Rebecca Henly BSc Hons MSc

THE USE OF NARRATIVE THERAPY IN PAEDIATRIC SETTINGS

Section A: A systematic review and narrative synthesis of the therapeutic use of 'narrative' methodologies in Pædiatric settings
Word Count: 7896 (+1445)

Section B: Developing through mentoring: young people's experiences within a Beads of Life group in a hospital setting
Word Count: 7999 (-149)

Overall Word Count 15895 (1296)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

April 2019

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

Firstly I would like to thank the young people who took part in this research, and who were so open with sharing their experiences with me. I hope this work does justice to each of your stories.

I would also like to thank Dr Trish Joscelyne and Dr James McParland for all their support and enthusiasm in the completion of this thesis, especially through the many times when I thought it was never going to come together.

Finally I would like to acknowledge the support of my housemates, your entertainment during the stressful time was greatly appreciated, and my family for all the emotional support along the way.

Summary of Portfolio

THE USE OF NARRATIVE THERAPY IN PAEDIATRIC SETTINGS

Section A: A systematic review and narrative synthesis of the therapeutic use of 'narrative' methodologies in Pædiatric settings

A systematic review was conducted to bring together the existing literature on the use of narrative methodologies, and more specifically narrative therapy within paediatric settings. Stated aims, potential mechanisms for change and perceived benefits were considered alongside evidence for effectiveness in improving health and wellbeing. Recommendations for future research were discussed.

Section B: Developing through mentoring: young people's experiences within a Beads of Life group in a hospital setting

The study aimed to explore the experiences of adolescent and young adult peer mentors within a psycho-oncology Beads of Life group. Eight interviews were conducted and analysed utilising Interpretative Phenomenological Analysis. Three super-ordinate themes emerged; identity and self, identity and other, and identity and relationship to cancer. The results are discussed in relation to the existing literature around peer mentoring, post-traumatic growth, narrative therapy, and identity theory. Implications for clinical practice and possibilities for future research are discussed.

Contents

Tables

Figures

PART C: Appendices

A systematic review and narrative synthesis of the therapeutic use of 'narrative' methodologies in

paediatric settings

Rebecca Henly

Canterbury Christ Church University

Word Count: 7896 (1450)

Abstract

Young people accessing paediatric settings are at increased risk of psychological distress, and vulnerable to dominant "problem-saturated" narratives of illness taking centre stage in their lives. Given the potential power of stories over our sense of self, this review seeks to explore the use of narrative methodologies, and specifically narrative therapy within paediatric settings.

Method: A systematic search of electronic databases was carried out to identify papers outlining the use of narrative methodologies within paediatric settings.

Result: Twenty studies were identified which outlined narrative methodologies within paediatric settings. A focus on narrative therapy identified 10 papers in line with narrative therapy principles; six papers either reported purely qualitative findings or a mix of quantitative and qualitative findings, two reported case-studies, and two were purely descriptive accounts. The review suggests an early stage of development for narrative therapy within paediatrics and although papers suggest promise for narrative therapy within paediatrics, they are far from providing an evidence base for use.

Research Implications: Several key areas are highlighted for further consideration to support development of an evidence base including consistency across: definitions, applications, intended outcomes, and measurement. A balance which allows 'evidence' progression within a framework congruent with narrative therapy is key.

Keywords: 'narrative therapy' 'paediatric' 'young people' 'psychosocial care'

A systematic review and narrative synthesis of the therapeutic use of 'narrative' methodologies in

paediatric settings

What's in a story?

Stories represent a fundamental means of communication and have been used for

centuries to pass down wisdom and knowledge across generations. White and Denborough

(1998) suggest that our lives, and relationships, are shaped by these stories which help us in

developing our sense of self. Stories are subjective (Greenhalgh & Hurwitz, 1999) and

influenced by others. From this perspective the construction of self can be said to:

"*exist in the stories we repeatedly observe, listen to and interpret. The narrative*

construction of identity… involves making sense of events and experiences in one's life by

constructing personal stories and adopting social and contextual stories that shape personal

stories" (Naidu & Shabangu, 2015, p77).

This review will firstly seek to introduce narrative therapy, it will then touch upon

therapeutic support within paediatric settings, some of the reasons this may be helpful, and the

current evidence base for narrative therapy. The tension between epistemological positions with

regards to understanding illness is considered followed by potential theories around why

narratives may be important within a paediatric setting. The epistemological position adopted by

the researcher is introduced and a review of the current literature linked to the use of narrative

methodologies within paediatric settings follows.

Narrative Therapy

Given the potential power of stories, narrative therapy pioneered by Michael White and colleagues has become an increasingly popular way of intervening to support those in distress (Etchison & Kleist, 2000). Narrative therapy is based on post structural ideas that problems are created in social, cultural, and political contexts and cannot be understood outside these contexts (White & Epston, 1990). In its post structural ideas, narrative therapy is sometimes classified as sitting within the family of systemic practice – but not necessarily within a family therapy paradigm as it is often used as an individual therapy model. In addition, narrative therapy has been criticized by some for moving away from its original strict post structural principles and also for having a lack of clarity around theoretical foundations (Meehan & Guilfoyle, 2014).

The central tenet of narrative theory postulates that meaning is differential not referential. White (2007) suggests that concepts such as "human nature" and "self" are social constructions rather than essences of a person. Personalities and identities are considered relational constructs organised into coherent narratives. Ideas such as hope and resilience are equally conceptualised as themes with the narratives acting to organise one's feelings and actions in meaningful ways (White 2007).

Within the narrative view, individuals' lives are viewed as multi-storied, and problems arise and are maintained by oppressive stories which dominate the persons' life (Carr, 2001). This understanding of how problems arise can be seen as a contrast to other theoretical understandings of psychological distress. For example, psychodynamic models might see the problem as an unconscious reaction to early childhood experiences that have not been 'processed', or cognitive theories might see the problems being connected to 'unhelpful' thinking which maintains the problem and prevents it from being tackled successfully (Johnstone &

Dallos, 2014). Most narrative therapists would not negate that people who present to services with problems have had difficult experiences, but the emphasis is put on the way these are constructed by society and then these constructions are internalised by the individual. Narrative practices would also emphasise the role that power plays in marginalising or strengthening some narratives over others. The possible tensions between epistemological positions, is discussed further below in the context of narrative therapy in a medical setting.

Within a socially constructionist view, White and Epston (1990) describe narrative therapy as a process of "storying" and/or "re-storying" lives and experiences. Within this approach, alternative stories become the anchor of the therapeutic process (Etchison & Kleist, 2000). One aim of narrative therapy would therefore be to uncover and support preferred identity stories and thus individuals are supported in 're-storying' and 'thickening' these stories.

Identity, within this model, can be seen to be constructed in living ongoing interactions in which identity is renegotiated through the reauthoring of stories. In the development of preferred identity stories, consideration is given to 'thick' and 'thin' descriptions and listening for the double meaning. Thin descriptions are interpretations of events which embody observers' unexamined and socially influenced preconceptions, whereas thick descriptions of these events embody the meaning of those directly involved. Narrative therapy seeks to move away from internalised discourses to externalising conversations. These conversations are intended in a gentle way to allow exploration of problems which are seen to arise from abuse of power and privilege. The intention, within this model is to enable separation of the person's identity from the problem and promote space for personal agency in 'fighting back' (Morgan, 2000).

Within a narrative approach, the therapist adopts a collaborative co-authoring position. Exploration of occasions when the problem is less visible - known as 'unique outcomes' allow entry points into alternative stories and re-authoring conversations that may include stories about the self that are less often articulated. Unique outcomes can be extended into the past and future and are constructed on two landscapes: a landscape of action and landscape of consciousness, with the intention of enabling individuals to form preferred self-narratives in which they are more powerful than the problem (White, 2007).

Carr (2001) has summarised White's narrative therapy approach as helping through the use of seven processes:

- Collaboration: is when the therapist takes a co-author role alongside the individual.

- Externalising: is the separating of the problem from the person and their identity.

- Unique Outcomes: is the exploration of 'exceptions' to the dominant stories.

- Outsider witness: is when significant others are invited to witness the new self-narrative.

- Using re-membering practices: is the reconnection of clients with internal representations of significant others.

- Incorporating literary means: is when certificates, letters, and other literary means are used to help document and celebrate new knowledge and practice.

- Facilitating bring back: is when clients are encouraged to share their expertise in tackling the problem with newer clients.

Wallis and colleagues, however, suggest that narrative therapy remains unclearly defined. Whilst experienced practitioners were able to identify a set of core concepts, values, and

techniques, with some consensus there was large variation in more general application (Wallis,

Burns, & Capdevila, 2011).

The focus towards the wider context as an integral part of the therapeutic process has led

to the development of several collective narrative practices, underpinned by key aspects of

narrative therapy. 'Tree of Life' (Ncube, 2006) for example has shown some positive effects with

vulnerable Zimbabwean children affected by HIV (Ncube, 2006) and in UK school settings to

increase pupils' self-concept (German, 2013). The evidence base around the effectiveness of

narrative therapy, however, is still in its infancy, when compared to other psychologically based

treatment models.

Psychological Support in Pædiatric Settings

Ten to twelve per cent of children internationally are affected by long term physical

conditions. The biopsychosocial model of health and illness (Engel; 1977, 1980) opened new

possibilities for psychologists in alleviating psychological distress linked to a physical illness.

Multiple reviews have shown that children with chronic/critical illnesses have elevated risk of

psychological distress. Possible contributing factors include; perceived lack of control,

frightening symptoms, peer rejection, restriction in positive activities, and increased fear of death

(Barlow & Ellard, 2006; Pinquart & Shen, 2011; Thabrew et al., 2018). If untreated the

psychological impact of chronic/critical illness extends into adulthood (Secinti, Thompson,

Richards & Gaysina, 2017) and often extends to family system, particularly if conditions are life

critical (Vermaes, Susante, & Van Bakel, 2012).

A review by Thabrew and colleagues suggested that interventions based on Cognitive

Behavioural Therapy (CBT) may be helpful in reducing mild symptoms of anxiety and

depression in children and young people (CYP) with chronic illness but there remains limited evidence these therapies are acceptable to CYP and that they can improve quality of life in this population (Thabrew et al., 2018). Given the differing aetiologies of chronic conditions many studies have focused on condition-specific interventions such as those for type 1 diabetes. Reviews suggest that CBT, counselling, and family system therapy have all demonstrated early potential for improving glycaemic control (Winkley, Landau, Eisler, Ismail, 2006). These therapies may also improve psychological wellbeing such as; stress, self-efficacy and quality of life - although it remains unclear which interventions are most effective and with whom (Serlachius et al., 2014).

Narrative Therapy in Pædiatrics

Several applications of narrative therapy in pædiatric settings appear in the literature such as Tree of Life groups, a practice pioneered by Ncube (2006) which draw on the metaphor of a tree to enable conversations around life and identity (Ralph et al., 2017; Casdagli, Christie, Girling, Ali, & Fredman, 2017), beading programmes (Portnoy, Girling & Fredman, 2016; Pitfield & Larner, 2017) and digital story creation (Laing, Moules, Estefan & Lang, 2017). Narrative ideas have also been used in paediatric settings to help shape network meetings (Fredman, 2014) and within education programmes for parents (Jackson et al., 2016).

Beading Programmes

Stutzer & Gove (2000) are widely recognised as the pioneers of the first beading program "Bravery Beads" within a pædiatric setting. The idea developed from summer camp achievement beads and attempted to help CYP document and honour their oncology treatment journey by

awarding beads at key treatment milestones. Several variations have subsequently emerged, including the "Beads of Courage" in America (Baruch, 2010) "The Beaded Journey" delivered in Alberta, Canada (Penkman, Scott, & Pelletier, 2006) and "Beads of Life" in a UK hospital (Portnoy et al., 2016). Programmes have expanded more generally to include children with chronic or life-threatening illness (Sisk, Walker, Gardner, Mandrell, & Grissom, 2012) and families undergoing treatments for cardiac conditions (Redshaw, Wilson, Scarfe, & Dengler, 2011). It is important to note that current beading programmes have varying theoretical underpinnings and only two approaches, 'Beads of life' (Portnoy et al., 2016) and 'Rhythmic Beats' (Pitfield & Larner, 2017) are aligned to the Tree of Life approach and have clear origins in narrative therapy.

The evidence-base for narrative therapies in pædiatric settings

Etchison and Kleist's (2000) review within the field of family therapy suggested that narrative therapy can be helpful for a variety of family therapy issues. However, much less is known about the operationalisation, application and effectiveness of narrative therapy when applied to care within pædiatric settings, suggesting a current gap in the literature.

The Construction of Illness: The Tension Between Epistemological Positions

One potential reason for this gap in the literature may be the incongruence between the medical environment and the paradigm of social constructionism which underpins narrative therapy. Pædiatric settings are often dominated by a bio-medical approach to illness, meaning professionals seek to identify, and categorize, an organic cause of distress and once established care is provided under medical authority (Schaefer-Schiumo & Atwood, 2009). Within this

model, the tangible effects of the illness and its physical manifestations take prominence over the psychological or social responses to the illness. A more recent shift towards a biopsychosocial model of health and illness (Eigel, 1977; 1980) goes some way to bridging the gap. Within this model, disease is seen within the context of a whole person and their social support. Interventions are given, both for physical management of the illness, but also for psychological and social issues related to it. Since this shift, evidence has mounted supporting the significant effect of thoughts, feelings, and mood on; onset, course, and management of illness (Sobel, 1995).

In contrast, the roots of narrative therapy lie within social constructionism. This perspective examines how individuals and groups contribute to producing perceived reality and knowledge (Berger & Luckmann, 1966). A 'hardline' social constructionist position would suggest that there is no reality to disease other than that which we construct. However, within the more usually accepted 'softer' position a subtle distinction is made between a biological condition or 'disease', and the 'illness' i.e. the social meaning of the condition (Eisenberg, 1977). Cohen and Shires (1988) suggest that whilst disease may exist independently of discourse it does not carry "meaning" without discourse. From this perspective, several ideas have been postulated around how the particular discourse around an 'illness' is developed for example: illnesses are embedded in cultural meaning, the illness experience is socially constructed at the experiential level, and medical knowledge is not necessarily given by nature but constructed by interested parties (Conrad & Barker, 2010).

Friedman (1970) suggests that illness has consequences independent from the biological effects. Cancer, for example, when seen through a purely bio-medical lens denies consideration of the possible re-defining process that may be required by the individual and their family. This

may include adjustments in family boundaries, construction of a reality centered around sickness, and potential changes in meaning systems around illness. A distinction may be helpful, therefore, between the illness experience, illness behavior, and the illness meaning (Schaefer-Schiumo & Atwood, 2009).

Whilst the bio-medical model may deny the individual's illness experience and downplays the social context of complicated problems (Lantz, Uchtenstein, & Pollack, 2007), the hardline social constructionist stance can be equally criticized for explicitly or implicitly denying the existence of the real and physical manifestations of health and ill-health. However, a 'softer' social constructionist approach would be more compatible with the epistemological stance of this thesis – i.e. that a disease has a reality, but the meaning and psychological processes around this disease are situated in personal and social contexts and therefore fall under processes of discourses in society.

An example of how setting up social and psychological processes 'against' biomedical models can by unhelpful is illustrated by Simblett (2013) in relation to the Diagnostic and Statistical manual (DSM; APA, 2013) a key text within the bio-medical framework, Simblett (2013) suggests that it can be too easy for a therapist to conceptualize the DSM as 'bad' and other practices, such as narrative therapy, as more 'creative' and 'liberating'. Viewing narrative therapy, and thus social constructionist ideas, as oppositional forces prevents movement towards new discourses of integration. A different position - which will be taken within this review - is therefore not to say that diseases such as cancer do not exist but to give consideration to knowledge and power around diagnosis, and how conditions are experienced by the individual in all their contexts (including the medical one).

Whilst previously narrative therapy has been suggested to "liberate" CYP (Madigan, 1992) in fact therapy can only seek to support patients from one power and knowledge structure to another (Meehan & Guilfoyle, 2014). In a medical setting this may be a move from the discourse of medical knowledge and power to alternative narratives about themselves. Such support does not seek to replace medical intervention but rather complement this by approaching support from the idea that people access therapy because the stories told about then do not match their preferred identities (Portnoy, 2019). It also seeks to gently challenge norms about what people's lives *should* look like in order to be 'healthy' (Portnoy, 2019). Such a stance allows the 'dance' between psychological and medically trained professionals to slowly become redefined (Valentino, Daniilidi, Watson, Parham, & Tong Gong, 2019)

Theories that might be relevant in an understanding of the importance of narratives in pædiatric settings

Researchers suggest that during illness, stories can help us to make sense and give meaning to uncertain times created by the disruption of self and community life (Sakalsys, 2003). Sharing stories can provide an opportunity to; express feelings, process challenges, and may support dying children in developing a "legacy" (Sisk et al., 2012; Moxley-Haegert, 2015). The process of getting ill, being ill and, potentially recovery or coping, can be thought of as enacted narratives within the wider story of ones' life (Greenhalgh & Hurwitz, 1999).

Within pædiatric settings CYP may be particularly vulnerable to dominant problem-saturated stories linked to illness taking centre stage and becoming embedded in the narratives of those around them. This can exclude alternative stories that may be more helpful to the person both in the present moment and in defining their future.

According to Pennebaker's (1997) inhibition theory, the 'inhibition' of thoughts or feelings can create a stressor which threatens physical and emotional wellbeing. Healing may begin when our voices and stories are listened to and heard (Badger, Royse, & Moore, 2010; Lesco & Block, 2005). CYP often find themselves in a position of powerlessness, as an unwilling recipient of medical expertise. Seller (2010) used imagery from the Little Mermaid to describe the lack of sensitivity to children's voices that often occurs in pædiatric settings. Much like the mermaid giving up her voice for acceptance by the prince, CYP may give up their voices in pædiatric settings to conform to social pressures and appease others.

Developmentally, Erikson (1959) suggests that adolescence is a time of "identity versus identity confusion". At a time when 'healthy' adolescents may be growing their independence and spending time with peers, the unwell adolescent is at risk of being forced into a position of dependence and peer isolation, thereby risking accomplishment of developmental goals. For CYP with cancer, Hind (2004) suggests theories of healthy adolescent development may not always fit and consideration should be given to the shifting perspective model of chronic illness, which allows for movement between illness in the foreground, versus wellness in the foreground. Chosen narratives may influence the position occupied.

The experiences linked to accessing pædiatric services, or around a life-threatening condition, may represent a 'trauma' therefore consideration should be given to the mechanisms underpinning trauma focused work. Although a negative response to trauma could be viewed through a positivist lens given that post-traumatic stress disorder (PTSD) is a recognised mental health condition with a cluster of symptoms that are common across individuals, in fact, the many different responses to a single 'traumatic' event suggests that individual experience and sense-making of an event may play an important part in the psychological response to that event.

Multi-level processing may be involved when coping with a potential trauma, including, emotional, biological (e.g. hormones), social and cognitive (Pearlin and Schooler, 1978). From a psychological viewpoint, cognitive models suggest therapies targeting perceptions, or cognitions, around the trauma can be beneficial (Ehler & Clark's, 2000; Ehlers, Clark, Hackmann, McManus, & Fennell, 2005). Whilst there might be some potential for overlap between the processes of re-telling of the trauma "story' and cognitive restructuring which underpin cognitive approaches, narrative approaches would also give greater emphasis to the narratives which form around the event. These may occur alongside cognitive processing. From a narrative perspective the 'healthy' individual holds a coherent, meaningful, and dynamic narrative of the self, and research suggests achievement of this, following a potentially traumatic event, can reduce PTSD symptoms (Tuval-Mashiach, Freedman, Bargai, Boker, Hadar, & Shalev., 2004). Howard (1991) suggests that identity is an issue of life story construction and psychopathology such as potential trauma or illness can therefore be seen as instances when life stories have been disrupted. From this perspective, therapy would seek to 'repair' stories, and one way of achieving this may be through narrative therapy.

The influence of cultural context and social meaning when processing potential trauma has also been acknowledge (Tuval-Mashiach et al, 2004). As a result, attempts have been made to develop a less individualistic approach to trauma to allow consideration of a more systemic development of distress (Dallos & Vetere, 2009). Re-authoring within narrative therapy may be a way of challenging the dominant perceptions of trauma responses as an illness through offering an opportunity to re-author life-stories in a way favourable to the individual. Such a shift may have the potential to promote post-traumatic growth (PTG; Tedeschi & Calhoun, 1995) a concept used to describe the process of positive psychological change experienced following traumatic

struggles. PTG can be viewed differently from symptom 'recovery' as it is possible for individuals to still feel pain and unhappiness, but at the same time to identify positive changes arising from their experiences. One way of understanding PTG through a narrative lens is that individuals go through a process of 're-authoring' their lives, moving from a position of the trauma as a completely negative experience that has happened to them, to one in which they can learn, change and develop from these experiences

This Review

Given the potential power of stories over our sense of self, this review will explore the use of narrative therapy techniques with CYP being treated within pædiatric settings. This is the first systematic review and narrative synthesis of narrative methodologies within paediatric settings and will therefore start with a brief consideration of how narratives are being used more widely. Following this, consideration will be given to how these approaches align with White and colleagues' narrative therapy principles before focusing on the quality of the current literature and perceived effectiveness of narrative therapy in pædiatric settings. Given the current socio-economic climate and strong move towards evidence-based practice within the NHS, this report will conclude with a discussion around some of the concerns linked to scientific validity, clinical implications and future research directions.

The lines of enquiry informing this review will be:

- What are the aims of narrative therapy within pædiatric settings?
- What are the theories and mechanisms for change, and perceived benefits and challenges with using narrative therapy in pædiatric settings?

- In what ways have narrative ideas been adapted for this setting and what developments are apparent from the literature?

- Is there evidence for the effectiveness of these therapies in improving health and wellbeing?

