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“I don't know if fear of flying is a diagnosis, but...”

*A longitudinal interview study with bereaved parents*

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***“I don’t know if fear of flying is a diagnosis, but...”***

Paper presentation at ICQI 2013, University of Illinois at Urbana-Champaign, May 2013.

Ester Holte Kofod, PhD fellow at Aalborg University, Denmark. Email: ester@hum.aau.dk

## **“I don’t know if fear of flying is a diagnosis, but...” A longitudinal interview inquiry with bereaved parents**

### **Introduction**

I’m a PhD fellow at Aalborg University in Denmark, where I’m working at a research project on grief experiences in parents who’ve lost an infant child. In a longitudinal interview study with a group of bereaved parents, I’m trying to explore the relations between their grief experiences and the cultural expectations and discourses their grieving takes place within. Further, I explore how the parents experience participating in The Danish Infant Death Association’s services and activities<sup>1</sup>. I’ll start off with a brief review of how I’ve approached my subject, and continue with some examples from my interviews. Further, I will discuss some of the troubling tendencies I see in how grief is interpreted and dealt with within the present context of our diagnostic culture<sup>2</sup>. Finally, I hope there’s time to raise some questions that I’d like to discuss with you.

I’ve approached my subject through a historical investigation of how grief has been articulated in different historical contexts:

- 1) Grief as a moral phenomenon in pre-modern times, with examples drawn from Ancient Greek philosophy and Biblical scriptures.
- 2) Grief as a psychological phenomenon in the age of modernity, from Romanticism and in the emerging discipline of psychology.
- 3) Grief as a pathologized phenomenon, or as a question of individual health and risk of pathology, in the contemporary late modernity – that is, within the field of medicine, most specifically within psychiatric research and recent developments within the diagnostic systems.

As you might be aware of, the long expected and debated revision of the DSM is released practically as we speak<sup>3</sup>. How is that relevant in this context? DSM-5 involves several significant changes that will affect individuals who are suffering from the loss of a loved one:

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<sup>1</sup> For further information about the organization, see: [www.spaedbarnsdoed.dk](http://www.spaedbarnsdoed.dk)

<sup>2</sup> The project is connected to the Diagnostic Culture Project at Aalborg University. See: [www.dc.aau.dk](http://www.dc.aau.dk).

<sup>3</sup> At APA’s annual congress in San Francisco, May 18<sup>th</sup> to May 22<sup>nd</sup> 2013.

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With the DSM-5, bereaved individuals’ experiences of even mild and transient depressive reactions following the death of a loved one might qualify for a depressive disorder or an adjustment disorder diagnosis. Further, bereaved individuals who experience intense longing, sorrow and emotional pain after the first year of bereavement might be diagnosed with so-called Adjustment Disorder Related to Bereavement<sup>4</sup>.

As you might have already guessed, my position toward these changes is a worried one. My concerns are: What happens to our ability to understand, make sense of and cope with painful life events such as death and loss when these experiences are increasingly being conceptualized within a medical, diagnostic language? While the logic of the medical discourse stresses treatment and symptom relief, how will this affect our tolerance (and patience) toward our own and other people’s suffering? Will we treat a bereaved parent’s sense of loss of existential meaning and identity after the loss of a child as an illness? When seeking acceptance, consolation, and someone who will listen, will we meet the bereaved with a demand to seek treatment and recovery?

### **Interview pieces: Parents on diagnosing grief**

In my empirical research, I’m following six bereaved couples and one mother in the first two years after the loss of an infant child during pregnancy or in the first year of the child’s life. I’m interviewing the parents at different times in this period – first time approximately one month after the death of their child, second time six months later, and last time one year after the second interviews. In the first round of interviews, I was interested in hearing about how these parents experienced their own grief, and what beliefs and expectations about grief they held themselves and met in their communication with family, friends, health care professionals etc. My research project is funded by and carried out in collaboration with The Danish Infant Death Association, which is also my former work place, and it’s my experience from my work as a counsellor that relationships between the parents and between them and

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<sup>4</sup> Due to massive critique from several significant voices in the field (c.f. Wakefield, 2012a; 2012b; Francis; 2013), the DSM committee has postponed the introduction of the latter diagnostic category. For the present this means that pathologization of grief experiences will revolve around depressive feelings after the loss of a loved one being diagnosed as major depressive disorder.

