

What does respite care mean for palliative care service users and carers? Messages from a conceptual mapping

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Abstract

Over the coming years, as an ageing population with multiple chronic illnesses increases, the number of carers and paid carers is set to decrease. There is, therefore, an urgent need to understand what types of services are most supportive in helping to sustain caring relationships. Respite care is frequently mentioned as a key factor in supporting family carers and improving their quality of life but there is a lack of research to support its efficacy. This paper will present a conceptual map of respite care in order to promote a greater understanding of the multiple tensions that the palliative care respite literature reveals. As learning more about carer's needs and the complexities of the caring relationship develops, it is an appropriate time to map the key messages from the literature to help us understand what respite care does actually mean to palliative care service users and carers.

Key words: Carers ● Concept maps ● Palliative care ● Person-centred care ● Public health approach ● Relationship-centred care ● Respite care

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There are indications that over the coming years an increasing amount of support for carers of patients with palliative care needs will be required. The literature refers to pressure in the UK, Europe and Australia, and the reasons for this include the fact that there is an ageing population, with fewer carers and paid carers, and increasing numbers of people with chronic illnesses requiring care (McNally et al, 1999; Palliative Care Australia (PCA), 2005; European Association for Palliative Care (EAPC), 2009; Grande et al, 2009). There are also changing patterns of care (Zapart et al, 2007), and in the UK and Australia, for example, studies have shown that up to 90% of patients with terminal cancer now spend the majority of their last year of life at home (Samar et al, 2005; Skilbeck et al, 2005). Such changes are also reflected in varying ways across Europe, the US and other parts of the world (Newton et al 2002; van Excel et al, 2006; Honea et al, 2007; EAPC, 2009) making this an international issue.

In recent UK policy and guidance (National

Institute of Clinical Excellence (NICE) 2004; Department of Health (DH), 2005; 2006; 2008a; 2008b) respite care is frequently mentioned as a key factor in supporting carers so that they may carry on caring for longer and have an improved quality of life. However, from an accumulative review of the literature over the last 3 years, it is difficult to see how respite care could have established itself as being of such value. Studies have shown that there is a lack of research to support its efficacy (McNally et al, 1999; Ingleton et al, 2003) and little is known about respite services for patients with a life-limiting illness (Owen and Johnson, 2005; Skilbeck et al, 2005). Anecdotal evidence which favours respite care though is very strong and it is almost as if it is so strong that it does not require research.

In this paper the authors will present a conceptual map of the key messages from the literature. Concept maps are used to organize and represent knowledge and in so doing, help the reader construct new meanings in the subject (Novak, 1991). It is hoped that the reader's understanding of the apparently straightforward concept of respite care will be enhanced (*Figure 1*).

The article will also discuss new approaches to our understanding of what respite care is, and what it means to palliative care service users and carers. It is worth noting at this point that it is becoming increasingly difficult to define exactly who the palliative care population is, as palliative care services move away from the provision of care that concentrated mainly on people with cancer to include people with other conditions (Payne et al, 2008). For the purposes of this article, literature relating to people with dementia has not been included but it is important to acknowledge that there is already a substantial body of knowledge about the problems associated with caring for a person with dementia (Clarke, 1999).

The definition and purpose of respite care

The term 'respite care' can refer to inpatient, day or home-based provision. Respite care has recently

been described as being considered to be ‘the cornerstone of care’ for many patient populations (McGrath et al, 2006). Respite care in palliative care is mentioned frequently in recent UK policy and guidance and is seen as a ‘key need’ for family carers of patients with palliative care needs (Barrett et al, 2009). However, there is currently no consensus definition of respite with clear criteria agreed for the purpose of respite services (Payne et al, 2004), with hospices themselves having no clear definition of respite care either (Satterley, 2007). A definition used by Payne et al (2004) in their survey of the perspectives of specialist palliative care providers of inpatient respite in the UK, is based on the assumption that respite is predominantly for the benefit of carers. But while the majority of respondents agreed with this definition, a large proportion disagreed, as they thought that respite should predominantly benefit the patient or mutually benefit the patient and carer. So although it is generally accepted that in respite care it is the carer who is intended to be the direct beneficiary (Ingleton et al, 2003) this is not made clear in the literature.

