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AALBORG UNIVERSITY
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Dissertation submitted

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ENGLISH SUMMARY

This thesis examines bereaved parents' experiences of grief after the loss of an infant child, and how cultural representations, expectations, and norms mediate individual bereavement experiences. It explores how bereaved parents interpret and mediate their own grief experiences and practices by drawing on interpretive repertoires that are available through their personal and family history, popular culture, personal accounts, bereavement communities, etc. In light of recent debates on diagnosing prolonged or complicated grief as a mental disorder within the diagnostic manuals, the thesis also explores how bereaved parents relate to professional and popular accounts of grief as a potential illness.

Each year more than 400 babies in Denmark die during the last half of the pregnancy (after 22 gestational weeks), during birth, and within the first year of life.[1] As infant mortality rates in the developed countries have declined throughout the last century, our cultural expectations towards pregnancy – at least after the first weeks where the risk of miscarriage is still considerably high – are highly optimistic. Hence, the shock of losing a baby is typically all the more devastating for the bereaved parents and their families. Research on parental bereavement after infant death indicate that a large proportion of these parents experience long-lasting and pervasive grief (Dyregrov et al., 2003; Kersting et al., 2011). Several researchers within the field of bereavement argue that a considerable proportion of these parents might develop a psychiatric disorder such as the proposed diagnosis for complicated or prolonged grief disorder. While our knowledge about how bereaved parents are affected by the symptoms described in the proposed grief diagnoses has increased, we know only little about how these very diagnostic understandings affect parental grief experiences. By analyzing how bereaved parents relate to professional and lay conceptions of healthy, normal and appropriate versus pathological, abnormal and inappropriate grieving, this thesis contributes to a limited literature on bereaved parents' experiences of cultural norms about suffering in general and grief in particular.

The analyses are based on data from a longitudinal (approx. 2 years), qualitative study with 13 bereaved parents (6 heterosexual couples and one woman participating without her husband, aged 26-42 years) who had lost children during the latter half of the pregnancy (>22 weeks of gestation), or within the first week of the child's life. With one exception (a couple participating in one interview approx. 2 years after the death of their child), all of the couples were interviewed at least three times during the two years: (1), 1-2 months after their loss; (2), 7-8 months after their loss; and (3),

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[1] E.g., in 2014, 242 stillbirths were registered (out of 57.572 births), and 229 children died within their first year (Statistics Denmark [Danmarks Statistik], 2017; National Board of Health Data [Sundhedsdatastyrelsen], 2017, advanced searches, Jan 9th, 2017).

approx. 2 years after their loss. All of the informants were recruited through my former workplace, The Danish Infant Death Association[2], who has also provided financial support for this project. Based on my background in the organization and my personal experiences with losing a child, the study also involves autoethnographic inquiries into my personal experiences with loss and the significance of these experiences for my research. Informed by a cultural psychological outlook, the study depicts grief as an historically embedded, culturally and materially mediated practice. Accordingly, the thesis argues that grieving is enacted and experienced in relations to the lost loved one, to other people, to historically contingent conceptions of life and death, personhood, parental attachment, suffering and disease, as well as socio-material practices and technologies such as images, gravesites, therapeutic practices, self-help communities, etc.

The thesis is organized as follows: Chapter 1 describes the background of the project and the structure of the thesis.

Chapter 2 outlines the theoretical outlook of the thesis.

Chapter 3 charts the major developments and transitions in the scientific and popular grief models and theories since the emergence of modern psychology up to contemporary suggestions to diagnose “complicated” or “prolonged” grief as a psychiatric disorder.

Chapter 4 presents a review of the literature on parental bereavement, focusing primarily on qualitative studies of parental bereavement experiences after infant death. The review reveals that parental bereavement after infant loss is associated with experiences of uncertainty and ambivalence concerning the status of the lost child and how to grieve such a loss. Furthermore, it reveals that parental grief is an ongoing process that involves parental identity, the relationship to the lost child and to other people.

In chapter 5, I outline and discuss some of the main methodological and ethical considerations that have been a part my research process.

In chapter 6, I highlight some of the main themes regarding the informants’ experiences of participating in the activities provided by the Danish Infant Death Association. I argue that by offering a platform for shared experiences and mutual support, such communities may facilitate negotiations of cultural norms concerning grief and loss, and provide alternative sources for understanding and acting in relation to loss. Furthermore, I demonstrate the inherently normative nature of the practices

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[2] In Danish: Landsforeningen Spædbarnsdød

provided by the bereavement organization. Finally, I emphasize the importance of including critical reflections of the normative dilemmas that arise from such practices.

Chapter 7 to 10 contains the four articles of the thesis. In the first article, ***"From morality to pathology: A brief historization of contemporary Western grief practices and understandings"*** (chapter 7) I present three ideal typical grief articulations drawn from three historical periods: 1) Grief as a moral practice in Ancient Greek virtue ethics, 2) Grief as an expression of an inner, authentic morality in the Romantic era, and, 3) Grief as a psychologized and increasingly pathologized phenomenon in modern psychology up to the present attempts to include separate diagnoses for pathological grief in the diagnostic manuals for mental disorders (American Psychiatric Association, 2013; World Health Organization, 2016). The purpose of this presentation is to shed light on current taken for granted notions of grief, and, by providing some historical background, challenge prevailing understandings that depict grief as an ahistorical, universal, intra-psychological and (potentially) medical condition that is analytically separate from historical, social, cultural and religious practices. Informed by a cultural psychological outlook (Brinkmann, 2016; Valsiner, 2014), I argue that the relationship between grieving individuals and their cultures is dialectical, mutually constituting and inherently normative, and hence, that the diagnostic approach to grief as an individual, causal reaction to loss is flawed. On this background, I argue that an acknowledgement of the inherent normativity of grief (as presented by the historical accounts) can potentially inform and enrich contemporary understandings and practices related to bereavement, ultimately to the benefit of people who suffer from grief.

In the second article, ***"Becoming a bereaved parent: Parental grief after infant loss"*** (chapter 8), I explore the connections between my own experiences as a bereaved mother and as a researcher interested in parental bereavement after infant loss. I describe my own struggle with integrating personal and professional encounters with loss, and discuss the ethical and epistemological significance of involving personal experiences with loss in my research on parental bereavement. I argue that while popular accounts depict normal grief as a transitory state, parental accounts present grief as a continuing and open-ended relationship with the dead child. In appreciation of this, this essay presents fragmentary, non-reifying narratives of the continuing realities of becoming a bereaved parent.

In the third article (chapter 9), ***"Grief as a normative phenomenon: The diffuse and ambivalent normativity of infant loss and parental grieving in contemporary Western culture"***, co-written with my Ph.D. supervisor, professor Svend Brinkmann, we draw upon empirical materials from the present interview study and analyze how grieving the loss of a small child in our culture is experienced, interpreted, and enacted within a diffuse and ambivalent, yet inescapable, moral framework. Further, we discuss some of the possible consequences for bereaved individuals when navigating the normative landscape of grieving in contemporary Western cultures: A landscape in which suffering is increasingly dealt with in psychiatric and medical terms and understood as an adverse and unnecessary condition to be overcome in order to maximize personal health, happiness and well-being.

In the fourth and final article, ***"Grief as a border diagnosis"*** (chapter 10), I explore how bereaved parents after infant loss relate to the current debates on diagnosing grief as a psychiatric disorder. Based on findings from my interviews with the bereaved parents participating in my study, I identify four different parental accounts concerning the question of diagnosing grief: (a) diagnosis as a legitimating and normalizing practice, (b) diagnosis as a demarcation practice, (c) diagnosis as pathologization, and (d) diagnosis as a normative ideal. Through the examples, I attempt to demonstrate how bereaved individuals do not merely passively adopt but reflectively use these kinds of understandings to deal with their grief.

In chapter 11, I summarize the major contributions of this thesis to the research on parental bereavement after infant loss, and point to avenues for future research.

DANSK RESUME

Denne afhandling undersøger efterladte forældres sorgerfaringer efter tabet af et spædbarn, og hvorledes kulturelle repræsentationer, forventninger og normer medierer individuelle tabserfaringer. Afhandlingen udforsker, hvordan efterladte forældre fortolker og medierer deres sorg gennem fortolkningsmæssige repertoirer, der er tilgængelige gennem deres personlige baggrund, populærkultur, personlige beretninger, sorgfællesskaber, etc. I lyset af de seneste års debat om indførelsen af en diagnose for forlænget eller kompliceret sorg i de internationale diagnosemanualer, undersøger afhandlingen også, hvordan efterladte forældre forholder sig til professionelle og almene forståelser af sorg som en potentiel sygdom.

Hvert år dør mere end 400 spædbørn i Danmark i løbet af sidste halvdel af graviditeten (efter 22 graviditetsuger), under fødslen og indenfor deres første leveår.[3] Efterhånden som spædbarnsdødeligheden i de udviklede lande har faldet gennem det sidste århundrede, er de kulturelle forventninger vedrørende graviditeter blevet tiltagende optimistiske—i hvert fald efter de første uger, hvor abortrisikoen stadig er relativ høj. Derfor er chokket over at miste et spædbarn typisk desto større for de efterladte forældre og deres familier. Eksisterende forskning indikerer, at en stor andel af disse forældre oplever langvarig og gennemgribende sorg (Dyregrov et al., 2003; Kersting et al., 2011). En række forskere inden for området hævder, at en væsentlig andel af disse forældre er i risiko for at udvikle en psykiatrisk lidelse, såsom den foreslåede diagnose for kompliceret eller forlænget sorg. Til trods for en forøget viden om, hvordan efterladte forældre påvirkes af de symptomer, der beskrives i diagnoseforslagene, ved vi kun lidt om, hvordan disse diagnostiske forståelser i sig selv influerer på forældres sorgerfaringer. Ved at analysere, hvordan efterladte forældre forholder sig til professionelle og lægmandsopfattelser af sund, normal og passende versus patologisk, anormal og upassende sorg, forsøger denne afhandling at bidrage til en begrænset litteratur vedrørende efterladte forældres oplevelser af kulturelle normer for lidelse i almindelighed og sorg i særdeleshed.

Analyserne er baserede på data fra et longitudinalt (ca. 2-årigt), kvalitativt studie med 13 efterladte forældre i alderen 26-42 år (6 heteroseksuelle par og én kvinde, der deltog uden sin ægtefælde), der alle havde mistet et barn i sidste halvdel af graviditeten (>22 graviditetsuger), eller inden for den første uge af barnets liv. Med én undtagelse (et par, der deltog i ét interview ca. 2 år efter at de mistede deres barn), blev alle forældre interviewet min. 3 gange i løbet af perioden: (1), 1-2 måneder efter

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[3] I 2014 blev der fx registreret 242 dødfødsler (ud af 57.572 fødsler), og 229 børn døde I løbet af deres første leveår (Danmarks Statistik, 2017; Sundhedsdatastyrelsen, 2017. Avancerede søgninger, 9. januar 2017).

tabet; (2), 7-8 måneder efter tabet; og (3), ca. 2 år efter tabet. Alle informanter blev rekrutteret gennem min tidligere arbejdsplads, Landsforeningen Spædbarnsdød, der også har bidraget med finansiel støtte til projektet. Baseret på min egen baggrund i foreningen og mine personlige erfaringer med at miste et spædbarn, inddrager studiet også autoetnografiske undersøgelser af betydningerne af disse erfaringer for min forskning.

Med afsæt i et kulturpsykologisk perspektiv forholder studiet sig til sorg som en historisk, kulturelt og materielt indlejret praksis. På den baggrund argumenterer jeg for, at sorg udfolder sig, gøres og erfares i relationer til den afdøde, til sig selv, til andre mennesker, og til historisk betingede forestillinger om liv og død, subjektivitet, tilknytning, lidelse og sygdom, såvel som til socio-materielle praksisser og teknologier som billeder, gravsteder, terapeutiske praksisser, sorgfællesskaber, etc.

Afhandlingen er organiseret på følgende måde: Kapitel 1 beskriver projektets baggrund og afhandlingens struktur.

Kapitel 2 beskriver studiets teoretiske afsæt i kulturpsykologien og relaterede perspektiver, der til sammen udgør en ramme for at begribe sorg som en situeret, normativ praksis.

Kapitel 3 kortlægger væsentlige udviklingslinjer og overgange i de videnskabelige og populærpsykologiske sorgmodeller og –teorier fra fremkomsten af den moderne psykologi og frem til nutidige forslag om at diagnosticere ”kompliceret” eller ”forlænget” sorg som en psykiatrisk lidelse.

Kapitel 4 præsenterer en gennemgang af den eksisterende litteratur vedrørende forældres sorg, med fokus på kvalitative studier af efterladte forældres sorg ved tabet af et spædbarn. Litteraturgennemgangen demonstrerer, at forældres sorg over at miste et spædbarn er forbundet med oplevelser af normativ usikkerhed og ambivalens knyttet til tabets betydning og hvordan man sørger over denne form for tab. Derudover peger litteraturgennemgangen på, at forældres sorg er en vedvarende proces, der involverer forældreidentitet, forholdet til det afdøde barn og til omverdenen.

I kapitel 5 redegør jeg for nogle af de væsentligste metodologiske og etiske overvejelser, der har indgået i min forskningsproces.

I kapitel 6 belyser jeg centrale temaer vedrørende informanternes erfaringer med at deltage i Landsforeningen Spædbarnsdøds tilbud og aktiviteter. Jeg argumenterer for, at sådanne fællesskaber—ved at tilbyde en platform for erfaringsudveksling og gensidig støtte—kan facilitere forhandlinger af kulturelle normer vedrørende sorg og tab, og tilvejebringe alternative fortolknings- og handlingsrepertoirer for efterladte. Med udgangspunkt i etnografiske data vedrørende foreningens praksisser peger jeg desuden på disse praksissers iboende normativitet. Endelig argumenterer jeg for nødvendigheden af, at inkludere kritiske refleksioner over de normative dilemmaer, der opstår i udformningen af denne form for praksisser.

Kapitel 7 til 10 indeholder afhandlingens fire artikler. I den første artikel, ***"From morality to pathology: A brief historization of contemporary Western grief practices and understandings"*** (kapitel 7) præsenterer jeg tre idealtypologiske artikulationer af sorg hentet fra tre historiske perioder: 1) sorg som en moralsk praksis i Antikkens dydsetik, 2) sorg som udtryk for en indre, autentisk moralitet i Romantikken, og 3) sorg som et psykologiseret og tiltagende patologiseret fænomen i moderne psykologi og frem til nutidige forsøg på at inkludere en selvstændig diagnose for patologisk sorg i de diagnostiske manualer (American Psychiatric Association, 2013; World Health Organization, 2016). Ved at skitsere en historisk baggrund for samtidens sorgforståelser, er formålet at udfordre nutidige forestillinger om sorg som et ahistorisk, universelt, intrapsykologisk og (potentielt) patologisk fænomen adskilt fra historiske, sociale, kulturelle og religiøse praksisser. Med udgangspunkt i et kulturpsykologisk perspektiv (Brinkmann, 2016; Valsiner, 2014) hævder jeg, at en opmærksomhed på sorgens iboende normativitet (vist gennem de historiske fremstillinger) kan informere og berige samtidens sorgforståelser og –praksisser, i sidste ende til fordel for sørgende.

I den anden artikel, ***"Becoming a bereaved parent: Parental grief after infant loss"*** (kapitel 8), udforsker jeg forbindelserne mellem mine egne erfaringer som efterladt mor og som en forsker, der interesserer mig for forældres sorg ved spædbarnsdød. Jeg beskriver min egen kamp for at integrere mine personlige og professionelle erfaringer med sorg og tab, og diskuterer de etiske og epistemologiske betydninger af at involvere egne tabserfaringer i mine studier af forældres sorg. I modsætning til almindelige forestillinger om sorg som en forbigående tilstand, beskriver jeg forældres perspektiver på sorg som et fortsat og foranderligt forhold til det døde barn. I anerkendelse af dette, præsenterer essayet fragmentariske og åbne narrativer om den vedvarende tilblivelsesproces det er at blive forældre til et dødt barn.

I den tredje artikel, ***"Grief as a normative phenomenon: The diffuse and ambivalent normativity of infant loss and parental grieving in contemporary Western culture"*** (kapitel 9), skrevet sammen med min ph.d.-vejleder, professor Svend Brinkmann, trækker vi på empirisk materiale fra det nærværende studie og analyserer, hvordan det at sørge over et lille barn i vores kultur erfares, fortolkes og gøres inden for en diffus og ambivalent, men uundgåelig moralsk horisont. Derudover diskuterer vi nogle mulige konsekvenser for efterladte forældre, der må navigere i samtidens normative sorglandskab: Et landskab hvori lidelse i tiltagende grad underkastes et psykiatrisk og medicinsk blik, og forstås som en ugunstig og unødvendig tilstand, der skal overkommes for at maksimere personlig sundhed, lykke og velbefindende.

I den fjerde og sidste artikel, ***"Grief as a border diagnosis"*** (kapitel 10), udforsker jeg, hvordan efterladte forældre efter spædbarnsdød forholder sig til de aktuelle forslag om at indføre en selvstændig diagnose for sorg. Med udgangspunkt i analyser af interviewdata fra det nærværende studie identificerer jeg fire forskellige perspektiver fremsat af forældrene vedrørende spørgsmålet om at diagnosticere sorg: (a) diagnosen som en legitimerende og normaliserende praksis, (b), diagnosen som en demarkationspraksis, (c), diagnosen som sygeliggørelse og (d), diagnosen som et normativt ideal. Gennem de empiriske eksempler demonstrerer jeg, hvordan efterladte forældre ikke blot passivt tilegner sig de diagnostiske forståelser, men refleksivt forholder sig til og inddrager modsætningsfyldte of forskelligartede fortolkninger i deres egen sorg.

I kapitel 11 opsummerer jeg afhandlingens væsentligste bidrag til forskningsområdet, og udpeger perspektiver for fremtidig forskning.

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Although writing is at times a lonely struggle, the pages of this thesis are populated with other people’s invaluable contributions, without which this work would not have come into existence. First of all, I am forever grateful to the parents who have participated as interview informants in this project. Thank you for generously and patiently sharing your painful experiences of loss and grief, as well as for sharing the precious experiences of love and affection for your children. Although I never have had the opportunity to meet the children you have lost, your children have been present in our meetings through your stories of love and loss.

Moreover, I owe a big thank you to The Danish Infant Death Association [Landsforeningen Spædbarnsdød]. Thank you for supporting the initial idea of this research project. Thank you for contributing to the funding that made it come into being, and for helping with finding informants to participate in the project. Thank you for your interest, encouragement, and valuable input along the way. Last, but not least, thank you for giving me the opportunity to spend four and a half years in one of the most meaningful positions I can imagine.

Thank you, all my dear colleagues at the Diagnostic Culture Research Project. I have always looked forward to our meetings, and you have been the most wonderful company throughout these years. You are my favorite kind of academics and my favorite kind of people, and I hope we’ll be able to infrastructure a continuing relationship beyond the Diagnostic Culture project.

Svend, thank you for your limitless support, wisdom, and encouragement, and for always expressing a belief in my project. Although you have become famous as the man with the “No hat”, I have come to know you for saying “yes” to (most of!) my blurry ideas and insecure steps. Through your impressive analytical skills and seemingly limitless horizon of knowledge, you have extended and scaffolded my thinking and helped me develop my ideas throughout my research.

Anders, thank you for stepping in as an informal co-supervisor, for seeing structure where there is none, and for contributing to a critical sociological gaze on my project. Although the pressure of a pending deadline has prevented me from following all of your good advice, I will definitely bring them with me in my future work.

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To our little girl who never got the chance to experience life outside my womb: I dedicate this thesis to her and to all the little children whose existence have changed the lives of their parents and families. Without her, this project would never have come into being. With and without her, *je est une autre*.

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“No man is an island, entire of itself; every man is a piece of the continent, a part of the main” (Donne, 1624/1959, p. 108).

CHAPTER 1. BACKGROUND AND STRUCTURE OF THE THESIS

> “I get so sad when people already start asking ‘do you feel better?’. I got that message yesterday, and I say “No! It’s been seven weeks—not even seven weeks—I do *not* feel better!” But the fact that they now—that I am now confronted with people believing I feel better… It makes me really, really sad. (…) And people beginning to look strangely at me already for not having returned to work yet. Seven weeks after… I can’t handle that. (…) I think it will be hard for me not to think of what other people think. Because it seems like people are beginning to think ‘she must be over it now!’. And I just can’t handle that.”

When I met Emma and her husband John[4] for the first time, it had been seven weeks since they lost their second child, Samuel, in a stillbirth. The pregnancy had been uncomplicated until the point where Emma noticed she could no longer feel the baby kicking in her belly. They went to the hospital “just to be sure everything was okay,” but as the ultrasound screen showed the pictures of their baby’s heart, everything stood still.

Emma recalls the midwife’s unbearable words: “Your baby’s heart has stopped beating”. At first, John and Emma just wanted everything to go away as fast as possible: The pregnancy; the inescapable birth of a stillborn baby; everything.

However, when I ask them about the birth and the time right after, Emma’s voice suddenly changes, she breathes out and says in a light voice: “It was so good! (…) It was so lovely because he was so warm and beautiful.” John affirms and adds that to him, the midwives’ guidance helped him realize that they had become parents, rather than just having had a “failed pregnancy.”[5]

John and Emma were the first couple I interviewed as a part of this Ph.D. project. However, in my former work as a counselor for bereaved parents in The Danish Infant Death Association[6], I have heard several stories of how giving birth to a stillborn baby, or to babies whom one knows will die shortly after birth, can be—in spite of the unbearable loss—a precious experience, after all. When I tell people about the

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[4] The names of the participating parents in this study are changed for reasons of confidentiality.

[5] This theme will be further explored in article 3, “Grief as a normative phenomenon: The diffuse and ambivalent normativity of infant loss and parental grieving in contemporary Western cultures.”

[6] In Danish: Landsforeningen Spædbarnsdød

regularity of these stories, I am met with astonishment and disbelief. How can a stillbirth or a birth of a baby that one knows will die be a precious experience? This is one of the many questions I address in this thesis. Like all of the stories of infant loss I have listened to during this Ph.D. study, Emma's and John's story reveals the complexity of parental grief as something that involves love, pride, and affection, as well as yearning, loss of meaning, struggles to come to terms with one's identity as a bereaved parent, concerns about how to live with the loss, and concerns about how to deal with one's own and other people's expectations. When I met Emma and John for the first time, the latter were among Emma's biggest concerns: As the introductory quote reveals, after seven weeks, people were beginning to ask if she was feeling better. In spite of the presumably good intentions behind this question, Emma immediately heard it as a demand; that she *ought* to feel better. However, by talking to her husband and other people with experiences of loss and crisis, Emma actively sought out alternative ways to interpret and act upon her grief experiences. In our conversations, she repeatedly stresses the importance of these people's affirmations that what she is experiencing is normal and expectable. John is faced with a range of other challenges in his grief. While Emma is granted 14 weeks of maternity leave after their son's death, John is expected to go back to work after 14 days. Emma is met with concerns about how she is doing, and so is he: He too is primarily met with concerns about how *she* is doing, and only few ask directly how he himself is affected by the loss of his son.

Although each story of losing a child is unique, experiences of being met with certain beliefs about what grief is and ought to be, and how to understand the loss of a small infant, are present in multiple ways in all the stories of loss I have listened to. In this thesis, I explore the mutual relations between individual loss experiences and socio-cultural practices, norms, and beliefs about infant death and parental grief. In addition to informing us about parental grief after infant loss, these examinations also shed light on the current conditions for human experiences of suffering in our culture.

1.1. STUDYING PARENTAL GRIEF EXPERIENCES: HOW AND WHY?

How can we understand the experience of losing a child that dies in the very beginning of life, or before birth? How can we understand the feeling of having lost a part of oneself, the yearning for a child one did not get the opportunity to know beyond the hopeful expectations of pregnancy, the kicks in the belly, the ultrasound images, or the first brief moments, hours, or days after birth? How can we understand the conflicting feelings of sadness, despair, guilt, anger, bitterness, fear, love, pride, and affection? How can we understand the loss of and search for meaning, or the sense of profound, yet unclear loss? How can we understand the fear of going crazy, of being stuck, of forgetting, or of other people forgetting? Within contemporary Western cultures, these experiences are increasingly being interpreted and understood within a medical, psychiatric and diagnostic language that draws borders between normal and pathological grief responses, and that depicts grief as intrapsychic and physiological reactions within the bereaved individual. My first article, “From morality to pathology: A brief historization of contemporary Western grief practices and understandings,” provides some historical background to how these conceptions have emerged as not only conceivable, but also more or less taken for granted in contemporary Western cultures.

Throughout the thesis, I explore how this contemporary tendency to depict grief as a question of the individual mourner’s health or illness mediates the experiences and practices of bereaved parents after infant loss, and how bereaved parents use, negotiate, and contest these understandings in their everyday lives. Drawing on empirical data from a longitudinal interview study with 13 bereaved parents (6 heterosexual couples and one woman participating without her husband) who have lost children during pregnancy (3rd trimester) or in the first week of life, my aim is to develop sensitive and non-reifying accounts of how grief can be experienced, reflected, and acted upon within contemporary Danish culture.[7] All of the informants were recruited through The Danish Infant Death Association (DIDA), who has also partially funded this Ph.D. project. Being interested in how culturally available repertoires for understanding and relating to the loss of a child inform grief experiences, I also explore how the bereavement organization’s services and activities provide sources for interpreting the loss, and how the parents draw upon these sources in their grief. As participation in these services and activities is intertwined with the everyday lives of the participants, it is difficult to make a clear-cut separation between the interpretive repertoires provided through these activities and those provided through other sources such as family, friends, and popular culture. Hence, the exploration of interpretive repertoires is guided by a first-person-perspective on how the participating parents experience and interpret their loss, which implicit or explicit assumptions and norms about grieving they encounter, and how they relate to, draw upon, and negotiate these understandings in their everyday lives. Accordingly, the exploration of the connections between parental experiences and socio-cultural repertoires of grief and infant loss runs as a red thread throughout the thesis.

Furthermore, I entered this study from a position as a counsellor in DIDA, and as a bereaved parent myself. Hence, my role as a researcher was intertwined and mixed up in several ways with my role as a psychologist working professionally with bereavement, and as a parent with personal experiences of infant loss. The significance and meanings of this will be elaborated on in my second article, “Becoming a bereaved parent: Parental grief after infant death.”

A substantial body of literature demonstrates the detrimental effects of infant loss on bereaved parents’ health and wellbeing (Badenhorst el al., 2006; Badenhorst & Hughes, 2007; Bennett et al., 2005; Dyregrov, 1990; Dyregrov et al., 2003; Murray &

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[7] Further details about the participants of the study can be found in chapter 5.

Callan, 1988; Nicol et al., 1986; Vance et al., 2002). However, there exists only little research that explicitly addresses how bereaved parents experience, use, and negotiate prevailing cultural understandings of infant loss and grief. The third article of this thesis, “Grief as a normative phenomenon: The diffuse and ambivalent normativity of infant loss and parental grieving in contemporary Western cultures,” represents an attempt to remedy this lack of research by analyzing how bereaved parents’ experiences of infant loss are mediated by diffuse, yet inescapable normative understandings concerning infant loss and parental grief.

Even less research exists on how the contemporary debates on diagnosing grief as a psychiatric disorder are conceived of by bereaved individuals in general, or by bereaved parents in particular. As bereaved parents are among the subgroups of bereaved individuals who are assumed to be especially vulnerable to pathological grief reactions (Kersting et al., 2011), it is relevant to explore how these parents experience and relate to the issue of diagnosing grief. In this thesis, this is most directly addressed in the fourth article, “Grief as a border diagnosis,” where I outline and analyze four different parental perspectives on the question of diagnosing grief as a psychiatric disorder.

1.2. RESEARCH FOCUS AND QUESTIONS: GRIEF AS A RELATIONAL AND SITUATED EXPERIENCE

Starting from my initial interest in the connections between individual grief experiences and cultural norms and beliefs about grief, I developed three tentative research questions that have guided my exploratory inquiries:

1. How do parents experience the loss of a child, and how are these experiences related to the practices and interpretative repertoires of grief that are available in our culture?
2. How do the current psychological, health oriented and increasingly diagnostic understandings of grief inform individual grief experiences and practices?
3. How do the parents engage in and draw upon the production and negotiation of meaning, identity practices and narratives about loss that are created within the grief support practices provided by DIDA?

The first question is primarily dealt with in the third article (“Grief as a normative phenomenon”), the second question primarily in the fourth article (“Grief as a border diagnosis”), and the third is most explicitly addressed in chapter 5 (“‘Here everybody knew I was a parent’: Grief in the Danish Infant Death Association”).

As the brief extract of Emma’s and John’s story in the opening lines of this chapter implies, grieving the loss of an infant is mediated by one’s own and other people’s implicit or explicit expectations—expectations that reflect cultural conceptions of normality and pathology, health and illness, as well as fundamental understandings of suffering and what constitutes a good life for human beings. It also illustrates that grieving cannot conceivably be reduced to a passive, causal reaction to loss, insofar as the grief experience itself is inherently mediated and altered through more or less reflective processes of negotiating, interpreting, and acting upon it. Hence, when my first research question asks how parental experiences of infant loss are related to culturally available practices and interpretive repertoires, I am not approaching the latter as causal and external factors affecting the loss experiences. Rather, my conception of individual experiences and agency is informed by a cultural psychological outlook that stresses the dialectical and mutually constituting relationship between persons and cultures (Brinkmann, 2016; Valsiner, 2014).[8] Furthermore, John's and Emma's story illustrates that grieving is a fundamentally relational and situated experience that involves the on-going relationship to the lost loved one, to other people, and to oneself. Summed up, it illustrates one of the basic arguments of this thesis, namely that grieving is a normative practice that is inextricably linked to historical, socio-cultural, and material conditions.

Through my reading of the literature as well as from the exploratory process of analyzing the interviews of this study, it has become increasingly obvious that the characteristics of the relationship to the lost child are crucial in parental grief experiences after infant loss. Hence, the initial research questions led to new questions and topics to explore, such as the significance of cultural conceptions of the personhood and human status of unborn and newborn children. In line with John's statement in the introduction, many bereaved parents after infant loss tell stories of how such losses can be difficult to define. If you haven't gotten to know your child, how can you know what you have lost, and how can you grieve such a loss? Can a child that dies before it has developed a distinct individuality and sense of self-consciousness be unique and irreplaceable? And how do you reconcile your grief over this specific child with a wish for having another, living child? As these questions came to the front of my research, the initial focus on cultural grief understandings and practices did not disappear. It became clear, however, that my focus was becoming increasingly phenomenological in the sense that I was primarily interested in how bereaved parents experience, from a first-person-perspective, the loss of an infant. Hence, my aim throughout the thesis is to analyze how bereaved parents' experiences of infant loss are situated in the phenomenological lifeworld of bereaved parents: A lifeworld that this thesis depicts as inherently normative.

Furthermore, as the research process developed, it became increasingly urgent to address the significance of my own background as a bereaved parent myself and as bereavement counselor within the very organization whose activities I was studying. As I started out on this project, these connections between my own background and

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[8] The cultural psychological outlook will be further elaborated in chapter 2.

my research project was an unresolved topic which I primarily dealt with by underplaying and bracketing my own experiences. However, through the encounters with my informants, who often inquired into my own experiences, as well as in the analytical process of writing about parental loss and societal beliefs about loss and grief, it became clear that I needed to explore these issues. Hence, new topics to inquire emerged, as I tried to explore the cultural significance of my reluctance to include my personal experiences of loss in my research, as well as the ethical and epistemic significance of including these experiences in my relationship with the informants and consequently in my research.

Summed up, my aim in this Ph.D. project is to examine individual experiences of infant loss among bereaved parents, mediated by and acted upon within a complex web of socio-cultural, normative, discursive, and material practices. Furthermore, through an autoethnographic inquiry of the relations between personal experiences, cultural assumptions, and research, my aim is to contribute to the existing literature on the ethical and epistemic significance of including personal experiences in qualitative research on experiences of suffering. The methodological, ethical, and analytical considerations that have informed this endeavor is outlined in chapter 5.

1.3. RESEARCH BACKGROUND AND AFFILIATIONS: THE DANISH INFANT DEATH ASSOCIATION AND THE DIAGNOSTIC CULTURE RESEARCH PROJECT

As already outlined, I embarked upon this project from a position as a psychologist working as a bereavement counselor in DIDA. The stories I listened to during my years in DIDA planted the seeds for this project. Listening to how people try to live with the loss of their children involved daily reminders of the complexity and diversity of grief, and made me weary about the prevailing tendency in our culture to judge grief by standards of normality, health, and appropriateness. As outlined in the previous section, this weariness was fueled and actualized by the developments within the diagnostic manuals at the time. As I took the initial steps into developing this project in 2012, there were heated debates on the expected introduction of a separate grief diagnosis in the forthcoming fifth revision of The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, the DSM-5 (American Psychiatric Association, 2013).

Due to my interest in the cultural distributions of psychological, diagnostic and psychiatric understandings of grief, my attention was directed to Svend Brinkmann's recent works on how psychiatric diagnoses shape experiences and practices of suffering in contemporary Western cultures (Brinkmann, 2010.). Briefly put, I contacted Brinkmann who soon offered to take on the role as a supervisor of the project, and helpfully assisted with the development of the project description and the process of applying for funding. Shortly after I started up on the Ph.D. project, Brinkmann received a Sapere Aude grant from the Danish Counsil for Independent

Research for a large, four-year-long research project on diagnostic cultures, and invited me to join the project as an associated researcher. The opportunity to join the Diagnostic Research group has meant immensely much throughout my research process. The group meetings have provided a safe and fun place to explore and develop ideas, and the analytical frameworks developed within the group have guided my research in several ways. The joint efforts and collaborations on analyzing the conditions and consequences of what we have termed "diagnostic cultures" (Brinkmann et al., 2014; Brinkmann, 2016) have been illuminating for my examinations of parental grief experiences in contemporary Danish culture. The concept "diagnostic cultures" designates cultures "in which psychiatric diagnoses and categories are disseminated and used by numerous actors as the most important means to understand various life problems and mental disorders" (Brinkmann et al., 2014, p. 692). The concept points to macro-sociological developments in terms of the emergence of new diagnostic categories, the widening scope of existing diagnostic categories to include behaviors and experiences not previously defined as disordered, and the growing number of people who are "living under the description" of a diagnosis (Martin, 2007). It also refers to transformations on the level of individual experiences, insofar as people's experiences of suffering and undesirable behaviors are increasingly mediated through medical and diagnostic understandings and practices.

Even though grief is yet to be introduced as a separate diagnostic category in the diagnostic manuals (and, accordingly, none of my informants have been diagnosed with a grief diagnosis), the cultural distribution of diagnostic understandings and practices concerning grief have proliferated throughout the period of my research. Hence, the analytical perspectives developed within the diagnostic cultures group have been highly relevant for my analyses of how bereaved parents experience grief within a culture that increasingly addresses and deals with suffering in diagnostic and medical terms. However, during the course of my interviews with the informants, it has also become clear that the diagnostic and medical understandings are in no way monolithic in how they conceive of and act upon their loss experiences. Insofar as alternative interpretive repertoires are used alongside with, simultaneously competing with and complementing diagnostic understandings, I approach the concept of diagnostic cultures as a heuristic and "sensitizing concept" (Blumer, 1954) to focus my attention to the ways people are informed by, negotiate, and contest diagnostic and medical understandings of grief. In my last article, "Grief as a border diagnosis," I analyze how the participating parents relate to the notion of grief as a mental disorder in multiple and sometimes contradictory ways. Rather than being passively subjectified by a monopolizing and repressing diagnostic language, the parents draw upon and negotiate diagnostic understandings in combination with other frames of references to deal with and understand their grief.

1.4. DEFINING THE SUBJECT MATTER

In the following, I will introduce some central concepts and definitions regarding the subject matter of this thesis, i.e., infant loss, bereavement, grief, mourning, etc. I will outline some commonly held positions concerning how to define these concepts, and clarify how I address and define these concepts in this thesis.

Infant and perinatal death

The World Health Organization (2006) defines perinatal death as the death of a fetus or infant occurring between 22 completed weeks of pregnancy and seven completed days after birth. Infant death is defined as the death of a child during the first year of life (Centers For Disease Control and Prevention, 2016). However, as this and several other studies demonstrate, once a couple define themselves as bereaved parents, it follows that they conceive of their loss as the loss of a child, regardless of the child's age (Layne, 2000). In the Danish Infant Death Association, there is no lower or upper limit regarding the age of the deceased child, insofar as anyone who define themselves as having lost a child, regardless of the child's age, are welcome to make use of the organization's services. (In cases where the child is considered too old to be called an infant, the organization will sometimes suggest that the bereaved parents contact other organizations targeted to help bereaved parents of older children. However, this is not based on rigid age criteria, but on a concrete evaluation of the parents' situation and opportunities.) As my informants are all recruited through the Danish Infant Death Association, I will adopt the organization's flexible definition of infant loss. Hence, I do not make conceptual delineations between fetuses and children, or between live born and stillborn babies. As the participants of this study all define themselves as parents, I choose to refer to their children as children rather than fetuses, regardless of whether their child died before, during, or after birth. When I occasionally use terms such as perinatal loss, pregnancy loss, and infant death, this is typically in relation to studies that address these phenomena as such. When the parents talk about experiences of having lost during pregnancy as a miscarriage or spontaneous abortion (implicitly meaning the loss of what they define as a fetus rather than a child), I also use the parents' definition. For example, in my second interview with Emma and John, Emma tells me she has miscarried since our last appointment. In contrast to the grief over the loss of their son, Emma refers to the miscarriage as a "disappointment", not as a loss of a child. Other parents might experience such a loss differently, in which case I would stay true to their definition of the experience.

Bereavement

Within bereavement research, bereavement is typically defined as "the state of having lost someone we care about or love through death" (Attig, 2004, p. 343). Although other kinds of losses may also have profound impact on people's lives (e.g., the loss of a pet, the loss of a relationship through divorce, the loss of mobility, health, etc.), bereavement research is primarily concerned with losses of significant others (i.e., human beings) through death. While acknowledging the profound consequences such other losses may have on people's lives, the scope of literature included in this thesis is also delimited to bereavement through death of significant other persons. However, the liminal status of early infant loss demonstrates that conceptions of personhood, and hence bereavement, are historically and culturally malleable (Lofland, 1985; Scheper-Hughes, 1993). As the American sociologist Lyn H. Lofland (1985) has argued, "societal patterns of relational investment are variable; that is, *which* others become significant and *how* significant they are change as time and space change" (p. 175). Lofland argues that historical changes in the conceptions of infant death, due to changed patterns of infant mortality as well as parent-child relationships, are likely to be connected to changed experiences of bereavement and grief. Likewise, the American anthropologist Nancy Scheper-Hughes (1993) has convincingly demonstrated that the processes of attributing human status and developing parental attachments to infants are shaped by socio-cultural and material conditions. Accordingly, the state of bereavement is arguably not as straight-forward as the initial definition implies. As demonstrated in the third article of this thesis ("Grief as a normative phenomenon"), how bereaved parents experience and deal with their grief is not only mediated by cultural norms about grieving in general. Rather, the latter are tightly connected to the cultural recognition of the legitimacy and significance of the loss as such, i.e., the extent to which a loss is socially acknowledged as a legitimate state of bereavement. The cultural acknowledgment of bereavement, and of the grieving individual's legitimate status as bereaved is therefore intimately connected to the grief experience. The American theologian and prominent bereavement researcher Kenneth J. Doka (1989) refers to grief experiences where people's loss "is not or cannot be openly acknowledged, publicly mourned, or socially supported" as *disenfranchised grief* (Ibid., p. 4). Due to the cultural uncertainty concerning the personhood of infants who die before or shortly after birth, the concept has been widely used within research on parental bereavement after perinatal loss (Cacciatore, DeFrain & Jones, 2008; Jones, 2010; Lang et al., 2011; McCreight, 2004). However, as I argue in my second article, "Becoming a bereaved parent," social acknowledgment is not an either-or-matter, but an ongoing process in which the bereaved individual can be actively involved in shaping the local understandings of his or her bereavement. Nevertheless, disenfranchisement serves as a useful "sensitizing concept" (Blumer, 1954) for addressing the conditions for grieving a loss that is culturally contested.

Grief

The Canadian philosopher Thomas Attig (2004) outlines two meanings of the word grief: The first meaning designates grief as an emotional reaction, "a reactive agony that happens to us after bereavement happens to us" (Ibid., p. 343). The second refers to grief as an active response. Attig argues that while grief reactions are not matters of choice, grieving "as an active response is pervaded with choice" (Ibid.). Although

Attig's analytical distinction resonates well with how many bereaved individuals describe their experiences of grief, the sharp distinction between involuntary and willed responses does not provide a comprehensive framework for analyzing the profound cultural mediation of our emotions asserted in this thesis. To this end, the American anthropologist Emily Martin's (2007) account on the performative aspects of suffering provides a useful framework for understanding the intimate relationship between involuntary and unreflective reactions on the one side, and willed and reflective actions on the other. Martin's ethnographic account of bipolar depression persuasively illustrates that people's suffering is not entirely involuntary displayed, nor entirely a matter of active and reflective volition. Rather than accepting the cultural dichotomies between the rational and the irrational, Martin asserts that the lines between them are arbitrary and fuzzy (Ibid., p. 95). Inspired by her account, I analyze the relation between the involuntary and volitional aspects of grief as a continuum rather than a dichotomy. Grief experiences, I assert, exist in the space in between the two poles, i.e., they are not entirely causally or mechanically inflicted, nor entirely voluntary acts of interpretations that the grieving individual can immediately choose to alter. Furthermore, I am inspired by the American sociologist Arlie Hochschild's (1979) emotion-management perspective on emotion. This perspective asserts that individuals' attempts to mediate their emotions in light cultural norms do not only take place at the level of performance, but also mediates the phenomenological experiences and qualities of these emotions. Referring to the commonly held notion of emotions as a psychobiological means of adaptation (analogous to other adaptive mechanisms such as shivering when cold, or perspiring when hot), Hochschild argues that "emotion differs from these other adaptive mechanisms, in that thinking, perceiving, and imagining—themselves subject to the influence of norms and situations—are intrinsically involved" (Ibid., pp. 554-555). This perspective challenges the widespread distinction between grief and mourning, which is unfolded in the following paragraph.

Mourning

In the bereavement literature, grief is commonly designated as "the feelings (or feeling actions) of the bereaved", while "mourning concerns the behavior socially prescribed in a culture as appropriate for those who have been bereaved" (Seale, 1998, p. 198). However, as the above presentations of bereavement and grief elucidate, this distinction is problematic. Firstly, historical, socio-cultural, and material conditions shape our understandings of what bereavement is, and grief experiences are in turn shaped by these understandings. Secondly, grief experiences are also mediated by cultural practices—including local practices of mourning. This does not mean that grief experiences and mourning can be conflated to one phenomenon. One might for example follow a sanctioned mourning practice such as appearing sad and grave at a funeral without actually feeling sad. However, this thesis asserts that the relationship between grief and mourning is dialectical rather than dualistic or dichotomous. As Arlie Hochschild's (1979) analyses of emotional management suggest, quite often the practices we are engaged in *will* actually involve an alignment of our experienced emotions in accordance with the normative demands of the situation. According to Hochschild, the social shaping of emotion involves a shaping of emotional experiences as “passively undergone” (e.g., the experience of being struck by sadness as one hears the organ prelude at a funeral), as well as how we interpret and act upon these experiences. In line with the dialectical argument of cultural psychology, Hochschild analyses these processes as continuously and mutually interacting. Likewise, I assert, the personal experiences of grief and the cultural mourning practices a grieving individual is involved in are intrinsically related and dependent upon each other.

The British sociologist Tony Walter (1999) points to another issue concerning the relationship between mourning practices and grief experiences in contemporary Western cultures, namely that “[t]he grief process replaces social mourning as the framework within which grief is regulated” (p. 187). In other words, as secularization and individualization processes of modernity have eroded formerly shared mourning rituals and practices, the psychological and psychiatric notions of “the grief process” have to a great extent taken the role as a regulatory framework for how we deal with loss. In this sense, grief and mourning *is* actually to a certain extent conflated within contemporary Western cultures, insofar as we mourn according to culturally defined notions of healthy, normal and appropriate grief.

Meaning and acceptance

The loss of a child involves a loss of meaning, insofar as a child (in our culture) represents a very significant meaning and value to the parents. Grieving is often described as involving a search for meaning, either in terms of understanding how and why the loss happened, or by searching for ways to find new meaning in a life that has been bereft of meaning due to the significant loss. The questions concerning meaning and meaninglessness are complicated and value-laden, insofar as bereaved individuals may experience a cultural expectation to regain meaning, accept the loss, and move on with their lives. However, many bereaved parents reject the idea that there should be any meaning hidden in their children’s death, and maintain that the loss itself is meaningless (see e.g. Davis et al., 2000). Likewise, the concept of acceptance is often challenged and questioned among bereaved parents, insofar as it seems inconceivable or impossible to accept a loss that is experienced as meaningless. In a qualitative study on parental grief experiences, Joan Arnold and Penelope B. Gemma (2008) identify “two distinctly different descriptions of acceptance; death must be accepted because it could not be changed, and acceptance was not possible because the loss was intolerable” (p. 667).

However, although the notions of meaning and acceptance might be rejected, the grief itself is not necessarily seen as a meaningless reaction to loss. In spite of the pain, most bereaved individuals stress that the grief makes sense, because it expresses the significance of their loss. Also, many bereaved parents strive to find meaning in the existence after the loss of a child. Although the loss itself might be interpreted as meaningless, they may try to find a meaning in having experienced such a loss. While such meanings are sometimes discussed in literature on trauma and bereavement as "posttraumatic growth" (Calhoun & Tedeschi, 2001), etc., it is important to stress that the meanings one might arrive at after a significant loss in no way needs to imply "closure" or "justification" of the loss, nor that these meanings are always present for the bereaved individual.

Finally, meaning in this thesis is approached as a social and cultural phenomenon, that is, meaning is not something individuals make up in isolation, but something that is created and found in intersubjective relations, situated in a world that is always-already shrouded in meanings and values. Grieving, in this perspective, cannot be satisfyingly accounted for as "problem solving" or completing "tasks". As Attig frames it,

> "as we grieve we engage with some of the most profound mysteries of life, including finiteness and limitation, change and impermanence, uncertainty and not knowing, fallibility, vulnerability and suffering, death and mortality, others and ourselves, love and relationship, and the meaning of life. (…) None of these can be solved, answered definitively, controlled, managed, or mastered. (…) Some responses are more sustainable than others, some more suited to some grievers than others. Our responses are always provisional, subject to change" (Attig, 2004, p. 352).

1.5. STRUCTURE OF THE THESIS

The thesis is structured in ten chapters which, taken together, aim at presenting the project's background, position it within the field of bereavement studies, and communicate my findings as well as the process that has led me to these findings.

Chapter 2 outlines my theoretical outlook. Chapter 3 describes some of the major developments in academic and popular conceptions of bereavement within the last century. Chapter 4 presents a literature review of qualitative studies on parental bereavement following infant loss. Chapter 5 addresses the methodological, ethical and analytical considerations that have emerged during the research process. Chapter 6 analyses some of the main themes regarding how the participating parents in this study experience participating in DIDA's services and activities. Chapter 7 presents the first article of this thesis. In this article, I analyze current conceptions of grief in light of historical material. On this background, I discuss some potential consequences of the contemporary individualized and diagnostic approaches to grief, and articulate a historically and culturally situated, relational and normative perspective on grief. Chapter 8 consists of the second article, in which I explore the cultural, epistemic, and ethical significance of including my own personal and professional experiences with loss in my research. Chapter 9 consists of the third article, co-written with my Ph.D. supervisor, Svend Brinkmann. Here, we draw upon empirical data from the present study to demonstrate that grief is a normative phenomenon, which does not only happen to people as an effect of bereavement, but which is done or enacted, relative to cultural norms. Chapter 10 presents the last article, in which I analyze interview data regarding how the bereaved parents in this study relate to the notion of grief as a potential psychiatric disorder. Chapter 11 summarizes the main findings and conclusions of this study and points to potential avenues for future research on parental bereavement.

