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Supporting self-management in palliative care throughout the cancer care trajectory

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Abstract

Purpose of review—Despite increased survivorship and the subsequent need for chronic management of cancer, the association of self-management and palliative care is still emerging within cancer care. Routine and timely use of self-management strategies in the palliative setting can help reduce self-management burden and maximize quality of life. In this review, we consider the complementary relationship of self-management and palliative care and how they support living with cancer as a chronic illness.

Recent findings—Recent studies provide evidence of support among patients, family caregivers and healthcare professionals for integration of self-management interventions into palliative cancer care. As a guiding framework, components of the revised Self and Family Management Framework correspond to the provision of palliative care across the care trajectory, including the phases of curative care, palliative care, end-of-life care and bereavement. Additional work among self-management partners facing cancer and other life-limiting illnesses, that is patients, family caregivers and healthcare professionals, would be useful in developing interventions that incorporate self-management and palliative care to improve health outcomes.

Summary—There is an increasing acceptance of the complementarity of self-management and palliative care in cancer care. Their integration can support patients with cancer and their family caregivers across the care trajectory.

Keywords

cancer; chronic illness; framework; palliative; self-management

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Conflicts of interest

There are no conflicts of interest.

INTRODUCTION

Self-management refers to the activities in which a patient and their family caregivers collaborate to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences of the patient's illness [1]. Improved treatments have extended survivorship for cancer, making it a chronic illness requiring self-management at home. Consequently, self-management support is critical for patients and family caregivers [2■]. Routine use of self-management strategies and timely use of palliative care can reduce self-management burden and maximize quality of life, yet, the combination of self-management and palliative care is not widely recognized [3■]. We review evidence supporting the complementarity of self-management and palliative care, as well as the revised Self and Family Management Framework (SFMF). Although we use the term, 'self-management', we note that self-management is performed by patients and family caregivers and is more completely termed 'self- and family management'.

SHARED PRINCIPLES OF SELF-MANAGEMENT AND PALLIATIVE CARE

Several principles are central to self-management [4]. An overarching principle is *improving quality of life* through management of symptoms and physical and psychosocial consequences of chronic illness to improve wellbeing. Improved quality of life is related to patients *shifting from a perspective of illness to health* [5] by keeping the health perspective in the foreground of illness management. The health perspective is achieved through proactive self-management of physical and emotional aspects of illness and a focus on health promotion. In performing self-management, there is an *interconnectedness of patient and family roles* as illustrated in the SFMF: family can be a risk and protective factor (e.g. family structure) influencing patient self-management (e.g. decision-making) [6]. Patient and family education in self-management, knowledge of their individual and interactive roles and self-efficacy to perform roles are integral to self-management. *Patient-family caregiver-provider relationships* are likewise central, with finding the right provider and establishing good communication being facilitators of self-management [7■]. Among the many self-management activities, *identifying and setting goals* and *decision-making and problem-solving* are core self-management skills that underlie other self-management activities such as medication management and advance care planning. Self-management is also an *ongoing and dynamic process*, with overlap of skill development and performance of self-management skills [8].

These principles of self-management are also central to palliative care per the World Health Organization definition of palliative care, which includes *quality of life for patients and their families facing life-threatening illness, prevention and relief of suffering, affirmation of life, support for patients and their families, use of a team approach, and early and ongoing application over the course of illness* [9]. Palliative care advocates taking care of the person as well as the disease. This integrative approach is supported in cancer care [10,11,12■]. The goals and activities of self-management and palliative care are well aligned and reflect a conceptual connection with applications to cancer and other serious, chronic conditions.

STUDIES DEMONSTRATING INTEGRATION OF SELF-MANAGEMENT AND PALLIATIVE CARE

Several reviews support the effectiveness of self-management interventions in improving quality of life outcomes in cancer [13■–16■]. A PubMed literature search of articles from the past two years using the terms ‘self-management’, ‘palliative care’, ‘cancer’ and ‘support’ yielded quantitative [17■–20■] and qualitative [21■–25■] studies that validate the uptake of self-management in the palliative setting for adult patients with cancer (Table 1). Interventions target various aspects of self-management (e.g. self-efficacy, symptom management, health communication), using various delivery modes, including by nurses in person or by telephone, self-guided and eHealth, including web-based and mobile applications. The interventions we identified focus on self-management, are patient-centered, and incorporate essential elements of palliative care such as goal-setting and decision-making. In these select articles, improvement was demonstrated in self-management and health outcomes such as symptom management and burden, function, knowledge of care options, desired role in self-management and caregiver stress.

