

Understanding Carer Support in Victorian specialist palliative care services

Australian Palliative Care Conference 1–4 September 2015: poster presentation

Policy context

Provision of respite is often mentioned as critical to enable carers to remain in their role for longer and to have an improved quality of life. However, critics argue that because anecdotal evidence for the benefits of respite is so strong, 'it is almost as if...it does not require research' (Wolkowski et al., 2010).

In order to combat the many physical, psychological, financial and social stresses associated with caring for someone with a life-limiting illness, steps need to be taken to meet the wide range of caregiver needs in relation to symptom management, information needs, practical care needs and emotional support (Kristjanson et al., 2003, cited in Aoun et al., 2005). Doing so has positive outcomes that extend to patients and to health systems as a whole (for example, reduced emergency department admissions, decreased length of stay in hospital, increase in proportion of at-home deaths) — and that can only be good for everyone.

Survey objectives

An environmental scan was conducted in order to gain a current understanding of the provision of respite and other forms of carer support by specialist palliative care providers in Victoria. The scan sought to understand how providers target clients most in need, what outcomes are achieved and how these outcomes are measured.

Survey methodology

The 51-question survey was emailed to all public-funded specialist palliative care services in Victoria, using the Survey Monkey software. The response rate was 73 per cent (n = 40) of all Victorian public-funded specialist palliative care services.

