

Title: Enabling Self-Identity Revisioning through Portraiture, for people living with Life Threatening and Chronic Illnesses: *Paint me this way!*

Doctoral Thesis

By Susan M. D. Carr ©

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Figure 1. *Bohemian Rhapsody*, by Susan Carr, 2011 (co-designed by Rose).

The healing power of art is not a rhetorical fantasy ... I know no pain that art cannot assuage ... [it] cuts through noise and hurt, opens the wound to clean it, and then gradually teaches it to heal itself. (Winterson 1995: 156-7).

Publications to date arising from this PhD project:

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<http://spcare.bmj.com/content/1/2/236.1.full.pdf+html?sid=b4b81475-1720-4ede-b83e-0e01fb0ef10e>

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Now the portraits must 'go and do their work' ... as Pinknola Estes once said 'art is not just for oneself, not just a marker of one's own understanding. It is also a map for those who follow after us' (1992:13).

Susan Carr
October 2014

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Acronyms & Definitions

I have reduced several words to acronyms throughout this thesis; these will be shortened after initial usage:

PR or PRs = Patient-Researcher or Patient-Researchers

ATR = Artist-Therapist-Researcher

LT&CIs = Life Threatening & Chronic Illnesses

EPI = End of Project Interview

ADS= Active Documentation Sketchbook

For ease of reference a reminder of these acronyms appear in the footer of each page.

I refer to participants in this project as ‘patient-researchers’ (PRs) so that their presence as co-researchers in the project is honoured, and to remind myself that their state of health is compromised and their time is precious. Reference may occasionally be made to participants, clients and patients within this thesis in order to aid understanding and context. I refer to myself as an artist/therapist/researcher (ATR), these terms serve to remind me of the dual and triadic roles which the PRs and I adopt within this study. For simplicity I refer to a person’s sense of self and identity as ‘self-identity’.

Within this thesis the term *revisioning* (Carr 2014), acknowledges the double hermeneutic involved in phenomenological interpretation, and relates this to the act of re-interpreting [painting] the ‘vision’ [the co-designed self-image] PRs wish me to portray within their portraits.

Within the analysis section I use coloured boxes to indicate specific types of ‘essence statements’. These are:

<i>Statement of Emergent Knowing</i>
<i>Statement of Emergent Learning</i>
<i>Statement of Reflexive Resonance</i>
<i>Statement of Intention</i>
<i>Prose Poems</i>

Abstract

Title: Enabling Identity Revisioning through Portraiture, for people living with life threatening and chronic illnesses: *Paint me this way!*

Arguably life threatening and chronic illness is not just an attack on the body, it is an attack on a person's sense of self-identity, shattering the means by which a person experiences the world, and by which they also are experienced, contributing to a person's sense of powerlessness and distress. People living with a life threatening or chronic illness, often describe the impact of their diagnosis, treatment and illness as having changed their sense of self-identity beyond all recognition. Seven participants, purposefully selected from those attending a weekly day-hospice session in Wiltshire, took part in the study. This qualitative, practice-based research project challenges the power dynamics in art therapy and attempts to equalise the relationship between researcher and participant through the development of a collaborative intersubjective relationship, within which the participants are recognised as 'experts' on their lived experience, and in a series of 'negotiations', co-design their own portraits directing how they wish to be portrayed. Through this process the 'participants' become 'patient/researchers' (PRs) and the 'artist/therapist/researcher' (ATR), by creating the portraits, also becomes a reflexive 'participant'. This project utilises an in-depth multiple case-study design and multiple creative data generation methods as well as a phenomenological approach to data analysis. This project reverses the terms of engagement within art therapy and uses the art therapist's artistic practice or 'third hand' to create portraits *for* patients. (This is based upon the assumption that most art therapy theories' terms of engagement include patients producing art within the therapeutic encounter, however some psychodynamic and psychoanalytic art therapists may use client art generation selectively or not at all). This raises important questions around 'who makes the artwork in art therapy interventions'. The use of portraiture as a 'third hand' intervention enables the art therapist to develop a sense of *positive focussed attention* and *mirroring and attunement* through the art object, enabling the addition of *coherence* through *aesthetic resonance* and the 'holding' of dualities through metaphor and symbolism. The results of this study demonstrate the power of portraiture as an intersubjective way of *knowing, being* and *relating*, enabling the *revisioning* of identities disrupted by illness, characterised by increases in participants' *creative capacity to adapt to illness* and feelings of *home-like-being-*

in-the-world, developing a *stronger*, more *coherent* lived experience of self-identity, effecting closure to difficult life experiences, and improving their overall quality of life.

The Prequel: Eileen's Legacy

If we start from the idea that creating knowledge is a practical affair, we will start not, as in traditional academic research, from an interesting theoretical question, but from what concerns us in practice, from the presenting issues in our lives (Reason 2006: 188).

This research project grew out of a growing recognition and concern for the perceived disruptions to self-identity that many of the patients at the day-hospice where I work as an art therapist talk about on a daily basis. This profound sense of loss is made manifest in statements such as 'I don't know who I am anymore, I'm not the person I used to be' and 'I look in the mirror and I think "who's that?"...' It also grew out of my art therapy work with a patient attending the day-hospice, called Eileen. Eileen was an 82-year-old lady, diagnosed with terminal cancer and severe osteoarthritis; she lived with her husband and her disabled daughter, who was her only child. One day Eileen brought an old photograph album into the day-hospice and through the photographs told me the story of her life, a life dedicated to looking after her husband and disabled daughter. One particular photograph was of herself as a ten year old child (see Figure 2) and this tiny photograph resonated with me.



Figure 2. *Eileen Aged 10 years.*

It had clearly been taken in an early ‘photo booth’ and I was struck by the innocent beauty in this young face. The dress Eileen was wearing was significant, as it had been Eileen’s Christmas present that year. Due to financial constraints Eileen had been asked to choose between a toy or a dress for her present and she chose the dress; made from pale green ‘floaty’ silk. The resonance I felt for this photograph was a recognition of the transitional moment between childhood and young-adulthood captured within it, where Eileen had chosen the ‘adult’ *dress* over the ‘childish’ *toy*. I asked if I could photocopy the photograph to use as reference for a portrait. Eileen seemed genuinely pleased and excited at the idea, her only reservation being that it might be better if I painted *her daughter* instead of her, however I assured her that her daughter would have a ‘presence’ of some sort within the portrait. Over several weeks we co-designed the portrait together, and I took in photographs of the portraits progression to discuss with Eileen. Eileen selected photographs of significant events in her life, including ones featuring her daughter, to be painted as if pinned to the wall behind her. This process of collaboration meant that our therapeutic relationship became very close, and Eileen trusted me with many of her fears and anxieties around her illness. As the weeks progressed, Eileen’s health deteriorated and she was admitted to the hospice inpatient unit. Fearing she would die without seeing the finished painting, I took it in to show her (see Figure 3), and even in its unfinished state her delight was obvious. “Oh” she said ... “you have painted me beautiful! ... I love it!” “You were a beautiful child” I said. “Well!” she said “I never knew that! I’ve lived for 82 years and I never knew that!”



Figure 3. *Eileen* by Susan Carr 2009.

Reflecting upon this conversation I realised that through the portrait and mirroring and attuning the ‘beauty’ I had seen – a connection had formed for Eileen with something previously *unknown* about herself. Eileen’s ‘love’ for this painting also reawakened a love for her ‘self’ as a vulnerable child, something she had become again through her illness, needing the constant care and support of others as she lay dying. Eventually Eileen slipped into a coma, and it struck me that even as I was painting her transitional moment from childhood to young adulthood, so Eileen had slipped into a transitional space between life and death.

The painting has been left unfinished since Eileen died, acknowledging the unfinished business that death brings, and in a way it seemed that it had fulfilled its purpose. However, this experience of co-designing *with* and painting a portrait *for* a patient was the main genesis for this project.

I was also inspired to use Edith Kramer’s (1971) ‘third hand’ art therapy model within this project by a patient called Hugh, who attended the day-hospice several years ago. Hugh was living with Motor Neuron Disease (MND) and had become so severely disabled, that he was virtually ‘locked’ within his own body, unable to speak or move, and it was difficult to see what benefit he gained from attending the day-hospice. I felt frustrated that I was unable to offer Hugh an accessible art therapy intervention. In an interview printed in a hospice brochure, Hugh reflected upon his fundamental need to reciprocate, and an understanding of how the physical embodiment of his illness could be used to help others when all other function had been lost, he said ... “If I can go to day-hospice and by my presence and by my own lack of function, make the other patients feel better about themselves, then I have achieved something”.



Figure 4. *Hugh*
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This project therefore acknowledges Eileen and Hugh and all the other patients at the day-hospice who helped in the developmental stages of this project, by attending focus groups and sharing their stories of self-identity disruption, knowing that it would be *others*, not themselves who would benefit from this project.

1.0 Chapter 1. Introduction: A phenomenological approach to revisioning self-identity through portraiture, ‘paint me this way!’

This qualitative, practice-based, phenomenological study reverses the terms of engagement within art therapy and uses the art therapist’s artistic practice to create portraits *for* patients. Within this project I have utilised an in-depth multiple case study design and multiple creative data generation methods, as well as a phenomenological approach to data analysis. Seven participants, purposefully selected from those attending a weekly day-hospice session in Wiltshire, took part in the study. This project attempted to equalise the relationship between researcher and participant through the development of a collaborative intersubjective relationship within which the participants, in a series of negotiations, co-design their own portraits directing how they wish to be portrayed. Through this process the ‘participants’ become ‘researchers’ and the ‘artist/researcher’, by creating the portraits, also becomes a reflexive ‘participant’.



Figure 5. *Carry Me This Way* by Michele Angelo Petrone, 1994.

The collaborative intersubjective approach within this study is captured within this painting (see Figure 5 above), which demonstrates the control and agency that I hope will be enabled within the PRs, as I become a ‘brush for their (self-) portraits’ (Pachter 2008). This acknowledges that the core experiences of trauma (van der Kolk

1987, 1988, 2003) are a sense of disconnection, disempowerment and disorientation. This project therefore seeks to go some way towards redressing this balance. As Judith Herman says (1992: 133) ‘the first principle of recovery is the empowerment of the survivor. She must be the author of her own recovery. Others may offer advice, support, assistance, affection and care, but not cure’. This, therefore is the foundation for the collaborative and intersubjective relationship, ‘*paint me this way!*’

Revisioning within this intervention focuses on a *creative* and *imaginative* visual process integrating aspects of past, present and future self-identities rather than a retrospective attempt to return to a pre-existing sense of self-identity. Through utilising compelling imagery art therapy can convey powerful messages that highlight the ‘universality and timelessness’ of an individuals suffering, as well as mediating between this and ‘collective suffering’, in order to bring about social action and change (Hocoy 2007: 22). In contrast behavioural and clinical science has ‘no category to describe suffering, no routine way of recording this most thickly human dimension of patients’ and families’ stories of experiencing illness’ (Kleinman 1988: 28). The co-designing process and viewing of the portraits provides a unique way of looking at the phenomena of disrupted self-identity and embodiment, enabling PRs to see themselves through the eyes of an empathic and attuning ‘other’.

This project was designed to enable the combination of multiple and disparate data collection methods, in order to reveal new kinds of knowledge, about how portraits help to re-vision self-identity, through the shifting of emphasis from narrative to visual forms, and a focus on the PRs lived experience of being painted.

In the prequel I acknowledged my initial interest in the field of portraiture as therapy, and I now briefly introduce the concepts of self-identity, self-identity disruption and the main philosophical and theoretical concepts used within this study in order to place the project within the social context. I also outline the various calls for research in this area as a way to situate this project within the fields of palliative care and art therapy.

1.1 Research questions

The central research question I address in this thesis is:

What role does portraiture play in enabling people living with life threatening and chronic illnesses (LT&CIs), who experience illness as a disruption to their self-identity, to develop a stronger, more coherent sense of self-identity and increase their quality of life?

This question can be broken down into further subordinate questions that I hope to explicate through this project:

- What are the PRs lived experiences of portraiture as a ‘third hand’ art therapy intervention?
- What role does *mirroring and attunement*, reflected within the portraits play in the process of *revisoning* self-identities?
- What role do portraits play in enabling meaning making and the exploration of existential questions around ‘being-towards-death’?
- What are the PRs experiences of the collaborative nature of this project?

As this is a phenomenological study, influenced by the work of existential phenomenologists (Heidegger (1962 [1927]) and Merleau-Ponty (2002 [1945])), I seek to answer these questions through the description and reduction to ‘essences’ of the PRs lived experiences of the intervention, using the portraits (and other artefacts), and the PRs voices through the use of verbatim extracts from their end of project interviews (EPI), to describe the collaboratively negotiated meanings. This study also includes a hermeneutic phenomenological aspect (Linesch 1994) in that it brackets back in collaboratively negotiated meanings and interpretations, in order to make sense of the data and explicate epistemological implications.

1.2 Aims and Objectives of the Study

The broad aims of this study includes gathering detailed description of PRs lived experience of co-designing and being portrayed in portraits, designed as an inclusive intervention to alleviate self-identity disruption, with a view to informing, extending and improving knowledge, policy and practice within art therapy and palliative care and increasing PRs quality of life. The aim is to develop a protocol for this intervention, allowing it to be replicated in clinical settings and other research projects.

My aims therefore include describing and extending knowledge about the following phenomena:

- Portraiture and the collaborative intersubjective design process.
- Portraiture as a ‘third hand’ mirroring and attuning art therapy intervention.
- The impact of LT&CIs on self-identity and changed ‘being-in-the-world’ experience.
- Phenomenology as an approach to explicate the lived experience of people living with LT&CIs.

My aims in relation to theory building within art therapy and palliative care, relate specifically to the art therapy models of ‘mirroring and attunement’ (Wright 2009) and the art therapist’s ‘third hand’ (Kramer 1971), and the development of *portrait therapy* (Carr 2014), and include questioning the taken-for-granted normalised assumptions regarding:

- Who makes the artwork in art therapy?
- The universal requirement for confidentiality irrespective of context.
- The interpretation of images based on the client’s unconscious drives and processes.
- The patient/expert divide.
- The *dys*-engagement with aesthetics as a healing force.

My therapeutic objectives included the development of an authentic intersubjective collaborative relationship with the PRs, empowering them to describe images and stories of self-identity, and enabling PRs voices to be *heard* and their sense of self-identity to be *recognised* and *acknowledged*. This is linked to another key objective that includes the creation of a safe and creative space within which PRs co-design the portraits, collage and prose poems.

My artistic objectives were to capture the essence of the PRs experience of self-identity through painting the portraits, making collages and writing prose poems and using these as a mirror within which to attune PRs self-evoking or self-changing stories of self-identity.

My objectives as a researcher/artist were to: describe the PRs lived experience of portraiture as a 'third hand' technique: to paint/create portraits (at least 3) and a series of collages and prose poems (at least 10) for each PR: and to reflexively self-reflect on this artistic practice.

1.3 Calls for further research in the fields of Art Therapy and LT&CIs

There have been recent calls within the art therapy literature and cancer care for more research studies to support 'art therapy's contribution to cancer survivorship' (Wood *et al.* 2011: 144) and a wider call for more research into art therapy practice in order to raise the empirical profile of art therapy and the role of the arts in health and illness in general (Waller & Sibbett 2005). In the field of chronic illness and self-identity studies there have been calls for interventions that 'support, maintain and even enhance' patients 'individual creative capacity' to adapt to illness, and which explore the 'embodied' nature of self-identity/illness experience (Reeve *et al.* 2010: 190). Hubbard *et al.* (2010) explored the biographical work of people living with a diagnosis of cancer and concluded that there is a need for the 'development of interventions to support those people who experience cancer as an assault on their identity' (*ibid.*: 143).

Whilst the link between self-identity disruption and illness has been explored dialogically through research into ‘illness narratives’ and ‘biographical disruption’ (Bury 1982), further research is necessary to explicate the *embodied* nature of illness and self-identity disruption, and the development of interventions that support, maintain and enhance ‘individual creative capacity’ (Reeve *et al* 2010). This study therefore seeks to answer these calls through the description of a creative, flexible, inclusive and collaborative intervention, exploring the embodied nature of PRs experience of LT&CIs as an assault on self-identity. This project also begins to answer the wider call for more research to raise the empirical profile of art therapy and its role within health and illness (Waller & Sibbett 2005; Wood 2011: 14).

1.4 Original Contributions to Knowledge

The contribution to knowledge provided by this study within the field of palliative care is the description and analysis of the PRs lived experience of a new intervention and protocol, designed to improve the quality of life of people who experience LT&CIs as a disruption to their self-identity. This project also offers further evidence to support the use of a phenomenological approach to art therapy research and analysis within health care and the medical humanities, with a focus on finding ‘health within illness’ (Carel 2008).

This project contributes to research that supports the role of art therapy within palliative care, specifically providing evidence for the efficacy of ‘third hand’ (Kramer 1971) interventions such as portraiture, that increase inclusivity, and the use of Wright’s (2010) theory of Mirroring and Attunement as a method for self-identity revisioning and coherence.

This project also offers a modest contribution to research about painted portraiture as a genre of art expression and healing, detailing how people facing the end of their lives and the deterioration of the body wish to be portrayed. These contributions to knowledge will be discussed further in the conclusion (chapter 7). In the following sections of this chapter I will introduce the general approaches I have used within this project, so that the concepts I refer to throughout may be clarified from the beginning.

1.5 Context: Setting the scene

As an artist and art therapist I believe in the power of art to heal, challenge, and transform meaning (Adamson 1984; Stuckley & Nobel 2010), and to build bridges between our *discursive* and *non-discursive* selves (O'Brien 2004). The creation of art has played an important role in all known cultures around the world (Dissanayake, 1988), and there is extensive anecdotal and growing empirical evidence that art therapy and the arts contribute to health and well-being in those living with LT&CIs (Hill 1945, 1951; McNiff 1992, 2004; Kramer 1971; Pratt & Wood 1998; Connell 1998, 1992; Luzzatto 1998; Malchiodi 1999a, 2007; Waller & Sibbett 2005). Historically this evidence has been based on the interpretation (by the therapist) of the clients images (Franklin & Politsky 1990). However, with the drive for more evidence-based practice, it is important for art therapists to carry out empirical research, and as the Arts Council of England (2006) claims ... 'there is an underdeveloped potential for the particular role of the visual arts across healthcare and medical professions, including helping patients to maintain a sense of personal dignity and control over their situation in what are often distressing circumstances.'

My art therapy practice within palliative care is based on the 'open studio' model outlined by Catherine Moon (2002) and other art therapists concerned with keeping the focus on 'art' within art therapy (Robbins 2000; Allen 1992, 2001; McNiff, 1986; Malchiodi 1999; Wix 2000; Cahn 2000; Brown 2008). This model aims to avoid the 'clinification' of art therapy (Allen 1992: 23), a syndrome that Allen says 'neglects to employ the very specialized knowledge that derives from our background in art making itself'. Allen's (1992) open studio model works on the premise that it is part of the art therapist's role to pursue his or her own art making as a way of creating 'a bridge to and from her core self to her role as therapist' (*ibid*: 26). Within this project I acknowledge that my therapist/artist/researcher identities merge, I therefore reflexively consider my positioning on given points and interpretations throughout the thesis.

This project is grounded within the ‘holistic’ palliative care paradigm (Saunders 1976, 1990), with its focus on the *physical, emotional, psychosocial* and *spiritual* aspects of a person’s experience of illness. Central to the ethos of palliative care is the improvement of patients’ quality of life and it is therefore important for art therapy to demonstrate the contributions it can make towards this aim (Bell 2008: 354). This includes the support of a person emotionally and spiritually (Waller & Sibbett 2005, Bell 2008), and I believe this intervention provides a transformative process within which to explicate and ameliorate experiences of suffering inherent within LT&CIs and self-identity disruption.

1.6 *Revisioning self-identities: Introduction to key theories and concepts used.*

In this section I introduce the key theories and concepts used within this project. I begin by exploring definitions and my understandings of self-identities, self-identity disruption, and portraits. This is followed by a description of self-identity formation through portraits becoming a channel for ‘mirroring and attunement’ (Wright 2009). This involves using portraiture as a ‘third hand’ (Kramer 1971) art therapy intervention and the creation of an ‘authentic’ intersubjective collaborative relationship between the PRs and myself (Rogers 1951, 1957). I then outline the phenomenological approach adopted within this study and a description of the feelings of unhomelike-being-in-the-world (Svenaesus 2011) often described by people living with LT&CIs, and the social and cultural implications of problematised bodies, gender, depersonalised care and ‘being-towards-death’ (Heidegger 1962).

1.6.1 What are self-identities and *disrupted* self-identities?

Concepts of ‘identity’ and ‘self’ have been and continue to be, a deeply contested and complex phenomena (Bauman 2004:77; Evans 2005a; Lawler 2008). Their meanings are elusive and ambivalent (Vecchi 2004: 2) and yet remain topics of key interest across the social sciences (e.g. Oyserman *et al.* 2012; Leary & Tangney 2012; Elliott 2011; Radley & Bell 2007; Gauntlett 2002, 2007; Gauntlett & Holzwarth 2006; Giddens 1991; Taylor 1989, 1991). Explaining the nature of self-identity is therefore ‘problematic and cannot be the preserve of any single perspective, because it is not an

objective entity and is subject to dynamic influences ultimately beyond the complete control of any individually identifiable agencies' (Evans 2005a: 40). However, the PRs search for a cohesive sense of self-identity is something this project supports. Akhtar & Samuel (1996) describe a 'cohesive identity' as comprising 'a realistic body image, subjective self-sameness, consistent attitudes, temporality, gender, authenticity, and ethnicity'. Revisioning self-identity involves a process of 'reorganisation', 'reintegration' and 'reorientation' and self-acceptance, a renewed sense of meaning or life values, re-evaluation and pursuit of personal goals, and creative negotiation of encountered obstacles (Livneh & Antonak 2005: 14).

My understanding of self-identity is closely aligned with Palmer's description of identity as:

[...] an evolving nexus where all the forces that constitute my life converge in the mystery of self: my genetic makeup, the nature of the man and woman who gave me life, the culture in which I was raised, people who have sustained me and people who have done me harm, the good and ill I have done to others and to myself, the experience of love and suffering [...] identity is a moving intersection of the inner and outer forces that make me who I am, converging in the irreducible mystery of being human (Palmer 2007: 14).

I therefore see self-identities as multiple and intrinsically relational, a 'reflexive project' (Giddens 1991: 32), which is characterised by fluidity and change. Sociologists believe that self-identity is built through social interactions within a cultural construct, where each person is a 'child of their time and place' (Evans 2005a: 40), and that 'definitions that value who and what we are, as persons, have been steadily diminishing over the last two centuries and now, at the start of the twenty-first century, have almost completely been eliminated' (Evans 2005: 7). Whilst such theories are contested I suggest that a lack of focus within the National Health Service on personalised care and the importance of recognising and working with unique individuals, highlights the need for new and innovative interventions to support people at end of life in ways that help people retain their sense of self-identity despite the impact of illness and medicalisation.

Charles Taylor's (1989) seminal thesis on identity draws heavily on the hermeneutic phenomenological tradition based on the work of Dilthey 1976 [1900], Heidegger 1962 [1927], Merleau-Ponty 2002 [1945], and Gadamer 1975, and suggests that we all have a fundamental need for a sense of meaning in our lives. However one of the key changes in thinking around self-identities and that which has come to characterize a post-traditional or 'late modern' (Giddens 1991) society, is the problem of meaninglessness, caused by the move away from a belief in traditionalist frames of identity, such as religion, to an emphasis on materiality, science and technology, something I believe has compounded self-identity disruption in people living with LT&CIs.

Very early in this research process I discovered this quote describing identity disruption, by counselling researcher Mitchell B. Young (1988: 32) he said ...

'To have one's identity disrupted is to travel without a compass [...]

This captures the essence of that which I have heard, and seen *as lived*, by people living with LT&CIs, during my art therapy work within palliative care. Patients often speak of a sense of *displacement* and *disorientation*, of not knowing which way to turn, or who they are now they are ill (Corbin & Strauss 1987). This sense of disorientation clearly causes problems in all aspects of their life world, impacting on decision-making, relationships with significant others and most importantly their relationship with themselves. People often describe the impact of their diagnosis, treatment and illness as having changed their sense of self-identity beyond all recognition (Charmaz 1983). As Bolen (1996: 14) says:

Illness is both soul-shaking and soul-evoking for the patient and for all others for whom the patient matters. We lose an innocence, we know vulnerability, we are no longer who we were before this event, and we will never be the same.

The diagnosis of a life threatening illness and the steady deterioration of a chronic illness is often experienced as highly traumatic (Livneh & Antonak 2005: 12), disrupting and altering a person's sense of self-identity, negatively impacting upon

their ‘creative capacity’ to adapt to illness (Reeve *et al.* 2010), and their quality of life (Mathieson & Stam 1995; Toombs 1988; Crewe 1980; Carel 2011). Patients often say ‘*I don’t know who I am any more*’ and ‘*I look in the mirror and I say ... who’s that?*’ - indicating a profound mismatch between their cognitive understanding of themselves and their perceived body-image. This disruption is also characterised by: increased stress, loss and grief; loss of meaning and disruption to future goals (Falvo 1999), and commonly results in depression and social isolation (Rodin & Littlefield 1991). Research has demonstrated that social isolation can reduce immune function, cause depression and shorten life expectancy (Jaremka *et al.* 2012), suggesting the importance of finding effective interventions.



Figure 6. *Out of This World* by John D Edwards, 1999.

In this painting (see Figure 6 above), artist John Edwards (2007) conveys the subjective experience of disruption to his life and identity cause by cancer. Edwards’ experience is echoed by Claire Smith (2008), talking about her own experience of ‘deep illness’ (Frank 1997):

I live in a bubble and I watch the world revolve around me from within it. No one sees my bubble, but it is there, a film deadening the noise and commotions of the world, as life goes on everywhere else (Smith, 2008).

Edwards’ painting clearly depicts the experience of ‘liminality’ (Sibbett 2004, 2005, 2005a, 2005b) often expressed by people suffering from LT&CIs. Liminality is described as a place where feelings of ‘limbo, ambiguity, embodied experience, chaos, playing with multifocal symbols, expression and transition’ are manifest, as

well as being a place of creativity and adaption where rites of passage are played out (Sibbett 2005: 68). What is characterised by Young's (1988: 22) quote is that people living with a diagnosis of LT&CIs often find themselves suddenly thrust into this liminal 'betwixt and between' threshold space (Turner 1969; Sibbett 2004, 2005, 2005a) an unknown world or landscape without a 'compass' to guide them. A place where social stigma and 'the sick role' cause feelings of shame and distress, and people are described in passive terms as 'dependent' (Fraser & Gordon 1994) or 'disabled' thus further disrupting self-identity. I argue within this thesis that the portraits therefore become *points of reference* within the journey into this unknown or liminal space (liminality will be discussed further in chapter 2).

Philosopher Havi Carel writes about her own experience of living with a chronic illness, about being 'unable to transcend the social barrier created by illness,' (2008: 50), about a 'bitterness' which is 'verboden', and the pressures of being manoeuvred into being courageous and uncomplaining (*ibid*: 55),

[...] first I am set up in a social context that forbids me from talking about my illness. Then, when I turn to other topics, I discover the social reward: I am seen as brave, graceful, a good sport. [...] This is how you are seen once you conform to the demands and expectations of society: once your "sick role" (as Talcott Parsons called it) is validated by those around you' (*ibid.*).

Carel (2008: 50) also talks about how illness brings with it a distinct change in self-perception, which is mirrored by changes in social perception she says ...

[...] the thought that was truly novel for me was this: I will never get better. All the usual rules that governed my life – that trying hard yields results, that looking after yourself pays off, that practice makes perfect – seemed inoperative here. It was the first instance, for me, of unconditional, uncontrollable failure. No matter what I did, I would only get worse. The inevitability of decline was the only principle governing my life (Carel, 2008: 63).

The disruption caused by illness also impacts upon the way patients think *others* perceive them ‘[...] I became aware that I had fallen from a position of respect, friendship and admiration, to one of pity, pitied by all, admired by none. An instant and unwelcome change. Who am I now?’ (Claire Smith, 2008). These accounts describe a double betrayal by the body, firstly in becoming the container for ‘disease’ and secondly in ‘revealing’ that disease, through the dysfunction of the body.

Bodies which have been changed by illness change how phenomena is experienced, which can result in a profound disruption to a person’s sense of self (Carel 2011: 36). For Merleau-Ponty the body is central to how we experience and interpret the world, it is the whole reason we have a world to experience (Merleau-Ponty 2002).

A focus on disrupted identities is a non-pathologising way of working with the many losses and changes to body, world and abilities that people who suffer from LT&CIs experience on a day-to-day basis. By collaborating with PRs and becoming a brush for their (self)-portraits, I make the art in art therapy accessible to those who choose not to make art or who are physically or psychologically unable to, offering a *flexible* and *inclusive* intervention at a time when *exclusion* has become predominant for those most severely affected by LT&CIs.

Within this project I endeavour to avoid using interpretative language, which is sometimes evident in psychodynamic and analytical analysis, or pathologising language as is implicated within the ‘clinification’ of art therapy (Allen 1992), instead focusing on intersubjective and thereby *co-created* interpretation of meanings.

Waller & Sibbett (2005: xxix) say that there is ‘insufficient attention paid to the psychological needs of patients with any serious illness’ and there is a tendency within palliative care and general medical practice to treat an emotional and physiological reaction to traumatic events as a ‘medical issue’ with the widespread use of drugs such as antidepressants to ‘blunt the impact’ (Grau 2006). The rationale often used is that patients living with LT&CIs do not have ‘time’ for lengthy therapeutic encounters that an exploration of root causes might require. Unfortunately antidepressants do not tackle the underlying problems of self-identity disruption,

whereas therapeutic processes enable a person to re-assimilate facets of their past and present identities, enabling traumatic experiences to be *transformed* (Etherington (2008: 53).

Within Svenaeus' phenomenological model of illness he defines the 'otherness' of the ill-body and the 'enforced inhabitation of an alien world' as 'unhomelikeness' (2011: 334). Diseases and the over medicalisation and objectification of the body are therefore a direct threat to our 'homelike being-in-the-world', through their 'radical and dreadful otherness' (Svenaeus 2011: 335).

... the unhomelike being-in-the-world of illness, in contrast to other forms of unhomelike being-in-the-world is characterized by a fatal change in the meaning-structures, not only of the world, but of the *self* ... (Svenaeus 2011: 337).

This sense of 'unhomelike being-in-the-world' is a key feature of identity disruption and is similar to Sibbett's (2005a; 2005b) notions of 'liminality' or 'liminal space', and Radley's 'world of illness' (2009). Svenaeus (2011: 336) suggests that health care professionals are duty bound to try to understand this 'unhomelike being-in-the-world' that patients experience and to 'bring it back to homelikeness again, or at least, closer to home', where a 'reinterpretation of the self' can be achieved (*ibid.* 338).

This project is a unique opportunity to research the way in which those living with illness wish to be portrayed, as well as to promote *health* within *illness* (Carel 2008). As Charmaz & Rosenfeld (2006: 37) suggest the tensions between body, self and identity are something that we all face in the light of the reflexive self-project, however in illness these tensions are 'accelerated, intensified' and 'magnified' (*ibid.*)

1.6.2 What are Portraits?

For the purpose of this study I use Cynthia Freeland's definition of what 'portraits' are or can be. Freeland describes portraits as:

[...] visual artefacts that are made in order to draw attention to the depicted person as a subject with his or her own intentionality; the artefact itself thus

manifests two distinct sorts of purposes (both intentional), that of the creator and that of the subject (Freeland 2010: 192).

Freeland (2010: 99) uses a typology to further define a 'portrait,' describing four key characteristics: 'accuracy of likeness,' 'testimony of presence', 'emotional characterization or evocations of personality, and revelation of a subject's uniqueness or their 'air' (Barthes 1985)'. The first characteristic 'accuracy of likeness' refers to a mimesis of the sitter's physical face/form. However, in this project PRs were given the opportunity to co-design portraits which deviated from this through giving them the option to use photographic reference depicting past images of self, or imaginary images reflecting an inner reality or landscape, in addition to the option of a mimeses of their current 'likeness'.

Within Freeland's second characteristic, 'testimonies of presence' she suggests that the portrait or photograph can be a powerful way of connecting with people even when they are not present, thereby providing a privileged contact with the dead or absent (Freeland, 2007: 101). Mullins (2006: 8) posits that portraits 'cheat death, and have the lure of immortalizing the sitter', and an 'ability to capture the essence of the sitter over the time it takes to paint it' giving these images 'much more authority than a single snapshot' (Mullins 2006: 8).

The third characteristic is 'evocations of personality' which might offer information about the sitter's personality, emotions or attitudes (Freeland, 2007:101). As a fourth characteristic, Freeland uses Roland Bathes' (1985:102) term, 'the revelation of a subject's uniqueness or their "air"'. For Bathes, a person's 'air' ... 'is that exorbitant thing which induces from body to soul ... a kind of intractable supplement of identity' (*ibid*: 109-110). I refer to this as a person's 'essence', which I understand to be the essential characteristics by which they are identified, as well as their 'presence' (West 2004: 12) or 'being-in-the-world' (Heidegger 1962).

Mullins (2006: 8) argues that the portrait, with its inherent subjectivity, 'does not engage with universality,' however if this were true, portraits in general would hold no interest to anyone except the person depicted and their family, which is belied by

the huge numbers of people who visit the National Portrait Gallery every year. Rather it is the *universality* of human existence that draws people to examine the faces of others and lures them to the gallery as a place where one is ‘licensed to stare’ (Nairne, 2009, quoting Michael Palin). As Freeland (2010: 298) says ... ‘Among a world of meaningful objects, portraits are among the most engaging of all because they reveal to us subjects in which we are all inevitably interested: persons’. Portraits usually feature faces and reading the face and facial expressions are key when attempting to understand another person’s changing emotional state or inner world. The eyes are often described as ‘windows to the soul [...] one of the most wonderful things in nature is a glance of the eye; it transcends speech; it is the bodily symbol of identity’ (Ralph Waldo Emerson). Also as Bruce & Young (1986) say ... ‘A face is the most distinctive and widely used key to a person’s identity’ (ibid: 305) and we are all highly attuned to recognizing emotional and behavioural clues, either in body language or facial expressions which indicate something about the thoughts and feelings of the person (Freeland 2010: 154).

Adams (2009) defines the painted portrait as something which, in the physicality of its creation, ‘sifts through time’ becoming - a ‘reflective space’ achieved through ‘sustained observation’. Freeland (2010: 290) talks of the ‘paradox of portraiture’ which questions how ‘something that is an artefact or object can ever succeed at capturing a person who is a living being, a subject?’ This paradox encompasses the *transformative* nature of art (Cauvel 1999), the way an artist uses inanimate objects, such as paint and canvas to recreate the sense of a person, with a ‘distinctive soul, essence or air’ (Freeland, 2010: 290), something that is utilised within this project (this will be discussed further in chapter 3). Pointon (2013: 11) proposes that portraits are both ‘*effective*’ and ‘*affective*’, an ‘instrumental art form, a kind of agency’, meaning that they can be actively ‘instrumental in changing lives’ as well as moving and thought provoking for those who view them. The portraits within this project therefore have the potential to capture time, portray the presence of a living person by transforming art materials into something instrumental, and effectively and affectively change lives.

1.6.3 Identity Formation: *Mirroring and Attunement*

This project is underpinned by an understanding that the formation of self-identities is intrinsically *relational* (Frank 1997, Grytten & Måseide 2006, Wright 2009). I have therefore used Kenneth Wright's (2009) theory of 'mirroring and attunement' (based in object relations theory) to support the idea of using portraiture as a way to *re-vision* self-identities. Wright's (2009) theory develops and connects Klein's (1952) *object relations theory*, Winnicott's (1971) *mirroring*, with Stern's (1985) notions about *attunement*, and applies them to the artist and the art object (Wright 2009). Building on the ideas of art critic Peter Fuller (1980) Wright argues that the surface of the canvas in a painting is 'derivative, or 'analogue' of the mother's expressive face in infancy, and functions in a similar way as a responsive and mirroring extension of the self' or 'surrogate adaptive mother' (Wright 2009:13). I have developed these ideas further to include the *portrait painted for* the PRs as an embodied, mirroring device, which acts as the *attuning* (m)other, enabling the reflection and integration of aspects of the PRs self-identity (Carr 2014).

Stern's concept of *attunement* (1985) is an important aspect of this study, as it describes the process whereby the (m)other reflects back her baby's affective states, in order to promote self-awareness, and therefore help the baby build a sense of self-identity. However Stern observed that this is not a process of mimesis – but a process where the (m)other 'attunes' a response to the baby which either validates the baby's experience or attempts to change that experience. The (m)other does this by adding something of her *own* to the reflected experience – e.g. down playing distress or exaggerating surprise, therefore the attunement becomes 'a recasting, a restatement of a subjective state' (Stern 1985: 61). Although Scaife (2001: 40) suggests that object relations theory does not address the adult art-making process, Wright's (2009) ideas seem to offer such a process through the portrait becoming a *symbolic* (m)other's face, and although Stern was mainly concerned with the early mother-infant relationship, he believed that attunement is important *throughout a person's life* (ibid: 23).

Through Wright's (2009) thesis the 'good enough (m)other' can also be translated into the 'good enough artist' and this has been both empowering and liberating for myself and my identity as *portrait artist*. There is also a sense of safe *merging* within the co-designing and portrayal of the portraits with the presence of the PR and the ATR captured within the layers of paint applied, with the portrait becoming a testimony to the success of that intersubjective relationship.

I also draw on Wilfred Bion's (1962, 1967) theory of containment and the (m)other's/therapist's task of 'holding', 'containing' and 'transforming' unbearable anxiety e.g. the fear of death. 'Third hand' (Kramer 1971) techniques allow the patients' lived experience to be temporarily held and contained by the therapist, and then transformed and transferred into the portraits in a process that involves the 'empathic passage through the other - a passage during which each experience acquires a maternal form' (Wright 2005). The relationship between the 'container' and the 'contained' is an intersubjective one, and this combined experience becomes in the portrait a concrete, sensory and symbolic form (Langer 1953), offering a unique way to hold, contain and safeguard this attuned experience (Wright 2005). Within psychodynamic and psychoanalytic art therapy this attunement is indicated through the art therapist's verbal and facial responses and therefore, unlike this intervention, no concrete evidence remains for ongoing reflection by the patients.

It is important to note that I am using object relations theory, not as a way to identify something *lacking* in the PRs primary relationships (unless this is presented by the PRs themselves) or in a Freudian sense to identify *unconscious fantasies* or *drives*, but as a way to *re-vision* or *re-integrate* aspects of the PRs past, present and future self-identities within the portraits, and therefore build a *stronger more coherent sense of self-identity* (Carr 2014).

1.6.4 Reversing the terms of engagement: Invoking Edith Kramer's concept of the art therapist's 'Third Hand' (Kramer 1971, 1986, 2000)

An expectation that patients will create artwork and talk about this within art therapy sessions does have some 'limitations' and 'problems' (Maclagan 2011: 8), particularly in palliative care. Often patients are too unwell, disabled or fatigued to

make art themselves, and (as with clients in other fields of art therapy) for a variety of reasons some are unwilling or unable to make art, despite the expectation that they do so. These sessions then become reliant on ‘talking therapy’, which while beneficial in its own way is not the point of *art* therapy and does not harness the power of art to transform meanings and experience.

Engaging with art materials can be an exciting new challenge for some patients, but for others it can be an insurmountable obstacle, and often no amount of reassurance that they don’t need to be ‘good at art’ will suffice. I agree with Luzzatto (1998) on this point when she says ‘in my mind I am on the side of the patients who feel empty, blocked and unimaginative, and I do not want to make them feel they ‘should’ become visually creative’. Although Wood (1998) observes that the act of representing themselves ‘in their own terms through their artwork can strengthen and validate their sense of identity’ (*ibid*: 2), I contend that despite the portraits in this project being created ‘third hand’, PRs were able to present themselves ‘in their own terms’ through the co-designing process, thereby enabling a strengthening and validation of their self-identities.

Kramer (1971, 1989, 2000) described her ‘third hand’ model as ‘an area of the art therapist’s functioning wherein artistic competence and imagination are employed in the empathic service of others’ (2000: 48) and ‘a hand that helps the creative process along without being intrusive, without distorting meaning or imposing pictorial ideas or preferences alien to the client’ (1989: 71). In order to help avoid this error I created a reference tool consisting of a portrait reference album (PRA) containing postcards/photographs of predominantly Western historical and contemporary portraits and portrait-sculptures (for a full list please see appendix no. 10). These portraits (by both famous and relatively unknown artists) were created using different materials and methods, and PRs were able to choose pictorial styles that resonated with them. This was documented within the PRs active documentation sketchbook (ADS), where initial ideas for portraits, and all supporting information was collected. The ADS is discussed further in chapter 3 (p74).

The models of art therapy used by Kramer (1971, 1986) and Lachman-Chapin (1983) utilize art as empathic ways of working with relational issues. Kramer (1971) also focused on ‘sublimation’ (the transformation of negative impulses or beliefs into something positive) through art, with the view that changing ‘chaos’ into ‘formed expressions’ facilitated ‘sublimation’ and integration of uncontrolled affect (*ibid.*).

Through using ‘third hand’ techniques to paint portraits *for* PRs, this intervention provides the opportunity to reintroduce the creative, imaginative process of co-designing and viewing self-referential images, into what would otherwise be *artistically barren* therapeutic encounters (Carr 2014). I realise that by painting (self)-portraits *for* patients, I have taken Kramer’s (1971, 1989, 2000) model of the art therapist’s ‘third hand’ to its extreme, however this intervention is not intended in any way as a replacement for the many and varied art therapy theoretical models within which patients/clients create the art objects, rather it seeks to extend opportunities and knowledge by visiting the borderlands of art therapy practice and portraiture, as well as developing a specific intervention for a defined client group.

Importantly Kramer herself used portraiture as a way to strengthen feelings of identity in her child clients, saying ... ‘they also loved it when, as a special treat, *I drew their portraits. My actions seemed to reassure them and to strengthen their feelings of identity*’ (Kramer 1971: 40 [my emphasis]). I query whether reassuring them and ‘strengthening their identity’ should be termed ‘a special treat’, rather ‘it seems to be a *fundamental* aspect of Kramer’s therapeutic input’ (Carr 2014: 57), and as such one of the key aims of this study.

The introduction of a third hand or proxy in the creation of a (self)-portrait, is something that is often used within research projects involving photography. In 2008 the National Portrait Gallery and photographer Marysa Dowling collaborated with the City of Westminster Connexions Teenage Pregnancy Support Unit, to produce a series of portraits of teenage mothers, prior to and after the birth of their babies, focusing on enabling them to think of themselves in a way that was not wholly defined by motherhood (Pointon 2013: 12-13). This project has similarities to the current project in that the portraits were produced ‘third hand’, with Marysa Dowling

telling the teenage girls that ‘Although I’m going to be taking the picture you’ll be directing me’ (quoted in Pointon 2013: 13), which underlines the importance and empowering nature of collaborative projects.

The collaborative relationships developed between myself and PRs within this project derive from the humanistic person-centred therapeutic relationship described by Carl Rogers (1951), and this intervention meets the *six necessary and sufficient conditions* required for therapeutic change (Rogers 1957). This includes forming a therapeutic alliance based on: psychological contact, empathic understanding, therapist authenticity, unconditional positive regard, and relational depth based on trust.

1.6.5 A Phenomenological Approach to Art Therapy and Illness

An embodied and existential phenomenological approach to the description of illness recognises the *central role of the body* in all aspects of perception, consciousness and human experience (Merleau-Ponty 2002), and therefore the recognition that LT&CIs impact on a person’s ‘entire’ life/world underpins this thesis. Phenomenology can be described as ‘the attentive practice of thoughtfulness’ or ‘a caring attunement’ (van Manen 1990: 12; Heidegger 1962), within the search for the *essence* of human experience. A phenomenological approach to research therefore encompasses a description of the *lived experience* or *lifeworld* of the participants (van Manen 1990: 9).

Phenomenology is not one distinct approach, there are many threads to phenomenology, however these approaches can be broadly characterised by the tension between a concentration on the *pre-reflective* purely *descriptive* consciousness of the lived world as in Husserlian *transcendental* phenomenology, and *reflective interpretative* consciousness as in Heidegger’s (1962 [1927]) hermeneutic phenomenology. Husserlian (1970 [1954]; 1977 [1929]) phenomenology concentrates on a ‘return to the things themselves’, which is the immediate pre-reflective (rather than reflective experience) and aims to develop a deeper understanding of that experience and its meanings as they are presented to consciousness. This form of phenomenology does not seek to explain *theoretically*; rather it seeks to gain insightful *descriptions* of that experience. Hermeneutic

phenomenological research aims at ‘seeking universal meaning’ from lived experience (van Manen 1990: 19), it is a search for the ‘fullness of living’ and takes into account the sociocultural traditions that give meaning to the *lifeworld* (van Manen 1990: 12).

Portraiture is also both an art form and a social practice, within which a complex web of subject-object relations are played out between artists, sitters, patrons and viewers (Pointon 2013: 14). Thus an awareness of constructivism, semiotics and symbolic Interactionism are part of this interpretative and *reflective* understanding (Lester 1999; Finlay 2011). By adding an interpretative aspect to phenomenological research, it is possible to use it as the basis for clinical theory development, enabling it to ‘inform, support or challenge policy and action’ (Lester 1999).

Historically it is the artists, philosophers, poets and writers who have instinctively used a phenomenological approach to their work, in order to ‘(re)unite them with the ground of their lived experience’ (van Manen 1990: 9). Phenomenology ‘is a poetizing project; it tries an incantative, evocative speaking, a primal telling’, it is a language that engages voices to ‘sing the world’ (Merleau-Ponty 1973 quoted in van Manen 1990: 13) rather than ‘abstractly speaking *of* it ... so that *in* the words, or perhaps better, *in spite of* the words, we find “memories” that paradoxically we never thought or felt before’ (van Manen 1990: 13 [emphasis original]). There are a growing number of art therapists who have used a phenomenological approach in their research (Rostron 2010; Tjansink 2010; Craig 2009; Persons 2009; Bell 2008; Quail & Peavy 1994; Reynolds & Prior 2003a) and those who support its use within art therapy (Betensky 1995; Skaife 2001).

Phenomenology can be applied effectively to the many different theoretical approaches within art therapy and is particularly relevant in describing ‘the relationship between seeing, making art, relating with others and “becoming” in a social context’ and promotes a greater ‘prominence for art in art therapy theory’ (Scaife 2001: 49). Tjansink (2010: 76) claims that a phenomenological approach within art therapy enables an exploration and transformation of what self-identity ‘was, is and can be’ whilst understanding the other as an ‘equal subject’ (Tjansink

2010: 76). Within a phenomenological approach to art therapy the therapist seeks to develop an *authentic* intersubjective and collaborative relationship with their clients, becoming a ‘mutual subject’ who remains ‘authentically present while being aware that the space is for the other’ (Tjasink 2010: 78).

Becoming a ‘mutual subject’ highlights the danger that a therapist may *unconsciously* direct clients to explore aspects of the therapist’s own issues. Attending regular supervision sessions with a trained therapist and developing a *reflexive* approach (Etherington 2004a; 2004b; 2004c) to this project was therefore important in order to create transparency, and to acknowledge my own subjective ‘internal and external responses,’ and ‘cultural or theoretical constructs’ (Etherington 2004b: 46). However, as ethnographer Sarah Pink (2007: 23) says, a reflexive approach does not suggest that subjectivity could or should be erased from the creative process, rather ... ‘subjectivity should be engaged with as a central aspect of ethnographic knowledge, interpretation and representation’. I therefore acknowledge my reflexive resonances and then ‘bracket them out’ in the phenomenological manner within the case-studies, referring to these as *statements of reflexive resonance* (this will be explained further in chapter 3).