A brief word about epistemology

When considering the application and 'effectiveness' of narrative approaches it is important to consider ontological, and epistemological viewpoints. As previously stated, narrative therapy largely takes a constructivist stance where there is no single truth, whereas quantitative research is more inclined to a position where there is a single truth that can be discovered (Roy-Chowdhury, 2003). This tension may inhibit clinicians within the narrative field in either the desire or means to 'evidence' their practices, thus hindering the development of an evidence base and the possibility of the treatment being included in National Institute for Clinical Excellence (NICE) guidelines. Given that clinical governance agenda require development of methods to evaluate work, a "both-and" rather than "either-or" position, as suggested by Roy-Chowdhury (2003), seems more appropriate. A critical realist position allows for this and will therefore be adopted for this research.

Qualitative research methods sit more comfortably within a social constructionist epistemological framework and are therefore likely to be the dominant approach within reviewed papers. When assessing quality of papers, an instrument designed for qualitative papers was therefore utilised when appropriate.

Literature Search Procedure

Several initial searches were carried out to identify the search terms most employed by some of the relevant literature (which had initially been identified through 'google scholar') and also which databases best represented the literature. Once identified, these terms (see table 1) were used for the more focussed and comprehensive searches described below.

Table 1: Summary of Search Terms:

Summary of Search Terms:
"narrative therap*" OR "narrative practice*" OR "narrative approaches" OR ["Tree of Life" OR bead* OR stor*] AND narrative*
AND Pædiatric* OR Pediatric* OR hospital* OR medical* OR patient*
AND Child* OR young pe* OR adolescen* OR teenager* or famil*

An electronic literature search was carried out using Medline, PsychInfo, and Web of Science covering the period up until 01st March 2019. Where search engines allowed, searches were limited to the terms being used in the abstract or title.

Following identification of relevant papers from the initial searches a full scan of reference lists was carried out, as well as a further "google scholar" search to explore the grey literature. In addition, contact was made with prominent practitioners in the field, to ensure key papers or helpful articles within this 'grey' literature had not been missed.

Table 2: Inclusion/Exclusion Criteria

Inclusion Criteria	All papers pertaining to interventions occurring in pædiatric settings with the young person under 25* years and/or their family members which focus on creating narrative or intention to link the work to narrative therapy ideas, and which either described the therapy in some detail and/or reported outcome findings. A full text version available in English. *25 years and under was chosen to allow for variation in service provision, and the age of transition to adult services which can be at the upper end of 'adolescence/ young adulthood.*
Exclusion Criteria	Intervention in a family therapy or mental health setting e.g. support for anorexia or OCD. Articles related to grief support for young people after parent loss within medical setting or other interventions targeting solely adult aged patients. Several poster presentations or conference papers were identified but excluded if after attempted contact with the authors no extended version was available for review

Quality Assessment Tools

The quality of qualitative or mixed method papers was assessed utilising the Critical Appraisal Skills Programme (CASP) Qualitative Research checklist (see appendix A) (CASP, 2018). The tool does not employ a scoring system as such; however, the appraisal tool enables users to systematically consider validity, significance, and usefulness of results when assessing quality and within this review consideration was given to how many of the ten criteria were met when attributing a quality rating (see appendix A).

For case studies, Yin (2000) criteria for judging quality of research design in case studies was adapted and applied (Yin, 2008). Quality ratings were determined by how well papers met criteria across the four areas; construct validity, internal validity, external validity, and reliability (see appendix B).

Given that the overall quality of reviewed papers was low when assessed in this way, and that the research appears to be in its infancy, no papers were excluded from the review as a result

of their quality rating. Instead the assessment tools were utilised to allow greater weight to be

given to finding from "better" rated papers. In addition, the tools were used to guide the reader

to the variety of shortcomings in the papers included in this review and to shape the final

synthesis of the findings.

Figure 1: PRISMA Flow Diagram

Identification

Records identified through database searching
(n = 1524)

Records after duplicates removed
(n =1042)

Screening

Records after title screened
N= 309

Records after abstract screened
N= 41

Additional records identified through other sources
(n=10)

Eligibility

Records after full text assessed for eligibility criteria.
N=20

Included

Studies included in this review.
(n =20)

Records excluded from titles (n =733)
Reasons for exclusion:
Sample over 25 years n = 121
Exploration of narratives n = 308
Narrative analysis n=21
Mental health focused n=60
Trauma focused n=36
Reviews n=41
Book Reviews n=39
Intro or commentary n=10
Theoretical (not NT) n=24
Not NT or exploration n=55
Narratives as Education n=3
YP but not pædiatrics n=15

Records excluded from abstract (n=268)
Reason for exclusion:
Narrative Exploration n=98
Narrative medicine n=35
Not Pædiatric n=32
Reviews n=4
Sample over 25 years n=26
Narrative Analysis n=12
Book Reviews n=14
Sharing fiction n=12
Theoretical not NT n=27
Introductions/commentary n=8

Source of additional articles:
Scholar Google n= 6
Reference check n=3
Professionals working in the area n=1

Full-text articles excluded (n =31)
Reason for exclusion:
Sample over 25 years n=6
Narrative Medicine n=1
Not pædiatric setting n=3
Abstract only/conference description/meeting n=6
No full text in English n=1
No full text available n=2
No distinct NT n=2
Theoretical not NT n=1
Narrative Analysis n=1
Exploration of needs n=6
Focus staff n=1
Reporting same findings n=1

General overview of the literature

Twenty papers were identified for inclusion in the review. Cancer was the dominant condition targeted by interventions but, there was also evidence of the use of narrative methodologies with diabetes, chronic heart disease (CHD), sickle cell disease (SCD) and chronic fatigue syndrome (CFS).

Six papers related to beading programmes, although two papers referred to the same setting (Baruch, 2010; Penkman et al., 2006; Wilson & Chando, 2014; Portnoy et al., 2016; Redshaw et al., 2011; Sisk et al., 2012). Two papers referred to Tree of Life groups (Casdagli et al., 2017; Moxley-Haegert, 2012) and four to digital story-telling interventions (Akard, et al., 2015; Laing, et al., 2017; Pereira 2017; Pereira, Muench, & Lawton, 2017).

Other approaches identified for patients were a 6- or 12-week self-investigation intervention utilising the self-confrontation method (SCM), a method designed to help people to gain insight into the organisation of their self-narratives, (van Geelen et al., 2011) and a case study of a young girl with surgical-related anxiety (Naidu & Shabangu, 2015).

Three studies targeted parents/carers. One study encouraged mothers to express, unpleasant emotional memories and experiences in writing every day for a week whilst with their hospitalised child (Farahani, Azad, & Sahebalzamani, 2017). The second was a feasibility and safety study for a computer-based intervention known as the 'experience journal' (DeMaso, Gonzalez-Heydrich, Erickson, Grimes, & Strohecker, 2000). The third utilised therapeutic scrapbooking with family members (McCarthy & Sebaugh, 2011).

One paper described a 'Day out' for CYP with SCD and their families (Lunn, 2008). Two papers outlined narrative techniques utilised with CYP with cancer or on palliative care pathways

and their families (Moxley-Haegert, 2012, 2015) whilst Hedtke (2014) used a family therapy case example to demonstrate generation of hope following cancer-related loss and grief.

Alignment of Approaches to Narrative Therapy

The brief descriptions of papers above, suggests that there is, not surprisingly, a wide and loose definition of narrative/stories to describe interventions within pædiatric settings. Given the focus of this review is those practices aligned to narrative therapy, the remaining sections of this review will focus on those practices which seemed most informed by, or relevant to the writing of Michael White and colleagues. The seven practices of narrative therapy described in the introduction were utilised to identify the most relevant papers from the initial searches, which could thus arguably fall in the 'narrative therapy' tradition. The focus remains on understanding the use of these practices within pædiatric settings.

Please see table 3 for the papers' alignment with narrative therapy practices. Ten papers were identified where at least one of the seven principles was present. The application and adherence to narrative therapy principles varied across studies. What is clear is that not all narrative interventions can be described as narrative therapy.

Table 3: Alignment of papers to narrative therapy principles

	Akard et al. (2015)	Baruch (2010)	Casdagli et al. (2017)	DeMaso et al. (2000)	Farahani et al. (2017)	Hedtke (2014)	Laing et al. (2017)	Lunn (2008)	McCarthy & Sebaugh (2011)	Moxley-Haegert (2015)
Did the paper state the intervention was based on Narrative Therapy? If not – alternative theoretical position	No Unclear Legacy making	No Unclear Resilience and suffering	Yes Tree of Life	Yes NT orientation alongside others	No NT" used to describe narrative writing	Yes	Partly Brief mention of link to NT	Yes	Yes NT foundation	Yes
Elements of White & Epston's NT										
(1) Collaboration	X	co-participation	✓*	X	X	✓✓	✓	✓✓	✓✓	✓
(2) Externalising the problem	X	X	✓✓	X	X	✓✓	X	✓✓	✓✓	
(3) Unique Outcomes	X	Resilience paradigm	✓	X	X	✓✓	X altho Own story	✓		✓
(4) Outsider Witness	X	X	✓✓	X	X	✓	Research assistant	✓	✓	✓✓
(5) Remembering practices	X	X		X	X	✓✓	LEGACY			✓✓
(6) Literary Means	X	X	✓✓	X	X		Video	✓✓		✓
(7) Bringing-it-back practices	X	X	✓✓	✓	X		X	✓	✓	✓
INCLUDE	NO	NO	YES	YES	NO	YES	YES	YES	YES	YES

* 2 ticks signifies ideas was explicitly mentioned in paper 1 tick evidence implicit

	Moxley-Haegert (2012)	Naidu & Shabangu (2015)	Penkman et al. (2008)	Pereira (2017)	Pereira et al. (2017)	Portnoy et al. (2016)	Redshaw et al. (2011)	Sisk (2012)	Van Geelen et al. (2011)	Wilson & Chando (2014)
Did the paper state the intervention was based on Narrative Therapy? If not – alternative theoretical position	Yes	Yes NT combined with Poetry	No Deny therapy component designed to help mobilise coping	No Trauma exposure and restructuring	NO Unclear	Yes Beads of Life	No Narrative construction in making sense of experiences	No Legacy based on Erikson	Based on self-confrontation method, which is linked to narrative and constructivist approaches	No Follow up to Redshaw et al. (2011)
Elements of White & Epston's NT										
(1) Collaboration	✔	✔	X	X	X	✔	X	X	?	X
(2) Externalising the problem	✔	✔✔	X	X	X	✔✔	X	X	X	X
(3) Unique Outcomes	✔	✔✔	X	X	X	✔	X	X	Not Determinable	X
(4) Outsider Witness	✔✔	✔✔	X	X	X	✔✔	X	X	X	X
(5) Remembering practices	✔✔		X	X	X		X	X	X	X
(6) Literary Means	✔✔	✔✔	X	X	X		X	X	X	X
(7) Bringing-it-back practices	✔		X	X	X	✔	X	X	X	X
INCLUDE	YES	YES	NO	NO	NO	YES	NO	NO	NO	NO

NB: 2 ticks signifies ideas was explicitly mentioned in paper, 1 tick evidence implicit

Of the original 20 papers, 10 remained that adopted at least one of the narrative therapy principles outlined by Carr (2001). These papers are now reviewed in more detail. A short description of each of the qualitative papers is provided in Table 4. Case studies and descriptive paper are outlined in Table 5. The two tables reflect the different tools that were used to assess quality.

Table 4: Description of Qualitative Papers

Authors	CASP (2018) Quality rating (see appendix A)	Description of Methodology and type of therapy	Type of Feedback or evaluation and recruitment strategy	Target population, how many participants, and demographic data Country of Origin	Main findings	Key strengths/weaknesses
Casdagli et al (2017)	Low	Qualitative group evaluation Tree of Life group	Group interview during workshop and FU telephone calls 2-4 weeks later Analysed with thematic analysis Recruitment: All individuals attending the workshop were invited to give feedback. Drop-out rate not reported	Young people with diabetes 93 CYP (60 Female: 33 Male) Recruited from 12 adolescent groups (13-19 yrs.) and 5 child groups (10-12 yrs.) No further demographics United Kingdom	Helped develop positive view of self separate from diabetes Two superordinate themes: connecting with others and building a positive view of self	Good description of ToL process and possible mechanisms of change Possible bias in responses due to group interviews occurring as part of the workshop
DeMaso et al (2000)	Low	Feasibility and safety study Experience Journal (EJ)	Semi-structured interview including Likert type questions alongside open ended questions Phase 2: As above measures pre- and post-intervention Analysis coded based on freq. and similarity to other responses Recruitment: Mothers of children hospitalised for cardiac disease at a single	Parents of CHD Phase 1: 9 mothers 1 patient Phase 2: 40 mothers Mothers Demographics: Age19-46 yrs. (M=36yrs.) Majority Caucasian (n=36) and married (n=32). 80% fell into top two socioeconomic levels of	5.8/7 and 5.7/7 overall satisfaction rating EJ safe and useful in reducing isolation and increasing understanding, and fostering positive reactions in mothers	Difficult to identify unique NT elements Focus on safety and feasibility so limited contribution to exploration of effectiveness Unclear how much participants are using the EJ – minimum for inclusion was 30 minutes, also no reference to what types of stories paritcipants are accessing

Authors	CASP (2018) Quality rating (see appendix A)	Description of Methodology and type of therapy	Type of Feedback or evaluation and recruitment strategy	Target population, how many participants, and demographic data Country of Origin	Main findings	Key strengths/weaknesses
			medical centre: Available for interview in English. Phase 2 74% rate of participation.	Hollingshead Four Factor Index of Social Status. Child demographics: age 3-16 yrs. (M=7.6) male n=17, female n=23) USA		
Laing et al (2017)	Medium	Qualitative interviews Digital stories	Semi-structured interviews Analysed in line with a hermeneutic methodology Recruitment: Purposive sampling, recruited via posters placed within a single hospital site, and a condition specific website	Oncology patients past and present and family members n = 16 Age range 5-39 yrs. 10 Female: 6 male. Canada	Way for others to understand experience and to allow further healing. Make sense or meaning Further away from diagnosis the more reflective the stories	Clearly presented methodology Suggest potential for cancer patients who would not normally engage with 'therapy'. Only brief mention of link to NT
McCarthy & Sebaugh (2011)	Very low	Group evaluation questionnaire Therapeutic Scrapbooking group	Group evaluation questionnaire (Likert and open-ended questions) Recruitment: Open group available to any caregiver of child treated as specific hospital. Asked to complete questionnaire on completion of 4 scrapbook pages	Parents in oncology settings n =122 Demographic data not reported USA	Overall group rating 4.9/5 Fun rating 9/10 Distraction that helped relax & cope with stress Item helpful in meeting others 8.7/10	Links to NT suggest intervention enables re-authoring of ones' story Views of those who attend but did not go on to complete 4 pages (front and back) were not captured. Unclear how themes were reached from open ended question responses

Authors	CASP (2018) Quality rating (see appendix A)	Description of Methodology and type of therapy	Type of Feedback or evaluation and recruitment strategy	Target population, how many participants, and demographic data Country of Origin	Main findings	Key strengths/weaknesses
Moxley-Haegert (2012)	Very Low	Workshop evaluation Pre- and post-questionnaires COURAGE Programme and Tree of Life (ToL) workshop	Exerts from collective book (unanalysed) Brief pre and post group measures and 'feedback' Recruitment: Unclear	Young people with cancer and their families Response rated unclear 29 families in first year of COURAGE programme. No further demographic details available Canada	Pre group importance for reasons to attend 8-10/10 Post ToL groups helpfulness rating 9 or 10/10 Helpfulness of COURAGE program 8-10/10 Positive feedback Families enjoyed talking Sharing ideas Time to reflect	Good integration of NT ideas but largely descriptive paper Minimal methodology information and no clear analysis of qualitative data. NB: COURAGE = Cancer as an Opportunity to Unite and share Resources in an Amicable Group setting that provides Encouragement
Portnoy et al. (2016)	Very Low	Qualitative group evaluation Beads of Life group	Case examples and feedback collected from questionnaires and semi-structured interviews Recruitment: Unclear process for accessing group other than treatment for cancer in specific hospital, but all group members invited to give feedback	Young people with cancer 60 YP participated in groups (29 male, 31 female) Age range: 7-25 yrs. United Kingdom.	Affirming feedback that group gave participants a safe place to stand Could change stories told about self, events they emphasise, meaning attributed	Good description of Beads of Life approach, a NT informed group, utilising case examples Analysis method for feedback unclear

Table 5: Description of Case Study and Descriptive Papers

Authors	Yin (2008) Quality rating (see appendix B)	Description of Methodology and type of therapy	Type of Feedback or evaluation and recruitment strategy	Target population, how many participants, and demographic data Country of Origin	Main findings	Key strengths/weaknesses
Hedtke (2014)	Very Low	Case Study Family therapy case	Case Example Recruitment: Reason for selection of case not reported	Young people with life threatening conditions and their families Single family cases study. Young person (male, 14yrs.) USA	Case study supported towards stories of strength and agency Disrupt stories of despair, create opportunities for new identities.	Excellent links to NT and provides good example of work with death and grief. Unclear if therapy typically occurring in paediatric setting Poor validity and reliability
Lunn (2008)	n/a	Descriptive Paper A 'day out' for families	n/a	Families accessing SCD services 15 parents and 35 YP attended group United Kingdom	Reflection: Witnessed an unfolding of a wealth of stories of coping and mastery	Good description of use of 'communities' to share knowledge and allow 'witnessing' of preferred identities No evaluative element
Moxley-Haegert (2015)	n/a	Descriptive paper	n/a	Young people and families within palliative care n = n/a Canada	n/a	Good overview of potential for NT with children who are dying and their families in palliative care No evaluative element
Naidu & Shabangu (2015)	Low	Case-study One-to-one therapy sessions	Case example Recruitment: Reason for selection of case not reported	Young person undergoing spinal surgery Single case Female 18 yrs. South Africa	Moved to position of hope. Interpretation of poetry helps explore changes in identity	Good use of integration of poetry and NT. Young person read and approved final paper before submission, but poor overall reliability and validity.

Description and Critique of the papers

Quantitative Studies

Although several papers reported quantitative findings from outcome questionnaires within their methodology, none utilised purely quantitative methodologies, therefore these papers are quality assessed and reported below alongside other qualitative studies.

Qualitative Studies

Six papers were identified which either reported purely qualitative, or a mixture of qualitative and quantitative, findings. A qualitative research approach fits well with the social constructionist roots of narrative therapy, and these papers appropriately explored the experiences and understanding of meaning.

Three papers targeted patients directly either in a group setting through a beading programme (Portnoy et al., 2016) or Tree of Life group (Casdagli et al., 2017); or one-to-one through a digital story intervention (Laing et al., 2017).

A single study was a feasibility and safety study for a computer-based intervention for families called the Experience Journal (DeMaso et al., 2000); and a study which focused on therapeutic scrapbooking groups for families (McCarthy & Sebaugh, 2011). There was also a predominantly descriptive paper which reported brief findings from 'Hopework', a group for families developed from the Tree of Life (Moxley-Haegert, 2012).

The beading group and Tree of Life groups all made explicit links between narrative therapy and the development of their group. Within these approaches, beads or a tree drawing, were used to prompt the telling of preferred stories of identity, whilst attempting to give the CYP a safe place to stand from which to story their journey. Within the beading programme, unlike

beading interventions outlined previously, beads were not only used for medical treatments or procedures but also included "life beads". The "life beads" string allowed for: daily living, skills and abilities, values, important people, 'where I come from', and hopes, wishes and dreams for the future in order to help development of a preferred identity. An important part of the group was the sharing of beads with others and witnessing others' stories. Portnoy et al. (2016) specifically linked the sharing of stories as a way to further acknowledge the many rich stories of the young people's identities.

Only one digital storying intervention acknowledged links to narrative therapy and demonstrated some overlap with the narrative therapy principles - namely a collaborative approach being employed, an opportunity to become experts in their own lives and tell their 'chosen' story and to have it witnessed by others. Laing et al. (2017) was explicit about the collaborative process with the research assistant, and opportunity for CYP to "find" the story and create this using selected images, videos and music. These were usually created together over 3 two-hour sessions, suggesting the ability of the individual to create a "preferred narrative".

McCarthy & Sebaugh (2011) introduced a bi-monthly open group for parents and carers to come together for scrapbooking to help caregivers discover meaning in their experiences and connect with other families, reduce stress, and enhance coping, whilst having an opportunity to reauthor their lives. Scrapbooking was seen as a way to take an expert position in one's life, externalise the problem, and create a document, within a group setting, which allowed for an audience or witnessing (McCarthy & Sebaugh, 2011).

DeMaso et al. (2000) tested the safety and feasibility of a psychoeducational intervention based upon a narrative model involving sharing of personal stories. The programme accepts stories/descriptions from families and organises these, through content analysis so that similar

stories are grouped together, and accessible to other families visiting the ward. The authors make

a brief mention to narrative therapy guiding the design although when considering this paper

within the table above, there was only suggestion of this being an opportunity for 'bring back'

whereby each family could share their stories and ideas for future families.

Quality

The quality of papers was assessed utilising the CASP Qualitative Research Checklist

(CASP, 2018; see appendix A for a summary of the appraisals.). No reviewed papers

incorporated a control group or used any type of reliable or validated measure demonstrating that

the overall quality within an empirical framework was low. Whilst qualitative methods were

deemed to be the most appropriate methodology, overall the singular level of reporting methods

was poor. For example, only the highest scoring paper made it possible to determine recruitment

strategy (Laing et al., 2017). No reported consideration was given to the relationship between

researcher and participant, and there was minimal reporting of attention to ethical issues. Within

one study the feedback was collected from a 'group interview' which formed part of the

workshop suggesting a lack of separation between intervention and evaluation (Casdagli et al.,

2017). All papers were able to make a clear statement around findings, However, in all but two

studies (Casdagli et al., 2017; Laing et al., 2017) it was not clear if the data analysis had been

sufficiently rigorous to reach these findings.

Interestingly, two of the three papers to score the highest within this quality framework

were also the two papers most loosely linked to narrative therapy (Laing et al, 2017; DeMaso et

al, 2000). It is possible, therefore, that some of the limitations on quality ratings within the 'truer'

narrative therapy papers may have been as a result of favouring a more narrative presentation of

research leaving little space for fuller discussions of area such as analysis method and ethical

issues.

