In the network of healthcare actors: A study of family-centred care for children with complex needs

Understanding and improving the respiratory care for children with cerebral palsy and multiple disabilities

Master's Thesis in the Master's Programme International Project Management

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ABSTRACT

Problem: Families to children with complex care needs face challenges in the Swedish healthcare system. Increasing differentiation and specializations without integration and coordination of healthcare actors has resulted in fragmentations and sub-optimizations within the system. The system has significant issues to align goals between actors and to establish clear roles and responsibilities between them. Simultaneously, the system suffers from poor leadership and lack of cross-functional collaboration, which result in old and inefficient processes, short-term solutions and reactive healthcare. Today healthcare actors do not know what other actors are taking or not taking responsibility for. Professionals are hindered to achieve holistic care, which increases the risk of working with contradictory treatments. The consequences for families to children with complex care needs are not only lack of involvement and family-centred care. The challenges increase the risk of diseases and reduce the children's chances of receiving proactive and coordinated respiratory care. In worst case, these children die an early death.

Method: Observations and interviews with about 20 healthcare actors, such as professionals at habilitations and hospitals, and interviews with four families to children with complex care needs, were held. The interviews and observations took place at the hospitals, in the homes of the families and over phone. The questions emphasized the families' well-being, how healthcare professionals managed families with complex care needs and how they managed respiratory issues. The answers were then compared, analysed and summarized into different focus areas.

Result: The study resulted in an overview of how families to children with complex care needs were managed and prioritized by different healthcare actors in Region Västra Götaland. Significant differences were identified, where most healthcare professionals lacked adequate prerequisites to create family-centred care in an efficient and proactive way. Common challenges for the professionals were lack of clear guidelines and responsibilities, inexistent or scarce collaboration with other key actors and lack of competence. The study identified inefficient processes, where professionals either performed contradictory treatment or wasted time on non-value adding activities. Instead of working as a collaborative network, with the aim to create holistic care greater than the sum of each actors' contribution, the actors focused on their own organizational benefit. Consequences were not only conflicts and sub-optimizations, but also reactive and inefficient management of respiratory issues. Those professionals who worked in cross-functional teams and focused on adequate and proactive care were identified as most successful. Availability, involvement and flexibility were key factors when collaborating with families to children with complex care needs. The interviewed families were satisfied with having a competent and experienced respiratory team at their local hospital, who they could contact whenever they needed. The families emphasized the importance of coordinated and family-centred care, with the opportunity to co-create value. Followed early and often by a respiratory team resulted in increased well-being of and reduced hospitalizations.

Conclusion: The study identified a Swedish healthcare system with poor management and individualistic perspectives, with actors who focused on their own organization rather than on their patients. A healthcare system full of fragmentations and lack of collaboration will never create anything else than sub-optimizations and low quality of care. While vulnerable families continue to struggle to avoid losing their children in early deaths, the healthcare system remain chaos without any sign of coordinated and synergized care. Even though the respiratory system is vital to every human being, few healthcare actors seem to focus on adequate and proactive care. According to this study, patients in need of coordinated care still are too complex for the system to manage and Sweden's vision of ensuring everyone efficient and equal access to healthcare services has never felt so far away.

Key words family-centred care, patient involvement, service logic, co-creation of value, network logic, improvement science, cerebral palsy, cp, profound intellectual multiple disabilities, pimd, healthcare

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I would like to express my greatest appreciation to the families I interviewed in this study. Thank you for sharing your story of how it is to be family to a child with complex care needs. You have changed my life forever and I truly admire you for your strength and courage.

I want to thank the respiratory team and the manager of BUM at Skaraborg Hospital in Skövde for giving me the opportunity to accomplish this case study. It was amazing to take part of your relationships with the families and to see your empathy and enthusiasm for these children.

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ABBREVIATIONS

Abbreviation	Word	Explanation
CP	Cerebral palsy	Cerebral palsy is usually caused by a brain damage before or during a baby's birth. CP is a disorder that affects motor skills, movement and muscle tone. CP may lead to other disabilities, such as hearing issues, speech problems or vision impairment
CPAP	Continuous Positive Airway Pressure	An aid used for respiratory issues
BUM	Barn- och ungdomsmedicin	The Clinic of Child and Adolescents
DSBUS	Drottning Silvias barn- och ungdomssjukhus	Queen Silvia Children's Hospital
-	Habilitation & Health (Referred as habilitation)	Habilitation & Health is a specialist activity centre within the Swedish healthcare. H&H provides specialized support, treatment and aids to individuals with disabilities (VGR, 2018). H&H functions as complement to other kind of support provided from municipalities, primary care and other healthcare
-	Habilitation Knoppaliden	Knoppaliden, located in Skövde, provides specialized medical treatment for children and adolescents with disabilities
GMFCS	Gross Motor Function Classification System	A five-level categorization technique to classify individuals with cerebral palsy and their voluntary movement, with emphasize on sitting and walking. See Appendix B for further description
-	Paediatric Pulmonologist	Diagnose, treat and manage respiratory issues and lung diseases for children from birth up until they are 18 years old
NÄL	Norra Älvsborgs länssjukhus	Norra Älvsborg Hospital
PEP	Positive Expiratory Pressure	An aid used for respiratory issues
PIMD	Profound Intellectual Multiple Disability	These individual's often have physical disabilities and sensory impairments. Individuals with PIMD is a very vulnerable group with a high dependence on personal assistance day as night
SKAS	Skaraborgs sjukhus	Skaraborg Hospital
SU	Sahlgrenska universitetssjukhus	Sahlgrenska University Hospital
SÄS	Södra Älvsborgs sjukhus	Södra Älvsborg Hospital

1 INTRODUCTION

The World Health Organization (WHO) emphasizes that a well-functioning healthcare system is crucial for creating and delivering health to the society's inhabitants (WHO, 2013). But at the same time healthcare systems are claimed to be one of the most complex systems to manage and countries all over the world face challenges managing their systems (Glouberman and Mintzberg, 2001). Sweden is one of those countries, who is said to have a healthcare system in crisis (Lindgren, 2018). The Swedish healthcare system is decentralized, where all legally inhabitants are provided healthcare from county councils and municipalities with supportive guidelines from the state, see *Figure 1*. Even though large amounts of resources are put on the healthcare system, it is claimed to be inefficient with long waiting times and shortage of employees (Lindgren, 2018). International comparisons show that Sweden has a relatively low degree of patient-centred care and lack of continuity, but greater success in delivering care of high medical quality (Socialstyrelsen, 2016). Regional and social differences in health and life expectancy does still exist, where factors as economy, living habits and language skills have strong impact (Lindgren, 2018; Socialstyrelsen, 2011). Reasons are lack of steering and control and increasing differentiation and specialization (Lindgren, 2018; Socialstyrelsen, 2016). Specialization is an advantage for medical quality, but absence of integration and coordination only foster fragmentations and sub-optimizations (Socialstyrelsen, 2016). The management of the system is criticized focusing too much on control, economism and bureaucracy, rather than on the patients and their well-being (Swedish Society of Medicine, 2018).

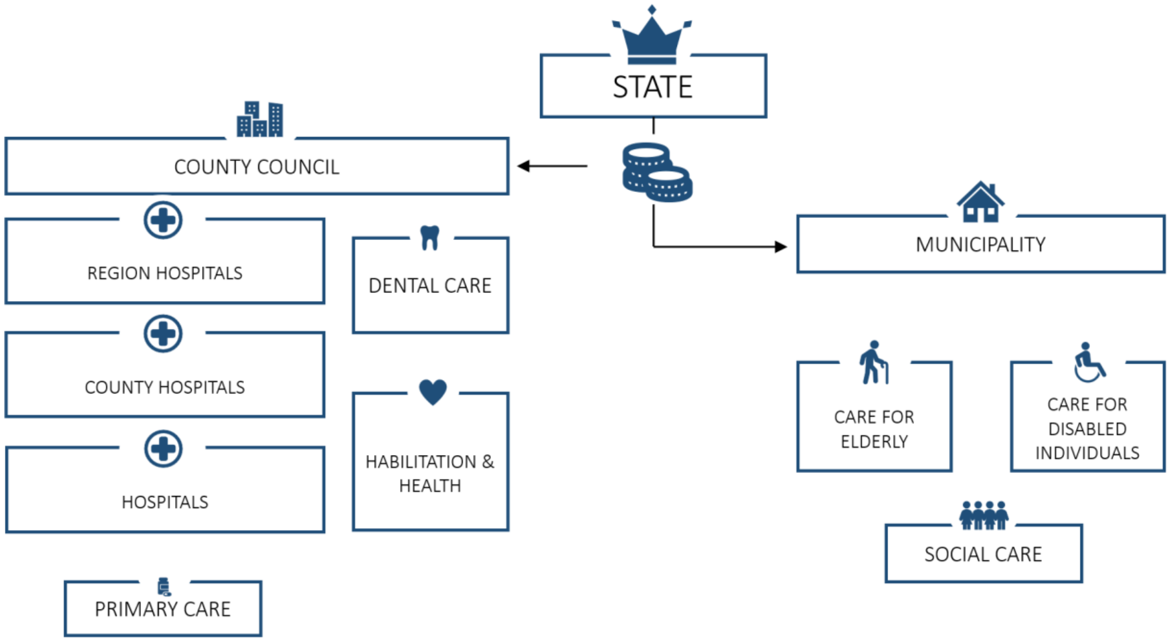

Figure 1: The Swedish healthcare system.

To reduce differences in health and transform the country into a sustainable welfare state, Sweden has created several goals and strategies to work with (Government of Sweden, 2017). One ambition is to be the leading country when it comes to implementing and realizing the action plan towards a sustainable world, the Agenda 2030 (Government of Sweden, 2017). The agenda includes seventeen Global Goals for sustainable development, which in turn balance the three dimensions of sustainable development; the economic, the environmental and the social (Government of Sweden, 2017). Countries all over the world are contributing and so does Sweden. One strategy is to increase the collaboration between academia, healthcare and industry to develop new medical technology and care methods. Though, as the number of medical and technical improvements are increasing do the society have better possibilities to save more lives than ever (Lifvergren, 2013). Relevant to this study, the number of preterm births is increasing, whereof many of the children develop respiratory issues (Owen et al., 2017). Preterm babies and babies born with complications are two groups of children who may develop chronic disabilities and in turn dependency to complex care. Sweden has for many years been criticized for lack of care to children with one or several disabilities (Civil Rights Defenders, 2016). Lack of integration and coordination of the healthcare professional from the municipality and the county councils is a well-known challenge, both within and outside the system (Socialstyrelsen, 2011). The responsibility allocation is often unclear for both the patient and the family as the professional who is providing the care (Socialstyrelsen, 2017). For instance, children with disabilities are managed by hospitals, primary care and Habilitation & Health, who have common responsible for providing care and support. But who has the main responsibility of a child with multiple disabilities is almost never clear, such as the professional who support with movement aids, visual aids or medical treatment (Ylvén, 2015). Each actor, such as a habilitation clinic or a hospital, makes their own assessments, planning and treatment without communicating it to the other ones (Ylvén, 2015). The parents are those who coordinates each actor's effort, rather than the system are working as a network. Many of parents to children with disabilities perceive the support from the system as complicated, without coordination and lack of satisfying the family's needs (Ylvén, 2015). The situation is described as chaotic and hard to manage, without support from someone who understands the special culture (Gough, 2013). Achieving a successful collaboration between actors is a challenge and those times it reaches success is because of committed professionals, rather than formal agreements (Gough, 2013). Swedish politicians have discussed the need of coordination support for more than 30 years, nevertheless concreate solutions to facilitate for families to children with disabilities are absent (Ylvén, 2015). Researchers continues to emphasize the need of integrating actors and their responsibilities to reach an efficient healthcare system of high medical quality (Glouberman and Mintzberg, 2001; Normann, 2001; Socialstyrelsen, 2016).

In line with Agenda 2030, Sweden makes a radical transformation of the existing healthcare system. To improve the continuity and manage the challenges of an increasing number of individuals with complex care needs, patient-centred care is put in focus of the transformation (Socialstyrelsen, 2016). The system improves the patient's possibilities to be a co-creator of their own care to increase the overall patient involvement (VGR, 2018). Except from national initiatives are regional initiatives created and realized too, such as within Region Västra Götaland (VGR). The region is currently formulating a new development plan of paediatric, which stress the need of early and proactive care for children and adolescents (VGR, 2018). The first phase of the plan focuses on children with chronic diseases and many healthcare contacts. It includes five different population groups, whereof one is premature born children with severe diseases. Extremely preterm born children most often develop chronic lung function issues and have a high risk for respiratory morbidity (Fawke et al., 2010). Among these five groups were other population groups discussed by the managers of VGR, such as children with epilepsy, long-term pain and children of respiratory issues (VGR, 2018). The initiative of a new development plan of paediatric correlates to Sweden's overall work of improving the healthcare for children with disabilities.

Furthermore, it is well known that parents to children with multiple disabilities many times gets exhaustive with reduced health and well-being as results (Broberg et al., 2014). The lack of coordination is one reason and the transition from paediatric to healthcare for adults is another, where the risk of falling in between cracks is high (Socialstyrelsen, 2011). A common issue for the family is the high employee turnover of healthcare professionals, which result in new professionals without experience and specialized competence. Or when the family gets different recommendations from different professionals, which establish uncertainties of who the parents should listen to (Mårtensson, 2017).

Not surprisingly, these parents face challenges of reduced well-being, sickness and unemployment, which lead to reduced quality in care of their child (Socialstyrelsen, 2017). Relationships are affected, both between the parents and to the other siblings within the family (Broberg et al., 2014; Socialstyrelsen, 2011). Therefore, to provide support for the rest of the family it is of importance to work with a holistic perspective (Broberg et al., 2014; Dempsy and Keen, 2008; Socialstyrelsen, 2017). One approach for such support is called family-centred care, which is claimed to be the best paediatric healthcare as it takes the whole family into perspective (Broberg et al., 2014). The approach of family-centred care is also emphasized by VGR in their formulation of a new development plan of paediatrics (VGR, 2018).

1.1 CHILDREN WITH CP AND/OR PIMD

Two other groups of patients with complex care needs are children with severe cerebral palsy (CP) and/or children with profound intellectual and multiple disabilities (PIMD). Every child with PIMD is unique common, but common challenges is reduced motor function, intellectual impairment, sleep issues, epilepsy and respiratory issues (Mansell, 2010; Ölund, 2016). Children with PIMD are some of the most disabled individuals within the society and are dependent on care and support from different professionals as well as assistance day as night (Mansell, 2010; Ölund, 2016).

Sweden has approximately 7000 individuals with PIMD, but the number of children is still unknown (Borgström and Carlberg, 2008). In Sweden almost 600 children live with severe CP, whereof about 90 lives in VGR (Hägglund, 2017). Children with severe CP included in this study have GMFCS level V, which is further explained in *Abbreviations* and *Appendix B.*

Table 1: Overview of the number of individuals with PIMD and CP in Sweden.

Individuals with PIMD **Year 2008**	**Children with CP** **Year 2017**		
	GMFCS* level	**Sweden**	**VGR**
Sweden 7000	I	1549	254
	II	581	103
	III	325	49
	IV	529	100
	V	576	87
	Not categorized	113	28
	Total	3673	621

**GMFCS is explained in Abbreviations. Numbers from Borgström and Carlberg (2008) and Hägglund (2017).*

As familiar, on common challenge for children with complex physical disabilities is respiratory issues, which in turn affect both life quality and life expectancy (Seddon and Kahn, 2003). Due to various causes, such as chronic lung disease, pneumonia, and sleep apnea, these children have an increased risk for respiratory failure (Kim et al., 2015). In fact, research shows respiratory failure is the most common cause of death for individuals with CP (Fitzgerald et al., 2009; Himmelmann and Sundh, 2015). In Sweden respiratory failure accounts for 53 % of the deaths for this patient group, which mainly is caused by aspiration and/or pneumonia (Himmelmann and Sundh, 2015). Children with severe CP (GMFCS level V) have 60 % chance to survive until 20 years of age, where children who lives in small areas have a threefold risk of dying an early death (Westbom et al., 2011). Regional differences in medical quality may be one reason for the variety of mortality between geographical areas (Westbom et al., 2011). The many various initiatives for children with CP may be another reason, which sometimes are unnecessary or even hurtful to the child (Westbom, 2017). Scoliosis treatment is an example of such contradictory intervention, with both positive and negative outcome. Scoliosis is a common issue for individuals with CP, which is treated by surgery or scoliosis bracing, depending on the severity (Koop, 2009). A scoliosis bracing is used to stop the curve to get worse but comes with an increase pressure on the child's abdomen, which have negative impact on the lung function (Stockholm County Council, 2014).

A common issue for children with CP is having an insufficient cough mechanism, which makes them not always cough even though they have severe respiratory infections (Seddon and Kahn, 2003). Professionals do not always notice a child's respiration impairment and due to professionals' unfamiliarity with a child's health treatment may be delayed. To achieve successful care professionals should use their medical knowledge in combination with the parent's expertise. In turn, every child should be entitled with an individualized and multidisciplinary assessment, even though nothing constructive can be done directly (Seddon and Kahn, 2003). The national guideline of CP gives same recommendations; identify respiratory issues at an early stage to hinder further complications and impairments (Stockholm County Council, 2014). Much more can be done to improve both health and well-being of individuals with disabilities, such as using relatively simple interventions (Fitzgerald et al., 2009; WHO, 2013). No matter what, the most fragile children should be followed by the most experienced teams with multi-professional competence (Westbom et al., 2011).

Children with severe CP and/or PIMD is the chosen group of patients emphasized in this research. The study was conducted as a case study at Skövde Hospital, which is one of four hospitals within the Skaraborg Hospital Group in Western Sweden. Together with other hospitals and healthcare actors, Skövde Hospital provides healthcare to the inhabitants within Region Västra Götaland (VGR), *Figure 2.* The responsibility is shared with Habilitation & Health, now referred as only habilitation, described in *Abbreviations.* As seen in *Figure 2,* the inhabitants of VGR are provided with healthcare from various actors at different levels within the system, sometimes also referred as the network. It is a constant challenge to manage such complex network, why the region currently is making a united effort to increase value for their patients (VGR, 2018). The network aims to use existing resources more efficiently, which are planned to be achieved by dividing healthcare into four focus areas; proximity-based care, concentration of care, digitalization and quality-driven healthcare development (VGR, 2018).

