

## Delivering long-term cancer care in primary care

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## **Delivering long-term cancer care in primary care**

In 2016, there were 17.2 million incident cases of cancer globally and the number of incident cases increased by 28% in the preceding decade<sup>1</sup>. Similar trends are anticipated in the United Kingdom (UK) with 2.5 million people living with cancer in 2015 which is expected to increase to 4 million by 2030<sup>2</sup>. Ten-year survival for all cancers has more than doubled in the United Kingdom from 24% to 50% over the last four decades<sup>3</sup>. This is due a combination of factors including better diagnostic technology, screening programmes and better treatments<sup>1</sup>. Recovery after cancer and its treatment presents new challenges including physical problems such as overwhelming fatigue, psychological problems such as fear of recurrence, social problems such as loss of employment, and the need for supplementary information. Primary care is well placed to provide proactive care to help with the interlinked biopsychosocial problems that may arise after the completion of cancer treatment.

There is no clear consensus where the responsibilities for care of cancer survivors, i.e. those living with and beyond cancer, lie on the primary-secondary-tertiary healthcare continuum. (Patients or clinicians do not universally adopt the term 'survivorship' as it implies a definite conclusion to treatment when this is not always clear). According to the National Cancer Research Institute (NCRI) and James Lind Alliance (JLA), the top priority for living with and beyond cancer research is to answer the question "What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology)?" The recently published European guidelines<sup>4</sup> for quality cancer care in primary care highlighted the need for more evidence in primary care-led care and the ability for primary care to manage the long-term consequences of cancer treatment.

This article aims to summarise the current tools used to address the consequences of cancer and its treatment.

## Tools for living with and beyond cancer care

There have been two contrasting approaches, often initiated by secondary care, to improve cancer follow-up care: needs assessment and survivorship care plans (SCPs) (see Useful Resources). Needs assessment can be subdivided into holistic needs assessments (HNA), and distress thermometer and problem lists (DT&PL).

The DT&PL were developed in 1998 and consist of a distress thermometer that provides a quick analogue scale accompanied by a longer checklist similar to the HNAs covering several domains but is not common in the UK. Interviews with clinicians and patients identified that the DT&PL legitimised and identified distress but its efficacy as a tool was limited by lack of time, support services and referral guidelines<sup>8</sup>. An unblinded randomised controlled trial comparing the use of DT&PL to usual care (n=220) in patients with different cancer types receiving chemotherapy and radiotherapy revealed that the DT&PL often served as an assessment tool alone - without a clear triage or management plan, and did not influence patients' mood<sup>9</sup>. However, this result could reflect poor trial design.

A similar approach in use is the holistic needs assessment. The HNA was developed in the UK following a national drive in 2010 to move from generalised to personalised care planning. The HNA, which is typically initiated at the end of treatment, often via a combination of electronic input and face-to-face contact with a secondary care healthcare professional, is designed to provide tailored health interventions according to individual situations rather than isolated disease processes. The components include:

- Physical concerns: fatigue, pain,
- Practical concerns: work, finances, travel, education, being a carer for others
- Family/relationship concerns: friends and family
- Emotional concerns: mental health, religious and spiritual concerns
- Lifestyle or information needs: support groups, physical activity, smoking

Despite this, HNAs are implemented in only one in four people who are living with and beyond cancer in the UK<sup>10</sup>. From 2016 to 2018, 83% of the 62,886 HNAs conducted identified care needs and most HNAs were implemented at the initial diagnosis or after the completion of treatment (unpublished data, Macmillan). The most prevalent concerns raised by patients included: psychological concerns, questions regarding diagnosis, sleep problems, pain, tiredness and weight changes (unpublished data, Macmillan). Macmillan Cancer Support is currently evaluating the nationwide effectiveness and use of HNAs. In contrast to the DT&PL, the HNAs should generate a personalised care plan with supportive resources (see Useful Resources).

Alternatively, survivorship care plans (SCPs) developed in 2006 as a result of US stakeholder collaboration involve a cancer-related treatment summary and an on-going care plan and aim to provide care coordination between primary care and secondary care, rather than identification of care needs. These are delivered directly via a one-off, face-to-face intervention with one or more healthcare professionals in secondary care but are sometimes posted directly to the healthcare professional. There is no consensus on the exact constituents of the SCP but broadly speaking there are five recommended domains<sup>11</sup>:

1. Treatment summary, care co-ordination & follow-up
2. Short & long-term effects, signs of recurrence & rehabilitation
3. Psycho-social, and spiritual support & sexual life
4. Health promotion, prevention, screening and genetic testing
5. Supportive resources

There have been several randomised control trials (RCTs) looking at the effects of survivorship care plans, which have reported no discernible benefit. A recently published systematic review<sup>11</sup> confirmed this and the authors concluded that study design heterogeneity and varying outcome measures which did not necessarily relate to the intervention were the probable reasons behind this. There are several reasons why SCPs might not have shown positive outcomes, which

may include differences in cancer types, cancer treatment even in the same cancer type, patient populations; differences in intervention components, delivery and timing.

