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Patient and health care professional co-development of an Acceptance and Commitment Therapy intervention to support hormone therapy decision-making and well-being in women with breast cancer

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ABSTRACT

Objectives: The aim of this work was to co-develop an Acceptance and Commitment Therapy (ACT) intervention to support medication adherence and quality of life in breast cancer survivors (BCSs). The research approach was intervention co-development.

Methods: The sample consisted of BCS focus groups (n=24), health care provider (HCP) interviews (n=10), and a co-development workshop (BCSs, n=12; HCPs, n=9). We conducted 6 BCS focus groups and 10 HCP interviews to understand the acceptability of ACT. We co-designed the intervention in a workshop.

Results: Participants reported high acceptability of an ACT intervention. BCSs preferred ACT exercises focused on values and self-compassion. Both groups recommended face-to-face intervention delivery, by a clinical psychologist, with a mixture of individual and group sessions. BCSs requested advice on side-effect management.

Conclusions: We effectively used patient and HCP co-design to configure an ACT intervention to support medication adherence and quality of life for BCSs. If feasible and efficacious, this ACT-based intervention could support breast cancer survivorship.

Introduction

Low adherence to adjuvant endocrine therapy (AET) among breast cancer survivors (BCSs) is common¹ and is associated with an increased risk of all-cause mortality and poorer survival.^{2–8} Women report intolerable side effects as a key reason for nonadherence.^{9–15} Mood, motivation, and

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associated factors such as memory are also involved in women's decisions to use medication.¹¹ Despite this common problem, interventions to support women with breast cancer have not successfully improved adherence.¹⁶

Existing interventions have focused on providing information about AETs and targeting contextual factors, such as improving communication between patients and care teams.¹⁶ It is therefore perhaps unsurprising that they have been ineffective, when considering the broad range of factors contributing to nonadherence.^{11,12,17,18} In addition to providing information, interventions that also target emotional and somatic factors may be necessary to improve adherence.

Acceptance and Commitment Therapy (ACT) may provide a suitable framework for such an intervention. ACT aims to help people align their behavior with their overarching goals in life by engendering "psychological flexibility": the ability to effectively make choices in situations based on one's values, while experiencing competing psychological demands.¹⁹ Therapy involves mindfulness, goal-setting, and perspective-taking exercises and fosters self-compassion. ACT may apply to AET nonadherence because this behavior might involve willingness to tolerate side effects, alongside difficult thoughts and emotions, and to connect medication-taking with longer-term goals and values. There is growing evidence to support the use of ACT in improving functioning with chronic pain and long-term conditions such as cancer.²⁰⁻²⁴ Preliminary studies and pilot and feasibility randomized controlled trials involving individual and group ACT sessions for patients with breast cancer have reported improvements in psychological distress, quality of life, and psychological flexibility.^{25,26} While the research evidence base largely comprises preliminary studies, clinicians appear to use ACT frequently in clinical practice with cancer populations, as shown in a recent survey.²⁷

To date, there have been no published ACT interventions supporting medication adherence in women with breast cancer. It is therefore unknown whether these patients or clinicians would find such an approach to managing medications acceptable or suitable. We used a structured patient and health care professional (HCP) co-design approach to develop an ACT intervention for female BCSs. Study 1 used qualitative inquiry to understand women's experiences of AET, identify patient preferences for an ACT intervention to support women after completing hospital-based treatments, and explore HCPs' opinions on how the intervention could function within clinical care. Study 1 informed study 2, a structured co-design workshop involving BCSs and HCPs. The workshop aimed to co-design an implementable ACT-based intervention that is acceptable to both BCSs and HCPs.

Study 1: focus groups with BCSs and interviews with HCPs

Method

Design

We recruited women with breast cancer to participate in six semi-structured focus groups (n=24). We undertook semi-structured telephone interviews with HCPs (n=10). LHH (PhD, female, research fellow experienced in qualitative methods) conducted the interviews and focus groups. Prior informed written consent was obtained. The Health Research Authority (London Queens Square, England) Research Ethics Committee granted ethical approval (IRAS #242034). The study conforms to the Declaration of Helsinki standards.

