Speaking of what matters most

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H1 Introduction: The spirituality and spiritual needs of children with chronic conditions during their development. Implications of age, context and culture.

Introduction

Within the health care of developed countries, we see a shift from a medical model towards an integral bio-psychosocial model in recent years. The World Health Organisation (WHO) showcased this by embracing the International Classification of Functioning (ICF) in 2001, which is much more focused on activities and functions instead only on illness and handicaps. A physician from the Netherlands (Huber, 2014) challenged the WHO further with a thesis calling for a radical revision of its view on health. She suggests a shift in this view on health not only as the absence of a medical condition of handicap but to see health as the ability to adapt and self-manage social, physical, and emotional challenges (Huber, 2014). Although this call for revision also received some criticism, as not all humans have the same opportunities and possibilities to shape this ability, it is a sign of a shift in perspective. This shift can be explained by the improvement of the medical possibility overall, a decrease in fatal diseases and the increase of people with chronic conditions, who accumulate more chronic conditions during a person's lifespan (Michaud, Suris, & Viner, 2007; Compas, Jaser, Dunn, & Rodriguez, 2012). This results in a growing population in most developed countries whose needs transfer from curative to chronic and preventive care.

This trend impacts not only the care for adults, but also the care for children. More children than before survive premature births but have lifelong complications or disabilities as a result; get cured from acute illnesses like leukaemia but stay under vigilant aftercare for years; or can have a relatively normal childhood despite having severe chronic conditions allowed by medical technical innovations (Mokkink et.al., 2007). All these children require specific care, usually from a very young age and throughout their childhood, not so much to cure their condition but aimed at maximising the quality of their life and support the coping with consequential disabilities. The only way to cater this demand caused by changing needs is a holistic perspective on their lives and health. Focusing on who they are and what they need as individuals and humans to live a fulfilling live, calls for this holistic perspective. Huber et al. (2016) did a follow up study to identify what it means to have a holistic perspective and found six dimensions, including a spiritual dimension. This is not the first time the importance of spirituality is advocated for in health care (Roehlkepartain, King, Wagener, & Benson, 2005, McSherry & Smith, 2007; Cobbs, Puchalski & Rumbold, 2014). Spirituality seems to be a key aspect influencing health and wellbeing, but little is known about its relevance among children with chronic conditions.

Impact of chronic conditions on children

In order to fully understand the requirements of holistic paediatric health care, we need to have a clear picture of the need of these children. Situations around the world differ greatly in health care, cultural circumstances and statistics, for this thesis we will use the Dutch situation as the contextual setting. So, who do we consider when we speak about children with a chronic condition?

A chronic illness or chronic medical condition is a health problem which lasts three months or more, affects a child's normal activities and requires frequent hospitalisation, home healthcare and/or extensive medical care (Mokkink, Van der Lee, Grootenhuis, Offringa, & Heymans, 2008). The prevalence is different between countries and depends on the definition used but based on available documentation estimations show that between 10,5% and 14% of all children in the Netherlands grow up with one or more chronic conditions (Gijssen et al., 2014). This translates to approximately half a million Dutch children with chronic conditions like obesity (14%), asthma (10%), eczema (6%), or with less common (<1%) conditions like diabetes, juvenile arthritis, cystic fibrosis hemophilia or epilepsy (Verhoof, 2015). A recent Dutch study (Van Hal et al., 2019) based on data from insurance companies, shows that as many as one in four children grow up with a chronic condition when using a definition that includes psychological conditions like ADHD.

Growing up with a chronic condition has a profound impact on the lives of these children. Children with a chronic condition live a slightly to very different life compared to their peers, often from a very young age, or even from birth. Because of the uncertainty of the development of many chronic conditions and the limited insight in the consequences of their condition, their perspective on the future is also influenced. Although children realize this more as they grow older, evidence shows that parents are aware of this fact immediately when the child is diagnosed with its chronic condition (Coffey, 2006), this also undoubtedly impacts their childhood.

A lot of the impact of a chronic condition is linked to (limited) participation. Dutch children between 8 and 18 years reported that they view 'full participation' not merely as the possibility to join an activity but as the way to belong and influence their peers (Nap-van der Vlist et al., 2019). Dutch young adolescents with a chronic condition reported recently on the implications and consequences on different domains of live (Van Hal et al., 2019). In this study they mark their lives lower in comparison with healthy peers, declining with age, and they report lower degree of self-worth and well-being. They need more help and aiding materials but have more difficulty asking these than their healthy peers. They feel less understood by peers, and with age they decreasingly share their condition, they feel alienated in sport clubs, work less than they would want to and feel misunderstood at work. This also show in health care needs: they feel often restricted by their health. For the future they report less excitement and more fear of not becoming self-sufficient in comparison with healthy peers (Van Hal et al., 2019).

