TAMPEREEN TEKNILLINEN YLIOPISTO
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LAURI LITOVUO

DIMENSIONS AND SERVICE ECOSYSTEM OF CHILDREN'S PATIENT EXPERIENCE CO-CREATION

Master of Science Thesis

Examiners: Professor Saku Mäkinen and Assistant Professor Leena Aarikka-Stenroos
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ABSTRACT

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The economic era today is emphasized by experiences and companies globally are increasingly positing customers' experiences at the heart of their strategies. At the same time, healthcare is undergoing a fundamental shift in business and operating models to survive with rising healthcare costs, increasing volume of patients and increasing complexity of healthcare service ecosystem. The increased complexity of healthcare ecosystem makes managing of healthcare's customer experiences, namely patient experiences, difficult. Patient interacts with these multiple actors of the ecosystem but assesses the experience in a dynamic and holistic way, meaning that every actor in an ecosystem participates to experience co-creation and influences to patients determinations of total experience. However, current knowledge on this complex yet important topic is at nascent stage. Therefore, to explore this phenomenon and to develop theory of the research field, this study aims to answer the following main research questions: *What does the dimensions children's patient experience co-creation consist of? What is the service ecosystem that co-creates the children's patient experience?*

To answer these research questions and to study this multi-level phenomenon a qualitative field study was conducted. The data used in this study included primary data and secondary data deriving from previous LAPSUS-project interviews. Primary data of 6 ecosystem actor interviews were collected through semi-structured interviews that were supported by illustrative drawings. Interviews and drawings were recorded and transcribed. Secondary data consisted of 23 semi-structured healthcare staff interviews and 18 narrative patients' parent interviews. The extensive data was thematically analyzed with coding framework based on preliminary analysis of secondary data and a review of literature of dimensions of service experience co-creation, patient experiences, service ecosystems and healthcare ecosystems.

As a result of this thesis, model on dimensions of patient experience co-creation and framework on children's healthcare service ecosystem were developed. Model on dimensions of patient experience co-creation consisted five co-creational dimensions: spatial, temporal, factual, emotional and locus dimension. Framework on children's healthcare service ecosystem included 11 different actor groups that were located in and beyond service setting. Actor groups were divided to 4 distinct categories that were healthcare actors, social and welfare services actors, ecosystem supportive actors and family, friends and other social group actors.

TIIVISTELMÄ

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Nykyinen talouden aikakausi korostaa kokemuksia ja yritykset maailmanlaajuisesti asettavat asiakkaiden kokemukset heidän strategiansa keskiöön. Samaan aikaan, terveydenhuollossa on meneillään murros liiketoiminnassa ja toimintamalleissa. Murrosta ajaa selviytyminen nousevista huoltokustannuksista, potilaiden määrän ja terveydenhuolto ekosysteemin kompleksisuuden lisääntymisestä. Terveydenhuollon ekosysteemin kompleksisuuden lisääntyminen tekee terveydenhuollon asiakaskokemusten, toisin sanoen potilaskokemusten, johtamisen vaikeaksi. Potilas on vuorovaikutuksessa näiden monien ekosysteemin toimijoiden kanssa, mutta arvioi kokemustaan dynaamisesti ja holistisesti, tarkoittaen, että kaikki ekosysteemin toimijat osallistuvat kokemuksen yhteisluontiin ja vaikuttavat potilaiden kokonaiskokemukseen. Saatavilla oleva tieto tästä kompleksisesta, mutta tärkeästä, aiheesta on vasta kehittyvässä vaiheessa. Valaistakseen tätä ilmiötä ja kehittääkseen tutkimusalueen teoriaa, tutkimus pyrkii vastaamaan seuraaviin päätutkimuskysymyksiin: *Mistä lapsien potilaskokemusten yhteisluomisen dimensiot koostuvat? Mikä on se ekosysteemi, joka luo yhdessä lasten potilaskokemuksen?*

Ladullinen kenttätutkimus toteutettiin, jotta voitaisiin vastata asetettuihin tutkimuskysymyksiin ja tutkia tätä monikerroksista ilmiötä. Tutkimuksen data koostui primäärisestä datasta ja aikaisemmin toteutettujen LAPSUS-projektin haastattelujen sekundääri datasta. Kuuden ekosysteemitoimijan primäärinen data kerättiin semi-strukturoiduilla haastatteluilla joiden tukena käytettiin havainnollistavia piirroksia. Haastattelut äänitettiin ja litteroitiin. Sekundäärinen data koostui 23 terveydenhuoltohenkilöstön semi-strukturoidusta haastattelusta ja 18 potilaan vanhempien narratiivisista haastatteluista. Kattava data analysoitiin temaattisesti alustavan sekundääri datan analyysin ja kirjallisuuskatsauksen pohjalta luodun koodaus viitekehyksen avulla. Kirjallisuuskatsaus pohjautui palvelukokemuksen yhteisluomisen ja sen dimensioiden, potilaskokemuksen, palvelu ekosysteemien ja terveydenhuollon ekosysteemien kirjallisuuteen.

Työn tuloksena kehitettiin potilaskokemuksen yhteisluomisulottuvuus –malli ja lasten terveydenhuoltopalveluekosysteemi –viitekehys. Potilaskokemuksen yhteisluomisulottuvuus –malli sisältää viisi eri dimensiota: spatiaalinen, temporaalinen, todenperäisen, emotionaalisen ja keskittymä dimensiot. Lasten terveydenhuoltopalveluekosysteemi –viitekehys sisältää 11 eri toimijajoukkoa, jotka sijaitsevat palveluympäristössä ja sen ulkopuolella. Toimijajoukot on jakautuvat 4 kategoriaan, jotka ovat terveydenhuolto toimijat, sosiaaliturvan toimijat, ekosysteemin tukitoimijat ja perhe, ystävät ja muut sosiaaliset toimijat.

PREFACE

Rehellisesti voin sanoa olevani tyytyväinen omaan suoritukseeni. Tutkimukseni aihe oli todella mielenkiintoinen ja tärkeä, mikä auttoi jaksamaan urakan läpi. Tarpeeksi kun jaksoi kehittää, viilata, kultivoida ja tehdä kirjoitusta sofistikoituneemmaksi ja myyvämmäksi niin tästähän tuli ihan palautettava työ.

Erityisen suuri kiitos diplomityö-ohjaajalleni ja tutkimusmaailman mentorille Leena Aarikka-Stenroosille. Kiitos kaikista antamistasi parannusehdotuksista ja kommenteista läpi projektin. Saamani tuki epävarmuuden hetkillä on ollut korvaamatonta, mutta niin on myös ollut antamasi lukuisat kommentit ja aina paremman vaatiminen varmuuden hetkillä. Työtä on ollut mielekästä tehdä, kun on saanut luottamusta, kehuja ja rakentavaa palautetta.

Kiitos diplomityön tarkastajalle Saku Mäkiselle, jonka ajatukset ja ideat antoivat mietittävää pitkäksi aikaa. Lisäksi haluan kiittää Pekka Lahdennetta johdatuksesta lastensairaalan maailmaan ja avusta haastateltavien saamisessa, Aalto yliopiston LAPSUS-kollegoita avusta ja hyvästä yhteistyöstä sekä kaikkia haastatteluihin osallistuneita, ilman teidän osallistumistanne tästä olisi tullut paljon laihempi lehtinen.

Diplomityöni saattaa myös tähänastiset opintoni loppuun. Kiitos siis TTY:lle ja teollisuustalouden laitokselle, jotka tarjosivat riittävästi valinnanvapautta ja joustavuutta omannäköisteni opintojen suorittamiseen. Pystyin opiskelemaan kulloisiakin kiinnostuksen aiheita ja toteuttamaan unelmia, mikä toi erityistä motivaatiota opiskella. Lisäksi se avasi mahdollisuuden tutustua erilaisiin aloihin, paikkoihin ja tieteen haaroihin. Lopuksi kiitos kaikille, jotka ovat olleet mukana tällä leppoisalla elämänpolulla.

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Lauri Litovuo

CONTENTS

LIST OF APPENDIXES:

LIST OF SYMBOLS AND ABBREVIATIONS

CX	Customer experience
E	Emotional
F	Factual
L	Locus
PX	Patient experience
S	Spatial
S-D	Service-dominant
T	Temporal

1. INTRODUCTION

1.1 Background of the Research

Distinct to the economic era of today is the importance of experiences. Need to personalize the value offerings has caused evolvement of the economy from goods economy to services and solution economy and recently to the experience economy (Pine & Gilmore 2013). Where products and services economy were characterized on customized goods and services and solutions combining those (Pine & Gilmore 2013; Hakanen & Jaakkola 2012), the experience economy is characterized by the individualized and compelling service experiences and value emerging through evaluations of experiences (Pine & Gilmore 2013; Helkkula & Kelleher 2010). Interest towards service experience management and research have increased rapidly in recent years. The pivotal work of Vargo and Lusch (2004, 2008) on service-dominant logic is fueling the discussion to emphasize the experiential nature of value. In addition, suggestions of service experience based strategies providing superior competitive advantage that companies are seeking have been presented (e.g. Verhoef et al. 2009). Companies have addressed this shift by positing customers' experiences to the heart of the strategies to create competitive advantage (Zomerdijk & Voss 2011).

However, experiences are extremely complex to manage, as they are subjective, dynamic and unique interpretations of events and dependent on many personal and contextual factors (Zomerdijk & Voss 2011). Furthermore, in a today's networked business environment multiple actors are participating to experience co-creation with intertwined value creation processes (Sampson 2012; Maklan & Klaus 2011). Customers are therefore increasingly encountering multiple providers in their customer journeys that are all affecting to the dynamic evaluation of experience (Tax et al. 2013). Experiences emerge through interactions and collaboration between network's actors that are resource integrators and co-creators of mutual value forming a service-ecosystem (Akaka et al. 2013). This makes this topic relevant and interesting to study.

The shift to the experience economy is influencing to all industries and healthcare is not an exception. Healthcare is globally undergoing a fundamental shift in business, clinical and operating models. Firstly, by healthcare companies in countries without strong publicly funded healthcare for the above mentioned reasons of gaining competitive advantage. Secondly, by healthcare companies in countries with publicly funded healthcare, for instance in Finland. Financial pressure combined to aging and growing populations with proliferation of chronic diseases is forcing healthcare providers, payers and govern-

ments and other stakeholders to reform the healthcare systems (Deloitte 2016). To respond to this challenge of rising healthcare costs and increasing volume of patients, improvements in effectivity and efficiency of healthcare is needed. Moreover, this needs to be done without expense of quality of care and satisfaction of patients. Relevantly, compelling service experiences are a way towards it. Studies suggest that service experience in healthcare context, namely patient experience, is positively associated with patient safety and clinical effectiveness and important determinant of degree of satisfaction (Bleich et al. 2009, Doyle et al. 2013).

Therefore, increasing attention for providing excellent patient experiences have been acknowledged in recent years (NHS Confederation 2010). However, scarce knowledge on patient experiences and complexity of managing experiences makes it extremely difficult to apply. Therefore, even if technical aspects of clinical operations and processes are developed to near excellence it might not transfer to excellent patient experiences (Bolton et al. 2014). Scarcity of knowledge on patient experiences is even more evident in the context of children's patient experience. Hence, there is a need for development of knowledge on service experiences in this socially important context of children's patient experiences.

Furthermore, the co-creation of experiences within ecosystem, as described above, is also concerning children's patient experiences. Defragmentation via mergers and acquisitions and collaborative relationships with providers is increasing service providers through patient's continuum of care (Deloitte 2016). That is, there are many actors participating to the child patient experience continuum that increases the experience's complexity (Bolton et al. 2014). Moreover, parents or carers of the child have generally a critical role in children's life. Therefore, presumably they are also active co-creators in the service-ecosystem in the context of children's patient experience that increases the complexity of experience co-creation even more. Hence, to provide top quality care and excellent patient experiences, healthcare providers and executives need to understand how the ecosystem co-creates children's patient experiences.

Therefore, this study is timely and important for three reasons. First, Finland is a middle of a substantial reformation in the policies concerning healthcare, social welfare and regional government. This legislative change will reform the way healthcare and social welfare services are organized and enhance the patient's freedom of choice on the service provider (Ministry of social affairs and health 2016). This means that there will be an emerging need for service providers in Finland to achieve dual emphasis – to achieve superior customer experience and efficiency simultaneously (Mittal et al. 2005). Additionally, multi-provider model between public, private and third sector must be able to co-create integrated healthcare and social welfare services in an effective, collaborative and cost-effective manner, so that public welfare and healthcare services can be produced with limited resources and under the pressure of cutting the public services costs. This

phenomenon is not limited to Finland; it is equally important to all similar welfare countries that provide public social welfare and healthcare services funded through taxation. The importance of the public sector is evident in every welfare country and the services provided by it is the fundamental part of the welfare society. Hence, it is important for practitioners, managers and policymakers to understand how the patient experience is co-created over the patient pathway. And to understand by whom and how the service is co-created by multiple actors within the healthcare ecosystem. Moreover, it is important for academics interested in public service sector to explore and to understand the aspects of collective and collaborative service experience co-creation.

Second, this study is important in a sense of gaining competitive advantage for firms in countries without strong publicly funded healthcare system. Customer satisfaction is positively associated to firm's long-term financial performance (Mittal et al. 2005) and customer experience based strategies might provide a superior competitive advantage (Verhoef et al. 2009), this drives companies also in healthcare to provide excellent customer experiences. In a competitive environment, hospital boards are forced to understand how their patients are experiencing care to effectively translate their needs and preferences into higher quality, safer and more efficient services (NHS Confederation 2010). Research field lacks papers that are exploring holistic service experiences in a children's healthcare context. Hence, it is important to develop knowledge in that field or research.

Third, this study will provide insights to special service context where customer experience is co-created within close relationship with multiple actors. In many cases of children's healthcare, the exact customer i.e. patient cannot provide information needed for a service by oneself hence other informant is needed in service co-creation. This special setting where third party actor has a major role on service production and service is co-produced by a service network, is both interesting and important in a research point of view. These insights will give valuable understanding how this kind of setting is affecting to service management. Therefore, this thesis explores the phenomenon and aims to develop the existing theory of service experiences, dimensions of service experience co-creation and service ecosystems by studying children's patient experience co-creation within an ecosystem. Moreover, this study will respond to the call by Jaakkola et al. (2015) to identify relevant actors involved in service experience co-creation and to explore the nature of service experience co-creation in different industries and cultural contexts.

As mentioned, despite the acknowledged importance of patient experience in the healthcare sector (NHS Confederation 2010), the research field lacks knowledge about children's patient experience. To fill the gap of knowledge and implement the findings to reach better children's patient experiences, a joint project of universities, university hospitals and hospital districts have been started in Finland. This thesis is written as a part of it. The LAPSUS-project (Finnish project name Lapsiperheiden uusiutuva sairaala, Renewing Hospital for Children and their Families) started beginning of 2015 and it is a

joint project of Aalto University, Tampere University of Technology, Hospital District of Helsinki and Uusimaa, Oulu University Hospital and Turku University Hospital. "Renewing Hospital for Children and their Families" project is funded by TEKES and the emphasis is on a novel concept of "patient experience". This thesis contributes by providing knowledge about characteristics of dimensions of children's patient experience co-creation and actors co-creating the experience. In addition, frameworks on dimensions of patient experience co-creation and children's healthcare service ecosystem are developed and introduced in this thesis. The development process of the frameworks is twofold. First, preliminary frameworks are developed by integrating current research knowledge. Second, the frameworks are further developed and refined based on the empirical study conducted in this thesis.

1.2 Research Questions and Objective

As described above, patient experience is an important component of high quality healthcare. However, complexity of experiences makes them difficult to manage (Bolton et al. 2014) and to even unanimously conceptualize (Helkkula 2011). In past few decades researchers have shifted their focus from hedonistic and extra-ordinary experiences (Arnould & Price 1993) to everyday lived experiences in social context. Recently theory models concerning the determinants of customer experience (Verhoef et al. 2009) and framework of the key dimensions of service experience co-creation (Jaakkola et al. 2015) have been presented. Showing that customer experiences share similarities regardless of the context but also that experiences are contextual (Vargo & Lusch 2008). This thesis takes service experience approach to patient experience. It is important to note that the context of patient experience might differ dramatically compared to the general customer or service experience. For example, patients do not have the freedom of choice to experience they are more or less forced to go through the service journey. In addition, in children's healthcare the situation can be extreme stressful to the child patient and his or her parents. Increasingly papers on patient experience is being published but research on children patient experience and holistic patient experiences are still on a nascent stage. Furthermore, these papers concentrate on measuring patient experience satisfaction rather than understanding the phenomenon and co-creation of the patient experience.

Papers in a field of children patient experience are focusing primarily on the children's experiences in the hospitalization (e.g. Carney et al. 2003, Coyne 2006, Uhl et al. 2013) or parents' experiences (Stratton 2004). These papers lack explaining in-depth the perception of the experience and the dimensions affecting to the children's patient experience co-creation approaching it only as provider led experience in the healthcare service setting. Therefore, studies concern only a narrow part and context of the children patient experience. Children patient experience literature has not followed the recent shift of the general service experience literature that encompasses the individual's overall valuation of the experience that emerges from encounters with service providers but also in the

everyday life of the customer. Clearly, what is needed is to deepen the understanding of children's patient experience in wider co-creational context. That is where this study contributes. This thesis approaches patient experiences from a phenomenological and co-creational standpoint and explores the nature of service experience co-creation dimensions presented by Jaakkola, Helkkula and Aarikka-Stenroos (2015) in children's patient experiences. The dimensions of service experience co-creation provide a holistic understanding of children's patient experience co-creation. Furthemore, it provides a structured approach to experiences by dividing this complex phenomenon to individual co-creational dimensions. This leads to the first research question:

RQ1: What does dimensions of children's patient experience co-creation consist of?

Furthermore, children and their families face multiple service providers during their care (Helkkula et al. 2013). These actors provide resources to the healthcare system co-creating the value together. Although each of these providers interacts with the patient and his or her family separately, they bound together as a network in a patient's mind (Tax et al. 2013). Therefore, the children patient experience is somehow co-created by this complex healthcare ecosystem. Although the co-creation of value and experience in healthcare is acknowledged (e.g. Helkkula et al. 2013), a limited attention has been paid to identifying and analyzing the actors within the ecosystem and their role in the ecosystem. Hence, a second research question will be:

RQ2: What is service ecosystem that co-creates the children's patient experience?

The second research question is be divided to sub-questions as followed:

What are the different actors co-creating the children patient experience?
What are their roles in the service ecosystem?
Which kind of actor categories can be identified from the ecosystem?

A qualitative empirical research is needed to answer above presented research questions and to understand a complex social phenomenon of patient experiences. The nature of this thesis is explorative and aiming for theory development. That is, by exploring and gaining insights from children's patient experience co-creation within an ecosystem, theories of service experiences, dimensions of service experience co-creation and service ecosystems may be further developed.

First, to get familiar with the topic a literature review is conducted. Second, an empirical research is conducted to reach empirical results concerning the children's patient experience co-creation within a service ecosystem. Patient experience co-creation will be explored from families' and ecosystem actors' perspectives to gain an extensive analysis on the phenomenon. Extensive empirical data is collected by interviewing healthcare professionals, ecosystem actors beyond the hospital environment and patients' parents with

a few interviewing methods. A path of how this thesis answers above presented research questions and detailed structure of this thesis are presented in the next sub-section.

1.3 Structure of the Thesis

The structure of this thesis is divided to six sections to answer the research questions. Introduction section is followed by theoretical background, research methodology, results, discussion and conclusion sections. Table 1 represents the paths to answer to both of the main research questions.

Table 1. *Sections concerning main research questions.*

<table>
<tr><th></th><th>RQ 1: What does dimensions of children's patient experience co-creation consist of?</th><th>RQ2: What is the service ecosystem that co-creates the children's patient experience?</th></tr>
<tr><td rowspan="3">2. Theoretical Background</td><td colspan="2">2.1 Towards patient experience</td></tr>
<tr><td>2.2 Dimensions of patient experience co-creation</td><td>2.3 Service ecosystem participating to patient experience co-creation</td></tr>
<tr><td colspan="2">2.4 Synthesis: Ecosystem that co-creates children's patient experience</td></tr>
<tr><td>3. Research Methodology</td><td colspan="2">Methodology for the empirical research</td></tr>
<tr><td>4. Results</td><td>4.2 Dimensions of children's patient experience co-creation</td><td>4.1 Ecosystem co-creating the patient experiences</td></tr>
<tr><td>5. Summing up results and discussion</td><td>5.2 Distinct dimensions of patient experience co-creation</td><td>5.1 Service ecosystem in children's healthcare context</td></tr>
<tr><td>6. Conclusions</td><td colspan="2">Conclusions of the thesis</td></tr>
</table>

Next, the theoretical background for the study is presented. The purpose of the sub-section 2.1. presents relevant literature of customer and service experience approaches to understand the phenomenon of patient experience. Section 2.2. of the literature review is to lay the foundations to answer to the first research question. In that sub-section dimensions of service experience co-creation is applied to phenomenological patient experience. Sub-section 2.3. lays foundations to understand the theory behind the ecosystems, reviews how ecosystems are studied in the healthcare context and is there any special characteristics in a children healthcare ecosystem. End of the section two a synthesis of the ecosystem and patient experience is presented.

In the third section research methodology of the study is presented that is followed by the results section. Results concerning the research question 1 are presented in the sub-section 4.2. Results for research question 2 is gone through in sub-section 4.1. Discussions of this thesis is presented in a fifth section. Finally, conclusions of this study are presented.

2. THEORETICAL BACKGROUND

2.1 Towards Patient Experience

Discussions about experiences approaches the subject from different perspectives in contemporary literature. In this sub-section, relevant literature of customer and service experience are presented to understand these different approaches and to understand the phenomenon of patient experience.

2.1.1 Patient Experience as a Service Experience

Experiencing events and nature is embedded to human nature; humans perceive living, their surrounding nature and events they live through. Hence, the "experience" is defined as "something personally encountered, undergone, or lived through" or "the act or process of directly perceiving events or reality" (Merriam-Webster 2016a). Importantly, experiencing is always present. Therefore, some *words are used for to indicate that the perception experience is taking place to a particular event or the role the person has* during the perception process. This thesis concentrates experience sub-categories of "service experience", "customer experience" and "patient experience"

"Service experience" is a type of experience that is perceived as person lives through an event of service. Therefore, *the "service" indicates the particular situation of perceiving experience* and encounters. *It does not take a stand on what role the experiencing actor has* in the experiencing process. Customer experience has a different indication to experience. Customer is defined as "one that purchases a commodity or service" (Merriam-Webster 2016b). Hence, *"customer" indicates the role person has while experiencing* and "customer experience" is something that can be perceived at least through the purchasing a commodity or a service. Therefore, the difference between these two terms is the perspective of an actor experiencing a service (Jaakkola et al. 2015). As *described "customer experience" posits an actor being a customer but "service experience" does not take a stand on what role the experiencing actor* has in the experience process.

However, in the contemporary experience research discussion, the concepts of customer experience and service experience are blurred and *the terms "customer experience" and "service experience" are used as synonyms* (Jaakkola et al. 2015). This is due the service-dominant approach that does not separate commodities from services but posits "service" to be an application of resources (Vargo and Lusch 2008). Therefore, *all "customer experiences" can be seen as "service experiences"*.

In a healthcare context, the most important customer is arguably a patient. In the contemporary research literature customer experience in healthcare context and patient experience are sometimes used interchanging. However, a difference should be noted. "Patient" is defined as "a person who receives medical care or treatment" (Merriam-Wester 2016c), this posits patient experience's beneficiary to be cared in a healthcare context, but "customer experience" does not take a stand on the beneficiary's position for care. For example, in a pediatric healthcare, parents can participate to child's caring in a hospital. In a definition vise, only the child can be the beneficiary of "patient experience" but both child and parents can be focal beneficiaries in a "customer experience" in healthcare context. However, in this thesis the "patient experience" concerns both the actual child patient and parents of the child. Therefore, *in this thesis parents are included to "patient experience" or "children's patient experience"*.

As mentioned above the service-dominant logic approaches all customer experiences as service experiences. This research vein draws from the phenomenological value that is interpret subjectively by an individual, e.g. customer. As value is one of the central terms in this research vein and experiences are linked to it, a brief intro on value is presented next before moving to experiences.

Customer's perceived value has been a widely discussed topic for nearly three decades and it has become a foundation for firms to survive and gain competitive advantage in competitive markets (Sanchez-Fernandez & Iniesta-Bonillo 2007; Flint et al. 2011; Woodruff 1997; Spiteri & Dion 2004). In addition, positing firms fundamental purpose of existence as to offer superior value for its customers (Slater 1997). To offer exceptional value to customers and to stay competitive, marketing practice and research have recently shifted focus from consumer product brands and service marketing to creating compelling customer experiences (Maklan & Klaus 2011).

Although the concept of customer experience is not new, as Holbrook and Hirschman (1982) theorized already in the early 80's that consumer behavior is affected by experiential aspects of consumption, in the past decade it has become a phenomenon among marketing and service management practitioners and academics. Importance of customer experience has been widely acknowledged among practitioners and increasingly also in the academic marketing literature (Verhoef et al. 2009). As many of the earliest customer experience papers focused primarily on hedonic, memorable and extra-ordinary customer experiences, as widely cited white river rafting paper by Arnould and Price (1993), recently the everyday lived experiences, including customer experiences in healthcare, have attracted a lot of interest.

This has evolved discussion to the point that creating superior customer experiences to customers should be one of the central parts of every companies' strategy (Verhoef et al. 2009). The benefits and advantages of positive customer experience are extensive. In the context of healthcare alone there are evidences linking high-quality customer or patient

experience to improved health outcomes and reduced care costs (NHS Confederation 2010). Moreover, in general customer experience literature, positive customer experience has been linked to stronger brand equity (Biedenbach & Marell 2010), increased purchase intention (Hsu & Tsou 2011) and customer loyalty (Berry et al. 2002; Haeckel et al. 2003; Pullman & Gross 2004; Mascarenhas et al. 2006; Zomerdijk & Voss 2010; Maklan & Klaus 2011), positive word-of-mouth (Pine & Gilmore 1998; Haeckel et al. 2003; Lloyd & Luk 2011; Maklan and Klaus 2011), and to better customer satisfaction (Berry et al. 2002; Mascarenhas et al. 2006; Zomerdijk & Voss 2010; Lloyd & Luk 2011; Maklan & Klaus 2011).

This thesis studies customer experiences in the healthcare context. In healthcare providers offer healthcare services for their customers, i.e. patients, who experiences by living these services through. Importantly however, concept of "services" is not unambiguous. That is, in the contemporary research there are a few differing views on the characterization of services. First, services are separated from the physical products by using the IHIP characterization (see e.g. Boyt and Harvey 1997). That is, services are intangible (I) and heterogenetic (H). Services' production is inseparable (I) from the consumption, and services are perishable (P). This view is vastly in use at retail context where goods are purchased and services are delivered. Although, this product-service view is vastly acknowledged in literature and among practitioners, differing view on service has taken root in a contemporary research drawing from phenomenological value and service experience blurring the distinctions between products and services; service-dominant logic.

As mentioned earlier, service-dominant (S-D) logic approach to service intervenes the distinction between products and services. Importantly, *in a S-D lexicon "service" is application of resources* (i.e. knowledge and skills) for the benefit of other rather than a particular type of offering with unique characteristics (IHIP) that is referred as "services" (Vargo & Lusch 2008). This approach is emerging from the pivotal work of Vargo & Lusch (2004, 2008).

In this thesis "patient experience" is studied as a service experience drawing from the S-D logic. The foundational premise of S-D logic is that service is the fundamental basis of exchange and *emphasizing experiential nature of value* (Vargo & Lusch 2008). In addition, service-dominant logic suggests defining and co-creating "value-in-use" with the consumer rather than embedding it in output (Vargo & Lusch 2004). *Taking a S-D logic perspective means that all products and services are seen as applications of resources and value is experienced through use of these resources perceiving service experiences*. Therefore, it differs from the traditional economic measures of value and represents value deriving through use of available resources (Akaka et al. 2015).

The creation processes of experience and value are integrated and there is a circularity if service experience and customers' perceived value (Helkkula and Kelleher 2010). The tenth fundamental premise of S-D logic additionally asserts: "*Value is always uniquely*

and phenomenologically determined by the beneficiary" (Vargo & Lusch 2008, pp. 7). "Phenomenological" being that besides value is experiential, it is idiosyncratic, contextual and meaning laden (Vargo & Lusch 2008). Clearly, S-D logic blurs the distinctions between products and services, and so all customer experiences can be seen as a "service experience". This thesis takes the S-D logical view on value as holistic experience.

2.1.2 Different Approaches to Service Experience

Contemporary literature approaches service experience from multiple different viewpoints (Helkkula 2011). This has led to a point that phenomenon of service experience can be characterized from few different perspectives. The concept of service experience and the way they approach this phenomenon differs between the characterizations. Taking a particular vein of service experience characterization implies a focus of the experience study following the chosen perspective. The typologies what characterizes these approaches have been studied and therefore these typologies are presented next.

The typologies of characterizing service experiences can be divided to three categories:

1) outcome-based characterization;
2) process-based characterization;
3) phenomenological characterization (Helkkula 2011).

The outcome-based characterization of service experience advances the experience "as one element in a model linking a number of variables or attributes to outcomes" (Helkkula 2011). The outcome-based characterization tends to focus on the results rather than the service experience process or perception. Experience is not seen individualistically but as a total service experience of multiple respondents (Helkkula 2011). Outcome-based characterization approach is appropriate to use for customer experience surveys. However, this study concentrates to examining the phenomenon itself. Therefore, it is not appropriate to use outcome-based characterization approach in this study.

Compared to outcome-based characterization the process-based characterization enhances the service experience process and the "stages" or "phases" of the service process (Helkkula 2011). The experience is seen as a chronological journey through these architectural elements, which encompasses all phases of the customer's path, including search, purchase, consumption and after-sales phases (Verhoef et al. 2009). Customers interact with a service provider across different designed phases, i.e. touchpoints, along with other phases that are not under providers control (Teixera et al. 2012). These service elements provide the context where the experience happens but the interactions and activities in these touchpoints unfolds the experience (Teixera et al. 2012). Alternatively, "the enterprise cannot deliver value, but only offer value propositions" (Vargo & Lusch 2008, pp. 7).

Importantly, as service *experience is constructed subjectively by customer based on his or her interpretation of touchpoints* and encounters designed by a service provider, the *experience cannot be fully controlled by the firm* (Zomerdijk & Voss 2010). In customer-experience literature these provided service elements are also referred as experience clues (Berry et al. 2002) or cues (e.g. Zomerdijk and Voss 2010). These clues encompass anything that can be perceived or sensed in the touchpoints by the customer, e.g. services for sale, physical setting, and employees' gestures, comments, clothing and tones of voice. Moreover, the context of a service, consisting physical and relational elements in the experience environment, also sends clues to the customer and influences customer's experience (Zomerdijk & Voss 2010). Customer asses these multi-channel touchpoints cumulatively synthesizing them to an overall assessment of the experience (Zomerdijk & Voss 2010).

However, it can be argued that defining patient experience from the process-based view it gives too narrow view from the phenomenon and it cannot be in-depth understood. For example, process-based characterization does not include the elements beyond the service provider touchpoints (Heinonen et al. 2010), so it engages only a portion of the total experience interpreted by the customer. *The concept of experience should take dimensions even beyond customer-market relations into account* (Carù & Cova 2003). This sociological dimension of the experience, as it usually takes place in a customer's social context, is considered as a "consumption experience" (Haeckel et al. 2003). That is, customer experience can include elements that are controllable by the company but also elements that fall outside the providers control, like behavior and attitude of fellow customers i.e. social environment (Verhoef et al. 2009). In that social environment customer consumes and experiences the product in his or her *social context which might include e.g. friends and family or fellow customers*.

Phenomenological characterization draws strongly from the S-D logic presenting service experience as a phenomenon. According to phenomenological vein, *service experience is internal, subjective, event-specific, and context-specific experience of an individual* (Helkkula 2011). Moreover, is *determined in a holistic and dynamic way* uniquely by that individual (Verhoef et al. 2009). The *co-creation of experiences among multiple actors is nested within phenomenological service experience characterization* (Vargo & Lusch 2011). The service experience co-creation occurs when interpersonal interaction influences an actor's subjective response or interpretations of the elements of the service (Jaakkola et al. 2015).

Literature concerning children's patient experience as a service experience is at a nascent stage. Therefore, there is an evident need to study the subjective experience of patients in the service phenomenon. Phenomenological characterization is suggested as the most appropriate approach for this kind of analysis (Helkkula 2011). Furthermore, researches utilizing the phenomenological approach on service experiences could provide a basis for new developments in process-based research of service experience (Helkkula 2011). As

important factor for choosing the phenomenological approach is that it takes the co-creational side of the experiences into account. Next, the chosen phenomenological characterization of service experience is reviewed.

2.1.3 Co-creational Phenomenological Service Experience Approach

Although phenomenological service experience is a hot topic in the service experience field and conceptual papers have been published from the topic but empirical studies in different contexts are still scarce (Helkkula 2011). However, to study experience phenomenon it is important to understand the concept of phenomenological service experience to lay foundations for further apply in the study. Therefore, the concept of phenomenological service experiences is reviewed next. Moreover, in this thesis below, the reviewed concept of phenomenological service experience is applied to the context of children's patient experiences (see section 2.1.5).

The phenomenological characterization of service experience concentrates on the subjective experience of the service phenomenon. According to phenomenological vein, service experience is internal, subjective, event-specific, and context-specific experience of an individual. (Helkkula 2011) Accurately, this subjective response of the individual can be affective, cognitive, emotional, social and physical (Verhoef et al. 2009). *Experience is also dynamic in nature*, meaning that customer's earlier experiences affect to given service experience valuation and is dynamically updated through new experiences (Heinonen et al. 2010).

Phenomenological characterization also includes the direct and indirect connections (Helkkula 2011). Mayer and Schwager (2007) defines customer experience as "the internal and subjective response customers have to any direct or indirect contact with a company" (pp. 2). These *direct and indirect connections can be lived or imaginary* (Jaakkola et al. 2015). The experiencing actor determines the experience according to *actual service encounters, direct or indirect, but also by past memories and imagined future experiences* (Jaakkola et al. 2015).

The process of perceiving events can be actualize through direct and indirect contacts with company (Mayer & Schwager 2007). Direct contact is usually initiated by the customer and it occurs over the purchase, use and service (Mayer & Schwager 2007). Evidently, creation of customer experience presumes some level of customer's involvement to the process and some kind of interaction between a company and customer. In other words, *experience cannot be provided and produced independently by a company*. Importantly, the involvement of a customer to the experience process can vary and cannot be presumed as a standard.

Customer experience also includes indirect contacts additional to direct contacts. This leads to that *customer experience begins before and ends after the actual purchase or transaction* (Haeckel et al. 2003). These indirect contacts often involve unplanned encounters with representations of a company's products, services or brands (Mayer & Schwager 2007). Importantly, indirect contacts are taking place in customer-market relation and seen as a dyadic contact between a company's offering and a customer. These experiences can be also considered as a "consumer experience" (Haeckel et al. 2003).

