NATIONAL QUALITY IMPROVEMENT PROJECT

National Caregiver Response Survey (CaRES)

Summary of FY2022 Report

June 2023

Prepared by:

Caregiver Survey Sub-Committee

National Palliative Care Quality Improvement Workgroup

On behalf of Singapore Hospice Council

SINGAPORE HOSPICE COUNCIL

Living before Leaving

Introduction

In line with the National Strategy for Palliative Care to develop local standards in palliative care, the Caregiver Response Survey (CaRES) was designed to measure the experience of bereaved caregivers with regards to the care given to the patient and their caregivers in the last week of life. A pilot phase was initiated in 2018, which demonstrated feasibility. Thereafter, CaRES has been carried out annually since, with annual reviews and iterations made.

Methodology of CaRES

Institutions were asked to survey caregivers of patients who passed away in a certain month of the year. The service provider who last cared for the patient prior to demise carried out the survey with the bereaved caregiver. The survey could be completed via phone call, an online form, postal mail, or email. Selected staff from each service provider were trained on administration of the survey and data entry prior to embarking on the survey.

In 2022, the survey was conducted from August 2022 to September 2022 in English and Mandarin. Caregivers of patients who passed away between 1 June 2022 and 30 June 2022 were invited to participate.

Various care domains were surveyed in CaRES: quality of patient care, psycho-social support, information giving, training provision, quality of care after office hours, whether a patient's preferred place of death was met, the overall satisfaction with the care provided, and the experience of caregivers with regards to grief and bereavement support.

Response of participating service providers and caregivers

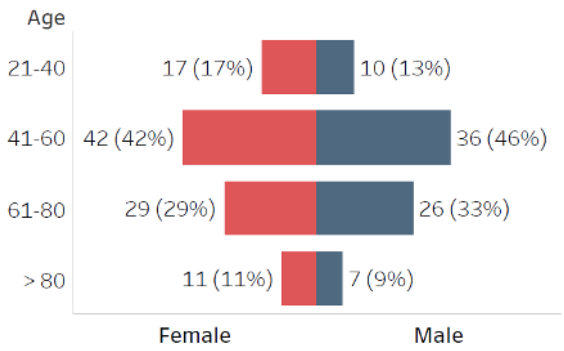
23 service providers participated in CaRES in 2022 – 9 acute hospital services, 7 inpatient hospice and palliative care services (IHPCS), and 7 home care services. A total of 178 caregivers provided responses. Survey via phone call remained the most common mode of response (122 out of 178; 68.5%), followed by completion of an online form (49 out of 178; 27.5%). Email was another mode of response.

Caregiver demographics and data regarding caregiving roles

More than half of the caregivers were female (56%) and almost half (44%) were aged 41-60 years (Figure 1a). Figure 1b shows the distribution of respondents' ethnicity.

The majority of caregivers (56%) were children or children-in-law (Figure 1c). 80% performed 3 or more caregiving roles, with decision-making, the provision of psycho-emotional support, and physical provision of care being the top 3 roles (Figures 1d and 1e).

Figure 1a. Age and gender of respondents



Note: Percentages reflected are for the respective gender.

