

Still Alive
Constructing identities & legacies following the death of a baby



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Agenda

● Introducing Re-membering

- Challenges in Re-membering Stillbirth
- How to
 - Make the relationship **visible**
 - Make grief evidence of the **ongoing** relationship
 - **Unfold** the ongoing relationship
 - **Introduce others** to the Angel child
- Q&A

Grief Psychology 101

- Conventional ideas about death limit the way in which we can speak, often placing an artificial barrier between the living and the dead
- When somebody dies, conventional ideas distant the relationship by placing it in the past, wistful memories
- People are encouraged to “move on”, “let go” and not dwell in the past
- These ideas are disseminated through discourses in professional psychology & lay literature alike

The Relationship Lives On

- Narrative therapy creates a different way to access stories and shape meaning that transcends conventional constructions.
- People, and babies, are born into a connection of relationships that hold spaces for the deceased.
- When babies dies, their influence does not stop simply because they are not here physically.
- Their influence continues to impact on those who love them and can change over time.

Their Life Continues to Matter

- Making space for the untold & ignored stories
- Exploring the personal and often very private meanings of where & how the relationship is present
- Knowing a child's life is not inconsequential, influences how we think and speak about a child that has died before or after a birth
- People want to know that their child will not be forgotten.
- We need to listen for the invitations to breathe life into a deceased child's memories & stories
- Death does not diminish stories, wishes or dreams
- Death does not cancel love



The Hyphen



- Re-membering is active, not passive
- It is more than reminiscing, but the "re" establishment of connections
- It is not only solitary
- It impacts on an individual, but on others who have been touched by the life and the death
- It means actively including someone after death

Myerhoff, 1982

Re-membering differently when it is a child that has died.

- Re-membering often picks up on themes, stories, or values of the deceased person.
- Re-membering can be informed by a wealth of lived experiences.
- Re-membering a baby that dies before or after a birth can be limited by lived memories.
- A child keeps influencing in ways that matters in life & how the relationship to the child is expressed in newly acquired skills, orientations and values.

"It makes me feel better when our two other sons talk about their brother. They tell me about how he [their brother] is in heaven and someday they will get to see him too. That give me peace."
 A mother whose baby died at 24 weeks

Stories Continue to Live On

- Stories of babies come into life long before conception
- We can invite stories of subjunctive dreams & language
- Children are placed into relational ways of being with parents, grandparents, siblings & larger communities
- Become a point of connection for future relationships (like with not yet born siblings)

Lorraine: What might your daughter appreciate about how you have continued to include her in the family?
 Dad: She would like that we speak about her and have her picture from the hospital up with our other kids.



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Make the relationship visible

The fetus is not a person

vs

A fetus is a marginalized person

The dominant discourse defining a fetus as not being a person makes the child-parent relationship invisible. As a result the child's influences during pregnancy hardly get explored and recognized

"I think it is harder to loose Ellie in such a young age because we don't have any experiences with her. If she was three years old then we would have had the memories to hold on to" (Ellie died in week 42).

In our work we see the unborn child as a little person being marginalized. We unfold the many experiences in the light of the child's influences that we would otherwise see as naturalistic effects of pregnancy

"I haven't thought about how much my little daughter made me into a mother. All these experiences with her during pregnancy. It is so nice to know she has made me see the value in mothering. And to know that even though the grief has been hard on me - I want to experience being pregnant again"

Make grief evidence of the ongoing relationship

Ongoing grief is abnormal

vs

Unborn children have "human rights"

Parents keep relating to their Angel children despite the age of the child. However this relating gets constructed as abnormal due to the discourse of grief

"When I am at the graveyard I think about how Anna-Rose might be freezing - I know it is stupid - but I don't want her til be cold or alone" (her daughter died in week 42)

In our work we see the unborn children as having the human right to be continuously loved, talked about and missed. We unfold grief as evidence of the ongoing relationship to the Angelchild and the fact that parenthood never stops

"It is like when we talk about Molly in this way it becomes possible not only to talk about all the things we have lost and feel so sad about. Now we can connect her with something positive" (her daughter died in week 38)

Unfold the ongoing relationship

There is no life after death

vs

The relationship keeps living

The discourses of death often makes the continuation of the relationship invisible for the parents and other.

Mother: If someone asked if I had a child I would say No

Therapist: Why is it that we only count the living children?

