University of Glasgow

A feasibility study of using a card sort task to explore mental health related outcome and treatment preferences in older adults

AND

Clinical Research Portfolio

Rasa Butrimaviciute, BSc (Hons), MSc

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

Institute of Health and Wellbeing
College of Medicine, Veterinary and Life Sciences

University of Glasgow

February, 2020

Contents

List of tables

Chapter 1 Systematic Review

Chapter 2 Major Research Project

List of figures

Chapter 1 Systematic Review

Chapter 2 Major Research Project

Acknowledgements

Firstly, I would like to sincerely thank all the participants who dedicated their time and shared their views during the study – it would not have been possible without your generosity.

I would like to thank Dr Clive Ferenbach for your expertise, enthusiasm and support that enabled this study to happen, and Professor Hamish McLeod for sharing your knowledge, ideas and wise advice throughout all stages of this project. Many thanks to all staff at NHS Lanarkshire Psychological Therapies for Older People team who supported the recruitment.

I would like to thank all my supervisors throughout my training, particularly Dr Susan Ross, Dr Leigh Whitnall and Dr Nicola Miller for your dedication in supporting my learning; you continue to inspire me.

Thanks to my wonderful mum and dad, who to this day enable me to chase my wildest dreams, and to my brother – for reminding me that dreams are to be chased.

Finally, I would like to thank my incredible friends, in Glasgow and across the world, for your patience, kind words and laughter shared together. Your support helped me through.

Chapter 1 Systematic review

The experiences of older adults living with mental health difficulties: a meta-synthesis

Rasa Butrimaviciute*

***Correspondence Address:**

Mental Health and Wellbeing Administration Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

E-mail: 1104425B@student.gla.ac.uk

Declaration of Conflict of Interest: None

Prepared in accordance with submission requirements to Qualitative Health Research (Appendix 1.1)

Word count (including references): 7,142

Abstract

Background: How older adults (OAs) describe their symptoms of mental health related difficulties might impact on recognition and treatment of mental health disorders in this population.

Objectives: This review aimed to synthesise OAs' experiences of mental health problems in order to provide a detailed understanding of how they conceptualise their difficulties and what common themes exist within this population.

Method: Systematic search of MEDLINE, CINAHL, EMBASE, PsycINFO, and PsycARTICLES was carried out in October 2019. Backward and forward citation searches, review of reference lists and the hand search of the journal 'Qualitative Health Research' supplemented the strategy. COREQ was used to assess the quality of reporting. Data from the available papers was integrated using thematic synthesis.

Results: Themes from 13 studies exploring experiences of depression, self-harm, suicidal ideation, sadness and mental health suffering were synthesised, resulting in five major themes: 'Suffering at the dusk of life', 'Threatened, disrupted self', 'Existing in isolation', 'Internalised stigma', 'Striving to live', and one minor theme: 'Anxiety in the shadow of depression'.

Conclusion: Instead of using symptom specific language, older adults report narratives of loss, adjustment and self-stigma being more prominent. This can make it difficult to recognise mental health symptoms in this population.

Keywords: older adults, mental health, experiences, meta-synthesis

Introduction

It has been suggested that different demographic groups understand and describe their experiences using a language that is unique to their cultural context (Wand et al., 2018a). Previous research also indicates that older adults (OAs) conceptualise mental health difficulties differently to the younger people (Hegeman et al., 2012). In Hegeman and colleagues' (2012) meta-analysis OAs complained of gastrointestinal symptoms, hypochondriasis and agitation, while younger adults presented with less physical and more emotional complaints. Although the question persists whether age-related physical conditions may overlap with some of the physical symptoms of mental health disorders, the authors concluded that it is possible for late-life depression to have a more somatic presentation. Sociocultural factors, age and ethnic origin may also underlie how mental health difficulties are experienced and perceived (Laidlaw and Pachana, 2009).

The way that older patients understand and report their symptoms has been linked to how they cope with their difficulties. For example, when biological causes for depression are emphasised, lifestyle management approaches are viewed as less helpful than medication or psychotherapeutic interventions (Nolan and O'Connor, 2019). In their study, Switzer and colleagues (2009) reported that OAs see depression as their 'individual responsibility'. These attitudes may differ to that commonly construed within the society, where depression is seen as a treatable mental health disorder, offering an explanation for why OAs may be less likely to seek support from services (Gordon et al., 2018). OAs may be less able to recognise and describe mental health difficulties in ways that are commonly understood, due to cohort beliefs and stigma, therefore making it difficult for healthcare professionals to recognise symptoms and refer appropriately (Sirey et al., 2014).

Two existing meta-syntheses have explored how OAs experience depression and self-harm (Corcoran et al., 2013, Wand et al., 2018a). In Corcoran et al. (2013) 13 studies published between 2001 and 2010 on experiences of depression suggested that negative feelings towards self, sadness, hopelessness, fear, powerlessness, isolation, declining overall wellness, pain and illness were described by depressed OAs. Limitations of the available literature on the topic

pointed to bias towards studies being conducted in developed countries, with predominantly female participants and variation in criteria used for defining depression.

Wand et al. (2018) meta-synthesised eight studies that explored the experiences of those OAs who committed acts of self-harm and attempted suicide. Conventional content analysis revealed themes of loss and powerlessness, alienation, disconnectedness and invisibility, and meaninglessness. Only three of the eight studies were rated as high quality, and only four addressed reflexivity. They also found inconsistencies in data triangulation and quality of sampling.

While these reviews explore distinct presentations of mental distress in OAs, no study to date has integrated the available literature on the phenomenology of mental health difficulties in this population. Although mental illness has been traditionally defined by medical diagnostic manuals, there has been a strong drive by professionals and service users towards a less medical approach incorporating the voices of people with experiences of mental distress (Collier and Grant, 2018, Johnstone et al., 2018).

Aims

The aim of this systematic review was to identify and meta-synthesise qualitative studies that describe experiences of mental health difficulties in OAs. It aimed to integrate studies that include medical diagnoses described in medical diagnostic manuals, as well as studies that focused on symptoms of mental health disorders.

The review aimed to answer the following questions:

1. How do older adults experience and describe symptoms of mental health difficulties and what are the common themes?

2. What is the quality of reporting across existing studies?

Methods

Search strategy

The databases were searched for any existing reviews. Two relevant reviews have been identified as described earlier; these guided the inclusion and exclusion criteria and determined the time range for the current review. The search strategy for this study included the systematic search of five electronic databases (MEDLINE, CINAHL, EMBASE, PsycINFO and PsycARTICLES) conducted in October 2019. The reference and citation lists of the identified articles were manually searched. Truncation (*) and Boolean operators (OR and AND) were used to combine search strings and to increase accuracy of searches. Thesaurus terms (MeSH headings) were used when possible. The database filters were applied as follows: peer reviewed, English language, 2010 – 2019. The terms were tested to increase sensitivity and specificity. The following search strategy, in line with the SPIDER search strategy tool, was identified as most accurate (Cooke et al., 2012):

1. older adult* OR older people OR older person* OR older patient* OR aged OR elderly OR late* life

   AND

2. mental* ill* OR mental health OR mental disorder* OR mental illness

   AND

3. interv* OR focus group* OR case stud* OR observ*

   OR

4. narrat* OR describ* OR experience* OR perspective* OR meaning OR living with

   AND

5. qualitative

The exact terms used for each database are provided in Appendix 1.2.

Inclusion and exclusion criteria

Studies were included if:

i. Focused on OA population (aged 60 or above) with experiences of mental health disorders or symptoms;
ii. Published in English language in culturally 'Western' countries (e.g. US, Europe and Australia);
iii. Full-text available;
iv. Published in peer-reviewed journals;
v. Used qualitative methods (including mixed-methods);
vi. Published between January 2010 and October 2019.

Studies were excluded if they focused on the following:

i. Other topics in the context of the lived experience of mental health difficulties;
ii. Substance abuse disorders;
iii. Mental health difficulties in the context of neurodegenerative conditions or delirium;
iv. Minority populations (i.e. sub-groups within the dominant society), due to experiences that typically set them apart from the majority group (Feagin, 1984);
v. Well-being or experiences of recovery, due to differences in semantic meaning (Collier, 2010).

The lead researcher conducted the systematic search, screened all identified titles and removed the duplicates. The abstracts of the included studies were then reviewed and full text articles of the relevant studies were read. Where studies did not clearly fit the criteria, they were reviewed by a second researcher and the consensus was reached for their inclusion or exclusion in the review.

Methodological critique

Quality appraisal was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ; Appendix 1.3) tool (Tong et al., 2007). COREQ is a 32-item checklist aimed to assess transparency of reporting in research and has been previously used as a tool to appraise quality in meta-syntheses (Prorok et al., 2013, Rocque and Leanza, 2015). It is divided into three domains: 'research team and reflexivity', 'study design', 'analysis and findings'. Although the tool has been designed to guide the process of reporting, the authors maintain that it can be used for appraising studies in a meta-synthesis (Booth et al., 2014).This recommendation corresponds with the wider controversy regarding the appraisal of quality of the qualitative research, such as what constitutes appropriate criteria for appraising studies and the lack of methods and standards for quality appraisal (see Majid and Vanstone (2018) for detailed discussion).

For the purposes of the present synthesis, the COREQ was utilised to assess the quality of reporting, and to guide the initial steps of the synthesis. The papers providing the most detail as to how the data was collected (Domain 2) and reporting the findings in a most coherent and detailed manner (Domain 3) were thematically analysed first in order to generate initial codes and infer the common themes (Gordon et al., 2018, Bjørkløf et al., 2015, Bonnewyn et al., 2014, Troya et al., 2019, Wand et al., 2018b). A sub-sample (*n* = 3) of the papers was reviewed by an independent rater with 96% agreement between their and the lead researcher rating. The main disagreement related to the explicit reporting of gender of the interviewers and the detail provided regarding the method of approach to participants.

Reflexivity

At the time of conducting this review, the lead researcher was conducting a quantitative study exploring treatment preferences in OAs (Chapter 2). In addition, the researcher had approximately one and a half year of experience delivering psychological interventions to OAs in an OA mental health service. These experiences have informed the researcher's psychological understanding of difficulties that OAs may experience and thus may have influenced the interpretation and presentation of themes generated from the identified studies. In particular, the themes of the changing identity have been observed in the

clients worked with; these were in relation to multiple losses that the clients had been experiencing in the face of physical health decline. It is likely that this work has lent the researcher a more in-depth understanding of psychological difficulties of old age and allowed for a more intimate engagement with the data gathered for the purposes of this review.

Data synthesis

Thematic synthesis has been chosen as it has been developed to directly inform policy and practice and allows for systematically synthesising heterogeneous data from studies with varying methodological approaches (Thomas and Harden, 2008). It involves interpreting the content of 'descriptive' themes in an attempt to synthesise the themes together in order to answer an initial research question. This method accommodates for heterogeneity across the primary studies thus allowing to combine and translate findings from data that may otherwise be difficult to compare (Barnett-Page and Thomas, 2009).

All text of the relevant themes (as listed in Table 1.1) was extracted as data from each primary study. This was read line-by-line and coded manually, where each unit of meaning was assigned a code (for an example of coded text see Appendix 1.4). All codes for each dataset were then extracted as a list and organised into themes, checking in with the data to ensure they fitted the meaning originally conveyed in each article. These were then collapsed for each paper, resulting into descriptive themes. Concepts were then translated from one study to another through comparison between all existing codes. Final stage of analysis consisted of 'going beyond' and inductively generating 'analytical' themes. The sample of coded text was reviewed by the second researcher to ensure the initial codes fitted with the data and accurately informed the overarching themes.

Results

The outcomes of the search strategy are presented in Figure 1.1. A total of 13 original papers were included in the meta-synthesis. Table 1.1 summarises the details of studies and themes included. Three of the studies used a mixed-methods design (Drageset et al., 2016, Drageset et al., 2015, Van Beljouw et al., 2014). One study included support workers as participants; only data related to OAs' accounts was used in the synthesis (Troya et al., 2019).

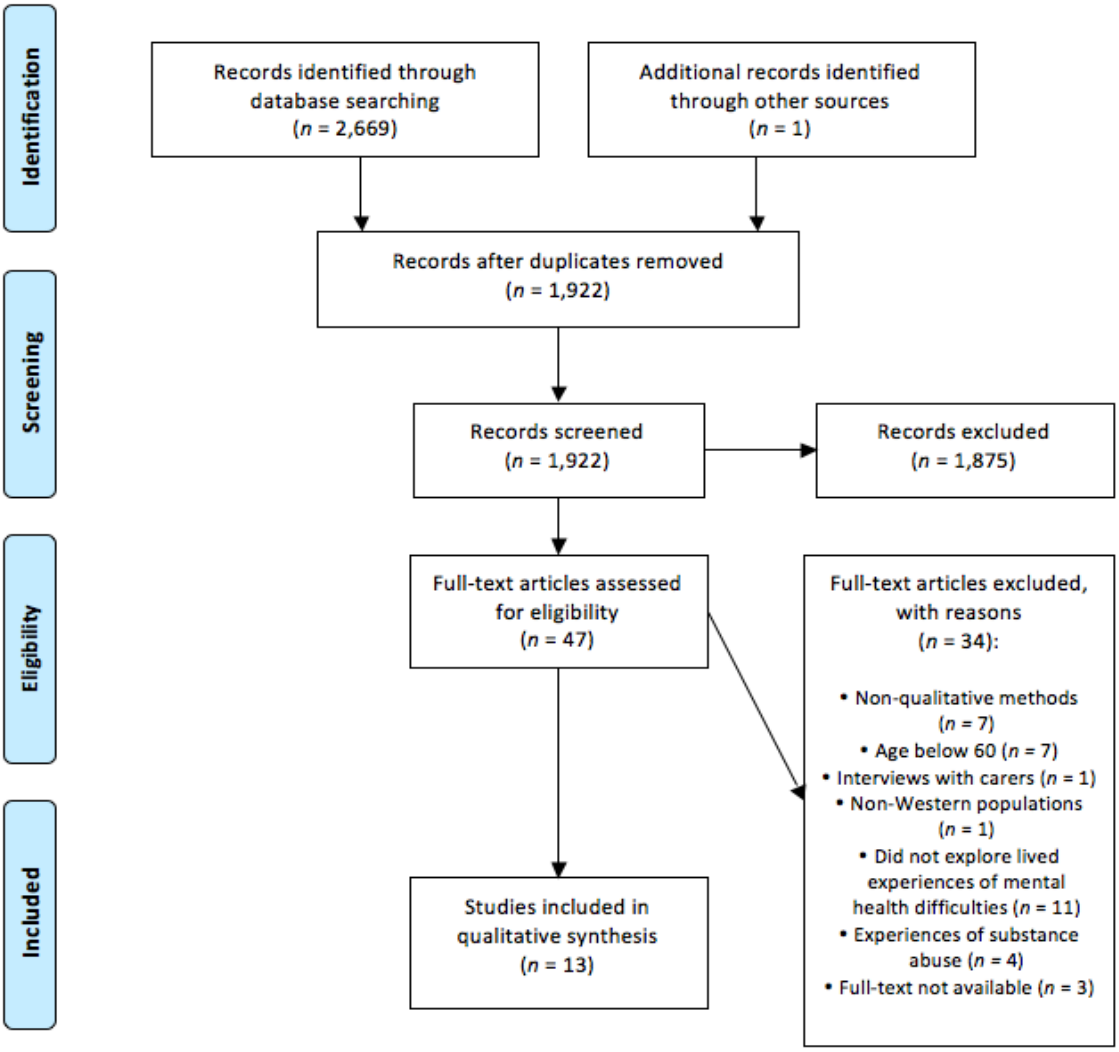


Figure 1.1: PRISMA flow chart

Table 1.1: Details of studies and themes included in the synthesis

Study, Year Country	Method of analysis	Participants	Themes
Bjørkløf et al., 2015 Norway	Phenomenological hermeneutics	18 patients (13 females, 5 males) in psychogeriatric hospital, mean age = 77.9	"Terrible suffering", "Being stuck", "Why did this happen?"
Bonnewyn et al., 2014 Belgium	Grounded theory	8 patients (6 females, 2 males) in a psychiatric ward, mean age = 71.8	"Life and self disrupted by loss", "Loneliness", "Loss of control", "Unwilling to continue"
Drageset et al., 2015 Norway	Qualitative content analysis	18 nursing home residents (11 females, 7 males), mean age = 84.8	"Lifelong suffering as a complex psychosocial experience"
Drageset et al., 2016 Norway	Qualitative content analysis	60 nursing home residents (39 females, 21 males), mean age = 85.3	"Sadness", "Coping with sadness"
Gordon et al., 2018 UK	Grounded theory	16 respondents in community (10 females, 6 males), age range 67 - 88	"Superficial Accepters", "Striving to Understand", "Unable to Articulate"
Holm et al., 2014 Norway	Thematic analysis	13 respondents (10 females, 3 males), mean age = 68	"Shadows from the past"
Holm et al., 2013 Norway	Hermeneutic interpretation	29 outpatients, minimum age = 60	"Relationships and togetherness"
Iden et al., 2015 Norway	Systematic text condensation	12 nursing home residents (8 females, 4 males, minimum age = 80	"Decay and loss of agency", "Loneliness in the middle of the crowd", "Reconciliation and identity"
Martinsson et al., 2012 Sweden	Phenomenological hermeneutics	7 respondents in community (5 females, 2 males), mean age = 72.6	"Struggling for existence"
Troya et al., 2019 UK	Thematic analysis	9 respondents in community (6 females, 3 males), mean age = 63.4	"Stressors contributing to self-harm, "Self-harm motivations"
Van Beljouw et al., 2014 The Netherlands	Grounded theory	24 respondents (18 females, 6 males) from general practices and a care home facility, mean age = 76.1	"The self-perceived relationship between depressive symptoms and loneliness, "Self-perceived causes of severe loneliness", "Self-perceived needs to alleviate emotional distress"
van Wijngaarden et al., 2015 The Netherlands	Analysis based on the reflective lifeworld approach	25 respondents in community (14 females, 11 males), mean age = 82 years	"A sense of aching loneliness", "The pain of not mattering", "The inability to express oneself", "Multidimensional feelings of tiredness", "A sense of aversion towards feared dependence"
Wand et al., 2018b Australia	Thematic analysis	30 respondents (15 females and 15 males) from inpatient and community services, mean age = 86.5	"Reasons for self-harm"

Methodological review of the studies

Comprehensiveness of reporting is presented in Table 1.2. In summary, the least information was provided within Domain 1 'Research team and reflexivity'. Only one study reported on participant knowledge of the interviewer (Gordon et al., 2018), and only two studies reflexively considered interviewer characteristics and the impact of these on data collection process (Bjørkløf et al., 2015, Gordon et al., 2018).

Within Domain 2, a method of approaching participants was poorly reported, stating who approached the participants without specifically describing the procedure. Only four studies provided data on non-participation, with only one study detailing reasons for this (Wand et al., 2018b). Only one study reported on the presence of non-participants during the interviews (Gordon et al., 2018). No study reported whether the questions were piloted. Only one study reported on returning transcripts for participant validation (Bjørkløf et al., 2015).

Within Domain 3, the process of data coding was well reported but only three studies reported on respondent validation, one of which reported participants having checked narrative reports (van Wijngaarden et al., 2015), and in one study emergent themes were summarised to participants at the end of their interview (Van Beljouw et al., 2014). Only two studies considered diverse cases or described minor themes (Gordon et al., 2018, Wand et al., 2018b).

Overall the reporting varied from 38% to 91% of items being reported, with the two mixed-methods studies having the lowest reporting rates.

Table 1.2: Comprehensiveness of reporting

COREQ domains			Studies													No of studies
			Bjørkløf et al., 2015	Bonnewyn et al., 2014	Drageset et al., 2015	Drageset et al., 2016	Gordon et al., 2018	Holm et al., 2014	Holm et al., 2013	Iden et al., 2015	Martinsson et al., 2012	Troya et al., 2019	van Beljouw et al., 2014	van Wijngaarden et al., 2015	Wand et al., 2018b	
Domain 1: Research team and reflexivity	Personal characteristics	Interviewer / Facilitator	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Credentials					✓		✓		✓				✓	**4**
		Occupation	✓	✓			✓	✓							✓	**5**
		Gender	✓				✓	✓	✓	✓	✓	✓	✓		✓	**9**
		Experience and training	✓				✓	✓	✓			✓			✓	**6**
	Relationship with participants	Relationship established	✓	✓			✓					✓			✓	**5**
		Participant knowledge of the interviewer					✓									**1**
		Interviewer characteristics	✓				✓									**2**
Domain 2: Study design	Theoretical framework	Methodological orientation and theory	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	**12**
	Participant selection	Sampling		✓			✓			✓	✓	✓	✓	✓		**7**
		Method of approach	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓		**10**
		Sample size	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Non-participation		✓			✓						✓		✓	**4**
	Setting	Setting of data collection	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓		**10**
		Presence of non-participants					✓									**1**
		Description of sample	✓	✓	✓		✓	✓			✓	✓	✓	✓	✓	**10**

			Bjørkløf et al., 2015	Bonnewyn et al., 2014	Drageset et al., 2015	Drageset et al., 2016	Gordon et al., 2018	Holm et al., 2014	Holm et al., 2013	Iden et al., 2015	Martinsson et al., 2012	Troya et al., 2019	van Beljouw et al., 2014	van Wijngaarden et al., 2015	Wand et al., 2018b	
	Data collection	Interview guide	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Repeat interviews					✓			✓		✓		✓		**4**
		Audio/visual recording	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	**12**
		Field notes	✓				✓					✓		✓	✓	**5**
		Duration	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Data saturation	✓	✓			✓			✓	✓	✓	✓		✓	**8**
		Transcripts returned	✓													**1**
Domain 3: Data analysis and findings	Data analysis	Number of data coders	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	**12**
		Description of the coding tree	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Derivation of themes	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Software		✓									✓	✓	✓	**4**
		Participant checking					✓						✓	✓		**3**
	Reporting	Quotations presented	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Data and findings consistent	✓	✓			✓	✓		✓	✓	✓	✓	✓	✓	**11**
		Clarity of major themes	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**13**
		Clarity of minor themes					✓								✓	**2**

Meta-synthesis

Five major themes emerged from the data synthesis: (1) Suffering at the dusk of life, (2) Threatened, disrupted self, (3) Existing in isolation, (4) Internalised stigma, (5) Striving to live, and one minor theme (6) Anxiety in the shadow of depression (see Table 1.3 for individual studies' contribution to the synthesis).

There is an overlap between the five major themes suggesting that the experiences are complex and multifaceted (Figure 1.2).

Figure 1.2: The overlap and interaction of main themes

Table 1.3: Each study's contribution to synthesis

Studies	Themes																	
	Sadness at the dusk of life			Threatened, disrupted self				Existing in isolation		Internalised stigma				Striving to live			Anxiety in the shadow of depression	
	Mourning the losses	*Wear and tear from life*	*Resigned to dying*	*Loss of lived identity*	*Self as a burden*	*Worth-less older self*	*With-drawal*	*Disconnected and estranged*	*Striving to connect*	*Don't diagnose me, understand me*	*Underlying shame*	*Minimise the suffering*	*Somatisation as a safe start*	*Wishing to understand*	*Coping is a virtue*	*Struggling to maintain control*	*Restless body*	*Muddled mind*
Bjørkløf et al., 2015	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓	✓	
Bonnewyn et al., 2014	✓		✓	✓	✓	✓	✓	✓	✓				✓			✓	✓	✓
Drageset et al., 2015	✓	✓	✓		✓													
Drageset et al., 2016	✓		✓			✓		✓	✓							✓		
Gordon et al., 2018		✓		✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓			
Holm et al., 2014		✓	✓												✓	✓		
Holm et al., 2013	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓				✓	✓		
Iden et al., 2015	✓	✓		✓		✓		✓	✓							✓		
Martinsson et al., 2012	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
Troya et al., 2019		✓						✓	✓	✓	✓			✓		✓		
van Beljouw et al., 2014	✓					✓	✓	✓	✓			✓		✓				
van Wijngaarden et al., 2015	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓				✓		
Wand et al., 2018b	✓	✓	✓	✓	✓	✓	✓	✓								✓		

1. Suffering at the dusk of life

One of the main factors contributing towards suffering are multiple losses experienced in the older age. Although the term depression is frequently used, the older adults' experiences seem to reflect sadness associated with grief (Drageset et al., 2016, Gordon et al., 2018, Iden et al., 2015). Those who are unable to resolve difficulties that arise during this transitory period may contemplate suicide (van Wijngaarden et al., 2015, Wand et al., 2018b).

Mourning the losses

Authors report losses of role, occupation, meaningful activity and physical health and social networks (van Wijngaarden et al., 2015, Van Beljouw et al., 2014, Bonnewyn et al., 2014). Physical pain and the slowing down of the body prevent OAs from living at their previous pace (van Wijngaarden et al., 2015). They feel hopeless about their failing bodies which impacts on their ability to engage with meaningful activities such as visiting friends, or partaking in their communities (Bjørkløf et al., 2015). These losses underpin how OAs experience present living:

> *"Participants described life after the loss inferior to life prior to the loss"* (Author's quote, Bonnewyn et al., 2014, p. 614).