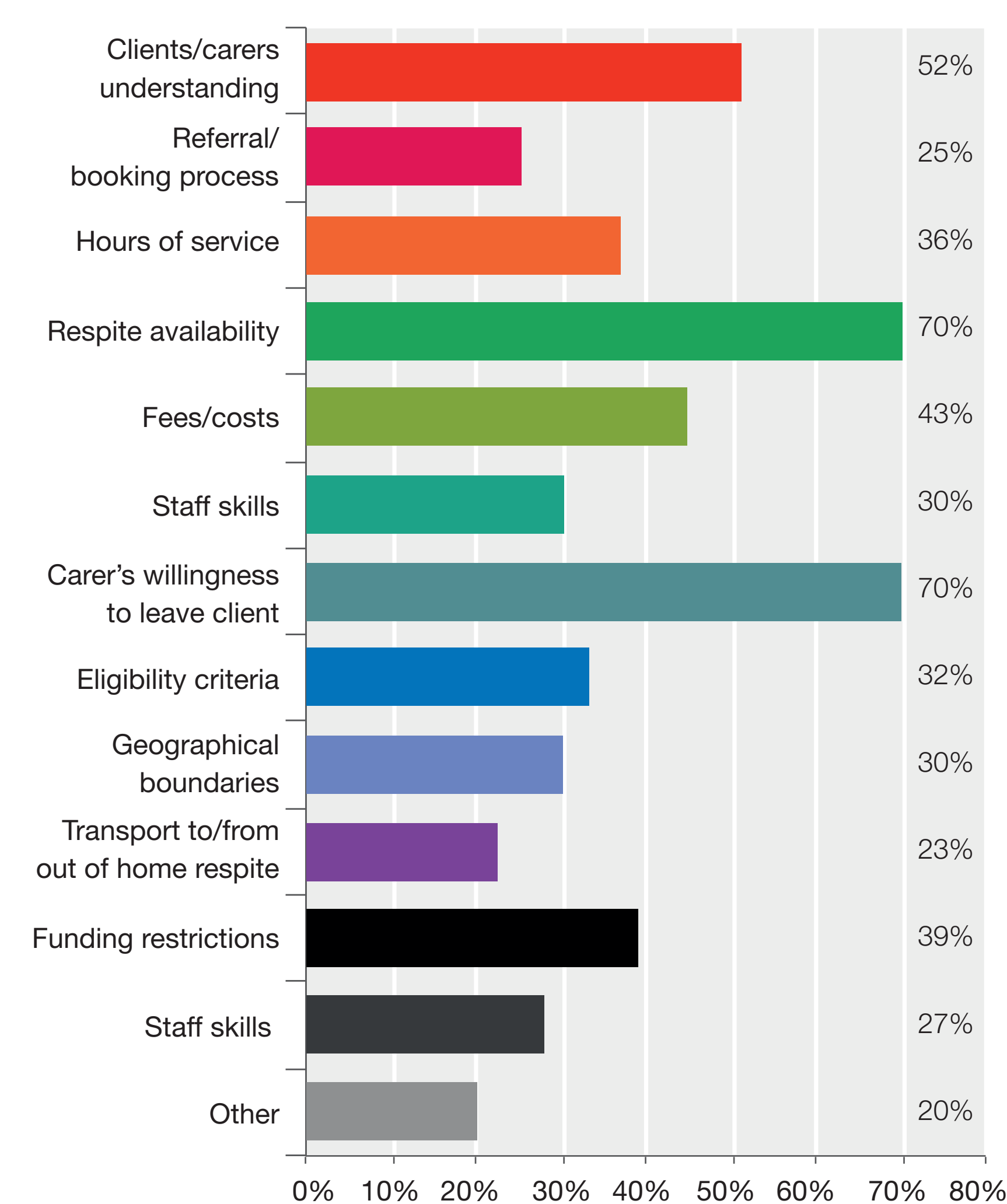
Results

Access to respite

- Twenty-three per cent of respondents have developed respite eligibility criteria. Those that developed criteria used a variety of approaches, including using risk factors for respite need as identified in the research literature or indicators of distress in either the patient or carer.
- Half of all respondents said they could deliver respite as requested, without placing clients on a waiting list, as well as having available staff to deliver the service.
- Respondents reported that the primary barriers to accessing respite included its availability, its