Case Studies

Two papers were identified to use a case study design. The case example outlined by

Naidu & Shabangu (2015) combined narrative therapy and poetry to support an 18-year-old

overcome anxiety towards spinal surgery. To achieve this, the authors attempt to support the CYP

to develop a preferred identity as a survivor over a dominant story of anxiety getting in the way

of surgery. They engaged an audience to "witness" this, made up of both family members and

medical practitioners (Naidu & Shabangu, 2015). Hedtke's (2014) paper outlines how a narrative

approach may help professionals to stand alongside children with cancer and life-threatening

conditions, and their family members, to create a space for hope. A case study is presented of a

family therapy session however it was unclear if the sessions were typically occurring within a

pædiatric setting. The case description, however, described good integration of White's narrative

therapy components and demonstrated the collaborative position adopted by the practitioner, the

types of questions asked to explore unique outcomes, examples of listening for the 'absent but

implicit' (White, 2000), and the potential for remembering conversations allowing a deceased

family members' views to join the conversation. The family were encouraged to externalise the

problem and label "the intruder", enabling the family to unite in their fight against 'the intruder'.

Quality

Yin's (2008) criteria for judging quality of research design in case studies was adapted to

assess the quality of included studies (see appendix B for a summary of the papers' appraisals).

Papers quality was low. Construct validity was limited by the inclusion of a single case study as the source of evidence although in Naidu and Shabangu's (2015) paper the participant reviewed the paper prior to publication suggesting some attempts at developing construct validity. Both papers used explanation building supported by narrative therapy theory. Reliability was limited by a lack of study protocol, case study database, or clear chain of evidence, so findings should be approached with caution.

Descriptive Papers

Two papers were identified which presented descriptive accounts of how narrative therapy ideas have been incorporated into practice (Lunn, 2008; Moxley-Haegert, 2015). The first describes an event for children with SCD and their families, designed to promote the narrative practice of 'spreading the news'. The group enabled the creation of an audience for individuals to live out their preferred stories. It also led to the development of a "community of concern" (Madigan & Epston, 1995), promoting collaboration, externalising, thickening stories of coping and accomplishment, documenting coping 'tricks' to share, and distributing certificates of achievement (Lunn, 2008).

The second paper presented an overview of narrative practices used with children who are dying and their families in palliative care and overlapped significantly with the interventions presented in the earlier paper by the same author which related to more general work within oncology. The author described the use of "re-membering" conversation in line with narrative therapy as helpful both before and after the death of a child. In line with some of the other programmes around multiple stories, there was a focus on searching for double stories and subordinate stories. Spreading the news or sharing stories was mentioned. Definitional

ceremonies were held allowing outside witness and a support group has developed to create a community. (Moxley-Haegert, 2015).

Quality

Given the lack of evaluation component in these two papers no suitable tool to measure quality was available within a research framework, and whilst these papers provide valuable insight into theory-practice links and might help others to set up narrative therapy-informed programmes, they added little to the evidence base for these therapies.

Synthesis

The poor quality of the current literature in the field of narrative therapy in paediatrics makes it impossible to draw conclusions around potential effectiveness of narrative techniques in improving outcomes (largely psychological in this case) for CYP. However, consideration of the early findings may help shape the direction of research in the future, and may offer guidance for practitioners in considering how to introduce narrative practices in their settings.

What were the stated aims of using narrative therapy?

Several studies utilised narrative therapy with the specific aim of prompting and supporting preferred identities (Casdagli et al., 2017; Portney et al., 2016; Naidu & Shabangu, 2015). This could include the explicit aim of separating the person from the condition and building a positive view of self (e.g. Casdagli et al., 2017), or simply an opportunity to choose the story told about oneself (e.g. Laing et al., 2017). Helping legacy development was a recurring theme within programmes supporting life-critical illnesses (Moxley-Haegert, 2015).

There was a strong focus towards assisting patients, and families, to find stories of skills and abilities in a way that helped them voice their special knowledge and uncover preferred identities (Casdagli et al., 2017; Moxley-Haegert, 2015; Naidu & Shabangu, 2015; Portnoy, et al., 2016)

Narrative therapy was seen as a dynamic way to foster the externalisation of chronic illness and facilitate conversations of unique outcomes (Naidu & Shabangu, 2015; Hedtke, 2014). The bringing together of communities was utilised with the aims of; helping develop connections to others, facilitating opportunities to share knowledge and experience ('bringing it back') and creating audiences to allow people to perform and 'live out' preferred identities (DeMaso et al., 2000; Lunn, 2008). Groups aimed to move away from support groups dominated by stories of suffering (Moxley-Haegert, 2012) and sought to enable CYP and families to shift position, from patients and receivers of medical interventions towards experts in their condition (Lunn, 2008).

What are the theories and mechanisms for change underlying the programmes and what are the perceived benefits or challenges?

There was variation across reporting on mechanisms, however, the most comprehensive explanation for the mechanisms of the narrative therapy process, provided by one of the 'higher' quality rated papers, was outlined by Casdagli et al. (2017). They suggest the Tree of Life programme helped CYP to share problems in ways that make them more psychologically robust by a focus on their strengths. Carefully chosen questions, enabled preferred story telling by giving group members a historical context, bringing them into relationships, and connecting

them to others. This allowed for the strengthening of these alternative stories, which were further supported by others' witnessing.

Several papers linked interventions to resiliency literature (DeMaso et al., 2000; McCarthy & Sebaugh, 2011), or the mechanisms of change being enabled by group process or group participation (Casdagli et al., 2017; DeMaso et al., 2000; Portnoy et al., 2016; McCarthy & Sebaugh, 2011). There was a perception that stories are meant to be told and perhaps clinicians are simply providing methods to help individuals derive meaning from their experiences, and reclaim their identity from the trauma and uncertainty of illness. Mechanisms for this included; becoming active participants in their treatment and recovery stories (Naidu & Shabangu, 2015; McCarthy & Sebaugh, 2011) or allowing movement of the narrative process from private meaning to shared (and potentially more accurate) meaning of the experience (DeMaso, 2000).

McCarthy & Sebaugh (2011) suggested that participants' perceptions of reality are often altered, and drawing on Neimeyer's (2000) concept of 'meaning making' as central to coping with loss, enabling the techniques of reauthoring one's story to promote benefits in line with post traumatic growth.

The most cited benefit of narrative therapy was the opportunity for new/preferred identity stories to form and 'thicken' (Casdagli et al, 2017; Portnoy et al, 2016; Hedtke, 2014). Narrative therapy was also hypothesised to help families to engage hope (Hedtke, 2014; Moxley-Haegert, 2012; 2015) or support personal growth and psychological adjustment (McCarthy & Sebaugh, 2011).

Unsurprisingly there was limited reference to potential problems with adopting a narrative therapy approach. Research design, and self-selection of participants may have impacted on this. Another inhibiting factor may have been researcher allegiance to narrative

methodologies. This may have impacted findings on a number of levels such as; participants

being aware of allegiances and therefore reporting what they thought researchers wanted to hear,

researchers may have only asked questions which sought to explore narrative therapy in a

positive light, or researcher bias may have meant only positives were identified at the analysis

stage or selected for reporting and wider dissemination. Only one of the better-quality rated

studies mentioned a possible negative to the process. Several mothers reported feeling

overwhelmed by empathising with families they were reading about. This could be a potential

challenge to narrative ideas of 'bring back' and 'outsider witness', however, all mothers wanted

to continue with the group, and still found the Experience Journal useful and helpful (DeMaso et

al., 2000).

In what ways have narrative ideas been adapted for this setting and what developments are

apparent from the literature?

　　　　Narrative therapies within pædiatric settings often provide something tangible such as

beads or a scrapbook to allow recording and honouring of the illness journey (McCarthy &

Sebaugh, 2011). Novel combinations of narrative therapy ideas have also integrated into general

approaches such as use alongside poetry writing (Naidu & Shabangu, 2015) to draw on the

unique strengths of the individual concerned.

　　　　Narrative therapy ideas have become a key component, sometimes overtly, and

sometimes accidentally, in work with terminally ill children through the development of "legacy

making" programmes or re-membering practices (Hedtke 2014, Laing et al., 2017; Moxley-

Haegert, 2015).

Working with CYP has meant that narrative ideas have needed to keep up with

technology in ways such as digital storytelling initiatives (Laing et al., 2017), interactive

psychoeducation and story sharing tools (DeMaso et al., 2000) and the development of virtual

communities (DeMaso et al., 2000; Moxley-Haegert, 2012).

Is there evidence for the effectiveness of these therapies in improving health and wellbeing?

Prior to consideration of effectiveness of narrative therapy within paediatric settings

several key limitations are outlined.

Generalisability is difficult to establish due to uncertainty around number of participants

across studies and a lack of demographic data. Feedback was obtained from approximately 175

family member, and 166 patients, however, numbers are likely to be inaccurate, because group

attendee numbers, rather than numbers interviewed were presented by Casdagli et al. (2016); it

was unclear how many contributed to feedback in Portnoy et al. (2017); and in Moxley-Haegert's

paper (2012) the number of families engaged with the service was reported, rather than how

many attended groups or contributed to feedback.

Whilst age and gender of participants tended to be reported, only one study reported more

extensive demographic information and noted that the majority of participants were Caucasian

and within the top two high socioeconomic levels (DeMaso, 2000).

As stated earlier, no validated measures were utilised, no two studies used the same

measurement tool and the majority of findings were based on informal feedback further limiting

conclusions around effectiveness.

Three papers included at least sections of their questionnaires or interview scripts, but the

use of positively slanted questions was noted within all three examples which may have led to

more favourable responses from participants (DeMaso et al., 2000; McCarthy & Sebaugh, 2011; Moxley-Haegert, 2012). Although the exact data collection process was unclear within Casdagli et al. (2016) it appeared that group feedback interviews were incorporated into the workshop. The blurred line between feedback and intervention was also presented in pre- questions within Moxley-Haegert (2012) which included; *"Please identify the strengths of your family…"*.

Further difficulties establishing effectiveness are created by lack of consistency around intervention aim and intended outcome. This section therefore, provides more of a description of change from the programmes, rather than a quantitative exploration of 'effectiveness'.

As would be expected within a narrative framework, many CYP and families saw the intervention as an opportunity to tell/share their stories. Across studies informal feedback suggested overall satisfaction and helpfulness attributed to participation in narrative interventions. Participation was described as fun (McCarthy & Sebaugh, 2011; Portnoy et al, 2016), an opportunity to reflect (Moxley-Haegert, 2012) and a welcome distraction (Laing et al, 2017; McCarthy & Sebaugh, 2011).

When considering narrative therapy, one of the key aims was to give CYP a safe place to stand and the opportunity to develop a preferred identity separate from their illness. Only two papers, which also showed good alignment with narrative therapy, made reference to patient feedback about identity separate from the condition (Casdagli et al., 2017; Portnoy et al., 2016). It remains unclear from the current literature how this separation of identity from illness benefits the CYP, although Casdagli et al. (2017) uncovered a superordinate theme from group interviews for connecting with others and building a positive view of the self, which included ideas of empowerment and improved self-esteem. Themes of feeling more connected through meeting

others, recognising support, and decreasing isolation was seen as a positive from all studies

incorporating a group setting.

Lunn (2008) reflected having witnessed an "unfolding of a wealth of stories of coping

and mastery" and families involved in McCarthy & Sebaugh (2011) scrapbooking reported that

the group was helpful in coping and managing stress, whilst those accessing the Experience

Journal felt it helped them with ideas for coping and increased hope (DeMaso et al, 2000). The

case studies presented, allowed an opportunity for the CYP to consider a shift in position towards

hope or stories of strength and agency. Interestingly the position of hope was achieved through

the interpretation of poetry. This opens up an interesting avenue for exploring impact and

effectiveness in the CYP through model-congruent narrative practices.

Constructs such as hope, personal agency and strength may all play a part in a 'preferred

identity' and all seem like worthwhile outcomes. However, it is unclear how one would

operationalise these and how these might be 'measured' effectively.

The process of narrative creation was seen as an opportunity for reflection (Moxley-

Haegert, 2012) and Laing et al. (2017) found that the further away from diagnosis the participant

was, the more reflective their stories. This may be because some mental processing has already

occurred, or perhaps reflects a need to support CYP with processing their stories whilst in

hospital in order to reach a more reflective perspective.

In several studies participants reported increased understanding of the health condition or

the CYP's experiences of illness. Participants in one Tree of Life group reported feeling more

able to respond to negative attitudes about their diabetes, and improved diabetes management

following participation (Casdagli et al., 2017), suggesting that whilst the state of the illness

couldn't necessarily be changed, the approach to managing that condition and relationship towards the illness could be.

Discussion, recommendations, and implications

This was the first systematic review and narrative synthesis of narrative methodologies and the application of narrative therapy in paediatric settings. The review demonstrates a wide range of applications of narrative methodologies and perceived benefits. However, similar to a variety of arts-in-health, recreational, and psychosocial programmes for CYP in health settings, the goals and outcomes of related programmes are not typically made explicit (Baruch, 2010). This makes it difficult to present a conclusive answer to questions linked to effectiveness.

This review suggests promise for individual, family, and group narrative therapy in paediatric settings. However, what is clear from this review, is that narrative therapy in pædiatric settings is in the early stages of development. The papers outlined above are useful in helping 'spread the word' but are far from providing the beginnings of an evidence base for use, which is important if narrative therapy is to continue in services given the shift towards evidence-based practices. Brown, Sole, Ferguson, & Nolte (2016) suggest that when the "stories of narrative practice in the NHS contexts are not made explicit we simply perpetuate a 'thin' story (obscuring richness, diversity, and complexity) about what constitutes effective practice" (Brown et al., 2016, p10). To "thicken" and allow effectiveness stories to flourish, several key areas are highlighted by the review that require consideration, including establishing consistency across; definition of narrative therapy, application, intended outcomes and measurement, as well as finding a balance which allows 'evidence' progression within a framework congruent with narrative therapy.

Recommendations for further research

Definitions. Creation of a common understanding and application of the therapy is key to supporting evidence-base development. A significant challenge is lack of a clear definition for narrative therapy among experienced practitioners (Wallis et al., 2011). Agreement around what constitutes narrative therapy, such as the seven practices outlined in the introduction, or the techniques identified most frequently by practitioners in Wallis et al (2011) research, would be helpful. Predictions about what areas of 'functioning' might change also need to be developed. These could perhaps draw on the larger knowledge base developed within a trauma field. The papers reviewed suggest that there may be outcomes such as development of a preferred identity; hope, mastery, or potentially within a trauma model, promotion of PTG narratives.

Methodological quality. Several conference abstracts were identified within the literature search related to narrative therapy groups. It is possible that, due to the tension within the research paradigm, clinicians are more concerned with 'spreading the news', so presenting at conferences rather than writing up scientific-based articles for academic journals. The impact of this tension was further observed in relation to perceptions of 'quality' in the reviewed papers. More narrative accounts, such as Portnoy et al. (2016), tended to receive lower quality ratings due to a move away from reporting in a structure more familiar to a positivist stance. In this context, the use of a quality assessment tool felt uncomfortable at times (Barker & Pistrang, 2005). Given that narrative therapy is informed by social constructionist philosophy which means eschewing the assumptions of empirical, positivist realism there is a need to develop a way of reflecting on quality within a social constructionist paradigm. Future research should seek

to use techniques congruent with the philosophical stance of narrative therapy such as narrative analysis.

Manualising programmes or multiple case studies. It is difficult to justify a more standardised approach to the delivery of narrative therapy given that the review suggests accidental elements of therapy, a need for flexibility to individual needs, and varying improvement pathways. However, consistency may be helpful in 'thickening' stories of effectiveness. Whilst the Tree of Life group is only one application of narrative therapy, attempts have been made to manualise the group in other settings (German, 2013) suggesting potential for this to occur.

Alternatively, each group could be conceptualised as a case-study. Reporting of case studies offers an opportunity to build up an evidence-base and has been used effectively for this purpose more generally in family therapy. (McLeod & Elliott, 2011). A multiple case study approach involving researchers doing similar methodologies (either with individuals, families, or groups) and depositing their 'cases' on a shared data base could be helpful.

Measuring change. If services were to manualise delivery of group interventions, or develop a multiple case study protocol, consensus of outcome measures would be helpful. As suggested by Flannery, Glew, Brewster, & Christie, (2018), a shift towards more narrative methods of outcome data collection rather than development of further 'measurement' tools may be beneficial and sit more comfortably with narrative therapy. Flannery et al. (2018) suggest a pragmatic approach to outcome data achieved through analysis and identification of important 'outcome' themes from verbatim 'stories' collected from CYP and their families. Analysis of 'stories' pre- and post- intervention may be an effective and patient-centred way of measuring change and 'evidencing effectiveness' in line with the philosophical stance of narrative therapy.

Given the infancy of the evidence-base identified by the review areas warranting further investigation are vast. Examples would be the use of digital interventions, the ability to access support alongside medical treatment, or the impact on wellbeing of altering stories around illness. One paper within the review made reference to peer mentors (Casdagli et al., 2017). An opportunity for further service user involvement allowing CYP to contribute to the learning and experience of others whilst developing their confidence through acknowledging their valuable contribution (White, 2007). This not only links to the idea of being experts in their own lives, but also allows for the practice of 'outsider witness'. This group represents 'experts' in the narrative therapy process, and yet no current research has included these 'experts' or focused on the therapeutic benefits of outsider witness, for the witnesses, and the benefits of taking on such a role for the young person.

Implications for Clinical Practice

The review suggests promise for narrative methods in cultivating hope and bolstering preferred identities - areas previously identified by a systematic review as important to interventions targeting mental wellbeing in CYP with chronic conditions (Venning, Eliott, Wilson, & Kettler, 2008). Given that narrative methods seem acceptable to patients and families, and it remains unclear which type of intervention style is most effective and with whom (Serlachius et al, 2014), opportunities for creatively implementing narrative methods arise. Within these opportunities, it is important for clinicians to continue to share practice-based evidence and contribute to strengthening the evidence-base by producing methodologically robust research.

The early promise of group interventions suggests that both patients and families accessing paediatric services may benefit from opportunities to develop and share stories and build connections through group-based interventions. Exploring ways to develop groups or promote opportunities for communication and sharing of 'expertise' may not only help support areas such as hope, meaning making and personal agency in relation to illness but also be more cost-effective than one-to-one interventions.

Theoretical Implications

The most comprehensive description of mechanisms underpinning narrative therapy mirrored processes within narrative ideas for processing potential trauma i.e. re-authorising and development of a coherent story of self, with carefully chosen questions seeking to uncover and develop 'alternative' stories. It remains unclear if illness is perceived as a disruption to the life story and whether or not narrative therapy "repairs" one's stories. The diversity of potential outcome findings may be a reflection of the many different responses to a single event and the multi-level processing involved with responding/coping.

The initial findings within the review show early promise for positive outcomes which may suggest that growth following the 'trauma' of illness may be possible through narrative methodologies. Conceptualising illness within a trauma framework enables ideas and theory linked to PTG to be considered and may provide support in understanding, and measuring change following narrative interventions.

The key aim of narrative therapy to uncover and support preferred identity stories appeared to be supported by the reviewed papers. The perceived changes in identity support

ideas of identity fluidity in line with identity process theory (Breakwell, 2014) and interventions may be enabling identity migration to occur (White, 1997).

Summary

This review suggests some early promise for the acceptability and perceived usefulness of narrative therapy in paediatric settings for supporting patients and families to make sense of their treatment journeys or illness experiences. However, this is hampered by poor quality of published research. The review highlights a wealth of research development potential, alongside some potential target outcomes and possible mechanisms to explore. Engagement in research and evidencing practice is essential if narrative therapy is to continue to be offered in NHS services. This review offers several suggestions of ways to progress the evidence base in ways which are congruent to the philosophical stance of narrative practices.

References

Akard, T.F., Dietrich, M.S., Friedman, D.L., Hinds, P., Given, B., Wray, S., & Gilmer, M.J. (2015) Digital storytelling: an innovative legacy-making intervention for children with cancer. *Pediatric Blood Cancer, 62,* 658-665, doi: 10.1002/pbc.25337

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)* Washington, DC: Author.

Badger, K., Royse, D., & Moore, K. (2010) What's in a story? A text analysis of burn survivors' web-posted narratives. *Social Work in Health Care, 50,* 577-594. https://doi.org/10.1080/00981389.2011.592114

Barker, C., & Pistrang, N. (2005) Quality criteria under methodological pluralism: implications for conducting and evaluating research. *American Journal of Community Psychology, 335,* 201-212 https://doi.org/10.1007/s10464-005-3398-y

Barlow, J.H., & Ellard, D.R. (2006) The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child: Care, Health and Development*, *32,* 19-31 https://doi.org/10.1111/j.1365-2214.2006.00591.x

Baruch, J. (2010) *The beads of courage program for children coping with cancer* (Dissertation, University of Arizona). Retrieved from http:hdl.handle.net/10150/193998 on 10.10.2018

Berger, P., & Luckmann, T. (1966) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. New York, Anchor

Breakwell, G.M. (2014) Identity process theory: clarification and elaboration in R. Jaspal, & G.M. Breakwell (Eds.) *Identity Process theory: identity, social action and social change (pp 20-39)*. Cambridge: Cambridge University Press

Brown, R., Sole, J., Ferguson, S., & Nolte, L. (2016). Creating ripples: towards practice-based evidence for narrative therapy within NHS contexts. *Clinical Psychology Forum, 284*, 48-52. Available from http://shop.bps.org.uk/publications/publication-by-series/clinical-psychology-forum.html

Carr, A (2001) Michael White's narrative therapy. In Carr, A (ed.) *Clinical psychology in Ireland Volume 4: Family therapy theory, practice and research* pp 15-39. Wales: Edwin Mellon Press retrieved from http://mellenpress.com/mellenpress.cfm?pc=9&bookid=4690 on 28.10.2018

Casdagli, L., Christie, D., Girling, I., Ali, S., & Fredman, G. (2017) Evaluating the Tree of Life project: an innovative way of engaging children and young people with type 1 diabetes. *Diabetes Care for Children and Young People, 6*, 9-15.

Cohan, S. and Shires, L.M. (1988) *Telling Stories: A Theoretical Analysis of Narrative Fiction*, London: Routledge.