Materials

The authors (clinical psychologists and behavioral scientists) developed separate interview guides for the focus groups and interviews, based on their clinical experience and existing literature on women's experiences of AETs.^{12,18} Both guides included a description of ACT and psychological flexibility, including its relevance in this context, questions on the acceptability of ACT in this context, and preferences for the intervention format. The HCP interviews also included an introduction to the problem of nonadherence in AETs and pragmatic questions on how best to implement this intervention within the UK's existing National Health Service (NHS) services. To ensure sufficient understanding prior to asking about preference, patient focus groups included further descriptions of ACT, along with examples of specific ACT exercises that target each aspect of psychological flexibility (Acceptance, Mindfulness, Values, Committed Action, Flexible Perspective Taking ["Self-as-Context"], and Distancing From Thoughts ["Cognitive Defusion"]). Focus groups also included questions on participants' experiences of taking AETs, including any barriers to taking them (Supplementary file 1, patient focus group guide).

Participants

BCS focus groups

Adult women were eligible if they had been diagnosed with early stage (1–3) breast cancer, finished their hospital-based treatment, and had been prescribed AET (eg, tamoxifen, aromatase inhibitors). Participants were recruited via a cancer support group's mailing list and social media. Focus groups were held in community locations across Yorkshire. Participants were offered a voucher to compensate for their time.

HCP interviews

HCPs were breast care nurses, oncologists, surgeons, and clinical psychologists involved in the care of BCSs. They were recruited by approaching NHS hospital sites with breast cancer clinics and clinical psychology services in Yorkshire. Recruitment was increased through snowballing. HCPs were offered monetary compensation for their time.

Measures

Medication adherence

BCSs completed the behavioral domain of the ASK-12 questionnaire²⁸ to assess their adherence to AETs. Participants answered 5 questions on the frequency of various medication-taking behaviors (eg, “taken a medication more or less often than prescribed”), with answer stems: “In the last week,” “In the last month,” “In the last 3 months,” “More than 3 months ago,” “Never.” Scores were out of 20, with higher scores indicating poorer adherence.²⁸

Perceived usefulness and acceptability

BCSs answered questions on their perceived usefulness of ACT for improving well-being, medication decision-making, and managing side effects. They also completed questions on whether specific ACT processes and exercises should be included in the intervention (Supplementary file 2, patient focus group guide).

Analysis

Focus groups and interviews were digitally recorded and transcribed verbatim. We used thematic analysis with a semantic, open-coding approach, from a realist epistemological stance, which reflects that participants’ language is understood as reflecting their reality.²⁹ NVivo plus 12 assisted in organizing codes into themes. LH (a researcher trained in qualitative methods) coded the transcripts and CG and SS checked the quotes and themes for coherence. COREQ guidance was followed.³⁰

Results

Participants

Patient focus groups

All participants were members of local cancer support groups. Average age was 53 years (range 28–70), and half reported being postmenopausal. Average adherence was 8.8 out of 20 (range, 0–18) (Table 1).

Table 1. Participant demographics from study 1.

Breast cancer survivor focus groups (n=24)					
Focus group No.	No. of participants	Menopausal status	Age, mean (range)	AET experience	ASK-12 Behavior score: mean (range)
1	4	2 pre, 2 post	52.5 (33–66)	2 anastrozole, 1 tamoxifen, 1 n/a	8.3 (6–11)
2	3	1 post, 2 unsure/other	57.6 (53–62)	1 tamoxifen and letrozole, 1 anastrozole, 1 tamoxifen and anastrole	6.6 (5–8)
3	2	2 post	55.5 (54–57)	1 tamoxifen, letrozole, 1 anastrozole	10.5 (5–16)
4	5	4 post, 1 unsure/other	56.6 (28–70)	2 tamoxifen, 1 letrozole, 2 anastrozole	8 (5–15)
5	3	1 pre, 2 post	53 (52–54)	1 tamoxifen, 1 anastrozole, 1 anastrozole then tamoxifen	8.3 (0–14)
6	7	2 pre, 1 post, 4 unsure/other	47.6 (37–53)	4 tamoxifen, 2 tamoxifen and anastrozole, 1 tamoxifen and exemestane	10.1 (7–18)
Health care professional interviews (n=10)					
Professional role	No. of participants	Gender	Age, mean (range)	Psychological therapies used	Years working with women with breast cancer: mean (range)
Clinical psychologists	4	75% female	36.8 (28–42)	ACT, CAT, CFT, EMDR, mindfulness, person-centered	6.7 (2–13)
Breast care nurses	3	100% female	48.6 (38–59)	Mindfulness, motivational interviewing	17.6 (7–30)
Surgeons	2	100% female	49.5 (47–52)	n/a	20
Oncologists	1	100% female	62	n/a	35