These findings are troubling, as especially children with a chronic condition will probably be part of our society for as long as their healthy peers. If this perspective derails at so young an age, this will likely have lifelong consequences. So, the question rises if we can address this impact on feelings of belonging and perspective of the future? But before delving in what this really means and what children exactly need, first a few of these concepts will be explored to define the contour of these thesis.

Spirituality as a part of holistic development of children

The concept of spirituality

The impact of living with a chronic condition as described above is not just a social one even though it influences relations, nor a psychological one even though it requires coping, and even though caused by a somatic condition, it is also not just a physiological one. It's more, or better, something deeper that those domains. It touches the purpose of life as experienced by these children, their

perceived and actual future and live perspectives; their reason d'etre as you will. The domain this impact is felt most deeply, is the spiritual domain. The social sciences were the first to consider religion and spirituality integral to their field, with most underlying literature of this domain stems from psychology: the psychology of religion and the field of psychoanalysis (Roehkepartain et al., 2006). This origin sometimes causes confusion or bias on what is meant when referring to spirituality. Beside this place of origin, it is also notable that Roehlkepartain et.al. (2006) report that before 1980 the search term 'spirituality' did not yield any results in the MedLine database. It is a relatively new domain. A third complicating factor is the fact that spirituality is an abstract concept that is hard to define. It's a new domain, but additionally a domain on which common conceptual consensus has not yet been reached.

Weathers, McCarthy, and Coffey (2016) state that each concept description usually consists of three main components: connectedness, transcendence and meaning of life. European professionals and scientist specialist in palliative care (EAPC) were able to reach a consensus on a broad, inclusive definition, although also reporting 'spirituality is difficult to define because of its multidimensional nature' (Nolan, Saltmarsh, & Leget, 2011, p.86). They identified three domains: the first, existential questions regarding identity, meaning and topics like suffering, hope and joy; second, value-based considerations and attitudes, described as: 'the things most important to each person such as…family, …ethics and morals, and life itself' (Nolan et al., 2011, p.88); and third, religious considerations and foundations such as faith, (religious) beliefs and practices. In this thesis their consensus-based definition is used to define the playing field as it includes, but not limits to, religiousness and uses concepts from different fields which enable multidisciplinary approaches: 'Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices' (Puchalski, Vitillo, Hull, & Reller, 2014, p.643).

Additionally, when applied to children it is important to consider the nature and development of this spirituality, for this we chose the viewpoint of the development of spirituality as a seeking, as Yust et al. (2006) state when they say: '*Spirituality is (..) something greater than the self. It propels the search for connectedness, meaning, purpose and ethical responsibility*' (Yust et al., 2006, p8).

Spirituality of children

Although the previous definitions are aimed at the spirituality of adults, the current idea in the literature is that the spiritual lives of children also appear to be rich and complex (Boynton, 2011; Drutchas & Anandarajah, 2014). Boynton (2011) states that the spirituality of children is an overlooked subject for research, especially regarding the theoretical concepts of spirituality in children, meaning that there is no child-specific discourse or definition. As most studies on spirituality are carried out in the Western world, dominated by Christianity and where spirituality is often confused with religiosity and where the language of spirituality is heavily influenced by religious vocabulary (Hay & Ney, 2006), we do not know much of the theoretical base of spiritual concepts for children.

In 1989, the United Nations declared that every human is a spiritual being, and therefore state that every child should have the universal right of an optimal spiritual development, claiming it to be a biological preposition, an innate 'spiritual awareness' (UN, 1989). A British study (Hay & Ney, 2006) showed that this awareness in primary school children between six- and ten-year-olds mainly seems to be a 'relational consciousness'. They describe a starting point for researchers and teachers on the concept of the spiritual sensitivity of children by identifying three categories: awareness-sensing, as being present in the here and now; as mystery sensing, being able to wonder and feel awe; and value-sensing, including meaning and knowing what is 'good'. These spirituality sensitivity categories that help explore spirituality are closely linked but not equal to the child's spirituality.