cost, the willingness on the part of the carer to leave the patient, and a lack of understanding of respite by the client/carers.

What are the primary barriers (real or perceived) to accessing respite?

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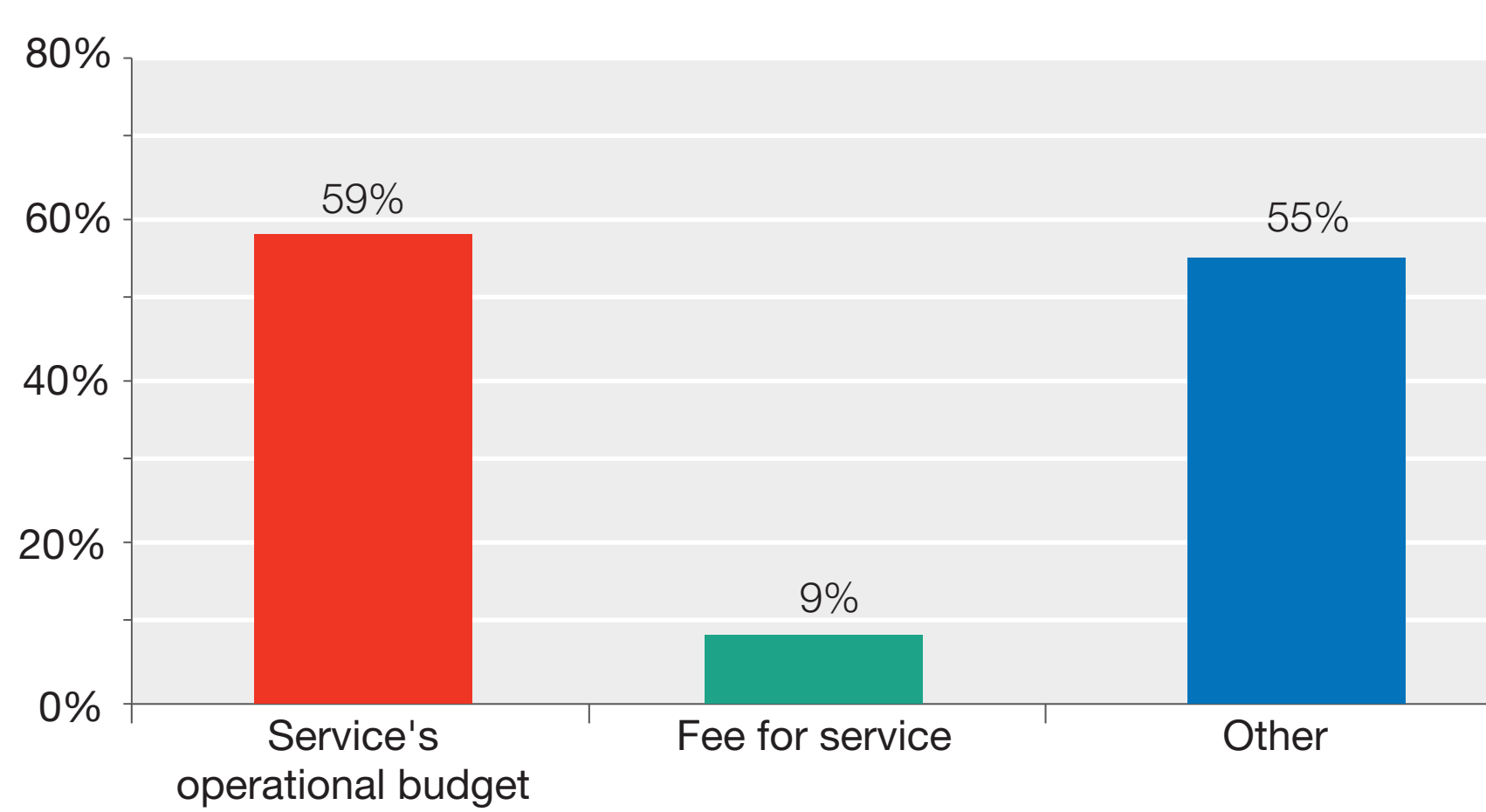
- Respondents suggested that barriers to accessing respite could be addressed by enhanced information about respite, better respite service coordination and better availability of a broad range of services, which could be tailored to meet the individual needs and circumstances of patients and carers and more/specific funding for respite.

