School of Psychology
Ysgol Seicoleg

A Systematic Review Evaluating the Effectiveness of Bibliotherapy for Reducing Psychological Distress in Cancer

and

A Qualitative Exploration of the Experience of Using a Bibliotherapy Intervention based on Acceptance and Commitment Therapy for People with Cancer

Thesis submitted in partial fulfilment of the requirement for the degree of:

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Preface

Being diagnosed with cancer is a life changing event that is associated with a range of challenges. The physical symptoms of cancer, along with the side effects of treatment, can be extensive, with issues such as fatigue, pain, and cognitive impairment being reported frequently among people with a diagnosis. Psychological difficulties such as dealing with uncertainty and fears about the future are also a common experience for people with cancer. With this in mind, it is not surprising that a significant number of people with cancer experience mental health difficulties relating to their illness. Although there is now a range of psychological interventions available for cancer-related mental health difficulties, many people who may benefit from these forms of support do not access them. There are a number of barriers which may prevent people with cancer from engaging in psychological support, including access to services, stigma, and a desire to deal with emotions independently. In order to address these barriers, more self-directed and accessible interventions are receiving attention. One such intervention is bibliotherapy, which is the therapeutic use of books and other reading materials. Although there is a growing amount of research suggesting that this form of intervention can be effective in helping people with difficulties such as depression and anxiety, there is less evidence of its effects for people with cancer.

The first paper in this thesis seeks to systematically review current research in order to evaluate the effectiveness of bibliotherapy for reducing psychological distress for people with cancer. Studies were included in the review if they evaluated an individual bibliotherapy intervention based on a psychological approach for adults with cancer. Four electronic databases were searched, and eight papers met the eligibility criteria. Although over half of these studies indicated that bibliotherapy can be effective in reducing psychological distress for people with cancer, it is difficult to draw any firm conclusions from the results due to the small sample size and high level of variability across the studies.

The second paper in this thesis presents a qualitative exploration of the experiences of using a self-help book for people with cancer. The book was written by psychologists in collaboration with people who have experience of living with cancer. The book is based on a psychological approach called Acceptance and Commitment Therapy (or ACT), which aims to improve psychological flexibility. Although previous research has demonstrated that ACT is an acceptable and effective model for working with people with cancer, this is the first study to explore the use of ACT through bibliotherapy. Ten participants were recruited from cancer charity organisations to take part in this study. They were asked to use the book for one month before taking part in an interview to share their experience. Interviews were transcribed and analysed using a process called reflexive thematic analysis. Five themes were generated from the data including: (1) The value of bibliotherapy (2) Timing is important (3) Resonating with cancer experiences (4) Tools of the book (5) ACT in action. Overall, it seemed that participants found the book to be an accessible and easy to use intervention. Many participants related to information in the book and found this to be normalising and validating. Participants engaged in different ways with the tools of the book, including audio and written exercises, and a number of participants found the interactive aspect of the intervention to be beneficial. It seemed that bibliotherapy was an acceptable format to deliver ACT, and many participants described engaging with core ACT processes as a result of using the book, including connecting with their values, detaching from distressing thoughts, and being more mindful.

Overall, both papers generated some interesting results about the use of bibliotherapy for people with cancer. Paper one demonstrated bibliotherapy to have some effectiveness in reducing psychological distress for people with cancer but indicated that more research is needed in this area, particularly with more diverse groups. Paper one also highlighted a lack of collaborative service user development among bibliotherapy interventions for people with cancer. Paper two suggested that bibliotherapy is an acceptable format of delivering ACT, however, as this was the first study evaluating this type of intervention further evaluation of its effectiveness would be beneficial. Strengthening the evidence base relating to bibliotherapy interventions for people with cancer could have important implications in terms of access to support for this population, given that bibliotherapy has been demonstrated to be an accessible and cost-effective form of intervention.

Paper One: Systematic Review

An Evaluation of the Effectiveness of Bibliotherapy for Reducing Psychological Distress in Cancer: A Systematic Review

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Abstract: 100

Paper one has been prepared in accordance with the submission guidelines for the *Journal of Health Psychology* (see Appendix 1). The DClinPsy 8000 wordcount limit has been used to ensure all relevant information has been included for the examiner. For ease of reading, tables and figures have been embedded in the main body of the paper, however these will be included within supplementary information for journal submission.

Abstract

Objective: This review aims to evaluate the effectiveness of bibliotherapy for reducing psychological distress for people with cancer

Methods: A systematic search of APA PsycINFO, PubMed, CINAHL, and Scopus identified eight papers meeting eligibility criteria, consisting of five RCTS and three feasibility studies.

Results: It is promising that over half of the included studies reported significant findings in terms of effectiveness. However, it remains difficult to draw firm conclusions due to small sample size and variation across studies.

Conclusion: Further research using consistent methodologies would be beneficial in furthering current understanding about the use of bibliotherapy for people with cancer

Introduction

Over the past decade the incidence of cancer has increased in the UK, and it is now estimated that one in two people will develop some form of cancer in their lifetime (NHS, 2019). Although the number of new cases is expected to continue rising - with estimations of 4 million people living with cancer by the year 2030 (Maddams et al., 2012) – rates of cancer survival are also growing thanks to better diagnostics and advancements in treatment (Arnold et al., 2019). Whilst it is positive that survival rates are improving, for many, surviving cancer now means living with a complex and chronic disease. Often, this can involve the long-term management of a range of physical symptoms and side effects of treatment including pain, fatigue, insomnia, breathlessness, nausea, hair loss, bladder and bowel problems, and susceptibility to infection (Macmillan, 2019). In addition to physical health challenges, a significant proportion of people living with cancer will also experience difficulties relating to their mental health and wellbeing. Psychological distress, which can be defined as unpleasant emotional or psychological experiences, including depression, anxiety and other mood disorders (National Comprehensive Cancer Network, 2020), is common among people affected by cancer, with research suggesting that approximately one third of all cancer patients will experience significant levels of cancer-related distress at some point (Carlson and Bultz, 2003; Zabora et al., 2001). Psychological distress can be highly prevalent and diverse at all stages of cancer care (Holland and Alici, 2010), and has been associated with a range of cancer-related factors including diagnosis, illness progression, treatment, and level of disability (Banks et al., 2010; McCarter et al, 2017). The implications of psychological distress among people living with cancer are significant and include non-adherence to treatment and reduced quality of life (Carlson et al., 2012).

In order to address cancer-related psychological distress, a number of psychological interventions have been developed including psychoeducation, counselling, and more specific forms of psychotherapy in a range of formats and orientations (Grassi et al., 2017). The literature on the effectiveness of psychotherapeutic interventions in oncology indicates a general benefit in reducing psychological distress (Okuyama et al., 2017; Yadav et al., 2021; Zainal et al., 2013), however a need for more rigorous and high-quality trials in this area has been highlighted (Chong Guan et al., 2016). Some of the interventions with the most empirical support include supportive-expressive therapy (Classen et al., 2008), cognitive-behavioural therapy (Tatrow & Montgomery, 2006), and mindfulness-based therapy (Piet et al., 2012). There is also a growing body of evidence supporting the use of integrative therapies for people with cancer, although many of these practices remained understudied (Greenlee et al., 2017).

Despite the fact that research has demonstrated a number of psychological interventions to be effective in reducing psychological distress, a significant proportion of people who experience cancer-related psychological difficulties do not access these forms of support (Jacobsen and Jim, 2008). Barriers to accessing psychosocial interventions for people with cancer may include factors such as cost (Greenberg, 20014), as well as issues such as stigma (Kissane, 2014) and wishing to manage emotional concerns independently (Christy et al., 2014).

As a result of the accessibility and delivery constraints associated with current interventions for cancer-related psychological distress, self-administered interventions requiring little or no therapist input are receiving increasing attention (Roberts et al., 2016). A systematic review carried out by Ugalde et al. (2017) suggested that self-guided interventions represent a potentially effective way of delivering support for people psychologically affected by cancer, although highlighted that further research is needed to develop the evidence base regarding their effectiveness for reducing psychological distress. A range of self-guided interventions for people with cancer have been explored to date, including those that are delivered online. Studies investigating interventions such as self-guided internet coping-skills training groups (Owen et al., 2005), online psychological programmes and peer discussion forums (Wootten et al., 2015), and internet peer-support groups for psychosocial adjustment to cancer (Høybye et al., 2010) have demonstrated the potential effectiveness of online interventions for improving psychological distress. Another form of self-guided intervention that has been explored is the use of resource packs, consisting of materials such as CDs, videos, and diaries. There is evidence to suggest that this form of self-guided intervention also has the potential to decrease psychological distress and improve quality of life for people with cancer (Krischer et al., 2007; Ramachandra et al., 2009).

Another form of self-administered intervention for cancer-related psychological distress that has been investigated is bibliotherapy. Bibliotherapy can be defined as the therapeutic use of books and other reading materials (Howie, 1988). Although many studies have demonstrated the acceptability and effectiveness of bibliotherapy for mental health difficulties such as depression and anxiety (Gregory et al., 2004; Haug et al., 2012), research into the use of bibliotherapy within the oncology domain is still in its infancy. However, preliminary findings have indicated that bibliotherapy is an acceptable intervention among patients with cancer. Semple and colleagues (2006) asked patients with head and neck cancer to share their preferences with regard to mode of delivery for a cognitive behavioural intervention. Out of four options, bibliotherapy was chosen as the second most preferential form of intervention (36%), after individual therapy (46%) and before computer (14%) and group (7%) formats. This suggests there may be a significant proportion of cancer patients who are interested in self-administered written support. In line with these findings, a qualitative study carried out by Roberts and colleagues in 2016 found that participants experienced a self-help workbook to be a useful and acceptable intervention, with seventeen out of eighteen participants in the study reporting that they would recommend the workbook to other patients with cancer.

At present there are only a small number of studies that have explored the effectiveness of bibliotherapy for cancer-related psychological distress. A systematic review conducted in 2017 examined the use of self-guided interventions for managing psychological distress in people with cancer and included a number of studies utilising written interventions such as booklets, workbooks, and journals (Ugalde et al., 2017). Overall, limited effectiveness was demonstrated for these interventions, with some short-term psychological stress reduction reported but no long-term benefits. However, many of the bibliotherapy interventions reviewed in this paper included additional components such as DVDs, audio tapes and online programmes, making it difficult to determine the effect of the written interventions alone. A meta-analysis of written self-administered psychosocial interventions for adults with a physical illness, including 12 cancer samples, documented more positive results (Lambert et al., 2017). This review concluded that self-guided bibliotherapy appeared efficacious in reducing anxiety, depression, and distress. However, subgroup analysis was not performed by physical health condition, and therefore the research lacked any focused evidence for efficacy specifically relating to a cancer population. Furthermore, the methodological quality of studies included in the review indicated that findings should be interpreted with caution. More recently, Malibiran et al. (2018) carried out a review of evidence regarding the efficacy of bibliotherapy for alleviating components of psychological distress for both child and adult patients with cancer. Their review, which included nine studies of mixed design and methods, concluded that bibliotherapy appears to be an acceptable and beneficial intervention in reducing patient-reported psychological distress, with frequent patient-reported outcomes including reductions in stress, anxiety and depression. Whilst this paper provides a useful summary of extant literature, many of the integral processes that contribute towards a robust systematic review are not reported upon. For example, methods of selection and data collection are not fully outlined, a comprehensive overview of included papers with narrative synthesis is not provided, and the outcomes of a critical appraisal are not included. It is also noted that a number of relevant studies were missing from this review, and further, a number of appropriate studies have been published since.

Given the lack of any comprehensive reviews of the impact of bibliotherapy on psychological distress for people with cancer to date, in addition to the publication of recent relevant studies in this area, there is now a need to conduct a systematic review of current literature in this field. As such, this systematic review aims to identify, synthesise, and critically appraise the existing evidence in this area. The review will focus on bibliotherapy interventions that are based on an established therapeutic approach, as these have been demonstrated to be generally more effective than information only written interventions (Matcham et al., 2014).

Method

Search strategy

A systematic search of relevant literature was carried out in January 2021 using four databases: APA PsycINFO, PubMed, CINAHL, and Scopus. Searches were conducted using a combination of population and intervention terms. Population terms included ‘cancer’, ‘oncology’, and ‘neoplasm’. Intervention terms included ‘bibliotherapy’, ‘psychoeducation’, and ‘therapy workbook’. See Appendix 2 for a full list of search terms. No restrictions were placed on searches in terms of language or publication date. In addition to database searches, citation chaining and hand searches of key journals were performed. Identified authors were also contacted and asked for relevant papers or articles in press.

Eligibility criteria

Inclusion and exclusion criteria for this review are summarised using the PICOS model (Richardson et al.,1995) in Table 1 below.

Table 1. Eligibility Criteria

PICOS Criteria	Description
Population	Adults with a diagnosis of cancer were the target population for this review. Studies using participants aged 18 or older with any type and stage of cancer were included. Studies using participants under 18 and/or without a cancer diagnosis were excluded.

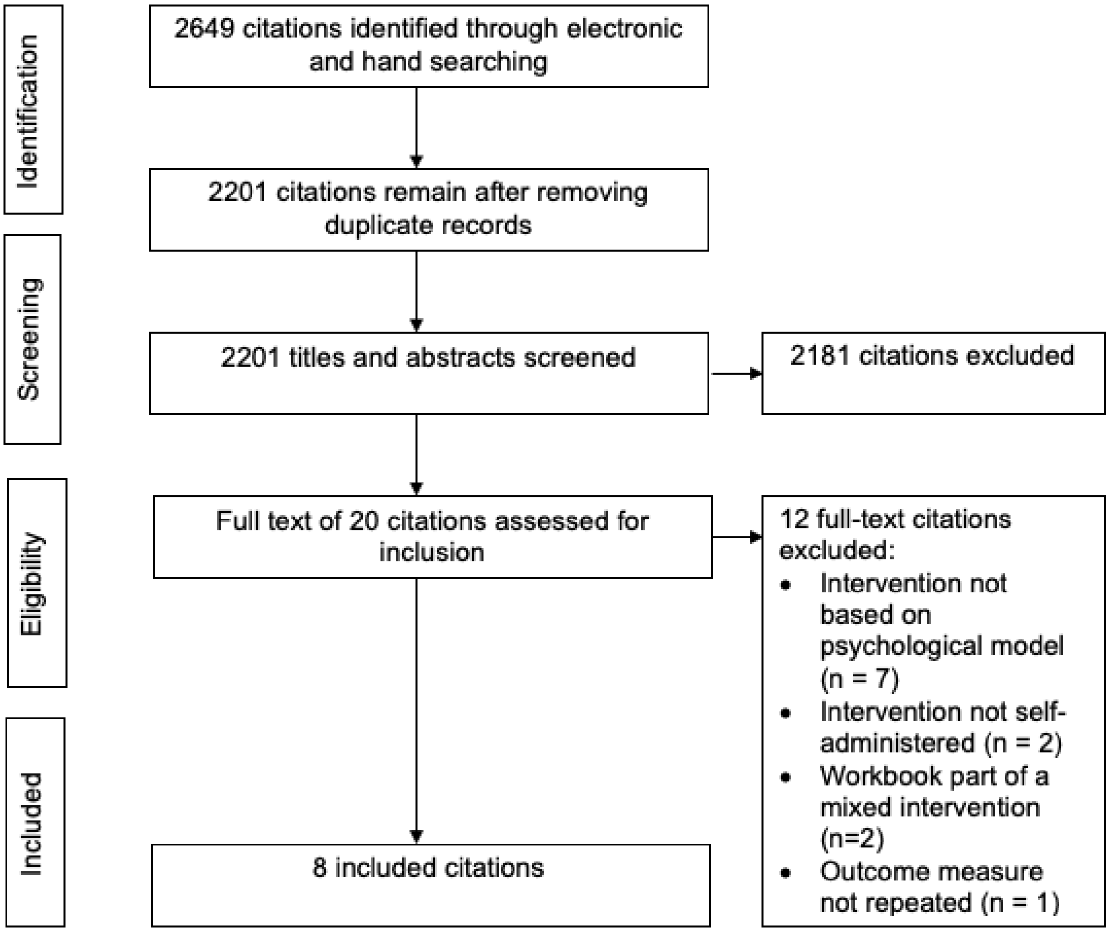
Intervention	Studies included in this review evaluated self-administered bibliotherapy for patients with cancer. The intervention had to be in the form of a printed or electronic booklet, book, or workbook and based upon a psychological model. Studies were excluded from the review if the intervention was delivered in a group format and/or alongside any other intervention e.g. telephone support. Studies were also excluded if the bibliotherapy intervention provided information only, without any inclusion of psychological approaches or ideas.
Comparator	Studies comparing the intervention to any other intervention, or no intervention were included in this review.
Outcome	Studies measuring psychological distress as either a primary or secondary outcome were included. This included measures of depression, anxiety, and stress.
Study design	Appropriate studies were defined as published randomised controlled trials, pilot studies, and feasibility studies.

Study selection

All citations identified from searches were imported to a referencing software programme and duplicates were removed. Titles and abstracts were screened by the first author using the inclusion and exclusion criteria. Full text papers meeting eligibility criteria were then obtained and screened. In order to reduce bias and enhance the robustness of this process, a random 10% sample of both title and abstracts and full text papers were also screened by a peer. An interrater reliability analysis using the Kappa statistic was performed to determine consistency between reviewers. Level of agreement was 96% and interrater reliability was found to be Kappa=0.79.

Searches identified 2649 citations in total. Once duplicates were removed, 2201 citations remained to be screened for inclusion by title and abstract. Of these, 2181 were excluded, leaving 20 full text papers. After applying eligibility criteria to these full text papers 12 citations were excluded. Seven of these evaluated interventions that were not based on a psychological model, two evaluated interventions that were not self-administered, two evaluated a workbook that was part of a larger, mixed intervention, and one did not include repeated outcome measures for psychological distress. One paper was deemed eligible for review, despite the age range of participants being 17-27, as contact was made with the author who confirmed that only one participant under the age of 18 took part in the study. This minor deviation from the eligibility criteria was felt to be acceptable when weighed against the information to be gained from including the paper. Figure 1 displays the process of study selection.

Figure 1. PRISMA flow chart of search process



Data Extraction

Data extraction forms were used to collect relevant data from identified studies (see Appendix 3). The template for this form was developed using Cochrane Training recommendations for data extraction (Li et al. 2021) and documented details such as authors, study design, aims, sample size and setting, participant demographics, details of intervention and control groups, outcomes, and results. Data was extracted independently by the first author and verified by the second authors.

Quality Assessment

The methodological quality of randomised controlled trials (RCTs) included in this review was assessed using the CONsolidated Standards of Reporting Trials (CONSORT) 2010 checklist (Schulz et al., 2010; Appendix 4). Pilot and feasibility studies were assessed using the CONSORT extension for randomised pilot and feasibility trials (Eldridge et al., 2016; Appendix 5). Whilst this extension does not directly apply to non-randomised pilot and feasibility trials (and therefore the three feasibility studies included in this review), CONSORT acknowledges that these studies have many similarities to their randomised counterparts and therefore many of the principles still apply (Eldridge et al., 2016). Furthermore, the use of this extension provides consistency in terms of quality assessment across the studies used in the paper.

