



# **MESSAGES FROM HEAVEN**

## **Unexplainable experiences among bereaved parents**

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## Parental grief

- The death of a child is one of the **most painful bereavement experiences**
- The **bond of attachment** between child and parent is unique
- Violent disruption of the **natural order**
- Consequences for **physical and mental health**
- Negative impact on **family dynamics, social relationships and professional performance**



## Bereavement support

- **Bereavement support** is an *integral* part of **palliative care** and *should* help families and loved ones to cope with the death of the child (WHO 2002).
- Bereavement care is **under-resourced** and **under-researched**
- Care for bereaved parents is not provided **systematically**
- **Bereavement care = the forgotten child of palliative care**

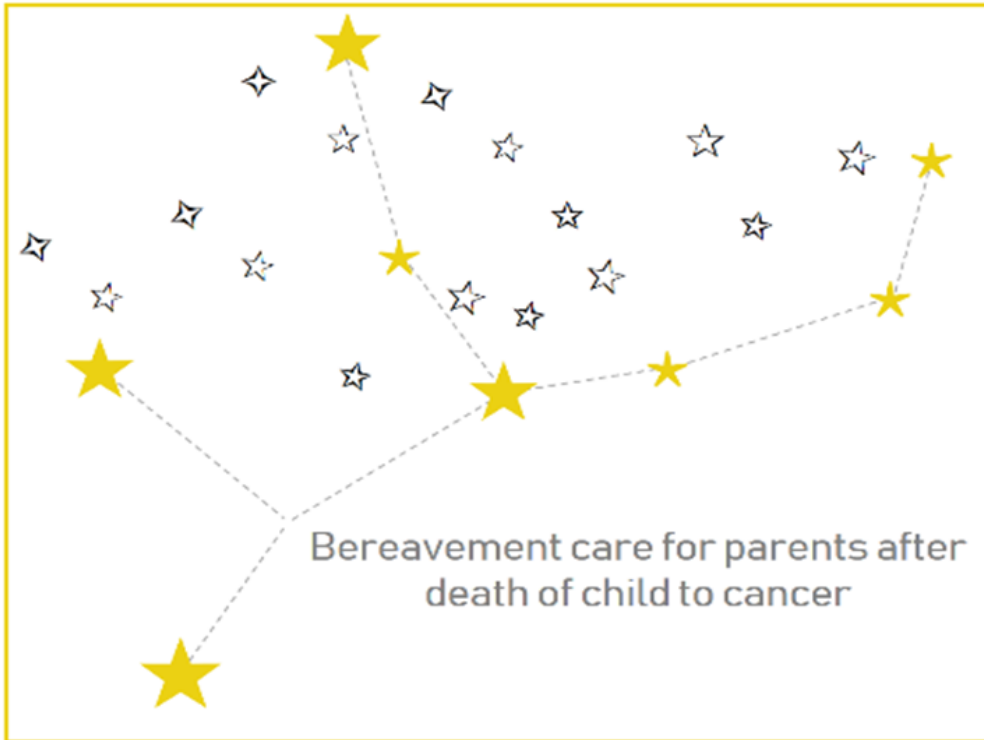


## Unexplainable experiences

- **Broad ranges of different experiences: spontaneous vs induced**
  - 1) Felt presence of the deceased
  - 2) Sensory experiences (e.g. seeing, hearing the deceased)
  - 3) Symbolic messages
  - 4) Inner communication with the deceased
  - 5) Dreams – visions
- **Widespread experiences** (culture, ethnicity, education, age) but apparent gender difference but widespread **non-disclosure**
- **Different terminology**
  - 1) Supernatural or paranormal experiences
  - 2) After-death communication, post-death contact/encounters
  - 3) Post-bereavement/grief hallucination or hallucinatory experience
  - 4) Sensory experiences of the deceased

Unexplainable experiences

- **Pathologization, stigma, reductionism** in Western culture



## OUR RESEARCH PROJECT

Our project aimed to improve the **bereavement support** for parents whose have lost a child to cancer. For this purpose,

Our research aimed to better understand (short/long term)

- 1) Parents' experiences of loss
- 2) Parents' coping mechanisms
- 3) Parents' complex needs

Qualitative part: **18 interviews** with parents in Switzerland with 23 parents (7 fathers and 16 mothers, 5 joint interviews) - child diagnosed with cancer at age  $\leq 18$  years & at least 1 year after loss of child

