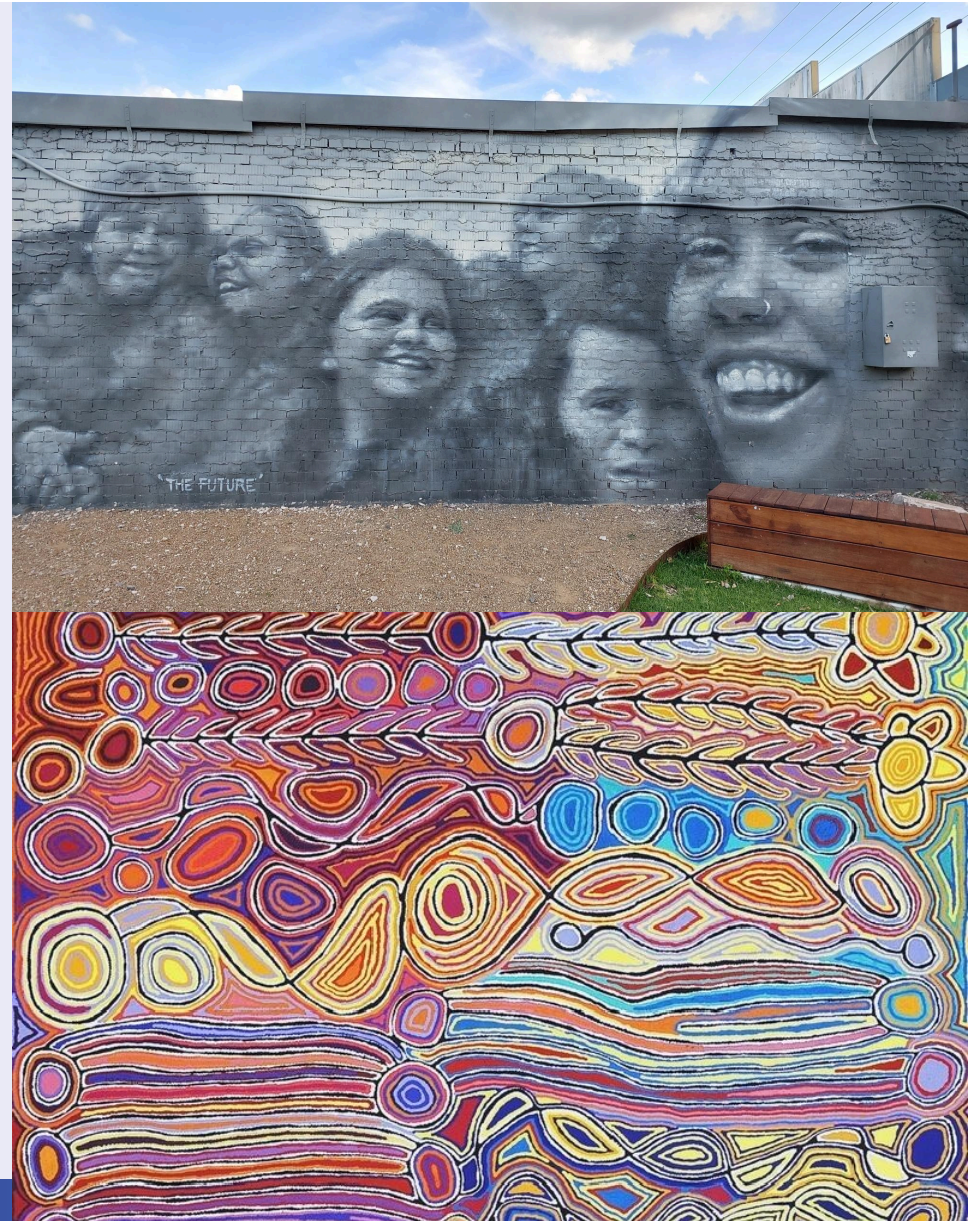


High unmet emotional and
financial needs among carers
of people with an upper
gastrointestinal cancer:
**Findings from an Australian
consumer survey.**

Sue Hegarty

Acknowledgement of country

I would like to begin by acknowledging the traditional owners of the lands that we are meeting on the Whadjuk people of the Noongar nation. I want to pay my respects to Elders past and present.

