An idiographic approach to formulation for people living with advanced cancer

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Lay Summary

Advanced cancer is a disease that cannot be cured. However, people living with advanced cancer are a wide-ranging group. They vary in length of time left to live, and the impact of the disease on their mind and body differs from one person to the next. People living with advanced cancer face a lot of complex challenges in their daily lives, and this can be distressing. 'Psychosocial' interventions aim to help people with difficulties arising in their social world and from their thoughts, feelings and behaviours. This project is made up of two parts. The first part is a scoping review, which aimed to map and describe the kinds of psychosocial interventions that have been given to people with advanced cancer to help reduce their distress. The second part is an empirical study. This aimed to tailor an existing psychosocial model made for cancer in general (not just advanced cancer) so that it became specific to a group of people with advanced cancer.

Scoping Review

There has been a lot of research that has tried to find out what psychosocial interventions might be helpful in this area. The current scoping review aimed to map out what kinds of interventions had been tried, and what they had involved. The review also aimed to find out whether the interventions had been useful and what the quality of the research was like. Studies could be included in the review if they had any type of study design, were from any date, and if they aimed to reduce distress (for example low mood and anxiety). Overall, 5768 studies were found from four databases. After screening out duplicates and seeing which studies were relevant, there were 127 studies included in the review from a total of twenty-five countries.

Findings of the Scoping Review

The review found that studies mapped into eight types of intervention overall: existential (31% overall); cognitive behavioural therapy (CBT) and cognitive-behavioural based (17%); acceptance and commitment therapy (ACT) and mindfulness based (16%); creative (10%); couples-based (7%); combined approaches (7%); complementary and alternative medicines (6%); other (6%). Of these, existential interventions showed the most promise for helping people with advanced cancer, although there were some inconsistent results. Findings were mixed for CBT. Some promising early findings were seen in more recent types of interventions such as ACT and combined approaches (such as using ACT and CBT together). Overall, the quality of evidence was of moderate to high quality. However, most interventions came from small-scale studies, so findings can only be viewed as preliminary. More large-scale research is needed to gain more certainty about what kinds of intervention are most helpful. Also, 85% of the studies were from Western countries, so more work is needed to see if findings apply in other countries and cultures. The studies also had lots of differences in the way interventions were delivered and tested. As the advanced cancer experience varies so much between individuals, it is important for further work to look at exactly what works and for whom. One suggestion arising from the current review was that an increased focus on individuals (rather than applying ‘one fits all’ interventions to groups of people) would be timely. For example, an increased focus on qualitative research could be useful. Qualitative research can explore what people need by directly asking them about their experiences. In this way, deep knowledge can be gained about the experiences of individuals with advanced cancer, and this can help explain and inform experimental studies.

Empirical Study

Recent research looking at psychosocial interventions for advanced cancer have often developed manuals to guide therapy. A large study recently tested whether cognitive behavioural therapy (CBT) was helpful for depressed people with advanced cancer who were using Improved Access to Psychological Therapies (IAPT) services. The therapists used a specially created manual based on an important theoretical model of how people adjust to cancer in general, and the therapists were rated as having been competent. Surprisingly, the study found that the therapy was not helpful for depression. One of the reasons for this may have been because therapists did not apply the cancer model specifically for individual people (the manual may have been too broad to meet the complex needs of their clients). In individual psychological therapy, a thorough 'case formulation' (mapping out a client's difficulties and strengths through discussion) can indicate specific inroads for support and change. Recent research with people living with advanced cancer has been based on more generalised approaches that might not identify the most optimal ways to help, especially given the many differences in how advanced cancer presents from person to person. The current project held semi-structured interviews with five individuals living with advanced cancer, with questions based upon an established theoretical explanation about how people adjust to their disease. This was the same theoretical model used in the study mentioned earlier, which had not found any effects for CBT on depression. Interviews were recorded, transcribed, and then analysed.

Findings of the empirical study

Analysis found five categories emerging from the interview data, with twelve subcategories. These showed that the concept of time for people with advanced cancer felt multi-layered. They also spoke of feeling like they were holding several states of emotion (negative and positive) at the same time. Illness-related events from the past were having important impacts on their ways of coping or not coping in the present. Using formal guidelines for creating an 'individual case formulation' (ICF), diagrams were created to carefully map out each person's difficulties, coping and world. Ideas about how these elements might be linked, and potential inroads to intervene, were included. The categories showed the overall story for the sample, and the diagrams represented the individual experiences within this. When taken together, the categories and the diagrams helped to show where the original cancer model could be made specific for people living with advanced cancer. A diagram was created to demonstrate this. This diagram therefore provides a practical tool grounded in detailed individual experiences and can be taken forward into research and clinical contexts. It offers a formal process to identify meaningful ways to intervene and meet the complex needs of people living with advanced cancer. The current project demonstrates the value in returning to the unique individual person as a source of evidence.

Chapter 1: Scoping Review

Interventions for treating psychosocial distress in adults with cancer not amenable to cure: A scoping review of the quantitative and qualitative evidence across all types of settings

Abstract

People living with advanced cancer face significant impacts from psychosocial distress. The recognition and provision of support for meeting psychosocial needs has been recommended by professional bodies within both the United Kingdom and internationally. This scoping review aimed to chart the volume and characteristics of psychosocial interventions that have been applied in this complex and heterogenous cancer sub-population, to provide a useful overview of a broad evidence base. A systematic database search was conducted in November 2021 with broad search criteria, unlimited to date or geography, and including both qualitative and quantitative sources across all types of setting. The search was restricted to English-language studies where the sample included at least 50% adults with advanced cancer. One hundred and twenty-seven sources met inclusion criteria. A brief quality assessment of included sources was applied using a tool suitable for assessing all types of study design. The review found that sources clustered onto intervention types, with eight cluster categories arising. Sources were discussed according to cluster, including summaries of quality. Heterogeneity was demonstrated across several domains including context, duration and delivery of interventions. Sources were largely homogenous in terms of being mostly Western, representing White ethnicity and weighted towards female gender. Most studies looked at samples with mixed cancer types, with studies focusing on single cancer types being predominantly focused on breast and lung cancer. Overall quality of studies across all design types was rated as moderate to high. Exploration of which types of intervention may be effective, and at which dose and mode of delivery, will be an ongoing endeavour in the literature. Widening the geographical application, and developing cultural adaptations for psychosocial interventions, is needed. Conclusions drawn include the recommendation for undertaking an umbrella review of systematic reviews, and a focus on increasing the volume of qualitative explorations linked to interventions, to gain deeper knowledge about the needs of this specific cancer population. Studies which incorporate feedback loops between empirical data and implementation at the level of clinics will be useful in building increased knowledge about the needs of this population.

Introduction

The context for a new scoping review

Advanced cancer is defined as an incurable disease, and the advanced cancer population is heterogenous and complex. The term includes people with varying stages of disease and prognoses, encompassing cancer that has metastasised (spread to distant body sites from the site of origin), cancer that has recurred and is deemed incurable, people living with advanced cancer as a chronic illness (Schmidt, 2016), people whose cancer is treatment resistant, and those who have reached palliative and end of life stages. Psychosocial distress can be defined as an unpleasant emotional experience that arises within psychological (cognitive, behavioural and emotional), social or spiritual domains and which impacts upon coping capacity (Holland & Bultz., 2007). The terms quality of life and wellbeing can be used to describe and measure aspects of distress, to assess the degree to which a person experiences life satisfaction and their ability to function in their daily lives.

People living with an advanced cancer diagnosis experience an array of threats to both their physical and mental wellbeing. Distress reactions may fluctuate over the course of disease, and within the context of receiving (or indeed not receiving) aggressive and invasive medical treatment. Depression has been found to be particularly prevalent in advanced cancer, affecting 15-30% of those within a palliative care setting (Hotopf et al., 2001), with a meta-analysis finding a pooled prevalence of 16.5% (Mitchell et al., 2011). Furthermore, depression has been found to be an independent predictor of poorer survival in those with advanced cancer (Lloyd-Williams et al., 2009). Levels of anxiety and depression may be related to cancer type (Batty et al., 2017) with varying prognostic factors, body image impacts, degrees of pain and neuropsychiatric effects of some tumours being associated with different cancer morphologies and treatments (Smith, 2015).

The UK National Institute for Health and Care Excellence (NICE) offers guidelines that those with advanced cancer are routinely screened and given treatment for depression (NICE, 2004), and international guidelines recommend that Early Palliative Care (EPC) and active treatment should be provided simultaneously (Ferrell et al., 2017). Such early palliative support should include multidisciplinary attention to the complex interaction between physical, emotional and spiritual distress. Given that experiencing at least some distress would be expected and viewed as normal for people with severe and life-threatening illness, it may be that strains on patient coping mechanisms may go unnoticed for advanced cancer at any phase. Those with advanced cancer who have not yet reached a palliative or end of life phase, and who are therefore not under the collaborative care of a palliative team, may be at particular risk of their psychosocial needs being left unmet. Given the increasing incidence and mortality of cancer globally (World Health Organisation, 2020), addressing the psychosocial facets of living with advanced cancer deserves a prominent focus.

A large literature for psychosocial interventions in advanced cancer exists, as is evident in the review base. The latter has been specific in research questions asked. Systematic reviews have focused on specific areas, particularly cancer type and therapy type, and have predominantly focused on literature arising from randomised controlled trials (RCTs). Metastatic breast cancer has been a dominant focus in the review base, with an updated review unable to draw conclusions across ten included studies of cognitive-behavioural and supportive-expressive group therapies as they differed in design, treatment type and outcome measures used (Mustafa et al., 2013). An earlier review, not limited to metastatic breast cancer, also found heterogeneity in the evidence base across a range of specific psychological therapies (Akechi et al., 2008). Despite findings of heterogeneity and methodological limitations, psychotherapy including CBT and collaborative care approaches have been found to be effective in reviews focusing on the treatment of depression in advanced cancer (Akechi et al., 2008; Price & Hotopf., 2009; M.Li et al., 2017; Okuyama et al, 2017). A review focusing on dignity therapy (DT) in life-threatening diseases including advanced cancer (Martínez et al., 2017) concluded that findings on efficacy for patients were inconsistent perhaps due to samples with low distress receiving less benefit. Similarly, a dignity therapy review focusing specifically on advanced cancer found inconsistent results (J. Xiao et al, 2019) with some facets of distress finding benefit (dignity-related distress and a domain of social support) with no efficacy found on other aspects of distress (anxiety and depression). Yet a systematic review looking at meaning-based interventions within advanced cancer delivered through RCTs suggested that these held particular benefit for this population (Teo et al., 2019). This raises interesting comparisons with the inconsistent findings on dignity therapy interventions as meaning-based and dignity-based approaches both draw upon existential tenets of finding meaning in life whilst facing inevitable death. In recent years, interest in the potential for acceptance-based approaches led to a review of six studies (H.Li et al., 2021) which concluded that acceptance and commitment therapy (ACT) held promise in improving a range of both physical and psychological outcomes in people with advanced cancer. In terms of psychosocial interventions that move beyond a specific psychotherapy, a recent scoping review on peer support interventions in advanced cancer concluded that these were often poorly defined, weighted towards consideration of breast cancer, and lacked tailoring to need (Walshe & Roberts, 2018). In the area of complementary and alternative medicines (CAMs), a recent systematic review and thematic synthesis of qualitative evidence in palliative care settings suggested that reflexology and aromatherapy are helpful in improving wellbeing in advanced cancer (Armstrong et al., 2019). However, a systematic review of randomised controlled trials found low quality and heterogenous evidence for aromatherapy, massage and reflexology in this population (Candy et al., 2020).

The inconclusive findings from review literature suggest that the most useful ways to support the specific advanced cancer population is still a developing field. Guidance from professional bodies has clearly recognised the importance of attempting to meet the psychosocial needs of this population. The review literature indicates that differences in intervention types, study settings (including whether an intervention is targeted at a palliative or pre-palliative phase of disease), choice of constructs to be measured, and outcomes measures used, has resulted in a wide-ranging and complex evidence base that can be difficult to interpret. This may leave healthcare providers unsure in deciding what psychosocial approaches are most useful.

Rationale for a scoping review approach

A wider review approach would be timely and offer a useful means to gather and clarify the volume and characteristics of interventions that have been applied in this field. Such an undertaking would provide an overview in terms of the evidence base, and support thinking about useful future research and review directions.

Gaining a clarifying perspective on the numerous interventions applied in advanced cancer requires wide questions to be asked. Scoping reviews enable broadness within research questions and examining the extent and features within a body of research are common and advocated reasons for choosing to conduct scoping reviews, rather than systematic reviews (Arksey & O'Malley, 2005; Peters et al., 2015; Munn et al., 2018). Scoping reviews allow sources to be drawn together from heterogenous or disparate evidence bases (regardless of their individual quality), and this exercise can result in gaps in the literature base being identified or might indicate useful questions for future systematic reviews (Arksey & O'Malley, 2005). Frameworks and guidelines for undertaking scoping reviews have undergone iterative revision, with the Arksey & O'Malley (2005) framework emerging as the most consistently used (Cacchione et al., 2016). The Joanna Briggs Institute (JBI) drew upon both this framework, and subsequent improvements that had been added (Levac et al., 2010), to create the JBI methodology for guiding the writing of scoping reviews. This review was conducted in accordance with JBI scoping review methodology (Peters et al., 2020).

Objectives

The overarching objective of this scoping review was to provide a comprehensive overview of the volume (extent), types and features of interventions used to treat psychosocial distress in adults living with advanced cancer not amenable to cure. A decision was made to additionally include an element of broad quality assessment within the research questions. Although assessment of methodological quality or bias is not usually performed within a scoping review (Khalil et al., 2016; Peters et al., 2015), an added level of quality assessment may enable stronger recommendations for areas of future research focus. A preliminary database search of the Cochrane Database of Systematic Reviews (CDSR), Figshare, the Open Science Framework (OSF) and JBI Evidence Synthesis was conducted, and no current or underway systematic or scoping reviews addressing this review objective were identified at point of commencement. One systematic review was identified which addressed a similar question (Teo et al., 2019) but this differed from the current review in several ways: it was limited to randomised controlled trials; looked at quantitative evidence only; was date-limited to the range 2007-2018; and excluded complementary and alternative medicine interventions that might have targeted a psychosocial component. An earlier systematic review was also limited to RCTs (Uitterhoeve et al., 2004). A paper focusing on recent RCTs offered a useful narrative overview of psychosocial interventions in advanced cancer, delineating these in terms of which showed most usefulness across the disease trajectory (Rodin et al., 2020). In aiming for a broad perspective, the current review was not limited by date or geography. All types of design (qualitative and quantitative) were considered for inclusion, from all settings and cancer types, and sources could include interventions arising from complementary and alternative medicine where a psychosocial component was measured.

The primary question for the current review was as follows:

1. What kinds of interventions have been used for treating psychosocial distress in adults with advanced cancer not amenable to cure?

Additionally, the review aimed to consider the following secondary questions:

2. Have intervention types clustered onto specific types of cancer?
3. Have interventions clustered onto specific types of study design?
4. What constructs have been targeted by interventions?
5. What is the broad methodological quality of studies in this area?

Method

Protocol and registration

A scoping review protocol was created according to JBI guidelines (Peters et al., 2020), and registered with Figshare (https://doi.org/10.6084/m9.figshare.21065665.v1).

Eligibility criteria

Eligibility criteria for source inclusion were determined based on the JBI framework of participants, concept and context (Peters et al., 2020).

Participants

Participants were defined as adults aged 18 years and over, of any gender or ethnicity, who were living with advanced cancer not amenable to cure. This equated usually to cancers at disease stage IV. Advanced cancer was further defined to include cancers known to have a poor prognosis (disease stage III lung, pancreatic and gynaecological tumours, and high-grade brain tumours). The American Joint Committee on Cancer (AJCC) Staging Manual (Edge et al., 2010) and the TNM Classification of Malignant Tumours (Sobin et al., 2011) were used to assess sources for inclusion where necessary.

Concepts

The concepts being scoped were psychosocial distress and interventions given to treat this distress. Psychosocial distress was defined for the purposes of this review as distress that affects a person's psychological (cognitive, behavioural and emotional), social or spiritual health (Holland & Bultz., 2007) and threatens their subjective sense of wellbeing or quality of life. Therefore, the concept of psychosocial distress could encapsulate target constructs such as wellbeing, quality of life, anxiety, depression, mood, stress, physical or mental health symptom distress, spiritual, existential and death distress. Any level of psychosocial distress was included, whether at non-clinical or clinical thresholds, given that distress in people with cancer is posited to exist along a continuum (Vitek et al., 2007).

Interventions were defined as a treatment given with the primary aim of creating behavioural or psychological change. Complementary and alternative medicine (CAMs) interventions were considered for inclusion if they had reduction of psychosocial distress as a primary target. Excluded from the definition of psychosocial intervention for the purposes of this review were physiotherapy (exercise) and nutritional (diet) interventions that had no primary psychosocial treatment aim, medical (pharmacological) interventions, and interventions with a primary reliance on physiological rather than psychological outcome measures. Sources with a main aim of looking at whether interventions extend survival were excluded, as were studies with a main aim of assessing the cost-effectiveness or cost utility of interventions.

Context

The context of this review was defined as any geographical location and any patient setting. This therefore had potential to include hospice, palliative care, hospital, other clinical centres and community settings, across all inpatient or outpatient and home-based forms of care. The setting was taken to represent the place from which the sample was drawn.

Types of sources

Sources were not limited to date or geography. For a source to be included, the sample needed to contain at least 50% people with advanced cancer. Both quantitative and qualitative sources of any study design were considered for inclusion. This could include randomised controlled trials; non-randomised controlled trials; single-arm studies; analytical observation studies including prospective and retrospective cohort studies; case-control studies; descriptive observational studies including case series and individual case studies; qualitative studies where an intervention has taken place and the index case aimed to benefit from the intervention was a person or persons with cancer. Feasibility and acceptability studies were included even if efficacy or effectiveness were not the primary focus, so long as preliminary measurement of psychosocial distress was performed and reported.

Systematic reviews, scoping reviews and study protocols were excluded as sources. Due to time limitations, grey literature (including unpublished theses) was excluded, reference lists were not searched, and citation chaining was not used. Non-English language sources were excluded, for reasons of practicality and time.

Databases

An initial limited search of PsychINFO and PubMed was undertaken to identify existing literature on the topic. The text words contained in the titles and abstracts of relevant studies, and the descriptive keywords used, were used to develop a full search strategy for PsychINFO, PubMed, Web of Science and CINAHL databases. A decision was made not to include further searches from the Cochrane Central Register of Controlled Trials (CENTRAL) or EMBASE, as it was not anticipated that these would give rise to sources not also appearing in the more specifically psychological databases. An initial full search was run in November 2021, with a further final search in January 2022.

Search strategy

The search strategy, including all identified keywords and index terms, was adapted for each of the four databases (PsychINFO, PubMed, Web of Science and CINAHL). No restrictions were made for date of publication or country. All searches specified filtering to the English language and to adults. Where no filter for adults was available this was addressed by adding a set of search terms for adults with the Boolean operator AND to the search, or by ensuring that sources unrelated to adults were excluded as part of the screening process. The search comprised of four search strings run as separate searches with individual terms combined using the operator OR, and then all four search strings were combined in a fifth search using the operator AND. Search strings were comprised of terms related to four groupings: specific psychological constructs or diagnosis of distress; specific cancer types; specific cancer stages; specific intervention types. Where available, MESH terms and free set texts were combined with the Boolean operator OR for specific cancer types. A full search strategy, with information as to limits used, is provided for PsychINFO (Appendix A).

Selection of sources of evidence

All identified source citations from the database searches were collated and uploaded into the RefWorks (ProQuest) reference management system, and duplicates were removed. The source citations were then uploaded into the Rayyan screening platform (Ouzzani et al., 2016) for abstract screening. Titles and abstracts were screened by the reviewer for assessment against the inclusion criteria. Where it was unclear from the title and abstract whether the source would meet criteria, then that source was retained for further consideration. Potentially relevant sources were next retrieved in full and imported into RefWorks (ProQuest). Four additional texts were identified for inclusion via handsearching. Unavailable full texts were requested from authors. Full texts were assessed in detail against the inclusion criteria by the reviewer, with 20% of full texts also checked by a second reviewer. Agreement for selection of studies at full-text review was 84%. Disagreements were resolved by discussion, and full texts for inclusion were finalised.

Data charting process

Data from full texts was extracted by the reviewer using an electronic spreadsheet designed to ensure standardisation of data. This data charting tool was piloted on two full text sources by the reviewer to check that data items were captured adequately, and additional spreadsheet fields were added when need became apparent during data extraction. It is recognised and acceptable to refine the charting tool at review stage for scoping reviews, with charting being an iterative process whereby the charting tool is updated to be most useful (Peters et al., 2020).

Data items

Thirty-one data items were extracted against each source. Key charted data included: source descriptions (author, date, country, aims and key findings), specific details relating to participants (sample size, mean age and/or age range, predominant gender and ethnicity percentages, cancer type, whether lower stage or non-cancer diagnoses had been included), data relating to concept (type of distress targeted, main outcome measures used, intervention type, number of sessions and whether interventions were group-based or individually delivered, description of intervention, who delivered the intervention); context (description of study setting from which sample was drawn) and type of study design. Where sources deriving from the same study were published separately, they were analysed as separate sources. The reviewer assigned an intervention type to a source where this was not explicitly stated. A second reviewer checked 20% of the charted data for accuracy, with agreement being 90%. Disagreements were resolved through discussion and any necessary changes were made to the data extraction.

Quality assessment of individual sources of evidence

A broad overview of the methodological quality and potential sources of bias in sources was undertaken. The rationale for this was to further inform the synthesis of the evidence base in the field of advanced cancer and to aid recommendations for future studies. The Mixed Methods Appraisal Tool (MMAT, Pluye & Hong., 2014) was chosen as it enables consideration of quantitative, qualitative, and mixed designs. MMAT criteria was rated for reliability and efficiency during development (Pace et al., 2012) and was found to have moderate to high interrater agreement. The most recent version of the MMAT tool was used (Hong et al., 2018).

All MMAT items were included for the purposes of quality assessment in this review. For quantitative sources, assessment considered aspects including attrition, confounds and study adherence. The MMAT has no absolute and standard threshold for what constitutes acceptable outcome data rates or attrition rates for sources of evidence. Therefore, a decision was made to uniformly apply a required value of 80% for outcome data completion, based on the lower suggested thresholds in the literature suggested in the MMAT guidance (Hong et al., 2018). For attrition (drop out) rates, a decision was made to apply an acceptable attrition rate of 20% during the intervention period, based on the mid-range values suggested in the MMAT guidance. For qualitative sources, assessment considered aspects including appropriateness of qualitative approach used, whether findings are adequately derived from the data and whether findings are sufficiently substantiated by the data (such as use of quotes). For mixed study designs, assessment considered aspects including whether there is adequate rationale for using a mixed method, whether the mixed components are effectively integrated to answer the research question, and whether divergences between quantitative and qualitative components are addressed.

Quality assessment data was extracted by the reviewer using a tailored electronic spreadsheet. Each MMAT item was given a column, and there were five data items per study design type. A decision was made to assign scores by summating the five columns with a possible score range of 0-100%. These percentages were assigned ratings of very low (0-20%), low (40%), moderate (60%), high (80%, or very high (100%). MMAT guidance states that for mixed studies (which require separate scorings for quantitative and qualitative components as well as an overall mixed design score) the total MMAT score cannot be higher than the lowest scoring design section. In the recent version of the MMAT it is discouraged to provide overall scores only (Hong et al., 2018), and therefore in the data synthesis for this review, quality assessment was also summarised narratively according to type of study design. This summarisation took a broad approach within the context of a scoping review.

10% of the quality assessment data was checked by a second reviewer, with agreement of accuracy being 97.64%. Any differences were resolved through discussion and any necessary changes were made to the data extraction.

Synthesis of results

Charted data was represented in diagrammatic form to provide an overall visual summary of key findings relating to the review question and objectives. Included studies were listed in tabular format. Findings were summarised using narrative synthesis according to type of intervention. Brief narrative summaries of the quality of study designs within intervention types, and for the body of evidence overall, were provided.

Results

Selection of sources of evidence

Initial database searches identified 5768 sources. Handsearching identified four additional sources. Following duplicate removal 3836 source titles and abstracts were screened for eligibility, and 3485 sources were excluded. At full text retrieval stage, 351 full texts were assessed for eligibility, with 18 of these being unobtainable or having no response from authors, and 224 full texts were excluded. One hundred and twenty-seven sources were included in the scoping review. A PRISMA-ScR flow diagram documents the study selection process and reasons for source exclusion (Figure 1) as per scoping review reporting guidelines (Tricco et al., 2018).

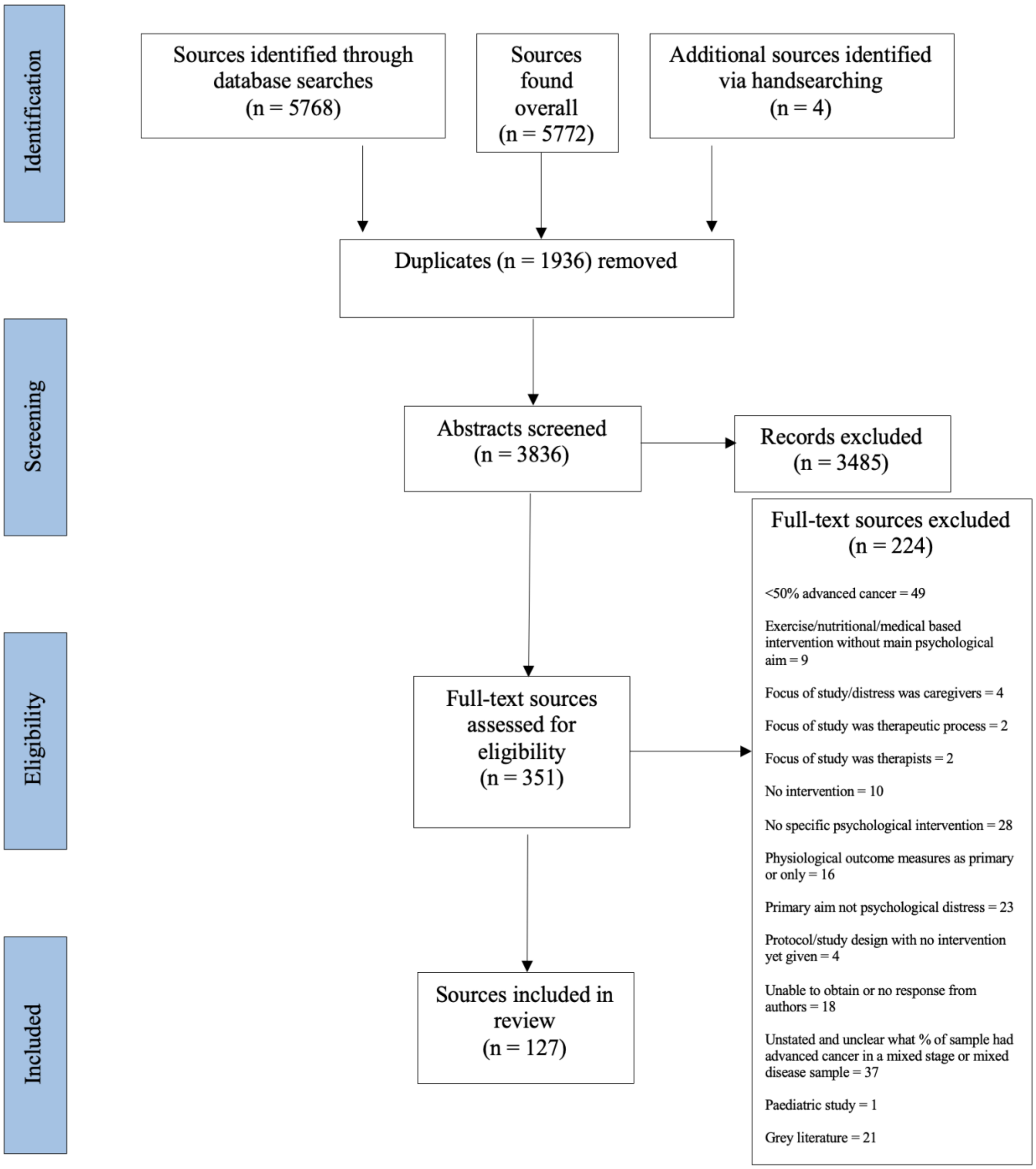


Figure 1: PRISMA-ScR flow diagram showing search results, source selection and inclusion process

Overview of source demographics

Sources covered a date range from 1991 to 2021. A graph shows the counts of studies over this period and demonstrates a trend for increased interest in this area across the years (Figure 2). Sample sizes ranged from one to 8333 (with 98% of studies falling within a range of 1-326 participants and two studies having 952 and 8333 participants respectively). Sources came from a total of twenty-five countries, with 85% from Western nations. The highest number of sources were from the USA (35% of sources) and Europe (31%). Only three sources spanned more than one country, and of these two were entirely Western, with the third spanning the USA and Singapore. A graph shows counts of studies per country (Figure 3).

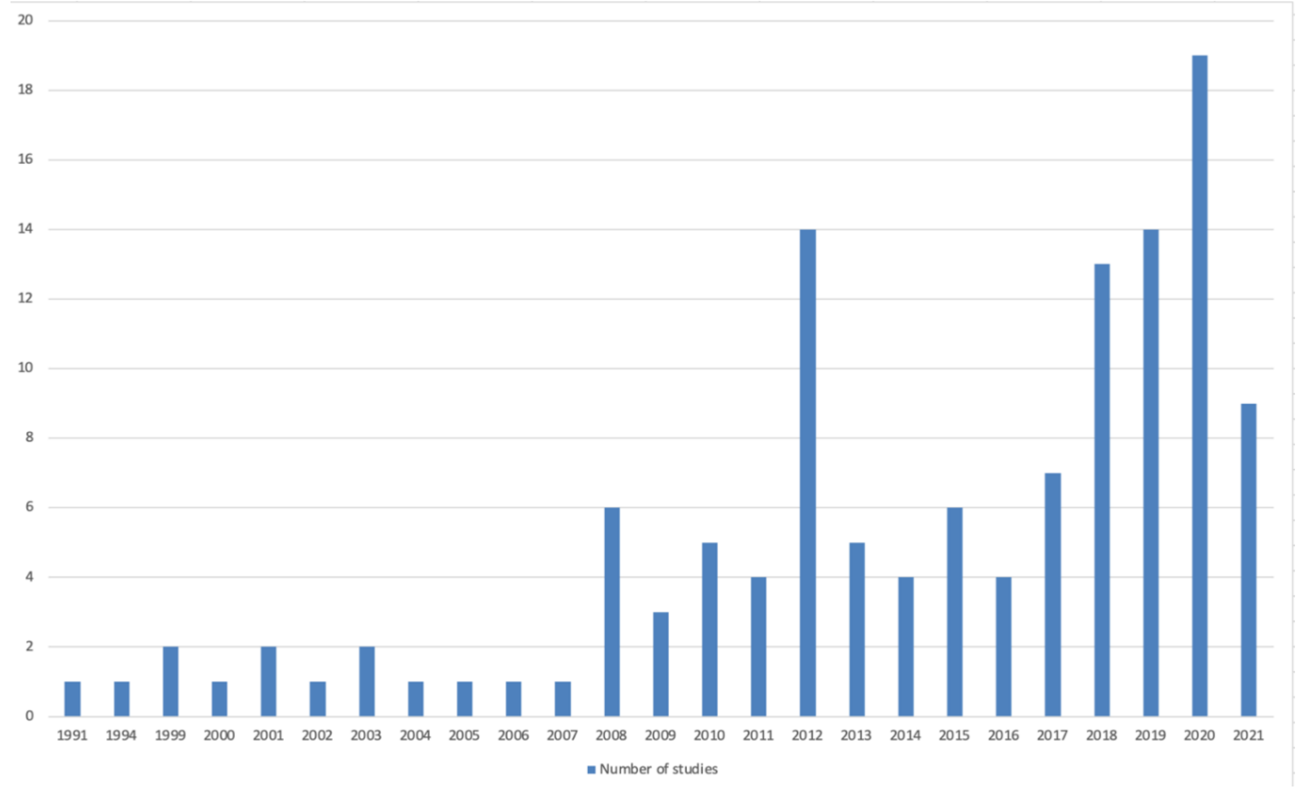


Figure 2: Sources counted by year

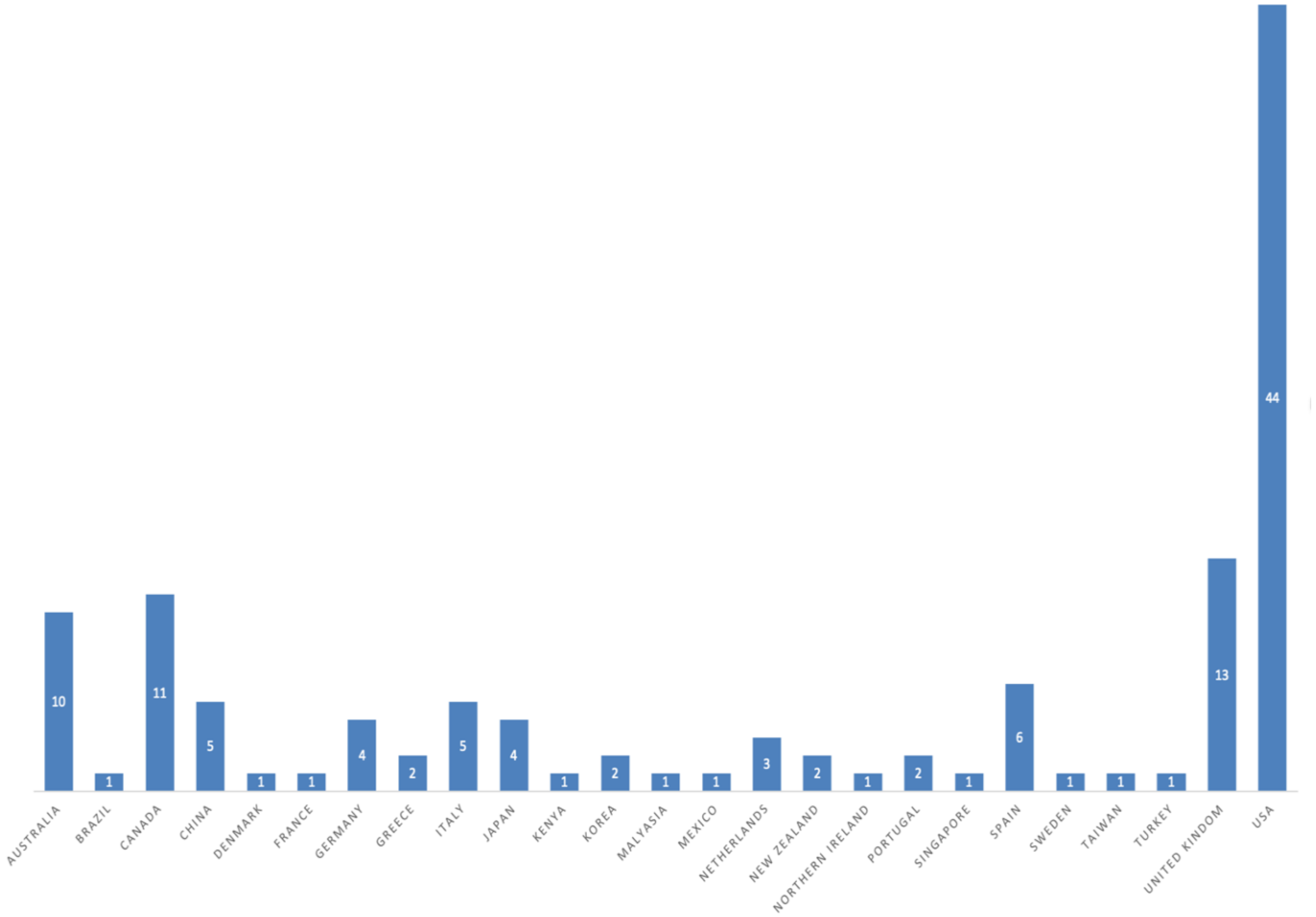


Figure 3: Sources identified per country

An overview diagram chart (Figure 4) graphically illustrates key extracted characteristics of included sources of evidence, shows intervention clusters that emerged from charted data, and states overall quality assessment ratings across all sources. A summary of MMAT quality scores assigned per type of study design appears in Table 1 below.