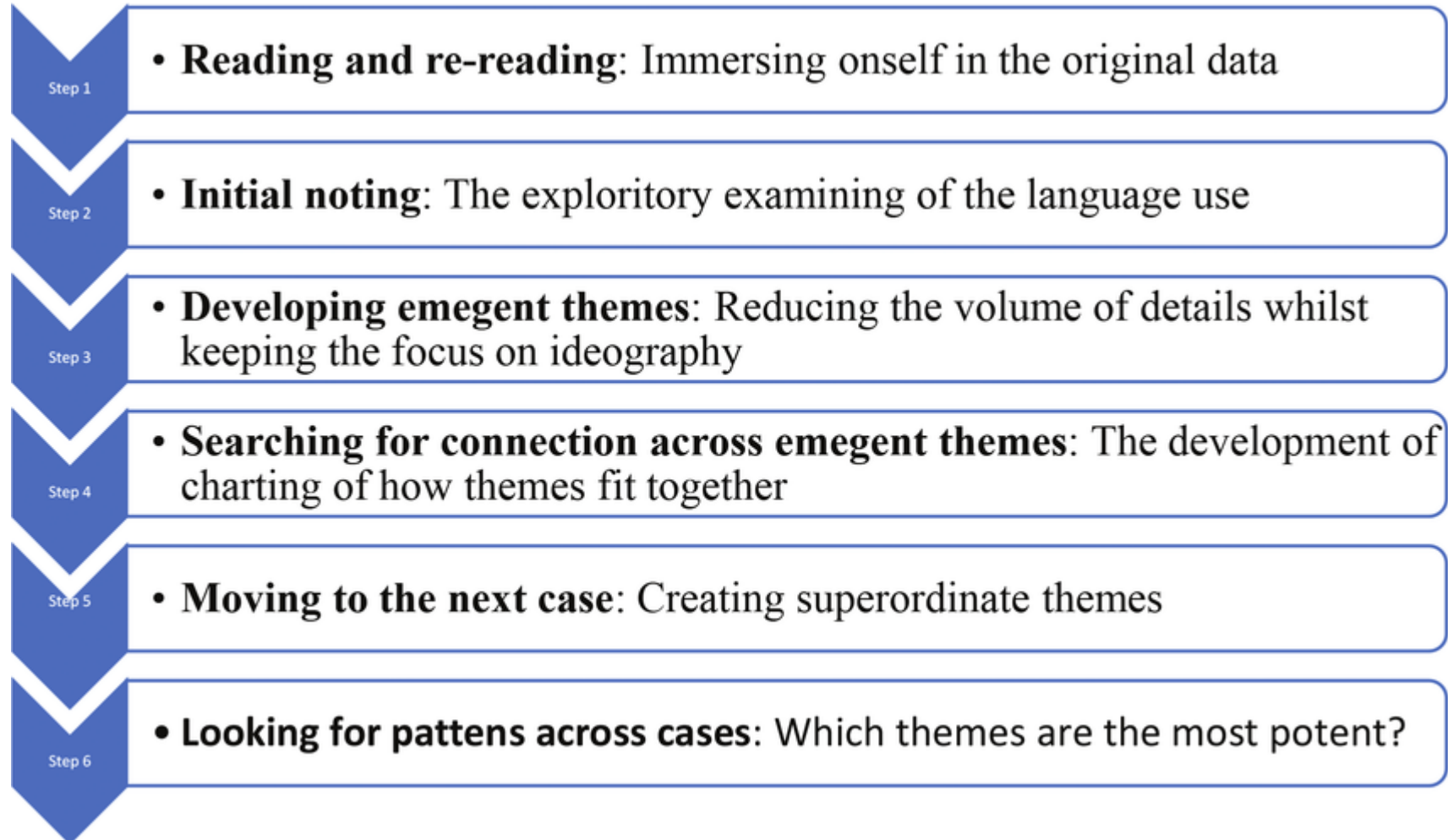
## STUDY OBJECTIVES

- During the analysis of the interview data on bereaved parents' support experiences, the research team noticed that many parents reported on unexplainable experiences which seemed to be a form of continuing bonds, one of the most common reported coping strategies among bereaved families.
- We therefore aimed to increase our understanding of **the nature and impact of these unexplainable experiences** in order to reduce potential stigma and to **improve grief support to bereaved families**

## METHODS

- We conducted a **secondary analysis (re-use) of the qualitative data** obtained through the semi-structured interviews, that is, we performed an in-depth analysis of data that were not focused on in the primary analysis
- Secondary analysis provides an opportunity to **maximize data utility** particularly with **vulnerable** and **difficult to reach populations** or about **sensitive** topics. Participants' time and effort in the primary study becomes even more worthwhile.
- **Interpretative phenomenological analysis (IPA)** was chosen to analyse the empirical data as the aim of IPA is to understand how persons make sense of their **life-experiences**, keeping in mind the **particular context** of each singular case. IPA views participants as experiential **experts**, but also recognizes that experiences can only be accessed through **interpretation**.