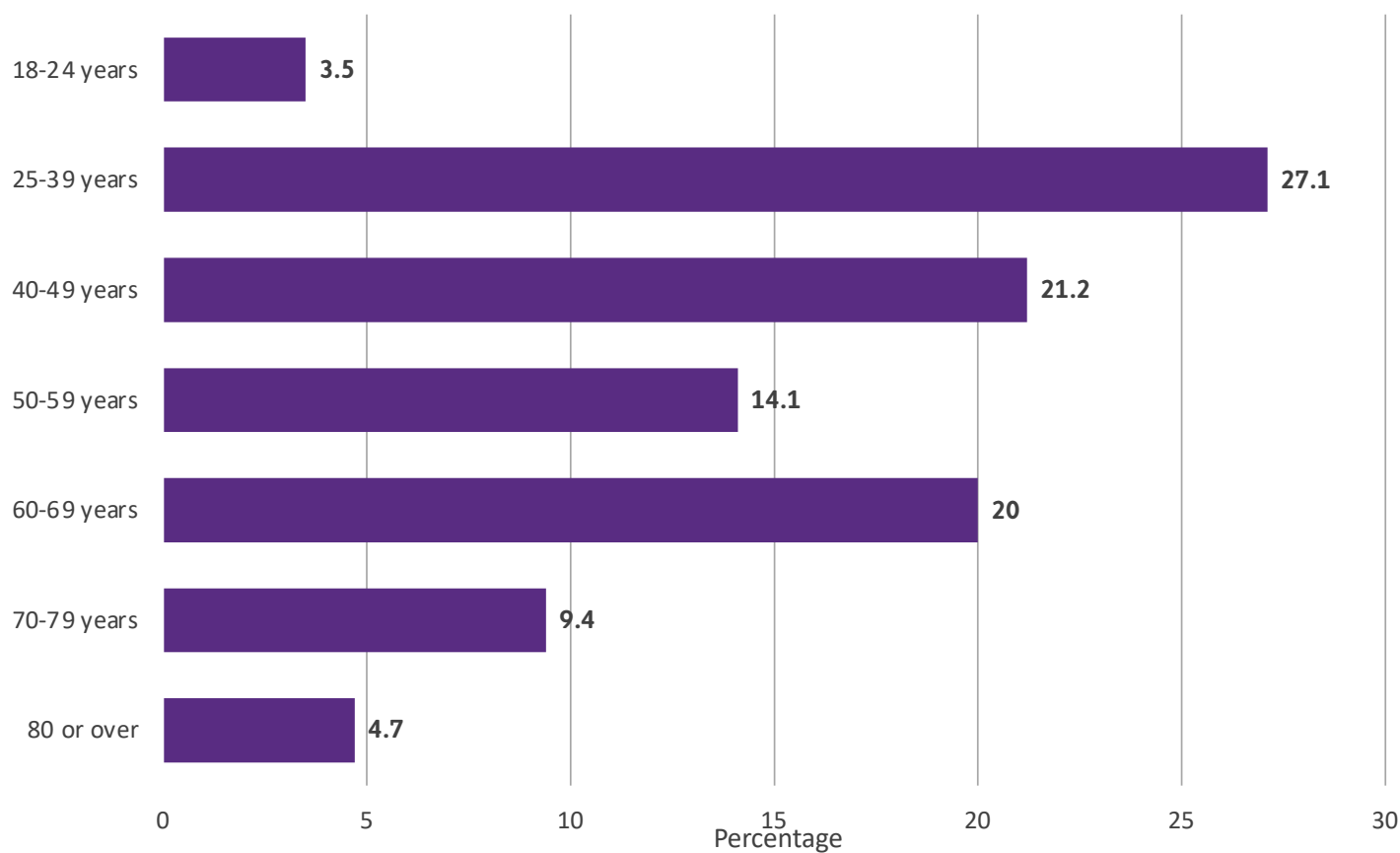


Study design

- A national, cross-sectional, online consumer survey comprising 35 questions was conducted.
- Survey items included multiple-choice, Likert-scale, and short-answer questions, with branching logic used to minimise respondent burden.
- Consent and skip-logic questions were mandatory; all other questions were optional.
- Descriptive statistics were used to summarise quantitative data, and short-answer responses were reviewed for contextual insights.
- Recruitment was via national consumer organisations and online networks.