CHAPTER 2. THEORETICAL OUTLOOK

From my many encounters with bereaved parents, I have heard stories of grief that involve experiences of fatigue, shortness of breath, sleeplessness, lack of appetite, sadness, emptiness, anger, despair, longing, yearning, lack of concentration, isolation, lack of meaning, and countless other experiences. In many books on bereavement, such experiences are charted in schemes of "normal grief reactions", neatly organized into physical, emotional, cognitive, behavioral, social, and even spiritual reactions (see e.g., Machin, 2014). Although such schemes may prove valid for most people in grief, the enlisted symptoms and reactions of grief gravely fail to depict how such symptoms and reactions are entangled with the complex realities of people's everyday lives. Indeed, I have often seen how symptom check lists themselves seem to shape bereavement experiences, by providing reassurance or creating doubts about whether one is reacting normally, by giving a language to communicate, understand, and act upon, and ultimately alter the experiences.

Consequently, an examination of grief experiences needs to move beyond isolated symptoms and reaction. It requires a perspective that takes into account the mutual and complex relations between the phenomenological, socio-cultural, and semiotic-discursive aspects of grief—that is, an outlook that can embrace how we simultaneously experience, enact, and interpret grief in our everyday lives. Such an outlook, I will argue, is provided by cultural psychology (see e.g., Brinkmann, 2016; Cole, 1996; Shweder, 1990; Valsiner, 2007, 2014), which serves as a meta-perspective for the analyses of parental grief experiences in this thesis.

Furthermore, I draw on theoretical insights from different perspectives regarding the role of culture, and the role of the human and social sciences, in the shaping of experiences and practices related to suffering, health, and illness. These include insights developed within anthropology, emotion history, and genealogical studies of subjectivity. Moreover, as this thesis seeks to explore the phenomenological experiences of parental grief from a first-person perspective, the phenomenological emphasis on the individual's embodied, embedded, and intentional "being-in-the-world" provides a framework for examining bereaved individuals' situated experiences of grief. By addressing the mutual and co-constituting relationship between such individual experiences and socio-cultural practices, cultural psychology directs our attention to the inevitably culturally mediated and normative nature of human being in the world.

2.1. CULTURAL PSYCHOLOGY

The origins of cultural psychology can be traced back to the works of the Soviet psychologist Lev Vygotsky who in the 1920's called for a human science of psychology that "must understand human mental life as deeply connected to the objects of human manufacture in the world around us" (White, 1996, xiii). Cultural psychology offers a perspective for examining how culture—manifest in human artifacts such as tools, words, routines and rituals—inherently mediate human activities, emotions, and experiences. Briefly put, cultural psychology is interested in analyzing psychological phenomena as mediated actions and experiences.

2.1.1. A DIALECTIC APPROACH TO CULTURAL AND MENTAL PROCESSES

Cultural psychology addresses the relationship between persons and cultures as *dialectic* rather than dualistic. In other words, instead of conceiving of the duality of cultures and persons as discrete entities interacting with each other on a causal level, cultural psychology is interested in how persons and cultures mutually constitute each other (Cole, 1996; Shweder, 1990; Valsiner, 2014). Hereby, a cultural psychological outlook directs our attention to the co-constructed nature of cultures and the minds of individuals. Related to this, cultural psychology conceives of cultural and mental phenomena as *processes* rather than entities, structures, or substances. These processes develop over time. In other words, cultural psychology emphasizes the *historicity* and *processual* character of mental and cultural phenomena.

2.1.2. A PERSON-ORIENTED PERSPECTIVE

From a cultural psychological perspective, neither cultures nor minds should be understood as variables with causal powers. Cultures (as well as any capacity of the human mind), are not "things" with agentive or causal power. Hence, cultural psychology rejects the notion of discrete "cultural" and "individual" variables that can be isolated and measured. Only *persons*—not cultures, brains or minds—are capable of thinking, feeling and acting (Brinkmann, 2011). Accordingly, cultural psychology asserts that psychological phenomena—i.e., phenomena such as cognition, emotion, motivation, and learning—apply to human beings as *persons*, rather than to entities, structures, or processes in their brains and bodies. Metaphorically speaking, our brains are no more capable of thinking than an oar is of rowing. However, we obviously cannot row without an oar (or some equivalent), or think without a brain. In Rom Harré's (1997) words, our brains, our nervous system, our practices, technological artefacts, etc. are *enabling conditions* for human mental life (p. 175).

2.1.3. CULTURES AS MEDIATORS OF HUMAN ACTIVITY

Instead of conceiving of cultures as independent variables that causally affect human behavior, cultures are conceived of as *mediators* for thinking, feeling, and acting (or enabling conditions, to use Harré's terminology). Brinkmann (2011) outlines four sources of mediators that need to be included in an integrative approach to the human mind: The brain, the body, social practices, and technological artefacts (Ibid., p. 1).

Accordingly, a cultural psychological outlook does not represent a social constructionist reductionism of reality to "whatever we say it is" (Harré, 1997, p. 174). The enabling conditions represented by physical as well as social and discursive conditions "afford each its own range of possible actions" (Ibid., p. 175). Understanding human intentionality, experiences, actions and emotions, i.e., psychological phenomena, requires an analytical framework, or a language, that makes such phenomena conceivable. As Brinkmann asserts,

> "We employ ontologies relative to the interests that we have, so when we are interested in neurophysiological aspects of human beings, we operate with the Molecular grammar, and when we are interested in humans as intentional creatures, we operate with the Person grammar" (Ibid.).[9]

In this thesis, I am interested in human beings as intentional, experiencing, "compulsive meaning-makers" (Valsiner, 2014, p. 1). Accordingly, my main frame of reference is the language of intentionality, phenomenology, and interpretation, rather than of e.g. causation or correlations. Without disregarding the impact of brain chemistry, neurological processes, genetics, upbringing, social and cultural circumstances, etc. on grief, my interest is mainly directed to how bereaved people perceive, experience, interpret, and act upon themselves in their daily lives. As Jaan Valsiner (Ibid.) states,

> "whatever we encounter in our lives we need to make sense of, rather than only react to or act upon. Or even more precisely, as we react to and act upon the world in the middle of which we live, we construct it as meaningful for ourselves. And it is that meaningful way of living that is central to us" (p. 1).

Without cultural resources in terms of languages, signs, tools, social practices, and technologies, we would not be capable of reflecting upon, acting upon, or making sense of our experiences. Language in particular makes us capable of creating a reflective distance to the immediate context of experience and our immediate impulses. Language enables semiotic mediation (Valsiner, 2007), i.e., the ability to reflect upon, interpret, and direct our actions instead of merely reacting upon stimuli and impulses. Meanings and intentions are mediated and enabled through language, or, as Wittgenstein stated, "When I think in words, I don't have 'meanings' in my

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[9] Brinkmann refers to Rom Harré's Wittgensteinian concept of grammars, i.e., "clusters of rules for how to express oneself meaningfully, and, as rules, (...) are normative and social" (Harré, 2002, cited in Brinkmann, 2011, p. 9). According to Brinkmann, "[the] Person grammar is always primary in psychology" (Ibid.), insofar as psychological phenomena are normative and intentional. (See also section 2.1.4., "The normativity of human practices and mental phenomena".)

mind in addition to the verbal expressions: rather, the language itself is the vehicle of thought" (Wittgenstein, 1953, § 329).

The enabling capacities of mediators are not entirely equivalent to a means-to-and-end logic, insofar as the latter designates the enabling of a priori intentions, "whereas mediators at once constitute and transform the intentions that they carry" (Brinkmann, 2016, p. 16). For example, I cannot conceivably have an intention of converting to Islam without the preexistence of a Muslim tradition (maintained by language, religious practices, communities, beliefs, writings, etc.). I might consider creating a new religion, but the intention of doing so presupposes (and is informed by) the preexistence of religious languages and practices to make such an intention available and conceivable. Likewise, in order to wonder if he or she is grieving normally, a bereaved individual must have access to a certain language that renders the notions of "normality" and "normal grief" meaningful. This obviously does not imply that normality is merely a linguistic matter. Rather, the meanings of normality are bound up to a range of practices and technologies, such as counseling, self-measurements, rating scales, etc. which mediate individuals' interpretations and actions. Rather than conceiving of discourses and languages as abstract representations of the world, this thesis conceives of language in a Wittgensteinian sense, i.e., as "part of an activity, or of a *form of life*" (Wittgenstein, 1953, §23).

2.1.4. THE NORMATIVITY OF HUMAN PRACTICES AND MENTAL PHENOMENA

Finally, and central to the objective of this thesis, cultural psychology conceives of the human mind as *normative* (an argument that is further developed in the third article, "Grief as a normative phenomenon"). Psychological phenomena like thinking, feeling, and acting differ from physiological phenomena insofar as only the former are (and can be) subjected to normative appraisal. In spite of common features such as physiological expressions and experiential qualities, only psychological phenomena can be judged by normative standards. E.g., while an emotion such as anger can be evaluated as legitimate or exaggerated, based on the circumstances in which it appears, it would be meaningless to attribute such evaluations to stomach aches. Although human emotions are sometimes experienced and conceived of as reactive, i.e., triggered by causal mechanisms, they are imbued with normative judgement. Our very concept of personhood involves a moral responsibility for our actions and emotions. Accordingly, a withdrawal of this responsibility (for example when an accused in a criminal prosecution is pleaded not guilty by reason of insanity) involves a withdrawal of moral agency and hence personhood. The normative evaluations of actions and emotions are based on "local moral orders" (Harré, 1983, cited in Brinkmann, 2011, p. 14), i.e., the norms and values of our practices through which "we learn to speak, to reflect, to act, to remember, to feel emotions, to discipline our bodies and exercise all the other skills that make up the mind" (Ibid.).

2.2. GRIEF AS EMOTIONAL PRACTICES

> "Because language, illness beliefs, personal significance of pain and suffering, and socially learned ways of behaving when ill are part of [the] process of mediation, the experience of illness (or distress) is always a culturally shaped phenomenon" (Kleinman, 1988, p. 7).

By examining the historicity and situated variety of human emotions, emotion history and anthropological studies challenge claims of universality of emotions, as well as traditional dichotomies between mind and body, culture and nature, rationality and emotionality, etc.

Relevant to the analytical aim of this thesis, the German historical and cultural anthropologist Monique Scheer's (2012) concept of *emotional practices* offers a promising analytical tool for examining how emotions are not just something we *have*, but also something we *do*.

Scheer argues that emotions are not just a *consequence* of human practices (i.e., that certain emotions are evoked by certain practices). Rather, she asserts, emotions *are* practices that involve "the self (as body and mind), language, material artifacts, the environment, and other people" (Ibid., p. 193). Emotional practices involve the mobilization, naming, communication, and regulation of emotions through embodied habits, rituals, and daily routines that sustain a community or culture. Inspired by Bourdieu's concept of habitus, Scheer emphasizes the embodied nature of emotional practices, as well as the "socially situated, adaptive, trained, plastic, and thus historical" nature of the human body (Ibid.). Accordingly, she argues,

> "Emotions change over time not only because norms, expectations, words, and concepts that shape experience are modified, but also because the practices in which they are embodied, and bodies themselves, undergo transformation" (Ibid., p. 220).

The practice perspective on emotions try to bridge the gap between structures and agents, and between culture and bodies, insofar as structures are maintained and changed through mundane and concrete human practices, while individual action and embodied experience on the other hand are enabled through these (embodied) practices. Our embodied subjectivity is thus shaped through historically and culturally specific practices.

According to this perspective, the experience of grief emerges through embodied and situated practices. To paraphrase Scheer, "the [grieving] subject does not exist prior to, but emerges in the doing of the emotion" (Ibid., p. 209).

Consistent with Scheer's emotional practice perspective, a widely-held position within contemporary anthropology of emotions suggests that "without culture we would simply not know how to feel" (Scheper-Hughes & Lock, 1987, p. 28). Scheper-Hughes & Lock calls for a "development of a new epistemology and metaphysics of the mindful body and of the emotional, social, and political sources of illness and healing" (p. 30). Their concept of the mindful body represents an analytic understanding of emotions as embodied, cognitively and morally oriented, culturally and socially situated (Ibid.). Seen through this lens, a grieving individual's experiences of sadness "entail both feelings and cognitive orientations, public morality, and cultural ideology" (Ibid.). Hence, sadness is not merely a "reaction" to loss, but a morally directed and embodied response that is situated in the grieving individual's social reality. In short, and significant for my argument in this thesis, grief is a normative and relational practice.

A similar approach to emotion as an inherently social practice is represented by the French sociologist Eva Illouz (2008). In her analysis of contemporary therapeutic and emotional culture, she argues that

> "through emotion we enact cultural definitions of personhood as they are expressed in concrete and immediate but always culturally and socially defined relationships. The intense, compact compression of cultural meanings and social relationships also gives emotions their prereflexive, often semiconscious character. Emotions are deeply internalized and unreflexive aspects of action, not because they do not contain sufficient culture and society, but because they contain too much of them" (Illouz, 2008, p. 11).

Likewise, the German philosopher Jan Slaby (2016) argues that affective phenomena––spanning from emotional categories with specific intentional contents, such as fear, anger, etc., via pre-intentional, pre-reflexive intersubjective affectivity, to unspecific moods, affective atmospheres, etc.,

> "are never merely matters of 'internal mental states,' nor just narrow ways of being affected, but usually encompass sequences of *active engagement* with the world, usually in highly social and relational ways" (p. 3, italics in original).

The directed nature of affective phenomena, Slaby asserts, places them in the field of normative evaluations, insofar as they can be assessed by the extent to which they realize the purpose of or holds significance to "what is ultimately at issue and at stake in the domain," (i.e., practice), the latter also being open to normative evaluation and negotiation (Ibid.). Slaby further criticizes the implicit user-resource model often asserted by situated perspectives on the human mind, i.e., the assumption "of a fully conscious individual cognizer ('user') who sets about pursuing a well-defined task through intentional employment of a piece of equipment or exploitation of an environmental structure ('resource') (Ibid., p. 5). Instead, he emphasizes the dialectical relationship between individual subjectivity and our socio-cultural reality, i.e., our subjectivity and personhood simultaneously shape and are shaped by our "in-medias-res human sociality" (Ibid., p. 9), a point that echoes the cultural psychological notion of mediation as a process that simultaneously shape and are shaped by the intentions they carry (see section 2.1.3 above). Slaby hereby articulates a radical unity between the normative and performative aspects of human practices and subjectivity, insofar as "[norms] exist only as concretely enacted and situated, while there are no acts which are outside the ambit of social rules and normative patterns" (Ibid., p. 8).

Taken together, the practice perspective of emotions highlights the inherent connections between our emotional experiences and the normative socio-material realities they are part of. Conceiving of emotionality and affectivity as enacted phenomena implies that they are imbued with normativity, insofar as such phenomena are only conceivable within normatively structured practices.

2.3. SOCIO-MATERIAL CONDITIONS OF GRIEF

As I was collecting notes to develop my arguments in this section, I coincidentally overheard a conversation between two young female Danish students about new-born babies: "They are fully developed when they are born," one of them stated. "They know their mother's voice even before they are born, and immediately after birth, they prefer to look at her and hear her voice rather than any others." Maintained through a web of cultural and material practices and technologies, such understandings are prevailing in contemporary Western societies, and hence, I as a researcher am arguably as much informed by such understandings as anyone else.

However, Nancy Scheper-Hughes' (1993) ethnographic studies of infant loss among people of the Alto, a poor rural community in Northeastern Brazil, have profoundly stimulated my awareness to the significance of the socio-material conditions of our beliefs and practices. Her sensitive and respectful account of parenting practices, attachment, concepts of personhood, and emotions in this community represent an illuminating contrast to "our" (Western) ways of relating to these phenomena. Through her sensitive and contextualized account of the people of the Alto and their brutal life conditions, Scheper-Hughes manages to make sense of practices and experiences that seem almost incomprehensible from the point of view of a Western, secularized, and privileged position. In the Alto, violence, poverty, illness, and, not the least, infant death is prevailing. Instead of analyzing these as causal factors that affect people's behavior, Scheper-Hughes explores how people's actions and understandings make sense within these conditions. From the point of view of the Alto's, infant death is not something to grieve, as dead infants are seen as privileged to escape the brutality of life in favor of eternal divine life. Moreover, she demonstrates how notions of personhood develops within cultural and material circumstances, and how these notions in turn inform our experiences and practices concerning parenthood, attachment, loss, and grief. As described in the previous chapter, infant mortality rates, cultural conceptions of life and death, material and technological practices inherently shape our experiences of loss. Furthermore, Scheper-Hughes argues, the relations between these phenomena are dialectical, insofar as our beliefs and experiences also shape infant mortality rates (a case she makes by examining the tragic circumstances and consequences of "the mortal neglect of certain soon-to-be-doomed babies" (Ibid., p. 20)).

Hence, socio-material conditions, cultural beliefs and practices mutually shape our emotions towards our children, our way of relating to them, and our way of grieving over them. In contrast to the encouraged practices concerning parental attachment and grief among the parents of my study (all citizens of the highly developed Danish well-fare state), the mothers[10] in Scheper-Hughes' study face infant death with resignation and accept, and even relief. In line with Scheper-Hughes' analyses—as well as with the overarching cultural psychological framework of this thesis— I conceive of these cultural differences as radically mediating not only our overt "behaviors," but in the most profound way our experiences and subjectivities.

2.4. GRIEF AS SELF-TECHNOLOGICAL PRACTICES

Michel Foucault's analyses of the mutual relations between power, knowledge and subjectivity inform my analyses of the bereavement literature and of my empirical material beyond what it is justifiably credited throughout this project. Likewise, the British sociologist Nikolas Rose's extensive analyses of the role of the human sciences in "making up people" (Hacking, 1986) informs my understanding of how the disciplines of psychology and psychiatry in particular have come to shape how we understand and act upon ourselves in relation to loss.

Rose's (1998) genealogy of contemporary notions of selfhood and subjectivity direct our attention to "the conditions under which our present ways of thinking about and acting upon human beings have taken shape" (p. 1). Throughout his academic career, Rose has examined how contemporary notions of subjectivity have been developed, first within what he has designated the *psy* disciplines (i.e., psychology, psychiatry, and related practices), and increasingly within the biomedical sciences (Rose, 1998, 2007). The leading question throughout his work is perhaps best formulated as "[How is] subjectivity (…) affected by the categories and technologies of modern society?" (Brinkmann, 2016, p. 132). In the following, I will focus on Rose's early analyses of how the psy disciplines shape contemporary practices and conceptions of subjectivity, which, I will argue, continues to be of relevance to the study of how bereaved individuals relate to and act upon themselves in the context of loss.

Rose's work give detailed descriptions of how individuals in contemporary Western societies are encouraged to "govern themselves" in light of scientific knowledge

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[10] Scheper-Hughes primarily address the loss experiences of the mothers, as infant care among the Altos is primarily a maternal task.

concerning normality and pathology, risk and prevention, etc. In his analyses, Rose draw upon a Foucauldian perspective of how subjectivity is constituted through historical, material, and social practices, and how the subject constitutes itself in an active fashion through "technologies of the self" (Foucault, 1988). These practices are "not something invented by the individual himself. They are models that he finds in his culture and are proposed, suggested, imposed upon him by his culture, his society, and his social group" (Foucault, 1997, p. 291).

Rose (1998) analyses how subjectivity in contemporary Western "enterprise culture" is constituted in complex relations between a political level of "governmentality" ("mentalities of governments"), an institutional level ("human technologies"), and an "ethical level" ("technologies of the self") (Ibid., p. 152 *ff*). Through this process, a certain kind of subjectivity is constituted that embodies "the presupposition that humans are, could be, or should be enterprising individuals, striving for fulfillment, excellence, and achievement" (Ibid., p. 154). In order to realize such subjectivity, individuals make use of technologies offered by therapeutic practices, self-help practices, coaching, etc. Through these practices, Rose contends, suffering is interpreted and acted upon as something "not to be endured but to be reframed by expertise, to be managed as a challenge and stimulus to the powers of the self" (Ibid., p. 159). This approach to suffering, I will argue, permeates contemporary understandings and practices related to grief as well, and provides a frame of reference for understanding how grief is currently being accounted for as a potentially mental illness that can and should be a target of medical and therapeutic interventions.

2.5. EXPERIENCES AS INTERACTIONS WITH CATEGORIES

The British philosopher Ian Hacking's (1995) concept of "the looping effects of human kinds" has informed my comprehension of the dynamic relationship between (scientific) concepts and categories (such as "pathological grief") and individual experiences and enactments of suffering. Like Foucault, Hacking is interested in how the human and social sciences "make up people" through interacting with the categories they study, i.e., "kinds of people, their behaviour, their condition, kinds of action, kinds of temperament or tendency, kinds of emotion, and kinds of experience" (Ibid., pp. 351–352). These "human kinds", Hacking argues, differ from the "natural kinds" studied in the natural sciences in important ways.

While natural kinds (like quarks, genes, sunsets, and common colds) are indifferent to the discursive descriptions applied to them, human kinds take an interest in how they are described and categorized because human kinds are "laden with values" (Ibid., p. 366). Unlike natural kinds, who can only be "good or bad" depending on what we use them for, human kinds are "kinds that people may want to be or not to be, not in order to attend some end but because the human kinds have intrinsic moral value" (Ibid., p. 367). Thus, while molecules behave independently of our categorizations, human kinds respond to and interact with, mirror, and oppose to the categorical descriptions of them, hereby altering the category, which, in turn, alters the ways we see ourselves, act "under the descriptions" given to us, and so forth (Ibid., p. 368). It is this interactive process between categorical descriptions and human kinds that Hacking terms *looping effects*.

In the case of grief, scientific categorizations of grief distributed into popular culture, clinical practices, etc. interact with the human kinds under description, as people come to see themselves as grieving normally or abnormally, act upon themselves to avoid or achieve certain categorizations, etc. In this process, not only individual behavior and self-interpretations are altered, but the category itself, which, in turn, makes us alter our categorizations. For example, at the moment, the bereavement literature suggests that approximately 10-20% of all bereaved individuals will meet the criteria for complicated or prolonged grief (Bonanno et al., 2002; Bonanno & Kaltman, 2001; Prigerson et al., 2009; Shear et al., 2011). However, as the category becomes more widely known and used, it is likely that bereaved individuals increasingly will be interacting with the category; describing themselves under it, distancing themselves from it, experiencing their grief through it, etc. Through this process, the category as we know it changes. That is, our knowledge of the category changes because the category is changed. (E.g., the current estimated prevalence rates might need to be altered). This, in turn, feeds back into the self-understandings and practices of the kinds of people it describes, and so forth.

2.6. GRIEF AS PHENOMENOLOGICAL BEING-IN-THE-WORLD

The anthropologist Michael Jackson (1996) defines phenomenology simply as "the scientific study of experience" (p. 2). In accordance with a cultural psychological perspective, phenomenologically oriented research is not concerned with explaining human behavior as a result of causal factors (culture, the brain, genetics, etc.), but of examining and describing experience as an embodied, directed, intersubjective, and situated phenomenon. Following this definition, the ambition of studying grief experiences is inherently phenomenological.

However, the nature of experience and how experiences can be studied are inevitably contested topics. As the previous section should have made clear, the concept of experience used in this thesis is informed by the cultural psychological emphasis on how experiences are inherently mediated. However, it is important to stress that mediation is not to be understood exclusively or primarily as reflective and conscious acts of interpretation. As Martin Heidegger's (1962) hermeneutically oriented existential phenomenology stresses, our existence as human beings (Dasein) is characterized by *thrown-ness:* We are *thrown* into existence in a preexisting world with other human beings whom we are always-already dependent upon. In our everyday lives, we are absorbed in a world that is always-already meaningful to us, and most of the time, our being in the world is characterized by a straightforward engagement with other people, places, things, and activities that immediately present themselves as meaningful to us. Heidegger understands this as another matter than individual entities merely “interacting” with the world as an environment. As Attig (2004) puts it, “[we] are primarily practical beings intentionally alive within our surroundings and capable of self-awareness and reflection when necessary. Knowing how grounds us in reality and shapes our lives” (p. 348). Only when our immediate, everyday being-in-the-world breaks down, we are involved in reflective attempts to interpret the world and ourselves. Obviously, bereavement might often represent such a breakdown, and consequently, grief often involves strenuous attempts to make sense of a world no longer experienced as immediately meaningful.

Moreover, our existence is also fundamentally constituted by our mortality; the fact that we live our lives towards an inevitable death. In Heidegger’s own words: *“Death is something that stands before us—something impending”* (Heidegger, 1962, p. 294, italics in original). Drawing on Heidegger’s thinking, Attig argues that “[because] caring engagement is the nature of our being, we are vulnerable to the loss of wholeness that bereavement entails” (Attig, 2004, p. 348). Such a perspective points to the fact that human life is inescapably constituted by vulnerability, mortality, and interdependence, all of which shape the conditions for human grieving. In sum, an existential-phenomenological perspective reminds us that grief is an experience that is constituted (but not determined) by the inescapable conditions of being thrown into a vulnerable and interdependent existence we have not chosen, but in which we must choose to live our lives and face our common mortality.

2.7. GRIEF AND SELFHOOD

The conception of selfhood that emerges from the theoretical outlook presented here emphasizes the interdependent and mediated nature of human selfhood. Bereavement throws our selfhood into sharp relief by highlighting the interdependent nature of our being in the world with others. Following Heidegger (1962), our most basic state of being is our caring engagement with the world (Ibid., p. 293). In this light, grieving is more than a reactive process leading to resolution and returning to a former status quo. Grieving challenges the concept of a bounded, unitary self, interacting with other selves. Like many bereaved individuals describe the phenomenology of grief, the loss of a significant other is often experienced as an amputation—a loss of a vital part of oneself. As such, grief sheds light on the intersubjective and interdependent nature of our selfhood.

Furthermore, human selfhood is inevitably an interpretive activity, insofar as we make sense of who we are through inherently normative socio-cultural and material practices. Self-interpretation is not an individual and purely mental achievement, but a socially situated, embodied practice. The socio-cultural and material conditions we are situated in simultaneously enables and restricts the range of possible and meaningful ways of experiencing, interpreting, and enacting ourselves in relation to what we conceive of as valuable, good, and meaningful. For the most part, this goes on in a rather habitual and pre-reflexive manner, as a part of our embodied, intentional, and affectively attuned being in the world as we know it (Attig, 2004; Scheer, 2012; Slaby, 2016). However, under certain circumstances, the matter-of-factly practical consciousness with which we go about in our everyday lives, breaks down. Significant losses often represent such circumstances. Through bereavement, our sense of ourselves and the world, our life stories and meanings are challenged, altered, and revised. This is mediated by historically specific socio-cultural and material practices, which in our time and culture are increasingly informed by the human and social sciences (Hacking, 1995; Rose, 1998). Concerning grief, former traditional beliefs and practices concerning death, grief, and mourning have to some extent been replaced by psychological notions of "healthy and normal" grief processes, etc. (Walter, 1999). Beyond mediating our ways of grieving, such understandings arguably also interact with how we experience, conceive of, and act upon ourselves, i.e., with our very selfhood and personal identity.

Summed up, this thesis comprehends selfhood as an embodied, affective, and interpretive practice. Furthermore, selfhood is intersubjectively, materially, and socio-culturally situated and mediated. Finally, selfhood entails pre-reflexive as well as reflexive experiences, interpretations and enactments. Bereavement represents an existential condition that threatens our everyday sense of identity and meaning. On this background, this thesis comprehends grief and personal identity as intrinsically related, insofar as significant losses profoundly alters our world and how we find ourselves in it.

2.8. SUMMARY: GRIEF AS SITUATED AND EMBODIED EXPERIENCES, INTERPRETATIONS, AND ENACTMENTS

In sum, the analytical outlook that informs this study stresses the interrelated and normative nature of psychological and cultural processes, and insists that neither can be understood as independent variables with causal agency. From this perspective, the cultural is a fundamental precondition for mental life as such. Indeed, Jaan Valsiner (2014) asserts, the cultural "is part of the general psychological system of a person, and belongs to the higher level of psychological phenomena" (p. 40). Without cultural resources in terms of historically developed languages, signs, tools, technologies, etc., human mental life would be inconceivable.

Furthermore, by insisting on a person-centered concept of agency and experience, cultural psychology distances itself from other psychological and neuroscientific approaches that attribute mental phenomena to (structural or processual aspects of) the minds or brains of human beings. Likewise, it distances itself from certain sociological approaches that see the social and cultural as structures or entities with agentive powers (Brinkmann, 2016, p. 16). From a cultural psychological perspective, only *persons* are capable of thinking, experiencing, and acting, and such higher mental phenomena are inherently normative. By conceptualizing human mental life as mediated and normative activity, cultural psychology provides a framework for analyzing human experiences as radically situated within historical, socio-cultural, and material conditions.

The cultural psychological outlook of this thesis is further expanded and informed by historical and anthropological studies of emotions that highlights the enacted, embodied, situated, and inherently normative nature of human emotion and affectivity. Furthermore, the Foucauldian line of thinking of human subjectivity as constituted through socio-material practices, and the emphasis on the role of the human sciences in the shaping of contemporary practices and conceptions of subjectivity, offers important insights into the current condition for grieving individuals in our culture. Likewise, Hacking's analyses of the looping effects of human kinds direct our attention to the inherent normativity involved in the scientific endeavor of comprehending the human condition. Finally, a Heideggerian attentiveness to the human condition of thrown-ness, interdependency, and finitude sensitizes us to the profoundly existential and relational dimensions of grieving.

Informed by the outlined perspectives in this chapter, this thesis comprehends grief as a radically situated and mediated experience and practice. Our personal experiences of grief are not prior to and isolated from our social reality of norms, beliefs and practices, but "dwells within it" (Jacoby, 1997, p. 104). Bluntly put, our "immediate experiences" are "immediately mediated", insofar as experiences are radically situated within a socio-material reality constituted by inherently normative practices. Experiences belong to the person, but cannot be reduced to events or essences within the person, isolated from their concrete and situated manifestations within the person's life situation. To illustrate this claim, a bereaved individual's embodied experiences of, for example, fatigue is manifest in relations to bodily sensations, prior experiences, intersubjective relations (including distributed roles and obligations within a family), socio-cultural norms and practices (e.g., medical practices that provide medical treatments and interpretations, norms concerning appropriate rest and activity patterns, perceptions of illness and health, normal and abnormal grief, etc.). Fatigue is thus not something that exists as an isolated experiential entity within the grieving individual, but something that is unfolded in a complex reality of bodily, intersubjective, material, and socio-cultural processes. Taken together, the present study examines grief as a simultaneously *experienced*, *interpreted*, and *enacted* phenomenon, situated within and conceived through normative socio-material practices that constitute our human condition.

CHAPTER 3. MODELS AND THEORIES OF GRIEF

In the opening lines of her ethnographic work on death, dying, and bereavement in contemporary British society, the social anthropologist Mary Bradbury (1999) states that "[the] last decade of the twentieth century has witnessed a quiet revolution in our relationship with mortality" (p. 1). In the wake of an historical era characterized by death-denial and taboo (Ariés, 1974; Becker, 1973; Gorer, 1955; Kübler-Ross, 1969; Littlewood, 1992), Bradbury finds herself writing in a time where death is (once again?) discussed and analyzed. With the reservation that my observations might be skewed by my own interest in the subject, I think it is fair to claim that a similar development is occurring in Denmark at the moment. Recently, two national research centers on grief are about to be established[11], the Crown prince and princess of Denmark's annual social prize for 2016 was awarded to the non-governmental grief support organization "Children, Youth & Grief" ["Børn, Unge & Sorg"], and a veritable flood of books about death and grief, primarily based on personal experiences, has been published.[12] Insofar as these many initiatives have a shared focus, it seems to be that grief is acknowledged as something that concerns us all.

Research into death and bereavement in the last decades has taken on new perspectives and abandoned old ones. For example, Christine Valentine (2006) identifies a current "resocializing" of grief (p. 58). This resocializing is evident in the growing interest in death and grief within the social sciences, and in new models of bereavement that move beyond presumptions of universal emotional reaction to include such phenomena as the social construction of narratives, and continuation of bonds with the deceased. Valentine ties this resocializing up to what she sees as the

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[11] In 2016, the Danish Health Authority ["Sundhedsstyrelsen"] has granted 8 mill. Danish Kroner to the non-governmental organization "Children, Youth & Grief" ["Børn, Unge & Sorg"] to the establishment of a national center for complicated grief, and the private foundation "The Obel Family Foundation" has granted 12,6 mill. Danish Kroner to a 5-year-long research project on grief culture (http://www.kommunikation.aau.dk/nyheder/Nyhed/forskningsprojekt-om-sorg-modtager-12-6-mio.-kr.-i-stoette-fra-det-obelske-familiefond.cid282321).

[12] See e.g., Dagbladet Politiken, March 26th 2016: "Tendency: The many landscapes of grief in the literature" ["Tendens: Litteraturens mange landskaber af sorg"] (http://politiken.dk/kultur/boger/article5616395.ece); Kristeligt Dagblad, October 7th, 2016: "Should we all have a children's book about grief?" ["Bør alle have en børnebog om sorg?"] (http:// http://www.kristeligt-dagblad.dk/kultur/boer-alle-boern-have-en-boernebog-om-sorg); and forlagsliv.dk, April 11th, 2016: "Trend: Books about death tops the best seller lists" ["Tendens: Bøger om døden til tops på bestsellerlisterne"] (http://forlagsliv.dk/boeger-om-doeden/).

inadequacy of medicalizing and pathologizing approaches to grief (Ibid.). Likewise, Bradbury (1999) finds that the psychiatric and psychological bereavement research "from the perspective of the medical model became not just unfashionable: it became unresearchable" (p. 169). However, although Bradbury's and Valentine's analyses still ring true in terms of the upsurge in a wider academic and public interest in death and grief, the medical model again seems to be gaining ground in contemporary bereavement research. In my first article, "From morality to pathology", I attempt to trace the historical conditions that have made such a model feasible and, I assert, dominant, in contemporary Western understandings of grief.

In the following, I will outline some of the main developments and controversies within bereavement research throughout the last century. The review of the literature is organized by two conflicting narratives of grief: One that primarily addresses grief as an individual and potentially medical, pathological phenomenon, and one that emphasizes the shared existential, social and cultural aspect of grief. Although such a structure is overly simplistic, it may emphasize some of the crucial controversies concerning how to deal with grief as a medical and cultural phenomenon in contemporary Western societies.

3.1. GRIEF AS AN INDIVIDUAL PROCESS

The 20th century's grand narratives of grief have been shaped by psychological, psychiatric, and clinical approaches to grief as an emotional, individual, and universal phenomenon. Inspired by Freudian notions of grief as an emotional process of severing ties to the deceased, theories and models of asserted universal phases, stages, and tasks have been developed on the basis of clinical observations and empirical studies. By the end of the century, these models were met by a growing body of critique, questioning the universality as well as the prescriptive assumptions of these approaches to grief (Valentine, 2006). However, in spite of this critique, the search for universally applicable criteria to delineate between normal and pathological grief is currently emerging as one of the most prevalent themes within contemporary bereavement research.

3.1.1. THE GRIEF WORK HYPOTHESIS

Sigmund Freud's psychoanalytical theory provided a central theoretical framework for the academic and popular conceptualizations of grief within Western cultures throughout the 20th century (for a review of Freud's influence on academic and popular understandings of grief, see article 1, "From morality to pathology"). In his famous essay *Mourning and Melancholia*, first published in 1917, Freud (1957) introduced the concept of "grief work" ("Trauerarbeit") to designate the process of accepting the reality of loss (in Freudian terms, obeying to "the command of reality") and withdrawing the attachments from the lost loved one. This process, Freud asserts, is

> “carried out bit by bit, at great expense of time and cathectic energy, and in the meantime the existence of the lost object is psychically prolonged. (…) Why this compromise by which the command of reality is carried out piecemeal should be so extraordinarily painful is not at all easy to explain in terms of economics. It is remarkable that this painful unpleasure is taken as a matter of course by us. The fact is, however, that when the work of mourning is completed the ego becomes free and uninhibited again” (Ibid., p. 244).

Although not explicitly formulated by Freud, the grief work hypothesis has been developed by his successors to involve an implicit suggestion of pathology as a consequence of failed or “unresolved” grief work. Thus, the “painful unpleasure” Freud asserted is taken as “a matter of course” has been subjected to a large body of research into the nature and course of normal and pathological grief. In the following, I will outline a selection of the theoretical positions and models in which the grief work hypothesis is implicitly represented (for further elaboration, see “From morality to pathology”). Subsequently, I will turn to one more recent model that incorporates elements from the grief work hypothesis, but rejects the general idea that “one needs to bring the reality of loss into one’s awareness as much as possible and that suppression is a pathological phenomenon” (Stroebe, 1993, p. 20). Although building on different theoretical and empirical foundations, the presented perspectives have a shared focus on the individual process of grief, how to distinguish between normal and pathological grief, and how to predict, prevent, and treat pathological grief reactions.

3.1.2. PHASES, STAGES, AND TASKS OF GRIEF

The phase model of grief was originally developed from John Bowlby’s attachment theory, building on a theoretical framework of Freudian psychoanalysis[13] and observational studies of young children’s reactions to maternal separation (Parkes, 1998). In collaboration with James Robertson, Bowlby developed a descriptive model of the sequence of reactions in a group of hospitalized children between 18 and 24 months during maternal separation. The original model involved three phases: (1), “Angry pining”, (2), “depression and despair”, and (3), “detachment” (Ibid., p. 21). Bowlby and his colleague Collin Murray Parkes subsequently applied the model to bereaved adults and added an initial phase of “numbness or blunting” (Ibid.).[14]

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[13] Although Bowlby’s initial work was informed by a psychoanalytical framework, he later departed from many of the central theoretical assumptions in psychoanalytical theory (e.g., the idea that feeding and sex should be the principal sources of human motivation) (Bowlby, 1982).

[14] Other researchers and clinicians have developed similar models of grief, e.g. Elisabeth Kübler-Ross (1969). Kübler-Ross’ model describes five stages: (1) Denial and isolation, (2),

With its theoretical foundation in attachment theory, Bowlby's phase model depicts grief as a relational phenomenon, insofar as attachment theory stresses the ability and need to form attachment as a fundamental pre-condition for survival and development. The theory asserts that the ability to form attachment is developed as a biological instinct through evolutionary history, and accordingly, the model is relevant to describe patterns of attachment (and reactions to separation) not only among humans, but also among other species (Bowlby, 1980, 1982).

Moreover, the theory asserts that the process of grieving depends on the quality of the attachment to the deceased loved one. This implies that healthy grieving is more likely to occur if the individual has had a secure attachment to the deceased, which, according to Bowlby, is founded in the early infant-parental attachment. In other words, individuals are likely to reproduce early taught patterns of attachment in later relationships, and, consequentially, their reactions to loss are shaped by these primary attachment experiences. This means that the grieving process can be healthy or disordered, depending on a combination of prior attachment experiences as well as the attachment to the lost loved one. Individuals who have experienced secure attachment to their primary attachment figures are likely to develop a secure attachment style that helps them to adjust to separation later in life, including separation through loss. Conversely, individuals who have been insecurely attached to their primary attachment figures are more vulnerable to separation distress and dysfunctional coping mechanisms in the face of loss (e.g., by anxiously clinging to the lost relationship, or by detaching from and avoiding the emotional pain caused by the loss).

In spite of the relational foundation in attachment theory, Bowlby's phase model depicts grief as an individual adaptation process that is more or less determined by previous attachment experiences. That is, relationships are depicted as mentally integrated in the coping styles of individuals, which tend to be reproduced during the developmental course of the individual life-span. Hence, relationships to other people during the life-course are seen as strongly determined by early attachment experiences, leading to developmental trajectories in positive or negative ways. This implicitly leads to individualized understandings of grief experiences, insofar as experiences of supportive or unsupportive social networks are seen as strongly determined by the individual's prior attachment experiences. Accordingly, attachment theory does not provide a framework for analyzing how cultural conceptions and practices related to grief and loss mediate individual grief experiences. Nevertheless, Bowlby's work on the significance of attachment experiences in grief (as well as in

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anger, (3), bargaining, (4) depression, and (5), acceptance. Although originally developed as a description of individuals' responses to dying, it has been widely applied as a model to describe and understand grief following bereavement as well.

mental suffering in general) indisputably represents one of the most influential and impressive contributions to contemporary understandings of grief.

However, the sophisticated and nuanced conceptualizations of the relationship between attachment and grief experiences in Bowlby’s work have to a large extent been “lost in translation” on its journey into clinical and popular understandings. This “translation problem” does not only apply to Bowlby’s work, but to a large extent to all of the traditional grief theories that depict grief as a series of phases, stages or tasks.[15] Although not explicitly intended as prescriptive models, and in spite of the original authors reservations against interpreting the models too rigidly, once the models have travelled into popular culture and clinical practices, these reservations have been largely dismissed. Indeed, the models’ appeal seems to be precisely their ability to provide a structured and predictable framework for understanding and dealing with grief. Hence, the attempted descriptive models have been translated into prescriptive norms for healthy grieving, both for individuals trying to deal with their grief, for their networks, and for clinicians trying to help grieving individuals (Valentine, 2006). However, as bereaved individuals (as well as clinicians and researchers in the field of bereavement) have begun to question the implications of these models, the models have in turn been modified (e.g., by emphasizing that the phases, stages or tasks are not to be understood too rigidly, and by modifying the conceptualizations of how the bonds to the deceased are transformed in grieving). In other words, as Hacking’s (1995) concept of looping effects suggests, the models’ descriptions constantly interact with the ways we normatively understand and deal with our grief.

As argued above, one of the main reasons for the traditional grief models’ large impact has probably been their ability to provide a framework for understanding and predicting the often terrifying, incomprehensible, and unpredictable experiences of grief.

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[15] Like the phase and stage models of grief, task models of grief (e.g., Worden, 1982) depict grief as an individual process of “grief work” that needs to be dealt with in order to resolve grief and move on with life. For a brief description of Worden’s and related task models, see “From morality to pathology”. By designating the grief work as “tasks”, these models emphasize the active and effortful process of grief, as opposed to the implicitly passive depiction of grief represented in the concept of phases and stages. However, the difference is arguably more on a semantic level than an actual theoretical discrepancy, insofar as the phase and stage models also generally describe grief as an active and strenuous process. However, the active notion is modified by the assumed predictability of grief, i.e., the assumption that grief involves a series of universally applicable stages, phases or tasks which the bereaved individual must go through in order to adjust to the loss without pathological outcomes.

However, as Tony Walter (1999) has argued, with the "postmodern turn" in Western cultures, these very same qualities have been challenged and problematized.[16] Bereaved individuals, as well as researchers and practitioners within bereavement, have begun to stress the individual variation of grieving. The grief work hypothesis' emphasis on the necessity to break the bonds with the deceased, and the very idea that grief work is necessarily beneficial for all have been challenged. However, in spite of this new awareness of the individual variation in grieving, the quest for understanding and differentiating between normal and pathological grief has not been abandoned. I will now turn to one of the more recent models of bereavement that attempts to take into account the individual (and cultural) variation in grief, while simultaneously providing a conceptual framework for understanding normal and pathological grief.

3.1.3. THE DUAL PROCESS MODEL OF COPING WITH BEREAVEMENT

Margaret Stroebe's and Henk Schut's (1999) *dual process model of coping with bereavement* provides a descriptive model of how bereaved individuals cope with loss over time in the context of their everyday lives. While the traditional grief models described above primarily focus on the emotional management of the loss, Stroebe's and Schut's model "identifies two types of stressors, loss- and restoration-oriented, and a dynamic, regulatory coping process of oscillation, whereby the grieving individual at times confronts, at other times avoids, the different tasks of grieving" (Ibid., p. 197). The inclusion of restoration oriented processes involves a broadening of the scope of the traditional grief work models. In addition to grief work (i.e., confrontation with the reality of the loss, transformation of the relationship with the deceased, etc.), Stroebe & Schut's model emphasizes the equally strenuous tasks of attending to life changes brought about by bereavement, doing new things, managing new roles and identities, etc.

Inspired by trauma theories, Stroebe & Schut's model depicts how avoidance and intrusion are typical responses to traumatic events. However, while trauma theories describe avoidance and intrusion as related to the traumatic event specifically, the dual process model sees avoidance and intrusion as responses related to the loss itself as well as to the restoration oriented tasks (i.e., whether intruding or voluntarily attended to, the efforts involved in coping with the loss requires a provisional avoidance of restoration tasks, and vice versa).

Furthermore, the model is informed by the distinction between emotion focused and problem focused coping described in cognitive stress theory. However, the dual process model does not equate loss oriented and emotion focused coping, or restoration oriented and problem focused coping. In bereavement, Stroebe & Schut assert, "emotion itself becomes the stressor" (Ibid., p. 206), and accordingly, dealing with distressing emotions (i.e., emotion focused coping) can be done in apparently

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[16] This argument is outlined in "Grief as a normative phenomenon."

problem focused ways (e.g., by distracting oneself from difficult emotions by attending to problems that can be solved).

While the grief work models emphasize the importance of confrontation with the reality of loss, the dual process model stresses that successful coping with loss also involves active avoidance of the emotional processes in grief in order to cope with the challenges of managing the changed life circumstances after bereavement. Instead of viewing avoidance per se as detrimental, Stroebe & Schut argue that maladaptive coping can be manifest as *excessive* avoidance—as well as excessive emotional confrontation with the loss. In other words, adaptive coping, they assert, is characterized by an ability to “oscillate” flexibly between loss and restoration oriented coping, while maladaptive coping involves a skewed focus on one of the two.

Stroebe & Schut argue that the model can account for personal and cultural variation in grief, e.g., women in our culture are typically more loss oriented, while men are more restoration oriented, reflecting cultural gender expectations and roles. Likewise, they assert, cultural grieving patterns can vary accordingly. Given the assumption that flexibility is pivotal for functional coping, it is not entirely clear how the authors interpret such variations. With regards to gender differences, they tentatively suggest that ”bereaved men and women may indeed follow their gender specific way, to the detriment of their health” (Ibid., 218). Whether the same assumption goes for cultures as well is not clear (i.e., given that cultural prescriptions favor one type of coping at the expense of the other, the outcome would be detrimental to the health of the individual grievers in that culture). On the one side, Stroebe & Schut criticize the grief work hypothesis for lacking universal application, and stress that “different conceptualizations of acceptable or ‘healthy’ ways of coping are to be found in non-Western cultures” (Ibid., pp. 203-204). In other words, “our” conceptualizations of health and normality are not universally applicable. On the other side, they argue that “[although] grief is essentially a universal human reaction to loss of a significant other, cultural prescriptions impact on the way that grief is manifested” (Ibid., pp. 219-220). Here it becomes unclear whether there are, after all, universally healthy ways of grieving, that can be supported or suppressed by cultural prescriptions. If the model is used merely descriptive, cultural (and individual) variation can be described according to the ways cultural prescriptions or individual coping styles vary in terms of loss oriented and restoration oriented focus. On the other side, the central (and normative) concept of oscillation implies that healthy/functional and unhealthy/dysfunctional grief can be universally defined. Indeed, Stroebe & Schut’s dual process model is extensively used in research and clinical developments regarding pathological grief (see e.g., Lund et al., 2010; Richardson, 2006; Shear et al., 2005), which I will turn to now.

