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“It is what it is”: Mothers’ experiences of providing bladder or bowel care to their life-limited daughters: an interpretative phenomenological analysis.

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ABSTRACT

Background

Informal carers (carers) support palliative patients to live at home. Most palliative patients require bladder and bowel care (B&BC) at some point. However, there is limited evidence about carers providing B&BC or how best to support them.

Aim

To explore carers’ experience of providing B&BC to life-limited young adults.

Methods

Interpretative phenomenological analysis of five interviews with purposively selected carers.

Findings

One overarching theme, *It is what it is*, and three superordinate themes emerged: *Whatever my daughter needs, Mum knows best*, and *Coping with caring*. While B&BC could be challenging at times, it was not a major concern. Instead it engendered closeness and opportunities to provide better care than carers felt professionals could.

Conclusions

This study informs how professionals should understand the support carers offer. Professionals should ensure carer/patient dyads who wish to manage B&BC are supported to do so, and that their support needs are regularly assessed.

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INTRODUCTION

Around 375,000 people living in England and Wales required palliative care in 2014 (Etkind et al. 2017). Due to factors including population aging and the rising prevalence of chronic conditions, these authors estimate the need for palliative care could rise by over 42% by 2040, a trend they predict will be replicated in many high-income countries. Most palliative patients spend their final year at home, with 90% receiving care in the community (Bee et al. 2009). An estimated 55% of this care, including bladder and bowel care (B&BC), is provided by informal carers (carers) (Jansma et al. 2005): partners, siblings, children, parents and friends. These carers are instrumental in enabling patients to be cared for and die in their preferred place, which for most is their own home (Hunt et al. 2014).

Most palliative patients require assistance with elimination at some point due to multiple reasons, including medication, reduced food or fluids, and underlying disease (Hanks et al. 2011). Up to 90% experience constipation (Clark et al. 2012), up to 44% faecal incontinence and up to 71% urinary problems (Van Lancker et al. 2014). Increasing dependency, loss of privacy, embarrassment, and stigma (Elenskaia et al. 2011, Chelvanayagam 2014) mean B&BC can be difficult and distressing for patients and carers (Norton 2004). Most carers did not choose their caregiving role, lack confidence, and have unmet needs (Bee et al. 2009, Morris et al. 2015).

The UK government is committed to supporting carers (HM Government 2010); however, there is little research regarding carers providing B&BC, especially their practical support needs (James Lind Alliance 2015). This is particularly apparent for carers of young adults with

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palliative care needs (Clark and Fasciano 2015). With medical advances and a focus on family-centred care, many more life-limited young adults are now being cared for, and often die, in their home environment with their family assuming the role of carers (Woodgate et al. 2015). This includes providing skilled nursing care, including practical support such as B&BC. This study focusses on carers of life-limited young adults. It aims to explore their experience of providing B&BC to palliative patients, how they made sense of these experiences, and to establish their practical support needs.

METHODS

This study was a qualitative investigation of individuals’ subjective experiences. Interpretative phenomenological analysis (Smith et al. 2009) was chosen as it focusses on exploring how everyday experiences can assume particular significance, and how individuals make sense of their experiences in their own unique contexts.

Sample

Interpretative phenomenological analysis places importance on sample homogeneity to enable insight into shared experiences (Smith et al. 2009). Potential participants under the care of one urban hospice were therefore purposively selected from those who met the inclusion criteria in Table 1, thereby ensuring participants had experience of the phenomenon of interest. Potential participants were approached by their Clinical Nurse Specialists, and all agreed to take part in the research.

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Data collection

Semi-structured interviews were conducted in participants’ homes by the first author (SC) from May-June 2016. These were audio-recorded, transcribed verbatim, and anonymised to maintain confidentiality. The interview schedule was developed with patient representatives, piloted prior to use, and included questions around the B&BC carers provided, their feelings about this, practical advice received, help-seeking behaviours and what they felt could improve B&BC. Probes and supplementary questions were used to clarify meanings and attain more comprehensive responses. Interviews lasted a mean of 55 minutes (range 30-90 minutes). Given interpretative phenomenological analysis’s focus on the way individuals make sense of their own experiences, data saturation was not relevant for this study.

