

The art of supporting identity following a life-limiting diagnosis: a systematic review

Holly Dyer

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The art of supporting identity following a life-limiting diagnosis: a systematic review

Holly Dyer*

ABSTRACT

This systematic review of art psychotherapy literature explored how art therapy or artmaking may support patient identity after a life-limiting diagnosis.

Background: Previous research shows the value of art therapy and artmaking in reducing physical and psychological symptoms at the end-of-life. Recent reports indicated that disruption to identity is a key challenge to this group of individuals.

Aims: This systematic review investigated art therapy and artmaking and examined and built upon previous research undertaken with patients facing identity concerns after a terminal diagnosis.

Methods: A robust and rigorous framework of criteria (PRISMA), was followed to select and review suitable research papers in order to gain new insights.

Results: The results indicate that many patients struggle to cope with a changing identity alongside the demands of a terminal illness. The key findings are threefold: art therapy and artmaking can help *maintain or reconstruct* a pre-illness identity and art therapy in particular can help enable a positive identity *transformation*.

Conclusions: Art therapy and artmaking hold benefits for positive identity support such as the re-evaluation and reinstatement of pre-illness roles, psychosocial-interventions and adjustment to major life changes.

Implications: It is recommended that art therapy and artmaking are offered to terminal patients at diagnosis, in order to support identity concerns promptly and allow patients to focus solely on their quality of life and limited time left. It is anticipated that the findings of this systematic review will be of benefit to patients, healthcare workers, art therapists and others within the palliative care community.

Plain-language summary

This review of art therapy literature explored how art therapy or artmaking may support patient identity after a life-limiting diagnosis. Previous research has showed the value of art therapy and artmaking in reducing concerns at the end-of-life. Many reports indicated that changes to identity are one of the main challenges to this group of individuals. This review aimed to compare art therapy and artmaking. It examined and added to earlier research with patients struggling with identity concerns after a terminal diagnosis. A set of standards were followed to select and review appropriate research papers. Results showed that many patients struggled to cope with a changing identity alongside the difficulties of a terminal illness. Patients tried to keep an identity that was separate from their illness and also maintain their pre-illness roles.

The main findings of this systematic review are that art therapy and artmaking can help keep or restore a pre-illness identity. Art therapy in particular can help bring about a positive identity change. The conclusions are that art therapy and artmaking are beneficial for supporting identity and help patients think about and recover their pre-illness roles. Art therapy and artmaking are also seen to help patients cope with major life changes. Recommendations are that further research is undertaken with larger, more varied groups of people, particularly males. It is recommended that art therapy and artmaking are offered to terminal patients when they are diagnosed. This would allow patients to focus on their wellbeing and their limited time left with loved ones. It is likely that the findings will be helpful to patients, healthcare workers, art therapists and others within palliative care.

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Art therapy; artmaking; life-limiting illness; cancer; palliative; terminal; identity maintenance; identity reconstruction

Introduction

While much effort is made within hospice care to focus on individualised wellbeing – such as offering personalised care plans – illness can sometimes eclipse the patient, causing significant psychological issues (Abram & Hinshelwood, 2018). At the hospice where the author works, patients frequently suggest that society continues to focus on their illness, attaching a medical label to them, rather than recognising them as individuals. Instead of being seen as ‘Michelle’;

they become ‘Michelle with cancer’ (Reynolds & Prior, 2006). Patients also comment that they feel their illness has altered their sense of identity and they feel a lack of autonomy in their lives because cancer has taken control. Listening to these reports from terminally ill patients, who are not just coping with pain and other physical symptoms but are also battling with a significantly altered sense of self, shaped the author’s desire to research the subject of art therapy and identity.

CONTACT Holly Dyer  hollyedyer@gmail.com

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This article has been corrected with minor changes. These changes do not impact the academic content of the article.

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Background

In western culture, the healthcare systems offer life-saving treatments, which may have led to the expectations that modern medicine is capable of curing all ill-health conditions. Receiving a terminal diagnosis may come as a shock (Mannix, 2018). Being told there is nothing more to be done, except be given medication to relieve symptoms and diminish pain, can be terrifying (Connell, 1998; Waller & Sibbett, 2005). Patients receiving palliative care may often feel overwhelmed and not in control, and waiting for tests and results may feel as if their lives are in limbo. Some may feel completely powerless as medical decisions are made without their input and they may feel they have no identity beyond their diagnosis (Pratt & Wood, 1998).

Art therapist Megan Tjasink's research (2010) with terminally ill patients shows there is often a multi-faceted breakdown of the individual's previous social context. A stay in hospital, recovering from invasive surgery or nausea caused by medication may affect an individual's ability to continue in their previous roles in their work or social life. Their sexuality, meaning and purpose may be affected, sometimes resulting in a feeling of disconnection not only from others but from their own sense of identity and role in life. Tjasink argues that body image and loss of function, for example, the consequences of medical treatments such as having a breast or testicle removed, temporary or permanent loss of bodily functions resulting from surgery, the loss of hair due to chemotherapy, or the advances of illness itself such as not being able to eat solid food or walk, can have a significant impact on identity. Chattoo and Ahmad (2004) agree that these physical consequences of surgery and medication are often experienced as a 'disintegrating' (p. 26) of self and identity.

There can also be an impact on identity if a patient must stay for long periods in hospital or a hospice. They are stripped of individuality and given the new identity of 'patient' (Kelly & Millward, 2004). When an individual has a serious condition, life generally revolves around that illness. Charmaz (1994) indicates that an illness may begin to dictate an individual's life and start to control them. She suggests that it is the visibility of one's illness – e.g. hair loss, use of a wheelchair, loss of a breast – that creates identity issues.