Figure 1b. Ethnicity of respondents

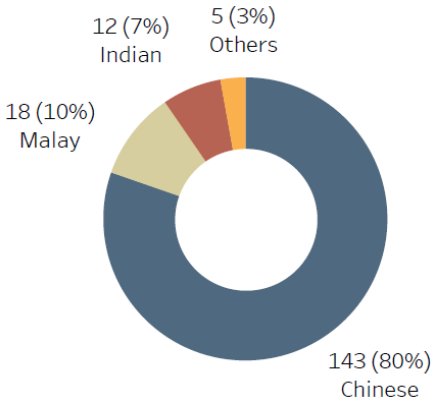


Figure 1c. Caregiver's relationship to patient

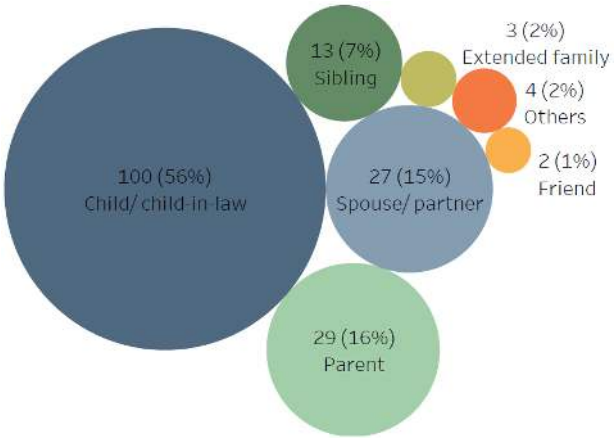


Figure 1d. Number of caregiving roles

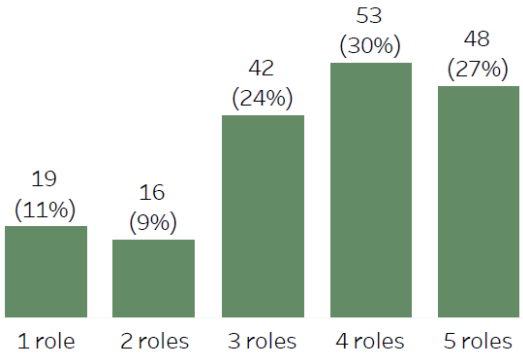
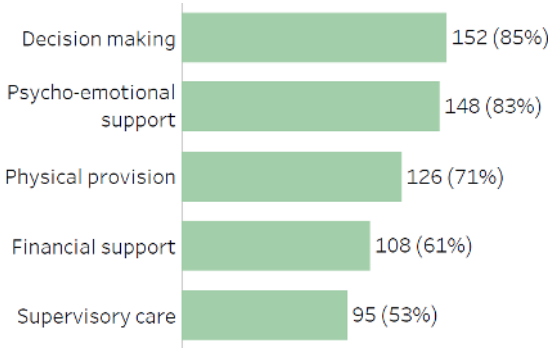


Figure 1e. Distribution of caregiving roles



Note: This question allows for multiple responses.

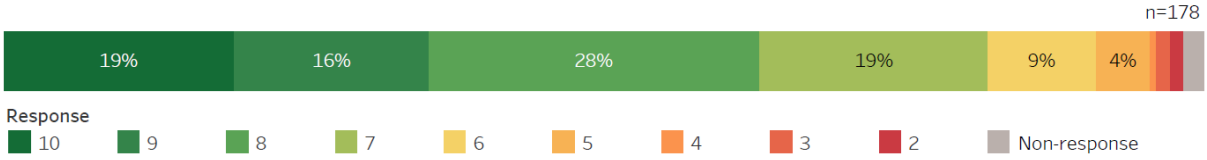
Key Findings

1. Caregiver satisfaction in 2022 remained high, although there was a general downward trend across most domains over the past 3 years.

Caregivers generally had a positive experience with the care provided to their loved ones. 82% of caregivers were satisfied with overall care (rating of 7 and above) (Figure 2). Most caregivers rated their experience positively in the domains of healthcare delivery (84%), psychosocial support (78%), information giving (77%), training provision (73%), and out-of-office-hours care (92%).

(Depending on question type, positive responses refer to "very satisfied" and "satisfied" responses, or "yes, given and adequate" responses (percentages calculated are after exclusion of "no, not needed" responses).)

