



Evaluation of Specialist Palliative Care Services from the perspectives of bereaved persons, a mixed method study.

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Background

The need to evaluate service users' experiences of care as a means of ensuring high quality service provision is well documented, both in healthcare generally (HSE, 2008; HIQA, 2012) and in palliative care specifically (NCPC, 2010). The validated Views of Informal Carer's Evaluation of Services (VOICES) tool has been employed in national surveys in the UK and in a recent Irish study.

Aims and Objectives:

To evaluate bereaved carers' experiences of care provided by inpatient, community specialist palliative care services (SPCS) and bereavement services and to identify required areas for improvement.

Methods:

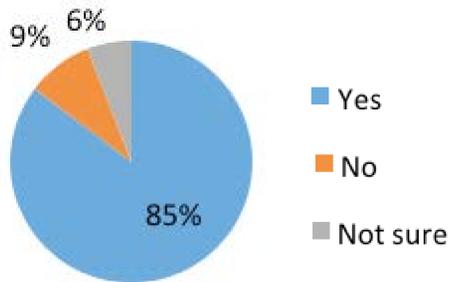
This mixed method, descriptive post-bereavement study gathered data retrospectively using a postal survey and focus group (8 participants) with bereaved relatives of patients. An adapted version of the VOICES, Short Form' (VOICES-SCH) was utilised.

The sample included relatives who were bereaved no earlier than three months and no longer than 6 months.

Results:

1) 53% (n = 72) response rate to survey.

Had the decedent enough choice about where they died? N=34



100% felt their loved one died in the right place although only 48.6% of respondents were aware the decedents preferred place of care at end of life.

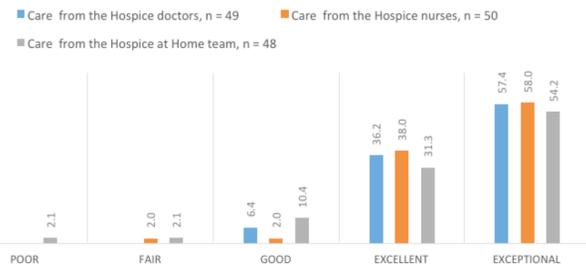
RESPONDENT 18:

"My husband would have liked to pass away at home but as his illness progressed and the pain became intolerable he decided Milford Hospice would be able to manage it better."

RESPONDENT 47:

"I will always be grateful that my husband's wish to die at home was fully supported."

Care received by the patient



95.7% reported that hospice doctors and 98% reported that nurses always treated the patient with respect and dignity. Emotional support and spiritual support needs were met by the multidisciplinary team in the hospice for more than 85% and 90% of respondent's respectively. There was no statistically significant difference in ratings of responsiveness to care needs by the community service in comparison to the care received in the hospice

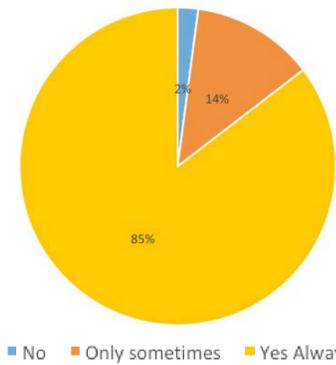
RESPONDENT 12:

"I cannot say one bad word about our time there and especially the care from the nurses that they gave to my late husband, myself and my family. Thank ye all."

RESPONDENT 37:

"I got great help any time I needed it", "absolutely felt they were there for all the family not just mam."

Did the patient see the Hospice at Home nurse as often as needed?, n=49



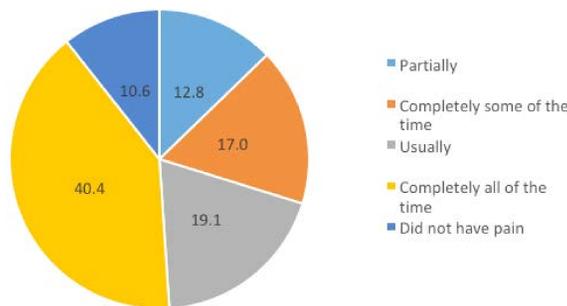
RESPONDENT 10:

"I got great help any time I needed it", "absolutely felt they were there for all the family not just mam."