3.1.4. GRIEF AS A DIAGNOSTIC CATEGORY

As we have seen, the Freudian grief work hypothesis suggests that unprocessed grief, i.e., grief in which the bereaved individual avoids confrontation with the loss, has detrimental health consequences. Bowlby's attachment theory provides a framework for understanding how such maladaptive responses occur as a consequence of detrimental attachment experiences. Stroebe & Schut's (1999) dual process model challenges the grief work theory by claiming that confrontation as well as avoidance are equally necessary, and that pathological grief can be described in terms of inflexibility (lack of oscillation) in the grief response. In different ways, all of these understandings have shaped and informed the recent suggestions to conceptualize grief as a mental disorder. In my first article, "From morality to pathology", I chart some of the developments within modern psychological and psychiatric bereavement research that have led to these understandings. Throughout the years, pathological grief has been conceptualized as delayed grief, chronic grief, traumatic grief reactions, adjustment disorder related to bereavement (this suggestion was withdrawn in the final process of the recent DSM revision), etc. In the following, I will briefly outline two of the most influential current suggestions to conceptualize pathological grief[17] (Prigerson et al., 2009; Shear, 2012), and how these are represented in the recent proposals to introduce a separate diagnosis for complicated or prolonged grief in the diagnostic manuals.

Mirroring the developments within the diagnostic manuals, the proposed diagnoses are intended to be based on empirical evidence, independent of theoretical frameworks. However, one fundamental premise for the current diagnostic understanding of pathological grief is that it represents an *individual dysfunction* that manifests itself through a range of clearly delimited *symptoms.* The presumed dysfunction underlying pathological grief (or any other mental disorder) is yet to be discovered. Moreover, the proposals to diagnose certain grief reactions as pathological are heavily debated and contested (see e.g., Thieleman & Cacciatore, 2014; Wakefield, 2012; Walter, 2006). However, at this moment there are good reasons to expect that a diagnosis of prolonged grief will be introduced in the next version of the ICD system (and, most probably, in some version in the next revision of DSM). In spite of the debates and critical objections, there seems to be a growing consensus concerning the symptoms of pathological grief among the proponents of a grief diagnosis.

The suggestions to introduce a grief diagnosis are based on empirical research that argues that pathological grief has distinctive symptoms, etiology and prognosis which differ from related disorders such as depressive disorders, posttraumatic stress

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[17] When addressing these different proposals together, I prefer the term "pathological grief", insofar as all of the suggestions imply that the grief reactions at stake represent a disorder or pathology.

disorders, and adjustment disorders, as well as from normal grief (Bonanno et al., 2007; Prigerson et al., 2009). Normal grief is depicted as a process that enables the individual to be "re-engaged in daily life, reconnected to others, and able to experience hope for a future with potential for joy and satisfaction" (Shear, 2012, p. 121). In contrast, complicated or prolonged grief is associated with prolonged and overly intense grief symptoms, suicidality, detrimental mental and physical health consequences, and reduced quality of life (Prigerson et al., 2009; Shear, 2012). On this basis, a grief diagnosis is advocated as a means to prevent, target and treat these kinds of debilitating, prolonged and intense grief reactions.

One of the two suggestions that are currently most supported is developed by Holly G. Prigerson and colleagues (Ibid.). The diagnostic criteria put forth by Prigerson and colleagues for *prolonged grief disorder* (hereafter referred to as PGD) include (a) an event (bereavement), (b) separation distress, (c) cognitive, emotional, and behavioral symptoms, (d) timing (min. 6 months after the bereavement), (e) impairment, and (f) differential diagnostics (i.e., "[the] disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder" (Ibid., p. 9). (For full list of diagnostic criteria, see table 1).

Another much-supported diagnostic suggestion is developed by Katherine Shear and her research group, who suggests a range of similar criteria for *complicated grief* (CG; see table 2). Like Prigerson and colleagues, Shear's proposed criteria for complicated grief stress the duration (min. 6 months since the loss) and intensity of the suggested symptoms criteria. Both suggestions describe symptoms of separation distress; difficulty accepting the loss, avoidance of reminders of the loss (in complicated grief: avoidance and/or proximity seeking); inability to trust others since the; bitterness or anger related to the death; difficulty moving on with life; feeling that life is unfulfilling, empty, or meaningless since the loss, and feeling stunned, dazed, shocked, or numbed since the loss.

While PGD lists confusion about one's role in life or diminished sense of self (i.e., feeling that a part of oneself has died) as the first on the list of emotional, cognitive and behavioral symptoms, such symptoms are not described in CG. On the other hand, CG describe symptoms of rumination about circumstances or consequences of the death; experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person; experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss. Finally, while PGD describe relations to other mental disorders, CG presupposes that "impairment is not better explained as a culturally appropriate response."

Category	Definition
A.	Event: Bereavement (loss of a significant other)
B.	Separation distress: The bereaved person experiences yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree.
C.	Cognitive, emotional, and behavioral symptoms: The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree: 1. Confusion about one's role in life or a diminished sense of self (i.e., feeling that a part of oneself has died) 2. Difficulty accepting the loss 3. Avoidance of reminders of the reality of the loss 4. Inability to trust others since the loss 5. Bitterness or anger related to the loss 6. Difficulty moving on with life (e.g., making new friends, pursuing interests) 7. Numbness (absence of emotions since the loss) 8. Feeling that life is unfulfilling, empty, or meaningless since the loss 9. Feeling stunned, dazed, or shocked by the loss
D.	Timing: Diagnosis should not be made until at least six months have elapsed since the death.
E.	Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).
F.	Relation to other mental disorders: The disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder.

Table 1. "Criteria for prolonged grief disorder proposed for DSM-V and ICD-11" (Prigerson et al., 2009, p. 9).

1. The person has been bereaved, i.e., experienced the death of a loved one, for at least 6 months
2. At least one of the following symptoms of persistent intense acute grief has been present for a period longer than is expected by others in the person's social or cultural environment:
    - Persistent intense yearning or longing for the person who died
    - Frequent intense feelings of loneliness or like life is empty or meaningless without the person who died
    - Recurrent thoughts that it is unfair, meaningless or unbearable to have to live when a loved one has died, or a recurrent urge to die in order to find or to join the deceased
    - Frequent preoccupying thoughts about the person who died, e.g., thoughts or images of the person intrude on usual activities or interfere with functioning
3. At least 2 of the following symptoms are present for at least 1 month:
    - Frequent troubling rumination about circumstances or consequences of the death, e.g., concerns about how or why the person died, or about not being able to manage without their loved one, thoughts of having let the deceased person down, etc.
    - Recurrent feeling of disbelief or inability to accept the death, like the person can't believe or accept that their loved one is really gone
    - Persistent feeling of being shocked, stunned, dazed, or emotionally numb since the death
    - Recurrent feelings of anger or bitterness related to the death
    - Persistent difficulty trusting or caring about other people or feeling intensely envious of others who haven't experienced a similar loss
    - Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person
    - Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss
    - Change in behavior due to excessive avoidance or the opposite, excessive proximity seeking, e.g, refraining from going places, doing things, or having contact with things that are reminders of the loss, or feeling drawn to reminders of the person, such as wanting to see, touch, hear, or smell things to feel close to the person who died. (Note: sometimes people experience both of these seemingly contradictory symptoms.)
4. The duration of symptoms and impairment is at least 1 month
5. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning, where impairment is not better explained as a culturally appropriate response

Table 2. "Proposed criteria for complicated grief" (Shear, 2012, p. 124).

In spite of these differences, the two suggestions are in agreement on central issues concerning the duration, intensity, and core symptoms of prolonged or complicated grief. Both proposals suggest that intense longing and yearning, and/or preoccupation with the deceased or with the circumstances of the loss that lasts for more than six months after the loss indicates pathology, provided that it is associated with clinically significant distress or impairment. While DSM-5's category of persistent complex bereavement disorder sets the duration criterion to twelve months, the current diagnostic proposal for prolonged grief disorder in the ICD-11 Beta Draft follow Prigerson et al.'s and Shear's six months' duration criterion (American Psychiatric Association, 2013; World Health Organization, 2016).

Drawing on Prigerson et al.'s and Shear's proposals, WHO currently suggest the following criteria for prolonged grief disorder, which is expected to be introduced in ICD-11 (scheduled for release in 2018):

> "Prolonged grief disorder is a disturbance in which, following the death of a partner, parent, child, or other person close to the bereaved, there is persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, difficulty in engaging with social or other activities). The grief response has persisted for an atypically long period of time following the loss (more than 6 months at a minimum) and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person's cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis. The disturbance causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning" (World Health Organization, 2016).

3.1.5. CRITICISM OF THE GRIEF DIAGNOSES

Although it is expected at this point that the diagnosis will be introduced in ICD-11, the suggestions have been met with critique and objections to what some see as an illegitimate pathologization of grief. For example, Jerome Wakefield (2012) has critically examined the arguments for introducing a diagnosis of prolonged or complicated grief in the diagnostic manuals. While acknowledging the basic assumption that grief reactions can indeed represent a mental disorder or dysfunction, Wakefield argue that the current suggestions "fail to discriminate disorder from intense normal grief and are likely to yield massive false-positive diagnoses" (Ibid., p. 499). Wakefield argues that there are no qualitative differences between normal grief and the current criteria for complicated or prolonged grief. Moreover, he argues, the diagnostic suggestions cannot distinguish between slow/long-lasting, but normal grief and asserted chronic cases of grief. Furthermore, he emphasizes that negative outcomes do not logically imply earlier pathology. For example, he argues, although bad marriages can have detrimental health consequences, this does not imply that bad marriages represent a mental disorder. Confusing risk management with treatment of disorders, he argues, leads to pathologization of life's difficulties (Ibid., p. 507). Furthermore, he scrutinizes the often-asserted comparison of grief to a physical wound (i.e., the assumption that just as the healing of a wound can be complicated, so can grief). However, Wakefield argue,

> "a broken arm is not merely a consequence of an injury, it is itself an injury, and it is not a biologically designed response and has no biologically designed function. In contrast, grief is a biologically designed emotional response to an altered mental structure. The pain one feels as a result of an injury, for example, is not a disorder and is an adaptive part of the overall healing process. Grief is more analogous to that pain than to the injury itself" (Ibid., p. 509).

Kara Thieleman and Joanne Cacciatore (2014) have critically analyzed the implications of the diagnostic proposals with focus on bereaved parent (and other traumatically bereaved groups). Instead of accepting the validity of the high prevalence rates of complicated grief reactions among bereaved parents, they refer to a rich body of literature that demonstrates the long-lasting nature of parental grief. Hence, they argue, instead of being especially at risk for pathological grief, bereaved parents' normally long-lasting and intense grief is especially vulnerable to pathologization and medicalization.

Although not directly addressing the consequences of a grief diagnosis, Emma L. Penman, Lauren J. Breen, Lauren Y. Hewitt and Holly G. Prigerson's (2014) study of public attitudes to normal and pathological grief also touches upon how individual grief experiences are likely to be affected by public norms. Based on a sample of 348 participants from different countries (e.g., Australia, New Zealand, United Kingdom, United States, Canada, Finland, Norway, Indonesia, Turkey, and Iran), they found a pervasive expectation of grief to decline steadily between 2 weeks and 6 months, regardless of the circumstances of the loss (p. 510). The authors argue that, due to the pervasiveness of these expectations, "it is expected that bereaved people may internalize these norms, shaping their perceptions of how well they are coping and their overall experience of grief" (Ibid., p. 514). Based on these findings, it is expectable that a grief diagnosis will reinforce the public expectations of grief as a relatively transient state. This, in turn, is likely to contribute to pathologization and self-pathologization of bereaved individuals whose grief does not fit the expectations of a steady decline within the first months after bereavement.

Tony Walter (2006) offers a social constructionist perspective of complicated grief as a multi-faceted and socially negotiated phenomenon. By outlining a range of "apparently competing, but perhaps ultimately complementary" (p. 71) perspectives on complicated grief, he challenges the assumption that complicated grief is (merely) an individual disorder. Instead, he asserts, complicated grief may also be conceptualized as a psychiatric construct developed to distinguish between normality and pathology; a necessary tool for bereavement agencies etc.; a disciplining concept, a label applied to those who resist cultural norms about grief; a product of contemporary "risk society"; and ultimately, a result of negotiations between different interests in the bereavement field (Ibid.). Accordingly, he argues,

> "the roots of complicated grief lie not just in the individual mourner's psyche, but also in the concern of family and friends to reduce suffering, to get the mourner back to autonomy and happiness, to reduce their own inconvenience and worry, to replace chaos and guilt with order and predictability. Without such concern, there would be no concept of complicated grief" (Ibid., p. 78).

Hence, Walter points to how the experience of grief is radically socially situated—a perspective that has yielded a line of research that challenges the traditional models of grief as well as the attempts to establish universal criteria for normal and pathological grief reactions in individuals. In the following, I will briefly outline some of these perspectives, and address how these perspectives conceptualize and understand the suffering involved in grief.

3.2. GRIEF AS A SOCIAL, CULTURAL AND RELATIONAL PHENOMENON

Over the last decades, a range of studies has challenged the 20th Century's positivist, individualized and medicalized approaches to grief (see e.g., Averill & Nunley, 2006; Bradbury, 1999; Charmaz & Milligan, 2006; Granek, 2010; Jakoby, 2012; Valentine, 2008; Walter, 1996, 1999). As a part of the asserted "quiet revolution" within death and bereavement research (Bradbury, 1999), these studies have analyzed grief as a socially, culturally, materially and historically embedded. Two prominent and interrelated themes have emerged from these studies: examinations of bereaved individuals' continuing bonds to the deceased, and examinations of the social and intersubjective processes of grief. Both lines of research pose a range of challenges to the traditional grief models, e.g., the assumptions that grief resolution must involve detachment from the deceased, and that grief is a universal emotional reaction of the individual mourner.

3.2.1. CONTINUING BONDS

As we have seen, the traditional grief work models stressed that successful grieving involves a painful, but necessary process of breaking the bonds to the deceased loved one. Attempts to "hold on" to the deceased, and experiences such as sensing the presence of the deceased have been depicted as symptoms of acute grief, or as signs of pathology (Lindemann, 1963; Gorer, 1965, Marris, 1958). However, in personal writing, Freud himself actually challenged this presumption. In a letter to his friend Ludwig Binswanger, who like Freud himself had lost a child, Freud wrote,

> “Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish” (Freud, 1992, p. 386).

Likewise, although Bowlby’s (1980) phase model of grief describes detachment from the bereaved loved one as a precondition for resolving grief, he also stressed that,

> “half or more of widows and widowers reach a state of mind in which they retain a strong sense of the continuing presence of their partner without the turmoils of hope and disappointment, search and frustration, anger and blame that are present earlier” (p. 96).

Moreover, Bowlby underlines that this sense of presence, unlike “most of the other components of the early phases of mourning” tends to “persist at its original intensity,” and that most bereaved individuals find it comforting (Ibid.).

This emphasis on the commonality and potentially comforting aspects of continuing bonds has been taken up in a range of studies on grief throughout the last decades. Most prominently, the concept of continuing bonds has been elaborated in the work of Dennis Klass and his colleagues (see e.g., Klass, 1993a; Klass, Silverman & Nickman, 1996). In his ethnographic work on parental bereavement, Klass (1988, 1993a, 1993b, 1999) demonstrates that the parents in his study regularly continue a relationship with their dead children. The parental narratives he has collected includes experiences of sensing the dead child’s presence, hallucinations, and feelings that the dead child still has an active influence in the parents’ and families’ continuing lives. Rather than interpreting these experiences as abnormal and detrimental to parental health and well-being, Klass and his colleagues suggest that the continuation of bonds to the deceased are common and often treasured experiences in grief that can be helpful in the process of adjusting to the loss.

Ironically, just like the original authors of the traditional grief models were translated into clinical practice and popular culture as prescriptive models of bereavement, Klass’ and his colleagues’ model has been subject to the same kind of translation. As the concept of continuing bonds has been applied in empirical research and clinical practice, Klass et al.’s attempts to describe and demonstrate *how* bereaved individuals continue bonds to the deceased have been interpreted as a causal explanation of “healthy adjustment”, and hence, as a goal for bereavement interventions (Klass, 2006, p. 844). However, Klass stresses that continuing bonds is not a matter of bonds being present or absent, as the quality of these bonds can vary in multiple ways. When initially introducing the concept, Klass and his colleagues were writing against a predominant belief that continuation of bonds was inherently harmful. However, in their attempts to demonstrate that it is a common and potentially helpful phenomenon in grief, their findings have been interpreted as if this is always the case.

Moreover, Klass argues, the possible benefits of continuing bonds are not exclusively dependent on the bereaved individual's isolated relationship to the deceased, but also on whether these bonds are acknowledged and reinforced within the family and the wider cultural practices. While the clinical use of continuing bonds has been prone to individualize the phenomenon, Klass emphasizes that it is crucial to "include the cultural narratives in which conversations with both the living and the dead are set" (Ibid., p. 852).

The concept of continuing bonds has been widely applied in studies on parental bereavement within the last decades (see e.g., Riches & Dawson, 1998; Rosenblatt, 2000; Talbot, 2002). It has also led to revisions within the traditional grief models' understandings of the process of transforming the relationship to the deceased (see e.g., Worden, 2008, pp. 50-53). In the next chapter, I will outline how the concept of continuing bonds have been applied in qualitative studies on parental grief after infant loss, and address how my own findings relate to the findings in these studies.

3.2.2. GRIEF AS A CULTURAL PHENOMENON

As described in the introduction to this chapter, within the last decades, several voices within the field of bereavement studies have challenged the medical and individualized perspectives on grief. For example, Mary Bradbury (1999) has argued that the medical model's implicit conceptions of the mind as an asocial entity and of cultures as "poorly defined variables" (p. 171) provides little hope for understanding "the profound nature of loss" (Ibid.). The new interest in death and bereavement within the social sciences has revealed a tension within the 20th century's bereavement literature between the psychologized and medicalized grief of modern Westerners, represented in the psychological and psychiatric bereavement literature, and the exoticized and romanticized mourning practices of pre-modern and non-Western others (Hockey, 1996; Valentine, 2008; Walter, 1999). Challenging this presumption of grief as an a-historical and pre-cultural psychological process, Walter (1999) has drawn attention to how the very notion of "the grief process", developed within psychology and psychiatry, shapes bereavement practices in contemporary Western grief culture.

Likewise, Robert A. Neimeyer, Dennis Klass & Michael Robert Dennis (2014) position their work "[in] contrast to dominant Western conceptions of bereavement in largely intrapsychic terms" (p. 485). In line with the perspective in this thesis, Neimeyer and his colleagues stress the intrinsically social and relational character of grieving, "as the bereaved commonly seek meaning (…) in not only personal and familial, but also broader community and even cultural spheres" (Ibid.). Mourning, they assert, "is a situated interpretive and communicative activity charged with establishing the meaning of the deceased's life and death, as well as the postdeath status of the bereaved within the broader community concerned with the loss" (Ibid.). Building on these assumptions, Neimeyer et al. advocate a social constructionist approach to grief that conceives of grieving as a relational process of narrative meaning making.

Furthermore, Neimeyer et al. briefly address how "contemporary psychotherapeutic culture" is prone to pathologize "those who are seen as grieving too much (prolonged or chronic grief), at the wrong time (delayed grief), or not at all (absent grief)". (Ibid., p. 493). Rather than exploring or elaborating on the multiple ways bereaved individuals may use, negotiate, interpret, and contest such understandings, the authors assert that the bereaved individual must "conform to, or actively resist, the dominant cultural narratives that script the 'proper' performance of grief in a manner coherent with the prevailing social order" (Ibid., p. 496). It is a bit unclear how they conceive of grieving individuals' possibilities to reflectively relate to, draw upon, and negotiate such dominating narratives, but the latter quote suggests a rather strong social shaping of bereavement experiences towards maintaining social order.

In contrast, Christine Valentine (2008) draws attention to "the way people use available cultural scripts to construct and express meanings that are particular and personal to them" (Ibid., p. 2). In line with the present study, Valentine emphasizes the multiple and highly individual ways bereaved individuals mediate their loss experiences through available cultural scripts. Drawing on narrative analyses of interviews with bereaved individuals in contemporary British society, her work carefully examines the social, intersubjective, and negotiated nature of death and bereavement experiences. By exploring how deceased loved ones "may retain a significant social presence in the life of survivors" (Ibid., p. 1), Valentine situates grief within relationships to the lost loved ones, to the bereaved individuals' social realities, as well as to the intersubjective context of the research situation. Her analyses embrace the experiences of the loved ones' dying, as well as of grieving the loss following bereavement. In the context of dying, she examines how discourses of medicalization are used and contested in highly individual ways, that "could be both supportive of human value and dignity as well as dehumanizing" (Ibid., p. 22). Likewise, her study emphasizes the diversity in peoples' interpretations of their experiences of loss, as well as the situated character of bereavement, insofar as grief constantly "interacts with other agendas and priorities to form part of their day to day social life and sense of identity" (Ibid., p. 15). Valentine also addresses how competing discourses are involved in the social negotiations of grief, e.g. when grieving individuals' enduring distress and preoccupation with the deceased invoke a competing discourse of 'letting go' (Ibid., p. 107). Although medicalization and pathologization of grief is not a prevalent theme in her analyses of the loss narratives, such observations do indeed inform us about how contemporary understandings of grief mediate bereavement experiences.

3.3. SUMMARY

The growing critique of the traditional grief models has led in at least two directions. Stroebe & Schut's (1999) dual process model of bereavement maintains a universal frame for grieving, but does so by broadening the scope of the traditional grief models and by allowing for more individual and cultural variation of grief. However, although allowing for more variation than the traditional models, their concept of oscillation nevertheless implies a universalist model for healthy and functional grief. Other perspectives abandon the search for universal mechanisms altogether, and analyze grief as a radically situated phenomenon, i.e., the experiences of grief are not only *affected* by the relational circumstances of grief, but intrinsically embedded and created in and through these circumstances.

In spite of the growing critique of the universalist and individualized presuppositions within traditional bereavement research, the search for a universal model of normal versus pathological grief has recently emerged as the most prominent theme within contemporary bereavement research. This is most evident in the recent developments within the diagnostic manuals. In the recent revision of the DSM, the proposed diagnosis of "persistent complex bereavement disorder" was included in section III as a condition for further studies. This happened after much debate. At the moment, it is expected that prolonged grief disorder will be included in the forthcoming revision of WHO's diagnostic manual, the ICD-11, due in 2018. Controversies concerning grief as a potential individual mental disorder persists, not the least when it comes to bereaved parents. One question is whether it is valid to infer a concept of health and functionality from a statistical normality, i.e., even though *most people* will experience a decline within the first six months in the symptoms described in the diagnostic proposals, this does not necessarily imply that symptoms lasting longer indicate pathology. Instead, as Wakefield (2012) has argued, it might simply mean that people who experience more symptoms are dealing with more complex losses, more complex circumstances, or other aspects that may involve a more intense and lasting grief response (personality, prior loss experiences, cultural differences, etc.). As Breen & O'Connor (2007) argue, "[we] need to emphasize that what is a description of a bereaved individual or sample is not necessarily a prescription for others" (p. 208). However, as this review has demonstrated, attempts to avoid such a Humean fallacy of moving from "is" to "ought" has repeatedly failed throughout the history of bereavement research. Informed by the cultural psychological outlook of this thesis, this is not surprising. Knowledge about human kinds is intrinsically normative, and, as Hacking (1995) demonstrates, we cannot describe human functioning without implying normativity, and without interacting with the normative practices and interpretations of human beings in their everyday lives.

CHAPTER 4. LITERATURE REVIEW: QUALITATIVE STUDIES OF PARENTAL GRIEF AFTER INFANT LOSS

In spite of a proliferating literature on parental grief after infant loss, literature that explicitly address the relationship between individual grief experiences and societal expectations and norms about grief is limited. Studies that do address this relationship tend to do so in ways that imply a causal relationship between external factors and individual reactions, for example by examining the impact of social support on individual grief reactions (see e.g., Hutti, 2005; Lasker & Toedter, 1991; Thuen, 1997). Considering the rich body of literature on complicated or prolonged grief reactions in bereaved parents, as well as the general proliferation of studies examining parental grief experiences, research on how bereaved individuals experience, use, and negotiate culturally distributed notions of grief is notably sparse. It is widely acknowledged that parental bereavement is associated with long-lasting and pervasive grief reactions (Bowlby, 1980; Keese, Currier & Neimeyer, 2008; Klass, 1988, 1999; Rando, 1985; Rogers et al., 2008; Rosenblatt, 2000). Likewise, a growing body of literature documents high levels of complicated grief reactions among bereaved parents (Dyregrov, Nordanger & Dyregrov, 2003; Kersting et al., 2011; Zetumer et al., 2015). On this background, bereaved parents are arguably among the groups most likely to be affected by the “diagnostic gaze” (Rose, 2006, p. 475) on grief, regardless of whether they meet the criteria for a specific grief diagnosis or not. Strikingly, however, remarkably few studies have examined how bereaved parents experience, use, and negotiate cultural notions of grief as a pathological and medical phenomenon. To illustrate, a search in APA PsychNET on a combination of “grief”, different words related to medicalization or pathologization (separated with “or” to include any version used in the text) and “parents” or “parental” (appearing in any field, published any year) generate three results, one of which is my own article “Grief as a border diagnosis” (Kofod, 2015), one article on raising kids with problems (Francis, 2009), and one article which critically examines professional interventions for traumatically bereaved populations (Dyregrov, 2004b). By modifying the search and repeating the search process in other databases, a few more studies appear, of which a couple are included in the present review (Malacrida, 1998; McCreight, 2008).

While the literature on bereaved parents’ experiences of pathologization and medicalization is limited, a line of qualitative studies on parental grief after infant death has provided rich accounts of how cultural conceptions of infant loss shape bereavement experiences. As I have argued in chapter 1, cultural conceptions about loss are inherently connected to conceptions about grief, insofar as cultural understandings of loss feed into the cultural understandings of which losses that are legitimate to grieve.

In the following, I will create an overview over some of the most relevant qualitative studies of parental bereavement experiences that include the experiences of societal norms and practices in individual grief. I choose to include research that implicitly or explicitly addresses how bereaved parents experience, interpret and deal with the loss of a child in light of societal norms and expectations. Consequentially, studies that focus on the "effects" of e.g. bereavement interventions, social support, marital intimacy, etc. on individual "outcome" of bereavement are omitted from the review. This is because I am not primarily interested in the symptoms of grief as isolated consequences of loss, but in how bereaved parents *interpret, experience* and *act* in relation to loss. Furthermore, studies that exclusively focus on parental experiences of health care professionals' attitudes and models of care in the medical situation are also omitted, unless these experiences are situated within a wider context of the parents' everyday lives. With this in mind, the included studies are assessed by the extent to which they situate individual grief experiences within the social reality of the bereaved individuals; how they analyze the relations between individual grief and e.g. family values, socio-cultural practices and expectations, etc., and to which extent they address the ways in which bereaved individuals use, negotiate and contest the understandings of bereavement represented in the professional and lay accounts of bereavement in general, or the diagnostic understandings in particular.

The studies have been found through repeated searches on databases such as Psychinfo, The Danish National Research Database, Google Scholar, ProQuest, and EBSCOhost. The process of searching and reading literature has been an integrated and continuous part of my entire research process. This process is best described as an iterative hermeneutic process, in which my research interests, developing data, literature searches, reading, analyzing, and writing has simultaneously informed and directed each other (Boell & Cecez-Kecmanovic, 2010). Accordingly, the present relatively narrow review of qualitative studies of (situated) parental bereavement experiences following infant loss has emerged from a much broader, messier, and long-stretched process of orienting myself within the overwhelmingly huge body of literature on death and bereavement in general, and parental experiences of infant loss in particular. To target studies for the present review, I have read through a huge amount of qualitative studies on parental bereavement experiences, directed my attention to studies that focus on the situated character of grief experiences, followed references and citations that have led me to further studies, and so forth. Through a hermeneutic circle, the reading of specific studies has informed my understanding of the body of literature as well as my own data, which in turn has guided the scope of my literature searches, and vice versa, until I have reached a provisional level of saturation. In the following, I limit myself to present prevalent themes within the literature on perinatal loss and parental grief, with focus on studies that relate to my own findings in this thesis. The aim is not to present a fully exhaustive overview over the complete literature on parental bereavement experiences, but rather to reflect some of the main themes within the literature of particular relevance to the present study[18]. Hereby, my aim is to position my own work within the existing literature, and to outline how the present study contributes to the literature on parental grief after infant loss.

4.1. AMBIGUOUS LOSS AND DISENFRANCHISED GRIEF

Several studies have explored how ambiguity and/or disenfranchisement mediate parental grief experiences following infant loss (Cacciatore, DeFrain & Jones, 2008; Golan, Leichtentritt & Ronit, 2016; Lang et al., 2011; McCreight, 2008; Sawicka, 2016). In a retrospective analysis of anonymous data collected by two bereavement organizations, Joanne Cacciatore[19], John DeFrain & Kara L. C. Jones (2008) explore how the loss of a stillborn baby is experienced by the parents and their families as an ambiguous loss. Moreover, they assert that grieving such losses are shaped by a social environment that rarely legitimizes such losses as real loss (Ibid., p. 440). On this background, they describe how families' grief following stillbirth may involve years of struggling to find answers to inherently unanswerable, existential questions raised by the loss (e.g., "Why did our baby die?"; "Did I contribute to the death of my baby?", "Can good be found in the midst of such tragedy?", etc.). Rather than addressing such questions as "tasks" that can be completed and solved, Cacciatore et al. draw upon Pauline Boss' (1999) conceptual framework of "ambiguous loss" to highlight how "[the] death of a baby is a horrendous event that generates an endless cascade of profound and essentially impossible questions" (Cacciatore et al., 2008, p. 453). The authors stress the ambiguity as inherent in "the experience of the baby's physical absence and psychological presence" (Ibid., p. 451). While any grief following death arguably involves such coexisting experiences of physical absence and psychological presence, the authors stress that the lack of social acknowledgement of stillbirth as a real loss adds to the complexity of the grief. However, instead of interpreting this complexity as pathological reactions, Cacciatore et al. advocates a perspective on parental grief after stillbirth and infant loss that embraces "the uncertainty and unpredictability of ambiguous loss" (Ibid., p. 444).

In a longitudinal interview study with 13 bereaved couples at 2, 6, and 13 months following the death of an unborn child or infant, the Canadian bereavement researcher and nurse scientist Ariella Lang and her colleagues (2011) "explore sources of ambiguity and disenfranchised grief related to perinatal loss" (p. 183). The majority of the parents in their study had lost children during pregnancy (mean gestational age

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[18] A schematic overview of the studies is presented by the end of the chapter.

[19] Joanne Cacciatore is, beyond being a professor in psychology and a much-cited researcher on perinatal bereavement, also the founder of the MISS Foundation, an American NGO for bereaved parents after infant loss, and a bereaved mother herself.

17 weeks); one child died shortly after birth, and one died 3 weeks old while still in hospital. Lang et al. identify different sources of ambiguity and disenfranchisement emerging from the bereaved parents' encounters with family, friends, society, and health care professionals (Ibid.). Like Cacciatore et al., they draw on Boss' framework of ambiguous loss to designate "the concurrent physical absence and psychological presence" (Ibid., 184) characteristic for perinatal losses, as well as Kenneth Doka's (1989) concept of disenfranchised grief, i.e., the experience of loss that is "not openly acknowledged, publicly mourned or socially supported" (p. 4). A prevalent theme among the parents in their study is the experience of insufficient information, support and acknowledgment of the loss from the health care professionals during the course of the loss. This relates to the physical process of loss as well as to how to make "arrangements for the remains" (Lang et al., 2011, p. 189). Also, the parents' sense of ambiguous loss involved difficulties related to telling other people about the loss, due to uncertainty concerning the meanings and significance of the loss, their role as parents, etc. (Ibid., p. 190). This, again, is related to their experiences of disenfranchisement, in the sense that health care professionals, family, friends, and society at large are perceived as not acknowledging the loss. Under these circumstances, the parents grieve in private, "in keeping with the perceived social norms that undermine the expression of grief surrounding perinatal loss" (Ibid., p. 192).

In her book *Mourning the Dreams: How Parents Create Meaning from Miscarriage, Stillbirth, and Early Infant Death,* the Canadian psychologist Claudia Malacrida (1998) explores "the connection between private loss and other dimensions of human life such as public acknowledgement, social support and prevailing social norms" (p. viii). Her data are based on personal experiences with perinatal loss, participant observations in a support group for parents after perinatal loss, focus group interviews, personal writing, and, most prominently, in-depth interviews with 25 bereaved parents following perinatal loss. Informed by Therese Rando's conceptual framework for complicated mourning, Malacrida argues that parental loss experiences after perinatal loss may often be complicated, not as an effect of complications within the mourner, but rather because of "some circumstances of death and some postdeath variables that in and of themselves complicate mourning regardless of the premorbid psychological health of the mourner" (Rando, 1992, p. 44). Grief after perinatal loss, Malacrida (1998) asserts, is complicated by a range of interrelated personal, relational, and social factors, such as cultural values of parenthood, lack of social recognition of early infant loss, and lack of well-established mourning practices and rituals in relation to these losses (Ibid., pp. 5-6). Malacrida describes how cultural conceptions of pathological grief may indeed complicate the mourning, as when expressions of grief are "deemed pathological" instead of being met with support (p. 68). In other words, rather than facilitating support, other people's interpretations of the grief as pathological adds to the grieving individual's feeling of isolation and lack of understanding, and hence "can make grief resolution very difficult" (Ibid.). In general, Malacrida's analysis amounts to a cultural critique of how social and cultural practices and beliefs work against the individual mourner's attempts to come to terms with his or her loss (Ibid., p. 104).

In a qualitative study of women's experiences of perinatal loss in Northern Ireland, the sociologist Bernadette S. McCreight (2008) explores emotional responses to loss and care received from the hospital staff. Based on narrative analyses of interviews with 23 women participating in pregnancy loss self-help groups, McCreight highlight how the women create spaces of resistance against medicalization and disenfranchisement by participating in these self-help groups. While the medical profession, family and wider community are described as devaluing the loss and disallowing the women's grief, the mutual help groups are portrayed as providing a space for embracing and giving meaning to the emotional turmoil of perinatal loss.

How parents may actively position themselves as bereaved parents after pregnancy loss and early infant death is examined in detail in the American anthropologist Linda Layne's (2000) ethnographic work on pregnancy loss and early infant death in contemporary American culture. Focusing primarily on mothers' experiences, Layne argues that women who experience such losses are "caught in the middle of two contradictory sets of cultural forces – the increasingly important role of the fetus in the public imaginary, and a deep-seated cultural taboo concerning pregnancy loss" (p. 322). Layne explores how members of pregnancy loss support groups "actively construct their babies-to-be and would-have-been babies as 'real babies' and themselves as 'real mothers', worthy of the social recognition this role entails" (Ibid.). Such positioning, of course, needs to be understood on the background of the intangible and culturally contested nature of such losses. Echoing the themes of ambiguous loss and disenfranchisement in the above-mentioned studies, Layne describes these losses as characterized by a "realness problem" (Ibid., p. 323). Furthermore, she describes how the bereaved mothers, mediated by material artefacts such as pictures, baby toys, etc., navigate between reinforcing and challenging cultural constructions of babies and parenthood. On the one hand, they accept and reproduce "dominant cultural constructions of babies as precious", of parenthood as a desirable life trajectory, and of "possessive individualism", insofar as the possession of baby things serve as a "powerful proof that 'a baby' existed" (Ibid., p. 339). On the other hand, by insisting on the right to define their dead babies as "real babies" and themselves as "real parents", they "challenge prevailing notions as to what qualifies for inclusion in this narrative structure" (Ibid.).

A recent study by the Polish sociologist Maja Sawicka (2016) also identifies how perinatal loss is socially disenfranchised, ambiguous, and "disembedded" (p. 1). However, based on content analysis of online communities for bereaved parents and interviews with the moderators of these communities, Sawicka's study also addresses how participation in such communities may lead to "the creation of local definitions of the situation of loss and formation of subcultural feeling and display rules of grief (…) that agents use to transform the existing emotional culture of grief" (Ibid.).

Hence, her study challenges the conception of disenfranchisement as a static cultural condition which bereaved individuals are passively repressed by. Instead, her study demonstrates how bereaved individuals collectively may resist disenfranchisement by negotiating and challenging the normative interpretations and practices surrounding grief.

Summed up, most of the above-mentioned studies emphasize how the lack of societal recognition of early infant loss may lead to experiences of ambiguity and disenfranchised grief. However, as Leslie A. Grout and Bronna D. Romanoff (2000) point out, the very brevity of these children's existence may in itself add to the conflictual experience of reality and unreality of the loss—here expressed by a bereaved father:

> "It's always hard for us, for me to deal with it because on the one hand she was a living being, she was our daughter. I certainly bonded with her, the minute I saw her and held her. But on the other hand... she never lived really. She only lived to die. She lived while she was in Susan's belly.... so I have these mixed feelings, and one of them is that she's just part of our imagination, our hopes, which is I guess what kids are anyway in a lot of ways .... It's a strange grief to deal with.... so that the grief, in effect, is grieving a little bit more for ourselves and for what we had lost than for the actual person" (Grout & Romanoff., p. 104-105).

Taken together, the societal lack of acknowledgement and the ambiguous feelings of having lost something profound, yet indefinable, poses a difficult challenge to bereaved parents in terms of how to deal with this ambiguity. I will address this topic by the end of this chapter, where I outline how my own study contributes to the existing research on parental grief experiences following infant loss.

4.2. PARENTAL GRIEF AS A CONTINUING RELATIONSHIP WITH THE DEAD CHILD

As noted in the previous chapter, Dennis Klass' observations of how bereaved individuals regularly continue to have a relationship to their lost loved ones emerged from ethnographic studies of bereaved parents (Klass, 1988, 1993a, 1993b, 1999). Since then, continuing bonds has become a prominent theme within the bereavement literature. This is also evident in the literature on parental grief following infant loss.

In his ethnographic studies of bereaved parents participating in a chapter of the American self-help organization the Compassionate Friends, Klass examines how parents continue their interactions with an "inner representation" of their dead children (Klass, 1988, 1993a, 1993b). Klass describes how the parents interact with these inner representations through sensing the child's presence, hallucinations, memory, use of linking objects, or through conscious incorporations of the child's characteristics into the self (Klass, 1993b, p. 255). He also stresses how shared inner representations represent a significant element in social support (Klass, 1993a, p. 346). Although his study is not limited to parental grief following infant loss, he addresses how the lack of societal recognition of such losses affects parental grief. Accordingly, he argues, “when the inner representation [of the dead child] is not social reality, it is difficult to use it for solace” (Klass, 1993a, p. 364). In his later works, the situated character of parental bonds to their dead children is further emphasized, which is reflected in the change of vocabulary from “inner representations” to “continuing bonds” (Klass, 1999).

Several studies address how the unclear and ambivalent cultural meanings of early infant loss are reflected in parental experiences and enactments of the continuation of the bonds to their dead infants. For example, in her Ph.D. dissertation on parental grief experiences after stillbirth and perinatal death, the British sociologist Kerry Jones (2010) argues that bereaved parents “experience not only the emotional pain of loss but also struggle with their embodied identity as a parent” (p. i). This identity, she argues, is mediated by social networks and dominant discourses of e.g. medicine, parenthood, etc., as well as “wider political and social structures” (Ibid.). Jones argues that some of the struggles experienced by bereaved parents are related to a “dissonance between mainstream culture and the culture of bereavement” (Ibid., p. 220). More specifically, she finds that the parents in her study continue their bonds to their dead children in spite of a dominant cultural discourse of grief as a process of breaking bonds to the bereaved. In line with Layne’s study outlined above, Jones describes how the parents in her study struggle for acceptance of their children as real children and, accordingly, themselves as real parents. Like in Layne’s study, this involves an active use of material artefacts such as photos of the dead child (Ibid.). Jones describes the parents’ experiences of continuing bonds as “a transition from loving in presence to loving in absence” (Ibid., p. 222). The parents in Jones’ study challenge cultural assumptions that imply that the parents would have preferred not having experienced their dead children, so that they could have been spared the pain of loss. For example, one of the parents in Jones’ study states that “the joy of having had him [her stillborn baby boy] outweighs the loss of having lost him” (Ibid., p. 223).

Several studies have examined how parents use physical artifacts, online media etc. to maintain a continuing bond to their dead children in their everyday lives (see e.g., Blood & Cacciatore, 2014; Christensen & Sandvik, 2015; Layne, 2000; Riches & Dawson, 1998). For example, in an ethnographic interview study with bereaved parents in support groups, Gordon Riches & Pamela Dawson (1998) illustrate how bereaved parents after infant loss use photographs and other memorabilia to introduce their children in conversations with others, confirm their children’s real existence (as well as their parenthood), and as a means to keep the memory of their children alive. Riches and Dawson address how the social uncertainty concerning perinatal loss is reflected in parental narratives. For example, when showing pictures of her prematurely born (stillborn) twins to the researchers, one of the bereaved mothers apologetically exclaims: “They don’t look like proper babies, really” (Ibid., p. 129). However, “the photographs, the locks of hair, the name tags and the markers in the cemetery each helped [her] represent the existence of the twins in time and in space––as real presences whose loss could be mourned rather than as potential children who never lived” (Ibid., p. 130).

In a qualitative study of Japanese women who had all lost a baby in stillbirth, Akemi Yamazaki (2010) examines how these mothers “raise” their dead children through “the development process of becoming a parent”, as she phrases it (p. 933). Based on interviews with 17 women who had experienced a stillbirth, Yamazaki points to how socio-cultural conditions such as “a weakening of the bonds between the family and the local community” contribute to women being alone with their experience (Ibid., p. 924). From a Western point of view, the ways the women matter-of-factly describe how they “raise the [dead] child” through daily routines such as offering rise and water to a Buddhist altar, talking to the child, modifying a chair into a high-chair, etc. are remarkable and interesting (Ibid., p. 929). Japanese ancestor worship plays an integral part of these mothers’ grief practices, e.g. by finding consolation in the faith that the child is with the ancestors, by striving for a meaningful life in order to avoid feeling shame when meeting the child in the afterlife, etc. While “continuing bonds” from a Western point of view is somehow “in spite” of the cultural understanding of grief as a separation process, Yamazaki stresses how “[the] Japanese have a lesser sense of self and others, and thus they have an instilled mindset of not quite accepting the separation by death with an important person as an absolute separation” (Ibid., p. 935). Finally, Yamazaki’s study highlights differences in terms of how bereaved parents cope with other people’s reactions and expectations regarding stillbirths and perinatal deaths. Although her findings echo findings from similar studies conducted in Western countries concerning experiences of other peoples’ lacking acknowledgement of the dead child’s existence, the bereaved mothers in her study worked with the loss by “coming to terms with the pace of other family members in accepting the loss” (Ibid, p. 930).

While most of the studies I have come across assert the widespread occurrence and potentially beneficial consequences of continuing bonds in parental bereavement, a study by Grout and Romanoff (2000) demonstrates that parental narratives of perinatal loss are highly variated in terms of the meanings attributed to the child’s place in the family narratives. The authors (who, by the way, both reveal personal as well as professional experiences and interests in the study of bereavement) identify three main patterns of family narratives among the bereaved parents participating in their study: (1) *Maintaining the connection by preserving the space*, in which the parents maintain the absence of the lost child as a continuing reality in the family structure (“someone is missing”) (Ibid., p. 100), (2) *Maintaining the connection by continuing the relationship*, e.g., through memorials, rituals, and storytelling (i.e., the dead child “inhabits a different space, but is still an important family member”) (Ibid., p. 101), and (3) *Replacing the loss* (“I never really got to know her”), in which the parents’ story represent the dead child primarily as “the loss of possibility, of parenthood, of potential relationship rather than existing relationship” (Ibid., p. 104). Hence, rather than the continuation of bonds with the dead child being interpreted as an unambiguous phenomenon, their study reveals that continuation of bonds can be experienced as an absence (“preserving the space”) as well as a presence (“continuing the relationship”). Furthermore, it highlights that not all parents construct a narrative in which continuation of bonds to the dead child is prominent. While previous studies have addressed parents’ wish to “replace” a dead child as a pathological phenomenon (Cain & Cain, 1964; Kirkley-Best & Kellner, 1982), Grout’s and Romanoff’s study challenges this presumption by nuancing the analyses of parental experiences of the loss. Instead of asserting that parents ought to bond with their dead infants, they solicit the parents’ interpretations of what the loss means to them. For some, the loss represents something concretely missing, for others, the child continues to be an important family member, albeit in a “different space”. However, for those who interpret the loss most of all as a loss of opportunity and potential parenthood, there notion of continuing bonds might seem less meaningful.

4.3. GRIEVING WITHIN THE COUPLE: RELATIONAL AND GENDER DYNAMICS IN PARENTAL GRIEF

In this section I will outline studies that examine the relationship between the bereaved parents, the significance of gender differences for the couple dynamics in grief, and the cultural aspects of engendered grief.

In a qualitative case study of a bereaved couple after the loss of their infant daughter, An Hooghe, Robert A. Neimeyer and Peter Rober (2012) examine how this couple individually and relationally deal with their grief in a “dialectic tension between the need to be close to the deceased child and the need for distance from the pain of the loss” (p. 1220). Drawing on Stroebe’s and Schut’s (1999) emphasize on the oscillation between confrontation and avoidance on the loss, Hooghe et al. examine how this couple describes their individual and relational grief experiences through a recurrent metaphor of “cycling around an emotional core of sadness” (Hooghe et al., 2012, p. 1220). Through this metaphor, they argue, the couple deals with the dialectical need “to stay close to their deceased child, while at the same time staying at a bearable distance from the agonizing pain associated with the loss of their child” (Ibid., p. 1229). By stressing how this dynamic represents a challenge for both parents individually as well as relationally, Hooghe et al.’s study demonstrates that emotion regulation is (also) a relational process (Ibid.). However, the analysis does not move beyond the couple dynamics by addressing how these dynamics are situated within relations to other people, cultural norms and expectations.

A range of studies address the relative absence of attention to fathers’ grief following perinatal losses, reflected in bereaved parents’ experiences as well as in the literature on parental bereavement (see e.g., Bonnette & Broom, 2011; McCreight, 2004;

O'Leary & Thorwick, 2006; O'Neill, 1998; Samuelsson et al., 2001; Weaver-Hightower, 2012). A recurrent observation in these studies is the prevalence of experiences of conflicting normative expectations among bereaved fathers. On the one side, they perceive a set of cultural expectations to be "strong" and supportive vis-à-vis their female partners in relation to their loss, while on the other side, their wives expect them to share and express their grief. With reference to Karl Tomm's systemic approach to family communication, Lang and her colleagues (2011) describe a common pattern of (mis)communication unfolding between bereaved couples: "the more the wife shows her grief, the more the husband tends to withhold showing his grief, to suffer internally or silently in order to protect or comfort his wife. The more he withholds and suffers internally or silently, the more isolated and misunderstood the wife may feel which increases her suffering" (p. 193). Such a pattern of communication is described in strikingly similar ways in several studies (see e.g., Malacrida, 1998; McCreight, 2004; Samuelsson et al., 2001; Weaver-Hightower, 2012). For example, Malacrida (1998) describes how "[men] are consistently told to be strong for their wives, locking them into a supportive rather than primary role, and sending a message that this is the wife's loss and men have no grief of their own to resolve. Thus, stoicism is socially reinforced for men, perhaps accounting for some of the silence that causes wives to feel isolated" (p. 65).

While Malacrida (1998) primarily focuses on the significance of such gender expectations for mothers' grief, others more explicitly address the consequences of such expectations for bereaved fathers. For example, based on observations within pregnancy loss support groups and interviews with 14 bereaved fathers participating in these groups, McCreight (2004) argues that "the perception that men have only a supportive role in pregnancy loss is unjustified, as it ignores the actual life-world experiences of the men, and the meanings they attach to their loss, in what may be a very personal emotional tragedy for them where they have limited support available" (p. 326). Likewise, Marcus B. Weaver-Hightower's (2012) simultaneously evocative and analytical autoethnography of living with the loss of his stillborn daughter examines how cultural conceptions of masculinity mediate fathers' experiences of parenthood in general, and bereaved parenthood specifically. Like several of the above-mentioned studies, he highlights how a cultural norm of "silent, stoic masculinity" (p. 481) mediated his way of relating to his loss, to himself, and to other people in the time following his daughter's death.