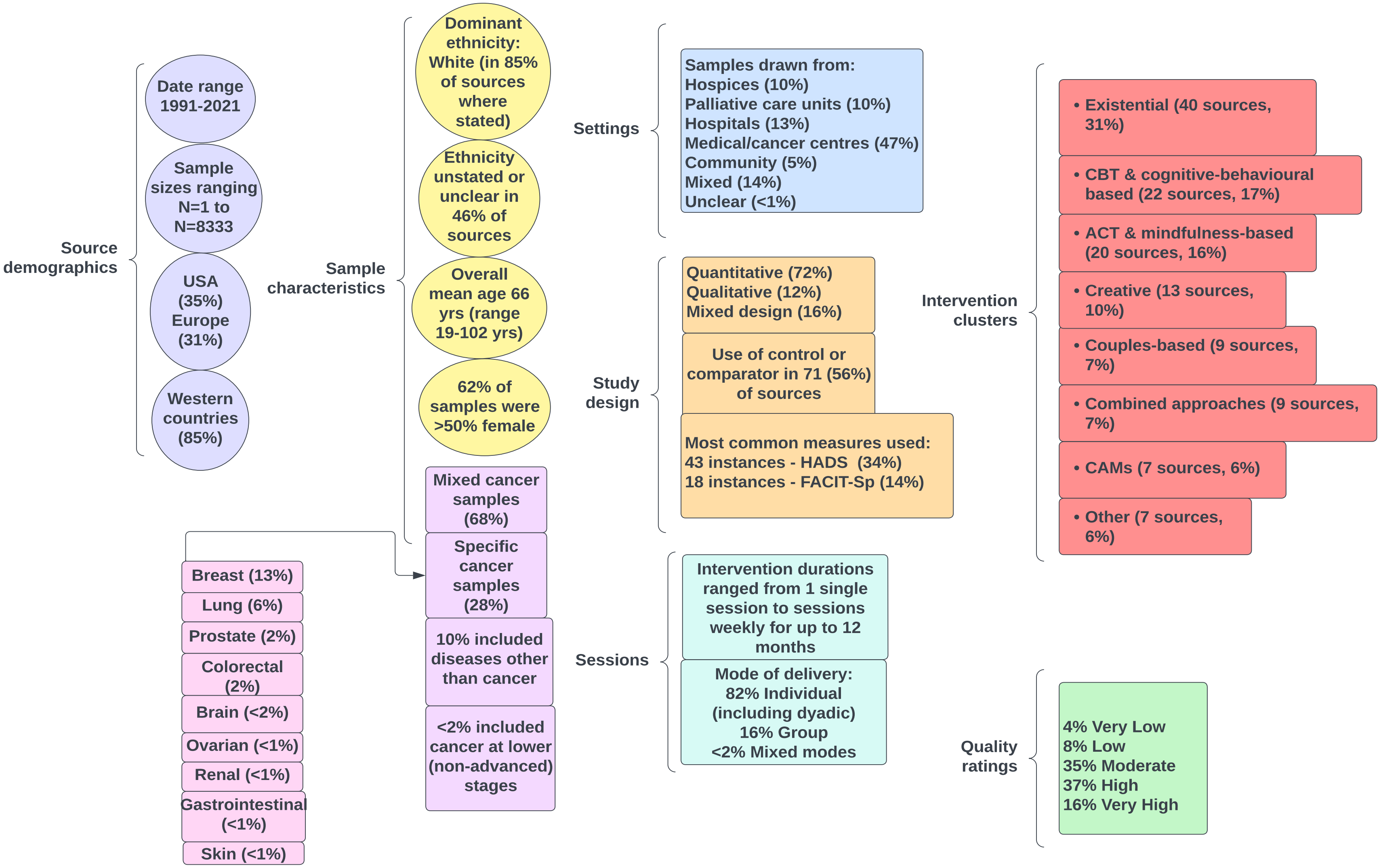


Figure 4: An overview of key characteristics of evidence, intervention clusters and overall quality ratings across sources

Note. ACT, acceptance and commitment therapy; CBT, cognitive behavioural therapy; CAMs, complementary and alternative medicines

Table 1: MMAT Quality scores assigned per type of study design, across all sources

Design type	Quality score assigned via MMAT					Total designs
	Very Low	**Low**	**Moderate**	**High**	**Very High**	
Randomised controlled trials	3	7	23	23	4	60
Non-randomised controlled trials	-	-	-	2	1	3
Single-arm studies	-	1	10	14	-	25
Single-case experimental designs	-	-	-	1	1	2
Mixed designs	2	2	11	4	2	21
Case reports with clear research aims	-	-	-	2	2	4
Qualitative designs	-	-	-	1	11	12
Total score count	5	10	44	47	21	*n* = 127

Overview of characteristics of samples

Across samples and where stated, participants ranged in age from 19 to 102 ($m = 66.04$), with 62% of samples having females as the dominant gender. The dominant ethnicity was White in 85% of sources where stated, with ethnicity being unstated or unclear in 46% of sources. Most sources included people with mixed cancer types (68%), with specific cancers the focus in 28% of sources. Type of cancer was unstated in 4% of sources. Of specific cancers, the predominant sites were breast (13% of sources) and lung (6% of sources). Only 10% of sources included diseases other than cancer, with percentages of other diseases ranging from 5-41% within samples. Less than 2% of sources included cancer at non-advanced stages.

Overview of settings

Study sources described samples being drawn from the following settings: hospices (10%); palliative care units (10%); hospitals (13%); medical and cancer centres (47%); community (5%); mixed settings (14%). Study settings were unclear in less than 1% of sources.

Overview of study designs

Ninety-one sources (72%) used a quantitative approach, including sixty randomised controlled trials, three non-randomised controlled trials, twenty-five single arm studies, two multiple baseline single-case experimental designs, and one single case study that used quantitative measures. Quantitative source sample sizes ranged from one to 8333. Within this, twelve quantitative studies had dyadic samples ranging from six to 476 dyads. Fifteen (12%) sources were purely qualitative in approach, which included three case reports. Five sources used thematic analysis, three used content analysis, three (all case reports) used a descriptive approach, one used framework analysis, one used Grounded Theory, one used a hermeneutic approach, and one specified using an immersion-crystallisation approach. Qualitative sample sizes ranged from three to 26, with one study with a sample of 13 dyads. Twenty-one sources (16%) were of mixed design, using both quantitative and qualitative methods. Mixed design source sample sizes ranged from ten to 109, including one study with a sample of six dyads. Overall, 56% of sources included a comparator or control group.

Overview of constructs and outcome measures

Target constructs of psychological distress were found to be predominantly: dignity-related distress (including death and existential distress); spiritual aspects of distress; depression; anxiety; wellbeing; quality of life. The most used outcome measures were the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) which was used in 43 instances, and the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being scale (FACIT-Sp-12; Peterman et al., 2002) which was used in 18 instances.

Overview of interventions

A range of clinicians and non-clinicians delivered the interventions, with nine categories arising. In order of predominance, these were: psychological professions and creative (such as music and art) therapists (61 sources, 48%); mixed professions (18 sources, 14%); nurses (11 sources, 9%); self-administered by participants (nine sources, 7%); medical doctors (seven sources, 5%); complementary and alternative therapists (five sources, 4%); social workers (three sources, 2%); research assistants (two sources, <2%); peer mentors (one source, <1%). Who delivered an intervention was unclear or unstated in ten (8%) sources.

Session numbers and durations ranged from a single session to sessions offered weekly for up to twelve months. Individual sessions (including individual sessions focusing on dyads) were the main mode of delivery in 82% of interventions. Group sessions accounted for 16% of mode of delivery. Less than 2% of interventions used a mix of individual and group delivery.

Eight intervention clusters arose from the sources. In order of cluster size these were: existential (forty sources, 31% overall); CBT and cognitive-behavioural based (twenty-two sources, 17%); ACT and mindfulness based (twenty sources, 16%); creative (thirteen sources, 10%); couples-based (nine sources, 7%); combined approaches (nine sources, 7%); complementary and alternative medicines (seven sources, 6%); other (seven sources, 6%).

Results of individual sources of evidence (clusters)

Individual sources of evidence are discussed according to intervention cluster assigned. Intervention content and key findings are described. Narrative summaries of study quality are provided for each separate cluster. Included sources are listed in three separate tables to facilitate the narrative description (Tables 2-4) and are grouped according to assigned cluster, in order of date published. Due to the high number of included sources a decision was made to assign numerical identifiers to each source in the table, and these are used to refer to sources within the narrative descriptions. An overall narrative summary of intervention types, findings and quality is provided in the Discussion section.

Existential cluster

Forty sources were assigned as existential intervention types (numbers 1-40 in Table 2). Existential sources dated between 2000-2021 and came from 13 countries including five from non-Western countries (three from China, one from Japan and one from Kenya). Existential interventions predominantly defined dignity-related distress, existential distress, spiritual wellbeing, depression, anxiety and quality of life as target constructs. Interventions were delivered by the psychology profession, nurses and medical doctors, and were delivered across a range of inpatient bedsides, residential settings and at outpatient appointments. Samples contained predominantly mixed cancer types. Existential sources were sub-clustered into the following therapy types: dignity-based (13 sources), meaning-based (10 sources), life review (8 sources), supportive-expressive (7 sources); narrative (2 sources). Sources are discussed according to these sub-clusters.

Dignity-based

Dignity-based interventions (1-13 in Table 2) all followed the protocol of Dignity Therapy by Chochinov and colleagues described in two included sources [1-2]. This model entails using a theme-based interview guide to elicit a tailored reflection on an individual's life as they approach their death, including hopes and wishes for loved ones and any advice they might wish to impart to them. The therapeutic interview is transcribed, read through with the patient and amended if needed, and presented in the form of a generativity document for the person to share with whomever they wish. All delivery was in person. The therapy model is brief, and all but one source applied two sessions over two weeks. One study extended the usual format to three sessions 2-3 weeks apart and added a goal development aspect via creating a life plan document [8]. Some sources described choosing to give patients the interview framework in advance of the therapeutic interview, to allow them to reflect on what they wished to talk about in advance [3] [9].

Findings varied as to whether effects were sustained at post-intervention follow up points. Across studies, promising effects (either significant or approaching significance) were found at immediate post-intervention for the following measured constructs: suffering and depressed mood [1]; hope [3]; depressive symptoms and anxiety [5] [7]; dignity-related distress [10]; maintained peace [11]; symptom distress [12]. A lack of significant findings was observed for the following measured constructs: dignity-related distress [2] [9]; hopelessness, desire for death, anxiety, will to live and suicide [1]; depression [6]; spirituality [10]; meaning, faith, purpose, distress and coping ability, existential distress [11]. Qualitative findings and quantitative questionnaire feedback included the following: participants found the interventions gave them a sense of heightened purpose, dignity and will to live [6]; helped them accept the state of things, heightened their sense of dignity and felt the intervention increased a sense of meaning in their lives [13]; an overarching theme of the meaningfulness of family [8]; a valuing of rapport with the therapist [4].

Meaning-based

Meaning-based interventions were brief with between two to eight sessions delivered over periods from 2-3 days to eight weeks. These interventions (14-23 in Table 2) were delivered as group interventions in four sources [14] [15] [19] [21] and all used the manualised Meaning-Centered Group Psychotherapy (MCGP) model developed by Breitbart and colleagues and grounded in the existential work of Viktor Frankl (1992). All other interventions were delivered individually, of which three [16] [20] [23] applied Individual Meaning-Centered Psychotherapy (IMCP), adapted from the previous group version. In one source [23] the model was applied to specifically address meaning-making within a palliative care context using a shorter (three session) approach. The MCP group and individual sessions all focused on finding meaning via a combination of discussion, experiential exercises, and didactics. An even briefer two session individual intervention, titled the ‘Meaning of Life’, was also grounded in logotherapy principles but differed from MCP by including a reflective session summary that was read aloud to the patient, who was also invited to write cards to express sentiments to loved ones [18]. An approach named Meaning and Purpose (MaP) therapy was used in two sources [22] [17], which is a manualised intervention using narrative storying (including material that may be confrontational) to find meaning in a person’s life and cancer. This intervention also differed from the other meaning-based approaches by placing a greater focus on goal setting and seeking new possibilities at the end of life. Although all the meaning-based interventions overlapped in content, they differed in the degree to which they were didactic and the dosage of delivery.

Taken together, meaning-based intervention types found effects that were significant, approaching significance or having at least small to medium effect sizes for constructs including: spiritual wellbeing, peace [15-16]; faith, quality of life, symptom burden and symptom-related distress [16]; quality of life and existential distress [18]; spiritual wellbeing, quality of life, depression, hopelessness and desire for hastened death [19]; gains in goals, choices and openness to new possibilities in life [22]; reduction in despair, anxiety, depression and emotional distress [23]. However, these effects were not consistently maintained at follow up points. Non-significant findings included: anxiety, depression and hopelessness [16]; anxiety [19]. Qualitative findings included: new themes of threat and uncertainty emerging from a Spanish sample, which should be considered in the Spanish population alongside the six original themes identified for Meaning-Cantered Group Therapy [21]; a sense of relief and clarification of life views [18]; benefits to being given space to ponder the place of meaning in life even if it could be confrontational [17]; the importance of connectedness to others within a group context [14].

Life review

Life review interventions were all brief (24-31 in Table 2), ranging between two to six sessions over periods between one week to six weeks. All were grounded in the founding work of Butler (1963) in which the final life stage (drawing from the psychosocial developmental theory of Erikson, 1950) is posited to give rise to despair in the face of existential threats to ego-integrity. All sessions were individual and in-person, apart from one which used a mix of individual online video calls and self-led online work [31]. The latter intervention was delivered via the multipurpose WeChat platform in China and involved an initial video session to formulate an ‘e-life review’, followed by self-led working through online modules to ultimately build an online ‘e-legacy’ product, such as a video booklet, as a spiritual memorial. Two sources looked at combining life review with memory-specificity training called the ‘Dear Memories’ intervention [28-29], which involved training patients to focus on recalling and becoming immersed in specific and positive autobiographical memories from across their life span, with a personalised booklet created for them by the therapist with photographs and pictures to reflect themes raised. The use of WeChat and memory training were both variations of the previous short-term life review interventions which had all focused on exploring questions related to autobiographical details and memories from childhood to the present, culminating in an album or life review booklet being presented to the patient, an approach used in four sources [24] [26] [27] [30]. One intervention titled 'Outlook' differed from all the others by not producing a booklet and by explicitly incorporating an orientation towards the future [25].

Overall, life review intervention found effects that were significant, approaching significance or having at least small to medium effect sizes for constructs including: anxiety, depression, suffering and increased happiness [24]; functional status, anxiety, depression and preparation for end of life [25]; hope, life completion and preparation [26]; ego-integrity [28]; spiritual wellbeing [30]; anxiety, depression and self-transcendence [31]. However, there were mixed findings with no significant differences found for constructs including: despair, anxiety, depression and quality of life [28] [30]. Qualitative study findings included: helpfulness with integration of unique life experiences, emotional relief, meaningfulness and moving towards acceptance [27]; an overarching theme of ego-integrity [29]; providing new ways of thinking and enhanced gratitude and connection with others [31]. Some participants felt the interventions had brought forth painful memories [27] and that there had been too little time to discuss negative emotions and events [29].

Supportive-expressive

Supportive-expressive interventions (32-38 in Table 2) differed in delivery time from previous meaning-based approaches, with sessions numbering from three sessions (spread over a period of months) to weekly over a whole year (durations ranged from three to twelve months, where stated). One intervention was in group format spanning the course of a year and focused on metastatic breast cancer [32]. Content was unstructured and aimed to facilitate emotional expression, provide space for discussion of difficult events (such as deaths within the attendees given the length of time covered by the intervention), facilitated discussion of relevant themes such as body image, and each session concluded with a self-hypnosis exercise. All six other sources involved the Managing Cancer and Living Meaningfully (CALM) therapy intervention [33-38]. This is a manualised individual therapy, comprising a therapeutic interview exploring four domains in which content is tailored for each person. Domains covered: symptom management and communication with the healthcare system; changes in self and interpersonal relationships; spirituality, meaning and purpose; issues concerning advance care planning and end of life (whilst incorporating ways to sustain hope).

Findings from supportive expressive interventions were significant or approaching significance for the following measured constructs: traumatic stress [32]; depressive symptoms, death anxiety and spiritual wellbeing [33]; lowered depressive symptoms with the CALM intervention were maintained for up to 6 months [35]; depression, attachment anxiety and attachment avoidance [36]. No significant differences were found for constructs including: mood disturbance [32]; secondary outcomes of major depressive disorder, generalised anxiety, death anxiety, spiritual wellbeing, quality of life (amongst others) [36]; depression [38]. Qualitative findings included: identification of five interrelated benefits of CALM therapy including being a safe place to process experiences within advanced cancer, permission to talk about death and dying, and resolution of relational strains [33]; finding relief through communicating distress around preoccupations with death and dying and perceiving the CALM therapist as a secure base with whom to engage in this [37]. These findings, which include a fully powered RCT [35] suggest effectiveness and promise for supportive-expressive interventions.

Narrative approaches

Narrative approaches (39-40 in Table 2) were the main element of meaning-based therapy in two sources [39-40]. Interventions in both sources consisted of a single therapeutic interview session, delivered individually to palliative patients. The semi-structured session encouraged the patients to story their experiences of distress, to identify what they felt were causal factors, and to discuss meanings arising. A strengths-based approach aimed to elicit personal resources for coping.

Within the narrative cluster, significant improvements were seen for depression and anxiety in one of the two studies [39]. However, no significant difference at any timepoint was seen for the construct of suffering [39], and a reduction seen in depression scores did not reach significance following the other intervention [40].

Quality assessment of existential cluster

Across all study designs, 48% of existential sources were scored as being of high or very high quality, and 35% scored as being of moderate quality. There were 22 randomised controlled trials, one non-randomised controlled trial, five single arm studies, nine were qualitative, and three of mixed design.

Of the twenty-two randomised controlled trials, randomisation was appropriately performed in all trials (where reported), groups were largely comparable at baseline, and there was overall a good degree of adherence to the intervention. Main aspects of difficulty identified were that RCTs were underpowered to detect effects, with small sample sizes, and all but six RCTs experienced high attrition, largely due to disease progression and death. The one non-randomised controlled trial gained a high score with a good completion rate with low attrition, but did not adequately account for confounds, and the non-randomised design raises the risk of bias in terms of interpreting causality. Of the five single arm studies, more than half had high attrition, the possibility of confounds was not adequately addressed, and potential problems of measurement choice arose where single-item screens had been used. Of the nine qualitative sources (which included two descriptive case reports) all were scored as high to very high quality, with strong use of specified analysis and interpretation. Of the three mixed designs, one had achieved blinding of both participants and outcome assessors and had low rates of attrition and high completion, whereas the other two experienced attrition difficulties.

Table 2*:* Existential clusters (list of included studies)

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating MMAT
1	Chochinov et al., 2005	Existential - Dignity Therapy	Mixed (Canada, Australia)	Quantitative (pilot single arm)	129	Low 40%
2	Chochinov et al., 2011	Existential - Dignity Therapy	Mixed (Canada, USA, Australia)	Quantitative (RCT)	326	High 80%
3	Hall et al., 2011	Existential - Dignity Therapy	United Kingdom	Quantitative (RCT)	45	Moderate 60%
4	Hall et al., 2013	Existential - Dignity Therapy	United Kingdom	Case study/report - used both qualitative and quantitative data	3	Very high 100%
5	Juliao et al., 2013	Existential - Dignity Therapy	Portugal	Quantitative (RCT)	60	Moderate 60%
6	Houmann et al., 2014	Existential - Dignity Therapy	Denmark	Quantitative (pre/post single arm)	80	High 80%
7	Juliao et al., 2014	Existential - Dignity Therapy	Portugal	Quantitative (RCT)	80	Moderate 60%
8	Dose et al., 2017	Existential - Dignity Therapy	USA	Qualitative	20	Very high 100%
9	Vuksanovic et al., 2017	Existential - Dignity Therapy	Australia	Quantitative (RCT)	70	Moderate 60%
10	Dose et al., 2018	Existential - Dignity Therapy & Life Plan	USA	Quantitative (pilot single arm)	20	High 80%
11	Iani et al., 2020	Existential - Dignity Therapy	Italy	Quantitative (RCT)	64	Moderate 60%
12	Weru et al., 2020	Existential - Dignity Therapy	Kenya	Quantitative (RCT)	144	High 80%
13	Nunziante et al., 2021	Existential - Dignity Therapy	Italy	Mixed design	37	Moderate 60%
14	Greenstein, 2000	Existential - Meaning-Centred Group Psychotherapy (MCGP)	USA	Case study/report - used qualitative methods	5	High 80%
15	Breitbart et al., 2010	Existential - Meaning-Centred Group Psychotherapy (MCGP)	USA	Quantitative (RCT - pilot)	90	Moderate 60%
16	Breitbart et al., 2012	Existential - Individual Meaning-Centered Psychotherapy (IMCP)	USA	Quantitative (RCT - pilot)	120	Moderate 60%
17	Lethborg et al., 2012	Existential - Meaning & Purpose (MaP) Therapy	Australia	Qualitative	6	Very high 100%
18	Mok et al., 2012	Existential - meaning-based, 'Meaning of Life Intervention' based in logotherapy	China	Mixed design	84	Moderate 60%

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating MMAT
19	Breitbart et al., 2015	Existential - Meaning-Centred Group Psychotherapy (MCGP)	USA	Quantitative (RCT)	253	Low 40%
20	Breitbart et al., 2018	Existential - Individual Meaning-Centered Psychotherapy (IMCP)	USA	Quantitative (RCT)	321	Moderate 60%
21	Fraguell et al., 2018	Existential - Meaning-Centred Group Psychotherapy (MCGP)	Spain	Qualitative	22	Very high 100%
22	Kissane et al., 2019	Existential - Meaning & Purpose (MaP) Therapy	Australia	Quantitative (RCT - pilot)	57	Very high 100%
23	Fraguell-Hernando et al., 2020	Existential - Individual Meaning-Centered Psychotherapy - Palliative Care (IMCP-PC)	Spain	Quantitative (RCT - pilot)	51	Low 40%
24	Ando et al., 2008	Existential - Short-term Life Review	Japan	Quantitative (pilot single arm)	30	High 80%
25	Steinhauser et al., 2008	Existential - brief Life Review, the 'Outlook' intervention	USA	Quantitative (RCT - pilot)	82	Moderate 60%
26	Ando et al., 2010	Existential - Short-term Life Review	Japan	Quantitative (RCT)	68	High 80%
27	Xiao et al., 2012	Existential - Life Review	China	Qualitative	26	Very high 100%
28	Kleijn et al., 2018	Existential - Life Review Therapy combined with memory specificity training (LRT-MST)	Netherlands	Quantitative (RCT)	107	Low 40%
29	Kleijn et al., 2019	Existential - Life Review Therapy combined with memory specificity training (LRT-MST)	Netherlands	Qualitative	20	Very high 100%
30	Kwan et al., 2019	Existential - Short-term Life Review	China	Mixed design	109	Very high 100%
31	Zhang et al., 2019	Existential - Life Review	China	Quantitative - non-randomised controlled trial	92	High 80%
32	Classen et al., 2001	Existential - Supportive-Expressive Group Therapy (SEGT)	USA	Quantitative (RCT)	125	Moderate 60%
33	Nissim et al., 2012	Existential - Supportive-expressive therapy (Managing Cancer and Living Meaningfully - CALM)	Canada	Qualitative	10	Very high 100%
34	Lo et al., 2014	Existential - Supportive-expressive therapy (Managing Cancer and Living Meaningfully - CALM)	Canada	Quantitative (pilot single arm)	50	Moderate 60%
35	Rodin et al., 2018	Existential - Supportive-expressive therapy (Managing Cancer and Living Meaningfully - CALM)	Canada	Quantitative (RCT)	305	Moderate 60%

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating MMAT
36	Lo et al., 2019	Existential - Supportive-expressive therapy (Managing Cancer and Living Meaningfully - CALM)	Canada	Quantitative (RCT - pilot)	60	Low 40%
37	An et al., 2020	Existential - Supportive-expressive therapy (Managing Cancer and Living Meaningfully - CALM)	Canada	Qualitative	17	Very high 100%
38	Mehnert et al., 2020	Existential - Supportive-expressive therapy (Managing Cancer and Living Meaningfully - CALM)	Germany	Quantitative (RCT)	206	High 80%
39	Lloyd-Williams et al., 2013	Existential - Narrative Therapy	United Kingdom	Quantitative (RCT - pilot)	100	Low 40%
40	Lloyd-Williams et al., 2017	Existential - Narrative Therapy	United Kingdom	Quantitative (RCT - pilot)	57	Very low 20%

CBT and cognitive-behavioural based cluster

Twenty-two sources were assigned in this cluster (numbers 41-62 in Table 3). The sources dated between 1921-2021 and came from nine countries. CBT and cognitive-behavioural based interventions predominantly defined anxiety, depression and quality of life as target constructs. These interventions had a range of delivery by the psychological professions, nurses, medical doctors, social workers, trained interventionists/facilitators (not otherwise stated), or were self-delivered by participants. Samples were predominantly of mixed cancer types. Specific cancer samples targeted were breast, lung, prostate and colorectal. Interventions are described according to their groupings of CBT-specific or cognitive-behavioural-based. Sources are discussed largely in chronological order to provide a sense of overview in developments within CBT and cognitive-behaviourally based intervention research.

CBT-specific sources

CBT-specific interventions (numbers 41-54 in Table 3) all used a manualised approach using combinations of core CBT techniques including goal setting, cognitive restructuring, relaxation, communication skills training and the use of diaries and homework. Interventions were delivered with varying numbers of sessions and time durations, ranging between three to twelve sessions, over a period of approximately one month to twelve months.

An early CBT case report [41] described delivery of nine individual sessions over five weeks to a single terminally ill patient. CBT techniques were applied with an aim of inducing fighting spirit (alongside a realistic hopefulness) as an active coping response. The report details the first use of adjuvant psychological therapy for a terminally ill cancer patient, describing a marked reduction in anxiety and depression despite increasing illness. A single-arm intervention targeting emotional wellbeing used a rational emotive framework for applying CBT techniques and was delivered over twenty weeks with a family session and three further monthly sessions [42]. A significant reduction in anger was found at three months, although no significance was found for state or trait anger or for improvement in self-esteem. An RCT group intervention [43] comprised 12 sessions followed by three monthly booster sessions, included a family night, and had expression of feelings and building of group support as a focus. Reduction in psychosocial distress occurred post-therapy but improvements were not evident at either the three or six-month follow-up points. A single case experimental design with six participants [44] used common CBT techniques and had a booster session at 3 months and a six month follow up which found sustained benefits for depression. This contrasts with the earlier findings of non-sustained effects following a group format, which may have prevented individualisation to needs [43]. An intervention with eleven individual sessions of CBT similarly used the concept of booster sessions to sustain effects over six month follow up and found significant effects at follow up on one of several depression measures [45].

A feasibility intervention delivered by a medical doctor used the shortest session count found within the CBT sources (3-4 sessions) and found promising findings, with qualitative feedback suggesting that longer durations could be inappropriate for people experiencing symptoms such as low energy and concentration [46]. Nurses successfully delivered up to six flexible sessions of CBT to foster daily coping, with effects found for anxiety that lasted to 16-week follow up, although no effects were found for depression [47]. Flexibly tailored CBT modules that targeted anxiety [48, 49] found significant effects in both pilot RCTs, though only in a subset of patients with high baseline anxiety. Whereas the earlier trial [48] had been delivered in person or via telephone, the latter trial [49] had adapted the intervention to be self-administered via a mobile app in a community setting, suggesting a usefulness of this mode of delivery for those with high anxiety. For a Latin American sample, a multiple-baseline single case experimental design with nine participants found effects for both depression (for two patients) and anxiety (for three patients) [50].

A fully powered multi-centre RCT used a manualised CBT protocol based upon an established theoretical model for cancer adjustment and was delivered either in person or via telephone by high intensity therapists from Improving Access to Psychological Therapies (IAPT) services [51]. No effects were found for depression in the clinically depressed sample, despite proficient quality of delivery by therapists. The authors concluded that referral for CBT at IAPT services for depressed people with advanced cancer is not recommended. In an Asian cultural setting, a manualised CBT protocol found no effect on psychological distress, which may have been partly due to low levels of distress at baseline [52]. An intervention that introduced third wave elements of mindfulness into later CBT sessions did so aiming to promote disengagement from persistently difficult thoughts and to foster attention to chosen activities. The authors found effects for anxiety, fear of recurrence, traumatic symptomatology, depression and quality of life [53]. Improvements were sustained at follow up for anxiety, traumatic symptoms and depression. An internet-delivered intervention, self-paced by participants, offered six themed lessons teaching CBT strategies with mindfulness and relaxation [54]. This intervention resulted in significant improvements for both anxiety and depression, maintained at follow up.

Cognitive-behavioural-based sources

Eight sources were classified as cognitive-behaviourally based (numbers 55-62 in Table 3). These were delivered with varying numbers of sessions and time durations ranging between 3 to 10 sessions, over a period of approximately four weeks to six months. One source related to a group intervention, and all other sources related to individually delivered interventions (including dyadic sessions).

One intervention with an RCT design used cognitive hypnosis techniques to promote functioning in daily life, increase self-efficacy and foster hope [55]. Anxiety and depression decreased, and participants qualitatively reported the intervention to be helpful and cited therapist rapport as important. Cognitive restructuring, mind and body education and end of life planning was supported by meetings with a designated social worker called a ‘Pathfinder’ at monthly intervals over six months [56]. Significant improvements were found at the three-month assessment for quality of life and distress scores. An RCT comprising 476 patient/caregiver dyads gave 3 educational sessions over one month using a problem-solving approach [57]. Dyads were provided with a booklet about cancer home care with information addressing physical symptoms, psychological symptoms (anxiety and depression), relationships and resources, and information about communicating with healthcare teams. No effect on quality of life was found for patients. A guided self-help intervention using memory-concreteness training included an initial individual training session followed by daily self-practice for a month, with the aim of preventing rumination and worry by building skills in concrete thinking that may shift negative cognitive bias [58]. A significant effect was found for anxiety but not depression. A telephone counselling intervention delivered over six weeks with thirty-nine dyads [59] used a tailored manual covering topics of self-care, stress and coping, symptom management, communication skills, problem solving and relationships. Large effect sizes were reported for anxiety and depression for patients. An online group intervention with content specific to prostate cancer was delivered by tablet computer, using cognitive-behavioural strategies and stress management skills to challenge negative appraisals and develop coping and interpersonal skills [60]. Improvements in depression were maintained at six-month follow up. A study using in person and online delivery aimed to increase the frequency of positive emotions to increase coping, using positive cognitive reappraisals and aspects of third wave cognitive-behavioural techniques [61]. Significant effects were found for depression at one-month follow up, regardless of whether someone received the intervention in person or online. A study from Latin America [62] applied a brief intervention drawing from CBT, focusing on psychoeducation, symptom management and preparing the patient for their first visit to a palliative care team. No effect was found for depression.

Quality assessment for CBT & cognitive-behavioural based cluster

Across all study designs, 45% of CBT and cognitive-behavioural based sources were scored as being of moderate quality, with 41% scoring as high or very high quality. Study designs were thirteen randomised controlled trials, three single arm studies, one case study using quantitative methods, two single-case experimental designs, and three mixed designs. This cluster contained no qualitative sources. In the thirteen randomised controlled trials, randomisation was appropriately performed in all trials, groups were largely comparable at baseline, and overall there was a good degree of adherence to interventions where stated. Main aspects of difficulty identified were: RCTs were mostly underpowered to detect effects, with small sample sizes; over half experienced high attrition largely due to disease progression and death; RCTs were mostly unblinded for outcome assessors (or did not report as to this criterion). The three single-arm studies were of moderate quality, with confounders unaccounted for in the design, and all experienced high attrition. The one case report was deemed of very high quality, with complete case demographics and appropriate measurement. Two multiple baseline single case experimental designs were of high and very high quality, although one had a high attrition rate. The three mixed designs were low to moderate in quality, with difficulties including high attrition rates or lacking clarity in whether the qualitative component adhered to the tradition of methodology involved.

ACT and mindfulness-based cluster

Twenty sources were assigned in this cluster (numbers 63-82 in Table 3). ACT and mindfulness-based sources dated between 2012-2021 and came from nine countries including two non-Western countries (Korea and Malaysia). These interventions specified a wide range of target constructs for distress, including aspects of acceptance and suffering. Additionally, this cluster targeted symptom-related constructs that impact on functioning such as fatigue, pain and sleep. Nearly half the interventions were delivered by psychological professions, and the rest by social workers, medical doctors, mindfulness instructors, a mix of professions, or self-administered whilst overseen by research staff. Samples contained predominantly mixed cancer types, although notably nearly half (45%) were directed at specific cancers (breast, lung, ovarian, prostate or colorectal). Interventions are discussed according to type of study design, firstly for those sources identified as ACT-specific, and then for those designated as mindfulness-based. Sources are discussed in chronological order, to provide a sense of overview within the development of ACT and mindfulness-based interventions.

ACT-specific sources

The six ACT-specific interventions (numbers 63-68 in Table 3) all had acceptance as their central focus, targeting distress via acceptance of difficult thoughts and feelings. All studies drew upon the six central tenets of ACT: mindful contact with the present moment; acceptance; cognitive defusion; concept of the observer self; identification of personal values; committed action in the direction of personal values (Hayes et al., 1999). Interventions were delivered with varying numbers of sessions and time durations, ranging between four to twelve sessions, over a period of approximately one to four months. All involved individual sessions with one source offering a mix of both individual (including dyadic) and group work.

Twelve individual ACT sessions with participants with advanced ovarian cancer (which incorporated ACT conceptualisations of creative hopelessness and control struggles as maintaining factors in distress) demonstrated significantly greater improvement than controls for quality of life, depression and anxiety [63], compared to a treatment as usual intervention containing cognitive-behavioural elements. Mediation analyses suggested that differences were mediated by ‘mental disengagement’ and ‘active planning’ for psychological distress and quality of life. A telephone-delivered six-session ACT intervention [64] was tailored to each person’s breast cancer related difficulties, and targeted depression, anxiety and symptom interference. The intervention had an emphasis on mindfulness skills, committed action in line with personal values and how to respond to symptom interference. No significance was found in any outcome, with reductions seen in both the ACT group and the comparator (education/support) group for depression. However, the ACT group demonstrated moderate decreases in sleep problems and fatigue, whereas the comparator group showed minimal changes. A related study again found no significant differences between groups, using a mix of individual and dyadic sessions delivered by telephone tailored for lung cancer [65]. In the recent CanACT pilot trial [66] a manualised ACT approach was used, with emphasis on therapists using the manual flexibly. Half the sessions socialised individuals to ACT concepts, with remaining sessions dedicated to practice of techniques to build psychological flexibility. At three-month follow up, the Talking Control group demonstrated better functioning than the ACT group. However, at 6-month follow up, ACT was indicated to have made greater gains than controls. A group-based intervention, with individual self-paced online work and daily online check-ins, found significant improvements over time for anxiety, depression and life meaning [67]. Mechanisms of change were posited to be acceptance and defusion increasing over time. A mixed study incorporating a single-case experimental design [68] measured quality of life and distress, and used a manual tailored to experiences in advanced cancer and delivered flexibly. Written session summaries were provided. Findings were inconclusive, although there was an indication that quality of life and distress improved with building of psychological flexibility (even though physical and functional status deteriorated).

Mindfulness-based sources

The fourteen mindfulness-based sources (numbers 69-82 in Table 3) comprised mindfulness-based cognitive therapy (MBCT), mindfulness-based stress reduction (MBSR) and mindfulness-meditation interventions. Interventions were delivered with varying numbers of sessions and time durations, ranging from individually delivered (including two dyadic caregiver) interventions (one with a single session, others with between 4-8 weekly sessions) and group delivered interventions (between 6 - 9 weekly sessions).

Two sources applied MBCT in an eight-week manualised group format specifically for prostate cancer, based upon an original manual for MBCT for depression (Segal et al., 2002). MBCT techniques included body scans, moving and mindfulness meditations, silent practice with bells and home practice self-help materials. The first [69] was a mixed method pilot study with the intervention delivered in person, finding significant improvement in anxiety demonstrated via lessened fear of recurrence and lowered avoidance of cancer. Qualitatively, acceptance of disease was linked to men having supported exposure to the experiences of others within the group context. The second study [73] was an RCT and MBCT was applied via teleconference, which was a feasible mode of delivery offering reach to more rural communities and to those less able to travel due to illness. However, in this second study no significant differences were found between men receiving the intervention compared to minimally enhanced usual care, although these findings may have been affected by inclusion of men with low baseline distress.

Eight sources applied MBSR based upon and modifying the original Kabat-Zinn model (Kabat-Zinn, 1990; Kabat-Zinn et al., 1985; 1992) aiming to build awareness of stress responses through mindfulness, meditation including loving kindness, yoga elements, body scan techniques and engaging in mindful dialogue (including around meanings in life). Four sources reported on individual and/or dyadic (caregiver) MBSR interventions. Findings in these sources were: significant improvement in stress and anxiety were found over time [70]; salient themes arose including enhanced coping and communication around disease, and stronger relationships [76]; significant changes towards acceptance and mindful coping in disease, though there was no significant change in search for life meaning [80]; themes involving a shift from feelings of vulnerability towards a sense of increased peace within uncertainty [81]. Four sources reported upon group MBSR interventions. Of these, findings were: significant reduction in anxiety, though not in depression [71]; no significance found for any outcome including anxiety or depression, although qualitatively participants reported insight-building into thoughts, body sensations and behaviours [72]; a significant reduction on a measure of distress compared to controls, although no significant differences on measures for anxiety, depression or quality of life [74]; significantly lowered depression and fatigue scores, with participants reporting helpfulness in coping with anxiety and stress and an increased ability to shift stuck patterns in thoughts and feelings via present-moment focusing [78].

Four sources reported upon mindfulness meditation interventions, of which three were delivered individually and one via group. The group intervention was delivered in person using formal mindfulness-meditation techniques with an added focus on advanced care planning in advanced cancer. The authors found significant and sustained improvements for depression, anxiety and lowered cognitive avoidance, alongside increased advanced care planning behaviours [79]. Of the individual mindfulness-meditation interventions, an audio-based self-practice format used MP3 players, a practice diary with daily motivational texts and weekly emails with links to themes. The authors found feasibility in the delivery mode, and preliminary findings of efficacy for reduced distress and anxiety, with qualitative feedback including a sense of increased peace and calmness [75]. Use of a commercially available online application involved participants being encouraged to first complete a 30-day foundation course for mindfulness, followed by choosing to complete courses of most relevance to themselves, such as for anxiety, sleep or relationships [77]. Study staff contacted participants if less than three sessions on the online application were made each week. Findings were that significantly greater improvements were found for emotional wellbeing and overall wellbeing compared to controls. However, no significant differences were found on measures of anxiety or depression. Qualitatively, participants reported usefulness but suggested improvements through wanting increased meditation reminders and more social connection such as through a webinar. A short five-minute guided loving-kindness meditation delivered in-person to palliative patients aimed to build self-compassion by repetition of positive statements [82]. Significant improvements in overall suffering and in spiritual quality of life were found compared to controls, with the authors concluding that the intervention was helpful to address ‘breakthrough’ suffering (rather than persistent ‘background’ suffering) within the context of palliation.