There are a number of authors who have explored the lived experience of *illness* from a phenomenological perspective (Carel 2007, 2008, 2011, 2012, 2013; Toombs 1988, 1990, 1992, 2001; Svenaeus 2000, 2001, 2011, 2012; Kirkengen & Ulvestad 2007), whose research is important for this study. Carel (2008, 2012) advocates a phenomenological approach to illness research saying:

A phenomenological approach enables the expression of these experiences in order to give a more complete description of the altered relationship of the ill person to her world and a better understanding of her experience (Carel 2008: 16).

A phenomenological approach allows a focus on the experiences of illness *as lived* by the ill person, encompassing ‘physical, psychological and social’ experiences, as well as a focus on the changes that define illness (Carel 2008: 11), whereas traditional methods such as the ‘naturalistic’ and ‘normative’ approaches of scientific research,

often obscures the voice of the ill person (*ibid.*). I see this refocus on the individual's lived experience as essentially liberating, as Hogan (1997: 37) says:

(...) a focus on the individual (as the site of suffering and distress) liberates art therapy from developing an over-reliance on, and rigid adherence to, set theories and *a priori* categories of meaning inherent in theoretical orthodoxy, which can obscure as much as illuminate human suffering.

Through using a phenomenological approach to this study I aim for a fuller understanding of illness experiences, and the description of an intervention which addresses 'real, rather than assumed needs', offering enhanced quality of life to patients (Carel 2011: 43). As Bell (2008: 354) says 'at the heart of palliative care is the improvement of quality of life. It is important for art therapy practice to demonstrate that it contributes to this aim'.

1.7 Unhomelike-being-in-the-world: The Cultural Milieu

In this section I discuss some of the stigmatising cultural constructs that people living with LT&CIs have to contend with on a daily basis. The body is 'informed and inscribed by many political, social and cultural discourses' (Cancienne & Snowbar 2009: 199) as are self-identities, it was therefore important to look at self-identity and the body from different perspectives including, aspects of sociology and philosophy which have influenced knowledge in this area (*ibid.*).

1.7.1 Problematised Bodies & Gender

In Western society the body is increasingly problematised and objectified, with a constant drive to 'improve' health and body-image feeding the consumerist drive to sell new products (Evans 2005a: 44-5). This leads to a belief that we can change who we are by changing our bodies or external props (e.g. hair colour, breast size, clothes), and historically there has been a human propensity to 'experiment with impersonation, to become momentarily someone or something else' (*ibid.*). This links into Goffman's (1959) thesis whereby people present their 'selves' theatrically to one another through different guises (using props and costume) depending upon their 'audience' and influenced by whether this takes place in a 'front' or 'back' stage situation. Charmaz and Rosenfeld (2006: 38) claim that people who conceal their

illness or disabilities utilize ‘a range of Goffmanian/dramaturgical techniques to produce a publicly and privately valued self, e.g. deference, physical grace, and props that signal healthy bodies’. Goffman’s (1963) ideas on ‘stigma’ are also important to consider, particularly in relation to the diseased body and attempts to use ‘information control’ around their illness as a way to manage what is *seen* or *not seen*, and so avoid social stigma.

The pressure to conform to the ‘sick role’ within caring institutions, and the medicalised objectification of the body, indicates the subtle institutionalised reconstruction of a person’s social self-identity, characterised not by individuality, choice or control, but by depersonalisation and powerlessness (Evans 2005a: 39). On the one hand the body is idealised and worshipped and on the other it is a focus of self-hatred, anxiety and depression, characterised by the two extremes of eating disorder: anorexia nervosa and obesity (*ibid*: 43). The body is further problematised by cancer treatments known as ‘slash, burn and poison’ (i.e. surgery, radiation, chemotherapy) (Sibbett 2005a: 59) as patients often feel their illness is a *punishment* for some past misdemeanour, which is logical when one considers how the body has historically been used for punishment and discipline.

In a study focused on self-identity it is important to be aware of how cultural constructs such as *gender* (Holmes 2011) influence self-identity in LT&CIs, and the role the portraits may play, overtly or covertly, within this (for a detailed overview of gender issues from an art therapy perspective see Hogan 2003). As soon as we are born our bodies are ascribed cultural meanings or are ‘encultured’ purely on the basis of what sex we are, and while we cannot totally escape cultural influence, we can learn to question the process of normalisation within socially constructed institutions (Hogan 2003: 14). As Butler (2006: 26) says:

Constituted as a social phenomenon in the public sphere, my body is and is not mine. Given over from the start to the world of others, it bears their imprint, is formed within the crucible of social life; only later, and with some uncertainty, do I lay claim to my body as my own, if, in fact, I ever do.

It is important to understand the cultural constructions around gender, in order to avoid imposing ‘preconceived or universalised ideas’ about what constitutes ‘gender norms in therapy’ (Hogan 2003:21). I have therefore sought to keep in mind throughout this project an understanding that social and cultural representations of gender can limit individuals and play a key role in how people think about themselves (Hogan 2003: 12), how people are treated within society and the opportunities or difficulties they may encounter (Hogan 1997).

Since the Renaissance portraiture has been an integral part of wealthy patriarchal societies and as such has also been a key part of gender identity construction (Pointon 2013: 14). Within this project ‘gender’ issues have manifested as an underlying tension in some of the portraits and collages, highlighting the covert pressures PRs suffered in trying to maintain roles and expectations around gender in the face of LT&CIs. These will be discussed further in the analysis chapters.

1.7.2 The Problem of De-personalised Care

The impact of ‘instrumental reason’ (Levinas quoted in Taylor 1991: 4) within the healthcare industry and (to a lesser extent) in hospices, means that increasingly patients are not treated as whole persons with a life story (Benner & Wrubel 1989; Benner 2003). Instrumental reason highlights things such as ...

[...] the medical practice that forgets the patient as a person, that take no account of how the treatment relates to his or her story and thus of the determinants of hope and despair, that neglects the essential rapport between caregiver and patient [...] (Taylor 1991: 105).

Healthcare also conversely ignores the embodied lived experience of illness and suffering, and the human need to *make meaning* out of such experience.

This research therefore highlights the impact of LT&CIs on self-identity, and specifically the need for intersubjective ‘I-thou’ (Buber 2004 [1937]) mirroring and attuning encounters which enable self-identity formation and validation. This involves the necessity for healthcare professionals to highlight ‘how and when the biomedical, disease model is inadequate to understand and support primary care’

(Reeve 2010a: 16). As Kleinman (2012: 1551) argues, care giving needs to be recognised as central to the discourse in healthcare, rather than the current focus on political and economic dimensions, which prioritise institutional and monetary issues, and demean the processes of healthcare, transforming it into ‘something that is hollowed of its humanity and moral value’ (*ibid.*). This system does not recognise individuality, or the need people facing end of life have for continued personal growth and development as a way to find ‘health’ within illness (Carel 2008: 16), and there needs to be a recognition of the *harm* that can be done by health care professionals who do not recognise their own power to ‘affirm or demean’ the self-identities of patients, within the medical or clinical encounter (Kinsella 2006: 25). This project therefore highlights these issues offering an *empowering* intervention for the PRs, which ‘affirms’ and gives voice to their sense of self-identity.

1.7.3 The Problem of ‘Being-Towards-Death’ (Heidegger 1962)

The literature which debates concepts about death and dying are huge and far reaching and there is insufficient space to do them justice here, I have therefore focused on the phenomenological view of death as outlined by Heidegger (1962: 277) and Elizabeth Kubler-Ross’ focus on death as ‘the final stage of growth’ (1975). The inevitability of death and the fear of dying is a frequent (if not always overt) presence within palliative care and Heidegger suggests that in order to understand our ‘being-in-the-world’ we need to recognise ourselves and our lives as finite, he called this ‘being-towards-death’ (Heidegger 1962: 276-7). Heidegger described being-towards-death as a recognition of the temporal nature of human existence, which propels us forward through time to our eventual death or non-existence. Conversely Heidegger is not interested in the *experience* of death, as he claims it cannot be experienced, his focus is on the ways people are affected by the anticipation of death, hence the emphasis is ‘being *towards* death’. This does not mean that Heidegger dismisses the losses surrounding death, as he says:

Death does indeed reveal itself as a loss, but a loss such as experienced by those who remain. In suffering this loss, however, we have no way of access to the loss-of-being as such which the dying man ‘suffers’ (Heidegger 1962: 282).

For Heidegger it is necessary to understand our finiteness, so that we can lead what he calls an ‘authentic life’ (Heidegger 1962), something that involves ‘perspicuity’, which is having a ‘clear overview of one’s life’ (Carel 2008: 99). Carel suggest this is achieved by ‘having a coherent grasp of one’s full temporal existence – past (birth), present and future (death) (*ibid.*)’. Responding in an *inauthentic way*, means ignoring or denying death, therefore we cannot escape from having one or the other attitude, meaning we are ‘bound by death’ (*ibid.*).

This project supports the aims of the Dying Matters Coalition (see website at <http://dyingmatters.org/overview/about-us>) which endeavours to change the current ‘knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make “living and dying well” the norm’.

1.8 Summary and signposting for the following chapters

In the prequel I reflected upon the genesis of this project within my art therapy practice in palliative care, indicating people and events that inspired this project. I then outlined the research questions and aims and objectives central to the study, as well as recent calls for research in this field. These included calls for the development of interventions to support patients who experience cancer as an ‘assault’ on their identity, and which develop their creative capacity to adapt to illness, as well as general calls for more art therapy research in this area. As this is a reflexive-relational and phenomenological study, I seek to answer these questions through the description and reduction to ‘essences’ of the PRs lived experiences of this collaborative, intersubjective intervention, using the portraits (and other artefacts) and verbatim extracts from the PRs End of Project Interviews (EPIs). This study also includes a hermeneutic phenomenological aspect in that it brackets back in collaboratively negotiated meanings and interpretations, in order to make sense of the data and explicate epistemological implications.

I then introduced the key theories and concepts used within this project, by exploring definitions and my understandings of self-identities, self-identity disruption, and portraiture. I argued that self-identities are ‘multiple’ and flexible, and that self-identity disruption caused by LT&CIs often negatively affects the whole

body/life/world of a person. I described the development of ideas for self-identity formation and *revisoning* through portraiture, identifying this as intrinsically *relational* I have used Wright's (2009) *mirroring and attunement* and Kramer's (1971) *third hand* art therapy model and outlined some of the perceived problems LT&CIs create in people's lives. These are *unhomelike-being-in-the world* as described by (Svenaeus 2011), Heidegger's (1962) *being-towards-death* and Turner's (1969) *liminal space*. I also discussed some of the stigmatising cultural constructs that people with LT&CIs face on a daily basis, as well as the implications regarding gender and depersonalised care within the health service. This system does not recognise the individuality of people facing end of life and their need for self-identity revisioning and affirmation, and highlights the harm that can be done by health care professionals who are unaware of their power to 'affirm or demean' the self-identities of patients (Kinsella 2006: 25). This project seeks to highlight these issues, offering an empowering intervention, which 'affirms' and gives voice to the PRs sense of self-identity.

In chapter two I review the literature pertinent to this project, focusing on the interdisciplinary boundary crossings, discussing the literature around portraiture, illness, art therapy how they correlate or deviate from the ideas supporting the *revisoning* of self-identity in this project.

In chapter three I begin by describing and discussing the practical and ethical issues surrounding this project, followed by a detailed description of the multiple creative methods, and protocols used to generate and analyse the data within the five phases of the project.

In chapter four I introduce the PRs involved in the study, followed by a summary of the findings. Using extracts from PRs case-studies, EPIs, portraits, collages and 'essence statements' as evidence I then discuss the themes and sub-themes that have emerged from the data, clustered under the heading *Increasing the PRs lived experience of their creative capacity to adapt to illness*.

In chapter five I discuss four emergent themes under the broad heading *Portraits Making Meaning: increasing the lived experience of homelike-being-in-the-world*. I argue that through this project PRs experience an increased sense of self-identity coherence and *home-like-being-in-the-world*.

In chapter six I describe the PRs lived experience of portraits as visual channels of *mirroring and attunement*, and how through this process PRs become aware of previously unknown and ‘untold’ aspects of self-identity. I argue that the portraits became a unique way of *being known*, both to themselves and others.

I describe the *intra*-subjective validation of self-identity that the portraits provide for PRs through viewing portraits and collages that *PRs need to see*, as well as the *intersubjective* validation provided by portraits they *need others to see*. I also describe a process of *aesthetic resonance*, which equates to adding meaning, complexity and coherence to the portraits, enabling PRs to recapture a sense of themselves as *valued*.

In chapter seven I draw tentative conclusions about how the findings from this study answer the research questions and calls for research in this area, and the implications for clinical theory development.

I acknowledge that painting *for* another, especially those who are in fragile health, is risky, and this sense of risk is synonymous with stepping outside of the boundaries into unknown, uncharted waters. When feeling fearful of being ‘good enough’ I remember Adrian Hill’s advice to his patients, he said ... ‘I exhorted them to *paint dangerously*’ (1945: 40 [my emphasis]).

2.0 Chapter 2. Literature Review: *Focusing the Gaze*

Within this chapter I review the literature pertinent to this project, focusing on the interdisciplinary boundary crossings; discussing the literature around portraiture, illness and art therapy and how the ideas put forward correlate or deviate from those supporting the *revisoning* of self-identity in this project. Although there is insufficient space within this thesis to explore the history of portraiture in detail, I begin with a short summary outlining some of the relevant points according to art historian Marcia Pointon (2013).

What we understand as naturalistic conventions in portraiture derive mainly from Rome's classical period and have persisted up to the present day within commissioned portraits of individuals for large institutions and multinational businesses (Pointon 2013: 13). The focus during the Renaissance for portraits of divinity underline the connections between portraiture and immortality, as well as the portrayal of people worthy of emulation, such as great leaders and warriors. This emphasis on emulation suggests the beginnings of a modern sense of self and a consciousness about 'the fashioning of human identity as a manipulable, artful process' (Pointon 2013: 60) and the power to control others perceptions of ones identity (ibid: 61). During the Renaissance, portrait artists employed the use of symbols and accessories to show character, personality, status and identity (Pointon 2013: 15). Painted portraiture in North America and Europe has traditionally occupied a 'default position as the art form of capitalist societies' (Pointon 2013: 9) and thus indelibly associated with power and wealth (ibid.). During the nineteenth century portraiture began to be linked with the study of phrenology (a pseudo science where skull shapes indicated stereotypical categories such as intelligence, class, morality etc.) (Pointon 2013: 13-14).

According to Pointon (2013: 62) postmodernism, with its methodologies derived within anthropology, social history, psychoanalysis and semiotics, transformed how portraiture was addressed, leaving it 'poised between resemblance and transfiguration, between objectification and psycho-social concepts such as identity' (ibid.). Portraiture has traditionally be viewed by academic art theorists as inferior to 'fine art' (Pointon 2013: 18), however it has continued to flourish, with competitions such

as the BP Portrait Prize receiving thousands of entries every year, and portraiture as a genre has been the subject of many conferences, exhibitions, books and articles (Pointon 2013: 21). During the past 30 years portraiture as a focus of research has gained popularity, as it offers a way to gain insight and understanding of historic and contemporary societies (Pointon 2013: 11) and features as central to historical narrative as ‘artefact, image and metaphor’ (ibid.). The importance afforded portraits is ingrained in our society; with faces used in most cultures as markers of identity (Pointon 2013: 7), and a passport or identity card without a portrait would be considered a useless document. However, our self-identity is thought to encompass much more than our physiognomy, and portrait artists invariably attempt to portray something of the character and ‘essence’ of the sitter, creating a visual narrative of who they are.

I will now explore the literature surrounding the shift in focus within this project from a reliance on biography as a way to ‘reconstruct’ self-identities to one focused on portraying the primacy of the body within illness. I discuss the work of the few art therapists who have painted portraits of their clients, and the positive impact they suggest this had on their therapeutic relationship and the client’s well being. I outline the two directly relevant research projects I have found, featuring the work of portrait artist Mark Gilbert, and the implications for this study. Because of the paucity of directly relevant literature surrounding this project I have widened the literature review to include photographic portraits, used to unlock hidden pain and transform it into something beautiful, confrontational and meaningful.

2.1 Portraits as Embodied Visual Portrayals of Self-identity

Although narrative is used within the prose poems and EPIs I suggest that the *visual* qualities within portraiture have the power to ‘extend’ the narrative view and acknowledge the primacy of the body within illness (Carel 2008). Therefore, whilst I acknowledge the huge and varied field of *narrative* and *biographical* research in healthcare (e.g. Martin 2011, 2008; Lawton 2009; Bingley *et al.* 2008, 2006; Mishler 1999, 2004; Charon 2001; Radley 1999, 2009; Riessman 1990, 2003; Charmaz 1983, 1994, 1995, 2002, 2006, 2008; Lieblich *et al.* 1998; Hydén 1997; Frank 1997; Lawrence-Lightfoot & Hoffmann 1997, Ricoeur, 1991; Kleinman 1988) and chronic

illness (Bury 1982, 1991, 2001; Williams 1984; Williams 2000; Faircloth *et al.* 2004; Reeve *et al.* 2010; Hubbard *et al.* 2010) I do not review this work here, although I do refer to some seminal papers throughout this thesis.

Critics of narrative enquiry suggest that an unhealthy dominance of textual narrativity has hindered the development of more creative and diverse ways of investigating lived experience (Strawson 2004: 429), therefore by utilising portraiture and other creative visual methods in this study I seek to contribute new understandings to this field. As Wright says: ... ‘discursive language, and arguably the language of interpretation, will generally lack the capacity of imagery to evoke and hold experience’ (2009: 190). Moving away from textual narrative and biography towards the visual, allows a reconnection to a more direct ‘sensual and intuitive’ way of understanding ourselves (Moon 2002: 50). As Freeland (2010: 157) said, regarding self-portraiture ‘the artist presents his or her embodied self to the world in a way that is simply *not narrative*’, therefore *narrative* could never be the ‘whole story’ in self-identity portrayal, as it can never fully express the body (Freeland 2010: 192). A portrait gives an illusion of life and presence, and also a physicality and materiality that is absent in text, meaning they can be used as objects within rites and ritual. Portraits are however also about ‘absence’ (Pointon 2013: 226-7) as a portrait sets up an ‘expectation of human presence that is immediately denied by the very plasticity and materiality of the portrait’ and that it is this ‘gap between the sign and the referent, that makes portraiture so compelling’ (*ibid.*).

There is no doubt that portraiture is imbued with its own visual narrative, one that is often employed by curators and writers alongside other fragments of data to *authenticate* identities. As Pointon (2013: 15) claims ‘biography and portraiture (and autobiography and self-portraiture) are often seen as contiguous disciplines, useful to each other, and both serving in the creation of an authentic likeness’. However, both biography and portraits require subjective choices and interpretation by the authors and writers, meaning that an ‘authentic likeness’ can only be ‘relative’ and ‘approximate’ (*ibid.*). Portraits therefore may be understood as ‘imaginative documents that also bear a complex relationship to history as actuality’ (Pointon 2013: 22), and may include ‘fictive’ elements, meaning it is problematic to consider a

portrait as an authentic record of a person's likeness (*ibid*: 26). Despite this historians have often tried to link a portrait to a particular individual to support their historical hypotheses (*ibid.*).

In visual anthropology, the relationships which images have iconographically with each other are surpassed by a focus on the way individuals interact '*with*' images and the 'interactions which individuals form with each other *through* images' [original emphasis] (Canals (2011: 228). I see self-identity formation as intrinsically relational, and these different ways of knowing the self are indicated in the portraits that PRs *needed to see themselves* and those *they needed others to see*. (This is discussed further in chapter 6).

Visual portraits are part of a complex tradition of human representation and display, where a portrait or self-portrait performs something important about being human, acknowledging the fact that we continuously 'present ourselves visually' to others and that 'there is something different about what we say in constituting ourselves and what we actually do when we go out and show ourselves to others in the world' (Freeland 2010: 190-1). I suggest that this difference is characterised by the way visual art utilises a specific kind of symbolism and metaphor, which work in a different way to narrative, with images having a more direct and immediate impact on our consciousness (Freeland 2010: 189; Kramer 2006). This can include an intuitive sense of liking or disliking an image and not knowing why or how to explain it. Knowledge that cannot be articulated adequately by verbal means is called 'tacit knowledge' and is something which 'becomes known and expressed through symbolic forms' (Jongeward 2009: 241) such as imagery. In images ambiguity is possible, meaning that interpretation is fluid and adaptable. As Jones (2003: 98) says ...

Art by its very nature has the deviant potential for ambiguity. It has the capacity for holding many notions, many angles, many colours and places, in a way that the written or spoken word rarely allows.

Within art therapy one of the functions of the art therapist, is the capacity to metaphorically 'hold' the experiences or affect offered by the client, and when a client creates an image around those experiences, the artwork is said to 'hold' those experiences, as they are separated from the client and can be looked at as separate. Within the portraits experiences are held, attuned and reflected back to the PR, utilising symbolism and metaphor as well as aspects of realism (Brown 2008: 23). I therefore suggest that part of the success of painted portraits is their ability to 'hold' contradictory 'truths' such as fact and fiction (Inckle 2010), and communicate these in a direct and sensory way allowing connections to be made to historical or contemporary symbols (Mullins 2006: 7).

When considering the redemptive value of 'works of illness' Radley suggests that they do not simply work as a 'repair' to their self-identity and that although some kind of reconstruction may take place '[...] it is not in essence a stitching back together of what has been disrupted by the onset of illness [...]' (2009: 122). As Radley says, '[...] the idea that people are engaged only in putting right a disrupted biography seems too simple a description of their actions' (ibid: 115). I suggest that the idea of 'redemption' or 'repair' is not the focus of this intervention, rather the focus is on 'transformation' through the revisioning process which enables a different way of 'seeing' and 'relating' to their self-identities, so that a different way of knowing the self may be found.

Within this section I have suggested that the 'visual' qualities of portraiture have the power to extend a purely biographical view of self-identity, acknowledging the primacy of the body within illness and developing a more sensory and intuitive way of understanding self-identity. I have also argued that an important reason for using portraiture is the relational interaction the PRs have with themselves through the images, and also the interactions that PRs have with others through the images. I have discussed how portraits are an important part of a complex practice of presenting the self to others, employing a visual narrative in which symbolism and metaphor are used to convey meaning, enabling the 'holding' and containing of dualities, the transformation of meanings and the development of new ways of knowing and being known.

2.2 Art Therapy, Portraiture and Palliative Care

In this section I review the recent literature concerning portraiture created to portray people living with LT&CIs. Due to the paucity of *research* studies in this field I have widened my search to include artists (non-research) who paint people living with LT&CIs. The lack of empirical research projects, and the diversity of art therapy approaches and perspectives used make the field of art therapy particularly difficult to analyse and validate (Wood 2005: 86).

Although the use of portraiture in art therapy is an area of practice that is largely unexamined or researched, several art therapists have written about the way painting portraits of their clients can help to build a therapeutic relationship and a strong empathic connection between themselves and their clients (Kramer 1971; Costello-Du Bois 1989; Franklin 1990; Jones 1983, 2006; B. Moon 1990; C. Moon 2002). While working in an American hospital for the mentally ill, Don Jones (1983, 2006) painted portraits of patients as a way to connect empathically with them. Catherine Moon (2002: 214) suggests that portraiture is one of the most direct ways that art therapists can ‘witness’ their clients, and through the portraits clients see themselves as she has seen them, which may promote feelings of being *acknowledged* rather than *judged*, and that ‘taking the time to do someone’s portrait is perceived as taking the time to notice and, at some level, to care’ (2002: 215). As mentioned earlier Kramer also drew portraits of her child clients as a way to ‘reassure them and strengthen their feelings of identity’ (Kramer 1971: 40). The experiences of these art therapists, are significant because of the connections they make between portraits and identity, and the power portrait possess to witness, acknowledge and care for clients.

In 1998 art therapist Michele Wood wrote an inspirational paper about a patient dying from AIDS who, in an art therapy session, used his own body intuitively as a ‘portrait’ (Wood 1998). Wood said that at the beginning of the session the patient asked for a large piece of paper to be placed on the floor, he then, with difficulty, lay down upon it (*ibid*: 142). Wood suggested that the patient’s presence, lying there on the paper, seemed to be saying ‘here I am, see me’, asking for a witness to his embodied illness story (*ibid*: 145). Wood reflected on this session saying ... ‘I was

guided by thoughts of invisibility, of his being ‘lost’ to the patient role and his battle to preserve his identity’ (*ibid*: 144). The description of how this patient instinctively combined the embodiment of his illness, within self-portraiture, added further weight to my conviction that portraiture could be used as an intervention for people who experience their illness as a disruption to their self-identity.

As this project is based within the interdisciplinary fields of art therapy, palliative care and portraiture, I now review the literature from these fields concentrating on where they converge. Both portraiture and palliative care are concerned with the body, and both ‘negotiate the tension between public and private’ (Pointon 2013: 213).

It was the British art therapy pioneer Adrian Hill (1945; 1951) who coined the term ‘art therapy’ and made the initial connection between medicine and art therapy in this country, through a recognition that art making was helpful in his own personal recovery from tuberculosis (Hogan 2001: 143). Michele Wood (1990, 1998, 2005, 2011, 2013), a more recent pioneer in this field, has written extensively on the subject. Wood along with Mandy Pratt co-edited the first academic book on the subject (Pratt & Wood 1998), which explored how art therapy approaches could be adapted to working in this area, something they claimed could ‘precipitate a profound exploration of personal issues which positively affects the individual’s health and quality of life’ (*ibid*. viiii).

Research into art therapy and LT&CIs is in its infancy and in Wood *et al.*’s (2011) recent survey into art therapy research in cancer care, they found only 11 published research studies world wide, only one being from the UK. However extensive anecdotal evidence does exist in the form of academic journal articles, describing a diverse range of individual therapeutic encounters and a general understanding of how art therapy may benefit patients living with LT&CIs (e.g. Fenton 2008; Reynolds & Hean 2007; Malchiodi 2007; Lerner 2005; Matho 2005; Hardy 2001, 2005, 2013; Luzzatto 2005; Reynolds 2003b 2003c; Wood 1998; McGraw 1999; Minar 1999; Arnheim 1986, 1990; Connell 1998).

The general themes covered in the literature include: facing death and dying, a search for meaning, hopelessness and the effects of illness and treatment on self-identity, body-image, agency and relationships with others. Wood (2005: 96) says that within art therapy and cancer care there are two main recurrent themes found in patients' artwork, these are an existential search for meaning and 'making adjustments to one's self-image in order to survive the threat posed by illness'. Sibbett (2005a: 22) found that common themes in her work with cancer patients were issues relating to power and control, with one client saying they felt 'helplessness and no control over what the doctor will decide'. Luzzatto (2005) talks of 'musing with death' within art therapy groups, where sometimes death is discussed covertly through symbolic images (Isserow 2013), making it more acceptable, or contained.

Other art therapists who have published on art therapy and palliative care include: Camilla Connell (1992, 1998); Mandy Pratt & Gill Thomas (2002); Sally Skaife (1993); Diane Waller & Caryl Sibbett (2005). These and other publications have explored the diversities and issues of practice, and the potential benefits for patients, mostly through descriptions of single case-studies, however none have discussed the use of portraiture as a 'third hand' intervention.

Matho (2005: 102) talks about how art therapy is able to 'fortify identity' in patients or help them 'come to terms' with a new identity after it has been 'devastated by illness and loss'. Lerner (2005: 163-171) claims that art therapy helps people find a voice to express their self-identity. An important finding in Sibbett's (2005b: 50) study was the embodiment of experience in cancer and art therapy, suggesting the importance of paying attention to the body, and gender and cultural influences for those living with LT&CIs. Sibbett also talks about art therapy being a valuable place to express previously unknown or unvoiced aspects of the illness experience, describing some aspects as being 'unspeakable' and other's 'unhearable' (*ibid.*).

The recent work of art therapist Susan Hogan and sociologist Lorna Warren (2012) is important to discuss as they used innovative and diverse therapeutic techniques including phototherapy (Martin 2009) and art therapy, to enable older women to create alternative visual representations of aging. Martin describes the process

whereby participants worked in pairs to perform their stories, choosing clothes and props to aid representation, with the partner/photographer 'there for' the other, 'as witness advocate and nurturer' (Rosy Martin quoted in Hogan & Warren 2012).

Hogan & Warren (2012: 329) suggest that their project challenges the 'biomedical model of aging' and that representations of aging are of particular importance, because women's experiences of aging are profoundly rooted in their appearance. The study included four individual projects using innovative visual and participatory research methods including 'art elicitation, photo diaries, film booths, and phototherapy' (Hogan & Warren 2012: 329).

Hogan and Warren's (2012) project embraces an interdisciplinary and innovative multi-method approaches, focusing on the empowerment of the individual clients through a collaborative design. Hogan & Warren suggest that using a multi-method approach enables data to be 'contrasted and juxtaposed' in order to produce a 'collage' of the investigated areas (*ibid*: 344), they also use participatory research methods to help mitigate power differentials felt by participants in research processes (*ibid*: 345). In a similar way to this project, their work challenges the power structures and assumptions of therapeutic interventions, exploring boundaries around client confidentiality, encouraging choice, individuality and the opportunity to challenge and direct others. Hogan and Warren recognise that artwork created in such projects can be used by the clients involved as politicized statements, highlighting inequalities and normative stigmatising social constructs, which often define vulnerable people in constricting and derogatory ways. Hogan and Warren's work, like this project, highlights the need to look beyond the surface of media images of older adults and those living with LT&CIs, and to give clients/patients the opportunity to portray *who they are*, often in surprising and innovative ways, e.g. see the portrait of *Hermi* (Hogan & Warren 2012: 339).

Suggestions have been made that art therapy helps to 'maintain the individual's sense of identity in the face of illness' (Wood 1998: 30), however I have found no published studies specifically researching this theory, although the use of art therapy to help restore a sense of self-identity is mentioned. For example Wood *et al.* (2011) suggest

that art therapy can help people suffering from cancer to ‘recalibrate’ (*ibid*: 144) their identity, saying that through ‘strengthening the person (by the fortification of the self) and providing a means of adjusting aspects of self-image, art therapy may be used to achieve stability and improve psychological and social functioning’ (*ibid*: 141).

Matho (2005: 116) says that patients approaching end-of-life, require an ‘extra strengthening of their inner resources in order to affirm their sense of humanity and own a self-identity that is larger than the name of their illness’ and that enabling the mobilisation of creativity at this time, ‘fortifies’ a person’s ‘life-giving inner resources.’

O’Neill (2008: 11) points out that when we merge the ‘sensory/sensuous experience of storytelling with the sensory/sensuous immediacy of visual representations’ we find ourselves in an ‘in between space’ which is ‘dialogic, visual’ and also a ‘potential’ (Winnicott 1971) or ‘inter psychic space.’ This is similar to Sibbett’s (2005: 68) place of ‘liminality’, a place where rites of passage are played out, where feelings of ‘limbo, ambiguity, embodied experience, chaos, playing with multifocal symbols, expression and transition’ are manifest.

Concepts of liminality originated within Van Gennep’s seminal paper on rites of passage (Van Gennep 1960), Turner’s later work on ritual around rites of passage events (Turner 1969) and Little *et al.*’s (1998) link to illness. Within Van Gennep’s (1960) anthropological study he describes rites of passage as containing ‘[...] all the ceremonial patterns which accompany a passage from one situation to another or from one cosmic or social world to another’ (*ibid*: 10). Van Gennep studied major life events such as childbirth, marriage and death, suggesting that as these events provoke change and uncertainty they cause profound anxiety, and therefore rituals such as baptisms, weddings, funerals have grown up around these events to give people a framework within which to pass through and witness these transitions. Van Gennep’s ideas are still used by contemporary researchers to understand and explain the experience of living with LT&CIs (Blows *et al.* 2012; Sibbett & Thompson 2008; Sibbett 2005; Meyer & Land 2003), and therefore important to consider for this study.

Liminality in experiences of cancer, (both her own and her art therapy clients'), has been extensively researched by Caryl Sibbett (2004, 2005, 2005a, 2005b). I suggest that within this 'liminal' space, portraits are 'made special' (Dissanayake 1988) and can be used, by employing process, materials and craft, as ritualistic symbols. As Dissanayake says:

One intends by making special to place the activity or artefact in a 'realm' different from the everyday [...] Both artist and perceiver often feel that in art they have an intimate connection with a world that is different from if not superior to ordinary experience (1988: 92).

Hogan argues that people who inhabit the borderlands of 'life and death', or 'self and other' may be viewed as 'liminal entities' (2013a: 418) and interestingly Turner (1969: 128-9) also views artists as 'liminal and marginal people', which may explain why artists often feel an affinity with, and seek to work alongside, those suffering from LT&CIs, perhaps recognising fellow inhabitants of the liminal sphere. Little *et al.* (1998: 1490) believe that liminality is a 'fundamental category of the experience of serious illness that needs separate recognition and examination in any account of serious illness [...].'

Turner (1969: 109) suggests that 'liminars' or 'threshold people' are seen by unliminal people as 'others' and hence initiate feelings of danger or distrust, and hospices (even with the best of intentions) could be seen as liminal places that 'hide' or segregate people with 'unbounded bodies' (Lawton 1998: 132; Evans 2005: 3), unconsciously adding to discourses that speak of 'dependence' (Fine & Glendinning 2005) and 'shame' (Street & Kissane 2001: 169). Sibbett (2005b: 69) warns that if healthcare professionals are unable to recognise the realities of their own 'unboundedness and death' then the 'vulnerability and unboundedness' of others may be regarded as 'weakness' or 'deviance' and thus 'terrifying' (*ibid.*).

An important paper to consider for this study was written by art therapist Michael Franklin (2010) about his experience of using and developing his own 'third hand' (Kramer 1986) interventions. Franklin's (2010:160) 'third hand' interventions, which are a synthesis of: John Bowlby's (1980) attachment theory; recent developments in

neuroscience on mirror neurons and empathy; and mindfulness-based therapy (Siegel 2007, 2010). Franklin describes this strategy as ‘empathically attuned art [...], which help[s] clients regulate their emotions and develop interpersonal relatedness’ (Franklin 2010: 160). Franklin claims that third hand strategies utilise ‘unique, aesthetic forms of empathic resonance’, developing a process of ‘visual listening’, which enables clients to ‘feel deeply seen’ (*ibid*: 166). Third hand interventions and the development of ‘aesthetic forms of empathic resonance’, mean that the art therapist’s artistic identity can be ‘active and of service to others’ (*ibid.*).

In this section I have discussed how this project is situated within the field of art therapy and palliative care, outlining the work of art therapists who have been pioneers in this field. I have shown how this project builds on the work of Costello-Du Bois (1989); Jones (1983, 2006); B. Moon (1990); C. Moon (2002) in their focus on the art in art therapy, and painting portraits of their clients, as well as Kramer (1971, 1986) & Franklin’s (2010) development of empathic third hand interventions. I have also outlined Sibbett’s (2004, 2005) focus on the world of illness as a ‘liminal’ space (Turner 1969, 1974) – requiring a creative, spiritual and ritualistic response, something I suggest is provided by intersubjectively co-designed portraiture.

2.3 Artists who have painted people living with LT&CIs

A literature search indicated a dearth of published research (art therapy or otherwise), which seeks to understand the effect of the painted portrait on a person’s sense of self-identity. I found only one published research study involving portraiture and LT&CIs which was carried out in Canada by Aita, Lydiatt and Gilbert (2010) called *Portraits of Care: Medical Research through Portraiture*, which used the creation of drawn and painted portraits to study the relationship between patients and their carers. In this study Aita *et al.* (2010: 5) also found no comparable research studies in their literature review, discovering only three studies with similar features, namely studies including artist-in-residency in a medical institution, which confirms my own findings regarding the paucity of directly relevant literature to review.

Within their study Aita *et al.* engaged artist Mark Gilbert to draw or paint portraits of a participant sample consisting of patients, carers and health professionals, 46 in all.

This study was designed in two phases, the artistic component (painting the portraits) and an exhibition of the paintings, where attendees were asked to complete a survey. This survey was then used to confirm or discredit the findings from the first ‘artistic’ phase of the study.

Interestingly, in designing the portraits, Gilbert made personal stylistic and compositional choices to ‘jettison anything that felt extraneous or irrelevant’ (Aita *et al.* 2010: 6) in the paintings, so most participants are posed within a blank space, with little in the way of personal reference which might indicate clues to ‘identity’ (see Figures 7 & 8). There were two exceptions where patients were painted with medical appliances such as a naso-gastric tube and a wheelchair, although Aita *et al.* said that these were painted in the early stages of the project before the methodological approach was fully developed (*ibid.* 2010: 6).



Figure 7. *Robin and Mardi* by Mark Gilbert, 2007, (Portraits of Care Project).

Aita *et al.* also claim that ‘all artworks were carried out in the presence of the subjects’ (*ibid.* 7), and yet they also said that when Gilbert decided to paint (rather than draw) a subject ‘the artist took photographs to assist in the process’ (*ibid.* 6) suggesting that he also worked on the portraits away from the participants, as I have done within this project. I suggest that requiring the patients to sit for the entire process would have been too onerous for the participants, and time working

independently enabled me to utilize my time more efficiently, spending more time discussing and co-designing the portraits alongside the PRs rather than observing them from behind an easel.

Within their analysis of the portraits painted/drawn by Gilbert, Aita *et al.* (2010) noted ‘a sense of ongoing identity formation especially during transitions in health status’ (*ibid.*: 7-8). This is significant to this study, as it suggests that it is possible to portray *identity formation* through portraiture, however they do not discuss whether this *identity formation* could be attributed to the process of being painted. Aita *et al.* (2010) claim that each session gave the artist and sitter ‘time to build a relationship over the period it took to work on the images,’ and this was considered an essential part of the artistic process by Gilbert that ‘[...] mirrored relationships that develop between patients and caregivers.’ However, there are no suggestions that a similar amount of time was given to each participant, but rather that Gilbert chose who he wanted to *draw* (perhaps in one session) and who he wanted to *paint* perhaps posing ‘multiple times’ (*ibid.* 6). I would question whether a single drawing session of one hour would give an artist the kind of privileged relationship suggested, as in my experience it often takes several sessions to establish a close and trusting intersubjective relationship, and although the focus of their project was ‘care givers and care giving’ there was no suggestion that the ‘care giving’ inherent in the painting of the portraits by Gilbert was evaluated to corroborate this suggestion.

Whilst Aita *et al.* (2010: 9) say that patient subjects ‘responded positively’ to their experiences of being drawn/painted and that the experience ‘appears to have a therapeutic effect’ particularly for those involved in the project for longer periods, they also question whether portraiture can be viewed as *therapeutic* for either the viewer or sitter. They say the fact that;

these portraits and this project were *moving* for the subjects and viewers appears inescapable, but their actual role as a *therapeutic intervention* is less clear. This important question [...] clearly requires further study and analysis (Aita *et al.* 2010: 11 [my emphasis]).

I suggest that the present project will add further understandings and evidence derived from the description of the PRs lived experience, to support the view that portraiture can be an effective therapeutic intervention when carried out by a trained art therapist.

Some of Aita *et al.*'s reported outcomes were; the development of new perspectives on health and illness, and in a reciprocal sense - 'helping others who will see the portraits recognise the strength in patients despite illness' (Aita *et al.* 2010: 9). One patient reported that when attending portrait sittings at the hospital she had a change in feelings towards visiting the hospital saying that instead of dreading the visits she found herself dressing up and 'putting on makeup for the first time since undergoing multiple surgeries on her face' (Aita *et al.* 2010).

Aita *et al.* also make suggestions regarding the use of arts based methodology in medical research saying that the study 'yielded a wealth of insight ... and helped investigators better understand how portraiture can be used to benefit patient care' (*ibid.*) and suggest that as a research model, their study (i.e. painted or drawn portraiture and its exhibition) could be applied to examine other aspects of health and illness (Aita *et al.* 2010: 12)

In their analysis Aita *et al.* noted that the portraits portrayed the 'interior' of the participants experiences, communicating through 'non-verbal facial and bodily expression', which enabled patients to be seen as 'whole people', rather than people 'fragmented by diagnosis' (2010: 8). They said that the portraits emphasised the way patients were 'living through their illness', portraying them 'remarkably *present* and functionally more *healthy* than might be expected given their illnesses' (*ibid.*).

However, as there is no suggestion that the patients or care givers collaborated in the portrait design, it begs the question as to whether these were the characteristics which Gilbert 'chose' to depict, rather than a reflection of 'realities'. However 'Roger' (a patient) is quoted as saying 'Mark captured the essence of what I feel in his work' and another patient 'Glenna' said the study enabled her to 'see myself as others see me. It helped me to accept the way I look' (*ibid.*: 8). Aita *et al.* stated they aimed to discover through exhibiting the paintings, whether the portraits aroused empathy in the viewers, however they found conflicting evidence saying that 'it was sometimes the

case that the subject did not feel as viewers had imagined' (*ibid*: 11). They concluded that:

[...] the essence of care is what assists a person physically and emotionally during a transition in identity brought about by a change in health status. Care is like the wind, seen only by its effects in one's eyes, corporeal presence, emotional strength and sense of identity. The effect of giving care mirrors the same qualities as seen in the one(s) for whom one cares (Aita *et al.* 2010: 12).

Aita *et al.* (2010) call for further research in this area, saying that the role of contemporary art in healthcare is a 'necessity' for those in the health professions to access a 'better intellectual and affective understanding of what is critical' and that art can enable healthcare to overcome some of its 'narrowness of vision' (*ibid*: 12).

In an earlier research project carried out between 1999 and 2000, artist Mark Gilbert was commissioned by surgeon Iain Hutchinson to paint portraits of patients before, during and after facial surgery. This resulted in an exhibition of 30 portraits called 'Saving Faces' (David 2002) which was exhibited nationally and internationally. It was claimed that the patients found the experience 'cathartic', developing a close relationship with Gilbert, which enabled them to confide in him 'details of their lives which they shared with no one else' (Farrand 2000). Gilbert used the same stylistic and compositional choices in this earlier study as he used in the later (Aita *et al.* 2010) study, e.g. in his painting of *Barry C* (see Figure 8), *Barry* is painted *on* rather than *in* a flat pink background, the only prop being a video game console. By using a personal stylistic choice, Gilbert may have prevented his subjects from adding their own design suggestions and personal input as well as metaphorical and symbolic content to the portraits, which may have limited their therapeutic value.



Figure 8. *Barry C* by Mark Gilbert, 1999, (Saving Faces Project).

Medical Psychologist Paul Farrand (2000) likened the 'Saving Faces' project to art therapy, with a reversal of roles, however he also warned that as an intervention portraiture would prove 'far too time-consuming for the patients and too expensive to be of widespread clinical benefit'. This thinking highlights Emmanuel Levinas' concept of *instrumental reason*, which Taylor describes as 'the kind of rationality we draw on when we calculate the most economical application of means to a given end. Maximum efficiency, the best cost-output ratio, is its measure of success' (Taylor 1991: 4). This results in things such as time and attention being measured in monetary terms, when in reality they are far more valuable than money. Also I have found that portraiture as a 'third hand' art therapy intervention does not necessarily take any longer than other person centred art therapy interventions. Also I suggest that, within the intersubjective therapeutic relationship, *time* and *attention* is a fundamental necessity for patients, in order to re-vision self-identity.

However, Farrand (2000) does not dispute the potential of portraiture as a therapy:

[...] in an age where science is seen as offering the best and only way through which to treat patients, the widespread benefits derived from the portraiture suggest that along with scientific advances, art, in its many guises, can also make a significant contribution (*ibid.*).

It has to be recognised that Mark Gilbert is a portrait artist rather than an art therapist and though art therapists and artists may share similar interests and backgrounds, the relationship between them has not always been easy (Wood 2005: 83; Learmonth 2002), with art therapists sometimes believing that artists without therapeutic training should not work with vulnerable people (Bolton 2004:79). However, in some hospices (e.g. St Christopher's Hospice and Trinity Hospice, in London), artists and arts therapists often work together alongside patients (Wood 2005: 84; Hartley & Payne 2008).

An organisation that uses artists to work with people living with LT&CIs is Rosetta Life, facilitating performance, film and writing projects. The main theme running through all Rosetta Life's projects is the idea of 'performing ourselves', which they claim 'enables the frail and the vulnerable to speak for themselves and to represent themselves directly', thereby changing perceptions and challenging 'stigma' (<http://www.rosettalife.org/>).

Heath Rosselli is a portrait artist who began painting portraits of people who are recovering from, or living with Cancer and other illnesses in 1997. Her most well known work is her painting entitled *Evelyn* (see Figure 9), depicted nude, seated and smiling confidently at the viewer, the symmetry of the painting is contrasted by the asymmetry of her breasts, a single diagonal mastectomy scar revealing Evelyn's fight against cancer. The painting has been exhibited in many exhibitions, including the Louvre, Paris, alongside Rembrandt's *Bathsheba*, Raphael's *La Fornaria* and Rubens's *The Three Graces* (Grice, 2009b). However, because the painting attracted negative, as well as positive responses from the public, it was eventually displayed behind protective glass as it was feared that it might be defaced in some way (Grice, 2009a). Perhaps the painting provoked a negative response in some of the viewers because *Evelyn* displays that which people generally avoid looking at, and through the portrait *Evelyn* refuses to 'live silently' with the pain of her disease (Radley 2002: 5). In 2009 I visited Rosselli in her studio and interview her about her portrait process, and she gave me valuable advice about the practical elements of this project. According to Rosselli (2009) painting portraits involves a 'subconscious interaction' between the painter and the sitter, and that 'what comes out [in the painting] is the

message.’ Rosselli’s portrait of *Evelyn* sought to show what is usually hidden from public view, Evelyn’s mastectomy scar, revealed like a medal of honour on her chest, declaring her an inhabitant of the liminal world of illness, and yet through celebrating five years clear of cancer, the painting demonstrates that there is life after cancer and Evelyn’s physical beauty had not been diminished by it.



Figure 9. *Evelyn* by Heath Rosselli, 1997.

Another artist who paints portraits of people living with LT&CIs is Antonia Rolls (2013, 2014a, 2014b), who was moved to paint a series of portraits of her partner Steve when he became terminally ill, painting him right up to the day he died, as a way to cope with the distress of his illness and the prospect of losing him (see Figure 10). Rolls (2014a) says ‘I began to paint him and found that his vulnerability, his beauty, his soul, was as wonderful in this state of dying as they were when he was well’. Rolls has since painted many people suffering from LT&CIs (Figure 11) and also their partners/carers, and has exhibited these works in a touring exhibition called ‘A Graceful Death’ (see website at - www.antoniarolls.co.uk), which she says ‘opens

up a discussion on what it means to die' (Rolls, extract from film at <http://www.youtube.com/watch?v=KtL-QZ8eJG8>).

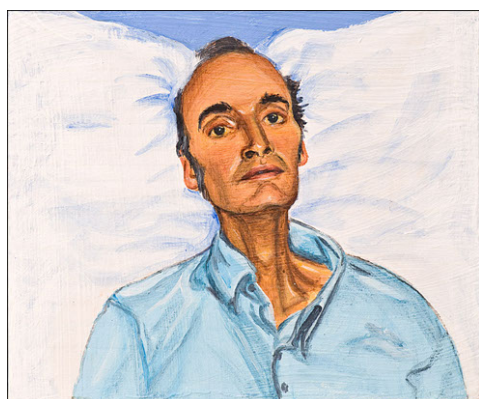


Figure 10. *Steve* by Antonia Rolls, 2007. Figure 11. *Julia* by Antonia Rolls

Rolls (2013) talks about the time it takes to build relationships with people who are dying, but also about how sometimes these relationships become deep and meaningful very quickly, allowing profound conversations about life and death (I will discuss this further in Chapter 6). There is a strong focus within Rolls' portraits on self-identity and Rolls (2013) says 'I want to know, now that their life is coming to an end, who they are and what they want to say' within their portraits. This process includes 'acknowledging' the person and seeing them 'without fear or prejudice' and giving their 'voice and presence an audience' (*ibid.*), allowing their 'truth to come out' (website film see above). Rolls talks about how sometimes the most important relationship she has when painting a portrait is with the family or partner as she sometimes paints retrospective portraits after a person has died, or when the person has become too ill to take an active role (2013). Rolls also uses poetry and words alongside her portraits and includes a 'wall of words' in her exhibitions, including poems provided by exhibition visitors and attendees to poetry workshops run alongside the exhibition. Rolls says, 'it seems that art and poetry can touch places which people have kept locked for a long time' (abstract from website film, see above). Rolls sees the portrait process as a way to give patients a voice, to affirm their sense of self-identity, to access places and memories people have kept locked up for a long time and for mourning and bereavement, all of which are themes found within the analysis of this project.