Such cultural expectations concerning gender are arguably connected to the disenfranchisement and lack of societal recognition in parental bereavement. While the grief following perinatal loss is sometimes described as a "forgotten grief" (Samuelsson et al., 2001), the grieving fathers after such losses are similarly referred to as "the forgotten mourners" (Ibid.). However, as this review has demonstrated, neither fathers nor mothers are prone to forget their loss. Instead, parental grief involves continuous and interrelated processes of interpreting and negotiating the significance of the loss, struggling for social recognition, and integrating the loss in one's individual and family narrative. None of these processes occur in a vacuum. Rather, they are embedded in cultural practices and beliefs concerning infant death, parental grief, gender differences, etc., all of which mediate the grief experiences and enactments of bereaved parents after infant loss.

4.1. POSITIONING MY STUDY IN THE LITERATURE ON PARENTAL GRIEF AFTER INFANT LOSS

The literature on parental grief after early infant loss informs us about how unclear and ambiguous cultural expectations concerning these losses contribute to experiences of ambiguity and disenfranchisement. Furthermore, some of the studies address how parents actively position themselves vis-à-vis such cultural conceptions by asserting the realness of their children and their parenthood. The traditional grief models' assumptions of grief as a process of severing ties to the deceased, reflected in public understandings of grief, are equally challenged by the multiple ways in which parents continue their bonds to their dead children. Finally, parental grief is described as involving not only personal emotions, but also dynamic processes of sharing, withholding, and interpreting each other's emotions and actions. I recognize all of these themes in my own research, as well as from my previous experiences as a counselor in DIDA. The parents in my study also struggle with other people's (or their own) implicit or explicit assumptions of early infant loss as less significant than other losses. They too struggle with feelings of ambiguous or unclear loss, and with finding a "proper place" for their dead children in their continuing lives. They too report patterns of miscommunications and misunderstandings within the couple (as well as with other people).

However, while most of the studies I have encountered tend to describe cultural beliefs and practices as working "against" bereaved parents need to express their grief, only few address how bereaved parents may also reflectively draw upon, resist and negotiate such beliefs in their daily lives. For example, although Lang et al. (2011) briefly address how the parents in their study contest cultural perceptions of early pregnancy loss, e.g., by protesting against health care professionals' use of medical terms such as "spontaneous abortion", "miscarriage" or "fetal tissue" (p. 191), the significance of such resistance is not elaborated on in their study. Instead, the study implicitly portrays the bereaved parents as passive victims of ambiguous loss and disenfranchisement, rather than as active participants in the shaping of their social realities.

Similarly, in spite of Malacrida's (1998) sensitive and highly reflective analyses of how contemporary cultural practices and beliefs shape parental grief experiences, her study does not elaborate on whether or how bereaved parents engage with such practices and beliefs. Instead, cultural and societal circumstances are largely described as detrimental to parental grieving. "In fact," Malacrida asserts, "because the possibilities for complications are so extensive, it is likely that any parent who has lost a child to perinatal death is at risk for at least some complications in resolving their grief" (Ibid., p. 81).

Indeed, such findings of how disenfranchisement and pathologization negatively affect parental grief experiences were what I expected to find when embarking upon this study. However, although I do find that the parents of my study also struggle with such problems, this does not represent the complete story. Instead, I have been surprised by the multiple and highly individual ways the parents draw upon, negotiate, and contest cultural conceptions of infant loss, parental grief, and pathologization.

Rather than confirming the findings from previous studies of pathologization and medicalization as unambiguously repressing or stigmatizing mechanisms, the present study echoes Anne-Marie Jutel and Sarah Nettleton's (2011) observations of diagnoses (and, arguably, other prevailing cultural practices and conceptions) as something that "can vindicate and blame, can legitimise or stigmatise, can facilitate access to resources just as it can restrict opportunities" (p. 797). Inspired by Jutel and Nettleson's observations, I wish to contribute to the existing literature on parental bereavement experiences by examining how bereaved parents relate to the culturally available repertoires of grief and infant loss. Informed by a cultural psychological and situated approach to bereavement, my aim is to contribute to the literature on parental grief by examining how individual grief is mediated through (rather than caused by) cultural norms, beliefs, and practices. Grief can neither be reduced to essences within the suffering individual, nor to socio-cultural and material factors or social constructions. Instead, this study argues a view of suffering as a dialectical process of situated experiences, interpretations, and actions. Rather than being causally inflicted by biological, material, or cultural factors, grieving is enabled and constrained, experienced and enacted, within the socio-cultural and material realities the grieving individual belongs to.

Study:	**Design:**	**Relevant themes and findings for the present study:**
Cacciatore, DeFrain & Jones (2008)	Retrospective analysis of anonymous data collected by two bereavement organizations. (US)	Ambiguous loss Disenfranchised grief Existential questions
Golan, Leichtentritt & Ronit (2016)	In-depth phenomenological interviews with 10 women following stillbirth. (Israel)	"ambiguity, uncertainty, and doubt infused women's experience of [stillbirth]"
Lang et al. (2011)	Longitudinal interview study with 13 bereaved couples 2, 6, and 13 months after perinatal/infant loss. (Canada)	Sources of ambiguity and disenfranchised grief
Malacrida (1998)	Autoethnography and ethnographic observations within pregnancy loss support groups; focus-group and individual interviews with 25 bereaved parents following perinatal loss. (Canada)	Disenfranchisement and pathologization leads to complicated grief.
McCreight (2008)	Narrative analyses of interviews with 23 women participating in pregnancy loss self-help groups (Northern Ireland)	Bereavement self-help groups as spaces of resistance against medicalization and disenfranchisement
Layne (2000)	Longitudinal ethnographic study of pregnancy loss support organization, interviews with key members of these groups, textual analysis of support organizations' newsletters (US)	"The realness problem of pregnancy loss"; material artefacts in the social negotiation the dead child's significance and parental identity.
Sawicka (2016)	Content analysis of selected Polish discussion lists for bereaved parents after miscarriage and stillbirth, and interviews with moderators of these list (Poland)	Perinatal grief as culturally disembedded and disenfranchised; bereavement communities as subcultures providing alternative, local definitions of loss and grief.
Klass (1988, 1993a, 1993b, 1999)	Longitudinal ethnographic study of communities of bereaved parents (the Compassionate Friends) and interviews with bereaved parents participating in the organization. (US)	Parents continue bonds with "inner representations" of their dead children. Social validation of continuing bonds represents a significant element in social support.
Jones (2010)	Qualitative interviews with 21 bereaved mothers and 6 bereaved fathers following perinatal and neonatal loss, recruited through a SANDS (a British support organization for bereaved parents after infant loss) (UK)	Social negotiations and struggles with embodied parental identity. Continuing bonds in spite of a dominant cultural discourse of grief as a process of breaking bonds.

Table 1: Schematic overview of the reviewed studies (continues next page).

Riches & Dawson (1998) (see also Blood & Cacciatore, 2014; Christensen & Sandvik, 2015; Layne, 2000)	Ethnographic interview study with 36 bereaved parents in support groups (age of the dead children ranged from prenatal to grown-ups). (US)	Significance of physical artefacts (photographs etc.) for continuing bonds within the parents' social realities.
Yamazaki (2010)	Qualitative interviews with 17 mothers after stillbirth (Japan)	Socio-cultural conditions influence the experience of "raising a dead child"; continuing bonds through everyday practices; Japanese conceptions of the connectedness of self and other encourages continuing bonds.
Grout & Romanoff (2000)	Qualitative interviews with 10 parents of seven families (3 couples, 1 father, and 3 mothers) who had lost a child in the perinatal period and had gotten living children subsequently (US)	Three main family narratives of infant loss: (1) maintaining the connection by preserving the space; (2) maintaining the connection by continuing the relationship; (3) replacing the loss
Hooghe, Neimeyer & Rober (2012)	A qualitative case study based on interviews with and written feedback from a bereaved couple after the loss of their infant daughter (Belgium)	Individual and relational coping with grief in a dialectical tension (oscillation) between a need for proximity to the dead child and distance from the pain of loss ("cycling around an emotional core of sadness")
Lang et al. (2011)	Longitudinal interview study (Canada)	Gender expectations mediate couples' relational and individual ways of dealing with the loss; miscommunication within bereaved couples.
McCreight (2004)	Observations and interviews with fathers in a pregnancy loss support group (Northern Ireland)	Cultural masculinity norms and expectations leads to limited support and misunderstandings of bereaved fathers' grief after infant loss.
Samuelsson et al. (2001)	Phenomenological analyses of interviews with 11 men after 3rd trimester pregnancy loss (Sweden)	Bereaved fathers after infant loss described as "forgotten mourners." The fathers emphasized the importance of "being able to protect their partner and to grieve in their own way."
Weaver-Hightower (2012)	Autoethnography of a father's grief following stillbirth (US)	Examines how cultural norms of "stoic masculinity" mediate paternal grief after infant loss.

Table 1: Schematic overview of the reviewed studies.

CHAPTER 5. METHODOLOGICAL, ANALYTICAL, AND ETHICAL CONSIDERATIONS

> “[Meaning-making] occurs within the everyday flow of events, speech and behaviour or discursive activity through which we define and structure our social reality. Social discourse then becomes the primary field of study and the research endeavour an interactive, intersubjective process, rather than the researcher being separate from the field of study” (Valentine, 2008, pp. 5-6).

This study set out with an ambition of examining grief as a personal and individual, yet simultaneously socially and culturally situated and intersubjective experience. This called for a methodology that could grasp the complexity of how experiences, interpretations, and meaningful actions unfold and intertwine within people’s social realities. Furthermore, my own background as a bereaved parent and bereavement counselor emphasized the need for an approach that acknowledges the researcher as an inherent part of the field of study.

In the following, I will describe the process of choosing an approach to the field, selecting design, finding suitable informants, developing interview guides, and conducting interviews. I will discuss some of the ethical and analytical concerns I have been faced with in the research process, and how I have sought to deal with them. I will reflect on how talking and writing about grief can be done in ways that give space to and acknowledge the inherently connected experiences of love and grief. I will describe the process of analyzing and writing up my findings, and how I have attempted to balance between the evocative and the analytical in order to create sensitive accounts of parental grief after infant loss. Finally, I will end the chapter with presenting the participating parents through brief stories of love, loss, and grief.

5.1. APPROACHING THE FIELD

Motivated by my interest in the situated, normative, and intersubjective aspects of parental grief, I was interested to talk to parents about their experiences, thoughts, and actions related to their loss. This could be done in several ways. One opportunity I considered was to visit some of the parental support groups organized by DIDA. This would provide an opportunity to listen to the conversation as it unfolds within the context of a small “community of bereaved parents”, and combine participant observation with focus group interviewing. This would in particular address the situatedness of grief processes.

However, I was also interested in exploring the parental loss narratives in more detail, how they experienced their everyday lives, and their experiences of participating in DIDA's services. Especially the latter would be difficult to achieve within the context of DIDA's services, as it is likely that the parents would feel uncomfortable with sharing these experiences with the group. For this reason, and due to the time-consuming nature of pursuing both approaches, I prioritized interviewing bereaved couples together in dyadic interviews (Morgan et al., 2013). This allowed for each couple to tell their story, and enabled explorations of the individual and intersubjective meanings of their loss. Whether one chooses to interview the partners in a couple together or separately, each approach yields different advantages as well as limitations. While individual interviews allow participants to express views and experiences they might have withheld in a couple interview, the latter enables the participants to dynamically explore, challenge, corroborate, and stimulate different aspects of their shared and individual perspectives (Morgan et al., 2013; Taylor & DeVocht, 2011). From the perspective of cultural psychology, the opportunity to explore the shared, negotiated, and co-constructed meanings as they unfold in the interview conversation provides a valuable insight into the situated nature of grief experiences. By enabling such joint explorations of the shared and individual meanings, experiences, and relationships, dyadic interviews represent "a viable third alternative to individual interviews and focus groups" (Morgan et al., 2013, p. 1276).

The interview approach used with the informants can best be described as informal, conversational and exploratory. A semi-structured design allowed me to simultaneously explore my research interests as well as inquiring into topics emerging during the flow of conversation. Although interviews thus became my primary source of data, my own background made it obvious to include autoethnographic inquiries of my relationship to the field and to the informants. Nevertheless, as unfolded in my second article, "Becoming a bereaved parent", this was not a straight-forward process. In the beginning, I was reluctant to elaborate on my background in the interview setting. Although I did tell the parents that I had entered this project from a background as a counselor in DIDA, my own loss was only mentioned if the parents asked into it. When they did (most often because the parents knew that all counselors working in DIDA at that time had a personal loss experience), I was very aware of not centering my loss, and chose my words very carefully. However, as the study progressed, and I gradually became more confident with my own background in the context of the research, I ventured on exploring the significance of this for my relationship to the field and to my informants. While some of the parents from the very beginning of the study had stressed the significance of me being "someone who know what it's all about" because I have experienced it myself, others did not seem to put too much into it. Bereaved or not, I obviously knew enough about the world of bereaved parents to pose relevant questions and, I hope, avoid stupid misconceptions about grief and infant loss. Only one of the couples were surprised to hear that I too had lost a child. This was revealed in my third interview with them, and it was indeed a rather awkward moment. I had mistakenly assumed that they knew, as they had been quite involved in DIDA's activities (we had even run into each other coincidentally at a couple of DIDA's arrangements). However, the fact that I had not been explicit about my loss felt like I had withheld important information from them. Once we had talked about it, they said it would have been nice to know, although they did not think it would have meant a huge difference in terms of how they had related to me during the interviews. Nevertheless, I did indeed feel that I owed them an apology for my messy process of "coming out" as a bereaved bereavement researcher.

Unflattering and embarrassing as it may be, the above example clearly illustrates that knowledge developed throughout the research process cannot be reduced to preexisting data obtained through a stringent use of neutral methodologies (Holstein & Gumbrium, 2004). First, any method used in research will interact in multiple ways with the subject of research. This is particularly true when the subject of research is human beings and their experiences, interpretations and meaningful actions. Whether I use observations, structured, or open interviews to inquire into the phenomenon I am interested in studying, the choice of methods will interact with the phenomenon I am studying in several ways (e.g., asking about grief symptoms arguably will create different kinds of knowledge than asking people to tell their story). Second, through the research process, I am myself an inherent part of the process, insofar as I interact with my field in multiple, and sometimes unintended ways. This is evident in the encounters with the informants, as well as in the analytical process of understanding, interpreting, orienting myself within the literature, and in writing about my findings. Throughout the entire process, I draw upon preexisting and developing experiences, beliefs, and knowledge about the field I am studying. I interact with the field, involve myself in the lives of the informants, and just like expectant parents may see pregnant women everywhere, my attention is constantly drawn to aspects of everyday life that inform or challenge my emerging understandings of the field I am studying. The point is that rather than trying to "minimize distortion" of preexisting data, it is crucial to include a reflective stance towards my own position within the field of study. As James A. Holstein and Jaber F. Gumbrium points out in relation to interviewing, "both parties to the interview are necessarily and unavoidably *active*. Meaning is not merely elicited by apt questioning, nor simply transported through respondent replies; it is actively and communicatively assembled in the interview encounter" (Ibid., p. 141, italics in original).

5.2. SELECTING DESIGN AND RECRUITING INFORMANTS

In order to explore how bereaved parents relate to their loss over time, I planned to conduct a series of interviews with the same informants across different points of time since their loss. Due to my interest in parental experiences of DIDA's services, all informants were recruited in collaboration with DIDA's counselors. While most of the informants were enrolled in the longitudinal study, an additional couple was later included for a single interview, two years after their loss. This was done in order to gain in-depth knowledge of how participation in DIDA's activities were experienced in retrospect by someone who had used the services to an extensive degree. For the participants in the longitudinal study, I aimed at conducting three interviews, respectively 1-2 months, 7-8 months, and 19-20 months after the loss of their child. This plan was followed (for one of the participants, the second interview was split up into two interviews, due to familial circumstances). None of the participants withdrew, although they were repeatedly informed of their opportunity for doing so at any point in the process.

The search for appropriate informants to participate in the research project was initiated early on, in close collaboration with the counselors at DIDA. The parents were sampled in order to create variation in the participants' geographical origin (e.g. urban vs. rural districts, different parts of Denmark), as well as different kinds of loss (early and late pregnancy, stillborn and born alive). Further, if possible, I wanted to talk with parents who had different fertility histories – including time used for planning pregnancy, fertility problems, etc. I wanted to talk to parents who had lost their first child, as well as parents who had children in advance. These criteria were not based on an ambition of examining the effects of demographic, social, or individual variables on loss experiences. Instead, my intention was to include a rather broad range of informants, reflecting the variety of parents who typically make use of DIDA's services. Except for the couple invited later for a single interview, a crucial aspect was the recency of loss, as I wanted to explore grief as it is experienced in the immediacy of loss as well as over time. In the process of selecting couples to ask, one couple was excluded because of language issues (interviews would have to be carried out via an interpreter). Based on the above-mentioned criteria, the counselors in DIDA presented me with anonymized data on potential informants, and after selecting those most relevant, the counselors informed the parents about my study. If the parents were interested, they were sent an e-mail invitation with more information about the study, including a request for consent if they wanted to be contacted by me for further information. All of the invited parents accepted the invitation. The parents, including the couple invited later on, are presented briefly in table 1.

It is important to stress that bereaved parents who use DIDA's services not necessarily reflect what is "typical for his or her society, or may represent the perspective of a particular group" (Otto, 1997, p. 98). For several reasons, for example related to the ambiguous conceptions of early infant loss in our culture, it is likely that some bereaved parents following such losses are more reluctant to identify themselves with the "community of bereaved parents". However, as the research process developed, it became evident that the participating parents, although they all had some kind of relationship with DIDA, they surely could not be seen as representing a unitary and uniform community. For some of the parents, DIDA became an important community, central to their identity as bereaved parents. For others, DIDA most of all served as an "outstanding source of first aid", as Chris phrases it. For Rita, the thought of having to relate to other people's grief and loss was too overwhelming, and apart from a single

Aliases:	**Age (1st interview):**	**Loss:**	**Living children at the time of loss:**	**Fertility history:**	**Education/ occupation:**	**Lives in:**	**Interviews:**
Sarah & Paul	37, 33	Eva (stillborn. 3rd trimester)	No	1,5 years of trying to conceive, uncomplicated pregnancy	Nurse, officer	Town in Northern Zealand	3
Jacob & Mia	26, 30	Sophie (stillborn, 3rd trimester)	No	Spontaneous, uncomplicated pregnancy	Student, pharmacist	Copenhagen	3
Emma & John	32, 33	Samuel (stillborn, 3rd trimester)	Yes (boy, 2,5 years)	Uncomplicated, planned pregnancy	Curator, archivist	Town in Northern Jutland	3
Thomas & Anna	29, 26	Oliver (stillborn, 3rd trimester)	No	Uncomplicated, planned pregnancy	Teachers	Aarhus	3
Linda & Chris	30, 31	Lucas (died 4 days old of congenital disease)	No	2 years of fertility treatment, uncomplicated pregnancy	Office assistant, student counselor	Copenhagen metropolitan area	3
Rita (husband not participating in the study)	42	Lily (died shortly after a premature birth (2nd trimester))	No	Fertility treatment due to Rita's age, complications in the latter weeks of pregnancy	Business consultant	Northern Zealand (rural area)	4
Eric & Diana	38, 36	William (died one week old of congenital disease)	No	Not known	Manager, insurance analyst	Copenhagen	1 (approx. 2 years after the loss)

Table 1: Participants in the interview study[20]

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[20] The parents are also presented with brief loss narratives by the end of this chapter.

conversation with a counselor from DIDA, she ended up not using any of the organization's services (although she and her husband did sign a membership). These differences in the parents' relationship to DIDA highlight that such services serve different functions and are used in multiple and individual ways. Accordingly, the parents are neither entirely representative for bereaved parents as such, nor for bereaved parents involved in DIDA. On the other hand, in spite of the huge variety of their experiences, the study also reveals themes that cut across the differences (several of which echo findings from previous studies), and that are arguably common to many bereaved parents in our culture, regardless of how or whether they are enrolled in specific communities such as DIDA.

5.3. INTERVIEWING

Except from Rita, whose husband did not want to participate in the study, all of the parents were interviewed together with their partner. As described previously, this dyadic approach allowed conversations and mutual reflections to unfold during the interviews, and gave me an opportunity to explore how the parents narrated their stories within the couple.

All interviews were conducted in the parents' homes. This was primarily done for practical reasons (as the couples lived in different parts of the country, it would be inconvenient for them to travel to the university, and it would be equally inconvenient for me to find suitable locations across the country). However, by being allowed into their homes, I also had the opportunity to experience some of the circumstances of the everyday lives in which their children were missing. In some homes, I was presented with pictures on the walls of their dead children. I could see the empty baby room, where boxes of baby items were collected for a baby that never got the opportunity to come home. Being exposed to these physical realities creates a sense of what they are missing in a different way than just hearing about it. However, inviting others into your home might also be experienced as exposing oneself, and as such, it can be a vulnerable experience. Accordingly, my being in their homes was as a guest, not as an inquisitor, and I had no intention of using their homes as a source of interpretation "behind their backs", for example by interpreting the presence of absence of pictures on the wall as a sign of how they dealt with their loss. Nevertheless, being in their homes created a different sense of getting to know them and their dead children than I think would have been possible if we met on neutral ground. As time went by, I saw rooms emptied of baby items, being arranged as provisional storage or work spaces, and, finally, rearranged into nurseries when a little baby sister or brother was born into the family. In the last round of interviews, these little babies created lots of delightful disruptions along the way, tangibly demonstrating the coexistence of joy and grief, presence and absence, in bereaved families.

The entire interview study consisted of 20 interviews ranging from approx. 1,5 to 3 hours. I initiated each interview by thanking for their willingness to participate, introducing myself and my relationship to DIDA, presenting the overall themes and aims of the project as well as the suggested topics and duration of the pending interview. I asked for permission to start audiotaping, and repeated information about confidentiality, informed consent, their right to withdraw their participation at any time, that they were not obliged to answer questions, etc. I also encouraged them to give feedback on how they experienced the interview situation, and to contact me if they had any further comments or questions after the interview. The interviews were loosely structured by an interview guide developed for each round of interviews. However, I encouraged the parents to talk freely, and used the guide more as a heuristic tool for remembering possible themes to explore in the flow of conversation. That is, rather than going through the questions in an orderly sequence, the guide was a useful tool to orient myself in along the way. An example of questions from an interview guide (from the first round of interviews) is presented in table 2 at the next page.

For the second and third round of interviews, I developed new interview guides that made room for addressing issues from the prior interviews, and follow up on events I knew had happened since last time we talked (e.g., new pregnancy, getting back to work, having another baby). Some of the general questions for the second round of interviews were, e.g., “Can you tell me a bit of how things have been for you since last time we talked?”, “How do your experiences with loss fit with your prior thoughts about loss and grief?”, “How do they fit with the expectations you meet from others?”, ”Are there anything that has become more important after you lost (...)?”, “(How) has this changed over time?”, “Which role, if any, has DIDA played?”, “What has been most important?, “Have you missed anything – if so, what?” (related to previous question about DIDA), etc. In the final round of interviews, all of the couples had gone through a subsequent pregnancy, and all had become parents to a living child. Hence, the relationship between being bereaved parents and parents of a living child became a natural focal point. Some of the questions for the third round of interviews were, e.g., “Do you want to tell me about the pregnancy, the birth, and the first time with (…)?”, “How would you describe how your loss of (…) is placed in your life now?”, “Has anything changed? (“What?”, “How is that?”), “Which place do you hope it (your child/your loss) will have in your future life?”, “Is there anything you would like to tell others in a similar situation, that you would have appreciated to have heard when you had just lost (…)?”, “Do you think one can become ill of grief?”, “If so: How do you think this is expressed?”, “What do you think of the suggestion to introduce grief as a psychiatric diagnosis?” (Asked after a brief introduction to the suggested criteria.). Finally, I had prepared some questions for the final interview addressing how they had experienced participating in the interviews, whether they thought my background as a counselor in DIDA and a bereaved parent had any significance for their experience of the interviews, and what had been their main motivation for participating.

<table>
<tr><td colspan="3">Introduce topics for the interview:
The pregnancy and the time preceding the loss
The story about your child and about your loss
Your experiences of the time following the loss
Your experiences with DIDA</td></tr>
<tr><th>Topics</th><th>Research questions</th><th>Interview questions</th></tr>
<tr><td><i>The time before the loss</i>

Emerging parental identity

Expectations and narratives of parenthood, children, and family life</td><td>How does parental identity and narratives about the child develop before birth?</td><td>Can you tell me a bit of the time before you lost (...)
Was it an unexpected or planned pregnancy? (If planned, how was the waiting time? How long did it take to get pregnant?)
How did you experience and relate to the pregnancy and to your expected child? (expectations, thoughts about the future?)
What about your family and friends – (how) were they involved in the pregnancy?</td></tr>
<tr><td><i>The story about the loss</i>

Receiving the message
Disruption of the expected life narrative</td><td>How do parents experience and interpret the situation of getting to know that one’s baby is dead or dying?</td><td>Can you tell me about how you got to know that (...) was dead? (or would/might die?)
How do you recall:
- time and place?
- who was present?
- what was said and done?
- how did you respond? (What did you think, feel, say, do?)
Did you contact your family? How, whom, what was said, etc.</td></tr>
<tr><td><i>The time with the child</i>

Narratives of the child, attachment, and parenthood</td><td>How does narratives of the child, attachment, and parenthood develop in the interactions between parents, health care professional, material, and discursive practices?</td><td>(How) were you prepared for what was going to happen?
How was the birth?
What happened when the child was born? How was that? (What did you think, feel, and do?)
How did you experience the healthcare professional’s (the midwives’) role?
Is there anything you remember as particularly helpful or not so helpful in the situation?
Can you tell me a bit about the first days after the birth/loss? (What preoccupied you most? E.g., feelings, thoughts, decisions, communication with others, etc.)</td></tr>
</table>

Table 2: Excerpt from interview guide (1st interviews).

All in all, the longitudinal design gave me an opportunity to get to know the parents, follow their lives and the development in how they experienced and related to their grief over time, follow up and further explore themes from previous interviews, and get their feedback on my emerging, tentative analyses. For example, during our second interview, Linda said she could imagine herself striving for a grief diagnosis in order to prove her love for her dead son (see article 4, “Grief as a border diagnosis). After the interview, I was uncertain of whether this interpretation was merely something she had arrived at rather coincidentally during the course of our conversation, or whether it would still hold significance for her. In our third conversation, a year later and approximately two years after the loss of their son, I ask Linda and Chris whether they think it is possible to become ill from grief. Both emphatically affirmed this possibility, and both supported the idea of a grief diagnosis as a valuable means for bereaved individuals to get recognition and support for their grief. Linda pointed to how a grief diagnosis would have felt more appropriate than the depression diagnosis she had recently been given as a consequence of reaching out for help to cope with her grief in relation to mothering their second child (born one year after the loss of Lucas). After talking about this, she spontaneously returned to her thoughts about how *not* getting such a diagnosis would have made her question the depth of her love for their dead son. She states: “I would feel that I ought to hit rock bottom at some point, in order to prove to myself that I loved my child so much”. Although Linda’s unprompted return to this perspective suggests that this held significance to her beyond the fleeting flow of our prior conversation, it is important to stress that I do not consider this as an argument for interviews as a neutral method for “digging out” experiences and thoughts from the informants (Brinkmann, 2013, p. 11). Linda’s reflections on this matter had emerged in the context of our conversation, and, as such, it demonstrates the socially negotiated and contextually situated nature of meanings. This does not imply that the account Linda arrives at in our conversation stands in opposition to some preexisting, more “real” or authentic, immediate experience. Instead, I argue a perspective on interviewing as an intersubjective process of exploring and developing meaningful accounts of personal and intersubjective experiences, interpretations, and actions. This involves a recognition of the significance of my own participation in the research process, and highlights the ethical responsibility inherent in the interview situation.

5.1. ETHICAL AND ANALYTICAL CONSIDERATIONS

Talking about sensitive matters like grief can and will most often be an emotionally exhausting experience. For this reason, I was aware of giving space for emotion, contemplation, and silence in the interview situations. This requires a careful attention to what is going on in the informants, knowing when to be silent, expressing empathy and recognition with words, bodily gestures, and sounds, and carefully assessing when to pursue or change a topic. Being sad and emotional is an inherent part of being in grief, and the interview “invite[s] people to tell stories of events from which they have suffered or are suffering” (McIntosh & Morse, 2009, p. 85). Thus, emotional distress is expected and anticipated in interviews about loss and grief. Moreover, when people are asked how they experience participating in interviews on emotionally distressing experiences, they often state that they find it relieving to share their experiences and emotions with someone who is willing to listen and acknowledge the pain (Dyregrov, 2004a; McIntosh & Morse, 2009). Rather than being a necessarily adverse side-effect or by-product of the interview situation,

> "[emotional] distress is integral to emotionally distressing circumstances; emotional distress is likewise integral to the telling of these circumstances in interviews that invite them. But more than this, emotional distress is integral to participants' responses to interview participation; it underpins and interconnects all the dimensions of participants' participation in interviews. Emotional distress motivates purposeful participation, creates relational connections, facilitates self-knowledge of participants' and their experiences, and expresses its voice in the emotional space afforded by the interview" (McIntosh & Morse, 2009, p. 91).

In my interviews in this project, as well as through my many conversations with bereaved parents in my role as a counselor in DIDA, the relieving potential of sharing emotionally distressing experiences has repeatedly been confirmed. Several of the informants explicitly state that, apart from being motivated by a wish to help others, one of their main motivations for participating in the interviews is the opportunity to talk about their painful experiences with someone who is willing to listen respectfully.

Nevertheless, as Paul C. Rosenblatt has argued,

> "[qualitative] interviews have an unpredictable, unfolding quality that makes it impossible to warn people of everything that will occur during them. It is also impossible to inform people fully about what they might experience during a qualitative interview because they cannot truly understand all that they read or are told, because they can only be told abstractly about what they will have to deal with, and because nobody can fully anticipate their reactions in the research situation" (Rosenblatt, 1995, p. 148).

Due to this unpredictable and unfolding nature of qualitative interviewing, Rosenblatt suggests that interviewers supplement the consent procedure at the beginning of the interview with a "processual consent" procedure during the interviews in order to give people an opportunity to stop or change the direction of the interview (Ibid.). In my own interviews, I involved such a procedure by including questions and comments such as, "I don't know if this is an appropriate question to ask, but…", "Could I ask you..?", "Please let me know if this is not okay for you to talk about right now", "Do you need a break?", etc. Likewise, at the end of each interview, I repeated that the parents were always welcome to write or call me in case anything came up after the interview which they wanted to ask or talk to me about. However, in spite of such precautions, emotional distress is likely to occur in the interview situation, and it takes careful considerations along the way to deal with.

Although the sensitive nature of interviewing people in grief poses ethical challenges to the interviewer, it is not so much the presence of emotional distress that has been my main challenges in the interview situations. The greatest ethical dilemmas I have encountered have been of a less obvious character. For example, how and what to share of my personal experiences has involved a range of ethical as well as analytical considerations. On the one side, revealing that I am a bereaved parent myself potentially gave access to a privileged position as a member of an invisible community of bereaved parents. However, as already addressed, I was hesitant to explicitly address my own loss in the context of my research. Regardless of how I chose to include (or try not to include) my own story, I was faced with ethical and analytical dilemmas: How would sharing or not sharing my own story affect the parents' experiences of the interview situation, and how might it affect what was told or not told? My brief and unelaborated answers to their occasional questions about my situation was motivated by an ambition to decenter my own loss, and to avoid implicitly presenting "my way" of dealing with loss as a normative standard. Indeed, the conversations with the informants were about their loss—not mine. Nevertheless, for some of the informants, I was one of the first bereaved parents they had ever talked to, and they were eager to know about my loss, and how it shaped my life after all the years that have passed. The latter posed another ethical dilemma, insofar as I intuitively sensed that they were searching for positive images of how their grief might become an integrated and natural part of their continuing life. And there I was, a bereaved parent to a nameless premature girl, whose grave is seldom visited, whose existence is not forgotten, but seldom mentioned. Moreover, I was researching parental bereavement while trying to downplay the connections between this professional endeavor and my personal life. Taken together, I did certainly not feel like a good role model. At the same time, however, I believe that being more explicit about these doubts (while still keeping a focus on their experiences), might have opened for further explorations into their doubts about being bereaved parents. My choice of eventually including my personal experiences in the context of research was not merely motivated by an ambition to create transparency and build rapport with my informants. As argued in my second article, "Becoming a bereaved parent", my reluctance to include my personal loss experiences in the context of research reflects a wider, cultural conception of grief as a private, emotional process with a goal of resolution and normalization (Walter, 1999). Accordingly, I have included my personal experiences not only because it sheds light on the research process, but also because I believe my process of integrating personal and professional loss experiences sheds light on some of the cultural assumptions surrounding grief in our society.

5.2. TALKING ABOUT THE LOSS: NOT ALWAYS KLEENEX AND CANDLE LIGHTS

In everyday conversations as well as in research on sensitive matters such as grief, the emotional distress of the situation is often assumed to represent the greatest challenge to the involved parts. Bereaved individuals testify to the widespread cultural conception that avoiding emotional distress is a goal when talking about loss and grief. The bereavement literature as well as my many conversations with bereaved parents suggest that a vast majority of bereaved individuals have experiences of people in their network trying to avoid the topic of loss out of an intention to avoid “ripping up” the wound and provoke sadness and distress. However, bereaved individuals often appreciate to have the opportunity to talk about their lost loved ones, even if it might provoke sadness and distress (see e.g., Arnold & Gemma, 2008, Walter, 1996). Although the therapeutic ethos of contemporary Western societies may have created a change in terms of people being more acknowledging of the “necessity to talk” about emotional matters (Walter, 1999), this seems to be shrouded in beliefs about this kind of talk as something potentially dangerous, something that requires extraordinary, perhaps even professional skills, as well as a carefully selected space and timing. Slightly caricatured, grief talk is seen as something that requires a solemn atmosphere with candle lights and Kleenex on the table, in order to create space for the difficult emotions of grief. Certainly, grief does involve difficult emotions, and there are indeed a range of situations in which bereaved individuals might feel it inappropriate or uncomfortable to be exposed to their loss. However, in spite of the emotional distress, and in spite of not wanting to talk about the loss with anyone anywhere, many bereaved individuals bemoan the cultural seclusion of grief talk from the everyday flow of conversation. In my own study, this was evident in the parents’ stories of other people’s silence when the talk fell on their dead children – or the living children of other people, for that matter. Several of the parents tell stories of how they have caused a halt in the flow of conversation by mentioning their dead children. All of a sudden, they report, the atmosphere changes, people become grave, silent, and uneasy. Some people might hesitantly ask how they are doing, after which someone usually will try to change the subject of the conversation. As the Danish journalist and bereaved father, Esben Kjær (2016) writes in his autobiographical book of living with the loss of his son: “It is as if he dies twice – first in reality, and then he is silenced to death” (p. 109, my translation). My point here is not to examine how or why this unwillingness to talk about loss and grief has developed in our culture. Instead, I want to highlight what bereaved people so desperately seem to miss in these situations, namely an opportunity to include their lost loved ones in their social reality—not only as a painful and unspeakable grief, but as a continuing, precious, and important part of their lives. For example, Linda mentions how she wishes to be able to say “I bet Lucas would have gotten red hair”, without other people responding awkwardly. I believe what is at stake here can best be analyzed as a case of othering (Sharp, 2011), through which the bereaved parents’ experiences and identities are treated as essentially different from parents of living children, evoking responses ranging from pity, estrangement and unease to praise for being "strong". In effect, the bereaved parents' experiences of pregnancy, child birth, and parental identity are excluded from the conversation. As I have described in my second article, "Becoming a bereaved parent", my own background as a bereavement counselor and a bereaved parent might have sensitized me to listen to and encourage conversations that include and normalize such experiences. In any case, by listening to the parents' stories, it is obvious that their grief also includes love, pride, and affection for their children. When this was highlighted and expressed, their children's existence was felt as an immediate presence during our conversations, poignantly illustrating the inseparable connections between grief and love.

5.3. ANALYZING AND WRITING

The process of analyzing and writing up my findings has been a continuous, inductive and explorative activity throughout the entire research period. From the very beginning, writing has been an integral part of the analytical process, insofar as writing not only (re)presents preexisting thoughts, but mediates and gives shape to thoughts and ideas. I have collected notes on the literature I have read, reflections I have had prior to and after interviews, as well as on everyday encounters with matters of relevance to my project (e.g., stories of bereavement, grief, mental health, suffering and illness represented in the mass media, social media, books, magazines, films, etc.). Moreover, this has been a socially mediated activity, insofar as I have discussed my thoughts and writings with others who have been willing to listen; with my supervisor, my research group, participants on Ph.D. courses and conferences, and my informants. Often, tentative analyses have been tested and challenged in these conversations. Moreover, two of the articles included in the thesis (article 1 and 4) emerged from papers presented at a conference and a Ph.D. course. Although they have been revised and elaborated on as I have progressed through the study, at some point, the reality of research life has forced me to let go and move on to new themes to explore and write about. This means that my project has not been a neatly progressing process moving from data collection to analyses. Instead, reading, interviewing, writing, and analyzing have mutually informed each other in a hermeneutical, and, admittedly, messy process. Encouraged and prompted by pending Ph.D. courses, conferences, or merely the opportunity to present emerging ideas for my research group or for DIDA (who, naturally, have been eager to hear about my findings), I have been forced to engage with my material, and to generate ideas and arguments that would not have emerged without the effort of writing. In spite of the messiness of this approach, I believe that a more linear approach would have made it difficult to me to develop self-reflective and sensitizing accounts of my findings. For example, although I am not proud of my hesitant and inept process of including my personal experiences of loss in the context of research, the cultural significance of this process would not have been tangible without continually reflecting on and analyzing my material and my engagement with the field.

The downside of this messy, ongoing analytical approach is arguably a lack of overview over my data. If I had followed a more linear approach from data collection to analysis and writing, I might have structured my articles differently. Most noticeably, I might have analyzed more systematically how the participants relate to grief over time. As I have presented my data in the articles now, I have not been explicit about when they were collected, i.e., which round of interviews and how long after the loss the selected data are drawn from. For example, in article 4, "Grief as a border diagnosis", I discuss Mia's statements about not letting grief change her, or only for the better (as a contrast to pathological grief, which she asserts "makes you a lesser person"). Although Mia to some extent maintains this position across the interviews, her own experiences makes her reconsider some of her previous perspectives. In the second and third interview, she describes how she has given up on her initial attempts to not let their loss change her, and not missing out of anything because of their loss (e.g., being close to her sister in her pregnancy, enjoying other people's living babies, etc.). In spite of her attempts to avoid it, grief has changed her, her relationships, and her priorities. Instead of trying to please other people's expectations of not "cultivating grief", she insists on her right to continue a relationship with their dead daughter, allowing herself to be "more egoistic" (e.g., by declining invitations, allowing herself not to listen to her sister's complaints about pregnancy, etc.). Such observations of how grief experiences, interpretations, and acts change over time could have made an important contribution to the thesis.

My analytical approach has primarily been informed by inductive and data-driven strategies (Charmaz, 2006; Gibbs, 2007), in which themes are allowed to emerge from the data, rather than attempting to force the data into preconceived categories. I have read and re-read my interview transcripts several times, familiarized myself with the data, written comments in the margins, sorted into tentative, emerging themes, etc. (see example from transcript with comments in table 3, p. 76).

Again, this process can best be described as a hermeneutic process, in which I have moved back and forth between the whole and the parts of the interview material, from reading within interviews to reading across, and from single statements and passages to emerging themes. In this process, my reading of the material has also been informed by my theoretical and practical knowledge of the field, as I have recognized themes that have either confirmed, challenged, nuanced, or expanded my previous understandings. For example, while familiarizing myself within the literature on parental bereavement, I have recognized themes emerging in my own data, such as disenfranchisement or ambiguity. These themes were also familiar to me from my background as a bereavement counselor. However, through careful readings and re-readings of my own data, new understandings of how disenfranchisement and ambiguity processes are experienced have emerged, e.g. how parents not only passively find themselves victims of such processes, but also actively participate in the negotiation of their social realities. In a broader sense, the latter observation is also informed by the dialectical perspective on the relations between individual experiences and cultural practices provided by the analytical outlook of the thesis.

Instead of coding my data in a stringent way, I have used my comments as a means of condensing and interpreting the data (Kvale & Brinkmann, 2009). Informed by my comments, I have clustered recurrent themes in my materials, such as "diffuse norms concerning infant loss – replaceable vs. irreplaceable", "other people's expectations of grief as 'either-or'/'black-and-white' vs. bereaved parents' experiences of grief and joy as coexisting", etc. Neither of these tentative codes are derived from preexisting theoretical concepts, although often, I have been able to find existing literature that sheds light on the themes developing in my material (see e.g. the reference to Tony Walter's article in table 3). Although the coding has thus been primarily data driven, my interest in certain aspects of grief has arguably informed my interviewing as well as my reading of the material. For example, my interest in the situated, relational aspects of grief has shaped the questions I have asked, as well as the themes I have pursued and explored in the data. In order to explicate my active role in the interviews and analyzing process, I have developed reflexive codes (Gibbs, 2007) to address my own role in the process (e.g., codes that address normative assumptions implicated in my questions and remarks, interruptions, etc.). In acknowledgement of the situated, mediated, and processual character of meanings, my approach to the coding process has been as tentative heuristics, rather than as fixed and unambiguous meaning entities. Through the entire process, it has been a goal to develop sensitive accounts of bereaved parents' experiences, interpretations, and ways of living with the loss of an infant.

While striving for analytical insight, I have also attempted to broaden the scope of understanding by including evocative accounts of grief and loss, most notably in article 2, "Becoming a bereaved parent." Beyond facilitating a more creative and inspiring writing process, evocative presentations also have the potential to give vicarious access to other people's experiences in ways that a purely analytical account cannot provide. A purely analytical approach to an emotionally complex phenomenon such as grief is incapable of providing a comprehensive understanding of how grief is experienced and lived. On the other side, a purely evocative approach is equally incapable of grasping the complex social, cultural and material conditions that contribute to shape individual grief experiences. Hence, my ambition has been to balance between the analytical and the evocative, in order to create sensitizing and open-ended accounts of grief that promotes understanding, compassion, and empathy.

Interview excerpt:	**My comments:**
Chris: They don't understand that you can... miss your dead child so much... [Ester: Mm.] …and at the same time, run around in an amusement park with Carl [Lucas' younger brother] and be happy. [Ester: Mm.] You can't do that! You can't… [Linda: Mm, mm…] The world is simply too black and white [Ester: Mm.] in many people's way to… that's not possible.	Other people's expectations of grief as something that is incompatible with joy and happiness ("black and white") vs. bereaved parents' experiences of joy and grief as coexisting.
Linda: And that's why people, at least those *I* talk to and surround myself with in my family and such. If you talk about Lucas, it is with deep sorrow. [Ester: Yes.] It can't just be in a… [Chris: Mmm.] joyful way… Like, "I imagine [indistinctly] Lucas would have been fiery red haired," or whatever, right? [Ester: Yes.] Like that, just as a passing remark. Instead it's like, "Arghrrghp!" [Ester: Ah...] So then it's either, "Oh, no, phew, now we'll have to talk feelings, now we must be sad, now it is grief, etc." [Chris makes affirmative sounds.] In the middle of a merry moment or something.	A wish to include the dead child in conversations without drawing attention to the grief vs. other people's expectations that anything concerning their dead child involves "deep sorrow". Walter, 1996 ("Bereavement and Biography…"): Grief as construction of durable biography through talk with others who knew the deceased (more than emotional processing). Early infant loss: Diffuse loss – others did not know the child. Loss of past vs. loss of future. (Memories vs. dreams and expectations)
Chris: But-	
Ester: Yes, yes. Like then it becomes kind of a state of emergency.	(Interrupts.)
Linda: Yes, exactly.	
Chris: Yes, but it's probably also – try to think of how much we've worked to place Lucas on the right shelf. [Ester: Mmm.] All those around us need to place him on the right shelf too. And right now it's just black and white.	"Together they construct a story that places the dead within their lives" (Walter, 1996, p. 1). Chris expresses hope that this is possible through continuing conversations…

Table 3: Excerpt from interview transcript with comments.

5.4. STORIES OF LOVE AND LOSS: BRIEF PRESENTATIONS OF THE PARTICIPATING PARENTS

Before ending this chapter, I will briefly present fragments of the stories of the parents I have talked to during this project. It is important to emphasize that these are indeed only tiny glimpses into the realities of living with the loss of a child, primarily focusing on the immediate situation of going through the loss of a baby. Some of the following narratives are presented in modified versions in article 2, "Becoming a bereaved parent". Here, I will let all of the parents and their children be presented by a brief narrative, in order to provide some context and empathic resonance for the interview data presented in the articles.

Emma & John

Emma’s second pregnancy had been going so well—everything was perfect, and although she had been a bit worried about not gaining much weight, the midwives had reassured her that everything was just fine. Their entire family was anxious to have a new member; their little two-year old toddler was to be a big brother, and Emma’s sister was pregnant at the same time. As Emma puts it, “everything was just as it should be.” A few weeks before the expected birth, she gets a little worried. She has not felt the baby kicking for a while, and although a regular check at the midwife’s office a couple of days earlier showed no sign of warning, she ends up contacting the maternity ward “just to be reassured.” She is not. She remembers the words of the midwife who did the ultrasound: “The little heart has stopped beating.” At first, Emma recollects, she just wants it to be “overcome as quickly as possible.” John remembers that he “really just thought it was a pregnancy that had gone wrong; an abortion.” However, with the gentle guidance from the midwifes at the maternity ward, they get used to the idea of giving birth to their child, and they both remember the birth as a pleasant experience. Emma gives birth to a boy. Here, I call him Samuel. As his warm body lies quietly on her chest, he seems absolutely perfect. John recalls how the midwives congratulated them on their son. When I ask what this meant to him, he explains that it was “a part of the recognition that he was a real human being, and (…) he was our son”. At this point, Emma starts to cry. I look at her. “You’re tearful now”, I say. Emma sits quietly sobbing for a moment, before she speaks: “It’s just that… Of course, he was a real human being.” “Mmm…”, John says, and nods affirmatively.

Thomas & Anna

Thomas and Anna have been together for eight years when they decide to try to have a child. Anna gets pregnant “at first ovulation”, and as the morning sickness gradually fades, they are kind of laid back, not being too busy planning, although looking forward to what was going to happen. The birth is getting closer, and one day Anna notices that she has not felt the baby kicking as much as it used to. She has been told that it is quite normal in late pregnancy, so she does not become that worried, but calls the maternity ward just to be sure. They ask her to come by, and they “bring the camera with them – just in case.” Birth might be close now. First a midwifery student and then an experienced midwife tries to find the baby’s heart beat with the ultrasonic scanner, without success. Anna recollects that she was not panicking, as she still could not imagine anything being seriously wrong. Thomas, on the other hand, recalls that “it began to dawn” on him. They are prepared for birth, and Thomas remembers being “devastated, as far down as I have ever been.” Anna, however, was fully concentrated on giving birth, and recalls the birth as a “really good experience—I can really do this!” As their little son is born, Anna holds him by her chest, and feels like any other proud new mother. She recalls the midwife saying she had rarely seen a stillborn baby this beautiful. In the evening after the birth, Thomas sits with his son. As he puts his finger into Oliver's tiny palm and his little fingers don't squeeze back, Thomas is hit by the irretrievable reality. Their son is dead. They both stress how the midwives gently "showed the way" (a phrase they both repeatedly use) to how they could be together with their dead son. As Anna states, "it was so natural to be together with him. If anyone had told me they'd been together with their dead child from Monday to Thursday, I would have thought it was macabre, but… (…) It has really helped the attachment…" Their son was named during birth, as Thomas gives the midwife permission to call him the name they had been thinking of during pregnancy. In this thesis, I call him Oliver.