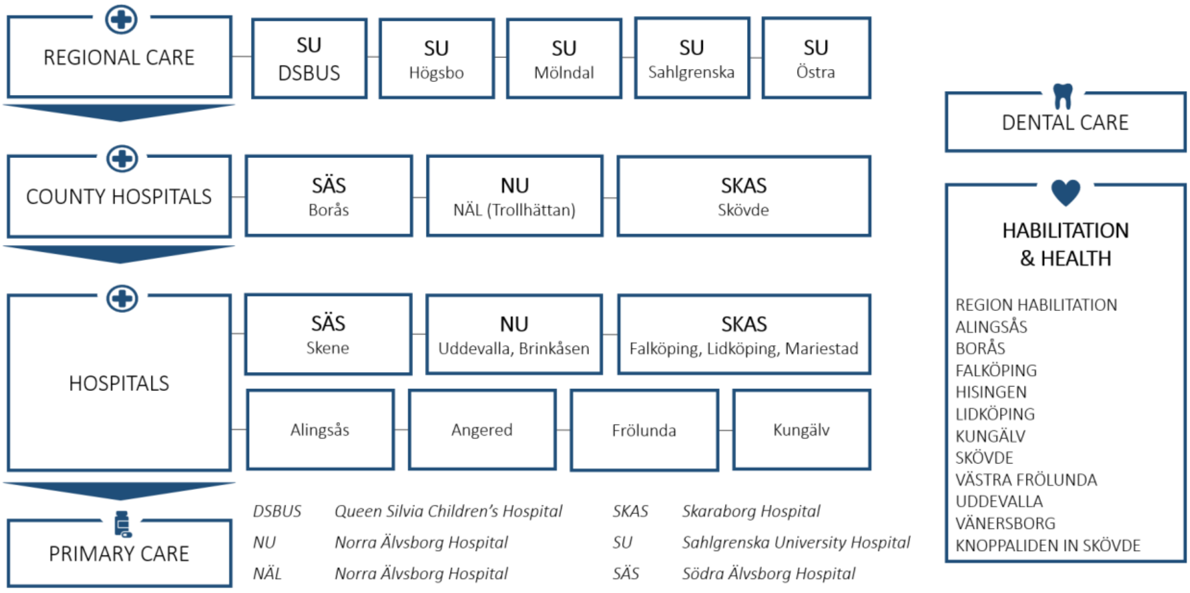

Figure 2: Overview of healthcare in Region Västra Götaland (VGR).

Per Gustafsson is a pulmonology paediatric and an associate professor, who has worked at both DBSUS and Skövde Hospital for many years. Gustafsson has developed several solutions for respiratory issues and is well-known internationally for his research and innovations (Astma- & Allergilinjen, n.d.). In 2015, Gustafsson and his colleagues established a specific respiratory team at the clinic of child and adolescents (BUM) at Skövde Hospital. One reason for establishing the team was the habilitations lack of competence and experience of respiratory issues. The habilitations also lacked appropriate treatment, why they could not manage the children with structured and proactive respiratory care (Gustafsson and Kadar, 2017). The respiratory team at Skövde Hospital are working structured with cross-functional competencies in a team of two paediatricians, one nurse and one physiotherapist. The team are working with investigation, treatment and follow-up of children with or risk for respiratory complications. In 2017 the team had about 75 registered children with various health issues and respiratory functions, whereof about 15 children with severe CP and/or PIMD. Except from Skövde Hospital, healthcare is mainly provided from habilitation Knoppaliden in Skövde and the Region Hospital of VGR, Queen Silvia Children's Hospital in Gothenburg (DSBUS). Before the respiratory team's existence, the children did not meet any pulmonologist at a regular basis. In case of respiratory issues, the families went to the emergency care and every time they met new healthcare professionals with scarce or no knowledge of their child's medical history.

1.2 PROBLEM DESCRIPTION

The empirical literature about children with CP and the correlation to respiratory issues is described as scarce, even though the issues are very common (Blackmore et al., 2016). First in recent years respiratory issues of this patient group have been emphasized, both national and international (Gustafsson and Kadar, 2017). Since this patient group has been unprioritized for so many years the proactive healthcare has been too (Gustafsson and Kadar, 2017). The Swedish healthcare network still lacks regional, national and international guidelines for how investigation, treatment and follow-up of respiratory issues should be managed and coordinated for the children (Gustafsson, 2017). Different surveillance programs with guidelines and recommendations for individuals with CP have existed in Sweden and Europe for decades, but none of them focus on respiratory issues. A Nordic surveillance program called CPUP follows hip dislocations and severe contractures of children with CP and researchers now stress the need of a similar follow-up program for scoliosis problems (CPUP, 2013; Hägglund et al., 2018). The lack of surveillance programs and guidelines of respiratory issues is significant since respiratory failure is the most common cause of death for individuals with CP (Fitzgerald et al., 2009; Himmelmann and Sundh, 2015). Especially since children with severe CP only have 60 % chance to survive until 20 years of age (Westbom et al., 2011).

A family's network of key actors, including the respiratory team at Skövde Hospital, is visualized in *Figure 3*. Children with severe CP and/or PIMD not belonging to Skövde Hospital are assumed to get their respiratory issues managed by other hospitals and habilitations within VGR, but how and whether the treatment is proactive and adequate or not is not known. Therefore, each actor within the network is assumed to manage respiratory issues of children with severe CP and/or PIMD independently, without sufficient knowledge of how other actors work. The actors within the families' network, such as habilitations and hospitals, have different knowledge, skills and perspectives of this patient group, and in turn different opinions of what treatment is adequate and not. Due to Sweden's decentralized healthcare system, activities are often performed without any greater knowledge of what other actors are doing (Eriksson, 2016). Since the system lacks professionals who coordinates the network actor's contribution, no one has a holistic view of the children's health or their ongoing and planned treatments (Ylvén, 2017). The care for these children and their families are assumed to be both diverse and unequal with various levels of medical quality. In turn, each families' language skills, socioeconomic background and living area are some factors that have impact on the healthcare outcome (Eriksson, 2016). These challenges, in combination with the lack of integrated and coordinated care provided from the patients' network, are assumed to reduce the families' overall well-being and health (Eriksson, 2016).

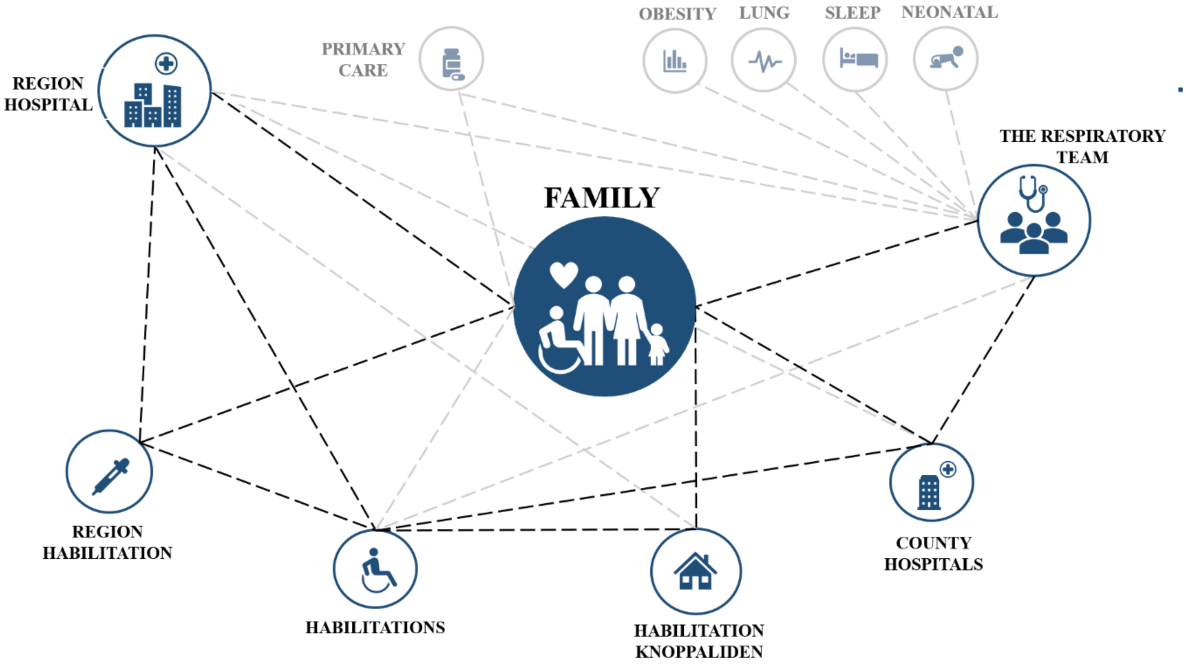

Figure 3: Overview of a family's network with key actors focused in this study.

As many others do the respiratory team at Skövde Hospital lack enough knowledge and a complete overview of the families' needs and expectations. Even though the respiratory team has existed since 2015 they have never done any kind of evaluation or assessment of their working methods. The team is not sure whether their working methods are adequate and efficient enough or what could be improved to increase the families' well-being. Routines and documents are scarce and as the number of children increase it is getting more challenging to manage and control their work. The team does not either have knowledge of the families' expectations or whether they are meeting their needs or not. The team is also interested in how other habilitations and hospitals in the network are managing these children's respiratory issues.

The respiratory team have request information about the families' well-being, their expectations and their needs. They are interested in how habilitations, the regional hospital DSBUS and the other county hospitals, Södra Älvsborg Hospital (SÄS) and Norra Älvsborg Hospital (NÄL), are working with respiratory issues of children with severe CP and/or PIMD. The three other hospitals and habilitations are from now on included in a network referred as the VGR network. That means the respiratory team would like to know whether the actors within the VGR network are managing these children's respiratory issues in a proactive and structured way or not. To collect information of these questions the research study is divided into three main areas;

- The respiratory team's processes, focusing on family-centred care and efficiency
- The lack of knowledge of the families' well-being, whether the respiratory team meet their needs or not
- The lack of knowledge of how healthcare actors in the VGR network are managing respiratory issues of children with severe CP and/or PIMD, and their belonging family

1.3 PURPOSE

The purpose of this study is to increase the understanding of how the needs of families to children with severe CP and/or PIMD are managed by the respiratory team at Skövde Hospital and other actors in the network. Other healthcare actors are the habilitation clinics and the hospitals within VGR, both at regional and county level. To understand how the respiratory team and the actors within the VGR network are working with these families' complex care needs the study is divided into three different perspectives; the respiratory team at Skövde Hospital, the VGR network and the families. The gained understanding will act as foundation for suggestions of improvements, which the team and other actors can realize to facilitate for families and improve their well-being. The study aims to contribute with knowledge of whether the respiratory team are meeting the families' needs or not and to compare their working methods with how other healthcare actors are managing respiratory issues of families to children with severe CP and/or PIMD. Furthermore, the identified knowledge from the study is important since it is applicable at other patient groups with similar challenges and diseases. The study will contribute with knowledge to VGR and in their initiative of improving healthcare for children and adolescents with complex care needs. By the investigation of the respiratory team, the VGR network, the families and the relationships between them, the study contributes to an overview of current situation of these families' well-being and how respiratory issues are managed by various actors within VGR. Finally, the study makes an overall contribution to the area of improvement science, including theory from the service logic and family-centred care.

1.4 RESEARCH QUESTIONS

To understand how the respiratory team and the actors in the VGR network are working with these families' complex care needs, and to suggest improvements, the study is based on two research questions. The first research question focuses on the interactions and relationships between the respiratory team, the VGR network and the families. The first research question contributes with information of how the respiratory team is working and whether they are meeting the family's needs or not. Additionally, it contributes with information of how the other actors with the VGR network are managing respiratory issues of families to children with severe

CP and/or PIMD. The second research question gives concrete suggestions of improvements to facilitate for families and increase their well-being. These suggestions stress what initiatives the respiratory team and other healthcare actors can do to improve when managing families with complex needs, focusing on network and family-centred care. The research questions are;

Research Questions I

How are the needs of families to children with severe CP and/or PIMD managed by the respiratory team and the VGR network?

Research Question II

How can the respiratory team and the VGR network improve their work in order to better meet the needs of the patient group and their families?

1.5 DELIMITATIONS

The study has several delimitations, which were decided in the beginning of the research. The study does only emphasize children with CP and/or PIMD, even though the respiratory team manage other patient groups as well. It focuses on four families belonging to Skövde Hospital, even though other families were observed and talked to during the hospital appointments. Since it was the respiratory team who chose the four families to interview this might have affected the result, as they could choose families they knew would answer in a specific way. Furthermore, the study did only include habilitations and hospitals from VGR.

2 THEORETICAL FRAMEWORK

This chapter presents the theoretical framework, divided into three main sections. The first section describes the theory of improvement science, while section two and three describes the complementing theory of service logic and family centred care.

The study was conducted from the perspective of improvement science, which is a theory that explicitly aims to contribute to the development of healthcare. For recent years the theory of improvement science has been criticized by several researchers, such as treating healthcare in isolation as well as having lack of patient perspective (Bergman et al., 2015a; Eriksson, 2016; Lifvergren et al., 2015). To achieve a holistic view and understand the complex setting, additional theory of concepts and models are added to the study. Therefore, the theory of improvement science will be extended by including the theory from service logic, network logic and family-centred care. This since the theory of improvement science usually treat healthcare as an isolated question, without consideration of other non-healthcare actors in the network or a family-centred care focus. By including service- and network logic, improvement science goes beyond the perspective of healthcare and includes other actors, such as social services.

2.1 IMPROVEMENT SCIENCE

Since the early 2000s quality management has contributed to the establishment of a new field of theory within healthcare - improvement science (Batalden and Davidoff, 2007; Berwick, 2008). As known is the theory of improvement science focusing on development of healthcare. Lifvergren et. al (2015) and Dixon-Woods et al. (2014) emphasize important aspects to achieve within the theory of improvement science, such as the importance of maintaining constant focus and establishing a vision with clear and understandable goals. Therefore, to develop a system based on safety and quality for patients, the system requires a well-established and anchored culture (Dixon-Woods et al., 2014; Lifvergren et al., 2015).

Usually processes are cross-functional and performed by actors within various functions (Hunt, 1996). A process is the step(s) in between every input and output, which can be performed by different actors and have different contents, e.g. administrative processes or customer processes (Hunt, 1996). But many times, steps within a process are unnecessary and inefficient for the overall process (Hunt, 1996). Such unnecessary steps should be eliminated, improved or simplified to make the healthcare system more efficient, which in turn could improve the patients' well-being and health (Hunt, 1996). In other words, there are many different steps, which is not always known or obvious, to change to improve the healthcare efficiency.

To achieve additional improvements within healthcare other aspects needs to be included as well, e.g. aspects from organizational knowledge (Lifvergren, 2013; Linderman et al., 2004). By integrating methods of creating, sharing and retaining both explicit and tacit knowledge (Linderman et al., 2004), other kinds of improvements can be achieved as well. Another solution to achieve additional improvements within healthcare is to develop well-integrated and coordinated multidisciplinary teams (OECD, 2017). This is beneficial for many reasons, such as to reduce duplication of work and improve the patient's well-being (OECD, 2017; Purdy, 2010; WHO, 2013). Even though researchers recommend professionals to work in teams, a team can also be fragile and unstable. For instance, the stability of a team and processes within it, can be affected when the group makes changes. The stability and efficiency could be affected by changing team members or making organizational transformations (Lemieux-Charles and McGuire, 2006). Changes in a team will affect the team's communication, coordination and cooperation as well as the overall climate within the team (Lemieux-Charles and McGuire, 2006). Marks et al. (2001) stress the challenge of being active in multiple teams, where boundaries between teams not always are clear and the teams many times aims for different goals. That means the professionals are members of teams with different goals and in turn issues to prioritize between each team's goals and objectives.

2.2 SERVICE LOGIC

The theory of service logic is included in the study to go beyond the traditional focus of internal operations and enable the patients to be co-creators of their own care (Bergman et al., 2015a; Lifvergren et al., 2015). As the theory of service logic does not take other actors into account, the theory of network logic is added to include the view of both healthcare and non-healthcare actors within the network as well (Christensen et al., 2009). Moreover, as the study focuses on families to children with complex care needs, the theory of family-centred care is included to cover the perspective of the families. The first two sections, 2.2.1 Customer as a creator of value and 2.2.2 Network logic, are two central parts of the theory of service logic. The third section, 2.3 Family centred-care, is a complement to service logic within a healthcare setting.

2.2.1 Customer as creator of value

Among many others Normann (2001) and Vargo and Lusch (2004a; 2008) change the traditional perspective of value creation. Instead of seeing value creation from the organization's perspective they change and see the creation from the customer's view. In this concept focus are placed on the experiences of the patient, rather than on those working within the organization (Kristensson, 2009; Osborne et al., 2012). The concept of service-dominant logic implicates the customer as an active co-creator, rather than a passive recipient as he or she has been historically (Vargo and Lusch, 2004a; 2008). Since the study takes place within a healthcare setting the customer will be referred as patient or child and service-dominant logic will be referred as only service logic (Normann, 2001). Many researchers have emphasized the perspective from the customers view. McColl et al. (2012, p.375) is one example, who defines customer value co-creation as:

> "*a benefit realized from integration of resources through activities and interactions with collaborators in the customer's service network.*"

However, Normann (2001) has criticized the healthcare system for focusing too much on curing the disease, rather than supporting the processes of proactive work and achieving increased health. In the concept of service logic, the patient is responsible for maintaining its own health by various activities, such as eating healthy, sleeping well and exercising. The healthcare system is having challenges with patient involvement, why it should be relevant to integrate patients as co-creators of value to improve their health and well-being (Nordgren, 2009). Though, it is important that the organization find the right activities of value-creation and align them with each patient's prerequisites (Normann and Ramiréz, 1994; Nordgren, 2009) It is also important that the organization provide adequate possibilities to the professionals, so they can support the patients in their co-creation (Nordgren, 2009). This should be of special importance for the families within the case setting, since their children are dependent upon their parents and the help and support from them.

Service logic is characterized by exchange of information, such as asking and answering questions to each other (Vargo and Lusch, 2004a). To create value in this theory, the patient must be an active integrator of resources, where the organization only can offer value ideas (Vargo and Lusch, 2008). The interaction between the patient and the organization is therefore the link in the process of value creation (Nordgren, 2009). The interactions can exist with few or many actors within the network, where activities are defined as doing or performing (McColl et al., 2012). Activities occurs at different levels, where low-level activities are described as simpler, such as gathering information or compliance with the service provider. Examples of high-level activities are to actively search for information or giving feedback within the network (McColl et al., 2012). It is of importance to address that value neither can be produced or delivered from the caregiver to the customer within the concept of service logic (Vargo and Lusch, 2008). Eriksson (2016) explain that a patient can integrate resources from other people, such as family members, which is benefit as family members have competence and skills that could be of value for the other network actors (Eriksson, 2016).

