

The need for quality self-management support in cancer care

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The number of people living with and beyond cancer is rising rapidly. With earlier detection and better treatments many people are living for years following a diagnosis of cancer. Healthcare systems need to adapt to manage this demand and better meet the needs of this growing population.¹

The consequences of cancer and its treatment are common, can arise at any point and may be long lasting.² They can have a significant impact on daily life and include a range of physical symptoms and late effects such as pain, fatigue, bowel dysfunction; psychological concerns such as anxiety, depression and fear of recurrence; and social impacts including disruption to previously enjoyed activities, ability to work and relationships.³ Lifestyle changes and long-term medications to reduce the risk of recurrence, hospital appointments, routine surveillance and monitoring for signs of potential disease progression can create additional burden. People may lack confidence and struggle to manage the impact on their daily lives resulting in disrupted lives and futures.⁴ This can exacerbate mental health problems such as depression and anxiety. Low confidence to self-manage and depression have been associated with worse health and well-being outcomes up to 2 years after diagnosis.⁵ In addition, as most people are diagnosed with cancer in later life, many are also living with long-term conditions which can exacerbate problems further.⁶ Understanding how best to support people to manage the consequences of cancer and its treatment to reduce health crises and quality of life is a global concern.⁷

The good news is that appropriate support can reduce health crises, enhance confidence to manage and improve mental health, quality of life and other outcomes.^{8,9} The National Health Service (NHS) Long Term Plan¹⁰ states that by

2021 ‘*where appropriate every person diagnosed with cancer will have access to personalized care, including needs assessment, a care plan, and health and well-being information and support*’ (p 61). Tailoring support and care according to need as soon as possible following diagnosis presents an opportunity to enhance confidence to manage consequences of cancer, mental health and quality of life outcomes during treatment.¹¹ This support should continue beyond treatment because the consequences of treatment may persist over time, late effects may emerge which require self-management and long-term lifestyle changes are usually required to reduce the risk of recurrence. New models of care are being developed and tested to support people after treatment and the evidence base is growing.^{12–14}

Self-management is a term used to describe what people living with long-term conditions do to manage their condition. It includes ‘*the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition*’ (p 177).¹⁵ Self-management has more recently been applied in the context of cancer and additionally includes routine surveillance and self-monitoring for signs of disease progression to reduce the risk of recurrence. The benefits of successful self-management include reduced crises involving emergency admissions to hospital, improved quality of life and greater confidence to manage the impact of cancer on everyday life in spite of challenging consequences and the associated disruption.^{16,17}

While it is recognised that people need support to manage the wide-ranging impact on their everyday lives, self-management support is inconsistently delivered in cancer care.⁷ A recent global



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call to action has highlighted the need for improved quality of self-management support to enable people to develop the knowledge, confidence and skills they need for optimal self-management.⁷ Without adequate self-management support, patients with cancer and survivors may struggle to manage the impact of cancer and treatment in their daily lives resulting in poorer health and well-being and poorer quality of survival.⁴

There is evidence that the right self-management support at the right time enables people to manage consequences of cancer during treatment and beyond.^{8 12 13} Howell *et al*¹⁸ demonstrate that both organisational and clinician barriers and enablers need to be considered in advance of implementation of self-management support to inform specific strategies for implementation within cancer care. The three cancer centres in Howell *et al*'s¹⁸ study each identified barriers and enablers to implementation and readiness to change which require different approaches to support implementation. Howell *et al*¹⁸ highlight key considerations, based on their experience in ambulatory cancer care involving patients with colorectal, lung and lymphoma cancer, that need to be acknowledged and planned for prior to implementation of self-management support in cancer care. First, healthcare professionals and the organisations in which they work need support in shifting from a paternalistic culture to one that engages patients as partners in their care. Second, healthcare professionals and those in administration and management need to understand what self-management support is, what it involves and what the benefits could be for people living with and beyond cancer. Third, recognition that healthcare professionals need support, tools and skills to enhance their practice of self-management support.

Howell *et al*'s¹⁸ study focuses on the preimplementation phase in a treatment setting. We can also learn from a UK study which assessed the introduction of supported self-management to the follow-up care pathway. The traditional approach to follow-up care where all patients have routine follow-up appointments and regular surveillance does not adequately address patients' needs and is not sustainable given the growing number of cancer survivors.¹⁹ The TrueNTH UK Supported Self-management and Follow-up Care Pathway (TrueNTH UK pathway) was introduced into parts of the NHS for men who have had primary prostate cancer treatment and are suitable for self-managed follow-up.²⁰ The TrueNTH UK pathway includes a Band 4 support worker who is the key point of contact and support for men after treatment; a 4-hour workshop which provides information and supports the development of men's skills and confidence to self-manage; remote monitoring with hospital appointments only when test results indicate further investigation is necessary; access to test results through an online portal; and holistic needs assessment made through contact with the support worker. This new

model of care has been shown to be more efficient and cost-effective than traditional follow-up and is acceptable to patients.¹² It has also been adapted for patients with colorectal and breast cancer. A toolkit to support implementation of supported self-managed follow-up has been produced.²⁰