The CONSORT checklist is based on the CONSORT statement (Begg et al., 1996); a protocol for reporting RCTs in a clear and full manner. The checklist is made up of 25 items pertaining to standards of how a trial should be designed, analysed, and interpreted, thus making it a useful tool for both conducting and evaluating the quality of research. Whilst the CONSORT checklist enables the critical appraisal of the quality of evidence provided in research, it does not specifically assess the risk of bias which is acknowledged to be an important element of evaluating study validity. Although not explicitly appraising bias, many of the items on the checklist relate to elements of research commonly associated with potential bias – for example recruitment, allocation and blinding – and therefore provide some insight into the level of risk and initiate further consideration of these issues. As such, narrative commentary on the risk of bias for included studies has been included in this paper. As the main intention of this review is to comment on the nature of the work conducted in this field, the CONSORT and associated extensions were felt to be sufficient in aiding the critical appraisal and interpretation of included studies. A random sample of 25% of full text papers was shared with a peer to be appraised using the CONSORT checklists. Any differences were considered together, and consensus was reached through discussion.

Data Synthesis

A meta-analysis was not completed for this review, due to heterogeneity across studies. Results have been synthesised and data relating to study characteristics, and main findings have been tabulated. A narrative summary of the data is also provided.

Results

Overview of Included Studies

Table 2 reports on the characteristics of the eight included studies. Publication dates ranged from 2003 to 2021. Three studies were conducted in Australia (Beatty et al., 2010a; Beatty et al., 2010b; Perumbil Pathrose et al., 2021), three in the USA (Angell et al., 2003; Carpenter et al., 2012; Schulman-Green and Jeon, 2017) and two in Canada (Allison et al., 2004; Körner et al., 2019). An RCT design was followed for five studies (Angell et al., 2003; Beatty et al., 2010a, Beatty et al., 2010b; Carpenter et al., 2012; Körner et al., 2019), with the remaining three studies using either a one-group pre-post-test design or a prospective non-randomised design (Allison et al., 2004; Perumbil Pathrose et al., 2021; Schulman-Green and Jeon, 2017). The majority of studies focused on participants with breast cancer (Angell et al., 2003; Beatty et al., 2010a; Beatty et al., 2010b; Carpenter et al., 2012; Schulman-Green and Jeon, 2017). Two studies used a sample of participants with various types of cancer (Körner et al., 2019; Perumbil Pathrose et al., 2021), and one study included participants with head and neck cancer (Allison et al., 2004). For all studies bar one, the mean age of participants was over 50 years old. Perumbil Pathrose et al. (2021) explored the effects of a workbook for young adults with a mean age of 21.65 years. Due to over half of the studies including participants with breast cancer, the majority of participants across the studies in this review were female. For studies looking into heterogeneous cancer diagnoses, females still made up the majority of the sample. Data for mean age and gender proportions was missing from one study (Allison et al., 2004). Data relating to ethnicity was only provided for three out of the eight studies (Carpenter et al., 2012; Körner et al., 2019; Schulman-Green., 2017). For these studies, the majority of participants were white/Caucasian.

Table 2. Study Characteristics

First author, year, country	Study design	Sample	Intervention/control groups and treatment duration	Psychological distress outcome measures	Findings
Allison (2004) Canada	Prospective non-randomised design	N = 49 patients with head and neck cancer Mean age: not stated Gender: not stated* Ethnicity: not stated	I: A workbook based on the '*NuCare*' model including covering strengths, positive behaviour, learning experiences and good coping. C: No control Duration: 3 months	Depression and anxiety measured using the Hospital Anxiety and Depression Scale at baseline and 3 months	No significant change in depression and anxiety (p=.201)
Angell (2003) USA	RCT	N = 100 women with breast cancer Mean age: 58.6 (SD 11.6) Gender: 100% female Ethnicity not stated	T: '*One in Eight: Women Speaking to Women'* – a community-based, interactive workbook-journal including information, survivor experiences, and journal space C: Usual care Duration: 3 months	Post-traumatic stress measured using the Posttraumatic Stress Checklist-Specific Version and mood disturbance measured using the Profile of Mood States at baseline and 3 months	No overall main effect on PTSD symptoms, but significant benefits for some subgroups – women farther out from diagnosis experienced less PTSD symptoms compared to usual care (t=-2.16, p=0.3). No between-group differences in mood disturbance
Beatty (2010a) Australia	RCT	N = 40 women with breast cancer Mean age: 53.05 (SD 11.44) Gender: 100% female Ethnicity: not stated	T: '*Women Moving On: A workbook-journal for women moving forward after treatment for breast cancer'* – a workbook based on cognitive behavioural therapy including worksheets, survivor stories, and audio C: No workbook Duration: 3 months	Post-traumatic stress measured using Posttraumatic Stress Scale Self Report at baseline, 3 months and 6 months	No significant group x time interactions found, however significant main effect for time on PTSD symptoms (p=0.003, d=0.2)
Beatty (2010b) Australia	RCT	N = 49 women with breast cancer Mean age: 55.2 (SD 12.7) Gender: 100% female Ethnicity: not stated	T: *'Finding your way: a workbook to help you cope with your breast cancer diagnosis and treatment'* – a self-help workbook covering issues such as emotional adjustment and body image with worksheets and survivor quotes C: Booklet containing identical information to workbook but with no suggestions, worksheet, or audio Duration: 3 months	Depression and anxiety measured using Depression Anxiety Stress Scales at baseline, 3 months and 6 months	Interactions at 3 month follow up showed intervention group had significantly lower levels of post-traumatic stress than control group (F[1,89]=7.01; P = 0.03) with effect sizes of d=-0.59 and d=-0.16 respectively. No significant interaction from baseline to 6 months.

Carpenter (2012) USA	RCT	N = 132 women with breast cancer Mean age: 50.9 (SD 9.9) Gender: 100% female Ethnicity: 19% racial or ethnic minority status	T: ‘*Coping with Cancer Workbook’* – including cognitive and behavioural coping strategies, interactive exercises, relaxation training, and guided expressive writing C: Waitlisted participants receiving usual care Duration: 10 weeks	Cancer related post-traumatic stress measured using the Revised Impact of Event Scale at baseline, 10 weeks and 20 weeks	Significant group x time interaction for cancer related post-traumatic stress symptoms F(1,108)=9.66, p= .002, n_2 = .088). Post hoc pairwise comparisons indicated that the conditions differ significantly at week 10 (p<.05), but not at week 20.
Körner (2019) Canada	RCT	N = 89 patients with cancer Mean age: 54 (SD 12.21) Gender: 77.5% female, 22.5% male Ethnicity: 80.9% white, 10.1% Asian, 2% Hispanic, 2% Black, 5% Other	T: ‘*Mastering the art of coping in good times and* bad’ – a self-administered workbook that emphasises training in skills such as mindfulness, relaxation and cognitive coping C: Usual care Duration: 6 weeks	Distress measured using the Hospital Anxiety and Depression Scale at baseline, 6 weeks, and 10 weeks	Changes in distress from pre- to post-intervention/waiting did not differ significantly between intervention and control group (p=0.29, d=0.28). The decrease in distress in the intervention group from pre-intervention to follow up differed significantly from the retrospective difference scores of the control group (p=0.01, d=0.64).
Perumbil Pathrose (2021) Australia	One group pre-post-test	N = 31 young people with cancer Mean age: 21.65 (SD 2.85) Gender: 80% female, 20% male Ethnicity: not stated	T: ‘*Be Mindful and Stress Less: 50 Ways to Deal with Your (Crazy) Life’* – a mindfulness-based e-book with modules incorporating audio, reflection, and interactive quizzes C: No control Duration: 6 weeks	Distress measured using the Kessler 10 Psychological Distress Scale at baseline and 6 weeks	Significant decrease in depressive symptoms (p=0.027) and stress (p=0.028) with a moderate effect size (d=0.53 and d=.05 respectively) in both areas
Schulman-Green (2017) USA	One group pre-post-test	N = 105 women with breast cancer Mean age: 52.3 (SD 10.4) Gender: 100% female Ethnicity: 78.1% white, 9.5% black, 5.7% Hispanic, 6.7% other	T: ‘*Managing Cancer Care: A Personal Guide’* – a printed, self-guided intervention in magazine format comprised of 7 modules including information, skills, tasks, and links to additional resources C: No control Duration: 2 months	Depression and anxiety measured using the Hospital Anxiety and Depression Scale at baseline and 2 months	No significant changes in anxiety or depression.

**Author contacted for missing data, no response*

Table 3. CONSORT Critical Appraisal

	Abstract/ introduction		Methods										Results								Discussion			
	Title and abstract	Background	Design	Participants	Interventions	Outcomes	Sample size	Randomisation	Allocation	Implementation	Blinding	Statistical methods	Participant flow	Recruitment	Baseline data	Numbers analysed	Outcomes	Ancillary analyses	Harms	Limitations	Generalisability	Interpretation	Other information
Allison (2004)	●	●	●	◒	●	●	○	N/A	N/A	N/A	N/A	○	◒	◒	○	●	◒	N/A	N/A	●	●	●	◒
Angell (2003)	◒	●	○	●	●	●	○	○	○	◒	N/A	●	◒	●	◒	●	●	●	N/A	●	●	●	◒
Beatty (2010a)	●	●	○	●	●	●	●	●	●	◒	N/A	●	●	●	●	●	●	●	N/A	●	◒	●	●
Beatty (2010b)	●	●	○	●	●	●	●	●	●	◒	N/A	●	●	●	●	●	●	●	N/A	◒	●	●	●
Carpenter (2012)	◒	●	○	●	●	●	●	◒	●	○	N/A	●	●	●	○	○	●	●	N/A	●	●	●	◒
Korner (2019)	●	●	●	●	●	●	●	●	●	●	N/A	●	●	●	●	●	●	●	N/A	●	●	●	●
Pathrose (2021)	●	●	●	●	●	●	●	N/A	N/A	N/A	N/A	●	◒	●	●	●	◒	●	N/A	●	●	●	●
Schulman-Green (2017)	◒	●	●	●	●	●	○	N/A	N/A	N/A	N/A	●	●	●	●	●	●	●	N/A	●	●	●	◒

● = *criteria met* ◒ = *criteria partially met* ○ = *criteria not met* N/A= *not applicable*

Quality Assessment

An overview of the quality assessment of included studies is presented in Table 3. Overall, the quality of studies as appraised by the CONSORT checklists was varied. One of the eight studies met all of the criteria set out by the checklist (Körner et al, 2019), and another met or partially met all of the criteria (Perumbil Pathrose et al., 2021). Elements of research that all studies were deemed to have completed and reported upon to a high standard included providing a scientific rationale for research and specifying aims, reporting interventions in sufficient detail for replication, defining pre-specified outcomes including how and when assessed, and providing an interpretation consistent with results with consideration of other relevant evidence. Areas that scored less highly included outlining trial design and describing how sample size was determined. The quality of randomisation was mixed for the RCTs; only three papers reported enough information for them to be assessed as sufficiently generating a random allocation sequence (Beatty et al., 2010a; Beatty et al., 2010b; Carpenter et al., 2012; Körner et al., 2019) and four as adequately implementing the sequence (Angell et al., 2003; Beatty et al., 2010a; Beatty et al., 2010b; Körner et al., 2019), which raises issues in terms of allocation bias. Only one RCT provided adequate detail about who generated the sequence, enrolled participants and assigned participants to interventions in the study (Körner et al., 2019).

Sample Sizes and Power

Sample size across the eight studies ranged from 31 to 132. Five studies reported carrying out power analysis to guide sample size (Beatty et al., 2010a; Beatty et al., 2010b; Carpenter et al., 2012, Körner et al., 2019; Perumbil Pathrose et al., 2021). Only two of these studies recruited enough participants for their research to be sufficiently powered (Carpenter et al., 2012; Perumbil Pathrose et al., 2021). The remaining three studies were underpowered, listing time constraints as a result of completing PhD or doctoral research projects and the implementation of a stopping rule due to slow recruitment as preventing them from reaching aspired sample size (Beatty et al., 2010a; Beatty et al., 2010b; Körner et al., 2019).

Recruitment

Five out of the eight included studies provided detail regarding their recruitment process (Angell et al., 2003; Carpenter et al., 2012; Körner et al., 2019; Perumbil Pathrose et al., 2021; Schulman-Green and Jeon; 2017). Three of these reported recruiting participants via means such as flyers, emails, word of mouth, and discussion boards (Carpenter et al., 2012; Körner et al., 2019; Perumbil Pathrose et al., 2021). All three of these papers acknowledged that their method of recruitment increased the risk of selection bias in their research due to participants self-selecting to take part, which limits the generalisability of their findings. Angell et al. (2003) described their recruitment process as a combination of approaching potential participants with an invitation to join the study and providing presentations to professionals in relevant settings with a request for referrals. Shulman-Green and Jeon (2017) reported that nurses approached potential participants to determine their interest in taking part in the study.

Outcomes

Three studies explored the effect of a bibliotherapy intervention on post-traumatic stress (Angell et al., 2003; Beatty 2010a; Carpenter et al., 2012). One of these three studies additionally measured mood disturbance (Angell et al., 2003). The remaining five studies focused on depression and anxiety (Allison et al., 2004; Beatty et al., 2010b; Schulman-Green and Jeon; 2017), and distress (Körner et al., 2019; Perumbil Pathrose et al., 2021). A range of tools were used to measure these outcomes. The Hospital Anxiety and Depression Scale was used within three studies (Allison et al., 2004; Körner et al., 2019; Schulman-Green and Jeon; 2017). Each of the remaining publications used a different outcome measure, including the Post-traumatic Stress Checklist and the Profile of Mood States (Angell et al., 2003), the Post Traumatic Stress Scale (Beatty et al., 2010a), the Depression Anxiety Stress Scales (Beatty et al., 2010b), the Revised Impact of Events Scale (Carpenter et al., 2012), and the Kessler 10 Psychological Distress Scale (Perumbil Pathrose et al., 2021). Only three studies commented on the internal consistency of the measures used: Körner et al. (2019) reported a Cronbach's alpha coefficient of 0.83 in their sample, Carpenter et al. (2012) reported 0.92, and Perumbil Pathrose et al. (2021) reported 0.93. Four studies measured outcomes at baseline and three months (Allison et al., 2004; Angell et al., 2003; Beatty et al., 2010a; Beatty et al., 2010b). Two measured outcomes at baseline and 6 weeks (Körner et al., 2019; Perumbil Pathrose et al., 2021), one measured outcomes at baseline and 10 weeks (Carpenter et al., 2012), and one measured outcomes at baseline and two months (Schulman-Green and Jeon, 2017). Four studies also included a second follow up time point (Beatty et al., 2010a; Beatty et al., 2010b; Carpenter et al., 2012; Körner et al., 2019) – two of these measured outcomes at six months after three months (Beatty et al., 2010a; Beatty et al., 2010b), one measured at 20 weeks after 10 weeks (Carpenter et al., 2012), and one measured at 10 weeks after six weeks (Körner et al., 2019).

Interventions

Six of the eight interventions were described as being in a workbook format (Allison et al., 2004; Angell et al., 2003; Beatty et al., 2010a; Beatty et al, 2010b; Carpenter et al., 2012; Körner et al., 2019). One intervention was in the form of a magazine (Schulman-Green and Jeon, 2017) and one was in the form of an e-book (Perumbil Pathrose et al., 2021). Six of the interventions were provided in a hard copy (Allison et al., 2004; Angell et al., 2003; Beatty et al., 2010a; Beatty et al., 2010b; Körner et al., 2019; Schulman-Green and Jeon; 2017) and two were electronic versions (Carpenter et al., 2012; Perumbil Pathrose et al., 2021). Three studies detailed that the intervention had been developed collaboratively with service users, using methods such as focus groups and usability testing (Beatty et al., 2010a; Beatty et al, 2010b; Carpenter et al., 2012). Angell and colleagues (2003) documented that information from interviews with women with breast cancer had been used in their workbook. Bibliotherapy interventions included in this review were based on a range of models and approaches, including the Nursing Care (NuCare) psychoeducation intervention (Allison et al., 2004; Körner et al., 2019), mindfulness (Perumbil Pathrose et al., 2021), cognitive behavioural therapy (Beatty et al., 2010a; Carpenter et al., 2012), written emotional expression (Beatty et al., 2010a), Antoni’s (2003) cognitive behavioural stress management programme (Carpenter et al., 2017), supportive-expressive group therapy (Angell et al., 2003), and the self and management family framework (Schulman-Green and Jeon, 2017). Interventions included a range of components including expressive writing or journal space (Angell et al., 2003; Beatty et al., 2010a; Beatty et al, 2010b; Carpenter et al., 2012; Perumbil Pathrose et al., 2021; Schulman-Green and Jeon, 2017), worksheets (Beatty et al., 2010a; Beatty et al, 2010b; Schulman-Green and Jeon, 2017) and quotes or personal stories from cancer survivors (Angell et al., 2003; Beatty et al., 2010a; Beatty et al, 2010b; Carpenter et al., 2012). Four of the interventions were reported to be accompanied by audio or visual materials (Beatty et al., 2010a; Beatty et al, 2010b; Carpenter et al., 2012; Perumbil Pathrose et al., 2021). Half of the studies reported an intervention duration of three months (Allison et al., 2004; Angell et al., 2003; Beatty et al., 2010a; Beatty et al., 2010b). The remaining studies reported intervention times ranging from two months to six weeks.

Comparisons

Four of the five RCT studies involved a control group receiving usual care or no workbook (Angell et al., 2003; Beatty 2010a; Körner et al., 2019; Perumbil Pathrose et al., 2021). Only one RCT used an active control, in the form of a booklet containing identical information to the intervention but without any of the additional materials including worksheets or audio files (Beatty 2010b).

Feasibility and Acceptability of Interventions

The feasibility and acceptability of interventions can be considered in terms of participant retention and engagement. Attrition was generally low across studies, with retention ranging from 64.5% to 98%. Six studies reported a retention rate of 80% or higher, indicating a low risk of attrition bias and strengthening the generalisability of findings. Whilst one study investigated differences between participants who remained in the study and dropped out of the study and found no significant risk factors for attrition (Perumbil Pathrose et al., 2021), another found that participants with lower levels of education were more likely to leave the study (Körner et al., 2019). It is of note that the study reporting the lowest attrition rate, had the youngest sample

(Perumbil Pathrose et al., 2021). Six studies reported on intervention engagement, including overall completion of the intervention and time spent using the intervention, assessed through a range of means including compliance measures and data from electronic logs. Three studies reported that participants used between 80-100% of the intervention. Reported time spent on average using the intervention ranged from between 1-15 minutes to one hour a week. One study (Perumbil Pathrose et al., 2021) collected qualitative data regarding the acceptability of their electronic e-book intervention, with all participants agreeing or partially agreeing that the book was easy to use and meaningful.

Effictiveness of Interventions

Three of the eight studies did not find significant outcomes in terms of the effects of a bibliotherapy intervention on psychological distress (Allison et al., 2004; Angell et al., 2003; Schulman-Green and Jeon; 2017). Two of these studies were feasibility trials of varying quality (Allison et al., 2004; Schulman-Green and Jeon; 2017) and one was an RCT of low quality in comparison to other studies of the same design (Angell et al., 2003). Although Angell et al. (2003) found no significant main effect of the intervention on PTSD symptoms, a significant interaction was found that indicated women experienced greater benefits from the intervention if they were further out from diagnosis, rather than newly diagnosed.

