



---

# *“Hear My Voice”*

A Multi-Method Exploration of Maternal Loss and Trauma

Ólöf Melkorka Laufeyjardóttir

Student number: 2583381

Vrije Universiteit, Amsterdam

Master Theology and Religious Studies, specialization Spiritual Care

Supervisor: Dr. Erik de Jongh

Second reader: Dr. Sara Green, University of South Florida, USA



## **Abstract**

The author begins her answer to the question, “What can we learn from the stories which mothers of extremely premature children born in NICU tell about their spiritual needs?” by presenting an analysis of her own life history in ethnographic form. A theoretical examination of the nature of spiritual care follows, in which it is shown to address in four dimensions (existential, spiritual, esthetic, and ethical) the needs of those who are failing to cope on their own with an existential crisis that has left them with neither sense of meaning nor purpose in life. Drawing from her own experience allied with voices from interviews conducted with other mothers who have given extreme premature birth, the author finds the compulsive need on the part of these mothers to answer the question, “Why did this happen to me?” as indicative of an existential crisis, while an excess of professionalism and a deficient ethic of care allow physicians and the hospital staff to be unprepared to interpret the healthy lamentations of a mother who feels disconnected from her expectations and any sense of purpose or meaning in her life; instead of recognizing her lamentation as a cry for help and comfort and making efforts to accommodate it, by repressing or dismissing her lament, they may heighten her trauma, resulting in her feeling silenced and contributing further to the mother’s feelings of disconnection, disempowerment and stigmatization.

**Keywords:** auto-ethnography, disempowerment, existential crisis, ethics of care, extreme motherhood, extreme premature birth, lamentation, professionalism, spiritual care, stigmatization.

This thesis is written in partial fulfilment of a MA degree of Theology and Religious Studies, specialization of Spiritual Care at the Vrije University of Amsterdam, The Netherlands, and may not be copied without the permission of the copyright holder.

© Ólöf Melkorka Laufeyjardóttir 2019

When you are sorrowful  
look again in your heart,  
and you shall see that in truth  
You are weeping  
for that which has been your delight.  
- Kahlil Gibran

For my daughters, Tara (pseudonym) 1973, Selma Rún 1991-1995 and Laufey Ósk 15.03.1996-16.03.1996 and my little shrimp lost at 14 weeks in 1997. Thank you all for the love I received from you. I carry you for eternity in my heart.

In the loving memory of Óskar my brother who died in a tragical accident in 1967, my dear stepfather Gunnar who died in 1977, my mother Laufey who died in 1995.

**With thanks to:**

Dr. Erik de Jongh, Dr. Sara Green, Rev. Bragi Skúlason, my husband Forni Eiðsson and my dear friends: Anna Sigríður Þráinsdóttir, Chip Insinger, Sólveig Friðriksdóttir, Annemiek Appelman, Adeline Tremonti and Mirjam vd Geur, who all kept me sane while writing this thesis.

## Student declarations

### Statement 1

I hereby declare that this MA thesis is an original work and is a result of my own research, written only by me, except as otherwise stated. When information and ideas from other sources are used, it is explicit and accurately quoted in the main text or is footnoted, and the author is indicated within the text and/or parenthetically. Reference list and Annex is included in this thesis.



Den Haag 02.01.2019

Ólöf Melkorka Laufeyjardóttir

### Statement 2

I hereby agree that after approval the Thesis is made available for copying and interlibrary loan and that the title and summary are available to external organizations, and may be published by the Vrije University, Amsterdam, The Netherlands.



Den Haag 02.01.2019

Ólöf Melkorka Laufeyjardóttir

# Content

INTRODUCTION.....	8
1.1 THE PROBLEM.....	8
<i>Professionalism</i> .....	9
<i>Ethics of care</i> .....	9
<i>Spiritual Care</i> .....	9
1.2 THE GOAL.....	9
1.3 RESEARCH QUESTION.....	10
1.4 SCIENTIFIC RELEVANCE.....	10
1.5 SOCIAL RELEVANCE.....	10
1.6 METHOD.....	10
1.7 THEORETICAL FRAMEWORK.....	11
2 MY OWN STORY.....	12
2.1 INTRODUCTION.....	12
2.2 BIRTH STORIES.....	12
2.3 AMBIGUOUS LOSS.....	12
2.4 JOY, LOSS AND GRIEF.....	13
2.5 YOUTH AND TRAUMA.....	14
2.6 STIGMA.....	14
2.7 GUILT AND SHAME.....	15
2.8 SELMA RÚN.....	15
2.9 SURVIVING THROUGH SPIRITUALITY.....	17
2.10 MISTAKES, DISCRIMINATION AND FORGIVENESS.....	18
3 SPIRITUAL CARE.....	20
3.1 INTRODUCTION.....	20
3.2 MAKING SENSE OF ONE’S LIFE.....	20
3.3 THE DOMAIN OF SPIRITUAL CARE.....	22
3.4 SPIRITUALITY.....	23
3.5 CONCLUSION.....	26
4 THE ETHICAL DIMENSION IN SPIRITUAL CARE.....	28
4.1 INTRODUCTION.....	28
4.2 THE IMPORTANCE OF LAMENTATION.....	29
4.3 NICU MOTHERS AND THE “WHY?” QUESTION.....	31
4.4 TRANSFORMED LIVES?.....	32
4.5 CONCLUSION.....	33
5 CONCLUSION.....	35
6 REFERENCES.....	37
7 ANNEX.....	40
7.1 ANNEX A: SELMA RÚN AND LAUFHEY.....	40
7.2 ANNEX B: INTRODUCTION LETTER.....	40
7.3 ANNEX C: INTRODUCTION AND ASKING FOR PARTICIPANTS VIA FB CHAT.....	40
7.4 ANNEX D: SAMPLE OF FB CHAT.....	40
7.5 ANNEX E: INTERVIEW SCHEMA.....	40
7.6 ANNEX F: DREAMS OF THE MOTHER OF P.....	40
7.7 ANNEX G: CONVERSATION WITH MOTHER – NOT INCLUDED IN THE INTERVIEW SCHEME.....	40
7.8 ANNEX H: CONVERSATION WITH MOTHER – THROUGH FB NOT INCLUDED IN INTERVIEW SCHEME.....	40
7.9 ANNEX I: LETTER FROM REV. BRAGI SKÚLASON.....	40

7.10	ANNEX J: MOTHER OF DISABLED BOY.....	40
7.11	ANNEX K: SCHEMATIZED INTERVIEWS .....	40
7.12	ANNEX L: SCHEMA THREE LABELLED INTERVIEWS .....	40
7.13	ANNEX M: DR. THOMAS IN REGARD TO THE ARTICLE “PARENT RESPONSE TO STRESS: PROMIS IN NICU.....	40
7.14	ANNEX N: RITUAL IN NICU IN ICELAND REV. BRAGI SKÚLASON .....	40
7.15	ANNEX O: EMAIL EXCHANGE WITH MYRNA WILLICK.....	40
7.16	ANNEX P: CORRESPONDANCE WITH DR. SARA GREEN ON PARENTS AND DISABLED CHILDREN .....	40

## Introduction

Around 15 million premature children are born worldwide each year. Because of medical advances and interventions these children live, some with severe disabilities and shortened life expectancies, after staying for weeks and sometimes for months in a Neonatal Intensive Care Unit (NICU).

The progress in neonatal care and modern medicine has extended the limits of viability and the survival rate for extremely premature born babies. It can be questioned if the full “armamentarium of modern neonatal care” to prolong the life of a premature child facing severe disability and an intolerable life for child and parents is appropriate (Orzalesi & Cuttini, 2011). Studies after 2000 in different countries show that children of 23 and even 24 weeks survive, but the risk of disability increases with lower gestational age at birth. These developments in neonatal care can be questioned if they are ethically correct (Abblas, 2004).

This thesis explores the governing principle in decision making with respect to pregnancy, becoming pregnant, deciding to stay pregnant, aborting or engaging in activities. I have extensive experience with the care provided in NICU.<sup>1</sup> I believe it should have been my final decision whether or not to prolong the life of my extremely premature baby.

Decision-making in NICU is only one aspect that is of concern to me in writing this thesis. Another aspect is the experience of anxiety, depression, and even trauma. Such experiences are thought to be related to the premature birth itself as well as the physical and emotional isolation that occurs in NICU when parents are separated from their child (Obeidat, Bond & Callister, 2009). This has been my own experience when my two daughters were born extremely prematurely.

Coping is considered to be the normal psychological reaction to these experiences. The psychological literature recognizes various ways of coping (Brelsford & Doheny, 2016). In my own way of coping as a NICU mother of two deceased premature children, one who became severely disabled and terminal, the second who died shortly after birth, I relied heavily on spirituality.

### 1.1 The problem

Mothers in NICU generally report feeling that their prematurely born children are well taken care of. However, the conditions to meet the spiritual needs of parents are not sufficient according to a research done by Heidari, Hasnapour & Foolandi on NICU mothers in 2012. In contrast with the psychological mechanism of coping, relatively little is known about the spiritual needs of parents in NICU. Yousof (2016) wrote a dissertation on her experience as a NICU mother. She chose to turn to her faith in God in order to make sense of what was happening to her children, both born extremely prematurely (one died in NICU and the other lived disabled). The explanation offered for parents being left without care is that this is “being unintentional and related to the workload of Intensive Care Staff” (Steyn, Poggenpoel & Myburgh, 2017). In this connection, I see three areas which need to be addressed: professionalism, the ethics of care, and the role of spiritual care.

---

<sup>1</sup> NICU is an abbreviation for Neonatal Intensive Care Unit. The abbreviation will be used throughout this thesis.

### *Professionalism*

In the dominant Western culture, the understanding of professionalism is characterized by evidence-based intervention, problem solving expertise, method and competence. The personal dedication to the client, which was traditionally seen as the hallmark of professionalism, is less important than before (Maister, Green & Galford, 2000). Within health care the trend is that clients have become an object of care. According to Green (2003), who is a mother of a disabled girl “the community of people with disabilities has expressed a growing frustration with professionals (quoted in Yousof, 2016:4). In view of the dominant assumptions of professionalism, little is to be expected from the disciplines involved in NICU to learn to listen to the voices of parents expressing their pain.

### *Ethics of care*

To the extent that there is no place in NICU for parents to express their pain, they are somehow silenced. In connection with the modern development of medicine, Hauerwas (2004) remarks that the suffering and death of children leave people speechless. Reinders (2014) wrote that there might be evil in disability, but it is a moral evil rather than a natural evil. As he explains, those who are disabled say that they do not suffer from disability, but from people’s responses to disability (2014:7). This is also true for NICU mothers whose baby has become disabled or terminal, and it pertains to family and friends as well as professionals working in NICU. In view of the moral issues at NICU, the services provided in NICU cannot be governed only by an ethics of justice.

### *Spiritual Care*

Spiritual needs are primarily concerned with making sense of experiences which disrupt the routine and expectations of one’s life (Ter Borg, 2000). In other words, spiritual needs spring from existential questions. The answers have to be discovered by the parents themselves. Within the hospital context, the only profession which addresses existential questions is spiritual caregiver (counselor). In many countries, such as Iceland, spiritual care is offered only by representatives of institutionalized religions. However, the head of pastoral care at Landspítali Háskólasjúkrahús<sup>2</sup>, pastors who have specialized in Clinical Pastoral Education work on multi-religious level (Rev. Matthíasson, e-mail exchange June 26<sup>th</sup>2016). In contrast, various Christian churches as well as other religions and the Humanistic Union are involved in the provision of spiritual care in The Netherlands. Besides these, spiritual care is also offered by professionals who are not related to any institution (VGVZ, 2015). All of them, whether related to an institution or not, are required to specialize in Clinical Pastoral (or Spiritual) Education.

## **1.2 The goal**

The purpose of this research is to contribute to the knowledge of spiritual care (multi-religious and secular spiritual care-giving) within NICU, both for parents and professionals.

This study aims at reaching an academic understanding of the spiritual needs of NICU mothers based on their experiences and personal responses with a child in NICU.

The second aim is to introduce the auto-ethnographic method as a research tool in the discipline of theology and religious studies.

