

KRISTI PARON

Child-patient autonomy:
interplay between normativity
and relationality



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LIST OF ORIGINAL STUDIES

This dissertation is based on the following original publications which will be referred to in the dissertation by their respective Roman numbers.

- Study I:** Paron, K. (2020). The Child's Autonomy in Decision-Making on Medical Treatment: Theoretical Considerations. *Juridica International*, 29, 124–132.
- Study II:** Paron, K., & Kutsar, D. (2023). Creation of child-patient's autonomy in a child-parent-doctor relationship: Medical doctors' perspectives. *Childhood*, 30 (2), 145–160.
- Study III:** Paron, K. (2024). Exploring Child-Patient Autonomy: Findings from an Ethnographic Study of Clinic Visits by Children. *Child Indicators Research*, 17, 99–121.

Author's Contribution

As the author of this dissertation, I have contributed to these studies as follows:

- Study I:** I am the sole author of the study.
- Study II:** I took the lead in formulating the research questions, producing the theoretical framework, interpreting the results and writing up the article.
- Study III:** I am the sole author of the study.

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INTRODUCTION: THE AIM AND CONTEXT OF THE STUDY

*“The key to world peace and sustainability lies in the way
we collectively relate to our children”
Robin Grille (2005)*

Research from Estonia and elsewhere demonstrates that children often feel that they are not heard in healthcare. Child-patients report, for example, not being given explanations, not understanding what physicians say, not knowing what is going to happen next, not being asked for their consent, or feeling that their opinion did not matter enough (Coyne & Gallagher, 2011; Kilkelly & Donnelly, 2006; Paron, 2018). According to a survey completed in the Council of Europe member states, 60% of children reported that health professionals should talk to children more, and 68% of children found that health professionals should listen to children more (Kilkelly, 2011). Even more strikingly, adults who are the guarantors of children’s rights are often not sure what rights children have as patients. Research in Estonia shows that 40% of adults are either not sure whether a child has the right to be informed about decisions regarding their health and the right to participate in making such decisions, or they even believe that a child does not have such rights (Praxis, 2018). Praxis research also demonstrates that there is a need to raise awareness about the health rights of children, as knowledge about those rights is lowest among adults in comparison to some other rights that were studied, such as the right to have a family and be cared for, and the right to protection by the state.

Even though international rules (UN Convention on the Rights of the Child, CRC) and domestic law in Estonia (*Võlaõigusseadus*) require that child-patients should have a say in matters of their health, respecting child-patient autonomy is a challenging and complex endeavour. The reason for this is the set-up of the autonomy framework created by Article 12 of the CRC, which is dynamic and whereby it is always an adult who decides how much weight a child’s opinion is given. Such a mechanism makes the realisation of the autonomy of children dependent on the training and knowledge of adults about the right children have to autonomy; and more broadly on their social skills. This is a scene where legal rules meet the social reality of everyday lives – where it becomes important to reconcile understandings of the rigid rights-based framework with a sociological approach to children’s lives and wellbeing. How then are the viewpoints between these two approaches different?

The children’s rights framework as envisaged by the CRC is based on the idea that the right of a child to be heard and taken seriously represents a fundamental value (CRC Committee, 2009). The CRC Committee has underlined that a key purpose of the CRC is to emphasise that human rights extend to children (Hodgkin & Newell, 2007). Therefore, the children’s rights framework has given children the status of rights’ holders (Verhellen, 2015). Given legal rights, as

opposed to moral rights, children are given a recognised status that states are bound to protect (Archard, 2015). Under the children's rights framework the full enjoyment by the child of all the rights recognised in the CRC is regarded as being in the child's best interests and ensuring their optimum development and wellbeing (CRC Committee, 2013).

In childhood sociology the central focus is placed on the notion of the agentic child and the child's agency (Corsaro, 2011; James, 2009; James & James, 2004; Mayall, 2002; Mayall, 2015) without really asking what purpose this agency serves (Varpanen, 2019). Children perform their agency in relation to others, mostly adults, and this is what makes agency a relational and intergenerational phenomenon (Alanen, 2014; James, 2005; James, Jenks & Prout, 1998; Mayall, 2000; Mayall, 2015). The relational nature of all societal phenomena has become the central idea for a whole branch of sociology – relational sociology (Powell & Dépelteau, 2013). According to relational sociologists, social change is produced by social relations (Donati, 2015); individuals are regarded as interactants who produce particular effects on one another (Burkitt, 2016), and they do so only in reaction to each-others' sayings and doings (Dépelteau, 2015), which in turn are influenced by their identities and interests (Prandini, 2015). Acknowledging and understanding children's agency, and its relationality, however, does not in itself create more opportunities for children to participate and realise their freedom of choice (Bonvin & Stoecklin, 2014).

In this dissertation I explore child-patient autonomy by bridging the above two frameworks – the legal framework of child autonomy and the relational sociological approach. Hence, from the perspective of its disciplinary boundaries, this dissertation falls within children's rights studies and childhood sociology, and aims, by linking these two streams, to make a step towards a sociology of children's rights. Children's rights, like any other societal phenomena, are socially constructed. Although put down in black and white, children's rights are practiced by human beings in their everyday relations. It is the everyday practice of relevant interactants that shape the content and meaning of rights. Child-patient autonomy is analysed in this dissertation through a relational lens focusing on triadic interactions between the child, the parent and the physician.

My dissertation is inescapably affected by the fact that my disciplinary cradle is legal studies; I am a children's rights practitioner and have worked as a lawyer for more than two decades. This may be viewed either as a limitation or as an advantage. I believe this background has allowed me to enter the field of sociology with openness and an innovative eye, and most of all to achieve interdisciplinarity that is so much needed in childhood studies (Freeman, 2012; Prout, 2005; Punch, 2016) and that is often hindered by the inability to step beyond the frames of our disciplinary homes. My practical experience as a children's rights lawyer has also taught me that legal measures alone cannot improve children's lives. The key to implementing children's rights is training and awareness (Kilkelly, 2017). I share the idea of François Dépelteau that the goal of sociology should not only be interpreting the world but changing it for the better (Dépelteau, 2015). This was my starting point when I entered the academic world with a wish to improve the status

of children in healthcare. Children's autonomy in healthcare and their participation in decision-making has not been studied in Estonia. There also seems to be a consensus among scholars elsewhere that there is a gap in the research into the involvement of children in decision-making, and that future research must study *inter alia* how parents, paediatricians and children negotiate the extent of their involvement (Ruhe et al., 2015), how child-patients interact with their families in decision-making (Pyke-Grimm et al., 2019) and what factors contribute to or inhibit a child's involvement (Moore & Kirk, 2009). There has also been criticism that there is an over-reliance on interviews as a research method (Moore & Kirk, 2009) in research about child-patient involvement in decision-making. Little is known about what actually happens in child-adult communication during clinical visits.

The aim of this dissertation is to gain insight into child-patient autonomy in healthcare. The dissertation is based on three original studies, it sets the following objectives and seeks to answer respective research questions:

Objective 1: To analyse the regulatory framework of child-patient autonomy (**Study I**).

Research question: How do international treaties and Estonian law regulate child-patient's participation in decision-making in healthcare?

Objective 2: To investigate medical doctors' perceptions about child-patient autonomy (**Study II**).

Research questions: How do medical doctors engage with children and parents during appointments, and how do they resolve child-parent disagreement? How do medical doctors involve children in decision-making and what are perceived as obstacles to that? To what extent are doctors aware of the international and domestic regulatory frameworks of child-patient autonomy?

Objective 3: To explore the functioning of child-patient autonomy in everyday medical practice (**Study III**).

Research questions: How is child-patient autonomy exercised in the context of a child-parent-doctor triadic relationship? How is communication between the parties affected by the fact that the patient 'consists' of two persons – the child and the parent (dual patient)?

Methodologically, **Study I** is based on a legal doctrinal study; within **Study II** data was collected via an anonymous web-questionnaire and analysed thematically; **Study III** involved ethnographic observations of clinical visits and the thematic analysis of the collected data.

The structure of this dissertation takes the following format. In the first section of the dissertation I present the theoretical framework by reflecting on the disciplinary boundaries of my dissertation, discussing what it means to think sociologically about rights and elaborating on normative thinking about rights, in particular about child-patient autonomy. In the second section, methodological considerations of the dissertation are discussed. The findings of the studies are presented in the third section, and discussed in the fourth. The dissertation ends with concluding remarks, recommendations and a short summary in Estonian.

1. THEORETICAL FRAMEWORK

1.1 Disciplinary boundaries

This thesis combines the disciplines of children's rights studies and childhood sociology, capitalising on the double expertise of the author and striving towards interdisciplinarity (Darbellay, 2015; Banakar & Travers, 2005). Consequently, the thesis falls within a broader framework of childhood studies – a term that is used for a broad academic field interested in children and childhood (Canosa & Graham, 2020; Tisdall & Punch, 2012) and involving a wide range of disciplines, such as sociology, psychology, history, geography, social policy, law and health (James, 2010). The evolution of the term designating the academic area of interest for childhood sociologists, which includes the sociology of childhood (e.g. Qvortrup, 1987; Mayall, 2000), social studies of childhood (e.g. James, Jenks & Prout, 1998; Qvortrup, 2005) and childhood studies (e.g. Qvortrup, Corsaro & Honig, 2009) illustrates the significance of the study object itself and not the discipline. According to James (2010), the disciplines we hail from should designate which tools and concepts we use when studying children and not that children should be studied within one certain discipline. For a holistic approach towards children and childhood it is important that researchers step out of their “disciplinary homes” so that childhood studies could be a meeting place of ideas (Prout, 2005). However, attempts to move beyond such disciplinary boundaries are still rare (Punch, 2016). With regard to corroboration between researchers of childhood sociology and children's rights studies, Freeman (2012) critically contends that there has been little dialogue.

Following the aspiration for disciplinary “beyondness”, this thesis pairs the sociological approach of studying children with the legal framework of children's rights. The dialogue between these two disciplines is a resourceful platform for understanding children's autonomy in different decision-making situations and contexts. The agency and autonomy of children, regardless of whether they are regarded from a sociological, psychological or pedagogical perspective, are most effectively applied with the help of the law, as the “law is one of the most significant symbols of legitimacy” (Freeman, 2009, p. 381). It is against this background that Freeman (2012) calls for moving towards a “sociology of children's rights”, the idea elaborated also by Bonvin and Stoecklin (2014), when they discuss the importance of studying children's rights from an interdisciplinary angle. This thesis is a step on that journey towards a sociology of children's rights.

1.2 Thinking sociologically about rights

Thinking “sociologically about rights”, to borrow the words of Morrow and Pells (2017, p. 127), means acknowledging that legal norms, and the rights therein, are practiced by human beings in their everyday lives – these rights are claimed, negotiated, disputed, respected and disrespected on a daily basis. Therefore, in

the context of this thesis, acknowledgement of the normative nature of child-patient autonomy – the right to participate in decision-making – is combined with a sociological understanding of those rights in practice. The sociological thinking about rights within this thesis is guided by two approaches to rights: (i) living rights; seeing children as actors in rights realisation processes, and (ii) the relationality of rights.

1.2.1 Living rights

Agency framework versus autonomy framework

The operating of legal rules is shaped by the social and cultural norms of a given society which are not static (Morrow & Pells, 2017). This is why Hanson and Nieuwenhuys (2013) speak about the living rights of children. According to them, children's rights are “an imperfect compromise negotiated at a certain moment in time and in specific contexts by individuals representing different local and organisational interests and possessing different kinds of knowledge, skills and power” (Hanson & Nieuwenhuys, 2013, p. 10). The idea of living rights accords with interpretations of rights as processes (Galant & Parlevliet, 2005; Mayall, 2015; Morrow & Pells, 2017), where the focus is on participation in negotiations in order to reach consensus. In the context of the implementation of Article 12 of the CRC, such a theorisation is particularly relevant as the degree of involvement or participation of a child in decision-making is always a result of negotiations within child-adult power relations. Therefore, it is the power of cultural norms and practices as operationalised by adults that “inhibit adults from implementing children's rights” (Mayall, 2015, p. 85).

