

LIIDIA MEEL

Interdisciplinary team based
pastoral care model for
Estonian healthcare institutions



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University of Tartu, Faculty of Humanities.

The dissertation has been accepted for commencement of the degree of Doctor of Philosophy in Religious Studies.

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Although adjusted in the light of practicing professionals' insight, the model is still open for the critics; all suggested improvements from different healthcare professionals at fieldwork are welcome and must be taken into account when actually applying the model in different institutions. The model is not meant to be a rigorous frame for service provision, but flexible guidelines for service development. Chapter 3.2. 'Professionals' insight and the final version of the model'.

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LIST OF PUBLICATIONS

This thesis is based on original publications:

STUDY I: Meel, L. 2015. Implementing spiritual care at the end of life: Estonia. *European Journal of Palliative Care*, 22 (1): 36–37.

STUDY II: Meel, L. 2016. Socio-Cultural Aspects of the Development of Contemporary Clinical Pastoral Care in Estonia: A Systematic Review. *Health and Social Care Chaplaincy*, 4(1): 57–70.

STUDY III: Meel, L. 2017. Defining the context for best practices: Institutional setting for clinical pastoral care in Estonia. *Journal of Religion and Health*, 57 (1), 328–332.

STUDY IV: Meel, L. and T. Lehtsaar 2017. Interdisciplinary team based pastoral care: A potentially adaptable model for Estonian healthcare institutions. *Occasional Papers on Religion in Eastern Europe*, 37 (3), article 2.

STUDY V: Meel, L. 2018. Interdisciplinary team based pastoral care model for Estonian healthcare institutions: The professionals' insight and the model adjustments. *Occasional Papers on Religion in Eastern Europe*, 38 (2), article 2.

AUTHOR'S CONTRIBUTION

I (Liidia Meel) am the sole author of studies I, II and V. In STUDY III I have the sole authorship of the article text and data analysis; the data of STUDY III originates from the wider research, conducted together with Marko Uibu (University of Tartu) and Indrek Linnuste (University of Tartu) (Meel, Linnuste, Uibu 2016¹). In STUDY IV I am the leading author, my co-author Tõnu Lehtsaar (University of Tartu) provided the theoretical background about the psychology of religion and contributed to the analysis of the current situation in Estonian pastoral care.

¹ Tervisevaldkonna spetsialistide arvamused ning kogemused spirituaalsuse, hingehoiu ja meditsiinilise pluralismi teemadel [‘Health-care specialists’ opinions about and experiences with spirituality, pastoral care and medical pluralism’].

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INTRODUCTION

The subject of the current thesis is interdisciplinary team based pastoral care and its applicability in Estonian healthcare institutions. The aim is to create an interdisciplinary team based pastoral care model that would be adaptable in different Estonian healthcare institutions, and to adjust the model according to the insight provided by different healthcare professionals at the fieldwork.

The thesis is based on original publications referred to in the text as STUDY I–V. STUDY I introduces briefly the situation of implementing spiritual care at the end of life in Estonia and it is a part of an international article series reporting from different European countries². STUDY II introduces the socio-cultural aspects of the development of contemporary clinical³ pastoral care in Estonia as a systematic review drawing information from the Statistics Estonia database (2010–2015), the related studies of the Estonian population and the public information of Estonian hospitals and the pastoral care education. STUDY III presents the institutional setting for clinical pastoral care in Estonia, addressing the Estonian medical staff’s knowledge about and attitudes towards spiritual support (the data originating from a quantitative research in 19 Estonian hospitals during 2015–2016). STUDY IV deals with the theoretical construction of the initial model of interdisciplinary team based pastoral care that would be potentially adaptable in different Estonian healthcare institutions which may have different organizational culture and already settled ways of interdisciplinary co-operation (suggesting the model as favourable guidelines, not to be seen as rigid prescriptions). STUDY V deals with the model adjustments which are based on the working professionals’ insight into including pastoral care as a part of interdisciplinary teamwork, and presents the adjusted version of the model. The professionals’ insight is gathered from Tartu University Hospital, North-Estonian Medical Centre and EELC Tallinn Diaconic Hospital, which all have included pastoral care service each in different organizational forms.

The appendices I–II present the STUDY III questionnaire in Estonian and Russian as these were used for the data gathering, appendix III presents STUDY III questionnaire English translation. Appendices IV–V present the semi-structured interview questions of the STUDY V in Estonian as used for the data gathering, together with the English translation. Appendix VI presents the final version of the model in Estonian.

² Currently: Estonia, UK, Ireland, Netherlands, Finland, Portugal, Germany, Italy, Spain, available at <http://www.eapcnet.eu/Themes/ProjectsTaskForces/EAPCTaskForces/SpiritualCareinPalliativeCare/RelatedPublications/tabid/1874/amid/3783/currentpage/1/Default.aspx>

³ Practical working experience shows that in Estonia the pastoral care service is often strongly related to the end of life care and not so much seen as supporting the curative treatment. Therefore in the current thesis the term ‘clinical pastoral care’ is used to refer also to the pastoral care service offered in different clinics and/or hospital departments, reaching out of the hospice and nursing care and applied also to outpatients.

Ethical considerations

The research of the current thesis is strictly concentrated on the service development; STUDY III used electronic anonymous questionnaire; in STUDY V the respondents' names, their institutions and departments are not revealed, and the analysis is presented in a way that does not enable identifying the respondents.

STUDY III research was accepted by the Research Ethics Committee of the University of Tartu as not requiring an official permission (e-mail 23.11.2015 preserved and available), and was conducted in the co-operation with the hospitals' and their units' managerial personnel who forwarded the anonymous questionnaire to the respondents in their institutions and/or departments. STUDY V research was accepted by the Tallinn Medical Research Ethics Committee of the National Institute for Health Development as not requiring an official permission, being focused merely on the service development (e-mail 05.12.2017 preserved and available).

Tasks, research questions and methodology

The research of the current thesis takes an interdisciplinary approach to pastoral care. The tasks, research questions and methodology of the studies I–V are summarized as follows.

The task of STUDY I is to present merely the starting point providing the initial insight to the spiritual support provision⁴ in Estonian healthcare institutions' end of life care. The reasoning for such starting point is the practical experience that shows the pastoral care service being often related especially to the end of life care, and the fact that the hospices in Estonia function either as official hospital departments or following the principles of hospice care and providing beds for example in the hospital departments of nursing care. The research question is: what is the state of the spiritual support provision in the end of life care at the beginning of the research? The information is drawn from the previous related publications and the public information of the healthcare institutions and the pastoral care education.

The following research focuses on the pastoral care service provision in the healthcare institutions, crossing the borders of the end of life care.

The task of STUDY II is to present the socio-cultural aspects of the development of contemporary clinical pastoral care in Estonia, in order to provide the

⁴ STUDY V showed that using the term 'spiritual support' in the model causes difficulties, for the word '*vaimne*' in Estonian language means either 'spiritual' or 'mental/intellectual', and 'spiritual support' was rarely used by the respondents while the term 'pastoral care' ('*hingehoid*') was understood to integrate also social and psychological aspects. Therefore the adjustments to the model also replace 'spiritual support' with 'pastoral care'. Also, the current thesis is focused specifically on the pastoral care service and not on possibilities of other specialists offering the spiritual support to the patients, the latter would require additional research and theoretical background.

informational basis of our specific socio-cultural context for model construction. The research question is: what are the cultural and social factors to be considered while making the propositions for pastoral care service development in Estonian healthcare institutions? It uses the method of systematic review drawing the information from the Statistics Estonia database (2010–2015), related studies of the Estonian population and the public information of Estonian hospitals and the pastoral care education, focusing on the main subthemes of the patient's psycho-social coping, ethnicity and languages, secularism and religious diversity.

The task of STUDY III is to complement the informational basis of the model construction with the insight into the institutional setting for clinical pastoral care in Estonia. The research question is: what are the institutional factors to be considered while making the propositions for pastoral care service development in Estonian healthcare institutions? It addresses the Estonian medical staff's knowledge about, experiences and attitudes towards spiritual support and pastoral care service. The quantitative research was conducted in 19 Estonian hospitals during 2015–2016. An anonymous questionnaire was combined with open questions for gathering the respondents' comments. The sample consisted of healthcare specialists who had daily contact with the patients or were managing the patient care. STUDY III addresses the responses in the questionnaire sections of religion and/or spirituality, spiritual support and professional clinical pastoral care. The responses went through statistical analysis. The respondents' comments went through conventional content analysis with categories derived from the data (Hsieh and Shannon 2005).

The task of STUDY IV is to create the initial theoretical model of interdisciplinary team based pastoral care that would be potentially adaptable in different Estonian healthcare institutions. The research question is: what would be the theory and context based proposals for the potentially adaptable model of interdisciplinary team based pastoral care for Estonian healthcare institutions? As a method it uses research synthesis for selecting and combining relevant studies in the subject field. The information is drawn from international research and Estonian current situation, which is presented through the preparatory context analysis and related research in Estonian pastoral care, healthcare and the socio-cultural background. The complementary theoretical background explains the interwoven nature of holistic care dimensions (physical, psycho-social, spiritual and also organizational). STUDY IV offers proposals in the main points: a) presentation of the pastoral caregiver; b) main actors; c) forms of co-operation; c) education and internal trainings. The first part of STUDY IV introduces the pre-existing foundations of clinical pastoral care in Estonia, the second part deals with the model construction, and the third part discusses the questions about its applicability.

The task of STUDY V is to present the adjusted version of the interdisciplinary team based pastoral care model for Estonian healthcare institutions. The research question is: whether the initial theoretical model needs any adjustments and what are the necessary adjustments according to the insight given by the

different healthcare specialists who are working in the field? The qualitative research was conducted in three Estonian hospitals (Tartu University Hospital, North-Estonian Medical Centre and EELC Tallinn Diaconic Hospital) that have hired the pastoral caregivers as official members of the staff. The expert sample consists of pastoral caregivers (chaplains and pastoral counsellors) and staff members (doctors, nurses, social workers and psychologists) who have continuously or have had a working contact with their institution's pastoral caregivers. The data was gathered using semi-structured interviews; the interview questions addressed each section of the initial theoretical model and are more thoroughly explained in chapter 3.2. The responses went through a directed content analysis (Hsieh and Shannon 2005) using the coding frame that was based on the initial propositions in each model part.

1. MAIN CONCEPTS, THEIR CONNECTIONS AND USE IN THE THESIS

1.1. Interdisciplinary approach

‘Interdisciplinarity’ has been marked down as ‘a concept of wide appeal’ and ‘also one of wide confusion’ (Klein 1990, 11). People in different fields turn to interdisciplinarity as an approach that would enable answering complex questions and dealing with broad issues, exploring professional and disciplinary relations, solving problems that cross the borders of one discipline, and achieving unity of knowledge (either limited or broader) (Ibid). The term ‘interdisciplinarity’ may refer to: a) research between two different disciplines (for example biochemistry); b) research across closely related disciplines (for example sociology, anthropology and psychology); c) fields and disciplines drawing on different disciplinary inputs; c) research exploring the same phenomena in different disciplines (for example patterns in natural world and social systems); d) research involving experts from different disciplines and stakeholders from practice areas for solving a common problem (Bammer 2013, 7–8). Addressing the ambivalent use of the term, it has been pointed out that interdisciplinarity does not promise any ultimate unity of knowledge, but innovation through combining different parts of knowledge (Weingart 2000, 41). ‘Interdisciplinarity’ is ‘a form or frame of scientific inquiry’ reasoned by the assumption that different problems of humanity are rarely limited to only one intellectual framework, and also the solutions to these problems ‘demand integrative contributions from many disciplines along a variety of intersecting dimensions’ (Rosenfield and Kessel 2008, 430).

At the same time, identifying a ‘discipline’ itself (for example for measuring interdisciplinarity when analysing and mapping interdisciplinary research) is accompanied by some complexity (Huutoniemi et al. 2010). As brought out for example in the context of environmental concerns: while universities are organised around scholarly disciplines, problems do not agree with that arrangement and demand often unexpected kind of collaboration (Brewer 1999, 331). A ‘discipline’ is an institutionally recognized organisation that can be mapped with different empirical measures, and having certain elements or parts (e.g. phenomena, underlying assumptions, epistemology) (Ibid.; Repko 2008, 3–7, 82–114). However, use of the term ‘interdisciplinarity’ in scholarly work suggests the conception of mixing ‘the intellectual landscape of knowledge’, not disciplines themselves (Huutoniemi et al. 2010). In this intellectual landscape the bodies of knowledge are dynamic non-hierarchical structures, having not only mutual overlaps and links, but also their own fractal distinctions causing a continuous slippage in the use of concepts and language (Abbott 2010, 10–15) and therefore generating ‘endless misunderstanding’ and providing ‘a disturbingly powerful tool for nonsubstantive argument’ (Ibid. 13).

Furthermore, there are multiple ways of interdisciplinary interactions (different types of interdisciplinarity), so that formulating a single definition of interdisciplinary scholarly activities is almost impossible. Huutoniemi et al., for example, differentiate between simply multidisciplinary research and interdisciplinary research even if the former is conducted in collaboration between the representatives of different disciplines. The research that merely imports, exports or pools the elements of knowledge across the disciplinary boundaries without adapting them through interaction can be considered as multidisciplinary, because research activities are mainly disciplinary and ‘different approaches speak as separate voices’ (Huutoniemi et al. 2010, 83). Research is interdisciplinary if it is based on active interaction between the disciplines, integrating specialized data bodies, concepts, theories, tools or methods, and aiming to provide a synthetic view or common understanding in the case of a complex issue or problem. Here the typology is based on the implementation of the research, so even if the problem setting is interdisciplinary the research is multidisciplinary if not followed by integrative methodology or integration of findings. The authors offer three types of interdisciplinarity: a) empirical (integrates empirical data of different fields); b) methodological (integrating different methodological approaches by not simply borrowing but also developing these for interdisciplinary context); c) theoretical (synthesizing or contrasting concepts, models or theories from different fields for supplying interdisciplinary analysis with theoretical tools). (Huutoniemi et al. 2010)

Addressing interdisciplinary scholarship, Lisa R. Lattuca (2001) proposes question-based typology. She has identified four types of combining different disciplines as being interdisciplinary: a) informed disciplinarity (discipline informed by other disciplines); b) synthetic interdisciplinarity (linking disciplines); c) transdisciplinarity (crossing disciplines); d) conceptual interdisciplinarity (without a compelling disciplinary basis, often implying a critique of disciplinary understandings). Close to her typology, Lattuca also points out other understandings, e.g. concept interdisciplinarity (supplementing or supplanting the models or concepts of other discipline) (Klein 1990) and different understanding of conceptual interdisciplinarity (covering both transdisciplinarity and critical interdisciplinarity (Salter and Hearn 1996). Arguing for her typology Lattuca stresses that interdisciplinarity must be seen as a defining element of a project, not as ‘merely a process or product’, so one can determine a project as interdisciplinary or disciplinary based on the motivating question behind it (Lattuca 2001, 118).

While a discipline as a particular branch of scholarly learning has its own knowledge domain, concepts, theories and methods (Repko 2008, 3–7), interdisciplinarity aims to integrate ‘the dots of knowledge’ that belong to different disciplines into a meaningful whole which is ‘larger than the sum of its parts’ (Ibid. 9). Interdisciplinary studies as a research process draw on both disciplinary and nondisciplinary knowledge (‘other sources’), borrow appropriate methods from disciplines, and seek to produce new knowledge through integration. The view of ‘integrating’ the disciplinary knowledge means recognizing

the need of symbiosis between disciplinary and interdisciplinary research, for many research problems require the contribution from different experts who address the problem in their specific disciplinary perspective. The 'other sources' of knowledge (e.g. the knowledge of workers, cross-cultural knowledge) are necessary for addressing the specific concern in a particular context, though their provided insight requires certain amount of scepticism if not carefully tested. (Ibid, 8–11)

The current thesis uses interdisciplinary research to address the inclusion of pastoral care (which is essentially interdisciplinary) in the actual interdisciplinary co-operation in healthcare fieldwork. The thesis does not fall into the category of informed disciplinarity (Lattuca 2001, 83; Wear 2009), because the question of including pastoral care in interdisciplinary teamwork is interdisciplinary by nature. In transdisciplinarity on the other hand disciplines do not provide components, but settings for testing transdisciplinary concepts, theories or methods that are intended to be applicable across disciplines (Lattuca 2001, 83, 116; Huutoniemi et al. 2010). That was not done in the current thesis. The thesis integrates theoretical background and empirical data from different fields, including also active integrative collaboration between the researchers from different fields (the researchers themselves having also the personal backgrounds of multiple disciplines) to gather and integrate the components for the interdisciplinary team based pastoral care model. Looking at the given types of interdisciplinarity by Huutoniemi et al. (2010) the overall research process of the thesis could fall into the categories of both theoretical and empirical interdisciplinarity; methodologically remaining in social sciences and humanities. If looking at the question based typology, the chosen type of interdisciplinary research in the current thesis is synthetic interdisciplinarity with questions in the intersections of disciplines (Lattuca 2001, 82–83; 115–116).