Government research into palliative care treatment has stressed the importance of patient-centred, individualised care. Reports from NICE (2011), the National Palliative and End-of-Life Care Partnership (2021) and NHS England (2020) focus on the importance of involving the patient in decision-making and have influenced recent hospice policy in the UK. Further charity and organisational reports suggest that '...one of the biggest challenges faced by patients is the preservation of their identity' (Zyga, 2012, p. 1) and 'loss of identity is... central to the experience of enduring illness' (Gillies & Johnston, 2004, p. 436). Additional reports focus on the importance of the arts for wellbeing, particularly for older people (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017; Arts Council of Northern Ireland, 2018; Fancourt & Finn, 2019; Sivapalan, 2015; The Mental Health Foundation, 2011). The Welsh NHS Confederation (2018) specifies that art therapy in particular can reduce anxiety, improve self-confidence and feelings of quality of life.

Furthermore, academic research indicates that art therapy can aid identity concerns with other client groups, such as learning disabilities (O'Farrell, 2017), childhood sexual abuse (Burt, 2002; Glaister, 1996), PTSD (Jones et al., 2018; Stace, 2014), domestic violence (Cardinal, 2014) and refugees (Zahra & Lovell, 2019). These papers not only show the rich benefits that art therapy can bring in regards to identity but serve to indicate the lack of research on the subject within palliative care.

The American Psychological Association describes identity as:

... an individual's sense of self ... the feeling that one is the same person today that one was yesterday ... (despite physical or other changes) (2020, 'APA dictionary of Psychology: Identity', para. 1).

Theories about human identity have a long history. Freud (2018, 1923) believed that the development of human personality and identity are complex. Erikson (1994) suggested that we must find a balance between fitting in and being accepted, and developing an individual identity. Bury (1982) explored the problems affecting identity brought about by chronic illness. He conceptualised chronic illness as a major disruptive experience, suggesting that this not only brings pain and suffering but affects identity and relationships. Bury coins this 'biographical disruption' suggesting it may cause '... a fundamental re-thinking of the person's biography and self-concept' (Bury, 1982, p. 169).

Psychologist Baumeister (1996) describes identity as '... a set of meaningful definitions that are ... attached to the self, including social roles ...' (p. 406). Garner (2004) suggests that one's identity is built from multiple and complex components and while aspects of one's identity may alter over time due to emotional, spiritual, physical, or other changes, there is a sense that the core of one's identity remains unchanged.

Definition of art therapy terminology

Initially it may appear that independent artmaking helps an individual in much the same way as art therapy. However, while independent artmaking as a creative endeavour can help as an ongoing process as patients adapt, adjust and redefine themselves after a diagnosis, art therapy with a trained therapist can facilitate this process for therapeutic purpose (Tjasink, 2010). Consistent with this, McNiff suggests that art can heal wherever it is practiced but states that art therapy within the guidance of a therapeutic relationship has resources that are unavailable to an individual making art on their own (McNiff, 2004).

Reynolds whose research focusses on artmaking, states that 'art for leisure generally serves broadly different psychosocial functions than art for therapy' (Reynolds et al., 2008, p. 219). Collie et al. (2006), argue that when creating art in a social group rather than as an art therapy intervention, the other participants become a source of psychosocial support for the patient. Collie et al., also suggest that in gifting a piece of artwork, the recipient 'witnesses' the gift-giver in a similar way to which the art therapist observes artmaking in art therapy.

This systematic review seeks to examine, draw together and build upon the elements of research from different

papers to build a bigger picture of how art therapy may help support patient identity after a life-limiting diagnosis.

Methods

Study design

This research paper used a theoretical methodology and was conducted following the PRISMA guidelines. The PRISMA guidelines consist of a four-phase flow-diagram and a 27-point checklist. The flow-diagram describes the identification, screening, eligibility and inclusion criteria of selected reports. The checklist includes essentials for transparent reporting in a systematic review (Moher et al., 2009). The author conducted a pilot test search utilising the CINAHL database, followed by a full search of databases using a combination of keywords (Box 1).

Box 1. Search terms.

SEARCH STRATEGY

art therap* or art psychotherap* or artmak* or creativ*

AND

life-limiting diagnosis or life limiting diagnosis or life-limiting illness or life limiting illness or life-limiting condition or life limiting condition or cancer or cancer diagnosis or palliative diagnosis or hospice care or terminal care or end-of-life care or end of life care or palliative care or incurable illness or life threatening illness or life-threatening illness or life threatening disease or life-threatening disease or terminal disease or terminal illness or terminally-ill or terminally ill or tumor or carcinoma or malignant growth or malignant tumor or neoplasm

AND

identity maintenance or identity reconstruction or self identity or self concept or personal identity or self identification or recalibrating identity or personal identification or personality or personal character

The literature search sought to identify research focusing on how art therapy, or artmaking may support identity concerns for patients with a life-limiting illness. This was formulated within a Population, Intervention, Comparison, Outcome (PICO) framework (Richardson et al., 1995) (Figure 1).

Searches were conducted in August 2020 using six digital databases and additional grey literature sources (see Figure 2, PRISMA diagram). Grey literature was used to aid comprehension of the study, offer balance and provide information unavailable from the database search (Paez, 2017).

Research inclusion criteria:

- Undertaken with adults
- Written in English
- Peer reviewed
- Any terminal illness from diagnosis to palliative care
- An art therapy or artmaking intervention, including discussion of identity.

PARAMETER	INCLUSION CRITERIA
Population	Patients with a life-limiting diagnosis
Intervention	Art therapy or artmaking
Comparison	No intervention
Outcome	Support of identity

Figure 1. PICO chart.

No limits were set as to where the research was conducted and no date limits were set (Bettany-Saltikov, 2012; Creswell, 2014; Davies, 2014; Denscombe, 2014).

Research exclusion criteria:

- Interventions other than art therapy or artmaking (i.e. drama therapy)
- Studies conducted with children and teenagers
- Non-terminal illnesses
- Written in languages other than English.

From these searches 311 research papers were identified and the titles and abstract were screened. Duplicates were removed and 300 abstracts were scrutinised to identify suitable records for inclusion. Further records were excluded as the research involved:

- Children and adolescents
- Cancer survivors
- Non-terminal illnesses
- Non-art therapy studies (i.e. music therapy)
- Art therapy and training for family, caregivers and health professionals
- Burnout in palliative care staff.