One feasibility trial did find significant results. Perumbil Pathrose et al. (2021) reported a significant decrease in depressive symptoms (p=.027) and stress (p=.028) after participants engaged with a mindfulness-based e-book for six weeks. Although appraised as being high in quality, this study was under powered and some risk of bias was detected; for example, in terms of selection bias as participants were self-selected.

Four RCTs found significant results (Beatty et al., 2010a; Beatty et al., 2010b; Carpenter et al., 2012; Körner et al., 20190). Körner et al. (2019) found that changes in distress from pre-intervention to six-week post-intervention/waiting did not differ significantly between the intervention group receiving the self-directed workbook and the control group receiving usual care. However, the decrease in distress from the intervention group from pre-intervention to 10 week follow up differed significantly from the respective difference scores of the control group. Distress improved in the intervention group, but not the control group. This study was assessed as having the highest quality of all of the studies included in the review. The level of reporting for certain sections of the paper also suggested a low risk of bias; for example, low risk of allocation bias due to the detail provided in terms randomisation indicating this process was carried out to a high quality. However, selection bias was highlighted for this study and the research was also underpowered to detect smaller effects.

Carpenter et al. (2012) found a significant group by time interaction for cancer related post-traumatic stress symptoms (p=.002). Analysis indicated that the groups differed significantly at week 10 (p=.05), but not at week 20. This study was of lower quality compared to other RCTs in the review, and the paper omitted important information such as a full overview of baseline characteristics and numbers analysed which caused some barriers to interpretation.

Both Beatty et al. (2010a) and Beatty et al. (2010b) explored the effectiveness of a bibliotherapy intervention for reducing psychological distress, measuring outcomes at three months and six months. Beatty et al. (2010a) found a significant main effect for time from baseline to three months for intervention participants (p=.003). Although psychological distress improved again slightly from three months to six months, this change was not significant. Beatty et al. (2010b) found that participants experienced a significantly greater decrease in post-traumatic stress if they received the workbook compared with control informational booklet after three months (p=.01). No significant interaction was found from baseline to six months, however benefits obtained by intervention participants were maintained and the loss of significance was the result of control group participants making later improvements.

Discussion

This review aimed to identify what is currently known about the use of bibliotherapy for alleviating distress among the cancer population**.** Studies that focused on the use of self-administered bibliotherapy for psychological distress among adults with cancer were included in the review. The bibliotherapy intervention needed to be in the form of a physical or electronic book, workbook, or booklet and based upon a psychological model. A systematic search of relevant literature identified eight papers that met the eligibility criteria, consisting of five RCTs and three feasibility studies. Critical appraisal using CONSORT checklists and consideration of bias highlighted that these studies were of mixed quality, with some strengths (e.g. replicability of interventions) and limitations (e.g. selection bias) seen consistently across the sample. The sample size of studies was generally quite low, and the majority of studies were either underpowered or did not report on power, suggesting their results should be interpreted with caution.

Over half of the studies included in this review reported a significant finding in terms of the intervention having a positive impact on psychological distress. One study found that, although the differences in distress between the intervention group and control group did not differ significantly at six weeks post intervention, changes were significant at 10 weeks follow up (Körner et al., 2019). This may indicate that longer exposure to the intervention results in better outcomes or that the benefits of the intervention were consolidated over time, with the authors hypothesising that additional time allows for opportunities to practice and implement learned coping skills.

In line with this idea, two studies exploring the effects of bibliotherapy on psychological distress over a longer period of time also found significant effects (Beatty et al., 2010a; Beatty et al., 2010b). Beatty et al. (2010a) found a significant main effect for time from baseline to three months for intervention participants and Beatty et al. (2010b) found that intervention participants experienced a significantly greater decrease in post-traumatic stress compared to control participants at baseline to three months. Neither found any significant changes when measuring outcomes again at six months, however Beatty et al. (2010b) acknowledged that in the case of their research, this was due to improvements in the control group rather than a deterioration of the intervention group. A third and fourth study assessing the impact of their interventions after a three-month period did not find significant results. It is worth noting that these were deemed to be the two studies of the lowest quality in the review (Angell et al., 2003; Allison et al., 2004). Overall, these findings suggest that further research is needed into the effects of bibliotherapy on psychological distress over time and that further exploration into the mechanisms that may facilitate this change (e.g. time spent practicing skills or reflecting on information) would be beneficial. It may also be advantageous for future research to explore the interaction between bibliotherapy interventions and time from diagnosis, given Angell et al.'s (2003) finding that women who had been diagnosed with cancer for longer appeared to experience greater benefits from the workbook than women who were newly diagnosed, to ascertain whether there is an optimum time for a person to receive this form of intervention in terms of acceptability and effectiveness.

Across the studies included in this review, many domains of cancer-related psychological distress were explored including anxiety, depression, and post-traumatic stress. As such, a range of outcome measures were used, causing inconsistency in terms of overall interpretation and comparison of results. Future research in the field using more consistent outcome measures will enhance our understanding of the effects of bibliotherapy on the different components of psychological distress in cancer and enhance the generalisability of findings.

An important finding of this review is that the majority of participants taking part in the studies were female. Although this is not unsurprising in the case of the five studies that were focused on breast cancer, the proportion of female participants in non-breast cancer studies was also significantly higher. Whilst this may be representative of the sample invited to take part, an alternative hypothesis, given self-selection was the most common form of recruitment across the studies, is that women may be more interested in taking part in research or may be more likely to seek sources of support in terms of their mental health (Gonzalez et al.,2011). Women may also have been more interested in bibliotherapy as the format of the intervention, given that statistics indicate that women are more likely purchase, borrow, and share books than men (Taylor, 2019). Although studying a population that is interested in engaging with this form of psychosocial support is valuable as patients with this preference will likely make up a significant proportion of the intervention's target audience, it is important to note that a group of people who may engage well with and benefit from bibliotherapy may be missing from the literature. As such, it may be of interest for future research to explore the use of bibliotherapy with a wider audience such as increased rates of males. Samples with a more diverse age range and comprising of more minority ethnic and racial groups would also be of interest given that the majority of studies included in this review had a mean age of around 50, and those that noted ethnicity reported a majority of white participants.

Another important finding of this review was that only three of the included studies detailed collaboration with service users in terms of the development of the intervention used. Service user involvement in the development and evaluation of behavioural and health interventions is increasingly being considered essential, with approaches such as Yardley and colleagues' (2015) Person-Based Approach offering methods to facilitate this way of working in order to obtain in-depth understanding of the views of service users and the contexts in which they engage with interventions. As such, it feels important to highlight the current lack of service user influence in the present interventions and for future work into the development and evaluation of cancer-related bibliotherapy to include service user involvement from this population.

Limitations

The current review has a number of limitations. First, only a small number of papers were included after study selection and among these there was significant variation in terms of study design, study quality, sample size, cancer type, intervention, and the measurement of outcomes. As such, a meta-analysis could not be completed, and it is difficult to draw any firm conclusions about the effectiveness of bibliotherapy for cancer-related psychological distress. A second limitation, as previously noted, is that the critical appraisal tool chosen for this review did not explicitly evaluate risk of bias. However, it was felt that this tool was sufficient for the aims of the review and additional consideration of bias was carried out in order to overcome this limitation. A final limitation relates to study selection. Although clear eligibility criteria were set, the process of identifying papers to include and exclude was at times challenging due to variations in the labelling and descriptions of bibliotherapy interventions - for example differentiating between online bibliotherapy and more broad psychosocial online interventions. As such, despite extensive efforts being made to comprehensively search the literature, it is possible that studies involving bibliotherapy interventions but described in a different manner may be missing from this review.

Conclusions

Bibliotherapy is an easy, accessible and cost-effective method of delivering psychological support (Yuan et al., 2018). Although the evidence base into the use of bibliotherapy for cancer-related psychological distress is growing, this systematic review has indicated that firm conclusions in relation to its effectiveness are still unable to be drawn. There is some evidence to suggest that bibliotherapy is an acceptable and efficacious intervention for people with a diagnosis of cancer, however further investigation is required to enhance our understanding of its impact and the ways in which it can facilitate change in terms of psychological distress.

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Paper Two: Empirical Paper

A Qualitative Exploration of the Experience of Using a Bibliotherapy Intervention based on Acceptance and Commitment Therapy for People with Cancer

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(8507 with corrections)

Abstract: 100

Paper one has been prepared in accordance with the submission guidelines for the *Journal of Health Psychology* (see Appendix 1). The DClinPsy 8000 wordcount limit has been used to ensure all relevant information has been included for the examiner. For ease of reading, tables and figures have been embedded in the main body of the paper, however these will be included within supplementary information for journal submission.

Abstract

Objective: This study aims to qualitatively explore the experience of people with cancer using a self-help book based on Acceptance and Commitment Therapy

Method: Ten participants with cancer took part in semi-structured interviews. Reflexive thematic analysis was used to analyse the data.

Results: Five themes were generated (1) The value of bibliotherapy (2) Timing is important (3) Resonating with cancer experiences (4) Tools of the book (5) ACT in action.

Conclusions: Bibliotherapy was experienced to be an acceptable and helpful format of delivering Acceptance and Commitment Therapy. Further investigation into the effectiveness of this intervention would be useful.

Introduction

Receiving a diagnosis of cancer is a life-changing event that can have a momentous impact on quality of life (Burdon-Jones and Baker, 2009; Fallowfield, 2002; Fitzpatrick, 2018). The physical symptoms associated with a cancer diagnosis and subsequent treatments can be wide-ranging, with fatigue, pain, sleep difficulties, cognitive limitations, and sexual dysfunction being reported consistently among heterogeneous cancer survivors (Harrington et al., 2010). Psychological difficulties such as dealing with uncertainty and fears about the future are also commonly reported among people with cancer (Grassi et al., 2017). With these issues in mind, it is unsurprising that a significant proportion of cancer patients experience mental health difficulties relating to their illness (Nakash et al., 2014). The presence of comorbid mental health difficulties in cancer patients has serious implications and has been associated with reduced compliance with treatment (Colleoni, 2000), reduced response to treatment (Giese-Davis et al., 2011), prolonged hospitalisation and rehabilitation (Corodova et al., 2017; Prieto, 2002), increased risk of suicide (Anguiano et al., 2012), and poorer survival (Pinquart and Duberstein, 2010).

In order to address cancer-related mental health difficulties, a range a of psychological interventions have been developed, including psychoeducation, counselling, group therapy, and individual psychotherapy (Grassi et al., 2017). Although many of these interventions have been demonstrated to be effective in improving the psychological wellbeing of people with cancer (Akechi et al., 2008; Chong Guan et al., 2016; Dimitrov et al., 2018), a large proportion of people who may benefit from psychological intervention do not access these forms of support (Jacobsen and Jim, 2008).

Research indicates that some of the barriers to accessing cancer-related psychological support include cost (Greenberg, 2004), stigma (Kissane, 2014), and a desire to manage emotional concerns independently (Christy et al., 2014).

In light of these barriers, self-directed interventions requiring little to no therapist input are receiving increasing attention (Roberts et al., 2016). One such intervention is bibliotherapy, which can be defined as the therapeutic use of books and other reading materials (Howie, 1988). Bibliotherapy has been used to address a wide range of psychological and physical health concerns (Hedman et al., 2016; Rodriguez-Martin, 2013; Tavallei, 2018) and bibliotherapy programmes seeking to enhance psychological and physical wellbeing can now be found globally (Brewster and McNichol, 2018). In the UK, programmes such as the ‘Reading Well – Books on Prescription scheme’ are available (The Reading Agency, 2021), which provide recommended reading lists for a wide range of mental and physical health conditions.

Although numerous studies have explored the acceptability and efficacy of bibliotherapy for mental health difficulties such as depression and anxiety (Gregory et al., 2004; Lewis et al., 2012), research into the use of bibliotherapy within the oncology domain is less extensive (Keenan et al., 2021). A small number of randomised controlled trials have been carried out with the aim of evaluating this form of intervention for cancer patients, however these yielded mixed results preventing any firm conclusions being drawn about the effectiveness of bibliotherapy for this population (Angell et al., 2003; Beatty et al., 2010a; Beatty et al., 2010b; Carpenter et al., 2012; Körner et al., 2012). There is also variation in the psychological basis of the cancer-related bibliotherapy interventions evaluated to date, which has included cognitive behavioural therapy, written emotional expression, and supportive-expressive group therapy. One psychological model that is yet to be explored in this format for people with cancer is Acceptance and Commitment Therapy (ACT).

ACT is a health-related therapy that combines metaphors, mindfulness, experiential exercises, and values-guided behavioural interventions to improve psychological flexibility and coping responses to adverse events (Hayes and Wilson, 1994; Hayes, 2004). In order to improve psychological flexibility, ACT is focused on six core processes. These processes and the interactions between them can be depicted using the ACT 'hexaflex' (Harris, 2009) which is presented in Figure 1.

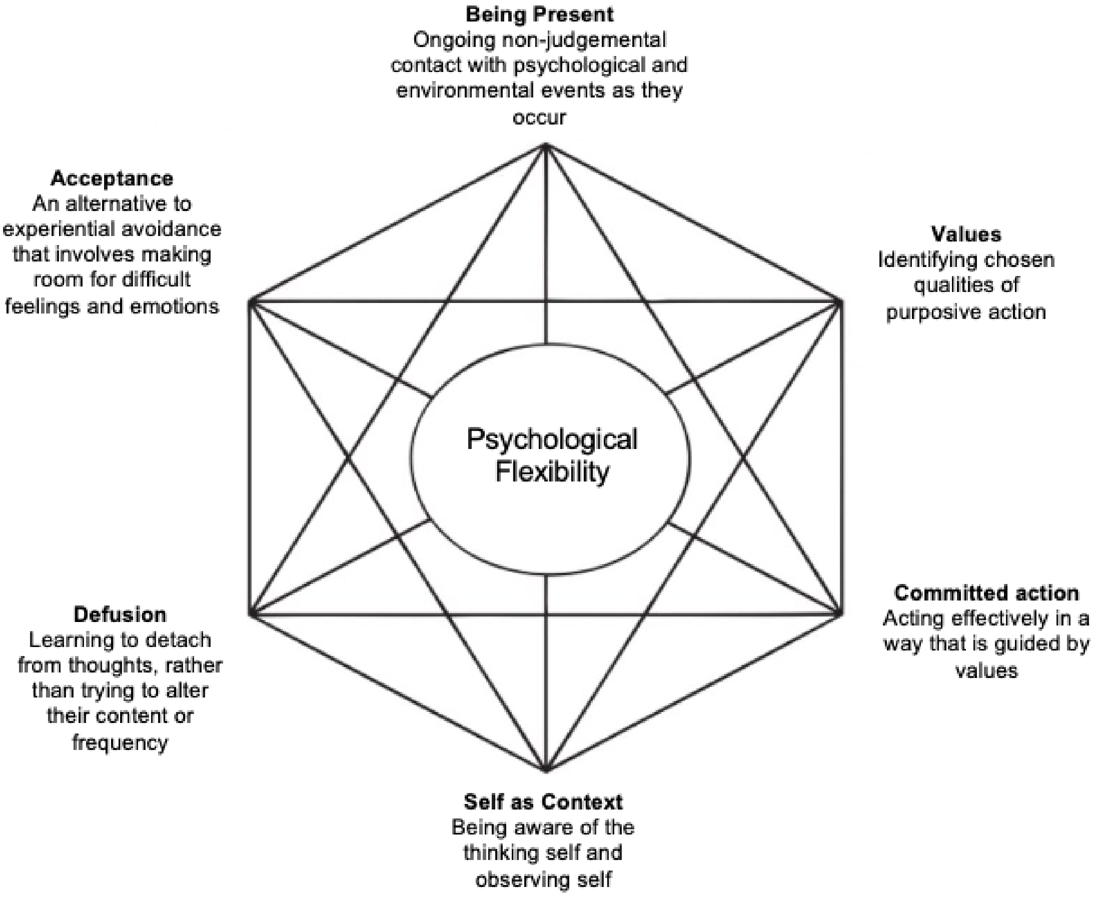

Figure 1. The Acceptance and Commitment Therapy ‘Hexaflex’

There is a growing body of evidence in relation the use of ACT in the context of physical health, including research into its effect upon health behaviour change such as levels of physical activity (Butryn et al., 2011), smoking cessation (Bricker et al., 2014), and eating behaviours (Manlick et al., 2013). The use of ACT for specific physical health conditions has also been investigated. Research has produced promising results regarding the use of ACT for a range of conditions including the management of chronic pain (Veehof et al., 2011), the reduction of seizure frequency for epilepsy populations (Barrett-Naylor, 2018), better self-care and stability of glucose levels for people with diabetes (Gregg et al., 2007) and increased self-related health status for stroke survivors (Majumdar & Morris, 2019).

The evidence base for the use of ACT in oncology settings has also increased over the past decade (González-Fernández and Fernández-Rodríguez, 2019; Li et al., 2021a; Li et al., 2021b). Research indicates that ACT may be a good fit for people with cancer, as psychological inflexibility has been shown to be related to psychological symptoms and quality of life for this population (Brown et al., 2020; Gonzalez-Fernandez et al., 2017). ACT may also provide patients with opportunities to non-judgmentally accept whatever experiences arise from their illness and engage in behaviours in line with their values, thereby leading to great improvements in cancer-related health outcomes and better quality of life (Gentili et al., 2019). Systematic reviews have documented that ACT has had significant positive effect on depression, anxiety, distress and quality of life for people with cancer (González-Fernández and Fernández-Rodríguez, 2019; Mathew et al 2020; Li et al., 2021a).

Whilst previous research has focused on the acceptability and effectiveness of ACT in individual (e.g. Low et al., 2016) and group (e.g Arch and Mitchell, 2016) therapy formats, to the best of the author's knowledge, there is yet to have been any exploration into the facilitation of ACT for people with cancer through the use bibliotherapy. Recently, Johnson et al. (2021) published a self-help book for people affected by cancer based on the ACT approach. The present study aims to investigate how people with cancer experience this book, along with the ACT ideas and techniques within it.

Method

Approach

In order to address the current gap in the literature regarding how ACT-informed bibliotherapy is received by people with cancer, the aim of this study is to carry out a qualitative exploration into service user experience of using an ACT based self-help book. In line with Yardley and colleagues' (2015) 'person-based approach', this study seeks to understand the perspectives of the population who will use this intervention. Thematic methods of analysis are extremely useful in investigating service user experience of novel interventions (Joffe, 2011), and there is now a growing body of evidence that has used thematic analysis to explore service users' experiences of therapeutic and health-based interventions (Allen et al., 2009; Arden-Close, 2017). Thematic analysis and its ability to identify nuanced patterns across meaning-rich data can also be useful in facilitating closer exploration of processes of change that may be occurring for service users a result of engagement with interventions (Elliott, 2011). With these benefits in mind, Braun and Clarke's (2006; 2019a) reflexive approach to thematic analysis was utilised for the present study.