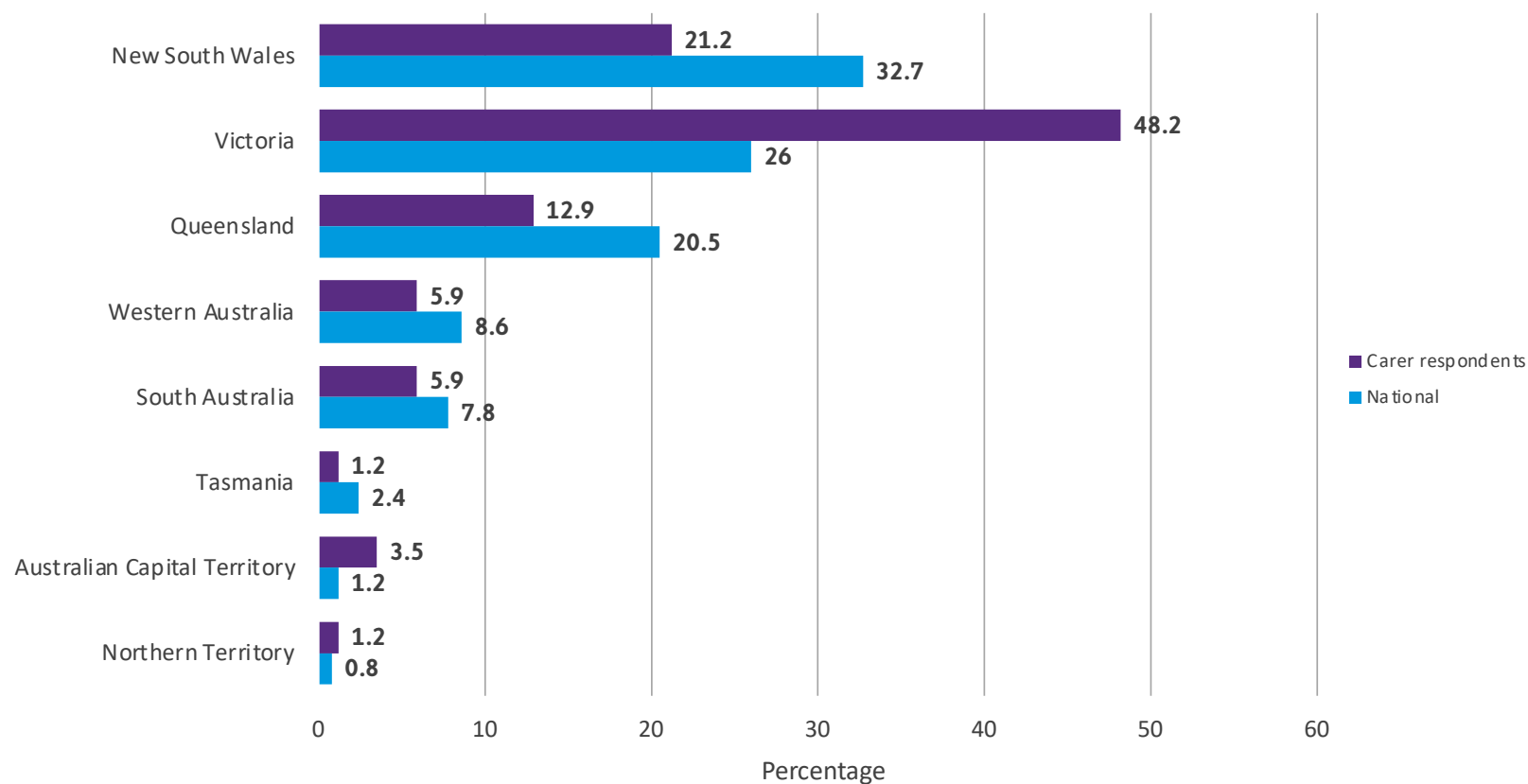
• 85 carers responded to the survey

Demographics - age



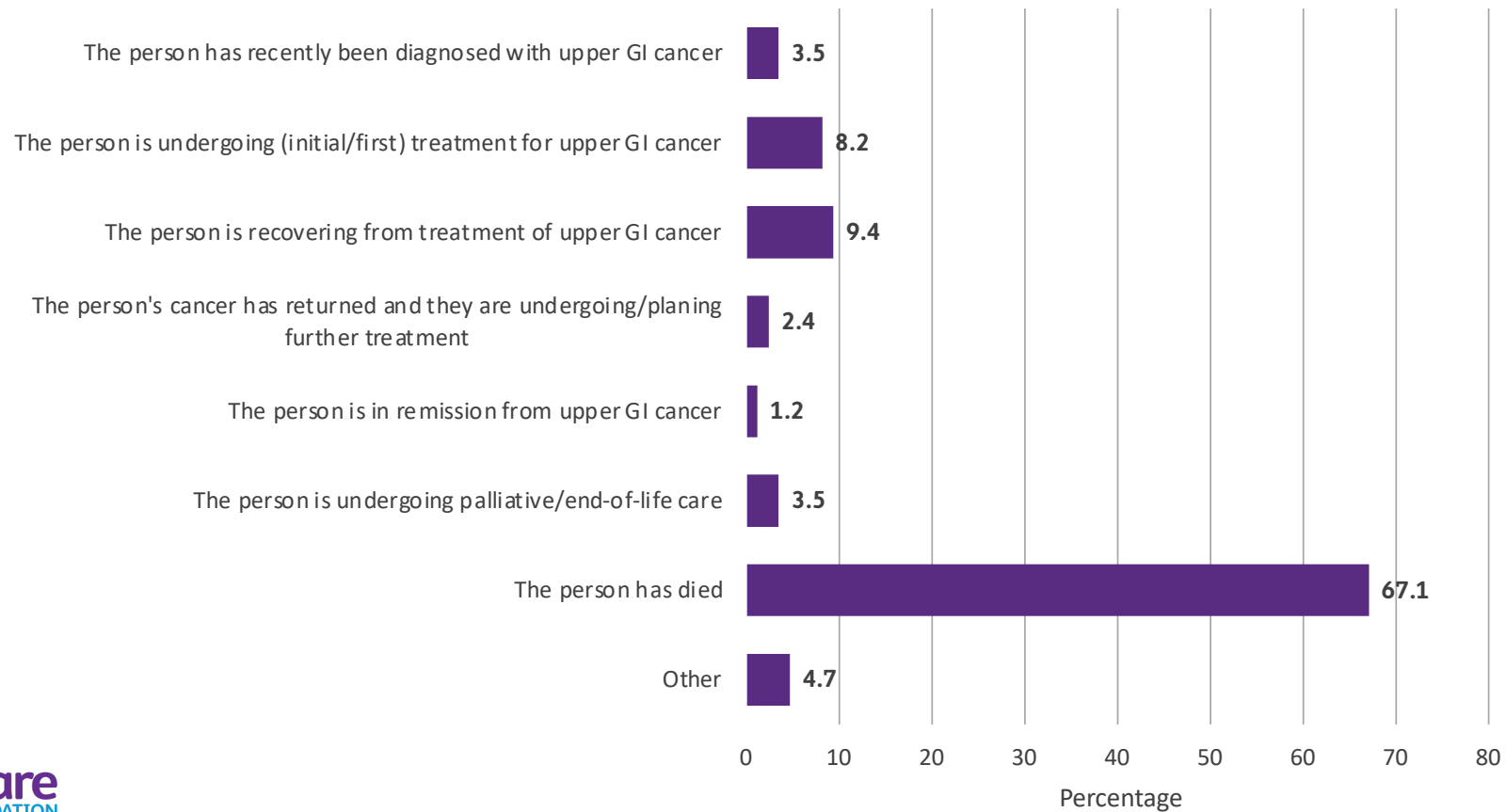
Demographics - location

The distribution of carers (n=85) respondents by jurisdiction compared with national incidence by jurisdiction (2021)



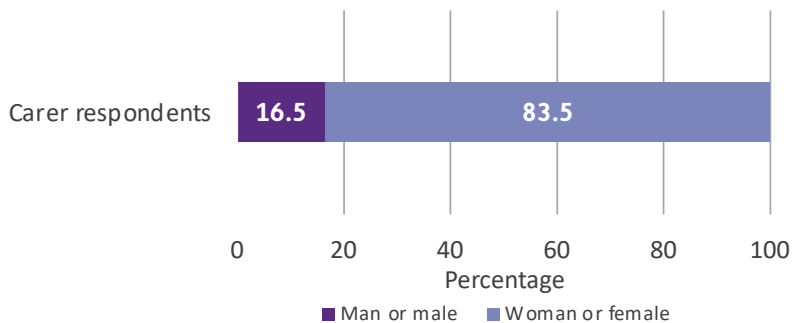
Demographics – stage of disease

The cancer status among patients cared for by respondents (n=85)