Procedures

These exclusions resulted in 45 full text records being given detailed appraisal to assess for eligibility. Caldwell et al.'s, 2011 framework and guidelines and CASP (recommended for novice qualitative researchers) were used to appraise the methodology and quality of the papers selected (see Figure 3).

The author excluded a further 30 papers due to minimal discussion of identity, not involving art therapy, artmaking or creativity or not relating to palliative care. However, three additional records were identified from the reference list and citation checking of papers.

After thorough and rigorous scrutiny 18 research papers were identified that met the inclusion criteria and were selected for the systematic review. An extraction document was completed using Davies and Logan's qualitative research worksheets (2012).

Ethics

The author is satisfied that all papers would adhere to the World Health Organisation guidelines governing research with human participants (2011). Furthermore, the author is confident that the selected papers are both beneficent and non-maleficent, are of benefit to individuals and society and follow ESRC's six ethical research principals (2020). This systematic review was granted ethical approval by the University of Chester FREC.

Results

The findings of the research illustrate that art therapy and artmaking have a significant part to play in supporting an individual's identity after a terminal diagnosis. The research also accords with previous studies demonstrating the benefits of

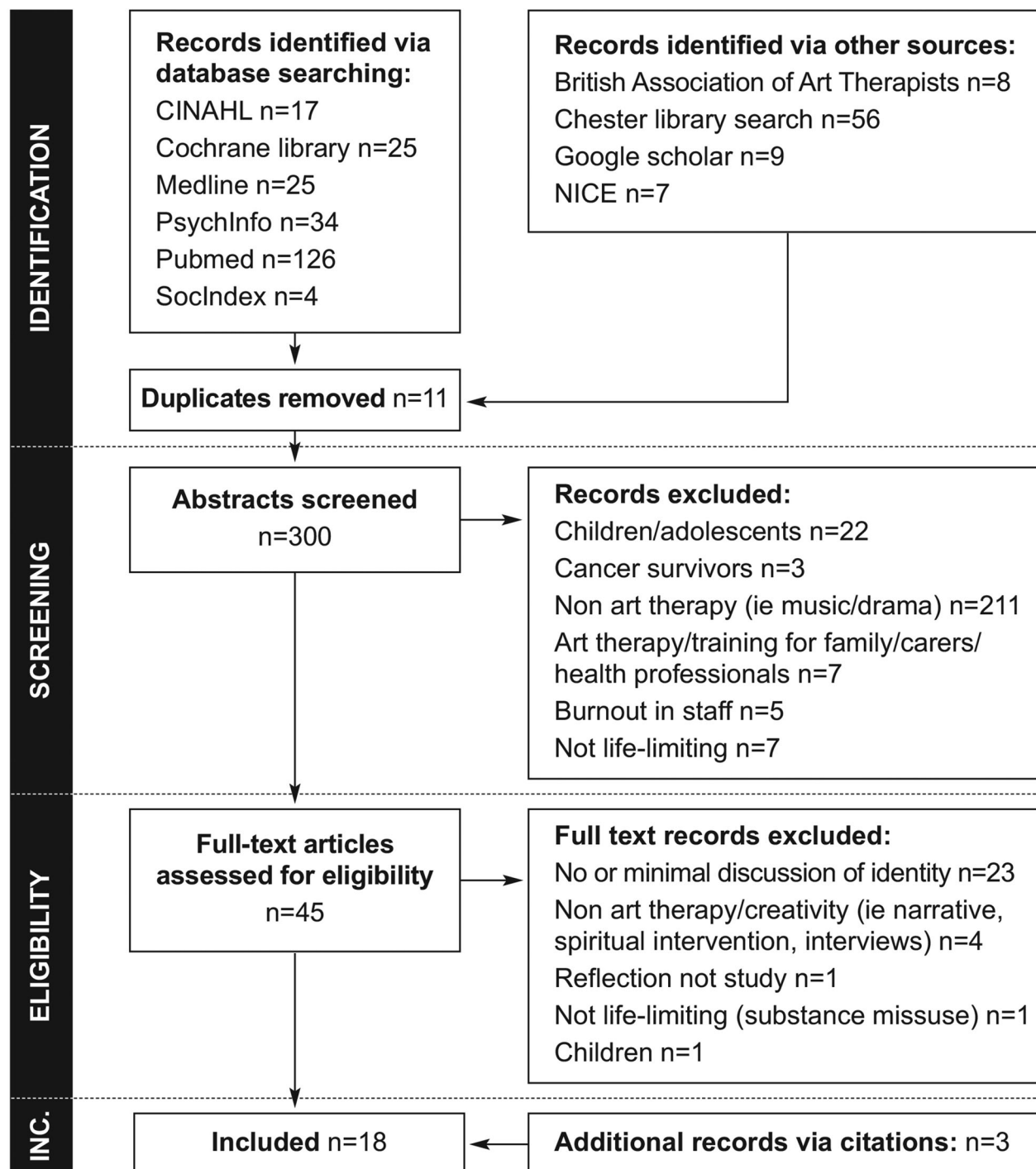


Figure 2. PRISMA diagram.

art therapy and artmaking for reducing physical pain and coping with anxiety and other psychological concerns at the end-of-life.

Only four papers from this systematic review's literature search *solely* explored the issue of identity, art therapy or artmaking and life-limiting illness. One of these is a literature review, two explore the role of artmaking with one paper focusing on art therapy using the 'third-hand technique' (Kramer, 1986), whereby the patient who is too ill to undertake artmaking, guides the art therapist to create the artwork. The remaining 14 papers found that art therapy or artmaking supported experience of self-identity as an additional outcome arising from the researchers' wider investigations.

After analysis of the selected studies, this systematic review has identified three distinct ways in which art therapy and artmaking appear to benefit terminally ill patients:

- **reconstruction of identity** – repairing or recreating the original pre-illness identity after damage or destruction.
- **maintenance of identity** – continuing to preserve or upkeep the original pre-illness identity, and
- **transformation of identity** – altering the pre-illness identity, in a positive and constructive way.

There is some overlap in the scope of each paper's findings, whereby some research details more than one of the three types of support, Figure 4 seeks to clarify these overlaps.