The findings from Howell *et al*'s¹⁸ study and the TrueNTH UK pathway align with a recent call to action from an international group of researchers and healthcare professionals—the Global Partners for Self-Management in Cancer—regarding workforce development and readying healthcare providers for successful self-management support.⁷ These include:

A NECESSARY CULTURAL SHIFT

Howell *et al*¹⁸ highlight the need for healthcare professionals and the organisations in which they work to shift from a paternalistic culture to a partnership arrangement where patients and healthcare professionals work together. This partnership will engage patients in their care and recovery to identify what matters to them, rather than what is the matter with them, and support them to be effective and confident self-managers equipped with the skills they need.^{7 8}

To achieve this, Howell *et al*¹⁸ emphasise the need for healthcare professionals as well as healthcare organisation administrators and managers to be involved in the design of new self-management programmes. This will allow a full understanding of concerns, barriers and enablers for the implementation of self-management support. Subsequent implementation strategies will engage with professional and organisational understanding of what self-management support is, why it matters, and attempt to overcome barriers arising from this understanding.

Early barriers experienced in implementing the TrueNTH UK pathway included lack of buy-in from clinicians; concerns about patient safety; concern that health professionals would have limited contact with those patients doing well after treatment; concern that introduction of the pathway could result in reduced funding; lack of understanding of the components of the new pathway; challenges of having to navigate multiple administrative systems; and challenges implementing and integrating the information technology (IT) system. These barriers were identified in the early stages of implementation and where these challenges were overcome, the pathway was successfully introduced, was acceptable to patients and reduced costs.¹² Howell *et al*'s study suggests that these barriers, both in terms of healthcare professional and organisational readiness to change, could have been identified at an earlier stage and strategies developed to inform smoother uptake prior to implementation.

Enablers to support the cultural shift needed to implement the TrueNTH UK pathway included identifying clinical leads to support early engagement with a wide range of stakeholders including commissioners,

clinical governance and service improvement leads, IT to support integration of self-management support into digital systems and administrative support to overcome the complexity brought about by multiple administrative systems. A working group led by a healthcare professional (eg, urologist, oncologist, clinical nurse specialist) responsible for implementation of the TrueNTH UK pathway and taking decisions on the development of clinical guidelines and governance protocols supported the implementation and delivery of safe and effective follow-up care. This group also supported teams to maximise understanding of the new pathway and what it entails, as well as collection of data to support accurate cost modelling.

PREPARING THE WORKFORCE

Howell *et al*¹⁸ emphasise that for successful implementation, a common understanding of what self-management in cancer care means, why it is important and what good self-management support looks like is a necessary starting point. Healthcare professionals need support to acquire the knowledge and skills required to enable patients to self-manage effectively and agree core curricula to support this.⁷

TrueNTH UK also emphasised the importance of wide stakeholder engagement to identify concerns and needs of different stakeholders throughout this process to develop a common understanding and identify local need and encourage buy-in. A local clinical champion to help drive this forward is beneficial to support clinical teams responsible for implementation to understand what is required and involve them in early discussions to shape the pathways, guidance and associated protocols.²⁰

CORE SET OF OUTCOME MEASURES

Both Howell *et al*¹⁸ and TrueNTH UK highlighted the importance of data to demonstrate the benefits of supported self-management, such as reduced emergency admissions. In order to determine whether or not self-management support is effective, consensus as to desired outcomes also needs to be established. An agreed core set of patient-reported outcome measures is also required. Evidence suggests that self-efficacy to manage the consequences of cancer and its treatment should be included as one indicator of successful self-management as it is both amenable to intervention and is a key predictor of health and well-being outcomes.^{5 21}

EXPAND REACH AND ACCESS TO SELF-MANAGEMENT SUPPORT

Both SMARTCare (Howell *et al*¹⁸) and TrueNTH UK pathway are designed to form part of routine care. The TrueNTH UK pathway has been integrated into routine care and is therefore not an optional extra: all eligible patients are placed on the pathway. Patients are supported to understand what self-management

support is and how to engage with it. In contrast, optional programmes tend to attract well-educated patients who already self-manage well.²² Consequently, those implementing self-management support need to consider the diversity of need within the population served so that those with greatest need are the focus of attention. The needs of the population served need to be assessed with involvement of those typically under-represented. Meaningful patient engagement to uncover needs should feed into the development of self-management support. Self-management support needs to come in a number of forms including workshops, digital support and one-to-one clinical conversations that are culturally sensitive and inclusive of those with low health literacy.

CONCLUSION

For self-management support to be a success, we need to anticipate, uncover and overcome organisational and healthcare professional barriers to implementation, have a clear understanding of what good looks like, have agreement regarding how to evidence successful self-management support and gather evidence of good practice so that this can be shared, replicated and adapted as appropriate. Champions in organisations across the globe are needed to lead the way in high-quality and consistent self-management support to improve the lives of those living with and beyond cancer.

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