

# Factors impacting on the effectiveness of palliative care



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Palliative care can vary significantly in its effectiveness according to condition, location, and type of patient (WHO, 2011; Gomes et al., 2013). This has long been recognised as an issue: Higginson et al. (2003) suggested that it has been difficult to prove the effectiveness of palliative care given the broad range of providers and the diverse nature of the clients. The World Health Organisation (WHO, 2011) has argued that palliative care has generally been unduly focused on the needs of cancer patients and is unsuited for the increase in older patients with diverse needs that are more common in many parts of the world. Part of this variation is the differences between the type of care required for various conditions and the fact that sometimes specialised care for a variety of conditions is required (Preston et al. 2014). There are also challenges posed to meeting patients' wishes for palliative care through patient-centred care, and Gomes et al. (2013) suggest that the desire of most patients to die at home can stretch resources or result in palliative care provision not reaching the wishes of their clients. Likewise, the extent to which palliative care can be effectively provided through interaction with other care providers, and the role of family or informal carers is often unclear (Hanson et al., 2012). This has led to a range of views on the effective provision of palliative care. In this essay, first the challenges posed by an aging population and the challenge of providing specialist care to specific population groups will be considered. Second, the challenge of providing home-based palliative care will be discussed. Third, the challenges of developing effective communication between caregivers and the family will be evaluated. Fourth, ways in which informal caregivers may be involved in palliative care will be discussed. Finally, the arguments for earlier intervention in some cases will be evaluated.

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The World Health Organisation argues that an important factor impacting upon the effectiveness of palliative care is the aging population in most countries that is coupled with a lack of attention to their complex needs (WHO, 2011). Older people more commonly experience multiple health problems, resulting in the need for such complex health needs to be more effectively supported (WHO, 2011). The model for palliative care traditionally focuses upon support for single diseases such as cancer, whereas people aged over 85 years are more likely to die from cardiovascular disease. There are also multiple debilitating diseases, such as dementia, osteoporosis and arthritis, and may require palliative care at any point in their illness trajectory (Gardiner et al., 2011). WHO (2011) indicate that palliative care does not usually form a part of traditional disease management, and with a combination of diseases the point at which palliative care is needed may become increasingly difficult to determine. The need for integration between different agencies is also cited as an important factor affecting older people (WHO, 2011). As such, palliative care for older adults must take into account the increasing variety of conditions that may develop, which is something that is not yet common amongst many care providers.

Solutions to these issues proposed by WHO (2011) include the need for palliative and primary care providers to receive more effective training in the needs of older people, and to gain a clearer understanding of the syndromes that affect this population group. This also includes a more effective understanding of the pharmacokinetics of opiates for pain management, and issues that are caused by comorbidity (Gardiner et al., 2011). Palliative physicians also need to improve their understanding of long-term care,

including the administrative and clinical issues that are associated with older people dying in care homes. Likewise, inter-agency collaboration in palliative care is required to ensure that diverse needs are met through carers with different specialisms (Neilson et al., 2013). This means that palliative care needs to adopt a more personalised approach that takes into account the specific needs of clients, making collaborative approaches more common (Vitillo & Puchalski, 2014). As such, partnership working is likely to play an increasingly prominent role in palliative care provision in the future.

Similar concerns involving the specialised care for specific groups is identified by Vollenbroich et al. (2012), who investigate the potential for providing home care for children. These results suggested that where a specialised paediatric care team was used, there were high improvements in the children's symptoms and quality of life. Additional benefits were seen as the reduction of the administrative barriers and improvement in aspects of communication between the care teams and the family. This supports arguments made by WHO (2011) which suggests greater specialisation is required to take into account the different diversities of patients who need palliative care. However, one aspect that is not identified by Vollenbroich et al. (2012) is the challenge posed by whether the condition should be considered as of greatest importance or whether the demographic considerations are needed (Gardiner et al., 2011). This suggests that perceptions of the age at death can significantly affect the patients' needs in palliative care, and further research may be required to investigate the extent to which such suppositions are borne out in practice.

The place in which palliative care is provided is also a significant factor when considering how far the care meets the wishes of the patients. The extent to which people can opt for their place of death is an important factor affecting the effectiveness of palliative care. In the European Union, most people do not die at home (WHO, 2011). However, this is the preferred place of death for most people. In England, 58% of deaths occur in NHS hospitals, 18% at home, 4% in hospices, and 3% in other places. There is clearly an interest amongst many patients for dying at home. Jordhøy et al. (2010) report on an intervention programme staged by the University Hospital of Trondheim, Norway, which was intended to enable patients to spend more time at home and for them to die there should they prefer. This demonstrates that in order to achieve this end, close cooperation was necessary with the community health-care providers, and a multidisciplinary consultant team was needed to coordinate the care provision. This research demonstrated that intervention patients spent a smaller proportion of the last month of life in nursing homes than was possible for the control sample (Jordhøy et al. 2010). This illustrated that to increase the proportion of patients who were able to die at home, a significant investment of resources would be needed. This manifested itself in the need for greater levels of training in palliative care for community care staff, thus increasing the costs associated with the provision of care (Jordhøy et al. 2010).