Conrad, P., & Barker, K. (2010) The social construction of illness: key insights and policy implications. *Journal of Health and Social Behaviour, 51*, 567-579 DOI: 10.1177/0022146510383495

Critical Appraisal Skills Programme (2018) *CASP Qualitative Checklist Online* Available at https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf

Dallos, R., & Vetere, A (2009) *Systemic therapy and attachment narratives: applications in a range of clinical settings*. London: Routledge

DeMaso, D.R., Gonzalez-Heydrich, J., Erickson, J.D., Grimes, V.P., & Strohecker, C. (2000) The experience journal: a computer-based intervention for families facing congenital heart disease. *Journal of American Academy of Child and Adolescent Psychiatry, 39*, 727-734 https://doi.org/10.1097/00004583-200006000-00011

Ehlers, A., & Clark, D.M. (2000) A cognitive model of posttraumatic stress disorder. *Behaviour Research and Therapy, 38,* 319-345 doi: 10.1016/s0005-7967(99)00123-0

Ehlers, A., Clark, D.M., Hackman, A., McManus, F., & Fennell, M. (2005) Cognitive therapy for post-traumatic stress disorder: development and evaluation. *Behaviour Research and Therapy, 43,* 413-431. https://doi.org/10.1016/j.brat.2004.03.006

Eisenberg, L. (1977) Disease and illness: distinction between professional and popular ideas of sickness. *Culture, Medicine, and Psychiatry, 1*, 9-23. https://doi.org/10.1007/BF00114808

Engel, G.L. (1977) The need for a new medical model: a challenge for biomedicine, *Science, 196,* 129-135. doi 10.1126/science.847460

Engel, G.L. (1980) The clinical application of the biopsychosocial model, *American Journal of Psychiatry, 137,* 535-544 doi: 10.1176/ajp.137.5.535

Erikson, E. (1959) *Identity and life cycle* New York: International Universities Press

Etchison, M., & Kleist, D.M. (2000). Review of narrative therapy: research and utility. *The Family Journal*: *Counselling and Therapy for Couples and Families, 8*, 61 -66 Retrieved from https://www.researchgate.net/profile/David_Kleist/publication/2383 on 07.04.2019

Farahani, H., Azad, S.A., & Sahebalzamani, M. (2017) Investigating the effects of maternal narrative writing on depression, anxiety and stress in pediatric stem cell transplantation. *NeuroQuantology, 15*, 56-62 doi: 10.14704/nq.2017.15.4.1153

Flannery, H., Glew, S., Brewster, A., & Christie, D. (2018) Measuring outcomes of psychological wellbeing within paediatric health settings. *Healthcare, 6,* 1 https://doi.org/10.3390/healthcare6010001

Fredman, G. (2014) Weaving net-works of hope for families, practitioners and

communities: inspirations from systemic and narrative approaches. *Australian and New Zealand*

Journal of Family Therapy, 35, 54-71 https://doi.org/10.1002/anzf.1044

Freidson, E. (1970) *Profession of Medicine: A Study of the Sociology of Applied*

Knowledge. New York: Harper and Row.

German, M. (2013) Developing our cultural strengths: using the Tree of Life strength-

based, narrative therapy intervention in schools, to enhance self-esteem, cultural understanding

and to challenge racism. *Educational and Child Psychology, 30,* 75-98

Greenhalgh, T., & Hurwitz, B. (1999) Narrative based medicine: why study narrative?

British Medical Journal, 318, 48-50 https://doi.org/10.1136/bmj.318.7175.48

Hedtke, L. (2014). Creating stories of hope: a narrative approach to illness, death and

grief. *Australian and New Zealand Journal of Family Therapy, 35,* 4-19.

https://doi.org/10.1002/anzf.1040

Hind, P.S. (2004) Shifting perspectives, a symposium presented at the seventh national

cancer nursing research conference, February 2003. *Oncology Nursing Forum, 31,* 281-287 doi:

10.1188/04.ONF.281-287

Howard, G. (1991) Cultures tales: a narrative approach to thinking, cross-cultural

psychology, and psychotherapy. *American Psychologist, 46,* 187-197.

http://dx.doi.org/10.1037/0003-066X.46.3.187

Jackson, A.C., Liang, R., Frydenburg, E., O Higgins, R., & Murphy, B. (2016). Parent

education programmes for special health care needs children: a systematic review. *Journal of*

Clinical Nursing, 25, 1528-1547. https://doi.org/10.1111/jocn.13178

Johnstone, L., & Dallos, R. (2014) (Eds.) Formulation in psychology and psychotherapy, making sense of people's problems. London: Routledge.

Laing, C.M., Moule N.J., Estefan, A., & Lang, M. (2017) Stories that heal: understanding the effects of creating digital stories with pediatric and adolescent/young adult oncology patients. *Journal of Pediatric Oncology Nursing, 34, 272-282.* doi: 10.1177/1043454216688639

Lantz, P., Uchtenstein, R., & Pollack, H. (2007) Health policy approaches to population health: the limits of medicalization. *Health Affairs, 26,* 1253-1257. https://doi.org/10.1377/hlthaff.26.5.1253

Leseho, J., & Block, L. (2005) Listen and I tell you something: storytelling and social action in the healing of the oppressed. *British Journal of Guidance and Counselling, 33,* 175-184. https://doi.org/10.1080/03069880500132706

Lock, S (2016) The Tree of Life: a review of the collective narrative approach. *Educational Psychology Research and Practice, 2,* 2-20 Accessed from file:///C:/Users/Bec/AppData/Local/Packages/Microsoft.MicrosoftEdge_8wekyb3d8bbwe/TempState/Downloads/Educational%20Psychology%20Research%20and%20Practice%202016%2003%20Lock%20(1).pdf on 28.03.2019

Lunn, S. (2008) Spread the news: coping tricks from the sickle cell clinic. The International *Journal of Narrative Therapy and Community Work, 3*, 41-46. Available from https://search.informit.com.au/documentSummary;dn=023651908330811;res=IELIND.

Madigan, S. (1992) The application of Michel Foucault's philosophy in the problem externalising discourse of Michael White. *Journal of Family Therapy, 14,* 265-279 https://doi.org/10.1046/j..1992.00458.x

Madigan, S., & Epston, D. (1995) *From 'spy-chiatric gaze' to communities of concern: From professional monologue to dialogue*. In S. Friedman (Ed) The reflecting team in action: Collaborative practice in family therapy (pp 257-276). New York: Guildford

McCarthy, P.G., & Sebaugh, J.G. (2011) Therapeutic scrapbooking: a technique to promote positive coping and emotional strength in parents of pediatric oncology patients. *Journal of Psychosocial Oncology, 29*, 215-230 http://doi.org/10.1080/07347332.2010.548443.

McLeod, J., & Elliott, R. (2011) Systematic case study research : a practice-oriented introduction to building an evidence base for counselling and psychotherapy. *Counselling and Psychotherapy Research, 11*, 1-10. http://dx.doi.org/10.1080/14733145.2011.548954

Meehan, T., & Guilfoyle, M. (2014) Case formulation in poststructural narrative therapy. *Journal of Constructivist Psychology, 28,* 24-39. http://doi.org.10.1080/10720537.2014.938848.

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Public Library of Service Medicine, 6*(7): e1000097. doi:10.1371/journal.pmed1000097

Morgan, A (2000) *What is narrative therapy? An easy-to-read introduction* Adelaide: Dulwich Centre Publications.

Moxley-Haegert, L. (2012) *Hopework. Stories of survival from the COURAGE programme: families and children diagnosed with cancer*. Retrieved from http://dulwichcentre.com.au/wp-content/uploads/2014/08/Hopework_by_Linda_Moxley-Haegert.pdf on 01.03.2019

Moxley-Haegert, L. (2015) Leaving a legacy and letting the legacy live: using narrative practices while working with children and their families in a child palliative care program. *The*

International Journal of Narrative Therapy and Community Work, 2015, no 2, 58-70 Available

from https://search.informit.com.au/documentSummary;dn=485448930605616;res=IELIND

Naidu, T., & Shabangu, S. (2015) Poetry and narrative therapy for anxiety about spinal

surgery. *Journal of Child and Adolescent Mental Health, 27, 75-84.*

http://doi.org/10.2989/17280583.2015.1034722

Ncube, N. (2006). The Tree of Life project: using narrative ideas in work with vulnerable

children in Southern Africa, *International Journal of Narrative Therapy and Community Work, 1,*

3-16. Accessed from http://ls-tlss.ucl.ac.uk/course-materials/PSYCGN48_69480.pdf on

28.03.2019

Neimeyer, R.(2000) Searching for the meaning of meaning: grief therapy and the process

of reconstruction. *Death Studies, 24,* 541-558 https://doi.org/10.1080/07481180050121480

Paterson, B.L. (2001). The shifting perspective model of chronic illness. *Journal of*

Nursing Scholarship, 33, 21-26 https://doi.org/10.1111/j.1547-5069.2001.00021.x

Pearlin, L., & Schooler, C. (1978) The structure of coping. *Journal of Health and Social*

Behaviour, 22, 337-356

Penkman, L., Scott, L., & Pelletier, W. (2008) A psychosocial program for pædiatric

oncology patients. *Journal of Psychosocial Oncology, 24,* 103-115, doi: 10.1300/J077v24n02_07

Pennebaker, J.W. (1997) Writing about emotional experiences as a therapeutic process.

Psychological Science, 8, 162-166. doi: 1 0.1111/j.1467-9280.1997.tb00403.x

Pereira, L. (2017) *Can making video narratives benefit adolescents with cancer*,

(Dissertation, Palo Alto University). Retrieved from

https://media.proquest.com/media/pq/classic/doc/4324739715/fmt/ai/rep/NPDF?_s=gCH7%2Fu

ck9p354e6q3p7243hBamQ%3D on 07.04.2019

Pereira, L.M., Muench, A., & Lawton, B. (2017). The impact of making a video cancer narrative in an adolescent male: a case study *The Arts in Psychotherapy, 55*, 195-201 https://doi.org/10.1016/j.aip.2017.06.004

Pinquart, M., & Shen, Y. (2011) Behaviour problems in children and adolescents with chronic physical illness: a meta-analysis. *Journal of Pediatric Psychology, 36*, 1003-1016 https://doi.org/10.1093/jpepsy/jsr042

Pitfield, C., & Larner, C. (2017) Delivering a psychological group intervention for young people with a cardiac condition in transition to adult services. *Archives of Disease in Childhood, 102,* A18 http://dx.doi.org/10.1136/archdischild-2017-084620.45

Portnoy, S. (2019) Recipes for good beginnings. *Clinical Psychology Forum, 320*, 7-11

Portnoy, S., Girling, I., & Fredman, G. (2016) Supporting young people living with cancer to tell their stories in ways that make them stronger: The beads of life approach. *Clinical Child Psychology and Psychiatry, 21,* 255-267 https://doi.org/10.1177/1359104515586467

Ralph, A., Jeffries, F., Bakshi, R., Marfleet, R., Gardner, J., & Muir, J. (2017) Tree of Life: a creative workshop for young people with health conditions. *Archives of Disease in Childhood, 102, A21-A22.* http://dx.doi.org/10.1136/archdischild-2017-084620.56

Redshaw, S., Wilson, V., Scarfe, G., & Dengler, L. (2011) Narratives of the heart: telling the story of children with a cardiac condition through a bead program. *Journal of Clinical Nursing, 20, 2802-2811* https://doi.org/10.1111/j.1365-2702.2011.03780.x

Roy-Chowdhury, S. (2003) Knowing the unknowable: what constitutes evidence in family therapy. *Journal of Family Therapy, 25,* 64-85 https://doi.org/10.1111/1467-6427.00235

Sakalsys, J. (2003) Restoring the patient's voice: the therapeutics of illness narratives. *Journal of Holistic Nursing, 21,* 228-241 https://doi.org/10.1177/0898010103256204

Schaefer-Schiumo, K., & Atwood, J. (2009) Kristin's journey through breast cancer: a

social constructionist perspective. *The American Journal of Family Therapy, 37*, 318-335

http://doi.org/10.1080/01926180802705649

Secinti, E., Thompson, E.J., Richards, M., & Gaysina, D. (2017) Research review:

childhood physical illness and adult emotional health – a systematic review and meta-analysis.

Journal of Child Psychology and Psychiatry, *58*, 753-769. https://doi.org/10.1111/jcpp.12727

Seller, L. (2010) *Why the little mermaid stopped singing: how oppressive social forces

silence children's voices and rob them of the opportunity to develop and exercise autonomy in the

health care context.* Master's Thesis, McGill University, Montreal, QC, Canada. Retrieved from

digitool.library.mcgill.ca/R/?func=dbin-jump-full&object_id=9494 on 01.03.2019

Serlachius, A., Scratch, S., Northam, E., Frydenberg, E., Lee, K., & Cameron, F. (2014) A

randomized controlled trial of cognitive behaviour therapy in improve glycaemic control and

psychosocial wellbeing in adolescents with type 1 diabetes. *Journal of Health Psychology*, *21*,

1157-1169. https://doi.org/10.1177/1359105314547940

Simblett, G. (2013) Dancing with the DSM – the reflexive positioning of narrative

informed psychiatric practice. *Australian and New Zealand Journal of Family Therapy, 34*, 114-

128 https://doi.org/10.1002/anzf.1007

Sisk, C., Walker, E., Gardner, C., Mandrell, B., & Grissom, S. (2012) Building a legacy

for children and adolescents with chronic disease. *Journal of Pediatric Nursing, 27*, e71-e76.

https://doi.org/10.1016/j.pedn.2012.04.008

Sobel, D. (1995) Rethinking medicine: improving health outcomes with cost-effective

psychosocial interventions. *Psychosomatic Medicine, 57,* 234-244. Retrieved from

https://www.researchgate.net/profile/David_Sobel2/publication/15547281_Rethinking_medicine

_Improving_health_outcomes_with_cost-

effective_psychosocial_interventions/links/542595b80cf238c6ea741f3f/Rethinking-medicine-

Improving-health-outcomes-with-cost-effective-psychosocial-interventions.pdf

Stutzer, C.A., & Gove, S. (2000) Creating meaning: a bead program for children with

cancer. *Journal of Pædiatric Oncology Nursing, 17,* 100.

https://doi.org/10.1177/104345420001700223

Tedeschi, R.G., & Calhoun, L.C. (1995) *Trauma and transformation: growing in the*

aftermath of suffering. Thousand Oaks, CA: Sage

Thabrew, H., Stasiak, K., Hetrick, S., Donkin, L., Huss, J., Highlander, A., … Merry, S.

(2018) Psychological therapies for anxiety and depression in children and adolescents with long-

term physical conditions. *Cochrane Systematic Reviews, 12*, *Art No: CD012488*

doi:10.1002/14651858.CD012488.pub2.

Tuval-Mashiach, R., Freedman, S., Bargai, N., Boker, R., Hadar, H., & Shalev, A. (2004)

Coping with trauma. *Psychiatry, 67,* 280-293 https://doi.org/10.1521/psyc.67.3.280.48977

Valentino, C., Daniilidi, X., Watson, S., Parham, S., & Tong Gong, A. (2019) Dancing

together: exploring medical consultant views on integrative care. *Clinical Psychology Forum,*

320, 28-32

Van Geelen, S.M., Fuchs, C.E., Sinnema, G., van de Putte, E.M., van Geel, R., Hermans,

H., & Kuis, W. (2011) Self-investigation in adolescent chronic fatigue syndrome: narrative

changes and health improvement. *Patient Education and Counseling, 83,* 227-233

https://doi.org/10.1016/j.pec.2010.05.023

Venning, A., Eliott, J., Wilson, A., & Kettler, L. (2008) Understanding young peoples' experience of chronic illness: a systematic review. *International Journal of Evidence Based Healthcare, 6,* 321-326 https://doi.org/10.1111/j.1744-1609.2008.00107.x

Vermaes, I., Van Susante, A., & Van Bakel, H. (2012) Psychological functioning of siblings in families of children with chronic health conditions: a meta-analysis, *Journal of Pediatric Psychology*, *37*, 166-184 https://doi.org/10.1093/jpepsy/jsr081

Wallis, J., Burns, J., Capdevila, R. (2011) What is narrative therapy and what is it not? The usefulness of Q methodology to explore accounts of White and Epston's (1990) approach to narrative therapy. *Clinical Psychology and Psychotherapy, 18,* 486-497.

https://doi.org/10.1002/cpp.723

White, C., & Denborough, D. (1998). *Introducing narrative therapy; a collection of practice based writings.* Adelaide, South Australia: Dulwich Centre Publications.

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York, NY: WW Norton & Co.

White, M. (1997) Challenging the culture of consumption: Rites of passage and communities of acknowledgement. *New Perspectives on addition, special issue of Dulwich Centre Newsletter*, 38-47 Retrieved from https://dulwichcentre.com.au/articles-about-narrative-therapy/deconstructing-addiction/challenging-the-culture-of-consumption/ on 07.04.2019

White, M. (2000) Re-engaging with history: the absent but implicit. In *Reflections on Narrative Practice: Essays and Interviews.* Adelaide: Dulwich Centre Publications

White, M. (2007) *Maps of narrative practice*. New York NY: WW Norton & Co.

Wilson, V., Chando, S. (2015) Parental experiences with a hospital based bead

programme for children with congenital heart disease. *Journal of Clinical Nursing, 24,* 439-446

https://doi.org/10.1111/jocn.12621

Winkley, K., Landau, S., Eisler, I., & Ismail, K. (2006) Psychological interventions to

improve glycaemic control in patients with type 1 diabetes: systematic review and meta-analysis

of randomised controlled trials. *British Medical Journal*, *333*, 65-70

https://doi.org/10.1136/bmj.38874.652569.55

Yin, R. (2018) *Case study research and applications design and methods*. London: Sage

Developing through mentoring: Young people's experiences of peer mentoring within a 'Beads

of Life' group in a hospital setting

Rebecca Henly

Canterbury Christ Church University

Word Count: 7999 (-161)

Target Journal: International Journal of Narrative Therapy

Abstract

Objective: To explore the experiences of young people who take on a peer mentoring role within a psycho-oncology service Beads of Life group

Method: Eight semi-structured interviews were conducted with peer mentors between the ages of 16 and 23. Interviews were analysed using Interpretive Phenomenological Analysis.

Results: Three super-ordinate themes emerged; identity and self; identity and others, and identity and relationship to cancer. Mentors perceived themselves as helpful and mentoring provided an opportunity to develop and grow as a person, as well as feel good from helping others. Mentors felt responsibility towards the group and valued their relatability. Mentors experienced positive development, tested out alternative roles, and experienced the benefits of challenging isolation, through connection to others and processing of the emotional burden of cancer. Mentors felt grateful for the opportunity but also wanted to make way for the next generation.

Conclusions: There was substantial overlap with themes expressed by young peer mentors within other settings. Findings suggest an impact on identity, with young people noticing changes in the self, their relationship to others, and their relationship to cancer. Overall young people reported positive experiences, suggesting future potential for peer mentoring and community narrative practices within paediatric setting.

Keywords: 'narrative therapy' 'paediatric' 'adolescence' 'psychosocial care' 'cancer'

Developing through mentoring: Young people's experiences of peer mentoring within a 'Beads of Life' group in a hospital setting

"We have two options, medically and emotionally: give up, or fight like hell"

(Lance Armstrong talking about cancer)

Armstrong highlights not only the medical/physical battle involved when diagnosed with cancer, but the emotional battle that may ensue. Advances in medical care continue to improve one's odds of physical survival, leading to greater call for psychological support that aids recovery and well-being. This paper first outlines the potential psychological impact of a cancer diagnosis for children and young people (CYP). A brief overview follows of current psychological support, and the potential for positive growth is explored.

Narrative therapy within paediatric settings is a growing area of clinical interest, and within groups there is opportunity for 'witnessing' and 'sharing of skills'. These approaches will be introduced and discussed, alongside the use of peer support and its possible therapeutic benefits. Identity formation is a key challenge of adolescence and this process will be examined alongside the possible negative impact on identity development from illness. The current study explores experiences of adolescents and young adults (AYA) that take on peer mentoring roles within narrative therapy groups.

Cancer and Young People

For CYP (aged 0-24 years) roughly 3240 new cancer registrations were recorded in England in 2016 (Office of National Statistics, 2018). However, trends in 5-year and 10-year survival for childhood cancer (0-14 years) have continued to improve (ONS, 2017) and 5-year survival rates Europewide for all cancers combined are 81% for children and 87% in AYA (Gatta et al, 2009). CYP are not only surviving but have opportunities to live longer, meaning that quality of life and supporting the psychosocial needs during treatment and into the future is a research and clinical priority.

Cancer can isolate CYP from developmental and childhood experiences. Isolation, illness anxiety and negative thoughts around illness and the future can negatively impact CYP's mental health. For example, cancer before the age of 25 is associated with increased risk of suicide (Gunnes et al, 2017) and symptoms of post-traumatic stress disorder (PTSD) are common (Taieb et al, 2003). Survivors have also shown higher reporting of significant mental health disorders compared to controls in adulthood (Seitz et al., 2010). Poorer quality of life, issues with body image, and potential disruption to sexual identity have all been highlighted as potential challenges faced by adolescent cancer patients (Abram, Hazen, & Penson, 2007).

Potential for Positive Psychosocial Growth

Not all research suggests negative psychosocial wellbeing. Social support, optimism, and new possibilities, such as a passion to work with cancer, have all been reported (Jaehee, Zebrack, Kim & Cousino, 2015; Zamora et al, 2017). Almost 85% of adolescent survivors of childhood cancer reported at least one positive consequence from their cancer experience and almost a third reported four or more positive changes (Barakat, Alderfer, & Kazak, 2005). This opens the

possibility of interventions designed to foster positive psychological changes following cancer in line with a post-traumatic growth (PTG) framework.

The term Post-traumatic Growth (Tedeschi & Calhoun, 1995) describes the process of positive psychological change experienced as a result of traumatic struggles. According to Calhoun & Tedeschi (2013) the experience of growth is reflected in five key factors: personal strength, relating to others, new possibilities, appreciation of life, and spirituality. These key factors fall within three conceptual categories; a changed sense of oneself, a changed sense of relationship with others, and a changed philosophy of life. Thornton (2002) suggests that in cancer populations changes in sense of oneself are less common than changes in other areas. A review in AYA cancer patients, reported PTG and resilience, described most commonly in terms of a changing view of life and feeling stronger and more confident (Greup et al., 2018). Cultivating PTG may be supported by perceived social support, which was found to be positively associated with PTG among AYA (Greup et al, 2018).

