Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice

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A B S T R A C T

Improvements in screening, early detection and treatment have led to more people surviving and living longer following cancer diagnosis. There is growing recognition that people living with and beyond cancer may experience symptoms and problems related to the disease and its treatment in the months and years following diagnosis. The impact this can have is variable, but with a growing number of cancer survivors it is important to know who needs support and how this should be delivered in a resource constrained health service. Researchers and policy-makers must find ways to work together to generate and use evidence to improve the quality of survival.

We must: (1) Continue to investigate this growing population and recognise the importance of patient reported outcomes and experiences in the design, planning and evaluation of services; (2) Focus on the most pressing research questions to improve the lives of people living with and beyond cancer. Understanding the experiences of people living with and beyond cancer will support future patients to make choices, manage the consequences of cancer and its treatment, identify who needs most support and how this should be delivered; (3) Acknowledge and seek solutions to the challenges of building the evidence and using it to develop, implement and sustain practice innovation. Challenges include identifying most effective ways for researchers to work with stakeholders (policy, practice, public) to maximise the impact of research, establishing mechanisms for effective implementation and sustainability of clinical services, securing large scale research funding and developing next generation of research leaders.

1. Introduction

More people are being diagnosed with cancer and living longer following treatment. A predicted 4 million people will be living with and beyond cancer in the UK by 2030 [1]. Rising survival rates are largely due to earlier intervention and improved treatments. The advent of new treatments, such as immunotherapy for cancers resistant to other forms of treatment, means an increasing number of people who would previously have had poor life expectancy can live for years, often on continuous treatment. This increase in the numbers of people living longer after, or on continuous, treatment poses challenges for an increasingly stretched health system.

The aims of this paper are to

- explain why research into the consequences of cancer and its treatment is needed
- outline what we know, and what we still need to find out, about new approaches to supporting patients after (or on continuous) treatment
- identify challenges and potential solutions to building research evidence and developing, implementing and sustaining practice innovation in this area

2. The context: why research into the consequences of cancer and its treatment is needed

More people are experiencing cancer, not as an acute or life-limiting 'incurable' disease, but as a life-changing and chronic condition. People can experience symptoms and problems in the months and years following (or on continuous) treatment that can be difficult to manage [2].

People affected by cancer have highlighted the need for support in managing the consequences of cancer on their lives [3], as they can be unprepared for the impact it can have, feel vulnerable, experience loss of confidence and struggle to access care and support [4,5]. Although the level of disruption to people's lives varies, and some people are well equipped and supported to manage [6], many will need some support from healthcare professionals (ranging from relatively 'light touch' through to more involved support) to help them manage. It is important that we identify who these people are, what level of support they might need, when and what form this should take. To do this robust evidence is needed.

Recent shifts in the political landscape reflect increasing recognition of the value of considering patient experiences and outcomes on an equal footing with improvements in survival. Recommendations from the Independent Cancer Taskforce [7] called for reduced variation in treatment, outcomes and experience; and implementation of the Recovery Package [8] a set of actions to improve experiences of cancer and treatment, including long term quality of life. Implementation of the Cancer Strategy for England has led to the development of a national Quality of Life metric [9]; an increase in wellbeing events; the Recovery Package becoming a national CQUIN (Commission for Quality and Innovation payment); and the development of a cancer dashboard to compare service performance and outcomes, including quality of life [10].

This increased focus on improving patient experience and outcomes means that good quality evidence regarding the impact of cancer and its treatment on people's lives is vital to inform decision making around the design and planning of effective services to bring about desired improvements in care and outcomes.

3. New approaches to supporting patients after treatment: what we know and what we still need to find out

In order to achieve tailored support that is effective and efficient, health services need to adapt. Traditional aftercare (also referred to as follow-up care), based on routine appointments for years following treatment, is neither sustainable nor effective [5]. One purpose of routine appointments has been to review whether cancer has recurred or progressed but there is evidence that most recurrences are detected in between appointments by patients themselves [11]. Such appointments can be anxiety provoking, time-consuming, and frustrating, especially if the person's needs are not discussed and remain unmet [5]. Clinics are often busy, limiting the time available for patients to raise or discuss symptoms or problems they may be experiencing. In recognition of this, aftercare is changing to take account of risk of recurrence and complexity of patients' needs rather than a one size fits all approach. An added impetus is the ageing population and resultant increase in people living with comorbidities alongside cancer. This brings additional complexity and potential burden to patients and their families. Although the evidence for managing the care of patients with multi-morbidity is limited [12], a multi-morbidity approach may address patients' needs more effectively [13].