2.2.2 Network logic

Today's fragmented healthcare system is not really an example of efficient resource utilization (Christensen et al., 2009). In a successful and efficient system, or so-called network, the actors are integrating and reinforcing each other's work (Christensen et al., 2009). For instance, efficiency could be achieved by having someone else than the physician providing the patient with routines and standards, such as the nurse (Christensen et al., 2009). Problems with integration of actors is nothing new and has existed for a long time. Two researchers, Normann and Ramírez (1993), emphasize the relationship between providers and customers by replacing the traditional value chain with a value network. According to them is the key for achieving success to redesign the actors into a value constellation instead of the traditional value chain. By reorganizing the roles and relationships new constellation and other opportunities will arise and create new work results (Normann and Ramírez, 1993). Moreover, the more actors within a network, the more complex it gets. To enable co-creation of value in a complex network Stabell and Fjeldstad (1998) has developed a variant of the network model. Within their model the network has a common pool of funds, which link indirect actors to each other (Stabell and Fjeldstad, 1998). One or several individuals are responsible mediators to enable efficiently and simultaneously multileveled activities. Mediators establish, monitor and terminate the direct and indirect relationships in the network (Stabell and Fjeldstad, 1998). The composition and size of the network needs to be emphasized and continuously adjusted to avoid unbalance. Geographically spread actors extend the network and therefore requires higher demands of coordination. To simplify even more, inter-networks or sub-networks can be established, based on various agreements (Stabell and Fjeldstad, 1998).

2.3 FAMILY-CENTRED CARE

Living a life with a chronic ill family member is demanding, which is why the theory of family-centred care is included as an extended theory within the study. Since children with severe CP and/or PIMD lacks the ability to clearly express opinions and needs, their families' competence and expertise needs be considered and included as an important aspect as well. The medical quality of neonatal, paediatric and adolescent healthcare depends upon to what degree the family members are involved in the support (Shelton and Stepanek, 1994). Professionals must know that the families need of control varies over time, which depends on their current capabilities and needs within different areas (Shelton and Stepanek, 1994). Since the parents are the truly cornerstones within the care of a child is it significant to understand the variances in needs to achieve successful collaboration between families and professionals.

However, the degree of collaboration between professionals and parents has changed during the years, where parents have not always been as involved as they are today. The model of family service and how professionals should manage families have developed and changed from low degree of family involvement to high degree of family involvement (Shelton and Stepanek, 1994). Historically, families have been viewed as incapable to solve challenges and issues related to having a child with complex care needs. At that time, professionals were the ones who delivered services of care and support to families of children with complex care needs (Shelton and Stepanek, 1994). First some years later, families got more responsibility, even though they still had limited options to make choices and decisions about care and support. The model of family service developed additionally and changed into a family-focused model, where the collaboration between professionals and parents became important. At this time the families were still viewed as service consumers, continuously in a need of professionals' guidance and advice. Finally, the model developed into a family-centred care model, which focused on the perspective of the family. Within this model the family contributes with expertise and competence, rather than being consumers of services from others. Family-centred care is built on true partnership, where the family is integrated as members of the healthcare team. Within this approach the family and professionals share own perspectives to create mutual benefits (Shelton and Stepanek, 1994). It is of importance not to view the family as objects but to treat them with fullest respect as they are the ones who are the experts on their own child and valuable for improving and maintaining their health (Shelton and Stepanek 1994).

2.4 SUMMARIZE OF THE THEORETICAL FRAMEWORK

By including the approach of service- and network logic, the study can focus on how families co-created value in interaction with other actors from the network, rather than being passive receivers of care (McColl-Kennedy et al., 2012; Vargo and Lusch, 2008). Since the study focuses on families with children of complex care needs, the theory of family-centred care was included to emphasize the perspective of the family. The theory of family-centred care was of special use within the study as the children had limited options to express their needs and co-create value by themselves. This combination of theories was of importance since a network requires coordination between actors to achieve successful help and support for families to children with complex and multiple disabilities (Ylvén, 2017).

3 METHODOLOGY

This chapter present the methodology used to conduct the re-search. The first section describes the research approach with an explanation of the chosen research strategy and research approach. The second section describes the methods of the data collection and the data analysis. The third section emphasizes the reliability and validity of the chosen methodology, while the fourth and last section describes the ethical consideration of the study.

3.1 RESEARCH APPROACH

3.1.1 Research strategy

According to Bryman and Bell (2011) the researcher can choose to conduct a study based mainly on a qualitative or a quantitative strategy. The two research strategies aim for various achievements and includes different methods. A qualitative study emphasizes the understanding of an individual's behavior and experiences as well as organizational culture. The second alternative, a quantitative study, aims to create theories and patterns, and requires measurable data (Bryman and Bell, 2011). Since this study aimed to understand interactions, relationships and processes with healthcare actors and families, the appropriate strategy to use was the qualitative approach. Furthermore, the study was conducted as a single abductive case study, which according to Yin (2003) is a preferred method when answering questions like *how* and *what*. Such method was suitable for this research since it involved actors from a real-life context. Moreover, a so-called abductive method was appropriate since empirical data was mixed with theory in an iterative process to develop new theory (Bryman and Bell, 2011).

3.1.2 Research process

The study was divided into three perspectives; the respiratory team at Skövde Hospital, the VGR network, including hospitals and habilitations, and the families. Research questions and focus areas was then created, such as family-involvement and network collaboration. Simultaneously was theory of service logic, network logic and family-centred care collected and searched for in books, scientific papers and websites, such as Chalmers Library, Google Scholar, Pubmed and ResearchGate. Qualitative data was collected, analysed and compared with theories until the researcher had enough data to discuss and answer the research questions.

3.2 DATA COLLECTION

To increase the validity the study followed recommendations of a mixed data collection method (Yin, 2003). The following sections describes the different methods for the data collection. Most of the data was based on qualitative interviews and observations. A small part of the data was collected by e-mail and phone calls, which not will be described more deeply as they are complementary information. Data was collected until saturation was achieved, which was when no new information was identified (Wray et al., 2007). The study finished the data collection when the same patterns were identified, and the researcher had a better understanding.

3.2.1 Direct and indirect semi-structured interviews

The study used the approaches of direct and indirect semi-structured interviews. Semi-structured interviews were used to have the flexibility to make changes and ask additional questions afterwards. This method enabled the interviews to be more as open dialogues and is recommended to use when making qualitative research studies (Bryman and Bell, 2011). The researcher created questions within different areas, which was used as guidance throughout all interviews. Creating guidelines is a recommended method to ensure that the interviews covers the research areas. Thus, the questions were constructed in such way they invited to open and describing discussions within various areas, such as habilitation, healthcare and coordinated care. Furthermore, the questions were adjusted to suit each respondent.

Direct semi-structured interviews were used with four families and took place in their homes or at another place that they suggested. The families could choose to be interviewed in pairs or individually, whatever felt most comfortable. Three interviews with the families were conducted with both parents and one interview with one of the parents. Depending on whether the interviews were held with one or two individuals it may have affected the result since they either could encourage or hinder each other. The respiratory team selected the families and then made the initial contact with each of them. The selection of families may have affected the result in such way the team could steer the chosen families to the ones they preferred. This is discussed in *7.2 Critical considerations.*

The reasons for using direct interviews with the families were many, such as to create confidence and gain trust. Depending on whether the interviews were held with one or two individuals can it have affected the result since their answers either could encourage or inhibit each other. Moreover, by meeting face-to-face could the researcher accomplish more deep and close interviews as well as interpret body language, expressions and relationships between the family members. Face-to-face interviews are recommended to use when aiming for collecting more deep data and having the possibility to make non-verbal observations (Sarantakos, 1998). Even though each family were unique with their stories, expectations, needs and perceptions, the researcher did reach saturation after four interviews. The families had different stories but after a while similar patterns could be identified.

Indirect semi-structured interviews were held at different organizational levels to gather diverse opinions and perspectives within the system. Because of the geographical distribution and time limit indirect semi-structured interviews were held over phone. These interviews did not have the same requirements since the study focused on the families and their opinions and thoughts. It is recommended to use telephone to collect quick and brief data (Sarantakos, 1998), which was an appropriate method for this data collection. The researcher was familiar with various kinds of challenges of this technique. One example is the increased risk of missing out on non-verbal language (Sarantakos, 1998), such as body language and interpret facial expressions. The actors who were interviewed over phone were the respiratory team at Skövde Hospital, all habilitation clinics as well as three other hospitals within the region. Mainly a pulmonologists or physiotherapist was interviewed, but at some hospitals also healthcare managers were interviewed. The reason for conducting interviews with different network actors was to gain a better understanding and a wider insight of the whole network and if and how each ones' contribution related to other ones. By listening to many respondents, they could contribute with different perspectives and opinions, which in turn was advantageous since it increased the trustworthiness for the study. Questions were created and adjusted to suit each professional but still contained questions within common areas. Most of the questions covered the areas of communication, documentation, roles, responsibility, respiratory treatment, collaboration and coordination. The answers were audio recorded but not transcribed. Instead the researcher wrote down the most significant information into a computer directly to save time. The interviews continued until they had provided enough data for the study.

Table 2: Overview of professionals interviewed in the study.

Professional	Skövde Hospital	Hospital A	Hospital B	Hospital C	Habilitations
Physician	2	2	2		2
Physioterapeut	1	1			8
Nurse	1				
Other*	2	2	1	1	2

*Leaders, process leaders, managers of BUM, managers and professionals from the habilitations.

3.2.2 Observations

Different kinds of observation methods were used in the study, both unstructured and participant observations. The purpose of the observations was to gain wider and deeper knowledge and understanding of the families, the respiratory team, the network and their relationships in between. The study mainly includes data from observations of the families and the respiratory team at Skövde Hospital. Some data were also collected by making observations at two conferences in Gothenburg for three days in total. The aim of participating in these conferences was to gain knowledge of CP and VGR's work with person-centred care. These conferences consisted of lectures by change managers, physicians, patients and researchers from Sweden, England, Norway and Denmark. The conferences focused on CP, research, partnership between patients and actors, patient involvement and co-creation of value. One advantage of observations is that gathered information can be used as a complement to other data collection methods, such as interviews (Pawar, 2004). Moreover, an unstructured approach was used when the researcher aimed for a specific purpose, such as observing the teams' communication methods or how they involved the patients. This approach is recommended when working with more open and flexible observations. Other times the researcher used more of a participant or non-participant approach. The researcher participated in the observations by asking questions to the families, the respiratory team and other actors. Other times the researcher just observed without asking any questions. The observations varied and depended on the situation and the aim. It is recommended to use participant observations when the researcher wants to interact with the respondents (Pawar, 2004).

3.2.3 Data analysis

After the data collection the gathered information was analysed at various levels. Since the research included both interviews and observations within a healthcare setting the approach of latent content was used to analyse the data (Downe-Wamboldt, 1992; Kondracki et al., 2002). This method deals with the underlying meaning of the data by making a deeper interpretation of it. The data from interviews and observations was used as a unit for analysis as researchers recommend (Graneheim and Lundmans, 2003). The last analysis created different sub-themes, whereof some of them were alike or similar to others. However, a map of the respiratory team's, the VGR network and the families' relationship as a network was established. A timeline of one of the families' medical history and a summarized table of the four families was created. A table of the habilitations and the hospitals was created to create a comparison easy to understand. By linking data to the theoretical framework interpretations of the meaning could be made. Going back and forth between the theoretical framework and the result generated an analysis from both empirical and theoretical perspectives. The analysis presents how the respiratory team's, the VGR network and the families are managing respiratory issues of children with severe CP and/or PIMD. It investigates the degree of family-centred care, and whether the patient's life situation has changed since they got in contact with the respiratory team or not. Finally, new understandings and insights drawn from the linking will be emphasized later in the study.

3.3 TRUSTWORTHINESS

To achieve as trustworthy research as possible, the study must be analysed and compared with the methods of generating data (Graneheim and Lundman, 2003). If the research findings can be described in such way that the reader can transfer the finding to another context, the trustworthiness will increase. To describe trustworthiness in a qualitative research three concepts are usually emphasized; credibility, dependability and transferability. The concept of credibility covers the confidence in how data and processes of the analyse is linked to the focus of the research. By including participants of various experiences, ages and genders the participant can contribute with different views of the research question. It is also of importance to choose a method well suited, depending on the data collection, amount of data as well as the complexity. Credibility also cover the categorizing of data in such way that no irrelevant data is included. The second concept of trustworthiness is dependability, which focus on instability and changes. Data is not always stable since it may change due to various reasons, such as extendedness or decision making. During interviews or observations, a need for asking following questions may arise, which sometimes can be an advantage as new data can create new insights. The third and last concept deals with trustworthiness in terms of transferability. The study aims for transferring the result to improve healthcare for other patient groups, why transferability is of special importance in this study. By giving suggestions the researcher create opportunities for the reader to use the findings and transfer them to other groups (Graneheim and Lundman, 2003). This can be achieved by describing the context, participants characteristics and the collection and analysis of data. It is also recommended to use quotations in combination as the result is presented.

3.4 ETHICAL CONSIDERATIONS

To avoid doing any harm to the participants the study includes ethical aspects. There are several factors that could affect the participants and non-participants of the study. Bryman et. al (2011) makes a comprehensive explanation of four significant ethical principles, which are recommended to be used for classification of ethical principles. These covers the aspects of doing any harm to the participants, whether the study involves deception or not, and if there is any lack of informed consent. The last principle covers whether there is a privacy invasion or not. The study involved several actions to inhibit these principles. All ethical aspects were discussed with the two supervisors, one of the managers at the hospital as well as one of the physicians. Ethical considerations were not only discussed and managed with several experienced professionals. Afterwards a secrecy agreement patient information was signed by the researcher. The researcher wrote a formal application at the habilitation to get approval of making the data collection. All direct interviewed participants received a letter with detailed information of the study. The letter explained the aim, interview length and information of the audio recording. Further, it included information of their participation, that it was voluntary and that they could terminate it whenever they wanted to. At last it informed that the answers would be managed confidential, and that they as participants were anonymous and were not going to be identified as individuals. The respondents got the information that their answers were going to be used as material to the paper and then be published on the internet. Thus, to avoid doing any harm, all participants had the opportunity to read through the paper and accept the content before the publishing. Finally, to make the participants feel comfortable they could choose interview location, such as their home or at the hospital.

4 EMPIRICAL FINDINGS

The following chapter describes the empirical findings divided into the three perspectives; the respiratory team, the VGR network and the families, each one categorized into focus areas.

4.1 THE RESPIRATORY TEAM AT SKÖVDE HOSPITAL

The following sections discuss the respiratory team and the team's establishment, their roles and responsibilities as well as their challenges. The team's working methods will be emphasized as well, such as their communication and documentation methods, routines and meeting structure. Relationships with other actors within the network will be discussed, focusing on the team's relationship with the families and Knoppaliden, a special habilitation clinic.

4.1.1 The need of a respiratory team

Year after year the professionals had witnessed lack of adequate and proactive respiration treatment of children with severe CP and/or PIMD. A proactive treatment of these children's respiratory issues had been a demand for many years, but due to many complex issues and many actors involved, no one had taken the main responsibility. Another reason for reactive respiratory care was the lack of resources, knowledge and competence to identify respiratory issues or potential risk factors for such ones. In general, the Region Hospital lacked resources and the habilitations lacked knowledge and experience. One of the paediatric pulmonologists, who had worked at Skövde Hospital for many years explained the children's need for care:

> The children may have healthy pulmonary function at first, but because of scoliosis, spasticity and other factors they often develop pneumonia and in worst case they die an early death.

When Skövde Hospital recruited a second paediatric pulmonologist these two pulmonologists felt strong and competent enough to establish their own respiratory team of five professionals to treat children with respiratory issues in a proactively and structured way. Since the start in 2015 the team still aims to work with proactive and structured respiratory care. One of the pulmonologists explained the history behind, why the hospital was in such a need of a team:

> The habilitation should have managed these issues in a proactive way, but they did not. They forgot to manage the most crucial aspect of these children's lives - their respiration. It is quite strange since the habilitation takes responsibility for making their lives as good as possible in other ways. Instead BUM needed to take the responsibility, often when the children already had crashed.

The physician continued to explain the importance of proactive respiratory treatment:

> It is crucial for children with multiple disabilities and chronic respiratory issues to get holistic treatment from a multi-professional team. It requires a broad paediatric pulmonary management.

The same physician stressed today's lack of management and clear responsibilities:

> Who is responsible for these children? Who is working proactive with their respiration issues? Maybe that is the problem - where the border is and who should take responsible for what? The Region Hospital? The habilitation? BUM? Due to this uncertainty these children and families are falling in between cracks. This is a question that healthcare and habilitation need to agree upon.

The nurse explained her perspective and emphasized the need of developed collaboration:

> Back in the days, no one really paid attention to these children. We really want to improve their life and well-being and these children can stay healthy for a longer time if we manage their respiration.

The manager of BUM was positive to the idea of a respiratory team at the hospital and the management at the hospital were overall positive to improvements and developments. The management's acceptance of a respiratory team was of course a significant aspect as the physicians probably not could have established the team without their agreement.

4.1.2 Roles and responsibilities within the respiratory team

One of the physicians emphasized the benefits of working as a cross-functional team with broad competence. He stressed the importance of consensus and the advantage of knowledge sharing:

> We need to work as a team in a structural way, otherwise we will never reach success and give a holistic care. Working as a team as we do make the whole system less vulnerable.

As a cross-functional team they had beneficial differences. The team consisted of both women and men, different nationalities, various ages and mixed personalities. The members had various history of education, experiences and competences. Roles and responsibilities within the team were clearly divided and well-structured. The physician who had been working at the hospital for many years was a paediatric pneumologist and researcher and was slowly retiring and phasing out his work. This paediatric pneumologist will from now on be referred to as the mentoring physician in the study. The mentoring physician was described by his colleagues as competent and ambitious, with beneficial authorities. His knowledge and competence after his many years as a paediatric pneumologist and researcher was a great advantage for the team. The other physician was also a paediatric pneumologist and researcher, who currently was the formal leader of the team. He moved to Sweden just a few years ago and was described as a skilled pneumologist by the team. The mentoring physician described him as follows:

> He is an extremely competent, experienced and fast thinking paediatric pneumologist. He can identify very severe pneumonia and is probably more competent than anyone else in Sweden. If something happens to him everything in the respiratory team will fall apart.