---

<sup>2</sup> Séra Gunnar Matthíasson, pastor, National University Hospital of Iceland (I. Séra e. Rev (pastor)).

### **1.3 Research question**

The research question for my study is:

What can we learn from the stories which mothers of extremely premature children born in NICU tell about their spiritual needs?

The sub questions are:

1. What is spiritual caregiving?
2. What can this approach contribute to the ethics of care?

A large part of the research is concerned with learning how to tell my own story according to the auto-ethnographic method in order to provide the basic material to answer each of the sub-questions.

### **1.4 Scientific relevance**

In a world of traumatized people, spiritual care is one of the disciplines that are of great help to people (Ganzevoort, 2011), so spiritual care in NICU should be one of the tools to help mothers to deal with the trauma of giving extremely premature birth. Staying in NICU, having to make decision as a parent or not being able or allowed to be free in decision making is stressful for the parents, the neonatal care is also ethically demanding and stressful area of professional practice (Caldeira & Hall, 2012). As far as I know the spiritual needs of parents in NICU have not been researched.

Auto-ethnography as method of research can make important contributions to spiritual care as the focus is on the subjective experience of the researcher. The scientific relevance of this research method in combination with ethnography is that the researchers is caught in the insider's perspective in auto-ethnography, but in ethnography the researcher is looking from the outsider's perspective, so by using auto-ethnographic methods the researchers is caught 'in-between-ness' of these two research approaches (Siddique, 2011).

### **1.5 Social relevance**

According to Pargament (1997) coping is a way people deal with a crisis-situation, from the idea that they need not be passive victims of their situation. Although auto-ethnographic writing on lived experience of the effect of extremely premature birth, disability and/or terminal illness, is very traumatic for the mothers and fathers, the pain is endured in order to give professionals who are working in NICU insight into the emotional and spiritual turmoil that takes place in the mother and fathers life, and to show how professional spiritual care in NICU may respond to the spiritual need of these mothers and fathers.

Further, this study will contribute to develop spiritual care with knowledge of medical ethics, spirituality, religious studies, philosophy as well as psychological and social insight as a great contribution to health care staff in NICU and within the world of disability.

### **1.6 Method**

This study will provide a different perspective to the field of spiritual care by sharing first hand experiences of me as researcher using auto-ethnography to reveal my own story as well as narrative method to tell the experiences of other mothers. Data have been collected through semi-structured, open-ended interviews by audio recording, FB chat and email exchange and analyzed according to qualitative research methods. Literature review has also been a part of the research. In the literature

study I will read and analyze academic texts and studies of preterm birth, counseling, coping, and spiritual views.

## **1.7 Theoretical framework**

In this auto-ethnographic thesis I will use article, book, literature, interviews with mothers who stayed in NICU and my own story in NICU.

Among the literature I will use is from Green (2002; 2003; 2007), who is a mother of a disabled girl, academic and a writer. Among the things she has written about and researched is the lived experience of mothers of children with disability, how they experience stress, stigma, have not had their needs met and how they try to cope (2007). Lawrence (2011), shares her feeling of being the mother's worst nightmare [...] her fairytale vision of a family coming to a drastic halt in 2005 when her daughter was diagnosed with genetic disorder (2011:1). Yousof (2016) writes also an auto-ethnographic dissertation. She is a mother of a twin born prematurely, one who died in NICU and the other lived disabled, her sharing is religious and spiritual; "Finally, religion was another important coping mechanism for several mothers. In some cases, mothers were already religious prior to having a child with disabilities, and in other instances, having the child increased their concern with spiritual matters and led them to find support through faith" (2016:26).

I will use the book by Reinders on Disability, Providence and Ethics (2014). The inadequacy of theodicy is explained, the scandal of suffering without finding comfort.

Within the theoretical framework, using auto-ethnography, my starting point is that sharing one's own lived experience as mother of a disabled extremely premature child is important to medical and pastoral staff and to that the contribution of spiritual and pastoral counselors can benefit the parent's well-being during loss experience.

The sociologist Meerten ter Borg is an advocate that spiritual care should be an independent discipline within professional organization, as a neutral way of working with philosophy of meaning of life as a part of recovery.

## 2 My own story

### 2.1 Introduction

Ellis, Adams & Bochner (2011) described auto-ethnography as a study of the self as subject through critical analysis of lived experience. It was in the late 1980s, that social scientists began embracing autoethnography as a legitimate and valuable method of empirical research (Riley, 1988; Berger, 1990).

As a part of recovery, coming to terms, accepting what I cannot change and change what I can change and in order to be able to continue my life happy despite my losses and trauma, I need to talk to other mothers and write about my children: Tara (pseudonym) my first born whom I did not raise from the age of 1 year; Selma Rún my extremely premature born, disabled and deceased daughter who passed away in 1995; and Laufey Ósk, my daughter who was also born extremely premature and lived for just one day (15.3.1996–16.3.1996). In this chapter I'll write about my experience as honestly as I can and dare.

### 2.2 Birth Stories

Sara Green (2003:2), a mother of a disabled girl and an academic researcher writes about the importance of mothers telling their birthing stories. Learning about her research was actually a turning point in my efforts to write a thesis in the discipline of theology and religious studies. I knew intuitively that she was showing a way of studying a subject which deeply affected me and was unable to bring forward in the dispassionate and objectifying mode which seems characteristic of the academy. So I have mounted my courage to tell m birthing stories. They are about loss after birth.

I lost all my children. The first loss was due to the incapability of raising my eldest born in 1973, which I had to part with due to my dysfunctional life and poverty – that loss has been the hardest to come to terms with and left me traumatized (Henney, Ayers-Lopez, McRoy, & Grotevant, 2007), I had no choice at that time. My surroundings felt I was not a responsible mother. From the time I parted with my first born when she was one year old, I experienced a shock, I denied, I blacked out. Later, I felt great sorrow, became depressed and suicidal. The shame I felt was overwhelming and the guilt did haunt me, and still does every now and again. I escaped into the mood-altering substance of alcohol as it gave me a temporarily relief from the pain and problems of daily life as a teenager alone and homeless in the capital of Iceland. I struggled at that time with intense emotional distress, trauma and mental health problems, and my only way to manage was to turn to alcohol to numb my feelings. Romanchik (1999) wrote: “that until accepting and coming to terms with loss”, women often do not want to have another child. I had that experience. After losing my first born, I never wanted to bear a child again. It was only when I came to accept my first loss, came to terms with and understood that I had given my oldest child a chance of a better life than I could give her 45 years ago, that I was able to think about returning to motherhood.

### 2.3 Ambiguous Loss

At 37 years of age I decided to become a mother again. However, I felt the sense of ambiguous loss (Boss, 1999).<sup>3</sup> I grieved my first born who was still alive. Losing a child because you are not able to fend for it is a totally different way of grieving than losing a child that has died (Powell & Afifi, 2005) or that

---

<sup>3</sup> The term “ambiguous loss” describes such feelings of loss and originates when Boss (1999) coined the term in a study of wives of pilots that were missing in Vietnam and Cambodia. These women had no official verification that their husbands were missing and experienced conflicting thoughts and feelings.

becomes disabled because of problems at birth. Ambiguity describes the feelings accompanying my first loss of a live child who was placed for adoption. My oldest child was alive, so there was no proof that something has been lost, and I had no-one to share the pain, frustration and loss, and the shame, I experienced then. Society allowed in those days back in 1974 no space for grief or sorrow for incompetent mother and ugly bad judgements were made, as I later read in documents I got access to in 1997 in regard to Selma's medical journals and then in 2009 the adoption documents when my first born was taken away from me. I am not making excuses that a child should be brought up in conditions where it is neglected, but often society, or people who thrive on having power over others, may contribute to the destruction of an emotional and mental life of a young person in trouble. My neglect and dysfunctional behavior are no excuse and that others violated me does not minimize me violating others.

Ambiguous loss also describes the feelings accompanying the premature birth of my second child who was born 14 weeks too soon, who became disabled and was very ill during the short time on earth. This experience hit me hard and traumatized me – this thesis is our story – as is the birth and death of my third daughter who was born at 25 weeks of gestation and lived for short 4 hours and died crying on my chest. This is also the story of the painful loss of the hope of ever being able to raise a child, when I lost my fourth child I called “shrimp” when I was 11 or 12 weeks pregnant at the age of 43, ended my hope of proving to myself and the world that I was a capable mother.

## **2.4 Joy, loss and grief**

Society expects joy when a child is born, but I as a mother of a premature infant lost out on the joy and felt confused. I had hoped that the last three months of the pregnancy should have been the time for me to prepare, both physically and emotionally/psychologically, for the birth of my so wanted child. What happened was a premature birth, with hardly any warning, leaving me shocked and confused about my role as a mother. I asked myself, “If my Selma is in NICU, how do I act as a mother?” I experienced the feeling of deep sorrow over losing out on full term pregnancy that is reported by other parents of disabled children (Green, 2002). The thought of having my first born taken away and placed in a foster home or a premature birth being a loss never entered my mind. I did not know that ambiguous loss is one of most distressful losses that leads to physical, emotional and mental symptoms that are not only painful, but often missed or mis-diagnosed (Boss, 1999: 6) by medical professionals.

Life is full of unexpected surprises. Sometimes the surprises are joyful, pleasant and wonderful to experience. Then there are unwelcome surprises that you secretly wish would not happen – a surprise out of the ordinary. For me the joyful surprises were the strong feeling of wanting to become pregnant and that I had no problem with conceiving, that was exiting. Then something out of the ordinary took place and an unwelcome surprise happened. I became a mother of an extremely premature child, a child who became disabled and terminally ill. Her death felt like it came out of the blue, even though I was prepared for her early departure from this world. It was a painful surprise to hold my child close to my heart, feeling the life-energy flow out of her, the body becoming colder and stiff and then the unbearable experience of feeling she was not “here” anymore – she was gone. It was a struggle for me that the heart of Selma “stopped beating while mine continued” (Yousof, 2016: 87). I have no words to describe my feelings or the impact of the losses of my children, the devastation, disbelief and sadness, the feelings are beyond words. Yousof (2016: 88) wrote that the diagnosis of her son Omar's “condition and his death caused an unfathomable amount of sorrow over the imagined child, the imagined future, and the actual child”. This is exactly how I felt at the time of the diagnosis

that Selma had suffered IV grade brain hemorrhage – my imagined dream and future of a full term, healthy and happy child had turned into a nightmare.

## 2.5 Youth and trauma

My story is incomplete and can only be fully told after I have left this earthly world. It is not a story like any other; I tell you the story, told through my eyes only. Sometimes I am in front and center of the story, sometimes I am at the periphery of the story (Ellis, 2004). This thesis is not only about the birth, disability, illness and death of Selma as I experienced it in my life. Like those of many people, my life-story holds many traumas.

Being a bastard<sup>4</sup>, and finding out that your loving father is not your father but your stepfather, was traumatizing at the age when I entered elementary school and found out I did not carry his name, but the name of my biological father I had never met and who, as I experienced it and was told, did not care for me. The trauma of losing my brother by tragic accident when he was ten years and I thirteen, and that it was my stepfather's car that took his life – I blamed myself for his death because during an argument the evening before I wished death upon him.

The word of the song, sung by Napoleon XIV 'They're coming to take me away'<sup>5</sup> echoed through my head and at times it still does, when I think back to the year 1970 when I was taken to the White House by the cliffs in Reykjavik, the Mental Home, the Crazy House, and locked up at 16 years of age when I tried to kill this "bad girl" who was evil and caused nothing but destruction with every footstep she took. The sane "I" could not deal with life, the pain, the loneliness of not being able to share the feelings except being drunk.

When I found a friend, Bacchus, who slowly took over my life, I became dysfunctional and felt I had broken free, thinking I could let go of the pain, the anger, escape the black dog called Depression and go wild. To hell with life and welcome death. In the White House<sup>6</sup> I became no-one, an object. As a young beautiful girl physically, my autonomy was taken away from me, I became the perfect prey to a highly educated man, a sex offender, a psychiatrist so charming and an expert in grooming.

