Forgotten Grievers.
An Exploration of the Grief Experiences of Bereaved Grandparents.

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Aim

• Background
• What the current literature says...
• What we have done so far
• Challenges/Issues faced
• Preliminary findings
• What are next steps...
• Acknowledgements
What current literature says..

- Anecdotal
- ‘Double Pain’
- The role of grandparents around the time of the loss of grandchild
- ‘Forgotten Grievers’
- Family Dynamics

What we have done so far

- Number of participants
- Geographical spread
- Background on participants
- Ethical considerations
Challenges faced

- Access
- Challenges for us as interviewers being in the presence of raw pain

Cumulative Pain
Collective pain associated with previous bereavements. (1 of 2)

Collective pain associated with these previous losses

- Children of their own either through miscarriage, still birth or in infancy
- Husbands
- Parents
- Siblings
Collective pain associated with previous bereavements. (2 of 2)

How pain associated with previous bereavements compares to pain associated with loss of grandchild

“I lost both my parents and 2 brothers and a miscarriage but nothing compares to the loss of _____(Name of Grandchild)”

Difference between pain associated with loss of brother and pain associated with loss of grandchild.

“I know when______ (brother’s name) died, I wanted to die and I just didn’t want to get up”
But for this participant...
“There is no comparability here with the death of ________(Name of Grandchild) because he never got the chance to grow up whereas the my brother and the rest of the deceased members of my family did...”
“The heartache of the long spells in hospital (In England), the drives in the middle of the night to catch a flight, leaving the house at 2 or 3 o clock in the morning...I wasn’t in the car but I at home constantly worrying...it was absolutely dreadful, such hardship...that went on for 6 years before he died....”
“I felt total disbelief that it could happen...unbearable pain...my God...i just felt that my heart was going to burst right out...nothing could ever be as bad, no sorrow-unbelievable bloody awfulness...there is never a sense of relief that he died...I know that some people say - ‘ah it was happy for him, a release for him, he was a long time suffering’ maybe I am selfish but I would have held onto him, I wouldn’t have let him go, if I had a choice, he wouldn’t have got going...ah it was that God awful pain, waking up in the morning and that pain there like a tonne of bricks...nothing, nothing could lift it...you wake up in the morning for one split second and then you think -‘oh’ and then you realise that pain is just there and it didn’t matter what you did, you could never, ever lift it...it was like if someone stuck a knife in ya and there was no release, no nothing could ease that pain. I never felt pain like it and I would never wish it on anyone...”

“When ______(Name of daughter) could not be present for the baptism and I was there in proxy and the priest used ______(Name of daughter)’s tears to baptise ______(Name of grandchild), that was absolutely...it was absolutely the most horrendous heartache that you could experience.”
Pain Associated with Losing Grandchild
(4 of 9)

Pain of holding death grandchild

“...the little baby was there and they (the nurses) were encouraging us to hold him and not to be afraid of him...when I held him I had to be very careful of his little head because it hadn’t like probably come together...(crying)...and just willing him to breath...please breath...please breath.....”

Pain Associated with Losing Grandchild
(5 of 9)

After grandchild dies...

“when I think about how ________(name of grandchild) died in his mother’s womb...I wonder...what did he feel the poor thing...was he looking for his mother...did he think...this is better for me cause at least I am clinging onto my mother when I’m dying...”
Pain Associated with Losing Grandchild
(6 of 9)
Shattered dreams

“We were looking forward to so much, we were deprived of ...oh....colossal pleasure. He was going to bring us nothing but pleasure, something new everyday, he would have achieved so much, he was great at music...(crying)”

Pain Associated with Losing Grandchild
(7 of 9)
Shattered dreams

“We were just sitting, ______ (daughter’s name) and I were talking the other day, I wonder what he would have been like...you often wonder what he would have been like as a person...I imagine because of his illness, he would have been a very accepting child because you often hear that where children who have illnesses are very accepting, very passive, don’t get stressed or uptight...I imagine he probably would have been like that”
“we were looking forward to this grandchild coming along..looking forward to the future and the cuddling and the babysitting and the all the nursing and all that doesn’t happened then you know...”

“I just would’ve loved to have been able to see him grow up..to enjoy him..to watch all the wee things”

“unless you’ve been through it (the loss of a grandchild), you cant realise, that is would be as easy for me to lose my son, as lose my grandson, there is no difference.....to me a grandchild and your own child there is no difference-where do you draw the line?”
Knowing that the baby is going to be born dead...

“When we knew that ______ (Daughter's name) was going to be induced and that her baby was dead, it was savage, savage pain….when any of my daughter’s go into labour, I go through the labour with them but I am waiting for the arrival of the perfect beautiful newborn baby…but this time I had to go through that with her, knowing that she was going to give birth to a dead baby- it was devastating”.