Service experience exceeds the interaction-region of the focal organization. Meaning that customers assess their experiences also *before and after service encounters with the focal organization* (Maklan et al. 2011). Service experience is assessed, in addition to a direct and indirect provider-customer contacts, in an independent processes of the customer (Sampson 2012). Therefore, service experience or value creation processes can be divided into provider sphere, joint sphere and customer sphere (Grönroos & Voima 2013). Provider sphere consists processes that customer cannot participate. Direct provider-customer interactions are taking place in joint sphere. Whereas *in a customer sphere customers create value independently* but can be influenced by indirect interactions by the service provider (Grönroos & Voima 2013).

Grönroos and Voima (2013) defines this customer sphere as the experiential sphere, "outside direct interactions, where value-in-use (real value) emerges (is created) through the user's accumulation of experiences with resources and processes (and their outcomes) in social, physical, mental, temporal, and/or spatial contexts." (Grönroos & Voima 2013, p. 142). Additionally, they state that customer's experiences and perceptions of value-in-use may be divided into *individual and collective phases in the customer sphere*. In this collective phase customer's value creation process *is influenced by the social network of actors* (Grönroos & Voima 2013), *consist of friend and family, and by other customers* (Helkkula & Kelleher 2010, Grönroos & Voima 2013). These kind of social factors of experience creation have been increasingly acknowledged in the service experience literature (Helkkula 2011).

According to S-D logic, both the focal company and a customer are seen as a resource integrators and value is co-created collaboratively through interactions. This view identifies *all actors participating in value creation as co-creators* rather than positing one being a producer of value and one being a consumer of value (Vargo & Lusch 2011). Each of the actors *contributes creation of service experience by providing resources to value co-creation. Co-creation refers to a collaboration among multiple providers integrating resources and forming the service delivery system for service experience* (Jaakkola et al. 2015). As stated, the service experience co-creation occurs when interpersonal interaction influences an actor's interpretations (Jaakkola et al. 2015). The co-creational aspects of the experience are studied and dimension model of the experience co-creation is presented to better understand the phenomenon of co-creation. Next, these dimensions are reviewed.

2.2 Dimensions of Patient Experience Co-creation

This sub-section lays foundations to understand the dimensions of patient experience co-creation. Importantly, this sub-section presents the dimensions of phenomenological service experience co-creation that is chosen as an approach to study the phenomenon of children's patient experiences. Below, the dimensions of service experience co-creation is connected to contemporary literature of patient experiences and end of this sub-chapter a preliminary framework of dimensions of patient experiences is presented.

2.2.1 Dimensions of Phenomenological Service Experience Co-creation

Literature on phenomenological service experience suggests that experiences are actor's holistic and dynamic perception of events and interactions in a specific context that are co-created among multiple actors in a context. Importantly, s*ervice experience has different co-creational "dimensions" but the beneficiary assesses the total service experience holistically* rather than these individual dimensions separately (Jaakkola et al. 2015). In recent service experience literature Jaakkola et al. (2015) presented dimensional framework of service experience co-creation. This dimensional *framework of service experience co-creation* is represented in figure 2.

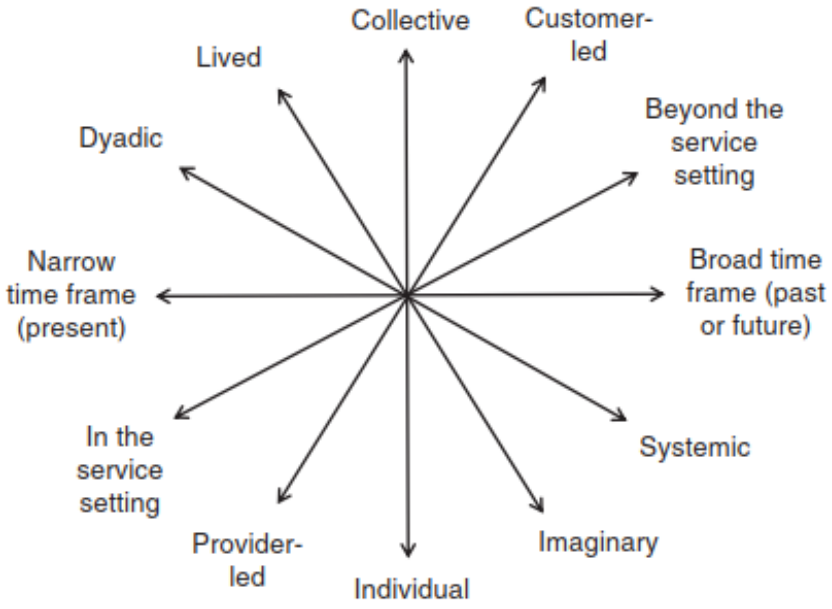

Figure 1. *Dimensions of service experience co-creation (Jaakkola et al. 2015)*

As represented in figure 1, framework posits experience co-creation to be co-created by six different dimensions: temporal dimension, factual dimension, locus dimension, spatial dimension, organization dimension and control dimension (Jaakkola et al. 2015). Next, the dimensions are presented more detailed.

Experience is dynamic in nature, meaning that customer's earlier experiences affect to given service experience valuation and is dynamically updated through new experiences (Heinonen et al. 2010). Hence, experience has a *temporal dimension* (Jaakkola et al. 2015). Experience valuation takes place at isolated moments in the *present* that is affected by *past memories* and imagined *future experiences* (Jaakkola et al. 2015).

Phenomenological characterization also includes the direct and indirect connections which can be either lived or imaginary (Helkkula 2011; Jaakkola et al. 2015). Therefore, service experience includes *factual dimension* (Jaakkola et al. 2015) Meaning that in healthcare context patient determines his or her experiences based on *lived experiences* and *imaginary experiences* in present, past or future.

Part of the service experience emerges in focal actor's everyday life. Service experience emerges in customers' life and consists all types of activities: ordinary, extraordinary, routine, mundane and everyday activities (Heinonen et al. 2010). In other words, some of the experience co-creation takes place *within the provider's service setting* and some of the experience is co-created *beyond the provider's service settings* (Jaakkola et al. 2015)

As argued above service experience includes the consumer sphere of the experience co-creation that can be divided to individual and collective phases (Grönroos & Voima 2013). In this collective phase customer's value creation process is influenced by the social network of actors (Grönroos & Voima 2013). Therefore, *the locus of the experience* co-creation can be divided to *experience of an individual* and to *experience of a collective* (Jaakkola et al. 2015).

The *organization dimension* or the service experience co-creation of the framework indicates that service experience co-creation may actualize in *dyadic* or more *systemic interactions among multiple actors* (Jaakkola et al. 2015).

As stated individual's subjective response can be emotional (Verhoef et al. 2009). Hence the experience is affected by *the emotional dimension*. However, the presented framework of service experience co-creation lacks this kind of dimension. Dimensionality of the emotions are often modeled with two-dimensional models, e.g. with Russel's Circumplex model of affect or models where *emotions can range from positive to negative* but also *the activation level of the emotions changes* (Richins 1997).

2.2.2 Approaching Phenomenological Patient Experience Co-creation

This sub-section lays foundations for framework of dimensions of patient experience co-creation presented in next sub-section. As stated, phenomenological service experience literature concerning "patient experiences" is at nascent stage. Therefore, this sub-section draws from knowledge of service and customer experiences in a healthcare context and

literature on patient experiences. The phenomenological service experience knowledge is reflected and applied to approach patient experiences as co-creational phenomenon. This sub-section also presents scarce knowledge available on distinctive co-creational aspects of children's patient experience.

As the service experience literature suggests *phenomenological patient experience can be seen as patient's subjective and holistic determination of a specific event, in a specific location at a specific point in time*. Patient experience being individual's subjective response it is affected and shaped by individual actor's unique values, actions, beliefs, motives, traditions, cultural background, possessions, and aspirations (Bolton et al. 2014; Wolf et al. 2013). Therefore, phenomenological patient experience is uniquely determined by the individual.

Patient experience (PX) defined by The Beryl Institute, the global community of practice dedicated to improving the patient experience, is "the sum of all interactions, shaped by an organization's culture, that influences patient perceptions across the continuum of care" (The Beryl Institute 2016). Clearly, the definition takes strong healthcare provider viewpoint suggesting that healthcare organization's culture shapes the patient experience. This indicates that the PX definition in this case is seen more likely as a process-based experience. However, it has also phenomenological characteristics as it is seen as total experience and the definition also posits that the *patient undergoes multiple interactions during their continuum of care*.

In healthcare context, this *journey of customers where they go through multiple interaction is also described by the word "pathway"* (Graham et al. 2015). This word choice is justified by the unique and unpredictable way the patients navigate through health and social services as they receive care for multiple conditions and from multiple providers (Graham et al. 2015). Furthermore, use of the terms "service line" or "patient journey", being synonyms for a highly structured clinical algorithms, is describing the experience creation in an unfavorable way. This enhances the uniqueness and subjectivity of holistic experience co-creation that indicates to phenomenological service experience co-creation. *The unique patient pathway derives from values, needs and wants* that the patient has when seeking in to the healthcare services (Nasutions et al. 2014). Generally, in a healthcare context, patients need and want solutions to their healthcare problems, experiences of healthy living, and a sense of wellness (Joiner & Lusch 2016).

As in phenomenological service experience literature suggest, patient experience need to take indirect encounters and patient's own processes of experience creation into account. *The patient pathway encompasses all clinical and non-clinical services that patient goes through during the care* (Wolf et al. 2013), in other words "across the continuum of care" (The Beryl Institute 2016). It includes all facets of the healthcare system, all encounters, all setting from non-clinical proactive experiences to long term medical experiences to the continuum of care (Wolf et al. 2013). As posited above, this positioning is also found

in general service experience literature and processes beyond organization-patient encounters in experience creation should be included. For example, in some cases, illness or *condition of the patient requires self-care that takes place in patient's everyday life* context and is part of patient's ongoing life.

Processes of the experience creation beyond service setting are taken into account in a work of Ponsignon et al. (2015) who explored how cancer patients and their caregivers perceive and evaluate the healthcare experience. They state that experience quality in healthcare "refers to the customer's perceptions and evaluations of all of direct, indirect and independent interactions that occur during the provision of care and treatment" (Ponsignon et al. 2015). Ponsignon et al. (2015) presented a framework for experience quality in healthcare in a context of cancer patients. In their framework there are nine categories affecting to experience quality in healthcare with direct interaction: staff attitudes and behaviors, personalization, communication, competence, availability of persons, relationships with other patients, relationship with staff, staff efficiency and staff reliability. Indirect interaction categories affecting to patient experience quality are: procedures and processes, premises and facilities, communication, timeliness, accessibility, food and beverages, atmosphere, service variety/choice. Independent interaction categories are: timeliness, reputation and brand, external communication, speed and medical outcome and relationship outcomes. Independent interactions in the treatment can be for example self-care between patients and their caregivers.

In a children's healthcare context parents are also involved in the experience co-creation processes. Important factors affecting to *parents' experience are feel of not being able to participate*, individual interaction, being able to make decisions concerning their child's illness and treatments and the care environment (Uhl et al. 2013). Customer's participation in the experience and the individual's connection with the environment of the experience can range from weak to strong i.e. customer can act a passive or active role in the execution of the experience and be estranged or immersed to the context (Carù & Cova 2003). This concerns especially direct contacts between a focal firm and a customer as direct contacts often rely on reciprocity.

Emotional responses have a major role in the healthcare service experiences (Bolton et al. 2014). Hospitalization of a child can be *sentimental event for the patient itself, but also for the parents* that participates to the care of the child. The *event can be stressful and emotionally challenging and can cause anxiety* that affects to individuals' emotional response (Uhl et al. 2013; Mahon et al. 2015). It is also argued that gender is an important factor in an individual's response to a stressful situation (Mahon et al. 2015). For example, mothers of ill child are experiencing more stress and anxiety than the fathers (Mahon et al. 2015). This concerns the subjective interpretations of an experience that is important part of the phenomenological service experience.

2.2.3 Framework of Dimensions of Patient Experience Co-creation

This section integrates reviewed literature in previous sub-sections. Based on reviewed literature, a framework of dimensions of patient experience co-creation is developed and introduced. Preliminary framework draws from current knowledge on phenomenological service experience, dimensions of service experience co-creation and patient experience. The purpose of the proposed framework is threefold. First, the framework summarizes and visualizes the key points of the literature review conducted. Second, the framework guides the analysis of the results presented in section 4.2. Third, the presented framework will be the core of discussion in the section 5.2 and will summarize the main findings of this thesis.

The proposed dimensions of patient experience co-creation framework is based on dimensions of service experience co-creation framework presented by Jaakkola et al. (2015) but further developed by altering and adding dimensions. First, dimension *framework was further developed by adding an emotional dimension to the dimensions of patient experience co-creation framework.* According to literature review, emotions have a major role in the patient experience co-creation (e.g. Bolton et al. 2014). Second, *organization and control dimensions were moved* from the proposed framework of patient experience co-creation. In this thesis, these dimensions are seen to be part of the ecosystem rather than part of patient experience co-creation framework. Therefore, those dimensions are integrated to children's healthcare service ecosystem framework presented later in this thesis.

As described earlier experience is context-specific and is determined in the specific location. In addition, *experiences are holistically determined but experience co-creation have different dimensions that influence to individual's determinations of an experience* (Jaakkola et al. 2015). In other words, because of the holistic nature of service experience these *dimensions overlap each other* forming a total determination of co-created experience. The proposed dimensions affecting to patient experience co-creation is represented in the figure 2.

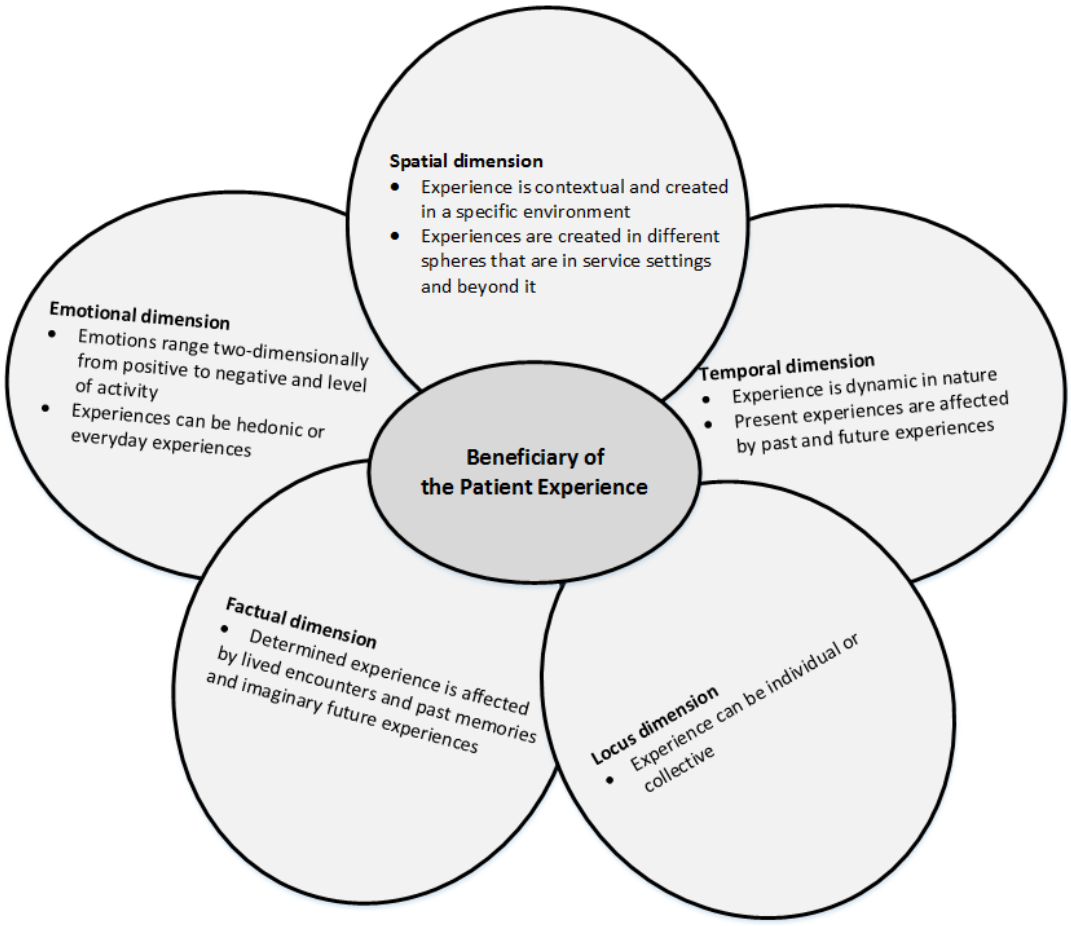

Figure 2. *Dimensions of patient experience co-creation.*

First, as can be seen from figure 2 patient experience co-creation includes *spatial dimension*. The spatial dimension can be divided to two factors hence part of the experience is co-created *in the service setting* and part is co-created *beyond the service setting* (Jaakkola et al. 2015). Patient's pathway encompasses all clinical and non-clinical services that patients go through during the care and part of the patient experience emerges in customers' life (Wolf et al. 2013; Heinonen et al. 2010). It includes all facets of the healthcare system, all encounters, all setting from non-clinical proactive experiences to long term medical experiences to the continuum of care (Wolf et al. 2013). So it can be argued that *some of the experience co-creation takes place within the provider's service setting* (Jaakkola et al. 2015), e.g. medical treatments in hospital, and *some of the experience is co-created beyond the provider's service settings* (Jaakkola et al. 2015), in patients' everyday life.

Moreover, experience is dynamic in nature, meaning that customer's earlier experiences affect to given service experience valuation and are dynamically updated through new experiences (Heinonen et al. 2010; Helkkula et al. 2012). Hence, experience has a *temporal dimension* (Jaakkola et al. 2015). Experience valuation takes place at isolated moments in the *present* that is affected by *past memories* and imagined *future experiences* (Jaakkola et al. 2015). *Past memories may include multiple clinical and non-clinical interactions that patients has gone through during their patient pathways* (Wolf et al. 2013;

Graham et al. 2015). Furthermore, patient experience also includes a *factual dimension*, meaning that patient determines his or her experiences based on *lived experiences* and *imaginary experiences* in present, past and future (Jaakkola et al. 2015). Imaginary future experiences may include, for instance, the needs and wants that customer or patient have before the encounter with provider's representative (Nasution et al. 2015).

Family has a major role in children's life and therefore it can be presupposed that they actively participate to experience co-creation also (Uhl et al. 2013). This indicates that *the locus of the patient experience* can range from *experience of an individual* to *experience of a collective* (Jaakkola et al. 2015). More widely, the collective experience co-creation is influenced by the social network of the child, including friends and other customers (Gröönroos & Voima 2013; Helkkula & Kelleher 2010).

Emotions play a critical role in the patient experience co-creation processes and influence on patient's and his or her family's perception of the experience (Bolton et al. 2014). Therefore, *emotional dimension* is added to the dimensions of patient experience co-creation. As stated above, this emergent dimension of experience co-creation is lacking, for instance, from dimensions of the service experience co-creation presented by Jaakkola et al. (2015). Emotions can *range from negative to positive and the activity or arousal state of the emotions vary* (e.g. Gurtman & Pincus 2003).

2.3 Service Ecosystem Participating to Patient Experience Co-creation

Patient experiences are co-created among multiple actors over the patient pathway (Helkkula et al. 2013), all of which influence to the patients evaluations of the total patient experience. These actors relate to the context of the experience co-creation as they form an ecosystem that co-creates the experience presented in previous sub-section. This sub-section lays foundations to understand the service ecosystem participating to children's patient experience co-creation. End of this sub-section a framework for children's healthcare service ecosystem is presented. The framework is applied in section 4.1 that presents the results of empirical research concerning ecosystem co-creating the children's patient experiences.

2.3.1 Co-creation in a Service Ecosystem

Drawing from terminology of natural sciences, ecosystems thinking is increasingly taking root in contemporary research of business and innovation. However, research literature on ecosystems is fragmented across different streams and disciplines encompassing business, innovation, start-up and service ecosystems (Aarikka-Stenroos et al. 2016). Different approaches to ecosystems differ mainly by in terms of focal actors participating to ecosystem and by the goal for their linkages (Aarikka-Stenroos et al. 2016). Business

ecosystems, introduced by Moore (1993), include actors participating to value chains of the products or services. The center of the business ecosystem is a focal organization that provides products and services to the customers (Iansiti & Levien 2004). Innovation ecosystems approach (e.g. Rohrbeck et al. 2009) underlines the creation of technologies and innovation and including actors participating to innovation creation. Start-up ecosystems approach (e.g. Isenberg 2010) posits ecosystems theory to the entrepreneurship context and to pursue for greater growth of a company. Service ecosystem (e.g. Akaka et al. 2013) draws from the service-dominant logic and underlines the systemic value co-creation within a network of actors (Aarikka-Stenroos et al. 2016). The focal actor of the ecosystem is the beneficiary of the phenomenological value (Akaka et al. 2015).

The service ecosystem approach was chosen for this study for two reasons. First, service ecosystem is naturally align with the co-creational nature of phenomenological experience as it draws from the S-D logic. Second, while business, innovation and start-up ecosystems posits the focal actor of the ecosystem being an organization, service ecosystem approaches the ecosystem from the individual beneficiary's perspective. Therefore, the focal actor in the ecosystem can be posited as individual patient or family rather than a healthcare organization. For those reasons, service ecosystems approach was seen to be most appropriate for this study and therefore recent literature concerning that approach is reviewed next.

Recent literature on service experience highlights the *collective, collaborative, evolving and dynamic nature of the service experiences* (McColl-Kennedy et al. 2015). Viewing service experience as dyadic, designed and produced by the firm for the customer brings out too narrow perspective of the *multi-party production of service experience*. Due to fragmentation of service delivery to multiple providers, customers increasingly encounter multiple providers in their customer journeys (Tax et al. 2013) that *all affect to the evaluation of experience.* In a networked environment actors co-create value facilitated by capabilities and assets of actors of network (Maklan and Klaus 2011) and evaluate experiences. Service experience co-creation may actualize in *dyadic interactions* or in *systemic interactions* among multiple different actors, which are the factors of *organization dimension* of the service experience co-creation model (Jaakkola et al. 2015). In other words, *organization dimension is nested within the service ecosystem that co-create experiences*.

One of the service-dominant logic's foundational premises is *the co-creation of value within networks of actors* (Vargo & Lusch 2008). Actors within the service network have different kind of relationships to actors which vary by the length and depth of the relationship. Relationships in a service context are particularly important whenever co-creation experiences take place (Capunzo et al. 2013), as the actors participate to dynamic experience creation. Managing customer experiences in this complex network of actors is extremely complex as multiple service providers and possibly multiple customers are participating to experience co-creation (Bolton et al. 2014).

Network actors are connected with bidirectional interactions and their value and *experience co-creation processes can be interviewed* (Sampson 2012). Phenomenological value emerges through interactions and collaboration between system's *actors that are viewed as resource integrators and co-creators of mutual value* (Akaka et al. 2013). These actors, or stakeholders, participating to the service ecosystem are interconnected through shared institutions and the provision of service (Akaka et al. 2013). Importantly, service ecosystem approach to value creation underlines the contribution of all actors in value creation viewing customer's network from a balanced, generic and *actor-to-actor perspective* (Akaka et al. 2013), rather than positing entities as "producers" and "consumers". That is, other actors creating and others destroying the value. Service ecosystem entities are co-creating value with each other through resource integration and mutual service exchange (Jaakkola et al. 2015). This normalization of entities has moved the conceptualization of networks to one of service ecosystems (Jaakkola et al. 2015). In service ecosystems, i.e. S-D logic research stream, the ecosystem is seen as "a relatively self-contained, self-adjusting system of resource-integrating actors, connected by shared institutional logics and mutual value creation through their service exchanges" (Vargo & Lusch 2011 according to Barile et al. 2016 pp. 660). Importantly, *within service ecosystem the experience is co-created and subjectively interpret by an individual or a collective*.

Ecosystems usually have a key actor, namely keystone of ecosystem, that represents only a small portion of the ecosystem but has an enormous influence on it (Iansiti & Levien 2004). In the service experience ecosystem, *the focal actor of the ecosystem is the beneficiary of the service experience* as the value derives from the beneficiary's determinations of the experience and is always determined from that actor's viewpoint (Akaka et al. 2015). The essence of ecosystem is that *actors participating to experience co-creation are not part of a chain but form a networked system* where collaboration is enacted and actors participate to experience co-creation by interacting in versatile ways and approaches (Jaakkola et al. 2015). The *criticality of actors participating to the ecosystem can vary* on what kind of influence they have on the value co-creation (Iansiti & Levien 2004).

The S-D logic's service ecosystem view elaborates the social aspects of resource integration and emphasizes the influence of institutions and institutional logics of the co-creation within a complex system (Akaka et al. 2015). Social structures and other institutions form a context where the experience or phenomenological value is co-created. The phenomenological value is *co-created in multiple levels of contexts but is always determined by the service beneficiary*. (Akaka et al. 2015) The service ecosystem approach emphasizes the contribution of all actors in value creation (Akaka et al. 2013). Including manufacturers, suppliers, retailers, customers, individual customer's social networks like family and friends and actors that control or allocate public resources like national governments (Akaka et al. 2013) Figure 3 represents the S-D logic approach to service ecosystem.

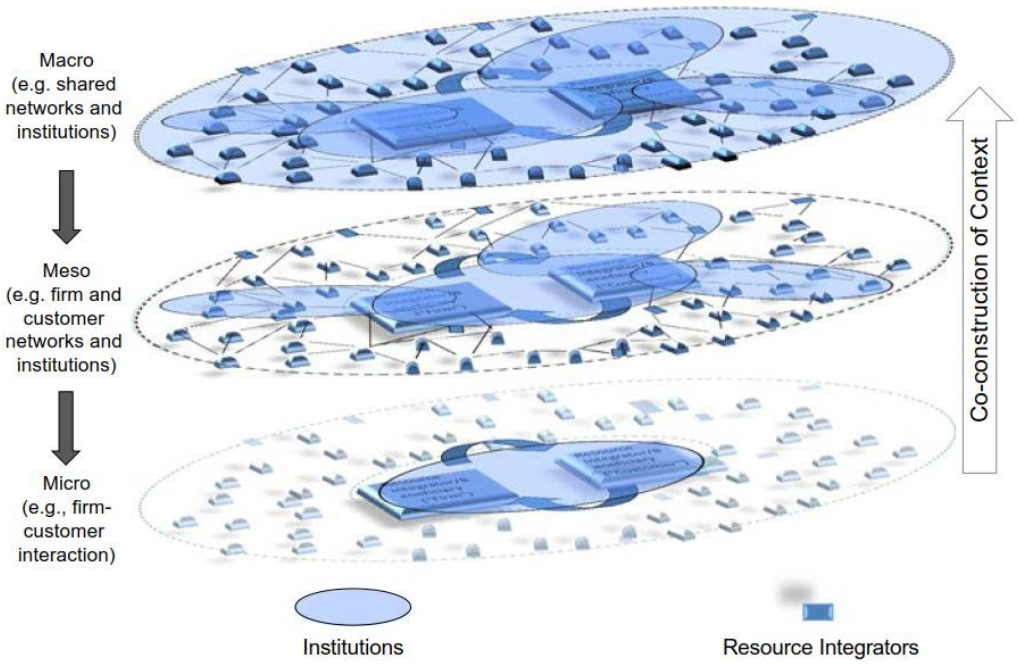

Figure 3. *Service ecosystem (Akaka et al. 2015)*

As represented in the figure 3 the co-creation of value and determination of service experiences are framed in *three levels of ecosystem: micro, meso and macro levels*. The levels of ecosystem are nested within each other (Akaka et al. 2015). Meaning that *evaluations of experience, other words value in micro level, is influencing and being influenced by the higher levels of the ecosystem* (meso and micro levels) (Akaka et al. 2015).

Micro level illustrates all the reciprocal interaction between individual actors at the lowest level of the service ecosystem (Akaka et al. 2015). These actors co-create value by integrating recourses in a service-to-service exchange. Experiences are evaluations of these encounters of value co-creation (Akaka et al. 2015). The encounters are framed by set of institutions, e.g. culture, which guide the service exchange. If the institutions differ dramatically it is likely that the service exchange is unsuccessful. (Akaka et al. 2013).

Meso level extends the ecosystem to concern broader set of actors and distinct set of institutions (Akaka et al. 2013). *Meso level actors are organizations participating to the micro level value co-creation* but also actors that are responsible for managing and implementing policies within the co-creation context (Helkkula et al. 2013). Meso level has its own set of institutions which guides the meso level actors (Akaka et al. 2013)

Macro level illustrates shared networks and institutions in the service ecosystem and the broadest context through which the experiences are evaluated (Akaka et al. 2015). Macro level includes actors which are responsible for developing and implementing policies and forming and structuring economic, social and cultural contexts (Helkkula et al. 2013). Importantly, service ecosystems should be examined through context of co-creation as

evaluations of an experience is always actualized in a specific context (Helkkula 2011). Therefore, next the service ecosystem is examined in a children's healthcare context.

2.3.2 Overview to the Children's Healthcare Service Ecosystem and Its Actors

This sub-section examines children's healthcare service ecosystem. Particularly, which kind of actors are included in each of the healthcare ecosystem levels children's healthcare service ecosystem according to current knowledge. In addition, what distinct features children's healthcare ecosystem have according to current knowledge.

There are *heterogeneity of actors and stakeholders at the healthcare ecosystem that are all sharing a common goal of patients wellbeing* (Capunzo et al. 2013; Wolf et al. 2013) and co-creating value to the benefit for all by providing different applications of resources to the ecosystem. Helkkula, Linna and Kelleher (2013) studied value co-creation in public healthcare and the service system's actors co-creating the healthcare in Finland. Healthcare service system is defined as "a network of micro, meso and macro level actors, which are directly or indirectly linked through sequential or shared participation in value co-creation in order to create, assemble, transform and make resources within the service system" (Helkkula et al. 2013, pp. 2). Although Helkkula et al. (2013) do not use the word service ecosystem it is relatively close to S-D logics assentation of service ecosystem. This is also by far closest examination of Finnish public healthcare ecosystem. Moreover, service experience literature lacks papers concerning children's healthcare ecosystem and co-creation of children's patient experiences.

Macro level in the healthcare system is a political level, which actors are responsible for developing and implementing health policies. Helkkula et al. (2013) identify those actors to be health ministry, health organizations and other professional organizations in the healthcare context. Additionally, Capunzo et al. (2013) includes actors which are responsible of the medical and scientific training and education to the healthcare ecosystem such as professional associations and universities.

Helkkula et al. (2013) point out that macro level's value objectives in a healthcare context prioritize more economical value calculations than the experiential value. These kind of value objectives include efficiency in the production of health and well-being of general population, responsiveness to the expectations of the population and fair contribution to national healthcare systems (Helkkula et al. 2013).

According to Helkkula et al. (2013) *meso level is accounted a healthcare service provider level*. They include hospital districts, hospital trusts, county councils, health maintenance organizations, third sector societies (e.g. diabetes association) and consumer communities (e.g. patient groups for specific medical condition) to this ecosystem level. Meso level

also includes important social groups (next of kin and friends), alternative healthcare providers and wellness services (Joiner and Lusch 2016). These meso level actors are co-creating value with micro level actors within the health policies and provisions of the macro level, and so meso level is accountable for both of the level actors (Helkkula et al. 2013). This is in line with Capunzo et al. (2013) who state that from the service systems point of view each system level is related with related supra-systems or sub-systems and hierarchy of these levels is dependent on the influence they have on the system.

Although Helkkula et al. (2013) state that value in meso level is measured and calculated as an estimate of aggregate value of healthcare while there is a lack of subjective and experiential value assessments, meso level actors clearly influence individuals patient experience. For example, diabetes association can connect patients for peer support purposes which can influence experience of an individual patient. In other words, these meso level actors might not be directly associated to the treatment practices but influence on the patient's overall assessment of the experience.

Finally, the micro level, i.e. individual level, of the public healthcare ecosystem includes patients, patients' family members, healthcare professionals (e.g. doctors and nurses), and other types of employees (Helkkula et al. 2013). That is, a patient faces multiple individuals during his or her patient pathway and interacts with them. Although each of these encounters could happen separately, *patient bounds these encounters together and dynamically and holistically determines a total experience* (Tax et al. 2013). Individuals in the micro level value their experiences in a subjective and holistic way within a social context (Helkkula et al. 2013).

According to Wolf et al. (2013) *patients, families and members of their support network are participating actively to care experience creation* and should be engaged. Patient experience, similar to general service experience, has an experiential or consumer sphere where patient creates experiences individually and collectively outside of the hospital's reach. This *collective sphere consists carers of the patient, friends, and family* (Ponsignon et al. 2015), who co-create experience with the patient. As hospital staff being responsible for more technical aspects of child's care and educators of parents, parents participate to care planning and decision making and caring the patient in other areas (e.g. feeding, holding and skin-to-skin care). (Altimier 2015) In other words, *parents are a vital part of child patients caring ecosystem and participates strongly to the co-creation* of patient experience and clinical outcomes and need to be engaged caring the patient.

2.3.3 Framework of Children's Healthcare Service Ecosystem

This section pieces together above reviewed literature. Theory concerning the co-creation of experiences in service ecosystems is applied to a healthcare context. Importantly, a framework for children's healthcare service ecosystem is developed and presented. The

framework summarizes the actors in the children's healthcare service ecosystem presented in previous sub-section and links them with theory of service ecosystems. Framework presented in this section is used as a representative tool and basis in the results analysis section 4.1 Ecosystem co-creating the children's patient experiences.

Although the healthcare network is complex system, all of the actors share a mutual goal of healthier people and sustainable well-being and forming a healthcare ecosystem. Phenomenological value in ecosystem emerges through interactions and collaboration between system's actors that are viewed as resource integrators and co-creators of mutual value (Akaka et al. 2013). Ecosystem actors are not a part of a chain but form a networked system where collaboration is enacted and actors participate to experience co-creation (Jaakkola et al. 2015), and therefore patient experiences are co-created among multiple actors over the patient pathway (Helkkula et al. 2013).

Services that the ecosystem are uniquely interpreted and experienced by patients but the experience co-creation is fragmented to many actors and contexts of the healthcare network, not just to single interactions between patient and the hospital staff. That is, patient experience co-creation may actualize in *dyadic interactions* or in *systemic interactions* among multiple different actors. That are the factors of *organization dimension* of the service experience co-creation model (Jaakkola et al. 2015). Taking an ecosystem view on experience co-creation definitely enhances the systemic interaction dimension of service experience co-creation.

Furthermore, criticality of actors participating to the ecosystem can vary on what influence they have on the value co-creation (Iansiti & Levien 2004). Some actors are therefore in the core of total experience co-creation while the others have only a minor or indirect influence on the experience co-creation. Therefore, *actors can be divided to by their impact on the total experience co-creation to "core ecosystem" or to "periphery ecosystem".* Representation of ecosystem is presented in figure 4.