The mourning for all that is lost takes place and is narrated as sadness by many participants (Van Beljouw et al., 2014).

Wear and tear from life

Several papers have articulated how the accumulation of stresses throughout life has resulted in mental health difficulties in the older age (Holm et al., 2013, Troya et al., 2019, Wand et al., 2018b). Life-long stresses, relational difficulties and unresolved traumas seemed to drain psychological resources and manifest as vulnerability in later life. Holm and colleagues (2013) called this experience as *"carrying a heavy shoulder bag"* (p. 760) and as *"shadows from the past"* (2014, p. 256). Mental health difficulties at this stage are a representation of how

multiple stresses in the absence of significant buffers undermine one's resilience:

> *"Some related self-harm to early aversive experiences, and of migration, including being stuck in the hardship, having survived it and the cumulative effects"* (Author's quote, Wand et al., 2018b, p. 866).

Resigned to dying

In a number of papers, depression was narrated as a stage in the process of dying (Bjørkløf et al., 2015, Drageset et al., 2015, Holm et al., 2014). Some OAs described their experience of living as filled with darkness and despair (Holm et al., 2014). Some found their present life unbearable and felt unable to continue living (van Wijngaarden et al., 2015). The lack of energy and drive that are typically attributed to depression were associated with age and death:

> *"Experiencing this condition was also described as being close to dying"* (Author's quote, Bjørkløf et al., 2015, p. 5).

Others resigned themselves to boredom and simply existing:

> *"I am here waiting for death"* (Participant's quote, Wand et al., 2018b, p. 866).

This sub-theme was prominent in some of the papers that dealt with suicidal experiences in older age (van Wijngaarden et al., 2015, Wand et al., 2018b).

2. Threatened, disrupted self

The multiple losses lead to fractured identity, suggesting an interaction between the first two themes (Figure 1.2). Challenges that come at older age lead to changes that are significant enough to disrupt participants' view of themselves and lead to identity crisis (Wand et al., 2018b). Others no longer recognise themselves when depressed (Bjørkløf et al., 2015). Loss of roles and the ability to live an independent, meaningful life is described as a loss of self as one knows it.

Loss of previous identity

Multiple losses described by the previous theme affect the structure of one's identity. Many participants struggle to recognise themselves in the older age (Wand et al., 2018b, van Wijngaarden et al., 2015). Martinsson et al. (2012) illustrates how being dependant on others' care affects one's identity:

> *"The management of daily life was under the jurisdiction of others, which resulted in being deprived of the possibility of being one's true self"* (p. 5).

The self that is depressed and sad is unfamiliar to an older person that always coped with life's challenges:

> *"I can't do anything anymore, nothing works out; I am no longer of use… I can no longer do the things which I used to do before anyway"*
> (Participant's quote, Bonnewyn et al., 2014, p. 614).

Being depressed means living in a way that is not recognisable to OAs (Bjørkløf et al., 2015). Van Wijngaarden et al. (2015) notes that participants' inability to carry out activities they were previously involved with is pertinent to their disrupted identity.

Self as a burden

A number of authors describe ways through which a possibility of becoming a burden threatens one's identity (Bjørkløf et al., 2015, Bonnewyn et al., 2014, Martinsson et al., 2012, van Wijngaarden et al., 2015, Wand et al., 2018b). In these papers OAs talk about fear of losing independence, becoming a hindrance, and losing control over one's body. Being or becoming a burden is threatening because it is *"utterly incongruous with their idea of who they are"* (Author's quote, van Wijngaarden et al., 2015, p. 262).

Worthless older self

Seeing self as being or becoming a burden leads to feelings of worthlessness (Martinsson et al., 2012). To be dependent means to be devoid of dignity (van

Wijngaarden et al., 2015). The sub-theme of worthlessness seemed to arise in the context of lost identity:

> *"You lose so much that you are no longer human, <…> I am treated as a person, that's not my point, but for myself… (…) I see nothing, I see nothing but blackness"* (Participant's quote, van Wijngaarden et al., 2015, p. 261).

The inability to work through this loss results in perceiving themselves as worthless. Although a sense of worthlessness may be viewed as a symptom of depression, for distressed OAs it is linked to challenges that accompany a difficult transition.

3. Existing in isolation

Feeling worthless and ashamed of who they have become, OAs disconnect from their surroundings and withdraw from the world and life as it is (van Wijngaarden et al., 2015, Holm et al., 2013). They exist in isolation, yet craving for connection and togetherness (Van Beljouw et al., 2014, van Wijngaarden et al., 2015). Under this theme, loneliness and isolation are voluntary and a product of an activated negative belief system rather than a direct result of shrinking social networks or losses.

Withdrawal

Feeling unworthy of other people's time and company, OAs disconnect from their surroundings and withdraw from the world and life as it is (Gordon et al., 2018, Holm et al., 2013, Van Beljouw et al., 2014, van Wijngaarden et al., 2015). They do so out of fear of being a burden to others (van Wijngaarden et al., 2015), that they have nothing to offer socially (Van Beljouw et al., 2014), or due to seeing their older self as unworthy (van Wijngaarden et al., 2015).

Disconnected and estranged

OAs feel estranged, yet this estrangement is much more than losing physical connection to people or activities (Martinsson et al., 2012; van Wijngaarden et al., 2015). It is losing connection to life and this world, in that OAs feel they lost

a function in the world that is different and relentlessly changing (van Wijngaarden et al., 2015). Some feel as though they float in a vacuum where the ties between themselves and the world around them are severed (van Wijngaarden et al., 2015). Through the loss of purpose and meaning they feel disconnected and no longer belonging to this world:

> *"So yes, I feel I have a lot of experience and knowledge in that area but the society doesn't need me anymore"* (Participant's quote, van Wijngaarden et al., 2015, p. 261).

Holm further described withdrawal from relationships that lead to sense of isolation:

> *"When supportive togetherness is lacking, poor, or simply obscured, a sense of strangeness occurs"* (Author's quote, Holm et al., 2013, p. 761),

while Martinsson et al. (2012) highlighted that the very status of a mental disorder created a sense of estrangement:

> *"To be an older person with mental disorders meant to be alone, both socially (no close friends) and mentally (alone within)"* (p. 3).

Striving to connect

Despite of feeling estranged and not belonging to the surrounding world, many felt a strong desire to connect to others, to be important, to feel heard and understood (Bjørkløf et al., 2015, Bonnewyn et al., 2014, Gordon et al., 2018, Holm et al., 2013, Martinsson et al., 2012, Van Beljouw et al., 2014). Due to feeling ashamed and worthless, older patients may not express it:

> *"usually this suffering is kept secret <…> even when in reality they silently wish to be connected to others and share themselves"* (Author's quote, Holm et al., 2013, p.761).

Others feared that by attempting to socially engage others they may be perceived as burdensome and lose much needed practical support (Holm et al., 2013, Martinsson et al., 2012). Yet others expressed resentment regarding their lack of connection (Bjørkløf et al., 2015).

Don't diagnose me, understand me

OAs desire a person-centred supportive approach, as opposed to being given a label (Holm et al., 2013, Gordon et al., 2018, Troya et al., 2019, Van Beljouw et al., 2014). As one of the participants explained, being able to communicate yourself, feel listened to and understood was key:

> *"I can talk to him [psychiatrist] and he doesn't try to give me medication all the time. <…> I trust him and the psychiatric nurse a lot."*
> (Participant's quote, Holm et al., 2013, p. 760).

Instead, being labelled indicated stigma and negatively affected the sense of self (Martinsson et al., 2012). Holm et al. (2013) detailed the characteristics of desired relationships:

> *"Non-supportive relationships were characterised by obligation, while supportive relationships were based on commitment, involvement and understanding"* (p760).

4. Internalised stigma

Through their narratives, ageist and stigmatising beliefs embody shame about one's suffering (Martinsson et al., 2012). The stigma that stems from within prevents help-seeking. The narratives of distress take shape of silence and whispers (Troya et al., 2019). It seems families, carers and health professionals must listen thoroughly to hear and recognise distress (Gordon et al., 2018).

Underlying shame

Stigma is at the back of thinking of one's mental health and is internalised as part of their identity; OAs fear that their diagnoses or problems are visible to others:

> *"it is not always easy to be with other people. One believes that others can see the problem and that the depression is written on one's face"*
> (Author's quote, Holm et al., 2013, p. 761).

The self that suffers with mental health difficulties is therefore shameful and must be hidden, which relates to the earlier theme of isolating oneself. Shame prevents interaction and help-seeking from others (Bjørkløf et al., 2015, Holm et al., 2013):

> *"Feelings of guilt and shame were described when broaching this issue, and of not being able to "pull myself together"* (Author's quote, Bjørkløf et al., 2015, p. 6).

Hide the suffering

Some described the experiences of poor mental health as 'their secret', striving to come across to others as being well and coping (Gordon et al., 2018). Due to the stigma that many were feeling, OAs made attempts to minimise the suffering and avoid speaking about their difficulties:

> *"This tendency to deny or minimize their depression conflicted with the open and accepting way they initially talked about it. With probing some comments revealed insecurities about having depression, which possibly stemmed from concern about a negative effect on their outward image"* (Author's quote, Gordon et al., 2018, p. 5).

Internalised stigma hence impacted on when and how they shared their inner experiences with others, if at all.

Somatisation as a safe start

When talking about depression, participants described bodily experiences such as physical pains and tensions in the muscles (Bonnewyn et al., 2014). Others used physical complaints to start a conversation about mental well-being:

> *"I didn't tell him [the GP] the details I just said, it started off with me feet and then I got a rash up me back and even in my face"* (Participant's quote, Gordon et al., 2018, p. 6).

Others talked about low mood as "heartbreak" or instead focused on physical pain as a way to express suffering (Gordon et al., 2018, p. 7).

5. Striving to live

In a number of studies older adults express their difficulties through the narrative of coping (Holm et al., 2014, Holm et al., 2013, Iden et al., 2015, Van Beljouw et al., 2014). The language of coping appears integrated in their experience of suffering, despite the researchers' exploration of suffering per se. The inclination and strong drive to cope defines their approach towards life, hence indicating how a person of their generation may talk about psychological difficulties.

Wishing to understand

Understanding one's difficulties and symptoms was important for the continuation of their identity (Martinsson et al., 2012). As Martinsson and colleagues (2012) put it,

> *"The need for advice and knowledge was immense as one attempted to understand the causes leading up to the present situation"* (p. 4).

Understanding why one was struggling with their mental health was key, particularly to those participants that have managed to rid themselves of stigmatising beliefs:

> *"I am not embarrassed to be labelled as a madcap but, hell! <…> I would like to know how mad I am"* (Participants quote, Martinsson et al., 2012, p. 5).

Many seek or wish to learn more about their mental state (Martinsson et al., 2012, Gordon et al., 2018, Van Beljouw et al., 2014).

Coping is a virtue

Ability to cope with their difficulties is seen as a virtue by many OAs. Despite of the papers being focused on suffering, coping has emerged as a theme (except of the work by Bjørkløf et al (2015), where coping was studied but narratives focused on distress). Being able to cope with difficulties means one can retain their dignity and self-respect (Martinsson et al., 2012). Some attempt to cope at

any cost until their bodies give up (Bjørkløf et al., 2015), others seek information about their illness (as in 'Wishing to understand'), yet others rely on less adaptive methods such as suicidal behaviours and self-harm (Holm et al., 2014).

Struggling to maintain control

Holm and colleagues (2013) reported the theme of "Holding the reins", in which participants expressed desire to maintain control over their lives and well-being:

> *"I have the strength and resources to want to do something. The psychiatrist wanted to try a new medicine, but I said, "No, thanks." I had enough of trying new medications. I stopped attending that psychiatrist"* (Participant's quote, Holm et al., 2013, p. 760).

Maintaining control means keeping personal dignity and "*having experience of being a person and not just a victim"* (Holm et al., 2013, p. 761). Van Beljouw et al. (2014) noted that the less distressed OAs placed particular importance on taking control over their difficulties in comparison to more distressed OAs who communicated a more passive wish to be understood. Van Wijngaarden et al. (2015) clarifies how suicidal ideation reflects a desire for control:

> *"They simply cannot surrender to life, suffering and dependence as it is/comes. Instead they feel ready to give up on life, actively ideating on ways to hasten death"* (p. 260).

Self-harm and suicidal behaviour is then viewed as another way of taking control over one's suffering (Holm et al., 2014, Troya et al., 2019, Wand et al., 2018b).

6. Anxiety in the shadow of depression

Narratives consistent with the symptoms of anxiety were reported by three papers (Bjørkløf et al., 2015, Bonnewyn et al., 2014, Martinsson et al., 2012).

Restless body

The experience of a perpetuating cycle of physical restlessness is described, where participants have been *"running on a high gear"* (Author's quote, Bjørkløf et al., 2015, p. 6) leading to feeling more restless and thus more activated. For some, this followed significant stresses such as being a carer for their spouse, for others it was driven by a fear of illness, dependency and death (Bjørkløf et al., 2015), yet for others it related to fear of losing control (Bonnewyn et al., 2014). Insomnia and physical exhaustion were also discussed in connection to this sub-theme. Bonnewyn et al. (2014) reported on other physical symptoms including trembling, difficulty breathing, heart palpitations, faintness, tightness in chest and weakness in legs.

Muddled mind

Bonnewyn et al. (2014) reported experiences of mind being undermined and overwhelmed. Metaphors of "*feeling like a zombie*", "*head as anthill*", and "*muddled head*" were described (p. 616). Loss of control over one's thoughts, inability to think clearly and to reflect were identified. Martinsson et al. (2012) also reported inability to get peace of mind and disturbance in ways of thinking.

Discussion

This meta-synthesis systematically reviewed and integrated qualitative research exploring OAs' experiences of poor mental health. The quality of reporting assessment highlighted gaps in reporting of researcher characteristics and relationship with participants, involvement of participants in data collection and analysis process, and poor reporting on minor themes. The quality of reporting was not consistent with the richness of the qualitative data. The 18 emergent sub-themes led to a construction of five major themes, indicating mental health difficulties in the older age to be a complex phenomenon constituent of issues related to identity and adjustment.

The present synthesis suggests that instead of using symptom-specific language, OAs focus on experiences of loss, changing identity and functional difficulties. One reason for this could be that self-stigma and shame, as indicated in the

synthesis, prevent OAs from using the more symptom congruent language (Conner et al., 2010). The impact of stigma is echoed in the review of younger adults' narratives of long-term mental illness (Collier and Grant, 2018).

In their review, Collier and Grant also reported narratives of explanation seeking, importance of coping and need for control. While these themes emerged in the present review, their content was qualitatively different; for example, the theme of coping was linked to the value of functional improvement in younger adults as opposed to positive self-esteem as seen in this review. Similarly, for younger adults, the theme of loneliness was related to physical disconnection to communities, which is in contrast to emotional experience of loneliness seen in OAs. These discrepancies suggest a likely difference between the experiences of distress across the two groups.

Reference to accumulation of life-long psychological burden (negative 'life history') was made by Collier and Grant (2018). This might be a chronological precursor to the sub-theme of 'wear and tear from life' of this review. This might indicate the developmental nature of mental health disorders in older age supporting the theory that unresolved conflicts from earlier life lead to vulnerability towards mental illness in older age (Erikson, 1950). Feeling worn out by life may also be linked to more complex traumatic events (Hedelin and Strandmark, 2001). With lack of existing research on the psychological experiences of older trauma survivors, this hypothesis is to be further explored.

Methodological strengths and weaknesses

This is the first review that aimed to synthesise the narratives of older adults suffering from a range of mental health difficulties. The findings of the review are based on studies of low mood, depression, adjustment and suicidal behaviour and self-harm, suggesting that the phenomenon of interest may only be partially described. It also explicates the two existing reviews on depression and self-harm in OAs, providing a conceptual link between the themes identified in this prior work (Corcoran et al., 2013, Wand et al., 2018a). In particular, it denotes that conflicts experienced as part of late-life psychosocial development might underpin some of the themes previously identified by the researchers in this population.

Exclusion of grey literature may have limited the results, although the reference lists and backward and forward citation searches were used to increase the scope and sensitivity of the search strategy. The review focused on Western populations to improve culturally specific understanding of the phenomena. Further research may synthesise studies with non-Western participants to allow for cross-cultural comparison. The review included a number of studies from two distinct research groups. For that reason, it is possible that there may have been an overlap of participants, although this is not possible to ascertain with the data available to the reviewers.

The lead researcher has conducted the systematic search and reviewed all available titles; only a small number of titles that did not clearly fit the inclusion/exclusion criteria were reviewed by the second researcher to reduce biases. An independent rater was used for the quality appraisal of a sub-sample of the reviewed studies and the accuracy of the codes generated for the synthesis were checked by the second researcher. While all efforts have been made to reduce any biases during this process, only a fraction of the work has been reviewed by an additional researcher leading to potential biases throughout the process. The final list of themes was a result of a three-step process of data analysis and interpretation. Although the researcher kept a reflective diary throughout this process, it is possible that their pre-existing understanding of the topic influenced their interpretation.

Implications

This review highlights a gap in literature of studies exploring the narratives of anxiety and trauma presentations. It has been suggested that anxiety may be a feature of loneliness, yet how OAs make sense and narrate such experience remains an area of investigation for future studies (Canham, 2015).

Although loneliness in OA population has been extensively researched, the current synthesis highlights the possibility of self-stigma that leads to withdrawal and disconnection, thus contributing to loneliness (Kitzmuller et al., 2018). This expands and adds detail to the view of loneliness explicating the barriers for help-seeking in this group. Service providers should consider raising

mental health awareness and psycho-education of this population in order to tackle self-stigma and self-isolation that might prevent OAs from using services.

A recent systematic review has highlighted poor mental health literacy of OAs (Malkin et al., 2019). Older people are likely to hide their distress and use generic more abstract language as detailed in this study (e.g. 'floating in a vacuum' instead of 'numb', 'feeling of no use' instead of 'worthless') rather than formulating psychological distress into a recognisable problem (Chew-Graham et al., 2012). This might partially account for mental health difficulties being unrecognised and services underutilised, highlighting the importance of incorporating the language used by this population when training staff, particularly in primary care settings.

Present findings are also consistent with Malkin et al. (2019) in that OAs clearly express a desire to understand and manage their own mental health but often feel unable to seek this knowledge themselves. Services might need to be set up in a way where guided self-help and psycho-education are offered routinely.

Conclusion

This meta-synthesis systematically reviewed and synthesised qualitative literature describing OAs experiences of mental illness. It indicated a lack of studies exploring presentations of anxiety and psychological trauma and highlighted issues with reporting, particularly in areas of researcher reflexivity and participant involvement in the research process. The five themes described in this synthesis support the developmental view of suffering in older age and suggest that OAs' narratives of mental health difficulties are qualitatively distinct to those of other populations.

Next steps

While the present review systematically evaluated the literature exploring OAs experiences of mental illness, it was conducted with an aim of informing both clinicians and researchers working with OAs to better understand the needs of this population. In particular, the process of synthesis and the themes that emerged as a result of this review were used to guide the development of a treatment preference elicitation tool, as described in the following chapter of the presented portfolio.

References

Barnett-Page, E. and Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review, *BMC Medical Research Methodology,* 9, 1-11.

Bjørkløf, G. H., Kirkevold, M., Engedal, K., Selbæk, G. and Helvik, A.-S. (2015). Being stuck in a vice: The process of coping with severe depression in late life, *International Journal Of Qualitative Studies On Health And Well-Being,* 10, 1-11.

Bonnewyn, A., Shah, A., Bruffaerts, R., Schoevaerts, K., Rober, P., Van Parys, H. and Demyttenaere, K. (2014). Reflections of older adults on the process preceding their suicide attempt: a qualitative approach, *Death Studies,* 38(6-10), 612-618.

Booth, A., Hannes, K., Harden, A., Noyes, J., Harris, J. and Tong, A. (2014) COREQ (Consolidated Criteria for Reporting Studies) in Moher, D., G., A. D., Schulz, K. F., Simera, K. and Wager, E., eds., *Guidelines for Reporting Health Research: A User's Manual*, Chichester: John Wiley & Sons Ltd.

Canham, S. L. (2015). What's loneliness got to do with it? Older women who use benzodiazepines, *Australasian Journal on Ageing,* 34(1), 7-12.

Chew-Graham, C., Kovandzic, M., Gask, L., Burroughs, H., Clarke, P., Sanderson, H. and Dowrick, C. (2012). Why may older people with depression not present to primary care? Messages from secondary analysis of qualitative data, *Health & Social Care in the Community,* 20(1), 52-60.

Collier, E. (2010). Confusion of recovery: One solution, *International Journal of Mental Health Nursing,* 19(1), 16-21.

Collier, E. and Grant, M. J. (2018). A Literature Review on the Experience of Long-Term Mental Illness, *Issues in Mental Health Nursing,* 39(6), 506-513.

Conner, K. O., Copeland, V. C., Grote, N. K., Koeske, G., Rosen, D., Reynolds, C. F., 3rd and Brown, C. (2010). Mental Health Treatment Seeking Among Older Adults With Depression: The Impact of Stigma and Race, *American Journal of Geriatric Psychiatry,* 18(6), 531-543.

Cooke, A., Smith, D. and Booth, A. (2012). Beyond PICO: The SPIDER Tool for Qualitative Evidence Synthesis, *Qualitative Health Research,* 22(10), 1435-1443.

Corcoran, J., Brown, E., Davis, M., Pineda, M., Kadolph, J. and Bell, H. (2013). Depression in Older Adults: A Meta-Synthesis, *Journal of Gerontological Social Work,* 56(6), 509-534.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B. and Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods, *Journal of Health Services Research & Policy,* 10(1), 45-53.

Drageset, J., Dysvik, E., Espehaug, B., Natvig, G. K. and Furnes, B. (2015). Suffering and mental health among older people living in nursing homes-A mixed-methods study, *Peerj,* 2015 (7) 1-18.

Drageset, J., Eide, G. E. and Hauge, S. (2016). Symptoms of depression, sadness and sense of coherence (coping) among cognitively intact older people with cancer living in nursing homes-a mixed-methods study, *Peerj,* 2016 (6) 1-16.

Erikson, E. (1950). *Childhood and Society,* New York: W. W. Norton & Compan.

Feagin, J. R. (1984) *Racial and Ethnic Relations,* 2nd ed., New Jersey: Prentice-Hall.

Gordon, I., Ling, J., Robinson, L., Hayes, C. and Crosland, A. (2018). Talking about depression during interactions with GPs: a qualitative study exploring older people's accounts of their depression narratives, *BMC Family Practice,* 19(1),1-11.

Hedelin, B. and Strandmark, M. (2001). The meaning of depression from the life-world perspective of elderly women, *Issues in Mental Health Nursing,* 22(4), 401-420.

Hegeman, J. M., Kok, R. M., van der Mast, R. C. and Giltay, E. J. (2012). Phenomenology of depression in older compared with younger adults: meta-analysis, *British Journal of Psychiatry,* 200(4), 275-281.

Holm, A. L., Lyberg, A., Berggren, I., Cutcliffe, J. and Severinsson, E. (2014). Shadows from the past: the situated meaning of being suicidal among depressed older people living in the community, *Crisis,* 35(4), 253-260.

Holm, A. L., Lyberg, A., Lassenius, E., Severinsson, E. and Berggren, I. (2013). Older Persons' Lived Experiences of Depression and Self-Management, *Issues in Mental Health Nursing,* 34(10), 757-764.

Iden, K. R., Ruths, S. and Hjørleifsson, S. (2015). Residents' perceptions of their own sadness-a qualitative study in Norwegian nursing homes, *BMC Geriatrics,* 15, 21-21.

Johnstone, L., Boyle, M., Cromby, J., Dillon, J., Harper, D., Kinderman, Longden, Pilgrim, D. and Read, J. (2018). *The Power Threat Meaning Framework: Towards the identifcation of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis,* Leicester: British Psychological Society.

Kitzmuller, G., Clancy, A., Vaismoradi, M., Wegener, C. and Bondas, T. (2018). "Trapped in an Empty Waiting Room"-The Existential Human Core of Loneliness in Old Age: A Meta-Synthesis, *Qualitative Health Research,* 28(2), 213-230.

Laidlaw, K. and Pachana, N. A. (2009). Aging, Mental Health, and Demographic Change: Challenges for Psychotherapists, *Professional Psychology-Research and Practice,* 40(6), 601-608.

Malkin, G., Hayat, T., Amichai-Hamburger, Y., Ben-David, B. M., Regev, T. and Nakash, O. (2019). How well do older adults recognise mental illness? A literature review, *Psychogeriatrics,* 19(5), 491-504.

Majid, U. and Vanstone, M. (2018) Appraising Qualitative Research for Evidence Syntheses: A Compendium of Quality Appraisal Tools, *Qualitative Health Research,* 28(13), 2115-2131.

