“It is what it is”

How informal carers experience providing bladder and bowel care to palliative patients compared with palliative community nursing staffs’ perception of that experience: A qualitative two-phase study

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Background

Around 90% of palliative patients spend their final year in the community (Jansma et al. 2005). Approximately 55% of their care is provided by informal carers (carers in this paper). One element is bladder and bowel care (BABC) which most palliative patients require at some point (Association for Continence Advice 2011). However, BABC can be challenging for patients and carers (Bee et al. 2009) and there is little research about carers providing it.

Aims

To explore carer’s experiences of providing BABC to palliative patients, and how they make sense and meaning of these experiences. The views of palliative community nursing staff (nurses) were also explored to facilitate a deeper understanding.

Methods

A two-phase qualitative design, with data collected during May and June 2016:

• Phase One: Interpretative phenomenological analysis (Smith et al. 2009) of semi-structured interviews with carers purposively selected from the community service of a London hospice.

• Phase Two: Thematic analysis (Braun and Clarke 2006) of a focus group of nurses selected from the same study site. Predefined criteria ensured sample breadth.

Results: Phase One

Five interviews with mothers of terminally ill daughters were analysed. One overarching theme, three superordinate themes and seven subthemes emerged (Figure 1).

A significant difference of views between the two groups was identified. Although carers agreed BABC could be challenging, situated in the context of their daughter’s disease, it was not a major concern. For carers, BABC engendered closeness and the opportunity to provide better care than patients and compare them with the perceptions of nurses.

Discussion, conclusions and clinical impact

• This study is the first to explore the experiences of carers providing BABC to palliative patients and compare them with the perceptions of nurses.

• A significant difference of views between the two groups was identified.

• Nurses saw BABC as abnormal and best carried out by professionals.

• For carers, BABC engendered closeness and the opportunity to provide better care than most felt professionals could.

• Healthcare professionals who support carer/patient dyads to manage BABC should ensure they have the requisite information, knowledge and equipment, and re-assess regularly to establish if they are able and willing to manage care as the patient deteriorates.

Limitations

• Recruitment of participants through a large London-based hospice.

• Recruitment of only mother and daughter dyads. However, focusing on this small, homogenous group, enabled a far greater depth of analysis.

References


