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A Cancer Personalised Activity and Lifestyle tool (CAN-PAL): A co-design study with patients and healthcare professionals

Abstract

Aims: To co-design a Cancer Personalised Activity and Lifestyle tool (CAN-PAL) based on an existing tool. To help cancer care workers support people affected by cancer to plan and integrate physical activity into lifestyles.

Design: Mixed-methods co-design study

Methods: *Phase 1:* Focus groups with people affected by cancer (n=10) or interviews (n=2) to discuss suitable physical activities and adaptation of the existing tool. Data were recorded, transcribed and analysed thematically. Themes informed the design of the prototype CAN-PAL and user guide. *Phase 2:* Healthcare Professionals considered the potential use of the CAN-PAL prototype and completed an online survey including the system usability scale and free text responses.

Results: *Phase 1:* identified suitable physical activities and four themes were identified including: Capability, Benefits, Barriers, and Resources which informed the prototype CAN-PAL and user guide. *Phase 2:* the user survey was completed by 12 Healthcare Professionals. Median (range) system usability scale was 80 (50-95) (best score 100), scores >68 indicate good or better usability. Themes from the free text comments included strengths, amendments, considerations and limitations. Results were used to finalise CAN-PAL and the user guide.

Conclusion: The co-designed CAN-PAL tool had good usability. Further work is needed to evaluate the impact of CAN-PAL on activity levels and behaviour in people affected by cancer.

Relevance to Clinical Practice: People affected by cancer need support to undertake physical activity. The purpose of CAN-PAL is to assist cancer care workers to support people affected by cancer to plan and integrate physical activity into lifestyles.

Patient or public contribution: Public partners considered the findings from Phase 1 and 2 and informed the design of the prototype, final CAN-PAL and user guide and co-authored the paper.

Reporting Method: The study adhered to relevant EQUATOR guidelines; the study was reported according to the COREQ checklist.

Keywords: Cancer, physical activity, personalised

Impact:

This study addressed low levels of activity in people affected by cancer. It developed a tool to personalise activity and goal setting.

CAN-PAL has potential to support cancer care workers to promote activity in people affected by cancer.

1 Introduction

Cancer is a leading and increasing cause of death and disability globally, (Fitzmaurice *et al.* 2019). People affected by cancer report more activity limitations and poorer general health than healthy individuals (Elliott *et al.* 2011). Physical activity is inversely related to mortality in people with cancer (McTiernan *et al.* 2019). Systematic reviews using quantitative and qualitative methods have reported the benefits of physical activity on quality of life in cancer survivors and advanced-stage cancer (Albrecht & Taylor 2012, Forbes *et al.* 2020), regardless of cancer type, stage and treatment status (Burke *et al.* 2017). Nevertheless, in the UK, 31% of people living with and beyond cancer are inactive (Department of Health. 2012), similarly in the USA approximately 65% of cancer survivors did not meet physical activity guidelines (Tarasenko *et al.* 2017). There is a need to promote activity in people affected by cancer, and setting goals and graded tasks along with instruction of how to perform behaviour, encouraged previously inactive cancer survivors to achieve international physical activity guidelines (Turner *et al.* 2018). The integration of physical activity into lifestyle has been shown to enable activity and change behaviour in older adults (Weber *et al.* 2018).

2 Background

In our previous work in 200 patients with lung or gastrointestinal cancer, participants reported low activity levels due to concerns that exercise would worsen symptoms and patients reported low motivation and self-efficacy to undertake structured exercise (Wasley *et al.* 2018). Recent research in people with lung cancer and healthcare professionals (HPs), identified principles to promote activity including: planning functional and flexible activities, setting goals, providing education and social support (Gale *et al.* 2023). A systematic review suggested setting goals and graded tasks along with instruction of how to perform behaviour encouraged previously inactive cancer survivors to achieve international physical activity guidelines (Turner *et al.* 2018).