Today I am close to celebrating 40 years of abstinence from alcohol and other drug substances.

## 2.6 Stigma

Stigma entered my life as if on my forehead I had a tattoo: "do to me whatever you please, I am nobody". I experienced what I know now is described as stigma. I had become different and my place in society had changed, I was the "other" (Lawrence 2011: 22–23). By turning against myself, I had prejudice towards myself as a person with a mental illness, which is explained as self-stigma (Hilton & von Hippel, 1996; Krueger, 1996). It was clear when I read the medical reports I requested to read after Selma's death, that I was being seen as the "other"<sup>7</sup> due to my behavior as a 16-year-old girl, a young mother who at the age of 20 was not able to fend for her child. It was easy and convenient for the medical staff, social workers to describe me as an ambivalent person, a tired mother, and a mother

---

<sup>4</sup> Born out of wedlock.

<sup>5</sup> Napoleon XIV. 'They are coming to take me away': Looked at and listened to on January 29<sup>th</sup>, 2018 at <https://www.youtube.com/watch?v=hnzHtm1jhL4>

<sup>6</sup> Called Kleppur in Iceland – and once you were placed in Kleppur your name was taken away from you – you no longer belonged to the human race.

<sup>7</sup> My own interpretation of being "other" is not belonging to the world of the sane of the normal in society as once you entered an institution for the mentally lament, you became the other (not the significant other) or different/stranger – strange to normal society (in Icelandic: "öðruvísi/skrítin").

who was troubled – it *did* camouflage the medical mistakes that had occurred in Selma’s treatment and later in the neglect of listening to me when I again was going into premature labor with my daughter Laufey, who died shortly after being born at 25 weeks. That I had been a recovering alcoholic from the 1979, admitting to having had problems with drinking and compulsive eating (eating-disorder) to escape my emotional and spiritual pain was turned against me and I experienced being blemished – me being obese at that time and growing in weight as Selma became more ill and more disabled, devaluated me as a person (Lawrence, 2011: 22–23). The voice, maybe an unhealthy voice, tells me that if I had not been stigmatized Selma would have been treated differently, she might even not have been born prematurely as the focus would have been set on the complications during pregnancy instead of being devaluated as ambivalent person with history of dysfunctional behavior and substance abuse as a young woman. I can’t help thinking about me being one of the individuals who was devaluated facing negative stereotyping in society (Crocker & Major, 1989; Lawrence, 2011: 23).

As I had not such a good experience with social workers when I was a teenager I did not trust them when they said they were going to help me when Selma was born, I was scared dead talking to them; how could I trust them, people whom I had trusted in the past and the only thing they did, as I experienced it then, was to take my first born away. What if I would talk to them and confide in them, would they not have taken Selma away from me? Should I trust them with the problems in my marriage, the domestic abuse that had been going on for years, the financial problems as I was not able to provide for us? I felt I/we had stopped having a private life, being the possession of the system and being under surveillance.

## 2.7 Guilt and shame

I have been overwhelmed by guilt and shame from the time I was taken to the “White House.” Why questions have followed me since childhood, not the innocent why questions - why is the sky blue and the grass green - no, why? *Why does all this happen to me to us, in our family?* Reinders writes on the why questions and that they are followed by guilt (Reinders, 2014: 37). The guilt of the abortion in 1974 follows me and I hold myself accountable for the cause of the premature birth, sure that the defective cervix has to do with a forceful abortion. During the time in NICU I felt that the help and understanding I sought with the medical profession about my depression, guilt and anger did not provide me with answers. The specialists were able to explain the cause and effect of the brain bleeding of Selma, to predict the outcome of the trauma causing her severe disability, but I never felt comforted by them (cf. Reinders, 2014:37). Even if I was given kind care and attention by a pastoral caregiver, theodicies to the “why” question only contributed to silencing me when I sought help or answers by a spiritual or pastoral person. I was not empowered to speak about my anger towards God or my despair about why God had left me (cf. Reinders, 2014: 47–48).

## 2.8 Selma Rún

There are many chapters in my life-story. The chapter belonging to this thesis is the story of me and Selma Rún:

“You came into this world so tiny and started your journey through life like a delicate baby bird. Your crying was like a distant echo that gradually died away. You came too soon and didn’t intend to stay. Life’s gales battered you roughly and there were dramatic changes in the weather over your lifetime. You came into our lives as a great teacher, uniting and maturing our harried souls. You didn’t speak to us in words, but your blue, intelligent eyes said more than the

words of many wise men. Your body was severely handicapped; your mind was pure and unspoiled. That's how you were, Selma Rún" (Ólafs, 1998, p. 4).<sup>8</sup>

Selma Rún was conceived when I was 37 years old going on 38, married with the father of my oldest daughter, whom I had met when I was 18 years. Our relationship was a very troubled one, it was a yo-yo relationship. On and off from 1972–1974 and then later from 1979–1999. It was an abusive relationship, full of violence and very dysfunctional, but not forgetting the beautiful moments, the romance, the passion and the love, addictively destructive, we felt for each other. Later I will explain to you, my reader, how I came to terms with our life together and learned to accept what could not be changed, how I gained the courage to change the things I could, and the wisdom to know the difference.<sup>9</sup>

When I became pregnant I was an advanced student of singing and had finally gotten to the stage I had so been longing for: to be able to go to study in the land of song – Italy. I was a postgraduate student of singing. In Italy I realized I was fully ready to have a child again. I had finally stopped mourning the loss of my oldest child, born when I was 19, taken from me and placed in foster home when I was twenty and because I loved her gave her the change of carry the name of her foster father and gave her up for adoption when she was almost 3 years old. I decided to let go of the pain and shame of not having been able to take care of her. When she was taken away from me I vowed I would never have another child until my life was put together and I could offer a child emotional and financial stability and was confident that nothing would go wrong.

Selma was conceived on 2<sup>nd</sup> of May 1991, and I had the proof on May 18<sup>th</sup> when I held my first song recital in Italy. I felt a cocktail of emotions, nervous, happy because I was fertile, but I felt fear; there was a voice whispering in my ears that something was not right. I had a dream about a woman. The dream of the woman I interpreted that there were difficulties were connected with the child I was carrying.

Selma's father and I used to go to church every day. I was not brought up Catholic, but I have always been fascinated by the beauty of Catholic churches and the liturgy. A few days after Selma was conceived, we went into a church that was in the care of nuns. What struck me when entering the evening song was that the church was full of disabled people and the people taking care of them. What also struck me, and moved me deeply, was the compassion I felt. I tell myself that I was being prepared and that I was given a sign that the child I was carrying would be disabled and ill. I was given a glimpse of the compassion that should be given to those who are not on the same footing as healthy people in terms of physical and mental ability. This was the beginning of Selma inside of me.

Selma came too soon, a whole fourteen weeks too soon. I didn't understand what was happening. I had been having contractions for 8 weeks and watery discharge and later I thought that it probably was the signs of premature birth, but the doctors I consulted assured me nothing was happening. The thought entered my mind that I might be having a miscarriage, but I turned a blind eye to that idea/feeling.

To have to watch your child suffer and die 3.5 years after being born extremely premature, to hold your child on your chest knowing it is going to die, to listen to that weak cry and how the little body gasped for breath and life, is devastating, cruel and a violation of life, but it can be survived.

---

<sup>8</sup> At the time of writing this account of my story with Selma Rún I carried the name of my first husband and biological father. I changed my name 4 years ago and now I am Laufeyjardóttir (Laufey, my mothers first name, dóttir/daughter – the daughter of Laufey).

<sup>9</sup> This is the serenity prayer from the American theologian and ethicist attributed to Reynold Niebuhr (1892–1971) [https://en.wikipedia.org/wiki/Reinhold\\_Niebuhr](https://en.wikipedia.org/wiki/Reinhold_Niebuhr) Accessed on 29 January 2018.

Selma Rún was born on a Wednesday October 23<sup>rd</sup>, 1991, weighing 900 grams and 35 cm long. Quick hands carried her off and I had to wait two hours before being allowed to see her. At the first glimpse I did not recognize her. In NICU my attention was fastened on a tiny baby in blue socks. That was not Selma, it was a boy who had been few weeks in NICU. Selma laid in an incubator, wires and tubes attached to her tiny body. She was lying the like a frog and I had no idea that extremely premature children looked like little strange creatures. But Selma was my baby and I felt how the love for her was born in my heart. She was mine and I believed the doctors were going to save her. I had waited for so many years for Selma that two or three months in NICU was not going to make any difference. Selma's arrival was my dream come true.

"Next day was Monday 29<sup>th</sup> May 1995. You lay in your bed in the same position as I had put you down the evening before. You were ashen pale and covered in cold sweat. There was a strange smell in the room, a "corpse smell" and it had been there all week. The nurses thought it best to leave you alone as much as possible so as not to disturb you; they didn't seem to realize that you were unconscious. You just lay there, very still, sleeping soundly. Your specialist came in and looked at you and said: "She does not look too bad." I said: "Selma's going now. I have noticed a corpse smell here all week long, and she hasn't long to go now." He smiled and looked at me, shook his head and said: "You're always the same. Always the same old pessimism." I denied this and said I had never been pessimistic about you, but I had had a premonition that the end was near (Ólaf, 1998:55)."

A couple of hours later after Selma had been taken to be revived and I stopped that as I wanted her to choose if she stayed in this life or would travel to the next life, she was brought to me and her father. We placed her between us in a narrow bed and she took her last breath at 13:50 on May 29<sup>th</sup>, 1995.

Despite the bad marriage and us treating each other badly for 27 years, I cry for my ex-husband and the memory of him holding Selma's dead body, holding her for the last time close to his heart pacing up and down the room. I realized that I was not the only one losing a child. He was losing his child as well. I feel for him as a parent losing a child. Selma is his and my creation, born out of me and him. All my children are fathered by him, and for that I am forever grateful.

Outside the door, life went on. Children were playing, laughing, some crying. Now and then a peal of laughter could be heard from the staff. On the floor above us, some workers were drilling and hammering. The whole hospital wing was alive. It was only in our room, where your lifeless body lay, that peace and silence reigned (Ólaf, 1998: 55–56).

I did let go of Selma, but it was difficult to let go and it still hurts when I think of my little extremely premature child, so disabled, so ill, my little teacher who taught me to love and finally to understand and to forgive.

## **2.9 Surviving through spirituality**

I was brought up with spirituality, believing in paranormal activities, as a part of my cultural background and in combination with my faith in Christ according the Evangelic Church of Iceland. I was a grief-stricken, traumatized parent who was in search of a way to cope with her feelings and experiences. So, I, like many Icelandic parents of children in NICU, sought additional help for my girl and for knowledge of the future from a range of 'alternative' sources to find help and healing. These included expressions of faith in God or a superior power, emergency baptism of the infant, interpretation of new dreams or reinterpretation of old dreams, visits to mediums for information about future prospects and additional help (Einarsdóttir, 2009).

## 2.10 Mistakes, discrimination and forgiveness

We are all humans, we all make mistakes – I hope that discrimination will stop and that we all can find compassion towards each other no matter how we look or appear in this world. I hope that stigma will vanish, that we gain the courage to admit when we do wrong, make amends and that those who have been molested and denied help and understanding may find it in their heart to forgive instead of hating.

I am 65 years old – I am happy. I consider myself fortunate. I have been a mother. I know what it is to love unconditionally persons that are “others” – different – disabled. I know how it is to lay a hand on the chest of a pediatrician who had told me I was pessimistic a few hours before my daughter’s death. I know how it felt to look into his pale face with fear and sorrow in his eyes and tell him; “it was not evil intention that you did not listen, I believe you believed you were doing your best.” I will never forget the tear running down the cheeks of the nurse as she was cleaning up the room after Selma died.

Too much knowledge has caused a part of my innocence to be lost. Is that bad, or is it good?