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their network tend to play a significant role in their experiences of grief. I was curious to find out what my research participants thought of the prospects of a grief diagnosis. In most of the interviews, the talk fell upon the subject as we talked about how other people’s expectations of recovery tend to show up at a rather early stage following the loss – typically a few weeks after – and most typically too premature for the bereaved persons to feel any support from it. Surprisingly though, to me at least, some of my informants were immediately quite positive to the thought of a grief diagnosis. I’ll give you a few examples from my transcripts – the first one from my interview with Emma and John<sup>5</sup>, a couple in the first thirties, whose second child was stillborn after an uncomplicated pregnancy:

Emma: It makes me really, really sad when people already start asking if I’m feeling well again. I got that message yesterday, and I say “no!” – it’s been seven weeks – not even seven weeks yet, and I’m not feeling well (...). And people start looking suspiciously at me, because I haven’t got back to work yet. (...) That’s difficult. I think it will be difficult for me not to think of what people think. Because I believe that – it seems as if people start to think, “she must be over it”, and I can’t bear the thought of that.

Me: That makes me think of – what you’re describing about those expectations – that now, after seven weeks, people start asking you if you’re past it and so on. In relation with the revisions of the diagnostic manuals on psychiatric disorders, it will probably be opened up for diagnosing grief... What are your immediate thoughts about that?

Emma: Well, I think that – right now, I feel strange about it being said that I’m on maternity leave. That I have 14 weeks maternity leave. Why shall I have 14 weeks, and my husband 14 days, just because that’s how it is if you get a living child? And then I actually feel bad about it being called parental leave. Why isn’t it called something with grief? (...) And why shall it be such a big difference? Because: Is he ready with grieving after 14 days, and I ready to work after 14 weeks? (...) So I think it would be better to have something related to the fact that one is grieving. Whether it be one or another... disease, or whatever. It might help to... Well, I don’t know. I just think that... I don’t know if it is just called parental leave, because it isn’t acknowledged that it is grief, or if it is just something like: “Ok, we just put it all in the same pot, we don’t have time to think of it”.

John: I don’t know what to think of it. It’s a little like... I don’t even know what it means that it is a psychiatric diagnosis...

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<sup>5</sup> The participants’ names have been changed for reasons of confidentiality.

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Me: It means, you have a list of criteria, that is used to assess – on the basis of intensity and duration of certain reactions, and then you assess whether the diagnostic criteria are met or not.

Emma: But is it possible to make such criteria? Because grief is so individual, isn’t it? I mean you can’t just be put in a box. I can’t just push a button and say, well, now it has been 14 weeks, so now I’m finished with grieving. You just can’t do that.

John: But on the other side, it is... something that really can... I mean, it’s a big thing, the grief. So if – well, I don’t know if fear of flying is a diagnosis, but... (Laughter).

Another of my participants, the 40-year-old woman Rita, had struggled with mental illness and fertility problems for a long time before finally getting pregnant. She and her husband lost their child shortly after a preterm labour. In my first interview with Rita, we talked a lot about her experiences with both the mental illness and the grief after the loss of her daughter:

Me: Has it changed anything in your views on what’s important in life?

Rita: It has given another perspective to it. I knew what was important, was very focussed on it... But being so hopelessly in love with such a little creature, to want to do anything for her to survive. It gives another depth. I thought I’d seen the bottom with these nervous breakdowns I’ve had: “You can’t get further down than this, right?” But I’m probably further down now. It’s not because I’m ill or depressive, it is just in a whole different way, where it’s probably the worst I’ve experienced in my life, but also at some points the best. Because she was the best. (...) When you’re sick, there is something overwhelming you. (Grief) seems like a natural thing (...) Not an external dynamic. You have ownership on how you want to react.

A last example of how the participants position themselves toward the question of diagnosing grief comes from my interview with Sarah and Paul, a couple in their late 30s who lost their firstborn due to complications during the birth. When introduced to the subject of a grief diagnosis, Sarah exclaims:

Sarah: Well, that’s difficult, I think. It sounds a little... I don’t know. I want to say crazy! (Laughs.)

Me: Why, do you think?

Sarah: Because I think it’s so different... People react so differently. Some need to cry for a long time, others don’t (...). Of course, it depends upon what they arrive at, and how long time

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they give it, sort of...