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“The night we arrived in _____(name of hospital) and the fear in me that night as I saw ________(name of daughter) ... It was phenomenal, I was just terrified for her, watching her, knowing that she was going to lose and have to ‘let go’ her child..”

“I was thinking in myself –I don’t think I’d ever have the courage to go through that and then remembering that I had done it (this Grandmother had lost a Preterm baby herself)... Many times I made that remark- it would be much easier to go through this pain myself than watch your child go through it...I still look back and say it was harder to actually watch the situation than be in it yourself”.
"I would never wish it on anyone, the abiding pain, the pain of feeling useless, knowing that I couldn't stop ...... pain. I knew I could do nothing for her. It's the worst thing I ever felt in my life. And it is only going through this that I realised the depth of a mother’s love. People say that a mother would kill for a child. Well I know that, I fully understand that now. I would kill for ...... in the morning...my daughter has been through hell on earth and you are not going to do anything else to her”.

"When ______(name of grandchild) died it was like...this is my little girl going to have her children/my grandchildren...it was actually the loss of a whole future now. It wasn’t just about ______(name of grandchild), it was ______ &_____ (name of daughter and son in law) thinking will they ever have children of their own..."
“When I lost my own premature daughter _____ (name of daughter), and went through the pain of that, I had the belief that my children could never have to go through the same patterns... So that night as I stood in the hospital I was thinking... this is not supposed to happen, so my belief was shattered by what was happening, that my children would have an easier time than I did..”
Pain Associated with Subsequent Changes in their Daughter (1 of 2)

“The pain of losing ______(name of grandchild) is beginning to show on her now. She was very brave, very brave, much too brave at first ... trying to be normal...now I can see she’s in bad health ...she is all screwed up... it is very hard to look at ... there is nothing I can do.”

Pain Associated with Subsequent Changes in their Daughter (2 of 2)

“She’s lost all her confidence in herself, all her belief in herself...she is a totally different person ...she is not the confident bubbly person that she was...her whole personality has changed...if she came in here she would be all 'sweetness and light’ but when you look in her eyes...she is full of self-doubt about herself, about her ability as a mother...she would often say....did we do enough for _____(Name of Grandchild)...should we have told them to go ahead and do more for him...should we have given him more chances...that will probably be with her until the day she dies...”
Pain Common to all Grief Experiences

Feelings/Emotions..


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Pain Common to all Grief Experiences

Regrets..

“I was so preoccupied with everything else...its amazing to actually say to you...I never actually picked up that child and cuddled him...the opportunity never arose at any point through the time...when he was weak on the Sunday, I remember ____ (name of daughter) was nursing him and I was thinking I cannot get in her space...this is my one regret...I didn’t actually hold him”

Pain Common to all Grief Experiences

Reminders..

“Christmas was just dreadful...the emptiness....”

“Every other grandchild’s birthday your thinking...what would he be doing now...whose pet would he be...”

“His anniversary is St Patricks Day...it’s the one day that I don’t want to know about...I would sooner it wouldn’t come at all because all the pain comes back up to the surface again”

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Death of Grandchild causes “Disequilibrium”

If Facilitation of Pain Takes Place – Equilibrium is Restored.
If Facilitation of Pain is Inhibited – it Causes Further Disequilibrium.

Combination of Pain being Facilitated and Inhibited.

CP - Cumulative Pain
F – Facilitation of Pain
I – Pain is Inhibited
The Factors that Facilitate or Inhibit the Resolution of this Pain

• Recognition/acknowledgement of Grandparent and Grandchild
  • Connection to own life story/beliefs
  • Role and function of Grandparent before, during and after the death of Grandchild

• Practical/Emotional Support
• Grandparent/Daughter Relationship
  • Other Family Dynamics
  • Health Professionals
  • Men’s grief
The Factors that Facilitate or Inhibit the Resolution of this Pain

- Neglect of self vs. self care
- Making sense of death
- Spirituality with or without Religion
- Pain of loss of Grandchild vs. intense joy/pleasure of subsequent grandchildren (Via the anxiety/worry of future pregnancies)

The Factors that neither Facilitated nor Inhibited the Resolution of this Pain

- Support from friends (Superficial) vs. the absence of support from friends wasn’t missed.
Next steps...

- Set up network of grandparents who have agreed to same.
- Make contact with remaining key organisations
- Further analysis of transcripts
- Returning to participants to explore the meaning of the concepts in order to develop further understanding.
- Meet bereaved grandparents who have agreed to participate.
- Explore remaining avenues in the media to publicise the study with the intention of recruiting further participants.
- The possible development of a further quantitative study that is linked with the current study.

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Daire  Olivia  Ricardo

Faye    Joseph  Ronan

Turlough  Tulip