Interdisciplinary research has been metaphorically explained as a journey or expedition in the unknown territories outside one's own discipline; it is important to set the constructive boundary around the research area, to chart the course, to assess the route, to navigate, and also to collaborate with the representatives from other disciplines (Lyall et al. 2011). At the same time interdisciplinary research process is both vertical (co-operation of disciplines at different levels, combining scientific research with best practices) and horizontal (co-operation of disciplines at the same level, but also co-operation of administrative bodies or different stakeholders in local planning) (Klein 2004, 519). As such, interdisciplinary research does not require an overarching theoretical or metatheoretical framework of one discipline; it is essentially open and flexible process, though building joint frameworks and learning the language of other disciplines is needed as well as mutual respect (Rosenfield and Kessel 2008, 430–446; Brewer 1999). There is a high risk of failure in interdisciplinary research if different subgroups misunderstand each other, either using different disciplinary language or being seated in different scientific worldviews, and worse if also failing to co-operate in order to transcend their disciplinary boundaries (LeRon Shults and Sandage 2006, 22–26; Bhaskar, Danermark and

Price 2018, 11–12). As ‘the need for meaningful interaction is everywhere’ (Klein 1990, 13), it is a challenge for every interdisciplinary work to map their territory of discovery, to set the route and finally to present the meaningful body of knowledge in the language that is also interdisciplinarily understandable. The current thesis takes the route limited with pastoral care inclusion in healthcare institutions, more specifically in healthcare teamwork, and as such also introduces the main concepts together with their interconnectedness. There is some interdisciplinary research collaboration included in the current thesis (STUDY III researchers from the fields of religious studies, psychiatry and psychology, healthcare social work and pastoral care), also the professionals’ insight to the proposed model in the thesis (STUDY V) has been gathered from different specialists in the fieldwork; and the concepts needed to be clarified early in cooperation. However, it is not only a necessary condition for successful research, it is also needed for publishing the work in a way that it would be easily followed by the representatives from different disciplines.

As previously brought out, the term ‘interdisciplinarity’ shares the common ground with ‘multidisciplinarity’ and ‘transdisciplinarity’, when referring to the type and degree of collaboration (‘multidisciplinarity’ – lowest, ‘transdisciplinarity’ – highest) between the different actors involved either in research process, policy making or practice (Klein 2004; Huutoniemi et al 2010; Bammer 2013, 8; Real and Poole 2016, 51–56; Ellingson and Borofka 2017, 89–91; Wright, Sparks and O’Hair 2013, 288–289), or applying to different approaches in the studies (Repko 2008, 15–17; Lattuca 2001, 81–83, 112–118). I hereby start following the chosen route in the thesis by addressing the terms in the context of healthcare. Since the terms ‘multidisciplinarity’ and ‘transdisciplinarity’ are often used interchangeably with ‘interdisciplinarity’ (Choi and Pak 2006), I briefly explain also the former two as they are understood in the current thesis.

Addressing the matter in healthcare context, combining multiple disciplines has been brought out as valuable for several reasons: a) resolving a real world problem (broader than single discipline); b) resolving a complex problem emerging in modern complex environments; c) providing different perspectives; d) leading a research with a comprehensive prospective theory-based hypothesis; e) developing definitions and guidelines for complex conditions/diseases; e) providing comprehensive services (Ibid). In this process of combining and collaboration the terms of ‘multidisciplinarity’, ‘interdisciplinarity’ and ‘transdisciplinarity’, all refer to involving many disciplines but to different degrees on the same continuum (Dziegielewski 2004, 120–121; Choi and Pak 2006; Hewitt-Taylor 2013, 133–135; Real and Poole 2016, 51–56; Ellingson and Borofka 2017, 89–91).

Multidisciplinarity in healthcare settings means that multiple healthcare professionals work independently to solve the problems of the individual, collaboration is limited to bringing their separate approaches and opinions together to provide comprehensive service delivery; interdisciplinarity on the other hand means collective planning of action in which each professional is expected to contribute and work on the common group goals (Dziegielewski 2004, 120–

121). While multidisciplinary uses the knowledge of different disciplines, it stays inside their disciplinary borders with little interaction or collaboration; interdisciplinarity transcends traditional disciplinary boundaries by analysing, synthesizing and harmonizing their interconnections with the aim to provide a coherent whole; transdisciplinarity transcends the traditional disciplinary boundaries through integrating natural, health and social sciences in a humanities context and recombining the elements of information to provide new knowledge (Choi and Pak 2006). In the case of healthcare teamwork these terms apply as follows: a) multidisciplinary means that the team members though working in conjunction with each other still function separately, providing each other with need-to-know information; b) interdisciplinarity means working in the same setting and interdependently (coordination to have shared routines, common responsibilities and making decisions together); c) transdisciplinarity⁵ means higher level of trust, confidence and collaboration, breaking the disciplinary boundaries through learning and also taking on roles and functions of other disciplines (Real and Poole 2016, 53–54). Interdisciplinary teamwork is further addressed in chapter 1.4. *Pastoral care service and interdisciplinary team in palliative care.*

Interdisciplinary nature of pastoral care

Personal human experience, regarded by Anton T. Boisen (1876–1965) as ‘living human documents’, has been central to clinical pastoral care. Here the attention is focused on human persons as the living documents to be read as well as the written materials. In that Boisen laid down the road also to interdisciplinary collaboration, because the idea involved the minister’s access to the medical files of the patient, attending therapeutic team meetings and having discussions with medical professionals. As such, Boisen was a pioneer of interdisciplinary approach in pastoral care; he set the particular human lives with their concrete realities in the centre of attention and insisted that other (non-theological) sources of different fields should be included in theological reflection. Furthermore, not only one-way but mutually beneficial for different specialists, Boisen saw a chaplain as a specialized member of an interdisciplinary team. Although Boisen developed his clinical pastoral training in the context of psychiatric hospitals (training for Christian ministry included not only taking services, but also working in the wards and talking to the patients), it has been adopted in other sectors as well for being suitable in different settings. (Dykstra 2005, 22–29; Burns 2015, 9–11)

⁵ Although Crawford and Price (2003) claim that transdisciplinary model is not used in healthcare, Real and Poole (2016, 55) describe transdisciplinary team for example functioning in long-term care enabling even more flexible caregiving than interdisciplinary teams, but with the danger of dilution and erosion of disciplinary skills.

While Boisen, too, was trying to understand people in the setting of their relationships (noting that the isolation from others is a common characteristic in the cases of mental illness), it was Bonnie Miller-McLemore who presented the idea of ‘the living human web’ to illustrate the need to understand and care for people in their cultural, social and religious context (Miller-McLemore 1996). She placed Boisen’s ‘living human documents’ into the wide interconnected context where wider social issues are as important as personal ones. Different fields of knowledge are needed to supplement theology to understand the web. As the public policy issues determine the health of that human web, social analysis (engaging different social sciences) of oppression, alienation, diversity, exploitation and justice are needed for gaining insight next to clinically assessing individual pathologies. Furthermore, it is important to bridge not only different disciplines but also different audiences (academy, church and society). (Miller-McLemore 1996; Dykstra 2005, 40–46; Burns 2015, 49–53)

Using the same vision of web, interdisciplinary nature of pastoral care can be explained through the understanding of compassionate care, as put by Carrie Doehring: ‘compassion can be understood as a life force throughout interconnected relational webs that sustains those in pain – persons, families, communities, and all of creation’ (Doehring 2006, 2015, xvii). In this compassionate care process both care seekers and caregivers are held inside these caring networks that at the same time spread much farther beyond them. When dealing with people from different cultural backgrounds and also with different theologies, pastoral caregivers must use their expertise (theological, cultural and psychological) to evaluate both public and personal theologies in order to address suffering in ‘complex systemic and interdisciplinary ways’. (Ibid. xvi–xvii)

This understanding of compassion as a life force moving through sustaining relational webs is similar to John Patton’s idea of pastoral care being both communal (remembering) and contextual (re-membering) (Patton 1993). Caring community (not necessarily congregation but also for example working groups), while offering a sense of being an important part of a larger whole, also shares a common memory as the groups are speaking about their history and experiences, and this common memory cannot be separated from their shared lives. Patton shares Parker Palmer’s (*The Company of Strangers*, 1981) notion of community being an ‘inward fact’ before becoming an ‘outward reality’; community is an act of contemplation rather than a sociological phenomenon, it seeks inner understanding of connectedness with each other and with God’s reality (Ibid, 22). God as the ‘author of community’ has created human relationality, it is an active state which involves working with differences to achieve genuine relationships while not negating but requiring individuality, as the differences enrich and fulfil the relationships. Pastoral care in the communal dimension is ‘the person-to-person response’ growing out of participation in a caring community, trying to enable people to experience community and to give and receive also community’s care (Ibid, 26–27). Remembering in this relational process contributes to the sense of identity and connects one story to a larger

one. Hurts that need healing are part of the story and Patton explains it through the meaningful suffering of Jesus: ordinary sufferings, too, are meaningful and for respectful remembering they must be heard as a part of particular life which has also a particular context. Context is the whole background that is important in the particular case, and Patton considers also the ‘problem’ itself as a context among others. He argues that the central act of pastoral caring is not problem solving but hearing and remembering, and human problems are the contextual background to this process. Pastoral caregiver must believe in the primacy of human experience and respect the different details of personal lives. (Ibid, 15–45)

In the institutional context of healthcare systems it is not only the direct work with the patients and the patients’ backgrounds that set interdisciplinary demands on pastoral care. The pastoral caregivers in hospitals are expected to contribute into maintaining the quality of healthcare through dissecting the patterns of healthcare practice and highlighting fundamental ethical principles⁶ which might be neglected in favor of either self-serving or specific pragmatic solutions (VandeCreek 1988, 2014, 3–13). Thirdly, as interdisciplinarity is valuable also for resolving complex problems that emerge in modern complex environments in healthcare context (Choi and Pak 2006), learning about the particularities of other disciplines and their daily practice can be useful for the pastoral caregiver to collaborate with other professionals respectfully⁷.

While stressing the importance of the competencies in other disciplines, the professional identity of the pastoral caregivers might benefit from clarifying disciplinary relationships. For example criticising the diffusion between the disciplines of pastoral counselling (as a part of pastoral care) and psychology Deborah van Deusen Hunsinger has proposed the Chalcedonian pattern to maintain the disciplinary distinction. Pastoral counselling is unavoidably interdisciplinary by nature as the pastoral caregivers must be both theologically and psychologically trained to answer different emotional and spiritual problems. But combining necessary psychological expertise with theological perspective raises many questions, including whether to integrate the disciplines into unified system of thought or keeping them distinct. Hunsinger suggests that contemporary pastoral counselling needs clarity about the relationship between the two disciplines, and that using the example of the Council of Chalcedon (451) is helpful for addressing different psychological and theological issues in a bilingual way. As the Christ was ‘complete in deity and complete in humanity’, being also both ‘without separation and division’ and ‘without confusion or change’, the same applies to the discipline of pastoral counselling. As the

⁶ VandeCreek analyses three assumptions as fundamental in healthcare: a) *the well-being of individuals and society must be promoted by healthcare*; b) *doctors and patients alike must show respect and build upon the relational nature of healthcare delivery*; c) *all patients must be treated equitably and with respect for their individual values* (VandeCreek 1988, 2014, 3–13).

⁷ In Estonian practice especially considering the limited time and the work overload of medical staff (STUDY III).

psychological and theological issues are co-existing, the pastoral counsellors must be able to address these issues in the languages of depth psychology and theology, and such bilingual competencies would enrich both languages without disciplinary confusion. (Hunsinger 1995, 1–16, 61–75, 212–217)

The example of Hunsinger's Chalcedonian pattern is also compatible with the differentiation between interdisciplinarity and transdisciplinarity. Interdisciplinary inclusion of pastoral care in different settings does not mean that the pastoral caregivers and other professionals must be able to take over the roles or tasks of each other. What they need is the ability to understand and speak different disciplinary languages to address the complex problems as a jointly functioning team.

1.2. Defining pastoral care for Estonian healthcare institutions

The current thesis defines pastoral care according to the occupational standards in Estonia: pastoral care is professional support in existential questions and faith issues that is offered according to the care-seeker's needs and beliefs by the trained specialists (pastoral counsellors and chaplains, both referred to in the text as pastoral caregivers). Pastoral caregiver must be either a member of a church that belongs to the Estonian Council of Churches (ECC) or a member of a faith union that is officially registered in Estonia. In the latter case the work of the pastoral caregiver must have an acceptance from the ECC. (*Occupational Standard of Pastoral Caregiver* level 6 and 7; *Occupational Standard of Chaplain* level 6 and 7, valid 2013–2018; STUDY II)

The current chapter reasons the chosen approach for the definition. The historical background of pastoral care is opened very briefly together with the extremes of the discipline and their critics. It is done in order to give some insight into the developments that have led to the difficulties of giving a definition of pastoral care that would be suitable in different contexts.

Looking at the historical backgrounds, pastoral care as we know it nowadays is summarized as a contemporary expression of the ministry or activity of 'the cure of the souls' that has been offered by religious people, sages, philosophers and communities through the centuries (Lartey 2003, 42). In Christian and Jewish context pastoral care has been historically understood to be supportive and crises care that was offered by both lay and ordained members of the religious communities; it is the shepherd's care of the flock that depicts the spiritual care that religious leaders and laity offer to their community members (Doehring 2006, xxii). This is not to be seen as universally pointing to Christian salvation (when merely looking at the Old Testament), but rather giving the fundamental model of pastoral care based on Ezekiel 34 about the sheep and the shepherd (Rogerson 2000, 15). The New Testament has been seen to keep up the quest of forming a cohesive community facing the possible problems and

divisions both outside and in, and retaining this is also the concern for the later Church (Graham 2000, 30–56).

In the 20th century West pastoral care became an area where secular professionals started questioning the ministry of the Church, for the secularization of institutional care had caused the role of the churches to diminish. Shaping particularly the further development of pastoral counselling, Paul Tillich (1886–1965) has been pointed out as possibly the most influential theologian who recognized the coherence between theological concepts and psychological language, seeing Christian revelation in correlation with existential and psychological issues. From this point on the character of the Church's pastoral care has been dominated by the therapeutic goal of wholeness, together with the secular practice of clinical care. That was the time during which individualistic understanding of personal growth gained popularity and was responded by the non-directive and unconditionally accepting method of pastoral counselling. At the same time the latter approach in pastoral counselling was also criticised for example as neglecting the seriousness of sin and human brokenness or being too non-directive with insufficient attention to what a person should do. (Bunting 2000, 383–400)

For the current thesis criticism towards the extremes of the discipline must be further considered in the social and cultural context, for instead of either analysing the psychological disorders or certain religious traditions, their theologies and congregations the thesis deals with secular institutions⁸ and official organising of service provision. Social and cultural approach has been chosen keeping in mind both the population of the patients and the staff members from various backgrounds.

Social context of pastoral care has been thoroughly addressed by George M. Furniss who presents the definition of pastoral care designed for our contemporary pluralistic world (Furniss 1994). Pastoral care demonstrates the common tendency of disciplines, that is moving through countervailing excesses with the emphasis swinging between the extremes. Furniss explains it through three types of orientation common to all cultures and subcultures: a) cognitive (questioning what is reality and what is knowledge); b) cathectic (whether something feels good or bad); c) evaluative (asking what is right or what is moral). It was a reaction to the 19th century pastoral care mainly evaluative emphasis (but also cognitive, keeping the correct religious doctrine) that pastoral care during the 20th century took the cathectic orientation and preferred 'the heart over the head' approach (Ibid, 1). Addressing the social context, Furniss aims to recover the wholeness of pastoral care through focusing on the cognitive orientation. The reasoning is as follows: a) cathectic orientation greatly depends on our assumptions about reality; b) evaluative orientation is also connected to our epistemology (which is cognitive). The critique is that while in the modern cultural pluralism and cognitive relativism pastoral caregivers see their role in

⁸ That is also the case of EELC Tallinn Diaconic Hospital, if considering the patients' and staff members' backgrounds.

supporting people in a person-centred and agenda-free way, norms of acceptance and tolerance have become so dominating that caregivers themselves are left confused about their identity and the value of their theological tradition in the process of counselling. Nevertheless, pluralism with its different worldviews has to be taken into account, and so the sociological definition of pastoral care is proposed to be ‘a dialogue exploring the possibility and implications of a religious definition of the careseeker’s situation’ (Ibid, 3). The explanation of this definition may be summarized as follows: a) ‘dialogue’ is a two-way communication between relatively equal conversational partners, dialogical character also means that both are transformed by the encounter; b) ‘exploring’ means joint and ongoing process of discovery; c) ‘religious definition’ refers to beliefs, practices and groupings that are oriented to transcendent or supernatural, and ‘possibility’ recognizes the difficulty (not impossibility) for modern people choosing these definitions. In the cases of religious people, religion may also be unhealthy and harmful, contributing to inadequate definitions of the situations. The goal of pastoral care is helping people to find adequate definitions to their life situations and to avoid inadequate ones through promoting healthy religion. (Furniss 1994, 1–7)

Another approach in pastoral care for meeting the needs of pluralistic world is interculturality. Intercultural approach recognizes the complexity that is involved in the interactions between people from different cultural backgrounds. To enhance interaction, intercultural approach gives people from different backgrounds a chance to express their opinions about the subject at hand under their own terms. Gathered information is not systematized into overarching theories, but used to collect clues for responding more adequately to the human needs⁹. As such intercultural approach opposes stereotyping, – it recognizes cultures influence on belief and behaviour but does not see it as determining them as the sole factor. It presents three basic principles: a) contextuality (pieces of behaviour and belief must be considered in the framework of surrounding beliefs and worldviews, also in social, economic, political and environmental contexts); b) multiple perspectives (equally rational people examining the same issue may arrive at different understandings which are equally deserving of attention, and combinations of the perspectives may be more adequate in coping with particular issues in certain context); c) authentic participation (everybody’s right to participate in examining and discussing an issue on their own terms, seeing the strengths and weaknesses in every approach). (Lartey 2003, 31–34)

David Augsburger states that the pastoral counsellor in the contemporary world actually needs to become an intercultural person. It may be the solution for Furniss’ concern about the pastoral caregivers’ confusion, for as Augsburger explains it: being intercultural does not mean being culture-free, but being culturally aware. In this case it is the awareness of one’s own culture that enables the person to disconnect their identity from cultural externals, crossing

⁹ Can be seen in the following chapter for example in the process of addressing the patients’ spiritual needs.

the boundary between the cultures and coming back to their own. Crossing the cultural boundaries leads the person to rediscovering oneself in their own culture, the second culture and also in the third culture that forms the boundary between the first two. (Augsburger 1986, 13–14)

Depending on the given context pastoral care may take various forms from the crisis intervention and supportive care in one tradition, to intercultural spiritual care crossing the borders of the caregiver's own tradition (Doehring 2006, 2015). It would be difficult to find the common denominator for pastoral care practice since the tasks in the various forms of pastoral care may be accomplished in very different ways; while counselling and therapy may be similar in most settings, care-giving ways in the cultures which have very different family and community traditions from the West may become unrecognizable (Augsburger 1986, 15–16). Also, not mutually exclusive but potentially overlapping in practice, understanding of pastoral care and its forms may differ on the basis, – whether pastoral care is seen rather as therapy, ministry, social action, empowerment, or personal interaction (Lartey 2003, 55–59).

