Caring for an adult receiving palliative care at home - An exploration of the perceptions and lived experiences of carers

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Background

In Scotland it is estimated that there are 657,300 carers who make a substantial contribution to the care of family members in the home and this equates to £7.68 billion annually (Buckner and Yeandle, 2007). Many family members assume this role as their duty but are often unprepared for this responsibility and for the challenges that lie ahead. Added to this, they are often untrained, unpaid, elderly, and can become unwell themselves (Stajduhar, 2003). There is often a presumption among professionals that family carers can perform this role adequately and over a twenty four hour period (Cheung and Hocking, 2004). Little seems to be known about the knowledge and skills needed for this role.

Aim

The principal aim of this study is to critically explore the lived experiences of carers providing care for an adult receiving palliative care at home.

Objective

This study explored carers' experiences about what they need to know to provide care to determine the practical skills that carers believe they need for their role.

Methodology

A qualitative research design and an interpretative phenomenological approach were chosen for this study. Recorded semi-structured interviews were undertaken and following transcription, Burnard's method (1991) was used to guide the analysis of the data until final themes emerged.

Results

A total of six interviews that involved eight carers were completed and details of the relationship and length of time spent in a caring role are detailed in the table below.

Carer	Relationship to the patient	Employment status while caring	Diagnosis of patient	Length of time spent caring (approximately)	Place of death of person cared for
1	Wife and daughter	Not employed	Stroke & stomach cancer Bowel cancer	11 years 1year	Hospital (husband) & Home (mother)
2	Daughter	Employed	Lung cancer	7 months	Home
3	Daughter	Employed	Addison's disease, Emphysema, COPD (mother) & Dementia (father)	2 years + Still caring for father	Home (mother)
4	Husband	Retired	Brain tumour	4 months	Hospice
5	Daughter	Employed	Cancer (type not known)	1 year 6 months	Hospital
6	Daughter	Not known			
7	Son	Employed			
8	Wife	Retired	Oesophageal cancer	1 month	Home

It was evident from carers' accounts that nearly all those being cared for had their wishes honoured; some remained at home, while others ended up in hospital or the hospice which was seen as their final preference and place of choice.

Carers in this study had a variety of similar experiences as well as some that were unique to their situation. The main themes that emerged demonstrated a significant gap in their knowledge and skills. Indeed, they needed to know what was the right thing to do and that they were doing the right thing at the right time. Their retrospective accounts provided an insight into each of their experiences, the uniqueness of their role and the challenges they faced.

Themes and sub-themes emergent from the study		
Overall phenomenon	Main themes	Sub-themes
The nature of what is involved in caring: Carers' lived experiences of the knowledge and skills needed to care for someone in the palliative phase of their illness, at home.	Knowing what is the right thing to do	Knowing the person and understanding their condition Intuitive / previous knowledge Knowing what to do and what to expect Knowing what is needed and knowing your limitations Knowing who to turn to
	Doing the right thing at the right time	Nature of what's involved in caring Moving and handling Medication management
	Personal experiences of caring	Dealing with conflicting pressures Sudden onset of caring role Soaking up the frustration Experiencing changes in health Experiencing a sense of satisfaction

Knowing what is the right thing to do

It was evident that each carer had a different situation and therefore their information and knowledge needs were not the same. Some carers overcame the gaps in their knowledge by *'learning on the job'* using a trial and error approach. Others were dependant on their knowledge from previous care related experiences. One family of carers summed up their caring experiences as *'trying to figure it all out'*. None of the carers acknowledged any assessment having been done of their knowledge needs. The insight into their experiences implied that an assessment of their knowledge was required at the outset of their role, and they would have benefited from a review at pertinent or appropriate intervals.