Brilliant (1991: 11) says that portraits ‘exist at the interface between art and social life’, which means that in their composition there is a pressure to conform to the present sociological value system, which may result in artists ‘idealising’ their sitters as in the private portraits that resemble funeral eulogies, i.e. portrayed in formulaically positive ways. David Fisher’s (2009) painting *Dead Man Posing: Portrait of Philip Ledbury* (see Figure 12) gravitates towards this, in the easy smiling and relaxed attitude, complete with cigarette, adopted within it, the title being the only suggestion that Philip is suffering from Leukaemia.

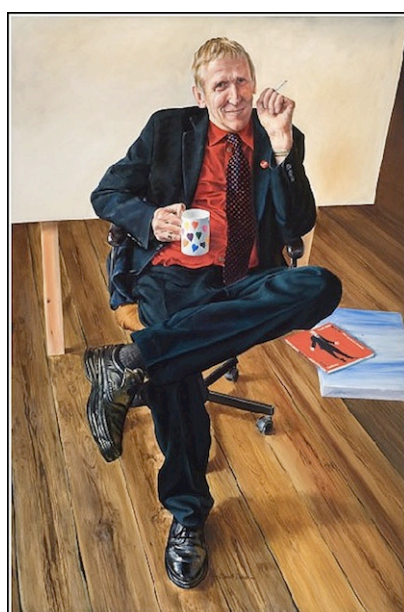


Figure 12. ‘*Dead Man Posing*’ *Portrait of Philip Ledbury*, by David Fisher, 2009.

This may, however be more indicative of the positive attitude which Philip has adopted throughout his illness and his enjoyment of the portrait process. The contemporary focus in popular culture on ‘celebrity’ as a state to be desired also affects the way portraits such as this signify, as well as the historical position that portraiture in North America and Europe has traditionally occupied, as an ‘art form of capitalist societies’ (Pointon 2013: 9) and thus indelibly associated with power and wealth (*ibid.*). Using Goffmanian ideas portraits could also be considered ‘performances’ making the subjects ‘actors’ in their own life story, and as actors say ... ‘if no one is watching you, you don’t exist.’ When I asked Ledbury about the experience of being painted he talked initially about the relational aspect of

portraiture, of becoming close friends with the artist David Fisher through the sittings, before citing the importance of being immortalized:

I am extremely honoured and flattered to be immortalised in oil paint, this portrait could be around for hundreds of years. The whole experience has been good ... (Ledbury: 2009 [personal email]).

I was privileged to meet both Ledbury and Fisher in 2009, after 'Dead Man Posing' won the Holburne portrait prize and was being exhibited at the Royal West of England open exhibition. The irony behind this portrait is that while Ledbury's Leukaemia remains in remission, artist David Fisher has since died of cancer.

In this section I have described how a paucity of research in the specific field covered by this project meant widening the search to include portrait artists who create portraits of people living with LT&CIs. I described how I found two studies featuring the portraits of Mark Gilbert (Farrand 2000; Aita *et al.* 2010). These studies demonstrated the potential of portraiture as a communicative, therapeutic and identity forming intervention. I also outlined the work of artists Heath Rosselli (Rosselli 2009; Grice 2009a; 2009b) and Antonia Rolls (2013), amongst others, and the similarities and differences found within this project.

2.4 Portraiture, Photography & LT&CIs

Within this project I have used photographs for photo elicitation in the early information gathering part of this project and sometimes as a reference tool when painting the portraits. Although I acknowledge that there are important differences between photography and painted portraiture, I explore here examples of some of the photographic artists who have over the past 30 years used self-portraiture as a way to interrogate death and dying and the effect of disease on the body. I also briefly outline some of the ways that these two mediums differ, both in the way they portray self-identity and also in the way they signify presence. Unfortunately there is insufficient space within this thesis to examine the history of portrait photography, and the many artists who have used photography as a tool within painted portraiture since its invention in the 1800s.

Pointon (2013: 17) claims that photographic portraiture is ‘subject to the same choices and conventions of image organisation, and the comparable challenges of medium, as portraits that are drawn, sculpted, painted or otherwise produced’, however she later acknowledges that photography focuses on ‘surface and physiognomy ... on the materiality of the subject as object’. I suggest therefore that there are important differences between photographic and painted portraits. The most important of which is that a camera can only ever make a *copy of reality* (of course it can be manipulated later on a computer), however in a painted portrait the portrait is something *wholly, and humanly created*. The human mind constantly analyses and interprets the sitter and the environment, and makes decisions on how to portray them. The painted portrait therefore becomes a physical and analytical creative expression of the sitter and the artist’s intentional relationship with them, captured over time.

2.4.1 Phototherapy and autopathographic photographic self-portraiture

This project builds on the work of photographers/artists Jo Spence and Rosy Martin who developed a therapeutic intervention they called *phototherapy* (Spence 1986; Martin 2009), which is a way of using photography, in particular portrait photography, to promote healing, as well as confront social issues. In her photographic series ‘The Picture of Health?’ (1982-1991), Jo Spence represented her own journey through treatment for breast cancer, using photographic self-portraiture as personal therapy, and as a way to ask questions about ‘ownership’ of the body in a medical context (Chambers, 2009). Spence said of this practice: ‘I still oscillate between going subject and object/victim, but am no longer ‘stuck’ and have begun to live in my own totality’ (Spence 2005: 374). Similarly Martin notes:

By creating a wide range of images I have been able to examine many different aspects of myself and my past history and to integrate these into a whole. By acknowledging aspects of myself and my past, which I might otherwise hide, or see as my shadow side, I have freed myself from internalised restrictions and oppressions and have come to accept myself as I am, complete with all the contradictions that have formed me. Phototherapy is photographic feelings in all their rawness (Martin 1986:174).

Hannah Wilke is another artist who used autopathographic images to document firstly her Mother's terminal illness in the exhibitions *So Help Me Hannah* (1978, P.S.I, New York City) and *Support Foundation Comfort* (1984, Ronald Feldman Fine Arts Gallery, New York City); and then tragically, her own in *Intra-Venus* (1992-1993). Images of suffering seem to send mixed messages, 'Stop this, it urges. But it also exclaims, what a spectacle!' (Sontag 2003: 77). As a photographer, Spence was obviously acutely aware of the viewer as 'audience' to her images, and therefore portrayed her 'self' in relation to that 'audience' (Bell 2002: 23). Tembeck, (2008: 87) argues that autopathographic images contain 'tactical rhetorical devices' which attempt to influence the way they are received by the general public and raise important ethical questions about the response of viewers and their 'responsibilities in the face of images of suffering'.

Clearly there is a dual aspect to autopathographic works, a restorative and therapeutic one, but also a confrontation, a demand to be seen, invoking a 'silent scream' in the viewer (Radley 2002: 5). These images are a stark reminder of our human mortality and the inevitability of suffering, however they go beyond this, as Tembeck says: 'Witness the fact that you are powerless before *my pain*, which is also *your pain*' (2008: 99) [my emphasis]. Photographs of 'wounds' could also be seen as an 'authentication' of suffering, a legitimisation or proof, which demands belief from its audience (Bell 2002: 24).

The photographic works of Spence and Wilke give 'voice' to an unspeakable suffering, and it is arguably this metamorphosis into *visible symbolic form* which brings about some amelioration from suffering. Through depicting their bodies in 'deep illness' (Frank, 2000), they were able to regain control over how their 'body-selves' were depicted, and therefore recover a sense of an autonomous person, or 'self'. The mirror-like qualities of the self-portrait, speak of both the symbolic 'capturing' of a moment and the curtailing of time, attesting to the 'tensions and contradictions' inherent in the experiences of illness and impending death (Tembeck, 2008: 99).

Pointon (2013: 215) suggests that in the last two decades portraiture and self-portraiture which explores death and dying has moved away from the body art of the 1970s and '80s, and reverted to a more traditional Western engagement with 'evaluative' and 'dialectical' portrayal, comparing the photographic body art of Spence and Wilke, to Sam Taylor-Wood's photograph *Self-Portrait in a Single Breasted Suit with Hare* (2001) created after her mastectomy. The photographic portrait (available to view at www.artfund.org) depicts Taylor-Wood stood in full frontal pose, in front of a white door, on a marble floor, wearing a black single breasted suit, holding a dead running hare vertically by its leg (suggesting *rigor mortis*) in her left hand, and the remote shutter release in her right hand. Unlike Spence's portraits, which speak of victimisation and lack of autonomy over her body, Taylor-Wood depicts herself as defiant and in control, and resonates with Rosselli's painted portrait of *Evelyn* (see Figure 9, p64), within which Evelyn is not afraid to appear nude –without identity signifying clothes or place, and therefore to risk being defined by her mastectomy. The difference here may be due to the change in medium, with the process of painting offering an important mediation through the body of the 'healthy' artist, where as Taylor-Wood's photograph is mediated through the unfeeling lens of a machine.

Despite photographic images becoming increasingly subject to manipulation, photographs have been imbued with what Foucault refers to as the 'truth effect' (Foucault quoted in Pointon 2013: 128), whereby the viewer is convinced that they have access, through the image, to historical facts (Pointon 2013: 128). This may have affected how images such as those created by Spence and Wilke signify, in that they are proclaiming their personal experience as 'the truth'. It could be argued that painted portraits also invoke the 'truth effect', through the recognition of a sitter's likeness, however as Alfred Stieglitz (1864-1964) claimed, an artist (in this case a painter of portraits) is someone who depicts 'the spirit of the truth' (Stieglitz 2000 [1922]: 229), rather than *a copy of reality*.

In this section I have looked briefly at the work of photographic artists who have used portraiture to portray their sense of self-identity and the impact of illness on their bodies, the *phototherapy* work of Spence (1986) and Martin (2009), and a

photographic self-portrait by Taylor-Wood (2001), and argued that these works have the potential to; confront, honour and transform stigmatised images of self-identity in those marginalised by society whilst also depicting *a copy, or trace of their reality*.

2.5 Collages & Prose Poems, self-identity, LT&CIs

Within the initial stages of this project I have used collages and prose poems as a way to help PRs to reminisce, organise and select stories of self-identity that are important to them and which may influence the co-designing of the final portraits. I therefore briefly look at the use of collages and prose poems within art therapy, self-identity research and also LT&CIs.

Artists have historically been drawn to collage as a personal expression during the final months and weeks of their lives (e.g. Matisse), and more recent examples include Ian Brakewell (1943-1995), whose final work was a life-sized black and white self-portrait photograph/collage entitled 'Parasite and Host' (Brakewell, 2005 available to view at www.npg.org.uk). Within this Brakewell depicts himself from the waist up, naked and emaciated, with a 'parasite', collaged from pictures including crabs legs leaves and seed pods, depicted over his left lung, indicating his diagnosis of inoperable lung cancer. The collaged 'parasite' resembles a bizarre button-hole flower or medal of honour, Brakewell's eyes in the portrait resemble black empty pools and as such his face looks mask like and uninhabited. Another example is filmmaker and photographer Derek Jarman, who died of AIDS in 1994, who turned to paint and collage in the final months of his life.

Collage as a medium for art therapy interventions is quite common and often involves a projective technique (i.e. verbalising a story in response to visual imagery), something that encourages communication between client and therapist (Malchiodi 2010). Helen Langarten (1993) an American art therapist developed an intervention she called 'magazine photo collage', something that social researcher Fatimah Awan used recently to investigate the self-identities of London students (2007). Art therapist Julie Brooker promotes the use of collage and found objects, saying that the use of assemblage or 'psychological collage' enabled her client to depict her 'fragile state' (Brooker 2010: 34).

I created prose poems to accompany the collages within the elicitation stages of this project to add a written narrative dimension that employs metaphor and symbolism, recognising that some people relate more to words than images. These poems were often co-created and sometimes created entirely by the PR (e.g. The Rainbow Snake by PR Susan (see page 180). The use of poetry as a means to celebrate the lives of patients within palliative care was used recently by poet and academic Phil Isherwood, who developed a ‘numinous’ approach to poetry in hospices. Isherwood’s (2014) approach develops the idea of poetry as a ‘personal mythology which forms a significant self’, with the ‘numinous’ encompassing paradox, the uncanny, the awesome, as well as cognitive science (*ibid.*). However within the present project, prose poems were not seen as an end in themselves, but rather as a part of the process of revisioning self-identities through portraiture. I discuss collage and prose poetry as a research method in chapter 3, point 3.4.2.

2.6 Summary

I began this chapter by looking at the shift of focus within this project, from a reliance on biography as a way to ‘reconstruct’ self-identities of those living with LT&CIs, to one focused on the primacy of perception and the embodiment of all experience (Merleau-Ponty 2002 [1945]), attempting to demonstrate that in portraits people can be seen as whole ‘embodied’ persons, and not just ‘stories’. I have outlined the way visual portraits engage with our human need to present ourselves visually to others and its inherent ability to depict ambiguity, experience or tacit knowledge through metaphor and symbolism (Hatch & Yanow 2008). I suggested that the idea of *redemption* or *repair* is not the focus of this intervention; rather the focus is on *transformation* through the revisioning process. I introduced the idea that through the portraits PRs find new ways of *seeing* and *relating* to their self-identities, which can produce a new way of *knowing*.

Within this chapter I have also reviewed the literature pertinent to this project, focusing on the interdisciplinary boundary crossings, discussing the literature around portraiture, illness, AT and photography, how they correlate or deviate from the ideas supporting the *revisioning* of self-identity in this project. I discussed the work of the

few art therapists who have used portraiture as a way to witness, acknowledge, care for, reassure, connect empathically with and strengthen the identities of, their clients. Due to the paucity of *research* studies in the field I widened my search to include artists (research and non-research) who paint people living with LT&CIs, and found two studies featuring the work of portrait artist Mark Gilbert. These studies demonstrated the potential therapeutic value of portraiture and the ability of portraiture to portray ‘identity formation’. By depicting the work of Heath Rosselli (Rosselli 2009; Grice 2009a; 2009b) I demonstrated how portraiture can celebrate *changed* self-identity, finding beauty and self-acceptance within illness. The work of Antonia Rolls (2013, 2014a, 2014b) demonstrates that portraiture at end of life can also be a way to achieve and depict ‘a graceful death’, acknowledge a person’s *presence* and self-identity, and giving voice to their personal ‘truths’. I also widened my search to look at those artists who used photographic portraiture, or ‘phototherapy’ to explore and depict the self as subject/object and the impact of aging, illness and the medicalisation of their bodies on their self-identity. These portraits (painted and photographed) offered glimpses into the private worlds and bodies of the artists and their sitters, demonstrating how for some people painted and photographed portraits can unlock hidden pain and feelings, and transform them into something tangible, beautiful, confrontational and meaningful, all of which adds evidence to support the concept of portraiture as a therapeutic intervention, enabling self-identity coherence and increased quality of life for those portrayed.

I also discussed briefly how collage and prose poems have been used as therapeutic interventions engaging a projective technique within art therapy and palliative care, suggesting that the prose poems recognise the essence of the ‘story’ behind the collages and portraits as understood by the PR. The portraits, collages and prose poems all speak of the physicality of the subject, and combined they offer a rich and complex way to celebrate a person’s ‘significance’, an acknowledgement that as people we are both ‘a work of art’ and ‘a story’ (Isherwood 2013).

3.0 Chapter 3. *Priming the Canvas*: Development of Research Methods

3.1 Introduction

Qualitative research methods have expanded exponentially in recent years, with a wide range of methods now being employed within social science research (Denzin & Lincoln 2005) with the use of the arts in research becoming an ever-expanding field, (Barrett & Bolt 2007; Knowles & Cole 2008; Leavy 2009; Jongeward 2009; Sullivan 2010; Pink 2012).

This research study is based in a *post*-positivist approach (recognising that all views of reality are essentially subjective), however prejudice still exists within health and medical research towards a positivist measurement of cause and effect. This is characterised by calls for Evidence Based Practice based on Randomised Controlled Trials (RCTs), and a dominance in the National Health Service for therapies such as Cognitive Behavioural Therapy, with its emphasis on explicit systematic procedures and the ‘measuring’ of effectiveness through tick box questionnaires.

I refer to RCTs particularly as there have been recent calls in the art therapy literature for more RCT based research in palliative care (Wood *et al.* 2011: 144) and an ongoing debate on their usefulness to art therapy research (Parry 1997, Edwards 1999). Art therapists and psychotherapists have countered this with support for case-studies as ways to produce ‘our own kind of knowledge’ which can then be ‘tested,’ to produce ‘our own kind of evidence’ (Gilroy 1996: 55; Denzin 2009). As Parry warns ...

The importance of establishing efficacy must not smother innovation; in the search for more effective ways of helping people, there has to be a phase of clinical theory development and closely observed case-studies before controlled outcome evaluation. The latter cannot precede the former and the former must be fostered and encouraged (1997: 12).

My aim was for a simple and flexible study design within which to research something as complicated and dynamic as self-identity, with the creative process providing additional ‘variability and depth’ (McNiff 2008: 32). As I sought to

understand the PRs lived experience of portraiture as a revisioning, ‘third hand’ intervention, a phenomenological approach to data collection and analysis within a broader case study (Yin 2009) framework was therefore thought most appropriate, within which to further understanding and theory building.

I follow Moon’s (2014: 3-4) foundations for theory building in art therapy, a process that is essentially ‘interpersonal, interdisciplinary, and contextual’ (ibid: 2), a way to ‘make sense of something’ [...] ‘a process of using experiences, observations, experimentation, and intuition to construct ideas about how something works’ (ibid), and is the ‘collective responsibility’ of art therapists working in the field (ibid: 10).

My aims in relation to theory building within art therapy include questioning the taken-for-granted normalised assumptions regarding; ‘who’ makes the artwork in art therapy, the universal requirement for confidentiality irrespective of context, the interpretation of images based on the client’s unconscious drives and processes, and the patient – expert divide. These epistemological commitments have formed the vary basis of art therapy practice since early in its inception, and as Moon (2014) says, art therapists who operate ‘unquestioningly and uncritically’ would perhaps be ‘mystified’ by making such challenges (*ibid*: 5).

I begin by explaining the PR sampling process and ethical considerations, followed by a description of the multiple creative data generation methods, and finally an explanation of the methods used for the analysis. I examine how the methods chosen facilitate answering the research question and the aims and objectives, and I include descriptions of the protocol followed.

3.2 The Patient-Researcher (PRs) sampling process.

PRs were recruited from the 36+ patients already attending the day-hospice where I work as an art therapist. I recognise that this posed potential risks involving research with a ‘captive’ patient group (Lee & Kristjanson 2003), however measures were taken to ensure that potential PRs were aware that their participation was entirely voluntary and would in no way effect their attendance at day-hospice, or the treatment they received there. Criteria for referral to the day-hospice is that it is for; men and

women over the age of 18 who are living with a LT&CI, usually with a prognosis of less than one year.

Careful purposive selection was used to help erect and maintain boundaries around the study. A maximum number of 8 participants (ideally 4 male & 4 female), their involvement spread over two years, was decided upon with my supervisors after consideration of the time and resources available, and the minimum number of participants required to create a valid cross section of patients attending the day-hospice (8 = 22% of patients attending this day-hospice service at any one time). Smith *et al.* (2009) suggest that between four and ten participants for doctoral phenomenological research studies is generally sufficient.

The selection of potential PRs was carried out within the day-hospice multi disciplinary team meetings (MDT) (comprising of; a state registered nurse, an occupational therapist, an art therapist [myself], a rehabilitation assistant and a chaplain, all with relevant palliative care experience). The aim was to select up to ten PRs who met the criteria for inclusion in the sample (it is through this meeting that patients are referred for other therapies, including art therapy, within day-hospice). It was thought necessary that the selection process took place within the MDT, to mitigate against any biases I may have through knowing the client group in my capacity as art therapist within the day-hospice. The criteria for inclusion and exclusion is identified in the table below:

PR inclusion or exclusion criteria
<p>The criteria for <i>inclusion</i> was to recruit people who were:</p> <p>Identified as ‘well enough’ by the team to take part Able to give informed consent (either written or verbal) Not in the ‘terminal stage’ of their disease (last weeks of life) Not undergoing invasive treatment Likely to live long enough to be involved for the length of the project. Identified as having experienced some disruption to their self-identities. Identified as likely to benefit from involvement in the project.</p>
<p>The criteria for <i>exclusion</i> was to exclude people who were identified as:</p> <p>Unable to give verbal or written consent. In the ‘terminal’ stage of their disease (last few weeks). Undergoing active treatment (e.g. chemotherapy, radiotherapy, surgery) at commencement of their involvement. Involved in any other research project. Unsuitable for the project for any other reason (e.g. multiple morbidities or attending any other psychological therapies).</p>

Figure 13. *Inclusion/Exclusion criteria table.*

Over a 24 month period eight PRs, four men and four women, were invited to join the project; seven took part for the duration of the project, and one (gentleman) declined after receiving the initial letter and information pack. The PRs were living with a broad range of LT&CIs, these included three diagnosed with different types of cancer, two with chronic obstructive pulmonary disorder, one with Motor Neuron Disease and one with brittle asthma, heart failure and arthritis. The signing of consent forms took place within the normal day-hospice setting and was facilitated by the day-hospice team leader, not the researcher. PRs were contacted, prior to a visit, by either: text message, email, or telephone (depending on choice), to ascertain whether they were feeling well enough for the session.

PRs involvement varied, therefore demonstrating the flexibility of the project, on average individual involvement was spread over 6 months, but sometimes with several weeks/months in between where no work could be carried out because of illness constraints. A sense of continuity within the project did not seem to be affected by these ‘breaks’, with PRs eager to resume as soon as was possible to discover out how far their portraits had progressed during this time. On average PRs attended 13 portrait sessions, lasting between 1-2 hours each. It was initially thought

that this project would only take approximately 7 sessions, each lasting 30-45 minutes, however, the process took longer than thought. Also it was envisaged that ten collages and one portrait would suffice, however from the first PR I painted at least 3 portraits and sometimes made up to 16 collages and prose poems (the rationale regarding the use of collages and prose poems as response art is discussed in chapter 3, sections 3.4.2.1 and 3.4.2.2 respectively). This was to accommodate the complexity of the PRs' self-identities and to fully explore the potential of portraiture, collage and prose poems as response art and as research methods.

The flexible nature of this collaborative design recognised that there would be some weeks when PRs might not feel well enough for sessions to take place, therefore reassuring them that a missed session did not mean a lost session, and that they would still be able to complete the project no matter how many missed sessions they had (within reason). This avoided the PRs feeling 'guilty' about missing a session, or 'forcing' him or herself to attend when they felt unwell.

Although it was made clear that the copyright and ownership of the portraits remained with the ATR, at the EPI PRs were given framed prints of their portraits and coloured copies of their collages and prose poems. The PRs were informed that they or (in the event of their death) their family, would be invited to attend any future exhibitions of the portraits when this occurs, should they wish to do so.

3.3 Ethical considerations

In year two of this project (2009) ethical approval was sought and granted from the Loughborough University Ethical Advisory Committee, however it was felt by the patient services director at the hospice (where the research was to be carried out), that ethical approval should also be sought from the National Research and Ethics Service (NRES). The majority of that year was taken up with completing application forms and finalizing a detailed protocol for the ethical approval, and all supporting documentation for the project (see appendix nos. 2-7). This was a lengthy and complex process, however it enabled the development of an ethically based and detailed protocol, which helped avoid potential problems during the project. Ethical approval was granted by NRES on 7th October 2010 and I began working with the

first PR on the 2nd November 2010. As I work as an art therapist on a self-employed basis I purchase public liability insurance for my art therapy practice (see appendix no. 8), (which includes cover for research undertaken) and this has been in place for the duration of the project.

Within this project, I have used the principles of INVOLVE (UK), whereby potential participants are engaged in all aspects of the research design, process and analysis. I was therefore able to incorporate hospice patients' insights into the design of the intervention, ethical issues and creative methods used. Strohm (2012: 100) suggests that involving potential participants in the early stages of research planning is 'ethically conscious' research and I also think this was a significant factor in the high take up rate (7/8) and zero drop out rate within the project despite the contingencies of illness and the length of time involved.

I have also used the British Association of Art Therapists (BAAT) ethical procedures as a guide, however to gain further insight into the ethical issues from an art therapy perspective, in 2009 I met with members of the Art Therapy Palliative Care Special Interest Group. The main ethical issues raised within this discussion were: confidentiality, avoiding exploitation, dual-role conflict (Hart & Crawford-Wright, 1999: 213; Martin *et al.* 2007), and burden on patients near end of life. These have therefore been central considerations in the design of the project and the methods engaged. I have outlined these ethical considerations and my response to these within the tables below (Figures 14, 15, 16, 17).

Ethical Considerations within this study

Confidentiality:

Guaranteeing confidentiality and anonymity is usually a prerequisite in AT (see point 10 in the *British Association of Art Therapists (BAAT) Code of Ethics and Principles of Practice*, available on the BAAT website), however as complete confidentiality was not possible in this project due to the identity revealing nature of portraiture, the gaining of PRs informed consent was of paramount importance (ibid. see point 10.2). All PRs were therefore fully informed about the limits to confidentiality in this project and my requirement to share information with relevant services should I believe that they, or a person they mention is at risk of harm.

I also believe that vulnerable groups such as those living with LT&CIs should be invited to join research projects which offer a platform for their insights (Spaniol 2005) on the impact of illness on self-identity, as well as the opportunity for reciprocity. Ultimately it is important to defend the right of palliative care patients to make their own decisions around being involved in research and to recognise our own obligation to carry out research 'which allows the voices of people with terminal illness to be heard' (Reeve et al. 2010: 183).

Figure 14. Confidentiality

Ethical Considerations within this study

Exploitation:

By involving the patients and PRs views in every stage of the research including the analysis of findings, I am reflecting a change from research carried out 'on' to research carried out 'with' participants, acknowledging their presence as valued co-researchers in this process (Springham & Woods 2014). This levelling of the traditional hierarchy of therapist/patient means that empathic understanding was increased (Vick 2000: 217) and instead of a focus on being 'helped', clients felt empowered through taking on the role of *expert* (Moon(2003: 290). I was also aware that as Pink (2001: 43) warns, PRs may not want the things they said within the collaborative intersubjective context made public in another context. However, the PRs involvement in a review of the case studies and analysis themes, ensured that they were able to revise statements made and recorded in different contexts, as well as suggest amendments to portraits, collages and prose poems. I included a question in the EPI asking the PRs if they felt in any way exploited by this project and all answered "No".

Figure 15. Exploitation

Ethical Considerations within this study

Dual-Role Conflict/'Insider' research:

The concerns expressed by my AT colleagues about the 'dual-role' (Martin et al. 2007) nature of my position in this project were important to consider, and the dual-role identified actually turned out to be a triadic one, with my researcher, art therapist and portrait artist identities all coming to the fore at different times. An awareness of these three aspects of my self-identity meant I was prepared for potential tensions and conflicts. A key aspect of the reflexive (Etherington 2004a) part of this project, therefore included the management of these three identities within the collaborative relationship. All three identities were however focused on the centrality of an ethic of care towards the PRs and the establishment of a collaborative intersubjective relationship based upon unconditional positive regard (Petruska 2003: xxxiii; Rogers 1957) and the commitment to *do no harm* (Hippocrates). In reconciling ethical considerations with research aims, it was important to be able to draw on my AT training (2002-2005) and experience of working in palliative care (2005-present) and this is a positive aspect of doing 'insider' research (Mercer 2007). I therefore possessed relevant knowledge and experience, and an established working relationship within the day-hospice MDT, with legitimate access to PRs clinical notes and contact details.

Figure 16. Dual-Role Conflict/'Insider' research.

I have been aware of feelings of ambivalence regarding what to call this intervention,

concern about why I have used three different titles when referring to it, i.e.: *a research study*, *portrait therapy* (Carr 2014) and *a portrait project*, I then realised that these correlate directly with the triadic identities of researcher, therapist and artist respectively, mentioned above.

Ethical Considerations within this study

Burden on Patients: Consideration was given to concerns regarding patients being upset by focusing on personal losses (Barnett, 2001) and of research involvement taking up precious time at the end of life, when people are easily fatigued (Addington-Hall, 2002; Barnett, 2001). However, instead of finding the project a burden time wise, PRs often wanted *more* time, often expressing feelings of regret that a session and/or the project was ending. The positive effects of research involvement may have given PRs a sense of ‘purpose’ (Barnett 2001) and feelings of ‘ownership’ over the study, enabling reciprocity, and reclamation of their ‘caring’ identity (Wahrendorf et al. 2010; Maiter et al 2008). There can be an inherent anxiety about raising issues with clients in palliative care, that they may not have the time or energy to resolve (Skaife (1993), however through using the creative elicitation techniques PRs self-selected the topics to discuss. I was careful not to ‘pry’ or ‘question’ where I sensed PRs did not want conversations to go. A collaborative approach to visual research can help to avoid harm to participants by allowing them to maintain control over the content of the images, thereby reducing anxiety (Pink 2001: 42). All the PRs expressed some anxiety and emotional affect at times during the process, however I would say this was ‘normal’ in my experience of working in palliative care, as emotions naturally run high and patients often need to express these emotions with someone other than their family (McPherson et al. 2007). Flexibility built into the project design was important to accommodate PRs needs to take breaks from the project due to the contingencies of LT&CIs. As an additional safeguard the participant information sheet contained the hospice 24 hour help and advice telephone line, which PRs could access at any time if required.

Figure 17. Ethical Considerations within this study

Gilroy (2006: 110) suggests there is ‘exciting potential for user collaboration in all kinds of art therapy research’ which facilitates embracing the subjective and collective insider/outsider experience as an important part of knowledge generation (*ibid.*). In counselling psychology research, Rennie (1994) suggests that researcher-participation should be promoted in all areas of a project, and that this collaboration is potentially therapeutic and can lead to greater insight. Hart & Crawford-Wright (1999: 211) say however, that true collaboration in research can only occur where both researcher and participant will benefit in the publication of findings. The PRs in this study have expressed a hope that by publishing their portraits and stories, others will understand the impact of illness on self-identity and that through the research this kind of intervention will become available to more people.

Although I stand to gain academically from this project (through gaining a research qualification), by developing an intervention which I believed would be of benefit to

the PRs, I hope to have at least ‘made a difference’ to their illness experience and to have minimised this issue through my endeavours to ‘give something back’ (Pink 2001: 44).

3.4 Research Methods

This project employs visual arts-based research methods, and as Pink suggests visual research can be applied successfully to projects that ...

[...] seek to represent the ways people experience certain dimensions of their everyday worlds and that create platforms on which people can represent their experiences, views, or culture. It facilitates the representation of embodied aspects of self [...], the use of metaphor and the empathetic communication of knowledge and experience that cannot be expressed using words alone (Pink 2004: 10).

All artistic creations employ ways to reduce phenomena to its essences, focusing on the particular within experience, and as such are congruent with a phenomenological study. For clarity in describing the methods used I have divided the project into six phases that are described below.

3.4.1 Phase 1: Emotional Distancing, Elicitation Tasks, and Active Documentation Sketchbooks (ADS)

During the first few portrait sessions with PRs I used two or three emotional distancing and elicitation tasks, and I have used the ADS to make the artistic methodological process explicit, by recording and collecting images, words, ideas and reflections pertinent to the PR and their stories. The protocol and reasoning for these are outlined within the following tables (Figures 18 & 19):

Multi-modal Methods	Protocol	Reasoning
<p>Button Self-Identity Elicitation Task (BSET)</p> <p>Materials: A box of 100 mixed buttons and a baize covered 31x31cm MDF board.</p>	<p>PRs were requested to choose buttons that represented aspects of their <i>pre</i>-diagnosis self-identity and place on the baize board. PRs were then asked to explain why they chose each button. Overall shape/design of the button sculpt was also noted and discussed. The process was then repeated asking PRs to choose buttons relating to their <i>post</i>-diagnosis self-identity. Both button sculpts were photographed for reference and the session audio recorded with the PRs permission. PRs were asked to dismantle their own button sculpts. This task took place within the first or second self-identity sessions.</p>	<p>The aim of this task was to enable PRs to talk about and remember aspects of their self-identity and the impact of LT&CIs. This creative task enabled tacit understandings to be made manifest, as well as a sense of emotional distancing and re-connection to stories of self-identity, acknowledging that ‘bringing emotional connectedness to a prior experience gives it a new perspective, a possibility of meaning beyond that currently held’ (Lett 1998). Buttons were chosen for this task because they are familiar, non-threatening, and easy to manipulate.</p>
<p>Lego Self-Identity Elicitation Task (LSET) (Gauntlett 2002)</p> <p>Materials: A box of mixed Lego bricks, including people and vehicle parts and bases was used.</p>	<p>PRs were requested to make a self-identity sculpture which represented aspects of their <i>pre</i>-diagnosis self-identity and then their <i>post</i>-diagnosis self-identity. PRs were asked to talk about what the sculptures represented for them. Both Lego sculptures were photographed for reference and the session audio recorded with the PRs permission. PRs were asked to dismantle their own sculpture. The LSET was used selectively with PRs, depending upon whether the PR possessed the fine motor skills required, and a need for more information.</p>	<p>This task enabled PRs to talk about and remember aspects of their self-identity and talk about the impact of LT&CIs on this. However it was also important to use a creative task which enables tacit understandings to be made manifest. This task enabled a sense of emotional distancing, as well as connection to stories of self-identity. Lego was chosen as it is a familiar and non threatening, yet expressive material.</p>

Figure 18. *Button & Lego Tasks protocol & reasoning*

Although elicitation methods such as photo elicitation are often associated with increasing participants’ emotional connection (Collier 1957 & 1967; Harper 2002), within this study the button and Lego tasks seemed to enable an *emotional distancing* to occur for the PRs. This was first noticed in the early stages of developing the protocol when working with patients at the hospice that had volunteered to pilot these two elicitation techniques. Several of the patients self reported an emotional distancing effect when using these tasks and this has been borne out within the study. This effect may be partly due to the creative processes within both the button and Lego tasks and correlates with Awan’s (2007: 240-1) findings, as she says ... ‘engaging participants in creative tasks for a set duration’ gives individuals time to reflect and formulate their thoughts and feelings and therefore mediate their response, rather than having to produce an instant perhaps more emotive response.

This finding seemed to be consistent with the way PRs used the tasks during this project, with the button and Lego tasks evoking memories but less emotion than e.g.

the photo elicitation. These initial tasks were generally undertaken early in the intervention and may have helped PRs to talk about their self-identity issues without being overwhelmed by emotional affect. Further research into the use of button and Lego tasks as emotional distancing techniques would be beneficial.

The button and the Lego tasks seemed to achieve similar things, in that they both offered a way to help PRs access insightful information about their perception of self-identity before and after they were diagnosed, and also to allow emotional distancing from painful issues or memories. I suggest that these creative tasks could potentially be useful in other areas of art therapy as tools to explore self-identity.

Multi-modal Methods	Protocol	Reasoning
<p>Photo Elicitation (Collier 1957; Harper 2002)</p> <p>PRs supplied photographs of themselves from birth onwards.</p>	<p>The photo elicitation took place in the first or second portrait session. PRs were asked to bring to the session photographs of themselves from throughout their lives, particularly those depicting turning points or significant moments. They were then asked to talk about the photographs they had selected. With the PRs permission some photographs were photocopied for reference and the session was audio recorded.</p>	<p>This enabled the ATR to see images of the PR at significant stages in their lives, bringing the <i>body</i> and it's potential into awareness and into the discussion, as well as a consideration of how to portray interior landscapes and meaning (Lett 1998: 332). This also brings in the relational aspects of self-identity, through photos of family and friends. Also the awareness of interpersonal and intrapersonal negotiations that occur when thinking about self-identity representation as body/subject. This is also an emotional distancing technique and a technique to elicit memories.</p>
<p>Active Documentation Sketchbook (ADS) (De Freitas 2002)</p> <p>Materials: An A5 ringed sketchbook</p>	<p>The ADS was used as a reflexive and reflective tool by the ATR recording intuitive and resonant thoughts and images about the creative processes and the PRs lived experience of the project. The PRs 'intention' (Hogan 2013: 17) for the portraits was also documented as well as ongoing changes and modifications.</p>	<p>The ADS can be used to 'identify the evolution of a work process, capture accidental progress or problematic blocks, articulate those phases of work that become invisible with progress' (De Freitas 2002). The ADS is a place for reflexive & reflexive writing and note taking, enabling the identification of themes, meanings and connections in PRs stories and portraits (Moon 2002: 120).</p>

Figure 19. *Photo Elicitation & Active Documentation Sketchbooks protocol & reasoning*

Collier (1957) found that photo elicitation techniques 'elicited longer and more comprehensive interviews but at the same time helped subjects overcome the fatigue and repetition of conventional interviews' as well as 'its ability to prod latent memory, to stimulate and release emotional statements about the informant's life' (Collier 1957: 858). Pink (2009) says that photo elicitation:

[...] relies on the idea of the photograph becoming a visual text through which the subjectivities of research and research participant intersect. It can evoke

memories, knowledge and more in the research participant which might otherwise have been inaccessible, while simultaneously allowing the researcher to compare her or his subjective interpretation of the image with that of the research participant (*ibid*: 93).

Within the initial discussions with PRs the use of photographs acted as a focus for the conversation, and allowed the PRs to control this through their self-selection of the images to show and talk about. This was a useful process and one which was difficult to replicate if PRs had no photographs or very few to show, which did happen with two PRs. This then required a more imaginative engagement with the PRs stories of self-identity in order to arrive at an acceptable mental and physical image with which to work.

The aim of the ADS is to make the artistic methodological process explicit, in order to outline a rigorous and respectable ‘artistic method’, specifically appropriate to arts based research which is equal in status to a ‘scientific method’ (Grey & Malins 1993: 12). Within the ADS I utilised the PRs collaboratively negotiated *statements of intention* as a brief for the design of the portraits, encompassing their ‘essence’, which may or may not have included a ‘contemporary’ accuracy of likeness, within the portraits I attempted to include Freeland’s (2010) ‘testimony of presence’, ‘air’ and ‘uniqueness’ of the subjects and the relationship between the interior landscape of the mind/soul/spirit and the exterior surface of the embodied experience. Information from the ADS was used within the analysis chapters as a bracketed reflexive and reflective account that contributes to the discussion of the themes and essences found within the data.

In summary phase one of the project involved using creative emotional distancing tasks, utilising familiar, non anxiety provoking materials, (Buttons, Lego & Photographic), in order to elicit PRs stories of self-identity. This phase on average lasted between 1-2 weeks at the beginning of the project, although they could also be used at any stage to elicit further information. The ADS is used within this phase to facilitate the making and recording of artistic, reflexive and self-reflective processes and observations.

3.4.2 Phase 2: Collage & Prose Poems, Co-designing the Portraits/creating a statement of intention and the Portrait Reference Album (PRA).

During the second phase of the project I created collages and prose poems as ‘response art’ (Miller 2007; Fish 2012) containing ‘mirroring and attunement’ (Wright 2009) reflecting back stories of self-identity PRs had told me within phase one.

3.4.2.1 Collage as response art

Collage as a form of *response art* (Fish 2012) was important for this project as it employs metaphoric or symbolic connotations, rather than literal expressions of an idea allowing new associations and connections to be made, which might otherwise have remained unconscious (Vaughan 2005, Brockelman 2001, Davis 2008, Williams 2002, Butler-Kisber 2008). Contrary to the ‘permanence’ of oil paint in the portraits, the collages have a sense of *impermanence* and were used most often by PRs to explore difficult feelings, memories and existential questions.

The protocol and reasoning is outlined below:

Multi-modal Methods	Protocol	Reasoning
Collages & Prose Poems Materials: Paper & Mixed media	Using the stories of self-identity elicited from the button & Lego tasks, photo elicitation, and audio recordings, the ATR made collages & prose poems as a form of ‘response art’ (Fish 2012) and as a way to reduce the stories down to their essences or essential characteristics or meanings.	The ATR selected stories based on an ability to ‘resonate with’, or relate to the PRs experience, with the view that this would add ‘authenticity’ to the collage or poem. This also enabled a process of authentic ‘mirroring and attunement’ (Wright 2009) to take place within the poems and collages. This can be described as a ‘deeply felt’, ‘intuitive response’ (Lett 1998: 341). The co-designing and reflecting back to PRs enabled within the collages and prose-poems was a crucial part of the project. It was also from these collages and prose poems that ideas for the portraits sprang.

Figure 20. *Collages & Prose Poems Protocol and Reasoning*

In my initial design for this intervention I envisioned the collage and prose poem phase of the project to end when the portrait painting begun, however it was not as clear cut as that and I often felt the need to create further collages right up until the

final sessions with PRs. This highlights the need for continued flexibility within the design, also a propensity in the PRs to continually *remember* the self, and make connections with past, present and future selves.

3.4.2.2 Prose Poems as stories of self-identity reduced to ‘essences’

In poetry the reduction of words to their focussed essential meaning can be equated to a phenomenological reduction, as well as an emotional distancing tool and ‘containing’ (Bion 1962, 1967) form for strong emotions. It can also be a useful way for researchers to ‘reconstruct and confirm the lived experience of others’ (Carr 2003: 1330). I see the prose poems not as a way to re-present the same data, but as a way to ‘evoke different meanings’ and issues (Leavy 2009: 64) offering a new ‘porthole onto an experience’ (ibid: 68). Poetry ‘engages not only our intellect but our aesthetic sensibilities as well, calling forth our capacities for understanding based at an empathic, experiential level’ (Moon 2002: 269-70), and this offers a ‘balancing effect’ to the detached and dominant discourse in medical and mental health (*ibid.*).

Prose poems are written without the constraints of ‘verse’, however poetic qualities such as heightened imagery, metaphor and emotional effects are preserved. As Furman *et al.* (2007: 302) say ...

Poetry has become an increasingly valuable tool for social investigators utilizing expressive arts [...]. As a document of social phenomena, poetry can be viewed as a vehicle through which to communicate powerful and multiple ‘truths’ about the human experience.

Interest is therefore growing within arts-based research for many forms of ‘poetic inquiry’ (Prendergast *et al.* 2009: xix) and the use of prose poems in qualitative research is becoming prevalent (Brady, 2004; Clarke *et al.*, 2005; Saarnivaara, 2003). Poetry within art therapy is less common, although not unprecedented, as in a recent project Vivian-Byrne & Lomas (2007) combine art therapy and poetry to study the experiences of foster carers.

Poetry allows a focus through words similar to the focus required by the artist in portraiture, requiring a deeper level of awareness, allowing us to ‘feel, taste, hear

what someone is saying’ meaning that something ‘economical’ yet ‘rich and resonant’ can be achieved (Nielsen 2004: 42). Poetry allows us to listen over and under and around the words, to focus and hear that which is said and unsaid, poetry ‘defies singular definitions and explanations’ and reflects the ‘slipperiness’ of self-identity (Faulkner 2006: 99).

The prose poems enabled the extraction of metaphorical meanings and ‘essences’ from the self-identity accounts that the PRs told during the elicitation sessions, these were then shared and amended within the portrait sessions. Involving participants in the fine-tuning process helped to deal with ethical issues and contributed to the ‘crafting’ of the poems (Butler-Kisber 2002: 235). One PR offered their own poem to accompany a collage (i.e. Susan’s poem ‘The Rainbow Snake’ p181), and often poems were created intersubjectively between the PR and myself within the portrait sessions.

Although the prose poems were meant as ‘accompaniments’ to the portraits and collages they were also important ‘mirroring and attuning devices’ through my attempt to capture in words, the essence of the ‘story’ or aspect of self-identity that the PR had told me. It was sometimes quite difficult to make the transition from the visual to the verbal and it was important to negotiate with the PR the different meanings inherent within the language chosen. The prose poems added another dimension to the data, and as Leavy (2009: 82) says, using poetry as a research method ‘increases rigor in the interpretation and writing process, it does not diminish it’.

3.4.2.3 Co-designing the Portraits: Creating a Statement of Intention, Portrait Reference Album (PRA) & Appropriation Art

An important aspect of the co-designing process was to identify a statement of intention for each portrait, based on a series of negotiations. Sometimes PRs had concrete ideas from the beginning about how they wanted to be portrayed or the stories of self-identity depicted. However some PRs needed some help with this, usually by revisiting the collages and prose poems and looking through the PRA, identifying images they felt ‘drawn to’. The use of historical or ‘famous’ artworks or images from popular culture is known as ‘appropriation art’, which is defined as ‘the

intentional borrowing, copying, and alteration of pre-existing images and objects' (Gemmell 2012). I have used appropriation within this project as a way to engage PRs in the art process, through their recognition of famous works, or through an unconscious 'drawing towards' certain images, without knowing initially why. Appropriating images has meant that the original works were sometimes used as symbols or metaphors by the PRs. Appropriation was popularised by artists such as Marcel Duchamp (e.g. *Mona Lisa L.H.O.O.Q.*, 1919) and Andy Warhol (e.g. *Campbell's Soup Cans*, 1962). Contemporary artists such as Yasumasa Morimura (e.g. *An Inner Dialogue with Frida Kahlo*, 2001) use known images to create a pastiche, which unlike forgery, does not attempt to deceive viewers that the art created is by the original artist, however appropriation does depend upon viewers abilities to *recognise* the original painting and all its cultural and symbolic significance (Gemmell 2012), although these may be changed subtly in the appointed image.

Metaphor and symbolism were often used within the portraits to add meaning or significance. Metaphor is something which imaginative thinking and art both make use of. Neuroaestheticists Ramachandran & Hirstein (1999: 31) believe that metaphor is an important part of the aesthetic appreciation of art and provide a useful description of metaphor for this study, saying that a metaphor is a 'mental tunnel between two concepts or precepts that appear grossly dissimilar on the surface', and metaphors are used in many ways in everyday life, not just art and language, and include unique ways of thinking and understanding diverse phenomena (Lakoff & Johnson 1980). As such they were useful additions to the portrait designs.

The protocol followed and reasoning for the methods are discussed below:

Multi-modal Methods	Protocol	Reasoning
<p>Co-designing the Portraits: Creating a Statement of Intention</p> <p>Materials: paper/ADS</p>	<p>Working collaboratively with the PRs we created concise statements of intention for each portrait. This involved negotiations around meaning, symbolism, metaphor, temporality, realism, abstraction, composition and medium.</p>	<p>This is a concise statement of the PRs ideas for the portrait and their portrayal of self-identity. This enables the ATR to refer back to this and keep focused on the PRs intention for the portrait and not inflict their own artistic style or ideas. However, some interpretation of <i>the statement of intention</i> is inevitable and necessary as a direct mimesis does not engage with attunement.</p>
<p>Portrait Reference Album (PRA)/Appropriation Art</p> <p>Materials: Photo album containing over 100 postcards of portraits and portrait-sculptures, mainly Western in origin by famous and non famous artists, selected for their diversity. (See Appendix 10 for complete list)</p>	<p>PRs were asked to select portraits or portrait-sculptures that they felt 'drawn' to. A discussion then ensued about their use as reference or appropriation to depict an aspect or essence of the PRs self-identity</p>	<p>The PRA was used selectively if PRs needed help to access the world of art and portraiture, and to spark imaginative ideas including decisions relating to style, medium or composition.</p>
<p>Metaphor & Symbolism</p>	<p>PRs were encouraged to think in metaphorical and symbolic ways about how to represent intuitive, tacit, embodied and experiential knowledge within the portraits.</p>	<p>I believe that visual art utilises a specific kind of symbolism and metaphor, which work in a different way to narrative, with images having a more direct and immediate impact on our consciousness (Freeland 2010: 189; Kramer 2004).</p>

Figure 21. *Statements of Intention, PRA & Metaphor & Symbolism*

In summary phase two involved a series of negotiations with the PRs to form *statements of intention* for each portrait, sometimes using the PRA as a way to access the world of portraiture, and utilising metaphor and symbolism to depict aspects of self-identity. This phase often overlapped with phases one and three, in that sometimes the first portrait was begun before all three were designed, and sometimes further collages and prose poems were created after the first portrait was completed.