Ethical considerations

Ethical approval was granted by North West Preston Research Ethics Committee (16/NW/0042) and access approvals granted by the hospice. The study was carried out in accordance with the Declaration of Helsinki, and written informed consent obtained.

Due to the sensitivity of the subject, participants were at risk of becoming distressed. They were therefore advised not to answer questions that made them uncomfortable, that they could stop the interview at any time, and SC, a palliative care nurse, managed distress as required. Participants were also advised to contact their Clinical Nurse Specialist if they became distressed following the interview.

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Data analysis

Analysis followed the approach set out by Smith et al. (2009). Transcripts were read and re-read while listening to the audio-recording. Line-by-line coding was used to make exploratory notes focusing on the language used, content, metaphor, and the researcher’s reflections (Biggerstaff and Thompson 2008). An iterative and inductive process, analysis moved from specific to general, descriptive to interpretative, developing exploratory comments into detailed, analytic accounts for each transcript (Smith et al. 2009). All cases were compared and contrasted to abstract prevalent cross-case superordinate themes representing all participants and variations in their account. Findings present a co-constructed analytic account representing participant experiences and researcher reflections (Brocki and Wearden 2006). Initial analysis was conducted by SC, all authors then reviewed the transcripts and agreed findings.

Rigour

Yardley’s four principles for achieving qualitative research quality (Yardley 2000): sensitivity to context; commitment and rigour; transparency and coherence; impact and importance, were adhered to throughout. Purposive sampling ensured participants had experience of the phenomena of interest. The interview schedule was developed with patient and public involvement and piloted with a carer representative, ensuring sensitivity to context. The transparent methods section has outlined each stage of the research process, and data were analysed systematically. Further, findings are supported by verbatim extracts to give voice to participants, and aid transparency and credibility (Smith et al. 2009). Additionally, a reflexive diary was completed contemporaneously with interviews. This was used to note environment

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and non-verbal communication, and captured preconceptions and observations throughout the process (Shaw 2010).

FINDINGS

Five participants, all mothers who provided B&BC to life-limited daughters, were interviewed. Participant characteristics are presented in Table 2.

One overarching and three superordinate themes with seven subthemes emerged through the analysis (Table 3). Themes were interrelated and while they are discussed separately here, should be considered as a whole to provide a more holistic picture.

It is what it is

The overarching impression was that while B&BC was challenging at times, it was not a major issue within the context of their daughter’s disease, something all participants spent the greatest part of the interview discussing. Instead B&BC was something to overcome and normalise, “...*we just have to get on with it...*” [Jane], and was often seen as a progression of childhood “...*I've been changing her since she was born, so it was just a natural progression...*” [Karen]. No matter how challenging the situation, there appeared a metaphorical shrug: ‘It is what it is’.

All participants were involved in various forms of B&BC including cleaning, managing constipation, and monitoring bladder and bowel function, and explained in detail the pharmacological and non-pharmacological strategies they used:

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“Sometimes you do feel like an inspector, a poo inspector or, you know, a wee inspector just to make sure everything's going okay... And I use it to spot urine infections and things like that. The quicker you nip it in the bud, even just by increasing the water sometimes you can just flush whatever's there out.”

[Karen]

All participants gave examples of strategies that did not work well. Laxatives did not have the desired effect [Alex, Karen, Ester, Grace], faecal incontinence was not controlled swiftly [Karen, Jane, Grace], bladder infections reoccurred [Ester], or equipment was not entirely suitable [all participants]. However, in general participants appeared to accept this was the way it was, and found a way to make things work for them and their daughter:

“...and we'd be pulling these... nappy pant things up, and in the end I just thought, 'This is just too traumatic. Let's just cut the sides and lift them up her'...”

[Alex]

Participants felt they received no advice regarding B&BC practicalities, but felt anything not immediately obvious was easy to learn. This appeared linked to how most saw B&BC as a continuation of childhood care:

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“...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]

However, Ester did find B&BC challenging initially, with faecal incontinence appearing particularly difficult. Nevertheless, by pushing through her boundaries, she was now providing all her daughter’s personal care:

“...now I’m doing everything. I couldn’t believe myself either!” [Ester]

Difficulties with incontinence may be related to Ester’s desire for cleanliness, emphasised throughout the interview. However, it may also be because incontinence can be seen to represent deterioration, something Jane and Grace also experienced difficulty with. Grace deflected questions regarding deterioration; Jane and Ester maintained strict toileting schedules. These reduced incontinence risk and meant the realities of deterioration were less apparent.