Three of the four intervention studies [17■,19■,20■] addressed cancer pain. Hochstenbach *et al.* [19■] demonstrated that patients’ pain could be monitored and feedback given with education and advice through a mobile device. Nurses supported patients remotely through a web application. Steel *et al.*’s [20■] intervention included a website incorporating written and visual self-management strategies to reduce pain, depression, fatigue and improve health-related quality of life. Patients randomized to the intervention group were seen by a care coordinator during physician visits, with telephonic follow-up every 2 weeks. These results show promise in helping patients and their family caregivers gain access to resources through the web.

Participants in the qualitative studies included patients, family caregivers and healthcare professionals. Participants reported challenges with the learning curve in self-management education, the definition of self-management roles, variation in self-management skill level, and perhaps most significantly, high physical and emotional distress. However, despite high burden, patients were willing to engage in self-management to learn about their cancer care, to have some control over symptoms and other aspects of their illness and to work collaboratively on self-management with family caregivers and healthcare professionals. Participants were receptive to different delivery modes of self-management support and were enthusiastic about eHealth options to enhance self-management and increase access to self-management support [21■,23■]. Additional work is needed to support family caregivers in their dual role of enabling cancer self-management and engaging in family management, particularly during end-of-life and bereavement phases. These recent studies, hailing from a range of countries, demonstrate increasing global recognition of the relevance of self-management and palliative care in cancer care.

INTEGRATION OF CANCER SELF-MANAGEMENT INTO PALLIATIVE CARE OR VICE VERSA?

A consideration in the relationship of self-management and palliative care is which comes first. Is self-management to be integrated into palliative care, or is palliative care to be integrated into self-management? The critical consideration is where the patient presents on the care trajectory. A healthy patient may be self-managing effectively and only later need to integrate palliative care into the self-management plan, while a patient receiving palliative care may need to integrate new self-management strategies into their care. Different self-management practices, facilitators and barriers may be salient during curative, palliative-focused, end-of-life and bereavement phases of care [26■,27■,28■]. Patients' and oncologists' perceptions of the content of goals of care conversations vary over time [29■]. More research is needed on how self-management may vary by phase of disease; however, as multiple studies support early palliative care in cancer for patients [30■] and family caregivers [31■,32■], it makes sense for self-management to also begin early and be tailored by phase of disease to ensure appropriate self-management over time.

THE SELF AND FAMILY MANAGEMENT FRAMEWORK AS AN ORGANIZING FRAMEWORK

The SFMF was created to guide research advancing self-management science [6]. The original version illustrated factors influencing self-management and potential outcomes. Individual and family self-management were depicted as interactive and as impacting health, patient, family and environmental outcomes. The SFMF was revised [33] (Fig. 1) based on emerging research on processes of and factors affecting self-management [7■,8]. The revised SFMF details self-management processes, proximal and distal outcomes, and facilitators and barriers that may influence self-management abilities and outcomes.

Components of the SFMF can be aligned with the provision of palliative care across the care trajectory (Fig. 2) [34]. The care trajectory spans overlapping phases of care, beginning with diagnosis and proceeding to the curative phase of care, a time of active, disease-directed treatment. The curative phase is concurrent with the palliative phase, during which efforts focus on disease control versus cure, on pain and symptom management, and on psychosocial and spiritual support. The curative and palliative phases have an inverse relationship, whereas the focus on curative efforts lessens, the focus on palliative care increases. The end-of-life phase is marked by comfort care only and is followed by the bereavement phase. In the following section, we review how components of the SFMF are expressed in each of these phases.

Facilitators and barriers

Facilitators and barriers to self-management include personal/lifestyle, health status, resources, environmental and healthcare system factors that are associated with self-management of chronic conditions [7■]. These factors play an integral role in determining how effective self-management is and what interventions are indicated. They are at the core of patient-centred palliative care. Throughout palliative care, from the curative phase to

hospice and end-of-life care, it is vital to examine facilitators and barriers in the initiation and maintenance of self-management. For instance, the sicker a patient gets (health status), the more self-management is required; yet, symptom severity can significantly affect the patient's ability to self-manage, thereby increasing family responsibility [35]. In addition, patients may not recognize or may deny the severity of their disease and symptoms, which is a barrier to effective self-management. Palliative care can facilitate prognostic awareness, allowing patients to self-manage in a way that improves quality of life and decision-making while reducing family caregiver stress and depression [35].