A number of online activity resources are available, including a generic resource on the NHS website (NHS 2022), as well as cancer specific resources such as the 'Move More Pack' (a 17-page guide to physical activity including patient stories) (Macmillan Cancer Support 2019). A randomised controlled trial to investigate the effect of the Move More Pack over 24 weeks, in cancer survivors, demonstrated improvements in physical activity compared to a control group, with improvements in self-efficacy and quality of life. However, the volunteer sample was recruited from people already engaged with Macmillan, required internet access and an email (Webb *et al.* 2019). This limits generalisability to people who are not engaged with charities and with less technology literacy. Other online tools exist including the Australian Cancer Exercise Toolkit, but this is to support healthcare professionals rather than for use with people affected by cancer (Dennett *et al.* 2022).

Integrating activity into lifestyles requires behaviour change in order to sustain activities. Behaviour Change Techniques have been associated with successful physical activity improvements in cancer (Grimmett *et al.* 2019). The Capability, Opportunity, Motivation, Behaviour (COM-B) model is one theory which suggests that behaviour is influenced by Capability, Opportunities, and Motivation (Michie *et al.* 2014). There is evidence that involving stakeholders in the co-design of interventions can benefit patients, communities, and researchers (Slattery *et al.* 2020). The research team has previously co-designed a

simple, paper based tool to promote physical activity in people with Huntington's disease (Jones *et al.* 2021). To provide an inclusive tool for promotion of activity in people affected by cancer, the redesign of PAT-HD was needed, as well as an initial evaluation of its usability by healthcare professionals. This novel, simple tool to personalise activity may be accessible to all patients including those who have not been referred for rehabilitation or prehabilitation.

3 Aim

To co-design a Cancer Personalised Activity and Lifestyle tool (CAN-PAL) based on an existing tool. To help cancer care workers support people affected by cancer to plan and integrate physical activity into daily life.

4 Methods

Design: Mixed method co-design project involving 2 phases.

Phase 1: Formative qualitative research to re-design existing tool

Phase 2: Evaluation of the usability of the prototype CAN-PAL tool by an online user survey

Study setting and recruitment

Phase 1: People affected by cancer were invited to participate through Maggie's Centre, Cardiff. Purposive sampling was used to include adults (>18years) affected by cancer including a current or past diagnosis of cancer, who were able to participate in an in-person focus group or online interview. Participants were not known to the researchers prior to participation, although the researchers introduced their background and the purpose of the research was made clear when inviting participation.

Phase 2: Healthcare professionals with at least 12 months experience in cancer care, who were able to complete an online survey were recruited using convenience sampling through clinical and specialist interest groups (Physiotherapists in Oncology, Wales Allied Healthcare Professionals and Nurse Cancer Research Network, which includes, physiotherapists, occupational therapists, dieticians, psychologists and nurses). The online survey was available for 4 weeks in November 2022.

Data collection and analysis

Phase 1: One in-person focus group (hosted at Maggie's Centre, with staff present) and two online interviews, due to participant availability) with people affected by cancer were undertaken. The workshop and interviews were facilitated by the research team (NG & UJ both PhD Physiotherapy Lecturers with experience in mixed-methods research and co-design, TR is a Nurse Lecturer, RN previously a cancer nurse). The discussions followed a topic guide which included: discussion of suitable physical activities, feedback on the existing PAT-HD tool, and further development of CAN-PAL (Appendix S1). Discussions were audio-recorded, transcribed verbatim and participants were asked to choose their own

pseudonym to ensure anonymity. Field notes were made during data collection to inform interpretations.

Data were analysed by open coding of each transcript by two coders (NG and research assistant). After familiarisation, codes were grouped to identify themes derived from the data using thematic analysis (Braun & Clarke 2006). The data were considered initially by the research team to consider themes and interpretations. Themes were then discussed with the co-design team, including two people affected by cancer, to make recommendations to develop CAN-PAL and the user guide. The themes and subthemes were mapped to the COM-B model, and relevant domains from the Theoretical Domains Framework were identified to inform the development of CAN-PAL. This framework provides a theoretical view of influences on behaviour (Michie *et al.* 2014). The recommendations were shared with a professional co-production company, Scarlet Design (<https://www.scarletdesign.com/>) who produced a prototype CAN-PAL.