Psychological Support for Young People with Cancer

A national survey (Edward 2010; as cited by Jacobs, Titman, & Edwards, 2012) found approximately 340 paediatric psychologists (predominantly Clinical Psychologist) across 90 psychology services - with the greatest input going to specialist medical services such as oncology. This number is likely to have increased considerably, given the recent introduction of NICE quality standards stating;

"Children and young people (aged 0–24 years) with cancer, and their families and carers, have their psychological and social needs assessed at key points in their care pathway and receive support based on their identified needs." (NICE, 2014, p.10)

A systematic review of Randomised Control Trials (RCT) evaluating psychosocial interventions for young oncology patients identified a diversity of interventions (4 CBT, 1 mixed CBT and physical exercise therapy, 2 family therapy, 2 therapeutic music video, 1 self-coping strategies, 1 wish fulfilment, and 1 joint family therapy and CBT) (Coughtrey et al, 2018). Findings suggested potential benefits for both psychological and physical outcomes following psychological intervention although a superior intervention was not established, and good quality empirical evidence remains limited, suggesting further exploration of potential interventions is necessary. One such intervention approach which has been used increasingly frequently, is narrative therapy. Whilst CBT based interventions have received some research interest across medical conditions, narrative therapy remains largely unexplored suggesting a current gap in the literature.

Narrative Therapy

Narrative therapy is based on the idea that problems are created in social, cultural, and political contexts; and an assumption lives are multi-storied. White and Epston (1990) propose the analogy of therapy as a process of "storying". Individuals are supported in "restorying" through uncovering and 'thickening' alternative/preferred identity stories that seek to challenge the problem-saturated narratives which often develop around life-threatening illness and treatment. Carr (2001) suggested seven key processes of narrative therapy: collaboration; externalisation of the problem; exploration of 'unique outcomes'; outsider witnessing' of new self-narratives; remembering practices; use of literary means; and facilitation of "bringing it back" whereby clients are encouraged to share their expertise with others.

Narrative therapy interventions seek to support development of alternative/preferred identities separate from illness/cancer (Portnoy, Girling & Fredman, 2016). Narrative techniques, and particularly remembering practices, have shown to be useful in supporting families following the death of a child to cancer (Hedtke, 2014; Moxley-Haegert, 2012; 2015). Group interventions based on narrative therapy principles include; 'Tree of Life' (Ncube, 2006) and 'Beads of Life' (Portnoy et al., 2016). Tree of Life is a collective narrative practice which uses the metaphor of a tree to enable conversations around life and identity. Drawing on the Tree of Life, Beads of Life, described more fully in the methodology section, invites participants to choose beads to represent areas such as skills and abilities. The beads are used as a way to 'story' preferred identities. Groups have shown to facilitate collective identity, counter feelings of isolation, and reduce individual psychology referrals (Portnoy et al., 2016).

Witnessing and Peer Mentoring

One aspect of narrative therapy which has remained largely unexplored in the literature is 'outsider witnessing'. This practice forms a key aspect of narrative therapy given its premise that our identities are formed in relationships with others. Outsider witnessing involves inviting an audience into therapy to listen and acknowledge alternative/preferred identity stories. White's (1995) use of witnesses in authenticating others' identities was influenced by developments in reflective teams (Anderson, 1987) and observations by Myerhoff (1982; 1986) around the ongoing process of peoples' selves and identity being constructed. The concept of outsider witness can be operationalised in a number of ways within paediatrics, such as inviting significant others into the therapy sessions to support and adopt a story of survival (e.g. Naidu &

Shabangu, 2015), or simply forming a group therefore providing an audience to *"allow people to perform and live out their preferred identities"* (Lunn, 2008, p42).

The use of mentors as outsider witnesses may be a powerful way of enabling CYP to contribute to services as 'experts by experience'. White states that "*time and again I have observed outside witnesses' retellings achieve what is quite beyond my potential to achieve in my role as a therapist"* (White, 2007, p218).

Service User Mentoring in Adults

Government policy advocates service user involvement in healthcare (Bowl, 1996; Department of Health, 2000). This user involvement has been interpreted in a number of different ways - one of which is the use of peer mentors. In a review of the literature Dennis (2003) concluded that peer support required three critical attributes: emotional, informational, and appraisal support. Theorists suggest that peer workers can engage troubled others at a deep and authentic level (Mead, Hilton & Curtis, 1991) whilst altruism benefits their own mental health (Mental Health Foundation, 2012).

Research exploring benefits for mentors is predominantly confined to adult mental health (Walker & Bryant, 2013; Gillard et al, 2013). Such research has shown both a facilitative and detrimental impact on personal recovery (Baille & Tickle, 2015). MacLellan, Surey, Abubakar, & Stagg (2015) propose mentors experience reframing of identity, occurring through reciprocal relationships with individuals. This can increase belonging, reduce isolation, and allow testing of a new recovery identity.

Mentoring in CYP

Peer mentoring among CYP is common in education settings with an estimated 62% of schools utilising some form of peer support schemes (Houlston, Smith, & Jessel, 2009).

Few studies have explored the psychological impact of becoming a mentor in adolescence, although initial findings suggest an impact on identity structure which enables exploration of a new 'professional' identity (Mayer & McKenzie, 2017). A recent review into the outcomes for CYP who mentor their peers across education and health settings demonstrated; personal growth, changes in perception of identity, psychosocial wellbeing, and universality (Douglas, Jackson, Woods, & Usher, 2018). However, all but one mentorship programme was delivered within a one-to-one framework, and only two were within health settings, suggesting findings may be limited in helping to understand the potential outcomes of those within a group setting in health.

Mentoring and chronic illness

Jerson et al (2013) suggest that AYA who mentored others undergoing liver transplantations, experienced a new "mentor identity" and this identity was a source of pride. Facilitation of social connection has been highlighted by mentors suggesting the importance of peer relationships to those dealing with chronic illness (Ahola Kohut, Stinson, Forgeron, Luca, & Harris, 2017).

A review of peer support in the context of cancer, which included two studies with groups for adolescents, concluded that programmes helped mentees by providing emotional and informational support from the perspective of shared personal experience (Dunn, Steginga,

Rosoman, & Millichap, 2005). However, there is no current research on the effects for the mentor within a cancer setting.

Identity Formation

Identity refers to how one sees oneself, the

"parts of a self- composed of the meanings that persons attach to the multiple roles they typically play" (Stryker & Burke, 2000, p284).

Breakwell's (1986, 2014) identity process theory (IPT) suggests identities are adjusting and reorganising in a fluid process of exploration, evaluation and adaption (Luyckx, Goossens , & Soenens, 2006). Within IPT, identity is regulated by two universal processes 'assimilation-accommodation' and 'evaluation'. The first process assimilation-accommodation describes taking on board new information and adjustments needed to 'accommodate' this. Evaluation then confers meaning and value to the potential change. Four identity principles were proposed by Breakwell (1986) in guiding these processes; continuity, distinctiveness, self-efficacy, and self-esteem, although Vignoles, Chryssochoou & Breakwell (2002) suggest seeking a sense of belonging and being able to derive meaning from life are also important. Within IPT, should an individual's identity come under threat through major life events such as serious illness, individuals have personal agency over constructing and regulating identity and therefore intrapsychic, interpersonal or intergroup coping strategies may be employed to protect one's identity.

From a narrative perspective, White (2007) suggests that identities are relational constructs organised into coherent narratives. Therefore, identity exists in the stories we tell

about ourselves and can be constantly changing. Lives are viewed as multi-storied which infers

the individual has multiple identities to choose between.

Identity Formation in Adolescence

Several progression models have been suggested in the development of identity.

Erikson's (1959, 1968) psychosocial development theory places identity formation as a key

component of adolescence which, with cultural shifts and new understanding of brain

development, may now extend into emerging adulthood (Arnett, 2000). Crisis in identity is

thought to happen due to multiple demands placed on adolescents to make choices around their

progression to 'adulthood'. Marcia (1966,1980) proposed four identity statuses based on stages

of consideration and commitment outlined in table 6 below. Within adolescence, moving towards

the third and fourth status is created by increasing external and internal pressures to enter

adulthood.

Table 6: Marcia's Identity Statuses

Stage	Consideration	Commitment
Identity diffusion	No consideration is given to identity issues	No commitment is made
Foreclosure	No consideration is given to identity issues	Commitment is made
Moratorium	Active exploration of alternatives occurs	No commitments are made
Identity achievement	Active exploration of alternatives occurs	Commitment is made

A review of longitudinal studies into identity formation suggests that higher stability of

identity is present in adults when compared to adolescence, and whilst limited evidence of a

developmental order was present, the development of research into narrative identity has consistently shown continuity of identity and coherence of the life story both grow in adolescence making this a critical time in identity formation (Meeus, 2011). Within this life stage, major cognitive and hormonal changes occur, and importance placed on peer relationships increases (Lerner & Steinberg, 2004). AYA face identity uncertainty and social relationships can play an important part in the construction of narrative identities (Pasupathi & Hoyt, 2009).

Chronic illness disrupts identity development (Luyckx et al, 2008) putting CYP at a disadvantage in attaining developmental goals alongside managing symptoms and potential isolation caused by hospitalisation. AYA may be particularly vulnerable to narratives of illness taking centre stage and this becoming a dominant identity story. Erikson's (1968) model suggests 'healthy' adolescents will be growing their independence and spending time with peers, whereas AYA with cancer are often in a position of powerlessness, dependence and focused towards immediate survival. This may lead to a learned patient role and adoption of a 'patient identity', finding affiliation with others who are labelled as 'ill' (Mead et al, 1991). Forming empowering identities and emphasising community identity is particularly important for this group (Cho & Park, 2015; Cheung & Delfabbro, 2016). Opportunities such as mentoring roles may allow challenging of patient roles and practice of 'new identities' (Mead, et al, 1991).

This Study

The growing body of literature around the potential of mentoring, and early promise of narrative therapies within paediatric settings suggest opportunities for development for those who volunteer as mentors. Given that adolescence is a key stage for identity formation, it might be expected that mentoring impacts on identity development and growth. It is hoped mentoring

would promote positive preferred identities and elicit themes linked to PTG, However, there is also the potential that mentoring could have some detrimental effects such as prolonging sickness identities. In understanding the psychological impact of mentoring, key questions include; why AYA seek out this role, what is their experience of the role; and what, if any, changes occur to their social identities. These questions being exploratory are best answered by qualitative methodologies (Willig, 2010). Several types of qualitative methodology were considered for this dissertation, but Interpretative Phenomenological Analysis (IPA; Smith et at, 2009) was ultimately chosen because the main aims of the research were to explore the phenomenon of peer mentoring very much from the young people's lived experience. However, epistemologically, narrative analysis might have fitted in better with the theoretical basis for narrative therapy, although it would have answered different questions about how young people 'talked' about their experiences.

Aim

This study explores the experiences of AYA who adopt the role of peer mentors following cancer treatment. It aims to increase understanding around the experiences of AYA who choose to take on an expert by experience role. Within narrative therapy terms, peer mentoring is a way of facilitating 'outsider witnessing' and 'bring it back practices' and allows the AYA to take on an expert position in tackling the problem.

Research Questions

- What do AYA identify as the key experiences of taking on a peer mentor role?

- What do AYA say about their experiences in making decisions around taking on a mentoring role?

- What do AYA say about their experiences in terms of benefits and/or challenges of peer mentoring?

- What do AYAs say about their experiences of mentoring in relation to their identity?

Methodology

Participants

Participants were recruited from a single NHS psycho-oncology service. In line with interpretative phenomenological analysis (IPA) principles, participants were recruited who were able to provide insight into the experience being researched – in particular they needed to have experience of being a mentor within a cancer setting on a group programme that used narrative principles. Arnett's (2000) suggestion of shifting age ranges of psychosocial development was utilised so that age of inclusion was 14-24. All peer mentors who met inclusion/exclusion criteria were invited to take part (n=13). No mentors actively declined and 8 agreed to further contact from the researcher (response rate 62%) and went on to consent and complete a single interview. Participants (Female n=5, Male n=3) were from a mix of ethnic backgrounds and aged between 16-23 (Mean = 20 S.D = 2.4). Further demographic data reporting has been omitted to protect anonymity of participants.

'Beads of Life'

The 'Beads of Life' group developed in line with beading programmes in paediatric settings allowing AYA to 'bead' their medical journey. Due to its grounding in narrative therapy, this approach developed a second bead string allowing exploration of group participants' daily lives, important people, strengths, and hopes and dreams for the future. The aim is to prompt AYA to tell preferred stories and create a 'safe place to stand' from which to story their cancer journey. The group positions AYA as experts in their own lives and aims to create hope and reduce the negative impact of cancer.

Previous group participants are invited back as 'peer trainer' to promote 'outsider witnessing' and 'bringing it back' practices. Groups occur on average 3-4 times a year.

Table 7 Inclusion/Exclusion Criteria

Inclusion criteria
All AYA (14 to 25 years) who attended the 'Beads of Life' workshop within an NHS psycho-oncology service and returned to the group at least once in the 'peer trainer' role for the full group were invited to take part. Participants under 16 had to have the consent of a parent or guardian in order to take part in the research.

Exclusion criteria
The care team were asked not to invite AYA to take part in the research if:

- there was concern about risk to themselves or others,
- their health meant that they would not be able to manage up to an hour's interview,
- there were concerns that the young person's current cognitive ability was such that they would not be able to understand the questions or respond to the question being asked – even with adaptations.
- young people would need an interpreter to take part. (Unfortunately, there was no funding attached to this project for interpreters - however, the care staff did not initially identify any potential participants for whom this would have been an issue.)

Procedure

Participants who met the inclusion criteria were sent information about the study via email or post by one of the clinicians in the service. This was followed by a telephone call by the same clinician two weeks later. If the AYA agreed, contact was made by the researcher and an information sheet and consent form sent (see appendices D and F). Parallel information and consent forms were available for parents/carers if the AYA was under 16 (see appendices E and S). A mutually convenient time was booked with those who consented to take part. Preference was given to conducting interviews at the treatment centre, however, due to geographic distance, or study/work commitments, an alternative telephone/skype/FaceTime option was available. All interviews lasted between 20 and 55 minutes. Prior to the start of interviews consent was confirmed and an opportunity was provided for participants to ask questions.

Interview Schedule

A semi structured interview schedule with potential prompts was developed to explore topics in line with the research questions. See Appendix H for a full list of questions and prompts.

Ethical Consideration

A local NHS Research Ethics Committee granted full ethical approval for this study to take place. Research and development (R&D) approval was also gained from the NHS trust involved (see appendix I and J). Professional codes of ethics and conduct were adhered to throughout (British Psychological Society, 2018; Health Care Professionals Council, 2016).

Due to the small population size special consideration was given to maintaining participant anonymity. For this reason, minimal demographic data is reported and quotes are not attributed to individual participants.

Data and Analysis

A critical realist position was adopted by the researcher. Semi-structured interviews allowed participants to share the stories around mentoring that mattered to them. Interviews were analysed thematically using interpretative phenomenological analysis (IPA; Smith et al., 2009). IPA was selected due to its commitment to phenomenological enquiry which allows the researcher to explore the meanings people make from their experiences (Smith et al, 2009).

Interviews were audio-recorded and transcribed verbatim. The analysis followed the procedure outlined in Smith et al (2009). Transcripts were read and re-read, alongside listening back to recordings, in order for the author to become immersed in both the spoken words and the

way that participants spoke about their views. Descriptive notes were made down the right of the

transcripts whilst conceptual comments and emergent themes were written in the left-hand

margin (see Appendix K). Once this process was completed for all scripts, emergent themes were

grouped together to form superordinate themes for each participant. Psychological knowledge

around narrative therapy, identity, and PTG were incorporated into the analysis in order to try

and make sense of these experiences within a theoretical framework although caution was

maintained not to lose links between interpretation and the participants' words. Exploration of

convergence and divergence between participants and identification of possible patterns of

meanings across peer mentors allowed the development of themes. Lastly a narrative emerged

from themes which drew on these themes and participants' own words to increase understanding

of how AYA make sense of their peer mentor role.

Quality Assurance

Although the idea of quality assurance in research, derives from a positivist paradigm, is

at odds with the critical-realist stance taken in this project certain guiding principles were

followed in this research to allow readers to have some confidence in the findings. Namely a

stance of reflexivity and transparency was taken throughout (Barker & Pistrang, 2005). In terms

of reflexivity, a bracketing interview was held to help explore assumptions and previous

experiences (See appendix N) and reflections were captured through a research 'journal',

following each interview and at key points in the research process, with the researcher constantly

engaging in self-questioning over assumptions and biases (see appendix M). In terms of

transparency, a second researcher read one full transcript and was asked to take a critical position

in judging the helpfulness of themes derived from the transcripts. Divergence was managed

through a reflective discussion, although there were only two examples where the 'critical friend'

questioned codes, and agreement followed discussion. In addition, final themes were discussed

with a Beads of Life facilitator, whose own reflections chimed with those of participant

experience allowing for some sense of 'experience triangulation'. Unfortunately, time constraints

did not allow for similar participant confirmation. To further support transparency, the results are

set out with frequent participant quotes to allow the reader to judge for themselves the

helpfulness of the themes in understanding participant experience.

Results

This section presents three super-ordinate themes outlined in table 8. Themes are not

entirely distinct. Each super-ordinate theme will be discussed, alongside subordinate themes

relevant to the understanding of the mentoring experience.

Table 8: Super-ordinate themes and related subordinate themes.

Super-Ordinate Themes	Subordinate Themes	Example Quote
Identity and Self	Helping "it's just the kind of person I am"	"I also like to help other people"
	"I can see progress"	"learning and growing"
	"Felt great to help people"	"I felt yeah a sense of achievement"
Identity and Others	Learning "from the people that have been before us"	"there were people that had been before me so you kind of pick up on what they want you to do"
	A "level up"	"like a leader"
	Making way "I want to give other people a chance to do it"	"you have to kind of make way for other people"
	We need to "keep things going" and "help people through"	"help other people to talk and encourage them to be involved"
	Connectedness: "like friends coming together"	"just like hanging out with a bunch of friends"
	Relatable: "I get what it's like to be young and have cancer"	"so relatable it just made everything much easier and so much more fun"
	"Would I prefer to be in their shoes?"	"You feel like comparing your story to theirs"
Identity and relationship to Cancer	"It helped me appreciate the scale of what had happened"	"processing has actually really helped"
	"Weaned off that dependency"	"view it with separation and distance"

Theme 1: Identity and Self

Within the theme identity and self, three sub-themes emerged linked to reasons to participate and impact of participation on the self:

1.1 Helping "it's just the kind of person I am".

Throughout the interviews there was a strong focus on identifying oneself as someone who helps others *"I did always like to try and help people".* This was presented in a number of different ways, such as by taking on mentoring as just one of many 'helper' roles adopted by the mentors, as well as a belief that there was an expectation that they needed to give back and *"make a contribution".*

1.2 "I can see progress"

The mentoring experience was described as providing opportunities to develop and grow. Psychosocial wellbeing was a key area, whether through increased confidence, empathy, or growing independence. Some mentors were actively seeking opportunity to develop, for example *"looking for opportunity to grow my independence",* whereas others reported it as an outcome of taking part such as *"did help my confidence"* or *"I've become more understanding of others".*

Growth was demonstrated through changes in beads, and suggestions that whilst some areas of one's original beads were constant, areas such as hopes and dreams for the future had evolved since initial participation in the group, showing changes in self between participant and mentor.

Important skills such as listening, facilitating groups, and encouraging others to talk, were all perceived to have developed as part of the experience, ready for their future self.

1.3 "Felt great to be able to help people"

An unexpected benefit for the self, seemed to be the personal joyful feeling from helping others, contributing to the group, or experiencing mentees' family's reactions to the sharing of

beading stories, with the potential to be a *"massive part of someone enjoying the day"*. There was a sense of achievement experienced and it being "*really fun to step back and watch everyone mingle with each other and then kind of getting their certificates"*. Satisfaction was gained from seeing connections developing which *"wouldn't necessarily happen without peer trainers"*.

Theme 2: Identity and Others

Seven subordinate themes emerged within this super-ordinate theme. These linked to development alongside others, enabling learning, and occupancy of a middle ground, before making way for others.

2.1 Learning From "people that have been before us"

There was respect expressed towards previous mentors and potential to *"take a little bit of inspiration"* in helping to develop into the type of mentors they wanted to be. There was also a strong idea that *"peer trainers help new peer trainers"* and of a natural progression.

2.2 A "level up"

Mentors experienced occupying a valuable middle ground between participants and professionals. The role seemed to provide an opportunity to change positions and test out new roles, at a *"level up", "like a leader"* or *"coach"*. Mentors were clear that they were *"not really a psychologist"* or nurses, just something new. This move could result in a new possible identity as a mentor, although this role tended to be downplayed - with several mentors choosing not to tell others outside the beading community about this position *"no-one knows",* and suggesting it had been difficult to identify peer mentors within the groups, when they previously participated.

2.3 Making way: "I want to give other people a chance to do it"

Mentors perceived an ending to their role and expressed a need to make way for the next 'generation' of trainers. There was a general feeling expressed that the experiences as a mentor had been enjoyable and something that they would like to continue, however, there was a sense of *"natural progression"* and the ending was something that *"has to happen"*. *"Every year there will always be like new kids that can sort of like take up that role so I'd like to give them the opportunity".*

2.4 We need to "keep things going" and "help people through"

There was a significant amount of responsibility expressed towards others and the group by mentors. Mentors expressed responsibility for the smooth running of the group in helping others understand expectations and setting the emotional tone, for example *"mentors are there to keep it a bit more upbeat".* Helping others feel comfortable and included in the group was important as was navigating the right amount of support to provide. *"if you don't have people egging you on, you don't write anything down, you don't get anything out of it, so it's definitely a balance".* Mentors put a certain amount of pressure on themselves to do a good job and really listen to others' stories recognizing this as a *"privileged"* position that few people experienced.

