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ACT+ for patients living with and beyond cancer: an exploration of patient use of ACT+ components and therapist delivery

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Abstract

With more people living with and beyond cancer, it is important to support people to manage post-treatment impacts on their lives. Acceptance and commitment therapy+ (ACT+), a tailored talking therapy intervention for those living with and beyond cancer, can improve quality of life for this patient group. This study sought to understand patient experience, both positive and negative, of ACT+ by exploring how they engaged with ACT+ components (like mindfulness) and other important factors. This qualitative, one-to-one interview study was situated within a randomised controlled trial of ACT+ (SUvivors Rehabilitation Evaluation after CANcer – SURECAN). ACT+ was for those living with and beyond cancer who had recently completed cancer treatment, were in remission and reported poor quality of life. Patients (n = 24) and ACT+ therapists (n = 5) discussed their experiences of receiving/delivering ACT+. Data were analysed using deductive and inductive thematic analysis. Themes were engagement with ACT+ processes; operationalising ACT+ concepts; ACT+ receptivity and relational influences regarding take-up. Various ACT+ components synergised to promote change, with the practical application of mindfulness exercises and the tangible 'doing what matters' outcomes promoted by the intervention being particularly important. Other important factors included ACT+ addressing the unmet psychological needs of patients, its adaptability to varying patient needs, the exercises/metaphors utilised during sessions, and the ACT+ manual. Skilled therapists were considered influential in positive therapy experiences. Findings support the integration of ACT+ within NHS care pathways. ACT+ can offer a meaningful and acceptable approach for cancer survivors who experience reduced quality of life.

Keywords: Cancer, Patients, Therapists, Psychotherapy, Qualitative, Interviews

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Introduction

It is estimated that around 3.5 million people are living with and beyond cancer in the United Kingdom (UK), and this number has increased by 0.5 million in the last 5 years[1]. This increase is due to factors such as earlier detection, treatment advances[2], and more cancer diagnoses due to the aging population, who are at higher risk of developing cancer[1]. These changes are reflected in policies such as the National Health Service (NHS) Long-term Plan for Cancer, which continues to seek ongoing improvements in cancer survival rates[3]. However, those living with and beyond cancer face the challenge of adjusting to a 'new normal', amid ongoing distress, fatigue, fears of recurrence and loss of confidence, with the ability to work, self-manage and access care impacted[4–6]. As such, the quality of life and emotional well-being of people who have had cancer treatment is an increasingly important issue to address.

Non-pharmacological treatments for quality of life—such as exercise, mindfulness-based stress reduction (MBSR) programmes, cognitive behaviour therapy (CBT), and acceptance and commitment therapy (ACT)—have been shown to have some efficacy in improving quality of life for cancer survivors[7–11]. Acceptance and commitment therapy differs from CBT in that it focuses on accepting difficult symptoms, thoughts and feelings, while encouraging goals based on personal values. Psychological flexibility[12] and engagement in valued activities are promoted through the cultivation of six therapeutic processes which can be organised under three 'pillars' or groupings: Open up (defusion, acceptance); Being present (the observing self, contacting the present moment); and Doing what matters (values and committed action)[13] (see Fig. 1)[12].

Acceptance and commitment therapy+ (ACT+) is a tailored version of ACT, developed specifically for people living with and beyond cancer. Retaining the structure, dosage, and content of ACT, ACT+ also introduced new content focusing on integrating goals around exercise and work (including unpaid meaningful activities, e.g., looking after grandchildren, volunteering) if it fitted with people's values and was identified by the participant as important. A therapist and participant manual was also developed to ensure it was appropriate for people who had been treated for cancer with curative intent[15]. This newly developed approach has been recently tested in the SURECAN randomised controlled trial (n = 362)[16].

Qualitative research is important when evaluating interventions, such as those developed for trials, and is particularly useful for newer initiatives. It can delve into the how and why an intervention works (or does not work)[17]. It can also highlight variations in responses by patients to interventions and the reasons for these, thus helping to improve or target an intervention for optimal patient outcomes. Currently, there is limited qualitative research investigating how ACT+ is experienced by cancer survivors. Our study addressed this gap by

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ACT therapeutic process	Description
Open up	
Acceptance	Making room for painful feelings and emotions rather than fighting them, running away or suppressing them (i.e. experiential avoidance).
(Cognitive) Defusion	To learn to observe, rather than get caughtup in our thoughts. The aim here is to take a step back and just watch our thinking for what it truly is.
Being present	
Contacting the present moment	Being conscious rather than lost in thoughts (i.e. dominance of the past and future).
The observing self (or self as context)	This represents the internal space from where noticing happens. Thoughts and feelings change all the time but the viewpoint from where noticing happens is the same, it is us.
Doing what matters	
Values	Values are what is important to us. This means to know what matters and what we want our life to be about.
Committed action	Taking action guided by our values–doing what matters. It also means being flexible and able to adapt in the face of obstacles that take us away from doing what matters.

Fig. 1 The six therapeutic processes of ACT to promote psychological flexibility and engagement in valued activities and actions[14].

investigating how patients gained perceived benefits from ACT+. It explored how they engaged with ACT+ components (e.g., mindfulness), as well as other important factors related to how well the therapy worked for patients. We examined ACT+ patient and therapist perspectives on the intervention and its delivery. Findings may inform future implementation and refinement of ACT+ and psychosocial care in cancer survivorship more broadly.