Phase 2: The online survey was developed according to good practice guidelines, Organisation for Economic Co-operation and Development (OECD 2012). Questions included the System Usability Scale (SUS), a rapid, valid and reliable tool for measuring usability. The SUS consists of a 10-item questionnaire with five response options from 1 (strongly disagree) to 5 (strongly agree), questions alternating between positive and negative phrases. The total score ranges from 0 to 100 (higher scores indicating better usability)(Lewis 2018). Scores were classified as follows: best imaginable, excellent (>80.3), good 68-80.3), OK (68), poor (51-68) and awful (<51) (Bangor *et al.* 2009).

In addition, participants were asked to score the usefulness of CAN-PAL to plan activity and set goals (1= very useful: 5 = not at all useful). Open text questions asked about: the potential use of CAN-PAL, including planning, goal setting, benefits, risks and suggestions for improvement (Jake-Schoffman *et al.* 2017) (Appendix S2).

Our co-design team considered the results and advised on the development of the final CAN-PAL and user guide.

Ethical considerations

The study was approved by School of Healthcare Sciences Research Ethics Committee SREC reference: REC886 Cardiff University May 2022. All participants provided written informed consent. The consolidated criteria for reporting qualitative research (COREQ): checklist for interviews and focus groups were used to guide the methods ensure rigour (Tong *et al.* 2007) (Appendix S3).

5 Results

The 12 participants (8 female, 4 male), age range 43-69 years, included people affected by breast (n=8), prostate (n=3), as well as head and neck (n=1) cancer. The duration of the focus group was 1hour and 36mins and the interviews were 24 and 28mins.

Participants discussed several physical activities that were undertaken or were appropriate for people affected by cancer. These ranged from low intensity; daily activities, yoga and walking to more intense swimming, cycling, running and exercise classes. Subthemes

identified were outdoor, home-based, exercise classes, keeping active (not just sport) and different activity levels (intensities).

Four themes were identified from the discussions including: Capability, Benefits, Barriers, and Resources.

Capability

The ability to undertake activity, included the subthemes: **cancer variability** including the type of cancer, treatment side effects and symptom variation. Additional subthemes were **support** (family, other patients, professionals), **information provision** (about cancer presentation, appropriate physical activity, potential risks and sources of help) and **personal factors** (experiences, approach and behaviours to manage difficulties), which appeared to affect individual capability. These included patience with recovery and acceptance of ability, and fitting in with a person's lifestyle (work, family commitments). A further subtheme **motivators**, factors that encourage PA, included: activities linked to function, participating in daily activities, having adaptable plans and goals to allow for variation in health due to symptoms or treatment.

'you move [through] different phases in different treatment, you start doing something and you're getting knocked back' Ellie

'if I knew how to deal with it or somebody helped me or they told me what exercises or want to do, I think it would have been a bit easier' Nala

'So I think listening to your body is great advice, being patient with yourself and being kind are, yeah, some major things that you sort of... I said this earlier tonight, but you've just... you have got to listen and have got to be patient' Sarah

'And you're trying to deal with your family life, you're trying to deal with your... possibly your work life, you're trying to deal with being retired, whatever your situation is' JJ

'I just want to be able to be mobile enough so I can just sort of get up myself and wash and that' Nala

'if you have chemo week one, you know that your... my... my goals that week were to be able to cook tea, which didn't always happen, but then if you go in surgery that... you know, so it's... it's... it's you need a different plan' Sarah

Benefits

Perceived benefits of activity included subthemes: **physical health** (fitness, posture and energy) and **mental health** (confidence, wellbeing) as well as **other benefits**: a sense of achievement and a change of environment. Some of the identified benefits were added to CAN-PAL as quotes to encourage activity.