Martinsson, G., Fagerberg, I., Lindholm, C. and Wiklund-Gustin, L. (2012). Struggling for existence—Life situation experiences of older persons with mental disorders, *International Journal of Qualitative Studies on Health & Well-Being,* 7(1).

Nolan, A. and O'Connor, C. (2019) The effect of causal attributions for depression on help-seeking and treatment preferences, *Journal of Affective Disorders,* 257, 477-485.

Noyes, J., Hannes, K., Booth, A., Harris, J., Harden, A., Popay, J., Pearson, A., Cargo, M. and Pantoja, T. (2013). Chapter QQ: Qualitative and Implementation Evidence and Cochrane Reviews in Higgins, J. and Green, S., eds., *Cochrane Handbook for Systematic Reviews of Interventions*, UK: Willey Blackwell Publishers, 1-26.

Prorok, J. C., Horgan, S. and Seitz, D. P. (2013). Health Care Experiences of People with Dementia and their Caregivers: a Meta-ethnographic Analysis of Qualitative Studies, *CMAJ,* 185(14), 669-680.

Rocque, R. and Leanza, Y. (2015). A Systematic Review of Patients' Experiences in Communicating with Primary Care Physicians: Intercultural Encounters and a Balance between Vulnerability and Integrity, *Plos One,* 10(10).

Sirey, J. A., Franklin, A. J., McKenzie, S. E., Ghosh, S. and Raue, P. J. (2014). Race, Stigma, and Mental Health Referrals Among Clients of Aging Services Who Screened Positive for Depression, *Psychiatric Services,* 65(4), 537-540.

Switzer, J. F., Wittink, M. N., Karsch, B. B. and Barg, F. K. (2006). "Pull yourself up by your bootstraps": A response to depression in older adults, *Qualitative Health Research,* 16(9), 1207-1216.

Thomas, J. and Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews, *BMC Medical Research Methodology,* 8.

Tong, A., Sainsbury, P. and Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care,* 19(6), 349-357.

Troya, M. I., Dikomitis, L., Babatunde, O. O., Bartlam, B. and Chew-Graham, C. A. (2019). Understanding self-harm in older adults: A qualitative study, *EClinical Medicine,* 12, 52-61.

Van Beljouw, I. M. J., Van Exel, E., De Jong Gierveld, J., Comijs, H. C., Heerings, M., Stek, M. L. and Van Marwijk, H. W. J. (2014). "Being all alone makes me sad": Loneliness in older adults with depressive symptoms, *International Psychogeriatrics,* 26(9), 1541-1551.

van Wijngaarden, E., Leget, C. and Goossensen, A. (2015). Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living, *Social Science and Medicine,* 138, 257-264.

Wand, A. P. F., Peisah, C., Draper, B. and Brodaty, H. (2018a). Understanding self-harm in older people: a systematic review of qualitative studies, *Aging & Mental Health,* 22(3), 289-298.

Wand, A. P. F., Peisah, C., Draper, B. and Brodaty, H. (2018b). Why Do the Very Old Self-Harm? A Qualitative Study, *American Journal Geriatric Psychiatry,* 26(8), 862-871.

Chapter 2 Major Research Project

A feasibility study of using a card sort task to explore mental health related outcome and treatment preferences in older adults

Rasa Butrimaviciute*

***Correspondence Address:**

Mental Health and Wellbeing Administration Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

E-mail: 1104425B@student.gla.ac.uk

Declaration of Conflict of Interest: None

Prepared in accordance with submission requirements to Clinical Gerontologist (Appendix 2.1)

Word count (excluding Plain Language Summary): 6,461

Plain English Summary

Title: A feasibility study of using a card sort task to explore mental health related outcome and treatment preferences in older adults

Background: Providing patients with choice over the treatments they receive is a key condition of person-centred care. There is a growing evidence base to show that considering patients' preference when providing treatment increases their satisfaction and attendance for treatment, which can improve clinical outcomes (Lindhiem et al., 2014). To date, fewer studies have looked into what older adults hope to gain when attending services and what types of treatment they prefer.

Aims: The current study focused on developing a quick and patient friendly method to measure what goals for treatment older patients have and what treatments they prefer for this. The aim was to test whether this method could be used in practice and what issues might arise. This method was also used to investigate preferences in the group of people that took part in the study.

Methods: The study consisted of two phases. In Phase 1, a literature search was conducted and a group of experienced clinicians was consulted to compile a list of potential goals for treatment and available treatment types. This way, a method for assessing preferences – the Card Sort Task (CST) was developed. In Phase 2, the method was tested with patients of NHS Lanarkshire Psychological Therapies for Older People service. Two groups of participants were recruited: those from the waiting list to receive psychological treatment, and those currently receiving treatment. To test the CST, participants were asked to take part in a three-part

task where they were required to sort the cards that describe various treatment goals and treatment types in order of importance.

Results: Twenty-seven participants were recruited and took part in the CST. Participants were able to complete the first two parts of the task but the administration instructions had to be simplified during the third task to not exceed the set time limit and to minimise the demand placed on participants. People waiting to receive treatment found the task more difficult to complete. There were no difference in preferences between participants who have not received psychological treatment, and those who were in treatment. Overall, the most important goal was to 'feel less bothered by memories from the past', and the most preferred treatment was 'to see a therapist weekly or two-weekly'.

Conclusion: A sufficient number of participants was recruited, which allowed to test the method and obtain information on how CST could be improved for future use. Although CST method requires further refinement, it could be used to study patient preferences in the future.

Key reference: Lindhiem, O., Bennett, C. B., Trentacosta, C. J. & McLear, C. (2014). Client preferences affect treatment satisfaction, completion, and clinical outcome: A meta-analysis. *Clinical Psychology Review, 34*(6), 506-517.

Word count: 464

Abstract

Background: Incorporating patient preferences into clinical decision-making can have a positive impact on clinical outcomes and is a core principle of patient-centred care. Despite this, no established methods exist for studying patient preferences with older adult (OA) population.

Objectives: The study aimed to develop a Card Sort Task (CST) preference elicitation method and to determine its feasibility and acceptability with the OAs.

Method: In a cross-sectional feasibility study, the CST was developed and its acceptability was explored with OAs waiting to receive ('Waiting list' group) and receiving psychological treatment ('In-treatment' group). The study procedure involved collecting patient feedback and qualitative observation data to aid further development of the tool. Preferences for outcomes and treatments were assessed. The data was analysed to identify patient preferences and difference between the two groups.

Results: Twenty-seven participants were recruited. Twenty-six completed the full procedure, with 85% (*n* = 22) rating it positively. The Tasks 1 and 2 were acceptable to participants; aspects of Task 3 were found laborious and require further refinement. There were no differences in preferences between the two groups. 'To feel less troubled by memories from the past' was ranked as the most important treatment outcome and 'to see a therapist weekly or two-weekly' was the most preferred treatment type.

Conclusions: It was possible to recruit for, and trial the CST with OAs who generally found the tool acceptable. Further refinement of the tool is required before adopting it for larger scale trials.

Keywords: treatment preferences, older adults, feasibility, psychological therapy

Introduction

Respecting and responding to patient wishes is a key principle of person-centred care and has become a quality standard for how services are provided (IAOP, 2004, The Scottish Government, 2010). In addition, in the recent years a strong focus has been placed on 'Realistic medicine' in Scotland (The Scottish Government, 2016b). Within this framework, cost-benefit decisions of healthcare are largely influenced by individual patient circumstances promoting a supported self-management approach to care (The Scottish Government, 2016a). Patient involvement through shared decision-making is likely to play a critical role in how services are delivered in the future.

One way to involve patients in their care is through incorporating their preferences in clinical decision-making. 'Patient preferences' refer to "the conditions and activities that patients desire in their treatment" and have been linked to improved patient care (Windle et al., 2019, p. 2). A meta-analysis of 32 studies on mental health treatment preferences consistently found small to moderate effect sizes for increased satisfaction with services received (ES_d = .34, $p < .001$), better treatment adherence (ES_d = .17, $p < .001$), and improved clinical outcomes (ES_d = .15, $p < .0001$) for patients who chose or otherwise received their preferred treatment (Lindhiem et al., 2014). Other meta-analytic data suggests that receiving a preferred psychosocial mental health treatment reduces drop-out rates (RR = 0.62, $p < .001$) and strengthens therapeutic alliance (ES_d = 0.48, $p = .01$), both known to improve therapeutic outcomes (Hardy et al., 2009, Windle et al., 2019).

The existing research has identified gender, age, ethnicity, past treatment experiences, severity of symptoms and type of disorders to influence patient preferences; however, none have been found to predict them consistently (Eiring et al., 2015). Patients' and other stakeholders' views may also differ when preferred treatment outcomes are being considered; thus treatment preferences may not be assumed based on presenting symptoms or clinical judgment (Kuhnigk et al., 2012, Eiring et al., 2015). For example, a study of depressed patients has found that their preferred treatment outcomes only partially related to the core symptoms of depression, with older patients placing more importance on functional symptoms (e.g. loss of energy) as opposed to

mood related outcomes (Zimmermann et al., 2013). This indicates that patient desired outcomes may only partially correspond to diagnostic symptoms.

Two main areas of focus have emerged in this research literature: 'treatment preferences' and 'outcome preferences'. 'Treatment preferences' typically refer to the types of treatment (e.g. psychological vs. pharmacological) and mode of delivery (e.g. individual vs. group) preferred by patients (Eiring et al., 2015, Gaudreau et al., 2015, Gum et al., 2006) while 'outcome preferences' describe what improvements patients desire to see when seeking treatment (Zimmermann et al., 2013).

While interest for outcome preferences in adults with psychosis (Kuhnigk et al., 2012, Bridges et al., 2018) and psychological trauma (Simiola et al., 2015) is growing, understanding of preference variation across mental health conditions is lacking. The evidence gap extends to older adult (OA) populations despite research indicating that this group may experience mental health difficulties differently to younger people (Van der Auwera et al., 2017, Zimmermann et al., 2013, Overend et al., 2015). This idea is supported by psychosocial theories of development indicating that adults and OAs face different psychosocial challenges at different ages throughout life, such as achieving wisdom through reflection in older age as compared to acquiring intimacy with others or achieving vocational goals in some of the earlier stages (Erikson, 1950).

Only a small number of studies have investigated OAs' treatment preferences (Atkins et al., 2015, Gum et al., 2006, Gaudreau et al., 2015). In a randomised clinical trial comparing collaborative versus usual care, Gum et al. (2006) found that counselling was preferred over medication in depressed OAs, and previous treatment experience was the strongest predictor of preference. In a survey by Atkins et al. (2015), OAs saw physical activity, brief and long term counselling and antidepressants as most helpful, with the oldest participants perceiving medication and bibliotherapy as less helpful. They found no difference in treatment preference between those currently receiving and not receiving treatment. Gaudreau et al. (2015) reported that Cognitive Behavioural Therapy (CBT) was significantly more acceptable when compared to CBT-informed guided self-help for treatment of anxiety, and both were significantly more acceptable than medication.

In summary, no study to date explored *outcome* preferences in OAs. When treatment preferences have been studied, the focus has been largely on modality (i.e. psychological vs. pharmacological) of treatment. Studies of the types of psychological interventions preferred by OAs are rare with no established validated methods to study treatment preferences.

The main aim of the current study is to develop and test for acceptability and feasibility a 'Card Sort Task' (CST) method to elicit outcome and treatment preferences in OAs. A card sort task has previously been used to elicit and organise symptoms of relapse in patients with psychosis within clinical settings but has not yet been utilised as a research tool for studying preferences in OAs or other age groups (Birchwood et al., 2000). While the use of this particular task for research purposes may be novel, ranking methods have been previously used when eliciting preferences in healthcare and have been popular due to the ease of administration of ranking tasks and interpretation of collected data (Ryan et al., 2001).

In line with the guidelines for early stage feasibility research (Arain et al., 2010), the current study bears the twofold aims of evaluating the acceptability and feasibility of the CST task itself, as well as exploring the possibility of conducting this type of research in the future. We will also aim to gather preliminary data to explore what mental health related outcomes and psychological treatments are most valued by OAs accessing psychological therapies, as well as exploring whether any differences exist in patient preferences between those waiting for, versus in psychological treatment due to some evidence that previous treatment experience has potential to influence treatment preferences in OAs (Gum et al., 2006).

Research Questions and Aims

1. Is the CST feasible and acceptable to investigate outcome and treatment preferences in the OA population?
    1.2. What is the number of potential eligible participants?
    1.3. What proportion of eligible participants consent to participate?
    1.4. What proportion of those complete the study procedure?
    1.5. Is the task acceptable to participants?
2. What mental health related outcomes are most valued by OAs accessing psychological therapies?
3. What types of treatments are preferred by OAs seeking treatment?
4. Do OAs who are waiting to receive treatment differ in their treatment preferences compared to those already receiving treatment?

Method

Design

This was a cross-sectional feasibility study comprised of: Phase 1, development of the CST, and Phase 2, testing of the feasibility and acceptability of the task with OAs.

Ethics

The ethical approval for the study was granted by the West of Scotland Research Ethics Committee (19/WS/0096, Appendix 2.2). The managerial approval was received by NHS Lanarkshire Research and Development Department (Appendix 2.3).

Participants

Participants were recruited from NHS Lanarkshire Psychological Therapies for Older People Team (PTOP). This is a board-wide community and in-patient service providing evidence-based psychological interventions to OA population of Lanarkshire. The service is part of the wider multidisciplinary OA service in Lanarkshire providing comprehensive mental health care to OAs, hence a large proportion of OAs seen in PTOP will be receiving input from psychiatry and

nursing colleagues. During the study, there were ten Clinical Psychologists, one Clinical Associate in Applied Psychology and two Mental Health Therapists delivering psychological interventions to eligible participants.

Patients on the waiting list and the outpatients receiving psychological therapies either individually or via a group format were eligible to participate. Exclusion criteria comprised patients who had a diagnosis of intellectual disability or cognitive impairment (such as diagnosis of dementia), lacked capacity or if their mental state would prevent meaningful participation (e.g. acute psychosis). Only participants that were able to travel to NHS premises were included in the study.

Procedure

Phase 1: Development of the CST

A literature review was carried out to inform the types of outcomes that might be preferred by OAs (Chapter 1) and resulted in a list of potential treatment outcomes desired by patients. The list of treatment options was generated through a review of treatments offered in PTOP as well as review of the Matrix service delivery guidelines, as applied to OAs (NES, 2015). The two initial lists (Appendix 2.3) were presented to clinicians working in PTOP at a face-to-face forum where their views were invited regarding the contents of the cards. They were asked to provide a judgement of a) how well the outcome list reflects typical clinical presentations of their patients; b) is the language congruent with that used by OAs, and c) how well the treatment cards capture the essence of different therapeutic modalities. The notes were taken of the comments provided and were used to further shape the content of the two lists (for the final version of the cards see Appendix 2.4).

The most commented on issue by the clinicians was the number of treatment option cards included in the task. In a study by Eiring and colleagues on outcome preferences in patients with bipolar disorder, participants were asked to rank 23 potential outcomes (Eiring et al., 2016), while in a previous study into OA population assessing preferences for attributes of quality of life, participants were presented with twelve dimensions to be ranked (Ratcliffe et al., 2017). An expert panel consisting of OA clinicians and researchers was formed to finalise

the number and the content of the cards and resulted in 16 treatment outcome and 20 treatment option cards. The QUAID tool (Question-Understanding Aid; Graesser et al., 2000) and the reading age check were used to check the clarity of proposed content.

Phase 2: Validation of the CST

All eligible participants on the waiting list were posted a leaflet (Appendix 2.5) about the study and followed up by a staff member in the team to determine their interest. Clinicians were asked to inform eligible patients of the study and provide them with study leaflets. Those who expressed interest were asked for permission for their details to be passed on to the research team.

At this stage, detailed study information (participant information sheet and consent form, see Appendices 2.6 and 2.7 respectively) was sent to potential participants after which they were contacted by the researcher to discuss the study. If interested, a suitable time and place were agreed to collect informed consent and carry out study procedures.

Two working age adults previously known to the researcher agreed to test the method prior to it being used with the research participants. Based on this preliminary testing with non-clinical subjects it was anticipated that the task would take between 30 to 60 minutes to complete. Following the administration of Tasks 1 and 2, the number of outcome preferences in the Task 3 was limited to ensure the total procedure does not exceed 60 minutes. The duration it took each participant to complete the task was recorded in minutes as part of feasibility assessment.

Task 1

Participants were presented with 16 cards, each containing a single treatment outcome. Participants were asked to read all the cards and were provided with blank cards to generate any missing outcomes, if necessary. They were then asked to sort the cards, from most important outcomes for seeking treatment to least important.

Task 2

Subsequently, participants were provided with a second list of cards containing treatment options. A standard explanation, as part of administration instructions, was made available to participants if the content of the cards was questioned (Appendix 2.8). Participants were instructed to sort treatment options in order from most helpful to least helpful.

Task 3

The planned instruction was to rank the treatment options for each treatment outcome selected as most important by the participants. During the initial administration of the task it became evident that the instruction was repetitive and time consuming thus a simpler instruction of selecting potentially helpful treatment options for desired outcomes was introduced. To adhere to the time limit set for the procedure, participants were instructed to consider no more than five outcomes. Ten treatment option cards earlier ranked as most useful were visually available to participants to select from, although they were instructed they could use other treatment option cards if appropriate.

Acceptability of the study

The acceptability of the study was determined by study participation, including the recruitment rates and the participants' engagement with the CST. The latter was assessed via researcher's observation of participants' ability to engage with the task, the time required to complete the task, the level of support required, and the qualitative feedback provided by participants during the administration of the task. All verbal comments related to the content of the cards and qualitative observations of participant engagement with the task were recorded as hand-written notes by the researcher during the administration of the procedure. Participants were also asked to complete a brief study experience scale surveying their views towards the CST (Appendix 2.10).

Sample size

As this was a feasibility study, the aim was to provide information that can be used for power and sample size calculations in future research (Lancaster et al., 2004). The target sample size of 30 was considered likely to be sufficient to address the questions regarding feasibility of the study and to test the CST as a method to elicit preferences (Browne, 1995). Eiring et al (2016) reported a similar analysis of ranking and comparing preferences across two groups (Type 1 Bipolar and Type 2 Bipolar) using a sample of 22 participants. Milte et al (2014) used a sample of 21 participants to produce frequency counts of 15 quality of life descriptors across the sample.

Data Analysis

Feasibility testing of the CST

Rates of recruitment, reasons for declining to participate, dropout and completion rates during the study were recorded. Time taken to complete the task and qualitative feedback from participants was recorded. Researcher observations and data from participant experience survey were also collected and reported. Participant generated outcomes were collected as qualitative data.

Exploration of outcome and treatment preferences

Medians and grand ranks for outcome and treatment preferences across two groups and separately for each group were calculated to check for initial differences between groups. Reversed grand ranks were used for visual exploration of the data. Friedman's ANOVAs were used to test for differences across treatment outcomes and treatment options, and pairwise post-hoc analyses were carried out. Between group differences were explored visually using reversed grand ranks and Mann-Whitney U tests were utilised for further comparisons.

Results

Is the proposed research methodology feasible and acceptable to investigate outcome and treatment preferences in the OA population?

Recruitment occurred over a five-month period between 1st of August and 31st of December 2019 (Appendix 2.9) with ten clinicians referring eligible participants into the study.

'In-treatment' group

One hundred forty-five potentially eligible participants were identified by the PTOP clinicians and *n* = 64 were approached. The most common reason for not approaching was "high psychological distress". Of those approached by clinicians, *n* = 44 declined to participate. Out of *n* = 20 who expressed interest, *n* = 3 were reassessed as not eligible, leaving *n* = 17 that were approached by the researcher. A total *n* = 13 (9%) attended on the day and completed the study procedure (Figure 2.1).

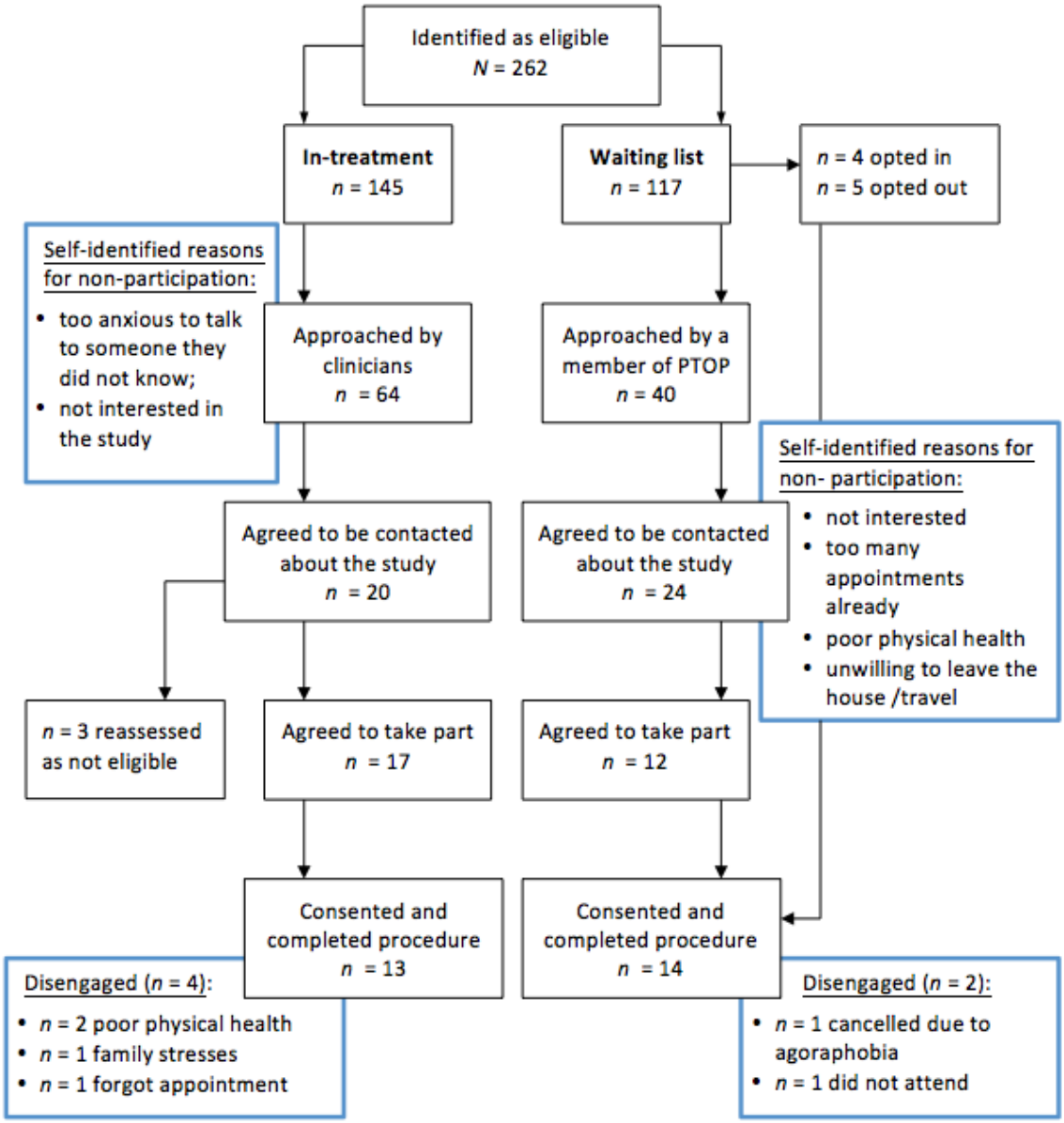


Figure 2.1: Flow diagram of participant recruitment procedure

'Waiting list' group

A total of *n* = 117 were identified as eligible and were sent leaflets about the study. Of these, *n* = 4 contacted the researcher to express interest and were recruited directly into the study, and *n* = 5 called to opt-out. Out of 40 contacted by a member of PTOP, 24 expressed interest with 10 disengaging after discussing study with the researcher. Two could not be included, as they required a home visit. Of 16 who agreed to take part, two did not attend on the day, leaving *n* = 14 (16%) who consented.

Demographic and clinical characteristics

Twenty-seven patients participated in the study (Table 2.1). The sample ranged in age from 66 to 88 years. Most participants were female (74%) and White Scottish (89%). The most common presenting problem was anxiety and/or depression (56%) with additional 22% of the sample presenting with anxiety and/or depression as a secondary problem.

