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

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This research study was undertaken as part of the award for MSc Nursing at University of the West of Scotland.

Background
In Scotland it is estimated that there are 657,300 carers who make a substantial contribution to the care of fragile family members in the home and this equates to £7.48 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. Add to this, the care of an often unremitting, unpaid, and non-commercially quantifiable, role that becomes their own (Stajduhar, 2003). There is often a presumption among professionals that family carers can perform this role adequately and over a twenty-four hour period (Chung and Hecking, 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 transcribed, Bumman’s method (1997) 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.

<table>
<thead>
<tr>
<th>Carer</th>
<th>Relationship to patient</th>
<th>Employment status</th>
<th>Caregiving role</th>
<th>Diagnosis of patient</th>
<th>Length of time spent caregiving (approximately)</th>
<th>Place of death person cared for</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Wife and daughter</td>
<td>Not employed</td>
<td>Stroke &amp; stomach cancer</td>
<td>Bevill’s disease</td>
<td>11 years</td>
<td>Hospital (husband &amp; home (mother))</td>
</tr>
<tr>
<td>2</td>
<td>Daughter</td>
<td>Employed</td>
<td>Lung cancer</td>
<td>Still caring for father</td>
<td>2 months</td>
<td>Home</td>
</tr>
<tr>
<td>3</td>
<td>Daughter</td>
<td>Employed</td>
<td>Addison’s disease, Emphysema, COPD (mother)</td>
<td>1 year 6 months</td>
<td>Home (mother)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Husband</td>
<td>Retired</td>
<td>Cancer (type not known)</td>
<td>Brain tumour</td>
<td>4 months</td>
<td>Hospice</td>
</tr>
<tr>
<td>5</td>
<td>Daughter</td>
<td>Employed</td>
<td>Dementia (father)</td>
<td>Still caring for father</td>
<td>2 months</td>
<td>Home</td>
</tr>
<tr>
<td>6</td>
<td>Daughter</td>
<td>Not known</td>
<td>Oesophageal cancer</td>
<td>Oesophageal cancer</td>
<td>1 month</td>
<td>Home</td>
</tr>
</tbody>
</table>

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. 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. 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 Ouse et al (2006). Some carers became more anxious and increased the decision-making process to honour wishes and take care of their relative at home. When end of life care was used to guide the analysis of the data until final themes emerged. Knowing what is the right thing to do and that they were doing the right thing at the right time.

Themes and sub-themes from the study

Overall phenomenon | Main themes | Sub-themes
--- | --- | ---
Knowing what is the right thing to do | Knowing the person and understanding their condition | Knowing what is needed and knowing your limitations | Knowing what to do |
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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 and unmet care needs | 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 dependent on their knowledge from previous care related experience. 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 valued the opportunity to administer the medication timeously and had a sense of achievement in that they enabled the person to fulfill 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 in this study had experienced feelings of anxiety as well as fear and uncertainty when faced with decisions concerning care. This was evidenced by the carers acknowledging any assessment having being 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 valued the opportunity to administer the medication timeously and had a sense of achievement in that they enabled the person to fulfill their wish to stay at home. Managing medications and recognizing 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.

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 go on to develop the ways in which they can learn about the role of caring for someone with palliative care needs at home can be improved and extended.

References

R. CT3-00369