

Family resilience and cancer:

A Grounded Theory investigation into the experiences of families positively adjusting post cancer treatment

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Introduction

Family resilience and cancer

Understanding resilience, and positive adjustment, following cancer treatment is crucial to the promotion of well-being and recovery in line with the National Cancer Survivorship Initiative.

Research on resilience and cancer to date has largely adopted an individual focus, studying the individual patient or individual carer's experiences. This study aimed to take a broader perspective to consider how families experience and show resilience following cancer treatment.

The study of resilience for cancer survivors and their families is a pertinent topic of research, consistent with national priorities. The Board on Health Care Services directly state;

"Although cancer is recognised as having a large impact on family members, it is rarely the subject of, or included in, research on psychosocial health care".



Maggie's Fife



Maggie's Newcastle



Maggie's Swansea

Maggie's

Maggie's Centres provide free practical, emotional and social support for people with cancer and their families and friends.

Built in the grounds of NHS hospitals, Maggie's Centres are warm and welcoming places, with qualified staff offering an evidence-based core programme of support developed to complement medical treatment.

Great design and architecture is vital to the support Maggie's offers and so world-renowned architects like Zaha Hadid and Richard Rogers use their skills to help deliver the calm, uplifting environments so important to the people who visit and work in the Centres.

Maggie's was specifically chosen as the setting to recruit families for the study.

www.maggiescentres.org

Methodology

Research questions

The study's primary research question was *"What are the experiences and processes of resilience in families that help with positive adjustment post treatment following cancer?"*

The study had three thematic aims:

1. To explore the experiences of families who have faced a cancer diagnosis and finished treatment.
2. To provide an understanding of the impact of these experiences on family life.
3. To develop a greater understanding of the roles of resilience and positive coping in these families.

Study design

A Qualitative design using Grounded Theory Methodology was used. Taking a constructivist approach, the categories presented are not meant as variables that hold explanatory and predictive power, but invited as one of many possible interpretive frameworks that present an abstract representation of four families reflections on their experiences.

Participants

Eight participants were recruited from Maggie's Oxford and interviewed in their respective family units as four couples. The eight participants were between 57 and 74 years of age, all in heterosexual relationships. The sample included participants who had experienced a range of primary cancers including renal cancer, lymphoma, leukaemia and bowel cancer. One couple had both experienced a cancer diagnosis and treatment. The length of time since finishing active surgical, chemotherapy or radiotherapy treatment ranged from four months to five years.

Procedure

Participants who expressed an interest in being contacted about the study were invited for interview that lasted 60-minutes. It was audio-taped and the data was transcribed verbatim by the researcher. A semi-structured interview schedule with open-ended action and process-oriented questions was used.

Data analysis

The transcripts were analysed using constant comparative methods until theoretical saturation, starting with descriptive codes which were developed with greater detail and abstraction, to arrive at a set of categories that reflected the original data.

Results

What does "finishing treatment" mean?

Ethnographic observations from the recruitment process and research interviews revealed complexities for families subjectively defining themselves as being "post treatment". Factors included the perceived possibility of recurrence, a fear of "tempting fate", and a reduction in confidence and trust given the challenge to previously held assumptions and beliefs about their health.

"How can we ever say that the treatment is behind us and we've finished treatment? There's always the possibility there will be more."

Understanding family contexts to understand family resilience

Accounts of family life post cancer treatment were intertwined with accounts of family life more broadly in the extended family, and family histories.

"I had an uncle that had cancer years ago and they told me he's only got a few months to live. Nothing wrong with me he said, three months later he was dead. That was the only thing I'd ever known about it, it's a bit frightening when you think about that sort of thing and makes you think about your own approach."

"My daughter-in-law had her father to deal with a cancer diagnosis, and then her mum had breast cancer to deal with so the three of us in one family. It has been quite significant, and has created quite a lot of worry and concern and upset... it has affected the family even more so because there have been the three of us dealing with it."

"I think it was relevant that my dad just got on with things, he taught us, he showed us that when you are up against it... it can be something you can cope with. And me and my sister took a lot from that. I'm sure it was relevant to me coping with all this."

Resilient relationships

Perceived reciprocity was central to participants' descriptions of resilient relationships.

"I knew what he was going through... I'd been there myself, and it's just, you don't know how you're going to react but I did feel I could help more having gone through it and for that I guess it was a good thing... It is good we were there for each other I suppose."

"I think it's brought us closer, a lot lot closer... it's been important to keep everybody up to speed about everything. Not to keep any secrets... I think it brought us as a family... I mean we had become closer since their dad had left but I think even more so as family, a lot closer."

"We'd only been married six years, so it was a big thing... it was a test for us but we came through with flying colours didn't we?"

Resilient outlooks in the face of uncertainty

Resilient outlooks consisted of families managing uncertainty, while taking control and positively orienting to the future with spontaneity.

"I don't know whether I'm in remission or not but at the moment it seems ok... it's a lot better than some people have it... but it casts a shadow over your life really."

"Doing things spontaneously, I might get up one morning and say 'shall we have a run down to the coast' or something like that as opposed to planning it a week ahead... it's made me think life's worth living... if it's something I want to do then I can do it and I will do it."



Conclusion

The findings suggest the importance of attending to the broader family context and family histories to understand how families adjust post treatment. The role of perceived reciprocity is highlighted to be central to resilient relationships to help families with the tasks of taking control and positively orienting to the future while learning to live with uncertainty.

With all participants recruited being interviewed as couples there is huge scope to develop these initial findings with a larger study including multiple perspectives on family experiences post treatment.

Maggie's Centres welcome all family members affected by cancer. This inclusive model enables flexible, individually tailored and responsive support for families recovering after cancer, which is both supported by, and further informed by, these findings.

References

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