After this publication, there has been some publications like Scott (2003), Boyton (2011) and Minor & Grant (2014) of scientist supporting this theory, the latter even indicating that nurturing this consciousness has a positive influence on spiritual well- being. But no studies have been done that validate the premisses in other cultural contexts. In recent years the publications in this field unfortunately have declined. Children, especially young children, are notorious underrepresented in studies regarding spirituality, which leads to gaps in our conceptual knowledge of what spirituality means to children, the statistical knowledge of correlation with quality of life and the practical implications for paediatric care to support the spiritual development of children.

Promoting holistic development of children

To acknowledge spiritual development as a right of every child does not automatically mean that this aspect of the development of a child is regarded by professionals as an integral part of the child's development. Spiritual development is a process, unique for every child, depending on each individual's experience (Mercer, 2006). To understand this spiritual development and recognise the expression of this in children it needs to be reviewed holistically in relation to the development of children on other domains (McSherry & Smith, 2007). Therefore, this paragraph will address the main developmental task of the cognitive, moral and religious domains.

Although spirituality is seen as innate and thus exist directly after birth, the psychological and developmental literature usually regards the period from ages six to twelve as the period during which a child has the cognitive and reflective ability to perform significant developmental tasks that influences their spiritual development. It is the period during which children develop an important part of their identity in terms of self-confidence according to Erikson (1963), and generally have a strong sense of belief in justice. According to the theory of Kolhberg (Van Beemen, 2001), children also develop an autonomous sense of morality and an underlying way of reasoning for their current and future moral decisions during this period. As spirituality also includes a transcendental aspect, it is helpful to know that according to Fowler (1981) children transfer in this period from the first intuitive stage of faith in which reality and fantasy mingle in what the child sees as truth or reality, into the second stage around the age of eight, known as the magical-literal stage, in which faith is primarily an experience, and all their experiences are made concrete in stories and rituals which help develop their faith. From the age of twelve children can either stay in this second stage as it becomes a fixed stage, with faith only evolving through the other developmental domains, such as the ability for abstract and analytical thinking (Van Beemen, 2001), or enter the third stage of faith which is characterised as a synthetic-conventional stage, where the child is able to reflect on its own ideology and the Ultimate is found in relations, including a loving and supportive relation with the Sacred or Other, this stage can also be the come a fixed stage (Neuman, 2011). This knowledge is fundamental to understand the holistic development of a child and connect to the child using vocabulary, emotions, experiences, or reflections fitting to the stage a child is likely to be at (see table 1). It also guides this study in selecting the target population, identifying this to be children between eight and twelve years old. As children that are too young, are not able to separate fantasy from reality and

have yet to learn to reflect on themselves as this cognitive competency is not yet developed. Children of twelve and older reach puberty and belong to a population among whom more research already has been done.

Brief List of Holistic Development of Children Combining Piaget (P), Erikson (E), Kohlberg (K), and Fowler (F).	
Prestage: Undifferentiated Faith Typical age 0–2 years	Reflexive behavior (P); Trust vs. mistrust; self is good, world is good (E); no morality— does what pleases child (K); love, courage, hope: if the environment is nurturing this supports the development of a sense of trust and feeling safe (F)
Stage 1: Intuitive-Projective Faith Typical age 3–7 years	Egocentric, magical, perception dominated (P); Control of self/ body, willfulness (E); learning rules, right, wrong and punishment, reciprocity (K); religion is learned by stories and images, fantasy and reality not distinguished, fluid thoughts; symbols are important; God surrounds like air (F)
Stage 2: Mythic–Literal Faith Typical age 7–12 years	Logical, systematic, concrete thinking (P); competence, master skills, work/ play with peers (E); morality— not disturb conscience; social sensitive, show respect/duty, obeys rules (K); belief in justice of the universe, fantasy confined to play, Deities as anthropomorphic, deals reciprocally with relations, metaphors and symbols often taken literal (F) Can become a persistent stage 2 from age 12–adult: Abstract thinking, analytical, (P) peers paramount, faith in self (E); majority rules, exception if violate welfare of person; laws for mutual good, cooperation (K); God as anthropomorphic, deals fairly and reciprocally with people, symbols literal, sense of trapped in narrative, cannot reflect on it (F)
Stage 3: Synthetic–Conventional Faith Typical age 12–21 years	Abstract thinking, analytical, (P); peers paramount, faith in self, development of identity (E); majority rules, exception if violate welfare of person; laws for mutual good, cooperation (K); God as companion, guide, support, loving; sees the "ultimate" in terms of interpersonal relationships; can reflect on symbols and values, chooses consistency and conformity to religious authority (F) Can become a persistent stage 3 from age 21+: Abstract thinking, analytical (P); characterized by love, mutuality (E); conformity to rules of society, internal locus of control, (K); God as companion, guide, support, loving; sees the "ultimate" in terms of interpersonal relationships; can reflect on symbols and values, and the system of beliefs as a system (F)

Table 1: Overview of holistic developmental stages of children. Table content based on Neuman (2011), with additions from Drutchas & Anandarajah (2014).