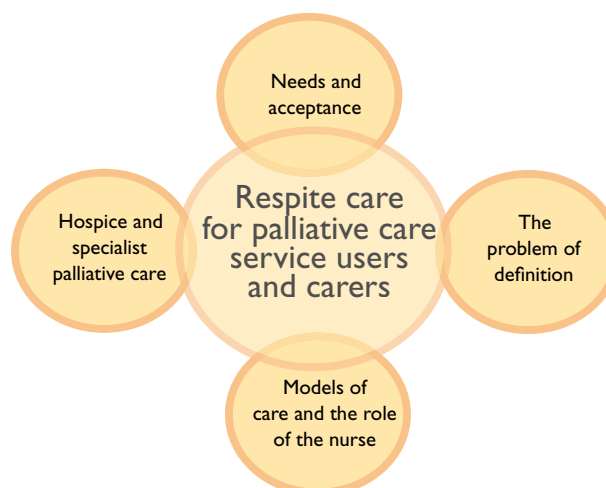
If the primary purpose of respite care is to benefit the carer, one might assume that patients would not necessarily require medical or nursing interventions during respite (Satterley, 2007) above what they would normally receive at home. However, a number of UK studies have shown that this is not the case, with the most commonly reported reason for respite care in hospices being the patient’s symptom management (Hicks and Corcoran, 1993; Owen and Johnson, 2005; Satterley, 2007). Added to this, the definitional blurring is further compounded by the idea that referral for respite care to specialist palliative care services (SPCS) often functions more to support members of the health-care team who may be struggling to manage a complex care situation, rather than assisting the informal carer with the provision of respite care (Ingleton et al, 2003). It appears, therefore, that there is ‘a basic problem of definition’ (Johnson, 2005) of respite care in palliative care both nationally and internationally. The EAPC (2009) have pointed out that a lack of common terminology in palliative care across Europe and the rest of the world has hampered the development of international standards. As such, the development of a consensus definition of respite and the agreement of a clear criteria for the purpose of respite services would be helpful (Payne et al, 2004).

Existing evidence base

A lack of research is referred to throughout the literature and studies, audits and systematic reviews specifically about respite care for patients with

cancer or palliative care needs are limited, (Hicks and Corcoran, 1993; Strang et al, 2002, Kristjanson et al, 2004; Payne et al, 2004; Owen and Johnson, 2005; Skilbeck et al, 2005; McGrath et al, 2006; van Excel, 2006; Satterley, 2007; Barrett et al, 2009). In a UK systematic review, which is often referred to in the palliative care literature as highlighting the evidence of the lack of research in this area, McNally et al (1999) identify 29 studies about respite care with different types of patients. Skilbeck et al (2005) stated that studies have tended to concentrate on patients with dementia, stroke, and those who are frail and elderly (McNally et al, 1999). This is not to say that they may not be relevant to issues around respite care for patients with palliative care needs—indeed, we would now probably say that these groups of patients would be redefined as having palliative care needs. The problem of definition in respite care also extends to the problem of definition in palliative care as the distinction between ‘acute’ and ‘chronic’ diseases continue to blur owing to changes in the diseases themselves, medical technology and treatment (Payne and Seymour, 2008). It is likely that these problems of definition make studying the effects of respite care problematic (Ingleton et al, 2003) which may well go at least some way to explaining why there is a lack of research on respite care in relation to palliative and end-of-life care. This may also indicate that the ‘umbrella’ term of respite care is no longer appropriate. The reality is that little is known about respite services for patients with life-limiting illnesses (Skilbeck et al, 2005) and so emerges one of the many tensions in this issue. Here is something, apparently so valued and so much needed. It is ‘mentioned repeatedly’ by carers in the consultations around the Strategy (DH, 2008a) and seen as the most commonly reported need for carers of

Figure 1. Conceptual map



• *The literature is starting to acknowledge that providing respite care is not as straightforward as it might initially seem* •

palliative care patients (Harding and Higginson, 2001) but with virtually no evidence in the literature to support its apparent value. Even now, as the body of evidence grows about carers' needs, there is still a lack of evidence about how best to address them (Grande et al, 2009).