Participants

Eligibility criteria for this study is presented in Table 1. Participants were recruited to the study via information sent to cancer charity organisations such as Tenovus and Maggie's (see Appendix 6). These materials were subsequently shared in a number of formats including social media posts, research bulletins, and physical displays in support centres (see Appendix 7). Thirteen potential participants responded to the advertisement. Two of these were unable to proceed with the study due to changes in circumstance, and one did not respond to further communication following their initial expression of interest. This resulted in a total of 10 participants taking part in the study. This sample size is commensurate with other qualitative explorations of bibliotherapy using thematic analysis (e.g. Gerlach and Subramanian, 2016; Malyn et al., 2020), and is likely to be of sufficient size to enable capture of theoretically and practically useful information.

Table 1. Eligibility Criteria

Inclusion Criteria	Exclusion Criteria
• Aged 18 or over • Current diagnosis of cancer (any type) • Able to read English	• Significant cognitive impairment or communication difficulty that would impact ability to provide consent or engage in study • Any direct experience of contributing to the development of the intervention • Receiving palliative care

The Intervention

The intervention was the book ‘Living Your Life with Cancer through Acceptance and Commitment Therapy: Flying over Thunderstorms’ (Johnson et al., 2021). This is a psychoeducational self-help book written by psychologists with experience of supporting people with cancer and other long term health conditions. The intervention was developed independently from the study team and with input from people with a diagnosis of cancer, their families and friends, and other professionals. This involved asking experts by experience to share their thoughts on early drafts of the book and again on later drafts of the resource. Quotes from people living with cancer were also collected for inclusion in the book.

The book uses ACT as a framework to cover four key areas: (1) Understanding the impact of cancer (2) Living a meaningful life after a diagnosis of cancer (3) Looking after yourself (4) Moving forwards. Colour illustrations are featured throughout the book to depict key ideas. A number of ‘tools’ are also featured throughout the book to enhance its contents, including quotes and stories from people affected by cancer, key messages summarising important information, written exercises, and audio exercises (accompanied by audio recordings accessible via a web link). A proofed, pre-published version of the book was used for the study (see Appendix 8).

Procedure

After expressing interest to take part in the study, all participants were provided with an information sheet outlining additional details about the research (see Appendix 9). Participants were then asked to provide their written consent to continue with the study (see Appendix 10). Once consent was received, participants were asked to complete a demographic questionnaire which was used to gain contextual information about the respondents in order to situate the sample (see Appendix 11). Participants were then provided with either a hard copy of the book or an electronic version, depending on their preference, and asked to use this over a period of one month. Experts by experience identified this time frame as being appropriate in terms of being able to read the contents and practice the strategies of the book for the purpose of the study. Telephone contact was made with participants at the beginning of the one-month intervention period. During this call participants were orientated to the general content and overall layout of the book, and it was explained that participants should aim to have read all of the book and have practiced as many strategies as possible by the end of the intervention period. Arrangements were then made to contact participants again halfway through the intervention period to review progress and answer any questions. A final telephone contact was made with participants at the end of the intervention period to arrange data collection.

Data collection

Interviews took place once the intervention period had ended. Interviews lasted between 18 and 67 minutes, with a mean length of 42 minutes. All interviews were semi-structured in nature and an interview schedule (presented in Figure 2) was used to provide a loose structure to explore the central question. The interview schedule was designed through discussion with the research team and a review of relevant literature, for example other qualitative explorations of bibliotherapy interventions and ACT interventions (Large et al., 2019; Roberts et al., 2016). Interviews were conducted via telephone and recorded on an encrypted Dictaphone. Following completion, interviews were transcribed in an intelligent verbatim style, omitting filler words and phrases. Interview scripts were then stored securely in order to be analysed.

Interview Schedule

1. Could you briefly tell me about your experience of living with cancer before using the book?
2. What interested you about the book?
3. Before using the book, did you have any expectations of it? If so, could you tell me about these?
4. How did you use the book? (Prompts: Did you read the book from beginning to end or read different sections at a time? Did you leave any sections out? Did you try the written and audio exercises?)
5. Could you tell me about your experience of using the book? (Prompts: How did using the book make you feel? Did any parts of the book stand out for you? Did any parts feel more of less relevant? What was your experience of the written exercises? What was your experience of the audio exercises?
6. How did your experience of the book compare to your expectations of it?
7. How would you describe the book to someone?
8. Could you tell me about any changes that you have noticed or made since using the book (if any)? (Prompts: thoughts, feelings, behaviours, ways of coping, lifestyle changes)
9. How do you feel about using the book again in the future?
10. Are there any other comments you would like to make about the book?

Figure 2. Interview Schedule

Data Analysis

Braun and Clarke’s (2006) six-phase process for carrying out reflexive thematic analysis was used in this study. Analysis was inductive in nature and carried out a semantic level to reflect the explicit content of participants accounts. A critical realist perspective was taken to report on an assumed reality of the data. In order to familiarise with the data, the author listened to all of the audio recordings and read through all of the transcribed interviews, making notes regarding any initial thoughts, ideas, or personal assumptions arising from each data item. Once the author felt confident in their familiarity with the data, the qualitive data analysis software 'NVivo' was used to begin generating codes for the dataset. Each data item was read again, and codes were systematically assigned to participant responses. A number of coding sweeps were then carried out, during which many codes were changes, merged, or removed (see Appendix 12 for an example of some of the analytic stages). Following completion of the coding process, initial themes were actively generated by seeking patterns across the dataset. This involved reading through coded transcripts on a number of occasions and clustering codes relating to similar ideas or meanings. Potential themes were then reviewed by considering them against the coded data to ensure patterns mapped well onto both sources of data. During this stage of the process, themes changed and evolved significantly (see Appendix 13). Once the author felt suitably confident with the generation of themes, they were defined and named. Finally, the data analysis was written up to be included in this paper. Consistent with the iterative nature of thematic analysis, some themes were redefined even during this final step.

Quality Assessment

Diverse positions are held on how achievable, or even desirable, it is to critically evaluate the quality of qualitative research. As a result of this debate, numerous methods of critical appraisal are available, however these have varying levels of applicability and appropriateness depending on the particular method of data analysis used (Spencer and Ritchie, 2011). For example, the concept of inter-rater reliability is not advocated for within the reflexive style of thematic analysis used within this study, due to the flexible and evolving nature of the coding process (Braun and Clarke, 2019b). As such, multiple coders were not utilised. However, in order to demonstrate credibility and rigour, the first author did discuss all steps of the analysis with supervisors to explore potential codes and themes, reflect on the process of data analysis, and explore any possible biases that may impact analysis. Evidence of each stage of data collection and analysis was shared with supervisors and the overall process of qualitative research was considered against the '15-point checklist of criteria for good thematic analysis' (reproduced from Braun and Clarke 2006; see Appendix 14). Participants were also contacted via email and provided with a summary of themes with an invitation to reply with comments. This process of 'returning research' (Taylor, 2001) aimed to gain feedback about whether participants felt there was a good fit between the representation of participants' experiences and the participants' own understanding of their experiences.

Reflexivity

Reflexive thematic analysis recognises that the active role of the researcher, along with their values and interests, will inevitably influence the analysis of data and generation of themes. As such, reflexivity is considered essential as it allows the researcher to acknowledge and reflect upon their own influence throughout the research process (Braun and Clarke, 2013).

The lead researcher of this study is a 29-year-old white Welsh woman undertaking doctoral training in clinical psychology. As part of this training, in addition to pretraining clinical experience, the researcher has had some experience of using both bibliotherapy as a mode of intervention and ACT as a therapy model. It is therefore possible that the researcher may have had preconceived ideas about the ways in which bibliotherapy and ACT may have been experienced by service users, which in turn may have influenced the generation of themes from the data. The researcher also has personal experience of the impact of cancer as a result of close relations living with the disease. This too may have influenced the researcher's beliefs about the use and experience of psychological support for people with cancer. Whilst it is inescapable that professional and personal factors will have shaped the findings in some way, steps were taken to prevent these from resulting in potential bias. For example, the researcher kept a reflective log and engaged in frequent discussions with their supervisor about the possible assumptions they may be bringing to the research. A transparent record of each stage of the analytic process was also kept so that supervisors could audit and critique the research process.

Results

Participants

The demographic characteristics of the participants can be found in Table 2.

Table 2. Demographic Characteristics of Participants

Demographic Characteristics	n
Age	
40 - 49	3
50 – 59	4
60 – 69	2
70 – 79	0
80 – 89	1
Gender	
Female	9
Male	1

Employment	
Employed	5
Retired	5
Highest education level	
GCSE	2
A Level	1
Diploma	3
Degree	3
Postgraduate qualification	1
Cohabiting	
Y	8
N	2
Dependents	
Y	4
N	6
Physical disabilities	
Y	4
N	6
Primary cancer	
Breast	3
Kidney	1
Lung	2
Non-Hodgkin’s Lymphoma	3
Skin	1
Secondary cancer present	
Y	4
N	6
Time since diagnosis	
0 – 1 year	2
1 – 2 years	0
2 – 3 years	5
3+ years	3
Received treatment	
Y	10
N	0
Type of treatment	
Chemotherapy	
Hormone therapy	2
Immunotherapy	4
Medication	1
Unstated	7
Radiotherapy	3
Surgery	
Stem cell therapy	1
Ablation	1
Mastectomy	2
Cancer excision	1
Currently in treatment	
Y	6
N	4

Finished treatment	
Y	2
N	8
Experienced psychological difficulties related to cancer diagnosis	10
Y	0
N	
Received support for psychological difficulties related to cancer diagnosis	6
Y	4
N	

Findings

Five themes were generated from the data. Themes, subthemes, and the number of participants who contributed towards these are displayed in Table 3.

Table 3. Themes, subthemes, and contributors

Themes	Subthemes	Contributors
The value of bibliotherapy	• Accessibility • Usability	9
Timing is important		9
Resonating with cancer experiences	• Recognising elements of own cancer journey • Normalising experiences • Validating experiences	10
Tools of the book	• Interactivity • Audio exercises • Written exercises	10
ACT in action	• Regaining control • Being present	9

Theme 1: The value of bibliotherapy

Accessibility

The majority of participants in this study indicated that they found bibliotherapy to be an accessible mode of intervention. Accessibility was discussed in a number of ways, including how readily available this form of psychological support can be:

> ‘I will buy a hard copy of the book when it comes out because I just think it was a great book to have… it’s a handbag book then isn’t it… it might be something that I can just carry around with you or have on the bedside a bit more conveniently’ (Penny)

Participants also spoke about the accessibility of bibliotherapy in terms of being easily able to use a book when other sources of support are unavailable. Some participants described an absence of an emotional outlet in terms of a lack of professional help or close personal relationships. With this in mind the book was considered accessible as it was completely self-directed and required no input from others. Other participants spoke about a perceived burden being placed upon family and friends as a result of discussing their cancer-related distress. For example, Penny said ‘I almost don’t want to go on about how I feel or keep going on about things because people get fed up with listening to you’. As such, it seemed the book allowed some participants to access support without feeling worried or guilty about the impact on others.

> ‘…you are isolated, so you are going back to a book, and you are finding it as company, in a way. Because you are reading something which is helping, you are almost talking it over with yourself and instead of seeing other people, you are going through the book, and it is almost like a friend’ (Elizabeth)

The book was also considered accessible to some participants in terms of it being available to use at any time. This seemed particularly important for some participants who highlighted cancer-related factors such as pain, fatigue, and illness as potentially impacting on engagement with other sources of psychological support.

> ‘You have really good and really bad days, and during treatment you have some horrible days worse than others that you're just so ill, but you can't predict it. That horrible day may be on the day that you've got this appointment that was booked three months ago because you're on a waiting list to see a psychologist. You don't want to miss that appointment, but you feel so crap you can't get out of bed, and you're not really going to benefit out of that session because you're probably not going to listen or engage as much because you feel unwell. Whereas if you're feeling like that and you can pick up a book and think, “Do you know what? This section will help me today. I'll read this and see if it can help me”'. (Vanessa)

Given the known barriers to accessing psychological support for this population, the finding that bibliotherapy is experienced as an accessible mode of therapeutic delivery feels particularly important.

Usability

In addition to its accessibility, the majority of participants also commented on the usability of the intervention. Participants described a number of features of the book as being useful in maintaining their attention and concentration, including the layout of information, the division and titles of sections, and illustrations breaking up the text. The ability to maintain focus on the book felt particularly significant to some participants, who highlighted factors such as cognitive difficulties as potentially interfering with intervention engagement

> ‘The pages are big and it's easy to read… I liked the way it was set out with the bullet points and the little drawings and things like that, it kept your attention because it wasn't pages and pages of text which I did find helpful. Because at any time your mind tends to wander off from things but especially when you've got things going on and I think it was very easy just to take a little chunk of it, read it and then if you did wander off or whatever, you could just go back and just catch up to where you were very easily’ (Tina)

> ‘I think the visual-ness really helps. If it was just text, then I probably wouldn't have got through it. I probably wouldn't have read the whole book…. I think that's really important, because I think concentrating is quite hard. With somebody going through treatment, it allows you to concentrate more’ (Vanessa)

Many participants also discussed the benefit of being able to easily ‘dip in and out’ of the book, reading sections that feel the most relevant in that moment.

> ‘This is the kind of book that you can just pick up and because of the way it’s laid out, you can just go to a relevant chapter, and I think it’s done in a way that would enable you to tackle things that are bothering you at that time’. (Penny)

Given the broad scope of physical and psychological symptoms that can affect a person with cancer at any given time, it seems particularly valuable that a reader would be able to identify and engage with personally relevant information from a wide range of content within this type of intervention.

Theme 2: Timing is important

While participant response indicated that bibliotherapy may be an acceptable mode of delivery for psychological support for people with cancer, many participants highlighted that the timing of such an intervention is important. One idea present across many interviews was that receiving a bibliotherapy intervention straight after diagnosis may be too overwhelming. This is unsurprising given the intense range of emotions that can be experienced by a person newly diagnosed with cancer including shock, anxiety, denial, sadness, anger, exhaustion and desperation (Cincotta, 2004). Cheryl indicated she could not have engaged with bibliotherapy following diagnosis as she was ‘still reeling with it all’ and Eve suggested ‘there’s just so much that you can’t take it on board if you’re newly diagnosed’. Participants reflected that if they were to receive a bibliotherapy intervention straight after diagnosis they would likely either fail to engage with it or fail to obtain the same benefit from it as they would receiving it a later date.

> ‘I think just after diagnosis your head is, well, for me my head was just so scrambled… if I'd walked past [the book] when I was in the treatment centre or something, I might have picked it up, but I think I probably would have not got so much from it as I have now, having sort of two years between diagnosis and now’. (Tina)

Many patients felt that a more appropriate and beneficial time to receive a bibliotherapy intervention would be after treatment. They reasoned that around this time cancer patients will have had more time to come to terms with their diagnosis, will have more time to engage with the intervention, and will have experienced more of the physical and psychological side effects for which they may require support.

> ‘I think right at the beginning would have been too soon…Basically, you're in denial first… then you start thinking about the long term. In your head when everybody's sleeping and you're awake, you start thinking about it. Then when you start your treatment it becomes a bit real. I don't think it's real until you actually start it, and you start getting the side effects. When I started getting some of my side effects, you tend to spend a lot of time in bed or poorly, and that's when you need something to read that's actually going to help you. When I was in chemotherapy, really ill in bed and I was up in the middle of the night being ill, that would have been a good book to say, 'Look, this is what you need, this will help you'. (Vanessa)

Theme 3: Resonating with cancer experiences

Recognising elements of own cancer journey

All of the participants expressed that they resonated with information in the book. For some, this involved relating to key ideas or metaphors in the resource.

> ‘The book caused me to think and there were certain things in the book…for example the concept of wearing a mask, which is what I’ve been doing, because I’ve been stressed out and not in in good spirits for about three years, because all this started three years ago, and I have just pretended. I’ve got three sons who live locally, and I’ve just pretended that everything is fine and I’m fine and there are no issues, but it’s just completely untrue… so when the book talked about wearing a mask, that resonated with me’. (John)

For others, relatable cancer experiences were found within the quotes from cancer survivors that are featured throughout the intervention.

> ‘…[quotes] like “I have gone from being a well person who feels in control of my life and my future, to facing the unknown with no road map” - that was a really good quote from someone, that resonated with me.’ (Nicola)

Some participants seemed to connect with the quotes as they related to aspects of their own cancer journeys.

> ‘[Reading quote aloud] “My consultant told me I was coping really well, but in the next appointment when she said, “we will need to delay the treatment” I cried” … there’s been bits like that where I’ve thought “yeah I remember that”’. (Eve)

Others seemed to appreciate that the quotes were from people who had actually experienced cancer.

> ‘I think for me, if the quotes weren’t there, I wonder whether this would just be another self-help book with very eminent psychologists…you then think, “well, how much do they really understand and get into the head of those patients?” Whereas by putting in these quotes, for me, that’s what makes the book different. It makes it feel like the authors really do understand because they’ve taken the time and trouble to really get into the heads of the people that are affected by cancer’. (Penny)

This seems to be linked to an idea that featured across many interviews; that despite their best efforts, friends, and professionals cannot truly understand the cancer experience unless they have lived through it themselves. For example, Cheryl stated “with all the will in the world, unless your friends and family, no matter how much they love you, unless they’ve been through it, they won’t understand”. With this in mind, it seemed that it was a refreshing and connecting experience for readers to have their own experiences reflected back to them from others who have had cancer.

> ‘I found it very relatable, and I found, do you know what? This book is telling me exactly how I felt when I was during this stage, and when I was low because of this reason, that reason… I almost felt like that book was hearing me, hearing my emotions.’ (Vanessa)

Although the majority of participants found the quotes in the book relatable, it is important to acknowledge that one participant expressed that they did not always find value in this feature of the book:

> ‘...and then the constant quotations from people you know… I thought why are you doing this? Why are you wallowing in all this “oh cancer is the most terrible thing in the world”? … I thought what these people seem to be doing is painting cancer as the worst disease that was ever created but we’re going to tell you how to deal with it…but don’t paint that terrible picture in the first place because it isn’t, today it isn’t that terrible. There are many illnesses which are more debilitating than cancer.’ (John)

This highlights how different parts of the book may be experienced by different people with cancer, which may be related to a number of factors including personal experience of cancer or general attitudes towards health and illness.

Normalising experiences

In addition to helping to convey key ideas and support the reader to feel heard, relatable content in the book also seemed to help normalise cancer experiences for participants, including responses to diagnosis, relationship difficulties, and reactions at different stages of the journey jarring with expectations of self and others.

> ‘It reinforces that sometimes the slight annoyance I feel when people say, “Oh, you’ve done so well, time to move on” and all this sort of stuff, sometimes I get annoyed about that because I think, “you really don’t get this”. So, to understand that all of those feelings are completely normal… and even if you know in your heart of hearts that what you’re feeling is normal and actually they are coping mechanisms, just to dip in and read that and reinforce how you’re feeling I think is really, really good.’ (Penny)

There may be a number of reasons why the normalisation of the cancer experience was important for participants, for example reassuring the reader that their reactions were understandable given the situation they were in or providing a sense of connection and community that others have experienced something in the same way.

