

Management of cancer and health after the clinic visit: A call to action for self-management in cancer care

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Abstract

Individuals with cancer and their families assume responsibility for management of cancer as an acute and chronic disease. Yet, cancer lags other chronic diseases in its provision of proactive self-management support (SMS) in routine ‘everyday’ care leaving this population vulnerable to worse health status, long-term disability and poorer survival. Enabling cancer patients to manage the medical, emotional consequences, and lifestyle/work changes due to cancer and treatment is essential to optimizing health and recovery across the continuum of cancer. In this paper, the Global Partners on Self-Management in Cancer (GPS) puts forth six priority areas for action. Action 1: Prepare patients/survivors for active involvement in care. Action 2: Shift the care culture to support patients as partners in co-creating health and embed self-management support in everyday health care provider practices and in care pathways. Action 3: Prepare the workforce in the knowledge and skills necessary to enable patients in effective self-management and reach consensus on core curricula. Action 4: Establish and reach consensus on a patient reported outcome system for measuring the effects of self-management support and performance accountability. Action 5: Advance the evidence and stimulate research on self-management and self-management support in cancer populations. Action 6: Expand reach and access to self-management support programs across care sectors and tailored to diversity of need, and stimulation of research to advance knowledge. It’s time for a revolution to better integrate self-management support as part of high quality, person-centered support and precision medicine in cancer care to optimize health outcomes, accelerate recovery and possibly improve survival.

The last decade has seen unprecedented advances in cancer treatment, improved survival rates and recognition of cancer as a chronic disease, alongside shifts to ambulatory and home care, shorter hospital stays, and same-day surgery.^{1,2} Individuals now experience the ‘life-altering’ nature of cancer and treatment outside the clinic, where the onus is on them to recognise, report and manage their disease and health recovery. Cancer patients and survivors (includes family/social network) are expected to manage acute treatment effects, adopt healthy lifestyles to reduce late effect risks, manage comorbid conditions and polypharmacy, and cope with the psychosocial ramifications alongside other everyday responsibilities. Expectations to self-manage these sequela of cancer, recover or optimize health, and navigate care is not just for highly motivated and self-directed patients; it is becoming necessary and expected of all patients. Patients leaving the cancer clinic assume responsibility for managing the effects of cancer and treatment, and deciding when and how to seek help whether capable and prepared or not. How successful patients are as self-managers depends on access to adequate self-management support and resources that may alter their clinical course of disease and quality of living.

Cancer care has evolved from an acute care model, whereby health care professionals (HCP) assume responsibility for managing disease and advising and directing patients. Less attention has been focused on helping patients become effective self-managers of cancer as a chronic illness. Cancer care lags other chronic conditions in incorporating principles of disease self-management into routine care, despite cancer presenting greater disease complexity, treatment and late effect risks, longer-term disability than many other chronic conditions.³ This leaves cancer populations vulnerable to further deterioration in health status, worse health recovery, and likely poorer survival. As the cancer community aspires to greater personalisation of cancer care, it is time to shift the care paradigm to ensure patients are supported to be active partners in cancer care, empowered and enabled to manage their disease and health – the role that they hold responsibility for twenty-four hours a day, every day. This requires major cultural shifts for both patients and HCP to motivate active involvement as partners in care and reorganization of care practices to systematize the integration of self-management support into ‘everyday care’ at all phases in the cancer continuum extending into the community and other care sectors. In this paper, we propose six key actions to “move the needle” towards better support of patient self-management, optimize health outcomes, accelerate recovery and perhaps mitigate long term disability across the cancer trajectory.

DEFINING SELF-MANAGEMENT AND SELF-MANAGEMENT SUPPORT

Self-management (SM) is “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”.⁴ This includes the ability to monitor one’s condition and utilize the cognitive, behavioral and emotional

responses necessary to maintain a satisfactory quality of life (QoL).⁴ For cancer patients, effective SM may include appropriate self-monitoring, recognition, reporting and management of symptoms, treatment side-effects and recurrent disease. This includes effectively managing biopsychosocial sequela and comorbid conditions to improve functioning in daily life, adhering to polypharmacy, successfully navigating transitions and coordinating care across disease phases and care sectors, and applying healthy lifestyle behaviors to reduce late effect risks.⁵ For those with incurable disease, SM necessarily requires they manage advanced, progressive disease as a chronic illness given generally increasing life expectancies,⁶ alongside early palliative care to facilitate SM of multi-symptoms, emotional distress, and adjustment to declining function and loss of autonomy.⁷

We emphasize that SM is not just participation in programs, i.e. self-help or peer support, but requires a willing and able patient supported to assume responsibility.⁸ SM tasks may also need to be delegated to or shared with family members or caregivers as social networks are instrumental in supporting patient SM efforts.⁹ While most patients undertake some degree of SM, whether effective or not,¹⁰ factors including socioeconomic, poor mental health, cognitive impairment, age, infirmity or other situational factors can impair engagement in SM.¹¹ Thus, SM in cancer care requires understanding of the patients' capacity and capability for SM, their role and motivation as partners in health care, written information that addresses health literacy (and e-health literacy)¹² and access to self-management support (SMS).¹³

SMS includes interventions or programs in the care pathway that enhance the patients' core skills, i.e. goal-setting and action planning, and building of self-efficacy for disease management through regular assessment of progress and problem solving support (Fig. 1).¹³⁻¹⁵ SMS emphasizes patient SM of four dimensions of health: managing medical aspects such as medication protocols and symptoms; coping with emotional consequences (anger, depression, acceptance, anxiety, fear of recurrence); and adapting/adjusting life roles and relationships including work/employment to accommodate illness, and lifestyle behaviours like physical activity, to facilitate health.^{5,16}

SMS approaches and techniques may include information provision, patient held records and online courses, and more active support, such as motivational interviewing or coaching for behaviour change, which works best to improve outcomes.¹⁷ Patients with cancer require SMS for developing and utilizing skills for problem solving, action planning, self-tailoring for adapting and adjusting behaviours to ones' own life situation and to manage dynamic fluctuations in illness and functioning in daily life, decision-making, utilizing resources and effectively collaborate with HCP. This approach, often utilising

cognitive-behavioural and other self-modification skills explicitly acknowledges and emphasizes that achieving better health outcomes requires a collaborative relationship between patient and provider.¹⁸

SMS has long been recognized as an essential practice in chronic disease management for non-malignant conditions such as diabetes, arthritis, cardiopulmonary, and cardiovascular disease¹⁹ with established evidence for efficacy and cost effectiveness across a range of settings and populations. SMS in other chronic disease is associated with better disease control, QoL, daily functioning, and fewer emergency department visits and acute admission episodes.²⁰⁻²² Globally, patient engagement in SM is considered essential to achieving the ‘Triple Aim’ healthcare reform goals of better health outcomes, improved patient experience, lower health care costs;²³ and as core to quality cancer care worldwide.²⁴