Spiritual needs arising during spiritual development

When reviewing the state of the art of various disciplines and the current knowledge in the field of paediatric nursing, the question that is still unanswered is: what spiritual needs can arise in conjunction with children's spiritual development when they are confronted with sickness and chronic conditions?

There is already a strong base of evidence proving that spirituality is a factor of influence on the well-being of youth with King & Benson (2006) summarizing research to conclude that spirituality has been positively associated with a reduction of risk behaviours in youth, an increase of resilience and the presence of positive development indicators. Oman & Thoresen (2006) elaborate on this by reviewing the proven health protective mechanisms relating to spirituality, varying from exercising, and the prevalence of being overweight unto lower suicidal ideation and suicidal attempts. Oman & Thoresen (2006, p. 402) stress the importance of studying these patterns and relationships in populations of children and adolescents as health behaviour learned during childhood often predicts adult health behaviour. These patterns and relationships extend to children depended on health care shown by Spurr et al., (2012) who, among others, prove the importance of integrated spiritual care as is supports paediatric patients to cope with illness and disability (Roehlkepartain, King, Wagener, & Benson, 2005; Swinton, 2012). We also know that spiritual coping can help children make sense of their condition or disability (Drutchas & Anandarajah, 2014) and help them adapt to a life with a chronic condition (Fosarelli, 2006; McSherry & Smith, 2007).

From this evidence we can deduce that lack of attention to spirituality of dismissal of spiritual coping can therefore lead to negative effect on health, wellbeing, and coping. But this has not been studied thoroughly. When we concurrently assume that children with chronic conditions have identifiably different health care experiences, compared to their healthy peers, we also should be aware of the spiritual needs that can arise during the child's spiritual 'seeking'.

Spiritual care for children

Related to the definition of spirituality, is the definition of spiritual care. For acknowledging spirituality as an innate part of being human and promoting holistic development as a responsibility of professionals to implement in their practice we need to be clear on what we understand spiritual care to be. In principle this responsibility should be one of every professional working with children, but especially those who work with sick children, whether this is in health care settings, ambulant settings or educational settings. As spirituality was originally strongly linked to religiosity, mainly psychologists and chaplains were seen as the primary disciplines who addressed aspect of care related to spirituality, religion and existential crisis. In recent years, within health care also other health care professional disciplines further recognised spirituality as an important aspect of care (Cobb, Puchalski & Rumbold, 2021). One of these disciplines consists of the nursing field. Martsolf & Mickley (1998) already state that within nursing there is little argument that a holistic nursing perspective includes spirituality and recognises this as an import aspect of holistic care. As nursing is in principle a more general, all-round and holistic disciplinary, already encompassing physiological, social and psychological knowledge, nurses can be excellent gate keepers for signs of spiritual distress in patients as they see the patients most frequent compared to other health care professionals. Especially paediatric nurses who are already educated in the development of children and trained to observe all life domains, can play a vital role in noticing occurring signs and symptoms. Although not many nursing theorists explicitly included spirituality into their theoretical frameworks and philosophies during the peak of nursing theory development, starting in the 1960s, some did; like Watson and Neuman (Tomey & Alligood, 2002). The acknowledgement of these theorists that spirituality is indeed one of the core domains of nursing, has led to research on spirituality and spiritual care to explore and define what it is, and what it is not. A recent collaborative international project called 'EPICC' resulted in the definition of professional practice of spiritual care (Van Leeuwen et al., 2020), adapting a description of the NHS Scotland as '*Care which recognizes and responds to the human spirit when faced with life-changing events (such as birth, trauma, ill health, loss) or sadness, and can include the need for meaning, for self-worth, to express oneself, for faith support,*

perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship and moves in whatever direction need requires' (Van Leeuwen et al., 2020, p.57).

This definition was formulated to be firstly applicable for nurses and midwives but characterized by a broad multidisciplinary scope of spiritual care, focusing on life events instead of age, context, or discipline. While the definition was not specifically developed for spiritual care for children, it is inclusive enough to be used in this thesis, as it focuses on life events which also can occur in childhood.