Table 2.1: Demographic and clinical characteristics

	'In-treatment'	**'Waiting list'**	**Total**
Age (*Mdn*, range)	73 (66-84)	72.5 (66-88)	73 (66-88)
Gender (*n*, %)			
Male	2 (15)	5 (36)	7 (26)
Female	11 (85)	9 (64)	20 (74)
Ethnicity (n, %)			
White Scottish	12 (92)	12 (86)	24 (89)
White British	1 (8)	2 (14)	3 (11)
Marital status (*n*, %)			
Single	1 (8)	-	1 (4)
Married	7 (54)	11 (79)	18 (67)
Widowed	5 (39)	2 (14)	7 (26)
Divorced	-	1 (8)	1 (4)
Clinical presentation			
Primary presenting problem or diagnosis (*n*, %)			
Depression (and symptoms of)	1 (8)	3 (21)	4 (15)
Anxiety (and symptoms of)	2 (15)	2 (14)	4 (15)
Mixed depression and anxiety	3 (23)	4 (29)	7 (26)
Complex trauma	2 (15)	2 (14)	4 (15)
PTSD[1]	2 (15)	-	2 (7)
Adjustment	1 (7)	2 (14)	3 (11)
Complex grief	1 (8)	-	1 (4)
Phobia	-	1 (7)	1 (4)
MUS[2]	1 (8)	-	1 (4)
Other reported symptoms (*n*, %)			
None	7 (54)	11 (79)	18 (67)
Depression (and symptoms of)	2 (15)	1 (7)	3 (11)
Anxiety (and symptoms of)	1 (8)	1 (7)	2 (7)
Mixed anxiety and depression	-	1 (7)	1 (4)
Interpersonal difficulties	1 (8)	-	1 (4)
Adjustment	1 (8)	-	1 (4)
Bi-polar disorder	1 (8)	-	1 (4)
History in services			
Previously seen in mental health services (*n*, *%)	7 (54)	5 (36)	12 (44)
Intervention previously received (*n*, %)			
Assessment only	1 (8)	-	1 (4)
Stress control classes	1 (8)	-	1 (4)
CBT[3]	1 (8)	2 (14)	3 (11)
Psychiatric input	3 (23)	1 (7)	4 (15)
Current type of intervention (*n*, %)			
CBT	6 (22)	-	6 (22)
ACT[4]	2 (7)	-	2 (7)
CFT[5]	2 (7)	-	2 (7)
Formulation driven	3 (11)	-	3 (11)

[1] = Post-traumatic Stress Disorder, [2] = Medically Unexplained Symptoms, [3] = Cognitive Behavioural Therapy, [4] = Acceptance and Commitment Therapy, [5] = Compassion Focused Therapy

Acceptability and feedback of the CST

For the 'In-treatment' group, participants were able to finish the three tasks and the Participant Experience Survey (Appendix 2.10) within the 60-minute time limit. For the 'Waiting list' group, the tasks took longer to complete. During the recruitment of the first three participants no more than five outcome cards had been considered and the procedure was stopped after 60 minutes to fit within the set time limit. Following this, the instructions for Task 3 were altered (Appendix 2.11). The updated instruction was then used for the rest of the data collection process for both groups. Despite this, two participants in the 'Waiting list group' (*n* = 2) did not manage to complete the experience survey within the one-hour slot.

Out of 26 participants who completed the Participant Experience Survey, 85% (*n* = 22) rated their overall experience of the CST as positive or very positive, while one described it as negative ("hard to choose and order, all important"). Eighty-nine percent (*n* = 23) reported the content of the cards to be relevant to them and 89% felt it was useful for expressing their preferences. Time required to complete the task was acceptable to 89% of the participants with two participants unsure. The qualitative feedback provided by the 'Waiting list' group was that the CST "made [them] think and identify issues" and was "really helpful, making [them] realise different traits in [them]". Others described their participation as "helpful and useful" and "thought provoking", while some felt the tasks had "a bit too many choices" and "too many questions of same sort, too much repetition". Participants 'In-treatment' felt the CST "helped put things into perspective" and was "useful".

No outcome cards were eliminated during Task 1 but two participants noted that it was redundant to rank treatment outcomes that are not important to them. The following additional treatment outcomes were suggested by seven participants:

- "Overcome difficulties with eating"
- "Be kinder to myself"
- "Learn to be more assertive"
- "Manage overwhelming emotions"
- "Get over my phobia"
- "Adjust to my body slowing down"
- "Be less frustrated with myself"
- "Reduce physical tension"
- "Stop my mind going into overdrive"
- "I want to feel like myself again"
- "Be less isolated"

One participant noted that having examples of problems indicated on the cards was distracting.

Qualitative observations

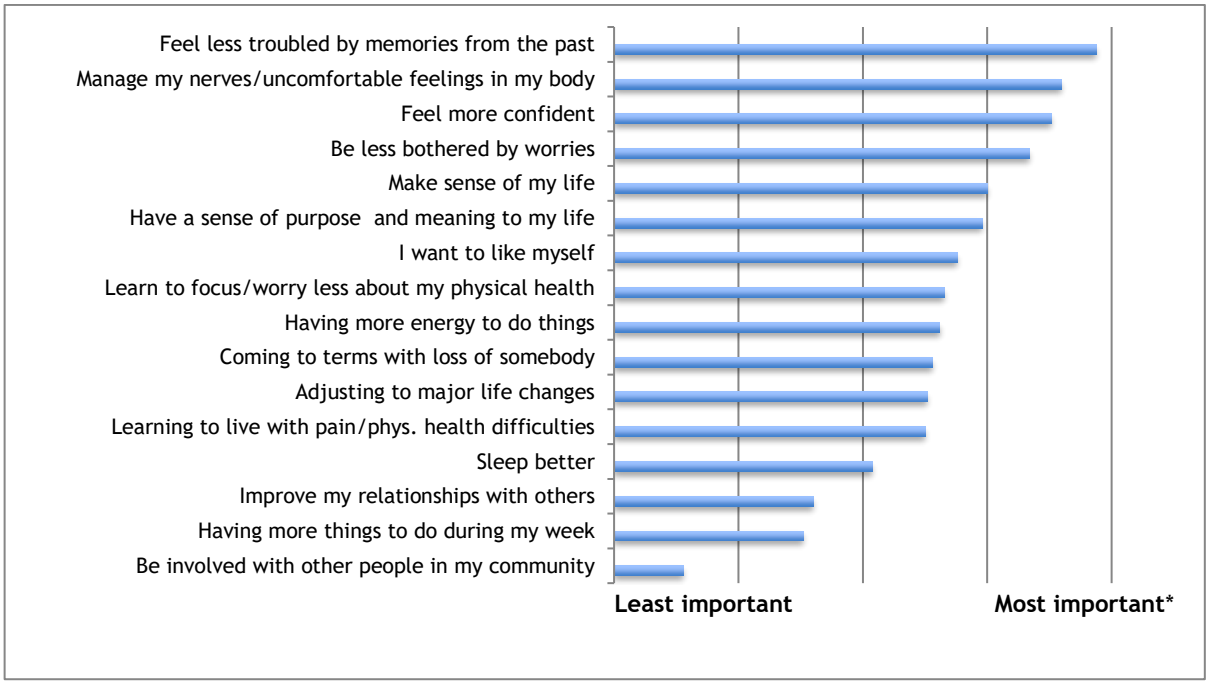
Participants in the 'Waiting list' group provided more detailed information regarding their presenting symptoms, with outcome cards acting as prompts (e.g. reading a card then proceeding to describe their experience with that problem) which added to the time taken to complete each task. The researcher was required to validate their distress and re-orientate to the task using comments such as "that sounds difficult, which card do you think best describes this problem" or "I can see this is bothering you, which treatment do you think could help you with this". Four participants in this group became tearful when talking about their experiences and required re-assessment as to their ability to continue. As a result, the procedure was terminated after Task 2 for one participant.

For both groups, some participants had difficulty differentiating between the two lists of cards, commenting that both lists sounded similar. This was evident during the administration of Task 3, where seven participants made comments indicating they were not differentiating between the two sets of cards (e.g. "these are the same"). Some misinterpretations of treatment options were noted (e.g. 'facing situations I fear or avoid' was interpreted as facing people they no longer see or addressing old relational conflicts). Some participants 'In treatment' group commented that they were ranking certain cards lower as those issues already had been addressed in treatment or they already received that type of help.

For Task 1 and 2 across both groups, a number of participants have intuitively sorted the cards into important/not important, helpful/not helpful piles and then required prompts to order the cards (e.g. "Are these in the right order?").

What mental health related outcomes are most valued by OAs accessing psychological therapies?

Figure 2.2 illustrates the ranked outcomes for seeking treatment. Across both samples, 'To feel less troubled by memories from the past' was ranked as most important to participants (*Mdn* = 4), while 'Being involved with other people in my community' was ranked as least important (*Mdn* = 13).



* = the bars represent reversed summed ranks

Figure 2.2: Total ranks of most to least valued treatment outcomes

A Friedman test comparing the ranks across 16 treatment outcomes indicated a significant difference between the outcomes, x^2 (15) = 45.41, p < .001. Dunn-Bonferroni post-hoc tests indicate that the significant differences were between the least important outcome ('Be involved with other people in my community') and the five most important outcomes as listed in Table 2.2.

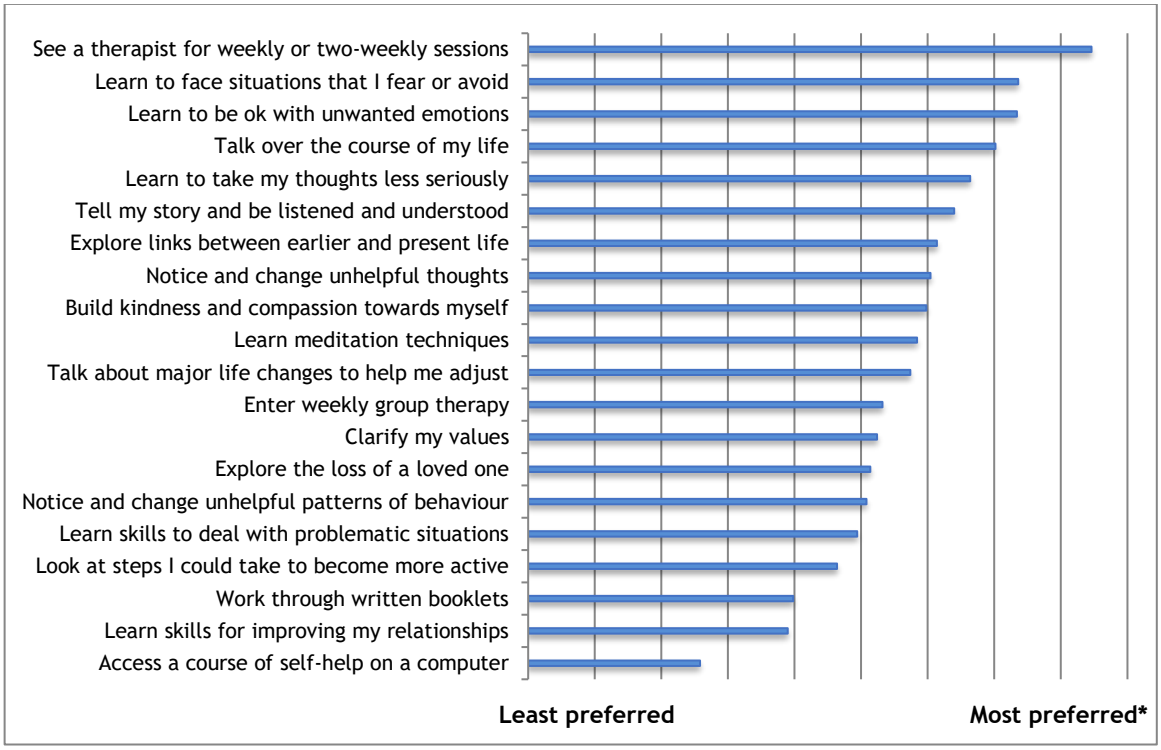
Table 2.2: Post-hoc analyses of treatment outcome preferences

Treatment outcomes (Median)	Dunn-Bonferroni post hoc analyses	Effect size[1]
	Be involved with other people in my community (13)	
Feel less troubled by memories from the past (4)	$p < .001$	.43
Manage my nerves and uncomfortable feelings in my body (5)	$p = .001$	.40
Feel more confident (7)	$p = .003$	.39
Be less bothered by worries (6)	$p = .008$	.37
Making sense of my life (7)	$p = .05$	.32

[1] = Pearson's *r*

What types of treatments are preferred by OAs seeking treatment?

Figure 2.3: illustrates the ranking of twenty treatment options.



* = the bars represent reversed summed ranks

Figure 2.3: Total ranks of most to least valued treatment options

A Friedman's ANOVA was carried out to compare the ranks across 20 treatment options indicating a significant difference between the treatments, x^2 (19) = 91.87, $p < .001$. Dunn-Bonferroni post-hoc tests were carried out suggesting a

number of significant differences, as detailed in Table 2.3. Significant differences within pairwise therapeutic modality comparisons were only found between ‘Learn skills for improving my relationships’ (*Mdn* = 16) and ‘Learn to face situations I fear or avoid’ (*Mdn* = 7, *p* = .008), ‘Learn to be ok with unwanted emotions’ (*Mdn* = 6.5, *p* = .04), ‘Talk over the course of my life to gain sense of perspective’ (*Mdn* = 6, *p* = .044).

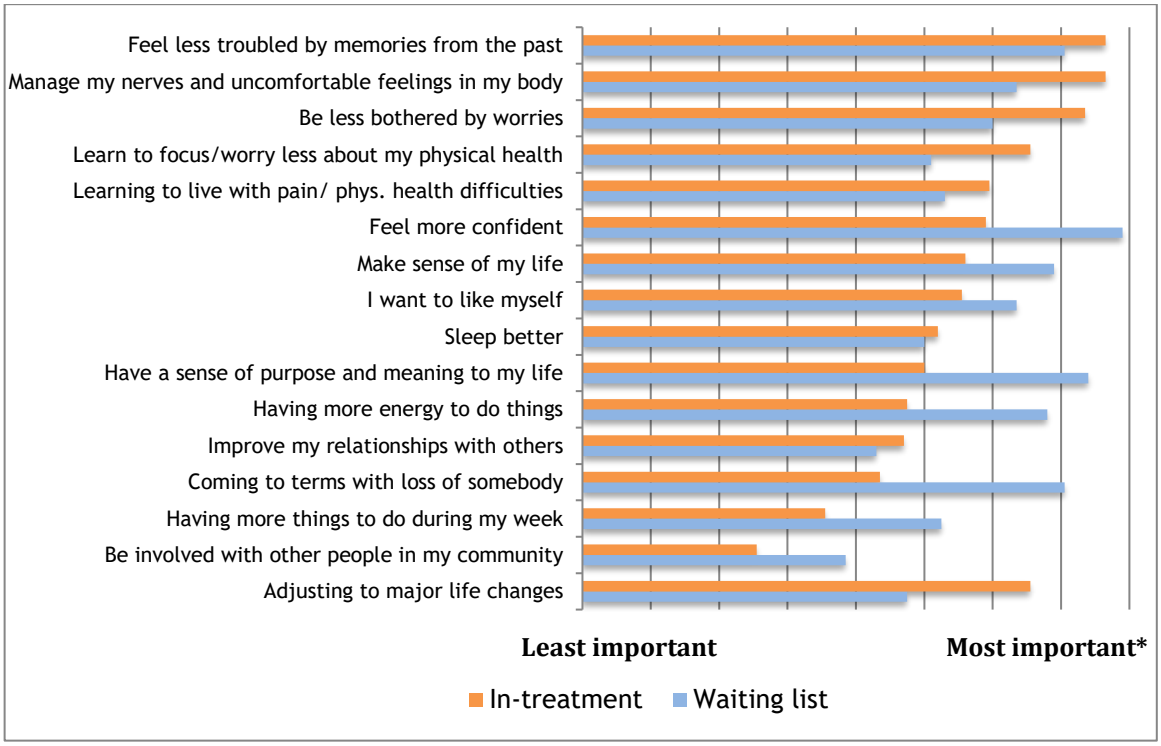
Table 2.3: Post-hoc analyses of treatment option preferences

Treatment options (Median)	Dunn-Bonferroni post-hoc analyses, effect sizes					
	Work through written booklets (15.5)		Access self-help on a computer (18)		Learn skills for improving relationships (16)	
	p	*r*	*p*	*r*	*p*	*r*
Learn to face situations that I fear or avoid (7)	= .019	- .28	< .001	- .39	= .008	- .30
Learn to be ok with unwanted emotions (6.5)	= .011	.29	< *.001*	.40	= .04	- .31
Talk over the course of my life (6)			< .001	.36	= .044	.27
Learn to take my thoughts less seriously (8)			= .001	.33		
Tell my story and be listened and understood (9)			= .005	.30		
Explore links between earlier and present life (8.5)			= .005	.30		
Notice and change unhelpful thoughts (10)			= .007	- .30		
Build kindness and compassion towards myself (10)			= .049	.27		
Learn meditation techniques (10.5)			= .04	.27		
Talk about major life changes to help me adjust to them (9)			= .025	.27		

Treatment options (Median)	Dunn-Bonferroni post-hoc analyses, effect sizes See a therapist (2.5)	
	p	*r*
Learn skills for improving relationships (16)	< .001	- .38
Access self-help on a computer (18)	< .001	- .48
Work through written booklets (15.5)	< .001	- .37
Clarify my values (11)	= .049	- .27
Notice and change unhelpful patterns of behaviour (12)	= .037	.27
Learn strategies and skills to deal with problematic situations (12)	= .037	.27
Look at step I could take to become more active (15)	= .005	.30

Do OAs who are waiting to receive treatment differ in their treatment preferences compared to those already receiving treatment?

Figure 2.4 illustrates the ranking of sixteen treatment outcomes, ranked by each group.

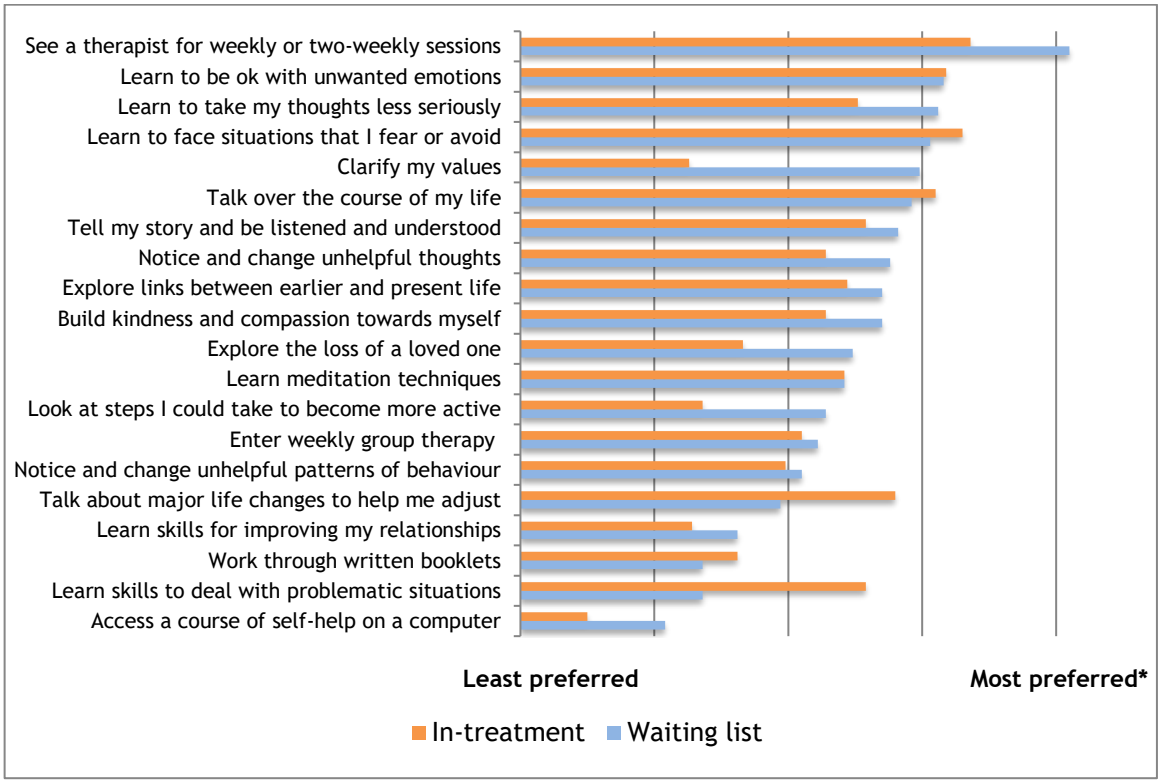


* = the bars represent reversed summed ranks

Figure 2.4: Between group differences in ranking of treatment outcomes

Mann-Whitney U tests (Table 1 in Appendix 2.12) found no significant differences between the groups on rankings of all treatment outcomes except 'Having a sense of purpose and meaning to my life' (U = 44, p = .02) with 'Waiting list' participants ranking these outcomes as more important (Mdn = 5), than those 'In-treatment' (Mdn = 10).

Figure 2.5 illustrates the ranking of twenty treatment options, ranked by each group.



* = the bars represent reversed summed ranks

Figure 2.5: Between group differences in ranking of treatment options

Further Mann-Whitney U tests (Table 2 in Appendix 2.12) found no significant differences between the groups on rankings of most treatment options except 'Clarify my values' (U = 28.5, p = .002) with 'Waiting list' participants finding it more important (*Mdn* = 7), than those 'In-treatment' (*Mdn* = 15) and 'Learn skills to deal with problematic situations' (U = 43, p = .019), with 'In-treatment participants ranking it as more helpful (*Mdn* = 8) than those in 'Waiting list' (*Mdn* = 16).

Discussion

Feasibility and acceptability of CST

The aim of the present study was to develop and assess for feasibility and acceptability the CST, and to test the recruitment strategy for a future study using CST to research treatment preferences in OAs. Within the five-month recruitment period, the target sample size was nearly reached. Main barriers to recruitment were participants' inability to travel to clinics due to poor physical health, lack of transport and/or anxiety/agoraphobia. Lanarkshire is a large geographical area spreading over remote rural parts and smaller towns with public transport links. Although the arrangements were made (or offered) to meet with participants at their local GP practices and a reimbursement for a return bus fare was available, this was not sufficient to recruit the patients who felt unable to leave their homes.

The barriers of distance to recruitment sites, transportation and physical health have been reported previously in OAs and the present study supports this view (Witham and McMurdo, 2007). It is likely that facilitating home visits or providing transportation will increase the recruitment rates (Mody et al., 2008), albeit resulting in longer recruitment procedure with additional financial and staff resources required (Witham and McMurdo, 2007). Although OAs are motivated to participate in research, only 3% proactively seek out participation (Witham and McMurdo, 2007). The current study supports this view, also evidencing a similar proportion of participants contacted from the waiting list who actively expressed interest to participate. A more proactive recruitment strategy, as detailed in this paper, seems appropriate with this population.

A significant number of eligible patients 'In-treatment' group were not approached by the recruiting clinicians. While exact reason for that may not be clear, it is possible that the clinicians may have been guided by the target sample size, as opposed to strictly adhering to stated recruitment criteria. In addition, a larger proportion of patients in this group refused to be contacted about the study, compared to those recruited from the 'Waiting list'. Clinician attitude might play a role in the adherence to the recruitment protocols, and how the study participation is presented to eligible participants. This draws

attention to how a study is presented and promoted to stakeholders (Witham and McMurdo, 2007). Although the present study was promoted at the monthly departmental meetings, informing clinicians of participant feedback as it is being collected might help to address any negative attributions or concerns. Additional education of clinicians to adhere to the recruitment criteria might be needed, as well as allocation of additional resources, to ensure clinicians have the time needed to approach all eligible participants. Mody et al. (2008) also suggest using incentives for clinicians. Sharing of outcome and treatment preference data with clinicians might enable them to use the preference data therapeutically.

Anxiety and depression were the most common presenting problems in the recruited sample, which is in line with research on mental health disorder prevalence rates in OAs (McCombe et al., 2018). Rates of anxiety and depression are typically higher in females, as also reflected in the present study (Bryant et al., 2008, The Royal College of Psychiatrists, 2018). Despite this, the treatment preferences of the older males remain under-represented. Matching gender of a recruiter and using strata samples may improve the recruitment rates of older males in future studies.

Feasibility and acceptability data indicate that the Tasks 1 and 2 of the CST were acceptable to both groups, with participants suggesting only minimal changes to the content of the cards (i.e. adding desired outcomes of assertiveness and self-compassion in Task 1). Task 3 was reported to be repetitive, with participants having difficulty differentiating between the two sets of cards. Refining the content of the cards, where therapy type is specified with each treatment attribute could overcome this difficulty in future designs. Participant fatigue is another factor that could explain difficulties with Task 3, varying the sequence of administration in the future might be useful in testing this hypothesis further (Mody et al., 2008). During procedure of Tasks 1 and 2, some participants have opted to sort the cards into two piles (‘important/not important’, ‘helpful/not helpful’) before ranking them, which suggests a strategy to reduce the cognitive load of the tasks (Bowling, 2005).