While the evidence regarding the efficacy of SMS interventions in cancer is more limited and fragmented in comparison to other chronic diseases, SMS is associated with reductions in symptom severity for specific problems such as fatigue, pain, anxiety, and other treatment side-effects, psychological distress and improvements in self-efficacy and QoL.²⁵⁻²⁷ Healthy lifestyle behavior interventions and rehabilitation programs targeting cancer survivors that integrate SMS as a core component have also shown positive effects on function, weight loss, and fitness parameters.^{28,29} Lastly, digital technology for remote monitoring of symptoms or physiologic data, i.e. physical activity, accompanied by SM advice and/or coaching have been shown to improve symptom management, reduce hospitalizations and emergency department visits,³⁰ and may provide a survival advantage when clinicians intervene in ‘real-time’.³¹

Cancer provides an exceptionally compelling case for SMS programs not just because of highly prevalent acute and long term biopsychosocial symptoms and late effects, but also because cancer frequently co-occurs with co-morbidities or increases risks of new chronic conditions (including additional cancers) further complicating and burdening patient/caregiver disease management and the cancer care system.³² Moreover, the dynamic nature and complexity of managing cancer can deplete the self-management, self-regulatory and often financial capacities of affected families.³³ Unsurprisingly, cancer survivors report heightened vulnerability and lack of confidence for initiating the SM behaviors necessary to recover health after treatment.³⁴ SM is particularly challenging in the setting of multiple comorbidities common in older adults³⁵ and in the context of late treatment effects. Similarly, patients living with advanced or relapsing disease may struggle with SM, declining function, and the emotional and psychosocial adjustments necessary to adapt to living, sometimes for years, with an incurable, life-limiting disease.⁷ Early palliative care programs that have integrated coaching in SM have shown positive

benefits on symptom severity and QoL,³⁶ but SMS as a core component of palliative care needs development.⁷

As the evidence of benefits of SM and SMS in cancer care is mounting, it is time to consider how to translate this evidence into clinical cancer care and stimulate further research. To address this knowledge gap, we recommend urgent action on a global scale in the six key areas below. Actions are briefly summarized in Supplementary Table 1.

Action 1. Prepare patients/survivors/caregivers for active involvement in care

A concerted effort to cultivate a culture that genuinely supports and empowers active involvement of patients/survivors/caregivers in SM of disease and health in collaborative partnerships with HCPs will be necessary to embed and sustain SMS in cancer care.^{37,38} Traditional, paternalistic models of care, whereby the ‘expert’ holds responsibility for treatment plans and emphasize patient compliance are pervasive in health care and attempts to embed SM in this context through increasing awareness have largely been unsuccessful.³⁹ Clinicians are reluctant to relinquish control and hold beliefs that few individuals are capable of SM, while both patients and HCPs poorly understand their roles as partners in achieving health.⁴⁰⁻⁴² Studies of promising practices show that multilevel changes are necessary to create “engagement capable” environments including: governance and leadership structures that foster active involvement of influential patients in care redesign; training and practice coaching of providers in participatory, collaborative communication styles and shared decision-making that provides clear guidance and support to patients in SM and health actions they can take to improve health (e.g. patient action pathways combined with treatment pathways); and patients may require psychological (willingness) preparation and appropriate SMS to assume an active role in care.⁴³ Facilitating health behavior change is no doubt challenging and SMS will need to be combined with other strategies. Health insurance plans that reward patients for gains in health behaviors and billing codes for assessment and counseling in disease SM for physicians/nurses may incentivize change.^{44,45} A wider educational effort and “whole system” change in cancer care is required.⁴⁶

Action 2. Embed SMS into ‘everyday’ practice and care pathways

Engagement of patients in SM at the earliest possible moment in their diagnosis, should be the start of a collaborative, empowering relationship between patients and their health-care providers. This will require developing a shared patient and HCP agenda for SM, but also guidance to patients in applying disease, symptom/treatment-specific SM strategies and health behaviors to address acute and chronic problems (e.g. neuropathy pain, fatigue).⁴⁷ Particular problems that may lead to unnecessary consultation dependency, specifically fear of recurrence, require early and targeted interventions and adequate

preparation of patients in self-monitoring to recognize signs/symptoms of disease recurrence to reduce distress.⁴⁸ Crucially, communication approaches must be assessment-oriented, person-centered and participatory to foster patient willingness and engagement in SM; and integration of personal SM goals and action planning into treatment plans.⁴⁹ However, person-centered SMS and care planning is not a “one-off” event but rather requires rethinking of care delivery including work flows and scheduling systems to accommodate regular review of SM at follow-up and at key points along the cancer continuum and when treatment goals change.⁵⁰

Every encounter across the cancer continuum should be considered a “teachable moment” and incorporate a structured assessment approach to enable tailoring of SMS to individual needs and SM capacity and population diversity. Given the rapid, episodic nature of cancer care and constrained resources, implementing SMS will likely require a stepped assessment and care approach⁵¹ similar to frameworks for low, medium and high touch interventions as articulated in the Supportive Care Framework⁵² and similar to guidance for management of emotional distress⁵³ and other chronic conditions.⁵⁴ As shown in Figure 2, all patients should receive SMS as part of routine care with intensification of support for those with higher needs as shown in the corresponding Table. Risk stratification is also important, as some patients will require close supervision (i.e. during immunotherapy or advanced disease) combined with intensive SM support, whereas those with more stable disease (early stage breast cancer), less complex needs, or low risk for recurrence/progression, can be referred to community-based programs for SMS.⁵⁵

Transform from Reactive to Proactive Care that Activates Patients/Survivors in SM

Embedding SMS into routine care requires “whole” system change (Fig. 3) inclusive of preparing the workforce, developing and disseminating SM programs, creating supportive systems and processes to embed SM in routine care and changes across multiple levels of the organization and care sectors.⁴⁶ The international chronic condition self-management support framework could be instructive for developing strategic directions for cancer care.⁵⁶ Strategies to address the multiple implementation barriers to SMS integration in care will be crucial.⁵⁷ Transformation in models of care delivery from the current reactive acute care focus to proactive care of cancer as a chronic disease that is underpinned by principles of health promotion and secondary prevention will be fundamental for effective delivery of SMS.⁵⁸

This transformation will require changes in healthcare provider practices (micro-system capacity), but also at the organizational level i.e. policy (macro-system), and in care protocols, pathways, and standards for cancer care delivery (meso-level). Reimbursement/incentives to participate in SMS, inclusion in oncology bundled payments and the time required in the clinical encounter to facilitate

behavior change require further examination as essential organizational and health policy levers. In Canada, assessment/management of patients with chronic diseases such as heart failure and diabetes are billable services.⁴⁴ Staffing resource constraints will need to be addressed and Advanced Practice Nurse (APN) and Nurse Navigator roles enhanced for delivering SMS with appropriate training in coaching health behavior change.⁵⁹ In these roles (APNs) could act as facilitators of practice change supporting staff nurses in key SMS functions (e.g. agenda setting, goal setting and action planning, teach back, closing the loop) to ensure continuity in routine care.