Figure 2. Overall satisfaction scores



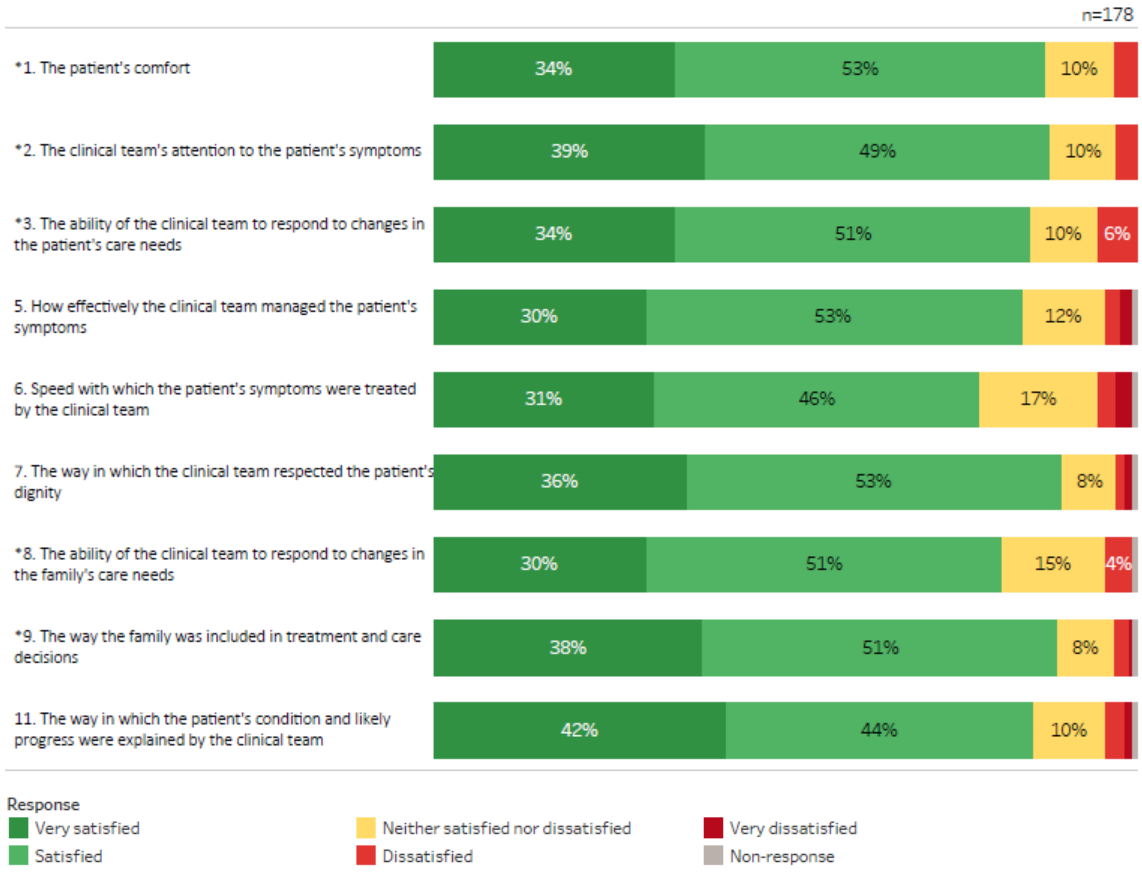
Note: On a scale of 0 to 10, 0 = most dissatisfied, 10 = most satisfied

There was a decline in satisfaction with overall care from 2020 to 2022 (92% to 87% to 83%). Declines were more evident in the domains of psychosocial support (88% to 81% to 78%) and training provision (81% to 78% to 73%). This trend will be monitored further.

(I) Healthcare Delivery

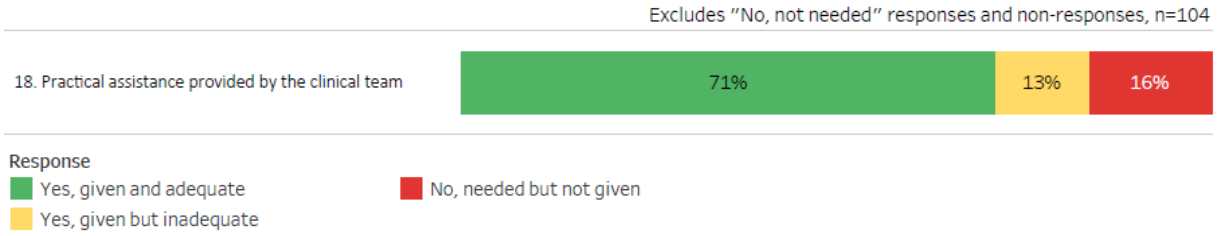
Most survey items had more than 80% of caregivers indicating "very satisfied" or "satisfied" (Figure 3a).

