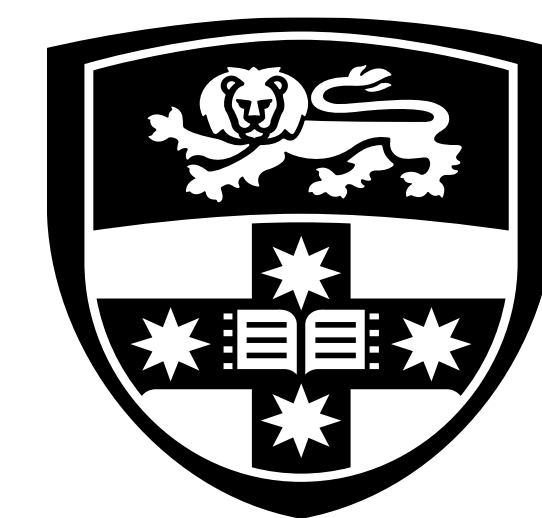


Ovarian cancer caregiver experiences of fear of cancer recurrence: A qualitative study



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Background:

In Australia, around 1400 cases of ovarian cancer are diagnosed each year.¹ Patients are supported by friends and family members who provide essential support, both physically and emotionally.^{2, 3} Fear of cancer recurrence (FCR) is defined as the “fear, worry or concern relating to the possibility that cancer will come back or progress.”⁴ Whilst patient experiences of FCR have been widely investigated, further examination of how caregivers experience FCR is required.

Aim:

To explore experiences of fear of cancer recurrence among caregivers of people with ovarian cancer.

Methods

Caregivers aged 18+ providing care for a friend or family member with ovarian cancer were recruited through Ovarian Cancer Australia (OCA)

Caregivers completed demographic questions and the Fear of Cancer Recurrence Inventory (Caregiver) (FCRI-c)

Semi-structured phone interviews were conducted to explore caregiver experiences of fear of cancer recurrence and progression. Thematic analysis was used to analyse the qualitative data.

Results (N= 24)

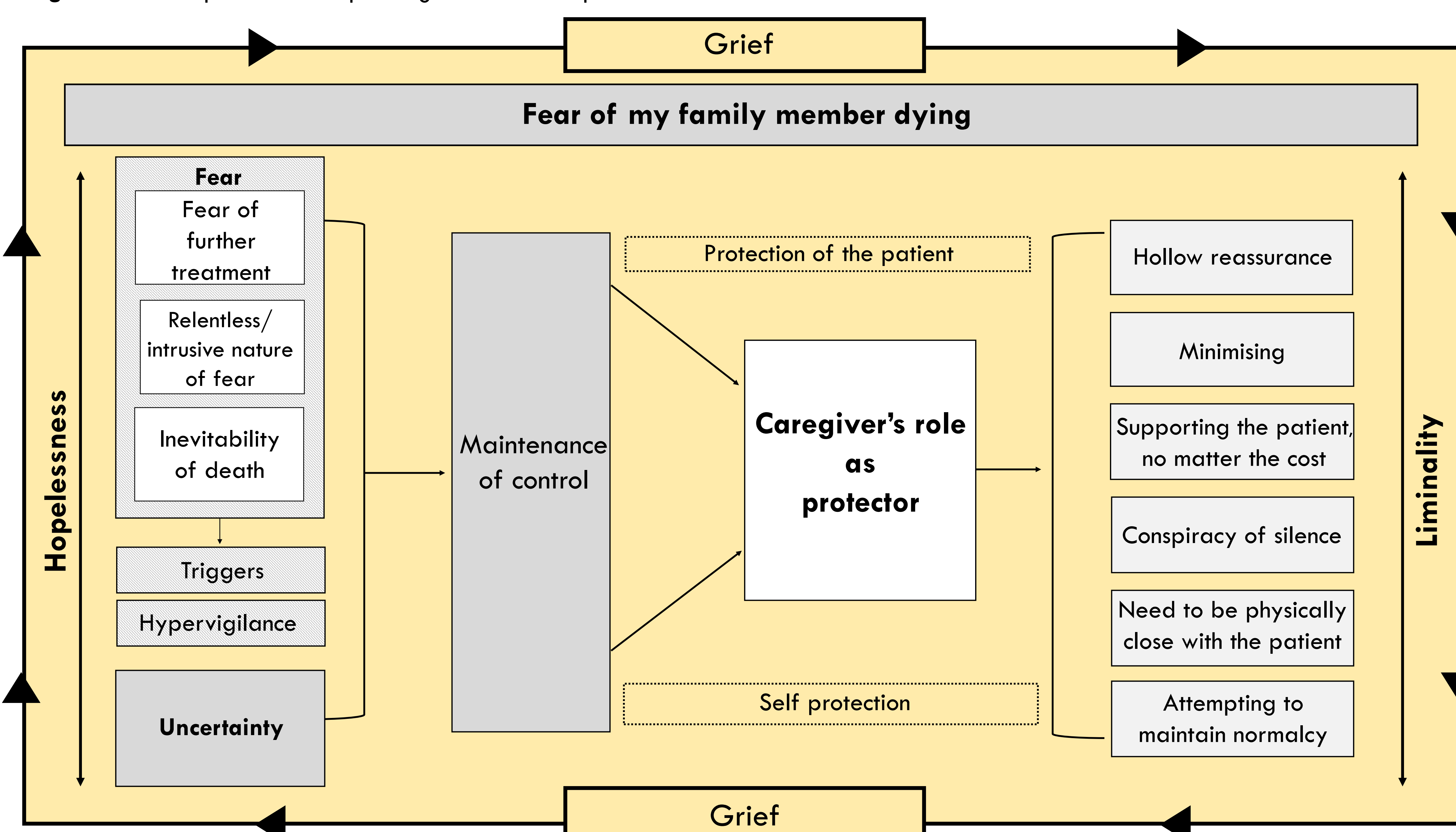
Four inter-related themes were identified:

Gender (% Male)	54%
Relationship	
• Spouse	14 (58%)
• Parent	6 (25%)
• Child	3 (13%)
• Other	1 (4%)
Age (mean)	57
FCRI-c (mean)	59.4
Patient cancer stage	Stage I-II= 5 Stage III- IV= 16

- Fear and worry:** Caregivers reported feelings of fear and worry about what may happen to the patient if their cancer were to recur or progress. These fears and worries were often pre-occupying and intrusive in nature, acting as a driver for some of the passive behaviours that caregivers engaged in (e.g., triggers and hypervigilance of the patient).
- Liminality:** Underpinned by uncertainty surrounding the patient’s disease trajectory, caregivers reported a state of limbo between two distinct life periods: pre-diagnosis and what was to come.
- Hopelessness:** Caregivers expressed an overarching sense of hopelessness. Many caregivers felt unable to help their family member in a meaningful way which was reported as distressing.
- Caregiver’s role as protector:** The protector role was dual in nature, described as a desire to protect the patient from the caregiver’s own concerns, and as a coping mechanism used for the caregiver’s own self-protection. Caregivers interpreted their own concerns as being “nothing in comparison” to what the patient was experiencing, expressing a need to minimise their own concerns or keep these from the patient entirely in order to avoid further burden.

An overarching theme, **Fear of One’s Family Member Dying** was also identified. This took varying forms, for some the consideration was imminent, caregivers aware the patient had few treatment options available, some questioning when a transition to palliative care may occur. For others, whose family member had not been diagnosed with a recurrence, or were in a disease-free period, the ever-present threat of disease recurrence acted as a reminder of the patient’s mortality. This theme was mentioned by all caregivers, including those whose family member did not have currently active disease.

Figure 1: Developed model explaining the relationship between identified themes and sub-themes



Conclusions

This study found that some aspects of caregiver FCR were unique. Caregivers play a vital role in supporting people with an ovarian cancer diagnosis. It is imperative that support tailored to the needs of caregivers is available. Future research should explore the nuances of FCR in caregivers, including caregiver experiences in cancer types with differing prognoses.

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Proudly supported by Cancer Institute NSW

Kyra Webb received conference registration support from Sydney Cancer Partners via a grant from the Cancer Institute NSW.