Methods

Design

This qualitative process evaluation was nested within a multi-centre, pragmatic RCT of ACT+[16]. One-to-one interviews adopted a semi-structured approach so that core topics could be covered, whilst, at the same time, topics of importance to participants could emerge.

The SURECAN trial

Participants (n = 362) were recruited to the SURECAN trial from secondary care settings within five London NHS Trusts and one NHS Trust in Sheffield. Eligible participants must have attended, or were being followed up by, a participating cancer clinic. They also had to be within 24 months of having completed cancer treatment with curative intent or be in long-term remission. Potentially eligible participants were identified by the site NHS clinical team and the SURECAN study research assistants. These potential participants were asked three screening questions: How would you rate your physical health? How would you rate your feelings of wellbeing? How would you rate your quality of life? (scored 1-poor to 5-excellent). Individuals whose scores indicated they may require support (a score of 10 or lower) were asked to complete the Functional Assessment of Cancer Therapy-General scale (FACT-G)[18] to identify those most in need (i.e., scoring 78 or less). Those eligible and interested in the trial were sent a baseline questionnaire along with the informed consent form and were randomised to either receive the ACT+ intervention (n = 179) or usual care only (n = 183) once completed. Therapists who delivered ACT+ were trained in CBT (including clinical psychologists, counselling psychologists, and CBT therapists) and received additional training in ACT+ for the trial. Supervision of therapists took place monthly. All treatment sessions were recorded and therapy integrity rated (results to be included in the main trial results paper). Full details can be found in the trial protocol[16].

Participants

Eligible patient participants for this qualitative study were identified from the SURECAN trial database while the trial was live, using the following criteria: consented at recruitment to be approached for interview; in the intervention arm of the trial and beyond their 12-month follow-up; received at least four sessions of ACT+ and were no more than 14 months beyond their final ACT+ session. Our aim was to recruit a diverse sample of up to 30 participants. We conducted purposive sampling, blind to participant ID and study data, to obtain variation in participants' cancer group (breast, lower gastrointestinal, urological, head and neck, haematological), age (35–54, 55–64, 65–74, 75+), gender (male, female) and ethnicity (White, Black, Asian, Mixed, Other).

With the number of individuals targeted for interview, simple selection methods may not have produced a sample that reflected the wider trial population. To address this, we used a random selection approach designed to reduce selection bias by ensuring that those selected for interview were similar, in key characteristics, to those not selected. This contributes to making the conclusions more generalisable. This approach, known as covariate-constrained randomisation, was implemented using Stata's cvcrand command[19]. To promote diversity, we

sampled at two time points, 6 months apart, allowing us to include participants across the range of characteristics and to target groups that were underrepresented in earlier sampling. The first data extraction identified 31 eligible participants, of whom 15 were randomly selected; the second extraction identified 31 eligible participants, of whom 20 were selected. Thus, a total of 35 potential participants were selected and sent a study information pack by post or electronically, comprising an invitation letter, information sheet, and a consent or e-consent form (and prepaid envelope if appropriate). Non-responders were contacted by phone/email during the 30 days following the mail-out to ascertain individuals' interest in participating.

Twenty-five participants expressed an interest in being interviewed, and 24 interviews were conducted (one participant was unable to commit to an interview at the time of the study)[20]. The final sample size was not determined by data saturation. Instead, we were influenced by the notion of information power, whereby the more relevant information the sample holds for the study aim, the fewer participants that are considered necessary[20]. Information power was maximised in this study by: (1) a focused study aim; (2) the specificity of the sample (participants who had received ACT+ within a clinical trial); (3) the variations in participant characteristics; (4) the use of an established theoretical framework (ACT) to inform analysis; and (5) the use of semi-structured interviews to elicit rich data. During analysis, later interviews did not generate substantially new insights relevant to the study aims, indicating that the dataset had good information power. This sampling approach led to the patient demographics amongst those interviewed in Table 1.

Eligible SURECAN therapist participants were identified using the following criteria: trained to deliver ACT+ and delivered ACT+ sessions to at least two patient participants in the trial. Our aim was to recruit a sample of therapists using a purposive sampling approach to obtain variation in therapists' host organisation, core profession, and gender to include a range of experiences and views. All eligible SURECAN therapists (n = 8) were sent a study information pack comprising an invitation letter, information sheet, and e-consent form. Follow-up emails were sent to non-responders during the 30 days following the mail-out to ascertain individuals' interest in participating. Three therapists did not respond to follow-up emails; five interviews were conducted. The majority were female (n = 4) and had therapy as their core profession (n = 4).

Table 1. Patient participant demographics.