The role of hospices and specialist palliative care services

Despite a lack of evidence promoting its worth and a lack of clarity about what it actually is, in the UK, respite care provision in specialist palliative care settings, namely hospices, is considerable (Payne et al, 2004) and apparently underpinned only by largely implicit assumptions of its value (Ingleton et al, 2003). Little is known about respite services in hospices (Payne et al, 2004) although respite care is said to be an important component of provision (Ingleton et al, 2003) through which patients have much to gain (Hicks and Corcoran, 1993). At the same time, there is evidence of an ambivalence toward providing respite care that seems to have its roots in the lack of consensus on the purpose of inpatient respite care. This ambivalence may well have led to a sizeable proportion of hospices and SPCSs no longer providing this service. The lack of an agreed definition and purpose of respite care runs through the hospice and SPCS literature. Hicks and Corcoran (1993), Owen and Johnson (2005) and Satterley (2007) all agree that respite care in hospices is rarely straightforward and 'significant interventions' (Owen and Johnson, 2005) are often required by patients. So on the one hand, the literature suggests that a number of hospices no longer provide respite services as they do not see it as their role. On the other hand, it would seem that respite care for palliative care patients is usually complex and specialist by nature (Owen and Johnson, 2005) suggesting that more general care, i.e. in a nursing home, would simply not be adequate. In terms of what this means to service users and carers, the literature suggests that a move toward less hospice care would not be welcomed. In the recent National Audit Office Report on patient and carer experiences of end-of-life care in England (2008), patients and carers specifically identified hospices as the preferred place for respite care. However, we know that even with hospice respite care, carers worry about whether the person they care for will be looked after properly (Skilbeck et al, 2005) making them ambivalent about using the service.

Needs and acceptance

As well as there being an apparently ambivalent attitude towards the provision of respite care, the

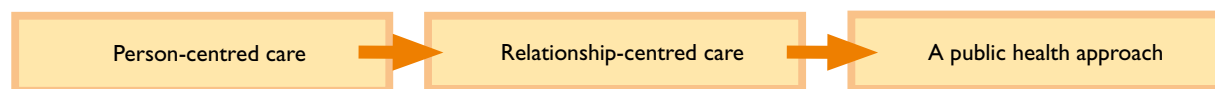
literature shows that despite the apparent need for it, carers of patients with palliative care needs are also ambivalent about receiving respite care. In two papers, Harding and Higginson (2001; 2003) describe how carers are highly ambivalent about their own needs. Time away from caring was the most commonly reported need in a study of 18 caregivers, but it was also the most difficult to meet owing to the carers' ambivalence about making the time (Harding and Higginson, 2001). In this context, respite care, although providing much needed time away from the caring role, may prove unacceptable to those carers unwilling to leave the person they are caring for (Harding and Higginson, 2003). They also say that respite care literature has 'rarely answered questions of acceptability' among this population. The discussion is set in the context of a systematic literature review about carer interventions in cancer and palliative care.

By acknowledging this ambivalence toward respite care the literature is starting to acknowledge that providing it is not as straightforward as it might initially seem (EAPC, 2009). This is evident in the fact that even when a service that is one of the most requested forms of support is available, uptake of respite care is low (Ingleton et al, 2003). The literature suggests some reasons why this might be the case, i.e. that the care offered is not of a suitable quality (Ingleton et al, 2003). However, it is also a clue to the uncovering of more complex issues concerned with the caring relationship and accepting support. The more recent literature talks about this complexity (EAPC, 2009; Kellahear, 2009) not only in terms of respite care but in the context of supportive interventions for carers and how it is likely to become more complex as people are likely to die in older age suffering from a number of co-morbidities along with sensory and cognitive impairments (EAPC, 2009). So, if interventions like respite care, in whatever form it comes, stand any chance of working in the way they are expected to work, there needs to be a better understanding of the complex issues surrounding the expression of need and the acceptance of help (Grande et al, 2009).

Models of care

There is increasing evidence that understanding the complex issues around needs and acceptance of support in family carers would be helped by services adopting an approach that acknowledged that caregiving can only be understood in the context of a relationship, which includes patient, carers and staff (Nolan et al, 2001). This approach is known as relationship-centred care (Nolan et al, 2001) and it marks a move away from the notion

Figure 2. Models of care



of person-centred care. It is promoted in the literature as a positive way forward in determining the needs of family carers and the person they are caring for (Payne, 2007; Kellahear, 2009; Payne and Hudson, 2009). Within the context of this literature, the lack of evidence supporting the efficacy of respite care is reinforced. The concept of respite care is framed within the deficit model of carer burden (Ingleton et al, 2003) in which the cared for person has to be taken away to give the carer a 'rest' (Payne, 2007). The view is that this approach, while helpful in some ways, does nothing to reinforce the expertise of the carer and ultimately the resilience of the family to cope with the demands of caring.