While participants described other challenges, these were generally spoken of as momentary but manageable, such as how Karen describes managing severe incontinence during an exacerbation of inflammatory bowel disease:

“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.”

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[Karen]

Finally within this theme is professional support. Equipment was a key issue, particularly from the continence service. For Alex, Ester and Grace the service worked well, for Karen and Jane, it was frustrating, adding an additional burden. To manage this Karen supplemented supplies that did not meet her daughter’s needs; Jane provided all products herself due to an “...insensitive...” service that would not supply products unless she specified the quantity of urine/faeces the pads would be required for each day:

“...in the end, I said, ‘Do you know what? I think I’m going to bag them up and send them to you and you can sort with it... I’m not interested’...”

[Jane]

Jane’s anger and frustration, repeated throughout the interview, appeared related to the seeming inability of services to recognise her daughter’s complexities. Others also expressed difficulties. Ester’s experience, still clearly painful, had influenced her trust in professionals and how she saw her caregiving responsibility:

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

[Ester]

This belief, that no one could care for their daughter as well as they could, is discussed further in ‘Mum knows best’.

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Whatever my daughter needs

This superordinate theme represents three subthemes. *The subsumed self*; the participants’ drive to provide whatever they felt their daughter needed, regardless of the impact on themselves. *The importance of empowerment and advocacy*; the strong drive participants expressed to advocate for and empower their daughter, and ensure others recognised them as people, not just their disease. *The importance of closeness*; how participants appeared to need to be close to their daughters, even if she were in professional care.

While some briefly described keeping well for their daughter’s sake (Jane, Ester, Grace), the overarching feeling was their daughter’s needs subsumed their own:

“...I really have no normal life. I have no... nine years staying at home look after someone. No any holiday. No any... actually, free time... If she’s going to Day Centre, I have to go to bank, to shops, food shop, buy that one, get this one. That’s it.”

[Ester]

Fulfilling their daughter’s needs included empowering them. For some this meant respecting independence, abiding by her choices, even if they did not agree, or ensuring she had relevant equipment:

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“She had to come up with it herself and I let her... with commodes and things like that, had to come from her.”

[Alex]

Empowerment also meant advocacy. While difficult for some, all acknowledged its necessity:

“You don't have a choice. She can't speak for herself so to me that's my job. I'll speak for her as long as I need to.”

[Karen]

Advocacy included ensuring people saw their daughters as people, not just an illness, stressing her personality and their pride in her achievements. While not usually related to B&BC, this topic formed a significant element of the interviews, further demonstrating how participants situated B&BC, and their caregiving experience, as of less importance than their daughter, the person.

Physical and emotional closeness to their daughters was seen as important, as was being “...on hand...” [Jane] if she was receiving professional care. All except Alex described worrying whenever they parted, and participants often continued caregiving even when their daughter was admitted to hospital or another institution.

For some, the thought of needing to receive B&BC was repellent:

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“...if it was you or me, I think we would have wanted a... long walk off a short plank.”

[Jane]

However, providing B&BC for their daughter was seen as special, a way to show love and affection. Whether this caregiving enabled closeness or fulfilled an innate desire is unclear. However, its loss, such as when professionals began assisting Karen’s daughter, was experienced as a wrench of separation:

“...you do miss that touch as well. You do miss that physical contact. It's not like [patient's] ever going to throw her arms round you and give you a great big hug or anything like that so... those times, those personal care times is also an intimate time...”

[Karen]

Mum knows best

This superordinate theme encompasses two subthemes. *The imperative to care*; the feeling participants knew their daughter and her needs better than anyone else and were best placed to provide care. *Establishing and re-establishing identity*; the way participants appeared to develop multiple identities to care for their daughter and cope with caring.

All participants, except Alex, felt that if they wanted their daughter to receive excellent care, they needed to provide it:

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“I suppose it’s a little bit of I like to know things have been done properly.”