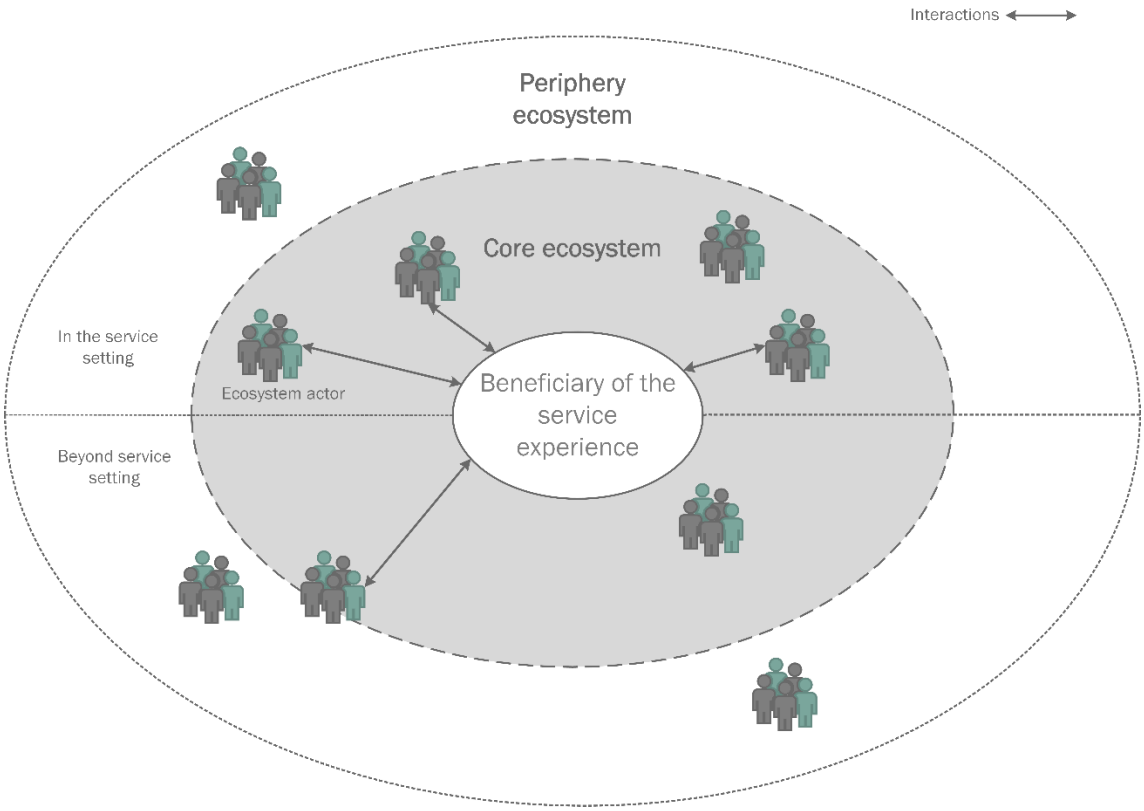

Figure 4. *Co-creation of experiences within ecosystem.*

As can be seen from figure 4, spatial dimension of experience co-creation divides experience co-creation to the service setting and beyond the service setting as stated earlier (Jaakkola et al. 2015). Therefore, as multiple actors are participating to patient experience co-creation (Helkkula et al. 2013), it can be presumed that *some of the actors are co-creating in the service setting and some beyond the service setting in patient's everyday life context.* Patient's participation in the experience can vary, i.e. patient can act a passive or active role in the execution of the experience (Carù & Cova 2003), but the *amount of active self-care in the patient's own individual experience co-creation sphere can vary* (Joiner & Lusch 2016). Next, the levels of the ecosystem are represented.

This thesis explores and concentrates on the meso and micro levels of the ecosystem. This means that macro-level of the ecosystem is not taken into account in this study. Albeit it is acknowledged that patient experience is influenced and shaped by values, beliefs, traditions and cultural background (Bolton et al. 2014; Wolf et al. 2013), i.e. shared institutional logics of the ecosystem but these are not on the study scope of this thesis.

First, *meso level of the ecosystem includes hospital districts, hospital trusts, county councils, health maintenance organizations, third sector societies (e.g. diabetes association) and consumer communities (e.g. patient groups for specific medical condition), important social groups (next of kin and friends), alternative healthcare providers and wellness*

services (Helkkula et al. 2013; Joiner and Lusch 2016). The representation of the meso level actors are represented in figure 5.

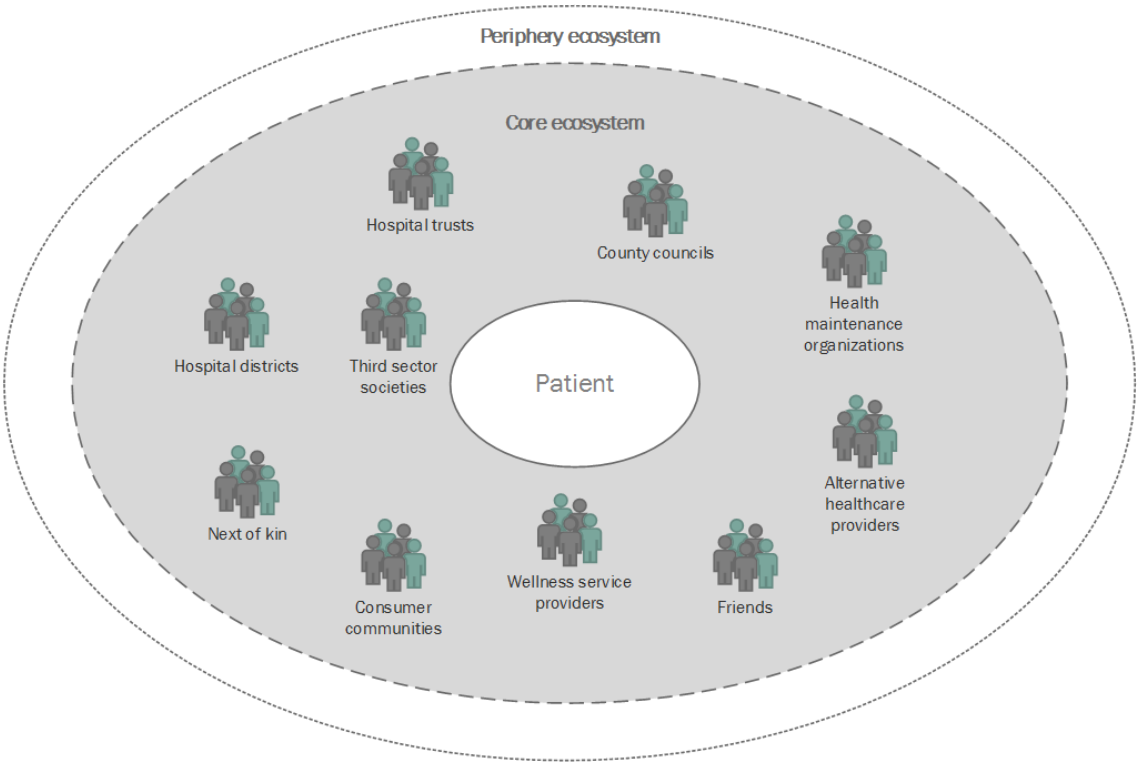

Figure 5. *Meso level of the ecosystem.*

In figure 5 all the actors in the meso level have been posited to the core ecosystem because it cannot be known which of the actors have direct and indirect connections to the patient. For same reasons the beyond and in the service setting line is not included to the representation.

Second, *micro level of the ecosystem includes patients, patients' family members, healthcare professionals (e.g. doctors and nurses), and other types of employees* (Helkkula et al. 2013). Representation of the micro level of the ecosystem is presented in figure 6.

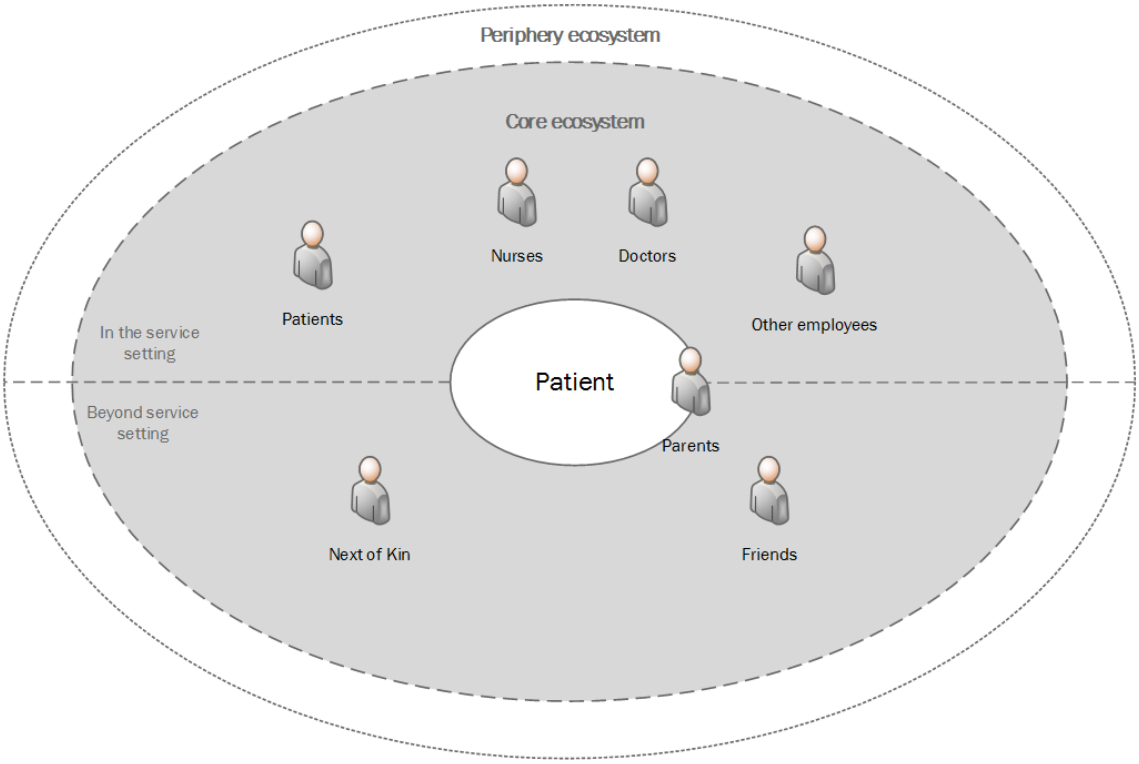

Figure 6. *Micro level of the healthcare ecosystem.*

As presented in figure 6, the micro level the actors are divided to actors in the service setting and beyond it. Beyond the service setting, or collective sphere (Ponsignon et al. 2015), includes carers of the patient, friends and next of kin. Other actors are presumed to locate in the service settings. The beneficiary of the service is not the child patient alone as patient's family is an active participant benefiting the service (Altimier 2015). Therefore, parents are posited to near the patient and between the lines of service setting and beyond it. In the next section, synthesis of reviewed literature is made to understand how the children's healthcare ecosystem co-creates the children patient experiences.

2.4 Synthesis: Ecosystem that Co-creates Children's Patient Experiences

This section synthesizes the literature reviewed. As there are not any previous frameworks that combines service ecosystem and experience co-creation dimension, a framework is proposed. The proposed framework combines the two frameworks presented in sections 2.1.6 and 2.2.3 to a one synthesizing framework.

This study is based on S-D logic view on service ecosystem and evaluating value as an experience. In S-D logic view on service ecosystem, the co-creation of value is framed by, in this thesis, meso and micro levels (Akaka et al. 2013). *Service ecosystem view presumes that experience co-creation occurs in systemic interactions between actors*. Micro level illustrates all the reciprocal interaction between individual actors at the lowest

level of the service ecosystem (Akaka et al. 2015). These actors co-create value by integrating recourses in a service-to-service exchange. Experiences are evaluations of these encounters of value co-creation (Akaka et al. 2015). *Experiences are evaluations of micro level encounters of value co-creation where multiple actors participate to value co-creation by integrating resources in a service-to-service exchange* (Akaka et al. 2015). *Experiences are holistically determined but experience co-creation have different dimensions that influence to individual's determinations of an experience*. These dimensions emerge from the micro level of the ecosystem. Figure 7 represents the ecosystem co-creating the children's patient experiences.

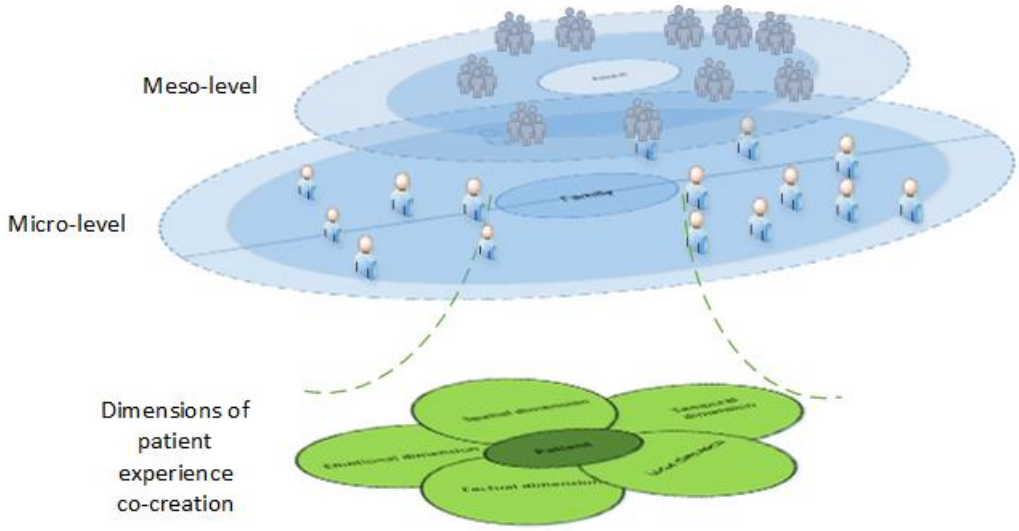

Figure 7. *Patient experience ecosystem and dimensions of patient experience.*

As represented in figure 7, patient experience is context-specific and is determined in the specific location. In other words, experience has a spatial dimension (Jaakkola et al. 2015). Additionally, the spatial dimension can be divided to two factors hence part of the *patient's experience is co-created in the service setting and part is co-created beyond the service setting*. Furthermore, the locus of the patient experience can range from *experience of an individual to experience of a collective*. Moreover, experience is dynamic in nature, meaning that *patients's earlier experiences affect to given patient experience valuation and is dynamically updated through new experiences* (Heinonen et al. 2010; Helkkula et al. 2012). Hence, experience has a temporal dimension (Jaakkola et al. 2015). Experience valuation takes place at isolated moments in the present that is affected by past memories and imagined future experiences (Jaakkola et al. 2015). Patient experience also includes factual dimension, meaning that patient determines his or her experiences based on lived experiences and imaginary experiences in present, past or future.

3. RESEARCH METHODOLOGY

3.1 Research Design and Research Strategy

This thesis studies children's patient experience co-creation through different service pathways in a multi-actor environment. The main research questions of this thesis are:

- *RQ1: What does dimensions of children's patient experience co-creation consist of?*
- *RQ2: What is the service ecosystem that co-creates the children's patient experience?*

The second research question is divided to three sub-questions as followed:

- *What are the different actors co-creating the children patient experience?*
- *What are their role in the service ecosystem?*
- *Which kind of actor categories can be identified from the ecosystem?*

The nature of this thesis is explorative and aims to develop the existing theory of service experiences, dimensions of service experience co-creation and service ecosystems by studying children's patient experience co-creation within an ecosystem. The nature of the first research question is not straightforward to specify. Nature of the first research question is explorative but also descriptive, as it requires exploration of the phenomenon of children's patient experience co-creation but also requires describing the characteristics of dimensions of children's patient experience. Nature of the second research question can be seen as explorative with a descriptive touch as it explores different actors in an ecosystem and their purpose but also to describe their roles in the ecosystem and describing the categories identified from the ecosystem. Hence, this study pieces together different research natures but its bottom nature is explorative.

This study is conducted with qualitative research design for two main reasons. First, the conducted study is explorative in nature and aims to develop existing provisional and nascent theory. Exploratory nature of research implies for qualitative research design (Saunders et al. 2009, pp. 140). This study integrates theories from dimensions of service experience co-creation and service ecosystems for basis of the study. Importantly, there are hardly any previous research conducted concerning children's healthcare ecosystems and research field lacks studies concerning dimensions of children's patient experience co-creation. Nascent theory involves exploring phenomenon through qualitative data (Edmondson & McManus 2007). Purpose of this study is to explore the phenomenon and use the knowledge empirically gathered to develop dimensions of service experience co-cre-

ation (Jaakkola et al. 2015) and service ecosystem theories (e.g. Akaka et al. 2013). Qualitative research design is appropriate in studies that aim to develop theory that is in immature state (Edmondson & McManus 2007). In contrast, using quantitative research design in explorative studies in a field of little previous research would be problematic, as the quantitative measures would have almost certainly an ambiguous relationship to the phenomenon (Edmondson & McManus 2007).

Second, the nature of experiences, as complex and subjective, governs the design of the research for qualitative research. That is, experiences "can never be observed or accessed directly, but only indirectly through the words and languages people use to describe it when they look back at it" (Bate & Robert 2007, according to Ponsignon et al. 2015). This also implies for qualitative research design to be most appropriate choice. Some studies concerning children's healthcare experiences and quality have been conducted with qualitative research designs. However, these studies concentrate on one or a few particular aspect of the experience e.g. particular spatial settings or particular time period during the patient pathway. For instance, Kortesluoma & Nikkonen (2004) studied pain experiences of hospitalized children concentrating on the physical feelings of patient experience by 44 interviews of 4-11-year old children. Curtis et al. (2004) and Forsner et al. (2005) concentrated to study what is positive and negative on local healthcare by narrative interviewing 4-19-year and 7-10-year old children. Sartain et al. (2001) concentrated on cost effectiveness and surroundings by comparing hospital and homecare experiences by interviewing 40 families and 11 of their 5-12-year old children. Case study of Stratton (2004) concentrated to explore parents' experiences in child's hospitalization period by interviewing 6 parents. Therefore, studies capturing the holistic and phenomenological nature of the topic are still absent. However, these studies justify the choice of qualitative research design that is seen most appropriate.

The multi-level nature of proposed frameworks in the previous sections implies to in-depth multilevel investigations of ecosystem actors and determinations of patient experience co-creation. This kind of multilevel approach serves to explore; what is the ecosystem that co-creates the patient experience and what does the dimensions of patient experience co-creation consist of. That is, ecosystem is constructed by actors in multiple levels of an ecosystem but patient experience is determined by an individual at the micro level of the ecosystem subjectively and holistically. To reach the aim of this study a qualitative field study was chosen. Field study is well suitable research strategy in studies that are exploratory in nature aiming for development of immature theory (Edmondson & McManus 2007). Researcher sheds light on the studied phenomenon, i.e. children's patient experience co-creation within an ecosystem, by obtaining data from the informants of the studied field, for example, by interviewing them (Edmondson & McManus 2007).

However, experiences are a challenging topic to study, especially when it comes to sensitive topic of ill children's experiences. That is, children, and especially children with illness, are a vulnerable group to study (Burns & Grove 2001, pp. 166), which causes

some assessments on the methodological choices. Children's feel stress more easily than adults in research situations, and it is more difficult for them to understand what it means to participate in a study (Kortesluoma & Nikkonen 2004). The research process can harm the child by causing emotional distress, as they need to reflect the experiences they have faced during their patient pathways. Therefore, it is important to assess if the potential risks of causing harm to the participants of the research can be avoided and is it justified not to use possible alternative participants to study the topic (Saunders et al. 2009, pp. 186).

In addition, the group of study and sensitivity of the subject causes few barriers and issues that researcher needs to overcome if data from the children are used to study children's patient experiences. First, the developmental stage of the children add a barrier for interviewing children. That is, for example in a context of infant patient, the experience description can be only accessed via the patient's carer as infant is not yet able to generate words. Second, the sensitivity of the subject increases the difficultness of gaining access and the complexity of access process. Researcher needs to reach the possible child patient participants through hospitals that provides care for them as they are secured by the privacy protection and hospital cannot disclose information for the researcher without permission of the parents of the child. After getting participants' information researcher needs to get consent usually from both of the parents and importantly also from child him or herself to participate to the research, who, as mentioned, might not fully understood all of the information about participation rights and purpose of the study. Hence, an alternative data sources were chosen to be used in this study based on time usable for this study and ethical considerations.

To shed light on this multilevel phenomenon an extensive qualitative data set from multiple sources is harnessed for the field study. First, narrative interview data of the beneficiaries of the patient experience co-creation, i.e. patient's parents, is used to study this phenomenon. This methodological choice tackles the ethical challenge that is related to interviewing child patient but gives a beneficiary's viewpoint on children's patient experience co-creation. In narrative interviews, narrator builds up a story of meaningful events that takes place in different times and places, which in turn reveals the storyteller's experiences (Helkkula & Kelleher 2010). Narrative interview technique therefore allows researcher to examine the experiences holistically (Helkkula & Kelleher 2010). Told stories can include the focal actors that were participating to co-creation of these experiences. Therefore, narrative inquiring technique also enables researcher to identify these focal actors and to explore patterns of dynamic multilevel and multi-actor phenomenon (Makkonen & Aarikka-Stenroos 2012). Therefore, data from narrative interviews is well suitable for exploring this multilevel and complex phenomenon from the beneficiary's perspective.

Second, qualitative data is used from ecosystem actors from the field of investigation. Exploratory interviews with ecosystem actors and informants helps researcher to identify

and investigate the key actors participating to the field studied phenomenon (Edmondson & McManus 2007). Semi-structured interview data was collected through interviews with 23 healthcare professionals and with 6 ecosystem actors including social worker, rehabilitation counsellor, kindergarten special education teacher and two third sector society actors. The use of semi-structured interviews enabled researcher to focus to a particular theme and to add depth to interviewees' answers (Saunders et al. 2009, pp. 324). The focus themes in healthcare professional interviews were children's patient experience and patient journeys and ecosystem actor interviews focused on the ecosystem theme. To support the semi-structured interviews and analysis an illustrative drawings were used in ecosystem actor interviews.

The research process of this thesis is represented in figure 8. Research started with a literature review presented earlier. Next, a preliminary analysis of the secondary data was conducted to get familiar with the data and topic and to gain knowledge to form an interview structure for primary data collection. Preliminary analysis of the secondary data was also used as a base in formation of secondary data coding framework. After interview structure formation six semi-structured interviews were conducted for ecosystem actors. To analyze the primary data an ecosystem coding framework was developed using existing theoretical knowledge. Next, the primary data was analyzed by using the coding framework. Outcome of the analysis were used to answer to research question two. The knowledge gained from the primary data analysis concerning ecosystem actors were also used in development of secondary data coding framework in addition to preliminary analysis care staff interviews and existing theoretical knowledge. After secondary data coding framework formation, the secondary data was analyzed. Analysis of the secondary data was used to answer to both of the research questions.

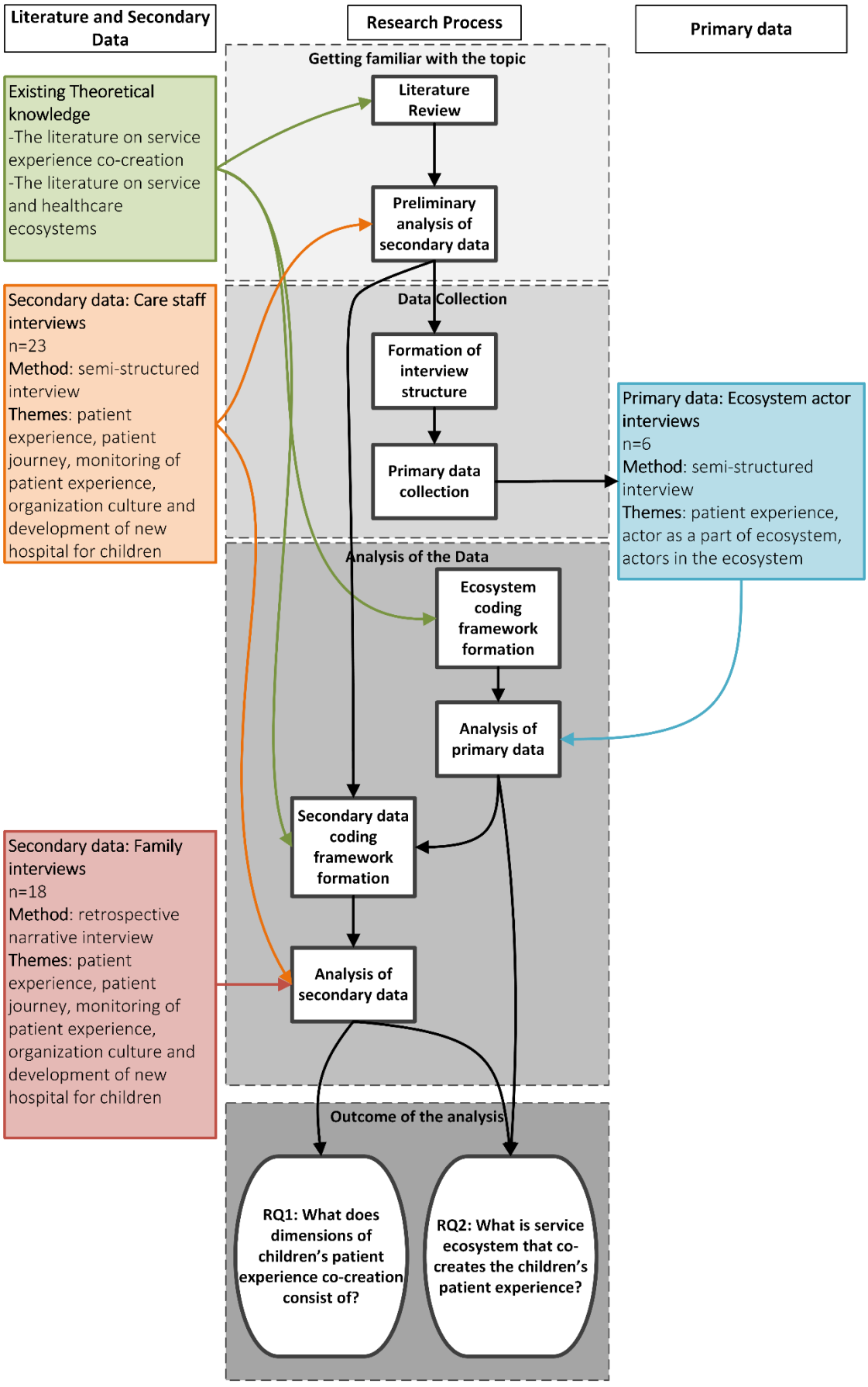

Figure 8. *The research process.*

The research process work was carried out between July 2016 and February 2017. Next section describes the data and data gathering of this study.

3.2 Data and Data Gathering

This study is based on primary data collected from semi-structured interviews and secondary data derived from previous LAPSUS-project interviews collected in late 2015. The purpose of primary data was to identify ecosystem actors, to understand ecosystem actors' purpose in the ecosystem and to understand how ecosystem actors' influence on the patient experience co-creation. Six specialist interviews were conducted to collect primary data. Detailed description of data sampling and settings are presented in section 3.2.1. These interviews are referred in this study as "ecosystem actor interviews".

Two sources of secondary data were used in this thesis. First source was transcriptions from earlier LAPSUS-project's semi-structured interviews. Interviews were conducted in late 2015 to healthcare personnel. Participants of the care staff interviews were 8 nurses, 4 staff nurses and 11 doctors. This secondary data is referred as "care staff interviews" in this study. This secondary data was used to understand what does dimensions of children's patient experience co-creation consist of from provider's viewpoint, to identify actors participating to children's healthcare ecosystem, to understand care staff's purpose in the ecosystem.

Second source of secondary data was transcriptions from earlier LAPSUS-project's narrative interviews. Interviews were conducted between late 2015 and early 2016 in spaces of Pediatrics Hospital of Helsinki. Interviews were conducted by LAPSUS-project researcher by interviewing pediatrics hospital's patients' parents. By narrative interview technique researcher is able to examine experience holistically and is in line with phenomenological approach (Helkkula & Kelleher 2010), as stories are told in a temporal and contextual way. This data is referred in this thesis as "family interviews". Both parents were participating to 7 interviews and remaining 18 of the interviews were held for mother (n=13) or father (n=5) of the patient. 18 of 25 narrative interview transcripts were used in this study as saturation was reached in that point. Saturation point reach was determined as interviews and results of analysis started to repeat themselves. Purpose of this data was to understand what does dimensions of children's patient experience co-creation consist of from family's perspective, to identify actors participating to children's healthcare ecosystem, to deepen understanding ecosystem actors' purpose in the ecosystem, to understand ecosystem actors' impact on patient experience. Data used in this study is represented in the table 2.

Table 2. *Data used in this study.*

Primary Data

Purpose of Data	Organization	Title	Amount	Method
To identify more ecosystem actors (RQ2); To understand ecosystem actors' purpose in the ecosystem (RQ2)	Pediatrics of Helsinki University Hospital	Social worker	2	Semi-structured interview
		Rehabilitation counsellor	1	
	City of Helsinki	Kindergarten special education teacher	1	
	Third sector society	Excutive director	1	
		Chief of family center operations	1	

Secondary Data

Purpose of Data	Organization	Title	Amount	Data type
To understand what does dimensions of children's patient experience co-creation consist of from service provider's perspective (RQ1); To identify actors participating to children's healthcare ecosystem (RQ2); To understand care staff's purpose in the ecosystem (RQ2)	Pediatrics of Helsinki University Hospital	Nurse	7	Transcription of semi-structured interview
		Staff nurse	1	
		Doctor	3	
	Pediatrics of Oulu University Hospital	Nurse	1	
		Staff nurse	3	
		Doctor	8*	
To understand what does children's patient experience co-creation consist of from family's perspective (RQ1); To identify actors participating to children's healthcare ecosystem (RQ2); To deepen the understanding on the ecosystem actors' purpose in the ecosystem (RQ2)	Customers of paediatric hospital	Parent	18	Transcription of retrospective interviews
		Total	47	

*One group interview with two interviewees

3.2.1 Primary Data Case Sampling and Settings

Participants to the semi-structured interviews were selected with purposive sampling. It enabled researcher to select informants based on self judgement on which are the participants best suitable for answering objectives of the research with a small sample size (Saunders et al. 2009, pp. 237). Based on the literature review (see e.g. Helkkula et al. 2013) it was expected that there are multiple actors participating to healthcare ecosystem. To gain a widest possible view on actors participating to healthcare ecosystem with available resources, heterogeneous sampling was chosen for purposive sampling strategy.

Heterogeneous sampling enabled researcher to select small sample that contains different informants. Although, heterogeneous sampling did not provide particularly in-depth knowledge of each ecosystem actor, it enabled collection of data from multiple perspectives. Moreover, Saunders et al. (2009, pp. 239) points out that patterns that emerge from data collected from heterogeneous sample are likely to represent the key themes of the studied phenomenon and to be of particular interest and value.

Data was collected through interviews from 6 selected sample informants. As represented in the table 2, three of the participants worked in the pediatrics department of Helsinki University Hospital (HUH); two pediatrics department's social workers and one pediatrics department's rehabilitation counsellor. Participants were pre-selected by HUH's senior consultants but final selection of participants were made by the researcher. Remaining three participants were: a kindergarten special education teacher, an executive director of a third sector society and a chief of family center operations of another third sector society. Five of the interviews were held in Helsinki and one in Tampere. Participants were asked to choose the place of the interview and it took place in the interviewees' office, meeting room or in class room.

3.2.2 Primary Data Collection

In the first phase, data were collected by semi-structured interviews and drawings. The interview themes and guide (Appendix 1) were based on interview structure used in previous LAPSUS-project interviews, preliminary analysis of secondary data and on reviewed literature. After two interviews the interview guide was refined (Appendix 2) to center the focus on healthcare network and ecosystem. To support the interview and data collection, participants were asked to illustrate by drawings their view on patient pathway and to complete the ecosystem map from their point of view. Interview guide were emailed to participants prior to the interviews. Interviews were carried out between July and August 2016. Interviews' duration varied between 52-70 minutes. Interviews were

audio-recorded for later use. Saunders et al. (2009, pp. 324) propose to use semi-structured or in-depth interviews to collect rich and detailed set of data with a large number and complex questions. Semi-structured interviews and supporting drawings were selected to undertake all the themes and to give room for flow of conversation. Ecosystem audio-records were transcribed using Microsoft word by the researcher. Drawings made in the interviews were redrawn to digital format using Microsoft PowerPoint by the researcher.

3.3 Data Analysis

Prior to closer analysis of the interview data researcher conducted preliminary analysis on the care staff interviews in order to get familiar with the secondary data and to find significant themes that data consisted.

Next, the drawings of the ecosystem actor interviewees were analyzed. Analysis concentrated on the mentioned ecosystem actors in the drawings. Mentioned ecosystem actors were divided to the groups. Division of groups was based firstly by the micro and meso-level ecosystem actors identified in the literature review and presented in the section 2.2.3 and secondly by the description the interviewees used for the actors they mentioned. Groups were hospital, patient's own support net, primary healthcare, third sector societies, education, social services, professionals chosen by social insurance institution of Finland and traveling agencies. These identified ecosystem groups were applied to the coding of ecosystem of care staff and family interviews in addition to the groups identified from the literature and first read-through. The ecosystem category list included codes macro, meso, hospital, education, own safety net, equipment and systems, third sector communities, primary healthcare, consumer communities, other professionals, social services, other patients, traveling agencies.

Next, secondary data was categorized. Development of relevant codes had few steps. First, care staff interview transcripts were gone through with qualitative analysis software and emerging codes were defined concerning the patient experience. Coding was based on observations that might be interesting concerning the studied topic. Then the initial coding was reviewed and extended to more general categories. Based on the read through, first round analysis and literature review, 12 categories of codes were presupposed as the basis of the analysis. Those were: ecosystem, control dimension, spatial dimension, temporal dimension, organization dimension, locus dimension, factual dimensions, emotional dimension, others, privacy, communication and different patient groups. Ecosystem and dimensions were based on the literature and others, privacy, communication and different patient groups were found as additional themes from the read-through first round of analysis. Second, the codes concerning the ecosystem was added under the ecosystem

category. For example, following quote was coded to spatial dimension and to pediatrics hospital actors code in the ecosystem category: "we had a good doctor at [pediatrics] hospital's emergency room that had the right attitude for [name of the patient], it was calming attitude and not like "this is nothing" attitude. And of course that when [name of the patient] was at ward it was not full or rushy, there was time for [name of the patient]". This connects patient experience co-creation to hospitalization period and particular spatial setting. Furthermore, it includes a doctor to ecosystem co-creating children's patient experience and therefore is coded to hospital ecosystem actors code.

After initial code development the actual data analysis was conducted. As suggested by Edmondson and McManus (2007) a thematic content analysis coding was applied. The actual analysis was based on the understanding about dimensions of patient experience co-creation and observations were posited under the relevant code and category. Coding was developed also during the analysis if some interesting observations were made it did not fit to any existent code. For instance, five ecosystem codes were added during the analysis of the family and care staff interviews that were ecosystem viewpoint, fluency of ecosystem, development of ecosystem, actor influences and private healthcare. Eventually, total of 57 codes were used to code secondary data. Data were coded and analyzed using QDA Miner 4 Lite software.

As described, the phenomenon was studied from multiple different perspectives including provider side and the beneficiary side of the experience phenomenon. Triangulation was therefore reached by a use of an extensive set of data and basing the study on multiple different sources of data. Data triangulation produces more accurate findings and conclusions of the phenomenon (Yin 2003). Results of this thesis concerning experience co-creation dimensions are presented first from the provider's perspective based on the care staff interview analysis and then from the family's perspective based on the family interview analysis. The findings from both of the analyses are combined end of each section. Comparisons of the results were not conducted in this study.

Comments from the interviews were translated from Finnish to English. Spelling of some quotes were edited to make them more understandable and clearer for the reader without changing the meaning of a sentence. However, translation might have caused some nuance differences from the original comments. For a convenience, only "she" pronoun is used when talked about a third person.

