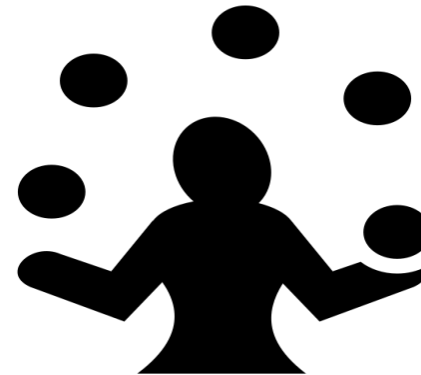
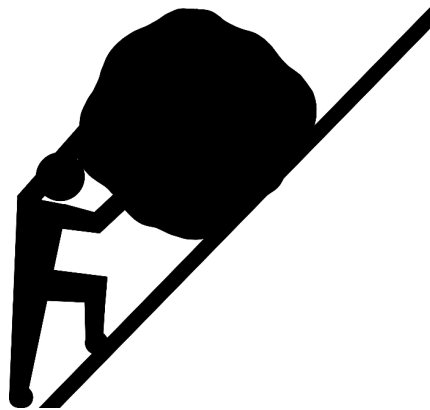


Juggling and Struggling – parent and professional experiences of accessing and providing neonatal palliative care within a children's hospice



Professor Jayne Price
Dr Rosa Mendizabal-Espinosa

Rome October 2018



Rome October 2018

What?

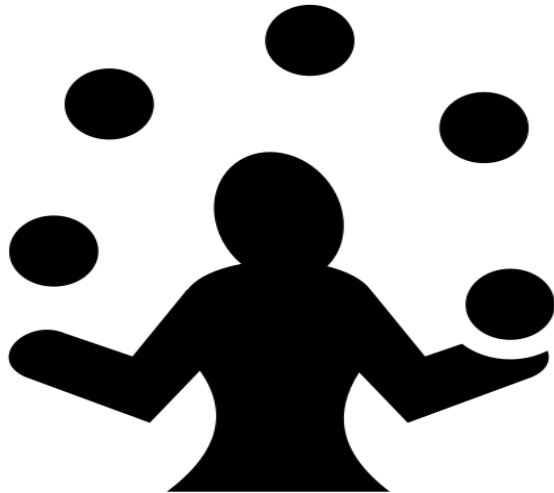
- ✓ Qualitative study (NePaCh Study)
- ✓ Examining experiences of neonatal palliative care in children's hospice
- ✓ Reference Group
- ✓ Ethical approval
- ✓ Interviews with parents (5)
- ✓ Focus Groups (3 with 17 hospice staff)
- ✓ Thematic analysis



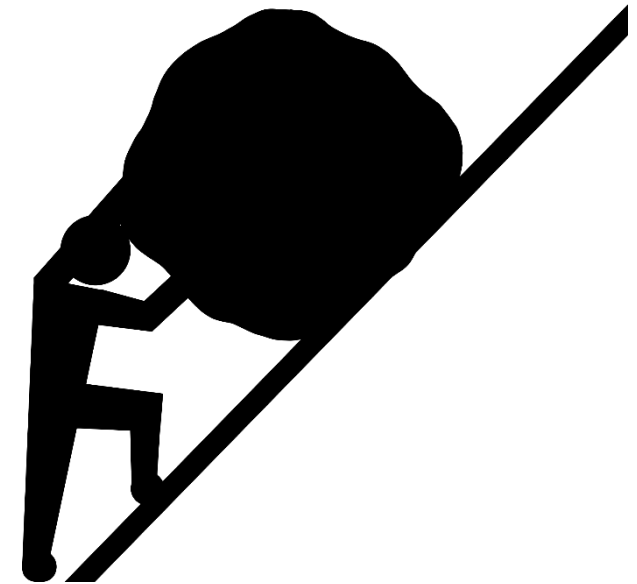
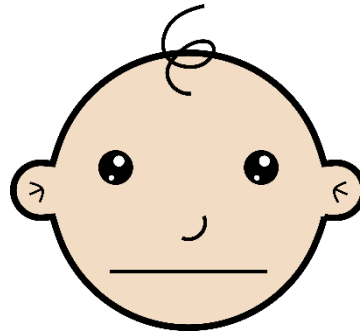
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So what – Findings?

Juggling



Struggling



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What next?

Implications

- Ongoing staff education
- IPL midwifery and children's nurses
- Lobbying hospice
- Early introduction of hospice
- Visit for parents
- Further research
- Hospice can provide added value

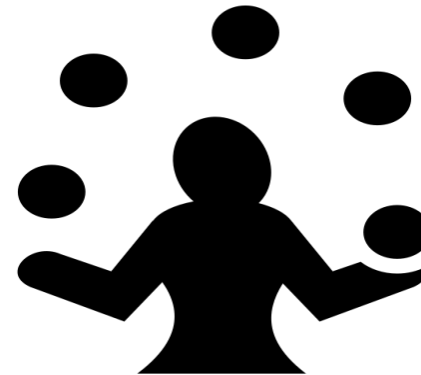
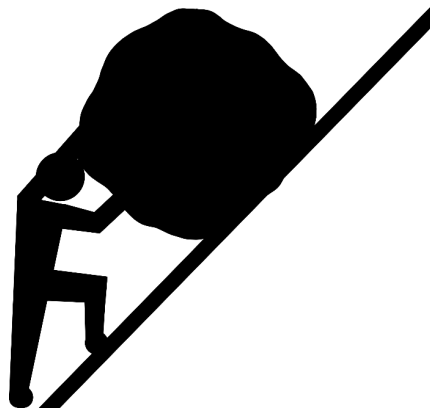


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Yeah I think that's it and I think that we are able to really look back on it... I mean it's so hard because it is just the worst thing, we are devastated and we are every day reminded of how awful it is but we do feel like we have the best possible experience of something that is going to be awful M1

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