Cancer care providers could promote this transformational process by assessing current organizational delivery of SMS using tools such as the Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management (PCRS) tool⁶⁰ and the Clinician Support for Patient Activation Measure (CS-PAM).⁶¹ Patients could also be surveyed to ascertain their perception of the quality of SMS currently delivered using tools such as the Partners in Health Scale⁶² or the Patient Assessment of Chronic Illness Care (PACIC).⁶³ Additionally, the use of best practices in knowledge translation, implementation science and quality improvement methods is fundamental to shifting entrenched care cultures and processes, and clinician attitudes towards embedding of SMS in routine care delivery. To date, little evidence has been generated about what implementation strategies are required for successful embedding of SMS in ‘real-world’ cancer settings to guide healthcare administrators and inform wide-scale spread.⁶⁴ The principles and techniques for experience based design⁶⁵ could be a key approach to capitalize on the collective experiences of clinical teams and patients as to how to achieve this change and following recommendations for global change in chronic condition SMS.⁶⁶

Action 3. Train health care providers with knowledge and skills for providing SMS

SMS requires prepared, proactive clinical teams that understand the rationale for SMS and hold positive beliefs about the individual’s ability to SM; and the knowledge and skills to deliver such support. While there are several practical techniques that can be used to counsel patients in SM, such as the 5 As (Assess, Advise, Agree, Assist, Arrange)⁶⁷ or other approaches such as motivational interviewing,⁶⁸ health care providers will need to be trained and assisted in embedding these in routine practice, particularly given the rapid episodic nature of cancer care delivery. The training must go beyond just skill acquisition and include clear clinical pathways that clarify clinical team responsibilities and how the clinical team will realign care and team collaboration to collectively provide SMS patient and scheduled follow-up visits to assess progress in SM. Training programs that emphasize the theoretical underpinnings of health behavior change and skills for effective coaching of patients to facilitate uptake and sustained use of SM behaviors will be critical, but also how these can be adapted for application in routine care practices.⁶⁹

A robust induction process, including the whole team, and targeted training of nurses in SMS and incorporated in new staff orientation and as part of mandatory and ongoing professional development pathways is needed. However, the cancer community needs to reach global consensus on the requisite core curriculum for preparing HCPs in the knowledge and skills for effective SMS delivery and for incorporation in undergraduate or graduate programs. Core international knowledge and competencies already developed could be adapted for training of cancer clinicians.^{70,71}

Action 4. Foster accountability for SMS as a performance metric in value-based care

The organizational changes required to adopt SM into cancer care require performance accountability using standardized, agreed process and outcome measures and data definitions, assessed in ongoing program evaluations. Patient SM and SMS engagement provide useful performance metrics in value-based care, which is also dependent on provider behavior changes as much as patient behavior changes to improve health outcomes.^{72,73} SMS could be leveraged as a key strategy for facilitating health behavior change as part of value-based care, included in accreditation standards, and assessed in patient experience measures for quality-based payment for performance. However, SMS outcomes and indicators are noticeably absent from many prominent PRO information systems⁷⁴ and patient experience measures.⁷⁵

Performance accountability can be facilitated through Patient Reported Outcome measures (PROMs) that capture the health status of cancer patients and survivors and their progress in SM across the cancer continuum. PROMs that assess patient's knowledge and self-efficacy in SM such as the Patient Activation Measure (PAM)⁷⁶ or PROMIS Self-Efficacy measures⁷⁷ are useful for tailoring or triggering intensification of SMS in routine care and could be important additions to information systems for measuring the quality and outcomes of SMS. Harmonization of health outcomes and agreement on minimum data sets for cancer-specific SM behaviours and for healthy lifestyle behaviours (smoking cessation, diet, activity) allows for population comparisons across different settings.⁷⁸ These comparisons would stimulate further research and inform global surveillance on penetrance of SMS in cancer care. Additionally, agreed outcome measures for SM behaviours that are universal across cancers and could be augmented with disease or problem-specific behaviour modules are needed.⁷⁹ PROMs for SM will need to be relevant to phase in the cancer continuum, i.e. adverse events versus long-term problems; and included in learning healthcare systems to inform future risks and care needs.

Action 5. Advance evidence on the effectiveness of SM and SMS in cancer populations

While the principles of SM and SMS are well established and warrant embedding into routine care today, there is a need for high quality efficacy trials testing and for priority-driven research into how best to

optimize SMS in specific populations and according to level of need and in real-world cancer care.⁸⁰ Consideration will need to be given to cancer or treatment type, multi-morbidity, disease stage, healthcare system resources, and to a range of personal characteristics (gender, age, socioeconomic determinants, geography, or other life/environmental circumstances, diversity)^{81,82} and framed from an equity lens.⁸³ Key priority areas of focus are highlighted below.

First, consensus on the core components and skills defining cancer SMS approaches is crucial. Uncertainty remains about whether SMS approaches and core skills effective in other chronic diseases are equally applicable to cancer, given the “one-size” approach of CDSM has been criticized for complex illnesses.⁸⁴ While systematic reviews and meta-analysis have shown evidence of effect of SMS interventions for adult survivors,^{25,26,85} scoping reviews have identified wide-variation in the core components and SM skills emphasized in SMS interventions and poor use of theory in program design, making it difficult to compare efficacy across studies.^{86,87} There is also a need to design and test SMS programs targeting specific problems, given a lack of effect in SMS programs focused on general behaviors when a problem-specific focus is required, i.e. SM for managing depression.⁸⁸

Second, development and consensus of outcome measurement framework(s) or minimum data sets for evaluating SMS programs/interventions’ health outcomes and health behavior impacts. Globally, SM behavior measures for cancer, harmonized collection of PROs that capture patient SM capability, and healthy lifestyle behavior criteria are needed to inform clinical care and enable surveillance. Ruiz and colleagues developed a pyramid approach comprised of five levels (individual, health systems, community, policy, and media) for setting up a national surveillance system on SM and SMS for chronic conditions that could be adapted for cancer.⁸⁹

Third, how best to provide SMS in the context of diverse social, cultural and geographic needs is an understudied area. As most SMS programs originated in high and upper middle-income countries, there is limited evidence on how to translate them into low income settings with fragmented healthcare systems, even though these may be precisely the settings where SM may be needed most to address existing gaps in the provision of care. Research that addresses the cross-cultural, economic, and social determinant aspects of SMS is urgently needed.⁹⁰ Specific interventions, programs, and care pathways culturally-tailored and appropriate for vulnerable, isolated and disadvantaged populations will need development and includes appropriate delivery mechanisms (face-to-face, group, eHealth).

Finally, there is a need to synthesize evidence on SMS in cancer using high quality systematic reviews, meta-analyses, and realist reviews to direct research towards identified gaps in knowledge. Economic evaluations of SM and SMS in cancer populations and implementation studies of SMS are needed to inform the wide-scale changes we recommend. Service evaluations to understand the effectiveness of health service innovations and implementation of SMS in ‘real world’ cancer settings are limited and largely drawn from other chronic diseases.

