NATIONAL QUALITY IMPROVEMENT PROJECT

National Caregiver Response Survey (CaRES)

Summary of FY2023 Report

May 2024

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 time period 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 2023, the survey was conducted from August 2023 to October 2023 in English and Mandarin. Caregivers of patients who passed away between 1 June 2023 and 31 July 2023 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

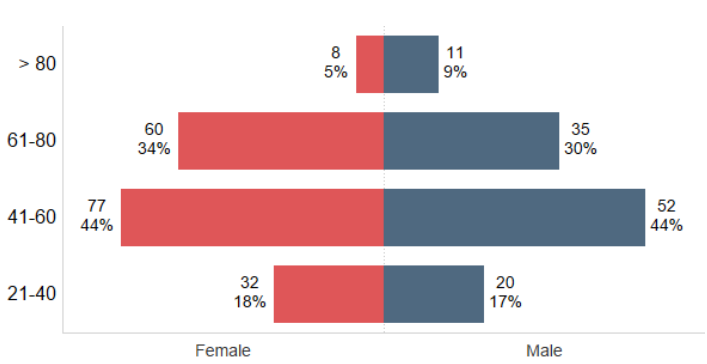
22 service providers participated in CaRES in 2023 – 8 acute hospital services, 7 inpatient hospice and palliative care services (IHPCS), and 7 home care services. A total of 299 caregivers provided responses. Survey via online form was the most common mode of response (193 out of 299; 64.5%), followed by survey via phone call (105 out of 299; 35.1%).

Caregiver demographics and data regarding caregiving roles

More than half of the caregivers were female (59.9%) and almost half (43.7%) were aged 41-60 years (Figure 1a). Figure 1b shows the distribution of respondents' ethnicity.

The majority of caregivers (61%) were children or children-in-law (Figure 1c). 74% performed 3 or more caregiving roles, with decision-making, the provision of psycho-emotional support, and financial support being the top 3 roles (Figures 1d and 1e).

Figure 1a. Age and gender of respondents



Note: Percentages reflected are for the respective gender.
This figure does not reflect missing data (n=4) for age.

Figure 1b. Ethnicity of respondents

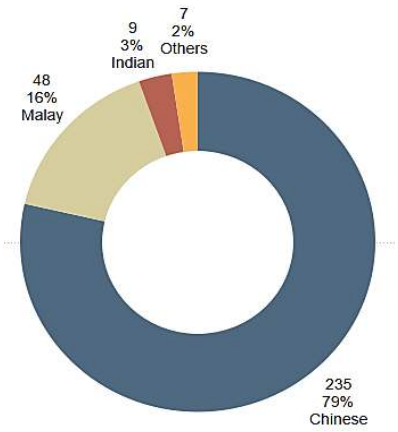


Figure 1c. Caregiver's relationship to patient

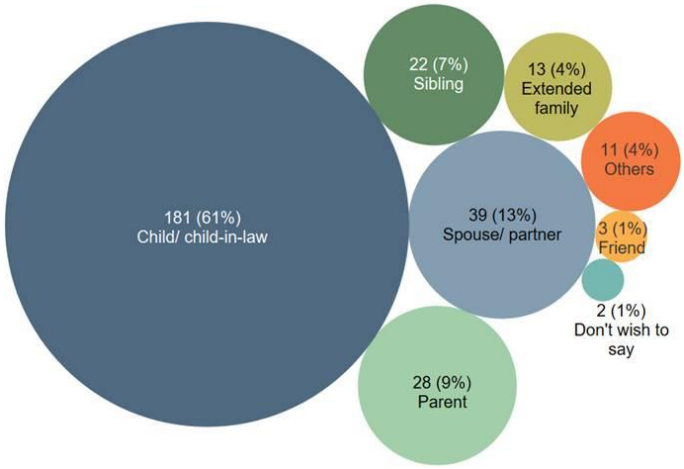


Figure 1d. Number of caregiving roles

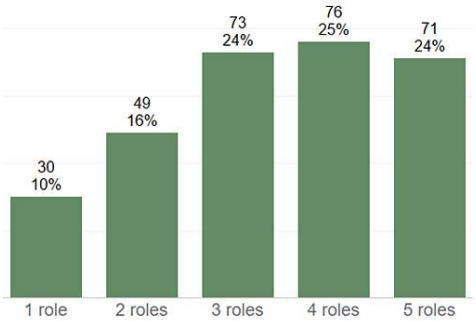


Figure 1e. Distribution of caregiving roles

Note: This question allows for multiple responses.