Similar considerations were made by Gomes et al. (2013), who argue that providing palliative care at home increases the chances of dying at home, while reducing symptom burden that people experience as a part of an advanced illness. This also reduces the intensity of grief for family members

if the patient dies (Gomes et al., 2013). However, Gomes et al. (2013) suggest that it is possible to provide home palliative care without significantly raising costs, but this is challenged by reports such as WHO (2011) who argue that for many patients, the complexity of the conditions experienced undermine the potential for home care to be effectively provided. Smith et al. (2014) suggest, however, that the context of increasing costs of healthcare means that the potential for palliative care to be provided in the home environment should be more closely investigated. In particular, this outlines that the quality of care can be significantly improved for home-based care, and in some cases the costs may be reduced by the fact that they may be spread between existing caregivers.

Communication between the patients and family members is often cited as an important factor leading to improved palliative care. Hannon et al. (2012) suggest that in contexts where family members are taken into account and given a role, family meetings can account for a significant improvement to the weekly workload for staff members. The study suggested that such meetings improved the particular areas of concern and worry for family members (Hannon et al., 2012). This demonstrates that such meetings can play an important role improving the experience of palliative care and indicate that one of the important roles of caregivers lies in the support that is given to the families of the patients as well as to the patients themselves (Hannon et al., 2014). However, although such meetings are considered appropriate and effective they may be undermined by the time constraints, the availability of appropriate staff, and the limitations of resources (Hannon et al., 2014). This may lead to less emphasis being placed on such aspects of

palliative care, particularly where the benefit is not directed wholly towards the patient. Nevertheless, against this criticism is the extent to which such issues may result in the needs of the patient being better identified by consultation with family members (Gomes et al., 2013). It can be argued that this would represent an area of particular benefit to the provision of palliative care.

Harding et al. (2011) point out that informal caregivers are of significance in providing effective palliative care. Given the diversity of the care provided by this group, there is a need for a range of intervention strategies to provide appropriate support, depending on the needs of the patient. However, Harding et al. (2011) suggest that the range of models that are available to meet caregivers' needs. Likewise, Harding et al. (2012) emphasise the significant costs to informal caregivers in terms of the emotional, physical and financial demands that informal caregiving places upon them. The conclusions of these studies indicate that support should be provided specifically to the caregiver and tailored closely to their needs, and the drawback of many existing approaches was the fact that interventions were not tailored to the caregivers' needs. This is an important aspect for improving palliative care, as many patients prefer the services of informal caregiving, and this can also reduce the burden on professional healthcare if appropriate (Aslakson et al., 2014). The potential for providing support that is tailored to the needs of the informal caregivers would seem an important and effective means by which the quality of palliative care can be improved (Brandstätter et al., 2014).

Zimmerman et al. (2014) identify that there are limitations to the provision of palliative care in home settings that depend upon the condition of the patient. In their study, patients with advanced cancer tend to have a much lower quality of life that worsens as their condition progresses. This suggests that for some patients, palliative care should be provided at an earlier stage than is usually the case. However, such developments would depend upon the prognosis, and in such cases it is important to avoid premature judgment. Yoong et al. (2013) also suggest that early palliative care can prove beneficial in situations where patients have advanced lung cancer. This suggests that the benefits allow the palliative care teams to focus on fostering relationships with patients and their families, and improving illness understanding amongst patients and caregivers. The potential for adopting a comprehensive approach in this case provided psychosocial benefits, such as improving the coping mechanisms for patients alongside the management of medical treatment (Bajwah et al., 2012). The research thus indicates that the involvement of palliative care teams at an earlier stage in the treatment may be appropriate for some conditions and may provide significant benefits to the quality and effectiveness of care.

In conclusion, many of the arguments discussed suggest that there is an important case to be made for a greater diversity in approaches to palliative care. The need to take into account the diversity in the psychosocial needs of different population groups illustrate the importance of a more personalised approach to palliative care. Likewise, the challenge in meeting patients' wishes to die at home requires significant attention as this can clearly provide significant benefits to patients. The research also indicates



that greater engagement with family members can help support patients and prove of wider benefit to the carers. This also indicates that the involvement of informal caregivers is also a significant area of development, given the wide-ranging role they can play in the provision of palliative care. The introduction of palliative care at an earlier stage may allow benefits to the care process, particularly where the patient is cared for at home, as it helps foster an effective working relationship between different parties. Thus far, the key deficiencies of palliative care are largely that it appears to be focused on particular conditions and specific locations; the challenge is to broaden the type of patient that can be cared for, provide greater support to informal carers and family members, and be more responsive to the wishes of the patient.

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