The mentoring physician was rarely involved in the team anymore and as the formal leader had other work areas too, the number of available appointments for patients was very limited. The team's physiotherapist worked at both BUM and the clinic of physiotherapeutic, which many times was a challenge regarding what prioritizations she needed to decide upon. She had responsibility for the technical area, such as prescribing and follow-up on equipment. Another challenge was the storage of equipment, which was not stored at BUM, why she wasted time going back and forth between the clinics to get material. Otherwise she was satisfied with her work in the respiratory team and her development since the start, mainly due to her patient experience and learning from the physicians. The team's nurse was responsible for coordinating the team, the patients and the communication with other network actors. She worked full time at the daycare of BUM, either with the respiratory team or with her other daycare patients.

4.1.3 The respiratory team's working methods

The team's main process consisted of three sub-processes: investigation, treatment and follow-up of respiratory issues, *Figure 4*. To be as efficient as possible, without losing the benefits of being a team, the team members did not participate at all patient appointments together. Most often they were two professionals for one hour, usually the physiotherapist and the physician. At the same time the nurse coordinated administrative tasks, such as booking patients or communicating with network actors. During the study, patients did sometimes not show up at the hospital at all. The reason for this was uncertain, but probably had the families forgotten the appointment time or not achieved the referral in time. Even though patients within VGR could get a SMS notification, the team was not completely aware of this service. That extra hour when a patient did not show up gave the team time to organize, plan and discuss their work.

Figure 4: The main process of the respiratory team divided into investigation, treatment and follow-up.

Every week the nurse scheduled one hour for emergency appointments, which was appreciated by the team since it gave them a flexibility to meet patients in need of acute care. The scheduling was otherwise a big challenge since all members within the team had multiple working areas, teams and responsibilities. The nurse always tried to facilitate by co-coordinating appointments for the families, so they could avoid traveling to the hospital more than necessary. It took some time to schedule, send referrals and contact social services, but if she only had time without getting disturbed, she could manage it. The respiratory team communicated mostly by direct conversations face-to-face or through the information system, which they were satisfied with:

> We have an open climate and it is very much like a democracy. The physician has the medical responsibility, but we discuss, resonate and make decisions together.

Unfortunately, the team lacked enough time for their patients, which resulted in no or little time to plan, discuss and develop their working methods. Even though the team used all hours for patients, they still lacked time to meet all patients as well as developing their work. Additional children with respiratory issues or risk of developing it existed at other clinics at Skövde Hospital, but since the team lacked time to manage the current number of 75 children, they were afraid of developing their collaboration with other clinics. The number of patients had grown since the start in 2015, *Table* 3, but the resources were still the same. An increased number of patients without extra resources would affect the current patients and their work too much.

Table 3: The number of patients managed by the respiratory team in 2015 and 2017.

Year	2015	2017
Number of patients	62	75

The team was enthusiastic in their work with patients but was limited by resources and the lack of understanding from other professionals. One of the team members explained the situation:

> There is a continuous lack of resources. My manager has requested if I could cut some work from the respiratory team, but that would be a disaster! These children really need us.

Lack of resources in terms of time was one of their biggest challenges and the absence of compiled information of patients and equipment created additional challenges for them. Not only so they could have an updated overview of their patients to plan treatments, but also to have time to establish standards and routines to achieve efficiency. The team's lack of common collaboration routines with other clinics created other challenges in terms of uncertainties, such as questions about responsibilities and referral information. The employee turnover within the team was another great challenge. For three years the team had already lost two physiotherapists and during the study the nurse terminated her job. The employee turnover was a problem in many aspects, such as the loss of knowledge and trust as well as the team collaboration methods they had established. After working together for so long they knew each other well and could work efficient as well as flexible. One of the physicians talked about their vulnerability of losing competence to other healthcare actors:

> Our most experienced physiotherapist just terminated her job and our nurse will quit the team in just a few weeks. Both got better job offers at other places, which is such an unfortunate.

The nurse had asked her manager to start with the handover several months before her last day, so that she could share her knowledge to the new nurse. Just one or two days before she quit, not one, but two new coordinators started. She had no chance at all to share everything she wanted too and before she quit, she was worried about the handover. The physiotherapist was also worried and explained her concern about the team's future:

> I do not know what we are going to do when she drops out of our team. She is the one organizing us and is the solid hub of our team. It is sad to lose her and the competence as well as knowledge she possesses. We know each other well and have established a great flow within the team. It will be a new process to have a new team member, where we all need to start over again.

However, to keep professionals within the team and to develop their competence, the team participated in various respiratory courses, both individually and as a team. This was very appreciated by all team members, who wished they could get even more education.

4.1.4 Relationships and collaboration with network actors

The team had connections to many healthcare and non-healthcare actors, such as other hospital clinics, the Region Hospital, county hospitals, habilitations, municipalities and county councils. It was mainly the coordinating nurse who had contact with non-healthcare actors, such as lawyers and schools. During the study several discussions of who had what responsibility within the network arose, e.g. whether it was the primary care or BUM at the hospital who had responsible for vaccination. Another challenge was un-updated rules and regulations about equipment, such as cough machines, CPAP and gastronomy feeding tubes. Innovations and developments were positive for these children's health, but also a challenge in terms of rules and regulations. The nurse explained the challenges for both the team and the families:

> We send the families' home with equipment's and machines. The challenge is the rules within the municipality and county councils, which does not keep up with the healthcare development.

As known, many of these children have a lot of other issues other than with their respiration. The team had frequent collaboration with the clinics of neonatal and sleep as well as the laboratory at lung function. More sporadic collaboration was with the clinic of ear, nose and throat as well as the cardiology and gastrostomy. The team sends some referrals to the Region Hospital, DSUBS in Gothenburg, such as for scoliosis surgeries. The communication before and after a surgery with DSBUS in Gothenburg was not working efficient though, where the respiratory team many times lacked information from DSBUS.

Routines for how to collaborate and manage network actors had neither been thoroughly discussed nor agreed upon with any of the other actors. Healthcare professionals lacked consensus regarding what care and support they should provide the children and when this should be done. For instance, some of the children had scoliosis braces that caused both pain and respiratory issues, which was something the physicians were very concerned about. Who decided about such treatment was neither obvious nor decided between the clinics.

However, the team's collaboration varied, and the closes one was with habilitation Knoppaliden. This cooperation was very appreciated by the respiratory team:

> Our collaboration with Knoppaliden is a huge advantage for us and the families. The system needs to start collaborating cross-functional over the boundaries. The overall coordination between

> habilitation and healthcare should be improved and this kind of collaboration should be performed at other places too. Such collaboration would help families as well as professionals.

The respiratory team and Knoppaliden had collaborated for many years, but it was not until the team was established that it improved and developed into a relationship with mutual benefits. The team had visited Knoppaliden to provide them with respiratory knowledge, so that they could create synergies and work more efficient. The nurse explained how Knoppaliden helped them with treatments and follow-ups and the advantages of their partnership:

> Our collaboration has improved our holistic perspective and the children are feeling much better.

The mentoring physician was satisfied with how they had solved the situation:

> The medical part is lacking within the habilitation. Since they do not have permanent physicians they do not have the competence. I do not think they should be responsible for the respiration since they do not have enough knowledge, but now when they have learned they can follow-up on treatments.

The respiratory team made the diagnosis, but the responsibility of treatment and follow-up was shared with the professionals at Knoppaliden. The physician was satisfied with the work processes at Knoppaliden since they studied the children during night and registered changes while the child was sleeping, which was not done at any other hospital or habilitation clinic. He wished that other habilitation clinic had more basic competence of respiratory issues:

> It would be very good if the habilitations had more knowledge of respiratory issues in general.

The physiotherapist had a similar opinion and shared her view of the current situation:

> It is great that we have the responsibility, but the collaboration should be developed. More simple equipment, such as PEP, should be managed in another way by the habilitation clinics. We meet most of the children with severe issues, but those with a little cough are not identified that easy and therefore not sent to us. The patients and their parents usually get the instructions of coming back in a year again and in the same time we lose the chance of proactive care.

The team expressed the need of someone with a holistic view that could help the families. The nurse explained her role, which only was a small part of a large network:

> The families have so many contacts and makes such a work coordinating all contacts and appointment. No one has a holistic view of these patients and there is no existing responsible coordinator, where I am just a small part of it.

Another challenge was the psychosocial aspect. The families should have been provided with support from the habilitations, but they had lack of resources to cover these needs. Neither could the respiratory team provide social workers, counsellors or psychologists and they were concerned about the lack of psychosocial support to the families. The mentoring physician stressed the importance of family-centred care and support:

> This is an extremely exposed group, with family members who gets affected. The psychosocial parts are important but very hard for us as to satisfy with current resources.

The other physician explained his view of the situation:

> It is so many psychological and social aspects that we just cannot ignore. The parents have struggled for 24 hours every day in 10-15 years. I cannot understand how they have coped with the situation for so long. I really wished we could help them more.

Additional one member explained the situation of the psychosocial resource shortage:

> It has been a shortage of counsellors and due to turnover, you never know whether there is anyone available right now or not. They do not need to be active in our team, but we would like to have the opportunity to call them and have a collaboration when needed.

4.1.5 The respiratory team's focus on family-centred care

The relationship between the team and the families varied and had developed over time. Both the team and the families were a bit careful in the beginning and the treatment could usually not start until they had built trust within their relationship. The physician explained the advantage of being the same team and meeting the same patients since you get to know each other after a while. The team tried to be as responsive as possible to the families' requests whether they wanted to meet once or several times a year. One of the team members emphasized the need of being cautious about the workload and said:

> We want to avoid the patients being hospitalized. They should not be suffering as they are doing. It is important to find a reasonable level of treatment the parents can cope with.

The team communicated with the families face-to-face or over phone when they were at home. They asked about the families' thoughts and opinions, and always communicated with their children. By prescribing equipment the team created opportunities for the families to co-create care at home. The team had some possibilities to provide medical rounds when the patients still were at home, such as analyzing data, but still lacked resources for this kind of work. The mentoring physician explained that the technology was there, but that they lacked resources for doing it. The other physician agreed and talked about the benefits of digitalization within healthcare. Even though the respiratory team had two physicians they had no access to the children's medical journal, which was a challenge for them to get a holistic view of their medical situation and health. Another challenge was the language barrier, which reduced the team's opportunities to provide and enable the families to work with co-created of care at home. Parents without language skills could neither call nor get acute help without having an interpreter, which was not always available for direct support.

4.1.6 The future of the respiratory team

The respiratory team was sure about their future - the team must remain, no matter what. The physician emphasized the importance of proactive respiratory care for these children:

> The situation gets critical if a child has mucus and then gets a pneumonia. In such case they are in a need of intensive acute hospitalization. If we can keep the lungs clean and healthy and avoid increased mucus, they can get an improved life quality and avoid hospitalization.

The team members were worried about the future respiratory care of the children without their existence. They knew the children's needs for help and treatment from them as a team:

> We cannot just ignore these children and argue that there is a lack of resources. The demand is already here and if you just open the door you will see it too.

The team emphasized their contribution of close and proactive respiration care and how the families could avoid traveling to Gothenburg as well as getting hospitalized due to their existence. The nurse explained her view of the team's future:

> I would be very surprised if the respiratory team did not exist in the future since these children are in such a need of our help. Our impression is that the children are feeling better due to reduced medical inlays and episodes of impairments. We are the only ones with this competence here in Skövde, so without our existence the only solution would be to travel to Gothenburg.

All members had the same opinion - the patient's respiratory and health had been improved and the team was certain about that their worked saved children and helped the families.

> We have noticed that the children survive instead of dying.

The large concern of the team today was the year when the children turn 18 years old. At that age the children would not belong to BUM and the respiratory team anymore, meaning they would not see a pulmonologist at a regular basis as they were today. When turning 18 years old, these children are managed by the primary care, which probably do not have the same competence about respiratory issues and identifying high risk individuals.

4.2 THE VGR NETWORK

Following chapter presents data from the VGR network, which is data from the habilitations, Hospital A, Hospital B and Hospital C within VGR.

4.2.1 The hospitals within the VGR network

The three hospitals Hospital A, Hospital B and Hospital C all had different methods for managing respiratory issues of children with CP and/or PIMD. Common challenges for all hospitals were lack of resources in terms of staff and adequate competencies and skills. Both Hospital A and Hospital C had respiratory teams in various size, while Hospital B neither had a respiratory team nor paediatricians with competence in lung and sleep medicine, *Table 4.*

Table 4: Summary of the three other hospitals management of respiratory issues, based on their own opinions and thoughts.

	Hospital A	**Hospital B**	**Hospital C**
Respiratory team (number of members)	Yes (20+)	No	Yes (2)
Proactive & structured respiratory care	No	No	No
Clear routines & responsibilities	No	No	No
Collaboration with habilitation clinics	Lack of	Yes	Yes
Respiratory competence & knowledge	Yes	No	Scarce

One of the managers at Hospital B explained that they lacked physicians with adequate competence and that they sent almost all their children to Hospital A, which had many years of experience within respiratory issues. The respiratory team at Hospital A started for several years ago and consisted of various professionals, such as nurses, physiotherapists and pulmonary physicians. Just until just a couple of years ago they did also take responsibility of the children that today belongs to the respiratory team at Hospital C. The team at Hospital C was established just a few years ago, but only consist of one physician and one nurse. The team at Hospital C was in a need of more resources, especially a physician with competence in lung and sleep medicine. A physiotherapist was involved in the team at Hospital C occasionally, but this resource was still not enough to cover the demands. One of the team members at Hospital C explained their lack of resources and their challenges:

> We have no physician for lung diseases at BUM, which we really are in a need of. We only have one physician with competence of allergy, but I am not sure about this person's lung competence or educational background.

The team at Hospital C knew how to manage much of the respiratory equipment, such as PEP, CPAP and cough machines, but sent their patients to the team at Hospital A for some of the more advanced treatment. Thus, the respiratory team at Hospital A did not only manage children within the area of Gothenburg since they got referrals from both Hospital B and Hospital C and sometimes even Skövde Hospital. The team at Hospital A expressed the advantages of a respiratory team at Skövde Hospital since it had decreased the number of children they needed to manage. They said they lacked resources and even though the team at Hospital A had been active for several years they still did not have a structured process for working with proactive respiratory care for children with severe CP and/or PIMD. One of the physicians from the respiratory team at Hospital A explained:

> We neither have time nor resources to take care of all these children with severe CP and/or PIMD. We do not search for them, but we treat them if we get a referral from the habilitation. We have a better organization when we manage children with muscle disease, where we are using special lung function programs. It is more challenging with those children who have multiple disabilities.

One of the managers at Hospital A explained his view of the situation:

> The children with CP and/or PIMD do not have the same prerequisites as other patients. They have so many various contacts at the hospital and I wish we had some sort of coordinator for these children. They end up at the emergency since they cannot call directly to a contact at the hospital. It is not equal care at all!

He talked about the increasing number of patients with complex care needs due to the increased number of saved preterm babies, and the lack of support from the management at a higher level. The physician was truly worried about the situation and how it was managed:

> We have tried to send signals about this problem for a long time but many of these questions never reach up to the level where decisions are made. Another challenge is that the number of children who are in a need of care and support for respiratory issues are increasing, such as preterm babies.

Another professional, both manager and physician at Hospital A, was interviewed about his involvement in the development of healthcare for children in VGR. He had not heard of the respiratory team at Skövde Hospital at all, even though he was a manager and worked with the development plan. He was surprised that he did not know anything about it and stressed the need for collaborating more regionally, so each actor knew what the others were doing.

4.2.2 The habilitation clinics within the VGR network

The habilitations were all working in various ways with different organizational structure, competencies and routines, summarized in *Appendix C*. Skövde had two habilitations; Knoppaliden and a general habilitation clinic, which was like the other habilitations in VGR. Many of the other habilitations did not send their children to Knoppaliden, mainly due to lack of information. The most common issue for the habilitations were the lack of professionals, mostly physicians, psychologists and counsellors. Of one the managers for all habilitation, at the Habilitation & Health, was interviewed over phone and explained her view:

> We help the children to cope with their daily life. We do not want to take responsibility for PEP, since such equipment should be managed at the lung clinic. It is just a few percentages of our children who has severe CP and we cannot send all those children on screening. Most of the children has a neuropsychological neurologist who decides about referrals to Hospital A.

Many of the habilitation clinics shared at one or several physicians, while a few habilitations had a permanent physician by their own. A few of the physicians were neurologists but most of them were neuropsychiatrists, with no or scarce competence about respiratory issues. To decrease the long waiting times consultants were hired, which created challenges to deepen relationships with children, families and professionals. A physician and researcher from the Region Habilitation was interviewed over phone and emphasized the children's respiratory problems. She stressed the need of a deeper investigation of these children's respiratory issues and talked about a potential study:

> We have discussed to investigate these children's respiratory issues for a while and now may be the time to do it. They have a huge challenge with their respiration and are struggling a lot.

In what way and how much a child could get their respiratory issues managed by the professionals at the habilitations depended on the professional's education, competence, experience and interest. Almost none of them were satisfied with their current competence and knowledge of such issues.

4.2.3 The boundary and responsibilities in the VGR network

The collaboration between the habilitations and hospitals varied, where some had good collaboration and others struggled. Many of the habilitations and hospitals lacked clear routines of who should take responsibility for what. One physiotherapist from a habilitation explained:

> There are no routines, which we really need. I assume it depends on the relationship with the patient, but most often we fail since there are no clear routines. Our habilitation physicians are never doing a follow-up and I do not know if the hospital is doing it either.

Another talked about routines and that she not could prescribe PEP anymore, even though she had done it for many years and had the competence of doing it. A third one said:

> I can only talk for myself, but in my opinion we at the habilitation should take responsibility for PEP. If we just got some education and equipment, we can manage it.

Some of the habilitations and hospitals did not communicate with each other at all, which made it harder to know what the other actor did and did not do. One habilitation professional said:

> We should have more routines to clarify the boundary, so we know when and how to do what. We have no common meetings with the hospital today. The best solution would be to have a well-developed collaboration and have more meetings. It would be great, so we could be more efficient.

Another professional at a habilitation clinic was really frustrated over the situation:

> There is a need of clear routines! We have no meetings to discuss our collaboration. Most there are uncertainties of who is doing what and when. I miss clear routines! The patients are sent back and forth, and BUM is just putting the responsibility at us. Who should do what?