	Assouline (2009) ¹	Buday (2013)	Carr (2014)	Carr & Hancock (2017)	Collie et al. (2006)	la Cour et al. (2005)	Oster et al. (2007)	Oster et al. (2009)	Reynolds (2003)	Reynolds et al. (2008)	Reynolds & Lim (2007a)	Reynolds & Lim (2007b)	Reynolds & Prior (2003)	Reynolds & Prior (2006)	Safrai (2013)	Sutherland (1999)	Tjasink (2010)	Zammit (2001)
Adult participants	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Clear aims of research	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Appropriate recruitment	-	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
² Appropriate sample	+	+	+	+	+	+	3	3	+	+	+	+	+	+	+	+	+	4
Appropriate design	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Art therapy intervention	+	+	+	+	+	-	+	+	-	-	-	-	-	-	+	+	+	-
Artmaking intervention	-	-	-	-	+	+	-	-	+	+	+	+	+	+	-	-	-	+
Support of identity	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Setting of data collection stated	-	+	+	+	-	+	+	+	+	-	-	+	+	-	+	+	+	-
Ethics discussed	-	-	+	+	+	-	+	+	+	+	+	+	+	+	-	-	-	+
Consent discussed	-	-	+	+	+	-	+	+	+	+	+	+	+	+	-	-	-	+
Statement of findings	-	+	+	+	+	+	+	+	+	+	+	+	+	+	-	-	+	+
Limits considered	-	+	+	+	+	+	-	-	+	+	+	+	+	+	-	-	-	-
Total score (max 13)	6	9	12	12	12	10	10	10	12	11	11	12	12	11	8	8	9	10

Notes:¹ MA research paper.² Requirement that participants had a life-limiting diagnosis.³ Research did not state what stage the women's cancer was at, i.e. if it was terminal.⁴ Artwork was made when the patient was given a terminal diagnosis, however the patient was later diagnosed as cancer free.**Figure 3.** Selection criteria checklist.**Reconstruction**

Eight papers related to reconstruction of identity: Carr (2014), Carr and Hancock (2017), la Cour et al. (2005), Tjasink (2010), Reynolds (2003), Reynolds and Lim (2007a, 2007b), Reynolds and Prior (2003). These papers focus on patients who have been adversely affected by their illness, losing their identity and how they view themselves in the process. These patients have then utilised art therapy or artmaking to refocus and reconstruct their pre-illness identity. Art therapy has the additional benefit over artmaking of the therapist witnessing the artwork and helping the patient to reflect on the meanings of this with regards to their pre-illness identity. In this

way the art therapist can aid the patient in reaffirming themselves (Carr & Hancock, 2017).

These research papers indicate that loss of identity is often accompanied by an inability to remember how one was before illness, particularly the positive elements of identity. Carr (2014) reveals that patients frequently declare, 'I don't know who I am anymore' (p. 54) and explains that her portraits of patients help them to revise and reconstruct aspects of their identity and build 'a stronger, more coherent sense of self-identity' (p. 57).

In her 2014 research, Carr utilises the collaborative process of the 'third hand technique' with 'Paul' who has Chronic Obstructive Pulmonary Disease (COPD) and

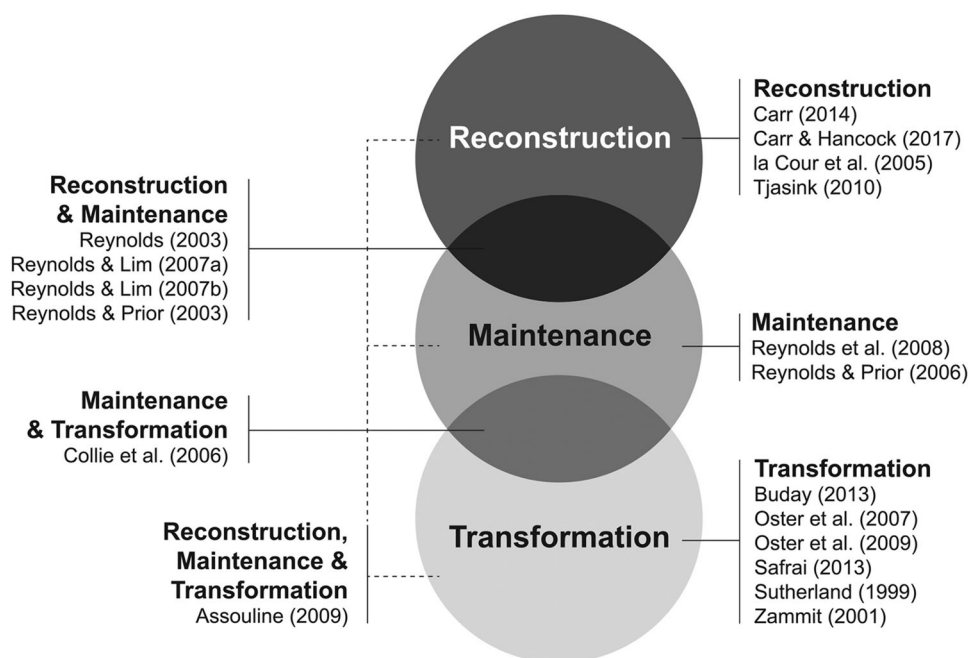


Figure 4. Diagram to illustrate overlap of findings.

is close to death. Due to his ill-health Paul has returned to live – and be looked after – by his mother; he is emaciated and dependent upon oxygen. Paul does not recognise himself or relate to his pre-illness identity and Carr suggests that Paul's visual perception has been distorted by the trauma and stress of his illness, as there is '... a profound mismatch between ... cognitive understanding ... and ... perceived body-image' (p. 54). Paul directs Carr to create a number of self-portraits of himself. One painting depicts Paul as a very sick and underweight man; he asked Carr, 'am I really that thin?' (p. 61), indicating that he was unaware of his own poor physical state. This portrait allowed Paul to see himself through another's eyes and to be aware of how fragile he had become. Carr noted that after this portrait was completed, Paul took better care of care of himself and began to eat more.

