

# 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.<sup>1</sup> 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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<sup>1</sup> 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<sup>2</sup>, 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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<sup>2</sup> 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.