The experiences of people living with cancer (PLWC) when undergoing care transitions.

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Background

There is currently limited evidence that describes the experiences of the care PLWC receive at transition points along the cancer pathway, and between services and providers.

The research aimed to identify the needs and measure the experiences of PLWC at these points.

Method

The research involved:

- a) scoping interviews and a literature review;
- b) a qualitative stage with 87 depth interviews using a journey mapping approach to explore the experiences of PLWC across care transitions, and
- c) a quantitative stage with 654 survey responses to measure the needs and experiences of PLWC.

The quantitative data were weighted by age, gender and cancer type. People from lower socio-economic and BAME groups were under-represented in the research.

Results

The literature review identified that this issue is under-researched. Primary research suggested a range of transitions that PLWC could experience at different stages of the cancer journey such as leaving treatment and having a change of circumstances in their lives. Physical and clinical needs, as well as information needs, tended to be most often met. People had more mixed experiences of the extent to which their emotional/psychological needs were met. Practical, social care, and family needs were often unmet. In general, PLWC felt less supported as their journey progressed.

Most felt their care was well co-ordinated. Those who did not report this felt that a number of different consequences occurred as a result including increased stress and anxiety and delays in care and treatment.

Conclusions

Health and care providers need to work together to ensure that transitions are well managed and PLWC have the information and support that they need throughout the cancer journey.

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'Everyone refers me to someone else... If I was to complain, I'm not sure who would be responsible for giving me better care.'

'Once treatment is over and you're left on your own that's when you need support the most.'

'When the pathway is laid out before you, that takes away a lot of the anxiety.'

Acknowledgments