THE UNIVERSITY OF HULL

Exploring Lived Experiences of Health and Dementia through Poetic Inquiry

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

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Acknowledgements

I would like to say a big thank you to every person who submitted a poem for the study. I appreciate the time and effort you took to craft each insightful and beautiful line. Thank you for your openness in sharing your experiences with me and with anyone who might read your anthology. It has been a privilege reading your words and I hope that this project might shed some light on how we might be able to foster hope in dementia discourses.

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Overview

This portfolio thesis consists of three parts. Part one is a systematic literature review, part two is an empirical paper and part three forms the supporting appendices. Together, they offer an exploration of the use of poetic inquiry in health research, particularly in dementia research.

Part One: A systematic literature review that explored the procedures, rationales, strengths and limitations associated with the use of poetic inquiry in health research. The review identified 12 articles. Using a metamethod approach, it was found that poetic inquiry was used during data collection, analysis and dissemination in health research. A narrative synthesis highlighted the added value and limitations of using these methods, which are discussed in relation to their implications for wider use.

Part Two: An empirical study that explored the meaning and experience of hope by people living with dementia. People with dementia submitted self-written poems on hope through voluntary sampling. Their poems underwent thematic analysis, and three main themes are reported in the findings. The study highlighted that hope serves a unique and protective function for people with dementia, that people with dementia have the capacity to experience hope, and that social interaction plays an important role in the experiences of hope by people with dementia. Implications of these findings in relation to future research and dementia care are discussed.

Part Three: Appendices providing supporting documentation for the systematic literature review and empirical paper. Reflective and epistemological statements are also provided.

Total word count (including tables, figures, references and appendices): 34052

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Part One: Systematic Literature Review

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Journal of Arts and Health

Please see Appendix A for submission guidelines

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Exploring the Use of Poetic Inquiry in Health Research: A Systematic Literature Review

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Exploring the Use of Poetic Inquiry in Health Research: A Systematic Literature Review

Abstract:

There are established methodological guidelines and benefits associated with the use of poetry in research within fields such as sociology. There is limited understanding of its use in health research, thus, the current review investigated the procedures, strengths, and limitations of the use of poetry across this discipline. Key databases were systematically searched for health-based research that used poetry as a methodological tool. From the 12 papers included in the review, authors used poetry during data collection, analysis, and dissemination. The added value, limitations and implications for wider use are considered.

Keywords: poetic inquiry; health research; qualitative research; art-based methods

Introduction

Qualitative research traditionally involves the analysis of data accumulated through interviewing and survey methods (Percy et al., 2015; Willig & Rogers, 2017). The findings of said analyses are frequently illustrated through quotes to represent participant voices (Furman, et al., 2007, p. 313). Since its inception in the 1920s, qualitative research has aided the exploration of subjective experiences, the depth of which is typically missed by quantitative methodologies (Leavy, 2020). Criticisms of traditional qualitative research, however, highlight an implicit elitism embedded within it. Participant experiences are retold through complex terminologies that make discoveries from research inaccessible to audiences beyond academia (Boydell et al., 2012; Knowles & Cole, 2008; Leavy, 2020). There are also concerns that participants' stories are filtered through this re-telling, running the risk of dulling the rich descriptions that the qualitative paradigm aims to provide (Leavy, 2020).

The need to holistically represent participant experiences and diversify audiences for data dissemination has influenced the emergence of arts-based research (ABR), particularly in education and sociology (Boydell, 2011a, 2011b; Butterwick, 2002; Cox et al., 2010; Eisner, 1981; Fraser & al Sayah, 2011; Hesse-Biber & Leavy, 2008; Knowles & Cole, 2008; Leavy, 2020; Rossiter et al., 2008; Savin-Baden & Major, 2013). ABR incorporates traditional qualitative research methods with creative practices at any or all stages of research, e.g., in data collection, analysis and dissemination (Knowles & Cole, 2008; Leavy, 2020). Creative practices used in ARB include visual arts (e.g., photography), performance arts (e.g., theatre) and literary arts (e.g., poetry) (Belliveau, 2006; Boydell & Gladstone et al., 2012; Boydell & Jackson et al., 2012; Knowles & Cole, 2008; Conrad, 2006). Concerns about ABR relate to considerations about the ownership of produced art (Boydell et al., 2012) and a lack of exploration of the emotional impact of engaging in ABR on participants (Fraser

& al Sayah, 2011). On the other hand, ABR is valued as a gateway through which participants can share their experiences beyond the realm of literal language, as well as improve and diversify audience engagement (Furman et al., 2006; Kontos & Naglie, 2007).

Poetry, especially, has been appraised as an effective method for exploring highly complex subjective experiences, such as hope (Campo, 2003; Shapiro, 2004; Bishop & Willis, 2014). Poetry in ABR is often termed poetic inquiry and encompasses the use of poetry during data collection, analysis and/or dissemination (Knowles & Cole, 2008; Leavy, 2020; Bishop & Willis, 2014). Drawbacks of poetic inquiry include a lack of a shared understanding of its procedures outside of education and sociology research where its use is more established (Leavy, 2020). In particular, studies that use poetic inquiry make up the smallest proportion of articles assessed in literature reviews that explore the use of ABR in health research (Knowles & Cole, 2008; Leavy, 2020). This is potentially due to the limited use of poetic inquiry in health research at the time of these reviews.

As such, an exploration of current developments in how and why poetic inquiry can be used in health research is needed to ascertain if the benefits of poetic inquiry in other disciplines are transferable to health research (Boydell & Gladstone et al., 2012; Fraser & al Sayah, 2011). Investigating this prospect would expand methods of exploring the health needs and experiences of patients, which can be used to inform health care practices. Thus, the current systematic literature review investigated the use of poetic inquiry to explore subjective experiences of health. The following questions were addressed: (1) what methods are employed in health-based poetic inquiry? (2) what rationales are evident when engaging in health-based poetic inquiry? (3) what strengths are evident when engaging in health-based poetic inquiry? and (4) what limitations are evident when engaging in health-based poetic inquiry?

Methods

Search Strategy

CINAHL Complete and MEDLINE were searched to access nursing, medicine, and allied health-based literature. APA PsycArticles and APA PsycINFO were searched to access mental health literature. Academic Search Premier, a multidiscipline database, was searched to capture any relevant journals not accessible through the health-specific databases. These databases were accessed through EBSCO. Reference lists and citations of all included articles were reviewed to identify any relevant literature not obtained through the database search. This review included papers published up to and including November 2021, which was when the literature search was carried out.

Search Terms

Preliminary scoping of the literature and reviews on ABR outside of health research supported the identification of keywords prevalent in articles relevant to the review topic. These were used to develop the search terms, a process which was supported by a Clinical Librarian at the University of Hull. The final search terms were:

(poet* or poem*)

AND

(research or data or study or qualitative)

AND

(health or care)

The preliminary scoping search identified that the word, poetry, was used in the titles of all relevant articles. Thus, the first group of search terms (i.e., poet* or poem*) was applied to the title of articles to narrow down the search. The asterisk Boolean operator ensured that articles that used alternative forms of the word were captured. To increase the quality of articles retrieved, and to ensure articles were in a language accessible to the author, two limiters were applied to the database search to ensure that articles were from peer-reviewed academic journals and were available in English.

Screening and Selection Strategy

After the removal of duplicates, 670 articles were retrieved from the database search. The articles were screened by their titles and abstracts to ascertain their relevance to the review. The remaining 44 articles after this were reviewed in full against the inclusion and exclusion criteria (detailed in Table 1).

Table 1

Inclusion and Exclusion Criteria Applied to Articles

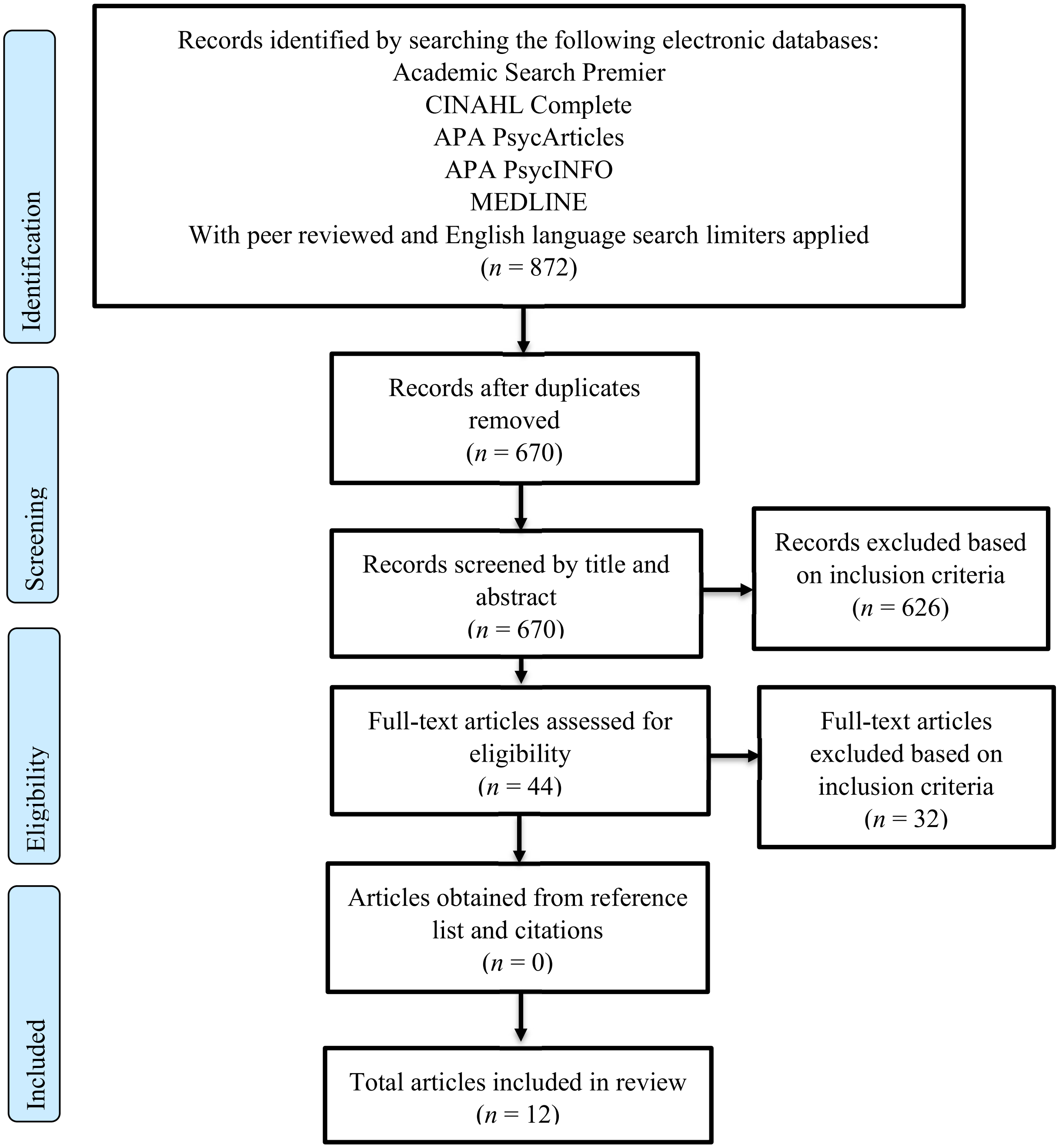
Inclusion criteria	**Exclusion criteria**	**Rationale**
Qualitative studies.	Quantitative studies. Reflective Journal.	To ensure articles stayed centred on exploring subjective experiences and therefore remained relevant to the review question.
Explored the subjective experiences of	Explored the subjective experiences of the researcher.	To keep the review clinically relevant and broaden understandings of how poetic

participants.		inquiry can be used to explore the experiences of participants to support health care practices.
Explored participants' experiences of physical and/or mental health. This included the experiences of a specific health issue, e.g., cancer, or experiences of health in general.	No exploration of health issues or experiences of health.	To ensure that articles were relevant to the review and stayed focused on the use of poetic inquiry in health research. Both mental and physical health were investigated as exploring them in isolation would not have retrieved enough articles for a comprehensive literature review.
Authors clearly stated that they used poetry at any or all stages of the study, such as in data collection, data analysis and data dissemination.	Authors did not clearly state that they used poetry at any point of the study.	To ensure that articles were relevant to the research questions.

Using the same criteria in Table 1, reference and citation lists of all included papers were hand searched, although no additional articles were found this way. The most common reasons for exclusion were articles being reflective journals and the use of researcher-written poetry as data. Figure 1 outlines a summary of how the screening and selection process produced 12 articles for review.

Figure 1

PRISMA Flow Diagram (based on Moher et al.,2009) Demonstrating the Article Screening and Selection Process



Data Extraction

A data extraction tool was created, with collected data relating to the procedures of poetic inquiry used (drawn from method sections of included papers) and the associated rationale, strengths, and limitations (drawn from the introduction and discussion sections of included papers) (see Appendix B for a data extraction example). The data extracted informed quality assessment and were synthesised to address the review questions.

Quality Assessment

The National Institute for Health and Care Excellence (NICE, 2012) quality appraisal checklist for qualitative studies was utilised (outlined in Appendix C). This was selected as it is an established tool specifically designed to be applicable to a range of qualitative research. It offered the opportunity to evaluate pertinent characteristics of methodological quality and was useful in addressing the first review question. To establish inter-rater reliability of the quality assessment, 17% of the included studies were randomly selected and rated by another researcher as a completely dual review process (Stoll et al., 2019) was not possible due to time constraints. There was a discrepancy in the ratings for an item on one of the papers regarding clarity of analysis, and this was discussed until an agreement was reached. Quality assessment scores were not implemented as exclusion criteria due to the limited number of final studies. The scores did, however, provide valuable insight into the quality of methods used to engage in when health-based poetic inquiry.

Data Synthesis

A metamethod approach (Paterson et al., 2001) was taken as the review aimed to determine and evaluate current procedures of health-based poetic inquiry. Metamethod is the study and evaluation of research methods and procedures (Paterson et al., 2001; Zhao, 1991). It aims to synthesise and critically evaluate pre-existing data to develop new insights and support the development of procedural rules for research (Paterson et al., 2001). Narrative synthesis is an analytical method that provides the opportunity for developing new insights within metamethod studies, as it involves the weaving of narratives surrounding a subject matter to create new understandings (Popay et al., 2006). It has also been useful in the study of ABR in education research (Coemans & Hannes, 2011). As such, a metamethod study using narrative synthesis was adopted for this review. Below is a summary of the narrative synthesis undertaken, following guidance by Popay et al., (2006):

1. Grouping: after the data extraction process, the final articles were categorised into distinct groups based on the specific method of poetic inquiry they utilised. This helped to answer the first review question.
2. Thematic Analysis: extracted data relating to the rationales, strengths and limitations of poetic inquiry were repeatedly read and succinctly described using codes. Codes that related to each other in meaning were organised into distinct themes, which were further organised under priori groupings relating to the rationales, strengths and limitations and helped to answer the second, third and fourth review questions.
3. Narrative Weaving: the relationships between each theme, as well as how these themes were related to and were affected by the specific methods of poetic inquiry used were investigated to develop new insights. Findings from the methodological quality assessment were also examined in relation to how they influenced the strengths and limitations of poetic inquiry.

Results

Overview of Included Studies

A total of 12 qualitative studies were included in the review, all of which were published between 2005 and 2021. Health issues explored were psychosis (*n*=1), general mental health (*n*=1), addiction (*n*=1), dementia (*n*=2), terminating pregnancies for medical reasons (TFMR; *n*=1), freebirthing (*n* =1), cancer (*n* =3), general physical health (*n* =1), and cystic fibrosis (*n*=1). The geographic distribution of these studies where: United Kingdom (*n*=7), United States (*n*=2) Canada (*n*=2) and Portugal (*n*=1).

Quality of Included Studies

Most of the studies (*n*=11) were of high quality and received a "++" rating, having met all or most of the checklist criteria. One study was found to be of adequate quality with a rating of "+", having met most of the checklist criteria (Shinebourne, 2012). Shinebourne (2012) did not receive a "++" due to a lack of participant involvement in the data analysis and a lack of detailed researcher reflexivity to address the potential effects of researcher characteristics on data analysis. Appendix D provides ratings on all checklist items for included papers.

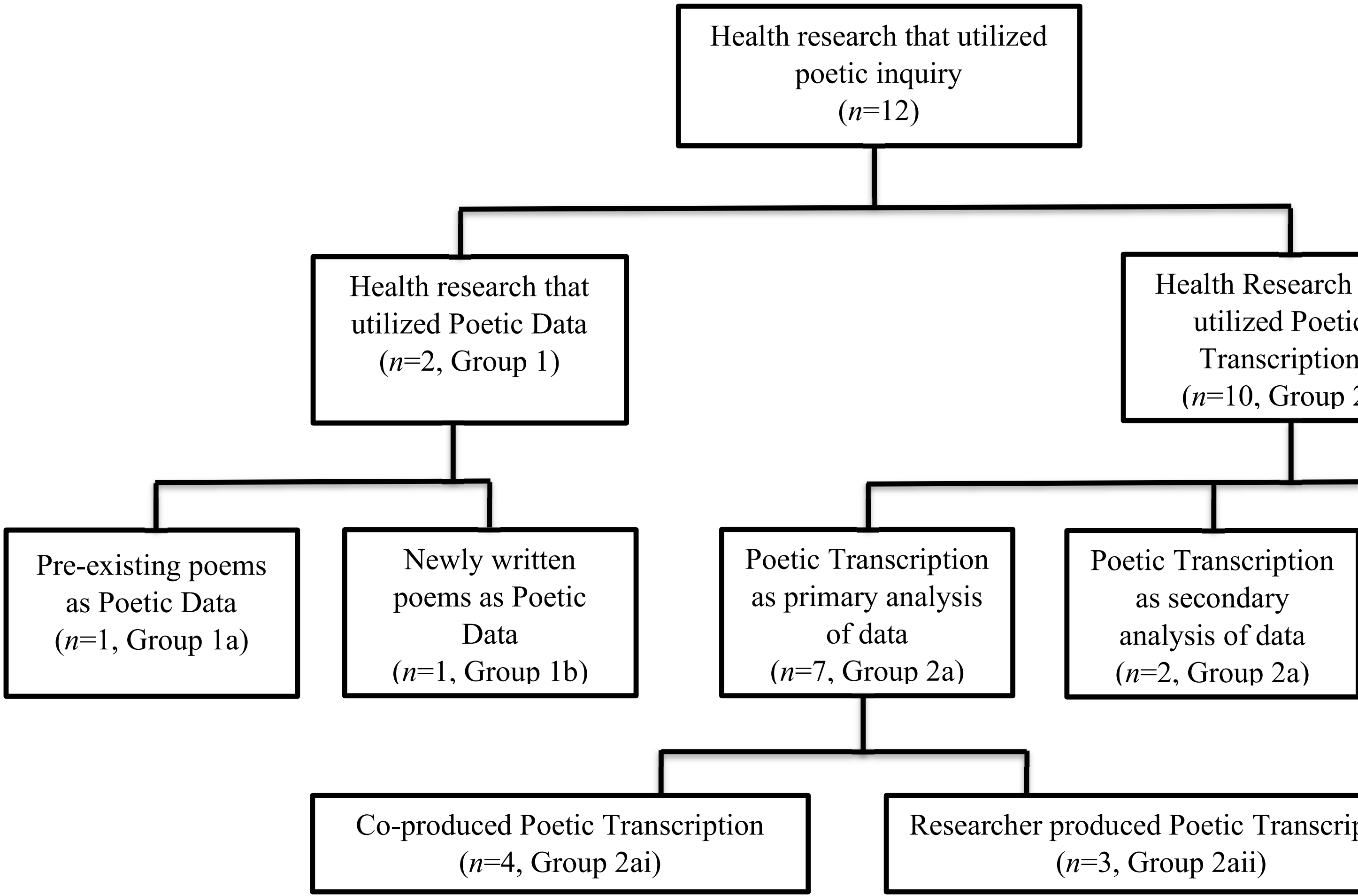
Data Synthesis

Grouping

Figure 2 is a diagram illustrating the different groups of studies based on the method of poetic inquiry they used. Tables 3 and 4 display descriptive characteristics of the studies. The findings of the included studies are not reported in the tables as that is not the focus of this review, although the richness of findings was considered in the quality assessment.

Figure 2

A Diagrammatic Illustration of the Grouping of Included Studies as Organised by Methods of Poetic Inquiry



Two main methods of poetic inquiry were identified. See Table 2 and Table 3 for all studies in Group 1 and Group 2, respectively, along with details about their research aims, design, methods, and cited epistemologies. The first group was poetic data (Group 1), which refers to the use of poems as research data. In this group, pre-existing collections of poems (Group 1a; Clark-McGhee & Castro, 2015) or newly written participant poems (Group 1b; Carvalho et al., 2021) were collected as research data.

The second method of poetic inquiry was poetic transcription (Group 2). This refers to the process of creating poems from the words of participants as gathered through traditional techniques, namely interviews (*n*=7), written narratives *(n*=2) and focus groups (*n*=1). Some poetic transcription methods created poems in a specified style i.e., the creation of "I" poems from the Listening Guide Method (LGM) and Voice Centred Relational Method (VCRM). "I" poems were created by isolating statements beginning with "I" from the data and organising these into prose and stanzas (e.g., McKenzie, 2021; Johnson et al, 2021). Others formed free verse poems, which were created by structuring verbatim participant sentences in prose and stanza. Most free verse poems only used words and sentences from participants. However, words from the researcher, relevant literature and the Bible were sometimes incorporated into poems as a means of interpretation (Kooken et al., 2007; MacDonald, 2017).

Group 2 could be further dived into three subgroups based on the purpose of poetic transcription. In Group 2a, poetic transcription was conducted as part of the primary analysis of data. Group 2a could be further divided into two subgroups. In Group 2ai, participants were involved during the poetic transcription process (McKenzie, 2021; Madill & Hopper, 2007; Stenhouse, 2014), and in Group 2aii, there were not (Duffy & Aquino-Russell, 2007; Guy, 2018; Johnson et al, 2021; Souter, 2005). In Group 2b (*n*=2), poetic transcription was a method of secondary analysis of pre-existing data gathered through interviews (Kooken et al., 2007; Shinebourne, 2012). In Group 2c, poetic transcription was used to disseminate data, as opposed to analysing data (MacDonald, 2017). That is, the data was analysed only through traditional means, with the poem transcribed being presented at the end of the report as a summary of the data. This is the only study that presented one poem to encompass the data from all participants, as opposed to creating one poem per participant as frequently done during poetic transcription.

The quality assessment ratings of all articles in Group 1 were high, suggesting that poetry can be analysed as data to derive in-depth and clinically relevant findings in health research. Almost all the articles in Group 2 received a rating of "++", indicating that the use of poetic inquiry in health research does not negatively affect research quality in isolation. This also indicates that poetry can be utilised in a rigorous way within high-quality qualitative research. Overall, there was also epistemological soundness within the use of poetic data across all groups. This was demonstrated as the use of poetry resulted in attention being paid to the language and poetic devices used to convey meaning by participants during data analysis, which is in line with cited post-modernist epistemologies such as social constructionism (e.g., MacDonald, 2017) and sociopoetics (e.g., Carvalho et al., 2021).