Many of the carers in this study had experienced feelings of anxiety as well as fear and uncertainty when faced with challenging situations and not knowing what to do or who to turn to for answers. When carers were worried about an aspect of their role, most turned for help and guidance to their community nursing team who were seen as a valuable resource, particularly when practical help for personal care was needed or to provide guidance on the administration of medicines. In contrast, GPs were also the main contact for many carers but seemed to have input only to regulate medication or when requested to visit.

Doing the right thing at the right time

The carers needed to know what to do but they also needed to know or be shown how to do it and to know that they were doing it correctly.

One carer described how he used his previous experiences as a taxi driver to guide him when moving his incapacitated wife in and out of their car.

Other carers experienced difficulties when they were provided with pieces of equipment to use for toileting the person they cared for. Once again they had to *'figure it out'* for themselves. Added to this, the intimacy involved with toileting care meant further adjustments in the original relationship between the person being cared for and their carer. One carer felt this was too undignified for him and his mother, therefore his sisters provided the intimate care. This is supported by other researchers who found that the majority of care at home is provided by women who are a spouse, partner or a daughter (Grande, Addington-Hall and Todd, 1998; Hudson, 2004; Visser et al, 2004). However, while most carers' assumed that essential care such as washing, dressing and toileting another person was the *'nature of what's involved in caring'*, others described it as an area that they needed skills in because they had *'never done anything like this before'*.

Although the carers in this study had access to twenty four hour community nursing services they voiced anxieties and a lack of confidence around the accuracy needed to administer medicines and remained anxious abou the responsibility of administering additional doses of strong pain medication. Other carers valued the opportunity to administer the medication timeously and had a sense of achievement in that they enabled the person to fulfil their wish to stay at home. Managing medications and recognising changes in symptoms were viewed by carers as a knowledge deficit with five of the carers highlighting medication as an area that they needed help with. This is supported by Terry et al (2006) who also found that carers had concerns about the timing and dosage of medications.

Personal experiences of caring

Many of the carers found themselves undertaking this role for the first time, under the assumption that this was expected of them and it was their duty to do so. Carers often experienced conflict in their role and this was evident during the decision-making process to honour wishes and take care of their relative at home. In some cases this had an impact on their employment and time off work. Other instances of conflict were related to siblings who were opposed to providing care at home or where they experienced dissatisfaction with hospital services.

Carers expressed that they became more anxious and stressed dealing with conflict. This is consistent with Stajduhar and Cohen (2009) who highlight the importance of psychological support for carers. While endorsing this viewpoint, Grande et al, (2009) related high levels of anxiety to poor information and the lack of practical and psychological support. The findings from the present study imply that knowledge of, as well as the ease of access to and availability of resources and support networks would have been beneficial to them as carers.

There seemed to be no guidance as to the duration of their role as a carer and sometimes there was no warning as to the intensity of their duties. Consequently carers experienced fatigue and changes in their own health which is supported by Osse et al (2006). Some carers became frustrated dealing with the challenges they faced, while others recognised the benefits from having a break, even if this was only time to do their grocery shopping. This is consistent with other researcher's findings where many carers feared leaving the person alone which resulted in feelings of isolation and restricted social activities leading to ill health. Other carers seemed to adapt their lives to suit the increasing dependency of the person being cared for and to enable their care to continue at home.

Despite the negative aspects of their experiences, the majority of the carers had reconciled these to create a sense of satisfaction since the death of their spouse or parent. It was evident that the relationship between the carer and the person cared for resulted in a strong sense of duty. One carer reflected that she had a better knowledge of her father's condition and counted her experience as a 'blessing' while others said it was 'worth it'.

Clinical implications for practice

Adequate preparation of carers with timely information and knowledge, assessment and provision of practical and emotional support as well as access to the necessary skills training and knowledge as and when required.

Conclusion

Carers need specific knowledge and skills at different points over the duration of their role. Ultimately carers need to know that they are doing the right thing and that appropriate help and guidance will be available as they need it. In these ways the whole experience of caring for someone with palliative care needs at home can be improved and extended.

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