4. RESULTS

4.1 Ecosystem Co-creating the Children's Patient Experiences

In this sub-chapter results of the empirical research concerning the ecosystem co-creating the patient experience is presented. Results of this section are used for answering to the second research question. First sub-section presents results concerning the systemic nature of interactions within the ecosystem. Results are presented to show what kind of interactions there are within the ecosystem co-creating the children's patient experiences and whether the ecosystem approach is appropriate in this context. Next, the diversity of ecosystem actor groups are presented in section 4.1.2. That sub-section sheds light on the complexity of the ecosystem and above proposed framework of children's healthcare context is further developed and refined based on the empirical resutls. Sub-sections 4.1.3-4.1.6 present the identified ecosystem categories, actors within those categories and their roles in the ecosystem. As mentioned earlier this study concentrates particularly to micro and meso level actors and institutions are not in the scope of this thesis.

4.1.1 Systemic Nature of Interactions within the Ecosystem

This sub-section presents results concerning the organization dimension of co-creation within the ecosystem. Organization dimension of co-creation describes are the interactions of co-creation dyadic or systemic with multiple different actors. *Results indicate that patient experiences are co-created within an ecosystem, or by systemic interactions with multiple different actors.* Organization dimension was divided to two factors: dyadic interactions and systemic interactions. Meaning that experience co-creation could be actualized in dyadic interaction or in systemic interactions in multiple different interactions. First, the care staff interview results concerning the organization dimension are presented. Second, the family interview results concerning the organization dimension are presented. Third, summary that combines findings is presented end of this sub-section.

The dominant factor concerning organization *dimension of the experience co-creation within ecosystem was systemic interactions*. Results show clearly that patient experiences are *co-created by multiple participants or actors*. In children's healthcare service experience co-creation *children's parents are often participating to the service experience co-creation*. Parents are also participating as a beneficiary of the experience. According to the interviews *parent's role as co-creators is most critical when patient is in low developmental stage or young*. However, criticality of the role and *amount of participation decreases when the patient develops and ages*. This causes that patients' role and amount

of participation increases at the same. Systemic interactions were referred as multi-professional healthcare team and interactions between care staff and family and healthcare service providers, family and third party. According to the care staff interviews, care in children's healthcare consists multiple actors. These actors are undergone more detailed later in this section. Results of concerning organization dimension of the patient experience co-creation are represented in table 3.

Table 3. *Organization dimension results from care staff interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Patient and healthcare professional interacting; patient-doctor interaction, patient nurse interaction **Meeting patient alone;** teenager appointments without parents; in some emergency situation parents can't participate when patient is cared **Talking directly to child patient;** playing with a child, asking her own opinion	*"I try to focus to the child what I will do." (HUS 2)* *"…if we have big teenagers we take them often alone first." (HUS 1)* *"…has [the patient] been able participated to interaction and participate to those decisions in a way, based on, that she has understood what she has been told…" (OYS 7)*	**Dyadic Interactions** (13)	**Organization Dimension**
Multi-professional healthcare team; patient meets multiple professionals, multi-professional workgroup, every child has two nurses; multi-professional collaboration **Care staff and family;** family of child, parents and siblings using healthcare services, nurse-doctor team and family, family meets professionals they need in different situations, family going throug multiple wards **Healthcare service providers, family and third party;** third sector society, school nurse, care equipments, social services, social media	*"…we have this kind of multi-professional that workgroup that we are here if needed…" (HUS 3)* *"…it is the interaction between the caring team and patient's parents. There is patient, we have of course parents and then the whole care team." (OYS 4)* *"…kidney and liver association have this care circuit activity […] if child is being hospitalized at some weekend so that parents can relax…" (HUS 9)*	**Systemic Interactions** (19)	

Dyadic interactions were referred to happen in patient and healthcare professional interaction, meeting the patient alone and talking directly to child patient. These dyadic interactions were increasing in teenager patients as they are prepared for transfer to the adult

healthcare. For example, patient's development stage affects to the encounters between the patient and the nursing staff. Many of the healthcare professionals described that when they encounter a young patient parents have a great role in the discussions. But when a patient comes to a teen age the discussion is held mainly between the patient and the professional and parents are left at the back.

Although interviewees referred *dyadic interactions* they described them to *happen in a very short time frame*. So it can be argued are those truly dyadic interactions or only a part of experience journey. That is, these dyadic interactions are part of systemic interactions. This argument was strengthened by the family interviews as presented in table 4 all the interviewees described only systemic interactions. This might be caused by the fact that all the interviewees were suffering from the difficult illnesses that needed multiple visitations to the hospital and often a specialists' opinion on the matters.

Next, results of family interviews concerning organization dimension are presented. In the systemic interactions were divided to two: multi-professional healthcare team and multiple organizations interacting with patient family. First describes the micro level interactions of the ecosystem with the medical experts and the second meso-level interactions in the ecosystem. Results of family interviews concerning organization dimension is presented in table 4.

Table 4. *Organization dimension of the experience co-creation of family interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
N/A	N/A	**Dyadic Interactions** (0)	**Organization Dimension**
Multi-professional healthcare team; multiple doctors and nurses, multiple appointments with multiple care staff personnel during hospital visits,	*"In fact we met two doctors. A ward doctor and neurologist, and then we met dialysisnurse. And dietary therapist. Social worker. It was very extensive that their all specialists who participates to dialysis care."*	**Systemic Interactions** (18)	
Multiple organizations interacting with patient family; pediatric hospital and municipal healthcare, multiple wards gone through, medical expert organization and education organization, social welfare and hospital, etc.	*"We went to the Myllypuro healthcare center and then at the afternoon we went to the pediatrics hospital."*		

As noted earlier the healthcare ecosystem includes multiple actors and for that reason, *the systemic interactions are strongly present in the children's patient experiences*. As seen from the table above patient and his or her family interacts with multiple healthcare professionals during their patient pathways. *Ecosystem nature of patient experience is indicated clearly from the results of the systemic interactions with multiple organizations*. Table 5 represents main findings concerning the organization dimension of the experience co-creation.

Table 5. *Main findings of organization dimension.*

Factor	Main findings
Dyadic interactions	• Only described by care staff interviewees by describing interactions in a very short time frame • Dynamic interactions between healthcare professional and patient itself increases as patient ages and develops as parents are left out from the appointments.
Systemic interactions	• Dominant factor concerning organization dimension and shows the ecosystem nature of the experience co-creation • Systemic interactions occur between individuals and organizations. • Parents are active co-creators and have important role connecting actors ○ Parents role is critical especially when patient is in low developmental stage or young

4.1.2 Overview to the Diversity of the Ecosystem

In this section, an overview to the diversity of the ecosystem participating to children's patient experience co-creation is presented based on the interviews. To represent the diversity, ecosystem actors have been grouped and posited to children's healthcare ecosystem framework.

Based on the interviews it is clear that ecosystem that is co-creating the patient experience is spatially complex. *Several dozen actors were identified from 11 different actor groups.* Groups *location in the ecosystem varied from in the service setting to the everyday life setting of the family and some of the actor groups influenced in both of those settings.* In addition, the roles of the group varied. *Identified groups were pediatrics hospital, primary healthcare, private healthcare, other professionals, social services, patient's own support net, care equipment and suppliers, third sector societies, consumer communities, education and traveling agencies.* Some of the actor groups were identified to affect directly to the patient experience and others indirectly to the patient experience. Actor groups that directly affected to the patient experience were segmented to the core ecosystem and indirectly affecting actor groups were segmented to the peripheral ecosystem. Actor

groups' position were segmented to in the service settings and beyond service settings. Actor group was segmented to the service setting if it the experience co-creation took place in the healthcare provider's setting or other professional service setting. Table 6 presents actors and citations that describes the location they have in the ecosystem map.

Table 6. *Actors and their location*

Location	**Actor group**	***Description***
In the service setting	Pediatrics hospital	*"First we went to the municipal healthcare center and from there to pediatrics hospital"*
	Primary healthcare	*"First we went to the municipal healthcare center and from there to pediatrics hospital"*
	Private sector healthcare	*"I had this insurance so we went to the private healthcare clinic in January and there was this one female doctor"*
	Other professionals	*"Then we went to the antioxidant clinic. And then we called to homoeopathist."*
In the service setting/ Beyond the service setting	Family's own support net	*"Class mates, friends and grandparents visited in the hospital."* *"Sometimes my mum [patient's grandparent] is home welcoming [the child] and sending her to school if we haven't been able to because of the work"*
	Social services	*"[talking about when is patient and when customer]..maybe week after that when we needed to visit in Kela, and then we were customer of Kela"* *"Kela offers us speech therapist and physiotherapist [who does treatments at home]."*

	Care equipment suppliers	*"[Talking about hospitalization period] It's that ventilator, when she was so long period in ventilator it has probably scarred her vocal cords"* *"[The child] needs to take the insulin shots by her self but the hemoglobin sensors and tells what the blood sugars are and stuff like this"*
Beyond the service setting	Third sector societies	*"We were at diabetics camping week in that autumn"*
	Consumer communities	*"I'm in few of these groups in Facebook where is kind of peer support"*
	Education	*"We informed school [about having diabetes]… it [the care] relies much on that [the child] can care herself in the school also*
	Traveling agencies	*"There's always that booking flights and of course again had this feeling that "okey, hopefully we don't get any sicknesses""*

Figure 9 is further developed framework from the framework presented in section 2.3.3 Framework of children's healthcare service ecosystem. It represents identified ecosystem actor groups and their location in the children's healthcare ecosystem. Preliminary framework based on the current literature was *further developed by elaborating the locations of the actor groups*. *Moreover, new actor groups were added to the framework*. New actor groups were *social services, care equipment suppliers, education, traveling agencies*. Some of the actor groups were also removed or refined. Removed actor groups were not mentioned in the extensive data set analyzed and therefore there is no empirical evidence that they are participating on the experience co-creation in studied context. *Removed actor groups were health maintenance organizations, wellness service providers, hospital trusts and county councils*. Refined actor groups were hospital districts, next of kin, friends, alternative healthcare providers. *Hospital districts were refined by dividing it to three distinct groups: pediatrics hospital, primary healthcare and private healthcare*. These were seen more descriptive to differentiate the healthcare provider types from each other. *Next of kin and friends were refined by combining both of the groups to family's own support net*. This was done as both of the prior actor groups can be seen to be part of

the family's social life settings. *Alternative healthcare providers actor groups name was changed to other professionals*. This was done due the actor group includes also other actors than alternative healthcare professionals (e.g. pharmacy).

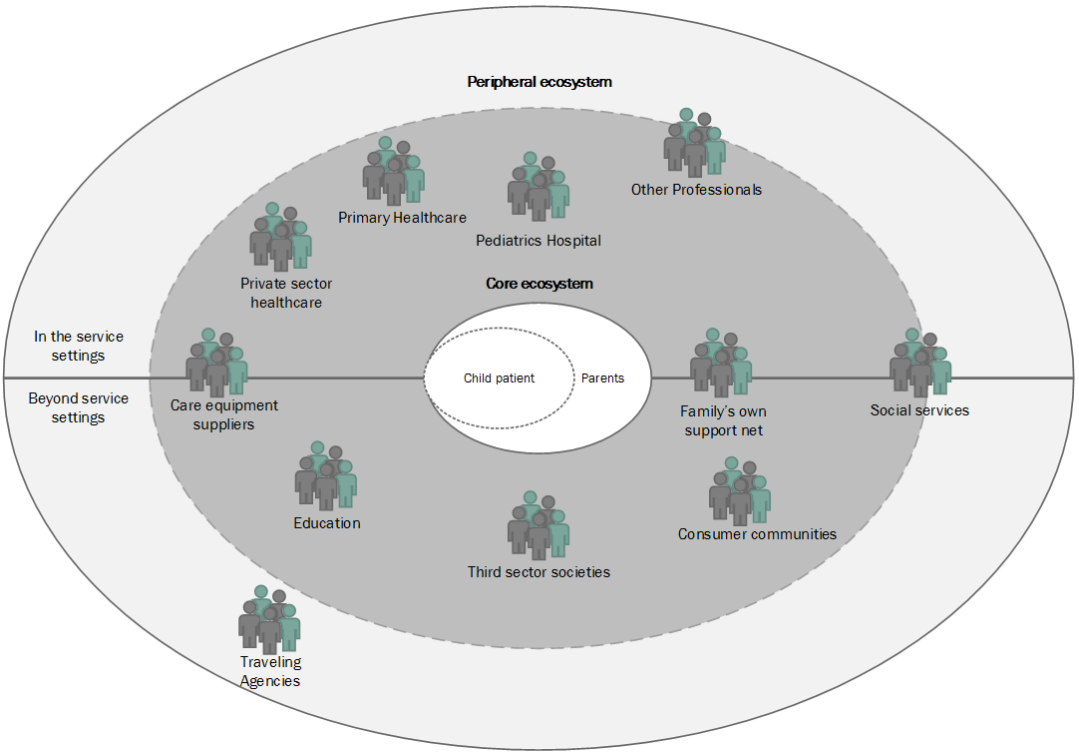

Figure 9. *Identified actor groups co-creating the experience.*

As represented in figure 9, ecosystem actor groups *segmented to the service setting were pediatrics hospital, primary healthcare, private sector healthcare and other professionals*. All were posited to the core ecosystem.

Family's own support net, care equipment and suppliers and social services were segmented to the line between in the service setting and beyond service setting because their position were not unambiguous as they *tended to move between service setting and beyond it*. Social services had a twofold role in the ecosystem co-creating the patient experience. First, social services can affect indirectly to the patient experience by providing financial support for family with ill child. Second, social services can affect directly with for example home help services for disabled.

Actor groups *beyond the service setting were education, third sector societies, consumer communities and traveling agencies*. All but traveling agencies were posited to core ecosystem as they directly affect to the patient experience. In the next section actors participating to these groups are gone through.

Care staff interviewees described strongly actors related to the service setting especially in hospital settings (appendix 6) while ecosystem actor interviews centered more on beyond the service setting actors. Actors identified from *the family interviews spread out evenly to concern both, actors in the service setting and beyond service setting*.

In next sections results concerning each individual ecosystem actor groups are gone through more detailed manner. Each of the groups presented contain multiple different actors which patients and their family interact during their patient pathways. In this section also the roles of each actor groups are presented. Groups are divided to categories by their roles. Section 4.1.2 presents results concerning the healthcare actor category and their role. Section 4.1.3 presents results concerning social and welfare services' actors and their role. Section 4.1.4 presents results concerning social actors and their role and finally 4.1.5 presents results concerning support actors and their roles. Appendixes 4,5 and 6 shows actors identified in each of the interview groups separately. Each of the groups interviewed mentioned a different sets of ecosystem actors which are combined in each section.

4.1.3 Healthcare Actors and Their Roles

One category identified from the ecosystem was healthcare actors. These actors *apply medical expertise* to care the patient, and in some occasions to the parents, that distinct them from other actors of the ecosystem. Healthcare actors are located in the service setting, i.e. in hospital.

53 different actors were identified from the pediatric hospital group. 19 from the primary healthcare actor group. 3 from the private healthcare actor group and 8 from other professionals' actor group. Identified ecosystem actors within service setting and their role in the ecosystem are represented in table 7.

Table 7. *Identified healthcare actors and their role.*

Actor group	Actors	Role

Pediatric Hospital	• Pediatric Doctors
	  ○ Named doctor
	• Specialized doctors
	  ○ Surgeons
	  ○ Cardiologists
	  ○ Neurologists
	  ○ Children's and Teenager's psychiatrics
	  ○ Neuro psychologists
	  ○ Psychologists
	  ○ Rheumatologist
	  ○ Orthopedist
	  ○ Senior physician
	  ○ Psychologist
	  ○ Anesthetist
	  ○ Dentist
	  ○ Radiologist
	• Nurses
	  ○ Named nurses
	  ○ Children's psychiatric nurse
	  ○ Head nurse
	  ○ Night nurse
	  ○ Pediatric nurse
	  ○ Surgical nurse
	  ○ Intensive care unit nurse
	  ○ Dialysis nurse
	  ○ Laboratory nurse
	  ○ Midwife
	  ○ Diabetic nurse
	  ○ Psychiatric nurse
	  ○ Line nurse
	  ○ Practical nurse
	  ○ Care staff
	• Therapists
	  ○ Physiotherapist
	  ○ Occupational therapist
	  ○ Speech therapist
	  ○ Children's psychotherapist
	  ○ Dietary therapist
	• Laboratory worker
	• Hospital equipment
		Medical experts
		• Applying medical expertise
		• Advancement of wellbeing
		• Monitoring, diagnosing, controlling, informing
		• Examining symptoms
		• Taking care of the child that parents can rest

	• Dietary planner • Rehabilitation counselors • Social workers • Interpreter • Secretary • Attendant	Supportive actors for everyday life • Helping to cope with everyday life with illness • Connecting families to other actors outside the hospital sphere • Applying expertise

	• Infant family workers • Teachers • Kindergarten teacher • Career instructor • Baby sitter • Leisure activities instructor • Cleaner • Hospital clowns • Hospital pastor • Theologian	Mental support and entertaining actors • Providing mental support for everyday life with illness • Support children's development • Make hospitalization enjoyable • Emergency baptism
	• Other patients and their families	Other patients and their families • Peer support • Understanding of uniqueness and making sense of proportion • Delays, cancellations and distraction

Primary Healthcare	Municipal healthcare
	• Doctors
	  ○ Named doctor
	  ○ Nephrologist
	  ○ Senior physician
	  ○ Psychiatric
	  ○ Cardiologist
	  ○ Orthopedist
	  ○ Psychologist
	• Nurses
	  ○ Psychiatric nurse
	  ○ Laboratory nurse
	• Therapists
	  ○ Physiotherapist
	  ○ Dietary planner or therapist
	  ○ Speech therapist
	  ○ Group therapy
	  ○ Psychotherapist
	Child welfare clinic
	• Public health nurse
		Medical experts
		• Applying medical expertise in municipal area
		• Information on child's development and situation
		• Ordering referrals to specialized doctors and to pediatrics hospital
		• Development monitoring in child welfare clinic

	• Social worker • Service for disabled worker • Care equipment center ○ Care equipment technician • Supportive sign language teacher	Supportive actors for everyday life • Support for coping everyday life

Private healthcare	• Private paediatric hospital
	  ○ pediatrics doctor
	  ○ other specialized doctors
	• Company doctor
		Medical experts
		• Applying medical expertise
		• Getting alternative diagnosis
		• Getting to care with shorter notice

		• Diagnose parents stress related illnesses

Other Professionals	• Professionals chosen by Social Insurance Institution of Finland
	  ○ Speech therapists
	  ○ Occupational therapists
	  ○ Physiotherapist
	  ○ Horse riding therapist
	  ○ Music therapist
		• Providing medical expert's opinion on needing financial and other support

	• Pharmacy
	• Alternative health services
	  ○ Chinese medicine doctor
	  ○ Homeopathy expert
		Medicines actors
		• Providing medicines prescript by medical experts
		• Getting alternative medication to treat the illness

As presented in table 7, the pediatric hospital group identified actors can be divided to four *sub-groups: medical experts, supportive actors for everyday life, mental support and entertaining actors and other patients and their families*. The division of the actors were made by their role in the ecosystem.

Medical experts included doctors, nurses, therapists and laboratory workers. Their role is to apply their medical expertise, to advance patients wellbeing, to examine symptoms, to monitor, to diagnose, to make control checks, inform patient and family about the situation and taking care of the patient that parents can rest. Some of the identified hospital actors are not directly in contact with the patients or the family but are participating to the ecosystem. They participate to the ecosystem by organizing human resources or finances, enabling the nurses to do their work and best possible work environment e.g. head nurse.

*Supportive actors for everyday life included dietary planner, rehabilitation counselor, social worker and interprete*r. Their role in the ecosystem was *to help to cope with everyday life with illness* and connecting families to other actors outside the hospital. Mental support and entertaining sub-group included actors whose role was to provide mental support for everyday life with illness, to support children's development, to make hospitalization and to make emergency baptism.

Other patients' and their families' had a positive and negative influence on the patient experience. They influenced *positively* to the patient experience *by participating to peer support* and they gave families an understanding of uniqueness and made sense of proportion. On the other hand, patient experience was *negatively* influenced by other patients and their families as they may cause *delays, cancellations and distraction during the hospitalization period*.

Family interviews gave a more detailed description what kind of actors are related to ecosystem. They mentioned multiple specialized doctors and nurses that was not been identified through the staff interviews or ecosystem actor interviews. *A major difference between two interview groups were also in mental support and entertaining sub-group*. Four new actors were identified from the family interviews additionally to those already mentioned in care staff and ecosystem actor interviews. Those were *career instructor, baby sitter, leisure activities instructor and cleaner*.

Primary healthcare actor group were divided to two sub-groups: to medical experts and to supportive actors for everyday life. *Two sub-groups in medical experts were identified: municipal healthcare and child welfare clinic*. Municipal healthcare sub-group included similar actors to the medical experts sub-group in pediatric hospital. *Role of municipal healthcare was to apply medical expertise in municipal area, to give information on child's development and situation, to order referrals to specialized doctors and to pediatrics hospital*. Child welfare clinics role was to monitor child's development and *to order referrals*.

Supportive actors for everyday life were social worker, service for disabler worker, care equipment technician and supportive sign language teacher. Their role was *to provide support for coping everyday life with illness*. Primary healthcare sector did not include entertaining actors and other patients and their families. These actor sub-groups were linked to longer hospitalization period which took place in the pediatrics hospital. *Primary healthcare was often posited as a starting point for patient journey in service setting*. That is, patients and their families seek into primary healthcare center and gain diagnosis and referral to the pediatrics hospital or need for further diagnosis is given in a regular check-up in child welfare clinic. As in the case of pediatric hospital, family interviews gave a more detailed list of actors participating to patients' ecosystem.

Private healthcare group included private pediatric hospital's doctor or other specialized doctors and company doctor. Private pediatrics hospital's roles in the ecosystem were to *apply medical expertise, to give alternative diagnosis and to give care with a shorter notice*. Company doctor's role was to help parent's with illnesses caused by stress and caring of child with an illness so it was more related to parent's patient experience rather than child's individual experience.

Other professionals' actor group included sub-groups of professionals chosen by Social Insurance Institution of Finland and medicine actors. First mentioned *provides expert's opinion on needing financial and other support*. The latter *provide prescript medicines* prescript by medical expert actors mentioned above and *alternative medication to threat the illness*. *Alternative health services were only mentioned in family interviews*.

4.1.4 Social and Welfare Services Actors and Their Role

Another category identified from the ecosystem was social and welfare services actors that includes the single actor group of social services. Social services are the only provider actor in the ecosystem that *offer social and especially welfare support*, i.e. financial support, for the family with an ill child. To be noted, patient's own support net also offers similar social support for the patient's family to cope with everyday life. However, social service group provides these services as public service provider's role rather than being in a social relationship with the family. Therefore, social and welfare services actors are categorized as distinct unit.

Social services group was divided to two sub-groups: *social welfare actors and social support actors*. These actors and their role are listed in table 8.

Table 8. *Identified social services' actor group actors and their role.*

Actor group	Actors	Role
Social services	• Social Insurance Institution of Finland • Social welfare for the disabled • Social workers	Social welfare actors • Welfare and social support • Monetary support for the family
	• Service for families with children • Home help service for families with children ○ Home help service worker • Social counselors • Social work for adults • Child welfare and protection • Informal care • Immigration services • Drug and alcohol worker • Family Rehabilitation services	Social support actors • Help for coping everyday life with illness • Solving family issues that has caused by difficult illness

As presented in table 8, identified social welfare actors were Social Insurance Institution of Finland, Social welfare for the disabled and social workers. *No individual persons were described* from Social Insurance Institution of Finland nor from Social welfare for the disabled. *These actors were described through the monetary and social help gained from them*.

Social support actors' role was to provide help for coping everyday life with illness and solving family issues that has caused by patient's illness. Most directly affecting to the patient experience were services for families with children, home help services for families with children and social counselors. Others actors were *indirectly affecting to the*

patient experience through parents. For example, child's self-care can suffer if there are issues between parents caused by her illness. In that case family rehabilitation services can help solve those issues and affect to child's patient experience.

4.1.5 Family, Friends and Other Social Group Actors and Their Role

Another category identified from the ecosystem was family, friends and other social group actors. This category includes *family's own support net, third sector societies, consumer communities and education actor groups*. This category *represents the social network of the patient and the family*. Category's groups are participating to ecosystem "voluntary" *due the social relationship to the patient and the family*. This distincts these groups from the other actor groups in the ecosystem. Identified ecosystem actors from these groups and groups' roles are presented in table 9.

Table 9. *Family, friends and other social group category actors and their roles.*

Actor group	Actors	Role
Familys's own support net	• Siblings • Grand parents • Next of kin • Friends • Hobbies • Other patients and their families	• Caring child and put the medical plan into practice • Mental support • Everyday life support • Taking child to the hospital • Peer support

Third Sector Societies	• Patient associations
	  ○ The Finnish Kidney and Liver Association
	  ○ Leijonaemot ry
	  ○ Societies for disabled
	  ○ Society of heart illnesses
	  ○ The Finnish Rheumatism association
	  ○ Diabetics association
	  ○ Ronald McDonald Association
	  ○ The Association of Friends of the University Children's Hospital
	• Food information databank
	• Other associations
	  ○ Parental Societies
	• Religious societies
		• Providing information about illness
		• Peer support
		• Stories on life with illness
		• Giving perspectives on future with illness

Consumer communities	• Social media ○ Facebook groups • Blogs • Internet forums	• Peer stories to gain knowledge of what will happen • Peer support

Education	• School
	  ○ Teachers
	  ○ Physical education teacher
		• Monitoring health and doing medical treatments

	○ School nurse ○ Friends ○ Other pupils ○ Other children with illnesses or disabilities ○ School doctor or nurse ○ School taxi or bus • Kindergarten ○ Kindergarten teacher ○ Child nurse ○ Kindergarten special education teacher ○ Other children • Day care • Clubs	• Feeling different among other children • Other children with illness or disabilities helps patients to blend in

As presented in table 9, *family's own support net* includes relatives, friends, hobbies and other patients' and their families. Their role in the ecosystem are to *care the patient and putting the medical plan into practice*. They also act as *a mental and everyday life support for the family*, help in transportation and *gives peer support*.

Identified *third sector societies* were patient associations, other associations, food information databank and religious societies. Patient associations provide mainly *information about illness, provide peer support* and stories on life with illness and gives perspectives on future with an illness. Food information bank *provides knowledge* about food for families with child patient who needs to monitor their eating and nutrition, for instance families with diabetic child. Other associations and religious societies role were seen to *help coping with everyday life with illness*.

Consumer communities included social media, blogs and internet forums. These actor's role were to *provide peer stories* on what will happen in future for a child with an illness. Social media included Facebook groups that were focused on some particular illness. Social media were seen to *provide peer support*.

Education included school, kindergarten, day care and clubs. Many individual actors were identified from school and kindergarten surroundings. Their role is *to monitor health and doing some medical treatments*. Child with illness can also suffer from being different in within these actors which affects to the patient experience. *Other children with illness or disabilities* within this actor group were seen to help the child to blend in more easily as they were *not feeling so special about their illness*.

4.1.6 Ecosystem Supportive Actors and Their Roles

Last category identified from the ecosystem was *ecosystem supportive actors*. This category includes *travelling agencies and care equipment suppliers groups*. The connecting factor of these groups is that they *support the functionality of the ecosystem*. That is, travelling agencies group support the transportation and accommodation of the family and care equipment suppliers support the medical care in the hospital and self-care in patients' everyday life settings. Table 10 presents identified ecosystem supportive actors and their roles.

Table 10. *Ecosystem supportive actors and their role.*

Actor group	Actors	Role

Travelling Agencies	• Transportation companies
	  ○ Taxis
	  ○ Flight companies
	  ○ Bus companies
	• Accommodation
	  ○ Hotels
		• Provides safe transportation and provides accommodation

Care equipment suppliers	• Dialyzer • Blood pressure meter • Nasal-gastric siphon • Pace maker • Body support equipment • Catheter • Hemoglobin sensor • Insulin pen	• Supports medical care • Enables and supports self-care and monitoring of condition • Causes additional hospital visits

As presented in table 10, traveling agencies included transportation companies and accommodation companies. Their role was to provide safe transportation and accommodation. These actors were mainly described in situation where patient and their family needs to go to the pediatrics hospital to be treated.

Care equipment suppliers *support the care, enables and supports self-care and monitoring of condition*. In some cases care equipment causes additional hospital visits which affects patient experience.

4.2 Dimensions of Patient Experience Co-creation

In this sub-chapter, results concerning co-creation of children's patient experience dimensions are presented. Chapter follows the framework presented in chapter 2.1.6 Framework of dimensions of patient experience co-creation. The above presented dimensions of patient experience co-creation were spatial dimension, temporal dimension, factual dimension, emotional dimension and locus dimension. Results are presented in sub-chapters in mentioned order.

4.2.1 Spatial Dimension of Patient Experience Co-creation

Concerning the spatial dimension of the experience co-creation all of the staff interviewees posited the patient experience to the hospitalization period or hospital in general. That suggests that *care staff interviewees posit the experience co-creation to happen in the service setting*. The length of the period that created the patient experience varied from single encounter between the patient and care staff to a multiyear journey as a hospitalized child. Interviewees described the co-creation of the experience in the service setting including things like hospitalization period, encounters, first contact, surroundings, play spaces and parking slots. Also some of the interviewees described that most of their work for indirectly creating patient experiences takes *place beyond customer interface like back-office processes* and doctor-to-doctor consultancy that is included to the service setting. Results of care staff interviews concerning the spatial dimension of the experience co-creation are represented in table 11. According to results the experience co-creation takes place mainly in hospital settings and in patients' everyday life surroundings particularly in home.

Table 11. *Spatial dimension results from care staff interviews*

Description	Citation Example	Factor (No. cases)	Dimension
Hospitalization period; overall picture about visitation in hospital, feeling about the hospital trip, hospitalization period, in the settings, in the system, appointment room, examinations	*"[Patient experience] it is what kind of feeling a child or youngster have about the trip when she visits here."(Hus 04)*	**In the service setting** (22)	**Spatial dimension**
Encounters; people that the family and child interacts with, communication, appointments	*"…how she [the patient] is receiced to the hospital, how she is listened when planning the care, how she is taken with for the desicions concerning the care…" (OYS 11)*		
First contact; First encounter, reception, letter, phone call, hospital lobby	*"I think that the first encounter is the most important. There have to be a person that welcomes, who gets it, those parents have serious emergency. " (HUS 4)*		
Play space; play room, hobby room, toy room, iPads and television and videos	*"what comes to children, can she play, is there play room, is there hobby room what ever child needs." (HUS 9)*		
Surroundings; Clothing of the care staff, conditions, exterior space, technical devices and strange noises, colors and lightness, noisiness, surrounding are not so relevant	*"Surely the syrroundings, what kind of environment it is. Moreover if you think child patient, it does more for children and the experience is more affected from the surroundings" (OYS 1)*		
Parking slots; available parking space, parking free of charge,	*"…these physical connections are here, or can be a bit difficult. That everytime you cannot get your car [parked) close." (OYS 6)*		
Beyond customers' visibility; backoffice processes, human recources allocation, doctor-doctor consulting, device preparement	*"But it is really kind of indirect patient work. That I care that there are every instruments and appropriate devices […] and then human resoursing and departments finacial matters…" (OYS 1)*		
Internet and phones; internet forums, social media (Facebook), googling, calling to friends, waiting for the call from hospital	*"…can contact to surrounding world via Facebook or via something else, so that it's not only the hospital world." (HUS 4)*	**Beyond service setting** (18)	
School; studying and hanging with school friend, to what patients can and cannot participate	*"…then of course comes these like going to school and studying and then also friends…" (OYS 5)*		
Home; receiving letter from the hospital, home dialysis, caring at home, medication, dialysis practices at home, continuing care at home	"…parents do that dialysis at home every night and these kids puke all the time…" (HUS 7)		

Patient societies; care circuits that gives care-free time	*"…they have this care circuit activity that [...] child is some time at hospital care for a weekend so that parents can relax…" (HUS 9)*		
Everyday life; sleepovers with friends, having normal life, living everyday life with illness, what can be done in life in general, getting social welfere, child's development among peers	*"...we strive for youngster's normal life, so she can go to confirmation camp next summer or to sleepover with friends…" (HUS 8)*		
Symptoms; seizures, diarreah	*"…but epilepsy can be that like those seizures happens quite rarely." (OYS 11)*		

As presented in table 11, dominant theme concerning e*xperience co-creation in service settings was hospitalization period and encounters*. Interestingly, one commonly described and *important setting was first contact*. This was due to the *emotions that parents and children have when they arrive to the service setting*. According the interviews first contact needs to calm down the situation that the possibility for successful experience increases and that the co-creation in the service setting is not shadowed by anxiety and fear. *Surroundings in the service settings* had opposite views as most of the interviewees that referred to it kept it in a great importance but one argued that it was not so relevant aspects concerning children's patient experience. She argued that more relevant for patients and their family is the fact that how they are encountered and how they are cared.

Playing areas were seen to have an important role as a service setting in the children's patient experience. Some of the interviewees noted that children's go through their experiences by playing and that makes it important for to provide that kind of settings. For patient's parents' good parking opportunities were seen to affect to the experience.

18 of the interviews described also experience co-creation beyond the service settings. According to them, *patient experience is assessed beyond the hospital environment and staff-patient encounters*. According to interviews these beyond service setting experience co-creations were often *related to patient's and his or her family's social settings*. Patients contact their friends and other important persons in their life using phone and internet. According to interviews patients *co-creates experiences in school settings and everyday life settings*. It was also related to symptoms that patient has because of the illness. It was seen that patients can have "normal" life without the illness affecting to their lives too much. Patient societies were also mentioned in the interviews.

Patient's home was a major theme emerging from the interviews concerning the spatial dimension. Some of the interviewees stated that *patient experiences start before the hospitalization period*. According to them, *patients assess their experiences before the first*

encounter with the hospital. Some of these posited the *experience to start from the first symptoms*, others from the letter or call of invitation to an appointment or contact to a system of appointment. These outside of the hospital assessments was thought to affect to the experience but *the actual experience were seen to be co-created during the hospitalization period*. It was seen that although the experience might start from the recognition of the first symptoms it ends to the hospital context where the actual experiences are created in encounters. The *continuity of an experience after the hospitalization period* was also noted in the interviews. As patients care themselves and carry through the care plan. Patient experiences were seen also be co-created in the everyday life situations and in patients' social world contexts.

Referrals to the spatial dimension of the patient experience was divided quite evenly to be co-created in both service settings and beyond it. In that sense, it seems that patient experience can be seen as a *dynamic process*. That is, in a simplified way patient experience *starts before the hospitalization period maybe in home continuing it to the service setting in this case to the hospital and after hospitalization period it continues beyond service settings*. Many interviewees described also that during patients' patient journey they might have *multiple of these hospitalization periods* which makes patient pathway complex, as *patient moves back and forth from beyond service setting co-creation to service settings co-creation*.

Next, family interviews results concerning the spatial dimension of patient experience co-creation are presented. Similarly to care staff interview results spatial dimension included experiences in the service settings and beyond the service settings. In the service setting co-creation included hospitalization period, encounters, waiting parents being separated from the child, surroundings of the service setting, changing care personnel, change of plans, malpractices, visitations at hospital, enjoyment at hospital, medical operations and information disruptions. Table 12 presents family interview results concerning the spatial dimension of experience co-creation.

