



COMMENTARY

The development of health behaviour change interventions for childhood cancer survivors: The need for a behavioural science approach

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1 | INTRODUCTION

Late effects of treatment, particularly second cancers and cardiovascular complications, account for significant morbidity and mortality in childhood cancer survivors (CCSs).¹ Health behaviours such as eating healthily, abstaining from smoking tobacco and engaging in regular physical activity are important and modifiable protective factors for CCSs' cardiometabolic health, and health in general.² It may even be argued that due to their elevated risk of disease, the establishment and maintenance of healthy behaviours is more important for CCSs than similarly aged people without a history of cancer. Therefore, health behaviour change interventions (HBCIs) aiming to help CCSs adopt and maintain healthier behaviours are a key strategy to prevent ill health, prolong life and maximise quality of life.

Reviews have previously identified that few HBCIs exist for CCSs.³⁻⁶ Methodological limitations in the testing of interventions (eg, small samples) and heterogeneity between studies (eg, intervention content) also limit the interpretation and robustness of findings.³⁻⁶

However, a further significant limitation exists, which has not previously been highlighted - namely that HBCIs among CCSs are failing to adopt a behavioural science approach, particularly in their development phase. The consequence of this is that we lack high-quality evidence- and theory-based HBCIs that provide realistic potential to effectively encourage and support CCSs to adopt, and maintain, healthier behaviours.

Below, we discuss four main areas where adopting a behavioural science perspective could improve the development of HBCIs among CCSs and aid the advancement of knowledge and practice of behaviour change in this population.

2 | USE OF FRAMEWORKS

Among recent advances in behavioural science is the establishment of several frameworks to support and guide researchers to rigorously develop interventions.⁷⁻⁹ These frameworks outline systematic steps to increase the likelihood that the resulting intervention will be evidence based, appropriately use theory, will be effective and can be implemented in practice. Despite this, developers often favour the

Abbreviation: CCSs, childhood cancer survivors; HBCIs, health behaviour change interventions; ISLAGIATT, it seemed like a good idea at the time; TDF, Theoretical Domains Framework.

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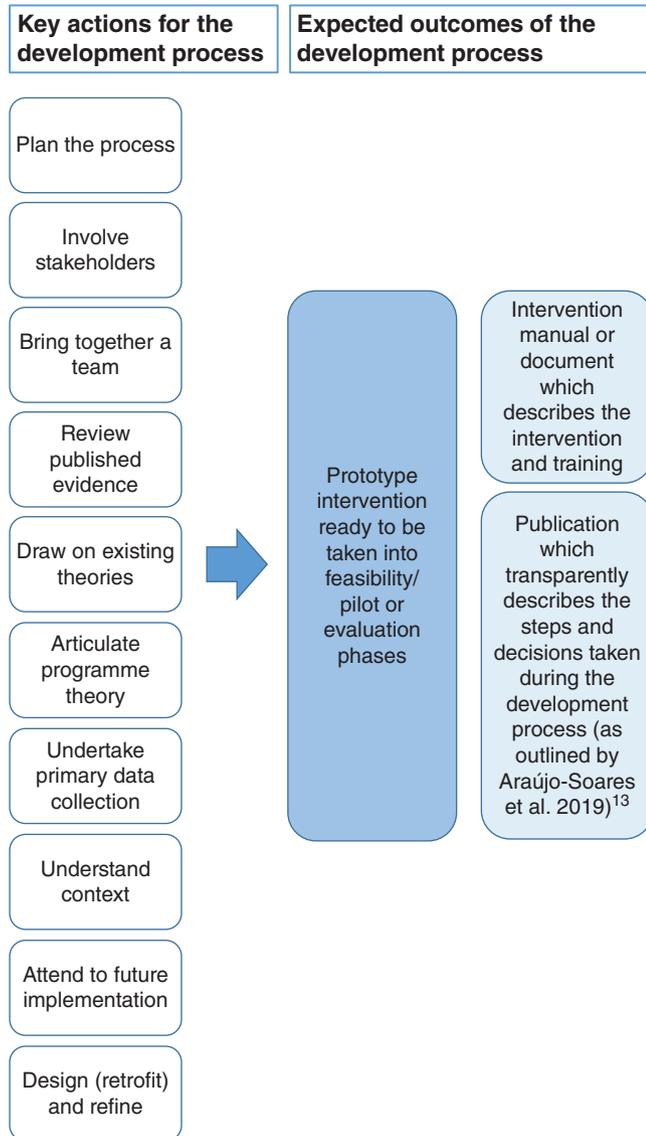


FIGURE 1 Key actions and expected outcomes of the intervention development process (adapted from O’Cathain et al. 2019)¹¹

ISLAGIATT (“it seemed like a good idea at the time”) approach to intervention development (Martin Eccles, personal communication). When following ISLAGIATT, developers decide from the outset what the intervention will be without undertaking proper steps to understand what it is the intervention will need to change (ie, the behaviour and what influences it), and exactly how it will aim to change it. Specific to CCSs, only one of 16 HBCIs in the aforementioned reviews cites use of an intervention development framework.¹⁰ In general, HBCIs with CCSs share very little about how their intervention was developed.

