

# “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

Sarah Combes<sup>1,2</sup> RN, MSc (Clinical Research), BSc.; Dr Sue Woodward<sup>1</sup> PhD, MSc, PGCEA, RN;  
Professor Christine Norton<sup>1</sup> PhD, MA, RN <sup>1</sup>Florence Nightingale Faculty of Nursing and Midwifery, King's College London, <sup>2</sup>St Christopher's, London

### 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 poster).

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).

Overarching	Superordinate	Subthemes
It is what it is	Whatever my daughter needs	The subsumed self
		The importance of empowerment and advocacy
		The importance of closeness
	Mum knows best	The imperative to care
		Establishing and re-establishing identity
	Coping with caring	Coping strategies
		The importance of partnership

#### Illustrative quotes for overarching theme “It is what it is”

“She had very bad experience. That's reason why I understand I have to be all the time there”  
Ester

“It's at those moments you could actually sit down and cry, I think, just like, ‘Oh my God, I can't do this anymore.’ But you do”  
Karen

“You get frustrated sometimes when you're out and it's [faeces] all over everywhere, and down you and down her and I've, I've got to clear up the toilet you're in and everything”  
Jane

“It's always been an ongoing thing from a baby. You don't mind washing a baby's bottom, do you? ...the fact that she's an adult, nothing's really changed”  
Grace

“And, and you learn from your mistakes as well and what's comfortable for the patient”  
Alex

### Results: Phase Two

Two clinical nurse specialists, two staff nurses and two healthcare assistants, with between two and 20 years' palliative care experience, attended one focus group. Three themes and nine sub-themes emerged (Figure 2)

Themes	It's not normal	B&BC is a huge challenge	Even for us, it's not simple
Subthemes	We don't talk about BABC	The challenges of BABC	BABC is challenging for professionals
	It's not what people normally do	Issues with professional services	The need to manage yourself
	The influence of relationships		The need for excellent assessment
	It's better when professionals step in		

#### Illustrative quotes from focus group professionals

When professionals step in: “It gives [carers] comfort because they were not used to have a relationship of cleaning the father/mother or whoever it is. But more a relationship of not so many physical intimate contacts? So I think at that point it's a relief for them”  
Lucas

“Even with bladder and bowel care it does strike a bit of a raw nerve and I find that I have to take a step away from myself sometimes, leave myself somewhere else and send my resilient clone into difficult situations”  
Ellen

Being more experienced in palliative care means you can: “...broach difficult subjects, even if it's not difficult for you but you can tell it's difficult [for carers/patients], you'll learn different ways of opening conversations”  
Rose

BABC is: “...a huge challenge... a massive, massive thing...”  
Sinead

“It's like Christmas. You walk in with a packet of pads and they're like, ‘Oh my God. How much do I owe you?’”  
Adam

“It's not something you would sit and have a conversation about”  
Louisa

### 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
- 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 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

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### Contact

Sarah Combes, RN, BSc (Hons),  
MSc (Clinical Research), Doctoral Student  
sarah.combes@kcl.ac.uk