Table 2

Descriptive Characteristics of Studies that used Poetic Data (Group 1)

Reference (country)	**Study Aim(s)**	**Health Issue**	**Participant Characteristics**	**Design and Analysis**	**Epistemological Position**
Studies that used pre-existing poems as Poetic Data (Group 1a)					
Clark-McGhee and Castro, 2015 (UK)	To explore how people given the diagnosis of dementia represent selfhood through their words and how this is affected by the current constructions of dementia and related practices.	Dementia	Twelve people living with dementia (mixed gender) and John Killick (a poet).	Sought permission to use four collections of poems co-written from the words of people living with dementia by John Killick and analysed through narrative analysis.	Social constructionist
Studies that used newly written poems as Poetic Data (Group 1b)					
Carvalho et al., 2021 (Portugal)	To explore nursing students' thoughts, feelings and perceptions about mental illness and health.	General mental health	Nursing students (*n*=40), mixed gender.	Participant written poems submitted through an online survey and analysed using a three-phase sociopoetic technique.	Sociopoetic

Table 3

Descriptive Characteristics of Studies that used Poetic Transcription (Group 2)

Reference (country)	**Study Aim(s)**	**Health Issue**	**Participant Characteristics**	**Design and Analysis**	**Epistemological Position**
Studies that used Poetic Transcription as part of the primary analysis of data (Group 2a)					
Duffy and Aquino-Russell, 2007 (Canada)	To explore the experiences of living with long-term cancer.	Cancer	Three women with long-term cancer (aged between 40 – 88 years old).	Written narratives, analysed and poetically transcribed with a descriptive phenomenological method.	Not explicitly stated
Guy, 2018 (US)	To examine the experiences of women who terminated their pregnancies late-term due medical reasons.	Termination of pregnancy due to medical reasons (TFMR)	Five white, heterosexual women (aged between 25 – 38 years old).	Written narratives , thematically analysed and poetically transcribed with the Listening Guide Approach.	Feminist
Johnson et al., 2021 (UK)	To explore the experience of daily and formal decision making between African American dementia dyads.	Dementia	Five African American women with dementia (aged between 69 to 90+ years old)	Dyadic interviews, with each transcript undergoing three distinct analyses: qualitative content analysis, the novel use of I Poems (created through the	Not explicitly stated

			and their six carers (five women and one man aged between 38-78 years old).	Listening Guide Approach), and quantitative content analysis.	
Madill and Hopper, 2007 (Canada)	To explore how four men from the same family construct health from their perceptions of professional athletes.	General physical health	For men (ages between 20 – 57 years old) from the same family.	Individual interviews, thematically analysed and a unique method of Poetic Transcription used. Participant feedback used to finalise poems.	Not explicitly stated
Mckenzie, 2021 (UK)	To demonstrate the theoretical background to I-poems, the variations in their form, explain the steps taken to create I-poems from interview transcripts from freebirthing women and to highlight poetry as a novel way of disseminating research results beyond an	Freebirthing	Sixteen women.	Individual narrative interviews, analysed and poetically transcribed using Voice Centred Relational Method (VCRM). Participant feedback provided on poems created.	Not explicitly stated

	academic audience.				
Souter, 2005 (UK)	To explore the experience of loss of appetite among palliative care cancer patients and their carers supported by a specialist palliative care team in the community.	Cancer	Seven palliative cancer patients and their carers.	Semi structured dyadic interviews, analysed with reflexive thematic analysis and poetically transcribed through the creation of "I" Poems. Participant feedback provided on poems created.	Not explicitly stated
Stenhouse, 2014 (UK)	To understand the experience of being a patient on an acute psychiatric inpatient ward.	Psychosis	Thirteen people with experiences of hearing voices (ages between 18 and 65 years old; six male, seven female).	Unstructured interviews analysed and poetically transcribed with holistic sociolinguistic narrative analysis. Participant feedback provided on themes before poetic transcription.	Narrative
Studies that used Poetic Transcription as secondary analysis of data (Group 2b)					
Kooken, et al., 2007 (US)	To obtain African American women experience on their survivorship of cancer.	Breast cancer	Twenty-one African American women (aged	Focus groups analysed and poetically transcribed with	Phenomenological

			between 38 –78 years old).	interpretive phenomenology.	
Shinebourne, 2012 (UK)	To explore women's experience of addiction and recovery.	Addiction and recovery	One woman, aged 52.	Semi-structured interview and poetically transcribed using Glesne's approach.	Not explicitly stated
Studies that used Poetic Transcription as data dissemination (Group 2c)					
MacDonald, 2017 (UK)	To explore the concept of normalcy in young people with cystic fibrosis and disseminate findings through poetry.	Cystic fibrosis (CF)	Ten people diagnosed with CF (ten male, four female; ages between 19–34 years old), their two carers and eleven members of a CF staff team.	Semi-structured interviews and poetically transcribed using a unique approach.	Social constructionist with symbolic interactionism

Thematic Analysis and Narrative Synthesis

Themes were organised under superordinate priori groups of Rationale, Strengths and Limitations, relating review questions two, three and four, respectively. Themes that fell under Rationale and Strengths heavily overlapped and were converged under a priori grouping termed Added Value. Overall, most themes related to all methods of poetic inquiry found. Exceptions are illustrated in the narratives below. Participant quotes are not used to illustrate themes as a metamethod study focuses on authors' reporting of their methodological approach (Paterson et al., 2001; Zhao, 1991).

A Priori Group: Added Value

Theme: Centres Participant Voices and Experiences

Articles in Group 2 often depicted poetic playbacks of the entirety of the original data (Guy, 2018; Madill & Hopper, McKenzie, 2021; 2007; Souter, 2005; Shinebourne, 2012; Stenhouse, 2014; Johnson et al., 2021). Authors reported that this allows for more holistic representations of participant experiences, as compared to the fragmented quotes used to illustrate interpretations made by researchers in traditional qualitative research (Duffy-Aquino-Russell, 2007; MacDonald, 2017; Shinebourne, 2012; Souter, 2005; Stenhouse, 2014; Johnson et al., 2021; Kooken et al., 2007).

Within their presented rationales, authors also described an implicit power imbalance in the relationship between participants and researchers as participants' experiences are traditionally retold through the interpretative lens of researchers. Through the centring of participant voices by presenting poems that encapsulate the entirely of original data, poetic inquiry was used to redress the impact of this power imbalance (Stenhouse, 2014).

People who are subject to marginalised discourses were often thought to be unheard in traditional qualitative research. This was attributed to the focus on researcher interpretations, which run the risk of succumbing to the unhelpful discourses. The centring of participants voices in poetic inquiry was reported to enable unhelpful narratives about taboo health issues, e.g., termination of pregnancies (Guy, 2018) and about marginalised populations, e.g., African American women (Kooken et al., 2007; Johnson et al., 2021), to be challenged. Furthermore, authors often presented individual poems for each participant in their reporting of studies. Shinebourne (2012) reflected that this was a useful way to highlight the individualised experiences of participants. This reduces possible oversimplifying of the intricacies of the experiences of people occupying marginalised discourses that may occur if collective voice is valued over individual voice. Thus, poetic inquiry in health research was thought to highlight silenced voices, challenge unhelpful discourses, and support the implementation of culturally sensitive health practices.

Some studies identified that through poetic inquiry, populations that researchers have thought to be difficult to recruit can be engaged in research. They highlighted that through the inclusion of participants in the process of poetic inquiry, participants can be empowered to directly influence how they are represented in research and therefore be engaged in research (Madill & Hopper, 2007; Souter, 2005). This was of particular value when discussing topics on social injustice where participants may face ramifications for how they are represented (Kooken et al., 2007). Authors also noted that involving participants in poetic transcription (Duffy and Aquio-Russell, 2007) or asking participants to submit poems as data (Carvalho et al., 2021) can engage people in research by making it an enjoyable experience and therefore facilitate the exploration of their experiences.

Theme: Facilitates Reader Engagement and Empathetic Understanding

Authors recognised that the use of poetic devices such as imagery and metaphor in poetic data and the special attention given to the language used by participants in poetic transcription opens new avenues for seeking knowledge and cultivating meaning (Carvalho et al., 2021; Clark-McGhee & Castro, 2015; Madill & Hopper, 2007). Namely, the use of poetry was thought to act as a gateway into which the more vivid and emotive features of life experiences could be witnessed (Carvlho et al., 2021; MacDonald, 2017; Shinebourne, 2012; Kooken et al., 2017; Johnson et al., 2021). Authors also noted that through poetry, meaning could be amplified to access deeply elusive yet profound aspects of lived experiences to enrich understandings (Clark-McGhee & Castro, 2015; Duffy & Aquino-Russell, 2007; Guy, 2018; Kooken et al., 2007; MacDonald, 2017; McKenzie, 2021; Shinebourne, 2012; Souter, 2005).

Carvalho et al., (2021) recognised that engaging participants in poetry fostered introspective thinking and enhanced creativity. Similarly, authors in Group 2ai noted that by involving participants in poetic transcription, they were given the opportunity to reflect on what they shared in the original data. As such, poetic inquiry was seen to facilitate self-awareness and emotional growth. Thus, the poems shared would encompass these newly found insights and promote truer and richer expressions of their experiences within the research (Carvalho et al., 2021; Madill & Hopper, 2007; MacDonald, 2017; McKenzie, 2021; Shinebourne, 2012). Madill and Hopper (2007) identified this as “catalytic validity” (p. 47), representing the process whereby participants gain a deeper sense of self-awareness and self-direction as a result of taking part in the research.

All authors noted that the use of poetic devices in poetic data, the attention to language in poetic transcription and the catalytic validity of poetic inquiry results in a unique process of data collection and analysis that provides an experiential representation of lived experiences. This visceral representation of lived experiences was thought to foster empathetic understanding and greater connectedness to participants' experiences, which in turn was seen to promote action from stakeholders in adapting care provisions to meet the needs of service users (Carvalho et al., 2021; Duffy & Aquino-Russell, 2007; Kooken et al., 2007; MacDonald, 2017; Madill & Hopper, 2007; McKenzie, 2021; Shinebourne, 2012; Stenhouse, 2014).

It was also thought that through the presentations of full poems that provide a playback of the entirety of the original data, readers could form their own interpretations and thus generate unique understandings of participant experiences (Duffy & Aquino-Russell, 2007; Kooken et al., 2007; MacDonald, 2017; Madill & Hopper, 2007; Shinebourne, 2012; Stenhouse, 2014). Specific to studies that aimed to highlight the marginalised voices, authors reflected that the increased access to participants' inner worlds propagated social and political engagement from the researchers (McKenzie, 2021), further highlighting the empathetic understanding facilitated by poetic inquiry.

Many authors in Group 2 highlighted that presenting research findings through poetry moves away from the use of jargon-heavy language when reporting findings. Poetic transcription was seen as an accessible way to disseminate findings beyond academia (Duffy & Aquino-Russell, 2007; McKenzie, 2021; MacDonald, 2017; Shinebourne, 2012; Souter, 2005). McKenzie (2021) noted that the poems had the potential to be presented alongside other creative modes such as animations to make dissemination accessible and therefore facilitate reader engagement.

A Priory Group: Limitations

Theme: Methodological Issues

Authors across all the groups of papers reported that they had concerns about the generalisability of their findings based on the homogeneity and/or size of their participant pool (Clark-McGhee & Castro, 2015; Guy, 2018; Johnson et al., 2021; Stenhouse, 2014; Souter, 2005). However, this is at odds with the qualitative research program, which does not seek generalisability (Stenfors et al., 2020). Some authors recognised this juxtaposition and noted that the purpose of poetic inquiry is not to uncover a singular truth and to be generalisable in principle. Instead, the aim was to be explorative in nature and capture a snapshot of the experiences of a particular health issue within a particular historical and social context (Souter, 2005; Stenhouse, 2014). As such, any policy and clinically relevant implications that arose within the findings could be culturally sensitive and individualised in their application. This was especially highlighted when the study aimed to explore taboo topics that lack exploration in health research (e.g., termination of pregnancies in Guy, 2018) or to highlight voices of marginalised groups whose experiences are typically silenced and therefore dismissed in health care provisions (e.g., people living with dementia in Clark-McGhee & Castro, 2005 and African American women in Kooken et al., 2007).

Shortcomings specific to different poetic inquiry methods were also identified. Clark-McGhee and Castro (2005), Group 1a, highlighted the lack of contextualising demographic data available in their study. This was due to their use of pre-existing collections of poems that were published without any demographic details. There were several methodological issues that were specifically identified in Group 2 studies. Some researchers expressed concerns that not all original data may be appropriate for poetic transcription and may generate poems with limited interpretive value (MacDonald, 2017; McKenzie, 2021; Shinebourne; 2012). Authors also highlighted concerns about the lack of formal quality assessment tools for the poems produced from poetic transcription (Shinebourne, 2012;

Souter, 2005), as well as concerns about the lack of literacy qualifications of researchers engaging in poetic transcription (Souter, 2005; McKenzie, 2021). McKenzie (2021) stressed that a preoccupation with quality assessment in poetic transcription may defeat the purpose of employing creative practices such as poetry in health research, the use of which is typically governed by the shift from the elitism often embed in traditional data dissemination. There was also a sense of difficulty in managing the balance between producing an artistic expression of participant voices and disseminating research findings that have useful implications (Shinebourne, 2012; Souter, 2005). However, the quality assessment undertaken for this review highlighted that poetic inquiry does yield findings that are embedded in theory and existing literature and have explicit implications for future avenues, whether for clinical practice, developments in policy or future research.

Theme: Issues of Power and Authorship

Authors in Group 2 frequently discussed if participants whose words were used to create the poems should be given full ownership over the transcribed poems as opposed to the researchers who conducted the poetic transcription process. There were concerns that the former risks the safety and anonymity of participants (MacDonald, 2017; Souter, 2005; Stenhouse, 2014).

Authors also reported concerns that researchers' own understandings and assumptions may influence which segments of the original data are highlighted in transcribed poems in Group 2 (MacDonald, 2017; McKenzie, 2021; Shinebourne, 2012; Souter, 2005). This was not of particular concern to authors in Group 1, possibly because the poems analysed as data were written by the participants themselves (Carvalho et al., 2021) or co-written with participants (Clark-McGhee & Castro, 2015). Studies that fell into Group 2ai were also exempt from these issues, with researchers highlighting that the involvement of participants during poetic transcription mitigated the influence of their own assumptions on the poems produced (Madill and Hopper, 2007; McKenzie, 2014; Stenhouse, 2014).

The risk of the researchers' assumptions and understandings affecting the privileged narratives in transcribed poems was not of particular concern to authors in Group 2 who transcribed "I" poems, as compared with authors who transcribed freestyle poems. This is potentially representative of the creation of "I" poems being more manualised, i.e., there is limited bias when pulling out statements being with "I" from the original data, compared with freestyle poems where the identification of segments to include in the poems is left up to the discretion of the researchers. However, Mckenzie (2021) highlighted that by focusing on the "I", researchers and readers may miss the opportunity to witness equally insightful stories that encompass the "we", "us", "she" and different aspects of participants' experiences. Mckenzie (2021) and Souter (2005) illustrate that this can be mitigated by including sentences with other pronounces such as "you", "we" and "she" in the same poem, or by creating separate poems that focus on specific pronouns, from the same data.

Most researchers highlighted that having access to richer representations of participant experiences and inner world is an added value of poetic transcription (discussed in the Added Value section). However, it is also recognised that by aiming to develop deeper depictions of participants' experiences in this way, aspects of participants' experiences that they may not have wished to share may be captured and displayed in the transcribed poems (Souter, 2005; MacDonald, 2017). In this way, researchers embody a powerful position where they may expose participants' vulnerabilities and experiences that they themselves did not have conscious access to or represent them in a way that they did not wish to be (Souter, 2005).

Discussion

The current review provided a methodological overview of how poetic inquiry can be utilised in future health research. Poetry can be used effectively as research data, as well as for data analysis and dissemination through poetic transcription. The review also discovered the rationales and strengths associated with health-based poetic inquiry, highlighting that it is an engaging and empowering method for exploring complex and intricate lived experiences as situated within specific socio-political contexts. Limitations related to methodological drawbacks and issues of authorship. These evaluations of poetic inquiry are consistent with those of other arts used in health-related ABR (Boydell et al., 2010; Boydell & Gladstone et al., 2012; Furman et al., 2006; Fraser & al Sayah, 2011; Kontos & Naglie, 2007).

There are additional ways of incorporating poetry into health research that was not captured in the findings of the current review. For example, Kebede et al. (2021) demonstrated that poetic data can be effectively used to explore people's knowledge on pertinent health issues, which can be used to inform health education policies. This study was excluded from the current review as it explored understandings, rather than the experiences, of health. An additional method of poetic inquiry is the analysis of researcher-written poetry, which can be used to explore professional experiences of providing health care (e.g., Clancy, 2017; Gallardo et al., 2009). Furthermore, Rhodes et al., (1995) investigated the difference in creativity between people with and people without a diagnosis of psychosis. This is particularly interesting, as it uses deductive content analysis of poetry by participants to explore symptomatic differences between a clinical and non-clinical population. Thus, health-based poetic inquiry goes beyond the exploration of subjective experiences and provides the opportunity to explore health in a multitude of dimensions.

In addition, poetry intervention studies demonstrate that people with health difficulties, e.g., dementia and cancer, benefit from writing poems as this enhances feelings of competence, self-efficacy, self-affirmation, well-being, personal growth and reduces feelings of isolation (Lillyman et al., 2014; Petrescu et al., 2014; Swinnen, 2016; Synnes et al., 2020; Tegnér et al., 2009). These evaluations of poetic interventions support findings in the current review about the ability of poetic inquiry to engage and empower participants in research. Poetic interventions have also worked to improve communication between people with dementia and residential home staff (Lillyman et al., 2014; Windle et al., 2020), aligning with findings in this review about the ability of poetic inquiry to support a richer understanding of health experiences. In both contexts of intervention (e.g., Windle et al., 2020) and research (as found in this review), this improved communication is thought to facilitate empathy from readers and propagate positive action from stakeholders and care providers to improve health practices for patients. It is not to be assumed that poetic inquiry acts as a therapeutic experience for participants. Instead, the comparison between findings from the current review and intervention studies provides a template for understanding how participants may experience being part of poetic inquiry and demonstrates how the benefits of poetic inquiry parallel the increasing use of poetry in health interventions (Synnes et al., 2020), further highlighting its added value.

The identified drawbacks to poetic inquiry must also be considered. The issues of authorship in poetic inquiry identified in this review can be addressed by seeking permission from participants to publish their poems with their names; their consent, or lack thereof, to which would not affect their participation in the research, as done in Amponsem et al., 2022. Additional drawbacks of poetic inquiry relate to the epistemological tension between study aims and chosen methods of poetic inquiry. Many studies aimed to represent participants holistically and claimed that poetic transcription provided this through the reporting of individual poems for each participant that represented the entirety of their original data. However, poetic transcription, by nature, involves fragmentation of data, although perhaps to a lesser degree than in traditional qualitative data. This is because researchers still assess which lines of the original data are included in poems, a process that is likely affected by their own interpretative lens, as well as which parts of participants' experiences are available to readers. The different methods of poetic inquiry from the findings offer ways to address this issue while reaping the identified benefits of poetic inquiry. That is, by involving participants at any or all points of poetic inquiry, there can be some further assurances that the poems produced are a holistic reflection of participants' inner world and reflective of how they want to be represented in the literature.

Strengths, Limitations and Future Research

The main strength of the current review is that it outlines clear guidelines for how authors can engage in health-based poetic inquiry while providing an evidence base for the value of doing so. Avenues for addressing the drawbacks in its use have also become evident through this review to support the rigorous implementation of poetic inquiry. However, it is important to note that overall evaluations of health-based poetic inquiry were presented from the point of view of researchers based on their experiences and theoretical backgrounds. Few reported the perceived added value of poetic inquiry from the point of view of participants as ascertained through participant feedback on the research process, with none reporting this from the point of view of readers and audiences. As the findings suggest that poetic inquiry holds added value for participants and audiences, it would be pivotal to conduct further studies that explicitly explore the experiences of participants and audiences to access the robustness of these findings.

Academic guidelines for conducting literature reviews necessitate quality assessment procedures (e.g., Cumpston et al., 2019). However, the current review highlighted that the preoccupation with quality assessment in traditional qualitative research embeds elitist values in data dissemination where findings are inaccessible to audiences outside of academia. The quality assessment and narrative synthesis of the current review demonstrated that poetic inquiry yields high-quality research while still being able to accessibly present data that fosters engagement. Thus, this review demonstrates that the use of poetic inquiry provides a balance between disseminating findings to diverse audiences while maintaining the academic rigour required by stakeholders to deem research findings as useful in developing clinical practice. The high quality of included papers also demonstrates that poetry can be used within a broadly robust methodological approach that future research would benefit from engaging with to support improved participant and audience engagement.

There are some limitations to the methods of this review that need to be considered. There was an overwhelming number of articles retrieved in the literature search (around 5000) before the first group of keywords (poet* or poem*) were applied only to the titles of papers. The time needed to review all these papers was outside of the scope of the current review. A preliminary scoping of the literature identified that the keyword poem was used in the titles of relevant articles, proving a rationale for using this limiter to narrow down the search. However, implementing this limiter likely caused the exclusion of a number of relevant articles that may have been useful in providing further insights. The review also used a very broad definition of health and included articles on mental, physical and general health experiences. This explorative stance was taken to provide an overview as, to the authors' knowledge, this is the first review on this topic. In addition, it would have been incredibly difficult to name all health issues and encompass them with the search terms. As such, the literature search was completed under the assumption that if "health" or "care" was used as a search term, the most salient work in this area would be captured. Thus, articles that just named the specific health issue they were exploring may have not been captured. It would be beneficial for future reviews to focus on specific aspects of health research, e.g., mental health alone or a specific health issue, as this may highlight any nuanced differences between the use of poetic inquiry in different health contexts which may have been missed by completing a broader review. This would also ensure that articles that just named the specific health issue they explored are captured to provide additional insight into health-based poetic inquiry.

Conclusions

The current state of the literature on how poetic inquiry is used in health research was explored. Several ways in which researchers can engage in health-based poetic inquiry were identified, the main overarching ways being through poetic data and poetic transcription. The added values of incorporating poetry in health research include accessible data dissemination that helps to diversify audiences and increases engagement with research findings. The findings suggest that poetic inquiry support richer and more holistic depictions of participant experiences that can be used to improve health care practices. Limitations of poetic inquiry speak to some epistemic tension between some specific methods of poetic inquiry and their supposed aims. The use of poetic inquiry methods that privileges co-production and heavily involve participants in data analysis is a way to ease these tensions. Further research is needed to explore the experiences and perceptions of participants and audiences about engaging in poetic inquiry. Based on the current review, the use of poetic inquiry in health research has merit. However, researchers need to be thoughtful in the selection of the specific methods used to ensure epistemological soundness in their research.