3.4.4 Phase 3: Painted portraits as 'third hand' intervention and research method

I have outlined in the table below the protocol and reasoning I have used for painting portraits as a research method and a 'third hand' art therapy intervention:

Multi-modal Methods	Protocol	Reasoning
<p>Painting the Portraits</p> <p>Materials: MDF boards, wood primer, oil paints and brushes, etc. The PR provided or posed for reference photographs where necessary. I purchased a digital SLR camera to ensure high quality images for reference, however I often had to use poor quality images provided by the PRs as these represented pre-illness images.</p>	<p>For portraits painted from life, a pose and location was agreed upon by the PR and ATR. The PR was made as comfortable as possible and told they could move if they needed to and take a break whenever required.</p> <p>Ideas for portraits developed mainly from the elicitation tasks, however the co-designing phase was ongoing. For studio created portraits once the design was decided upon the ATR discussed initial sketches with the PR and modified accordingly. Subsequently photographs of the portraits development were shown for the continued checking and modification by the PR. (Occasionally an initial idea was decided upon and the PR saw the portrait for the first time in its finished state, however the ATR remained open to subsequent modifications if required).</p>	<p>Portraits are relational in that they are created by someone for another. Portraits embody the self-identity of the person depicted. Directing how they wish to appear enables PRs to think about who they are and how they want to be remembered. The portrait becomes a tangible, physical object, imbued with the mirroring and attunement from the ATR. The portraits exist in present time, and can be handled and looked at by others. The portraits have an ‘as if’ quality, and the possibility to use ambiguous or symbolic imagery, which is able to hold contradictory or dualistic beliefs. Portraiture has the ability to ‘immortalize’ the sitter, and capture the time and attention afforded the PR by the ATR. Portraits can ‘strengthen’ a person’s sense of self-identity (Kramer 1971).</p>

Figure 22. *Painting the Portraits*

Within portraiture there is the potential for a ‘contest of wills’ between artists and their subjects over the way a person is represented, as an artist may wish to present their own vision or perceptions based on personal insight, which may mean the subject’s ‘air’ is lost in such contests (Freeland (2010: 115). The collaborative nature of the research and the co-designing phase of the portraits had an important role in mitigating this, with each PR viewed as the ‘expert’ on their lived experience of self-identity and how they wish to be portrayed. It was also important to remember that ‘to be portrayed by an artist is to appear in public’ (Brilliant 1991: 11), however, the focus was not necessarily about depicting the mirror like qualities of a ‘photographic’ portrait (unless the PR specifically choose this). PRs were given the choice to be painted in a way that reflected different aspects of their self-identity, which might include how they looked: in the present, prior to their illness, or in their early life. I refer to portrait ‘sessions’ rather than ‘sittings’ as ‘sittings’ imply ‘passivity’ on the part of the PR – whereas the aim was for empowerment and engagement in the collaborative co-designing process.

The amount of time I spent working on collages and portraits away from the PRs varied, depending upon the design choices of the PRs, however I found that the time devoted to this was important for the therapeutic process and also for my own cathartic processes to mitigate feelings of embodied counter-transference (Booth *et al.* 2010) (as discussed in section 3.3). Some portraits took several weeks to complete, whilst others took less than an hour, this depended upon the size, medium and style requested by the participant, (e.g. a small cubist or impressionist style portrait could be achieved in a couple of hours, whereas larger highly detailed work took several weeks to complete). In hind sight I would restrict the number of portraits or portrait-sculptures produced for each PR to 3 as a general rule, however it is also important to be flexible and patient-led on this, and I think this flexibility was a key element in the success of the project. There is always a danger within palliative care to feel an existential need *to do more for patients*, caused by an institutional fear of *annihilation* inherent within palliative care (Duesbury (2005: 202), certainly this is something which I have experienced within this project, and highlights the importance of having a clear ending (Edwards 1997) focused on the completion of the portraits and the EPI, in order to help mitigate this.

Most portrait sessions with PRs were audio recorded, however, sometimes it was not possible to do so, either because the surroundings were inappropriate, e.g. noisy, or because of PRs choice, or failure of equipment. In these instances I took contemporaneous field notes, which were typed up later that day. These recordings and field notes were then used to facilitate the making of collages and prose poems to reflect back to PRs, the validity of the content was therefore verified throughout this process.

In this section I have described the protocol and reasoning for using portraiture as a ‘third hand’ therapeutic intervention and research method within this study. I have highlighted potential problems with this method and how I have attempted to resolve or mitigate these. Phase 3 ended with the semi-structured end of project interviews (EPIs).

3.4.5 Semi-structured End of Project Interviews (EPIs)

During the EPIs PRs had the opportunity to view the framed originals of all their completed portraits, collages and prose-poems and were given framed prints of each portrait and coloured copies of the other creative output. The EPI protocol and rationale is detailed below:

Multi-modal Methods	Protocol	Reasoning
End of Project Interview (EPI)	The interview was semi-structured, with a core set of flexible and open-ended questions attempting to avoid questions that were value laden and leading (for a full list of questions asked see Appendix 9). All final interviews were recorded and transcribed verbatim and are included at the end of each PRs' case-study. Case-specific questions were sometimes added to ascertain whether I had correctly understood and interpreted the PRs responses and stories, introducing themes that were identified as important to the participant within the portraits.	Semi-structured interviews were chosen as these are flexible within a framework, a conversation engaged with the PRs, rather than a directed list.
PR Checking of themes and voices within the Analysis	I spent time with each PRs after the analysis and case study stage to discuss the interpretations, meanings and findings and modified if necessary.	This meant that PRs had the opportunity to discuss final interpretations and meanings of the data, to ensure a reflection of their lived experience.

Figure 23. EPI and PR Checking

Within the EPI I used the *reflexive-relational phenomenological* research approach (Finlay 2011) where interviews may be 'unstructured conversations or semi-structured' with pre-prepared questions used as an '*aide-memoire*' focusing device, or a combination of the two (ibid: 199). The aim within a phenomenological research interview is to gain as full a description as possible of each PRs lived experience of the phenomena in question (Giorgi 2009: 122).

I drew from transcripts of these interviews when conducting the analysis, using PRs verbatim accounts in order to corroborate the 'essences' and themes that emerged from the visual data. In consultation with the PRs I also identified a section of the

PRs voice recordings (condensed to approximately 3-5 minutes) to be used as an audio testimony, to accompany the portraits when exhibited or published or used to create an audio-image recording (AIR) (Springham & Brooker 2013).

Within the final interview transcripts I have included my own part in conversations as a way to make the process more transparent, and acknowledge that within the intersubjective encounter, meanings were co-created (Rapley 2001: 319; Etherington 2004b: 46; Etherington & Bridges 2011: 13). During a follow up meeting to read through their case-studies together, the PRs were given the opportunity to read and amend their EPI transcripts, and discuss the interpretations and meanings drawn. Several made amendments at this stage. PRs were given a copy of their case study/analysis and EPI transcripts to keep and reflect upon further if they desired.

In the EPI extracts some changes were made to improve readability and understanding, such as deleting repeated words or hesitations such as 'erm' and adding material to aid understanding. Where words are cut this is indicated by [...] and where they are added they appear within square brackets as [e.g.]. Also any identifying information may have been changed or removed.

Within this section I have described the EPI process and rationale, and how I have used this within the analysis and case-studies. I have shown that PRs were given the opportunity to amend the EPI transcripts if they so wished.

3.5 Phase 4: Methods for Visual Analysis

In this section I begin by explaining the methods of phenomenological analysis I have adapted to create a synthesis method for the various creative elements of this study, why I chose them and how they helped to answer my research questions. This study seeks to answer epistemological questions about what can be *learned* or *known* about self-identity revisioning through portraiture and the intersubjective mirroring and attunement therein. This has involved, discovering and creating ways to explicate and analyse PRs lived experience of self-identity revisioning, within the multiple data modalities.

There are many debates about what constitutes ‘appropriate’ phenomenological research (Finlay 2009: 25) and no ‘clear-cut recipes explaining how to engage in phenomenological analysis’ (Finlay 2011: 228), therefore Finlay suggests developing an approach that ‘works for you’ (*ibid.*).

In selecting and adapting methods for analysis I am aware that I am constructing a ‘theoretical and ontological’ filter through which to analyse the PRs identities (Mauthner & Doucet 1998: 23). Whilst I accept that this choice will affect the results achieved, the process itself aims to be transparent, enabling other researchers to trace the procedures followed as well as my reflexive decision making process (*ibid.*). It is often in the analysis stage of research that the power differentials over PRs is most highlighted (Mauthner & Doucet 1998: 23), and whilst it is impossible to avoid some degree of researcher-interpretation within the analysis and conclusions, I hope to have mitigated this by working with the PRs to intersubjectively negotiate interpretations and meanings within the case-studies.

3.5.1 Arts-based Life/World Phenomenological Analysis

Phenomenological research is ‘discovery-orientated and offers a way of explicating the essential qualities and structures of art therapy phenomena’ (Quail & Peavy 1994: 45-6) as well as employing ‘phenomenological reduction, which implies the bracketing of past knowledge about the phenomenon being experienced’ (Giorgi 1992: 5). The phenomenological method is a process of becoming aware of our ‘preconceptions and understandings’, what Sartre called ‘self-reflective

consciousness’, thereby ‘making ourselves transparent’ in order to ‘disentangle’ the ‘fusion of horizons (to use Gadamer’s terms) between subject and object’ (Finlay 2002) and an acknowledgement that ‘what we can learn and know about another arises within the intersubjective space *between*’ (Finlay 2009).

There are many different ways of carrying out phenomenological analysis and this was initially confusing for myself as a first time researcher in this field. It was difficult to find descriptions of analysis protocols, particularly those that incorporated a variety of verbal, written and artistic data with a collaborative approach. However, I found the MIECAT (Melbourne Institute of Expressive & Creative Arts Therapies) experiential phenomenological approach (as developed by Lett, Allen, Morrish and Rumbold in 1997, website at <http://www.miecat.org.au/>); and Finlay’s (2011) Reflexive-relational Phenomenological model particularly insightful for this study, leading to the development of the analysis method I have used within this project. This incorporates both *phenomenological reduction* (Husserl 1977 [1929], 1970 [1954]) and *phenomenological hermeneutic interpretation* (Heidegger 1962 [1927]; Gadamer 1975), in order to bring together the *life* experience (the return to the things themselves through reduction to essences) and the *world* (the re-introduction of cultural and historic meanings and understandings) of lived experience. It therefore recognises that *life* or experience does not happen in a vacuum, it is always situated in the *world* and therefore understandings and meanings are co-created relationally through both *primary pre-reflective knowing* and *secondary reflective learning*, in order to make sense of experience. This acknowledges the critics of Husserlian phenomenology who have claimed that phenomenological reduction ignores the cultural and historical being-in-the-world and its meaning.

The principle of ‘intentionality’ is also important for this study and can be described as our ‘inseparable connection to the world’ (van Manen 1990: 5), how we are always directing our attention *towards* something. This project therefore focuses on the ‘cooperation of intention with intuitive searching, together with the transformations from inner to outer representations and the processing through reexperiencing’ (Lett 1998), in order to evaluate the significance of the phenomena in question. This approach shifts the emphasis from ‘researcher verification to a joint co-researchers’

intersubjectivity in pursuit of dependable and articulated understandings' (Lett 1998: 333) and coherent meanings.

I have combined both approaches within the analysis to further the understandings gained within this project. This equates to a 'stepping into' the portraits, to experience them 'as if' I am there within the image, experiencing it anew, and then stepping out and stepping back from the portrait, in order to experience its significance within the sociocultural life world of the PR. I then use these two experiences to create essence statements of *knowing* and *learning* respectively.

Finlay (2009) warns that within phenomenological studies researchers must be closely supervised in order to avoid common mistakes such as becoming preoccupied with their own experiences and emotions. I have attended supervision/personal therapy with a state registered drama therapist prior to and during this project, as well as attending supervision at the hospice and Loughborough University, and therefore hope to have minimised this risk.

I have used six steps for the *Arts-based Life/World Phenomenological Analysis* and outline them in the following table:

Reduction to Essences	Protocol	Rationale
1. Make a statement of Reflexive Resonance for the portrait	This process brackets out, but acknowledges any personal resonances, or what the image means for the ATR.	This is a reflection on the phenomena from a personally reflexive and reflective position by the ATR. This serves to bracket out the ATRs personal interpretation of the phenomena.
2. Step into the image. Experience being in the image as it is the first time you have been there, employing intuition, wonder and curiosity.	Write down any sensory, intuitive and resonant words and phrases that come to mind (Lett 1998: 332). Bracket out any prior knowledge or assumptions.	Husserl's (1970 [1954]) <i>transcendental</i> phenomenology involves bracketing out prior knowledge and assumptions to enable a 'return to the things themselves' and a pure description of the essence of a phenomena, to elucidate the phenomena, to find out what can be known. This process uses <i>pre-reflective</i> experiencing (Spinelli 1995: 24) as a way to immerse one's self in the phenomena, and achieve an 'amplified awareness' (Lett 1998: 340) or 'indwelling' (Moustakas 1990: 24).
3. Step back from the image create distance and focus on the bigger picture including cultural or symbolic references.	Write down any words or phrases that come to mind.	This description gathers subjective and cultural meanings to elucidate the sense PRs are making of the phenomena. This process uses <i>reflective</i> experiencing, dwelling on the data to discover meaning and sense.
4. Sorting & Titling Self-Identities (Lett 1998: 332)	Group the words generated by steps 1&2 into lists of similar words to make self-identity categories. Title the lists as voices of PRs self-identity.	This is a process of gathering, sorting and reflecting upon the data, to create lists of words based on their 'sensed connectedness and shared meaning' (Jones 2008: 10).
5. Extracting the Essences (Lett 1998: 332)	Create an essence statement/description of experience for each list/theme, based on the words within it.	This is a process of identifying the essential features or themes of the phenomena.
6. Synthesis of Essences	Write two final essence statements: Statement of Emergent Know?ing This statement focuses on the essences derived from stepping into the image and experiencing it anew. Statement of Emergent Learning This statement combines and brackets back in the cultural and symbolic references identified in step 2.	Heidegger's (1962 [1927]) <i>hermeneutic</i> phenomenology goes beyond the description of essences to discover the <i>meaning</i> of an experience by including <i>interpretation</i> . This is a way of combining the data to discover something further about the phenomena itself, through the synthesis of essences.

Figure 24. Six steps for the Arts-based Life/World Phenomenological Analysis

The MIECAT (Melbourne Institute of Expressive & Creative Arts Therapies) approach leads to identifying ‘personal themes and individual patterns of being in the world’ (Jones 2008: 42) and sees each person as *expert* on their own experience and acknowledges that we experience the world and each other through multi-sensory and intersubjective ways.

3.5.2 Phase 5: Voice Centred Interpersonal Analysis

Portraits are silent and yet they ‘speak’ a universal language. It seemed logical therefore to look for ‘voices’ of self-identity as well as themes when analysing the portraits using the *arts-based life/world phenomenological analysis*. This led to identifying several different self-identity voices personal to each PR, which could then be listened for and identified within the *voice centred relational analysis* (Balan 2005; Gilligan *et al.*, 2003; Mauthner & Doucet 1998). I chose to adopt more than one approach to the analysis for this study, as I felt that focusing on just one method might have biased the interpretation to ‘fit’ the chosen model, and that by using two a more rigorous analysis could be achieved.

For the analysis of verbal data gathered within the end of project interviews I have therefore used an adaptation of *voice centred relational analysis*, developed by Brown & Gilligan and their colleagues in the USA (see Brown & Gilligan 1991, 1992, 1993; Brown *et al.* 1988; Gilligan 1982) during their feminist research into the lives of women and girls in the fields of developmental psychology and education (Mauthner and Doucet 1998: 8). The method is rooted in relational theory and hermeneutics (Brown & Gilligan 1992) and aims to explore within individuals’ verbal accounts: ‘their relationship to themselves, the people around them’ and ‘to the broader social structural and cultural contexts within which they live’ (Mauthner & Doucet 1998: 9).

I used the protocol as outlined by Balan (2005) as an example of Gilligan *et al.*’s (2003) voice-centred relational analysis method that I could easily adapt for this project. Gilligan *et al.*’s (2003) method consists of four main steps that involved multiple ‘listenings’ to voice recordings of participants, these were:

1. To listen for the plot.

2. Listening for and underlining 'I-Me' statements to make an 'I Poem'.
3. Listening for and underlining contrapuntal (multiple) voices.
4. Composing an analysis.

As I had already used the Arts Based Life/World Phenomenological Analysis to analyse the portraits, which had generated a list of 'identity voices' for each PR and a list of emergent themes, I therefore adjusted this analysis for the following purposes:

1. Listening for and underlining 'I-Me' statements to make an 'I Poem'.
2. Listening for and underlining contrapuntal (multiple) voices of analysis as identified within the portraits.
3. Listening for and underlining the emergent themes.
4. Composing an analysis in the form of the case studies and for cross case analysis.

The 'I Poems' helped with gaining an overall picture of the PRs' sense of self-identity and the multiple listenings for voices of identity served to check the validity of, and enhance the phenomenological analysis of the portraits. Listening for the emergent themes enabled a cross case analysis of the themes to take place.

I have therefore adapted this method to *listen for* (and highlight within the transcripts) the different voices of identity as identified by the *Arts-based Life/World Phenomenological Analysis*, through a process of multiple 'listenings'. As Gilligan says, 'The need for a series of listenings arises from the assumption that the psyche, like voice, is contrapuntal (not monotonic) so that simultaneous voices are co-occurring' (Gilligan *et al.*, 2003: 159). It is also important to *listen* for voices of self-identity – rather than *reading* them, because *listening* requires a different sensory modality, with intention and meaning contained within tone of voice, inflection, pauses and emphasis. This process enabled a further period of 'indwelling' (Moustakas 1990: 24) or 'dwelling with the data' (Finlay 2011: 228), recognising that analysis is an ongoing process.

The process, protocol and rationale are discussed in Figure 25 below:

Adaptation of Voice Centred Interpersonal Analysis	Protocol	Rationale
Identifying PRs voices of self-identity within the EPIs	Whilst listening to the PRs EPI audio recording, I used different coloured highlighter pens to mark the transcript of the PRs end of project interview (EPI) where the individual self-identity voices, as identified in the <i>arts-based life/world phenomenological analysis</i> , were heard.	This enables the voices of self-identity found within the phenomenological analysis of the portraits to be searched for within the EPI text. This is a way of double checking that the voices of self-identity emerging from the visual analysis can be found in the EPIs, thereby increasing rigor and validity.
Voices of Self-identity Essence statements	Write a statement about each self-identity voice.	Note where the different voices take precedence over other voices, or other dominant voices. The way these voices interact and dominate or are subversive, say something about the PRs experience.
Identifying Themes	Listen to the EPI audio recording again and using different highlight pens, mark the transcript of the PRs (EPI), where you hear the different themes as identified in the <i>arts-based life/world phenomenological analysis</i> ..	This enables the individual themes to be identified within the PRs EPIs and their ‘voices’ used within the case studies to explicate their lived experience of the intervention.
Identifying Master Themes	Look for correlations between PRs lived experiences. Move sections of PRs EPI transcripts into lists of text relating to the themes.	This enables a cross case analysis of themes, found within the PRs EPIs, and the discovery of master themes. These can then be explicated to describe where the lived experience of the PRs converge and therefore how their experience can be generalised.

Figure 25. *Voice Centred Interpersonal Analysis*

I have chosen this method as it attempts to keep the voices of the PRs intact, and enables a direct link between the verbal and visual data, as well as insight into how the different ‘voices of self-identity’ interact, dominate or intercede within the EPIs.

3.5.3 Multiple case-study design

A case-study is defined as an ‘empirical inquiry’ which ‘investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are

used.’ (Yin 2009: 23). Following the analysis phase I used the emergent themes and voices of self-identity to write case-studies for each PR, drawing in the different elements for an overall view and discussion. The decision to use a case-study design was influenced by the need for a qualitative research method that could incorporate the multiple data collection and dual data analysis methods within this study (Yin 2012: 10). Finlay (2011: 175) suggests that case-studies are ‘most appropriate’ for a relational-centred approach to phenomenological research into ‘existential topics, particularly when conducted by psychotherapists who are already familiar with reflexive and relational approaches to working’ (*ibid.*).

Art Therapist David Edwards (1999: 6) identifies the case-study as a method of enquiry which addresses key aspects of clinical work in art therapy, specifically it: focuses on ‘the ‘individuality’ of the client and the way they communicate through actions, words and images,’ it embraces the ‘richness, diversity, messiness and complexity’ of clients’ lived experience and the art making process. It doesn’t require that we turn ‘subjects (i.e. people) into objects’, and it allows us to write about research in a way that is ‘recognisably human’. Case-studies are also inexpensive compared to large scale studies, and encourage the inclusion of the voices, personalities and creativity of the clients and therapist/researcher (Edwards 1999: 6).

An important consideration was the way each of the individual cases stood alone as an explication of the PRs lived experience, whilst cross-case analysis enabled the drawing of convergent understandings or ‘triangulation’ (Yin 2011: 13). Some critics suggest that due to the small number of cases researched, it is not possible to generalise the findings or establish reliability, however as Hogan (1997: 237) says, the relevance of one or more person’s experience to others in a similar situation is a key way that case-studies gain validity. Also within phenomenological studies the aim is for detailed accounts of participants’ lived experience and for researchers to make *tentative generalisations* from the cross case analysis (Smith *et al.* 2009), however as Warnock (1987, cited in Smith 2004: 42) says, ‘delving deeper into the particular also takes us closer to the universal’. The focus of the cross-case analysis is therefore concerned with explicating the PRs unique experiences and how these relate to the PR group as a whole, and the implications of this for wider contexts.

3.6 Reliability and Validity in Phenomenological Research

Issues around reliability and validity are considered differently in phenomenological studies, where ‘essential meaning, the sense of the empirical rather than facts’ is highlighted (Quail & Peavy 1994: 47). Giorgi (1989) suggests that trustworthiness within phenomenological research can be established through the researcher presenting a convincing and thorough investigation, and establishing worthwhile results when measured against the original aims of the study. It is also important to demonstrate methodological congruence (rigorous and appropriate procedures) and experiential concerns that provide insight in terms of plausibility and illumination about a specific phenomenon’ (Pereira 2012: 19).

For the purposes of this study I use Finlay’s (2011) four ‘Rs’ of ‘good’ phenomenological research:

Finlay’s (2011) four ‘Rs’ of ‘Good’ Phenomenological Research:
<p>Rigorous phenomenological research includes: competent management, transparent systematic processes, critical reflection, coherent description, plausible and convincing interpretations. The use of quotes from interviews to illustrate themes. The testing of knowledge claims through discussions with co-researchers, supervisors and colleagues. (Finlay 2011: 61)</p>
<p>Resonant phenomenological research includes: tapping into the emotional, aesthetic and spiritual, generating and presenting findings in a rich and elegant way that ‘touch’ others vividly, powerfully, and gracefully, pushing the boundaries of what is already known (Finlay 2011: 62)</p>
<p>Reflexive phenomenological research includes: The researcher accounting for their subjective responses and impact on research and exploring the creation of shared meanings within the intersubjective relationship. Demonstrating ‘ethical integrity and concern for the wider impact of the research’ as well as displaying ‘humility’ through an acknowledgement of the limitations inherent in any findings or knowledge generated (Finlay 2011: 62).</p>
<p>Relevance phenomenological research includes: Consideration for the ‘value of the research in terms of its applicability and contribution’, adding to knowledge around a social or human issue or therapeutic practice or processes and ‘empowering’ or ‘growth-enhancing for either the co-researchers involved and/or the readers’. (Finlay 2011: 61-2)</p>

Figure 26. *Finlay’s (2011) Four ‘Rs’ of ‘Good’ Phenomenological Research.*

I have demonstrated a **rigorous** and competent management of the project, helped by the development of a detailed protocol within the second year of this study, and the use of transparent methodical procedures within the data generation and analysis. In my position as art therapist I have attended courses on data protection, ethics and safeguarding adults, all of which have been useful within this study. I have employed visual cues within the analysis chapters to help create a coherent description, e.g. by using different coloured boxes for the various statements of essences. This study involved ongoing PR feedback or ‘member checking’ (Doyle 2007) in all aspects of this study, including a review of the analysis and emergent identity voices and themes (van Manen 1990). This gave the PRs and myself the opportunity to negotiate meanings and find areas of convergence in our perspectives (Bradbury-Jones *et. al.* 2010: 29).

To ensure **resonance** I made all efforts to reflect the PRs lived experience through the portraits, collage and prose poems in a way that encapsulates the ‘essence’ of who they are, incorporating spiritual and aesthetic meaning. When the portraits were exhibited, viewers found the work powerful, and when presented at conferences delegates have spoken of the ‘power’ of the portraits, collages and prose poems, to resonate with them. I push the boundaries in art therapy by reversing the terms of engagement and employing the art therapist’s ‘third hand’. Portraiture is an innovative and as yet little researched method.

The project is highly **reflexive**, I have documented my thoughts and feelings within the ADS, I see myself as a co-researcher with the PRs, and acknowledge that the artwork and interpretations within this study are all co-created. I have not edited out my own voice within the EPI in order to offer transparency. I have considered the ethical implications of the study, seeking advice from my art therapy colleagues, university supervisors, other portrait artists and colleagues within palliative care. I acknowledge that the findings from this study are limited due to the nature of reflexivity, and that another ATR working with these PRs may have resulted in different outcomes. I also recognise the transient and constantly evolving nature of all knowledge and my own re-interpretation or ‘attunement’ of the PRs images of self-

identity within the portraits, collages and prose poems, and it is with this in mind that I tentatively offer the *statements of emergent knowing* within the analysis chapters.

This project demonstrates **relevance**, through answering calls for further research in this area and the development of an art therapy intervention to ameliorate self-identity issues as identified within my own art therapy practice within palliative care. As such this project offers a valuable contribution to knowledge within art therapy practice and wider implications within palliative care, portraiture and self-identity studies. In order to ensure relevance for the PRs, patients attending day-hospice were involved in the initial design and development of the project protocol. All the PRs talked in their EPIs of the project being of significant value to them.

3.7 Summary

In this chapter I began by describing and discussing the practical and ethical issues surrounding painting portraits *for* PRs, as well as the importance of using multiple methods of data generation, that recognise the PRs as experts with autonomy over the design of the portraits and control over how they are represented within them. I then described and discussed the methods used to generate the data for analysis within the five phases of the project. In phase one the emphasis was on the use of button, Lego and photo elicitation tasks, to help PRs describe their lived experience of self-identity and the impact of LT&CIs, and the development of the ADS as a creative, reflexive and reflective space to document the processes involved. Phase two focused on the use of collages and prose poems as *response art*, reflecting the PRs stories back to them in a visual and poetic form, and the subsequent negotiation of *statements of intention* for the portraits. Phase three included a discussion of the reasoning behind the use of portraiture as a third hand art therapy intervention, and the protocol used for painting the portraits, which may have included painting from life, or using reference photographs and the *appropriation* of works by other artists through the PRA. I have highlighted potential problems with this method and how I have attempted to resolve or minimise these. Phase three ended with the semi-structured end of project interviews (EPIs), I have shown that PRs were given the opportunity to adjust or amend the EPI transcripts if they so wished.

Phase four included the visual analysis of the data generated by this project; I have outlined the reasoning behind the selection of a *reflexive-relational* (Finlay 2011) and *experiential* (Lett 1998) phenomenological analysis methods to adapt for the visual data, and the perceived advantages for this project. I described the combination of transcendental and hermeneutic phenomenological approaches to the analysis, which facilitated the description, and interpretation of the lived experience of the PRs, as well as the bracketing out of my preconceptions and reflexive resonance. I also described how this study correlates with Finlay's (2011) four 'R's' of 'good' phenomenological research.

Phase five consisted of the adaption of *voice centred relational analysis* (Balan 2005; Gilligan et al. 2003; Mauthner & Doucet 1998), which enabled PRs voices of identity

to be identified and used within the discussion. I have adapted this method to *listen for* (and highlight within the transcripts) the different voices of identity as identified in the *arts-based life/world phenomenological analysis* through a process of multiple 'listenings'.

I also described my rationale for a multiple-case study-design and how this fits with a phenomenological study. These case-studies were then offered to PRs for their final adjustment and approval, ensuring that the descriptions and negotiated interpretations accurately reflected their lived experience of the intervention. In chapter four I first introduce the seven PRs collaborating in this study, followed by a description of the findings. I then begin looking at the data in more detail, focusing on those themes clustered under the heading *increasing the PRs creative capacity to adapt to illness*.

4.0 Chapter 4. ‘Paint me this way’: The PRs lived experiences of portraiture

Within this chapter I will first introduce the PRs involved in the study, followed by a summary of the findings. I then discuss the themes and sub-themes that have emerged from the data, clustered under the heading *increasing PRs creative capacity to adapt to illness*.

In order to ensure the PRs voices are fully heard, as far as possible I have used the PRs dialogue translated verbatim from the EPI within the discussion. However to improve readability I have sometimes made minor changes, removing word repetitions, etc. I have indicated missing material by using bracketed dotted lines [...], and where I have added material to explain what a PR is referring to, this is indicated within square brackets [e.g.]. Dotted lines without brackets e.g. ... indicate a pause or a break mid sentence.

4.1 The Participants: Patient/Researchers (PRs)

The names used for the participants are those they elected to be known by and may or may not represent their ‘given’ first name. The ages presented are the age of the PRs at their commencement of the project. The following are descriptions taken from those offered by PRs about their self-identities during the portrait sessions. The participants in this study were all white British citizens, which reflected the demographic of the hospice. This demographic does limit the findings and it would have been useful to include people from other ethnic backgrounds had that been possible. The PRs (3 men and 4 women aged between 49-92) were all from different social and economic backgrounds, and living with a diverse range of LT&CIs, therefore offering further sample diversity.

4.1.1 Rose

Rose, a 61-year-old lady, was diagnosed with Motor Neuron Disease (MND) over twenty years ago and therefore has what she described as a ‘slow onset’ form of MND. MND is a neurological disorder which has primarily affected Rose’s speech, swallowing and the muscles in her face. Rose has a facial palsy and her lower lip falls open unless she holds it closed, which she tends to do when she speaks and eats. Rose is unable to smile or make any other facial expression and her speech is severely

affected with communication therefore difficult. Rose was an only child and her father died when she was 15, and said she did not 'get on' with her mother. Rose lives in a flat which she rents from the borough council, she has been married and divorced twice, has two sons and a daughter from her first marriage, as well as a grandson and granddaughter. Rose is estranged from her daughter and one of her sons. Her other son lives nearby and has severe mental health problems. Rose sees her grandson and granddaughter frequently; they are in their early 20's. Rose had worked in various shops and factories prior to, during and after bringing up her children (for the most part) alone.

Rose engaged enthusiastically with this project, using the photo elicitation and button and Lego tasks to outline her stories of self-identity. Together we co-designed three portraits, and ten collages and prose-poems.

4.1.2 Hilary

Hilary, (a 64 year old lady) was diagnosed with Cancer six years prior to commencement of our work together. Hilary is married with three grown up children and several grandchildren, ranging in ages from 6 months to 11 years. Hilary was the youngest of three children, with an older brother and sister. Hilary comes from a religious family and has a strong Christian faith, and is licensed as a lay reader within the Church of England, allowing her to preach and conduct services. Hilary describes herself as non-academic at school, saying her siblings were both 'cleverer' than her. Hilary described her mother and sister as 'gregarious' whilst she has always been the 'shy' one. Hilary has a keen interest in genealogy and ancestry, particularly of her father's family. Hilary's father was a famous and creative person. Hilary has red hair, whilst her family and siblings were all dark haired, although one of her grandchildren has inherited her red hair. Hilary is primarily affected by her disease through suffering pain, fatigue and sickness, and can only eat a limited diet. Hilary has undergone extensive treatment for her disease including several operations, chemotherapy and radiotherapy.

Hilary found engaging in this project difficult at first – however as we worked together Hilary allowed herself to be more imaginative, and she gradually became

more confident in the process. Together we co-designed three portraits and 10 collages and prose poems.

4.1.3 Peter (& Mark)

Peter is a 69 year old gentleman, diagnosed with Chronic Obstructive Pulmonary Disease (COPD) (a progressive lung disease for which there is limited treatment and no cure). Peter is married with four grown up sons (one of whom, called Mark, died recently aged 47). Peter has several grandchildren between the ages of 5 and 16. Peter has a half brother, who he sees quite frequently. Peter's parents divorced when he was 11 years old, and Peter became estranged from his father. Peter blames his mother for poisoning his mind against his father. Peter's mother remarried and Peter's half brother was born a few years later. Peter's family ran a florist shop and Peter remembers going up to Covent Garden with his father to buy flowers, and making up posies at a young age. Peter joined the army at the age of 16 and was transferred to Kenya. Peter was a flyweight boxer in the army. Peter was involved in a fatal accident whilst in Kenya, when the lorry he was travelling in went over a cliff. Peter had been on his way to the airport to return to England for his wedding. Peter recovered from his injuries, suffering psychological damage. Peter's first child Mark was born in Kenya.

Peter left the army to help work in the family florist shop. Peter later became a fruit and vegetable wholesaler, however this business eventually folded for which Peter blamed himself. Peter then became an insurance salesman. Peter enjoyed playing golf before he became ill, and taught his sons, including Mark to play. Peter also enjoyed going to horse racing events and placing some bets. Peter's illness has severely compromised his life style as he struggles to breathe most of the time, needing to use oxygen frequently. At the time of meeting Peter his son Mark had died six months previously at the same hospice he now attends. Mark died of cancer, and had suffered from severe epilepsy from one year of age. Peter blamed the epilepsy drugs prescribed to Mark for giving Mark cancer. Mark had difficulties with reading and writing, which Peter said was due to his epilepsy and although he lived alone, Mark received continued support from his parents and brothers. Mark was very good

at playing golf and won many trophies, and Peter was very proud of him and devastated by his death.

Peter engaged with this project wholeheartedly despite his recent bereavement and together Peter and I co-designed six portraits (including two of Mark, two of Peter and Mark, and two of Peter), and 12 collages and prose poems.

4.1.4 Bill

Bill (a 91 year old gentleman) was diagnosed with cancer a few years prior to the commencement of this study. Bill was born in London and had two sisters, now deceased. Bill's father ran a butchers shop, where Bill worked on leaving school. Bill's mother died suddenly of a heart attack when Bill was still a young man and his father never remarried. Despite working in a profession where he was exempt from being 'called up', Bill joined the army during the Second World War, volunteering for the army flying corps. Bill was physically very fit as a young man, becoming a boxer in the army winning many fights, he also won cycling races in his hometown. Bill trained as a glider pilot and gained the rank of staff sergeant. Bill was involved in flying missions during D-Day, Pegasus Bridge and Arnhem. During the battle for Arnhem Bill was shot in the right lung and captured by the Germans. He was then sent to Stallag 11B prisoner of war camp, where he remained until the end of the war. In the POW camp Bill was made a 'barrack chief' in charge of 200 prisoners of war.

Bill met his wife whilst he was undergoing flying training, however they were not married until two years after the war ended, as Bill was sent to a sanatorium to recover from his (untreated) wounds. After they were married Bill joined his father-in-law's painting and decorating business, and his two children, a girl and a boy were born. Bill has several grandchildren and great grandchildren. Bill's wife died ten years ago, and Bill nursed her at home throughout her illness. Up until recently Bill was an active member of his local army veterans club, giving talks about his experiences, including appearing in several television programs about the war. Bill's mobility has been severely affected by his illness, and he is no longer able to walk. This causes Bill many problems as he lives alone and he relies on carers to support

him with his basic needs. Bill's family live nearby and also give him as much support as they can.

Bill engaged enthusiastically in the project, and together we co-designed four portraits and sixteen collages and prose poems, as well as appearing on ITVs *Tonight* program together (05/07/2012) talking about the portraits.

4.1.5 Susan

Susan (a 62 year old lady) was diagnosed with cancer several years ago and although her disease was 'inoperable' has undergone radio and chemotherapy treatments. Susan has one half-brother from her father's previous marriage –although she was essentially an only child as her half-brother did not live with the family and she seldom saw him. Susan described her childhood as 'miserable', saying her father had an unpredictable temper and she described him as 'a brute'. On leaving school Susan worked for an accountancy firm. Susan married young, and had two children, however the marriage ended in divorce and several years later her ex-husband died. Susan met and married her present husband several years later and they have been very happy together. Susan's parents have both now died, her mother dying of cancer. After Susan's children left home she returned to studying and gained her BA, MA and PhD degrees, beginning an academic career at a university, gaining recognition for her academic writing. Susan has three grandchildren.

Before Susan's diagnosis she was physically fit, enjoying travelling, walking and playing golf. Unfortunately these pursuits are no longer possible, as Susan's disease and treatment have severely affected her mobility, suffering extreme pain and discomfort meaning she is only able to walk very short distances with crutches, and mainly uses a wheelchair or motorised scooter.

Susan engaged instantly with the project and was an insightful and enthusiastic co-researcher. Susan and I co-designed four portraits, five portrait-sculptures' and ten collages and prose poems. Susan also wrote one of the poems 'The Rainbow Snake' in its entirety (see page 180).

4.1.6 Norma

Norma (a 59 year old lady) has suffered ill health throughout her life, and has been diagnosed with brittle asthma, heart failure and arthritis. Norma has also suffered from several strokes recently that has left her with a weakness down her left side. Norma was born in Aberdeen and was abandoned by her mother when she was three days old. Her parents were unmarried and her father wanted to adopt her, however her mother refused. Norma was sent to an orphanage run by Nuns, where she stayed until she was three years old, she was then placed with various foster families. A year or so later she was adopted, however, there were already two male siblings in the family who did not accept her. When she was first adopted Norma was very withdrawn and frightened and would not do anything without being told to. Norma underwent heart surgery when she was seven years old and was absent from school for about a year, which resulted in Norma struggling academically. Norma left school when she was 14 and went to work in a 'fish factory' in Aberdeen. Norma met and married her husband when she was 18 years old. Norma suffered many miscarriages and stillbirths, losing seven babies over the years including a two-year-old son who died of cancer. Norma has two surviving sons and several grandchildren. Recently Norma has embraced the North American Indian spirituality and has been adopted into a Native American Indian tribe. Norma engaged enthusiastically with this project and together we co-designed four portraits, nine collage and prose poems and co-created one portrait-sculpture.

4.1.7 Paul

Paul, a 49 year old single gentleman, was diagnosed with Chronic Obstructive Pulmonary Disease (COPD) (a progressive lung disease for which there is limited treatment and no cure), three years prior to him attending day-hospice. Paul's COPD has developed to the stage where he is dependent upon oxygen during the day and a Bi-pap machine (which breathes for him) during the night. The slightest exertion leaves Paul fighting for breath and extremely fatigued. Being unable to work or care for himself, Paul has been forced to give up his independence, returning to live with his mother. Paul's family life was characterised by estrangement and isolation, stemming from his parent's divorce when he was a young child. For Paul this resulted in suppressing his negative feelings, isolating himself from others, poor self-

care and self-image, depression and anxiety attacks. Paul was anxious about leaving the house alone, and consequently he had not been out alone for many months, only leaving his room to attend day-hospice and hospital appointments. Paul described a disruption to his sense of autonomy and of being 'unable to be' the *Paul* he used to be, talking about feeling 'low, helpless, hopeless, trapped and frustrated'. As Evans (2005: 28) says, some patients express 'claustrophobic feelings of being trapped inside their diseased body, and the person who existed before diagnosis crumbles, becoming a new unwelcome identity'.

When discussing potential participants for the portrait project the day-hospice multi-disciplinary-team suggested Paul as a possible candidate. I was surprised when Paul accepted, as he had previously refused all offers of psychological or emotional support, including art therapy.

4.1.8 My own reflexive statement: Susan Carr Artist/Therapist/Researcher

As reflexivity of the researcher is a key part of this project and to acknowledge the heuristic aspects of this study, I have included my own reflexive statement in the form of a prose poem/portrait. This serves to highlight my cultural background and my personal experiences of the 'world of illness', 'liminality' and death, as well as my interest in disrupted self-identities. I have felt hesitant about placing this statement within the body of the thesis and so in order to acknowledge yet 'bracket' this it can be found in Appendix no. 12.

4.2 Findings

Within this study there was a 7/8 take-up rate for the project and a zero drop-out rate. On average the PRs involvement within the project extended for 8 months, with an average of 11 collages and prose poems, 4 portraits and 1 portrait sculpture being completed for each person. All PRs completed a button task and 3/7 PRs also completed a Lego task. The total number of portraits and portrait-sculptures created was 37, with 80 collages and prose poems being completed overall. Some portraits were painted from life, however for most I used reference photographs and sketches, this was to enable portraits to be completed at a faster rate and to prevent PRs from becoming overtired by posing for the portraits for long periods. However, I spent

time either drawing or painting each PR from life at some point in the project. The average number of PR portrait sessions was 13 with 91 completed overall. Each portrait session lasted between 1 and 2 hours.

Within the end of project interview (EPI) all the PRs claimed that their involvement in the project had been a positive one, using words to describe their experience such as: *extremely interesting, imaginative, fascinating, very good, informative, rewarding and emotional*. All (7/7) participants indicated that through the project they had; discovered new or forgotten parts of their self-identity. This correlates with the findings from the studies carried out by Gilbert (2014: 145). PRs also indicated that the project had helped them feel heard, and that it had given them an overall *stronger* sense of self-identity. When asked how their families had reacted to the portraits and collages, all said very positive things, and of the 37 portraits completed only two portraits were disliked by their families, and these were embodiments of PRs pain and suffering. All said that they thought the project would help other people diagnosed with a similar illness to them, with 4/7 adding that it would also benefit people with other issues, such as depression. When asked how they felt about the paintings going into an exhibition all responded positively, using words such as: *wonderful, I shall be pleased, I like that idea, very proud, an honour*. PRs were asked if they felt in any way exploited by the project and all said 'no', with 3/7 adding that it had been the reverse of exploitative.

Whilst the EPI data is encouraging and suggests the efficacy of portraiture as a 'third hand' intervention for these 7 people, within the following three chapters I will describe the main themes identified within the case-studies. These have been grouped together under three headings or master themes, which they help to support (see Figure 27 *Matrix of Themes table* below). These master and subordinate themes then form the basis for the following three chapters, within which I describe the lived experience of the PRs, through the portraits, collages, prose poems and direct quotation of the PRs voices from their EPIs. I also offer negotiated (with the PRs) interpretations or sense making of the data, and their wider significance within the field. The implications of the findings are then considered finally within chapter 7.

<p><i>Patient-Researcher's (PRs) Lived Experience of revisioning self-identities through portraiture. The main themes identified, with quotes from PRs End of Project Interviews (EPIs):</i></p>		
Chapter 4	Chapter 5	Chapter 6
<p>Increasing the PRs 'creative capacity' to adapt to illness</p>	<p>Portraits Making Meaning increasing the lived experience of <i>homelike-being-in-the-world</i>.</p>	<p>Mirroring and Attunement through Portraiture: Intersubjective and Symbolic ways of <i>knowing, being and relating</i>.</p>
<p>Transforming meanings & changing perspectives: through re-imagining self-identity.</p> <p>'it's helped me to clarify how I felt and the connections that have arisen because of my illness and it's helped me to understand myself better, understand the way that I've responded to the illness' (Susan EPI)</p> <p>'it made me realise that I could still explore different things' (Rose, EPI)</p> <p>'Yes I enjoyed it, something quite different in my life' (Hilary EPI).</p> <p>Humour: An adaptive and imaginative way of being-in-the-world</p> <p>'I've enjoyed it, and a lovely girl paints me! So I mustn't grumble about that. <i>And I've never given her the brush off! [laughs]</i>' (Bill EPI)</p> <p>Adaption through mourning losses: Learning to live with Being-Towards-Death</p> <p>'What it has done is help me accept the loss of Mark' (Peter EPI).</p> <p>'It's helped because I have been able to put closure to some of it ... it has healed both of us [self & husband]' (Norma EPI)</p> <p>'It allowed me to express this emotional journey' ... 'you can</p>	<p>'Making Special', Making Meaning: <i>Spirituality & 'Souls', Ritual & Myth</i></p> <p>'with a painting you get ... a different personality or aspect comes through' (Peter EPI).</p> <p>'It's like someone took notice, and what to me was just an everyday thing, you've made it into something' (Rose EPI).</p> <p>Portraits of Belonging and Remembering: linking past, present and future self-identities.</p> <p>'It helped me bring back all kinds of memories' (Peter EPI).</p> <p>'[it] brought my past alive' (Norma EPI).</p> <p>'I could see that all of the things in between in my life made me able to cope with things now' (Susan EPI)</p> <p>'I was a glider pilot [in WW2] and people don't know what that was. So I am glad that these [portraits & collages] are here to show' (Bill EPI).</p> <p>Embodied empathy: Increasing lived experience of a worthwhile and valuable self/life.</p> <p>'Yeah, because now, instead of being a 'nobody' this is as if I have done something with my life' (Rose EPI).</p> <p>'It made me realise that I have had quite an interesting life</p>	<p>Knowing the self through portraiture: portraying stories of self-identity PRs had waited a lifetime to tell.</p> <p>'I have recounted things to you that I have never mentioned to them [my family]' (Bill EPI).</p> <p>'it's to have somebody understand you, because most of the rest of the time with this, you are protecting the people around you from knowing how you feel, because you know you don't want to put them through that, whereas you know I can say things to you that I wouldn't say to anyone else' 'in fact there's a whole raft of things that I've never told anyone before' (Susan EPI).</p> <p>'I have told you quite a lot more things that I wouldn't have told anyone else' (Paul EPI).</p> <p>'[through the portraits & collages] you told me the story of myself' (Paul EPI).</p> <p>'I didn't know how it would turn out, but it's very telling really, very accurate' (Hilary EPI).</p> <p>Intra-subjective validation of self-identity: Portraits PRs needed to see</p> <p>'It is interesting to see somebody else's vision of yourself, because you can't envision yourself' (Peter EPI)</p> <p>'Your input more or less got me to a 'T' (Paul EPI).</p> <p>'It's you taking things hidden inside my head and making them visible to me ...and then I can see it made into something that expresses what I</p>

<p>look at it in a pain free way, because I am intrigued about the process and that takes the sting out of a lot of it' (Susan EPI).</p> <p>'It's been very therapeutic, because I was getting very depressed because of my illness' (Peter EPI).</p> <p>Adaption through increased agency & flexibility, & changes in perceptions of 'control'.</p> <p>'this gives you something that helps you function in the world outside' (Susan EPI).</p> <p>'just because you have been told you are ill, told you are never going to get better, doesn't mean to say you can't carry on. I think that is what this has done for me.' (Rose EPI).</p> <p>'I can see how it [LT&CI] affects who I am now, but it doesn't <i>control</i> who I am now' (Susan EPI).</p>	<p>actually' (Peter EPI).</p> <p>'I felt worthless and useless when we first started this project. But by having to relive my life, by telling the story, I've realized that I've actually become stronger through the illness. The iller I've got, the stronger I've got. And that no, I'm not useless, I've got a purpose in life and I'm fulfilling it' (Norma EPI).</p> <p>'If just one person who sees it [exhibition of the portraits] says 'well that's helped me', that would be a very big bonus' (Norma EPI).</p> <p>Legacy & temporality: immortalizing the sitter/cheating death</p> <p>'[The portraits are] ... something solid out there that will be you ... you know when you aren't there, something that will go on into the future' (Susan EPI).</p> <p>'[This project enables] people to feel that they have this kind of projection into the future, that they're not just going into the hospice and dying and the world moves on and forgets that they ever existed, it [the portrait project] does give people some kind of existence beyond that point ...' (Susan EPI).</p> <p>'That one of Mark there, he comes through it, he comes out of it ... it's <i>as if he's there</i>' (Peter EPI).</p>	<p>wanted to say in a way that perhaps even I didn't realise' (Susan EPI).</p> <p>'It's lending me your vision on my life (Susan EPI).</p> <p>'It reminds you of yourself' (Peter EPI).</p> <p>'this seems to be a much more effective way of dealing with hidden pain and giving someone who tends towards depression, the opportunity to recognise all the good parts of their lives that can be overshadowed' (Susan EPI).</p> <p>Intersubjective validation of self-identity: Portraits PRs needed others to see</p> <p>'It's nice for someone else to express the emotions that you can't' (Susan EPI).</p> <p>'People say I am brave and strong, I'm not really, but if that is how they see me I would say this has helped me in building that image' (Hilary EPI).</p> <p>Portraits, collages & prose poems as 'containers' of duality: holding hope and despair</p> <p>'It copes with fears and things that you are pleased or proud of as well, it makes you into a real person again ... and I quite like this idea of me still being me despite everything' (Susan EPI).</p> <p>'What we are looking at is an emotional life story, which you have to find metaphors to express, which I think is what this [project] does' (Susan EPI).</p> <p>Portraits of transformation through aesthetic resonance</p> <p>'[In the portraits] you're turning it [negative aspects of the self] around into something that's beautiful and lasting and giving them back something that's not tainted by misery or pain or anything else' (Susan EPI).</p>
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Figure 27. Matrix of Themes Identified table

I recognise that these themes reflect only *one* of many possible ways of viewing the PRs experiences and that the themes identified do not cover all aspects of the PRs experience. I acknowledged my own subjectivity has influenced these selections and that other ATRs may have focused on other aspects of the PRs experience. However, by discussing the case-study analysis with PRs and negotiating interpretations I hope to have found themes which best express the individual PRs experience of self-identity revisioning through portraiture.