Another image depicts Paul as he remembers himself pre-illness, giving him an identity to remember and reconstruct. After seeing the portrait Paul began to socialise again after months of self-imposed confinement. The art therapy intervention – with the therapeutic relationship between therapist and patient – provided proof to Paul that he was valued and important which helped him reconstruct positive aspects of his identity that he had forgotten.

When coping with a terminal illness, it can be difficult for patients to see positives in their lives, particularly in relation to themselves. Refocusing on the past and telling stories of pre-illness via artwork acts as a reaffirmation of identity. The art therapist can encourage the patient to look at these images and acknowledge the positive aspects of self that still exist (Carr & Hancock, 2017; Tjasink, 2010). Artmaking can facilitate a remembrance of a life that has been full and complete, enhancing self-worth and allowing some reconstruction of this pre-illness identity.

Loss of roles has a major impact on a patient's identity. Art therapy helps maintain an individual's roles from pre-illness, it can also be helpful in reconstructing these. For example, Reynolds and Lim (2007a) suggest that creating artwork enabled participants to become '... reconnected with a familiar self-

image as an effective, capable person' (p. 4). One participant, 'Marie', who had taken early retirement due to her illness, stated that her artmaking provided her with intellectual development and challenge similar to that she had enjoyed in her career (Reynolds & Lim, 2007b). la Cour et al. (2005) concur with this view, suggesting that artmaking reaffirms a patient's sense of self, may help to reconstruct their roles in life and can aid '... acts of defining and reconstructing ... [to] take place' (p. 108).

The research for this systematic review suggests that an initial breakdown of identity is common after a terminal diagnosis due to shock, stress and uncertainty. Patients report that after this initial phase of chaos, artmaking has enabled them to reconstruct important elements of their pre-illness identity such as being busy, active, useful and pro-active individuals (Carr, 2014; Reynolds, 2003; Reynolds & Lim, 2007b). Artmaking enabled patients to find resilience in the face of adversity by offering new opportunities, adaptability and embracing of positive growth (Reynolds & Lim, 2007a). Importantly artmaking allowed patients to once again feel capable of doing something well and successfully, their artwork being physical evidence of this (Reynolds & Lim, 2007a).

Many patients who are coping with a life-limiting illness become overwhelmed and struggle with personal agency as illness takes over their life. Much of their time may be spent in hospitals, undergoing unpleasant medical interventions, they may feel they are losing their lives, their sense of self and identity. With this in mind, Tjasink (2010) describes a single session with 'Steven' who was feeling that his sense of self had been destroyed. Steven describes being unable to communicate with his wife about this loss of identity and how this made him feel abandoned and alone. The resulting art therapy intervention enabled Steven to recognise how these feelings were affecting him and his artwork facilitated communication between him and his wife. Similarly, la Cour et al. (2005), describe how creative activity can hold the potential for patients to reconstruct attachments with others and remember past identities that can be

Table 1. Data extraction.

AUTHOR	TITLE	AIMS	SAMPLE
Assouline. (2009). Canada. R/M/T	<i>Uncovering identity within the experience of chronic illness: Art therapy and integration</i>	To explore how individuals with chronic illness use art therapy to discover their identity.	
Buday. (2013). USA. T	<i>Engage, empower, and enlighten: Art therapy and image making in hospice care</i>	To document the potential benefits of art therapy within a hospice.	(n = 1)
Carr. (2014). UK. R	<i>Revisioning self-identity: The role of portraits, neuroscience and the art therapist's 'third hand'</i>	To evaluate the process of identity revisioning by using the art therapist's 'third hand' to paint portraits of patients with life-limiting illnesses.	(n = 1)
Carr and Hancock (2017). UK. R	<i>Healing the inner child through portrait therapy: Illness, identity and childhood trauma</i>	To explore how portrait therapy can help patients live with life-threatening illnesses after childhood trauma.	(n = 1)
Collie et al. (2006). USA. M/T	<i>A narrative view of art therapy and artmaking by women with breast cancer</i>	To understand how women with breast cancer use art therapy and art making.	(n = 17)
la Cour et al. (2005). Sweden. R	<i>Creating connections to life during life-threatening illness: Creative activity experienced by elderly people and occupational therapists</i>	To discover the benefits of creative activities for elderly people with life-threatening illnesses.	(n = 15)
Öster et al. (2007). Sweden. T	<i>Art therapy for women with breast cancer: The therapeutic consequences of boundary strengthening</i>	To explore how art therapy may improve breast cancer patients access to beneficial interpretive repertoires.	(n = 42)
Öster et al. (2009). Sweden. T	<i>Women with breast cancer and gendered limits and boundaries: Art therapy as a 'safe space' for enacting alternative subject positions</i>	To understand how women with breast cancer used art therapy to give meaning to gendered limits and boundaries.	(n = 42)
Reynolds. (2003). UK. R/M	<i>Reclaiming a positive identity in chronic illness through artistic occupation</i>	To explore the role of artistic occupation in the process of reconstructing and reclaiming identity in illness.	(n = 10)
Reynolds et al. (2008). UK. M	<i>Images of resistance: A qualitative enquiry into the meanings of personal artwork for women living with cancer</i>	To explore the significance of self-directed artwork for women living with cancer.	(n = 12)
Reynolds and Lim (2007b). UK. R/M	<i>Turning to art as a positive way of living with cancer: A qualitative study of personal motives and contextual influences</i>	To discover why some women turn to artmaking after a cancer diagnosis.	(n = 11)
Reynolds and Lim (2007a). UK. R/M	<i>Contribution of visual artmaking to the subjective well-being of women living with cancer: A qualitative study</i>	To explore how visual artmaking contributes to the subjective well-being of women living with cancer.	(n = 12)
Reynolds and Prior (2003). UK. R/M	<i>'A lifestyle coat-hanger': A phenomenological study of the meanings of artwork for women coping with chronic illness and disability</i>	To explore the meanings and functions of art for women living with illness.	(n = 35)
Reynolds and Prior (2006). UK. M	<i>The role of artmaking in identity maintenance: Case studies of people living with cancer</i>	To understand why individuals turn to artmaking after a cancer diagnosis and to discover how artmaking supports identity maintenance/ reconstruction after a cancer diagnosis.	(n = 3)
Safrai. (2013). USA. T	<i>Art therapy in hospice: A catalyst for insight and healing</i>	To illustrate how art therapy assists a hospice patient.	(n = 1)
Sutherland. (1999). USA. T	<i>Art therapy with a woman who has multiple medical conditions</i>	To illustrate how art therapy supports a patient with multiple medical conditions.	(n = 1)
Tjasink. (2010). UK. R	<i>Art psychotherapy in medical oncology: A search for meaning</i>	To explain the role of an art psychotherapist on an oncology ward.	(n = 3)
Zammit. (2001). Australia. T	<i>The art of healing: A journey through cancer: Implications for art therapy</i>	To examine how art assists an individual suffering from a life-threatening illness.	(n = 1)