Quality assessment for ACT & mindfulness-based cluster

Across all study designs, 25% of ACT and mindfulness-based sources were scored as being of moderate quality, with 75% scoring as high or very high quality. Study designs were six randomised controlled trials, one non-randomised controlled trial, four single arm studies, two qualitative, and seven mixed design. All six randomised controlled trials were of moderate or high quality. Randomisation was appropriately performed in the majority (with one unclear), groups were largely comparable at baseline, there was overall a good degree of adherence to the intervention where stated and four out of six trials achieved blinding of outcome assessors. Main aspects of difficulty identified were: RCTs were mostly underpowered to detect effects, with small sample sizes; 50% experienced high attrition, largely due to disease progression and death. The one non-randomised controlled trial was of high quality, although there were confounds unaccounted for in the design. The four single-arm pilot studies were of high quality, being representative of the target population with complete outcome data and interventions administered as intended. However, confounds were unaccounted for in these studies. The seven mixed designs were moderate or high in quality, with one study deemed very high quality. Overall, these mixed designs effectively integrated quantitative and qualitative components and demonstrated appropriate use of qualitative components with adequate substantiation of findings via quotes from the data. The two qualitative sources were deemed high quality, with detailed description of qualitative methods used and findings demonstrated by strong use of illustrative quotes.

Table 3: Cognitive behavioural therapy (CBT) and cognitive-behavioural based, acceptance and commitment therapy (ACT) and mindfulness-based clusters (list of included studies)

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating MMAT
41	Santos & Greer, 1991	CBT	United Kingdom	Case study/report - used quantitative measure	1	Very high 100%
42	Cocker et al., 1994	CBT	Australia	Quantitative (pilot single arm)	10	Moderate 60%
43	Edelman et al., 1999	CBT	Australia	Quantitative (RCT)	124	Moderate 60%
44	Levesque et al., 2004	CBT	Canada	Quantitative - multiple baseline Single Case Experimental Design (SCED)	6	High 80%
45	Savard et al., 2006	CBT	Canada	Quantitative (RCT)	45	Very high 100%
46	Anderson et al., 2008	CBT	Northern Ireland	Mixed design	11	Moderate 60%
47	Moorey et al., 2009	CBT	United Kingdom	Quantitative (RCT)	80	Moderate 60%
48	Greer et al., 2012	CBT	USA	Quantitative (RCT - pilot)	40	High 80%

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating MMAT
49	Greer et al., 2019	CBT	USA	Quantitative (RCT - pilot)	145	High 80%
50	Landa-Ramirez et al., 2020	CBT	Mexico	Quantitative - multiple baseline Single Case Experimental Design (SCED)	9	Very high 100%
51	Serfaty et al., 2020	CBT (CanTalk trial)	United Kingdom	Quantitative (RCT)	230	Moderate 60%
52	Teo, Tan et al., 2020	CBT	Singapore	Quantitative (RCT - pilot)	60	High 80%
53	Curran et al., 2021	CBT	Australia	Quantitative (pilot single arm)	12	Moderate 60%
54	Murphy et al., 2021	CBT (*iCanADAPT* Advanced')	Australia	Mixed design	27	Low 40%
55	Liossi & White, 2001	Cognitive-behavioural based - clinical hypnosis	Greece	Mixed design	50	Moderate 60%
56	Abernethy et al., 2010	Cognitive-behavioural based	USA	Quantitative (pilot single arm)	50	Moderate 60%
57	Meyers et al., 2011	Cognitive-behavioural based - problem-solving, psychoeducational	USA	Quantitative (RCT)	476 dyads	Low 40%
58	Galfin et al., 2012	Cognitive-behavioural based - guided self-help	United Kingdom	Quantitative (RCT)	34	Low 40%
59	Badr et al., 2015	Cognitive-behavioural based	USA	Quantitative (RCT)	39 dyads	High 80%
60	Yanez et al., 2015	Cognitive-behavioural based - stress management	USA	Quantitative (RCT)	74	High 80%
61	Cheung et al., 2017	Cognitive-behavioural-based - Positive affect skills (LILAC: Lessons in Linking Affect and Coping)	USA	Quantitative (RCT - pilot)	39	Moderate 60%
62	Do Carmo et al., 2017	Cognitive-behavioural based	Brazil	Quantitative (RCT - pilot)	63	Moderate 60%
63	Rost et al., 2012	ACT	USA	Quantitative (RCT - preliminary)	47	Moderate 60%
64	Mosher, Secinti, Li et al., 2018	ACT	Germany	Quantitative (RCT - pilot)	47	Moderate 60%
65	Mosher et al., 2019	ACT	USA	Quantitative (RCT - pilot)	50 dyads	High 80%
66	Serfaty et al., 2019	ACT (CanACT trial)	United Kingdom	Quantitative (RCT - pilot)	42	High 80%
67	Arch et al., 2020	ACT (M-ACT multimodal ACT)	USA	Quantitative (pilot single arm)	35	High 80%

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating MMAT
68	Hulbert-Williams et al., 2021	ACT	United Kingdom	Mixed design	10	Very high 100%
69	Chambers et al., 2012	Mindfulness-based - Mindfulness-Based Cognitive Therapy (MBCT)	Australia	Mixed design	19	Moderate 60%
70	Lengacher et al., 2012	Mindfulness-based - Mindfulness-based stress reduction (MBSR)	USA	Quantitative (pilot single arm)	26 dyads	High 80%
71	Eyles et al., 2015	Mindfulness-based - Mindfulness-based stress reduction (MBSR)	United Kingdom	Mixed design	19	High 80%
72	Van den Hurk et al., 2015	Mindfulness-based - Mindfulness-based stress reduction (MBSR)	Netherlands	Mixed design	35	Moderate 60%
73	Chambers et al., 2017	Mindfulness-based - Mindfulness-Based Cognitive Therapy (MBCT)	Australia	Quantitative (RCT)	189	High 80%
74	Lee et al., 2017	Mindfulness-based - Mindfulness-based stress reduction (MBSR)	Korea	Quantitative - Non-randomised controlled trial	32	High 80%
75	Atreya et al., 2018	Mindfulness-based - Mindfulness meditation	USA	Mixed design	33	High 80%
76	Cottingham et al., 2019	Mindfulness-based - Mindfulness-Based Stress Reduction (MBSR)	USA	Qualitative	13 dyads	Very high 100%
77	Kubo et al., 2019	Mindfulness-based ('POEM' Practice of Embracing each Moment)	USA	Mixed design	97	Moderate 60%
78	Poletti et al., 2019	Mindfulness-based - Mindfulness-based stress reduction (MBSR)	Italy	Mixed design	20	High 80%
79	Johns et al., 2020	Mindfulness-based - Mindfulness meditation	USA	Quantitative (pilot single arm)	13 dyads)	High 80%
80	Zimmerman, Jordan et al., 2020	Mindfulness-based - Coping with Cancer Mindfully (CCM) using mindfulness-based stress reduction (MBSR)	New Zealand	Quantitative (pilot single arm)	20	High 80%
81	Zimmerman, Burrell et al., 2020	Mindfulness-based - Coping with Cancer Mindfully (CCM) using mindfulness-based stress reduction (MBSR)	New Zealand	Qualitative	20	Very high 100%
82	Lim et al., 2021	Mindfulness-based - Mindfulness meditation	Malaysia	Quantitative (RCT)	60	High 80%

Couples-based cluster

Nine sources were assigned in this cluster (numbers 83-91 in Table 4). Couple-based sources dated between 2003-2021 and were all from Western countries (USA or Canada) with one exception (Japan).

Sample sizes ranged from 1- 75 dyads. These interventions predominantly defined anxiety, depression, relationship quality and spiritual wellbeing as target constructs. Delivery of interventions was either in person or via teleconference and administered by the psychological professions, a cancer nurse specialist, social workers and a mind-body specialist with a master's degree. Session numbers ranged from 4-8 over a duration of two weeks to three months. The majority (56%) of interventions targeted specific cancer samples (lung, brain and gastrointestinal) with 33% targeting mixed cancer types. Interventions are described according to groupings of type of therapeutic approach used.

Two sources by the same authors described use of an emotionally focused couples therapy approach, in a pilot study [83] followed by an RCT [84]. These interventions were manualised and modified for advanced cancer and aimed to foster change within marital relationships by identifying and altering interpersonal interactions that cause distress and to enhance mutual understanding between partners when facing particular issues such as existential concerns, physical and role changes, and difficulties in communication and decision-making. In the pilot, marital functioning improved in 87.5% of couples by the final session (with improved scores maintained in 60% of couples at three-month follow-up) and a significant reduction in depression was also observed. Similar findings were replicated in the RCT compared to controls for marital functioning, although no difference was seen between groups for depression after controlling for differences at baseline.

A single arm pilot [85] administered a meaning-based intervention to couples drawing from existential psychotherapy and was based upon experiential exercises between partners (including an interactive life review exercise, sharing of one another's personal values including those around communication, sharing of wishes towards end of life and reflections upon life meanings). In patients a reduction in appraisals of illness threat was observed, but there were no significant changes in depression or anxiety (although a reduction in these outcomes was observed for partners). Another source offered couples therapy based around shared meaning-making, exploration of values and ways to facilitate communications around end of life [91]. The patients in these couples demonstrated a significant reduction in death distress and marginally significant findings were seen for depression. A case study design from Japan [86] also delivered a meaning-based psychotherapy approach and focused upon aspects including themes of identity, legacy and hope. Qualitative findings reported that couples had an increased readiness to face existential concerns and had fostered increased hope for the future, with partners later reporting a good death including expression of gratitude and meanings from their shared life.

Mindfulness-based approaches with couples were used in three sources. A single arm study [87] delivered the intervention in person and aimed to foster interpersonal connection and gratitude and comprised techniques including mindful breathing and compassion-focused meditation. Medium effect sizes were reported for cancer-specific distress in patients, with small effect sizes reported for depression and spiritual wellbeing. Two pilot RCTs by the same author group delivered a mindfulness-based intervention via teleconference, with session content focusing on compassion, gratitude, mindfulness exercises and shared emotional disclosure. The first [88] found significant differences for depressive symptoms, relationship wellbeing and compassion in patients (but not in partners) compared to patients receiving usual care. The second RCT [89] also found significantly lower depressive symptoms in patients compared to usual care, and additionally reported medium effect sizes for depressive symptoms and cancer stress compared to a supportive-expressive (attentional control) condition. These findings were maintained at three-month follow-up.

One source described a peer-helping intervention consisting of telephone sessions in which dyads created resources to help other couples coping with cancer, based on their own shared experience and advice [90]. Sessions also aimed to build the coping skills of couples, with goals set between sessions. Findings were that this combined peer-helping and coping skills-based intervention did not increase spiritual wellbeing compared to a comparator condition (which used the coping skills element only).

Quality assessment for couples-based cluster

Across all study designs, 33% of couples-based sources were scored as being of moderate quality, 56% scored as high quality and one source was deemed very high quality. Study designs were four randomised controlled trials, three single arm studies, one mixed design and one qualitative case study. Half the randomised controlled trials were of moderate quality, with one of high and one being very high quality. Randomisation was appropriately performed in all studies, groups were largely comparable at baseline, there was a good degree of adherence to interventions in all trials, with 50% achieving blinding of outcome assessors. Main aspects of difficulty identified were: RCTs were underpowered to detect effects, with small sample sizes; 50% experienced high attrition, largely due to disease progression and death. The three single-arm studies were of moderate or high quality, being representative of the target population and with interventions administered as intended. However, confounds were unaccounted for in these sources, and one source did not have complete outcome data. The one case report was deemed high quality, with appropriate use and substantiation of qualitative method used. The one mixed design source was of high quality with good adherence to the intervention and good use of qualitative interpretation.

Creative cluster

Thirteen sources were assigned in this cluster (numbers 92-104 in Table 4). Creative sources dated between 2002-2021 and were all from Western countries with one exception (Turkey). These interventions measured a range of constructs, including anxiety, depression, stress, emotional distress, pain, tiredness, quality of life, wellbeing, ill-being, existential wellbeing, psychological wellbeing and spiritual wellbeing. Delivery of interventions was individual (in person or via telephone) and there was one group delivered in person. Where stated, interventions were administered by music therapists or music therapy trainees, art therapists, nurses and researchers from the psychology or nursing professions. Session numbers ranged from 1-16 over a duration of one day to four months. Where stated, the majority (69%) of interventions targeted mixed cancer samples, with 23% targeting specific cancer types (breast and renal). Interventions are described according to groupings of type of therapeutic approach used.

Expressive writing interventions comprised four (31%) of the sources. A pilot RCT [92] instructed patients to write about their deepest thoughts and feelings related to cancer whilst they waited to receive medical treatment, over four sessions. Compared to a usual writing group (who wrote about health behaviours) no significant differences were found for distress symptoms, stress or mood (except for on a subscale for vigor, which was seen to be higher in the intervention group). However, a reduction in sleep disturbances was seen in the intervention group compared to controls. In the mixed design source, a telephone-delivered expressive writing intervention over four sessions [93] comprised of twenty minutes of writing time in which patients were instructed to write about their most difficult or traumatic experiences, feelings and thoughts or about a cancer-related event they had not spoken of before. Compared to a neutral writing group, no significant differences in state-trait anxiety were seen before and after each writing session. Qualitative analysis suggested that patients had tended to write down a series of chronological medical events, used little emotional expression, and that many of the texts focused on positive rather than negative experiences. Another intervention delivered via telephone used a twenty-minute writing time over four sessions [94] and found no main effect for psychological outcomes including depressive symptoms or cancer-related intrusive thoughts. In contrast to the earlier study [92] no significance was found for physical symptoms such as sleep disturbance. However, there was some indication that the intervention was helpful for those who had been more recently diagnosed with advanced breast cancer or who had lower levels of social support, as they showed a reduction in intrusive thoughts over time. For those women who had been diagnosed for longer, a contraindication effect was found as these women reported being less able to sleep over the time of the intervention. The authors posit this increased sleeplessness may have been due to an increase of intrusive thoughts reactivated via expressive writing. A further telephone-delivered intervention used twenty-minute writing across four sessions [95] and no significant findings arose for measures including existential or psychological wellbeing. However, there was a significant increase in use of mental health services in these participants during the study compared to a neutral writing group, which the authors suggest may indicate a benefit of expressive writing as an exercise to grow awareness of support needs.

Music therapy interventions comprised five (38%) of the sources, with all notably being delivered in hospice contexts. An intervention offered sessions up until death [96] with music therapy (using live music) being delivered within a cognitive-behavioural framework (in that the music therapy was tailored to treat main current problems and encouraged emotional expression). Even when physical function declined, significant improvements on quality-of-life measures were found compared to controls. A single music therapy session of between 20-40 minutes in duration [97] was tailored to the individual and could include aspects such as live or recorded music, singing, music-based relaxation, improvisation, music and imagery, and music-assisted counselling. A significant reduction in anxiety was observed compared to controls (who received a single volunteer visit with non-music related activities). In another source [98] up to five sessions of music therapy were offered based around use of the Body Tambura instrument which was played by the therapist and placed either on the patient's body or a distance away, with family being allowed to participate. The patient remained passive, with the instrument aimed to produce states of trance and relaxation. Patient interviews conveyed themes of relaxation, perceived changes in body sensations, pleasant visualisations and memories, and a valued sense of connection with participating family members. An intervention delivered via four sessions within one week [99] was tailored to the patient and included aspects such as song discussions chosen by the patient, relaxation and visualisation exercises, verbal and non-verbal expression of feelings, song writing, playing instruments and musical life review. Family members were invited to attend the final session. Improvements in scores of wellbeing, anxiety, depression and other symptoms were significant compared to controls (who received standard care alone). An intervention delivered individually over two sessions [100] comprised an initial biographical interview in which a personally relevant song choice was made, and which elicited positive memories for the person. A live performance of this song choice was delivered by the music therapist in a second session, in the style of a lullaby. Space for reflection and a debriefing discussion was provided afterwards. This study relied on several visual analogue scales for outcome measurement, which suggested positive changes in wellbeing and relaxation after the intervention. A measure of life closure also demonstrated a slight improvement in scores, although the authors note ceiling effects on this measure as scores for life closure were high at baseline.

Sound therapy, as distinct from music therapy, was used in one source [101]. Six individual sessions over three months comprised patients receiving bodily vibrations from Tibetan singing bowls and hearing other sounds (such as wind chimes) with no verbal component. No significance was found in longer questionnaire-based measures of anxiety, depression, distress or quality of life, although a significant pre-post difference was seen using a simple visual self-rating of general distress.

Art therapy interventions comprised two (15%) of the sources. Both involved interventions delivered individually to palliative hospital inpatients. In the earlier study [102], a variety of art media was available for the patient to use (sculpture, painting, drawing, modelling, photography) with the choice of subject decided by the patient, who was encouraged to create an artwork that held personal meaning for them. Up to ten sessions were offered depending on length of inpatient stay, and across all participants even just one session was found to correlate with a reduction in global distress, with correlational reductions in all six measured symptoms (pain, anxiety, ill-being, tiredness, sadness and depression). However, amongst individual participants the amount to which symptoms reduced had wide variation. A later study [103] used an art therapy framework derived from phenomenological and existential humanistic psychotherapeutic approaches. A median of four personalised art therapy sessions were delivered with family members participating at points. Art media included collage, modelling and painting and made associations with self-representations, memories, sensations and emotions. The artwork was sometimes combined with music, creative writing and breathing exercises. The art therapist engaged patients in free commentary and enquiry upon finishing an artwork. Significant improvements were found for anxiety, depression and wellbeing, and a reduction in pain across time was observed. Open-ended qualitative feedback found descriptive categories including fostering deeper self-knowledge and identity, and a sense of shift towards feeling more like a person than a patient.

Dramatherapy was used in a source from Turkey and delivered by two nurses, one with training in psychodrama techniques using enactments of real-life scenarios to foster empathy and understanding of psychosocial interactions [104]. An in-person group was delivered over sixteen sessions, with each being three hours in length. Techniques used included role reversals and mirroring, with participants engaging in expression of emotions and being asked to listen non-judgementally to one another. Qualitative analysis found themes including relief of death anxiety and suffering, building of resilience and reduced powerlessness, and increased life meaning. Within the context of Turkish culture, the authors posit that psychodrama offers a valuable alternative means of addressing the taboo subject of death.

Quality assessment for creative cluster

Across all study designs for creative sources, two (15%) were of very low or low quality, three (23%) were found to be of moderate quality, five (38%) scored as high quality and three (23%) were deemed very high quality. Study designs were five randomised controlled trials, one non-randomised controlled trial, three single arm studies, two qualitative, and two mixed design. All five randomised controlled trials were of at least moderate quality. Randomisation was appropriately performed in the majority (with one unclear), groups were largely comparable at baseline, there was overall a good degree of adherence to the intervention where stated and all sources reported complete outcome data and low attrition rates. Main aspects of difficulty in these RCTs were that they all had limited power to detect effects, with small sample sizes. The one non-randomised controlled trial was of very high quality according to MMAT criteria, as it controlled for several confounds (pharmacological and non-pharmacological) and had complete outcome data. However, the sample size was small, and the absence of randomisation inevitably raises the risk of bias. The three single-arm studies were moderate to high quality pilots which were representative of the target population, had complete outcome data and interventions were administered as intended. However, confounds were unaccounted for in these studies and bias may have arisen due to therapists being present whilst self-assessment measures were completed, with one study relying heavily on visual analogue scales. The two mixed designs were of very low or low quality, with difficulties including high attrition rates, a lack of exploration of divergences between quantitative and qualitative components, or lacking clarity in whether the qualitative component adhered to the tradition of methodology involved.

Complementary and alternative medicines (CAMs) cluster

Seven sources were assigned in this cluster (numbers 105-111 in Table 4). CAMs sources dated between 2007-2020 and were all from Western countries. These interventions looked at a variety of target constructs including anxiety, depression, existential and psychological distress, acceptance, wellbeing, quality of life and physical symptoms including pain and fatigue. Delivery of interventions was via yoga instructors, massage therapists, an acupuncturist, complementary therapists not otherwise specified and psychologists. Samples were 57% from specific cancer types (breast, brain and skin) with the rest of mixed cancer type. Sessions ranged from 5-12 sessions over durations of two weeks to four months. Interventions are described according to groupings of type of CAMs approach used.

There were two yoga sources, both describing group interventions consisting of eight sessions over eight weeks. One described the ‘Yoga of Awareness’ behavioural intervention for advanced breast cancer [105] which was tailored to each group participant from a protocol with aspects including yoga postures, breathing, meditation and talking-based aspects such as didactic teaching and group discussions. The intervention emphasised home practice and examples of how yoga was relevant to daily life (such as fostering acceptance whilst experiencing pain). Using analysis of physical and psychological processes (recorded in daily diaries to reduce recall bias) significant improvements were found in acceptance, with trends also seen towards reduced pain and increased ability to relax. The other yoga source [106] was a pilot RCT study using a form of Hatha yoga (which emphasises mindfulness techniques). Techniques used in the group were very similar to the previously described study, but with the addition of formal study of pertinent topics and home practice via guided videos. This study used a control condition (support group control) and a trend was indicated towards improvements in fatigue, anxiety and depression scores in the yoga group (although statistical inference was not used).

Massage interventions were found in two sources. One consisted of nine sessions of hand and foot massage [107] delivered silently with light pressure lasting twenty-five minutes followed by a half hour of rest. Qualitative findings used existential concerns as a framework for analysis and found that the massage generated an experience of respite from existential distress via a short inner feeling of release from illness. Swedish massage techniques were applied over eight sessions in the other source [108], which included techniques such as kneading, friction, tapping and shaking motions. Distress as measured via visual analogue scales was seen to reduce significantly across sessions, with distress one week after the intervention had ended remaining lower than baseline.

Spiritually focused meditation (framed within the spiritual or religious worldview of participants) was used in one RCT source [109]. The five-session intervention followed a structured but flexible session manual with themes including maintenance of quality of life and how to cope with loss of control. These themes were discussed in the first part of sessions, and an applied meditation then followed with the aim of fostering spiritual coping resources. Over time, those in the spiritual meditation condition reported less depression and more positive affect than controls in both secular meditation and usual care conditions. This led the authors to suggest that meditation that is not specifically identified as mindfulness-based may be helpful in advanced cancer.

Reflexology or relaxation sessions were provided over six sessions in a palliative context [110]. Relaxation included progressive muscular relaxation (PMR), breathing, meditation and guided imagery. Reflexology aimed to achieve bodily homeostasis by easing stress. Although anxiety and depression significantly decreased in both groups, a greater significance was found at the end of the reflexology intervention condition for anxiety, depression and quality of life.

One source described an acupuncture intervention [111] with twelve sessions over eight weeks. Pre-prepared acupuncture protocols were used by trained acupuncturists using ten body points, with further points being used depending on the symptom distress being reported by the patient. Significance was found in both immediate self-reported reductions and across time for anxiety, depression, pain and fatigue. Improvements were maintained one month after the intervention had ended. Reductions in anxiety were greater for patients who were less than fifty years of age. However, comparisons were likely underpowered and may have arisen by chance due to multiple comparisons being made.

Quality assessment for complementary and alternative medicines (CAMs) cluster

Across all study designs, 43% of CAMs sources were scored as being of moderate quality, 43% scored as high quality and one source was deemed very high quality. Study designs were three randomised controlled trials, two single arm studies, one qualitative, and one mixed design. All three randomised controlled trials were of moderate or high quality. Randomisation was appropriately performed, groups were largely comparable at baseline, and there was a good overall degree of adherence to interventions. However, all RCTs were underpowered to detect effects, with small sample sizes. One RCT experienced a very high attrition rate of 64% mostly due to severity of illness and death [109] but used an intention to treat analysis. The two single-arm studies were of moderate and high quality, being representative of the target population and with interventions administered as intended. However, confounds were unaccounted for in these studies and one did not have complete outcome data. The one mixed design was moderate in quality, with confounds uncontrolled for in the single arm component and lacking clarity in whether the qualitative component adhered to the tradition of methodology involved.

'Others' cluster

Seven sources were assigned to this cluster (numbers 112-118 in Table 4). These sources comprised interventions that appeared to stand outside the other therapeutic intervention clusters. Sources dated between 2013-2021 and 71% were from Western countries, with 29% non-Western (Taiwan and Korea). Target constructs were anxiety, depression, mood, quality of life, psychological wellbeing, psychosocial and spiritual distress, symptom distress and pain. Delivery of interventions was via psychological professions, medical doctors, nurses, physiotherapists, social workers, a hospital chaplain, and 57% involved aspects of self-delivery by participants. Samples were predominantly of mixed cancer types. Specific cancer samples targeted were breast and lung. Interventions are described according to groupings of approaches used, with five using technology-based interventions, one being a peer support intervention and one being a multidisciplinary team (MDT) collaborative intervention.

Trained peer support mentors met with patients 1-2 times weekly (for up to twelve weeks) to hold informal conversations up to two hours in length [112]. These meetings occurred in informal places chosen by participants such as patient homes or in a café. Whilst those in a control group (receiving usual care alone) experienced a decline in quality-of-life scores, those in the intervention group demonstrated an improvement. Qualitative data supported the quantitative findings, with the dynamic being viewed (by both patients and peer mentors) as a helpful blend of friendship with the extra advantages of shared illness experiences to foster coping.

An RCT source described a collaborative MDT intervention [113] which comprised of six structured in-person sessions addressing facets of quality of life (cognitive, physical, emotional, social and spiritual). In each session, physiotherapists gave conditioning exercises which were followed by other staff leading depending on given topics (for example, a hospital chaplain led a spiritual discussion, and a psychologist led a discussion around cognitive-behavioural coping strategies). Each session concluded with breathing or guided imagery exercises. This series of six sessions was then followed by ten brief counselling sessions delivered via telephone, which aimed to foster the uptake and continuation of strategies learnt. Compared to standard medical care controls, those in the intervention group had higher overall quality of life scores, although the brief counselling sessions were not seen to improve scores further.

Five sources described technology-based interventions. A source from Korea involved a mobile game that generated an avatar representing the participant, with the aim of fostering gameplay effects in real life [115]. Gameplay was recommended for at least thirty minutes, three times per week across a three-week period. The game involved education about chemotherapy side effects, encouragement to engage the avatar in valued activities to aid mood, and the avatar undertaking quests to use self-management strategies. Self-assessment was also undertaken via avatars. No reductions were found on specific anxiety and depression measures, although the mobile game group did demonstrate some improvements in certain facets of quality of life (including physical and psychological) compared to the usual care comparator. One source described a didactic web-based health intervention for lung cancer [116] in which participants were self-taught to learn symptom management strategies over three months. The web program contained lung cancer education and pre-recorded peer stories and invited participants to express their symptom experiences. Any questions were responded to within 24 hours by the researchers. Compared to usual care controls, intervention participants had a significant increase in global quality of life scores and emotional function and showed significantly lowered specific symptom distress. Three sources involved the use of virtual reality. A virtual reality computer program wheeled to patients' bedsides invited them to navigate through virtual environments with a choice of exploring an 'emotional park' or walking in nature, over four sessions [114]. A psychologist was present at each session to provide a session theme (such as joy or relaxation). Although positive mood change reached significance, these findings were limited due to use of visual analogue scales only. In another source [117] a single virtual reality session used a travel paradigm. Participants could choose to 'travel' to destinations of their choosing. These virtual travels were discussed with the researchers and family members (if present). Trends towards improvement were seen for psychosocial distress and spiritual wellbeing, and qualitative themes suggested the virtual travels enabled reminiscence, meaning-making and provided a sense of escape from present illness. Unlimited use of a virtual reality headset at home over four days [118] provided an immersive experience of nature-based and relaxation scenarios and offered an interactive game that aimed to promote personal resilience, courage and friendship. There were no significant findings after the four days on specific measures of anxiety, depression and pain. However, immediate benefits after using the virtual headset were seen on a broad symptom measure assessing pain, depression, anxiety, wellbeing and shortness of breath.

Quality assessment for 'others' cluster

Across all study designs, 29% of sources designated as 'other' were scored as being of moderate quality, with 57% scoring as high quality. Study designs were three randomised controlled trials, one single arm study, and three mixed designs. All three randomised controlled trials were of high quality, with one being fully powered to detect effects [113]. Randomisation was appropriately performed in all three, groups were largely comparable at baseline, all had complete outcome data and there was overall a good degree of adherence to the intervention. Attrition rates were low (between 5-8%) in all three sources. The main aspect of difficulty in these RCTs were that two were underpowered to detect effects, with small sample sizes. The single-arm study [118] showed innovative use of virtual reality in patient homes and was of high quality (representative of the target population, having complete outcome data and with the intervention administered as intended). However, potential confounds remained uncontrolled for (such as having no specified usage time for the virtual reality headsets). The three mixed designs were moderate in quality, with difficulties including high attrition rates, lack of clarity in whether the qualitative component adhered to the tradition of methodology involved or lacking depth of qualitative description.

Combined cluster

Nine sources were assigned in this cluster (numbers 119-127 in Table 4). Combined sources dated between 1999-2020 with 67% from Western countries, 22% from non-Western countries (China and Japan), and one spanning Western and non-Western countries (USA and Singapore). These interventions targeted a variety of constructs, including anxiety, depression, mood, emotional and symptom distress, worry, wellbeing, quality of life and adjustment to cancer. Delivery of interventions was via the psychological professions, nurses, social workers, or were self-delivered by participants. Samples were predominantly of mixed cancer types. Specific cancer samples targeted were breast and lung. Sources are discussed in chronological order within groupings of therapeutic approach used, to provide a sense of overview in developments of interventions using combined therapeutic approaches.

Four sources combined CBT and ACT and were all pilot studies. An intervention comprising 6-8 weekly in-person group sessions (with five groups running overall) was manualised and utilised a blend of CBT and ACT elements including delineation of personal values, mindfulness skills, psychological flexibility addressed via goal setting and evaluation of problematic thoughts and behaviours [124]. Significant reductions were seen in depression, anxiety and stress. ACT-based measures of psychological flexibility, compassion and mindfulness were shown to increase in a positive direction. Three individually delivered sessions across six weeks had a 'symptom cluster' as a target outcome [125], and used psychoeducation, relaxation skills, personal values, consideration of the interaction of thoughts and behaviours and of values and worries, behavioural activation and problem solving. Mindfulness, acceptance and committed action were interweaved throughout. Compared to waiting list controls, strong effects were seen on several symptom cluster aspects including worry, sleep, fatigue, depression and emotional distress. Individual telephone sessions over four sessions [126] applied CBT-based coping skills training, values-guided activity scheduling, and addressed difficult thoughts via a combined process of both cognitive restructuring and defusion. Some small reductions were suggested in areas of pain, fatigue, psychological distress and improvements were indicated in ACT-based targets of acceptance and committed action for values-guided activity. An intervention over a cross-cultural setting (USA and Singapore) offered four individual sessions across eight weeks [127]. A manualised protocol used flexibly delivered combined CBT and ACT techniques including psychoeducation, symptom skills training, activity pacing, mindfulness and values-based action scheduling. Whereas anxiety, depression and fatigue were seen to worsen in the waiting list controls, those who received the intervention demonstrated improved or stable scores in these areas (with effect sizes stronger in those from the USA). Both countries rated the intervention as being culturally sensitive.

Two sources contained combinations of CBT and existentially-based approaches. One source [119] combined a long-term psychotherapy support group with CBT skills building, offering thirty-five sessions weekly over eight months. The support group element drew upon existential tenets around facing death and dying and encouraged ventilation of emotions. The CBT aspect was a home-practice course lasting twenty weeks which ran simultaneously to the support group. No significant differences were found over time between the standard care (which included home practice covering content from a weekend-based coping skills part of the program) and the intervention groups, except following an intensive coping skills training weekend in which the intervention group showed significant improvement. However, therapists themselves reported important clinical changes over time, which the authors posit may indicate the difficulty in capturing change in long-term interventions by standard psychometrics. A multisite pre-post study with a very large sample size drew from multiple approaches tailored to need, with an overall humanist focus [123]. The intervention drew upon cognitive-behavioural, narrative, life review, meaning-based, and dignity-based approaches and lasted between 2-5 individual sessions. On overall trend analyses, those who experienced higher suffering at baseline showed greater improvements in mood, anxiety and distress. Those with lower suffering at baseline maintained stable scores in these constructs, which may indicate the intervention was preventative despite disease progression.

Two sources combined mindfulness-based aspects with other approaches. One source combined positive psychology and mindfulness meditation [120] which was self-administered with telephone guidance. Participants kept a wellbeing diary as a positive daily log, practised mindful body scans and planned pleasurable activities. A significant improvement was seen in quality of life, and qualitative feedback suggested acceptability and helpfulness although some wished the skills taught had increased in complexity. A further source combined mindfulness with art therapy over two individual sessions, in Japan [122]. Guided in-person mindfulness by a psychologist was followed by expression of feelings through artwork creation. Small reductions were seen for dimensions of tension-anxiety, depression-dejection and confusion-bewilderment, and overall mood scores positively improved. There were no changes in fatigue, spiritual wellbeing or the dimension of anger-hostility.

One source looked at patterns of change within a symptom cluster by combining psychoeducation and progressive muscular relaxation over six weeks of individual sessions [121]. An educational package was delivered for symptom management and training in formal techniques of PMR was provided. Compared to usual care at the six-week timepoint, the symptom cluster showed significant improvement both as a composite of constructs as well as individually (fatigue, anxiety and breathlessness).

Quality assessment for combined cluster

Across all study designs, 33% of combined approach sources were scored as being very low quality, 33% were moderate quality and 33% were deemed high quality. Study designs were four randomised controlled trials, four single arm studies and one mixed design. There was overall a good degree of adherence to the intervention in the four RCTs. However, RCTs were mostly underpowered to detect effects, with small sample sizes. Two randomised controlled trials were of very low quality [119; 121], with difficulties including very high attrition, lack of complete outcome data, and having groups that were not largely comparable at baseline. The four single-arm studies were moderate to high quality pilots, which were representative of the target population, had complete outcome data and interventions were largely administered as intended. However, confounds were often unaddressed in these studies such as having unrestricted access to other forms of mental health support [124]. The one mixed design was of very low quality [120] quality, with a very high attrition rate and a lack of qualitative description. Notably there were several low-quality studies in this cluster often due to high attrition, unreliability in measurement, and imbalance between groups suggesting a failure of the randomisation process.

Table 4: Couples-based, creative, complementary and alternative (CAMs), other approaches and combined approaches (list of included studies)

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating (MMAT)
83	McLean et al., 2008	Couples - Emotionally Focused Couples Therapy	Canada	Quantitative (pilot single arm)	16 dyads	High 80%
84	McLean et al., 2013	Couples - Emotionally Focused Couples Therapy	Canada	Quantitative (RCT)	42 dyads	High 80%
85	Wagner et al., 2016	Couples-based - Meaning-based psychotherapy	USA	Quantitative (pilot single arm)	12 dyads	High 80%
86	Hayashi & Onishi, 2021	Couples-based - Meaning-centered couples psychotherapy	Japan	Case study/report - used qualitative methods	1 dyad	High 80%
87	Milbury et al., 2018	Couples-based - Mindfulness-based (CBMB)	USA	Mixed design	6 dyads	High 80%
88	Milbury, Weathers et al., 2020	Couples-based - Mindfulness-based (CBMB)	USA	Quantitative (RCT - pilot)	35 dyads	Moderate 60%
89	Milbury, Li et al., 2020	Couples-based - Mindfulness-based (CBMB)	USA	Quantitative (RCT - pilot)	75 dyads	Moderate 60%
90	Mosher, Secinti, Johns et al., 2018	Couples-based - coping skills	USA	Quantitative (RCT)	50 dyads	Very high 100%
91	Mohr et al., 2003	Couples-based- not otherwise stated	USA	Quantitative (pilot single arm)	6 dyads	Moderate 60%
92	De-Moor et al., 2002	Creative - Expressive Writing	USA	Quantitative (RCT - pilot)	42	High 80%
93	Bruera et al., 2008	Creative - Expressive Writing	USA	Mixed design	24	Very low 20%
94	Low & Stanton, 2010	Creative - Expressive Writing	USA	Quantitative (RCT)	76	High 80%
95	Mosher et al., 2012	Creative - Expressive Writing	USA	Quantitative (RCT)	87	Very high 100%
96	Hilliard, 2003	Creative - Music Therapy	USA	Quantitative (RCT)	80	Moderate 60%
97	Horne-Thompson & Grocke, 2008	Creative - Music Therapy	Australia	Quantitative (RCT)	25	High 80%
98	Teut et al., 2014	Creative - Music Therapy	Germany	Qualitative	11	High 80%
99	Planos Domingo et al., 2015	Creative - Music Therapy	Spain	Quantitative - Non-randomised controlled trial	68	Very high 100%
100	Warth et al., 2018	Creative - Music Therapy - 'Song of Life' intervention	Germany	Quantitative (pilot single arm)	15	Moderate 60%
101	Bidin et al., 2016	Creative - Sound therapy (distinct from music therapy)	Italy	Quantitative (pilot single arm)	12	Moderate 60%
102	Lefevre et al., 2016	Creative - Art Therapy	France	Quantitative (pre/post single arm)	22	High 80%
103	Collette et al., 2021	Creative - Art Therapy	Spain	Mixed design	83	Low 40%

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating (MMAT)
104	Kamisli & Gokler, 2021	Creative - Psychodrama group therapy - dramatherapy	Turkey	Qualitative	12	Very high 100%
105	Carson et al., 2007	CAM - Yoga - Yoga of Awareness Program (a palliative care yoga intervention)	USA	Mixed design	13	Moderate 60%
106	Porter et al., 2019	CAM - Yoga - Mindful yoga	USA	Quantitative (RCT - pilot)	63	High 80%
107	Cronfalk et al., 2009	CAM - Soft tissue massage	Sweden	Qualitative	22	Very high 100%
108	Keir & Saling, 2012	CAM - Massage Therapy	USA	Quantitative (pilot single arm)	25	High 80%
109	Cole et al., 2012	CAM - Meditation - spiritually-focused meditation	USA	Quantitative (RCT)	83	Moderate 60%
110	Mantoudi et al., 2020	CAM - Reflexology & Relaxation	Greece	Quantitative (RCT)	88	High 80%
111	Dean-Clower et al., 2010	CAM - Acupuncture	USA	Quantitative (pilot single arm)	32	Moderate 60%
112	Walshe et al., 2020	Other - Peer support mentors	United Kingdom	Mixed design	12	Moderate 60%
113	Clark et al., 2012	Other - Multidisciplinary Team (MDT) collaborative	USA	Quantitative (RCT)	131	High 80%
114	Baños et al., 2013	Other (Virtual Reality)	Spain	Mixed design	19	Moderate 60%
115	Kim et al., 2018	Other (Mobile game)	Korea	Quantitative (RCT)	76	High 80%
116	Huang et al., 2019	Other - web-based health education	Taiwan	Quantitative (RCT - pilot)	55	High 80%
117	Kabir et al., 2020	Other (Virtual Reality) - virtual travel	Canada	Mixed design	27	Moderate 60%
118	Moscato et al., 2021	Other (Virtual Reality)	Italy	Quantitative (pilot single arm)	14	High 80%
119	Edmonds et al., 1999	Combined approaches - long-term psychotherapy group with CBT skills building	Canada	Quantitative (RCT)	66	Very low 20%
120	Ramachandra et al., 2009	Combined approaches - positive psychology & mindfulness meditation	United Kingdom	Mixed design	46	Very low 20%
121	Chan et al., 2011	Combined approach - psychoeducational & progressive muscular relaxation	China	Quantitative (RCT)	140	Very low 20%
122	Ando et al., 2016	Combined approaches - Art Therapy and mindfulness	Japan	Quantitative (pilot single arm)	10	High 80%
123	Mateo-Ortega et al., 2018	Combined approaches – based on need, with humanist focus	Spain	Quantitative (pre/post single arm)	8333	Moderate 60%

Source Number	First Author, Date	Cluster	Country	Study design	Sample size	Quality rating (MMAT)
124	Ramos et al., 2018	Combined approaches - CBT and ACT	USA	Quantitative (pilot single arm)	39	Moderate 60%
125	Wells-Di Gregorio et al., 2019	Combined approaches - CBT and ACT	USA	Quantitative (RCT - pilot)	28	Moderate 60%
126	Plumb Vilardaga et al., 2020	Combined approaches - CBT and ACT	USA	Quantitative (pilot single arm)	24	High 80%
127	Teo, Plumb Vilardaga et al., 2020	Combined approaches - CBT and ACT	Mixed (USA & Singapore)	Quantitative (RCT - pilot)	85	High 80%

Discussion

Summary of sources of evidence in relation to scoping review aims and objectives

This scoping study aimed to provide a comprehensive overview of the volume (extent) and characteristics of interventions that have been applied to treat psychosocial distress in people living with advanced cancer not amenable to cure. Additionally, the scoping review aimed to provide a broad overview of the quality of studies in this area. The primary question for the current review was:

1. *What kinds of interventions have been used for treating psychosocial distress in adults with advanced cancer not amenable to cure?*

Additionally, the review aimed to consider the following secondary questions:

2. *Have intervention types clustered onto specific types of cancer?*
3. *Have interventions clustered onto specific types of study design?*
4. *What constructs have been targeted by interventions?*
5. *What is the broad methodological quality of studies in this area?*

For usefulness and clarity, questions 1 and 5 will be considered together to provide an overview of which interventions demonstrated promise for people with advanced cancer, whilst taking into consideration the broad associated quality of studies for each cluster. Questions 2-4 will then be considered separately.