Financial resources can also affect this dynamic, for example in the ability to hire a home health aide. Access to care (e.g. insurance) can affect ability to self-manage. Palliative care can help patients to better access care that meets their needs, reducing financial strain and unmet care needs [36]. Personal beliefs and the lived environment may affect the willingness of the patient or family to accept help.

Processes

Processes of self-management include focusing on illness needs, activating resources and living with a chronic illness [8]. When focusing on illness needs, patients and family caregivers may be learning about the illness, taking ownership of health needs and performing health promotion activities to optimize health. Activating resources involves putting into place the healthcare, psychological, spiritual and social resources integral to optimal self-management. Living with a chronic illness involves processing emotions, adjusting, integrating the illness into daily life and meaning making. These processes vary in intensity and complexity depending on the illness trajectory and the role that patients and family caregivers can assume in managing the illness.

During the curative phase, self-management efforts for patients and family caregivers are directed towards addressing illness needs, preventing complications and maintaining health. As the patient shifts from the curative to the palliative phase, prioritization of self-management tasks and skills may shift, for example less emphasis on health promotion activities and more on symptom management. Thus, during the palliative phase, patients and families may need to activate different resources to meet changing needs.

During the end-of-life phase, self-management priorities will shift dramatically. Symptom management and comfort care become a priority. Various resources are necessary to meet the physical, emotional and spiritual needs of the patient and family. Meaning making may heighten as the end of life nears. Among adults with advanced cancer, the transition from curative to palliative care has been reported as difficult [37]. During treatment, patients strove for a sense of normalcy, engaging in self-management and maintaining hope. Patients at the end of life reported optimizing coping, acknowledging self-limitations and impending death, needing better symptom management and experiencing profound exhaustion and helplessness. During the bereavement phase, the family caregiver becomes the central care recipient. Skills and knowledge learned by family caregivers can also be used for themselves. Thus, different self-management interventions are needed across the care trajectory.

Proximal outcomes

Proximal outcomes are the concepts or variables that mediate change in the distal, or long-term, self-management outcomes. Proximal outcomes are indicators of how well a patient has navigated the processes of self-management. Several proximal outcomes are described in the SFMF, including behaviours, cognitions, biomarkers and symptom management. In the context of palliative care, proximal outcomes can look very different at different phases of care.

Examples of behaviours and cognitions to consider include engagement in life, health-directed behaviours [38■], skill and technique acquisition, health service navigation and social integration and support [39]. These outcomes can be evaluated at all phases of palliative care; however, the specifics of these behaviours and cognitions can vary across phases. For example, in early palliative care when the emphasis is on curing and/or controlling disease, behaviours and cognitions that demonstrate an understanding of the chronicity of the diagnosis and the expected disease trajectory are key proximal outcomes. When care shifts to being more palliative, behaviours and cognitions such as seeking out resources to maximize independence in the context of declining performance status [40■] should be considered. At the end of life, behaviours and cognitions of interest may shift to those of the family caregiver, such as their ability to activate social support.

There are likewise expected variations across the care trajectory regarding biomarkers and symptom management. Symptoms and symptom management are outcomes that can be improved when increased survival may not be a realistic outcome; however, symptom monitoring has been shown to impact survival in metastatic cancer [41■]. Symptoms can be measured across multiple dimensions, including prevalence, occurrence, severity, distress from individual symptoms or total symptom burden [42■], or symptom interference. These concepts are potentially useful proximal outcomes across all phases of care.

Distal outcomes

Distal outcomes include health status, individual and family outcomes, and healthcare outcomes, and represent ultimate self-management aims. Distal outcomes largely align with palliative care outcomes across the care trajectory. Outcomes related to health status include disease control, morbidity and mortality. Control of disease is a key outcome once cure is not an option and recedes in importance towards the end of life [43■]. Reducing morbidity is a desired outcome in terms of minimizing disease effects [44■,45■]. Palliative care may influence mortality to the extent that its early introduction into self-management can increase survival [30■].