KEY: R = Reconstruction, M = Maintenance, T = Transformation.

Design: All papers were qualitative.

brought to the fore to assist with the current challenges of ill-health.

There are many examples of patients using an art therapy or artmaking intervention during these times of crisis to help come to terms with their feelings and reconnect or re-establishing important relationships (Tjasink, 2010). Tjasink describes how patients use the art materials in their therapy sessions to vent their anger, frustration and sorrow at their current situation. Artmaking or even scrawling, slashing and scratching in a safe, therapeutic environment can help acknowledge and release negative emotions, which in turn may permit patients to make constructive changes or reconstructions in their lives: 'art psychotherapy ... provides an opportunity for people to renegotiate their values and identity and to make changes ...' (Tjasink, 2010, p. 79).

Maintenance

Seven of the research papers' findings relate to maintenance of the identity: Collie et al., 2006; Reynolds, 2003; Reynolds & Lim, 2007a, 2007b; Reynolds et al., 2008; Reynolds & Prior, 2003, 2006. All but two of the nine artmaking research papers are included in this category. These papers focus on the opinion that an individual's identity, while continually altering and adapting, has some consistency across time. Reynolds et al. (2008) and Reynolds and Prior (2006) concur that adaption to illness is in part helped by the retention of that core identity and the artmaking that supports it.

Patients who fit into the theme of *maintaining* identity, appear to create artwork unrelated to their diagnosis. Instead, the themes of the artwork '... reflected the interests, traits and careers that typified participants prior to illness ...'

(Reynolds et al., 2008, p. 216). The large majority of participants in this category had to leave jobs or retire early from their careers due to failing health (Collie et al., 2006; Reynolds, 2003). Artmaking enabled patients to fill these occupational voids as illustrated by a patient in Reynolds (2003) study who had been a geography teacher before she received a life-limiting diagnosis. Her artwork continued to focus on geographic forms. Similarly, 'Jessica' maintained her pre-cancer role as a teacher after her diagnosis, when she mastered cross-stitching enough to begin teaching others the craft (Reynolds & Prior, 2006).

When illness disrupts a life, it often creates a loss of roles. Artmaking can be used to maintain these familiar roles and allow the patient to continue to view themselves as a whole person. 'David' whose defining pre-illness roles of father and gardener were under threat due to his illness, began textile artmaking after a terminal diagnosis. Exercise and heavy lifting became unmanageable for David and made it impossible for him to continue to garden or take his children walking or swimming. However, he maintained his identity as a gardener and father by creating botanically inspired textile art for his children: 'art seemed to preserve continuity in David's identity' (Reynolds & Prior, 2006, p. 338). Reynolds and Prior (2006) suggest that artmaking '... can be understood to have a powerful role in maintaining a familiar, positive identity in cancer' (p. 333).

Making artwork seems to be a way to either divert attention from a terminal illness or gives the patient control to limit the attention it is paid. For example, 'Joyce' did not wish to be defined by her cancer and did not tell people she had a terminal diagnosis. She preferred to be known for her artistic skills and what she could, rather than could not, do (Reynolds & Prior, 2006). Similarly, Jessica discovered that her artmaking gave her an interest to talk about which diverted the attention from her diagnosis, allowing her to be '... more than a cancer patient' (Reynolds & Prior, 2006, p. 337). Another participant also describes artmaking as an interest that she shared with others that had nothing to do with her cancer; it helped to '... maintain a familiar noncancer identity' (Reynolds et al., 2008, p. 211).

Many patients maintained their identities by joining or rejoining groups where the participants shared interests, values and ideas. Forming or reforming these social relationships helped to maintain the terminally ill individuals' identity as part of that group. For example, Jessica found fulfillment through her cross stitching, which enabling her to engage in a wider social world, her '... artistic occupations appeared to provide her with normal social roles' (Reynolds & Prior, 2006, p. 337).

Other participants' artwork revived interests or memories from childhood which maintained family traditions. Reynolds (2003) suggests that 'identity... was associated partly with maintaining a strong sense of connection to the past' (p. 126) and that using traditional skills that have been learned from older family members can help maintain social and personal continuity. One breast cancer patient very explicitly stated that her artmaking created a bridge between herself before and after her cancer diagnosis. This enabled her to retain an element of continuity during the changes to her health and roles in life (Reynolds et al., 2008).

Reynolds et al. (2008) note that many patients expressed a need to reciprocate the care they had been shown by others. There is great value in being able to give handmade artwork

as a gift, and this enabled the participant's status to be restored to that of an individual person, rather than an ill person. Gift-giving also served to maintain the patients' roles as caring, creative beings, 'the act of giving also contributed to maintaining ... the status of the person with cancer' (Reynolds et al., 2008, p. 7) and '... the women were able to retain a view of self as a wife, mother, or friend who continued to reciprocate care, rather than being defined solely as a care-recipient' (Reynolds & Lim, 2007b, p. 69).

Transformation

Seven of the papers suggest a transformation or complete change of identity via art therapy and artmaking. Interestingly, of the six papers that explore their research through individual case studies, four of these fall into this category of transformation: Buday (2013), Safrai (2013), Sutherland (1999), Zammit (2001).