Main Findings

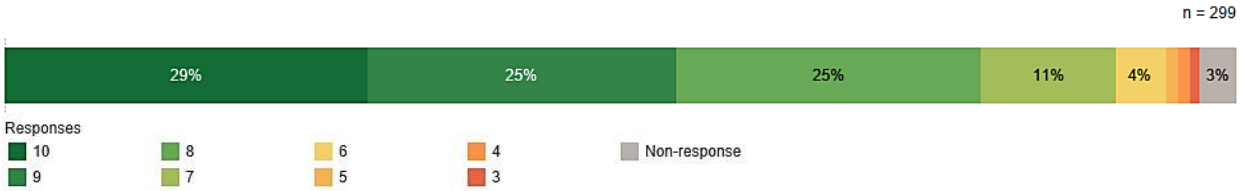
1. Caregiver experience was generally positive and improved compared to 2022.

90% of caregivers were satisfied with overall care (rating of 7 and above) (Figure 2). This was an improvement compared to 2022 (82%).

Most caregivers rated their experience positively in the domains of healthcare delivery (91%), psychosocial support (84%), information giving (89%), training provision (83%), out-of-office-hours care (95%, applicable to home care services only), and grief and bereavement support (85%).

(Depending on question type, positive responses refer to "very satisfied" and "satisfied" responses, or "required and received, and it was adequate" responses (percentages calculated are after exclusion of "not required" responses and non-responses).)

Figure 2. Overall satisfaction scores



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

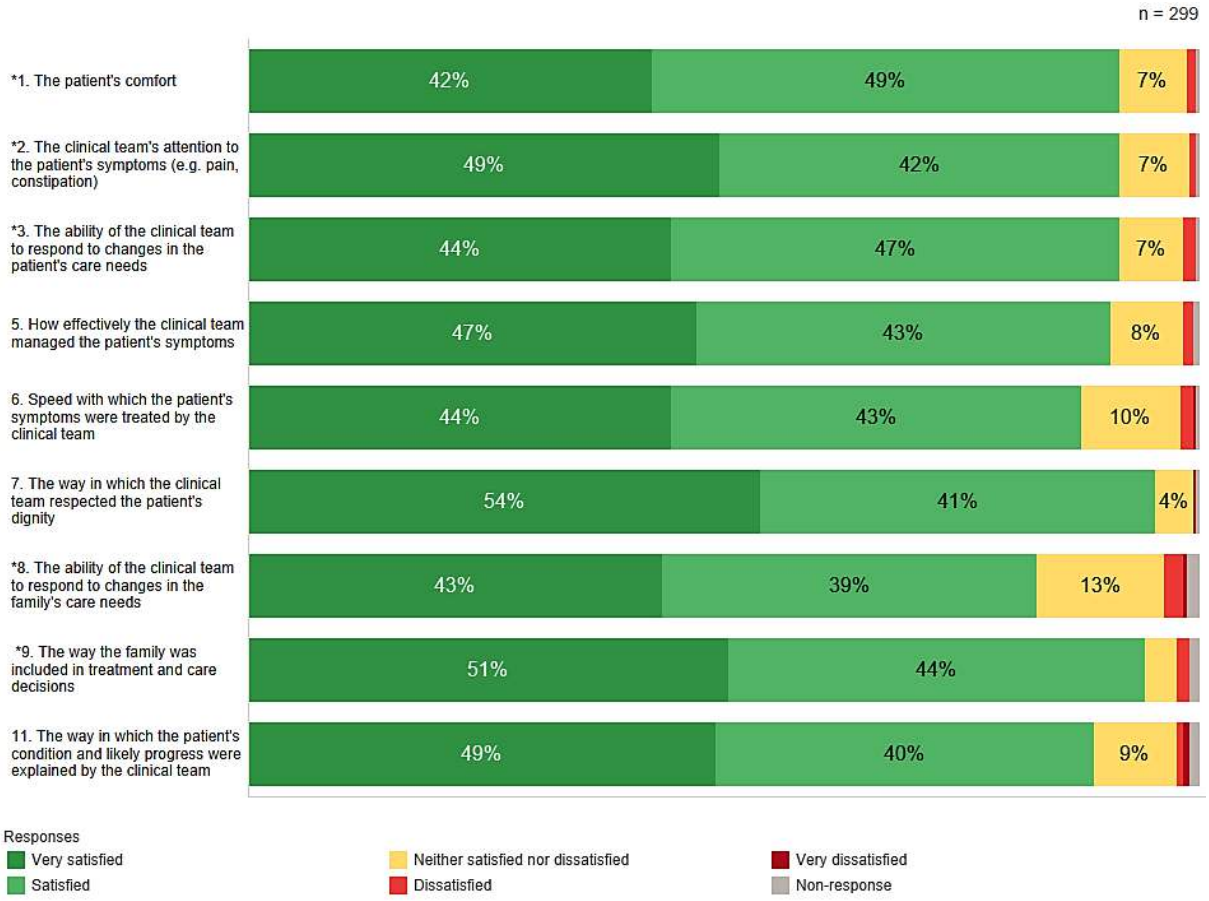
Caregiver experience improved in most domains compared to 2022. Improvements were most evident in the domains of information-giving as well as grief and bereavement support, which were identified in previous years to have been areas in which caregivers reported poorer experience.