Figure 3a. Domain of healthcare delivery



With regards to practical assistance provided by the clinical team, 71% of caregivers who needed it felt that the assistance received was adequate (Figure 3b).

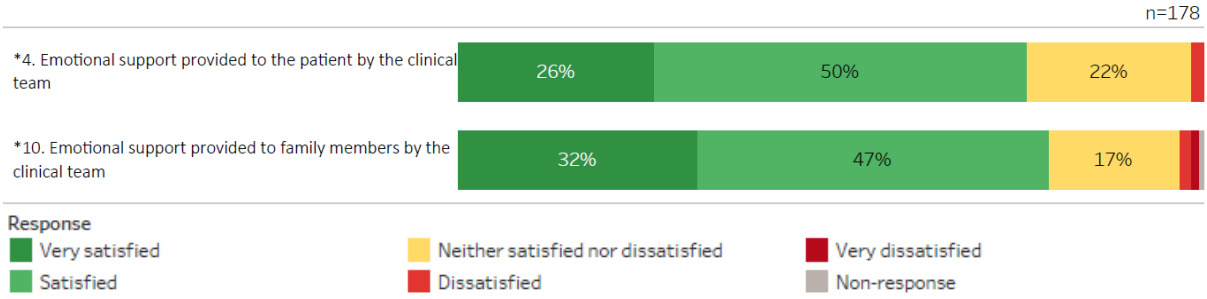
Figure 3b. Domain of healthcare delivery (practical assistance) – after exclusion of "No, not needed" responses and non-responses



(II) Psychosocial Support

At least 75% of caregivers indicated they were 'very satisfied' or 'satisfied' with emotional support provided to the patient or family members by the clinical team (Figure 4).

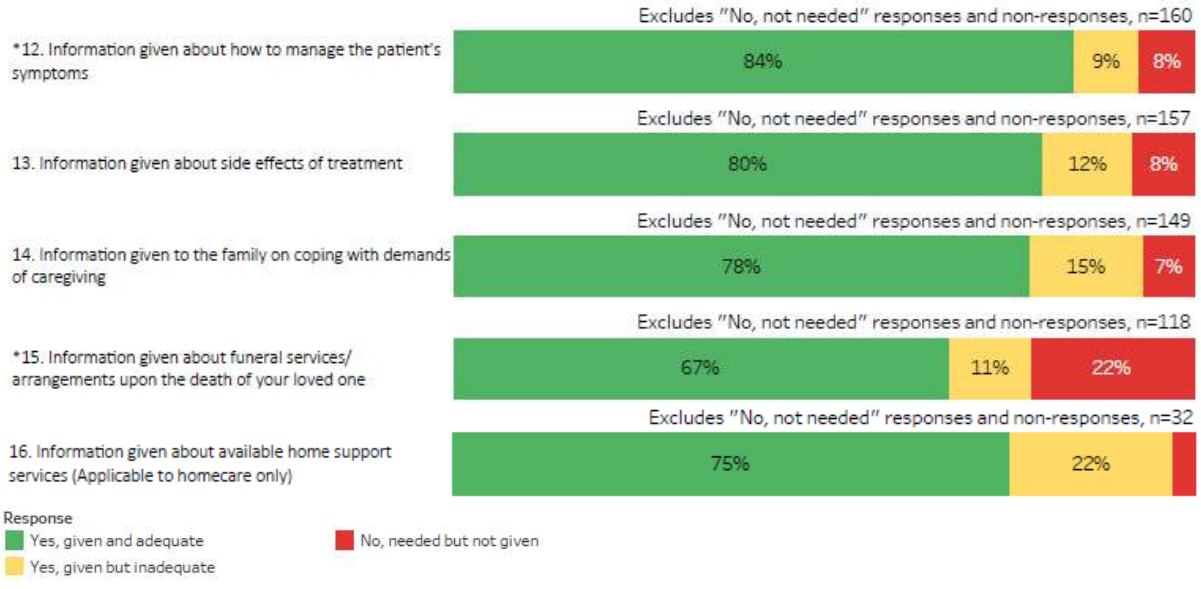
Figure 4. Domain of psychosocial support



(III) Information Giving

While caregivers were mostly satisfied with the provision of information, there can be improvement in providing information on funeral services/ arrangements (Figure 5).