The effects of illness, even a life-limiting one, are not always negative and some patients report positive aspects that have changed their identity (Assouline, 2009; Collie et al., 2006). Reynolds and Prior (2006), suggest that a terminal diagnosis can lead to an epiphany of sorts where radical re-appraisals of life, identity, relationships and goals may take place. Reynolds and Prior (2006) propose that undertaking creative work after a life-limiting diagnosis can act as a wakeup call, enabling changes to patterns of unwanted behaviour and enabling a positive transformation of identity. For example 'Sarah's' artmaking '... cleared the way emotionally' and enabled her to '... forge a new path that will let breast cancer be a positive part of her life' (Collie et al., 2006, p. 771).

The four case studies detailed under this transformation theme describe how patients with terminal illnesses used art therapy and artmaking to facilitate their own personal epiphanies, leading to transformations of their lives and identities. When Maria, a doctor, was diagnosed with medically incurable cancer she '... did not consider herself an artist' (Zammit, 2001, p. 29). Maria decided to go against her own medical training and doctor's advice and to use meditation and artmaking to prepare herself for her impending death. Maria began to paint powerful images that were exhibited in a gallery, Zammit suggests that Maria '... transformed former conceptions of herself' (p. 34) from doctor to recognised artist. Maria began to identify with her own healing power via her artmaking and shortly after her exhibition discovered that she was cancer-free. Maria believed that artmaking had helped transform her from a patient with a medically incurable illness to someone without cancer.

The transition from an uncreative and ordinary pre-illness existence to identifying as an adventurous artist after an art therapy or artmaking intervention, appears common. 'Eli' is described as a very ordinary and predictable man pre-illness, describing his life as '... quiet and uneventful' (Safrai, 2013, p. 125). Art therapy enabled Eli to transform and start thinking in different and unpredictable ways. Safrai describes Eli as changing from being rigid, fearful, and unconfident, always needing to be safe, to taking risks, working with great confidence and assurance with a willingness to try new things.

Similarly 'June' (Buday, 2013) and 'Nancy' (Sutherland, 1999) both used art therapy to transform their identities. June's art therapy enabled a change from life-long insecurity

and isolation to '... wanting to be a part of life' and connecting with others by joining in social activities (Buday, 2013, p. 84). One of the goals of Nancy's art therapy was for her to find '... acceptance of her life and situation' (p. 84) and to help her come to terms with her wheelchair-bound existence and her terminal condition. Nancy's artwork included much figurative work including self-portraits but she '... never depicted herself in a wheelchair' (Sutherland, 1999, p. 90). The trusting and secure relationship with Sutherland, allowed Nancy to face her fears and transform her denial into acceptance of her changed identity when 'for the first time ... Nancy had painted herself in her wheelchair' (p. 97).

Öster et al.'s research (2007, 2009) focusses on boundaries, in particular creating space for one's own needs and recognising the physical, psychological and symbolic violations of these boundaries. The research suggests that art therapy played a part in transforming the female patients' emotional strength and greatly increased assertiveness in their roles in life. The physical act of drawing enabled female patients to become aware of issues or problems that they needed to change. This is highlighted by one patient's artwork, which depicted her aching shoulder. The patient came to the realisation that the pain had developed because she was continually looking after others. Subsequently she began protecting her boundaries and started to say 'no' to requests that depleted her limited energy. Her artwork was a link between somatic experience and her illness and gave her the strength to transform her behaviour and identity.

Öster et al. describe the challenge of transforming an identity from a lifetime of looking after others – such as children and husbands – to putting one's own needs first. This research suggests that these transformations had been enabled, in part, by an art therapy intervention which establishing an assertiveness and a '... newly gained personal strength' (Öster et al., 2009, p. 33). Art therapy enabled one patient to say '... I will never be the way I used to be ... I will learn to live, not just be there for others ...' (Öster et al., 2007, p. 283).

Discussion

The findings indicate that art therapy and artmaking can play a large part in the maintenance of an individual's identity. They also show that art therapy and artmaking can help individuals whose identities have been damaged by their diagnosis to re-focus and reconnect with their pre-illness selves. The findings have shown that art therapy and artmaking can help an individual transform their identity from pre-illness in positive ways.

The findings of this systematic review provide new insights into the differences between art therapy and artmaking interventions. Artmaking would appear to assist ongoing identity maintenance but was mostly not reported as supporting an identity transformation as an art therapy intervention can. The findings have shown that the act of simply being creative builds an identity that is separate from one's illness and can help patients continue to socialise regardless of their illness.

An art therapy intervention with its unique triangular relationship (Schaverien, 1999), appears to enable a deeper exploration of identity concerns and may, for some people facilitate an extensive identity transformation. Significantly, seven of the research studies detailed how art therapy

appeared to be beneficial in enabling this transformation, whereas only one artmaking intervention had this effect.

Research and literature have noted how 'the loss of self-identity ... was tied up with the loss of ... 'doing' and 'being' roles ...' (Carr, 2018, p. 94); the inability to fulfil one's specific roles in life due to the limitations of a life-limiting illness is an enormous assault to one's identity (Reynolds & Prior, 2006). Therefore, the importance of maintaining these familiar roles for patients with a terminal illness is important. The findings of this systematic review indicate that art therapy and artmaking can play a part in preserving a patient's roles in life.

Evans (2005) suggests that with a terminal illness, '... our status as persons has changed; we are alienated from the normal and the healthy, and now defined by the name of our illness' (p. 3). The findings of this systematic review suggest that both art therapy and artmaking can help a patient to view themselves as unique individuals rather than simply being labelled by their illness. These individuals can then continue with their interests and elements of their lives unrelated to illness.

Tjasink (2010) asserts that '... being poked, prodded and exposed to poisons or to radiation is often essential in oncology and can be deeply unpleasant, objectifying and dehumanizing' (p. 75). Tjasink advises that maintaining a strong identity can counteract some of these negative aspects of modern doctoring. The findings of this systematic review suggest that an art therapy intervention can work holistically alongside necessary medical interventions, while helping to fortify an identity.