In addition, participants in ‘Waiting list’ required more time to complete the overall study procedure. This was partially related to higher level of distress

amongst this group and more time spent describing their experiences of symptoms, as prompted by the content of the cards. As a result, Task 3 administration was altered to shorten overall procedure. While the change was exercised as a way to increase acceptability and feasibility of CST, this highlights the possibility of introducing researcher/interviewer biases into card administration. In fact, the likelihood of biases in tasks administered face-to-face by a researcher is high with the mode of administration significantly biasing the outcome (Bowling, 2005). Asking participants to complete the tasks without a researcher present might minimise possible administration biases.

Outcome and treatment preferences

While the CST method might require further refinement, the study indicates that it was able to reveal outcome preferences of OAs. Our results suggest that 'to feel less troubled by memories from the past', followed by reducing worry and physical symptoms of anxiety, improving confidence and making sense of the life lived were the most important outcomes. These findings are in line with the developmental conceptualisation of mental disorders in later life, suggesting that earlier unresolved traumas or conflicts may later resurface and manifest as distress (Erikson, 1950). The findings also correspond with the sample characteristics, since anxiety and depression comprised the largest proportion of presenting difficulties. Reducing anxiety symptoms in particular might be desired as it could be linked to better daily functioning as previously demonstrated by Zimmerman et al. (2003).

Although 'learn to face situations I fear or avoid' has been included as an exposure element of CBT, qualitative data provided by participants suggest that their interpretation was that of facing old conflicts and people they no longer see. This highlights potential issues in the content of the treatment cards, where lacking clarity over the meaning of different treatment attributes may have biased the ranks. Nevertheless, the study was able to detect differences in preferences for treatment modality, with a strong preference for individual therapy over guided bibliotherapy and computerised CBT (but not group therapy, which was generally ranked as acceptable). This is in line with some previous research, where OAs favoured individual CBT over CBT informed self-help (Gaudreau et al., 2015). While the current task was able to elicit preferences

similar to those revealed in these studies, future research will be needed to establish its reliability over time.

Finally, there were a small number of differences in preference between patients waiting to receive, and currently receiving treatments. While this is in contrast to Atkins et al. (2015) who found no such differences in their study, it is possible that due to the small sample size and multiple comparisons carried out these apparent differences would not be reliable.

Strengths and limitations

The study recruited 27 participants as recommended for feasibility studies and it was the first study, to our knowledge, examining outcome and treatment preferences in a clinically representative sample of OAs (Browne, 1995). It delineated a recruitment strategy in prospective research with this population and offers direction of further development of preference elicitation instruments. The dynamic nature of CST has been demonstrated to be acceptable to participants, with all participants being able to order the cards during the first two tasks and most reporting positive experiences with the task, suggesting that this method, albeit requiring further refinement, could be used with OAs.

Although notes with qualitative observations were taken throughout, a more systematic way of collating and analysing this qualitative data would produce more reliable findings and would be advised in future studies. Due to participants discussing clinically sensitive information with the researcher, it was difficult to accurately measure the timings of the tasks as well as note all observations. Presence of a second researcher or video recording of each session could allow more accurate extraction of qualitative data while supporting administration of the procedure and potentially reducing biases known to arise during a direct face-to-face interaction with participants (Bowling, 2005).

Conclusion

Although the OA population is growing, our knowledge of what older people wish to gain from mental health treatment and how, remains sparse. This study aimed to test for feasibility and acceptability a new method – the CST to elicit

preferences in this population. Near complete target sample size was reached and most participants were able to complete the task, after some changes to the initial design were introduced. While CST procedure is acceptable to use with this population, further refinements of the tool include reducing time required and cognitive load of the tasks, as well as changes to how treatment options are presented.

References

Atkins, J., Naismith, S. L., Luscombe, G. M. and Hickie, I. B. (2015). Elderly care recipients' perceptions of treatment helpfulness for depression and the relationship with help-seeking, *Clinical Interventions in Aging,* 10, 287-295.

Birchwood, M., Spencer, E. and McGovern, D. (2000). Schizophrenia: early warning signs, *Advances in Psychiatric Treatment,* 6, 93 - 101.

Bowling, A. (2005). Mode of questionnaire administration can have serious effects on data quality, *Journal of Public Health,* 27(3), 281-291.

Bridges, J. F. P., Beusterien, K., Heres, S., Such, P., Sanchez-Covisa, J., Nylander, A.-G., Chan, E. and de Jong-Laird, A. (2018). Quantifying the treatment goals of people recently diagnosed with schizophrenia using best-worst scaling, *Patient Preference and Adherence,* 12, 63-70.

Browne, R. H. (1995). On the use of a Pilot Sample for Sample Size Determination, *Statistics in Medicine,* 14(17), 1933-1940.

Bryant, C., Jackson, H. and Ames, D. (2008). The prevalence of anxiety in older adults: Methodological issues and a review of the literature, *Journal of Affective Disorders,* 109(3), 233-250.

Eiring, O., Landmark, B. F., Aas, E., Salkeld, G., Nylenna, M. and Nytroen, K. (2015). What matters to patients? A systematic review of preferences for medication-associated outcomes in mental disorders, *Bmj Open,* 5(4), 1-13.

Eiring, O., Nylenna, M. and Nytroen, K. (2016). Patient-Important Outcomes in the Long-Term Treatment of Bipolar Disorder: A Mixed-Methods Approach Investigating Relative Preferences and a Proposed Taxonomy, *Patient-Patient Centered Outcomes Research,* 9(2), 91-102.

Erikson, E. (1950). *Childhood and Society,* New York: W. W. Norton & Compan.

Gaudreau, C., Landreville, P., Carmichael, P.-H., Champagne, A. and Camateros, C. (2015). Older Adults' Rating of the Acceptability of

Treatments for Generalized Anxiety Disorder, *Clinical Gerontologist*, 38(1), 68-87.

Graesser, A. C., Wiemer-Hastings, K., Wiemer-Hastings, P. and Kreuz, R. (2000). The Gold Standard of Question Quality on Surveys: Experts, computer tools, versus statistical indices. In *Proceedings of the American Statistical Association Section on Survey Research Methods*, American Statistical Association, 459-464.

Gum, A. M., Arean, P. A., Hunkeler, E., Tang, L. Q., Katon, W., Hitchcock, P., Steffens, D. C., Dickens, J., Unutzer, J. and Investigators, I. (2006). Depression treatment preferences in older primary care patients, *Gerontologist*, 46(1), 14-22.

Hardy, G., Cahill, J. and Barkham, M. (2009). Active Ingredients of the therapeutic relationship that promote client change: A research perspective in Gilbert, P. and Leahy, R., eds., *The Therapeutic Relationship in the Cognitive Behavioural Psychotherapies*, Hove: Routledge.

IAOP (2004). *What is Patient-Centred Healthcare? A Review of Definitions and Principles*, International Alliance of Patients' Organizations (IAOP).

Kuhnigk, O., Slawik, L., Meyer, J., Naber, D. and Reimer, J. (2012). Valuation and Attainment of Treatment Goals in Schizophrenia: Perspectives of Patients, Relatives, Physicians, and Payers, *Journal of Psychiatric Practice*, 18(5), 321-328.

Lancaster, G. A., Dodd, S. and Williamson, P. R. (2004). Design and analysis of pilot studies: recommendations for good practice, *Journal of Evaluation in Clinical Practice*, 10(2), 307-312.

Lindhiem, O., Bennett, C. B., Trentacosta, C. J. and McLear, C. (2014) Client preferences affect treatment satisfaction, completion, and clinical outcome: A meta-analysis, *Clinical Psychology Review*, 34(6), 506-517.

McCombe, G., Fogarty, F., Swan, D., Hannigan, A., Fealy, G. M., Kyne, L., Meagher, D. and Cullen, W. (2018). Identified mental disorders in older adults in primary care: A cross-sectional database study, *European Journal of General Practice*, 24(1), 84-91.

Mody, L., Miller, D. K., McGloin, J. M., Freeman, M., Marcantonio, E. R., Magaziner, J. and Studenski, S. (2008). Recruitment and Retention of Older Adults in Aging Research, *Journal of the American Geriatrics Society*, 56(12), 2340-2348.

NES (2015). *The Matrix: A Guide to Delivering Evidence-Based Psychological Therapies in Scotland*, Edinburgh: NHS Education for Scotland (NES).

Overend, K., Bosanquet, K., Bailey, D., Foster, D., Gascoyne, S., Lewis, H., Nutbrown, S., Woodhouse, R., Gilbody, S. and Chew-Graham, C. (2015). Revealing hidden depression in older people: a qualitative study within a randomised controlled trial, *BMC Family Practice,* 16.

Ratcliffe, J., Lancsar, E., Flint, T., Kaambwa, B., Walker, R., Lewin, G., Luszcz, M. and Cameron, I. D. (2017). Does one size fit all? Assessing the preferences of older and younger people for attributes of quality of life, *Quality of Life Research,* 26(2), 299-309.

Simiola, V., Neilson, E. C., Thompson, R. and Cook, J. M. (2015). Preferences for trauma treatment: A systematic review of the empirical literature, *Psychological Trauma: Theory, Research, Practice and Policy,* 7(6), 516-524.

The Royal College of Psychiatrists (2018). *College Report CR211: Suffering in silence: age inequality in older people's mental health care*, The Royal College of Psychiatrists.

The Scottish Government (2010). *The Healthcare Quality Strategy for NHS Scotland*, Edinburgh: The Scottish Government.

The Scottish Government (2016a). *The Health and Social Care Delivery Plan*, The Scottish Government.

The Scottish Government (2016b). *A National Clinical Strategy for Scotland*, The Scottish Government.

Van der Auwera, S., Schomerus, G., Baumeister, S. E., Matschinger, H. and Angermeyer, M. (2017). Approval of psychotherapy and medication for the treatment of mental disorders over the lifespan. An age period cohort analysis, *Epidemiology and Psychiatric Sciences,* 26(1), 61-69.

Windle, E., Tee, H., Sabitova, A., Jovanovic, N., Priebe, S. and Carr, C. (2019). Association of Patient Treatment Preference With Dropout and Clinical Outcomes in Adult Psychosocial Mental Health Interventions: A Systematic Review and Meta-analysis, *JAMA Psychiatry*, Published online December 04, 2019.

Witham, M. D. and McMurdo, M. E. T. (2007). How to get older people included in clinical studies, *Drugs & Aging,* 24(3), 187-196.

Zimmermann, T. M., Clouth, J., Elosge, M., Heurich, M., Schneider, E., Wilhelm, S. and Wolfrath, A. (2013). Patient preferences for outcomes of depression treatment in Germany: A choice-based conjoint analysis study, *Journal of Affective Disorders,* 148(2-3), 210-219.

Appendices

Appendix 1.1: Manuscript submission guidelines to Qualitative Health Research

Manuscript Submission Guidelines: *Qualitative Health Research*

This Journal is a member of the Committee on Publication Ethics

This Journal recommends that authors follow the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

Please read the guidelines below then visit the Journal's submission site https://mc.manuscriptcentral.com/qhr to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned. Remember you can log in to the submission site at any time to check on the progress of your paper through the peer review process.

Only manuscripts of sufficient quality that meet the aims and scope of *Qualitative Health Research* will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere. Please see our guidelines on prior publication and note that ***Qualitative Health Research* may accept submissions of papers that have been posted on pre-print servers**; please alert the Editorial Office when submitting (contact details are at the end of these guidelines) and include the DOI for the preprint in the designated field in the manuscript submission system. Authors should not post an updated version of their paper on the preprint server while it is being peer reviewed for possible publication in the journal. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your paper is accepted, you must include a link on your preprint to the final version of your paper.

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Qualitative Health Research*, please ensure you have read the Aims & Scope.

1.2 Article types

Each issue of *Qualitative Health Research* provides readers with a wealth of information —, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.2.1 What types of articles will QHR accept?

QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main *QHR* webpage.
- Search the *QHR* journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- *QHR* accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- *QHR* is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in *QHR* provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.
- QHR does NOT publish pilot studies.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

1.3 Writing your paper
The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable
For information and guidance on how to make your article more discoverable, visit our Gateway page on How to Help Readers Find Your Article Online

2. Editorial policies

2.1 Peer review policy
Qualitative Health Research strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are initially reviewed by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Ensure your manuscript does not contain any author identifying information. Please refer to the editorial on blinding found in the Nov 2014 issue: http://qhr.sagepub.com/content/24/11/1467.full.

QHR maintains a transparent review system, meaning that all reviews, once received, are then forwarded to the author(s) as well as to ALL reviewers.

Peer review takes an average of 6–8 weeks, depending on reviewer response.

As part of the submission process you may provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

You will also be asked to nominate peers who you do not wish to review your manuscript (opposed reviewers).

Please note that the Editors are not obliged to invite/reject any recommended/opposed reviewers to assess your manuscript.

Qualitative Health Research is committed to delivering high quality, fast peer-review for your paper, and as such has partnered with Publons. Publons is a third party service that seeks to track, verify and give credit for peer review. Reviewers for *QHR* can opt in to Publons in order to claim their reviews or have them automatically verified and added to their reviewer profile. Reviewers claiming credit for their review will be associated with the relevant journal, but the article name, reviewer's decision and the content of their review is not published on the site. For more information visit the Publons website.

The Editor or members of the Editorial Board may occasionally submit their own manuscripts for possible publication in the journal. In these cases, the peer review process will be managed by alternative members of the Board and the submitting Editor/Board member will have no involvement in the decision-making process.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

(i) Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data,
(ii) Drafted the article or revised it critically for important intellectual content,
(iii) Approved the version to be published,
(iv) Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please do not upload or include the acknowledgments during the initial submission and review. IF your article is going to be accepted, you will be instructed to "unblind" the manuscript, and then you may add this section to your document.

2.3.1 Writing assistance

Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance. It is not necessary to disclose use of language polishing services.

2.4 Funding

Qualitative Health Research requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests
It is the policy of *Qualitative Health Research* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here

2.6 Research ethics and patient consent
Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals:

- All papers reporting animal and/or human studies **must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval.** Please ensure that you blinded the name and institution of the review committee until such time as your article has been accepted. The Editor will request authors to replace the name and add the approval number once the article review has been completed

- **For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.**

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials
Qualitative Health Research conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines
The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

2.9. Research Data
At SAGE we are committed to facilitating openness, transparency and reproducibility of research. Where relevant, The Journal encourages authors to share their research data in a suitable public repository subject to ethical considerations and where data is included, to add a data accessibility statement in their manuscript file. Authors should also follow data citation principles. For more information please visit the SAGE Author

Gateway, which includes information about SAGE's partnership with the data repository Figshare.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway

3.1.1 Plagiarism

Qualitative Health Research and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarized other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway

3.4 Open access and author archiving

Qualitative Health Research offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

4. Preparing your manuscript

4.1 Article Format (see previously published articles in QHR for style):

- Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- Methods: QHR readership is sophisticated; excessive details not required.

- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including othergeographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics

- Figures: Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e. INSERT TABLE 1 HERE).
- Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
    - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
    - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
    - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

5. Submitting your manuscript

Qualitative Health Research is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit https://mc.manuscriptcentral.com/qhr to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission,

supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID IDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID ID you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID ID will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID ID is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID ID please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission
You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions
Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

6. On acceptance and publication

6.1 SAGE Production
Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorizing the change.

6.2 Online First publication
Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article
SAGE provides authors with online access to their final article.

6.4 Promoting your article
Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the *Qualitative Health Research* editorial office as follows:

Vanessa Shannon, Managing Editor
Email: vshannonqhr@gmail.com

Appendix 1.2: Search strategy and terms for each database

Search terms

Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
"older adult*" OR "older people" OR "older person*" OR "older patient*" OR aged OR elderly OR "late life"	"mentally ill" OR "mental health" OR "mental disorder*" OR "mental illness "	interv* OR "focus group*" OR "case stud*" OR observ*	narrat* OR describ* OR experience* OR perspective* OR meaning OR "living with"	qualitative

Search strategy: [S AND P] AND [(D OR E) AND R]

Database specific terms

CINAHL (n=872)

Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
(MH "Frail Elderly") OR "older adult" (MH "Aged+") OR (MH "Frail Elderly") OR "older people" OR "older patient" OR "aged" OR (MH "Aged, 80 and Over+") (MH "Aged") OR "elderly" "late life" OR "older adult*" OR "older people" OR "older person*" OR "older patient*" AND TI (elderly OR "late life" OR "older adult*" OR "older	(MH "Mental Disorders+") OR "mentally ill" (MH "Mental Health") OR "mental health" (MH "Mental Disorders") OR (MH "Mental Disorders, Chronic") OR "mental disorder" OR "mental illness"	(MH "Semi-Structured Interview") OR (MH "Interviews+") OR "interview" OR (MH "Focus Groups") OR "focus group" OR (MH "Case Studies") OR "case study" OR interview* OR "focus group*" OR "case stud*" OR observ*	(MH "Narratives+") OR "narrate" OR narrat* OR describ* OR experienc* OR perspective* OR meaning OR "living with"	(MH "Qualitative Studies+") OR "qualitative" OR (MH "Phenomenology")

people" OR "older person*" OR "older patient*") OR AB (elderly OR "late life" OR "older adult*" OR "older people" OR "older person*" OR "older patient*")				

MEDLINE (n=738)

Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
(MH "Frail Elderly") OR "older adult" OR (MH "Aged+") OR (MH "Frail Elderly") OR "older people" OR "aged" OR (MH "Aged, 80 and Over+") (MH "Aged") OR "elderly" "older adult*" OR "older people" OR "older person*" OR "older patient*" OR "late life"	(MH "Mental Disorders+") OR "mentally ill" (MH "Mental Health") OR "mental health" (MH "Mental Disorders") OR (MH "Mental Disorders, Chronic") OR "mental disorder*" OR "mental illness"	(MH "Semi-Structured Interview") OR (MH "Interviews+") OR "interview" OR (MH "Focus Groups") OR "focus group" (MH "Case Studies") OR "case study" OR interview* OR "focus group*" OR "case stud*" OR observ*	(MH "Narratives+") OR "narrate" OR narrat* OR describ* OR experienc* OR perspective* OR meaning OR "living with"	(MH "Qualitative Studies+") OR "qualitative" OR (MH "Phenomenology")

PsycINFO (n=192)

Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
DE "Late Life Depression" OR DE "Geriatric Patients" DE "Gerontology" OR DE "Geriatrics" OR DE "Geriatric Assessment" OR DE	DE "Chronic Mental Illness" OR DE "Chronic Psychosis" OR DE "Mental Disorders" OR DE "Borderline States" OR DE "Thought Disturbances" OR DE "Affective Disorders" OR DE "Anxiety Disorders" OR DE "Autism Spectrum Disorders" OR DE "Bipolar Disorder" OR DE "Chronic Mental Illness" OR DE "Dissociative Disorders" OR DE "Eating Disorders" OR DE "Gender Dysphoria" OR DE "Mental Disorders due to	DE "Semi-Structured Interview"OR DE "Interviews" OR DE "Focus Group Interview" OR DE "Intake Interview" OR DE "Interview Schedules" OR DE "Job Applicant Interviews" OR	DE "Narrative Analysis" OR DE "Narratives" OR narrat* OR describ* OR experienc* OR meaning* OR "living with" OR perspective*	Qualitative OR DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-

"Geriatric Psychiatry" OR "older adult*" OR "older people" OR older person*" OR "older patient*" OR aged OR elderly OR "late life" AND TI (elderly OR "late life" OR "older adult*" OR "older people" OR "older person*" OR "older patient*") OR AB (elderly OR "late life" OR "older adult*" OR "older people" OR "older person*" OR "older patient*")	General Medical Conditions" OR DE "Neurocognitive Disorders" OR DE "Neurodevelopmental Disorders" OR DE "Neurosis" OR DE "Paraphilias" OR DE "Personality Disorders" OR DE "Psychosis" OR DE "Sleep Wake Disorders" OR DE "Somatoform Disorders" OR DE "Stress and Trauma Related Disorders" OR DE "Substance Related and Addictive Disorders" OR DE "Hoarding Disorder" OR DE "Hoarding Behavior" OR DE "Mental Health" OR DE "Mental Status" OR DE "Schizoaffective Disorder" OR DE "Acute Psychosis" OR DE "Affective Psychosis" OR DE "Alcoholic Psychosis" OR DE "Capgras Syndrome" OR DE "Childhood Psychosis" OR DE "Chronic Psychosis" OR DE "Experimental Psychosis" OR DE "Hallucinosis" OR DE "Paranoia (Psychosis)" OR DE "Postpartum Psychosis" OR DE "Reactive Psychosis" OR DE "Schizophrenia" OR DE "Senile Psychosis" OR DE "Toxic Psychoses" DE "Disruptive Mood Dysregulation Disorder" OR DE "Major Depression" OR DE "Seasonal Affective Disorder" OR DE "Dissociative Disorders" OR DE "Depersonalization" OR DE "Depersonalization/Derealization Disorder" OR DE "Dissociative Amnesia" OR DE "Dissociative Identity Disorder" OR DE "Fugue Reaction" OR "mentally ill" OR "mental health" OR "mental disorder*" OR "mental illness"	DE "Psychodiagnostic Interview" OR DE "Semi-Structured Interview" DE "Focus Group" OR interview* OR "focus group*" OR "case stud*" OR observ*		Structured Interview" OR DE "Thematic Analysis" OR DE "Thematic Analysis" OR DE "Narrative Analysis" OR DE "Interpretative Phenomenological Analysis" OR DE "Grounded Theory" OR DE "Content Analysis" OR DE "Digital Content Analysis" OR DE "Discourse Analysis" OR DE "Narrative Analysis" OR DE "Sentiment Analysis" OR DE "Social Network Analysis" OR DE "Thematic Analysis"

PsycARTICLES (n=107)

Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
"older adult*" OR "older people" OR "older person*" OR "older patient*" OR aged OR elderly OR "late life"	"mentally ill" OR "mental health" OR "mental disorder*" OR "mental illness"	interview* OR "focus group*" OR "case stud*" OR observ*	narrat* OR describ* OR experienc* OR perspective* OR meaning* OR "living with"	qualitative

Embase (n=760)

Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
exp aging/ or exp aged/ or older adult.mp. exp elderly care/ or exp aged/ or older people.mp. or exp aging/ exp aged/ or older patient.mp. elderly.mp. or aged/ exp late life depression/ or late life.mp. ("older adult*" or "older person*" or "older people" or "older patient*" or aged or elderly or "late* life").mp. ("older adult*" or "older person*" or "older people" or "older patient*" or aged or elderly or "late* life").m_titl.	mentally ill.mp. or exp mental disease/ mental health.mp. or exp mental health/ mental disorder.mp. or exp mental disease/ mental illness.mp. or exp mental disease/ ("mental* ill*" or "mental health" or "mental disorder*").mp.	exp unstructured interview/ or exp interview/ or interview.mp. or exp semi structured interview/ focus group.mp. case study.mp. or exp case study/ (interview* or "focus group*" or "case stud*" or observ*).mp.	narrate.mp. or exp narrative/ meaning.mp. or exp qualitative research/ perspective.mp experienc* or narrat* or describ* or meaning* or perspective* or "living with").mp.	exp qualitative research/ or exp qualitative analysis/ or qualitative.mp.

Appendix 1.3: COREQ tool

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

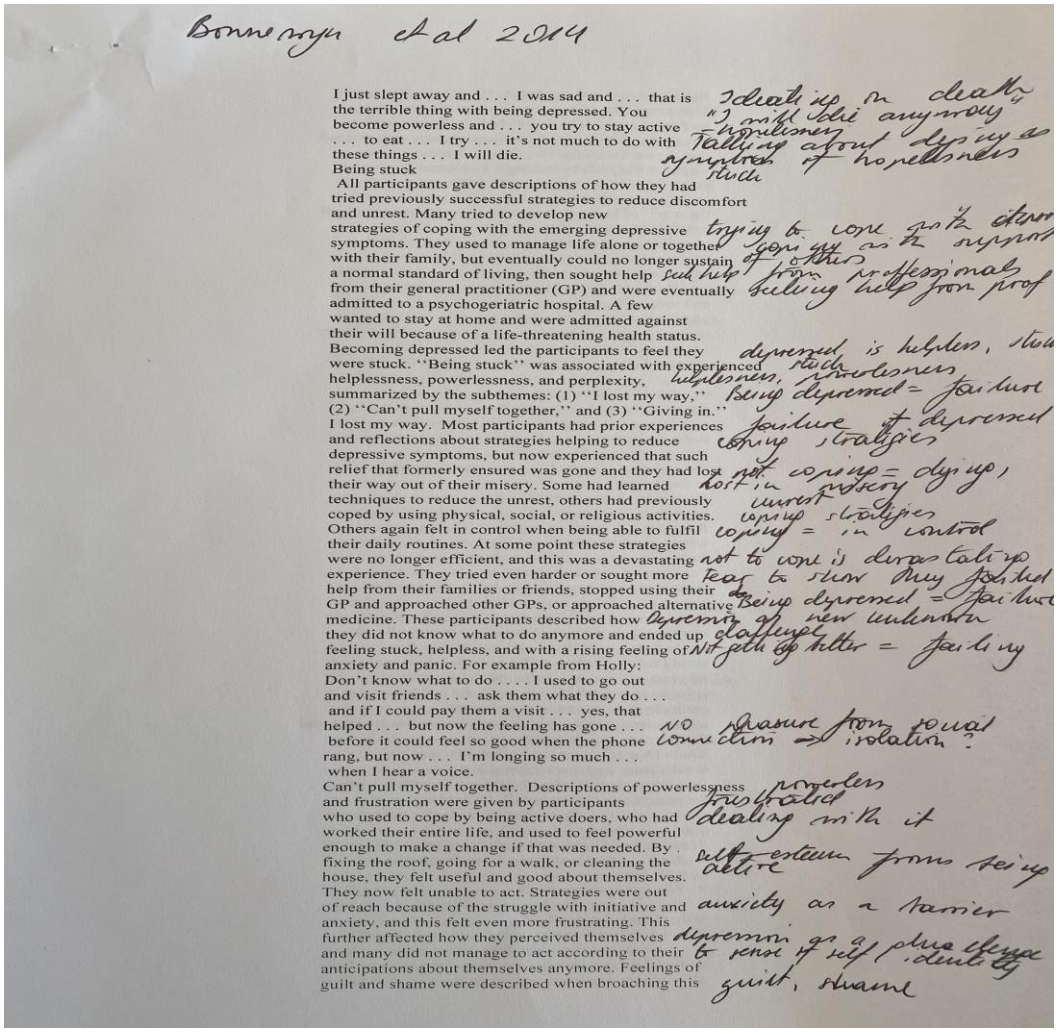
Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 1.4: Example of data coding



Bonnevyn et al 2014

I just slept away and . . . I was sad and . . . that is the terrible thing with being depressed. You become powerless and . . . you try to stay active . . . to eat . . . I try . . . it's not much to do with these things . . . I will die.