Action 6. Expand reach and access to SMS programs across care sectors

Cancer SMS programs must be sufficiently flexible to meet diverse goals, needs, preferences and capabilities given varied sociocultural contexts and illness trajectories from disease manifestation to end-of-life (e.g. multi-symptomatic lung cancer vs prostate cancer patients on hormone treatment). SMS for long term survivors is a stand-alone priority area for action, offering the opportunity to integrate cancer SM with other health conditions to build wellness over time, though the prominence of cancer SM may wane in relation to other health priorities. SMS has been identified as a key element of personalized survivorship care that accommodates the evolving changes in need across the cancer continuum and the risk and challenges of late effects.⁵⁶ Developing appropriate SM interventions to assist survivors in managing health is also an unprecedented opportunity for improvement in care and reduction in health care costs for the growing subset of survivors living with the effects of cancer as a chronic illness. SMS programs are increasingly adopted in some countries within a public health approach. For example, in Canada, SMS programs based on the Stanford program have been financially supported for wide-scale implementation.⁹⁰ However, patients with cancer or survivors are seldom aware of these programs or feel well enough to attend during the acute phase of cancer treatment. Programs such as The Cancer Thriving and Surviving Program⁹¹ and other SMS programs tailored to cancer populations could be targeted for wider-scale spread globally. Online programs such as the American Cancer Society’s Springboard Beyond Cancer (<https://survivorship.cancer.gov>) could also be beneficial in building SM skills.

Risk-based models of follow-up care that integrate SMS programs and enhance system sustainability are another important area for action and research.⁹² Stepped approaches to follow-up care in England that integrate SMS as the initial step for low-risk populations met patients’ needs while enhancing care efficiency and cost savings. SMS is delivered systematically in workshops for low-risk populations with options for rapid re-entry for additional support by clinical nurse specialists or oncology care.⁹³ These approaches will require better integration of SMS within primary care and community-based programs and for co-management of other chronic conditions.

Finally, it is not just about access to SMS programs at point of need, but across the board changes in the culture of cancer care that is required, including preparing patients/caregivers for active involvement in care, change in HCPs communication and SMS skills and organizational transformation.

CONCLUDING REMARKS

Cancer self-management, a priority for cancer care, is a powerful lever for achieving personalized, high quality care. We have highlighted six key actions for SMS integration to improve health outcomes. Cancer patients/survivors are an underutilized resource essential for sustaining economic viability of the cancer system.⁹⁴ In his 2014 American Society of Clinical Oncology presidential address, Richard Schliskey remarked: “patient engagement in health is the 4th revolution in personalized cancer medicine alongside genomics and big data analytics” (<https://www.medscape.com>). Enabling patients in effective cancer SM is key to this revolution!

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Figure Titles and Legends

Figure 1. Core Skills for Self-Management of Cancer as a Chronic Disease

Figure 2. Stepped Care Framework for Delivering Cancer Self-Management Support

Figure 3. Whole System Change for Self-Management in Cancer Care

Figure 1.

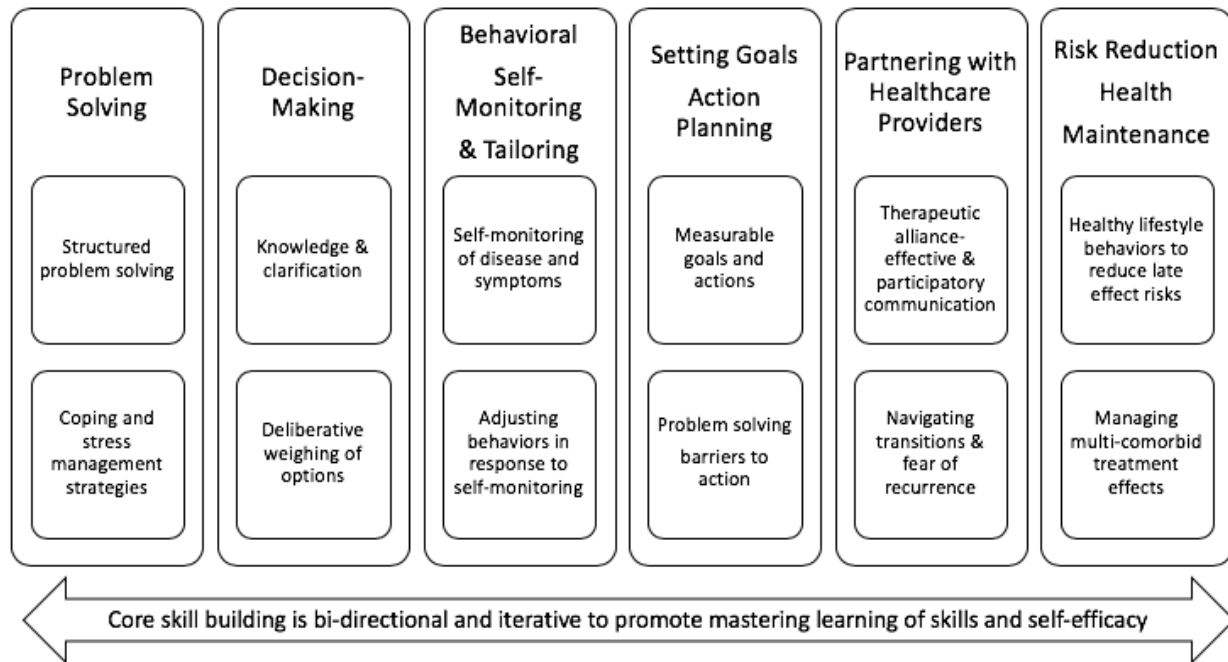


Figure 2.