# METHODS

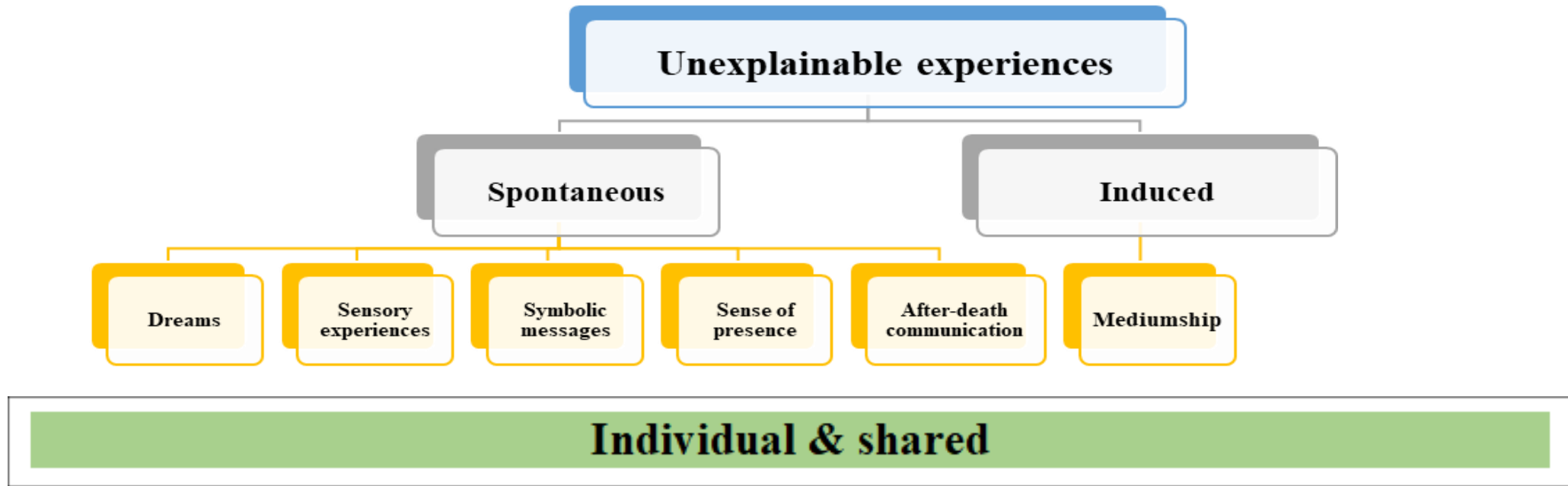




## RESULTS

- Almost **all** parents – **both mothers and fathers** – *spontaneously* reported on these experiences, independently of child's age, years of bereavement, religiosity
- Common among **siblings** of deceased children (as reported by parents)
- Some parents emphasized that these experiences are **normal** and **not pathological**
- Parents reported on a **wide variety** of unexplainable experiences
- **None** of the parents described them as scary, strange, anxiety provoking or unwanted intrusions
- **Beneficial**: sign of their **child's well-being**, they are in a **good place**, and hope of being **reunited**
- **Not unequivocally beneficial**: (1) realization of irreversible death; (2) desire for more experiences & dependency; (3) lower frequency = **fading memory/fear of forgetting**

# RESULTS: WIDE VARIETY OF UNEXPLAINABLE EXPERIENCES



## RESULTS: SOME ILLUSTRATIVE QUOTES

I went to see three **mediums** I think. And we found one who was just incredible. I actually recorded the sessions and made my children listen. They took it without any questions. For them Theo is there. **Theo sees us. He is somewhere else but he's here with us and they'll see him again** one day. Also my husband believes in it (mother of Theo, age 14, died 5 years ago)