Father: Because you don't have a relationship to the dead child

In our work we unfold how the child continue to influence the family and how that creates a relationship that is not limited to the to pregnancy, but is ongoing

"We often ask ourselves what would Merle say. She is wise, she gets to have the role of supporting us in doing what we feel is the right thing to do. She is our little helper. It is nice to know she can be part of our life"
Father (lost a girl in week 22)

Introduce others to the Angel Child

It is best not to talk too much about loss

VS

The child did not die in vain

The discourse of death and grief silence parents in talking about their ongoing relationship, and other people worry about asking about the child fearing it may make the parents sad. As a consequence the child become taboo

"My mother-in-law said to me that it is like a tumour, you better forget about it and get over it"

In our conversations we see the Angelchildren as children who can influence other people in significant ways - not only their parents -but the people they get introduced to. As a consequence the child make it possible to bring change to society

"After we have started to talk about Augusta and how we still relate to her, my parents-in-law have started to talk about the little girl they lost 30 years ago, and my father-in-law for the first time has been able to talk about the feelings he still has for his little girl"

Change of discourse necessary to re-member stillbirth

Dominant Discourse

A fetus is not a person

No memories available for constructing the identity of the child

Ongoing grief is abnormal

The relationship to the child is pathologized

There is no life after death

The child no longer exists

It is best not to talk too much about loss

The child become taboo in relation to other people

Alternative Discourse

A fetus is a marginalized person

Experiences during pregnancy can be ascribed to agency of the child

Unborn children have "human rights"

The parents grief can be seen as signs of an ongoing relationship

The relationship keeps living

The child can continue to influence the life of the family

The child did not die in vain

The child makes it possible to bring change to society

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Rendering Visibility to Life

We need to be curious about:

- How is the parent/person refusing suggestions from others/discourse to let go or move on.
- How is the parent/person being a witness to the relationship with the child?
- How does this experience & expression reflect on what is valued?
- What does this experience & expression of caring for a deceased child's legacy suggest?
- What do these practices say to the parent & others about how the child continues to matter?

"Mom: I have had a couple of events recently where I am meeting people and they say, 'you have the 2 boys'. That's hard cause I want to say, 'I have 3 boys and I would love to tell you about him' But it is like if I tell them I have a 3rd child but he died, then I get this total sympathy that doesn't feel right.

When I am with people who knew Teddy, I'm good. Everyone knows about him and everyone talks about him. The pain is really when I am in a situation where he is just not known. Or that even if he is known, he is not acknowledged. That's really hard cause he is still here for me. I am not actually holding his hand, but he is still here. There's joy when others know too that we are holding his hand."

3 months after her son died at birth

Deconstructing the discourse of fetus

- The many experiences or interactions during pregnancy are traditional seen and described as naturalistic effects of pregnancy.
- This is due to the fact that a unborn child is not described as one that has agency or one that can actively influence their parents in those moments.
- In his work Michael White was keen to ascribe and make visible the agency or identity of the marginalized. Groups of people where their identity and voices had been robbed.
- We can define **agency as being able to influence others – as being able to do something to another person.**
- We are political in the sense that we see these small unborn children as being marginalized. Their agency and identity is being robbed.
- The many possible experiences with a unborn child expand when we see and explore the many moments where the interaction or relating has taken place and the child is being described as being active and doing something to others in those moments.
- These influences becomes stories of the child's agency and significant influences on their parents.

Experiences during pregnancy

- Moments of discovering the pregnancy
- Moments of scanning
- Moments of talking about the unborn child
- Moments of the unborn child kicking
- Moments of giving birth
- Moments of sitting with the dead child



Andrea, Scanning

Questions that unfolds experiences

- How has the unborn child influenced the parents in those exact moments
- *What did the little unborn child do to the parents in that moment?*
- *What did the little unborn child make possible for the parents to experience, to notice and to talk about?*
- *What feeling did the little unborn child implant in the parents in that moment?*



Andrea, Scanning

The child's agency during pregnancy

How did Andrea come into your life? Did you fight for her or did she come easily?
 I fought a lot. I went into fertility treatment. I tried for 1 year to get pregnant and I almost lost hope. And then suddenly I got pregnant

Wow so you fought a lot for her. What did Andrea do to you, when you discovered that you were pregnant with her, did she create certain feelings in you or?
 I Smiles) yes she made me so happy.

Wow so she made you so happy, was it a kind of happiness you have experienced before or was the happiness she created different?
 It was very different. It was a strong feeling of meaningfulness.

Can you tell me more about that meaningfulness that Andrea so strongly connected you to - that she made you experience?
 It was a meaning about how much sense it makes for me to become a mother.

What did she make you experience in the moments with her in the pregnancy about being a mother?
 The experience of wanting to take care and protect ...

How was that feeling - did you like it - how is that feeling for you?
 yeah it was so nice. It makes so much sense. It makes much more meaning to my life then anything else.