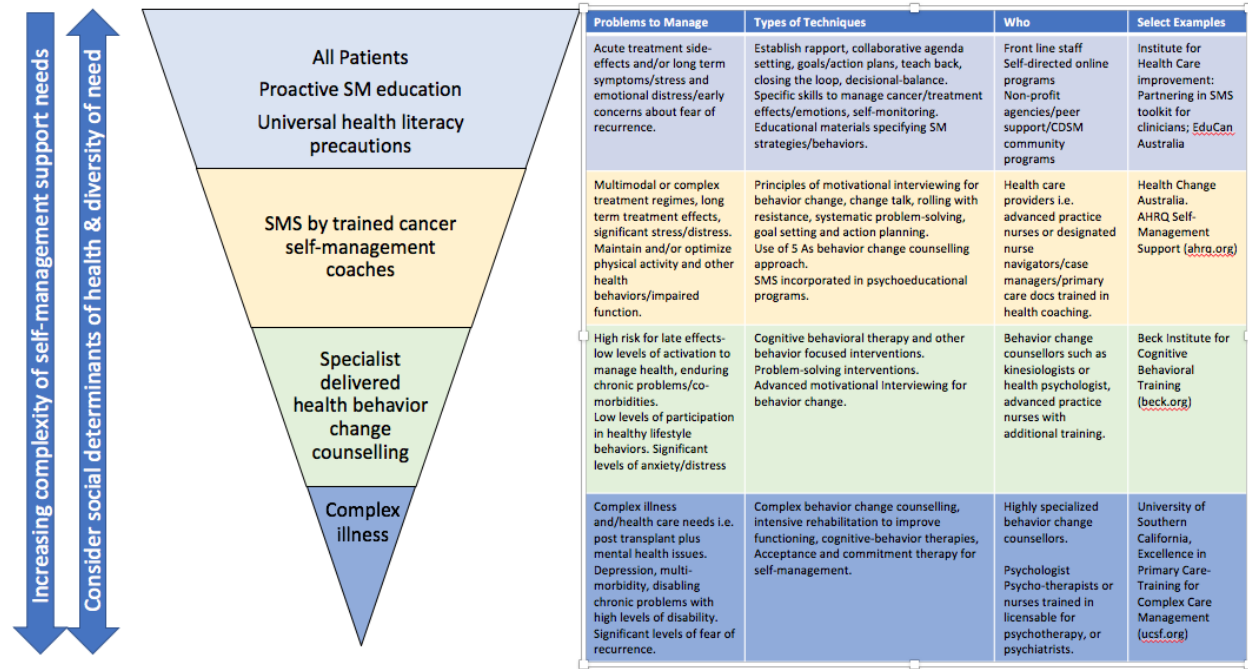
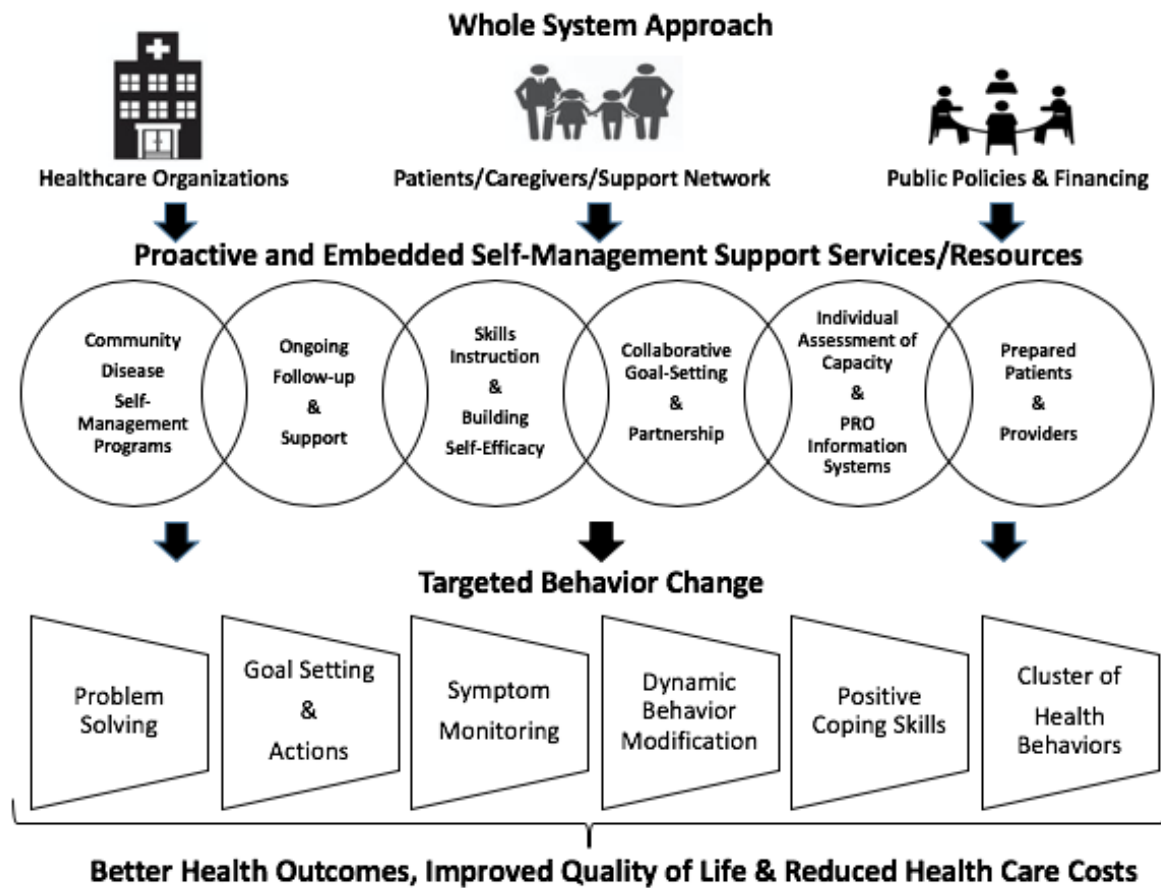


Figure 3.





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What happens to patients after the clinic visit? A call to action for self-management in cancer care

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Abstract

Individuals with cancer and their families assume responsibility for management of cancer as an acute and chronic disease. Yet, cancer lags other chronic diseases in its provision of proactive self-management support (SMS) in routine ‘everyday’ care leaving this population vulnerable to worse health status, long-term disability and poorer survival. Enabling cancer patients to manage the medical, emotional consequences, and lifestyle/work changes due to cancer and treatment is essential to optimizing health and health recovery across the continuum of cancer. In this paper, the Global Partners on Self-Management in Cancer (GPS) puts forth six priority areas for action including: 1) preparing patients/survivors for active involvement in care; 2) shifting the care culture to support patients as partners in co-creating health and embed self-management support in everyday health care provider practices and in care pathways; 3) prepare the workforce in the knowledge and skills necessary to enable patients in effective self-management and reach consensus on core curricula; 4) establish and reach consensus on a patient reported outcome system for measuring the effects of self-management support and performance accountability; 5) advance the evidence and stimulate research on self-management and self-management support in cancer populations; 6) Expand reach and access to self-management support programs across care sectors and tailored to diversity of need, and stimulation of research to advanced knowledge. It’s time for a revolution to better integrate self-management support as part of high quality, person-centered support and precision medicine in cancer care to optimize health outcomes, accelerate recovery and possibly improve survival.

INTRODUCTION

The last decade has seen unprecedented advances in cancer treatment, improved survival rates and recognition of cancer as a chronic disease, alongside shifts to ambulatory and home care, shorter hospital stays, and same-day surgery.^{1,2} Individuals now experience the ‘life-altering’ nature of cancer and treatment outside the clinic, where the onus is on them to recognise, report and manage their disease and health recovery. Cancer patients and survivors (includes family/social network) are expected to manage acute treatment effects, adopt healthy lifestyles to reduce late effect risks, manage comorbid conditions and polypharmacy, and cope with the psychosocial ramifications alongside other everyday responsibilities. Expectations to self-manage these sequela of cancer, recover or optimize health, and navigate care is not just for highly motivated and self-directed patients; it is becoming necessary and expected of all patients. Patients leaving the cancer clinic assume responsibility for managing the effects of cancer and treatment, and deciding when and how to seek help whether capable and prepared or not. How successful patients are as self-managers depends on access to **adequate self-management support and resources that may** alter their clinical course of disease and quality of living.