[Grace]

This meant monitoring medical management, whether their daughter was at home or in an institution, and revising advice as they felt necessary:

“...if I have no choice I give them [laxatives] but giving her more fruits, warm water, after fruits; something like that. If it’s not working, then some medicine.”

[Ester]

The belief that they could provide the best care for their daughter was illustrated by Karen, who prided herself on providing everything for her daughter. However, when faced with administering a vaginal pessary, she feared “...violating...” her. Retelling the experience was clearly upsetting, changing Karen from the confident, in control person she appeared to be, to become hesitant and quiet. This experience appeared to challenge Karen’s identity as carer, and perhaps mother:

“...I didn't think I'd ever find that line but I did, so... and it's only recent, so yeah. It was dreadful... [laughs].”

[Karen]

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Karen’s use of laughter seemed to flick a switch, lightening her mood and allowing her to continue. Humour is discussed further in ‘Coping with caring’.

Within each narrative carers’ language and experiences demonstrated how their identities established and re-established; mother, wife, advocate, educator and many others. However, all participants appeared to be seeking validation for their caregiving role. While this is likely multifaceted, two reasons resonate. The interviewer was a nurse; participants may have felt obliged to prove their knowledge, to articulate that they were capable and competent to care for their daughters, even though Jane and Grace were healthcare trained. Perhaps of greater relevance was the participants’ identity as primary carer appearing a significant part of their psyche, demonstrated through their language, experiences, and assumption of the caregiving role. This recognition may therefore be linked to their choice to fulfil the role, although none would likely refuse it:

“...she’s my daughter. I just do it.”

[Jane]

Coping with caring

This superordinate theme encompasses two subthemes. *Coping strategies*; general strategies used to help with B&BC and caring as a whole. *The importance of partnership*; partnerships participants found beneficial in supporting them as caregivers.

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Participants utilised various coping strategies from deflecting conversations [Grace] to strictly scheduling B&BC [Jane, Ester]. Some used rationalisation [Alex, Grace], and all agreed time out, to reconnect with themselves and to feel “...normal...” [Ester], was important. Peer support was used by all, except Jane:

“...on social media we have a [name of syndrome] community, so all the young mums ask the old mums... for practical tips and advice.”

[Karen]

Humour appeared throughout the interviews, most often after participants described harrowing experiences. This seemed to diffuse tension. Shown previously through Karen’s pessary experience, Grace’s experience of her daughter not defecating until one week after birth, something she described as being extremely worrying at the time, also applies:

“And so she finally went and I rushed out into the corridor and said ‘she’s been!’ and everybody went ‘Hooray!’ [Laughter].”

[Grace]

All expressed that partnership, whether with a partner, friends, family, church, or their daughter, helped them feel supported and able to care, no matter the amount or type of support offered:

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“...when we would come home from hospital and there was a meal on our doorstep, wow! I'm coming out in goose bumps of just how brilliant all of that was.”

[Alex]

“...my husband’s brilliant, so he’s a great..., but obviously, he works but he’s very, very good...”

[Jane]

DISCUSSION

This study explored mothers’ experiences of providing B&BC to their life-limited daughter, and how they made sense of these experiences. For these participants, B&BC, when situated in the context of their daughter’s disease, was not a major issue. Instead it was an opportunity for physical and emotional closeness. B&BC was seen as special care, enabling them to show love and affection, its loss felt as a wrench of separation. These experiences may be related to touch. In the receiver, touch induces relaxation and can decrease anxiety, suffering and pain (Ozolins et al. 2015). However, it also impacts the giver, enabling shared biopsychosocial comfort and affection and increasing carer satisfaction (Connor and Howett 2009). Of particular relevance in this cohort, touch is seen as a tool for connection and communication (Connor and Howett 2009). Further, it engenders the belief that givers can ease recipients’ suffering, and facilitates the formation of deep therapeutic relationships (Edvardsson et al. 2003).

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All participants were mothers of life-limited young adults. They spoke with conviction about how they knew their daughter and her needs better than anyone else and how this meant they provided the best care. This agrees with the wider literature regarding mothers of disabled children (Van Wyk and Leech 2016), which found mothers believed only they could understand their child well enough to provide excellent care. This belief appears to be based on a combination of factors including believing professionals were not equipped to care for intellectual disability (Nicholl and Begley 2012), lacked knowledge and understanding of needs, and carers’ experience of poor care (Burkhard 2013, Woodgate et al. 2015).