		N	%
Gender	Female	18	(75.0)
	Male	6	(25.0)
Age (years)	35–44	2	(8.3)
	45–54	5	(20.8)
	55–64	14	(58.3)
	65–74	2	(8.3)
	≥ 75	1	(4.2)
Cancer group	Breast	10	(41.7)
	Lower gastrointestinal	9	(37.5)
	Head and neck	3	(12.5)
	Haematological	1	(4.2)
	Urological	1	(4.2)
Ethnicity	White British	16	(66.7)
	Asian or Asian British	3	(12.5)
	Black or Black British African	3	(12.5)
	Mixed White and Black Caribbean	1	(4.2)
	Missing	1	(4.2)
Employment status at baseline	Employed (full or part time, including self-employment)	13	(54.2)
	Retired	6	(25.0)
	Unable to work due to long-term sickness	3	(12.5)
	Looking after home/family	1	(4.2)
	Missing	1	(4.2)

Interviews

All interviews were conducted via telephone (n=12) or online using Microsoft Teams (n = 17). Interview guides were developed collaboratively by the study team, drawing on: team expertise, pre-pilot study interviews, and guides used in a similar study[21]. For patient participants, key topics covered included experiences of engaging with and receiving ACT+, perceptions of the impact of the therapy, barriers and facilitators to doing ACT+, and relevant contextual factors influencing these experiences. Patient participants were not asked about the specific components of ACT+ because we wanted to gain their lay understanding of ACT+. For therapist participants, topics included their experiences of training in ACT+ for SURCAN and using supporting materials, perceptions of ACT+ philosophy, experiences of delivering ACT+, challenges, perceptions of patient participant experiences (see Supplementary File 1 for full interview schedules and Supplementary File 2 for authors' positionality statements). All interviews were audio-recorded and transcribed verbatim.

Analysis

Discussions with the qualitative research team proposed a direction for the paper. We agreed that the focus should be on how partaking in ACT+ sessions as part of the SURECAN ACT+ trial was experienced by trial participants, including both positive experiences as well as where things worked less well. DR initially drew up a coding framework, informed by research questions and subjects covered in interviews. ROB then tested this framework with a sample of interviews (n = 6), adding to the framework (including themes grounded in the data and coded at a semantic level). This was discussed with DR and the team, and additions were made particularly around interrogating ACT+ elements. The initial eight interviews were re-examined with the new coding framework, and the remaining interviews were coded. These themes were then discussed and debated with the study team to arrive at the final coding framework. Using the final framework, data were coded line-by-line in NVivo 14. If more meaningful and helpful to interpretation, larger sections of text were coded. Lines or sections of text were assigned multiple codes if they could be interpreted as having meaning in the context of different categories. Constant comparison was used to develop the coding framework and develop ideas about themes. Discussion with DR, and later with the wider group, raised further analytic questions about analytic groupings (e.g., younger cancer patients vs retired cancer patients and work vs meaningful activity). AC explored the themes in the data codes, including how participants experienced ACT+, as well as exploring important wider elements of ACT+ to participants. Therapists' perspectives of patient experiences were analysed alongside patients' data in order to understand patient experiences. After additional discussion with the qualitative team, the final structure of the paper was confirmed. AC wrote up the findings, and further adjustments were made to the paper structure after reviews by the rest of the authors.

Thus, a thematic analysis that utilised both deductive (based on the key elements of the ACT+ model) and inductive (where themes relevant to the research question emerged from the data) approaches was adopted for this paper[22]. Themes were both semantic (identified through the explicit or surface meanings of the data) and latent (attempts to identify hidden meanings or underlying assumptions,

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ideas, or ideologies that may shape or inform the descriptive/semantic data)[23].

Whilst views of both ACT+ patients and therapists were analysed, the main focus of this paper was on patient participants; therefore, from this point on, we refer to patient participants as 'participants' and therapist participants as 'therapists'. Quotes are presented to support themes and labelled P for patients and T for therapists.

Results

The analysis produced four key themes (deductive and inductive) that develop our understanding of how participants engaged with ACT+ (Table 2).

Engagement with ACT+ processes

Mindfulness

Teaching mindfulness ideas and techniques is a key element of ACT+, and mindfulness emerged as particularly important to participants in how they understood ACT+ and described any benefits. Some participants referred to mindfulness in a nebulous or general way, for example, '*mindfulness was helpful*' or it helped them to look '*at things in a different way*'. Other narratives explored mindfulness more deeply, separating the individual components of ACT+ they had practised (i.e., being in the present moment, acceptance, defusion, observing oneself). We observed that participants in this second category tended to have had experiences of mindfulness practice prior to ACT+.

'Well at one time I didn't want to go out, and it made me get out. She [therapist] says, look, just do certain things and use this mindfulness. And it did work, and it got better and better. Because they were all different, each session; in the book, it was giving you all different mindfulness actions, like the parrot chirping in the background. It did help.' P22

Being present

The 'being present' pillar of ACT+ comprises the two therapeutic processes 'being in the present moment' and 'the observing self'. Of the individual therapeutic processes of ACT+, 'being in the present moment' was the most discussed in interviews. This element was variously described in terms of 'grounding', taking a step back, descriptions of being a witness to emotions, thoughts and the realities of living with or beyond cancer, or via outlining exercises involving directing attention to the body/senses:

'It's a sort of mindfulness exercise where you get yourself in the moment of what you can feel and smell and see or hear…If I was feeling anxious or anything, that would calm me down. So I was actually doing that activity, like just on a, like probably two or three times a week, when I was feeling anxious or anything, I would do that activity.' P9

Whilst the 'observing self' element of ACT+ (i.e., that there is a part of ourselves that can observe our thoughts, beliefs, and feelings) fits with 'being present' in the ACT+ model, participant narratives on the observing self were more closely linked to those regarding the element of 'defusion' (i.e. unhooking from thoughts enough so as not to automatically believe or follow them). This finding suggested that participants may not need to embody or internalise all the separate elements of the ACT+ model to experience benefits.