Occupational standards of pastoral caregiver and chaplain, however, state the official basis of the pastoral care service. This approach in the current thesis is chosen in order to address the organizational aspects of pastoral care service provision. The Estonian occupational standards are therefore used for defining pastoral care in our specific context, for the nature and the extent of pastoral care service might be understood differently in different cultural (including religious) backgrounds and also based on the individual understanding of religion and spirituality.

1.3. Religion and spirituality in the context of healthcare

As described above, pastoral care is referred to as religious and/or spiritual support. But there are no universal and commonly agreed definitions of religion and spirituality, both being complex multidimensional concepts and having different meanings for different groups (Nelson 2009, 9).

The term 'religion' may be explained through the aspects of transcendence (relationship to the divine), and through the activities and the way of life, in that sense being immanent in the bodily life, practices and daily experiences (Nelson 2009, 4–8). Religion has also been described as a certain kind of ideology that involves the person in a unique commitment where evidence or rational argument is absent, and also in a unique network of relationships which can be both real and imagined (Argyle and Beit-Hallahmi 1975, 5). Religion has been seen in the relation to human values (things that carry particular importance) and as a social phenomenon with different dimensions, such as ritualistic, experiential, intellectual and consequential, and having implications for our ethics and behaviour (Nelson 2009, 6). The dimensions of religion have been similarly brought out as practical and ritual, experiential and emotional, narrative or mythic, doctrinal and philosophical, ethical and legal, social and institutional, and

material (Smart 1998, 13–21)¹⁰. Religion has been admitted to perform many functions which may be very various in their appearance, even though their core might represent the same elemental human needs and roles (Hood, Hill and Spilka 2009, 8). As such, religion is a ‘set of beliefs, practices and language that characterizes a community that is searching for transcendent meaning in a particular way, generally on the basis of belief in a deity’ (Sumalsy 2002).

Religion in the current thesis is considered in the perspective of coping with personal difficulties (specifically in the case of illnesses). On the one hand religion may be seen as a system of beliefs, symbols, rituals, feelings and relationships that are not perceived to have any strong connection with individual lives or situations (for example seeing oneself as a religious person but having difficulties with connecting the readings, the sermon or the songs with personal life). On the other hand religion may be viewed as an inner reservoir of potential support to be revealed by the stressful times during which it comes into light what it individually does or does not contain. Nevertheless, alleviating stress cannot be considered as the sole purpose of religion even in the context of coping with difficulties. Religion is not a passive bystander, but offers the directions where to go and how to reach the destination. Religion emphasises the limitations of material goods, personal wishes and individual lives, teaching us to value what is out of our control and to look above ourselves to find the solutions. (Pargament 1997, 4–6)

For distinguishing the concepts of spirituality and religion Nelson uses the question of whether it is possible to be spiritual without being religious. The answer is “yes” if being spiritual means engaging in a spiritual quest without being a formal member of a religious group (Nelson 2009, 10–11). Yet it is difficult to completely separate the two concepts, for being distinct but related the concepts of spirituality and religion may both be seen in a similar way either a broader concept or “add-on” to another: either spirituality is the core of religious life, or religion is a form of spirituality that is searching for the sacred within a traditional sacred context (Ibid; Zinnbauer and Pargament 2005, 35–37).

It has been pointed out that the connotations of the term ‘spirituality’ are rather personal and psychological while the term ‘religion’ carries the institutional and sociological connotations (Hood, Hill and Spilka 2009, 9). There have been brought out some differences between the definitions of spirituality and religion as follows: a) spirituality being personal and subjective; b) spirituality not requiring an institutional framework nor consensus concerning its authenticity; c) spiritual person as being deeply concerned about value commitments; d) the possibility of being spiritual without a deity; e) viewing religiousness as a subset of spirituality, with the possibility of nonreligious spirituality (Hood, Hill and Spilka 2009, 10–11; Gorsuch 2002, 8).

In the context of healthcare and psychology definitions of religion and spirituality are most useful if they are in resonance with popular usage; as for

¹⁰ Smart though admits that there are religious movements or manifestations where some of these dimensions might be weak or virtually absent (Smart 1998, 21–22).

example following the use of these terms in common speech facilitates validity of the questionnaire measures in health research (Oman and Thoresen 2005, 438–439). It is therefore appropriate to be guided by the use of the term in practical care for the patients. Analysis of the meaning of spirituality in the perspective of patient care has identified a framework consisting of the self, others and ‘God’ and the relationship between them, – within that framework we can explore the spirituality and articulate the emerging themes (Dyson et al. 1997). Compatibly with the given framework, literature analysis in healthcare context shows that spirituality is also by many authors considered as the broader term referring to relationship with the transcendent however it may appear, either expressed in religious practice or in the relationships with arts, nature, philosophy, friends and family etc. (Astrow, Puchalsky and Sumalsy 2001; Sumalsy 2002).

Placing religion under the broader term of spirituality can be explained also through the way spirituality and religion function in the illness experience. Spirituality and religion in healthcare settings gain importance especially in the cases of life-threatening illnesses, at the end of life and in the cases of serious illnesses threatening the patient’s way of life (Astrow, Puchalsky and Sumalsy 2001; Koenig 2002, 6; T. Balboni *et al.* 2010; Edwards *et al.* 2010; T. Balboni et al. 2013). While religion is a vital part of identity for many people, it is also helpful in coping with such difficult life situations because the difficulties and suffering is also central concern of major religions (Pargament 1997, 1–6, 131–162; Koenig 2002, 5–7; Hood, Hill and Spilka 2009, 435–476). In the case of illness religious beliefs and practices reduce emotional distress, give meaning to the suffering, increase either hope or sense of control, and influence the patients’ medical decisions (Koenig 2002, 6–8). The relationship between religion and health (both physical and mental) may be either direct or indirect, and religion’s positive influence can appear through different mechanisms e.g. better health behaviours, more positive psychological states, more effective coping (additional ways of dealing with stressors) and greater social support network (Hood, Hill and Spilka 2009, 473–439; Oman and Thoresen 2005). At the same time it has been argued that if spirituality is the search for transcendent meaning, then both secular and religious people deal with spiritual questions; in this sense illness is not only a biologic fact but also a spiritual challenge for everyone, religious or non-religious (Astrow, Puchalsky and Sumalsy 2001).

Therefore spirituality in the current thesis follows the summarizing definition of being a personal search for meaning and purpose in life, which may but does not have to be related to religion. Spirituality entails connection to self-chosen and/or religious beliefs, practices and values, giving meaning to life. As such spirituality inspires and motivates individuals to achieve their optimal being, which in connection brings also faith, hope, peace, and empowerment. Spirituality may offer joy and forgiveness, promote physical and emotional well-being, and raise the ability to face and accept the mortality and hardships. (Tanyi 2002, 506)

Finally it has to be kept in mind that spirituality and religion may have also negative effects on health, either worsening health problems or conflicting with medical care. Literature analysis has shown potentially negative effect of spirituality or religion for example in the cases of death and disability causing the patients to feel being abandoned by God or to become more dependent on their faith than their medical treatment (Powell, Shahabi and Thoresen 2003); and in the case of teenagers if feeling angry towards God, feeling of being punished by God or being criticised by their religious community (Cotton et al. 2006; Exline, Yali and Sanderson 2000; Pargament, Koenig and Perez 2000; Pearce, Little and Perez 2003). Also studying the patients with chronic pain has shown that healthy emotional functioning may be impeded by negative religious coping (e.g. anger towards God, feeling abandoned by God, avoiding reliance on God), seeming to contribute to poor mental health and increasing the intensity of pain (Rippentrop et al. 2005).

Negative examples have been seen on one hand in the cases where religion is used instead of medical treatment, e.g. refusing prenatal or obstetrical care and life saving treatments, resisting childhood vaccination, and stopping medications after healing service. On the other hand there are cases when religion may lead to alienation and exclusion, be extremely restricting and limiting, or encourage magical thinking in a way that may backfire in either disappointment or being disheartened if the prayers are not answered. Since these uses of religion have potentially negative effect on illness and the patient's treatment (e.g. increasing stress and depression, or contradicting medical treatment), it is another reason for the spiritual and religious issues to be addressed as an integral part of healthcare. (Koenig 2002, 77–79)

At the same time it has been admitted that the fact of abuses and misuses existing inside religion is no different from the cases of any other social institution. In order to avoid the abuses and misuses of religious beliefs and practices it is necessary to understand the health effects of religion, and it can be best achieved through dialogue between science and religion. (Miller and Thoresen 2003)

Spiritual and religious needs in healthcare

In connection with spirituality and religion, the current thesis is concerned with supporting the patients in accordance with their spiritual needs. Here the spiritual needs are seen as a broader concept including also particular religious needs. Spiritual needs in healthcare settings have been identified for example as the need for meaning, purpose and hope; the need of having the relationship with God; the need for spiritual practices and religious obligations; the need for having interpersonal connections, and professional staff interactions (Hodge & Horvath 2011). Whether the patients or the staff hold any religious beliefs or not, they have expressed the needs for love, meaning, purpose and transcendence (Murray et al. 2004). It has been noted that spiritual needs of the patients

involve different emotions during hospitalization, search for meaning, transcendence, maintaining formal religious practices, fear and loneliness alleviation, and God's presence (Clark, Drain and Malone 2003).

It is possible to see the patients' spiritual needs as directly connected to the illness experience. Based on literature review, Edwards et al. (2010) bring out the patients' reported spiritual needs: a) the need to finish business or 'illness work' (e.g. feeling ready to leave without regrets, need for reconciliation and forgiveness in order to die in peace, make right with God and get closer with relatives, letting go and dealing with grief, having the answers, accepting the inevitability of death); b) the need for involvement and control (some control over daily activities, remaining involved with family and decisions concerning their lives, remaining independent and relying on inner strengths, actively preparing for death); c) the need for positive outlook (e.g. remaining positive to deflect the speed of decline, keeping an opened mind and happy thoughts, the need for humour and laughter for lifting the spirits, living in the moment for 'embracing the significance of here and now') (Edwards *et al.* 2010).

The patients' overall spiritual needs (not necessarily connected with the illness experience) have been divided into categories for example as: a) the relation to an Ultimate Other; b) positivity, hope and gratitude; c) giving and receiving love; d) reviewing beliefs; e) preparing for death (Taylor 2003). Based on the narrative responses of patients, nurses and chaplains the categories of spiritual needs have also been presented as: a) religious aspects (e.g. transcendence and prayer); b) experiences beyond earthly existence; c) affective feeling (incl. peace, comfort, happiness); c) values (e.g. health, faith, hope); d) communication (verbal and nonverbal); e) the "other" (questions with death and voids) (Emblen and Halstead 1993). Some of the patients' spiritual needs may also be expressed through caring for bodily needs, as for example caring for hygiene has been noted by a patient to confirm their human dignity (Fagerström et al. 1999). Based on thematic analysis of literature (empirical and theoretical) Kathleen Galek et al. propose 7 constructs of patients' spiritual needs as follows: a) love/belonging/respect (for example feeling unconditionally accepted, being connected to self and others, giving and receiving love and respect); b) divine (religious rituals and prayer, connection with the divine, being part of a community); c) positivity/gratitude/hope/peace (e.g. peace, enjoyment of life, expressing humour and laughter); d) meaning and purpose (reason for living, meaning in personal history); e) morality and ethics (living ethical and responsible life); f) appreciation of beauty (connecting with beauty, nature, art, music, and also the creative process); g) resolution/death (addressing the life and death related concerns, understanding death and dying, resolution about letting go, putting a closure on life and offering forgiveness (Galek et al. 2005).

As part of spiritual needs, particular religious needs may vary not only according to the patients' religious background but also according to their individual understanding of their religion. In healthcare context the patients' preferences for religious support reflect their perceived religious needs, be those following the religious traditions (for example taking part of the mass), pastoral

care visits or even involving staff in religious care (Fowler et al. 2012, 324–326). Patients’ religious needs have been explained for example through categories of: a) religious items (e.g. literature, prayer cards, rosaries and crucifixes, holy water, prayer rugs, prayer compass, Sabbath kit, electric candles); b) dietary needs (e.g. Kosher and Halaal food, also marking the menus in the cases of liquid diet to declare that for example the used gelatine is Kosher); c) modesty (doctors, nurses and carers of the same gender as the patient; longer hospital gowns or pyjama pants for covering knees while praying; not interrupting the prayers); d) blood (the right to refuse the blood transfusion); e) birth and death (e.g. the birth custom of an adult male being the first to speak to a child and bless them; decreasing sedation at the time of death for enabling the patient to fulfil the religious obligation of witnessing God; baptism and Sacraments of the Sick, deathbed confession); f) visiting (clergy, family and community members); g) buildings (e.g. larger family areas, built-in prayer compasses, chapels, separate parking space for hearses close to the morgue and not too close for example to the public entrance); h) unexpected themes (such as appropriate and plain clothing of the clergy, flexible hospital rules, and early contact with the patient’s religious support system) (Davidson, Casey and Walden 2008).

Specific attention has been paid to the spiritual needs of hospitalized children and their families (e.g. Hart and Schneider 1997; Feudtner, Haney and Dimmers 2003; Meert, Thurston and Briller 2005; Bull and Gillies 2007). For example children with cancer diagnosis have the unique spiritual needs that rise from the loss of normalcy, relationships, body image, physical stamina and future goals; in these cases it is important to find the ways how children can continue relationships, help children to find meaning and purpose in life, and to help children transcend beyond the self (Hart and Schneider 1997). In the cases of hospitalized children with complex health needs (requiring both medical and social services) spiritual needs are connected with the main themes of: a) relationships (family, friends, healthcare staff), b) the impact that the hospital environment has on the child, c) having to cope with invasive procedures, d) the child’s belief system and views about their condition; children’s beliefs and needs should be identified and addressed, for their relationship with God may help them to cope with fears and anxieties that are connected to the hospitalization (Bull and Gillies 2007).

In the cases of child’s death in the paediatric intensive care unit the main spiritual need of the parents is to maintain the connection with the child both during the death by physical presence, and after the death by memories, mementos, memorials and different altruistic acts. Following the need of connection, other spiritual needs of bereaved parents have been identified as need for a) knowing the truth, b) feeling compassion, c) prayer, rituals and sacred texts, d) having connection with others, e) receiving bereavement support, f) feeling gratitude, g) finding meaning and purpose, h) ability to trust, i) expressing anger and blame, j) having dignity. While offering caring presence through words and actions healthcare providers can also meet the parents’

spiritual needs by enabling them to stay connected with the child during the death and creating memories for the future. (Meert, Thurston and Briller 2005)

According to the pastoral caregivers who work in paediatric settings parents have more various spiritual needs than patients. The children's spiritual needs were mostly seen in connection with fear and anxiety, coping with physical symptoms (including pain), and in connection with both the relationship with their parents and between their parents. The spiritual needs of the parents were mainly connected to fear and anxiety, coping with child's physical condition, seeking for additional medical information about the illness, pondering about the reason of the child's illness, finding meaning and purpose of suffering and feeling guilty. These main themes are followed by variety of others, e.g. being angry with God, feeling helpless/hopeless/worthless, feeling angry/bitter/hostile, difficult relationships between parents etc. Specific spiritual and religious concerns in the case of a child's illness also include questions if the illness is God's punishment for the family's sins, questions about whether limiting or withdrawing the child's medical care is ethical or in accordance with the family's religious beliefs, or whether the received care is in accordance with the their religious beliefs. (Feudtner, Haney and Dimmers 2003)

Spiritual and religious support

Spirituality and religion have a potentially positive effect on physical and mental health when acting as stress relief, supporting coping with illnesses and reducing risk-taking behaviour (e.g. Speck *et al.*, 2004; Culliford 2002; Patel *et al.*, 2002; Coward 1991; Tanyi 2002; Hay & Hunt 2000). The broad understanding of spiritual support proposes that different members of the interdisciplinary team can be expected to notice and react to the patients' spiritual needs through supportive presence and by referring to particular spiritual (including religious) support in accordance with the patient's background, e.g. the possibility of inviting their own institution's pastoral caregiver or inviting the patients religious leader from outside (e.g. Balboni *et al.* 2013; Howard *et al.*, 2013; Balboni *et al.* 2010; STUDY II). In this sense spiritual support is not limited to particular religiosity but including it, and spiritual support for the patients may also be interwoven with spiritual support for the staff, because in the case of healthcare professionals spirituality has been explained to entail the search for meaning in their work and the significance of their role in the patients' lives (Arshinoff 2011, 178). But spiritual support is also explained as the vertical dimension of religious support, in this case seeking the support directly from the divine; here the source of support is religious faith and the perception of direct experiences with the divine, also for example the images of loving and supporting God in religious literature (Pargament 1997, 208–210).

Distinguishing between the concepts of spiritual support and religious support is, however, difficult if not impossible. For example, religious support has been explained as the two dimensional support gained through religious

faith, involvement, interpersonal relationships, activities, practices and materials (e.g. literature, images, music) (Pargament 1997). It is also important that religious traditions articulate the visions of how we should respond to often painful nature of human condition (Ibid, 3). As previously described, spiritual support within the concept of religious support is seen as the vertical dimension (Ibid, 208–210). The horizontal dimension of religious support is interpersonal and functions in two directions, being sought and offered; offering and seeking the support is understood to be equally relevant, since attempting to sustain the others may help to sustain also the person offering the support (Ibid, 210–212). But it would be difficult to separate spiritual and religious support even in this horizontal (interpersonal) dimension, for people also come to know the transcendent and express their spirituality through their relationships; and while deriving the support from the congregation's members, leaders and/or clergy, the effects of it may be strengthened by the awareness of prayers being offered on behalf of the person and the belief that God works through others (Hill and Pargament 2003). Together with for example social support, religious support has been simply referred to as religious beliefs and the support that is provided by the religious community (Stone et al. 2003). Religious support has also been addressed through 3 dimensions covering both spiritual and emotional support: a) emotional support from church members (whether the coreligionists make the person feeling loved and cared for, or listen to their private problems and concerns; b) spiritual support from church members (whether the fellow parishioners help the person in maintaining and deepening their faith, or apply their religious beliefs in their daily life); c) emotional support from the pastor (listening the private problems of people, and expressing interest and concern in their wellbeing) (Krause et al. 2001).