While the caregiver experience was most positive in the home care setting and least positive in the acute hospital setting in 2022, this difference has become less marked in 2023, due to improvements seen in the acute hospital setting.

(I) HEALTHCARE DELIVERY

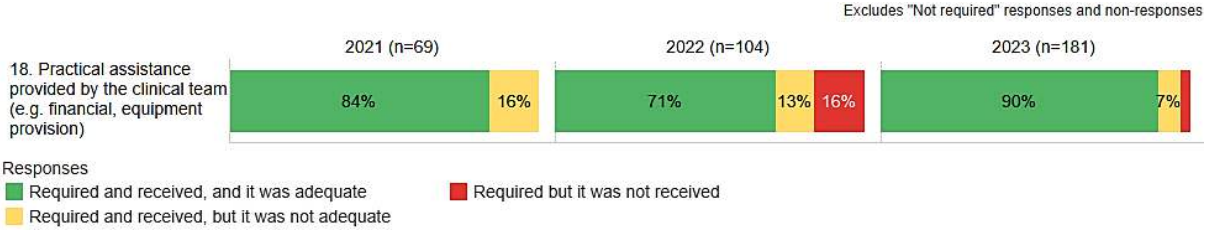
All survey items had more than 80% of caregivers indicating “very satisfied” or “satisfied” (Figure 3a).

Figure 3a. Domain of healthcare delivery



With regards to practical assistance provided by the clinical team, 90% of caregivers who needed it felt that the assistance received was adequate (Figure 3b). This was an improvement compared to 2022.

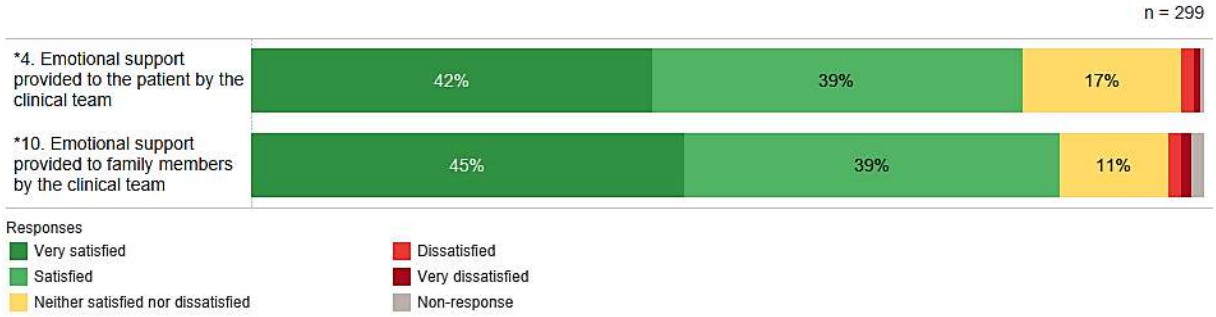
Figure 3b. Domain of healthcare delivery (practical assistance) – after exclusion of “Not required” responses and non-responses



(II) Psychosocial Support

More than 80% 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

There has been a general improvement from previous years in the domain of information giving (Figure 5).

Figure 5. Domain of information giving from 2021 to 2023 – after exclusion of "Not required" responses and non-responses

Note: For question 12: n=125 in 2021, n=160 in 2022, n=263 in 2023.
For question 13: n=118 in 2021, n=157 in 2022, n=259 in 2023.
For question 14: n=120 in 2021, n=149 in 2022, n=226 in 2023.
For question 15: n=91 in 2021, n=118 in 2022, n=203 in 2023.
For question 16: n=36 in 2021, n=32 in 2022, n=47 in 2023.

(IV) Training Provision

Amongst the caregivers who indicated they needed practical training, 83% were satisfied with the support they received. This has improved compared to 2022 (Figure 6).

