



Transfer and transitioning between palliative care settings

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Across the globe, most palliative patients prefer to remain at home for as long as possible, and also wish to die in their homes (1,2). A plethora of existing literature has highlighted the home as the preferred place of death for many at the end of life (3,4). A lot of attention has now shifted towards home-based, and community palliative care which has also been proven to be cost-effective more inclusive and easily accessible and adaptable to take account of geographical and cultural contexts (5,6). Policies and practices are evolving to support, in a practical way as possible, both such long home stays and home deaths (7), informed by the essential provision that the home is considered safe (8). Despite this preference, the patient's condition, caregiver situation, and other contextual issues may require transfer to other care settings such as a nursing home, hospital, or hospice (9).

Transitioning or transfer in palliative care refers to the movement of patients from one location or setting to another to ensure continuity of care. Transitioning may occur for a variety of reasons such as stepping down a patient with low acuity levels or stepping up a patient to receive critical/emergency care services. It is a phenomenon of change, and the patients involved in transitions are often highly vulnerable to health risks and poor outcomes. A transitioning process is often a complex event with multiple provider-identified opportunities to improve healthcare quality. Findings from a recent qualitative systematic

review offer a starting point as to the requirements to facilitate an effective transitioning/transfer process. The study highlighted a need to: (I) assess and prepare for the transition, (II) organise and facilitate the logistics of the transition, and (III) coordinate and collaborate transitional care across sectors (10). Crucial to the interdisciplinary and interprofessional roles that are needed for continuity of care between palliative care settings are effective relationships and efficient collaboration (10). There is a great need to understand the dynamics of care and professional/interprofessional roles in the transitioning process (11). Despite these considerations, transitioning or transferring between multiple care settings can be problematic with a critical need to understand the perspectives of the patients involved to smooth the process as much as possible to improve its outcome. This editorial gives (I) an overview of different forms of palliative care settings, (II) the cultural and contextual factors of palliative care settings globally, (III) the factors that influence the choice of a particular palliative care setting for people with life-limiting illnesses, and (IV) experiences across these settings.

Although a very common practice in, and an important area of, palliative care transitions between care settings have not been given adequate research attention. Even with the available published articles to date regarding palliative care transitioning experiences from acute care to community-

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based care (10,12), concerns such as heterogeneity of study designs and poor methodological quality have made it challenging to draw strong conclusions (13). Besides, most of the existing studies have been reported in high-income settings, a context which creates a critical gap regarding the limited studies in low-resource settings (10,13). Although patient-reported outcome measures (PROMs), and patient-reported experience measures (PREMs), which evaluate domains such as (I) patient safety during transitions, (II) continuity of care, (III) care coordination, and (IV) quality of transition have been developed and validated across varied settings, none has focused on palliative care patients (13). The lack of validated PROMs/PREMs makes measuring transition outcomes difficult in this particular population. In this editorial, we try to appeal persuasively and encourage stakeholders in the delivery of palliative care to act and improve the transition quality of patients between palliative care settings.

As one would expect, the transfer of care between palliative care settings is not seamless. The transition is not always unidirectional but could be bi- or even multi-directional. As a result, patients and families may struggle to get appropriate support and could fall through the cracks in the process. During transitions, patients may experience various challenges such as (I) disruptions in their plan of care, (II) poor communication, (III) feelings of uncertainty, and (IV) concerns regarding their safety. An individual with complex disease management needs may be particularly vulnerable to experiencing challenging transitions, especially at the end of their life. The transition process may lead to a situation where family caregivers take on burdens they may be unprepared for, become overwhelmed, and neglect their own needs leading to physical and emotional issues (10). These concerns warrant a well-coordinated and continuous system for the transition of patients and their families between palliative care settings. As a result, current research that explores patients' experiences of transfers between care settings in palliative care is not only appropriate but timely (8).

Moreover, care transition in palliative care can be burdensome; particularly the consistency in the care when patient transitions are involved, which has been an issue noted by others. Hence the need for an integrated network of competent providers (8). Now, there appears to be a global clarion call for the provision of palliative care as part of an integrated health care system. For example, the traditional 'emergency care model' has shifted to a model that supports the restructuring of emergency care to include a palliative care component, should the patient

need it (14). The period during, and the aftermath of, the COVID-19 global pandemic has also impacted the choice of palliative care settings. For example, vulnerable patients and families may be required to wear a face mask or be isolated to protect them from infection (15). Equally, health institutions need to plan for a surge in the number of palliative care patients beyond their capacity (16). The World Health Organization (WHO) has recommended that palliative care should be integrated into all settings of health care to enhance the provision of quality primary health care (PHC), and to realise the achievement of universal health coverage (UHC). Such integration could ensure consistency and accessibility of quality care to patients (17). The WHO further adds that to achieve such a milestone, the following six components are required:

- (I) Empowerment of local communities where care is palliatively delivered;
- (II) Palliative care health policies;
- (III) Robust palliative care research to inform practice;
- (IV) Education and training of palliative care personnel across all levels;
- (V) Availability and use of essential palliative care medicines;
- (VI) Integrating palliative care provision in health service systems.