Opening up

The 'open up' pillar of ACT+ comprises the two therapeutic processes 'defusion' and 'acceptance'. Whilst defusion was described less often by participants than 'being present', it was articulated by participants as being a helpful way to feel less overwhelmed by worries. Participants described stepping back from some thoughts and beliefs as well as recognising they were unhelpful. Participants also recalled the 'thought train' exercise (a mindfulness technique to help people observe their thoughts non-judgmentally and create distance from them).

'So since having the therapy has really made me look at myself, because I'm naturally a strong person, and I think when you have a disease like cancer, you're fighting…you're not going to beat me, I'm strong, and I'm going to be… And sometimes you have to take a step back and say, listen, listen to your body, listen to what's being said to you, and it's okay.' P14

'It's about observing rather than feeling; it's about noticing rather than…yes, rather than reacting. So I think there's a very calming way through.' P4

The 'acceptance' element of ACT+ was commonly cited by participants as benefiting them. Although acceptance in ACT+ is focused on emotions, symptoms of fatigue, and thoughts, including acknowledging that it is OK to have difficult feelings or cry, participants described acceptance more broadly to include personal contexts. Participants reported acceptance of circumstances, e.g., of having cancer and the changes it brought. For a small number of participants, acceptance was expressed in terms of self-acceptance and a desire for more self-compassion.

'My therapist went through everything, the sessions with me. So that's when I became…I became surprised that, oh okay, so it's okay for me to be having those thoughts, but to accept that now this is me, this is my life now, and I can accept it. And learn how to live with it.' P17

Doing what matters

The 'doing what matters' pillar of ACT+ comprises two elements: 'values' (knowing what matters in life/life direction) and 'committed action' (taking effective action guided by values). There were mixed reports regarding values: around half of participants and two therapists specifically mentioned identifying values as being helpful in terms of aiding participants to learn more about themselves and understand what aspects of their lives to focus on. Some mentioned the values cards as supporting this process. However, there were few descriptions in participants' narratives of what they had specifically identified as their values, and one therapist said that their patients had not found the values aspect of ACT+ particularly useful.

'There were too many of them (values cards), and it was a bit bewildering, and they (patients) agreed with lots of them and we couldn't quite… Well, it was difficult to translate that into practice. I found it actually a bit easier to focus on what and who is important to them and

Table 2. Key themes and sub-themes.

Theme	Sub-theme
Engagement with ACT+ processes (deductive)	Mindfulness
	Being present
	Open up
	Doing what matters
	'+'
Operationalising ACT+ theory (inductive)	Flexible/individualised approach or 'person-centred'
	Exercises/metaphors
	Manual
Autopoietic cycles (inductive)	
Receptivity and relational influences regarding ACT+ take-up (inductive)	Addressing an unmet need
	Willingness and ability to engage
	Relational issues

what sort of…just one or two things, hobbies or interests or people. That's the important thing that they would prefer to focus on in terms of valued activities.' T25

When participants did describe their values, they related to relationships, being active, or creativity. One explained that values identification had helped her to manage the loss of her job, and two said their values had not been 'what they expected', making it a useful learning experience. Some therapists were able to provide richer descriptions of how patients worked with values identification:

'Before her cancer, she'd had a very close relationship with her family, with a group of friends, and she'd actually found that she was isolating from her friends and isolating from her family. And we'd identified the value of connection, and then we… So, she was able to see that her actions were actually completely contrary to her values.' T23

Committed actions (relating to participants' values) were more comprehensively narrated by patients than their values. Actions were mostly about getting back to their life before cancer, including taking action despite challenges they faced, like continuing to feel unwell. Sometimes this meant having to find new activities and actions to substitute for the things they could no longer do. Committed actions ranged from restarting everyday activities (e.g., leaving the house, engaging in personal care), to activities connected to recovering from cancer (e.g., mental engagement, processing what had happened, 'recovering'), as well as meaningful activities like creative pursuits, connecting with friends/partner, going back to work, doing exercise, and making time for self-care. Participants reported that encouragement and sometimes guidance/suggestions from therapists were important for initiating these first steps.

'The ACT+ encouraged me to widen my horizons, because my full focus was that I want to get back to teaching. What I was doing, but recognising that my life will never be like that again, ever. … what else have I got where I can focus my energy sort of thing … My husband was playing bowls, so just by accident I ended up playing. So, I've got a new social life doing that. And then somebody was in a choir, so I've gone back to singing.' P10

In terms of ACT+ components to support 'doing what matters', goal setting/planning was commonly discussed and was seemingly key in supporting participants to convert their values into actions. Participants also frequently talked about the benefits of breaking things down into manageable chunks/steps. This was particularly important as it allowed participants to feel they were achieving something at a difficult time in their lives. Feeling they were progressing in life contrasted with the seeming lack of progress or 'stuckness' they felt related to living with cancer. In turn, this sense of progress supported some participants to feel more optimistic about the future. A few participants specifically mentioned still using the ACT+ planning technique at the time of the interview. Participants also described gaining new skills, but these were almost exclusively those gained from ACT+ rather than skills learnt from new activities/courses. In particular, managing stress, communication skills, goal setting, reminding themselves of their values, and getting out of cycles of negativity were described by participants.