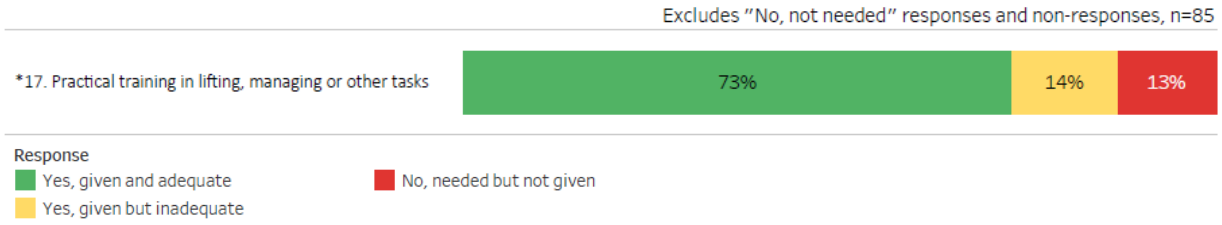
Figure 5. Domain of information giving – after exclusion of "No, not needed" responses and non-responses



(IV) Training Provision

A significant proportion of caregivers (52%) expressed that they did not need practical training in lifting or other tasks. Amongst those who needed the training, 73% were satisfied with the support they received (Figure 6).

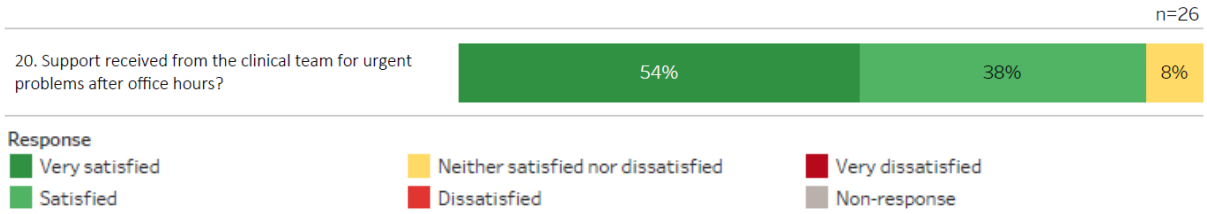
Figure 6. Domain of training provision – after exclusion of "No, not needed" responses and non-responses



(V) Out-of-Office-Hours Care (for Homecare Services only)

In 2022, 26 (67%) out of 39 home care patients accessed out-of-office-hours service. Amongst them, the experience was largely positive, with 92% being "very satisfied" or "satisfied" (Figure 7).

Figure 7. Domain of out-of-office-hours care

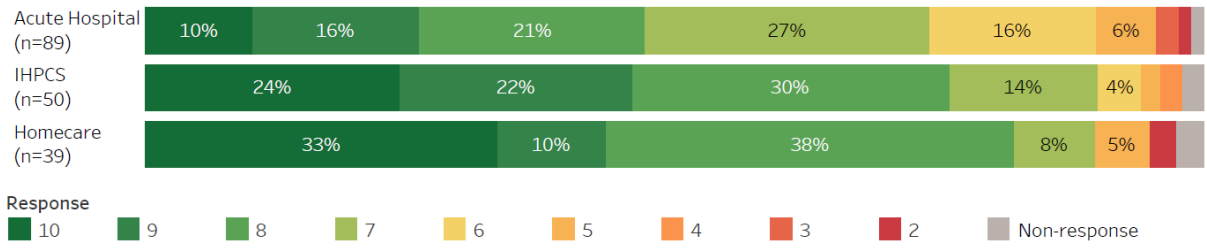


2. There was highest satisfaction with care in the home care setting, and lowest satisfaction in the acute hospital setting.

There was a trend showing higher care satisfaction in the home care setting compared to the acute hospital setting. The differences were most evident in overall care satisfaction (Figure 8), and in the domains of healthcare delivery and practical assistance provision, psychosocial support, information-giving about funeral services/arrangements, and grief and bereavement support.