What kinds of interventions have been used for treating psychosocial distress in adults with advanced cancer not amenable to cure? What is the broad methodological quality of studies in this area?

Eight intervention clusters emerged from the charted data. In order of volume, these were: existential (31% of sources); CBT and cognitive-behavioural-based (17% of sources); ACT and mindfulness-based (16% of sources); creative (10% of sources); couples-based (7% of sources); combined approaches (7% of sources); CAMs (6% of sources); other (6% of sources).

Existential interventions comprised of various sub-clusters. These represented differing approaches which all drew upon shared tenets about meaning in life, death and dying. In order of volume, these were: dignity-based; meaning-based; life review; supportive-expressive; narrative. Overall, existential sources differed in their dosage and duration, but shared overlapping content. In comparison to other intervention types, this cluster contained a notable number of non-Western studies (particularly from Asia). This would seem to attest to the broad human-focused and pan-cultural relevance of existential interventions. Findings of efficacy in these existential interventions indicated promise, particularly the supportive-expressive sub-cluster sources, which included a fully powered RCT [35]. However, taken as a whole, existential source findings were inconsistent. This may in part be due to difficulty in accurately operationalising and capturing facets of existential distress via standard psychometric measures but may also be due to the varying levels of distress experienced by participants in these sources as several studies suggested that effects may have been missed due to inclusion of low distress at baseline. The overall quality of sources within the existential cluster ranged from moderate to very high. Most studies were underpowered with small sample sizes, and a large number experienced high attrition (including all but six out of twenty-two RCTs). Notably, this cluster contained a higher proportion of qualitative sources compared to other intervention clusters. These were all high to very high quality, which suggests an importance for qualitative research in an area where quantitative measurement of existential tenets is problematic.

CBT and cognitive-behaviourally based sources offered varied intervention content and modes of delivery. Tailored intervention content, use of technology-assisted input and the involvement of multidisciplinary staff demonstrated promise in these sources. Overall, findings were promising for anxiety but were mixed for depression, with a fully powered RCT finding no improvement for depression with manualised CBT [51]. Session numbers varied, with some studies concluding that longer durations may be inappropriate for those with severe illness and symptoms such as low energy and brain fog. The use of multiple baseline single case designs demonstrated useful applicability in these sources, enabling effects to be more likely attributable to the intervention rather than to extraneous factors [44] [50]. Regarding the quality of this cluster, most sources were deemed moderate to high quality although studies across all designs suffered high attrition. Many were underpowered to detect effects, with small sample sizes. There was notable absence of any purely qualitative sources within this cluster.

An increased interest in recent years for ACT interventions is evident in these sources. Overall, sources suggested that ACT has demonstrated feasibility and acceptability (including for telephone delivery) and some promising preliminary efficacy for reductions in symptom-related distress were indicated (such as sleep and fatigue concerns). However, substantial distress reduction was not observed in these sources overall. Low baseline levels of distress may have accounted for some of the lack of findings pertaining to distress reduction. Feasibility and acceptability for mindfulness-based interventions was also found in these sources. However, the interventions gave rise to variable preliminary findings, and the only large trial [73] did not demonstrate the significance found in an earlier single arm pilot for MBCT in prostate cancer (although these two studies had different modes of group delivery and the results of the RCT may have been affected by inclusion of low baseline distress). ACT and mindfulness-based studies were all scored as being of moderate to very high quality, with main identified difficulties being low power, small sample sizes and high attrition. The two purely qualitative sources were both deemed of high quality.

Creative cluster sources had mixed findings overall, although feasibility of delivery within palliative and hospice settings was generally demonstrated. There were conflicting findings as to whether expressive writing may help quality of life in advanced cancer by improving sleep-related disturbances. There was some suggestion that expressive writing may help people to recognise when they should seek mental health support. However, these sources did not suggest that expressive writing is effective as a therapeutic intervention in advanced cancer. For music therapy (even with a single session) interventions demonstrated positive findings for constructs including quality of life, wellbeing and anxiety, with the potential for connectedness with friends and family arising as qualitatively important. Psychodrama was posited to be helpful in cultures where death is a taboo subject of exploration as it can enable alternative means of expression and empowerment. Quality assessment of these sources was variable and ranged from very low to very high. All RCTs experienced low attrition in this cluster, attesting to the feasibility of delivery of creative interventions even within end-of-life contexts. However, all studies including RCTs had limited power to detect effects. The frequent presence of therapists whilst self-assessments were completed may have raised risk of bias in some studies.

In the couples-based cluster, use of emotionally focused and meaning-based approaches demonstrated promise for couples living with advanced cancer. The use of nurses trained in delivering meaning-centred work was found to be useful in Japan, where psychologist provision is insufficient. Feasibility was demonstrated for mindfulness-based interventions with couples. Although preliminary efficacy of mindfulness-based interventions was variable for both partners, it was positively indicated for patients in both pilot RCTs. In this cluster, quality was overall moderate to high, although studies were underpowered to detect effects, with small sample sizes. Half the RCTs experienced high attrition.

For sources using combined therapeutic approaches, feasibility and some promising efficacy was evident. The use of combined CBT and ACT elements suggest particular promise for advanced cancer via relatively brief interventions, although all sources were pilot studies and therefore larger studies are needed. A promising development added to the advanced cancer literature is the use within two interventions (one combining CBT and ACT, another combining positive psychology and mindfulness) of measuring ‘symptom clusters’ whereby symptoms can be measured both as a composite as well as individually. This may be useful for future research looking at the complex range of facets of distress that concurrently exist in advanced cancer. Within the combined cluster, quality was variable, with a third of the studies (including two RCTs) being deemed of very low quality. Studies encountered high attrition, unreliability in measurement and unaddressed confounding variables.

The CAMS cluster represented approaches that offered overall feasibility of delivery for advanced cancer, including within palliative and end of life contexts. However, all findings related to preliminary effects on small sample sizes, with positive findings often in the form of directional trends rather than significance. Massage interventions found significance through analysis of visual analogue distress scales, and qualitative analysis suggested an inner experience of existential respite. When compared with relaxation, reflexology demonstrated greater significance in one study. More studies that directly compare types of complementary therapies in advanced cancer would be useful to determine efficacy. CAMs sources were of moderate overall quality, with all RCTs underpowered to detect effects and one experiencing a very high attrition rate of 64% [109].

Sources clustered as ‘other’ demonstrated feasibility alongside some positive findings such as the use of peer mentors and a fully powered trial assessing a collaborative MDT session series. Technology-based studies represented an innovative addition to targeting psychosocial distress in advanced cancer, with longer intervention durations and higher amounts of interaction with web-based games and virtual reality suggesting increased positive findings, though these did not always reach significance. Problems with operating the technology and the initial novelty fading over time were cited as potential difficulties with self-administered technological interventions. Virtual reality interventions offered preliminary promise for immediate short-term relief of symptom distress by providing a mechanism of escape from current illness. These sources were all scored as being of moderate to high quality. One source was fully powered [113] and all RCTs had low rates of attrition, although all other sources had low power and small sample sizes.

Secondary research questions

Have intervention types clustered onto specific types of cancer?

Sources clustered predominantly onto mixed cancer samples (68%). Specific cancer samples accounted for 28% of sources, of which the largest percentage was breast cancer. Advantages to a focus on mixed cancer samples are that it provides wider representation and potential generalisability. However, it can also raise questions over how useful an intervention might be to specific cancers and therefore it is important to increase the number of studies relating to specific cancer types, particularly the less common cancers which were underrepresented in these sources. Other notable sample characteristic clusters arose; studies from western countries predominated (85%), and samples were weighted towards female gender (62%).

Have interventions clustered onto specific types of study design?

Interventions clustered onto quantitative approaches, accounting for 72% of sources overall, including sixty randomised controlled trials and twenty-five single arm studies. Qualitative studies accounted only for 12% of sources, and mixed studies for 14%.

Other notable clusters arose around how interventions were delivered. Individual rather than group delivery accounted for 82% of interventions. Interventions were delivered across a heterogenous range of settings, which is important in gaining an understanding of how best to provide psychosocial interventions in a population which is itself highly heterogenous in terms of prognosis. More work is needed to further elucidate what interventions work best in the range of different settings used across the phases of advanced cancer (pre-palliative, palliative and end of life) and at what therapeutic dosage. Providing interventions flexibly across settings according to need (including within a patient's own home) would decrease the risk of attrition but is complex and costly within study designs. Furthermore, a range of clinicians and non-clinicians delivered the interventions. After psychological professions (which accounted for 48% of delivery) the use of mixed professions accounted for 14% of who delivered interventions. Nurses delivered 11% of interventions. It is notable that sources found feasibility and acceptability in having interventions delivered by multidisciplinary professionals, which has importance in increasing the potential reach of support for patients. This may be particularly key for populations living in rural areas or non-Western countries in which the provision of psychology may be less available.

What constructs have been targeted by interventions?

A wide variety of constructs were targeted relating to psychosocial distress, which would make it challenging to compare studies within their intervention clusters (although in depth consideration of study findings was beyond the remit of this scoping review). Notably in the existential and CAMs clusters, there were questions arising over the most appropriate measures to use. Use of targeting symptom clusters (combining physical and psychological facets of distress) offered a promising means to measure multiple and concurrent types of distress in advanced cancer.

General summary

In summary, feasibility and acceptability of types of intervention were generally indicated across all eight intervention clusters. Although a majority of studies were scored as being of moderate to high quality using the MMAT criteria, findings need to be interpreted with caution when particular aspects of methodology are considered. The clear majority of intervention work in the sources rested on preliminary findings from pilot studies and small-scale feasibility and acceptability and underpowered RCTs. The proliferation of small sample sizes and the lack of power restricts statistical inferences and raises potential to miss effects respectively. However, pilot studies are necessary for early intervention investigations to establish feasibility and acceptability and are not required to generate statistical inference with small sample sizes. Apart from a few studies that achieved blinding of outcome assessors, an overall lack of blinding may hold a risk of bias. Bias was also potentially introduced in both the large number of single-arm studies due to having no control groups, and the small number of non-randomised trials, due to an absence of randomization. There were notably few purely qualitative sources (these accounted for just 12% of the overall body of evidence, with mixed studies accounting for 16% overall).

Challenges in balancing study design with the needs of such a severely ill population were evident in the high levels of attrition and variable completion of outcome measures often encountered within the evidence sources, predominantly due to death or disease progression. This is an inherent difficulty in palliative samples (Jordhøy et al., 1999). A pilot single-arm study decided that a retention rate of 67% was acceptable [21] and a fully powered RCT [51] found challenges in recruitment and retention, with attrition occurring in a third of the sample.

Limitations

This review had several limitations. Effort was made to include databases representing both psychological and medical literature. The inclusion of studies aimed at improving wellbeing and quality of life will have widened the number of included sources, but these were important to include as distress, wellbeing and quality of life are inevitably interlinked. However, although a comprehensive database search with broad search terms was attempted, it is likely that this scoping review was limited by definitions used. Although a large quantity of sources was found, some relevant papers are likely to have been unidentified. Due to time limitations and reasons of practicality, the decision to only include published literature (excluding grey literature) and to only include sources in the English language may have introduced publication and language bias. As this was a scoping review, level of detail was limited as the aim was to chart volumes and characteristics of interventions rather than attain a critical level of detail regarding efficacy, and there was no attempt to perform a meta-analysis. Use of the MMAT (Pluye & Hong, 2014) may have introduced bias via the subjectivity of the researcher. Furthermore, the decision to use an 80% cut-off to score for attrition may have been too high, given that attrition rates for advanced cancer may require a lower threshold than that applied in other cancer populations. Nevertheless, the MMAT results serve to highlight the intrinsic problem of attrition in the advanced cancer population.

There were also limitations within the sources of evidence. A high proportion of underpowered and preliminary studies limited conclusions regarding efficacy. Generalisation of findings was limited, as although samples were representative of the advanced cancer population in all sources, they were overwhelmingly of White ethnicity and clustered onto Western geographies.

Conclusions

This scoping review was the first attempt to map and summarise a large body of literature in interventions for advanced cancer, without restrictions on date or methodology. Furthermore, the review used a broad quality assessment which helped inform where strengths and weaknesses exist within the evidence base. Overall, emergent clusters indicated eight intervention types used to address psychosocial distress in those living with cancer not amenable to cure. Although findings were overall heterogenous, some promising and mostly preliminary findings were indicated along with general feasibility and acceptability. However, these sources suggest that further research is required to understand which interventions work most effectively. As the advanced cancer population is highly heterogenous (for example, in terms of prognostic range) it is also important that further research clarifies for *whom* interventions work (including across an increased range of cultures and non-Western countries). Several recommendations arise from consideration of included sources.

Recommendations

It was notable that 46% of sources in this review did not report ethnicity. It will be important for the purposes of generalisability for future studies to consistently report ethnicity and to expand focus to non-Western geographies.

Where possible, it would be of benefit for studies to make use of attentional control groups, to help assess the degree to which findings are attributable to an intervention. However, this can be difficult in settings where usual care already involves psychosocial support, as it may not be ethical to provide an alternative instead. Best practice would be use of three-arm trials which utilise both usual care and a comparator that controls for time and attention.

As distress in advanced cancer can be defined in multiple interlinked ways that can be hard to accurately measure in isolation, changes could be missed due to inaccurate or inappropriate construct measurement. Targeting symptom clusters therefore offers an alternative means of helpfully capturing change within interventions.

The range of interventions and the heterogeneity of efficacy indicated within these sources suggest that an umbrella review of systematic reviews would be a timely next step within the advanced cancer intervention literature, enabling a comprehensive analysis to determine efficacy to inform useful directions of intervention research.

An increased focus on qualitative work with appropriate choice of analytic methodology would complement quantitative investigation, yielding insights into therapeutic processes in interventions and enabling exploration of any discrepancies between quantitative and qualitative findings.

More single case experimental designs (SCEDs) would be helpful to explain the process and impact of interventions, and to deeply explore the specific needs of individuals within this specific subset of the cancer population. Across the quantitative and qualitative sources, just three case studies were found. Further case studies would be valuable to undertake in this population as they are closely embedded within the clinical context, thereby increasing ecological validity. Finding interventions that translate into the clinical context is key for people living with advanced cancer, who have fluctuating needs, limited energy, limited time due to demands of medical care, and limited lifespan. Therefore, widening the use of study designs beyond gold standard RCTs becomes particularly important in this cancer sub-population.

Chapter 2: Empirical Paper

An idiographic approach to formulation for people living with advanced cancer

Abstract

People living with advanced cancer have been identified at national policy levels as a group whose psychological needs are a priority to address. The existing evidence base for psychosocial interventions in advanced cancer is broad, with heterogeneity arising across intervention characteristics, therapeutic approaches tested, and mostly preliminary findings from underpowered feasibility or pilot studies. Recent research based on manualised therapy approaches may be problematic when seeking optimal inroads for intervention, given the complexity and differences in how advanced cancer presents from person to person. In individual psychological therapy, a thorough case formulation can indicate tailored inroads for support where needs are complex and multiple. This study aimed to take an established general model of adjustment to cancer and see where it required particularisation for a representative sample of people living with advanced stage cancers. The general cancer model was first operationalised within a systematic individual case formulation approach and then taken to a series of semi-structured interviews across two cancer charity sites within London and Surrey. An exploratory qualitative design was used, with Grounded Theory applied to analyse interview data. Additionally, an established methodology for creating individual case formulation diagrams was applied to carefully map out each individual's current difficulties, coping and world. Five higher order categories and 12 sub-categories emerged through analysis, and these reached the level of a theory by identification of a core conceptual category to explain participant experiences. A particularised representation of the original cancer adjustment model was then constructed for the advanced cancer sample. This was put forward as a practical research and clinical tool grounded in detailed individual experiences, to help find meaningful ways to specifically support people living with advanced cancer. Limitations and the potential for future research are discussed.

Introduction

Current state of the evidence for psychosocial interventions in advanced cancer

People living with advanced cancer, defined as cancer not amenable to cure, have been recognised as a specific sub-population whose psychological needs are a priority to address (NICE, 2004; Ferrell et al., 2017). Advanced cancer patients have shared that they wish to have their personal values and goals understood and incorporated into their medical treatment plans (Best et al., 2015). Despite a large body of existing literature within the field of psychosocial interventions in advanced cancer, confusion remains as to what interventions may be most helpful.

The existing evidence base is heterogenous across types of contexts in which interventions are applied, session number, duration, mode of delivery and findings. The scoping review in Chapter 1 identified eight overarching intervention types. A clear majority of this evidence consisted of preliminary findings from pilot and smaller-scale feasibility studies and there was heterogeneity of findings regarding efficacy. Furthermore, a high rate of attrition has been experienced within this population due to disease severity or death (Jordhøy et al., 1999). The strongest evidence base for intervention approaches in advanced cancer has existential underpinnings. Including some fully powered randomised controlled trials (RCTs), these approaches have found significance in reducing aspects including depression and death distress (Breitbart et al., 2018; Breitbart et al., 2015; Rodin et al., 2018). An emergent interest in applying acceptance and commitment therapy (ACT) has demonstrated feasibility and acceptability in both a recent pilot RCT (Serfaty et al., 2019) and a mixed-method study using a single-case experimental design (Hulbert-Williams et al., 2021) although significant reductions of distress have not been seen. Findings for cognitive behavioural therapy (CBT) have been mixed, with two underpowered RCTs finding an improvement in depression in metastatic breast cancer (Edelman et al., 1999; Savard et al., 2006) but with differing outcomes as to sustained effects at follow up. Other small-scale RCTs found improvements in anxiety but not depression (Greer et al.,2012; Moorey et al., 2009).

Recently a robust, fully powered RCT (the CanTalk study) compared CBT and treatment as usual within the context of Improving Access to Psychological Therapies (IAPT) services for people with advanced cancer and depression (Serfaty et al., 2020). Delivery of CBT was manualised based on an established model of adjustment to cancer (Moorey & Greer, 2012). Therapy was delivered by high intensity IAPT therapists, who were provided with training to apply the manual for advanced cancer and were permitted to utilise this with some degree of flexibility for their clients. No significant effects on depression were found, despite therapist delivery being rated as proficient. This was a surprising outcome, given that CBT delivered via the IAPT program is recommended in NICE guidelines for depression in adults, including for those with long-term conditions which includes cancer (NICE, 2009). This trial also experienced challenges in recruitment and retention, with attrition in a third of the sample. However, even after conducting a sensitivity analysis (which assumed that all those who dropped out had recovered) still no benefit of CBT was found. An embedded qualitative component within the CanTalk study found that patients felt a need for greater tailoring to their needs and suggested that other forms of intervention such as space to talk may be more helpful. Interestingly, the recent CanACT pilot trial (Serfaty et al., 2019) also found that patients valued the space to talk provided within the Talking Control condition (although both ACT and the control condition were well received and acceptable to the sample). The high intensity therapists that delivered the CanTalk CBT intervention provided feedback that they struggled with the rigidity of IAPT policies when treating this population (Hassan et al., 2018). The authors suggest that alternative means of delivering CBT may have yielded different findings.

Nomothetic versus idiographic tensions

The CanTalk trial concluded there was no benefit in delivering CBT for depressed people with advanced cancer via IAPT services. Yet there are questions arising here that are relevant to the wider body of evidence in advanced cancer. It is notable that author, patient and therapist voices arise at several points in the literature suggesting a need for more tailored, individualised approaches to intervention delivery (Hassan et al., 2018; Zimmerman, Burrell et al., 2020) including to sustain benefits over time

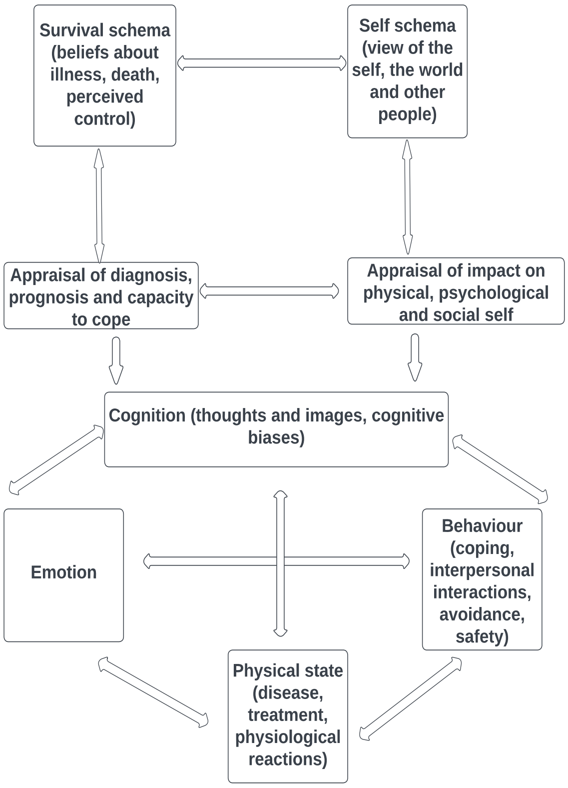
(Edelman et al., 1999). A recent meta-analysis of manualised interventions for patients with breast cancer of all stages (not just advanced cancer) looked at RCTs and concluded that these manualised interventions provided only short-term benefit (Temple et al., 2020). A small sample pilot study found significant improvements with a novel CBT intervention based on a specific theoretical model in advanced cancer (Curran et al., 2021). Other interventions based on specific models have seen only small effect sizes, which suggests that greater specificity of models is necessary for this population (Kang et al., 2019). The manualised approach delivered by the CanTalk study demonstrated feasibility for delivery within the context of IAPT services and applied an established model of adjustment to cancer (Moorey & Greer, 2012). Yet the approach taken may have been too broad to fully meet the needs of complex presentations within advanced cancer. Therapist emphasis was not on formulating within the model at a tailored individualised level.

There is therefore a tension arising here between applying a model in a generalised (nomothetic) way and a need, voiced by both therapists and patients in the study, to have a more tailored (idiographic) approach to therapeutic intervention. This point has relevance in context of the findings of the scoping review in Chapter 1. A low number of qualitative or mixed studies in intervention research for advanced cancer is apparent, and a clustering of the evidence base onto (predominantly underpowered or pilot) quantitative designs was found in the scoping review in Chapter 1. Although RCTs are considered gold standard for causal evidence, there is perhaps a need within the area of advanced cancer for further exploratory work using qualitative methodologies. A return to person-based conversations including in medical clinics, and the value of qualitative approaches within clinical research to inform treatment (rather than over-reliance on manuals derived from trial data) has been advocated within healthcare (Greenhalgh et al., 2014). Such work would enable the gathering of increased knowledge of what patients with advanced cancer experience and provide insights into what would be most helpful. The evidence base, together with the drive towards delivering CBT for long term conditions through IAPT, suggests a clear benefit in developing workable individualised approaches to meeting distress in those with advanced cancer which can then be implemented by both expert and non-expert therapists.

The Moorey & Greer (2012) model of adjustment in cancer

The core model of adjustment to cancer (Moorey & Greer, 2012) is reproduced in Figure 5, consisting of schemas relating to survival and self, cognitive appraisals, and a cross-sectional area eliciting thoughts, emotions, physical state and behaviour. This theoretical model was built over time through the clinical experience of its founders working with cancer patients, within a CBT orientation.

Figure 5: Cognitive model of adjustment to cancer (Moorey & Greer, 2012)



The model can be situated within a canon of cognitive models seeking to explain how people cope with illness, and which have a foundation in the work of Lazarus and Folkman (1984). In all such cognitive models, appraisal of a stressor mediates how someone responds emotionally and behaviourally. Appraisals involve a meaning-based judgement being made of the stressor within the worldview of the individual

(Folkman, 1997). Schemas are activated which determine choice of coping strategies available to a person. Within the model of adjustment to cancer (Moorey & Greer, 2012) it is therefore assumed that appraisals (meanings assigned, and interpretations made about illness) determine an adjustment style. Importantly, this model differentiates between impacts upon self-schema (threat to self) and survival schema (threat to life). One or both schemas may be particularly salient for any given individual, and the theory underlying the model presents four ways by which cancer can challenge belief systems. If a person has held rigid positive beliefs in their worldview their beliefs about the safety of the world may prove brittle and are shattered by a severe illness event, and overaccommodation occurs from a very positive to a very negative worldview (Janoff-Bulman, 1992). Other people who have held entrenched negative beliefs about the world being unsafe may find their beliefs confirmed by severe illness, with the negative illness event assimilating into an already negative worldview. For other people positive beliefs may be challenged but they are able to assimilate the illness event as they are able to flexibly apply strengths and personal resources. For others, severe illness undermines prior coping beliefs and resources, and negative core beliefs that are usually hidden rise to the surface.

Importantly, the Moorey and Greer model situates a person within their interpersonal and societal context, recognising that their adjustment style will be further impacted by the existence and quality (including reactions and beliefs) of systemic networks. A cross-sectional area is incorporated into the model to enable specific problems to be elicited. There is no single point of primacy within this area of the model, recognising that distress may arise from thoughts, emotions, physical state and behaviour in an interlinked manner. The information gathered here may then link back into the appraisal and schema areas of the model, offering feedforward and feedback linkages between areas. The term ‘hot cross bun’ has been used throughout the current study to describe the cross-sectional area of the Moorey and Greer model, an analogy attributed to the work of Greenberger and Padesky (1995).

The Hallam (2013) method for individual case formulation (ICF)

Formulation has been posited as a bridge between the theoretical research base and the clinical room (Blackburn et al., 2006). A specific method of individual case formulation (ICF) established by Hallam (2013) offers a systematic way of extending nomothetic theoretical models by stipulating rules about what can go into an ICF diagram and what evidence this is based on. Hallam's ICF method produces diagrams which enable visual coherence and accessibility in reformulating if later required. The method rests on eliciting functional analyses of behaviour and is therefore applicable across therapeutic approaches, unallied to any one theoretical standpoint. Mediators (often but not always beliefs that act as links in maintaining a functional behavioural sequence), moderators (factors that influence functional behavioural sequences analogous to a volume switch being turned up or down), and aspects of functional equivalence (events, feelings, thoughts and behaviours that represent similar triggers or which have similar consequences) are identified to help determine causal and contextual links within an individual's experience. Therefore, Hallam's method provides a means of systematically eliciting best fit causal explanations (applying abductive reasoning) for an individual's difficulties. To achieve this, the method uses a careful hypothesis-driven interviewing technique. Referring to the value of applying hypothesis-driven interviewing in building a thorough case formulation, Hallam notes that "human life is simply too complex to be grasped within one conceptual model or method of interpretation" (Hallam, 2013, p.133). Hallam's interviewing method is flexible, relying 'moment to moment' upon a balance of open and more directive questions to follow hypotheses and obtain accurate behavioural descriptions (Hallam, 2013, p.177). Furthermore, the interview technique aims to establish a foundation of initial trust and rapport between therapist and client by listening carefully to the interviewee, being flexibly led by what they say and offering a means to accurately represent their experience. Ultimately, an ICF formulation within the Hallam method aims to identify the most useful inroads for tailored, idiographic therapeutic intervention.

Purpose of the current study

The current study set out to operationalise the established Moorey and Greer (2012) model of cancer adjustment within Hallam's ICF framework, and to then systematically 'road-test' this with a sample of people with advanced cancer. It was important to discover what was both general and individual in the experiences of a sample of people with advanced cancer. Hallam's hypothesis-driven interviewing technique enabled a detailed walk-through of the core model space. Use of Grounded Theory was chosen to analyse iterative interviews. The resulting theory, grounded in the data, would then enable consideration of whether the data was a 'good fit' to the areas of the core cancer model. Simultaneous construction of ICF diagrams for each interviewee would complement the emerging theory by looking for causal and contextual factors and helping to elucidate individual differences (moderators) arising within the data. Taken together, the two processes would enable consideration of whether the core Moorey and Greer (2012) model provides a good fit (in terms of areas covered) for this cancer sub-population, where it may require particularisation, and which individual differences are captured for clients.

In summary, this study aimed to synergise Hallam (2013) and Moorey and Greer (2012) by operationalising the core model of cancer adjustment within the Hallam mode of hypothesis-driven interviewing and ICF diagramming. The study therefore took an established model of cancer adjustment as a conscious starting point. If the use of the Hallam approach served to contextualise (particularise) the core cancer model for people with advanced cancer (by enabling systematic identification of where the model needs particularising for this population) this would result in a formulation model specific to a sample of this cancer sub-population. This model could then be a useful tool to take forward within both clinical and research contexts, enabling the gathering of deep knowledge and indicating starting points for tailored interventions for people living with advanced cancer. The aim and research questions for the current study were as follows:

Study aim

- Taking an established generic model of cancer adjustment as a starting point, this project aims to develop an individualised formulation process specific to people living with advanced cancer

Research questions

1. What form does particularisation take when the Moorey & Greer model for general cancer adjustment is operationalised within Hallam's formal ICF approach?
2. Are interviews, delivered by operationalising the Moorey & Greer model within the Hallam method, indicated to be acceptable as a platform for forming a therapeutic alliance in preparation for intervention?

Method

Participants

Sample and setting

An initial target of ten participants was adjusted to 5-6 following recruitment difficulties. The justification for this modest sample size was the difficulty found in recruiting from the advanced cancer population even in large-scale quantitative studies (Serfaty et al., 2020) and there having been no previous study using interviews generating individual case formulations to operationalise an existing theory for this specific sub-population within cancer.

Five people participated in the study, recruited from two cancer charity sites serving London and Surrey. The sample was 60% male, with a mean age of 59. One participant had two advanced primary cancers. All were receiving current psychological support and had been selected as not being in acute crisis. Sample demographics, information pertaining to interview modality and illness characteristics of the sample are summarised in Table 5 below. Demographic detail is provided to enable rigor within Grounded Theory in terms of the limits of generalisability and potential verifiability (Corbin & Strauss, 1990).

Table 5: Sample demographics, interview modalities and illness characteristics

Demographics, interview modes and illness characteristics	
Number of participants	n = 5 (identified as P1, P2, P3, P4, P5)
Mode of interview	Online = 3 In person = 2

Demographics, interview modes and illness characteristics	
Gender	M = 3
	F = 2
Age	Age range 45 - 74
	Mean age = 58.8
Ethnicity	White British = 3
	White Spanish = 1
	Mixed (British, Middle Eastern) = 1
Relationship status	Married and living with partner = 3
	Separated and living with adult child = 1
	Single and living alone = 1
Number of primary advanced cancer types represented overall	n = 4
Primary cancer sites	Breast = 2
	Prostate = 2
	Lung = 1
	Head and neck = 1
Secondary cancer sites	Bone = 3
	Liver = 2
Type of psychological support currently received	Individual therapy with Clinical Psychologist = 3
	Group-based and individual with Clinical Psychologist = 1
	Group-based with availability of individual support if needed = 1

Inclusion Criteria

Participants were adults (aged 25+) with a diagnosis of cancer not amenable to cure. For the purposes of this study this was defined as including people with varying disease stages (usually Stage IV), varying prognoses, and encompassing cancer that has metastasised (spread to distant body sites from the site of origin), cancer that had recurred and was now deemed incurable, people living with advanced cancer as a chronic illness (Schmidt, 2016), treatment resistant cancer, and people who had reached a palliative stage. Exclusion criteria included being in acute mental health crisis, being within imminent end of life stage, and not speaking English to a level enabling sufficient understanding of interview questions.

Recruitment: Sampling and data saturation

Recruitment occurred via purposive sampling, with participants selected based on their experience of living with advanced cancer and having current distress for which they have sought psychological support. After the first two participants had been recruited, subsequent interviews were arranged using theoretical sampling according to the methodology of Grounded Theory (Corbin & Strauss, 1990: Corbin & Strauss, 2015; Glaser & Strauss, 1967). That is, participants were selected based on potential for exploring concepts arising within the ongoing data analysis. The hope had been to recruit until a point of data saturation had been reached (whereby no new data was arising), thereby enabling the concept of theoretical saturation to be satisfied. However, time constraints and recruitment difficulties meant that the alternative of achieving theoretical ‘sufficiency’ was adopted as a suggested alternative from the literature (Dey, 1999). As an alternative to theoretical saturation, theoretical sufficiency aims to develop categories containing enough depth and variation to be able to support a theory grounded in the data.

Ethics

Ethical approval was granted by the Research Ethics Committee (Royal Holloway, University of London) on 05/11/2021 (Appendix B). As the project involved charity sites and not settings within the National Health Service, approval was not required from the NHS Health Research Authority. Ethics procedures appertaining to involved local sites were adhered to.

Ethical considerations

Consultations were held with psychological practitioners and site managers within the charity settings, to discuss local site ethical procedures. The research interviews held the potential to give rise to distress, given that they would be exploring aspects of difficulty within the lived experience of advanced cancer. Therefore, these consultations helped develop the inclusion criteria in the following ways: participants should be deemed emotionally robust to take part in the study; participants should not be in either an acute mental health crisis or an imminent end of life phase of their disease; participants should be currently receiving psychological support at the charity site, which would scaffold any potential distress arising during the interview process; the researcher would respond to any distress by drawing upon clinical skills of active listening, compassion and validation, and would follow safeguarding and risk management protocols for local sites.

Two pilot interviews were held with people who had recovered from cancer and who were known personally to the researcher, with the aim of exploring where and how potential distress might be mitigated. For reasons of ethics, these pilots were undertaken as role plays, with the individuals answering not as themselves, but as if from the perspective of someone currently living with cancer. Pilot interviews provided the researcher with familiarity in how delivering these interviews might feel. They informed the phrasing of questions within the interview schedule, and the wording of the Consent Form and Information Sheet, to help ensure that language used was clear and compassionate. For example, the suggestion that the interviewer should check at the start of each interview whether an individual has a preferred wording to refer to their illness and use this throughout, was incorporated into the interview schedule.

Procedure

Site involvement

Emails were sent to managers and psychologists based within six cancer charity centres. Meetings were held with two centres, who agreed to participate in the study. Psychologists at recruitment sites made the first point of contact from their caseloads according to their clinical judgement. Psychologists had seen a copy of the Interview Schedule to help them make decisions around whether their client would be deemed emotionally robust to answer the types of questions asked. Potential participants were given a Consent Form (Appendix C) and Information Sheet (Appendix D) by their psychologist. Interested potential participants agreed to be contacted by the researcher, who explained the study and answered any questions. Participants were then given time to make an informed decision as to whether they would like to take part, and for all those who wished to participate consent was gained within two weeks. An interview date and time was arranged.

Participants were provided with a choice of whether to have their interview in-person at their cancer charity site, or online via a secure video platform approved by Royal Holloway, University of London. This choice was considered important given the potential for mobility issues and fatigue when living with an advanced illness and gave participants an option to move online if they were concerned about travelling during the ongoing Covid-19 pandemic. Where in-person was the expressed preference, liaison with cancer sites occurred to find a room and appropriate time for interviews. Before the day of their interview, participants signed and returned the Consent form (Appendix C) and read the Information Sheet (Appendix D) which outlined the centrality of confidentiality within the boundaries of exception for risk.

Interview Procedure

At time of interview, issues related to confidentiality and consent were verbally reiterated. The researcher stated that rest breaks were invited during the interview, and that the participant should feel free to share only what they felt comfortable with. At the end of the interview, participants were asked whether they would wish to add anything further, and what the interview experience had felt like for them. Immediately after the interview, a verbal debrief was provided and participants were reminded that their psychologist was available should they wish to discuss anything that had arisen. Participants were made aware that they had the right to withdraw until point of data analysis, without providing a reason or their care being affected in any way. Participant data was stored securely and anonymised using numerical identifiers. Throughout the project, the researcher received support from their academic supervisor and from psychologists at the project sites, who were aware and available whenever an interview was taking place either in person or online. An issue of potential risk arose in one instance during an in-person interview. An immediate post-interview meeting was held between the researcher and the treating psychologist to discuss this, about which the participant was fully informed.