'I do think that exercise does give you energy and it makes you feel better about yourself. My muscles at the moment aren't feeling 100%, but I know it as I build up, that I feel better my posture's better and things like that. I want... and I like spending time with the kids outside doing things' Sarah

'But I try to stay as physically active as... as I could throughout all of it. And I just feel like it really helps me cope mentally' Ziggy

'I think that if you can get to grips with physical activity, it will, it will help. It should help build confidence because you're not someone with cancer. You're someone who can do something whether that's gardening or running upstairs or doing a marathon.' Adam

Barriers

A number of activity barriers were identified with subthemes which related to **treatment side effects**, (particularly fatigue), **availability of services** (provision of services, work restrictions), **individual** factors (self-confidence) and **risk** (of harm) appeared to limit participation in activity.

'it's never mentioned about the fatigue, the tiredness and it just takes over your life' Eleri

'it's really annoying because all the classes like which are specialised to recovering are all in office hours' Ang

'prior to diagnosis, I did a lot with her (the horse). But since then, I haven't done a lot because I can't really muck out a stable still. I'm not... you know, I haven't got the strength to do it. I don't want to do myself any damage' Laura

Resources

Several resources were suggested to promote activity including the subthemes: **people** (to provide specialist cancer classes, healthcare professionals other people affected by cancer) and **online resources** (websites, mobile applications, including monitoring).

'But from my point of view, I need... you know, I can't do stuff online, that doesn't sort of stimulate me, doesn't interest me in the slightest. I need to go to a class where you're with people, because I feel that sort of like stimulates you to sort of to do and make the effort' Morgan

'And one of the things that I think helped to get me back on the road was that Covid had arrived. And the BBC on... the on the website, it got to new year and they put out something like ten videos of different exercises that different types of things that people could do. So there was... there was walking, there was Tai Chi, there was yoga' Bobby

'And the lady I spoke to, she was from Yorkshire, she had the same breast cancer as me, she was about the same age. And she told me a few things, and I tried it, and it worked' JJ

Development of prototype CAN-PAL

Using the COM-B and Theoretical Domains Framework to map themes and subthemes; it was identified that Capability to change behaviour can be influenced by support of knowledge and skills, which was integrated into CAN-PAL, through providing examples of a range of activities (organised by different levels according to Ainsworth *et al.* (2011)) and including benefits of physical activity. Opportunities to overcome barriers included social influences and resources which were included in CAN-PAL by asking what support was needed and adding a list of resources. Motivation may be impacted by beliefs about capabilities and reinforcement which were targeted through the inclusion of quotes about undertaking activity and providing a diary to record activity and goals achieved. CAN-PAL is a prompt targeting multiple mechanisms to plan activity and goals to enable behaviour change.

Generally, people liked the graphics of the original PAT-HD tool although some changes were suggested to increase relevance to people affected by cancer and emphasise physical activity rather than sport. To recognise that capability may be variable, a winding road was added to CAN-PAL (page 1) to indicate that activity levels can change and progression may not be linear.

'As I say, you know, for me looking at it, it's a good prompt sheet' Sarah

'I think the strength one, that is kind of, for me almost off-putting because it's implying going to the gym' Laura

It was felt that the questions about what activities are important, currently undertaken and what activities the person would like to do were useful to plan activity. To help people overcome potential barriers a question was added to the physical activity plan 'What concerns about activity need to be discussed with a healthcare worker?'

The activity diary was added, including different intensity activities, to allow individuals to monitor progress including space to note how the individual is feeling that day as well as a section to record milestones. Development as an electronic or a mobile application was suggested by a number of people which will be considered for future development.

'for lots of people, I think, having a diary is (useful) because it... you feel you need to fill it in therefore you feel you need to do something to fill it in' Laura

'an app should measure impact + target-reward points + allow to set goals + Track activity' Adam

'So more techie, like the... people... a lot of people have things on their phones or iPads' Ang

The co-design meeting with our public partners identified the need for inclusion of activity guidelines to aim for i.e. 150mins of activity per week as recommended by the World Health

Organization (Bull *et al.* 2020), but taking account of symptoms which was included in the diary. Based on this the prototype CAN-PAL and a brief user guide for cancer care workers was developed to introduce and guide the use of CAN-PAL. Further to the codesign meeting this was adapted to include activity precautions, adapted from Macmillan (Campbell *et al.* 2012).

