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Integrative Whole Person Oncology Care in the UK

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Abstract

The term 'whole person cancer care' - an approach that addresses the needs of the person as well as treating the disease - is more widely understood in the UK than its synonym 'integrative oncology". The National Health Service (NHS), provides free access to care for all, which makes it harder to prioritise NHS funding of whole person medicine, where interventions may be multi-modal and lacking in cost-effectiveness data. Despite this, around 30% of cancer patients are known to use some form of complementary or alternative medicine (CAM). This is virtually never medically led, and usually without the support or even the knowledge of their oncology teams, with the exception of one or two large cancer centres. UK oncology services are, however, starting to be influenced from three sides; firstly, by well-developed and more holistic palliative care services; secondly, by directives from central government via the sustainable healthcare agenda; and thirdly, by increasing pressure from patient-led groups and cancer charities. CAM remains unlikely to be provided through the NHS, but nutrition, physical activity, mindfulness, and stress management are already becoming a core part of the NHS 'Living With and Beyond Cancer' agenda. This supports cancer survivors into stratified pathways of care, based on individual, self-reported holistic needs and risk assessments, which are shared between healthcare professionals and patients. Health and Wellbeing events are being built into cancer care pathways, designed to activate patients into self-management and support positive lifestyle change. Those with greater needs can be directed towards appropriate external providers, where many examples of innovative practice exist. These changes in policy and vision for the NHS present an opportunity for Integrative Oncology to develop further and to reach populations who would, in many other countries, remain underserved or hard-to-reach by whole person approaches.

Integrative Whole Person Oncology Care in the UK

Introduction

The term 'whole person cancer care' is more widely understood in the UK than its synonym 'integrative oncology'. Whole person care describes an approach that addresses the needs of the person as well as treating the disease. This involves, for example, giving people the skills, therapeutic support and confidence they need to build their resilience and manage their symptoms, alongside treatments that help them live as well as possible, for as long as possible. Conventional oncology services are delivered alongside patient education and self-management programmes and are co-ordinated with supportive care that addresses psychological, emotional, and spiritual/existential needs. In this article we will review the key initiatives and policies that have facilitated the development of a whole person approach to cancer treatment in the UK.

Mainstream medical provision in the UK is almost exclusively organised through the central government funded National Health Service (NHS). Hospitals and primary care/family physicians (General Practitioners, GPs) provide care that is bought by loco-regional commissioning groups, and, in England, often directed by the National Institute of Health and Care Excellence (NICE). NICE assesses individual healthcare treatments and interventions for cost-effectiveness and declines re-imburement if they fall below the NICE threshold of cost per quality adjusted life year (QALY) based on available research data (1). In cancer, some additional high-cost drugs not meeting the NICE cost/QALY metric, but deemed to meet certain efficacy criteria, are available through a separate funding structure, the Cancer Drugs Fund (CDF). There are downsides to this system that provides free access to care for all - it limits the availability of cancer treatments compared to some other countries, notably sections of the US and Germany, and it makes it harder to prioritise NHS funding of whole person medicine, where interventions may be multi-modal and currently lacking in cost-effectiveness data. This has led to the erosion of the few complementary

medicine services that had been available on the NHS. There has also been little in the way of support for academic institutions to research integrative approaches, despite some Department of Health investment in capacity building for CAM research in the early 2000s. While some University Departments of Community Medicine or Health Sciences continue to undertake small projects related to CAM, there is no co-ordinated or funded national programme of CAM research. Without this clinical and academic base, it has been more difficult to conduct and attract funding for the robust research studies on CAM therapies needed by NICE for its assessments.

How do people with cancer access complementary and alternative medicine?

Despite the threat to provision of CAM in the UK, around 30% of cancer patients are known to use some form of complementary therapy (2). This is virtually never medically led, and usually without the support or even the knowledge of their oncology teams. There are one or two notable exceptions where large cancer centres have small departments of complementary therapy and contribute to the international research evidence base on CAM in cancer (3). In the absence of a strong national body or guidance, the provision of CAM for people affected by cancer is largely provided privately or by voluntary sector (charitable) organisations and is somewhat fragmented. The palliative care sector is a clear case in point. The UK has a strong tradition in holistic palliative and end-of-life care for cancer patients, and its services are among the best in the world. Care is generally provided through independent charitable hospices, which receive some NHS staffing and funding and are supported by the NHS primary care services, as well as by palliative care teams within NHS hospitals. Within the NHS, there is no formal physician ownership of patients, financial or otherwise, allowing palliative care services to be available to patients alongside their normal oncological treatment from the point of diagnosis onwards. Despite this, the service provided is largely along traditional palliative care lines of complex symptom management and high quality end-of-life care. Although many hospices also offer some counselling, complementary therapies such as massage and reflexology, and respite care, these are

usually more focussed on the patient at the end of the cancer journey rather than promoting whole person wellbeing.

