

# Geschiktheid van een kinderafdeling

geschikt tot welke leeftijd?



orginele titel: Appropriateness of a peadiatric ward



Stichting Kind en Ziekenhuis bevordert al ruim 40 jaar kindgerichte medische zorg vanuit het perspectief van kind en ouders in het ziekenhuis, thuis of elders. De kinderstem en daarmee de rechten van het kind vertegenwoordigen wij vanuit de visie Handvest Kind & Ziekenhuis en Kind & Zorg. In grote mensen taal Kind & Ziekenhuis Het recht op een Kind & Zorg Zieke kinderen hebben het fundaoptimale medische behandeling is ook voor kinderen mentele recht op kindgerichte zorg, wat zoveel betekent een fundamenteel recht. als gezinsgerichte zorg en ontwikkelingsgerichte zorg. Zieke kinderen en hun ouders worden te allen tijde gestimuleerd om hun behoeften en wensen ten aanzien van Kinderen worden niet in een ziekenhuis opgenomen als de zorg die zij nodig hebben thuis, in dagbehandeling of poliklinisch kanworden verleend. de zorg kenbaar te maken en over de zorg mee te beslissen. Zieke kinderen worden altijd verpleegd en behandeld door professionals die specifiek voor deze zorg aan kinderen zijn opge-leid. Die professionals beschikken over de kennis en ervaring die nodig is om ook aan de emotionele psychologische en spirituele behoeften van het kind en het gezin tegemoet te komen. Kinderen hebben het recht hun ouders of verzorgers altijd bij zich te hebben Ouders wordt accommodatie en de mogelijkheid tot overnachting naast het kind aangeboden zonder dat daar kosten voor in rekening worden gebracht. Ouders worden geholpen en gestimuleerd bij het kind te blijven en deel te Zieke kinderen worden niet in een ziekenhuis opgenomen. als de zorg die zij nodig hebben ook in dagbehandeling, poliklinisch of thuis kan worden verleend. nemen aan de verzorging en verpleging van het kind. Kinderen en ouders hebben recht op informatie. De informatie Zieke kinderen hebben mogelijkheden om te spelen, zich te vermaken en zich te ontwikkelen, al naar gelang hun leeftijd wordt aangepast aan leeftijd en bevattingsvermogen van het kind. Maatregelen worden genomen om pijn, lichamelijk ongemak en emotionele spanningen te verlichten. 4 en lichameliike conditie. Het is voor zieke kinderen altijd mogelijk om hun ouders of verzorgers bij zich te hebben, waar zij ook behandeld en/ of verpleegd worden. Ze hebben recht op verblijf in een stimulerende, veilige omgeving waar voldoende toezicht is en Kinderen en ouders hebben recht op alle informatie die noodzakelijk is voor het geven van toestemming voor onderzoeken, ingrepen en behandelingen. Kinderen worden beschermd tegen overbodige behandelingen en onderzoeken en tegen oneigenlijk gebruik van persoonlijke gegevens. die berekend is op kinderen van hun eigen leeftijdscategorie. Kinderen worden in het ziekenhuis gehuisvest en verzorgd Zieke kinderen hebben recht op bescherming tegen alle samen met kinderen in dezelfde leeftijds- en/of ontwikkelings-fase. Kinderen worden niet samen met volwassenen verpleegd. 6 vormen van lichamelijke en geestelijke mishandeling en/of verwaarlozing zowel in het gezin als daarbuiten. Er bestaat geen leeftijdsgrens voor bezoekers. Kinderen hebben recht op mogelijkheden om te spelen, zich te vermaken en onderwijs te genieten al naar gelang hun leeftijd en lichamelijke conditie. Kinderen hebben recht op verblijf in een stimulerende veilige omgeving waar voldoende toezicht is en die Elk ziek kind en ieder lid van een gezin met een ziek kind wordt benaderd met tact en begrip en hun privacy wordt te allen tijde gerespecteerd. berekend is op kinderen van alle leeftijdscategorieën. Kinderen worden behandeld en verzorad door medisch Een ziek kind wordt verpleegd en behandeld door zoveel Nitueren worden behandeld en verzorgd door medisch, verpleegkundig en ander personeel dat speciaal voor de zorg aan kinderen is opgeleid. Het beschikt over de kennis en de ervaring die nodig zijn om ook aan de emotionele eisen van het kind en het gezin tegemoet te komen. nogelijk dezelfde personen die onderling samenwerken in een multidisciplinair team en individueel en vanuit het team op een open en eerlijke manier communiceren met het kind en het gezin. Zieke kinderen worden beschermd tegen onnodige Kinderen hebben recht op verzorging en behandeling door behandelingen en onderzoeken en maatregelen worden genomen om pijn, lichamelijk ongemak en emotionele zoveel mogelijk dezelfde personen, die onderling optimaal samenwerken. spanningen te voorkomen dan wel te verlichten. Elk ziek kind en leder lid van een gezin met een ziek kind wordt gedurende het hele zorgtraject, van diagnose tot eventueel overlijden, voorzien van correcte en relevante informatie die Kinderen hebben het recht met tact en begrip te worden benaderd en behandeld. Hun privacy wordt te allen tijde gerespecteerd. op een voor hen begrijpelijke manier wordt verstrekt

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### List of Abbreviations

Abbreviation	Full description
UNCRC	United Nations Convention of the Rights of the Child
UN	United Nations
CCC	Child-Centred Care
FCC	Family-Centred Care
EACH	European Association for Children in Hospitals
Kind&Ziekenhuis	Stichting Kind en Ziekenhuis



### 1 Nederlandse Samenvatting

De Verenigde Naties Conventie voor de Rechten van het Kind is het meest geratificeerde verdrag in de geschiedenis van de rechten van de mens. Kinderen over de hele wereld hebben gezondheidszorg nodig en hoewel arme landen andere dingen nodig hebben dan rijkere landen, wil de VN goede gezondheidszorg voor alle kinderen. Deze studie heeft met name gefocust op de zorg voor kinderen in Nederlandse ziekenhuizen.

Hoewel het verdrag de rechten van zieke kinderen duidelijk weergeeft, worden die rechten nog niet overal geïmplementeerd en heeft kindzorg nog niet overal een prioriteit. Dit wordt vooral duidelijk in ziekenhuizen waar kinderen op volwassenafdelingen of volwassenen op kinderafdelingen mogen verblijven.

Daarom was het doel van deze studie om te achterhalen of kinderafdelingen de juiste vorm van medische zorgverlening aan kinderen zijn. De voor- en nadelen van kinderafdelingen voor kinderen van verschillende leeftijden en de leeftijdslimiet werden geëvalueerd door te identificeren wat verschillende stakeholders (kinderen, ouders en medische zorgprofessionals) belangrijk vinden in de context van kindzorg.

Een mixed-methods design is gebruikt. Kwalitatieve interviews werden gehouden met kinderen, ouders en zorgprofessionals. De thema's die belangrijk bleken uit deze interviews werden omgezet in een vragenlijst, om de resultaten te testen bij een groter publiek.

De resultaten wezen uit dat alle deelnemers het eens waren over het belang van de integratie van kinderen en ouders als het centrum van de zorg. Zorg moet rondom de emotionele en fysieke behoeften van het kind heen gepland worden en ze worden meegenomen in de beslissingen rondom hun zorg. Kinderen moeten zich comfortabel en veilig voelen. Ook moet de informatie die ze krijgen aangepast worden aan hun leeftijd en niveau (belevingswereld) en tevens begrijpelijk zijn voor ouders. Zij moeten namelijk beiden begrijpen wat de situatie is en goede uitleg en voorbereiding kan angst en pijn verminderen. Een ander aspect dat belangrijk bleek te zijn is dat kinderen altijd verzorgd worden door zorgprofessionals die daar in gespecialiseerd zijn. De promotie van zelfstandigheid bleek tevens erg belangrijk en hier werd ook een verbeterpunt aangestipt, aangezien kindzorgverleners kinderen nogal kunnen betuttelen. Deelnemers waren het niet eens over de geschiktheid van de zorg voor kinderen op volwassenafdelingen. Over het algemeen was de conclusie wel dat kinderen alleen op volwassenafdelingen verzorgd kunnen worden in uitzonderlijke gevallen. Ook over de leeftijdsgrens van kinderafdelingen waren deelnemers het niet eens. Hoewel sommigen geen bezwaar hadden tegen het opnemen van jongvolwassenen op kinderafdelingen als zij dat willen, vonden anderen dat dit de veiligheid van de kinderen in gevaar brengt. Zij vinden dat hoewel jongvolwassenen ook speciale behoeften hebben en geen volwassenen zijn, een andere oplossing voor hen gevonden moet worden. Denk hierbij aan het creëren van een speciale adolescentenafdeling of het verbeteren van de transitie naar volwassenenzorg.