Two interviews were held in person at the participant's cancer charity site. Three interviews were held online. Interview length was 75 minutes for one participant, excluding breaks. Four interviews lasted 90 minutes excluding breaks with consent gained from participants (at the 75-minute mark) who all wished to continue.

Materials

Interview Schedule

An Interview Schedule was required to perform the complex function of operationalising the model for adjustment to cancer by Moorey and Greer (2012), whilst also representing this model in terms of the diagramming conventions for the ICF method specified by Hallam (2013). The Interview Schedule was therefore represented in two formats. Firstly, it was mapped out as a diagram with co-ordinates to reflect all areas of the core model by Moorey and Greer (2012) and to represent this model in terms of Hallam's ICF diagramming conventions (Appendix E). Secondly, the Interview Schedule was represented as a linear script, which outlined potential questions that could be asked led by what the participant was saying, or to indicate what questions could be deliberately asked if participants did not 'visit' certain model areas (Appendix F). The linear script specified questions related to the following core model areas: survival schema (related to beliefs about illness, death and perceived control); self-schema (related to beliefs about self, world and other people); appraisals of concerns within survival schema (including beliefs about ability to cope and about the meaning of cancer); appraisals of concerns within self-schema (including beliefs about the biopsychosocial impact on the self and meanings-made); a 'hot cross bun' area which focused upon eliciting a current main difficulty (with questions to map thoughts, emotions, behaviours and physical state). To inform the creation of an ICF based on Hallam conventions, questions were included which might elicit aspects of functionally equivalent triggers or consequences (questions exploring potential differences and similarities within contexts or experiences described by the individual) and which might help to identify potential moderators for that individual (such as eliciting information about what may be helpful or unhelpful in their coping, their personal strengths, potentially relevant aspects of their personal history and resources available to them). The interview commenced with an open general question about how things had been lately for the participant, then narrowed into eliciting a current main difficulty in detail, followed by a re-widening of the focus with a blend of open and more focused questions to explore other core model areas.

Design

Rationale for use of Grounded Theory

An exploratory, qualitative design was preferred, to enable in-depth exploration of individual experiences, thoughts, feelings and behaviours whilst living with advanced cancer. Grounded Theory methodology (Corbin & Strauss, 2015; Glaser & Strauss, 1967) was selected for its central aim of producing a theoretical framework to explain (and not just describe) phenomena (Willig, 2001). Furthermore, use of Grounded Theory enables identification and linkages of processes at individual, interpersonal and broader contextual and systemic levels. Grounded Theory was considered more suited to the research aims than Thematic Analysis (Braun & Clarke, 2006) which derives meaningful thematic patterns across a body of data. Interpretative Phenomenological Analysis (IPA) was a potential alternative option. IPA (Smith et al., 2009) explores how meanings-made arise from subjective experiences. The approach asks that the researcher takes a position of duality in recognising that participants are attempting to make meanings out of their world, whilst in turn researchers themselves are attempting to make sense of this. However, the purpose of IPA is exploration rather than explanation, and the methodology is therefore not used to construct theory (Larkin & Thompson, 2012). Grounded Theory was deemed most concordant with a study which relied upon simultaneous construction of a) individual case formulations to capture causal links and identify individual differences and b) the generation of a theory that captures causally linked concepts representing the 'average' person within the data. The two research processes (construction of individual case formulation diagrams and construction of a grounded theory to represent all participants) would complement and inform one another, through their attention to causal connections (what leads to what, and under which circumstances).

Rationale for using evolved Grounded Theory methodology

An evolved Grounded Theory approach described in Corbin & Strauss (1990; 2015) was chosen over both a traditional version (Glaser & Strauss, 1967) and Constructivist Grounded Theory (Charmaz, 2014). This decision was made as the evolved Grounded Theory method provides a specific coding paradigm enabling the systematic exploration of causality, process and context within data. Furthermore, this approach acknowledges that researchers can engage in Grounded Theory to extend existing theoretical frameworks. Given that this study took an existing theoretical model as it's starting point, and aimed to particularise it for a certain population, this was an important rationale for selecting this specific methodology.

Analysis

Interviews were manually transcribed verbatim by the researcher, to aid immersion in the data and gain a general sense of what the participant was saying. Transcripts were then imported into NVivo 12 software for analysis. Memos and diagrams to aid the analytic process were produced via a combination of handwritten notes and within NVivo 12. Data collection and analysis was a cyclical process, with further data sought based on the analysis of preceding data to foster comparative analysis and drive theoretical sampling (Glaser & Strauss, 1967). Interview questions relating to how the interview had felt for participants were not included within the Grounded Theory analysis, as these were intended as questions addressing the second research question only.

Use of a coding paradigm

Informed by the suggested coding paradigm set out by Corbin & Strauss (2015), coding was of three types (initial, axial and selective coding) and followed a series of steps. Initial codes were generated by breaking the data into chunks to arrive at the essence of a piece of data, which could be an abstraction of what had been said by the participant. Sometimes an *in vivo* initial code was used to reflect the participant's own words. At points where the researcher felt stuck, initial coding occurred line by line to closely attend to actions arising in the data. With axial coding, higher order conceptual categories and sub-categories were formed by identifying initial codes that clustered together. Sometimes an initial code became elevated to become a higher order category. These categories and sub-categories indicated the direction and emergence of a theory. During axial coding, attention was paid to what conditions arise for the participants, what gives rise to those conditions, what actions are taken by the participants, what the consequences of these actions are, and what contexts are indicated. Finally, selective coding involved the identification of an overarching category which drew all other categories together, explaining the relationships between them.

ICF diagrams

ICF diagrams were created by the researcher using Lucidchart software. Construction of ICF diagrams formed part of the data analysis process and occurred following each interview. The common underlying process between Hallam's ICF method (Hallam, 2013) and the coding paradigm by Corbin & Strauss (2015) is the use of functional analysis. Therefore, one often informed the other by opening the researcher up to alternative meanings and explanations of the data. A key use of ICF diagrams was to map out a current source of distress for the participant, and to help identify potential moderators (individual differences), aspects of functional equivalence (events, feelings and behaviours that serve a similar function) and to record the researcher's hypotheses. The ICF diagrams demonstrate the areas of the core Moorey and Greer (2012) model that were visited within each interview, and suggest which areas were of particular relevance for each individual participant.

The resulting anonymised ICF series was shown to the founder of the method (Hallam) for comment to increase adherence to the diagramming method. The researcher additionally considered the ICFs against a scale designed to assess skills in their construction (Hallam et al., 2023) although formal scoring of the ICFs was not applied in this study. All participants had opted to have their ICF shown to them, with a view to it being potentially useful as a reflection of their individual cancer experience. The full ICF series can be found in Appendix G, in which personally identifiable details have been altered or redacted.

Use of self-reflexivity

Although this study did not use Constructivist Grounded Theory (Charmaz, 2014) which places a central recognition on the impact a researcher themselves has upon the work, it is important to note that the chosen method of evolved Grounded Theory does not preclude consideration of the researcher's self-reflexivity within the data (Corbin & Strauss, 2015). Although reflexivity was not prioritised as a central cornerstone of the 'grounding' process as it is with a Constructivist approach (Ramalho et al., 2015), this study acknowledged that it is not possible to separate 'who we are as persons from the research that we do' (Corbin & Strauss, 2015, p.27). Exploration of the positioning of the researcher in relation to the research occurred via reflections within memo-writing during analysis, and through continued use of a research journal until the end of the project to inform write-up. Reflecting upon assumptions, past or current personal experiences and ways that the research may be affecting the researcher enabled consideration of potential bias. Analytic strategies such as 'waving the red flag' (Corbin & Strauss, 2015, p.98) for identifying potential researcher assumptions or biases were incorporated into the analysis, and aided reflection on whether miscoding or overlooking of concepts might have occurred. Such strategies helped to prompt the researcher to remain open to alternative understandings of the data.

Quality of the research

Throughout the study, quality guidelines for qualitative research were considered and incorporated into the process of the work (Elliott et al., 1999). To foster self-reflexivity and openness around their own perspective, the researcher considered the placement of themselves within their choice of evolved Grounded Theory methodology, wrote reflective and summary memos throughout analysis, kept a reflective research journal, and held reflective discussions with both their academic Supervisor and psychologists at participating charity sites. Credibility checks were provided in the construction of materials, by way of involving both involved professionals at charity sites and pilot interviews with two service users known to the researcher. Credibility checks for the Interview Schedule and the ICF series occurred, being read by both the Academic Supervisor and by founders of both the theoretical model and the ICF method upon which the study is based. Following data analysis, a conversation was also held between the researcher and their Academic Supervisor, in which the researcher told the 'story' of the data to help them adopt a position of reflective distance at a point where they had felt too personally close to the data. Feedback on individual case formulations and the final Grounded Theory model was invited from the participants themselves, to gain their perspective on whether their experience had been captured and whether the final model resonated with them. Demographic details were gathered and reported in order that quality guidelines of transparency, and judgements about generalisability and verifiability, might be made (Corbin & Strauss, 1990).

Results

Overview of Grounded Theory higher categories and sub-categories

Five higher order categories emerged from the interview data. These were 'Experiencing the present', 'Contemplation of the future', 'Impact of previous cancer-related experiences (the meaning of cancer)', 'Impact of significant previous life events unrelated to own cancer' and 'Perception of personal history'. These five categories contained 12 sub-categories overall and are outlined in Table 6, accompanied by 51 lower-level codes from which they were derived. These lower-level codes emerged from constant comparisons and groupings of initial codes. In summarising the Grounded Theory coding, it was also important to reflect the operation of key moderators (individual differences) that affect how people cope and adjust in their daily lives. These moderator codes arose during the later analytic stage of building process and context into the Grounded Theory analysis and were selected as being factors that had a clear influence on how people coped to adjust. For clarity, Table 6 identifies moderator codes by listing them underneath the sub-category (or sub-categories, as these moderators could appear across categories) to which they are relevant. To preserve confidentiality, narrative exploration of categories and sub-categories uses quotations with personally identifiable information removed or changed, and uses anonymous participant identifiers throughout (P1, P2, P3, P4 and P5).

Table 6: Higher-order categories, sub-categories and lower-level codes

Higher order categories (theoretical codes)	Sub-categories (including moderator codes)	Lower-level codes
1.Experiencing the present	**1.1. Occupying multiples states of emotional or physical experience simultaneously (including experience of 'echo events')**	Confusion and fog Stasis whilst carrying on in the face of death Feeling of carrying on but not really coping Holding dual states of feeling Awareness that advanced cancer can change quickly Having comorbidities alongside cancer Echo events in current problems from previous distressing cancer experience, or other distressing events
	1.2. Coping strategies: helpful and less helpful strategies/actions *Moderator: degree to which social network perceived as supportive* *Moderator: degree to which having religion or spirituality is perceived as helpful*	A need to story - situating the self Use of metaphors to express emotional experience Appraising cancer as a challenge to be engaged with Appraising cancer with 'what will be will be' Self-critical thinking, negative self-talk and procrastination are unhelpful in current presented problems
2. Contemplation of the future	**2.1. Holding on to time**	'Stretching elastic on statistics' (*in vivo* code arising from participant's own choice of words) 'Holding on to a clockface' (*in vivo* code arising from participant's own choice of words)
	2.2. Future-oriented coping strategies: helpful and unhelpful actions or inactions	Making or not making plans around preparation for death Having meaningful conversations about illness and death

Higher order categories (theoretical codes)	Sub-categories (including moderator codes)	Lower-level codes
	Moderator: degree to which social network perceived as supportive	Concern for important others
3. Impact of previous cancer-related experiences (the meaning of cancer)	**3.1. Cancer experiences of self** *Moderator: degree to which social network perceived as supportive*	Advanced cancer changes the way you see yourself, others and the world Holding dual lives (pre and post cancer selves) Grief for self-identity Perception of life-stage (age) can affect coping *(Moderator)*
	3.2. Perceived relationship to healthcare team *(Moderator code)* *Moderator: perceived cultural differences in healthcare systems*	Being done to or having to compete to get on trials Being made to fit into a box, being passed around, not heard Not worth asking healthcare staff questions Saviour doctor or surgeon Sense of personal connection to healthcare staff is important for this population
	3.3. 'Echo events' of initial diagnosis experience and subsequent recurrence or progression events	Inherent uncertainty in cancer is magnified with advanced cancer Appraisal of cancer as threat to life, cancer equals death Appraisal of cancer treatment as threat to life, treatment as toxic Appraisal of cancer as threat to self Appraisal of cancer treatment as threat to self
	3.4. Previous cancer-related coping: helpful and less helpful for current coping *Moderator: degree to which someone draws on previous or current occupational skills*	Cancer coping changes over time to reflect needs of advanced cancer Proactively doing your own research and asking for second opinions Being kinder to self Use of humour is helpful

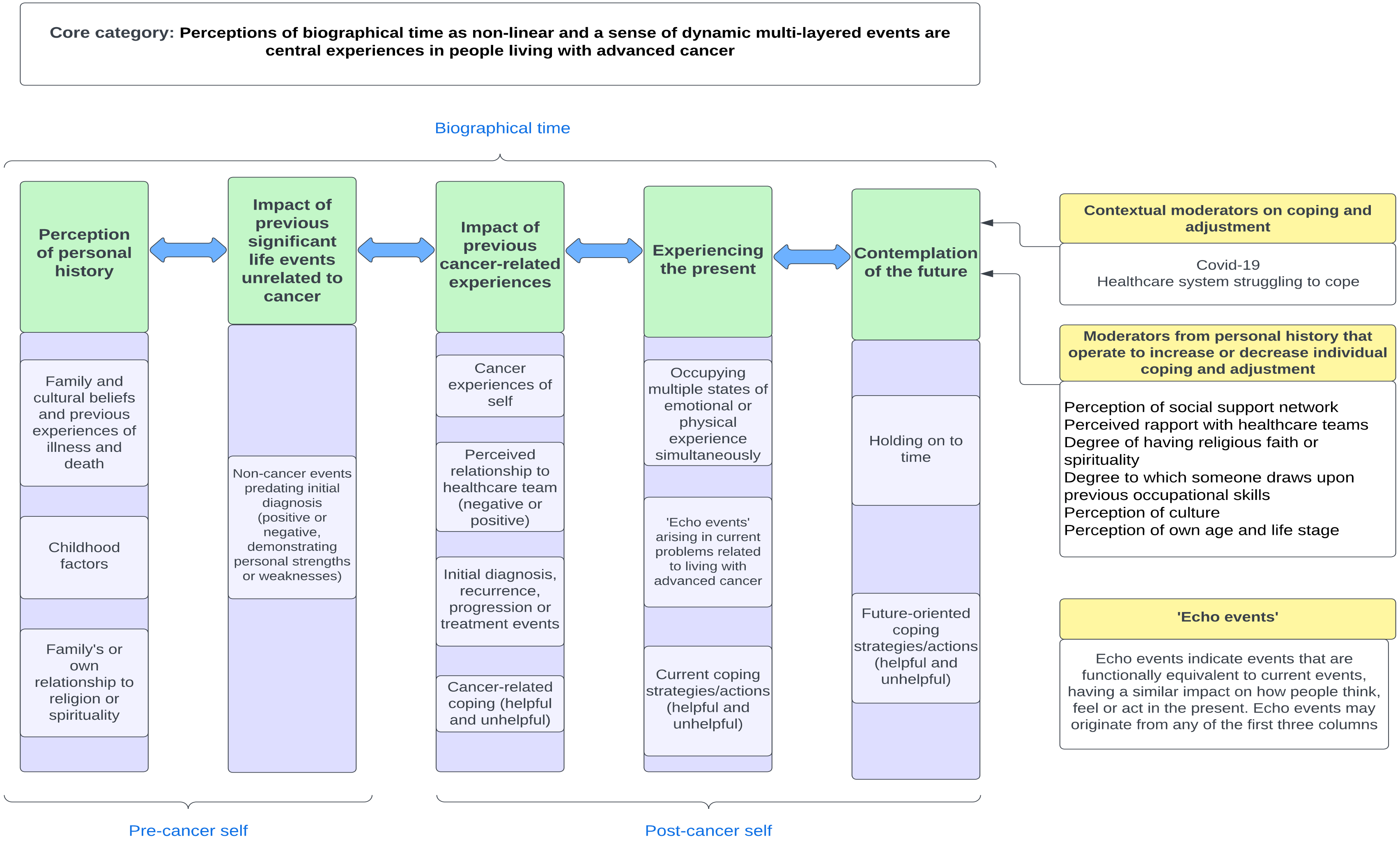
Higher order categories (theoretical codes)	Sub-categories (including moderator codes)	Lower-level codes
		Cancer prompts changes in priorities which can be positive Avoiding reality of having advanced cancer can be helpful or unhelpful Making friends with other people with cancer can be double-edged sword (can be both helpful and unhelpful) Blaming self
4. Impact of significant previous life events unrelated to own cancer	**4.1. 'Echo events' predating initial diagnosis**	Death of parent holds similarities to diagnosis and treatment events Occupational or other life achievements or difficulties Times when individual felt threatened, a lack of control or weakness
5. Perception of personal history	**5.1. Family and cultural beliefs and experiences of illness and death impact current coping**	Family beliefs do not necessarily endure, but can change over time Family beliefs can endure and inform current coping Choosing or wanting to do things differently to family of origin Recalling family experience of death as a chance for reconciliation
	5.2. Childhood factors on coping not specific to illness or death, but which still impact current coping	Being motivated by parents to be resilient Being taught to put others first Feeling that had no control as a child
	5.3. Family's or own relationship to religion or spirituality *Moderator: degree to which having religion or spirituality is perceived as helpful*	Death as a part of life The power of prayer

A Grounded Theory model

The final Grounded Theory model is presented in Figure 6. The resulting model unifies the five higher order categories in terms of biographical time, representing how sense of time was experienced in a 'lifetime' sense within the mental space of the sample. To reflect participant experiences, it was important that the concept of biographical time within the model was captured in two ways; linearly and non-linearly. The higher order categories are arranged in columns from left to right in terms of chronological linear time (ranging from early life experiences to the present) and are also divided between a 'pre-cancer' and 'post-cancer' experience of self to reflect descriptions of a time-based division of self-identity in relation to illness. However, bidirectional arrows between categories represent the non-linear perception of biographical time that emerged from the data. It was important that the model captured a fluid interconnection between and across the overarching time-based categories. The concept of 'echo events' relates to how salient events from the first three columns can reverberate across time and influence how current cancer-related difficulties are perceived. The model places the identified sub-categories within their relevant columns to reflect combined participant descriptions about what was important and in what time period.

A unifying core conceptual category was identified at the stage of selective coding, which was 'Perceptions of biographical time as non-linear and a sense of dynamic multi-layered events are central experiences in people living with advanced cancer'. This core concept was present in every interview and served to provide an explanation of how the Grounded Theory model linked together across categories and sub-categories. Boxes to the right of the model display moderators (individual differences) found within the sample. Identified moderators are individual differences arising both from participants' contexts and personal history. In summary, moderators within this sample arising from personal history were perception of social support network; perceived rapport with healthcare teams; degree of having religious faith or spirituality; degree to which someone draws upon previous occupational skills; perception of culture;

perception of own age and life stage. These moderators operated to increase or decrease likelihood of current coping based on their salience, presence or absence within current circumstances. Contextual moderators were the Covid-19 pandemic, and the political backdrop of a healthcare system struggling to cope. The contextual moderators had the effect of raising anxiety and sense of helplessness within the sample. Moderator boxes are connected by arrows feeding into the ‘Contemplation of the future’ category, to demonstrate how these factors have the potential to influence future adjustment challenges as well as present ones.



Echo events indicate events that are functionally equivalent to current events, having a similar impact on how people think, feel or act in the present. Echo events may originate from any of the first three columns

Figure 6: Grounded Theory model emerging from interview data

Findings from the ICF case series

Creation of tailored ICFs following each individual interview was a concurrent process alongside the Grounded Theory analysis. Whereas the grounded model provides a synthesis of all interviews, the ICF series visually illustrates detailed individual representations of each person's current experience of living with advanced cancer.

The ICFs demonstrated two particularly key aspects of interviewees' experience, which were prominently present in each individual interview. Firstly, the importance of functional equivalence (of previous events, emotions, thoughts, physical state and consequences) was clearly apparent within the ICF series for each individual. Functional equivalence also emerged as a key higher-level concept with the Grounded Theory model, coded as 'echo events' (Figure 6). Secondly, the ICF series clearly indicated the existence and operation of moderators (individual differences) associated with degree of coping and adjustment in each person's daily life. The moderators identified via construction of ICF are identified for each individual person in the ICF case series in Appendix G. The emergent importance of these two aspects of experience (functional equivalence and operation of moderators on likelihood of coping) enabled the building of context and process within Grounded Theory analysis. In this way, drawing the ICFs aided the researcher in maintaining a zoomed in (individual) perspective alongside the ongoing conceptualisation within the (collective) Grounded Theory process.

An example ICF diagram is shown in Figure 7 below, with the full ICF case series (altered from the originals to preserve anonymity) displayed in Appendix G. The diagramming conventions of Hallam (2013) are used as follows: circles contain observations made by the interviewee themselves; rectangles display the researcher's working hypotheses; functionally equivalent thoughts (beliefs and opinions), emotions, sensations, and behaviours are shown grouped proximally together in clusters of circles. Additionally, functionally equivalent past events are placed to the left of the hot cross bun area. This positioning reflects how elicitation of a current main difficulty often included simultaneous connections with salient and distressing events from the past. Moderators from personal history and current contexts are shown in boxes to the right-hand side of the diagrams and provide individual-level detail as to how these moderators are operating for each unique person. These moderators are factors which operate on the person's coping responses in a manner akin to a turning up or down of salience or volume (depending on varying combinations of context or individual characteristics, a person may be more or less likely to cope and adjust). Potential inroads for intervention are suggested in the lower right-hand corner of the diagram. Although inclusion of intervention suggestions does not form part of the conventions for an ICF diagram (Hallam, 2013) they are included to demonstrate the central purpose of any case formulation, and as an example of the tailored nature of interventions that may be indicated by ICF. Each individual diagram demonstrates that optimal inroads for intervention vary for each unique person (Appendix G).

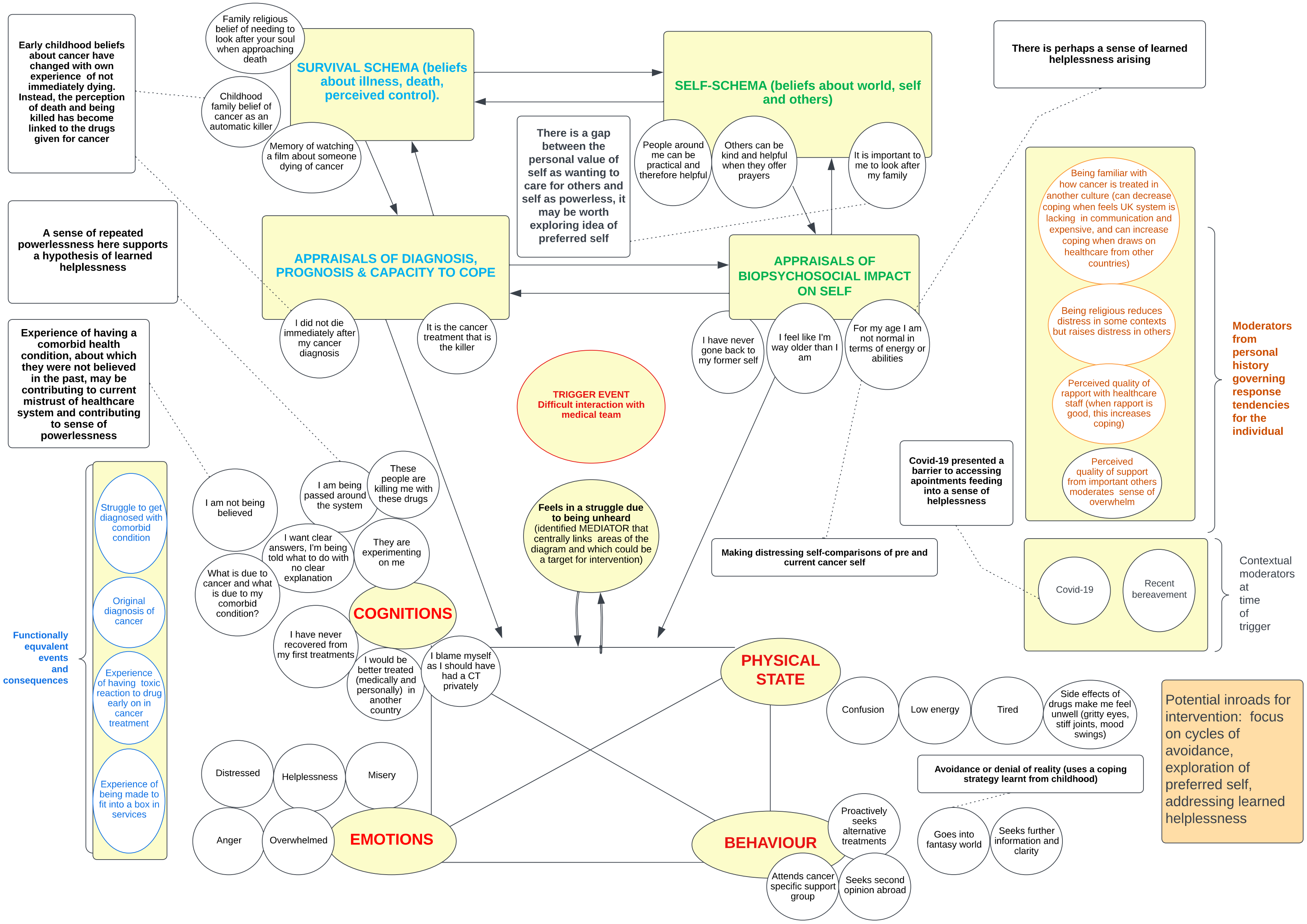


Figure 7: Individual case formulation example

A particularised model for adjustment in advanced cancer (ICF-MG)

The diagram presented in Figure 8 suggests where the core areas of the Moorey and Greer model (2012), when combined with Hallam's formal ICF approach, might be particularised specifically for people living with advanced cancer, based on knowledge gained from both the Grounded Theory analysis and the process of ICF construction. It has been named the 'ICF-MG' model, to capture its origins in the operationalisation of the core cancer model areas from Moorey and Greer ('MG') within Hallam's ICF method of interviewing and diagramming. It represents the contextualisation of the core cancer model for this sample. A box capturing functional equivalence (also seen within the Grounded Theory analysis in terms of 'echo events') serves to particularise the hot cross bun area. In this way, the hot cross bun area captures equivalent experiences (feelings, emotions, behaviours and events) arising at other times in the person's life, and which the person with advanced cancer might talk about simultaneously when discussing a current main difficulty. A bidirectional line has been added to capture the flow of feedforward and feedback experiences within the participants' sense of biographical time. This particularises the core model to explicitly represent the multi-layered experience of biographical time arising within this sample. Boxes for moderators from personal history and context enable individual differences to be explicitly sought and recorded, which will inform formulation around how these moderators may operate across varying situations. Two arrows from these moderators feed directly into the hot cross bun area representing the current main difficulty, and into the future. Contemplation of the future (in terms of coping) has been captured at the base of the diagram. Areas that are particularisations to the original core model areas are set in yellow.

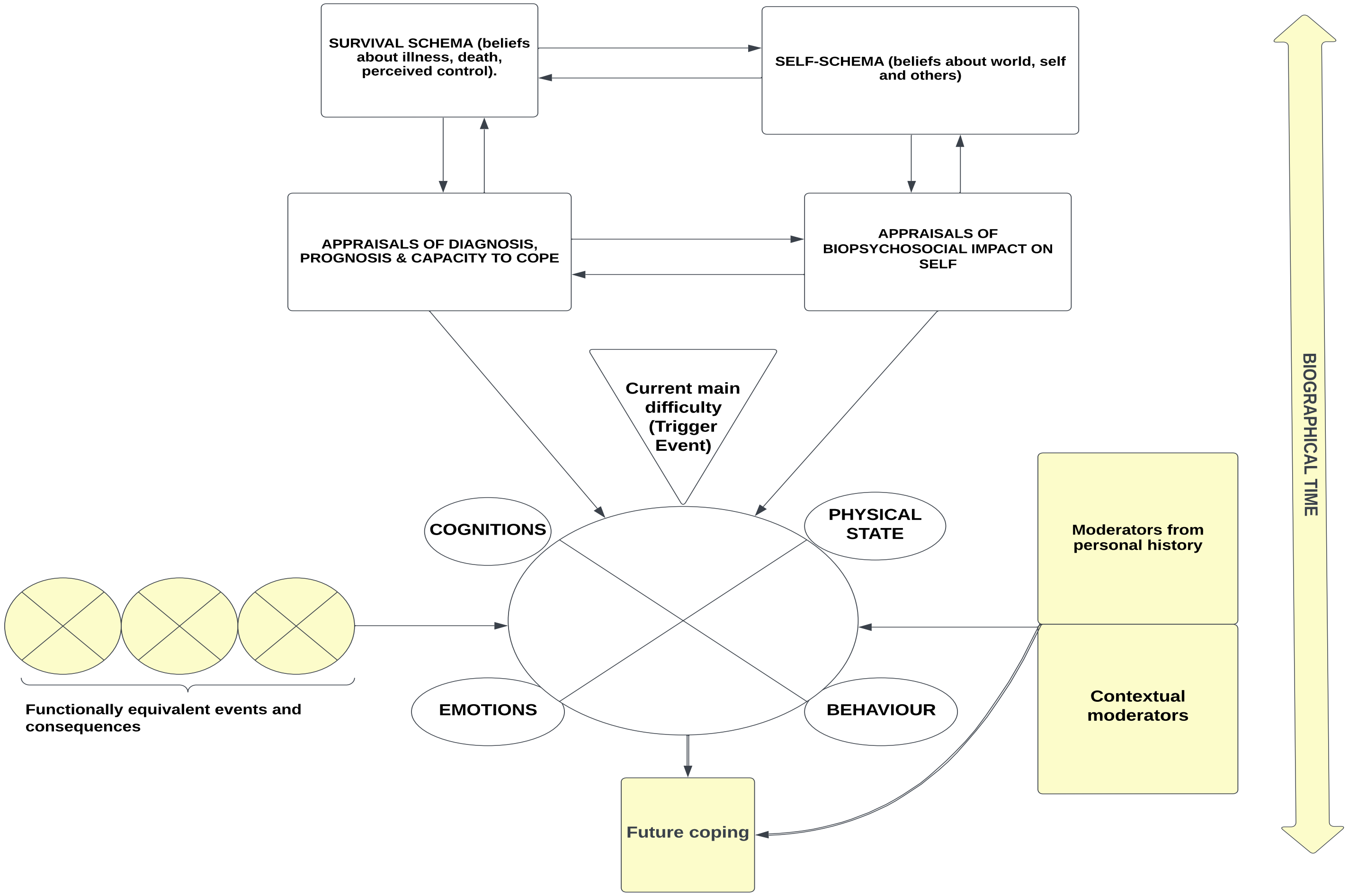


Figure 8: A contextualised model for adjustment in advanced cancer: the ICF-MG model

Narrative exploration of coded data

1. Experiencing the present

1.1 Occupying multiple states of emotional or physical experience simultaneously

This category captures a current shared sense amongst participants' of holding multiple simultaneous positions within emotional and physical experiences in their daily lives. There is a dynamic and busy energy to the words participants' use to try to explain their present reality, whilst also conveying a sense of stasis. One way this multiple self-positioning emerged was related to a sense of confusion and fog sometimes experienced in living with advanced cancer, which was particularly apparent in trying to elicit an example of a current main difficulty within the interviews. When P1 attempted to focus on a recent distressing event, they found it hard to narrow the time window down beyond a recent 48-hour period. P1's experience of distress within this time window feels dynamic and chaotic, impossible for them to grasp exact detail within the recent present.

> When I look back to the fog that I had about the whole situation…I think there were…they are maybe not in a logical order this, but just as I sort of remember them and think about it...it was like within those 48 hours there was one heck of a lot going on (P1)

P2 also reflects this sense of difficulty in homing in on a specific recent example of distress.

> Researcher: I wonder about this interview, when I ask you to give a specific example, is this something that you find quite difficult to do?
> P2: Yes, it's difficult. I might have missed something but this precise moment in time as far as the cancer, I just don't know where I am…I just don't know how I feel emotionally you know (P2)

There was also a sense of ongoing uncertainty about how to position oneself in the present within the context of what advanced cancer means in terms of prognostic time, as advanced cancer can be both incurable and treatable simultaneously: “I didn’t know what it means incurable, does it mean I’m going to die in three months’ time and as it happens, how many years has it been, six years’ time you know?” (P3). P5 speaks of the difficulty of holding a position of unknowingness.

> I think it’s that that blows my mind…I know it’s a reality of life, we don’t know what’s around the corner but living with advanced cancer you really don’t know what’s around the corner. And you feel, you really feel that you don’t know what’s around the corner. You live in that uncertainty all the time, and you manage to ignore it until something triggers you (P5)

There were also descriptions pertaining to a feeling of the present time being static whilst carrying on in the face of death. Participants often described being in a place of waiting (waiting for medical results, awaiting plans for trials) and there was a sense of time not moving. However, simultaneous with that there was a sense of how participants were also engaged in the minutiae of their everyday lives, as described by P3 when they explain “it’s about not losing the will to live for the fear of dying…we should be making plans but we are choosing curtain materials but that’s also important” (P3). A feeling of holding a dual position through carrying on but not necessarily coping was described by participants, including P2 who shared that “you don’t really cope you take every day as it comes” (P2). Participants frequently held dual states of emotion, as expressed by P1 when they had difficulty in pinpointing the right word to describe their current state of feeling.

> I was going to use the word happy, I can’t say that is the word I would use...So it is a question of yeah I’ll accept this situation, I’m not happy about it, but I will accept it providing I feel that there is nothing more that I could have done (P1)

Within the present, participants described the awareness that the trajectory of advanced cancer can suddenly change. Alongside the static sense of present time there is an inherent sense that things can move quickly, as when P5 describes "…that moment is only forty-eight hours away and that can totally change my life...things can change your life so fast in the journey of advanced cancer" (P5). There can be a bewildering realisation of holding opposite states of health at the same time, of feeling well yet needing to be prepared to receive negative medical results at any moment in the present. Participants who lived with comorbid conditions alongside their advanced cancer spoke of a further sense of duality, a sense of confusion arising when trying to understand the source of symptoms and side effects.

> And my other condition which is the fatigue I cannot myself really say which is which you know?... The side effects [of cancer treatment] made me feel unwell, and my fatigue is maybe part of the side effects or a condition of itself, or whether I was doing too much…this is an issue that I struggle to unravel (P2)

When talking about their present difficulties, participants often spoke of the past in a manner that was fluidly interweaved with current problems. It was as if the past felt closer, a sense of chronological time feeling blurred, and this experience was coded in terms of 'echo events' across biographical time for participants. For example, they spoke fluidly about present struggles with cancer adjustment and coping (during eliciting a current problem within the hot cross bun area of the core cancer model) in relation to previous distressing events (both cancer and non-cancer related).

> And it had the same reaction I think with the sport and the business situation, which both were crises, then I think my…I've never called it this bizarrely, but some people might call it a survival instinct kicked in…and I think there is part of me that I am very proud of, and sometimes I put it

> down and I shouldn’t do that and I should be very proud of it, that these types of adversity bring out the best of me (P1)

> At the moment I don’t want assisted dying but you know watching my dad dying well I wouldn’t mind that but even if you have assisted dying you don’t know what…nobody knows what dying is like do they (P4)

1.2. Coping strategies - Helpful and less helpful strategies/actions

Participants talked about helpful and unhelpful ways in which they were presently coping, with this being an important aspect to elicit within the core model of cancer adjustment by Moorey and Greer (2012). Notably, all participants demonstrated a need to situate themselves within the present using medical language, as if the chronology of medical terminology was anchoring in some way. This was often accompanied by story-style phrasing, and the sense of chronology within the narrative was in notable contrast to the difficulty participants had when trying to describe a recent distressing event. P1 contextualises themselves within the “present second” in the manner of a “resume” which denotes an ordered summary. Therefore, a need to story as a form of coping emerged in these interviews. The phrasing by P1 holds a sense of a long journey, a sense of pauses and transitional spaces: “ok very brief resume...where I am at the present second is that I am sort of in this, I think they call it the wash out period...I am in between potential treatments at the minute” (P1). Story-style language was also used by P3: '…it was stage four, metastasised to bones and right at the beginning...well I need to tell you a little story about how the week panned out really' (P3). P4 wanted to offer a chronological treatment-focused summary prior to addressing a specific recent event, again using story-style language: “I think I’ll just start from the beginning and then say where I’m at” (P4). The anchoring function of puncturing the narrative with dates linked to medical events, in order to define present positioning, was clear in an extract from P2 (details changed to preserve confidentiality).

> I had major operation at end of February. Before that I had 16 infusions and after the operation I had 6 more infusions. I would say that the last one was the end of May and at this moment in time I have recovered well from the operation (P2)

Metaphors were used by participants to describe their emotional experience, suggesting this is an important means to help them adjust and cope by enabling effective communication of their inner world. When talking of a sense of internal pressure to get things done, P3 mentioned that "It's a metaphor isn't it, hanging on to time…eventually it runs out doesn't it" (P3). For P4, metaphors about a loved pet dog offer a way to communicate current existential concerns to the younger people in the family. The metaphor has initiated a realisation around a need for future planning.