A third habilitation professional was more irritated about the lack of information from the management, who did not communicate the information from the top thoroughly. Much of the information the professionals managed was strictly limited due to the secrecy, which created challenges to communicate and document. The most common issues were responsibilities and routines regarding try-outs, prescriptions and follow-up of PEP. The routines were undefined, and most of the professionals were uncertain about what they should do and when. The lack of clear routines and responsibilities wasted energy and time from them. One professional said:

> Hospital A takes the responsible, but it is a constant discussion every time, which is irritating and takes energy from us. It is such a slow process with much frustration to solve this. The try out is done at the hospital, but should the habilitation or BUM take the responsibility after that step? Routines would it facilitate for everyone. As it is today, we just re-invention the wheel.

A physician at Hospital A explained that they need to find a solution for how and when they should send referrals. He stressed the lack of common routines and how it affected the patients:

> The patients are sent back and forth since no one really knows what to do.

Another physician explained the same problem and how undefined routines affected their work:

> Unfortunately, these children are falling between the cracks. The habilitations need to manage these patients first, before they send referrals to us. We cannot manage all children directly. We wish the habilitations could take more responsibility and do simple treatments, such as PEP. We had meetings with the habilitations before, but then they just dropped out of the meetings.

4.3 THE FAMILIES

4.3.1 General information about the families

The families were in many ways similar, but also very different. Various age, ethnicity, gender, educational and income level as well as personalities were some differences, *Table 5*.

Table 5: Overview of the four families, their life situations and their child's medical history.

	Family A	**Family B**	**Family C**	**Family D**
Country of birth	Sweden	Other	Sweden	Sweden
Family constellation	. Father & mother . Daughter with CP . Younger daughter	. Father & mother . Son with CP	. Father & mother . Daughter with CP . Older son	. Father & mother . Older daughter . Son with CP
Employment	Father (100%) Mother (75 %)	Assistants (100%)	Father (100%) Mother (75 %)	Father (100%) Mother (75 %)
CP	GMFCS LEVEL V	GMFCS LEVEL V	GMFCS LEVEL V	GMFCS LEVEL V
Issues	. Epilepsy . Hearing impairment . Mucus . Speech disorder . Temperature issues . Tiredness . Visual impairment	. Epilepsy . Mucus . Speech disorder . Tiredness . Vomiting	. Dystonia . Epilepsy . Spasticity . Speech disorder . Swallowing disorder	. Epilepsy . Spasticity . Swalloing disorder . Speech disorder
Treatment	. Botox injuctions . Inhalations	. Botox injuctions . BiPAP . Gastrostomy . Baclofen pump . Inhalations . PEP	. Botox injuctions . Gastrostomy . Baclofen pump . BiPAP . Inhalations	. Baclofen tablet . Cough machine . Gastrostomy . PEP
Devices and aids	. Bed . Hearing . Orthosis . Standing & walking	. Bed . Orthosis . Scoliosis brace . Standing	. Bed . Orthosis . Scoliosis brace . Standing & walking	. PEP . Walking
Assistants	Afternoons/evenings	-	Afternoons/evenings	Day and night (24/7)
Short term living	Week days and weekends	1 weekend/month	1 weekend/month	

One of these families was very aware of their many advantages in life and explained:

> We both speak and write Swedish, we have a university degree, one of us is working with laws and healthcare contacts daily, which makes our situation a lot easier. Neither is none of us afraid of conflicts and negotiation. These four examples are winning factors in this world. You need to be a special kind of parent to get adequate and proactive care.

This family had a child who was quite "healthy", compared to other children, which of course had an impact. Such situation was not a guarantee, which the family emphasized several times. The same family had assistants full time, which none of the other families had. Another family had a different living situation and more challenges. They had a child with many complications and diseases but only assistants during afternoon and nights, *Figure 5*.

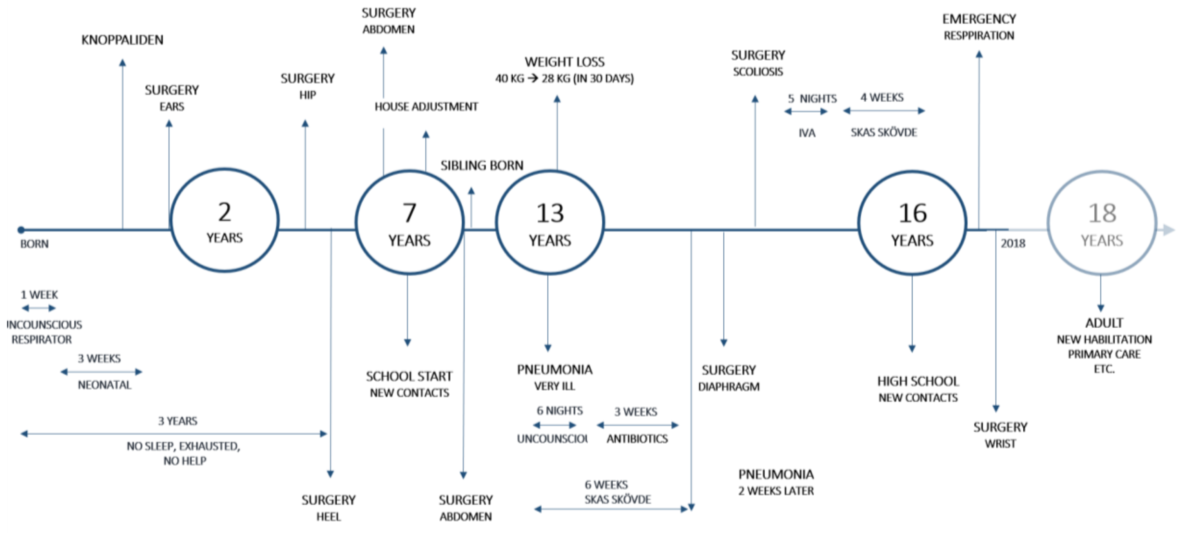

Figure 5: Timeline of one of the family's history of medical treatments, hospitalizations and surgeries.

It was obvious that the parents were tired and had more challenges and needs, compared to other families. During the interview, both parents said:

> Both of us are completely exhausted. We have no own life.

The family had tried to get more hours at the short-term living where their child stayed so they could get some support, but their request was rejected. With more assistant hours they would have better opportunities to re-energize and spend more time with their other child. Some of the children visited the short-term living a couple of days per week, while others were there one weekend per month. Common for the families was to use these days to refill energy, work out, administrate tasks, meet friends and spend time with their other children.

4.3.2 The families view of the network and the actors' collaboration

One of the most common challenges the families had was the many contacts in the network. These varied, depending on the families' current prerequisites and needs. It was not unusual to have about 60-70 contacts active at the same time. A child with many complications increased the number of surgeries and treatments and in turn the number of contacts and interactions with network actors. The number of contacts usually increased in specific periods, such as school transitions and surgeries. Usually the families visited each healthcare contact about 2-6 times a year in both Gothenburg and Skövde. The respiratory team, Knoppaliden and two different types of orthopedics at Skövde Hospital was their key contacts. In Gothenburg the families visited the orthopedics and the Region Habilitation on a regular basis. For surgeries they visited DSBUS, such as for scoliosis surgeries. Except from respiratory issues all children had problems with severe spasticity. To reduce the spasticity the children got regularly drug treatment through an infusion pump or other treatment. The pump needed to be refilled about 3-4 times a year, which was done at the habilitation in Gothenburg 10-15 minutes each time.

The families' experiences and opinions of Knoppaliden were almost only positive. The personnel were very helpful and friendly, and all families had developed close relationships to the professionals. One of the parents emphasized the effectiveness of meeting professionals in teams instead of independently:

> You have so incredibly many contacts when you have a child with disabilities. It is not only healthcare professionals, but also assistance coordinators, schools, training school and so on. It is a half time job to coordinate all these contacts so meeting them in teams really facilitates for us.

The families had experienced both good and bad healthcare from the habilitations and the hospitals during the years with a child of complex care needs. Some of them experienced a tough start with scarce information and lack of support, while others had a better start with supportive information. A recurrent challenge for the families was in critical situations when they went to the emergency care those times their child was in acute need of help. Most often the parents met professionals who neither had knowledge of children of multiple disabilities nor was able to identify important information in the patient journal. A mother explained:

> The problem is when we are going to the emergency care. We always need to tell the same story about our child. I just wish they could read a short summary of our child's issues in the journal.

Another family told about the many times they had conflicts and discussions with caregivers:

> The worst is to meet a physician who has never met our child before. First, the physician needs to read the patient journal, which is really long. Then we need to explain our story. Unfortunately, some physicians have a hard time to accept that we, as parents, have such wide and deep knowledge of our child's medical history as we have.

The families had various medical history but many of them had been hospitalized for months, especially when the child was newborn. Pneumonias and other serious complications were common issues these families had struggled with. One of the parents appreciated the help they had got from a psychologist in the first years when everything was new for them:

> It was a huge help in the beginning since it was such a traumatic experience in many ways. We still ask ourselves - how did we survive?

All four families stressed the absence of coordinated care and support from county councils and municipalities. One of the families shared their view of the lack of collaboration between them:

> It does not work at all. We have always carried the heavy load by ourselves. And I wish it was not that extremely difficult with all these applications. They need to be formulated precisely and you need to write a new application for every new thing.

The opinions whether the care was constructed according to their needs or not varied. The answers depended very much on the child's medical history. Those families with a "healthy" child were more satisfied, while the families with more issues were less satisfied. The families had different coping strategies to manage their daily life. Some parents used internet to search and share information, while others went to exhibitions to take part of the latest news.

4.3.3 The families view of the respiratory team

The families' experiences of the respiratory team at Skövde Hospital were only positive and their interaction with the team members were explained as good. The families told stories of appointments and how they always received care with both empathy and love. One family shared a memory of when their daughter a couple of years ago got a very severe pneumonia. She was unconscious for a long time but one of the physicians in the respiratory team treated her, which the family forever will be thankful for. The mother of the family said:

> He did not give up. If it was not for him, she would have died.

Another family shared their view of the respiratory team and their work:

> Our experience of the respiratory team is extremely good. I am so happy they exist! Without the team we would still struggle with chasing someone else at the hospital to help us. The physician has always emphasized how important the respiration is and how it affect our child's health and well-being. Our proactive respiratory care has been a huge advantage for our child's health.

Meeting the same caregivers time after time have developed a relationship built on trust and mutual commitment. The parents expressed the advantage of meeting the same professionals:

> The availability to the team compared to other caregivers is really good. The best thing is that we meet the same people every time and that they meet and communicate. It is much better with clear responsibilities, which we did not have before.

Another family had the same opinion and explained the benefit of meeting the same caregivers:

> We are really satisfied with the respiratory team and specially to meet the same people time after time. They have another kind of knowledge for our child than other caregivers. They are competent, serious and work with a great approach. We have an open dialogue and are so grateful for this team. The physician within the team is our permanent healthcare contact, which is great. The close collaboration between Knoppaliden and the respiratory team is also great because of the many correlations.

The families were well aware about the actors' different responsibilities within the network. As mentioned before the families did not have a permanent physician as they had today. One of the mothers expressed their feelings about the physician in the respiratory team:

> He is the most amazing and wonderful physician I have met in my whole life. When we arrive, he only has eyes for her. He ignores us and goes straight ahead to our child. He gives her a hug and then after that, he says hi to us, which is exactly how it should be. Unfortunately, a lot of physicians still talks over our daughters' head.

All families had an open two-way communication with the team, where the parents' opinions were listened to. The information was usually received verbally, but instructions were always provided in written text. Moreover, none of the families said it was inefficient to meet them as a team, rather the opposite. Instead they could meet multiple caregivers at one time and learn by following the team's discussions with each other. One of the families said:

> We have developed a really good relationship and can ask all kinds of questions. By regular contact we get to know each other in another way. We also learn so much by meeting the team together just listening to their discussions.

4.3.4 The families' view of family-centred care

The respiratory team involved the families by prescribing equipment, so they could work with home care by themselves. All children used regular inhalations during the days and most of them had additional equipment, such as cough machines, CPAP and PEP. All families perceived that the equipment fulfilled their children's needs and that such kind of proactive care had increased their child's health and well-being. Those who had contact with the pulmonary paediatricians already from the start had a benefit of receiving proactive and early treatment. Other families got in contact at a later stage, often when the respiratory issues were worse. Nevertheless, all families emphasized the advantages of respiratory treatment, whereof one said:

> It is a huge difference in our son's health since he started to use PEP! It helps very much.

The number of appointments as well as the team's structured work of diagnosis, treatment and follow-up was appreciated by all families. One family told about the help from the team:

> Sometimes I am so tired that I almost collapse, but I know how important the mask is for her. But she has not that much mucus now, since we get such good help from the respiratory team. It is also great to come back and do these regularly follow-ups.

The same family gave an example of when their child needed oxygen and the respiratory team prescribed a toolkit, so the family could avoid being hospitalized. Such home care solutions had not always been possible, but it was really appreciated by the families.

One family was currently worried about their child's scoliosis surgery, which they had been waiting for a long time for. The professional who managed the contact at DSBUS in Gothenburg did not answer anymore and the mother was worried about her child's lung function and respiration. She explained the situation and the lack of information from DSBUS:

> We are waiting for the scoliosis surgery. DSBUS told us that they would do the surgery in this autumn, but I do not now know what is happening since the coordinator at DSBUS does not answer anymore. This waiting is not good for our daughter's lungs.

Another family explained how the respiratory team had helped them during these years:

> Our son has had zero pneumonias and just a few intensive care inlays, so he is basically a miracle. He receives great respiratory treatment from our assistances, who also change his position during nights. The mentoring physician was the one who emphasized the importance of physical movement. We were also lucky that we had habilitation personnel who understood the importance of being active as much as possible. All of this has had huge impact on our sons' health!

Other families had more concerns and challenges with their child's health and respiration:

> She had no mucus at all just until some years ago. She was barely having a cold and then she just crashed because of her scoliosis. She had a scoliosis brace at that time but could not take deep breaths and widen her lungs with it. After many hours of respiratory training she could do her surgery, which was fantastic for her lungs!

The parents explained how close their daughter was from not making the surgery:

> Without the respiratory team she would probably never have managed the surgery. It is crucial that you have a strong lung function to survive such long narcosis, otherwise you might not wake up. It was a risk, but we needed to take it.

However, none of the families had any troubles with the equipment and felt comfortable when using the aids. They received the support they needed. One family said:

> Most of all I do think that they are making reasonable demands on us as parents. There is a limit of how much you as a parent can cope with, which they do have an understanding of. You need to look at it from a realistic perspective as well.

The families only had one complain – the sibling support from the hospital. The siblings are often forgotten as well as disappear in all this mess and it would facilitate if the hospital provided sibling support. One of the parents explained how hard these years had been for them:

> We have tried but we have almost never been available for our other child at the same time. In the first months one of us always lived at the hospital and the other parent at home. It is impossible to give our children the same opportunities and time.

4.3.5 The families' needs for maintaining and improve their well-being

The two most expressed needs were to get a permanent physician already from the start and a coordinator who managed much of the communication with other healthcare and non-healthcare actors. One couple explained the benefits of a coordinator:

> The dream would be a care coordinator who could coordinate a whole day at the hospital. Every appointment at the hospital is a new tension for our son.

The families had different needs, worries and challenges. This means all families had different needs of help and support as well. One common challenge for all families was the concern about the future healthcare of their children. When their child turns 18 years old, they are moved from BUM to the primary care and from Knoppaliden to a habilitation clinic for adults. In other words, new professionals with other kind of competence. One family shared their worries:

> We are really worried about the future when our child does not belong to Knoppaliden anymore. How many lung specialists to they have at the primary care?

Another concern was the assistant turnover, where every change of an assistant was a change of knowledge and trust regarding their child's health. Many of the families were also anxious of losing their assistant's and what such change would result in. One family criticized the healthcare for not taking their responsibility, who should have knowledge about rules and laws.

> The healthcare is bad at informing their patients about this. They assume that other actors take responsibility, but they do not. The healthcare needs to start taking responsibility for this and especially for these children with severe respiration issues.

5 ANALYSIS

The following chapter analyses the empirical founding's, divided into the three perspectives; the respiratory team, the VGR network and the families. The empirical founding's is compared to the theory from the theoretical framework, where similarities and differences are discussed.

5.1 THE RESPIRATORY TEAM AT SKÖVDE HOSPITAL

The following sections analyses the respiratory team's work, collaboration and relationships. The sections do also emphasize the team's focus on family-centred care and future needs.

5.1.1 The need of a respiratory team at Skövde Hospital

The respiratory team at Skövde Hospital was established in 2015, mainly by two ambitious physicians. Since respiratory care usually was within the responsibility of a Regional Hospital a team with that purpose had not existed before. The mentoring physician had year after year witnessed lack of adequate and proactive respiratory treatment for children with severe CP and/or PIMD. He had knowledge of how critical the situation could be for these children if they did not get help with their respiration in time. After many years as a physician he had experienced children with severe pneumonias and other respiratory issues, probably due to scoliosis and other issues. Respiratory failure did sometimes cause these children an early death, which may be the result of reactive respiratory care. It is well known that children with complex physical disabilities develop respiratory issues, which affects both life quality and life expectancy (Seddon and Kahn, 2003). Even though the mentoring physician and his colleagues were experienced and had competence as well as did everything they could, many patients already had "crashed" when they met them. Usually the families "crashed" with them, exhausted and helpless, which is common for parents to children with complex care needs (Broberg et al., 2014). There are probably many answers to why children "crash" before someone can save them, such as professionals lack of competence to identify respiratory issues (Seddon and Kahn, 2003). Other reasons may be lack of clear responsibilities within the network of actors as well as absence of early respiratory intervention programs to identify high risk children (Fitzgerald et al., 2009; Kadar and Gustafsson, 2017; Socialstyrelsen, 2017).

Even though the children received healthcare from multiple healthcare actors and had many different contacts, no one seemed to take the overall responsibility for them. Neither from a holistic perspective nor with focus on respiratory issues. Historically, these children did neither get adequate nor proactive respiratory care. The respiratory team mentioned some potential reasons for this, such as lack of resources at DSBUS, national guidelines and clear responsibilities between hospitals and habilitations. Moreover, the respiratory team knew there was a lack of physicians at the habilitations and that the neurologists did not have sufficient competence of respiration issues. It is a common issue that professionals not always notice changes in children's respiration, just as in VGR (Seddon and Kahn, 2003). The reasons for this may be lack of competence or resources, which can lead to delay of important treatment (Seddon and Kahn, 2003).