Linda & Chris

Linda and Chris start by telling me that their son—I call him Lucas—was "made with fertility treatment." After trying for two and a half years, pregnancy was going "fantastic." Due to a medical condition, Linda was having extra weight scans, but their "little football player" was doing fine, and as birth was getting closer, they were "excited as a child before Christmas." Lucas is born one week after the due date, and in spite of being a bit smaller than they expected, he is fine. After a few days in the hospital to get breastfeeding on track, they go home. Linda does not feel like sleeping. "I just lay there watching him. When I slept, you [Chris] held him. It felt safe. (…) Having my two boys in the living room. It was nice." At a point, though, they cannot get Lucas to eat, and as they are a little worried about his weight, they decide to call the "nursing hotline" for advice. The person they talk to advises them to wait until morning, where they are scheduled for an appointment anyway. However, Lucas seems to be getting worse. He is not responding to touch, and his skin color is changing, so Chris insists that they come in with him immediately. When this is rejected, he hangs up and calls 911. The ambulance crew takes over, and in a state of shock, Linda and Chris cooperate on getting to the hospital with their son: Linda in the ambulance, and Chris following after in their own car. In the days that follows, Linda and Chris stand by the side of his incubator, encouraging him to fight for his life. "I kept telling him about all the wonderful things that should happen when we got back home with him", Linda recalls, "how proud we were of him, how much we loved him, that he should fight, that we fought with him." The doctors cannot say what is wrong with Lucas, and he is getting more and more sick. After repeatedly having turned it down, Linda and Chris get to the point where they accept the offer of an emergency baptism. Shortly after the ceremony, Lucas is released from all the tubes that have been attached to his little body. "He breathes out in our arms," Linda says quietly. "It was how it was supposed to be, when it had to be like this. In that moment, our world fell apart."

Rita

Rita has been struggling with mental illness for many years when she meets her husband. She is in her late thirties when they meet, and they soon decide they want to have children together. Becoming pregnant turns out to be a struggle too. After two years of trying, including arduous periods of fertility treatment, Rita finally gets pregnant. During pregnancy, she attends a program for "vulnerable parents", due to her pre-history with mental illness. The process is hard on her, as she experiences it as an unduly "digging" into her problematic past. She is stressed out by it, and finds herself in a dilemma between wanting to back out of it, and at the same time being afraid of "closing the door" to potentially needed help during the pregnancy and afterwards. With her doctor's consent, she decides to quit the weekly appointments in the program, and "concentrate on being carefree pregnant," enjoying all the expectations, and planning for this very planned baby to come. Halfway through pregnancy, Rita's water suddenly cracks, and after two weeks in a hospital bed, fighting to delay a premature birth, Rita gives birth to a little girl. Here, I call her Lily. As they realize that the birth cannot be prevented, and that it is still too early to hope for Lily to survive, Rita focuses on giving her a gentle birth, and to experience as much as they can with her in the short time they might get with her. "In the middle of all the tragic and traumatic," she recalls, "all of a sudden there was something life-giving—after all—in all this darkness. So she was born, and… she was alive. And she was so beautiful and unharmed. Because I thought: The only thing I can do for her is to be good at giving birth to her, so she wouldn't have to suffer too much." Lily dies peacefully on Rita's chest shortly after birth, with her father's arms around her. "It was the right way to leave this world," Rita says with a trembling voice. "It means a lot, because we got the opportunity to become parents, even though we knew she wouldn't survive."

Paul & Sarah

Although Paul and Sarah had been trying for some time to get pregnant, they did not worry too much about it. After a year and a half, including a "brief detour" to a gynecologist, Sarah became pregnant, and everything was going "nice and quietly." Sarah had never regarded herself as especially fond of babies, and when she was younger, she was not sure she would want to have children of her own. As the baby started kicking, she was getting used to the thought of becoming a mother and to the fact that their world as they knew it was about to change for good. One day, about two months before the expected delivery, Sarah notices that her stomach feels a bit tense. As she is about to go to sleep, she cannot feel the baby kicking, and when she visits the toilet half an hour later, she faints onto the bathroom floor. Peter is away for a period because of his work, so she calls her parents-in-law, who live nearby. They take her to the hospital where a midwife tries in vain to find the baby's heartbeat. Doctors show up to do an ultrasound. Even before their final confirmation, Sarah knows it is over, and is already pondering what is going to happen now. They eventually succeed in getting in contact with Paul, who is rushed home by plane a few hours later, in due time to be there during the birth. Both their families are at the hospital when their little girl is born, and afterwards, they are happy that they all saw her: “[She] was an absolutely fine and healthy baby, just a bit small. Our families saw that. There was no doubt she was a child (…) Nobody has questioned our grief.” Their little girl got the name they both had been most keen on before the birth. Here, I call her Eva.

Mia & Jacob

Mia and Jacob have just met when they find out that Mia is pregnant. For a week or two, they are in doubt, lying awake at night: Are we going to have a baby? Shall it be us? An appointment with the doctor makes it “100% clear” that they did not want an abortion: “I don’t think it was a hard decision”, Jacob recalls. Time rushes away as they are planning for their new life together: moving together, meeting each other’s friends and families for the first time, and sharing the big news with them. Throughout the pregnancy, they exercise together, Mia with the doctor’s and midwife’s consent: “Pregnancy is not an illness.” However, by week 30, she has to take sick leave from work due to signs of threatening preterm labor. This passes, and a few days before the estimated date of delivery, they are invited to a family get-together a few hours away from home. Mia feels she is about to go into labor, but she is stoic, and does not say anything, although “the women who had given birth noticed.” It is Jacob’s mother who eventually suggests that they head homeward. In the car, Mia tells Jacob she has not felt the baby kicking for a while. They pull over, and Jacob puts his ear to her belly, as he has done so many times during the last months. This time, he cannot hear the little heart ticking. They call the hospital, and a midwife reassures them this is quite normal; “but if you’re really worried, you can come by.” Although Mia feels a bit stupid, Jacob insists they go by the maternity ward. Neither a stethoscope nor an ultrasound can find any heartbeat. Mia recalls: “I kept hoping. For me, it is not until the doctor scans me (…) and we can see that the little heart is all still, that I truly realize it. (…) Then everything stops. I go into shock. The contractions stop…” Jacob continues, “It’s the worst night of my life. It can’t be right. I still think that.” “Sometimes I think,” he says, turning to Mia, “have you been pregnant at all?”

After a few hours back home, they return to the hospital. Mia goes into labor. “It was beautiful—nice and quiet,” Mia recalls. “When I was about to give up,” she says to Jacob, “you encouraged me. It was like when we’ve been training together.” They have not decided on what to do when their little girl is born, but when it happens, they have no doubt. “Of course we should hold her,” Mia says. “That’s what they had recommended, although it would be okay if we didn’t want to. (…) All of a sudden, each second was really precious.” The first time I speak to Mia and Jacob, their little girl is called by an affectionate nickname. Later on, they decide to give her a real name. Here, I call her Sophie.

Eric & Diana

Two years before we meet, Eric and Diana become parents to their first child, William. Diana has dreamt of having a child for years, Eric tells me. The first night after birth, she can hardly sleep. She just lies there, looking at their little boy. She thinks his respiration is strange, but the hospital staff tells them not to worry: Newborn babies' breathing tend to be a little irregular. In the evening the day after he is born, William falls asleep during breastfeeding, and Diana lets him sleep. All of a sudden, she is worried: "Is he breathing?" she asks Eric, and as she hands him over to her husband, William's little body is motionless and limp. Eric runs out to call for help, and after some chaotic minutes, the doctors hurry to resuscitate William. He is brought back to life, but with severe brain damage. He is kept alive for five days before he dies, six days old. Eric recalls how often Diana has talked about the first 24 hours with William as the best time of her life. For months, William's death is unexplained, and when seeing parents walking their babies in their strollers, Diana wonders how they dare to. "We thought babies just stopped breathing", she recalls, "without any warning." However, after waiting for months, the final autopsy report lets them know that William was born with a rare disease that caused him to stop breathing. Getting an answer is a relief, especially because they are told that it is not a hereditary disease. At the same time, the extreme rarity of William's condition adds to the feeling of an incomprehensibly bad fortune. Eric recalls, "For so many years you wanted to have children. And then it happens, and he is fine and healthy, and then he just dies—all of a sudden. It is so incredibly unfortunate. I remember I thought so for a very long time afterwards, and I still think so. It's incomprehensible that it could happen. Still. Absolutely incomprehensible."

CHAPTER 6. “HERE EVERYBODY KNEW I WAS A PARENT”: GRIEF IN THE DANISH INFANT DEATH ASSOCIATION

> “As I entered [DIDA’s annual meeting], it was like everyone could *see* – I brought William with me. I mean, here everybody *knew* I was a mother. That I had a son. Because when you come there, you’ve lost someone, and everybody just knew. Of course, they didn’t know I had a *son*, but… That meant a lot to me. It was as if it was the first time I brought William with me out to show him to the world”
>
> (Diana, two years after the loss of her firstborn son).

Like many other bereaved parents, perhaps especially parents who have lost a child in the very beginning of life, Diana’s story testifies to the complexity of bereaved parental identity. In the months after their son’s death, she struggled with realizing that he had been there; that it had all happened; that it had not merely been a dream. She was a mother—or was she? Eric tells that she repeatedly asked herself (and him) this question. Consequently, their first visit to a DIDA gathering with other bereaved parents became crucial to her parental identity. Diana’s story of doubting and searching for confirmation of her parental identity is far from unique among the parents I have interviewed. As Dennis Klass (1988) notes, bereaved parents are faced with reestablishing themselves in a changed world (p. 99). This reestablishment involves their own identity as bereaved parents, their ways of interpreting and dealing with their loss, how to find a place for the loss and for their dead child, and how to see themselves in a future that is changed by the loss. For some parents, participating in DIDA’s services for bereaved parents becomes a part of the process of learning how to live with the loss. (For the sake of clarity, an overview of DIDA’s history, organizational structure, and services is presented in table 1 next page.)

In the next, I examine how DIDA’s services have been involved in these processes for the parents participating in my study. First, I examine how parental identity is mediated by the involvement in DIDA’s services. Second, I examine how the services may provide experiential repertoires for how to deal with and interpret the loss, and how the parents reflexively use these repertoires in their everyday lives. Third, I discuss how the parents relate to the authority of personal experience as a contrast to or supplement to professional expertise concerning grief and loss. Forth, I examine how the parents position themselves and navigate between the repertoires provided by the bereavement community and the “outside world” of their personal networks

DIDA’s history and organization:

DIDA emerged in 1983 as a subgroup within the association “Parents and Birth” [“Forældre og Fødsel”], initiated by a bereaved mother in order to improve support for bereaved parents after infant loss. In 1992, it was established as an independent, private, nationwide association under its current name. DIDA is a humanitarian membership-based organization with approx. 1000 members (bereaved parents and families), 70 volunteering members (bereaved parents who volunteer in peer-to-peer support services), and five employees at the secretariat (including the secretariat leader, three bereavement counselors, and one administrative employee). The board of the association, elected among the members at the annual general assembly, is responsible for making major decisions concerning the organization. Since 2004, Her Excellency Countess Alexandra Christina of Fredensborg has served as protector of the association.

DIDA’s services used by the participating parents in this study:

1. ***Counseling conversations*** with DIDA’s professional bereavement counselors (primarily telephonic, but also occasional face-to-face meetings). The counseling can consist of single or multiple conversations, depending on the bereaved parents’ situations and needs. According to DIDA’s web page, “the counseling can be used to talk about the loss […], gain insight in one’s own and other people’s reactions, get information about grief and grief reactions, […] rules and rights, hear about other people’s experiences from a similar situation, and get information about the association’s services.”[21]
2. ***Monthly meetings*** led by volunteers who have lost a child, all of which receive training and supervision from DIDA’s counselors. The meetings are open for parents and their grown-up friends and relatives. When I conducted the interviews, these meetings usually included a presentation round, where the parents were invited to tell their story, a presentation by a professional or a lay-person on a predefined topic, e.g. “celebrating Christmas without one’s child,” “communicating about grief,” etc., and a more open conversation based on presented topic or whatever the participants preferred to discuss.
3. ***Parental groups***, i.e., smaller, closed groups of 3-4 couples or single parents who are matched by DIDA’s counselors and who meet in each other’s homes. At the first four meetings, a volunteer from DIDA facilitates the conversation, after which the parents can choose to continue meeting each other on their own.
4. ***Annual meetings*** where the members of the organization (regular members, volunteers, and board members) meet to socialize, listen to presentations, etc. The annual meetings also include the general assembly of the organization, where the members elect the board and make decisions for the organization’s future.
5. ***Hospital based bereavement support group***, led by health care professionals who were initially trained and supervised by DIDA’s counselors (only one of the couples, Paul and Sarah, participated in this service.)

Other activities and services include weekend gatherings for bereaved parents, telephonic conversations with a volunteering contact person with the aim of providing identification and support, All Saints masses in churches all over the country where families can come and memorialize their dead children, public events such as a photo exhibition of bereaved parents’ tattoos, the opportunity to enroll in a team for DIDA in a public running event, etc.

Table 1: DIDA’s history, organizational structure, services and activities (at the time of the interviews).

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[21] DIDA’s web page: http://spaedbarnsdoed.dk/tilbud/radgivning/ (Accessed February 24th, 2017.)

and the wider culture. Fifth, I examine how DIDA's services provide resources for seeing oneself in the future, and how the parents' positions and roles within the services may change over time. Finally, I will briefly discuss some of the normative dilemmas involved in decisions about DIDA's practices, and how these decisions inevitably enable or restrict certain normative practices and interpretations related to infant loss, parental grief, and identity.

6.1. PARENTAL IDENTITY IN A COMMUNITY OF BEREAVED PARENTS

As I attempt to demonstrate in my second and third articles, bereaved parental identity in contemporary Western cultures is a continuous process mediated by diffuse and ambivalent, yet inescapably normative practices and understandings concerning infant loss and parental grief. Drawing on a Heideggerian existential-phenomenological perspective, Thomas Attig (2004) describes grief as a process of "learning practical ways to live meaningfully again through reshaping our daily life, redirecting our life story, and reestablishing connections with larger wholes of which we are a part" (p. 350). For some of the bereaved parents in my study, this process is mediated by practices and interpretive repertoires provided by DIDA. For many of the parents, coming to see themselves as belonging to a community of bereaved parents was not a straight-forward and easy process. Echoing a much-used Danish proverb, several of the parents express an initial feeling of being struck by something one usually thinks "only happens to one's neighbor," implying that we usually do not imagine bad things happening to ourselves. The identity as a bereaved parent is new, unfamiliar, and unsolicited, and the thought of identifying with others in such a situation can be overwhelming. As Dennis Klass (1988) frames it, entering and identifying with a community of other bereaved parents are accompanied by concerns of whether the people there are "like I want to be" (p. 104). These concerns are also present among the parents in my study. For example, Linda recalls how she imagined the other participants prior to their first participation in a DIDA meeting as "drug addicts and young mothers," i.e., someone radically different from herself. Likewise, Jacob describes their reluctance before entering the first meeting like this,

> "the first time we went there [to DIDA's monthly meeting], it was like 'we're not going there, are we? This only happens to somebody else!' That was difficult to begin with."

Several of the parents express similarly reluctant and ambivalent feelings concerning seeing themselves as members of such a community. On the one side, there is a comfort involved in belonging to a community and knowing that you are not alone. On the other side, it is a community you definitely do not want to belong to. In our last interview, I ask Linda and Chris to describe what DIDA has meant to them in the time following the loss of their son. Linda replies,

> ”To belong somewhere. I don’t know if that’s good or bad. I can’t figure that out. Because it’s a group you don’t want to be a part of. But then again, you *are*. And there’s just this sense of community. I mean, regardless of how close or far away you are from it [DIDA]… Now of course we’re a bit farther away from it, but… You still have this sense of belonging. You have a place.”

In spite of the initial reluctance, many of the parents emphasize that meeting others for the first time was a relieving experience. As Mia frames it,

> “You don’t feel alone, because all of a sudden you sit in a room with twenty other people who are all in the same boat.”

In fact, merely knowing that there is a community of bereaved individuals, represented by an organization, can provide a sense of comfort and recognition, because it proves that you are “not all alone in the world”, as several of my informants express it. Engaging in such a community may provide a sense of shared identity based on the shared condition and experiences, regardless of other differences between the participants. Due to the culturally contested nature of early infant loss, the existence of such a community may serve as an important social recognition of one’s loss and identity as a bereaved parent. As Diana’s quote in the introduction to this chapter illustrates, the recognition of one’s parental identity and dead child is implicitly present in the very existence of such a community, prior to any verbal expression of recognition. Whether one talks or not, belonging to a community of others who has similar experiences can be significant (Walter, 1999, p. 43). Chris illustrates how the mutual recognition of sharing the same fate enables ways of being together and talking about the loss that are difficult to achieve with others,

> “It’s like you don’t have to pre-explain a lot of things. Each time you meet new people who don’t know what this is, you feel you have to explain and elaborate on what kind of feelings… and that just makes it very, very… heavy. [Linda: Yes, and cold.] Yes, cold too, right? Then, when you enter the room for the first time at a meeting [in DIDA] and say ‘Okay, we’re here, let’s get started! We know what we’re up to’. That is relieving.”

Rather than merely focusing on the emotional distress involved in grieving, the bereavement community provides social recognition of the parents’ identity as bereaved parents. Moreover, by talking together and sharing experiences of being parents of dead children, their dead children gain social existence (Klass, 2006, p. 845). Several of the parents describe the comfort provided by other bereaved parents’ recognition of their dead children. While people outside the bereavement community often become silent when they talk about their children, the bereavement community represents a forum in which it is welcomed to talk and share stories of their children, remembering birthdays, etc. For example, several of the parents describe the special significance of other bereaved parents congratulating them on their children, instead of merely condoling their loss. Referring to another bereaved couple in her personal network, Linda says,

> "They were the first to say congratulations—congratulations on your son. Because they knew what it was all about."

By congratulating, in spite of the loss, the bereaved parents express their acknowledgment of the child's existence and the bereaved parents' parenthood. Likewise, many of the parents explain how new pregnancies are referred to in the bereavement community as their dead children becoming big brothers or sisters. In addition to being an acknowledgment of the dead children's continuous status as their parents' children, this is also used by many of the parents as a way to introduce a new pregnancy to outsiders, hereby stressing that a new pregnancy does not imply that they forget their dead children. This leads me to another issue, namely how the parents reflexively use DIDA's services and communities as experiential repertoires for dealing with and interpreting the loss in their everyday lives.

6.2. SHARING IDEAS AND EXPERIENCES, DEFINING ONE'S OWN WAY

> "If I shall try to explain how we used DIDA… I think it can be explained by… it's as if you walk in a dead alley. You don't know where you are, you don't know where you're going. So it's a kind of guidance, I think. What do other people do in this situation? Because the situation seems so hopeless. So it's nice to listen to someone who has been in the same situation."

(Eric, two years after the loss of their firstborn son)

In addition to providing interpretive repertoires for mediating one's relationship to oneself as a bereaved parent to a dead child, DIDA's activities also provide resources for dealing with all sorts of issues and dilemmas the parents are faced with in their everyday lives after the loss. As Eric's quote indicates, learning to live with the loss of an infant is an unknown and difficult territory to navigate in. Unclear cultural norms, lack of public acknowledgment, and few common rituals add to the experience of not knowing how to live with such a loss (Rando, 1992; Malacrida, 1998; Walter, 1999). In this situation, many bereaved parents search for guidance among others who are dealing with the same difficulties. Sometimes, merely being reassured that others have the same experiences is sufficient to provide comfort. Like Paul expresses it,

> "I can walk around with some frustrations and thoughts, and then there's someone sitting there [in the bereavement support group] with exactly the same, and then you think, 'okay, so it's probably okay to feel like this.' (…) Not because it's a goal to be normal, but just so you don't feel… all alone in the world."

Other times, listening to the other parents give more concrete ideas to how one can face the challenges and dilemmas involved in living with the loss. For example, several of the parents explain how listening to the other parents they have met through DIDA has given them ideas to what they can do in their continuing lives as bereaved parents. This may for example involve "how to include the dead child in the family without cultivating it," as Anna phrases it in our last conversation. Inspired by another mother participating in DIDA's monthly meetings, she and Thomas had decided to buy a candle holder to memorize Oliver. Such decisions are often described by the parents as carefully thought through in order to find out "if it fits" with their own values and norms for how to deal with their loss. As Anna explains it, "We've been inspired and then we have talked about what would feel right for us."

In my time as a counselor in DIDA, the role of the volunteering parents who lead these activities (the monthly meetings and the parental groups) was often discussed. The fact that they are not professionals, although they have a huge responsibility for leading these activities in a skillful way, was a frequently occurring concern among the counselors who were responsible for training and supervising them. One major concern was whether the volunteers unintentionally may come to imply normative assumptions of how to deal with loss based on their own notions of what constitutes "good grieving." In spite of a huge focus on this, the parents participating in my study do indeed testify to experiences of volunteers who express their own norms about grief. However, this does not seem to concern the parents. For example, Mia describes how the volunteers express their grief in different ways, someone by accepting the loss, others by expressing bitterness. When I ask how she experiences this, she states that it "provides a very realistic picture" of how grief can be. As she says, "You can certainly disagree with those who sit there [the volunteers], and make up your own mind."

Whether ideas and advice come from fellow participants or from the volunteers, the parents seem to reflectively use and negotiate them to fit with their own values and beliefs. In other words, rather than being passively shaped by normative standards imposed through DIDA, the parents mediate their own grief through the cultural repertoires provided through DIDA—as well as through the wider cultural practices the parents are situated in.

6.2.1. ACCEPTING DIFFERENCES AND INDIVIDUALIZING NORMALITY

Another subject that is often stressed by the parents is how participation in DIDA's services has played a role for how they relate to differences within the couple in dealing with the loss. For example, Linda describes the importance of "learning to accept that we are different, and that we grieve differently." This is so commonly described that I can probably find almost exactly the same quote in several of the interviews. Rather than explaining these differences in essentialist terms, most of the parents address this as a matter of different conditions for men and women. These include different rights concerning parental leave after the loss of a child, different cultural expectations and social support to fathers and mothers following infant loss, gender socialization concerning how to deal with emotional distress, as well as the different physical relationship to the child during pregnancy (this is interestingly almost exclusively addressed by the fathers). Although these differences are easily explained by the parents, learning to accept them is another matter. For example, in my conversation with Diana and Eric, Diana repeatedly stresses the importance of getting advice and information about these issues. She says,

> “[The bereavement counselor] clearly stressed that it is different how you react in grief. And that it was okay to react in the way that you do. One should accept it, right? (…) I remember Eric sometimes asked “What’s the normal thing to do here?” And then she said “Oh, but that is so different. Somebody does this and this”, and then she came up with some examples. But it’s important that you do it your own way – that you accept your own way.”

When I ask why this was important to her, Diana responds that she had felt “so enormously wrong.” She had been convinced that Eric’s way of dealing with the loss was “more right,” and that he was going through the loss more easily than her. However, the bereavement counselor reassured her that people grieve differently. Moreover, and perhaps at least as important, the counselor stressed that “just because you don’t cry, that doesn’t mean you’re not sad,” as Diana phrases it.

In terms of differences, the fathers sometimes say they have missed the presence of more men participating in the activities. As Thomas states, “it would have been nice if more men joined—that would bring up some other subjects… instead of—I don’t know… women’s stuff. As time went by, I felt it became less relevant for me to be there [at the monthly meetings].” When I ask him what he thinks could have made it more relevant for him and others like him to participate, he says, “I have good experiences with walking, for example. Instead of just sitting across to each other and talk feelings. *Do* something, you know. I guess it’s got something to do with gender socializing…”

John reflects on gender differences as well several times during our interviews. In our first conversation, he notes that he was intrigued by how one of DIDA’s counselors had been talking about gender at one of the monthly meetings. In contrast to his experiences and preconceptions, the counselor had stressed the individual character of grief and that there are no “male” or “female” ways of grieving. In our first conversation, John seems to doubt this interpretation. However, in our last conversation, he returns to this issue. He recalls that Emma had asked her psychologist, who had made it clear that there are indeed gender differences in grief. Nevertheless, John states, he appreciates that DIDA had stressed the individuality instead of the gender differences. When I ask him why he thinks so, he replies, “It would be terrible if someone sat there and were happy to be there and be normal…

Then it would be upsetting to be told that you're a minority by responding like you do." In other words, by stressing the individuality of grief, he asserts, the counselors in DIDA represent an including conception of normality, hereby allowing individual variation that cut across gender stereotypes. According to Tony Walter (1999), such rejection of popular cultural as well as clinical conceptions of grief is typical for what he terms mutual help groups in bereavement. On the one side, Walter asserts, such groups "typically reject popular culture with its notions of getting over grief in a matter of weeks, but on the other hand they typically also reject clinical lore with its notions of resolution, stages and normality" (p. 155). While "clinical lore" has arguably changed since Walter wrote this in 1999, conceptions of normality still mediate bereavement experiences. In DIDA's individually oriented normality conception (as it has been portrayed by the informants in my study), the organization seems to represent what Walter terms "a fourth kind of knowledge about bereavement, sometimes conflicting with both clinical lore and research findings, and almost always conflicting with popular culture" (Ibid.). In the following, I examine how this "fourth kind of knowledge", i.e., the personal experiences of bereaved parents, is used as a contrast to or supplement to professional expertise concerning grief and loss.

6.3. THE AUTHORITY OF PERSONAL EXPERIENCE

In line with Walter's (Ibid.) observations of the skepticism towards many of the popular and clinical conceptions of grief, most of the parents in my study emphasize the significance of experiential knowledge as a source for understanding and relating to grief. While sometimes relating to the experiential knowledge as supplementing professional knowledge, at other times they express more outright skepticism towards knowledge that is not rooted in personal experiences. For example, in our second conversation, Chris reflects on their expectations before attending their first monthly meeting in DIDA,

> "Before we drove out to the first parents evening [the monthly meeting], I remember we talked a lot about: "Have they tried this themselves? [Or] are they just – "just" – some experts sitting there, who have read some books about this? Or do they actually know what they're talking about?" It was very important – for me, at least – that they could tell their own story. And say "I know…" They know what it's all about. Then it becomes legitimate for them to talk about it. Because without doubt, for you [talking to Linda] – correct me if I'm wrong – but there's definitely a wall that comes down when someone hasn't tried it."

When I ask Chris and Linda whether they think there is a difference between what someone who has tried something similar is "allowed" to say, compared to someone who has not, Chris exclaims emphatically and with what I hear as a self-ironical twinkle,

> “Yes, definitely! Because we feel so special. We feel that this grief, you only know what you talk about if you’ve tried it yourself.”

Linda elaborates,

> “It’s like you belong to a group. Like if you have a disease, then you belong to this group. It’s a bit like putting it in a box, but you feel a bit like you belong to this group now, and that it is only those in this group that are allowed to talk about it or comment on how you feel, or…”
>
> Chris: “At least at that point. I think it’s easier now. Now I can talk to others as well.”
>
> Linda: “But still, nobody shall come and tell me how it really is…”

While others are less dismissive of the usefulness of professional support and knowledge, all of those who have participated in services that involves meeting other bereaved parents emphasize the importance of experiential knowledge. In our first conversation, Mia states,

> “I’ve been to a psychologist before, but in this process, I feel like I can talk with everybody about it. I don’t miss anyone to listen or who gives tools for coping, I miss someone who can say “I know how you feel”. I miss other mothers who says “Yes, my body does such and such. I also listen for my [dead] child”.

The parents alternately move between portraying the bereavement community as a supplement and as an alternative to “outsider’s” knowledge and support. Chris mentions how this to him has been a process developing from being dismissive of outsider’s attempts to understand their loss towards a more appreciative attitude. Likewise, several of the informants stress that while the bereavement support network has been crucial for learning how to live with the loss, this does not eliminate the importance of other people’s acknowledgment and support. In the following, I will address how the parents in this study navigate between the interpretive repertoires provided from “inside” and “outside” the bereavement community in their mediation of grief.

6.4. DIDA AS ALTERNATIVE INTERPRETIVE SOURCES TO POPULAR CULTURE’S GRIEF UNDERSTANDINGS

In their study of bereaved parents’ experiences of participating in bereavement communities, Gordon Riches and Pam Dawson (1996) emphasize how they repeatedly have been “struck (…) by the strength of the boundary between those who have been through the experience of child bereavement and those who have not, and by the strong identification by parents of a community of 'insiders'" (p. 145). In similar veins, Paul C. Rosenblatt (2000) talks of a "chasm" between bereaved parents and other people (p. 93), and Dennis Klass (1988) notes that "[sometimes] there seems to be a rather strange feeling of estrangement from the natural support system that moves people to find a place where they will fit in" (p. 102). According to the American sociologist David Karp (1996), a commonly described function of "subcultures among disvalued groups is to provide support for alternative, non-stigmatizing, definitions of their common circumstance" (p. 47).

To a certain extent, my interviews with the parents participating in this study echoes such findings. However, rather than describing their relationship to the bereavement community and to the 'outside world' as fixed and unambiguous, the parents seem to navigate and draw upon interpretive resources available to them in multiple and highly individual ways. For example, in my first interview with Mia and Jacob, they both express how it is important to them "not to get too far away from the normal," and to avoid "cultivating" and being stuck in their grief. To this endeavor, they actively draw upon cultural conceptions of normality and pathology that are available through communication with their family, health care professionals, etc. They also draw upon what they see as negative examples of coping which they have encountered during their participation in DIDA's services, as well as in a bereaved friend whose grief they repeatedly refer to as "their worst horror scenario." However, they also describe examples of how their attempts to mediate their grief through these conceptions of normality have failed, and how participation in DIDA's services has served as alternative sources to mediate these experiences. Mia explains,

> "We chose to pull the plug and celebrate New Year's Eve alone, just Jacob and me. Our parents said they understood, but I could sense that they were a bit worried. And then, in the group [DIDA], of course *nobody* had celebrated New Year's Eve. We had at least dressed up. (…) The others had *really* pulled the plug. We have tried to seem as strong as possible. Not that there hasn't been room for a little tear, but we've been so busy becoming as normal as possible again… To avoid this label of being those who have lost."

Although Mia and Jacob at times distance themselves from how the other participants relate to their loss, the bereavement community nevertheless serves as an interpretational repertoire for understanding and relating to their own experiences and societal expectations. At other times, the parents portray their participation in DIDA's services as a "safe base" that prepare them to engage with the outside world, without necessarily feeling estranged from this outside world. For example, in our second conversation, Chris states,

> "Those around us, they don't really get it… But now I can meet the world. Perhaps because I have a safe base in DIDA. So, when the world gets too stupid and moves on too fast, then once a month I am allowed to stop and

> say, ‘phew! I’m still here.’ I think that’s what *I* use it for. I can feel now, at work, that things are moving fast now. In the first two or three weeks, I had colleagues who were immensely good at covering me. Now, the train is moving.”

While DIDA’s services might serve as alternatives to cultural norms that the parents find difficult or undesirable to strive for, the implicit norms of the bereavement community might also at times be experienced as problematic for the parents. For example, Thomas and Anna repeatedly mention how the atmosphere at the monthly meetings has involved a sense of normative pressure towards expressing their grief in a certain way. In our second conversation, Anna explains it like this,

> Anna: “[With some of] the other participants, you can barely hear what they say, because they cry so much. Then it’s difficult when it’s my turn.”
>
> Me: “You feel there’s a normative pressure?”
>
> Anna: “Exactly. Should I sort out the positive things, and talk more about the difficult, dark things?”

They both stress the volunteers’ role in creating this atmosphere. As Thomas describes it, “I get so tired of that overly pedagogical voice going ‘Now I will tell you… two years ago, I lost…’” Anna laughs and finishes his sentence, “veeery slow… now it’s *really* dark and sad!” When I ask them what they feel this invites to, Anna states that she feels an expectation of “having some feelings you don’t have, like they want you to say something specific.” At the same time, they acknowledge, the volunteers’ task is a difficult one, insofar as they cannot be too upbeat either. In any case, Thomas’ and Anna’s example illustrates how grieving is a socially situated, normative practice that involves active “emotion work” and negotiations of situated “feeling rules” (Hochschild, 1979; see also chapter 1, “Defining the subject matter” (pp. 10-11)). Although reflected upon and contested in our conversation, it is likely that the experience of the feeling rules of the situation is rather tacit and unreflected. The rules and normative demands of the situation are sensed as an affective atmosphere (Slaby, 2016) that enables and inhibits, encourages and discourages specific enactments of grief (cf. chapter 2, “Grief as emotional practices” (pp. 18-21)).

6.5. SEEING ONESELF IN THE FUTURE

> “As a matter of fact, what took up most energy in the time after Michael died was perhaps: ‘Can you really have a normal life?’ (…) You kind of grope in the dark, thinking ‘Now everything just falls apart.’ Perhaps you looked for some inspiration… Perhaps we searched for an image of how the future could look like… In reality, right?”

(Eric, 2 years after the loss of their firstborn son).

As I illustrate in my second article, “Becoming a bereaved parent,” parental identity after infant loss is an ongoing, culturally mediated process. Relearning the world (Attig, 2004) and developing “a durable biography that enables the living to integrate the memory of the dead into their ongoing lives” (Walter, 1996, p. 7) take time and effort. In the following, I examine how DIDA’s services provide resources for seeing oneself in the future, and how the parents’ positions and roles within the services may change over time. In his ethnographic work on bereaved parents in a bereavement network, Dennis Klass (1988) stresses that developing an identity as a bereaved parent and imagining the future after the loss of a child is a painful and frightening process. For some parents, he notes, “the discovery that the new self can be socially validated within a group of others who share the same condition provides a beginning place to rebuild” (Ibid., p. 105). Eric’s quote above echoes this observation, and illustrates how other bereaved parents may serve as examples of how one might live with the loss and enact a parental identity over time.

Throughout the interviews, the fear of forgetting the loss, the grief, and the dead child is a frequently occurring theme. Several of the parents mention how this fear has been alleviated by meeting parents who have been living with the loss for a longer time. For example, in our first conversation, John says,

> “What I feared the most after the first days, when you didn’t cry all the time, that was that I would forget it really fast. Because then I feel I would have lost everything. So the fact that there are someone sitting there [at DIDA’s monthly meetings] who has lost… I think it was nine years ago, and who also had reacted like this—returned to work fast and such. But that they still haven’t lost everything—they still have the memories and such… That makes me feel more safe about it.”

Likewise, his wife Emma explains how she felt “almost high” after their first meeting in DIDA, because listening to the other parents had given her hope that they might indeed learn to live with their loss without forgetting. There are different ways in which these other parents may serve as resources for seeing oneself in the future. First, the circumstances of their lives, e.g., whether they seem able to live what Eric terms “normal lives,” parent living children, etc., may give hope that this is possible to achieve. At the same time, the fact that these parents still are engaged in DIDA illustrates that the loss is not left behind. In this way, these parents provide images of how bereaved parental identity may be enacted, and how their dead children may become a continuing presence in their ongoing lives. For example, in our first conversation, Thomas says he thinks it is nice to hear someone (at DIDA’s monthly meetings) saying that they still feel sad about their loss five years after it happened. When I ask why he thinks this is nice, he responds, “Because then you obviously don’t forget.”

At other times, those who have lived with their loss for a longer time may provide hope that the pain of grief will be less intense and give space for more positive emotions over time. As Mia states in our first conversation,

> “It’s nice to see how they [the volunteers at DIDA’s monthly meetings] deal with their grief today. Because, for us, when we visit the cemetery, it’s still really tough. When they go to the cemetery, it’s a joyful and pleasant thing. I look forward to that. I don’t doubt that we’ll get there, it will just take some years. It’s nice to hear that they’ve all gotten there. In that sense, they are a sort of role models.”

Over time, the parents’ own role in the bereavement communities may change as well, as they gradually become more experienced and newcomers enter into the group (this is relevant for DIDA’s monthly meetings and the hospital based support group). The open structure of these groups enables “new” and “older” members of the group to share experiences, the older being able to identify their own progression since their loss, and the newer members to imagine their own future through identifying with the older members of the group. For example, in our second conversation, Sarah and Paul describe how their role in the hospital based grief group changed over time,

> Sarah: “You kind of become the experienced one who are able to say: ‘Oh yes, we recognize that”, and “We felt like that too”. You become kind of…”
>
> Paul: “Yes, when we were there for the first time, we thought ‘We’ll never get through this’, right? And then there’s someone there who has been there for two months or something like that, right. And then you can say “Well, they seem quite normal, so I suppose we’ll make it too, after all.”
>
> Sarah: “Yes. So you kind of become the supportive one, instead of gaining so much from it yourself… after some time, right?”

The hospital group differs from DIDA’s community based activities insofar as they are led by health care professionals, and that participation in the group is typically limited to a few months, after which the parents gradually are prepared to “stand on their own feet,” as Sarah describes it. This means that the parents typically won’t meet other parents who have lost several years ago, like they might often do in DIDA’s volunteer-led activities. Some of the parents who have participated in these services express thoughts of “giving something back” by volunteering in the organization at a later point. Like Linda says in our second conversation (she also repeats this point in our third conversation a year later),

> “We’ve talked about involving as volunteers at some point in the future. Because we’ve benefited so much from it. So we’d like to share our… what *we* have learned, and what *we* can contribute with to people who lose

> [a child], right? Because it has meant so much to *us.* I could certainly see myself, at some point when I am ready to... deal with other people's grief."

Linda's last sentence points to a central conflict in relation to participating in community based grief support services. Although meeting others in a similar situation can often be experienced as comforting, and as a source of social validation of one's loss and parental identity, being confronted with other people's loss and grief can also be emotionally overwhelming. This is an inherent conflict involved in putting people together based on shared, traumatic circumstances. For several of the parents I have talked to, the need to protect themselves from being exposed to "new losses" before they feel ready for it has been one of the main reasons for not continuing going to monthly meetings, attending weekend seminars, etc. Instead, some of them have continued to meet in private with parents they have met through DIDA's activities, sometimes by developing new friendships based on a very special kind of mutual understanding. For example, Diana describes their relationship to a couple they met at DIDA's weekend seminar, a little less than two years before our conversation,

> "It's strange how fast you can become this close to each other. Because it feels like we've been friends for *years*. Which we haven't, really."

For other parents, DIDA becomes what Benedict Anderson (1993) has termed an "imagined community." Although they might not interact much with the organization in their daily lives, the organization may maintain a special significance for their identity as bereaved parents, as a place where they "belong," as Linda and Chris repeatedly express it.

Some of the parents stress the importance of DIDA as a site for raising public awareness about infant loss and parental grief. More than merely providing immediate support to bereaved parents after infant loss, they emphasize that the organization ought to represent bereaved parents' interest in the society. For example, Linda and Chris talk about the importance of creating societal awareness and recognition of infant loss and parental grief, and how DIDA might work to promote this through, e.g., cooperating with television companies about producing documentary programs about infant loss, by arranging public memorial ceremonies etc. Chris states,

> "It's about emphasizing… to say: 'We are here too. Recognize us!' Why shall it be so much of Robinson and Paradise Hotel? I mean: Recognize us, too!"

This is indeed also one of the organization's declared goals, expressed for example in awareness campaigns, events, and in their contributions to media coverage on infant loss and parental grief. In addition to the immediate support represented through counseling and network services, the organization represents a shared platform for creating public awareness and recognition of infant loss and parental grief. As such, parental engagement in DIDA may range from using the organization's services as mediators in one’s own grief, sharing and “giving back” personal experiences, and fighting for public awareness and recognition. In his autoethnographic essay about the loss of his stillborn daughter, Marcus Weaver-Hightower (2012) describes how one of his “reactions to grief—which, along with philanthropy, seems quite common among the bereaved [Cook, 1988, 299]—included becoming politically active on stillbirth issues, involving actions like writing legislators, calling businesses about their problematic practices, contributing financially to political action, and speaking publicly as a father as often as I could” (p. 479). Although Weaver-Hightower slightly self-ironically refers to these initiatives as “grief reactions,” it is obvious that such actions are normative practices that certainly does not merely “happen” to you as a cause of loss. For most bereaved parents, pursuing such motivations may be too demanding to do alone. Hence, involving in or supporting the work of a bereavement organization can be a way to fight for public recognition of infant loss and parental grief—simultaneously helping others in a similar situation and honoring one’s own child’s existence.

6.6. THE NORMATIVITY OF BEREAVEMENT SUPPORT PRACTICES

From my experiences as a counselor in DIDA as well as through my continuous encounters with the organization during my Ph.D. project, I have been involved in many conversations and reflections about the normativity inherent in the organization’s practices. Just like the parents struggle with finding good ways to deal with their loss and their changed identities over time, so does the bereavement organization face normative dilemmas in their practices. Working with bereavement is inescapably normative, and regardless of which decisions that are made, these decisions will inevitably enable and restrict certain practices, ways of interpreting, and ways of feeling about loss for the parents who are engaged in the practices.

Surprisingly often, some of the most pressing normative dilemmas seem to be related to very mundane and material conditions, such as whether or not to put a candle light in the grief support kit handed out at the hospitals to newly bereaved parents. While this might seem like an insignificant detail, these kinds of decisions are loaded with ethical dilemmas: Is giving a candle a way to signal recognition of the parents’ loss and grief? Or does it impose a normative pressure on the parents to engage in certain interpretations and practices related to their loss? Will the box set without the candle seem sterile and distanced, compared to a box set including a candle? There are no easy solutions to such dilemmas.

Similar dilemmas unfold in a range of daily decisions within the organization. Each year, DIDA arranges All Saints masses (memorial services) in remembrance of deceased children in churches all over the country. In some of the local churches, the volunteers and/or the priest have suggested to set up a memorial wall by the entrance where those attending the ceremony can choose to hang a picture, a poem or another token to commemorate their dead children. However, this practice has given rise to careful considerations within the organization about its implicit normativity. For many parents, the opportunity to publicly share pictures and memories of their children is experienced as a much-welcomed acknowledgment of their loss. On the other side, inviting to such a practice may also represent a normative expectation to enact one's grief and loss in accordance with a norm of continuing bonds, and indirectly questioning the grief of those who live with their loss in other ways. Moreover, the practice may also reinforce unofficial grief hierarchies between the parents, insofar as they inevitably are invited to compare their own loss with the loss of the other parents. While the official dogma in DIDA is that "you cannot compare grief," i.e., parental grief cannot be measured or quantified by the circumstances of the loss, the parents who use DIDA's services inevitably do compare with each other. Hence, whether or not DIDA choose to set up a memorial wall, the parents are invited into inherently normative practices of enacting and interpreting their loss and parental identities.

Another illustration of the normative nature of DIDA's services and activities is a photo exhibition DIDA arranged in 2015 with pictures of bereaved parents' tattoos created in memory of their dead children.[22] Through this photo exhibition, DIDA's ambition was to "create visibility about losing a child and abolish taboos about grief in general and infant death in particular" (DIDA's newsletter, June 2015). Regardless of the good intentions, such an exhibition inevitably involves normative dilemmas similar to those I illustrated above. While the tattoo campaign is a very efficient way to communicate the significance of early infant loss, it's identification of parental love with physical imprints on the body can be experienced as a strong normative expectation for bereaved parents. Although I was not aware of the campaign when I conducted my interviews, Anna refers to it in our last conversation. Her thoughts about such memorial tattoos clearly illustrate the normative implications of such initiatives:

> "I read an article [in DIDA's newsletter] of people getting tattoos with something about their children. I could relate to getting a tattoo of a hand print or whatever. But I couldn't understand why they would want to place it where it is visible [to others]. And then I thought: 'Why are you so opposed to that, Anna? Why won't you attribute that significance to Oliver?'"

Anna's reflections illustrate that such a campaign—or any other initiative aimed at helping bereaved parents—is involved in normative interpretations and practices in multiple and highly individual ways. Rather than striving to eliminate the normative

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[22] See media coverage in Kristeligt Dagblad, August 25th, 2015: "Tattoos help parents in their grief over their dead children" ["Tatoveringer hjælper forældre i sorgen over deres døde børn"]. https://www.kristeligt-dagblad.dk/kirke-tro/tatoveringer-hjaelper-foraeldre-i-sorgen-over-deres-doede-barn (Retrieved February 20th, 2017.)

dilemmas involved in such practices, I believe it is essential for organizations such as DIDA to constantly engage in self-reflective awareness of the normative implications of their practices.

6.7. CONCLUDING REMARKS

For some bereaved parents, DIDA’s activities become a part of their process of living with the loss, developing identities as bereaved parents, and gaining social validation of their dead children’s existence and significance. Throughout this process, the parents are informed by—but also reflectively draw upon, negotiate, and contest—the normative interpretations and practices that are available in DIDA as well as in the “outside” world to create their “own way” of living with the loss. The community of bereaved parents provides resources for mediating their way of living with the loss here and now, as well as towards the future. The parents’ involvement in DIDA includes mediating their own loss and grief, receiving and providing support, and fighting for public awareness and recognition. The practices provided by an organization such as DIDA are inherently normative, and, accordingly, those responsible for developing and maintaining these practices need to pay attention to the normative implications and dilemmas involved in this endeavor.

CHAPTER 7. FROM MORALITY TO PATHOLOGY: A BRIEF HISTORIZATION OF CONTEMPORARY WESTERN GRIEF PRACTICES AND UNDERSTANDINGS

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From Morality to Pathology: A Brief Historization of Contemporary Western Grief Practices and Understandings

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Abstract

In this paper I present three ideal typical grief articulations drawn from three historical periods: 1) Grief as a moral practice in Ancient Greek virtue ethics, 2) Grief as an expression of an inner, authentic morality in the Romantic era, and, 3) Grief as a psychologized and increasingly pathologized phenomenon in modern psychology up to the present attempts to include separate diagnoses for pathological grief in the diagnostic manuals for mental disorders (American Psychiatric Association, 2013; World Health Organization, 2016). The purpose of this presentation is to shed light on current taken for granted notions of grief, and, by providing some historical background, challenge prevailing understandings that depict grief as an ahistorical, universal, intra-psychological and (potentially) medical condition that is analytically separate from historical, social, cultural and religious practices. Informed by a cultural psychological outlook (Brinkmann, 2016; Valsiner, 2014), I argue that the relationship between grieving individuals and their cultures is dialectical, mutually constituting and inherently normative, and hence, that the diagnostic approach to grief as an individual, causal reaction to loss is flawed. On this background, I argue that an acknowledgement of the inherent normativity of grief (as presented by the historical accounts) can potentially inform and enrich contemporary understandings and practices related to bereavement, ultimately to the benefit of people who suffer from grief.

Keywords: grief, loss, mental illness, diagnostic cultures, historical transformations, pathologization

Introduction

Historically, grief in most societies has been articulated and interpreted within a metaphysical framework of religion, providing rituals for experiencing and acting in relation to loss. By contrast, grief in the late modern era is increasingly becoming a subject of psychiatry and psychology – a matter of individuals' mental and physical health and risk of pathology (Stroebe, Schut, & Stroebe, 2007; Stroebe & Stroebe, 1987). During the last decades, several leading research groups within the field of bereavement have advocated for the introduction of separate diagnostic categories for pathological grief reactions (Horowitz, Bonnanno & Holen, 1993; Prigerson et al., 2009; Shear et al., 2011). The understanding of grief as a potentially pathological phenomenon can be seen as an example of how bio-medical, psychiatric, and diagnostic understandings are becoming increasingly central for how we deal with suffering and deviance in contemporary Western "diagnostic cultures" (Brinkmann, 2016). My aim in this article is to use historical examples of how death, dying and bereavement have been accounted for in different historical eras in order to shed light on the implicit assumptions underlying our contemporary understandings of grief. In the words of Michel Foucault: *"We have to know the historical conditions which motivate our conceptualization. We need a historical awareness of our present circumstance"* (Foucault, 1982, p. 209).