4.3 Increasing the PRs *creative capacity* to adapt to illness

This chapter and chapters 5 and 6 discuss the themes identified within the analysis (see Figure 27 *Matrix of Themes table*), bringing in elements from the different forms of data generated within this project. I use extracts from the PRs case-studies, EPIs, portraits, collages and ‘essence statements’ as evidence within the discussion.

The title ‘increasing creative capacity to adapt to illness’ was selected as a master theme for this group of themes, as all the subordinate themes seem to have an adaptive element to them, incorporating agency and autonomy. Within the literature review I described my understanding of ‘creative capacity’ as similar to Higgs’ (2008: 551) description as: ‘adaptive behaviour through imaginative potential’.

In her later work Charmaz (1994, 1995) looks at how people rebuild loss of self and identity through arranging their lives in order to adapt to illness. For Charmaz (1995: 657) adapting ‘implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways’ (Charmaz 1995: 657).

4.3.1 Adaption through transforming meanings & changing perspectives: re-imagining and revisioning self-identity.

Art offers a way for us to enter into this paradox, where imagination forms reality and fiction reveals truth (Moon, 2002, p243).

Art therapist David Maclagan (2001, 2005, 2011) argues that ‘art therapy is not just a therapy *with* imagination, but a therapy *of* imagination’ that imagination, within both ourselves as artists and the people we work with, needs to be ‘restored and renewed’ before therapeutic work can commence (2005: 23 [my emphasis]). Maclagan sees

imagination as fundamental to all aspects of our life, ‘it colours our perceptions, it recreates our memories, it contributes to shaping and solving problems’ as well as being ‘the creative wellspring of art-works’ and ‘a principle means of responding to them’ (*ibid.*) Eisner (2008: 11) suggests that what we need is to unfetter our imaginations, to find new ways to see and understand the world, creating ‘vivid realities that would otherwise go unknown’, a way of utilizing the creative imagination to expand worlds shrunk by illness. The neuroscience behind imagination, has shown that when we visualize something, the activity shown in our brain resembles that associated with the real experience (Buckner & Carroll 2006), which suggests that ‘our imagination has a real and tangible impact upon how we feel. Imagined phenomenon therefore are not just *a figment of our imagination* they are part of our *embodied experience*’ (Carr 2014: 10).

In the EPIs several of the PRs talked about how their involvement had enabled a change in perspectives and meanings and especially the way the project caused them to look at things *differently*.

S: Well, it has been really good for me anyway, I have really enjoyed it,

R: So have I because ... it’s so ... *it makes you look at things quite differently.*

**S= Susan, (ATR) Artist/Therapist/Researcher R= ‘Rose’ (PR) Patient/Researcher
EPI 22/3/2011**

It is therefore this transformation of meaning or experience of *change*, in the way PRs ‘look at’ and experience things, which I will identify here. Transformation of meaning may include changing PRs preoccupation from a dominant (often negative) story of self-identity, to a more positive story, which enables them to think of themselves *differently* and therefore *act* differently or *creatively* (Burt 2012: 25). This is highlighted within Hilary’s portraits:



Figure 28. *The Window & The Heart of the Home* by Susan Carr (co-designed by Hilary)

Initially it seemed that these portraits were fairly straight forward depictions of past and present selves, however, within the analysis process unexpected things emerged. In the *statement of emergent knowing* (see below) created for *The Heart of the Home* portrait, it becomes clear that Hilary has used symbolism heavily within her portrait. When painting these portraits and visiting Hilary, I became aware of a recurring question in my mind which said ... ‘where is Hilary in all of this?’ The loss of self-identity for Hilary seemed to be profound, and was tied up with the loss of her matriarchal ‘doing’ and ‘being’ roles, which are a focus in *The Heart of the Home* portrait.

Statement of Emergent Knowing: ‘The Heart of the Home’

Hilary smiles a welcome into the heart of her home, a place where children have played and grandchildren still play. A place where adults drink tea and talk and read, a fireguard protects, and a mantelpiece supports, precious memories. Hilary is relaxed and happy here, at ease in the place she loves – the stage for her most devoted roles of wife, mother and grandmother. Surrounded by so many reminders of others Hilary risks losing her self, however she is held firmly in the chair which once held her father.

Statement of Emergent Learning: ‘The Heart of the Home’

Through surrounding herself with so many possessions, Hilary risks losing her *self*. Hilary labels things so that her family will know what they are, where they have come from, and why they must not be thrown away. Perhaps this is a way of working out ... ‘Where is Hilary in all of this?’

Statement of Reflexive Resonance: 'The Heart of the Home'

I have come to learn that amassing more and more 'things' makes us invisible ... it is perhaps a way of hiding ourselves? I felt somewhat overwhelmed when visiting Hilary because of all the 'things' in her house? Hilary was trying to put labels on things to itemize them, so that her family would know the significance of them, or perhaps it was a way of working out what was Hilary and what wasn't?

This collage encapsulated the issues Hilary faced, losing her beloved self-identity as a 'proper Grandma' (see Figure 29).



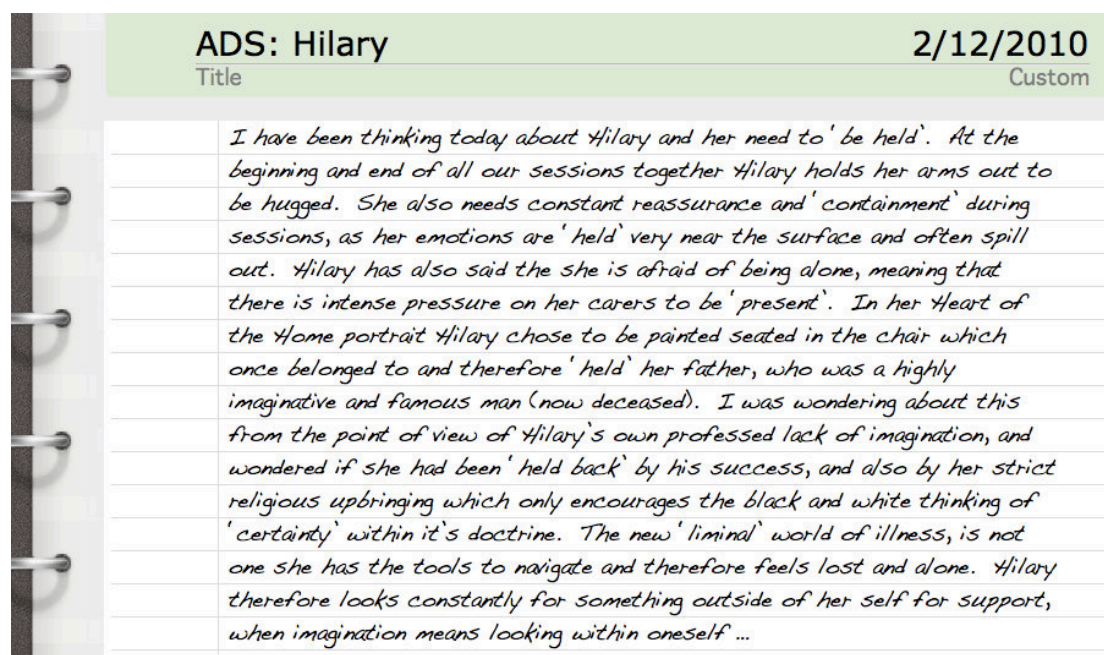
Figure 29. *A Proper Grandma* by Susan Carr

This collage led to a discussion to identify what Hilary thought was a 'proper' Grandmother, and whether her 'fixed' ideas around this could be extended creatively, to include e.g. 'sitting and reading to her Grandchild' or 'playing a game', also looking back at whether Hilary's own Grandmothers had got down on the floor and played with her (which she said they hadn't, despite them still being in her eyes 'proper' Grandmothers).

A possible clue to Hilary's lack of confidence in her imaginative potential is highlighted within the *Statement of Emergent Knowing* (see above) which says ... 'Surrounded by so many reminders of others Hilary risks losing herself, however she is held firmly in the chair which once held her father'. Hilary's choice to be painted

in her father's chair indicates her feelings of solidarity with him and mourning his loss, however, her father was famous for his imaginative talent, and as such may have overshadow Hilary's belief in her own imaginative abilities.

A sense of containment was elusive for Hilary and the theme of needing to be 'held' was a constant one, and something I reflected upon in the ADS:



This 'holding back' and avoidance of existential questions is outlined at the end of the project in Hilary's EPI where she says 'not to dwell too much on "I wonder why?"

H: Yes, yes ... When you first explained it to me I didn't know how that [the portraits] would turn out ... but it's very telling really, very accurate.
S: So do you think that this kind of project helps to reinforce a sense of identity? ...
H: Yes. I think this probably helped in ... I mean people say I am brave and strong, I'm not really but if that is how they see me, ... I would say this has helped me in building that image, having to think back and reflect. Not to dwell too much on "I wonder why" but to just carry on. If the hospitals can keep saving me then ... [laughs].

Listening for Contrapuntal Identity Voices:

Reading 1. Listening for Adaptive Matriarchal Hilary.

Reading 2. Listening for Religious, I believe in Angels Hilary

Reading 3. Listening for Souls and Shadows (Shy, Could do better Hilary)

Reading 4. Listening for Ancestral Hilary (Where is Hilary in all of this?)

S= Susan, (AR) Artist-Researcher & H = 'Hilary' (PR) Patient-Researcher. EPI 20/02/2012

Within this section of Hilary's EPI her 'adaptive matriarchal' voice of self-identity comes through strongly, over and above the other three perhaps less adaptive self-identities. As we continued on through the project, I believe that Hilary's imaginative potential and therefore creative capacity developed. This is characterized in her final painting (see Figure 30), my thoughts around this are noted in the ADS:

Hilary		18/02/2011 14:05
Title		Created
	<i>ADS: I was surprised today because when I went to see Hilary she had come up with a very imaginative idea for her third portrait. She said 'Paint me being held by an angel!' She said she would like the angel to be in a sort of garden surrounded by animals and spring flowers. She said she had a picture by her bed that she'd had since she was a young child, showing Jesus surrounded by animals. I said I would bring some sketches and some angel paintings by Burne-Jones to show her next week as Hilary said she liked more traditional kinds of painting.</i>	



Figure 30. *Held by an Angel* by Susan Carr (co-designed by Hilary).

I will discuss this portrait (Figure 30) further in chapter 5 as it became for Hilary a spiritual and ritualistic symbol and therefore 'made special' (Dissanayake 1988). It seemed that Hilary's imaginative potential was inhibited at the beginning of the project, which may have affected her ability to adapt to illness, as in her fixed views regarding 'a proper grandma'. McNiff (2004: 5) believes that the central premise of healing within art involves

the ‘cultivation and release of the creative imagination’ and that once liberated the creative process will always find its way to what requires ‘attention and transformation’. The challenge therefore is ‘first to free our creativity and then sustain it as a disciplined practice’ (*ibid.*).

Within this section I have shown how involvement in this project enabled Hilary to awaken her creative and imaginative potential and use it as an adaptive tool within her life, finding relief and comfort in a portrait of herself finally and eternally ‘held by an angel’. Hilary was also able, through the collages and prose poems to revise memories and concrete beliefs into a more positive and adaptive way of being-in-the-world.

4.3.2 Humour: An adaptive and imaginative way of being-in-the-world.

One of the things that struck me particularly when I began working in palliative care, was the use of humour by patients and staff as a way to ‘lighten the atmosphere’ in difficult situations, and how reciprocal laughter was a way to show both appreciation and gratitude, to each other (Weisfeld 1993). Humour has therefore been an important component of this project and is something that I see as intrinsically *adaptive* (Hellema 2011). A ‘ludic’ (Turner 1982: 27) defence mechanism, such as humour or black humour, can help practitioners face and manage liminality, indeed in traumatic work humour can be liminal itself (Sibbett 2005b: 240). The use of humour in palliative care has been acknowledged in its ability to ‘build therapeutic relationships, relieve tension, and to protect dignity and a sense of worth,’ it has also been found to be helpful in ‘managing stressful situations and maintaining a sense of perspective’ (Dean & Gregory 2004). Using humour is an *imaginative way of being* (Hellema 2011), in which a sense of intimacy is created, through the tacit intersubjective knowing required to understand personalised humour. It is a way of testing the intersubjective connection and asking “Do you get it? Do you get me?” and also “Do you *know* me?” By making humorous remarks about difficult subjects, a sense of emotional distance can also be created (Hellema 2011: 163). However, McCreddie & Wiggins (2007) warn that humour is a ‘complex, challenging, context-dependent’ skill and one must be mindful of the danger of misinterpretation especially when communicating with ‘disempowered patients who may be struggling to cope with illness.’ This is contested by Dean & Gregory (2004) who say their findings

support the view that humour and laughter are significant ‘humanising dimensions’ when caring for the terminally ill. I believe that humour must initially be patient-led and when expressed needs to be appreciated and reflected sensitively by the ATR, until they know the PRs sufficiently to understand the boundaries of their humour.

There were significant moments of humour within most visits to PRs, with the male PRs using humour most frequently. Bill (aged 92) would often joke about me being ‘his girl’ and was very clever at introducing a ‘play on words,’ this is highlighted by the exchange at the beginning of Bill’s EPI:

S: First question is ... how have you found the experience of being painted and having paintings made of you?

B: Very proud I think, very proud and I’ve been made a celebrity in this local place! (Laughs) S: Yes (laughs) B: I’ve enjoyed it, and a lovely girl paints me! So I mustn’t grumble about that. And I’ve never given her the brush off! (laughs)

S: No! (Laughs) I’ve got to put this in my PhD! (Both laugh) So have you enjoyed it then? B: Yes I have! (Laughs)

S= Susan, (ATR) Artist/Researcher B= ‘Bill’ (PR) Patient/Researcher (EPI 24/04/2012)

This sharing of humour demonstrates the closeness of the intersubjective relationship built up between Bill and myself during the project and the deep connections that were made.

Similarly Paul would make jokes during his portrait sessions, and humour seemed to be something that he *trusted*. I related the following in the ADS after a session with Paul where we were looking for portrait design ideas within the portrait reference album (PRA):

ADS: Paul	15/10/2012 16:25
Title	Created
<i>ADS: When we looked through the PRA Paul discovered the Frida Kahlo self-portrait 'Broken Column', exclaiming ... 'that's a bit naughty!' He later returned to it and said he liked it, because it showed Frida's pain and he could identify with it. I wondered about the sense of 'naughtiness' within the painting, the fact that she was showing her breasts, or the fact that she was showing her 'insides'. I was surprised that Paul was taken with it, but he said he thought we could design a portrait of him around the image. I think Paul meant the 'naughtiness' in a sort of 'ouch' way, when you looked at the image. I also wondered when he was able to 'be a bit naughty' in any real sense since his illness? Also whether he wanted to 'shock' people with the portrait, and if this was because his illness was not visible to others, perhaps they did not recognise or acknowledge his inner pain?</i>	

This resulted in the following *statements of intention*:

Statement of Intention: Broken Lungs

Paul said 'paint me like Frida Kahlo in *Broken Column*, cut down the middle, and instead of showing a broken vertebrae you can show my broken lungs.

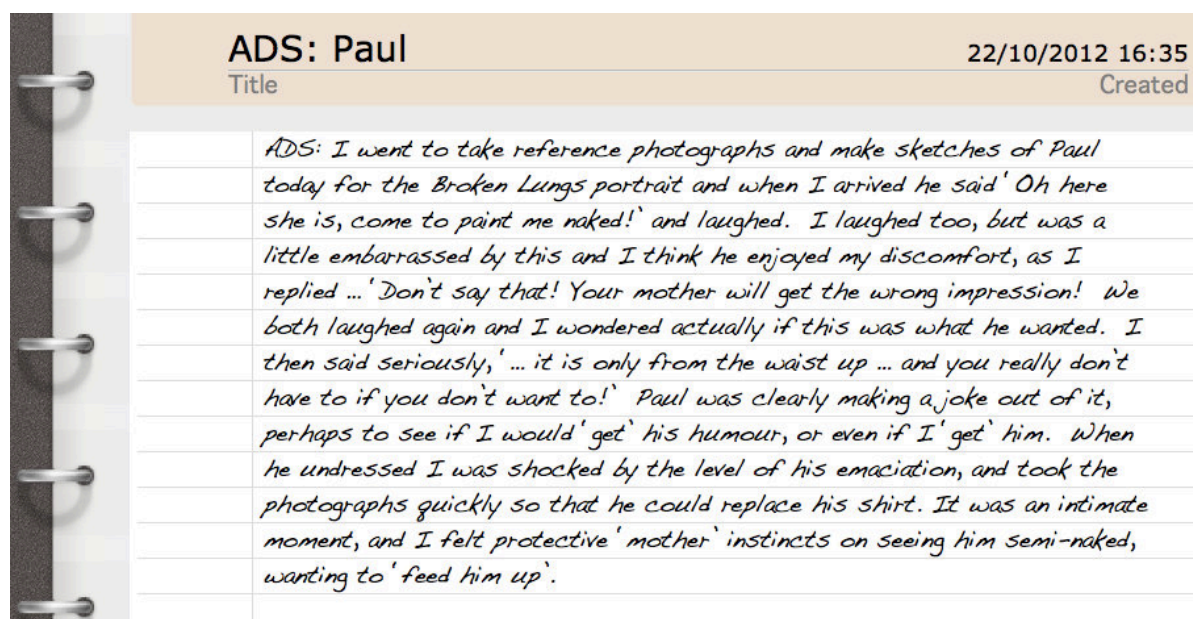


Figure 31. *Broken Lungs* by Susan Carr (Co-designed by Paul)

Broken Column (1944) by Mexican Surrealist artist Frida Kahlo [available at <http://www.fridakahlofans.com/c0480.html>], is an iconic self-portrait of physical suffering and stoicism, an image Paul claimed never to have seen before. The painting explores 'what it is to be embodied' (Latimer 2009: 50) and reveals the pain

and suffering Kahlo endured following her injuries in a serious bus accident aged 17 years. In Broken Column Kahlo depicts herself semi-naked in a barren landscape, her chest ripped open, a broken Ionic pillar replacing her vertebrae. Kahlo said her paintings reflect her lived experience or personal 'reality' and within Broken Column she portrays a divided, fragmented and leaky body-self, existing in the borderlands between object and subject (Latimer 2009: 46), revealing the 'fragility of and the extraordinary effort and machinery it takes to hold all the fragments together to produce an image of a whole' (ibid: 51). In Kahlo Paul recognised a fellow inhabitant of the 'world of illness' (Radley 2009), or liminality (Turner 1969; Sibbett 2005) saying he chose Kahlo's painting because 'you can see that she's in pain ... you know what she's going through.' Paul suggested that I paint him into the same barren landscape and instead of the cut-open chest revealing a broken 'column' Paul's portrait could show his 'broken lungs'.

The following week I had arranged to visit Paul to take reference photographs for this portrait, I recorded the following exchange in the ADS:



Reflecting on this I believe my discomfort was largely due to the recognition that it is usually only the medical profession or our life partners who have the privileged view of our naked or semi-bodies, and to Paul I was neither. I was also very aware of a discrepancy in power as I stood there with my camera preparing to photograph his emaciated body. However I reminded myself that this was Paul's idea and his design

and as such I needed to trust we were co-designing the portrait *he needed to see* and also that which he also *needed others to see*. This will be discussed further in chapter 6.

In this section I have identified humour as an adaptive process, facilitated and developed within this project, which enabled PRs to manage their experience of 'liminal' (Turner 1969; Sibbett 2005) or 'unhomelike-being-in-the-world' (Svenaues 2011). Containing elements of ritual, humour tests the intersubjective connection between PR and ATR, asking the important question 'do you *get it?*' or 'do you *get me?*' – highlighting humour as an important function of *being known*. Humour was also used to manage stressful situations and maintain a sense of perspective.

4.3.3 Adaptive dualities: creating emotional distance and connection

Art therapy works on the premise that through making the artwork clients are able to externalise a problem into an art form, and by effectively controlling that art form, the relationship of the client to the problem can be changed. However results from this study indicate that the 'third hand' art therapy approach works well as an emotional distancing/connection technique, despite the artwork being created *at once removed*. Through the revisioning process and the manifestation of aspects of self-identity within *externalized objects*, hidden pain and suffering is brought into being in the present, so that they can be *held, contained, moved, worked on* and *reflected upon*. Susan talks of the importance of this in her EPI:

SC: I don't know what you think ... but in a way, its power of fear promotion, the way that it affects you, is different in an object

S: Yes, it doesn't have such a hold over you. I think also that you reflect on the effect on you, but when you see something like the camera [*Pin Hole Camera* portrait sculpture (see Figure 32) you can see how you were vulnerable, that it was actually somebody else's issue and it affected you when you couldn't understand that. You know, you think about how you felt but it takes it outside and puts the issue with somebody else. It's something that I shouldn't have to have felt but did, so yes *it contains it and puts it away*. But understands it, it doesn't put it away by belittling the fear, it takes on board the fear in all its manifestations I suppose and contains it elsewhere.

SC = Susan, (ATR) Artist-Researcher & S = Susan (PR) Patient-Researcher (EPI 18/10/2012).



Figure 32. *Pin Hole Camera* by Susan Carr (Co-designed by Susan)

(This portrait-sculpture will be discussed further in the following section).

Susan goes on to talk about the differences this project employs opposed to emotional distancing techniques in ‘talking’ therapy. The attuning process highlights this difference, where I reflected back stories of self-identities through creating the artwork *for* PRs:

S: ... there’s a difference between you asking me specific things that relate to the objects, it was easier for me to say what I felt than if you had simply said ‘did you have a difficult childhood?’ and all that sort of thing. It gave a catalyst to ... it was the catalyst that allowed me to let some of these things out. *And then I can see it made into something that expresses what I wanted to say in a way that perhaps even I didn’t*

realise.

SC = Susan, (ATR) Artist-Researcher & S = Susan (PR) Patient-Researcher (EPI 18/10/2012).

Susan highlights the importance of *Pin Hole Camera* as a ‘catalyst’ to connect to and to ‘let some of these things out’, but also its ability to ‘hold’ difficult issues, saying ‘it contains it and puts it away’. Susan also highlights the importance of my mirroring and attunement within the portraits, saying ‘and then I can see it made into something that expresses what I wanted to say in a way that perhaps even I didn’t realise’ (mirroring and attunement within the portraits will be discussed further in chapter 6).

Within this section I have described the PRs experience of the portrait-sculpture as an externalised object, containing significant aspects of their self-identity, ‘holding’ and containing aspects of hidden pain and suffering, enabling both connection and emotional distancing to take place, and new meanings to be developed.

4.3.4 Adaption through mourning losses: Learning to live with *Being-towards-death*

Volkan (1997: 36) argues that human beings are unable to accept change without mourning what has been lost and portraits have historically been linked to mourning (Hilliker 2006), with some of the earliest painted portraits of people (from the 1st Century BC) being *funeral* portraits discovered in Egypt’s Fayum district. In Judith Butler’s (2004b) book about the 9/11 attacks on the World Trade Centre in New York, she examines the nature of mourning, we need to mourn, Butler suggests, as a way to acknowledge our ‘ontological indebtedness’ to each other ...

It is not as if an ‘I’ exists independently over here and then simply loses a ‘you’ over there, especially if the attachment to ‘you’ is part of what composes who ‘I’ am. If I lose you, under these conditions, then I not only mourn the loss, but I become inscrutable to myself. Who am ‘I’ without you? (Butler 2004b: 22).

I suggest that Butler’s (2004b) quote also explains the relationship that PRs have to lost aspects of their self-identity, meaning the question ‘who am I without you?’ (ibid.) becomes intensely *intrasubjective*, and without mourning these losses PRs

become ‘inscrutable’ to themselves (*ibid.*). This offers an explanation for why patients living with LT&CIs often say ‘I don’t know who I am anymore’.

I had initially thought that PRs may focus on losses to physical function and indeed these were expressed, however I was surprised at how they used it intuitively to mourn losses to their self-identity caused by the death of loved ones. This is exemplified in work Peter and I designed together. Peter’s son Mark had died at the hospice six months prior to our beginning this project and it quickly became clear to me that if I was going to work with Peter, I would also have to work with his son Mark, or at least Peter’s lost father-of-Mark identity. Klass, Silverman & Nickman, in their theory of ‘continuing bonds’ (1996) recognise that for some people it is imperative to retain some sort of an ongoing relationship with a lost loved one even after they have died.

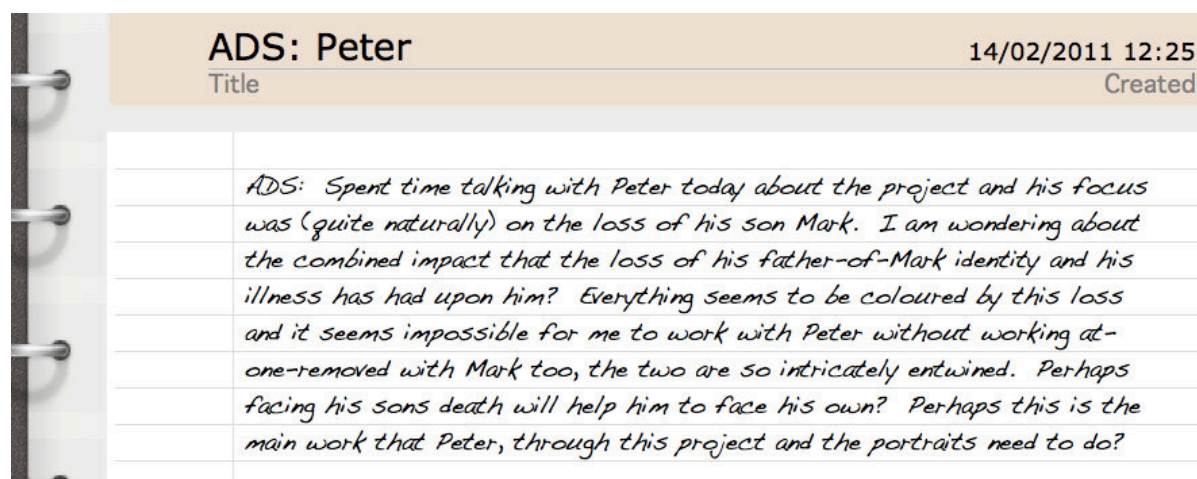
Butler (2004a & 2004b) suggests that who we mourn and why tells us about which lives are seen as worthwhile. Mourning losses to identity seemed therefore important to acknowledge and elucidate through the co-designing process, the collages and prose poems, and within the portraits. Mourning was particularly important for Peter and Norma as they had both lost children, and therefore were mourning, not only their child/children, but their ‘mother of’ and ‘father of’ identities.

Peter talked about how the project helped him ‘accept the loss of Mark’, an acknowledgement of adaption and closure:

S: So is it important to you that your contribution to this project might help other people in a similar situation to you? **P:** Yes, and it’s nice to be part of and *what it has done is help me to accept the loss of Mark.* **S:** Has it?
Oh good ... **P:** *It’s helped me in that respect, I don’t know why but it has,* and I can talk about him now without filling up with tears, which I couldn’t before ...

S= Susan, (ATR) Artist/Researcher P= ‘Peter’ (PR) Patient/Researcher (EPI: 27/02/2012)

The following account from Peter’s ADS explains how we began working together:



Focussing on the loss of his *father of Mark* self-identity we co-designed portraits of Mark and Peter, including two portraits of the two of them together (see Figures 37 & 38). Rando (1991) talks of a lady who was both a bereaved parent and a widow who said ... ‘when you lose your spouse, it is like losing a limb; when you lose your child it is like losing a lung.’ As a COPD sufferer Peter did focus on his breathing difficulties, and these were reflected within the collages (see Figure 33), however Rando’s quote above seems to indicate that Peter had suffered a double blow where his breathing was concerned. In the following collage Peter talks of the inherent focus required by the body in deep illness:

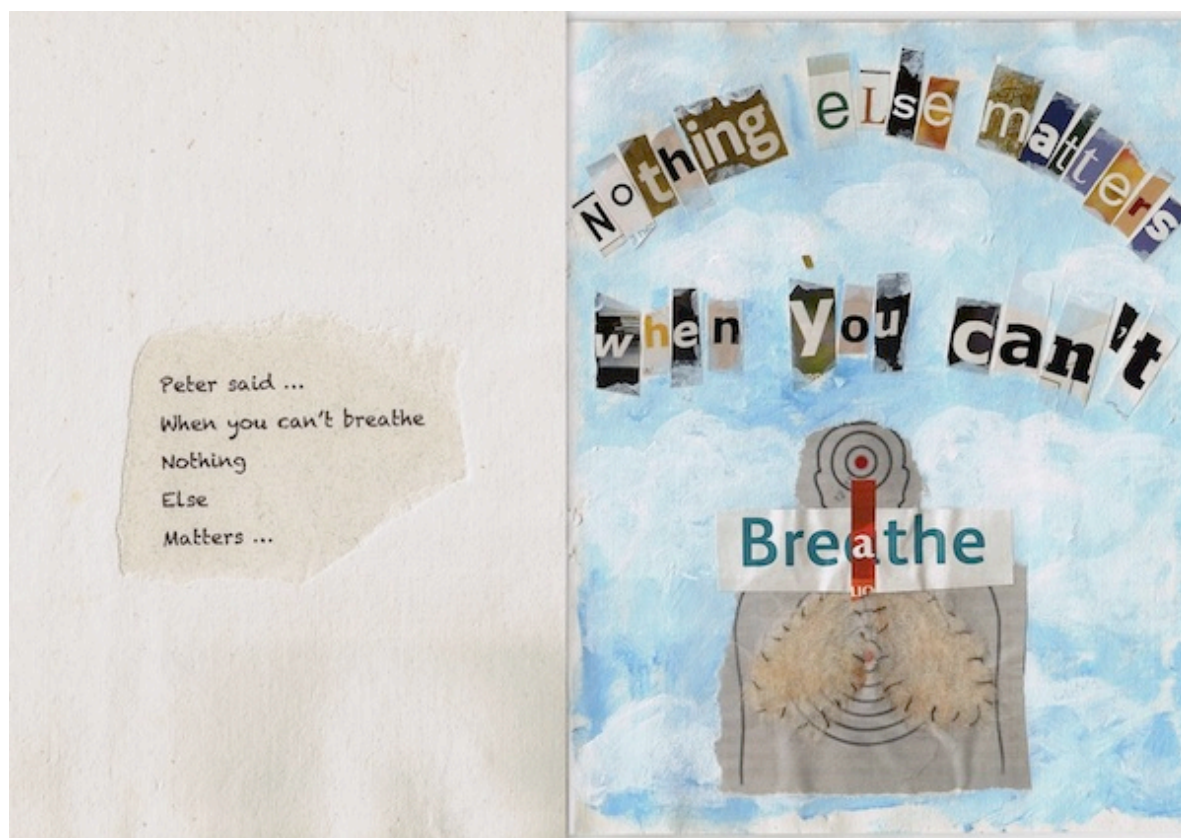


Figure 33. *Can't breathe* collage by Susan Carr, 2011.

This focus on revisiting Peter's 'father of Mark' identity through the portraits was not in the sense of 'denying' Mark's death, but as a way to contain and 'visibly mend' (Jones 2008) this lost relationship, therefore perhaps an attempt to reclaim a lost metaphoric 'lung'. The first portrait I painted of Mark *for* Peter was *Mark, Charlie & Rusty*:



Figure 34. *Mark, Charlie & Rusty* by Susan Carr (co-designed by Peter)

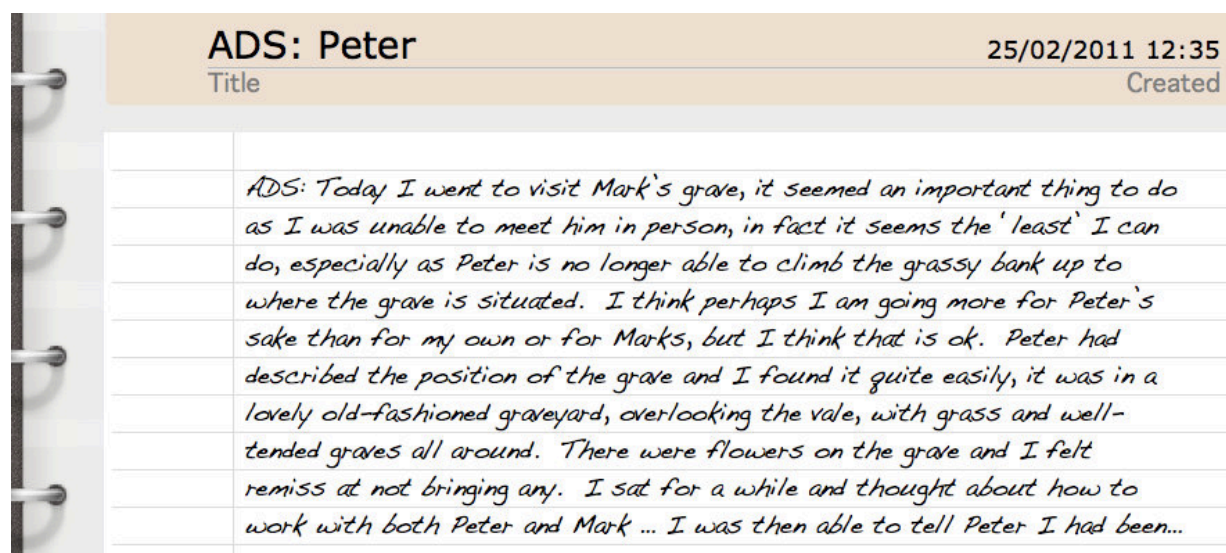
It seemed important to Peter that Mark's love of animals and his humorous side was acknowledged, as well as honouring the family cat who had died the same day as Mark:



Figure 35. *RIP Mark & Rusty* collage by Susan Carr, 2011.

I had met Charlie (Peter's little white West Highland Terrier) many times on my visits to see Peter, and his presence held by Mark in the portrait, seemed to link us all together.

Although I couldn't meet Mark, I wanted to learn all I could about him, so I encouraged Peter to tell me what kind of person Mark was. I also went to visit Mark's grave and I documented this in the ADS:



As Peter told me stories of self-identity about both himself and Mark I began to put together a picture of Mark in my mind, and resolved to paint a double life sized portrait of Mark to show the prominence of this relationship in Peter's life (see Figure 36). One of the things Peter would often say was 'there was *something about Mark* ...'

I used several photographs of Mark as reference for the portrait, and I was worried that because I had never met him, I would not be able to capture that 'air' or 'essence' that Barthes (1985) and Freeland (2010) talk about.



Figure 36. 'There's Something about Mark, RIP' by Susan Carr

Whilst painting the portraits of Mark I was also painting portraits of Peter, and although he was deeply interested in these it was clear that his main focus were the paintings of Mark. In his EPI Peter talked about how important this double life-sized portrait would be to both him and his family:

S: This is the portrait of Mark ...

P: Oh is this the big one?

S: Yes [unwrapping *There's Something About Mark, RIP* to show Peter].

P: My word! ... What a lovely ... oh my goodness gracious ... that is superb, that is superb ... goodness gracious me ... you have really got it ... oh my son's would love that. And to see it that size as well!

S: Yes I really loved doing that ... his eyes are just so intense ...

P: I wonder if my sons are around? They would love to see it ... Do you mind if I give them a buzz ...?

S = Susan, (ATR) Artist-Researcher & P = Peter (PR) Patient-Researcher. (EPI 27/02/2012)

As the portraits progressed I took photographs to our sessions to show Peter and to get his opinion about modifications, colours etc. I also began the dual portraits of the two of them, one of Peter holding Mark as a baby (see Figure 37) and the other *At The Races* (see Figure 38) of them both at Cheltenham racecourse enjoying a day out together.



Figure 37. *Peter & Mark in Kenya* by Susan Carr (co-designed by Peter).



Figure 38. *At the Races* by Susan Carr (co-designed by Peter).

The *essence statements* derived from the *At the Races* portrait highlights the bond between a father and his first-born son:

Statement of Emergent Knowing: At the Races

I tell a joke, you smile and laugh, we are there for the races, a small bet to place, not really for the winning but for being together and sharing our time, father and first born son, united, relaxed. No oxygen required, your presence mends my broken lungs ...

Statement of Emergent Learning: At the Races

Peter is happy in his treasured father of Mark role, reunited in the painting, the relationship is remembered and validated and together without illness and pain they rest in each other's enjoyment.

Through the portraits, collages and prose poems Peter was able to acknowledge the stories and events from his life which have shaped his self-identity, both those that have *made* and *un-made* him. The portraits of Mark enabled Peter to still *do* something for Mark and himself, to still be able to *be* in that caring '*father of Mark*' role, whether through imaginative or prospective processes, not as a *denial* of Mark's death, but as an honouring of his life. Peter was therefore able to revisit that aspect of his self-identity, to talk actively and with a sense of agency and purpose, about how to portray himself and Mark within the portraits, and the artwork gave a focus to our discussion, enabling emotional distancing.

Peter's feeling of helplessness, loss, and guilt about outliving Mark were replaced with adaptive feelings of agency through his active role in co-designing the portraits,

bringing in aspects of his *past*, *present* and *future* self-identities. The *past* aspect included the remembering of happy times at the races and being with Mark, the portrait was produced in the *present* as tangible results of our collaborative relationship involving action and agency, and the portrait also suggests that Peter and Mark will one day in the *future* be reunited in death. The portrait also exists in *present* time and will exist in the *future*, even after Peter has died. There was also a sense of the portraits being an acknowledgement that Mark's life was worthwhile and that he will be remembered.

In a similar way to Peter, there was a sense of urgency within Norma to talk of the many personal losses in her life and how these had impacted upon her sense of self-identity. The first such loss is talked of in the following collage:

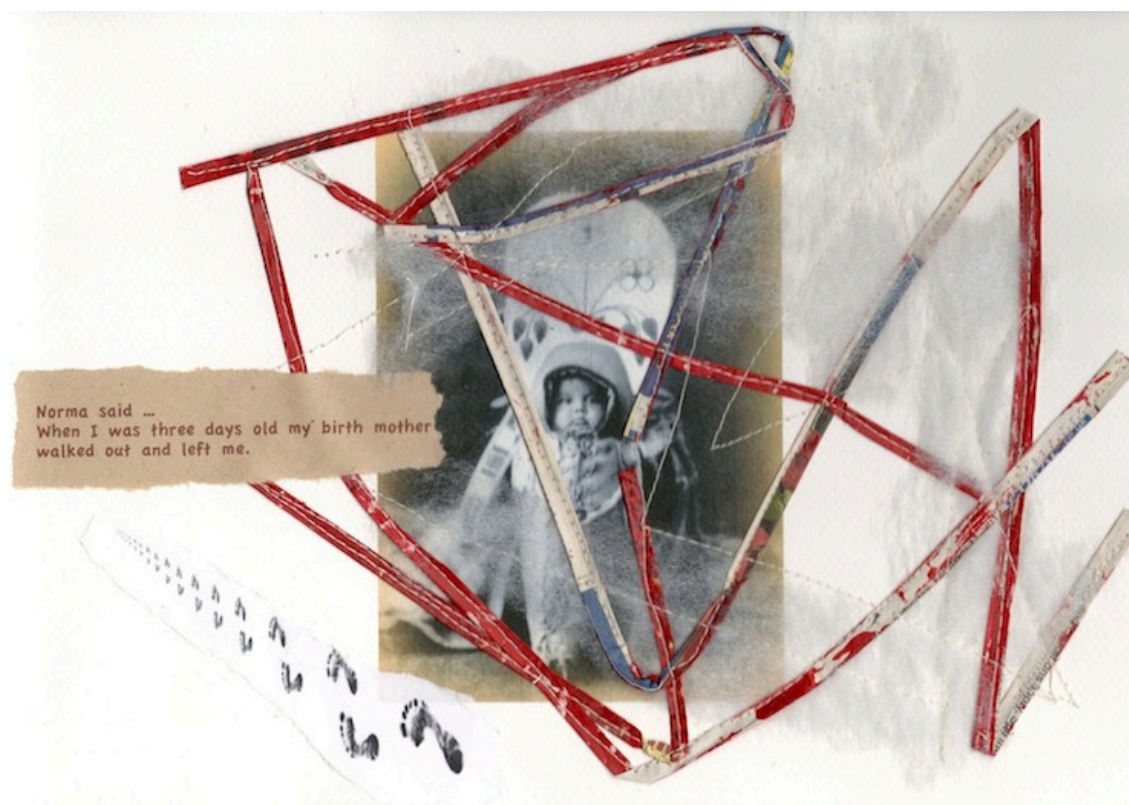


Figure 39. *Mother Walked out and left me* collage by Susan Carr, 2012.

This early abandonment and subsequent time in orphanages and foster care had a severe impact on Norma's sense of herself as a worthwhile person, saying that she

had spent her life searching for her self-identity. Norma also talked about ongoing ill health as a child and adult and the consequential loss of seven babies:

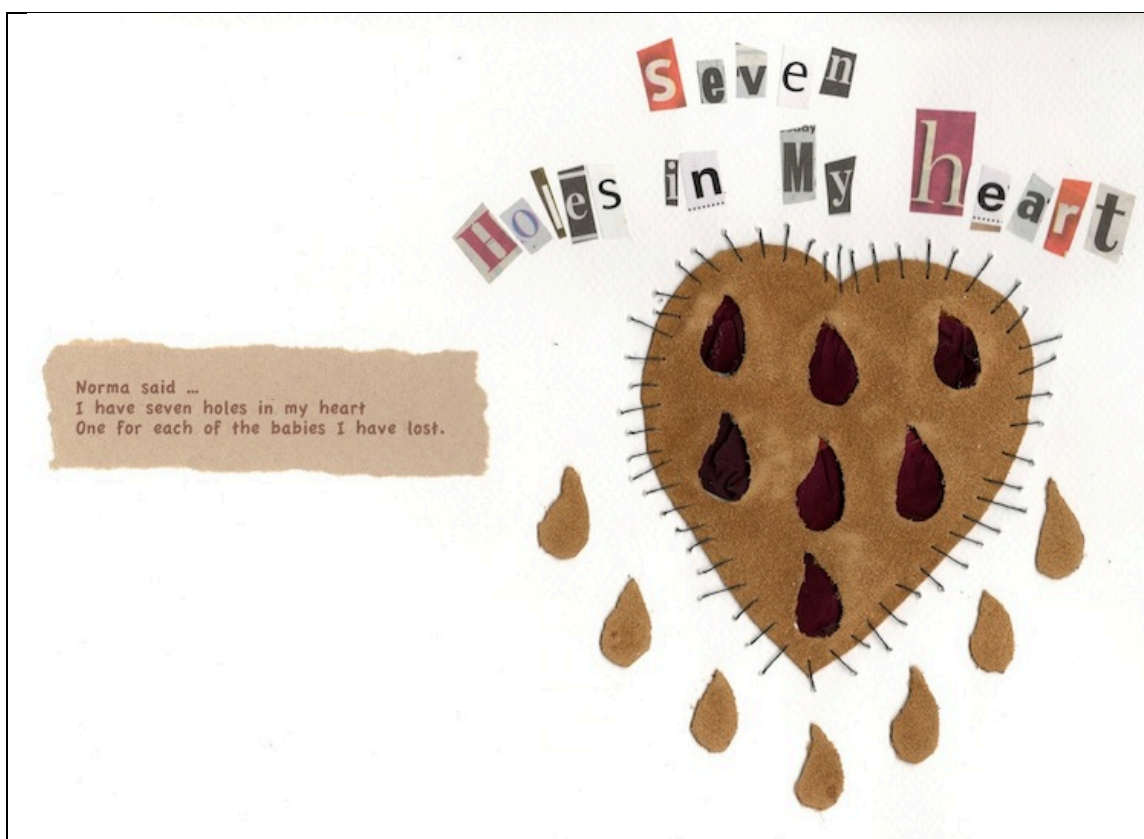


Figure 40. *Seven Holes in My Heart* collage by Susan Carr, 2012.

My reaction to Norma's stories of bereavement resonated with my own loss of a baby and I recorded this in Norma's ADS:

ADS: Norma	22/08/2012 10:15
Title	Created
<i>ADS: When Norma told me about the loss of her babies I immediately thought about the loss of my own son halfway through my first pregnancy and how I used art making to heal myself through post-natal depression. I thought about how I created a baby dress out of muslin, on which I sewed my poem 'unwelcome contradictions of death in birth,' and then made the muslin 'baby' to wear the dress. I thought about how sewing together the 'baby', and the stitching of the poem was therapeutic, as well as being able to 'hold' and dress the baby. I wonder if it would be possible to replicate this in some way as a healing experience for Norma?</i>	

Remembering how important it was for me to actually 'hold and feel' the 'baby', I thought about making a portrait-sculpture for Norma, so I showed her a photograph of

the ‘baby’ I had made to facilitate my own mourning process (see Figure 41 below) and we discussed it together.