Wow. Is it ok so say it is a big or a little thing - do you recon - to open a mum's eyes to?
 It is huge thing.

How is that for you that Andrea has done that?
 It makes me proud

The child's agency during birth



Andrea and her mother

The event of giving birth to a dead child or a child who only lived for a very short moments is very often described in the light of the horrific effects of death.

It becomes a moment that is described in the grammar of loss and it all about saying goodbye.

This moments of interaction can be explored as a one of the greatest moments of saying hallo. This is actually the first time that these parents see their little child.

This is a moment were the relationship to the little child develops tremendously.

We can make the child's influence in those moments visible and it has the effect on making stories not only about loss but also of being influenced in this relationship by your child. Your child has done something significant to you.

An example of "Saying hullo"

Sif Ane only lived 2 minutes (cries) I had her on my chest while she died
Is it ok to ask a little about how it was to experience Sif Ane. I know it was the first time you actually saw her?

Yeah

When you saw Sif Ane and she was put on you chest - what did she do to you when you saw her? did she make you have certain feelings?

Yeah she was so beautiful

Wow she was so beautiful. What did you notice was so beautiful about her?

Her fine little nose and fingers

Ahhh her fine little nose and fingers - wow when you saw her little nose and how beautiful she was, did Sif Ane make you experience something you haven't felt before?

I felt so proud of her ...

So she really made her mum experience being proud, and you had her on own you chest?

Yeah ...

While you had her own your chest can you say more about what she did to you, what she made you experience, did she made you experience warmth or?

She made me experience a strong warmth and love yeah a connection

What was that love and connection like?

It was so unique. It was the best

Was it a love between a mum and her daughter or how would you describe it?

Yes - she made me a mum

How is that for you that she made you experience this proudness, connection, and love for the first time as a mum?

It makes me so proud to know she did it.

Making the child influential by being a witness

- In honoring this moments of birth and interaction, we can bring the little Angelchild to the center of the relationship.
- The child can be made influential not only in how it has influenced the parents in that moment but also by giving it agency as a witness to the interaction and the responses of the parents to it.
- The parents sees themselves through the eye of their unborn child.
- This has the effect of transporting the parent's in the experience of themselves as a parent and the child becomes influential in where they get transported to.



Sif Ane and her mother

An example of making the child an influential witness

Wow can you tell me what did you do to Sif Ane, how did you response to her while she was on your chest?
 I caress her and I kissed her
 So you caressed and kissed her. What did you want Sif Ane to experience from these kisses, what did you intended to tell her?
 That she was loved
 That she was loved. What differences do you think it made for Sif Ane that she felt all this love?
 (cries) a lot ...the whole world ...
 If Sif Ane could have a voice what would she say the love that she experienced tell her about her mum?
 That her mum did everything she could for her ...
 If your daughter could have a wish for you how do you think she wants this knowledge to influence you?
 That I don't feel bad or ... feel guilty about what happened
 What would her voice be like it could have words to it?
 Mum you did you best
 How is that for you think about her voice in this way?
 It is nice ... I can feel her ...

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Membership

- "A life, then, is not envisioned as belonging to the individual who has lived it but it is regarded as belonging to the world, to progeny who are heirs to the embodied traditions, or to God. Such re-membered lives are moral documents and their function is salvific, inevitably implying, 'All this has not been for nothing'."

Myerhoff



Standing against invisibilizing

- Supporting people to make visible the effects of the relationship
- Introducing the deceased child to the rest of the world
- Others may need to be coached as to how to respond
- Supporting parents to know how to respond to condolences
- To find places where the life is shared and not only the way in which a child died
- Finding places that can become an appreciative audience for the deceased child

Lorraine

Double listening

- Listening at the same time to the problem story and the counter story
- Double listening hears both
 - the pain of the problem story & the story of hope
- We need to be alert for both the other stories
- For example, where there is pain, it is also testimony to love

Mom: We typically don't name our kids until they are born, but when we learned there was a problem we felt like we needed to name him immediately. Naming him meant he was something that wouldn't be taken away and can't be taken away from us.

Lorraine: In naming him before he was born, in what way did this make a commitment to your son?

Dad: It helped us put a name to the face. And really get to know him. Even though he wasn't born yet, we really got to know him.

Lorraine: How has his name guided your connection to your son over the past weeks since his birth?

Dead children have "human rights"

- In making visible the ongoing relationship we become political. We are giving back the rights of these marginalized children and their parents.
- Living children have the right to be continuously loved by their parents through the parent's whole life and the parents have the right to do so.
- Living children have the right to be continuously talked about by their parent's through the parent's whole life and the parents have the right to do so.
- Living children have the right to be continuously felt and thought of by their parent's through the parent's whole life and the parents have the right to do so.
- All this gets named as skills in parenthood but when a parent to an Angelchild does the same it gets labeled as grief.