Need for contextual instruments

Most studies about spirituality of children are executed in English-speaking countries, with much of the available knowledge coming from the United States (Roehlkerpartain et.al., 2006). The applicability of this knowledge in other cultural contexts is limited and that of the developed instruments problematic when working or researching with children in non-English speaking countries. Most studies are consequently done in populations where the majority of people identify with Christianity, and most studies use religious concepts and vocabulary. This again limits the applicability to children who grow up in more secularized societies. But also, for researchers and professionals to study the concept among the population or discuss this topic with children in their care as it limits the scope in which children can express their spirituality. These observations suggest that the need for a study in the native language of children in other countries is important. Even more so, as one might argue that the development of spirituality in children is dependent on their (religious) language, cultural context, and societal influences (Boynton, 2011).

We already did address the prevalence of children with a chronic condition from a Dutch perspective, but it would be informative to outline the specific characteristics of the Dutch culture. It is notable that more than half of the Dutch population (51%) reported in 2017 for the first time ever, not being religiously affiliated (CBS, 2018). This shows a degree of secularisation that is important in relation to a study on spiritually, as it demands a definition and approach that includes children growing up in families with and without religious affiliations. The Netherlands is a relatively small country in the northwest of Europe, covering 41.543 km^2 with approximately 17,5 million citizens (in 2021), with 24,2% having a migration background according to the dashboard of Central Bureau of Statistics (www.cbs.nl). There are twelve regions or 'provincies' differing greatly in population density and natural habitat. The Dutch are aware of their dependency on other countries and international partners, they value the participation in the European Union for example, as various international export markets are a big part of the economic stability and growth. This awareness shows in the fact that all children are taught English during the last year of their primary education. The Netherlands has a school system that differentiates between public school and special schools, these special schools have the right to offer education and set certain conditions according to a religious or pedagogic principle. In 2020-2021 the CBS reported that of the almost 1,5 million children going to primary school, about one third of all children in this age attends a special school. All schools are financed by the government and officially free of charge. The main language is Dutch, but three additional regional languages have been acknowledged, and hundreds of dialects are still spoken today alongside languages that citizens with a migration background have introduced.

Dutch healthcare is organised on a principle of competitive market forces: almost all citizens are obliged to have a health care insurance. Everyone who is obligated to have a Dutch health insurance must be insured for at least the basic health insurance. This insurance covers care like the GP, medicines and hospital- visit and stay. If you need extra care, you can apply for additional health insurance. Via the additional insurance, you have the option to cover multiple cares such as physical therapy, dental care or alternative care although this does not mean all health care is free. There are over 300 hospitals in total, and seven university hospitals, all with a specialized paediatric department. Paediatric care is preferably organized at home, with only admittance to the hospital during a relapse or other medical urgency.

So, as the Dutch context has its own unique cultural features, in order to truly understand and address the spirituality of Dutch children and consequently assess the spiritual needs of Dutch children with a chronic condition, we need to ask *them* what they consider to be their spirituality.

Importance of 'the HOW'

It is probably not without reason that children often omit in research on spirituality. The concept itself is abstract. So how to include children? How to address the spiritual domain without the bias of scientific or religious vocabulary? How to formulate and disseminate knowledge to influence practice as objectively as possibly? How do we take children seriously in their expression yet account for the fact that how we regard the competencies of children influences how scientist and professionals listen and talk to children? Pondering this brings us beyond the 'what'-question of spirituality and spiritual needs. It addresses the importance of the 'how'-question of communicating, assessing, and supporting children in this regard.

We also already established that there is religious vocabulary available that is unsuited for children, that there are knowledge gaps regarding 'neutral' spiritual vocabulary, and we know that among professionals, like nurses, there is a need for communication training to successfully assess and address spiritual needs (Ferrell et.al., 2016). In health care as a whole, little is known about the needs of children themselves regarding communication about spiritual aspects, as studies often target nurses as respondents instead of children themselves. So, for this study, an introduction video was made, explaining the nature of spirituality (or 'zingeving' as it is more widely used in the Netherlands), including as little scientific concepts or vocabulary regarding the topic. This video was distributed among parents and children willing or eligible to participate in the study.

SCAN ME

Figure 1: QR code of the instruction video for children and their parents.