The above idea of living rights encompasses the rights holders – children – as key actors in rights realisation processes. In sociological discourse on childhood, an essential characteristic that children as actors present is agency (Corsaro, 2011; James, 2009; James & James, 2004; Mayall, 2002; Mayall, 2015), and under the children's rights framework, children are given power to act through their right to autonomy. There is a fundamental difference in regarding a child as someone who is able to do and who does things (agency framework) or as someone who is entitled to do those things (autonomy framework). However, there is little dialogue between those two discourses (Freeman, 2012; Prout, 2005; Punch, 2016), even though theorisations of those concepts – agency and autonomy – partly overlap. Agency, for example is quite often interpreted as autonomy or self-determination in childhood studies (Frønes, 2016; Kuczynski, 2003; Wyness, 2006). This thesis aims to put the concepts of agency and autonomy into dialogue through a critical account.

James (2009) sums up the change in paradigm in childhood sociology that took place in the 1970s and 1980s with regard to the child's role in society. Before the 1970s, children were mostly regarded as incompetent, incapable and incomplete (*becoming* members of society), whereas the new paradigm saw the rise of a notion of the agentic child and children's agency. The Online Etymology Dictionary refers

to the use of the word *agency* in English from the 1670s as “a mode of exerting power or producing effect,” and the origin of the word is from medieval Latin *agentia*, the abstract noun from Latin *agentem* (nominative *agens*) meaning “effective, powerful”.

It is noteworthy that there is no equivalent to the word “agency” in French or German (Beauvais, 2019, p. 69).¹ In order to understand what “agency” means in childhood sociology, one has to start with works by Giddens, the initiator of the structure/agency debate in sociology (James, 2009; King, 2004). Giddens calls an agent an “acting self” (1984, p. 2). According to him, the human being is a purposive agent who has reasons for his or her activities and is able to reflect (elaborate discursively) upon those reasons. “To be an agent is to be able to deploy (chronically, in the flow of daily life) a range of causal powers, including that of influencing those deployed by others” (Giddens, 1984, p. 14). The ability to “make a difference”, “have effect on others” is thus a key element of human agency, according to Giddens, and this has become a central idea in the work of childhood sociologists (Corsaro, 2011; James, 2009; James & James, 2004; Mayall, 2002; Mayall, 2015). A child as an agent is someone who does something with other people and in doing so has a wider impact on social reproduction (Mayall, 2002). The proof of children being agents is seen in all kinds of measures of ideological control and social interventions that are put in place to regulate children’s lives – if children would not be agents and their actions would have no effect on adults, such regulations would be redundant (James & James, 2004).

During a recent decade, scholars have become critical of the settled theorisations of children’s agency. It has been argued that the agency movement is ethnocentric, classist and hegemonic (Lancy, 2012); that it is mostly used as a slogan without representing an operational concept (Bonvin & Stoecklin, 2014) and that it has been theorised without taking into account its context-relatedness (Greene & Nixon, 2020; Tisdall & Punch, 2012) or inter-relational perspectives (Reynaert & Roose, 2015). Sociological theorisations of children’s agency have also been criticised due to not acknowledging that children cannot perform agency from birth on (King, 2004). Varpanen (2019) and Alanen (2019) ask critically what purpose children’s agency actually serves and how its theorisation serves the progress of childhood studies. Furthermore, Spyrou et al. (2019) argue that agency has been “fetishised” to the point of making it an obstacle to gaining new or alternative knowledge.

When compared to theorisations of agency within the field of childhood sociology, the concept of autonomy in children’s rights studies stands on a strong

¹ There is no settled equivalent for the word *agency* in the Estonian language either. Two terms are mostly used by Estonian researchers – “*agentsus*” (e.g. Vihalemm, T., Keller, M., Kiisel, M., 2013. Kuidas parandada maailma. Kommunikatsioon sotsiaalsete muutuste kujundamisel. Veebiõpik, Tartu Ülikool) and “*toimevõime(kus)*” (e.g. Kõuts-Klemm, R., Kalmus, V., Kutsar, D. et al. 2019. Noored ja ühiskond: osalus, rahulolu ja toimevõime. Riigikogu toimetised 40/2019). The author of this dissertation uses the term “*agentsus*” in Estonian, as the term “*toimevõimekus*” accentuates capacity (*võimekus*) which may overshadow the essential part of agency – namely “having effect” on somebody/something.

normative foundation – every human being’s autonomy is a fundamental principle of all human rights treaties. According to Article 1 of the Universal Declaration on Human Rights (1948) all human beings are born free and equal in dignity and rights. The same principle is anchored in the preamble of the CRC – children must be treated as subjects of their own rights. The freedom to determine one’s own destiny or lead one’s life is also called self-determination in human rights discourse. Children realise their autonomy by participating in decision-making (Article 12 of the CRC).

Against the normative background of human autonomy, which serves the goal of improving people’s lives, especially those belonging to vulnerable groups, the concept of autonomy may be better suited for theorising children’s right and their freedom to make choices for themselves (Sutterlüty & Tisdall, 2019; Daly et al., 2019). Theorisations by childhood sociologists on children’s agency focus on the meaning-making of children’s actions and their *acting selves*. Acknowledging and understanding children’s agency, however, does not in itself create more opportunities for children to participate and realise their freedom of choice (Bonvin & Stoecklin, 2014). Agency depends on opportunities (to act as an agent) and the individual skills of a person (Bonvin & Stoecklin, 2014; Biggeri et al., 2011; Ballet et al., 2011). The participation of children in decision-making is the focal point from which children’s wellbeing can be improved (Ben-Arieh & Tarshish, 2017). The normative basis of autonomy – the right to autonomy – is thus a prerequisite of exercising agency in decision-requiring situations, like, for example, in healthcare, as explored in this thesis.

1.2.2 Relationality of rights

Another essential dimension of sociological thinking about rights focuses on the relationality of rights (Somers & Roberts, 2008). Even though technically the duty-bearers with regard to children’s rights are states (Vandenhole, 2015), on an everyday level children’s rights are honoured or disrespected by individual adults working with children, making the realisation of children’s rights a relational endeavour. This may explain why there is a growing tendency in recent children’s rights scholarship to conceptualise children’s rights, most of all the child’s right to self-determination, as relational (Daly, 2020; Tobin, 2017; Varadan, 2020). Such relationality is most evident in the family context. Parents have the right and responsibility over the upbringing of their children, giving them age-appropriate guidance and direction, taking into account children’s needs and abilities, whereas children have the right to receive care, guidance and nurturing from their parents. Therefore, the rights of children are not to be isolated from their parents and family (Tobin, 2017). Denying such relationality of rights risks harming the interdependency and reciprocity within the family network, as legal instruments alone can never have the ability to arrange social relationships (Reynaert & Roose, 2015).

Child-patient autonomy, although having a normative foundation, emerges as the effect of reciprocal actions reiterated by the social actors involved, as in case of any other social phenomena. Relationality is a sociological approach used in recent years to better conceptualise both children's agency in the field of childhood sociology (Abebe, 2019; Spyrou et al., 2019; Greene & Nixon, 2020) and children's autonomy in children's rights studies (Daly, 2020; Reynaert & Roose, 2017; Tobin, 2017; Varadan, 2020). Spyrou et al. (2019, p. 8) argue that "relational ontologizing signals a shift from childhood as an identity category to the practices which enact it as a particular phenomenon" and such thinking signals a shift from "what childhood is" to "how childhood is done". It has been a common argument of those critical of a *simplistic* theorisation of agency that children's agency is not something that children happen to have, it does not function in a social vacuum but is shaped by interactions and the interdependency between children and adults (Abebe, 2019; Alanen, 2014; Mayall, 2015, Spyrou et al., 2019 Greene & Nixon, 2020). In these relationships, children negotiate and renegotiate their agency on a daily basis, especially within family networks, where parents are more receptive to their children's influence (Abebe, 2019; Greene & Nixon, 2020; Kuczynski, 2003; Kuczynski et al., 2014, 2018).

It is important that children themselves view childhood as relational. As Mayall points out (2000, p. 256):

Whilst Western liberal thinkers have regarded the autonomous, independent moral agent as the highest form of life, children regard relationships as the cornerstone of their lives. It is of crucial importance to them to work with and through family relationships, to care about those who live elsewhere as well as those they live with.

Therefore, children's agency may often be shaped by their desire to sustain family solidarity (Abebe, 2019). Research demonstrates that children assess their quality of life by the quality and meaningfulness of their close relationships (e.g. Bradshaw & Rees, 2017; Casas, 2011; Lee & Yoo, 2015).

The relational sociological approach to social phenomena enables us to get closer to the unique and individual social experiences of people than universal theories do (Dépelteau, 2015). Relationalists view social relations as a reality that produces social change (Donati, 2015), or in other words that produces social phenomena. As Donati has worded it "society is made *by* individuals and not *of* individuals" (*ibid*). Individuals produce particular effects on one another through their relational connections and joint actions, and could therefore be thought of as *interactants*, not just as actors (Burkitt, 2016). When relating to one another, those interactants do not have a single-valued position or status, like being clearly dominant or dominated, being active or passive. "In interrelation, interdependence and interactions with others, interactants are always active and passive, powerful and yet vulnerable to various degrees, acting on others and being acted on by those others" (Burkitt, 2016, p. 336).

In the case of child autonomy in healthcare, three interactants – the child, the parent and the doctor – create child-patient autonomy within their interdependent

actions. All of them do what they do only in reaction to what each of them says or does, and because of the kind of people they are (Dépelteau, 2015). This means that the social relation between interactants is shaped by their “identities and interests, the cultural institutions involved, their networked culture, their interchanges, their strategies, conflicts, struggle for recognition, their reputation management, balance of power, etc” (Prandini, 2015, p. 13). This emergent effect of reciprocal actions forms the very essence of a social relation – “a molecule of the social world” (Donati, 2015).

1.3 Thinking normatively about rights

It is on the basis of the law, giving the child the status of a rights holder, that children (and/or their guardians on the children’s behalf) can claim what they are entitled to. Given legal rights, as opposed to moral rights which children may also have, children are given a recognised status (Archard, 2015) and the state has a duty to guarantee the protection of this status, when necessary with enforcement by police, courts and other institutions. As such, a *legal right* is “stricter, more stable, and more secure than *moral right*” (Biggar, 2020). Therefore, the adoption of the CRC has had a central role in advancing children’s legal status. It is claimed that the CRC has exercised “an extraordinarily pervasive and significant influence on the way in which law- and policy-makers think about the status of children” (Archard, 2015, p. 107), that it has advanced considerably international law on children’s rights (Vučković-Šahović et al., 2012) and most of all, it has given children the status of rights holders (Verhellen, 2015).

1.3.1 The normative foundation of the autonomy of a child as a patient

The child’s right to health is one of the most fundamental rights of a child provided by the CRC (Kilkelly, 2020), the treaty on children’s human rights ratified by all countries in the world, except the USA (Tobin, 2019). Being in good health is a precondition for enjoying all other rights (Kilkelly, 2020). Article 24 of the CRC requires State Parties to recognise the “right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”. The child’s right to health encompasses both freedoms and entitlements, whereas the freedoms include the right to control one’s health and body (CRC Committee, 2013). Even though neither the CRC nor the general comments of the CRC Committee mention patient’s informed consent, it is an established principle of human rights law and medical ethics that informed consent must be obtained from a patient before any medical procedure (Tobin, 2019; Beauchamp and Childress, 2001; Herring, 2018). Both in human rights law and medical ethics the above rule derives from the principle of autonomy. Article 1 of the Universal Declaration of Human

Rights stipulates that all human beings are born free and equal in dignity and rights. The same is emphasised in the preamble of the CRC. In medical ethics, respect for one's dignity and autonomy means that a patient's right to hold views and have personal values is honoured (Herring, 2018) and when making decisions, the patient is not under the control of others and is free from limitations (Beauchamp & Childress, 2001).