2.4.1 "The superglue to make people…get along"

There was also a responsibility to aid communication and connection through encouraging integration and socialising within group participants experienced by mentors. There was a need to help others *"out of their shell"* to get the most out of the group experience and allow connections to form.

2.5 Connectedness: "like friends coming together"

Connections and the sense of community developed within the mentor role were repeatedly expressed. Challenging isolation and a need to meet others in a *'similar situation'* was a potential motivator for taking on the role, but also a product of involvement, with many making *"friends that I'm still friends with".* Friendships weren't necessarily the type of friendships that involved meeting up face-to-face regularly but, rather, friends that understand what it is like to be *"cancer kids"* who you could connect with via social media platforms.

2.5.1 *"You're not alone"*

Connectedness and friendship was experienced as a way to combat isolation both for the mentors personally as well as for participants. Cancer, and treatment, were viewed as isolating sufferers, and having an impact on their *"openness to be talkative to others".* The shared identity as *"kids with cancer"* was experienced as normalising allowing participation in "normal" conversations and activities, such as eating pizza together and listening to music.

2.6 Relatable: "I get what it's like to be young and have cancer"

Linked to the ideas of connections and friendships fostered within the group was the value placed on the role of mentor as being relatable due to shared cancer experiences and similar age. Value was placed on having members of the group who were familiar with the group process but who were also young and had experienced cancer. An assumption that shared experiences and similar age would make mentors more approachable than professionals was considered *"cool that they have other people that are similar to our age help".*

2.7 "Would I prefer to be in their shoes"

A surprising theme to emerge was the idea of in-group comparison to peers. This was expressed by one mentor as *"shameful"* and by another as something done in one's head rather than openly in the group, suggesting sensitivity towards others. Consideration was given to whether one's experience was similar enough for acceptance by the group, or if others had reacted in a similar or different way, and possible reasons why. At times, comparison allowed for a positioning of others as having a worse situation which enabled more positive feelings around one's own experiences - for example *"some people have got it really bad and then it kind of makes you feel less crappy about your situation".* There was recognition that whilst everyone shared an identity as a young person who had experienced cancer *"everyone's story is different".*

2.7.1 We're not "too different"

The group was experienced as a *"safe place"* due to perceived "sameness" and mentors made multiple references to not being *"too different"* and, as previously mentioned, downplayed the role's distinctness to participants. Importance was placed, while occupying the middle ground and being relatable, on maintaining this idea of similarity to others.

Theme 3: Identity and relationship to cancer

The group allowed for emotional processing linked to the cancer experience and movement towards a position away from cancer.

3.1 "It helped me appreciate the scale of what had happened"

The role of mentor, and group more widely, was experienced as an opportunity to come to terms with the emotional impact of cancer and mentors felt *"liberated afterwards having shared your story".* There was opportunity to acknowledge the potential magnitude *"I could have died",* and acceptance of feelings related to cancer. Part of this acceptance was formed by realising *"I wasn't alone in feeling this way"* and acknowledgement that *"everyone's got different thoughts about cancer but they all felt sad at the beginning and I'm not alone".* Cancer was expressed as carrying an emotional burden or *"trauma"* that could take over lives and needed time and space to heal. The group was unexpectedly therapeutic for some and could help prompt self-compassion.

3.1.1 "Talking about cancer … it's quite hard for them, and it was quite hard for me"

Talking about the cancer journey was perceived to be difficult to talk about and mentors felt they needed to support others in opening up and sharing their stories and engaging in the process to experience the perceived benefit they had previously gained.

3.1.2 "It's emotional but it can really help"

Within the mentor experience there was an understanding of the emotional burden on the mentor of hearing others stories. However, all felt that enduring this was worth it for the benefits the group allowed.

3.2 "Weaned off that dependency"

Participants spoke about mentoring as a possible support to gradually break away from their medical experience. There was appreciation that one could *"still [be] involved in that*

world" referring to the hospital in some way, but their role was changing and contributed to being *"weaned off"* gradually and reaching a point of *"distancing myself from cancer".*

3.2.1 Navigating cancer identity "I'm not sick anymore"

Within the 'weaning off' there was an idea expressed by some mentors that at some point one would reach a point of needing to say *"I'm not sick anymore"* and within the language used by mentors there was a distinction being made between 'patients' and 'mentors', suggesting a shift in position - although equally there was a shared cancer identity expressed with the repeated term *"us"* used to refer to the collective beading community. Navigating the cancer identity was tricky; some AYA appear to be growing up alongside cancer, whilst others had felt they were treated like they were cancer by others, or identity was something which needed to be claimed back from cancer. *"They get confused with you and cancer".*

Discussion

The current study explored the experiences of AYA peer mentors within a "Beads of Life" group for oncology patients. Three superordinate themes emerged; identity and self, identity and others, and identity and relationship to cancer. Initially AYA describe being motivated to help others. During the experience AYA feel responsibility towards the group and value their relatability. AYA experience positive psychosocial development, progress transferable skills for future endeavours, test out alternative roles, and experience the benefits of challenging isolation, through connection to others, and processing of the perceived emotional burden of cancer. Learning is passed through the group and eventually, whilst having enjoyed the experience, mentors leave to make way for the next generation.

Personal Growth and Psychosocial Development

Key areas of PTG were highlighted, with personal strength and new possibilities reflected through all mentors reporting at least one positive psychosocial development, such as increased; confidence, or empathy towards others. This suggests opportunities for personal growth may be created by the mentoring experience. Unlike Thornton's (2002) suggestion that changes in sense of self are less common in cancer patients, changes in self emerged within this sample. This may represent a unique characteristic of the AYA population and lends support to the idea that self-identity is more changeable in AYA than adulthood.

Douglas et al's., (2018) review identified growth through opportunities to test out new identities. This was discussed in the current study by mentors in their uncertainty around where they positioned themselves and feeling 'a level up'. An identity away from cancer and treatment was inferred as a result of the mentoring experience rather than a specific "mentor identity" which has previously been suggested (Jerson et al., 2013).

Universality and Connectedness

Another key area of PTG, relating to others, was demonstrated by importance placed on universality and connectedness by mentors. These themes again overlapped with Douglas et al's (2018) review. Participants expressed concern over the isolating impact of cancer and saw the group as an opportunity for connections for themselves but also felt responsible for helping mentees to make connections. This takes findings from previous mentoring programmes in health settings a step further. In this study the importance of mentoring was not only an opportunity to connect with similar-aged peers but included mentors taking responsibility in anticipating the need in others and supporting others in those connections (Ahola et al., 2017;

Jerson et al., 2013). This suggests a particular type of 'communitas' (Turner, 1969) was created.

Themes in the group resonated with the literature on Group Analytic Theory, particularly the

work of Foulkes (1948). Group processes such as the need to be the same and different from

others in the group, and the comparison of self to others in the group are ways in which Foulkes

would consider the 'matrix' would form early in the life of a group. In a longer term group,

"shameful" feelings such as deriving relief from others' conditions being worse would be worked

with as part of the group, but it is interesting that participants felt able to share these difficult

feelings with the researcher, and suggested that some trust in group had transferred to the

interview process.

The significant overlap with themes from Douglas et al's (2018) review findings suggests

that benefits seen more generally for AYA mentors in education and health are likely to be

applicable to mentors in an oncology context, and potentially narrative therapy 'outsider witness'

context. What is also important is the potential applicability of findings from one-to-one on-

going peer mentorship programmes, (which dominated the previous review), to a short-term

group setting.

Challenges of Mentoring

Possible challenges differed from those identified in Douglas et al.'s (2018) review and

there was no mention of issues with programme structure or supervision. Support provided by

the group environment and training days may have negated these concerns. Only establishing

relationships seemed to be an overlapping concern.

A distinct challenge highlighted was the potential emotional burden from hearing others'

difficult stories. This may represent a unique outcome for AYA and families facing life-

threatening conditions or within narrative practices. Research shows mothers within a narrative

informed ward-based programme have previously reported feeling over-whelmed by empathising

with other families although, similar to this study, both felt this was a worthwhile burden for the

perceived benefits (DeMaso et al., 2000).

Links to Identity Literature

The changing over time experienced by participants suggest a sense of fluidity in identity

(e.g. changes in beads overtime) and positioning (e.g. 'level up'). The findings from this study sit

well within Breakwell's (1986; 2014) IPT whereby identities are adjusting and reorganising in a

fluid process of exploration, evaluation and adaption.

From a narrative theory perspective, there was a noticeable lack of domination of illness

stories - instead positive self-narratives of development and growth and support of others

emerged, which could also be loosely linked to themes of PTG. Rather than mentors getting

'stuck' in the medical journey, there was a sense of natural progression and making way for the

next generation of mentors, similar to the narrative ideas of identity migration. Michael White

(1997) has spoken about the 'migration' of identity and rites of passage. It is possible the group

offers an opportunity to revise one's relationship with illness, but involves leaving the illness

identity behind, a territory which may have been occupied for some time and solidified by

others. Similar to the experience of the peer mentors at the start, the final destination is unclear.

The rite of passage involves three phases; separation, liminal, and reincorporation (van Gennep,

1960). Beads of Life appears to provide a group structure for the separation and reincorporation process. Choosing to attend the group represents the separation phase, and participants enter the liminal phase - a time of identity uncertainty. Peer mentors may act as guides to the uncertain territory and mentors expressed great responsibility towards mentees' group experience which may encompass helping them 'prepare' for the migration of identity. Acting as witnesses may help participants formalise the rite of passage. The positive self-narratives may represent the reincorporation phase, where by peer mentors have achieved a firmer sense of self.

Within the findings, comparison to others and need for acceptance, support the idea that identities are created in social contexts whilst 'friends' support the construction and maintenance of narrative identities. When considering the solidification of illness identities, it is interesting that whilst AYA did seem to find affiliation with others who are 'cancer patients', the relatability was seen as a positive and a 'normalising' attribute allowing AYA to live out 'normal' AYA development goals. The development of empathy skills and responsibility felt towards others suggests maturation of higher-level moral reasoning and may reflect a developmental shift facilitated through mentoring.

Emotional Processing

Emotional processing appeared to be significantly helped by challenging isolation and the sharing of stories. The group may have allowed time and space for emotional healing. Talking through as part of the process was experienced as hard but felt necessary, and the experience suggested similarities to mechanisms underpinning interventions for trauma. The group

facilitated an opportunity to revisit painful memories and 're-story' versions of self, and support with achieving this was created by peer mentors.

The Power of the Group

The unanimous positive regard for the group and perceived benefit may have been facilitated by the group setting, and the suggested association between PTG and perceived support (Greup et al., 2018). It may have also been facilitated by activation of Yalom's (1995) group 'curative' processes.

Yalom and others have highlighted how group therapy can be more powerful than individual therapy because of the added factor of support and sharing provided by the group. For these young people, the group helped to undo the possible sense of isolation from other young people that was one of the results of their cancer. For the peer mentors, not only did they experience the support of the group, but they were also expressly participating to support others. For them, Yalom's curative factors of altruism and imparting of information, may have been particularly salient, although across the interviews, the other curative factors also seemed important such as universality, cohesiveness, development of socialising techniques, interpersonal learning, imitation of behaviour through modelling for others, and inferred catharsis from the telling of stories to others and the experience of acceptance. Whilst the instillation of hope was not specifically mentioned this is likely to have been one of the intentions for the group.

The experience of fun, the shared common topic focus and the expressed need to increase comfort of participants are several of the ways which have been suggested to optimise these factors (Delucia, 1997).

Summary of Findings

The following table brings together the areas covered more generally in this discussion in

answering key research questions

Table 9: Research Question Summary

Research Question	Findings
What do young people identify as the key experiences of taking on a peer mentor role?	Three superordinate themes emerged; identity and self, identity and other, and identity and relationship to cancer. Mentors perceived themselves as helpful and mentoring provided an opportunity to develop and grow as a person, as well as feel good about helping others. Mentors felt responsibility towards the group, and valued their relatability. Mentors experienced positive development, tested out alternative roles, and experienced benefits of challenging isolation, through connection to others and processing of the emotional burden of cancer. Following participation mentors considered making way for others to experience the role.
What do AYA say about their experiences in making decisions around taking on a mentoring role?	Motivators: Altruism Seeking connectedness to relatable others
What do AYA say about their experiences in terms of benefits and/or challenges of peer mentoring?	Benefits: Self-development - both psychosocially and through transferable skills for future self Connectedness and friendship Universality Challenges: Emotional burden of hearing others' difficult stories Negotiating the balance between supporting and 'listening'

Research Question	Findings
What do AYAs' say about their experiences of their mentoring in relation to their identity?	Mentors suggested an impact on identity, with young people noticing changes in the self, their relationship to others, and their relationship to cancer
	Changes overtime experienced by mentors suggest identity fluidity
	From a narrative perspective there was a lack of domination of illness stories suggesting the group experience may have supported the development of preferred identities, and identity migration may have occurred.
	The super-ordinate theme of Identity and Others supports the important role of others in helping to shape who we are
	Interestingly whilst participants seemed to find affiliation with others who were also 'cancer patients', this relatability did not appear to help solidify an illness identity but instead was seen as a positive and a 'normalising attribute'.

Strengths and Limitations

This study adds to the research on expert by experience, community practices of narrative therapy, and AYA psychological interventions. It demonstrates that a one-off or infrequent task focused group can be experienced as therapeutic and can cultivate many of Yalom's therapeutic factors whilst providing a 'rite of passage'. It shows early promise for peer mentoring in narrative therapy groups as a dual process of the group environment facilitating curative factors whilst simultaneously supporting the specific development of a preferred narrative of self, separate from illness.

The exploratory design and semi-structured interviews allowed for rich patient-centred data to emerge and enabled the AYA to tell the 'preferred' narratives and stories which they perceived important to share. The interview process could also be conceptualised as an opportunity for further outsider witnessing and an opportunity to live out preferred identities.

The generally positive view of participants does suggest that participants may have thought that the researcher needed to hear positive stories about the group. This was despite a question deliberately asking about negative impacts. They were, however, able to explore some negative feelings, though these were about themselves rather than the group.

As in all small scale qualitative studies, the aim of the study was not one of generalisability, however, given the significant overlap with themes presented in other adolescent mentor populations it is hoped findings can offer some support for peer mentoring, "outsider witnessing" or "bringing it back" practices in other AYA health settings.

 It is important to note that the peer mentors in this study were self-identified so may have been on a different journey from those who did not choose to be mentors or did not choose to be part of this study. Given the emergence of altruism as a key motivator in becoming a

mentor, it is possible that altruism played a part in motivation to participate and was another

opportunity to live out 'helper' identities, further sustaining altruism as a dominant theme across

studies more generally.

Lack of participant triangulation of results is a limitation. Although steps were taken to

acknowledge potential researcher bias, the results still represent only one person's interpretation

of the participants' narratives and it is always possible within an interpretative work that the

researcher failed to identify key features of the narratives due to the influence of researcher

beliefs and experiences within the topic area. As with narrative practices, there may be multiple

stories that could be told from these accounts.

Clinical Implications

This study highlights the potential worth of psychological support in oncology services in

facilitating the processing of the emotional burden of cancer. The experience may be enhanced

by the group setting producing a dual process effectiveness combining both narrative therapy

intentions and enabling group process benefits in line with Yalom's curative elements. Findings

support consideration of the interpersonal as well as the intrapsychic healing potential of groups

within AYA services.

The relatability and universality factors are likely to appear in other health conditions and

highlight the potential for services to adopt peer mentoring as a mutually beneficial system for

supporting psychosocial development and narrative practices of identity 'migration', whilst

reducing isolation that may occur due to illness.

Results suggest an element of uncertainty and learning about expectations of mentoring,

and whilst this study offers staff the opportunity to better inform AYA about the potential benefits

and challenges of becoming a mentor, it is important to balance the need for more prescriptive information and definition of the role with the explorative and learning potential of the group process. Any role or testing of new identities is psychologically challenging. The priority of clinical application should therefore be keeping AYA safe and ensuring they have a 'safe place to stand' to look back over past experiences, and opportunities for support with the potential emotional burden of mentoring.

Future Research

Future researchers should seek to replicate the findings across medical conditions and narrative therapy groups as well as further exploration of the changes in narratives created by the group experience and points at which curative factors arise. Empirically speaking this study could be conceptualised as a single case study of 'the group'. Those working in the field should seek to connect with others similarly positioned to help the development of multiple case studies. The tension between narrative therapy and experimental design is likely to make this more difficult, and novel ways may be required to measure alternative narratives emerging, by using narrative analysis.

Studies seeking to explore those who choose not to become mentors, and convergence and divergence of findings with mentors, remains an area in need of further exploration.

Given the overlap with themes of PTG, other areas for further investigation could include the use of PTG measures to explore differences in PTG themes across group participants and mentors, or, for individuals overtime at key time points.

Conclusion

This study was the first to consider the experience of AYA in narrative therapy groups when involved as 'outsider witness' or 'bringing it back' practices. This study demonstrates substantial overlap between the experiences of mentors within this study and themes expressed within other education and health settings. The experience suggested an impact on identity, with mentors testing out new roles, and noticing changes in the self, their relationships to others, and their relationship to cancer. Themes overlapped with Yalom's (1995) principles of group therapy supporting possible mechanisms for change within the narrative therapy group and specifically peer mentoring. Overall AYA reported positive experiences which have important implications and point to future potential for community narrative practices within paediatric settings as a way to support emotional healing.

References

Abram, A.N., Hazen, E.P., & Penson, R.T. (2007). Psychosocial issues in adolescents with cancer. *Cancer Treatment Reviews, 33*, 622-630 https://doi.org/10.1016/j.ctrv.2006.12.006

Ahola Kohut, S., Stinson, J., Forgeron, P., Luca, S., & Harris, L. (2017) Been there done that: the experience of acting as a young adult mentor to adolescents living with chronic illness. *Journal of Paediatric Psychology, 42,* 962-969 https://doi.org/10.1093/jpepsy/jsx062

Anderson, T. (1987). The reflecting team: dialogue and meta-dialogue in clinical work. *Family Process, 26,* 415-428 https://doi.org/10.1111/j.1545-5300.1987.00415.x

Arnett, J.J. (2000) Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist, 55*, 469-480 http://dx.doi.org/10.1037/0003-066X.55.5.469

Bailie, H.A., & Tickle, A. (2015) Effects of employment as a peer support worker on personal recovery: a review of qualitative evidence. *Mental Health Review Journal, 20*, 48-64 https://doi.org/10.1108/MHRJ-04-2014-0014

Barakat, L.P., Alderfer, M.A., & Kazak, A.E. (2005) Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology, 31,* 413-419 DOI: 10.1093/jpepsy/jsj058

Barker, C., & Pistrang, N. (2005) Quality criteria under methodological pluralism: implications for conducting and evaluating research. *American Journal of Community Psychology, 335,* 201-212 https://doi.org/10.1007/s10464-005-3398-y

Bowl, R. (1996) Legislating for user involvement in the United Kingdom: mental health services and the NHS and community care act 1990. *International Journal of Social Psychiatry, 42,* 165-180 https://doi.org/10.1177/002076409604200301

Breakwell, G.M. (1986) *Coping with threatened identities.* London: Methuen

Breakwell, G.M. (2014) Identity process theory: clarification and elaboration in R. Jaspal,

& G.M. Breakwell (Eds.) *Identity Process theory: identity, social action and social change (pp*

20-39). Cambridge: Cambridge University Press

British Psychological Society (2018) *Code of Ethics and Conduct*. Leicester: BPS

accessed from

https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%

20Ethics%20and%20Conduct%20%28Updated%20July%202018%29.pdf

Carr, A (2001) Michael White's narrative therapy. In Carr, A (ed.) *Clinical psychology in*

Ireland Volume 4: Family therapy theory, practice and research pp . Wales: Edwin Mellon Press

retrieved from http://mellenpress.com/mellenpress.cfm?pc=9&bookid=4690 on 28.10.2018

Calhoun, L.G., & Tedeschi, R.G. (2013) *Posttraumatic Growth in Clinical Practice.*

London: Routledge

Cheung, S.Y., & Delfabbro, P. (2016) Are you a cancer survivor? A review on cancer

identity, Journal of cancer Survivorship: *Research and Practice, 10*, 759-771.

http://dx.doi.org/10.1007/s11764-016-0521-z

Cho, D., & Park, C.L. (2015) Cancer related identities in people diagnosed during late

adolescence and young adulthood. *Health Psychology, 20*, 594-612.

https://doi.org/10.1111/bjhp.12110

Coughtrey, A., Millington, A., Bennett, S., Christie, D., Hough, R., Su, M., … Shafran, R.

(2018) The effectiveness of psychosocial interventions for psychological outcomes in pediatric

oncology: a systematic review. *Journal of Pain and Symptom Management, 55,* 1004-1017 DOI:

10.1016/j.jpainsymman.2017.09.022

Delucia, J.L. (1997) Editorial: the importance of processing activities, exercises, and events to group work practitioners, *Specialists in Group Work, 22,* 82-84 https://doi.org/10.1080/01933929708414370

Department of Health (2000) *The NHS Plan: a plan for investment a plan for reform.* Leeds: Department of Health.