Satisfaction in the inpatient hospice palliative care services (IHPCS) varied, but mostly fell between that in the acute hospital and home care settings.

Figure 8. Overall satisfaction scores, across service settings



Note: On a scale of 0 to 10, 0 = most dissatisfied, 10 = most satisfied

3. There was low concordance with patients' preferred place of death (PPOD) among hospital deaths.

The home remained the most common PPOD according to caregivers (Figure 9).

Concordance of PPOD with actual place of death (POD) remained the highest among patients who passed away in the home care setting (90%) in 2022 (Figure 10). This is consistent with the trend in previous years.

Figure 9. PPOD from caregivers' perspectives

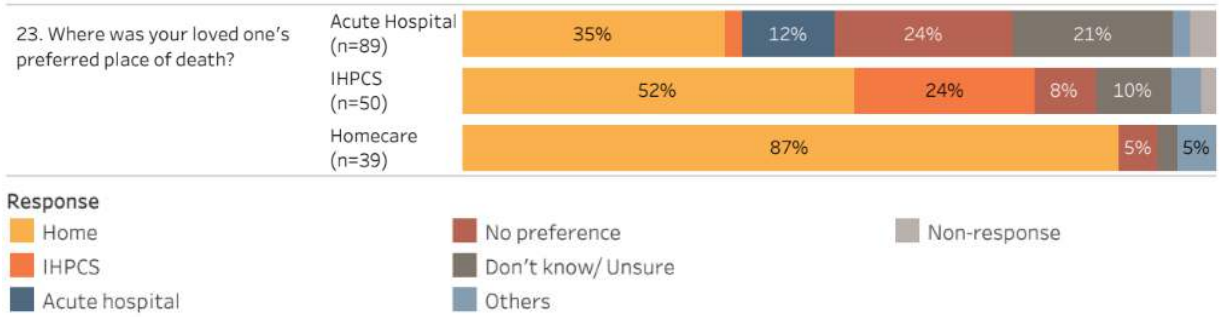
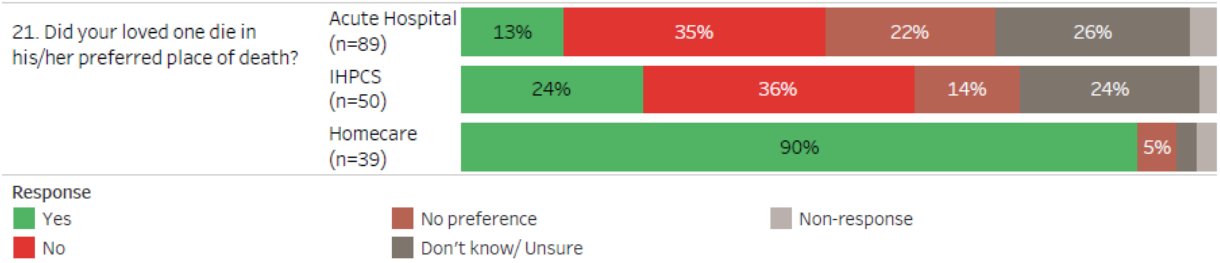


Figure 10. Concordance between PPOD and actual POD

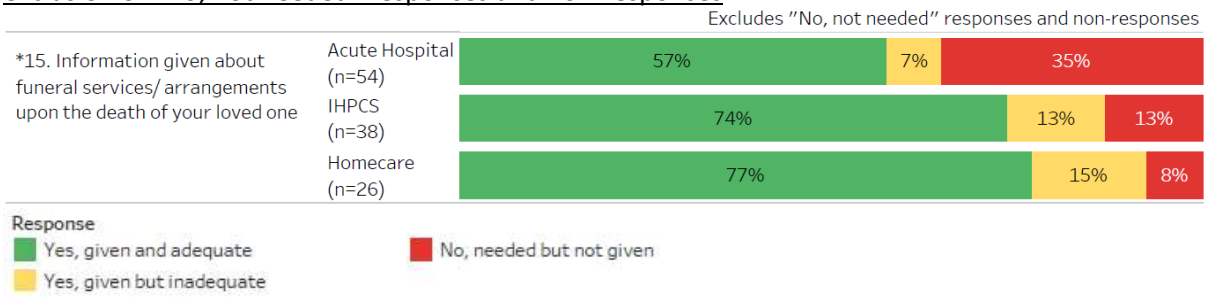


The most common reasons cited by caregivers for the discordance in PPOD and actual POD were that the family was unable to manage care (17 caregivers), the patient had high care needs requiring medical attention (11 caregivers), or rapid deterioration of the patient (8 caregivers).