The professionals in the respiratory team had the competence, experience and interest and could not just stand aside and watch these children and families feel bad anymore. Especially since they knew they were going to take care of these children after they had "crashed" anyway. As many other researchers and organizations, the members in the respiratory team criticized the healthcare system for not providing adequate care and support to families with complex needs (Mansell, 2010). Thus, when Skövde Hospital recruited additionally one competent and experienced paediatric pulmonologist they had enough skilled professionals to establish the team. Since these children have increased risk for respiratory failure (Kim et al., 2015), the respiratory team only had one goal - to improve the physical and psychosocial well-being of the children with respiratory issues, including their families' well-being. Even the strategy was clear - to work proactively with diagnosis, treatment and follow-up of respiratory issues.

5.1.2 Roles and responsibilities within the respiratory team

The team consisted of diverse and multidisciplinary professionals from various clinics at the hospital. The physicians had many years of experience and medical competence. The physiotherapist had another kind of competence, who could manage much of the technical equipment. The nurse had the coordinating role within the respiratory team, quite similar to a mediator described in the network model (Stabell and Fjeldstad, 1998). Working in a cross-functional team was a strategic choice by the paediatric physicians, much since research show that improvements of families' well-being can be achieved by working with a multidisciplinary approach (Fitzgerald et al., 2009; Seddon and Kahn, 2003). During the study the members emphasized the importance of integration and coordination. Without focusing on those factors an increase in the families' well-being would be hard to achieve (OECD, 2017). The team's primary processes consisted of diagnosis, treatment and follow-up of respiratory issues, and because of a diverse group of professionals they could work cross-functionally. A multi-professional team with experience and competence is a recommended approach to manage these children's issues (Westbom et al., 2011). Moreover, by taking main responsibility for all three processes the team could reduce risks of communication mistakes with other actors as well as reduce the risks of children falling between the cracks.

5.1.3 The respiratory team's working methods

They team were quite few, only four to five members, and had therefore beneficial opportunities for reaching close collaboration and achieve efficiency in their work. They were very satisfied since a small team created possibilities for knowledge sharing and increased the flexibility. The team worked integrated with a structured and planned flow of patient appointments. They communicated well and had discussions in an open climate, either through information systems or face-to-face. It was obvious that they knew each other's way of working, which was something each of them emphasized in the interviews. The nurse, who was the coordinator of the respiratory team, tried to link all direct and indirect relationships and contacts together as efficient as she could. Combining different clinics and work tasks created challenges for her to find available times for patient appointments. Even though cross-functional processes can be improved or simplified (Hunt, 1996), they can make it more complex as well. The nurse had challenges to schedule the team members as well as combining her work in the respiratory team with her work at BUM. Consequences was stress and irregular work, where she was interrupted every now and then. She expressed feelings of constantly bad conscious since she struggled with combining two teams and not having enough time for any of them, a common challenge (Marks et al., 2001). To save resources in terms of time the nurse did not always participate in patient appointments. Instead she could focus on integrate, coordinate, book appointments and get in touch with families. Other times the nurse or the physiotherapist could meet patients' parts or whole of appointments without the physician. Usually a follow-up routine was not as complex as a diagnosis and by making such flexible solutions the team could avoid cancelling patients. By having someone else than the physician performing all tasks and activities the team could work more efficient and in turn save valuable time to put on other tasks, which is a great example of how a team successfully reinforce each other (Christensen et al., 2009).

More resources in terms of time and professionals was the team's greatest need. Even though the team used all hours and minutes they could find it was not enough for managing all patients.

They had worked as a team since 2015 but still lacked routines, standards and documents in their work. Not surprisingly, they prioritized patients before organizational development and improvement of the team. The interviews and observations found several examples of processes that could be improved, such as messy and loud work areas as well as equipment and material far away from their working area. The information systems were another obstacle for efficient work, which not only were old but also lacked smart functions.

One main challenge was the team's vulnerability for employee turnover and loss of competence. During the study the nurse quit in the team and two new nurses started as coordinators. The nurse had intentions to do the handover properly at an early stage, so the new professionals could take part of all her knowledge. Even though the nurse had requested the name of the new coordinator she did not get the information before the day before she quit and most of her knowledge was probably not kept within the team. The nurse had developed relationships to the families as well as the team members and had both explicit and tacit knowledge the team could benefit from (Linderman et al., 2004). A new constellation means new challenges in terms of coordination, communication and collaboration, and changing members within a team can affect both the stability and the cooperation, including communication and coordination (Lemieux-Charles and McGuire, 2006). The new team hopefully prioritize to develop methods for creating, sharing and retaining knowledge, just as Linderman et al. (2004) recommends.

5.1.4 Relationships and collaboration in the VGR network

Habilitation Knoppaliden and the respiratory team managed the same children for many years before they started to collaborate as close as they did today. The collaboration developed during a couple of years but was strengthened after the respiratory team started in 2015. Of all the respiratory team's relationships and interactions, the relationship with Knoppaliden was the most developed one. Both actors were satisfied with the collaboration and realized the many benefits of it. The respiratory team knew that habilitation professionals had no special competence of respiratory issues, why they developed their collaboration to identify all children with existing or potential risks of respiratory issues. The team did not want the habilitations to take the main responsibility for the children's respiration, but they wanted help and support to manage them. Such solution, where a child is diagnosed by a paediatric pulmonologist, is a recommended solution for such situations (Stockholm County Council, 2014).

However, the disperse of responsibility between the team and Knoppaliden was clear and through continuous communication they always knew what the other actor was doing. They shared information and send status reports about their patients to each other. This could be compared to so called efficient networking, where actors are reinforcing each other, which is used to reduce the risk of duplicated work (Christensen et al., 2009). The team had sporadic contact with other healthcare clinics and hospitals as well, such as neonatal, sleep and DSBUS. None of these collaborations was as good as the one with Knoppaliden. One of the reasons was the lack of clear routines of how they should collaborate with other actors.

The team expressed needs of more resources in terms of psychologist or a counsellor they could use whenever they needed. Not only to satisfy the family's needs, but so that the nurse and the other professionals could concentrate and focus on their original tasks. Several times the nurse contacted schools, lawyers and social services to communicate patient information, which not always was within her responsibility area. Those times when the families needed support the team members took the role as a counsellor or psychologist, even though they lacked both time and competence. Hired psychosocial professionals at the hospitals most often quit after a short while to be replaced by a new one. Such regular changes of professionals would mean continuous new team constellations, which affect the team’s stability and work processes (Lemieux-Charles and McGuire, 2006). Not to mention how such change of employees affect the relationship and support to the families and the children.

5.1.5 The respiratory team’s focus on family-centred care

The physicians who had been in the healthcare setting for many years knew how the society had viewed those families historically; incapable to solve their child’s issues without a professional’s help (Shelton and Stepanek, 1994). This has changed due to several reasons. Not only because of how the perspective of service has changed (Normann, 2001; Vargo and Lusch (2004a; 2008), but also because of the new possibilities medical and technical innovations has brought (Lifvergren, 2013). Nowadays the involvement of families is more common, and it was clear that the team neither viewed the children nor the families as objects, who they managed with both empathy and respect. With the aim to involve and improve the family’s well-being, the team integrated the families as co-creators of value and care (McColl et al., 2012). The team involved the families as co-creators by providing them various kinds of equipment to use at home as well as supporting them over phone whenever they needed help. The team worked with family-involvement by carefully listening and responding to the families’ different needs, just as recommended by several researchers (Seddon and Kahn, 2003). The team took advantage of their medical competence and experience, and then combined this with the families’ expertise to share knowledge, which is essential for reaching successful care (Seddon and Kahn, 2003). The team tried to include all family members needs to achieve as much family-centred care as possible, which is claimed to be of importance in a paediatric setting (Broberg et al., 2014). By sharing knowledge and perspectives in this way they could create mutual benefits and advantages.

Even though digitalization enables new possibilities for co-creation of care (Normann, 2001), current rules and regulations does not keep up and limit the team to use it. The opportunities for home care based on digitalization are many, but if rules and regulations not support such care the team cannot make use of it. Such lack of adequate and efficient prerequisites is another example of obstacles to create successful healthcare and improve the families’ well-being. Right prerequisites are necessary for professionals, also when creating opportunities for the families to co-crate value at home (Nordgren, 2009). Whether it is the management of the hospital, the region or the state that hinder healthcare professionals to use and make advantages of digital solutions, this is an example where focus is put on the organization, rather than on what is best for the families (Kristensson, 2009; Osborne et al., 2012).

Unfortunately, relationships were not as developed and deep with all families. One of the team’s main challenges was the language barrier, where the collaboration many times was affected by the families’ and professionals’ language skills. Even though the team used an interpreter it was obvious that both parts struggled with the communication, which in turn was an obstacle for developing and building a relationship built on trust. Lack of family involvement is crucial since it most probably reduces the medical quality of the healthcare to the child (Shelton and Stepanek, 1994). Several times during the study the team expressed how impressed they were of the families’ strength and struggle of hospitalizations, medicines and treatments. The lack of coordination support was emphasized by the respiratory team, just as from many other actors within the huge network of healthcare and non-healthcare actors (Broberg et al., 2014; Riksrevisionen, 2011; Socialstyrelsen, 2011). The most common need for this kind of families was a coordination service (Socialstyrelsen, 2011), which the team tried to help the families as much as possible with. By meeting them as a team and coordinating appointments with other actors the team reduced the families’ number of contacts and appointments.

5.1.6 The future of the respiratory team at Skövde Hospital

According to the respiratory team there was no other option than keeping the team at Skövde Hospital in the future. All professionals emphasized the need and demand of adequate and proactive respiratory care, which the children will not get without the teams' existence. During the years they have experienced how children's and families' well-being have improved. If the team would ignore these children, they would get reduced respiratory function and well-being. Without treatment many of them would develop aspiration or pneumonia and in worst case die (Himmelmann and Sundh, 2015). Thus, stop following these children and quit managing them with proactive and structured respiratory treatment is not a choice, neither according to the respiratory team nor researchers (Stockholm County Council, 2014; Westbom et al., 2011).

5.2 THE VGR NETWORK

This section presents the findings from the VGR network, divided into three sub-sections. The first section describes the perspective of the hospitals, followed by the perspective of the habilitations. The third section describes the interrelation been the hospitals and habilitations.

5.2.1 The hospitals management of respiratory issues

Comparing healthcare from county hospitals with healthcare from region hospitals is not equal as they have different competencies, responsibilities and resources. As healthcare specialization has increased (Socialstyrelsen, 2017), each hospital's responsibilities have increased as well. In 2013, Hospital C started their own respiratory team of two professionals, one nurse and one physician. They managed much of the respiratory care by themselves but still sent referrals to the Region Hospital every now and then for more complicated treatment. The team struggled with lack of competencies and needed a pulmonary paediatric to provide adequate care. Hospital B also lacked resources and neither had a respiratory team nor any paediatricians with competence of lung and sleep medicine at all. They did therefore send all referrals to Hospital A. But one challenge at Hospital A was limited resources, why they appreciated that the respiratory team at Skövde Hospital and Hospital C took responsible for their own patients.

The three other hospitals worked with treatment by providing cough machines, PEP and other kind of equipment. None of them had established a structured way of working with the children's respiratory issues and they all admitted that proactive and structured care was poor and needed to be improved. The reasons for this may be many, such as lack of early intervention programs or processes to identify and follow high-risk children (Fitzgerald et al., 2009). Even though Hospital A had a large respiratory team with competence and experienced professionals they did not work proactive and structured to identify children with severe CP and/or PIMD. This was a surprise as those children have risks of respiratory issues, where both well-being and life expectancy are affected (Seddon and Kahn, 2003). The two interviewed managers at Hospital A emphasized the lack of equal and coordinated healthcare to this patient group, which is a common challenge for many existing healthcare systems (Mansell, 2010). As many other researchers, the managers stressed the need of a coordinator and someone with a holistic perspective (Broberg et al., 2014; Dempsy and Keen, 2008; Socialstyrelsen, 2017).

5.2.2 The habilitations management of respiratory issues

One obstacle for identifying respiratory reduction could be the challenge of high employee turnover, which many of the habilitations struggled with. Shortage of resources, such as physicians, psychologists and counsellors were common challenges for the habilitations. Due to the lack of physicians, the habilitations could not always provide a permanent physician and many of the habilitations had overall long waiting times. This is known since before, that one of the most common cause of delays in respiratory treatment is when the professional is unfamiliar with the child (Seddon and Kahn, 2003). Furthermore, a high employee turnover is an obstacle in Sweden’s aim for balancing the three dimensions of sustainable development (Government of Sweden, 2017). Regular change of employees is not an example of social sustainability, neither for the professionals nor the patients. The habilitations in Gothenburg shared physicians and hired consultants to reinforce their medical area. Some of the physicians were neurologists but most of them were neuropsychiatrists, which means none of them had competence in lung and sleep medicine.

Furthermore, the overall knowledge of respiratory issues at the habilitations varied. Since children with severe CP and/or PIMD is a quite small patient group not all professionals get in contact with them. Those who had competence and knowledge were often more experienced or had a special interest in respiratory and were aware of how these children and families were fighting and were fully aware of the risks with respiration issues. Few professionals had additionally respiratory education other than the basics at the university and the majority wished they could get more education. The physicians and physiotherapists lack of knowledge is probably the greatest obstacle for identifying respiratory issues. Even though professionals would learn to recognize changes in a child's health is it not sure they would notice all kinds of changes to full degree (Seddon and Kahn, 2003). Especially since children not always cough or making other signs when having severe respiratory infections (Seddon and Kahn, 2003).

Another interesting founding was the habilitations various routines for managing equipment. For instance, managers and professionals had different opinions whether the habilitation should take responsibility for PEP and other simple equipment or not. The question of responsibility had been a problem for many years, where managers and professionals had different views.

5.2.3 The unclear responsibilities within the VGR network

The hospitals and the habilitations shared responsibility for children with multiple disabilities and complex care needs, or at least they should. How this responsibility was divided between them was very uncertain for all actors involved. Not only for the habilitation professionals, but also for the hospital professionals. Such uncertainty of responsibility allocation is a common challenge for actors at various levels within the Swedish healthcare (Socialstyrelsen, 2017). Many professionals criticized the lack of clear boundary between them and lack of information and directions from the management. Discussions of unclear responsibilities consumed unnecessary energy and time as well as created conflicts. This affected the patients as well, who were sent back and forth between the habilitations and the hospitals. Even though reports show that fluid responsibilities are common within the Swedish healthcare system (Socialstyrelsen, 2017; Ylvén, 2015), they still exist and creates challenges for both professional and patients.

The most common challenge concerned the respiratory equipment. One physician at Hospital A argued that the habilitations should take responsibility for simple treatment, such as PEP, which many professionals at the habilitations also agreed upon. In fact, most of the habilitation professionals wanted to manage both the try-outs and prescriptions of PEP, mainly because it was such an easy task to perform and they met the children for other issues anyway.

Another challenge was the lack of communication between the hospitals and the habilitations, which in many times not existed at all. Some of them had meetings or communicated regularly over phone, while others assumed and guessed what the other actor in the network (hopefully) took responsibility for. Since the habilitations and the hospitals had different information systems, they could not communicate through sending messages either. Only the physicians had access to both systems, but as not all habilitations had permanent physicians, and many suffered from employee shortage, habilitation professionals did not always have access to all necessary patient information. Without access to the systems or available physicians the professionals had limited knowledge of their patients' medical history. The lack of integration and coordination hindered professionals to create and provide efficient healthcare, a common challenge within healthcare networks (Glouberman and Mintzberg, 2001; Normann, 2001; Socialstyrelsen, 2016). As long as the management not gives the professionals adequate prerequisites, such as clear processes and tools for collaborating, the cooperation between them will probably not be improved. Neither will the coordination of patients, the efficiency nor the knowledge sharing be. The sometimes-non-existing collaboration between the actors was quite surprising. Treating the same children, who had so many correlated issues, one could assume more knowledge sharing and collaboration between the actors existed. Researchers recommend children with severe CP and/or PIMD to be followed by the most experienced multidisciplinary professional teams (Westbom et al., 2011), but based on this study this is not the case in VGR. Both hospitals and habilitations argue that they lacked enough resources in terms of time, competence, knowledge and equipment to work with proactive and structured respiratory care but whether this is the problem or not needs to be discussed further.

5.3 THE FAMILIES

This chapter analyses the perspective of the families. The first section covers some general information about the families, followed by the families view of Swedish healthcare. The last two sections emphasize family-centred care and the families' needs to improve their well-being.

5.3.1 General information about the families

The four interviewed families were different but still had a lot in common. Every family had a child with severe CP and/or PIMD. These families had spent more days hospitalized in a year than many of us will do total in our whole life time. Several times each year the families visited the hospitals, sent in applications for every new medicine or aid, discussed and negotiated with authorities and professionals and did everything they could for their child's best. Many times, they negotiate with the professionals, who many times questioned their knowledge and competence. For some of them it was a full-time job only to manage all administrative tasks. Except from coordinating appointments and contacts, the families spent many hours each day to keep their child as healthy as possible by using different medicines, machines and workout programs. Some of these families managed their life quite well after more than ten years as parents to a child with severe CP and/or PIMD. Other families had more challenges, especially those with unhealthier children with many hospitalizations. Those families were completely exhausted and had reduced well-being, which are common problems for families in such life situations (Broberg et al., 2014; Socialstyrelsen, 2011;).

5.3.2 The families view of the network and the collaborations in it

The families had both good and less good experiences of the network and the actors' collaboration as well as their individual performance. The families lacked a permanent physician from the day their child was born, who knew them as a family and their child's medical history of diseases and disabilities. Back in the days, hospitalizations resulted in meeting new healthcare professionals with lack of knowledge and competence of severe CP and/or PIMD. Being parents to a child with multiple disabilities was challenging as it was, and it did not get easier with the lack of coordinated and integrated support from the municipalities and county councils. Often it got worse with different recommendations from different actors, another well-known issue in healthcare systems (Mårtensson, 2017). Absence of coordinated healthcare forced the parents to take all responsibility by themselves, which many other families to children with complex care needs experiences as well (Broberg et al., 2014; Socialstyrelsen, 2011). A healthcare system will neither reach efficiency nor high medical quality without integrated and coordinated actors (Glouberman and Mintzberg, 2001; Normann, 2001).

5.3.3 The families view of the respiratory team

The families knew their life situations could have been worse. Not everyone had access to a respiratory team at their local hospital, who they could meet regularly and contact whenever they needed. They were well familiar with the risks of respiratory issues, and how crucial it is to prevent such issues. According to the families the respiratory team had helped them to reduce the number of medical healthcare appointments, the number of contacts as well as increased their child's well-being. Involving families as co-creators of care is said to increase their well-being and reduce challenges the healthcare system is facing (Nordgren, 2009). The families appreciated the relationship with the team, which was said to be built on trust and continuity. Having the team as permanent healthcare contact reduced their uncertainties and worries. By listening to the professionals' discussions, the parents could learn and develop their knowledge of their child's health and respiratory issues. The families always felt they were listened to and had discussions in an open climate. The team's close collaboration with habilitation Knoppaliden was appreciated as it reduced their responsibility to communicate between them.