Figure 6. Domain of training provision from 2021 to 2023 – after exclusion of "Not required" responses and non-responses

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

In 2023, 38 (66.7%) out of 57 home care patients accessed out-of-office-hours service. Amongst them, the experience was largely positive, with 94% being "very satisfied" or "satisfied" (Figure 7).

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

(VI) Preferred Place of Death (PPOD)

Home was the most common PPOD. 43% of caregivers of patients who passed away in the acute hospital and 36% of caregivers of patients who passed away in IHPCS settings indicated that the patient's PPOD was home.

Concordance of PPOD with actual place of death (POD) remained the highest among patients who passed away in the home care setting in 2023 (Figure 8). This is consistent with the trend in previous years.

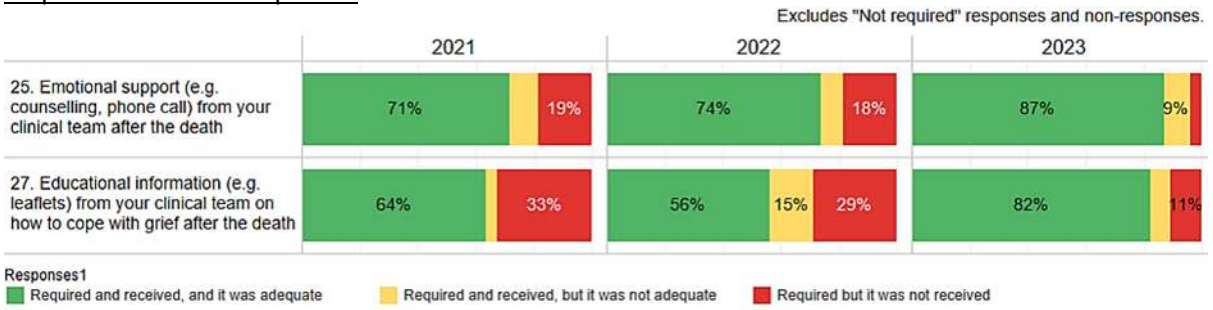
Figure 8. Concordance between PPOD and actual POD from 2021 to 2023, across service settings - after exclusion of "Don't know/Unsure" responses and non-responses

Abbreviation: IHPCS, Inpatient Hospice Palliative Care Service
Note: For acute hospital: n=38 in 2021, n=63 in 2022, n=95 in 2023.
For IHPCS: n=26 in 2021, n=37 in 2022, n=98 in 2023.
For home care: n=46 in 2021, n=37 in 2022, n=53 in 2023.

(VII) Grief and Bereavement Support

Of the caregivers who indicated that grief and bereavement support were required, 87% reported that the emotional support they received post-bereavement was adequate, while 82% reported that the educational material on coping with grief was adequate. This was an improvement compared to previous years (Figure 9).

Figure 9. Domain of grief and bereavement support from 2021 to 2023 – after exclusion of "Not required" responses and non-responses

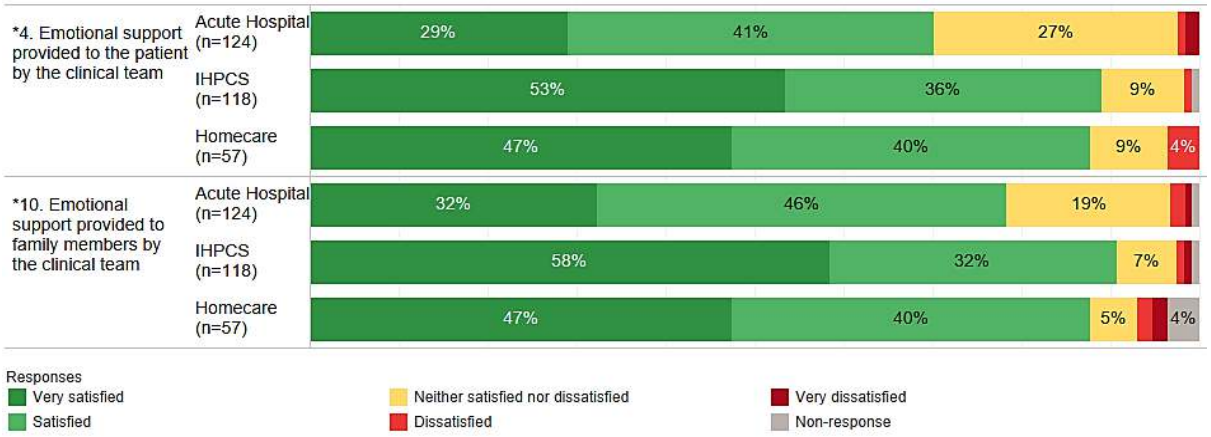


Note: For question 25: n=70 in 2021, n=114 in 2022, n=148 in 2023.
For question 27: n=55 in 2021, n=87 in 2022, n=148 in 2023.