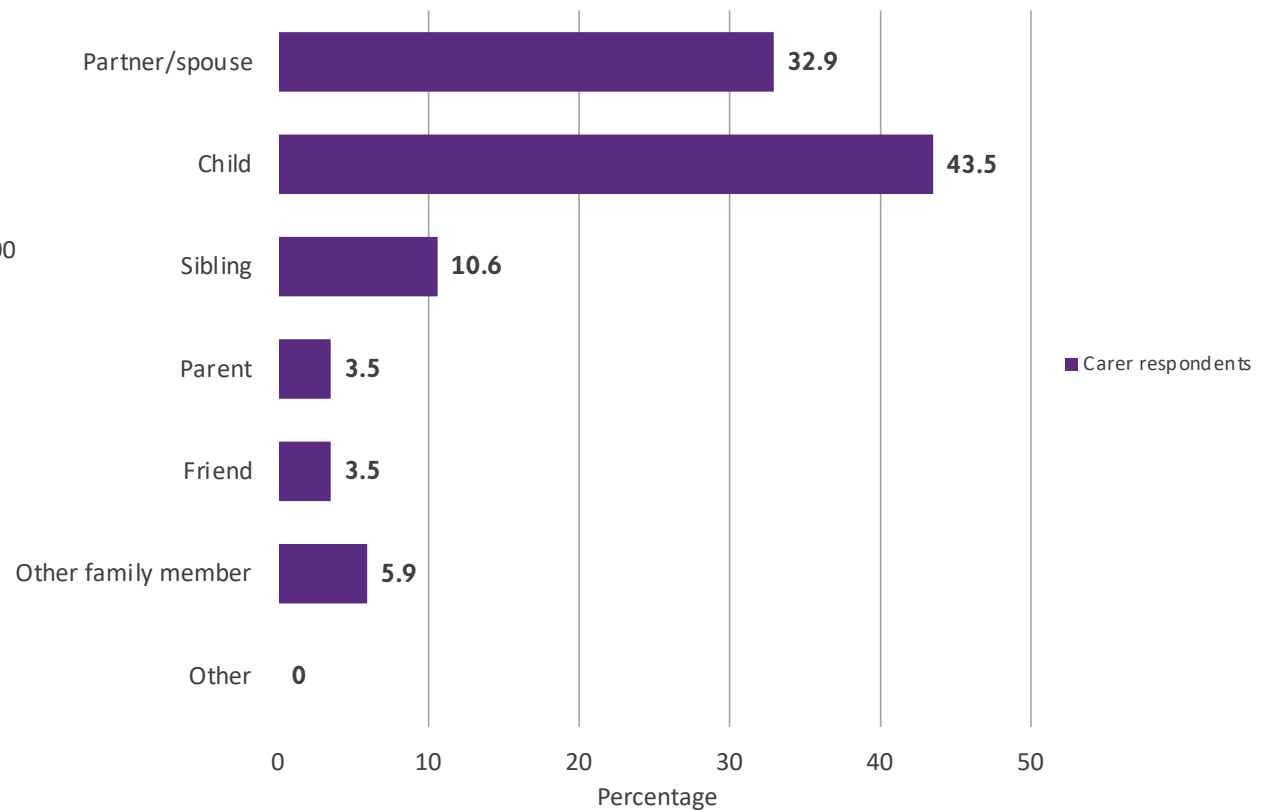


Demographics - gender and relationship

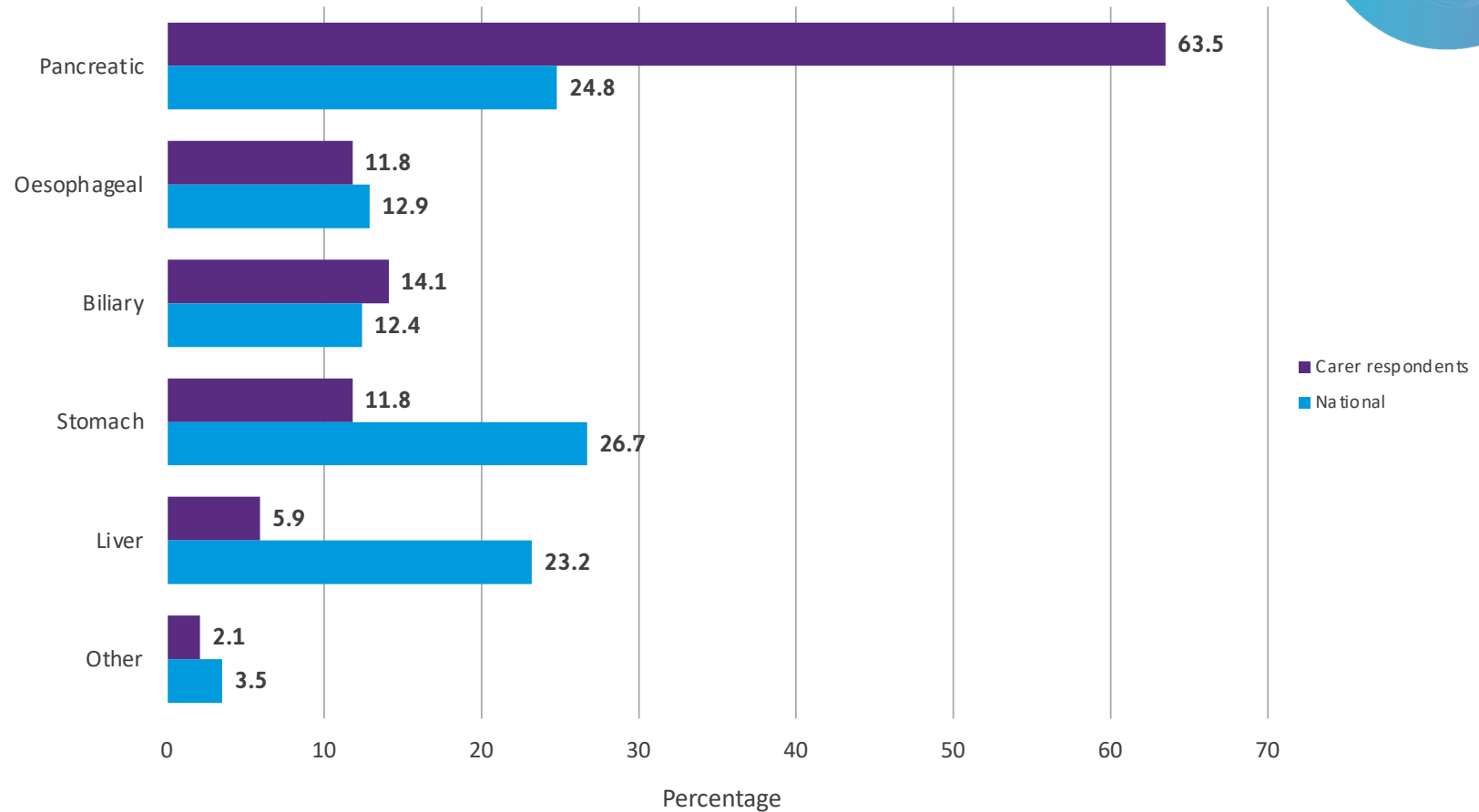
Carer gender



The relationship of the main support person to the cancer patient carer



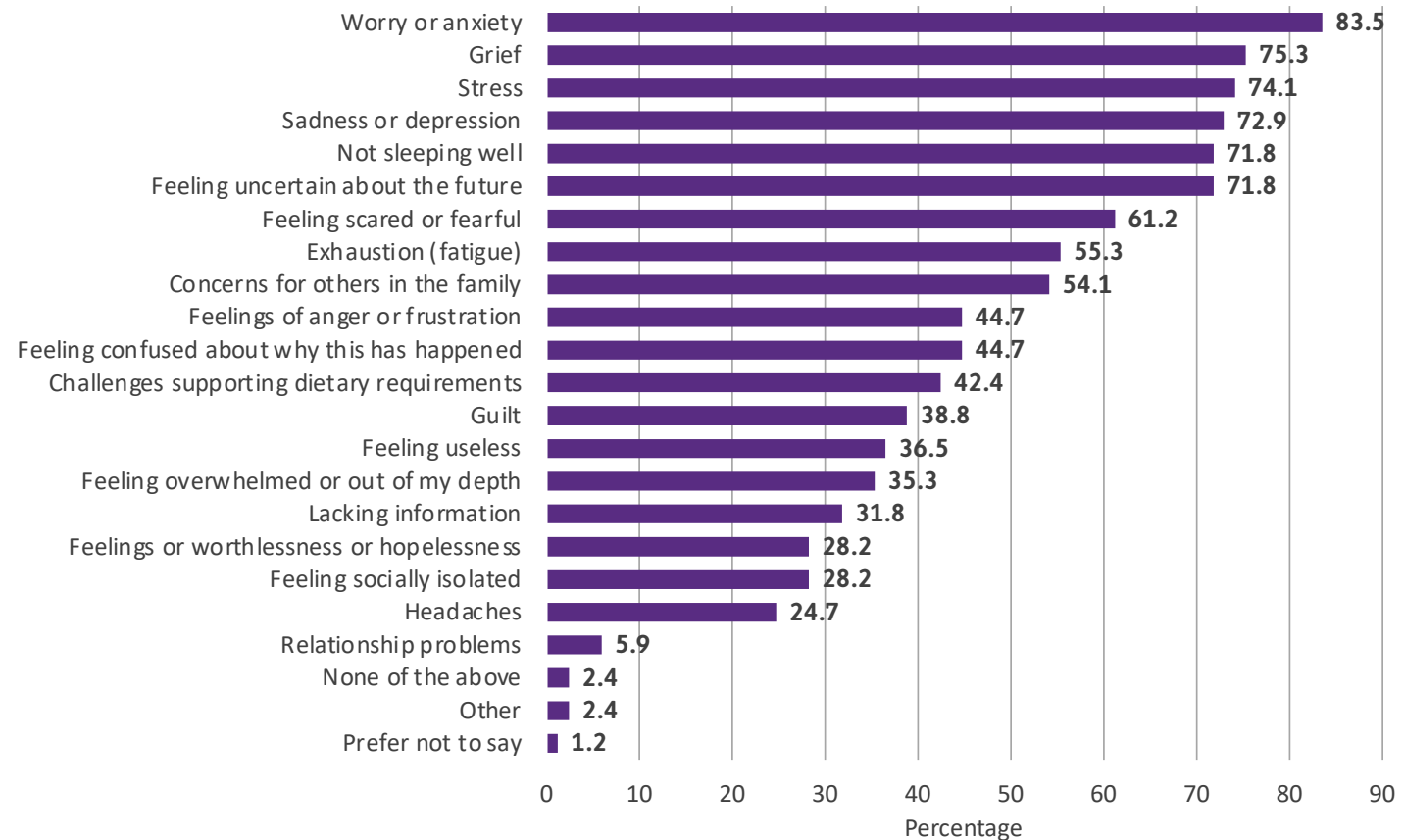
Demographics – disease type



Emotional impact carers

Survey data revealed a high emotional burden among carers, with 96.5% (n=82) reporting at least one of the listed potential impacts.

Notably, 839 responses were recorded across the various listed impacts, indicating that carer respondents reported experiencing approximately 10 different types of emotional, mental health, social, or relationship impacts on average.



Challenges

Most challenging aspects of supporting someone with upper GI cancer identified by carers (n=75)