Cancer care has evolved from an acute care model, whereby health care professionals (HCP) assume responsibility for managing disease and advising and directing patients. Less attention has been focused on helping patients become effective self-managers of cancer as a chronic illness. **Cancer care lags other chronic conditions in incorporating principles of disease self-management into routine care, despite cancer presenting greater disease complexity, treatment and late effect risks, longer-term disability than many other chronic conditions.**³ This leaves cancer populations vulnerable to further deterioration in health status, worse health recovery, and likely poorer survival. As the cancer community aspires to greater personalisation of cancer care, it is time to shift the care paradigm to ensure patients are supported to be active partners in cancer care, empowered and enabled to manage their disease and health – the role that they hold responsibility for twenty-four hours a day, every day. This requires **major cultural shifts for both patients and HCP to motivate active involvement as partners in care and** reorganization of care practices to systematize the integration of self-management support into ‘everyday care’ at all phases in the cancer continuum extending into the community and other care sectors. In this paper, we propose **six key actions to “move the needle” towards better support of patient self-management, optimize health outcomes, accelerate recovery and perhaps mitigate long term disability across the cancer trajectory.**

DEFINING SELF-MANAGEMENT AND SELF-MANAGEMENT SUPPORT

Self-management (SM) is “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”.⁴ This includes the ability to monitor one’s condition and utilize the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life (QoL).⁴ For cancer patients, effective SM may include appropriate self-monitoring, **recognition, reporting and management of symptoms, treatment side-effects and recurrent disease. This includes effectively** managing biopsychosocial sequela and co-morbid conditions to improve functioning in daily life, adhering to polypharmacy, successfully navigating transitions and coordinating care across disease phases and care sectors, and applying healthy lifestyle behaviors to reduce late effect risks.⁵ For those with incurable disease, SM necessarily requires they manage

advanced, progressive disease as a chronic illness given generally increasing life expectancies,⁶ alongside early palliative care to facilitate SM of multi-symptoms, emotional distress, and adjustment to declining function and loss of autonomy.⁷

We emphasize that SM is not just participation in programs, i.e. self-help or peer support, but requires a willing and able patient supported to assume responsibility.⁸ SM tasks may also need to be delegated to or shared with family members or caregivers as social networks are instrumental in supporting patient SM efforts.⁹ While most patients undertake some degree of SM, whether effective or not,¹⁰ factors including socioeconomic, poor mental health, cognitive impairment, age, infirmity or other situational factors can impair engagement in SM.¹¹ Thus, SM in cancer care requires understanding of the patients' capacity and capability for SM, their role and motivation as partners in health care, written information that addresses health literacy (and e-health literacy)¹² and access to self-management support (SMS).¹³

SMS includes interventions or programs in the care pathway that enhance the patients' core skills, i.e. goal-setting and action planning, and building of self-efficacy for disease management through regular assessment of progress and problem solving support (Fig. 1).¹³⁻¹⁵ SMS emphasizes patient SM of four dimensions of health: managing medical aspects such as medication protocols and symptoms; coping with emotional consequences (anger, depression, acceptance, anxiety, fear of recurrence); and adapting/adjusting life roles and relationships including work/employment to accommodate illness, and lifestyle behaviours like physical activity, to facilitate health.^{5,16}

SMS approaches and techniques may include information provision, patient held records and online courses, and more active support, such as motivational interviewing or coaching for behaviour change, which works best to improve outcomes.¹⁷ Patients with cancer require SMS for developing and utilizing skills for problem solving, action planning, self-tailoring for adapting and adjusting behaviours to ones' own life situation and to manage dynamic fluctuations in illness and functioning in daily life, decision-making, utilizing resources and effectively collaborate with HCP. This approach, often utilising cognitive-behavioural and other self-modification skills explicitly acknowledges and emphasizes that achieving better health outcomes requires a collaborative relationship between patient and provider.¹⁸

SMS has long been recognized as an essential practice in chronic disease management for non-malignant conditions such as diabetes, arthritis, cardiopulmonary, and cardiovascular disease¹⁹ with established evidence for efficacy and cost effectiveness across a range of settings and populations. SMS in other chronic disease is associated with better disease control, QoL, daily functioning, and fewer emergency department visits and acute admission episodes.²⁰⁻²² Globally, patient engagement in SM is considered essential to achieving the 'Triple Aim' healthcare reform goals of better health outcomes, improved patient experience, lower health care costs;²³ and as core to quality cancer care worldwide.²⁴

While the evidence regarding the efficacy of SMS interventions in cancer is more limited and fragmented in comparison to other chronic diseases, SMS is associated with reductions in symptom severity for specific problems such as fatigue, pain, anxiety, and other treatment side-effects, psychological distress and improvements in self-efficacy and QoL.²⁵⁻²⁷ Healthy lifestyle behavior interventions and rehabilitation programs targeting cancer survivors that integrate SMS as a

core component have also shown positive effects on function, weight loss, and fitness parameters.^{28,29} Lastly, digital technology for remote monitoring of symptoms or physiologic data, i.e. physical activity, accompanied by SM advice and/or coaching have been shown to improve symptom management, reduce hospitalizations and emergency department visits,³⁰ and may provide a survival advantage when clinicians intervene in ‘real-time’.³¹

Cancer provides an exceptionally compelling case for SMS programs not just because of highly prevalent acute and long term biopsychosocial symptoms and late effects, but also because cancer frequently co-occurs with co-morbidities or increases risks of new chronic conditions (including additional cancers) further complicating and burdening patient/caregiver disease management and the cancer care system.³² Moreover, the dynamic nature and complexity of managing cancer can deplete the SM, self-regulatory and often financial capacities of affected families.³³ Unsurprisingly, cancer survivors report heightened vulnerability and lack of confidence for initiating SM behaviors necessary to recover health after treatment.³⁴ SM is particularly challenging in the setting of multiple comorbidities common in older adults³⁵ and in the context of late treatment effects. Similarly, patients living with advanced or relapsing disease may struggle with SM, declining function, and the emotional and psychosocial adjustments necessary to adapt to living, sometimes for years, with an incurable, life-limiting disease.⁷ Early palliative care programs that have integrated coaching in SM have shown positive benefits on symptom severity and QoL,³⁶ but SMS as a core component of palliative care needs development.⁷

As the evidence of benefits of SM and SMS in cancer care is mounting, it is time to consider how to translate this evidence into clinical cancer care and stimulate further research. To address this knowledge gap, we recommend urgent action on a global scale in the six key areas below. Actions are briefly summarized in Table 1 Supplementary File.