There was a time when I wanted to go to a **medium** (...) to enter into contact, but I didn't do it because I was afraid that if I really could get in touch with him, **I'd become a slave to that and I did not want to live in a parallel reality** I have two other children (...) I had to free myself from that (...) what's missing most is his presence, so you look for it in your dreams, in mediums (...) the day after he died, I got his first name tattooed (...) in this way I can still touch him (...) through me, I'm in contact with him (mother of Leo, age 5, died 10 years ago)

In the beginning, **she was so present in this world, I felt like I heard her, I saw her**, I always had the feeling 'Ah now she's coming round the corner'. And at some point I realized, no, she's not coming (...) I **dreamt about her** so often and (...) somehow **I desperately held on to it** because I just didn't want to understand that it was really true (...) sometimes I find it even **more painful** when she comes, because then I wake up screaming realizing again that she is no longer there (...) I have phases in between where I realize I can face my grief (...) then I talk to her, then I paint a stone, (...) during the holidays, we were like 'Hey, we have to look for a nice stone and then we'll bring it to her, (...) **if we're actively doing something with this love** (...) I have the feeling that **after two years, a lot of her has been forgotten. People around me hardly ask any questions.** And I don't think that should happen. That can't be right! (mother of Ava, age 6, died 2 years ago)

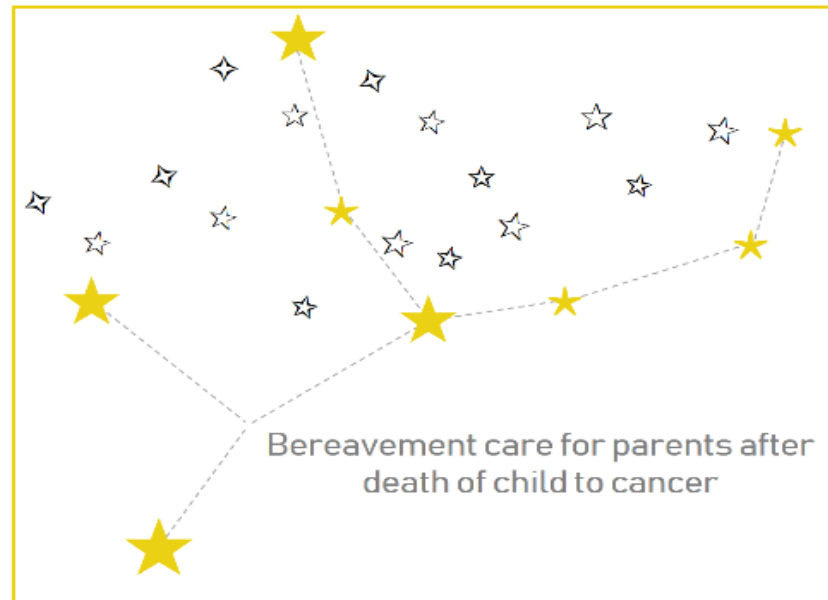
I used to go run to the cemetery, it was one of my weekly rituals for a long time, and in the beginning **it almost felt like he was running next to me**, it was something that I don't know, but it made me feel really good but then when it wasn't happening anymore, I tried sort of like **force it back** but it's not the same (...) I'm conscious that this is normal, **with time we start to forget certain things** (...) a bit of anger or frustration comes in, because he's always supposed to be there but he's not so (father of Noah, age 4, died 4 years ago)

## DISCUSSION

- Unexplainable experiences are **very common** among cancer bereaved parents
- Parents (and siblings) experience **many different types** of experiences, some spontaneous, others induced, some individual, others shared (= **relational grieving**)
- Parents did **not seem to fear stigma** and spontaneously disclosed their experiences, independently of sex
- As a form of spiritual **meaning-making** and **continuing bonds** with the deceased child, these experiences can alleviate the grieving process.
- **Ambiguous gifts** due to risk of dependency & loss of reality
- More research on the need/desire of unexplainable experiences and **grief illiteracy** (fear of forgetting)

## CONCLUSIONS





### Study Team

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# Thank you



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### Funding

*This project has received funding from Research Committee (FoKo) of the University of Lucerne, European Union's Horizon 2020 research and innovation program under the Marie Skłodowska-Curie grant No 801076, through the SSPH+ Global PhD Fellowship program in Public Health Sciences (Global-P3HS); and the Swiss Cancer League grant (No KFS-4995-02-2020) and Cancer League Central Switzerland*

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