Self-management by the person affected by cancer, a concept informed by chronic disease models of care [14], is one response to these challenges. This can include managing consequences such as symptoms and emotional impact, seeking support when appropriate, recognising and reporting signs and symptoms of possible disease progression and making lifestyle changes to promote health, well-being and survival [15]. However, evidence from the UK prospective cohort of over 1000 colorectal cancer patients treated with curative intent surgery (CREW) has revealed that poorer quality of life in the first two years post-surgery is associated with depression and low pre-treatment confidence to self-manage illness related problems (especially fatigue and pain), with little change in confidence over time [6,16].

Identifying who is struggling to self-manage and supporting them effectively as early as possible is important as this may help improve

experiences and outcomes beyond treatment. Such self-management support could include group education sessions, telephone coaching, monitoring symptoms with technology, self-management programmes, and psychological behaviour change interventions that support people to be actively involved in their healthcare [17]. Evidence suggests that interventions to support self-management can make a significant difference to confidence to manage and quality of life [18]. Availability of self-management support to enable people to manage, often complex, symptoms and problems is an essential part of this.

There is currently limited empirical evidence regarding what self-management involves for people living with and beyond cancer in the short, medium and longer term to inform policy initiatives to improve the lives of those living with the consequences of cancer. There have been a number of evaluations of service innovation but there is relatively limited evidence to support the development of self-management support within cancer care systems [19,20]. Consequently, evidence to inform the type and timing of self-management support from healthcare professionals has generally been drawn from the chronic illness literature [20]. Although there are likely to be some commonalities between the self-management support needs of people with cancer and those with chronic illnesses such as diabetes, we need robust evidence to inform policy initiatives and clinical innovations for people affected by cancer that takes into consideration the complexities of cancer (e.g. multiple types, highly varied treatments, recurrence rates, consequences of treatment, demographic profiles of patient populations, their understanding and needs).

Pressing questions we need to address in order to improve the outcomes and experiences of people living with and beyond cancer include:

1. How do we best prepare patients for what to expect at the end of curative treatment in terms of symptoms and problems resulting from their cancer diagnosis and treatment?
2. What impact do symptoms and problems have on patients everyday lives?
3. What services or resources are available to support self-management and are they effective?
4. Do people know what support is available and how it can be accessed? If so, what are the barriers and motivators to engagement with such support?
5. How do we prepare and support patients who are receiving continuous non-curative cancer treatment? Do these patients have specific needs and concerns?
6. How do we best identify those who are most likely to struggle with self-management following their cancer diagnosis and treatment?
7. What is the impact of living with cancer and other co-morbid conditions?
8. What is the impact of personalised and stratified medicine on patients, what are their specific needs and concerns and the best means to address these?
9. What services should be in place, and when, to enable a range of self-management support for those requiring light touch to more involved support?
10. What are the outcomes that we need to measure to know whether or not self-management support is cost-effective?

4. Challenges to building the evidence and developing, implementing and sustaining practice innovation

There are a number of challenges that need to be overcome if robust evidence is to inform policy and practice and improve the lives of those living with and beyond cancer. Many are not unique to cancer care. Researchers have to tackle the right problems that address the big questions in healthcare i.e. those that lower costs, achieve better clinical outcomes, improve the experiences of patients and clinicians, and use the right methodologies to produce the evidence that policy makers

need. Researchers need to be aware of the mechanisms by which evidence shapes and informs policy to extend influence and impact beyond the academic community, including engaging with policy, practice and public audiences [21].

A specific challenge to research focusing on living with and beyond cancer is funding. It is a significant challenge to secure funding for large-scale studies such as observational cohorts and trials of complex interventions in a highly competitive research funding environment and against competing priorities such as finding cures and more effective diagnostic techniques. Macmillan Cancer Support has a long history of funding cancer survivorship research, including large scale research grants. However, up to now, a very low proportion of UK cancer research spend has funded this type of research [22].

