

Voices that Matter...

Bereaved Relatives and their experience of care



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1 Background & aim

43% of all deaths in Ireland occur in acute hospitals¹. Several studies have reported on excellent end of life care provided in acute hospital settings in Ireland, however, others have found deficiencies^{2,3}.

The aim of this study was to assess quality of care and family support, as perceived by bereaved relatives, using *Voices MaJam*, an adapted version of the VOICES validated survey tool⁴.

2 Methodology

A 39-item post-bereavement questionnaire was administered to bereaved relatives of people who died in two adult acute hospitals.

Family members were invited to complete the questionnaire 3-9 months following the death of the person.

The qualitative component of the study is based on three open-ended questions that gathered descriptive data.

The coding frame used in the management of the qualitative data is based on current end of life and palliative care literature.

Qualitative data were analysed thematically using a template analysis framework approach⁵.

Data were coded using NVivo data management software. Inter-rater reliability tests were conducted with results indicating a kappa score of 0.62.

3 Results

Eight key themes emerged from the comments made by bereaved relatives, these are presented here:



4 Relatives told us

- > 356 bereaved relatives (46% response rate) completed the *VOICES MaJam* questionnaire
- > Three quarters of respondents answered one or more of the open-ended questions

Examples of comments made by relatives under three of the themes are outlined here:

She died on the ward at 2am so as we gathered we had to be fairly quiet so as not to disturb the sleeping patients. It would have helped if she had been in a room on her own.

I cannot speak highly enough about the care the nursing staff gave to my relative. Unfortunately the lack of availability of a single room was an issue. I was with my relative when she died as I stayed all night she passed away early in the morning. My family (5 siblings) could not all stay and were not with my mum when she died. We were fortunate that she was sharing with a lovely lady who was VERY understanding of the constant visiting.



Physical care environment

Final days in a room on his own with open visiting for relatives. Great care and attention from nursing staff, doctor's and consultants.

We were able to visit dad outside visiting hours which we really appreciate now as we didn't realise that this would be his last month.

My Mother passed away on a Friday and we were not allowed to see her in the hospital mortuary until after the weekend. This was very distressing for family members who hadn't seen her on the night she died.



Family support

I have to say all the staff, doctors etc., were excellent & attentive & did everything with dignity. They were very supportive to the family during the night shifts.

The immediate family were quite shocked at my father's sudden death...We accept my father was a very sick man, however, the communication channels which we encountered were disjointed. It would have been beneficial to have had a family meeting with Dads care team to have things explained to us all, therefore leaving us with no doubts or misunderstandings of the situation.



Person centred care

My mother received excellent care from all the staff...I would like to thank them all for their kindness and professionalism in my mother's last few weeks... every single person involved in this wonderful place deserves a special thanks for all their hard work. They are extremely warm generous and caring people, and of course efficient and professional.

As I have said Mam's care overall was exceptional... On her last admission she was treated with the greatest respect as she always had been. It was surreal to be at her bedside when she passed on, to hear laughter at the nurse's desk. This was a little insensitive; however, I understand that their work day continued as normal.

The care, attention and humanity offered to my much loved irreplaceable Aunt was all I could have wished for... when she was taken to your hospital she was treated with the utmost care, gentleness and respect which has meant so very, very much to myself and the rest of the family. Thank you so much.

5 Conclusions

Findings highlight the crucial importance of getting qualitative feedback from bereaved relatives on their experiences of end of life care to give a greater understanding of the quality of that care. The data confirms the need to further invest in end of life care in acute hospitals.

The study offers both hospitals the potential to enhance end of life care for future patients and their relatives.

The *VOICES MaJam* survey of bereaved relatives is a useful tool in ascertaining the quality of care at end of life in an acute hospital setting.

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