Since the early 1980s, cancer charities have provided increasing amounts of informal support, information and complementary medicine (e.g. mindfulness, acupuncture, natural products) to various groups of cancer patients. Most (if not all) of these charities were started by people who had experienced cancer treatment themselves and saw the necessity for holistic approaches to care. Examples include Penny Brohn UK, The Haven, Cavendish Cancer Care and Maggie's Centres, to name a few. These charities actively seek to establish relationships with traditional medical oncology professionals. Penny Brohn UK is now working with the NHS and other partners to provide self-management education and complementary support for cancer patients around the UK, and there are now 19 Maggie's Centres in NHS hospitals across the UK providing professional practical, emotional, and social support to people with cancer. The Haven also provides self-management education and complementary therapies for people with breast cancer, over multiple sites in England.

Key developments supporting whole person oncology care.

The development of closer relationships between the charity sector and NHS is in part due to the 2007 Cancer Reform Strategy (4) which, for the first time, outlined a national directive at improving the experience of cancer patients, rather than just improving medical outcomes. This was in part driven by Macmillan Cancer Support, a large national charity, which supports NHS cancer teams by funding clinical nurse specialists (CNS) and other patient support-worker posts. The national directive included better information sharing and continuity between primary care physicians and hospital-based medical services, improved face-to-face communication skills of oncologists, and enshrining the central role of the CNS as the patient advocate in the medical team. The National Cancer Survivorship Initiative (NCSI) was created to coordinate an extensive analysis of the unmet needs of cancer survivors (5). This work led to 'well-being' being recognised as a valid outcome in cancer

medicine worth funding and a “Recovery Package” for all people with cancer being recommended. The Recovery Package includes access to: Holistic Needs Assessment and Care Planning, Treatment Summary, Cancer Care Review, and Health and Wellbeing Events (6).

Concurrent to the development of this Recovery Package, was the development of a patient-reported outcome measure called Measure Yourself Concerns and Wellbeing (MYCaW), which provides an opportunity to quickly capture and track the severity of patients’ primary concerns in clinical consultations (7). MYCaW is now used in integrative oncology internationally. Data that directly reflects the patients’ voice, and therefore is fully patient-centred (as opposed to reflecting what professionals think the patient needs) has been used to support the development of interventions for people with cancer at a time when such interventions were being required for the Recovery Package. Such interventions have resulted in patients having increased knowledge, skills and confidence (“activation”) to improve their situation, which positively impacts on their health and their ability to sustain positive behaviour change. These factors enable improved health-related quality of life and improvements in concerns and wellbeing up to 12 months later (8). These data indicate high potential for long-term financial savings and clinically relevant improvement in outcomes. Moreover, the needs of carers and supporters can also be addressed through similar interventions.

In 2014 the Government set out its vision of the NHS to meet new and current challenges in healthcare, which included a transformation of the NHS’ approach to living with and beyond cancer - by putting patient experience on a par with clinical effectiveness and safety, and placing more emphasis on prevention and greater control of patients over their own care, “including the option of shared budgets combining health and social care”(9). An Independent Cancer Taskforce then reported on how to translate this vision into cancer services, highlighting that patient experience should be on a par with clinical effectiveness

and safety, together with a “Transform[ed] ... approach to support people living with and beyond cancer”(10). An ancillary benefit is that supporting people into self-management and recovery, alongside regular screening investigations and rapid access to hospital review if there are symptoms or concerns, should create NHS savings by freeing up money currently spent on routine hospital-based follow up of asymptomatic patients. Furthermore, in England, there are now 44 strategic regions (STPs), with their own 5-year strategies on how budgets for health and social care are allocated. This is facilitating the Government’s recent sustainable healthcare transformation agenda to promote self-management, person- and community-centred care, and ‘social prescribing’ (referring people from primary care into social or lifestyle support and self-management programmes as opposed to default prescribing of drugs). This strategic shift away from a one-size-fits-all approach to service provision and funding has provided an opportunity for some localities to fund CAM therapies as part of their social prescribing provision, rather than as part of their healthcare provision. There is no centralized approach to do this, but STPs may bid to the Cancer Transformation Fund, (a short-term NHS based fund), in order to facilitate achieving this aspect of their STP strategy. Funds may, for example, come from the public health budgets, the primary care budgets, local authority budgets or a combination of these depending on the strategy for each STP region.