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Part Two: Empirical Report

This paper is written in the format ready for submission to the journal

Journal of Dementia

Please see Appendix E for submission guidelines

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The meaning and experience of hope by people living with dementia as expressed through poetry

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The meaning and experience of hope by people living with dementia as expressed through poetry

Abstract

Background: Narratives of dementia undermine the ability of people to live well. Positive psychology, concerned with the cultivation of personal strengths, is a model through which people's capacity to have positive experiences can be researched. This study explored the meanings and experiences of hope, a positive psychological construct found to facilitate well-being, in people with dementia.

Methods: People with dementia submitted poems about the meanings and their experiences of hope through an online platform. The submitted poems (*n*=29) underwent thematic analysis.

Results: There were three main themes: (1) "*hope is light in the darkness*" encapsulated the meaning ascribed to hope as a resource that spotlights what is still possible, (2) "*poetry gives voice to experiences of hope"* captured the role of poetry in communicating the otherwise elusive concept of hope, and (3*) "peers uphold hope and cast away the darkness"* captured that participants' hope was blocked by stigmatising views held and expressed by others but facilitated through positive social interactions.

Conclusions: People are capable of having hope in the context of dementia, with hope being a uniquely functional strength that supports wellbeing. Health professionals, family and society have a clear role in supporting people with dementia to maintain their hope.

Keywords: hope, dementia, positive psychology, poetry, stigma, psychosocial interventions

Introduction

While managing the challenges associated with dementia, studies demonstrate that people can have positive experiences and live well (e.g., Cahill et al., 2004; Katsuno; 2005; Pearson et al., 2022; Hickman et al., 2018). Despite this, narratives of dementia remain focused on loss and deficit (Aquilina & Hughes, 2006; Behuniak; 2011; O'Malley et al., 2022). Dehumanising views permeate public discourses where people consider dementia as one of the most burdensome conditions of later life (Ferri et al., 2005). Counter-frames of such hopeless views are relatively absent in news and media (Hakola, 2019; O'Malley et al., 2022; Van Gorp & Vercruysse, 2012). Researchers are preoccupied with prolonging survival and slowing symptom progression, with limited exploration of how to support people to live well with dementia (e.g., Pardo-Moreno et al., 2022; Prince et al., 2013; Yiannopoulou & Papageorgiou, 2020).

These hopeless and stigmatising views are not inconsequential and play a significant role in the well-being of people living with dementia. They have been found to propagate negative self-stereotyping (Moniz-Cook et al., 2006; Scholl and Sabat, 2008), poor self-image, and experiences of discrimination (Naue & Kroll, 2008), which in turn, exacerbates feelings of isolation and reluctance to seek diagnosis, support, and participation in research (Garand et al., 2009; Mitchell et al., 2013; Patterson et al., 2018; Sweeting & Gilhooly, 1997). To improve the care, personal outlooks, and quality of life of people with dementia, it is essential to address this stigma and explore balanced narratives of dementia that capture people's capacity to live well (Swaffer, 2014).

A framework through which alternative narratives can be explored is positive psychology, as it is concerned with cultivating personal strengths and social environments that foster well-being (Peterson & Seligman, 2004; Seligman & Csikszentmihalyi, 2000). An important concept within positive psychology is hope. Seligman (2002), credited as the founder of positive psychology, proposes that a hopeful outlook is vital for a good quality of life. Hope has been positively associated with reduced levels of depression and anxiety (Feldman & Snyder 2005), improved quality of life (Duggleby et al., 2021) and better subjective wellbeing after controlling for variance due to self-efficacy and optimism (Magaletta & Oliver, 1999). Hope is also evidenced to be a larger predictor of lower burnout compared to resilience (Pharris et al., 2020), distinguishing it from other positive psychology constructs.

Despite robust findings of its positive influence on wellbeing, scholars and philosophers have struggled to develop a singular description for hope, with as many as 29 different empirical definitions and 32 standardised measures available (Schrank et al., 2008). Non-traditional data collection methods such as poetry have been effective in exploring complex and difficult to define concepts (e.g., Amponsem et al., 2022; Campo, 2003; Shapiro, 2004), with evidence demonstrating that poetry is particularly useful for investigating hope (Bishop & Willis, 2014).

Older adult and terminal health research provide some robust conceptualisations of hope. Older adults are thought to face threats to hope such as depleted energy, hopelessness in others, and impaired cognitive ability (Herth, 1993). However, they are able to adapt to these challenges and have a capacity for both generalised hope e.g., hopes about others and the world, and specified hope, e.g., hopes for the self (Dufault & Martocchio, 1985; Lapierre et al., 1997; Rapkin & Fisher, 1992). For those facing life-limiting conditions, hope is experienced as a resource that changes over time and allows people to affirm life and connect with their environment and those around them (Daneault et al., 2016; Soundy et al., 2014; Johnson, 2007).

While limited and often found serendipitously, there is evidence to suggest that people with dementia can also experience hope (e.g., Cohen, 1991; Cutcliffe & Grant, 2001; MacRae, 2010). There were two studies that explore this topic directly at the point of writing. Wolverson et al. (2010) explored the subjective experience of remaining hopeful in early-stage dementia. Hope was expressed as both an internal and external process that was thought to maintain well-being and self-esteem. Similarly, Cotter et al. (2018) found that hope accounts for 25% of the variance in self-esteem in people with dementia. These studies suggest that hope plays a role in maintaining well-being. However, findings from Wolverson et al. (2010) are limited to early-stage dementia, while findings from Cotter et al. (2018) are quantitative and do not offer an explorative inquiry into the experiences of hope.

Additional work is therefore needed to develop richer conceptualisations of hope in dementia, which can be used to cultivate hope fostering discourses and support people to live well. Exploring hope through poetry provides the opportunity to expand understandings beyond what has been found in previous research using traditional methods, substantiating the need for further study of hope in dementia (Bishop & Willis, 2014). Poetry has also been found to affirm the value, identity, and hope in people with dementia when used as research data (Castro & Clark-McGhee, 2014; Killick, 1999). Thus, the current study aimed to explore shared meanings and experiences of hope by people living with dementia through the analysis of participant-written poems. The following research questions were addressed: (1) what meanings do people living with dementia ascribe to hope and (2) how do people living with dementia experience hope (including facilitators and barriers to hope).

Methods

Design

A qualitative design was used to explore and make sense of the shared meanings and experiences of hope when living with dementia.

Recruitment and Participants

Ethical approval was granted by the Faculty of Health Sciences Ethics Committee at the University of Hull (See Appendix F). The inclusion criteria for participants were a diagnosis of dementia (of any subtype) and the capacity to write a poem in English about hope (with or without support from family/friends). Extensive exclusion criteria were not imposed due to the explorative nature of the study.

Many participants were recruited through online social media platforms. They volunteered their participation in response to adverts placed on Facebook, Instagram, Twitter and The UK Network of Dementia Voices website. Others were recruited through local voluntary dementia groups in and around Hull, UK; activity coordinators for the East Riders, Time and Placers, and the Dementia Advisory Group were asked to inform their members about the research. Interested members were directed to contact the primary researcher or gave verbal consent for their emails to be shared with the researcher.

While there are no standardised guidelines for participant numbers when using poetry as data, 10-50 participants have been recommended for “small projects” (student projects) when using participant-generated text as data. The justification for this alludes to the prevention of an overwhelming amount of data while having enough data to demonstrate patterns of meaning (Braun & Clarke, 2013, p.50-51). Thus, data collection took place between July 2021 and March 2022 and ended when 31 participants were recruited.

Procedure

Promotional posters (Appendix G) and a video (Appendix H) were distributed online and among activity coordinators of local voluntary dementia groups to share with their members. The posters and video detailed that participants could ask others to help them participate in the study and that only poems in the following styles would be accepted:

- Acrostic poems: where the first letter of each line spells out hope.
- Sense poems: where poems are constructed by completing some/all of the following sentences – “hope is…”, hope tastes like...”, “hope sounds like…”, “hope smells like…”, “hope looks like…” and “hope makes me feel...”.
- Freestyle poems: poems of any or no specific stylistic choice.

The inclusion criteria for poems were adopted from Bishop and Willis (2014). They highlighted that people may become preoccupied with notions that poetry is a complex art requiring specialist knowledge and may therefore become discouraged from participation in poetry-based research. They found that providing guidelines for two specific poetic styles mitigated this potential barrier, with the addition of freestyle poems encouraging people of mixed abilities to take part in the study. Thus, this guidance was adopted for the current study so that people living with dementia with varying cognitive and literacy abilities were supported to write their poems on hope.

Participants used a link available on the posters and video to submit their poems on an online submission platform (created with Online Surveys). On this platform, participants were prompted to download the participant information sheet (Appendix I), with an easy read version available (Appendix J). Participants could also download an instruction sheet with further details about how to write poems using the three accepted poetic styles (Appendix K).

Participants could submit up to three poems per person. A group of participants could also submit a poem written together. Details of their right to withdrawal, anonymity and data storage were all included in the information sheet. Participants could not submit their poems and demographic information until they confirmed that they had read the information sheet and provided informed consent. Some participants opted to email their poems to the primary researcher after reading the information sheet. These poems were included in the study once participants had signed and returned a consent (Appendix L) and demographic data form (Appendix M) via email or post. Participants were asked if they would like their poems to be included in an anthology of submitted poems at the end of the research (with or without their names). Their decision did not affect the anonymous inclusion of their poem in the study. Consent was given for 21 of the submitted poems to be included in the anthology (see Appendix N for the anthology).

Data Analysis

Submitted poems underwent reflexive thematic analysis (TA) (Braun & Clarke, 2006; 2021), an analytical choice governed by a number of rationales. Reflexive TA provides clear analytical guidelines that are applicable to textual data, such as poetry (Braun & Clarke, 2006). It involves the analysis of patterns across participants, proving a way for shared meaning and experiences of hope to be interpreted (Braun & Clarke, 2006; 2021). Reflective TA is theoretically flexible, making it appropriate for a range of research philosophies. The variation of reflexive TA used in this study was underpinned by ontological realism and epistemological relativism, taking a philosophical framework of critical realism (see Appendix V for an epistemological statement expanding on this position). In line with the explorative nature of the study, an inductive orientation to data was taken. Meanings were explored latently as participants used stylistic poetic techniques to convey underlying meaning, however, the focus of meaning remained semantic where appropriate.

Below are the steps that were taken to analyse the data, as outlined by Braun and Clarke (2021). This was a non-linear, iterative process that facilitated a rigorous analysis.

1. **Familiarisation with the data**: the primary researcher repeatedly read through all the data and wrote reflective poems in response to each submitted poem (see Appendix O for an extract of the reflective poems).
2. **Coding**: for each submitted poem, lines that were relevant to answering the research questions were labelled with a succinct code (see Appendix P for an extract).
3. **Generating initial themes**: related codes were grouped together to formulate significant broader patterns of meaning across the data set to form initial themes (Appendix Q details thematic maps of these initial themes).
4. **Reviewing themes:** the initial themes were thought to act as topic summaries after being checked against the dataset and discussed with the research supervisor (second author). Stages four to five were repeated, and new initial themes were developed. These were reviewed as being reflective of distinct central organising concepts relevant to the research questions (Appendix R details thematic maps for these).
5. **Defining and naming themes**: defining and naming the themes occurred as part of the previous and next stage.
6. **Writing up:** analytic narratives of the themes were written. The use of full poems to illustrate themes is valued in art-based research as a way to empower and holistically represent participants (e.g., Amponsem et al., 2022; Furman et al., 2007). However, this is not always possible due to constraints on word count in academic writing. To

address this, an anthology of submitted poems can be found in Appendix N as a way of centring participant experiences.

Researcher Reflexivity

The primary researcher engaged in active reflexivity to consider how personal values and experiences interacted with data analysis. This involved a disciplined practice of critically interrogating decisions and the effect this could have on the findings and the epistemological soundness of the research. A research journal, reflective practice groups, poetry and regular supervision with two qualified clinical psychologists and researchers were the main tools used in this endeavour. Appendix W contains a reflective statement with detailed discussions about the main themes and personal reactions during the research process.

Findings

Overview of Poems and Participant Demographics

Overall, 33 poems were submitted, of which four were excluded as they were not written by people living with dementia. Of the 29 poems included, 3 were acrostic, 8 were sense and 18 were freestyle. One of these poems was written by a group of four participants, another one was written by a different group of four participants and two participants submitted three poems each. The remaining 21 poems were written by 21 different participants. That makes a total of 31 participants (22 female and 9 male) included in the study. These participants were between 51 and 70 years old and had been diagnosed with dementia between 2.7 and 7 years. Types of dementia reported were Alzheimer’s, Vascular and Mixed. All participants resided in the UK and lived in their own homes. Other demographic data requested were current/most recent occupation and ethnicity, although an overview of this cannot be provided as they were infrequently reported.

Overview of Themes

There were three main themes: (1) "*hope is light in the darkness*", (2) "*poetry gives voice to experiences of hope*" and (3) "*peers uphold hope and cast away the darkness*" (see Table 1 for a thematic map). Unique narrative points of each theme are presented in Table 1. To avoid the addition of structural complexity at the expense of analytic depth as warned by Braun and Clark (2021), these are not structured as subthemes. Instead, they are presented as narrative points to highlight their significant contributions to the overall narrative of their respective theme.

Table 1

Thematic overview and significant narrative points.

Theme	Central organising concept	Narrative Points
Hope is light in the darkness	The function of hope when living with dementia	The darkness arises
		Where will I go from here
		Hope spotlights the important things
Poetry gives voice to experiences of hope	The capacity of people living with dementia to have hope	Hope is a slippery thing
		Poetry sheds a light on the experiences of hope
Peers uphold hope and	The role of others in	Seeing me as I want to be seen

cast away the darkness	fostering hope for people living with dementia	Creating hope together

Themes

Theme One: Hope is a light in the darkness

Hope is positioned as a uniquely functional resource (a light) that facilitates coping in the face of challenges that arise when living with dementia (the darkness). Some of the challenges named were the sense of limited time that the terminal and progressive nature of dementia creates, as well as cognitive and physical difficulties. "The darkness arises" as these challenges interfere with established routines and goals, casting a shadow on what is still possible and emphasising a sense of loss and despair.

Poem Six

With an ear that's failing, and a brain that's decidedly wonky
The ear can be fixed
The brain can't

Poem Eight

Not knowing how much longer I have to cherish them; to live and love them
They are my memories; they are my thoughts and my every action is for them
Until there is nothing more to forget, nothing more to give, nothing more…

With the "darkness" casting a shadow over previous goals, people felt a great sense of uncertainty about their future. Some people's outlook on what is possible and what they are capable of grows smaller, so much so that life starts to look bleak and meaningless. Some participants began their poems by questioning whether it was even possible to have hope at all, suggesting that being diagnosed with dementia is a barrier to hope.

Poem Four

Perhaps I'll die suddenly before I'm stuck staring out front

Perhaps I'll manage to end it myself…but when? and how?

Perhaps I'll end up in a really nice care home…

Coin toss chance?

Poem Twenty-Six

Now the "old age" is here…

Sadly, our little world is falling apart...

Because of one single word:

Dementia!

In the face of the darkness and uncertainty, it was hope that many participants longed for. They felt that hope allowed them to both accept and adapt to the challenges of living with dementia, shedding a light on what was important to prioritise. Hope, therefore, did not eradicate the darkness. Instead, it acted as a spotlight that bring to attention what is now possible despite the presence of the darkness. As such, "hope spotlights what is important" based on what can realistically be achieved in the context of dementia.

Poem Twenty-Three

Hope is what I cling to

Hope is an umbrella shielding me from the rain

…

Hope feels like never losing sight of possibilities

Poem Four

Hoping against the odds that all will be well

Believing life is worth living

Getting up each day with enthusiasm

Hope was also conceptualised as a driving force that energises and facilitates active movement towards these newly identified and reprioritised positive possibilities.

Poem Eighteen

Hope gives me strength, gives me a strong vision

To continue with life, I'm now on a mission

Without hope, living with dementia is represented as being engulfed in the darkness. In such a case, a person may be stuck in the "where do I go now" position where they are overwhelmed by uncertainty with no clear sense of direction as to what is important or what is possible.

Poem Eighteen

Whatever it is, we hold on to hope

Not to fall down, the slippery slope

…

Where would I be without this word Hope

Living my life without much scope

Appendix S is a thematic map of theme one and illustrates that the relationship between the three narrative points is non-linear, nor are they distinct unitary positions. That is, people can move back and forth between these positions based on their ever-changing daily challenges and the resources available to them to foster their hope.

Poem Twenty-Five

Yet knowing that, sometimes, I

find my 'me' undone and left

behind.

Lost in thoughtless, meaningless

Visions

Then best retreat.
Stand back!
Review!

Theme Two: Poetry gives voice to experiences of hope

A thematic map of theme two can be found in Appendix T. Participants alluded to the idea that "hope is a slippery thing" that was difficult to define. They often questioned where hope was felt, how it could be obtained and its existence. This elusive and mysterious air around hope seemed to foster a hopeless discourse around living with dementia, as it was difficult to have hope when hope couldn't be defined.

Poem Twenty

Are you in my heart
My memory, my brain?
Where do you go to

Will you come back again?

…

Or will you disappear again?

I hope you stay

Poetry seemed to play a unique role in allowing people to clearly conceptualise the otherwise elusive nature of their capacity for hope. Poetic devices such as similes, metaphors and imagery provided a way for hope to be conceptualised beyond what is possible with literal language, providing a gateway through which participants could envision and communicate their experience of hope. Through these poetic devices, participants clearly listed experiences of hope and highlighted their capacity for hope. People equated hope to the mindful enjoyment of daily life, nature and food.

Poem Twenty-One

Hope tastes of chocolate

Hope smells of Mustique

Hope is in talking and conversations

Hope is Fresh air

Hope is sunshine

Hope is Strawberries…. And cream

Poem Twenty-Three

Hope sounds like singing in the chapel

Hope smells like a field of blooming flowers

Hope looks like the brightest summer day

Hope tastes like the sweetest fruit

Poem Twelve

Hope is a good night's sleep

Sounds like peace and quiet

Smells like bacon sandwiches

Looks like sunshine

Tastes like a good glass of wine

People also noted that hope is felt in the celebration of daily achievement. Hope is also experienced when people recognise and engage with their personal strengths, capabilities and hobbies such as creativity and travelling, and note that hope spotlights the ways in which they can still engage in and enjoy these personal interests.

Poem Twenty-Two

Day by day I look for the things I can achieve

Achieve them and notch them up as a success

Poem Six

So I hope for friendship

I hope to paint and write and laugh

Notably, people also make mention of hope residing in future possibilities, as they describe an ability to practice acceptance of the prognostic realities of dementia while hoping for a good quality of life.

Poem Six

I hope for a cure of course, everyone does

But it's probably not coming

So I hope…

To live a good life

…

I hope for the disease to be slow
To treat me kindly

Hope for the future went beyond the self, with people highlighting their ability to hold onto hope for a better future for their families and the world. As such, there was so much capacity for hope when living with dementia, both residing in the present and the future, and about the self and others.

Poem Twenty-Seven

HOPE makes me feel like the world is my forever!
HOPE gives me hope that one day,
our world will be as one!
I hope xx

Poem Twenty

Will you give me hope
For peace in Ukraine

Theme three: Peers uphold hope and cast away the darkness

This theme highlights that the action of others can either block or foster hope for people with dementia (see Appendix T for a thematic map). Some participants expressed that people with dementia are positioned in society as hopeless and incapable of having positive experiences and that these unhelpful narratives acted as barriers to their hope. Participants found it difficult to hold onto hope when others around them continued to be preoccupied with negative outlooks on their lives. These narratives feed the darkness that enters people's lives when diagnosed with dementia, thus, making it harder to have hope and see "the light in the darkness".

Poem Twenty-Eight

Do we have a goal?

Or we have a wish.

Do we have a dream?

Or we have a faith.

No, we have dementia!

End of story here! Yes?

Some participants used their poems to express their personal realities of living with dementia, challenging these disabling narratives held by others. This spoke to a desire of "seeing me as I want to be seen" as participants expressed a longing for their personhood to be acknowledged and valued.

Poem Twenty-Two

I want to scream, I'm still me

Me, it's me inside, it's just words

Words come out differently and not as they should

Should I stay at home and shy away

Away! Hell no, I'm still for living, still for giving

Giving what I still have left, helping when I can

Can I go on living a life worthwhile, you bet I WILL!

Will I be quiet about my dementia and feel ashamed

Ashamed NO! Not even sad, for I am still ME!

The experience of being diagnosed is presented as a pivotal point at which the size of the shadow dementia casts on life is determined. Some participants highlight that the darkness can be mitigated by health professionals engaging in hope fostering discourses such as orientating toward what is still possible as opposed to being preoccupied with what might be lost when communicating a diagnosis.

Poem One (full)

One word we don't hear at diagnosis,
one word we so desperately need,
sinking into a depth of despair
simply because that one word is missing,

one word for the life still to be lived,
one word offering encouragement,
one word that could help us see light,
amidst this dark black tunnel,

One word that smiles,
that brings about relief,
one simple word to help us cope,
what is that word?
It's HOPE.

Furthermore, hope was seen as something that can be created together. Specifically, positive social interaction is privileged as a catalyst for increasing experiences of hope when living with dementia. Several poems suggested that social gatherings create opportunities for having fun with family members, friends and communities. It affirms people's capacity to have positive experiences and encourages them to seek out further pleasurable opportunities. A few people also noted that their experiences of positive social interaction include occasions where people gather to seek and share new developments about dementia as this fuelled their hopes for the future. A sense of reciprocity in caring for each other also fostered their hope, both by affirming their own strengths when they can care for their family and feeling hope through displays of love when they are cared for by loved ones.

Poem Eight

I find Hope in having a community of people just like myself,
Regardless of culture or country; race or religion, who love me as I am – me!
What I bring to the table: poems, articles or just a reassuring word
We research our common thread and try to understand – Dementia
I find happiness in their happiness; courage in their courage
I find purpose in this community of people, just like me, just as I am

Poem Nineteen

Peers uphold our hope and cast the darkness away

Poem Twenty-Three

Hope is the love of my family
Hope is the support of my friends

Discussion

Using poetry as data, the current study explored the meanings and experiences people with dementia attributed to hope. Hope was defined as a personal resource that plays a vital role in managing well-being after a diagnosis of dementia. It did so by orientating people to their personal capabilities and current possibilities in the context of dementia while acting as an energising force that facilitated engagement with pleasant activities. Without hope, life was seen as being full of fear and despair. Participants also highlighted several facilitators and barriers to hope. Facilitators included positive social interactions while barriers included hopeless discourses held by others.

The representation of hope in the current study as a personal resource that supports people with dementia to identify and engage in meaningful activities differs from Snyder's Hope Theory, a dominant conceptualisation of hope. Snyder's Hope Theory depicts hope as a cognitive process that requires future goal setting, pathways thinking and a sense of agency (Snyder et al., 1991). When models of hope that are preoccupied with the future and cognitive ability are imposed on a population living with progressive and terminal illnesses, it is argued that this only leaves room for hopeless discourses about people's capacity to have hope. Participants reported blockages to goal setting, such as the limited outlook of the future as imposed by others, to their pathways thinking, such as cognitive difficulties, and their successful agency, such as functional impairments. However, the current study suggests that by expanding conceptualisations of hope to include a process of adapting to challenges and prioritising what is currently important, discourses of hope become inclusive of people with terminal illnesses whose future is filled with uncertainties, such as people with dementia.