> You know, I have a dog, who's a very lovely dog…and he had some kind of dog episode and he can't walk properly anymore and he's gone blind and stuff like that. And when the children came up to see him the [grandchild] was very upset, it was a shock, to me it made it very clear that [grandchild] needed to know that I might go at some point (P4)

Participants spoke of currently coping by appraising cancer as a challenge, which fits within the adjustment style conceptualisations underlying the core cancer adjustment model. It is important that this arose specifically within the context of advanced cancer, a sense of fight confirmed as both helpful and possible:

> Within 48 hours, and I mention it particularly as I am looking at the sticker that is on the wall right in front of me, which I didn't just put here just because I knew I was on the call, but it's been here ever since, is I actually wrote down and stuck on the wall 'how can we fight back?...I am very stubborn, I am very determined, I think, to not let the cancer win…I don't want to leave any stone unturned (P1)

Rather than viewing advanced cancer in terms of a fighting challenge, P4 speaks of sometimes having an attitude of “what will be will be” which can be both helpful and less helpful depending on the situation. For helping deal with uncertainty, it can be helpful, but for an aim of hoping to communicate important conversations to significant others (which is the context of the following quote) it can be a block or a form of avoidance.

> Researcher: How do you deal with the uncertainty that you have mentioned earlier in our discussion?
>
> P4: Beyond a certain point, there’s no point in thinking about. What will be will be
>
> Researcher: Do you find that useful, to think what will be will be?
>
> P4: Well it’s a good fallback isn’t it…there seems to me there are things that aren’t worth investigating” (P4)

Participants raised negative thinking as being unhelpful in current presenting problems, with P1 describing an experience aligning with an adjustment style captured by the underlying core cancer model, in which severe illness can undermine prior coping beliefs and resources, and latent negative core beliefs rise to the surface: “In those 48 hours I really…my self-talk was very negative, quite destructive actually in relation to what happened, and I would say it…it reached areas that I rarely have reached in my life” (P1)**.** P3 described how night-time procrastination was currently unhelpful for coping with a desire to get on with things in daily life, as disrupted sleep then affects daytime mood and energy: “It annoys me a bit, yes, partly impatience and then when I actually get down to looking at my to do list, you procrastinate, it’s when you are lying in bed” (P3).

Moderators on present coping

Specific moderators of the ways participants' cope to adjust arose within the data throughout this category. The degree to which someone's social support network, and the degree to which someone expressed having religious beliefs or spirituality operated to make them more or less likely to cope currently and into the future. Where a participant viewed their support network as helpful, it was notable that they often used the pronoun 'we', conveying a perception of themselves and significant others as a team.

> If I am asked to name the biggest challenge it is when my wife gets upset, that's the thing I find most difficult to deal with of anything, because she's incredibly strong and resilient you know she is extraordinary and I just don't know how we would have coped without her (P1)

Participants described gaining support from a sense of spirituality in relation to their current coping, whether they were religious or not, such as this memory of a postcard being helpful to a sense of being carried by something or someone undefinable, despite P4 being non-religious.

> There was an American woman who makes post cards…and it's erm, it's a picture of a person who I think one presumes is Jesus, carrying somebody, two sets of footprints going across a desert and then it turns into one set of footprints and it's Jesus carrying this man (P4)

2. Contemplation of the future

2.1. Holding on to time

Participants expressed a sense of contemplating the future from the perspective of wanting time to hold still or slow down. P5 expressed a sense of feeling that they had been stretching elastic on advanced cancer statistics and reflected upon this as being linked to experiencing advanced cancer at a young age where you feel you should be able to stretch out the survival time further, although they had reached a point where they were now worried the elasticity had decreased.

> It’s because I’m younger I’d like to think that I’ve got a longer expectation, that I can keep going for longer. But statistically I’m not even sure I should be here, kind of thing...so there’s a side of me that feels really lucky but there’s a side of me that says am I coming to my end, which is when I get the fear of getting my results. That’s an age thing as well...how much longer can I pull this elastic past the stats (P5)

For P3, there is an urge to tackle practical matters to plan for their family’s future, alongside worries about whether there is enough time. P3 described a feeling as if they were hanging onto the face of a clock: “Oh yeah, I want to get it all done…One of my parents’ favourite films was a 1923 film...this scene this is how I feel [shows researcher a still image of actor hanging from a large clock face]” (P3).

2.2. Future-oriented coping strategies: helpful and unhelpful actions or inactions

Whereas some participants found making plans for the end of life helpful for their adjustment to advanced cancer, others found it negatively impacted their mood and found themselves avoiding such planning despite there being a recognised personal need.

> You know one of the songs if they have a funeral ceremony is a record that my dad had…he always liked a bit of jazz like Count Basie…and there’s a song written by (inaudible) and it was called ‘Accentuate the Positive’ so that’s a theme (P3)

Whereas the above participant finds plans anticipating end of life helpful, another finds this necessary but unhelpful for current mood: “I’m going to have to cope with it if it happens and that’s part of what’s hard thinking about, well realising that I won't be able to remain in my house" (P4). Further variation was added to this category as P4 spoke about contemplation of future planning around worsening illness being particularly unhelpful when it occurred as rumination in the night.

> If I'm trying to sleep and pain is interfering with that then I'll have thoughts about what it will be like in the future...I think it would be nice if they were in a position to look after me, but I don't know what sort of looking after I'll need, erm if I need to have 24 hour attendance obviously I can't expect them to look after me (P4)

Participants expressed a need to communicate effectively with others about future health deterioration and death, but this was easier when communicating with other adults, or where family communication was viewed as positive. The degree to which someone feels able to communicate with supportive family and healthcare networks served to moderate participant coping. When P3 shared that "I keep my children informed, they are adults now anyway" (P3), this gave rise to the question of how someone may communicate with young children. A participant with young grandchildren described the distress felt around them not being told anything. A feeling of being stuck arises because of difficult family relations, resulting in P4 feeling isolated and concerned about the future. P4 feels in a state of inaction around being able to communicate with their support network.

> I don't think [my child] has told [grandchild] about me and I think it's important, I think that's very important...I think they will be very, very upset when I die if they don't know that I'm going to die (P4)

Concern for protecting important others can lead individuals with advanced cancer to feel a positive sense of looking after others which can aid their own sense of coping as when P1 mentioned that "I know I need to be resilient not just for me but for others involved in this situation" (P1). However, concern for protecting important others by withholding information about health status can also lead to feelings of guilt around not telling them.

> I’ve got some other friends…and I was going to tell them you know I’ve got this advanced… and I thought well they’ve got their own problems, so I won’t mention it and I feel guilty about that…but I’ll have to mention it (P3)

3. Impact of previous cancer-related experiences (the meaning of cancer)

This category spoke to how participants’ past cancer-related experiences (of both self and others) impacted on their daily adjustments to living with advanced cancer. A specific moderator on coping was identified within this category, which was the degree to which a person’s social network was perceived as supportive. In previous events of distress arising during having advanced cancer, the degree to which someone’s social support network was deemed helpful or unhelpful impacted on how they coped at the time and into the present. P2 describes how their support network could be both helpful and unhelpful.

> Sometimes it’s confusing, sometimes it’s very practical. It's confusing when they start telling about alternatives treatments you could do you know...The stress of the death part, you know, people telling you you need to think of your soul...but I’m not dead yet or on my death bed” (P2)

For P1, who shared they had a sense of themselves and their support network as a team, the available support network around previous cancer experiences had been very positive and P1 feels willing to approach them for support in the present.

> I am immensely lucky to have a very, very good support structure and the thing that is probably slightly different I've found in dealing with cancer is I've drawn far more exhaustively on my support structure around dealing with managing cancer than in my business or sport (P1)

3.1. Cancer experiences of self

Participants shared a sense of shift around how they view themselves, the world, and other people as a result of having advanced cancer, and this demonstrates the resonance for this population of the model area relating to 'Self schema' within the core cancer model. One participant described a sense of clarity and a sense of behaving differently towards others in terms of the way they found themselves communicating.

> It has changed the way I see other people, the cancer has, the pandemic has...I feel, interestingly enough, I feel I see other people and the world in a much clearer way that I've ever done before. And maybe, ok, maybe I'm a little bit harsher than I used to be…I'm not sure I'd have the tolerance and patience that I had then now (P1)

There is a sense here that the contextual risk of Covid-19 interacted with having advanced cancer and influenced perceptual shifts in views of self, others and the world. P1 describes this further as a sense of combined risk which is hard for people without advanced cancer to understand. The world has become a much riskier place. The context of the pandemic moderates anxiety around trying to stay well in order to be strong enough to receive cancer treatment, changing P1's view of certain previously trusted people.

> There are others who are so wrapped up, their heads are so far up themselves that they really don't get for example why if they come and see us they need to do lateral flow tests and they are they have been extremely disappointing and upsetting (P1)

For someone else, their view of others had shifted because advanced cancer had denied them the chance to have hoped-for children of their own. This emotional pain had the effect of changing friendship dynamics.

> With my friendships, like one of my closest friends had a baby last year and I couldn't deal with it and I haven't seen her as much. We still text but all her issues now are baby issues obviously and I think I…all my friends have had children…I have detached from the relationships because I couldn't be around, especially when they were proper babies (P5)

There was a theme arising around views of self being split into pre-cancer and post-cancer selves, such as for P5 who had advanced cancer diagnosed at outset, and P2 who finds comparisons between what they used to be able to do (even with a pre-existing comorbid condition) and what they can currently do (since being diagnosed with advanced cancer) very distressing: "I definitely feel like I've had two lives. I've had the one before cancer and the one during cancer… You lose your identity in cancer, you really do" (P5). P2 also describes a sense of fracturing into pre and post-illness selves.

> I have never gone back to my former self, in that with my former self I was able to go to the gym, do one hour and a half three times a week. I was able to do my shopping by hand, I was able to manage my household, do my cooking. So I would be tired but I was able to do so many more things. I have never gone back to being able to do that (P2)

This sense of a change in self gave rise to a grief response for P1, at times when they had contemplated what they might no longer be able to do in their daily life.

> A substantial part of the way that I was feeling was grief, and understanding that grief was very much a living breathing thing as well as grieving for someone who might not be there, so grieving for what I might not be able to do, what I couldn’t do, what I was limited to doing (P1)

Perception of age arose as a moderating factor in determining coping responses. Both younger and older participants felt that living with advanced cancer was harder at a younger age. P3 spoke of being diagnosed towards the end of their career and deciding to retire as a result of cancer, a life change which is experienced as positive, without regret, and in line with age-group peers.

> It came at a time…I was [retirement age] anyway and I wasn’t taking on so much work…I wasn’t so worried about paying bills and everything and the children had grown up...so that stress of work has gone so it’s only…I’m far less stressed because I don’t have responsibility (P3)

However, P5 describes how being diagnosed with advanced cancer at a younger age was disruptive to career ambitions: “I was doing my master’s at that time at uni and I had to finish a paper…I was doing [philosophy] and erm we were talking all about death, it was really full on” (P5). For P5, a further cruel shattering of hopes occurs, conceptualised as a sense of loss in being unable to become a parent whilst still young: “Out of the whole process of advanced cancer, the biggest way that it smacked me in the face, the way it hurt me the most, is not having kids. All I ever wanted was to have children” (P5)

3.2. Perceived relationship to healthcare team

This sub-category explains how participants’ relationships with their healthcare systems served to moderate current coping depending on whether the relationship was deemed positive or negative. There is a strong sense that for advanced cancer (in which even healthcare professionals may be unwilling to discuss prognosis) the patient experiences distress when left feeling confused or abandoned, and copes better when they feel heard and actively involved (rather than remaining passive and being ‘done to’).

Perceived cultural differences in the healthcare system was a further moderator within this sample, informed by theoretical sampling which added new perspectives to the previous participants. Where conflict was perceived between medical and alternative perspectives in the UK, this caused distress for one individual, and they addressed this distress by seeking alternative treatment in another country: "In this country the protocol that is preferred is prioritise drugs… Then a friend said oh let's try something. We went to Holland. In Holland they do hypothermia, which was an interesting experience' (P2). The communication style of healthcare professionals encountered within the UK in comparison to other cultures was also a source of distress for this participant. There is a very personal sense of being 'done to' when P2 talks about their interaction with healthcare teams providing cancer treatment.

> They are experimenting on me…these people are going to kill me with these drugs, and I should be more concerned about the cancer killing me, but really I am concerned about the side effect of the drugs because they are quite horrible (P2)

Within past cancer experiences of participants, a sense of distress was apparent in the way information and treatment was delivered, often in ways that left participants' feeling unheard. Participants spoke to a sense of being passed around and communication styles experienced as didactic.

> You go to the GP and he doesn't know what to do with you, but you go to the oncologist and he doesn't know what to do with you...you are there struggling with what are these people going to do with me?... the consultant themself didn't have time to waste, just do what you're told, that was the approach (P3)

Some participants felt there was no longer any point in seeking information from healthcare professionals based on past cancer experience. The distress around living with the uncertainty of prognosis in advanced cancer is evident in the following quotation.

> I generally get no helpful answer, I know that it is very difficult for them to answer questions...They don’t tell me things, well it’s not fair to ask them how long I’ve got because they don’t know and mostly they don’t want to tell you if they have an idea (P4)

A notable aspect arising from the data was that participants described certain healthcare professionals (usually doctors or surgeons, but also including a yoga instructor) as being akin to saviours within the context of advanced cancer. These descriptions stood in marked contrast to the experiences presented previously and introduced variation into this category. Such experiences fostered current coping by providing very positive past experiences of advanced cancer care, such as for P2: “I would be dead by now, or in a hospice if it wasn’t for the surgery, for the surgeon” (P2). Participants sometimes described their admiration for such saviour clinicians as including a sense of emotional connection. Feeling close to a member of the healthcare team, and feeling heard and understood at more than just a medical level, was important.

> I met a palliative care doctor and it was terrific and they were the only doctor, well some of the registrars don’t mind being called by their first names, but the first thing [the doctor] said was what should we call each other you know and er I’ve really taken to them (P3)

However, a variation within this positive relationship to a saviour clinician emerged where someone felt personally close to them and was left feeling vulnerable when that professional was no longer available to treat them. For P5 this was experienced in a profound way when the clinician died: “That amazing man that I love and adore, who saved my life, died' (P5). This gives rise in P5 to fear about the future, and a profound sense of the uncertainty in daily life. The world has become a more threatening place.

3.3 Echo events of initial diagnosis experience and subsequent recurrence or progression events

Memories of their original diagnostic event, and for any recurrence or progression events, were prominent for participants in their consideration and description of current presenting problems. Such events were termed ‘echo events’ during the Grounded Theory analysis, as they had a reverberation effect across time. Recollection of their initial diagnostic experience held a sense of clarity for P5 which the later diagnoses of secondaries did not, with a conveyed sense of uncertainty increasing across these events that results in current distress:

> When you hear of the primary there is a clear goal, but with the diagnosis of secondaries, metastases, it is more uncertain, a sense of something being continually uncertain and the inherent lack of control that goes with that (P5)

P2 provides an example of how their initial diagnostic event was associated with a film they watched at the time, and the memory of this is contributing to distress in the present by confirming a belief of helplessness.

> I watched a film when I was first diagnosed…I watched it and it’s cruel but it makes the point. It’s a story about this very young woman who goes to primary cancer treatment and then it’s really overwhelming for her because she’s not even in her thirties you know, a very traumatising experience and all the people around her, and then it comes back and then she dies. So that sums it up (P2)

The toxic experience of cancer treatment is described as a reason for why someone may decide to have no further treatment in the present: “They give me chemo what does that do it makes you feel worse, makes you feel nauseous, even more sick” (P5). There was a sense for P1 that in comparison to their initial treatment round they currently felt more vulnerable: “I think what happened with the hospital visits in the first round it was definitely more around the brutality. But I think how I see myself differently is more vulnerable, more fragile" (P1). For P4, recollection of previous treatment events has led to a decision to decline further treatments.

> I think I've already made up my mind what I'm going to do, which is nothing because I don't see the point in going through more unpleasantness when the end result is going to be the same. It would be better to have less unpleasantness in the time I've got (P4)

Advanced cancer was also seen as a threat to self. Describing a recent event in which cancer had caused a secondary injury, P1 relates this recent event to the original diagnostic event. Sense of self and personal values are threatened once more.

> I felt I was being challenged in a dramatic way, almost sort of the equivalent of the challenges I initially felt in realising what was going on with my original diagnosis, totally to the core of what I stand for as a person, what my values are, what makes me happy, what I love doing (P1)

3.4 Previous cancer-related coping as helpful or less helpful for current coping

There were a range of helpful and unhelpful coping strategies for current coping (some of which are represented by quotations below) linked specifically to previous cancer-related experiences. A specific moderator arose within the data relating to a person's previous occupation. The degree to which someone is able, or wants, to draw on previous occupational skills was mentioned as a key approach to coping in the present. P3 sums this up nicely as someone from the creative industries, using this skill in the immediate present to draw strength from their immediate surroundings which reminded them of a church.

> There is something ecclesiastical about this building, I think, you know, churches...you know, I'm not religious at all, I don't have religion at all...But you know, I do like going to churches…the reason

> for it is they are uplifting spaces… it's partly because they've got this clear storey lighting which churches have… in a church it's always high level lighting coming from the sides, you've got the space…there is a pause space here as a physical aspect (P3)

An important observation arising from participant data was that the way they had coped with cancer had altered over time, to reflect specific needs of advanced cancer. P3 describes a difference they have noticed in a previous coping strategy of mindfulness.

> I find it quite difficult to sit there for half an hour and listen to the voice...I did find it useful more earlier on, now I find it more useful at the moment just focusing on, focusing more on practical things and getting things done (P3)

There were several examples of participants' continuing to use previous coping strategies of seeking information for themselves, which was in part related to the earlier theme of difficult communications with healthcare teams.

> You have to take control of your treatment. You have to understand, like I say to you I don't know the side effects, but I have researched what's best technique, or what's the best medication for me, or what medications there are for me and I'll do reading around all that kind of stuff. You know, you do that old thing of 'the doctor's know what they are doing but I don't believe that, I've had experience of them getting it wrong many, many times, you really have to be on it (P5)

Participants often used humour to cope in the present, including within the interview context. Past jokes were drawn upon to provide a sense of comfort in difficult material. When talking about having had multiple previous surgeries, P5 describes how this was given a humorous angle which was helpful: "We joked that he was going to make me into bionic woman"' (P5). When asked about their use of humour in the interview, P4 described how they often found humour helpful when talking about existential issues and related this to a way they hope to solve the current problem of raising the issue of death with a loved one: “I would like for me I suppose the reassurance that she knows and that we can make it into, not a joke but more or less a joke” (P4).

Drawing on past coping specifically in relation to cancer, P1 shares that having the confidence to alter priorities can be helpful: “If you can be confident enough to do what may be not what your first choice is, that helps” (P1). For someone of retirement age, switching priorities to give up a stressful job after being diagnosed with advanced cancer proved a helpful change, and fostered coping by reframing cancer in terms of opening up positive possibilities.

> It means changing priorities I think, dealing with practical things, not very efficiently but well sort of efficiently...my thing at the moment now I’m not working I try to do more [DIY]…there is an expression ‘cancer saved my life’ and before I never really understood what people meant...erm obviously not literally but emotionally probably, as you’re able to do things that…open up other…that opened up opportunities (P3)

Avoidance of reality emerged as a strategy used in the past that was still helpful for some participants to cope in the present.

> I live in a fantasy world, but I have always been living in a fantasy world because you don’t think about the cancer. You do things you like there...you change, you think about other things, think about doing other things (P2)

> I spent a long time in denial, like many years in denial, I think I still have times when I am in denial …I think it was a) my determination to be normal and b) my avoidance of what was going on…

> Sometimes you don’t have a choice and you just have to get on with things and avoid things that may stay on my mind (P5)

Self-blaming arose for several participants, a coping strategy they had developed to seek answers for why they had originally got cancer. P4 expressed self-blame linked to lifestyle factors.

> I was pretty gobsmacked to discover that I had cancer, but at the end of the day…it didn’t surprise me, you know, I smoked. I stopped smoking I think ten years ago now which isn’t very long ago but it’s a bit of a bugger that having stopped I then got it but you know sod’s law. I think also you get cancer for all sort of reasons I mean there are all sorts of things involved in the getting of cancer, negativity in your own life I suppose (P4)

For P5, self-blame also holds a useful aspect as it enables a sense of having control over the cancer.

> I do think that the hardest thing for human beings to accept is the loss of control and not having control.... it was something about moving from I’m responsible because if I’m responsible than I can change it. But if I’m not responsible and it’s random then I can die.…So the blame game is useful in that way, as it is a way of saying well I’m culpable here so I’ll find a reason, I’ll look for a reason and I’ll trace it back (P5)

4. Impact of significant previous life events unrelated to own cancer

4.1. ‘Echo events’ predating initial diagnosis

Events that seemed to reverberate across time for participants were coded as ‘echo events’. Such events contained contemplation of personal strengths or weaknesses which informed current coping. P1 describes how the death of a parent has been recalled at key timepoints over having cancer.

> I think it is interesting actually…I found…if I’m looking at the impact that finding out I had advanced cancer and all that goes with that that’s had on me since, I probably had the same reaction as I did when my mum died in particular, which is I was in shock for quite a considerable amount of time (P1)

Some echo events related to non-death events, including within previous careers. P1 describes how similar feelings and behaviours were playing out in their responses to a current main difficulty.

> In the [career] context after a run of years of success, I suddenly found myself with a gun at my head, you know, likely to lose my job, in a seemingly impossible position…and the cancer injury had the same reaction I think with the sport and the business situation, which were both crises (P1)

Another type of echo event arising during previous and current cancer experiences was expressed as linked to a traumatic loss of control similar to that experienced when younger. This influenced current coping in the form of a need to seek control over living with advanced cancer.

> I think that was all the conflict of the control of my parents……I started mucking around with food and then I was hospitalised at the age of twenty…my whole thing is control, because I never had control (P5)

5. Perception of personal history

5.1. Family and cultural beliefs and experiences of illness and death impact current coping

Participants described familial and cultural belief systems, and illness experiences, that were influencing their current coping. Appraisals of these had changed over time, some had endured, and sometimes participants were actively trying to resist or change them. P2 expressed a sense that once rigidly held beliefs about severe illness from within their culture and family of origin had seemed to alter, that their perspectives had shifted from what they had learned in the past. This shift in belief system (from threat to life towards threat to self) had occurred directly through experience of living with advanced cancer.

> P2: When I was growing up it was you get cancer, you die straightaway
>
> Researcher: So in a way it has shifted your perspective of what you might have learnt in your past? It sounds like those very clear messages about you get cancer, you die, may have altered?
>
> P2: Yes, it is no longer so black and white there are more grey areas there. If anything for me my biggest bother is that I am limited in what I can do (P2)

Once entrenched family beliefs had also changed over time for P4.

> Cancer means death...but also its maybe because you are talking about you know back in the day perhaps it wasn’t such a…I mean my mum grew up on [an agricultural setting] and perhaps it is that old mentality, I mean nowadays it isn’t like that (P4)

For P5 there was a sense of having challenged dominant cultural beliefs about cancer, to feel ownership of their illness through spoken words.

> Cancer means death, cancer means death. I think in the whole community cancer means death…I think in my culture, you know, you don’t really talk about illness, it’s all very secretive and that’s been one of the hardest things of me owning my illness because I wasn’t allowed to own my illness, it had to be a secret (P5)

P3 describes a conscious decision to approach illness and death differently to their parents. The emotive reasoning for this becomes clear when P3 recalls a memory of a parent dying of cancer that is currently influencing current decision-making around end of life: "You know my mum called me up and said oh you better come over he hasn't got long. It was horrible sitting there and watching him die. I really don't want my kids watching me die" (P3). For P4, a salient and comforting memory of death within the family (even where there had been fractured relationships) offers an image of reconciliation and a mending of previously difficult communication. This held a hopeful significance within P4's current concerns about what the end might look like.

> My mother used to sit with him at night, I don't know why she did, and I used to go and sit with him in the daytime. And erm …his hand came out of the bed and took my hand, which is quite amazing (P4)

5.2. Childhood factors on coping not specific to illness or death, but which impact current coping

Parental styles in upbringing were a childhood factor for P1 in the form of instilling toughness which they drew upon regularly in their current fighting style of coping.

> My father drove and encouraged me, but he drove and encouraged me to a very obsessive level and was absolutely merciless in pushing me and pushing me to be better and better. Now this sounds…there was a lot of good in that, so it has given me tremendous sort of competitiveness, I am an incredibly competitive person and have a hunger and a determination to be the best (P1)

P1 also describes drawing upon the gentler style of their other parent to cope in the present, a description that held similarities to the help their psychologist was providing.

> Mum would be the one who would, you know, tell me what I needed to improve but do it in a way that I listened to it, so she was the one who would pick me off the ground and put me back together again (P1)

Familial and cultural childhood beliefs about how someone should behave and think had persisted into the present for P5, and this was having a difficult impact on current coping as they struggled to put themselves first.

> I've been conditioned to look after whoever else is in the room rather than myself. My mum's the same…I wasn't allowed to stay at anyone's house, not even for one night, not even family, and not allowed on school trips. So I had no control, and the only control I had was what I ate, I'll control that thank you very much (P5)

A strict upbringing had given rise to a need to gain control as a child. In the present, previous efforts to gain control felt undermined and reversed by an increasing sense of uncertainty within the world.

5.3. Family's or own relationship to religion or spirituality

The degree to which someone held a sense of religion or spirituality arose as a moderator operating on current coping, in ways that could be helpful or unhelpful. When contemplating the prospect of death, P4 found that previously longstanding spiritual beliefs around reincarnation seemed to be losing their helpfulness within the context of advanced cancer: "I think they used to be helpful, but I don't think they are anymore" (P4). Another participant had experienced a loss of religious faith, which was directly linked to the experience of advanced cancer.

> I lost my faith, which was horrible. I still struggle with that. I've never been extremely religious, but my family are…but I, I definitely lost my faith in god. I think when I couldn't have children, I think that was the hardest, hardest, hardest thing for me (P5)

Someone else found spirituality helpful via a lens of art and architecture and linked this to a sense of community with others which helped them to cope.

> Researcher: Is there something about having a sense of spirituality, whether that's in the beauty of artwork or buildings, that is important for you?
> P3: Oh yes, in that sense yes yes, in that sense…it's an emotion isn't it and also like I was trying to explain it's not just an individual emotion it's an emotion of communities isn't it (P3)

Having religion was suggested to be helpful as it could offer a sense of comfort, and when someone did not have religion this gave rise to some anxiety around contemplation of dying.

> I'm not afraid of being dead, I'm afraid of dying. Because not having any religion is quite, I mean I was sent to a boarding school, I think my mother was probably slightly religious although I don't remember her ever going to church, but they both had priests at their funerals erm so you know yes it's the process of dying (P3)

For P4, a sense of death as part of life arose from the contexts of both their childhood upbringing and from their adult family life.

> It was easier for me to find out about death and for my children to, because we had a lot to do with the countryside and farm animals, which you are not particularly emotionally attached to but you take on board as a part of life which is important about death, as death is a part of life, it's not…I

> think a lot of people tend to think of it as the end of life, I don't think it is, I think it is just part of life (P4)

The power of prayer from others arose within the data, both in examples where the participant was religious and when they were not: "When they pray for me that's nice, there is power in prayer, they work' (P2).

> P3: My neighbour across the road when I told her...she actually put her hand on my shoulder and said a prayer for me and I thought that was really sweet
> Researcher: Because of the human connection underneath?
> P3: Yes, because she believed it (P3)

Interview feedback from participants

Open questions relating to how the experience of the interview had felt were not included in the Grounded Theory analysis, as they did not relate directly to exploration of cancer adjustment. The part of the interview focusing upon a current distressing event was described as useful as it was so immediately important to the person: "I knew there was an amount of opening up. I think it's been good to reflect on the [current distressing] experience as it's been so current and it's going on as we speak" (P1). The wider focus encompassing other times of life and other contexts was also viewed as helpful: "Knowing or getting to know and understanding the bigger picture is fundamental" (P1). There was a sense of the interview offering participants' an opportunity to review their current situations within the context of their lives: "You have given me lots of space today to talk, it is helpful for me to talk things through...it gives me the opportunity to review things, to process things" (P2). An experience of the interview having elicited a lot of information was commented upon as somewhat surprising: "Oh it's been interesting, it's covered a lot more details than I thought it would" (P4). One participant shared that they had wanted to come to the interview specifically to speak about distress they were currently experiencing.

> I have to say one reason I wanted to meet here is because this is happening…I didn't think this [emotion] was going to happen…you can't talk about it without being tearful erm but I thought I'd got over that… thank you for letting me ramble on (P3)

Within this quotation there is a suggestion that the interview enabled expression of emotion and space to talk freely. Other participants commented on the interview reaching areas of emotional challenge whilst feeling contained: "I found aspects of today challenging but I think you, you've come from a position of support, you come from a position of interest, and I genuinely want to share things that might help other people" (P1). During the interviews, there were points where participants shared that summaries and testing of hypotheses was helpful: "Yeah, I like that, that's brilliant, I think you're right, you've nailed it, actually it's really important to not get caught up in that. You lose your identity in cancer" (P5). Participants also seemed to gain a sense of encouragement around sharing their difficulties when explanatory normalisations provided a rationale for asking questions, such as for P3 when they had difficulty describing emotions.

> P3: I don't know how I feel emotionally you know, I'm a sort of empiricist
> R Yes. Sometimes people find it easier to link what is going on for them in thoughts or feelings to their body. Sometimes you might become aware of a bodily sensation and then have thoughts or become aware of feelings that are bound up with the sensation
> P3: I think partly because this week has been quite tiring I've been here three times this week and I was also basically two days in the hospital waiting around and I was quite grumpy this morning. I'm not particularly chatty in the mornings anyway, and I felt…I wasn't feeling very happy this morning (P3)

Discussion

Overview of aims and findings

The current project arose at the intersection of nomothetic (general) theory and idiographic (unique individual) evidence gathering, originating from a sense of curiosity around why a recent fully powered RCT had found no effect of IAPT-delivered manualised CBT on depression for people with advanced cancer (Serfaty et al., 2020). A question arises as to whether the manualised approach taken may have been too broad to fully meet the complex needs of people living with advanced cancer. The value of returning to exploratory methodology by taking case formulation directly to a sample of people with advanced cancer seemed timely based on the heterogenous evidence base within intervention research in this field, evidenced by the scoping review under Chapter 1 of the current project. Therefore, this project aimed to take the established theoretical (general) model of cancer adjustment by Moorey and Greer (2012) as a conscious starting point and operationalise it through a formal method of individual case formulation established by Hallam (2013). By operationalising the core cancer model within Hallam's flexible yet hypothesis-driven interviewing mode (and subsequent construction of diagrams according to Hallam's specified conventions) the project aimed to explore the ways the core model could be particularised for a sample of people with advanced cancer. Data analysis occurred in two concurrent ways; through use of Grounded Theory and the construction of ICF diagrams. In essence, building a grounded theory aimed to identify what was general (nomothetic) across the participants, whereas the construction of individual (idiographic) case diagrams offered detailed insight into the current difficulties of individuals living with advanced cancer.

Five higher order categories emerged from the grounded data to represent the perception of biographical time for the sample: 'Experiencing the present', 'Contemplation of the future', 'Impact of previous cancer-related experiences (the meaning of cancer)', 'Impact of significant previous life events unrelated to own cancer' and 'Perception of personal history'. The grounded data reached the level of a theory through identification of a unifying core conceptual category, which was ‘Perceptions of biographical time as non-linear and a sense of dynamic multi-layered events are central experiences in people living with advanced cancer’. A Grounded Theory model was proposed (Figure 6), representing the general findings across the interview series. Together with detail from the ICF diagrams, the Grounded Theory model informed the representation of a particularised model specific to a representative sample of people with advanced cancer. The resulting ICF-MG model (Figure 8) is proposed as a useful tool to identify inroads for intervention for advanced cancer, within both future research and clinical contexts.

Research questions

1. *What form does particularisation take when the Moorey & Greer model for general cancer adjustment is operationalised within Hallam’s formal ICF approach?*

Coverage of core model areas within the interviews

To answer the first research question, the degree to which the interviews managed to explore all areas of the core cancer model needs to be considered. Coverage for each individual interview can be seen in detail within the ICF series in which a ‘map’ of each person’s experience was captured (Appendix G). All core components of the cancer model were explored across the ICF diagram series, suggesting that all core areas held current resonance for participants based on the experiences they shared during the interviews. Just one interview found a ‘cold’ area in the diagram, where ‘survival schema’ was not felt to be currently relevant to the participant (this is indicated by a greyed-out area in one diagram in Appendix G). However, it is perhaps unsurprising that within a sample of advanced cancer patients, most felt a high sense of threat to both their life and to their self-concept. Within the visitation across the core model areas, it was notable that discussion of coping strategies could arise at any point and were often spontaneously shared by participants. This served to elicit a range of helpful and unhelpful coping strategies within the data analysis. This is an important intention of the core cancer model in which the coping strategies currently available to a person interact with their interpretation of stressors they are experiencing, and thereby facilitate or hinder adjustment (Moorey & Greer, 2012). This suggests that operationalising the model within the Hallam framework allowed this aspect of the core model to be captured thoroughly. The Hallam interview method relies upon a careful blend of open and more focused questions, allowing flexibility for interviewees to talk freely whilst enabling follow-up on specific lines of inquiry. For example, when participants brought up ways in which they coped, use of focused questions then helped to explore hypotheses (both during the interviews and afterwards at diagramming stage) around where previously helpful coping might have become unhelpful coping. Within the Grounded Theory analysis, a time-based framing of coping emerged from the data, with distinct sub-categories arising for current, past, and future-oriented coping. This enabled explanations of what was helpful or unhelpful across the whole sample, by comparing data between and within individuals using the Grounded Theory techniques of constant comparison and generation of further questions to explore via the next iterative interview (Corbin & Strauss, 2015). In this way, analysis sought to build variation and depth into emerging categories.

Furthermore, the full coverage of the model areas attests to the technical ability offered by application of the ICF method in capturing a large and detailed amount of knowledge. This was striking given that these interviews were delivered within a one-off interview context. In clinical practice, Hallam's ICF method states that although an initial assessment should not take an unreasonable length of time and should be as comprehensive as possible, there is a recognised need for ongoing assessment particularly in cases where a person's problems are complex (Hallam, 2013). Given that the presenting difficulties of the current sample were multiple, this attests to the value of using the systematic ICF method to 'map' difficulties in a comprehensive way, even within a single interview outside a therapeutic context.

Particularisation for the hot cross bun area of the core cancer model

Particularisation of the hot cross bun area of the core cancer model was indicated to be important to this sample. This was suggested in both the application of the Hallam method, and within the final Grounded Theory model (Figure 6). The non-primacy of any aspect of the hot cross bun, which emphasises an interplay between thoughts, emotions, physical state and behaviour is centrally important within the established general cancer model (Moorey & Greer, 2012). Therefore, cognitions are not given primacy over the other areas, allowing for a distress trigger to arise from any part of the hot cross bun. The hot cross bun may then link back into the appraisal and schema areas of the model, offering feedforward and feedback linkages between areas. A previous study (Roberts et al., 2018) had used Grounded Theory to revise an earlier (non-cancer specific) cognitive model for coping with illness set out by the work of Folkman and Greer (Folkman, 1997; Folkman & Greer, 2000). However, the study was not specifically designed to operationalise the model as in the current study, and authors were aiming to extend (rather than particularise) the illness model. Yet there were interesting similarities to the current findings in terms of the identified importance of non-linearity for this population. The authors found that the original linear illness model (in which people were posited to go through a linear appraisal and coping process culminating in a state of positive coping) required flexibility to capture the impact of multiple (rather than single) events, appraisals and feedback loops in coping. People with advanced cancer, as in the Grounded Theory findings of this study, were found to hold concurrent awareness of a multiplicity of events and coping was not a linear process. Indeed, participants within the current sample expressed holding dual states of emotion simultaneously and described being in a place of both coping and not coping at the same time. The state of occupying non-linear positions is captured well within the linkages between areas of the core model by Moorey and Greer (2012).

Related to this, the systematic walk-through of the core model space via the Hallam method indicated that the concept of functionally equivalent events assumed key resonance for this sample. For each person, the ICF method elicited several instances of functional equivalence (previous other events that resembled the current trigger event in a meaningful way, giving rise to consequences in the form of comparable thoughts, emotions, physical states and behaviours). For example, in the example diagram (Figure 7) four examples of functionally equivalent events and consequences arose in relation to the current main difficulty of distressing interactions with the healthcare team. These comprised a memory of previously struggling to be heard and diagnosed with a comorbid condition, the original cancer diagnostic event, a cancer-related treatment event accompanied by the belief that the healthcare system was doing toxic harm, and the recollection of feeling made to fit into a protocol within IAPT psychological therapies. All these prior recollections of threat and the appraisals of these threats were currently contributing to the cognitions, emotions and behaviours related to the present difficulty. The hypothesised result was that a sense of powerlessness and learned helplessness was currently arising, which could be a useful inroad for tailored psychosocial intervention. As the story started to emerge from the data, a sense of layered multiplicity to past and present events became clear. Participants appeared to be holding multiple simultaneous recollections and responses to highly salient and accumulated distressing events. This gave rise to a sense of difficulty or confusion around providing a focused example of a current difficulty within the hot cross bun. A sub-category (‘Occupying multiple states of emotional or physical experience simultaneously’) also took shape across the iterative interviews by using deliberate questioning around why participants were finding it difficult to home in on a specific example of current distress.

Particularisation via explicit reference to perceptions of biographical time

The Grounded Theory analysis and ICF process indicated that an explicit focus on the concept of perception of time was important for this advancer cancer sample. There is support within the literature for an altered perception of time in people with advanced cancer compared to when they were in a relatively healthy phase. In one study (Lövgren et al., 2010) this interesting change in time perception within palliative lung cancer patients was posited in terms of a distinction between ‘clock time’ and ‘embodied time’ arising from sociological literature (Davies, 1994; 1996). ‘Clock time’ is conceptualised as a linear, socially normative view of time. According to a clock-based view of time, a person can feel a sense of needing to hurry, to get things done, which can affect how they feel and behave. Therefore, it may be suggested that a linear sense of time in advanced cancer can give rise to a sense of pressure, a feeling of running out of time (demonstrated within an in vivo code in the current sample of trying to hold onto a clockface). Yet there is another conceptualisation, representing how an individual experiences a more complex form of time inside themselves. ‘Embodied time’ describes how each unique person inhabits a body which is enmeshed in contexts that are systemic and interpersonal, including historical (Davies, 1996). For a sample of 35 palliative lung patients (Lövgren et al., 2010) thematic content analysis suggested a narrowed perception of time where the person existed largely in the present as a coping strategy (rather than thinking about the past or the future) in the face of a finite future. Interestingly, this time concept was suggested to collide with a healthcare-based view of time, which helped explain why patients found waiting times so distressing. The concept of embodied time therefore became dominant over clock time. In another study, a difference was suggested between a future-oriented focus on time for recovered cancer patients, and a present-focus for end-of-life advanced cancer patients (van Laarhoven et al., 2011). Also, within a hospice or palliative context, patients were found to exhibit a changed sense of time, whereby they paced themselves differently by choosing to focus on the day to day rather than on the past or the future (Rovers et al., 2019).