The historical examples are selected with the purpose of challenging current taken for granted notions of grief, rather than providing a thorough analysis of the examples and the complex historical conditions they are embedded in. By focusing mainly on philosophical and literary sources, I do not claim to say anything about the actual distribution or meanings of grief practices in the periods referred to. Instead, the presented perspectives should be read as *ideal types* (Weber, 1904/1949), i.e., sketchy analytical constructs intended to illuminate certain characteristic phenomena of each presented period. More specifically, I will limit myself to delve into three selected sources drawn from pre-modern philosophy, Romanticism and modern psychological and psychiatric bereavement research, in order to present different historical conceptions of grief, demonstrate the historical embeddedness of our contemporary understandings and practices, and discuss potential benefits and problems of the different accounts presented throughout the article.

Initially, I address grief as a *moral practice* in pre-modern times, with examples drawn from Ancient Greek virtue ethics. Subsequently, after a brief review of the historical transformations of the death practices throughout the Middle Ages, I explore how Romanticism might be seen as a transitional phase between a pre-modern and an emerging modern worldview. During this period, the morality of grief was relocated from external to internal sources – a transition that heralded the depiction of grief as a natural and psychological process in modern psychology. Following this historical trajectory, I analyze how grief is transformed into a *pathologized phenomenon* in contemporary late modernity, where it has become a full-fledged subject of psychiatric research and diagnostics.

In an attempt to limit a potentially very broad scope of analysis, non-Western traditions concerning death and mourning are omitted from the present analysis, although such an inclusion would indisputably enrich our understandings of contemporary Western grief practices. (For such analyses, see e.g. Scheper-Hughes, 1993; Rosenblatt, 2001). By focusing on how contemporary practices and understanding have a cultural history, I will try to avoid the interpretive fallacy of analyzing historical practices through "the view from the present" (Hockey, 1996). In other words, my aim is to develop a historical awareness of contemporary practices, as well as an awareness of how our contemporary understandings affect how we read and interpret the practices of other places and times. Indeed, as I will try to elaborate later, our contemporary inclination to see grief as the main concern of death has a history too, as do our preoccupation with, for example, the health outcomes of different grief practices. Several researchers within the field of bereavement and death studies have warned against interpreting the accounts of earlier practices through the lenses of contemporary psychologized understandings (Hockey, 1996; Rosenblatt, 2001). Hence, my aim with the present historical account is not to argue that former practices were better at promoting health and well-being, but rather to provide some historical background for understanding how the very question of health has become a main focus of contemporary understandings of grief.

A cultural psychological outlook

The theoretical outlook for this analysis is informed by cultural psychology (Brinkmann, 2016; Valsiner, 2014). Cultural psychology addresses the relationship between persons and cultures as a *dialectical* rather than a dualistic one, and emphasizes the *historicity* and *processual* character of mental and cultural phenomena. From a cultural psychological perspective, neither cultures nor minds should be understood as variables with causal powers. Only *persons* – not cultures, brains or minds – are capable of thinking, feeling and acting. Instead of conceiving cultures as independent variables that affect human behavior, cultures are conceived as *mediators:* Tools (e.g., language, material artifacts, practices) that mediate persons' capacity for thinking, feeling and acting. Mediators are not entirely the same as means, insofar as means indicate a realization of a priori intentions, "whereas mediators at once constitute and transform the intentions that they carry" (Brinkmann, 2016, p. 16). For example, I can only strive for "mindfulness" in my daily life insofar as I have access to a certain language, certain practices (e.g., meditation, specific "mindfulness exercises") and technologies (e.g., a yoga mat, mindfulness books and courses, means of creating a quiet space, etc.).

Furthermore, cultural psychology conceives of the mind as *normative:* Psychological phenomena like thinking, feeling and acting differ from physiological phenomena insofar as only the former are (and can be) subject to normative appraisal. For example, although both fear and stomach ache have physiological expressions and experiential qualities, only the former can be subject to praise and blame. (E.g., while it makes sense to say that fear is legitimate or illegitimate, depending on the situation, it is meaningless to attribute such normative judgments to stomach aches.) In sum, the cultural psychological outlook that informs the following analysis stresses the interrelated and normative nature of psychological and cultural processes, and insists that neither can be understood as independent variables with causal agency.

Ancient Greek philosophy: Grief as a moral practice

In pre-modern times, death and loss – like all other aspects of human existence – were interpreted within a cosmological framework that provided guidelines for people's actions and interpretations. A central subject of ancient Greek moral philosophy was the idea of virtues as moral guidelines for human action (e.g., the cardinal virtues: wisdom, justice, courage, and temperance). In relation to death and loss, Plato's writings on the death of Socrates might serve as an illustration of how Plato conceived emotionality as something that needed to be regulated and subjected to reason:

> Up to that time we had been able to restrain our tears fairly well, but when we watched him drinking and saw that he had drunk the poison, we could do so no longer, but in spite of myself my tears ran down in floods, so that I wrapped myself in my cloak and wept for my self; for it was not for him that I wept, but for my own misfortune in being deprived of such a friend. Crito had got up and gone away even before I did, because he could not restrain his tears. But Apollodorus, who had been weeping all the time before, then wailed aloud in his grief and made us all break down, except Socrates himself. But he said, "What conduct is this, you strange men! I sent the women away chiefly for this very reason, that they might not behave in this absurd way; for I have heard that it is best to die in silence. Keep quiet and be brave." Then we were ashamed and controlled our tears (Plato, Phaedo 117 c-e, trans. 1914).

The passage reflects Plato's concern with the "blindness" and involuntary aspects of emotions, and the primacy of reason over passion in his moral philosophy. Although the Aristotelian virtue ethics also gives primacy to reason over passion, the Aristotelian conception of the relationship between reason and passion is somewhat more complex. The guiding question in the Aristotelian virtue ethics is *'What constitutes the good life of man?'*. In accordance with the teleological approach of Aristotelian philosophy, the answer to this question should be found by clarifying the proper function (*telos*; purpose) of man – what it means for human beings to work at their best as human beings. Aristotle gives a universal answer: The proper function of man is *"activity of soul in accordance with virtue"* (Nicomachean Ethics, book 1, 7). In other words, living a good life was not a matter of seeking subjective pleasure or finding one's own unique purpose in life, but of realizing one's potentials as a human being, by cultivating virtues that were commonly acknowledged as good and praiseworthy. To develop virtue was an act of developing good judgment in particular situations, of finding the right balance (the golden mean) between too much and too little of the trait that is called for in the particular situation: To act courageously would mean to balance between acting cowardly and foolhardily, practicing temperance to find the proper balance between asceticism and overindulgence, etc. (Johansen & Vetlesen, 1996).

In order to elaborate on the implications of this for the topic of grieving, it is necessary to consider Aristotle's view on emotions in relation to virtue. In contrast to the Platonic view of emotions, Aristotle emphasized the *intentional* aspects of emotions. According to Aristotle, emotions are not mere passive reactions towards what happens in our lives. Rather, emotion, perception and intellectual understanding should interact and guide each other, and must be cultivated properly in order to develop virtue. Hence, to extrapolate to the topic of grief, the emotional pain involved in grieving should not merely be understood as an involuntary and adverse *reaction* to the loss. On the contrary, a person who realizes intellectually that a beloved person is dead, but who does not respond with grief, lacks something significant of what Aristotle calls moral virtue. Without an emotional responsiveness, our understanding of situations and phenomena in the world is substantially deficient (Vetlesen & Nortvedt, 1997). Emotional reactions to loss should indeed be subject to voluntary regulation and cultivation. Rather than conceiving grief as a matter of authentic expression of emotional reactions, grieving must be seen as a *moral practice* involving a reflective mediation of emotional responses in accordance with moral values. Hence, the feelings accompanying loss are necessary, but not sufficient, to guide the bereaved individual, and (contrary to what seems to be widely held conceptions of grief in contemporary Western societies) the emotional aspects of grieving are not merely something that involuntarily *strikes* people as a causal reaction to loss. Rather, the emotional, perceptual and intellectual aspects of loss should mutually guide each other in order to grieve properly.

Our death, my death, thy death: The changing conceptions of death and dying in Medieval Europe

The French historian of mentalities, Philippe Ariès, has conducted some of the most thorough and prominent analyses of the historical transformations of the conceptions and practices related to death and dying in the Western world. According to Ariès, the practices and conceptions of death, dying, and mourning have gone through a series of subtle, yet significant changes throughout the history of the Western cultures (1974). In contemporary Western cultures, we are inclined to think about time as a linear movement from the past, through the present, towards the future. In contrast to this, the Medieval man did not differentiate strongly between the past, present and future: The past was, like the present, merely a time "in between" (i.e., *medieval*) the Creation on the one side, and the resurrection of Christ and the final judgement on the other. Hence, the living and the dead existed in a shared time, awaiting the resurrection and judgement day, and the people of the Middle Ages were connected to the dead through prayers and requiem masses (Mai, 2010). In the first phase of the Middle Ages, death was omnipresent and expected, and hence, according to Ariès, the rituals associated with dying were simple and non-dramatic. Ariès called this period *the tamed death* (1974, p. 14). During this period, people's relationship with death was characterized by a straight-forward and non-dramatic acceptance of death as a common destiny. From approximately the 12th century, death increasingly became a question of *the individual person's* salvation or perdition. Ariès referred to this as *one's own death* (p. 52). During this period, we see the emerging contours of the modern individual, with its emphasis on the individuals' responsibility for his or her personal destiny. During both of these two periods, however, death was primarily conceived of as something that concerned the destiny of the dead or dying person, rather than the destiny of the survivors. From the beginning of the 18th Century, this began to change, according to Ariès. With the emergence of the Romantic Era, the focus was turned toward the survivors and their grief over the loss of their beloved – *thy death*, as Ariès termed this period (p. 68). In other words, with the Romantics, *grief* came to the front as the most salient concern in Western man's relation to death and dying.

Romanticism: Grief as an expression of an inner morality

The Greek Antiquity and the Medieval period both represent historical periods in which human practices concerning death, suffering, and distress took place within a shared cosmological framework. With the secularization processes that took place in Western Europe from the Renaissance and onwards, and the proliferation of the rationalist ideas of the Enlightenment, the inevitability of these cosmological frameworks were gradually challenged and questioned. The emergence of the Romantic Era in Western Europe from the latter half of the 18th Century can be seen as a culmination of these processes. In a disenchanted world (Weber, 1946), the Romantics turned their focus inward—to the individual soul's capacity to experience the sublime through its own *imagination*. Spiritual matters, beauty and divine presence were transformed and reduced to "projections of the soul", a phrase borrowed from the German poet Hölderlin (Izenberg, 1992, p. 6). The Romantics' celebration of the unique individual's active imagination and emotional expressionism can be seen as heralding the 20th century's prevailing ideals of authenticity and expressive individualism (Bellah, Madsen, Sullivan, Swidler & Tipton, 1985; Warner, 2010).

Furthermore, the Romantic preoccupation with subjective spontaneity, creativity and imagination was also associated with a pursuing of emotional intensity, as strong feelings of pain, terror and awe were seen as sources of accessing the sublime. As a consequence, grieving was regarded by the Romantics as an opportunity to express the significance of one's relationship to the deceased, and, not least, to express the depth of one's own spirit. Neglecting the grief would be seen not only as neglecting the importance of one's relationship with the deceased, but also as neglecting one's own sense of self-worth and spirituality. Accordingly, from the perspective of the contemporary Western "happiness culture" (Stearns, 2012), the picture that emerges of the ideal Romantic griever is a rather tragic figure: One who deliberately holds on to grief, and lives heroically with a broken heart. A few lines from Jane Austen's *Sense and sensibility* (2004, first published in 1811) might give a hint of this endorsement of a "broken heart's ethics" (Stroebe, Gergen, Gergen & Stroebe, 1992):

> The agony of grief which, overpowered them at first, was voluntarily renewed, was sought for, was created again and again. They gave themselves up wholly to their sorrow, seeking increase of wretchedness in every reflection that could afford it, and resolved against ever admitting consolation in future (Austen, 2004, ch. 1).

Austen's characters express the Romantic preoccupation with emotional pain, not as a condition to be overcome, but rather as an "instructor of the wise", as Lord Byron's poetic figure Manfred states in the famous poem of the same name (Byron, *Manfred,* 1, i, 7-11.). In Byron's poem, "sorrow is knowledge", and "they who know the most [m]ust mourn the deepest o'er the fatal truth" (*Manfred,* 1, i, 7-11.). The Romantic ethos depicts sorrow and grief not as meaningless, adverse states to be overcome, but as sources of knowledge and wisdom – or rather, as Byron's poem spells it out: sorrow *is* wisdom. As we shall see, with the rise of modern, scientific psychology, this acknowledgement of grief's moral and epistemic value is undermined and replaced by a focus on "resolving" grief, detaching the energy from the lost relationship and "reinvesting" it in the future.

Early modernity: Grief as a universal and natural process

The Romantics altered our conception of death and dying by relocating the attention from a focus on the destiny of the dead towards a preoccupation with the destiny of the bereaved survivors. (From *one's own death* to *thy death*, to use Ariès's terminology.) The British sociologist Tony Walter has argued that the very notion of grief being the main object of concern after death, is in itself a fundamentally secular idea:

> The idea that the real problem after death is the grief of the survivors rather than the journey of the soul is a secular idea. Religious beliefs are judged according to whether they assist grieving rather than assisting the souls of the dead. Hence, the very concept of bereavement is a secular one (Walter, 1997, p. 187).

The Romantic preoccupation with grief – and the related internalization of morality to the inner realm of the individual person's soul – heralded the pervasive subjectivization and psychologization of values that imbues mainstream modern psychology (Brinkmann, 2011). Regarding grief, Sigmund Freud's works represent a pioneer contribution to grief becoming understood and practiced as a *psychological* phenomenon: That is, as a phenomenon concerning an inner realm of mental dynamics, representations, emotions and dispositions of the individual. While the art and poetry of the Romantic era idealized and celebrated the inconsolable broken heart as a mark of honor, Freud wrote his groundbreaking work *On mourning and Melancholia* (1917/1957) in a time marked by the unfathomable sufferings and losses caused by the 1st World War. Under these conditions, grief, death and loss were increasingly secluded from the public sphere, and confined to the private, emotional life of the individual. The bereaved individual was encouraged to put the loss behind and look to the future, and Freud's works provided a framework for accomplishing this. The Freudian "grief work hypothesis", i.e., "[the] view that it is essential to undertake grief work in order to adjust without lasting mental and/or physical health detriments to the loss of a loved one" (Stroebe, 1993, p. 20), has had a significant influence on professional and popular accounts of grief in the 20th Century (Wortman & Silver, 2001; author citation, 2015).

In a famous essay from 1937, the Austrian-American psychoanalyst Helene Deutsch argued that "the death of a beloved person must produce reactive expression in the normal course of events; (…) omission of such reactive responses is to be considered just as much a variation from the normal as excess in time or intensity; and (…) unmanifested grief will be found expressed to the full in some way or other" (p. 224). Hereby, she introduced the idea that not only overt grief, but also seemingly absent grief, is pathological.

A few years later, grief was systematized by the German-American psychiatrist Erich Lindemann (1963) as a "definite syndrome with psychological and somatic symptomatology" (p. 8). Like Freud, Lindemann asserted that "[the] duration of a grief reaction seems to depend upon the success with which a person does the grief work, namely, emancipation from the bondage to the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships" (p. 11). According to Lindemann, a failure to accomplish this grief work was associated with a range of symptoms for pathological grief, including somatic distress, preoccupation with the image of the deceased, guilt, hostility, and a "lack of capacity to initiate and maintain organized patterns of activity" (p. 10). Lindemann's work represented a pioneer contribution to an increasingly empirical and quantitative approach within bereavement research. In the following decades, academic bereavement research has been characterized by different attempts to identify universal patterns in individual bereavement reactions, and to differentiate between normal and pathological grief reactions (Valentine, 2006; Kofod, 2015). "Morbid", "pathological", "unresolved", "absent", "delayed", "abnormal", "complicated", "traumatic", "chronic" and "prolonged" grief are only some of the terms that have been suggested in order to designate grief reactions that fail to meet the expectations of normality. The wide variety of labels reflects the comprehensive and vigorous attempts within contemporary bereavement research to establish grief as a legitimate target of psychiatric research and intervention.

Contemporary late modernity: Grief as a pathologized phenomenon

The impact of these conceptualizations of grief can be traced up to recent attempts to define diagnostic criteria for pathological grief. With the recent release of the DSM-5 (American Psychiatric Association, 2013), bereaved individuals who experience even mild and transient depressive reaction might qualify for a depressive disorder as soon as 14 days after the death of a loved one (p. 161). Furthermore, "Persistent Complex Bereavement Disorder" has been included in section III of the DSM-5 for further research and potential implementation in future revisions, and prolonged grief disorder is suggested as a separate diagnostic category in the forthcoming revision of the World Health Organization's diagnostic manual ICD-11 (World Health Organization, 2016).

The different proposals for a grief diagnosis suggest slightly different diagnostic criteria, each focusing on the duration and intensity of the grief response, and to which extent the response exceeds expected social, cultural or religious norms of the individual's background. For example, the proposed criteria for prolonged grief disorder in the forthcoming revision of the ICD system involve "longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, difficulty in engaging in social or other activities)" that persists for "an atypically long period of time following the loss" (>6 months), "clearly exceeds expected social, cultural or religious norms for the individual's culture and context" and "causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning" (World Health Organization, 2016).

The diagnostic proposals are remarkable for several reasons: First of all, grief represents a form of suffering that all human beings are likely to experience, insofar as we are mortal, vulnerable and mutually dependent on each other in order to live meaningful lives. Even within the DSM, grief, defined as an "expectable or culturally approved response to a common stressor or loss, such as the death of a loved one", has so far been used as an example of non-disordered distress in DSM's own definition of mental disorders (American Psychiatric Association, 2013). This means that grief responses that are "expectable and culturally approved" per definition represent non-disordered, and hence non-treatable, normal distress. However, whether or not we evaluate a certain grief response as "expectable and culturally approved" depends on the particular circumstances of the loss, e.g., the relationship between the bereaved and the lost loved one, and therefore there cannot be a general cultural standard for how long or how intense grief should be. For example, what we would consider to be expectable for a bereaved parent of a dead child is not the same as for the child's neighbor (although we might think that both are entitled to grieve, in most situations we would probably find it disrespectful and inappropriate if the neighbor claimed to grieve as deeply as the parents of the child). This leads us to another noteworthy feature of the diagnosis, namely its ambivalent and somehow paradoxical position on the diagnosed subject's moral accountability. On the one side, the evaluation of whether or not a specific response is appropriate involves a moral evaluation of the response (e.g., we might evaluate the neighbor's grief as exaggerated, while the parents' similar response is regarded as expectable and appropriate). On the other side, the diagnosis implies a dysfunction in individual functioning that partially exempts the individual from moral responsibility. Yet again, by assessing the grief response as inappropriate, we are inclined to meet the grieving individual with moral demands of managing his or her grief in a way that complies with the cultural expectations, e.g. by seeking treatment.

Furthermore, given the complex context-sensitive nature of our evaluations of the appropriateness (or inappropriateness) of any given grief response, the medical assessment of whether or not an individual's grief response is normal or disordered will demand knowledge of his or her personal, social, cultural and religious background that goes far beyond what is provided in the current diagnostic guidelines, and arguably also beyond what is reasonable to expect in a typical diagnostic assessment interview. Hence, whether this complexity of personal, social, cultural and religious norms can be adequately accounted for in real-life medical practice is arguably questionable.

Finally, the diagnostic category itself is likely to interact dynamically with our interpretations and actions in relation to loss, in the sense that the category simultaneously shapes and is shaped by prevailing ideas of what grief is and ought to be. Ian Hacking refers to this dynamic process as "the looping effects of human kinds":

> To create new ways of classifying people is also to change how we can think of ourselves, to change our sense of self-worth, even how we remember our own past. This in turn generates a looping effect, because people of a kind behave differently and so are different. That is to say the kind changes, and so there is new causal knowledge to be gained and, perhaps, old causal knowledge to be jettisoned (Hacking, 1995, p. 369).

In other words, it is likely that the grief diagnosis will simultaneously reflect and influence the ways we will interpret, experience and act in relation to loss in the future, and even the ways we will relate to and understand past losses and griefs.

Discussion

In the following, I will try to outline some of the potential consequences of applying the different perspectives of grief put forth in this article. Which actions, feelings and interpretations of grief are made available – and which are restricted or sanctioned – when grief is approached through the presented (ideal-typical) images of Ancient Greek virtue ethics, Romanticism, early modern psychology, and contemporary diagnostic accounts?

Plato's perspective on emotions implies an emphasis on the necessity to restrain and control them. Hence, emotional expressions of grief become a dubious and potentially immoral phenomenon, something that threatens to undermine our capacity to act with reason and virtue. In contrast, Aristotle's virtue ethics offers a perspective of the motivational and, hence, moral aspects of emotions. He appreciates emotions as necessary, but not sufficient, resources for moral action and reasoning. Seeing grief through Aristotelian glasses gives a perspective on the *intentional* and *relational* aspects of grieving. Grief has a motivational and emotional *directedness* towards what is considered morally valuable: The emotional pain involved in grieving is not merely to be understood as an involuntary *reaction* to the loss. Rather, the feelings of grief are connected to the moral value of affectionate relationships – feelings that are fundamentally human, and ought to be cultivated virtuously.

As we have seen, the very idea that grief is the main concern following death is arguably not a universal and ahistorical phenomenon (Walter, 1997). Although death and loss are human universals, and although people of all times and cultures are likely to grieve over their dead, the experiences, practices and interpretations related to death and loss are embedded in profoundly different historical, social, cultural and material conditions. According to Walter and Ariès, the cultural preoccupation with grief, rather than with the destiny of the dead, is a phenomenon that emerged with the individualization and secularization processes of early modernity.

Following this analysis, the Romantic Era can be seen as representing a shift from the former focus on "my death" (i.e., the destiny of the dead and dying) toward the destiny of the survivors who had to live on without their deceased loved ones. In a disenchanted world no longer experienced as imbued with moral order and meaning in itself, the locus of morality was turned inward, to the individual's active imagination and ability to project meaning and significance to the world. Under these conditions, suffering from a broken heart became a mark of honor: A way to express one's moral depth and sensibility, and a source of wisdom.

Although the Freudian and later modern psychological understandings of grief as a universal, time-limited, intra-psychological process of emotional separation and reinvestment of energy are increasingly challenged and rejected within contemporary bereavement research (see e.g. Klass et al., 1996; Valentine, 2006; Wortman & Silver, 2001), they continue to live within popular culture. At a glance, these ideas might seem very different from the Romantic ideal of broken hearts. However, they share a common notion of grief as an intra-psychological process analytically separate from external cultural bonds. The idea that grief evolves from within the individual and needs to be expressed authentically is frequently expressed in popular culture, self-help literature and autobiographical accounts of bereavement (see e.g. Leick, Davidsen & Nielsen, 1991; Westberg, 2010).

The recent developments within the diagnostic systems can be seen as a part of an increasing tendency in contemporary late modern society to articulate and understand painful and difficult life experiences within a medical, psychiatric discourse (Conrad, 2007; Brinkmann, 2016). Firstly, while balancing between excess and deficit – between "too much" and "too little" – was regarded as a matter of *moral* importance in the Greek virtue ethics, the contemporary diagnostic approach to grief emphasizes the *health* consequences of grieving "too little" or – most notably – "too much". Secondly, grief is conceived within the diagnostic account as a *natural process*; a *causal* reaction to loss, rather than as a normatively shaped *response* to bereavement. As within the Romantic and early modern psychological accounts of grief, grief is conceptualized as a process that occurs spontaneously from inside the individual, and as analytically separate from cultural practices of mourning. Thirdly, the diagnostic approach to grief largely depicts grief as a *time-limited process*, with an aim of full recovery of the individual's "normal functioning". While the Romantics regarded long-lasting grief and broken hearts as potential signs of spirituality, contemporary discourse considers "broken hearts" as an undesirable pathological reaction that needs to be treated. The idea of grief as a time-limited process is connected to the Freudian ideal of recovery, detachment and autonomy as the goal of the grieving process. Although there is a growing interest in the importance of "continuing bonds" in contemporary bereavement research (see e.g. Klass et al., 1996), while the continuation of bonds in the Romantic ethos was a moral goal valued independently of health outcome, contemporary bereavement research addresses it as a question of whether it promotes or prevents healthy grieving.

As we have seen, since the Romantic era, emotional reactions to loss have been analytically separated from cultural practices of mourning. Within early modern psychology, the idea that grief and mourning were analytically separate was further developed, and within contemporary bereavement research, complicated grief reactions are seen as intra-psychological dysfunctions that are equally separable from cultural norms of grieving. However, from the perspective of cultural psychology, neither psychological nor cultural phenomena represent separate variables that affect people's behaviors and reactions. Rather, cultures provide tools that are used by people to mediate their thoughts, emotions, and actions. In other words, our mental life is intrinsically relational, situational, and social, and cannot be reduced to either individual (e.g. psychological or physiological dysfunctions) or cultural variables (e.g., social norms of illness and health).

If we approach cultures (and brains and bodies) as complex and heterogeneous mediators that simultaneously inform and are transformed through persons' active engagements in the world, the symptoms expressed and experienced by an individual cannot be isolated from the web of meanings, socio-material practices and technologies that make these symptoms possible to express, interpret, evaluate and act upon. From this perspective, a phenomenon such as complicated or prolonged grief cannot be reduced to an essence within the suffering individual (e.g., a neurological or psychological dysfunction, personality traits or the like). On the other side, neither can the suffering people experience be reduced to (a failure to comply with) socio-cultural norms and contingent social constructions. Instead, we need to acknowledge that problems of living, for example people's experiences and enactments of grief, are radically *situated* (Brinkmann, 2016): "[Illness] and disorder are always found in a *relation* between a person (or organism) and life situations (constituted by socio-material practices)" (p. 120). Grieving, like all psychological phenomena, are intrinsically related to material, social, cultural, and normative conditions, and from this perspective, it is not possible to reduce grief to either individual, biological or socio-cultural factors. Accordingly, the symptoms enlisted in the diagnostic criteria for complicated or prolonged grief cannot conceivably be evaluated as appropriate or inappropriate without taking into account the situational context in which these symptoms are expressed, the socio-material technologies and normative practices that render these symptoms problematic or even tangible, and ultimately, the meanings people attribute to the symptoms they experience. For example, an individual's experiences of "longing for the deceased" as something that persists for "an atypically long period", "exceeds expected social, cultural or religious norms for the individual's culture and context", and "causes significant impairment in (…) important areas of functioning" involve not only individual emotional and bodily experiences, but also normative expectations concerning individual performance, functionality, and health, as well as socio-material practices concerning work-life, well-fare services, diagnostics and interventions, etc.

Hence, the evaluations and interpretations of these kinds of symptoms can neither be isolated to individual experiences nor to socio-cultural conditions, but must involve a focus on the *relations* between all of these factors (Brinkmann, 2016, p. 121). From a phenomenological perspective, this means that the experience of grief is informed and shaped by biological, personal, bodily, material, and socio-cultural conditions, and ultimately, that all of these factors are involved in people's experiences, interpretations and enactments of grief. Simply put, although longing for the deceased is arguably a painful experience for us living in contemporary diagnostic culture as well as for the imagined Romantic griever, whether the longing is conceived of as an expression of a moral bond or as a symptom of mental illness shapes our experiences and ways of dealing with this kind of suffering in profoundly different ways.

However, neither of these interpretations determine the experiences of grief independently of the socio-material realities they take place within.

Conclusions

The basic argument developed throughout this paper is that grief is always already embedded in socio-cultural and material practices, without which individual experiences and interpretations of loss would be inconceivable. Different perspectives promote different moral values, hereby enabling and restricting different actions and understandings. Throughout this article, I have attempted to demonstrate that the contemporary inclination to separate individual experiences of grief from cultural norms of mourning is problematic for several reasons: From a cultural psychological perspective, grief experiences are radically situated and relational. Our experiences of grief are inseparably linked to the socio-cultural and material repertoires available for mediating and interpreting these experiences. Furthermore, grief cannot adequately be depicted as a causal reaction, because psychological phenomena are normative, i.e., unlike for example bodily functions, grief is subjected to moral evaluation. Although bereaved individuals sometimes experience grief as something that simply "strikes" them (e.g., when one is overwhelmed by strong emotions), these experiences are constantly shaped, mediated and interpreted in light of cultural norms. Rather than being a causal effect of loss (e.g., like a fracture is caused by a trauma), grief is a response that is imbued with meaning and normativity. By translating painful life experiences of death and loss into a medical and diagnostic language, we risk to impoverish the interpretative repertoire people use to go about these life conditions, and ultimately to impair people's abilities to endure, cope with and provide support for each other when life hurts. On this background, I believe that the Aristotelian and the Romantic appreciation of grief and broken hearts as more than just adverse and meaningless reactions to loss (i.e., their acknowledgment of the normativity of emotional responses) can inform contemporary understandings of grief. By being aware of the normative implications of our own understandings and practices, I believe that researchers and practitioners within the field of bereavement will be more capable of understanding grief as a phenomenon, and providing support for people who suffer from grief.

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CHAPTER 8. BECOMING A BEREAVED PARENT: PARENTAL GRIEF AFTER INFANT LOSS

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Becoming a Bereaved Parent: Parental Grief after Infant Loss

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Abstract

In this essay, I explore the significance of involving personal experiences with loss in my research on parental bereavement. By intersecting autoethnography and findings from a qualitative interview study with bereaved parents after infant loss, I argue that while popular accounts depict normal grief as a transitory state, parental accounts present grief as a continuing and open-ended relationship with the dead child. In appreciation of this, this essay presents fragmentary, non-reifying narratives of the continuing realities of becoming a bereaved parent.

Keywords: Parental grief; infant loss; autoethnography

My story

There are multiple entrances to the story of how grief became a focal point of my work as a psychologist. One begins with my name: I was named after my brother, Espen, who died in a car accident fourteen months before I was born. He was a seven-year-old boy, blond-haired, and toothlessly smiling in the school portrait taken shortly before the accident. It was December 1st, and my family was on their way to visit relatives for a birthday party. The roads were slippery due to the newly fallen snow. A truck driver in the opposite lane lost control of his vehicle, and within seconds, the future of my family was irreversibly altered. Espen died at the hospital a couple of days later. My maternal grandfather was the only one from our family who saw him after the accident, and the sight of his tiny, wrecked body haunted him for the rest of his life. Eager to protect his daughter from the gruesome realities, he ensured that my mother was held back from attending the funeral. As a result, she was kept in hospital until the following day.

As a child, I did not comprehend the loss my family lived with. To me, Espen was a series of enjoyable stories, an idealized image of a big brother, the boy with the smiling face on the pictures in our home, the one from which I inherited toys and clothes, the one we visited in the cemetery. After I grew up, my father has spoken to me about the silence at the dinner table following Espen's death. My mother has talked about the unfathomable pain and emptiness of coming home to his untidy room, left in the midst of play. My sister, who was ten years old when the accident occurred, has described how her childhood ended abruptly with Espen's death. Witnessing our parents' abysmal grief, she silently thought it would have been better if she had been the one who died instead of him. I still doubt whether I will ever be able to grasp the magnitude of my family's loss. However, the images of my mother's absence from the funeral, the silent dinner table, the untidied room, and the little girl who thought about death, give me a wordless and fleeting comprehension of what grief can be like.

Thirty years after Espen's death, my husband and I were expecting our first child. We were on our honeymoon, a few days after our wedding, when I slowly realized I was in labor. Once we got to the hospital, it was too late to stop the birth, and our daughter was born—three months early and too early to survive. My only image of her is an elusive remembrance of her seemingly thoughtful expression, delicate skin, and gentle, muscular body. She did not get a name; she was "our little girl." That is what we had inscribed on her tombstone: Our little girl. Our subsequent children sometimes refer to her as their big sister. Unlike my parents, we don't have a great deal of stories to tell—but every now and then, they want us to tell how small she was, how old she would have been now, and how happy we became when they were born afterwards. Our little girl did not get the opportunity to experience the world outside my womb. We never got to look into her eyes. (Were they blue, by the way—like our other daughter's and youngest son's? Or brown like our middle son's?) We will never get to see her growing up and becoming a person of her own. We will never attend any school meetings, arrange play dates, comfort her when she would have been distressed, and laugh with her when she would have been amused. Nevertheless, our little girl is written into our life story and into our hearts. Present by her absence, she opened the door to motherhood for me.

My study

Three years after our daughter's death, I started as a counselor in The Danish Infant Death Association (DIDA), a private, nationwide association for bereaved parents following infant loss. Throughout the following years, I have talked with hundreds of parents who have been trying to find out how to live their lives after the loss of a child or—for some—children. Listening to the many different stories of these parents has influenced me far beyond my role as a professional. It has affected how I relate to the fundamental vulnerability of existence, and has been a constant reminder of not taking life for granted. It has made me humble toward the different ways people deal with painful life experiences. Moreover, it has made me critical towards the current trend in contemporary bereavement research and practice of judging people's grief by general standards of appropriateness, functionality, or health. This skepticism was a point of departure when I began my Ph.D. project on parental grief following infant loss, from which this essay has developed. My main research[23] interest has evolved around the interactions between individual grief experiences and cultural norms and expectations concerning grief. Thirteen parents who were recruited through DIDA (six heterosexual couples and one woman participating without her husband) have generously given their time to share their stories, thoughts and reflections about their painful experiences of losing an infant. Over a period of two years, starting shortly (1-2 months) after the loss of their children, each of the parents has participated in three semi-structured interviews about their loss (with one exception; a couple that was interviewed once, approximately two years after their loss). Except for the woman participating alone, all of the parents have been interviewed together with their partner (dyadic interviews), allowing conversations and mutual reflections to unfold during the interviews.

In previous articles, I have written about how the parents relate to the current tendency within Western culture to pathologize grief, and have argued that grief needs to be understood as normative *responses* to loss, rather than as causally inflicted *reactions* (Kofod, 2015, 2017; Kofod & Brinkmann, 2017). In this essay, I will explore how parental loss responses may unfold, how the parents' accounts of their loss and grief are related to my engagement in the interview situation, and how they are related in a broader sense to cultural norms and expectations concerning grief.

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[23] In Danish: Landsforeningen Spædbarnsdød.

Autoethnography and grief

For a long time, I was reluctant to write about my own experiences with loss in the context of my research. I was concerned about how these personal experiences of loss might influence how my intentions for working professionally and writing about grief would be interpreted. Would my working with, and writing about, bereaved parents be regarded as an effect of unresolved grief, possibly casting doubt on my professionalism and my ability to decenter my own loss? Or would my, sometimes distanced, manner of relating to my own loss be regarded as a sign of a shallow nature? Would describing my own way of living with loss be seen as implicitly held normative standards for "good coping"? These questions lurked at the back of my mind, evoking a strange sense of unease that prevented me from explicitly addressing them. As a consequence, I downplayed my own personal relationship with grief on many occasions—most notably in the context of my research. However, this state of silence grew in me like a cancerous tumor, a malady in the heart of my research, one that prevented me from integrating my personal and professional experiences.

The critical moment of "coming out of the closet" was not planned for or thought through in advance. I had just presented a paper at a conference when a distant research colleague praised my presentation for being "refreshingly free from personal experiences," in contrast to the many autoethnographic accounts presented throughout the conference. Feeling the shame of my silence, I burst out, telling him I had indeed lost a child, but "that was not the topic of my research." As my colleague continued to praise me for "keeping the private private," the awkwardness of the situation persuaded me that the perceived "privacy" of my loss was indeed a relevant topic to explore. My urge to remain silent about my loss in the context of working with bereavement reflects a prevailing cultural split between the private, emotional and subjective vis-à-vis the public, rational, and objective. This split is also represented in the 20th century's grand narratives of grief as a private, emotional process with a goal of resolution and normalization (i.e., returning to public life) that continue to shape present understandings and practices of grief in Western societies (Walter, 1999). Hence, when private experiences are so deeply related to professional identity, as in my case, the latter becomes susceptible to suspicion. This is perhaps especially pronounced when the private involves experiences of grief, loss, death, and sadness—and when the professional identity at stake is that of an academic (Granek, 2009).

Moreover, it is relevant to explore the significance of my own loss for my relationship with the bereaved parents participating in my study. As a trained psychologist, I have learned to decenter my own experiences. Paradoxically, however, my experiences as a practitioner have taught me that moments of transforming trust can emerge when I share personal experiences and vulnerabilities with my clients. This is also the case in relation to the parents participating in this study. Being a bereaved parent myself enables a dual relationship with my informants—as a researcher, but also as a member of an invisible community of bereaved parents, implying an assumption of mutual understanding and shared worldview (Jenks, 2005). Revealing that I am not only professionally engaged with the topic of bereavement—but also a bereaved parent myself—arguably affects the stories I am told. As the British sociologist and feminist writer, Ann Oakley, has argued, "Personal involvement is more than dangerous bias—it is the condition under which people come to know each other and to admit others into their lives" (Oakley, 1981, p. 58).

Most, if not all, of the parents I have talked to about grief, tell stories of the differences between talking to someone who has experienced loss or other major life crises and someone without such experiences. While those "outside" often either avoid the topic altogether, or seem eager to mitigate the pain of loss, the "insiders" are much more straightforward and less reluctant to talk about the loss, the grief, and the dead child. Moreover, those with personal experiences of loss and crises are less likely to expect grief to disappear, and less likely to interpret signs of joy and laughter as expressions of resolved grief. This lessens the risk of disclosure, and gives the parents an opportunity to talk about the painful experiences of loss, as well as the precious experiences of love and affection for their dead children, or even humorous experiences. For example, one of the parents I interviewed has laughingly told me how she threw out an ugly candleholder given as a gift to memorize her dead child. These kinds of stories are more likely to be told when the narrator trusts the audience to acknowledge the coexistence of joyous and painful experiences.

An autoethnographic inquiry of the relations between my personal experiences, my engagement with my topic and with my informants enables me to connect "the personal to the cultural" (Bochner & Ellis, 2016, p. 65), and to challenge the cultural dichotomies between the private and the public, the emotional and the analytical, the personal and the professional. Although my need for privacy continuously makes autoethnographic writing a vulnerable struggle, the potential to explore the cultural and epistemic significance of the relations between my private experiences and my research hopefully makes the effort worthwhile.

Parental narratives of infant loss

While every death of a child involves the loss of a future, this is almost all there is when a child dies in the very beginning of life. It is the story of what should have been, not of what has been. As such, the loss of a small child is the loss of hopes and dreams—the loss of an anticipated future. When a person dies later in life—also in childhood—there is a history to share among the bereaved. The stories express the deceased person's significance for the bereaved, for their network, and sometimes even for future generations (Kempson, Conley & Murdoch, 2008). When a child dies early in life, the stories of the child are typically more fleeting. For the parents, this might have several meanings. For some, narrating the child's life story becomes even more crucial, as part of a struggle for recognition of the child's continuing significance in their lives (Kofod & Brinkmann, 2017). Kenneth J. Doka (1989) has introduced the concept of *disenfranchised grief* to designate “grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (p. 4). It has been suggested that grief following perinatal loss (i.e., during pregnancy or in the first week of life) is particularly vulnerable to disenfranchisement, hence adding an extra burden to the bereaved parents (Lang et al., 2011). However, as Patricia Robson and Tony Walter (2013) have highlighted, social recognition is not an either-or matter, but rather a question of more or less. By narrating their children’s stories, bereaved parents actively position themselves as parents and their children as “real” children—children they continue to love. Hence, grief is not conceived of as a terminable process, but instead as a lifelong relationship with their dead children. Consequently, the stories to be told are also continuous and open-ended, and any attempt to do justice to this in the context of a brief research essay is evidently doomed to fail.

Each of the stories I have heard are heartbreaking, illuminating and unfinished. Writing them down inevitably involves an act of selection that could be performed in innumerable other ways. Should I tell the stories of the events and conditions preceding the death of their children? Or the stories of how the parents came to realize that their child was dying or dead? Or of the precious time spent with their child? The stories of pride, love and affection? Of emptiness and meaninglessness? Of listening for the dead child to cry and knowing that it will never happen? Of looking for similarities between the dead child and her siblings? Of deciding how to spend Christmas without the dead child? The stories to tell are virtually infinite, and trying to fit them into an overly linear narrative scheme will only produce a false sense of closure that cannot do justice to the open-ended, continuing stories of living with the loss of a dead child. In appreciation of this, I will limit myself to present fragments of the parental stories I have heard. These fragments present tiny glimpses into the complex and continuing realities of becoming a bereaved parent. In the following, I focus on the stories of having and losing a child. Subsequently, after exploring the ethical and epistemic significance of recognition and difference for my relationship with the participants in my study, I compare the parental narratives of living with loss with popular accounts of grief presented in academic and popular bereavement literature.

Stories of having and losing

Each story of losing a child has a prehistory that begins long before the child is born. For some of the parents I have talked to, these stories involve years of arduous struggle to become pregnant. For others, having children was less planned for, but never a random choice. Like most parents in our part of the world, all of the parents I have talked to describe the pregnancy as a reflective choice and a process of preparing, emotionally as well as practically, for their child to come. Parenthood and emotional bonds develop through everyday activities such as considering a name for the unborn child, seeing ultrasound images, feeling the baby's movements in the belly, decorating the nursery, reflecting on one's coming identity as a parent, etc. Although fear of losing is a well-known experience among expectant parents, the death of a child is not, and cannot, be prepared for before it is an inevitable

reality. Hence, each of the stories the parents have told me involve a before and an after the moments of unbearable realization. For some, these moments occur during pregnancy; for others, after the child is born. However, love and attachment does not begin or end with these moments of realization.

For those who haven't experienced the loss of a child, going through childbirth knowing that one's child is dead or will die might sound ferociously cruel. However, most of the parents I have talked to describe the birth of their child as a beautiful and precious experience (Kofod & Brinkmann, 2017). For example, Rita, who lost her long-expected firstborn daughter after a preterm labor, explains it like this: "In the midst of all the tragic and traumatic, there was suddenly something life-giving—after all— in all of this dark and gloomy." When knowing that death was inevitable, Rita focused on giving her child a gentle birth and ensuring her daughter would not suffer too much. "I was happy she was alive, and that we got these few minutes with her", Rita says.

Although parents may be together during their child's birth, their experiences of labor can be profoundly different. While Anna went through their stillborn son Oliver's birth in an almost elevated state of focused attention, her husband Thomas was as far down as he had ever been. As Anna held Oliver in her arms, she was overwhelmed with pride and affection. The midwives told them they had rarely seen a stillborn baby this beautiful. In the evening after the birth, Thomas sat with his son. As he put his finger into Oliver's tiny palm and his little fingers didn't squeeze back, Thomas was hit by the irretrievable reality. Their son was dead.

The midwives gently introduced them to some of the many decisions they were faced with along the way: Had they thought of a name? Would they like to see a priest? Did they want the priest to bless Oliver? Would they like the staff to arrange a meeting with an undertaker, or would they rather find one themselves? Would they accept the offer of a post-mortem examination? Moreover, through their way of being around and taking care of Oliver, the midwives showed Thomas and Anna how they could be together their son in a way that felt natural to them. "We were *together* with Oliver," Anna recalls. "We kind of played being this little family."

Thomas stresses the importance of having received visits from their family while they were at the hospital with Oliver: "They [members of their family] are so incredibly glad they got the opportunity to come and *see* him. Because then they have an image of who it is—and who *we* miss, right?… So it means really, really much, actually—that they were a part of it. … They're the only ones who've seen him—alive, at least…" "'Alive'?" Anna interrupts, before he realizes his slip of tongue. We all know what he means. The days together with Oliver were the only ones they would ever spend with him, and although he was not alive, he was—and continues to be—present in his parents love and grief.

Unlike Rita, Thomas and Anna, Linda and Chris happily returned home from the maternity ward with their firstborn son, Lucas. They had fought so long to have him, and the first few days went by in a state of sleepless appreciation of their little wonder. However, they had difficulties with getting Lucas to eat, and as they called the "nursing hotline" for advice, they seemed to be losing contact with Lucas. When the midwife from the nursing hotline refused to take him in before their scheduled appointment the next morning, Chris hung up and called 911. From that moment on, everything that happened seemed like watching a bad movie. The doctors fought for Lucas' life. Linda and Chris stood by the side of his incubator. "I kept telling him about all the wonderful things that should happen when we got back home with him", Linda recalls, "how proud we were of him, how much we loved him, that he should fight, that we fought with him…" The doctors could not say what was wrong with Lucas, and he was getting increasingly ill. After repeatedly having turned it down, Linda and Chris got to the point where they accepted the offer of an emergency baptism. Shortly after the ceremony, Lucas was released from all the tubes that had been attached to his little body. "He breathes out in our arms", Linda says quietly. "It was how it was supposed to be, when it had to be like this. In that moment, our world fell apart."

Each of the stories I have been told of losing a child involves worlds falling apart. However, they are also—and perhaps most of all—stories of love. Regardless of the unbearable loss, the parents are grateful of having had the opportunity to experience their children. As Eric expresses it, two years after the loss of his firstborn son due to a congenital disease:

> I would gladly have taken one more day, and one more day, and one more day. All the experiences I should have had with him. Then some people think, that would make me know him better as a person, and then the loss would probably be greater. But I don't mind that. I mean, I would accept that the loss was greater. I just want an extra day, and an extra day, and an extra day. I want to know how he would have become. So every extra minute would have been good. So in that context, it's actually irrelevant whether the loss would have been greater. I just wish I could have had one more minute.

In spite of the pain of loss, and in spite of his expectation that this pain might have been even more profound if his son had lived longer, Eric would have been willing to "pay the price" to gain more time with his son. In other words, while acknowledging the widespread cultural assumption that the loss is somehow relative to how long one has known the child, Eric highlights the loss of future that is so profound when a child dies early in life. The grief is not only related to the loss of what has been, but also—and perhaps most of all—the loss of what should have been. In the following, I explore the significance of comparing the magnitude of loss with reference to the child's age and uniqueness, and how my doubts concerning my own loss reflect cultural ambivalences regarding infant loss and parental grief.

Ethics of recognition and difference

When talking about other people's losses, I talk about grief. However, I am reluctant to use the term for my own loss. When talking to other bereaved parents, my loss gives me credibility as someone who "knows what it is all about." Nonetheless, I tend to become hesitant when they ask me how I relate to my loss, grief, and dead child today. This is only partly due to my intention to decenter my own loss. In addition to this concern, my reluctance is also related to my reservations against positioning myself (and being positioned) as someone who shares their fate. Sometimes I doubt that the circumstances of my own loss qualify me as a legitimate participant in the community of bereaved parents: Is my loss "big enough" to be considered a "real loss" by those who have experienced "greater losses"? Several of the informants reflect on the issue of whether or not the magnitude of their loss is in any way related to the age of their children. Although the standard practices of care for bereaved parents after infant and perinatal loss in our culture involve acknowledging these losses as "real losses of real children", there is also a common cultural assumption that the loss of a younger, less mature infant is somehow less severe than the loss of a relatively older child whom one has "gotten to know" (Kofod & Brinkmann, 2017). Furthermore, my hesitation is probably also related to the fact that my own loss is not something I "deal with" in a very explicit way anymore. I do not talk much about it, I do not pay regular visits to the cemetery, and when asked how many children I have, I seldom mention my dead child.

So when the parents ask me how I relate to her today, I am in conflict between being honest on the one side, and keeping a decentered focus on what they are (often)—implicitly or explicitly—asking for: positive images of how their grief might become an integrated and natural part of their continuing life. However, confronted with people who grieve, I feel like humbling myself by claiming to share their fate. In some ways, the fact that I did not get to know my daughter has indeed made the loss more bearable to me. And yet, this is also what makes the loss so absolute. I lost everything of what should have been her. I loved her, yet she never knew. Not only she, but also us—our relationship as mother and child—was almost mere potential, yet to become reality. In many ways, she was a "loss of possibility, of parenthood, of potential relationship rather than existing relationship" (Grout & Romanoff, 2000, p. 104). However, in my eagerness to acknowledge the parents' experiences of having lost "real children," I am reluctant to talk about these experiences. By admitting that my loss sometimes feels more like a loss of an imagined possibility than of a real child, I fear that I implicitly fail to acknowledge not only my own loss, but also the losses of the parents who share their stories with me.