In 2012, The British Society of Integrative Oncology (BSIO) was established, along the lines of the international Society of Integrative Oncology, as a multidisciplinary organisation. It recognises the increased patient demand for whole person care, as well as the current lack of involvement of the oncology care team in complementary therapy decisions, and therefore the potential for increased risks of unintended adverse effects and interactions. The BSIO therefore promotes balanced discussion between healthcare professionals, complementary medicine practitioners and researchers, about the evidence for CAM within the provision of whole person cancer care.

Conclusion

UK oncology services are starting to be influenced from three sides; firstly, by well-developed and more holistic palliative care services; secondly, by directives from central government via the sustainable healthcare agenda; and thirdly, by increasing pressure from patient-led groups and cancer charities. Within the NHS, the focus remains on supporting cancer survivors into stratified pathways of care, based on individual, self-reported holistic needs and risk assessments, which are shared between healthcare professionals and patients. Unmet needs can then be addressed via the Recovery Package's Health and Wellbeing events, which are built into cancer care pathways, designed to activate patients into self-management and support positive lifestyle change. Those with greater needs can be directed towards appropriate providers external to the NHS, where many examples of innovative practice exist. CAM remains unlikely to be provided through the NHS, but nutrition, physical activity, mindfulness, and stress management are already becoming a core part of the NHS 'Living With and Beyond Cancer' agenda.

A cancer diagnosis provides a unique, "teachable moment"(11), where people are often highly motivated to make positive lifestyle changes that they might not have considered before. The national public healthcare system in the UK, through national guidelines, government directives and working alongside the UK's influential national voluntary (not-for-profit) sector presents an opportunity for Integrative Oncology to develop further and to reach populations who would, in many other countries, remain underserved or hard-to-reach by whole person approaches.

References

1. Lewison G, and Sullivan R. The Impact of cancer research: how publications influence UK cancer clinical guidelines. *Br J Cancer*, 2008; 98(12):1944-50.
2. Posadzki P, Watson LK, Alotaibi A, Ernst E. Prevalence of Complementary and

Alternative Medicine-use by UK Cancer Patients: A Systematic Review of Surveys. *J Integr Oncol*. 2012; 1:102. DOI:10.4172/2329-6771.1000102

3. Molassiotis A, Bardy J, Finnegan-John J, Mackereth P, Ryder DW, Filshie J, Ream E, Richardson A. Acupuncture for Cancer-Related Fatigue in Patients With Breast Cancer: A Pragmatic Randomized Controlled Trial., *Journal of Clinical Oncology*, 2012; 30(36):4470-4476. DOI: 10.1200/JCO.2012.41.6222
4. Department of Health. Cancer Reform Strategy, 2007
<http://www.nhs.uk/NHSEngland/NSF/Documents/Cancer%20Reform%20Strategy.pdf>
5. Glaser A, Fraser L, Corner J, Feltbower R, Morris EJA, Hartwell G, Richards M, Wagland R. Patient-reported outcomes of cancer survivors in England 1-5 years after diagnosis: a cross-sectional survey. *BMJ Open*, 2013; 3: e002317.
6. Department of Health. Living With and Beyond Cancer to Improve Outcomes. 2013.
<https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes>.
7. Jolliffe R, Seers H, Jackson S, Caro E, Weeks L, Polley MJ, Responsiveness, Content Validity, and Convergent Validity of the Measure Yourself Concerns and Wellbeing (MYCaW) Patient-Reported Outcome Measure. *Integrative Cancer Therapies*, 2014;14(1):26-34.
8. Polley M, Jolliffe R, Boxell E, Zollman C, Jackson S, Seers H. Using a whole person approach to support people with cancer: a longitudinal, mixed-methods service evaluation. *Integrative Cancer Therapies*, 2016: 1-11.

9. National Health Service England. Five Year Forward View. 2014.
<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

10. Independent Cancer Taskforce. Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020. 2015.
https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

11. Lawson PJ, Flocke SA. Teachable moments for health behavior change: a concept analysis. Patient Education and Counselling, 2009; 76(1): 25-30.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2733160/>