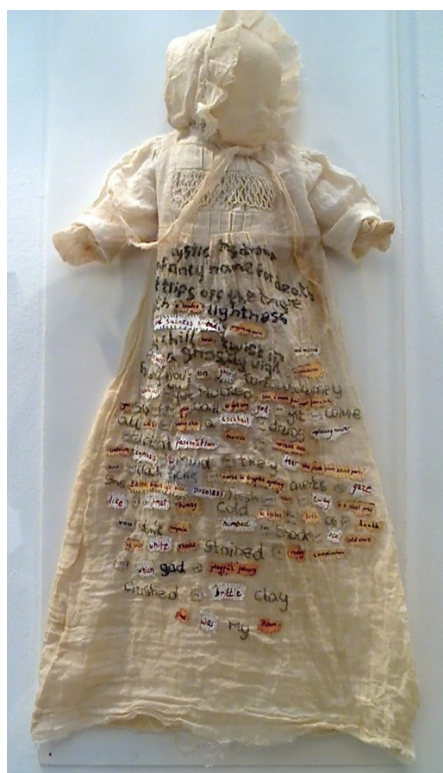
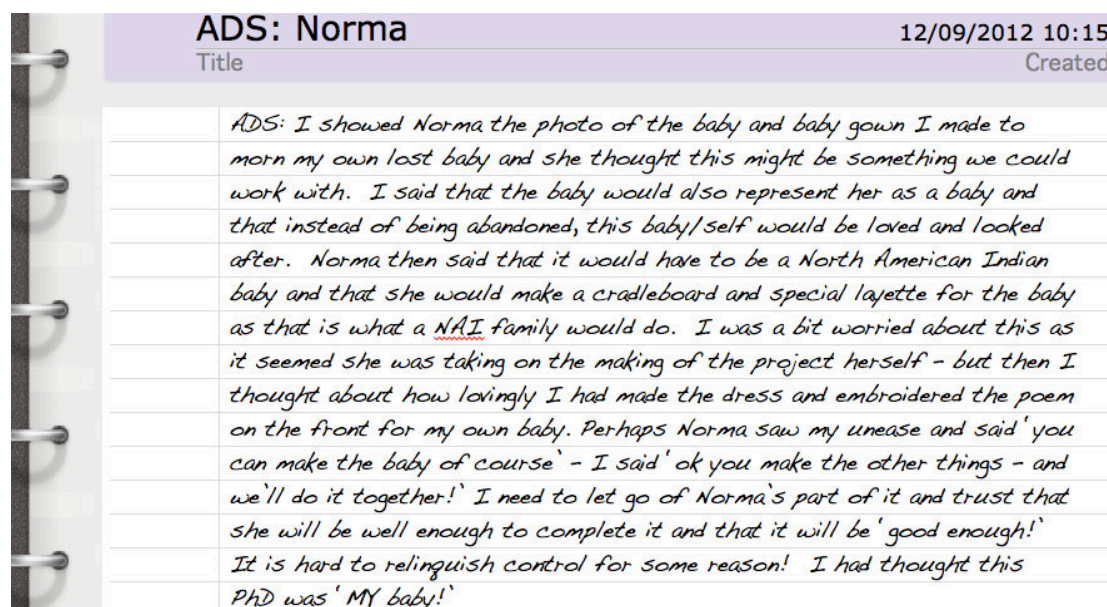


Figure 41. *Unwelcome Contradictions of Death in Birth* by Susan Carr 1999

The creation of bereavement portraits of babies and children was common in the 16th and 17th centuries (Mander & Marshall 2003) and with the advent of photography bereavement photographs became popular in the Victorian era. This practice has been brought back into maternity units, after a period (up to the mid 70's) where stillbirths and miscarriages were seen as a ‘non-event’ and mourning rituals were not encouraged or facilitated (Rådestad *et al.* 1996: 209). My own experience of losing a baby in the early 1980s fell into this ‘non event’ category, with the baby taken away immediately, without me seeing or holding him, with no acknowledgement that his death (at 19 wks) was a major event in my life which required the healing processes of ritual and meaning making.

I reflected on Norma’s reactions to the idea of the ‘baby’ portrait-sculpture in the ADS:



Norma and I therefore co-designed and co-created the portrait sculpture *My Baby/My Self* (see Figure 42), I made a full sized Native American Indian newborn 'baby' from muslin, stretched and sized over a newborn baby 'mould', then removed and stitched together, and Norma made Native American Indian cradleboard and layette for the 'baby'. The 'baby' represented a merging of Norma's lost babies, with her own self-identity as a previously abandoned baby now 'found'. Caring for bereaved mothers, offering emotional, psychological and spiritual support, now feature in interventions used within maternity hospitals, with a focus on 'creating memories' (Mallinson 1989) which may include *memento mori* such as photographs, wristbands, locks of hair, foot/hand prints, etc. (Rådestad *et al.* 1996). These interventions are relatively recent (Gohlish 1985) and no such bereavement care was offered to me when I lost my baby in January 1987, although interventions were beginning to be implemented during this time. In a study looking at the bereavement interventions offered to a group of eight mothers Moulder (1998) found that mourning photographs of their baby were an extremely important part of the grieving process for all the mothers interviewed indicating that the creation of a portrait-sculpture may be helpful to Norma.



Figure 42. *My baby/My Self* by Susan Carr & Norma

In the EPI Norma talks about how the project had enabled healing for both herself and her husband, saying it had given her a sense of ‘closure’:

S: So, how have you found the collaborative process? So, we’ve been talking about what we wanted to do ...

N: Painful at times when I’ve had to go back and think about the past, because some of the past has been quite painful. *But, it’s helped, because I’ve been able to put closure to some of it, which has been really helpful.*

S: And, I know that it has sparked conversations with your husband about the ‘7 holes in the heart’ [collage & prose poem see Figure 40].

N: And, for the first time, he actually cried openly. Being a true Englishman, it’s like ‘we are tough’, stiff upper lip, men don’t cry and he actually cried openly.

S: Do you think that was a healing process?

N: Yes. Losing seven children is not a pleasant thing to do. *It has healed both of us, there has been healing for both of us.*

SC = Susan, (ATR) Artist-Researcher & N = Norma (PR) Patient-Researcher (EPI 26/10/2012).

In this section I have used Butler's (2004b: 22) quote to highlight the need for PRs to mourn losses to self-identity caused by LT&CIs, as a way to enable acceptance and a process of adaption and change to begin. This study has shown that failure to engage in this process can result in people become 'inscrutable' to themselves. In their EPIs both Peter and Norma talk about finding a sense of 'closure' regarding important bereavements in their lives, bereavements that had stripped away part of their relational self-identities. The portraits therefore became an opportunity to engage in creative and adaptive rituals, enabling a process of *revisioning* or 'visible mending' (Jones 2008) to occur.

4.3.5 Adaption through increased Flexibility and Agency, and Changes in Perception of 'Control'.

Peter and Norma's experience of 'closure' and healing may also have been due to a lived experience of 'control', through their active involvement in the co-designing (and in Norma's case co-creating) process. This perception of control and autonomy mitigates the sense of helplessness, caused by uncontrollable losses such as bereavement and illness (Werner-Seidler *et al.* 2011).

Within Susan's post-diagnosis button task (see Figure 43 below), she created a design that depicted the impact of illness on her self-identity. Within the design Susan identifies her 'self' as the mermaid, 'trapped' within a metaphorical 'box'. The small 'gap' left at the top, she said is a space where 'memories could still get in' but which was too small to enable her to 'get out'.



Figure 43. Susan's post-diagnosis button task

Buttons are neutral and ambiguous and can be moved and changed by the PR, subtly changing the PRs relationship with a problem. Seeing the mermaid in the ‘box’ enabled Susan to see how ‘boxed in’ she felt and link that to feeling over-protected/and under-protected as a child. This initial theme of the ‘box’ became one that recurred throughout Susan’s involvement in the project, with Susan developing creative and adaptive strategies to ‘get out of the box’.

The metaphor of ‘being boxed in’ is reflected within one of Susan’s collages and prose poems, here the box becomes synonymous with being confined to a wheelchair and also Susan’s dislike of being photographed (see Figure 44 below).



Figure 44. *Back in that Box* collage by Susan Carr, 2012.

This then led to a further development of the ‘boxed in’ metaphor into a 3D portrait sculpture, *The Pin Hole Camera* (see Figure 45) and the following exchange demonstrates the ongoing co-designing process:

SC: Ok, then about ‘avoiding having your photo taken’, about this thing, about ‘being in a box’, black and white frame.

S: I quite like the idea of the camera. I don’t know if you want to do something again but the camera there instead of the sea, I could be captured in it you know?

SC: Yes, almost like someone squashed into a very small space. A bit like Alice in

Wonderland, where she becomes very big in a very small space.

S: Yes, just like that.

SC = Susan, (ATR) Artist-Researcher & S = Susan (PR) Patient-Researcher. (MPI 22/03/2011)

Within this early co-designing phase, Susan and I were able to adapt ideas to fit Susan's thoughts and feelings and the *Pin Hole Camera* became symbolic of Susan's relationship with her father, a father she described as a 'brute' who she lived in fear of. One of the aspects Susan highlighted regarding her relationship with her father was his obsession with photographing her as a child, and this is reflected in; the prose poem which accompanied the portrait-sculpture, the essence statements from the analysis, and my reflection in the ADS:



Figure 45. *Pin Hole Camera* by Susan Carr (Co-designed by Susan)

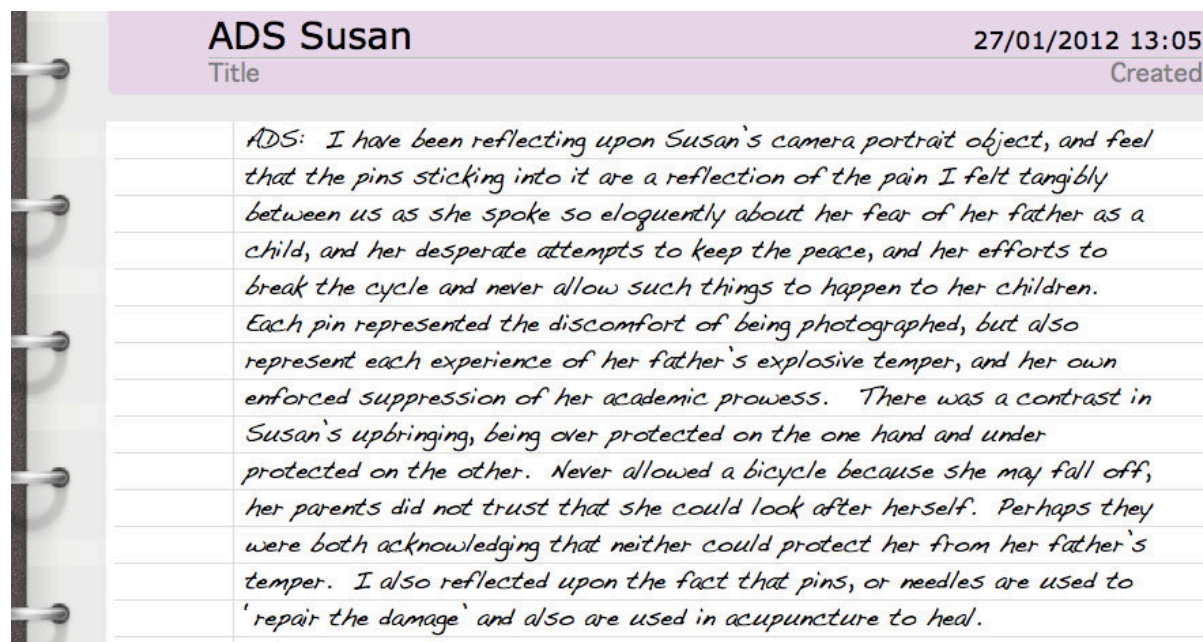
Susan said,
Throughout my childhood
My father was obsessed
with photographing me ...
I learned to dread the
camera coming out ...
And the orders to face the
camera and smile
To face the sun and not
squint
To please ...
Albums and albums of
photos remain
A testament to my father's
persistence
And my stoic acceptance
and Attempts to keep the
peace ...

Statement of Emergent Knowing: Pin Hole Camera

I stand or sit doll-like, pretty in pink and bows, trapped by the lens, my coloured world converted into black and white. Each photograph a pin prick of discomfort, as my likeness is taken against my will, 'snapped' 'captured' 'caught', again and again and again.

Statement of Emergent Learning: Pin Hole Camera

Multiple images bear witness to a father objectifying his daughter in monochrome, and yet he captures only the surface, Susan complies to keep the peace, but only partially and retains her subjectivity within herself.



Within Susan's EPI she reflects upon how exploring the theme of being 'boxed in' has changed her lived experience of agency:

S: I wonder whether you find that perhaps you are getting outside of the box...now.

SH: Yes, I think having recognised it, *I've recognised the steps that I need to take to change it.* I don't think when we set out on this that I would have, I don't think I was fully aware of that feeling. I think articulating it made it visible to me, I think. I think that's one of the reasons that I've got the crutches, partly because my back really hurts if I'm in the chair too long, but the crutches are a positive step out of that, I think. And, taking more care putting make-up on, nails, this kind of thing, is saying that I'm not going to be in *that box* if I can avoid it. So yes, *I think that has made a difference to stepping outside.* ('Susan' EPI: 18/10/2012)

S= Susan, (ATR) Artist/Therapist/Researcher SH= Susan (PR) Patient/Researcher EPI: 18/10/2012

Susan and I also co-designed the *Swan Island Book* (see Figure 46 below), which depicted a positive mentalisation Susan employed when undergoing radiotherapy treatment. Susan describes how this reminded her of adaptive strategies she had used in the past:

SC: And that was a prototype for the book.... [*The Swan Island book*]
S: Yes, it's interesting to see that made visible. All of that went on in my mind at the time. **SC:** Yes, that idea of the swan breathing fire and burning away...yes.
S: And then the soothing, being looked after, but not in a controlling way, in a gentle, positive way...In a safe place, a safe place to turn whenever you need. [...] *I suppose as well it kind of reminds me that I did have strategies that worked for me, as well, so some control over the illness. Probably a delusion but a good feeling.*
SC: No, I suppose that it's a self-healing strategy...
S: Yes.
SC= Susan, (ATR) Artist/Therapist/Researcher S= Susan (PR) Patient/Researcher (EPI: 18/10/2012)



Figure 46. *The Swan Island Book* by Susan Carr (co-designed by Susan)

Increasing perceptions of control, was another theme identified within the analysis and are utilised by Rose within the portraits as a way to 'control' her image and how people saw her. Charmaz & Rosenfeld (2006a: 37) talk about how 'embodiment complicates self and identity for people with chronic illness' and the tension between visibility and invisibility results in people attempting to control how they are portrayed, as indicated in the prose poem written to accompany Rose's 'Paint Me Like a Picasso' portrait:



Rose said:
Picasso painted in a quirky
way ...
So if you paint me
like a Picasso,
People won't notice
My quiriness ...

Figure 47. *Paint me like a Picasso* by Susan Carr (co-designed by Rose)

The following exchange recorded in Rose's EPI explains why a sense of control was important for Rose:

S: Hmm that's great. You also mentioned something interesting when we were talking about the *Paint me like a Picasso* portrait. Because you were saying your friend asked you why you liked it, and you said that it was because your face was "not going to fall down in the painting. I don't need to worry ..."

R: Yeah, because in a photograph this [indicating fallen lower lip/face] people are going to look and notice. But in this [indicating the painting] they won't notice.

S: Do you feel that with that one as well? [indicating *Bohemian Rhapsody* portrait]?

R: Yeah, because, although that is slightly down [indicating side of mouth] people won't notice. Because I won't have any more photos taken because of that. You doing this ... is, ... because that's not going to happen.

S: So it's like you can control this more, so you can control your image and you can control how people see you?

R: Because, I know my face is like this, [shows face fallen] but up here [points to brain] it's not, I still think of myself as ... with the control in my face, because when I look at people and I smile, that [points to mouth] doesn't smile, that [points to head/brain] does, I don't think of my face like this, so you doing that [indicating the portrait], that's the thoughts. ('Rose' EPI: 22/03/2011)

S= Susan, (ATR) Artist/Researcher R= Rose (PR) Patient/Researcher (EPI 22/03/2011)

Rose is indicating in this exchange that the portrait represents a melding of her inner and outer realities and as such the processes employed within the *Paint Me Like a Picasso* portrait enabled the portrayal of a kind of 'visible mending' (Jones 2008), with a black line and blue triangular shadow below Rose's mouth outlining the place where her lower lip falls forward, acknowledging this as part of Rose's identity but

‘controlling’ it within the portrait. This brings the embodied reality back in-line with Rose’s imagination and observation, *‘that’s the thoughts’*.

Towards the end of the project Rose demonstrated her new found determination to challenge the restrictions placed on her through illness, in creative and adaptive ways:

Rose said ...
‘I’m going to walk 15 Kilometres for the hospice,
Dressed as a florescent fairy!
People say “You can’t do that!”
I say “Maybe not, but I’ll have a damned good try!”



Figure 48. *I'll give it a damn good try* collage by Susan Carr, 2012.

Rose also talks about this in her EPI. I have left the highlights of Rose’s self-identity voices identified in the voice analysis, to show how Rose’s ‘Resilient, see me/hear me’ self-identity voice dominates and has the last word:

R: That’s determined! [indicating *Bohemian Rhapsody* portrait]
S: And also that sense of, you know, I’m here, yes I have got this but I am going to carry on. It’s almost like ... ‘don’t you stand in my way.’ [laughs]
R: It’s like my t-shirt has got on it ‘don’t stop me now!’ that’s a Queen song. I’ve got a t-shirt with it on.
S: Yes ...
R: I am determined to make the most of myself, so ...
S: Yes, I think it does ... I think it has got a lot of courage in it. Courageous ...
R: Yes because I could turn round and say I can’t go shopping, because I can’t ask for what I want, but I do go, I say to my son, I say it twice, I don’t give up ... I say give us some paper and I will write it down, but I don’t say to people come with me and

ask [for me], I do it myself. I don't give up, I do still try.

S: Yes, I think that would be an inspiration to a lot of people, seeing that painting actually.

R: On Facebook I said, 'Don't tell me I can't do it, *watch* me do it!', words to that effect. Like when I said I will do that walk. Friends of mine said but you can't do that. I said why? They said 'you can't walk that far'. I said 'well maybe not but I shall give it a good try!'. Why, just because it is a long way, why should it stop you trying? But I think I will do it because I will get myself to a steady pace and stick to it. I won't try to finish it in a rush ... quickly. No ... I shall set myself a pace. I shall do it.

S: I am sure you will ...

R: I shall do it. By next day I may be on my hands and knees. But I think I can do it. I didn't think I could, I wouldn't try, *but now I think ... you can do it!*

Listening/reading for Contrapuntal Identity Voices:

Reading 1. Listening for 'Resilient, see me/hear me Rose'.

Reading 2. Listening for 'Invisible, silenced Rose'

Reading 3. Listening for 'Earth-Spirit Warrior Child'

Reading 4. Listening for 'Isolated City Child'

SC = Susan, (ATR) Artist-Researcher & R = Rose (PR) Patient-Researcher (EPI 22/03/2011).

In her EPI Rose reflects upon her determination to overcome challenges and to maintain her independence, both of which are characteristic of an increase in creative capacity and the ability to find health within illness (Carel 2008):

R: I think *this is a message*, well to me, *you're diagnosed with a terminal illness but that doesn't mean you gotta stop, you gotta keep going*, don't give in to it. Just because you have been given a life sentence, just because you have been told you are ill, told you are never going to get better, doesn't mean to say you can't carry on, *I think that that is what this has done for me.*

S= Susan, (ATR) Artist/Researcher R= Rose (PR) Patient/Researcher (EPI 22/03/2011)

In this section I have described the increase in feelings of agency, control and autonomy that PRs have reported in their EPIs, mitigating feelings of helplessness caused by uncontrollable losses.

This process enabled Susan to recognise the steps she needed to take to get 'outside the box', and allowed her to see the way illness had made her feel like a child again 'captured' and helpless. I have also shown how portraits and portrait-sculptures become a way to rediscover and re-member adaptive strategies from the past, enabling PRs to utilise these once more, increasing their perceptions of control. I

have suggested that in this respect portraits effect a kind of ‘visible mending’ which acknowledges both *brokenness* and *adaption* at the same time, highlighting again experiences that have both ‘made’ and ‘unmade’ the PRs sense of self-identity.

4.4 Summary

Within this chapter I began by introducing the PRs involved in the study, followed by a summary of the findings. Using extracts from PRs case-studies, EPIs, portraits, collages and ‘essence statements’ as evidence I then discussed the themes and sub-themes that have emerged from the data, clustered under the heading *Increasing the PRs lived experience of their creative capacity to adapt to illness*. I described how Hilary found an increased capacity for imaginative thinking, finding relief and comfort in a portrait of herself ‘finally and eternally held’. I identified *humour* as an adaptive process facilitated and developed within this project, helping PRs to manage their experience of liminality or unhomelike-being-in-the-world. This also enabled PRs to ask the question ‘do you get it?’ and ‘do you get me?’, highlighting the importance of humour as a function of *being known*.

I described how PRs used the portraits as externalising objects, capable of containing and holding hidden pain and suffering, enabling both *emotional connection* and *distancing* to take place and new meanings to be developed. I identified *mourning losses* as a key adaptive process facilitated by this project, describing PRs experience of finding a sense of *closure* regarding important bereavements and losses within their lives. The portraits also became an opportunity to engage in creative and adaptive *rituals*, enabling a process of *visible mending* to occur. I also described PRs increased feelings of control and autonomy, and the rediscovering of adaptive strategies used in their pre-illness lives, resulting in increased self-care and agency. In chapter five I explore how the intervention increased PRs perceptions of a *homelike-being-in the world*.

5.0 Chapter 5. Portraits Making Meaning: increasing the lived experience of *homelike-being-in-the-world*.

In this chapter I will discuss four emergent themes using the different forms of data generated within this project as evidence. I will argue that a sense of ‘home-like-being-in-the-world’ (Svenaeus 2011) is often lost when people are plunged into ‘liminal space’ (Turner 1995; Sibbett 2005: 12-37) or the ‘world of illness’ (Radley 2009) following the diagnosis of a LT&CI and that through this project PRs experience an increased sense of self-identity coherence and *home-like-being-in-the-world*.

When considering embodiment as central to all experience (Merleau-Ponty 2002), the idea of the body as *home* can be developed, and the portraits therefore become a depiction of that *homelike-being-in-the-world*. As Dupuis & Thorns (1998: 30) say, the idea of ‘home’ as a place of security combines a sense of permanence and continuity, with a protective material environment, which contains intensely emotional significance and meanings. ‘Home’ can therefore be a secure base from which to construct self-identities and a space where ‘ontological security is [or may be] maintained’ and where people generally feel a strong sense of control in their lives (Dupuis & Thorns 1998: 28).

The emergent themes also reflect the ways PRs have used the portraits potentiality for ritual and ‘making special’ activities and as points of reference that help them navigate through their illness (Achterberg *et al.* 1994: 3).

5.1 ‘Making Special’, Making meaning: Spirituality & ‘Souls’, Ritual & Myth

Within the ongoing debate regarding self-identity and the impact of social constructs, academic and psychotherapist Ken Evans (2005b: 46) suggests that materialism and consumerism have had a major influence on current thinking, and that ‘the primacy of the body’ has become the ‘dominant belief about “self”’, coinciding with a change in belief systems from the dualist/religious belief in ‘body and soul’ to a reliance on ‘scientific’ explanations (Evans 2005b: 44). A dualist distinction between the soul and body gave people the comfort of believing that whilst their bodies may have been attacked by disease, their souls remained intact, however for materialists ‘they themselves become “a diseased body” [...]’ (Evans 2005a: 46), and death becomes

the final stripping away of all that constitutes self-identity. Despite this, in my experience talking to patients in palliative care, there is still a strong belief that human beings are ‘more’ than consciously aware bodies (ibid: 49), and this is reflected in the eclectic range of religious and spiritual beliefs explored by the PRs in this study. The need to support patients’ spirituality and meaning-making processes has been identified as one of the key aspects of art therapy within palliative care (Waller & Sibbett 2005: xxviii; Bell 2008; Balboni *et al.* 2007; Puchalski *et al.* 2009), and I suggest ‘art’ as a spiritual meaning-making practice within art therapy has a lot to offer in its ability to support individual eclectic beliefs (Farelly-Hansen 2001), as demonstrated within this project. In my experience severe illness results in a natural drawing towards an eclectic myth/meaning making, as a form of self-made spirituality. This project has been a way to facilitate this movement towards creating meaning and spiritual connections, with some of the portraits taking on aspects of religious icons and becoming ‘containers’ of spiritual experience.

I would suggest the portraits also enable positive moves towards an amelioration of existential anxiety (Kierkegaard [1844] 1944), which is described as a form of stress pertaining to: our freedom to act and therefore make decisions, and also a fear of the unknown. Existential anxiety can also equate with a fear of *annihilation* (Falk 2005), which is perhaps the most fundamental and primal anxiety human beings face and one that is brought to the fore in LT&CIs. This underlines the deep human terror of helplessness, which Bauman suggests is contributed to by ‘the terror of uncertainty’ and ‘the horror of the unknown’ (Bauman 2004: 72), which is exacerbated by the failure of science and reason to offer a sense of meaning in LT&CIs. As Sacks says following his personal experience of severe illness:

Science and reason could not talk of nothingness, of hell, of limbo; or of spiritual night. They had no place for absence, darkness, death. Yet these were the overwhelming realities of this time. ... And I turned to the mystics, and the Metaphysical poets too, for they also offered both formulation and hope – poetic, aesthetic, metaphoric, symbolic, without the blunt plain commitment that ‘religion’ involved (Sacks 1984: 89-90).

PRs in this project have used the collages and portraits to explore their lived experience of existential anxiety, suggesting that meaningful engagement in exploring self-identity through portraiture has spiritual and meaning making potential, and the ability to make inroads into the void left by the Western World's move away from *organised religion* as the traditional place where such terrors are explored and given meaning.

Taylor (1989: 22) suggests that during the past two centuries, there has developed an increased recognition of the power of visual expression, which has led to an admiration of the artist/creator that is higher than that held by any former civilisation. The artist is seen as someone who 'sees further' than the materials at hand, and that 'what meaning there is for us depends in part on our powers of expression' (Taylor, 1989: 22). The 'great cathedrals' of Western art, which are visited by millions every year, who go to stand in awe before 'famous' works, are testimony to this view. PRs may therefore see their painted portraits as something which 'makes special' (Dissanayake 1988), transcending the mundane and the uncertainty of this world, enabling a return to the 'primitive science' of myth making (Segal 2004: 13). Like Evans (2005) I believe that art can provide a space to create spiritual meanings and to 'honour and explore' the 'strange sense we have that we are more than simply our bodies, and that our sense of self is not entirely physical' (*ibid.* 49).

One of the ways this project seeks to ameliorate a sense of meaninglessness is through ritual and 'making special' (Dissanayake 1988). Through creating objects and portraits, and bringing them into being in the present, they can be used in a ritualized way to develop meaning and feelings of homelike being-in-the-world and enable a lived experience of healing to occur. In this section I will look at how PRs were able to co-design portraits imbued with spiritual significance and meaning, something I suggest is important for people who find themselves in the *unhomelike* world of 'liminality' (Turner 1995).

Sibbett (2005a: 15) describes Turner's (1995) concept of 'liminality' as a transitional or threshold phase of rites of passage, and focuses on ritual and four characteristics of liminality 'limbo, power/powerlessness, playing and communion. The term 'ritual' is

used here to represent the use of social or private behaviours or rites involving ‘sacred or secular symbols’ (Cohen 2002) which give ‘significance to life passages’ (Achterberg *et al.* 1994: 3). Ritual is often at the forefront of ‘formulating experience’ and ‘can permit knowledge of what would otherwise not be known at all’ (Douglass 1966: 64).

Within this project, several of the PRs attached spiritual meaning making to the portraits, with ritual being part of this process. Both rituals and portraits are ‘bracketed’ in that they are set apart from the ordinary and the mundane, are invested with meanings often hidden within heavy symbolism and metaphor, and significance that goes beyond the painted surface (Dissanayake 1995: 20).

During the photo-elicitation stage of the project Norma, Susan and Rose described having searched for and found alternative spiritual beliefs, i.e. Native American Indian, Buddhist and Spiritualist beliefs respectively, and other PRs talked about having no experience of personal religious or spiritual beliefs e.g. Peter and Paul. Despite Hilary’s strong religious faith (Church of England), in the collage entitled *I don’t want to just disappear* (see Figure 49) Hilary explored her feelings of ontological insecurity indicating that her sense of ontological *security* had been severely shaken by her illness and the recognition of ‘being-towards-death’ (Heidegger 1962 [1927]).

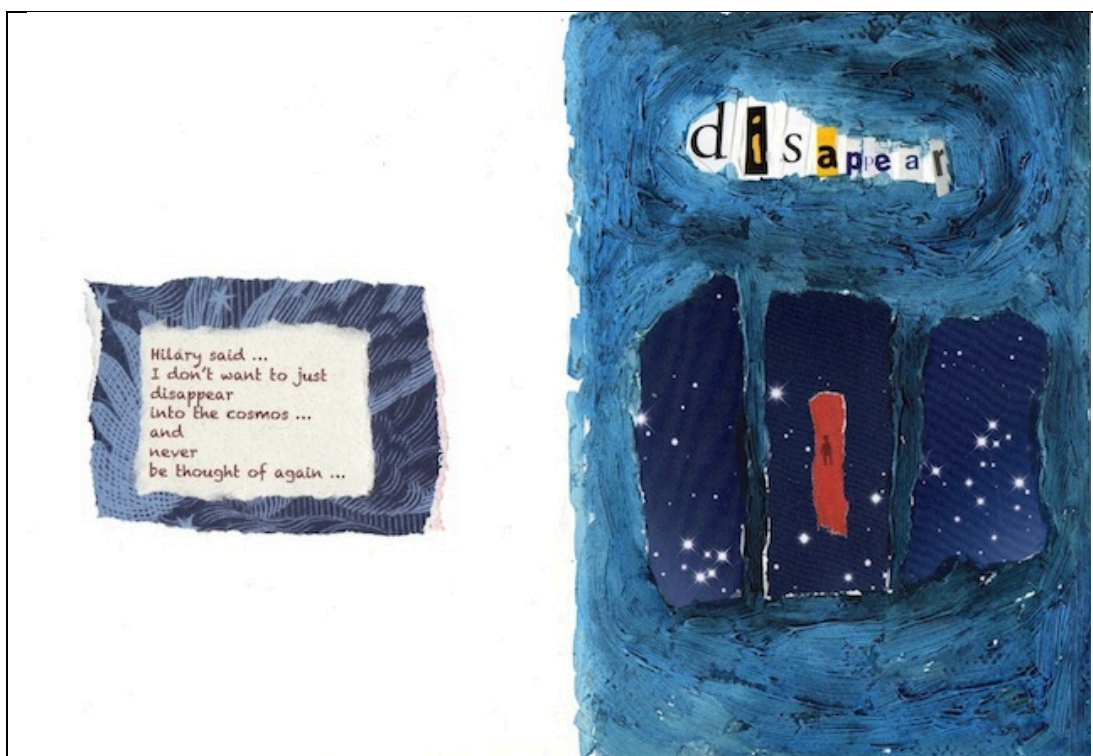


Figure 49. *I Don't Want to Just Disappear* Collage by Susan Carr 2010.

Despite constant disturbing images of death both real and fictional within popular culture, death is considered the last taboo (Kubler-Ross 1975), and there is in our Western culture an 'unspoken agreement' not to speak about our own death (Sibbett 2005: 69). However without the development of a symbolic language, rich with metaphor and ritual, thoughts and feelings surrounding death cannot be integrated (*ibid.*). As Sibbett says 'art therapy rituals and symbols have particular value in metaphorizing the body, thus enabling expression of emotions and bodily states including conscious and unconscious aspects otherwise deemed unspeakable, unhearable, unseeable and unthinkable' (Sibbett 2005: 71-2).

In chapter 4 I discussed how Hilary and I co-designed the *Held by an Angel* portrait (see Figure 50 below) and how this portrait became a manifestation of her increased ability to use her imagination. However, when reviewing Hilary's portraits it seemed that *Held by an Angel* had a dual meaning, with the 'angel' offering 'holding' either in life or death. Luzzatto (2005: 170) says that visual imagery enables the combination of conflicting symbols within the same painting, and that this combination of contradictory dualities is comforting for patients to see, providing a sense of balance.



Figure 50. *Held by an Angel* by Susan Carr (co-designed by Hilary)

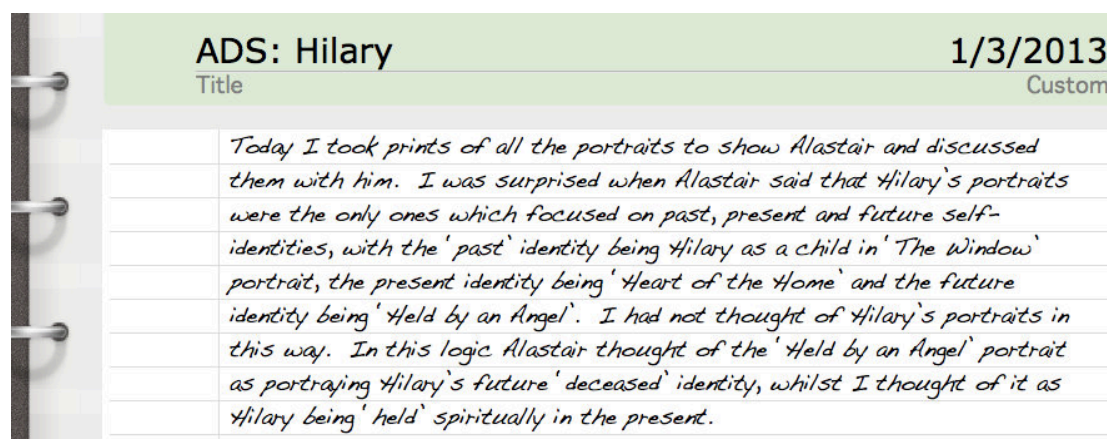
On one of my visits to Hilary, shortly after completing the portrait 'Held by an Angel', Hilary asked me to give her a copy of it:

Hilary	27/06/2011 15:25
Title	Created
<i>ADS: Today Hilary asked me if I could give her a photograph of the 'Held by an Angel' painting as she wanted to keep one with her at all times, saying if she went into hospital again she would take it with her so she could see it from her bed. I wondered if this image had become a kind of religious icon for Hilary, something invested with powers of protection or healing, physical or psychological?</i>	

The significance of Hilary's *Held by an Angel* portrait becomes manifest therefore in the way it was 'made special' (Dissanayake 1988) and invested with the resonance of a ritualised transitional religious icon (Freeland 2010: 49), serving as a constant reminder of *being held*, a testimony of the care of her 'guardian angel'. The portrait also becomes a testimony of *my care* (Moon 2002), and as a meaning laden object, the portrait resonates with the remembered intersubjective co-designing process, the hours taken by me to paint it, and through this the worthwhileness of her self and her life is suggested and confirmed, enabling Hilary to feel more ontologically secure. This is perhaps why Hilary wanted a

copy of the portrait to 'keep with her at all times'. (Peter also asked for copies of his and Mark's portraits to 'keep with him at all times' placing them in his wallet).

When I discussed Hilary's portraits (see Figures 28 [p120] & 50 [p158]) with my supervisor he saw them as a reflection of Hilary's past, present and future self-identities:



This shows the ability of the portraits to hold and contain dualities such as hope and despair (mine and the PRs) and to be used as a ritualised object.

The portrait as ritualised object invested with spiritual meanings is also highlighted within the smudging ceremony carried out by Norma to 'bless' the portrait sculpture *My Baby/Myself* (see Figure 51).



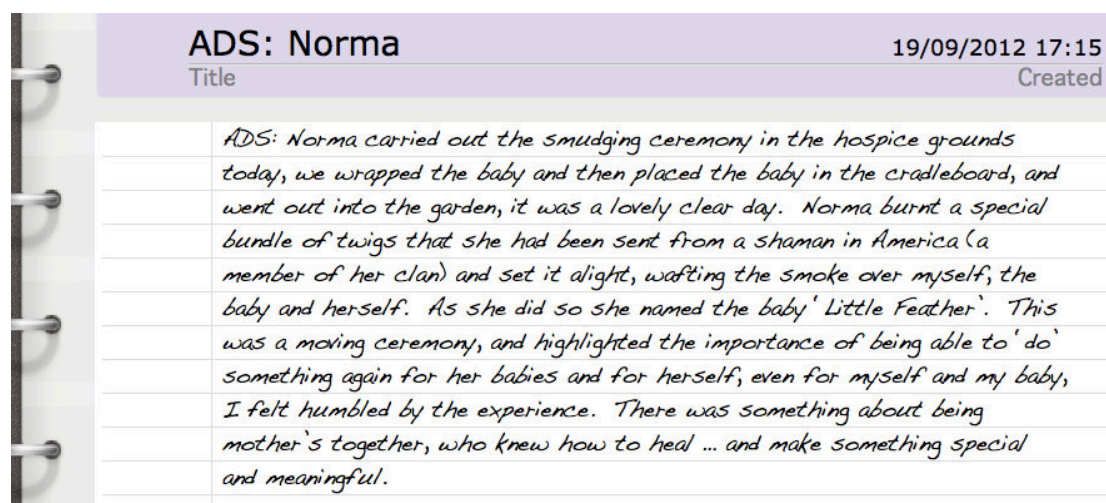
Figure 51. *My baby/My Self* by Susan Carr (Co-designed and co-created by Norma)

As discussed in the previous chapter, Norma and I co-created the Native American Indian ‘baby’, cradle-board and layette, as a way to transform the abandonment that Norma experienced as a baby, as well as mourn the loss of seven of her own babies and one of my own. When I was making the muslin baby, I was conscious of trying to make the ‘baby’ as realistic as possible, this included adding rice to the body, head and limbs to give it an authentic feel and weight. I remember when I made Unwelcome Contradictions (see Figure 41 on page 140) I did not do this, and the ‘baby’ felt too light and unrealistic when held. However, I wondered if I had made the ‘baby’ too realistic and before the smudging ceremony I felt I had to warn Norma about how realistic the ‘baby’ seemed when held. I noticed a distinct change in Norma’s demeanour when holding the ‘baby’ and how easily she assumed the ‘caring mother role’, gently and reverently holding, rocking and stroking the ‘baby’. Norma used a shawl that was special to her to wrap the ‘baby’ in, adding a sense of continuity and connection and homelikeness, as Norma explains in her EPI:

S: Good, and so next week, hopefully we’ll do the smudging ceremony and I’ll bring the baby so we’ll... N: Smudge her. **S: And dress her and...** N: And then put her into the ... [cradleboard] ... I’ve got something that I’m going to wrap her in and that has come from my great grandmother and it was hand made. So, the baby will be wrapped in that. It will be used this one last time by me, to wrap my seven babies in. Because they were all in it, even my little girl, even though she passed away, I still wrapped her up in it, so there is a part of her in it, because every child that has been wrapped in it has left something into it. *It’s made it special.* There’s a bit of every child in it who had it on them. **S: Ah, that’s lovely.** N: So, that is quite a precious little gift, and it’s coming to the exhibition for you. To wrap the little baby in, to wrap my seven babies in.

S= Susan, (ATR) Artist/Therapist/Researcher N=Norma (PR) Patient/Researcher (EPI: 26/09/2012)

Although Norma refers to the ‘baby’ as ‘her’ (i.e. female) – Norma has lost male as well as female babies, and perhaps she was focussing on herself as an abandoned baby ‘now found’. Norma demonstrates understanding of the process of ‘making special’ when she talks about her great-grandmother’s shawl, and there also seems to be a real sense of ‘wrapping herself’ as an abandoned baby in the shawl, doing what her mother didn’t do when she was born, using the action of wrapping to contain her grief and physically enable feelings of ‘closure’. I reflected on the smudging ceremony experience in the ADS:



These sentiments also correlate with the essence statements for 'My Baby/Myself':

Statement of Emergent Knowing: My Baby/Myself

A fragile baby endlessly sleeping, held securely, cared for and wanted, wrapped up with love. Precious riches adorn laboriously made, for this world or the next?

Statement of Emergent Learning: My Baby/Myself

A baby reunited with a spiritual family, lost babies and the mother identity mourned, as Norma becomes wise women/elder.

Statement of Reflexive Resonance: My Baby/Myself

The loss of my own baby halfway through a pregnancy meant that I was able to empathize with Norma in her mourning, and enter into the smudging ceremony as one who understands the depths of her despair and the value of art in healing all wounds. Making the baby portrait-sculpture was a therapeutic process both for Norma and myself. Together we became wise, understanding the need for ritual and grace in death and grief.

By creating the baby layette and facilitating the smudging ceremony Norma was able to give her abandoned baby/self and her lost babies, the love and care that would have been offered within the Native American Indian spiritual tradition, allowing a sense of closure on painful episodes in her life, and connection to her new spiritual beliefs. Norma was able to physically *do* something for her self and her lost babies, something that linked her present Native American Indian identity, with that of her past (Scottish) identity. Norma engaged in a process of 'liminal play' involving ritual objects enabling change to happen through 'performing symbolic actions and manipulating symbolic objects' (Turner 1982: 32).

In a contemporaneous portrait of herself and as a natural progression from this understanding Norma asked to be portrayed as the *wise woman/elder* of her Black Foot clan, stood by a lake in the wilds of North America. By placing herself in a landscape she had longed to be in (but due to her illness never had), the portrait is imbued with all the spiritual significance of Norma being there in reality. It literally took Norma out of her 'liminal space' and placed her where she could feel a sense of homelike-being-in-the-world.



Figure 52. *North Bear* by Susan Carr (co-designed by Norma)

This portrait shows Norma portrayed within the land of her adoptive ancestors, a spiritual space, which acts as confirmation of her Native American Indian identity, one that she can 'show' to others. Norma adds her own significance to the portrait by *seeing* 'bears' within the sea, clouds and moon, something she will enjoy asking others if they can 'see':

N: I can see part of a bear...can you see where?

S: (Long pause) I don't know really.

N: It's not a brown bear,

S: A white bear? You'll have to show me.

N: There's the head of a polar bear. (S: Oh, is there? Hmmm) If you look really hard, you can see his body just under the water.

S: Oh, ok. Well, I'm glad there is a bear.

N: But he's not obvious.

S: He's not obvious, no.

N: And if you're not looking for a bear, you won't find him. If you look, you can just

see the head about the water. It's a very abstract bear, but you can still see him. If you look at the shadow of the water there, there's a bear and that looks like his leg.

S: Oh yes, I can see that now.

N: And you did it without trying!

S: I did yes, that's true. Yes, it just appeared.

N: And there's another bear, I just noticed.

S: Is there? Where's that then?

N: There's his head.

S: Oh yes, it could be. Yep. Hmmm.

S = Susan, (ATR) Artist-Researcher & N = Norma (PR) Patient-Researcher. (EPI: 26/09/2012).

In this exchange I felt chastised by Norma for being unable to 'see' the bears she could see, wanting confirmation that the bears had just 'appeared' within the portrait without my consciously putting them there, saying ... 'and you did it without trying!' There was a sense in Norma that the spiritual would find its way into the present through the portraits, depicted through symbolism, metaphor, serendipity and intuitive understandings. My *intuitive knowing* without being *told*, was very important to Norma throughout her involvement in this project. I believe this underlined a need in Norma *to be known* on a spiritual level, something that my *attunement* within the portraits depicted in a concrete way, allowing Norma to reflect on and find joy in discovering herself.

In this section I have used examples to describe how PRs used the portraits and portrait-sculptures in ritualistic and sacralizing ways, and how these processes enabled feelings of homelike-being-in-the-world. Hilary and Peter demonstrated the value of the portraits to them through asking for small reproductions to 'keep with them at all times'. Norma used the project to grieve for her abandoned baby-self as well as her own lost babies, bringing her past into the present to be engaged within the ritualised practices of the Native American Indian smudging ceremony. Norma's final portrait of herself as North Bear situated within the wilds of North America, depicted a longed for spiritual experience of homelike-being-in-the-world. The portraits therefore enabled the development of ritualistic behaviour, which is tied to the PRs own sense of being and self-worth and the development of new meanings and new ways of knowing the self and *being known*.

5.3 Portraits of Belonging and Re-membering: Linking past, present and future self-identities.

All the PRs to some extent utilized this project to connect to something or people they felt a sense of *belonging* to, acting as a bridge to significant others, and a way of connecting to humanity as a whole, or to reaffirm identity ‘frames’ (Taylor 1989) that PRs have belonged to in the past. As Kinnvall (2004: 742) says ‘[...] as individuals feel vulnerable and experience existential anxiety, it is not uncommon for them to wish to reaffirm a threatened self-identity. Any collective identity that can provide such security is a potential pole of attraction’. This sense of belonging to a collective identity enables feelings of *being part of something larger than themselves*. One of civilization’s earliest self-identity ‘frames’, and one that is to some extent still prevalent today, is the ‘honour ethic’ as described by Taylor (1989). This is characterised by the warrior or citizen soldier, who fights for his/her country, and is deemed to be a person of a higher order than one dedicated to purely economic and peaceful pursuits (*ibid.*), ‘[...] to be ready to hazard one’s tranquillity, wealth, even life for glory is the mark of a real man’ (Taylor 1989: 20).

The ‘warrior’ self-identity frame was particularly evident within Bill’s portraits. When I began to work with Bill (a 91 year old gentleman) it became very clear that the area of his self-identity he wished to portray through the portraits was that encapsulated by his experiences as a glider pilot in the Second World War. Over the 8 months we worked together Bill related his war experience and we co-designed 16 collages and prose poems as response art, and painted four portraits, all reflecting back these stories of heroism, fear, pain, suffering, brotherhood and loss. In the ADS I note the transient thoughts and feelings engendered through listening to and being with Bill:

ADS: Bill	02/08/2011 14:05
Title	Created
<i>ADS: Spent time with Bill today talking about his war experiences. He told me about how he was shot in the chest and while waiting on a stretcher on the back of a Jeep came under enemy fire and rolled off the back to avoid getting shot again. How he fell onto his gun cartridge and broke three of his ribs into the bargain. He took my hand and pressed it into the scar in his chest - saying "feel that", I felt the "hole" in his ribs where the bullet had struck, and imagined Bill as a young man - lying wounded by the side of the road in Arnhem in pain and probably full of fear. Afterwards unbuttoning his shirt he said "look here's the scar where the bullet entered". Bill said that he thought he was going to die - as he lay there wounded - and blood filled his lungs - he thought he would 'drown' in his own blood. Through the power of touch and sight I was able to feel his wound and acknowledge his pain and his bravery. I felt Bill's showing me was a direct visual way to convey the authenticity of his war stories and his suffering. The scar becoming a 'badge' of authenticity?</i>	

I wondered about the significance of being present with Bill and witnessing stories of his war time self-identity, and if this might help to mitigate some of the feelings of 'aloneness' he'd felt at the time.

ADS: Bill	02/08/2011 14:05
Title	Created
<i>As Bill told me of his experiences he continued to hold onto my hand. And while I sat there, I was aware that even though Bill is 91 years old, in that moment I was holding the hand of the young Bill shot through the chest, a young man who had a few hours earlier courageously carried an injured soldier through gunfire to safety. This too was the young injured man thrown on a train and sent to a POW camp, alone and afraid, thinking that he would die. It was a very moving experience and I wondered if, by being present with Bill now, by holding his hand as he relived those experiences, that this might help to mitigate the feelings of aloneness he must have felt at the time.</i>	

As mentioned in chapter 5, Bill always added a twist of humour even to the most harrowing of tales. In the collage below (Figure 53) Bill talks about one of the German orderlies on the train offering him a moment of compassion and kindness. When relating this story Bill launched spontaneously into a wonderful rendition of the poem *Gunga Din* by Rudyard Kipling (1892):

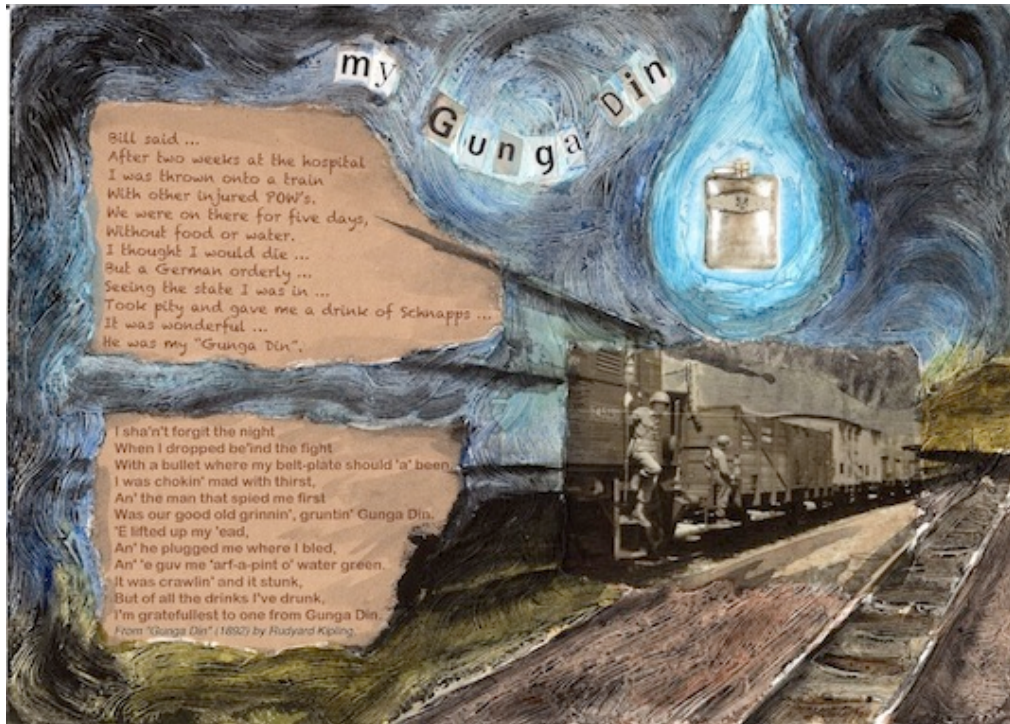


Figure 53. *My Gunga Din* by Susan Carr, 2012.