Today we live in a world where countless people tell scary stories about abuse in their childhood, as teenagers and grown up people. Stories about psychological, physical and/or sexual abuse, domestic violence on the part of their partners and being victims of institutional violence in the form of denial and protection of the perpetrator. The world we live in today is a world where the media thrive on these stories and they do not tire from telling them. We read about abuse, bullying and memories of past trauma that resurface, and that may even drive young and old to take their own lives because family, friends and society are unable to open ears or eyes to their suffering. Victims are ostracized through the silence of society that turns a blind eye and a deaf ear to their stories and in my opinion by doing so become active participant in violent behavior. The abuse has become a collective “something”.

Will my soul-baring bring me the healing I seek? How and where can I find the way to heal the wounds inflicted upon me by others and by myself? Is it possible for me to reconcile with the cruelest person who has inflicted the pain that at times drives me into the dense darkness of mental anguish? Will forgiving let the light into the dark hole I have escaped into and set me free? Is it freeing to become aware that we do not have to be victims of our past and can learn new ways of responding? “But there is a step beyond this recognition... It is the step of forgiveness” (Arnold, 2007:69). Can I agree on that? Can I forgive? Do I truly understand forgiveness?

Nelson Mandela suffered excruciating violence through discrimination as a person of color. He personified the power of forgiveness and the best values in humankind. However, Mandela himself admitted having his own share of human weakness, being stubborn, proud, naïve and impetuous. Looking in my own heart, I ask myself, am I innocent of being a participant of bullying, neglect, of forcing my will upon others? The honest answer I must give is “**No**”, I am not – I am a part of the herd too. Going against an accepted behavior separates me from others, so I fall into the role of the denier, so I participate – I bully, I turn a blind eye. I excuse both my own behavior as well as the behavior of the group I want to be a part of. It is easier that way, I thought. It’s hard to stand alone and fight for the justice and the protection of the sufferer.

How come I can like and even love a person who inflicts pain upon others? When I do not experience the evilness a person has within him/her, I am charmed by the kindness and charisma that person has. Again I’ll use the words of Mandela: “I never know whether I’m dealing with a Saint or with

Machiavelli".<sup>10</sup> That is why it is so difficult to believe the one who has suffered violence, when you only know the perpetrator as a nice person.

I love my mother no matter how much pain she inflicted upon me, because I know it was not evil that caused her behavior, it was her own hurt and abuse she experienced that turned her into a neglecter and abuser when Bacchus took over and when the Black Dog (depression) took her on the leash and *Mania*<sup>11</sup> wanted her on the leash as well. I understand her because I have the same tendency, to hurt when I feel hurt. The difference between me and my mother is that I got the chance to divorce myself from the Black Dog and Bacchus, I met people who were willing to listen and help instead of mock me or amuse themselves when I turned into a pitiful clown under the influence of my own hurt and molestation in the companionship of Bacchus. Do I love my ex-husband who hit me and spit on me for 27 years, who beat me to the floor when I was pregnant? **Yes-No-Yes-No** – I admit, I love the memories of his soft hands on my body, his tender kisses, his flirting and his words when he admired my brown eyes, round lips and red hair – that person I love. I have grown enough and learned that it is not going to benefit me to hate him as the hate will only burn me up. Will I forgive him? No, I am not ready to forgive his behavior because there is no remorse. Will I forgive my mother? Yes, as she always told me she loved me, and she did her best to change herself for the better. Will I forgive my biological father for his refusal to recognize me as his daughter? **Yes**, because he did not know what he did – and I carry in me his DNA.

I still grieve, I still feel the loss, but I can live and enjoy life despite having the feeling that life has not always treated me well. I have survived these losses with scars, but they do not prevent me from enjoying life and continually hoping for a better life. My hope is that writing the story of Selma and me will contribute to putting a stop to discrimination and stigma. I hope that in the future the medical and social work professions do not pass judgment those who are different, that they will not cover the mistakes which may occur and silence the victims. I pray for love, understanding and compassion towards all living beings – for peace and the courage and strength to forgive.

Goodbye my love, thank you for everything. I bid you farewell with tears of regret and joy (Ólafs, 1998: 60).

---

<sup>10</sup> National Geographic, blog 2013. Retrived 01.09.2017 from <https://blog.nationalgeographic.org/2013/12/06/nelson-mandela-and-the-power-of-forgiveness/>

<sup>11</sup> Bipolar disorder.

## 3 Spiritual care

### 3.1 Introduction

In chapter two I told my story with Selma Rún, its circumstances and impact on my life, and how I struggled to survive. I have told the story not in an unreflected way, but I made a deliberate effort to render my experience as raw as possible. In this chapter I will put my experience as a NICU mother, as told in chapter 2, within the framework of spiritual care as it is provided in The Netherlands. This will enable me to attend to the process of sense-making.

My effort towards sense-making (or search for the meaning of life) led me back to my own religious and spiritual roots, and also to the academic study of religion and theology. Fortunately, at the age of 59 years, I took my first steps in this academic field in The Netherlands (after having finished my Bachelors in Theology at the University of Iceland), where hospital chaplaincy is not any longer the prerogative of the established churches. Since the 1960's humanistic counselors as well as Buddhist, Muslim and Hindu chaplains have been admitted to hospitals. Apart from these spiritual caretakers who belong and represent a specific tradition, recognition has also been given to those who are working independently from any institution. My encounter with this rich landscape has drawn my attention to the discipline of spiritual care. It will be clear that this landscape is infinitely wider than pastoral work in the tradition of the Church of Iceland, which had been my only option as a mother in NICU.

The leading question in this chapter is "What is spiritual caregiving?". In order to answer this question I propose three steps. First, I will outline the domain of spiritual care. The Dutch have a particular word to designate the field of expertise of chaplains. It is spelled *zingeving* and it does not have an English equivalent (nor in any other language, as far as I know). What it means will be explained in paragraph 3.2. The next step will be to show how the domain of spiritual care is shaped as a field of expertise, which undergirds a profession which is exercised in The Netherlands (and nowhere else in the world, as far as I know). This will be the subject of paragraph 3.3. Finally, in paragraph 3.4, I will focus on the concept of spirituality within the domain of spiritual care. In the conclusion I will take up my own story, as described in chapter 2, and draw out some aspects where I would have welcomed spiritual care in NICU.

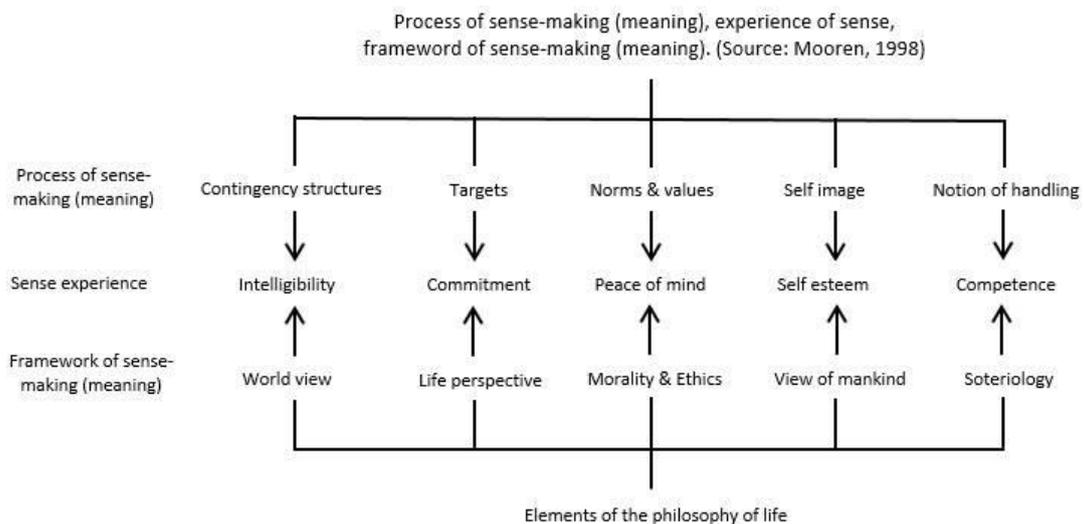
### 3.2 Making sense of one's life

Sense-making is the continuous process in which people answer to 'life itself' (Fowler, 1981:33). The mere fact of our existence, that we are there, implies for every human being a question that we ask: "I live, and now what?" We can call this the fundamental life question. Thus, sense-making is a signification of our existence as human beings. Hekking (2003:50) explains that sense-making is the way people live. Human beings cannot live otherwise unless their brain or mental condition imposes limitations of consciousness and/or reflectiveness.

This one life question which follows from 'being there' sprawls over many more existential questions: Where do I come from, where am I going to, how will I bring life to a good end, what is a good end anyway, what is a good life? Making sense of life (that is, giving meaning to one's experiences) is a continuous process. The answers that people give in this continuous process gradually shape their life vision, or philosophy of life. Mooren, who became interested in *zingeving* as a psychologist, explains that such a life vision may be understood as a frame of reference which determines how people interpret life-events.

The conceptual model presented by Mooren shows *zingeving* as a multi-faceted process with different layers. First of all, he identifies five elements that are of importance at the experiential level, namely: intelligibility, commitment, peace of mind, self-esteem and competence. My own story may serve to illustrate the importance of these elements. Taking my competence as a mother as an example, I named my experience with my first-born as one of failing. The social workers and psychologists who stood around me perceived that I didn't handle my child well. They acted upon my incompetence by taking my child away from me.

Mooren's model suggests that the social workers and psychologists intervened in the *process* of sense-making at the level of handling the situation. I am not questioning the decision of the professionals to take my child away. As I wrote in the previous chapter, I was poor and had a dysfunctional life. I was really incapable of raising my eldest born. But I also wrote that the loss of my first child has been the hardest to come to terms with and left me traumatized. I had been left alone, ashamed and filled with guilt. And to make my life even more miserable I was stigmatized as an incompetent mother. Much later I found out that ugly bad judgements were made. Mooren's model suggest that something went terribly wrong for me in terms of the *framework* of sense-making.



The model shows in the upper level some key notions of sense-making which belong to the field of psychological expertise. However, these notions are not sufficient to enable the sense experience of their patients. In Mooren's model, the process of sense-making is informed by a normative framework. In the example of my experience with my first-born, the social workers and psychologists were preoccupied with the well-being of my child. I cannot look into their framework of sense-making, but it appears to me that their framework was not questioned. In any case, I had no choice at that time. But life goes on, and you have to make some sense of your experiences. Mooren's model suggests that the framework of sense-making is all important. The Evangelic Church of Iceland, with its Christian framework was of no help at all. Instead, it was Bacchus who slowly took over my life, making me think that I could let go of the pain, the anger, escape the black dog called Depression and go wild. I now recognize this way of thinking as an illusion, but one that effectively provided a framework to make sense of life – to hell with life and welcome death.

### 3.3 The domain of spiritual care

The Professional Standard of Spiritual Caregivers in The Netherlands describes the domain of spiritual care with two terms which have already been mentioned in the previous paragraphs, i.e. 'philosophy of life' and 'sense-making'. It is time now to focus on these terms, because they are by no means self-evident. As a matter of fact, these words are just an initial attempt to translate two Dutch words which do not have a single equivalent in English (nor in Icelandic).

Let me start with 'sense-making'. In the Professional Standard it is described as "the continual process in which an individual, in interaction with one's surroundings, seeks meaning and purpose for his or her life. From this definition it follows that 'sense-making' has two components, i.e. meaning and purpose. For this reason I have chosen not to use the English word meaning-making, which would have confined the process of sense-making simply to the cultural nature of being human. There is something more to the process than just giving meaning; it also involves a sense of what is meaningful. In this connection, the Professional Standard (2015:10) refers to 'an essential role' for religion and world views in the process of ascribing meaning to life. Therefore, sense-making is anchored in the human condition and is derived from personal experiences that are interpreted within the context of a tradition (Heitink, 2000:214). Since Heitink is a Christian theologian, albeit open to other religions, it appears to me that "tradition" refers to religious traditions. I will return to the question what counts as "tradition" later in this chapter.

This brings me to the second word in the definition – "philosophy of life". If sense-making, for the Dutch, is connected with religious traditions, it makes sense to extend the context within which personal experiences are interpreted with other (non-religious) philosophies, such as humanism, liberalism, socialism and hedonism. What appears to be important for the domain of spiritual care is the reference to a normative framework which gives direction in the process of sense-making.