De kwantitatieve resultaten waren over het algemeen in lijn met de kwalitatieve resultaten.

**Concluderend**, is de kinderafdeling de juiste vorm van zorg voor kinderen tot 18 jaar. Het voordeel van de kinderafdeling is dat ze aan bijna alle behoeften van kinderen voldoen waar een volwassenenafdeling dat niet doet. Momenteel zijn de grootste nadelen dat de kinderafdeling nogal betuttelend kan zijn en dat de transitie naar volwassenzorg nog niet voldoende is. Deze studie bewees ook dat jongvolwassenen andere behoeften hebben en dat de kinder- en volwassenafdeling niet de juiste plek voor hen is.



Vergelijkingen tussen de resultaten en de actuele literatuur zijn gemaakt met betrekking tot het betuttelen van kinderen, de transitie naar volwassenzorg en adolescentiegeneeskunde. Het werd duidelijk dat deze onderwerpen populair zijn in veel landen over de hele wereld en dat er meer onderzoek en aandacht nodig is om oplossingen te vinden.

#### De volgende aanbevelingen zijn gedaan:

- 1. Kinderen dienen verpleegd te worden op kinderafdelingen.
- 2. Kinderafdelingen dienen minder betuttelend te worden.
- 3. Er dient meer aandacht gegeven te worden aan het verbeteren van de transitie naar volwassenzorg.
- 4. Het concept van adolescentiegeneeskunde dient verder verkend te worden.



# 2 Engelse Samenvatting

The United Nations Convention of the Rights of the Child (UNCRC) is the most widely ratified treaty in the history of human rights. Children all around the world require healthcare, and while low and middle income countries have other needs and priorities than high income countries, the United Nations (UN) want to ensure health for all children. This study will focus on care for children in hospitals in particular.

While a charter with the rights of sick children, based on their physiological and psychological needs, was made by the UN and the Association for Children in Hospitals, it is not implemented widely yet and paediatric care remains under prioritised. This becomes evident in hospitals where children are admitted to adult wards or adults are admitted to paediatric wards.

Therefore, the objective of this study is to assess to what extent paediatric wards are the appropriate form to provide healthcare for children. The advantages and disadvantages of the paediatric ward for different age categories and age limit were evaluated by identifying what aspects different stakeholders (children, parents and healthcare providers) value in the context of paediatric care and how a paediatric ward can secure these aspects.

A mixed-methods design was used. Semi-structured one-on-one interviews were conducted with children, parents and healthcare providers. After analysis of these results, a questionnaire containing 10 statements about important aspects of paediatric care was created and broader group of participants were asked to rate to what extent they agreed to them for different age categories.

Results showed that all participants agreed that the integration of children and their families in care was important. Care should be planned around the emotional and physical needs of the child and they should be involved in the decision making process. Children have to feel comfortable and safe. Moreover, information must be adjusted to the level of children and parents at all times. They need to understand their situation and sufficient explanation and preparation to procedures can minimise pain and fear. Another aspect deemed important by all participants was that children are cared for by paediatric healthcare providers. Promotion of independence was shown to be important as well, yet this shed light on a point of improvement for paediatric care, as paediatric healthcare providers tend to be quite patronising towards older children. Participants were divided regarding the appropriateness of care on adult wards, but generally, the conclusion was that children can only be cared for on adult wards in special circumstances. Participants were divided regarding the age limit of paediatric wards as well. While some would not object to young adults being admitted to a paediatric ward if they want, others stated that this could endanger the feeling of safety of other children. They state that young adults might have different needs than adults too, but that other solutions have to be found in the form of adolescent wards or a better transition to adult healthcare.

The quantitative results of the questionnaire that was filled in by children (N = 22), parents (N = 65) and healthcare providers (N = 85) were generally in line with the qualitative results.

**In conclusion**, paediatric wards are the appropriate form of care for children until the age of 18. The advantage of paediatric wards is that they take almost all needs of children into account while adult care does not. Currently, the main disadvantages of paediatric wards are patronising attitudes of care providers and insufficient transition to adult care. This study found that young adults definitely have special healthcare needs as well, however, the paediatric ward does not seem to be the best place for them.



Comparisons to current literature were made regarding to patronising children, transition to healthcare and adolescent medicine. It was found that these key findings were topics of interest in many countries around the world and future research and advocacy is needed to find solutions for them.

#### The following recommendations were made:

- 1. Children should be cared for on paediatric wards.
- 2. Paediatric wards should be less patronising
- 3. More attention should be given to improve the transition into adult healthcare
- 4. The concept of adolescent medicine and specialisation in the field should be explored further.



#### 3 Introduction

#### 3.1 Cause

The United Nations Convention of the Rights of the Child (UNCRC) is the most widely ratified treaty in the history of human rights. Children all around the world require healthcare, and while low and middle income countries have other needs and priorities than high income countries, the United Nations (UN) want to ensure health for all children. Therefore, article 24 states that "Every child has the right to the best possible health." (Unicef United Kingdom, n.d.).

Child health and child healthcare are terms that encompass the mental and physical state of well-being of children in the settings of their home and healthcare centres like hospitals (MedicineNet, 2018). This study will focus on care for children in hospitals in particular. Figaji (2017) stated that children experience a hospital visit or stay differently than adults do as it can be both frightening and stressful. Moreover, the differences between adults and children in both a physiological and psychological perspective are often underestimated by adult physicians and hospital managers, resulting in suboptimal or inappropriate child care. These differences lead to special healthcare needs during hospitalization.

In the past years, some researchers have focussed on the physiological differences between children and adults and therewith on the extra precautions to be taken when treating children (Figaji, 2017). The Centre for Disease Control (2019) described that children are more likely to get sick or injured as they have thinner skin and less fat to protect their bones and organs. Moreover, the risk for hypothermia is greater in children, as they have a larger relative body surface, and fluid loss affects them more. Furthermore, small children suffer from airway obstruction more and the blood pressure and development status of internal organs differs per age category (CDC, 2019). Figaji (2017) claims that treating children brings more difficulties due to these physiological differences, resulting in a need for specialised paediatric care professionals.

With regards to the psychological differences, children deal with sickness and hospitalisation in different ways than adults (Boztepe, Çınar, & Ay, 2017). When these differences are not recognized by the caregivers, hospitalisation can have negative effects. A number of classic studies conducted in the second half of the 20th century showed these negative effects (Imelda Coyne & Conlon, 2007; McClowry, 1988; Visintainer & Wolfer, 1975). Children cannot express themselves in the same way as most adults can and might not be able to communicate where they are hurting and what they feel, which negatively influences the quality of treatment. Moreover, due to their young age, they might lack experience on how to cope with stress, which increases the impact of mental stress on children (CDC, 2019).

Moreover, many children experience feelings of fear and discomfort during and prior to their stay in the hospital. Coyne & Conlon (2007) have illustrated the main agents driving this fear and discomfort across different age categories. The most common ones include; not knowing what is going to happen; noisy and bright wards; being bored; lack of privacy; needles and blood tests and lastly being alone. Studies from Coyne & Colon (2007) and Öztürk & Topan (2018) show that children of all ages experience these fears and discomforts, however, some are more common in young children and some are more common in teens. Furthermore, several studies illustrated that the discomfort resulting from separation from parents has a particular big influence on young children. Therefore, they benefit a lot from continuity and regular contact with the same care givers, as it gives a sense of familiarity (Boztepe et al., 2017; Carney et al., 2003; Schalkers, 2016). Besides this regularity in contact with caregivers, presence of parents was shown to be important. Not only should the child be able to be around its family, the child and parents should also be integrated in the healthcare process. This is called child-centred care (CCC) and family-centred care (FCC) and will be elaborated on in next chapters (Ford, Campbell, Carter, & Earwaker, 2018). The differences in healthcare needs between adults and children have been recognized by the UN and the European Association for Children in Hospitals (EACH), A charter stating 10 rights for children in hospitals was formed and is in line with the UNCRC (European Association for Children in Hospital, n.d.). This charter includes the statement that children should be admitted to a paediatric ward which is defined as a hospital unit to which only children are



admitted. The staff is specialised in paediatric care and they give extra attention to the child's needs (HealthyChildren.org, 2015). This helps to solve problems of lack of specialised medical knowledge and preventable mental stress resulting from hospitalisation. Despite the fact that the quality of child healthcare has improved a lot over the years, the paediatric ward remains under prioritized in some cases. This can be seen in the admission of children on adult wards or the admission of adults on paediatric wars, which goes against the charter protecting hospitalised children mentioned above and leads to suboptimal child healthcare. Moreover, many stakeholders with different interest are involved in this matter – eg. children, family, paediatricians, hospital board members etc. –(Turchi et al., 2014) and while many have studied aspects of child hospitalisation, none have been able to give a comprehensive overview of the interests of all the stakeholders in the matter of the appropriateness and therewith the possible importance of a paediatric ward.