Remembering the sacrifice of his fellow servicemen was a constant theme throughout the collages and prose poems I created for Bill. Here Bill remembers one young man's personal sacrifice:

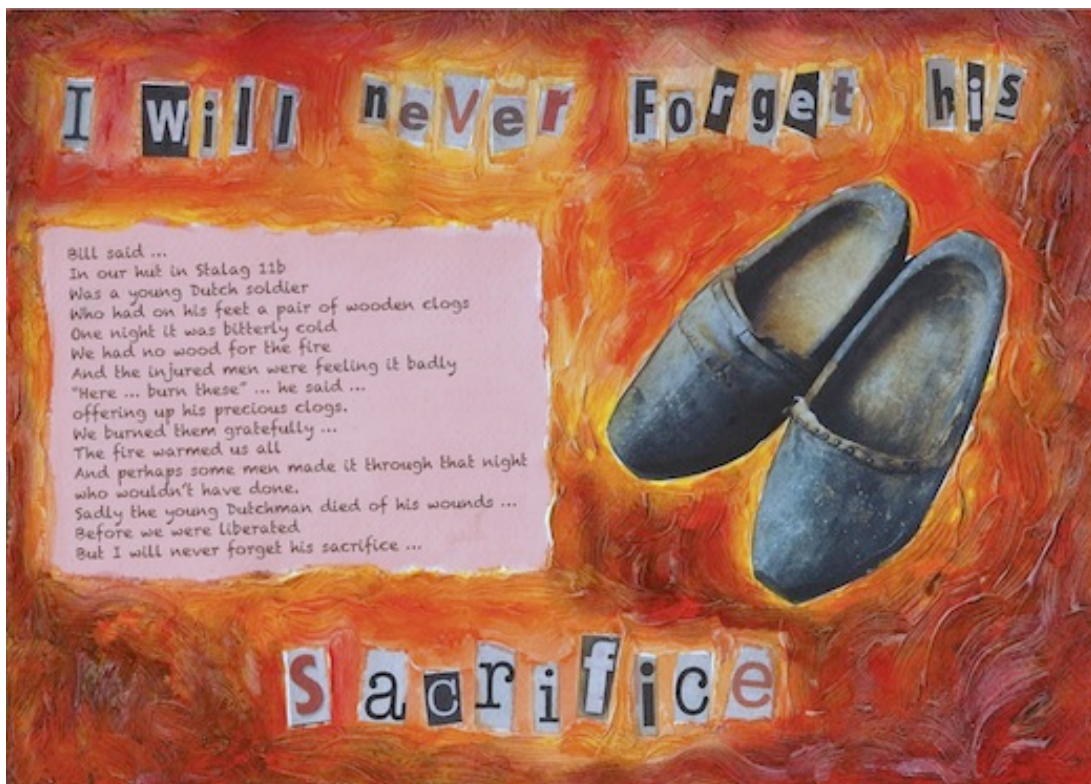


Figure 54. *Sacrifice* by Susan Carr, 2012.

I was concerned initially that Bill's preoccupation with his war experiences may have been a way to avoid talking about his present sense of self-identity and a denial of his illness. However, it occurred to me that Bill's present self-identity, which he described as 'the old man', did not even begin to express the self-identity that Bill identified with most strongly, and that ultimately the war experiences Bill related, expressed everything he needed to tell me about his self-identity. It told me his values, his concerns, his sense of belonging and brotherhood, it told me what he would and wouldn't do, in short Bill told me 'who' he was, in a way that relating stories of his present self-identity never could. It was the period in Bill's life where his self-identity was formed and broken and reformed, the scars I saw and felt, were his *badge of membership* (Anzieu 1989) to the veteran brotherhood, an evidence of 'visible mending' (Jones 2008), lending an indisputable authenticity to his stories (Anzieu 1989). I wonder therefore if the propensity for older people to 'talk about the past' is less about a lack of memory of the present, and more to do with maintaining and reaffirming past self-identities, and as such should be considered a vital aspect of psychological and emotional support for older adults.

In Hogan & Warren's (2012) study older women were given the opportunity to depict themselves in ways that challenged the stigmatised view of aging, and some chose images displaying themselves in ways that expressed *youthful exuberance* despite their age, which correlates with Bill's desire to be portrayed as a healthy and vital young man.

The following (Figure 55) are the three initial portraits Bill and I co-designed and I painted:



Figure 55. *The Flying Ace, Pegasus Bridge & The Veteran* by Susan Carr (co-designed by Bill)

On reviewing these portraits I was concerned that I may have unconsciously *aestheticised* or *romanticised* Bills war experiences:

ADS: Bill	08/12/2011 17:05
Title	Created
<i>ADS: I was reflecting upon Bill's paintings today and wondered if I had unconsciously romanticized or underplayed the horror of his war experiences, in Flying Ace and Pegasus Bridge. I think that I need to paint a final portrait which goes some way to expressing the horrors of war, not in a 'dangling a dead rat' sense, and perhaps it can even be 'beautiful' but something that recognizes Bill's heroism, and the risks he took to serve his country?</i>	

After reflecting on Bill's portraits I discussed with Bill the idea of painting a final portrait, set within a battle scene, based on his experience of being 'mentioned in despatches'. See collage below:

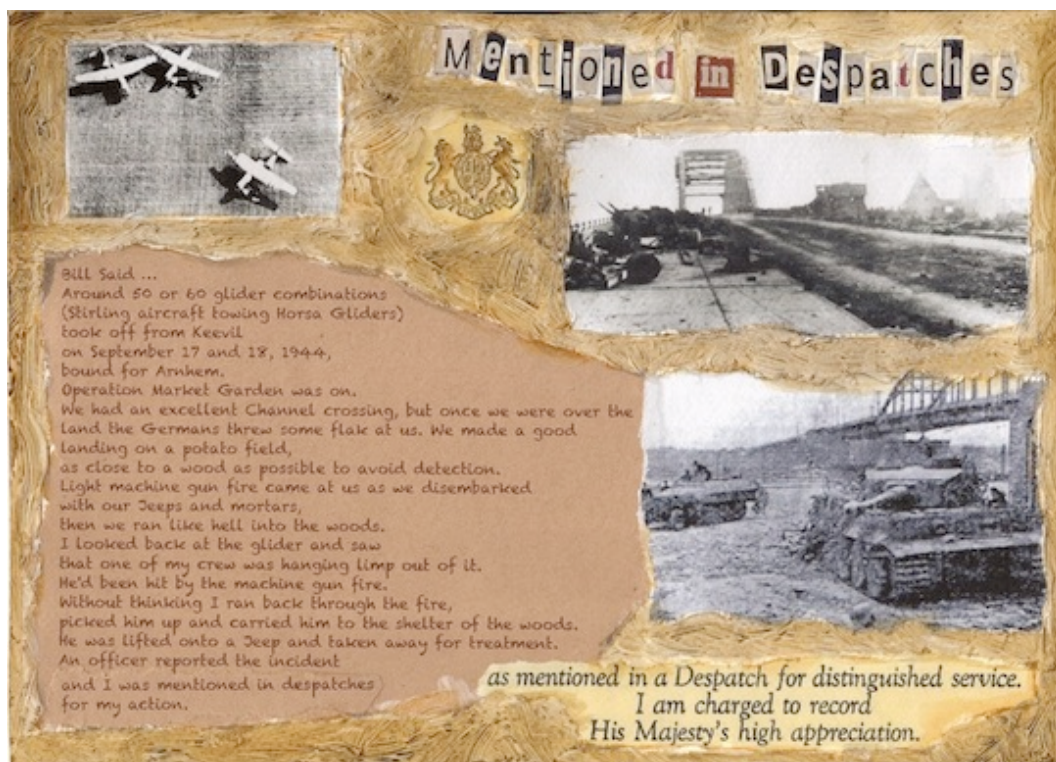


Figure 56. *Mentioned in Despatches* collage by Susan Carr, 2012.

I was conscious of attempting to portray in the portrait the lived experience of action and confusion in a battlefield, and the moment that Bill rescued the injured soldier. I used the paintings of former First World War artist and art therapy pioneer Adrian Hill for reference and inspiration.



Figure 57. *Mentioned in Despatches* by Susan Carr, 2012 (co-designed by Bill)

All Bill's portraits seemed to reflect the theme of *belonging* and *re-membering*:

S: So how do you feel about the fact that these portraits will go into an exhibition and be seen by lots of people? B: Well I shall be pleased because ... I tell you what ... the Glider Pilot Regiment was the biggest airborne regiment in the War and yet very little is said about it you know, I don't know why, why it is, it was a big operation, there were thousands of gliders in it and a big operation. *But I like people to know what it was ... I like to be attached to what it was ...*
SC = Susan, (AR) Artist/Researcher B = Bill (PR) Patient/Researcher (EPI: 24/04/2012)

Like Bill, Rose was keen for her portraits to reflect her sense of belonging to something greater than herself, and this is explored in her *Bohemian Rhapsody* portrait (Figure 58). The prose poem that accompanied this portrait outlined her identification with Freddie Mercury.



Rose said:
Paint me like Freddie Mercury
In Bohemian Rhapsody
Strong and defiant ...
I'll wear his rings ... I have copies you know
And a rose in my garden named after him,
Roses are sparky, Like me ...
Like I've had to become
To survive the uncertainty ...
I used to visit Freddie's house every year
A kind of pilgrimage
To read the messages on the wall
To light a candle ...
Now it's all gone ... there is nothing there
People complained it was too untidy ...
But then life is untidy ... and I have learned
Not to complain ... but to live ...

Figure 58. *Bohemian Rhapsody* by Susan Carr (co-designed by Rose)

When I first visited Rose's home it was immediately obvious that she was a fan of Freddie Mercury, as on almost every surface of her lounge there was a picture or reminder of him. Therefore Rose's request to be painted as Freddie wasn't a great surprise, although her choice of the iconic *Bohemian Rhapsody* pose was. I arranged

with Rose to take some reference photographs for the portrait and Rose dressed for the part, wearing a similar outfit to Freddie's and replica rings for the session. When I saw the photographs I was a bit shocked by the 'corpse like' pose, and Rose also had reservations that she did not reveal at the time, but discussed later in the EPI:

S: Ok ... that's great. So looking at the paintings now, is there anything you would change about them?

R: No. ... No

S: That's good ...

R: I was a bit bothered about that to start with [indicating *Bohemian Rhapsody* portrait] when I saw the [reference] photographs.

S: Bothered about it?

R: Yeah, I thought "oh dear I don't like that", but the painting has changed it completely, *I like it now*.

S: I think it has a real strength to it ...

R: It's got that ...

S: A real strength ... that is in you ...

R: and determination.

S: Yes determination.

R: *That's determined!* [Indicating *Bohemian Rhapsody* portrait]

S= Susan, (ATR) Artist-Researcher & R= 'Rose' (PR) Patient-Researcher. (EPI 27/03/2011]

The sense of belonging that Rose felt through aligning herself with her idol Freddie, was outlined within the essence statements created in the visual analysis process:

Statement of Emergent Learning: Bohemian Rhapsody portrait

In posing as her musical idol Freddie Mercury, Rose is demonstrating her solidarity and identification with him and his suffering, and also her personal strength, courage and determination to 'keep on fighting to the end' (Mercury 1975).

Historically the people painted in portraits were of high social status, either the 'great and the good' or the very wealthy, who through their deeds demanded our respect, implying that 'their life and integrity is sacred or enjoys immunity, and is not to be attacked' (Taylor 1989: 25). Through aligning herself with her idol, Rose not only becomes Freddie in that moment, and all he means to her in the way of stardom and celebrity, but also acknowledges the solidarity Rose feels around them both being diagnosed with terminal illnesses and therefore, both dwellers of 'liminal' space (Turner 1995; Sibbett 2004, 2005).

The theme of belonging and remembering was also evident in Paul's *English Gothic* portrait (see Figure 59), where he asked to be portrayed with the three people he had been closest to in his life, these were his Grandmother, Grandfather and Uncle. Paul's grandfather ran a farm and so it is with this farming community and family that Paul aligns himself, selecting the painting *American Gothic* by Grant Wood (1930) as reference material. Paul's portrait reflects a sense of homelike-being-in-the-world. I documented in the ADS our first discussion around this portrait:

ADS: Paul	08/10/2012 16:25
Title	Created
<i>ADS: Today in our first session I talked to Paul about the project and how we can incorporate people and things that mean the most to him or reflect his sense of self-identity. He said that the three people he had been closest to in life had died, and these were his grandparents and his uncle, who he said was more like a brother to him. Paul was visibly moved when telling me this, a rare slip of the jovial laid back mask I normally see at day hospice, and with Paul's show of emotion I also felt moved. I was also acutely aware of a sense of isolation and vulnerability around Paul in his alone-ness, I wonder if anyone has ever really known Paul?</i>	



Figure 59. English Gothic by Susan Carr (co-designed by Paul)

Statement of Emergent Knowing: English Gothic

A farming family pose in front of their homestead, steeped in traditional values, growing food for humanity, unafraid of hard work. Calloused hands wield a pitchfork, protecting family bonds ... reunited.

Statement of Emergent Learning: English Gothic

Paul identifies with his hardworking farmer grandparents and relations in this

painting, remembering the shared experience of working on the farm ... worthwhile work, communing with nature and surrounded by family who valued him and his contribution.

Through Paul associating himself with a former autonomous self-identity that contributed positively to society and family, feelings of self-worth were enhanced and affirmed. As Kinnvall (2004: 744) says 'going back to an imagined past by using reconstructed symbols and cultural reference points is '[...] an attempt to recreate a lost sense of security'. This lived experience of *belonging* is therefore self-identity affirming, and even if that sense of belonging is part of their *past* identity, through the portraits it is brought back to the *present*, *re-membered*, *re-lived* and *re-integrated* and thereby invested with meaning.

Whilst a sense of belonging is suggested within this portrait it is also about being-towards-death. Paul is portrayed with the three people he has been closest to in his life – but they are all deceased. Paul literally puts himself in the company of the dead – suggesting that his own death will be a kind of homecoming. When viewed from this perspective this portrait becomes a holder of multiple dualities, of life and death, hope and despair, past and future, belonging and separation. Paul is able to explore his own forthcoming death, through exploring and coming to terms with the death of those closest to him.

The sense that portraits are able to hold dualities correlates with Susan's experience of co-designing and seeing the portrait sculpture *The Paper Dress* (see Figure 60 below):

Statement of Intention: The Paper Dress: Stitching Words Together

Susan said that as a child her mother had made all her clothes, a favourite had been a little dress with heart shaped pockets. Susan said that she had inherited none of her mother's skills with a needle and was a writer instead. We decided to use photocopies of pages from an academic book Susan had written, and photographs of herself as a child, to make a paper full sized replica of the child's 'dress with the heart shaped pockets'. This was to acknowledge that Susan's mother 'stitched fabric together' and Susan 'stitched words together', linking them both through *The Paper Dress with the Heart Shaped Pockets*.

The use of needle and thread within this portrait-sculpture evoked images of the 'good enough (m)other', repairing or making, and artist Louise Bourgeois equates the power of the needle to magical reparation saying, 'The needle is used to repair the damage. It's a claim to forgiveness' (Louise Bourgeois Quoted in Darwent, 2010).

Portraits usually depict subjects who are clothed, whether that be every day clothes, historical or fancy dress, these all signify temporality, fixing subjects within particular historical eras (Pointon 2013: 20). Portraits also engage with materiality through the clothes and objects depicted within the portrait, and also through the very fabric of the portrait itself (Pointon 2013: 128).



Figure 60. *The Paper Dress* by Susan Carr (co-designed by Susan)

In her EPI Susan talks about how a sense of connection was made between herself and her mother through *The Paper Dress* portrait-sculpture:

SC: Yes, that's good. So in a way that's about telling your life story but looking at it in a different way because we are looking at how we can make pictures, or lasting images about it. Do you think that changes how you look at it?

S: Yes, I think so because if you asked me for my life story, I wouldn't necessarily have said the things I've said. What we are looking at is an *emotional life story*, which you have to find metaphors to express, which I think is what this does. You know, I would perhaps concentrate on getting the degrees and writing and you know, maybe,

meeting the Queen and all that kind of thing but they are not my emotional life story. *And my emotional life story is more important, really.*

SC: Hmmm, that's interesting.

S: I mean this is what thinking about the art enables you to do, *this isn't about me having dresses made, it's my whole part of my relationship with my mother and things like that. I think it's much more important to express.*

SC = Susan, (AR) Artist-Researcher & S = Susan (PR) Patient-Researcher. (EPI 10/10/2012)

The Paper Dress portrait-sculpture, therefore enabled a sense of connection between Susan and her late mother, bringing the past and present together in the one object, allowing Susan to reconcile the difference she felt between herself and her mother with a renewed sense of connection, meaning and *continuity*. Susan also explores the loss of her mother in this piece, continuing the theme of exploring death and mourning through examining the loss of her 'daughter to a beloved mother' identity. The sense of continuity inherent within her portraits is something Susan talks of in her EPI:

SC: I have done a little bit more on the [*In the Library*] picture [...]

S: I think you've got everything there, gosh. *You can see the continuity there can't you?* [indicating all four of the portraits] (see Figure 61 below).

SC = Susan, (AR) Artist/Researcher S = Susan (PR) Patient/Researcher (EPI: 18/10/2012)

Susan's four portraits:



Figure 61. Susan's four portraits: *Little Susan*, *Saying Goodbye to the Sea*, *Being Pandora* & *The Library* by Susan Carr (co-designed by PR Susan).

In this section I have described examples where PRs found an increased sense of belonging, re-mem-bering and continuity through the portraits, linking and integrating aspects of past, present and future self-identities. Bill's WWII experiences depicted within the portraits, collages and prose-poems revealed everything he needed to tell me about his self-identity, and how it had been formed, broken and reformed, despite

the gap of nearly 70 years since the war. Rose celebrates her sense of belonging and connection to Freddie Mercury in her portrait *Bohemian Rhapsody*, someone she recognises as a fellow inhabitant of liminal space, through LT&CIs. Paul finds a sense of homelike-being-in-the-world in his *English Gothic* portrait, depicted with his deceased relatives, at the same time acknowledging an acceptance of being-towards-death. Susan finds a sense of connection with her deceased mother in The Paper Dress and a sense of continuity of being within her four portraits. As Duesbury (2005: 207) says working within palliative care is characterised by not only the ‘intimate depth’ of the work but also the ‘breadth’ ... ‘we are working with past, present and future as an entirety’. This is evident within the PRs efforts to make connections between their different temporal self-identities, giving a sense of ongoing continuity of self necessary for ‘ontological security’ (Giddens 1991: 35) and ‘homelike-being-in-the-world’ (Svenaeus 2011).

5.4 Embodied empathy: Increasing the lived experience of a worthwhile & valuable self/life

Elkins (1996:137) identifies with Robert Vischer’s embodied definition of empathy, he says ‘the body swells when it enters a wide hall. It sways, even in imagination, when it sees wind blowing in a tree’. The body is arguably central to a phenomenological study, as Merleau-Ponty (2002) says, ‘It is through my body that I understand other people’ (*ibid*:186) and all experience is essentially embodied, as it is all experienced through the body. Finlay describes ‘embodied intersubjectivity’ as ‘our corporeal commonality’ (Finlay 2009: 8) or the ‘horizon of experience’ through which we can access another person’s experience (Wertz 2005: 168). Finlay (2009: 9) warns that researchers must be able to put ‘oneself into the experience of the patient as much as possible, feeling it as if in one’s own body – without losing a separate sense of self’ (Yontef 2002: 24).

When writing Rose’s case-study and analysing her portraits, I was struck by the physicality inherent within all of them (Figures 62, 63, 64). They all capture Rose ‘in action’ in a moment of *doing* or *becoming*, she is not ‘passive’ in any of them. Delegates mirrored this physicality when I exhibited *Bohemian Rhapsody* (see Figure 64) and several other portraits at a London art therapy conference (Carr 2013), I

noticed that when people were talking about the portrait, they often made the arms across the chest gesture to describe it.



Figure 62. *The Poppy Field* by Susan Carr (co-designed by Rose)



Figure 63. *Paint me like a Picasso* by Susan Carr (co-designed by Rose)



Figure 64. *Bohemian Rhapsody* by Susan Carr (co-designed by Rose)

The link between empathy and imagery has been explained through Rizzolatti *et al.*'s (1996) discovery of 'mirror neurons' which revolutionized the way automatic physical responses to sensory images (seen either directly in life or in art), are understood, contributing to the knowledge that human beings have a 'body based understanding of the world' (Gallese & Lakoff 2005: 466). Understanding our bodies from the perspective of mirror neurons suggests that mimicking this 'arms across the chest' gesture signals an empathic engagement with Rose through the portrait, as muscles contract and relax in the exact same way that they do in the portrait. They are literally putting themselves in Rose's position. I reflected upon this in the ADS:

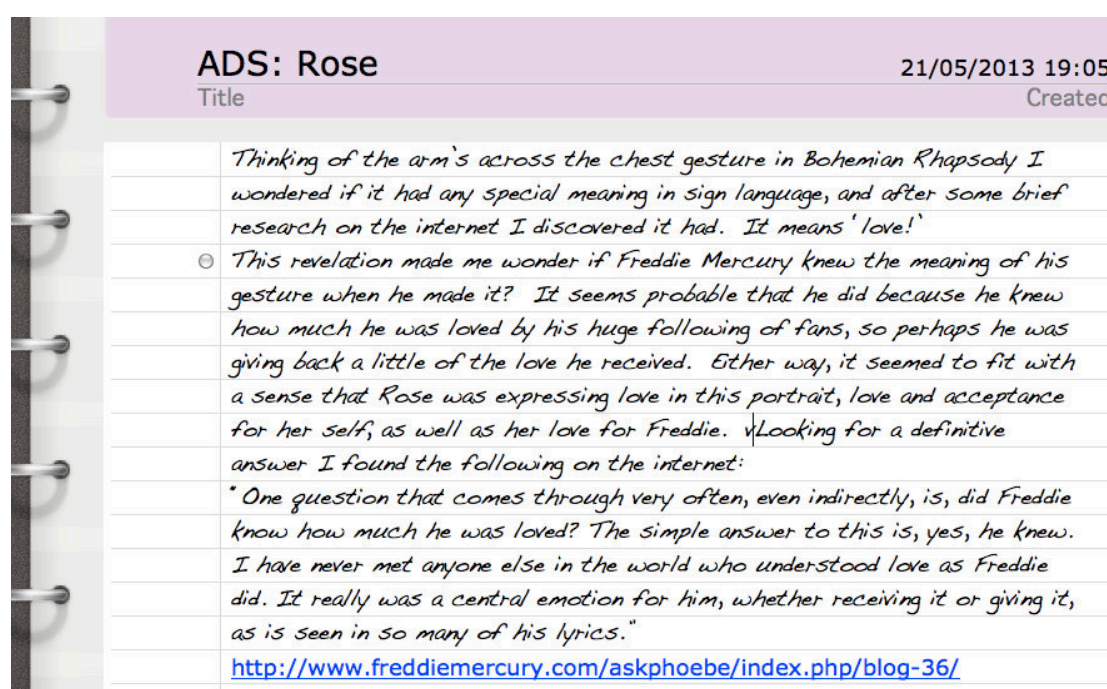


Figure 65. Sign language for 'love' & *Bohemian Rhapsody* by Susan Carr (co-designed by Rose)

This sense of self-love and appreciation is reflected in Rose's 'determination' to make the most of herself:

R: It's like my t-shirt has got on it 'don't stop me now!' that's a Queen song. I've got a t-shirt with it on. **S: Yes.**

R: *I am determined to make the most of myself.*

S = Susan, (ATR) Artist/Researcher R = Rose (PR) Patient/Researcher (EPI: 22/03/2011)

Portraits are unique manifestation in that they are objects, which represent persons and as such they can be touched, handled and reflected upon, and as a companion/witness, I am also able to say that I too *love* a portrait or a collage. This is an acceptable way of expressing *love* for a patient, albeit again *third hand*, even so the significance is not lost on PRs. When I said *I loved* a portrait, PRs often smiled and nodded and more often than not agreed with me, and my implication that yes their portrayed sense of self-identity, which we had co-created together, was *lovable*. PRs also talked freely about how much they *loved* the portraits, collages and prose poems, here Susan talks about the Rainbow Snake collage and how it encompasses 'everything' she had talked about, good and bad (see Figure 66):

S: Yes, it's so detailed, it's really good! Yes, that's everything there. Hmm, *I love* that one !

SC = Susan, (ATR) Artist-Researcher & S = Susan (PR) Patient-Researcher. (EPI 10/10/2012)



Figure 66. *The Rainbow Snake*, by Susan Carr (co-designed by Susan)

Here is the poem Susan wrote entitled 'The Rainbow Snake':

THE RAINBOW SNAKE (Written by PR 'Susan' 7th October 2011)

Silent and sinuous
The Rainbow Snake carries my life through the Universe.
Dull coils and bright coils.
Blue coils, indigo and violet coils – no one hears them crying in the silences of space,
But tears were born in the origins of existence;
Red coils, orange and yellow coils – no one hears them laughing in the silences of space,
But laughter was born in the origins of existence.
For me there have been whirling planets of activity,
Things done, things achieved;
Briefly visited, but left behind in immeasurable distances of time and space.
For me there have been pulsing stars of joy,
Babies born, marriage shared;
A love experienced, that lights the way through immeasurable distances of time and space.
But now a pinprick, a hole in the fabric of existence, grows ever nearer, ever bigger.
Where does it lead?
Does it bridge a fold in time and lead to new existence, glad renewal,
As the green coils of the Rainbow Snake emerge through the spring leaves on a new journey?
Does it lead to non-existence? Or eternity? Or ...?
The Rainbow Snake cannot stop, cannot pause, cannot wait for me to know or choose.
Just a pinprick, just a hole in the fabric of existence, pointing to beyond. But what will
happen when all existence arrives inexorably at that point?
Will that pinprick, that hole in the fabric of existence, growing bold, swallow all that began so
infinitely long ago?
Breathe it out, maybe, into the maelstrom of a new first moment;
Or reveal itself as portal to another place? Or ...?
The Rainbow Snake whispers nothing of this and moves on.

In her EPI Susan also talks about loving the portraits:

SC: This one was about the idea of the mermaid, wasn't it?

S: Yes, I *love* those.

SC: And we've got the other one, as a child.

S: Yes, I *love* that one too.

SC = Susan, (ATR) Artist-Researcher S= Susan (PR) Patient-Researcher (EPI: 18/10/2012)

People often talk about 'loving' things, even trivial things, however I think that admitting love for something that represents one's self – particularly in the light of self-identity disruption and the stigma of illness – is a significant step forward. This is a benefit of 'third hand' (Kramer 1971) practice and 'response art' (Fish 2012). Through making images *for* clients *emotional distance* is created but also conversely *emotional connection*. I have noticed in my art therapy work that if a client makes an image they find it very hard to look at it without seeing all the faults within it, and one flaw (which no one else will ever notice) overshadows the meaning of the image for them. However, when I make the images for the PRs the situation is reversed, and they are free to 'love' the image, and do not seem to notice the 'flaws' that I as its creator see all too easily.

The benefits of self-love are wide and far-reaching, as has also been shown with Paul in chapter 4, through increasing self care and pride in his appearance and a renewed sense of agency. In her EPI Susan also notices similar benefits and talks about ‘taking more care, putting make-up on, nails ...’

SC: I wonder whether you find that perhaps you are getting outside of ‘the box’ ...now.

S: Yes, I think having recognised it, I’ve recognised the steps that I need to take to change it. I don’t think when we set out on this that I would have, I don’t think I was fully aware of that feeling. I think articulating it made it visible to me ... I think that’s one of the reasons that I’ve got the crutches, partly because my back really hurts if I’m in the [wheel] chair too long, *but the crutches are a positive step out of that, I think. And, taking more care putting make-up on, nails, this kind of thing, is saying that I’m not going to be in that ‘box’, if I can avoid it. So yes, I think that has made a difference to stepping outside.*

SC = Susan, (AR) Artist-Researcher & S = Susan (PR) Patient-Researcher. (EPI 10/10/2012)

This correlates with Aita *et al.*’s (2010) findings where they describe one of the participants in their study saying that since being painted she has found herself dressing up and ‘putting on makeup for the first time since undergoing multiple surgeries on her face’.

Another theme, which emerged from the analysis, is how the portraits as *intentionality-made-visible*, reveal a sense of *becoming*, which is an acknowledgement of the PRs embodied self-identities in a state of *transition* or *change*. Within one of the themes identified by Aita *et al.* (2010: 7) in their study involving painting portraits of patients and their carers, they noted ‘a sense of ongoing identity formation especially during transitions in health status’ (*ibid.* 7-8). This *identity formation* may correlate with the sense of *becoming* noted within this project. This is highlighted in Rose’s *The Poppy Field* portrait:

Rose said ...
 'I was Born and bred in London
 and yet ...
 Every summer ... till I was 10 years old
 Mum and Dad took me to Yorkshire
 And left me at my Aunts ...
 For 5 weeks.
 I ran around barefoot, wild and free,
 And lay down in a poppy field
 Where no one could see me ..."



Figure 67. *The Poppy Field* by Susan Carr (co-designed by Rose)

When co-designing *The Poppy Field*, Rose said she often used a mentalisation of a poppy field as a 'safe space' to go to in her mind when she is stressed or anxious. By combining this positive mentalisation with Rose's childhood experience of being taken to Yorkshire and left for 5 weeks with her Aunt, the portrait could therefore be recalled by Rose as a 'vivid' *positive* image (Werner-Seidler & Moulds 2011:1100) a creative device to use when she is stressed, anxious or depressed. The essence statements for this portrait also show the transition between 'isolated city child' and 'earth-spirit warrior child' and the implied adaptation entailed:

Statement of Emergent Learning: The Poppy Field

There is a sense of continuation of being and spiritual presence in mother nature. *The Poppy Field* depicts the moment of *identity transition* and *adaption* in which 'isolated-city-child' *becomes* 'earth-spirit-warrior child'.

Within the phenomenological analysis of Rose's portraits, four self-identities were found. These were:

'Resilient, see me/hear me Rose'
'Invisible, silenced Rose'
'Earth-Spirit-Warrior-Child'
'Isolated-City-Child'

Figure 68. Rose: Essences of self-identity found within the portraits.

Through 'The Poppy Field' portrait, Rose accesses her 'earth-spirit-warrior-child' self-identity once again, and experiences the *transition* between 'isolated-city-child' and 'earth-spirit-warrior-child' demonstrating an autonomous sense of *becoming*. This sense of *transition* and *adaptation* correlates with the development of 'resilient, see me/hear me' Rose, as found in the EPI voice analysis.

Listening/reading for Contrapuntal Identity Voices:

Reading 1. Listening for 'Resilient, see me/hear me Rose'.

Reading 2. Listening for 'Invisible, silenced Rose'

R: [...] Why because you are ill, let it *stop* you doing things? You should think I *can* still do it, that's how I look at it.

S: yeah

R: For instance I can't drink, 'cause I can't go to the pub and have a pint because I would be sick but it doesn't stop me going and sitting with friends, I can still go and sit there and have a water or something. You've just gotta change it round.

S: Yeah, just adapt?

R: Yeah adapt it.

S= Susan, (ATR) Artist-Researcher & R= 'Rose' (PR) Patient-Researcher. (EPI 22/03/2011)

When commencing the analysis of *The Poppy Field* and stepping inside the painting (*indwelling*) I realised that I had inadvertently painted Rose laying in an approximation of the 'recovery position' (see Figure 69), perhaps indicating on my part an unconscious reflexive addition of 'hope' to this painting, a hope of 'recovery'.



Figure 69. Recovery position



Figure 70. The Poppy Field

However, on reflection I realise that this unconscious use of the recovery position could also indicate a sense of *denial* of Rose's ill health, and a false sense of holding 'hope' for Rose. The ambiguities evident within this painting enable the holding of dualities such as life/death or hope/hopeless or denial/recognition, and these dualities are also depicted within the *Paint me like a Picasso* portrait (see Figure 63 above).

In this section I have described the PRs experience of portraiture as a way to increase the sense of a worthwhile and valuable self/life, and the portraits' capacity, through mirror neurons, to elicit feelings of embodied empathy within its viewers. This gives

PRs a sense of embodied empathic engagement with their own portrait, but also a recognition that other viewers of the portraits will feel this too. The portraits also become a focus and channel for 'love' with PRs and myself able to express 'love' for the portraits without this being misconstrued. This was helped by the portrait being created 'third hand', meaning PRs were able to express their 'love' for the portraits without feeling inhibited by anxiety about aesthetic judgements or boastfulness and narcissism.

5.5 Legacy & Temporality: Immortalizing the sitter/Cheating death

One of the ways that LT&CIs threaten a person's 'homelike-being-in-the-world' (Svenaues 2011) is through a change in their perception of time and the future (Crossley, 2003: 439). Acknowledging our temporality is perhaps akin to acknowledging our mortality and therefore the passage of time acts as a reminder of the weakness of the human body damaged by illness (Seymour 2002: 141).

Seymour defines time in relation to illness thus:

Time is physical and mechanical, experiential and cultural: temporality is the context for our lives. [...] Clear in the knowledge that it is time that will triumph in the end, we spend our lives negotiating the boundaries of our enslavement. Encouraged by small gains, we bargain and negotiate, obscure and reconceptualise our relationship with time, but victory is always tentative; time is inexorable. Time is the fundamental element in the unfolding of our mortal lives and in their impending termination. (Seymour 2002: 136).

I have noticed in my work with patients living with LT&CIs that people often describe feeling stuck in a 'void' between their 'past identity' (I was), which feels lost to them, their 'present identity' (I am) which they do not recognize, and their 'future identity' (I will be) which is often a feared unknown. As Oliver Sacks (1984, 1990) has said when writing about the disrupting impact of illness on his self and identity ... 'There was a gap – an absolute gap – between then and now; and in that gap, into the void, the former 'I' had vanished' (Sacks 1984: 63).

Svenaesus (2011: 339) proposes that, in illness, an ‘alienation’ develops between a person’s temporal experience of past and future ...

Illness ruptures my life, to the point that the past and the future appear in a new light – or perhaps a new darkness – in which they acquire a strange quality of being, simultaneously mine and yet no longer mine (Svenaesus 2011: 342).

As the body is both ‘a physical object, made of matter, *and* the seat of consciousness’, distance or a void can arise between the physical/biological body and the lived/experienced body (Carel 2013: 351). However, I suggest that the body-as-object can be *reclaimed* in the portrait process, through PRs directing how they want to be perceived. The portrait therefore becomes a ‘subject-object’ (Carel 2011: 37), a link between the PRs body as object/material and their body as subject/consciousness. Similarly past, present and future identities can be contained within the portraits, enabling a revisioning, re-connection and integration of the fragmented self-identity.

While working with the PRs I became aware that one of the unique qualities that portraits offer is: *time*, combined with *positive focused attention*, and that this combination results in *vivid positive memories* (Werner-Seidler & Moulds 2011). The equation is simple but effective, *we remember* when someone gives us his or her *undivided attention and time* and during a portrait sitting or the co-designing process this combination is provided in abundance. It could be argued that this combination is also a feature of therapeutic relationships within the many and varied approaches to art therapy, however, there are several unique aspect to the time and attention given in portraiture. The first is that the portrait becomes a tangible *testimony* of this time and attention; it exists *because of* the time and attention given by the artist/therapist in order to paint it. Secondly a proportion of the time and attention happened *away* from the PR in the studio, therefore the time and attention *continued* outside of their presence, allowing a sense of *being-held-in-mind* by the ATR with implications for PRs personal value and of being *worthy of being remembered*. Also, their *being-held-in-mind* is *testified* within the portrait and continues when exhibited in a gallery and displayed in PRs homes, enabling a sense of a valued *future* self. All these are I suggest important in enabling an increased sense of homelike-being-in-the-world, and the sense that PRs and their lives are important enough to be remembered.

In her EPI Rose talks about how in the project ‘it’s like someone took notice’ gaining a sense of self-worth through that attention, with the *transformational* power of portraiture highlighted when she says ‘you made it into *something* ...’:

S: And how about the telling of your story and someone listening to you and then interpreting that into a painting?

R: Yes because, it’s like, *someone took notice* and what to me was just an everyday thing, *you’ve made it into something*, does that make sense? (S: yes) you made it interesting.

S: Hmm ... so we are fixing an image of yourself and giving it meaning, aren’t we?

R: Yes.

S = Susan, (ATR) Artist/Researcher R = Rose (PR) Patient/Researcher (EPI: 22/03/2011)

When I first worked with Paul he described his experiences of illness as constricting and frustrating and the theme of being ‘trapped’ or of *being unable to be ‘Paul’* was a constant one (see Figure 71). As Evans (2005: 28) says, ‘some patients express claustrophobic feelings of being trapped inside their diseased body, and the person who existed before diagnosis crumbles, becoming a new unwelcome identity’:

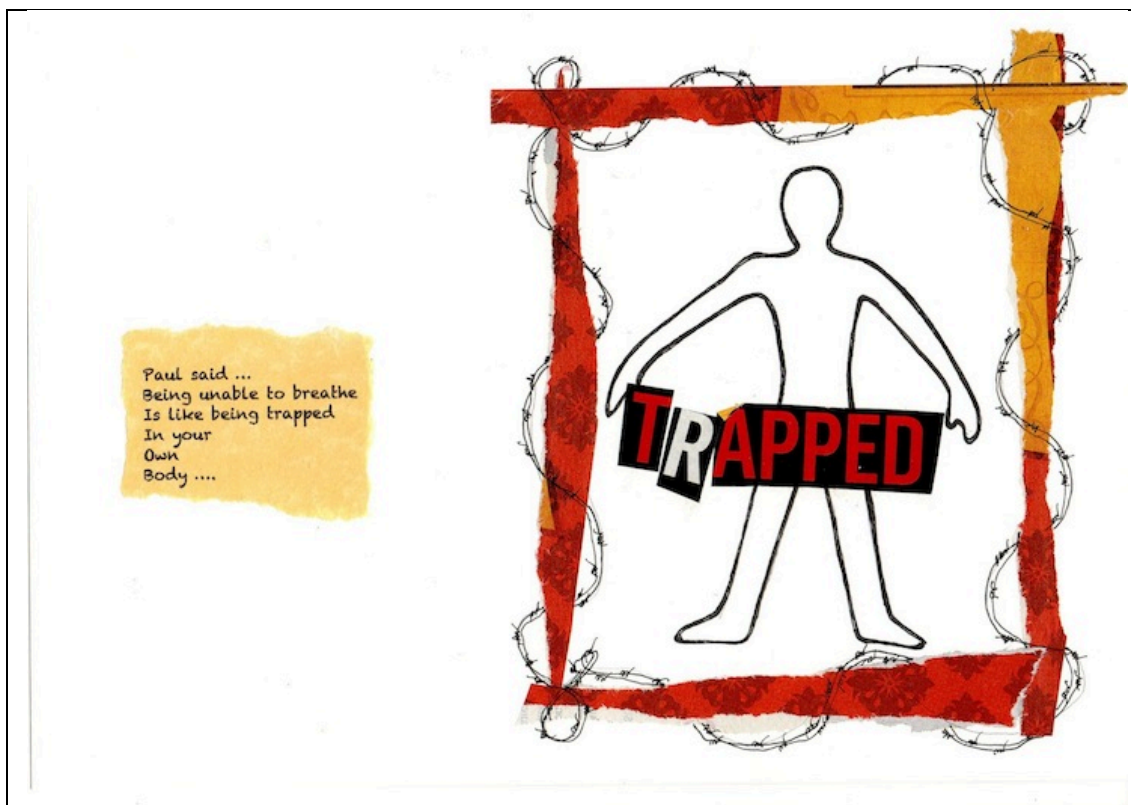


Figure 71. *Trapped* collage by Susan Carr, 2012.

For Paul's third portrait we decided that I would paint him 'from life' at his home. During one portrait session Paul decided to play a game on his Playstation while I was painting him. The experience of watching Paul *be* 'Paul' within the virtual world of the game was quite revealing and I gradually became acquainted with 'virtual Paul'. I recorded this in the ADS:

ADS: Paul	03/03/2013 16:35
Title	Created
<i>ADS: Today I painted Paul in his room as he was not feeling well enough to go downstairs. While I was painting him he played on his playstation game. In the game he became a character who was able to run, jump, climb, and fight, to effect change on his environment, to 'be'. This 'Paul' was somebody who (virtual) people took notice of. I felt that Paul was showing me his 'virtual self-identity' or even his pre-illness identity, and perhaps it was also adaptive, in that he could 'be' himself or someone else, even for a short time. I said that in his game he could 'do and be' all those things, and he said that even though it was only a game, he still got out of breath playing it. Perhaps reminding me that it was only a game, and he was still 'trapped' in his body.</i>	

This then formed the basis of Paul's portrait and we called it *Virtual Paul*:



Figure 72. *Virtual Paul* by Susan Carr (co-designed by Paul)

Reflecting on this portrait I find that ‘virtual Paul’ conversely exists in a liminal space – as do Mark Gilbert’s subjects (see Figures 7 & 8), although I was not aware of any thoughts of mimesis at the time. Portraits act as a bridge between the present, past and future, as well as all other imagined ‘virtual realities’. Just as Paul is able ‘to be at home’ in his virtual game, so within the portrait his *capacity to be* changes. Paul injects humour into our discussion about the portrait, reflecting upon the fact that I neglected to paint the chair he was sitting in:

S: But I quite like that one [indicating *Virtual Paul* portrait] because it is really stripped back ... so there is nothing apart from you in the picture ... so it is real focussed ...

P: I must be quite fit to stay like that! [laughs]

S: [Laughs]

S = Susan, (AR) Artist/Researcher P = Paul (PR) Patient/Researcher (EPI: 03/06/2013)

The ‘as if’ nature of portraits, combined with the mirror neuron effect (Rizzolatti *et al.* 1996), enables us to feel actions in our bodies, meaning that within the portrait, and *felt empathically* within his body, Paul is, *able to be* ‘quite fit’. The Paul caught in the painting’s surface is also protected from temporality, curtailing the relentless pace of time, so old age and sickness can no longer affect ‘virtual Paul’. As West says:

... a portrait also serves magically to freeze time and to extend artificially the life of the represented individual. Portraits can thus appear to be both records of specific events and evocations of something more lasting. The power of portraiture rests largely in this tension between the temporal and the permanent. (West 2004: 44).

The idea of immortality within portraiture has historically been tied to Renaissance paintings of religious subjects and the portrayal of those ‘worthy of emulation’ (Pointon 2013: 60), however with the moving away from a belief in organized religion in the West there has been a growing secular focus on ‘fame’ (Taylor 1989: 43) and ‘celebrity’. Whilst the link with religion is present within Hilary’s ‘Held by an Angel’ portrait (see Figure 30, p123), for the other PRs ‘immortality’ may focus more on fame and celebrity through the potential exhibition and publication of the portraits. All PRs suggested that they were keen for their portraits to go into exhibitions and be seen by others, reiterating the sense of portraits as bridges to *being*

known. Radley (2009: 211) warns that putting works of illness into a gallery setting, risks changing its meaning, and takes the artwork further away from those who made it or those for whom it was made (Radley 2009: 211). However, exhibiting the portraits is one of the key ways that a portrait is able to go and ‘do its work’ (ibid: 214). This sense that portraits have a job to do imbues them with the ‘as if’ human characteristics of the person portrayed, which becomes part of the PRs *future*, ‘immortalised’ self-identity.

In her EPI Rose talks about how the project has transformed her perception of herself from being a ‘nobody’ to someone who has ‘done something with my life’:

S: But what I am saying is, has it helped you ... well you said it has helped you recognise parts of yourself? **R:** Yeah. **S:** And maybe given you a stronger sense of self and identity? **R:** Yeah, because now, instead of being a nobody, this is as if I have done something with my life, your know ‘cause, that with the poppies, it was just nothing, now it’s got meaning, ... I can’t describe it ... **S:** No that is fine.
(‘Rose’ EPI: 22/03/2011)

S= Susan, (AR) Artist/Researcher **R= ‘Rose’ (PR) Patient/Researcher**

This links to the idea of the portraits as legacy or remembrance, and the idea of legacy has within it an implicit acknowledgement of one’s *mortality*. The anticipation of an exhibition of the portraits allows for the development of a belief in a *future-self* one that does not depend upon being *alive*. Through maintaining the perception of an ongoing ‘life’, the portraits provide a sustained ‘contact’ with people in the future (Freeland 2010: 42), which enables the embodiment and sense of continuation of an irreplaceable uniqueness or ‘presence’. Susan talks about how the portraits become part of a PRs *future identity*:

SC: So, how do you feel about these portraits going into an exhibition and being seen by people? [...]
S: Yes, I think there are two good things about that. I think that it offers evidence for the value of this kind of interaction, so hopefully it will help to make it happen for other people. *And secondly, to feel that you’re not ..., that there’s something solid out there that will be you, you know when you aren’t there. It’s quite nice.*
SC: Other people have thought of that as their future self, you know that we all need that future self to ... and I guess your book is like that as well?
S: Definitely, I guess they are similar issues, something that will go on into the future.
SC: Leaving a legacy or something like that?
S: But also, as I say, I hope that the evidence will be persuasive and make people,

other people, think about what happens in this kind of therapeutic situation.

SC = Susan, (AR) Artist/Researcher S = Susan (PR) Patient/Researcher (EPI: 18/10/2012)

Susan reiterates her point later in the interview:

SC: So, another question, do you feel this kind of project would benefit other people who have a similar illness or similar issues to you?

S: Yes, I think it would help. It helps people in my situation, but I think it would help a broader range of people, I think it would be particularly important to people suffering from depression, to try to create something visual that would lift them ... to see the positive aspects of themselves, so yes, I would say people with psychological illnesses and people psychologically affected by physical illnesses, so both sides of the coin. *And a particular thing in the hospice situation is where people know that their own death is not a long way away, so that to help people to feel that they have this kind of projection into the future, that they're not just going into the hospice and dying and the world moves on and forgets that they ever existed, it does give people some kind of existence beyond that point, so that's another reason for it in the hospice context I would think. [However] I certainly would see that it could have a lot of validity in people who aren't dying.*

SC = Susan, (AR) Artist/Researcher S = Susan (PR) Patient/Researcher (EPI: 18/10/2012)

The idea of legacy and the alchemy of portraiture meant that for Peter the portraits embodied the person depicted even after that person's death. Peter talks about the 'as if' nature of the portrait *There's Something About Mark, RIP* (see Figure 73) and how this seems to have brought Mark 'back' to him and his family:

S: So how do you feel about these portraits going into an exhibition? [...]