Me: There are different suggestions in the different manuals, from 6 months to a year...

Sarah: OK... I also think: What are the consequences? Does it mean that you’re supposed to take a pill if you still cry after six months, or what? Or what is then supposed to happen?

Paul: I believe, fundamentally, you have to accept that you can be really sad, and cry and... without anything being wrong with you. (...) Of course, strictly professionally, you can’t go to work if you sit around crying constantly, that is obvious. But fundamentally, there’s nothing wrong. I feel like – that is precisely what is our problem sometimes when we talk to people, right? Because they don’t want you to be sad.

## **Discussion**

So, while some of my informants – also others than those mentioned here – stress the possibility of acknowledgement associated with a diagnosis, others, like Sarah and Paul in the latter example, refuse the notion of pathologizing the sadness caused by the loss. In another passage, Sarah expresses that somehow, in spite of the pain, she actually likes feeling sad. She states: *“Well, it is such a feeling that... well, then she’s here. Or, then I feel close to her... I think. (...) You recognize so clearly that she matters, right?”*

It is precisely this level of meaning I fear is threatened by a diagnostic approach to grief. If a person like Sarah feels the same way after a year (and previous research on bereaved parents suggest that a majority actually do<sup>6</sup>), then her sensitive reflections of the significance of her feelings for her daughter might well qualify for a mental disorder. According to the diagnostic criteria put forth by the DSM-5 committee, daily experiences of intense longing and yearning for the deceased (insofar as it is judged to be “out of proportion or inconsistent with cultural or religious norms”) is sufficient to diagnose a bereaved person with Adjustment Disorder Related to Bereavement.

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<sup>6</sup> C.f. Dyregrov, Nordanger, & Dyregrov, 2003.

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Advocates of a grief diagnosis argue that it is necessary to diagnose in order to provide optimal treatment for people who are still suffering from grief after the first 6-12 months after bereavement. However, by individualizing and pathologizing grief experiences, we risk reducing the complexities of both the reasons and the causes of the pain: The “reactions” mentioned in the diagnostic criteria are not mere reactions. They are feelings and thoughts that have meaning, and that people feel ownership of. They might indeed be painful, but that doesn’t mean they are not reasonable. Further, what causes the pain is not merely intrapsychic states rising from within the bereaved. It’s something that is tightly connected to their relations with others, and to their relations with the one they’ve lost. Finally, judging pathology by cultural standards, as the diagnostic criteria propose, is begging the question, because the introduction of a diagnosis itself affects the very cultural norms that are being used for diagnostic assessment. While a diagnosis might open up possibilities for treatment, insurances, sick leave, and possibly for others to recognize the severity of grief, my concern is that it also reduces the cultural repertoires available for us to make sense of, to tolerate and to endure painful life experiences.

**Summary: Experiences from talking with people in grief**

- 1) Most often, people in grief (and probably a range of other troubling, existentially difficult life conditions as well) neither want to be pitied or having their pain trivialized, but to be able to talk about their situation – and about the person they have lost. (It seems to me that many parents happen to be proud – also of their dead children!)
- 2) Most people in grief are ok with being emotionally touched during interviewing, and with you being it too: The painful emotions of grief are not mere adverse effects of an internal, mental condition, but something that is inextricably linked to the love and significance of the one they have lost.
- 3) A significant part of the painful feelings people experience during grief is directly associated with bad communication, expectations they feel they can’t live up to, and other people’s attempts to remove the pain instead of acknowledging it. Hence, grief is always embedded in relationships with one’s own and others expectations, values and beliefs – and these are aspects a medical, diagnostic approach fails to account for.

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**Questions for discussion**

However, in the same manner as my research participants are challenging my ideas of the harmful effects of pathologizing grief, I invite you to do the same. So my final questions to you are:

1. How do we – as researchers interested in the painful aspects of human existence – avoid being interpreted as someone arguing that people just need to pull them selves together and live with it?
2. How can we move beyond critical “diagnosis of the time” toward constructing alternative solutions to the troubling tendencies we observe?
3. If it is true that the social communities in late modernity are dissolving and fragmented, the question arises: Are there any realistic alternatives to the current individualized, pathologizing account that might actually help people?
4. And how do we, as well-meaning, emancipatory researchers, avoid running the errand of politicians that might end up using our research to legitimate financial cutbacks and impairments for those our research is supposed to benefit?



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