Deconstructing Grief as evidence of ongoing relationship/parenting

- The parent who continues to :
 - experience emotional pain or incidences of sadness
 - act in regard to the child
 - think about and miss the child
 - hugging Angelchild's stuffed animals
- are seen as grieving and not as a parent who are experiencing or finding ways to continue the parenthood of an Angelchild.
- Making these experiences visible as skills in keep relating and being a parent for an Angelchild makes them changes them from something that needs to be stopped to something that can continue or being honored.
- In unfolding the present but invisible relationship or the parental skills in relating to the Angelchild we ask ourselves:
 - **How is what the parent is experiencing or expressing or doing a witness to continuously relating to the child?**
 - **How does this experience or expression or doing of the parent reflect parenthood?**
 - **What does the parent intend in relation to their Angelchild?**
 - **What does this experience or expression or doing of the parent tell the Angelchild about how it keep mattering?**

Making grief/guilt into sign of ongoing relationship/parenting

M: I feel guilty that I was not able to look after Magnus, that my body failed
 T: **does the guilt that you experience as a mum to Magnus say something about what you so strongly intended or wished for him?**
 M: yeah to look after him, to protect him and to make him live
 T: **does that say something about what is so presence in your relationship to Magnus?**
 M: yeah love...that he is my son
 T: **is the guilt connected to this being a mum that loves, a mum that wants to protect?**
 M: yeah if I didn't love him I wouldn't feel guilty
 T: **does this experience of guilt fit with being a mum, do mothers more easily experience guilt in regard to their children?**
 M: yeah I think so, yeah it is a mum-thing.
 T: **what would it tell Magnus about what he means for you that you are still thinking about how you could have protected him against something you didn't know how to protect him against?**
 M: that he is my son and that I would do anything to protect him.
 T: **what do you think Magnus would hope this would do to you, him knowing this about you?**
 M: that I can forgive myself ..
 T: **what do think it would sound like if you could imagine he could speak or voice this hope?**
 M: mum I know you did what you could...I love you (cries)

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The Angelchild keeps influencing after his or her physical death

- In making the Angelchild's influences visible, we can construct and unfold the influences from the child after it's death. Its influences on values, skills, how to do life and how to understand life
- Some of these influences on parents are traditionally ascribed to effects of loosing or the effects of the trauma.
- Often we can asked about how the Angelchild has changed the person contributed to new understandings of life, skills, or doing of life. We can connect some of the effects of what they went through to the child's influences.



Andrea's hand

An example of Posthumous Agency

Has Andrea somehow influenced, effected or changed how you are as person? Has she for instance influenced how you talk with other people or?

She has made me less cold before I was very hard on the outside. Today I can speak more openly about my feelings

So she has influenced you to speak more about you feelings. What would be a recent example of that?

Hmm well when I visited my work this week I talked about Andrea and how I feel about her to some of my colleagues

What did you experience it did to more openly share these feelings, what did it do?

M: I think I got more close to my colleagues, they get to know how much my daughter matters for me

So sharing feelings openly can make you closer to other people and make it more visible for others what matters for you?

yes

Does it make sense to ask what else has Andrea made possible for you to discover that is important for you when you speak more openly about your feelings?

That I can trust other people . Usually I thought other people would turn their backs to me

What do think about this influence from Andrea?

M: it makes me proud

The Angelchild's influences can live on

- If we make the child's influences and agency visible in regard to values, skills, understandings of life we can unfold:
- **how these influences from the child on the parents can live on in the future – how can the parents keep making use of the new values, skills, understandings of life**
- **what role can the child play in supporting the influences to live on – how can the parents make us of the Angelchild**
- This has the effect on expanding the richness of the influences, making the ongoing relationship visible, making the parents available for those influences.