Phase 2: The survey was completed as a first step to evaluate CAN-PAL by 12 HPs (all female), (9 physiotherapists, 1 occupational therapist, 1 dietician and 1 clinical nurse specialist). Median (range) experience in cancer care was 21.5 (5-25) years.

The median (range) SUS score was 80 (50-95). The scores for 10 of the 12 participants were ≥ 68 suggesting the tool was good or better (Bangor *et al.* 2009). The median rating for CAN-PAL to plan activity was 4 (3-5) and set goals 4 (3-5) indicating high utility (max score 5) to plan activity and set goals.

The open text responses from the user survey were coded and organised into themes as follows (Table 1): **Strengths** related to ease of use, person centeredness, starting conversations about activity, and monitoring, which could be useful for prehabilitation.

Amendments included changes to wording and format (such as space for goals, use of inclusive font and colours), where to go for help and additional information such as strength and balance guidance, as well as activity precautions.

Considerations comprised support and training for users, use with existing tools such as the holistic needs assessment, as well as further development of an online/mobile phone application.

Potential **limitations** included time for completion of another form and its use in complex conditions. The comments and themes were discussed with our public partners to create the final version of CAN-PAL and the user guide (Appendix S4 & S5).

Table 1 Open text responses from Health Professionals User Survey

6 Discussion

Using a two phase co-design process, this work co-designed a novel Cancer: Personalised Activity and Lifestyle tool (CAN-PAL) and user guide based on co-production principles, to more effectively engage users (Batalden *et al.* 2016). The purpose of CAN-PAL is to support cancer care workers to help people affected by cancer to plan and integrate physical activity into daily life.

Thematic analysis of the focus group/interviews with people affected by cancer identified four themes: capability, benefits, barriers, and resources. A range of physical activities (from low to more intense activities) were suggested, which highlights the need for personalised activity planning and goal setting as well as integrating activity into lifestyle, which has an important role in behaviour change (Bailey 2019). The development of CAN-PAL identified that PA behaviour change through the COM-B model may be facilitated by

influencing knowledge and skills, social influences, resources, beliefs about capabilities and reinforcement.

The activity benefits and barriers identified in the present study align with the results of a systematic review including 98 papers which suggested people with cancer identify activity benefits including physical and mental health and wellbeing. Barriers identified included cancer-related side effects such as fatigue, low motivation, fear of movement as well as inaccessible facilities and services (Elshahat *et al.* 2021). A systematic review of barriers and facilitators to exercise in cancer (19 studies) found symptoms, information and lack of time. Facilitators of exercise were: feelings of control over their health, managing emotions and mental well-being, with walking as the preferred activity (Clifford *et al.* 2018). To overcome barriers and facilitate capability, CAN-PAL emphasises consideration of symptoms and offers different types and levels of activities to align with personal factors. It signposts information and support including healthcare websites, patient and community-based activities to people affected by cancer.

The majority of HPs considered CAN-PAL as good or better using the SUS. Scores above 68 indicate the need for minor improvements, below 68 require research and solutions (Bangor *et al.* 2009). The SUS results are consistent with a recent systematic review and meta-analysis of digital health apps, suggesting CAN-PAL will be well received by HP's. In this review, physical activity apps scored more highly than other apps, which was explained by their provision on the most popular apps, increasing useability (Hyzy *et al.* 2022). As the SUS does not indicate areas which require changes, questions with open text responses were used to inform amendments to the prototype CAN-PAL. Open text feedback included changes to wording, format, the addition of guidance and precautions. Strengths of CAN-PAL suggested were ease of use, person centeredness, initiation of conversation about activity and monitoring.

