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 deficiencies2,3.

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 tool.

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.

Data were coded using NVivo 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:

Physical care environment
- 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.

Family support
- 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 (is 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.

Person centred care
- 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 final meeting with Dad's care team to have things explained to us all, therefore leaving us with no doubts or misunderstandings of the situation.

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 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.

References:

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