The current study also demonstrates that people with dementia have the capacity for hope and that having hope is important to live well with dementia. A review of 27 studies found that through enjoyment, hope, love, support, facing dementia, growth and transcendence, people with dementia can ascertain positive experiences (Wolverson et al., 2016). The current study demonstrates that hope is not unitary nor separate from the other avenues for positive experiences identified in Wolverson et al. (2016), and is, instead, a multidimensional augmentation of all these. This expansion in previous findings emphasises the need to foster hope for people with dementia, as hope permeates through a large proportion of people's lives, positively influencing internal processes such as the acceptance of dementia diagnosis, motivation to seek present enjoyment and ability to adapt to the challenges of dementia.

The current study provides some avenues for hope fostering interventions in dementia care. Participants experienced hope by immersing themselves in pleasant activities in the here and now, suggesting that interventions that orient people's attention to the present can be used to develop and maintain hope. Indeed, there is further evidence for the positive influence that being present-focused has on well-being. Mindfulness interventions, which aim to foster increased awareness of the present moment, have been growing in healthcare (Baer, 2003; Creswell, 2017). Used with people with dementia, mindfulness interventions have been found to improve well-being (Leader et al., 2013), mood (Leader et al., 2013, Kemp et al., 2016) and quality of life (Leader et al., 2013, Churcher-Clarke et al., 2017). Churcher-Clarke et al. (2017) only found statistically significant improvements in quality of life, and not in anxiety and depression measures post-intervention. However, the reliability of these findings was likely affected by the fact that it was an inadequately powered pilot study. Russell-Williams et al., (2018) provide further evidence for the value of mindfulness interventions, demonstrating that people with dementia, mild cognitive impairment and subjective cognitive decline report improved cognitive functioning, perceived stress, and quality of life after mindfulness-based interventions. The participant base of this study was broader and affects the transferability of these findings to people with dementia. However, overall findings for mindfulness intervention studies support the current study and indicate that engaging people with dementia in mindfulness activities has value, as it has the potential to improve the wellbeing and maintain the hope of people with dementia.

The current study highlights the significant role that others have in maintaining the hope of people with dementia. It demonstrates an ongoing need to challenge stigmatising discourses of dementia, as these act as barriers to hope. Post-diagnostic support would benefit from going beyond a preoccupation with reducing symptoms (Spector et al., 2006) to include interpersonal hope fostering interventions. Health care professionals can do this by highlighting retained strengths during and post-diagnosis to highlight what people are still capable of in the context of dementia. It would also be beneficial to support carers and family members of people with dementia to maintain their hope, as hope was depicted as a reciprocal experience where others' hope helped to maintain the hope of people with dementia. Findings from previous research align with these avenues for facilitating hope. For example, positive social interactions were also identified by Wolverson et al. (2010) as being vital for hope. While the findings of Wolverson et al. (2010) were limited to the importance of maintaining personal relationships, this study highlighted that health professionals and society at large also had a role in fostering the hope of people living with dementia.

Poetry was found to be a useful gateway through which people could clearly demonstrate their capacity for hope. As such, poetry can be used to facilitate hope fostering discourses, challenging the hopeless and stigmatising narratives of dementia. This would be particularly useful to implement in healthcare settings as hopelessness in healthcare staff affects the quality of care and clinical outcomes in dementia (Kontos et al., 2020; Spector & Orrell, 2006). There is evidence to suggest that poetry interventions can be used to maintain the personhood of people with dementia in the eyes of those who care for them (Gregory, 2011). In a study evaluating a poetry-writing intervention, poetry was found to improve communication between people with dementia and their professional carers (Gregory, 2011). In addition, Garrie et al. (2016) found that medical students' attitudes toward people living with dementia significantly improved when they engaged in a poetry writing workshop with people living with dementia. Thus, poetry interventions can be used to improve the quality of care for people with dementia by supporting health professionals to develop balanced narratives of dementia. This would facilitate the challenging of stigmatising and hopeless narratives and influence the provision of hope fostering care practices.

Limitations and Future Research

Participants rarely provided details of their ethnicity on the demographic data form. As such, there is a lack of understanding of the diversity of recruited participants and whether findings are transferable to a range of ethnic identities. This is an important consideration as one of the main findings was the negative effect that stigma and hopeless discourses held by others had on the capacity for people with dementia to hold onto hope. Research highlights that negative narratives of dementia are heightened within Black and Ethnic Minority Groups, with people from these communities in the UK conceptualising dementia as "a white person's illness" (Berwald et al., 2016, p. 11). Thus, the experience of hope is likely to be different in Ethnic Minority Groups who face increased stigma and discrimination in health care settings. On the other hand, people in Ethnic Minority Groups may have unique resources, with concerns about help-seeking relating to a perceived risk of compulsory institutionalisation and the desire of families to hold care responsibility (Berwald et al., 2016; Roche et al., 2021). With findings in the current study suggesting that strong family relationships facilitate hope, this is also likely to affect hope experiences. Thus, the explicit exploration of hope and dementia in Ethnic Minority Groups remain highly relevant for future research, which can support culturally sensitive hope fostering discourses in dementia care.

Additional limitations are also related to the sampling issues within this study. This study originally had a Phase Two of the recruitment processes where activity coordinators in care homes were contacted and asked to run poetry writing workshops on hope for their residents with dementia. With the informed consent for their residents, these poems would have then been submitted as part of this study. Phase Two was designed to diversify participants to include those with more moderate to severe dementia. Due to limited staff and pressures on care homes as a result of COVID-19, none of the care homes contacted had the capacity to participate in this research. As such, all participants lived in their own homes and had an average of 5 years since the time of diagnosis. The further losses in independence and increased impairment that people in later life experience may influence the experiences of hope in people with advanced dementia (Erickson, 1977; Moniz-Cook et al., 2006). The findings of this study cannot, therefore, reflect the experience of hope in those with severe dementia in supported living, and explorations of hope in people with advanced dementia remains an important avenue for future research.

Conclusions

The current study took a unique approach to exploring the lived experience of people with dementia, highlighting the value of using poetry to explore complex experiences such as hope. This study demonstrates that people with dementia are capable of hope, and highlights that hope supports people to live well with dementia. Given the protective and adaptive function of hope in the lives of people with dementia, hope fostering interventions are needed to support the development and maintenance of hope in clinical practice. A key finding here is the role that others play in maintaining the hope of people living with dementia. Hope can be supported through valuing the personhood of people with dementia and providing opportunities for engaging in pleasant experiences in the here and now, with specific avenues for support being mindfulness-based and poetry interventions. It would be beneficial for future research to explore how mindfulness-based and poetry interventions affect hope and the overall well-being of people with dementia.

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The Authors declare that there is no conflict of interest.

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Part Three: Appendices

Appendix A. Submission Guidelines for Journal of Arts and Health

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- Data Sharing Policy
- Publication Charges
- Copyright Options
- Complying with Funding Agencies
- My Authored Works

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- Systematic and Literature Reviews
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    - Endnotes
- Should contain a structured abstract of 150 words.

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- **Main part of manuscript:**
  Background. This should establish the context and rationale for the research and provide an overview of the paper. It should also provide a critical account of current relevant research, showing how evaluation of its strengths, limitations and gaps supports the rationale for the current study.
- *Research approach and methodology*. This should begin with a statement of the research aims and objectives. As well as informing the reader about the rationale for the approach taken this section should provide a critical account of the methods used. It should address the responses by the researcher/s to any methodological or ethical challenges they faced during the study.
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Appendix B. Data Extraction Example for Systematic Literature Review

Group: Poetic Transcription

Subgroup: Poetic transcription as a primary data analysis

Paper, country: Stenhouse, 2014 (UK, Scotland)

Health context and research aims

To understand the experience of being a patient on an acute psychiatric inpatient ward (people who hear voices).

To open up spaces for the voices of participants to be heard.

Participant characteristics

13 people (6 male, 7 female; aged 18–65; a variety of diagnoses and numbers of hospital admissions). Recruited from an acute ward in a large psychiatric hospital serving an urban–rural area in Scotland between May and August 2006. Interviewed two-weeks post discharge.

Rationale of poetic transcription

To address issues of power and authorship (how much of the service user's voice is heard when there is issues of power in the relationship and analysis process – which parts do the authors value) and decenter the researcher's voice and center the participant's voice to be heard.

Those to occupy marginalized discourses struggle to be heard within dominate discourse if health care – need to find a way to center the voices of the marginalized.

"As we speak about the people we study, we also speak for them. As we inscribe their lives, we bestow meaning and promulgate values. (Richardson 1990, p. 12)"

Not meant to represent a generalizable truth, rather they are meant to sensitise the reader to the issues experienced by the research participants.

Epistemological position/research principles

Narrative epistemology – human beings represent experiences through narratives/language, and create reality through narrating and linguistic choices used to do this. Co-production, interpretive

Post-modernist epistemologies

Method of poetry creation

Unstructured interviews (so narratives can be structed as participants chose) – researcher as active listener. Interviewed in place of choice (all chose home, duration = 25mins to 2hrs).

Interviewed -> main themes summarised -> summary sent to participants -> second interview based on summary to clarify and opportunity to change/edit -> transcription -> conceptualised as small narratives within a big narrative -> small narratives = units of analysis -> units transcribed, focus on use of structure to create units -> how small units/narratives form the bigger whole narrative -> poems created with verbatim phrases and images central to narratives

Method of analysis (and dissemination)

Analysis perspective: sociolinguistic theories -> holistic analysis -> focused on the context and structure of the narratives in the interviews and capture these in the poems. One poem created for each participant to represent their narrative.

Strengths of using poetic data

Allows readers to engage with the experience as they have to actively interpret the meaning of the (policy makers, practitioners and educators) - poems enabled holistic re/presentation of each participant's experience - traditional presentational style, using chunks of narrative to support the interpretation of data, is congruent with a fragmentary rather than holistic approach to narrative analysis. Allows use of imagery, metaphors and phrases used by participants are part of these resources and used deliberately by them to represent their experiences.

By creating a poem where participants language and speech style is maintained, this prevents silencing participants and reduced researcher's power who might use their own language to present the data. Allow individual, rather than the collective voice, to be heard – people experience the same things differently based on values, believes etc.

Research – ensuring participant voices are heard

Identifies avenues to further research – use of re/presenting

Clinical relevant findings – allowing nurses to engage with participant experiences more

Findings relevant to policy – deeper understanding can allow for policy changes relevant to participants

Limitations of poetic data

Consider the impact of their authorship on the re/presentation of the experience of the other.

This was a small qualitative study using a small sample in a particular historical and social context - findings therefore represent a snapshot of the experience of being a patient on an acute psychiatric inpatient ward.

Focus on individual narratives – can it be generalized?

Findings

Poems presented as the findings (4), each representing small narrative intertwining to form a large whole narrative – very comprehensive and allows readers to fully engage with the voice of the participants

Theoretical conceptualisation of findings

Compassion, empathy, individuality, person-centered care, concepts of recovery – not heavily discussed by present.

Appendix C. NICE Quality Appraisal Checklist for Qualitative Studies

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do?	Clear	Comments:

For example: - Is the purpose of the study discussed – aims/objectives/research question/s? - Is there adequate/appropriate reference to the literature? - Are underpinning values/assumptions/theory discussed?	Unclear Mixed	
Study design		
3. How defensible/rigorous is the research design/methodology? For example: - Is the design appropriate to the research question? - Is a rationale given for using a qualitative approach? - Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? - Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:

Data collection		
4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and	Clearly described Unclear Not described	Comments:

presented to the participants?		
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		

8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'? For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:

10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feedback on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:

12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		

14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comment

Appendix D. Included Studies Quality Assessment

Paper	NICE (2009) Checklist Item Number													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Rating
Carvalho et al. (2021)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Clark-McGhee and Castro (2015)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Duffy and Aquino-Russell (2007)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++
Guy (2018)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++
Johnson et al. (2021)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Kooken, et al. (2007)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Not sure	++
MacDonald (2017)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Madill and Hopper (2007)	Appropriate	Clear	Defensible	Appropriately	Clearly Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Mckenzie (2021)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Shinebourne (2012)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Souter (2005)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Stenhouse (2014)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Appendix E. Submission Guidelines for Dementia

Manuscript Submission Guidelines:

This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/dementia to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Dementia 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 ***Dementia* 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.

If you have any questions about publishing with SAGE, please visit the SAGE Journal Solutions Portal

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

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

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to 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.

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

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

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.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia 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 Dementia 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, and 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 have provided the full name and institution of the review committee, in addition to the approval number.

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. The confirmatory letter may be uploaded with your submission as a separate file.

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

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

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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

Dementia 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 plagiarised 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.

3.3 Open access and author archiving

Dementia offers offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

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4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

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

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

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

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

4.4 Supplemental material

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

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

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

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Visit http://mc.manuscriptcentral.com/dementia 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.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

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).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

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.

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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 authorising 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.

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7. Further information

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

dem.pra@sagepub.com

Appendix F. Confirmation of Ethical Approvals

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PRIVATE AND CONFIDENTIAL
Sherry Amponsem
Faculty of Health Sciences
University of Hull
Via email

9th June 2021

Dear Sherry

REF FHS340 - The meaning and experience of hope by people living with dementia as expressed through poetry

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

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PRIVATE AND CONFIDENTIAL
Sherry Amponsem
Faculty of Health Sciences
University of Hull
Via email

27th July 2021

Dear Sherry

REF FHS340 - The meaning and experience of hope by people living with dementia as expressed through poetry – Form C

Thank you for your submitting your ethics Form C: Notice of Substantial Amendment to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

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PRIVATE AND CONFIDENTIAL
Sherry Amponsem
Faculty of Health Sciences
University of Hull
Via email

9th March 2022

Dear Sherry

REF FHS340 - The meaning and experience of hope by people living with dementia as expressed through poetry – Form C

Thank you for submitting your ethics Form C: Notice of Substantial Amendment to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

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Appendix G. Main Recruitment Poster

UNIVERSITY OF HULL

ARE YOU LIVING WITH DEMENTIA?

WOULD YOU LIKE TO SUBMIT A POEM ON WHAT HOPE MEANS TO YOU?

My name is Sherry and I am a Trainee Clinical Psychologist at the University of Hull.

I am carrying out research to explore the meaning and experience of hope for people living with dementia.

With my love for poetry, I would like to read your poem on this topic!

Please visit the website below to download and read the research information sheet before taking part.

https://hull.onlinesurveys.ac.uk/hope-dementia-and-poetry

Here are there poetry styles that you can write your poem with

Free style: where you write in whatever style you like

Acrostic poem: where you write a poem and the first letter of each line spells out H>O>P>E

Sense poem: where you complete some/all these lines:
Hope is...
Hope sounds like...
Hope smells like...
Hope looks like...
Hope tastes like...
Hope makes me feel like...

IF YOU OR THOSE YOU WOULD LIKE TO SUPPORT YOU WITH WRITING/SUBMITTING THE POEM HAVE ANY QUESTIONS ABOUT THIS RESERCH, PLEASE CONTACT ME BY EMAIL ON S.AMPONSEM-2019@HULL.AC.UK

Appendix H. Recruitment Video

https://www.youtube.com/watch?v=zbFcBQwvBTo

Appendix I. Participant Information Sheet

Version number: 1
Date: 30/04/2021

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Hope and Dementia Research Study
Research Information Sheet – For Participants

Research Title: The meaning and experience of hope by people living with dementia as expressed through poetry.

My name is Sherry Amponsem, and this is an information sheet about the Hope and Dementia research I am undertaking for my thesis. Before deciding whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish (easy read version also available).

Please feel free to contact me if there is anything that is not clear or if you would like more information. Additionally, if you would prefer me to talk this information through with you on the phone then please contact me – my number is at the end of this document.

What is the purpose of the research?

People are very frightened about dementia and much of what is written about dementia is very negative, so it is important to talk about the things that can help people to live well. As such, we hope to use this research to learn about what hope means to people with dementia and what people hope for. Poems submitted about hope will also be gathered in an anthology to be shared online and with participants with the aim of showcasing the creativity of people living with dementia, while giving space for their voices to be heard.

Who can take part in the research?

If you are a person living with dementia who would like to write a poem about hope, and can do so in English, then you can take part in this research. You can receive support from family members, friends or carers to write and submit your poem about hope.

Do I have to take part in the research?

It is completely up to you whether you take part in the research. If you decide not to take part in the research, this will not affect your current or future use of any services and sources of support in any way.

What will I have to do if I take part in this research?

1) **Reading the information sheet.** Please read this information sheet thoroughly and contact me if you have any questions before taking part in the research.
2) **Writing a poem.** Write a poem about the meaning and experience of hope. Each person can submit up to three poems. Please write your poem using one of the following three poetry styles:
    a. **Free style poem** – your poem can be in any poetry style you like, e.g., where words do not have to rhyme with each other or be in any particular order.

   b. **Acrostic poem** – the first letter of each line of your poem spells out HOPE. Your poem can be longer than four lines where you start with H again on your fifth line.
   c. **Sense poem** – each line of your poem starts with a combination or all these starter sentences:
      i. Hope is…
      ii. Hope tastes like...
      iii. Hope sounds like…
      iv. Hope smells like…
      v. Hope looks like…
      vi. Hope makes me feel…
3) **Submitting your poem.** Once you have written your poem, please visit https://hull.onlinesurveys.ac.uk/hope-dementia-and-poetry to submit it so I can see it.
4) **Submitting some information about you.** You will be asked to submit some information about yourself, e.g., your age, your gender, type of dementia (if known), city/country of residence and ethnicity.
5) **Contact details.** You would then be asked for the address you would like your copy of the anthology to be sent to.
6) **Consent.** Finally, you will be asked to submit the filled form, showing that you agree to share your poem and to take part in the research. You will have the following three consent options to choose from:

   a. I consent for my poem and information to be used in the research.
   b. I consent for my poem and information to be used in the research and for my poem to be included in the anthology without my name.
   c. I consent for my poem and information to be used in the research and for my poem to be included in the anthology with my name (you will be asked to provide the name you would like published with your poem).

   The inclusion of your poem in the anthology is optional and choosing not to have your poem published will not affect your participation in the research.

Are there any possible risks or disadvantages in taking part in the research?

It may take a while to write your poem, and we cannot pay you for your time or your poem. However, we hope that you will enjoy writing a poem about hope. Additionally, you have until the end of the data collection period of the research (which will be around March 2022) to submit your poem, so you can take your time with this, and you do not have to write the whole poem in one sitting.

You may want you take part in this research but may find that you have never written a poem before and are not sure where to start. This may be frustrating. The three different styles of poems outlined for this research should hopefully provide you with a starting point. For example, you can choose to write an acrostic poem and just note down words that come to mind when you think of hope that starts with H, then O and so on. Remember, you can also ask family members, friends, and carers to help you write and submit your poem.

You may also find the experience of writing about hope and thinking about your dementia difficult. If this happens, please take a break from the activity, and only come back to it if you feel able. There are some potential sources of support later down this information sheet if you feel like it might help to someone about how you are feeling.

What are the possible benefits of taking part in the research?

We cannot promise that you will have any direct benefits from taking part in the study. However, we hope that you will enjoy taking part in the research and in the poetry writing activity. You will have the opportunity to share your experiences and contribute to research. It is hoped that the poems you write will help us to understand more about the meaning and experiences of hope by people living with dementia.

Will information about me be kept confidential?

If you want a copy of the poetry anthology with all the poems in, then we will need your name and address. We will record this in a safe place and delete it once we have sent the anthology to you. All your personal data will be handled according to the Data Protection Act.

We will publish your poems and talk about them in the research report, but your name will not be included in this. Your poem will only be connected to your name in the anthology if you choose to have it published with your name.

Information about you will be stored very securely and will be only accessible to the researcher and her supervisors. All personal details will be destroyed at the end of the research.

What if I change my mind about taking part in the research?

Once you submit your data, you have can withdraw your data up to the point of data analysis (which will be two weeks after submission). You can withdrawal without providing a reason, and all your data will be destroyed and not included in the research and anthology. After the point of data analysis, your data may be committed to the final report, with demographic data and personal information stored separately to submitted poems.

What will happen to the results of the study?

The results of the study will be summarised in a written report as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk/. The research may also be published in academic journals or presented at conferences. Submitted poems will also be published in the anthology (as your consent details) and will be shared online and with participants.

Who can I contact if I need to talk to someone?

We hope that people will enjoy writing poems about hope. However, if you feel upset and would like to talk to someone, the following options might be worth exploring:

- Family and friends
- Staff (e.g., if you live in a residential home)
- Your GP
- Free Admiral Nurse Dementia Helpline on 0800 888 6678 or email helpline@dementiauk.org (Admiral Nurse are a registered nurses and experts in dementia care. They give practical, clinical, and emotional support to families living with dementia)

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details.

Sherry Amponsem
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07976 071109
E-mail: S.Amponsem-2019@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you have any additional questions or concerns that you do not wish to discuss with the primary researcher, or if you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisors' details below for further advice and information:

Dr Emma Wolverson
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0)1482 464170
E-mail: E.Wolverson@hull.ac.uk

Dr Christopher Clarke
E-mail: C.Clarke@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix J. Easy Read Participant Information Sheet

Version Number: 2
Date: 30/04/2021

UNIVERSITY
OF HULL

Hope and Dementia Research Study – Information about the research

Research Title: The meaning and experience of hope by people living with dementia as expressed through poetry.

My name is Sherry Amponsem.

I am inviting you to take part in a research project on Hope and Dementia.

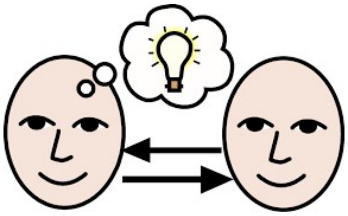
Before deciding whether you want to take part, it is important for you to understand why the research is being done and what taking part will involve.

Please take time to read this information sheet carefully and discuss it with others if you wish.

Please ask me if you have any questions or if there is anything that is hard to understand (my contact details are at the end of this information sheet).

What is this research about?

This research is to use poems to find out the meaning and experience of hope for people who are living with dementia.



It will also help us understand more about the meaning of hope for people with dementia and what people hope for.

Poems submitted about hope will also be gathered in an anthology to be shared online and with participants. This is to show the creativity of people living with dementia.

Who can take part in the research?

People who are living with dementia and who would like to write a poem in English.

You can ask for help family members, friends, or carers to write and submit your hope poem.

Do I have to take part in the research?

It is up to you if you take part in the research.

You can say yes or no.

If you say no, you will still get the care and support you need.

What will happen if I decide to take part in the research?

1. **Reading the information sheet.** You will need to read this information sheet. Please email/phone me if you have any questions before you take part in the research.