ACT, Acceptance and Commitment Therapy; AET, adjuvant endocrine treatment; ASK-12, Adherence questionnaire; CAT, Cognitive Analytic Therapy; CFT, Compassion-Focused Therapy; EMDR, Eye Movement Desensitization and Reprocessing Therapy.

HCP interviews

Ten HCPs from five NHS Trusts participated: four clinical psychologists, three breast care nurses, two surgeons, and one oncologist. Their average number of years experience in breast cancer was 16 (range, 2–35) (Table 1).

BCSs' experience of AETs

Women discussed their experiences of AETs, which grouped into five themes (Appendix B): (1) *benefit vs risk*: participants questioned whether the risk reduction of AETs were worth the reduced quality of life they caused; (2) *control*: some participants took their medication to feel they were doing everything they could to prevent a recurrence, and others took them because they did not feel like they had a choice; (3) *fluctuating levels of professional support*: participants received a lot of support during hospital treatments, but felt this ended upon discharge, leaving many struggling to cope; (4) *survivor guilt*: feeling guilty they had survived when others had not; and (5) *self-identity*: AETs made them feel older, and many struggled to accept their post-cancer bodies as their own.

Preferences and opinions on an ACT intervention

Intervention acceptability and suitability

BCSs wanted a supportive intervention after their treatment to help them during the transition from patient to survivor.

... there needs to be something that runs alongside the medication, some talking therapy, somewhere where you can talk about it and be reassured instead of just giving you a prescription and told you are going to take that for 10 years—Lisa, FG2, 53 years

Both BCSs and HCPs were positive about the concept of an ACT-based intervention. All BCSs indicated that an ACT based intervention would be “a little helpful” (33%, 50%) or “very helpful” (66%, 50%) for improving well-being and supporting medication decisions, respectively. BCSs preferred the values and self-compassion exercises ([Supplementary file 2, supplementary figure 1](#)).

Several BCSs felt the intervention could empower them to make decisions, as ACT focuses on taking steps toward individual goals and values.

I think [an intervention to help people make decisions based on values] is really positive. I mean, I've actually changed how I'm feeling about this just from what we've just said ... —Lisa, FG2, 53 years

HCPs agreed that support after hospital treatment would be helpful, and those familiar with ACT felt it would be suited to this population.

[ACT] has much greater relevance than just the medication adherence (...), it's actually equipping people to deal with so many different impacts of living with ... and beyond breast cancer. I think you are hitting lots of birds with one stone. ... When you were talking about the education-focused approaches... used previously,

they are very specific to medication, whereas this actually has a much greater benefit to people.—Clinical Psychologist 1

Despite the overall positive review of ACT in this context, there was some uncertainty among the BCSs as to how the intervention could help with side effects.

I can't quite see where it would help with dealing with the pain or the hot flushes ... —Unidentified Speaker, FG5

HCPs were cautious about how this intervention could work in practice, given the current limited resources in the NHS health care system:

I read that [funding application] and thought, “Wow, that's really good. That's exactly the kind of thing we need.” But ... it seems so much harder now we have talked about it. It seemed like such an easy idea before [laughing] but it seems like logistically, it's actually quite difficult ... —Surgeon 1

Format of the intervention

BCSs generally preferred that the intervention was delivered face-to-face, rather than via telephone, on a website, or in a printed leaflet/workbook.