Religious support can be seen to function in different ways: a) close spiritual connection with God; b) congregational support (religious leaders and congregation members); c) religious reframing of the situations, the situation is attributed to God's will and love. While dealing with the difficult situations in life, people may use different coping strategies, such as conservation of significance and transformation of significance. In the conservation of significance people hold on to the old values and meanings through preserving the former lifestyle, or finding a new way to the old values through attributing the old meanings to the new things. In the transformation of significance people are trying to create a new value system, it includes searching the new religious purpose and maximizing the significance through the attempts to change the nature of significance. None of these strategies is better or worse, but the efficiency depends on the individual situation, and religious support (here spiritual support within the concept of religious support) can be helpful in both. (Pargament 1997, 198–232)

For supporting patients' and families' spiritual beliefs and practices in healthcare settings Clark *et al.* (2003) suggest certain emotional and spiritual care resources such as books (also audio versions), multimedia (for example music for reducing clinical anxiety) and support groups (knowledgeable in the

illness, providing expertise and reassurance); also quiet and secluded space for meditation and prayer, and having meal choices for each religion. The authors also propose: a) emotional and spiritual care improvement team for analysing patient data and identifying resource needs of their patient population; b) chaplaincy/pastoral care team to provide in-depth spiritual care, to influence the organizational behaviour and processes to respect the patients' preferences and to co-operate with other professionals; c) support networks (local pastors/religious leaders, and trained nurses to meet the prayer needs of the patients) (Clark, Drain and Malone 2003). In the overall process of offering spiritual and religious support, professional pastoral caregivers can be expected to recognize and respond to patients' different problems that should also be addressed through different levels of co-operation with other specialists (STUDY II). Spiritual support can be seen also in the case of actual caring for the patients, in which case spiritual care can be simply defined as caring for the patients according to their religion and/or spirituality and attending to their spiritual needs (T. Balboni *et al.* 2013; Fowler *et al.* ed.-s 2012). Providing spiritual support through interdisciplinary co-operation in healthcare settings has been addressed for example in the context of palliative care and hospice teams, in which cases spiritual support has been either associated with higher quality of life near death and reducing the aggressive treatment at the end of life (e.g. T. Balboni *et al.* 2010; T. Balboni *et al.* 2013). Spiritual support has been also considered as an integral part of holistic care and overall culture of medicine (e.g. WHO definition of palliative care; Koenig 2002; Koenig 2014; M. Balboni, Puchalski and Peteet 2014; M. Balboni and Peteet ed.-s 2017). An important notion to be kept in mind is that spiritual care as carrying spiritual support (e.g. displaying 'good qualities of human kind', compassion, comfort, belonging, love; valuing and affirming the patients as human beings and supporting them in their worldview) does not have to be seen as a task or intervention, but to be seen as a way care (also physical care) is given in relationships (Edwards *et al.* 2010; Grant *et al.* 2004; Stephenson, Draucker and Martsolf 2003; McGrath 2003; Chao, Chen and Yen 2002).

Since spirituality and religion in healthcare settings appear most important in the cases of life-threatening illnesses, at the end of life and in the cases of serious illnesses threatening the patient's way of life (Astrow, Puchalsky and Sumalsy 2001; Koenig 2002, 6; T. Balboni *et al.* 2010; Edwards *et al.* 2010; T. Balboni *et al.* 2013), the current thesis further addresses spiritual and/or religious support as the pastoral care service in healthcare institutions' palliative care.

1.4. Pastoral care service and interdisciplinary team in palliative care

The meaning and scope of palliative care

There are different understandings about the meaning and scope of palliative care. The first modern palliative care¹¹ program was developed by Dame Cicely Saunders (1918–2005) during 1960s in London St. Christopher's Hospice, aiming to care for the dying patients and their families, covering their physical, psycho-social and spiritual needs (Saunders 2006; Billings 1998, 2007, 489). So the approach in the beginning was clearly hospice centred although its contents nowadays form the basis for palliative programs in different settings throughout the world (Billings 1998, 2007, 489). By now the scope of palliative care ranges between symptom alleviation, quality of life improvement, care in the final months of life, care in the case of complex and serious illnesses, care for the patients who are not responsive to the curative treatment, and also specifically as a subspecialty of oncology. Use of the term 'palliative care' is overlapping with the terms connected to the imminent end of life (such as 'terminal care', 'hospice', 'thanatology'), it may be applied in the case of possible death ('patients who may die soon'), and also overlapping with 'comfort care' and 'supportive care'). As such, palliative care is a 'second wave of hospice movement' that embraces the hospice philosophy of covering physical, psycho-social and spiritual needs of the patients and families, and seeks to integrate this approach into clinical practice. (Ibid, 489–492)

Palliative care has been primarily associated with 'cancer care', although for example heart failure may cause greater suffering and worse prognosis than many forms of cancer. Especially the term 'end of life care' has been used to expand the scope of palliative care to cover also other health conditions such as Coronary Heart Disease (CHD), Chronic Obstructive Pulmonary Disease (COPD), Motor Neurone Disease (MND), Multiple Sclerosis (MS), Parkinson's Disease (PD) and dementia, which all cause suffering during a time of chronic illness before the patient's death. (Dean 2006, 145)

The current thesis follows the WHO definition of palliative care, for it has been adopted in Estonian healthcare (<http://www.pallium.ee/et/palliativne-ravi> , Suija 2007), it is not limited to certain diagnosis (like cancer) or imminence of death (is applicable also to the patients who may die soon), and it is applicable to different phases of illness and to different settings (not limited to hospices or nursing departments).

World Health Organization (WHO) defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and

¹¹ Although the term 'palliative care' itself was coined later, 1974 by the Canadian cancer surgeon Balfour Mount (1939-) (Clark 2008).

treatment of pain and other problems, physical, psycho-social and spiritual' (WHO <http://www.who.int/cancer/palliative/definition/en/>). Palliative care aims to: a) relieve distressing symptoms (including pain relief); b) affirm life while considering dying as a normal process; c) neither postpone nor hasten death; d) integrate both the psychological and also spiritual aspects of patient care; e) offer a support system that would enable the patients to live as actively as possible; f) offer a support system for the patients' families to help them in coping with their close one's illness and their own bereavement (if indicated); g) address the patients' and their families' needs through team approach; h) enhance quality of life (also the possibility of positively influencing the course of illness; i) be applicable in the early phases of illness, together with other therapies that intend to prolong life (e.g. chemotherapy and radiation), including also investigations that are needed for understanding and managing distressing clinical complications (Ibid).

Particular attention has been also paid to the palliative care for children. The specific paediatric hospice and palliative care started in the 1970s, and in 1978 Myra Bluebond-Langner in her book *The Private Worlds of Dying Children* first challenged the belief that the hospitals provide the best care for children dying with cancer, leading to the development of children hospices and palliative home care programs. Since then the scope of palliative care for children has expanded from the cancer diagnoses to cover life-limiting or terminal conditions. (Bluebond-Langner 1978; McNamara-Goodger and Feudtner 2010, 2012, 3–4; Hain and Jassal 2010, 4–5)

There are certain dilemmas that specifically palliative care for children must face when deciding which patients and how they are to be cared for: a) medical intervention often prolongs life to be lived with serious illness (for example cystic fibrosis or Duchenne muscular dystrophy); b) predicting life expectancy in paediatrics has been noted to be especially difficult, and also many children who are not expected to die in childhood need palliative care; c) there are for example neurodegenerative or genetic disorders which cannot be identified and therefore the prognosis is unpredictable. In all cases the intervention should do more good than harm, the treatment should aim to benefit the child while trying to avoid the side effects as much as possible, and all the dimensions of a child's experience need to be addressed. At the same time combining these principles might mean that physical benefits must be balanced against spiritual ones for example. While the latter is often the case also in adult palliative care, dealing with children requires addressing the issues of development and growth. Palliative care for children also places the greater emphasis on family dynamics, issues of autonomy and consent, and faces a greater intensity of grief and bereavement. (Hain and Jassal 2010, 3–5)

Palliative care for children has been specifically defined by WHO as 'the active total care of the child's body, mind and spirit', involving also the support for the family. Palliative care begins when the patient gets the diagnosis, and is offered regardless of receiving or not receiving other treatments directed at the disease. A child's physical, psychological, and social distress must be evaluated

and alleviated. To be effective, palliative care requires a broad multidisciplinary approach, including also the family and available community resources. Palliative care can be provided in healthcare institutions or in the patients' homes. (WHO URL: <http://www.who.int/cancer/palliative/definition/en/>)

WHO definition of palliative care has gained certain critique concerning the underlying understanding of palliative care (Randall and Downie 2006). First of all, although WHO definition presents a condensation of palliative care minimum philosophy it is still rather a set of beliefs about how things should be done. For example, using the word 'impeccable' to describe assessment and treatment is not realistic but rhetorical. In reality palliative care teams simply must try to do their best to offer high quality care to the patients. The critique applies also to the shift of emphasis in the understanding of palliative care. The roots of modern palliative care reach back to the religious orders where conception of 'good death' involved accepting human mortality, forgiving sins and being connected to one's family. As such, death was not a medical event, but rather a family or community event, 'the signature of a meaningful life' (Ibid, 5). This understanding was taken over also in the 20th century hospice movement emphasizing the personal meaning and fulfilment, encouraging the relatives to visit the patient, and also standing against the artificial prolonging of death, stressing rather the patient's dignity and quality of life. Instead of the mainstream medicine's idea of 'curing', hospice movement expressed the idea of 'healing' as referring to 'making whole' (paying attention to all aspects of human being, later used as 'whole person care' or 'holistic care'). In this understanding 'healing' was stressed with accepting human mortality and recognising the importance of peaceful environment, privacy and the patient's unique personality. Palliative care as developed by Cicely Saunders followed this understanding and it is also expressed in the WHO definition. But the emphasis in palliative care has shifted to generalizability, rules, principles and measurable outcomes that are inherent to interventionist approaches of scientific medicine. Not only distorting the original approach of palliative care, this shift of emphasis also blinds practitioners to the individuality of particular case. (Ibid, 3–23)

Individuality of different cases must be stressed and kept in mind because there are different bio-psycho-social and cultural (also spiritual/religious) factors that influence individual coping with illness, and therefore demand also multi-dimensional assessment and individualised interdisciplinary care (Leigh and Clark 1997, 2007, 807–812; Baldwin 2011, 8–9; Billings 1998, 2007, 496; Hallenbeck 1998, 2007, 517–526; Muir et al. 1998, 2007, 507–516; Mazanac and Kitzes 2003, 178–189).

Physical factors include, for example, type and stage of the disease, treatment effects and duration, the disease progression, the patient's age and gender, physical limitations and permanent disabilities, possibility of disfigurement, presence and severity of different symptoms. Connected to the previous are also individual experiences with the particular illness and illnesses in general, also how the symptoms affect the patient's life (sleep, movement, eating mood etc.) There are also individual psychological strengths and weaknesses which are

brought into the illness experience (such as coping mechanisms, previous emotional problems and other mental health concerns, communication skills, motivation, self-esteem etc.). Social aspects (such as marital status, family, social roles, social inclusion, employment, financial issues) add to the previous and also demand specific consideration. (Leigh and Clark 1997, 2007, 807–812; Muir et al. 1998, 2007, 507–516)

Additionally to bio-psycho-social factors palliative care in pluralistic society must recognize cultural differences. Both health and illnesses are experienced in cultural contexts, applying not only to the patients but also to healthcare workers. The patients are likely to be cared for by the healthcare workers from very different cultural backgrounds. Different cultural groups have also different health beliefs and practices. There is also hospital's culture with its rituals surrounding the patients and the staff. (Hallenbeck 1998, 2007, 517–526; Mazanac and Kitzes 2003, 178–189)

Considering different cultural backgrounds of the patients and staff, two aspects might be highlighted as particularly important for pastoral care as a part of palliative care. While better understanding of culture generally helps to avoid misunderstandings and conflicts, especially death and dying are major cultural transitions accompanied with rituals and rites through which meaning is both created and expressed (Hallenbeck 1998, 2007, 517). Another notion is that symptoms may have cultural meanings as they are interpreted in accordance with their cultural norms (e.g. hallucinations being caused by ghosts, or gastrointestinal symptoms being caused by witchcraft), and their management requires understanding of individual beliefs and practices (Mazanac and Kitzes 2003, 178–189).

Interdisciplinary team in palliative care

WHO definition of palliative care states the idea of addressing the patients' and their families' needs through team approach (WHO <http://www.who.int/cancer/palliative/definition/en/>).

There are different types of teams in healthcare settings, each having their own strengths, weaknesses and challenges; in order to be effective the team type must be in accordance with the tasks at hand and involved healthcare issues, while it is also influenced by the institution's organizational culture; the ideal is that the team 'should be tailored to the demands of the situation' (Real and Poole 2016, 54–55). To meet the patients' various needs palliative care teams include different professionals e.g. doctors, nurses, pastoral caregivers, social workers, psychologists, different therapists, dietitians and volunteers (Crawford and Price 2003; Speck 2006, 15–16). Patients and their families may also be viewed as the team members (Speck 2006, 15). Hospital based palliative care teams which are aiming to imply the hospice care principals in acute care settings, vary within the composition, leadership, titles, structure and approaches (Ingham and Coyle 1997; Hockley 1999; Jack et al. 2004). The styles of palliative team-

work are often related to the place of care delivery, available resources and palliative care program's evolutionary stage (Speck 2006, 13). Although one of the core elements of palliative care is interdisciplinary collaboration within the team (Goldsmith et al. 2010; Meier and Beresford 2008; Liben, Papadatou and Wolfe 2008; Crawford and Price 2003), the team may function in a simply multidisciplinary way for example in its early stage of formation (Jünger et al. 2007) or in medical settings where a member's professional identity weighs over their affiliation to the team (Speck 2006, 12–13).

Multidisciplinary functioning of palliative care team means sharing the information mainly through medical records and reports during the team meetings. Such teams are usually led by the highest ranking member; each member in the team has their defined role and their contribution is often made in isolation from the other members of the team. When pastoral caregiver in such team reports back during the team meeting, it may be that the shared information is not further integrated into the teamwork. One step towards higher integration is to have a 'key worker' for individual patients in order to provide continuous care. However, to achieve the best quality of care through good coordination in care planning and delivery over time, many palliative care teams move to an interdisciplinary model of teamwork. (Ibid, 12–13)

Interdisciplinarity means more inter-relatedness and interdependence between the team members, the team is working towards the common group goals, vital element of such team is interaction, and contributions of different members are respected and valued (Ibid, 14–15; Dziegielewski 2004, 120–121; Real and Poole 2016, 53–54). Communication structure of interdisciplinary team includes both formal and informal meetings, medical records, checklists, sites for informal interaction, and fewer status differences than for example multidisciplinary teams (Real and Poole 2016, 55).

Leadership in interdisciplinary team varies being either designated or distributed, and based on the case or situation (Ibid, 55). Negative extremes of leadership in palliative care appear if leadership is provided by sponsoring agency (in which case not necessarily having palliative care focus), or if leadership is based merely on clinical expertise and not on leadership skills; it has to be reminded that leadership depends on the relationship between the leader and the team members as well as on the surrounding context and the task at hand (Crawford and Price 2003).

Advantages of interdisciplinary team are flexibility, adaptiveness, collaboration and linking the expertise of different disciplines; at the same time challenges of interdisciplinary team are heavy communication load, possibility of conflict, and unbalanced input and disciplinary representation (Real and Poole 2016, 55). Team members benefit from the knowledge and support of their colleagues, supporting also the goals of their fellow team members (Crawford and Price 2003). But the problems may rise for example from internal and external stressors, individual issues or corporate problems, poor definition of authority and roles (also responsibilities), poor feedback, conflicts between the team members, and reluctance to cooperate and compromise (Ibid).

One way to face the challenges in interdisciplinary palliative care teamwork is collaborative communication. Collaborative communication means both exchange of information and collaborative relationship between the communication partners (whether between the professionals themselves, or in the case of communicating with patients and their families). While better communication leads to more effective collaboration, skilful collaboration in turn enables better communication. Collaborative communication is distinguishable by following characteristics: a) collaborative efforts are guided by common goal or set of goals; b) mutual respect and compassion; c) understanding of different perspectives; d) aiming for clarity and correctness of communicated information; e) controlling intra- and interpersonal processes that affect communication. (Feudtner 2007)

Effective interaction between the professionals in interdisciplinary teams enables the team members to extend their skills, and acknowledge the limits of their competence through learning from each other. The roles of the team members are less defined than in the multidisciplinary team, meaning that different team members can ‘cover’ for each other to some extent. At the same time learning from each other through interaction helps different team members also to recognize the need of involving another specialist team member. In the latter case another specialist either works directly with the patient or supports the team member who has the primary relationship with the patient. To avoid stereotyping and tension-creating assumptions in interdisciplinary teamwork, it is important that the team members should not loan and follow the ‘second-hand’ descriptions of roles but should explore and understand the roles inside their own team. (Speck 2006, 14–19)

Complex environments of healthcare are characterized by time pressure, information overload, different decision-makers, uncertain and quickly changing situations, and serious consequences in case of an error (Baker et al. 2005). Healthcare teams do not work in isolation of these environments, but as a part of these are shaped by surrounding environmental factors (Real and Poole 2016, 57). Outside their own team palliative care specialists may have to co-operate with multidisciplinary ward teams and also volunteers who can contribute to the palliative care teamwork by bridging the in-patients with the outside world (Speck 2006, 15, 20). The team may have some contact with the patient even before they are fully involved in the patient’s care, – during the curative treatment palliative care team may be consulted about pain and symptom management and asked to support the patient (Dahlin 2003, 37). There are some difficulties involving palliative care team in intensive care units (e.g. fast-paced environment, concerns about prematurely encouraging the patient’s close ones to withhold life-prolonging treatments, difficulties with distinguishing the effects of sedation from fixed cognitive deficits) (Smith 2006; O’Mahony et al. 2010). At the same time, integrating palliative care in intensive care is: a) the possibility to lessen the intensive care clinicians’ burden of communicating about poor expected outcomes, b) fostering the respectful care to the patients of

different cultural backgrounds, c) meeting the patients' and families' spiritual needs and d) debriefing the intensive care team (O'Mahony et al. 2010).