Majse and her mother

Example of making the influences keep living

This skill or inspiration from Majse to not judge other people but to contain and listen to them is that something you want her to keep inspiring you to do? Is that a skill you like to hold on to?
 Yes indeed
 Why do you want to hold on to it?
 Because it makes me feel more connected to other people, not to distance myself to them.. It helps me to understand other people
 Are there situations where you can imagine yourself in the future to make use of this skill in not judging other people but listen to them?
 Yes when I start work again I know it will be hard to hold on to it but I like to
 What will it do to your relationship to Majse to hold on to this skill?
 It will make me feel connected to her
 How can she support you in holding on to this influence of hers to not judge but listen first to other people?
 I have thought about getting a necklace with the letter M
 Wow a letter M that stands for mother and Majse .. two in one
 (smiles) I haven't thought the two in one, but that is nice to think about
 Wow so could it be like every time you see or touches the necklace Majse can remind you of that, to not judge but to listen first?
 Yes that would be nice
 What will it do to know that touching the M can always make you connected to Majse's influence of not judging other people but first listen to them ..
 (smiles) It makes me think she can always be my little helper

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The Angelchild becomes taboo

The continuation of the relationship to an Angelchild is something that is hardly known in our society. The known and familiar responses are:

- Condolence
- Silence
- How are you

The grammar of continuing the relationship is so undeveloped and not widespread that people unfamiliar with it don't know how to talk about the child in ways that support the ongoing relationship. Rather people are influenced by discourses of death and grief that makes them worry about how the parents are still relating to the dead child.

This effect the parents to become invisible as parents, to not share their the Angelchilden with others and their little childen becomes silenced or tabooed

Making the Angelchild influential in changing society

- In our conversations we see the Angelchildren as children who can influence other people in significant ways - not only their parents - but the people they get introduced to.
- We try to find ways to save the Angelchild for being silenced.
- The parents can be positioned as missionaries, educators and activist. It is society who needs to be educated about how the Angelchild keeps mattering, the continuation of the Angelchild's significant influences and the continuation of being a parent for the Angelchild
- In these conversation we speculate and develop ideas to how to introduce others to this different grammar of continuing the relationship
- We unfold the parents knowledge about what other people need to know in order for these people not to respond in accordance to the discourses of grief and death but to be changed or informed by them and their Angelchild

Example preparation of parents to be missionaries

I am not sure people out there know about this relationship that you have to your Esther. I am thinking about this area is so undeveloped that people don't know what to ask about in regard to Esther, did you know about this before you experienced these things with Esther?

F: no not at all,
M: no I didn't .. I think I wouldn't have had an understanding of how it is to have an Angelchild ..
So in a way this is what Esther has brought into you life .. She has change what you know about this
F: yes she has ..
I think you have a knowledge that only few people have .. And that you need to share this knowledge with other people in order for them to know about this and to be able to listen and make room for talks about Esther
M: yeah I think you are right
You said you parents response to your tears when you talk about Esther with changing the subject .. What do they need to know about the tears for them to response in a different way .
F: I think they need to know that they don't have to fix the tears that I want the tears to be there because they are connected to the feelings I have for Esther ... I like to talk about how I relate to Esther ..
And what do they need to know about this so they don't worry about this as grief?
M: I think we need to tell them that Esther is our Angelchild ...that we will always connect with her and we don't want to change that

Example of the Angelchild being an activist

These talks you have had where you experience it becomes possible to talk about Esther is it a kind of missionary work?

M: (laughs) yes it is. And my father in Law actually suggested to me that I should make contact to my work and educate them on what to do when you experience grief. We have no policy on this. My boss didn't response to what happened he was silent. I have thought about making contact to my work and make them know the importance of talking about the dead children, I want to develop a policy of how to response

If Esther knew she is influencing her mother to stand up for this and make this knowledge more visible what would it do her? What would it do to her understanding for herself knowing she is in this work of making it more visible and change things for future bereaved people?

M: (smiles) She would be proud ... I think she would like to change things for the better

A motherly heart doesn't just stop – it keeps beating

Can you describe what you feel or experience when you see other small babies?

M: then I feel sad ... I wish it was me who experienced that with Esther and then I don't feel happy about their babies.. But it is not that I am not happy about them

Do you think the best description is jealousy or... what do you think you experience so strongly in those moments in regard to your Esther?

M: Pain. It is painful that I can't experience those things with her. I wanted to hug and cutie her and sit with her

That you can experience this pain in regard to Esther in those moments and you can experience the strong wish to hug her, can it tell us something about you as a mum?

M: that I love her..

This ability of yours to love Esther - what does that say about you as a mum?

M: that I have a motherly heart

Would you say that Esther activated your motherly heart or made you have a motherly heart

M: she made me have a motherly heart and a heart does not just stop to pound

No it is a heart. So it doesn't stop pounding. Your motherly heart keeps pounding. When you experience the pain - when you see other parents with their small babies - what is your motherly heart then pounding for in regard to Esther?

M: that I could have experienced that with Esther..

When you keep talking about Esther is that also your motherly heart that is pounding?

M: Yes it is

And what does it pound for in those moments

M: That Esther should be talked about and experienced by others as our daughter. I want her to keep influencing us

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● Q&A
