The meaning of how 'significant others' can support parents to make decisions when their child has cancer

I did this research study for a PhD project at Oxford Brookes University.

I knew from my previous clinical practice as a children's cancer nurse that parents may be faced with many decisions when their child has cancer and that this can feel very stressful. Previous researchers had explored how health care professionals may support parents with making these decisions, but I was interested to understand how other people in parents' lives may be supporting them.

I interviewed 6 parents of children with cancer between November 2021 – September 2022. The types of cancer that the children had varied and they had been diagnosed between 6 weeks and 3 years before the interview. All of them were still receiving care for cancer.

Each interview took place online. I asked the parents to tell me a little about the story of their child being diagnosed with cancer and what types of decisions they had been faced with. We then made diagrams (ecomaps) of the support networks around the family, and this led to conversations about how people from these networks had supported the parents (or not supported them) with making decisions.

The support networks around each family were unique, but often the network consisted of extended family members, friends, colleagues, other parents of children with cancer, and in some cases health care professionals. The levels of support from people in the network varied, and sometimes relationships were a source of stress rather than support. Some parents explained that they often found themselves giving support to people in their network as well as receiving it.

The decisions that parents talked about included decisions relating to cancer treatment, decisions relating to associated medical care (such as how to support their child's nutrition), but also many decisions relating to managing life outside of the hospital like childcare and school / nursery attendance. Often parents felt that they were limited in their involvement in decisions relating to cancer treatment, and they felt that these decisions were for the medical team to make rather than them as parents. However this did change over time for some families.

Support from social networks ('significant others') with making decisions was important, although this support was not necessarily explicitly given in relation to decision-making. Several of the parents who I spoke to experienced a profound loss of confidence in themselves at the time of their child's diagnosis. They talked about feeling overwhelmed and lost at sea with the decisions that they were facing. People in their social networks could play a very important role in shaping that confidence. Whilst there may have been times where it was helpful for a friend or family member to step in and give the parents advice about a particular decision, often this was not helpful as this could further undermine the parent's confidence. What felt more supportive was when other people could show compassion by being present and listening to the parents. This could help to empower parents that they were able to make the decisions that were best for their child.

It is important for health care professionals to understand how parents may be feeling about making decisions, and how people outside of the health care setting may be able to offer support to parents. It is also really important that the findings of this research are shared with the general public so that members of social networks supporting parents living through

situations like this know how to help. It may be assumed that if somebody is faced with a difficult decision, the best thing that we can do as friends or family members is to jump in and offer advice. However, it is important to be open to the possibility that this may not be helpful, and that instead, offering compassion and empowering parents that they can make the best decisions, can be enormously powerful.

Whilst this study has formally ended, I now plan to share these findings by creating a short film, and holding public engagement events.

I would like to thank the study participants who gave their time to this project, and so generously shared their stories.

Further information about the study can be found on the study website here: https://sites.google.com/brookes.ac.uk/liz-jestico-phd-study/home