Individual and family outcomes of quality of life, psychosocial status and family function remain imperative self-management outcomes across the care trajectory [46■,47■]. Perceptions of what constitutes quality of life may shift over time [48■]. For example, early in the palliative phase, maintaining employment may be an important quality of life indicator, while later being pain-free may be a patient priority, and lowered anxiety a family caregiver priority. Psychosocial status is relevant across the care trajectory as psychosocial needs, including emotional and social well being, are high, and how they are managed

affects other care and symptom outcomes. For example, among individuals with head and neck cancer, one study found that depression, resilience and social support affected communication [49■]. Family functioning is likewise a salient outcome across phases of care, extending into bereavement as the family must endure following patient death [50■■].

UTILITY OF THE SELF AND FAMILY MANAGEMENT FRAMEWORK TO SUPPORT CANCER SELF-MANAGEMENT

Self-management interventions that are grounded in the SFMF may impact clinical changes, particularly around emphasis on patient and family caregiver education, so they understand their respective roles in self-management and can actively self-monitor. Healthcare professionals may use components of the SFMF in different ways, for example for assessment purposes to identify facilitators and barriers to self-management, self-management processes that may benefit patients and family caregivers and self-management outcomes important to them. Such assessments can drive treatment goals, spur learning and skill development, and help determine activation of resources.

CONCLUSION

Self-management and palliative care are integral components of cancer care that together can support patients and family caregivers across the care trajectory. The SFMF may be used to guide related research and clinical practice. Continued focus on the integration of self-management and palliative care in cancer care would be useful in developing and implementing interventions that improve cancer outcomes.

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- 47■. Boland L, Bennett K, Connolly D. Self-management interventions for cancer survivors: a systematic review. *Support Care Cancer* 2018; 26:1585–1595. [PubMed: 29199362] A review of randomized controlled trials, systematic reviews and meta-analyses of self-management programme conducted with cancer survivors. This study illustrates the range of self-management outcomes over various time periods postdiagnosis.
- 48■. Tessier P, Blanchin M, Sébille V. Does the relationship between health-related quality of life and subjective well being change over time? An exploratory study among breast cancer patients. *Soc Sci Med* 2017; 174:96–103. [PubMed: 28013110] An example of how self-management needs may change over time, in this case, social aspects of health-related quality of life.
- 49■. Eadie T, Faust L, Bolt S, et al. Role of psychosocial factors on communicative participation among survivors of head and neck cancer. *Otolaryngol Head Neck Surg* 2018. [Epub ahead of print] A cross-sectional study of survivors of head and neck cancer that investigated the effects of the psychosocial factors of perceived social support, perceived depression and resilience on communicative participation, with the clinical recommendation to use these patient-reported outcomes to inform patient counselling and communication interventions.
- 50■. Hudson J, Reblin M, Clayton MF, et al. Addressing cancer patient and caregiver role transitions during home hospice nursing care. *Palliat Support Care* 2018; 15:1–8. This study discusses role changes among patients and family caregivers during advancing illness and the need to negotiate conflicts (patient independence and patient and caregiver emotions) due to these transitions to achieve higher quality patient care and improved caregiver adjustment. Authors suggest that nursing support in the form of problem-solving, mediating, leading discussions about conflicts, validating and reassuring can help facilitate these transitions, and that learning mediation skills should be part of nursing education.

KEY POINTS

- Despite their alignment, integration of self-management and palliative care has not been well recognized.
- Routine and timely use of self-management strategies in the palliative setting can help reduce self-management burden and maximize quality of life.
- Evidence to support the linkage of self-management and palliative care is growing and gaining global recognition.
- The Self and Family Management Framework may be used to guide research addressing self-management in the palliative setting.
- Additional work is needed to develop interventions that integrate self-management and palliative care to support patients with cancer and their family caregivers across the care trajectory.