Action 1. Prepare patients/survivors/caregivers for active involvement in care

A concerted effort to cultivate a culture that genuinely supports and empowers active involvement of patients/caregivers in SM of disease and health in collaborative partnerships with HCPs will be necessary to embed and sustain SMS in cancer care.^{37,38} Traditional, paternalistic models of care, whereby the ‘expert’ holds responsibility for treatment plans and emphasize patient compliance are pervasive in health care and attempts to embed SM in this context through increasing awareness have largely been unsuccessful.³⁹ Clinicians are reluctant to relinquish control and hold beliefs that few individuals are capable of SM, while both patients and HCPs poorly understand their roles as partners in achieving health.⁴⁰⁻⁴² Studies of promising practices show that multilevel changes are necessary to create “engagement capable” environments including: 1) governance and leadership structures that foster active involvement of influential patients in care redesign; 2) training and practice coaching of providers in participatory, collaborative communication styles and shared decision-making that provides clear guidance and support to patients in SM and health actions they can take to improve health (e.g. patient action pathways combined with treatment pathways); and 3) patients may require psychological (willingness) preparation and appropriate SMS to assume an active role in care.⁴³ Facilitating health behavior change is no doubt challenging and SMS will need to be combined with other strategies. Health insurance plans that reward patients for gains in health behaviors and billing codes for assessment and counseling in disease SM for

physicians/nurses may incentivize change.^{44,45} A wider educational effort and “whole system” change in cancer care is required.⁴⁶

Action 2. Embed SMS into ‘everyday’ practice and care pathways

Engagement of patients in SM at the earliest possible moment in their diagnosis, should be the start of a collaborative, empowering relationship between patients and their health-care providers. This will require developing a shared patient and HCP agenda for SM, but also guidance to patients in applying disease, symptom/treatment-specific SM strategies and health behaviors to address acute and chronic problems (e.g. neuropathy pain, fatigue).⁴⁷ Particular problems that may lead to unnecessary consultation dependency, specifically fear of recurrence, require early and targeted interventions and adequate preparation of patients in self-monitoring to recognize signs/symptoms of disease recurrence to reduce distress.⁴⁸ Crucially, communication approaches must be assessment-oriented, person-centered and participatory to foster patient willingness and engagement in SM; and integration of personal SM goals and action planning into treatment plans.⁴⁹ However, person-centered SMS and care planning is not a “one-off” event but rather requires rethinking of care delivery including work flows and scheduling systems to accommodate regular review of SM at follow-up and at key points along the cancer continuum and when treatment goals change.⁵⁰

Every encounter across the cancer continuum should be considered a “teachable moment” and incorporate a structured assessment approach to enable tailoring of SMS to individual needs and SM capacity and population diversity. Given the rapid, episodic nature of cancer care and constrained resources, implementing SMS will likely require a stepped assessment and care approach⁵¹ similar to frameworks for low, medium and high touch interventions as articulated in the Supportive Care Framework⁵² and similar to guidance for management of emotional distress⁵³ and other chronic conditions.⁵⁴ As shown in Figure 2, all patients should receive SMS as part of routine care with intensification of support for those with higher needs as shown in the corresponding Table. Risk stratification is also important, as some patients will require close supervision (i.e. during immunotherapy or advanced disease) combined with intensive SM support, whereas those with more stable disease (early stage breast cancer), less complex needs, or low risk for recurrence/progression, can be referred to community-based programs for SMS.⁵⁵

Transform from Reactive to Proactive Care that Activates Patients/Survivors in SM

Embedding SMS into routine care requires “whole” system change (Fig. 3) inclusive of preparing the workforce, developing and disseminating SM programs, creating supportive systems and processes to embed SM in routine care and changes across multiple levels of the organization and care sectors.⁴⁶ The international chronic condition self-management support framework could be instructive for developing strategic directions for cancer care.⁵⁶ Strategies to address the multiple implementation barriers to SMS integration in care will be crucial.⁵⁷ Transformation in models of care delivery from the current reactive acute care focus to proactive care of cancer as a chronic disease that is underpinned by principles of health promotion and secondary prevention will be fundamental for effective delivery of SMS.⁵⁸

This transformation will require changes in healthcare provider practices (micro-system capacity), but also at the organizational level i.e. policy (macro-system), and in care protocols, pathways, and standards for cancer care delivery

(meso-level). Reimbursement/incentives to participate in SMS, inclusion in oncology bundled payments and the time required in the clinical encounter to facilitate behavior change require further examination as essential organizational and health policy levers. In Canada, assessment/management of patients with chronic diseases such as heart failure and diabetes are billable services.⁴⁴ Staffing resource constraints will need to be addressed and Advanced Practice Nurse (APN) and Nurse Navigator roles enhanced for delivering SMS with appropriate training in coaching health behavior change.⁵⁹ In these roles (APNs) could act as facilitators of practice change supporting staff nurses in key SMS functions (e.g. agenda setting, goal setting and action planning, teach back, closing the loop) to ensure continuity in routine care.

Cancer care providers could promote this transformational process by assessing current organizational delivery of SMS using tools such as the Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management (PCRS) tool⁶⁰ and the Clinician Support for Patient Activation Measure (CS-PAM).⁶¹ Patients could also be surveyed to ascertain their perception of the quality of SMS currently delivered using tools such as the Partners in Health Scale⁶² or the Patient Assessment of Chronic Illness Care (PACIC).⁶³ Additionally, the use of best practices in knowledge translation, implementation science and quality improvement methods is fundamental to shifting entrenched care cultures and processes, and clinician attitudes towards embedding of SMS in routine care delivery. To date, little evidence has been generated about what implementation strategies are required for successful embedding of SMS in ‘real-world’ cancer settings to guide healthcare administrators and inform wide-scale spread.⁶⁴ The principles and techniques for experience based design⁶⁵ could be a key approach to capitalize on the collective experiences of clinical teams and patients as to how to achieve this change and following recommendations for global change in chronic condition SMS.⁶⁶

Action 3. Train health care providers with knowledge and skills for providing SMS

SMS requires prepared, proactive clinical teams that understand the rationale for SMS and hold positive beliefs about the individual’s ability to SM; and the knowledge and skills to deliver such support. While there are several practical techniques that can be used to counsel patients in SM, such as the 5 As (Assess, Advise, Agree, Assist, Arrange)⁶⁷ or other approaches such as motivational interviewing,⁶⁸ health care providers will need to be trained and assisted in embedding these in routine practice, particularly given the rapid episodic nature of cancer care delivery. The training must go beyond just skill acquisition and include clear clinical pathways that clarify clinical team responsibilities and how the clinical team will realign care and team collaboration to collectively provide SMS patient and scheduled follow-up visits to assess progress in SM. Training programs that emphasize the theoretical underpinnings of health behavior change and skills for effective coaching of patients to facilitate uptake and sustained use of SM behaviors will be critical, but also how these can be adapted for application in routine care practices.⁶⁹

A robust induction process, including the whole team, and targeted training of nurses in SMS and incorporated in new staff orientation and as part of mandatory and ongoing professional development pathways is needed. However, the cancer community needs to reach global consensus on the requisite core curriculum for preparing HCPs in the knowledge and skills for effective SMS delivery and for incorporation in undergraduate or graduate programs. Core international knowledge and competencies already developed could be adapted for training of cancer clinicians.^{70,71}

Action 4. Foster accountability for SMS as a performance metric in value-based care

The organizational changes required to adopt SM into cancer care require performance accountability using standardized, agreed process and outcome measures and data definitions, assessed in ongoing program evaluations. Patient SM and SMS engagement provide useful performance metrics in value-based care, which is also dependent on provider behavior changes as much as patient behavior changes to improve health outcomes.^{72,73} SMS could be leveraged as a key strategy for facilitating health behavior change as part of value-based care, included in accreditation standards, and assessed in patient experience measures for quality-based payment for performance. However, SMS outcomes and indicators are noticeably absent from many prominent PRO information systems⁷⁴ and patient experience measures.⁷⁵