Pastoral care service as a part of palliative care

Based on the WHO definition of palliative care spiritual/religious support can be seen as an integral part of palliative care. As the attention in palliative care must be paid to the whole person, spiritual/religious needs of the patients must be addressed among other needs. Responding to the patients' spiritual/religious needs requires clarifying and reinforcing these needs in palliative care teamwork. All caregivers in palliative care must acknowledge that hope and meaning-making are important for coping with illness and death. Pastoral care in this process is 'the expertise to help patients to find answers to complex philosophical and theological questions'. (Hermsen and Have 2004)

As argued before, since human hurts are part of their personal stories, the central act of pastoral caring is hearing and remembering, respecting the details of personal lives and connecting their stories to a bigger whole (Patton 1993, 15–45). When the personal narratives collapse facing the trying times, the pastoral caregiver can help to create the new meaning and a sustainable story; by listening and remembering the pastoral caregiver enables the connections between life experiences and across generations, giving also 'sacramental recognition to moments of personal crises' (Swift 2014, 175).

At the same time it cannot be taken for granted that all people are narrative by nature. It may well be that the pastoral caregivers are simply more likely to meet these people who already being spiritual or religiously involved see their stories belonging within a bigger whole. But while narrative as a framework might not be applicable to all illness situations, story is still a key aspect of pastoral care even if not put in the verbal form. Story may also be spoken through signs and silence, as well as through objects and gestures (Walton 2002). Pastoral caregivers often belong to multiple communities and therefore have experienced also the tension rising from the differences between narratives. Knowing this tension themselves, pastoral caregivers can bring 'sensitivity for the broken stories of others' (Swift 2014, 176). In this way, being the conversational partners of the patients and their families, the pastoral caregivers help them to adapt the challenging experience in their personal and family narrative. (Ibid, 175–176)

Although palliative care scope has expanded from cancer to other diagnoses and from the end of life care to the patients 'who may die soon' and life limiting illnesses (Billings 1998, 2007, 489), pastoral care as a part of palliative care is still greatly concerned with death and dying. It has been noted that terminally ill patients are more concerned with spirituality (whether linked to religious beliefs or not) than patients with non-terminal illness (Reed 1987; Daaleman and VandeCreek 2010). Whatever the interpretation of spirituality is, meaning-making and sensing the life's purpose are suggested as its primary components

(Fitchett and Handzo 1998; Daaleman and VandeCreek 2010). If in palliative care death is seen as 'the signature of a meaningful life' (Randall and Downie 2006, 5), end of life is the epilogue to human narrative. It is a place to remind Hallenbeck's notion of death and dying being cultural transitions which are accompanied with rituals and rites both creating and expressing the meaning (Hallenbeck 1998, 2007, 517). While palliative care teams are seeking to enable 'good dying' for the patients, there are various understandings about the meaning of 'good death' itself, considering either different cultural (incl. religious) backgrounds or the age and condition of the patient (for example children and dementia patients) (Coward and Stajduhar ed. 2012).

In cultural diversity knowledge about different religions serve to support the pastoral care dialogue in particular cases, but the caregiver should not assume that their knowledge is necessarily consistent with the patient's understanding (Hall 1997; Coward and Stajduhar 2012). Differences between cultural (incl. religious) backgrounds are to be respected, but even more so the patient's personal understanding of their tradition (Coward and Stajduhar 2012; Walter 2002). If religion and faith traditions are seen as 'part of the scaffolding' for meaning-making when death approaches, the person's spirituality may be viewed as 'the actions and interactions of an embodied human actor who is facing death and creating a personally meaningful social world' (Daaleman and VandeCreek 2010; Seale 1998). It must also be kept in mind that while due to cultural limits everybody cannot offer spiritual support universally to everybody, individual differences also occur inside the same religious background (for example if Christian widows are sensing the presence of their dead spouses they cannot be well supported by Christian pastoral caregivers who do not take their experience seriously) (Walter 2002). Caring for the patients must also respect cultural traditions surrounding personal autonomy and family interdependence, and the ways of information sharing. In some cultures interdependence inside family and community is more important than individual autonomy (the latter may be seen even burdensome for the patient); in some cultures blunt truth telling about the patient's prognosis may be seen as disrespectful (Mazanac and Kitzes 2003, 185; Liben, Papadatou and Wolfe 2008).

There are certain issues that although prevalent in pastoral care with adults, gain more importance if dealing with children. The notion about nonverbal narrative (Walton 2002; Swift 2014, 175) is especially important with children since they require communicating at their own level, either using simple expressions or non-verbal means (Lester 1985, 28–29). Pastoral care with hospitalized children includes also encouraging and advising the parents to be honest with the child, as well as dealing with what the child's illness means to them (Arnold 1985, 2006, 93–106; Davies and Attig 2012, 257–256). In the case of a child's death for example some families may be very clear about and find comfort in their spiritual/religious practices and beliefs, placing 'everything in God's hands', while the other families may find no comfort at all; it should also be kept in mind that terminally ill 3–4 year old children themselves may be more knowledgeable in the matters of illness and dying than much older but healthy

children (Davies and Attig 2012, 257–256). Pastoral care for child palliative care patients is also concerned with the issues of a child's development and future, for many child patients are not expected to die in childhood and many may have lingering health conditions demanding continuous care in the future (S. Nash, P. Nash and Darby 2015, 23; Hain and Jassal 2010, 3–5). Especially important in pastoral care for child palliative care patients are also the children's need for sense of normalcy and relationships (S. Nash, P. Nash and Darby 2015, 23; Kamper, Cleve and Savedra 2010). Normalisation and attaining the sense of community can be achieved through: a) both peer and family support, c) creating the sense of supportive community in hospital, d) doing 'normal' things together, e) helping the patient to feel valued as a community member (S. Nash, P. Nash and Darby 2015, 23).

Pastoral care for patients with dementia has also its specific challenges. Dementia is a loss of mental functions; 'it is an acquired and persistent impairment in multiple areas of intellectual function not due to delirium', which operationally compromises mental activities in three or more of the following spheres: memory, language, perception, praxis, conceptual or semantic knowledge, calculations, executive functions, social behaviour, emotional awareness or expression (Mendez and Cummings 2003, 4). In pastoral care perspective it is important that dementia (referring to many conditions with similar symptoms) causes the loss of memory, loss of cognitive capacity, loss of social skills (including normal social and emotional responses), and changes in behaviour (MacKinlay 2017, 332–334; Kirkwood 2005, 33–34). It has been noted that 'fear retards quality of relationships' when people start wondering how exactly to communicate in such situations (MacKinlay 2017, 341). People tend to assume that if a person with dementia is not able to respond to simple facts they cannot respond at all, while actually person with dementia is more able to respond to the topics about meanings and answering the questions may simply take more time (Ibid., 342). To support a person with dementia it is important to validate them and foster their self-esteem and dignity, rather than correcting the factual information (Kirkwood 2005, 38–39; Knutson 2003, 215). Fostering the self-esteem and dignity of the patients with dementia may also require counselling their close ones and caregivers. Negative attitudes of surrounding people lead to treating a person with dementia in a way that 'overlooks their personhood' and also neglects their spirituality; pastoral caregivers can address whatever actors underlying these negative attitudes, urge the community to remember for the person with dementia, and restore the understanding of personhood (Sapp 2003, 358–359).

2. IMPORTANCE OF THE SUBJECT

2.1. Enhancing pastoral care provision in Estonian hospitals: arguments based on the studies I–III and V

In Estonian healthcare institutions pastoral caregivers' engagement in interdisciplinary teamwork is often questionable, for example in the cases where pastoral caregivers are invited from outside (STUDY II and III), or the cases where the institution's pastoral caregiver reports to be working mostly individually (STUDY V preparatory discussions for sampling). Pastoral care service provision in Estonian healthcare is also uneven and pastoral care in Estonian hospitals is often related especially to the end of life care, not so much seen as supporting the curative care (STUDY I–III). The current thesis aims to broaden the focus of Estonian healthcare institutions' pastoral care to cover also the cases where the patient's life is not threatened by illness while need for support is nonetheless indicated. These cases also require interdisciplinary approach for noticing, understanding and meeting the patients' different needs, as well as the cases of palliative care.

While pastoral caregivers are involved in some Estonian hospitals (either as members of palliative care team, working in different clinics or departments, or visiting the hospital) (STUDY I and II), most Estonian hospitals do not provide pastoral care service at all. Interdisciplinary team based pastoral care model created in the current thesis takes into account Estonian socio-cultural and institutional background, is adjusted according to the insight given by the professionals at healthcare fieldwork, and is given in flexible guidelines to make it adaptable for different healthcare institutions. As such the model is intended to be useful for both: a) involving pastoral care in these institutions which are planning to include pastoral care in their service provision but are not certain about how; b) enhancing interdisciplinary teamwork in pastoral care provision of these institutions which already have included pastoral caregivers as staff members.

Although pastoral care service provision is greatly dictated by financing issues (not being financed by the state budget's health insurance funds) (STUDY II, III and V) this broadened focus is one step towards more holistic healthcare care in Estonia, and might be helpful for offering the pastoral care service also hand in hand with curative care. Respondents in STUDY V noted for example that limited resources prevent involving pastoral care in many cases. For example, even in the cases of life-threatening illnesses and patients who would benefit from pastoral care and would wish it, it is not always possible that pastoral caregiver would accompany them to the decision boards and stay with them after they receive bad news; it is not possible to include pastoral caregivers in all morning rounds and staff meetings even if it would be beneficial; and it is not wise to overload few pastoral caregivers of the institution with the matters of service development even though their insight is needed. Instead we must find

and invent the best ways to spread the ‘butter knob’ of limited pastoral care resource as carefully as possible, with the help of other healthcare professionals. Now, the resources of other professionals (especially time) is limited too. These best ways of pastoral ‘butter spreading’ can be found and invented through interaction between the people involved, and exact ways of co-operation may be different in institutions and departments. The model created in the current thesis offers both: a) flexibility that respects the differences between institutions and departments, b) information that is already extracted from the fieldwork and from theoretical background concerning different aspects of human being. For example, although it may seem as extra work in the beginning, commonly agreed indicators for pastoral care referrals in fact enable quick decisions about whether to invite the pastoral caregiver or not. How these indicators are agreed upon (during internal trainings, informational meetings or simply gathering suggestions in departments) is to be decided inside the institution or department. Although the model suggests consultations and internal trainings which enable other professionals also to understand the background of these indicators, it does not dictate these forms of co-operation but highlights them as beneficial.

STUDY III indicated good will for interdisciplinary co-operation with a pastoral caregiver among medical staff. The respondents considered spirituality and/or religion to be beneficial in healthcare, and marked that medical staff should be aware of patient’s beliefs. While willingness for interdisciplinary co-operation with a pastoral caregiver is indicated, there is no clear understanding among Estonian medical staff about pastoral care service and about the role of the pastoral caregiver. STUDY V showed the need for role clarification especially between the pastoral caregivers and psychologists. Considering the previous the model also aims for pastoral caregiver’s role clarification through professional presentation. Pastoral caregiver’s professional presentation in the model stresses the importance of supportive presence and pastoral caregiver’s proficiency in dealing with spiritual/religious and existential issues, but does not dictate the role in any rigorous borders. As noted in addressing the interdisciplinary teamwork (chapter 1.4.), for avoiding stereotyping and tension-creating assumptions it is important that the team members do not loan the ‘second-hand’ descriptions of roles but explore and understand the roles inside their own team (Speck 2006, 14–19). Like the exact ways of co-operation, exact roles are also to be clarified through interdisciplinary teamwork in institutions and departments.

Subject of the current thesis is also important for pastoral caregivers’ own professional clarity. Role clarification through interdisciplinary teamwork helps the pastoral caregivers to avoid taking over the tasks which are either out of their competence or would be a waste of limited pastoral care resource. But STUDY II demonstrated also Estonia’s multicultural (including multi-religious) society, with different ethnic groups and traditions. This demands from pastoral caregivers the ability to accept the differences, and to support patients and co-workers from different cultural backgrounds. On the one hand pastoral caregivers must respect different beliefs, on the other hand they need to keep their own faith and professional clarity. STUDY II suggested that pastoral caregivers in

Estonia should keep their professional clarity by aligning with the European professional community: ‘pastoral caregiver as a religious practitioner rooted in his/her own faith, but who also reflects theologically and spiritually on the cultural and social context’ (European Network of Health Care Chaplaincy 2014; STUDY II), that is also in accordance with Estonian occupational standards of pastoral caregivers.

2.2. Ethics-driven arguments: studies IV and V

The current thesis, although mentions, does not concentrate on the measurable effects and outcomes of pastoral care. I do believe that spirituality and religion is one sphere of human life that should not be measured and calculated in order to reason its need, especially in these fragile situations that people are facing in healthcare. It is not to say that outcome-orientation and need for pastoral care research as presented for example by George Handzo and many others (e.g. Handzo et al. 2014; Greggo and Lawrence 2012; Jankowski, Handzo and Flanelly 2011; VandeCreek ed. 2002; STUDY IV) is not valuable; outcome-orientation surely contributes to more effective service provision and also fosters the understanding about the effects of pastoral care or wider spiritual support. After all, the constructed model in the current thesis is also based on research. What the following ethical arguments stand for, is that the need for pastoral care provision in general should not be reasoned by measurable outcomes but by the simple human right to be connected to the sphere of their existence that is important to them. These ethics-driven arguments do not delve into clinical or medical ethics in connection with pastoral care, that is another broad subject and hopefully to be addressed more deeply in the future additionally to the current thesis. In Estonian healthcare pastoral care is still rooting (STUDY I–III and V) and the current thesis deals with initial organizing of pastoral care service provision. Being the author of the current thesis, I am merely worried that emphasizing the outcome-orientation in the thesis (although considered in STUDY IV) would too quickly shift the focus from ‘laying the foundation’ to ‘building the walls’.

STUDY IV proposes stressing both pastoral caregiver’s supportive presence for granting the ethical minimum of pastoral care provision, and outcome-orientation for ‘addressing the patients’ particular problems and for further organizational planning’. It was argued that outcome-orientation would enable us to present pastoral care benefits to the institution’s management. At the same time it was acknowledged that assessment is complicated and that pastoral care provision should be based on ethical foundation. STUDY IV introduces Steve Nolan’s invitation to re-evaluate chaplaincy in a way that would benefit from outcome-orientation and evidence-based approach, at the same time valuing and promoting spiritual/religious care through a person-focused presence (Nolan 2013; Nolan 2012). STUDY IV also acknowledges Handzo et al. (2014) notion that ‘the evidence for chaplaincy outcomes can be developed without

compromising the sacredness of the chaplain-patient relationship' and that research-developed evidence are to be included only as one of the drivers of better care. While acknowledging the previous, STUDY IV still points out that outcome-orientation may become a problem if the institution's management and healthcare policy-makers see the outcomes as the only reasoning for pastoral care financing. STUDY IV argues that this potential problem is ethical if considering the decency of healthcare institutions. It highlights Clemens Sedmak's (2014) view of non-humiliating institutions. Inspired by Avishai Margalit's book *The Decent Society* (2009), Sedmak claims that institutions are 'decent' if they 'do not humiliate people'; this decency is seen by Sedmak as 'minimum standard for humane hospitals' which 'should not be hellish'; what humiliates people and makes the institution 'hellish' in pastoral care perspective is: a) 'no opportunity for discussing the question *Why*', b) 'no room for individual thinking and expression' (Sedmak 2014; STUDY IV).

STUDY IV also points out Margalit's (2009) view that people should not be deprived (or feel isolated) from essential parts of their lives. This may easily happen to the hospital's inpatients if they cannot follow their usual religious/spiritual life anymore, in which case the spiritual/religious support should be granted by the hospital whether there are any measurable outcomes or not. Since STUDY V results also spoke strongly against outcome-orientation in pastoral care service provision, stressing measurable outcomes for 'addressing the patients' particular problems and for further organisational planning' was left out of the final version of the model. Again, it does not mean that any outcome-oriented research should not be done at all, but merely that the model does not insist it at least in this stage of pastoral care service provision in Estonian healthcare institutions.

3. MODEL CONSTRUCTION AND ADJUSTMENTS

The current chapter summarizes the process of model construction, the applicability of the model and the adjustments to the final version of the model. This chapter also presents the model in tables of which the final version is proposed for using at Estonian healthcare institutions fieldwork together with occupational guidelines of the institutions. This chapter also presents some examples of pre-existing models, and introduces the process of creating the semi-structured interview questions for gathering the professionals' insight.

3.1. Building the model body

The initial theoretical model of interdisciplinary team based pastoral care for Estonian healthcare institutions was constructed in STUDY IV. The model was aimed to be in accordance with the Estonian local socio-cultural and institutional background, and potentially adaptable in Estonian healthcare institutions. The model's actual applicability was left open for following qualitative research (STUDY V).