2. **Writing a poem.** Write a poem about hope. Each person can share up to three poems. Please write your poem using one of the following three poetry styles:
    a. **Free style poem** – your poem can be in any poetry style you like, e.g., where words do not have to rhyme with each other.
    b. **Acrostic poem** – the first letter of each line of your poem spells out HOPE.
    c. **Sense poem** – each line of your poem starts with a combination or all these starter sentences:
        i. Hope is…
        ii. Hope tastes like...
        iii. Hope sounds like…
        iv. Hope smells like…
        v. Hope looks like…
        vi. Hope makes me feel…

3. **Submitting your poem.** Go online here https://hull.onlinesurveys.ac.uk/hope-dementia-and-poetry to submit your poem.

4. **Submitting some information about you.** You will be asked to submit some information about yourself.

5. **Contact details.** You would then be asked for the address you would like your copy of the anthology to be sent to.

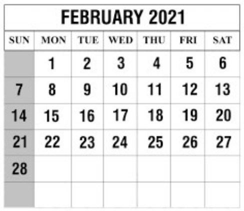
6. **Consent.** Finally, you will be asked to submit the filled form, showing that you agree to share your poem and to take part in the research.

   You will have the following three consent options to choose from:

   a. I consent for my poem and information to be used in the research.
   b. I consent for my poem and information to be used in the research and for my poem to be included in the anthology without my name.
   c. I consent for my poem and information to be used in the research and for my poem to be included in the anthology with my name (you will be asked to provide the name you would like published with your poem).

   The inclusion of your poem in the anthology is optional and choosing option (a) will not affect your participation in the research.

Are there any possible risks or disadvantages in taking part in the research?

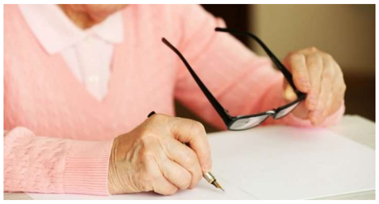


FEBRUARY 2021

SUN	MON	TUE	WED	THU	FRI	SAT
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28						

It is going to take a while to write your poem and sadly, we cannot pay you for your time or poem.

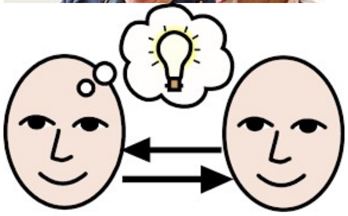
However, you have until the end of March 2022 to submit your poem. So, you can take your time with this, and you do not have to write the whole poem in one sitting.



You may want you take part in this research but may find that you have never written a poem before and are not sure where to start. This may be frustrating. The three different styles of poems outlined for this research should hopefully provide you with a starting point.

Remember, you can also ask family members, friends, and carers to help you write and submit your poem.

You may also find the experience of writing about hope upsetting. If this happens, please take a break from the activity, and only come back to it if you feel able.



What are the possible benefits of taking part in the research?

We cannot promise that you will have any direct benefits from taking part in the study. However, we hope that you will enjoy creating a poem.

It is hoped that the poems you write will help us to understand more about the meaning and experiences of hope in dementia.

Will information about me be kept private?

The research team will store all the information from the research very carefully, to keep information about you private.

They will also keep information on their secure computers. The computers are protected by private passwords.

What if I want to stop being in the research?

You can stop filling in the survey at any point. Once you submit your poem, you can ask me to delete your information and poem up to two weeks after your submission.

You do not have to give a reason for

changing your mind.

You will just have to tell me which poem was yours that you do not want to be used in the research.

What will happen to the information from the research?

I will write a report about the poems and about what hope means to people with dementia.

Your name will not be put in the reports, or anything else that tells people who took part in the research.

The information about yourself you give will not be connected to your poem.

At the end of the research, everyone who took part and wanted a copy of the anthology will be sent one.

Who can I contact if I need to talk to someone?

We hope people will enjoy writing their poem. However, if you feel after that you would like to talk to someone, here are some options you might want to explore:

- Family and friends
- Carers
- Your GP
- Free Admiral Nurse Dementia Helpline on
- 0800 888 6678 or email helpline@dementiauk.org (Admiral Nurse are a registered nurses and experts in dementia care. They give practical, clinical, and emotional support to families living with dementia)

Who should I contact for further information?

If you have any questions or want more information, please contact the me using the following contact details.

Sherry Amponsem
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07976 071109
E-mail: S.Amponsem-2019@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you have any additional questions or concerns that you do not wish to discuss with the primary researcher, or if you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisors' details below for further advice and information:

Dr Emma Wolverson
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0)1482 464170
E-mail: E.Wolverson@hull.ac.uk

Dr Christopher Clarke
E-mail: C.Clarke@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix K. Questions to support poetry writing

UNIVERSITY OF HULL

Version Number: 1
Date: 07/07/2021

Hope and Dementia Research Study

Research Title: The meaning and experience of hope by people living with dementia as expressed through poetry.

<u>Questions to help you write your poems.</u>

To write <u>freestyle poems</u>, you may go through the following questions to help you:

a. What comes to mind when you think about hope?
b. What does hope to mean for you?
c. How does it feel?
d. Is there an image that comes to mind when you think about hope?
e. What words come to mind when you think about hope?
f. If I could feel what hope feels like for you, what would that be like?
g. Could you describe it more?
h. Is there someone you think of when you think about hope?
i. When do you feel hope the most?
j. What is that like?

To write <u>acrostic poems</u>, you may go through the following questions to help you:

a. When you like of hope, what other word comes to mind for you that starts with H?
b. Does that word go on to make a sentence about what hope means and feels like for you?
c. Is there another word that comes to mind when you think of hope, this time one that starts with an O?
d. Does that word go on to make a sentence of what hope is like for you? It is okay if it does not, and that word can stand alone.
e. We can now think about P – is there a word that comes to mind about what hope means when you think about the letter P?
f. Does that word go on to make a sentence about what hope means and feels like for you?
g. When you like of hope, what other word comes to mind for you that starts with E?
h. Does that word go on to make a sentence about what hope means and feels like for you?
i. We can go through the letters of hope again and make the poem longer if you would like? Or we can finish the poem here as well if you would like.
j. Is there anything you want to change in your poem about hope?

To write <u>sense poems</u>, you may go through the following questions to help you:

a. If I read these sentences, could you complete them if what comes to find for you?
b. Hope is…
c. Hope tastes like…
d. Hope sounds like…
e. Hope smells like…
f. Hope looks like…
g. Hope makes me feel…
h. Are there any other things that hope feels like to you?
i. Is there anything you would like to change in your poem about hope?

Appendix L. Participant Consent Form

Version Number: 1
Date: 03/05/2021
Name of researcher: Sherry Amponsem

UNIVERSITY
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Hope and Dementia Research Study
Participant Consent Form

Research Title: The meaning and experience of hope by people living with dementia as expressed through poetry.

Please initial box

1. I have read the information sheet dated 30/04/2021 (version 1 or 2). I have had the opportunity to consider the information, ask questions and understand what is involved. ☐

2. I understand that I can request to be withdrawn from the study before poetry submission, and two weeks after poetry submission, without giving any reason. I understand that this will not affect my future or current use of services. ☐

3. I understand that a copy of the anthology created at the end of the research will be sent to me. ☐

   Please provide the address for this to be sent to below:

Consent Options (please tick one and provide additional details as required)

☐

a) I consent for my poem and personal information to be used in the research. ☐

☐

b) I consent for my poem and personal information to be used in the research and for the poem to be included in the anthology without my name.

c) I consent for my poem and personal information to be used in the research and for the poem to be included in the anthology with my name.

Please provide the name to be published with your poem in the anthology:

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix M. Demographic Data Form

Version Number: 1
Date: 03/05/2021

UNIVERSITY
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Hope and Dementia Research Study

Demographic Data Form – For Participants

Research Title: The meaning and experience of hope by people living with dementia as expressed through poetry.

This information provided here will not be connected to your poem after the two-week window where you can withdraw your third part consent. The information is collected to get idea about the group of people who take part in the research.

Once completed, please post or email to the researcher (details below) along with a completed and signed consent form.

Demographic information	Please state
Age	
Gender	
Ethnicity	
Type of dementia (if known)	
Time since diagnosis (if known)	

Most previous occupation (if known)

City/country of residence

Place of residence (care home or community)

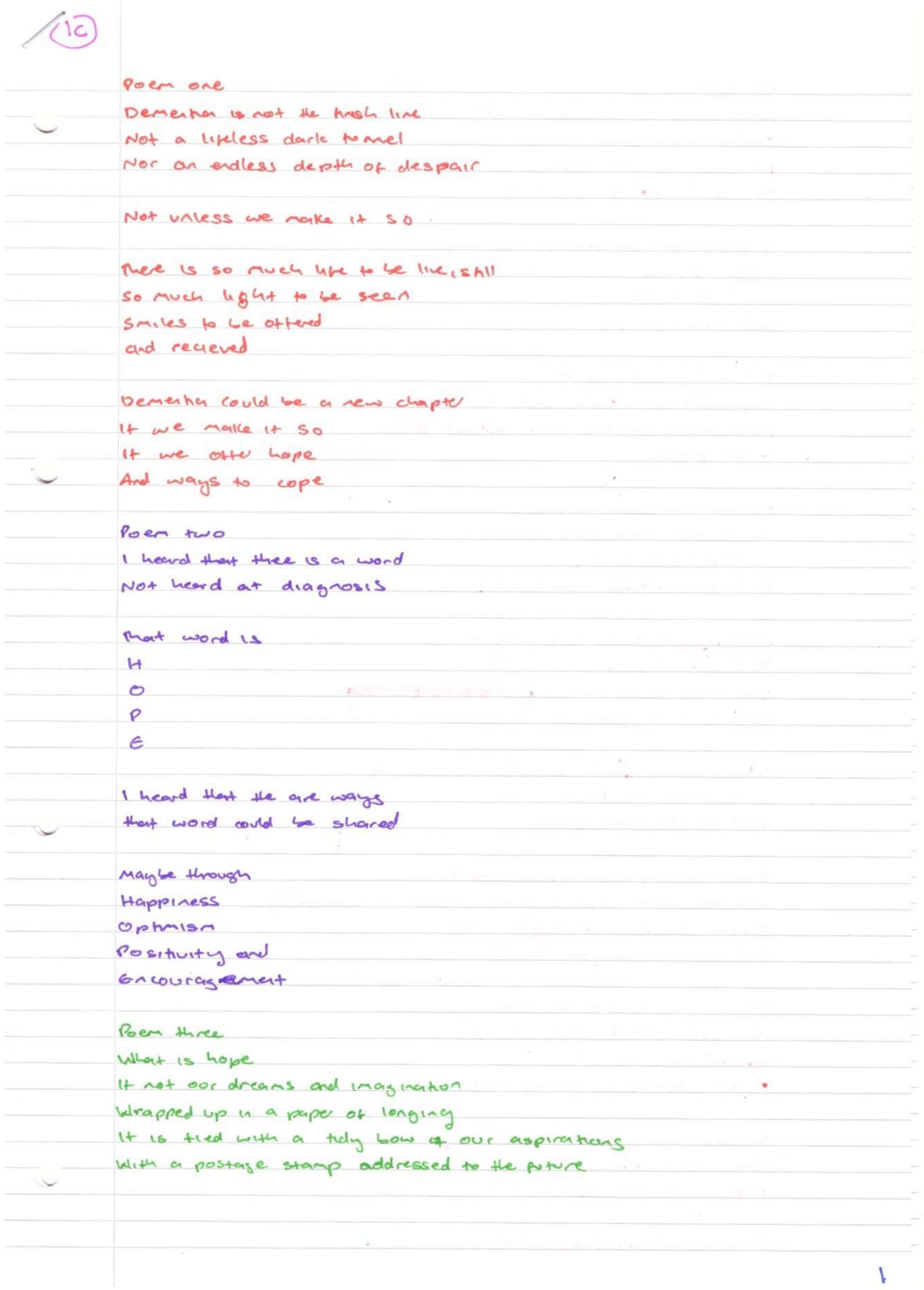
Thank you for taking the time to complete this form. Please find contact details for the researcher below.

Sherry Amponsem
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07976 071109
E-mail: S.Amponsem-2019@hull.ac.uk

Appendix N. Anthology of Participant Poems

https://www.canva.com/design/DAFBplNp6RU/rXxA7daEkhRTHIjZrQiXkw/view?utm_content=DAFBplNp6RU&utm_campaign=designshare&utm_medium=link&utm_source=publishsharelink

Appendix O. Extracts of poems written during familiarisation of data



1c

Poem one
Dementia is not the harsh line
Not a lifeless dark tunnel
Nor an endless depth of despair

Not unless we make it so

There is so much life to be live, still
So much light to be seen
Smiles to be offered
and recieved

Dementia could be a new chapter
If we make it so
If we offer hope
And ways to cope

Poem two
I heard that there is a word
Not heard at diagnosis

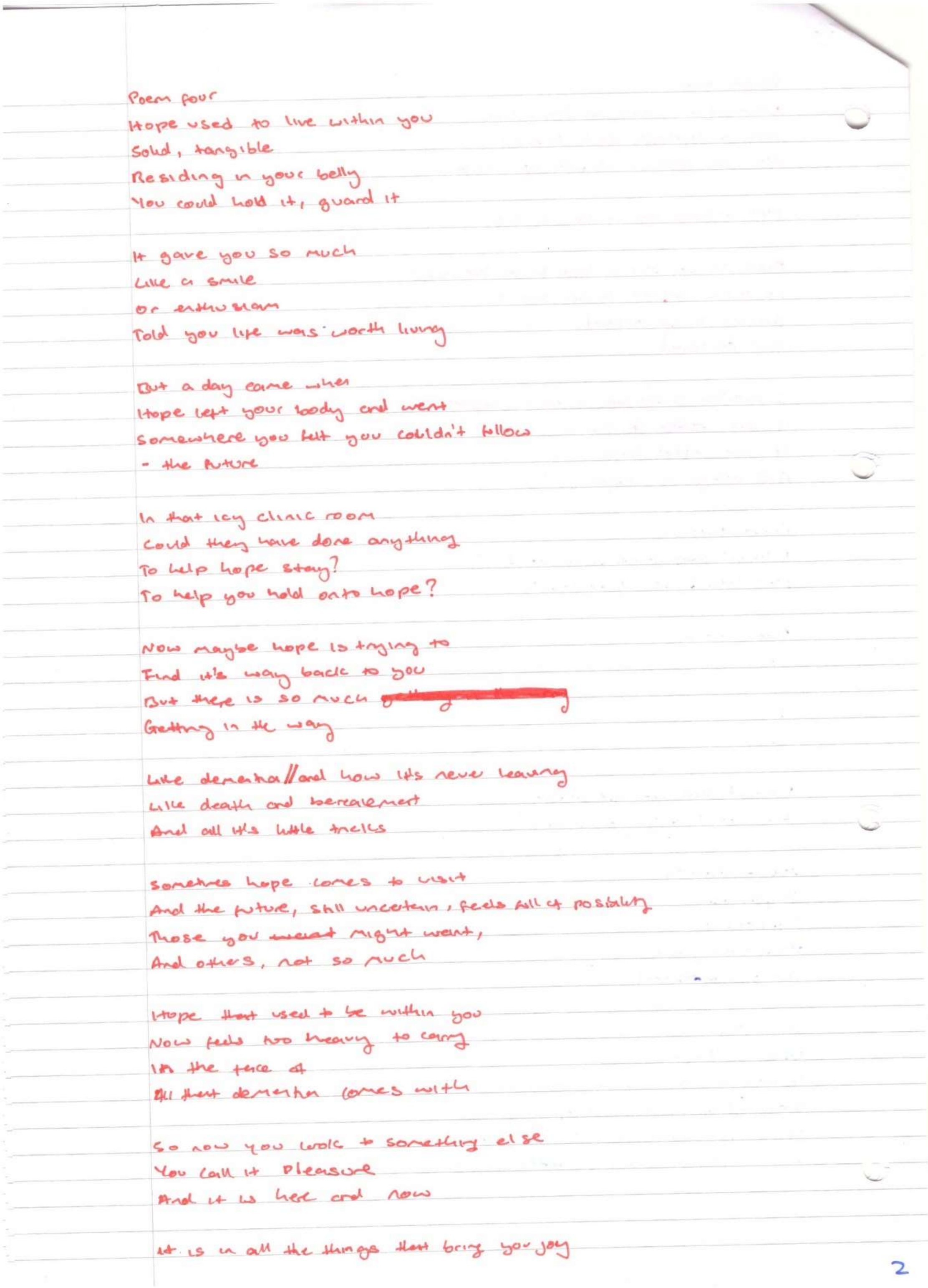
That word is
H
O
P
E

I heard that there are ways
that word could be shared

Maybe through
Happiness
Optimism
Positivity and
Encouragement

Poem three
What is hope
It not our dreams and imagination
Wrapped up in a paper of longing
It is tied with a tidy bow of our aspirations
With a postage stamp addressed to the future

1



Poem four
Hope used to live within you
Solid, tangible
Residing in your belly
You could hold it, guard it

It gave you so much
Like a smile
or enthusiasm
Told you life was worth living

But a day came when
Hope left your body and went
somewhere you felt you couldn't follow
- the future

In that icy clinic room
Could they have done anything
To help hope stay?
To help you hold onto hope?

Now maybe hope is trying to
Find it's way back to you
But there is so much ~~[illegible]~~
Getting in the way

Like dementia // and how it's never leaving
Like death and bereavement
And all it's little tricks

Sometimes hope comes to visit
And the future, still uncertain, feels full of possibility
Those you ~~meant~~ might want,
And others, not so much

Hope that used to be within you
Now feels too heavy to carry
In the face of
All that dementia comes with

So now you look to something else
You call it Pleasure
And it is here and now

It is in all the things that bring you joy

2

Like nature, family and food

I wonder// does it look like hope
to you// like it does to me?

These little pleasures,
that tell you life is worth living

Poem five
Hope does things for us
Like keep us connected
And keep us living
It is wanted
It can be given
If so chosen
Hope is here, there and everywhere
It is here, in the now
Found in the sounds and colours of nature
It is there, on your faces
Found in your warmth and smiles
It is everywhere, like in the past
Embracing memories of youth

Poem six
There is so much to hope for
But let's not forget the fear...
Of how the disease will progress
And what this means for me
How there is no quick fix

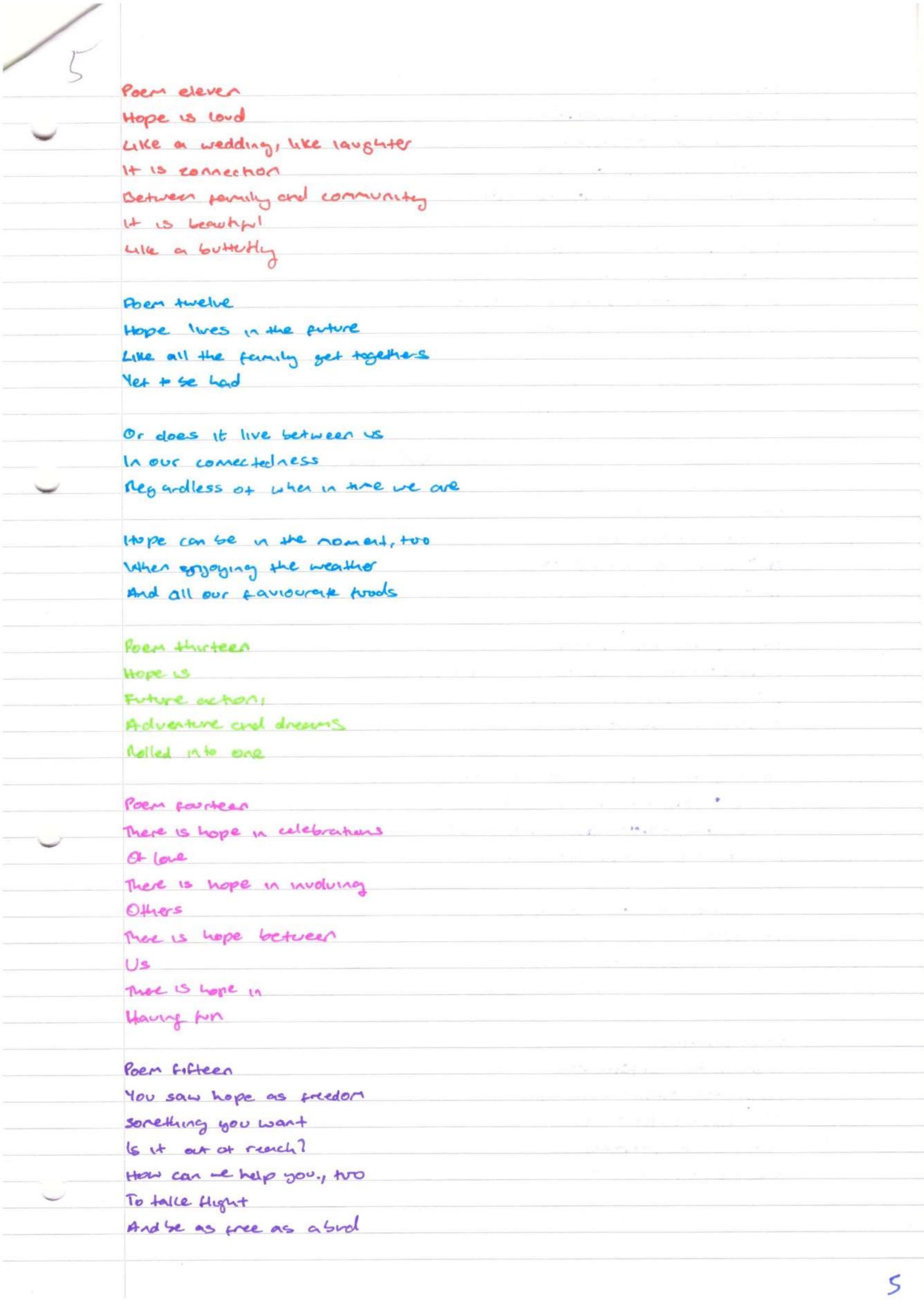
But my hope is multi-dimensional
I hope for a cure,
A better future
While living in laughter, friendship and creativity,
Mindful of the present

Poem seven
I am on an endless journey
With a deadline that dementia has put in place
On this journey I am searching for hope
I am looking for hope in those around me
Maybe there hope will give me hope
I am looking for hope in my medical professionals
Maybe thee understanding will give me hope
I know what hope me
Maybe peace and fearless nights
I am on an endless journey
On this journey I am searching for hope
Will you help me find it?

