanwege de consequenties van dergelijke beslissingen voor de gezondheid en welzijn van het kind.

Op twee uitzonderingen na zeiden professionals dat ze niet gewend zijn om kinderen te vragen hun ziekenhuiservaring te evalueren (mesoniveau) of hen te betrekken bij beleidsprocessen (macroniveau). Professionals erkennen het gebrek aan specifieke evaluatiestrategieën voor kinderen als een tekortkoming. Zij hebben het gevoel dat kinderen dingen vaak anders waarnemen of zich op andere aspecten van de zorg richten dan hun ouders. De deelnemers uitten een sterke behoefte aan passende methoden om de ziekenhuiszorg te evalueren vanuit het perspectief van kinderen en adolescenten. Bovendien benadrukten zij de noodzaak dat het recht op kinderparticipatie ook op andere afdelingen, zoals de chirurgie en de SEH, beter wordt nageleefd.

Methoden voor betekenisvolle participatie
Dit onderzoek heeft kennis opgeleverd over geschikte methoden voor het faciliteren van kinderparticipatie op verschillende niveaus van besluitvorming in de gezondheidszorg (micro, meso, macro). We hebben een aantal strategieën en instrumenten geïdentificeerd die artsen, verpleegkundigen en pedagogisch medewerkers hebben ontwikkeld om ervoor te zorgen dat kinderen kunnen participeren in individuele consultaties (microniveau). Pedagogisch medewerkers gebruiken verschillende methoden om kinderen te ondersteunen bij het uiten van hun mening. Deze methoden varieerden van het stellen van algemene vragen zoals 'Is er iets dat je nodig hebt?' tot speciaal ontworpen "pijnpaspoorten" waarin kinderen persoonlijke rituelen, specifieke

wensen en copingstrategieën kunnen opschrijven die ze in de loop der tijd ontwikkeld hebben tijdens pijnlijke situaties. De geïnterviewden vertelden dat kinderen vaak inbreng mogen geven over hoe en wanneer bepaalde procedures worden uitgevoerd. Ze bieden alternatieve opties, bijvoorbeeld de keuze tussen een kapje of een injectie voor het toedienen van de anesthesie. Ook geven ze kinderen vaak de gelegenheid om de timing van invasieve procedures te bepalen en om te bepalen wie hen daarbij gezelschap houdt.

Professionals geven aan dat ze voor feedback over de geleverde kwaliteit van zorg en dienstverlening terugvallen op ouders (mesoniveau). Deze studie heeft een aantal methoden/instrumenten geïdentificeerd die geschikt zijn voor het verkrijgen van betekenisvolle feedback van kinderen over hun ervaringen met de zorg en hun ziekenhuisopname. Deze methoden zijn Photovoice, online/face-to-face interviews, brief aan de directeur en de Ervaringsmonitor. De onderzochte methoden hebben met elkaar gemeen dat ze kinderen in staat stellen om hun mening te uiten op een manier die past bij hun mogelijkheden en voorkeuren en hen helpt om hun verhaal te vertellen vanuit hun eigen unieke perspectief. Daarnaast genereert de Photovoice-methode visuele metaforen van wat de kinderen willen zeggen, waardoor meer empathie wordt gecreëerd dan met woorden alleen. De methoden verschillen in de mate waarin diepgaand en gecontextualiseerd inzicht in de leefwereld van kinderen wordt verkregen, de mate waarin het proces bijdraagt aan empowerment van kinderen en de mate waarin de ideeën van kinderen worden opgevolgd.

De participatie van kinderen op hogere niveaus van besluitvorming, waaronder het opstellen van onderzoeksagenda's en het ontwikkelen van klinische richtlijnen (macroniveau), wordt onderschreven door internationale organisaties zoals de WHO en UNICEF. Onze bevindingen wijzen er echter op dat kinderen in de praktijk nauwelijks deelnemen aan de planning en beleidsprocessen van de diensten die ze gebruiken. In Nederland bijvoorbeeld staat het betrekken van kinderen bij richtlijnontwikkeling nog in de kinderschoenen, terwijl dit voor volwassenen steeds meer gemeengoed wordt. Veel richtlijnontwikkelaars beschouwden de participatie van kinderen in richtlijnontwikkeling als een uitdaging en zij hebben twijfels en vragen over de bekwaamheid van kinderen om hieraan deel te nemen, zoals: beschikken kinderen over de juiste vaardigheden? Vanaf welke leeftijd kunnen zij betrokken worden? Is het niet te veeleisend voor hen? Hoe moet het georganiseerd worden? Dergelijke vragen zijn nog niet beantwoord voor volwassenen, maar staan centraal bij het faciliteren van participatie van kinderen. Ondanks alle vragen en moeilijkheden erkenden professionals wel het belang en de voordelen van kinderparticipatie en zij verwelkomen verdere verkenningen van de mogelijkheden om kinderen te betrekken bij richtlijnontwikkeling.

