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Models and tools for those living with and beyond cancer

Dear Editor,

We read the "ECCO Essential Requirements for Quality Cancer Care: Primary care" (Banks et al., 2019) with great interest and are very grateful to the authors for highlighting the important and understudied area of living with and beyond cancer and the role of primary care. We noted the attention drawn to survivorship care plans (SCPs) however, whilst SCPs can theoretically improve care coordination and communication between patients and healthcare care providers, there is limited evidence for their clinical efficacy. A recent systematic review (Jacobsen et al., 2018) identified randomised controlled trials evaluating SCPs (13 studies; n = 4008) and found no evidence that they improved a variety of outcomes such as psychological distress and quality of life, compared to controls. This negative finding could be explained by heterogenous methodology including lack of standardised outcomes and lack of long-term follow-up. Alternative approaches include assessment tools such as distress thermometer and problem list (DT&PL), and holistic needs assessment (HNAs) with personalized care plans. Both the DT&PL and HNAs involve checklists across domains such as practical concerns e.g. related to work or physical symptoms e.g. pain. Johnston and colleagues (Johnston et al., 2019) concluded that HNAs coupled with care plans and appropriate direction to services are effective at decreasing patient distress and pain for up to 12 months (4 trials, n = 3141). Thematic analysis identified that it is more important how the HNA is implemented rather than what is implemented to understand the effects on patient outcomes such as distress. The engagement with support after a HNA may be a more appropriate outcome rather than conventional outcomes such as physical or emotional symptoms.

Tools such as HNAs and SCPs represent different working methods (or "models") of survivorship care. Other existing models of cancer survivorship care can be broadly divided into multi-disciplinary, disease-specific, shared care or risk-stratified, and chronic care models (Jacobs and Shulman, 2017). The multi-disciplinary and disease-specific models focus predominantly on secondary care and often are based in designated survivorship clinics. The multi-disciplinary model typically involves multiple providers and provides same-day care whilst the disease-specific model provides clinics for individual diseases. In contrast, the risk-stratified and chronic care models focus on primary care. The risk-stratified model stratifies clinical risk into low, moderate and high risk where the low risk is exclusively primary care delivered survivorship care whereas high risk is exclusively secondary care delivered oncological care. For example, the risk-stratified model is partly in operation in British primary care where patients having had treatment for prostate cancer have annual prostate specific antigen tests (PSA) to rule out recurrence.

The chronic care model (Jacobs and Shulman, 2017), implemented with many chronic diseases such as diabetes, utilises dedicated care reviews, access to medical care, evidence-based guidance, disease registers and self-management resources. There is no consensus which model is most effective for those living beyond cancer in primary care or whether universal recall of all patients who have had treatment for cancer would be beneficial to patients or resource efficient.

Model evaluation would require outcome measures (Halpern and Argenbright, 2017) that have been context-validated including quality of life, care satisfaction, symptoms, and patient knowledge. Other outcomes, not included in SCP trials to date (Jacobsen et al., 2018), could include functional status, social support, health equity and perhaps even employment.

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