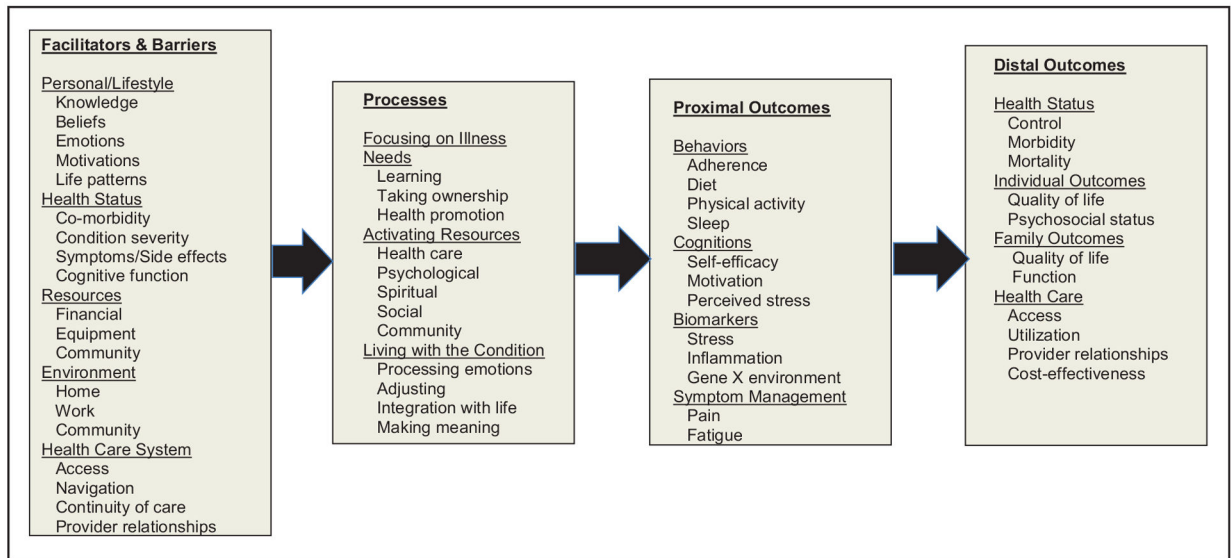


FIGURE 1. The revised Self and Family Management Framework. The revised Self- and Family Management Framework outlines facilitators and barriers to self-management, processes of self-management, proximal outcomes and distal outcomes and their relationships. Reproduced with permission from [33].