Similar to the SCP, in the UK the secondary care team may produce a 'treatment summary' which provides patients and GPs with a single page summary of treatments, ongoing tests, financial support, symptoms requiring medical attention, and outstanding actions for the GP and other professionals involved in care. There is variable uptake nationally of this initiative, which could ease transition of care from the hospital to the community.

### Stakeholder views on the role of Primary Care

A systematic review collating the views of patients<sup>5</sup> and GPs<sup>6</sup> on the role of the General Practitioner (GP) outlined that patients expected their GPs to provide 'general primary care'; biopsychosocial care related to cancer treatment and beyond; palliative care when appropriate; appropriate information; and to act as an advocate for appropriate referrals<sup>5</sup>. Research including the entire primary care team and that relating just to GPs generally comes to similar conclusions. European guidance<sup>4</sup> delineated the need to use the full breadth of primary care teams from community pharmacists and nurses to geriatricians and palliative care physicians. Furthermore, policymakers must recognise the importance of unpaid carers and their needs.

Patients wanted GPs to be better engaged in cancer care especially with specialists, to have access to guidelines, to be more knowledgeable in long-term cancer care, and to provide better support with pathways for referral and recurrence monitoring<sup>5</sup>. GPs felt a shared care model would provide better psychosocial support for patients and financial savings at a patient and system level<sup>6</sup>. However a 2015 survey found that although GPs felt that they are best placed within primary care to initiate and coordinate care they felt they lacked the time and knowledge to provide adequate care for those living with and beyond cancer<sup>7</sup>.

Barriers to providing cancer care included limited time and resources, lack of care coordination with secondary care, including poor communication and inconsistent information from

secondary care, lack of training and time for training, and financial constraints<sup>5 6</sup>. GPs questioned the feasibility of implementing a proactive model compared to a reactive approach<sup>6</sup>. Such a proactive model called the 'cancer care review' has been introduced in the UK but there is danger of it being a 'tick-box' exercise without acknowledgement of the personal impact of the cancer diagnosis and current treatment. As a template within electronic record systems, 'cancer care reviews' are linked in the UK to payment for performance measures within 6 months of a cancer diagnosis being made under the Quality and Outcomes Framework (QoF). Anecdotally, the offer of a proactive appointment especially during treatment can legitimise patient concerns and initiate the start or continuation of relationship with a GP long after completion of treatment.

### Future Directions

In the UK, GPs have guidelines<sup>12</sup> for caring for those living with and beyond cancer. However, the awareness and implementation of this guidance in clinical practice amongst existing GPs is currently unknown. Identification of barriers and facilitators to delivery of this guidance, and perhaps the aforementioned tools, could help ensure good delivery of care by GPs who are postgraduate learners. Future work must identify the most effective models of care and how they can deliver personalised care using validated outcome measures. Primary care is already the site of the majority of patient contacts and will require further resources to deliver care for those living with and beyond cancer.

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### Useful Resources

- Distress Thermometer & Problem List - from National Comprehensive Cancer Network: [https://www.nccn.org/patients/resources/life\\_with\\_cancer/pdf/nccn\\_distress\\_thermometer.pdf](https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf)
- Holistic Needs Assessment - from London Cancer: [http://www.londoncancer.org/media/79850/London-Holistic-Needs-Assessment\\_print-version\\_v2.2\\_HW.pdf](http://www.londoncancer.org/media/79850/London-Holistic-Needs-Assessment_print-version_v2.2_HW.pdf)
- Survivorship Care Plan – from American Society of Clinical Oncology:

[http://www.cancer.net/sites/cancer.net/files/survivorship\\_care\\_plan\\_template\\_final.docx](http://www.cancer.net/sites/cancer.net/files/survivorship_care_plan_template_final.docx)

- Treatment Summary – from Macmillan Cancer Support:  
[https://www.macmillan.org.uk/documents/aboutus/health\\_professionals/recoverypackage/treatmentsummary.pdf](https://www.macmillan.org.uk/documents/aboutus/health_professionals/recoverypackage/treatmentsummary.pdf)
- The UK Top living with and beyond cancer research priorities: National Cancer Research Institute; 2018. Available from: <https://www.ncri.org.uk/lwbc/>

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