I would agree with face-to-face because I sometimes think there is so much on the internet that you actually scare yourself. [Agreement from two other participants.] —Ellen, FG4, 56 years

They argued that human interaction was necessary to provide appropriate emotional support and help reduce the isolation felt by many patients with cancer during and after treatment.

... being able to come and have human interaction. Because a lot of people who are going through treatment for cancer, you become very isolated, you want to shut your door and shut the world out.—Emily, FG4, 70 years

Participants were also supportive of being able to access [supplementary information](#) online. It was felt that a website would make it easier to access key information when women were particularly struggling with side effects or emotions.

... some sort of online access (...). There are times when ... I would need help ... more in that week than I would in another week. So if you could access ... even just exercises or like grounding exercises ... remotely when you needed them.—Unidentified Speaker, FG6

Both BCSs and HCPs suggested having a mixture of both individual and group intervention sessions. The group sessions may help reduce isolation by enabling connection with other women in a similar situation.

[Group sessions] offer that opportunity for people to have their experiences normalized and go away with a sense of not being on their own. I think in groups it can have a much more profound impact, people coming together and finding that they have a shared experience.—Clinical Psychologist 1

The individual sessions might allow for deeper personal reflection through having one-on-one time with a therapist.

So I think if you do it only in a group you are possibly missing out some opportunities to get people to think really, really deeply, which is what you need them to do when you are getting them to think about values.—Cassie, FG2, 58 years

BCSs had a preference for clinical psychologists to deliver the intervention, as it was felt they had more experience delivering group-based therapy.

I think you need a psychologist there because the dynamics of the group may drive different things out of it (...). It's being able to answer those questions and help people with some really serious stuff that's close to them. And I think helping them with the right mindset. So I think you have to have somebody who knows that kind of stuff.—Unidentified Speaker, FG5

HCPs agreed that a clinical psychologist is best placed to deliver the intervention. However, they felt that clinical psychologists are a limited resource and considered whether a breast care nurse could be trained to deliver the intervention. This raised concerns regarding training costs and capacity issues elsewhere in the clinical service.

It [ACT] doesn't say that it has to be a psychologist. But I think there would be benefits to it being a psychologist. So yes, I don't think it would have to be, but again the ideal world type stuff.—Clinical Psychologist 3

Regarding the number of therapy sessions, BCSs suggested that around 4 would be acceptable. HCPs agreed that a lower number of sessions would increase the likelihood of attendance:

I would say probably 4 is a good number and wouldn't be off-putting.—Claire, FG3, 57 years

I think the [fewer] sessions for people to attend, the better, because I think they'll come to more. ... So if you've got 6 sessions, people probably attend 4...—Clinical Psychologist 3

Feasibility of the intervention

HCPs often reflected on the gap between the ideal intervention and what was feasible given existing resources. A common suggestion was to embed the intervention into existing self-management programs.

... my initial thought would be to try to incorporate it somehow into the Moving Forward program, because you do capture a lot of women and it tends to be at that point they have a lot of questions about the tablets, the side effects ... and even if you couldn't particularly deliver it on the same day ... you could at least introduce it and then have a separate day set up potentially for [women using AET].—Breast Care Nurse 3

To improve uptake, recruitment, and feasibility of the intervention, HCPs discussed the need for all staff, and particularly the breast care nurses, to be supportive of the intervention.

I think the key is having someone on the ground ... a clinician on the ground who will help you with that rather than sort of coming in externally, and having someone who really believes in the research, is an advocate for it, and I would say someone like a breast care nurse rather than a medical doctor just because they would possibly have a bit more time to talk it through with people.—Clinical Psychologist 2

Study 2: BCS and HCP co-design workshop

Method

Design

We held a 3-hour workshop in a community center to design the intervention format. In 3 mixed and balanced groups of approximately 8 BCSs and HCPs, attendees completed tasks to optimize the configuration of the intervention. This process aimed to bring key stakeholders together to allow consideration of both BCSs' preferences and HCPs' perspectives on the feasibility and acceptability of an ACT-based psychological intervention.