Therefore, the objective of this study is to assess to what extent paediatric wards are the appropriate form to provide healthcare for children. To answer this question, the advantages and disadvantages of the paediatric ward for different age categories need to be evaluated by identifying what aspects different stakeholders (children, parents and healthcare providers) value in the context of paediatric care and how a paediatric ward can secure these aspects. Because previously mentioned literature suggest that older children experience negative effects from hospitalisation too, all children, meaning until the age of 18, will be included in this study. With this information, the appropriateness of care on a paediatric ward can be assessed and could therewith serve as a basis for future reforms to optimize child healthcare. Moreover, the study will assess whether young adults would benefit from the specialised care on a paediatric ward or whether adult wards are more appropriate for them.

#### 3.2 Background

#### 3.2.1 Historical Background of Paediatric Wards

Before the nineteenth century, children's health was generally viewed a mother's responsibility and medical institutions hardly focussed nor admitted children as they were costly and required a lot of attention. However, in a number of large cities, charity-based institutions were found to care for the abandoned and sick children. These informal hospitals did not only nurse children back to health, but also taught them skills to prepare them for adult life (Coram, n.d.; Golding, 2007).

Due to high child mortality, social reformers and physicians advocated for better child health and the first paediatric hospital opened in 1802. Others followed soon. While at first, family merely had a visiting role, midway through the nineteenth century, adverse effects of separation from family became apparent and the advantages of family-centred care (FCC) were increasingly recognised (Kuo et al., 2012).

In 1988, the EACH created a charter that specified the rights of sick children, which was in line with the UNCRC. The charter focusses, among other things, on the right of children to be cared for at home as much as possible, the presence of parents and the integration of children and family in the care process (European Association for Children in Hospital, n.d.). While the Netherlands ratified the UNCRC in 1995, they did not sign the EACH charter and its contents are not implemented everywhere yet (Stichting Kind en Ziekenhuis, n.d.-a).

#### 3.2.2 Present Day Paediatric Wards

In the last decades, many institutions like Kind&Ziekenhuis and the Ronald McDonald House Charity have committed themselves to improve hospitalisation of children for both families and the children themselves (Ronald McDonald Kinderfonds Nederland, n.d.). Moreover, paediatric hospitals have tried to improve the situation of children in hospitals as well. Some problems however, are not dealt with sufficiently yet, like the participation of parents and children in decision making on their treatment. Moreover, according to Carney et al. (2003), being heard is crucial for children. So while FCC is advocated for, there is a need to



promote child-centred care (CCC) as well (Ford et al., 2018). both of these concepts will be explained further in the next chapter.

Not only the interest of children, but also those of the hospitals themselves play a role in the care for children. Kuo et al. (2011) described that financial issues might restrict paediatric care. Moreover, they state that a lack of academic knowledge negatively affects the quality of paediatric care.

#### 3.3 Contextual framework

#### 3.3.1 Definition of a Child

Before diving into the theoretical background of paediatric wards, some concepts need to be defined. The first and foremost concept of this study is that of the child. Following the definition in the UNCRC, a child is a person below the age of 18 unless the law indicates another age (UNICEF, n.d.). All children are protected by the UNCRC regardless of their age. This means that a child of almost 18 years old is just as well protected by these rights as a 4year-old. And that they deserve to be treated accordingly (Kinderrechtencollectief, n.d.). The National Academy of Sciences, Engineering, and Medicine (2015) states that a child can also be defined by characteristics, instead of just by age. Some main characteristics are that children develop constantly and they all develop at different rates. Because they are still developing, experiences during childhood can affect them greatly on the short- and long term. Furthermore, children are more sensitive to their environments than adults are. Also, children are curious and want to explore the world. This phenomenon is present in children from all age categories. How children learn is different per age category however. So the way in which children should be addressed has to be different as well. While older children that are verbally strong look for vocabulary input, younger children learn from touching, feeling and looking at the things surrounding them. Finally, because of the continuous development, children benefit from structure and continuity in the people surrounding them (National Acedemy of Sciences, Engineering and Medicine, 2015). Clarifying this definition might seem redundant, however it is of great importance to realize that not only small children, but also teenagers require extra care when facing hospitalization and they should therefore not be forgotten (Imelda Coyne, Amory, Kiernan, & Gibson, 2014). To make sure that health seeking behaviour among teenagers is promoted, appropriate paediatric care for teenagers should be encouraged (Boersema, Wyk, & Louw, 2019).

#### 3.3.2 Family-centred and Child-centred Care

Subsequently, a distinction should be made between the concepts of FCC and CCC. Ford et al. (2018) defined FCC as: "a way of caring for children and their families that ensures health care is planned around the whole family, not just the individual child/person." (page 845). And CCC as: "care that situates children and their interests at the centre of thinking and healthcare practice and involves the inclusion of children and young people as participants in their care and decision-making." (page 845). In the 1950s, FCC emerged as a preferred healthcare approach, which meant a reform of the existing care structures of doctors and nurses as they had to build their routines around the family. However, following this approach, only care providers and parents were seen as active participants in the healthcare process. Children were thought not to be mature enough to participate and were merely seen to play a passive role (Imelda Coyne, Hallström, & Söderbäck, 2016). In the early 21st century, the CCC approach gained acceptance after the release of the Bristol Royal Infirmary Inquiry Report that placed children at the centre of care together with their families. Currently, a shift from FCC to a combination of FCC and CCC is happening to secure the rights of the children (Ford et al., 2018).

One of the main problems with the parents being the centre of the FCC approach, is the difference between the child's and the child perspective. The child's perspective is the view



of children themselves on what is happening around them. Young children are not always able to express themselves sufficiently. Therefore, the view of adults on what children need and experience, the child perspective, is often used (Imelda Coyne et al., 2016). However, as Schuster (2015) explained, this adult perspective often is not an accurate description of how the child actually feels (Schuster, 2015).

#### 3.4 Stichting Kind en Ziekenhuis

Kind&Ziekenhuis is an independent patient organisation for children in medical health care. We stimulate child and family centred care from the perspectieve of the child and their parents. The rights of all sick children and their parents, regardless of the severity of their disease (Stichting Kind en Ziekenhuis, n.d.-b) is promoted vai the EACH Charter. Kind&Ziekenhuis needs sufficient academic indications of what is important for children in order to advocate for their rights. Therefore, this study will be conducted.

#### 3.5 Research questions

The proposed framework (see appendix 1.) can serve as a guide to assess whether paediatric wards offer what is needed to provide good healthcare to children. In order to answer the question 'To what extent is a paediatric ward the appropriate form to provide care to children?' the aspects deemed important to children, parents and healthcare providers have to be identified and the framework can serve as a guide in this process. Moreover, the (dis)advantages of paediatric wards perceived by these stakeholder groups need to be assessed. Furthermore, to assess the appropriateness of care on paediatric wards, the appropriateness of care outside of paediatric wards has to be investigated. Lastly, it has to be studied until what age the aspects of good paediatric healthcare apply. The following research questions are proposed;

#### Main question

To what extent is a paediatric ward the appropriate form to provide care for children and until what age?

#### **Research questions**

- What are the most important aspects of child healthcare for children, parents and healthcare professionals?
- What are the perceived advantages and disadvantages of paediatric wards for children, parents and healthcare professionals?
- Can these aspects be guaranteed outside of a paediatric ward?
- Until what age do these aspects remain important?



#### 4 Results

In the following section the results of both the qualitative and the quantitative data analysis will be provided. Firstly, the qualitative results are described using the theoretical model and codes that show links between the codes from the theoretical model. Secondly, the quantitative results will be described according to the order of the questionnaire.