A related challenge is the development of the next generation of leaders in the field. In 2004 it was recognised that there was lack of research capacity and leadership in the area [23]. Initiatives such as the NCRI Supportive and Palliative Care Research Collaboratives, have attempted to build capacity through training, developing partnerships and collaborations, building elements of sustainability and continuity and investing in appropriate infrastructures [24]. To achieve this there was substantial financial investment over a 5 year period and it is unclear whether the capacity building has sustained or further developed since the end of the funded initiative.

An analogous initiative in the area of Living With and Beyond Cancer is now underway to address funding and capacity challenges in this area. The NCRI Living With and Beyond Cancer Research Initiative [25] is supported by funding from Macmillan Cancer Support, Department of Health, Medical Research Council, Economic and Social Research Council, Chief Scientist Office (Scotland) and Health and Social Care Public Health Agency Research & Development Division (Northern Ireland). The initiative includes a James Lind Alliance Priority Setting Partnership focused on Living With and Beyond Cancer and involving patients, carers, and health and social care professionals working together to identify and prioritise relevant research questions. The NCRI will then work with relevant research funders to promote funding of the identified research priorities. The initiative also involves a grantsmanship programme to upskill the research community and support them to secure grants for research in this area. Capacity building and developing the future leaders in the field is an ongoing challenge but may be resolved by securing large scale, long term, programmatic funding that builds critical mass in priority areas and enables investment to support the development of the next generation of researchers in the field.

Robust evidence takes time to gather and interpret and it can be a challenge for research to keep up with the speed of practice developments and shifts in the policy landscape such that the findings remain relevant and useful to decision makers. A further challenge is for researchers to reach and work with these decision makers and thereby increase the likelihood of robust research evidence informing future policy and practice at local, national and international levels. Although 'evidence-based policy-making' has been an expectation for some time in the UK, the most effective way for academics, who generate much of this evidence, to engage with policy makers is less clear [26].

To achieve this researchers must work with a range of policy makers and influencers to build the demand for research information [27]. Two factors are key to the demand for evidence by policy makers; a) having the capacity (the skills and knowledge to find and interpret research) and b) having the motivation to do this [27]. Recent evidence indicates that academics need to do much more to understand the priorities of policy makers. They should develop relationships with mutual benefit, co-produce evaluations and understand the most effective ways of communicating with policy makers [26]. Creating opportunities to bring together researchers and research-users from the conception and design stage of research onwards, as well as ensuring effective dissemination of research findings, would help ensure that research undertaken meets the needs of those who will use it. The importance of sustaining and scaling innovation is recognised by NHS England

through the development of an innovation roadmap to increase support for all stages of innovation [28]. The NHS Innovation Accelerator (NIA) aims to speed up the uptake of high-impact innovations through the 15 Academic Health Science Networks across England scaling evidence-based innovations for greater patient benefit [29].

Research to understand the processes involved in implementation could play a vital part in supporting the uptake of research into policy and practice [30]. Research is also demonstrating the effectiveness of new ways of working in cancer services. For example new aftercare models and self-management programmes [31,32]. However, these service innovations can face considerable challenges in implementation due to their impact on modes of service delivery and the culture of care. It is recognised, for example, that a cultural shift is required [33] to successfully deliver self-management support and the role of healthcare professionals (HCPs) in enabling a culture and providing structures through which this model of care can thrive is critical [34]. We need to appreciate the views of all stakeholders (healthcare professionals, patients, carers, commissioners, among others) to understand the barriers and facilitators to changes in clinical services, not only financially and practically, but also culturally, and what this means for relationships between healthcare professionals and cancer patients.

5. Conclusion

Robust evidence is required to prepare those living with and beyond cancer for what to expect, when common symptoms and problems might improve, what can be done to manage their impact and live fulfilling lives in spite of consequences of disease and treatment. Robust evidence is also essential to inform the development of health services and other forms of support to minimise the disruption to people's everyday lives. Programmes of research must have the infrastructure in place to support the development of future leaders in this field; without this, the future of the field will be compromised. Equally important is for healthcare providers, researchers and policy makers to work together to enable the uptake and dissemination of research in practice and to scale and sustain service innovation.

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Conflicts of interest

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References

[1] J. Maddams, M. Utley, H. Moller, Projections of cancer prevalence in the United Kingdom, 2010–2040, Br. J. Cancer 107 (2012) 1195–1202.