Previous context analysis (STUDY II and STUDY III) together with the analysis of the current situation in Estonian pastoral care (Lehtsaar, Soom and Schihalejev 2015) was used as a basis for the model and addressed in the process of model building through the theoretical background and earlier related studies in the field. The basis suggested the pastoral caregivers in Estonian healthcare institutions to be: a) outcome-oriented; b) prepared for interdisciplinary co-operation (also addressing social and psychological issues and potential cultural conflicts; c) supporting also the institution's staff and giving internal trainings; d) open minded towards cultural diversity but also recognizing potentially harmful spiritual/religious practices; e) being rooted in their faith but not propagating their worldviews. On that basis the model body was sketched in the sections of: a) presentation of the pastoral caregiver; b) main actors; c) forms of co-operation; d) education and internal trainings. These model sections were built up choosing the material from related international research and theoretical background, taking into account Estonian specific characteristics (e.g. financing, staff resource; staff understanding, attitudes and experiences with spiritual support and pastoral care; organizational aspects in the institutions; socio-cultural factors). The data sources for informing the model construction were chosen in the following categories: a) research and international discussion about the nature of pastoral care (more outcome-oriented and evidence-based, or emphasizing the supportive presence); b) research and theory of interdisciplinarity and teamwork in pastoral care and in healthcare settings (e.g. role conflict and confusion, structure and hierarchy in the team, education, forms of co-operation); c) patient-centred approach (engaging patients and their families in the direct care and service development). Model

construction used the method of research synthesis to select and combine related studies that would inform each section of the model. Estonian specific institutional and socio-cultural characteristics were presented through the preparatory context analysis and related research in Estonian healthcare, pastoral care, and socio-cultural background. The search for the international literature used the combinations of keywords “healthcare”, “spiritual support”, “pastoral care”, „interdisciplinary“, „chaplaincy“, “holistic care”, “teamwork”, “outcome/s oriented” and “patient centred” and was conducted in MEDLINE, EBSCO, Scopus, Social Science Research Network and Google Scholar databases. The complementary theoretical background is used to explain the mutually interwoven nature of holistic care dimensions, such as physical, psycho-social, spiritual and also organizational. Some pre-existing models were also considered for getting an insight into engaging pastoral care in interdisciplinary teamwork. The theoretical model construction admitted that different professionals who would participate in such teamwork might have their own proposals for each model section, and the model’s applicability may also depend on the particular institutional culture. (STUDY IV)

Some examples of pre-existing models

The current chapter introduces some examples of including spiritual support (pastoral care and/or broader understanding of spiritual support) in interdisciplinary co-operation. It is not the ambition to map the historical course of model building for spiritual support integration in healthcare. It merely shows how the matter has been addressed by different authors, inspiring also the author of the current thesis and providing an insight into the process of model construction.

Speaking against the traditional illness-based treatment model of both mental and physical disorders, Thomas J. Sweeney and J. Melvin Witmer presented the Wheel of Wellness model of wellness and prevention (Sweeney and Witmer 1991; Witmer and Sweeney 1992), and together with Jane E. Myers addressed the model as a basis for treatment planning and counselling interventions (Myers, Sweeney and Witmer 2000). The authors defined wellness as ‘a way of life oriented toward optimal health and well-being in which body, mind and spirit are integrated by the individual to live more fully within the human and natural community’ (Ibid, 252). Though not specifically for organizing teamwork, the Wheel of Wellness model has a multidisciplinary focus and was built upon theories of human growth and behaviour, as such providing also the grounds for interdisciplinary co-operation and the counsellors’ continuous education in other disciplines. The originally published Wheel of Wellness model proposed five life tasks, with spirituality placed in the centre as the source of all other dimensions of wellness. Spirituality is surrounded by the life task of self-direction and its following twelve subtasks: sense of worth, sense of control, realistic beliefs, emotional awareness and coping, problem solving and creativity, sense of humour, nutrition, exercise, self-care, stress management, gender

identity and cultural identity; surrounded by the life tasks of work and leisure, friendship, and love. Here the different dimensions of wellness are seen to overlap and interact, and as such working with one area is an opportunity to improve the others. Since the components of the Wheel of Wellness model are drawn from interdisciplinary research, the counsellors might perceive the need to collaborate with other professionals or educate themselves in the areas outside their own discipline. (Myers, Sweeney and Witmer 2000)

Recognizing the importance of patients' spiritual concerns particularly at the end of life, Sumalsy (2002) expanded the bio-psycho-social model of end of life care to include also the spiritual matters. Sumalsy describes the biological, psychological, social and spiritual dimensions as being distinct but not separable, for the different aspects cannot be disaggregated from the whole. All aspects of the person can be differently affected by both illness and personal history; everyone having also their own spiritual history which for many people unfolds in the context of religious tradition. Spiritual history shapes the whole person and as such is important because, as Sumalsy argues based on Ramsey (1970), life-threatening illness strikes everyone in their totality. In Sumalsy's model clinicians (at minimum) must ensure that spiritual assessment is performed at the patient's consent. However, it does not mean that the clinicians have to do it themselves nor that they have to provide spiritual services. The importance of spiritual assessment may be seen in both: for enabling proper referrals to a chaplain or other clergy, and for overall provision of the end of life care. Here Sumalsy emphasises the importance of relationships, – the patient as a human being is 'a being in relationships' in biological, psychological, social and transcendent spheres. It is hereby appropriate to acknowledge the author's phrasing (based on: Lonergan 1958; Davidoff et al. 1996): 'Illness disrupts all of the dimensions of relationship that constitute the patient as a human person,' therefore a bio-psycho-social-spiritual model provides a foundation for holistic care. In Sumalsy's model personal spiritual history and bio-psycho-social history must be considered together in the person's present spiritual and bio-psycho-social state that only then can be modified by respective spiritual intervention, aiming for higher quality of life during illness and more peaceful death. (Sumalsy 2002)

Christina M. Puchalski, Mary H. Harris and Rabbi Tamara Miller (2006) have stressed the responsibilities of the entire interdisciplinary team in providing spiritual care for the patients, and have presented the collaborative model of providing spiritual care for seriously ill and dying patients. Spiritual care is explained as involving an intrinsic aspect underlining altruistic and compassionate care and being also an important element of professionalism; and extrinsic aspect including spiritual history, assessment of spiritual issues and resources of strength, and also incorporating the patients' spiritual beliefs and practices into the treatment or care plan. Although the chaplain in the team is the trained spiritual care expert, the other team members have also their responsibilities in providing spiritual care. The authors propose the physician (offering compassionate presence, addressing spiritual issues in the clinical

interview and incorporating these in the spiritual care plan), the nurse (e.g. helping the patient and family deal with life-threatening illness and later the changing goals of care; conveying dignity, respect and trust; spiritual assessment), the social worker (while addressing the practical issues, asking also the questions about the patient's spirituality/religion) as the main members of an interdisciplinary team. The chaplain works with the team by addressing the patients' spiritual issues more in-depth, and also assisting other team members in creating and implementing the spiritual care plan. Additionally might be included other specialists, such as therapists, nutritionists, parish nurses, pastors etc. according to the patient case. (Puchalski, Harris and Miller 2006)

Identifying the challenges of providing spiritual care in critical care settings, Amy Rex Smith (2006) has proposed using the synergy model. In critical care settings physiological needs predominate. Working culture in these settings is created in the fast-paced environment while dealing with the cases of multiple life-threatening problems which set competing demands. The key feature of the synergy model is the nurse-patient relationship, where nurses' competences coincide with patients' needs. The synergy is achieved by assigning nurses with spiritual care expertise to the patients with spiritual needs. Since the nurses cannot provide all of the needed spiritual care, the importance of adequate referrals to the chaplains (also consultations) must be recognized, as well as creating the possibilities of practicing religious rituals at the bedside. The synergy model proposes five nursing interventions: a) caring practices (identifying the patients' spiritual needs); b) responding to diversity (matching the nurses who have spiritual expertise with the patients whose spiritual needs are identified); c) supporting resiliency (consulting with and referring to the pastoral caregiver or spiritual companion, and creating the opportunities for their privacy); d) supporting resiliency (creating the opportunities for spiritual practices and religious rituals, such as giving uninterrupted time or trying to create suitable environment as possible); e) supporting resource availability (enabling the patients' connections with their spiritual support systems). (Smith 2006)

To enable the practice of whole person care in both outpatient and inpatient settings, Koenig (2014) has presented a structured model of spiritual care team. Koenig proposes the physician as the leader of the spiritual care team, having the responsibility of briefly assessing and identifying the spiritual needs and documenting the responses in the cases of certain patient groups (serious, life-threatening conditions; chronic, disabling illness; depression or significant anxiety; newly admitted patients; the patients coming to well-patient exam). In this model the physician has to be the one to actually make the assessment. A nurse or a clinic manager is proposed as the spiritual care coordinator with multiple duties (e.g. reviewing the results of spiritual assessment, also identifying and prioritizing the spiritual needs; seeing that the patients' spiritual needs are met, including the provision of resources or making referrals; if referring to the chaplain, then preparing both the patient and the chaplain for the chaplain's visit; gathering feedback from the chaplain and communicating it to the physician). The chaplain in the spiritual care team is the trained spiritual care

specialist who (after getting the referral) assesses and addresses the patient's spiritual needs much more deeply than the physician. The chaplain also develops a patient centred spiritual care plan to meet the patient's spiritual needs, and works (if possible) with the social worker to implement the spiritual care plan also after the patient's discharge from the hospital or clinic. Additionally to the direct work with the patients and their families, Koenig proposes the chaplain to also take part of the ethic committees or the hospital's institutional review boards, and to be involved in the hospital rounds and discussions about the patients. In the case of the chaplain's absence, the spiritual care coordinator will find another specialist with respective training to address the patient's spiritual needs. Everyone in the spiritual care team should be also trained to give 'spiritual first aid'. The social worker in the team has the tasks to contact the patient's faith community or identify a faith community for the patient, also to find the pastoral counsellor and make the appointments to keep the continuity of spiritual care after the patient's discharge. The social worker may also notice the patient's spiritual needs during social assessment, and help the chaplain to follow up with the patient for determining whether the spiritual needs were met. The receptionist or ward clerk is also proposed as one of the spiritual care team members, with the duty to mark the patient's religious affiliation in the medical record for saving the physician's time. (Koenig 2014)

Summarizing the initial theoretical model

The above presented models are not directly taken as the basis for the model construction in the current thesis (not borrowing the structure or weighing the necessity of having the same elements), but have been together with the author's own fieldwork guiding the overall approach in covering the relevant aspects of pastoral care service provision in the context of holistic care.

STUDY IV offered theory, related research and context analysis based proposals for the model in the main points of: a) presentation of the pastoral caregiver; b) main actors; c) forms of co-operation; c) education and internal trainings. The initial model is hereby summarized in Table 1 to enable easy tracking of later adjustments.

Table 1: Meel and Lehtsaar (2017), ‘Interdisciplinary team based pastoral care: A potentially adaptable model for Estonian healthcare institutions’.

<p>1. Professional presentation</p>	<p>1.1. Stressing the importance of supportive presence for granting the ethical minimum* of spiritual support provision.</p> <p>1.2. Stressing the measurable outcomes for addressing the patients’ particular problems and for further organisational planning.</p> <p>1.3. Highlighting the proficiency in spiritual/religious issues and existential questions.</p> <p>1.4. Stressing the complementary nature of acquired knowledge in other disciplines for better team work.</p> <p>1.5. Outlining the needs and possibilities for internal trainings and personal continuing education.</p> <p>*The pastoral caregiver’s presence at least according to the patient’s or their close ones’ expressed wish and the possibility of inviting the pastoral caregiver if the need is perceived by other staff members.</p>
<p>2. Main actors / key actors</p>	<p>2.1. Patient/close ones, pastoral caregiver, doctors/nurses, institution’s psycho-social support (clinical psychologists and social workers as equal partners in reciprocal continuous education and in research informing the decision making process in treatment, management and healthcare policy.</p> <p>2.2. Nurses with respective will and training to recognize patient’s spiritual distress as complementary links between patients and the pastoral caregiver.</p> <p>2.3. Pastoral caregiver, nurses, institution’s psycho-social support as mediators balancing the traditional authority of doctors’ expertise and patients’ values and preferences.</p> <p>2.4. Pastoral caregiver as a specialist and staff’s educator particularly in the matters of spiritual support and Estonia’s religious/spiritual diversity.</p> <p>2.5. Patients’ support groups as additional support according to the particular case and the patient’s wish.</p>
<p>3. Pastoral caregiver’s co-operation with other specialists / forms of co-operation (additionally to the contact with patients and their close ones)</p>	<p>3.1. Pastoral caregiver as an official member of the staff for enabling better co-operation; if the pastoral caregiver is invited from the outside, it should not be random but a potentially long-time working relationship that would allow to engage them in team.</p> <p>3.2. Client- and consultee-centred case consultations and educational consultations as initial platforms for awareness raising and expanding the consultation range to program/service development and management;</p> <p>3.3. Engaging the pastoral caregiver directly in the decision making process at the will of the patient; all patients should be informed about this possibility;</p>

	<p>3.4. Client- and consultee-centred case consultations and educational consultations as platforms for awareness raising about the possibilities of engaging the pastoral caregiver in team meetings and morning rounds;</p> <p>3.5. Coordination between the pastoral caregiver, clinical psychologist and social worker for avoiding overlapping, duplication and contradictions;</p> <p>3.6. Consultations and internal trainings as platforms for clarifying the indicators that should trigger mutual referrals between different specialists.</p>
<p>4. Professional preparatory education / internal trainings</p>	<p>4.1. Engaging the medical staff in creating joint and mutually beneficial internal trainings.</p> <p>4.2. The initial subjects for spiritual support training would be:</p> <ul style="list-style-type: none"> • spiritual/religious issues connected to death, grief and illness related crises; • valuing life (passed life, joy of life) and the need to change and learn; • the issues connected with starting or ending the active treatment; • the indicators for triggering mutual referrals; • spiritual screening and assessment tools for helping the referrals; • ethical and organisational questions in interdisciplinary co-operation; • Estonian religious/spiritual diversity for helping the staff to value the importance of the patients' different backgrounds.

3.2. Professionals' insight and the final version of the model

STUDY V addressed the applicability of the interdisciplinary team based pastoral care model in Estonian healthcare institutions. The professionals' insight was gathered to evaluate the applicability of the propositions in each section of the initial theoretical. The aim was to adjust the model to be adaptable to different Estonian healthcare institutions with potentially different organizational culture.

Qualitative research was conducted in three Estonian hospitals where pastoral caregivers are hired as official members of the staff but the pastoral care service is provided in different organizational forms. The expert sample consisted of pastoral caregivers, and staff members (doctors, nurses, social workers and psychologists). The sampling required from the respondents at least

minimum co-operational contact with the pastoral caregiver¹², considering it as a prerequisite for any practical insight into engaging pastoral care in teamwork. 16 semi-structured interviews were conducted, followed by a directed qualitative content analysis using the coding frame that was based on the initial propositions in each model part. The coding frame used the main categories of *roles/tasks of the pastoral caregiver, team members, co-operation, indicators/need for the pastoral caregiver, supporting the inclusion of the pastoral caregiver, hindering the inclusion of the pastoral caregiver*. The results were presented non-comparatively and not focusing on the pros and cons of the different pastoral care organizational forms. The model propositions' applicability was addressed and (if indicated for the proposition) the model adjustments were made solely based on the insight given by the respondents, not including any additional theoretical background. The model is not presented as a rigorous frame dictating how exactly 'things must be done'. Rather, it should be seen as a collection of guidelines that do not eliminate the possibility of differences in service provision due to different organizational culture or the possible future changes in the pastoral care service funding. (STUDY V)

Creating the interview questions

At the beginning of STUDY V two approaches to creating the interview questions were considered. One approach was to show the initial theoretical model to the respondents prior to the interviews and ask for their comments about its applicability separately in the cases of each proposition. Another approach was to create the semi-structured interview questions for each model section, addressing the propositions more generally and this way allowing the information to flow more freely, not dictating the propositions but later addressing the applicability of the propositions in the light of the gathered insight. The latter approach was chosen for the reason that showing the model itself might be too constraining, and considering the possibility that setting these frames, although reasoned by the researchers, might not be accepted by the practicing professionals at all.

The semi-structured interview questions were created according to each model section in two sets. The first set contains the basic questions for addressing the model sections as freely as possible, letting the respondents reflect on their own terms. These questions are given in the following table. Some of these questions (e.g. 1.3., 2.3., 3.3.) do not appear at first sight to be connected to the model section under which they are presented. However, these were created assuming (based on theoretical background and the context analysis) to give insight most of all to these model sections (not eliminating the possibility of informing also the others). For example, the question 1.3. *If anything, then what*

¹² This requirement significantly narrowed the sample, for there were potential respondents who refused the interview feeling that the co-operational contact has not been frequent or deep enough.

has hindered the inclusion of the pastoral caregiver as a team member? was created based on STUDY II and III pointing out that not knowing what the pastoral caregiver exactly does (also prejudice, connecting with death) or not knowing about the pastoral caregivers existence in their institution at all can be seen as the main thing hindering the inclusion of the pastoral caregiver in the teamwork. Question 2.2. expects the answers to give realistic insight into what specialists and to what extent might be included for early noticing of the patients' spiritual needs. Question 3.3. assumes that knowing about the patient's spirituality/religion would enable the better inclusion of the pastoral caregiver. The first basic set of interview questions was adjusted consulting the healthcare specialists (nurse, social worker and pastoral caregiver) and test interviews.

Table 2: STUDY V semi-structured interview questions.