The CRC does not address autonomy explicitly. Nevertheless, the principle of human autonomy is tacitly included in the preamble of the CRC, which manifests that everyone, without distinction of any kind, is entitled to all the rights as agreed in the Universal Declaration of Human Rights and the International Covenants on Human Rights. Within the CRC framework, children exercise their autonomy by participating in the process of decision-making according to Article 12 of the CRC (CRC Committee, 2009). Article 12 of the CRC requires that the child who is capable of forming his or her own views must be assured the right to express those views freely in all matters affecting the child, whereby the views of the child must be given due weight in accordance with the age and maturity of the child. Thus, children's autonomy under Article 12 of the CRC is limited (Daly, 2018; Hart, 2008; Reynaert et al., 2009) – it is always an adult who decides how much weight the child's view is given. This is why Alderson (2017, p. 211) puts in question the status of Article 12 as a child's right.

The CRC does not give guidelines on how to assess the child's maturity, leaving it a challenge for practitioners who have to make decisions concerning children (Freeman, 2009; Kilkelly, 2015). However, it is clear from Article 12 of the CRC that age must not be taken alone to determine the significance of a child's view (CRC Committee, 2009). The child's views must be assessed on a case-by-case basis, taking into consideration both the child's age and maturity. The CRC Committee (2009, p. 8) defines maturity as the "capacity of a child to express her or his views on issues in a reasonable and independent manner". Maturity in children can also be understood as being emotionally balanced or fully developed/unlikely to change significantly (Archard, 2015).

Another *tool* that CRC offers to conceptualise the growing autonomy of children is the concept of "evolving capacities" enshrined in Article 5 of the CRC. Article 5 of the CRC stipulates the right and duty of a parent to provide appropriate direction and guidance to the child in the exercise by the child of his/her rights, in a manner consistent with the evolving capacities of the child. The concept of evolving capacities has been theorised as an enabling principle that considers the individual maturation process of every child, through which skills, competencies and understanding are acquired which allows children to take increasing levels of agency in the exercise of their rights, and diminishes parents' rights at the same time (CRC Committee, 2016; Lansdown, 2005). The more the child knows, has experienced and understands, the more the parent (or other legal guardian) has to transform direction and guidance into reminders and advice (CRC Committee, 2009). The paradox of this maturation process or becoming an independent decision-maker is that a child may display immaturity/incompetence in something just because they have been prevented from doing what would give

them such competence (Archard, 2015). In other words, to become an independent and mature decision-maker the child must be given ample opportunity to practice decision-making in supportive and secure conditions (Freeman, 2009; Verhellen, 2015). In addition to that, it is not only the child's innate and acquired abilities and experience that shape their decision-making competence; it is as much dependent on the attitudes of parents and healthcare professionals (Mårtensson & Fägerskiöld, 2008), the information children are given (Adewumi et al., 2001), their disease experience (Pyke-Grimm et al., 2019) and other situational and contextual factors.

Principles involved in Article 12 of the CRC are also stipulated in the Council of Europe's 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (or the Oviedo Convention), which is the only binding international legal instrument on the subject of bioethics. Article 6 of the Oviedo Convention addresses those who are not able to give consent, including children. According to Article 6, it is open to the signatory states to determine the relevant threshold of the capacity of minors. If a minor does not have the capacity to consent to an intervention by domestic law, the intervention may only be carried out with the authorisation of their legal representative (usually a parent). The Oviedo Convention also stipulates that the opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to their age and degree of maturity.

All the above principles are applicable to the autonomy of child-patients and their decision-making in Estonia. Estonia has ratified the CRC and the Oviedo Convention. The general principles of the CRC, such as the obligation to hear the child in any matter concerning them, are also transposed to the Child Protection Act (2014). In addition, the contractual issues related to healthcare services, such as the duty to inform the patient and acquire the patient's consent, are regulated by contract law in the Law of Obligations Act (2001). Subsection 766(4) of the Law of Obligations Act provides:

[I]n the case of a patient with restricted active legal capacity, the legal representative of the patient has the rights specified in subsections (1) and (3) of this section² in so far as the patient is unable to consider the pros and cons responsibly. If the decision of the legal representative appears to harm the interests of the patient, the provider of health care services shall not comply with the decision. The patient shall be given information required by law and shall be informed of the decisions made to a reasonable extent.

The above means that the competence of child-patients (as persons with restricted legal capacity) has to be decided on a case-by-case basis, where the law gives one criterion for assessing competence: the ability to consider the pros and cons responsibly. Therefore, Estonian law uses a concept of children's maturity and

² Subsections (1) and (3) regulate the patient's right to information and the right to give informed consent.

competence that is similar to that in the CRC, which regards maturity as the child's ability to express their opinion in a reasonable and independent manner, and deems such ability as gradually growing (Article 5 of the CRC).

1.3.2 Limitations of the established models of child participation

In the light of the above discussion, Article 12 of the CRC aims to offer a dynamic concept of child autonomy, acknowledging the gradual shift from dependence towards independence in children. The theories surrounding Article 12 of the CRC have been conceptualised therefore as *participation*, the term that is widely used to describe processes which include information-sharing and dialogue between children and adults (CRC Committee, 2009). Such an approach, however, may hinder respecting children's autonomy, as it makes it possible to limit children's involvement to a technical/procedural opportunity of providing input on the matters concerning them. Within this conceptualisation, children are usually seen as participating in decision-making but not as decision-makers. In this way it is overseen that when the child's maturity is comparable to that of an adult, the child's opinion should become paramount in decision-making (Lundy et al., 2019); that is, the child should become the decision-maker.

For long, scholars have tried to envisage the gradual increase of the involvement of children, their *participation*, through various models of child participation (e.g., Hart, 1992; Lundy, 2007; Shier, 2001). In 1992, Hart wrote in his essay that participation "is the means by which a democracy is built and it is a standard against which democracies should be measured" (Hart, 1992, p. 5). He offered a diagram called The Ladder of Participation as a beginning typology for thinking about children's participation in different projects within the public domain (school, community groups, other organisations or informal groups). On this ladder, he visualised eight levels of child participation, starting with "manipulation", where children say and do what adults suggest them to say and do, and ending with "child-initiated, shared decisions with adults", where children have the ideas which they want to realise and invite adults to join them in decision-making. Inspired by Hart's ladder, Shier (2001) elaborated a child participation model omitting the lowest three levels of the ladder (manipulation, decoration and tokenism) that are labelled non-participation. Shier's model envisages five levels of children's participation:

- (1) children are listened to;
- (2) children are supported in expressing their views;
- (3) children's views are taken into account;
- (4) children are involved in decision-making processes; and
- (5) children share power and responsibility for decision-making.

What is missing in Shier’s model, as well as in the other models considered above, is the conceptualisation of a child’s participation as a process that the child shares with his/her parent (or other legal guardian). In real-life situations, especially in healthcare, a child is usually represented by a parent (Paron, 2018). This means that the child and the parent participate in decision-making together vis-à-vis a professional, be it a doctor, social worker or other specialist. Consequently, the child’s participation usually takes place in a triadic relationship – the child, the parent, and the professional – taking the decision in question. The participation models do not engage all participants of the relationship as social actors. This is a limitation of participation models that can be rectified using the relational approach as envisaged in this dissertation.

1.3.3 A triadic relational model of child-patient autonomy – an abstraction

To rectify the above limitations of theorisations on child participation (Article 12, CRC), I propose the following model, as an abstraction, that combines the normative foundation of child autonomy with a relational sociological approach (Figure 1).

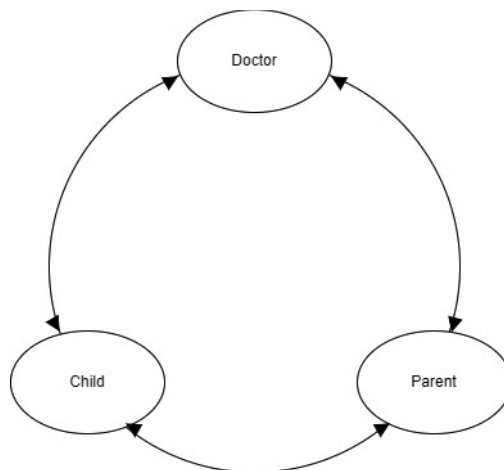


Figure 1. A triadic relational model of child-patient autonomy

This model conceptualises child-patient autonomy as a constant interaction between the child, the parent and the healthcare professional. It considers the relational nature of autonomy, accepts the rights of the child under the CRC – above all the right to self-determination – and is non-hierarchical. It is essential within this model, that each party understands their role and is aware of the rights framework of a healthcare relationship. It is guided by newer concepts of interdependent power asymmetry and acknowledges that both children and adults

have relational resources to influence one another (Kuczynski, 2003). Inspired by Kuczynski's framework analysis of child-parent interaction (2003), this model is neither vertical nor static, but is visualised through circular causality. All three parties to the relationship are involved in communication and negotiations, and their interaction produces the child's autonomy in a constant circulation. Although non-hierarchical, this model is child-centred. Child-centredness means that the adult parties understand and acknowledge that the child is the patient, and both the doctor and the parent support the child's autonomous decision-making by offering advice and explaining alternatives. The child's autonomy grows gradually according to their actual knowledge, experience and understanding (i.e. evolving capacities) where the adult parties gradually reduce their intervention and directions (Articles 5 and 12, CRC). Such a fluid model of autonomy serves the concept of evolving capacities better than models that determine specific stages of a child's consent according to intervals of age limits, as this is regulated in some countries, since it is not possible to draw age-based lines between the stages of independence. Open and trustworthy communication between all parties is a central value of a child-centred relational autonomy model.

An approach to child-patient autonomy that follows the above abstract model carries imminent complexities for real-life practices – guiding and supporting child autonomy in a way that is adjusted to each individual child and their evolving capacities (Article 5 of the CRC) is not an unambiguous exercise. It raises questions about adults' social skills, their comprehension of the basic legal principles of child autonomy and understandings of child development.

2. METHODOLOGICAL CONSIDERATIONS

In this chapter, I will give an overview of the methods used in this dissertation. I describe how the data was collected and analysed, and discuss ethical aspects faced when carrying out the studies, as well the limitations of my research. Awareness and understanding of children's rights in healthcare is low among Estonian health professionals and also within society at large (Paron, 2018; Praxis, 2018). Therefore, the first step in the research was to make a legal analysis of the regulative framework of child-patient autonomy applicable in Estonia (**Study I**, see 1.3). According to binding international principles and national law, medical doctors have the responsibility to assess how much the child should be involved in healthcare decision-making according to the child's maturity and competence. Therefore, the aim of **Study II** was to explore how medical doctors, as key-players in encouraging and enabling children's involvement in decision-making perceive the autonomy of children as patients. Finally, my research aimed to understand how child-patient autonomy functions in everyday medical practice in the triadic child-parent-doctor relationship (**Study III**).

2.1 Legal doctrinal study (Study I)

Study I was based on a legal doctrinal study that forms part of the theoretical framework of this thesis (see Theoretical Framework, Thinking normatively about rights). According to McConville and Chui (2007, p. 4), the aim of the doctrinal study or "black letter" research is to "systematise, rectify and clarify on a particular topic by a distinctive mode of analysis to authoritative texts that consist of primary resources and secondary sources". The uniqueness of standard legal scholarship, when compared to the natural sciences and social sciences, is its prescriptive character (Rubin, 1997) – legal research has to describe and analyse what the law prescribes or in other words how the law reads. "Explaining the whys and wherefors of legal concepts" is an important part of doctrinal research (van Hoecke, 2011, p. 8). Hence, the main activity of a legal researcher is the interpretation of legal texts (van Hoecke, 2011) as was the case in this study.

As the character of legal scholarship derives from the law itself, it has been criticised as rigid and formal, not taking into account the context and social reality (McConville & Chui, 2007; van Hoecke, 2011). Therefore, a remarkable rise in the prominence of socio-legal studies – analysing law in context – can be noted in recent years (e.g., Creutzfeldt et al., 2019; Mulcahy & Cahill-O'Callaghan, 2021; Wheeler, 2020), and that is the approach that is also applied in this thesis. However, a necessary starting point in research concerning a phenomenon framed by law, such as child-patient autonomy, is the legal analysis/doctrinal study of law. Doctrinal legal expertise is of crucial importance for formulating the right research questions (Van Gestel & Micklitz, 2011). The legal analysis within **Study I** was a foundation for the following studies and served the design of Studies II and III.