In line with the other studies discussed above, the current study also found an altered perception of time within the advanced cancer sample, with the concepts of clock time and embodied time represented in terms of linear and biographical time. Participants expressed a sense of occupying a position of existing within both static and dynamically moving time, which aligns with the changed pacing of time found in Rovers et al., (2019). Participant distress at healthcare system waiting times and the fear of sudden medical results serving to quicken linear time, correspond well to the findings in Lövgren et al., (2010). However, in the current study time was perceived as being less present-focused than in the previously discussed studies. Rather, time felt multi-layered and complex in the way events interacted over time to inform present cancer coping, with past and future feeling overlapped with the present. Distressing past and potential future events felt saliently present to participants, whilst they also voiced a feeling of an incongruous clash between linear and biographical time by feeling internal pressure to make plans for end of life whilst also looking towards normal aspects of their future such as choosing curtain materials.

This conceptualisation of a changed perception of time in the current sample (an interweaving of past, present and contemplation of the future) provides further rationale for particularisation of the hot cross bun area of the core model within the current sample, as this enables a fluid capturing of simultaneous events within time. The bidirectional arrow within the ICF-MG diagram serves to provide a reminder of how linear time is acknowledged as useful to provide a sense of chronological clarity for the current sample (analogous perhaps to their identified need for storying) yet holds an altered importance in terms of fluid feedback and feedforward of experience. Childhood and earlier adult experiences around death, illness and self-identity felt salient to participants, influencing current responses to difficulties both in helpful and unhelpful ways. It may be that as advanced cancer patients get closer to imminent end of life (which for ethical purposes the current sample were not) the present time takes greater precedence than the past or the future, in order to cope.

Particularisation of the core model by explicitly identifying moderators

Further contextualisation of the core model is provided by identification and diagrammatic recording of moderators. In the current sample, these provide a sense of likely coping direction (factors operating to make someone more or less likely to cope) for individuals. The systematic walk through the model space provided by application of the Hallam method enabled identification of moderators (individual differences) of both personal history and a person's context. Moderating factors were also captured during Grounded Theory analysis in the form of moderator codes. In the ICF example (Figure 7), identified moderators from personal history were: level of familiarity with cancer treatment in other cultures (including awareness of how communication about treatment can differ between cultures) which is serving to increase coping when the participant is able to draw upon second opinions abroad or when they meet clinicians who can speak the same language; having religion (which can increase coping when prayer is perceived as powerful, yet also decrease coping when others cause distress when they talk about the soul); perception of quality of rapport with the healthcare team (when rapport is good, the participant feels better able to cope); perceived quality of support from important others (which can lead to a sense of overwhelm when others are perceived as making helpful practical suggestions, yet also decrease coping when others are perceived as offering confusing advice). Contextual moderators identified in the example ICF were a recent bereavement (which may be moderating a sense of overwhelm and have the effect of making them less likely to cope in situations involving complex decision making within the healthcare system) and the context of the Covid-19 pandemic (which is hypothesised to be moderating a sense of feeling helpless in the face of a barrier to accessing appointments within the healthcare system). Other moderators relevant to each participant can be seen in the ICF diagram series in Appendix G and include moderators such as perception of age and life stage, and childhood lack of confidence. Specific identification of moderators serves as a useful indicator for how someone may cope more or less effectively across a range of situations, and thus informs useful directions for intervention.

Summary

In summary, the ICF method was useful in elucidating participant experiences by exploring them in terms of functional equivalence, unpicking strands of distress and following up on what they resembled from other events, in what ways, and why they were relevant to current coping. 'Echo events' arising within the Grounded Theory analysis were analogous to the ICF concept of functional equivalence. Furthermore, the overarching core concept arising from the Grounded Theory analysis of the data (non-linear perception of time and multi-layered events) can be viewed as nicely reflecting the importance of non-primacy emphasised in the core cancer model. It is therefore proposed that the core cancer model be particularised via the addition of functional equivalence (placed next to the main hot cross bun area); explicit boxes to identify and record moderating factors to formulate around situations where someone may be better or less able to cope; a bidirectional indication of time to capture the sense of holding a multi-layered experience of past, present and future. For the current sample living with advanced cancer, such a particularisation of the model offers explanatory power in unpicking and making sense of holding multiple complex events and experiences simultaneously. Furthermore, this particularisation is useful to help identify tailored inroads for potential intervention, specifically for each unique individual with advanced cancer.

2. *Are interviews, delivered by operationalising the Moorey & Greer model within the Hallam method, indicated to be acceptable as a platform for forming a therapeutic alliance in preparation for intervention?*

Hallam's ICF framework states that in clinical practice the interview assessment is "the means by which a trusting relationship is established" (Hallam, 2013, p.177) and emphasises that the interview process seeks to deeply understand a unique life. Although interviews in the current study occurred within a research context, it was important that the interviewer try to flexibly balance open and focused questions to enable flow within the dialogue (for example, letting a participant lead in response to open questions and then following up with related focused questions). Participant feedback (examples of which are provided above in the Findings section) indicated that space to talk freely had been part of their interview experience. Additionally, the Hallam method suggests that making the formulation process transparent, perhaps by providing reflective summaries and sharing some hypotheses, is important to foster rapport. Participant feedback suggested this had been a helpful part of their interview experience, with comments suggesting that the interview had served a clarifying function which helped contextualise their current distress by exploring the bigger picture. For example, a chance to explore potential connections between events (functional equivalence) was experienced as enabling them to have clarifying or new perspectives on their experience. Within the research interview context, it was important that the interviewer provided person-centred conditions of warmth, genuineness, empathy and unconditional positive regard (Beck et al., 1979; Rogers., 1957). Participant feedback included reference to feeling that the interviewer had come from a position of interest and support, and also mentioned that participants had felt able to open up even when it felt emotionally challenging to do so.

In summary, given the comments made by participants during and after their interviews, it is suggested that the application of Hallam's ICF approach to the core cancer model was acceptable for forming a therapeutic alliance, which would be important if interventions had followed. Notably, participant feedback attests to the usefulness of even a one-off research interview to help a person make sense of their experience.

Limitations of the research

This study has a several limitations. One of the major limitations was the small sample size, which reflected the recognised recruitment difficulties seen in other studies with this population (Serfaty et al., 2020). This inevitably affected data saturation within the Grounded Theory methodology, as a larger sample size would have included further voices with which to build further depth into categories. For example, it would have been beneficial to have included participants within younger age brackets, as the current sample was focused on the fifth decade and older. However, efforts were made to work to the concepts of theoretical sampling to build data saturation. For example, data analysis generated new questions to deliberately ask at subsequent interviews (such as with someone younger than the rest of the sample, or by deliberately raising the topic of religion with someone who identified as religious rather than as spiritual). Further questions arising during data analysis were also answered by returning to previous interview data, for example when looking for exceptions or differences within the data, which is a suggested activity within the method (Corbin & Strauss, 2015). It should also be acknowledged that the study used a less common application of Grounded Theory by consciously taking an established theoretical model as a starting point, although this is an accepted use of the chosen approach (Corbin & Strauss, 2015). Although quality standards for qualitative research were followed (Elliott et al, 1999), there are limitations that should be considered. The decision not to use a constructivist version of Grounded Theory meant that the quality standard of 'owning your own perspective' may not have been emphasised as fully with the chosen version of the methodology. However, to mitigate personal assumptions and biases arising within the findings the researcher kept a research diary, wrote memos throughout the coding process (including summary memos) and told the story of the data to their supervisor at a point where they had felt too personally close to the data. Another potential limitation regarding quality standards for Grounded Theory is that the researcher had conducted a scoping review prior to analysing the qualitative findings, which may have influenced the findings through existing prior knowledge of the advanced cancer field. The researcher was also concurrently working clinically with a palliative population during part of the study.

A further limitation of the study was that the research interviews consisted of one-off interviews (although these were lengthy). As regards clinical practice application of the ICF method, Hallam describes that when a client's difficulties are complex and multiple, the interview process should continue beyond one assessment session. Therefore, it is possible that the ICF diagrams did not provide sufficient information with which to reach fully informed formulations on which to base interventions. It is also important to acknowledge that the Grounded Theory and ICF-MG models may not generalise to people with advanced cancer who are facing imminent death, as for ethical reasons participants within the current study needed to be deemed emotionally robust and also well enough to attend a lengthy interview. Furthermore, the fact that participants needed to be deemed to not be in acute distress to participate might be argued to have contributed to the difficulty experienced in eliciting a current main difficulty within the hot cross bun. However, this difficulty was shown to be more about holding a specific focus on one current difficulty, rather than not having salient levels of distress (which were seen to be multiple in this sample). The fact that all participants were currently being held within a form of psychological support might also be said to impact the study findings as these participants may have been familiar with formulation and psychological concepts.

A further limitation was that the researcher's skill level in applying the Hallam method was not formally measured within the study, although ICF diagram were shown to (and modified) based on feedback from the founder of the method. Formal use of the recently developed Individual Case Formulation Rating Scale (Hallam et al., 2023) would have been an informative addition to aid validity of findings as being adherent to the Hallam method. Furthermore, gaining insight and feedback from participants' about both the Grounded Theory and the ICF-MG models would have been beneficial to enrich the findings.

Strengths of the research

This study is timely and relevant, given the recognised need to identify interventions to meet the specific needs of the advanced cancer population (NICE, 2004; Ferrell et al., 2017). The heterogenous and overwhelmingly quantitative evidence base, including the recent lack of findings in a fully powered randomised trial for CBT targeting depression in advanced cancer (Serfaty et al., 2020) suggested a timely need for seeking new knowledge about the needs of this cancer sub-population. Particularisation of an established general model of cancer (Moorey & Greer, 2012) via application of a systematic methodology for undertaking a detailed individual case formulation (Hallam, 2013) was a novel means of seeking to arrive at a useful tool to help identify the specific difficulties and to delineate tailored interventions for this population. The development of an interview schedule aiming to operationalise the Moorey and Greer model (including by consulting one of the founders of the model) was a strength, as it served to orient the researcher within a complex interview methodology. Together with sharing the resulting ICF diagrams with the founder of the ICF method, these aspects of the project aimed to increase validity of findings (although no formal method of measuring ICF interview or diagramming skill was used).

Use of a qualitative methodology enabled the voices of a sample of people currently living with advanced cancer, and therefore current service users of healthcare systems, to be heard. Application of the rigorous process of Grounded Theory, alongside detailed mapping of ICF diagrams for each person, enabled consideration of the data at both nomothetic and idiographic levels. Reaching the level of a grounded theory is another strength of this research. Identification of an overarching core category served to embed the theory across data from the whole sample, and this is not always aimed for within Grounded Theory analyses (Corbin & Strauss, 2015). Use of a reflective research diary, using memos as ways to reflect on potential assumptions and biases brought to the process by the researcher, telling the 'story' of the data and drawing upon core clinical skills within the clinical interviews are other strengths of the chosen methods employed within this study which served to position the researcher within the analytic process.

The feedback around the research interview experience was a strength as it was important not to just apply the core model within the Hallam method, but to gain an understanding of how this had felt for people living with advanced cancer. How such an in-depth interview technique might feel for people living with advanced disease and experiencing current distress had also been identified as important though consultation with two experts by experience (via pilot interviews) and stakeholders from a cancer charity at project development stage.

Despite the sample being small, a strength of the study was a good degree of heterogeneity within the sample. Participants were a mix of genders, included representation from non-UK and non-Western countries and included a range of primary and metastatic cancer sites (including an example of a rarer form of cancer). Although people younger than the fifth decade were not represented in the sample, the age range spanned across three decades. This can be argued to increase generalisability of the model, although Grounded Theory does not specifically aim for this (Corbin & Strauss, 1990).

Potential for future research

There are several possibilities that arise regarding the future direction of the findings within the current study. Given the ongoing context of the Covid-19 pandemic, particularly for vulnerably ill populations, it would be interesting to investigate whether the grounded model might alter in a future non-pandemic context, as models arising from Grounded Theory are acknowledged to be subject to changes across societal contexts (Charmaz, 2014). It would also be useful to present the resulting Grounded Theory and ICF-MG models to experts by experience, perhaps within a focus group, to explore whether they generalised beyond the current sample.

Another potential direction for these findings could be to take the ICF-MG model into a clinical context for advanced cancer and use single case experimental designs to measure any observed change due to the interventions chosen based on it. Such designs have seen utility with this population (Hulbert-Williams et al., 2021; Levesque et al., 2004). To apply the ICF-MG model reliably, a formal training programme could be developed (using the Hallam framework for individual case formulation) for use in both research and clinical contexts.

Finally, the ethos of the current study can be seen to align with the recently emergent CauseHealth movement, a philosophical framework that advocates a return to the unique individual as a source of causal evidence across the multi-disciplinary health professions (Anjum et al., 2020). Within the writings associated with this movement, individual stories are viewed as complementary to nomothetic theories and quantitative research design. Current gold-standard means of seeking causal evidence (including in psychology, in the form of RCTs and other quantitative designs) result in a statistically derived average treatment (or intervention) for a patient, with treatment often becoming manualised. However, manualisation may miss aspects of causality that may be uniquely relevant to a given individual and therefore optimal inroads to intervention could be missed. Therefore, qualitative research offers an equally important contribution to causal knowledge. In this way the current study can be seen to align with the 'causal dispositionalist' stance taken within CauseHealth, which ascribes primacy to individual cases as a source of evidence and seeks to acquire deep knowledge around the complexity of individuals. Such causal complexity has been referred to as a 'constellation' within the CauseHealth movement (Anjum et al., Chapter 8). A future use of the ICF-MG model could employ the concept of vector drawings as put forward within CauseHealth (Anjum et al., 2020, Chapter 7). These are simple diagrams that are used to draw out the current main difficulties for a person and help them understand what causal mechanisms are occurring and how they are linked to their personal history. These vectors are collaboratively created with the participant (or clinical client). Such simplistic vector representations of difficulties are intended to become a useful skill for people to take forward to help them cope in their daily lives.

Conclusion

An idiographic formulation approach designed for those living with advanced cancer would seem both timely and important for this population, given the complexity with which they tend to present, and the corresponding heterogeneity of the existing evidence base for interventions. Whereas the Grounded Theory analysis captures an overall story for this sample, the ICF series complements this by revealing the detailed individual stories within it. The contextualised ICF-MG model, derived from careful exploration of both general-level and individual-level data, offers a method of specifically formulating for people living with advanced cancer. The current research provides support to the concept of returning to the unique individual patient as a source of important and credible causal evidence and demonstrates the value of a shift in perspectives around what constitutes causal evidence in research. For people living with advanced cancer, researchers and clinicians require a skillset to work within a multidimensional complexity of causal interactions. Eliciting carefully tailored formulations, rather than applying theoretical models from a position of manualised remove, offers value in identifying the most useful interventions for this sub-population. The benefits of such an approach have potential to extend into future research studies, training environments and clinic rooms.

Chapter 3

Integration, Impact and Dissemination

Integration

There was a connection between the scoping review and empirical sides of the current project, having a shared focus on approaches to distress in people living with advanced cancer. The scoping review identified the wide volume and characteristics of interventions that have been used to treat various constructs of distress within advanced cancer. Furthermore, the review provided a rationale towards undertaking the empirical project. The highly heterogenous evidence base and its weighting towards quantitative research indicated a usefulness in applying an exploratory qualitative methodology in a systematic way to obtain deep knowledge about the needs of this population. Both sides of the project attempted to approach the psychosocial field of advanced cancer in novel ways. To the researcher's knowledge, there had been no prior attempt to undertake a scoping review for psychosocial interventions in advanced cancer with such broad inclusion criteria. The empirical project was the first to apply a systematic individual case formulation methodology to an established model of adjustment in advanced cancer by Moorey and Greer (2012). Taken together, the two sides of this project offer an increased understanding of the volume and characteristics of the existing psychosocial intervention evidence base in advanced cancer, and then put forward a systematic approach to formulating unique individual needs to identify optimal inroads for support.

Reflections on challenges within the project

Challenges arose within both sides of the project, with both aspects feeling daunting at points. Scoping reviews are a relatively new methodology within the review literature, and they necessarily ask broader research questions than systematic reviews (Arksey & O'Malley, 2005; Munn et al., 2018; Peters et al., 2015). The high volume of included studies was a challenge to synthesise, and I found myself feeling concerned about reaching a balance between being able to fully answer the review questions whilst keeping the paper within reasonable length. A necessary compromise was to present shortened tables for charted data within the write-up, whilst narratively summarising large amounts of detail. For the empirical study, use of Grounded Theory was challenging as I had not applied this methodology before. The fact that I had carried out a scoping review within the area of interest meant that I needed to reflect on any potential assumptions and biases I may be bringing to the Grounded Theory analysis, as reading several hundred papers for the scoping review at full text stage and then extracting detailed data from over one hundred papers, meant that I was carrying a considerable knowledge of the intervention literature. I needed to be mindful around how this may impact Grounded Theory analysis, perhaps particularly around papers which had contained qualitative aspects related to existential interventions. I found these studies absorbing and was aware that they may implicitly influence how I imagine the experience of my participant sample. Yet the current study held strength in the emergence of a new Grounded Theory model which both resonated with, and differed from, previous qualitative findings around the experience of time for people with advanced cancer. Importantly, I had not sought out this literature until after I had written up my own findings. This meant I was both anxious and excited to learn about how my own grounded model findings might fit within existing literature.

It was important throughout interviews and analysis to reflect upon my own personal circumstances with advanced cancer. I found this project emotively difficult at many points, as I had recently lost a loved family member to advanced cancer. When I started the project, I wanted to partly do this in their memory. During the project, one of my parents was also found to have developed advanced cancer. These experiences meant that at times looking at the data felt almost viscerally painful, particularly as some of the shared content from participants held echoes with what was being said at home. Memos needed to reflect where participant voices and home voices started and ended. At a point where I felt too subjectively close to the data, I asked if I could try to tell the story of the data to my academic supervisor. I experienced this as helpful and clarifying, and it enabled me to move forwards with the core categorisation of the final grounded model. I also found it helpful to find literature validating the distress that can be experienced by researchers who are qualitatively exploring people's experience of existential concerns including death and dying (Woodby et al., 2011). The latter paper describes how the process of coding within qualitative methodologies may have a cumulative effect on distress for the researcher, which the authors liken to 'emotional labour'. Interestingly, these authors describe a particular emotional difficulty that can arise when a researcher assumes the role of both interviewer and coder. During the current study I identified with the difficulty inherent within this dual role. Having met and closely remembered the participants from their interviews, this meant that the coding process gave rise to emotional nuances ascribed to meeting the person in the room. I felt a strong sense of gratitude for what they had chosen to share with me and wanted to do justice to their voices. Furthermore, the coding process held further ramifications within my own personal circumstances. Occupying such a dual role as an interviewer and coder holds a very different feeling to the task of coding manuscripts from a secondary perspective. At times I felt that being able to work as part of a team during the coding process would have been helpful, as this would have provided opportunities to hold interpersonal discussions around self-reflexivity during coding.

Application of the Hallam method of individual case formulation also felt daunting, particularly as it involved the sense that I was occupying a position of intersection between clinical and research overlap. Within the interviews, I felt at times that I could easily be pulled towards a therapeutic role and anchoring myself using the interview diagram and linear script was key to prevent this. Furthermore, the linear script and interview map prevented me from feeling like I might become lost within the interview process. At the same time, it was important that I lean on my core clinical skills of empathy, active listening and summarising, so the divide between being a researcher and a clinician did not feel clear cut.

At the outset I wondered whether concurrent use of both Grounded Theory and ICF diagramming might feel confusing. However, in practice they served to complement and inform one another in a process that felt symbiotic. Both Grounded Theory and the Hallam method aimed to elucidate process (thinking about what leads to what) and to build context for the sample. The focus within the Hallam interview framework of narrowing down and eliciting a functional analysis of antecedent, behaviour and consequences, was fundamental in helping to attain detail about how events and consequences were connected. Within Grounded Theory, causal connections or exceptions served to build complexity into categories through constant comparisons and axial coding. It helped to remind myself to view the process as one of ultimately attaining knowledge about a general story across the sample (via an emergent theory grounded in the data) and capturing detail around individual stories (through the iterative process of ICF diagramming). The ICF aspect of the project also felt somewhat exposing to me as a clinician, because as a trainee I was aware that I was putting my formulation skills on display (via both delivery of a hypothesis-driven interview technique and the technicality required of the diagramming method). When difficulties initially started to arise for participants in focusing on a specific example of recent distress within the hot cross bun area of the core cancer model, I found myself worried that this could reflect poor clinical skills on my part. However, over iterative interviews the data suggested that the participants' difficulties were an important part of their wider experience with advanced cancer. This realisation, tied to the data, helped me to lean into the process of Grounded Theory and to trust the data (rather than bringing an assumption of poor clinical skills on my part). At the end of analysis, I wished that I had been able to request feedback on the grounded model and ICF diagrams with participants, as I felt this would have provided an important level of validation to the project.

Impact

The findings from both sides of this project have potential relevance across research and clinical contexts. The findings of the scoping review have potential to inform next steps in considering the intervention evidence base for advanced cancer. The heterogeneity arising within the large body of literature suggests that future research should focus on clarifying for whom interventions work, at what dosage and in which modality (particularly across a range of cultures and non-Western countries). Targeting of symptom clusters (rather than attempting to isolate strands of distress as constructs), increased use of attentional control comparator groups, and increased numbers of qualitative studies would all be informative to move the intervention evidence base forward. Both the scoping review and empirical study indicate a usefulness of future studies applying single case experimental designs to this sub-population within cancer. These would help provide explanatory information about the process and impact of interventions, and to deeply investigate the individual needs of these service users. Finally, an umbrella review is suggested to be useful as a timely next step within the review literature, which would enable comprehensive insights into efficacy, thus informing useful directions for interventions.

For the empirical study, the experience of applying a systematic case formulation methodology has impacted the researcher as a clinician at a very immediate level. Overall, undertaking this project has increased the researcher's confidence in formulation, and this is an aspect that has been taken immediately forward into their own clinical patient work within a physical health context. It would be important to take the Grounded Theory and ICF-MG models to experts by experience, perhaps within a focus group context, to gain their perspectives on relevance beyond the current study sample. It would be useful to ensure the Grounded Theory and ICF-MG models are robust across significant changes in the systemic landscape, such as beyond the Covid-19 pandemic context. The findings of the empirical study also have potential to impact training environments. For example, a training programme could be developed as a next step to train researchers and professionals (for example within IAPT contexts) to apply the core cancer model reliably via the ICF-MG. Single case experimental designs could also be taken forward using the ICF-MG for advanced cancer, to measure any change arising from interventions specifically chosen based on the method.

Dissemination

The findings of this study have already been discussed within the context of a clinical reflections meeting at the researcher’s current place of work, which has the potential to impact immediate clinical practice within the team. Liaison with stakeholders at recruitment sites is planned, to determine the most useful means to disseminate the findings of this research. A summary of the study will be supplied to participants who took part in the project. It is also important to find means to make information accessible to service users more broadly. Other dissemination in liaison with stakeholders could take the form of developing a poster and integrating findings within an existing support group for people living with advanced cancer. A presentation of the research findings to a psycho-oncology team within the NHS has been confirmed, and there are opportunities arising to present within conference contexts in the upcoming year. Finally, it is the intention of the researcher to prepare and submit both sides of the project (as two separate papers) for publication in peer reviewed journals, to enable a wider reach of dissemination.

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Appendices

Appendix A: Example database search for PsychINFO

A specific psychological construct or diagnosis, targeted by an intervention:
#1
"distress" OR “distressed” OR "emotional distress” OR "psychological distress” OR “stress” OR "anxiety” OR "depression” OR "depressive disorder” OR "adjustment disorder” OR "anxiety disorder” OR "generalised anxiety disorder” OR "GAD” OR "Panic disorder” OR "Post-traumatic stress disorder” OR "PTSD” OR "obsessive compulsive disorder” OR "OCD” OR "mental health disorder” OR "severe mental health disorder” OR “mental disorder*” OR "psychosis” OR "schizophrenia” OR "bipolar disorder” OR "personality disorder” OR "comorbid*"

A specific cancer:
Combine MESH and free text sets with OR

#2
MESH terms: “Neoplasms” or “Oncology” or “Cancer” or “Tumour”

OR

"oncology" OR "cancer" OR "cancers" OR “cancer-related” OR "tumour" OR "tumor" OR "tumours" OR "tumors” OR "neoplasm” OR "neoplasms” OR "malignancy” OR "malignant” OR” malignancies" OR "breast cancer” OR "prostate cancer” OR "pancreatic cancer” OR "lung cancer” OR "liver cancer” OR "oesophageal cancer” OR ”esophageal cancer” OR "bowel cancer” OR "colon cancer” OR “colorectal cancer” OR "brain cancer” OR "gynaecological cancer” OR "gynecological cancer” OR "endometrial cancer” OR "ovarian cancer” OR "haematological cancer” OR "hematological cancer” OR "carcinoma” OR "lymphoma” OR "leukaemia” OR "leukemia” OR "sarcoma” OR "carcinoma” OR "adenocarcinoma” OR "adenocarcinomas” OR "head and neck cancer” OR "melanoma” OR "skin cancer” OR "bladder cancer” OR "kidney cancer” OR "urological cancer"

A specific stage:
#3
"advanced” OR "not amenable to cure” OR "end stage” OR "metastatic” OR "metastases” OR” metastasised” OR “incurable” OR “non-curative” OR "terminal” OR "recurrence” OR "recurrent” OR "recurred” OR "recurring” OR "late-stage” OR “end of life” OR "Stage 4” OR "Stage IV” OR "palliative” OR "palliation"

A specific intervention type:
#4
"psychotherapy” OR "psychological intervention” OR “psychosocial intervention” OR “psychological therap*” OR "manualised therapy” OR “manualized therapy” OR “psychological treatment” OR “individual psychotherapy” OR "cognitive therapy” OR "behavior therapy” OR "behaviour therapy” OR "cognitive-behavioural” OR “cognitive-behavioral” OR “cognitive behavioral” OR “cognitive behavioural” OR "CBT” OR "mindfulness” OR "meditation” OR "CALM” OR "meaning-make” OR "meaning-making” OR "meaning-centered” OR “meaning-centred” OR “narrative” OR "compassion-focused” OR "CFT” OR "ACT” OR “acceptance and commitment therapy” OR "acceptance therapy” OR “acceptance-based” OR "counselling” OR “psychosexual” OR "family therapy” OR "systemic therapy” OR "couples therapy” OR "art therapy” OR "music therapy” OR “dance therapy” OR "group therapy” OR "support group” OR "support groups" OR “peer support” OR "group intervention” OR "complementary therap*” OR "alternative

therap*" OR “CAMs” OR "acupuncture" OR “reflexology” OR “massage therap*" OR "mindful yoga" OR “mindful meditation” OR "psycho-education" OR "self-help" OR "self-care" OR "cognitive rehabilitation" OR "relaxation" OR "stress management" OR “self-management” OR "Mindfulness-Based Stress Reduction" OR “mindfulness-based” OR "MBSR" OR “LILAC” OR “qualitative”

#5
S1 AND S2 AND S3 AND S4

APA PsychInfo Search set up:
Untick ‘Apply Equivalent Subjects’
Search Modes & Expanders: Boolean/Phrase
Limit results to: English language
Limit results to: Adults (18+)

MESH terms used:
Neoplasms or Oncology or Cancer or Tumour in Search #2

Appendix B: Ethical approval confirmation

From: Ethics Application System <ethics@rhul.ac.uk>
Sent: Friday, November 5, 2021 11:09:12 AM
To: Bonney, Catherine (2019) <Catherine.Bonney.2019@live.rhul.ac.uk>; Brown, Gary <Gary.Brown@rhul.ac.uk>; Ethics <Ethics@rhul.ac.uk>
Subject: Result of your application to the Research Ethics Committee (application ID 2641)

PI: Dr Gary Brown
Project title: An idiographic approach to formulation for patients living with advanced cancer

REC ProjectID: 2641

Your application has been approved by the Research Ethics Committee.
Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee ethics@rhul.ac.uk

Appendix C: Participant Consent Form

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Consent Form (Project ID: 2641)

Researcher: Catherine Bonney-Murrell (Trainee Clinical Psychologist), supervised by Dr Gary Brown (Research Director, Department of Psychology at Royal Holloway, University of London)

Study Title: An idiographic approach to formulation for people living with advanced cancer

Research Participants: Please read each of the below statements carefully, then confirm whether you do or do not wish to participate in this study using the tick boxes.

- ☐ I have read and understood the information sheet, and have had the opportunity to decide if I would like to voluntarily take part
- ☐ I have been given the opportunity to ask and discuss any questions that I have via email (catherine.bonney.2019@live.rhul.ac.uk)
- ☐ I understand that the study involves completing a research interview lasting approximately 1 hour 15 minutes, either in person or remotely via MS Teams (whichever is my preferred choice)
- ☐ I understand that the research interview will be recorded using a secure audio recording device
- ☐ I understand that I am free to withdraw at any point up until analysis of the data (within two weeks after the interview takes place) without giving a reason and without any detriment to myself
- ☐ I understand that no personal identifying information will be reported in any subsequent publications

☐ Yes, I consent to participate in this study

☐ Yes, I consent to my interview being recorded on a secure audio recording device

☐ Yes, I give consent for my individual case formulation (created following my interview) to be shared with my current psychological support worker at the site where I was recruited

☐ No, I do not wish for my individual case formulation to be shared with my current psychological support worker at the site where I was recruited

☐ No, I do not consent to participate in this study

Participant name: ……………………………………………………………………………

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

Appendix D: Participant Information Sheet

Department of Psychology
Royal Holloway, University of London
Egham, Surrey TW20 0EX
www.royalholloway.ac.uk/psychology

Information Sheet for Participants (Project ID: 2641)

An individual approach to formulation for people living with advanced cancer

My name is Catherine Bonney-Murrell. Thank you for your interest in this study. I hope the following information will be helpful.

What is the study about? Why is it important?
In therapy, an 'individual case formulation' (ICF) can help to understand a person's problems. It can act like a map, pointing to useful changes in someone's daily life.

This study will use ICF to help understand how individual people adjust to living with advanced cancer. It will apply an ICF approach to key ideas in psychology about how people adjust to living with cancer more generally. This may lead to new areas for future research and help provide more tailored support for people living with advanced cancer.

What does the study involve? How long will it take?
If you decide to take part, I will invite you to attend one interview. This will take around 75 minutes. Interviews can take place either in person or remotely via a secure MS Teams account approved by the college. I will be flexible around your needs.

Do I have to take part?
You do not have to take part in this study if you do not want to. You can withdraw without giving a reason at any point until the data has been analysed (within two weeks after the interview takes place).

Are there any risks or benefits to taking part?
This is a one-off research interview. If you wish, your ICF can be shared with your current therapist. This could make your ICF a useful part of your work together.

Confidentiality
Only myself, my supervisor and my examiner will be able to see your interview data. In the study you will be known only by a number.

A record of your name and participant number will be kept for the purposes of identifying and withdrawing the data if necessary. This will be kept separate from interview data and will be available to the researcher only.

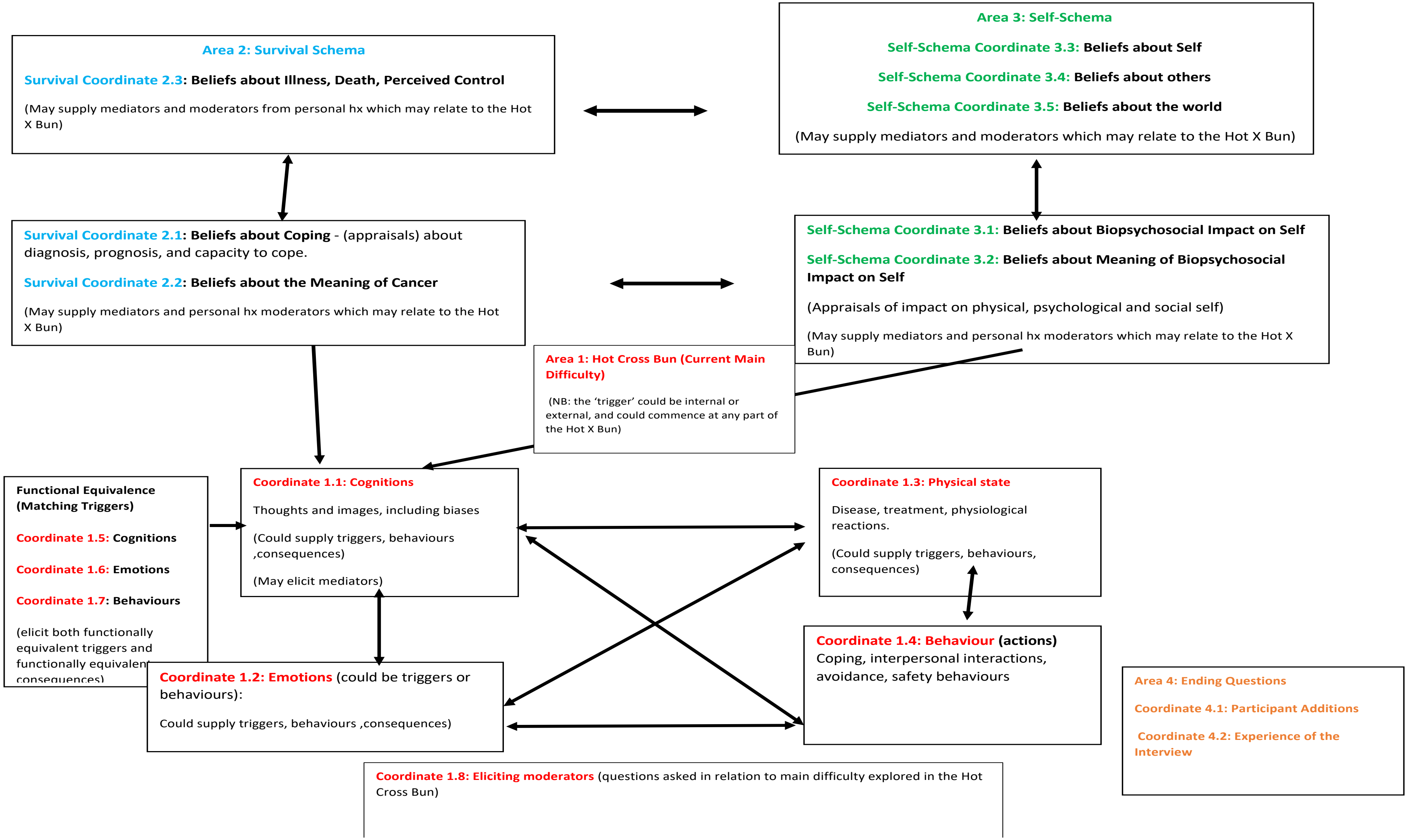
Interviews will be recorded using a secure audio recording device. The recording will be transferred to a secure computer (and deleted from the recording device) as soon as possible after the interview.

All your information will be stored securely and confidentially.

If you share information about any risk to yourself or others during your interview, I have a duty of care to pass this information to your therapist at your recruitment site. This is so that you can be best supported. Your ICF will not be available to your current therapist unless you give specific consent in your Consent Form.

The findings of the research may be written up as part of my doctoral thesis. They may also be published in a scientific journal or presented at relevant conferences. If the study is published, the anonymised data may be made available to third parties upon request, however none of this information will contain any identifiable information.

Appendix E: Interview Schedule Operationalisation Diagram with Colour Co-ordinates Linking to Linear Script



Area 2: Survival Schema

Survival Coordinate 2.3: Beliefs about Illness, Death, Perceived Control

(May supply mediators and moderators from personal hx which may relate to the Hot X Bun)

Area 3: Self-Schema

Self-Schema Coordinate 3.3: Beliefs about Self

Self-Schema Coordinate 3.4: Beliefs about others

Self-Schema Coordinate 3.5: Beliefs about the world

(May supply mediators and moderators which may relate to the Hot X Bun)

Survival Coordinate 2.1: Beliefs about Coping - (appraisals) about diagnosis, prognosis, and capacity to cope.

Survival Coordinate 2.2: Beliefs about the Meaning of Cancer

(May supply mediators and personal hx moderators which may relate to the Hot X Bun)

Self-Schema Coordinate 3.1: Beliefs about Biopsychosocial Impact on Self

Self-Schema Coordinate 3.2: Beliefs about Meaning of Biopsychosocial Impact on Self

(Appraisals of impact on physical, psychological and social self)

(May supply mediators and personal hx moderators which may relate to the Hot X Bun)

Area 1: Hot Cross Bun (Current Main Difficulty)

(NB: the 'trigger' could be internal or external, and could commence at any part of the Hot X Bun)

Functional Equivalence (Matching Triggers)

Coordinate 1.5: Cognitions

Coordinate 1.6: Emotions

Coordinate 1.7: Behaviours

(elicit both functionally equivalent triggers and functionally equivalen consequences)

Coordinate 1.1: Cognitions

Thoughts and images, including biases

(Could supply triggers, behaviours ,consequences)

(May elicit mediators)

Coordinate 1.3: Physical state

Disease, treatment, physiological reactions.

(Could supply triggers, behaviours, consequences)

Coordinate 1.2: Emotions (could be triggers or behaviours):

Could supply triggers, behaviours ,consequences)

Coordinate 1.4: Behaviour (actions)

Coping, interpersonal interactions, avoidance, safety behaviours

Area 4: Ending Questions

Coordinate 4.1: Participant Additions

Coordinate 4.2: Experience of the Interview

Coordinate 1.8: Eliciting moderators (questions asked in relation to main difficulty explored in the Hot Cross Bun)

Interview Schedule: Linear Script

This linear script is intended to orient the research interview within the space of the accompanying diagram. Colour-coding of questions relates to co-ordinates mapped within the diagrammatic representation of the interview.