<i>The model part</i>	<i>Questions</i>
<i>1. Professional presentation</i>	<p>1.1. <i>Please describe how you understand the role of the pastoral caregiver in the treatment team?</i></p> <p>1.2. <i>What do you consider to be more important in the pastoral caregivers work: offering the supportive presence or concentrating on achieving the observable/measurable outcomes?</i></p> <p>1.3. <i>If anything, then what has hindered the inclusion of the pastoral caregiver as a team member?</i></p>
<i>2. Main actors / key actors</i>	<p>2.2. <i>Who would you name as the main actors and the key actors in the interdisciplinary treatment team?</i></p> <p>2.3. <i>How to ensure that the patients' spiritual needs are recognised as soon as possible?</i></p>
<i>3. The pastoral caregiver's co-operation with the other specialists / forms of co-operation (additionally to the contact with patients and their close ones)</i>	<p>3.1. <i>What do you consider to be necessary for including the pastoral caregiver as a team member?</i></p> <p>3.2. <i>How do you feel/what do you think about including the pastoral caregiver in the decision making process, for example the decision boards (dangers, possibilities, weaknesses, strengths)?</i></p> <p>3.3. <i>How do you feel/what do you think about asking and storing information about the patients' spirituality/religion when the patients are signed in to the hospital (whether to do it at all, how thoroughly, what questions should it cover)?</i></p>
<i>4. Professional preparatory education/ internal trainings</i>	<p>4.1. <i>What do you consider to be the best ways for raising the staff's awareness about the pastoral care profession?</i></p> <p>4.2. <i>What topics from your own profession would you recommend for the preparatory education of the hospital pastoral caregivers?</i></p>

The second set of the interview questions contained the additional questions. These were used after the first set for addressing these important aspects that were left uncovered during the testing of the first set. The additional questions are given in the following table.

Table 3: STUDY V semi-structured interview questions (additional)

<i>The model part</i>	<i>Additional questions</i>
1. <i>Professional presentation</i>	<p>1.1. <i>Have you experienced any confusion or conflict in your contact with the pastoral caregiver (with another professional, if the respondent is the pastoral caregiver), due to the different understanding of the roles? If yes, then:</i></p> <ul style="list-style-type: none"> • <i>what was it about;</i> • <i>how was it solved;</i> • <i>what is needed to prevent such situations?</i> <p><i>If not, then:</i></p> <ul style="list-style-type: none"> • <i>what has been helpful in your opinion for preventing such situations?</i> <p>1.2. <i>What kind of support might the pastoral caregiver offer to other staff members (whether only related to the patient case/ in the case of the conflicts between the staff members/ connected to personal worries/ other)?</i></p>
2. <i>Main actors / key actors</i>	<p>2.1. <i>Who would you name as the key actors in the interdisciplinary treatment team in the following fields:</i></p> <ul style="list-style-type: none"> • <i>training and research that would inform the decisions about the treatment, management and healthcare policy;</i> • <i>alleviating the possible tension between the authority of the doctor and the patient's values and preferences;</i> • <i>other?</i> <p>2.2. <i>If and how to include the patients' support groups in the named fields or others?</i></p>
3. <i>The pastoral caregiver's co-operation with the other specialists / forms of co-operation (additionally to the contact with patients and their close ones)</i>	<p>3.1. <i>What do you consider to be necessary for including the pastoral caregiver as a team member (whether the pastoral caregiver to be an official member of the staff or invited from the outside/ how thorough must the other team members' knowledge be about the pastoral care profession and pastoral caregivers' knowledge about the other professions/ the attitude of the management/ others)?</i></p> <p>3.2. <i>How important do you think it is to include the pastoral caregiver in the following forms of co-operation:</i></p> <ul style="list-style-type: none"> • <i>consultation about the patient case (individual or in the group);</i> • <i>consulting the other staff members about their questions, worries or inner conflicts that may affect their work (individual or in the group);</i>

	<ul style="list-style-type: none"> • consultations about the service development and management; • morning rounds? <p>3.3. <i>There may be duplications and contradictions between the spiritual support (the pastoral caregivers) and the psycho-social support (the psychologists and the social workers). What would be the best way to prevent the conflicts and the duplications (mutual coordination/ jointly given internal trainings/ jointly created informational leaflets/ other)?</i></p> <p>3.4. <i>If and what must the commonly agreed indicators be to automatically trigger the co-operation between the different specialists (the patient's suicidal thoughts/ aggression/ refusing the treatment/ other)?</i></p>
<i>Professional preparatory education/ internal trainings</i>	4.1. <i>How do you perceive the need to include the pastoral caregiver in creating and giving the hospital's internal trainings (also what subjects)?</i>

Model applicability and adjustments

Model applicability was evaluated considering whether the propositions in each model section are applicable to Estonian healthcare institutions in the light of the working professionals' insight. If the respondents' answers ran counter to the proposition, the proposition was eliminated or (if indicated) replaced with a new one based on the respondents' insight, weighed also on the theoretical background and the context analysis (STUDY II–IV). If the respondents' answers simply did not verify the propositions' applicability (but not contradicting it), the proposition was considered once more in the light of theoretical background and the context analysis (STUDY II–IV), and also considering whether it needed any rephrasing to fit the overall language use of the respondents. The latter was also considered in the cases of the proposition's applicability being verified by the respondents' insight. (STUDY V)

Proposition 1.2 in the initial theoretical model ('Stressing the measurable outcomes for addressing the patients' particular problems and for further organisational planning') was not applicable and was eliminated from the final version of the model. The applicability of propositions 1.3.–1.5 in the initial theoretical model was verified and the propositions remained in the final version of the model. Proposition 2.2 in the initial theoretical model ('Nurses with respective will and training to recognize patient's spiritual distress as complementary links between patients and the pastoral caregiver') was also not applicable and was eliminated from the final version of the model. The other propositions for the main actors in the initial model section 2 were specified and rephrased. Proposition 3.1. in the initial theoretical model ('Pastoral caregiver as an official member of the staff for enabling better co-operation; if the pastoral caregiver is

invited from the outside, it should not be random but a potentially long-time working relationship, that would allow to engage them in the team’) applicability was questionable in the case of inviting the pastoral caregiver from outside. The adjustment to the final version of the model left out the part of the proposition 3.1. (inviting the pastoral caregiver from outside). Propositions in the model section 3 for consultations as the forms of co-operation are adjusted and rephrased; also adding the list of general indicators for mutual referrals between the specialists in different hospital units. Model section 4 was supplemented with additional subjects for internal trainings. (STUDY V)

Summarizing the final version of the model

The professionals’ insight was asked about the initial theoretical model’s each section. The model was adjusted based on the respondents’ answers and presented in the summarizing table (STUDY V). However, the final step for the thesis once more repeated the back and forth translation of the model (Estonian-English-Estonian). While translating the model back into Estonian language some minor inaccuracies still appeared that needed to be corrected either by rephrasing or adding explanations; some rephrasing was needed due to the differences in Estonian and English languages, in these points rephrasing aimed to present the English version of the model more in compliance with Estonian version. The current chapter presents the final version of the model (Estonian version in Appendix VI) as it may be suggested for using in Estonian healthcare institutions together with pastoral care occupational guidelines.

Table 4: Interdisciplinary team based pastoral care model for Estonian healthcare institutions (final).

<p>1. Professional presentation</p>	<p>1.1. Stressing the importance of pastoral caregiver’s supportive presence for granting the ethical minimum* of pastoral care provision.</p> <p>1.2. Highlighting the pastoral caregiver’s proficiency in addressing spiritual/religious issues and existential questions according to the patient’s background and needs.</p> <p>1.3. Stressing the complementary nature of acquired knowledge in other disciplines for better team work.</p> <p>1.4. Outlining the needs and possibilities for internal trainings and personal continuing education.</p> <p><i>*Ethical minimum</i> means: a) the pastoral caregiver’s presence at least according to the patient’s or their close ones’ expressed wish; b) the possibility of inviting the pastoral caregiver to visit the patient if the need is perceived by other staff members. Stressing the importance of supportive presence refers to pastoral care service being independent of whether its positive effect is measurable. Ethical minimum of pastoral care provision is reasoned by the individual’s right to be connected with and find support for the sphere of life that is important to them.</p>
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<p>2. Main actors / key actors</p>	<p>2.1. Doctors, nurses, carers, social workers, psychologists and pastoral caregivers as constant members of the team.</p> <p>2.2. Patient and close ones, pastoral caregiver, doctors, nurses, carers, psychologists and social workers as equal partners in: a) reciprocal continuous education; b) research informing the decisions about holistic care in treatment, management and healthcare policy.</p> <p>2.3. Pastoral caregiver, as a mediator balancing the possible tension between the authority of doctors' expertise and patients' values and preferences.</p> <p>2.4. Pastoral caregiver as a specialist and staff's educator particularly in the matters of pastoral care and Estonia's religious/spiritual diversity.</p> <p>2.5. Occupational therapists, physiotherapists and nutrition advisors to be included according to the patient's needs in different units; peer counsellors and patient support groups to be included according to the patient's wish in particular cases.</p>
<p>3. Pastoral caregiver's co-operation with other specialists / forms of co-operation (additionally to the contact with patients and their close ones)</p>	<p>3.1. Pastoral caregiver as an official member of the staff for enabling better co-operation.</p> <p>3.2. Client- and consultee-centred case consultations for staff; educational consultations about pastoral care service the platforms for: a) awareness raising about pastoral care profession; b) awareness raising about the different possibilities of engaging the pastoral caregiver in their institution (e.g. team meetings and morning rounds, additionally to the counselling of the patients and their close ones).</p> <p>3.3. Joint coordination between the pastoral caregiver and the psychologist for avoiding contradictions and excessive duplication.</p> <p>3.4. Consultations and internal trainings as platforms for clarifying the specific indicators that should trigger mutual referrals between different specialists in particular units.</p> <p>3.5. Some general indicators for mutual referrals in all hospital units: the patient's apathy (if not connected to medications), changes in behaviour or emotional state, not accepting the diagnosis, grief, economic and social coping issues, worries connected to the patient's family (also under aged children, disabled family members, different expectations of family members towards the patient's care), anxiety and depression, crises in life (also additional to the crisis caused by illness), unexpected change in illness or life.</p> <p><i>*Referral</i> means: a) informing the patient about the possibility of inviting a certain specialist (e.g. pastoral caregiver, social worker, psychologist etc.); b) informing the certain specialist about the patient who might need pastoral care. <i>Specific indicators</i> refers to the possible differences in the indicators respectively to the particular unit (different diagnoses, but also different age groups).</p>

<p>4. Professional preparatory education / internal trainings</p>	<p>4.1. Engaging the hospital staff in creating joint internal trainings to promote the provision of holistic care.</p> <p>4.2. Possible subjects for internal trainings by the pastoral caregiver:</p> <ul style="list-style-type: none"> • the basics, scope and possibilities of pastoral care; • spiritual/religious issues connected to death, grief and illness related crises; • supporting the dying patients and their close ones, telling the close ones about the patient's death; • communicating with difficult patients (e.g. refusing the treatment, unrealistic expectations, blaming), dealing with hopelessness; • valuing life; personal wholeness and the need to change and learn; • the issues connected to starting or ending the active treatment, in the field of spirituality/religion; • the indicators for triggering mutual referrals; • preventing the burnout; • spiritual screening and assessment tools for helping the inclusion of pastoral caregiver; • ethical and organisational questions in interdisciplinary co-operation; • Estonian religious/spiritual diversity and the basic knowledge of different religions for helping the staff to value the importance of the patients' different backgrounds.
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Although adjusted in the light of practicing professionals' insight, the model is still open for the critics; all suggested improvements from different healthcare professionals at fieldwork are welcome and must be taken into account when actually applying the model in different institutions. The model is not meant to be a rigorous frame for service provision, but flexible guidelines for service development. There is no doubt that many of the propositions in the model are already in practice, and much in the service provision might be already decided by the organizational culture of the institutions. But nevertheless, the model might be useful when hiring new pastoral caregivers in the institutions that do not yet provide pastoral care service.

4. SUMMARY

The subject of the current thesis is interdisciplinary team based pastoral care and its applicability in Estonian healthcare institutions. The research of the current thesis is concentrated on the service development and takes an interdisciplinary approach to pastoral care. The thesis deals with creating an interdisciplinary team based pastoral care model, and adjusting it according to the insight given by different healthcare professionals at the fieldwork.

The thesis is based on original publications (STUDY I–V). Introduction presents STUDY I–V research questions, tasks, methodology, and ethical considerations. STUDY III research was accepted by the Research Ethics Committee of the University of Tartu (e-mail 23.11.2015 preserved and available). STUDY V research was accepted by the Tallinn Medical Research Ethics Committee of the National Institute for Health Development (e-mail 05.12.2017 preserved and available).

The first chapter of the thesis presents the main concepts, their connections and use in the thesis. It starts by introducing an interdisciplinary approach and the interdisciplinary nature of pastoral care (Chapter 1.1), and defines pastoral care for Estonian healthcare institutions (Chapter 1.2). The concepts of spirituality and religion are opened in the context of healthcare, explaining the spiritual/religious needs and spiritual/religious support in healthcare (Chapter 1.3). Chapter 1.4 explains the meaning and scope of palliative care, addresses interdisciplinary teamwork in palliative care, and introduces pastoral care service as an integral part of palliative care. Chapter 2 addresses the importance of the subject. Chapter 2.1 presents the arguments based on studies I–III and V, concerned with enhancing the pastoral care provision in Estonian hospitals. Chapter 2.2 presents the ethics-driven arguments based on studies IV and V. The third chapter introduces the model construction and adjustments. It describes the process of building the model body, presents some examples of pre-existing models, and summarizes the initial theoretical model in Table 1 (Chapter 3.1). Chapter 3.2 introduces the process of gathering the professionals' insight for model adjustments, and summarizes the final version of the model in Table 4.

In the current thesis interdisciplinary research is used to address the inclusion of pastoral care in the interdisciplinary co-operation in healthcare fieldwork. Looking at the different types of interdisciplinarity (Huutoniemi et al. 2010) the research process of the thesis falls into the categories of theoretical and empirical interdisciplinarity, methodologically remaining in social sciences and humanities. Considering the question based typology, the current thesis uses the synthetic interdisciplinarity with its questions in the intersections of disciplines (Lattuca 2001, 82–83; 115–116). The thesis draws theoretical and empirical information from different fields, and includes also active integrative collaboration between the researchers from different fields to gather and integrate the components for the model.

Pastoral care in the current thesis is defined according to the occupational standards of pastoral counsellor and chaplain in Estonia: ‘pastoral care is professional support in existential questions and faith issues that is offered according to the care-seeker’s needs and beliefs by the trained specialists (pastoral counsellors and chaplains, both referred in the text as pastoral caregivers)’, and ‘pastoral caregiver must be either a member of a church that belongs to the Estonian Council of Churches (ECC) or a member of a faith union that is officially registered in Estonia’, in which case the work of the pastoral caregiver must have an acceptance from the ECC (*Occupational Standard of Pastoral Caregiver* level 6 and 7; *Occupational Standard of Chaplain* level 6 and 7, valid 2013–2018; STUDY II). The interdisciplinary nature of pastoral care is explained through the interrelatedness of the different aspects of the human existence. Different fields of knowledge are needed to inform pastoral care in order to understand and meet the needs of the patients. Interdisciplinarity in the current thesis is also opened in the context of interdisciplinary co-operation between the different professionals in healthcare, being especially important in palliative care teamwork.

Understanding of palliative care in the current thesis follows WHO definition of palliative care, for it is used in Estonian healthcare (<http://www.pallium.ee/et/palliatiivne-ravi>; Suija 2007) and it is not limited to particular diagnosis, imminence of death, phases of illness or particular settings (e.g. hospices or nursing departments). Palliative care is ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual’ (WHO URL: <http://www.who.int/cancer/palliative/definition/en/>). While highlighting the pastoral care service provision as a part of palliative care the current thesis expands the focus of pastoral care also out of the borders of palliative care (to the cases where the patient’s life is not threatened by the illness while the need for support is nonetheless indicated).

The second part of the thesis presents the publications as a step-by-step process of model building and adjusting. STUDY I provides the initial insight to the spiritual/religious support provision in Estonian healthcare institutions’ end of life care (pastoral care in Estonian healthcare is mostly, though not always, understood in connection with death, dying and grief). The following research in the thesis crosses the borders of the end of life care. STUDY II presents the socio-cultural aspects of the development of contemporary clinical pastoral care in Estonia. It provides the informational basis about Estonian specific socio-cultural context for the model building. STUDY II uses the method of systematic review; the data originates from the Statistics Estonia database (2010–2015), studies of the Estonian population, and the public information of Estonian hospitals and pastoral care education. Research in STUDY II focuses on the subthemes of the patient’s psycho-social coping, ethnicity and languages, secularism and religious diversity. STUDY III complements the informational

basis of the model with the insight into the institutional setting for clinical pastoral care in Estonia. It addresses the Estonian medical staff's knowledge about, experiences with and attitudes towards spiritual support and pastoral care service. The quantitative research using anonymous questionnaire was conducted in 19 Estonian hospitals; the sample consisted of these healthcare specialists who had daily contact with the patients or were managing the patient care. STUDY IV deals with creating the initial theoretical model of interdisciplinary team based pastoral care for Estonian healthcare institutions. It uses research synthesis for selecting and combining studies in the subject field. The information is integrated and presented through the previous context analysis and related research in Estonian pastoral care, healthcare and socio-cultural background. STUDY V presents the final version of the interdisciplinary team based pastoral care model for Estonian healthcare institutions. It adjusts the initial theoretical model according to the insight provided by the professionals in healthcare fieldwork. The qualitative research was conducted in three Estonian hospitals that have the pastoral caregivers working as official members of the staff. The sample consisted of pastoral caregivers, and staff members who have continuously or have had a working contact with their institution's pastoral caregivers. The data was gathered using semi-structured interviews, addressing each section of the initial theoretical model.

The context analysis (studies II and III) showed that Estonian multicultural, mainly secular and at the same time multi-religious society sets a complex framework for clinical pastoral care. Based on the context analysis and the analysis of the current situation in Estonian pastoral care, STUDY IV suggested that pastoral caregivers in Estonian healthcare institutions should: a) be mainly outcome-oriented (pastoral caregivers should conduct research and express their working outcomes); b) work closely with the institution's psychologists and social workers to uphold the idea of holistic care; c) focus on existential questions and spiritual/religious reflections while also being able to address psychosocial issues and cultural conflicts; d) be supportive members of the institution's working community: adjusted to interdisciplinary teamwork, giving internal trainings and supporting the staff; e) be open-minded towards cultural (incl. spiritual/religious) diversity, but also able to detect harmful practices; f) be rooted in their own faith but not exclusively propagating it. STUDY IV gave proposals for the model in the sections of professional presentation, main actors, forms of co-operation, and education/internal trainings (summarized in Table 1). In the initial model outcome-orientation was outweighed by ethics-driven arguments and was left out of the adjusted and the final versions of the model (STUDY V). STUDY V adjusted the model according to the professionals' insight. However, while translating the model into Estonian and back to English some minor additional adjustments were needed, mainly due to the differences between English and Estonian languages. The final version of the model is summarized in Table 4.