[2] E. Jefford, A. Karahalios, C. Pollard, M. Baravelli, J. Carey, S. Franklin, P. Aranda, Survivorship issues following treatment completion–results from focus groups with Australian cancer survivors and health professionals, J. Cancer Survivorship 2 (2008) 20–32.

[3] J. Corner, D. Wright, J. Hopkinson, Y. Gunaratnam, J.W. McDonald, C. Foster, The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study, Br. J. Cancer 96 (2007) 875–881.

[4] C. Foster, M. Breckons, P. Cotterell, D. Barbosa, L. Calman, J. Corner, D. Fenlon, R. Foster, C. Grimmett, A. Richardson, P.W. Smith, Cancer survivors' self-efficacy to self-manage in the year following primary treatment, J. Cancer Survivorship 9 (2015) 11–19.

[5] J. Armes, M. Crowe, L. Colbourne, H. Morgan, T. Murrells, C. Oakley, N. Palmer, E. Ream, A. Young, A. Richardson, Patients' supportive care needs beyond the end

of cancer treatment: a prospective longitudinal survey, J. Clin. Oncol. 27 (2009) 6172–6179.

[6] C. Foster, J. Haviland, J. Winter, C. Grimmett, K. Chivers Seymour, L. Batehup, L. Calman, J. Corner, A. Din, D. Fenlon, C.M. May, A. Richardson, P.W. Smith, Members of the Study Advisory, Pre-Surgery Depression and Confidence to Manage Problems Predict Recovery Trajectories of Health and Wellbeing in the First Two Years following Colorectal Cancer: Results from the CREW Cohort Study, PLoS One 11 (2016) e0155434.

[7] Independent Cancer Taskforce, Achieving World-Class Cancer Outcomes. A Strategy for England 2015–2020, (2015) Available from: http://www.cancerresearchuk.org/about-us/cancer-strategy-in-england.

[8] Macmillan Cancer Support, The Recovery Package, (2017) Available from: https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package.

[9] Macmillan Cancer Support, Developing a National Metric for Quality of Life, Available from: https://www.macmillan.org.uk/_images/developing-a-national-metric-for-quality-of-life_tcm9-307201.pdf.

[10] Public Health England, Cancer Data, Available at: https://www.cancerdata.nhs.uk/dashboard#?tab=Overview.

[11] K. Beaver, K.A. Luker, Follow-up in breast cancer clinics: reassuring for patients rather than detecting recurrence, Psychooncology 14 (2005) 94–101.

[12] S.M. Smith, H. Soubhi, M. Fortin, C. Hudon, T. O'Dowd, Managing patients with multimorbidity: systematic review of interventions in primary care and community settings, BMJ 345 (2012) e5205.

[13] Department of Health, Comorbidities: a Framework of Principles for System-wide Action, (2014) Available from: www.gov.uk/government/publications/better-care-for-people-with-2-or-more-long-term-conditions (Accessed August 2016).

[14] L. Haas, M. Maryniuk, J. Beck, C.E. Cox, P. Duker, L. Edwards, E.B. Fisher, L. Hanson, D. Kent, L. Kolb, S. McLaughlin, E. Orzeck, J.D. Piette, A.S. Rhinehart, R. Rothman, S. Sklaroff, D. Tomky, G. Youssef, F. Standards Revision Task, National standards for diabetes self-management education and support, Diabetes Care 36 (Suppl 1) (2013) S100–108.

[15] C. Foster, Survivorship and self-management in cancer care, in: D. Wyatt, N. Hulbert-Williams (Eds.), Cancer and Cancer Care, Sage, Place Published, 2015.

[16] J. Grimmett, J. Haviland, L. Winter, A. Calman, A. Din, P.W.F. Richardson, C. Smith, Colorectal cancer patient's self-efficacy for managing illness-related problems in the first 2 years after diagnosis, results from the ColoREctal Well-being (CREW) study, J. Cancer Survivorship 11 (2017) 634–642.

[17] D. de Silva, Helping People Help Themselves A Review of the Evidence Considering Whether It Is Worthwhile to Support Self-Management in Evidence, London Place Published, Health Foundation, 2011.