Poem eight
Your hope is my hope
And my hope is your hope
Hope is something that keeps us together
It blooms within communities
Is blind to our differences
And sensitive to our similarities
Wheather we are together as
People living with dementia, as
People of the same faith, as
People of the same family
Hope is within us / between us
And for eachother

Poem nine
Hope is asked for
It can be given
If we try
Through listening
Through respect
Hope can be given
Just as it' is asked for

Poem ten
Hope,
It is in the
Here and now
In the little things
That bring us happiness



5

Poem eleven
Hope is loud
Like a wedding, like laughter
It is connection
Between family and community
It is beautiful
Like a butterfly

Poem twelve
Hope lives in the future
Like all the family get togethers
Yet to be had

Or does it live between us
In our connectedness
Regardless of when in time we are

Hope can be in the moment, too
When enjoying the weather
And all our favourite foods

Poem thirteen
Hope is
Future action,
Adventure and dreams
Rolled into one

Poem fourteen
There is hope in celebrations
Of love
There is hope in involving
Others
There is hope between
Us
There is hope in
Having fun

Poem fifteen
You saw hope as freedom
Something you want
Is it out of reach?
How can we help you., too
To take flight
And be as free as a bird

5

Poem sixteen
Hope is so much more
Than can be contained
In the A B Cs of any
Words we can come up with

Hope has something to give
It makes promises
It keeps those promises, often
In reality or in dreams

It helps us overcome
laugh
connect
and live

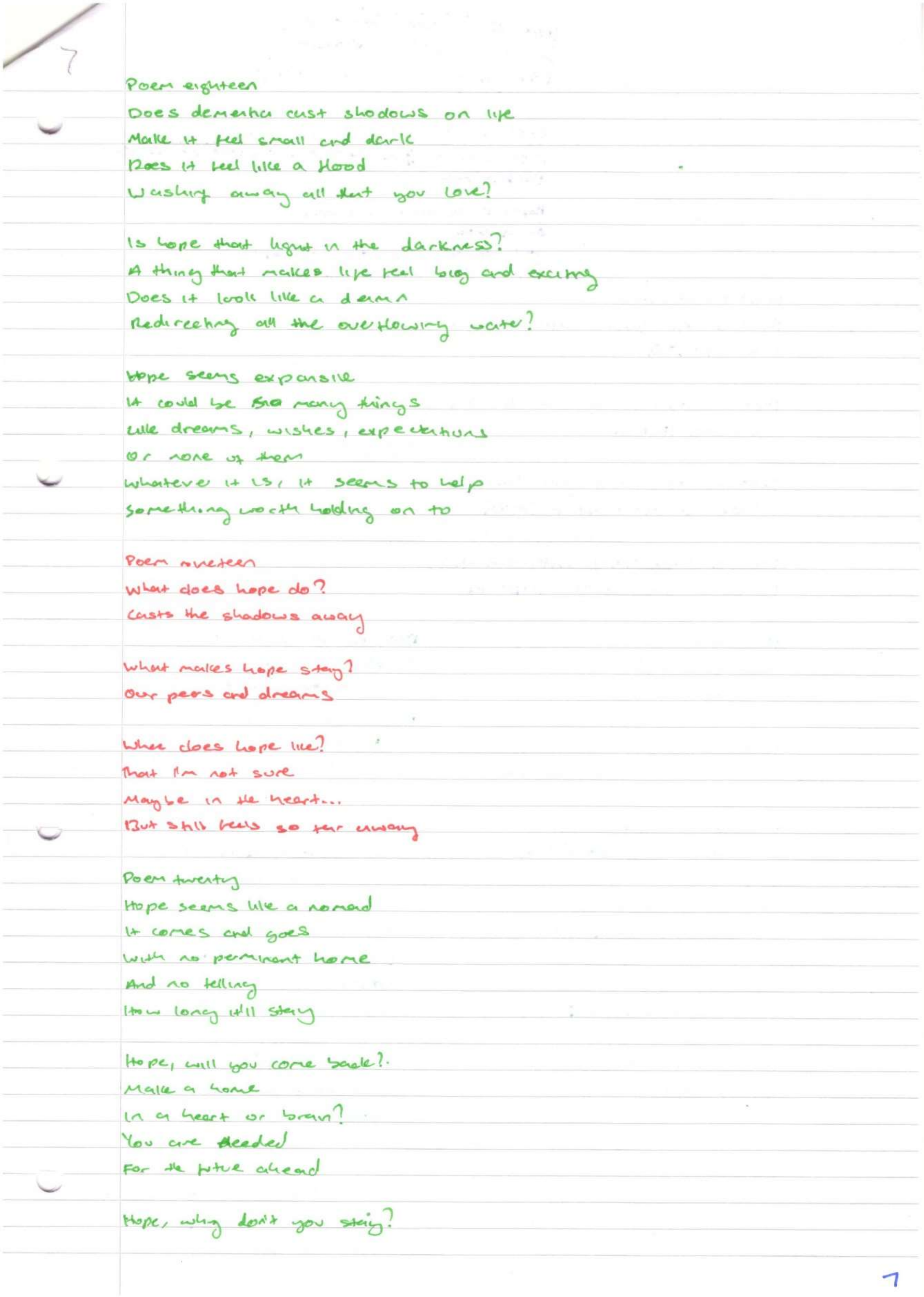
Hope is alive
It lives within us
~~[illegible]~~ it is all around us
Both felt and seen

Hope is reliable, eternal
Trandsceeds limits of time and space
But it is sometimes illusive
A perfect justaposition

Hope guides and lights the way
It is vestibule and Xanadu
It is the journy, the destination
And the rest stops along the way

It gives us time to think
To reflect
regroup
and carry on

Poem seventeen
Hope is held within me
Keeps me optimistic, and
My expectations alive
Living in the moment,
one day at a time



7

Poem eighteen
Does dementia cast shadows on life
Make it feel small and dark
Does it feel like a flood
Washing away all that you love?

Is hope that light in the darkness?
A thing that makes life feel big and exciting
Does it look like a damn
Redirecting all the overflowing water?

Hope seems expansive
It could be so many things
Like dreams, wishes, expectations
Or none of them
Whatever it is, it seems to help
Something worth holding on to

Poem nineteen
What does hope do?
Casts the shadows away

What makes hope stay?
Our fears and dreams

Where does hope live?
That I'm not sure
Maybe in the heart...
But still feels so far away

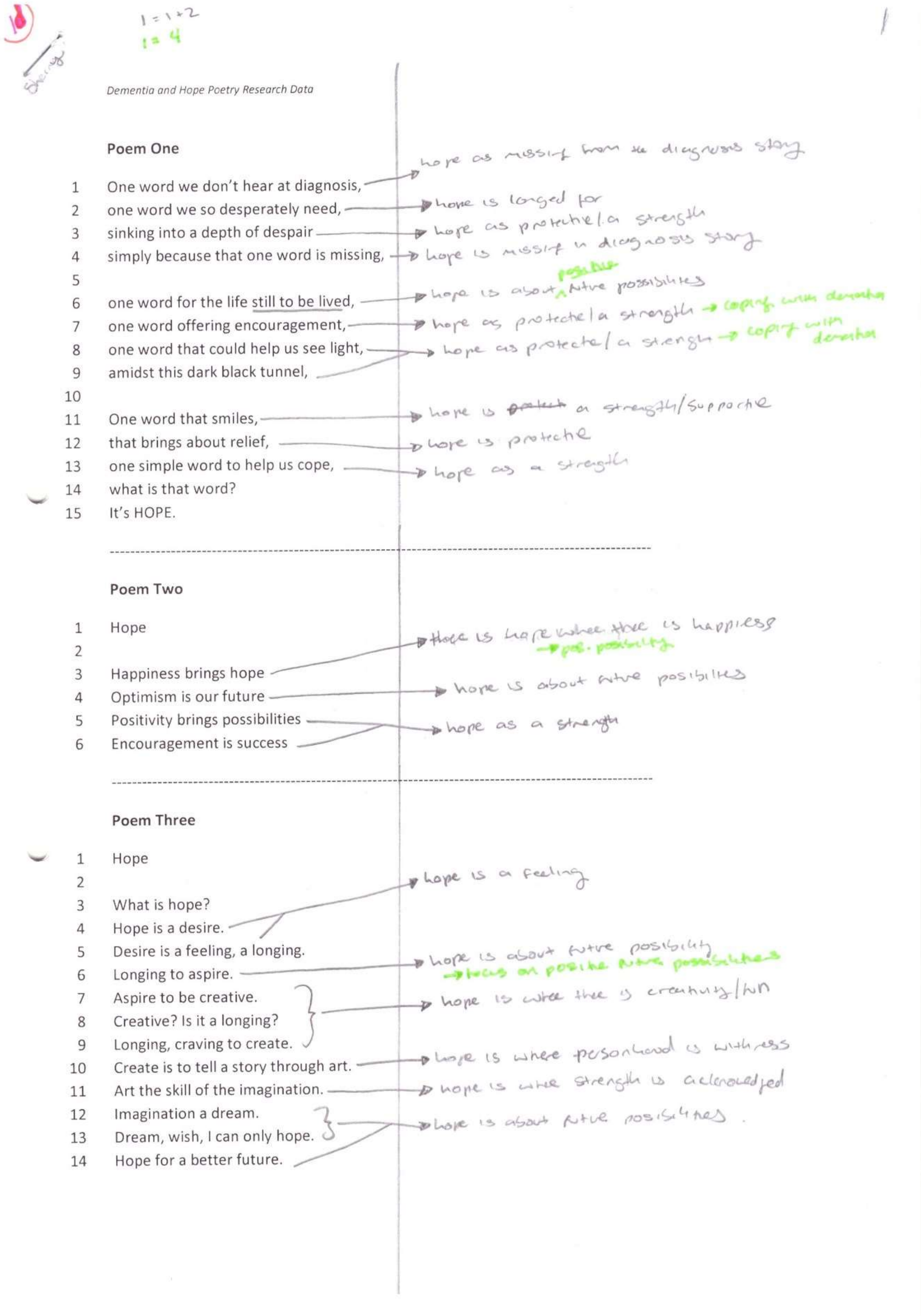
Poem twenty
Hope seems like a nomad
It comes and goes
With no perminant home
And no telling
How long it'll stay

Hope, will you come back?.
Make a home
In a heart or brain?
You are needed
For the future ahead

Hope, why don't you stay?

7

Appendix P. Extract of Coding



10

1 = 1+2

1 = 4

Sharing

Dementia and Hope Poetry Research Data

Poem One

One word we don't hear at diagnosis,
one word we so desperately need,
sinking into a depth of despair
simply because that one word is missing,

one word for the life still to be lived,
one word offering encouragement,
one word that could help us see light,
amidst this dark black tunnel,

One word that smiles,
that brings about relief,
one simple word to help us cope,
what is that word?
It's HOPE.

hope as missing from the diagnosis story
hope is longed for
hope as protective/a strength
hope is missing in diagnosis story
hope is about positive future possibilities
hope as protective/a strength → coping with dementia
hope as protective/a strength → coping with dementia
hope is ~~protect~~ a strength/supportive
hope is protective
hope as a strength

Poem Two

Hope

Happiness brings hope
Optimism is our future
Positivity brings possibilities
Encouragement is success

Hope is hope where there is happiness
→ pos. possibility
hope is about future possibilities
hope as a strength

Poem Three

Hope

What is hope?
Hope is a desire.
Desire is a feeling, a longing.
Longing to aspire.
Aspire to be creative.
Creative? Is it a longing?
Longing, craving to create.
Create is to tell a story through art.
Art the skill of the imagination.
Imagination a dream.
Dream, wish, I can only hope.
Hope for a better future.

hope is a feeling
hope is about future possibility
→ focus on positive future possibilities
hope is where there is creativity/fun
hope is where personhood is witness
hope is where strength is acknowledged
hope is about future possibilities.

Future is my tomorrow.
Tomorrow brings me back to hope.

hope is about future possibilities

Poem Four

Hope

What might we hope for
Living with dementia?

It's not easy to have hope
In your head when your
Brain disease is killing you.

Barriers to hope
- progression of dementia

There's no cure, we're told, so
Why get diagnosed?

lack of cure as barrier to hope

There's little help or understanding…
Precious gems that occasionally tickle you.

lack of support as barrier to hope
lack of understanding as barrier to hope
hope in fun/humour?

Bereavement plays its tricks.
You've been struck off the list of longevity.

Bereavement as barrier to hope
Narratives around dementia as barrier to hope

The grandchildren
The garden
Walking
Working
Trips you've dreamed about while you
Stared at a screen.

social connection is where hope is
hope is in mindfulness of the present / have you have (as opposed to what you want)
hope directs focus to values/goals

All might be gone
Or not
In a foggy distance…

hope is embeded in uncertainties/possibilities

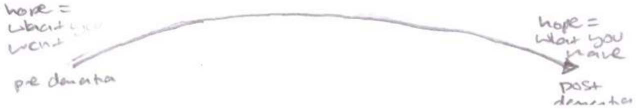
Hope is a smooth round pebble in your stomach.
You carry it with you
Caress it, cradle it
And guard it longingly
As long as you can.

hope is located in the body
hope is fought for
-having hope is an active process

Hope is…

Perhaps I'll die suddenly before I'm stuck staring out front
Perhaps I'll manage to end it myself…but when? and how?

hope is embedded in uncertainties/possibilities



Perhaps I'll end up in a really nice care home…
Coin toss chance?

Hope is…

Optimism
Hoping against the odds that all will be well
Believing life is worth living
Getting up each day with enthusiasm
A smile

There is, after all, no hope for us.
Quickly or slowly,
In a few years or two decades,
We will have withered on our vines and
Fallen.

How do you continue to breathe and eat and smile when
You lose all that makes it worth it?

No, it's not hope we need,

- there is none -
But joy in the little, tiny pleasures
The here and now.

The smell of woodsmoke
Sounds of spring birds rejoicing
Damp leaves under foot
Scented sweet peas on the table
Butterflies dancing in the sun
Birch leaves rustling breezily
A good cup of coffee
Your favourite cake
Sharp sweet tomatoes fresh from the greenhouse
Fox tracks in light snow
The crusty bark patterns of an old oak
And fresh crusty bread out of your oven

Pleasures.
What else is there?

The stone dropped out of hope in that icy clinic room, a few years back.
Now there is pleasure.
Find it wherever you can.

hope is embeded in uncertainties

hope is a strength/helpful
hope is perseverance
hope is a strength
hope as a strength/helpful
hope is in new beginings
hope is an active process
self – self
self – others
self – the world

narratives of dementia as barrier to hope
terminal nature of dementia as block/barrier to hope
loss as barrier to hope
without hope, there is difficulty
hope as unwanted
narratives of dementia as block/barrier to hope
Shift of future based hope to present based hope after dementia

Hope is mindfulness of the present
nature
food

diagnosis as barrier to hope

active process

1

Poem Five

Hope is a reason to keep on living
It tastes like sparkling wine, frothing across my tongue
Hope sounds like the crashing of ocean waves upon a rocky shore, connecting me to nature's rhythm
Hope smells like the fragrant purple heather, laying it's carpet across the moorland of my youth
It appears as a warm caring smile on a friendly face
And hope makes me feel contented loved and unafraid
Please give me hope

hope as a resource/strength
hope is in mindfulness of the present
food
nature
hope is in social comection
hope is in celebration of the past
hope as a resource / strenght
hope is longed for
hope is absent
hope is a gift
hope is given

Poem Six

They used to sing ' I hope I die before I get old'
But now I am old, and I am dying
With a hear that's failing, and a brain that's decidedly wonky
The hear can be fixed
The brain can't
So what do I hope?
I hope for a cure of course, everyone does
But it's probably not coming
So I hope for friendship
I hope to paint and write and laugh
To leave a good life
To keep busy, and we'll
And I hope not to deteriorate too fast
I know what I fear
I fear losing control, not being able to talk
Losing independence
So I hope for the disease to be slow
To treat me kindly
To let me die when I am old

fear of getting old
narratives around aging
blocks/barries to hope
death
barries to hope
health difficulties
terminal nature of dementia
hope for a cure
insight into realities of cure
hope in community / social interaction (comections)
hope in creativity
hope in fostering strengths
hope in fun
hope for a good life
hope for good health
fear as oppositional to hope
Barrier to hope / progession of dementia
hope for good health
hope for good death

Poem Seven

Is there HOPE after being dx'd with Dementia? Hopefully so...I hope my brain lasts long enough to figure it out.. I hope that the people who surround me have hope for me to survive this dreadful disease.. I hope I can gain some faith with my medical professionals that they truly understand this journeyi I am on.
I hope there comes a time when my tears stop falling and I can rest peacefully once again... like i hope for so many times!! hope is peace in my body and soul!!

hope in dementia is uncertain
hope for good health
there is hope in community
hope can be held for another
hope for a cure
hope is there when there is understanding
hope for peace

there is hope where there is happiness
hope is something that is shared
hope is a two-way street

Poem Eight

My Community
I find Hope in having a community of people just like myself,
Regardless of culture or country; race or religion, who love me as I am – me!
What I bring to the table: poems, articles or just a reassuring word
We research our common thread and try to understand - Dementia
I find happiness in their happiness; courage in their courage
I find purpose in this community of people, just like me, just as I am
hope where there is community

I find Faith in my church community, who are all like me and know me
Pilgrims on a ragged road; seeing thru a glass darkly, our final reward
We love one another, most of the time; some of the time or is it once in a while?
We try to love everyone the same; despite our flaws and failures
I find happiness in their happiness; courage in their courage
I find purpose in this community of people, just like me, just as I am
there is hope where there is social connection

I find Love in my family and friends, in my own community, in this life before me
Not knowing how much longer I have to cherish them; to live and love them
They are my memories; they are my thoughts and my every action is for them
Until there is nothing more to forget, nothing more to give, nothing more…
I find happiness in their happiness; courage in their courage
I find purpose in this community of people, just like me, just as I am

"…now in the end, these 3 remain Hope, Faith and Love. But the greatest of these is Love." 1 Corinthians 13:13

hope is embed in the past

there is hope where there is community
there is hope when personhood is acknowledged
there is hope when strengths are acknowledged
there is hope in learning/new knowledge
there is hope in empowerment
hope in perciverance
there is hope where there is community
there is hope when personhood is acknowledged
hope in perciverance
there is hope where there is community/social connections
there is hope in acceptence
hope is embeded in posibilites
hope is embeded in uncertanties

Poem Nine

Hope is all we ask for,
Our voices to be heard .
Peace to live our lives with dignity.
Each and everyone of us deserve.

hope is currently missing
hope is outside of us
hope can be given
hope is a gift
hope is desired
hope is felt when personhood is acknowledged

Poem Ten

Hope sounds like happiness
Hope smells like baking bread
Hope looks like a rising sun, the start of a new day
Hope tastes like roast beef

there is hope where there is sun
hope is being mindful of the present → food → nature
hope is in new beginnings

6

Poem Eleven

1 Hope is future happiness, its a wedding
2 Hope sounds like laughter
3 Hope smells like an autumn bonfire
4 Hope looks like our grandchildren
5 Hope tastes like a cream tea
6 Hope makes me feel like a butterfly

→ hope is about what the future holds
→ hope is where there is celebration
→ hope is where there is fun
→ hope is where there is celebration | community
→ hope is where there is family
→ hope is being mindful of the present
→ hope as a good thing
hope does something good for us

Poem Twelve

1 Hope is a good nights sleep
2 Sounds like peace and quiet
3 Smells like bacon sandwiches
4 Looks like sunshine
5 Tastes like a good glass of wine
6 Hope is for a better future and family get togethers

→ hope is about what the future (might) hold
→ hope is being mindful of what the present holds → nature → food
→ thee is hope whee thee is family
→ hope is embeded in uncertainties
hope is about what the future holds

Poem Thirteen

1 Hoping to go on holiday
2 Fly or cruise
3 To faraway places
4 Sunshine or rain, but
5 Where will we go

hope is planning for the future
→ thee is hope wee thee is fun
hope is considering the possibilites (of the future)
→ hope in perciverance?
→ hope is embeded in uncertainties

Poem Fourteen

1 Hope is for a hell of a good time
2 O for occasion for all the family
3 P for full participation
4 Experience for wedding remembrance of 50 years

→ thee is hope whee thee is fun
→ thee is hope whee thee is family
→ hope is something you do
→ thee is hope whee thee is celebration

Poem Fifteen

1 I saw dove - white, big, calm, standing in front of me
2 Felt relaxed
3 Felt the flick of its soft feathers of its wings
4 Felt freedom - I could fly whenever, wherever
5 I want, I hope

→ hope as a strength
→ hope is tangible
→ hope is about future possibilities
→ hope is desired
longed for
currently missing

Poem Sixteen

An Alphabet of HOPE

Hope is **absolute**
Sometimes revealed
Hope is **binary**
A two way street
Hope is **creative**
Helping dreams become real
Hope is **defined**
As restorative and true
Hope is **eternal**
Whilst sometimes seeming inconclusive
Hope can be **fractured**
But never fully broken
Hope is a **green** day
When dawn greets a red sky
Hope is **humour**, **honour** and **humility**
Trying one's best to deliver its promise
Hope is **inclusive**
Of all with no differences
Hope fulfils the promise of **joy**
Making our faces shine brightly
Hope is compassion born of **kindness**
With love as the bearing midwife

Hope is always **living life**
To the full each and everyday
Hope is climbing **mountains**
In reality or in our minds
Hope is about travelling **north**
When others say "Go west"
Hope may be viewed from the **outside**
Though it's always felt within
Hope is keeping our **promises**
Sincerely made in good faith
Hope is thinking quietly
When what you want is to SHOUT
Hope is **resolute**, **reliable** and **renewal**
Never vain, pompous or judgemental
Hope is overcoming a **st st stammer** or **st st stutter**
To speak with confidence and assurance
Hope goes with you wherever you **travel**
Guiding your way like a beacon of light

hope exists outside one's self
hope is shared /shown
Hope is shared
Others hope give hope
hope is there when personal strengths are acknowledged
hope is about future possibilities
hope as a strength
hope as eternal
hope as hard to achieve
hope can be lost
hope as a strength
there is hope when there is..
humour, → fun
honour } personhood
humility } acknowledged
hope is about future possibilities
hope as a strength
hope is where there is kindness
hope is there when there is love
hope is being mindful of the present / of what you love
hope as a strength
hope is external
hope is seen
hope is internal
hope is felt
hope is about future possibilities
hope as a strength
hope as a strength
hope as a guide
hope is eternal

Hope will always **universally**
Aim you for the stars when told the sky's the limit

hope as a strength

Hope is a way to a comfortable **vestibule**
Where we can sit, relax and take stock

hope allows for reflection

Hope will **watch** over us whilst
We connect to family and friends

hope is when there is social connection

Hope is a journey to far off **Xanadu**
Guiding our steps along the way

hope as a strength
hope is about future possibilites

Hope is about seeing you
As you really want to be

hope is there when personhood is acknowledged

Hope is awake, hope is **zizz**

hope is alive

At the start, the middle, the end of the day

hope transcends time
hope is always present

2.3.22

Poem Seventeen

Hope

Hope is within me, held deep inside

hope is internal
hope is inside me
hope is felt

Optimistic, I'm alive

what you have
hope as a strength

Planning, living one day at a time

what is possible
hope is about the present/here and now
hope is about the future

Expectations… living my life

what is possible
hope is about the present
hope is about the present with room for thinking about possibilities of the future
hope is about desires ~~for~~ the future

Poem Eighteen

Hope

Is it a dream that's in my head

hope is about desires for the future
hope is internal
hope is located in the head

Or an expectation that maybe stopped dead

hope is about future possibilities
Dementia is a block to expectations so have hope?