#### 4.1 Qualitative Results

The results have been organised by the theoretical framework. Results that came forward during the interviews, but did not correspond to any of the framework characteristics characteristics, like age limits, advantages and disadvantages of a paediatric ward will be discussed in the end.

Moreover, the differences and similarities in opinion between participants of different categories has been assessed. For the sake of clarity however, only the differences in opinions will be outlined. When no difference in opinions is specified, it can be assumed that all participants agreed on and raised that topic. With regards to the quotes, the participant that was quoted is indicated by a 'C' if it is a child, a 'P' if it is a parent or a 'HP' if it is a healthcare professional

#### 4.1.1 Child- and Family Integrated Care

All participants agreed that healthcare should be organised around the patient. This entails multiple aspects; (1) the needs of the child, (2) the involvement of parents and family, (3) attention for emotion, (4) fear and comfort, (5) involving them in decision making, and (6) attention for decoration of their surroundings and facilities they can use.

"In the end the most important thing is that we organise around the child." (HP1)

In order to provide appropriate healthcare to children, their needs need to be assessed and be taken into account while forming a treatment plan. A consulted healthcare professional explained that you shouldn't only look at the medical aspects of care:

The most prominent topic within this aspect of healthcare were the medical and emotional needs of children. All interviewees indicated that children have different healthcare needs than adults, which is the reason why children should be treated on separate paediatric units.

"Do you want to put a 15-year old diabetic on a pump all day, which is the best option medically speaking. Or do you tell her that she has to inject insulin twice a day, so that she still can go on school trips or to a bar with her friends." (HP8)

One of the foremost differences is that children are inextricably linked to their parents. Until the age of 16, parents have the legal rights to be involved in medical decision making. Moreover, children are emotionally dependent on their parents. The presence of parents can



make children feel safe in the hospital environment, which is, for most children, unknown and scary. Parents know their child best and are therefore capable of comforting their child.

"Parents know their child best. And the experience of being admitted to a hospital can have a great impact on a child. So they want to have the things and people they trust with them. And usually that's your parents." (HP5)

Medically speaking, children differ from adults a lot. Their anatomy, the recommended doses of medication and procedures have to be child-friendly. Because of these differences, special medical facilities are required. Another difference between adults and children that was brought up often was the fact that children manage *emotions* and *fear* in a different way. Due to their young age, medical procedures can be extremely frightening and there is necessity to prevent future psychological problems.

"So you need the medical knowledge to care for them, but you'll have to know how children handle stress and fear as well. And how you can assist them in that of course." (HP7)

To emotionally support children and to positively impact the healing process, they have to feel comfortable and safe. This can be done by making their rooms into a safe space. No procedures should take place in their rooms and the surroundings and decorations should be adjusted to their age. Also, as has been stated shortly before, the presence and support of parents can contribute greatly to the emotional wellbeing of the child because they know the child and can make them feel safer. Lastly, the knowledge and experience of paediatric staff can contribute greatly to this emotional wellbeing, yet this will be discussed further on.

"I am convinced, yet this is based on my own beliefs only and not on any science, that the wellbeing of children and the capacity to heal as quickly as possible has to do with them feeling comfortable. ... Moreover, I think that feeling safe and comfortable is a central aspect of getting better." (HP1)

Moreover, it is very important to secure that children do not get behind on social or educational levels. This requires facilities that adult wards generally do not offer. Children have to be able to meet and play together in play or teen rooms, yet also need to be given the opportunity to be alone and get some privacy if they want. Also, for them to express themselves, they need to be around peers. Since education is part of children's lives, they should not fall behind on that either, so that they can continue their education with their friends.

"You're already in the hospital and that sucks because you can't be with your friends and classmates. But when you can't even have any contact with other children, you can fall behind even further" (C1)

A side note to all these needs was made by most parents and children. Everyone is different, especially children of different ages, which leads to different approaches for everyone. Many



stated that currently, paediatric wards and its staff is mainly focussed on young children and that teenagers might experience the paediatric ward as childish and feel misunderstood. They need a place that is not decorated for babies where they can play videogames and be themselves. Hence, clustering age categories is important to be able to fulfil the needs of all children.

"Children should be able to be themselves. Moreover, they have different patterns. Young children need to sleep during the day, watch different programs, talk about other things. While teenagers usually are a bit louder. It just isn't a match. If you hear what some teenagers say, you don't want a 12-year old to hear all of that." (HP4)

The last aspect of child and family integrated care is to involve them in decision making. In order for children to grow up to be independent adults and for families to be able to manage the health of the child, both child and family should be involved as equal partners. This aspect will be discussed further in the next section

#### 4.1.2 Comprehensive, Proactive and Planned Care

A shared opinion from almost all participants is that or children to feel safe and comfortable, they have to be aware of their situation at all times and have to know what will happen to them. By informing and preparing them in a child-friendly way, fear can be minimized.

"If a child has to undergo a certain procedure, you can't just say 'Just grit your teeth for a second'. ... You explain what you are going to do to the child, but in the most pleasant way possible." (HP5)

To explain and prepare children – and their parents – well for what is to come, different approaches that are adjusted to the child's development are needed than when you inform adults. Medical information can be difficult to understand for both children and parents. Therefore, an environment in which asking as many questions you want is allowed and in which things are explained multiple times is important.

"Sometimes we explain the new treatment plan five times because most people do not really process everything the first time and parents and children are left with many questions. When the paediatrician has to visit again to explain once more, we do that. This is extremely important because you want to know what is going to happen to your child." (HP3)

Lastly, in light of the involvement in decision making discussed in the previous paragraph, parents can help the medical staff by taking a translating role for their children and they can guard that no mistakes are being made.

"I really think that parents are experts of their child. They know exactly what is normal for their child and what isn't. And they can immediately see whether their child is feeling anxious or not. Moreover, parents often act as translators for their child and that's really important for us, not only for young children." H4



#### 4.1.3 Specialised Care professionals

From the data, it became evident that specialised paediatric care professionals is a requirement for good child healthcare. While their knowledge and experience about the medical aspects, which was mainly mentioned by healthcare professionals, is crucial, their role goes way beyond. The extra attention they give the children, the way they address them, the preparations before procedures and the personal bonds they build with the children makes the children feel safer and more comfortable. Sufficient training in these competences was deemed extremely important for all participants as they recognised that without training in these competences, a nurse would not be able to provide appropriate care for a child.

"It's an entirely different profession. I'm a nurse myself, but I definitely do not have the knowledge to care for children. You have to know the whole body. And the reference values are totally different for adults and children. That's something you'll learn during your specialisation. And it's really important to have that knowledge and experience when you want to deliver quality care for children" (HP6)

Another quality of the paediatric care professionals was shown to be their recognition of the role of parents. They know the importance of parents for their children. Furthermore, they understand how hurt parents can be seeing their child being sick and take this into account by comforting them. Moreover, by involving parents in the care process, as was mentioned before, they show their recognition of the parent role.

"You'll see that specialised paediatric nurses clearly have a different view on the role of parents and that parents and child belong together. And they will secure this immediately. So you see a difference in the way they act, but also in the way they think" (HP4)

Something that was raised by part of the healthcare professionals was that there are cases in which paediatric care professionals might not have the required knowledge. Some diseases or health problems are uncommon in children. When there is a patient with a clinical picture that doesn't suit the paediatric ward, it might be better to transfer this patient to an adult ward where they do have the required knowledge even though the child has not reached the age of 18 yet. Although, these are exceptions.

#### 4.1.4 Promotion of Self-Management and Independence

For most children, being at home with your family is the most comfortable place you can be, especially when they are already feeling sick because they are accustomed to their homely surroundings. Paediatric care professionals therefore strive towards making hospital stays as brief as possible. This can often be accomplished by teaching a parent, or the child if it's old enough, to manage their disease themselves. Although, some healthcare providers and parents raised concerns about the complications of taking up your child's care.

One mother explained that she used to provide all medical home care for her teenage son, but that it caused too many awkward situations and too much involvement in his personal life. Therefore, participants that raised these concerns, stated that parents should be



informed well on the consequences of providing home care for their child. However, most participants had positive attitudes regarding parents taking up part of the care for their child.