> ‘It just makes you think yes, I wasn’t losing it, these are quite common feelings … it’s quite nice, for me, the idea that actually some of these things are common. That doesn’t annoy me, that’s completely the opposite, I think that’s great. In a way it’s a shame because you think “oh no other people go through that as well”, but on the other hand it makes you feel better because you think “oh okay I’m not crazy, I’m not on my own”.’ (Hazel)

Validating experiences

Participants also found that recognising aspects of their own cancer journey in the book helped to validate their cancer experiences and responses to these. In particular, many participants found that many of the strategies recommended in the book were practices they were already taking part in.

> ‘And that’s basically what you were saying in your book and so it’s so lovely that it all ties up and the things that I’ve been trying to do over the past two years have really kicked in and made a difference… I just found that so many things actually tied up with my thoughts and feelings anyway’. (Eve)

This seemed to have a positive impact on participants, leading them to reflect on their progress and feel reassured about the coping skills they were utilising. This finding is consistent with research carried out by Roberts et al. (2016), who found that people with cancer engaging in a bibliotherapy intervention had a positive experience reading the resource despite many of the strategies not being novel, because it reinforced the coping skills they already had.

Theme 4: Tools of the book

Interactivity

The current self-help book uses a number of features to convey ACT ideas and skills including informative text, visual information, audio exercises, and written exercises. Many participants reported that they engaged well with these components of the book, suggesting that they provided a choice of interactivity which in turn created a person-centred experience. Although not every participant used or enjoyed all of the features of the book, it seemed that each person was able to find something within the resource that was meaningful and helpful to them.

> ‘I liked some of the graphics, some of the illustrations, writing down your own distractions, solving problems – all those sorts of things I thought was really useful because it felt like a

> workbook then, that you could add something to it that was important to you… I didn't do it all, but the bits I wanted to, I did'. (Nicola)

A number of participants also spoke about the benefits of being able to interact with different parts of the book at different times, depending on the sort of support needed by the individual in that moment. This seemed to provide a sense of freedom in seeking support, that was well-received by participants.

> 'When I thought about it, using the book… I thought a trellis is a great idea because you're the plant obviously growing but you just need that little bit of support and then once you're on one bit of support, sometimes you'll need another different bit of support so you're moving around and up this trellis, onwards, outwards, sideways, every direction depending on what sort of a plant you are… a ladder is one thing, but a ladder sounds like you've got a direction, you know you've got to go somewhere, a trellis is just you could be going in any direction it doesn't matter, you know there's no necessary right or wrong way to go it's just a support whichever sort of plant you are.' (Hazel)

Audio Exercises

One feature of the book that many participants commented on were the audio exercises. Some participants reported that they did not engage with audio exercises at all, while others just read the written accompanying scripts. Reasons for not engaging in audio exercises included lack of time, accessibility of audio files, and personal preference.

> 'I did only listen to a couple of them, but I found it easier just to read it actually, for me, and to sort of be able to go back and read it a bit again rather than having it as audio'. (Tina)

Those that did engage in audio exercises reported that they experienced these positively. The accounts of these participants indicated that the exercises facilitated engagement with a number of core ACT processes, including being in the present moment, acceptance, and cognitive defusion.

> ‘You had the book but then you had the audio exercises that went along with it which really did add to it…the three-stage breathing which I thought was good as well because you find it calms you down as well, it sort of brings you back into the moment, it focuses you a little bit more, which I found was great because your mind just does tend to wonder and you are thinking about the next treatment or the next appointment’. (Elizabeth)

Written Exercises

Similarly to the audio exercises, engagement with written exercises was varied. Reasons for not writing in the book included time, personal preference, and having completed similar activities in the past. A number of those who did engage with this element of the resource spoke about their value, specifically in relation to increasing psychological flexibility through processes of ACT. For example, Nicola reported ‘the values list I really enjoyed doing… there were things in there like learning, I had forgotten how much I like to learn.’ Nicola went on to share that she was going to begin reading more as a result of completing this exercise, suggesting that the process of engaging with her values had the potential to translate into committed action. Tina also completed a number of written activities and described how one in particular helped her with the process of defusing from her thoughts:

> ‘I normally sort of shy away from things like that if it had been in some other subject but, you know, having tried one or two [written exercises] at the beginning… especially that one I said where I wrote the things before about noticing about what you were thinking and I realised that really, really did work for me’. (Tina)

Some participants reported that they revisited written tasks after their completion. This appeared to have many benefits, including consolidation of learning. For example, Elizabeth said ‘it was like I wrote it down and then the following day I went back to see what I had written – oh yes, I get it now!’ For others returning to completed exercises seemed to facilitate reflection, with Elizabeth reporting ‘I sort of left it for a bit and then I went back and then I read it and I thought I didn’t realise I was thinking like that!’. This finding has relevance to some of the ideas presented in Theme 1 in terms of one of the benefits of bibliotherapy being the ability to use and revisit different sections at different times.

Theme 5: ACT in action

Regaining control

A number of participants described experiencing a loss of control following their cancer diagnosis, related in part to a loss of control over thoughts and feelings. Some participants described ruminating over cancer reoccurrence, including Penny who commented ‘it’s in the background all the time because, you know, it might come back.’ Other participants described having intrusive worries about the future, such as Vanessa who said ‘as a parent I’m also worried about not being there for my children’. It is positive then, that a number of participants found that they were able to regain some control over their thoughts as a result of engaging with content in the self-help book.

> ‘I liked the way it worked through the fact that you can regain control of some of your feelings and, not just regain control necessarily, but you can observe and note and notice improvements and see what’s going on and check in with yourself.’ (Hazel)

Interestingly, and in line with the principles of ACT, it was the opposite act of attempting to gain control over thoughts that resulted in this outcome for some participants. That is, through engaging with cognitive defusion exercises and trying to detach from thoughts rather than alter their content of frequency, participants were able to gain control over the affect their thoughts had on them (rather than control the thoughts themselves).

> ‘I think just the initial idea of looking at your thoughts from a slightly detached space… I think I wrote down a thing of “I noticed that I'm thinking about a certain thing” … doing little things like that actually did really work for me. I did say out loud “the thing that was worrying me” and then I realised that when you then put in those other words before it…it actually does take away the power of it…you realise that it's something perhaps you can have more say over rather than it just controlling you… that has made a real conscious thing that I can think about that in a different way now.’ (Tina)

Cognitive defusion may be a particularly beneficial process for people with cancer, given that many of the difficult thoughts commonly associated with the disease are likely accurate, such as distress relating to treatment or fears about the future (Hulbert Williams and Owen, 2015). As such, it is unlikely that attempts to deny or change these thoughts will be helpful, and instead acknowledging difficult cognitions without letting them dominate ongoing behaviours may be a more beneficial strategy.

> ‘I just thought if I can make that work in my head a bit better so that instead of just automatically trying to block out all of the thoughts, I can find a way to, you know, either explore them all or to accept them as they are, that sounded like what I needed to do really.’ (Tina)

Some participants also spoke about regaining control of a sense of what was important to them through their involvement with the book. Participant accounts indicated that there are a range of significant changes that can take place over the course of a cancer experience, which can result in a loss of control over meaningful aspects of life. For example, many described having to give up work, adjust their roles within their family and friendship systems, and alter their daily routines to fit in with appointments and treatments. Engaging with content in the book relating to values seemed to be one way in which participants were able revaluate what mattered to them and plan or carry out committed action based on this.

> ‘[Reading aloud] “Am I doing what matters to me? Am I acting in a way that fits with how I ideally want to treat myself, others or the world?” …it really resonated with me because the answer was no, I was concentrating at the time on things that were irritating me’ (Cheryl)

The ACT approach proposes that effective interactions about values can create a sense of liberation and help people to realise that, even in desperate situations, choices are still available to take us into meaningful directions (Harris, 2009). The potential to enhance a sense of control for people with cancer through this process feels particularly valuable given how many elements of the cancer experience may result in feelings of hopelessness.

> ‘The book has helped me thinking about how I take control and what I do, and that is mainly my relationship with others, with the oncologist, with people who maybe have suggestions for you, thoughts for you, ideas, you should do this, do that. It is about knowing when to say no or when to say, “can we think about this differently?”’ (Nicola)

Living mindfully

A number of participants discussed positive outcomes of engaging with mindfulness exercises from the book. Reported benefits included feeling more relaxed, improved sleep, connecting with emotions, and increased capacity to replace automatic reactions with more conscious responses. A number of these outcomes are in line with research findings relating to cancer-related mindfulness, including studies which have reported this type of intervention to reduce symptoms of stress and sleep disturbance (Nakamura et al., 2013), and improve attention (Chiesa et al., 2011).

> The most I really did find really helpful was the mindfulness, because it does let you put things out of your mind…maybe I’ve just been running on adrenalin sort of thing, and I’ve never really sort of slowed down… I have taken away the mindfulness.’ (Valerie)

Some participants described becoming very busy after finding out they had cancer, with the time from diagnosis to treatment being highlighted as particularly hectic due to planning and attending hospital appointments. Whilst some participants may have perceived this change of pace as a positive in terms of having little time to ruminate on their situation, it may have resulted in an element of experiential avoidance for some whereby they were able to evade engaging with their thoughts and emotions. Whilst this may be comforting in the short term, ongoing avoidance behaviours have been associated with increased psychological distress for people with cancer (Manne et al., 2005). Therefore, using mindfulness practice to engage with the present moment and connect with thoughts and feelings seems like a valuable skill for people with cancer.

> ‘The breathing, so it talks about keeping still, pushing your feet on the floor and breathing. And, just thinking about where you are now. That sort of thing just brings you back, brings you back to now. Don’t let your mind run away too far away’ (Nicola)

In addition to just engaging with mindfulness when using the book, it is positive that some participants went on to incorporate mindfulness exercises into their daily routines.

> ‘I have noticed that I do the mindful walking a bit more… I used to go out and whenever I went for a walk, I used to put headphones on. I’ve stopped doing that now and I just go for a walk and listen to my footsteps, listen to the noises around me and just try and switch off and listen to the natural noises more than just artificial noises if you like and just trying to learn to switch off the autopilot’ (Elizabeth)

Although there is likely still benefit in short term engagement with mindfulness exercises, a recent study has demonstrated that ongoing practice of mindfulness skills is a moderator of improved psychological distress following an ACT intervention (Butler, 2021). This suggests that patients embedding mindfulness techniques into their daily lives may have long term benefits.

Discussion

This study sought to investigate how adults with cancer experience and use an ACT-based bibliotherapy intervention. Five themes were generated from the data including (1) The value of bibliotherapy (2) Timing is important (3) Resonating with cancer experiences (4) Tools of the book (5) ACT in action.

Overall, bibliotherapy as a delivery mode appeared to be experienced positively by participants in this study. This is consistent with the (limited) existing literature in this field (Roberts et al., 2016; Semple et al., 2006; Semple et al., 2006). One perceived benefit of this form of intervention was found to be its accessibility in terms of its availability and self-directed nature. This is an important finding, given the range of known barriers to accessing psychological support for the cancer population. A second quality of the book that participants appreciated was its ease of use. This was highlighted as a particular strength in relation to cancer-related cognitive difficulties that can affect engagement with psychological interventions. Cancer related cognitive difficulties are frequently reported among cancer patients during treatment, with prevalence rates of up to 75% (Janelsins et al., 2011). This suggests that an intervention that is easy to engage with despite these difficulties would be particularly valuable for this population.

An interesting finding to come out of this study was participants' ideas about the timing of receiving a bibliotherapy intervention. A patterned response across the dataset was that receiving bibliotherapy straight after diagnosis may be too overwhelming. A number of participants also reflected that if they were to receive a bibliotherapy intervention straight after diagnosis they would likely either fail to engage with it or fail to obtain the same benefit from it as they would receiving it a later date. This is in line with research carried out by Angell and colleagues (2003), which found that cancer patients experienced greater benefits from a bibliotherapy intervention if they were further out from diagnosis, rather than newly diagnosed. Many participants indicated that a good time to receive such an intervention might be after treatment. This has important implications in terms of potentially optimal timeframes for people with cancer to access bibliotherapy.

In addition to adding to the existing evidence base with regards to the use of ACT with people with cancer, this study has also added a novel finding to the field – that bibliotherapy seems to be an acceptable format of delivering ACT to this population. It was identified that a number of bibliotherapy tools, such as quotes, illustrations, audio exercises, and written exercises, provided an interactive and person-centred experience through which readers could engage with the principles of ACT. Furthermore, a number of these tools resulted in participants resonating with cancer experiences, which in turn facilitated experiences of normalisation and validation. Further quantitative exploration of this combination of delivery mode and psychological model would be beneficial to develop an understanding of the effectiveness of ACT delivered through bibliotherapy, for example measuring its effect on psychological distress and psychological flexibility. The effectiveness of such an intervention would have important implications in terms of clinical practice, given that wider research has demonstrated bibliotherapy to be a cost-effective treatment that encourages patient participation (Chamberlain et al., 2008). In line with findings from this research, it may be particularly beneficial for professionals to recommend this form of intervention to people with cancer around the time of treatment, either as a sole intervention, as a therapeutic support whilst waiting for professional support, or in conjunction with face-to-face therapy. This form of bibliotherapy could also be considered for a scheme such as the ‘Reading Well – Books on Prescription’ in the UK so that it can be made accessible to a wide audience, including those who may not access psychological support via other means.

Whilst this study has generated some promising findings, it is important to acknowledge its limitations. Firstly, the qualitative nature and small sample size of the study has implications in terms of the transferability of results, that is the extent to which findings have applicability in other groups or settings (Lincoln and Guba, 1985). Descriptive data has been summarised in order for readers to evaluate the applicability of the findings to other contexts (Lincoln and Guba, 1985), however this data highlights a further limitation which is a noticeable lack of diversity among participants. For example, all but one of the participants were female, and the entire sample was aged 40 years or over. Information regarding ethnicity is not presented as this data was not obtained from participants due to an oversight, which is a further limitation. Another issue to consider in terms of the findings of this study is that all the participants reported that they had experienced cancer-related psychological difficulties prior to their involvement in this research as a result of their cancer diagnosis, and over half had accessed some sort of psychological support for this. This is important to note as it is possible that these factors may have influenced participants’ experience of the current intervention in some way. For example, participants who benefited from psychological support in the past may have been more motivated to engage in with the self-help book. Participants may have also engaged with components of the ACT intervention (such as mindfulness) prior to using the book via other sources of psychological support, which may have resulted in them being more or less likely to practice these strategies for the purpose of this study. A final point to consider, is the potential impact of the authors beliefs and assumptions on the analysis of the data. Possible professional areas of bias were related to the authors prior understanding of bibliotherapy and use of ACT. The authors personal background will also have inevitably impacted on the way they viewed and analysed data, including the ways in which cancer has impacted on their own life. Although this is not necessarily a limitation, and the reflexive process of thematic analysis used in this study acknowledges the inescapability of research being influenced by the research team (Braun and Clarke, 2019b), it is important to acknowledge that these factors will have likely shaped the findings in some way. Whilst this may have been unavoidable, some protection against this resulting in potential bias was maintained via the analytic process being transparent in a way that allowed supervisors to follow, audit, and critique the research process (Polit et al. 2006, Sandelowski 1986, Streubert-Speziale, 2007).

In conclusion, participants appeared to experience a novel self-help book based on the ACT model as an acceptable and influential intervention. The findings from this study have added to the evidence base regarding the use of ACT as a psychological model for the cancer population. Although not explicitly or quantitively evaluated, participant accounts indicate that, overall, the resource was perceived to be a helpful intervention in increasing psychological flexibility. Specifically, ACT core principles of cognitive defusion, values and committed action, and being present were highlighted as being of benefit in terms of supporting participants to regain a sense of control over their lives and be more present. This suggests there is merit in furthering our knowledge and understanding of how this form of intervention, and particularly the interaction between mode of delivery and psychological model, may benefit the cancer population.

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Appendix 1 – Journal Guidelines for Paper Submission

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Journal of Health Psychology, please ensure you have read the Aims & Scope.

1.2 Article Types

The Editorial Board of the **Journal of Health Psychology** considers for publication:

(a) Reports of empirical studies likely to further our understanding of health psychology
(b) Critical reviews of the literature
(c) Theoretical contributions and commentaries
(d) Intervention studies
(e) Brief reports
(e) Signed editorials (about 1000 words) on significant issues.

Intervention studies

Publication guidelines for intervention studies are published in Volume 15, Issue 1, pp. 5-7.The journal normally publishes papers reporting intervention studies of up to 8,000 words allowing 500 words per table and figure.

The Journal of Health Psychology welcomes research reports regardless of the direction or strength of the results. However the JHP will only consider reports of clinical trials that have been pre-registered at http://www.clinicaltrials.gov/ or http://www.controlled-trials.com/

Please consult the Editorial concerning “Publication Guidelines for Intervention Studies in the Journal of Health Psychology” by David F. Marks J Health Psychol January 2010 vol. 15 no. 1 5-7: http://www.sagepub.com/content/15/1/5.full.pdf+html The criteria for publication include the application of the CONSORT, TREND and PRISMA statements.

Brief reports

The Journal also publishes Brief Reports of up to 3,000 words. Brief Reports should include an abstract of 100 words, and may include a table or figure in lieu of 500 words of the 3,000-word maximum.

Article length and house style

Articles should be as short as is consistent with clear presentation of subject matter. The word count for articles is 8,000 words, including footnotes and a reference list. Articles over the word count should be ran by the Editor first. Tables and figures count as 500 words each which should be attached as separate pages at the end. “INSERT HERE” signs should be noted within the text. The title should indicate exactly, but as briefly as possible, the subject of the article. It is essential that your literature review is completely up to date. Please check recent issues of the **Journal of Health Psychology** and other key journals to ensure that any relevant papers are cited. Papers that fail to do this will be rejected. An Abstract should be at the start of the manuscript and not exceed **100 words** (in spite of what is stated on the ScholarOne website) accompanied by **five** keywords should be selected from the list provided on the JHP ScholarOne website. References are not numbered but appear in alphabetical order by first author surname.

Preparing your manuscript for submission

Please ensure that your manuscript is suitable for publication and completely free of errors before you submit. Please pay particular attention to SAGE guidelines on Authorship and the SAGE Correction Policy.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Language and terminology

Authors must follow the Guidelines to Reduce Bias in Language of the Publication Manual of the American Psychological Association (6th ed). These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

The language used in your manuscript should be inclusive and language that might be deemed sexist or racist should not be used. All submissions should avoid the use of pejorative terms and insensitive or demeaning language and submissions that use unacceptable language will be returned by the editor.

Useful websites to refer to for guidance

We recommend that authors consider looking at the below guidance:

- APA guidelines on Bias Free Language
- Words Matter
- Authors are encouraged to refer to land use any language guidelines that relate specifically to their research

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's *Manuscript Submission Guidelines*

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files

4.5 Reference style

Journal of Health Psychology adheres to the SAGE Harvard reference style. View the SAGE Harvardguidelines to ensure your manuscript conforms to this reference style.