Being stuck

All participants gave descriptions of how they had tried previously successful strategies to reduce discomfort and unrest. Many tried to develop new strategies of coping with the emerging depressive symptoms. They used to manage life alone or together with their family, but eventually could no longer sustain a normal standard of living, then sought help from their general practitioner (GP) and were eventually admitted to a psychogeriatric hospital. A few wanted to stay at home and were admitted against their will because of a life-threatening health status. Becoming depressed led the participants to feel they were stuck. ''Being stuck'' was associated with experienced helplessness, powerlessness, and perplexity, summarized by the subthemes: (1) ''I lost my way,'' (2) ''Can't pull myself together,'' and (3) ''Giving in.''

I lost my way. Most participants had prior experiences and reflections about strategies helping to reduce depressive symptoms, but now experienced that such relief that formerly ensured was gone and they had lost their way out of their misery. Some had learned techniques to reduce the unrest, others had previously coped by using physical, social, or religious activities. Others again felt in control when being able to fulfil their daily routines. At some point these strategies were no longer efficient, and this was a devastating experience. They tried even harder or sought more help from their families or friends, stopped using their GP and approached other GPs, or approached alternative medicine. These participants described how they did not know what to do anymore and ended up feeling stuck, helpless, and with a rising feeling of anxiety and panic. For example from Holly:

Don't know what to do . . . . I used to go out and visit friends . . . ask them what they do . . . and if I could pay them a visit . . . yes, that helped . . . but now the feeling has gone . . . before it could feel so good when the phone rang, but now . . . I'm longing so much . . . when I hear a voice.

Can't pull myself together. Descriptions of powerlessness and frustration were given by participants who used to cope by being active doers, who had worked their entire life, and used to feel powerful enough to make a change if that was needed. By fixing the roof, going for a walk, or cleaning the house, they felt useful and good about themselves. They now felt unable to act. Strategies were out of reach because of the struggle with initiative and anxiety, and this felt even more frustrating. This further affected how they perceived themselves and many did not manage to act according to their anticipations about themselves anymore. Feelings of guilt and shame were described when broaching this

Appendix 2.1: Author guidelines for submission to Clinical Gerontologist

About the Journal

Clinical Gerontologist is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Clinical Gerontologist accepts the following types of article:

- Original research reports
- Original brief reports
- Conceptual Reviews
- Clinical comments
- New and Emerging Professionals

COI Disclosure Form

Clinical Gerontologist requires each co-author of each accepted manuscript to fill out the ICMJE Form for Disclosure of Potential Conflicts of Interest. Please use the "COI Disclosure Form" designation to upload these forms. We will need to receive them before accepting your manuscript for publication. Please click here to download the COI disclosure form. Should not be included on initial submission but rather with acceptance of your paper.

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Taylor & Francis is a member of the Committee of Publications Ethics (COPE). COPE aims to provide a forum for publishers and editors of scientific journals to discuss issues relating to the integrity of their work, including conflicts of interest, falsification and fabrication of data, plagiarism, unethical experimentation, inadequate subject consent, and authorship disputes. For more information on COPE please visit https://publicationethics.org/.

Certifications Form

Each article published in Clinical Gerontologist is accompanied by a certification statement that discusses ethical principles, funding, and acknowledgements. Please modify the provided certifications form as appropriate for your submission and upload it using the "Certifications form" file designation. We will need to receive this form before accepting your manuscript. Please click here to download the certifications form.

Preparing Your Paper

Original research reports

- Should be written with the following elements in the following order: title page; abstract; keywords; introduction, methods, results, discussion; and clinical implications (2-3 short bulleted points); acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 5000 words (not counting abstract, tables, figures and references).
- Includes randomized intervention studies, cohort observational studies, survey research, and studies of assessment or diagnostic tests. If describing scale development, please include a useable version of the scale as an appendix when possible. If not, please indicate where the scale can be obtained.

Original brief reports

- Should be written with the following elements in the following order: title page; abstract; keywords; introduction, methods, results, discussion; and clinical implications (2-3 short bulleted points); acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 2000 words (not counting abstract, tables, figures and references).

Conceptual Reviews

- Should be written with the following elements in the following order: title page; abstract; keywords; introduction, methods, results, discussion; and clinical implications (2-3 short bulleted points); acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 6000 words (not counting abstract, tables, figures and references).
- May include systematic reviews of the literature, meta-analyses, and/or manuscripts presenting new or revised theoretical models. All reviews should provide systematic, critical assessments of literature that yield conclusions of direct clinical importance to the behavioral health care of older adults.

Clinical comments

- Should be written with the following elements in the following order: title page; abstract; keywords; introduction, methods, results, discussion; and clinical implications (2-3 short bulleted points); acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 2500 words (not counting abstract, tables, figures and references).
- Clinical comments may be program evaluation or quality improvement projects or case studies. Importantly, clinical comments should describe a novel approach to

an important clinical problem, filling a gap in the literature. Novelty may be represented by the application of a new treatment, or a new application of an existing treatment in a complex or unusual presentation. The introduction section to the Clinical Comment should directly address what is novel in the case or clinical innovation.

New and Emerging Professionals

- Special consideration will be given for papers submitted where the primary author is a student, post-doctoral fellow, or newly appointed faculty member. Papers by new and emerging professionals may be of any manuscript type and should follow the instructions for that category.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use American spelling style consistently throughout your manuscript.

Please use double quotation marks, except where “a quotation is ‘within’ a quotation”. Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us here.

References

Please use this reference guide when preparing your paper.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: What to Include

1. **Title page.** Please include a concise informative title not to exceed 120 characters and a short running head not to exceed 50 characters. Anonymous review is available on request if indicated in the cover letter. Manuscripts in this case should be prepared to conceal the identity of the author(s). The cover page and footnotes that identify the author(s) should be omitted.
2. **Author details.** All authors of a manuscript should include their full name, highest academic degree, and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
3. Include a 200-word structured abstract, using the headings: objectives, methods, results, conclusions, and clinical implications. Abstracts for clinical comments should be structured if appropriate, but for case studies may be in paragraph form. You can opt to include a **video abstract**with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. **Keywords.** Please provide 5–10 keywords for indexing purposes. Note that while a drop-down menu is available when you submit, you can also use keywords not on that menu. Keywords can make the difference in whether your article is cited or not. General keywords are important to helping your article be found such as: aging, older adults, dementia, caregiver, social, cognitive, long term care.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.
7. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
8. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
9. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
10. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For

information relating to other file types, please consult our Submission of electronic artwork document.

11. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
12. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
13. **Units.** Please use SI units (non-italicized).

Using Third-Party Material in your Paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Submitting Your Paper

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in ScholarOne. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

Please note that *Clinical Gerontologist* uses Crossref™ to screen papers for unoriginal material. By submitting your paper to *Clinical Gerontologist* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this informationregarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication Charges

There are no submission fees, publication fees or page charges for this journal.

Colour figures will be reproduced in colour in your online article free of charge. If it is necessary for the figures to be reproduced in colour in the print version, a charge will apply.

Charges for colour figures in print are £300 per figure ($400 US Dollars; $500 Australian Dollars; €350). For more than 4 colour figures, figures 5 and above will be charged at £50 per figure ($75 US Dollars; $100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

Open Access

This journal gives authors the option to publish open access via our Open Select publishing program, making it free to access online immediately on publication. Many funders mandate publishing your research open access; you can check open access funder policies and mandates here.

Taylor & Francis Open Select gives you, your institution or funder the option of paying an article publishing charge (APC) to make an article open access. Please

contact openaccess@tandf.co.uk if you would like to find out more, or go to our Author Services website.

For more information on license options, embargo periods and APCs for this journal please go here.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Article Reprints

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact the Taylor & Francis Author Services team at reprints@tandf.co.uk.

Queries

Should you have any queries, please visit our Author Services website or contact us here.

Appendix 2.2: Ethical and board approvals

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Professor Hamish J McLeod
Professor of Clinical Psychology, Programme Director, Doctorate in Clinical Psychology
Institute of Health and Wellbeing.
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Rd, Glasgow
G12 0XH

West of Scotland REC 1
West of Scotland Research Ethics Service
Ward 11
Dykebar Hospital
Grahamston Road
Paisley PA2 7DE
www.nhsggc.org.uk
Date 08 July 2019
Direct line 0141-314-0212
e-mail WosRec1@ggc.scot.nhs.uk

Dear Professor McLeod

Study title: **An exploration of mental health related outcome and treatment preferences in treatment seeking older adults**
REC reference: **19/WS/0096**
Protocol number: **3**
IRAS project ID: **260465**

The Research Ethics Committee reviewed the above application at the meeting held on 02 July 2019. Thank you for attending with Ms Rasa Butrimaviciute to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Number	Condition
1	On page 2 of the PIS, please change "To explore these themes, the researcher will ask you to order some cards, rating what things would be important to you in a treatment, and what would be less important." to "To explore these themes, the researcher will ask you to place some cards which have desired outcomes or treatment options written on them in a preference order. You will be asked to rating what things would be important to you in a treatment, and what would be less important. Please note that all of the treatment options written on the cards may not be available or suitable for your condition."
2	Please add a timescale to the leaflets of when the study may run so that someone who is interested knows they may not be able to take part if they are after this time.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of

the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For clinical trials of investigational medicinal products (CTIMPs), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC Sites

The favourable opinion applies to all NHS/HSC sites taking part in the study taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland)being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Leaflet]	3	26 April 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Glasgow insurance]		06 August 2018
GP/consultant information sheets or letters [Letter to referrer]	1	26 April 2019
IRAS Application Form [IRAS_Form_11062019]		11 June 2019
Letter from funder [University proceed to ethics]		27 February 2019
Letter from sponsor [Sponsor confirmation]		30 May 2019
Letters of invitation to participant [Letter to Patients]	2	14 June 2019
Non-validated questionnaire [Study survey]	3	26 April 2019
Participant consent form [Consent form V3]	3	03 May 2019
Participant information sheet (PIS) [PIS V5]	5	26 April 2019
Referee's report or other scientific critique report [Sponsor's peer review]		28 May 2019
Research protocol or project proposal [Protocol V3]	3	30 May 2019
Summary CV for Chief Investigator (CI) [Professor Hamish McLeod]		20 March 2019
Summary CV for student [Ms Rasa Butrimaviciute]		25 April 2019
Summary CV for supervisor (student research) [Dr Clive Ferenbach]		

Document	*Version*	*Date*
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Synopsis]	1	10 June 2019

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

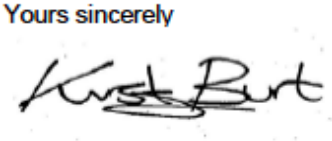
HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/WS/0096	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



On behalf of
Dr Malcolm Booth
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Mr Raymond Hamill , NHS Lanarkshire
Lead Nation

West of Scotland REC 1

Attendance at Committee meeting on 02 July 2019

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Gazala Akram	Lecturer and Advanced Psychiatric Pharmacist	Yes	
Dr Malcolm Booth	Consultant in Anaesthesia and Intensive Care (Chair)	Yes	Chair of Meeting
Dr Katriona Brooksbank	Clinical Trial Manager	No	
Dr Anne Marie Coleman	Psychotherapist	No	
Dr Ross Fairgrieve	Consultant in Paediatric Anaesthesia and Pain Management	Yes	
Dr Natasha Fullerton	Consultant Neuroradiologist	No	
Mrs Elspeth Fulton	Retired Senior Clinical Research Associate (CRA)	No	
Miss Linda Galbraith	Former Management Consultant	No	
Mrs Lynda Hamilton	Retired Manager	Yes	
Dr Peter Hutchison	GP (Vice Chair)	Yes	
Dr Derek Manson-Smith	Information Research Consultant (Retired)	Yes	
Dr John D McClure	Statistician	Yes	
Dr Colin Petrie	Physician and Cardiologist	No	
Mr Elliot Porter	General Teaching Assistant-Philosophy	Yes	
Mrs Laura Rooney	CRUK Lead Research Nurse	No	
Dr Patricia Roxburgh	Medical Oncologist	No	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Veronika Burgess	Assistant Coordinator
Mrs Kirsty Burt	Senior Co-ordinator

Written comments received from:

Name	*Position*
Miss Linda Galbraith	Former Management Consultant

Professor Hamish J McLeod
Professor of Clinical Psychology
University of Glasgow
Institute of Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 18.07.2019
Enquiries to Elizabeth McGonigal,
R&D Facilitator
Direct Line 01236 712445
Email elizabeth.mcgonigal@lanarkshire.scot.nhs.uk

Dear Professor McLeod

Project title: An exploration of mental health related outcome and treatment preferences in treatment seeking older adults

R&D ID: L19028|

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE
Ms Rasa Butrimaviciute	Trainee Clinical Psychologist	Principal Investigator

As you are aware, NHS Lanarkshire has agreed to be the Sponsor for your study. On its behalf, the R&D Department has a number of responsibilities; these include ensuring that you understand your own role as Chief Investigator of this study. To help with this we have outlined the responsibilities of the Chief Investigator in the attached document for you information.

All research projects within NHS Lanarkshire will be subject to annual audit via a questionnaire that we will ask you to complete. In addition, we are required to carry out formal monitoring of a proportion of projects, in particular those projects that are Sponsored by NHS Lanarkshire. In either case, you will find it helpful to maintain a well organised Site File. You may find it helpful to use the folder that we have included for that purpose.

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK and EU Data Protection legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.show.scot.nhs.uk/cso/ or the Research & Development Intranet site: http://firstport/sites/randd/default.aspx.
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Rasa Butrimaviciute	Trainee Clinical Psychologist	1104425b@student.gla.ac.u	Principal Investigator
Raymond Hamill	Senior R&D Manager	Raymond.Hamill@lanarkshire.scot.nhs.uk	Sponsor Contact
Dr Clive Ferenbach	Clinical Psychologist	Clive.Ferenbach@lanarkshire.scot.nhs.uk	Field Supervisor

Enc 1 x Site File
1 x Responsibilities as Sponsor Notes

Responsibilities as Sponsor

Site File

As an aid to the conduct of your study we have provided a Site File that you may wish to use. As Sponsor of the study we are required to carry out audit of all project, and to conduct detailed monitoring visits for a proportion (approximately 10%) - The study Site File should help you ensure that you have the relevant documentation to assist in this process. If your project is selected for monitoring, we will contact you well in advance to arrange a suitable time.

Our responsibilities as Sponsor are defined within the Research Governance Framework for Health and Community Care. A summary of these, along with those of the Chief Investigator, is provided in the following table for your information.

RESPONSIBILITIES OF CHIEF INVESTIGATOR	NHSL RESPONSIBILITIES AS SPONSOR
Obtain relevant / appropriate Research Ethics opinion.	Assess adequateness of the independent, expert review.
Obtain NHSL Research Management Approval.	Ensure that the Chief/Principle Investigator has the necessary expertise, experience and education to conduct the study.
Ensure that the members of the research team have the necessary expertise, experience and education to perform their roles.	Provide a formal written agreement of sponsorship conditions, and notification of confirmation of the sponsorship role.
Ensure the necessary resources are available for the study.	Provide NHS indemnity to the Chief Investigator and research team.
Act in accordance with regulations set out by your professional body(s) and the conditions of your employment contract.	Provide mechanisms and processes to exploit any potential Intellectual Property.
Identify archiving arrangements at the study outset.	Project monitoring commensurate with risk.
Record and review significant developments that may affect the study, particularly those which put the safety of the individuals at risk or affect the scientific direction and report to the sponsor as appropriate.	Make available local, national and international guidelines, regulations and legislation governing research in the UK.
Record, report and review all untoward medical occurrence (adverse events or reactions) including classification of causality, seriousness and expectedness.	Provide ongoing advice and guidance to promote quality study management and conduct.
Notify R&D and appropriate REC of significant news, changes, amendments and modifications to the study.	Determine the acceptability of the archive arrangements proposed by the Chief Investigator and, if the archive facility becomes unsuitable, provide alternative arrangements.
Maintain a record of all incidents, providing an annual report to the sponsor.	Determine length of archive/retention period for essential study documents and subsequent destruction date
Inform REC and R&D of the study end.	
Maintain a log of archived documents and their location.	
Inform R&D of any publications arising from the study or dissemination of findings.	
Inform R&D of any potential Intellectual Property.	

Appendix 2.3: Initial list of treatment outcomes and options

Treatment outcomes

1. Have a sense of purpose and meaning to my life
2. I want to like myself
3. Having more energy to do things
4. Improve my relationships with others
5. Learn to focus/worry less on my physical health
6. Be involved with other people in my community
7. Sleeping better
8. Having more things to do during my week
9. Feel less troubled by memories from the past
10. Learning to live with pain and other physical difficulties
11. Feeling more confident
12. Be less bothered by worries
13. Manage my nerves und uncomfortable feelings in my body (eg sickness in stomach)
14. Making sense of my life
15. Coming to terms with loss of somebody
16. Adjusting to major life changes (eg retirement)

Treatment options

1. Notice and change unhelpful thoughts. Learn to think differently.
2. Notice and change unhelpful habits or patterns of behaviour.
3. Learn to face situations that I fear or have been avoiding.
4. Look at steps I could take to become more active.
5. Enter a brief group therapy where I will be taught skills to cope with my difficulties.
6. Work through written booklets to help me cope with my difficulties, with a support of a professional who sees me occasionally.
7. Access a course of self-help through a computer to coach me to notice and change unhelpful patterns of thoughts, feelings and behaviour.
8. Learn to take my thoughts less seriously and be less caught up in them.
9. Learn to be ok with my emotions, even if I can't get rid of them completely.
10. Learn meditation techniques.
11. Clarify what my values are – what is really important to me in life and what kind of person I want to be.
12. Build kindness and compassionate towards myself and learn ways to be less critical of me.
13. Explore links between earlier life, including events in childhood, and how this affects my life presently.
14. Learn skills for improving my relationships.
15. Talk over the course of my life, so I can put things in perspective and gain a sense of peace about the past.
16. Attend a course of therapy where I will be taught skills to deal with problematic situations.
17. Spend time with a therapist to explore the loss of a loved one.
18. Spend time with a therapist helping me to adjust to life changes.
19. To tell my story and have someone listen and understand.

Appendix 2.4: Cards developed for the CST

Treatment outcome cards (Task1 and 3)

1. Have a sense of purpose and meaning to my life	2. I want to like myself
3. Having more energy to do things	4. Improve my relationships with others
5. Learn to focus/worry less on my physical health	6. Be involved with other people in my community
7. Sleeping better	8. Having more things to do during my week

9. Feel less troubled by memories from the past	10. Learning to live with pain and other physical difficulties
11. Feeling more confident	12. Be less bothered by worries
13. Manage my nerves und uncomfortable feelings in my body (eg sickness in stomach)	14. Making sense of my life
15. Coming to terms with loss of somebody	16. Adjusting to major life changes (eg retirement)

Treatment option cards (Task 2 and 3)

A. Notice and change unhelpful thoughts; learn to think differently	B. Notice and change unhelpful habits or patterns of behaviour
C. Learn to face situations that I fear or have been avoiding	D. Look at steps I could take to become more active
E. Learn strategies and skills to deal with problematic situations	F. See a therapist for weekly or two-weekly sessions of psychological therapy
G. Enter a weekly group therapy where I will be taught skills to cope with my difficulties	H. Work through written booklets to help me cope with my difficulties, with a support of a professional who sees me occasionally
I. Access a course of self-help through a computer – to teach me to notice and change unhelpful patterns of thoughts, feelings and behaviour	J. Learn to take my thoughts less seriously and be less caught up in them
K. Learn to be ok with unwanted emotions, even if I can't get rid of them completely	L. Learn meditation techniques

M. Clarify my values – what is important to me in life and what kind of person I want to be	N. Build kindness and compassion; learn ways to be less critical of me
O. Explore links between earlier life, including events in childhood, and how this affects my life presently	P. Learn skills for improving my relationships
Q. Talk over the course of my life, to put things in perspective and gain a sense of peace about the past	R. Explore the loss of a loved one
S. Talk about major life changes to help me adjust to them	T. Tell my story and be listened and understood

Appendix 2.5: Study leaflet

University of Glasgow

NHS Lanarkshire

Are you?

- **Attending at NHS Lanarkshire Psychological Therapies for Older People (PTOP)**
- **Waiting to receive OR receiving psychological therapy (i.e. a 'talking therapy')**
- **Keen to share your thoughts on treatments that are on offer**
- **Willing to tell us what is important for people who seek treatment**
- **Able to spare between 30 – 60 minutes**

THEN…

You may be eligible to take part in the study:

"An exploration of mental health related outcome and treatment preferences in treatment seeking older adults"

In the study we will:

- Explore with clients what kind of therapy they would prefer
- To see whether we are providing people with the service they really want

A member of our team will be in touch to check if you would like to participate, or you can contact Rasa Butrimaviciute in PTOP at:

☎ 01698 210021

✉ PTOP@lanarkshire.scot.nhs.uk

VOLUNTEERS NEEDED

Please note, if we do not hear from you before 1st of December 2019, you may not be able to participate.

V4, 09/07/2019

Appendix 2.6: Participant information sheet

Participant Information Sheet

1. Study title:
An exploration of mental health related outcome and treatment preferences in older adults

2. Who is conducting the study?
The study is being carried out by:

- Rasa Butrimaviciute, Trainee Clinical Psychologist and Principal Investigator (University of Glasgow, NHS Lanarkshire)
- Prof Hamish McLeod, Professor of Clinical Psychology (University of Glasgow)
- Dr Clive Ferenbach, Senior Clinical Psychologist (NHS Lanarkshire)

3. Invitation
You are being invited to take part in a research study. Before you decide if you would like to take part it is important that you understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. One of the researchers will go through this information sheet with you and answer any questions that you have. This should take about 15 minutes. It is important that you take time to decide whether or not you wish to take part.

4. What is the purpose of the study?
Research suggests that considering patients' preferences for treatment increases their satisfaction and attendance for treatment, which can lead to better clinical outcomes. This study will aim to develop a quick, meaningful and user-friendly method to elicit goals for treatment and the preferred ways to achieve them. The aim will also be to lay ground for further research and to investigate patient preferences for accessing treatment. The study is being carried out as part of Rasa Butrimaviciute's research portfolio in order to complete the Doctorate in Clinical Psychology at the University of Glasgow.

5. Why have I been invited?
We are looking for participants accessing NHS Lanarkshire mental health services for older people because they are experiencing symptoms of emotional distress. Essentially, we want to learn more about what goals people have when entering treatment, and what kind of support they would

prefer from their therapist. It is important for the NHS to understand *what clients really want*.

6. Do I have to take part?

No, participation in this research is voluntary. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form at your next appointment. You can withdraw from the study at any time without giving a reason. If you decide to withdraw from the study, the information that you have provided up to that point will be retained in anonymised form unless you ask for it to be withdrawn from the study and destroyed. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive now or in the future.

7. What will happen to me if I take part?

If you agree to take part, you will be invited to attend at an NHS Lanarkshire outpatient clinic at a time that suits you. The appointment will aim to explore:

1) What your desired outcomes are for treatment (i.e. what your goals are, what you'd like to gain from therapy);
2) What you think a helpful talking therapy might involve for you (i.e. what you hope or expect your therapist might do).