5.3.4 Family-centred care

The families had various experiences of family-centred care. They criticized both Skövde Hospital and other network actors for not providing support for the siblings. Without support to the whole family a network will never reach holistic care (Broberg et al., 2014; Dempsy and Keen, 2008; Socialstyrelsen, 2017). The first years involved almost no family-centred care at all, where the traditional perspective of value creation still existed (Normann, 2011; Vargo and Lusch, 2004a; 20089). Conflicts and negotiating with professionals other than the ones from the respiratory team were part of their daily life, especially since professionals still viewed them as passive recipients (Vargo and Lusch, 2004a; 2008). As the years went by the families got more knowledge and competence of their child's health and medical issues. In the same time the general view of a parent's role changed into a benefit for mutual knowledge sharing (Eriksson, 2016). The families and the team discussed what actions were suitable for them, which is important to do to find out what is most valuable for them as a family (McColl et al., 2012; Nordgren, 2009; Normann and Ramiréz, 1994; Vargo and Lusch, 2004a). Such kind of partnership, where families are integrated as team members, is said to be the core of family-centred care (Shelton and Stepanek, 1994). All families emphasized the benefits of how the team involved them as co-creators, e.g. by suggesting and enabling various kinds of activities to do at home (McColl et al., 2012). The families performed both low and high-level activities (McColl et al., 2012), such as gathering information from internet or conferences, as well as used respiratory equipment at home care (McColl et al., 2012; Vargo and Lusch, 2004a; 2008).

5.3.5 Unsatisfied needs for achieving improved well-being

Except from the lack of sibling support, the families stressed the need of a coordinating service, known as one of the most debated needs for families with complex care needs (Broberg et al., 2014; Riksrevisionen, 2011; Socialstyrelsen, 2011). The collaboration between the actors were in many times insufficient and the families were most often the ones who communicated and coordinated the care between them. A coordinating service was a need for many reasons. For instance, so they could focus on their roles as parents, rather than working as coordinators or caregivers. Since the parents are the truly cornerstones within the care of a child (Shelton and Stepanek, 1994), it would be a disaster for the whole family if (when) the parents got burnt-out because of too high work load. Even though many families struggle with reduced health and well-being due to the lack of coordination (Broberg et al., 2014), decades of discussions between politicians and managers has yet not resulted in any concrete solution (Ylvén, 2015).

6 DISCUSSION

The following chapter discusses the two research questions of the study. The first section discusses research question number one, once again divided into the three perspectives. The second section summarize and compare all three perspectives. The third section consist of a discussion by research question number two, which focuses on suggestions of improvements.

6.1 RESEARCH QUESTION I

The first research question focused on understanding how the respiratory team and other healthcare actors in VGR managed respiratory issues and how families to children with severe CP and/or PIMD perceived it. The first research question was as follows:

How are the needs of families to children with severe CP and/or PIMD managed by the respiratory team and the VGR network?

6.1.1 The respiratory team at Skövde Hospital

The respiratory team's main processes were investigation, treatment and follow-up of respiratory issues. The children of the team had varied degree of respiratory issues, whereof some had very severe issues. Other children had not yet developed respiratory issues but were high risk children, and therefore in a need of proactive respiratory treatment (Kim et al., 2015). The team described themselves as multi-professional team with broad competence and experience. By focusing on respiratory treatment could they improve the children's well-being and health directly, and indirectly the families' well-being as well. Since respiration is such a vital function of the human body, proactive respiratory treatment has made a huge difference for all these four families. The team compared the families' well-being before and after treatment and what positive difference it had resulted in. Some of the children would probably not have been alive today, which is a sign of how important their work as a respiratory team is. The team managed the family's needs in many ways, such as by providing equipment so the families could work with co-created care at home. Co-creation of value is said to increase the whole family's well-being (Nordgren, 2009), which was one of the main goals within this situation. By this solution the families could avoid being hospitalized more days than necessary and the team could use the saved time to manage other families. In case of acute help, the team always had a free time spot each week, which the families could use for urgent issues.

Even though the team lacked time they were well-aware about the importance of family-centred care, why they tried to involve the parents as much as they could. Many times, the team used the approach of family-centred care, e.g. by asking the parents how they were doing and what they could do to help them. Even though the team did a lot for these families, they could not satisfy the family's needs in terms of psychosocial support and sibling support. Whether this was within the team's responsibility or not was unclear, but as other actors did not seem to take this responsibility either, none of the families got their psychosocial needs or needs of sibling support satisfied. Without enough resources nor right prerequisites in terms of competence and experience the team could not satisfy the families' needs.

One of the greatest challenges for the team was the turnover of team members. Every new recruitment in a team is usually a loss of both explicit and implicit knowledge (Linderman et al., 2004). The employee turnover had impact on relationships and trust within the team as well as to the families A high turnover of employees is not only a loss of knowledge, but also negative for social sustainability. Inefficient processes and waste of professionals in healthcare will probably be one huge obstacle for Sweden's work with Agenda 2030, who aims to be the leading country when it comes to implementing and realizing their action plan (Government of

Sweden, 2017). A new team member does not only change stability and make uncertainties regarding knowledge and trust arisen (Lemieux-Charles and McGuire, 2006). It also requires new ways of collaborating and communicating, which may affect both efficiency and quality of medical care. Nevertheless, being a member of multiple teams at different clinics affect the overall goal achievement as team members usually aims for different goals (Marks et al., 2001).

By working as a multi-professional team with close collaboration to habilitation Knoppaliden, they aimed to create synergized results and favor as much as possible for the families. Through continuous communication and coordination of treatment and related tasks they did work in a proactive and structured way with respiratory care. As soon as a new family to a child with or with risks for developing respiratory issues the respiratory team got contacted, either by Knoppaliden or by other clinics at the hospitals. After years of absent respiratory care, the team had set up a well-functioning team to manage children with respiratory issues. They had developed routines and processes, even though many of those could be improved to increase their performance. One example is the old and dysfunctional information system, which reduced their opportunities to communicate and work efficient. The current information system was not only challenging to work with, but also complex and impossible to integrate with other systems. In turn, much of the equipment was stored in different places, which resulted in waste of time and waste of transportation for both professionals and families. Neither had the respiratory team communicated their needs to responsible managers, such as the need of psychosocial support or help to improve and make their processes more efficient. Lack of such information make it harder for managers to make correct decisions.

Even though the respiratory team did much good several processes and collaborations should and could be improved. One example is the lack of collaboration with the professionals at DSBUS in Gothenburg. Having the same patients, they should collaborate and communicate much more than today. The lack of prioritization regarding planning and improving is another criticism against the respiratory team. Time to plan and improve may be seen as unnecessary, but in the long run improved processes will create more time with patients. To improve their processes as much as possible the team should take help from process and quality managers, who have both competence and experience of such work. However, even though the team did everything they could for these families, their work was just a small piece in a large puzzle of different actors with different opinions and perspectives. That means top management must establish processes for coordination, collaboration and communication with other actors.

6.1.2 The VGR network

The data collection resulted in gathered information of how habilitations and hospitals within VGR managed respiratory issues of children with severe CP and/or PIMD. The research found that none of Hospital A, Hospital B or Hospital C worked with structured routines for investigation, treatment and follow-up of respiratory issues. Neither did they work as proactively with respiratory treatment as they desired. None of the hospitals worked with structured identification of children to enable the families to work with co-created and proactive respiratory care. Hospital A was the only one with specialized competence and years of experience of respiratory issues. The only problem was that the professionals, according to both physicians and managers, did not have enough resources to manage all children within VGR. Hospital C did have a small team of two people, but still lacked competent and experienced professionals to manage all kind of respiratory issues. As known Hospital B did not have any respiratory team at all, which was why they sent all families to Hospital A in another town.

Very few of the physiotherapists at the habilitations had competence and knowledge of respiratory issues. Most of the habilitation professionals stressed the need of developing their knowledge to better meet the needs of the children and the families. Without enough competence and knowledge, it was a challenge and many times impossible to identify respiratory changes. Especially since all habilitations lacked competent and experienced physicians to collaborate with. As familiar, child neurologists do usually not have the same competence and experience of lung medicine as paediatric pulmonologists. The question is, how bad have these children's respiratory issues developed before the habilitations have identified the changes and sent referrals to a hospital? And how long does it take before the hospital have enough resources to manage and follow-up on these children's issues?

Current management of respiratory issues from hospital A, B and C as well as the habilitations are also assumed to be affected by the lack of collaboration between them. Few hospitals and habilitations communicated with each other and the lack of clear responsibilities and routines was appalling. Such lack of communication and integration between actors mostly make professionals perform contradictory and hurtful efforts, rather than improving children's well-being (Glouberman and Mintzberg, 2001). Unfortunately, these network actors seemed to focus on their own work, rather than aiming for achieving a holistic perspective. Instead of aiming for coordinated and integrated healthcare, much time and energy seemed to be put on the wrong things, such as negotiating about who should do what and when. Such poor routines and unclear responsibilities made the children and families feel forgotten in the middle of a constant chaos. It was clear that the interviewed professionals were tired of the unclear boundary and the vague information from their managers. Managers who gives unclear and insufficient information does not really create adequate prerequisites for the professionals to work with. This perspective is an example of when focus is placed on the happenings within their own unit or organization, rather than on what is best for the patients (Kristensson, 2009; Osborne et al., 2012).

Due to many reasons the VGR network is not assumed to manage respiratory issues with as much collaboration, involvement and proactivity as the respiratory team at Skövde Hospital. Mainly because of the lack of structured identification of high-risk children, unclear routines, uncertain responsibilities and high employee turnover. Few actors seemed to know what others were doing and most of the professionals argued that the existing working methods and responsibilities should be both changed and improved. Even though a few of the habilitation professionals had some knowledge or experience of respiratory issues it is assumed to be too little to cover and meet the needs of families to children with severe CP and/or PIMD. Without adequate competence is it hard or even impossible for professionals to identify a child's respiratory change and to manage their needs sufficiently (Seddon and Kahn, 2003).

6.1.3 The families

The interviews with the families resulted in several important findings, such as needs and prerequisites for maintaining or improving health and well-being. All families differed from each other, which is important to bear in mind. They had some challenges and needs in common but managing families in the same way based on assumptions may be a huge risk. Some families preferred assistants in order to be parents as much as possible, without giving medical treatment at all. Other wanted to have full responsibility for everything, from coordinating contacts and appointments to giving respiratory therapy and changing position during nights. The families' needs changes over time and depends on several factors, such as the child's health, language skills, personal skills and socio-economical factors. The data collection identified clear differences between the interviewed families, such as health and well-being. This is no new information. It is well known that the Swedish healthcare system has significant differences at regional and social level, and that each families' economy, living habits and language skills correlates strongly to health and overall well-being (Socialstyrelsen, 2011). Standardized solutions will not satisfy all families all times. In worst case they may only create conflicts and feelings of not being understood, trusted and involved. The most effective way to learn and identify families' needs should be continuous communication so that the professionals and the families can develop a relationship built on trust and mutual benefits.

To better understand what needs families to children with severe CP and/or PIMD may have, *Figure 6* can be used as a framework. Bear in mind that no family is the same as another family and that their needs and prerequisites change over time. The matrix below describes examples of factors that have been identified as important and sometimes even crucial. For instance, the need for support is high when the child has severe issues, the family lack Swedish language skills or has a full-time employment. Lack of competent healthcare professionals and families with bad living habits affect the overall family's health and especially the child's health. Families who lacks many or all these factors are assumed to have a higher need of support than others. The level of support does of course depend on the child's well-being and whether he or she have many health-related issues or not. Families usually have more needs for support when the child is young, compared to when being a teenager. A family's well-being and need of support is strongly correlated to different factors, which is why each family needs to be viewed from an individual perspective with focus on involvement and family-centred care.

HIGH	Parents with full-time employment	Parents or network actors lack skills in Swedish language	Disabled child has severe and many diseases/issues
Need of support	Multiple children family	Lack of network knowledge (actors, laws, acts and regulations)	Lack of permanent, competent and experienced healthcare professionals
LOW	Parents lack important personal skills (managing conflicts, negotiating etc.)	Assistant challenges (high turnover or few allocated hours)	Parents with bad living habits (lack of sleep and working out etc.)
	LOW		**HIGH**
		Degree of impact at family's health	

Figure 6: Matrix over different prerequisites, which correlates to a family's health and need of support.

However, during the years most of the families had experienced professionals who either had refused to discuss and create mutual benefits or had viewed their child as an object, rather than a human being. The waiting time for receiving help or support had sometimes been terrible and hard to manage. But even though the families were quite satisfied with each actors' contribution from an independent perspective, the coordinated care was totally absent. Not surprisingly, the most expressed need was a coordinating support, who could manage most of the communication between the network actors and coordinate both appointments and applications of treatment.

Even though no actor had a holistic view of the situation, with knowledge of other actor's contribution or knowledge, the families were satisfied with the respiratory team at Skövde Hospital. The families had similar expectations on the team and emphasized the importance of trust, continuous communication and mutual benefits. They appreciated the team's way of working with continuity, collaboration and their way to enable co-creation of care at home. Most importantly they were satisfied to have a permanent physician, with both competence and interest, who they could contact whenever they needed to.

6.1.4 Summarize of Research Question I

Families to children with severe CP and/or PIMD is a complex group with various needs and expectations. The study focused on four families with four different perspectives and stories to tell. The analysis identified their challenges and needs and how these correlated to different factors. Most important is to have knowledge about key factors that may affect the degree of a family's need of support, described in *Figure 6*.

However, the four hospitals included in the study and their management of respiratory issues are summarized in *Table 6*. The habilitations answers are summarized in *Appendix C*. Based on the interviews and the observations the study identified that the respiratory team satisfied most of the families' needs through proactive and regular treatment, availability, trust, empathy and knowledge. It is known that the best approach for paediatric healthcare is family-centred care (Broberg et al., 2014; Dempsy and Keen, 2008; Socialstyrelsen, 2017) and it is of importance to stress that the respiratory team not covered all aspects within this approach. Lack of sibling support and psychosocial resources were two main obstacles for achieving success regarding family-centred care. Even though they lacked family-centred care did the respiratory team provide the families proactive and structured care with focus on involvement and co-creation. According to the answers of the families and the respiratory team the proactive respiratory care did improve the children's and families' well-being and reduce the number of hospitalizations due to respiratory issues.

The other hospitals (A, B and C) lacked, according to themselves, structured methods for identifying, treating and follow respiratory children with severe CP and/or PIMD. Two hospitals lacked competent and skilled pulmonologists with experience of respiratory issues and lung medicine, while the third hospital lacked resources to manage all children with proactive and structured care. All this is described in *Table 6*.

Table 6: Summary of the four different hospitals in VGR and their respiratory care of patients with severe CP and/or PIMD, based on interviews and observations.

	Skövde Hospital	**Hospital A**	**Hospital B**	**Hospital C**
Respiratory team at the clinic of child and adolescents (number of people)	Yes (4)	Yes (20+)	No	Yes (2)
Proactive respiratory care for children with severe CP and/or PIMD	Yes	No	No	Lack of
Collaboration with habilitations in VGR	Yes	Lack of	Yes	Yes
Clear routines & responsibilities in collaboration with habilitations	Yes	No	No	No
Respiratory competence & knowledge at the clinic of child and adolescents (BUM)	Yes	Yes	No	Lack of

The lack of constant resources is an interesting aspect that should be further discussed. Every hospital and habilitation in the study lacked resources. If it not was equipment it was professionals with adequate competence, experience, interest or enthusiasm. Many of the interviewed professionals criticized the healthcare network for lack of collaboration and coordination, lack of information from management, lack of clear responsibilities and lack of well-functioning information systems to work in. The lack of resources is questioned by the researcher. Maybe the healthcare system that lack adequate and efficient ways of working, rather than resources in terms of professionals. During the study the researcher observed several inefficient processes, with lack of cross-functional collaboration between clinics, hospitals, habilitations and regions. When using existing resources in the wrong way, professionals will obviously lack adequate prerequisites and request more resources. The problem is that more resources not necessary will improve and make professionals work more efficient. Putting more resources into a system full of fragmentations and inefficient processes will most probably not create anything other than chaos, conflicts and reduced quality of care. Directives from management were often unclear and uncertain and many professionals criticized the management for lack of information. Even though professionals were tired of waiting on management decision, the families and the children were the ones who suffered the most. Falling in between the cracks due to lack of clear routines and collaboration should neither happen nor be accepted in 2018. Lack of efficient processes and lack of competent professionals slow down the child’s chances of receiving help in time. In worst case these children die an early death when waiting for help and support.

To summarize research question one; healthcare actors in VGR have different processes and perquisites to work with proactive and structured respiratory care. Hospital A, B and C are not assumed to provide as proactively and structural respiratory care as the respiratory team at Skövde Hospital does. Why the respiratory team at Skövde Hospital have a better respiratory treatment needs further investigation, but other hospitals should review current respiratory management of children with severe CP and/or PIMD. Even though both professionals and families suffer from a Swedish healthcare system full of fragmentations and lack of coordination, Skövde Hospital is an example of how to create family-centred care with existing resources. With a team of multi-competent professionals, close collaboration with other key actors and trust from management, the team work with proactive and structured respiratory care. Based on this study, respiratory management is not equal for families to children with severe CP and/or PIMD in VGR. Families belonging to Skövde Hospital are managed with proactive and structured family-centred care, while others are sent back and forth between healthcare actors who refuse to take responsibility and collaborate with others. In 2018, families to children with complex care needs are still too complex for most of the healthcare actors to manage. Whether this is about lack of resources, inefficient processes or incompetent professionals do not all children with severe CP and/or PIMD receive proactive and adequate care for their respiratory issues. Some lucky ones are, but many of them seems to be identified and treated late. The worst part is that some children most probably never will be identified and treated due to the lack of competence and proactive treatment. But as long as the healthcare system lack clear guidelines and decided processes for how and when to manage these children’s respiratory issues, who can blame anyone for doing wrong?