The originality of this thesis is, among other things, that it combines classical legal research with sociological approaches, aiming to step outside the boundaries of socio-legal study that is traditionally conducted within legal scholarship.

2.2 Survey exploring medical doctors' perceptions (Study II)

Study II aimed to find out how medical doctors engage with children and parents during an appointment (including how they solve child-parent disagreement); how they involve children in decision-making and what are perceived as the obstacles to that; and whether they are aware of the international and domestic regulatory framework of child-patient autonomy. The study was based on an anonymous web-questionnaire that was carried out in 2021. The invitation to participate in the study was distributed via the mailing lists of the Estonian Family Doctors Association and the Estonian Paediatricians Association. The sample was limited to paediatricians and family doctors, as the initial intention was to compare the two largest groups of medical doctors working with child-patients. However, due to the relatively small number of respondents in both groups, it was not possible to compare the two groups in the end. Fifty-two medical doctors participated in the survey. Their service experience mostly varied from 10 to 30 years, 14 doctors had been in service for more than 30 years and 8 of the doctors less than 10 years.

The relational sociological approach to autonomy (see section “Theoretical framework”) served as the conceptual basis for creating the questionnaire. Based on the stages of the healthcare relationship the questionnaire was divided into five thematic blocks:

- (i) getting to know the child/communication with the child;
- (ii) participation of the child in decision-making;
- (iii) taking into account the child's opinion;
- (iv) refusal of the child from treatment;
- (v) a separate thematic block was created regarding cases where a child visits the doctor alone.

The main research question that led the questionnaire was: How is child-patient autonomy exercised in a child-parent-doctor triadic relationship? Therefore, doctors were asked to explain in free wording how they find contact with the child and how they communicate with the child and the parent. In order to find patterns in sharing information with the child and the parent, doctors had to say who they mostly communicate with – either mostly with the child, mostly with the parent or with the child and the parent. As health autonomy is exercised through consent in the decision-making process, the doctors were also asked about the factors that influence child-patient participation in decision-making. Doctors were given a

list of factors and they could add in free-form writing other factors they considered relevant. The questionnaire included 3 types of factors: (1) factors related to the doctor's behaviour, (2) factors related to the parent's behaviour, and (3) factors related to the child's capacities and age. A sliding scale of answers was created – doctors had to choose between “fully agree”, “rather agree”, “rather not agree”, “do not agree” or “cannot say”.

Another conceptual aspect that served the design of the questionnaire was the Estonian legal rule requiring that in order to regard a child-patient able to consent autonomously, they must be able to weigh all pros and cons of the planned medical intervention responsibly. The study intended to analyse how doctors make such an assessment. Doctors were given a list of aspects, and they could add any other aspects they considered relevant. A sliding scale of answers was also given for that question – the doctors had to choose between “fully agree”, “rather agree”, “rather not agree”, “do not agree” or “cannot say”. Doctors were also asked about obstacles to assessing child maturity.

To analyse the gathered data, quantitative and qualitative approaches were combined. Univariate analysis was used to demonstrate the distribution of responses on the agreement scales, while the doctors' responses to open-ended questions were analysed thematically (Braun & Clarke, 2006; 2012) by applying the deductive approach to themes following the themes of the questionnaire and the normative theoretical framework of child-patient autonomy.

2.3 Ethnographic observations of clinical visits (Study III)

To obtain an in-depth understanding of how child-patient autonomy functions in practice, **Study III** focused on observations of clinical visits by children. Ambulatory (outpatient care) appointments with doctors by 29 children and 2 young adults (13 males and 18 females) ranging age from 2 to 19 years were observed within the study. The intention of the study was to include only children (i.e. persons under 18 years of age) in the sample. However, two young adults (aged 18 and 19) visited the children's clinic during the observation. These young adults were included in the sample to enrich the data analysis. Another aim of the study was to observe appointments where a child visited a doctor with their parent(s), to explore the child-parent-doctor triadic relationship. Four young patients, one 15-year-old, two 17-year-olds and one 18-year-old, visited the doctor alone during the observation. They were included in the study as these appointments serve as a valuable reflection point for analysis.

Methodologically, **Study III** is an ethnographic study. Against the backdrop of heavy debates about what ethnography actually means (Delamont & Atkinson, 2021; Hammersley, 2018; Mannay & Morgan, 2015; Walford, 2009), my study aims to be “social research that emphasises the importance of studying first-hand what people do and say in particular contexts” (Hammersley, 2005, referenced in Mannay & Morgan, 2015, p. 169). The study explores the actions and practices of children, parents and doctors in everyday life in the healthcare field (Lüders,

2004), and aims to provide a possibly realist account of those. In simplest terms, the study's aim is production of knowledge (Hammersley, 2002). To gain knowledge about the actual functioning of child-patient autonomy, I entered the site where the social actors – the child, the parent and the doctor meet (Delamont & Atkinson, 2021) and observed their interaction. I regarded observation as a tool that can “help to overcome the discrepancy between what people say and what they actually do” (Mays & Pope, 1995). Followed by this aspiration, I aimed to stay in the background throughout the doctors' appointments.

During the observations I took shorthand notes of the appointments. I did not use any observation protocol with the aim to have an open mindset and observe as much as possible. I rewrote the fieldnotes into thorough transcripts at the end of each day of observations. I did not use video or audio recording in this study, as, based on previous research experience, the patients would have considered it more intrusive on their privacy.

In the process of the data analysis, I interpreted the meaning of the spoken and unspoken child-parent-doctor interactions by verbally describing and explaining it (Atkinson and Hammerlsey, 1998). I analysed the collected data thematically (Braun & Clarke, 2006; 2012) by applying deductive and inductive approaches to identify themes. The themes were guided by Shier's (2001) five-level participation model as a theoretical framework (see also Theoretical Framework). For the purpose of the study, each level of participation constituted one theme. Shier's model was best suited as an analytical tool for this study, as it facilitates a deconstruction of the participation process into procedural fractions or stages, reflecting the exact 'status' of a child's involvement in the decision-making process.

2.4 Self-reflection: ethical considerations and limitations of the study

Two empirical studies, **Study II** and **Study III**, were carried out as part of my doctoral studies. **Study II** did not require approval of the ethics committee as it was based on an anonymous web-questionnaire and targeted professionals within their professional capacities. However, there were several ethical dilemmas that I faced when drafting the questionnaire. First, as I knew from my previous professional experience, child-patient autonomy is a topic that is not very familiar to medical doctors. Moreover, it is a matter causing tension among health professionals as they may feel reproof from not respecting the autonomy of children as required. This may have caused the respondents to provide socially acceptable responses. I aimed to handle the social desirability bias by staying alert to the above considerations when drafting the questionnaire – first of all by wording questions as neutrally as possible and giving doctors the space to explain things in their own words, and add comments whenever they felt it was necessary. In my cover letter addressing the doctors, I emphasised that there are no right and wrong answers, it is their opinion that matters. Furthermore, the respondents remained anonymous when answering the questionnaire.

Study III involved children and was approved by both the Ethics Committee of the National Institute for Health Development and by the legal representatives of the clinics involved. I was faced with multiple ethical dilemmas when planning and carrying out the research. First of all, I knew from my previous research experience that it is very difficult to find medical doctors who would agree to participate in a social study as their everyday work is very intense and they suffer from a lack of time. According to my knowledge, no ethnographic studies involving children have been carried out in Estonian health institutions. Against this background, I struggled with conflicting feelings. On one hand, I would have liked to stay as an observer in the health institutions for as long as possible, I even considered the option of being involved in the everyday work of a health institution as a voluntary non-medical assistant (e.g. a play-pal for hospitalised children). On the other hand, I realised that the whole complexity of data protection issues evoked by such a case would burden and prolong my research disproportionately. My worry was also that I wanted to burden doctors with my presence as little as possible. Furthermore, I knew from my previous experience that it is very hard to find doctors to participate in this kind of research. I approached a children's hospital and a family medical centre to find doctors who would agree to allow their appointments with patients to be observed. Two paediatricians and three family doctors agreed to participate in the study.

A fundamental ethical issue within **Study III** concerned the informed consent of children and parents. I discussed with the doctors how to organise consent procedures in the best way, honouring and respecting the dignity and privacy of the children and parents. Based on doctors' proposals we decided that I would be in the doctor's room when the patient enters, the doctor will shortly introduce me and thereafter I would introduce the research and give the child and the parent the consent/information form to sign. In practice this arrangement worked well. I informed the participants about the purpose of the study and the ethical rules of voluntary consent, the confidentiality of their data and anonymous data processing. With younger children, the parents mostly wished to explain additionally to their children. I stressed repeatedly to the children and the parents during my introduction that they can ask me to leave the doctor's room at any time. I asked all children, regardless of age, whether they allow me to observe their doctor's appointment. The consent forms were signed by the parents and also by any children who were at least 12 years of age, in order to support their autonomy, and based on research evidence that children from 11.2 years and above are competent to decide on participating in research (Hein et al., 2015). To ensure the anonymity of the participants, I did not refer to their personal data either in the fieldnotes or in the full transcripts of the observations. The children were identified in the fieldnotes and in the full transcripts only by their gender and age. The children's medical data and diagnoses were not the focus of the study. Such information was referred to in a generalised way, only if it provides relevant context (e.g., a child with a long history of diabetes is generally well aware of the treatment options – counting carbohydrates in food, checking blood sugar and injecting insulin). To summarise, I was positively surprised about the readiness of children and parents

to allow me to observe their clinical visit, none of the patients approached for the study refused to participate. It also astonished me that most children and parents seemed to forget about my presence right after they starting talking to the doctor. This may be related to the fact that patients are used to having several personnel around them in health institutions, especially those patients who have more experience due to a chronic illness.

Throughout the research I aimed to stay sensitive to the fact that I bring along my own values and experiences from the healthcare field, both positive and negative, as a patient, and as a parent. Within my studies, the avoidance of subjectivity was dealt with by following transparent and documented research procedures. The aim of transparency was also attempted by presenting my results in as neutral and realistic a way as possible in the Overview of Findings section. However, it is an inherent property of qualitative research that it relies on the researcher's subjective perception as a component of the evidence (Flick, Kardoff & Steinke, 2004). This is especially true in ethnography, which is based on subsequent personal reporting by the researcher of what has been observed and perceived (Lüders, 2004).

3. OVERVIEW OF FINDINGS

In this chapter, I will discuss the findings of my original empirical studies (**Study II** and **Study III**). The results of **Study I** form part of the theoretical framework of this dissertation (see 1.3.) and will be summarised in the discussion.

3.1 Medical doctors' perceptions about child-patient autonomy

Study II aimed to obtain knowledge on how medical doctors understand child-patient autonomy, and in practical terms, how they perceive the participation of children in communication and decision-making during clinical visits. First, the study revealed that doctors have limited awareness about child-patient autonomy rights based on international and Estonian law. Over one-half of the doctors said that they knew about the provisions of the CRC and the domestic law regarding the right of children to participate in decision-making, but not enough, while a quarter admitted that they were not aware of such rules. The doctors' answers to the proposed questions and their expressed perceptions of this topic must be analysed against this background.

Doctor-patient communication. For doctors, it is important that both parents and children take active part in communicating during the clinical visit. However, there were only a few doctors whose approach demonstrated focusing mostly on the child in their communication. The study reveals that it is important for doctors that both the child and the parent understand the information shared by the doctor. The doctors' responses also suggest that the child is seen rather as a source of essential information from the medical perspective, and the doctors do not relate the child's involvement in decision-making to their rights as patients. Doctors distinguish discussions (with the child) from decision-making (with the parent). According to the study, doctors base their way of communication with the child primarily on the child's age or capacity.