Apart from a normative framework, the definition of sense-making in the Professional Standard takes into account as well that direction in the process of sense-making may also be found in a purpose for one's life, quite apart from what religious traditions may have to say about the purpose of human life. In this connection, it is interesting to draw attention to Mooren's definition of sense-making as "the complex of cognitive and evaluative processes that take place in an individual during their interaction with the environment and that result in motivational commitment and psychological well-being" (Mooren, 2011:11). This definition emphasizes that the proof of the pudding of sense-making is in the motivation to make something of one's life and to feel good about it.

In conclusion, this excursion into the Dutch vocabulary shows the rich context which is available to give direction in an individual's life provided that the context is made manifest in word and thought, both by the spiritual caregiver and the client. The Professional Standard (2015:11) states it as follows: "Philosophy of life and sense-making are two sides of the same coin, embracing different aspects of finding sense as well as religious practices". A spiritual caregiver operates in this domain, and, whatever more may be said about his or her role, it is primarily about making the normative framework of the client manifest in order to help the client to find his or her way in the various circumstances of life.

The Professional Standard considers sense-making as the informal, individual aspect of the domain of spiritual caregiving and philosophy of life as the more reflective, formal, and communal aspect. The domain is further elucidated by four "key dimensions", i.e. existential; spiritual; ethical; and esthetic. I will briefly expand on the existential and esthetic dimensions. The spiritual dimension will be discussed in the next paragraph. The ethical dimension will be more extensively discussed in chapter 4.

### *The existential dimension*

The existential dimension refers to “the experience of life as such”, as the Professional Standard says. “Life as such” is understood, first of all, as the ordinary lives that people live on a daily basis in their homes, at work, with family and friends, in sport and culture, and so on. This ordinary, daily life of people is marked by routines. But in everybody’s life there are also moments when the routine is interrupted. Some people may even find their lives at some point being completely turned upside down by some tragedy. The Professional Standard speaks of (contingent) experiences of horror and amazement and everything in between. The term ‘contingent’ refers to the experience of being hit by unexpected, accidental, unforeseen happenings which leave people baffled and without control (Scherer-Rath, 2007). It is much like losing the ground under your feet. The comparison with being hit by a tsunami comes up. The notion of contingency is intimately linked with spiritual caregiving. As Scherer-Rath explains, an individual who experiences a loss of control over her or his life is also at a loss how to interpret the tragedy and how to make sense of the situation (or how to give meaning to it). Ter Borg (1991) makes the distinction between daily sense-making and existential sense-making. He argues that people provide spiritual care to one another in their ordinary, daily lives. But when they lose the ground under their feet, the daily sense-making with their family and friends is not sufficient to find their way. This is when professional spiritual care is called for.

### *The esthetic dimension*

The esthetic dimension refers to the significant experiences that people may have with beauty, both in the various expressions of human culture and in nature (VGZ, 2015:10). These experiences are not only significant (in the sense of meaningful); they are also “formative”, that is, they are considered as building blocks of human well-being. In connection with spiritual care, the esthetic dimension is especially important when rationality does not provide any answers in the face of tragedy. Spiritual caregivers do not only work with normative frameworks, but also with art, poetry and music.

## **3.4 Spirituality**

The spiritual dimension warrants a special paragraph in order to distinguish it from the two terms which define the domain of spiritual care, i.e. ‘philosophy of life’ and ‘sense-making’. The word spirituality means different things to different people. The *Handbook of the Psychology of Religion and Spirituality* (Paloutzian & Grant, 2014) observes that:

In view of the burgeoning interest [in the psychology of religion], one might imagine that the terms *religion* and *spirituality* are well defined and well understood – but the contrary is true. Many researchers espouse preferred definitions, but the field lacks an overall consensus (Oman, 2013:24).

Against this background it is interesting to note that the Professional Standard struggles with the notion of spirituality. As a matter of fact, the previous version of the Professional Standard (issued in 2002) described the domain of spiritual care in terms of ‘sense-making’ and ‘spirituality’ instead of ‘sense-making’ and ‘philosophy of life’. The Professional Standard explains the shift from ‘spirituality’ to ‘philosophy of life’ by referring to the problem of translating the Dutch word *zingeving* in English. In paragraph 3.3 I argued that “zingeving” could be translated with “meaning-making”, but that there is something more to the process of *zingeving* than just giving meaning; it also involves a sense of what is meaningful. Therefore, I opted to translate *zingeving* with sense-making. Now the Professional Standard observes that, in the English literature on spiritual care, the word “spirituality” dominates

over “sense-making” (or the *search for meaning in life*). It suggests that ‘sense-making’ and ‘spirituality’ are synonyms, interchangeable words. In my view that is not the case.

The Professional Standard argues that spirituality is a dimension of spiritual care, along with the existential, ethical, and esthetic dimensions (Beroepsstandaard<sup>12</sup>, 2015:38). It appears that the Beroepsstandaard follows Mooren and Walton, who consider the adjective ‘spiritual’ in spiritual care to signify a particular perspective on meaning-making which is concretized in sense-making and philosophy of life (Mooren & Walton, 2013:24-32). The overall concern of the Beroepsstandaard is to claim the particular perspective on meaning-making, which takes place within the context of ultimate meanings and concerns, for the profession of spiritual caretakers (Beroepsstandaard, 2015:42).

The Beroepsstandaard emphasizes that the *context of ultimate meanings and concerns* has been marginalized in the course of the process of secularization in Dutch society, and is at risk of being abandoned entirely. Against this background it seems that the Beroepsstandaard has chosen to put all its eggs in the basket of meaning-making. This is evidenced in the description of the spiritual dimension of spiritual care as referring to “transcendent meaning and experience”.

In view of the fact that sense-making is anchored in the human condition and is derived from personal experiences that are interpreted within a normative framework (see paragraph 3.3), it seems to me that it is superfluous and even confusing to relate spirituality to “transcendent meaning”. The Professional Standard does not explain what that might be, other than another normative framework. In this connection, Ter Borg writes that human beings place everything they encounter in life in a framework, so that they know how to handle it (2000:13). He explains that animals appear to do the same, except for placing the initial framework in larger frameworks. Ultimately, human beings have recourse to what Ter Borg calls normative frameworks. Elsewhere he writes:

... in that respect one can always search for a wider framework and with imagination the sense-making system can continually be broadened, concerning cognitive and affective processes of orientation, interpretation and evaluation i.e. separating sense-making and nonsense in everyday experience and on a deeper existential experiences (Ter Borg, 1999).

One of the dimensions Ter Borg discusses is the level of transcendence, in a continuum of placing events in immediate frameworks concerning the “here and now” to frameworks “in the light of eternity”. He discussed that sense-making is not only about situations that deal with liminal experiences or stress, but that every event and/or experience tends to lead to sense-making. He explains that the other side of flexibility is the despair that man does not automatically feel ‘ontologically certainty’ in his experience, as the environment does not coincide with his necessity (framework), so people do look for a certainty: to look that their experience of the world as they see, perceive and think the world is, in order to survive and making the world a manageable place to live (Ter Borg, 1999:19). Therefore, I conclude that the operation of normative frameworks is always characterized by transcendence. Since I have already accounted for those normative frameworks in relation to meaning-making, there is no need to do so again with respect to spirituality.

So, if it makes no sense to view the spiritual dimension in terms of “transcendent meaning”, it may be worthwhile to consider the spiritual dimension in terms of “transcendent experience”. The Professional Standard (d. Beroepsstandaard/VGVZ) refers to what it considers as a broad “consensus definition” of spirituality in the context of palliative care:

---

<sup>12</sup> VGVZ is also referred to as Beroepsstandaard or the Professional Standards of Spiritual Caregivers (counselors) in The Netherlands.

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski, Ferrell, Virani, Otis-Green, Baird, Bull, Chochinov, Handzo, Nelson-Becker, Prince-Paul, Pugliese, & Sulmasy, 2009).

This definition emphasizes the functions of spirituality, i.e. to seek and express meaning and purpose, and to experience connectedness. The latter function draws attention to a dimension which has indeed remained hidden in the discussion of sense-making and philosophy of life so far. Instead of the cognitive dimension which is emphasized when experiences are interpreted within a normative framework, the experience of connectedness *to the moment, to self, to others, to nature, and to the significant or sacred* emphasizes a deeper level. In the literature on spiritual care, several levels are distinguished at which existential questions may be addressed. Dijkstra, for example, names four levels: rational, emotional, existential, and, finally, “the deepest Self, God, the Absolute, Allah, Brahman” (Dijkstra, 2007: 35). In the *experience of connectedness* these levels beyond the rational resonate. Dijkstra compares these levels with different parts of the human body. The head represents the rational level; the belly the emotional; the legs the existential; and the feet the Absolute.

In chapter 2 – where I rendered my experience as raw as possible – I made only one explicit reference to spirituality in connection with my belief in paranormal activities, as a part of my cultural background and in combination with my faith in Christ in accordance with the Evangelic Church of Iceland. Taking a closer look at my story of birth and loss I think that the emotional and existential level can be easily recognized. In relation to spirituality I want to refer especially to my need for comfort, as in the case of the loss of Selma:

The specialists were able to explain the cause and effect of the brain bleeding of Selma, to predict the outcome of the trauma causing her severe disability, but I never felt comforted by them.

The need for comfort is an experience at the emotional and existential level. This need cannot be addressed at the rational level of meaning-making, because there is no rational meaning at all to be found in the loss of Selma. Reinders addresses this point very well, but this will be the subject of the next chapter. At this point I will just draw attention to the level of the Absolute in my story:

Even if I was given kind care and attention by a pastoral caregiver, theodicies to the “why” question only contributed to silencing me when I sought help or answers by a spiritual or pastoral person. I was not empowered to speak about my anger towards God or my despair about why God had left me.

Since I didn’t find comfort in the Church of Iceland, I sought help and healing from a range of ‘alternative’ sources, including expressions of faith in God or a superior power, emergency baptism of the infant, interpretation of new dreams or reinterpretation of old dreams, and visits to mediums for information about future prospects. In these words the level of the Absolute is evident. Mooren and Walton adequately distinguishes five ways in which spirituality is defined: (a) a type of human experience; (b) an activity or collection of practices; (c) a dimension of human existence with respect to meaning and purpose; (d) a reference to specific traditions and institutions; and (e) a reference to transcendence (Mooren & Walton, 2013:1-16). Each of these understandings of spirituality, with the exception of a type of experience, can be recognized in my story. First, by visiting a medium I was engaging in a spiritual activity and by asking for emergency baptism of Selma I engaged in a collective practice. Second, by attending to the interpretation of my dreams I was looking for meaning and

purpose. Third, I referred to specific traditions in Icelandic culture and to the Church of Iceland as an institution. Last, I called out to the transcendent God who appeared to have abandoned me.

Although the Beroepsstandaard quotes Mooren's & Walton's five ways of defining spirituality, it retains only "transcendent meaning and experience". My own story affirms that spirituality is a dimension of sense-making and philosophy of life. But it seems to contradict that spirituality is sufficiently understood as "transcendent experience". This will be further explained in the next chapter.

### 3.5 Conclusion

In this chapter I have reflected on my experiences as a NICU mother by utilizing concepts drawn from the Professional Standard of Spiritual Caregivers in the Netherlands and the Dutch literature on spiritual care. It was helpful to see how *zingeving* is framed in the "domain of spiritual care" with its four dimensions (existential, spiritual, ethical and esthetic) and how philosophy of life and sense-making are treated as two sides of the same coin, embracing different aspects of finding sense as well as religious practices. In studying the concept of spirituality, I was surprised to discover that it is not only concerned with meaning at the cognitive level, but also, and perhaps primarily, with affective experience. In these respects there is a marked difference between spiritual care in The Netherlands and the pastoral care that I received in Iceland at the time of my NICU experiences.

In terms of Mooren my overall sense experience, as a NICU mother in Iceland, was close to non-existent. As I wrote in paragraph 3.2, in the case of my first-born, the social workers and psychologists were preoccupied with the well-being of my child, and I was not given any choice at that time. In this situation, the Evangelic Church of Iceland was of no help to me at all. The conceptual framework of spiritual care in The Netherlands helped me to see the importance of sense-making for all those concerned in NICU, in order to find their way in that precarious situation. The implications of this understanding go way beyond my initial cry for freedom of choice (in the raw material of my life story).

