

Intervention co-design with teenage and young adult cancer patients: a mutually beneficial approach

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Abstract

Background

Fatigue is the most prevalent and distressing symptom experienced by teenagers and young adults with cancer. Young patients report finding existing fatigue management strategies unhelpful. Co-design is an approach that is increasingly used to optimise healthcare services but is rarely applied to the development complex interventions. We describe the first use of co-design methods to develop an intervention that meets the needs of young cancer patients.

Methods

Thirteen patients and ten parents were recruited. Patients were aged 16-27 and within a year after the end of cancer treatment. In an iterative multiphase study design, participants took part in semi-structured interviews and focus groups. They then received the co-designed prototype intervention, before a final phase of feedback and amendment.

Results

Young patients and their parents were keen to be involved in the co-design process, and recruitment was rapid. Although data saturation was achieved within seven weeks, the study briefly re-opened to recruitment because of ongoing interest in participation. Despite a study duration of 25 weeks in a vulnerable patient cohort, the attrition rate was less than 20%. Engagement was high, with participants describing altruistic and therapeutic benefits from being involved as co-researchers. As well as identifying distinct age-related intervention needs, the co-design process generated research outputs that surpassed expectations, including determining the likely intervention mechanism and raising public awareness on social media.

Conclusion

Intervention co-design is a valuable method for complex intervention development. The process was highly acceptable to young cancer patients and led to unanticipated mutual benefits.

Patient and Public Involvement (PPI)

The co-design process was, in itself, an exercise in patient and public involvement. As well as during the research process itself, an e-focus group advised during the study set-up phase, and a former patient was a member of the core research team, providing advice at every stage. A key research

output, videos 'made by young people for young people' (funded by Macmillan Cancer Support) led to over a million hits on social media. Public dialogue occurred at five subsequent live events, including the keynote lecture at the Shine Cancer Support national conference for over 100 young adults with cancer.