Moreover, children have to grow up and gain independence. Data showed that this can be difficult for children that are hospitalised often. Paediatric specialists shared that they tend to patronise children and decisions are often made by medical specialists and parents. To increase the child's independence and to therewith prepare them for adult life, children have to be involved as equal partners. This can be achieved by gradually decreasing the active role of parents and increasingly asking children questions about their well-being and opinions and involving them in conversations more.

"We see a lot of children with chronic illnesses and they will eventually have to become self-sufficient and autonomous adults. However, the medicalised and patronising approach until a high age is hinders this." (HP9)

#### 4.1.5 Cost-Effectiveness of Care

Cost-effectiveness of paediatric wards was only mentioned by a couple of healthcare providers as parents and Children did not mention this topic at all. There is financial and logistical pressure on paediatric wards. They have a fluctuating bed occupancy as the number of planned hospitalisations is low. Since empty hospital beds are expensive, some hospital boards would like to fill these beds with other patients.

Another logistical challenge is clustering of children. Previous paragraphs have highlighted that for children to be able to be themselves, they need to be clustered with peers. One participant explained that clustering might mean that a room for two or more children, can only be used by one child when it is the only child within that age category, which blocks another hospital bed.

#### 4.1.6 Access to Care

Access to care has not been discussed elaborately by any of the participants. However, some did discuss in relation to paediatric wards being full. By these participants, mainly parents and healthcare professionals, the question of the importance of proximity to home was raised. When a paediatric ward is full and the nearest hospital with a paediatric ward is an extra thirty minutes away, one could ask themselves whether it might be better to admit the child to an adult ward. However, the age of the child and the duration of the hospital stay should be considered while making this decision.

"Sometimes you don't know what is coming in. So you can say that a child MUST be admitted to a paediatric ward, but when you don't have any space left, they would have to go to another hospital further away. What would be better?" (HP1)

Some data did not fully belong to any of the previously described concepts or related to two or more concepts. Therefore, by inductive coding, new codes were created. In this section the appropriateness of putting children on adult wards, age limits for paediatric wards will be discussed.



#### 4.1.7 Appropriateness of Care on an Adult Ward

Opinions about the appropriateness of adult care for children varied among participants. Approximately a third of participants declared that children do not belong on adult wards with no exceptions. Children have different healthcare needs that have been discussed before and adult wards are not able to guarantee everything children need. Moreover, children will feel out of place on adult wards as the majority of patients are elders and the surroundings and facilities are not adjusted to their needs.

"I don't think that children should be admitted to adult wards. The first time I had to go to an adult ward there were only old people. That didn't feel right. Moreover, they did not consider that I might fear injections and it's nicer when your parents can be with you all the time." (C1)

Most participants however, agreed that there might be circumstances in which admission of a child to an adult ward might not be disastrous. For young children, the only conditions in which it would be appropriate to admit them to an adult ward, would be when the adult ward is transformed into a paediatric ward as much as possible. This includes bringing paediatric nurses and other facilities to adult wards.

When discussing older children, the conditions in which they would be allowed to be admitted to an adult ward softened, however, they do really depend on the development of the child. One 17-year old might be more mature and independent than the other. Moreover, when a paediatric ward is full due to a crisis situation, and a teen is suspected to have a short stay, two participants stated that temporary admission on an adult ward will not do a lot of damage. Other reasons for admittance to adult wards can be the clinical picture. As was discussed before, paediatric ward might not always be able to provide optimal care. Thus, most participants agreed that in some cases, admittance to an adult ward might be appropriate, however only in exceptional cases.

"I think it really depends on the development of the child. The one child might be more mature than the other. And maybe a child might feel the need to go to an adult ward while other children might still feel way more comfortable on a paediatric ward." (P3)

Participants were divided on the topic of letting children chose themselves whether they want to be admitted to a paediatric- or and adult ward. All children and some healthcare providers and parents encouraged children choosing themselves if they want to, yet the remaining half of the participants stated that children should be protected against this choice.

"personally, I'm in favour of keeping everyone under 18 here, despite their own choice. If you've never been in a hospital, you have no idea what you're choosing. So I guess this is to protect them." (HP4)

#### 4.1.8 Age Limit of Paediatric Wards

Participants were divided concerning the topic of age limit. While, two thirds of children, half of the parents and half of the healthcare providers advocate to raise the age limit to 21 or



23, the remaining participants absolutely oppose this development. Firstly, reasons to raise the age limit and secondly, reasons not to raise the age limit will be provided.

Many participants raised the issue of the ambiguity of the term 'child' in the field of healthcare. According to Dutch law, you are an adult at 18. However, medically speaking, you are autonomous at the age of 16 already. Other participants mentioned that the term child should not be defined by calendar age, but by developmental age. They state that if a 19-year old still has the same needs as a 17-year old, they should receive care of the same quality.

Moreover, as has been mentioned before, a 17-year old will not feel comfortable on an adult ward because of the high average age, however, a 19-year old will not feel comfortable there either. Furthermore, the young adults stated that they did not feel prepared for the difference in approach on an adult ward and that the transition was insufficiently guided.

"Well, how do you define a child? If you look at our legislation, it remains unclear. Above 16, you get to make all decisions yourself. So then you'd set the age limit at 16. ... but mentally you can set the bar at 23 or 25. And what about mentally disabled people. When a 25-year old functions as a 12-year old, do they still belong on an adult ward?" (HP2)

Opinions about the consequences of admitting young adults to a paediatric ward for younger children vary. Some state that as long as you do not put them in the same room, these consequences will be minimal. However, they did mention that this should not mean that all mentally disabled people that function as children should be admitted to a paediatric ward, as they do develop physically and might make other children feel uncomfortable. Yet most recognise that bringing any young adult to a paediatric ward might affect the feeling of safety of the other children. They understand that young adults have different care needs as well, however, they do not see a paediatric ward as an appropriate place for them, also because the care professionals is not trained to care for young adults. Moreover, some raised the improvement of the transition into adult healthcare as a more viable solution to make young adults feel comfortable on adult wards.

Another solution was raised by several participants. Namely, an adolescent ward on which patients between the ages of 16 and 23 or25 can be admitted. This would mean that they have a place to be among peers and that nurses and doctors with affinity for this age category can work there. However, the financial and logistical pressure on paediatric wards has already been discussed. So even though, it could be a solution for paediatric hospitals, general hospitals, are unable to open adolescent units as the numbers of adolescents being admitted to the hospital are too small. Thus a separate unit within a paediatric ward was proposed to prevent mixing with younger children and to still give young adults they need.

"There's a very small group of young adults here. When you look at the number of people between 18 and 21 being hospitalised, it's just not that many. So you can't open a separate unit for them." (HP5)



#### 4.2 Quantitative Results

In total, 172 people have filled in the questionnaire. Of these 172 people, only 22 were children, 65 were parents and the remaining 85 were healthcare professionals. The number of child participants is considerably lower than the other two groups, however, the number of children still exceed the required sample size of 16.

To start, a Cronbach's alpha test was executed to test the questionnaire's reliability. The test showed a result of 0.9, which means that the test has high reliability (Taber, 2018).

#### 4.2.1 Children have different healthcare needs than adults

1. Children ha	1. Children have different healthcare needs than adults											
Age Category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
8-11	3.81	0.01	0.02	0.06	0.27 P = 0.06	0.34 P = 0.01	0.07 P = 0.67	0.05				
12-15	3.61	0.01	0.01	0.01	0.48 P = 0.01	0.68 P = 0.01	0.21 P = 0.11					
16-17	3.16	0.01	0.01	0.01	0.7 P = 0.01	1.07 P = 0.01	0.37 P = 0.02	0.15				
18-23	2.83	0.01	0.01	0.01	0.85 P = 0.01	1.14 P = 0.01	0.28 P = 0.20	0.12				

Table 1: Quantitative results of statement 1

In general, participants agreed with this statement. The mean outcomes were highest, 3.87 out of 4, for age category 0-7 and concomitantly decreased to 3.16 for age category 16-17. Children only gave a mean score of 1.5 for category 18-23, which suggest that they do not believe that young adults have different healthcare needs than adults (Appendix 4). This contradicts the previous findings in which young adults declared that they still have the same needs as children.

Significant differences between groups were detected by the chi-square test in age category 8-11, 12-15, 16-17 and 18-23 of which p-values are depicted in table 3. ANOVAs confirmed these results for category two to five. In almost all four cases, children significantly agreed less with the statement than adults and healthcare professionals. Only in the 16-17 category, a significant difference between parents and healthcare providers was detected. The effect size for category 8-11 was low (Table 3).