Tasks

Participants were provided with an overview of ACT by a clinical psychologist, and a patient provided her experience of using AETs. Then, the groups were asked to design what they considered to be the most optimal and feasible intervention to support medication decision-making in women with breast cancer. Groups were provided with colored cards to represent different idea categories ([supplementary file 2](#), [supplementary Table 2](#)). For example, green cards represented the "setting" category such as "hospital," "support group," and "remote." Participants were told they could produce new ideas and were not restricted to the cards. Groups were asked to discuss the options, collectively select their preferred choice for each category, and place the appropriate card(s) onto a flip chart.

The groups were asked to reflect on their choices from several perspectives, to see whether this would lead to changes in choices. We facilitated this by adapting the “Three hats” exercise from the “Thinking differently toolkit.”^{31,32} Groups were asked to spend 3 minutes on each of the following: negatives/risks; positives/benefits; and new ideas/possibilities. Paper hats colored black (negatives), yellow (positives), and green (possibilities) were placed on each table, to encourage discussions to remain focused. The groups were encouraged to amend their original chart throughout this exercise.

The groups then presented their proposed intervention format to each other, and further amendments were permitted. Each group’s proposal was finalized and recorded for discussion among the research team. Additionally, attendees were invited to provide anonymous suggestions using sticky notes on a chart at the back of the room: BCSs were asked what additional information they would like in an intervention; HCPs were asked to provide examples of questions they often get asked by their patients using AET. Suggestions were collected to inform whether any additional information should be provided within the intervention.

The workshop was exempt from ethical approval according to the Health Research Authority (HRA) screening tool.³³

Workshop attendees

Eligibility criteria were identical to study 1. Participants from study 1 who consented to be contacted were recruited by email, and a cancer charity advertised the workshop through their mailing list and Facebook. Posters were put up in community centers to increase group diversity. A snowballing method was used to recruit additional HCPs. Attendees were offered a monetary incentive, a Continued Professional Development certificate, and lunch.

Measures

Attendees provided demographic information on age, sex, profession, AET experience, and ACT experience. BCSs were asked to complete the behavioral domain of the ASK-12.²⁸

Analysis

We examined the groups’ intervention configurations from the workshop in parallel. Where possible, the suggestions from each workshop group were combined by consensus. Where there were discrepancies between

groups, we considered how pragmatic each option was and how many groups suggested each option. Similarly, if something was suggested by a single group, we considered its feasibility and potential value to the intervention. We grouped attendees' suggestions for additional information into common themes.

Results

Workshop attendees

Twelve BCSs and nine HCPs attended the workshop. The majority of participants had not taken part in study 1. BCSs' mean age was 53 (range, 33–67), and average adherence score was 8.5 out of 20 (range, 5–14). Most BCSs were postmenopausal (10/12), with 11 of 12 having experience of taking aromatase inhibitors and 4 of 12 with experience of taking tamoxifen. Four clinical psychologists, four breast care nurses, and one trainee surgeon attended. Attendees were split into 3 groups containing a mixture of BCSs and HCPs. A researcher facilitated each group.

Findings

Compromises were made regarding the number of sessions between BCSs' preferences and HCPs' thoughts on feasibility (many/unlimited sessions vs fewer, respectively). The "three hats" exercise successfully elicited BCSs' perspectives during the "positive" section and potential limitations from HCPs during the "negatives" section. All groups amended their ideas as a result of this task and the feedback round.

The suggestions for additional information requested by BCSs and common questions received by HCPs were grouped into themes ([supplementary file 2, Supplementary Table 2](#)). The most common questions related to treatment side effects and coping with emotional issues. Some suggestions reflected the discussions during the focus groups: for example, low levels of understanding regarding the risk reduction afforded by AETs and low awareness of typical symptoms were mentioned. This information was used to inform the content of a website that will supplement the ACT sessions.

There was consensus between workshop groups in the final intervention configurations ([Table 2](#)), particularly with regard to medium (primarily face-to-face, with option of video call), day (during the working week), and additional resources (website). There were discrepancies between groups on the suggested setting and intervention deliverer. Findings from study 1 were therefore used to inform final configuration decisions.

Table 2. Final configuration suggestions from each workshop group (n=21).