In spite of my reluctance to use the term grief for my own loss, I seem to assume that my informants are comfortable with addressing their loss experiences as grief, and that they feel equally comfortable with the notion of grief as a life condition. By attempting to acknowledge the significance of their loss by addressing their condition as grief, am I implicitly reifying a normative assumption that the intensity and duration of the parents' grief expressions reflect the intensity and duration of their love for their dead children? After losing my daughter, a friendly colleague whom I hardly knew called me to show her sympathy and share her own story of losing a child with me. In spite of her good intentions, I remember a feeling of awkwardness due to her repeated questions of our daughter's name. It was as if the fact that we had not given her a real name indicated a failure to acknowledge her real existence and significance.

In contemporary Western cultures, characterized by low infant mortality rates, advanced birth control technologies and a high degree of individualism, the process of attributing human and individual status to the infant is likely to be faster and more pronounced than in societies with higher infant mortality rates and lower levels of individualism (Scheper-Hughes, 1993). Naming practices are a part of this cultural pattern. As the American anthropologist, Nancy Scheper-Hughes, has argued: "Our firm belief that every child has a constitutional right, as it were, to his or her individual name reflects our markedly individualistic way of thinking." (Ibid., pp. 414-15). In this light, then, not giving our child a name indicates a failure to grant her individuality. To me, however, calling her "our little girl" stresses our relationship with her, while acknowledging that we did not get to know her as a unique person. Although she was indeed our little girl, we would never have the chance to call her by a name, and she would never be able to respond to one. In any case, I believe that my urge to justify our choice of not giving her a proper name (even in the context of this essay) expresses the blurred and ambivalent cultural norms concerning infant loss and parental grief, as well as the intrinsically normative relations between love and the expression of grief (Kofod & Brinkmann, 2017). This relationship between love and grief is also often implicitly or explicitly addressed by the parents in my study, for example by Anna, who repeatedly expresses her concerns about whether she "grieves enough" for her dead son:

> I would have thought that I wouldn't be able to hold myself together… If I had that feeling before, that if you lose someone, then you can't possibly hold yourself together. And now, when it's actually me who has lost someone, I've been distressed about the fact that I do hang together. Why haven't I been out so deep that I can't float?

Anna is not alone in addressing these issues. Several of the parents, most notably the mothers, share similar concerns about whether their ability to feel joy—or conversely—their inability to feel grief all the time, reflect their failure as loving parents of their dead children. Like myself, all of the parents I have interviewed have lost very young children, with whom none of us have had the opportunity to spend much time. In some ways, this adds to the complexity of the loss experience. As Thomas expresses it in our last conversation, a little less than two years after his son's death, "I have to make my daily life work again without my child, but then again, I've never had a daily life with him. I had dreams and expectations – things that should have been, but they haven't been. It's hard to tell exactly what you miss. … It's so intangible…" Equally, also in our last conversation (approx. two years after the loss of their son), Chris and Linda discuss the difficult acknowledgement of not only missing their dead son, but also "a child":

> Chris: We miss Lucas. Of course we do. But… we also missed… a child.
>
> Me: A living child.
>
> Chris and Linda: Yes.
>
> Linda: Yes. And sometimes I think that's kind of ugly…
>
> Me: Yes? How so?
>
> Linda: Yes, actually… I kind of… not that he, at all, but… but I think, when you say it out loud, then it just sounds like… Then he's just forgotten. And then he means *nothing.* Or so it may sound for the outside world…

Apparently, some of the parents seem to share my fear of being seen as someone who does not grieve, and hence, does not love their children enough. Nevertheless, in spite of my responsiveness towards the parents' struggles to come to terms with their roles as parents of their dead children, I wonder if sharing more of my own experiences with these issues could have opened up further explorations of the complex, normative nature of grieving the loss of a child whom one has not gotten to know.

The interplay between parental and popular narratives of grief

Through the analytical process of preparing and writing this essay, one aspect of the relationship between the cultural narratives of grief, as presented by the parental versus the popular and professional accounts of bereavement, has become increasingly obvious to me. There seems to be a discrepancy between the stories told by bereaved parents themselves and the narratives of grief with which they are confronted in their everyday lives. Bluntly put, the parents talk about grief as a continuous affectionate relationship with their dead children. In contrast, the narratives they encounter in their everyday lives seem to depict grief as a painful process that they need to "go through" in order to return to a "normal" or perhaps a "new normal" level of functioning (Freud, 1957; Worden, 1982). Although most of the parents in this study do indeed "return" to what might be called some kind of normalcy, insofar as they gradually find themselves able to return to work and social life, most of them stress the importance of "finding a place" in this new life for their dead children. The notions of "going through" and "getting over" grief are repeatedly referred to as hurtful, insulting and fundamentally mistaken.

Along with the cultural narratives of "going through" and resolving grief, grief is also often depicted as a developmental process, as a *healing pain*, through which the bereaved individual potentially grows and develops as a human being (Leick, Davidsen-Nielsen & Stoner, 1991, p. 7). A narrative of *personal growth through crisis* is reflected in numerous professional and popular accounts of bereavement, for example in the growing interest for so-called "post-traumatic growth" (Calhoun & Tedeschi, 2001). In essence, these narratives reproduce the well-known aphorism, "What doesn't kill you makes you stronger," i.e., like a Phoenix out of ashes, burned individuals rise and fly—wiser, stronger and better than before. As Granger E. Westberg (2010) states in the preface of his bestselling book *Good Grief*, first published in 1962: "We come out of it stronger, for we have had to learn how to use our spiritual muscles to climb the rugged mountain trails" (Ibid., preface). Throughout the interviews, I have talked with the parents about these different narratives of grief as a process of growth, development and change. Although some of them do indeed occasionally talk about grief as a transformational process, at other times they stress the experience of stagnation, or lack of new insights as an equally significant experience in grief. At times, our conversation unfolds like "discourses crossing swords" (Tanggaard, 2007), i.e., differing assumptions brought forth by me and by the interview participants "cross each other and become the context of a productive negotiation of meaning" (Ibid., p. 160). For example, in our second conversation, approx. 8 months after the loss of their daughter, I ask Paul and Sarah whether there is anything that has become "more important" for them after her death, after which the following conversation unfolds:

> Paul: Hmm… I don't know, really...
>
> Sarah: I don't know if there's anything that has become more *important*… I mean, everything is a little uncertain, you might say. Afterwards, right? And… Of course you learn to… appreciate… each other. I think. I mean, I've really feared that anything should happen to Paul. It was like all balls were kind of thrown up in the air, and everything could… Everything could happen. So… losing more was not… unlikely, if you know what I mean? All the little things were certainly *unimportant*. But I don't know if there was anything in particular that got extra *important*.

In spite of their hesitant response, I pursue the topic:

> Me: But some kind of change of perspective related to…
>
> Sarah: Yeah, definitely.
>
> Me: … what's important, and what's less important?
>
> Sarah: Yes, I think so. (…) Umm, I don't know if there was anything that became especially important.
>
> Me: No, it isn't because you necessarily find… a new meaning with life.
>
> Sarah: No, that hasn't come yet. Almost the opposite, right? We're not there yet at all yet, or I'm not, at least. There are really many things that don't give any meaning. (…) [It] becomes kind of… it doesn't matter, right? I mean, if the flowers stand straight in the flowerbed. Yeah, whatever!

When re-reading this, it strikes me how my seemingly innocent question of whether "anything has become more important" implicitly reflects and reproduces the popular narrative of grief as a (positive) transformation process. However, instead of silently accepting this implicit assumption, Sarah and Paul actively reject it. Despite Sarah's reluctant statement about "learning to appreciate each other," they both stress that they do *not* feel that anything has become more important—almost the opposite, Sarah maintains. The sense of meaninglessness that pervades her experience of losing their daughter is replicated in her experience of everyday situations, where things she used to find meaningful appear bereft of meaning and value after the loss. However, although such a sense of meaninglessness seems to be a very common experience among bereaved parents, contemporary bereavement research addresses this as a pathological reaction to loss (American Psychiatric Association, 2013; World Health Association, 2016). Thereby, the cultural ideal of the rising Phoenix is implicitly reflected in professional accounts of bereavement, by defining failure to regain meaning after a loss as a pathological condition that requires treatment.

When people from English-speaking countries—and several other Western countries—talk about grief, implicit assumptions of transience and exception seem to be some of the crucial features of what is conceived of as grief: "To be grief-stricken", "in grief", "going through grief", etc., are all ways of saying that grief is something people should ultimately "get over". In contrast, in many personal accounts of bereavement, the sorrow that follows a loss is not necessarily regarded as something that should pass. This rejection of grief as a transitory state is also increasingly being expressed and acknowledged within contemporary bereavement research, for example in the concept of "continuing bonds" presented by Dennis Klass, Phyllis A. Silverman and Steven L. Nickman (1996) and within narrative psychology (see e.g., White, 1988). However, this acknowledgement of grief as a continuing relationship with the deceased loved one seems to be delimited to those who are able to do so in ways that are considered as “healthy” and “functional”, i.e., without interfering with the bereaved individual’s daily functioning, identity, and well-being. For example, in the recent suggestions to introduce a separate, diagnostic category for complicated or prolonged grief, pathological grief is associated with “confusion about one’s role in life”, “difficulty accepting the loss”, “bitterness or anger”, “difficulty in moving on with life”, or “feeling that life is unfulfilling, empty, or meaningless since the loss” (Prigerson et al., 2009, p. 9). In other words, normal grief is implicitly depicted as a rather non-dramatic phenomenon with little impact on the bereaved individual’s sense of identity and meaning. Furthermore, this delineation between normal and pathological grief implicitly depicts the grieving individual as a unified subject with a once and for all clarified and unambiguous relationship with the lost loved one. However, the parents participating in this study often describe their relationship to their loss, not as a matter of “either-or”, but rather in terms of “both-and”: feeling sad and proud at the same time; feeling sad and sometimes actually appreciating the sadness as a way to sense their child’s continuing presence in their lives; accepting the loss in some ways and not in others; longing for their child, while at the same time being able to go on with their lives; avoiding certain social situations and finding comfort in others, etc. Seen through a list of diagnostic criteria, these experiences might easily resemble a psychiatric disorder. However, although the love implicit in the yearning and sadness remains invisible, without it, there is no grief.

Epilogue: A place for the dead

If she had lived, my daughter would have turned eleven this summer. As we went through the cemetery on our way to soccer training last week, my seven-year-old son wanted to go visit her grave. His request came as a surprise to me because he seldom talks about her. I can only recall a few times before when he has asked to go see her grave. However, I remember how we imagined this when we chose this particular gravesite: The beautiful liveliness of this cemetery, its function as a local park where people come by to sit in the sun, or just walk through on the way to soccer training on a Monday afternoon after school. I imagined going there with our future kids, just like this, without any special occasion, just as a regular thing to do, a bit of everyday life.

“Afterwards”, I responded, “or we’ll be too late for your training.”

“I wish she was here”, he said, “Why couldn’t she live?”

I answered, as I have done before, that she was born too early, her lungs were not ready to breathe on their own yet.

“But *why* was she born so early, if she wasn’t ready?” he continued.

"It just happened", I answered—once again falling short of giving a meaningful answer to her meaningless death.

However, although her death was meaningless, her existence was not. Although I cannot know how my life would have been without having and losing her, I know that I am a different person and a different parent than I would have been without her. As for the interviewed parents' questions concerning her place in my life, she does indeed hold a place, although it is a quiet and private one. My children talk about her every now and then, and although I am reluctant to call it grief, they do seem to miss the idea of a protective and loving big sister. More than grief, her death has given them an awareness of the fragility of life which I sometimes wish I could have protected them from a bit longer.

Walking through the cemetery with my son's hand in mine, looking at the birds, the trees and the people walking by, I imagine her being a part of everything, a tiny piece of the big puzzle of life. We did not walk by after training. It was late, we were hungry, and school work was waiting. Maybe next time.

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CHAPTER 9. GRIEF AS A NORMATIVE PHENOMENON: THE DIFFUSE AND AMBIVALENT NORMATIVITY OF INFANT LOSS AND PARENTAL GRIEVING IN CONTEMPORARY WESTERN CULTURE

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Grief as a Normative Phenomenon: The Diffuse and Ambivalent Normativity of Infant Loss and Parental Grieving in Contemporary Western Culture

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Abstract

Grief is often conceived in causal or reactive terms, as something that simply strikes people after a loss. But, on closer scrutiny, there are good reasons to think of grief as a normative phenomenon, which is done or enacted by people, relative to cultural norms. To substantiate the claim that grief should be thought of as normative, we draw upon empirical examples from a qualitative interview study with bereaved parents after infant loss, and analyze how grieving the loss of a small child in our culture is experienced, interpreted, and enacted within a diffuse and ambivalent, yet inescapable, moral framework. Further, we discuss some of the possible consequences for bereaved individuals when navigating the normative landscape of grieving in contemporary Western cultures: A landscape in which suffering is increasingly dealt with in psychiatric and medical terms and understood as an adverse and unnecessary condition to be overcome in order to maximize personal health, happiness and well-being.

Introduction

Grief is often conceived in causal or reactive terms, as something that simply strikes people after a loss, in contrast to mourning, which is typically described as “the social expressions or acts expressive of grief, which are shaped by the practices of a given society or cultural group” (Stroebe & Schut, 1998, p. 7). A standard definition, such as that provided by Gross in his textbook on grief, states for example that grief is ”a universal reaction to bereavement, involving both psychological and bodily experiences.” (Gross, 2016, p. 5). Grief is thus depicted in rather passive terms, as a response or reaction. Of course, there is also a more active notion of “grief work”, which is “the process by which the bereaved individual comes to terms with his/her bereavement” (p. 5), but this is typically seen as analytically separate from the grief reaction itself. For example, Thomas Attig (2004) distinguishes between grief as the “reactive agony (…) that happens to us after bereavement happens to us” and “our active response to loss” (p. 343). However, as we attempt to demonstrate in this article, the reactive responses and the active shaping of emotions and acts are deeply entangled and situated within cultural, normative practices. Hence, there are good reasons to think of grief as a normative phenomenon that not simply happens as a causally inflicted event, but which is done by people, relative to cultural norms. Grief, like mental phenomena in general, we will argue, are performed or enacted rather than passively undergone. This means that grief can be done in more or less adequate ways within local moral worlds and hence is normative (Harré, 1983).

In this article, we outline what we mean more specifically when we claim that grief should be understood in normative terms. To substantiate this claim, in the latter half of the paper we draw upon empirical examples from a qualitative interview study conducted in Denmark with bereaved parents after infant loss, and analyze how grieving the loss of an infant in contemporary Danish culture is experienced, interpreted, and enacted within a diffuse and pluralistic, yet inescapable, moral framework. Finally, we highlight and discuss some of the possible consequences for bereaved individuals when navigating the normative landscape of grieving in contemporary Western cultures.

The normativity of grief as a mental phenomenon

In their ambitious attempt to build a normative psychology (i.e., a psychological science that acknowledges the basic normativity of psychological phenomena), Harré and Moghaddam (2012) cite Kalat’s introductory psychology textbook to illustrate how the normative approach differs fundamentally from the standard causal one. Kalat (2005) states that psychologists qua scientists should “act on the basis of determinism, the assumption that everything that happens has a cause, or a determinant, in the observable world” (p. 5). This, Kalat argues on the same page, is a key point of the scientific approach as such that consists of seeking the “immediate causes” of an event instead of its “final causes” (e.g. the purpose of an action). This means that the phenomena studied by psychologists – how humans think, feel, and act – should in principle be treated like all other observable events in the world (such as planets orbiting the stars or glaciers melting to form rivers). Although other textbooks use slightly different phrases, it is probably a fair verdict to conclude that something like this represents the standard approach to scientific practice in psychology (leaving aside such perspectives as phenomenology, discursive psychology, and cultural psychology).

According to Harré and Moghaddam (2012), many things are misguided about this standard causal approach. For one, they note that it (ironically) seriously misrepresents the natural sciences that it otherwise seeks to emulate. The natural sciences do not in general operate with simple Humean positivist causality (A is the cause of B if and only if there is a constant conjunction – to quote David Hume – between A-type events and B-type events), but employs models that are much more sophisticated, and which notably include references to the mechanisms or dynamic systems that mediate relationships between A- and B-type events. But even worse, the standard approach leaves out acting persons entirely, since these cannot be conceived in causal terms. If persons' acts simply happened to them causally, they could not be held accountable for their doings, and, in a sense, there would not be any acts, but only behaviors or events. And if persons' emotions simply happened mechanically in a given situation, no one could ever legitimately be blamed for exaggerated aggression or praised for suppressing an impulse to express anger.

Throughout his career as a scientific psychologist, Harré has sought to demonstrate that we can only conceivably imagine and understand psychological phenomena in the first place, because we have access to a realm of normativity. The reason why dread and anger are psychological phenomena (i.e., emotions), but not indigestion or exhaustion – although all have behavioral manifestations as well as fairly distinctive experiential qualities – is that only dread and anger fall, for us, within a moral order (Harré, 1983; see also Brinkmann, 2011). Harré says ”for us”, since he believes that classifications of what does or does not belong in the normative moral order are at least partly culturally relative, which means that what counts as a psychological phenomenon likewise becomes partly culturally relative.

In one way, the normative approach to psychology is "old news" in Western thought and was thoroughly examined and articulated by Aristotle. In the *Ethics*, Aristotle was concerned with the human being as an intentional creature whose operations demands teleological explanation. He was concerned with the human being as a minded creature who lives in a normative space and is responsive to reasons for acting and feeling, and mental life thus cannot be grasped in a causal framework. Like Harré and Moghaddam (2012), Aristotle saw the need for a "hybrid psychology" that can integrate knowledge of the working mechanisms of the organism and its brain with knowledge of the person as an active, intentional being. For example, when he discussed motivation, he did not think that it could be fully understood by the natural scientist (the *phusikos*). We also need the work of the "dialectician" in order to grasp it (Robinson, 1989). For the latter "would define e.g. anger as the appetite for returning pain for pain, or something like that, while the former would define it as a boiling of the blood." (Aristotle quoted from Robinson, 1989, p. 81). The dialecticians – the cultural psychologists of the day, we might say, place anger in a normative space of reasons, and know that there is such a thing as *justified* anger in the face of outrageousness. What makes "boiling of the blood" (or some modern neurophysiological equivalent) *anger* has not just to do with its natural scientific properties, but is precisely that it is situated in a context where it makes sense to question, justify, and state the normative reason for "boiling of the blood". Anger is thus a psychological phenomenon in so far as it is done, performed, or enacted. In other words, in so far as it is a moral phenomenon, subject to praise and blame. If it were entirely outside the realm of normativity, we should confine it instead to the science of physiology.

Similarly, to turn to the subject matter of the following analysis, grief is also on this account *done* or *performed* by skilled human actors, who can only *grieve properly* if they know their local moral order, i.e. know *how*, and *how much*, grief is called for in the social practices of their culture. This is not to say that grief is an action that can simply be stopped (like playing football with friends, which stops whenever the players become bored with the game or are leaving because of other appointments). But it is to say that grief should not be thought of as a purely mechanical reaction that is causally inflicted, but rather represents a normative response to a loss. The loss is not simply a *cause* that triggers an emotion, but is an event that provides a *reason* for feeling and expressing grief in a certain way. This also explains why grief (like other emotions) may be evaluated morally: The person who does not grieve sufficiently is easily seen as shallow or aloof (whether justified or not), whereas the person who is experiencing extreme grief (in a situation that does not call for deep mourning) can be accused of "overdoing it". As we shall see below with reference to a study of parents' grief after the loss of an infant, people in such a tragic situation do not only struggle with the loss as such, but also with navigating the rather unclear normativity in this tragic situation: On the one hand, there is a cultural discourse claiming that the worst thing a human being can experience is the loss of a child, but, on the other, there is also a discourse implying (to put it bluntly) that the loss is supposed to be less intense when the child is relatively young at the time of its death, compared to older children that the parents "have gotten to know" (there is also a cultural discourse, which implies that the loss of very old persons should call for less intense forms of grief). How – and how much – should one grieve then? This is not an easy question, especially not in a Western culture with relatively diffuse norms about grief and few common rituals. In order to understand how these conditions shape parental grief after infant loss, we will now outline some of the cultural-historical changes in the normative understandings and practices specifically related to infant death and parental grief.

Historical changes in the perception of infant death and parental grief

In most Western countries prior to the late 1970s, the standard care for bereaved parents after stillbirths and perinatal losses (i.e., when an infant dies in the latter half of the pregnancy or in the first week of life) was to encourage the parents to put the loss behind them and look to the future. The dead babies were typically hid away and disposed of by the hospital staff, bereaved mothers were placed next to mothers of healthy new-born babies in the hospital ward, and any mentioning of the dead child was discouraged (Hughes & Riches, 2003; Lasker & Toedter, 1994). These practices were based on the assumption that confrontation with the loss and contact with the dead child would be harmful for the parents, reflecting the focus on 'letting go' in the dominating grief models of the time (Davies, 2004).

However, inspired by the counter-cultural movement of the 1960s, grass-root associations questioning the dominating practices of care arose across several Western countries during the late 1970s and early 1980s. Bereaved parents, primarily mothers, protested against what they experienced as mechanical and emotionally oppressing practices (Hughes & Riches, 2003). These protests formed the background for the radical changes in the psychosocial management of stillbirth and perinatal bereavement that have occurred throughout the last decades in most Western countries. These movements have fought for public recognition and awareness of pregnancy and infant loss, and challenged the earlier practices of care. The change of perspective was also reflected in the publication of academic literature on parental bereavement, addressing the need for acknowledgement of the severity of the parents' loss, and claiming that lack of contact with the dead child was associated with inhibited mourning (see e.g. Lewis, 1979).

Today the model of care for bereaved parents after infant loss involves encouraging the parents to have contact with the dead child in order to create attachment and facilitate the grieving process (Davies, 2004). These new practices are associated with changes in the view on grief and bereavement, from the former focus on letting go towards understandings of grief stressing the importance of continuing bonds with the deceased (Klass, Silvermann & Nickman, 1996).

However, in spite of these changes, cultural practices and expectations surrounding infant loss still reflect tensions and ambiguities concerning the normative practices and interpretations of the loss itself as well as the grief associated with losing small children (Cacciatore, Defrain & Jones, 2008; Lang et al., 2011).

The British sociologist Tony Walter argues that contemporary Western grief culture is characterized by "an interplay between public provision and private experience" (Walter 1999, p. 187). On the one hand, we see a rise in the public expression of private grief experiences (e.g. via autobiographical accounts, internet blogs etc.), and these individual experiences have become increasingly authoritative in the professional understanding of bereavement. Simultaneously, the professional vocabulary of grief developed within the disciplines of medicine and psychology provides an interpretive framework for individuals' grief experiences. According to Walter, the notion of the "grief process" has replaced social mourning as the main regulatory framework for grief in contemporary Western societies. Walter argues: "Insofar as the self is free to define its own grief, so that there is a diversity of voices undermining any notion of a single, universal grief process, we may refer to *postmodern* grief. Insofar as professional expertise dominates, we may refer to *late modern* grief" (p. 187). In this article, we will describe the outlines of the normative landscape of parental grief as it is experienced by a group of bereaved Danish parents after infant loss, and also explore some of the consequences for these parents of grieving within the cultural framework of contemporary Danish society.

An empirical study of today's grief experiences and practices

Methodological approach

The data are drawn from 20 in-depth semi-structured qualitative interviews conducted by the first author over a period of 2 years (from December 2012 to October 2014) with 13 bereaved parents following infant loss. The participants – six heterosexual couples and one woman participating without her partner – were all recruited through a nationwide, private Danish organization that offers counselling and network support to bereaved parents after infant loss. With one exception (a couple participating in one interview approximately 2 years after the loss of their child), all participants were interviewed three times; shortly after the loss (<2 months), 7-8 months later, and finally approximately 2 years after the loss. With the exception of the woman participating alone, all participants were interviewed together with their partner, and all interviews were carried out in the participants' homes.

The sample of participants was selected in order to reflect the variation in terms of geographical location, circumstances of loss, family situation and social background of the parents who ordinarily make use of the services provided by the bereavement organization. The participants had lost children who died shortly before or after (< 1 week) birth, all born in the 2nd or 3rd trimester of pregnancy. One of the couples had lost their second child, whereas the other participants had all lost their first-born child. The participants' age ranged from 26 to 42 years, with a mean age of 33,3 for the female participants and 31,7 for the male participants. The interview guide was developed as a semi-structured guide in order to cover the research questions for the overall project, which were formulated as follows:

- How do parents experience the loss of a child, and how are these experiences related to the practices and interpretative repertoires of grief that are available in our culture?
- How do the current psychological, health oriented and increasingly

diagnostic understandings of grief inform individual grief experiences and practices?

- How do the parents engage in and draw upon the production and negotiation of meaning, identity practices and narratives about loss that are created within the grief support practices provided by the bereavement organization?

All interviews were audio recorded and transcribed verbatim. During the process of interview transcription and analysis, significant statements were selected and developed into tentative codes and subsequently categorized into themes developing in the data (cf. Charmaz, 2006). For the purpose of this article, we have read through the transcripts to find interview passages that directly or indirectly address the normativity of grief, i.e., statements in which the participants reflect upon their own and other people's evaluations of their loss, grief reactions, and responses. During the analytical process, the emergent findings were shared within our research group as well as with other scholars within the fields of psychology, sociology and anthropology, who continuously have challenged and discussed our interpretations.

Findings: Diffuse status of the loss, diffuse normative framework for grieving

Numerous studies and clinical practice support the popular assumption that parents (most notably mothers) are the "chief mourners" when a child dies, and the loss of a child is generally perceived as one of the most severe types of bereavement (Robson & Walter, 2013; Sanders, 1980). Historical and anthropological studies indicate that this may be particularly pronounced in modern societies with low child mortality, compared to societies with high child mortality that have formed and still form the conditions for many people around the globe (Lofland, 1985; Scheper-Hughes, 1993). However, in contemporary Western societies with low child mortality, the loss of a small child in pregnancy or within the first weeks of life is nonetheless associated with diffuse and conflicting understandings of the magnitude and character of the loss (Cacciatore, Defrain & Jones, 2008; Lang et al., 2011). As we have seen, earlier practices of care as well as public discourse have tended to view these losses as less severe than the loss of an older child whom one have "gotten to know". In contrast, today the prevailing practices of care for these bereaved parents explicitly acknowledge the dead child's status as a 'real child', and encourage the parents to make bonds and create memories in order to help the grieving process (Callister, 2006). These two views represent contrasting, yet coexisting views of the loss these parents experience. Bluntly put, the former represents the loss as a more or less replaceable loss of a 'foetus', 'stillborn', 'miscarriage' or 'unknown child', while the latter promote an image of the child as unique and irreplaceable. As we shall see, these opposing views are reflected in several ways in the participating parents' accounts.

The blurred status of the child in early infant loss

Even though most of the participating parents in this study express that they have been met with support and sympathy for their loss, most of them also refer to situations in which their loss have been met with comments which they have experienced as diminishing, inappropriate or offensive, such as "It was good it happened now instead of later", "It is good you didn't get to know him/her first" etc., implying that the loss of a smaller child is somehow replaceable and hence less severe than if the child had been older. For example, Linda[24], whose firstborn child died four days after he was born due to an unrecognized congenital disease, recalls from their son's funeral:

> Then one of Chris' [her husband's] parents' friends came over, exclaiming 'You'll just have to get back in the saddle!' My son lies in the coffin, and we're on our way to bury him!

Likewise, Paul, who lost his firstborn child in a stillbirth, recalls:

> We've gotten some weird comments from people, like 'You're young, you can have another one.' I understand what's meant, but it's not like a pair of trousers. The woman who said so has three children of her own. If she lost one of them, that [having two other children] would not make her grief less.

However, even though most of the participants explicitly reject the notion that their grief is relative to the age of their child, at other times they seem to accept that there is indeed a difference. For example Mia, who also lost her firstborn child in a stillbirth, puts it this way:

> Mia: I feared to be put in a [grief support] group with someone who had lost a two-year-old child. Grief cannot be compared, but that must be so awful. I'd feel that our loss is nothing compared to that…

In spite of stating that grief "cannot be compared" – an expression that is often used throughout the different interviews – Mia does actually compare her loss with others and finds her own to be less significant than someone who has lost older children. In this sense, there seems to be an unofficial "grief hierarchy" that is both rejected ("grief cannot be compared") and accepted ("our loss is nothing compared to that"). This is an indication of what might be called normative ambivalence.

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[24] The names of the participating parents in this study are changed for reasons of confidentiality.

Sarah, who lost her daughter in a stillbirth, reflects on the issue of social recognition of the loss being dependent on other people's ability to relate to the child as a unique person; as someone one has "gotten to know":

> Sarah: I think it makes a difference for people that they didn’t get to know her. I think the understanding would have been greater if she had lived for some months. (…) [But] it’s not just an abortion. You don’t just move on…

The subject of the dead child’s individual and human status can be a sensitive matter. When John and Emma, who lost their second child in a stillbirth, think back to the time after their son’s birth, John recalls how the midwives:

> …play a crucial part in making us conceive of him as our child. At first it was just a failed pregnancy – an abortion or something like that…

His wife Emma interrupts him, stating:

> It’s you who think like that, I don’t.
>
> John: No, okay- (they both laugh a little) That’s okay. (…) But I think the way these midwives act… (…) After the birth, they say ‘Congratulations with your son’ and such. (…) To me that has made me think he’s our son, and it was a real child. (…)
>
> Emma bursts into tears, exclaiming: Of course he was a real human being!

Although many parents—also in the present study—react with initial shock and disbelief when confronted with the message that they are to go through a natural labour, most of them look back on the delivery and the time spent with their dying or dead baby as a precious experience. (It is necessary to stress that this applies to parents who by the time of birth knew that their baby was dead or would die soon after birth, and that the circumstances for parents who lose their children due to unanticipated events and medical failures during the course of birth will often be different.). The parents’ trajectories from their initial response of shock and disbelief to their retrospective accounts of the birth as something "natural" and precious are mediated by the hospital staff's (most prominently the midwives’) guidance throughout the process. For example, Thomas and Anna describe how the midwives “showed the way” to how they could be together with their dead son after the birth. Anna states:

> [The midwife said] ‘You’ve had a son who is dead’. That hadn’t dawned on me at all. She shows the way: ’May I see Oliver?’ She unwraps him, and then she leaves again. Kind of shows the way—‘this is how you are parents to a dead child’. It made it so natural to be with him, really. If somebody had told me they’d been with their dead child from Thursday to

> Monday, I would have found it macabre, but…It just made it such a natural thing. We are so happy and grateful they gave us the opportunity to give Oliver a lot of care and love – and to be attached to him. It has helped with the attachment.

Anna’s reflections on how she believes she would have reacted before is an expression of the cultural expectation of stillbirths and infant death as something macabre. Several of the parents describe how they take these cultural expectations into account when considering how to share their experiences with others. The assumed limits of other people regarding how much they can tolerate hearing about the loss can pose a dilemma for the bereaved parents: While they may feel an urge to share their experiences of pride and affection for their dead children with others, they are concerned about whether other people might find this offensive, something that illustrates the normative ambivalence of grief in this context. Linda and Chris recall:

> Linda: I still find it hard to look at the pictures [of him], but when I meet people, I really feel a need to show them the pictures. I am just as proud of my son, even though he’s not here.
>
> Chris: That’s why it was so important to us that so many attended the funeral. It was important to tell that he was here. It was important that everybody got a picture of him on the funeral brochure.
>
> Linda: It’s the only picture of him with open eyes. We put it on the leaflet instead of on the coffin. That would be too explicit for people…

Diffuse norms about how to grieve: Grieving too much or too little

Associated with the diffuse and ambivalent understandings of the loss itself is a similar lack of clearly defined norms about how much or little grief that is called upon in the context of infant loss. The parents’ accounts contain multiple experiences with uncertainty and confusion concerning their own and other people’s expectations of what is understood as appropriate intensity, duration and expression of their grief. On the one side, there is a dominating discourse against ‘cultivating’ or ‘overdoing’ grief, which is often associated with pathological grief reactions. For example, the participants repeatedly distinguish between “feeling sad” and “processing” versus being “stuck in”, “cultivating” or letting grief “take over” in order to distinguish between appropriate and exaggerated grieving – illustrated below by Mia’s reflections on the grief of a friend, who has also lost an infant:

> Her grief reactions [excessive anger and bitterness] have been my worst horror scenario. In my eyes, she became ill from it. (…) It’s okay to feel sad, but the grief shouldn’t take over. (…) We should process it, not cultivate it.

On the other side, there is a challenging discourse against grieving ‘too little’, that might be interpreted either as an expression of poor psychological coping (e.g. as repression), or as a failure to acknowledge the dead child’s significance. For example, Anna reflects:

> Several times I’ve gotten a bad consciousness about being able to sit and laugh… (…) I’ve doubted whether it’s the right way to cope (…) Am I supposed to sit and stare and be sad and cry for twelve hours a day..?

Likewise, Linda talks about her ambivalent feelings when people praise her for “being strong”:

> My first thought is: ‘Okay, do I not love my son enough?’ Then I push it aside. I know I love him.

The normative balancing between grieving “too much” and “too little” is a recurring theme in the interviews, and even though the participants frequently talk about grief reactions as something that “strikes” them, this does not mean that they deny responsibility for how they deal with their grief. For example, when Mia reflects on her moral accountability regarding how she responds to her loss, she suggests that there are grief reactions (like outbursts of anger or crying, etc.) that she cannot fully control. However, how she responds to these reactions (e.g., by being aware of her limits regarding social engagements in the time following the loss, apologizing for unrighteous behaviours etc.) is indeed her moral responsibility as she sees it:

> Mia: To me there’s a difference between grief reactions and conscious choices. We must have our own person with us. That’s what I’ve feared the most. Not so much the grief reactions. All of a sudden, everybody has seen you cry. (…) But my focus has been on not changing our values or personality. (…) We fine-tune our personalities. It mustn’t make us lesser persons.

In Mia’s account, health and morality seem to conflate, in the sense that how one relates to and mediates one’s grief reactions—and not so much the reactions per se—is crucial for evaluating the healthiness as well as the morality of the grief: Her friend’s anger and bitterness are simultaneously evaluated as unhealthy and morally blameworthy grief responses, while healthy grieving is associated with personal development (“fine-tuning of their personalities”).

Discussion

In this article, we have argued first theoretically that grief cannot convincingly be accounted for in causal and reactive terms, but rather must be understood as a normative practice. Then, we gave empirical examples to explore how the status of the loss itself, as well as the cultural norms for grieving the loss of an infant, are both associated with *normative ambivalence*. This ambivalence is reflected in parental grief experiences and practices in several ways: The evaluations of the parents' grief responses (as well as their own evaluations and mediation of these responses) depend on the extent to which their loss is conceived as replaceable or irreplaceable, relative to or independent of how long the parents have known the child.

Parenthood in the modern West is shaped by normative ideals of unconditional love and of cherishing the individual uniqueness of one's child. Within this moral framework, each child is by definition irreplaceable and parental love and attachment should be independent of how long one has "known" the child. The American anthropologist Nancy Scheper-Hughes (1993), who has lived for decades among people in the poor regions of North Eastern Brazil, has given persuasive accounts of how cultural, material and social conditions shape the process of parental attachment. In contemporary Western societies, a prevailing culture of individualism, combined with low child mortality rates, prenatal diagnostics, family planning patterns etc., has led to increasingly earlier and more pronounced "anthropomorphization" of infants and unborn fetuses (i.e., the attribution of developed human qualities and individual personhood). In contrast, Scheper-Hughes describes how the parents of the poor shantytowns in which she has conducted her field work, faced with the harsh realities of high infant mortality rates, are much more reluctant and slow in forming attachments and attributing human and individual qualities to their new-born babies. Under the conditions of devastating poverty and hopelessness, infant deaths are met with resigned acceptance, rather than grief, and parental attachment is only gradually developed as a child proves it is "strong enough" to live. Grief is thus shaped, not only by cultural ideals, but also in the most profound way by the material and social conditions under which human beings live their lives.

In contrast to the parents in Scheper-Hughes' study, the parents participating in the present study are shaped by a culture in which infant deaths are rare and unexpected and widely considered against "the natural order". However, the normative ambivalence reflected in the parental accounts concerning infant loss indicates that even in this culture, anthropomorphization is a gradual and negotiated process. In spite of a cultural encouragement of early parental attachment, the personhood, human status and irreplaceability of infants who die before, during or shortly after birth are still culturally contested. As an effect, parental grieving after infant loss requires a constant negotiation of the significance and legitimacy of the loss itself. Related to this, the parents' grief responses are also shaped by normative ambivalence concerning what is conceived as appropriate grieving. The parents need to balance between grieving "too much" and "too little", and both extremes can be interpreted as an expression of a disproportion between the loss itself and the grief response. Whether the balance tips in the direction of "too much" or "too little", this can be interpreted as unhealthy, abnormal, or even explicitly immoral responses (e.g., when grieving "too little" is interpreted as a failure to appreciate the child's significance). Healthy, normal and appropriate grieving is associated with cultural ideals of personal growth and development through "processing" the grief (allowing feelings of sadness, as long as these feelings do not "take over").

Following Walter's argument of the interplay between public provision and private experience, individual grief practices are shaped by professional accounts of healthy versus pathological grief, while at the same time, professional accounts are also shaped by the normative practices of everyday life. Although we have outlined the contours of an ambivalent normative landscape for grief in general and parental grief in particular, current developments within our culture indicate a movement towards more fixed norms for grieving, most notably with the recent suggestions to introduce a psychiatric diagnosis for complicated or prolonged grief (American Psychiatric Association, 2013; World Health Organization, 2016). While such a diagnosis arguably will shape bereavement experiences and practices in the future, the diagnosis itself will also reflect the prevailing cultural understanding of suffering as an adverse and unnecessary condition to be overcome in order to pursuit personal health, happiness and well-being (Kofod, 2015).

Conclusions

With reference to examples from a study of parental grief experiences after infant loss, we have attempted to demonstrate that human emotions, including grief, should be understood as normative, insofar as they are necessarily directed towards "objects" in the world in more or less culturally appropriate ways. When grief experiences become diffuse and ambivalent, this is related to cultural uncertainty regarding the status of the lost object (e.g., the human status of infants who die before, during or shortly after birth), as well as to ambivalent norms regarding the appropriate intensity and expression of the emotion. Grieving the loss of an infant in our culture requires a constant balancing within this ambivalent normative landscape. We believe that researchers and practitioners within the area of bereavement and grief should pay more attention to the diffuse and ambivalent normativity of grief in order to understand the nature of this form of human suffering today.

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CHAPTER 10. GRIEF AS A BORDER DIAGNOSIS

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Grief as a Border Diagnosis

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Abstract

Grief is sometimes poetically described as the price of love: An inescapable existential condition of human life. However, throughout the 20th Century grief has increasingly come to be understood as a pathological condition that requires psychological and/or medical intervention. With the release of DSM-5 (American Psychiatric Association 2013), grief came close to being included as a separate mental disorder. However, the diagnostic revisions concerning bereavement have been met with criticism of medicalizing grief, and of exceeding the territory of psychiatry beyond its legitimate borders. On this basis, I argue that grief is currently a border diagnosis, i.e., a condition, whose meanings are informed in heterogeneous ways by medical, psychiatric and psychological understandings, yet constantly challenged by alternative, non-medicalizing discourses. Drawing on empirical findings from an on-going interview study with bereaved parents after infant loss, I analyze and discuss four different accounts concerning the question of diagnosing grief: (1) Diagnosis as a legitimating and normalizing practice, (2) diagnosis as a demarcation practice, (3) diagnosis as pathologization, and (4) diagnosis as a normative ideal. Through the examples, I attempt to demonstrate how bereaved individuals do not merely passively adopt, but reflectively use these kinds of understandings to deal with their grief.

Keywords: *grief, mental disorder, DSM-5, parental bereavement.*

Introduction

Historically, death, loss and grief have been experienced and practiced within an interpretive framework of religion and morality. However, in Western societies since the beginning of the 20th Century, the disciplines of psychology and psychiatry have played an increasingly central role in our understandings and practices related to loss. This is part of a general historical line of development, in which "in short, more and more people and problems were opened up to the diagnostic gaze and therapeutic interventions of psychiatry" (Rose 1986; in Rose 2006 p. 475). Bluntly put, the main problem of death in pre-modern societies concerned the destiny of the deceased person's soul in the afterlife. In contrast, the main problem of death in modern secular societies is that of the health and wellbeing of the survivors. Walter (1996) argues that the very concept of *bereavement* is a secular notion, in the sense that it reflects a shift from religious to secular concerns: From questions of salvation and condemnation to questions of health and illness, normality and pathology, risks and prevention.

This inclusion of bereavement under a "diagnostic gaze" has given rise to heated debates on the legitimate territory and limits of psychiatry. Most recently, this debate has been raised in relation with the release of the DSM-5 (American Psychiatric Association, 2013). The two most contested revisions concerned the elimination of the bereavement exclusion criterion for major depressive disorders, and the inclusion of complicated or prolonged bereavement reactions (currently named *persistent complex bereavement disorder*) in section III of the manual as a condition for further studies (Ibid.; criticized e.g. in Frances 2013; Wakefield 2013). Without the bereavement exclusion, studies indicate that one-third to one-half of bereaved individuals will meet the diagnostic criteria for major depressive disorder within the first month after the loss (Clayton & Darvish, 1979; Zisook & Shuchter, 1991; in Horwitz & Wakefield 2007, p. 31 *ff*). For bereaved parents, the prevalence rates are estimated to be even larger, more intense and longer lasting (ibid.).

This is not the place to account for the various arguments that have been raised in relation to these revisions. Here I want to highlight just one main argument that has been brought forth in the criticism of diagnosing bereavement reactions: In short, the argument that it represents an illegitimate *medicalization* of normal and natural experiences of human suffering (see e.g., Frances 2013; Wakefield 2013). This is by no means a new critique of psychiatry. Indeed, Rose (2007) refers to medicalization as a "cliché of critical social analysis" (p. 700), and argues that medicalization alone "should not be the conclusion of an analysis" (p. 702). Why, he asks, "should it seem ethically or politically preferably to live one aspect or department of life under one description rather than another?" (p. 701). In other words, it is not sufficient to state *that* medicalization processes occur; we need to analyze *how* they occur, and with which individual and societal consequences. In this article, my aim is to contribute to this analysis by articulating four different positions taken up by bereaved individuals towards diagnosing grief: (1) *Diagnosis as a legitimating practice*, (2) *diagnosis as a* *demarcation practice (delineating pathology from normality*), (3) *diagnosis as (illegitimate) pathologization*, and (4) *diagnosis as a potential normative ideal*. The examples are based on empirical findings from an on-going interview study with bereaved parents after infant loss.

While the overall study aim of the research project is to explore the relations between individual grief experiences and cultural understandings of grief, this article more specifically explores how the participating parents reflect upon the specific topic of diagnosing grief as a mental disorder. Furthermore, I will address and discuss some of the normative expectations towards grieving that are reflected in the parental accounts on diagnosing grief. Finally, by focusing on how diagnostic understandings are actively used and interpreted by individuals in social practices, I hope to contribute to the understanding of the complex relations between contemporary discursive practices and individual experiences of suffering.

Theoretical framework

The following analysis draws upon a cultural psychological perspective. Cultural psychology is based on the premise that culture mediates and enables human intentionality and activity. Following a cultural psychological perspective, intentional agents reflectively and unreflectively use culturally available semiotic and material tools to interpret themselves and the world, and to mediate their actions and emotions (Valsiner, 2007). Another central point in cultural psychology is the emphasis on the potential for creative use of cultural artefacts, and the co-constituted nature of mind and society.

Consistent with this approach, I examine the ways in which bereaved parents experience, interpret and act in relation to their loss, and how they draw upon culturally available interpretive repertoires related to grief in this process. Experiencing grief is a culturally mediated process, in which the individual draws upon past experiences, culturally available interpretive repertoires and norms concerning how and when to grieve, how to interpret one's own and other's loss responses etc. How do these processes occur? How do bereaved individuals use and negotiate—and how are their experiences of grief shaped by—the grief discourses and practices of contemporary Western cultures? These questions become increasingly urgent in the light of the prevailing medical and diagnostic approaches to grief, as it is in this context individuals experience, interpret, evaluate and "do" their grief.

Methodological approach

In this article, I analyze interview material from a series of in-depth semi-structured qualitative interviews with bereaved parents after infant loss in order to explore how these parents relate to the idea of diagnosing grief as a mental disorder.

The data are drawn from 20 interviews conducted over a period of 2 years (from December 2012 to October 2014) with 13 bereaved parents following infant loss. The participants—six heterosexual couples and one woman participating without her partner—were all recruited through a nationwide, private Danish organization that offers counselling and network support to bereaved parents after infant loss. With one exception (a couple participating in one interview approx. 2 years after the loss of their child), all participants were interviewed three times; shortly after the loss (<2 months), 7-8 months later, and finally approx. 2 years after the loss. With exception of the woman participating alone, all participants were interviewed together with their partner. Furthermore, all of the interviews were carried out in the participants' homes.

The sample of participants was selected in order to reflect the variation in terms of geographical location, circumstances of loss, family situation and social background of the parents who ordinarily make use of the services provided by the bereavement organization. The participants had lost children who died shortly before, during or after (< 1 month) birth, all born in 2nd or 3rd trimester of pregnancy. One of the couples had lost their second child, whereas the other participants had all lost their first-born child. The participants' age ranged from 26 to 42 years, with a mean age of 33,3 for the female participants and 31,7 for the male participants. The interview guide was developed as a semi-structured guide in order to cover the research questions for the overall project, which are formulated as follows:

- How do parents experience the loss of a child, and how are these experiences related to the practices and interpretative repertoires of grief that are available in our culture?
- How do the current psychological, health oriented and increasingly diagnostic understandings of grief inform individual grief experiences and practices?
- How do the parents engage in and draw upon the production and negotiation of meaning, identity practices and narratives about loss that are created within the grief support practices provided by DIDA?[25]

The diagnostic and medical understandings of grief represent one aspect of bereaved parents' loss experiences that I was eager to explore. This was reflected in my interview guides' questions concerning the parents' grief experiences, including how they perceive cultural expectations about grieving, how they consider grief in relation to illness, what they think about the proposed diagnostic category for complicated grief etc. (E.g. questions such as "How do your current experiences with grief fit with your prior notions of grief?", "How do they fit with the way you experience other people's expectations?", "Has this changed over time?", "Do you think it makes sense to compare grief to an illness? Why/why not? In your opinion, what are the similarities and what are the differences?", and "It has been proposed to introduce a psychiatric

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[25] This part of the research project will not be pursued in this article.

diagnosis for complicated or prolonged grief (followed by a brief introduction to the proposed criteria). What are your immediate thoughts about that?" etc.).

All interviews were audio recorded and transcribed verbatim. In order to address the topic of this article, my approach has been to read across the transcripts to find interview passages where the participants talk—either spontaneously or as a response to my questions—about the topic of diagnosing grief, how they experience cultural expectations toward grieving, and how they regard differences and/or similarities between grief and mental disorder, most notably depression. During the process of interview transcription and analysis, significant statements were selected and developed into tentative codes and subsequently categorized into themes developing in the data, informed by the guidelines of the constructivist version of grounded theory as outlined by Kathy Charmaz (2006). During the analytical process, my emergent findings were shared with my research group and other scholars within the fields of psychology, sociology and anthropology, who continuously have challenged and discussed my interpretations.