Respite funding

While 59 per cent of respondents said that respite was funded from their service's operational budget, 55 per cent said it was also funded from other sources, including: philanthropic sources/charities/not-for-profits, volunteers, community palliative care unassigned bed funding, HIP funding and carer self-funding.

How is respite funded?

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Targeting/triage

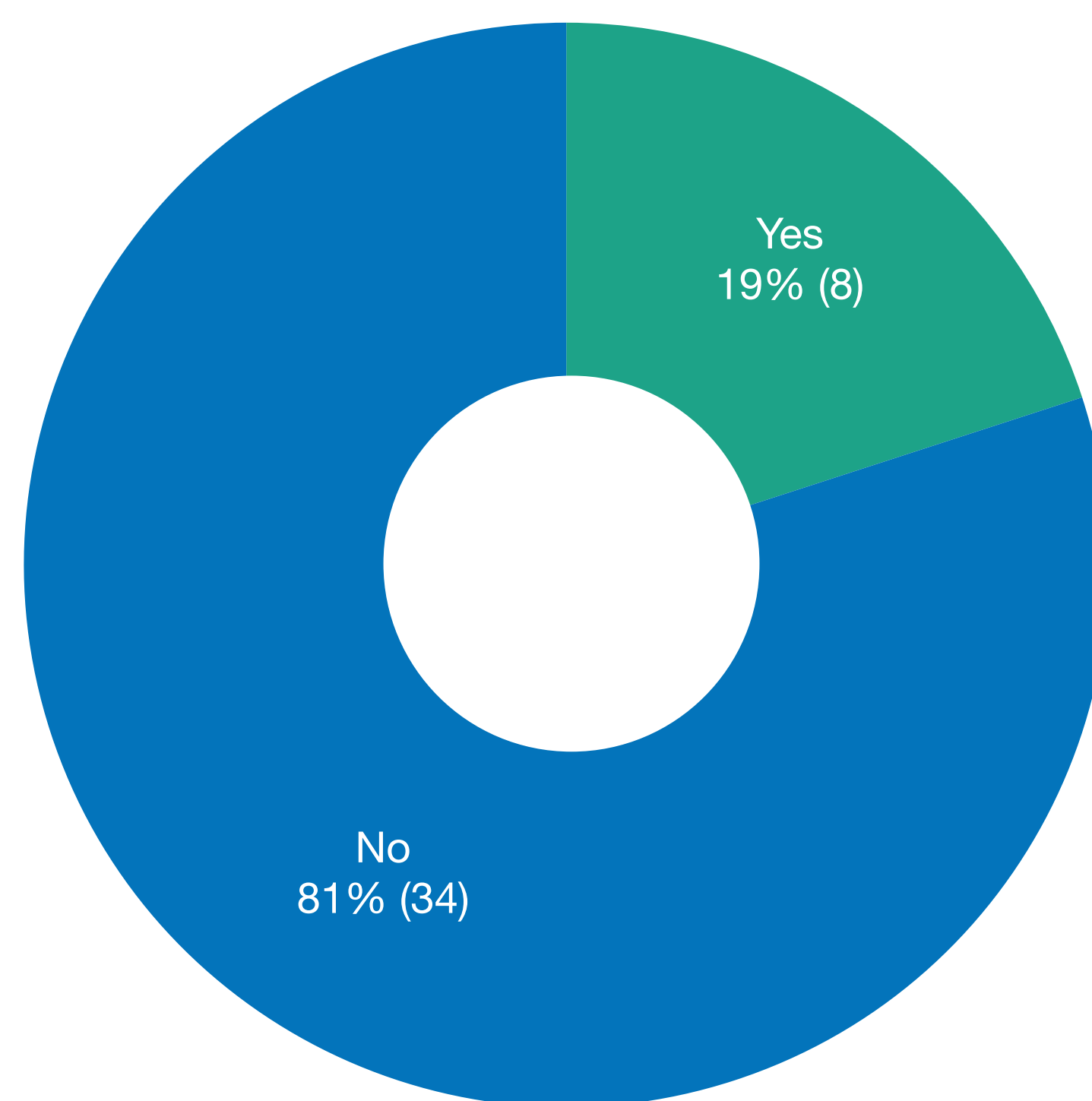
Eighty-eight per cent of respondents stated that they had a process for identifying which carers are at risk of adverse outcomes. In free-text responses to this question, most respondents indicated that they used a combination of validated carer risk screening tools and ongoing professional assessment of carer needs during admission to the inpatient service and/or during home visits as part of community palliative care. One respondent commented that patients/families identified as high risk of carer burden are offered respite in the unit every four to six weeks.

Quality of service delivery

Nineteen per cent of respondents have developed criteria for determining the quality of respite delivered, and 24 per cent of respondents have developed mechanisms for measuring the outcomes achieved as a result of respite provision. For example, some respondents assessed client satisfaction as part of standard service delivery arrangements; while others used changes in PCPSS and SAS scores (which are collected through PCOC) to assess outcome. Other respondents chose to have informal discussions with patients and carers as a means of assessing outcomes.

