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Speaking of what matters most

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rijksuniversiteit
 groningen

Speaking of what matters most

The spirituality and the spiritual needs
 of Dutch children with a chronic condition

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Speaking of what matters most. The spirituality and the spiritual needs of Dutch children with a chronic condition

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Preface

You are about to start your own journey in this thesis that I had the pleasure of preparing, executing and perfecting over the course of more than four years. It has taught me so much; about myself as a researcher, about my passion towards the theme I choose to study and about the joy children can share when you invite them to.

In this thesis I wanted to show that children, especially with chronic conditions, have spiritual needs. Spiritual needs that need to be addressed by their parents and community, but also by health care professionals. As a nurse I met children in hospital that showed this spiritual need and, in the research, before I started, I found enough foundation for this research project.

I have been warned to only include acknowledgements, if I can make sure not to forget anybody. Well, this seems impossible to me as so many colleagues, fellow researchers, students and other wonderful people I already knew or met in these four years were willing to help me out with statistical advice, paper revisions, expert input, language checks, enthusiastic call sessions to primary schools and so on. To all these people: you know who you are, thank you from the bottom of my heart. But unfortunately, I cannot name you all personally without getting this preface to be the size of the actual thesis. There are, however, a few persons that stayed by my side throughout the ride, of whom I feel so blessed for having my back that they undoubtedly deserve a mention.

As I am what is called in Dutch a ‘buitenpromovendus’, this research is conducted by SHARE, de Graduate School for Health Research belonging to the UMCG (The University Medical Center in Groningen), the Rijksuniversiteit Groningen, and the lectorate “Health Care and Spirituality” (Zorg en Zingeving) at the University for applied sciences Viaa, Zwolle. From the university and the medical centre, I was lucky to find professor dr. Petrie Roodbol willing to supervise my research journey which she did with unwavering encouragement and by supporting my professional growth like a true critical friend. With her patience, empathy and intellect she has been a role model and inspiration for me. Thank you, Petrie, I will always remember how you concluded our very first meeting stating that I should not worry as you only begin this journey with someone if you have faith they can end it successfully. That optimism has stayed with me until this day. Professor dr. van Leeuwen, the professor of the lectorate, joined our team as my daily supervisor, and was always on my side with creative ideas, stern advice and his beautiful humour. His influence on my career, both in terms of my passion for spirituality as his teaching by example is greater than he realises. René, thank you so much for being who you are. I cannot thank the both of you enough for your faith in me.

During my research I was also working as a teacher in a nursing bachelor program and as a researcher on spirituality in health care while also trying to be a nice human being. This was not always easy and would not have been possible at all if I had not found my social support system being there every step of the way. First and foremost, this whole endeavour would have failed miserable if not for my husband, Menno, who is not only the love of my life, but also the petrol in my engine. Thank you so so much, for always finding a way to keep me going, to keep my eye on the prize. I will never forget how proud you were when my first article of this thesis was published, and you framed it for me, just to help me remember why I was doing this.

I hope you, the reader, will be able to sense all this effort when you read this thesis. If it contributes to you taking the spirituality of children more serious than before reading, my mission is accomplished.

Aliza Damsma Bakker

Zwolle, September 20th 2021

Publiekssamenvatting

Er is groeiende bewijs dat integrale spirituele zorg van verpleegkundige professionals van belang is voor patiënten om te kunnen omgaan met ziekte, lijden en handicaps. Aandacht voor spiritualiteit werkt preventief, bevordert individuele gezondheid en stimuleert de ervaren kwaliteit van leven. Deze promotiestudie wil de spiritualiteit, de spirituele ervaringen, taal en behoeften van kinderen met een chronische aandoening verkennen en beschrijven. Deze thesis richt zich op kinderen in de leeftijd van 8 tot 12 jaar. Dit is de leeftijd waarin de ontwikkelde cognitieve vermogens reflectie mogelijk maken, maar waar de puberteit met zijn eigen complexiteit nog geen intrede heeft gedaan. Juist voor deze doelgroep is dit soort onderzoek internationaal nog weinig en in Nederland nog bijna niet gedaan, met name niet in de seculiere Nederlandse (zorg)context. De resultaten van deze promotiestudie zijn enerzijds een verkenning van de spiritualiteit van Nederlandse kinderen als ook van de manier waarop we met kinderen praten over spiritualiteit en op welke wijze we dit vanuit ethisch oogpunt verder kunnen onderzoeken. Samen vormen deze twee aspecten de benodigde kennisbasis om vanuit theoretische basis de spirituele zorg voor kinderen in de praktijk te kunnen bevorderen.

Summary for the public

There is growing evidence that integrated spiritual care for nursing professionals is important for patients in order to cope with illness and handicaps. Spirituality works preventive, promotes health and stimulates quality of life. This research aims to explore and describe the spiritual experiences, language and needs of Dutch children with a chronic condition, which is yet unexplored. Especially children between the age of eight and ten are at the centre of this study, as they are able to reflect, but are yet uninfluenced by puberty with its own complexity. Internationally this has only been done on a small scale, and for the specific context of the Netherlands essential knowledge to identify and address this spirituality is still missing. This research thus provides simultaneously the necessary knowledge to improve theoretical foundations of spirituality of children and the more practical and ethical implications of how to speak to children about spirituality and how to do research with them on this topic.

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