Table 12. *Spatial dimension of experience co-creation of family interviews.*

Description	Citation Example	Factor (No. cases)	Dimension
Hospitalization period; time at pediatrics hospital, time at hospital's emergency room, time at ward, time at personal room at hospital	*"That there was no hurry and she [the patient] felt that she has nice nurses that she has really a good time there at the hospital."*	**In the service setting** (17)	**Spatial dimension**
Encounters; doctor's appointment, getting diagnosis, making examinations, check-ups, care staff acting professionally or unprofessionally, good attitude towards child, practicing self-care	*"We had a good doctor at hospital's emergency room that had the right attitude for [name], it was calming attitude and not like "this is nothing" attitude. And of course that when [name] was at ward it was not full or rushy, there was time for [name]."*		
Waiting; waiting at hospital's waiting room, waiting for getting to surgery at hospital, waiting for surgeries to be over	*"Anesthesies are never without a risk. I always wait at the door and I get more nervous the longer it takes that the information arrives that it's over and [name] has woke up."*		
Parents are separated from the child; emergencies at hospital, visitation period ends	*"Then suddenly when we were visiting her at hospital we were told that "now everybody out", or then there was these situations when we were told that we can quickly visit her but then after a while we were told to leave [because something happened]."*		
Surroundings; noises at hospital, too small rooms, nice private rooms, unfamiliar devices, lots of cables and monitors, rushiness and unrushiness	*"Yes that ringing bell is awful there [at hospital]…It is awful when thet ring that bell, its always like "oh no!"."*		
Changing care personnel; from primary healthcare to private healthcare, changing doctors and nurses at hospital, personnel changes during patient journey, care changes from ward to ward	*"Once happened that we had another nurse and she did not know where the medication was because we kept it there [at hospital] or they wanted that we keep it there."*		
Change of plans; moving patient to other ward, change in medication, getting personal room, changes in appointment times, change because of some other illness like nosocomial infection	*"We were called that don't wonder that [name] has been moved to other ward. At this other ward nurses did not use disinfectant that much and everything else, it was awful."*		
Malpractices; by hospital staff	*"There has been three or four malpractices during [name's] care. One was when a trainee but oral medication to injection siphon, luckily nurse in charge notived that and pulled that away."*		

Visitations at hospital; friends visit at hospital, school personnel visits at hospital, grand parents visit	*"One teacher and class mate visited [name] at the hospital. [Name] thought that it was really nice."*		
Enjoyment at hospital; activities for patient, able to feel like being in everyday life, playroom	*"[Name] had activities to do. There was this leisure activities instructor who organizes activities for kids and youngsters there [at the hospital], so she came to our room to give [name] something to do."*		
Medical operations; nasalgastric siphon placement, surgeries, taking blood samples, injections, medicating, anesthesia	*"They needed to take multiple blood samples and [name] developed a fear of needles, in fact it became earlier as a younger child in a vaccination situation."*		
Information disruptions; from ward to ward, from hospital to hospital	*"The problem lies in that information from ward K3 did not go to K5 and vice versa. Those are in the same building but the information does not transfer."*		
Life with illness elsewhere; going school with illness, being ill with childrens of the same age, bullying because of the illness	*"It's like if children with same age do something she would also like to participate but she scares a lot to do things [because of the illness]. "*	**Beyond service setting** (17)	
Everyday life changes; dietary changes, restriction of hobbies and doing sports, sick leaves from school, restricticting the ability to go out and some places, scarying for infections, changes in future plans like profession and military service, having to move because of the illness, life in a wheelchair, learning to walk after muscle athrophy, monitoring the illness, waiting to get to the surgery or check-up	*"Yes that is especially that diet for like this kind of friends' collective happenings and like that, you have to lear to take your own packed foods with you that you don't need to cause any additional sensations."*		
Caring at home; parents care at home, physiotherapist visits, speech therapist visits, giving injections, dialysis, blood pressure monitoring, patient does self-care, insulin shots, grand parents care the patient, care with care equipment	*"[name's] fysiotherapist have been paritcipating quite closely. When she visited here at home at the beginning before daycare… also speech therapist have been changed during this. She also visited home some time and the other also."*		
Medicating; taking pills, practicing medication, medicating in school	*"We started those medications and I was staying home the next day with [name]. And there it started. We practiced that medication"*		
Rehabilitation; swimming rebabilitation,			

Doing self-diagnoses; based on TV,	*"I was watching a TV program in morning. There was this cancer doctor and chattered about these. And there was also story about [name's] illness that it could turn to cancer. It scared me a bit."*		
Information about the illness; reveicing letter to home from hospital, searching from the internet, asking in the facebook groups, info from the third sector societies	*"It was just a piece of paper that came to our home. Then there was some nice latin term which we did not understood at all. We thought that do we want to find out these or is it better to not… but I think both of us have been searched what those mean from the internet."*		
Noticing the symptoms; parents or patient notices the symptoms, someone from the family's support net notices the symptom, person with same illness notices symptoms	*"Maybe the beginning of the illness, we did not know what was that about. It was very confusing. I noticed that everything is not alright."*		

An can be seen from table 12, generally *to the co-creation of the experience in the service setting participated care staff, patient and patients' family, more accordantly parents*. In some situations, *the experience co-creation took two different places at the same time, one for the actual patient and one for his or her parents*. For example, during surgeries the patient is being operated in the surgery room and patient's parents are at the waiting room or similar to wait the surgery being over.

Beyond the service setting co-creation included life with illness elsewhere, everyday life changes, caring at home, medicating, rehabilitation, doing self-diagnoses, information about the illness and noticing the symptoms. *Most of the described experience co-creations beyond the service setting took place at home with family's own support net*. But also school, kindergarten, third sector societies, consumer communities and were mentioned. Most active participants to patients' experience co-creation were their parents as stated also earlier. Summary of spatial dimension findings is represented in table 13.

Table 13. *Summary of spatial dimension findings.*

Factor	Main findings

In the service setting	• Patient experience co-creation in the service setting concerns the multiple encounters in the hospital settings
	  ○ Starting from the first contact and developing through the patient pathway
	  ○ First contact situation is important to affect to the emotions linked to patient experience
	• Service settings surroundings' importance had opposite views. Majority kept it in great importance.
	  ○ Playing areas were seen particularly important for children's positive experiences. As they can go through their experiences by playing and feel like being in everyday life
	• Care staff uses resources in the back-office processes that influence indirectly to patient experiences so that it enables experience co-creation, for instance human resources allocation

Beyond service settings	• Patient pathways usually starts beyond the service settings as patient or family member notices first symptoms
	• Patients and their family co-creates patient experiences beyond the service settings
	  ○ Takes place especially in home, school and other everyday life situations
	  ○ Co-creation of experiences also included actors from school, kindergarten, third sector societies and consumer communities.
	• Being patient affects the whole family's everyday life and therefore to the total patient experience
	  ○ It causes changes in everyday life, need for care at home and medication.

As table 13 presents, patient *experience co-creation in the service setting concerns the multiple encounters in the hospital settings*. The encounters starts from the first contact and develop through the patient pathway. *First contact situation is important* to affect to the emotions linked to patient experience. First contact's ability calm down the situation and decrease the anxiety and fears linked to the situation affects to following touchpoints.

Service settings surroundings' importance had opposite views. Majority kept it in great importance. *Playing areas in the service settings were seen particularly important for children's positive experiences* as they can go through their experiences by playing and feel like being in everyday life. Care staff uses resources in *the back-office processes that influence indirectly to patient experiences* so that it enables experience co-creation, for instance human resources allocation. This happens beyond customers view.

Interestingly, *patient pathways usually starts beyond the service settings as patient or family member notices first symptoms*. After noticing the symptoms they seek out to the healthcare provider's service setting.

Beyond service setting experience co-creation relies on patients and their family. Experience co-creation *beyond service setting takes place especially in home, school and other everyday life situations*. *Having a patient in a family affects the whole family's everyday life which influences the total patient experience*. Having a patient in family especially changes everyday life, causes need for care at home and medication. These underline the *importance of family's participation to the patient experience co-creation*. Co-creation of experiences beyond service settings also included actors from school, kindergarten, third sector societies and consumer communities. As presented in the chapter concerning the ecosystem.

4.2.2 Temporal Dimension of Patient Experience Co-creation

Concerning *temporal dimension* of the experience co-creation it was clear that *experience was seen to emerge from the present experiences but also rather strongly affected by past and future experiences*. Results of the care staff interviews concerning temporal dimension are presented in table 14.

Table 14. *Temporal dimension results from care staff interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Present feeling; this experience or encounter wasn't good, feeling about the hospital trip, feeling about the place, feeling about the care person or doctor	*"It is that what kind of feeling that kid or youngster have about the trip when she comes here [hospital]" (HUS 04)*	**Present** (21)	**Temporal Dimension**
Evaluation of hospitalization; overall picture about hospitalization, experience of entering the hospital, evaluation of hospitalization environment	*"I would think that it's kind of comprehensive, a overall picture what patient has about visit in hospital, whether it's outpatient clinic or ward visit." (HUS 11)*		
Evaluation of encounter; evaluation of individual encounter, how is listened and informed, is it on time, how is treated, evaluation of interaction, became seen and heard, getting specialist viewpoint	*"…total of that, is the patient become seen and heard and is the matter told to her in a way that she has understood…" (OYS 7)*		
Evaluation of care; quality of care, quality of given information, total of care	*"I think like it would be the patient's own experience of given care and how she is treated and respected and have she gotten quality care")HUS 05)*		

Evaluation of possibilities to participate; becoming seen and heard, ability to participate to decision making	*"…how she is listened when planning the care, how she is included to decisions about the care…" (OYS 11)*	
Functionality of care; getting help, outcome of help	*"I would think that good patient experience at least is that the matter is treated and then having a feeling that it was properly cared" (OYS 2)*	
Present problems; present everyday life worries, today's condition,	*"Chronically ill teenager is much more attached to present day. That is that, todays everyday life worries are very important for her." (OYS 7)*	
Bad previous appointments; previous appointment wasn't on time, something bad happened but cannot remember what	*"…some bad previous patient experience can affect in a way that "you always have delays in appointments" or something else." (OYS 2)*	**Past** (14)
Past experiences of pain; fear of needles, all people with white and green jacket will hurt me	*"…child that totally fears needles. Well, where it has became? It has come from our work, that is where it has come." (HUS 4)*	
Background; family's background, background of illness, someone in the family with same illness,	*"Diabetes is equally serious illness for all, the seriousness does not change who ever are we talking about. But there can be families that have a diabetic already. So they are already familiar with the illness." (OYS 1)*	
Parents' previous experiences; parents are fearing the hospital, parents have fear of needles, memories of the diagnosis; growing out of the fear of losing a child	*"Those come from parents' experiences and from previous generations. They have these grandmother-mother-child -chains." (OYS 04)*	
Routine; routine of taking shots, routine of being treated, illness is part of identity, familiar going to hospital (chronic disease)	*"And then over time this time became shorter and shorter, this preparation time, until one beatiful day she climbed to the bunk and said "stick there"…" (HUS 2)*	
Patients without any previous illnesses; new situation causes anxiety and stress; scaryness of becoming treated	*"…if you have never been in hospital before even the little operation can be really scary." (HUS 6)*	
Uncertainty; what the diagnosis will be, uncertainty of future, what future will bring up	*…can have kind of uncertainity and concern about what will happen and how we will survive." (HUS 5)*	**Future** (13)
Fear about death; will I die, fear of losing child	*"…then they fear death and child's death and dying and quilty and you name it." (OYS 4)*	

Ilness' affect on future; how it will affect on life; panic about future with cronic disease, how it affects social life, how they will succeed; going school with illness **Curability;** is this illness incurable, can it be cured in future, prognosis	*"…teenagers are concerned about how it will affect on their social world." (HUS 7)* *"…probably the fear of what will happen to me and what is this…" (OYS 10)*		

Twenty-one of the interviewees described experiences having a present factor as can be seen from table 14. Present experience co-creation was referred as present feelings, evaluation of hospitalization, evaluation of an encounter, evaluation of care, evaluation of possibilities to participate, functionality of care and present problems. Present feelings, evaluation of hospitality and encounters were the most referred ones. Present experience was strongly linked to spatial dimension as all were more or less co-created in the service settings. This might be due the fact that interviewees were working in the hospital.

Past experiences were referred as bad previous appointments, past experiences of pain, background, parents' previous experiences, routine and patients without any previous illnesses. *Bad previous appointments, past experiences of pain and patients without any previous illnesses were seen to affect or as a possibility to affect negatively to the present experience co-creation*. Interestingly, one care staff interviewee described that a child patient might not remember what happened in the previous appointment but only remembers that something bad happened. This was caused by the developmental stage of a patient as patient's memory might not be developed to a stage where one can remember actual happenings of an anxious situation. However, *parents' previous experiences also affect to the present experience co-creation* as they might recall their previous bad experiences concerning some illness or treatments in a hospital. *Patients without any illnesses might cause negative effect on the present experience co-creation as patients' are facing an unfamiliar situation that causes them fear and anxiety*.

Background, parents' previous experiences and *routine were seen both positively and negatively to affect to the present experience co-creation*. According the care staff interviews all of these might cause *positive effect to the present experience co-creation as patients and their parents are familiar with the situation* that decreases the negative emotions linked to the situation. Dynamic nature of an experience was well described by one interviewee as she described that it might be difficult for parents to grow out of the fear of losing a child that they are felt in the beginning of the patient journey.

Future experiences consisted uncertainty of future, fear about death, illness' effect on future and curability of an illness. All of these are rather imaginary experiences as they

are not lived but rather imagined by patient or family members. *Future experiences were seen to affect to the present experiences as they caused emotional reactions that had an affect on the present appointment or hospitalization period*. All of these mentioned future experiences had a negative echo in them and no positive future experiences were mentioned.

Next, the results of family interviews concerning the temporal dimension are presented. Similarly to results of the care staff interviews, the present experiences were the most described one, followed by past experiences and least described experiences were future experiences. Table 15 presents the family interview results concerning temporal dimension of experience co-creation.

Table 15. *Temporal dimension of the experience co-creation of family interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Present feeling; feeling pain, feeling shocked, shocked about diagnosis, feeling that it could be worse, feeling that the child is unfamiliar, nice to go to the trip with parents	*"[hearing the diagnosis] was quite shocking. To know that she will never get well."*	**Present** (18)	**Temporal Dimension**
Evaluation of encounter; friendly care staff, professional care staff, understanding something at the encounter differently than ment, evaluation of care personnel's attitude	*"Well, care staff in every place have been very friendly and in a way, I think, it show that in a pediatrics hospital they care children."*		
Evaluation of possibilities to participate; parents are denied to participate	*"Doctor made a rain check for me and did not take me in with [name], doctor wanted to discuss with [name] alone. I was like "what, no way, this is not OK for me". But I stayed at the waiting lobby anyway."*		
Functionality of care; feeling better, medicines does not change anything, medicines remove the symptoms	*"And then when she noticed that now is a bit better feeling, she started to trust that this is a good way"*		
Present problems; living at the moment	*"I think I didn't dare to think. That tried to live normally and do the normal stff and just go on. Did not dare to think what will happen."*		
Present diagnosis; removes the uncertainty,	*"At the beginning they did not talk about rheum, I think or did they mentioned it.. But anyway more we went through what else it could be."*		

Past hospital visits; familiar operations, memories of being injected, getting a nice band-aid but taking it off hurt, familiar staff, familiar surroundings and knowing where to go, knowing what will happen, remember to be left without parents	*"[name] was anesthetized to another operation before so she was not nervous about this no more."*	**Past** (16)
Routine; routine of being hospitalized, routine of visiting hospital, routine how parents to treat the child, routine of insulin shots	*"These things go by the routine that you know that you go there and then there and then we will be in x-ray and time in lab."*	
Parent's past experiences; experiences of being ill, having the same illness, past experiences has caused bad feeling towards hospitals, past experiences of being a parent, familiar with the illness	*"If there's a hospitalization period [the father] doesn't want, if not necessary, to be at the ward with the child because he have had an illness that he's been a lot in hospital so he does not enjoy staying there."*	
Compering to past visits; better or worse care than at the other hospital, treated differently as in previous time, past appointment was late will it be this time, comparing care staff	*"That you gladly drive to pediatrics hospital for 45 minutes and takes the treatments there and also trips to visit there because the care there have been better [than at the other hospital]."*	
First visit to hospital; not knowing what will happen but after first visit knows, first time is very confusing when did not know where to go	*"Well it's the first visit that stays in mind. Because in the second visit you already know where to go and what to expect."*	
Past experiences affect feelings; decreasing stressfulness and anxiety, not so confusing, causing more fear and stress, fear of needles, fear of losing a child comes back every time visiting at hospital	*"It felt horrible to go to the second surgery because the brutality of the first surgery was little surprising at that time. But you knew what to wait from the second surgery but I think it was more scary."*	
Uncertainty of the condition; uncertainty of what's wrong, uncertainty of the future diagnosis	*"Of course there was nervousness that morning when she had at first, already at eight o'clock leave to the examinations. Of course it was for [name] that what they will find out."*	**Future** (14)
Future life with illness; how will we cope with it, what we will do, what will the future bring, how going to school will bring up, will parents' responsibility and work increase with ill child, how will it affect future choice of profession, how will it effect on hobby or military service, how will it affect on everyday life, what if something happens and hospitals are far away	*"I guess there was this certain worry and little fear about what will the future bring out [after hearing the diagnosis]."*	
Future operations and hospitalizations; how will it be treated in future, how long the next hospitalization period will be,	*"And yes, you think that what infections there will be again. That*	

how will the surgery go, risks included to the operations	*pericarditis is something that recurs that how long hospital periods there will be."*		
Functionality of care plan; functionality or unfunctionality of medication, will the medication have side effects, how will long medication periods effect on body	*"What if medication will not work and condition will get worse, what then. And the fear was that what it will lead and what will happen to [name]."*		
Fear about death; fear of losing a child	*"[name] was being ill a very long period and in that point was like will this girl survive because it's also possible that you can die for that, during the care can pass away if you're unlucky."*		
Incurability of an illness; being ill the rest of one's life	*"That's an illness that won't cure so it's final in that point. Maybe it stays in a way, or it stopped me at that point."*		
Feeling excitement about the future; getting to play room	*"Children were exited that "now we will leave to Helsinki! And to Mäkki-house and playroom." and these are all what is interesting and nice things for a child"*		

As can be seen from table 15, present experience co-creation were described as present feelings, evaluations of encounter, evaluation of possibilities to participate, functionality of care, present problems and present diagnosis.

Past experiences included past hospital visits, routine, parent's past experiences, comparing to past visits, first visit to hospital, past experiences effect on feelings. According to interviews it seems *that past experiences can reduce the active negative emotions of present experiences by building a routine for the care*. This *reduces anxiety* of the family as they know what to expect for the care. As can be seen the children's patient experiences are dynamically percept and past experiences are affecting to the present evaluations of experiences.

Future experiences included uncertainty of the condition, future life with illness, future operations and hospitalizations functionality of care plan, fear about death, incurability of an illness and feeling excitement about the future. Summary of temporal dimension is represented in table 16.

Table 16. *Main findings of temporal dimension.*

Factor	Main findings
Present experience	• At present experience co-creation patients and their families evaluate on going encounter, functionality and quality of given care and possibility to participate • Each given time have feelings and emotions related to it • Each given time families have individual problems and issues that they seeks help for and given diagnosis decreases uncertainty that family members are having
Past experiences	• Evidently, present experience co-creation is influenced by positive and negative past experiences o Past experiences relates especially to hospital settings o As patients face multiple actors during their patient pathways they compare the past experiences in present experience co-creation • Multiple past experiences build up a routine which for instance decreased the anxiety related to hospital visits o In opposite, first visit to hospital can be very confusing and families feel high anxiety and stress • Past experiences were experienced by the patient herself or patient's parents
Future experiences	• Children's patient experience co-creation is strongly influenced by imaginary future experiences. o Mainly negative future experiences were described which negatively affected to present experience co-creation • Future experiences relate to uncertainty of future and will the patient survive alive and how the illness will influence patient's and family's everyday life • Future experiences concerned also future operations and functionality of the care • Imaginary future experiences are imagined by patient itself or patient's parents

As presented in table 16 concerning present experience co-creation, patients and their *families evaluate on going encounter, functionality and quality of given care and possibility to participate*. Patients and families have at each given time feelings and emotions related to the situation of present experience co-creation. Each given time families have also individual problems and issues that they seeks help for and given diagnosis decreases uncertainty that family members are having.

Evidently, present experience co-creation is *influenced by positive and negative past experiences*. Past experiences relates especially to hospital settings. Patients and their families *compare the past experiences in present experience co-creation*. This *concerns especially systemic interactions as patients face multiple actors during their patient pathways*.

Multiple *past experiences build up a routine* which for instance decreased the anxiety related to hospital visits. Routine in patient experience co-creation is therefore *a positive matter*. In opposite, *first visit to hospital can be very confusing and families feel high anxiety and stress*. Past experiences were experienced by the patient herself or patient's parents

Children's patient experience co-creation is strongly influenced by imaginary future experiences. Mainly *negative future experiences were described which negatively affected to present experience co-creation*. Future experiences *relate to uncertainty of future* and *will the patient survive alive and how the illness will influence patient's and family's everyday life*. Future experiences concerned also future operations and functionality of the care. Imaginary future experiences are imagined by patient itself or patient's parents.

4.2.3 Factual Dimension of the Patient Experience Co-creation

First, results of care staff interviews concerning factual dimension of the patient experience co-creation is presented. Factual dimension was divided into two factors, lived experiences and imaginary experiences. *Lived experiences were seen as a dominative characteristic in the children's healthcare experiences*. Results of the experience co-creation in factual dimension is represented in table 17.

Table 17. *Factual dimension results from care staff interviews*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Encounter situations; interaction in encounters, appointments, situations where patient is met	*"Patient experience, in hospital that is, is an experience of how she is become heard about his symptoms or matters…" (OYS 6)*	**Lived Experiences** (17)	**Factual Dimension**
Ambiance; busyness and bad ambiance	*"And general ambiance […] you sense for example busyness or bad ambiance.." (HUS 1)*		
Experience of pain or painlessness; painlessness of operations, relief of pain and bad feelings, feeling pain, symptoms	*"Pain, feeling pain." (OYS 10)*		
Participation to care processes; total of care processes, experiences from many places and stages	*"I think it is the total process which starts already when you receive the invitation letter to home…" (HUS 7)*		
Visit to hospital; concrete visit, physical experience coming to hospital	*"…in concrete that visit, of course it is kind of totally physical experience.." (HUS 8)*		
Waiting; waiting in home, waiting in lobby,	*"…how patient experiences when she waits visit in different phases.." (HUS 9)*		

Arriving to hospital; information given, getting car parked	*"…getting a letter to home that is there enough information that doctors appointment, lab, ultra, x-ray, or some other doctor, schedule and how to go and where to come." (HUS 9)*		
Devices; beeping sounds and blinking lights in devices, monitors	*"Devices are beeping, strange gadgets with blinking lights…" (OYS 11)*		
Functionality of care; how care is organized and how it affects	*"Well of course the most important is the care. People come here to care their ailments and that how it is organized, availability of care, schedule and so forth.." (OYS 3)*		
Symptoms; fever, seizures, earache	*"It is rough if you think that you're sick for example child having earache, child with fever who's squirms and cries, so it makes you impatient to wait with her." (OYS 11)*		
Imaginary future with illness; what will happen and how to survive, how it affects to everyday life	*…can have kind of uncertainty and concern about what will happen and how we will survive." (HUS 5)*	**Imaginary Experiences** (9)	
Fear about death; will I die, fear of losing child,	*"…parents have this totally acute concern almost that this baby will die although it would not be in any way a real risk." (HUS 10)*		
Illness' affect on future; how it will affect on life; panic about future with chronic disease, how it affects social life, how they will succeed; going school with illness	*"…teenagers are concerned about how it will affect on their social world." (HUS 7)*		
Mental images; imagines from TV, images of some other's illness or cause of death, imaginary diagnosis from symptoms	*"Often they have quite good imagination that they are able to generate all kinds of diseases from their symptoms and of course they might be scared of that and also might be scared about the future…" (OYS 11)*		
Preparation to hospitalization; how parents are prepared children for visit to hospital, how is prepared for operations	*"it depends on that how parent's are prepared that child to coming to hospital" (HUS 6)*		

As can be seen from table 17, lived experiences were referred as encounter situations, ambiance, experience of pain or painlessness, participation to care processes, visits to hospital, waiting, arriving to the hospital, devices in the hospital, functionality of care and symptoms of an illness. These lived experiences were *either experienced by the actual*

patient or the next of kin of a patient. For example, *experienced pain and symptoms of an illness were directly experienced by a patient* but arriving to hospital for example was seen experience of a parent. Rest of the referred descriptions were experienced by both the patient itself and parents or family in general. This suggests that even though patients and their parents might have different lived experiences as individuals the patient experience must be seen as a *collective experience of a family*.

Imaginary experiences were referred as imaginary future with illness, fear about death, illness' effect on future, mental images and preparation to hospitalization. As stated above these imaginary experiences were mostly linked to future experiences but past experiences were also mentioned. For example, one interviewee described that seen TV shows might cause mental images of hospital surroundings and affect to the patient experience. In addition, *how parents have been prepared children for visit to hospital and patient's own preparative work for operations were seen to affect to the experience*. Clearly, imaginary experiences are created in both narrow and *broad time frame* and not in one particular moment of a patient journey.

Next, results of family interviews concerning factual dimension are presented. Lived experiences included encounter situation, experiencing pain or painlessness, visits to hospital, putting care plan into action, atmosphere, life with an illness, symptoms and feelings. Imaginary experiences included future life with illness, future images of illness, functionality of care and future complications and illnesses. All of the described imaginary experiences were concerning future experiences. Although, it is difficult to say if families described past experiences were lived or imaginary as researcher cannot know what actually happened. Table 18 presents family interview results concerning the factual dimension of the experience co-creation.

Table 18. *Factual dimension of the experience co-creation of family interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Encounter situation; doctor and nurse appointments, interacting with care staff, emergency baptism	*"We had a good doctor at hospital's emergency room that had the right attitude for [name], it was calming attitude and not like "this is nothing" attitude. And of course that when [name] was at ward it was not full or rushy, there was time for [name]."*	**Lived Experiences** (18)	**Factual Dimension**

Experiencing pain or painlessness; stomach pain, pain in injections	*"And yesterday she said that in hospitalization period the worst thing was that when they put the drip on, that cannula. And not the cannula it self but that it hurt."*		
Visits to hospital; preparing for surgery and not eating, taking medication, medical operations, getting diagnosed, playing and other enjoyment, separation of parents and a child, walking on the long hallways, cancellation of operations, waiting	*"It was really nice when there have been possibility to do arts and crafts in the hospital […] That the number one thing is still from the early times those pigs and others made from magic paste."*		
Putting care plan into action; medication, injections, dialysis	*"We immediately had to take it to the pharmacy and pack it up, that it can't be evaporate. And then they said that I should inject it. [name] did not agree on that, no way. She feared that I will do something wrong because the medicine was so important and dangerous."*		
Atmosphere ; not rushy, full/unfull, chaos,	*"We went to hospital in a hurry and at that visit there was this horrible chaos there at the emergency room when we went to pediatrics hospital. Nobody really knew what was it and they put the mask on and gave oxygen."*		
Life with an illness; have to live with illness, life with uncertainty, not able to do things that would want to, life with illness that is incurable, illness feels unfair, life on caution, traveling to the hospital multiple times, missing important staff because of the hospital visits	*"That the only thing that has bothered [name] about the limitlessness is that although everybody always says that it won't limit anything but it will, at least few professions away from professions to choose from."*		
Symptoms; bleeding, diarreah, vomiting	*"Then she was very tired. About all the bleeding and all that, that she will dehydrate because of the diarreah and then theres tiredom and others.."*		
Feelings; feel of success, feeling emotions, fear, panic	*"And in the previous visit hat doctor who was there, doctor not nurse, said that we have to get a blood sample. It is understandable that you have to get it but the child is in total panic because there have been multiple tests also before it."*		

Future life with illness; how the family will cope with a child with illness, how will it be like to go school with illness, how will it affect hobbies and military service, how will it affect everyday life	*"It was like, as even getting a child is a new thing for us, as [name] was the first child for us. Then comes this other stuff [being ill] that now you have to monitor everything that for myself it felt like can we cope with this kind of nurturing and monitoring."*	**Imaginary Experiences** (15)	
Future images of illness; illness getting worse, images of the possible diagnosis, side effects of the care, fear of losing a child, images about losing limbs because of the illness	*"I was watching a TV program in morning. There was this cancer doctor and chattered about these. And there was also story about [name's] illness that it could turn to cancer. It scared me a bit."*		
Functionality of care; if the medication does not work, waiting how the surgery went, risks in operations, what if care equipment fails, how the care will affect on the child's development	*"Just like if the medication will not work and condition gets worse and worse, what then. And the fear was that where that will lead and what will happen to [name]."*		
Future complications and illnesses; what if there will be adjuvant illnesses	*"I read from the doctors' internet database about the illness. Of course there are lot of things that scares […] Some surgical things and complications and staff like that. Or part of adjuvant illnesses are really scary, that they can be lethal."*		

As can be seen from table 18, the results from family interviews were very similar with the results of the care staff interviews. However, the family interviews' lived experience results concerned also the families' home settings which were absent in the results of care staff interviews. Table 19 presents summary of the results of factual dimension.

Table 19. *Result summary of factual dimension.*

Factor	Main findings

Lived experiences	• Lived experiences took place mainly to the healthcare settings including encountering situations, visits to hospital, hospital's atmosphere, waiting and participation to care processes.
	  ○ Families also described lived experiences in the home settings like life with an illness and putting care plan into action in home
	• Lived experiences were gone through by patients and their parents
	  ○ Strongly suggest that children patient experience is collective experience of family
	• Child's individual lived experiences were the experience of pain or painlessness.

Imaginary experiences	• Imaginary experiences were strongly linked to future experiences as patients and their families imagine the future with the illness, how it will influence their everyday life and how the illness will develop • Patients and their families also imagine cases which relate to functionality of care and how the medical operations will go • Mental images related to stories from TV and from other families with child with illness and self-made diagnoses influenced to their patient experiences

As table 19 presents, *lived experiences took place mainly to the healthcare settings including encountering situations, visits to hospital, hospital's atmosphere, waiting and participation to care processes*. Families also described *lived experiences in the home settings like life with an illness and putting care plan into action in home.*

Lived experiences were gone through by patients and their parents. This strongly suggest that *children's patient experience is collective experience of family*. From mentioned lived experiences *child's individual lived experiences were the experience of pain or painlessness.*

Imaginary experiences were strongly linked to future experiences as patients and their families imagine the future with the illness, how it will influence their everyday life and how the illness will develop. Patients and their families also imagined cases that relate to functionality of care and how the medical operations will go through. Mental images related to stories from TV and from other families with child with illness influenced the patient experiences. In addition, self-made diagnoses based on, for instance, googling and internet forums influenced to their patient experiences. These caused imaginary future scenarios.

4.2.4 Emotional Dimension of Patient Experience Co-creation

According to care staff interviews *emotions have a great influence on children's patient experience co-creation* and it was brought up as an emergent dimension to the service experience co-creation framework presented. Emotional dimension was divided to four factors: active negative emotions, passive negative emotions, passive positive emotions and active positive emotions. *Dominant factor among these according the results was the active negative emotions*. Results shows also that children's patient experience is extremely sentimental experience. Emotional dimension results of care staff interviews are represented in table 20.

Table 20. *Emotional dimension results from care staff interviews.*

Description	Citation Example	Factor (No. cases)	Dimension
Fear; fearing parents, fear of losing a child, fearing child denies the diagnosis, fearful child, fear leads to aggression, fear of dying, fear of getting injected and holded on, about the child's situation, fear about the treatments	*"It is much about parents' fears and about parents' and child's fears and of course about in what state parents understand that matter." (OYS 4)*	**Active Negative Emotion** (19)	**Emotion Dimension**
Despair; horror	*"Yes, without a doubt they have all from despair to total tiring out and all between." (HUS 10)*		
Anxiety; parents' anxieties, child's anxieties	*"I think that a lot is affected by the inner anxiety and fear." (HUS 11)*		
Crying; child is crying, parents crying	*"Child haven't been scared and neither cryish that we have been able to make examinations what are wanted." (HUS 11)*		
Distress; parents are in distress, distress about the situation, distress about the child's future, acute distress, distress about the illness	*…on the other hand how iller one is the more distressed it might feel because the situation is unfamiliar… (OYS 5)*		
Concern; concern about future, concern about the situation, unfamiliar words increases concern, concern about the pain	*"Of couse that parents' have an ill child an they have terrible concern and distress about it." (OYS 1)*		
Scaryness; child is scared	*"…some of them are really scared…" (HUS 5)*		
Suicidal behavior; child behaves suicidal	*"diabetic who's not taken her injection multiple times and always comes with a unhappy face -- that's suicidal behavior…" (OYS 4)*		
Stress; parents' stress	*"…it's linked to the seriousness of the illness and of course it is increasing the stress of the parents…" (OYS 5)*		
Sadness;	*"that you get that information that you are [ill], and then [they] deny and scares and are sad.." (HUS 6)*		
In shock; parents are shocked; in panic, in crisis, starting point panic	*"I think that at the beginning, as everybody knows that it is the shock phase and it takes time before you can handle the matter." (HUS 1)*		
Denial; total denial, child denies the diagnosis	*"There is both the total deniyment and then also that kind of very strong reacting, both." (OYS 6)*		
Unwillingness; uninterested, don't caring on things	*"And can be that because often they [teenagers] have this little bit "I don't care" attitude." (HUS 11)*	**Passive Negative Emotion** (9)	

Reserve; family or child is reserved, weary **Tiring oneself out;** parents are tiring out, tiredness **Regression** **Incompliance;** parents are incomplianced	*"Then there can be that kind of situation that they are reserved that family or patient" (HUS 10)* *"You maybe notice from the parents that they are tired themselves out or totally finished" (HUS 1)* *"…it's absolute fact that when a person gets ill there comes this regression" (HUS 4)* *"Then actually in some stage can turn up that they are not compliance that they don't give medication or skip check-ups." (HUS 2)*		
Calm; families are taking treatments, unflappable, **Satisfaction** **Relief**	*"…regardless of what the illness or diagnosis is, they [family] are calm and discussive." (HUS 10)* *"…I have this experience that majority of our parents are extremely satisfied." (HUS 7)* *"…if the patient is really sick it might feel reliving coming to the hospital…" (OYS 5)*	**Passive Positive Emotion** (9)	
Happiness; in a good mood, happy feelings	*"Also often after that they are recovering from it [a surgery] and so on but when we reach that kind of stable state that is already often that kind of happiness, happy feelings, having a good mood and that." (HUS 5)*	**Active Positive Emotion** (1)	

As can be seen from table 20, active negative emotions were referred as fear, despair, anxiety, crying, distress, concern, scariness, suicidal behavior, stress, sadness, in shock and denial. The most often referred ones were fear, distress and concern. Fear included fearing child and parents but the subject of fear varied. Children's subjects of fears were the actual illness, situation and treatments. Parent's dominant subject of fears was losing the child and child's situation. This was also similar in the cases of distress and concern. Fear and concern were also linked to family's and patient's future.

Active negative emotions were linked in some cases to specific situation and actors. For example, in acute illness the situation of *active negative feelings were linked to the first contact and the person at the first contact*. Often this person was referred as receptionist or similar. According to interviews, these actors' role is to reduce the active negative emotions linked to the situations.