Preliminaries:

Information Sheet:

- Check in re: understanding of Information Sheet.
- Reiterate the limits to confidentiality; duty of care/risk as outlined on the Information Sheet.
- Check whether any previous questions that the participant had have been answered to their satisfaction.

Consent form:

- Check that the participant has read and signed the consent form and ask for verbal confirmation that they wish to proceed with the interview.

Any Questions?

- Check whether the participant has any/further questions they wish to ask before starting the interview.

Let the participant know that the audio recording will start now.

START AUDIO RECORDING AT THIS POINT

Introductory Statement:

'The reason I have been asking people to participate in this study is to find out what might bring people to seek psychological support. I am interested in how your experience can help pave the way for the most appropriate support being given to others in a similar situation to you in the future.

As this is a research interview, there are boundaries to my role. I will be asking about personal aspects of your experience within the context of living with advanced cancer and I want to reassure you that I am not doing this to be nosy. You don't need to share with me anything that you do not want to share. I won't be able to offer advice as this is a research context and not a therapeutic context, but I will be able to signpost you towards advice if needed'.

Initial overview:

I just wanted to start out with a quick check-in. How are things/ how have things been lately for you?
*I would just like to check in with you about whether you have a specific wording that you prefer to use for your illness? (**Use participant's preferred choice of language throughout the interview**).*

[Information gathered from these initial open questions might provide information that could be mapped to the developmental boxes which feed into the hot cross bun. They are also intended to help build rapport.]

Area 1: Hot Cross Bun (Current Main Difficulty)

What I wanted to start out with is the current sense of things for you, and what your central concerns are.
Could you give me a brief idea of the main difficulty that you are currently experiencing?

Prompts: *What's been at the forefront of your mind lately? What are your current central concerns*?

Questions to elicit a functional analysis of the main difficulty:
[The hot cross bun part is where I gather the FA elements such as NATs, and the longer-term beliefs that are underpinning those rules for living/assumptions and core beliefs (if they can be got at). Gather functional equivalence.]

(NB: the 'trigger' could be internal or external and could commence at any part of the Hot X Bun – this section will be participant led in terms of the appropriate questions to ask first within the space of the hot cross bun).

Can you give me a recent specific example in detail? Let's first try and capture the scene.
Where were you?
What time of day was it?
Who was there?
What was going on just before/around you?

[Coordinate 1.1 Cognitions]
What went through your mind at the time – thoughts? Images?

[Coordinate 1.2 Emotions]
How did you feel at the time?
How did you feel afterwards?

[Coordinate 1.3 Physical state]
What did you notice about how your body felt at the time?
How did your body feel afterwards?

[Coordinate 1.4 Behaviour]
What did you do at the time / how did you react? Did it help?
Was there anything you did at the time that may have been unhelpful for the situation?
Is there anything else that you felt an urge to do at the time?
What made it important for you to do X rather than something else?
If there were other people present, what did they do?
What happened after you did X?

[Coordinate 1.5 Functionally Equivalent Cognitions]
Thinking about the thoughts that went through you mind at the time, do similar thoughts/images crop up at other times/ in other kinds of situations?

[Coordinate 1.6 Functionally Equivalent Emotions]
Thinking about how you felt at the time, do similar feelings arise at other times / in other kinds of situations?

[Coordinate 1.7 Functionally Equivalent Behaviours]
Thinking about what you did at the time, are there other situations in which you have reacted in this way / done this?
(eg: Have you avoided other situations too?)

[Coordinate 1.8 Eliciting moderators] These questions will be asked to supplement the exploration of the current main difficulty above.
Have there been other times involving similar situations where you have responded differently/where you felt differently/where these thoughts/feelings/bodily sensations/behaviours did not occur? If so, what was different about those times? (for example, who was around/not around?)
What makes the difficulty better/what helps?
What makes the difficulty worse/what is unhelpful?

[May supply moderators, such as moderators from personal history, which may be relevant to the difficulty elicited with the hot cross bun]

NOTE: Depending on whether the described current main difficulty focuses predominantly on threat to survival or on threat to self, one of the following sections [Area 2 or Area 3] will be explored depending on which is dominant.

Area 2: Survival Schema

[Survival Coordinate 2.1: Beliefs about Coping]
Every person's response to illness is unique, and there are no 'one-fits-all' helpful or unhelpful coping strategies. Often people might say that they try to do more of what has worked in the past to help them cope when living with illness, but they find it doesn't work so well now.
Thinking about yourself, what have been the main ways that you have coped when things have been difficult in your life? What (or who) has helped you to cope when things have been tough in the past? What has been unhelpful? (Elicit personal strengths and resources, which may act as moderators)

[Survival Coordinate 2.2: Beliefs about the Meaning of Cancer] *Sometimes what we hear when people talk about feeling a certain way is that there is a kind of voice from their history, or a memory, that is prompting that feeling.*
Is this something you have felt/experienced? What messages did you receive about cancer/serious illness in your early life? What does cancer mean for you personally?
[May supply mediators and personal hx moderators which may relate to the Hot X Bun]

[Survival Coordinate 2.3: Beliefs about Illness, Death, Perceived Control] *When people speak about experiencing serious illness we often hear that their understanding of serious illness has changed over time. Is this something you have felt/experienced?'*
Has your understanding of serious illness changed since your diagnosis and, if so, in what ways?

Area 3: Self Schema

[Self-Schema Coordinate 3.1: Beliefs about Biopsychosocial Impact on Self]
If we think now about the everyday life aspect of living with your illness, how have any illness-related changes impacted on your ability to live your daily life?
What, or who, has helped you to cope?
What has been helpful? Unhelpful?
[Elicit personal strengths and resources, which may act as moderators]

[Self-Schema Coordinate 3.2: Beliefs about Meaning of Biopsychosocial Impact on Self]
Sometimes what we hear when people talk about feeling a certain way is that there is a kind of voice from their history, or a memory, that is prompting that feeling.
Is this something you have felt/experienced?
What messages did you receive about personal appearance/physical fitness/mental health in your early life?
[May supply mediators and personal hx moderators which may relate to the Hot X Bun]

[Self-Schema Coordinate 3.3: Beliefs about Self]
A lot of times when people speak about illness we hear that the way they see themselves has altered. We often hear difficult circumstances sometimes seem to become bound up with long-standing beliefs about ourselves, or they may seem to challenge standards we hold about ourselves.
Does that bring up anything for you?
Has the way you see yourself (your sense of who you are/your identity) changed at all since your diagnosis and, if so, in what ways?

[Self-Schema Coordinate 3.4: Beliefs about Others]
We sometimes hear that illness has changed the way someone sees other people.
Has the way you see other people changed, and if so, in what ways?

[Self-Schema Coordinate 3.5: Beliefs about the World]
We also sometimes hear that illness has changed the way someone views the world.
Has the way you see the world changed, and if so, in what ways?

[Coordinates 3.3, 3.4 & 3.5 may supply mediators and personal hx moderators which may relate to the Hot X Bun]

Area 4: Ending Questions:

[Coordinate 4.1: Participant Additions]
Is there anything else you feel is important in relation to your experience of living with cancer, that we haven't touched on so far?
Or anything you would like to add to what we have talked about?

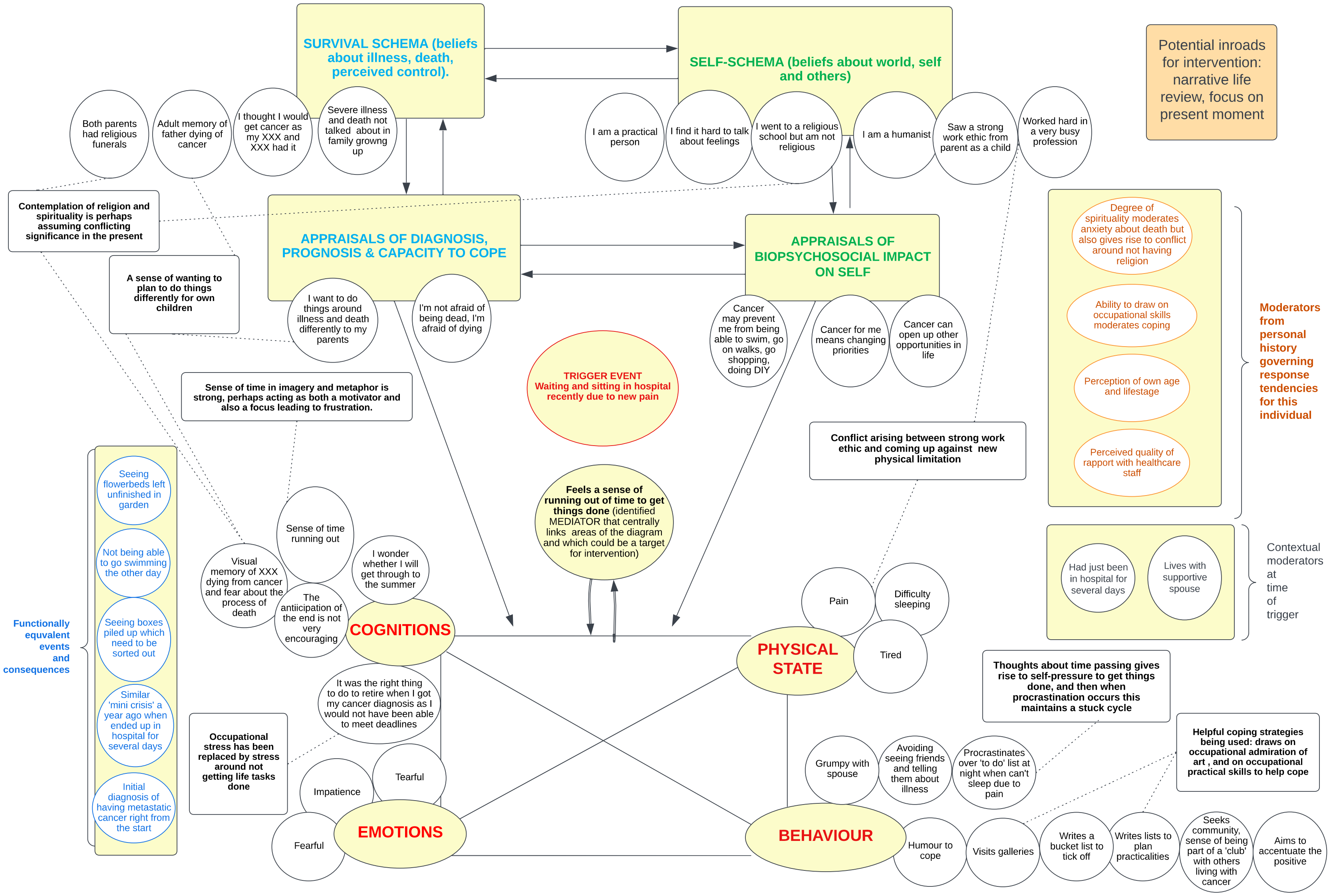
[Coordinate 4.2: Experience of the Interview]
How has this interview felt for you today?

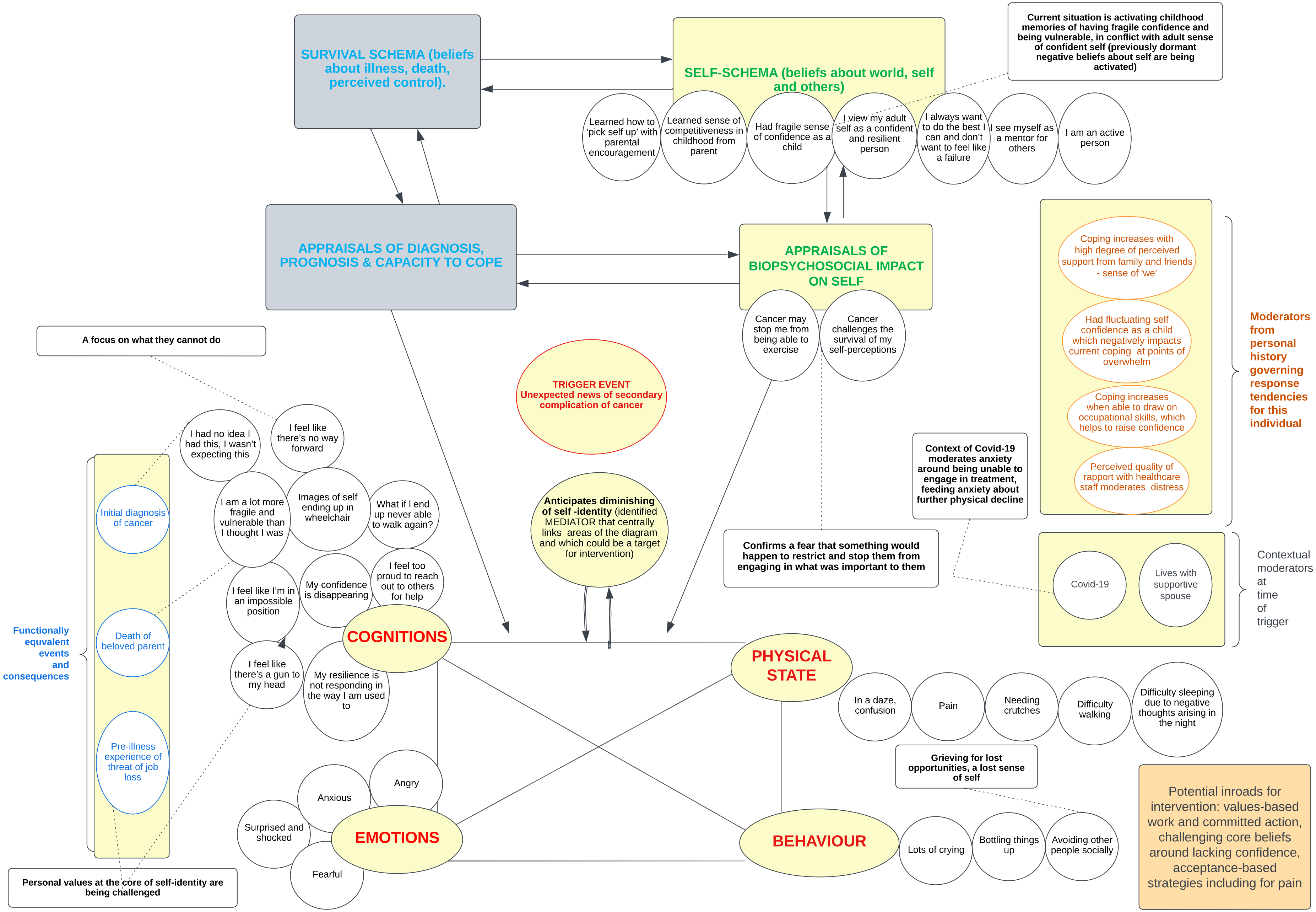
Thank the participant for attending the interview.

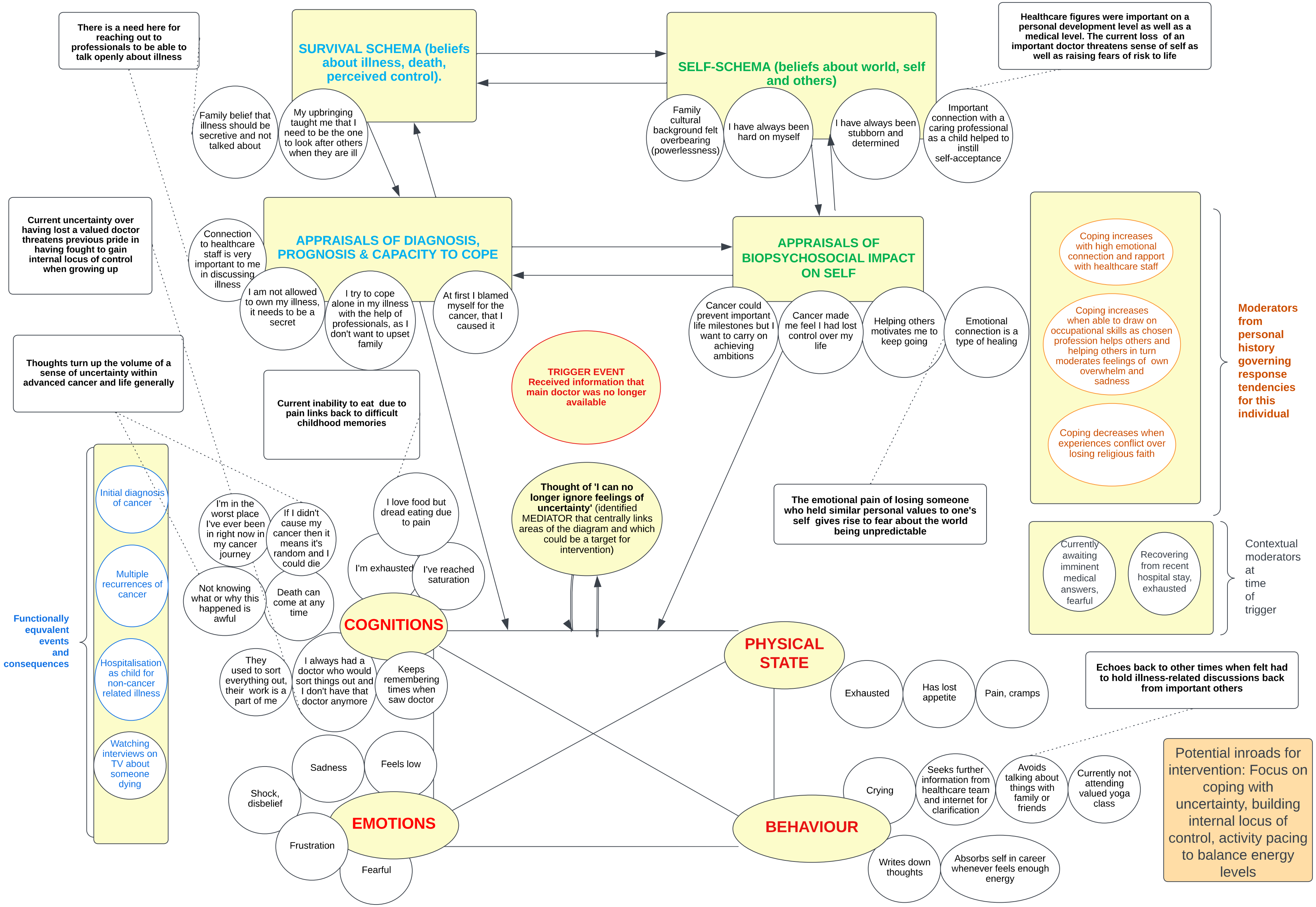
State that audio recording will now end.

End audio recording.

Appendix G: Individual Case Formulation Diagram Series




SURVIVAL SCHEMA (beliefs about illness, death, perceived control).
SELF-SCHEMA (beliefs about world, self and others)
Current situation is activating childhood memories of having fragile confidence and being vulnerable, in conflict with adult sense of confident self (previously dormant negative beliefs about self are being activated)
Learned how to 'pick self up' with parental encouragement
Learned sense of competitiveness in childhood from parent
Had fragile sense of confidence as a child
I view my adult self as a confident and resilient person
I always want to do the best I can and don't want to feel like a failure
I see myself as a mentor for others
I am an active person
APPRAISALS OF DIAGNOSIS, PROGNOSIS & CAPACITY TO COPE
APPRAISALS OF BIOPSYCHOSOCIAL IMPACT ON SELF
Cancer may stop me from being able to exercise
Cancer challenges the survival of my self-perceptions
Coping increases with high degree of perceived support from family and friends - sense of 'we'
Had fluctuating self confidence as a child which negatively impacts current coping at points of overwhelm
Coping increases when able to draw on occupational skills, which helps to raise confidence
Perceived quality of rapport with healthcare staff moderates distress
Moderators from personal history governing response tendencies for this individual
A focus on what they cannot do
TRIGGER EVENT Unexpected news of secondary complication of cancer
Context of Covid-19 moderates anxiety around being unable to engage in treatment, feeding anxiety about further physical decline
Anticipates diminishing of self -identity (identified MEDIATOR that centrally links areas of the diagram and which could be a target for intervention)
Confirms a fear that something would happen to restrict and stop them from engaging in what was important to them
Covid-19
Lives with supportive spouse
Contextual moderators at time of trigger
I had no idea I had this, I wasn't expecting this
I feel like there's no way forward
I am a lot more fragile and vulnerable than I thought I was
Images of self ending up in wheelchair
What if I end up never able to walk again?
I feel like I'm in an impossible position
My confidence is disappearing
I feel too proud to reach out to others for help
COGNITIONS
I feel like there's a gun to my head
My resilience is not responding in the way I am used to
Initial diagnosis of cancer
Death of beloved parent
Pre-illness experience of threat of job loss
Functionally equivalent events and consequences
PHYSICAL STATE
In a daze, confusion
Pain
Needing crutches
Difficulty walking
Difficulty sleeping due to negative thoughts arising in the night
Grieving for lost opportunities, a lost sense of self
Anxious
Angry
Surprised and shocked
EMOTIONS
Fearful
BEHAVIOUR
Lots of crying
Bottling things up
Avoiding other people socially
Potential inroads for intervention: values-based work and committed action, challenging core beliefs around lacking confidence, acceptance-based strategies including for pain
Personal values at the core of self-identity are being challenged



There is a need here for reaching out to professionals to be able to talk openly about illness

SURVIVAL SCHEMA (beliefs about illness, death, perceived control).

Family belief that illness should be secretive and not talked about

My upbringing taught me that I need to be the one to look after others when they are ill

SELF-SCHEMA (beliefs about world, self and others)

Family cultural background felt overbearing (powerlessness)

I have always been hard on myself

I have always been stubborn and determined

Important connection with a caring professional as a child helped to instill self-acceptance

Healthcare figures were important on a personal development level as well as a medical level. The current loss of an important doctor threatens sense of self as well as raising fears of risk to life

Current uncertainty over having lost a valued doctor threatens previous pride in having fought to gain internal locus of control when growing up

APPRAISALS OF DIAGNOSIS, PROGNOSIS & CAPACITY TO COPE

Connection to healthcare staff is very important to me in discussing illness

I am not allowed to own my illness, it needs to be a secret

I try to cope alone in my illness with the help of professionals, as I don't want to upset family

At first I blamed myself for the cancer, that I caused it

APPRAISALS OF BIOPSYCHOSOCIAL IMPACT ON SELF

Cancer could prevent important life milestones but I want to carry on achieving ambitions

Cancer made me feel I had lost control over my life

Helping others motivates me to keep going

Emotional connection is a type of healing

Coping increases with high emotional connection and rapport with healthcare staff

Coping increases when able to draw on occupational skills as chosen profession helps others and helping others in turn moderates feelings of own overwhelm and sadness

Coping decreases when experiences conflict over losing religious faith

Moderators from personal history governing response tendencies for this individual

Thoughts turn up the volume of a sense of uncertainty within advanced cancer and life generally

Current inability to eat due to pain links back to difficult childhood memories

TRIGGER EVENT
Received information that main doctor was no longer available

Thought of 'I can no longer ignore feelings of uncertainty' (identified MEDIATOR that centrally links areas of the diagram and which could be a target for intervention)

The emotional pain of losing someone who held similar personal values to one's self gives rise to fear about the world being unpredictable

Currently awaiting imminent medical answers, fearful

Recovering from recent hospital stay, exhausted

Contextual moderators at time of trigger

Functionally equvalent events and consequences

Initial diagnosis of cancer

Multiple recurrences of cancer

Hospitalisation as child for non-cancer related illness

Watching interviews on TV about someone dying

I'm in the worst place I've ever been in right now in my cancer journey

If I didn't cause my cancer then it means it's random and I could die

I love food but dread eating due to pain

I'm exhausted

I've reached saturation

Not knowing what or why this happened is awful

Death can come at any time

COGNITIONS

They used to sort everything out, their work is a part of me

I always had a doctor who would sort things out and I don't have that doctor anymore

Keeps remembering times when saw doctor

PHYSICAL STATE

Exhausted

Has lost appetite

Pain, cramps

Echoes back to other times when felt had to hold illness-related discussions back from important others

Sadness

Feels low

Shock, disbelief

EMOTIONS

Frustration

Fearful

BEHAVIOUR

Crying

Seeks further information from healthcare team and internet for clarification

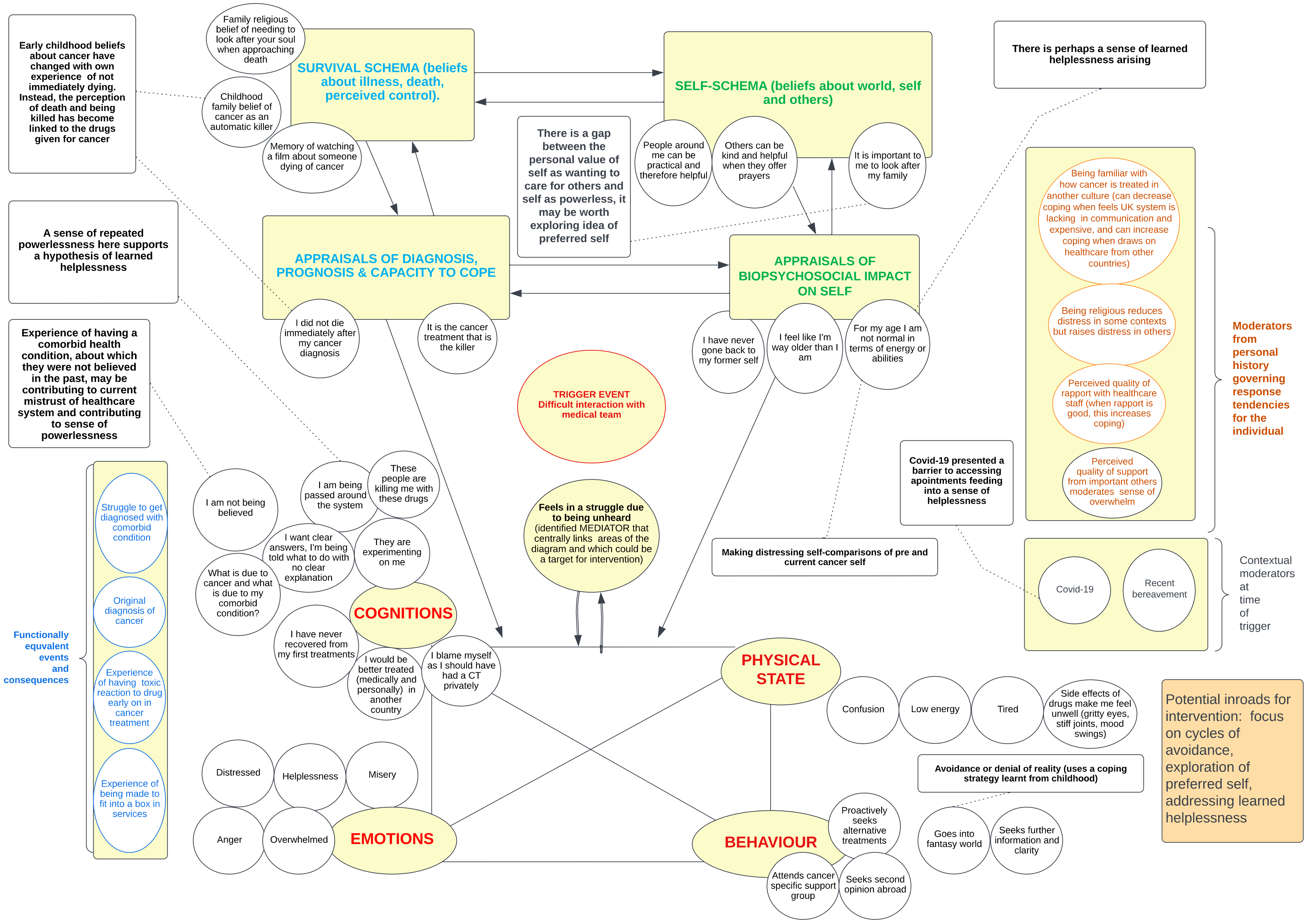
Avoids talking about things with family or friends

Currently not attending valued yoga class

Writes down thoughts

Absorbs self in career whenever feels enough energy

Potential inroads for intervention: Focus on coping with uncertainty, building internal locus of control, activity pacing to balance energy levels



Early childhood beliefs about cancer have changed with own experience of not immediately dying. Instead, the perception of death and being killed has become linked to the drugs given for cancer

Family religious belief of needing to look after your soul when approaching death

Childhood family belief of cancer as an automatic killer

Memory of watching a film about someone dying of cancer

SURVIVAL SCHEMA (beliefs about illness, death, perceived control).

SELF-SCHEMA (beliefs about world, self and others)

People around me can be practical and therefore helpful

Others can be kind and helpful when they offer prayers

It is important to me to look after my family

There is perhaps a sense of learned helplessness arising

There is a gap between the personal value of self as wanting to care for others and self as powerless, it may be worth exploring idea of preferred self

A sense of repeated powerlessness here supports a hypothesis of learned helplessness

APPRAISALS OF DIAGNOSIS, PROGNOSIS & CAPACITY TO COPE

I did not die immediately after my cancer diagnosis

It is the cancer treatment that is the killer

APPRAISALS OF BIOPSYCHOSOCIAL IMPACT ON SELF

I have never gone back to my former self

I feel like I'm way older than I am

For my age I am not normal in terms of energy or abilities

Experience of having a comorbid health condition, about which they were not believed in the past, may be contributing to current mistrust of healthcare system and contributing to sense of powerlessness

TRIGGER EVENT
Difficult interaction with medical team

Being familiar with how cancer is treated in another culture (can decrease coping when feels UK system is lacking in communication and expensive, and can increase coping when draws on healthcare from other countries)

Being religious reduces distress in some contexts but raises distress in others

Perceived quality of rapport with healthcare staff (when rapport is good, this increases coping)

Perceived quality of support from important others moderates sense of overwhelm

Moderators from personal history governing response tendencies for the individual

Covid-19 presented a barrier to accessing apointments feeding into a sense of helplessness

Making distressing self-comparisons of pre and current cancer self

Covid-19

Recent bereavement

Contextual moderators at time of trigger

Functionally equvalent events and consequences

Struggle to get diagnosed with comorbid condition

Original diagnosis of cancer

Experience of having toxic reaction to drug early on in cancer treatment

Experience of being made to fit into a box in services

I am not being believed

I am being passed around the system

These people are killing me with these drugs

I want clear answers, I'm being told what to do with no clear explanation

They are experimenting on me

What is due to cancer and what is due to my comorbid condition?

Feels in a struggle due to being unheard (identified MEDIATOR that centrally links areas of the diagram and which could be a target for intervention)

COGNITIONS

I have never recovered from my first treatments

I would be better treated (medically and personally) in another country

I blame myself as I should have had a CT privately

PHYSICAL STATE

Confusion

Low energy

Tired

Side effects of drugs make me feel unwell (gritty eyes, stiff joints, mood swings)

Potential inroads for intervention: focus on cycles of avoidance, exploration of preferred self, addressing learned helplessness

Avoidance or denial of reality (uses a coping strategy learnt from childhood)

Distressed

Helplessness

Misery

Anger

Overwhelmed

EMOTIONS

BEHAVIOUR

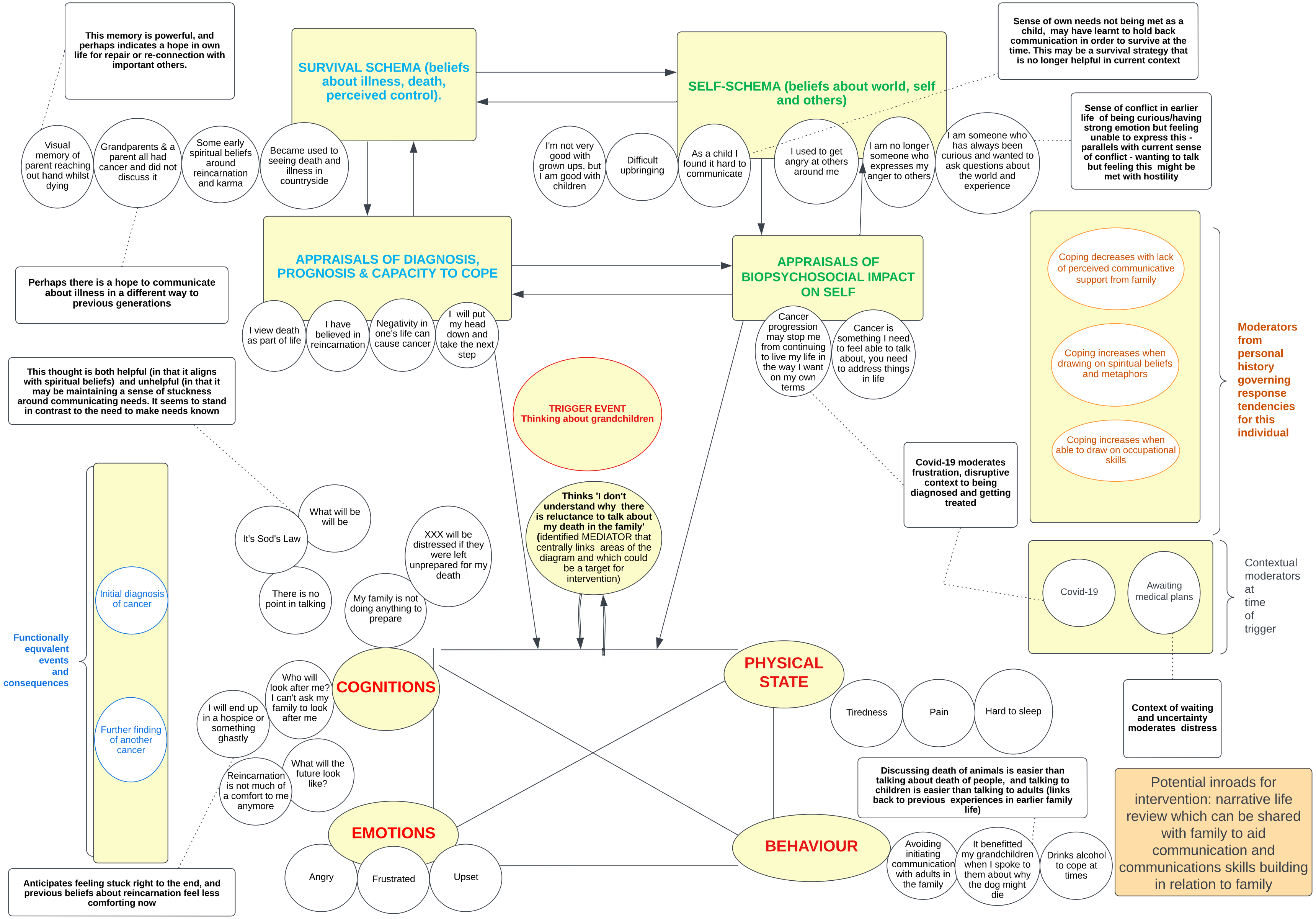
Proactively seeks alternative treatments

Attends cancer specific support group

Seeks second opinion abroad

Goes into fantasy world

Seeks further information and clarity



This memory is powerful, and perhaps indicates a hope in own life for repair or re-connection with important others.

SURVIVAL SCHEMA (beliefs about illness, death, perceived control).

SELF-SCHEMA (beliefs about world, self and others)

Sense of own needs not being met as a child, may have learnt to hold back communication in order to survive at the time. This may be a survival strategy that is no longer helpful in current context

Sense of conflict in earlier life of being curious/having strong emotion but feeling unable to express this - parallels with current sense of conflict - wanting to talk but feeling this might be met with hostility

Visual memory of parent reaching out hand whilst dying

Grandparents & a parent all had cancer and did not discuss it

Some early spiritual beliefs around reincarnation and karma

Became used to seeing death and illness in countryside

I'm not very good with grown ups, but I am good with children

Difficult upbringing

As a child I found it hard to communicate

I used to get angry at others around me

I am no longer someone who expresses my anger to others

I am someone who has always been curious and wanted to ask questions about the world and experience

Perhaps there is a hope to communicate about illness in a different way to previous generations

APPRAISALS OF DIAGNOSIS, PROGNOSIS & CAPACITY TO COPE

APPRAISALS OF BIOPSYCHOSOCIAL IMPACT ON SELF

I view death as part of life

I have believed in reincarnation

Negativity in one's life can cause cancer

I will put my head down and take the next step

Cancer progression may stop me from continuing to live my life in the way I want on my own terms

Cancer is something I need to feel able to talk about, you need to address things in life

Coping decreases with lack of perceived communicative support from family

Coping increases when drawing on spiritual beliefs and metaphors

Coping increases when able to draw on occupational skills

Moderators from personal history governing response tendencies for this individual

This thought is both helpful (in that it aligns with spiritual beliefs) and unhelpful (in that it may be maintaining a sense of stuckness around communicating needs. It seems to stand in contrast to the need to make needs known

TRIGGER EVENT
Thinking about grandchildren

Covid-19 moderates frustration, disruptive context to being diagnosed and getting treated

Thinks 'I don't understand why there is reluctance to talk about my death in the family' (identified MEDIATOR that centrally links areas of the diagram and which could be a target for intervention)

Covid-19

Awaiting medical plans

Contextual moderators at time of trigger

It's Sod's Law

What will be will be

XXX will be distressed if they were left unprepared for my death

There is no point in talking

My family is not doing anything to prepare

Initial diagnosis of cancer

Further finding of another cancer

Functionally equivalent events and consequences

COGNITIONS

PHYSICAL STATE

Tiredness

Pain

Hard to sleep

Context of waiting and uncertainty moderates distress

I will end up in a hospice or something ghastly

Who will look after me? I can't ask my family to look after me

What will the future look like?

Reincarnation is not much of a comfort to me anymore

Discussing death of animals is easier than talking about death of people, and talking to children is easier than talking to adults (links back to previous experiences in earlier family life)

Potential inroads for intervention: narrative life review which can be shared with family to aid communication and communications skills building in relation to family

EMOTIONS

BEHAVIOUR

Angry

Frustrated

Upset

Avoiding initiating communication with adults in the family

It benefitted my grandchildren when I spoke to them about why the dog might die

Drinks alcohol to cope at times

Anticipates feeling stuck right to the end, and previous beliefs about reincarnation feel less comforting now