Discussie & Conclusie

In de afgelopen drie decennia is steeds meer erkenning gekomen voor het feit dat kinderen niet enkel objecten zijn van zorg, maar goed geïnformeerde maatschappelijke actoren die het recht hebben om inspraak te hebben in medische beslissingen die hen aangaan. In de praktijk is het faciliteren van betekenisvolle participatie van kinderen en jongeren echter behoorlijk complex. Deze studie heeft als doel om beter te begrijpen hoe de participatie van kinderen en hun ouders kan bijdragen aan het versterken van de kwaliteit van kind- en gezinsgerichte zorg in Nederlandse ziekenhuizen.

Het evalueren van de kwaliteit van zorg vanuit het perspectief van kinderen en jongeren vergroot het bewustzijn en begrip voor de ervaringen en dagelijkse realiteit van kinderen. De lessen die wij uit deze ervaringen getrokken hebben zijn direct relevant voor de klinische praktijk. Een aantal van de domeinen die door kinderen en ouders naar voren zijn gebracht, onderschrijven huidige ‘good practices’, zoals onbeperkte bezoektijden op de kinderafdeling, de mogelijkheid voor ouders om bij hun kind te blijven slapen en de cruciale rol van pedagogisch medewerkers. Enkele andere kwaliteitsindicatoren die door de deelnemers aan dit onderzoek zijn genoemd onderschrijven het belang van interventies om de ziekenhuiszorg beter te laten aansluiten bij de behoeften van jonge patiënten. Veel van de geïdentificeerde verbeterpunten zijn door ziekenhuizen direct opgepakt. Voorbeelden zijn het blinderen van ramen en deuren, zodat kinderen meer privacy hebben, en het ontwikkelen van kindvriendelijke menu’s die werden geproefd door een speciaal testteam. Andere actiepunten konden niet direct worden opgepakt, maar krijgen momenteel aandacht of zijn hoog op de agenda geplaatst. Dit toont aan dat participatieve methoden niet enkel geschikt zijn als instrumenten voor het in kaart brengen van ervaringen; ze hebben ook de potentie om veranderingen te bewerkstelligen waar kinderen van profiteren.

Vanuit theoretisch oogpunt is het perspectief van kinderen en ouders op de kwaliteit van ziekenhuiszorg een waardevolle aanvulling op reeds bestaande standaarden en beleidskaders. Sommige kwaliteitscriteria die door kinderen en ouders in deze studie naar voren zijn gebracht, ontbreken in één of meerdere van de bestaande kwaliteitsstandaarden (zie theoretische achtergrond). Het belang van afleiding en begeleiding bij invasieve medische procedures werd door kinderen in deze studie bijvoorbeeld herhaaldelijk genoemd, maar dit kwaliteitscriterium komt in geen van de drie beleidskaders expliciet terug. Bovendien is de perceptie van kinderen op de kwaliteit van zorg waardevol voor het verfijnen en operationaliseren van bestaande kwaliteitsnormen en standaarden. Er wordt bijvoorbeeld in het algemeen verondersteld dat kinderen recht hebben op een ‘kindvriendelijke’ ziekenhuisomgeving. Kinderen in deze studie specificeerden wat dat voor hen onder andere betekent: kleurrijke kamers en gangen, een groot aanbod aan recreatieve activiteiten en in staat zijn om goed te kunnen slapen.

De percepties van kinderen en ouders op ‘goede zorg’ ondersteunen tot slot het besef dat de ervaringen van patiënten een belangrijke pijler van kwaliteit zijn. Met uitzondering van de kindvriendelijke ziekenhuisomgeving hebben de domeinen die kinderen en ouders benoemen vooral betrekking op relationele aspecten van zorg (zoals bejegening en communicatie), in plaats van functionele aspecten, zoals continuïteit, toegankelijkheid en *evidence-based care*. De erkenning dat kwalitatief goede zorg meer is dan alleen technische zorg, ondersteunt bredere definities en evaluaties van kwaliteit. Niemand kan de relationele aspecten van zorg immers beter beoordelen dan de patiënt zelf. In die zin kan de kwaliteit van pediatrische ziekenhuiszorg aanzienlijk worden verbeterd door het (structureel) inzetten van participatieve evaluatiemethoden. Niet enkel cijfers maar juist ook de daadwerkelijke ervaringen van patiënten zijn van grote waarde voor het monitoren en verbeteren van de kwaliteit van zorg.

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