Dennis, C. (2003) Peer support within a health context. A conceptual analysis. *International Journal of Nursing Studies, 40*, 321-332 https://doi.org/10.1016/S0020-7489(02)00092-5

DeMaso, D.R., Gonzalez-Heydrich, J., Erickson, J.D., Grimes, V.P., & Strohecker, C. (2000) The experience journal: a computer-based intervention for families facing congenital heart disease. *Journal of American Academy of Child and Adolescent Psychiatry, 39*, 727-734 https://doi.org/10.1097/00004583-200006000-00011

Douglas, L., Jackson, D., Woods, C., & Usher, K. (2018) Reported outcomes for young people who mentor their peers: a literature review. *Mental Health Practice, 21,* 35-45 doi: 10.7748/mhp.2018.e1328

Dunn, J., Steginga, S., Rosoman, N., & Millichap, D. (2003) A review of peer support in the context of cancer. *Journal of Psychosocial Oncology, 21*, 55-67 https://doi.org/10.1300/J077v21n02_04

Erikson, E.H. (1959) *Identity and the life cycle*. New York: International University Press

Erikson, E.H. (1968) *Identity, youth, and crisis*. New York: Norton

Foulkes, S. H. (1948). *Introduction to Group-Analytic Psychotherapy*. London: Heinemann

Gatta, G., Zigon, G., Capocaccia, R., Coebergh, J., Desandes, E., Kaatsch, P., … Stiller, C.A. (2009) Survival of European children and young adults with cancer diagnosed 1995-2002. *European Journal of Cancer, 45,* 992-1005 https://doi.org/10.1016/j.ejca.2008.11.042

Gillard, S.G., Edwards, C., Gibson, S.L., Owen, K., & Wright, C. (2013) Introducing peer worker roles into UK mental health service teams: a qualitative analysis of the organizational benefits and challenges. *BMC Health Services Research, 13*, 188-202 https://doi.org/10.1186/1472-6963-13-188

Greup, S.R., Kaal, S., Jansen, R., Manten-Horst, E., Thong, M., Van der Greef, W., … Husson, O. (2018) Post-traumatic growth and resilience in adolescent and young adult (AYA) cancer patients: an overview. *Journal of Adolescent and Young Adult Oncology, 7*, 1-14 https://doi.org/10.1089/jayao.2017.0040

Gunnes, M.W., Lie, R.T., Biorge, T., Ghaderi, S., Syse, A., Ruud, E., … Moster, D. (2017) Suicide and violent deaths in survivors of cancer in childhood, adolescence and young adulthood – a national cohort study *International Journal of Cancer, 140,* 575-580. https://doi.org/10.1002/ijc.30474

Health and Care Professionals Council (2016) Standards of conduct, performance and ethics. London: HCPC Retrieved from https://www.hcpc-uk.org/globalassets/resources/standards/standards-of-conduct-performance-and-ethics.pdf

Hedtke, L. (2014). Creating stories of hope: a narrative approach to illness, death and grief. *Australian and New Zealand Journal of Family Therapy, 35,* 4-19. https://doi.org/10.1002/anzf.1040

Houlston, C., Smith, P., & Jessel, J. (2009) Investigating the extent and use of peer support initiatives in English schools *Educational Psychology, 29.* 325-344 https://doi.org/10.1080/01443410902926751

Jacobs, K., Titman., P., & Edwards, M. (2012) Bridging psychological and physical health care. *Psychologist, 25,* 190-193 Retrieved from https://thepsychologist.bps.org.uk/ volume-25/edition-3/bridging-psychological-and-physical-health-care on 19.03.2019

Jaehee, Y., Zebrack, B., Kim, M.A., & Cousino, M. (2015). Posttraumatic growth outcomes and their correlates among young adult survivors of childhood cancer, *Journal of Paediatric Psychology, 40*, 981-991 https://doi.org/10.1093/jpepsy/jsv075

Jerson, B., D'urso, C., Arnon, R., Miloh, T., Iyer, K., Kerkar, N., & Annunziato, R. (2013) Adolescent transplant recipients as peer mentors: a program to improve self-management and health-related quality of life. *Pediatric Transplantation, 17,* 612-620 https://doi.org/10.1111/petr.12127

Lerner, R.M., & Steinberg, L. (2004) *Handbook of adolescent psychology (2nd ed.)* Hoboken, NJ: Wiley

Lunn, S. (2008) Spread the news: coping tricks from the sickle cell clinic. The International *Journal of Narrative Therapy and Community Work, 3*, 41-46. Retrieved from https://search.informit.com.au/documentSummary;dn=023651908330811;res=IELIND.

Luyckx, K., Goossens, L., & Soenens, B. (2006). A developmental contextual perspective on identity construction in emerging adulthood: Change dynamics in commitment formation and commitment evaluation. *Developmental Psychology, 42*, 366–380. http://dx.doi.org/10.1037/0012-1649.42.2.366

Luyckx, K., Seiffge-Krenke, Schwartz, S.J., Goossens, L., Weeks, I., Hendrieckx, C., & Groven, C. (2008) Identity development, coping and adjustment in emerging adults with a chronic illness: the sample case of type 1 diabetes. *Journal of Adolescent Health, 43*, 451-458 https://doi.org/10.1016/j.jadohealth.2008.04.005

MacLellan, J., Surey, J., Abubakar, I., Stagg, H.R. (2015). Peer support workers in health: A qualitative meta synthesis of their experiences. *PLoS ONE, 10.* 1-17 https://doi.org/10.1371/journal.pone.0141122

Marcia, J.E. (1966) Development and validation of ego identity status. *Journal of Personality and Social Psychology, 3,* 551-558 http://dx.doi.org/10.1037/h0023281

Marcia, J.E. (1980) Identity in Adolescence In Adelson, J. (ed) *Handbook of Adolescent Psychology* (pp 159-187) New York: Wiley & Sons.

Mayer, C., & McKenzie, K. (2017) …it shows that there's no limits: the psychological impact of co-production for experts by experience working in young mental health. *Health and Social Care in the Community, 25*, 1181-1189. https://doi.org/10.1111/hsc.12418

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: a theoretical perspective. *Psychiatric Rehabilitation Journal, 25*, 134-141. Retrieved from https://cabhp.asu.edu/sites/default/files/mead_peer-su on 08.04.2019

Meeus, W. (2011) The study of adolescent identity formation 2000-2010: a review of longitudinal research, *Journal of Research on Adolescence, 21,* 75-94 https://doi.org/10.1111/j.1532-7795.2010.00716.x

Mental Health Foundation (2012) *Doing good does you good: a pocket guide*. Mental Health Foundation: London.

Moxley-Haegert, L. (2012) *Hopework. Stories of survival from the COURAGE programme: families and children diagnosed with cancer*. Retrieved from http://dulwichcentre.com.au/wp-content/uploads/2014/08/Hopework_by_Linda_Moxley-Haegert.pdf on 01.03.2019

Moxley-Haegert, L. (2015) Leaving a legacy and letting the legacy live: using narrative practices while working with children and their families in a child palliative care program. *The International Journal of Narrative Therapy and Community Work, 2015, no 2, 58-70* Available from https://search.informit.com.au/documentSummary;dn=485448930605616;res=IELIND

Myerhoff, B. (1982). Life history among the elderly: performance, visibility and remembering. In Rudy, J (ed) *A crack in the mirror: reflexive perspectives on Anthropology* (pp20-35). Philadelphia: University of Pennsylvania Press.

Myerhoff, B. (1986). Life not death in Venice: its second life. In Turner, V., & Bruner, E. (eds.) *The Anthropology of Experience* (pp. 25-40) Chicago: University of Illinois Press.

Naidu, T., & Shabangu, S. (2015) Poetry and narrative therapy for anxiety about spinal surgery. *Journal of Child and Adolescent Mental Health, 27, 75-84.* http://doi.org/10.2989/17280583.2015.1034722

Ncube, N. (2006). The Tree of Life project: using narrative ideas in work with vulnerable children in Southern Africa, *International Journal of Narrative Therapy and Community Work, 1,* 3-16. Retrieved from http://ls-tlss.ucl.ac.uk/course-materials/PSYCGN48_69480.pdf on 28.03.2019

National Institute for Health and Clinical Excellence (2014) *Cancer services for children and young people (QS55).* Retrieved from

https://www.nice.org.uk/guidance/qs55/resources/cancer-services-for-children-and-young-

people-pdf-2098728855493 on 11.04.2019

Office of National Statistics (2018) Dataset: cancer registration statistics, England: 2016

final Retrieved from

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddisea

ses/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland on 21st March 2019.

Office of National Statistics (2017) Childhood cancer survival in England: children

diagnosed from 1990 to 2014 and followed up to 2015. Retrieved from

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddisea

ses/bulletins/childhoodcancersurvivalinengland/childrendiagnosedfrom1990to2014andfollowedu

pto2015 on 21st March 2019

Pasupathi, M., & Hoyt, T. (2009) The development of narrative identity in late

adolescence and emergent adulthood: the continued importance of listeners. *Developmental

Psychology, 45,* 558-574 http://dx.doi.org/10.1037/a0014431

Portnoy, S., Girling, I., & Fredman, G. (2016) Supporting young people living with

cancer to tell their stories in ways that make them stronger: The beads of life approach. *Clinical

Child Psychology and Psychiatry, 21,* 255-267 https://doi.org/10.1177/1359104515586467

Seitz, D., Beiser, T., Debatin, K., Grabow, D., Dieluweit, U., Hinz, A., … Goldbeck, L.

(2010) Posttraumatic stress, depression and anxiety among adult long-term survivors of cancer in

adolescence. *European Journal of Cancer, 46,* 1596-1606

https://doi.org/10.1016/j.ejca.2010.03.001

Smith, J.A., Flowers, P., & Larkin, M (2009) *Interpretative phenomenological analysis:

theory, research, practice*. London: Sage

Stryker, S., & Burke, P.J. (2000) The past, present and future of an identity theory. *Social*

Psychology Quarterly, 63, 284-297 Retrieved from http://www.jstor.org/stable/2695840

Taieb, O., Moro, M.R., Baubet, T., Revah-Levy, A., & Flament, M.F. (2003)

Posttraumatic stress symptoms after childhood cancer. European Child & Adolescent Psychiatry,

12, 255-264 https://doi.org/10.1007/s00787-003-0352-0

Tedeschi, R.G., & Calhoun, L.C. (1995) *Trauma and transformation: growing in the*

aftermath of suffering. Thousand Oaks, CA: Sage

Thornton, A.A. (2002) Perceiving benefits in the cancer experience. *Journal of Clinical*

Psychology in Medical Settings,9, 153-165 https://doi.org/10.1023/A:1014996127535

Turner, V. (1969). *The ritual process: Structure and anti-structure*. New York, NY: Aldine

de Gruyter.

van Gennep, A. (1960) *The Rites of Passage*. Chicago: University of Chicago Press.

Vignoles, V.L., Chryssochoou, X., & Breakwell, G.M. (2002) Evaluating models of

identity motivation: self-esteem is not the whole story. *Self and Identity, 1,* 201-218.

https://doi.org/10.1080/152988602760124847

Walker, G., & Bryant, W. (2013) Peer support in adult mental health services: a meta-

synthesis of qualitative findings. *Psychiatric Rehabilitation Journal, 36*, 28-34

http://dx.doi.org/10.1037/h0094744

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends.* New York, NY:

WW Norton and Co

White, M. (1995) *Re-authoring Lives.* Adelaide: Dulwich Centre Publications

White, M. (1997) Challenging the culture of consumption: Rites of passage and

communities of acknowledgement. *New Perspectives on addition, special issue of Dulwich*

Centre Newsletter, 38-47 Retrieved from https://dulwichcentre.com.au/articles-about-narrative-therapy/deconstructing-addiction/challenging-the-culture-of-consumption/ on 07.04.2019

White, M. (2007) *Maps of narrative practice.* New York NY: WW Norton & Co.

Willig, C. (2010) Introducing qualitative research in psychology. Maidenhead: Open University Press McGraw-Hill.

Yalom, I. (1995) *The Theory and Practice of Group Psychotherapy*. (4th Edition) New York: Basic Books

Zamora, E.R., Yi, J., Akter, J., Kim, J., Warner, E.L., & Kirchhoff, A.C. (2017) Having cancer was awful but also something good came out: post-traumatic growth among adult survivors of pediatric and adolescent cancer. *European Journal of Oncology Nursing, 28*, 21-27. https://doi.org/10.1016/j.ejon.2017.02.001

SECTION C

Appendices

Appendices

Appendix A: CASP (2018) Qualitative Research Check List

	DeMaso (2000)	McCarthy & Sebaugh (2011)	Moxley-Haegert (2012)	Portnoy, Girling, & Fredman (2016)	Casdagli et al. (2017)	Laing et al. (2017)
Was there a clear statement of the aims of the research?	**Yes** Feasibility and safety	**Partly** Description of program, theoretical underpinning, and perspective of those involved plus outcome measures	**No** Aim of paper to document details of experiences and the narrative practices used	**Yes** Explore the experiences and effects of participating in the approach Unclear relevance	**Yes** Title evaluation of Group, although not explicit in the main text Unclear relevance	**Yes** How might we understand the meaning of, value of, and effect on… in creation of digital story
Is a qualitative methodology appropriate?	**Yes** Mixed method allows expression of experiences	**Yes** Mixed method allows expression of views	**Yes** Not enough information	**Yes** Experiences	**Yes** Allow for exploration of group experience	**Yes**
Was the research design appropriate to address the aims of the research?	**Yes** Basic information on perceived safety and usefulness	**Yes** Basic outcome measure	**n/a** Very basic outcome date reported	**Yes** Subjective experiences	**Yes** Subjective experiences but within the group so whole group interview	**Yes** Determining if and understanding how
Was the recruitment strategy appropriate to the aims of the research?	**Can't tell** Clear how many chose not to take part, but sampling method unclear	**Can't tell** Unclear response rates, sample not outlined fully	**Can't tell** Report numbers accessing the service not clear how many completing feedback	**Can't tell** Sample outlined briefly, unclear if self-selected, or all provided some feedback	**Can't tell** Suggests that all those attending groups gave feedback Self-selected group	**Yes** Purposeful sampling of person who can best inform understanding
Was the data collected in a way	**Yes** Semi-structured interviews, in	**Yes**	**Yes**	**Can't tell** Questionnaires and semi-structured	**Can't tell** Research issue unclear	**Yes** Semi-structured interviews, audio

that addressed the research issue?	person or over the telephone	Feedback to support clinical practice	Feedback to support clinical practice	interviews but no further details	feedback interviews at the end of day. Interview method not explicit	recorded some in person some over skype (justified why)
Has the relationship between researcher and participants been adequately considered?	**Partly** Considered as a limitation	**No**	**No**	**No** Assumed that the feedback interviews are with those delivering and writing up the findings, this is not addressed in article	**No** Assumed that the feedback interviews are with those delivering and writing up the findings, this is not addressed in article	**No** Not mentioned
Have ethical issues been taken into consideration?	**No** No mention of ethics	**No**	**No**	**Can't tell** Reference is only made to ethics around consent	**"can't tell"**	**Can't tell** Ethical approval mentioned
Was the data analysis sufficiently rigorous?	**Can't tell** No supporting quotes, unclear if responses to multiple choice or open-ended	**Can't tell** Unclear how dominant themes were established, no quotes included.	**No**	**Can't tell** Unclear analysis method Quotes provided to support statements	**Yes** Thematic analysis, more than one team member involved Examples included	**Yes**
Is there a clear statement of findings?	**Yes**	Basic findings from outcome measures	Basic findings	**Yes**	**Yes**	**Yes**
How valuable is the research?	Some mention of clinical implications	**Can't tell**	**No** didn't fit with style of paper	**"No"** didn't fit with style of paper	**"Yes"**	**Yes**
Notes	No mention of White but mention NT	Outcome reporting seems secondary to descriptions		Consistent with NT article written in storytelling style	Target audience, diabetes professionals sharing practice	Creating digital stories after cancer

Appendices

Overall Yes/Can't tell/no	Yes: 5 Partly: 2 Can't tell: 2 No: 1 **LOW***	Yes: 3 Partly: 2 Can't tell/partly: 3 No: 2 **VERY LOW***	Yes: 2 Partly: 1 Can't tell: 1 No: 6 **VERY LOW***	Yes: 4 Partly: 0 Can't tell: 4 No: 2 **VERY LOW***	Yes: 6 partly: 0 Can't tell: 3 No: 1 **LOW***	Yes: 8 partly: 0 Can't tell: 1 No: 1 **MEDIUM***

*Determining Quality Rating

Consideration was given to how many of the ten criteria were met by each paper when attributing a quality rating. As a general guide quality was considered:

Very Low: if papers met four or less criteria

Low   5-6 criteria

Medium: 7-8 criteria

High: 9-10 criteria.

Appendices

Appendix B: Criteria for judging the quality of research design (case studies)

Yin, R. (2018) Case study research and applications design and methods. London: Sage (p43)

Criteria	Naidu & Shabangu (2015)	Hedtke (2014)
Construct Validity Use multiple sources of evidence	No - Single case study	No - Case Example
Construct Validity Have key *informants* review draft case study report	**Reviewed by case study**	No
Internal Validity Do pattern matching	No	No
Internal Validity Do explanation building	**Yes**	**Yes**
Internal Validity Address rival explanations	No	No
Internal Validity Use logic models	No	No
External Validity Use theory in single-case studies	**Narrative Therapy technique mentioned**	**Narrative Therapy and Grief theory**
External Validity Use replication logic in multiple case studies	No	No
Reliability Use case study protocol	No	No
Reliability Develop case study database	No	No
Reliability Maintain a chain of evidence	No	No
OVERALL YES/NO and subsequent rating	Yes: 3 No: 8 **LOW***	Yes: 2 No: 9 **VERY LOW***

*Determining quality:

Quality ratings were determined by how well papers met criteria across the four areas; construct validity, internal validity, external validity, and reliability Addressing less that three of the four areas was considered very low. Considering 3-4 of the four areas but only one dimensionally was considered poor, whereas giving deeper consideration to at least 2 areas was considered medium and giving thorough consideration across the four areas was considered high.

Appendix C: Advertising Flyer

A STUDY ABOUT THE ROLE OF PEER TRAINER

'Experiences of being a Beads of Life/ Just Bead It Peer Trainer'

WHO AM I?

Hello, my name is Bec Henly. As part of my doctorate degree in Clinical Psychology I am doing a study looking at the experience of being a peer trainer in the 'Just Bead It' group

WHY DO THIS STUDY?
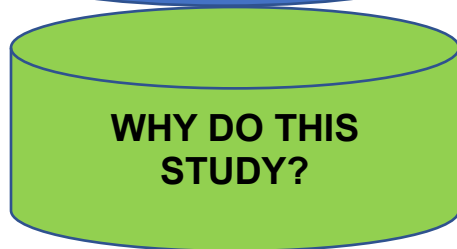
I am interviewing young people about their experiences of being a Peer Trainer with the aim of finding out more about what inspires young people to take on the role and how the role affects them as a person. There is very little research exploring the role of peer trainers. I am hoping that by interviewing young people like yourself it will help us find out more, and might help other services think about introducing peer trainer roles.

Have you attended a Just Bead It group as a Peer Trainer?

If the answer is YES to the above questions, then please talk to the team you normally work with and ask them for more information, OR, contact me directly by emailing me at b.m.henly224@canterbury.ac.uk

Would you be interested in talking about your experiences in a one-off interview?
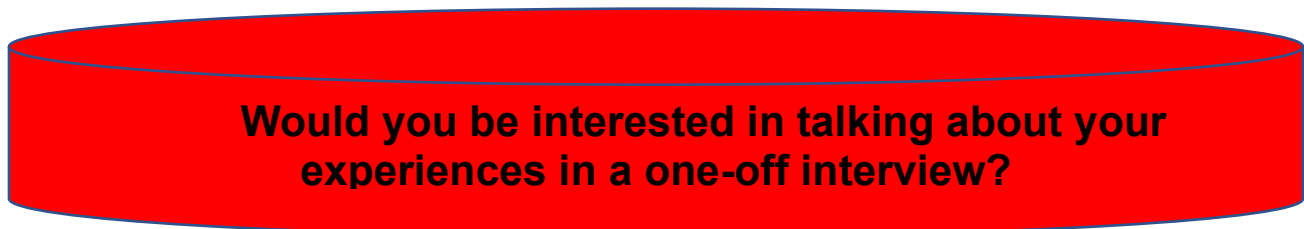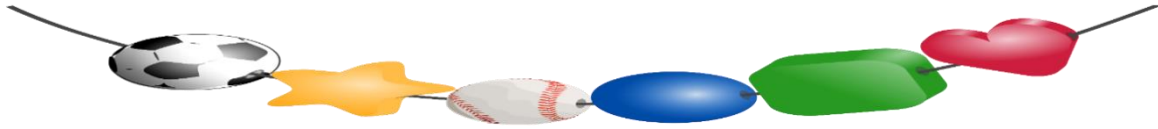
Appendix D: Information Sheet for Young Person
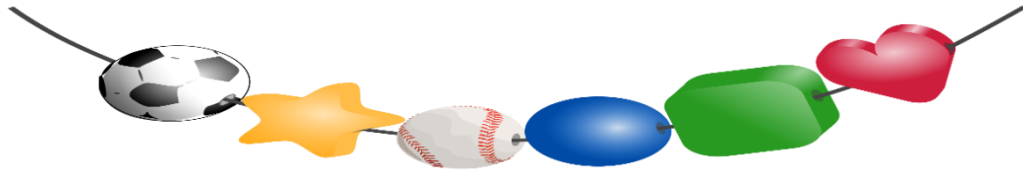
Young Person Information Sheet

'Experiences of being a Peer Trainer'

PICTURE OF RESEARCHER REMOVED	Hello, my name is Bec and I am training as a psychologist. As part of my psychology course I am doing a project asking young people about their experiences of being a peer trainer. I would like to invite you to take part in this research. Before you decide it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.

- Part 2 gives you more detailed information about the conduct of the study

PART 1

What is the Project about?

The project is about young people's experiences of being a peer trainer. I would like to hear about how you became a peer trainer, what you like about the role, what some of the challenges might be and if anything has changed for you since becoming a trainer.

Why have I been asked to take part?

You have been invited to take part because you have attended the training day for peer trainers and have helped at a Just bead it day. You have also told myself, or one of the psychologists working alongside you, that you would like to find out more about the project.

Do I have to take part?

You can choose to join the project or not. It is your choice to reply yes or no. If you do not want to take part it is OK. This project is separate from your care at XXXX and saying no to the project will not affect any part of your care or your role as a peer trainer.

If you have any questions about the project or if you would like to speak to me before you choose 'yes or no' we can arrange a time to talk.

If you decide you would like to take part I will ask you to complete a consent form which you will be given a copy of to keep.

What will happen to me if I take part?

If you decide that you would like to take part, I will invite you to meet with me to talk about your experiences as a peer trainer. We would talk for about 1 hour together in a quiet room in the hospital and with your consent I will be recording our voices.

What we talk about will be private. I will not tell the staff or your parents what you say. But if you let me know that you weren't safe or that someone you know wasn't safe then I would have to tell someone else so that we could help you or them.

I will ask you questions around your journey to becoming a peer trainer and your experiences since taking on this role.