Factors influencing the child's involvement in decision-making. According to the doctors' responses, the primary determinant of a child's involvement in decision-making is the way doctors communicate with the child. In addition, while some doctors recognised the importance of providing explanations and opportunities for participation, a greater number of doctors placed more significance on the parent's behaviour than their own as a factor encouraging the child's involvement. Most doctors agreed that a child's age and intellectual abilities play a significant role in their participation in decision-making. In contrast, the doctors considered a child's ability to express themselves and their previous health experiences to have less influence on their effective participation.

Assessing children's decision-making capacity. According to the study, child-centred factors are the most significant for doctors in assessing the children's capacity for decision-making. With one to two exceptions, all of the doctors

participating in the study fully agreed or rather agreed that they judge the child's maturity by: the child's ability to understand information she/he is given; the child's ability to form a view based on that information; the child's age; and the child's intellectual abilities. It is noteworthy that the readiness among doctors to trust the parent's judgement on their child's capacities is rather modest. This is surprising since, generally, parents know their child the best and the parents' knowledge of their child would provide valuable information for the physicians. The doctors' perceptions may reflect their understanding that parents would not be able to make an impartial judgement on their child's maturity or would not have enough expertise for a relevant evaluation. Such a suggestion may be supported by the finding of the study that a child's own opinion on his/her maturity is more relevant for doctors than the evaluation of the parent. The fact that a child may visit a doctor alone was also regarded as less relevant with regard to the child's decision-making capacity by the doctors. This is in contrast to practical examples given by doctors of situations where they have based treatment only on the child's consent – all such examples were related to the child visiting the doctor alone, suggesting that such events are of crucial importance in deeming a child capable. Doctors also consider other factors, such as chronic illness and the seriousness of the decision at hand. For example, in situations where a decision could potentially put the child's life at risk or carry high risks, doctors believe that the issue should be discussed more extensively with greater involvement of the parents compared to a simple cold.

Age as a criterion of child's competence/maturity. The study also aimed to explore whether doctors associate a certain age with a particular level of competence in children. In the questionnaire the doctors were asked from which age (on average) children are competent to decide independently (i) on vaccination, (ii) on low-risk medical interventions, and (iii) on high-risk medical interventions. The responses differed considerably but two age limits stood out most prominently with regard to children's decision-making capacity – 16 and 18. Twenty doctors out of 46 found that 16-years-olds are able to decide on vaccinations; 22 doctors out of 46 found that 16-years-olds are able to decide on low-risk medical interventions. Remarkably, the majority of doctors (30 out of 46) found that children are not able to decide independently on high-risk medical interventions, as they associated such competence with 18-years-olds.

Handling child-parent disagreement. In situations where a medical intervention is in question, children and parents may not always be in agreement. The study identified three distinct approaches that doctors take in these situations: (i) child-parent shared autonomy approach; (ii) parent-centred approach or (iii) child-centred approach. In the case of a child-parent disagreement it is most common that doctors ask the child and the parent to discuss the matter among themselves and attempt to reach agreement. However, doctors differ in how they see their role in this process. Some of them take part in finding a compromise or convincing the party that disagrees with their medical opinion. In contrast, some doctors leave the process of finding agreement solely in the hands of the parent and child, indicating their reluctance to interfere in family relations. This study

suggests that some doctors believe they cannot overrule the parent's decision in any cases. These doctors accept the parent's decision in the case of child-parent disagreement. The doctors participating in the study emphasised the role and example of parents in developing the child's ability to take responsibility for her/his own health and wellbeing. In conclusion, according to this study, it is rare that the approach adopted by the doctors would fully support the child's autonomy and their right to make decisions about their health.

3.2 Functioning of child-patient autonomy in a triadic child-parent-doctor relationship

Study III aimed to understand how child-patient autonomy functions in everyday medical practice. Shier's (2001) model of participation was used as an analytical tool, as it facilitates a deconstruction of the participation process into procedural fractions or stages, reflecting the status of a child's involvement in the decision-making process (see also Theoretical Framework). According to Shier's stages of participation, I looked at: (i) whether children are listened to; (ii) whether they are supported in expressing their views; (iii) whether children's views are taken into account, and (iv) whether they are involved in decision-making and share the power and responsibility for decision-making. Within the last stage of participation Shier's levels four and five were explored together in my study, as the collected data did not allow them to be distinguished from each other.

3.2.1 Listening to children

Physical space and proximity. The findings of the study highlight the importance of physical space and proximity in healthcare settings for effective communication between doctors and child-patients. The study demonstrates, for example, that the position of the doctor's desk and chairs in the examination room had a significant impact on how the child and their parent were seated, and on their ability to communicate with the doctor. For example, in cases where the doctor's desk was positioned in such a way that it obstructed eye-contact between doctor and child, direct communication was hindered between them. Conversely, in another case, the doctor had a chair with wheels, which allowed her to easily move closer to the child and facilitate communication. According to the study, the use of computers during appointments has an impact on communication, as doctors have to divide their attention between the computer and the patient. Only one doctor had a nurse present during appointments to assist with documentation, while in other cases, the doctor had to find and insert data themselves, leading to less time for the patient and interruptions during the appointment. For younger children, toys and playful elements played an essential role in breaking the ice and creating a more relaxed environment. In rooms with toy boxes, doctors were able to engage with young children and quickly alleviate their anxiety and fear.

Expressing interest towards the child and willingness to listen. The study demonstrates that doctors generally express interest towards the child. The doctors involved in the study made some introductory remarks or asked general questions to initiate a conversation with the child. In the case of younger children, some doctors showed interest in something the child had, like asking about a toy in the child's hand or complimenting the child's dress or nail colour. A clear distinction could be drawn from the observations that the doctors tended to ask more about the personal lives of the child if the child was a regular patient of that particular doctor. They asked about events that they knew were happening in the child's life, such as trips or sports competitions or graduating from school or kindergarten. This created an informal and friendly atmosphere for the child. The study also shows that doctors are willing to listen to the children when they share their thoughts and concerns. At no time during any appointment did any doctor's behaviour reflect reluctance to listen to the child. Moreover, on several occasions, the doctors showed their willingness to listen to the child even in cases where the parent's reaction tended to suppress the child's self-expression.

3.2.2 Supporting children in expressing their views

Ways of communication. The study revealed that communication between doctors and their child-patients is challenging as the child 'consists of' two individuals: the child and their parent. The doctors faced that challenge by choosing constantly who to address during the consultation: the child, the parent, or both. The study identified two linguistic patterns used by doctors to address the dual patient. Some doctors addressed both the child and parent in the plural form, while others made a clear distinction between addressing the child or the parent by using the child's name or indicating the switch. However, only one out of five doctors had an evident practice of making clear whether she is turning to the child or the parent. The study also found that doctors adapted their communication style based on the age of the child. With younger children, doctors would often bend or squat down to be on the same level as the child. Doctors also used creative ways to communicate with children, such as using pain scales with face images and measuring the child's height by first measuring the parent. My study also demonstrates that parents often guide their children on how to communicate with the doctor, with some encouraging their child's active involvement in discussions, while others hindered it by doing most of the talking themselves and not letting their child answer the doctor's questions.

Encouragement/discouragement of the child by the parent. According to the study, there are considerable differences in parent behaviour with regard to supporting their child's involvement. Although the study demonstrated positive practices from some parents, it also revealed that some parents did not encourage their child's involvement in discussions, and some even hindered it by doing most of the talking themselves or not letting their child answer the doctor's questions, replying to the questions addressed to their children themselves.

Encouragement/discouragement of the child by the doctor. The study found that doctors generally encourage children to be involved in the consultation by opening the discussion with an invitation to the child to express themselves. However, there are practices that do not support the child's involvement. For example, some doctors asked closed questions from the child (e.g. "Do you feel well?") or asked about something in a negative form, such as "Doesn't it hurt here?". Another practice, found by the study, that does not support the child in expressing their views is directing a question to the parent instead of a teenage child.

3.2.3 Taking children's views into account

Children's negotiations with adults. The study revealed that children are not just passive recipients of information and instructions, instead they quite often disagree or are reluctant to comply; for example, when taking samples was proposed during the doctor's appointments. Children's responses in cases of disagreement about medical procedures were either negotiations or resistance. However, in most cases of disagreement, parental decision-making ultimately prevailed, indicating that the parents held the dominant power in the dual patient relationship.

Who decides whether the child's opinion is taken into account? In a triadic child-parent-doctor relationship, taking the child's opinion into consideration is not a straight-forward exercise. The parent has parental power and responsibility towards the child and the doctor has professional medical authority towards the dual patient. In such a situation, a doctor's view may clash with the parent's view as to what is best for the child or whether the child's opinion should be considered. This study demonstrated that in situations where the doctor asked about procedural issues (a new appointment, taking samples), it was most often the parent who decided whether to take the child's opinion into account, not the doctor. This demonstrates that the doctor accepted parental authority as a decisive factor, and were reluctant to intervene.

3.2.4 Involving children in decision-making processes, sharing power and the responsibility for decision-making

Presence of the decision-making phase. The findings of my study suggest that it is rare that doctors clearly tell children that decisions about treatment have to be made and they have a say in this. Decision-making as such was hardly ever clearly addressed during clinical visits. However, this may be characteristic to healthcare decision-making in general, not only in child healthcare. The routine practices of only one doctor reflected that the doctor evidently addresses decision-making (verbally) and invites the child to be involved in the decision-making.

Illusory involvement in decision-making. The findings reveal that involving children in decision-making may sometimes be expressed verbally by adults without the readiness to actually give weight to the child's view. There was an

incident where a 7-year-old boy was offered a choice to decide on his vaccination (in words) by the parent and the doctor, but when the child opposed the vaccination, then ultimately the father made the decision for him. While it may be acceptable and lawful that parents take decisions for their children (until a certain age), it is important to give children a fair account of whether they truly have a choice or not.

Decision-making when the child visits the doctor alone. The study shows that the instances where a child visited a doctor alone were the only occasions where the child clearly shared power and responsibility for decision-making with an adult specialist. It must be kept in mind, however, that it may have been “forced” involvement, as there was no other option since the parent as a possible counterpart was missing. However, a previous study (Paron, 2018) shows that in cases where a child visits a doctor alone, one of the strategies used by doctors is to postpone decision-making or contact the parent (e.g. via telephone) to discuss treatment. Therefore, it may have been a well-considered choice by the doctors to share decision-making with the child only. It is also important that in both cases where the doctor and the child made the decision together, the child was a regular patient of the doctor which made assessment of the child’s maturity easier.

4. DISCUSSION

Thesis 1: Child-patient autonomy is a relational phenomenon

The right to autonomy or self-determination is one of the most fundamental human rights. As analysed in **Study I**, children exercise this right by participating in the process of decision-making according to Article 12 of the CRC. This norm requires that the child who is capable of forming his or her own views must be assured the right to express those views freely in all matters affecting the child, whereby the views of the child must be given due weight in accordance with the age and maturity of the child. Therefore, in child healthcare, children must be allowed to participate in decision-making about their health. However, the amount of involvement depends on the age and maturity of the child, and in health decisions also on their ability to understand medical information and weigh the pros and cons of the proposed medical intervention. The above abilities of the child are assessed by adults. This renders the child right to autonomy limited (Alderson, 2017; Daly, 2018; Hart, 2008; Reynaert et al., 2009) and means that the realisation of child-patient autonomy is a process of constant interaction between the child and the adults – in the case of healthcare, the health professional and the parent(s) as was demonstrated by **Study II** and **Study III**. The findings of this dissertation (**Study II** and **Study III**) confirm that child-patient autonomy is a relational phenomenon. The child, the parent and the health professional are interactants who generate a triadic relation wherein they produce particular effects on each other and each other's behaviour through their relational connections. These findings are in accordance with relational conceptualisations of children's agency and autonomy (Abebe, 2019; Alanen, 2014; Alderson, 2007; Daly, 2020; Greene & Nixon, 2020; Kuczynski, 2003; Kuczynski et al., 2014; Kuczynski et al, 2018; Reynaert & Roose, 2017; Tobin, 2017; Varadan, 2020) and the relational sociological approach (Burkitt, 2016; Dépelteau, 2015; Donati, 2015; Prandini, 2015).