Then there seems to be a lack of spiritual paediatric care resources, because although there is some work done on assessing spirituality in children, on closer examining the target population is often adolescents. What we also do not know is how to adequately assess spiritual needs of younger children. The few validated assessment scales concerning spirituality of children are in all English and developed in/for a few specific cultural contexts. So especially in non-English-speaking countries, assessing the spiritual needs of younger children is still a big challenge. Fisher (2007) reports on available scales for younger children, concluding that only one or two scales appear to have the broad scope of spiritually as meant in this thesis. In this thesis we will investigate and -if needed- translate valid scales for young children, to see which scale(s) will be applicable for Dutch children, and to find out if and how religiousness should be addressed, implicitly or explicitly, in more secular countries like the Netherlands.

Boyton (2011) stresses the importance of bringing knowledge from different disciplines together to study spirituality of children, adding that because there is a lack of reliable scales and therefore a need to combine qualitative and quantitative information. This thesis will therefore include a broad, multidisciplinary approach, even though the primary targeted discipline will remain nurses and nursing specialists, to enable them to act as gatekeepers on this domain in health care settings. Quantitative as well as qualitative methods will be deployed, using existing literature on methods specified for children to build upon. In all of this, the perspective of the child will be the centre of attention. Creative methods will be incorporated to give them a say in the research process and adapt this to their possibilities and wishes. They will be given the opportunity to react to the (translation) work of adults, testing what the grown-ups think they're capable of. Their needs guide this study, as their spiritual needs should guide our spiritual care.

When considering spiritual paediatric care, it is uncertain if enough is studied about spiritual care interventions for children to impact clinical practice. Tebyani (2011) did some explorative work on how to nurture children's spirituality by formulating outcomes of this nurturing, and Hay & Ney (2015) identified four responsibilities of teachers, including encouraging personal awareness, and exploring ways of seeing. But the how of this nurturing, this encouraging, is still very much unexplored. With this ho, also a moral and ethical issue present itself as children are vulnerable as a population, but also when dealing with a topic like spirituality. Issues surrounding social pressure, safety and religious taboos require a neutral, open and respecting attitude of professionals. If this thesis can identify spiritual needs in children with chronic conditions, these findings could also be used to develop educational interventions for professionals and interventions for the children to address these needs.

Aim of this thesis

In response to all the raised topics in this introduction this thesis focusses on the experiences, vocabulary and needs of children regarding their spirituality, their spiritual development, and their spiritual needs.

The most important aim of this study is to explore the what of the spirituality of children in their native language, in this study this will be Dutch. This exploration of vocabulary used by children to express an abstract concept like spirituality is essential to the spiritual development assess potential spiritual needs: *'How do young (Dutch) children with a chronic condition express their spirituality?'*

The parallel aim, with whom this thesis will begin to lay down an ethical framework for the following chapters will be concerned with the how of communication, assessment, intervention, and research on the topic of spirituality with the specifics of the population of young children that do not comprehend the scientific concepts and vocabulary of it. This question, and the answers we hope to find are applicable to a broader audience of professionals: '*In what way and with which tools can researchers, health care professionals and educators' asses, address and stimulate the spirituality and spiritual development of children?'*

Thesis outline

This thesis consists of seven individual chapters, most of them already published in a (peer reviewed) journal. Although they can be read independently, together they tell a fascinating story of the experiences of children, especially those with a chronic condition and what they deem most important in their lives. This introduction (H1) sets the tone as the first chapter, introducing main concepts and identifying gaps in our knowledge regarding spirituality, spirituality and spiritual care for children. It explores existing definitions and ends with the formulation of the aim of this thesis.

The first main part focusses on the 'what' of spirituality in children, especially those with a chronic condition. The first chapter (H2) in this part, qualitatively reviewed all relatively recent (2000 and on) studies on the spirituality of children with a chronic condition, to distinguish what we do and do not know on this topic. For this study, the population criteria were broadened to include children between zero and 21-years old, in an attempt to discover all relevant information gathered so far.

The second chapter (H3) in this part focusses on the main target population: Dutch children with a chronic condition between eight and twelve years old. The children were invited to tell the story of their life focussing on what is most important for them in life, without mentioning their condition or spirituality as a concept. Different qualitative methods in this study are deployed to assist children in telling their story using their own language, expressions and utilizing playfulness to support their own way of storytelling.

As we also need more quantitative tools to assess spirituality and spiritual needs, the last chapter (H4) of this first part reports on the meticulously translation to Dutch and validation in the Dutch context of two already reliable tested scales that measure spirituality of spiritual sensitivity; the 'Spiritual Sensitivity Scale for Children' and the 'Feeling Good, Living Life' questionnaire. With the expertise of various professionals from different disciplines and the feedback of healthy children of the targeted ages, this chapter present these two translated scales including an evaluative report of the experiences of the participating children.