[18] C. Foster, C. Grimmett, C.M. May, S. Ewings, M. Myall, C. Hulme, P.W. Smith, C. Powers, L. Calman, J. Armes, M. Breckons, J. Corner, D. Fenlon, L. Batehup, E. Lennan, R.M. C, C. Morris, A. Neylon, E. Ream, L. Turner, L. Yardley, A. Richardson, A web-based intervention (RESTORE) to support self-management of cancer-related fatigue following primary cancer treatment: a multi-centre proof of concept randomised controlled trial, Support. Care Cancer 24 (2016) 2445–2453.

[19] T. Howell, J. Harth, C. Brown, S. Bennett, Self-management education interventions for patients with cancer: a systematic review, Support. Care Cancer 25 (2017) 1323–1355.

[20] E.A. Hammer, F. Ercolano, V.V. Wright, D. Dickson, G.D. Chyun, Self-management for adult patients with cancer: an integrative review, Cancer Nurs. 38 (2015) E10–E26.

[21] Health Foundation, Section 3: Extending Influence and Widening Impact. Part of the Research Communications Toolkit, (2017) [cited 2017 September]; Available from: http://reader.health.org.uk/s3-extending-influence-widening-impact.

[22] National Cancer Research Institute, Research Database, (2017) [cited 2017 September]; Available from: http://www.ncri.org.uk/research-database/.

[23] National Cancer Research Institute, Supportive and Palliative Care Research in the UK: Report of the NCRI Strategic Planning Group on Supportive and Palliative Care, (2004) (London), https://www.ncri.org.uk/wp-content/uploads/2013/11/2004-NCRI-Supportive-and-Palliative-Report.pdf.

[24] National Cancer Research Institute, Impact of the NCRI Supportive and Palliative Care Initiative, (2013) London https://www.ncri.org.uk/wp-content/uploads/2016/06/2013-NCRI-Impact-of-the-NCRI-Supportive-and-Palliative-Care-initiative.pdf.

[25] National Cancer Research Institute, The NCRI Living With and Beyond Cancer research initiative (http://www.ncri.org.uk/accelerating-cancer-research/lwbc/living-with-and-beyond-cancer-research-initiative/).

[26] L. Wye, E. Brangan, A. Cameron, J. Gabbay, J.H. Klein, C. Pope, Evidence based policy making and the 'art' of commissioning – how English healthcare commissioners access and use information and academic research in 'real life' decision-making: an empirical qualitative study, BMC Health Serv. Res. 15 (2015).

[27] K. Newman, C. Fisher, L. Shaxson, Stimulating demand for research evidence: what role for capacity-building? IDS Bull. 43 (2012) 17–24.

[28] NHS England, Innovation Road Map, Available from: http://www.innovation.england.nhs.uk/road-map.

[29] NHS England, NHS Innovation Accelerator, About the NHS Innovation Accelerator (NIA), Available from: https://www.england.nhs.uk/ourwork/innovation/nia/.

[30] C.R. May, F. Mair, T. Finch, A. MacFarlane, C. Dowrick, S. Treweek, T. Rapley, L. Ballini, B.N. Ong, A. Rogers, E. Murray, G. Elwyn, F. Legare, J. Gunn, V.M. Montori, Development of a theory of implementation and integration: normalization Process Theory, Implement Sci. 4 (2009) 29.

[31] J. Frankland, H. Brodie, D. Cooke, C. Foster, R. Foster, H. Gage, J. Jordan, I. Mesa-Eguiagaray, R. Pickering, A. Richardson, Follow-up care after treatment for prostate cancer: protocol for an evaluation of a nurse-led supported self-management and remote surveillance programme, BMC Cancer 17 (2017) 656.

[32] K. Batehup, H. Porter, P. Gage, P. Williams, E. Simmonds, L. Lowson, N.J. Dodson, R. Davies, J.D. Wagland, A. Winter, A. Richardson, J.L. Turner, Follow-up after curative treatment for colorectal cancer: longitudinal evaluation of patient initiated follow-up in the first 12 months, Support. Care Cancer 25 (2017) 2063–2073.

[33] The Health Foundation, A Practical Guide to Self-management Support. Key Components for Successful Implementation, (2015) Available from: http://www.health.org.uk/publication/practical-guide-self-management-support.

[34] N.D. Hughes, S.J. Closs, K. Flemming, M.I. Bennett, Supporting self-management of pain by patients with advanced cancer: views of palliative care professionals, Support. Care Cancer 24 (2016) 5049–5057.