If you use *EndNote* to manage references, you can download the SAGE Harvard EndNote output file.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Appendix 2 – Search Terms

APA PsycINFO and PubMED search terms

1 exp Neoplasms/
2 oncolog*
3 adenocarcinoma*
4 tumour*
5 tumor*
6 cancer*
7 neoplasm*
8 1 or 2 or 3 or 4 or 5 or 6 or 7
9 exp Bibliotherapy/
10 bibliotherap*
11 biblio therap*
12 psycho education*
13 psychoeducation*
14 Psychoeducation/
15 Self-help techniques
16 reading therap*
17 book therap*
18 therapy workbook
19 therapy book
20 self-help
21 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22 8 and 21

CINAHL and SCOPUS search terms

S1 MH “Neoplasms+”
S2 “oncolog*”
S3 “adenocarcinoma*”
S4 “tumour*”
S5 “tumor*”
S6 “cancer*”
S7 “neoplasm*”
S8 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
S9 MH “bibliotherapy”
S10 “biblio therap*”
S11 “bibliotherap*”
S12 MH “Psychoeducation”
S13 “psychoeducat*”
S14 “psycho educat*”
S15 “reading theap*”
S16 “book therap”
S17 “therapy book”
S18 “therapy workbook”
S19 S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18
S20 S8 AND S19

Appendix 3 – Data Extraction Form

DATA EXTRACTION FORM

Review title or ID	
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	

General Information

Date form completed *(dd/mm/yyyy)*	
Name/ID of person extracting data	
Reference citation	
Publication type *(e.g. full report, abstract, letter)*	
Notes:	

Study eligibility

Study Characteristics	Eligibility criteria *(Insert inclusion criteria for each characteristic as defined in the Protocol)*	Eligibility criteria met? Yes	No	Unclear	Location in text or source *(pg & ¶/fig/table/other)*
Type of study	Randomised Controlled Trial	☐	☐	☐	
	Quasi-randomised Controlled Trial	☐	☐	☐	
	Controlled Before and After Study Contemporaneous data collection Comparable control sites At least 2 x intervention and 2 x control clusters	☐	☐	☐	
	Interrupted Time Series At least 3 time points before and 3 after the intervention	☐	☐	☐	

	Clearly defined intervention point		
	Other design (specify):	☐ ☐ ☐	
Participants		☐ ☐ ☐	
Types of intervention		☐ ☐ ☐	
Types of comparison		☐ ☐ ☐	
Types of outcome measures		☐ ☐ ☐	
INCLUDE ☐		EXCLUDE ☐	
Reason for exclusion			
Notes:			

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

Characteristics of included studies

Methods

	Descriptions as stated in report/paper		**Location in text or source** *(pg & ¶/fig/table/other)*
Aim of study *(e.g. efficacy, equivalence, pragmatic)*			
Design *(e.g. parallel, crossover, non-RCT)*			
Duration			
Duration of participation *(from recruitment to last follow-up)*			
Ethical approval needed/ obtained for study	☐ ☐ ☐ Yes No Unclear		

Notes:

Participants

	Description *Include comparative information for each intervention or comparison group if available*		Location in text or source *(pg & ¶/fig/table/other)*
Population description *(from which study participants are drawn)*			
Setting *(including location and social context)*			
Inclusion criteria			
Exclusion criteria			
Method of recruitment of participants *(e.g. phone, mail, clinic patients)*			
Informed consent obtained	☐ Yes ☐ No ☐ Unclear		
Total no. randomised *(or total pop. at start of study for NRCTs)*			
Clusters *(if applicable, no., type, no. people per cluster)*			
Baseline imbalances			
Withdrawals and exclusions *(if not provided below by outcome)*			
Age			
Sex			
Race/Ethnicity			
Severity of illness			

Co-morbidities		
Other relevant sociodemographics		
Subgroups measure		
Subgroups reported		
Notes:		

Intervention groups

Copy and paste table for each intervention and comparison group

Intervention Group 1

	Description as stated in report/paper	Location in text or source *(pg & ¶/fig/table/other)*
Group name		
No. randomised to group *(specify whether no. people or clusters)*		
Theoretical basis *(include key references)*		
Description *(include sufficient detail for replication, e.g. content, dose, components)*		
Duration of treatment period		
Timing *(e.g. frequency, duration of each episode)*		
Delivery *(e.g. mechanism, medium, intensity, fidelity)*		
Providers *(e.g. no., profession, training, ethnicity etc. if relevant)*		
Co-interventions		

Economic information *(i.e. intervention cost, changes in other costs as result of intervention)*		
Resource requirements *(e.g. staff numbers, cold chain, equipment)*		
Integrity of delivery		
Compliance		
Notes:		

Outcomes

Copy and paste table for each outcome.

Outcome 1

	Description as stated in report/paper		Location in text or source *(pg & ¶/fig/table/other)*
Outcome name			
Time points measured *(specify whether from start or end of intervention)*			
Time points reported			
Outcome definition *(with diagnostic criteria if relevant)*			
Person measuring/ reporting			
Unit of measurement *(if relevant)*			
Scales: upper and lower limits *(indicate whether high or low score is good)*			
Is outcome/tool validated?	☐ Yes ☐ No ☐ Unclear		

Imputation of missing data *(e.g. assumptions made for ITT analysis)*		
Assumed risk estimate *(e.g. baseline or population risk noted in Background)*		
Power *(e.g. power & sample size calculation, level of power achieved)*		
Notes:		

Other

Study funding sources *(including role of funders)*		
Possible conflicts of interest *(for study authors)*		
Notes:		

Data and analysis

Copy and paste the appropriate table for each outcome, including additional tables for each time point and subgroup as required.

For RCT/CCT
Dichotomous outcome

	Description as stated in report/paper	Location in text or source *(pg & ¶/fig/table/other)*
Comparison		

Outcome					
Subgroup					
Time point *(specify from start or end of intervention)*					
Results	Intervention		Comparison		
	No. with event	Total in group	No. with event	Total in group	
Any other results reported *(e.g. odds ratio, risk difference, CI or P value)*					
No. missing participants					
Reasons missing					
No. participants moved from other group					
Reasons moved					
Unit of analysis *(by individuals, cluster/groups or body parts)*					
Statistical methods used and appropriateness of these *(e.g. adjustment for correlation)*					
Reanalysis required? *(specify, e.g. correlation adjustment)*	☐ Yes ☐ No ☐ Unclear				
Reanalysis possible?	☐ Yes ☐ No ☐ Unclear				
Reanalysed results					
Notes:					

For RCT/CCT
Continuous outcome

	Description as stated in report/paper	Location in text or source *(pg & ¶/fig/table/other)*
Comparison		

Outcome							
Subgroup							
Time point *(specify from start or end of intervention)*							
Post-intervention or change from baseline?							
Results	Intervention			Comparison			
	Mean	SD *(or other variance, specify)*	No. participants	Mean	SD *(or other variance, specify)*	No. participants	
Any other results reported *(e.g. mean difference, CI, P value)*							
No. missing participants							
Reasons missing							
No. participants moved from other group							
Reasons moved							
Unit of analysis *(individuals, cluster/ groups or body parts)*							
Statistical methods used and appropriateness of these *(e.g. adjustment for correlation)*							
Reanalysis required? *(specify)*		☐ Yes ☐ No ☐ Unclear					
Reanalysis possible?		☐ Yes ☐ No ☐ Unclear					
Reanalysed results							
Notes:							

For Controlled Before-and-After study (CBA)

	Description as stated in report/paper				Location in text or source *(pg & ¶/fig/table/other)*
Comparison					
Outcome					
Subgroup					
Time point *(specify from start or end of intervention)*					
Post-intervention or change from baseline?					
No. participants	Intervention		Control		
Results	Intervention result	SE *(or other variance, specify)*	Control result	SE *(or other variance, specify)*	
	Overall results		SE *(or other variance, specify)*		
Any other results reported					
No. missing participants					
Reasons missing					
No. participants moved from other group					
Reasons moved					
Unit of analysis *(individuals, cluster/ groups or body parts)*					
Statistical methods used and appropriateness of these					
Reanalysis required? *(specify)*	☐ Yes ☐ No ☐ Unclear				
Reanalysis possible?	☐ Yes ☐ No ☐ Unclear				
Reanalysed results					

Other information

	Description as stated in report/paper	**Location in text or source** *(pg & ¶/fig/table/other)*
Key conclusions of study authors		
References to other relevant studies		
Correspondence required for further study information *(from whom, what and when)*		
Notes:		

Appendix 4 – CONSORT Checklist for RCTs

CONSORT 2010 checklist of information to include when reporting a randomised trial*

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a randomised trial in the title	
	1b	Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)	
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale	
	2b	Specific objectives or hypotheses	
Methods			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	
Participants	4a	Eligibility criteria for participants	
	4b	Settings and locations where the data were collected	
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	
	6b	Any changes to trial outcomes after the trial commenced, with reasons	
Sample size	7a	How sample size was determined	
	7b	When applicable, explanation of any interim analyses and stopping guidelines	
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	

Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	
	11b	If relevant, description of the similarity of interventions	
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	
	13b	For each group, losses and exclusions after randomisation, together with reasons	
Recruitment	14a	Dates defining the periods of recruitment and follow-up	
	14b	Why the trial ended or was stopped	
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	
Discussion			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	
Other information			
Registration	23	Registration number and name of trial registry	
Protocol	24	Where the full trial protocol can be accessed, if available	
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	

*We strongly recommend reading this statement in conjunction with the CONSORT 2010 Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials. Additional extensions are forthcoming: for those and for up to date references relevant to this checklist, see www.consort-statement.org.

Appendix 5 – CONSORT Extension for Pilot or Feasibility Trials

CONSORT 2010 checklist of information to include when reporting a pilot or feasibility trial*

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	
	1b	Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials)	
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	
	2b	Specific objectives or research questions for pilot trial	
Methods			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	
Participants	4a	Eligibility criteria for participants	
	4b	Settings and locations where the data were collected	
	4c	How participants were identified and consented	
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	
Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	
	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	
Sample size	7a	Rationale for numbers in the pilot trial	
	7b	When applicable, explanation of any interim analyses and stopping guidelines	
Randomisation:			
Sequence	8a	Method used to generate the random allocation sequence	

generation	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	
	11b	If relevant, description of the similarity of interventions	
Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	
	13b	For each group, losses and exclusions after randomisation, together with reasons	
Recruitment	14a	Dates defining the periods of recruitment and follow-up	
	14b	Why the pilot trial ended or was stopped	
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group	
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group	
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	
	19a	If relevant, other important unintended consequences	
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	
Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	
Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	
Protocol	24	Where the pilot trial protocol can be accessed, if available	

Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	
	26	Ethical approval or approval by research review committee, confirmed with reference number	

Citation: Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, et al. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ. 2016;355.

*We strongly recommend reading this statement in conjunction with the CONSORT 2010, extension to randomised pilot and feasibility trials, Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials. Additional extensions are forthcoming: for those and for up to date references relevant to this checklist, see www.consort-statement.org.

Appendix 6 – Recruitment Advert

Exploring a New Self-Help Book for People with Cancer

Call for research participants

Researchers at Cardiff University want to explore how a new self-help book is experienced by people with cancer.

The book has been developed by psychologists and a group of individuals affected by cancer. It is based on a psychological approach called Acceptance and Commitment Therapy and includes strategies for coping with some of the physical and psychological affects of cancer.

We are looking for people with a diagnosis of cancer to use the book for one month before taking part in a telephone or video interview to share their experience and thoughts on the book.

How to get involved

If you are 18+, live in the UK, have a current diagnosis of cancer, and are interested in taking part in this study or would like more information please contact **Emma Keenan at keenane@cardiff.ac.uk**

Appendix 7 – Example of Dissemination of Recruitment Advert

TCCResearchTeam
@TCCResearchTeam

Please RT - @tenovuscancer share opportunities to get involved in research. Right now, Cardiff University are exploring the use of a new self-help book for people affected by cancer. If you would like to take part please contact keenane@cardiff.ac.uk buff.ly/3bWZ6kC

Exploring a New Self-Help Book for People with Cancer

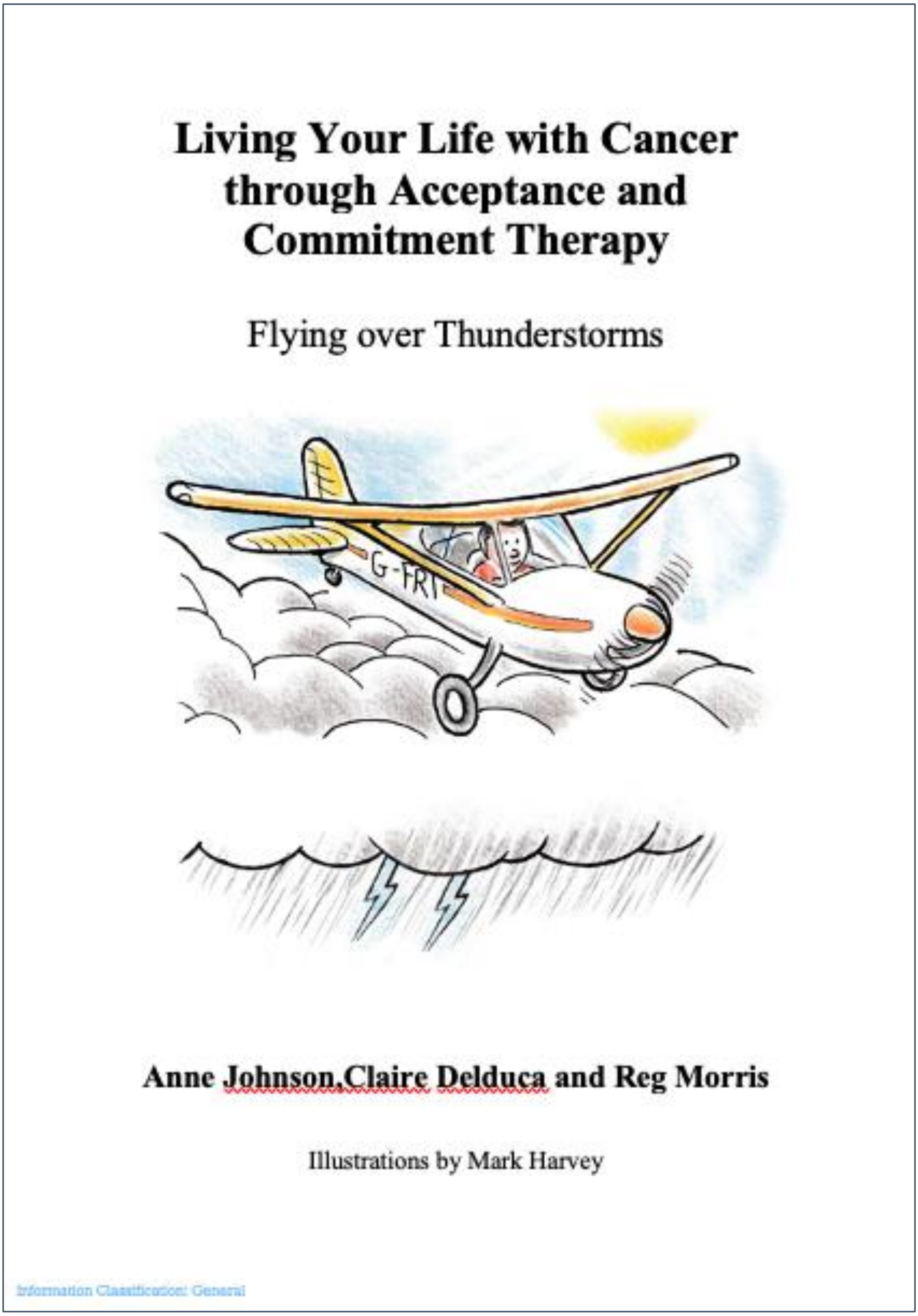
Call for research participants

Researchers at Cardiff University want to explore how a new self-help book is experienced by people with cancer.

The book has been developed by psychologists and a group of individuals affected by cancer. It is based on a psychological approach called Acceptance and Commitment Therapy and includes strategies for coping with some of the physical and psychological affects of cancer.

We are looking for people with a diagnosis of cancer to use the book for one month before