#### 4.2.2 It should be possible for parents to stay the night with their child

2. It should l	2. It should be possible for parents to stay the night with their child											
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
8-11	3.81	0.04	0.06	0.06	-0.01 P = 0.99	0.17 P = 0.28	0.17 P = 0.06	0.03				
18-23	2.26	0.05	0.29	0.35	0.31 P = 0.43	0.37 P = 0.26	0.07 P = 0.91	0.02				

Table 2: Quantitative results of statement 2

Participants seemed to agree with this statement slightly less for higher age categories than in the previous one. However, overall means for the category 0-7 until 16-17 were between 3.89 and 2.88, which are the highest scores of all. Again, the mean score for the last age category was lower than for other age categories appendix 4.

The outcomes of statistical tests did not correspond and therefore, no conclusions can be drawn on these results (Table 4).



#### 4.2.3 Children should be admitted together with children of the same age

Again, participants agreed to this statement. Interestingly, the highest mean score, of 3.43 is given to category 12-15 instead of 0-7. Moreover, while category 18-23 scored lowest, its mean score is still relatively high and this corresponds to results in previous sections that stated that young adults feel uncomfortable around all the elderly on adult wards (Appendix 4).

#### 4.2.4 Children should be cared for by care professionals with a paediatric specialisation

4. Children sho	4. Children should be cared for by care professionals with a paediatric specialisation											
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
0-7	3.81	0.01	0.01	0.01	0.27 P = 0.02	0.42 P = 0.01	0.15 P = 0.06	0.11				
8-11	3.78	0.01	0.01	0.01	0.27 P = 0.02	0.46 P = 0.01	0.19 P = 0.01	0.13				
12-15	3.66	0.01	0.01	0.01	0.17 P = 0.43	0.46 P = 0.01	0.29 P = 0.01	0.08				
16-17	3.32	0.047	0.01	0.01	0.35 P = 0.6	0.65 P = 0.01	0.30 P = 0.01	0.07				

Table 3: Quantitative results of statement 4

Appendix 4 shows the largest decrease in mean scores between consecutive categories for this statement, namely, between category 16-17 and 18-23. This corresponds to qualitative results describing that paediatric care professionals are not able to care for young adults appropriately.

While the difference between mean scores of children and healthcare professionals was shown to be significant in the first four categories, the differences between children and parents and parents and healthcare professionals were only significant in the first two and the last two categories respectively (Table 5).

#### 4.2.5 Children need pedagogical assistance and extra emotional support

5. Children need pedagogical assistance and extra emotional support											
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size			
0-7	3.66	0.01	0.01	0.01	0.40 P = 0.02	0.67 P = 0.01	0.26 P = 0.02	0.12			
8-11	3.73	0.01	0.01	0.01	0.37 P = 0.01	0.54 P = 0.01	0.17 P = 0.14	0.10			
12-15	3.60	0.01	0.01	0.01	0.13 P = 0.72	0.47 P = 0.01	0.34 P = 0.01	0.07			

Table 4: Quantitative results of statement 5

Participants agree with this statement for all age categories. Interestingly, children give the highest mean score out of the three groups for the last age category (Appendix 4). Differences between the groups were shown to be significant for the first three age categories. With the exception of the difference between children and parents for category 12-15, and the difference between parents and healthcare providers second category (Table 6).



#### 4.2.6 Information and preparation should be adjusted to children

6. Information	and prepar	ration shou	ıld be adjust	ted to childr	en			
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – professional children – professi		Effect Size	
0-7	3.78	0.01	0.01	0.02	0.44 P = 0.02	0.52 P = 0.01	0.08 P = 0.58	0.10
8-11	3.8	0.04	0.01	0.07	0.3 P = 0.03	0.37 P = 0.01	0.07 P = 0.65	0.06
12-15	3.71	0.02	0.01	0.01	0.70 P = 0.83	0.28 P = 0.05	0.21 P = 0.03	0.05
18-23	2.99	0.01	0.03	0.04	-0.23 P = 0.52	0.15 P =0.74	0.38 P = 0.02	0.04

Table 5: Quantitative results of statement 6

The results for this statement show that again, children score higher than the rest for the last age category. Moreover, adjustment of information is valued most for children between 8 and 11.

Significant differences were detected between children and parents and children and healthcare professionals in the first age category. The difference between parents and healthcare providers was shown to be significant in category 12-15 and 18-23, but the effect size in these categories was low (Table 6).

# **4.2.7** Children need extra facilities as playrooms, teen rooms and help with school work From the results of this statement (Appendix), it becomes clear that parents and healthcare professionals value extra facilities more than children for the first four age categories.

However, no significant differences in mean scores could be found in any of the categories.

#### 4.2.8 There should be extra effort to prevent pain and fear in children

8. There shoul	8. There should be extra effort to prevent pain and fear in children											
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
12-15	3.76	0.01	0.01	0.01	0.47 P = 0.01	0.54 P = 0.01	0.07 P = 0.56	0.20				
16-17	3.52	0.01	0.01	0.01	0.49 P = 0.01	0.68 P = 0.01	0.19 P = 0.17	0.10				
18-23	3.26	0.01	0.01	0.01	0.27 P = 0.30	0.58 P = 0.01	0.31 P = 0.02	0.07				

Table 6: Quantitative results of statement 8

This statement got the highest overall mean scores for the last four age categories (Table 8), which is not surprising as the need to prevent pain and fear was stressed in the qualitative results as well.

The differences in mean scores between children and healthcare providers were significant for age category three to five, while the differences between children and parents only were significant in category three and four. The effect size in category 12-15 was great.



# 4.2.9 Children should be able to decide for themselves whether they want to be admitted to a paediatric ward or an adult ward

9. Children sho	9. Children should be able to decide for themselves whether they want to be admitted to a paediatric ward or an adult ward											
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
12-15	0.95	0.02	0.04	0.04	-0.21 P = 0.75	-0.59 P = 0.09	-0.38 P = 0.12	0.04				

Table 7: Quantitative results of statement 9

The mean scores for this statement (Table 9) were lowest of all and it is the first statement for which mean scores increase with increasing age. This is not really surprising, as the low scores for babies and young children are logical.

However, it is interesting that the only significant difference can be found in age category 12-15, the early teenagers. Moreover, this is the first time that healthcare professionals score lowest of all. The significant difference has a low effect size however.

#### 4.2.10 There should be a separate ward for teenagers and young adults

10. There sho	10. There should be a separate ward for teenagers and young adults											
Age category	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
0-7	2.37	0.01	0.02	0.01	1.00 P = 0.01	1.07 P = 0.02	0.07 P = 0.96	0.05				
8-11	2.48	0.01	0.01	0.01	1.15 P = 0.01	1.20 P = 0.01	0.05 P = 0.97	0.06				
12-15	3.29	0.01	0.01	0.01	1.08 P = 0.01	1.05 P = 0.01	-0.03 P = 0.97	0.14				

Table 8: Quantitative results of statement 10

Table 10 shows that the only significant results occur in the first three age categories. Assuming that none of the respondents wants to put babies and young children on a ward for young adults, these results will be neglected.

#### 4.2.11 Age limit and Transition age

Age limit and	Age limit and transition age											
	Total Mean	Chi <sup>2</sup> Sig.	Anova Sig.	Welch Sig.	Difference children – parents Sig.	Difference children – professional Sig.	Difference parents – professional Sig.	Effect Size				
Age limit	19.2	0.07	0.38	0.25	0.35 P = 0.85	-0.24 P = 0.92	-0.59 P = 0.35	0.01				
Transition Age	19.2	0.01	0.03	0.07	1.25 P = 0.049	0.62 P = 0.45	-0.64 P =0.17	0.03				

Lastly, participants were asked to give their opinions on the age limit of paediatric wards and from what age they believe the transition towards adult care should start.

The overall mean age limit was 19.20. Parents gave the highest mean age limit, and healthcare professionals the lowest (Appendix 4). No significant difference was detected (Table 11)

The overall transition age was 19.23 and in this case, children gave the lowest mean age (Appendix 4). Table 11 suggests that there is no significant difference.

An overall observation is that children generally give lower mean scores than parents and healthcare professionals of which the last group generally has the highest mean scores. This could be due to different interpretation of the value of the scores. Although, in some cases, children do score higher, so this could be investigated further in future research.