As demonstrated by **Study II** and **Study III**, doctors adjust their behaviour according to the child's age, capacities and expressive ability and also according to the degree of parental intervention in the patient-doctor relationship; the behaviour of children is influenced by the doctor's social skills and ways of communication, and also by their parents' parenting practices and the child-parent relationship dynamics. Parental behaviour in turn depends on communication patterns they have with their children, and also the power dynamics between the parent and the doctor. The above is in conformity with Prandini's (2015) position that the social relation between the participants, in this case the child, the parent and the doctor, as interactants is shaped by their identities, attitudes, values, communication strategies etc. It also resonates with Dépelteau's (2015) viewpoint that all parties to a social relation do what they do only in reaction to what each of them says or does. Therefore, child-patient autonomy is "made of" elements

that come partly from the health professional, partly from the parent and partly from the child (Donati, 2015). The interactions between those three counterparts constitute the very essence of child-patient autonomy. Therefore, child-patient autonomy can never be the same, it is constantly changing, and is uniquely shaped by the participants of the healthcare relationship and their personal characteristics.

Thesis 2: The child-patient's right to autonomy is a "living right" that is continuously shaped by the parties to the healthcare relationship

In this dissertation child-patient autonomy is analysed as a social phenomenon and as a right. The bridging of those two approaches must consider relationality and normativity as united. The aspects of relationality, as discussed in *Thesis I* above, shape the right of the child to be autonomous. The findings of this dissertation (**Study II** and **Study III**) demonstrate that the child-patient's right to autonomy is not simply a rule expressed in black and white, rather it is a living "instrument", shaped by people who have to apply this rule in the every-day social reality. This accords with the concept of living rights (Hanson & Nieuwenhuys, 2013; Morrow & Pells, 2017). According to Hanson and Nieuwenhuys (2013), children's rights are always a compromise that is negotiated in a specific situation, in a specific context by individuals with different levels of knowledge, skill and power. Even though the CRC respects children as subjects of rights, it is within the operational scheme of Article 12 of the convention that it is always an adult who decides the appropriate level of involvement of the child in decision-making (**Study I**). Therefore, implementation of Article 12 functions as a constant process of negotiation.

The findings of **Study III** suggest that children often disagree or argue with adults about what is proposed during doctor's appointments, whereas their main strategies are either negotiations or resistance. Those findings are in conformity with the theoretical position that children negotiate and renegotiate their agency on a daily basis, especially within family networks, where parents are more receptive to their children's influence (Abebe, 2019; Greene & Nixon, 2020; Kuczynski, 2003; Kuczynski et al., 2014, 2018).

The results of **Study II** and **Study III** also demonstrate that parents hold the dominant power in the dual patient relationship. Those findings conform with the position of Kuczynski et al. (2014) that parental effectiveness as an agent is supported by their knowledge of the child. The findings of **Study II** suggest that doctors tend to accept parental authority as a decisive factor in the case of child-parent disagreement, and they are reluctant to intervene in such situations. However, strategic communication by the doctor that specifically addresses a child may increase the child's involvement, regardless of the parent's restrictive practices (findings of **Study III**). This, in turn, indicates that being equipped with

good social skills and communication techniques, doctors may be able to affect parental behaviour and child-parent dynamics. The crux lies in finding the right balance of child involvement – giving the child too much autonomy that does not accord with their level of maturity and competence may render the child helpless and vulnerable, the same may occur by excessively limiting the child’s autonomy. What is important is the goal in the process of realising child autonomy (Article 12 of the CRC), which should be to maximise the child’s capacity, not the reverse.

Thesis 3: In child-healthcare, patient autonomy is exercised by a “dual patient” in a triadic relationship

The uniqueness of patient autonomy in child healthcare is that it usually involves a dual patient, as the patient is represented in most cases by two individuals – the child and the parent(s). This makes functioning of patient autonomy a complex relational process and renders acknowledging and honouring patient autonomy a challenging exercise for a health professional. The findings of this dissertation (**Study II** and **Study III**) demonstrate that patient autonomy in child healthcare is not clearly attributed to either the child or the parent by the doctor, but is shared between them; patient autonomy is exercised by a dual patient. Such duality, however, is not reflected in the participation models established in children’s rights scholarship (e.g., Hart, 1992; Lundy, 2007; Shier, 2001). The child-adult interaction in those models could be visualised as an axis having the child at one end and an adult at the other, who then together go through several stages on this axis, this process culminating with a decision concerning the child that the adult has to take. However, the child is not faced with a decision-making adult, be it a health professional, a judge or a social worker, alone. Instead, the child is represented by his/her parent, as a general rule. This creates a triadic relationship between the child, the parent and the professional with multiple and sometimes contradictory roles for the adult parties in the relationship, as suggested by **Study II** and **Study III**.

Looking at the doctor-patient relationship from the medical professional perspective, the doctor bears responsibility towards the patient, based on medical ethics and professionalism. The patient, in this dissertation, consists of two individuals, the child and the parent (dual patient). This means that the doctor bears a professional duty towards both of them. When using Shier’s five-level participation model (2001) as an example, and adjusting it to the reality of a healthcare relationship (**Study III**), the responsibilities within each participation level should be rephrased respectively, identifying the doctor as the primary duty bearer (see **Table 1**). However, when looking at the doctor-patient relationship as one between the child and the adults, using the normative guidance of the CRC principles (**Study I**), the adults should be identified as duty-bearers towards the child in this example (see **Table 1**).

Table 1. Patient-orientated approach compared to child-orientated approach in a triadic healthcare relationship

Patient-orientated approach	Child-orientated approach
Doctors listen to the child and the parent	Doctors and parents listen to the child
Doctors support the child and the parent in expressing their views	Doctors and parents support the child in expressing his/her views
Doctors take into account the views of the child and the parent	Doctors and parents take into account the child's views
Doctors involve the child and the parent in decision-making processes	Doctors and parents involve the child in decision-making processes
Doctors share power and responsibility for decision-making with the child and the parent	Doctors and parents share power and responsibility for decision-making with the child

Table 1 emphasises and explains the complex roles that the adult parties, health professionals and parents, have in a healthcare relationship. It could serve as an educational tool that helps to understand and acknowledge the responsibilities (**Study I**) that adults have in supporting children's autonomy and enabling children to practice autonomy in a safe environment and a transparent framework. The findings from **Study II** and **Study III** allow us to suggest that the practices of healthcare professionals in Estonia follow the patient-orientated approach rather than the child-orientated approach. Even though the patient-orientated approach acknowledges the reality of the dual patient, the thinking about child-patient autonomy should also encompass understandings of the shared responsibility of adult parties towards the child and towards maximising the capacity of the child. The child-orientated approach pinpoints the importance of cooperation between the health professional and the parent. This relationship builds on, *inter alia*, the professional authority of the doctor and parental authority of the parent. These must be carefully balanced. The doctor, having professional authority and expertise, can encourage the parent to consider the child's position and may be the only person in a position to do so. Moreover, Article 12 of the CRC and Article 766 of the Law of Obligations Act, may oblige doctors to favour the child-patient's right to autonomy over parental rights in certain situations. Hence, a doctor's distancing from a child-parent disagreement raises both an ethical and legal dilemma. If the doctor considers the child capable of deciding autonomously and the child's choice is justified from a medical point of view, it may be unethical or even illegal (under Estonian law) to leave the resolution of the issue to the sole discretion of the child or parent. The doctor is a professional who should be aware of the law governing child-patient autonomy. Therefore, the child's autonomy will depend, *inter alia*, on how the doctor and parent resolve their power relations and how the doctor's professional authority and medical expertise balance against parental authority and knowledge of the child.

Thesis 4: Child-patient relationality does not contradict its normativity

When applying the relational approach to child-patient autonomy, it is important to ask critically whether such an approach could harm the whole idea of child autonomy rendering it a flexible instrument in the hands of adults only. I argue that the relationality of child-patient autonomy does not contradict its normativity. This dissertation applies the relational approach to child-patient autonomy and does not dispute the universal applicability of children's rights as provided by the CRC and Estonian law. On the contrary, relationality is theorised in this dissertation as an enabling and empowering concept, which emphasises the responsibility of adults to allow and guide children's autonomous decision-making within reciprocal interactions. Applying Articles 12 and 5 of the CRC and Article 766(4) of the Law of Obligations Act (as analysed in **Study I**) is in itself a relational process. The more the child knows, has experienced and understands, the more the adults surrounding the child have to transform direction and guidance into reminders and advice. Finally, in order to become an independent decision-maker, the child must be enabled to practice decision-making, interacting with the adults.

Nevertheless, the approach that honours the normative foundation of child-patient autonomy and simultaneously acknowledges its relational nature, must be applied with caution and be based on knowledge about children's rights, child wellbeing and child development. On one hand, there is evidence that the fulfilment of an innate psychological need for autonomy directly impacts the health and wellbeing of human beings (Ryan et al. 1997; Ryan & Deci, 2000), and more specifically that supporting children's autonomy, by involving them in decision-making about their health, increases their self-esteem, reduces their fear and makes them more satisfied with their treatment (Adewumi et al., 2001; Kelly et al. 2017). On the other hand, research demonstrates that children assess their quality of life by the quality and meaningfulness of their close relationships (e.g. Bradshaw & Rees, 2017; Casas, 2011; Lee & Yoo, 2015). Hence, maximising the child's autonomy should not come at the cost of deteriorating the child's relationship with their family. However, the aim of saving the child's relationship with their family should not justify disrespecting the child's autonomy in the framework of their evolving capacities or leave children under the arbitrary power of their parents.

Finally, applying the relational approach to child-patient autonomy should not lead to paternalistic attitudes and practices towards children. Children's rights would lose their value if there is always someone superior, an adult, deciding whether the child is allowed to exercise their right or not, or whether a certain contextual reality upholds the right. Therefore, the starting point in any conceptualisations of children's rights should be respect for the child's autonomy that is a core value of human rights.

CONCLUSIONS

I think it is generally true that sociology does not discover what no one ever knew before, in this differing from natural sciences. Rather, good social science produces a deeper understanding of things that many people are already pretty much aware of. (Becker, 2008, cited in Dépelteau, 2015)

This interdisciplinary thesis explores child-patient autonomy by bridging the normative framework of child autonomy and the relational sociological approach. Children's rights, as any other societal phenomena, are socially constructed; it is the everyday practice of social relations that shape the content and meaning of rights. Child-patient autonomy is analysed in this dissertation through a relational lens focusing on triadic interactions between the child, the parent and the physician. By doing so, a deeper understanding of the inner dynamics of those three parties is gathered that enables to draw conclusions and make recommendations for healthcare policymaking.

The right to autonomy is one of the most fundamental human rights. Children exercise this right by participating in the process of decision-making according to Article 12 of the CRC. Even though the CRC respects children as subjects of rights, it is within the operational scheme of Article 12 of the convention, as well as within the rules of Article 766(4) of the Law of Obligations Act, that it is always an adult who decides what is the appropriate level of involvement of the child in decision-making according to their age and maturity (**Study I**). This renders the child's right to autonomy limited (Alderson, 2017; Daly, 2018; Hart, 2008; Reynaert et al., 2009) and makes it highly dependent on adult attitudes and behaviour (Darabos et al., 2021; Mårtenson & Fägerskiöld, 2008; Pyke-Grimm et al., 2019). Therefore, this dissertation focused on the behaviour of the parties to a healthcare relationship and aimed to understand perceptions of healthcare professionals about child-patient autonomy. Child-adult interaction is also central to the model – an abstraction, that I propose in this dissertation for child-patient autonomy that combines the normative foundation of child autonomy with the relational sociological approach (**Figure 1**). Within this model, all three parties of the healthcare relationship are involved in communication and negotiations, and their interaction produces the child's autonomy in a constant circulation. The child's autonomy grows gradually according to their actual knowledge, experience and understanding (i.e. evolving capacities), where the adult parties gradually reduce their intervention and directions (Articles 5 and 12, CRC).