To explore these themes, the researcher will ask you to order some cards, rating what things would be important to you in a treatment, and what would be less important. You will also be asked to fill out a brief questionnaire, to tell us about your experience of taking part in the task. It is anticipated that the session will take an absolute maximum of 1 hour, but probably a shorter time than this. Taking part in this study will not effect the treatment you receive in any way.

8. What are the possible benefits of taking part?

Although there are no direct benefits, you may find the experience of participating in the research interesting. There is a possibility that you may come out of the study being better informed about various mental health treatments. The information gathered will potentially be helpful in shaping the services offered to people seeking talking therapy.

9. What are the possible risks of taking part?

There are minimal risks associated with taking part. There is a time burden, as you are being asked to take part in the card sort task. You may experience some emotional distress as a result of thinking about some of your difficulties, but the researcher would support you should strong emotions arise.

10. Will my taking part in this study be kept confidential?

All information collected for the duration of this study will be kept strictly confidential. None of the information you provide will be directly associated with your identifiable personal information. You will be given an anonymous Study ID which will be used in place of your name throughout the study.

11. Will my psychiatrist and GP be notified?

Yes, we will ask for your consent to inform your Psychiatrist (if applicable) and GP that you are taking part in the study. Your Psychiatrist and GP will have no other involvement in the study.

12. What happens when the research study ends?

Your participation will end but the anonymised data that you provide will be used for the purposes of this study. You can find further details about how your data would be used and managed in Section 18 of this document.

13. What will happen to the results?

The results of the study will be written into a report and submitted to the University of Glasgow, as part of Rasa Butrimaviciute's requirements to complete the training on the Doctorate in Clinical Psychology program, by April 2020. They will be shared with colleagues working with older people and may be published in suitable academic journals. You will be able to request a summary from NHS Lanarkshire Psychological Therapies for Older People department.

14. Who is organising and funding the research?

The researched is organised via the University of Glasgow and is supported by the NHS Lanarkshire. There is no commercial funding associated with this research.

15. Who has reviewed this study?

All research in the NHS is reviewed by an independent group of people called a Research Ethics Committee to protect your interests. The West of Scotland Ethics Committee has reviewed this study and favourable opinion has been given.

16. If you have any further questions

If you have any further questions or concerns about the study, please contact the Chief Investigator:

Rasa Butrimaviciute, Trainee Clinical Psychologist
University of Glasgow
Institute of Health and Wellbeing
1055 Great Western Road

Glasgow, G12 0XH
tel: 01698 210021
email: rasa.butrimaviciute@lanarkshire.scot.nhs.uk
If you would like more information about the study and wish to speak with someone who is not closely linked to the study, please contact Dr Tom McMillan, University of Glasgow, email: thomas.mcmillan@glasgow.ac.uk, tel: 0141 2110354.

17. If you have a complaint about any aspect of the study

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance. The normal NHS complaint procedure is also available for you. The contact person for making a complaint in NHS Lanarkshire is: Laura Jack, NHS Lanarkshire Headquarters, Kirklands Hospital, Fallside Road, Bothwell, G71 8BB, tel: 01698 858321, email: laura.bryan@lanarkshire.scot.nhs.uk.

18. Additional information about the storage and management of data

As the research sponsor, NHS Lanarkshire will be using information from you in order to undertake this study and will act as the data controller. This means that NHS Lanarkshire are responsible for looking after your information and using it properly. NHS Lanarkshire will keep identifiable information about you (for 12 months after the study has finished). The University of Glasgow will also store and use your anonymised research data in order to conduct this study.

Your rights to access, change or move your information are limited, since your information needs to be managed in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, NHS Lanarkshire and University of Glasgow will keep the information about you that was already obtained. To safeguard your rights, and as outlined above, the minimum personally-identifiable information possible will be used. Please note that NHS Lanarkshire's Data Protection Notice can be viewed on NHS Lanarkshire's public website: http://www.nhslanarkshire.scot.nhs.uk/data-protection-notice, or you can also ask a member of staff for a copy.

NHS Lanarkshire will keep your name, NHS number and contact details confidential and will not pass this information to other organisations. NHS Lanarkshire will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from NHS Lanarkshire and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NHS Lanarkshire will only receive information without any identifying

information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

Appendix 2.7: Consent sheet

Participant Consent Form

An exploration of mental health related outcome and treatment preferences in older adults

Researchers:		Contact Details:
Rasa Butrimaviciute Professor Hamish McLeod Dr Clive Ferenbach		Email:rasa.butrimaviciute@lanarkshire.scot.nhs.uk Mental Health and Wellbeing Gartnavel Royal Hospital 1055 Great Western Rd Glasgow G12 0XH tel: 0141 211 3920

Please initial box

1) I confirm that I have read and understand the Participant Information Sheet dated _____ Version __ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2) I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3) I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities and NHS Lanarkshire where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4) I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

5) I agree to my Psychiatrist (if applicable) and GP being informed of my participation in the study. ☐

6) I agree that the research team will access the relevant sections of my mental health record and/or speak to other clinicians involved in my care, to verify information that is necessary for the purposes of this study. ☐

7) I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Person taking consent	Date	Signature

Appendix 2.8: CST administration guidelines

Task 1
Here is a number of cards that describe common things or goals that people say they would like to get when attending for psychological treatment.
You are asked to order these cards, starting with most important ones at the top to the least important ones at the bottom **(on the table, point to cue cards 'most important' and 'least important')**. Pay attention to the order of the goals that are important to you but don't worry too much about how you sort the ones that are not important. Just put those in some order.
If you have other goals that are very important, you can write them on blank cards, and add them to the list.

Task 2
Here is a number of cards, each describing a type of psychological treatment. Order these cards from what you think would be most helpful for you **(on the table, point to cue card 'most helpful')** to the ones that you think would be least helpful **(point to cue card 'least helpful').** Pay attention to the most and least helpful ones. Don't worry too much about how you sort the ones in the middle, just put them in some order.
<u>Cues for treatment cards</u>

1. Notice and change unhelpful thoughts; learn to think differently

   Sometimes our difficulties come from how we interpret what happens to us. By learning to think differently about daily situations, we can improve how we feel.
2. Notice and change unhelpful habits or patterns of behaviour

   We all have habits or particular behaviours to cope with difficult situations; for example, we might withdraw from friends or family, or stop doing things when we feel low. These habits or behaviours can be unhelpful and keep us stuck. By noticing what our own unhelpful habits are, we can start changing them and so change how we feel.
5. Learn strategies and skills to deal with problematic situations

   Our ability to solve problems can be negatively affected when we feel low or anxious. This therapy will teach you a systematic strategy that looks at steps involved in solving a challenging situation. The aim is to teach you a systematic way to look for solutions to problematic situations.

12. Explore links between earlier life, including events in childhood, and how this affects my life presently

    Explore how things that happened to me affect how I am and behave now, including how I interact with other people, and how I experience various situations.
13. Learn skills for improving my relationships

    Sometimes the way that we are with other people in our lives can put others off and leave us feeling lonely and isolated. Exploring our way of relating and responding to other people can help better understand our relationships and find ways to improve them.

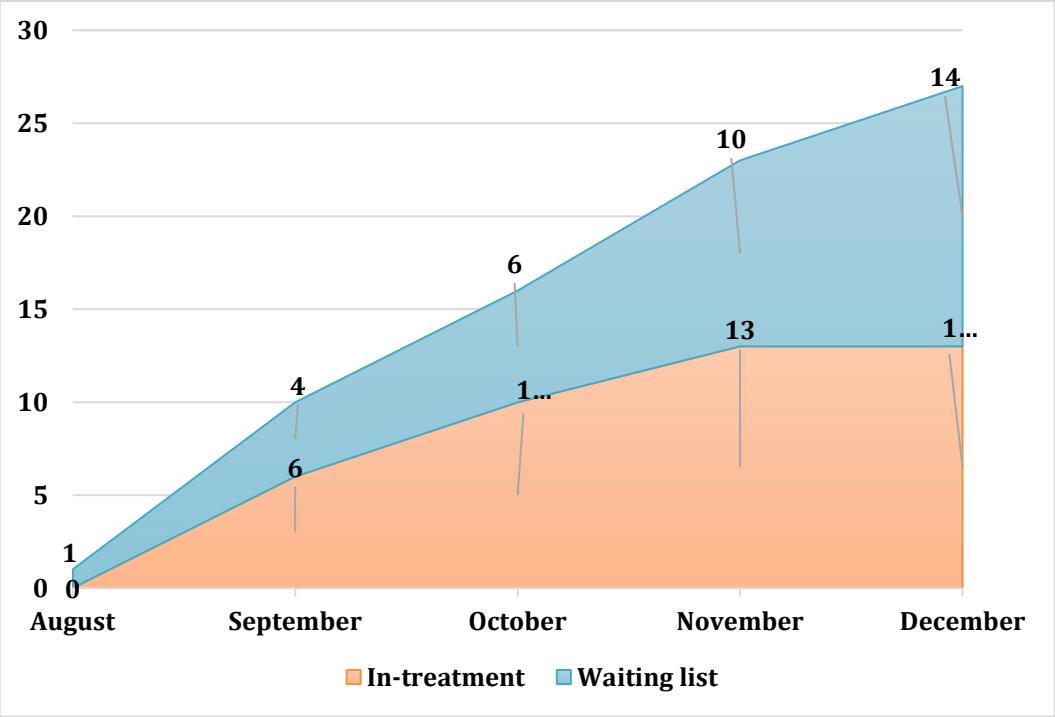
Task 3

(Point to the ordered cards of Task 1) Out of all of these goals, which ones are most important to you? Let's focus on them for the third task. **(Remove the other cards off the table)**

(Point to the ordered cards of Task 2) Out of all of the cards that you ordered**,** which treatments, in your opinion, would be most helpful for you? Let's focus on the treatments that you most prefer. **(Remove the other cards off the table)**

Your task now is to consider each goal **(point to the first order of cards)** more thoroughly. Consider which of the available treatments would be best for each goal. To do this, use your chosen treatment cards **(point to the second order of cards)**, and rank them in order, from most helpful treatment at the top, to the least helpful treatment. Don't rank the ones that you think wouldn't be helpful. Just leave them out. Once you have ranked for your top goal, we will reshuffle the treatment cards and move onto the next goal.

Appendix 2.9: Recruitment curve



A stacked chart displaying figures of recruitment process

Appendix 2.10: Participant experience survey

University of Glasgow

NHS Lanarkshire

An exploration of mental health related outcome and treatment preferences in older adults

Participant experience survey

Thank you for taking part in the study. The following questions explore your experience of taking part in the card sort task. There is no right or wrong way to answer. We are only looking to find out what taking part was like for you, and how the experience could be improved.

1. How was your overall experience of taking part in the card sort task?

Very Negative	Negative	Neutral	Positive	Very Positive
O	O	O	O	O

Comments:

" _____ "

_____

2. The content of the cards was relevant to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
O	O	O	O	O

Comments:

" _____ "

_____

3. The task was useful for expressing my treatment preferences.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
O	O	O	O	O

Comments:

" _____ "

_____

4. The time it took to complete the task was acceptable to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
O	O	O	O	O

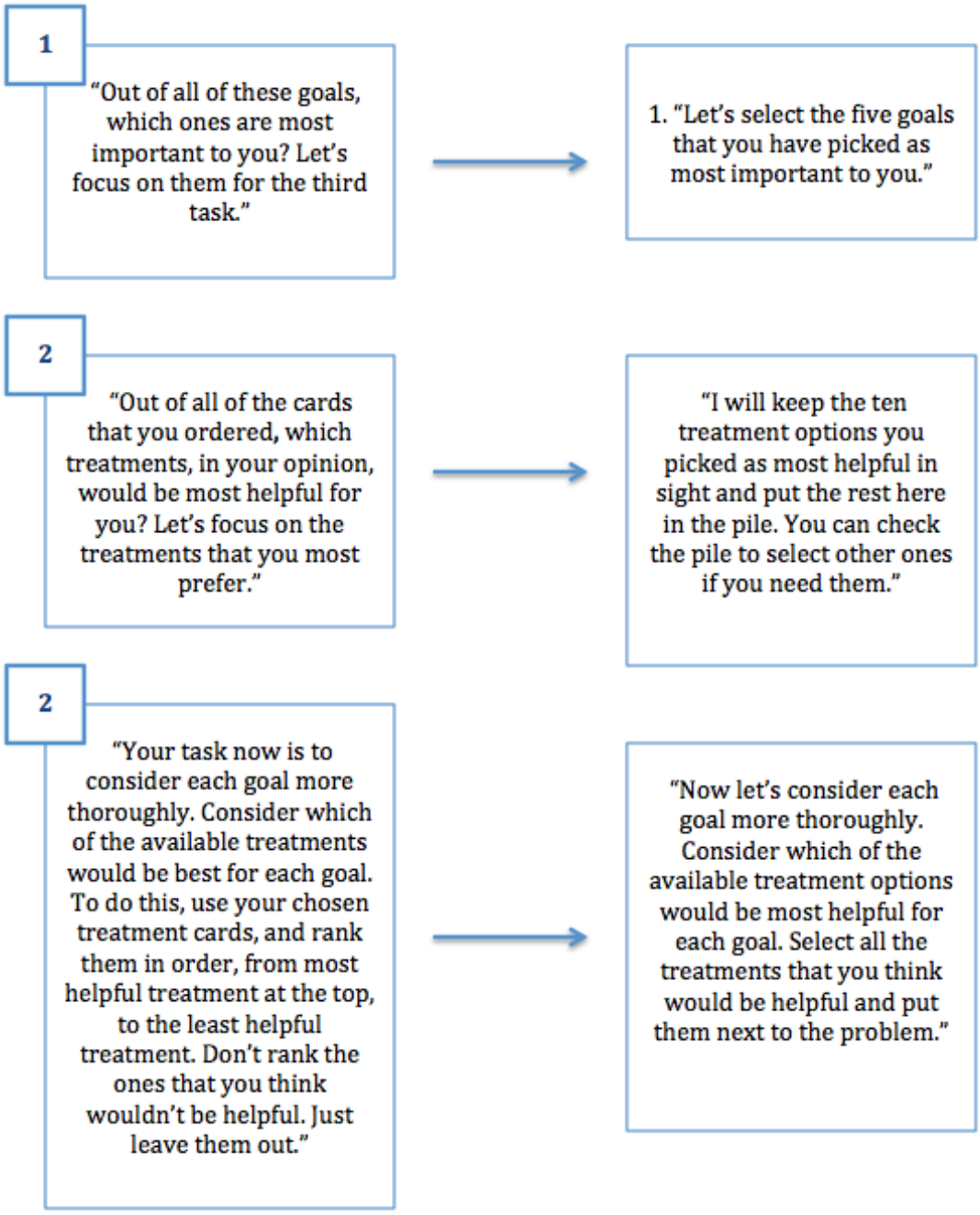
Comments:

" _____
_____ "

Please add any other comments below:

" _____
_____ "

Appendix 2.11: Modified administration procedure



Appendix 2.12: Between group comparisons

Table 1: Between group differences for each outcome

Desired treatment outcomes	Medians		Test statistic[2]
	Waiting list	In-treatment	
Feel less troubled by memories from the past	5[1]	2	73.5, p = .42
Manage my nerves and uncomfortable feelings in my body	7	3	60, p = .141
Be less bothered by worries	7	5	51.5, p = .54
Learn to focus/worry loss about my physical health	9.5	7	65, p = .22
Learning to live with pain and other physical difficulties	10	9	*75, p* = .458
Feeling more confident	4.5	8	*60, p* = .141
Making sense of my life	6.5	7	*74.5 p* = .43
I want to like myself	9	9	*83.5, p* = .72
Sleep better	12.5	8	*81.5, p* = .65
Have a sense of purpose and meaning to my life	5	10	***44, p = .02****
Having more energy to do things	6.5	10	*60, p* = .141
Improve my relationships with others	11	9	*72.5, p* = .366
Coming to terms with loss of somebody	5.5	13	*60.5, p* = .141
Having more things to do during my week	8	12	*70, p* = .325
Be involved with other people in my community	12	14	*70.5, p* = .325
Adjusting to major life changes	12.5	5	*60.5, p* = .141

[1] = Lower numbers denote higher importance; [2] = Mann-Whitney U; * = significant finding if $p < .05$

Table 2: Between group differences for each treatment option

Preferred treatment options	Medians		Test statistic[2]
	Waiting list	In-treatment	
See a therapist for weekly or two-weekly sessions	2[1]	5	80, p = .616
Learn to be ok with unwanted emotions	7	6	82.5, p = .685
Learn to take my thoughts less seriously	7	8	75, p = .458
Learn to face situations that I fear or avoid	7.5	6	66, p = .239
Clarify my values	7	15	**28.5, p = .002***
Talk over the course of my life	6.5	5	69, p = .302
Tell my story and be listened and understood	9	9	90, p = .981
Notice and change unhelpful thoughts, learn to think differently	8.5	12	84, p = .756
Explore links between earlier and present life	8.5	9	90, p = .981
Build kindness and compassion towards myself	11	9	83, p = .96
Explore the loss of a loved one	11	14	72, p = .375
Learn meditation techniques	10	10	87, p = .867
Look at steps I could take to become more active	9.5	17	74, p = .430
Enter a weekly group therapy	10	10	85.5, p = .793
Notice and change unhelpful patterns of behaviour	13.5	10	80, p = .616
Talk about major life changes to help me adjust	14	9	53.5, p = .068
Learn skills for improving my relationships	16	15	87, p = .867
Work through written booklets	16	15	81.5, p = .650
Learn skills to deal with problematic situations	16	8	**43, p = .019***
Access a course of self-help on a computer	18	19	68.5, p = .28

[1] = Lower numbers denote higher importance; [2] = Mann-Whitney U; * = significant finding if $p < .05$

Appendix 2.13: Study protocol

University of Glasgow
Institute of Health & Wellbeing

NHS Lanarkshire

PROTOCOL

Title of project: An exploration of mental health related outcome and treatment preferences in treatment seeking older adults

Version no: 3
Date: 30.05.2019

Chief Investigator: Prof Hamish McLeod

Principal Investigator: Ms Rasa Butrimaviciute

Local collaborators: Dr Clive Ferenbach

Contacts

Principal Investigator/ (DClinPsy student)

Ms Rasa Butrimaviciute

Trainee Clinical Psychologist

Mental Health and Wellbeing

1st Floor, Admin Building

Gartnavel Royal Hospital

1055 Great Western Rd

Glasgow, G12 0XH

Tel: 07527881133

Email: 1104425b@student.gla.ac.uk

Chief Investigator/(Academic Supervisor)

Prof Hamish McLeod

Professor of Clinical Psychology, DClinPsy Programme Director & Honorary Clinical Psychologist

Mental Health and Wellbeing

1st Floor, Admin Building

Gartnavel Royal Hospital

1055 Great Western Rd

Glasgow G12 0XH

Tel: 0141 211 3922

E-mail: Hamish.McLeod@glasgow.ac.uk

Field supervisor/(Lead Local Collaborator)

Dr Clive Ferenbach

Senior Clinical Psychologist

Psychological Therapies for Older People

Airbles Road Centre

Airbles Road

Motherwell

ML1 2TP

tel. 01698 210021

E-mail: cliveferenbach@nhs.net

1. Abbreviations

GCP	Good Clinical Practice
NHSL	NHS Lanarkshire
OA, OAs	Older adult, older adults
PIS	Participant information sheet
PTOP	Psychological Therapies for Older People Team

2. Study Synopsis

Full title of project:	An exploration of mental health related outcome and treatment preferences in treatment seeking older adults
Abbreviated study title:	An exploration of outcome and treatment preferences in OA
Study centres:	NHS Lanarkshire University of Glasgow
Duration of study:	Apprx. 10 months* *The aim is for recruitment to last from June 2019 to December 2019, analysis completed by end of January 2020, and submission due February 2020.
Primary objective(s):	To develop and trial a method to elicit mental health treatment and outcome preferences in older adults, and to assess the acceptability of this method to older adults.
Secondary objectives:	To assess treatment and outcome preferences in treatment seeking older adults. To assess whether any differences exist in treatment and outcome preferences between those who are receiving, and those seeking treatment.
Target sample size:	30 participants in total; 15 for treatment receiving group, and 15 for treatment seeking group.
Main inclusion criteria:	Capacity to consent; Seeking or receiving treatment from NHS Lanarkshire PTOP; Psychiatric diagnosis or severity of mental health symptoms that would make a person eligible to attend PTOP.
Main exclusion criteria:	Diagnosis of intellectual disability; Diagnosis of cognitive impairment that could prevent meaningful participation; Mental state disturbance that would prevent meaningful participation (e.g. acute psychosis); Lack of English language skills that would prevent meaningful participation.
Statistical analysis:	Descriptive analysis, grand rank calculations, non – parametric tests exploring differences between means.

3. Timeline of the study

	2019					2020		
Task	Apr-May	May-Jun	Jun-Oct	Nov	Dec	Jan	Feb	Person Responsible*
Ethics application								RB, HMc
Refine card sort task								RB, HMc, CF
Recruitment and data collection								RB, CF
Data analysis (preliminary)								RB, HMc
Data analysis (final)								RB
Report writing and Thesis Submission								RB

** RB: Rasa Butrimaviciute, HMc: Prof Hamish McLeod, CF: Dr Clive Ferenbach*

4. Abstract

Background: Patient centred care, where treatment decisions are partially determined by patient choice and their particular circumstances and wishes, has become a core value of care delivery. There is a growing recognition that incorporating patient decisions can promote patient satisfaction as well as aid treatment effectiveness. Yet, little is known regarding older adult patient preferences.

Aims: The aim of the present study will be to develop a method for eliciting outcome and treatment preferences that is acceptable to an older adult population. The study will investigate what treatment outcomes are most valued by older adults and what treatments they wish to receive when aiming to achieve these outcomes. The study will investigate for difference in preferences for patients in receipt of, as compared to those waiting for treatment.

Methods: Treatment outcomes and methods will be generated using literature review and expert consultation. A card sort task, in which participants will be asked to rank and match treatment outcomes and treatment options, will be used to explore the potential validity of this method of eliciting preferences. Treatment waiting and treatment receiving clients will be recruited from the NHS older adult mental health team.

Applications: The study will provide for further opportunities to investigate patient outcome and treatment preferences within research and clinical settings. Developing an acceptable method of eliciting preferences will allow incorporating patient choice when planning and providing services.

5. Introduction

In recent decades, there has been an expansion of evidence based therapeutic interventions for adult mental health disorders (NICE, 2015). This is now extending to older adult (OA) settings, where treatment effectiveness for this population is increasingly studied, and the evidence base for different modalities of interventions is growing (Luci *et al.*, 2016; McGuire *et al.*, 2014). With more evidence-based approaches being developed, clients could be in a position where a number of clinically suitable treatments could be available to them, allowing room for preference.

According to Chewning and colleagues (2012), a trend is emerging where more people in recent studies prefer to be involved in choosing an appropriate treatment for them, as compared to older studies, where fewer people wished to make an active treatment choice. This trend is also present in OA mental health settings where historically patients were known to be less involved in care planning (Van der Auwera *et al.*, 2017). As the population is ageing, people from the so called 'baby boomers' generation are now entering OA services (Gum *et al.*, 2006). The cohort trend research indicates that this generation is more influenced by the consumer choices culture and may expect to play a more active role when using services (Lim & Yu, 2015).

It has been argued from several perspectives that patient involvement and participation in choosing treatment is important. Respecting and responding to patient wishes is a key principle of person-cantered care (IAOP, 2004). This principle has been increasingly adopted as a quality standard for how patient care within services is provided (Scottish Government, 2010). With an increasing emphasis on 'realistic medicine', whereby cost-benefit decisions are largely influenced by individual patient circumstances, patient involvement through shared decision-making is likely to play a critical role in how services are delivered in the future (Scottish Government, 2018).

Alongside ethical considerations, there is an emerging body of research demonstrating that involving patients in their care may have a number of benefits (Lindhiem *et al.*, 2014). The research into the area indicates that providing patients with a choice over the treatment can significantly improve treatment attendance; therefore indirectly leading to reduced clinical symptoms (Kwan *et al.*, 2010; Swift & Callahan, 2009). Other studies have demonstrated a direct positive effect of collaborative care (i.e. discussing preferences with a patient) on symptom reduction in OAs with depression (Gum *et al.*, 2006), and improved objective functioning in adults with psychosis (Macias *et al.*, 2005). Therefore, it is possible that

considering patient preferences could potentially reduce over-utilisation of services and lead to more effective care.

Although including patient preferences in service delivery appears beneficial, our understanding of factors that influence what is preferred by patients is limited. The existing research has identified that gender, age, ethnicity, past treatment experiences, severity of symptoms and type of disorders all play a role; however, none of these factors have been found to consistently predict a specific treatment being preferred (Eiring *et al.*, 2015). In addition, Eiring et al. (2015) suggest that patient preferences differ from other stakeholders' when treatment outcomes are being considered. For example, a study of depressed patients has found that patient preferences only partially related to the core symptoms of depression suggesting that clinicians' and patients' views towards desired outcomes differ, and that desired outcomes are influenced by patients' subjective experience (Zimmermann *et al.*, 2013).