	Group 1	Group 2	Group 3
Medium	Face-to-face	Face-to-face (with remote video call option)	Face-to-face (initially) Telephone/Skype (follow-up) Website YouTube, Podcast
Format	Group sessions	1 individual, then group	Mixture of group and individual
Frequency	Fortnightly/monthly	Not specified	Fortnightly or monthly (Plus direct contact via website or alternative)
Session length	2 hours	60–90 minutes (individual) Full-day (group)	90 minutes
No. of sessions	3	1 (individual) and finite (group)	3 and optional 3
Deliverer	Psychologist or nurse (if trained)	Nurse Expert in medication	Psychologist with support from nurse/physiotherapist Expert by experience
Location	Community center	Hospital (individual) Support group (group)	Hospital (nonclinical room) Support group Home practice
Day of week	Weekday	Weekday 9–5 (individual) Weekend 9–5 (group)	Weekday 9–5
Additional resources	Website with audio and video clips and exercises, CD/DVD for those not IT-literate	Internet, video clips (YouTube, DVD)	Website, with direct contact Testimonials of treatment journey

Agreeing to a final configuration

The findings from both studies were discussed within the core research team and at a multidisciplinary Trial Management Group meeting. The findings from both studies were mostly consistent, especially with regard to the medium of face-to-face (Table 3). The proposed intervention was presented to the Trial Management Group, who agreed to this configuration (Figure 1). More detail on the content and therapeutic methods used in the ACTION intervention, including the specific aims of each session, are detailed in Supplementary File 2, supplementary table 4. The one-to-one session (session 1) involves a conversational assessment between the therapist and the participant on psychological flexibility to see where this could be enhanced in the participant's day-to-day life. This includes conversations about their salient experiences of treatment (hospital and AETs) and how they approach concomitant thoughts and feelings, alongside a conversation about what is important to them. This culminates in a very brief individualized formulation suggesting some possibilities for enhancing psychological flexibility in order to enhance well-being. The following 3 group sessions give participants the opportunity to engage in group discussion, self-reflection, and experiential exercises designed to enhance different aspects of psychological flexibility. In group session 1, the focus is on enhancing contact with values and then the possibility for defusion to enable effective actions. This session includes established ACT exercises,

Table 3. Comparison of results from studies 1 and 2.

	Focus group (BCSs, n=24)	Interview participants (HCPs, n=10)	Workshop participants (BCSs and HCPs, n=21)
Format			
Group individual		✓	
Mixed	✓		✓
Primary medium			
Face-to-face	✓	✓	✓
Internet			
Audio recordings			
Workbook			
Video call			✓
No. of sessions			
2			
3			✓
4	✓	✓	
5	✓		
6	✓		
Intervention deliverer			
Clinical psychologists/ therapist in oncology	✓		✓
Breast care nurse		✓	
Time of day			
9–5 weekday	✓		✓
Outside of 9–5 working hours		✓	

BCS=breast cancer survivor; HCP=health care professional.

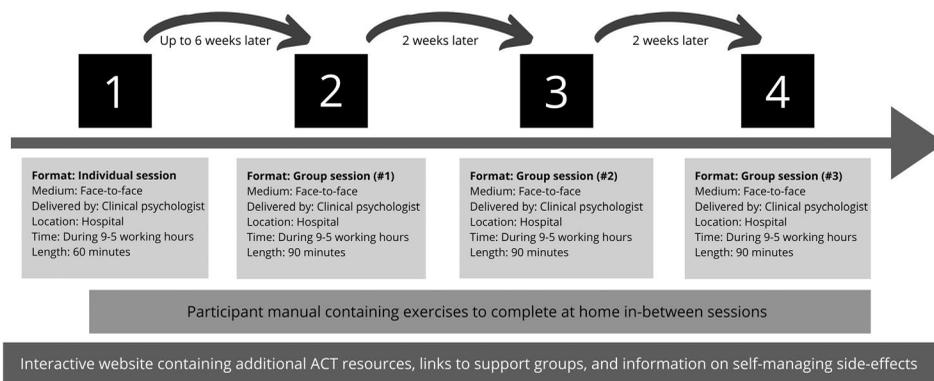


Figure 1. Final intervention configuration: 1 individual session followed by 3 group sessions.