The findings of my original studies (**Study II** and **Study III**) demonstrate that child-patient autonomy functions as a process of constant interaction between the child, the parent(s) and the healthcare professional, making child-patient autonomy a relational phenomenon. The child, the parent and the healthcare professional are interactants who generate a triadic relation wherein they produce

particular effects on each other and each other's behaviour through their relational connections.

It is noteworthy that healthcare professionals themselves perceive child-patient autonomy as relational (**Study II**). For doctors, it is important that both parents and children take an active part in communication during the clinical visit and understand the information shared by the doctor. The findings allow to suggest, however, that the doctors often distinguished discussions (with the child) from decision-making (with the parent). When asked about factors that influence the child's involvement in decision-making, the doctors acknowledged the importance of their communication style as the primary determinant. The doctors' communication style, in turn, is primarily determined by the child's age and capacities.

This dissertation contributes to better understanding of the functioning of child-patient autonomy by exploring how it is practiced within everyday clinical visits. The findings of **Study III** demonstrate that the child's participation journey starts from the conditions created by the physical space in healthcare institutions (safe environment) – the room design and allocation of furniture and seating arrangements may either support or oppress the child's autonomy and opportunity to be involved in healthcare discussions and decision-making. Furthermore, the ways of communication and even linguistic patterns used by healthcare professionals may have an essential impact on the child's opportunity to exercise patient autonomy. As demonstrated by **Study III**, addressing the child and the parent jointly with “you” in plural (Estonian *teie*), and asking closed questions, may not encourage children to respond. In addition, a clear verbal indication of decision-making, and inviting a child to participate in this, is rare. The study also suggests that it is rare that doctors clearly tell children that decisions about treatment have to be made and that they have a say in this, making it difficult for children to exercise their autonomy as patients. One of the most valuable findings of this dissertation is that parents, their behaviour and parenting practices essentially affect the exercise of child-patient autonomy. The parents often guided their children on how to communicate with the doctor, with some encouraging their child's active involvement in discussions, while others hindered it by doing most of the talking themselves and replying to questions addressed to their children. The parent's role is also decisive in cases of child-parent disagreement. In most cases of child-parent disagreement, parental decision-making ultimately prevailed, indicating that parents held the dominant position of power in the dual patient relationship. **Study III** showed that doctors accepted parental authority as a decisive factor, and they were reluctant to intervene in this. This was confirmed by the findings of **Study II**, where the doctors reported that in cases of child-parent disagreement it is most common that they ask the child and the parent to discuss the matter among themselves and attempt to reach agreement.

In conclusion, the findings of my dissertation highlight many positive practices of healthcare professionals and parents that support children's involvement in healthcare discussions and decision-making. However, my dissertation also pinpoints main challenges to the exercise of child-patient autonomy, such as low

awareness of children's rights, insufficient social skills of doctors and parents, and some autonomy limiting practices by adults, including the overuse of parental power.

The findings and postulations of my dissertation are relevant not only in the Estonian context. Although the socio-cultural context plays an essential role in human behaviour, studies made elsewhere about children's involvement in health-care decision-making (Adewumi et al., 2019; Coyne & Gallagher, 2011; Mårtensson & Fägerskiöld, 2008; Pyke-Grimm et al., 2019) make it possible to suggest that the core issues with regard to child-parent-doctor interaction are similar. Therefore, the deeper understanding of child-patient autonomy presented in this dissertation offers a valuable insight for researchers and practitioners elsewhere. It provides an original account of how child autonomy functions in a triadic child-parent-doctor relationship and how autonomy is exercised by a *dual patient* (my original term, inspired by the needs of my study). Furthermore, my dissertation contributes to the broader theoretical debate and better understanding of child autonomy in general, as the theoretical framework and discussion of this dissertation are relevant not only in healthcare, but also in any other contexts in children's lives. I also hope that with my work throughout the last four years I have managed to raise awareness about child-patient autonomy and make health professionals, students of medicine and social sciences, and other members of society better understand what it means to respect child-patient autonomy and why this is good for children.

Further research could concentrate on the practices of a larger variety of healthcare professionals, including nurses who are often the main contact point for patients in hospital settings, the school environment and family medicine. There is also a need to study the possible institutional obstacles that may diminish the realisation of child-patient autonomy within health organisations. An indication of such structural complexities (furniture arrangements not considered in health institutions, limitations of appointment times, the use of computers by doctors limiting communication, etc.) also emanated from this dissertation.

RECOMMENDATIONS

The above conclusions guide my recommendations for improving policy and practice regarding child healthcare and child-patient autonomy:

1. Encouraging the involvement of children in healthcare discussions and decision-making should start by creating a safe space for children in clinics and by thinking through all the aspects of the child-patient's journey in the clinic. First, room design itself may have an essential effect on children – where they can sit, whether they can sit next to their parent(s), whether the allocation of furniture contributes to direct contact between the healthcare professional and the child or hinders it, are there toys for younger children, etc.
2. Clinics should have clear routines in place with regard to the use of computers during a visit, as this affects whether attention is given to the child and how. For example, assistance by the nurse in adding necessary information to the digital health records would allow doctors to offer more attention to children.
3. Guidelines about child-friendly and age-appropriate ways of communication in healthcare should be developed via the interdisciplinary cooperation of institutions responsible for providing medical education and assuring healthcare quality. Those guidelines should encompass among others how to address children, which questions can be asked and which should not be asked of children of certain ages, what are age-appropriate choices, how to involve younger children who may not be able to express themselves verbally, and above all, how to support child-patient autonomy. A good example in this respect is the Handbook of Interviewing Children, *Lapse küsitlemise käsiraamat* (Liivamägi-Hitrov & Kask, 2016) developed for practitioners working with children in court proceedings and published by the Ministry of Justice.
4. All curricula in the field of medicine should include teaching on patients' rights, including child-patients' rights and on the assessment of child-patients' decision-making capacity. In addition, the curricula should include social skills education, as patient autonomy is exercised within human relationships. It is emphasised in the Medical Ethics Manual of the World Medical Association (2005) that good communication skills must be developed and maintained with conscious effort and periodic review.
5. Healthcare professionals should be offered training on child-patient rights and on the assessment of child-patients' decision-making capacity. Such training should focus, among others, on practical aspects of decision-making in a triadic child-parent-doctor relationship and include the development of the social skills of healthcare professionals.
6. State policy should target awareness raising among the wider population, especially children and parents, about child-patients' rights, peculiarities of child-patient autonomy, and about the importance of supporting children's

agency and autonomy and the benefits thereof. This could be done within a wider framework of increasing health literacy as proposed by the Council of Europe (2023) for assuring equitable access to healthcare in order to empower all people, including those in vulnerable situations. There are several ways to raise awareness of these matters. One effective way is to distribute educational leaflets or show educational videos in the waiting rooms of clinics or use other means for the online distribution of information.

7. Healthcare professionals and parents should be made aware of their complex roles in the triadic child-parent-doctor relationship and the need to cooperate in fulfilling their common duties towards the child in encouraging and supporting the child's autonomy. Table 1 presented in this dissertation may serve as assisting material.
8. Finally, state policies should aim to raise awareness in all groups of society about children's rights in general, and to promote the idea of a child-friendly society that respects everyone's dignity and hears everyone's voices regardless of age.

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SUMMARY IN ESTONIAN

Lapspatsiendi autonoomia. Otsides tasakaalu normatiivse ja suhetekeskse lähenemise vahel

Õigus autonoomiale ehk enesemääramisõigus on üks inimõiguste tuumpõhimõtetest. Tervishoiuvaldkonnas väljendub patsiendi enesemääramisõigus õiguses anda meditsiiniprotseduuriks või raviks teavitatud nõusolek ning see õigus on vahetult seotud meditsiinieetikast pärit patsiendi autonoomia põhimõttega. Meditsiinieetiline autonoomia printsiip ei nõua aga kõikide patsientide otsuste aktsepteerimist, vaid üksnes selliste, mille on teinud kompetentne patsient. Seepärast suhtutakse lastesse meditsiini valdkonnas teatud määral paternalistlikult, kuigi paternalismil põhinev mudel, mille kohaselt arst teeb valikuid patsiendi eest, on tänapäeva tervishoiukäsitluses asendunud patsiendi autonoomial põhineva mudeliga.

Lapse kui patsiendi autonoomia mõtestamisel tuleb lähtuda ÜRO lapse õiguste konventsiooni (LÕK) ja Oviedo konventsiooni põhimõtetest ning võlaõiguseaduse (VÕS) sätetest. LÕK artikli 12 järgi tuleb lapsele, kes on võimeline iseseisvaks seisukohavõtuks, tagada õigus avaldada oma arvamust igas teda puudutavas asjas ning lapse arvamusele tuleb anda kohane kaal vastavalt lapse vanusele ja küpsusele. Seega rakendub lapse autonoomia seeläbi, et laps tuleb kaasata teda puudutava otsuse tegemisse ning ta peab saama sisuliselt osaleda selle otsuse tegemises vastavalt oma vanusele ja küpsusele. Ka VÕS § 766 lõikes 4 on seotud lapspatsiendi autonoomia tema küpsuse ja võimetega. Meditsiiniprotseduuriks või raviks iseseisva nõusoleku andmine on seatud sõltuvusse sellest, kas laps-patsient on võimeline kõiki poolt- ja vastuargumente vastutustundeliselt kaaluma. Seega on nii rahvusvaheliste kui ka riigisiseste normide järgi lapspatsiendi autonoomia piiratud ning sõltub täiskasvanute otsustest.

Lapspatsiendi autonoomia ei ole siiski üksnes õiguslik nähtus. Sarnaselt teiste sotsiaalsete nähtustega on laste õigused sotsiaalselt konstrueeritud. See tähendab, et õiguste olemust ja tähendust kujundavad inimesed omavahelistes suhetes ning õigusnormide toimimist mõjutavad ühiskonna sotsiaalsed ja kultuurilised normid, mis ei ole oma olemuselt staatilised (Morrow & Pells, 2017). Seepärast on laste õiguste teoreetilistes käsitlustes üha levinum õiguste suhetekeskne mõtestamine (Daly, 2020; Tobin, 2017; Varadan, 2020) sarnaselt lapsepõlve sotsioloogias juba pikaajaliselt kinnistunud suhetekeskse lähenemisega laste agentsusele ehk toimevõimekusele (Alanen, 2014; Greene & Nixon, 2020; Kuczynsky, 2003; Kuczynski jt, 2014; Kuczynski jt, 2018; Mayall, 2000; Mayall, 2015; Reynaert & Roose, 2017; Spyrou jt, 2019). Käesolev doktoritöö ühendabki lapspatsiendi autonoomia uurimisel laste õiguste raamistiku ja suhetekeskse sotsioloogilise käsitluse (Burkitt, 2016; Dépelteau, 2015; Donati, 2015; Prandini, 2015).

Doktoritöö põhineb kolmel uurimusel, mis on avaldatud artiklitena rahvusvahelistes eelretsenseeritavates ajakirjades. Doktoritöö aluseks olnud uurimustel oli kolm eesmärki:

1. Analüüsida lapspatsiendi autonoomia regulatiivset raamistikku (Uurimus I).
2. Uurida, millised on arstide arusaamad lapspatsiendi autonoomiast ning hoiakud selle suhtes (Uurimus II).
3. Uurida lapspatsiendi autonoomia toimimist igapäevases meditsiinipraktikas (Uurimus III).