As seen from the table 20 active *negative emotions were without a doubt the dominant factor in emotion dimension*. That shows *that children's patient experience is extremely sentimental experience* and clear character of it. As both parents and the actual patient are having this kind of strong emotive response to this experience supports the results that children's patient experience is a collective experience. *Emotions also affect to actors' participation to the co-creation of an experience*. For example, denial and suicidal behavior affects in a way that parents or patients are not participating to the healthcare service co-creation effectively or affect negatively to the co-creation of an experience.

Passive negative emotions were unwillingness, reserved, tiring oneself out, regression and incompliance. Unwillingness was described as teenager's emotion. Tiring oneself out and incompliance were the emotions that parents might be having. Both of those were seen to effect negatively to children's patient experience and to functionality of care, and in that way to co-creation of experiences. Passive positive emotions were calmness, satisfaction and relief. The only active positive emotion was happiness. These were referred to affect neutrally or positively to the experience co-creation.

Next, results of family interviews are presented concerning emotional dimension. Emotional dimensions four factors were all described. Active negative emotions were the most common one. Interestingly, over half of the *interviewees also described positive emotions that differs dramatically from the care staff results.* Results of the emotional dimension of the experience co-creation are presented in table 21.

Table 21. *Emotional dimension of the experience co-creation of family interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Fear; fearing because not able to do anything for the child, fearing parents, fearing what the diagnosis will be, fearing that if the child will not survive (operations and illness), what will happen in future, child fears to be alone in school, will there a hospitalization circles, fear of needles, sibling fear that it will be transmitted, fear of dying and death	*"The time before diagnosis. It was dark, really scary and tough. [...] That fear that is [the patient], it happened so.. That does she have a cancer or something like that. It scared me a lot."*	**Active Negative Emotion** (16)	**Emotion Dimension**
Despair; parents are in despair ,	*"It was an emotional rollercoaster, so to say. I was having feeling despair from time to time that what we'll do now."*		
Anxiety; parents are in anxiety about what will happen, how will care staff treat their child, about will their child woke up from the anesthesia, child is in anxiety about the injections	*"I remember when we were in that ward inserting that dialysis catheter as we both got like electric shocks and anxiety hysterics that how they treated her."*		

Distress; malpractices causes distress, life with illness causes distress, trying multiple medicines causes distress, to became ill at teenage causes distress	*"[talking about malpractices.] It makes you impatient when something happens to your child so many times. And then when it happens sequentially then its distressing, very distressing."*		
Concern; parents' are concerned about the child, sibling concerned about the child, concern about the future, concern of how parents can help	*"But yes, still in a way there was this concern and little fear that what now will happen in the future."*		
Scariness; child scares injections, scariness about the side effects, what will happen in the hospital	*"Well of course it little scared and anxietied and [the patient] even more than me, that injection."*		
Sadness; sad about being different	*"Well, for her [the patient] it, she also said, felt sad. That, you always have to go for measurements, away from the group [at kindergarten], and the food eaten was measured, asked what you eat, will you eat this, how much, one spoonful or two, and the measured."*		
In shock; shocked about the diagnosis, what this means for the everyday life, rarity of an illness shocks, shocking that had to go straight to the ward, to see the child after the surgery	*"There was kind of shock and kind of fear. That what this means. And what this will mean then for our family."*		
In anger; parent is in anger or in rage, in anger after surgery is cancelled	*"[talking about postponing the surgery]…felt a little angry and cranky that we were just here [at the hospital], we have been waiting and the child is in bad condition and we have been there multiple times"*		
Grief; for child losing her health	*"Grief. Grief, that she lost her health. And still today, it's been a year, I still cry almost every time when she injects and measures [hemoglobin] because it takes a lot for that young girl."*		
Worry; about soccer hobby, not very worried about the illness	*"..only worried about what will happen for her hobby of soccer, as it was were dear to her."*	**Passive Negative Emotion** (7)	
Feeling sad; about the illness, not smiling	*"Of course it possibly depressed and felt bad [for being ill]."*		
Feeling tired; parents feel tired, patient feels tired of being ill	*"Child have suffered a bit when she has noticed that dad and mom don't really cope as we are so tired…"*		
Feeling bored; bored to wait	*"It was like just waiting, boring waiting."*		

Feeling disappointed; parents feel disappointed	*"It was disappointing when that doctor said that they were not able to do full fix, that they needed to make the same semi-fix for her."*		
Feeling uncertain; uncertainty of future	*"There was this uncertain feeling and kind of dark cloud about living home when we did not know what the situation exactly was."*		
Calmness; child is calm after the diagnosis, calm after getting used to treatments, parents staying calm that the child does not panic, calm after getting used to symptoms	*"I can't say did [the patient] anything about it in any way. That I think she was very stable and calm and she just said "it [bleeding] happened again". Of course when that bleeding started she was very hysteric. But that when it came every day you get used to it, that the child is just that "it happened again""*	**Passive Positive Emotion** (11)	
Relief; relief that child is still alive, relief to know what is wrong and to live normal life,	*"I don't know, maybe in that situation there was some kind of relief that the child is still alive and that we can go home and live that normal everyday life."*		
Hopefulness; that everything will go great, after having peer support, after realizing that it's not the end of the world,	*"A lot of hopefulness. I mean a lot of that kind of hopefulness that now [everything will go great]."*		
Feeling safe; safe to come hospitalized	*"First was that kind of shock and a little fearful. But after that it was that kind of good and safe feeling. Here is although good welcoming and nice staff."*		
Satisfied; satisfied for the service, satisfied for the care	*"We have been very satisfied for the care that we have been given at the ward. […] [the patient] goes satisfied to there and in a way there's not been that kind of opposite reaction that she does not care it appropriately."*		
Excited; excited about future operation, excited to go back home, that surgery went well	*"That insulin pump thing is very nice, she waits that excitedly now that she's like "yey!""*	**Active Positive Emotion** (12)	
Positive feelings; towards hospitalization, about care staff,	*"Those visits to hospital are very positive. That [name's] nurse is also every time says "hang in there!". And the doctor is really friendly."*		
Happy; happy about medication, about able to travel, happy about hospital clowns, happy to go back home	*"Our family, [name] feels positive and family feels really positively. […] We have been happy."*		

As can be seen from the table 21, active negative emotion dimension included fear, despair, anxiety, distress, concern, scariness, sadness, shock, anger and grief. Fear, anxiety, distress and shock were the most common ones.

Passive negative emotions included worry, feeling sad, feeling tired, feeling bored, feeling disappointed and feeling uncertain. Passive positive emotions included calmness, relief, hopefulness, feeling safe and satisfied. Active positive emotions were described as exited, general positive feelings and happy.

The positive emotions were linked to latter processes of experience co-creation. The patient experience pathways started with negative emotions and positive emotions were emerging on later. This is parallel with results reached from care staff interviews. Table 22 presents main findings concerning emotional dimension.

Table 22. *Main findings of emotional dimension.*

Factor	**Main findings**

Active negative emotions	• Active negative emotions dominate the beginning of the patient pathway
	  ○ Negative emotions may influence to patient and family engagement as they feel deny and even suicidal
	  ○ Generally active negative emotions decline when patients go further in their patient pathways
	  ○ Setbacks raise active negative emotions, for instance malpractices or unsuccessful interactions
	• Patients and their families were both having negative emotions that presents collective nature of patient experiences

Passive negative emotion	• Passive negative emotions, for instance, feeling tired or totally tiring out influenced experience co-creation negatively as patients or family were not engaged to the care • There were no clear connection with passive negative emotions and particular stage of the process ○ However, for instance, tiring took place after multiple intensive process stages • Emotions were felt by all family members

Passive positive emotins	• Passive positive emotions influenced to patient experience co-creation neutrally or positively
	  ○ For instance, staying calm while doing treatment enabled care staff to focus on the actual treatment rather than calming down the situation.
	  ○ Link to present experience co-creation
	• Hopefulness describes positivistic image of the future
	  ○ Linked to future imaginary experiences
	• Relief and satisfaction relates to past experiences
	• Emotions were felt by all family members

Active positive emotions	• Active positive emotions were mostly described by family interviewees ○ Suggests that these emotions takes place beyond service setting • Active positive emotions are also linked to narrow and broad time frames of experience co-creation • Emotions were felt by all family members

As presented in table 22, *active negative emotions dominate the beginning of the patient pathway* and were described most in the interviews. Generally, *active negative emotions decline when patients go further in their patient pathways*. This was due, for instance, by routine that build up when patients and their families go through multiple similar processes in healthcare settings. However, *setbacks may raise active negative emotions* in latter patient pathway processes, for instance malpractices or unsuccessful interactions between healthcare professional and family. *Negative emotions may influence to patient and family engagement* as they feel deny and even suicidal. This may affect to functionality of the care as unengaged patients and family neglect medication and self-care. Passive negative emotions had similar influence. That is, for instance, *feeling tired or totally tiring out influenced experience co-creation negatively as patients or family were not engaged to the care*. There were no clear connection with passive negative emotions and particular stage of the process. However, for instance, tiring out took place after multiple intensive patient pathway processes.

Passive positive emotions influenced to patient experience co-creation neutrally or positively. For instance, staying calm while doing treatment enabled care staff to focus on the actual treatment rather than calming down the situation. *Emotions were linked interestingly to temporal dimension* concerning both narrow and broad time frames. Calmness was linked especially to present experience co-creation representing narrow timeframe. Hopefulness describes positivistic image of the future and is therefore linked to future imaginary experiences and broad time frame. In addition, relief and satisfaction relates to past experiences. Active positive emotions are also linked to narrow and broad time frames of experience co-creation. Interestingly, active positive emotions were mostly described by family interviewees. Suggesting that *active positive emotions takes place beyond service setting* rather than healthcare settings. The emotions described were felt by patient itself or parents that care the child. Based on the results the *patient experience is extremely sentimental experience.*

4.2.5 Locus Dimension of Patient Experience Co-creation

Locus dimension of the service experience co-creation was divided to three factors: child's individual experience, parent's individual experience and family's collective experience. First, results of the care staff interviews are presented. Results of care staff interviews are presented in the table 23.

Table 23. *Locus dimension results from care staff interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Changes in the body; medication causes chances in looks	*"…anti-rejection medication which dramatically increases hair growth…" (HUS 7)*	**Child's Individual Experience** (14)	**Locus Dimension**
Enjoyment during hospital visit; playing, doing something else than operations, enjoyable spaces, is the space scary or looking nice, spaces does not remind hospitals, gadgets for enjoyment,	*"To have time to go to the room to do something else than those needles and other bad things." (HUS 4)*		
Mental support; normal discussions about illness and medication, feeling different among peers, relieving anxiety and stress, removing misery about the illness	*"find this kind of serious illness and then when, how she, sees that terrible misery, of that young…" (HUS 8)*		
Everyday life support; how youngster's everyday life is going, chatting with a child,	*"Try to keep that what is included to that kind of normal young's life and how maybe we could help or how we could act that some matter gets easier…" (HUS 8)*		
Feeling pain; feeling ill and pain, stomach pain, mental pain, pain caused by medical operations	*"…of course it [the patient experience] is affected by how sick the baby is, how ill the baby is…" (OYS 5)*		
Painlessness; removing pain feelings, removing feeling ill,	*"…that the care causes harms as little as possible. That's that painlessness and feeling ill are treated and sampling are appropriate." (OYS 2)*		
Encountering as individual; interacting as individual, child's viewpoint on matters, focusing questions on children, ability tell something that does not want parents to hear, asking the opinion	*"young children of course acknowledging the child, but especially when moving to elder kids that particularly ask from them, not from the parents…" (OYS 9)*		
Teenagers' illnesses; fears about the future; understands the seriousness of an illness,	*"…teenager can already be concerned about her own health…" (OYS 5)*		

Functionality of treatment; removing cause of illness,	*"…removing the reason, caring, fixing the reason that she has come to the ER." (OYS 5)*	
Peer support;	*"Or course peer support. It is something that starts with those teens." (HUS 4)*	
Concern about the child; concerned as a parent, distress about the child, stress about the situation, scary and anxieting situation	*"often that parents' have that really acute concern almost that this baby will die" (HUS 10)*	**Parent's Individual Experience** (18)
Peer support with other parents	*"Comes to mind that here chronically ill that parents have health support with each other." (HUS 4)*	
Mental support; coping with everyday life, tiring themselves out of caring, coping mentally, discussion times	*"…the parent's coping it, both mental and physical coping it is possibly one important matter." (OUS 5)*	
Coping with financial matters; social matters at home, help with social welfare matters	*"…there additionally might appear-all financial matters and all kind of working related things for to thing and even worry." (HUS 1)*	
Relationship to the care staff; familiar nurses and doctors, trust to care staff,	*"…it is nice that when you can say to parent that "I remember you" or of course when you have longer relationship that knows automatically" (HUS 8)*	
Interpretation of what is told; interpretation is affected by concern, contrary interpretation what is meant,	*"That, it is that parent's experience, she or he has experienced as bad that what is said." (OYS 1)*	
Communication; speaking clear and explaining understandably, giving overall picture and future predictions, information about present state, noticing parents, informing that the matter is taking care of	*"…explaining what is happening and noticing those parents all the time there, not just children." (HUS 5)*	
Caring home related matters; caring other children and their everyday life, situation in everyday life	*"The perspective can be a little different [about every day life]. And mom can be thinking that it's not going well in any way, and the other [the patient] can be fully satisfied…" (OYS 1)*	
Making time for care; working full time, traveling times to care centers	*"…these parents are work age people, in general they are workers. So yes, it is tried to do that many times as possible if there is visits, that they would be here which is reasonable and then closer to theirs." (OYS 6)*	

Parents participate to child's healthcare; parents come to the appointment with a child, child needs parents to come with, parents are always with, always care the whole family, parents' are responsible for the care, **Communication with all participants;** interacting to both a parent and a child, communicating with parents and children, noticing also the child, interacting with other children or siblings, customer is the whole family **Sensing family members feelings;** child senses parents' feelings, parent feels the pain of a child, mirroring each others feelings or acting	*"That what it is in children's healthcare its own aspect that there is always the family participating in a totally different way than in adult side." (HUS 8)* *"But also there have to direct words to a child that not just talk over the child with parents. The more what older the child is." (HUS 11)* *"Because child senses if those parents are totally in distress and in anxiety and almost faints in there." (HUS 4)*	**Family's Collective Experience** (13)	

As presented in table 23, child's individual experience consisted changes in the body, enjoyment during hospital visit, mental support, everyday life support, feeling pain, painlessness, encountering as individual, teenagers' illnesses, functionality of treatment and peer support. *Enjoyment during hospital visit, encountering as individual and mental support* were the most referred ones. Enjoyment during the hospital visit included activities that were not medical treatment that made the child's time in hospital more enjoyable. Mental support was mainly targeted to the teenager patients as their social world was seen more developed than a younger patient and in that sense a teenager needs more mental support than their younger peers. This was also the case in the everyday life support and peer support. Encountering as an individual were seen also to increase when child develops and ages and needs to became also heard and seen. *Higher development stage of a patient also increased the patients' awareness of their own illness and changes in their body and their individual experiences as a patient*. Functionality of treatment, feeling pain and painlessness were not connected in a similar way as all patients, regardless of their developmental stage, were seen to experience those.

Parent's individual experiences factor was described by 18 of the interviewees. That is four interviewees more than mentioned child's individual experiences. That suggests that parents are participating to the children healthcare services as active co-creators but also as beneficiaries of the service. Parent's individual experience consisted concern about the child, peer support with other parents, mental support, coping with financial matters, relationship to the care staff, interpretation of what is told, communication, caring home related matters and making time for care. Concern about the child was one of the dominant themes according the parents' individual experience. That is strongly linked to the emotion dimension of the experience co-creation. Communication and relationship to the

care staff are related strongly to organization dimension as these are happening or result of interactions.

Parents' individual experiences are also strongly linked to their social context and to everyday life. Coping with financial matters, caring home related matters and making time for care are all suggesting this. According to the care staff interviewees they provide resources to affect these matters and effect to the parents' experiences in that way. Interestingly, parent's peer support was only mentioned once. That might suggest that care staff did not find it as a relevant factor.

Although parents' individual experiences were considered as an individual factor in the analysis it shows clearly that *"children's patient experience" has multiple beneficiaries*. That is, the actual child patient experiences the healthcare service but also patient's next of kin experiences it. In that sense, it is logical that *"children's patient experience" can be seen as a collective experience*. Collective experience of a family was referred mostly as parents' participation to the child's healthcare and communication with all participants. *Parents' role as active co-creators of healthcare service was identified as a characteristic for children's healthcare services*. One interviewee stated that parents are responsible for the care beyond the service settings. Communication with all participants included child patient, parents, patient's siblings and other children in the family.

Interestingly, family's collective experience included *sensing family members' feelings*. According the interviews child senses parents feelings and parents child's. This causes that child or parent might mirror their feelings or acting from the other participant and in that way affect to that individual's experience. That is especially relevant as children's patient experience might be extremely emotive experience to a child and patients' parents.

According to the care staff interviews *child patients' ecosystem transforms during their patient pathway*. Development and aging of a child and progress of an illness causes some actors to draw back from the ecosystem and other actors to come part of the ecosystem. Dominant theme emerging from the interviews concerning the transformation of the ecosystem was parents' role during the patient pathway. *Parents role in the ecosystem is more critical in young age or low developmental state of a patient*. When a patient is developing and aging to a late teen age parents' role and effect on patient experience are becoming less critical and important. According to the care staff interviews this transformation is led by the care organization as they try to prepare the child for adult healthcare and to take responsibility for his or her own illness. The transformation is also affected on the actual development of a child as the parents' role in their everyday life is changing as they turn to adulthood

Next, results of family interviews concerning locus dimension are presented. According to family interviews, child's individual experience included feeling pain, side effects of medicines, missing everyday life things, operations and appointments, life with illness and enjoyment of life. Parent's individual experience included caring child, parent's hospitalization period, caring everyday life related matters, interacting with ecosystem actors, concern about the child, own hospital experiences. Family's collective experience included sensing family member's feelings, parents' participating to child's care, communicating with all family members, having patient in family affects everyday life of family. Family interview results are presented in table 24.

Table 24. *Results of locus dimensions of family interviews.*

Description	**Citation Example**	**Factor** (No. cases)	**Dimension**
Feeling pain; after surgery, caused by illness, painlessness, injections, taking of a band-aid	*"The pain [name] felt was so horrible that it did not, those painkillers we ate were not enough, that is why we went there [to hospital]."*	**Child's Individual Experience** (15)	**Locus Dimension**
Side effects of medicines; nausea, feeling tired and weak	*"Those rheumatism medicines are their selves pretty strong, that those causes, at least at the beginning quite a lot side effects. That those are now subsided, nausea still comes the next day or day after that in general."*		
Missing everyday life things; hobby practices, school, some professions	*"She was only worried about what will happen to her football hobby because it was very dear to her."*		
Operations and appointments; not able to eat when preparing for operations, preparing child to the operations, personal appointments, operation caused scars to vocal cords, emotions linked to operations (fear, anxiety…)	*Doing the viewing was heavy maybe that emptying when you through up the nasal gastral sphyral tout and have the runs from the other end… [--] we put that sphyral five times in that visit that hospitalization period of viewing. It's not nice. Although, that anesthesia and all that she don't suffer."*		
Life with illness; going school, taking medication and doing self-care, symptoms, fearing to live with illness, body developments caused by illness, everyday life changes after the illness, talking to friends about the illness, imaginary life with illness, body changes	*[Talking about insulin injections.] She [the patient] wanted to keep it in a way, she wanted to learn to be with the illness and injections, that she had a need to experience that this is an easy thing and I cope with it myself."*		

Enjoyment of life; playing in hospital, fun trips to other city, fun trips to home,	*"[name] has just now been able to talk about herself. Before this she's been too young. After this previous cathethrin trip and also before she was just excited to go to Helsinki [pediatrics hospital] by plane. That she did not understood what was coming."*	
Caring child; taking care of the child after work, responsible of the care, practicing the care at home in the hospital	*"[the patient] was at the hospital the whole time, I was there basically the wiiks and the my husband came there after work that I can go shower and sleep and change clothes to home."*	**Parent's Individual Experience** (15)
Parents' hospitalization period; no room for parents, will there be long hospitalization periods, separated from the child, seeing the child uncounceness and with incisions after operation, waiting to hear about operations	*"Well, the spaces what we had were small for parents to be. There's almost no room for parents really. "*	
Caring everyday life related matters; taking care of siblings, going to work, everyday life responsibilities,	*"Maybe it is just like organizing that there's home and that, there should be and here [at pediatrics hospital] should be in and who have time to be where. And then you should do work while to while."*	
Interacting with ecosystem actors; calling to hospital, discussing with medical experts, with company doctor about their own mental health, etc.	*"one morning I called to the ER again like every morning to ask that "how is it going" and then he told me that [the patient] is still in a uncoucnosness stage like you left her yesterday."*	
Concern about the child; will the child have a normal life, how the operation will go, will the child survive the operation, what if care equipment fails, how the child will survive with the illness, fear of losing the child	*"I think, there's a terrible fear of losing. It is, i remember when I thought at that time, it's the fear of losing [the child] is the most largest one."*	
Own hospital experiences; fear of hospitals, fear of needles, going to psychiatrics	*"I have had a kind of fear of hospital. It started right away, when someone other is sick and someone else is feeling unwell."*	
Sensing family member's feelings; child with pain is hard for parents, postponing surgery is hard for both actors because not getting help for pain, siblings does not sense that much, child sensing parent's concern, all family members crying together	*"Because it was tough for [the patient] and in that way to the whole family. [--] Those pains were really bad that it was difficult to watch from the close."*	**Family's Collective Experience** (16)

Parents' participating to child's care; care in hospital, giving care at home, cooking appropriate food for patient, giving medication, postponing surgeries or appointments, making decisions on medication and care and the child, responsible for the care, taking care of the care equipment, all can be in the same room at the hospital, keeping the child still when giving a shot	*"[talking about postponing the surgery]…felt a little angry and cranky that we were just here [at the hospital], we have been waiting and the child is in bad condition and we have been been there multiple times, at the heart station whole time, every two weeks and calling there all the time when she's getting in worse condition and now there's no [surgery]. We were pretty angry behalf of the child that they're not doing this now."*		
Communicating with all family members; the whole family is receiving care, all family members are participating to care practicing, mental care for the whole family, informing next of kin, doctor communicating to patient and parents	*"[the patient] practiced this mechanical way of this care these measuring and injecting stuff. And we other family members who wanted, mainly me and [patient]'s father and then [patient]'s big brother, we were also taught those and thought injecting."*		
Having patient in family affects everyday life of family; to care of siblings, have to give time for patient, positively affecting trips to other city, challenging the maternal bond to form, have to have accommodation for parents when child is being hospitalized, planned holiday trips are cancelled due the illness, going through illness and discussing, living in "quarantine" at home because fear of getting sick	*"At the beginning when the child was born and was taken immediately to emergency care, the maternal bond do not begin to form normally between mother and a child and there's no breast feeding. And the breast feeding did not begin at all in this case, we give up on that and went straight to the bottle feeding."*		

Based on the results presented in table 24, it seems that *patient's and parent's experiences are strongly intervened.* The family's strong participation to child's care and the affect that illness have on the whole family's life seems to play a major role in the children's patient experiences. Importantly, *families are sensing each other's feelings* so that experiences are formed in a collective manner. Furthermore, the locus of the patient experience can range from experience of an individual to experience of a collective. Figure 10 represents findings from the locus of the experiences and interconnected family experiences combining results from both groups interviewed.

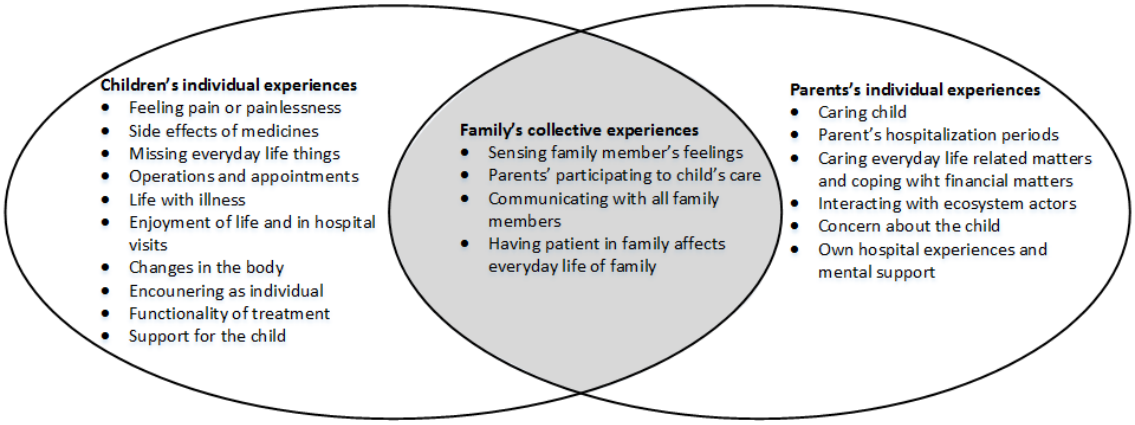

Figure 10. *Locus of the children's patient experiences.*

As can be seen from figure 10, locus of the experience concerns *child's and parent's individual experiences and also collective experiences of the family*. Relationship between child and parents are often very close and intensive and therefore it is evident that they experience as a collective. *Locus dimension links also to emotional dimension as family members sense each other's feelings*. As family member senses others' feelings they *might mirror the emotions and change their behavior based on that*. As described earlier *having a patient in the family influences to family's everyday life* and emerges as a collective patient experience. Table 25 presents combined main findings concerning the locus dimension of experience co-creation.

Table 25. *Main findings of locus dimension.*

Factor	Main findings

Child's individual experience	• Enjoyment of life in hospital and beyond service settings were seen as important factor for child's patient experiences
	• Teenagers have more individual experiences than their younger peers as teenagers are socially more developed and aware of themselves
	  ○ Pain and painlessness were seen as individual experiences regardless of the developmental stage
	  ○ As teenagers social life is more developed individual experiences like missing hobbies and school becomes more relevant and influences child's patient experience
	• Child's individual patient experiences takes place beyond (for instance going to school with illness) and in the service setting (playing in hospital)
	• Physical pain and painlessness are experiences by the patient he or her self

Parent's individual experience	• Parents are strongly engaged to the patient experience emotionally as concern about the child was the most referred one of parent's individual experiences ○ Parent's individual experiences are strongly linked to sentimentality of the experience

	• Parents individual experiences takes place beyond the service setting (everyday life related) and also to service settings (experiences during hospitalization) • In some cases parents' past individual experiences influenced experience co-creation ○ For instance, one of the parents could not participate experience co-creation in hospital settings as he had fear of hospitals
Collective experience	• Close relationships and emotional bond between a child and parents makes children's patient experiences collective experiences. • Having a child patient in a family influences family's everyday life and family need to face the experience as a collective • Sensing other family member's feelings underlines the collective nature of children's patient experiences

As can be seen from the table 25, e*njoyment of life in hospital and beyond service settings, e.g. in home, were seen as important factor for child's individual patient experiences*. The individual experiences of children were seen to increase as older the child gets. That is, *teenagers have more individual experiences than their younger peers*. This was due to that teenagers are *socially more developed and aware of themselves*. As teenagers social life is more developed individual experiences like missing hobbies and school becomes more relevant and influences child's patient experience. However, some experiences were experienced regardless of the age and development stage of a child. For instance, pain and painlessness.

Parents are strongly engaged to the patient experience emotionally as concern about the child was the most referred one of parent's individual experiences. Therefore, parent's individual experiences are strongly linked to sentimentality of the experience. In some cases parents' past individual experiences influenced experience co-creation. For instance, one of the parents could not participate experience co-creation in hospital settings as he had fear of hospitals. This *links locus dimension to temporal and emotional dimension*.

Close relationships and emotional bond between a child and parents makes children's patient experiences collective experiences. Having a child patient in a family influences family's everyday life and family need to face the experience as a collective and co-create patient experiences in everyday life situations. *Sensing other family member's feelings* underlines the collective nature of children's patient experiences.

As described earlier experiences are co-created beyond and in the service setting. Spatial dimension is also linked to locus dimension as individual experiences and collective experiences took place in both factors of spatial dimension. For instance, child's individual

patient experiences beyond service setting was described as going to school with illness and in the service setting as playing in hospital. Parent's individual experiences beyond service setting was caring everyday life related matters and hospitalization period in the service setting. In collective experience, for instance, sensing family member's feelings varied spatially in and beyond service setting.

In the next section, results reached in this chapter are summed up and discussed. Results are posited to proposed frameworks presented end of the theoretical background chapters.

5. SUMMING UP RESULTS AND DISCUSSION

5.1 Service Ecosystem in Children's Healthcare Context

This section presents new information concerning the ecosystem co-creating children's patient experiences derived from the results. The results are compared with the existent literature reviewed earlier. Similarities and differences are reflected from the prior studies.

As stated in the results section, taking the service ecosystem approach to the experience co-creation *underlines the systemic interactions* concerning the organization dimension of service experience co-creation. Results showed that interactions can happen between individual actors in the micro level but also between different meso-level actors as different actor groups were interacting with each other.

Phenomenological value emerges through interactions and collaboration between ecosystem's actors that are integrating resources and co-creating mutual value (Akaka et al. 2013). All of the actors *share a mutual goal of healthier people* and sustainable well-being. According to literature, meso level of the ecosystem included hospital districts, hospital trusts, county councils, health maintenance organizations, third sector societies (e.g. diabetes association), consumer communities (e.g. patient groups for specific medical condition), important social groups (next of kin and friends), alternative healthcare providers and wellness services (Helkkula et al. 2013; Joiner and Lusch 2016). The empirical results of this study shows that meso level include also additional actor groups: social services, educational actors, traveling agencies, care equipment suppliers. Healthcare professionals were found to be divided to three groups: private healthcare sector, primary healthcare sector and pediatrics hospital. For patient and family, *private healthcare and primary healthcare groups act as a gateway to get to the pediatrics hospital* as those two actors offer referrals to pediatrics.

Service ecosystem participating to patient experience co-creation includes four actor categories; healthcare actors, social and welfare services actors, family, friends and other social group actors and ecosystem supportive actors. Figure 11 represents these actor categories and their main roles in the ecosystem.

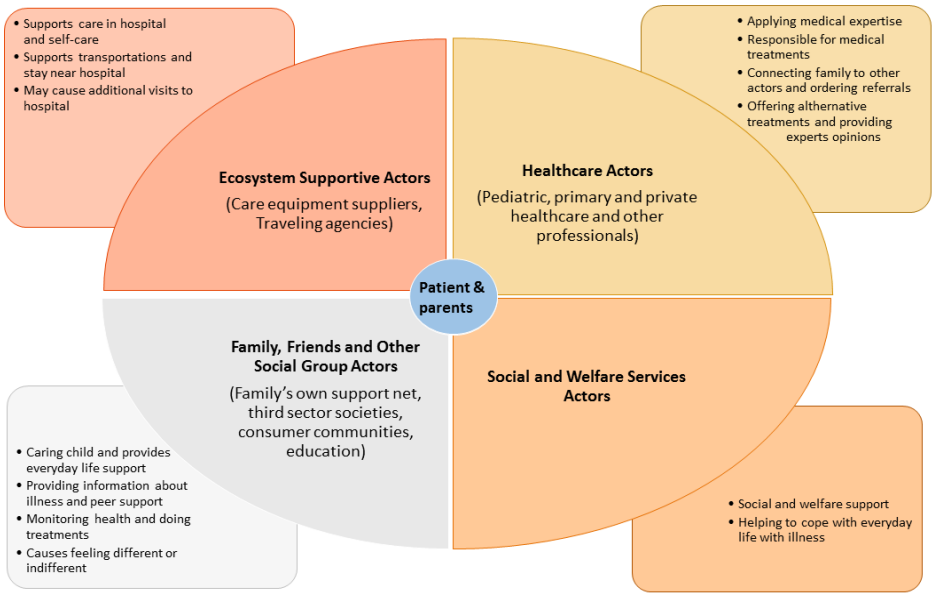

Figure 11. *Ecosystem actor categories and their roles.*

As presented in figure 11 healthcare actor category patients and their *families may interact with multiple healthcare groups* during their care including pediatric, primary and private healthcare groups. Ill children and their families might want additional opinions and alternative treatments if they feel that afore mentioned healthcare groups cannot provide the information or functionality of care they are seeking. Therefore, *other professionals may be included* as resource integrators to the ecosystem.

Illness of a child is mentally challenging for the child but also for the parents. Care and treatments of *ill child can cause financial pressure* that may cause additional stress for the family. The social and welfare services actors role is to support the family with ill child *to cope everyday life mentally and financially*. Social workers in the hospital helps to build a connection between family and social services.

As Helkkula et al. (2013) argued the family, friends and *other social group actors have a major role in the patient experience co-creation*. *Family with ill child needs peer support and help to cope with the illness*. In children's ecosystem that participates to co-creation *include also kindergarten or school*. Having an illness in school may cause feel of being different or even cause bullying which influences to the children's patient experience. Education actors, like school doctor, may also participate to self-care by giving for instance insulin shots.

The care that ecosystem provides and experiences it co-creates is supported by *supportive actors*. These actors support care in hospital and self-care by *providing and maintaining the care equipment and helping to use those equipment*. Care support *may cause additional hospital visits* that influences patient experience negatively as in situations where equipment fails or equipment needs maintenance for other reasons. The supportive actors also include transportation and accommodation actors as patients and their families need to visit hospital. Figure 12 represents the ecosystem's connections and their roles in the ecosystem.