As planned, it was indicated that CAN-PAL should be used with the support of a person such as a healthcare professional/worker. To assist its use, a simple, 3 page, user guide was developed to support a range of healthcare workers to use the tool, which will be the next phase of evaluation. All cancer patients meet clinical nurse specialists or cancer support workers who are, thus, well placed to promote activity but may need assistance to involve patients in activity in addition to supporting daily activities. CAN-PAL can be used during routine care alongside accepted assessments such as the holistic needs assessment, to initiate conversations enabling the development of individualised activities and goals. These can be adapted to potential changes in capabilities due to cancer and its treatment, allowing progression and regression which is in contrast to other self-administered tools. CAN-PAL can be shared with the person as a prompt to support behaviour change. This aligns with a meta-analysis of behaviour change techniques to increase physical activity in cancer survivors which found prompts, graded tasks and rewards were significantly related to larger effect sizes (Finne *et al.* 2018).

A recent qualitative study recognised the need to embed physical activity promotion in usual care, identifying the benefits of brief interventions to promote physical activity across healthcare professionals and in trainees (Robinson *et al.* 2022). However, a systematic

review demonstrated a perceived lack of knowledge and skills to integrate physical activity into lifestyles to promote long-term behaviour change amongst physiotherapists (Lowe *et al.* 2018). Hence there is a need for resources such as CAN-PAL to assist cancer care workers to promote activity in people affected by cancer.

Strengths and limitations

A strength of this study is the inclusion of people affected by cancer and healthcare professionals to co-design the tool to personalise activity and integrate activity into lifestyles. This was underpinned by behaviour change theory which identified facilitators of activity, which may be applied to the development of future interventions to change behaviour. The potential use of CAN-PAL was evaluated using the System Usability Scale, a quick, valid and reliable method of assessing the usability of design. The comments and suggestions from a range of HPs with extensive experience, provided valuable insight into the development of the final version of the tool.

The recruitment of participants from a third sector organisation, who may be interested in self-management, and the inclusion of a large proportion of people affected by breast cancer limits transferability to other clinical settings. Nevertheless, people with a range of cancer sites were included, offering differing perspectives and in general there were similar experiences and opinions. Additionally, as CAN-PAL will personalise activities, it is likely to be adaptable to other cancer types and across different stages of the disease. Follow-on research is needed to test utility and relevance for other cancers and at earlier stages of the disease pathway.

The experience of the physiotherapy researchers with a background in physical activity may have influenced the analysis. However, this was countered by the inclusion of a nurse and public partners who considered the results. As a co-design project with limited resources, we did not aim for data saturation, but recurring themes were identified. Also given the limited time available, transcripts were not returned to participants which is a drawback. The shortcoming of open text survey data is limited depth, however, it did allow rapid capture of the potential use of CAN-PAL. The sample was small, but suitable for a co design project.

Recommendations for Further work

Further work on the acceptability and impact of CAN-PAL on physical activity is now needed, including assessment of activity levels and quality of life as well as maintenance of behaviour changes. Additionally exploring the effect of CAN-PAL on capability, motivation and opportunity to engage in physical activity, will enhance understanding and may enhance behaviour change. The use of CAN-PAL by family, carers or mentors may be warranted.

Relevance to Clinical Practice:

People affected by cancer need support to undertake physical activity. The purpose of CAN-PAL is to assist cancer care workers to support people affected by cancer to plan and integrate physical activity into daily life.

It is the intent that CAN-PAL is used by cancer care workers with patients during routine care, and it may be completed alongside routine assessment. It may support activity before and after treatment (prehabilitation and rehabilitation) and in people who have not met referral criteria. As a simple tool, suitable for all, the use of CAN-PAL, could increase accessibility.

The use of the CAN-PAL by people affected by cancer, will help to integrate activity into daily life, and signposting to other resources to minimise need for additional services. This will promote independence, self-management and wellbeing.

7 Conclusion

This study co-designed a simple, novel tool: the Cancer Personalised Activity and Lifestyle tool (CAN-PAL) which had good usability. It has potential to help cancer care workers to support people affected by cancer to set personalised plans and goals, to integrate activity into daily life. Further work is needed to evaluate the impact of CAN-PAL on activity levels and behaviour in people affected by cancer.

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