The implication for the person who provides spiritual or pastoral care to the mother (or the parents, as the case may be) is that the framework of sense-making of the client must be respected at all times – whether you like it or not. The person providing spiritual or pastoral care cannot impose the more reflective, formal philosophy of life or religion that he or she represents on the client, because sense-making is a highly personal and individual task and it is the client who must find his or her own way in life. Focusing on the question of "why did this happen to me?" served to repress any expressions of the anger I felt toward God and the despair I felt about why God had departed me, leaving me in a state of nearly total disempowerment, I would have wanted help with dealing with the existential question arising and would have liked to do so, hand in hand with spiritual caretaker. My healthy feelings of absolute abandonment were in my experience of being silenced. Instead, the question that was repeatedly proposed that I work toward answering the "why" question that amounted to an invitation to go down a rabbit hole in search of something resembling the Holy Grail.

The implication for the other professionals who provide care in NICU is that by attending to their patient – the prematurely born baby – they are also intervening in the sense experience of the mother (or the parents, as the case may be). This can be seen most clearly at the level of the process of sense-making, where professionals set targets, transmit notions of handling or influence the self-image of the mother. As a mother who has been twice through the NICU experience, I have found that the experience of disconnection through the interventions of the professionals severely hampered my ability to make sense of the situation and contributed to my traumatization. My study shows that

professionals must enter in a relationship with the mother while being aware of their own frameworks of sense-making.

## 4 The ethical dimension in spiritual care

### 4.1 Introduction

The Professional Standard considers sense-making as the informal, individual aspect of the domain of spiritual caregiving and philosophy of life as the more reflective, formal, and communal aspect. As we have seen, the domain is further elucidated by four “key dimensions”, i.e. existential; spiritual; ethical; and esthetic. The existential, spiritual and esthetic dimensions have been discussed in the previous chapter. In this chapter the focus will be on the ethical dimension. We shall see that this dimension sheds an unexpected light on the spiritual dimension. Therefore, I wish to remind the reader at the outset of this chapter that the various ways of understanding spirituality in the Professional Standard do not seem to get to the heart of the matter. I was engaging in a spiritual activity by visiting a medium. I was also engaging in a collective practice by asking for emergency baptism of Selma. I was definitely looking for meaning and purpose by attending to the interpretation of my dreams. I also referred to specific traditions in Icelandic culture and to the Church of Iceland as an institution. And with all the strength that was in me, I called out to the transcendent God who appeared to have abandoned me. But I did not find anything significant in spiritual activity, practice, calling out to the transcendent God or looking for transcendent meaning and purpose. In spite of my openness for a transcendent reality appearing in the material world I came to think that, as a NICU mother, I would have to settle for some kind of basic human morality in order to make some sense of my experiences.

In the autobiographical account of my experience as a NICU mother, it is clear that many decisions were taken about me, and without me. The decision to bring me to the White House, and the medical interventions in the lives of my prematurely born children have had a huge impact on my life, largely for the worse. This aspect of my life story evidently touches on an ethical issue. Less apparent, ethical issues are also at stake in such instances as being stigmatized because of dysfunctional behavior as a teenager, not being able to fend for her firstborn, and being in an abusive relationship. In the medical and nursing literature ethical aspects are extensively discussed. For example, saving lives with the outlook on severe disability and prolonging inevitable death raises not only existential questions but also ethical questions (Nuffield Council on Bioethics, 2006: 34). In the field of medicine and nursing as well as in social work extensive attention is given to the need for consent. However, as important as these issues are, I wonder if they are really at the heart of the ethical dimension of spiritual care. My experiences of stigmatization and abusive relationship indicate something else. I want to avoid being drawn in a discourse on ethical norms of conduct and how professionals in health care and social work should abide by such norms.

What interests me from an ethical perspective is how easily professionals in health care and social work dismissed my expressions of pain, helplessness, resistance, and so on. In retrospect many of these expressions were concerned with making some sense of my situation. Although Mooren’s model suggests that the social workers and psychologists are involved in the process of sense-making, my life story show that I experienced many of them as lacking in empathy for my cries of despair. In the course of this study I had to abandon the idea that NICU mothers should be respected in their freedom of choice. In fact I was then struggling to find a deeper sense in my suffering. At that point the theological ethicist Hans Reinders drew my attention with a single word: lamentation.

## 4.2 The importance of lamentation

Reinders is engaged with people living with disabilities. Although I have never viewed myself as a disabled woman<sup>13</sup>, I find it easy to identify with them. They are often stigmatized too. And they ask the same question that I asked myself so many times without getting any satisfactory answer: “why?”.

As the title of his book *Disability, Providence, and Ethics* shows, Reinders connects ethics with the material world (disability) and a transcendent reality (providence). His point of departure is exactly the “why?” question, which is related to one’s identity in this world. As he writes:

Disability experience is a fragmented reality because it is identity related. It is not just that people go through different things in their lives; they do so as people with different convictions and beliefs, the mix of which shapes different identities (Reinders, 2014: 6).

True to this point of departure, he looks at two different kinds of disabilities. The first kind occurs at birth and results in a cognitive or developmental disability (usually addressed as “intellectual disability”). The second occurs as in an accident that results in acquired brain damage. Reinders underlines that the differences among people living with disability often remain unrecognized by those who are talking about disability in general. Ignorance of the difference is demonstrated, for example, when people with acquired brain damage are treated as if they had an intellectual disability. The consequences of making such distinctions becomes apparent when Reinders observes that “making sense” is very different for someone who has to adjust to a new kind of life following an accident, than for those who have never known themselves otherwise than in their present condition.

While my own life story does not exactly fit with the two kinds of disability that Reinders draws to the fore, I was very moved by what he wrote about the importance of lamentation. In my view the book does not deal with any specific disability; it deals with contingent happenings in the lives of people who have been struck by unexpected events in life – violence, losing a child, broken up marriage, being homeless, loss of dreams about the future. In his book Reinders tells various stories. The story of the parents of a child with Down Syndrome. The tragic story of a man who had bleeding of his brainstem that left him with a locked-in syndrome. A woman who tells the story of her husband who sustained a major brain injury in a boat accident. This book came as a revelation to me, For the first time I felt someone understood me, my trauma, my lament, my loss.

According to Reinders the “why?” question expresses the need to make sense of one’s situation. He argues that people need answers to this question in order to find ways to live a new life with old selves that must change (Reinders, 2014: 32). This position is not as evident as it may seem to those who have never found themselves asking precisely that question. Reinders observes that there are two ways to react to the “why?” question. One is to consider it as a key factor in our resilience and a help to find out how to go on living. The other is to consider it as useless: what matters is getting over it (Reinders, 2014: 33). As for me, I have been able to get over abuse in relationships and also over stigmatization which, incidentally, occurs in relationships as well. But I have never been able to get over

---

<sup>13</sup> Being an addict and an alcoholic I can argue that I have a disease and while I was active I was disabled by it. “Many people don’t understand why or how other people become addicted to drugs. They may mistakenly think that those who use drugs lack moral principles or willpower and that they could stop their drug use simply by choosing to. In reality, drug addiction is a complex disease, and quitting usually takes more than good intentions or a strong will. Drugs change the brain in ways that make quitting hard, even for those who want to. Fortunately, researchers know more than ever about how drugs affect the brain and have found treatments that can help people recover from drug addiction and lead productive lives (NIDA <https://www.drugabuse.gov/related-topics/addiction-science> ).

the loss of my three children.<sup>14</sup> Their loss has continued to be a cause of lamentation throughout my life.

If all that matters, is getting over my loss there is no room for lamentation. The presupposition is, of course, that lamenting does not help to resolve the situation. In some way that is true, because the situation cannot be reversed. But that I was well aware of. Reinders draws attention to another way of reacting that would have been more helpful to me. He says that telling people to get over it:

... does not appear as a way of taking people seriously in their grief, does it? Of course it is always possible to explain their lament in terms of a psychological need (“human beings do not like to be in the dark about things, it makes them feel insecure”) but the fact of the matter is that in asking the “why?” question, people do not merely report a *feeling*. They report a sense of crisis in their worldview also. Part of their agony is that they find the world they knew shattered. It is falling apart, and they themselves seem to be falling apart also (Reinders, 2014: 33-34).<sup>15</sup>

Telling people who are lamenting to get over it and get on with their lives is a way of silencing them. There are many ways in which lament can be silenced. Reinders comes up with the example of John Swinton how theological responses to the “why?” question may contribute to silencing people, rather than empowering them to speak out about their anger and despair. The theological responses he has in mind are theodicies (Reinders, 2014: 47-48). Theodicies are concerned with the question how all the suffering in the world may be reconciled with God’s justice (Van den Brink & Van der Kooi, 2012: 301). Swinton argues that “theodicies often end up silencing the lamenting voice of the sufferer” (quoted in Reinders: 48). In a footnote Reinders underlines that a particular strand of Christian theology even runs the risk of making suffering persons responsible for their own suffering.

In one of the interviews which I had with other NICU mothers the role of theology in silencing the sufferer resonates:

I don’t know, I know so little about spiritual support, more about Christian religion and I know of pastoral care. I think I would not want pastoral care as I don’t want to talk about God or religion. I have had enough of that. I was told to hold my mouth and trust God when I was young. (Fragment 1.21)

Reinders goes on to discuss the role of medicine in silencing those who are lamenting. For this he turns to Stanley Hauerwas, who is concerned with the silences which are created by “turning patients into passive recipients of medical expertise, and their illnesses as senseless interruptions of their lives” (Reinders, 2014: 48). Hauerwas considers the inability to name the silence around the experience of childhood illness a decisive challenge. My own experience was that the medical team in NICU was only interested in the medical history of Selma (and in my own history only as a troubled person). There was no interest at all in my story. I recognize my NICU experience in the description by Hauerwas of illness (in my case extremely premature birth) as “an isolated series of biological events with no connections

---

<sup>14</sup> I have been reunited with my first born and we have a good relation, however, I find I can’t get over the loss, the shame of being disabled by addiction and dysfunction at the time of her life, not being able to fend for her, and putting her through endless suffering from birth until the age of one. In combination with gratefulness, I admit having lost out on raising her, care for her and nourish her with love, leaves me still today grief stricken and scared I will lose her again.

<sup>15</sup> I am not sure if the reader can understand that while I read this chapter in Reinders’ book, I cried out in despair, in joy and in thankfulness that I have found literature that gives me the permission to accept my feelings and vulnerability. I feel finally understood after experiencing being silenced by authorities for close to sixty years. I am spiritual, I am a believer, I have faith, but through educated ignorance I was silenced.

to their biography, such that there is no vocabulary available at times when medicine fails to fulfill its promises” (quoted in Reinders, 2014: 48). Hauerwas characterizes this experience of being silenced in a medical context – my story or the stories of other NICU mothers – as “muted life stories” (quoted in Reinders, 2014:48).

Reinders observes that those who lament need to be comforted. That reads like an ethical principle; a principle that holds for every human being, including the professionals whom I encountered in NICU.

### 4.3 NICU mothers and the “why?” question

For this research project into the spiritual needs of mothers of extremely premature children I have relied on my own two-fold experience in NICU as well as interviews with other NICU mothers in Iceland. In this paragraph I will demonstrate that, for many NICU mothers, the “why” question is inescapable.

The mothers who kindly allowed me to interview them (in complicity, including my own confused thoughts and vulnerability) talked about the overwhelming guilt they felt because of their children being born extremely premature. They asked themselves “what did I do in life for these things to happen?” Mothers I interviewed admitted having fallen into the habit of locking in anger and resentments in regard to bad things happening to their children affecting their future lives. The mothers talked about other life altering traumatic experiences surfacing after given premature birth.

I decided right away when I knew I was pregnant after the rape not to abort, but there was no way I could raise him (*cries*). You know, my daddy was a devout Catholic, so this was difficult (*keeps crying*)! [...] and, the couple that I had found to adopt my son, they sometimes assisted me when I was pregnant (Fragment 4.21).