#### 5 Discussion and conclusion

In this final chapter, the research questions will be answered. Moreover, a comparison of the following key findings to current literature will be made; Patronisation and childishness; Transition to adult healthcare; and adolescent medicine and lastly, some recommendations will be given.

#### 5.1 Conclusion

Answering the main research question to what extent a paediatric ward is the appropriate form of providing care for children, the answer is yes. Children definitely have special healthcare needs and paediatric wards are adjusted to these needs. Children, parents and healthcare professionals generally agreed on the most important aspects of appropriate child care. Most importantly, children have to be the central component of their care and therefore, care has to be planned according to their needs. As children are inextricably connected to their family, this means that their needs have to be taken into account as well. Secondly, children require a lot more attention for their emotion and the reduction of fear. Results show that this can exclusively be done by care professionals that has had sufficient training to care for children. The last aspects are being yourself, being taken seriously and becoming an independent adult. These aspects suggest that children should have facilities to be able to behave and develop like regular children, that they should be treated appropriately for their age and that they should be taught how to manage their disease properly themselves, to participate in the decision making process and how to handle the transition to adult healthcare. Unfortunately, the latter does not happen appropriately.

It was shown that the main advantage of paediatric wards is that they are adjusted to all these needs and that care on adult wards is not appropriate for children in most cases. Furthermore, disadvantages to paediatric wards were scarce. However, paediatric wards currently tend to be a bit too patronising for older children. The other disadvantages are logistical and therefore do not have a lot to do with the children.

Finally, with regards to the age limit of paediatric wards, special healthcare needs continue to exist for young adults, however, the paediatric ward is not the best place for them and therefore, the age limit of a paediatric ward should be 18. Unfortunately, the preferred option to create a separate adolescent ward remains unfeasible for most hospitals.

#### 5.2 Comparison of Key Findings to Current Literature

#### 5.2.1 Patronisation and Childishness

One outcome of this study is that paediatric healthcare professionals can be rather patronising and that teenagers might experience paediatric wards as childish. Some studies focussed on the childish environments in hospitals and that hospitals tend to focus on young children while decorating paediatric wards. This can cause discomfort for older children as they might not feel at home (Curtis, 2018; Verschoren, Annemans, van Steenwinkel, & Heylighen, 2015). Literature described in the fourth chapter indicated that it is important to involve children in decision making and to increase independence (Antonelli et al., 2009; Stichting Kind en Ziekenhuis, 2017). However, results show that this does not always happen. Unfortunately, only one article could be found that stated that older children had negative hospital experiences due to patronising and condescending attitudes of paediatric



professionals (Ali, Vitulano, Lee, Weiss, & Colson, 2014). Since research on this theme is scarce, the effects of patronisation and childishness on paediatric wards could be a topic for future research.

#### 5.2.2 Transition to Adult Healthcare

One aspect of paediatric care that was shown to be insufficient, is the transition to adult healthcare. Many studies confirm the lack of adequate transition (Bhawra, Toulany, Cohen, Moore Hepburn, & Guttmann, 2016; I. Coyne, Sheehan, Heery, & While, n.d.; Dean & Black, 2015; Vaks et al., 2016). Bhawra et al. (2016) show that patients feel like the change to adult wards is too abrupt, they are not well prepared and that the staff on adult wards is not prepared for them. Young adults, and especially those with chronic illnesses that require this transition, are already quite vulnerable due to the transfer to higher education, not being around their friends all the time and the pressure to become self-sufficient adults. Which makes a smooth transition only more important (Bhawra et al., 2016). Dean & Black (2015) list some of the discomforts young adults face. They are often not prepared for adult wards with regards to their fellow patients being elderly, change in surroundings and the more formal relationship with care providers. Moreover, healthcare providers are not always prepared for the young adults either. Their feelings of being misunderstood and discomfort are often shown through anger or non-communication, which can be perceived as rude by the medical staff (Dean & Black, 2015). The variety of studies performed in various countries – eg. the USA, Australia, the UK – together with comparable results in this study, shows that this problem occurs in countries all over the world. Making it a global problem. Vaks et al. proposed some solutions, including guidance to increase self-management, which complies with the result of this study, creating a checklist based transition program and getting to know the adult healthcare provider early on in the transition process. These solutions lead to higher patient satisfaction and better health outcomes (Vaks et al., 2016).

#### 5.2.3 Adolescent Medicine

One healthcare provider participating in this study stated that improving the transition to adult healthcare could be part of a broader concept: A specialisation in adolescent medicine. The clinical pictures young adults face, are different than those of young children. Moreover, research has been done on the skeletal and sexual maturation and the neurocognitive and behavioural development of young adults, which showed, that there remains a physiological difference between both young adults and children and young adults and adults. In the last 20 years, the special healthcare needs of adolescents have been recognised globally and advocacy for the need for a medical specialisation concerning adolescents has increased (Rieder, Alderman, & Cohen, 2005). In the USA, a three year post graduate specialisation in adolescent medicine, nursing, psychology and nutrition can be followed. Moreover, in Canada and Australia, increases in adolescent specialists can be seen due to official accreditations. However, there still remains a shortage of adolescent specialists and redesign of the training is necessary (Lee, Upadhya, Matson, Adger, & Trent, 2016).



#### 6 Recommendations

After comparing some of the key findings with current literature, some recommendations can be made regarding problems that became apparent in this study.

- 1. Generally, children until the age of 18 should definitely be cared for on paediatric wards. There are exceptions, but children and their parents benefit greatly from the child and family integrated care implemented on paediatric wards and being cared for by paediatric professionals
- 2. Paediatric wards should try to be less patronising. By involving children in the decision making about their care and teaching them how to manage their disease properly, they can become self-sufficient adults. Moreover, paediatric care professionals should be more adjusted to teenagers on a social level and facilities should be adjusted to them as well.
- 3. More attention should be given to the transition to adult healthcare. Transition should be a process in which the patient is prepared well and meets their future doctor early on. Moreover, medical staff with affinity for young adults should be appointed to care for these children. Improving the transition can positively affect their satisfaction with care on adult wards.
- 4. Young adults have different healthcare needs than adults as well, however, paediatric wards are not the appropriate form of care for them. The concept of adolescent medicine and specialisations in the field should be explored further. This includes a better transition that is mentioned in the previous point, but the experience on young adults on adult wards could also be improved by trying to cluster them.



# Appendix Method

#### Theoretical Framework

In this chapter, theories explaining the central aspects of well-functioning child healthcare will be provided and discussed. Several theories and frameworks will be combined into one comprehensive overview of the most important aspects of well-functioning child healthcare. On this framework, four research questions will be based.

#### Theoretical Background of Well-Functioning Paediatric Care

Through a thorough literature research, no fitting theoretical framework could be found that describes either the importance of paediatric care nor an overview of a well-functioning paediatric healthcare system. Therefore, several theories and frameworks will be combined into one framework describing the characteristics of a well-functioning paediatric care system. This description of a well-functioning paediatric care system will help to assess whether a paediatric ward is the appropriate form of child healthcare provision.

#### Antonelli, McAllister and Popp

Antonelli, McAllister & Popp proposed a framework on the coordination of paediatric care in 2009. They state that a paediatric healthcare system needs the following characteristics to work effectively; (1) It must be patient- and family-centred; (2) It needs to be proactive, planned and comprehensive; (3) It needs to promote self-care skills and independence; and (4) it emphasizes cross-organizational relationships (Antonelli, McAllister, & Popp, 2009). In order to create this model, Antonelli et al. have made the following assumption: "optimal patient- and family-centred outcomes are the result of relationships in which children, youth and their families participate in a fully informed partnership with their primary care provider and a supportive, proactive health care team." (Antonelli et al., 2009 - p. 8). Moreover, they state that good care can only be achieved as a team-based activity that is designed to the child's needs. With these statements and assumptions, the model can be explained as characteristic 2, 3 and 4 all contribute to the centre of paediatric care; the child and its family.