'I've started socialising. I even told my therapist that. I was not going out, I said, and then I think he advised me, said if I can start with just one friend, keep one friend, and go out with this friend and see how it goes.' P17

The '+' element of ACT+

The '+' aspect of ACT+ had a specific focus on getting participants back to work or meaningful activities and supporting greater levels of exercise/activity—if these were congruent with participants' values. However, there was limited mention of the work and exercise aspects of the ACT+ approach in participant and therapist narratives. This may, in part, be explained because many participants were already back at work at the time of the interviews or retired. Nevertheless, there were two reports of ACT+ being used by participants to support more effective functioning at work. One participant said ACT+ helped her come to terms with not being able to work. Employment itself could be perceived as a barrier to engagement in ACT+ therapy due to time pressures.

'He (patient) managed a team, but he wouldn't delegate anything. … So we worked a lot on what his values were, which were family, and then looked at the amount of time he was working… By the end of the eight sessions, he had leaned into the discomfort of delegating; he was delegating… By the end of it, he was saying I can't believe I could've done this years ago. He was able to go on holiday with his (family), and he said, 'I enjoy work so much more.' T23

The exercise element of ACT+ was generally not discussed by participants. However, some participants mentioned that their health problems had held them back, suggesting that they thought this element of ACT+ was a step too far for them.

'I mean a year ago I was going up Scottish mountains. I was very active. When I was diagnosed with cancer, I was told that a certain drug I was on was too dangerous for me, and as a result I developed severe arthritis, which still now means that I can't walk more than 5 or 10 min. So, I couldn't do the exercise bit.' P11

Therapists were not in agreement regarding the use of structured exercise. One said they had done a lot with this aspect of ACT+ with their patients; another said the structured exercise was beyond their patients. Others found it helpful to incorporate when exploring techniques to improve well-being, a finding supported by four participants who endorsed walks for well-being and 'getting out and about'. Some participants were already doing exercise as they were already self-motivated to do so, or exercise had already been identified as an issue by other professionals before ACT+. Here, ACT+ could support what they were already doing.

'Both of those two (patients), it did increase their exercise. So, one of them started walking, got off the bus one stop earlier, and walked, for example. And he had a stoma, I believe, and that was a really difficult thing for him to get going again in terms of exercise.' T27

Operationalising ACT+ theory

Our analysis showed how the operationalisation of ACT+ theory was important for how well sessions worked. Here, patient reports suggested that the use of a flexible, person-centred approach and the suitability of the ACT+ approach for those living with and beyond cancer were critical issues. In addition, the exercises and metaphors used in the programme, the availability of an ACT+ manual, and the therapist sessions to support and explain ACT+ worked well in combination (the role of the therapist is explored in a separate section below).

Flexibility

Participants came to sessions with different types of cancer and cancer experiences. Thus, built into the programme was the consideration that patients would have varying needs and require different approaches. Several participants mentioned finding ACT+ relevant, in terms of addressing some of the issues faced by those recovering from cancer. Additionally, many had other things going on in their lives, with varying approaches to life, worldviews, and personalities. Narratives highlighted that the adaptability in the ACT+ programme was appreciated by both participants and therapists. ACT+ was able to contain widely varying patient perspectives and experiences.

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'Like the mindfulness techniques, she was already meditating. But what she did was very much meditation, at home, sitting on my sofa, at this time in the morning. And so, for her, it was okay, could you take these techniques out?' T23

'I think obviously (following a bereavement), because I got very depressed as well. And it got to a stage where I just thought you've got to do something, because I would've just sat in the chair and died. … But the therapist was very good. She didn't push, and she didn't make me feel I had to separate the two.' P14

Exercises/metaphors

Narratives were percolated with descriptions of ACT+ exercises and metaphors, and participants often used them to convey the benefits of ACT+. This suggested that these aspects of ACT+ resonated with patients.

'The unhelpful thoughts. I mean, they talk about it in terms of it's a train, and you know it's going to pass. But actually, it's not going to be nice while it's here, sort of thing. It's that type of thing.' P2

Participants reported they found therapy exercises relatively straightforward and easy to do. Their popularity seemed to be centred around their practicality and being 'hands-on'. Therapists reported that mindfulness exercises in particular could have an immediately noticeable effect (e.g., calming), meaning participants were able to appreciate their value in real time.

'I enjoyed the mindfulness when I would work through with them, and they liked how I had worked through with it. And when they were feeling a bit anxious or stressed, I would put it in those points, and there would be an instant change in their demeanour when I'd do that. So those are the parts of it that have been really kind of helpful and beneficial to the client and to see instant changes in session as well.' T26

Whilst many enjoyed doing exercises during sessions, it was noted that not all participants engaged with them outside of sessions. Some participants specifically required professional recordings to listen to in order to support home engagement; thus, therapists sometimes recorded exercises for home practice.