They shared that the premature birth, illness and disability of their children had made them angry at the world:

[...] I believed him so strongly and I adored him, but when all what the other doctor had told me so harshly eehhhhh [...] I became very angry and I became to dislike the other doctor very much for giving me these hopes [...] I don't say I hated him, but I could have kicked his behind, you know. When I think about it... I guess it is right of the doctors to be honest on what can eventually happen with the child [...] But please do it humanely, with care and compassion [...] when I think about it, it makes me sad that she was one of 25 percent to develop serious lasting disability and die, but not fall in the category of fifty percent that have mild disability, such as learning and having behavioral problems [...] But when I say this (frowns with the brows and looks very concentrated) is it ethical to experiment with such an extremely premature child – is the medical world creating a bunch of disabled individuals that will become burden on the families and society [...] (Fragment 3.11).

Also, that their behavior had been and still is two faced. On the one hand the behavior of a survivor, a strong person with stamina showed to the outside world. On the other hand, that is internal and shows the anger, pain, frustration, self-destructive behavior, reflecting the feeling of being silenced by the medical world:

But when I say this (frowns with the brows and looks very concentrated) is it ethical to experiment with such an extreme premature child. Is the medical world creating a bunch of disabled individuals that will become burden on the families and society [...]. My daughter did cost a lot, not only to us as parents (not only financially but also emotionally) and some parents become bankrupt, yes also emotionally bankrupt [...]. I read this story in the paper about a judge's ruling that a child should be taken off life support because he suffered brain damage

due to premature birth – I mean, this is crazy, first resuscitate, keep alive, parents become to love them, hope for miracle and then [...]? (Fragment 3.10).

The doctors are able to explain the cause and effects of brain bleeding, to predict the outcome of the trauma caused by extreme disability, but many mothers, like me, never felt being comforted by the medical team:

[...] going to a psychologist or other professionals, is not soothing me or comforting, it does not take away my fear (Fragment 1.13).

From my interviews with Icelandic mothers of premature children, they experience it as a brutal violation of life when their children are surviving extremely premature birth, become disabled, become terminally ill and some die after years of suffering. For these mothers this playground in life is devastating, cruel and violates life (Reinders, 2014:37), so there is no wonder they continue to ask “why?” questions – questions that are essentially pertaining to the purpose of life.

#### **4.4 Transformed lives?**

In Reinders I have found an ethicist who has an altogether different discourse on disability and ethics. As we have seen his discourse starts with taking the “why?” question serious. He argues that people need answers to this question in order to find ways to live a new life with old selves that must change (Reinders, 2014: 32). The interviews with NICU mothers in Iceland, and my own life story, demonstrate that the experience of extreme premature birth involves various ways of intense suffering. Most important in the context of this research project, however, is that the lives of these mothers – and the world in which they live – have become incomprehensible. They literally have to make sense of their lives and of the world again. The craving for accountability is inescapable, as is the guilt that accompanies feelings you have no control over as you cannot understand what has happened to you and your child. Asking who can be held accountable for the bad things happening in their lives is normal (Reinders, 2014: 37). But what if there is no one to be held accountable? What if there is no agent involved?

What remains are mere sequences of events. Consequently, a universe that consists of sequences of events has no purpose, nor has it any other meaning other than that what happens, happens. The things happening to people are either prearranged by fate, or they happen as a matter of chance (Reinders, 2014: 50).

From the perspective of spiritual care, that is, the quest for meaning and purpose in human lives Reinders offers an alternative way of proceeding with contingency. The alternative is based on the rejection of belief in fate or chance as blind and anonymous forces in human lives. My personal experience is that it has helped me to continue to ask the “why” question, even if I sometimes make the people who are around me “crazy”. Why? It has brought me closer to accept and come to terms with something I do not understand as it has given me the certainty that there is a reason to why Selma Rún and Laufey Ósk came into my life. I as many other parents have experienced that professional and the surrounding tries to silence you: “You have to get on with your life, so that continuing to question the inevitable does not seem to be of much help. What would there be to say anyway? At this point Reinders observes that there is a difference between the “why?” question being smothered in silence and a silent waiting (Reinders, 2014: 50–51).

Silent waiting is very hard to do for people. Reinders finds examples of exercising silent waiting among Jews, Christians and Muslims. They have someone to wait for: God. Taking refuge in God, is presented as an alternative for belief in fate or chance as blind and anonymous forces in human lives. This possibility is made available by the belief “that the universe is not left to its own devices but answers to the will of its Creator” (Reinders, 2014: 50).

This way of proceeding resonates with my own experience of letting go, at a certain point, and let God in, as in the twelve steps of Alcoholics Anonymous – one cannot change the past, life can and must continue, but ostracizing what has happened and pretending that all is OK will not help anyone in recovery from addiction. And I would say the same about recovery from contingency. In both instances we are entirely helpless to do anything by ourselves and completely vulnerable.

Reinders explains that “religious people used to have a sense that somehow God might change [devastated lives] for the good” (Reinders, 2014: 48). Lamentation reflects the agony when people find the world they knew shattered. It is falling apart, and they themselves seem to be falling apart also (see footnote 11). We are here at the heart of spiritual care – the need for healing in human lives beyond the means which health care can provide. In some way the experiences of NICU mothers testify with their stories of loss and broken dreams to this deep need for healing.

According to the theological reflection by Reinders a transcendent reality – providence – may intervene in the human experience of loss and broken dreams of the future. The way to such an intervention is opened by lamentation and waiting in silence.

Reinders tells the story of Martha and John, believers, people of faith who gave birth to a son with Down syndrome. Martha and John both explain about the transformation the entering of Adam into their lives. “Sharing their lives with Adam changed their views of many of the things they have been dreaming of, but once he is around these things lose their attractiveness (Reinders, 2014: 67) Martha and John transform through the disability of Adam, like I transformed through the disability of Selma transformed my life. Transformation took place in my life long before the birth of my premature child, that is when I realized, by the grace of God and hearing a voice and being touched by something greater than myself, I sobered up and stopped using mind changing chemicals. Being a recovering alcoholic for almost 40 years with the help of the philosophy of Alcoholics Anonymous, I have learned or trained myself to live by the day, but that does not take away that I continue to ask the “why” question. In the *Serenity Prayer* of Nierbuhr it says: “Change the things you can change and accept things you cannot change” – I know this to be true, but I still use my energy to ask “why” questions. My questions have turned into “reconciliation, but not developed into resignation”.

From this research project I have learned that my continued lamentation – and the lamentation of other mothers of extremely premature children – may become more meaningful when it is accompanied by silent waiting in order, perhaps, to discover one day that:

You turned my lament into dancing (Psalm 30:11–12)

## 4.5 Conclusion

In Chapter 4, I argue that the ethical dimension of spiritual care sheds an unexpected light on the spiritual dimension. In the Professional Standard the spiritual dimension is understood as “transcendent meaning and experience”. I suggested that this does not seem to get to the heart of the matter.

My investigation of the ethical dimension has been guided by the work of the theological ethicist Hans Reinders. My starting point was that ethics, for the NICU staff as well as many parents, is

traditionally and mainly about consent for medical interventions and questioning whether treatment of the new born or disabled child should continue. Based on a strand of Reinders' work in which Hauerwas is cited, my attention shifted from this traditional ethical focus to the importance of lamenting. It is less than ethical practice to dismiss the lament of parents, like me, who, having given an extreme premature birth, then face inevitably and immediately a raging, full-blown existential crisis. Some of us experience this dismissiveness as an attempt at silencing, adding fuel to our rage which is the opposite of what anyone would wish for. Quotations from interviews with other Icelandic mothers who have given extreme premature birth allied with my own voice to express this existential crisis.

The last step in my investigation was to attend to my crying while reading the work of Reinders. This was a healing crying for being understood in my lamentations. This brings me, first of all, to the conclusion that NICU staff, from an ethical perspective, must make efforts to accommodate the lamentations rather than joining in the effort of silencing the parents who are in their care. But studying the work of Reinders made me see beyond the importance of lamentations to consider the possibility of transformation in human lives. Finally liberated from its guilt-inducing Christian facets I admit to the spiritual dimension as an integral part of making sense of human lives.

## 5 Conclusion

In chapter 1, the research question was formulated as follows: What can we learn from the stories which mothers of extremely premature children born in NICU tell about their spiritual needs?

In order to answer this question I have taken three steps. As a mother who has given birth to two extremely premature children in NICU, the first step was to begin telling my life story as a story of loss and from there to develop it into an autoethnography, relating it to my cultural background as a native of Iceland while focusing on the serial effects of those losses and analysing my past progressively in terms of youth and trauma, stigma, grief, ambiguous loss, guilt and shame, Selma Rún (my disabled daughter who lived 3.5 years and whose arrival, survival, and departure mark a large moment on which my life turns). After that it becomes a story of surviving through spirituality, and though it is still ongoing, I bring it to a close for the purpose of this thesis, admitting I have made mistakes, protesting discrimination against those who are disabled, and evaluating of my own capacity for forgiveness.

The first part of step 2 was to examine what spiritual care is (chapter 3) and was designed to answer the first sub-question, “What is spiritual caregiving”? In chapter 3 we have seen that Ter Borg finds that people provide spiritual care to one another in their daily lives, and that sense-making among family and friends is a form of spiritual caregiving. However, it is more the other variety of spiritual caregiving that he writes of that would be suitable for mothers of extreme premature children. At this level, spiritual caregiving is an interactive process that occurs between a spiritual caregiver and a client who has lost a sense of purpose or has meaning of life issues. The caregiver provides assurance, guides the client’s search for purpose and meaning, and is also capable of providing appropriate rituals, spiritual offerings (such as texts, prayers, songs, etc.), and conversational content consonant with the client’s life view or religious traditions. The spiritual caregiver is trained to identify and help the client with cognitive and affective issues as they relate to sense making, and can team with psychologists and social workers with the aim of helping the client in that pursuit. In terms of theory, in the case of a mother in existential crisis over having given birth to an extreme premature child, spiritual caregiving is the process of helping to enable her to manifest her own framework of meaning and sense-making and working toward restoring her sense experience. In terms of Pulchalski’s definition of spirituality, this means helping her to achieve a sense of connectedness, and to express meaning and purpose as well as how she experiences connectedness “to the moment, to self, to others, to nature, and to the significant or sacred.” Professional spiritual caregiving requires attentive and loving presence, compassion, as well as a strong ethical sense on the part of the caregiver. Spiritual caregiving focuses on how questions of the meaning of life are handled.

The second part of the second step was to add to my own voice the supporting voices from interviews I recorded with other mothers of extreme premature children and showing how our experiences coincide with Reinders’ observations about lamentation with respect to disability, allowing me to explore the ethics of spiritual care as a means of challenging how mothers of extremely premature children are silenced when they lament, or when they give voice to the question, “Why did this happen to me?” or perhaps taking it on at an even more personal level, as we heard one mother articulate, “What did I do in life for these things to happen?”

Based on the investigation of the two sub-questions, the third step is to merge the salient results from each in order to state what we can learn from the stories which mothers of extremely premature children born in NICU tell about their spiritual needs.

Many of the assumptions these women and I had made about our lives and our futures are overturned from the moment we give extreme premature birth which coincides with the beginning of our NICU experiences.

We need our lamentations to be heard until we are comforted rather than silenced. When someone asks, “Why is this happening to me?” or “Why has this happened to me?” again and again—seemingly uncontrollably, as if obsessed--as is common among mothers of extreme premature children, according to Reinders the person needs to be comforted, not silenced.

A stigmatization attends us and our immediate family members and reinforces our silence.

A professionalism among health care workers and an ethic of care that disconnects us from our life-stories, contributes further to the silencing of our healthy lamentations which could instead be interpreted as a cry for help and for comforting.

As individuals we mothers still feel a compelling desire to find answers for why this happened to each of us.