Palliative care focuses on the active and holistic care of persons of all ages with serious health-related suffering and especially those at the end of life (18). Palliative care is complex, involves a multidisciplinary team, and sometimes care is delivered in different settings to ensure the continuity of that care. The critical role of palliative care in relieving health-related suffering warrants its application across varied settings including hospitals, nursing homes, outpatient settings, specialised clinics, hospices, residential care facilities, and the patient's home (19). Moving from one setting to another is a reality which creates a need to ensure continuity of care. What causes a patient with palliative care needs to require care in multiple healthcare settings varies according to a range of factors such as the patient's preference, prognosis, and resources needed for care. The considerations involved can be challenging for patients and family caregivers alike. For example, in resource-limited settings where there are no or inadequate institutional palliative care settings, home-based care provided by family members becomes an indispensable option (6). A patient's preference for a care setting may also play a role, as does that setting's affordability (7). Palliative care practitioners, persons with life-limiting illnesses and their caregivers are

often engaged in complex calculations to assess patients' and caregivers' wishes. They need to take into account: (I) the available options, (II) the caring burden's impact on caregivers, (III) the ability of caregivers to effectively manage difficult symptoms in the home setting and (IV) to maintain the dying person's comfort and dignity (20). The likely timeline for the terminal illness will also impact the choice of palliative care setting.

The availability of family caregivers to support the patient at the end of their life can facilitate care delivery in the home (21). Cultural factors may also emerge in the process. In one Australian study that included Aborigines from rural and remote settings, it was resonated that the patient's preference was to receive end-of-life care in the home, to be 'connected to land and family' (22). He argued that the choice of dying at home is based on the belief that it is important to pass on sacred knowledge to the appropriate family member, to ensure that the dying individual's 'animal spirit' can return to the land. In this specific cultural context, the 'right person' in the family network needed to be available to provide the care (22). Another study that focused on patients with cancer at the end of life in rural settings in mainland China also reported a strong preference for the delivery of end-of-life care in the home, where they could be close to other family members (23). Despite these considerations, disease trajectories and fluctuating illness levels among patients suffering from life-limiting illnesses can lead to a transfer from the home to the hospital or nursing home to treat the exacerbating symptoms (24).

Transitions in palliative care can further be fraught with operational and practical challenges, as well as differences in the treatment approach. Though transitions between acute and community care are common, transitions can be mired in difficulties relating to care coordination, communication, and liaising between these different settings. As highlighted by a recent study (8), another major challenge with transitions between palliative care settings is the lack of understanding of the different settings that work to ensure continuity of palliative care delivery. Healthcare providers also experience multiple complex roles during the transition facilitation process which can further impact that process (10). The perception of patients, family caregivers and health care professionals could either facilitate or hinder the transition between palliative care settings. These concerns will almost certainly have escalated during the COVID-19 pandemic, considering the increasing demand for palliative care services across settings. The consequences of such an increase can often be dire; including increased health service consumption,

increased health care spending, poor quality care, and threats to patient safety. Thus, now more than ever, there is a great need for more work to smooth the transition process to improve the quality of health care and its outcomes.

As an initial step to improving the situation, particularly for palliative care patients and persons at the end of life, there is a need for more stakeholder engagement and research across contexts and cultures to underpin the development of interventions that can facilitate smooth transitioning or transfers across care settings. These interventions may include transitional care support which continuously offers: (I) comprehensive care, (II) connects patients and their families to other health and social care services as required, and (III) equips healthcare staff with the required skills. The perspectives of palliative care patients who have experienced transfers between care settings remain central in the development and delivery of good quality consistent continuity of care. Existing studies have highlighted the critical roles of advanced practice nurses in helping to ease the transitioning of patients and their families. For instance, a study in Hong Kong, which focused on a nurse-led service for persons with chronic kidney disease, observed the programme helped improve symptom management, sleep, satisfaction, and overall health status (25). Similar results have been reported across other disease states, such as for patients with end-stage heart failure and coronary heart disease.

Further to the above, policies are required to promote the full integration of palliative care services into primary health care services (17) as well as in traditionally non-palliative care settings such as trauma/acute care (14). Integrating palliative care services is likely to improve continuity of care for, regardless of the healthcare setting a patient is in, he or she is likely to be connected to the required services. Also, there is a need for more training opportunities for healthcare staff to improve the integration of palliative care into traditionally non-palliative care settings.

In conclusion, transfers of seriously ill patients from one setting to another may become necessary, even at the end of life. However, the burdens of the transfer process and the transitioning across settings should be minimal for patients, their families, and healthcare providers. Poor transitioning leads to poorer outcomes for patients, which can escalate levels of health service utilisation. To attain smoother transitioning across settings to ensure the continuous provision of comprehensive care commensurate to emerging needs, there is a requirement for more stakeholder engagement to strengthen the evidence base,

develop policies, and work towards integrating palliative care into traditionally non-palliative care settings.

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