Uurimuse II ja Uurimuse III tulemused kinnitavad, et lapspatsiendi autonoomia on suhetekeskne, kujutades endast pidevat lapse, lapsevanema ja arsti vahelist interaktsiooni protsessi. Lapse, lapsevanema ja arsti vahel tekib eriline kolmik-suhe, mille käigus iga suhteosaline ja tema käitumine mõjutab teisi suhteosalisi ja nende käitumist. Uurimus II kinnitas ka, et arstid ise tajuvad lapspatsiendi autonoomiat kui suhetekeskset nähtust. See peegeldub asjaolus, et uurimuses osalenud arstid pidasid valdavalt oluliseks, et nii lapsed kui ka vanemad osaleksid aktiivselt arsti-patsiendi suhtluses ning et mõlemad mõistaksid arsti antud teavet. Samas võimaldavad uurimuse tulemused järeldada, et arstid teevad vahet arutelul, kuhu kaasatakse laps ja vanem, ning otsustamisel, kuhu kaasatakse pigem vanem üksi. Kui aga arstide käest küsiti, millised faktorid mõjutavad lapse osalemist otsustamises, tunnistasid nad, et nende endi suhtlemise viis on üks peamiseid mõjutajaid. Arstide suhtlemise viisi mõjutavad omakorda kõige enam lapse vanus ja tema võimed.

Minu doktoritöö püüab lapspatsiendi autonoomiat kui sotsiaalset nähtust süviti avada, vaadeldes, kuidas see igapäevases meditsiinipraktikas toimib. Uurimus III näitab, et lapse nn osaluse teekond saab alguse tervishoiuasutuses loodud füüsilisest keskkonnast. Ruumi kujundus, mööbli paigutus, istekohtade asetus, tööpõhimõtted – kõik sedalaadi tingimused võivad lapse autonoomiat ning tema võimalust arutelus ja otsustamises osaleda kas toetada või vastupidi, maha suruda. Nii näiteks selgus uurimuse tulemustest, et mööbel võib arsti kabinetis olla paigutatud selliselt, et see piirab arsti ja lapse vahelist silmsidet või et arsti ja lapse vahetu suhtlemise takistuseks võib saada asjaolu, et arst peab pidevalt arvutist andmeid otsima või neid sinna sisestama. Lapse osalemisvõimalusi mõjutab ka arsti suhtlemisviis ja keelekasutus. Nagu selgus Uurimuse III tulemustest, võib lapse suhtlusaktiivsust piirata temalt suunavate või kinniste küsimuste küsimine, mis eeldavad üksnes „ei“ või „jah“ vastust, samuti see, kui arst jätab lapse ja vanema poole pöördudes ebaselgeks, kumma poole ta täpselt pöördub. Ühtlasi selgus, et lapsega otsustamisest rääkimine ning lapsele selgelt otsustamisest märku andmine on harv. Siiski esines ka sellist tunnustust väärivat praktikat, kus arst otsesõnu lapsele ütles, et nüüd peame otsustama, mida edasi teha, ning kaasas lapse selgelt otsustamise protsessi.

Üks doktoritöö väärtuslikumaid tulemusi on vanema rolliga seonduva parem mõistmine. Uurimuste II ja III tulemused kinnitavad, et lapsevanema käitumine ning vanemluspraktika on lapspatsiendi autonoomia teostamise seisukohast

määrava mõjuga. Uurimusest III nähtus, et lapsevanemad juhendavad sageli oma lapsi arstiga suhtlemisel. Mõned neist julgustavad oma lapsi rohkem arstiga suhtlema, teised aga, vastupidi, piiravad lapse autonoomiat, kas teadliku või alateadliku käitumisega, näiteks rääkides peamiselt ise või vastates ise lapsele suunatud küsimustele. Uurimuse III andmetel on vanema seisukoht määrav ka lapse ja vanema vahelise eriarvamuse korral. Enamikul juhtudel, kui laps ja vanem olid mingis küsimuses eriarvamusel, sai määravaks lapsevanema seisukoht. Eeltoodu kinnitab, et lapsevanemal on duaalse patsiendi (laps-lapsevanem) sisesuhtes domineeriv roll. Uurimus III näitas, et arstid aktsepteerisid lapsevanema vanemlikust vastutusest tulenevat võimu ning ei soovinud sellesse sekkuda. Sellist järeldust kinnitas ka uurimus II, milles analüüsiti arstide hoiakuid. Arstid selgitasid, et lapse ja vanema vahelise eriarvamuse korral paluksid nad lapsel ja vanemal lahendada erimeelsus omavahel ning jõuda kokkuleppele. Samas viitavad Uurimuse III tulemused sellele, et arsti strateegiliselt läbimõeldud kommunikatsioon võib suurendada lapse osalust, vaatamata vanema piiravale käitumisele. See omakorda juhib tähelepanu tervishoiutöötajate suhtlemisoskuste olulisusele. Hea suhtlemisoskusega tervishoiutöötaja saab suunata lapsevanemat toetama lapse kaasrääkimist ja kaasamõtlemist ning otsustamises osalemist. Võti peitub õige tasakaalu leidmises: andes lapsele liiga palju autonoomiat, mis ei vasta lapse küpsusele ja võimetele, muutub laps haavatavaks, kuid samasugune tagajärg on lapse autonoomia liigsel piiramisel, mis võtab lapselt võimaluse kaasrääkimist ning otsustamist harjutada.

Kokkuvõttes toovad minu uurimuste tulemused välja mitmeid kiiduväärt tava-
sid, kuidas arstid ja lapsevanemad toetavad lapse aktiivset osalemist oma tervist puudutavates aruteludes. Siiski selgus ka mitmeid takistusi, mis piiravad laste osalemist aruteludes ja otsustamises ehk teisisõnu lapspatsiendi autonoomia teostamist, nagu näiteks madal teadlikkus lapspatsiendi õigustest, puudujäägid lapsevanemate ja tervishoiutöötajate sotsiaalsetes oskustes ning muu lapse autonoomiat piirav käitumine, sh lapsevanema liigne sekkumine arsti ja lapse vahelisse suhtesse.

Uurimuste tulemuste põhjal saab anda mitmeid soovitusi tervishoiukorralduse lapsesõbralikumaks muutmiseks ning lapspatsiendi autonoomia toetamiseks:

1. Lapse kaasamine tema tervist puudutavatesse aruteludesse ja otsustamisse peab alguse saama sellest, et lapsele luuakse tervishoiuasutuses turvaline ja toetav füüsiline keskkond ning mõeldakse läbi kõik lapse patsienditeekonnaga seotud aspektid. Esiteks võib lapse osalemisele olulist mõju avaldada ruumi kujundus: kus laps saab istuda, kas ta saab istuda oma vanema(te) kõrval või mitte, kas mööbli paigutus ruumis toetab tervishoiutöötaja ja lapse vahelist otsest kontakti või takistab seda, kas kabinetis on mänguasjad nooremate laste jaoks jne.
2. Tervishoiuasutustes peaks olema läbi mõeldud kindel arvuti kasutamise kord visiidi ajal, kuna arvutikasutus mõjutab seda, kui palju saab arst vahetult lapsega suhelda. Arstil oleks võimalik lapsega paremini suhelda näiteks sel juhul, kui arvutist otsiks andmeid ja sisestaks neid sinna õde.

3. Vaja oleks koostada soovitusel tervishoiutöötajatele lapsesõbralike ja eakohaste suhtlemisstrateegiate kohta. Selliste soovitude väljatöötamisse peaks olema kaasatud mitme valdkonna (meditsiini, psühholoogia, eetika, tervishoiukorralduse) eksperdid asutustest, mis vastutavad tervishoiutöötajate hariduse ja täiendkoolituse ning tervishoiu kvaliteedi eest. Muu hulgas tuleks anda soovitusi, kuidas lastega rääkida, kuidas esitada küsimusi vastavalt lapse vanusele, mis on lapse vanusele kohased valikud, kuidas suhelda väikelastega ning erivajadustega lastega, kes ei pruugi end sõnaliselt väljendada, ja kuidas toetada lapse autonoomiat. Heaks eeskujuks on „Lapse küsitlemise käsiraamat“ (Liivamägi-Hitrov & Kask, 2016), mis koostati kohtumenetlustes lastega töötavatele spetsialistidele Justiitsministeeriumi tellimisel.
4. Kõigis meditsiini valdkonna õppekavades peaks käsitlema patsiendi õiguseid, sh lapspatsiendi õiguseid ja lapspatsiendi kaalutusvõime hindamist, samuti suhtlemisostkust, kuna patsiendi autonoomia toimimise aluseks on head inim-suhted. Ka Maaelmu Arstide Liidu „Arstieetika käsiraamatus“ (2005) rõhutatakse, et head suhtlemisostkust tuleb teadliku pingutusega ja regulaarse hindamisega arendada ning säilitada.
5. Tervishoiutöötajatele tuleks pakkuda täiendkoolitusi lapspatsiendi õiguste ning lapspatsiendi kaalutusvõime hindamise kohta, mis peaks muuhulgas käsitlema lapse-lapsevanema-arsti kolmiksuhtes toimuva otsustamise praktilisi aspekte. Samuti peaks täiendkoolitused keskenduma tervishoiutöötajate sotsiaalsete oskuste arendamisele.
6. Riigi poliitikakujunduses tuleks sihiks seada lapspatsiendi õiguste ja lapse kui patsiendi autonoomia eripära tutvustamine ning selgitamine, miks on lapse autonoomia ja toimevõimekuse toetamine oluline. Selline teavitust aitaks laiemalt parandada inimeste tervisekirjaostkust, mida käsitleb Euroopa Nõukogu oma tervisekirjaostkuse juhendmaterjal (2023). Inimesi on võimalik neis asjus harida mitmel moel, abi võib olla näiteks infolehtede jagamisest tervishoiuasutuste ooteruumides ja arstikabinettides või veebiteavituste tegemisest.
7. Tervishoiutöötajatele ning lapsevanematele on vaja selgitada nende põimivaid rolle ja ühist vastutust lapse autonoomia toetamisel lapse, lapsevanema ja arsti vahelises kolmiksuhtes. Siinses doktoritöös esitatud tabelist 1 võib saada abi nende ülesannete mõtestamisel.
8. Poliitikakujunduse üldiseks eesmärgiks peaks olema lapsesõbraliku ühiskonna kujundamine ning lapse õiguste tutvustamine kõigile ühiskonnaliikmetele. Oluline on, et iga inimese väärikust austatakse ja tema häält võetakse kuulda vanusest sõltumata.

Lõpetuseks, lapspatsientide autonoomiat ning nende osalemist oma tervist puudutavate küsimuste otsustamisel pole Eesti teadustöös varem uuritud. Ka rahvusvahelises teaduskirjanduses on juhitud tähelepanu lünkadele selle teema käsitlustes ning osutatud vajadusele uurida, kuidas lapsed, lapsevanemad ja arstid

laste osalemise ulatust läbi räägivad (Ruhe jt, 2015); kuidas toimib lapse ja vanema vaheline suhe otsustamisprotsessis (Pyke-Grimm jt, 2019) ning millised faktorid soodustavad ja takistavad laste kaasamist otsustamisse (Moore & Kirk, 2010). Seega võimaldab käesolev doktoritöö esmakordselt lähemalt vaadelda lapse kui patsiendi autonoomia küsimusi, töö püüab sügavamalt mõista selle nähtuse olemust, rakendades seejuures interdistsiplinaarset lähenemist. Doktoritöö annab väärtusliku panuse lapse autonoomia sügavamaks mõtestamiseks üldiselt, sest töö teoreetiline käsitlus ja arutelu ei puuduta üksnes tervishoiuvaldkonda, vaid on asjakohased kõigis lapse elu puudutavates valdkondades. Tulevikus võiks teadusuuringutes keskenduda laiemalt tervishoiuspetsialistide hoiakutele ja laps-patsiendi autonoomiat toetavatele tavadele. Eriti oluline on analüüsida meditsiiniõdede rolli, sest õde on tihti patsiendi peamiseks suhtluspartneriks, näiteks peremeditsiinis, haiglas ja koolis. Samuti tuleks analüüsida institutsionaalseid takistusi, mis võivad tervishoiuorganisatsioonis laps-patsiendi autonoomia teostamist raskendada.

PUBLICATIONS

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Paron, K. (forthcoming). Child autonomy and vulnerability in healthcare. In D. Kutsar, M. Beilmann, & O. Nahkur. *Child Vulnerability and Vulnerable Subjectivity – Interdisciplinary and Comparative Perspectives*. Springer.

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