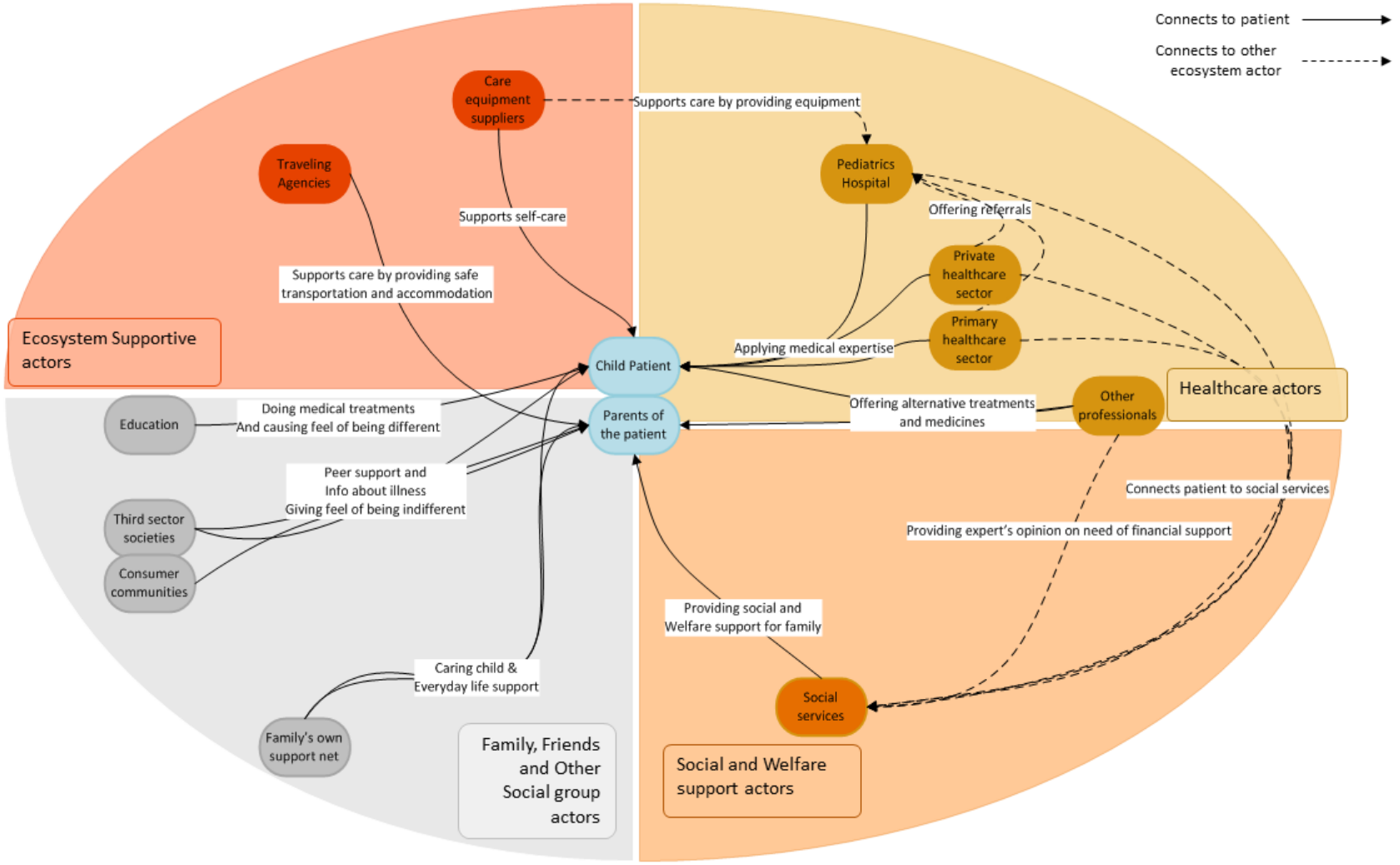

Figure 12. *Ecosystem actor connections within ecosystem.*

Empirical study shows that *are several dozen actors participating to the children's patient experience co-creation*. The results extend the knowledge about the micro or individual level actors presented in the contemporary research (Helkkula et al. 2013; Ponsignon et al. 2015). Founded individual ecosystem actors are listed in result sections 4.1.2-4.1.5. Because of the amount of individual actors participating to co-creation of children's patient experience co-creation, the representation of these actors was not seen appropriate. However, this underlines the complexity of managing and mapping co-creation of experience within an ecosystem. Moreover, the service ecosystem framework suggested in this thesis (see sections 2.3.3 and 2.4) is not elaborated enough to for mapping this complex ecosystem.

The actors participating to co-creation *varies by the illness and need of help the families were facing*. The results also showed that *patient and his or her parents have a great role on adjusting the ecosystem* in a way that they connect their selves to additional actors. Ecosystem is clearly a *dynamic and evolving during the beneficiary's journey*. Arguably, the service ecosystem is a self-adjusting system (Vargo & Lusch 2011 according to Barile et al. 2016 pp. 660), but the *self-adjusting nature is driven by the focal actors in the ecosystem*. In addition, the *influence and importance of each actor varied as children's patient experience* is subjectively interpret. This is natural for ecosystem actors participating to co-creation (Iansiti & Levien 2004). For instance, in one case the cleaner in the hospital had a negative influence on patient experience co-creation as child was scared of the cleaner.

The experience co-creation within ecosystem varied between co-creation with a service provider (e.g. healthcare professional) to co-creation emerging among the other actors beyond the service setting. In addition, the amount of self-care that takes place beyond the service setting can vary (Joiner & Lusch 2016). In children's patient experiences one factor that *influences to the amount of self-care is the type of illness* that patient have. *This also emphasizes the combination of actors participating to experience co-creation* in ecosystem. For instance, if the care of the illness relies on the self-care of the patient, for instance in the case of diabetes, the ecosystem includes multiple actors beyond the service setting but not that many different medical professionals. On contrary, illness like heart defect that needs several medical operations, treatments and surgeries to be cared, the ecosystem actors emphasizes the healthcare actors to participate to co-creation. The difference between these two illness group actors are presented in appendix 7. This also shows that *the amount of actors participating to experience co-creation over the patient pathways may differ dramatically in relation to the illness that the child has*.

As mentioned, the actors participating to ecosystem share a mutual goal of healthier people. Healthcare services are uniquely interpreted and experienced by patients but the experience co-creation is fragmented to many actors and contexts of the healthcare network, not just to single interactions between patient and the hospital staff. Individual actors or even actor group's influence of single dimension of experience co-creation is impossible to posit as family's individuals interpret the experience holistically and dynamically (Verhoef et al. 2009; Heinonen et al. 2010). Next, this holistic, contextual and dynamic experience is summarized and discussed.

5.2 Features of Dimensions of Children's Patient Experience Co-creation

In this section, model for dimensions of patient experience co-creation is presented (figure 12). The model summarises knowledge derived from the results concerning the spatial (S), temporal (T), factual (F), emotional (E) and locus (L) dimensions of patient experience co-creation. The inner circle of figure 13 presents these findings. The preliminary framework of *dimensions of patient experience co-creation was well suitable for studied phenomenon*. The proposed framework was based on the service experience co-creation dimensions (Jaakkola et al. 2015) and emotions related to experiences (e.g. Bolton et al. 2014). There were extent amount of results reached that were suitable for service experience co-creation dimensions in patient experience context. Holistic nature of the patient experience phenomenon was evident as results were linked to multiple dimensions.

Approach of this thesis posited patient experience co-creation as service experiences. Therefore, the findings derived from this study are extended to general service experience co-creation field. The outer layer of the figure 13 represents wider implications for the field of service experience co-creation. The derived results are discussed and compared with the existing literature reviewed earlier. In the model *dimensions of patient experience co-creation overlap each other* which represents the holistic nature of patient experiences. Dimension are interconnected to each other and patient evaluates patient experience as a total. The interconnected nature of patient experience is also discussed in this sub-section.

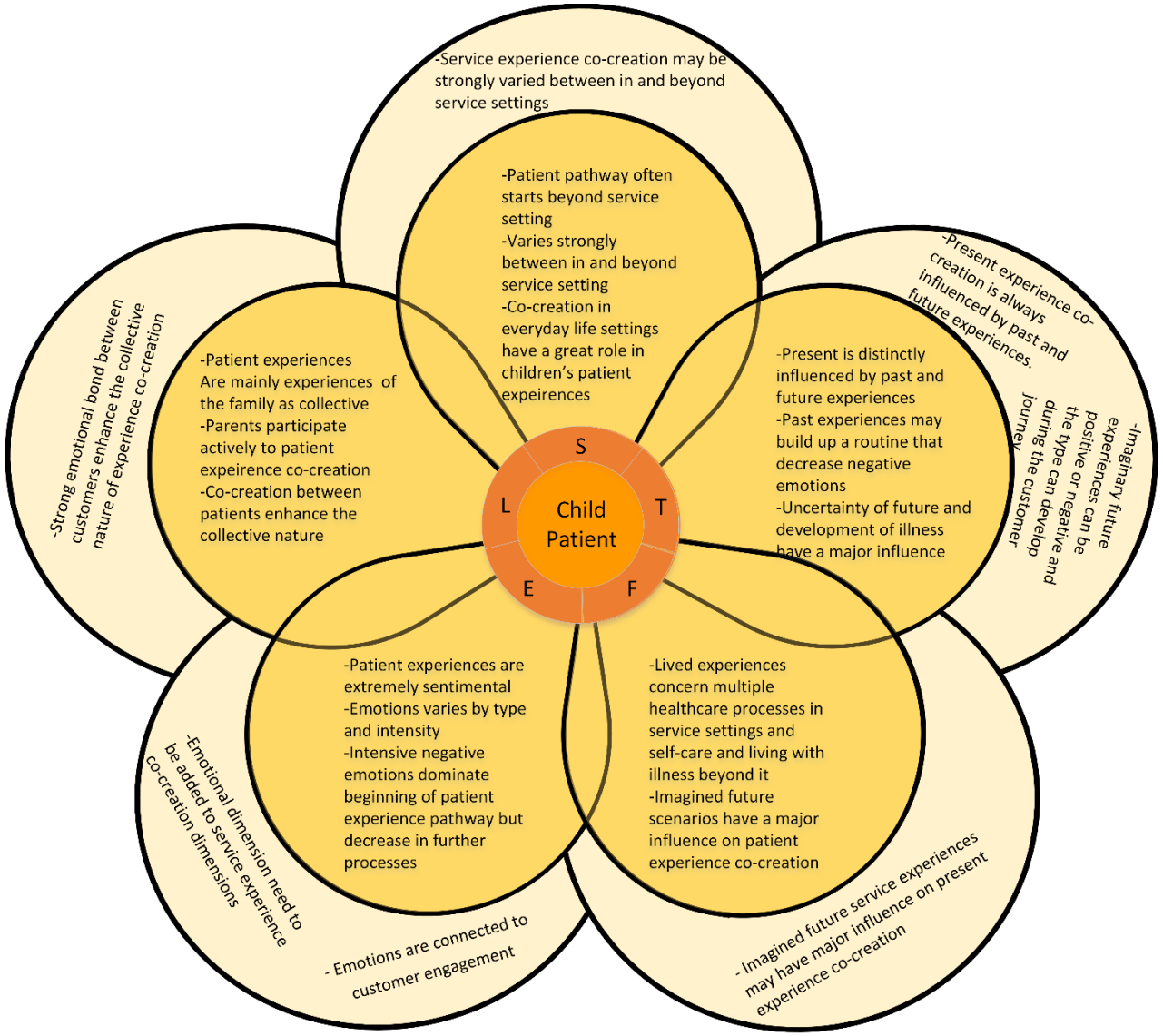

Figure 13. *Model for dimensions of patient experience co-creation.*

The results of the empirical study indicate that experiences are co-created *in and beyond the service setting*, as previous knowledge proposed (Jaakkola et al. 2015). As can be seen from figure above, patient experience co-creation in the service setting concerned *multiple encounters in healthcare service providers' settings*. The encounters in the service settings started from the first contact, for example, contacting receptionist, and developed through the patient pathway by multiple interactions with several different ecosystem actors.

Results concerning the importance of service setting surrounding were not unanimous. Majority of the informants kept service setting surroundings in great importance. For example, results indicated that the "unfamiliar devices" or "too small rooms" influence families' experiences negatively. Moreover, p*laying areas in the service settings are particularly important for children's positive experiences* as they can go through their experiences by playing and feel like being in everyday life. Therefore, it can be argued that setting surroundings have *direct influence* on patient experience rather than indirect as is argued by Ponsignon et al. (2015).Patient experience co-creation included also *indirect interactions*. In the context patient experience co-creation providers' indirect interactions were for instance human resource allocation, doctor to doctor consulting. Human resource allocation influenced indirectly as patients needed or did not need to wait to get to the care and enabled direct experience co-creation. This gives insights on service experience co-creation including direct and indirect interactions (e.g Mayer & Schwager 2007).

Beyond service setting experience co-creation relies on patients and their family. Experience co-creation beyond service setting *takes place especially in home, school and other everyday life situations*. Having a patient in a family affects the whole family's everyday life that affects the total patient experience. Having a patient in family changes everyday life, causes need for care and medicating at home. These underline the *importance of family's participation* to the patient experience co-creation. Results support findings of e.g. Uhl et al. (2013) about children's parents participation but refine them to include the whole scope of spatial dimension. Co-creation of experiences beyond service settings also included actors from school, kindergarten, third sector societies and consumer communities as presented in the chapter concerning the ecosystem. Interestingly, *patient pathways usually starts beyond the service settings* as patient or family member notices first symptoms. After noticing the symptoms they seek out to the healthcare provider's service setting. This may give valuable information for practitioners interested in service experience management.

Children's patient experience co-creation is *strongly influenced by imaginary future experiences*. Negative future experiences that were described influenced negatively to present experience co-creation. However, multiple *past experiences build up a routine* which for instance *decreased the anxiety* related to hospital visits. Routine in patient experience co-creation is therefore a positive matter. In opposite, *first visit to hospital can be very confusing* and families feel high anxiety and stress. Hence, present patient

experience co-creation is strongly influenced by past and future experiences. Although, patient and parents evaluate the experiences in isolated moments of experience co-creation, evaluations are *influenced by past and future experiences*. Based on the results of this thesis, it can be argued that the *narrow or present experience co-creation is always influenced by the customer's imagined future experiences and past experiences* as customers are never clean canvases without expectations and some kind of past experiences. This may elaborate the knowledge on temporal dimension factors presented by Jaakkola et al. (2015) and provides empirical evidences that present, past and future factors of temporal dimension are co-existing simultaneously.

Above discussion describes also the factual dimension of patient experience co-creation. Factual (F) dimension of service experience co-creation posited that service experience beneficiary determines his or her experiences based on lived experiences and imaginary experiences in present, past or future (Jaakkola et al. 2015). Empirical results indicate that *lived experiences* are taking place in healthcare settings including encountering situations, visits to hospital, hospital's atmosphere, waiting and participation to care processes. Families also described lived experiences in the home settings like life with an illness and putting care plan into action in home. *Future imaginary experiences* relate to uncertainty of future and will the patient survive alive and how the illness will influence patient's and family's everyday life. Future imaginary experiences concern also future operations and functionality of the care. Imaginary future experiences are imagined by patient itself or patient's parents and as stated above these imagined future scenarios have a major influence in present patient experience co-creation. This study *extends the knowledge on imaginary experiences* in general service experience co-creation (e.g. Jaakkola et al. 2015) and in healthcare context (e.g. Joiner and Lusch 2016), implicating that *there are both negative and positive future imaginary experiences*.

Dimensions of service experience co-creation was developed by adding emotional (E) dimension to patient experience co-creation framework based on argument that emotions have a major role in healthcare experiences (Bolton et al. 2014). Results of this thesis indicated *that patient experiences are extremely sentimental*. Emotions during the patient pathway vary between the type and intensity. That is, patients feel emotions from negative to positive which vary by the activity of the emotion. Negative emotions dominate the beginning of the patient pathway. However, these type emotions generally decline when patients go further in their patient pathways due the routine but may be raise again if patients and their family face setbacks. *Active and passive negative emotions may influence to patient and family engagement.* Non-engagement may affect to functionality of self-care and therefore to care in total. Passive positive emotions influenced to patient experience co-creation neutrally or positively. Arguably, empirical results of this study indicated that *service experience research need to consider emotions as one of the co-creational dimensions*.

Service experience co-creation dimensions posit locus (L) of the experience to be co-created as experience of an individual and experience of collective (Jaakkola et al. 2015). Collective experience includes customer's social network actors to experience co-creation processes in the consumer sphere (Gröönroos & Voima 2013). Close relationships and emotional bond between a child and parents makes *children's patient experiences collective in nature* as parents participate actively to patient experience co-creation. In addition to emotional bond, parents are legal guardians of the patient and are legally obligated to participate to child's care and experience co-creation. However, the obligatory point of view were not mentioned in the interviews which indicate *the natural maternal bond between child and parents* that binds parents tightly to children's patient experience ecosystem. Results concerning the patient-patient experience co-creation underlines the collective nature of the experience. That is, experiences are co-created collectively by "consumers" of the service (Jaakkola et al. 2015). The collectivity of experience is a distinct nature of children's patient experiences. The individuality of patient experiences increase as the child develops and ages. This underlines the contextual and dynamic nature of service experiences but more importantly the uniqueness of service experiences. This also may indicate that locus of the service experiences may develop from collective experience co-creation to individual experience co-creation or vice versa, particularly during longer relationships with customers. Next, the holistic nature of patient experience and connections between different dimensions are discussed. No previous knowledge on the interconnected nature of service experience dimensions was found from the literature.

The connection between emotional and spatial dimensions is evident. The connection between these two dimensions were described for instance as the importance of first contact situation in hospital and fear of hospitals. According the results first contact *needs to calm down the situation* that the possibility for successful experience increases and that the co-creation in the service setting in following encounters is not shadowed by anxiety and fear. This also connects *spatial and emotional dimensions to temporal dimension* as present experience co-creation influences to future experience co-creation. Some positive emotions were felt beyond the service settings, i.e. after the hospitalization period and the family was heading home which might explain why staff interviewees were not aware of this kind of emotions. Therefore, active positive emotions were mostly described by family interviewees. This indicates that most of the *positive emotions takes place beyond service setting* rather than healthcare settings and enhances the spatial and emotional dimensions connection.

Results also indicated that *emotional and spatial dimensions are connected to temporal dimension*. For example, patients and families have at each given time feelings and emotions related to the situation of present experience co-creation as they evaluate on going encounter, functionality and quality of given care and possibility to participate. Evidently, present experience co-creation is influenced by positive and negative past experiences. *Calmness was linked especially to present experience co-creation* representing a narrow timeframe. This suggests that calmness is not a steady emotional state but emotions changes

during the patient pathway. Hopefulness describes positivistic image of the future and is therefore linked to future experiences and broad time frame. *Empirical results truly indicate that these emotions are subjective,* that is in line with e.g. Verhoef et al. (2009), *but also that emotions can be responded with similar emotions between two customers in a close relationship*, like in the situation of child mirroring parent's feelings. Past experiences of temporal dimension relates, for example, to hospital settings where patients and their families compare the past experiences in present experience co-creation. This also refine the process-based characterization of patient experience (e.g. Wolf et al. 2014) to concern comparement of process phases. This concerns especially systemic interactions as patients face multiple actors during their patient pathways. That connects these dimensions to the ecosystem that co-creates the patient experiences over the patient pathway.

Negative emotions dominate the beginning of the patient pathway. However, these type emotions generally active decline when patients go further in their patient pathways. This was due, for instance, by routine that build up when patients and their families go through multiple similar processes in healthcare settings. In addition, relief and satisfaction relates to past experiences as patients feel relief after diagnosis or satisfied after an encounter. This elaborates argument by Bolton et al. (2013) that emotions have an important role in healthcare experiences, by indicating that *emotions have major role especially at beginning of the patient pathway*.

The nature of future experiences connect temporal dimension to the factual dimension of patient experience co-creation as future experiences are imagined by the patient or parents. Therefore, imaginary experiences were strongly linked to future experiences as patients and their families imagine the future with the illness. The connection between future imagined experiences to spatial dimension is indicated as family interviewees described situations where they imagined how the illness will influence their life. That is, how will they cope with ill child beyond the service settings. Furthermore, factual dimension is connected to locus dimension as lived experiences were gone through by patients and their parents. This strongly suggest that *children patient experience is collective experience of family*. However, from mentioned lived experiences *child's individual lived experiences were the experience of pain or painlessness*. Feeling pain as an experience influencer is in line with the Verhoef et al. (2009) who include physical aspects to the experience.

Spatial dimension is also linked to locus dimension as individual experiences and collective experiences took place in both factors of spatial dimension. For instance, child's individual patient experiences beyond service setting was described as going to school with illness and in the service setting as playing in hospital. Parent's individual experiences beyond service setting was caring everyday life related matters and hospitalization period in the service setting. In collective experience, for instance, sensing family member's feelings varied spatially in and beyond service setting. Parents are strongly engaged to the patient experience emotionally as concern about the child was the most referred one of parent's individual

experiences. Therefore, parent's individual experiences are strongly linked to sentimentality of the experience. In some cases parents' past individual experiences influenced experience co-creation. For instance, one of the parents could not participate experience co-creation in hospital settings as he had fear of hospitals. This links locus dimension to temporal and emotional dimension.

As all dimensions were tightly linked together, it is evident that patient experience is a holistic experience and should be approached as a phenomenon. Conclusions of the study are presented in the next section.

6. CONCLUSIONS

6.1 Academic Contribution

This study has given in-depth and elaborate understanding of children's patient experiences and the ecosystem co-creating those experiences. There were no similar studies conducted before this study. Therefore, studies concerning service experience co-creation, emotions in service experience, patient experience and service ecosystems were combined and resulted deep insights of patient experiences co-creation within the ecosystem. Conducted study contributes to three fields of research: service experience research, service ecosystems research and service management research. The research implications of this thesis are presented in table 26.

First, this study contributes on the field of service experience research concerning phenomenological service experiences and co-creation of service experiences. The model for dimensions of patient experience co-creation was developed and introduced. The proposed model contributes to research by further developing the dimensions of service experience co-creation. The developed model was successfully applied to study children's patient experience co-creation and may be applicable to study other contexts of service experiences also.

In addition, this study contributed by studying empirically phenomenological service experiences in a special service context of children's healthcare. Study provided knowledge on what the phenomenological service experience may be consist of.

Moreover, this study responded to the call by Jaakkola et al. (2015) to identify relevant actors involved in service experience co-creation and to explore the nature of service experience co-creation in different industries and cultural contexts. This study provided insights to a special service context, children's patient experiences. Study revealed the major extent of actors participating to children's patient experience co-creation. The co-creation of experiences was surprisingly focused on beyond the service settings in patients' everyday lives and therefore beyond the reach of the healthcare service providers.

Second, this thesis contributes to the research field of service ecosystems. This study empirically studied and tested service ecosystem framework presented in service-dominant logic literature (e.g. Vargo and Lusch 2011; Akaka et al. 2015) in a healthcare context. Study explored the actors of service ecosystem and studied how they are located spatially. Furthermore, study elaborated actor's differing roles in the ecosystem.

Table 26. *Research implications of this thesis.*

Field of research	Example authors (year)	*Implications for research*
Service Experience	Vargo & Lusch (2008); Verhoef, Lemon, Parasuraman, Roggeveen, Tsiros & Schlesinger (2009); Jaakkola, Helkkula & Aarikka-Stenroos (2015)	*-Empirically studied and further developed dimensions of service experience co-creation.* *-Empirically studied what the phenomenological service experience consists of in a special service context of children's patient experience* *-Identified relevant actors involved to service experience co-creation in a context of children's patient experiences.*
Service Ecosystems	Vargo and Lusch (2008, 2011); Akaka, Vargo & Schau (2015)	*-Empirically studied and tested service ecosystem framework in healthcare context, elaborated actors and their role in experience co-creation within ecosystem.*
Service management	Zomerdijk & Voss (2010, 2011); Helkkula, Linna & Kelleher (2013); Wolf, Niederhauser, Marshburn & LaVela (2014); McColl-Kennedy, Cheung & Ferrier (2015)	*-Empirical study in healthcare context indicate that service management literature with process-based characterization need address increasing focus on processes beyond service setting.* *-Empirical study generated knowledge to general service management literature about the complexity of service experience management in a multi-actor environment*

Third, this study implicates to service management research by empirically studying healthcare and extending knowledge of service experiences in healthcare. Particularly, this study provided evidences to service management literature approaching service experiences as process-based characterized (e.g. Zomerdijk & Voss 2010, 2011) that total service experience is affected by processes and touchpoints beyond provider's service settings. This implies that service management research should address increasing focus on process beyond service setting. In addition, this empirical study provides knowledge about complexity of service experience management in a multi-actor environment.

This offers healthcare service researchers and service management researchers in general valuable insights and push to expand their view on how to manage service experiences. Furthermore, the knowledge

how complex the ecosystem co-creating the service experience is. Moreover, for academics interested in public service sector this gave a thorough understanding about the dimensions of collective and collaborative service experience co-creation.

6.2 Managerial Implications

Healthcare providers globally need to understand how service experiences in healthcare are co-created within the ecosystem of multiple actors. This thesis will give extent views on the complex ecosystem co-creating the experiences. Study showed that healthcare professionals are having a too narrow view on the patient experience and actors participating to co-creation. Study helps managers to understand that experience co-creation goes well beyond healthcare service provider's settings. Identifying the actors of core and peripheral ecosystems guides managers in their work of service experience development. The understanding of characteristics of children's patient experience helps managers to focus on the needs and preferences of their patients in order to offer higher quality, safer and more efficient services. Moreover, healthcare service providers that view healthcare as a part of an ecosystem will be able to better design and create their value propositions for the patients (Joiner & Lusch 2016).

For practitioners, managers and policymakers of strong publicly funded healthcare system this study sheds light on care beyond the service setting that this is important to provide healthcare services with limited resources. Ecosystem actors beyond the service settings also share a mutual goal of healthier people. Therefore, the functionality of the ecosystem have influence on the total assessment of patient experience. In brief, better the functionality of the ecosystem is the better results it generates. Therefore, managers of different ecosystem actor organizations should support the functionality of the ecosystem and identify themselves as one of the many ecosystem actors that patients and their families interact with during their patient pathways.

This topic offers a potential to the healthcare firms in a competitive environment to excel in patient experiences by understanding the full phenomenon of children's patient experiences. Strategies enhancing patient experiences can provide a superior competitive advantage in the competitive market (Verhoef et al. 2009). Positive patient experiences might lead to better patient satisfaction (Berry et al. 2002; Mascarenhas et al. 2006; Zomerdijk & Voss 2010; Lloyd & Luk 2011; Maklan & Klaus 2011) which is associated to firm's long term financial performances (Mittal et al. 2005). Findings of the study provide insights on how managers in the pediatric healthcare should design their children's patient experience co-creation to better support patients' needs. Managerial recommendations based on findings of this study are presented in table 27.

Table 27. *Managerial recommendations for pediatrics hospitals.*

Dimension of patient experience co-creation	Finding	Managerial recommendation(s)
Organization dimension	-Patient experience co-creation emerges from systemic interactions between individual actors from multiple different parts of organizations and other organizations.	-Support information sharing within the organization and other actors of the ecosystem. Avoid information discontinuity and having family to inform same information multiple times.
	-Parents have important role connecting actors.	-Support parents role by providing information about other actors of the ecosystem
Spatial dimension	-First contact in the hospital settings have influence on the emotions and is connected to later patient experience co-creation.	-Support and provide training on empathy and dealing panicky customers for front-line employees. Emphasize empathy on new employee recruitment. -Avoid long waiting times in the first contact situations. -Provide clear information and visual guidance so that navigation to care at first visit is untroublesome.
	- Service setting surroundings influence on the children's patient experience.	-Avoid high noises in hospital, for example ringing bells or calling patients using loud speakers. Provide functional games and toys and clean playing area.
	-Self-care of the illness beyond service setting plays important role and being a patient influences the whole family's everyday life and to total assessment of patient experience.	-Support self-care by providing sufficient training and functioning equipment for the patients and their parents.
Temporal dimension	-Families evaluate functionality of given care and possibilities to participate.	-Provide opportunities to participate and alternatives to choose from to the families. Support parents participation to decision making. Avoid processes that parents are denied to participate. -Support information sharing on the functionality of the care.
	-Families compare past visits and appointments.	-Support sharing best practices through the organization and ensure standardized medical processes. -Share best practices and standardized processes with the municipal healthcare organizations.
	-Negative imaginary future experiences influence particularly on the early stages of patient pathway.	-Enhance mental care and peer support opportunities on the early stages of patient pathway. Support guidance

		to mental care and peer support providers for families.
Factual dimension	-Lived experiences includes visits to hospital.	- Avoid last moment cancellations to surgeries and serious medical operations. -Avoid long waiting times especially in stressful and distressing situations. Support sufficient informing if long waiting times are unavoidable. -Support family's enjoyment during hospitalization by providing homely feel.
	-Imaginary future functionality of the care concerns families.	-Support informing, for example, in situations when child is in surgery.
Emotional dimension	-Negative emotions in the beginning of the patient pathway may influence negatively to family's engagement on care.	-Enhance mental care and peer support opportunities on the early stages of patient pathway. Support guidance to mental care and peer support providers for families -Train front-line employees to be emphatic.
	-Feel of tire or tiring out may influence negatively to engagement of care.	-Provide supportive care for the patient's parents.
	-Family mainly feels positive feelings beyond service settings.	-Support functions in the hospital that makes children feel happy, for instance, playing and hospital clowns.
Locus Dimension	-Teenagers have more individual experiences than their younger peers as they are socially more developed and aware of themselves.	-Provide teenagers possibilities to connect to their social circles and school when hospitalized. Support friends to visit to hospital. Support peer support activities as teenagers may need to feel belonging to teenagers alike. - Provide functional games and toys for younger children.
	-Parent's emotional experiences, especially concern about the child's future, influences the co-creation of patient experiences.	- Support parents' seek into mental care and provide them time to participate in the mental care.
	-Close relationships and emotional bond between child and parents makes children's patient experiences collective experiences.	-Support the bonding and parents participation to the care. Avoid or minimize separating young children from their parents.

6.3 Meeting the Objectives

This thesis concentrated on understanding the children's patient experiences and the ecosystem co-creating experiences. This thesis aimed to answer two main research questions:

RQ1: What does dimensions children's patient experience co-creation consist of?

RQ2: What is the service ecosystem that co-creates the children's patient experience?

The second research question was divided to sub-questions as followed:

What are the different actors co-creating the children patient experience?
What are their role in the service ecosystem?
Which kind of actor categories can be identified from the ecosystem?

A model for dimensions of patient experience co-creation was presented to answer to the first research question. See section 5.2 and figure 13: Model of patient experience co-creation. The analyzed extensive data set gave two perspectives of the characteristics of the children's patient experience that were combined together.

Identified ecosystem actors and their roles are represented in the section 4.1. that answer the first sub-question. Moreover, an representation of actor categories of children's healthcare ecosystem was also presented that answer to the third sub-question of the second main research question (see section 5.1 and figure 11 and 12). To conclude, the thesis reached its aims and answered the set research questions.

6.4 Limitations and Critical Review

There were several limitations concerning methods and results of this thesis. The most relevant limitations of qualitative research are reliability and validity (Bryman & Bell 2015, pp. 400).

Reliability of the research estimates whether the results gained through the interviews could be obtained by alternative researcher and the accuracy of the answers (Saunders et al. 2009, pp. 326). The reliability difficulties in qualitative research are always present as the data collected is unstructured and interpretations are profoundly influenced by the subjective leaning of a researcher (Bryman & Bell 2015, pp. 414) Therefore, reliability of the study can decrease by multiple of reasons and is linked to interviewer and interviewee biases. Two data collection techniques were used to collect the data used in this study: semi-structured interviews and narrative interviews.

First, in semi-structured interviews the interviewer, in this thesis the researcher, can cause error through commenting, tone or non-verbal communication during the interviews. By doing so interviewer tries intentionally or unintentionally impose his or her own beliefs and to guide the answers to be parallel with existent beliefs of the interviewer. Interviewer bias can be also actualizing while analyzing the responses (Saunders et al. 2009, pp. 326). Interviewee bias is caused by interviewee's unwillingness to discuss on

certain themes or sub-themes of the interview or give answers that he or she thinks that are desirable but not give an overall picture of the phenomenon (Saunders et al. 2009, pp- 326-327). This is relevant especially in the sensitive matters.

Second, in narrative and unstructured interviews are influenced by the interviewer's characteristics, like age, personality, gender, etc. (Bryman & Bell 2015, pp. 414). Interviewees can therefore tell a different story depending on the interviewer.

Validity can be divided to two components internal and external validity. First, the internal validity focuses on the formulation of theoretical assumptions of the chosen theoretical concepts based on the researcher's data analysis (Bryman & Bell 2015, pp. 400). The internal validity therefore depends on whether or not the researcher was able to match the made observations and theoretical ideas they might have developed. Validation of the findings concerning the ecosystem co-creating the patient experiences were made by presenting findings for several healthcare professionals and patient experience researchers in a LAPSUS-project workshop late 2016. There were no arguments presented concerning the ecosystem actors. Internal validity concerning the dimensions of patient experience co-creation were not validated ding the study. Furthermore, children's were not interviewed so the data collected were not exhaustive and might influence the internal validity of the study. However, the results reached with empirical research were consistent with applied theoretical predictions and framework of dimensions of patient experience co-creation. Hence, the study can be claimed internally valid.

Second, external validity of the study refers to the degree in which findings of the study can be generalized across social settings. This has been addressed to be especially problematic in qualitative research. (Bryman & Bell 2015, pp. 400). The generalization problematic nature of qualitative case studies lies in use of small sample size that results that findings of the study might only represent participants view on the phenomenon in the context of the study in a certain time. The cultural background and other contextual factors influenced to validity of this study and the generalization of the findings to other social and cultural contexts. This study also concerned patient experiences in a publicly funded healthcare context. Therefore, findings may not be generalized to countries without strong publicly funded healthcare as is.

It can be also argued that the nature of experiences as subjective interpretation are always influencing to external validity. That is, objective and generalizable studies are extremely difficult or even impossible to conduct as experiences are always unique and influenced by temporality and context.

Additionally, a critical review of the thesis is needed. Firstly, at the time of conducted ecosystem actors the literature was only partly covered. Therefore, the questioning frame have some deficiencies. However, this concerned only a small part of total data used in this study. Secondly, some interviewees found it difficult to understand used terms and language in conducted interviews. This lead to a situation where

rephrasing of the question or explanation of terms were needed. This may have affected to their answers and therefore to results. Thirdly, use of secondary interview transcripts may have caused some misinterpretations during the made analysis. Fourthly, all interviews were held in Finnish and quotes used in this study were translated before usage. This might have caused some misinterpretations of the results. Moreover, the complexity and amount of micro level actors made it inappropriate to use synthesis framework proposed.

6.5 Future Research

This study raised several interesting future research topics concerning service experience co-creation theory and management. The study concentrated the characterization of children's patient experiences and ecosystem co-creating those experiences. However, research to manage the children's patient experiences and ways to enhance the functionality of ecosystem stays uncovered. Therefore, there is a need for future research concerning the managerial aspects of this phenomenon. Firstly, the future research, for instance, take a process-based view on the children's patient experience co-creation presented in section 2.1.2. The research could address a focal clues related to processes and sub-processes patient encounters trough his or her patient experience pathway. Furthermore, managerial tools should be developed to manage different situation of the patient experience co-creation so that organizations could offer better and "fail proof" service experiences to their patients. These research topics should concentrate on particular patient groups so that accurate knowledge of each pathway could be gained. Secondly, ecosystem co-creating the patient experiences need a further research as this thesis did not include the institutions influencing to the patient experience co-creation within the ecosystem. Therefore, future research could examine the institutions and barriers of co-creation within the ecosystem to expand the underlying knowledge of the context co-creating patient experiences.

As described in limitations of this study, there were no data collected directly from the child patients themselves. Child's evaluations of the studied phenomenon could differ from the results gained in this thesis. Therefore, further studies on the topic should cover the children's viewpoint on the topic in question. Interesting research topics could study experience co-creation dimensions from the child's perspective. Findings from this study can be used as a basis for that study. Further studies from child patients' perspective on ecosystem actors could identify more actors especially interacting with the patient he or herself. In addition, as described in this thesis parents act as a connecting actors between different ecosystem actors. Therefore, the child's own ecosystem might not include all the actors presented in this thesis. Further studies on this topic from the child's perspective could reveal how different child's and parent's ecosystems co-creating the patient experiences are.