Participants in this study therefore took on primary responsibility for caregiving, even when they received external help or their daughter was admitted into an institution. As with the wider literature, participants demonstrated high levels of knowledge and understanding of all caregiving aspects, constantly monitored professionals, adapted medication regimes (Nicholl and Begley 2012), undertook advanced care, and worried if they were apart, fearing professionals would not keep their daughter safe (Burkhard 2013, Woodgate et al. 2015). Further, they advocated for their daughter, and as with other mothers of disabled or life-limited children (Burkhard 2013, Woodgate et al. 2015, Van Wyk and Leech 2016), participants became their child’s nurse, a guardian, educator and a constant student in order to provide their daughter with the best care.

While B&BC was seen as necessary, it was not described as a major burden, contrasting with the argument of caregiving as a biopsychosocial burden in the literature (Grande et al. 2009,

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Harrop et al. 2014). Instead, as found in a recent unpublished literature review conducted as a preliminary to this study, participants accepted caregiving as hard at times, but found meaning and benefit from providing it. Research regarding the positive elements of caregiving is sparse, but suggests it can positively enhance quality of life for both giver and receiver (Shim et al. 2012), and enables personal growth, increases confidence, and self-esteem (Green 2007).

STRENGTHS AND LIMITATIONS

This study is the first to explore the experiences of carers, in this case mothers of life-limited young adults, in providing B&BC to a palliative patient. The use of interpretative phenomenological analysis enabled the analysis of rich, deep data, and the emergence of an understanding of the sense and meaning that carers attribute to this care. The potential subjectivity of qualitative research is acknowledged, as is the potential impact of the researcher being a nurse and the influence this may have had on participant’s responses. However, a transparent approach to the research process has been followed and documented. Recruitment of participants through a large, urban hospice may have influenced participant responses, as may lack of ethnic diversity and gender. While the small sample size limits generalisability, it has enabled a greater depth of analysis (Smith et al. 2009).

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CONCLUSIONS AND IMPLICATIONS

As far as we are aware this is the first study to focus on carers’ experiences of providing B&BC to palliative patients. Carers in this study, all mothers of life-limited young adults, felt B&BC was not a major issue when situated within the context of their daughter’s disease. Instead, providing B&BC facilitated closeness and intimacy and, most believed, meant their daughter received a better standard of care than professionals could provide.

Practice recommendations:

Healthcare professionals should be aware that caregiving can engender benefits and ensure carer/patient dyads who wish to manage B&BC are supported to do so, and have all the information, knowledge and equipment required. They should also ensure these dyads are assessed regularly as the patient’s needs change.

Future research recommendations:

Future research should explore the experiences of a broader range of carer/patient dyads to ascertain if meaning-making is similar to this cohort. It should also seek to understand healthcare professionals’ perceptions of carers providing practical support and how professionals can better support caregivers wishing to provide practical care.

Key words

Palliative care; Caregivers; Carer perspectives; Continence; Nursing; Phenomenology

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Table 1

Table 1: Inclusion criteria

- Current or bereaved carers who are/have been actively involved in supporting a palliative patient with B&BC in their own home
- Both carers and patient over 18 years
- If carer was bereaved this should be at least 6 months previously

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Table 2: Participant and patient characteristics

Participant pseudonym	Ethnicity	Daughter’s age	Daughter’s diagnosis	Long-term bowel issue?	Long-term bladder issue?	B&BC from infancy?	Bereaved
Alex	White British	Early 20s	Cancer	C	No	No	1 year
Karen	White British	Late 20s	Neurological disorder and inflammatory bowel disease	C&FI	Yes	Yes	No
Jane	White British	Early 20s	Neurological disorder	FI	No	Yes	No
Ester	White (other)	Early 20s	Unknown	C	Intermittent	From late childhood	No
Grace	White British	Early 30s	Connective tissue disease	C&FI	Yes	Support from infancy, full care from 20s	No

Key: C=constipation, FI=faecal incontinence

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Table 3:

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