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CONFERENCE ABSTRACT

Needs assessment for person-centred palliative and end of life care in the Isle of Man

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Introduction

Isle of Man (IOM) is a British crown dependency with 83,000 residents. To provide an evidence-base for the Island strategy on integrated palliative and end of life care, Hospice Isle of Man carried out a needs assessment, which involves the collection and analysis of data describing services and identifying gaps. Many data sources normally used for this purpose are not available in the IOM so we compensated by extensive engagement with those working in relevant services and organisations as well as the public. This paper focuses on what we learned about carers.

Methods

Interviews were carried out with over 60 professionals who work with people with life-limiting illness and twelve patients/carers. The questions were: “What works well?” What does not work well” and “What are the gaps” from your perspective in integrated palliative and end of life care.

Results

We found that some people at end of life have no carers but, even for those that do, some don’t ask for help because they don’t recognise that they are carers, that they need help or that they don’t ask because they are afraid of being separated from their loved one. Carers’ needs are often overlooked and can be emotional, physical or financial and can cause problems even long after bereavement. There was a perception that carers with links to Hospice were well supported. A need for better communication between the professionals and with patients and families was highlighted as well as a need for better involvement of patients and their families in decisions. Carers provide and coordinate care but they are not recognised by the system. Having a professional to help navigate the system is invaluable as is better information about the support services available. In the particular case of the IOM, off-Island care is a substantial burden for patients and carers. Many patients and carers feel alone and not understood and both patients and carers are at risk of mental health problems when facing end of life.

Discussion/Conclusions

The problems faced by carers in the IOM are similar to those in other communities. However, there are additional challenges due to being on a small island. An effective resolution of these problems is essential if we are to achieve integrated care in an appropriate setting at the end of life. Some initiatives already in place should help but new approaches are needed. The data already collected will be a useful basis for future evaluation.