In short, the suppression of each of these mother’s laments represents a failure of the health care system and the larger society to engage at the spiritual level with the challenge faced by its members who have given birth to an extreme premature child. This same ethic that allows individuals in existential crisis to be left without proper treatment is needlessly cruel given the existence of people who are trained specifically to address such an issue; until the cause of these lamentations receives proper treatment, the ethic that suppresses it will continue to disable many of these mothers from a form of assistance that could help them toward recovering a meaning and purpose for their lives.

Leaving it at that might raise another question: Is this thesis which states and examines a novel question in an organized, fact-based way, and results in demonstrating that the mothers of premature children are subject to deep spiritual problems that are being silenced, in itself, a lament? As earlier in my conflicted capacity for forgiveness, I will answer both yes and no. Yes, it may be read as a lament, in so far it is at times passionate, barely coherent and may seem a bit whiney.

And that may raise yet another: As mother of two extreme premature children, how can I claim these mothers of premature children whom I interviewed were silenced, count myself among them on the one hand, and then turn around and with the other write a rather noisy thesis about being silenced? My answer lies largely in the passage of time allied with the fact that to the best of my knowledge, I differ from the other mothers I interviewed in that I received some help along the way through the peculiar effort of that imperfect and suboptimal pastoral care provider who early on, when I was at such a loss I felt I had nearly nothing more to lose, somehow found the grace to step out of his role and helped to set me on the project to discover a sense of meaning and purposefulness which this thesis, as imperfect and sub-optimal as it may be, both springs from and exemplifies. While being a thesis and a lament, this is also, at least in part, a humble song of praise.

## 6 References

- Alblas, A. (2004). Cloacal glands of the group-living lizard, *Cordylus cataphractus* (Sauria: Cordylidae) (Thesis in MSc.). Stellenbosch University, Botany and Zoology, Stellenbosch. Retrieved from <http://scholar.sun.ac.za/handle/10019.1/49884>
- Arnold, J. C. (2014, May). *Why Forgive?*. Farmington, USA and Robertsbridge, UK: Plough Publishing House. Retrieved August 31 from <https://www.plough.com/en/topics/life/forgiveness/why-forgive>
- Berger, B. (1990). *Authors of their own lives: Intellectual autobiographies*. Berkeley, CA: University of California Press.
- Beroepsstandaard geestelijk verzorger 2015* (VGvZ). (2016, December). Retrieved July 10 from <https://vgvz.nl/wp-content/uploads/2018/07/Beroepsstandaard-2015.pdf>
- Borg, M. B. ter. (1999). "What is religion?" In the Pragmatics of Defining Religion, Contexts, Concepts & Contests, edited by J. G. Platvoet and A. L. Molendijk, 397–408. Leiden: Brill.
- Borg, M. B. ter. (2000). *Waarom geestelijke verzorging? Zingeving en geestelijke verzorging in de moderne samenleving* [Wh spiritual care? The search of meaning and spiritual care in modern society]. Nijmegen: KSGV.
- Borg, M.B. ter (1991) Een uitgewaaierde eeuwigheid, Het menselijk tekort in de moderne cultuur, Baarn: ten Have
- Boss, P. (1999). *Ambiguous Loss*. Cambridge, Massachusetts: Harvard University Press.
- Brelsford, G. M. & Doheny, K. K. (2016, February). Religious and Spiritual Journeys: Brief Reflections from Mothers and Fathers in a Neonatal Intensive Care Unit (NICU). *Pastoral Psychology*, 65(1),
- Caldeira, S. & Hall, J. (2012, December). Spiritual leadership and spiritual care in neonatology. *Journal of Nursing Management*; 20(8):1069–75. doi: 10.1111/jonm.12034
- Crocker, J. & Major, B. (1989). Social Stigma and Self-Esteem: The Self-Protective Properties of Stigma. *Psychological Review*, 96(4), 608–630.
- Dijkstra, K., Kaschak, M. P., Zwaan, R. A. (2007, January). Body posture facilitates retrieval of autobiographical memories. *Cognition*, 102(1), 139-49. doi: 10.1016/j.cognition.2005.12.009
- Einarsdóttir, J. (2009, March 21). Emotional experts: parents' views on end-of-life decisions for preterm infants in Iceland. *Medical Anthropology Quarterly*, pp. 34-50.
- Ellis, C. (2004). The ethnographic I: A methodological novel about y. Walnut Creek, CA: AltaMira Press.
- Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An overview. *Historical Social Research*, 12(1), 273–290.
- Fowler, J. W. (1981). *Stages of Faith. The Psychology of Human Development and the Quest for Meaning*. San Francisco: Harper & Row.
- Ganzevoort, R. R. (2011, October). Trauma en geestelijke verzorging. Retrieved December 4 2017 from <https://ruardganzevoort.wordpress.com/2011/10/26/trauma-en-geestelijke-verzorging/>
- Green, S. (2002). Mothering Amanda: Musings on the experience of raising a child with cerebral palsy. *Journal of Loss and Trauma*, 7, 21–34. 178.
- Green, S. E. (2003). They are beautiful and they are ours: Swapping tales of mothering children with disabilities through interactive interviews. *Journal of Loss and Trauma*, 8(1), 1–13.

- Green, S. E. (2003, October). "What do you mean 'what's wrong with her?'": stigma and the lives of families of children with disabilities. *Social Science & Medicine*, 57(8), 1361–1374. doi: 10.1016/S0277-9536(02)00511-7
- Green, S. E. (2007). We're tired, not sad: Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64, 150–163.
- Hauerwas, S. (2004). *Naming the Silences: God, Medicine, and the Problem of Suffering*. Edinburgh: A&C Black.
- Heidari, H., Hasanpour, M. & Fooladi, M. (2012, January). The Iranian Parents of Premature Infants in NICU Experience Stigma of Shame. *Medicinski Arh*; 66(1), 35–40. doi: 10.5455/medarh.2012.66.35-40
- Heitink, G. (2000). *Pastorale Zorg, theologie differentiatie praktijk*. Kampen: Kok.
- Hekking, R. (2003). Het domein van de geestelijk verzorger. Overwegingen bij de beroepsstandaard. *Tijdschrift Geestelijke Verzorging*, 6(29).
- Henney, S. M., Ayers-Lopez, S., Mcroy, R., & Grotevant, H. (2007, December). Evolution and resolution: Birthmothers' experience of grief and loss at different levels of adoption openness. *Journal of Social and Personal*, 24(6), 875–889. doi: 10.1177/0265407507084188
- Hilton, J., & von Hippel, W. (1996). Stereotypes. *Annual Review of Psychology*, 47, 237–271. doi: 10.1146/annurev.psych.47.1.237
- Krueger, J. (1996). Personal beliefs and cultural stereotypes about racial characteristics. *Journal of Personality and Social Psychology*, 71(3), 536–548. doi: 10.1037/0022-3514.71.3.536
- Lawrence, L. (2011). Through My Mother's Eyes: The Lifelong Journey of Raising Children With and Without Disabilities. *Electronic Theses and Dissertations*, 855. Retrieved November 5 2017 from <http://digitalcommons.du.edu/etd/855>
- Maister, D. H., Green, C. H., & Galford, R. M. (2000). *The Trusted Advisor*. New York: The Free Press.
- Marshall, L. (2013, December 6). Nelson Mandela and the Power of Forgiveness [Blog]. National Geographic. Retrived January 1, 2019 from <https://blog.nationalgeographic.org/2013/12/06/nelson-mandela-and-the-power-of-forgiveness/>
- Mooren, J. H. M. (2011). Verbeelding en Bestaansoriëntatie (p. 47). Utrecht: Uitgeverij de Graaff.
- Mooren, J. H. M., & Walton, M. N. (2013). Geestelijke verzorging. Over de veelvormigheid en de fluiditeit van het geestelijke. *Tijdschrift Geestelijke Verzorging*, 16(70), 24–32.
- Napoleon XIV. (2017, August 31). 'They are coming to take me away' [Video]. Retrieved January 1, 2019 at <https://www.youtube.com/watch?v=hnzHtm1jhL4>
- NIDA. (2015, July 29). Addiction Science. Retrieved January 3, 2019 from <https://www.drugabuse.gov/related-topics/addiction-science>
- Nuffield Council on Bioethics. (2006). *Critical care decisions in fetal and neonatal medicine: ethical issues*. London: Nuffield Council on Bioethics.
- Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The Parental Experience of Having an Infant in the Newborn Intensive Care Unit. *The Journal of Perinat Education*; 18(3), 23–29. doi: 10.1624/105812409X461199

- Ólafs, de Bont, Ó. (1998). *You are mine Selma Rún and the doctors are going to save you*. London: Avon Book.
- Orzalesi, M. M. & Cuttini, M. (2011). Ethical issues in neonatal intensive care. *Ann Ist Super Sanita*, 47(3), 273–277. doi: 10.4415/ANN\_11\_03\_06
- Paloutzian, R. F., & Park, C. L. (2014). *Handbook of the Psychology of Religion and Spirituality*. Second Edition. Ed. Paloutzian, R. F., & Park, C. L. New York: Guildford Press
- Pargament, K. I. (1997). *The psychology of religion and coping: Theory, research, practice*. New York: The Guilford Press.
- Powell, K. A., & Afifi, T. D. (2005, February). Uncertainty management and adoptees' ambiguous loss of birth parents. *Journal of Social and Personal Relationships*, 22(1), 129–151. doi: 10.1177/0265407505049325
- Puchalski, C., et al. (Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., Pugliese, K., & Sulmasy, D.). (2009). Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *Journal of Palliative Medicine*, 12(10). doi: 10.1089/jpm.2009.0142
- Reinders, H. S. (2014). *Disability, Providence, and Ethics: Bridging Gaps, Transforming Lives (Studies In Religion, Theology, and Disability)*. Waco, Texas: Baylor University Press.
- Reinhold Niebuhr. (2018, August 2). *Wikipedia, The Free Encyclopedia*. Retrieved August 10, 2018, from [https://en.wikipedia.org/w/index.php?title=Reinhold\\_Niebuhr&oldid=853091930](https://en.wikipedia.org/w/index.php?title=Reinhold_Niebuhr&oldid=853091930)
- Romanchik, R. (1999). *A Birthparent's Book of Memories*. New York: R-Squared Press.
- Scherer-Rath, M. (2007). Contingentie en religieus existentiële zorg. *Tijdschrift Geestelijke verzorging*, p. 30.
- Siddique, S. (2011). Being in-between: The relevance of ethnography and auto-ethnography for psychotherapy research. *Counselling and Psychotherapy Research: Linking research with practice*, 11(4), 310–316. doi: 10.1080/14733145.2010.533779
- Steyn, E., Poggenpoel, M. & Myburgh, C. (February, 2017). Lived experiences of parents of premature babies in the intensive care unit in a private hospital in Johannesburg, South Africa. *Journal of the Democratic Nursing Organization of South Africa*, 40(1)a, 1698. doi: 10.4102/curationis.v40i1.1698
- Yousof, Z. H. (2016, December). Joy for what it is: Narratives of two mothers on raising their children with disabilities. *Electronic Theses and Dissertations*. 345. Retrieved July 14 from <http://scholarworks.uni.edu/etd/345>

## **7 Annex**

See document Part II – Annex.

- 7.1 Annex A: Selma Rún and Laufey**
- 7.2 Annex B: Introduction letter**
- 7.3 Annex C: Introduction and asking for participants via FB chat**
- 7.4 Annex D: Sample of FB chat**
- 7.5 Annex E: Interview Schema**
- 7.6 Annex F: Dreams of the mother of Þ**
- 7.7 Annex G: Conversation with mother – not included in the interview scheme**
- 7.8 Annex H: Conversation with mother – through FB not included in interview scheme**
- 7.9 Annex I: Letter from Rev. Bragi Skúlason**
- 7.10 Annex J: Mother of disabled boy**
- 7.11 Annex K: Schematized interviews**
- 7.12 Annex L: Schema three labelled interviews**
- 7.13 Annex M: Dr. Thomas in regard to the article “Parent Response to Stress: Promis in NICU**
- 7.14 Annex N: Ritual in NICU in Iceland Rev. Bragi Skúlason**
- 7.15 Annex O: Email exchange with Myrna Willick**
- 7.16 Annex P: Correspondance with Dr. Sara Green on parents and disabled children**