4. There is potential for improvement in information provision for funeral services and arrangements, especially in the acute hospital setting.

67% of those who needed information on funeral services/arrangements reported receiving adequate information. This gap was most marked in the acute hospital setting (Figure 11).

Figure 11. Information given about funeral services/arrangements, across service settings – after exclusion of "No, not needed" responses and non-responses

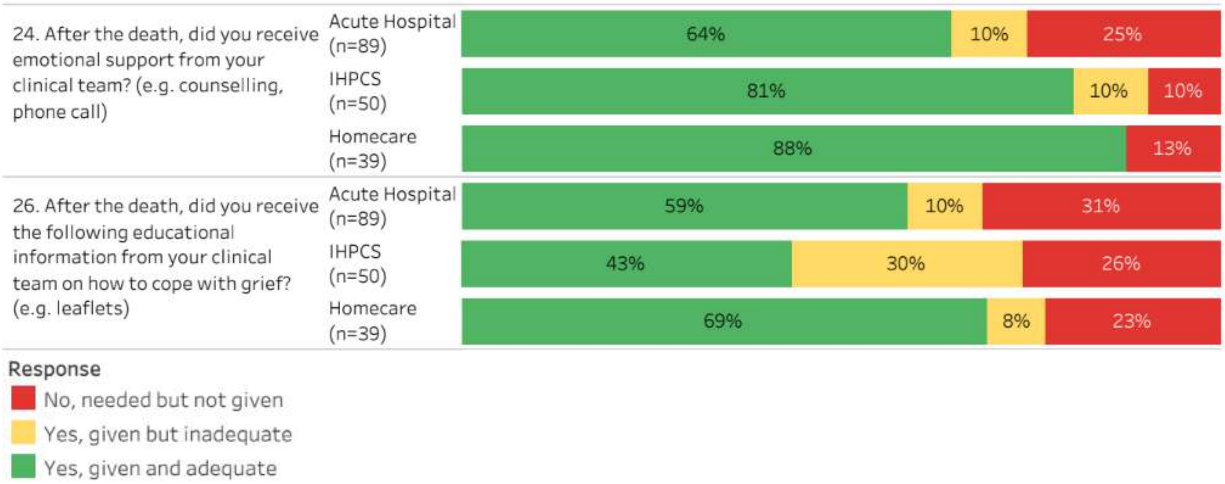


Abbreviation: IHPCS, Inpatient Hospice Palliative Care Service

5. There is greater grief and bereavement support needed, particularly in the IHPCS and acute hospital settings.

Among caregivers who required grief and bereavement support, 74% perceived that they received adequate emotional support and 56% perceived that they received adequate educational information on coping with grief. The perceived adequacy of support was higher in the home care setting compared to the IHPCS or acute hospital settings (Figure 12).

Figure 12. Domain of grief and bereavement support, across service settings – after exclusion of "No, not needed" responses and non-responses



The most common forms of bereavement emotional support were phone calls, condolence cards, and in-person visits. The most common forms of bereavement educational information were leaflets/brochures, practical advice given verbally by the medical team and medical social workers (comprising 11 of the responses within the "Others" category), and online resources.

Conclusion

Feedback from caregivers has remained generally positive and provides acknowledgement of the efforts of the palliative care fraternity in providing good end-of-life care. Responses to certain survey items (such as the provision of practical assistance, information-giving relating to funeral arrangements, concordance to preferred place of death, and adequacy of grief and bereavement support) have highlighted gaps in service provision, and services should consider further evaluating these issues in depth. The decline in caregiver satisfaction observed in CaRES 2022 warrants further monitoring.

CaRES 2023 will continue to provide valuable information for benchmarking and quality improvement efforts.