such as Workability and Verbal Distancing.^{34,35} Group session 2 focuses on values and committed action in more detail, with exercises such as the Values Compass used to help participants clarify what’s personally meaningful then the Smallest Possible Step exercise suggested as a homework to initiate new enriching activity. In this session, participants are offered the opportunity to specifically reflect on HT decisions and side-effect management from within the framework of their own personal values. This session also gives participants the opportunity to see the possibilities for well-being within acceptance-based approaches to experiences, using

established metaphors, such as Passengers on the Bus.³⁴ The final session outlines ways of stepping back from unhelpful self-stories, via exercises such as Notice Who Is Noticing³⁴ and Letting Go of Unhelpful Labels.³⁶ It also invites participants to notice whether anything experienced or learned in ACTION has been helpful.

Discussion

We used a co-design approach to develop an ACT-based intervention to support AET medication decisions and quality of life in BCSs. The methodology enabled us to incorporate the perspectives of both BCSs who would be eligible to participate in the group and HCPs who could be involved in delivering it.

Study 1 identified women's difficulties with AET, their challenging experiences with the transition between treatment and survivorship, and their reports of debilitating side effects and perceived low levels of support. This is consistent with literature from the UK and the US, highlighting that BCSs desire supportive interventions at this stage in treatment.^{12,18} ACT was considered acceptable for supporting BCSs, with particular enthusiasm for exercises focused on understanding their individual values and goals and fostering self-compassion. BCSs reported skepticism around ACT's use in relation to side effects, suggesting that this may need to be addressed when communicating with patients about this therapy. Commensurate with data showing that psychological therapists in cancer contexts favor ACT approaches,²⁷ HCPs' feedback was similar. However, concerns were raised regarding NHS capacity to deliver such an intervention.

Study 2 involved a co-design workshop and effectively consolidated and refined the suggestions from study 1. Three mixed groups of BCSs and HCPs proposed similar intervention configurations. This workshop highlighted the perceived usefulness of providing online resources for reference between and after the sessions. Suggestions for website content were made, such as the inclusion of patient stories and practical strategies for managing side effects. Such narrative information may help women adjust to their illness and treatment.³⁷ Our data support that using patient narratives in this setting is acceptable to BCSs.

Clinical implications

We identified the period immediately following hospital-based treatment as the optimal period for delivering psychological support and information on AET. This supports epidemiological data demonstrating that the first months are likely to be key for supporting medication side effects and

adherence.³⁸ There is a therapeutic opportunity for greater discussion and shared decision-making regarding AETs at this stage.³⁹ Furthermore, ensuring that consultations are patient-centered may improve patient satisfaction with information⁴⁰ and increase long-term adherence to AETs.¹² Our intervention has been designed to be implemented rapidly within the breast cancer care pathway; however, feasibility and efficacy trials are needed prior to implementation.

Study limitations

Participants in the focus groups and workshop were similar in age and ethnicity. Therefore, key issues that may be relevant to underrepresented groups, including specific religious or cultural ideals, may be missed within the content of the intervention. The majority of BCS participants were members of breast cancer support groups, which may reduce generalizability and may have resulted in selection bias toward those who favor group-based support services. ACT is a complex psychological theory, and explaining it to a lay audience in a limited timeframe may have led to misunderstanding. This work was undertaken prior to the COVID-19 pandemic; therefore acceptability of remote interventions (eg, video calls) is likely to be underestimated. Encouragingly, in study 2, 2 of the 3 groups indicated that they would consider the option of attending the therapy sessions remotely. Understanding the acceptability of ACT in the future pilot trial will be key to confirming the data reported here.

Conclusions

Using a co-design approach, we developed an ACT-based intervention that was considered to be acceptable and feasible to both potential intervention users and deliverers. Incorporating views and preferences of both BCSs and HCPs involved in their care, a consensus was reached on the configuration of the intervention. Further research is needed to examine the actual acceptability, feasibility, and efficacy of this co-designed intervention.

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Raw data, beyond those displayed in this article, are not shared.

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