Is there light at the end of the tunnel
Or flowing water through a funnel

hope as a strength

What ever it is, we hold on to hope

having hope is an active process

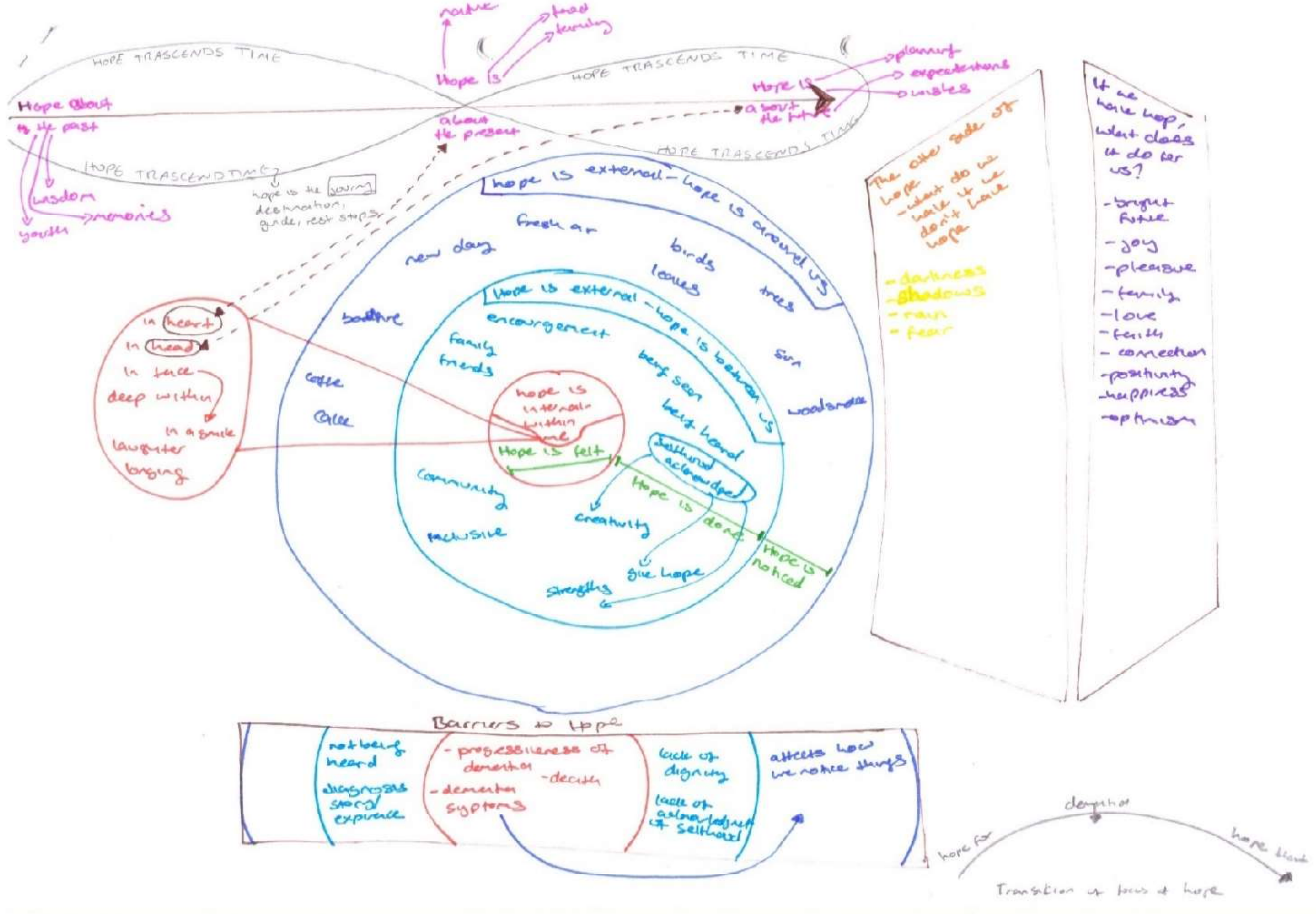
Not to fall down, the slippery slope

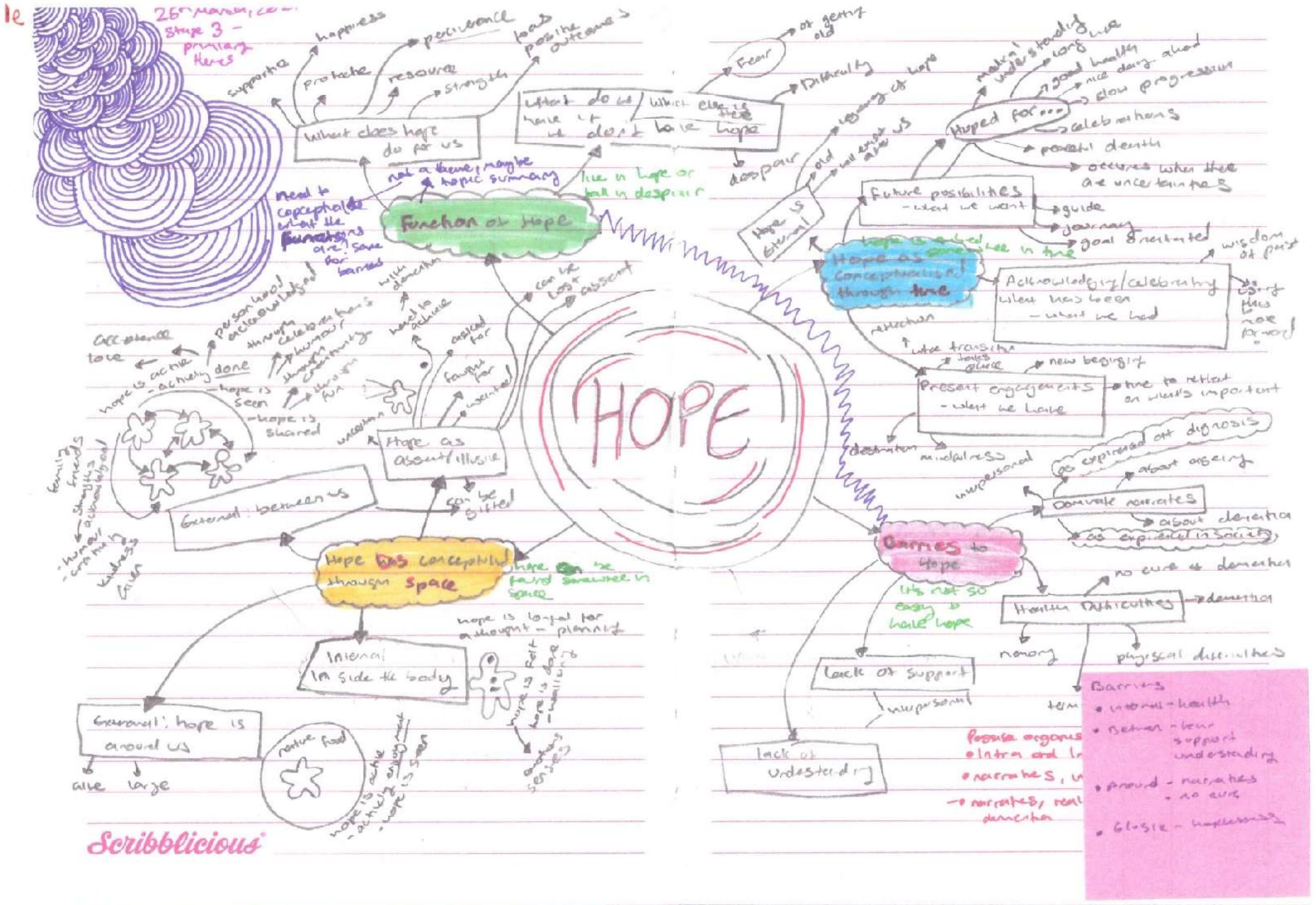
without hope there is difficulty

Is hope a promise, or a wish to come true
Maybe it's something i can aspire to

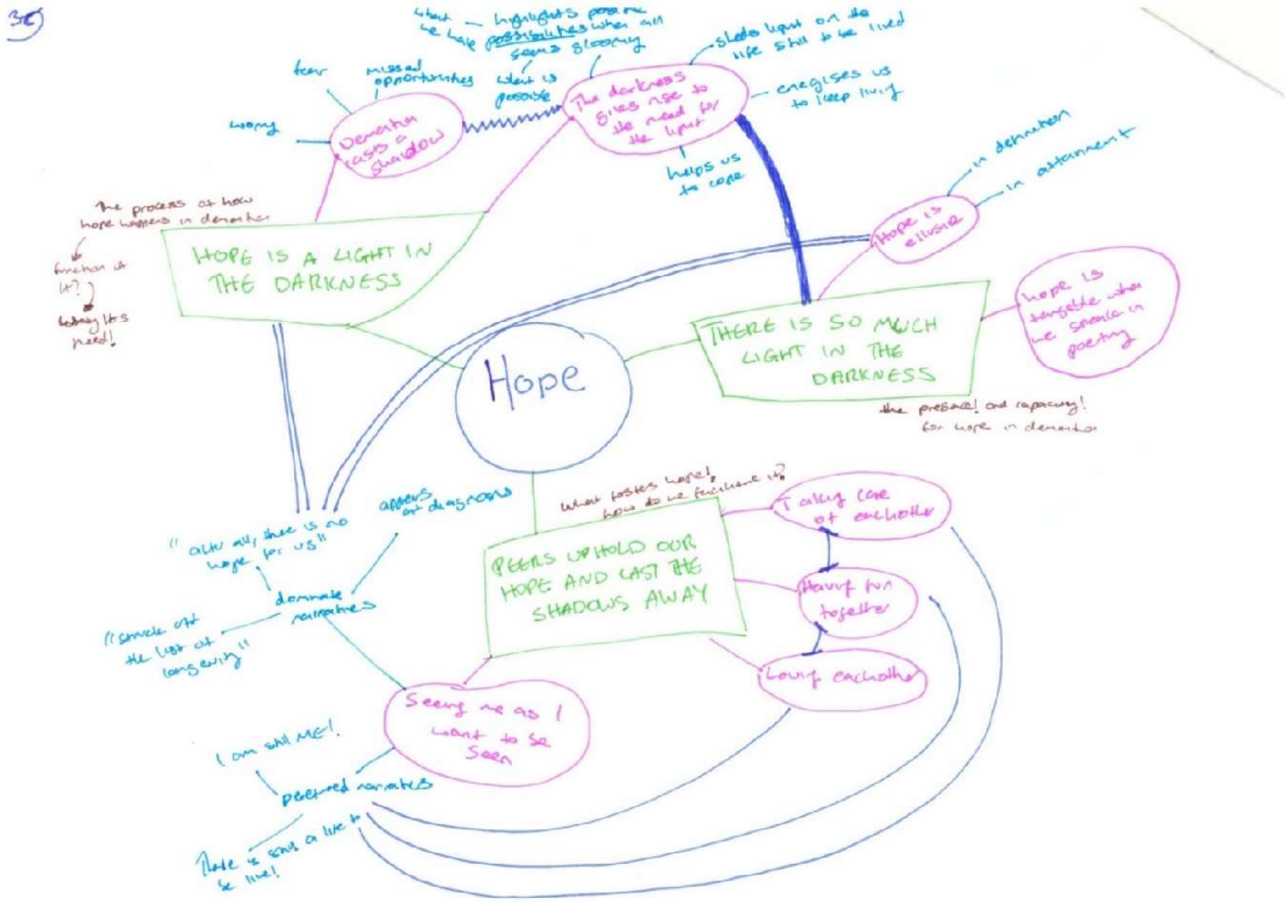
hope is embedded in uncertainties

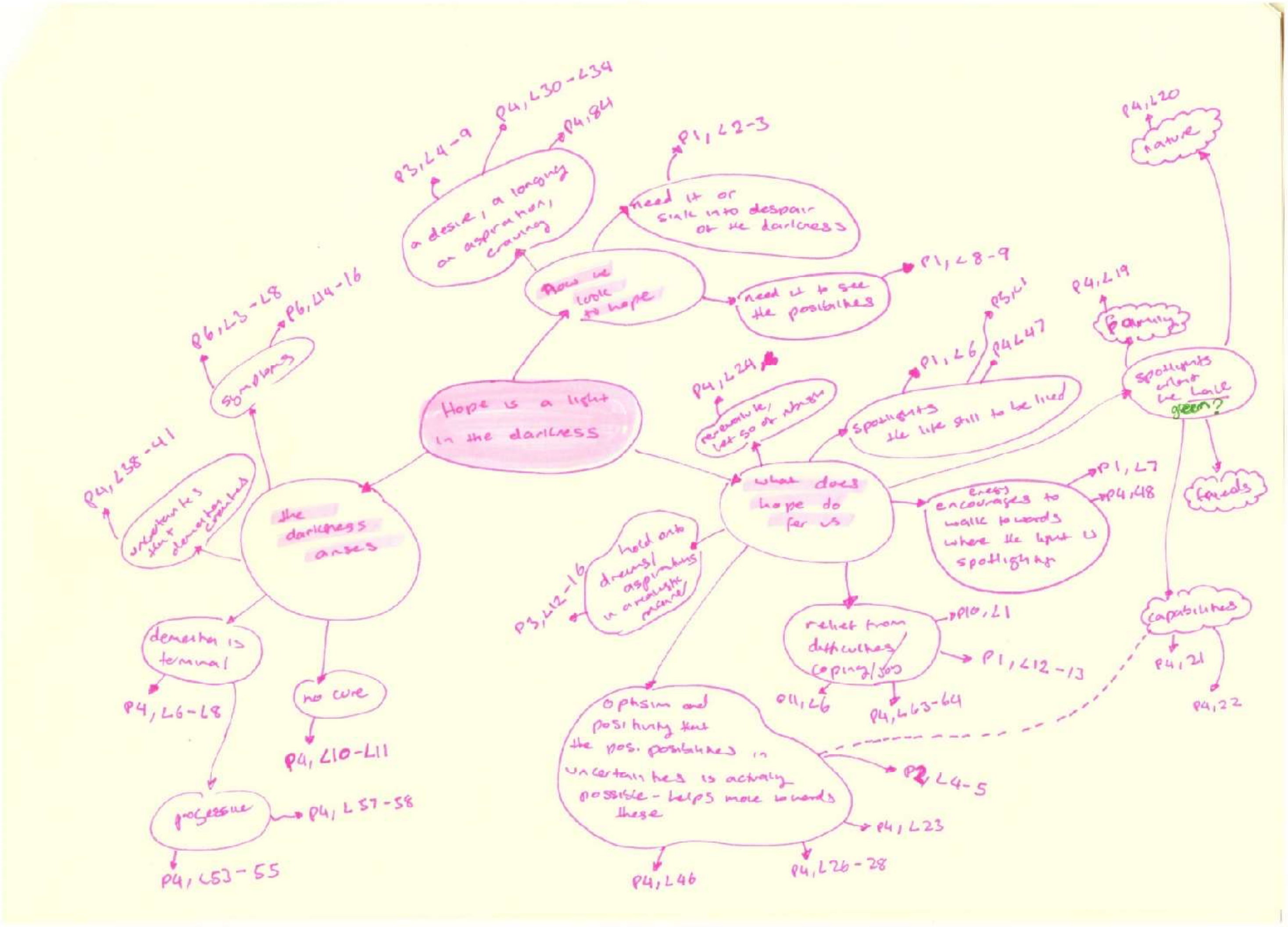
Appendix Q. Thematic Maps of Initial Themes



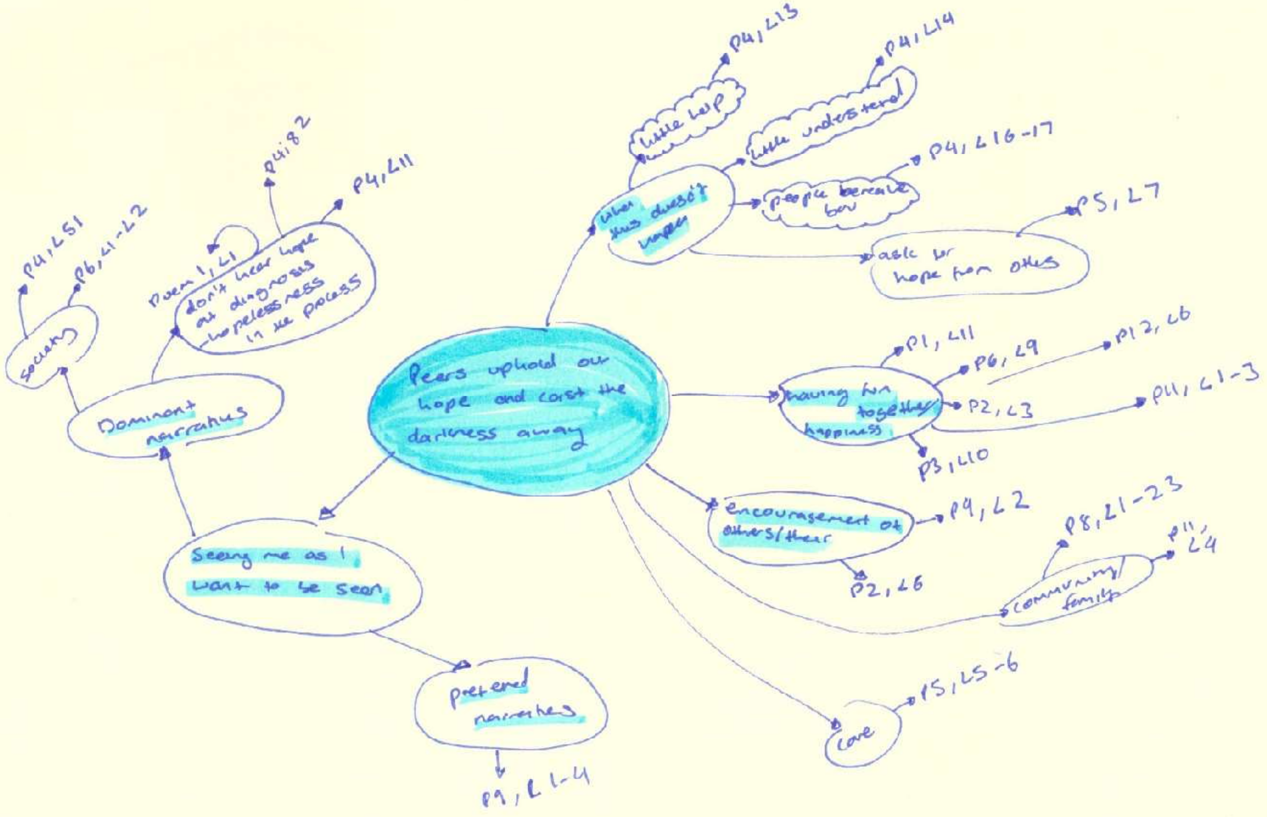

26th March, 20..
Stage 3 - prelim themes
HOPE
Function of Hope
need to conceptualise what the functions are! Save for barriers
not a theme, maybe a topic summary
What does hope do for us
supportive
protective
happiness
resource
perseverance
strength
positive outcomes
What do we have if we don't
What else is there
have hope
Fear
of getting old
Difficulty
despair
live in hope or fall in despair
Hope is eternal
old
legacy of hope
will exist as we are
Hope as conceptualised through time
hope is available somewhere in time
Future possibilities - what we want
Hoped for...
medical understanding
long life
good health
nice day ahead
slow progression
celebrations
peaceful death
occurs when there are uncertainties
guide
journey
goal orientated
Acknowledging/celebrating what has been - what we had
wisdom of past
using this move forward
reflection
when transition takes place
new beginning
Present engagements - what we have
time to reflect on what's important
distraction
mindfulness
impersonal
Barriers to Hope
it's not so easy to have hope
Dominate narratives
as expressed at diagnosis
about ageing
about dementia
as expressed in society
Health Difficulties
no cure 4 dementia
dementia
memory
physical difficulties
terminal
Lack of support
impersonal
lack of understanding
Possible organise
• Intra and In
• narratives, W
→ narratives, real dementia
Barriers
• internal - health
• Between - lack support understanding
• Around - narratives - no cure
• Global - hopelessness
Hope as conceptualised through space
hope can be found somewhere in space
Hope as absent/illusive
can be lost
absent
asked for
fought for
wanted
uncertain
need to achieve
with dementia
can be gifted
External: between us
hope is active - actively done
acceptance
love
personhood acknowledged
through celebrations
through humour
through creativity
through fun
- hope is seen
- hope is shared
family
friends
strengths acknowledged
- humour
- creativity
kindness
faith
Internal
Inside the body
hope is longed for
a thought - planning
hope is felt
hope is done
- wellbeing
emotions
senses
General: hope is around us
alive
large
nature
food
hope is active
- actively enjoyment
- hope is seen
Scribblicious

Appendix R. Thematic Maps of Final Themes

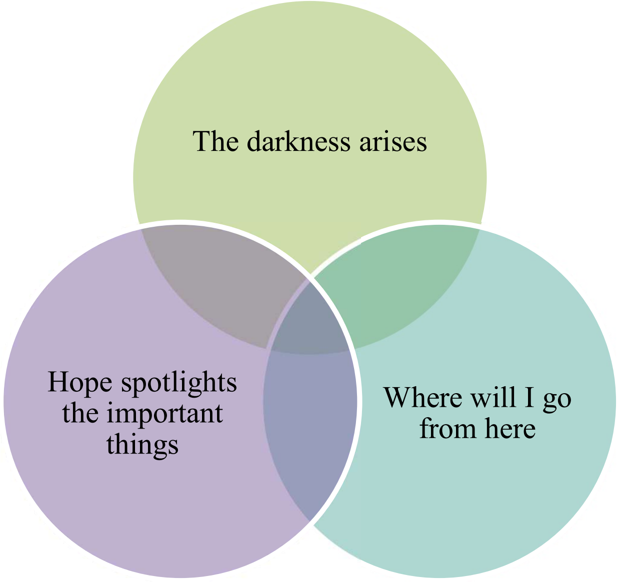



Hope is a light in the darkness
How we look to hope
a desire, a longing or aspiration, craving
P3, L4-9
P4, L30-L34
P4, 84
need it or sink into despair or the darkness
P1, L2-3
need it to see the posibilities
P1, L8-9
the darkness arises
symptoms
P6, L3-L8
P6, L14-16
understandings that dementia creates
P4, L38-41
dementia is terminal
P4, L6-L8
no cure
P4, L10-L11
progressive
P4, L57-58
P4, L53-55
what does hope do for us
renewable, let go or strength
P4, L24
spotlights the life still to be lived
P1, L6
P3, L1
P4 L47
spotlights what we have
green?
family
P4, L19
nature
P4, L20
friends
capabilities
P4, 21
P4, 22
energy encourages to walk towards where the light is spotlighting
P1, L7
P4, L48
hold onto dreams/ aspirations in a realistic manner
P3, L12-16
relief from difficulties/ coping/ joy
P10, L1
P1, L12-13
P11, L6
P4, L63-64
Optimism and positivity that the pos. possibilities in uncertainties is actually possible - helps move towards these
P2, L4-5
P4, L23
P4, L26-28
P4, L46