2. Patients and caregivers can be better supported emotionally.

Across all settings, an average of 81% and 84% of caregivers reported being "very satisfied" or "satisfied" with emotional support provided by the clinical team to the patient and caregiver respectively. The experience was more positive in the home care and IHPCS settings compared to the acute hospital (Figure 10).

Figure 10. Domain of psychosocial support, across service settings

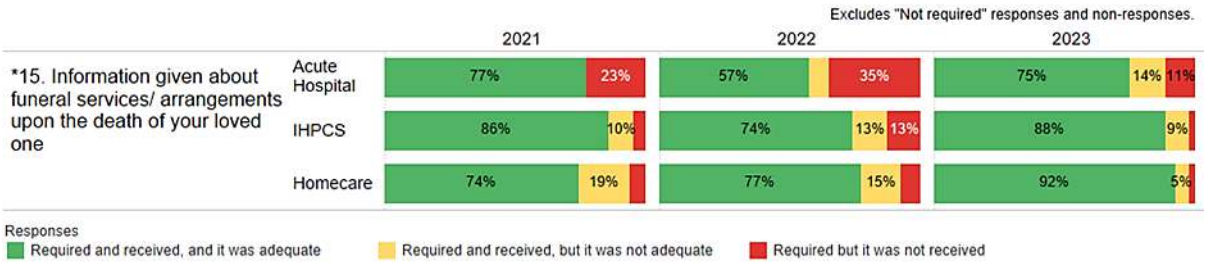


Abbreviation: IHPCS, Inpatient Hospice Palliative Care Service

3. There is potential for improvement in the provision of information about funeral services and arrangements in the acute hospital setting.

75% of caregivers in the acute hospital setting who needed information about funeral services and arrangements felt that it was adequate. This has increased from 2022 but remains an area for further improvement (Figure 11).

Figure 11. Information given about funeral services/arrangements from 2021 to 2023, across service settings – after exclusion of "Not required" responses and non-responses

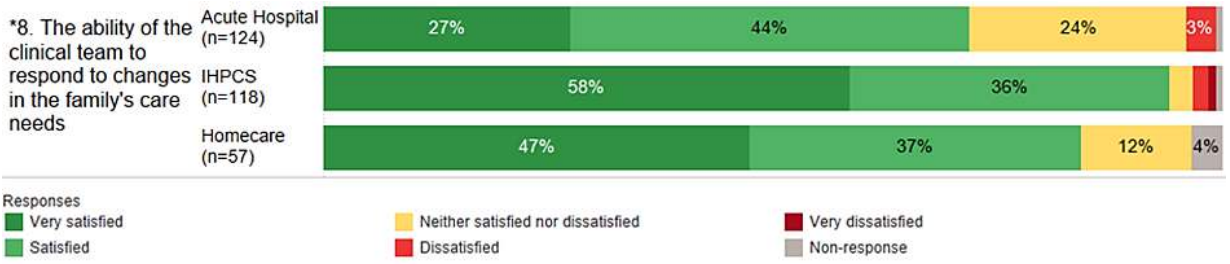


Abbreviation: IHPCS, Inpatient Hospice Palliative Care Service
Note: For acute hospital: n=39 in 2021, n=54 in 2022, n=79 in 2023.
For IHPCS: n=21 in 2021, n=38 in 2022, n=85 in 2023.
For home care: n=31 in 2021, n=26 in 2022, n=39 in 2023.

4. The ability of the clinical team to respond to changes in the family's care needs can be improved.

82% of caregivers across all settings reported they were "very satisfied" or "satisfied" with the ability of the clinical team to respond to changes in the family's care needs. The experience was most positive in the IHPCS setting (94%), followed by home care (84%) and acute hospital (71%) (Figure 12).

Figure 12. Ability of the clinical team to respond to changes in the family's care needs, across service settings



Abbreviation: IHPCS, Inpatient Hospice Palliative Care Service

Conclusion

Feedback from caregivers has generally improved from 2022. This provides acknowledgement of the efforts of the palliative care fraternity in improving end-of-life care and its commitment to quality improvement. The caregiver experience regarding psychosocial support, information provision for funeral services and arrangements, and the ability of the clinical team to respond to changes in the family's care needs are areas for further improvement – these warrant further in-depth evaluation by service providers.

CaRES 2024 will continue to provide valuable information for benchmarking and quality improvement efforts.