As mentioned before, the how of working with children in research, education and health is equally important when addressing academic and conceptual topics like spirituality. The first chapter (H5) of this second part explores the ethical considerations one should review in researching or working with children. It offers guidelines to judge considerations, which has also provided leading principles in the preparations and execution of the other chapters.

The next chapter (H6) uses the literature of the spirituality and spiritual development of the introduction and the previous chapter, mainly the experiences of the children who assisted in the validation of the scales and one of the validated scales to design an educational program for primary

schools to support the spiritual development of children. It describes a proposition for a study, which was not possible to execute during the COVID-19 pandemic, to test and further develop spiritual interventions that help professionals provide a safe space for children.

Then in the discussion (H7) all results are gathered to formulate a coherent conclusion and showing the merits of this thesis, but also the gaps that remain. Implications for health care and educational practices are given special attention, as it is my conviction that the advancement of science and practice should be considered hand in hand.

As multiple chapters have previously been published, multiple reference systems have been used in documenting the literature and can be found in this thesis. Where chapters differ from the published articles this is explicitly mentioned, except for small grammatical issues.

References

Ashwill, J. W., James, S. R., & Droske, S. C. (2002). Nursing care of child principles & practice. USA: Saunders.

Boynton, H. M. (2011). Children's spirituality: Epistemology and theory from various helping professions. International Journal of Children's Spirituality, 16(2), 109–127.

Bull, A., & Gillies, M. (2007). Spiritual needs of children with complex healthcare needs in hospital. Pediatric Nursing, 19(9), 34–38.

Central Bureau of Statistics (s.d.). *Dashboard*. Retrieved from www.cbs.nl on July 19th, 2021. S*chool Attendance*. Retrieved from: https://www.cbs.nl/nl-nl/cijfers/detail/03753?dl=55979 on July 12th 2021.

Centraal Bureau voor Statistiek (2018) *Meer dan de helft Nederlanders niet religieus.* Available at: https://www.cbs.nl/nl-nl/nieuws/2018/43/meer-dan-de-helft-nederlanders-niet-religieus

Cobb, M., Puchalski, C.M., Rumbold, B. (2014). Oxford Textbook of Spirituality in HealthCare. Oxford: Oxford university Press.

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. Annual Review of Clinical Psychology, 27(8), 455–480. https://doi.org/10.1146/annurev-clinpsy-032511-143108.

Drutchas, A., & Anandarajah, G. (2014). Spirituality and coping with chronic disease in pediatrics. Rhode Island Medical Journal, 97(3), 26–30.

Erikson, E. H. (1963). Childhood and society (2nd ed.). New York: WW Norton.

Ferrell B, Wittenberg E, Battista V and Walker G (2016) Exploring the spiritual needs of families with seriously ill children. *International journal of palliative nursing*, *22*(8), 388-394.

Fisher, J. (2009). Getting the balance: assessing spirituality and well-being among children and youth. International Journal of Children's Spirituality, 14, 273–288.

Fosarelli, P. (2006). Care of children. In M. Cobb, C. M. Puchalski, & B. Rumbold (Eds.), Oxford textbook of spirituality in health care. 2012.. Oxford: Oxford University Press.

Fowler, J.W. (1981). Stages of faith. The psychology of human development and the quest for meaning. San Francisco: Harper & Row.

Gijsen R, Van Oostrom, SH and Schellevis FC (2014) Hoeveel mensen hebben één of meer chronische ziekten? In: *Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid.* Bilthoven: RIVM.

Hay, D., & Nye, R. (2006). The spirit of the child (revised ed.). London: Jessica Kingsley Publishers.

Huber, M.A.S. (2014) Towards a new, dynamic concept of health : Its operationalisation and use in public health and healthcare and in evaluating health effects of food. CAPHRI School for Public Health and Primary Care Maastricht, Thesis. PI: urn:nbn:nl:ui:27-506e3a0d-e5ec-4ee2-8604-59f317d2724a

King, P.E., & Benson, P.L. Spiritual Development and Adolescent Well-Being and Thriving. In: Roehlkepartain, E. C., King, P. E.,Wagener, L., & Benson, P. L. (2005). The handbook of spiritual development in childhood and adolescence. London: Sage Publications.

Martsolf, D.S., & Mickley, J.R., (1998). The concept of spirituality in nursing theories: Differing world-views and extent of focus. Journal of Advanced Nursing, 27, 294-303.

McSherry, W., & Smith, J. (2007). How do children express their spiritual needs? Paediatric Nursing, 19(3).