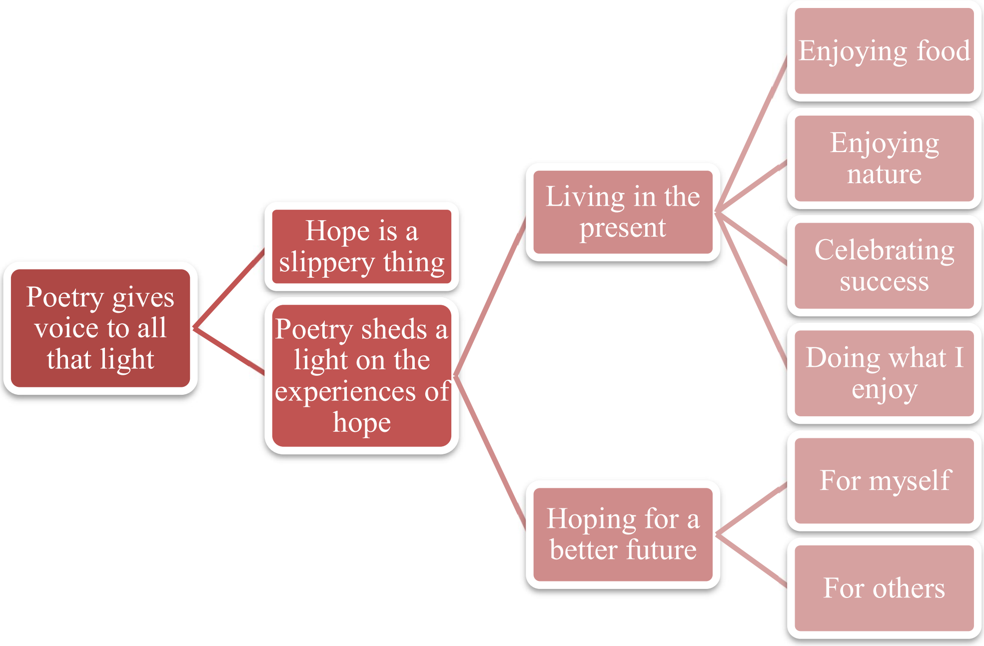

There is so much light in the darkness
hope is elusive
in definition
in attainment
P4, L62-64
Poetry makes it easy to talk about hope
define it and how we have it
ways poetry is present
creativity art
P3, L3
food
P4,69; 72-74, 77
P12, L2 L6
P5, L2
P11, L5
P10, L2, 4,
family
nature
P12, L4
P4, L66-68, 70-71, 75
P5, L3-L4
P10, L3
hoped for thing
health
P12, L1-2
holidays
P3, L1-3
slow progression
P6, L12-13
good life
P6, L11


P4,L13
P4,L14
little help
little understand
P4,L16-17
when this doesn't happen
people become bored
P5,L7
ask for hope from others
P4,82
P4,L11
P4,L51
P6,L1-L2
Poem 1,L1
don't hear hope at diagnosis
-hopelessness in the process
society
Dominant narratives
Peers uphold our hope and cast the darkness away
P1,L11
P6,L9
P12,L6
P11,L1-3
having fun together/ happiness
P2,L3
P3,L10
encouragement of others/their
P9,L2
P8,L1-23
P11, L4
P2,L6
community/ family
Seeing me as I want to be seen
preferred narratives
P9,L1-4
P5,L5-6
care

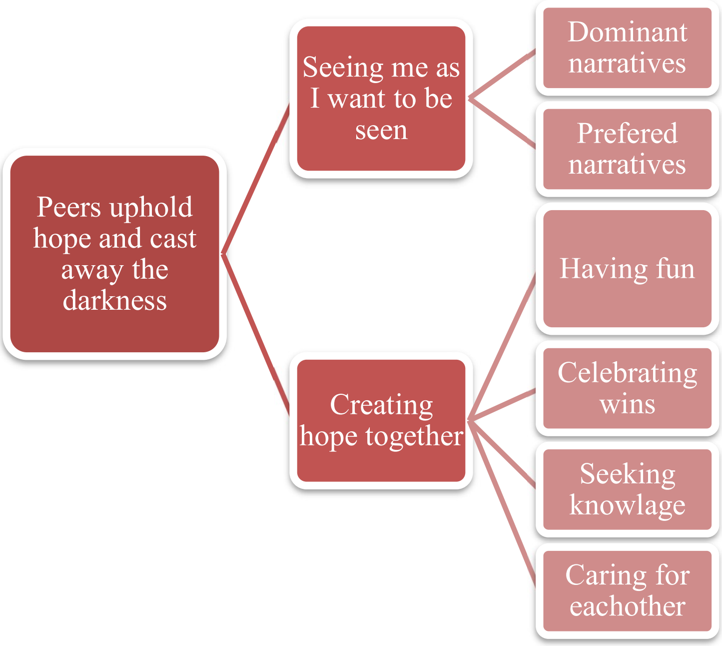
Appendix S. Thematic Map of Theme One: "*hope is a light in the darkness*".



Appendix T. Thematic Map of Theme Two: “*poetry gives voice to experiences of hope*”.



Appendix U. Thematic Map of Theme Three: "*peers uphold hope and cast away the darkness*".



Appendix V. Epistemological Statement

This statement explores the ontological and epistemological underpinnings of this thesis, making clear the overall philosophical position on knowledge held by the researcher. Ontology refers to the assumptions made about the nature of reality (Willis & Jost, 2007). The ontological position of realism views reality as being objective with distinctive truths, while anti-realism maintains that reality is subjectively constructed (Jenkins, 2010). Epistemology refers to how we come to know reality (Willis & Jost, 2007). On one extreme is positivism, which maintains that reality can be objectively observed without bias (Willig, 2013). Quantitative research typically takes a positivist position and is concerned with finding out singular truths about reality (Green & Thorogood, 2014). Such research is typically preoccupied with the generalisability and reliability of findings (Stenfors et al., 2020). On the other extreme is constructionist and relativist epistemologies, which maintain that no one truth exists and that the conceptualisation of reality is restricted to the specific contexts in which it is observed (Burr, 2015; Green & Thorogood, 2014). Qualitative research is typically governed by such positions and is concerned with the transferability and credibility of findings (Stenfors et al., 2020). That is all to say, it is important to consider the specific philosophy that underpins any research, as this influences methodological decisions and how data is considered and analysed, which therefore affects the implications of findings (Braun and Clarke, 2021).

From preliminary scoping of art-based research before undertaking the systemic literature review, it was clear that many scholars in this field viewed creative arts as a way to access deeper parts of the already existing experiences of different participant groups that traditional qualitative research methods had failed to explore (Knowles & Cole, 2008; Leavy, 2020). This eluded to a position of realist ontology, meaning that there was a specific truth to be explored about participants' experiences. However, the ability of researchers to access this reality was limited by the methodological approaches employed, with the reality observed being influenced by these methods. This eluded relativist epistemology (Blaikie, 2007). Indeed, the medium used to collect data affects the data gained (Gelman et al., 2013). Participants' interview transcripts are viewed not necessarily as a reflection of their "truth" (Riessman, 1991, p.45), but rather as co-constructed representations influenced by the researcher and research methods. As such, the systematic literature review was governed by a realist ontology and epistemological realism, maintaining the position that methods of qualitative research need to be expanded to allow for data collected to be closer to participants' true realities. Under the relativism epistemology, no one method can provide a perfect reflection of reality. However, it is argued that some methods are more efficient in this endeavour and that mainstream methods should expand to consider these.

This position of ontological realism and epistemological relativism transferred to the empirical research, meaning that the thesis was underpinned by a philosophical framework of critical realism (Braun and Clarke, 2021). That is, the philosophy underpinning the study maintained a concept of reality and truth, but conceptualised that social and research practices shaped how this reality was experienced and perceived. An essentialist approach was taken to the reflexive TA used in the study. That is, language was valued simply as a way to view the subjective meanings and experiences of participants, rather than as a way to create reality (Braun & Clarke, 2021). In line with relative realism, the influence of societal norms on meaning-making and experiences was still captured under this essentialist approach. This stance allowed the researcher to explore and analyse the data as representations of participants' distinctive truth while acknowledging that the researcher's own social lens, assumptions, and methodological choices limited the extent to which the findings purely reflected these realities. Reflexive thematic analysis was chosen to analyse the data as it is not governed by any specific theoretical frameworks. It, instead, requires the researcher to engage in active and constant reflexivity to ensure that how data is considered and analysed is epistemologically congruent with the research methods and governing research philosophies (Braun & Clarke, 2021). Thus, the position of critical realism could be flexibly applied to this analysis. This process was supported by regular supervision, peer reflection groups, the use of poetry and a reflective journal. Poetic data was deemed appropriate within this philosophical position as it had been valued as a way to access richer and deeper parts of participants' experiences and therefore supported increased access to participants' realities (e.g., Amponsem et al., 2022). The research questions asked were also epistemology sound, as they related to participants' experiences of hope, the findings of which were considered as being contextually situated.

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Appendix W. Reflective Statement

I met the prospect of completing a thesis with much apprehension, but through this process, I learned so much about myself. I learnt that I do, in fact, love research. It was only the little voice in my head that told me I had to be perfect at everything I did or not do them at all that filled me to the brim with dread when faced with the challenge of completing a thesis. I learned to work with this little voice I had carried with me my whole life, which had only become louder the older I got. I learnt to nurture it, to teach it that the goal is progress, not perfection. Some days, the voice was louder than I was. On those days, I told myself that it was okay to take a break, take a breath, and reflect, so I can come back stronger. It was by no means an easy process, but by the end, I was thinking about how else I could get involved with research; how else I could hold the mic so those silenced individuals could roar and tell their stories. In the end, grew a passion for research as something that could be used to fight injustice and demonstrate inclusion. Here is the story of how all this happened, with a few poems here and there.

The battle ahead

Holding onto hope was a battle throughout this journey

Offers of support were what saw me through

Poetry, my weapon of choice

Enthusiasm for research, an unexpected outcome

Choosing research topic

I lived in Ghana as a child where there was a very strong collectivist culture. My home was in a large compound where three generations of my family and family friends also lived. I enjoyed how everyone was valued for their unique experiences and everyone's personhood was cherished despite any difficulties that might arise. Our older relatives were particularly respected and valued for the wisdom that accompanied the years they had been alive before us.

Moving to the UK, I had a very different experience. It seemed that the topic of ageing was taboo and it almost felt like the older generations were hidden in little pockets around communities, separate and despondent. I volunteered as an activity coordinator for several care homes during my undergraduate studies and witnessed how there was a lack of effort to engage and hold onto the personal strengths of older adults, particularly those living with dementia. There was an inescapable narrative of hopelessness, which I think inadvertently leads to a lot of the interpersonal difficulties experienced when living with dementia.

Not to say Ghana was perfect in this regard. I have heard many horror stories as an adult about how some Ghanian families treated their relatives with dementia, sometimes believing they had been possessed or that they are witches. From my personal experiences, and within my personal context, older family members were cherished and seen as individuals who were still capable and deserving of fun and fulfilled lives.

<u>My mother's name</u>

This morning, I called her name

She brushed my hair behind my ears

And called me by my mother's name

She told me to fetch a blanket,

And maybe a pillow or two

This morning, there was a vacancy in her eyes
I know it too well now -
Recognise it like an old friend
This vacancy, where my name belongs
I feel its absence like the sun at midnight

This morning, I held her hand
She held me close to her body
And she cradled my head in the nook of her neck
She sang to me and rocked me in her arms
I feel like the sun sets within my chest

This morning, and every other morning now,
Her memories seem to float at the edges of her mind
They move in a dance of ebbs and flows -
Always moving...
Always dancing... toward and away

This morning, and I hope, every other morning,

Her heart is full - full of something.

I think it is love, maybe contentment

Or both... and more

Whatever it is, it makes her smile

Whatever it is, it makes my heart swell with hope

I had mostly just fleetingly reflected on these ideas during my undergraduate studies. I didn't stew on them. I didn't think there was anything I could do with these observations. This all changed during the research fair in December 2019. I had many discussions with plenty of supervisors and left them all thinking, "sure, I could do a thesis on their topic of interest". I was as indecisive as I was open to new ideas, so all the topics my potential supervisors brought piqued my interest. I could relate to all of them in one way or another: yes, I could research childhood trauma because my clinical interests lie in working with children and families; yes, I could research subjective experiences of health difficulties because I am really enjoying the health placement I am currently on; and so it went. My second-to-last discussion was with Emma Wolverson and Chris Clarke. By then, I had mentally and prematurely planned about six different empirical studies in my over-imaginative brain and was feeling quite mentally drained and ready for a nap. However, their passion and excitement for dementia and positive psychology were contagious. "Forget the nap, we have one more study to plan", I silently screamed at my brain. They spoke about where their passion stemmed from, how they have a few papers published in this area with previous trainees and all the gaps there are left to explore. I was on board before I even left my seat. Later that day, while reflecting on the fair and why that particular topic felt like "the one", all my experiences in Ghana and reflections from undergrad came flooding back. I knew this topic was "it" because it meant that finally, I could do something about these thoughts I had been having. Finally, the capacity for people with dementia to have positive experiences was being explored and I was going to be a part of it. It felt like the beginning of an exciting, albeit terrifying, endeavour.

<u>Dear people with dementia</u>

Was it destiny

Destiny that had I wondered

Wondered about your strength and wisdom

Wisdom that has gone ignored

Ignored for far too long

Long enough for us to forget

Forget that it ever existed

Existed in your actions and words

Words we will now hear

Hear through study and research

Research I now have the privilege

Privilege of being a part of

Designing the research and choosing a review topic

I was quite set on the idea of exploring hope in the context of dementia and positive psychology as soon as I decided on this research topic. I chose hope, as opposed to any other positive psychology construct, as there have been a few papers on hope in dementia from the perspectives of carers. As I wanted to particularly highlight the voices of people living with dementia, I felt that expanding on a construct that had already been explored in some form in the area would be a good place to start. With the narratives around dementia being quite hopeless, I also felt it symbolic to explore hope from the people living with dementia, both to highlight the capacity to have positive experiences while living with dementia and to highlight what might get in the way of hope while living with dementia.

Hello?

Hope, are you there?

Do you come knocking for people with dementia?

Some say you don't

That you have forgotten the faces of all those past a certain age

I don't quite believe that

How can you forget, when they long for your presence

Hope, are you there?

Do you come knocking for people living with dementia?

Why don't we try and find out

A decision that took longer to come to was how data was going to be collected. Among other things, I am a poet, so I know that poems are incredibly useful in communicating very complex experiences and intricate experiences far better than conversations ever could. Poems can also have a very emotional impact on readers and give people a real visceral sense of the writer's world. When I shared this interest and view with Emma and Chris, they jumped on board and suggested that I could use participant-written poems as my data. I was sceptical of this idea. I had thought, "this is a thesis, not an art project!". They pinpointed me in the direction of John Killick, a poet who had been writing poems with people with dementia for years as a way to maintain and communicate their personhood. The more I read about his work and the work of researchers in different fields who used poems as data to the same effect, I was shocked that it was possible for my personal interests and academic work to could collide in this way. My interest in the idea of using poems as data grew, along with my annoyance at the fact that I hadn't even known this was possible or viable. So, in the same breath, the decision to use poetry as data in my study and the decision to explore how poetry was used in health research in my literature review were made. For the former, I wanted not only to explore the capacity for people to have positive experiences in a research setting. I also wanted to demonstrate this and using poems, which could be collected in an anthology and shared at the end of the research, felt like a perfect way to do this. For the latter, I wanted to produce a piece of work that would have been helpful for me to have when I was deciding how to design a study that uses poetry as data. I wanted to produce a review that demonstrates the value of doing this to support future researchers to consider doing the same.

Conducting the research

Ethics Application

The most difficult part of the ethics application was filling up the application form. The voice that tells me that I had to be perfect at everything I did or not do them at all was loudest during this process. The form was this scary, steep, jagged mountain that I was never going to be able to climb without slipping. So, as the voice advised, I procrastinated to the inch of my life. The suggested ethics deadline approached and I could not possibly ignore it any longer. I had done all other assignments needed until that point, redecorated my flat numerous times, decluttered my wardrobe and had nothing else to procrastinate with. The little voice isn't all bad. Once I got to fill out the form, it made me do it so meticulously that I breezed through ethical approval and minimal issues. It also definitely helped that I didn't need NHS ethics – imagine how loud the voice would have been then! In the end, I realised that things are rarely ever as scary as we imagine them to be. Once I started the form and took it one section at a time, the mountain became one hill at a time that was more manageable and less panic-inducing.

Recruitment

Once I got through ethics, I thought "the worst is over". I couldn't have been more wrong. I set up my research on Twitter, Facebook and Instagram. I shared my posters, got prominent people in the dementia community to share my poster and went on Instagram lives to ask people to share the research. I was regular with posting about the research, even posted some of my own poems, and yet, nothing was happening. My frustrations grew day by day, and I became disheartened in the research process. I felt like I was never going to be able to complete it and even wondered if I had chosen the wrong topic after all. Then I wondered, here is a population of people who are stigmatised and typically ignored even when they try to speak out about their experiences, and here was me, a random person they have never met asking them to write about deeply personal experiences! Instead of catastrophising about my research competence, I started thinking about potential obstacles getting in the way of people participating. I moved away from my internal processes and started considering the external contextual factors. From there, I decided to speak with activity coordinators of dementia volunteer groups who I could get to know and talk to about my project. Through this, members of these groups could be informed about the study by a familiar face who could create a supportive space for them to write their poems. One of these activity coordinators, Liz Jennings, made the suggestion of making a video explaining the study to be shared around. I made this video to introduce myself and tell people about why I was doing the research and why I would love for them to be a part of it. I think this connected a face to the random survey link I was previously sending around for people to click on. From there, more and more people started submitting poems. Some people even submitted multiple poems! In the end, thinking about problems widely, seeking support and being innovative in problem-solving were what really helped me get this process along.

Data analysis

I had never done thematic analysis on such a large scale before and constantly felt overwhelmed during this process. When I started the first stage of analysis, I found myself just reading the words on the paper, not really comprehending anything. It started to feel like I had lost my talent for poetry (a scary prospect for a poet). Upon reflection at the time, I realised I was feeling scared that I no little to no time for data analysis and that I needed to hurry if I was going to complete my thesis. My mind was spiralling into all the scenarios in which I couldn’t finish my thesis and my life would be over (my over-imaginative brain hardly ever takes breaks, that’s for sure). I decided to take a step back. It was important to me that I really paid attention to the data, to value and respect all the rich and personal life stories that had been shared with me. It was in no way helpful to approach data analysis distracted or in a hurry. Certainly not in this particular research where I really wanted to highlight the voices of my participants.

During my break, I had the most splendid idea of writing a poem in response to each participant-submitted poem. This would allow my brain to slow down and really take in each poem to support data familiarisation while honouring the words of each participant. The feelings of fear gave way to excitement and fun during this process and I could hardly believe how much I was able to pick up from the poems. I really understood why Braun and Clarke (2021) repeatedly spoke of the value of taking a step back during data analysis. It was during this time away that I was able to address the anxieties of my thesis, create a solution to a problem I had been facing and reignite my passion for the research.

The obstacles did not end there. I went through the whole first five stages of thematic analysis feeling like I had found my main themes, only to realise that I had just created topic summaries. I felt so passionately about highlighting the voices of my participants that I wanted to encapsulate EVERYTHING they had said in my themes. However, these initial themes missed the mark in being able to clearly answer the research questions, provide unique insights into my participants' experience of hope and represent distinct central organising concepts. While I knew this in my heart, I came out of the supervision meeting that confirmed it feeling deflated. Another step back was needed. This time, the step back was not as refreshing and energising as anticipated. It was the consistent support of my partner and friends that helped me see the light. They spent time doing their best to cheer me up and offer their own insights which went a long way in shifting my perspective. I went back to the drawing board with fresh eyes, keeping my research questions at the forefront of my mind. New thematic maps were developed, and new insights became apparent. I felt the most excited when I went into the next supervision with my new themes, which were distinct, honoured the experiences of my participants and clearly provided insights relevant to the research requestion.

Reflexive TA considers researcher subjectivity as an analytic tool (Braun & Clark, 2021). As such, it was important during that research process, for me to engage in active reflexivity to consider how my own biases and experiences interacted with the interpretations of the data. This involved a disciplined practice of critically interrogating what I was doing, how and why there were done and the impacts and influences of this on the research. I kept a research journal to aid this process. For example, I believe in the capacity for people to have positive experiences when living with dementia and the importance of this on wellbeing. Thus, I noticed at the start of data familiarisation that I would become discouraged reading about the challenges of how people sometimes struggle to have hope. Through the reflecting process, I was also to engage with these aspects of the reality being interpreted and did not overlook them to privilege my own dominant story of what it means to live with dementia. An example of this was poem four, to which my response poem was as follows (edited from when first written as presented in Appendix N):

Icy Cold

Hope used to live within you
Solid, tangible, residing in your belly
You could hold it, guard it

It gave you so much
Like a smile, or energy

Told you, life was worth living

But a day came when hope left your body
And went somewhere you felt you could not follow
- the future

In that I icy clinic room, could they have done
Anything to help hope stay
To help you hold onto hope

Now, maybe hope is trying to find its way back to you
But there is so much getting in the way
Like dementia, and how it's never leaving

Sometimes, hope comes to visit
And the future, still uncertain, feels full of possibility
Those you might want, and others, not so much

Hope that used to be within you

Now feels too heavy to carry

In the face of all that dementia comes with

So now you look to something else

You call it pleasure, and it is here and now

And it is all the things that bring you joy

I wonder, does it look like hope to you, like it does to me

All these little pleasures

That tells life is worth living

Writing up

For a poet, one would think I have learnt to appreciate the beauty of drafting and editing. However, there is nothing more daunting to my perfectionistic tendencies than a blank word document. The voice that tells me I must be perfect at everything I do or not do them all really shows its ugly head when I open a new document. It feels as if every sentence I write must be perfectly crafted. There is no margin for error, and everything I write is a reflection of my academic ability. Taking a step back and reflecting on why I was so scared helped with my writing process. Like with the ethics from, I broke down the beast of a mountain, tacking it one little hill at a time. I allowed myself little breaks, with a side of uninvited guilt, every time I reached a block. Little by little, I saw myself getting through my write-up. Each time I made progress, I tried to celebrate. Valuing this over perfection, which no one could ever really achieve, helped me greatly along the way.

Final reflections

Being able to tackle a research topic that I had a passion for really helped this process. There were so many times that it felt easier to give up, tell the voice that yes, you are right, I can't do this perfectly so I am going to stop trying. It was remembering how much effort my participants had put into their poems and what it has the potential of achieving that brought me back on track. It was seeing the excitement from my supervisors about the topic and their passion that reminded me of why I needed to carry on. It was reading poems about people's capacity to have hope even in the face of all the changes they were facing that lit a little candle of hope in my own heart.

In the end, this thesis was an exciting, scary, fruitful and valuable journey that I am privileged to have been a part of. I am proud of the work I have achieved. This thesis provided the opportunity for me to learn so much about myself and ignited an interest in research. It taught me the value of progress over perfection, a lesson I will continue to learn through all aspects of my life.

References

Braun, V., & Clarke, V. (2021). *Thematic Analysis: A Practical Guide*. Sage.