Theme	Number	%
Emotional burden, grief and helplessness	48	64%
Pain management and physical deterioration	26	34.7%
Navigating the healthcare system and advocacy	22	29.3%
Coping strategies and resilience	16	21.3%
Lack of information	16	21.3%
Impact on family dynamics and relationships	15	20%
Symptom management and daily living	15	20%
Social isolation and support networks	8	10.7%
End-of-life/death	5	6.7%
Financial challenges	4	5.3%
Total	75	100%

"Challenges included educating and finding facts on GI cancer, the treatment process, and timelines. Caring for someone receiving chemotherapy and the lack of physical support and awareness of the services available."

- Carer

What would have helped

Reported supports that would have helped carers manage challenges faced when caring for someone with upper GI cancer (n=70)

Theme	Number	%
Information and education	17	24.3%
Advocacy and system navigation	16	22.9%
Healthcare system navigation	11	15.7%
Specialist and tailored support	10	14.3%
Family and wider support	6	8.6%
Emotional and mental health support	6	8.6%
Financial and logistical support	2	2.9%
Peer and community support	2	2.9%
Palliative and practical care	1	1.4%
Total	70	100%



"More support up front, information packs automatically provided on diagnosis, helplines to call to ask the hard questions. There were many times I felt alone and scared when I was caring for my father, and it wasn't until he had finally given up and was ready to go to the hospital that I had access to support outside of the family, and even that felt minimal."