A natural progression from, and including, relationship-centred care is that we exist in our relationship with others and our surroundings (Clarke, 1999). A public health approach acknowledges the contribution of not only the cared for person, the carer and the staff but also the wider community (Figure 2). Kellahear (2009) describes models of palliative care from Australia to reinforce the important role the wider community can play in enhancing the capabilities of carers. This approach builds on the deficit model of respite care which is helpful to carers only because its set against a world where carers are subject to poor social support, discrimination and social isolation. In this world, respite care is a 'sticking plaster' or a 'repair' strategy (Grande et al, 2009), as opposed to a preventative strengthening strategy. In this world, strategies for strengthening families and communities are seen as ultimately more positive and more helpful than traditional respite care alone (Kellahear, 2009).

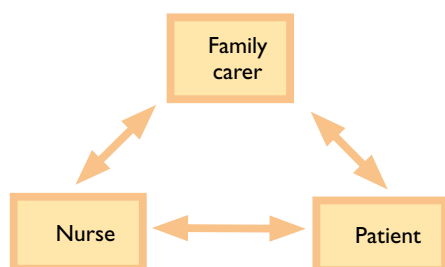


Figure 3. Adapted from the participant triad in the community nursing context (Carr, 2004)


The role of the nurse

Australian studies have shown that respite care provided in the home by nurses is highly valued (Kristjanson et al, 2004; Barrett et al, 2009). This emphasizes the importance to carers of a qualified nurse in providing skilled care for the patient. In a US study, Honea et al (2007) found that nurses are in a unique position to assess caregiver strain and burden and to provide appropriate interventions. In a UK study, Bliss (2006) suggests that district nurses have an important role in assisting with the carers' assessment process. We should be careful, however, of over simplifying the concept of care by solely focusing on one party's needs. This partial approach, which has been noted as being common in care policy (Forbat, 2008), runs the risk of contributing to the polarization of carer and cared for person, thus potentially denying the needs of the cared for person as well as the very complexity that the current literature is rightly starting to acknowledge. Nurses in the community have been used for some time to working in a collaborative way with patients and carers, even though there is limited guidance or literature on how to achieve this and deal with the clinical reasoning consequences (Carr, 2004). Carr describes the ethical dilemmas that community nurses have to grapple with when there is a conflict between the needs of the patient and those of the carer. A relevant example is given of a carer being keen to take up the offer of respite care when the patient was not. The nurse is trying to take both views into account but acknowledges that 'it's difficult to know whose view to support' (Carr, 2004). This example demonstrates the complex issues that lie beneath what appears to be a simple offer of support, and it emphasizes the role of the nurse as a clinician who is in an ideal position to acknowledge the needs of the carer and the cared for person, and somehow act as a broker between the two.

Conclusion

There is nothing straightforward about respite care for palliative care service users and carers. There is a problem with defining respite care. An umbrella term is no longer acceptable and there are too many variables now to take a one-size-fits-all approach. The definition of a palliative care patient is increasingly blurred. Diseases are less acute,

more chronic, and different diseases bring different trajectories and different problems. Added to this are the complexities of family relationships and the issues around needs and acceptance make the term 'respite care' on its own seem increasingly trite, inadequate and outdated in terms of addressing the needs of people with such complex needs.

Dynamic new approaches to supporting family carers suggest that strategies with a public health focus aimed at strengthening relationships and communities and promoting resilience will be more helpful to carers in the long run, making the most of their expertise rather than just temporarily relieving them of their duties. However, at the moment respite care remains the most commonly described carer need. In developing new approaches, we cannot ignore what service users and carers are saying is most important for them but we do need to know more about it. And maybe there is a need to look at how respite care services can be developed that are not just about repair but about promoting resilience too. Also, the skills needed to deliver relationship-centred care, which by definition, requires clinicians to take the needs of both the carer and cared for into account, should not be underestimated. This is not acknowledged in the literature but may well be a challenge which, within the context of a multidisciplinary team, the nurse is ideally placed to firmly grasp and take forward. 

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