

Self-care or self-management in palliative survivorship care in Asia: A call for more research

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Abstract

A rising trend of survivorship and palliative care calls for innovative ways to manage the chronic phases of cancer condition. Self-management support is not a new concept but there are evidences of benefits in developed countries. However, the complementary relationship between self-management and palliative care to enable survivors to live with cancer as a prolonged chronic illness in Asia must be evaluated in terms of appropriateness and timeliness.

This paper highlight some of Asia's strong culture and some lessons learnt from a patient self-management intervention with women living with breast cancer trial conducted longitudinally over 6 years. Although many studies have provided evidence of better support among patients, caregivers and healthcare professionals when self-management interventions are integrated into palliative cancer care, across the care trajectory (from curative care, palliative care, end-of-life care and bereavement phases), tailored interventions are needed to assimilate the culture to improve health outcomes in Asia. A distinction is also made between self-care and self-management.

Summary: In resource limited countries, a call to better partnership with (and to support) cancer survivors and their caregivers, across the care trajectory is essential, but adaptations to the methods of deliveries are likely to ensure effectiveness of service. More research is needed in this emerging area so as to optimize care for the rising incidences.

Rising cancer and chronic disease management

The World Health Organization defines chronic diseases as having one or more of the following characteristics: are permanent, involves residual disability, caused by non-reversible pathological alteration, require special training/ rehabilitation, or require a long period of supervision, observation, or care [1]. Therefore, some cancer like breast and prostate are classified as a form of chronic illness, with challenges being faced over indefinite periods of living with the condition. The Long-Term Medical Conditions Alliance recognized the effect that long-term conditions have on people's emotional and social well-being, and the opportunities available to improve a person's quality of life [2,3]. The ultimate goal of intervention for cancer as a chronic and palliative condition, is the maintenance of pleasurable - independent living, not cure [4].

Self-care vs self-management concept

Chronic disease management aim to manage chronic conditions using a systematic care approach that employs multiple treatment modalities [5]. Self-management support is one of the key modalities proposed in the model for chronic condition management, which highlights the three elements of - i) the self-management support, ii) the informed-activated patient and iii) the prepared-proactive team -- interacting productively toward functional and clinical outcomes [6]. As a way to support to the health system which is not able to cope with the rising chronic conditions, 'Self-management support' (or the process of making multilevel changes in health care systems, and also in the community) arise - in order to facilitate patient self-management [7]. Unlike acute care, the management of a chronic disease is characterized by the responsibilities patients need to take [4,8].

However, Asian are more familiar with self-care concept. The terms (self-management and self-care concept) have been used interchangeably and confusingly, because the distinction between them is not clear. Both concepts refer to a range of methods and behaviour that enables people to manage their health and illness, leading to a range of positive outcomes [9]. self-care refers to actions and decisions taken independent of interaction with a health professional [10].

Self-management can be referring to, as a subcategory of self-care (Figure 1) and takes place in the context of a recognized medical condition with a level of health service input [9]. The essential feature here is that, both health professional and patients play collaborative roles as partners for better chronic care management in the three broad tasks of medical, emotional and role tasks, utilising five core skills of, problem solving and decision making, resource utilization, developing effective partnerships with healthcare providers and taking action [11,12]. The driver for self-management support resulted from the attempt to enhance the ability of patients to self-manage the day-to-day challenges of their condition successfully, by linking them to health professionals [13]. These concepts need more work and more research to evaluate how best it can be facilitated to enhance independent living.

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Key words: self-care, self-management, palliative, survivorship, Asia

Received: December 12, 2018; **Accepted:** December 26, 2018; **Published:** December 28, 2018

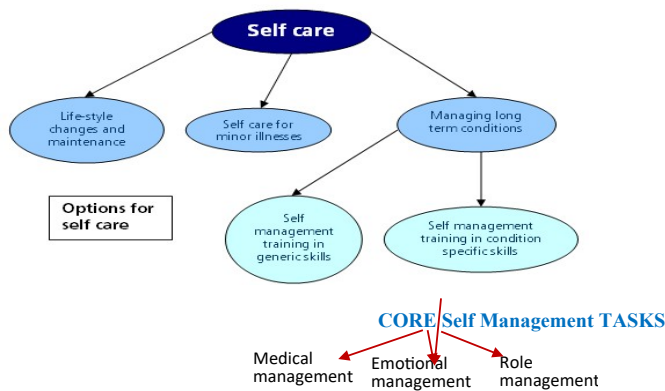


Figure 1. Self-management vs self-care

Cultural adaptations of self-management for Asia

Independent living in the community suggest several adaptations informed by cultural nuances, stance and beliefs. In a longitudinal trial, evidence of patient's self-management showed evidence of improved QOL although it must be highlighted that the trial was conducted in an urban metropolitan medical centre which may not represent the general multi-ethnic Malaysians with breast cancer [14,15]. This paper attempts to highlight at least seven cultural related issues that needs to be considered when incorporating patient self-management. Unique cultural nuances such as spiritual and language-specific support resource needs (Singh-carlson et al, 2013) must be considered in patient self-management.

First, when a person suffers from chronic illness, the person themselves is not the only one affected by the health condition, and this is especially significant in Asia's extended family system - where the whole family can become a 'unit of patient'.

Second, the self-management needs for persons with chronic conditions can be divided into three types: medical management, role management, and emotional management [16,17]. This needs to be slowly introduced to Asian patients, who have been 'nurtured' as passive recipient, to take orders from medical doctors seen by some as 'god'.

Third, the day-to-day care responsibilities by patients and their families are real challenges that need to be dealt with, whereby the resultant challenges/ threats from cancer (suggesting unmet needs with the current medical model) calls for better ways to manage and calls for collaborative partnership with health care providers [6]. Adaptation is also needed in Asia's entrenched medical model governance of health deliveries, where medical doctors leads and are only beginning to learn to collaborate interdisciplinarily with other health professionals [18,19].

Fourth, management of illness aspects is often insufficient in Asia's resource limited scenario where health budget and policies focus on medical doctor and less on healthcare professionals which have been long neglected [6].

Sixth, the emotional wellbeing aspects are needed as part and parcel of the work that people living with chronic palliative conditions, and which must be managed for better outcome and effective living with the condition (Loh psychological Japanese). Emotional distress as a core indicator of patient's wellbeing has been promoted as the sixth vital sign in cancer care [20]. Emotional distress varies in level of intensity, depending on severity of disease and phase of treatment [21]. Evidence suggest that women with (breast) cancer (n=723, 801)

compared to women in the general population were 37 percent more likely to commit suicide and the elevated risk of suicide persisted long after diagnosis [22].

Seven, throughout Asia, the number of health professionals is way below the norm. As an illustration for comparison, there are 26,000 occupational therapists in Australia's 25 million population but only a handful (less than 2000) occupational therapist in Malaysia's 33 million population [18]. The availability of psychologists is also lacking calling for a better model of group intervention to address the often neglected and unmet emotional-psychosocial issues, and community program with a focus on self-management on wellbeing, rather than focusing on intervening distress may well be the optimal way forward.

Eight, improvements in life expectancy of cancer survivors have also led to a greater emphasis on QOL [23]. QOL assessment can be used in diagnosis, predicting prognosis, assessment, patient monitoring, clinical decision making, communication and treatment [24].

Conclusion

There is much limited information about patient self-management with Malaysian women, and a critical lack of research and/or a lack of valid, reliable instruments to measure patient-reported outcomes [25]. This paper ends with a strong call for more research in highlighting the lack of health professionals and resources in Asia 's traditional health care deliveries which is incompatible with the rising burden of cancer.

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