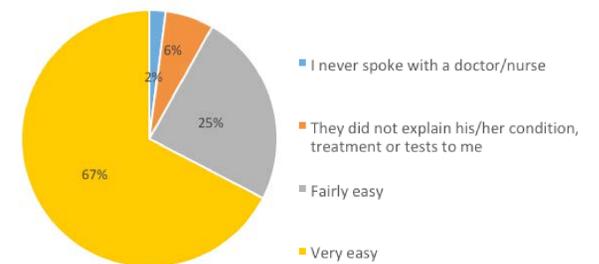
RESPONDENT 59:

"I would have liked to receive calls with updates. I worked fulltime so could not be there when they called all of the time."

Pain Relief in the Community, n=47

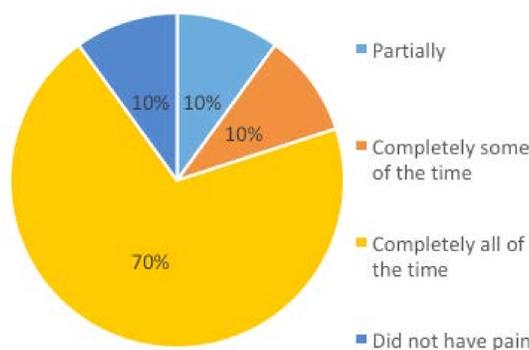


Explanations about Care and/or Condition in the Community, n=49



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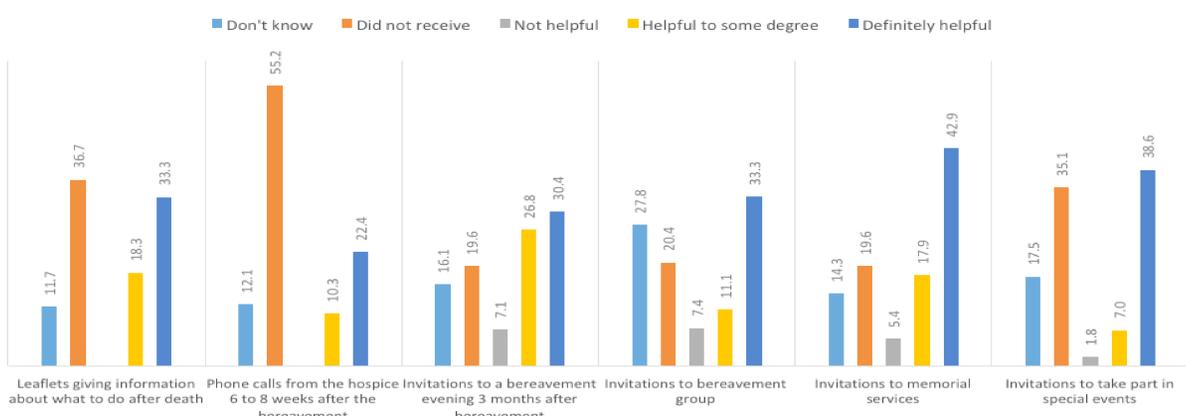
Pain Relief while in the Hospice, n=50



Conclusions/ Recommendations

- Consideration should be given to developing processes to capture email addresses of next of kin
- Processes to communicate with patients and families regarding end of life care preferences and advance care planning should be reviewed.
- Availability of hospice at home staff to respond to patient needs should be reviewed. Some respondents experienced visits as rushed or that the service was only available Monday to Thursday.
- Some families report they did not always understand information that was provided to them. This finding should be highlighted to health care staff and mechanisms to assure good communication skills should be reviewed.
- Review processes of offering bereavement information and follow up to assure consistency within the available resources.

Bereavement follow-up, n=58



Acknowledgements

Thank you to families who so generously gave of their time to participate in this research.