Research with cancer patients in a hospital palliative care unit, carried out by Collette et al. (2021) and published after the completion of this systematic review's database searches, offers explanations as to how identity transformation may occur. Collette et al.'s research suggests that art therapy lessens the intensity of pain, thereby alleviating suffering, anxiety and depression, and increases wellbeing. This allowed participants a deeper understanding of self and a strengthening of identity.

Previous writing about art therapy indicates that the psychological trauma brought on by a terminal or life-limiting diagnosis may lead to a complete breakdown of identity and to patients having distorted and often unfavourable opinions of themselves (Carr, 2018; Connell, 1998). The findings of this systematic review indicate that patients can be offered an alternative view of themselves via the therapeutic relationship with the art therapist. This may enable the patient to revise their self-identity to be more positive (Carr, 2018). This is demonstrated by Carr's work with Paul and indicates how art therapy can be beneficial in ways that artmaking may not, due to the presence and 'witnessing' of the art therapist.

It is interesting to note that some patients – supported by an art therapy intervention – viewed their terminal diagnosis as an opportunity to make positive, transformative changes to their lives (Collie et al., 2006). It could be argued that their diagnosis had been a catalyst and art therapy strengthened their character and enabled these patients to focus their limited time on living an authentic, meaningful life.

As has been suggested, the rehabilitation of identity is of major importance after a terminal or life-limiting diagnosis: '... identity loss and reconstruction are recognised as key challenges ...' (Reynolds & Prior, 2006, p. 332). A thought-

provoking outcome of this systematic review is that patients at the end-of-life, despite having significant medical concerns, choose to spend their remaining time using art therapy or artmaking to reconstruct, maintain or transform their identities. It should be noted that this is often challenging and energy depleting work, at a time when the body is often already weak. The author would suggest therefore that identity consolidation, aided by art therapy or artmaking, is psychologically important, particularly at the end-of-life.

Further points of significance to this systematic review are that the patients participating in the research had a wide age range. The youngest participant was 23 years-old and the eldest 82 years-old. The individual diagnosis of each patient was very varied. These points suggest that art therapy and artmaking can be beneficial to a diverse range of illnesses and for adult patients of any age.

The author would suggest that the findings of this systematic review are important for a number of reasons. They show that art therapy and artmaking work alongside essential medical interventions. They also illustrate a new insight into the different benefits of, and differences between, art therapy and artmaking. Finally, no harm or negative consequences of either intervention were reported.

Limitations

The author selected the papers without independent checking from another colleague. The author is aware that as a white, middle-class female of middle-age with an involvement in hospice art therapy there is a possibility that the neutrality and analysis of the research may be affected. Additionally, this paper is limited to the strengths and weaknesses of the PRISMA and PICO guidelines used. However, the author is satisfied that adherence to research guidelines, selection and analysis in line with the stated aims and objectives has been achieved and this will counteract any unintended biases (Bettany-Saltikov, 2012).

The major limitation of this systematic review is that all selected research had a small number of participants involved. Even the largest studies had only 42 participants, while six of the research papers were individual case studies. In addition to limited numbers of participants, all the research papers have a large predominance of female participants. There were only eight male participants. Furthermore, all female participants were principally well-educated, middle-class and of white ethnicity. In addition, there were no control groups in any of the studies.

Further limitations are that Reynolds wrote six of the research papers. Reynolds also advertised for participants in UK craft magazines, craft websites and adult education centres holding craft classes. It could be argued that the participants in these studies already had an interest in the benefits of artmaking and other participants were excluded from the studies.

Some studies were undertaken with patients at hospices and hospitals where the art therapist researcher was employed. It could be argued that these studies may be motivated to identify art therapy as a beneficial intervention for patients with a terminal diagnosis. Similarly, it may also have benefitted researchers to use purposefully selected patients who allowed for certain findings or data to be highlighted.

No quantitative measures were reported, and papers were of variable quality. It is also important to note that academic research focusses more heavily on art therapy and perhaps does not justly capture the benefits of artmaking alone.

Finally, due to the search strategy requiring that research be available in English, there is a European and North American bias to the papers included. It is possible that different conclusions may have been drawn from research papers written in other languages.

Notwithstanding these limitations, the author is satisfied that the findings of this systematic review offer valuable insights into how art therapy or artmaking can benefit a terminally ill patient coping with identity concerns.

Conclusions

As the studies in this systematic review generally researched art therapy and artmaking with white, middle-class, financially secure females, further research is needed to establish the outcomes for a wider and more diverse ethnic, socio-economic population and additional research involving male patients is recommended. Future studies should be undertaken with larger numbers of participants in order for results to be extrapolated further.

This systematic review confirms previous, but limited research on the benefits of the interventions and has indicated that identity concerns are major challenges for patients after a terminal diagnosis. This research has shown how art therapy and artmaking may play a '... powerful role in maintaining a familiar, positive identity.' (Reynolds & Prior, 2006, p. 333). It has also illustrated that art therapy and artmaking can offer a beneficial intervention for the reconstruction, maintenance and transformation of identity whilst also working alongside conventional medicine. This paper has indicated how art therapy in particular counteracts the psychological identity damage that a terminal illness can create, and this could have wide ranging benefits for all terminal patients and healthcare providers. The author suggests this review may give healthcare staff an opportunity to re-evaluate the importance and versatility of art therapy.

The author would recommend that art therapy be offered as a standard early-intervention for all patients at the diagnosis of a life-limiting illness. Similarly, there should be provision for more opportunities for personally meaningful creative activities as well. These steps would allow patients who are already coping with physical pain to be offered psychological support via art therapy to work on identity concerns caused by their illness.

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Notes on contributor

Holly Dyer completed her Art Therapy MA at the University of Chester in May 2022. Her first degree was in Graphic Design from the University of Brighton. Holly completed her MA placement with patients at the Severn Hospice in Telford. Holly focussed on art therapy within palliative care

throughout her MA and after qualification has been employed as an art therapist at the Severn Hospice.

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