When I have finished talking to all the young people I will look at what everybody has said and try and identify common experiences, themes, and ideas about what it's like being a peer trainer and the roles benefits and challenges. I will ask you if you would like to meet with me to hear about what I have found out and you can choose if you would like to do this or not.

If you choose to join the project your travel costs up to £10 can be refunded for your journey to the interview and you will also receive a £10 voucher when the project is finished. This is to say thank you for your time and involvement in helping with the project.

Do I have to answer everything?

If you do not want to answer some questions you can just say no. If you would like to leave before we finish the questions that's OK. You can ask to stop and leave at any time.

What are the possible advantages and disadvantages of taking part?

Possible benefits: Participation will give you the opportunity to talk and think about your experiences as a peer trainer and, like attendance at the beads of life group might be another opportunity to share your story. Your shared expertise may help improve the peer trainer role for future young people within the service. It may also help encourage other services to develop this role in supporting young people in a similar way.

Possible disadvantages/Risks: If your journey as a peer trainer has been difficult, talking about this might be difficult and might make you think about it more but if there are questions you do not want to answer you can just say no.

Thank you for reading about my study,

If this information has interested you and you are considering taking part, there are a few more

important things for you to know in part 2 before you make a final decision.

Don't forget if you have any questions please feel free to contact me either by e-mail or telephone!

Rebecca Henly
Trainee Clinical Psychologist
Canterbury Christ Church University
e-mail: b.m.henly224@canterbury.ac.uk
tele: 07843 242807

Part 2 of the information sheet
What will happen if I don't want to carry on with the study?
You are free to choose to not take part at any time. If the interview has started you can ask to stop, either just for a break or because you have changed your mind about taking part. You would be free to leave and this would not affect your peer trainer role. If we stop in the middle of the interview we would like to use the recording taken before stopping as part of the research. If you decide to stop and ask us not to use your recording it will be destroyed.

What if there is a problem?
If there is a problem you can speak to myself, the researcher, either face to face or over the telephone (07843 242807) and I will try to help. If this does not stop the problem there may be somebody in your care team that it able to help.

Complaints
If you have a concern about any aspect of this study you should ask to speak to me and I will do my best to address the concern (07843 242807). If you remain unhappy and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology – paul.camic@canterbury.ac.uk,

Will information from or about me from taking part in the study be kept confidential?
Your voice will be recorded during the interview. Following the interview this data will be transferred to a secure memory stick and removed from the audio recording machine. Data will be listened to by the researcher and transcribed which means a written account of the interview is created. This will be stored securely. The data will be analysed and written up as part of a doctorate research study. During this process, your information will be kept strictly confidential, your names will be changed and any details that might help people spot that it was you being interviewed will be removed. Findings may be written up and submitted for publication, but care will be taken to make sure you cannot be recognised. On completion of the study data will be stored securely for a further 5 years at the university before being destroyed securely.

There are only two occasions when I might need to break our confidentiality (privacy), this would be if you were to say something that made me worry that you or someone else may be at risk. I would normally talk to you first before breaking your confidentially in this situation unless I thought this would lead to further risk to you.

What will happen to the results of the research study?
At the end of the research participants can opt to meet with the researcher to hear about the findings or a short outline of the findings will be available for participants on request. Findings will be written up as part of a doctorate research project and results will be published in a relevant journal. In the initial write up and subsequent publications anonymised quotes from interviews will be used but care will be taken to make sure nobody can spot that it was you.

Who is organising and funding the research?
This project is funded by Canterbury Christ Church University.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central Berkshire Research Ethics Committee

Further information and contact details
If you have any further questions about the research project or just want to find out more you can leave a message for me on a 24-hour voicemail phone line at 03330117070. Please say that the message is for me (Rebecca Henly) and leave a contact number so that I can get back to you. Alternatively you can contact me on the e-mail address or telephone number listed at the end of part 1 of the information sheet.

Thank you for reading about my study

Appendix E: Information Sheet for Parents/Guardian of children under 16 years

Parent/Guardian Information Sheet

'Experiences of being a Peer Trainer'

PHOTOGRAPH OF RESEARCHER REMOVED	Hello, my name is Rebecca Henly (Bec) and I am a trainee clinical psychologist at Canterbury Christ Church University. As part of my psychology course I am doing a project asking young people about their experiences of being a peer trainer. I would like to invite your child to take part in this research study. Before you and your child decide it is important that you understand why the research is being done and what it would involve for your child.

Part 1 tells you the purpose of this study and what will happen to your child if they take part. Part 2 gives you more detailed information about the conduct of the study.

What is this study for?
The project is about young people's experiences of being a peer trainer. I would like to hear about what inspired your child to become a trainer, what they like about the role, what some of the challenges have been and if, and how, the role has affected them as a person.
There is very little research exploring the role of peer trainers for young people in health settings so I am hoping that these interviews will help us find out more about how young people experience the role, and might help other services think about introducing peer trainers.

Why has my child been invited?
Your child has been invited because they have attended the peer trainer training day and have helped at a 'Just Bead it' day. You and your child have also expressed interest in finding out more about the study.

Does my child have to take part?
It is up to you and your child to decide to join the study. If you agree to take part, I will then ask you to sign a consent form which you will be given a copy of to keep. You and your child are free to choose not to take part at any time, without giving a reason. This project is separate from your child's care at XXXX. No part of your child's care from the service will change if you choose not to take part.

What will happen to my child if they take part?
If you decide to take part your child will be invited to be interviewed by me. This will normally take place in a confidential space within the hospital. The interview will take up to one hour and with your consent I will be taping our voices. I will ask questions around your child's journey to becoming a peer trainer and their experiences since taking on this role. This research is separate from your child's involvement with the service and will not affect their involvement with the team.

If you, and your child, have questions about the project and would like to speak to me further before deciding please feel free to contact me by e-mail or telephone using the details below.

Expenses and payments
Travel costs up to £10 can be refunded for the journey to interview. At the end of the project your child will also receive a £10 voucher to say thank you for their time and involvement in the project.

What will My Child be asked to do?
Your child will be asked to attend a one-off interview with me in a quiet room at the hospital. This talk will last up to 1 hour and involve talking about their experiences of being a peer trainer. With yours, and your child's, consent I will be audio recording the interview.

What your child says will be confidential unless I am worried about their safety or the safety of others.

When I have finished talking to all the young people involved I will look at what everybody has said and try to identify common experiences, themes, and ideas about what it is like to be a peer trainer and the roles potential benefits and challenges. I will ask you and your child if you would like to meet with me at the end of the project to hear about what I have found and you, and your child, can choose if you would like to do this or not. You can also choose instead to receive a short report about the study.

What are the possible disadvantages and risks of taking part?
If your child's journey as a peer trainer has been difficult, talking about this might be difficult and make them think about it more. Your child will be made aware that if there are questions they do not want to answer they can just say no and we will move on.

What are the possible benefits of taking part?
Participation will give individuals the opportunity to consider and talk about their experiences as a peer trainer and may provide another opportunity to have their positive stories about themselves heard. Their shared expertise may help improve the peer trainer role for future young people within the service. It may also help encourage other services to develop this role in supporting young people in a similar way.

What if there is a problem?
Any concerns or complaints you have about the way you, or your child, have been treated during this study or any harm they might suffer will be addressed. *The detailed information on this is given in Part 2.*

Will information from or about me and my child from taking part in the study be kept confidential?
Yes. I will follow ethical and legal practice. This means that all information about you and your child will be kept private. *This is explained further in Part 2.*

Thank you for reading about my study

If this information has interested you and your child, and you are considering taking part, there are a few more important things for you both to know in part 2 before you make a final decision.

Don't forget if you have any questions please feel free to contact me either by e-mail or telephone.

Rebecca Henly
Trainee Clinical Psychologist, Canterbury Christ Church University
e-mail: b.m.henly224@canterbury.ac.uk
telephone: 07843 242807

Part 2 of the information sheet

What will happen if we don't want to carry on with the study?
You are free to choose to not take part at any time. If the interview has started you (or your child) can ask to stop, either just for a break or because you have changed your mind about taking part. Your child would be free to leave and this would not affect their peer trainer role. If we stop in the middle of the interview we would like to use the recording taken before stopping as part of the research. If your or your child request that their data is not used in this situation it will be destroyed.

What if there is a problem?
If there is a problem you can speak to myself, the researcher, either face to face or over the telephone (07843 242807) and I will try to help. If this does not stop the problem there may be somebody in your care team that will be able to help.

Complaints
If you have a concern about any aspect of this study you should ask to speak to me and I will do my best to address the concern (07843 242807). If you remain unhappy and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology – paul.camic@canterbury.ac.uk,

Will information from or about my child from taking part in the study be kept confidential?
Yes. Your child's voice will be recorded during the interview. Following the interview this data will be transferred to a secure memory stick and removed from the audio recording machine. Data will be listened to by the researcher and transcribed which means a written account of the interview is created. This will be stored securely. The data will be analysed and written up as part of a doctorate research study. During this process, your child's information will be kept strictly confidential, your child's name will be changed and any details that might help people spot that it was them being interviewed will be removed. Findings may be written up and submitted for publication, but care will be taken to make sure your child cannot be recognised. On completion of the study data will be stored securely for a further 5 years at the university before being destroyed securely.

There are only two occasions when I might need to break our confidentiality (privacy), this would be if your child was to say something that made me worry that they or someone else may be at risk. I would normally talk to your child first before breaking their confidentially in this situation unless I thought this would lead to further risk to them.

What will happen to the results of the research study?
At the end of the research participants can opt to meet with the researcher to hear about the findings and a short outline of the findings will be available for participants on request. Findings will be written up as part of a doctorate research project and results will be published in a relevant journal. In the initial write up and subsequent publications anonymised quotes from

interviews will be used but care will be taken to make sure nobody can spot that it was your child.

Who is organising and funding the research?
This project is funded by Canterbury Christ Church University.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central Berkshire Research Ethics Committee

Thank you for reading about my study

Appendix F: Consent Form 16-24 years

Canterbury
Christ Church
University

Salomons Centre for Applied Psychology

CONSENT FORM 16-25 years
An Exploration of the Experiences of being a Peer Trainer

Centre Number:
Study Number:
Participant Identification Number for this study:
Name of Researcher: Rebecca Henly

Please take your time to read the following statements carefully and circle 'yes' if you agree with them or 'no' if you do not. If you have any questions or are just a little unsure please speak to the researcher, Bec, before completing this form;

I confirm that I have read and understand the information sheet dated 15th April 2018 (version 3) for the above study.	YES NO
I have had the opportunity to think about the information, ask questions and have had these answered satisfactorily.	YES NO
I understand that taking part in the study is voluntary and that I am free to withdraw at any time without giving any reason, and without my care being affected in any way.	YES NO
I agree to my interview being audio-recorded	YES NO

I agree that anonymous and disguised quotes from the interview may be used in academic work and published reports of the study findings

I agree to the research supervisors having access to my anonymised interview transcript.

I agree to the principal researcher (Rebecca Henly) accessing my medical notes purely for the purpose of collecting demographic information about me for example my age and diagnosis.

I agree to take part in the above study

Thank you for taking the time to read through the above statements. Please print and sign your name below;

Name of Participant _____ Date_____

Signature _____

Name of Researcher taking Consent_____ Date _____

Signature _____

Once completed this form is to be kept by the participant and a copy kept by the researcher

15th April 2018 Version 3   IRAS: 233387 REC: 18/SC/0145
      Favourable ethical approval obtained from South Central Berkshire Research Ethical Committee

APPENDICES

Appendix G: Additional Information and Consent Form for Skype Interviews

Salomons Centre for Applied Psychology

Young person / family consent for Skype

There are some risks associated with using such services that you should be aware of

These risks include:

- Such services transmit data across the internet in an encrypted format – whilst this offers reasonable security, it is by no means 100% secure
- Poor quality internet connections can often interfere with the quality of video conferencing
- As Skype is a free service the Trust does not have a contract or service level agreement in place with the service providers and therefore makes no warrantees as to the quality or security of the service

These risks can be somewhat mitigated by:

- Ensuring Skype appointments are not used to discuss matters that are particularly confidential or sensitive in nature

- Ensuring that you discuss confidential and/or sensitive matters in a private space (i.e. where the conversation cannot be heard)

Participant Confirmation	I can confirm that I have been made aware of the risks of being contacted via Skype, and I am happy for the researcher to contact me using Skype
Participant Name	
Skype ID	
Participants Signature	
Parent Signature	

(if under 16)	
Date	

Appendix H: Interview Schedule and Prompts

Possible Questions and Prompts

(1) Please can you tell me what you have done (or can do) as a peer trainer/mentor?

(2) What did you think about the peer trainers when you first attended the group?

(3) Can you tell me about how you came to get this role?
- What (if anything) motivated you into the role?
- Were there reasons that motivated you
- If helping others – Were there reasons other than helping others that motivated you?

(4) Can you tell me about your experiences of being a peer trainer (general/group specific)
- What are some of the good and bad bits?
- In what ways has it impacted on you/ What are some of the ways its impacted on you?
- What kinds of things have you learned from taking on the role?
- Tell me about what its like to be in the group with a different hat on?
- In what ways is being a peer trainer different to when you initially attended the group?
- Tell me about your thoughts and feelings about peer mentoring?
- How did you feel after completing the group?

(5) Have you taken on similar roles elsewhere?
In what ways is this group and your role in the group different/or the same as other groups or other roles you have?

(6) What have you noticed about what family/friends feel/think about you being a peer mentor?

(7) If you were talking to someone else who was thinking about becoming a peer trainer/mentor what would you say to them?

(8) What was it like for you being interviewed today?
- I've asked a lot of questions, do you have any questions for me?!

APPENDICES

Appendix I: NHS Ethical Approval Letter

This has been removed from the electronic copy

Appendix J: Letter of Access and Email Confirmation of Capability and Capacity

This has been removed from the electronic copy

Appendix K: Coded transcript

This has been removed from the electronic copy

Appendix L: Theme Development tables

This has been removed from the electronic copy

Appendix M: Example Exerts from Research Diary

This has been removed from the electronic copy

Appendix N: Extract from Bracketing Interview

This has been removed from the electronic copy

Appendix O: Guidelines for possible Journals

This has been removed from the electronic copy

Appendix P: NRES Form

This has been removed from the electronic copy

Appendix: Q: End of Study report to Ethics and R&D

This has been removed from the electronic copy

APPENDICES

Appendix R: Summary to Participants

Feedback to Participants

Developing through mentoring: Young

people's experiences of peer mentoring

within a Beads of Life group in a hospital
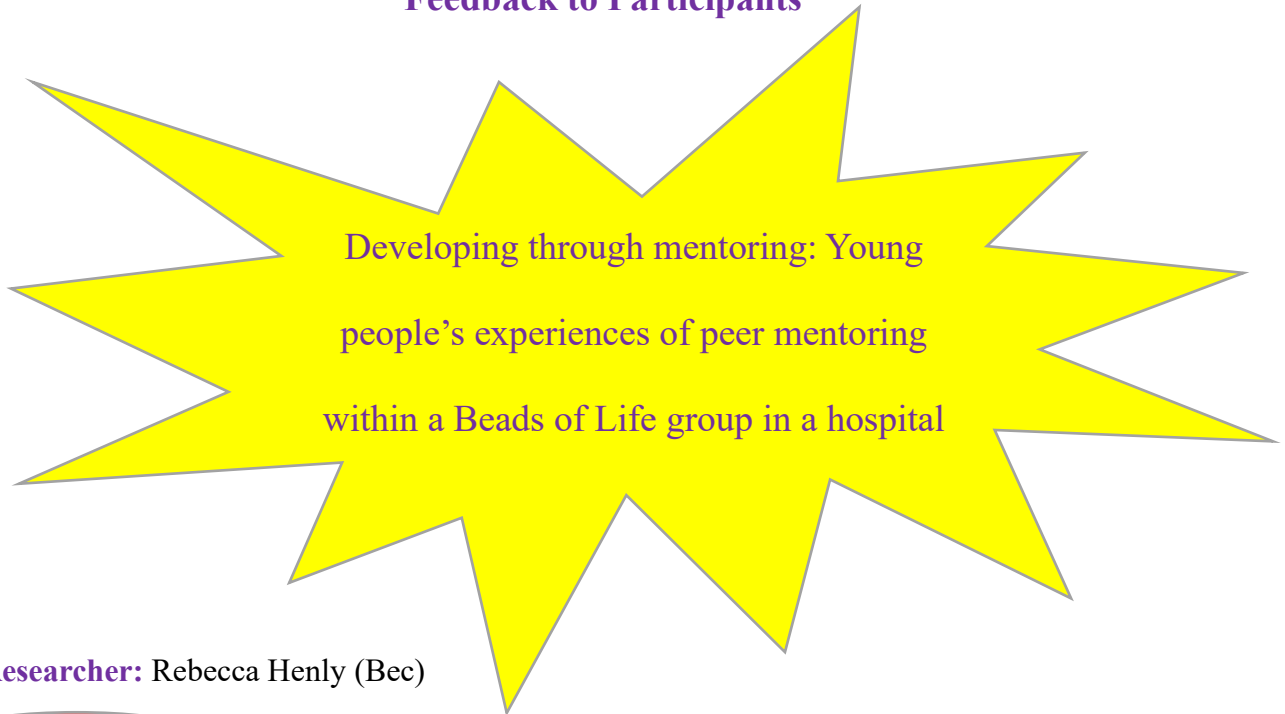
Researcher: Rebecca Henly (Bec)

Aim   To explore the experiences of peer trainers within the Beads of Life Group

Method -
what I did

Eight young people from the Beads of Life group were interviewed about their

experiences as a mentor within the group. Interviews were recorded and then I

made a written copy of what was said. I looked at all the interviews together to find common

experiences which are described as themes.

Results –
What I
found

Three overarching themes that related to the experiences of peer mentoring

emerged:

Identity and
self

Identity and
relationship to
cancer
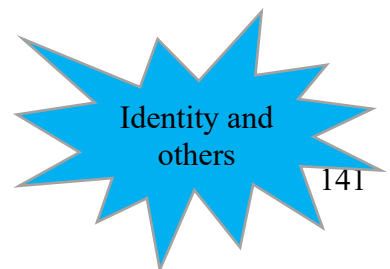
Identity and
others

Within these three areas the mentors noticed a variety of changes.

Motivation Mentors were motivated to help others

During the Mentoring Mentors felt responsibility towards the group, making sure that it ran smoothly, they offered the right amount of support, and they kept the atmosphere upbeat so that participants could get the best out of the group

Mentors appreciated the added value which was created by also being young and having experienced cancer.

Mentors experienced several changes including: Positive psychosocial development (e.g. increased confidence or independence)

Being a mentor also gave an opportunity to test out different roles such as a 'leader' or 'coach' and gave young people the opportunity to experience the benefits of challenging isolation, through connecting with others and having an opportunity to work through the emotional burden of cancer.

Making way for new mentors Learning was passed through the group from the more experienced mentors to the newer mentors and from mentors to participants. All mentors interviewed reported that they had enjoyed the experience of mentoring and would recommend it to others. Most mentors felt that whilst the role was enjoyable, they may not want to do it forever and they wanted to make way for other young people to experience.

Conclusions

Findings overlap with the reported experiences of young peer mentors within other health and educations setting, and suggest potential benefits to the young person from taking on a mentoring role. Findings suggest an impact on identity, with young people noticing changes in the self, their relationship to others, and their relationship to cancer. Overall young people reported positive experiences which suggests future potential for peer mentoring roles and the use of community narrative practices within paediatric settings as a way to support emotional healing.

APPENDICES

Appendix S: Consent Forms for Parents/Guardian and Child if Child under 16 years

Salomons Centre for Applied Psychology

PARENT/GUARDIAN CONSENT FORM
Research Title: An Exploration of the Experiences of being a Peer Trainer

Centre Number:
Study Number:
Participant Identification Number for this study:
Name of Researcher: Rebecca Henly

If your child would like to participate in this study please read through each of the following statements carefully and place your initials in the box next to each statement if you agree. If you have any questions or concerns please speak to the researcher Bec Henly before completing this form;

I confirm that my child and I have read and understand the information sheet dated 15th April 2018 (version 3) for the above study.	
My child and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my child's participation is voluntary and that we are free to withdraw at any time without giving any reason, and without my child's care being affected in any way.	
I agree to my child's interview being audio-recorded and anonymous quotes appearing in academic work and possible future published reports	
I agree to the research supervisors having access to my child's anonymised interview transcript	
I agree to the principal researcher (Rebecca Henly) accessing my child's medical notes for the purpose of collecting demographic information as part of the study e.g. age and diagnosis.	
I agree for my child to take part in the above study.	

Name of Participant_____

Name of Parent/Guardian if under 16 years _____ Date_____

Signature _____

Name of Researcher taking Consent_____ Date _____

Signature _____

      This form is to be kept by the parent/guardian and a copy kept by the researcher

Salomons Centre for Applied Psychology

CONSENT FORM (CHILD UNDER 16)
An Exploration of the Experiences of being a Peer Trainer

Centre Number:
Study Number:
Participant Identification Number for this study:
Name of Researcher: Rebecca Henly

Please read the following statements carefully and circle 'yes' if you agree and 'no' if you do not agree;

Yes, I have read the information sheet (dated 15th April 2018,version 3) and understand this.

Bec gave me time to think about what I read and ask questions about it. I am happy with her answers and understand these.

I understand that I am choosing to take part in this interview, and I can change my mind at any time and don't need to tell Bec why. Choosing to take part doesn't affect my peer mentor role or support from the service in any way.

I agree that Bec can record my interview. I am happy for her to use bits of what I say in her work as long as nobody could spot that it was me who was interviewed.

I agree that Bec can use quotes from my interview in any published papers as long as I can't be recognised.

I agree that members of the wider research team can look at the written version of my interview once my name has been changed so that they can help Bec with her study.

I agree that Bec can access my medical records to collect information about me needed for the study.

Because I am under 16 years, I have talked to my parent/guardian about taking part in the study and they have agreed that I can take part.

Name of Participant_____ Date_____

Signature _____

Name of Researcher taking Consent_____ Date _____

Signature _____

Once completed this form is to be kept by the participant and a copy kept by the researcher

Version 2 15/04/2018   IRAS: 233387 REC: 18/SC/0145
Favourable ethical approval obtained from South Central Berkshire Research Ethical Committee

147