Appendix 8 – Excerpts from Self-help Book



Living Your Life with Cancer through Acceptance and Commitment Therapy

Flying over Thunderstorms

Anne Johnson,Claire Delduca and Reg Morris

Illustrations by Mark Harvey

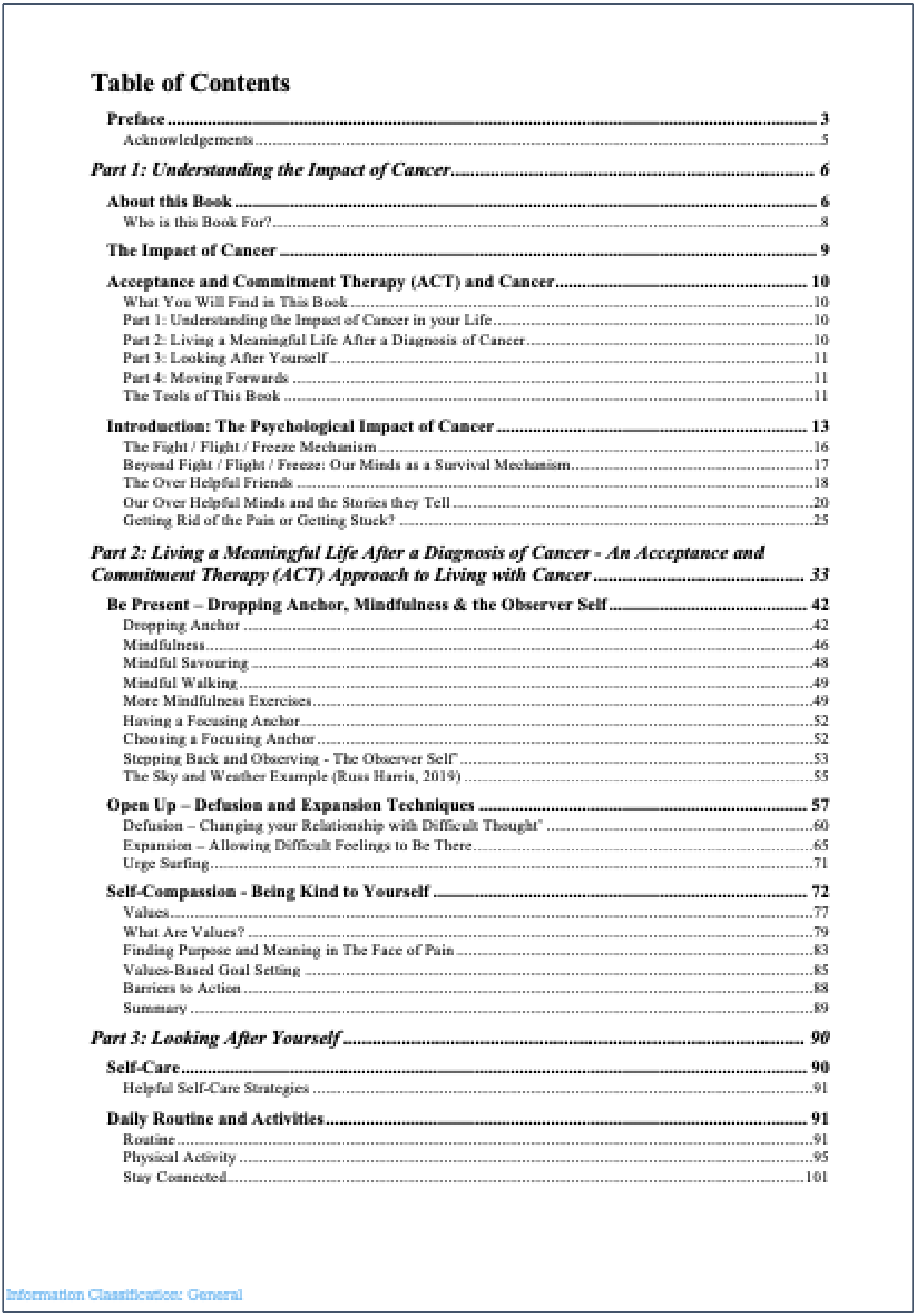
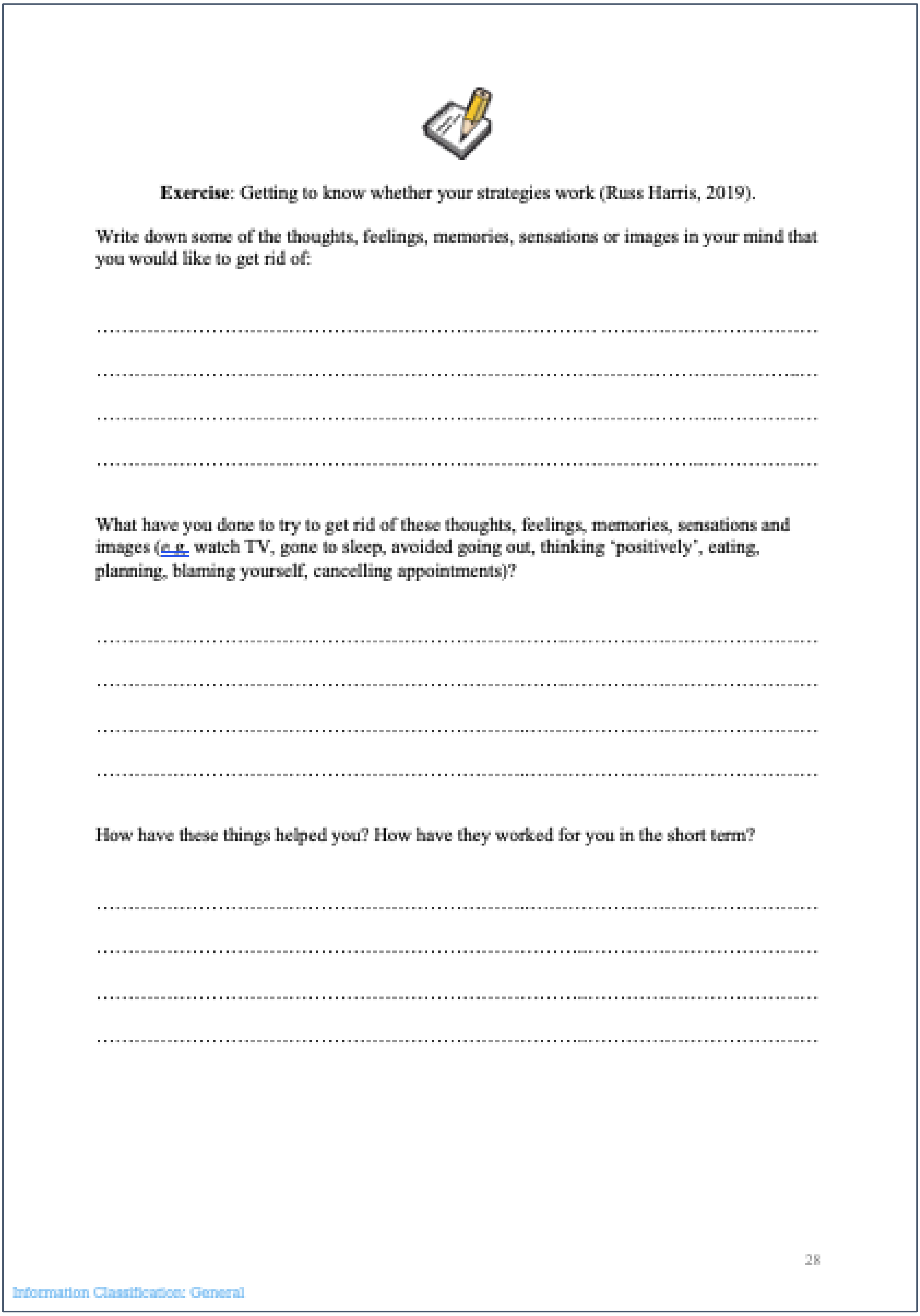


Table of Contents



Exercise: Getting to know whether your strategies work (Russ Harris, 2019).

Write down some of the thoughts, feelings, memories, sensations or images in your mind that you would like to get rid of:

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

What have you done to try to get rid of these thoughts, feelings, memories, sensations and images (e.g. watch TV, gone to sleep, avoided going out, thinking 'positively', eating, planning, blaming yourself, cancelling appointments)?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

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……………………………………………………………………………………………………

How have these things helped you? How have they worked for you in the short term?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

The Sky and Weather Example (Russ Harris, 2019)

It can help to think about you and your thoughts and feelings like the sky and the weather:

- Your thoughts and feelings are continually changing, like the weather. It could be sunny one day and stormy the next.
- You are like the sky - whether you can see the sky or not, it is always there, and it always has space for the weather.
- No matter how bad the weather gets, it cannot harm the sky.
- Even if a storm is hanging around, sooner or later the weather changes.
- Similarly, your thoughts and feelings cannot hurt you. They will pass with time. You can notice and make space for these thoughts and feelings until they pass.
- You are the same 'you' that has always been there since you were small.

Noticing that you are different from your thoughts and feelings then practicing mindfully observing them can help you to step back and unhook from them. Difficult thoughts and feelings come and go on their own. Sometimes they hang around, sometimes they go quite quickly. Like the clouds in the sky, they will all eventually pass – without you needing to put time or effort into controlling them or pushing them away.

Appendix 9 – Participant Information Sheet

Participant Summary Information Sheet

What is the purpose of the study?

The purpose of this study is to explore how a new self-help book is experienced by people who have been affected by cancer. The book has been written by three psychologists with experience of supporting individuals with cancer and other health conditions and a group of people who have personally been affected by cancer (through receiving a diagnosis themselves or caring for someone with cancer).

The book is called ‘Flying Over Thunderstorms’ and is based on a psychological approach called ‘Acceptance and Commitment Therapy’. It includes information about some of the physical and psychological changes that can occur following a diagnosis of cancer and strategies to cope with these - for example, changes to appetite and sleep routines. It also includes strategies for dealing with difficulties that are not so straightforward to manage - for example, dealing with uncertainty and fears about the future. Throughout the book there are quotes from people who have been affected by cancer, written exercises, and audio exercises.

Do I have to take part?

Your involvement in this study is completely voluntary. You will be involved in the research only after reading this information sheet and signing the consent form. If you decide to take part, but later change your mind, you can withdraw from the study at any time without having to give a reason. Choosing not to take part in the study will not affect any current care you are receiving or any future care you may receive.

What will I need to do?

If you would like to take part in this study, you will be contacted by the researcher to complete a short demographic questionnaire. You will then be provided with a pre-proofed version of the book either in pdf format via email or in a printed format via the post. You will be asked to use the book for a period of four weeks. You will be contacted by the researcher at the beginning of this four-week period and again halfway through to discuss how you plan to use the book and to answer any questions you may have. At the end of the four weeks you will be contacted once more to arrange a follow up interview. This interview can take place over the phone or via a video call and will last around 1-2 hours. You will be asked 10 questions about your experience of using the book and your responses will be audio recorded. Once all of the participants involved in this study have been interviewed, the researcher will analyse the data collected to look for themes about how the book has been experienced. Once these themes have been identified you will be invited to join a panel of participants to have a look at these themes and provide feedback on whether you think they are accurate.

Will my taking part in the study be confidential?

If you take part in this study, all of the information that you provide will be kept confidential. Unique identifier codes will be allocated to each participant and used to link questionnaire and interview data anonymously. Interview recordings will be stored securely on a password protected computer until they have been transcribed. They will then be deleted. Information obtained from the demographic questionnaire will also be stored securely on a password protected computer and deleted once the study has been completed. Any and all data collected during the study will only be seen by the researcher and their supervisor.

What are the benefits of the research?

We hope that by taking part in this study you are introduced to a resource that provides you with useful information and allows you to develop helpful skills with regards to living with cancer. The study will also provide an opportunity for you to reflect on your use of this resource, to consolidate anything new you have learned, and to encourage you to practice the things you have found helpful.

It is hoped that your participation will also benefit others in the future. As this is a new book, we hope that your direct feedback and views can help to contribute towards the development of psychological support services for those affected by cancer.

How will any information I provide be used?

The results of the research will be written up as a thesis and submitted as part of a Doctorate in Clinical Psychology. It is also hoped that the results will be published in a scientific journal. All information provided on questionnaires will be anonymised and you will not be identified in any report or publication related to the research. If you choose to take part in this study, you can register your interest in receiving a summary of the research findings.

Who has reviewed this study?

This research has been reviewed by the South East Wales NHS Research Ethics Committee [*EC.20.07.14.6055R2A*] who have given it a favourable ethical opinion for conduct. This project has also been reviewed, according to procedures specified by Cardiff University Research Ethics Committee and allowed to proceed.

Contact for further information

If you are interested in taking part in this study or would like some more information please contact Emma Keenan at keenan.e@cardiff.ac.uk.

Thank you

Thank you for taking the time to read this information sheet. Please feel free to discuss this with others and don't hesitate to contact myself or my supervisor if you have any concerns or questions. If you agree to take part in the study, you will be asked to sign a consent form and be given a copy of this for your own records.

Researcher
Emma Keenan
(Trainee Clinical Psychologist)
South Wales Doctoral Programme in
Clinical Psychology,
Cardiff & Vale UHB
Email: keenane@cardiff.ac.uk

Academic Supervisor
Professor Reg Morris
(Consultant Clinical Psychologist)
South Wales Doctoral Programme in
Clinical Psychology,
Cardiff & Vale UHB
Email: morrisr8@cardiff.ac.uk

School of Psychology Research
Ethics Committee
psychethics@cardiff.ac.uk

Appendix 10 – Participant Consent Form

Consent Form

Title of Study: Exploring the Experience of Bibliotherapy for Individuals with Cancer

Name of Researcher: Emma Keenan

Please write your initials in the boxes below if you agree with the following statements. Once you have read all the statements please also sign and date the bottom of the form.

1. I confirm that I have read and understood the Participant Information Sheet for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without it affecting my care or rights in any way.	
3. I understand that all of the information I provide during the study will be held securely and in confidence by the research team, unless they are legally required to disclose information due to concerns about my safety or the safety of others.	
4. I understand that any and all questionnaires and interviews I complete as part of this study will be kept confidential. Any and all information I provide will only be seen by the researcher and their supervisor.	
5. I understand that any interviews I take part in will be recorded using a Dictaphone. Interview recordings will then be stored securely on a password protected computer until they have been transcribed. Recordings will then be deleted.	
6. I understand that any information I provide on questionnaires will be stored securely on a password	

protected computer. This data will then be deleted once the study is complete.	
7. I am aware that information I provide on questionnaires and in interviews may be used by the researcher within their thesis or other papers published in scientific journals or presented at conferences for the purpose of research. I give permission for this information to be used with the understanding that I will remain anonymous.	
8. I understand that the anonymised research data and all other paper records (including this consent form) will be retained securely at Cardiff University for a period of 15 years.	
9. I agree to take part in this study.	
10. I **would** like to receive a summary of the findings of this study once finalised by the research team. I understand that the receiving of these findings is for personal reference to read at my leisure and I will not be required to do anything with them. I agree that the summary may be sent to the email or postal address provided below.	

Participant signature: ………………………………………………………..

Name (please print): ………………………………………………………...

Date: ………………….

Researcher signature: ………………………………………………………...

Name (please print): ………………………………………………………...

Date: ………………….

If you would like to receive a summary of the findings of this study, please leave an email address or postal address below:

Appendix 11 – Demographic Questionnaire

Participant Questionnaire

The information provided for this questionnaire will be used anonymously in the study. Please answer as many questions as possible. However, you do not have to answer anything that you don't want to. Thank you.

Today's date: ____/____/______ **Participant Number [office use]: _______**

Age: ________

Gender: Male ☐ Female ☐ Prefer to self-describe as__________________ ☐

Are you currently in employment? Yes / No **Are you retired?** Yes / No

Current / previous work:

____

____

At what age did you leave education? ___________________________________

Highest level of qualification obtained? _________________________________

Do you live by yourself? Yes / No **Number of dependents _________**

Do you have any physical disabilities: Yes / No

When were you diagnosed with cancer?_________________________________

What type of cancer were you diagnosed with? ___________________________

Have you been diagnosed with more than one type of cancer? Yes / No

If yes, what other types of cancer have you been diagnosed with?

____

Have you had treatment for your cancer? Yes / No

If yes, what treatment have you had?___________________________________

Are you currently in treatment? Yes / No

Have you finished treatment? Yes / No

Have you been affected by psychological problems such as anxiety or depression since you were diagnosed with cancer? Yes / No

If yes, please tell us how you were affected:

____

____

____

Have you received any treatment/support for this? Yes / No

If yes, please tell us about the treatment/support you received:

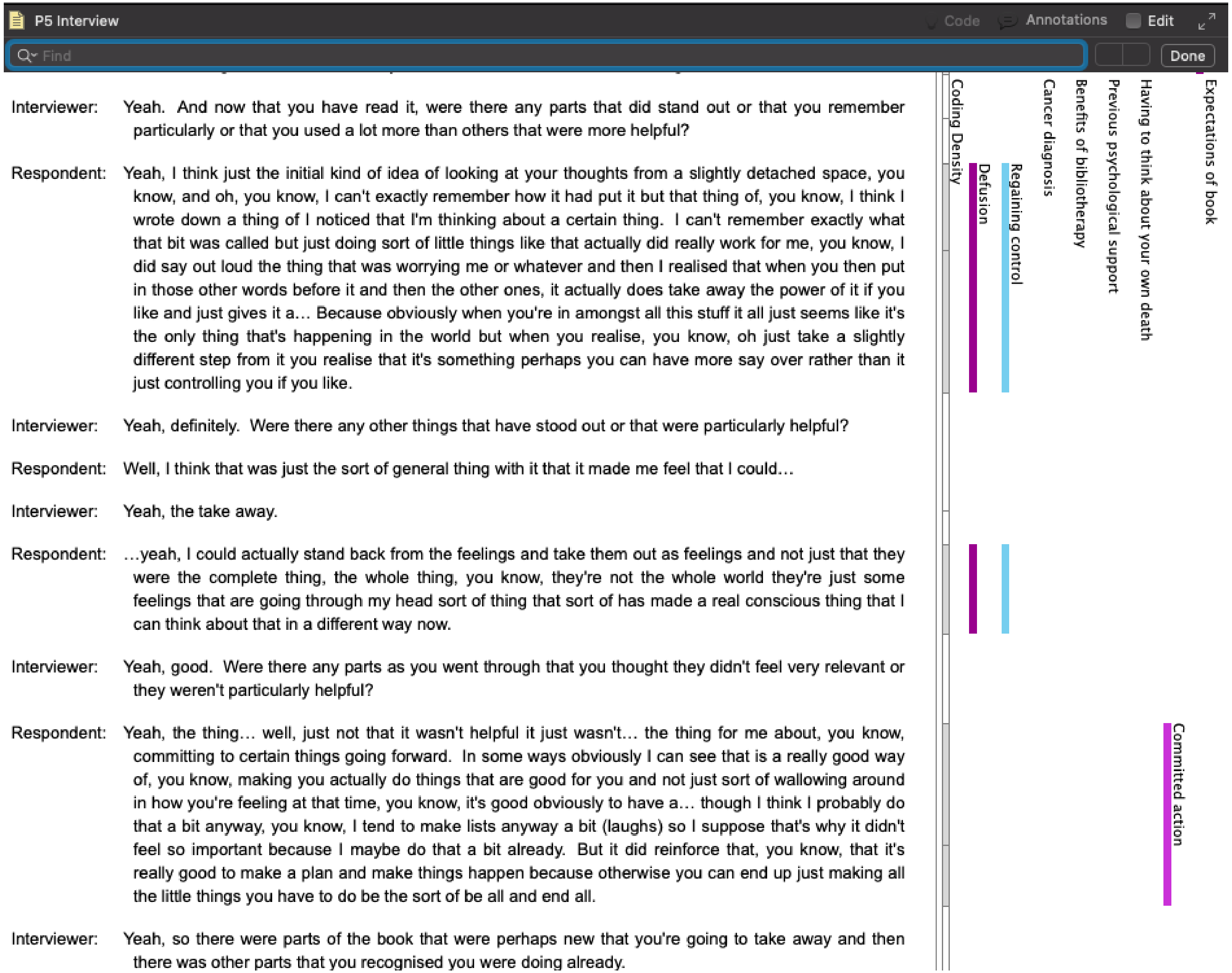
____

____

____

Thank you for completing this questionnaire

Appendix 12 – Analytic Stages



Interviewer: Yeah. And now that you have read it, were there any parts that did stand out or that you remember particularly or that you used a lot more than others that were more helpful?

Respondent: Yeah, I think just the initial kind of idea of looking at your thoughts from a slightly detached space, you know, and oh, you know, I can't exactly remember how it had put it but that thing of, you know, I think I wrote down a thing of I noticed that I'm thinking about a certain thing. I can't remember exactly what that bit was called but just doing sort of little things like that actually did really work for me, you know, I did say out loud the thing that was worrying me or whatever and then I realised that when you then put in those other words before it and then the other ones, it actually does take away the power of it if you like and just gives it a… Because obviously when you're in amongst all this stuff it all just seems like it's the only thing that's happening in the world but when you realise, you know, oh just take a slightly different step from it you realise that it's something perhaps you can have more say over rather than it just controlling you if you like.

Interviewer: Yeah, definitely. Were there any other things that have stood out or that were particularly helpful?