- Carer respondent

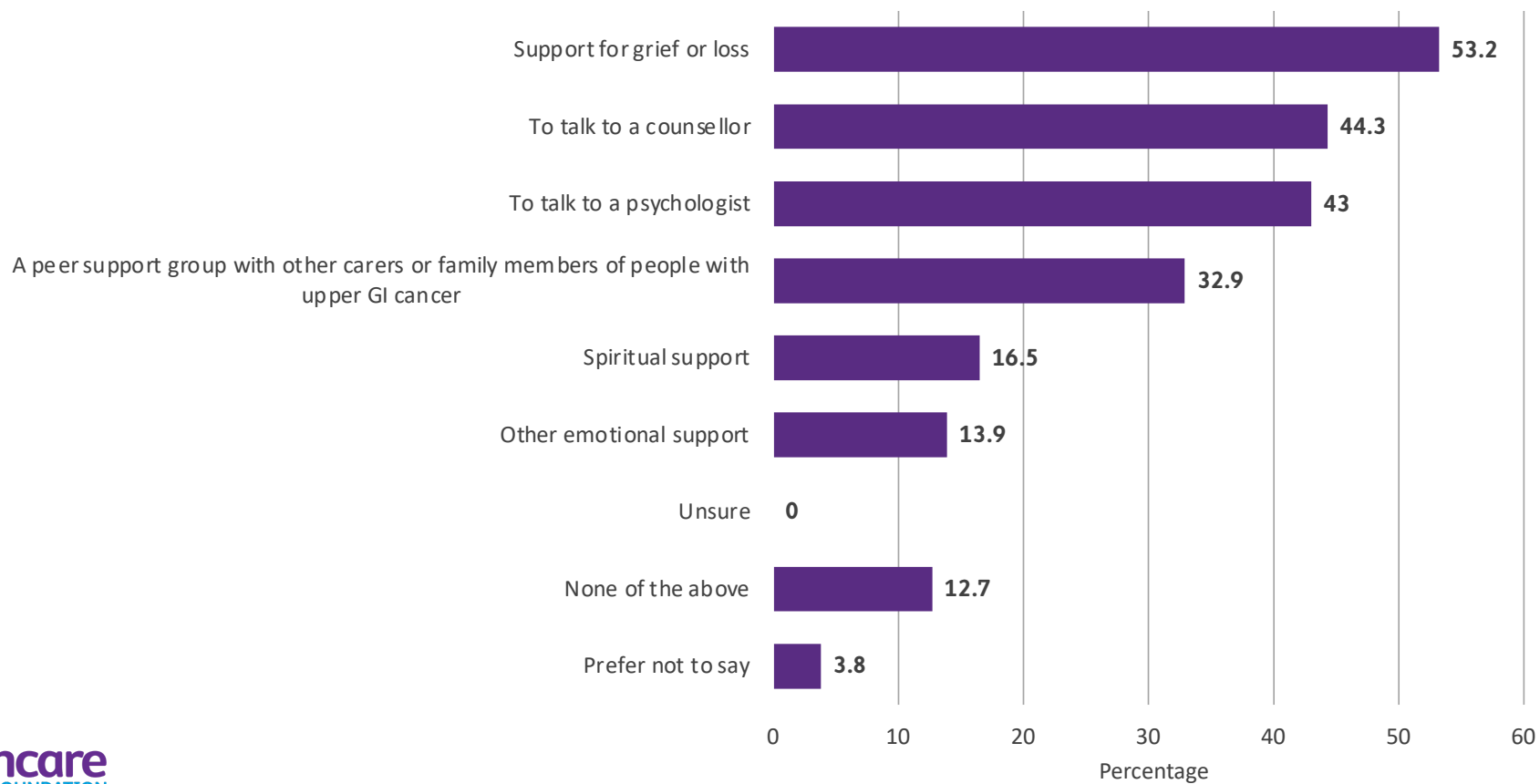
Financial Impacts

Financial impacts experienced by carer respondents (n=85)

Impact	Number	%
I have not experienced any financial impacts	26	30.6%
Reduced my work hours	24	28.2%
Increased transport costs	24	28.2%
Lost income	23	27.1%
Out-of-pocket expenses for treatment or medication costs	22	25.9%
Out-of-pocket expenses for specific medical equipment or supplies	21	24.7%
Financial hardship or stress (trouble paying for things like rent/mortgage, food, or bills)	12	14.1%
Went into early retirement	10	11.8%
Lost my job	2	2.4%
Other	4	4.7%
Prefer not to say	1	1.2%
Total	85	100%

Support needs

Emotional supports required by carer respondents (n=79)



Barriers to accessing support

Barriers to accessing support (n=15)

Theme	Number	%
Timing and availability of support	6	40%
Awareness and navigation of support services	4	26.7%
Financial	2	13.3%
Geographical isolation and access	1	6.7%
Ability to meet other carers and socialise	1	6.7%
Work	1	6.7%
Total	15	100%

Informational needs

Reported information that carers found difficult to find (n=23)

Theme	Number	%
Dietary information/meal plans post-surgery	7	30.4%
Side effects/symptoms	6	26.1%
Alternative therapies/clinical trials	4	17.4%
Genetic studies	2	8.7%
Key signs of cancer to look out for	2	8.7%
Post-Whipple procedure information	1	4.3%
Cancer medication	1	4.3%
Information on providing first aid for low blood sugar episodes	1	4.3%
Hospital data	1	4.3%
Patient success stories	1	4.3%
List of specialist/health professionals to go to	1	4.3%
Total	23	100%

Conclusion

- Carers of people with upper GI cancer experience substantial emotional and financial burden, alongside persistent gaps in information relevant to daily care and symptom management.
- These findings highlight the need for early and ongoing assessment of carer needs and the delivery of targeted emotional, informational and practical support.
- Oncology nurses are ideally positioned to identify unmet needs, initiate timely referrals, and support carers across the cancer care continuum, including during bereavement.
- In response to the consumer survey, Pancare Foundation are: developing a specific resource for carers, increasing promotion of the Pancare Helpline/counselling to carers, developing a model of care for carers and developing a Diet Hub with evidence-based information.

Thank you

- Survey participants
- Pancare Foundation co-authors Melanie Regan – Special Projects Manager, Prue Watson – Upper GI Cancer Nurse and Joanna Fanos – Wellbeing Counsellor
- Consumer Survey Advisory Committee
- BeOne Medicines for providing funding to conduct the consumer survey.



A world **free** from
upper GI cancers.

pancare.org.au