Performance accountability can be facilitated through Patient Reported Outcome measures (PROMs) that capture the health status of cancer patients and survivors and their progress in SM across the cancer continuum. PROMs that assess patient's knowledge and self-efficacy in SM such as the Patient Activation Measure (PAM)⁷⁶ or PROMIS Self-Efficacy measures⁷⁷ are useful for tailoring or triggering intensification of SMS in routine care and could be important additions to information systems for measuring the quality and outcomes of SMS. Harmonization of health outcomes and agreement on minimum data sets for cancer-specific SM behaviours and for healthy lifestyle behaviours (smoking cessation, diet, activity) allows for population comparisons across different settings.⁷⁸ These comparisons would stimulate further research and inform global surveillance on penetrance of SMS in cancer care. Additionally, agreed outcome measures for SM behaviours that are universal across cancers and could be augmented with disease or problem-specific behaviour modules are needed.⁷⁹ PROMs for SM will need to be relevant to phase in the cancer continuum, i.e. adverse events versus long-term problems; and included in learning healthcare systems to inform future risks and care needs.

Action 5. Advance evidence on the effectiveness of SM and SMS in cancer populations

While the principles of SM and SMS are well established and warrant embedding into routine care today, there is a need for high quality efficacy trials testing and for priority-driven research into how best to optimize SMS in specific populations and according to level of need and in real-world cancer care.⁸⁰ Consideration will need to be given to cancer or treatment type, multi-morbidity, disease stage, healthcare system resources, and to a range of personal characteristics (gender, age, socioeconomic determinants, geography, or other life/environmental circumstances, diversity)^{81,82} and framed from an equity lens.⁸³ Key priority areas of focus are highlighted below.

First, consensus on the core components and skills defining cancer SMS approaches is crucial. Uncertainty remains about whether SMS approaches and core skills effective in other chronic diseases are equally applicable to cancer, given the “one-size” approach of CDSM has been criticized for complex illnesses.⁸⁴ While systematic reviews and meta-analysis have shown evidence of effect of SMS interventions for adult survivors,^{25,26,85} scoping reviews have identified wide-variation in the core components and SM skills emphasized in SMS interventions and poor use of theory in program design, making it difficult to compare efficacy across studies.^{86,87} There is also a need to design and test SMS programs targeting specific problems, given a lack of effect in SMS programs focused on general behaviors when a problem-specific focus is required, i.e. SM for managing depression.⁸⁸

Second, development and consensus of outcome measurement framework(s) or minimum data sets for evaluating SMS programs/interventions' health outcomes and health behavior impacts. Globally, SM behavior measures for cancer, harmonized collection of PROs that capture patient SM capability, and healthy lifestyle behavior criteria are needed to inform clinical care and enable surveillance. Ruiz and colleagues developed a pyramid approach comprised of five levels (individual, health systems, community, policy, and media) for setting up a national surveillance system on SM and SMS for chronic conditions that could be adapted for cancer.⁸⁹

Third, how best to provide SMS in the context of diverse social, cultural and geographic needs is an understudied area. As most SMS programs originated in high and upper middle-income countries, there is limited evidence on how to translate them into low income settings with fragmented healthcare systems, even though these may be precisely the settings where SM may be needed most to address existing gaps in the provision of care. Research that addresses the cross-cultural, economic, and social determinant aspects of SMS is urgently needed.⁹⁰ Specific interventions, programs, and care pathways culturally-tailored and appropriate for vulnerable, isolated and disadvantaged populations will need development and includes appropriate delivery mechanisms (face-to-face, group, eHealth).

Finally, the need to synthesize evidence on SMS in cancer using high quality systematic reviews, meta-analyses, and realist reviews to direct research towards identified gaps in knowledge. Economic evaluations of SM and SMS in cancer populations and implementation studies of SMS are needed to inform the wide-scale changes we recommend. Service evaluations to understand the effectiveness of health service innovations and implementation of SMS in 'real world' cancer settings are limited and largely drawn from other chronic diseases.

Action 6. Expand reach and access to SMS programs across care sectors

Cancer SMS programs must be sufficiently flexible to meet diverse goals, needs, preferences and capabilities given varied sociocultural contexts and illness trajectories from disease manifestation to end-of-life (e.g. multi-symptomatic lung cancer vs prostate cancer patients on hormone treatment). SMS for long term survivors is a stand-alone priority area for action, offering the opportunity to integrate cancer SM with other health conditions to build wellness over time, though the prominence of cancer SM may wane in relation to other health priorities. SMS has been identified as a key element of personalized survivorship care that accommodates the evolving changes in need across the cancer continuum and the risk and challenges of late effects.⁵⁶ Developing appropriate SM interventions to assist survivors in managing health is also an unprecedented opportunity for improvement in care and reduction in health care costs to the significant and growing subset of survivors living with the effects of cancer as a chronic illness. SMS programs are increasingly adopted in some countries within a public health approach. For example, in Canada, SMS programs based on the Stanford program have been financially supported for wide-scale implementation.⁹⁰ However, patients with cancer or survivors are seldom aware of these programs or feel well enough to attend during the acute phase of cancer treatment. Programs such as The Cancer Thriving and Surviving Program⁹¹ and other SMS programs tailored to cancer populations could be targeted for wider-

scale spread globally. Online programs such as the American Cancer Society's Springboard Beyond Cancer (<https://survivorship.cancer.gov>) could also be beneficial in building SM skills.

Risk-based models of follow-up care that integrate SMS programs and enhance system sustainability are another important area for action and research.⁹² Stepped approaches to follow-up care in England that integrate SMS as the initial step for low-risk populations met patients' needs while enhancing care efficiency and cost savings. SMS is delivered systematically in workshops for low-risk populations with options for rapid re-entry for additional support by clinical nurse specialists or oncology care.⁹³ These approaches will require better integration of SMS within primary care and community-based programs and for co-management of other chronic conditions.

Finally, it is not just about access to SMS programs at point of need, but across the board changes in the culture of cancer care that is required, including preparing patients/caregivers for active involvement in care, change in HCPs communication and SMS skills and organizational transformation. Summary of actions in Table 1 (Supplementary File).

CONCLUDING REMARKS

Cancer self-management, a priority for cancer care, is a powerful lever for achieving personalized, high quality care. We have highlighted six key actions for SMS integration to improve health outcomes. Cancer patients/survivors are an underutilized resource essential for sustaining economic viability of the cancer system.⁹⁴ In his 2014 American Society of Clinical Oncology presidential address, Richard Schliskey remarked: "patient engagement in health is the 4th revolution in personalized cancer medicine alongside genomics and big data analytics" (<https://www.medscape.com>). Enabling patients in effective cancer SM is key to this revolution!

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All authors read and approved the final manuscript.

1. DH and BK made substantial contributions to the writing of the manuscript.
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