Respondent: Well, I think that was just the sort of general thing with it that it made me feel that I could…

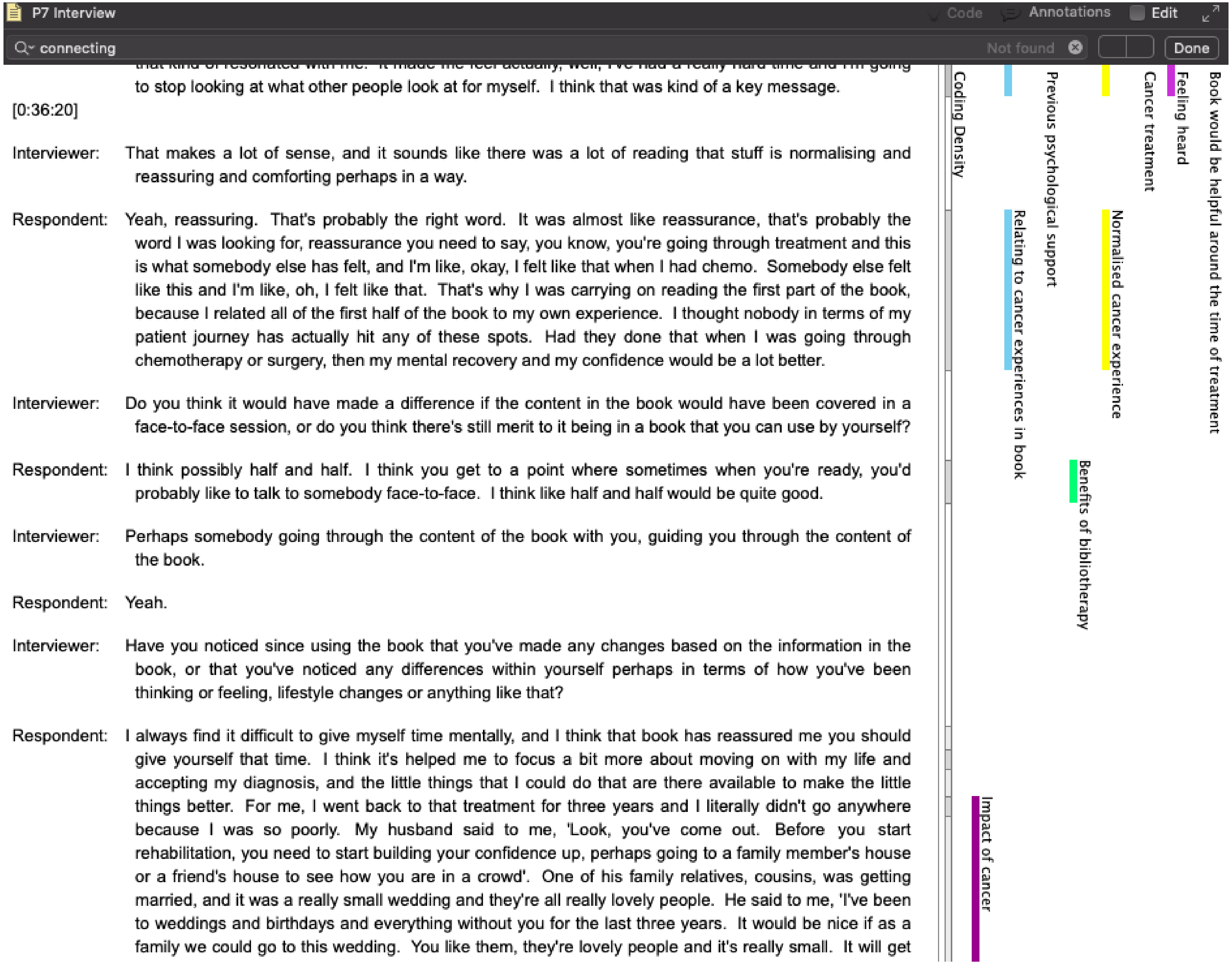
Interviewer: Yeah, the take away.

Respondent: …yeah, I could actually stand back from the feelings and take them out as feelings and not just that they were the complete thing, the whole thing, you know, they're not the whole world they're just some feelings that are going through my head sort of thing that sort of has made a real conscious thing that I can think about that in a different way now.

Interviewer: Yeah, good. Were there any parts as you went through that you thought they didn't feel very relevant or they weren't particularly helpful?

Respondent: Yeah, the thing… well, just not that it wasn't helpful it just wasn't… the thing for me about, you know, committing to certain things going forward. In some ways obviously I can see that is a really good way of, you know, making you actually do things that are good for you and not just sort of wallowing around in how you're feeling at that time, you know, it's good obviously to have a… though I think I probably do that a bit anyway, you know, I tend to make lists anyway a bit (laughs) so I suppose that's why it didn't feel so important because I maybe do that a bit already. But it did reinforce that, you know, that it's really good to make a plan and make things happen because otherwise you can end up just making all the little things you have to do be the sort of be all and end all.

Interviewer: Yeah, so there were parts of the book that were perhaps new that you're going to take away and then there was other parts that you recognised you were doing already.



to stop looking at what other people look at for myself. I think that was kind of a key message.

[0:36:20]

Interviewer: That makes a lot of sense, and it sounds like there was a lot of reading that stuff is normalising and reassuring and comforting perhaps in a way.

Respondent: Yeah, reassuring. That's probably the right word. It was almost like reassurance, that's probably the word I was looking for, reassurance you need to say, you know, you're going through treatment and this is what somebody else has felt, and I'm like, okay, I felt like that when I had chemo. Somebody else felt like this and I'm like, oh, I felt like that. That's why I was carrying on reading the first part of the book, because I related all of the first half of the book to my own experience. I thought nobody in terms of my patient journey has actually hit any of these spots. Had they done that when I was going through chemotherapy or surgery, then my mental recovery and my confidence would be a lot better.

Interviewer: Do you think it would have made a difference if the content in the book would have been covered in a face-to-face session, or do you think there's still merit to it being in a book that you can use by yourself?

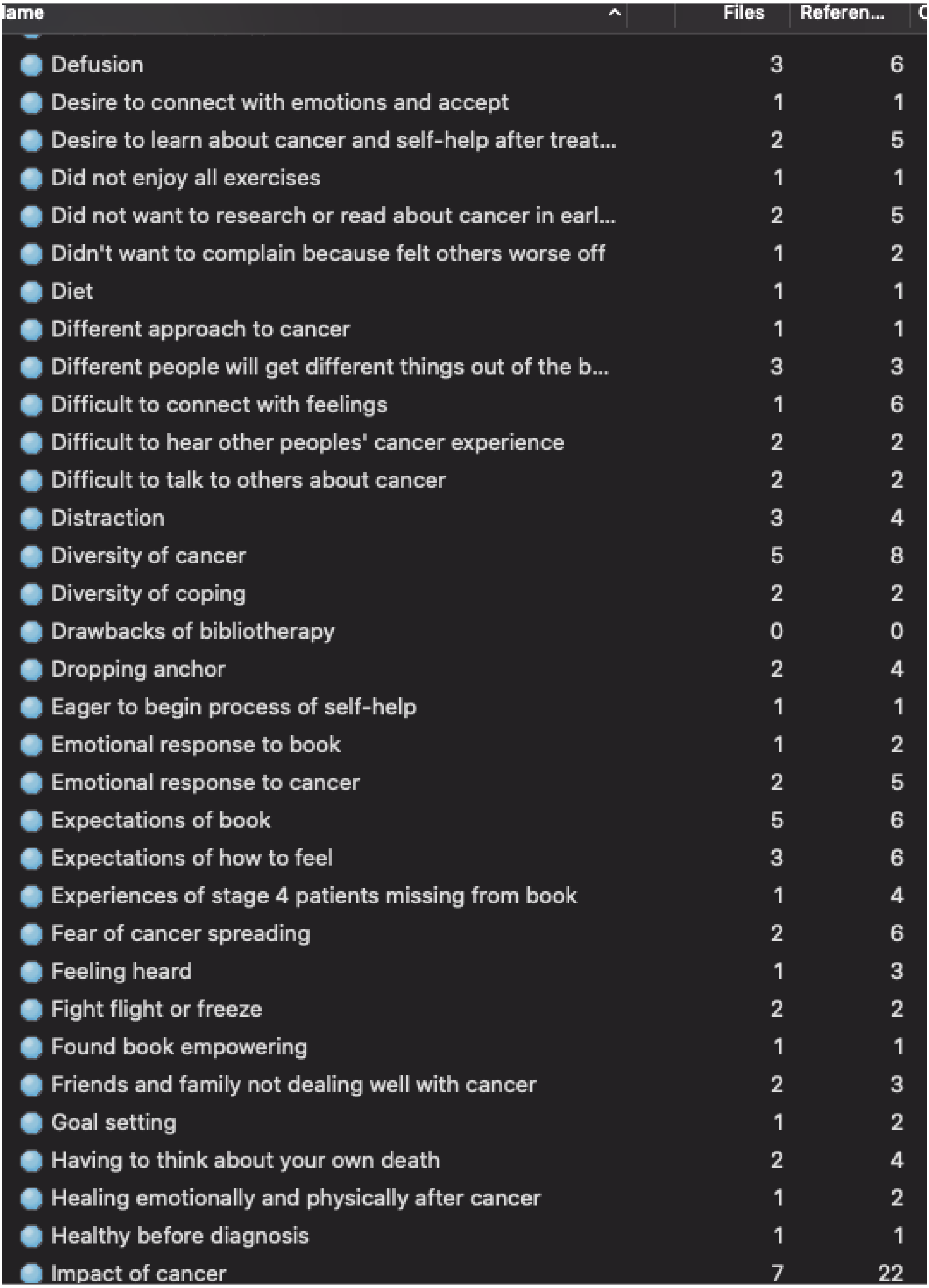
Respondent: I think possibly half and half. I think you get to a point where sometimes when you're ready, you'd probably like to talk to somebody face-to-face. I think like half and half would be quite good.

Interviewer: Perhaps somebody going through the content of the book with you, guiding you through the content of the book.

Respondent: Yeah.

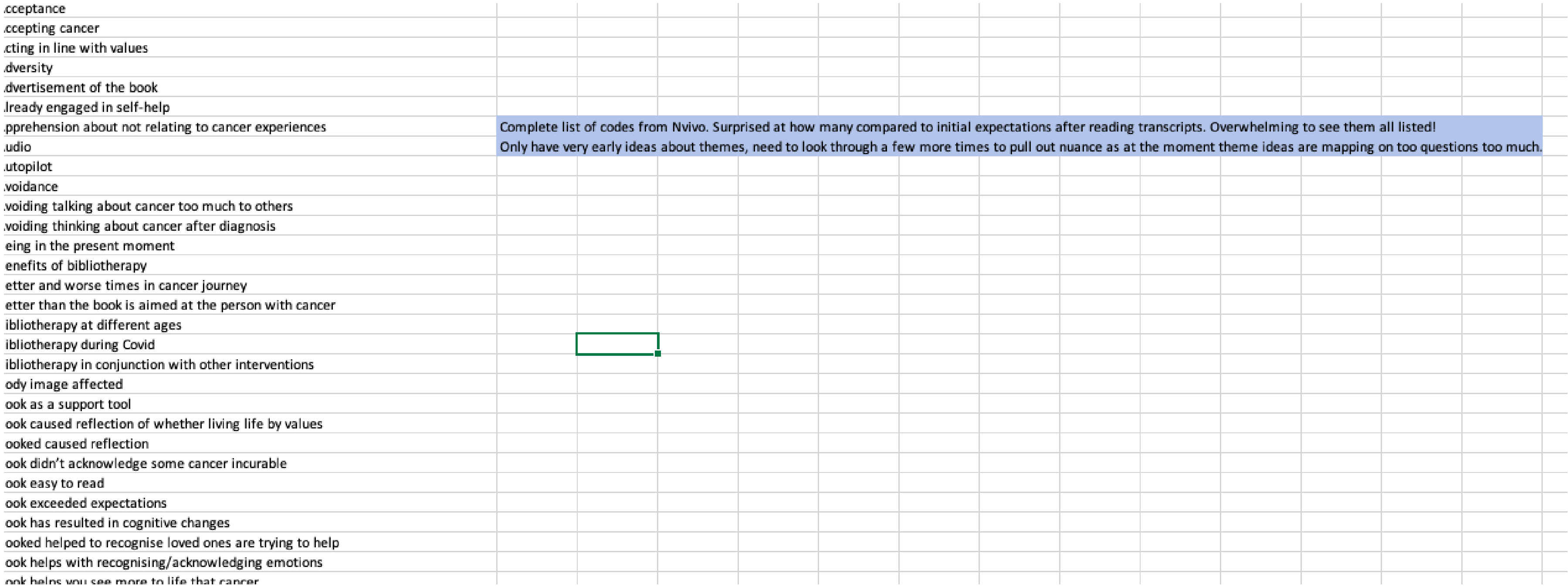
Interviewer: Have you noticed since using the book that you've made any changes based on the information in the book, or that you've noticed any differences within yourself perhaps in terms of how you've been thinking or feeling, lifestyle changes or anything like that?

Respondent: I always find it difficult to give myself time mentally, and I think that book has reassured me you should give yourself that time. I think it's helped me to focus a bit more about moving on with my life and accepting my diagnosis, and the little things that I could do that are there available to make the little things better. For me, I went back to that treatment for three years and I literally didn't go anywhere because I was so poorly. My husband said to me, 'Look, you've come out. Before you start rehabilitation, you need to start building your confidence up, perhaps going to a family member's house or a friend's house to see how you are in a crowd'. One of his family relatives, cousins, was getting married, and it was a really small wedding and they're all really lovely people. He said to me, 'I've been to weddings and birthdays and everything without you for the last three years. It would be nice if as a family we could go to this wedding. You like them, they're lovely people and it's really small. It will get



Name	Files	Referen...
Defusion	3	6
Desire to connect with emotions and accept	1	1
Desire to learn about cancer and self-help after treat...	2	5
Did not enjoy all exercises	1	1
Did not want to research or read about cancer in earl...	2	5
Didn't want to complain because felt others worse off	1	2
Diet	1	1
Different approach to cancer	1	1
Different people will get different things out of the b...	3	3
Difficult to connect with feelings	1	6
Difficult to hear other peoples' cancer experience	2	2
Difficult to talk to others about cancer	2	2
Distraction	3	4
Diversity of cancer	5	8
Diversity of coping	2	2
Drawbacks of bibliotherapy	0	0
Dropping anchor	2	4
Eager to begin process of self-help	1	1
Emotional response to book	1	2
Emotional response to cancer	2	5
Expectations of book	5	6
Expectations of how to feel	3	6
Experiences of stage 4 patients missing from book	1	4
Fear of cancer spreading	2	6
Feeling heard	1	3
Fight flight or freeze	2	2
Found book empowering	1	1
Friends and family not dealing well with cancer	2	3
Goal setting	1	2
Having to think about your own death	2	4
Healing emotionally and physically after cancer	1	2
Healthy before diagnosis	1	1
Impact of cancer	7	22

Appendix 13 - Themes



cceptance	
ccepting cancer	
cting in line with values	
dversity	
dvertisement of the book	
lready engaged in self-help	
pprehension about not relating to cancer experiences	Complete list of codes from Nvivo. Surprised at how many compared to initial expectations after reading transcripts. Overwhelming to see them all listed!
udio	Only have very early ideas about themes, need to look through a few more times to pull out nuance as at the moment theme ideas are mapping on too questions too much.
utopilot	
voidance	
voiding talking about cancer too much to others	
voiding thinking about cancer after diagnosis	
eing in the present moment	
enefits of bibliotherapy	
etter and worse times in cancer journey	
etter than the book is aimed at the person with cancer	
ibliotherapy at different ages	
ibliotherapy during Covid	
ibliotherapy in conjunction with other interventions	
ody image affected	
ook as a support tool	
ook caused reflection of whether living life by values	
ooked caused reflection	
ook didn’t acknowledge some cancer incurable	
ook easy to read	
ook exceeded expectations	
ook has resulted in cognitive changes	
ooked helped to recognise loved ones are trying to help	
ook helps with recognising/acknowledging emotions	
ook helps you see more to life that cancer	

Experience of being diagnosed with and living with cancer??	Bibliotherapy as method of delivery	Ideal time for intervention	
Cancer diagnosis	Can relate to different parts of book at different ti	Book would be helpful after diagnosis	
Cancer isn't 'over' just because you've finished treatment	Bibliotherapy in conjunction with other things	Book would be helpful around time of treatment	
Cancer treatment	Benefits of bibliotherapy	Book would be unhelpful after diagnosis	
Connecting with people who have had cancer	Bibliotherapy during Covid	Book would have been helpful earlier	
Coped through faith	Audio exercises	Can relate to different parts of book at different times	
Coping strategies	Book is interactive workbook	Might not want to read the book at a later stage as don't want to revisit what happened	
Dealt with cancer	Written exercises	Book relevant for people at all stages of cancer journey	
Didn't want to complain because felt others worse off	Flow of book	Book relevant for people in remission	
Side effects of treatment	Key messages	Desire to learn about cancer and self-help after treatment	
Sleep difficulties	Layout of book	Can relate to different parts of book at different times	
Previous experience of self-help	Book easy to use	Only begin processing after treatment	
Previous psychological support	Quotes		
Healthy before diagnosis	Target audience of the book		
Impact of cancer	Good that book is general to all cancer		
Fear of cancer spreading	Illustrations		
Mental health prior to cancer	Book particularly helpful if cancer first significant life event		
Symptoms of cancer	Book would be helpful for family and friends		
Telling others makes it real	Strategies in the book		
Loss of control	Title of book		
Lost sense of self	Eager to begin process of self-help		
Difficult to talk to others about cancer	Expectations of book		Started grouping themes and ideas
Having to think about your own death			Very superficial at the moment
Healing emotionaly and physically after cancer			
Others can't truly relate unless they've had cancer			
Did not want to research or read about cancer in early stages	ACT	How book used	
Diet	Acceptance	Can dip in and out of book	
Diversity of cacner	Autopilot	Reading strategy	
Diversity of coping	Avoidance	Revisited parts of book	
Emotional response to cancer	Being in the present moment	Used book differently as part of project	

Value of bibliotherapy	Timing is important	Resonating with cancer experiences	Tools of the book	ACT in action
Benefits of bibliotherapy	Book would be helpful after diagnosis	Relating to cancer experiences in book	Book is interactive workbook	Mindfulness
Can relate to different parts of book at different times	Book relevant for people at all stages of cancer journey	Feeling heard	Audio exercises	Dropping anchor
Revisited parts of book	Book relevant for people in remission	Quotes	Written exercises	Being in the present moment
Using the book again	Book would be unhelpful after diagnosis	Normalised cancer experience	Book causes reflection	Autopilot
Book easy to use	Only begin processing after treatment	Book validated cancer experiences	Metaphors	Values
Layout of book	Desire to learn about cancer and self-help after treatment	Recognising strategies in book already doing	Some exercises will work some won	Living a meaningful life with cancer
Can dip in and out of book	Book would be helpful around time of treatment		Some strategies wouldn't try	Committed action
Benefits of bibliotherapy	Book would have been helpful earlier		Parts of the book that felt less releva	Acceptance
Would recommend to others with cancer			Did not enjoy all exercises	Thought supression
			Different people will get different th	Avoidance
				Compassionate hand
				Defusion
				Observing self
				Book helps with recognising/acknowledging emotions
				Regaining control

Appendix 14

A 15-point checklist of criteria for good thematic analysis (reproduced from Braun & Clarke, 2006)

1. Transcription: The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'
2. Coding: Each data item has been given equal attention in the coding process
3. Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive
4. All relevant extracts for all each theme have been collated

5. Themes have been checked against each other and back to the original data set
6. Themes are internally coherent, consistent, and distinctive
7. Analysis: Data have been analysed – interpreted, made sense of - rather than just paraphrased or described
8. Analysis and data match each other – the extracts illustrate the analytic claims
9. Analysis tells a convincing and well-organised story about the data and topic
10. A good balance between analytic narrative and illustrative extracts is provided
11. Overall: Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly
12. Written report: The assumptions about, and specific approach to, thematic analysis are clearly explicated
13. There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent
14. The language and concepts used in the report are consistent with the epistemological position of the analysis
15. The researcher is positioned as active in the research process; themes do not just 'emerge'.