Further studies from different context are also needed to develop the theory of service experience co-creation. For instance, aross-field analysis on the co-creation of experiences between different service context could engage the similarities and differences concerning the service experience co-creation and ecosystems co-creating the experiences. This could expose the specialty of patient and the difference between customer and patient. The difference between customer and patient could be approached for instance on the freedom of choice as described in the following quote from a staff nurse:

> *"...customer has choices. But patient usually have to accept the service that is offered to her. Of course, in theory, there is a possibility to choose treatments, but she [the patient] is not paying nothing but the statutory amount, which does not [belong] to customership. That belongs to customership is that you can choose the service by the price. I think there is a vast difference."*

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APPENDIX 1: ORIGINAL INTERVIEW STRUCTURE FOR ECOSYSTEM ACTOR INTERVIEWS

Haastateltavat: ekosysteemitoimijat

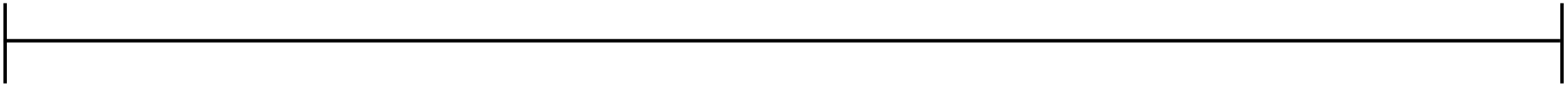
1. **Haastattelijan tausta**
    a. Työ/toimenkuva?
    b. Kauanko toiminut tehtävässä / onko toiminut muissa yksiköissä?
    c. Millaisia tehtäviä työhön kuuluu?
2. **Potilaskokemus**
    a. Miten määrittelisit potilaskokemuksen?
    b. Miksi potilaskokemuksen painottaminen on/ei ole tärkeää?
    c. Mitä erilaisia puolia potilaskokemuksessa on?
    d. Millainen on hyvä potilaskokemus? Kuvaile hyvää potilaskokemusta.
    e. Kuinka hoitotapahtuman ympäristö vaikuttaa potilaskokemukseen?
    f. Kuinka työntekijöiden hyvinvointi vaikuttaa potilaskokemukseen?
    g. Kuinka sairauden laatu vaikuttaa potilaskokemukseen?
    h. Kuinka potilaan ja vanhempien odotukset ja uskomukset vaikuttavat potilaskokemukseen?
    i. Kuinka potilaan tai vanhempien aikaisemmat kokemukset vaikuttavat potilaskokemukseen?
3. **Toimija osana hoitoverkostoa**
    a. Mikä on (haastateltavan edustaman organisaation) perustehtävä ja toiminnan tarkoitus?
    b. Kuinka toimintanne linkittyy potilaskokemukseen?

    Haastateltavaa pyydetään piirtämään näkemys potilaspolusta*

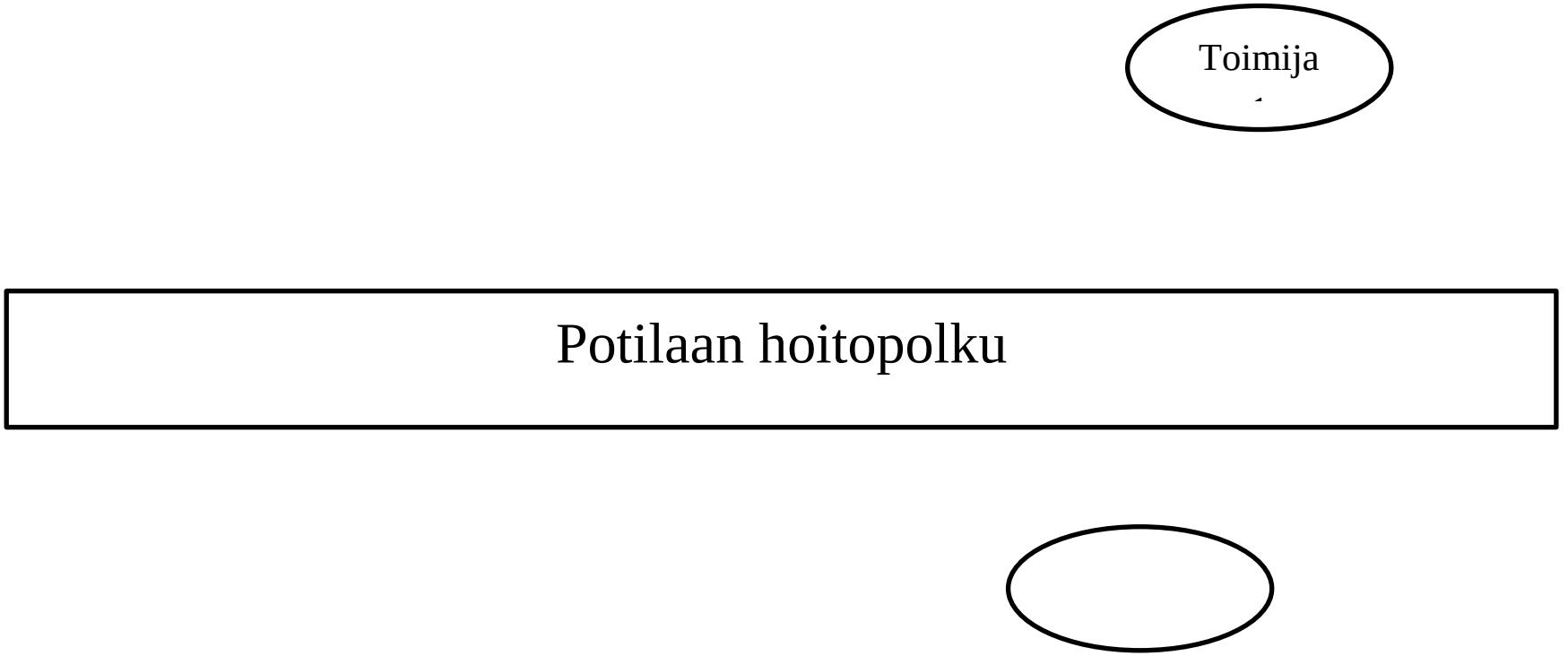
    c. Missä kohdissa potilaspolkua (haastateltavan edustama toimija) kohtaa potilaan/hänen perheensä?
    d. Minkälaisia palveluita tai toimintoja tarjoatte potilaille, ja ketkä toteuttavat nämä palvelut?
    e. Kuinka vaikutatte palveluilla potilaskokemukseen?
    f. Missä potilaspolun kohdissa lapsipotilaan kokemusta <u>erityisesti</u> tehdään?
    g. Miten potilaspolun pituus vaikuttaa potilaskokemukseen?
    h. Mitkä asiat vaikuttavat palveluketjun sujuvuuteen?
4. **Muut ekosysteemitoimijat**

a. **Haastateltavaa pyydetään täydentämään ekosysteemikarttaa ****: Mitä muita toimijoita (haastateltavan toimijan lisäksi) on mukana potilaan hoitopolulla? / Mitä toimijoita kuuluu potilaan hoitoverkostoon?
b. Missä kohtaa potilaspolkua nämä toimijat vaikuttavat?
c. Miten verkoston eri toimijat voivat omalla työllään vaikuttaa potilaskokemukseen?
d. Miten eri toimijat voivat vaikuttaa potilaiden vanhempien asiakaskokemukseen?
e. Minkälaisista vaiheista potilaskokemus rakentuu potilaspolun aikana?
f. Miten verkoston eri toimijat ovat kytköksissä toisiinsa?
g. Miten verkoston toimijoiden määrä vaikuttaa potilaskokemukseen?
h. Mitkä asiat vaikuttavat verkoston toiminnan sujuvuuteen?
i. Mitä hyvää/huonoa nykyisessä toimintamallissa on?
j. Minkälainen rooli potilaalla itsellään on potilaskokemuksen syntymisessä?

*Potilaspolku



*Ekosysteemitoimijakartta



APPENDIX 2: REFINED ECOSYSTEM ACTOR INTERVIEW STRUCTURE

Haastateltavat: ekosysteemitoimijat

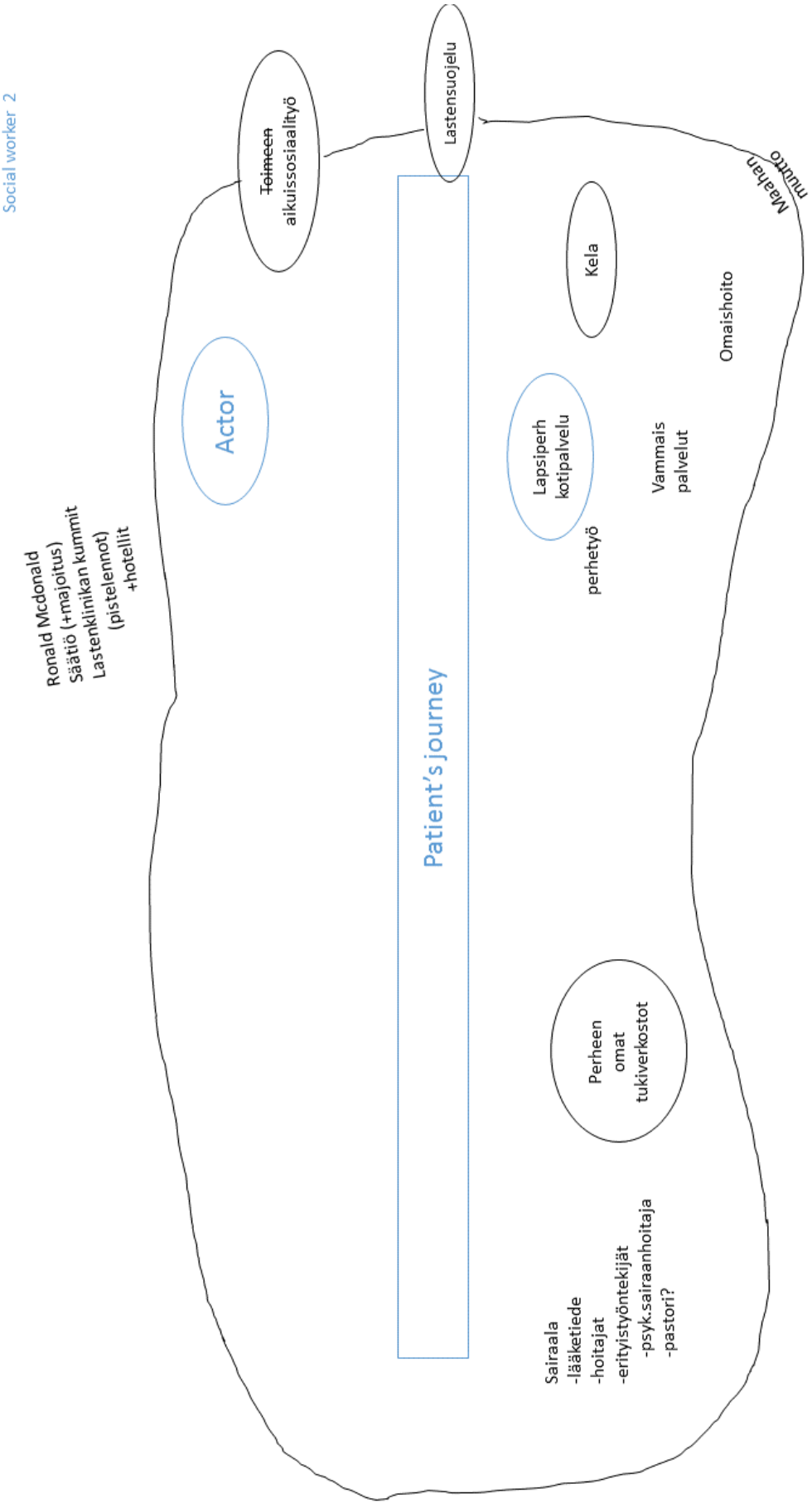
1. **Haastattelijan tausta**
    a. Työ/toimenkuva?
    b. Kauanko toiminut tehtävässä / onko toiminut muissa yksiköissä?
    c. Millaisia tehtäviä työhön kuuluu?
2. **Potilaskokemus**
    a. Miten määrittelisit lapsen potilaskokemuksen?
    b. Mitä erilaisia puolia lapsen potilaskokemuksessa on?
    c. Millainen on hyvä potilaskokemus? Kuvaile hyvää potilaskokemusta.
    d. Kuinka sairauden laatu vaikuttaa lapsen potilaskokemukseen?
    e. Kuinka potilaan ja vanhempien odotukset ja uskomukset vaikuttavat potilaskokemukseen?
    f. Kuinka potilaan tai vanhempien aikaisemmat kokemukset vaikuttavat potilaskokemukseen?
3. **Toimija osana hoitoverkostoa**
    a. Mikä on (haastateltavan edustaman organisaation) perustehtävä ja toiminnan tarkoitus?
    b. Kuinka toimintanne linkittyy potilaskokemukseen?

    Haastateltavaa pyydetään piirtämään näkemys potilaspolusta*

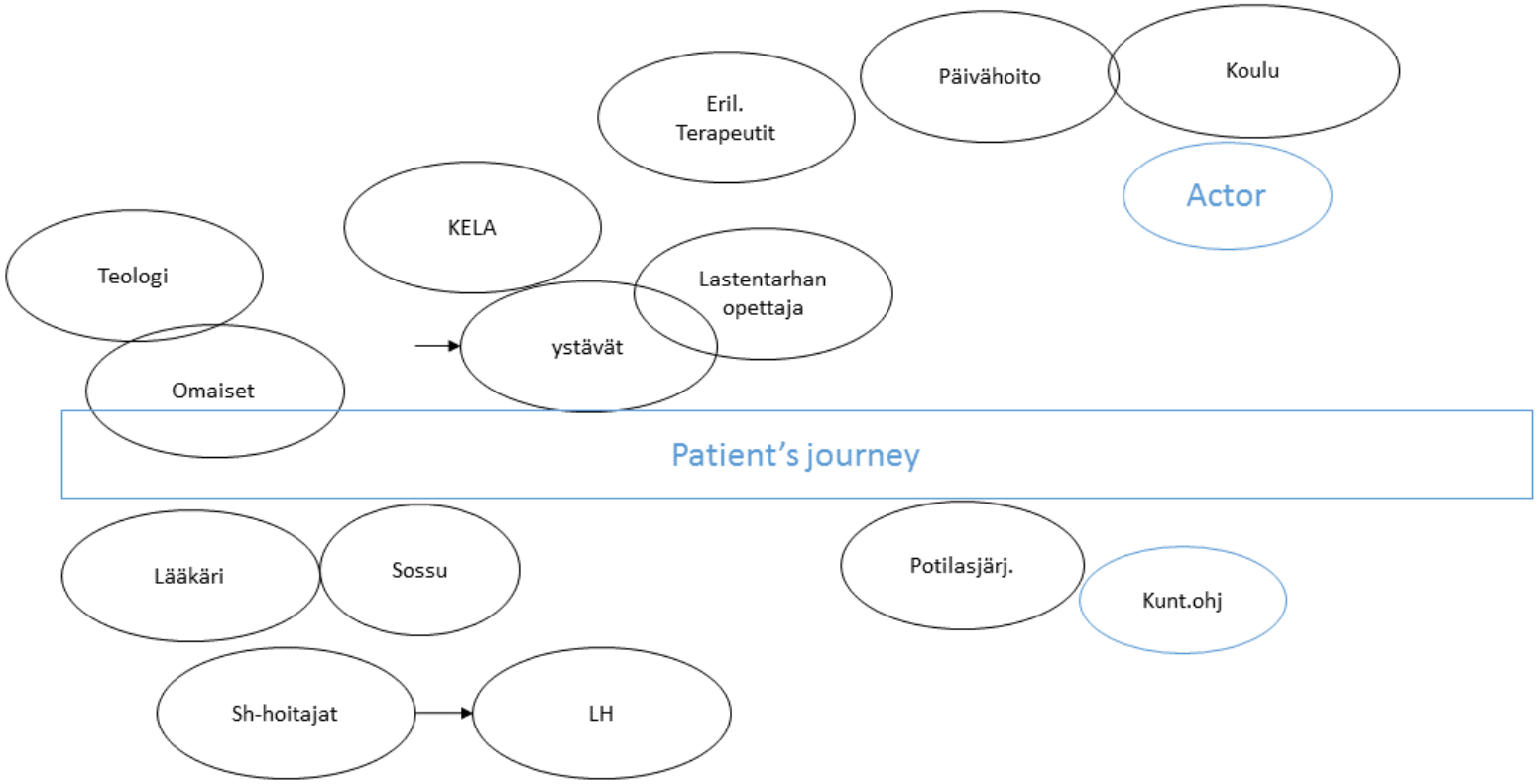
    c. Missä kohdissa potilaspolkua (haastateltavan edustama toimija) kohtaa potilaan/hänen perheensä?
    d. Minkälaisia palveluita tai toimintoja tarjoatte potilaille, ja ketkä toteuttavat nämä palvelut?
    e. Kuinka vaikutatte palveluilla potilaskokemukseen?
    f. Missä potilaspolun kohdissa lapsipotilaan kokemusta erityisesti tehdään?
    g. Miten potilaspolun pituus vaikuttaa potilaskokemukseen?
    h. Mitkä asiat vaikuttavat palveluketjun sujuvuuteen?
4. **Muut ekosysteemitoimijat**
    a. **Haastateltavaa pyydetään täydentämään ekosysteemikarttaa ****: Mitä muita toimijoita (haastateltavan toimijan lisäksi) on mukana potilaan hoitopolulla? / Mitä toimijoita kuuluu potilaan hoitoverkostoon?
    b. Missä kohtaa potilaspolkua nämä toimijat vaikuttavat?
    c. Miten verkoston eri toimijat voivat omalla työllään vaikuttaa potilaskokemukseen?
    d. Miten eri toimijat voivat vaikuttaa potilaiden vanhempien asiakaskokemukseen?
    e. Minkälaisista vaiheista potilaskokemus rakentuu potilaspolun aikana?
    f. Miten verkoston eri toimijat ovat kytköksissä toisiinsa?

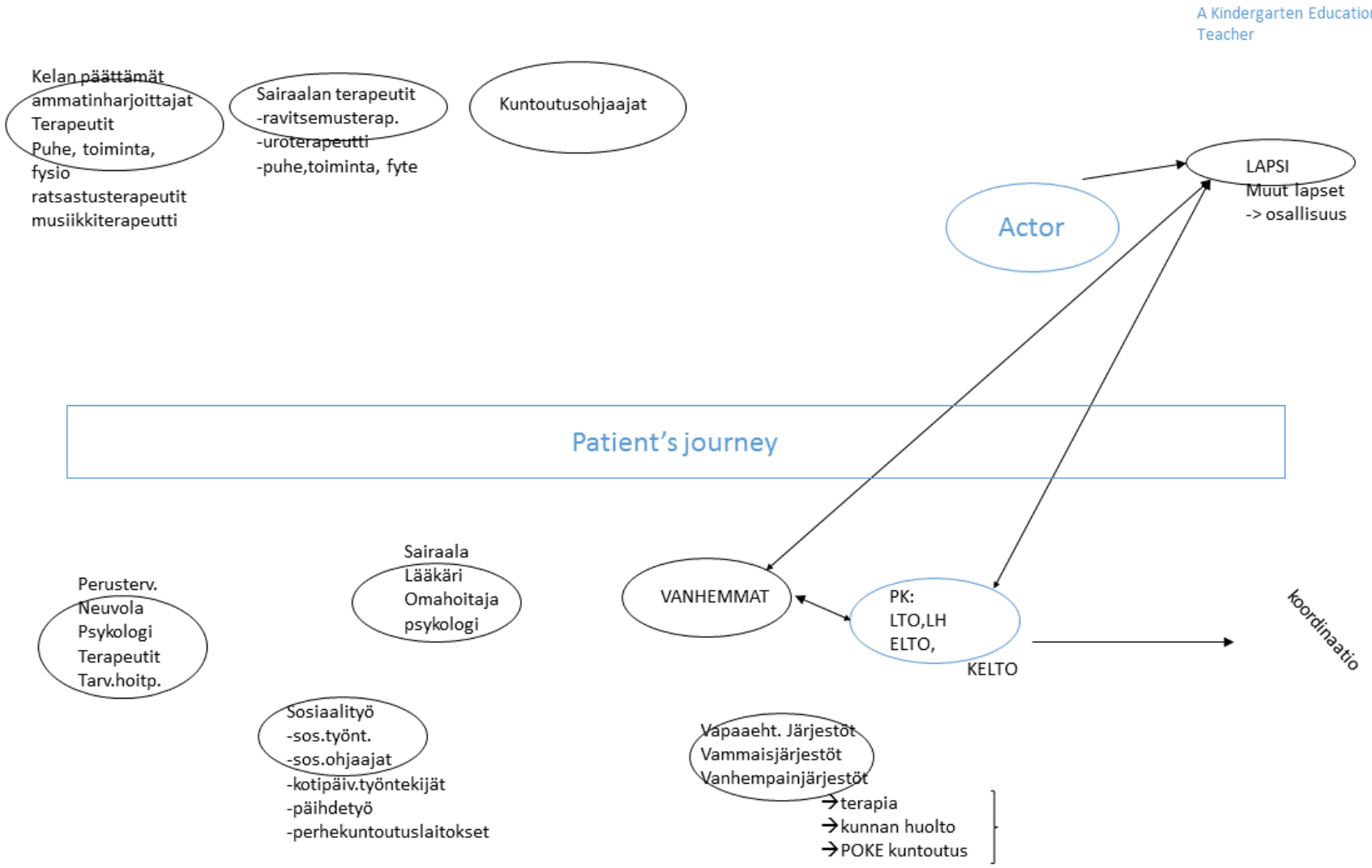
g. Miten verkoston toimijoiden määrä vaikuttaa potilaskokemukseen?
h. Mitkä asiat vaikuttavat verkoston toiminnan sujuvuuteen?
i. Mitä hyvää/huonoa nykyisessä toimintamallissa on?
j. Minkälainen rooli potilaalla itsellään on potilaskokemuksen syntymisessä?

APPENDIX 3: ECOSYSTEM ACTOR DRAWINGS

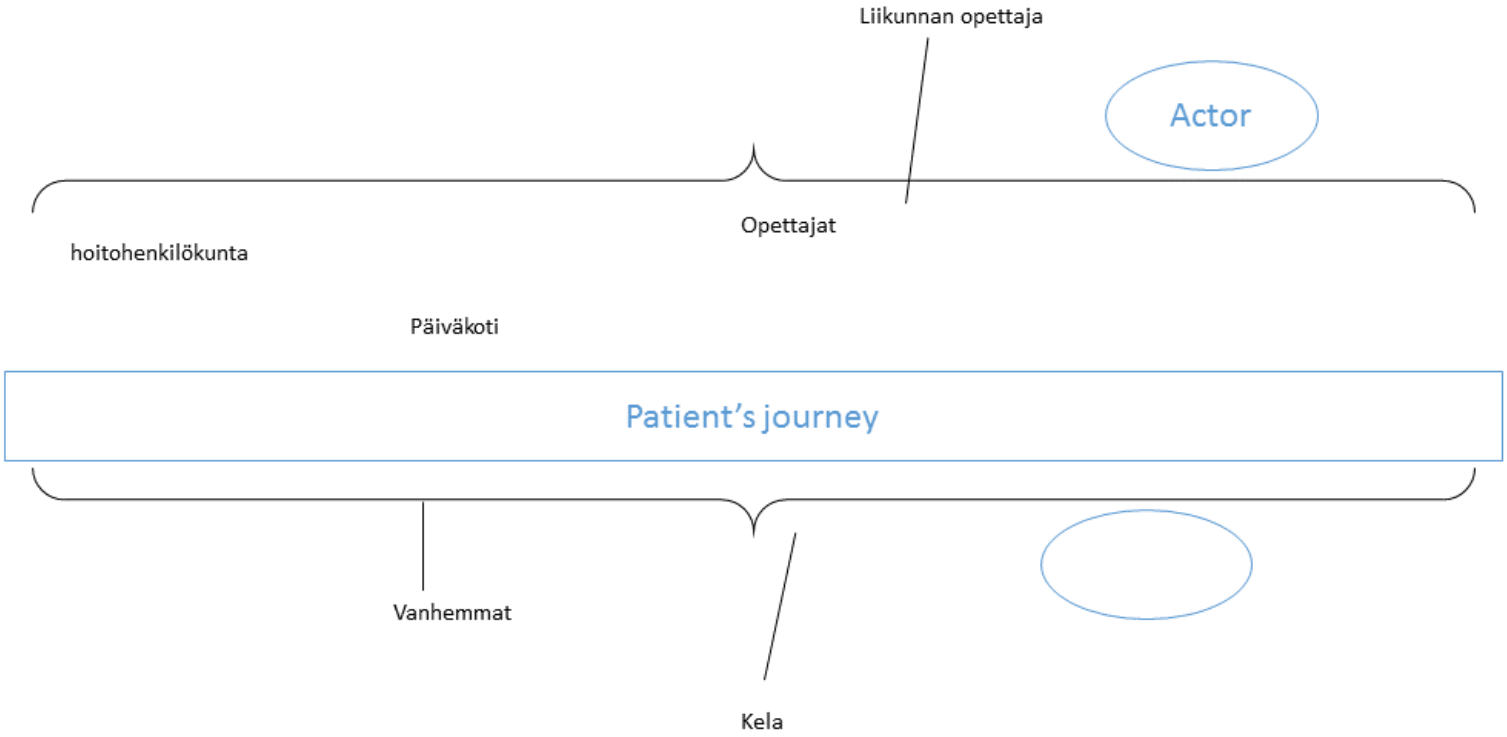

Social worker 2
Ronald Mcdonald
Säätiö (+majoitus)
Lastenklinikan kummit
(pistelennot)
+hotellit
Actor
~~Toimeen~~
aikuissosiaalityö
Lastensuojelu
Maahan muutto
Kela
Omaishoito
Lapsiperh
kotipalvelu
perhetyö
Vammais
palvelut
Patient's journey
Perheen
omat
tukiverkostot
Sairaala
-lääketiede
-hoitajat
-erityistyöntekijät
-psyk.sairaanhoitaja
-pastori?

Rehabilitation councellor




A Kindergarten Education Teacher
Kelan päättämät
ammatinharjoittajat
Terapeutit
Puhe, toiminta,
fysio
ratsastusterapeutit
musiikkiterapeutti
Sairaalan terapeutit
-ravitsemusterap.
-uroterapeutti
-puhe,toiminta, fyte
Kuntoutusohjaajat
LAPSI
Muut lapset
-> osallisuus
Actor
Patient's journey
Perusterv.
Neuvola
Psykologi
Terapeutit
Tarv.hoitp.
Sairaala
Lääkäri
Omahoitaja
psykologi
VANHEMMAT
PK:
LTO,LH
ELTO,
KELTO
koordinaatio
Sosiaalityö
-sos.työnt.
-sos.ohjaajat
-kotipäiv.työntekijät
-päihdetyö
-perhekuntoutuslaitokset
Vapaaeht. Järjestöt
Vammaisjärjestöt
Vanhempainjärjestöt
→terapia
→kunnan huolto
→POKE kuntoutus

Executive director of a third sector society



Chief of family center opertaions of third sector society

Actor

Patient’s journey

APPENDIX 4: INDENTIFIED ACTORS FROM THE ECOSYSTEM ACTOR DRAWINGS

Sphere / organization	Actor

Hospital	• Doctors
	• Children psychiatrics
	• Neuro psychologists
	• Nurses
	  o Practical nurse
	  o Named nurse
	  o Psychiatric nurse
	  o Care staff
	• Different kind of therapists
	  o Dietary therapist
	  o Speech therapist
	  o Urology therapist
	  o Occupational therapists
	  o Physiotherapists
	• Social workers
	• Rehabilitation counselors
	• Infant family workers
	• Teachers
	• Kindergarten teachers
	• Hospital clowns
	• Theologian
	• Hospital pastors

Patient's own support net	• Parents • Grandparents • Next of kin • Friends • Hobbies
Primary Healthcare	• Child welfare clinic • Psychologist • Therapists • Care equipment center
Third sector societies	• Patient societies • Different kind of associations • Ronald McDonald Association • The Association of Friends of the University Children's Hospital • Societies for disabled • Parental societies

Education	• School
	  o Teachers
	  o Physical education teacher
	• Kindergarten
	  o Kindergarten teacher

	○ Child nurse ○ Kindergarten Special education teacher ○ Other children • Day care • Clubs
Social services	• Social Insurance Institution of Finland • Social welfare for the disabled • Child welfare and protection • Service for families with children • Social work for adults • Immigration services • Informal care • Home help service for families with children ○ Home help service worker • Social workers • Social counselors • Drug and alcohol worker • Family Rehabilitation services
Professionals chosen by Social Insurance Institution of Finland	• Therapists ○ Speech therapists ○ Occupational therapists ○ Physiotherapist ○ Horse riding therapist ○ Music therapist
Travelling Agencies	• Flight companies • Hotels

APPENDIX 5: IDENTIFIED ECOSYSTEM ACTORS FROM THE CARE STAFF INTERVIEWS

Actor group	Actors

Pediatrics Hospital	• Doctors
	• Specialized doctors
	  o Surgeons
	  o Cardiologists
	  o Neurologists
	  o Children's and Teenager's psychiatrics
	• Nurses
	  o Named nurses
	  o Children's psychiatric nurse
	• Psychologist
	• Dietary planner
	• Therapists
	  o Physiotherapist
	  o Occupational therapist
	  o Speech therapist
	• Laboratory worker
	• Rehabilitation counselors
	• Social workers
	• Hospital pastor
	• Teachers
	• Kindergarten teacher
	• Other patients
	• Interpreter
	• Hospital equipment
	• Hospital clowns

Patient's own support net	• Parents • Siblings
Primary Healthcare	• Child health clinic
Third Sector Societies	• Social media • The Finnish Kidney and Liver Association • Leijonaemot ry
Education	• School nurse
Social services	• Child welfare and protection
Care equipment	• Dialyzer • Blood pressure meter

APPENDIX 6: IDENTIFIED ECOSYSTEM ACTORS FROM FAMILY INTERVIEWS

Actor group	Actor

Pediatrics hospital	• Doctors
	  ○ Named doctor
	  ○ Pediatrics doctor
	  ○ Rheumatologist
	  ○ Cardiologist
	  ○ Surgeon
	  ○ Neurologist
	  ○ Orthopedist
	  ○ Senior physician
	  ○ Psychologist
	  ○ Anesthetist
	  ○ Dentist
	  ○ Radiologist
	• Nurses
	  ○ Named nurse
	  ○ Head nurse
	  ○ Night nurse
	  ○ Pediatrics nurse
	  ○ Surgical nurse
	  ○ Intensive care unit nurse
	  ○ Dialysis nurse
	  ○ Laboratory nurse
	  ○ midwife
	  ○ diabetic nurse
	  ○ lab nurse
	  ○ psychiatrics nurse
	  ○ line nurse
	• Therapists
	  ○ physiotherapist
	  ○ children's psychotherapist
	  ○ dietary therapist
	  ○ Speech therapist
	• Social worker
	• Secretary
	• Babysitter
	• Hospital teacher
	• hospital kindergarten teacher
	• Attendant
	• Career instructor
	• Leisure activities instructor
	• Hospital clowns
	• Ventilator
	• Cleaner
	• Hospital priest or pastor

	• Other patients and their families
Patient's own support net	• Parents • Siblings • Grand parents • Other relatives • Friends • Hobbies • Other patients and their families

Primary Healthcare	Municipal healthcare
	• Doctors
	  ○ Named doctor
	  ○ Nephrologist
	  ○ Senior physician
	  ○ Psychiatric
	  ○ Cardiologist
	  ○ Orthopedist
	  ○
	• Nurses
	  ○ psychiatric nurse
	  ○ lab nurse
	• Therapists
	  ○ Physio therapist
	  ○ Dietary planner or therapist
	  ○ speech therapist
	  ○ group therapy
	  ○ psychotherapist
	• Social worker
	• Service for disabled worker
	• Care equipment technician
	• Supportive sign language teacher

	Child welfare clinic • public health nurse
Private healthcare	• Company doctor • Private pediatrics doctor • Private specialized doctor

Third sector societies	• Patient Associations
	  ○ Society for heart illnesses
	  ○
	• Associations
	  ○ The Finnish Rheumatism association
	  ○ Kidney and liver association
	  ○ Diabetics association
	• Food information databank
	• Religious societies

Education	• School
	  ○ Teachers
	  ○ Friends

	○ Other pupils ○ School taxi or bus ○ School doctor ○ School nurse ○ Other children with illnesses or disabilities • Kindergarten ○ Kindergarten teacher ○ Other children
Social services	• Social Insurance institution of Finland • Municipal social service system
Consumer communities	• Social media groups ○ Facebook groups • Blogs • Internet forums •
Other professionals	• Alternative health services ○ Chinese medicine doctor ○ Homeopathy expert • Pharmacy
Travelling Agencies	• Transportation ○ Taxis ○ Flight companies ○ Busses • Accommodation ○ Hotels
Care equipment	• Nasal-gastric siphon • Pacemaker • Dialyzer • Body support equipment • Blood pressure meter • Catheter • Hemoglobin sensor • Insulin pen • Insulin pump

APPENDIX 7: IDENTIFIED ECOSYSTEM ACTORS CONCERNING CHILD WITH HEART DEFECT AND DIABETIC CHILD

Sphere / organization	Child with heart defect actors	Diabetic child's actors

Hospital	• Doctors
	  ○ Pediatrics doctor
	  ○ Cardiologist
	  ○ Neurologist
	  ○ Surgeon
	  ○ E.R. doctors
	  ○ otologist
	  ○ eye specialist
	  ○ Rheumatologist
	  ○ Anesthetist
	  ○
	• Nurses
	  ○ Own nurse
	  ○ Lab nurse
	  ○ Midwife
	  ○ E.R nurses
	  ○ Psychological nurse
	  ○ Line nurse
	  ○ Night nurse
	• Therapists
	  ○ Speech therapist
	  ○ physiotherapist
	  ○ Psychologist
	  ○ Diet therapist
	• Social worker
	• Other patients and their families
	• Hospital priest
	• Hospital nanny
	• Cleaner
		• Doctors
		  ○ Named doctor
		  ○ Diabetics specialist
		• Nurses
		  ○ Diabetics nurse
		  ○ Named nurse
		  ○ Lab nurse
		• Psychologist
		• Hospital teacher
		• Leisure activities instructor

Own Support net	• Siblings
	• Grand parents
	• Friends
	• Other families with child with heart defect
	• Parents working friends
	• Neighbors
		• Siblings
		• Grandparents
		• Friends
		• Other diabetic families
		• Hobbies
		  ○ Scout team
		  ○ Football team

Primary Healthcare	• Child welfare clinic
	  ○ Public health nurse
	• Municipal healthcare
	  ○ Cardiologist
		• Municipal healthcare
		  ○ Doctor
		  ○ Nurse

	○ Nurses ○ Psychologist ○ Doctors ○ Physiotherapist ○ Lab nurse ○ Psychiatric nurse ○ Group therapy • Service for disabled worker • Company doctor	
Private sector	• Private pediatrics hospital ○ Rheumatologist	
Third sector societies	• Society for heart defect ○ Peer patients ○ Cardiologist ○ Surgeon ○ Neurologist ○ Psychiatric nurse	• Food information databank • Religious societies • Diabetics Association • Peer support groups
Consumer communities	• Other patients • Facebook-group for the illness • Blogs • Internet forums	• Internet forums • Food information databank
Education	• Kindergarten teacher	• School ○ Teachers ○ Friends ○ Other pupils ○ School doctor ○ School nurse ○ Other children with illnesses or disabilities
Social services	• Social insurance institution of Finland • Municipal social service system	• Social insurance institution of Finland
Other Professionals	• Third sector medical association ○ Doctor ○ Speech therapist	• Pharmacy
Care equipment suppliers	• Nasal-gastric siphon • Pacemaker	• Hemoglobin sensor • Insulin pen • Insulin pump
Travelling Agencies	• Transportation ○ Flight companies • Accommodation ○ Hotels	