To date, there has been a stronger emphasis on studying treatment as opposed to outcome preferences (Eiring *et al.*, 2015). The former approach is generally focused on identifying preferred types of treatment (i.e. psychological vs. pharmacological) and mode of delivery (i.e. individual vs. group; Eiring *et al.*, 2015; Gaudreau *et al.*, 2015; Gum *et al.*, 2006), yet does not allow for a thoroughly meaningful understanding of what is important for a treatment seeking patient, or what they may desire to gain from attending services. With less focus on preference variation across specific disorders, there is no consensus on how symptoms of a particular disorder, the cognitive impairments associated with a disorder (as in the case of some patients with anxiety, depression and/or psychotic disorders) or psychosocial circumstances interact with patients' outcome preferences. There may also be particular idiosyncrasies relating to OA population, with some OAs possibly experiencing mental health difficulties in a different way to younger people and more often seeking treatment for physical as opposed to emotional symptoms of depression or anxiety (Overend *et al.*, 2015).

This idea is supported by psychosocial theories of development which indicate that adults and older adults have different psychosocial aims (e.g. Erikson, 1950), and it is possible that this may influence what they hope to gain when seeking services for psychological difficulties (Lim & Yu, 2015). Ratcliffe and colleagues (2017) conducted a general population survey of 1000 of Australians assessing health related quality of life preferences and found, that older adults value independence, and ability to manage their

care and daily living while younger adults placed more importance on symptom reduction, sense of safety and social relationships.

These findings are in line with Socioeconomic Selectivity Theory, that has been used to study economic and social decision making (Carstensen *et al.*, 1999). It proposes that time horizons have an impact on goal selection: when time is perceived as limited, a person is more likely to focus on the here-and-now and selectively choose the goals that have the immediate potential to bring most social and emotional gain. As older adults find themselves at the psychosocial stage that requires some integration and review of the years lived, they may experience a growing sense of time as being limited. Thus, more value may be placed on immediate improvement in their current functioning and affective states. In contrast, younger people who perceive time as open-ended may focus more on exploratory goals, targeted at information gain, skills development, future contact and prospects (Lim & Yu, 2015; Robertson & Swickert, 2018).

In summary, there appears to be a void in the current understanding of what outcomes and treatments are valued by older adults who seek psychological treatment. When patient preferences have been studied, the focus has been largely on the modality (i.e. psychological vs pharmacological) and the delivery type of treatment (i.e. individual vs group) as opposed to treatment outcomes that would be valued by patients. In the research to date, patients are rarely involved in selecting what difficulties are seen as being in need of treatment. In addition, most past research has focused on the general adult population and on specific disorders within this population, resulting in poor understanding of treatment preferences in older adults. As Scotland is taking a 'Realistic Medicine' approach, there is a growing emphasis on what clients hope to gain from seeking services (Scottish Government, 2018). Understanding patient outcome and treatment preferences is likely to help services become more aware of what patients expect when seeking help. This could allow service providers to develop a more consistent approach to incorporating patients' views, thus ensuring a more meaningful approach to planning and delivering mental health care to older adults.

6. Aims

The primary aim of the study will be to develop and trial methods for obtaining outcome and treatment preferences in OAs. This will entail developing a research methodology for investigating outcome and treatment preferences in this population, with a further aim to determine the acceptability of this new method of assessing treatment preferences in OAs.

The study will also aim to investigate outcome and treatment preferences in this population while exploring whether a difference exists in those currently receiving treatment as compared to those waiting for treatment.

6.1. Research questions

5. Is the proposed research methodology acceptable to investigate outcome and treatment preferences in the OA population?
6. What mental health related outcomes are most valued by OAs accessing psychological therapies?
7. What types of treatments are preferred by OAs seeking treatment?
8. Will OAs who are waiting to receive treatment differ in their treatment preferences compared to those already receiving treatment?

7. Plan of investigation

7.1. Participants

Participants will be recruited from NHS Lanarkshire Psychological Therapies for Older People team (PTOP). Patients on the waiting list and the outpatients who are receiving psychological therapies either individually or via a group format will be invited to participate. There is on average 30 new referrals for psychological therapies received by the service each month, with an average of a three months waiting list at any given time. This allows 90 potential participants waiting to receive therapy to be approached about the study at a single time point, with 30 potential participants each subsequent month. The number of potential participants already attending the service will be dependant upon the clinical caseloads and group programme; these vary depending on the service needs and demand.

7.1.1. Inclusion and exclusion criteria

Eligible participants will have capacity to consent to their participation in the study and will be seeking or receiving treatment from PTOP. They will present with a psychiatric diagnosis and/or symptoms of any mental health condition that is of severity to make them eligible to attend the service. PTOP service typically accepts referrals of people who are 65 years or older, but younger patients presenting with the difficulties that are characteristic of treatment seeking OA population may also be seen within the service and will be included in the study. Participants will be excluded from the service if they had a diagnosis of intellectual disability (ID) or cognitive impairment (such as diagnosis of dementia) that would prevent meaningful participation. They will also be excluded if they were attending the service due to mental state disturbance that would prevent meaningful participation

(e.g. acute psychosis). Participants whose command of English requires an interpreter will be excluded from the study. Participants will also be excluded, if they presented with risk to self and/or others during their contact with the researcher. In such case, PTOP risk management protocol will be followed.

7.2. Recruitment procedures

Participants will be recruited from the pool of patients currently on the NHS Lanarkshire PTOP waiting list for psychological therapies and those already attending for psychological treatment, with an aim to recruit an equivalent number from each group. The recruitment will stop once the target sample of 30 participants in total is achieved, 15 in each group.

Patients who are currently on the waiting list will be contacted by post to confirm their place on the waiting list alongside some brief information (study leaflet) about the study, explaining that they will be contacted by telephone shortly to ascertain whether they are interested in receiving further information. Following this, an assistant psychologist at PTOP, who is not linked to the research, will phone and ascertain whether individuals wish to receive further written information, and whether they consent to being contacted via telephone by the researcher. Further information about the study will then be sent, including the participant information sheet (PIS) and consent form. Participants will then be contacted by the researcher, to discuss the study in more detail. At this occasion, their eligibility criteria will be checked, the initial questions about the study will be answered and a suitable time will be arranged to discuss the study in more depth, obtain the written consent and carry out study procedures. Patients who are waiting to start a therapeutic group will be invited to participate at pre-assessment interview, if they are to start attendance at the group in due course.

Patients currently receiving individual or group therapy will be informed of the study by the treating clinicians. Those who expressed interest in taking part will then be provided with further details about the study (PIS and consent form), and asked whether they would be willing for the researcher to contact them to discuss the study. The researcher will then telephone those who agreed. During this contact, eligibility criteria will be checked, initial questions about the study will be answered and a suitable time arranged to discuss the study in more detail, obtain written consent and carry out research procedures.

PTOP staff will initially screen patients already attending at the service for eligibility to participate. To ensure the consistency in screening for inclusion/exclusion criteria of patients already attending the service, clinicians will be asked to consider each case on their case load individually, in line with the list of criteria. Clinicians will be asked to exclude the clients, whose psychology file states a diagnosis of LD or dementia. They will be asked to use their clinical judgement to exclude those patients who lack capacity at a time or are otherwise unable to meaningfully engage with the study (e.g, are experiencing acute psychotic episode), and/or whose language is other than English. For those on the waiting list, the eligibility for the study will be assessed by PTOP staff who will be asked to screen the referral information for inclusion/exclusion criteria and contact only those patients, who meet the criteria. The inclusion/exclusion criteria will then be checked at the initial telephone contact with the researcher. Clinical judgement will be used to ensure patients' capacity to participate. To ensure accuracy, the eligibility criteria will also be checked as further part of the process of acquiring demographic information for the study (see Section 7.4.1.). Patients will then be excluded from participation, if they met any of the exclusion criteria listed previously.

7.3. Design

This will be a feasibility study using a cross-sectional design aiming to ascertain the acceptability of the card sort task to OAs and to lay ground for further research into this methodology and area of investigation. Outcome and treatment preferences will be ranked by OA participants and these rankings will be analysed between subjects to compare preferences in those waiting for treatment vs. those already receiving treatment.

7.4. Study procedure

7.4.1. Demographic data

As part of overall consent for the study, permission will be sought from participants to collect their demographic data that has been previously shown to play a role in treatment preferences. This will include information on age, gender, main presenting problem/diagnosis, history of previous involvement with mental health services, previous and current, if applicable, receipt of treatment, and the type of treatment received. Permission will be sought to obtain this information either directly from their mental health record or by speaking to clinicians involved in their care (e.g. clinical psychologists, psychiatrist, GP, CPN).

7.4.2. Treatment and outcome preferences

A card sort task is a dynamic method previously used to elicit and organise symptoms of relapse in patients with psychosis (Birchwood *et al.*, 2000). It has potential as a meaningful and acceptable method for eliciting attitudes and preferences for treatment in patients. This method will be developed and its use and acceptability to older adult population will be verified as part of the current project.

Development of the task

Phase 1

A literature review, potentially as part of a larger systematic review for the project, will be carried out reviewing relevant studies that focus on qualitative and quantitative descriptions of mental health symptoms and outcome preferences in OAs. Based on the existing literature, a number of problems related to mental health symptoms and functioning will be identified and listed as potential treatment outcomes for patients. The list will be reviewed and edited by a group of clinicians with experience and expertise of OA population presenting to mental health services. Furthermore, a list of treatment options will be generated by the same expert group. The example of potential treatment and outcome preferences is presented below.

Sample treatment outcomes	**Sample treatments**
Symptom focused: - Improve mood - Increase energy - Improve sleep - Reduce worry - Manage physical signs of anxiety (e.g. breathlessness, racing heart, sweating)	**Psychoeducation:** - Self-help books - Internet based information - Leaflets from GP practice
Functional: - Increase activity - Extend social circle - Improve quality of relationships	**Psychotherapies:** - Cognitive Behavioural Therapy (CBT) - Interpersonal Therapy - Acceptance and Commitment Therapy (ACT) - Mindfulness
	Skills based: - Anxiety/arousal management - Assertiveness training

In previous research using similar methods, the number of options ranged from 23 (Eiring *et al.*, 2016) to seven (Milte *et al.*, 2014) per theme of investigation. A previous study into OA population employing similar methods had used twelve outcomes in their ranking task (Ratcliffe *et al.*, 2017). The final number of outcome and treatment options will be determined by the clinical group in collaboration with the principal investigator, based on their knowledge of this population and treatments available.

Phase 2

The alignment of the objective (expert and literature generated) and subjective (patient generated) outcome preferences will be explored and objective outcome preferences verified during Phase 2. Alongside the expert generated outcomes, participants will be provided with blank cards to note any outcome preferences that they consider missing. They will be asked to use newly generated outcomes as part of their card sort task. Similarly, participants will be instructed to remove any outcomes that they considered irrelevant to them, in order to align the list with their subjective experience.

7.4.3. Card sort task

Based on preliminary testing with non-clinical subjects it is anticipated that the task will take 30 to 60 minutes to complete (depending on how many target problems and preferred treatments participants select). Given that this study is piloting the measure, we will record the completion times so that these can be used to refine and improve the card sorting task protocol for future studies.

Part 1

Participants will be presented with a number of cards, each of which containing a single treatment outcome as exemplified above. Participants will be asked to read all the cards and will be provided with blank cards to generate any missing outcomes, if necessary. They will then be asked to sort the cards, from most important outcomes for seeking treatment to least important. They will be given an option to remove any cards that they did not consider relevant, these will be assigned a score of zero in later analysis. Subsequently, participants will be provided with a list of therapeutic approaches as exemplified above, with a brief description of each treatment on a separate information sheet. As for the treatment outcomes, they will be asked to rank the available treatments in terms of preference, removing any options that they would rather not receive at all. These will be assigned a score of zero in planned analyses.

Part 2

For the second part of the study, participants will be asked to rank the treatment options for each outcome that they identified as important to them. As there is currently no research that has studied OA treatment preferences for each outcome, the aim will be to explore any patterns in participant choices. Participants will be instructed to sort the treatment options from those considered most helpful to least helpful, for each desired treatment outcome. This is likely to involve a relatively small number of outcomes considered important to each participant. The treatment options to be ranked will depend on the number and type of outcomes chosen by each participant during Part 1 of the task. Based on pilot testing it is estimated that three minutes will be needed to rank treatment options for a single chosen outcome. To ensure that the procedure would last no longer than the maximum set time of one hour, a stop rule will be set advising participants that no more than their top ten outcomes need to be considered.

7.4.4. Acceptability of the study

The acceptability of the study to the OA population will be determined by the study uptake, and identification of any issues that may arise during the course of the study and the participants' engagement with the card sort task. The latter will be assessed by researcher's observation of participants' ability to understand and follow the instructions for the task, the time required to complete the task, and the level of support required (e.g. frequent clarification, prompting to stay on task). In addition, participants will be asked to complete a brief study satisfaction scale surveying their views towards the process of the card sort task and the procedural aspects of the study participation. Participants will be encouraged to provide further feedback for any negative ratings to enable further development of the study methodology and the card sort task.

7.5. Data analysis

All data will be collected and stored using a Statistical Package for Social Sciences (SPSS). Descriptive information regarding the sociodemographic characteristics of the sample will be collected and summarised.

Part 1

Descriptive analysis will be carried out to investigate most to least preferred mental health outcomes and types of treatment across the sample. These will be ranked where the higher ranks to the higher ordered cards and the lower ranks to the lower ordered cards will be assigned. Any cards that were not used, as well as any additional cards with patient

generated outcomes will be assigned a score of zero. The grand ranks for each outcome and for each treatment option will then be calculated across the sample.

Part 2

To explore participants' treatment preferences for each individual outcome, further descriptive analysis will be conducted looking specifically at treatment rankings for each identified problem. The grand ranks of treatment options for each treatment outcome that has been ranked by more than one participant will be calculated. When a particular treatment outcome was considered by only one participant, the rankings of treatment options, as identified by that participant, will be reported.

Part 3

Further statistical analysis will be carried out to explore if any differences exist in the data gathered during Phase 1 and 2, between those receiving and those waiting to receive treatment. The differences in mean ranks across the two groups will be explored using a non-parametric test (e.g. Mann-Whitney U).

7.6. Justification of target sample size

As this is a feasibility study, the sample size recommendations are tentative. A target sample size of 30 is likely to be sufficient to address the questions regarding feasibility of the study and to test the card sort task as a method to elicit preferences. This number of participants has been previously recommended for feasibility studies (Browne, 1995). Eiring et al (2016) reported a similar analysis of ranked preferences, and comparison of preferences across two groups (Type 1 Bipolar and Type 2 Bipolar) using a sample of 22 participants. Milte et al (2014) used a sample of 21 participants to produce frequency counts of 15 quality of life descriptors across the sample. Therefore, a sample of 30 is considered to be sufficient to investigate preferences in the present study.

7.7. Settings and equipment

The study procedure will take place within the NHSL PTOP setting, and a clinical room will be booked for data collection.

Equipment	Source
Recruitment: - Information and consent packs - Return envelopes and stamps	Printing costs Stationary and postage costs
Card sort task: - A set of cards	Printing and laminating costs

8. Health and safety considerations

Additional details relating to health and safety can also be found in the Appendix A.

8.1. Researcher safety

The data collection will take place on a NHSL site and within the NHSL working hours. Other staff will be available in the building. Procedure for using panic alarm will be followed and a panic alarm will be carried by the researcher.

8.2. Participant safety

The facilitation of the card sort task will take place within the NHSL settings which are designed to be compatible with the health and safety regulations of the health board. Building health and safety regulations and procedures will be followed.

There is a small possibility that the topic of investigation could be emotive to participants. They will be informed that they may take a break or exit the data collection process at any point. The researcher has been trained in dealing with mental health related distress and will be able to assess for any presenting risk.

The information about the next of kin is typically held on file for patients accessing and using the service and the admin support will be available to access this information in case of physical health emergency.

9. Ethical considerations

The project will be submitted to NHS REC for approval. Management approval from NHSL R&D will be sought following reception of ethical approval. Detailed information about the study will be provided to participants and the explicit consent will be sought. Their capacity to consent and participate in the study will be continuously assessed through the duration of contact with the PTOP and/or the researcher, and in line with the Adults

with Incapacity (Scotland) Act 2000. If there is any evidence that a participant may lack capacity, their participation will be terminated and a referral to a psychiatrist for detailed assessment will be made. If, during their contact with the researcher, participants presented with active risk to themselves and/or others, PTOP risk assessment and management protocol will be followed. All data will be anonymised, with participant ID being assigned. Once anonymised, all data will be stored in locked filing cabinets or password protected databases.

10. Data handling

10.1. Data Storage, Access & Confidentiality

Signed consent forms and paper questionnaires, will be securely stored in locked filling cabinets within the NHS Lanarkshire premises, and will be assessed for secure destruction one year after the completion of the study.

Each participant will be assigned a unique case number to ensure anonymity, and data will be then coded and entered in a password encrypted SPSS file, in line with the Data Protection Act (2018), Freedom of Information Act (2000), the NHS Confidentiality Code of Practice on Protecting Patient Confidentiality (2002) and the University of Glasgow data protection, confidentiality and research ethics guidelines.

Only the chief (Prof Hamish McLeod) and principal (Rasa Butrimaviciute) investigators will have access to research data.

10.2. Record retention

Raw data will be kept until the qualification has been awarded (usually no longer than one year). Anonymised electronic files will be kept for ten years from publication, in line with the relevant national, NHS and University of Glasgow policies.

10.3. Study monitoring and auditing

Study site file will be maintained by the research team. The study may be selected randomly for audit from Research & Development database.

11. Insurance and indemnity

It is expected that the study will be sponsored by NHS Lanarkshire. The project has also been approved by University of Glasgow and given permission to proceed to ethics.

12. Funding

Costs will be minimal and mostly constrained to obtaining paper and pen resources. A detailed summary is provided in Appendix B.

13. GCP Compliance and Protocol Deviations

13.1. Good Clinical Practice (GCP)

This study will be conducted in accordance with the protocol, the sponsor's standard operating procedures, national regulatory requirements, provisions of the relevant ethics committees and GCP principles.

13.2. Protocol Deviation Reporting

A protocol deviation is any departure from the approved protocol. All deviations will be recorded and reported to the sponsor, who will decide whether or not to authorise such deviations (e.g. if the deviation is necessary to eliminate an immediate hazard).

14. Practical applications

The study has a direct aim to investigate patient preferences for treatment. As such, the results are expected to inform what services older people wish to receive and how services can be shaped to suit their needs. A procedure for evoking patient treatment preferences prior to entering treatment will also be piloted. This has a potential to aid shared-decision making when delivering services. As discussed previously, considering patient preferences is linked to improved clinical outcomes, service engagement, and is in line with current policy trends for service planning.

15. Dissemination of findings

This research is the major research project of the principal investigator which is a requirement of the Doctorate in Clinical Psychology. The final thesis will be available through the University of Glasgow's Library and will be published on the University's Enlighten service which is accessible to the wider public to promote research dissemination. We also hope to publish the research in an appropriate journal.

16. References

Birchwood, M., Spencer, E. & McGovern, D. (2000). Schizophrenia: early warning signs. *Advances in Psychiatric Treatment, 6*, 93 - 101.

Browne, R. H. (1995). On the use of a Pilot Sample for Sample Size Determination. *Statistics in Medicine, 14*(17), 1933-1940.

Carstensen, L. L., Isaacowitz, D. M. & Charles, S. T. (1999). Taking time seriously - A theory of socioemotional selectivity. *American Psychologist, 54*(3), 165-181.

Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A. & Makoul, G. (2012). Patient preferences for shared decisions: A systematic review. *Patient Education and Counseling, 86*(1), 9-18.

Eiring, O., Landmark, B. F., Aas, E., Salkeld, G., Nylenna, M. & Nytroen, K. (2015). What matters to patients? A systematic review of preferences for medication-associated outcomes in mental disorders. *Bmj Open, 5*(4).

Eiring, O., Nylenna, M. & Nytroen, K. (2016). Patient-Important Outcomes in the Long-Term Treatment of Bipolar Disorder: A Mixed-Methods Approach Investigating Relative Preferences and a Proposed Taxonomy. *Patient-Patient Centered Outcomes Research, 9*(2), 91-102.

Erikson, E. (1950). *Childhood and Society*. New York: W. W. Norton & Compan.

Gaudreau, C., Landreville, P., Carmichael, P.-H., Champagne, A. & Camateros, C. (2015). Older Adults' Rating of the Acceptability of Treatments for Generalized Anxiety Disorder. *Clinical Gerontologist, 38*(1), 68-87.

Gum, A. M., Arean, P. A., Hunkeler, E., Tang, L. Q., Katon, W., Hitchcock, P., . . . Investigators, I. (2006). Depression treatment preferences in older primary care patients. *Gerontologist, 46*(1), 14-22.

IAOP. (2004). *What is Patient-Centred Healthcare? A review of Definitions and Principles*. International Alliance of Patients' Organizations (IAOP).

Kuhnigk, O., Slawik, L., Meyer, J., Naber, D. & Reimer, J. (2012). Valuation and Attainment of Treatment Goals in Schizophrenia: Perspectives of Patients, Relatives, Physicians, and Payers. *Journal of Psychiatric Practice, 18*(5), 321-328.

Kwan, B. M., Dimidjian, S. & Rizvi, S. L. (2010). Treatment preference, engagement, and clinical improvement in pharmacotherapy versus psychotherapy for depression. *Behaviour Research and Therapy, 48*(8), 799-804.

Lim, K. T. K. & Yu, R. (2015). Aging and wisdom: age-related changes in economic and social decision making. *Frontiers in Aging Neuroscience, 7*.

Lindhiem, O., Bennett, C. B., Trentacosta, C. J. & McLear, C. (2014). Client preferences affect treatment satisfaction, completion, and clinical outcome: A meta-analysis. *Clinical Psychology Review, 34*(6), 506-517.

Luci, K., Jacobs, L. & Hagemann, L. (2016). ACT for Older Adults: Group Therapy for Fostering Psychological Flexibility in Older Adults. *Gerontologist, 56*, 59-59.

Macias, C., Barreira, P., Hargreaves, W., Bickman, L., Fisher, W. & Aronson, E. (2005). Impact of referral source and study applicants' preference for randomly assigned service on research enrollment, service engagement, and evaluative outcomes. *American Journal of Psychiatry, 162*(4), 781-787.

McGuire, B. E., Nicholas, M. K., Asghari, A., Wood, B. M. & Main, C. J. (2014). The effectiveness of psychological treatments for chronic pain in older adults: cautious optimism and an agenda for research. *Current Opinion in Psychiatry, 27*(5), 380-384.

Milte, C. M., Walker, R., Luszcz, M. A., Lancsar, E., Kaambwa, B. & Ratcliffe, J. (2014). How important is health status in defining quality of life for older people? An exploratory study of the views of older South Australians. *Applied health economics and health policy, 12*(1), 73-84.

Overend, K., Bosanquet, K., Bailey, D., Foster, D., Gascoyne, S., Lewis, H., . . . Chew-Graham, C. (2015). Revealing hidden depression in older people: a qualitative study within a randomised controlled trial. *Bmc Family Practice, 16*.

Ratcliffe, J., Lancsar, E., Flint, T., Kaambwa, B., Walker, R., Lewin, G., . . . Cameron, I. D. (2017). Does one size fit all? Assessing the preferences of older and younger people for attributes of quality of life. *Quality of Life Research, 26*(2), 299-309.

Robertson, S. M. C. & Swickert, R. J. (2018). The stories we tell: how age, gender, and forgiveness affect the emotional content of autobiographical narratives. *Aging & Mental Health, 22*(4), 535-543.

Scottish Government (2018). *Practising Realistic Medicine.* Edinburgh: Scottish Government.

Scottish Government (2010). *The Healthcare Quality Strategy for NHS Scotland*. Edinburgh: Scottish Government.

Swift, J. K. & Callahan, J. L. (2009). The Impact of Client Treatment Preferences on Outcome: A Meta-Analysis. *Journal of Clinical Psychology, 65*(4), 368-381.

The National Institute for Clinical Excellence (NICE) (2015). *Common Mental Health Disorders: The NICE Guideline on Identification and Pathways to Care.* Retrieved from https://www.nice.org.uk/guidance/cg123.

Van der Auwera, S., Schomerus, G., Baumeister, S. E., Matschinger, H. & Angermeyer, M. (2017). Approval of psychotherapy and medication for the treatment of mental disorders over the lifespan. An age period cohort analysis. *Epidemiology and Psychiatric Sciences, 26*(1), 61-69.

Zimmermann, T. M., Clouth, J., Elosge, M., Heurich, M., Schneider, E., Wilhelm, S. & Wolfrath, A. (2013). Patient preferences for outcomes of depression treatment in Germany: A choice-based conjoint analysis study. *Journal of Affective Disorders, 148*(2-3), 210-219.