Pastoral caregivers' inclusion in Estonian healthcare institutions' interdisciplinary teamwork is often questionable. These are for example the cases where

pastoral caregivers are invited from outside or are working mostly individually. Pastoral care provision in Estonian hospitals is also uneven, – pastoral caregivers are working in some Estonian hospitals (belonging to palliative care team, belonging to different clinics or departments, or visiting the hospital), but most Estonian hospitals do not offer pastoral care service. The interdisciplinary team based pastoral care model that is created in the current thesis is intended for: a) involving pastoral care in the institutions which are planning to include pastoral care in their service provision; b) enhancing interdisciplinary teamwork in pastoral care provision of these institutions which have already included pastoral caregivers. The model offers flexibility that respects the possible differences between institutions and departments, and information that is extracted from the fieldwork and from theoretical background about different aspects of human being.

The appendices present the research questionnaires and the semi-structured interview questions of the current thesis. Appendix VI also presents the final version of the model in Estonian.

5. SUMMARY IN ESTONIAN

Interdistsiplinaarse meeskonnapõhise hingehoiu mudel Eesti tervishoiuasutustele

Käesoleva artiklil põhineva doktoritöö teema on interdistsiplinaarne meeskonnapõhine hingehoid ja selle rakendatavus Eesti tervishoiuasutustes. Uurimistöö on keskendunud teenusearendusele ning kasutab interdistsiplinaarset lähenemist hingehoiule. Doktoritöö sisuks on: a) interdistsiplinaarse meeskonnapõhise hingehoiu mudeli loomine Eesti tervishoiuasutuste jaoks, b) loodud mudeli täpsustamine vastavalt Eesti haiglates praktiseerivatelt erinevatelt tervishoiutöötajatelt kogutud informatsioonile.

Töö sissejuhatus esitab uuringute I–V uurimisküsimused, ülesanded, kasutatud uurimismeetodid ning vastavuse eetilistele nõuetele. Käesoleva doktoritöö uuringud III ja V on saanud nõusolekud Tartu Ülikooli inimuuringute eetika komiteelt (e-mail 23.11.2015 säilitatud) ning Tallinna Meditsiiniuuringute Eetikakomiteelt (e-mail 05.12.2017 säilitatud).

Doktoritöö esimene peatükk tutvustab peamisi töös kasutatud mõisteid, nende vahelisi seoseid ning nende kasutamist töös. Esmalt on selgitatud töös kasutatud interdistsiplinaarset lähenemist ja hingehoiu interdistsiplinaarset olemust (peatükk 1.1) ning peatükk 1.2 pakub välja hingehoiu definitsiooni Eesti tervishoiuasutuste jaoks. Spirituaalsuse ja religiooni mõisted on avatud tervishoiu kontekstis, selgitades patsientide spirituaalseid/religioosseid vajadusi ning spirituaalse/religioosse toe pakkumist tervishoius (peatükk 1.3). Peatükk 1.4 selgitab palliatiivravi tähendust ja ulatust, interdistsiplinaarset meeskonnatööd palliatiivravis ning hingehoiuteenust palliatiivravi osana. Doktoritöö teine peatükk käsitleb teema olulisust. Peatükk 2.1 esitab uuringutel I–III põhinevad argumendid, mis on seotud hingehoiuteenuse pakkumisega Eesti haiglates. Peatükk 2.2 esitab uuringutel IV ja V põhinevad eetilised argumendid. Doktoritöö kolmas peatükk tutvustab mudeli konstrueerimise ja täpsustamise protsessi, toob mõned näited varasematest mudelitest ning esitab algse teoreetilise mudeli kokkuvõtvas tabelis (Tabel 1). Peatükk 3.2 tutvustab mudeli täpsustamise protsessi (poolstruktureeritud intervjuu küsimuste loomist ja kvaliatiivse uuringu V teostamist) ning esitab kokkuvõtlikus tabelis mudeli lõpliku versiooni (Tabel 4).

Käesolevas doktoritöös on kasutatud interdistsiplinaarset lähenemist, et käsitleda hingehoiu kaasamist tervishoiuasutuste interdistsiplinaarses töös. Vaadates erinevaid interdistsiplinaarsuse tüüpe (Huutoniemi et al. 2010) võib käesolevas töös kasutatud lähenemise liigitada teoreetilise ja empiirilise interdistsiplinaarsuse kategooriasse, jäädes meetoditelt sotsiaal- ja humanitaarteaduste raamesse. Uurimisküsimustel põhineva tüpoloogia järgi on käesolevas töös tegemist sünteesiva interdistsiplinaarsusega, mille puhul uurimisküsimused asuvad erinevate distsipliinide lõikepunktides (Lattuca 2001, 82–83; 115–116). Käesolev doktoritöö ammutab teoreetilist ja empiirilist informatsiooni erinevatest valdkondadest, samuti on osa uuringust teostatud erinevate valdkondade

esindajate koostöös ning mudel on konstrueeritud kogudes ja integreerides erinevatest valdkondadest pärit komponente.

Hingehoid on käesolevas töös defineeritud vastavalt Eestis kehtivatele hingehoidja ja kaplani kutsestandarditele: hingehoid on professionaalne tugi eksistentiaalses ja usulistes küsimustes, mida pakutakse vastavalt toetatava inimese vajadustele ja uskumustele ning koolitatud spetsialisti (hingehoidja või kaplani) poolt; hingehoidja kuulub kas mõnda Eesti Kirikute Nõukogu liikmeskirikusse või Eestis ametlikult registreeritud usuühendusse, millel on Eesti Kirikute Nõukogu heakskiit (*Hingehoidja kutsestandard* tase 6 ja 7; *Kaplani kutsestandard* tase 6 ja 7, kehtiv 2013–2018; uuring II). Hingehoiu interdistsiplinaarset olemust on käesolevas töös selgitatud läbi inimese olemasolu erinevate aspektide omavahelise seotuse. Erinevad teadmiste valdkonnad aitavad hingehoidu informeerida ja vastata patsientide erinevatele vajadustele mõistes nende vajaduste omavahelist seotust. Interdistsiplinaarsust on käesolevas töös selgitatud ka tervishoiuasutuste interdistsiplinaarse töö kontekstis, keskendudes eraldi meeskonnatööle palliatiivrasvis.

Käesolevas töös on kasutatud Maailma Terviseorganisatsiooni (WHO) palliatiivravi definitsiooni, kuna see on Eesti tervishoius omaks võetud (<http://www.pallium.ee/et/palliatiivne-ravi>; Suija 2007) ning ei ole piiratud konkreetse diagnoosiga, surma vältimatusega, haiguse staadiumiga ega asutuse/osakonnaga (näiteks hospiits või õendushooldus). Palliatiivravi on lähenemine, mis parandab elu ohustava haigusega patsientide ja nende lähedaste elukvaliteeti, ennetades ja leevendades kannatusi (füüsilisi, psühhosotsiaalseid ja spirituaalseid) läbi nende varajase identifitseerimise ja hindamise ning vastavalt valitud meetmete kasutamise (WHO URL: <http://www.who.int/cancer/palliative/definition/en/>). Kuigi käesolevas töös on rõhutatud hingehoiuteenuse rolli palliatiivravi osana, on siin hingehoiu fookust tervishoius ka laiendatud palliatiivravi piiridest väljapoole (katmaks ka neid juhtumeid, kus patsiendi elu pole haiguse poolt ohustatud, kuid toevajadus on siiski märgatav).

Käesoleva doktoritöö teine osa sisaldab publikatsioone, mis on järjestikused sammud mudeli konstrueerimise ja täpsustamise protsessis. Uuring I annab esialgse sissevaate spirituaalse/religioosse toe pakkumisse Eesti tervishoiuasutuste hospiits- ja õenduse/hoolduse osakondades (hingehoidu seostatakse Eesti tervishoius peamiselt, kuigi mitte alati, surijate ja nende lähedaste toetamise ning leinaga). Järgnevad uuringud ei ole piiratud elu lõppfaasiga. Uuring II esitab Eesti kaasaegse haiglahingehoiu arengu jaoks olulised sotsiaalsed ja kultuurilised aspektid, pakkudes mudeli loomise jaoks vajaliku Eesti sotsiaalkultuurilise konteksti. Uuring II kasutab meetodina erinevatesse valdkondadesse kuuluvate andmete süstemaatilist analüüsi (*systematic review*). Andmed on pärit Eesti Statistika Andmebaasist (2010–2015), Eesti rahvastikku iseloomustavatest sotsiaalteaduslikest ja kultuuriuuringutest ning Eesti haiglate ja hingehoiu haridust pakkuvate asutuste avalikest andmetest. Uuring II keskendub alateemadele: a) patsientide psühhosotsiaalne toimetulek, b) rahvus ja keeled, c) sekulaarsus ja religioosne mitmekesisus. Uuring III annab sissevaate Eesti haiglahingehoiu institutsionaalsesse konteksti käsitledes Eesti tervishoiutöötajate teadmisi, koge-

musi ja suhtumisi seoses spirituaalse/religioosse toe ja hingehoiuteenusega. Kvantitatiivne uuring teostati 19-s Eesti haiglas kasutades anonüümset veebipõhist küsitlust; valimisse kuulusid need tervishoiutöötajad, kellel oli igapäevane kontakt patsientidega või kes tegelesid ravi/hoolduse juhtimisega. Uuring IV tegeleb interdistsiplinaarse meeskonnapõhise hingehoiu mudeli esialgse teoreetilise mudeli loomisega Eesti tervishoiuasutuste jaoks. Selles uuringus on kasutatud uuringusünteesi (*research synthesis*), et valida välja ja kombineerida mudeli konstruktsiooni informeerivaid uuringuid erinevatest valdkondadest (n hingehoid, religioonipsühholoogia, sotsiaaltöö, tervishoiu korraldus, organisatsioonikäitumine). Kogutud informatsioon on omavahel seostatud ja esitatud läbi eelneva kontekstianalüüsi. Uuring V täpsustab loodud mudelit vastavalt praktiseerivatelt tervishoiutöötajatelt kogutud informatsioonile ning esitab mudeli täpsustatud versiooni. Täpsustav informatsioon on kogutud poolstruktureeritud intervjuudega kolmes Eesti haiglas, kus hingehoidjad kuuluvad ametlikult töötajaskonna hulka. Valimisse kuulusid nimetatud asutuste hingehoidjad ja need tervishoiutöötajad, kellel oli vähemalt minimaalne tööalane kontakt oma asutuse hingehoidjaga. Intervjuu küsimused puudutasid esialgse teoreetilise mudeli igas osas tehtud ettepanekuid.

Kontekstianalüüsist ja Eesti hingehoiu hetkeseisu analüüsist võis järeldada, et Eesti tervishoiuasutustes töötavad hingehoidjad peaksid: a) olema orienteeritud oma töö tulemuste hindamisele ja väljendamisele (teostama hingehoiualaseid uuringuid ning väljendama oma töö tulemusi teistele erialadele arusaadavas keeles); b) tegema koostööd psühholoogide ja sotsiaaltöötajatega, et anda panus tervikliku tervishoiuteenuse pakkumise edendamisesse; c) keskenduma eksistentsiaalsetele ja spirituaalsetele/religioossetele teemadele olles samal ajal võimalised käsitlema ka psühhosotsiaalseid teemasid ja võimalikke kultuurilistest erinevustest kerkivaid konflikte; d) olema oma asutuse töötajaskonna toetavad liikmed: valmis interdistsiplinaarseks meeskonnatöök, andma sisekoolitusi ning toetama teisi töötajaid; e) olema avatud kultuurilisele (ka spirituaalsele/religioossele) mitmekesisusele, kuid samal ajal märkama potentsiaalselt kahjulikke praktikaid; f) olema juurdunud oma usus, kuid seda mitte propageerima. Uuring IV pakkus välja esialgse mudeli järgmises jaotuses: a) ametialane presentatsioon; b) põhitegelased; c) koostöövormid; d) erialane ettevalmistus/sisekoolitused (Tabel 1). Esialgses mudelis kaalusid eetilised argumendid üle tulemustele orienteeritud lähenemise ning ettepanek tulemustele orienteerituseks jäeti mudeli täpsustatud ning viimasest versioonist välja. Uuring V esitab täpsustatud mudeli kokkuvõtlikus tabelis, kuid mudeli kontrolltõlkimisel (inglise-estli-inglise) lisandusid veel mõningad täpsustused, peamiselt keeleliste erinevuste tõttu inglise ja eesti keele vahel. Mudeli lõplik versioon on esitatud tabelis 4.

Hingehoiu pakkumine Eesti tervishoiuasutustes on ebaühtlane – hingehoidjad on kaasatud mõnes Eesti haiglas, kus nad kuuluvad kas palliatiivravi üksusesse, kliiniku või osakonna koosseisu või külastavad haiglat mittekoosseisulisena. Enamus Eesti haiglatest ei paku ametlikult hingehoiuteenust. Hingehoiu interdistsiplinaarne kaasamine Eesti tervishoiuasutuste töös on tihti küsitav ka juhul,

kui asutuses on hingehoid patsientidele võimaldatud: a) juhul kui hingehoidja on kutsutud väljast (ei ole koosseisuline); b) juhul kui koosseisuline hingehoidja tajub end pigem individuaalse töötajana. Käesolevas töös loodud interdistsiplinaarse meeskonnapõhise hingehoiu mudel on mõeldud: a) hingehoiu interdistsiplinaarseks rakendamiseks tervishoiuasutustes, kus plaanitakse hingehoidja kaasamist koosseisulisena; b) interdistsiplinaarse koostöö tõhustamiseks hingehoiu pakkumisel neis tervishoiuasutustes, kus hingehoidjad juba koosseisulistena kollektiivi kuuluvad. Mudel pakub nii paindlikkust, mis võimaldab arvestada erinevustega asutuste ja osakondade vahel, kui ka konkreetseid soovitusi, mis põhinevad patsientide erinevaid vajadusi käsitleval teoreetilisel taustal ning praktiseerivate tervishoiutöötajatega teostatud intervjuudel.

Töö lisades on esitatud uuringute III ja V küsimustikud, poolstruktureeritud intervjuu küsimused ning mudeli eestikeelne versioon.

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3/31/2018, 2:21 AM

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PUBLICATIONS

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Currently (since 2014): Tartu University, Faculty of Theology, religious studies, PhD.

Tallinn University, 2011, Master's degree in social sciences (social work: mental health and wellbeing; specialising in bereavement crisis).

Tallinn University, 2009, Bachelor's degree (social work: child protection).

Institute of Theology of the Estonian Evangelical Lutheran Church, 2014, professional higher education (pastoral care)

Work experience and practice during studies:

- Since 2017 North-Estonia Medical Centre, palliative care unit, pastoral counsellor.
- Since 2016 Lecturer in Institute of Theology of the Estonian Evangelical Lutheran Church.
- 2016 Supervised pastoral care practice in Marie Curie Hampstead and Liverpool hospices (included visitations to Pembridge Palliative Care Unit in St Charles Centre of Health and Wellbeing, and to Royal Trinity Hospice in London).
- 2014–2015 Tartu University Hospital, Haematology-oncology clinic, pastoral counsellor.
- 2013–2014 Pastoral care practice in Tartu University Hospital, Haematology-oncology clinic.
- 2010–2011 North Estonia Medical Centre, oncology clinic, social worker.
- 2010–2011 North Estonia Medical Centre, palliative care project, social worker.
- 2009–2010 Supervised social work practice in Tallinn Children's Hospital.
- 2008 Tallinn Diaconic Hospital, volunteer

Publications:

- Meel, L. 2015. Implementing spiritual care at the end of life: Estonia. *European Journal of Palliative Care*, 22 (1): 36–37.
- Meel, L. 2016. Socio-Cultural Aspects of the Development of Contemporary Clinical Pastoral Care in Estonia: A Systematic Review. *Health and Social Care Chaplaincy*, 4(1): 57–70.
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Tallinna Ülikool, 2009, sotsiaalteaduste bakalaureus (sotsiaaltöö: lastekaitse).
EELK Usuteaduse Instituut, 2014, rakenduskõrgharidus (hingehoid)

Töökogemus ja õpingutega seotud praktika:

Alates 2017 SA Põhja-Eesti Regionaalhaigla Palliatiivravi keskus, hingehoidja.
Alates 2016 EELK Usuteaduse Instituut, lektor.
2016 Superviseeritud hingehoiupraktika Marie Curie Hampsteadi ja Liverpooi hospiitsides (külastuspäevadega: Pembridge palliatiiv-ravi üksusesse ravikeskuses St Charles Centre of Health and Well-being ja Royal Trinity hospiitsis Londonis).
2014–2015 Tartu Ülikooli Kliinikumi Hematoloogia-onkoloogia kliinik, hingehoidja.
2013–2014 Superviseeritud hingehoiupraktika Tartu Ülikooli Kliinikumi Hematoloogia-onkoloogia kliinikus.
2010–2011 SA Põhja-Eesti Regionaalhaigla onkoloogia keskus, sotsiaaltöötaja.
2010–2011 SA Põhja-Eesti Regionaalhaigla palliatiivravi projekt, sotsiaaltöötaja.
2009–2010 Superviseeritud hingehoiupraktika SA Tallinna Lastehaiglas.
2008 SA Tallinna Diakooniahaigla, vabatahtlik.

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Meel, L. 2015. Implementing spiritual care at the end of life: Estonia. *European Journal of Palliative Care*, 22 (1): 36–37.
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DISSERTATIONES THEOLOGIAE UNIVERSITATIS TARTUENSIS

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