Manual

The accompanying manual for ACT+ was an electronic, 92-page document made available alongside sessions. It provided an introduction to ACT+, a detailed explanation of the different ACT+ components in lay language, mindfulness exercises for home practice and accompanying materials, like values cards. Participant reports about the manual were less frequent compared with therapy exercises/metaphors. Nevertheless, there were positive comments about the written material being easy to understand and well structured. Some participants mentioned continuing to refer to the manual when they were going through a difficult period. Others had found it too long and complex, particularly when they were tired from their cancer treatment.

'Today I, if I feel down, I know I can go and pick that book and read, and I'll find something to help me.' P17

'I remember thinking that it was a lot for somebody with things going on and not feeling so well in themselves. So, I think it could be a lot better presented. There's nothing within it that was not of use. So, it was trimmed down in that kind of sense. But it needs to be so much more in writing, I think. I'm not quite sure how.' P4

Autopoietic cycles

In contrast to the spiralling cycles of negative thinking and action that can be triggered by having cancer, autopoietic cycles that allow psychological adaptation, regeneration, and better self-maintenance could emerge from ACT+. Here, our data suggested that different elements of ACT+ could work together to create positive spirals, where participants described better managing negative thinking and difficult emotions, being more open, moving forward, planning, achieving small goals, and getting out of a rut.

'Just the thing of going towards things … I do remember there's a drawing in there (manual) of a tug of war going on. It was like a Gruffalo figure pulling the bloke towards this big hole. … That summed it all up for me. That's what I was allowing to happen.' P16

A few participants spoke about how all the different elements of ACT+ worked together and were important for the results they received. However, participants did not typically overtly link improved mindfulness with their ability to engage in 'doing what matters'. Nevertheless, reported outcomes of mindfulness did seem to connect the two. Here, self-knowledge, cognitive flexibility, taking back control, empowerment, choice, boldness, and increasing confidence were all cited.

'The whole thing was the identification, working out ways of setting your values, your goals, making them realistic, making them things that you can actually do. And then the identification of what's actually bringing you down, shall we say. And the ability to actually say, well, that's…I don't want to get into a reinforcement cycle of that.' P2

'And building a framework of what you like about things, and what you don't like about things. And how you can change things, and how you know, sometimes take a step back and consider. And just to…it's a grounding and an understanding of different ways of looking at things.' P10

Receptivity and relational influences regarding ACT+ take-up

For any therapy programme to work, participants need to engage with it sufficiently. Generally, participants said they were keen to engage, although some threw themselves into it more than others, e.g., by ensuring they did all the home practice. Some mentioned finding the reading too difficult or too much like school or work. Occasionally it was noted that ACT+ was not the right fit for a participant because, for example, they were not ready to talk about cancer, mental health issues, or had preferences for less structured therapy support (e.g., art therapy). Participants who wanted to engage also encountered barriers, for example, 'chemo brain' or memory/cognition issues, managing the trauma of cancer, competing time pressures, and other things going on in life. Here, the flexibility of ACT+ and the therapist's skills (discussed below) could go some distance in countering such challenges to meet participants where they were at:

'We just did manageable things. And she'd be like, Oh, you don't have to do that; you just do what's (possible)…because then I think because where I work is quite corporate, and it'd be like it (therapy) felt like my objectives or something… I think naturally I'd be more inclined to be just like how when I had the art therapy I found that really useful.' P24

Emotional isolation was commonly reported by participants. A number described their cancer treatment as medically oriented and lacking the psychological support they needed, such as the limited scope for discussions with overstretched NHS staff. They also noted a wider lack of informal support outside of the NHS. For example, their culture/families might not have been forthcoming with emotional support, and/or were unable to discuss emotional problems or understand mental health challenges.

'It's that overwhelmingly, it's that lack of time for patients. Nurses and doctors just have almost no time. And so everything's focused on the next intervention and the next blood test or what has to be done, and it's all incredibly medically orientated.' P11

'It's no disrespect to people that are around me, but I don't; it's probably the type of person I am as well. I didn't feel like I had anybody where

I could have those kinds of conversations that aren't drunken and outside a pub when you've had two bottles of wine.' P13

Some participants described how they had become personally shut down or numb, having gone through the stress of having and being treated for cancer. They reported needing support to process what they had been through and to find ways to open up and connect with loved ones again. Others also reported concurrent major life events going on around the same time (e.g., death of a loved one, divorce, other health conditions).

'I think I had shut down; I was more into myself, didn't want to do anything. And didn't want to socialise, even at my workplace, my home life too. Didn't want to open up, because I was thinking people would feel sorry for me. It was a very difficult time for me, and I do understand why my body is not responding too, like before.' P17

This all meant that ACT+ therapists could become critically important people at a crucial time in participants' lives. Therapists were key to how ACT+ worked for participants, underpinning the effective delivery of ACT+ elements as described in this paper. Therapists were required to interpret their training in ACT+ and use their interpersonal skills to work effectively with participants with diverse needs. The opportunity for human connection provided by ACT+ appears to be one of the key successes of the programme, which is particularly important given the isolation many reported. Descriptions of therapists were overwhelmingly positive in narratives, where participants described them as 'lovely', 'professional', 'non-judgemental', 'trusted', 'empathic', 'caring', 'human', 'warm', and 'kind'. Being a flexible professional and adapting the ACT+ approach was a critical skill highlighted by participants. The ability to build a good rapport with participants was a therapist skill highlighted by both participants and therapists. This enabled participants to feel safe and supported enough to disclose issues and speak freely, maximising the benefits of sessions.