Of particular relevance, recent guidance that resulted from a large consensus exercise funded by the UK Medical Research Council and National Institute for Health Research outlines 10 key actions that should be considered in the development phase of an intervention (Figure 1).¹¹ The intensive development phase begins by planning activities (eg, identifying the problem) and involves all actions through to publishing a paper describing the development process, producing

a detailed intervention manual (including a training programme for those delivering the intervention, if needed) and having a prototype intervention ready to take to the feasibility/piloting or evaluation phase. These actions are not sequential but should be considered in a dynamic, iterative and flexible way. Even in situations where an effective intervention to change the behaviour of interest may already exist, further research, as described below, is needed to ensure that the intervention is adapted (retrofitted) to the new context and population.¹²

3 | UNDERSTANDING THE TARGET BEHAVIOUR

Prior to providing a solution, we need to understand the problem. Therefore, for interventions to be effective, we need a detailed understanding of the factors (determinants) that influence the performance of the behaviour that our intervention aims to change. Behavioural determinants span demographic, cognitive, emotional, physical, social, environmental, socioeconomic, commercial and cultural and, potentially, health care system-related factors. Identifying determinants that are both potentially modifiable and have a strong relationship with the behaviour will uncover what it is the intervention will need to target in order to change behaviour.⁷ Importantly, we need an understanding of how behavioural determinants manifest in the particular group(s) we aim to help.⁷ Compared to the general population, cancer survivors are known to experience additional barriers and facilitators to healthy behaviours. For example, in the limited number of studies that have explored the barriers and facilitators to physical activity in CCSs who have completed treatment, a lack of time, money and facilities have been reported to hinder activity^{13–15}; these barriers are also present in the general population.¹⁶ However, CCSs have also reported additional barriers specific to the cancer, including fatigue, the ongoing impact of treatment-related inactivity and frustration at not being as physically able as they had been prior to their cancer.^{13–15}

Determinants may even differ within specific (sub-)groups of CCSs. For instance regarding physical activity or exercise, brain tumour survivors may be more likely to experience neurocognitive issues that make some activities difficult; those treated with anthracyclines may be warned against participating in extreme sports or weightlifting; solid tumour survivors may be more likely to experience physical limitations; and patients still in treatment may have ongoing side effects, while long-term CCSs may be dealing with late effects of treatment. The determinants of health behaviours such as physical activity will also differ depending on the developmental stage of the survivor (eg, childhood and adolescence) and (potentially) their gender.¹⁷ Therefore, interventions should be both targeted to the needs and context of the group to which they pertain (eg, CCSs or a specific subgroup of CCSs) and tailored to the individuals within that (sub-)group.⁷ Indeed, there is evidence from a range of areas that tailoring is a key determinant of intervention effectiveness.^{18,19}

Understanding can be achieved by reviewing existing evidence on the determinants of the target behaviour and, ideally, primary research

with the intended recipients of the intervention.^{7,8,11} Qualitative research using a tool such as the Theoretical Domains Framework (TDF) to inform interviews and/or coding/analysis can be useful to identify the many influences on the target behaviour.²⁰ However, only five of 16 HBCIs identified across the reviews explicitly state research with CCSs informed their intervention,^{10,21–24} and it is unclear to what extent this research identified the behavioural determinants as opposed to more general views. Overall, there is limited research exploring specific barriers and facilitators of health behaviours in CCSs and, therefore, a lack of formative research to underpin HBCIs, indicating that primary research is urgently required.

4 | USE OF THEORY

Intervention development frameworks advocate the use of theory.^{7–9,11} Theory aims to describe the drivers of behaviour enactment and behaviour change. Although interventions based on theory are more likely to be effective, there are several theory-related and methodological issues that may hinder this (eg, inaccuracy of the theory itself, or not fully using the theory).²⁵ However, without theory we cannot hypothesise how and why behaviours could change, decide which tools or techniques may be useful in changing behaviour, or understand why an intervention has succeeded or (more often) failed in initiating and maintaining behaviour change. In practical terms, this means that behavioural determinants should be mapped onto relevant constructs from one or more theories. Relevant theory(ies) may be identified from the outset to inform the intervention, although the TDF offers a route by which determinants can be identified, then organised to ascertain the most relevant theoretical approach. However, although several HBCIs with CCSs state use of theory, it is not clearly evidenced what led to the selection of the theory(ies), nor is it clear how theory informed intervention content and delivery.

5 | INVOLVING KEY STAKEHOLDERS

Involving stakeholders throughout the development process will increase the likelihood that the resulting intervention is perceived as relevant, acceptable, engaging, useable and feasible by those whom it aims to help (eg, CCSs and their parents/guardians), those who will deliver it (eg, health professionals) and even those who are expected to fund it (eg, policy makers).^{7,11} Engagement is also crucial for legacy. Prioritising stakeholders' perspectives can help to recognise their needs and preferences and anticipate and address potential issues. Therefore, active involvement of CCSs and, in some instances, their parents (due to the role that they play in their child's health behaviour)¹⁶ is key. Despite, the importance of stakeholder involvement, only four HBCIs with CCSs identified by the reviews refer to user involvement of CCSs or their parents.^{10,21,26,27}

Stakeholders can be involved in various ways from giving input and feedback via interviews and surveys at key points throughout the development phase, through being involved in decision-making

processes by participating in a steering group, to taking part in co-design workshops to help shape the actual intervention.²⁸ The person-based approach describes methods for capturing stakeholder perspectives through the development process.²⁹

6 | CONCLUSION

Knowledge remains limited on how best to support CCSs to improve and maintain positive health behaviours. However, the research community can make significant progress in supporting CCSs by embracing recognised behavioural science principles of intervention development. Specifically, future HBCIs in CCSs should aim to employ a systematic and evidence-based approach to development, be based on a thorough understanding of the target behaviour and on recognised theories of behaviour change, and incorporate stakeholder perspectives. This will maximise the chances that HBCIs will be acceptable, feasible, effective and sustainable across time.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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