6.2 RESEARCH QUESTION II

The following sections discuss research question number two, which is based on the result and analysis from research question number one. Research question number two was as follows:

> *How can the respiratory team and the VGR network improve their work in order to better meet the needs of the patient group and their families?*

The improvement suggestions are focusing on improving the families' well-being and health. Some suggestions make a difference directly, while others are making a difference in the long run. The suggestions of improvements give examples of what the respiratory team and other network actors can do to facilitate for families to children with complex care needs and increase their well-being. The suggestions emphasize the importance of proactive work, such as having competent and skilled professionals, guidelines and screening processes. Family-centred care and co-creation of care are overall recommended approaches, which all actors should follow and adapt. Furthermore, the respiratory team received an extended list of suggestions, specified to them and their processes. Some of these suggestions are listed in *Appendix A*.

6.2.1 Coordinator support

This need was the most expressed need from both families and professionals. By providing the families a coordinator who manage most of the administrative tasks, such as booking appointments and writing applications, the parents can use time and energy for other more value creating activities. The coordinator should have knowledge about the different network actors, how they interact and how the overall network is working. The coordinator could join meetings and appointments to take notes as an objective assistant. He or she could coordinate appointments as well as write and send in applications of new medicine or treatment. The coordinator could basically do most of the administrative tasks to make it easier for the families.

6.2.2 Sibling support

Families with multiple children should have access to a sibling support. The support should aim to put focus on the siblings, who often are forgotten in these life situations. A sibling support service is a good way for siblings to meet other siblings in the same situation. It would also be relieving for the parents, who often have continuously bad conscious. A sibling support would especially help those parents who does not have any relatives or others to get support from.

6.2.3 Collaborative network

Geographically spread actors require a higher demand of coordination, which is the case for VGR. With few professionals per medical area they struggle to provide well-functioning healthcare (VGR, 2018) so to succeed with coordination the network needs to align their goals (Socialstyrelsen, 2017). Today the actors could neither collaborate nor communicate as much as they wanted due to the lack of routines, guidelines and tools. The actors need to increase their collaboration by communicating through meetings and well-functioning information systems. The responsibilities and roles must be clarified and especially between the habilitations and the hospitals. The network should aim for creating synergies and reach a holistic healthcare by involving the families and the key stakeholders as much as possible.

6.2.4 Process improvement

The researcher identified several processes that were both inefficient and unnecessary. Material was stored in other areas at the hospitals, referrals were sent back and forth between actors and families visited the hospitals several times each year. The researcher identified many processes that should be reviewed and improved. The refill of baclofen visualized in *Figure 7* below is one example of an inefficient process. Currently the families are traveling six hours to

Gothenburg for a treatment that takes about 10-15 minutes. This procedure is done four times a year. As the treatment is quite simple it does not necessarily need to be done in Gothenburg. The researcher recommends the network to re-design the process and think of what is best and most easy for the families. Habilitation Knoppaliden or the parents should manage this by themselves. The researcher suggests a change of the process, visualized in *Figure 8*.

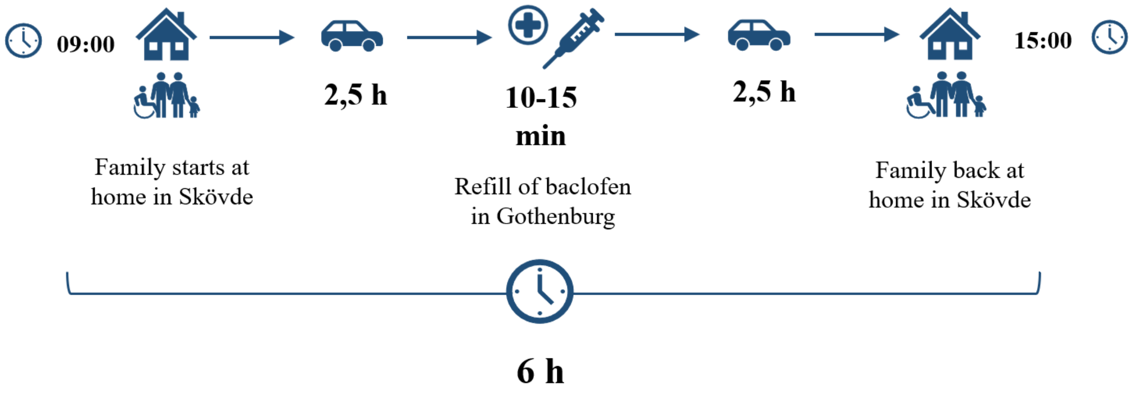

Figure 7: Example of one of many inefficient processes visualized in a timeline

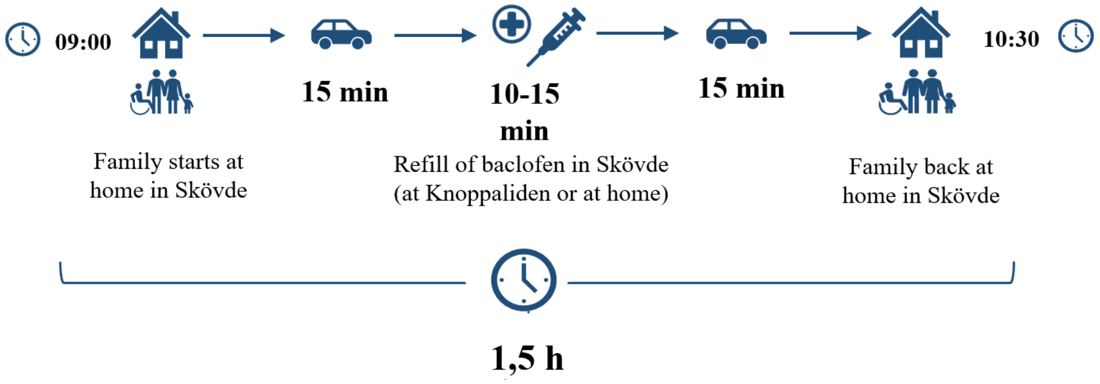

Figure 8: Example of how the process could be improved and more efficient.

6.2.5 Secure competence of respiratory management

None of the habilitation professionals had any special education or training within respiratory issues but still managed high-risk children. Each habilitation clinic should have at least one or two professionals with broader competence and knowledge of respiration issues. The network should also focus on educating both parents and assistants, so these have the right prerequisites to co-create respiratory care as well. Both professionals and relatives should develop their knowledge and get trained by competent and experienced pulmonologists, such as the respiratory team at Skövde Hospital.

6.2.6 Regional and national guidelines

Today there are no existing guidelines for how and by who investigation, treatment and follow-up of respiratory issues should be managed (Gustafsson, 2017). Clear guidelines regarding responsibilities, competence and collaboration needs to be established and communicated to both professionals and families. The guidelines should emphasize respiratory treatment and clarify the collaboration between habilitations and hospitals, with focus on responsibilities and routines. The regional and national guidelines should be updated regularly and include the perspectives of both the families and the professionals.

6.2.7 Pulmonary function screening

Even though many of these children die in respiratory issues there is no existing screening to identify high-risk children to initiate early treatment. As a basic tool screening could help healthcare actors to identify children who are likely to develop respiratory issues. The population needs to be discussed, but there are many patient groups with risks of respiratory issues and reduced pulmonary function. With a screening program the children's issues could be identified at an early stage and treatment started proactively. Structured and proactive identification, treatment and follow-up could in the long run reduce the number of unidentified and un-followed individuals. That means the numbers of hospitalizations and deaths related to respiratory issues are assumed to be reduced with pulmonary function screening.

6.2.8 Respiratory surveillance program

A respiratory surveillance program is needed to perform collection, analysis and interpretation of respiratory issues. The program should work with continuous and systematic activities to in order to improve and develop respiratory treatment. The data should be easy to collect, understand and integrate with other data. A surveillance program for hip dislocation and severe contractures (CPUP) have existed for individuals with CP for decades, and research now stress the need for a program for scoliosis problems (Hägglund, 2018). The benefits of a surveillance program are many and there are many reasons for why a respiratory surveillance program should be established. By establishing a follow-up program knowledge and research could be shared regional, national and international level.

7 CONCLUSION

This chapter presents the conclusion of the study, followed by critical considerations and suggestions for further research.

7.1 CONCLUSION

The purpose of this study was to increase the understanding of how the needs of families to children with severe CP and/or PIMD are managed by the respiratory team and the VGR network. The VGR network consisted of habilitation clinics and three hospitals at both county and regional level in Region Västra Götaland, Western Sweden. The understanding gained in the study was used as a foundation for the improvement suggestions in research question number two. The study aimed for contributing to the overview of families to children with severe CP and/or PIMD, their needs and how to improve their well-being. Theoretically the study contributed to the area of improvement science by including theory from both service logic and family-centred care. The reason for extending the theory of improvement science was because improvement science usually treats healthcare as an isolated question, which the theory of service logic does not. Since the children were severely disabled and had limited opportunities to co-create value by themselves, they were highly dependent on their families, why family-centred care was included as theory as well.

The study investigated in one of the many sub-networks within the differentiated and fragmented Swedish healthcare system. The study resulted in an overview of healthcare for families to children with severe CP and/or PIMD, focusing on respiratory issues. The result validates previous research at many points, such as the lack of coordinated care, continuity and equal healthcare. The study identified similarities and differences between healthcare actors in Region Västra Götaland. One of the most significant findings was the lack of clear responsibilities and routines for how habilitations and hospitals should manage respiratory issues in terms of investigation, treatment and follow-up. The study found that three of four hospitals in the region lacks structured and proactive respiratory care for children with severe CP and/or PIMD. The fourth hospital worked proactively but lacked efficient processes and some important requirements in family-centred care, such as sibling support. The responsibility allocation between the actors were many times unclear, both for the professionals and for the families. The study validates the previous reports of reduced well-being of families to children with disabilities, where socio-economic differences were significant.

As medical and technical improvements are increasing, Sweden among other countries have better opportunities to save more lives than ever. At the same time the number of pre-term babies with respiratory issues and patients with complex care needs are increasing. Individuals with complex care needs is a patient group Sweden still cannot provide enough healthcare and support. The increasing differentiations and specializations within the system makes it even more challenging. No one seems to have a holistic perspective, and no one seems to take the fully responsibility for achieving it either. Current lack of collaboration and coordination of healthcare makes it hard to believe that the system ever will achieve a well-functioning network where actors and families to patients co-creates synergized healthcare together. The organizational perspective is many times superior the patient perspective. Without a shift of the managements' mindset professionals will continue to have wrong prerequisites in order to perform their work with higher medical quality, improved efficiency and increased family-involvement. Without a patient mindset the healthcare system will continue to consist of sub-optimizations and harmful treatments with terrible consequences in terms of children with reduced well-being or in worst case - early deaths.

7.2 CRITICAL CONSIDERATIONS

The study was performed as a case study as a request by the respiratory team at Skövde Hospital. The study included observations and interviews of only this team but no observations of professionals at other hospitals or habilitations. The other teams and professionals did not have the same prerequisites to explain their work, processes and perspective of the situation in the same way as the respiratory team at Skövde Hospital had. In other words, the study was not completely equally performed when comparing teams, hospitals and professionals. The interviewed team members were assigned to various hospitals with different resources and the teams had also been around for different years and had reached different levels of maturity. Moreover, the interviewed families were chosen by the respiratory team at Skövde Hospital. The families may have been chosen due to their possible answers, which was outside the researchers' control. However, as the respiratory team aimed for an investigation of their work the researcher does not think the team chose families with only positive experiences. Furthermore, the research study was performed by a researcher without any competence, knowledge or experience within the area of medicine. This may have affected the researchers understanding and interpretation of interviews, observations and data analysis. However, as this study did not aim to improve the medical area this should not affect the conclusion of the study.

7.3 FURTHER RESEARCH

Even though much of the previous research have identified similar challenges and issues as in this research, some further research is recommended to perform.

- Investigate the possibilities of establishing a coordinator service for families to children with complex care needs and many network contacts.
- Analyse the possibilities of a screening program and a surveillance program for children with severe CP and/or PIMD, focusing on respiratory issues.
- Investigate and compare results with families who belongs to other hospitals.
- Analyse statistical data to identify patterns, such as number of hospitalizations due to respiratory issues and correlations to when treatment was initiated.
- Analyse correlations between treatment, such as respiratory aids and scoliosis bracing.
- Compare respiratory treatment between hospitals in other regions and countries and focus on organizational structure, success factors and challenges, collaboration with other team's and benefits from digitalization.

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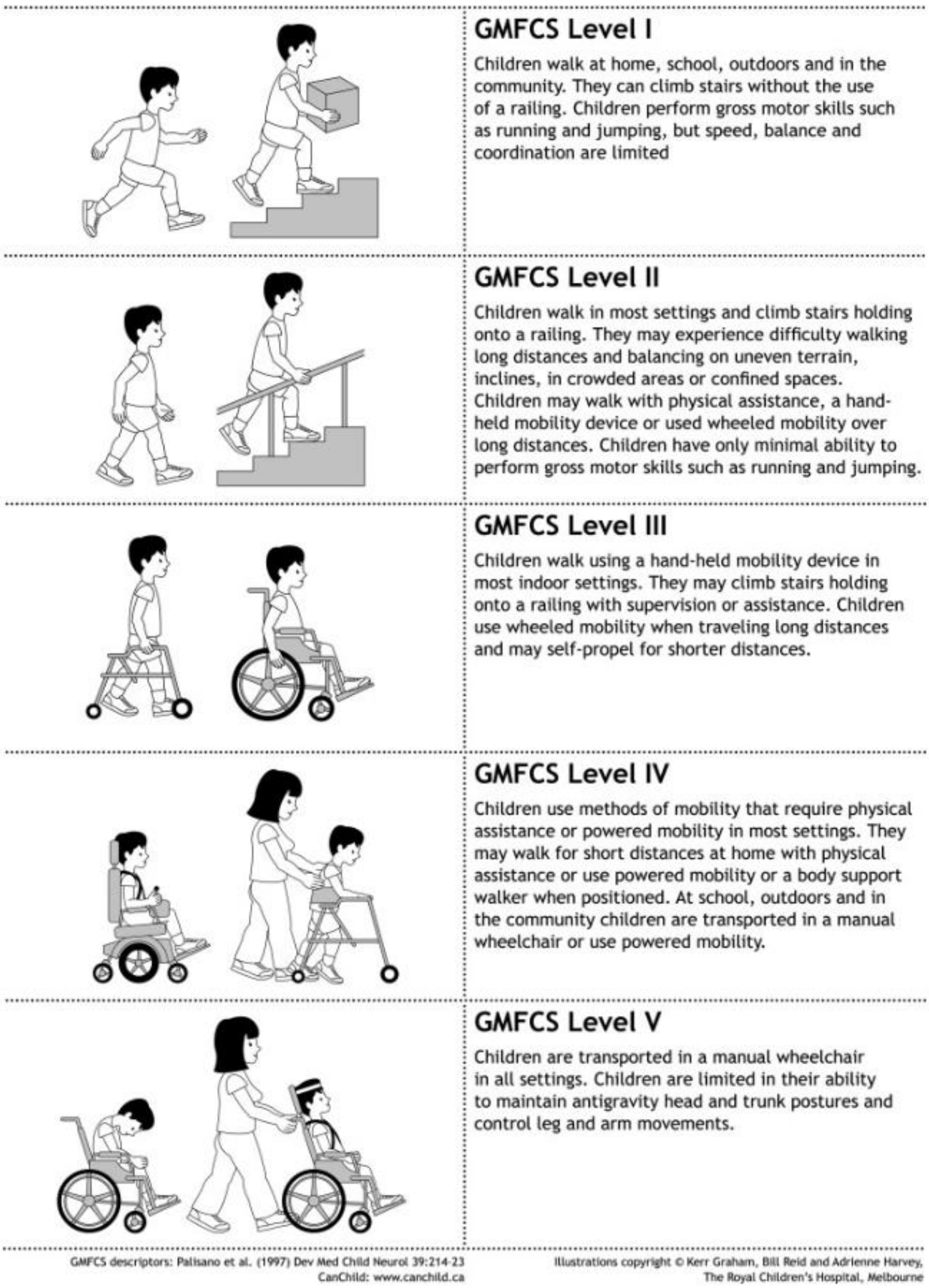
APPENDIX A

A table of some of the improvements suggested to the respiratory team at Skövde Hospital. These can be adjusted and adapted by other teams, hospitals and regions as well.

SOLUTIONS	OUTCOME
Let the families decide date and time of next appointment	Families can choose time a suitable for them, such as a specific week or a certain time at the day
Meet the families at Knoppaliden or other clinics	Reduces the families' appointments within the healthcare and increases the collaboration
Send referrals and reminders by e-mail and SMS	Decreases the number of missed appointments
Recommend sources of information to families	Families increase competence and knowledge
Provide paper and pen at appointments and/or take notes for the parent/parents	The parents document important information and can concentrate at listening
Visualize translations with text and pictures	Clarified communication to people with lack of Swedish language skills
Let the families listen with the stethoscope	The family gets involved and develops competence of respiration through knowledge sharing
Video meetings with interpreters	Improved communication with interpreters or other actors, compared to talking via speaker
Encourage and facilitate co-creation of value	Give suggestions of activities or network groups
Support the team with organizational development	More efficient working methods
Educate the team in data systems and how to work with data, categorizing etc.	The professionals can work more efficient and increase the quality of healthcare

APPENDIX B

Gross Motor Function Classification System (GMFCS). The five-level categorization technique to classify individuals with cerebral palsy and their voluntary movement.



GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited

GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

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The Royal Children's Hospital, Melbourne

APPENDIX C

Overview of each habilitation clinic in Region Västra Götaland.

	HABILITATIONS								
	ALINGSÅS	BORÅS	FRÖLUNDA	HISINGEN	KUNGÄLV	LIDKÖPING	SKÖVDE	UDDEVALLA	VÄNERSBORG
CHALLENGES	LACK OF PSYCHOLOGIST	LACK OF PSYCHOLOGIST	LACK OF PHYSICIAN & PHYSIOTERAPEUT	LACK OF PSYCHOLOGIST	LACK OF PHYSICIANS	ONLY ONE WITH RESPIRATORY COMPETENCE	-	LACK OF PHYSICIAN	LACK OF PHYSICIAN
RESPONSIBILITIES	UNCLEAR	UNCLEAR	UNCLEAR	UNCLEAR	UNCLEAR	CLEAR	CLEAR	UNCLEAR	UNCLEAR
ALLOWED TO PRESCRIBE PEP YES / NO	NO	YES	NO	NO	NO	YES	YES	NO	YES
SENDS REFERRAL TO KNOPPALIDEN	NO	NO	NO	NO	NO (LACK OF INFORMATION)	YES	YES	YES	NO (LACK OF INFORMATION)

APPENDIX D

Overview of some of the many contacts a family to a child with complex care needs have. Common for families is to have about 70-90 contacts to coordinate and communicate with.