'It was just the right type of counselling for me, and I put that down to the counsellor.' P11

'Because they had somebody who was invested in their care. And they really like that because they didn't receive that. And a big part of it is actually loneliness.' T26

Nevertheless, one participant reported finding it challenging to build a rapport with their therapist. Another had had a good relationship with her therapist, but sessions ended prematurely and abruptly due to the therapist's sickness, which, along with a lack of timely follow-up, had left the participant feeling upset.

'What I said about ending abruptly … it made me feel a bit lost. I felt like somebody…you know where you have, somebody pulls the rug out.' P19

Discussion

This paper sought to understand how patients gained perceived benefits from ACT, exploring how they engaged with ACT+ components (e.g., mindfulness), as well as establishing other important factors related to their experience of ACT+. Whilst various ACT+ components potentially worked together to transform patient experiences, mindfulness and 'doing what matters' emerged as particularly key for participants. Other important factors for participants were the flexible/individualised or person-centred approach of ACT+, the exercises/metaphors that were utilised during sessions, and the ACT+ manual. Also important was ACT+'s suitability for a cancer population, where it appeared to address participant unmet needs, facilitating engagement. Key to supporting the whole process were skilled therapists who were instrumental in the participant experience. Research shows quality of life can continue to be impacted for decades-post cancer diagnosis if issues like psychological impact are not addressed, highlighting the importance of interventions like ACT+.

The ACT+ model

ACT+ comprised six core processes organised under three pillars: Open up (acceptance and defusion), being present (contacting the present moment and the observing self), and doing what matters (values and committed action). Mindfulness and 'doing what matters' (particularly 'committed action') elements of ACT+ emerged as particularly key for participants. Mindfulness skills are a key part of ACT+ that work by developing being present and opening up. They can improve emotional regulation, reduce stress, and help people manage symptoms more effectively, facilitating acceptance rather than the struggle. Mindfulness has grown in popularity in the UK over the last two decades (Cook, 2021), becoming an integral part of popular culture approaches to mental well-being[24]. Existing public awareness of mindfulness may make it more readily acceptable as a therapeutic concept, thus supporting ACT+. Indeed, a number of the participants had already used mindfulness, and these participants described a deeper understanding of the practice. 'Committed action' was also a popular part of the intervention, suggesting participants value the tangible outcomes that the intervention promoted. Actions included restarting valued everyday activities, activities connected to recovering from cancer, and meaningful activities like creative pursuits and connecting with friends/partner.

There was varied comprehension of the other ACT+ components. Some were clearly understood, such as 'being in the present moment', consistent with popular culture depictions. Other components like 'defusion', were less well understood by participants. 'Acceptance', was broadly understood in that people embraced personal circumstances that were out of their control, as well as being self-accepting and compassionate. Our study found that different elements of ACT+ appeared to work together to create positive spin-offs, where participants were better able to manage negative thinking and difficult emotions, whilst being more open, moving forward, planning, achieving small goals, and feeling less stuck.

ACT+ aims to increase psychological flexibility: the ability to adapt to demands, shift perspectives, and balance competing desires and needs. Our findings suggest that ACT+ core processes were doing just that. Patients reported taking a step back, witnessing and accepting emotions and thoughts (being present) while finding new ways to 'do what matters'.

ACT+ introduced new possibilities for this patient group: integrating goals around exercise and work (including unpaid meaningful activities, e.g., looking after grandchildren, volunteering) if it fitted with their values. However, going back to work was not commonly raised. Many in this sample had already returned to work or were retired (79% at baseline). Nevertheless, aspects of work and meaningful activity were discussed. Regarding the structured exercise element of ACT+, some participants felt held back by their health problems and one therapist said that it was too much for their particular patients to consider[21,25]. It may be that a more formal graded exercise approach would be helpful for this population, given the importance of exercise in cancer prevention, as graded exercise builds on one's current ability no matter how limited it may be[15]. One therapist described how they integrated exercise as part of the activities of daily living to support well-being. Future research might specifically establish the value of the '+' elements for this population and its usefulness in future implementation of ACT+.

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Wider aspects of ACT+

The study also sought to understand what was important for ACT+ delivery beyond the core processes. ACT+ appeared to address unmet needs for this population, in particular social and emotional isolation. Isolation is a common experience for those living with and beyond cancer[26,27], with numerous negative effects on the health of patients such as psychological well-being and all-cause mortality[27,28]. Indeed, our participants reported feeling social support was lacking in the medically orientated treatment they received, as well as from family and friends. Some felt emotionally shut down as a result of the stress of treatment. Here ACT+ could support participants to reconnect through working towards meaningful goals in their lives, such as reconnecting with friends or opening up emotionally to a partner. Additionally, the opportunity for connection with the ACT+ therapist appeared to be one of the key successes of the programme, with overwhelmingly positive accounts of therapy relationships provided.