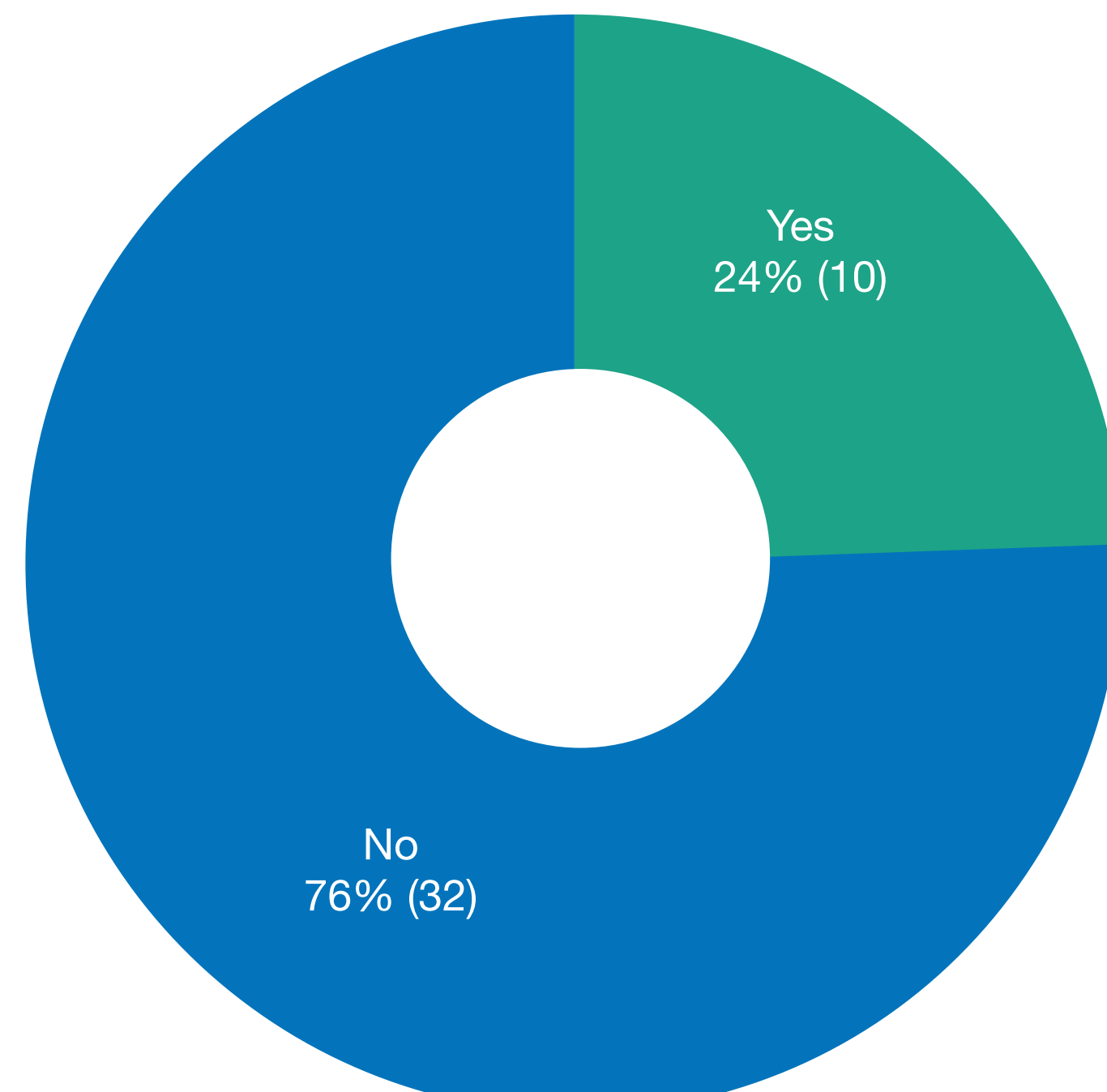
Does your service have criteria for determining the quality of respite delivered?

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Does your service have a mechanism for measuring the outcomes achieved for your clients and carers as a result of respite provision?