Michaud, P. A., Suris, J. C., & Viner, R. (2007). The adolescent with a chronic condition. Epidemiology, developmental issues and health care provision. Geneva: World Health Organization.

Minor C.V., & Grant, B. (2014) Promoting spiritual well-being: a quasi-experimental test of an element of Hay and Nye's theory of children's spirituality International Journal of Children's Spirituality, 19(3-4), 213–227. DOI: http://dx.doi.org/10.1080/1364436X.2014.960916

Mokkink, L. B., Van der Lee, J. H., Grootenhuis, M. A., Offringa, M., & Heymans, H. S. A. (2008). Defining chronic diseases and health conditions in childhood (0–18 years of age): National consensus in the Netherlands. European Journal of Pediatrics, 167, 1441–1447. https://doi.org/10.1007/s00431-008-0697-y.

Nap-van der Vlist, M. M., van der Sprenkel, E. E. B., Nijhof, L. N., Grootenhuis, M. A., van der Ent, C. K., Swart, J. F.,Kerkhof, A., Van Grotel, M., Van De Putte, E.M., Nijhof, S.L., & Kars, M. C. (2021). Daily life participation in childhood chronic disease: a qualitative study on the child's and parent's perspective. *BMJ paediatrics open*, *5*(1). doi: 10.1136/bmjpo-2021-001057

Neuman, M. E. (2011). Addressing children's beliefs through Fowler's stages of faith. Journal of Pediatric Nursing, 26, 44–50. https://doi.org/10.1016/j.pedn.2009.09.002.

Nolan, S., Saltmarsh, P., & Leget, C. (2011). Spiritual care in palliative care: Working towards an EAPC task force. European Journal of Palliative Care, 18(2), 86–89.

Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the spiritual dimension of whole person care: Reaching national and international consensus. Journal of Palliative Medicine, 17(6), 642–656.

Roehlkepartain, E. C., King, P. E.,Wagener, L., & Benson, P. L. (2006). The handbook of spiritual development in childhood and adolescence. London: Sage Publications.

Scott, D. G. (2003). Spirituality in child and youth care: Considering spiritual development and "relational consciousness". Child and Youth Care Forum, 3(2), 117–131.

Smith, J., & McSherry, W. (2004). Spirituality and child development: A concept analysis. Journal of Advanced Nursing, 45(3), 307–315.

Spurr, S., Bally, J., Ogenchuk, M., & Walker, K. (2012). A framework for exploring adolescent wellness. Pediatric nursing, 38(6), 320.

Swinton, J. (2012). Healthcare spirituality: a question of knowledge. In M. Cobb, C. M. Puchalski, & B. Rumbold (Eds.), Oxford textbook of spirituality in health care. 2012.. Oxford: Oxford University Press.

Tomey, A.M, & Alligood, M.R., (2002). *Nursing Theorist and their Work*. Fifth ed. St. Louis: Mosby.

UN (1989). United Nations Convention on the Rights of the Child. London: Unicef (2018, August 15). Retrieved from http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf.

Van Beemen, L. (2001). Ontwikkelingspsychologie. Groningen: Wolters-Noordhoff.

Van Hal, L., Tierolf, B., Van Rooijen, M., & Van Der Hoff, M. (2019). Een actueel perspectief op kinderen en jongeren met een chronische aandoening in Nederland. Omvang, Samenstelling en Participatie. Utrecht, FNO in samenwerking met het Verweij Jonker Instituut.

Van Leeuwen, R., Attard, J., Ross, L., Boughey, A., Giske, T., Kleiven, T., & Mcsherry, W. 2020. The development of a consensus-based spiritual care education standard for undergraduate nursing and midwifery students: An educational mixed methods study. *Journal of Advanced Nursing*. DOI: 10.1111/jan.14613.

Verhoof E (2015) *Consequences of success in pediatrics. Young adults with disability benefits as a result of chronic conditions since childhood.* S.N. Available at: https://issuu.com/gildeprintdrukkerijen/docs/proefschrift_verhoof

Weathers, E., McCarthy, G., & Coffey, A. (2016). Concept analysis of spirituality: An evolutionary approach. Nursing Forum, 51(2), 79–96. https://doi.org/10.1111/nuf.12128.

Yust K, Johnson A, Sasso S and Roehlkerpartain E (2006) *Nurturing Child and Adolescent Spirituality: Perspectives from the World's Religious Traditions.* Lanham: Rowman & Littlefield Publishers.