The importance of therapeutic relations in intervention delivery is well established: Therapist skills and experience are key to forming a positive therapeutic relationship[29], which in turn is important for successful therapeutic outcomes[30–32]. In our study, therapist skills filled a need for connection and appear to have been useful in delivering the flexible and person-centred approach required by patients with different cancer diagnoses. The metaphors used in sessions and exercises provided were popular with participants, but generally relied on therapist delivery rather than via the patients' manual. Whilst some participants reported finding the manual helpful, others felt it was too complicated for their 'chemo' brain.

Strengths and limitations

We had a good-sized sample for qualitative research (n = 25), who were purposely selected from those participating in the SURECAN RCT, with representation of different ethnicities. Interviews and analysis were conducted without knowledge of the RCT results. Nevertheless, some demographics such as men, not working due to ill health, and some types of cancer were less well represented in the sample; thus, there may be more to understand about the experiences of these groups. In addition, ethnic minority groups are not monolithic, and different ethnic minority groups' experiences may be underrepresented.

Patients who had attended fewer than four ACT+ sessions were not interviewed (only 26% of trial participants in the intervention arm received fewer than four sessions). Receiving four sessions of the intervention was our pre-determined definition of compliance (adherence) to the intervention[33]. One aim of the qualitative study (results reported elsewhere) was to compare the experiences of participants whose quality of life did, and did not improve after receiving ACT+. Thus, findings reported here reflect experiences of engaged participants ('compliers'). As such, negative or disengaged perspectives are underrepresented. Such patients may have had varying experiences, such as additional barriers to access and less positive opinions, which are not captured by this analysis. Interviews were conducted some months after ACT+. This was intended so participants had sufficient time to reflect on ACT+ and its impacts. The specific ACT+ therapeutic processes were not asked about directly, as this may have produced different results.

Conclusions

Within the UK National Health Service (NHS), post-treatment cancer care is not consistently available and does not always address key patient needs, like fear of recurrence, fatigue, changes in physical capabilities, anxiety, and depression[34]. The findings of the current study suggest that ACT+ can offer a meaningful and acceptable approach for people living with and beyond cancer who experience reduced quality of life, particularly by addressing subjective sense of isolation and unmet needs for supportive care. Although more could be done to understand the limitations of the approach by interviewing those who dropped out of the intervention. In particular, mindfulness and committed action resonated with participants, highlighting the value of practices that bring people into the present and provide tangible steps towards valued living. Clinically, this underlines the importance of incorporating flexible, person-centred approaches that can accommodate varied levels of readiness, different health statuses, varying values, as well as mixed understandings of mindfulness and acceptance. The therapeutic relationship was viewed as a central mechanism of benefit, reinforcing evidence that therapist qualities, including flexibility, are critical for engagement. While many participants valued ACT+, a minority found aspects such as structured exercises or written materials overwhelming, suggesting the need for clinicians to pace and tailor delivery sensitively. Taken together, these insights support the integration of ACT+ within NHS care pathways; it may enhance quality of life for patients otherwise discharged from services, provided trial evidence is forthcoming, and therapists are adequately trained to flexibly adapt the approach to patient need. Whilst resources in cancer settings vary considerably, there are already specialist therapists working in cancer services in the UK who are keen to be trained in the approach in both the NHS and within the charity sector. However, much of the intervention in the study was delivered by specially trained High Intensity Therapists from NHS Talking Therapies—an existing workforce who have the potential to play an important role in the widespread delivery of ACT+ for cancer survivors with low quality of life, were it to be implemented across the UK NHS. Therapists need to foreground the relational connection with patients, and support them to translate ACT processes into relevant, everyday life undertakings. When thinking about future implementation of ACT+, co-designing content/therapeutic resources and materials with diverse patient groups (e.g., those experiencing fatigue) may enhance engagement and equity of access.

Effectiveness of psychological interventions for cancer survivors can vary between subgroups[35], making it important for future research to explore cancer subgroups and delivery modality (e.g., remotely) for ACT+. It has been highlighted that more needs to be done to support those with treatable but not curable cancer and those who have experienced repeated cancer recurrences[36], thus these may be important avenues for future research to explore. In addition, participants in the SURECAN trial had been screened for lower quality of life. We do not know if ACT+ would benefit all people living with and beyond cancer. Finally, understanding the limitations of the approach by speaking to those who dropped out of the intervention would be an important population to explore.

Ethical statements

The study has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. Ethical approval for the study was obtained from the Health Research Authority, Southwest—Cornwall and Plymouth Research Ethics Committee (22/SW/0157). All participants provided valid informed consent prior to participating.

Author contributions

The authors confirm their contributions to the paper as follows: study conception and design: Ridge D, Taylor SJC, Chalder T, Khan I,

Robinson C, Korszun A; data collection: Donovan S, Moschopoulou E; analysis and interpretation of results: Cheshire A, Ridge D, O'Brien R, Taylor SJC, Chalder T, Moschopoulou E; draft manuscript preparation: Cheshire A, Ridge D. All authors reviewed the results and approved the final version of the manuscript.

Data availability

For all data sharing requests please contact the Pragmatic Clinical Trials Unit at QMUL www.qmul.ac.uk/pctu/for-investigators/data-sharing, all data sharing requests are reviewed by their data sharing committee.

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Conflict of interest

The authors declare that they have no conflict of interest. The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NIHR, PGfAR or the Department of Health and Social Care. Verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NIHR, PGfAR programme or the Department of Health and Social Care.

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