Answered: 42 Skipped: 2

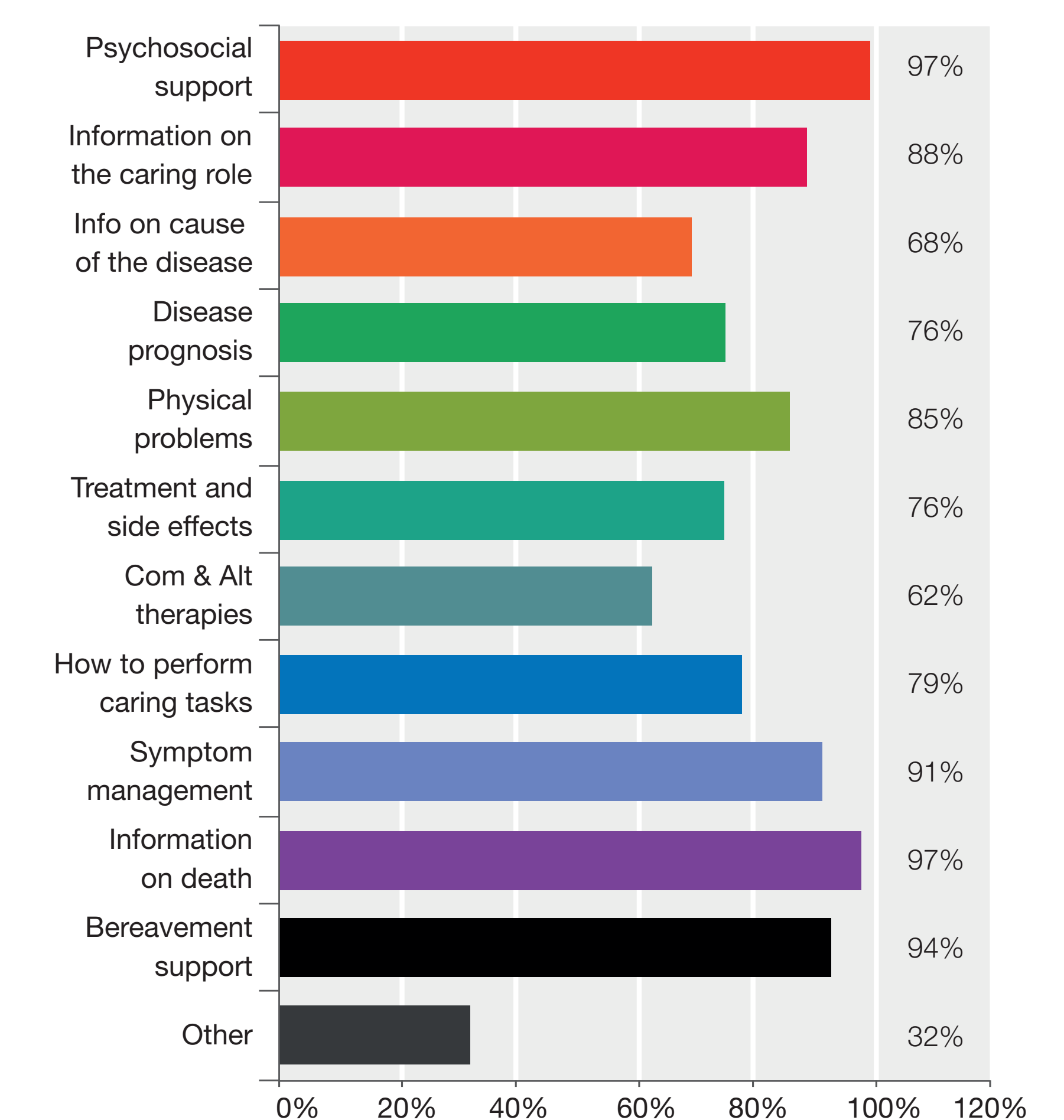


Fifty per cent of respondents tailored the interventions offered to carers according to the phase of the patient's illness. For example, one respondent identified that carer stress was higher when the patient was unstable, and as a result, got a family support worker to make contact with the carer during these periods. Unsurprisingly, respondents stated that more intensive support and interventions are delivered in the unstable, deteriorating and terminal phase.

The overwhelming majority of respondents (81 per cent) also provided other types of support to carers — most notably dealing with symptom management, practical care, psychosocial support, bereavement support, information on death, physical problems that can be expected, treatment and its side effects, disease prognosis and information on the caring role. It is pleasing to note that these interventions are consistent with what the research literature suggests as effective support to carers.

Other types of carer support interventions provided

Answered: 34 Skipped: 10



For future consideration

More work needs to be done to:

- determine the quality of respite and measure the outcomes achieved as a result of respite provision
- develop appropriate criteria for respite in line with risk factors for need, as identified in the research literature
- develop innovative models of respite provision, including funding models
- ascertain if there is value in tailoring the interventions offered to carers according to the phase of the patient's illness, in line with the documented research literature.

Literature cited

Aoun S, Kristjanson L, Currow D, Hudson P (2005) Caregiving for the terminally ill: at what cost? *Palliative Medicine* 19: 551–555.
Wolkowski A, Carr S, Clarke C (2010) What does respite care mean for palliative care service users and carers? *Messages from a conceptual mapping*. *International Journal of Palliative Nursing* 16(8): 388–392.

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