#### Child and family centered criteria Stichting Kind en Ziekenhuis

Kind&Ziekenhuis have created a quality mark called the 'Smiley' with which we assess the quality of paediatric care in Dutch hospitals. We have based the criteria for the Smileys on four themes which are the following; (1) Information; (2) Presence and collaboration with parents; (3) Being a child, pain and fear; (4) Appreciation, respect and privacy (Stichting Kind en Ziekenhuis, 2016). The themes proposed by Kind&Ziekenhuis have been developed from the articles and rights as stated by the EACH Charter and the UNCRC. Children should receive sufficient information about their condition and should understand what will happen to them. Moreover, to ensure their feeling of safety and comfort, their parents should be able to be present at all times and should be involved in the decision making process. Furthermore, children must be treated as equal partners because they are experts on their own bodies and feelings. Moreover, while being in a negative situation like hospital admission, their privacy must be ensured and respected. Furthermore, fears and pain should be taken seriously to relieve stress, but mostly, children should be able to be children and to keep up on a social and educational level (Stichting Kind en Ziekenhuis, n.d.-a). Kind&Ziekenhuis also proposed a framework on patient integrated care, in which they illustrate the following principles; (1) Appreciation and respect; (2) Sharing information; (3) Participation; (4) Cooperation with family and (Stichting Kind en Ziekenhuis, 2017). This framework has some overlap with the previously described framework form Kind&Ziekenhuis, but also with the framework that will be discussed in the following paragraph



#### **Picker Institute**

The Picker Institute has proposed their 'Eight principles of patient centred care and the principles that are most relevant for paediatric care are the following; (1) Access to care; (2) Physical and emotional support; (3) Involvement of family and friends; (4) And information and education (Picker Institute, 2019). The Picker Institute has based these principles on numerous focus groups with patients, professionals and family members. The participants showed that confidence in the availability of care close to home was a common requirement of good care. Moreover, patients often feel emotionally and physically distressed. They valued attention and support for this distress greatly. A large component of the emotional distress was the fear of not knowing what is happening. This fear can be reduced when patients can trust the health professionals to be completely open and honest about the patient's conditions and the procedures to come. Lastly, the participants showed that the presence of family and friends and also their involvement, is important for recovery. This presence and involvement reduces anxiety in patients and comforts them (OneView, 2015).

#### Ambresin, Bennet, Patton, Sanci & Sawyer

Ambresin et al. (2013) also studied what people find important regarding healthcare. They found that among other things, staff attitude, communication, medical competency and youth involvement are important. Moreover, they stress the importance of access to care and the involvement of family and friends as children might experience separation anxiety (Ambresin, Bennett, Patton, Sanci, & Sawyer, 2013).

#### **Theoretical Model**

After analysing all frameworks and identifying the most important aspects, none of them seemed adequate or complete as none of them contained all important aspects that have been identified up until now. Since Antonelli's framework for "High-Performing Paediatric Care Coordination" (2009) seems most complete, Figure 1 is adapted to this framework with input from the Picker Institute (2019), Kind&Ziekenhuis (2017) and Ambresin et al. (2013). The framework can be found below in Figure 1

The main characteristics of a well-functioning paediatric care system are provided at the top of the table and at the bottom, more detail of what the characteristics entail is given. The main characteristics of well-functioning paediatric care systems are provided at the top of the table. At the bottom, more detail of what the characteristics exactly entail is given. This more detailed explanation will also be provided in the following paragraphs that are structured per characteristic. Some characteristics relate to each other as well. For example, characteristic 2 to 6 contribute to the first characteristic of patient- and family integrated care. Moreover, comprehensive, proactive and planned care can only be achieved by the presence of specialised care professionals. A more detailed description will be provided below.

The first and maybe most important characteristic is patient- and family integrated care. This does not only include that parents and child are involved in decision making on therapies and that a child's emotional state is taken into account, but also that the care is flexible to the child's and parent's needs (Antonelli et al., 2009). An important aspect is that children are seen as equal partners in the decision-making process. Patient- and family integrated care also means that the child ideally does not fall behind on educational and social level and parents and brothers and sisters get the opportunity to be with their child as much as they want (Stichting Kind en Ziekenhuis, 2017).

The second aspect relates to first as comprehensive, proactive and planned care is in the best interest of both the child and the family. It is of great importance that medical information is shared with child and family in a way that they can comprehend (Stichting Kind en Ziekenhuis, n.d.-a). Moreover, the needs of both child and family need to be assessed and responded to constantly, which corresponds to the flexibility towards child's and family's changing needs (Antonelli et al., 2009; Stichting Kind en Ziekenhuis, 2016; Turchi et al., 2014).



Promotion of self-management skills and independence is an important aspect of paediatric healthcare as it empowers both child and family and could limit the time the child has to spend in the hospital (Antonelli et al., 2009). It again involves the comprehensive information sharing and also includes assistance in the development of self-management skills and independence.

As was shown in the introduction, children are different than adults on both physiological and emotional levels and therefore should be treated by providers with specialised knowledge (Ambresin et al., 2013). This specialised care professionals is not only beneficial for children, but it is one of their rights (UNICEF, n.d.). Their specialised knowledge will improve health outcomes and for this specialised knowledge to continue, education of care providers is needed.

The fifth aspect has shown to be important for almost all health systems as cost-effectiveness of care makes the system more sustainable (Turchi et al., 2014). This cost-effectiveness includes the prevention of repetitive actions by effective communication, which also makes care more child-friendly. Also the promotion of self-management reduces hospital costs and empowers the child and the family. Cost-effectiveness includes; prevention of repetitive actions by communication between care providers; And again the promotion of independence and self-management.

Lastly, access to care has shown to be very important. As has been illustrated before, children and parents find it very important to be close to each other during hospitalization of the child (Boztepe et al., 2017). This can be made possible if the paediatric care can be provided in health facilities close to home. This also allows friends and other family to visit the sick child, which decreases the chance of social isolation.

#### Research method

For this research, a mixed methods study design was used. More specifically, after considering Creswell's 'Checklist of Questions for Designing a Mixed Methods Procedure' (Creswell, 2014), a sequential exploratory design in which qualitative data collection and analysis, followed by quantitative data collection and analysis was used. This design was chosen because the qualitative data can provide better insight in the important aspects and the (dis)advantages of the paediatric ward as perceived by the different stakeholders (children, parents, child health providers and unspecialised health providers). These insights have been used to create a to-the-point questionnaire to validate these opinions in a broader audience and to test whether certain aspects are valued more by one stakeholder than by another stakeholder.

#### Qualitative Data Collection and Analysis – Phase 1

In total, sixteen interviews were conducted. The majority of interviews were held with healthcare professionals, namely nine. A variety of healthcare professionals was interviewed; paediatricians, non-paediatrically specialised doctors, paediatric nurses, pedagogical helpers and head of paediatric wards. Three participants of the category children were interviewed. Two of them fell in the age category 18-23 and one of them in age category 12-15. Finally, four parents were interviewed. One parent had a background in healthcare themselves, but since they mainly expressed opinions from the parent perspective, they were all put in the parent category. Table 1 shows a summary of the information above.

#### **Qualitative Data Analysis**

All interviews have been verbatim transcribed and subsequently, Atlas.it was used for coding. The coding of the data has been deductively based on the proposed theoretical model and it consisted of 3 phases (Creswell, 2014). keholders.

Quantitative Data Collection and Analysis – Phase 2



Phase II of this study consisted of validating the results found in phase I, by collecting quantitative data among a larger population. The aspects deemed to be important and (dis)advantages identified in the first phase became the topics of the questions in the survey. Children, parents and healthcare professionals have been provided with ten statements and were asked to rate to what extent they agreed with them for the following age categories; 0-7, 8-11, 12-15, 16-17 & 18-23. Since children, parents and healthcare professionals all have different reading levels, the statements were adjusted to these levels and three different surveys were created. Furthermore, to shed light on an appropriate age limit for paediatric wards and on the age at which transition should take place, participants were asked what they find suiting age limits and transition ages.

#### **Quantitative Data Analysis**

The questionnaire provided us with information on what aspects of paediatric care are deemed most important. With this analysis, differences and agreements in opinions within the three groups were identified. The aspects that were shown to collectively be found important have been compared to the proposed model of paediatric care and the competences of paediatric wards described in the qualitative analysis. Based on these assessments, recommendations on the importance of paediatric wards and points of improvement can be provided.

#### **Ethical Considerations**

With regards to all the data acquired during this study, it has all been handled anonymously and confidentially. The data was solely used for the purpose of this study and has been destroyed afterwards. The participant's contact information was only kept for future research purposes if the participant agreed to that and information can be deleted at any time upon request. Furthermore, all participants can be confident that their data was not shared with others and they had the right to refuse to answer a question at any time. Lastly, before any interview or questionnaire started, the research purposes were explained again and consent was asked to record the conversation and to keep the data stored for the time being.



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