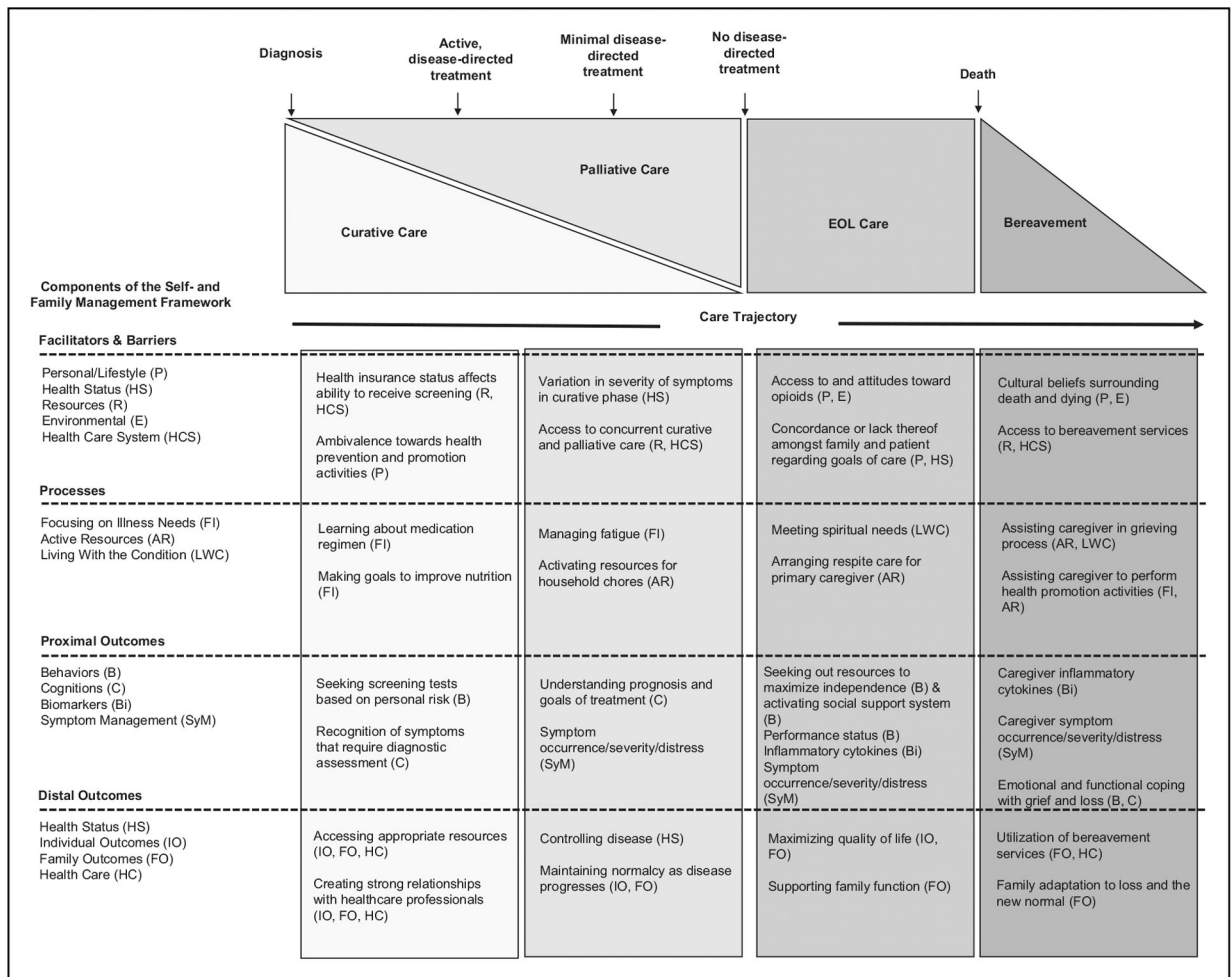


FIGURE 2. Self and family management across the care trajectory. This figure illustrates how components of the Self and Family Management Framework, including Facilitators and Barriers, Processes, Proximal Outcomes and Distal Outcomes can be aligned with provision of palliative care across the care trajectory. Examples of self-management activities by phase of care are provided. Adapted from [34].

Table 1. Studies demonstrating integration of cancer self-management in the palliative setting

Theme	Ref.	Year	Country	Key findings
Intervention studies	Koller <i>et al.</i> [17■]	2017	Germany	The Anti-Pain intervention, composed of information, skill building and nurse coaching and delivered in-hospital and by telephone, was effective in improving function and self-efficacy among adult oncology inpatients of a palliative care consultation service.
	Schulman-Green and Jeon [18■]	2017	United States	The Managing Cancer Care: A Personal Guide intervention, composed of self-guided modules on self-management and goal-setting, care options, communication with clinicians and family caregivers, transitions, self-efficacy and symptom management, produced significant improvements in knowledge of care options and desired role in self-management among women with nonmetastatic breast cancer.
Qualitative studies	Hochstenbach <i>et al.</i> [19■]	2016	The Netherlands	A mobile and web-based intervention co-used by outpatients with moderate to severe cancer pain and registered nurses was reported as highly learnable, usable and desirable by patients. Nurses reported some challenges but were enthusiastic about and supportive of patient self-management.
	Steel <i>et al.</i> [20■]	2016	United States	A web-based collaborative care intervention including a psychoeducational self-management website (symptom information/recording, journaling, chat room, audiovisual library, resource library) and a collaborative care coordinator skilled in cognitive behavioural therapy and psycho-oncology reduced depression, pain and fatigue and improved quality of life among patients, and reduced caregiver stress and depression.
	Cooley <i>et al.</i> [21■]	2017	United States	Although patients desire face-to-face communication with clinicians about their cancer care, nominated components for an eHealth system to support patient-clinician communication included ability to track symptoms over time, access to web-based information, decision-support on when to call clinicians, peer support and access to medical records. Caregiver support to process copious cancer care information is essential.
	Lie <i>et al.</i> [22■]	2017	Norway	A shared care model involving oncologists, general practitioners and patients may best address patient needs. Patient education about late effects of cancer and follow-up care would support patient self-management.
	Stev <i>et al.</i> [23■]	2017	The Netherlands	Nurses value self-management support for patients and family caregivers managing advanced cancer. Psychological support may be regarded as secondary to physical support but is an important aspect of palliative care. Collaborative goal-setting, follow up on self-management plans and support for informal caregivers require more attention. eHealth has advantages but was not felt to be a substitute for in-person care.
	Hughes <i>et al.</i> [24■]	2016	England	Specialist palliative care professionals support patient self-management of advanced cancer pain, believing that it is desirable for patients to have some control over their pain and that self-management of pain is achievable when patients take ownership and are motivated. Patients' self-management of pain could be problematic but improving patient knowledge and patient-clinician collaboration supports patient self-management.
	Stacey <i>et al.</i> [25■]	2016	Canada	In tracking uptake of the pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) protocols for nurse-delivered, telephone-based support of patient self-management of symptoms, nurses, patients and family members reported that protocol use could improve consistencies across clinical settings in guiding patient self-management.