

Holding On and Letting Go: Experiences of Parents of Adults with Early Psychosis

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Close to
home . . .

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Work in the
Community



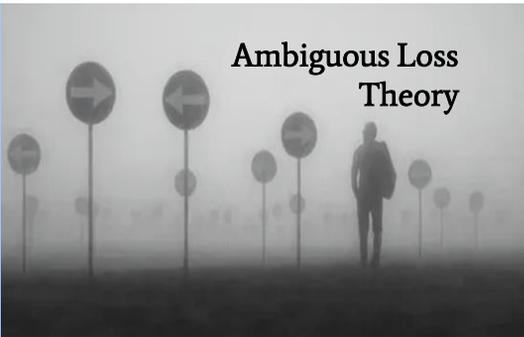
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Education and Research



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Ambiguous Loss Theory



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- Dr. Pauline Boss
- Loss where there is mix of absence and presence (Boss, 1999, 2006)
- Loss involving ...
- Uncertainty
- No clear end



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Boundary
Ambiguity

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Psychosis typically starts in the “launching” stage which is *already uncertain and stressful*.

Psychosis brings about an unexpected change and requires unanticipated adaptation

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Why parents?

Family members (*predominantly parents*) are often the first people to notice psychosis (McCann et al, 2011).

Parents' relationships with their children are unique. Having family involved (Iyer et al, 2020) helps to ensure and facilitate treatment and also reduces hospitalization and relapse of psychotic symptoms (Norman et al, 2004).

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Focus on
Pathology

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Why Grief?

Research has shown that *grief* is a common response in parents of children experiencing psychosis (Patterson et al., 2005).

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Research:
In thinking about grief in parents of adults with early psychosis, we have something to learn from ambiguous loss theory.

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Research

I conducted two studies exploring the application of ambiguous loss theory to grief in parents of adults with early psychosis.

One quantitative study where I used surveys to explore parents' relationships with their children and their experiences of grief, and one qualitative study where I interviewed parents about their experiences of grief.

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Survey results (caution)

The results of the survey showed that the stronger (higher) the parent-child relationship, the lower the grief. Parents' grief was highly associated with their own uncertainty about their role as parents with their child and their child's role in their family (boundary ambiguity).

The boundary ambiguity measure has not previously been used with this population.

Further research is needed on how the boundary ambiguity measure could be adapted for this population.



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Study 2

I explored grief experiences of parents of adults with early psychosis through parent interviews.

Question: "What is the nature of parents' grief experiences?"



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Methodology: Hermeneutic Phenomenology

Goal: Capture the *essence* of complex lived experiences.

I interviewed participants using open-ended questions to "unearth something telling, something meaningful, something thematic in the various experiential accounts" (van Manen, 1990, p 86).



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Study 2: Sample

Following informed consent, I interviewed 13 parents (12 mothers; 1 father) for 45-90 minutes over Zoom.

Because this sample was from the participants who completed the survey, this was also a highly homogenous sample.

All participants indicated that they had a spouse or partner.

10 out of 13 (77%) reported having a college degree or higher.

I asked questions such as, "Describe what your life has been like for you since your child became ill" and "Describe what your relationship has been like with your child since they became ill?" I also ended with a question asking them for what advice they would give to other parents in a similar situation.

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Findings

- It is important to note the experiences of grief were not described as discrete events or experiences. Rather, they were complex, dynamic, and interconnected.
- I found three themes that appeared to capture the essence of parents' grief: **uncertainty, paradox of holding on and letting go, and overwhelming emotions.**
- These themes fell largely into three overlapping domains related to the adult child, the parent, and the parent's relationship with their adult child.
- Please note I am using pseudonyms of the participants.

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Themes	Domains		
	Adult Child	Parent's relationship with the Adult Child	Parent
Uncertainty	Where is my child? What happened?	What can my child do? What can I expect from my child?	How do I parent?
Overwhelming emotions	Sadness, Guilt, Anger	Sadness, Fear, Guilt	Guilt, Sadness
Paradox of holding on and letting go	A changed child with a changed future and yet still my child	I want to be close to my child, and it's not the same	I am not the same person and I want to be a loving parent

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First Theme: **Uncertainty**

Uncertainty: Where is my child? What is happening?



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Molly a mother of a son with psychosis for four years stated . . .



“It was (his) senior year when it really went bad and he clearly was having a psychotic episode and it was when we fully knew it, but we didn't know what it was, but we're just like “What the hell?””

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Uncertainty: What can I expect from my child?

Jessica a mother of a son experiencing psychosis for two years stated:

“But I think the grief comes in, because again from the perspective of that sort of the trajectory that he was on prior to all of this happening was we had no reason to think that he wasn't going to sort of take a more traditional path and whatever that meant to him.”

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Uncertainty: How to parent?

One mother of a son with psychosis for five year described this uncertainty about her interactions with her son who was experiencing cognitive deficits:

“You know there's times, where I'll explain things to my son and he'll say “Mom, I'm not a child,” and I understand that but I'm like, I never know if I'm explaining too much or too little you know so it's a really weird spot to be in.”

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Paradox of Holding on and Letting go

Of their child and their relationship with their child.

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"It's rough because it's just so different. I feel like that this one I had, God, so I have to learn to love and relate to this new son who is different and it's hard, because he's prickly, and it can be difficult and I've also got to keep, you know, I know he's sick, but there's only so much I have to say... I don't have to let him treat me in a way that I'm not comfortable with, because he's sick and so, it's just, it's harder. We used to do a lot together before he was sick, and he used to have a lot of interest in things and it's- it's harder to enjoy that time together. Our relationship has changed, and I miss it."

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Paradox of Holding on and Letting go to their role as parent
Dorothy, a mother of a daughter experiencing psychosis for three years who stated,
"That's the hardest part is knowing how to walk that tightrope of how much do you help and how much do you let a 26-year-old figure it out."
Francis described this struggle of holding on and letting go to her own role with her son:
"So I do wonder a lot like, 'What is my role here?' Do I just sit back and let it deteriorate in front of my eyes? Or what am I supposed to do? So, my role which I've told him and told him yesterday because we kind of talked yesterday but it didn't go great, but I said I'm going to, you know, I'm not giving up with the drug. You have to take your medication. There's no negotiation about that. I'm going to bother you about your medication."

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Overwhelming Emotions

Sadness
Fear
Guilt
Anger



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Discussion: So what?

- The nature of grief in the lived experiences of parents involved in this study is shrouded in *tremendous uncertainty about their child's illness and what the future holds for both their child and their family.*
- The parents I spoke with were highly emotionally invested in a relationship with their child, and they struggled with the "paradox of holding on and letting go."
- Concepts from ambiguous loss theory such as **boundary ambiguity** and **uncertainty** were evident throughout parents' descriptions.

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Implications for supporting parents



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