Limitations

Some points need to be made about the methodological approach, and the limitations and scope of the current analysis. Firstly, it is necessary to clarify that the subject of diagnosing grief is only one area of interest I pursue, as a part of a broader interest in cultural practices and interpretive repertoires related to grieving.

Secondly, as the current diagnosis is not yet introduced in Denmark, none of the participants in my study have been in a situation where their grief has been diagnosed as a grief disorder. However, several of the participants have been diagnosed with a depressive disorder following the loss. Some have met tentative suggestions from their doctors—or from their personal network—that they might be suffering from depression. In other words, even though a diagnosis for prolonged grief is yet to be introduced in Denmark, several of the informants report that their grief has been associated with a psychiatric condition (primarily clinical depression).

Thirdly, I make no claims about the frequency or specific distribution of the presented accounts. Rather than reading the following accounts as stable positions held by different groups of individuals, I believe they should be approached as heuristic typologies that inform us about the different ways diagnoses may be accounted for by grieving individuals in contemporary Western cultures.

Ethical considerations

The project is carried out in accordance with The National Committee on Health Research Ethics in Denmark and has been notified to the Danish Data Protection Agency. Inviting bereaved parents to participate in a research project on parental grief is associated with a number of ethical considerations due to their vulnerable position. My own background as a clinical psychologist with several years of experience from working with bereaved parents has developed my awareness for attending to the individually different circumstances and needs of bereaved parents. Although it is important to be aware of the potentially vulnerable state these parents may be in, it is equally important to avoid reproducing what many bereaved individuals experience as a fear of contact from their environment towards their loss. My personal experience from talking to bereaved parents mirrors what is frequently stressed by bereaved individuals: While most bereaved parents express a wish to talk about what has happened, they often experience that many people tend to avoid confronting the topic of death in general, and especially the death of a child (Dyregrov 2003; Lehman et al. 1986, Rönnmark 1999).

In a Norwegian study of bereaved parents' experiences of participating in research projects, all participants (63) rated it as a positive experience, and none of the respondents expressed regrets of having participated (Dyregrov 2004). In this and similar studies (see e.g. Breeze et al. 2011), the possibility to help others in a similar situation is stressed as a central motive for participation.

Grief and the *psy* disciplines

Medicalization has had a profound influence on the interpretive frameworks that are available for people's normative understandings and practices related to grief. More specifically, psychiatry and psychology (the *psy* disciplines; Rose 1998) have contributed to shape our notions of what it means to grieve "properly", of the goals and pitfalls of grieving, and of which practices that are approved of and sanctioned (Walter, 2000). While medicalization refers to understanding certain aspects of human behavior, thoughts and emotions as *medical* phenomena suitable for medical intervention, I use the term psychologization to refer to how psychological knowledge have come to shape our notions of who we are, as a certain kind of beings with an inner realm of mental dynamics, representations, emotions and dispositions. As such, medicalization and psychologization of grief reflect broader historical processes of modernization, in which medicine and the *psy* disciplines increasingly have come to play "a constitutive part in 'making up people'" (Rose 2007, p. 700).

In this process, psychiatric diagnoses have become significant "boundary objects" in the contemporary West, i.e., pragmatic constructions that have "different meanings in different social worlds", yet still remain "robust enough to maintain a common identity across sites" (Bowker & Star 2000, p. 297). Likewise, Pickersgill (2012) analyses the DSM as polyvalent text that works as a "connective tissue" for the different groups of actors that have a stake in psychiatry (Lakoff 2005; in Pickersgill 2012, p. 331). In the diagnostic cultures of contemporary West, these multiple actors are not confined to different groups of professionals, but include laypersons, patient organizations, media etc. (Brinkmann et al. 2014).

The processes of medicalization and psychologization of grief are interrelated and not easy to disentangle, and I will treat them as two sides of the same general tendency towards understanding grief as a psychological process, and—increasingly—as a matter of individuals' mental and physical health and risk of pathology. However, as indicated above, merely pointing out processes of medicalization and psychologization does not help us understand how, why or with what consequences these processes have occurred (Rose 2007, p. 701). For example, while the anti-psychiatric movement from the 1960's and onwards highlighted the stigmatizing consequences of psychiatry, psychiatric diagnoses today seem to have heterogeneous and complex functions ranging from social control to legitimating and explaining individual suffering: ”A diagnosis can vindicate and blame, can legitimise or stigmatise, can facilitate access to resources just as it can restrict opportunities. A diagnosis can be welcomed or eschewed" (Jutel & Nettleton 2011, p. 797). What, then, are the consequences of diagnosing grief, and with which arguments is a grief diagnosis welcomed or eschewed by bereaved individuals in our present cultural context?

Grief as a border diagnosis

Psychiatry and psychology do not represent single entities. Both have heterogeneous effects on how grief is experienced, interpreted and acted upon in contemporary Western cultures. However, I argue that it is possible to identify some common themes between the psy disciplines and the grief discourses they have contributed to shape: On the one side, grief is accounted for as a matter of authentic emotional disclosure, of affectionate bonds and broken hearts. On the other side, grief is described in terms of work, tasks, coping strategies, risk factors and health consequences. I argue that these different accounts reflect an implicit tension within contemporary discourse of grief as on the one side a "natural" and existentially significant process, and on the other side as a potential risk of adverse mental and physical health consequences.

Grief entered the field of psychology with Sigmund Freud's ground-breaking essay "On mourning and melancholia" (Freud 1957). Freud's idea that a period of "grief work" is necessary for the individual to break the attachment to the deceased in order to regain autonomy has had a significant influence on grief counselling, literature, and general public understanding of grief throughout the 20th Century (Wortman & Silver 2001). Although Freud recognized grief as a fundamentally *natural process,* that neither could nor should be treated medically, a significant consequence of his work has been the positioning of grief as an object for psychological and psychiatric research and intervention (Granek 2010).

Throughout the 20th Century, bereavement research increasingly followed an empirical and quantitative approach. Studies based on predominantly white, middle-class, widowed female populations aimed at presenting systematic descriptions of grief symptoms and reactions (e.g. Marris 1958; Hobson 1964; Parkes 1964; 1970).

A common feature across these different empirical studies was the privileging of emotional reactions at the expense of e.g. cultural and social aspects of grief (Valentine 2006). Another common feature was the assumption of universalism at the core of the theoretical claims built upon these empirical findings. Individual experiences were subjected to theoretical systematizing and generalizing, and translated into universal theories of phases, stages and tasks that bereaved individuals were expected to go through in their mourning (Ibid.). These theoretical conceptualizations of grief were linked to strategies of interventions and therapeutic practices aimed at managing and treating bereaved individuals. The aim of the treatment was typically structured around solving the identified tasks. Hence, what were initially put forth as mere *descriptions* of grief became *prescriptive* targets of a clearly delimited grief process. Another central contribution to the bereavement research in the 20th century is the development of standardized questionnaires aimed at systematic measurement of individual grief reactions. From the 1970s, a series of influential grief inventories were produced in order to diagnose, manage and treat grief, as well as establishing grief as a scientific construct within the field of psychology and psychiatry (Granek 2010). By the end of the 1980s, Stroebe, Stroebe & Hansson (1988) identified mental and physical health consequences along with pathological forms of grief as the two major themes of the bereavement research of the time.

These briefly outlined historical developments form the basis of the last decades' attempts to formulate a diagnosis for complicated or prolonged grief (Shear 2012; Prigerson et al. 2009). The proposed diagnostic criteria put forth in the different suggestions involve intensity and duration of reactions such as longing/yearning, diminished sense of self, difficulty accepting the loss, bitterness or anger related to the loss, feeling that life is unfulfilling, empty or meaningless since the loss, etc. (Ibid.).

According to the DSM definition, a mental disorder is a syndrome that "reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning" (American Psychiatric Association 2013, p. 20). However, according to the same definition, "(an) expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder" (Ibid.). Similarly, academic texts on grief disorders typically opens with a statement of the natural and universal character of grief, before they move on to discuss how grief can develop into a mental disorder for some individuals (see e.g. Shear 2012; Prigerson et al. 2009). In other words, although grief is regarded as a potential risk of mental disorder—and even as a potential disorder in itself—the reluctance to pathologize "normal" grief is reflected even in the "diagnostic bible", the DSM. On the one side, authentic expression of emotional pain is encouraged as a means to self-fulfillment, personal growth and healing. Tellingly, the bestselling book on grief in Denmark throughout the last three decades bears the title "Healing pain" (The original Danish title translates as "The necessary pain") (Leick, Davidsen-Nielsen, & Stoner, 1991). On the other side, prolonged and overly intense grief reactions are considered to be risk factors and symptoms of mental disorder, hereby representing an object for medical, psychiatric and psychological science.

Parental accounts on diagnosing grief

In my interviews with the parents participating in this study, grief is repeatedly referred to simply as love. However painful, grief is also in some way appreciated as recognition of their dead children's continuing significance in their lives. When asked whether they would appreciate it if there were a "pill that could make the pain of grief go away", all of them object. Nevertheless, although some of the parents are critical towards the idea of a grief diagnosis, several of them immediately support it. Their reasons for objecting to or supporting the notion of a grief diagnosis form the basis for the present analysis, and I will briefly describe four positions identified throughout the interviews.

Diagnosis as a legitimating practice

The first account, diagnosis as a legitimating practice, refers to a tendency among bereaved parents in my study to view a diagnosis as a form of *legitimization of the suffering* of grief; as a means of *achieving rights and privileges*, either emotionally ("to have the right to grieve"), materially (e.g. in form of access to sick leave, economic and therapeutic support etc.), or relationally (to have a legitimate way of communicating one's suffering to others). When I ask what they think of the notion of a grief diagnosis, several of the participants state that they think it is nice to get the "system's recognition" of the severity of their loss. As one of the male participants, John,[26] argues: "Why should grief not be a diagnosis, if e.g. fear of flying is?" Likewise, one of the female participants, Diana, argues that a diagnosis would have made it easier to claim her rights in front of her employer, who had shown little support in the time following her child's death.

Similarly, some emphasize that a diagnosis would probably make it easier for their friends and relatives to understand and relate to their problems. E.g., Paul ponders,

> I think it would have made it easier for them [their relatives] to say 'Okay, they're depressive! Instead of 'They're just sad…' That's kind of…

Others stress the possibility of using the diagnosis as a means to understand their own experiences, to explain it to others, and to use the language provided by the diagnostic descriptions as a communicative tool. Furthermore, and quite interesting given the widely-held criticism of psychiatric diagnoses as stigmatizing, some of the

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[26] The names of the participating parents in this study are changed for reasons of confidentiality.

participants mention the potential *normalizing* consequences of a diagnosis. Thomas states,

> To get other people's word for… Kind of: This happens to others too. It's a normal reaction, and it's a symptom of this. Okay! That's nice. Because then you have something tangible to relate it to.

In other words, rather than interpreting the diagnosis as a description of *abnormal* reactions, the very opposite might sometimes be the case: The diagnostic description might be interpreted as recognition of the *normality* of the reaction, i.e., as a description of *common* experiences one might have after a loss, rather than as a description of pathological or exceptional experiences.

Diagnosis as a demarcation practice

In the next perspective I will present, the idea of a grief diagnosis is recognized as a generally acceptable way to differentiate between healthy/normal/natural and unhealthy/pathological/dysfunctional grief reactions.

This reflects the majority view of the proponents of a grief diagnosis, in which a diagnosis is viewed as a means to identify and diagnose those in need of preventive or therapeutic intervention. Demarcations between normal and pathological grief are made with reference to normative standards of intensity, duration and content of emotional expressions: Normal grieving allows for a certain degree and duration of emotional pain, while pathological grief is associated with prolonged, overly intense and negative emotional expressions like bitterness and anger. E.g., when I ask what they think of the idea of differentiating between normal and pathological grief, Mia and Jacob recall a woman they met in a grief support group they attended after the loss of their daughter:

> Mia: I felt like shaking her: 'You need help!'
>
> Jacob: The thoughts she had… so much bitterness and anger. It was one year ago [since she lost her child]. At that point, we should be able to talk about it…
>
> Mia: Without such anger…

For Mia and Jacob, demarcation practice is stressed as a part of their self-regulation, as they actively monitor "warning signs" in each other. For example, they have been told that it's okay to stay in bed for one day, but if it is for several days, this is a sign that something needs to be done. Furthermore, grief reactions are monitored according to normative standards of personal development. As Mia states: "It must not change us. Or it changes us—but it must be for the better".

Similar to the use of demarcation practices as a means to steer away from pathological grieving, is the positive use of them as reassurance of normality. For example, Rita, who has a prehistory of mental illness, tells that she was worried that she was about to become ill again, but that her therapist had reassured her that her reactions where "normal". Several, if not all, of the participants in this study, highlight the importance of reassurance of normality from professionals or from others with personal loss experiences. To know that their experiences of suffering, in spite of their often frightening intensity, are normal, makes it easier to accept them. Additionally, several of them stress that feeling confident about the normality of their reactions makes it easier to resist the normative pressure from friends and family to "resolve grief" and achieve "closure". Several of the participants object to the idea that grief should be "resolved", and prefer expressions such as "learning to live with it", "carrying him/her/the grief in one's heart" etc.

Diagnosis as (illegitimate) pathologization

The third account I want to highlight, diagnosis as illegitimate pathologization, mirrors the medicalization critique described briefly in the introduction to this article. This perspective maintains that even intense and long-lasting grief ought to be considered as a normal reaction to a profound loss. As Sarah states,

> I'm quite certain that, when a year has passed, I'll still think about it, I most certainly will… (Cries). I don't know. I think I would find it strange to get a diagnosis, because then it becomes something pathological, that must not be there…
>
> Interviewer: Do you think, if we imagine it as a psychiatric disorder, would they think 'she can't help it', or would they think 'she should pull herself together, she just sits there and wallows in this grief'?
>
> Sarah: Yeah, I think so – more the latter, that you wallow a little too much in it…

While the first account stressed the diagnoses' potential to raise public awareness and acknowledgement of the suffering people in grief experience, the latter focus on the opposite possibility, i.e. that a diagnostic approach to grief might *reduce* other people's tolerance and put pressure on bereaved individuals to resolve their grief and/or seek treatment.

Another objection against diagnosing grief is that a diagnosis does not allow for individual differences, which many of the informants stress as a crucial aspect of grief. For example, Emma exclaims,

> But is it at all possible to make such criteria? Because grief is so individual… Isn't it? I mean, you cannot just lump people together…

However, even though this perspective is presented by several of the informants, this is not necessarily associated with a plain rejection of any medical intervention in the case of painful grief. For example, some of the participants argue that even though grief reactions might be perfectly normal and natural, they might be so distressing that some kind of intervention—be it medical, psychotherapeutic or something else—might be required. As Rita argues,

> There are many people who have to fight alone with their grief; who don't have a big man to cuddle them, right? And on such an occasion I'd say that such things as tranquillizers, perhaps sleeping medicine, might be something that is necessary to use. Because if you can't sleep, your chances of getting along gets even worse. So, I think it's highly individual, and I think that if a person asks for help in such a situation, it means that he or she really does need help, whether it be this one or another diagnosis.

In this case, diagnoses are accounted for primarily as pragmatic tools for practitioners to help and intervene when people feel they can't handle their problems alone. Given that medical intervention might actually help, it is suggested that it should be offered, regardless of whether the reactions are normal or symptoms of mental disorder. Linda too reflects on the pragmatic aspect of diagnosing (the relation between diagnosis and availability of treatment), and like many of the participants, she argues that she would 'rather have a grief diagnosis than a depression diagnosis'. Likewise, Mia and Jacob refer to a bereaved mother whom they met through a grief support group. The woman had been diagnosed with a depressive disorder. Mia recalls,

> I could hear she missed a grief diagnosis, actually. Because the doctor labelled her as depressive. She was frustrated about that. She didn't feel she was depressed, but in grief. But she needed the diagnosis in order to get her sick leave.

At other times, the participants were ambiguous towards the idea of a grief diagnosis. E.g., Thomas reflects,

> [Yesterday] we talked about this: Grief is so… individual. I think that's at the core of this. I wouldn't like being labelled with a grief diagnosis.
>
> Interviewer: Why, do you think?
>
> Thomas: Because then I think it's pathologized. I don't want to be pathologized because of this, because it's a grief and it should be allowed to take space without me necessarily being ill. Because that's how it is when you lose someone. You get sad. And you should be allowed to be so, without being ill. But on the other side, I can imagine that there might be someone who does become ill from it. I believe you might, if you

> become depressed or really struck by it. I can really understand if someone does, so it's both…

Several of the informants pursue a view similar to Thomas's: They express a reluctance towards considering grief as an illness, but on the other hand, they can imagine—and have perhaps met—someone who might be ill from grief. As complicated grief is not yet introduced as a diagnosis, it is plausible to argue that it is still more contested than widespread diagnoses such as depressive disorder, which is also reflected in the informants' accounts. Several times the informants state that grief that 'develops into a depression' is another matter than grief in itself.

Thomas's fluctuating position illustrates one of the basic claims of this article: Psychiatric diagnoses increasingly function as semiotic mediators for individuals to understand and act upon their experiences of suffering and distress (Brinkmann 2014). However, as this analysis has attempted to show, this happens in multifaceted and at times contradictory ways. People use, negotiate and challenge the understandings provided by the psychiatric language, and combine them in ways that cannot be accounted for as either exclusively iatrogenic or therapeutic, repressive or emancipating. Rather, the relationship between psychiatric diagnoses and practices, socio-political realities and individual self-practices are complex and heterogeneous.

Diagnosis as a normative ideal

The fourth account is represented by only one of my informants, but is included because of the intriguing challenge it poses to the widely held notion of psychiatric diagnoses as stigmatizing: Linda interestingly states that given a grief diagnosis, she would feel an urge to "live up to" the criteria in order to prove to herself (and others) that she loved her dead child: "If I didn't get the diagnosis… I would think 'Do I not grieve enough for my child?'"

Linda returns to this topic several times during our conversations, and elaborate on her own struggle to acknowledge that her ability to cope with the loss does not indicate that she does not love her son or that he has less significance than if she were more depressed or grief-struck:

> We've had to reassure each other that it's okay to feel like we do… And that we may also laugh. We don't need to sit and cry 24/7. That doesn't mean we don't miss our son and wish that he was here, and that we love him more than anything on earth.

Although not directly associated with the topic of diagnosing grief, Anna reflects along similar lines on the normative implications of the suffering of grief:

> I would have thought that I wouldn't be able to hold myself together. … If I had that feeling before, that if you lose someone, then you can't

> possibly hold yourself together. And now, when it's actually me who has lost someone, I've been distressed about the fact that I do hang together. Why haven't I been out so deep that I can't float?

In our last conversation, Anna returns to this topic. Turned towards her husband, Thomas, she states,

> We've just talked about it, where you said to me that you think you still can get struck by it [the grief] in another way than I can. I mean, it strikes you harder. Not that it has bigger or lesser significance, but that it can strike you harder than it strikes me. And then I can feel like I'm being thrown back to the start – that was how it was in the start. I didn't feel I was struck by it. And why? And then again: Is that wrong? … Why doesn't it hurt my heart the same way?

While some of the participants describe a pressure towards resolving grief and regaining "normal functioning", the normative ideal reflected here seems to be associated with another aspect of contemporary grief discourses, i.e., the one that speaks of grief as a morally significant expression of love. When this side of the normativity of grief is stressed, the grief diagnosis might be seen as a normative ideal worth striving for in order to express and prove one's love and affection for the deceased. This is closely related to Romantic ideals of grieving described in Stroebe, Gergen, Gergen and Stroebe (1992), in which the sustaining of emotional bonds to the deceased loved one, "despite a broken heart" (p. 1208), was valued as morally superior to ideals of functionality and health.

Discussion

Which normative understandings are reflected when grief is perceived through the lenses of a diagnostic account? How does a "diagnostic gaze" inform and shape individuals' experiences and interpretations of their suffering, and how might it affect cultural practices and expectations concerning grief? No straightforward answers emerge from the present analysis. However, it seems plausible to argue that the various accounts on diagnosing grief reflect a tension between seeing grief as a morally significant expression of love on the one side, and as a threat to the individual's striving for health, autonomy, self-fulfillment and efficacy on the other.

A grief diagnosis might legitimate the suffering caused by loss, enhance public recognition and awareness, and give access to professional and emotional support. A diagnosis might be a part of a normative self-regulatory practice, as e.g. when individuals and their networks use the diagnoses as tools to assess grief reactions as normal or deviant. The normative connection between grief and love might urge some bereaved individuals to strive for a diagnosis as a proof of their love to the deceased––or, conversely, to reject it as an illegitimate pathologization and devaluation of the grief's moral and existential significance. However, the latter position is not necessarily associated with a plain rejection of a medical account of grief. As argued by some of the informants in this study, a pragmatic use of diagnoses and medical intervention might be compatible with maintaining that grief reactions are “natural”, normal and not pathological.

As the present analysis has attempted to demonstrate, medicalization processes are not adequately accounted for in terms of repressing power dynamics and stigmatizing practices. Individuals in a diagnostic culture are not merely passively subjectified by repressing diagnostic labels. Rather, the powers of the psy disciplines work productively, by contributing to make us “the kinds of people we have become” (Rose 2007, p. 702). The kinds that emerge from the present analysis are not “medical dopes”, whose interpretations, experiences and practices of grief have been absorbed entirely by a morally depleted medical language. Rather than replacing morality, medicalization processes are inextricably involved in the shaping of the ethical regimes and forms of life that characterize contemporary Western cultures. However, as I have tried to illustrate throughout this article, the moral ideals reflected in diagnostic and medical languages are not fixed; rather, they are polyvalent and malleable. This is perhaps particularly evident in the case of grief. Given the conflicting ideals of grief as a morally significant expression of love and connectedness vs. grief as a threat against individual health and well-being, a grief diagnosis might be embraced or rejected with arguments stressing either sides of this tension.

One last point needs to be made. The broadened scope of psychiatry is often described as a “pathologization of normality” (see e.g. Frances 2013). However, as prevalence rates rise, and psychiatric diagnoses diffuse into everyday practices and conversations, a reverse process takes place simultaneously: A *normalization of the pathological*. In other words, when grief is pathologized, it does not necessarily mean that it is transformed from a shared human condition to a pathological exception, but rather, that pathological grief is turned into a potential risk for all grievers. The psychiatric and diagnostic language is no longer exclusively associated with pathology and deviance—and not even necessarily with something unambiguously negative (as the example with diagnoses as normative ideals illustrated.) The diagnostic and medical language is also used to legitimate and normalize individual experiences of suffering. Rose (2009) has argued that psychiatric disorders in our time is regarded “simultaneously [as] a condition to be treated and a mode of existence to be expected” (p. 79). Health and normality are no longer defined by the absence of illness, but rather as something to be “worked upon” through continuous health-promoting and self-developing practices.

“And so what?”, one might rhetorically ask. If more people are diagnosed with psychiatric disorders, and experience that this helps them to understand and cope with certain aspects of their lives, is that necessarily a problem? Several critics have addressed this question and offered different answers to it (see e.g. Francis 2013).

Here I only want to point to two potential risks associated with the diagnostic account of grief, and with the tendency to normalize pathology.

The first issue concerns the localization of the diagnosis within the individual that is implied in a diagnostic understanding of human problems. Brinkmann (2014) argues that psychiatric diagnoses are commonly understood as "entities" within the individual, which are used as explanations of the problems individuals' experience. Regardless of the circular character of these explanations (i.e., the diagnosis is based on the very same symptoms it is supposed to explain), one effect of this "entification" is that the individual's external conditions are left out of the picture, or accounted for solely in terms of risk or preventive factors for individual illness. In the case of grief, this means that bereaved individuals' possible experiences of e.g. lack of support (emotional, economic or other) are treated as risk factors of individual mental illness. However, this fails to account for how an individual might have very different experiences of e.g. support or lack of such from one context to another. For example, several of the participants in the present study describe different experiences of support across different social contexts, and hence different experiences of their grief across these situations. These complex relations between individuals and their external conditions seem poorly accounted for by a diagnostic approach to grief.

Secondly, a diagnosis is not merely a description of suffering; it is also a target of intervention. As such, treatment is not merely an opportunity for the diagnosed individual. Rather, treatment easily amounts to a normative demand, as individuals are reinforced not to endure, but to act upon their suffering in order to transform it into personal growth and development. Hence, in spite of the potential benefits of the normalization of pathology regarding its de-stigmatizing and empowering effects, a diagnostic account might simultaneously reduce individual and cultural tolerance of suffering. In the case of grief, the pressure to seek treatment might marginalize individuals' experiences of grief as a morally significant appreciation of love. Further, this persistent confidence in treatment and transformation might also marginalize individuals' experiences of inconsolable loss; i.e. the experience of loss as a condition the individual cannot, and perhaps do not wish to, overcome. As a bereaved father wrote in response to the DSM proposal for a grief diagnosis,

> If you don't experience "intense yearning or longing" ... "on more days than not" for more than twelve months after the death of your own child, if you don't have "a diminished sense of self," you have a problem that goes deeper than anything contemplated in the DSM. There are some things in life to which one should never hope to become adjusted (Adler 2012).

Or as one of the couples in my study state,

> Chris: It's important that people recognize that he has been here—and is here… It's not something you just get over. You are in it. It's a part of you that's always with you.
>
> Linda: We must accept that it has happened, and learn to live with it. But we'll never get over it. That's a key word. I get mad when people say "get over."

Perhaps we need to ask ourselves whether we ought to accept certain kinds of suffering to escape the promises of treatment and transformation offered by contemporary psychiatry. However, the dilemmas that arise when grief is accounted for as a psychiatric disorder raise new questions as to how the needs of bereaved individuals can best be met. Provided that there are dilemmas associated with the individually oriented diagnostic approach to grief, how can we ensure the availability of adequate help and support to bereaved persons in need of such? How can we distinguish between those in need of professional intervention and those who are not? And how can we ensure an optimal use of public resources, if we do not have the current diagnostic system to differentiate between the conditions? These are only a few of the questions that demand answers, before there can be any serious changes in the way we handle human suffering and existential problems in the pervasive diagnostic culture of contemporary Western societies.

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CHAPTER 11. CONCLUSIONS AND PERSPECTIVES FOR FUTURE RESEARCH

In this thesis, I have examined bereaved parents' experiences of infant loss in contemporary Danish culture. Summed up, the present study argues a perspective on grief as a radically *situated, relational, and normative phenomenon*. Grief can neither be reduced to an individual or intra-psychological process delimited from the individual grievers situated being in the world, nor to factors external to the individual, such as socio-cultural practices, norms, or discursive constructions. Grieving involves the bereaved individuals' relationship to the lost loved one, to oneself, and to other people. These relationships are mediated and informed by the normative practices we are involved in in our everyday lives.

I have attempted to develop analytical as well as evocative accounts of the lived experiences of grief after infant loss, and to relate these experiences to contemporary cultural practices and ways of understanding grief, suffering, and personhood. My research has been guided by a dialectical relationship between my initial research questions and the themes that have emerged during the analytical process of doing interviews, listening to interview records, transcribing, writing, reading, and talking with colleagues and others who have been interested in hearing about my project.

As I have described in chapter 4, in spite of a proliferating literature on parental grief after infant loss, only few studies have addressed how bereaved parents experience, draw upon, and negotiate culturally distributed understandings and practices related to grief after infant loss. While parental bereavement has been linked to detrimental health effects and mental disorders, few studies have explored how such a "medical" and "diagnostic gaze" in itself informs and shapes parental bereavement experiences. The studies that do address these issues tend to analyze medicalization and pathologization as detrimental processes that prevent, disturb, and disenfranchise parental grief. Although I initially shared and still share some of these concerns, my research has challenged my initial conceptions of diagnostic and medical approaches to grief as unambiguously restricting, pathologizing, and marginalizing parental grief experiences. Throughout my research, I have examined how parental grief is experienced, interpreted, and enacted within cultural practices and repertoires that include diagnostic, existential, and moral perspectives. I have examined grief as a radically situated phenomenon that involves the relationship to the lost loved one, to oneself, to other people, and to normative understandings and practices of grief and suffering.

In the following, I will outline the main arguments, contributions, and conclusions of the thesis. Lastly, I will point to some possible avenues for future research on grief experiences in contemporary Western cultures.

11.1. GRIEF AS SITUATED AND MEDIATED EXPERIENCES, INTERPRETATIONS, AND ENACTMENTS

The four articles as well as my empirical chapter on parental experiences of DIDA's practices (chapter 6) offer different perspectives on how individual grief and cultural norms, beliefs, and practices mutually constitute each other. Taken together, the articles and the empirical chapter provide different perspectives and answers to my research questions, as well as to some of the analytical concerns that have emerged during my research process.

The first article traced the historical background for our contemporary understandings and practices related to grief. The second article explored the cultural, epistemic, and ethical significance of my role as a bereaved researcher in the study of bereavement. In the third article, co-written with Svend Brinkmann, we examined how parental grief following infant loss in contemporary Danish culture is mediated by diffuse, yet inescapable normative understandings of infant loss and parental grief. The normative nature of grief was further investigated in the empirical chapter on DIDA's practices (chapter 6). Here, I examined how such practices may be involved in the development of parental identity and social validation of infant loss. Finally, in my fourth article, I examined how contemporary understandings of grief as a potentially pathological condition is conceived of and experienced by bereaved parents after infant loss.

11.1.1. HISTORICAL ACCOUNTS OF GRIEF

In my first article, "From morality to pathology," I examined some of the historical background for how grief has been conceptualized in contemporary Western cultures as a question of the individual mourner's health and illness. The aim was not to provide a comprehensive account of historical practices and beliefs related to grieving. Rather, my ambition was, more modestly, to provide some historical context for our current prevailing understandings of grief. Informed by a cultural psychological framework, the selected historical accounts served to illustrate that grief is mediated by historically specific and inherently normative practices. This perspective highlighted some limitations inherent in the current diagnostic account of grief as an individual reaction, analytically separated from cultural-historical norms and practices. On this basis, the article developed a perspective of grief and suffering as radically situated, involving a mutual interplay of personal and cultural, experiential and discursive factors.

11.1.2. SENSITIZING ACCOUNTS OF GRIEF

In my second article, “Becoming a bereaved parent,” I explored the significance of my own background and involvement in the co-production of qualitative accounts of suffering and loss, and related this to cultural conceptions of grief as a private, emotional and time-limited process delineated from a public, rational, and normal state of being. By intersecting autoethnography and inquiries into the interview encounters with the participating parents in this study, I demonstrated the co-narrated character of interview accounts, as well as the open-ended and transforming process of becoming a bereaved parent and integrating the loss of a small child in one’s continuing life story. Through balancing between the evocative and analytic, my ambition was to provide insight into the continuing realities of becoming a bereaved parent, and to challenge the cultural dichotomies between grief as either present or absent, transient or permanent, resolved or unsolved, etc. The underlying theme “becoming a bereaved parent” suggested that parenthood and parental relationship to a deceased child is not a straight-forward and once-and-for-all dealt-with matter. Instead, the relationship between the parents and the deceased child is an on-going process which meanings and significance might alter over time.

11.1.3. NORMATIVE ACCOUNTS OF GRIEF

The third article (“Grief as a normative phenomenon”) provided some answers to my first research question of how parental bereavement experiences are related to culturally available practices and interpretive repertoires. Informed by an Aristotelian and teleological line of thinking, we[27] challenged the reactive and universalist conceptions of grief as causally inflicted, passive responses to loss represented within mainstream scientific psychology (leaving aside phenomenological, discursive, constructivist, cultural psychological and related perspectives). Instead, we articulated a normative perspective on psychological phenomena that emphasizes the dialectical relations between experiential, interpretive, normative, and cultural aspects. Following this perspective, we argued that grief is performed or enacted, rather than merely passively undergone. The performative aspect should not be understood as an entirely voluntary and reflective process. Rather, experiences, interpretations and enactments of grief (or any other mental phenomenon) are dialectically mediated, restricted, and enabled in and through the individual’s situated being within an inherently normative social reality. Based on an analysis of the recent cultural-historical developments regarding the conceptions of infant loss and parental grief in our society, we argued that parental grief following infant loss in contemporary Danish culture is mediated by diffuse and conflicting, yet inescapable normative understandings of infant loss and parental grief. Illustrated with findings from the present study, we demonstrated how cultural norms and practices not only “affect”

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[27] This article was co-written with Svend Brinkmann.

parental grief, but are involved in reflective and pre-reflective ways in the parents' mediation of their experiences, interpretations, and enactments of grief. Rather than merely being "repressed" or disenfranchised by cultural norms about grieving such losses, the parents actively negotiate the significance and meanings of their loss and grief. In other words, the parents' grief responses are not causally inflicted by cultural norms and practices, insofar as these norms and practices are open to alteration and negotiations through individuals' reflexive and pre-reflexive acts and interpretations. Finally, we briefly discussed some possible consequences of the current development within contemporary Western cultures towards conceiving of suffering as adverse and unnecessary conditions to be dealt with in medical and psychiatric terms, in order to maximize personal health, happiness, and well-being.

Chapter 6, "Here everybody knew I was a parent," shed light on my third research question concerning how DIDA's services are involved in parental experiences, interpretations, and enactments of grief. Throughout the chapter, I explored how the practices and interpretive repertoires provided by DIDA are involved in the participating parents' mediation of their relationship to themselves, to their loss, and to other people. The present study echoes findings from previous studies regarding the potentially important role of communities of bereaved in terms of offering social validation of the dead children's significance and bereaved parents' identities. Furthermore, the chapter illustrated how the participating parents in this study navigate between cultural repertoires available in DIDA and in the wider social realities of their lives. In line with the normative argument outlined above, the findings suggested that bereaved parents relate to the normative understandings and practices represented through the organization in reflective and highly individual ways. Finally, I argued that practices provided by an organization such as DIDA are inherently normative, and that those responsible for developing these practices need to pay attention to the normative implications and dilemmas involved in this endeavor.

11.1.4. DIAGNOSTIC ACCOUNTS OF GRIEF

In my fourth article, "Grief as a border diagnosis," I examined how contemporary understandings of grief as a potentially pathological condition is conceived of and experienced by bereaved parents after infant loss. The article contributes to the existing literature by providing new perspectives on how bereaved parents relate to medicalization and pathologization of grief. While previous studies have tended to portray parental grief experiences in opposition to pathologized and medicalized conceptions of grief, the present study demonstrates that bereaved parents may relate to pathologization and medicalization in multiple, and sometimes contradictory ways. Based on the interview data, I identified four different positions towards diagnosing grief. The first position suggested that a grief diagnosis can serve as a potentially normalizing and legitimizing practice, insofar as the diagnosis may provide a language for articulating the suffering of loss and hence enhance public awareness and understanding. Secondly, the diagnosis was conceived of as a potential source for mediating and regulating one's way of living with the loss, by providing guidelines for differentiating between normal and complicated grief responses. Thirdly, the diagnosis was conceived of as an illegitimate pathologization of long-lasting, but normal grief. Finally, a fourth position indicated that a diagnosis may also serve as a normative ideal to strive for in order to prove one's love for the deceased child. However, rather than representing stable positions towards the question of diagnosing grief, the parents often shifted between these different perspectives during the flow of our conversations. For example, the parents could easily move between critically voicing a skeptical position towards the diagnosis as illegitimate pathologization, seeing it as a way to normalize and legitimize the suffering of grief, and as a pragmatic tool for providing necessary help and support. Based on these findings, I argued that how people relate to and draw upon diagnostic understandings cannot be accounted for as exclusively iatrogenic or therapeutic, repressive or emancipating. Rather, in line with the cultural psychological outlook of this study, the findings suggest that the diagnostic language is involved in cultural forms of life (Wittgenstein, 1953). That is, the meanings of the diagnostic language are not fixed, but polyvalent and malleable, depending on the situated practices in which the language is used.

11.2. GRIEF AS A RADICALLY SITUATED, RELATIONAL, AND NORMATIVE PHENOMENON

Taken together, the four articles and the empirical chapter on DIDA's practices have presented and analyzed historical, sensitizing, normative, and diagnostic accounts of grief, and argued that grief is an inherently situated, relational, and normative phenomenon. For bereaved parents after infant loss, grieving is mediated by cultural norms and understandings of parenthood; of the personhood and human status of babies who die before or shortly after birth, and of health, normality, and pathology. Ultimately, our ways of relating to grief inform us of our current cultural conceptions of the place of suffering in what we conceive of as a good life. As such, examining the cultural conditions of grief represents an avenue for broader analyses of the human condition, insofar as grief is a form of suffering that is inextricibly linked to our existential condition as thrown into a vulnerable, mortal, and mutually dependent existence with each other.

As the present study has suggested, the cultural conditions within which grief is experienced and enacted in our time and culture are increasingly informed by medical and diagnostic accounts of human suffering. Since the beginning of the 20th century, grief has been subjected to psychological, psychiatric, and diagnostic understandings. Like Walter (1999) has argued, formerly shared rituals and practices has to a certain extent been replaced by cultural conceptions of normal and abnormal, healthy and pathological grief reactions. In this process, Walter asserts, "the grief process" has become our main frame of reference for dealing with loss. As the present study has shown, the scientific and professional accounts of grief have increasingly been distributed into popular culture, where it informs us of how to deal with loss in our everyday lives. In spite of the descriptive intentions of such scientific accounts, the present study has demonstrated the inherent normativity involved in the production of knowledge of human kinds (Hacking, 1995). Throughout the history of modern bereavement research, descriptions of normality have repeatedly and inevitably been translated into normative prescriptions for allegedly healthy and normatively preferable ways of grieving. Through the looping effects described by Hacking, these normative ways of understanding grief shape bereavement experiences, interpretations and actions, which again feeds back into the scientific descriptions of grieving human kinds. Rather than standing outside the realm of normative human practices, research concerning the human condition is in itself an inherently normative practice. Consequently, rather than trying to evade the normative implications of our research by striving for scientific neutrality, we need to develop a critical awareness of the normative and moral consequences of our scientific endeavors.

This, of course, also applies to the present study. Some of the normative dilemmas I have recognized in my own approach are connected to how it sits with the bereaved parents I am giving voice to in this study. For example, while articulating a critical position toward individualizing and pathologizing diagnostic accounts of suffering, I am simultaneously aware of the potential unintended consequenses of such a critical position for those who are suffering. Embarking upon this study, I imagined myself giving voice to people's resistance against being pathologized and stigmatized due to their grief. I honestly thought most bereaved individuals would be alarmed by the prospect of grief as a mental disorder. However, my own notion of pursuing a liberating project against medicalization and pathologization was soon challenged by the voices of those I thought I should empower. Their quest for recognition certainly did not map neatly on to my critical perspective of diagnoses and pathologization. Although some of the informants expressed perspectives similar to my own critical position, surprizingly often they welcomed the idea of a diagnosis as a legitimization rather than a stigmatization of the suffering of grief. Indeed, by raising a critical position towards the current diagnostic and individualizing accounts of grief, my message runs the risk of being translated (by the very language I am critically addressing) into an argument against the realness of the suffering of grief. Although this is certainly not my intended message, an argument against a grief diagnosis might easily be translated into a message that people really just need to pull themselves together. However, a radically relational perspective of suffering implies that none of the conditions we are faced with in our lives can be addressed solely on an individual level. As the Danish theologician and philosopher K. E. Løgstrup (1956) has pointed out, we never have something to do with another person without holding some of the other person's life in our hands (p. 27). The ethical demand that rises from this intrinsically interdependent nature of human existence ought to inform our practices for dealing with suffering, so that we not mistakenly exclude human interdependency from our analytical gaze and practical interventions.

One question that might be drawn from the present study is whether the attempts to dodge the issue of normativity (by insisting on descriptive, value-neutral accounts of grief; abandoning grand theories in favor of increasingly individualized approaches to grief, etc.), contributes to amplify the normative uncertainty experienced by many grievers in contemporary society. In a secularized and individualized world, people search for normative standards where they can find it, regardless of whether these standards were set forth as such or not. Accordingly, descriptive models of grieving have been subjected to the so-called humean fallacy, not because human beings apply faulty logics, but because descriptions of human practices are inherently laden with moral significance. In this light, communities of bereaved, personal accounts, self-help literature, as well as the recent suggestions to introduce a diagnosis for complicated or prolonged grief may offer normative frameworks which fill the gap of former common practices, rituals, and normative standards for grieving. Indeed, the present study indicates that this is exactly one of the functions of such accounts, e.g. when the participating parents welcome a grief diagnosis as a way to legitimize the suffering of grief, conceive of it as guidelines for regulating their grief, or even as a normative ideal worth striving for.

This gives rise to a range of questions concerning the conditions for grieving in contemporary Western cultures. One question is how the current normative frameworks for grieving, increasingly informed by medical and diagnostic accounts, shape the conditions for grieving in contemporary cultures. If grief is comprehended as a phenomenon to be assessed by standards of health and pathology, how does this enable articulations of existential, moral, and relational dimensions of loss? If suffering is understood as a detrimental and fundamentally meaningless effect of loss, how does this shape the experience of grief as an affectionate relationship to the deceased loved one? If grief is conceived of as a mental disorder of the individual griever, how does this mediate the relationship between the grieving individual and his or her friends, family, and wider social reality? These are all questions that need to be addressed in future research on bereavement. Due to the socially contested and normatively ambiguous status of parental grief after infant loss in contemporary Western societies, these questions are perhaps even more urgent in this context.

The main lessons to be drawn from this is that in order to understand as well as alleviate the suffering of grief, we need to take the following into account:

- *Grief is a relational and situated phenomenon:* In the most fundamental sense, grief is a relational phenomenon. First and foremost, grief is in itself an existentially significant relationship to the lost loved one which is intrinsically intervowen with our sense of self, meaning, and being in the world with others. Moreover, experiences, interpretations, and enactments of grief are inevitably situated in relations to other people, and to material and socio-cultural circumstances.
- *Grief is a normative phenomenon*: The suffering involved in grieving cannot

be accounted for merely in terms of causal reactions to loss, insofar as grief involves meaningful reasons for experiencing, interpreting, and acting upon a loss. Hence, grief cannot adequately be accounted for in terms of individual symptoms without taking into account the meanings they hold for people. This, in turn, cannot be understood without taking into account the relational, cultural, and normative frameworks that render such meanings conceivable.

- Hence, grief can only conceivably be "prolonged" or "complicated" in relations to other people and cultural norms. A comprehensive analytical and interventional approach to grief need to include this situated and normative nature of grief as a meaningful and existential human condition.

On this background, the present study argues that we need other interpretational resources for understanding and dealing with grief than those provided through the diagnostic accounts: We need to include languages and practices that enable us to address grief as something that does not merely concern the individual's physical and mental health and well-being, but also its existential and moral significance. We need languages that acknowledge that the suffering is not merely an adverse reaction or symptom to be reduced in the same manner as we reduce the pain caused by a physical illness. Unlike the suffering caused by the latter, the pain involved in grief is evaluated by normative standards of meaning. The pain has a potential moral and epistemic value, which may explain why grieving individuals are often so afraid of forgetting. Because forgetting means losing again—losing the existential connection to what the loss meant to you, and losing a sense of the reality of what was lost. In the diagnostic suggestions, this is evident in the persistent preoccupation with the deceased loved one or with the circumstances of the death. However, what is missed out from the diagnostic framework is the significance of the social reality in which this preoccupation is situated. As the present and several other studies have addressed, social lack of acknowledgment and disenfranchisement of the loss and grief may magnify the need to stay preoccupied with the loss, because other people do not help the grieving individual to integrate the loss in his or her social reality. Likewise, the lack of interest in or ability to engage in social activities, etc. are arguably often related to the difficult social encounters grief is so famous for provoking. For many people in grief, the prospect of yet another social situation marked by awkward silences, pretending to be okay, or being reminded of one's good luck in spite of the loss (the seemingly endless series of positive circumstances people so eagerly need to remind grieving individuals about) might simply be too much to put up with. The responsibility for these situations does not entirely belong to those in the bereaved person's network, but it certainly neither belongs entirely to the suffering individual. From this perspective, it does not only seem unfair that the "problem" is located within the grieving individual, but also genuinely misguided. Simply put, an individual account of grief fails to address the relational, social and cultural circumstances which contribute to complicate or prolong grief. Moreover, a comprehensive understanding of grief needs to include how the grieving individual makes sense of his or her responses. Rather than merely probing individual symptoms, it is essential to gain an understanding of the grieving individual's experiences of his or her social reality. As a culture, we need to critically examine the conditions we create for suffering individuals to be a part of the social life. Rather than merely targeting and treating complicated and prolonged grief as an individual phenomenon, we need to include the relational and cultural level in our analyses and interventions.

11.3. AVENUES FOR FUTURE RESEARCH

In this research project, I have had the opportunity to follow my informants during an extraordinarily difficult and stressful period of their lives. Although my ambition has been to examine grief in a life perspective, for most of the parents, these two years will probably be looked back upon as a critical and exceptional time. During the time I followed the parents, they were learning to live with the loss of a child, going through new, stressful pregnancies, and becoming parents again to living children. As I have indicated in my second article, "Becoming a bereaved parent," integrating the loss in one's life story and identity is an ongoing and arguably never entirely ending process. However, as my autoethnographic inquiries have indicated, the meanings and significance of the loss in one's continued life may change over time. Studying grief following early infant loss over a longer period of time could provide important insight into how such changes occur. This could for example shed light on how the ambivalent normative expectations concerning infant loss are involved in bereaved parents' and families' ways of living with the loss in their social realities over time. For example, how do the parents involve their loss in their everyday practices and personal narratives over time? How do other people in their social world relate to this? Does grief become more privatized with time, or do the parents pursue social validation of their loss by seeking out communities that provide recognition of their loss?, etc.

Another interesting avenue for future research could be to further develop the situated perspective on grief that has been argued in this project by including the material and embodied aspects of grief to a further extent than the present study has allowed for. This could for example involve further examinations of grief as emotional practices (Scheer, 2012) that are temporally, materially, socio-culturally and relationally situated. A related and promising perspective for examining grief is offered by the growing body of studies examining the human mind as extended and distributed (see e.g., Slaby, 2016). From this perspective, the human mind, including our emotionality, is not limited to our individual brains and bodies, but is extended and distributed throughout (as well as invaded by) socio-material practices and artefacts. While several studies have examined the use of material artefacts such as pictures, memorabilia, etc. in parental grief (Blood & Cacciatore, 1014; Christensen & Sandvik, 2015; Layne, 2000; Riches & Dawson, 1998), the analytical approach to human emotions offered by this line of research could potentially broaden our understanding of grief as a radically relational and situated phenomenon. The profound embodied and technologically mediated nature of perinatal loss makes this perspective highly relevant for examining such loss experiences. For example, it would be interesting to examine the significance of fetal diagnostics, the use of so-called "cuddle cots" (a refrigerated bassinet used in some hospitals for stillborn babies, allowing the parents to keep their baby close for a longer period of time after a stillbirth), and a range of other socio-material practices and technologies for parental grief experiences following early infant loss.

Finally, a crucial avenue for future research is to examine the cultural distribution and consequences of the expected grief diagnosis as it sets through within the next years. How will experiences, interpretations, and practices related to grief and loss be shaped and transformed in light of the introduction and dissemination of the grief diagnosis? How will it mediate individual loss experiences, and how will it manifest itself within the institutional practices of medicine, psychotherapy, bereavement support organizations, etc.? How will the cultural distribution of a diagnostic approach to grief shape cultural understandings of grief and suffering? As argued in the present study, the culturally contested nature of early infant loss—combined with the intensity and longevity of parental grief—makes these questions especially pertinent to address in relation to such losses.

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SUMMARY

This thesis examines bereaved parents' experiences of grief after the loss of an infant child, and how cultural representations, expectations, and norms mediate individual bereavement experiences. It explores how bereaved parents interpret and mediate their own grief experiences and practices by drawing on interpretive repertoires that are available through their personal and family history, popular culture, personal accounts, bereavement communities, etc. In light of recent debates on diagnosing prolonged or complicated grief as a mental disorder within the diagnostic manuals, the thesis also explores how bereaved parents relate to professional and popular accounts of grief as a potential illness.

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