P: That is an added benefit, but *the important thing is seeing the result*. I think when my sons and my wife see that [indicating *There's Something About Mark RIP* portrait Figure 73] it will bring tears to their eyes.

S: Good ones?

P: Oh yes ... happy memories ... *it is as if he is there with us*, it's so wonderful.

S = Susan, (AR) Artist/Researcher P = Peter (PR) Patient/Researcher



Figure 73. *There's Something About Mark, RIP* by Susan Carr (co-designed by Peter)

Within this section I have described the PRs experience of portraits as legacy, and as an important part of their future self-identity, thereby equating to a sense of immortalisation or cheating death. Portraits capture time within the painting process and this is combined with the ATRs positive focused attention, resulting in feelings of being-held-in-mind, the formation of positive memories and an increased sense of self-esteem. The 'as if' nature of portraits and Peter's belief that through the portrait Mark 'is there with us' does not equate to a denial of Mark's death, because although we look at a portrait and view 'a person' we do not expect them to *move* or *speak* to us. We are able to hold the concept of 'as if reality' and 'physical reality' in our minds at the same time. This 'as if' quality means that the portrait exists for Peter, in both realities, and as such equates to an adaptive acceptance of connection and separation from Mark within the portrait. Through *loving* the portraits, collages and prose poems *of* and *about* themselves, PRs are reawakening a sense of self-love and empathy, which impacts positively on their self-esteem and home-like-being-in-the-world.

5.6 Summary

In this chapter I have discussed four emergent themes under the broad heading *Portraits Making Meaning: increasing the lived experience of homelike-being-in-the-world*. I have argued that a sense of home-like-being-in-the-world (Svenaesus 2011) is often lost when people are plunged into 'liminal space' (Turner 1995; Sibbett 2005: 12-37) or the 'world of illness' (Radley 2009) following the diagnosis of a LT&CI, and that through this project

PRs experience an increased sense of self-identity coherence and *home-like-being-in-the-world*. I began with a description of the PRs experience of portraiture as a way to develop their sense of spirituality by *making special* and *making meaning*. I argued that art therapy as a spiritual meaning-making practice within palliative care has a lot to offer in its ability to support individual eclectic beliefs, enabling an amelioration of existential anxiety and meaninglessness. I described how through creating portraits and portrait-sculptures, and bringing them into being in the present, they can be used in a ritualized way to develop meaning and a lived experience of healing may occur. I used examples from the visual and verbal data to describe how PRs used the portraits and portrait-sculptures in ritualistic and sacralizing ways, and how these processes enabled feelings of homelike-being-in-the-world. Hilary and Peter demonstrated the value of the portraits by asking for copies of the portraits to ‘keep with them at all times’. Norma used the project to grieve for her abandoned baby-self as well as her own lost babies, bringing her past into the present to be engaged within the ritualised practices of the Native American Indian smudging ceremony.

I have described examples where PRs found an increased sense of *belonging*, *remembering* and *continuity* through the portraits, linking and integrating aspects of past, present and future self-identities. Bill’s WWII experiences depicted within the portraits, collages and prose-poems revealed *everything he needed to tell me* about his self-identity, and how it had been *formed*, *broken* and *reformed*, despite the gap of nearly 70 years since the war. Rose celebrated her sense of belonging and connection to Freddie Mercury in her portrait *Bohemian Rhapsody*, someone she recognises as a fellow inhabitant of liminal space, through LT&CIs. Paul found a sense of homelike-being-in-the-world in his *English Gothic* portrait, depicted with his deceased relatives. Susan finds a sense of connection with her deceased mother in *The Paper Dress* portrait-sculpture and a sense of continuity of being within her four portraits. All the PRs to some extent utilized this project to connect to something or people they felt a sense of *belonging* to, the portraits therefore acted as bridges offering connection to significant others, and to humanity as a whole.

I then described the PRs experience of portraiture as a way to increase their sense of a *worthwhile* and *valuable self/life*. The portraits therefore became a focus and channel for ‘love’ with PRs and myself able to express ‘love’ for the portraits without this

being misconstrued. This was helped by the portrait being created ‘third hand’, meaning PRs were able to express their ‘love’ for the portraits without feeling inhibited by anxiety about aesthetic judgements, boastfulness or narcissism. I also described the PRs experience of portraits as *legacy*, and as an important part of their *future* self-identity, thereby equating to a sense of *immortalisation* or *cheating death*. I outlined how portraits capture *time* within the painting process and this is combined with the ATRs *positive focused attention*, resulting in feelings of *being-held-in-mind*, the formation of *positive memories* and an increased sense of self-esteem and *home-like-being-in-the-world*.

In chapter six I will describe the PRs lived experience of portraits as visual channels of *mirroring and attunement*, and how through this process PRs become aware of previously unknown and ‘untold’ aspects of self-identity. I will argue that the portraits became a unique way of *being known*, both to themselves and others. I will describe the *intra*-subjective validation of self-identity that the portraits provide for PRs through viewing portraits and collages that *PRs need to see*, as well as the *intersubjective* validation provided by portraits they need *others* to see. I will also describe a process of *aesthetic resonance*, which equates to adding meaning, complexity and coherence to the portraits, enabling PRs to recapture a sense of themselves as *valuable* and *beautiful*.

6.0 Chapter 6. Mirroring and Attunement through Portraiture: Intersubjective and Symbolic ways of *knowing, being and relating.*

This chapter describes the PRs lived experience of the portraits as visual channels of the ATRs ‘mirroring and attunement’ (Wright 2009). Visual communication is relied on extensively by humans in their daily life, both in reading body language and facial expressions (Mandal & Ambady 2004: 23), and in navigating their world. Arguably discursive language is less effective at expressing the ‘quality, intensity and nuancing of emotion and affect’ needed for diverse social circumstances, than is the face, with its myriad of expressions (*ibid.*). The preference for familiar faces defines the self throughout a person’s life (Schore 2000), as Merleau-Ponty (2002: 146) said, ‘I live in the facial expressions of the other’. James Elkins, in his book *The Object Stares Back* (1996), talks about a ‘need to be seen by objects and by people;’ a ‘need to be caught in that intersection of gazes’. Elkins cites Lacan’s emphasis regarding our equally important need to see ourselves in a mirror. He says ‘by looking into the mirror each morning I check to make sure that I am the same person who went to bed last night – the person who dissolved into darkness and dreams’ (Elkins, 1996: 70). The familiarity of a person’s own face is therefore paramount to their self-identity however, it is something which illness and invasive treatments can distort and change until people become unrecognizable to themselves. This highlights the importance of creating portraits that the PRs recognise as themselves.

As discussed in the literature review, within the design of this intervention I have extended Wright’s (2009) relational model of mirroring and attunement, into a concept where the portraits become derivative of the (m)other’s mirroring and attuning expressive face, and I, as a ‘good enough’ (m)other/artist validate their sense of self-identity. The mirroring and attuning process is I have argued, dependent upon my own ability to *empathically engage* with the stories of self-identity presented by the PRs, as well as using the phenomenological approach of ‘indwelling’ (Moustakas 1990: 24), to gain intuitive understandings and resonance within the analysis process. Wright (2005: 534) describes *resonance* as a ‘felt and immediate response’, and as ‘a feeling of being in the same state, the same place as the other’ (*ibid.*). It is known that human beings have used art as a ‘feeling form’ (O’Neil 2008) to heal the body, mind and spirit, for at least the past 30,000 years, it is therefore the oldest healing resource

in the world (Achterberg 1985). Portraits therefore become containers of self, presented to others as *intra* and *intersubjective* ‘feeling’ in all its myriad forms:

Humans have a self that is relational and that by its very nature involves self-presentation to others, with an awareness and concern about how one is seen, and this is part of what is rendered when an artist creates a portrait. (Freeland, 2010: 104).

This intervention therefore offered PRs the opportunity to share aspects of themselves as told through stories of self-identity facilitated by the button, Lego and photo elicitation tasks, which were then ‘mirrored and attuned’ (Wright 2009) within the portraits, collages and prose poems. All the PRs said at one time or another that they had told me stories of self-identity that they had *never told anyone else before*, and three repeated this within the EPI. This process of revealing the self enabled the PRs to learn about themselves and how their illness had affected their perception of self-identity (Alea & Bluck 2003). The findings from this study correlate with the observations made by Mark Gilbert in his ‘Saving Faces’ (Farrand 2000) portrait project (as discussed in the literature review), whereby Gilbert’s sitters shared ‘details of their lives which they shared with no one else’ (ibid.). I therefore suggest that this could be a unique *portrait effect*, a distinctive quality of the relationship between subject and artist found within portraiture.

Susan describes this effect:

S: Yes, I felt perfectly free to say where I thought something didn’t work or did work so much freer, much more comfortable ... Yes so, *in fact there’s a whole raft of things that I’ve never told anyone before*, so there you go!

SC: A lot of people have said that! (EPI 18/10/2012)

SC= Susan (ATR) Artist-Researcher & S = Susan (PR) Patient-Researcher

Paul outlines what he thinks it is about portraits that prompt sitters to tell stories of self-identity that they have never told before:

S: So do you think this project has given you a stronger sense of self and identity? So knowing who you are basically ... looking back on your life.

P: Well I sort of already knew ... I was quite a shy sort of person anyhow ... but with you doing this I suppose it has opened me out a lot more than I would have with somebody else. To tell the truth, *I have told you quite a lot more things that I*

wouldn't have told anyone else.

S: It's funny because everyone has said that.

P: You are my therapist! In a sense I have put a lot of trust in you haven't I?

S: Yes ... true. P: Part of the family! [laughs]

S: [laughs] I'll put me in the middle then shall I [indicating the *English Gothic* portrait]. P: Yeah [laughs].

S: Yes it is strange how everyone has said that ... but it was one of the things I thought about portraits ... that people talk and people tell you things that they haven't told anyone else before.

P: I suppose it is because you want to see the person as they are rather than just a photograph ...

S: Yes ... get to the essence of the person.

P: Deep underneath what you are asking ... *there is a heart* as such ...

S= Susan, (ATR) Artist-Researcher & P = Paul (PR) Patient-Researcher. (EPI 03/06/2013).

Paul is saying in this exchange that he thinks sitters reveal secret stories of self-identity because they *recognise intuitively* that the portrait artist is attempting to depict not just the *outer likeness*, but the *inner essence* or *significance* of a person, and that this requires a *different kind of knowing*. This different kind of knowing requires the artist to see 'further' and deeper than others see (Taylor, 1989: 22). In order to show the inner heart of the person subtly within the portraits I have used metaphor and symbolism, as Paul says they reveal that ... 'deep underneath what you are asking ... *there is a heart* as such'. A successful portrait therefore is capable of showing what is not ordinarily visible, a glimpse into a person's subjective inner world (Brough 2001: 43-4), this holding of dualities e.g. *revealing* and *concealing* is I suggest one of the key reasons why portraits are able to enhance a person's sense of self-identity *coherence*. Through this process, as PRs see themselves and are seen, a sense of *re-cognition*, *re-integration* and *re-membling* is instigated. Through becoming aware of previously unknown or forgotten aspects of self-identity, they become *known* to themselves and others.

6.1 *Intra-subjective validation of self-identity: Portraits PRs needed to see*

In this section I outline those portraits and collages that PRs *needed to see* themselves as a powerful way to validate and combine inner and outer realities, and the reflection and attunement of stories of self-identity that had never been told before.

An awareness and concern about how one is *seen*, both by the self and others, is one of the emergent themes within this project, highlighting the tension within illness between *being seen* and *not seen*, and the implications within that of risking anonymity, of not being heard or acknowledged, or facing social stigma. Being unable to conceal one's illness is therefore often a central concern, as Carel says:

[...] intimate details become the first thing a stranger sees about you. Instead of being in charge of what you disclose about yourself, you become a passive vessel of information provided through your own betraying body, a body that cannot keep a secret. A stranger takes a cursory glance at you and already knows so much about what is sensitive, intimate and painful (Carel 2008).

This concern about how the body-self is represented is therefore compounded by LT&CIs, and our inability to 'count on our bodies to look, behave, or move as they once did' (Charmaz & Rosenfeld 2006: 46), meaning that the image we believe others have of us changes in a negative way (*ibid.*) with 'judgements of character, ranging from saintly, courageous, dependent, or slothful to morally tainted [...]' (*ibid.*: 36) all being linked to stigma in illness. The embodiment of illness therefore 'complicates' self-identity for people living with LT&CIs (Charmaz & Rosenfeld 2006: 37) and weakens 'boundaries of the self-concept', meaning they 'become vulnerable to redefinition – whether positive or negative' (*ibid.*: 47). One of the interesting things about this project is the ability of the PRs to direct how they wish to appear in the portraits and the harnessing of art's *transformational* power to adjust or change meanings. As Eisner (2008: 11) says:

Art often creates such a powerful image that as a result we tend to see our world in terms of it, rather than it in terms of our world. Put another way, art does not always imitate life. Life often imitates art (Eisner 2008:11).

If as Eisner (2008) says life 'imitates art' it follows that PRs may begin to 'imitate' their portraits, or at least begin to see themselves more clearly through the portraits so as to affect 'change' in themselves or their lives. A portrait that Paul *needed to see* was his *At Home* portrait (see Figure 75). As outlined in chapter 4, Paul (at age 49) had been forced by the deterioration of his lung condition, to move back in with his

mother and spent almost all of his time (except for hospital appointments and hospice visits) alone in his bedroom. For Paul, connected almost constantly to an oxygen supply, the world had become a liminal, unhomelike, hostile and dangerous place, and Paul's sense of social isolation and frustration is reflected in the collage I made for Paul entitled *Hard to Leave the House*:

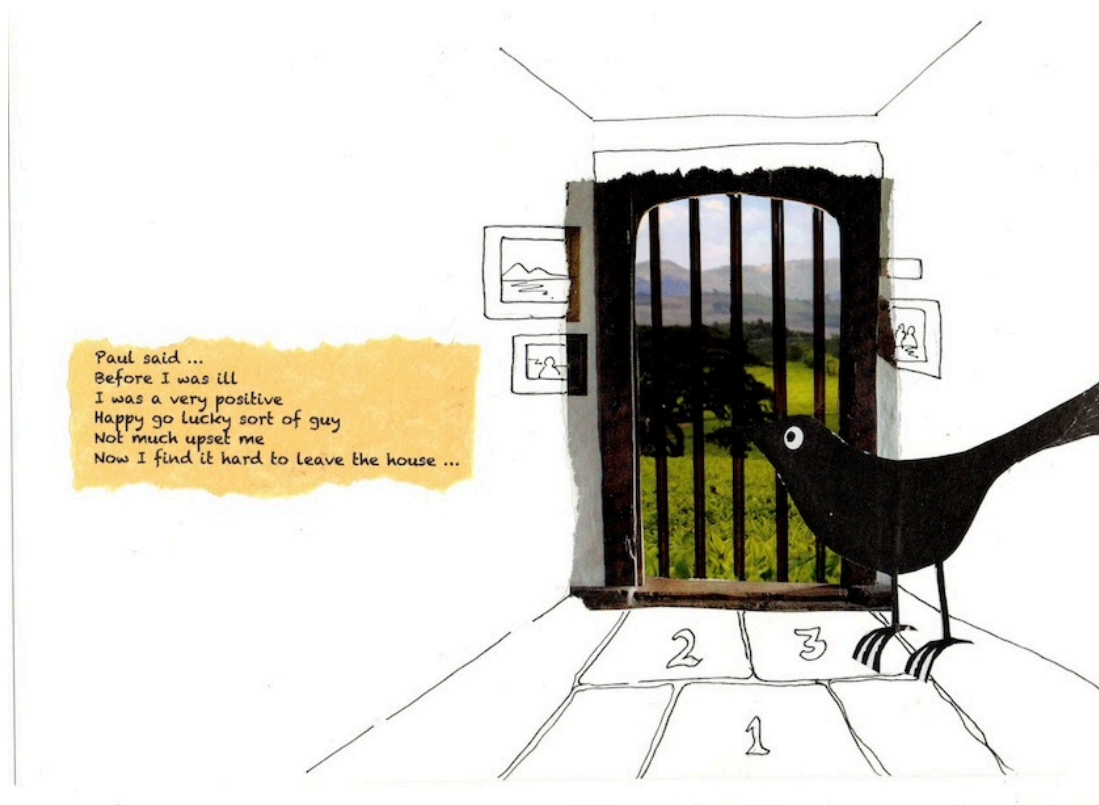


Figure 74. *Not Going Out* by Susan Carr

Having already painted three portraits for Paul (i.e. Broken Lungs, English Gothic and Virtual Paul), I had thought these were 'enough', however when I sat down to review these portraits I was not so sure, I documented my thoughts in the ADS:

ADS: Paul	14/05/2013
Title	Custom
<i>ADS: I spent time looking at Paul's portraits, collages and prose-poems and I thought that the portraits didn't really reflect Paul's previously described 'happy go lucky' well self-identity. I thought there needed to be more of a balance. I then thought about doing a further portrait which would do this. We had planned a portrait of Paul in a bar, perhaps in the style of Edward Hopper, the suave male loner figures that often feature in these paintings. I have not mentioned the portrait to Paul as I am afraid I will not have time to complete it before the EPI. I realise I am taking a risk, since Paul will not get an opportunity to advise me of changes he wishes to make, however I will focus on our initial discussions.</i>	

Following my intuition I painted a final portrait for Paul and called it *At Home*:



Figure 75. *At Home* by Susan Carr

I told Paul when I arrived for the EPI that I had another portrait to show him:

S: [...] so this one, you know we talked initially about doing a portrait of you in a bar, like an Edward Hopper painting, so I thought shall I do one? I didn't tell you about it because I thought I might not get time to do it, but anyway I did.

P: So this is a surprise one is it?

S: This is supposed to be you in a bar with some drink and the ...

P: Gangster sort of thing isn't it.

S: Yes in a way ... but this idea of you being ...

P: I look quite well there!

S: I called it 'At Home' because you said you felt at home ...

P: Well considering I lived in a pub, pubs and what have you ...

S: It's sort of like Humphrey Bogart, you know that kind of ...
P: Yeah ... no *I like that actually!*
S: It's sort of a 'well Paul' kind of one ...
P: *It isn't far off actually ... yeah, I like that one!*
S: It's good to have a balance with the paintings.
P: *At one time I always used to wear a suit jacket like that, a brown pin striped thing.*

S = Susan, (ATR) Artist/Researcher P = Paul (PR) Patient/Researcher (EPI: 03/06/2013)

By saying 'I always used to wear a suit jacket like that' Paul is indicating his 'ownership' of the 'self' depicted within it, and goes on to acknowledge the adaptive change he may implement through *imitating* the portrait:

P: Very good ... *I do like that one ...*[indicating At Home] ...
S: *That is the reason I wasn't here last week ... trying to get it finished ...*
P: *I will have to get a jacket now ... go to the hospice like that!*

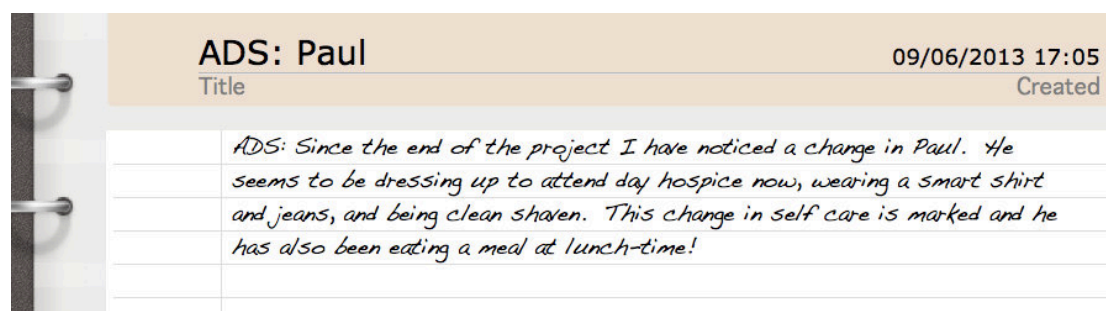
S = Susan, (ATR) Artist/Researcher P = Paul (PR) Patient/Researcher (EPI: 03/06/2013)

Although this may seem a small thing to do, to buy a jacket, it implies a degree of self-worth and self-care, something that had been lacking in Paul's presentation of himself in day-hospice. In the portrait Paul is extracted from his liminal space and placed where he feels a sense of home-like-being-in-the-world, something Paul says he would like to return to:

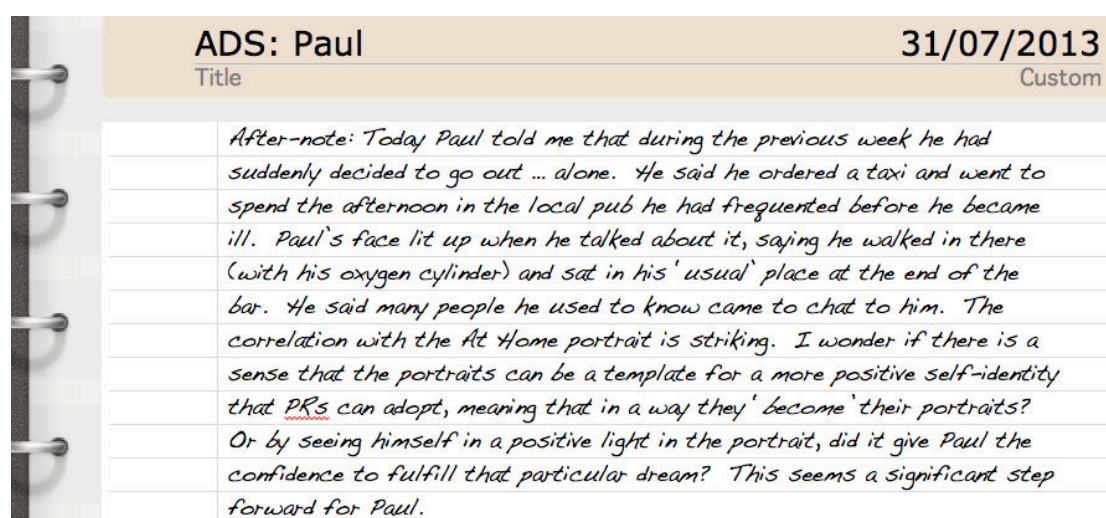
S: *And maybe a return to this one here [indicating the 'At Home' painting]?*
P: *By the time I return to that I won't be able to afford a pint! [laughs] I would love to go out ... even now I would love to go to my local and have a pint ... just walk in there sort of thing.*

S = Susan, (AR) Artist/Researcher P = Paul (PR) Patient/Researcher (EPI: 03/06/2013)

I was worried when I painted the portrait that Paul may see it as the embodiment of his 'lost' self, however since the completion of our sessions together there were opportunities to catch up with Paul in the day-hospice and I noted further changes and developments in the ADS:



The difference between Paul in *Broken Lungs* and Paul in *At Home* is stark, and demonstrates why I felt it was important to paint the latter as a contrast, and it did seem to be the catalyst for positive changes in Paul's self-esteem and autonomy, and this continued and developed after the completion of the project. I recorded in the ADS a conversation I had with Paul a few weeks later at day-hospice:



Perhaps for Paul, the experience of seeing his portraits enabled something to change or shift within him, giving him a sense of self-worth and agency, as artist Antony Gormley (2002) says: '[...] art confronts life, allowing it to stop and perhaps change direction'. The local pub Paul went to visit was a place where he was known and welcomed, and the portrait encapsulates this sense of *being known* that is implied in *being At Home*.

This capacity portraits have to reflect that which PRs *need to see* is also highlighted in Norma's experience. We had decided to paint a portrait of Norma using Frida Kahlo's *The Two Fridas* (1939) (available at <http://www.fridakahlofans.com/c0290.htm>) as reference, as the idea was to depict the two central aspects of Norma's self-identity,

which she described as ‘Scottish Catholic’ born in Aberdeen, and also ‘North Bear’, her Native American Indian identity after being adopted into the Black Foot Tribe.

In *The Two Fridas* Kahlo paints the two halves of her self-identity, one wearing early 20th Century European clothes, and the other a traditional Mexican Tehuana dress ripped at the chest to reveal a bleeding, broken heart. The two Fridas are sat on a bench holding hands, joined by an artery travelling between the two hearts, painted against a stormy sky. Within the portrait Kahlo shows her duality, using a visual language that speaks of herself as ‘divided, unintegrated and uncontained fluidity’ (Latimer 2009: 51).

In *The Two Normas* (see Figure 76) the dual nature of Norma’s self-identity is reunited and validated.



Figure 76. *The Two Normas* by Susan Carr (co-designed by Norma/North Bear) (After *The Two Fridas* by Frida Kahlo, 1939)

Through this portrait Norma was able to *see the difference* between the two sides of her self-identity for the first time:

S: So, has this project helped to give you a stronger sense of yourself and your identity? N: Yes. S: And could you give me some examples of this?
N: It made me realize that I'm not the only child that was abandoned at a very early age, and it's made me realize that yes, I am probably a stronger person because of that. And, finding the Indian [NAI] side of myself, that has made a great difference in my life. I didn't realize how big a difference that it had made until we first spoke. ... I knew it had made a difference, and everybody said that when I'm in my regalia, I'm North Bear, I'm not Norma. I'm a totally different person. *I didn't realize that until I just looked at that picture.* [indicating *The Two Normas*] *You can see there is a total difference.*
S= Susan, (ATR) Artist-Researcher & N = Norma (PR) Patient-Researcher. (EPI: 26/09/2012).

Norma goes on to say how 'Norma' is supported by 'North Bear'. This new way of thinking about herself correlates with the essences statements for *The Two Normas*:

Statement of Emergent Knowing: The Two Normas

Culturally diverse identical twins are linked in the holding of hands together, united in strength and compassion, two parts of a whole, supporting and nurturing each other.

Statement of Emergent Learning: The Two Normas

Norma acknowledges that North Bear supports her Scottish self, especially when she is anxious or ill. Norma is becoming aware of how different aspects of her self-identity can be called upon in times of need, which contributes to a creative and adaptive way of being.

In her EPI Norma clarifies how the different aspects of her identity support each other:

S: Again, it's unusual. I like that unusualness [referring to *The Two Normas*].
N: It's different. The two sides of one person.
S: Sort of meeting and supporting each other.
N: That's a good way of putting it because *North Bear does support Norma and Norma supports North Bear. And when Norma's not very well, she becomes North Bear, and North Bear comes through and carries her through it. ...*
S= Susan, (ATR) Artist-Researcher & N = Norma (PR) Patient-Researcher. (EPI: 26/09/2012).

Norma realises that North Bear as an aspect of her self-identity can be relied upon not to abandon her at times of need. The dualities explored within this portrait are therefore characterised by hope and despair, of suffocation and breathing, of life and death and the ability of the portraits to ‘hold’ these dualities is an important way in which they function, and dissipate ‘cognitive dissonance’ (Festinger 1962). (The function of portraits as holders of duality will be discussed further in section 6.3).

Norma summarises her experience of revisioning her self-identity through portraiture; going from a place where she felt ‘worthless’ to one of ‘purpose’.

N: *I felt worthless and useless when we first started this project. But by having to relive my life, by telling the story, I've realized that I've actually become stronger through the illness. The iller I've got, the stronger I've got. And that no, I'm not useless. I've got a purpose in life and I'm fulfilling it.*

S= Susan, (ATR) Artist-Researcher & N = Norma (PR) Patient-Researcher. (EPI).

In this section I have described the intra-subjective validation of self-identity that the portraits provided for the PRs, using the portraits *At Home* (Figure 75) and *The Two Normas* (Figure 76) as examples. Paul found a renewed sense of agency after viewing his portrait freeing him from his agoraphobic fears, and enabling him to make a final visit to a place he ‘loved’ and where he was *known*. In *The Two Norma's* portrait Norma is able to *see the difference* between two important aspects of her self-identity and realise for the first time how they support each other. Norma says the intervention enabled her to move from a position where she saw herself as ‘worthless and useless’ to one where she says ‘I have a purpose in life and I’m fulfilling it’, equating in itself to a home coming experience.

6.2 Intersubjective validation of self-identity: Portraits PRs needed others to see

Humans have a self that is relational and that by its very nature involves self - presentation to others, with an awareness and concern about how one is seen, and this is part of what is rendered when an artist creates a portrait. (Freeland, 2010: 104).

While personally viewing the individual portraits fulfilled different needs for the PRs as this project progressed, it became clear that sometimes it was equally important for

PRs to know that their portrait was going to be *seen by others*. This is based on a view that portraits as objects hold significance, are ‘made special’ and as such act as *participants* in the world, able to influence and effect change in the views of people and through them – society in general.

One of the prevailing themes identified within Rose’s portraits (see Figure 77 below) is the tension between being seen and unseen. When analysing the portraits I noted a progression within them from ‘invisibility’ (Charmaz & Rosenfeld 2006) within *The Poppy Field*, where Rose says ‘I lay down in a poppy field *where no one could see me*’, to semi-invisibility in *Paint me Like a Picasso* where she says ‘Picasso painted in a quirky way ... so if you paint me like a Picasso, *people won’t notice* my quirkiness ...’ Then in *Bohemian Rhapsody* Rose is finally *visible* confronting the viewer with a defiant, strong and forthright look. As she says ‘Paint me like Freddie Mercury ... strong and defiant!’



Figure 77. *The Poppy Field, Paint me like a Picasso & Bohemian Rhapsody* by Susan Carr (co-designed by Rose).

This sense of confrontation, and determination to be seen on her own terms, was highlighted in the *statement of emergent knowing*:

Statement of Emergent Knowing: Bohemian Rhapsody

I take a risk and step out of the shadows into the light ... through self-acceptance and strength ... I look you in the eye ... I will be seen and heard.

When viewing all three of Rose’s portraits together I noticed they all held an element of *performance* and *intentionality*, each with a distinct ‘costume’ and ‘set’ ... which suggests that Rose may be playing a ‘role’ in each of them. This is poignant because autonomy, intentionality and the ability to ‘be’ who she chooses is something that

may be lost to Rose if/when her illness progresses. The fear of this happening was highlighted within the collage and prose poems:



Figure 78. *All I might be to do*, collage by Susan Carr

In a similar way Peter needed others to see the portraits of himself and Mark (see Figure 79 *At the Races*), and also himself as a fit and active young man climbing Mt Kilimanjaro (see Figure 81).



Figure 79. *At the Races* by Susan Carr, (co-designed by Peter)

As discussed in chapter 5 Peter asked for photographs of the portraits to keep in his wallet ready to show people he met. I saw him show these images regularly to other patients and staff at the day-hospice. For some reason it seemed easier for Peter to show the portraits of his deceased son, rather than photographs, again bringing in a sense of emotional distance and yet connection inherent within the portraits. The fact

that the portraits were painted by someone other than him seemed to give Peter ‘permission’ to show them and talk about his lost ‘father of Mark’ identity, as well as a sense of pride that he and Mark had been painted together.

Peter spoke about the contrast or difference between himself prior to diagnosis and how illness had impacted on who he was able to be now. This contrast is captured in the following collage I created for Peter:

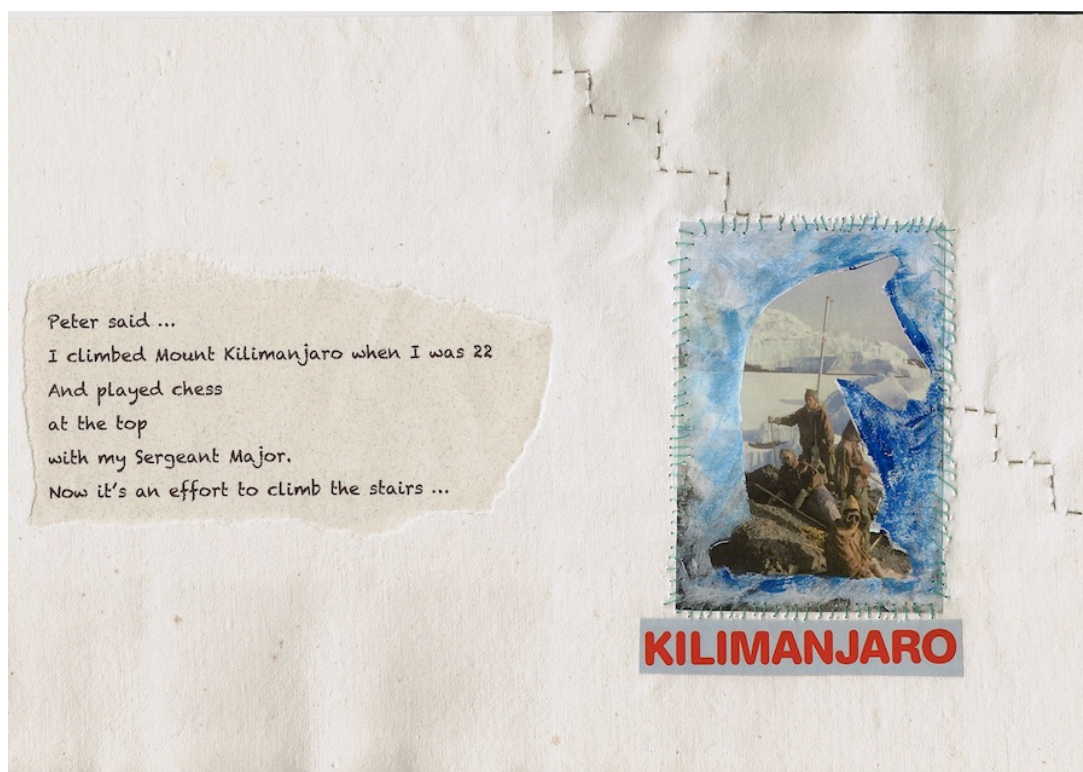


Figure 80. *I climbed Mount Kilimanjaro* by Susan Carr

When co-designing the portraits Peter’s focus was also on portraying his autonomous, masculine self-identity, as this he felt had been most negatively impacted by LT&CIs. It seemed that Peter needed people to see what his illness had done to him – that he was still this fit young man inside, as shown in his Mt Kilimanjaro portrait:

Statement of Intention: Climbing Mt Kilimanjaro

Peter said: paint me as a young boy soldier climbing Mt Kilimanjaro, I climbed it so easily back then, I don’t even remember getting breathless! No need for oxygen! Peter chose an Impressionist style for this portrait and although he did not express a direct understanding of Impressionism as a school of painting, he did express a desire for me to ‘capture the moment and the light’.



Figure 81. *Climbing Mt Kilimanjaro* by Susan Carr (co-designed by Peter)

Statement of Emergent Knowing: Climbing Mt Kilimanjaro

A young man surveys the world, his mountain to climb and his life to live – a boy soldier without a care in the world conquers nature, noticing only the beauty and majesty, confident in this harsh terrain, the boy-soldier becomes a man.

For Peter this then became a reclamation and validation of his masculine, adventurous and autonomous self, something he feared he had lost due to his illness. Showing others this image enabled them also to see Peter in a new light, to look beyond his illness and disability to who he was ... and still is ... inside.

Similarly there were portraits that Paul needed to see. Viewing the Broken Lungs portrait enabled Paul to see how thin he had become:

ADS: Paul	20/01/2013
Title	Custom
<i>ADS: I took the Broken Lung portrait to show Paul today ... I was a bit worried about showing him, because it seems quite shocking to me ... and when he saw it he exclaimed ... 'I'm not that thin am I?' and I said 'yes I'm afraid you are ...' he said 'good god' I better try to eat more ... the consultant says I can't be put on the heart lung register until I am at least nine and a half stone ... but I have never been nine and a half stone in my life ... I have always been thin ... but not that thin ...!' I felt disturbed that the portrait may have held up a mirror for him that he didn't want to see ... and yet there was also a feeling that perhaps he needed to see it ... in order to take action, to try to eat and put on weight, so that he could have the hope of a transplant.</i>	

Paul's emaciation – whilst obvious to see even through his clothes, was for whatever reason *not seen* by Paul and his ambivalence to food highlighted this, usually refusing

all offers of food at day-hospice. However, soon after this discussion Paul's attitude to eating changed, at least at day-hospice, where he began to eat a (small) meal each week with the other patients. I believe that for Paul seeing himself mirrored through the eyes of another, enabled him to see a more 'accurate' vision of himself, resulting in a renewed sense of agency.



Figure 82. *Broken Lungs* by Susan Carr (co-designed by Paul)

Broken Lungs was also a portrait Paul needed *others* to see, as a way to validate his inner reality and his invisible illness. Paul talks about how his Mother reacted to the portrait:

P: Well it was actually, for no reason, like today ... I was being pushed in a chair and just getting out of the chair into the car I just had to stop for five minutes just to catch my breath [...] It just gets you now and then, it just gets you ... it hits you really hard ... it's weird.

S: So do you think that it reflects that ... the *Broken Lungs* painting?

P: Yeah, yeah definitely.

S: Yes ... because people have said it is a very powerful painting ... when I had it in that exhibition ...

P: My mum hates it! [laughs].

S: Well I can understand that ... because she is your Mum.

P: It is horrible I must admit ... but I tried to explain to her ... that is me ... I am damaged.

S: Yes.

P: That is skinny though isn't it. [laughs]

S = Susan, (ATR) Artist-Researcher & P = Paul (PR) Patient-Researcher. (EPI 03/06/2013).

Paul's reflection that his mother 'hates' his *Broken Lungs* portrait may indicate a sense of denial or an inability to acknowledge or 'hold' Paul's feelings of despair and pain. However, through the portrait, Paul is able to talk to his mother about his illness, and being 'damaged'. Exley & Leatherby (2001) say that people whose expectations around their future lives has been challenged by a disrupted life course, 'engage in emotion work on and for their selves and on and for others'. The co-designing of portraits *for others to see* may therefore indicate a need for PRs to enable relatives and friends to come to terms with the PRs illness and mortality.

For different reasons Bill needed others to see his *Flying Ace* portrait (Figure 83) – to witness the young vital self that he had been willing to sacrifice for his country, something that many of his friends *did* sacrifice. The portrait was therefore a way of remembering and acknowledging their loss through bringing into being a self-identity hidden by the mask of time and illness, but still present within him. This was therefore an internal landscape, made visible for others to see and validate.



Figure 83. *Flying Ace* by Susan Carr, 2011 (co-designed by Bill)

In this section I have described the way Rose used the portraits to confront others with her intentionality and autonomy, with a gradual sense of determination *to be seen by others*, but on her terms. For Peter it was important to keep images of the portraits with him at all times, in order to show others the significance of his lost *father of Mark* identity and as a way for others to witness the autonomous, adventurous masculine part of his self-identity, something he felt had been lost through the impact

of illness. Paul needed his Mother to see and hold the Broken Lungs portraits and it was the catalyst that enabled Paul to talk to her about his illness. Bill needed others to see his young and vital self, something he had been willing to sacrifice for his country and a reminder of the many who did make the ultimate sacrifice. Also drawing back the scourge of time and illness to reveal an inner reality – an inner self that was ... is Bill.

6.3 Portraits, collages & prose poems as ‘containers’ of duality: *holding hope and despair*

One of the ways portraits hold dualities such as ‘hope and despair’ (Clayton *et al.* 2005, 2008), is through the use of metaphor and symbolism, and while Husserlian phenomenology seeks to reduce phenomena to its pre-reflective origins, the use of symbolic interactionism (Mead 1934; Cooley 1902; Blumer 1969) is not incompatible with a phenomenological approach (Lester 1999; Finlay 2011), particularly within the interpretative *hermeneutic* tradition (Heidegger 1962 [1927]; Gadamer 1975). Indeed metaphor and symbolism can also be seen as another way of reducing complex phenomena to ‘essences’. These ‘essences’ can then be subtly changed through aesthetic or metaphoric attunement, and held within the portraits. As Wright (2009: 25) says, being or feeling in touch with another person requires a kind of ‘symbolic capability’ in at least one of the people who are interacting, to hold the experience in a symbolic form and therefore allow its realization. This ‘symbolic capability’ became highly developed between Rose and myself, and many of her collages and prose poems contained metaphor and symbolism e.g.:

Rose said ...
‘I collect Freddie Mercury Plates
On a display shelf
One day it slipped
And all my plates came crashing down ...
I am still picking up the pieces.’



Figure 84. *All My Plates Came Crashing Down* collage by Susan Carr 2010

Within this collage the ‘shelf of plates’ ‘crashing down’ becomes a metaphor for the moment when Rose was diagnosed with Motor Neuron Disease (MND), highlighting the dualities of helplessness and agency through the ‘sudden’ catastrophic event and through Rose ‘still picking up the pieces’.

Dualities are also held within Rose’s *Paint Me Like a Picasso* portrait (see Figures 77 & 85). Within the portrait Rose is wearing flamboyant colourful ‘parts’ of clothes or costumes, something that equates to a kind of ‘camouflage’. The poppy motif returns in this portrait, and although a positive symbol for Rose (being her favourite flower), the metaphoric connotations of a poppy are of remembrance, mourning and death. Similarly the canary in the cage was suggested by Rose to indicate that she had bred canaries for several years, however the cage could also be seen as a metaphor for MNDs propensity to ‘lock’ sufferers within their bodies. Although Rose’s intentions for these motifs were positive at the time of designing the portrait they do hold dual meanings.

I became aware of a sense of ‘holding’ hope and despair for Rose within her *Paint me like a Picasso* portrait while I was painting it:

Statement of Reflexive Resonance: Paint Me Like a Picasso

When painting this portrait I felt unable to paint the door on the bird-cage closed. This would, to me, have been a symbolic extinguishing of hope. I could not do it. So the door remains open. The Canary could therefore be seen as both *inside* and *outside* the cage.

A sense of hope is reflected in the portrait through the ‘open door’ on the birdcage (Figure 85), allowing the possibility of ‘escape’.



Figure 85. Detail of the canary in the cage, from *Paint me like a Picasso* by Susan Carr 2011, (co-designed by Rose)

In this portrait Rose physically ‘presents’ us with the canary in the cage, which also becomes a symbol of her ambivalence. For Rose there is a sense of needing to be in control of what she reveals or conceals about her illness, she therefore reveals the canary – but at the same time presents it inside the cage, suggesting that Rose is ‘hidden’ within the portrait, a way of both *being seen* and *not seen*. This is outlined within the phenomenological essence statements:

Statement of Emergent Knowing: Paint Me Like a Picasso

If I wear my identity brightly people may be blinded by the brightness, so they do not notice the darkness of my illness. I stand at the edge of the cage and ask ‘can I still fly?’

Statement of Emergent Learning: Paint Me Like a Picasso

By choosing a Cubist style of painting, which breaks the surface into facets viewed from different angles, there is a sense of ambivalence in Rose revealing herself, and the opportunity for Rose to ‘hide’ herself within the brokenness of the image.

Ultimately the portrait becomes a container and holder of dualities, of Rose’s sense of hope and despair about her illness.

When reviewing Susan's portraits I became aware of how they also held complex dualities. During the initial stages of my work with Susan, she spoke about her childhood as 'miserable', with a father she described as a 'brute' and a mother who was unable to protect her from him, of how she was on the one hand idealised and over protected, and on the other unacceptable and unprotected, and faced with a father figure who's 'rages' she lived in fear of.

These issues were depicted within the collages I produced for Susan:

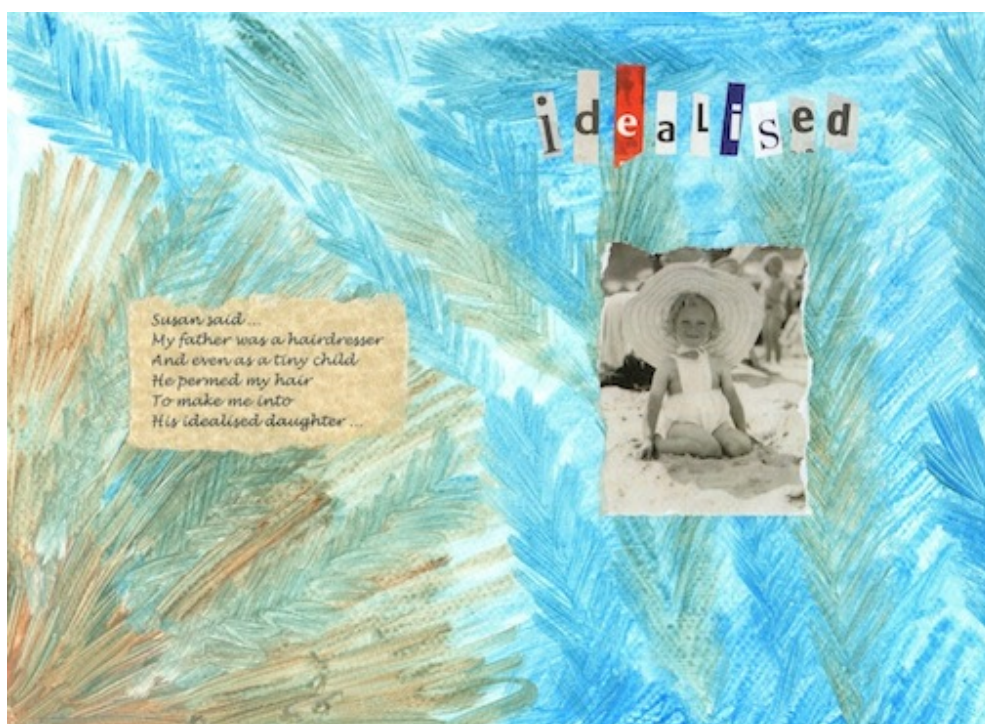


Figure 86. *Idealised* by Susan Carr

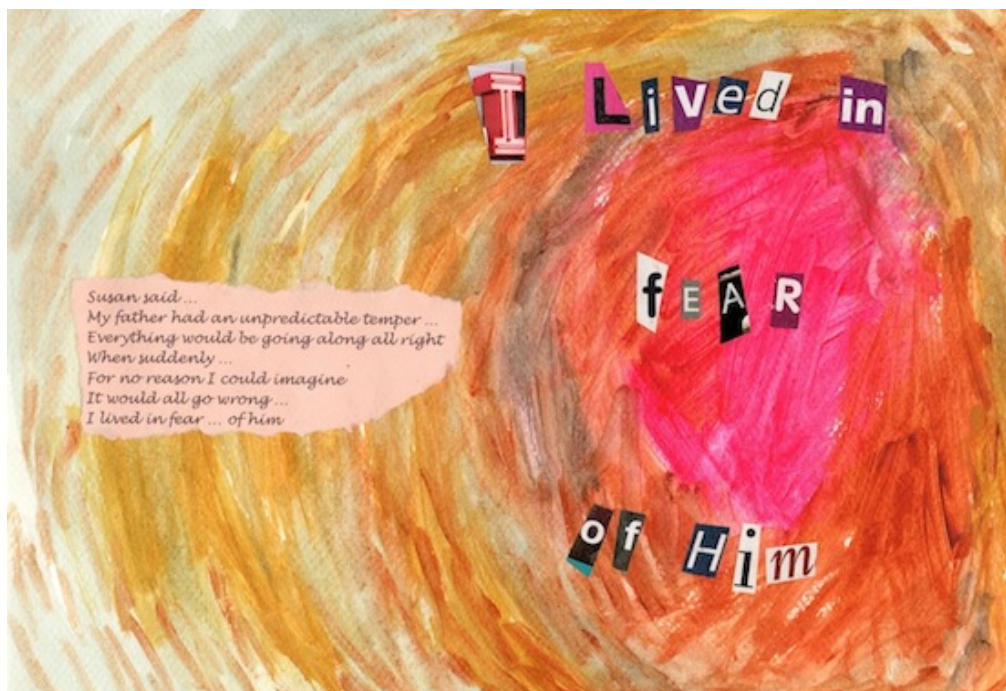


Figure 87. *I Lived in Fear of Him* by Susan Carr



Figure 88. *Over Protected*, collage by Susan Carr, 2012.

These collages highlighted the overt patriarchal domination within Susan's early life and the requirement to appear *feminine* and *submissive*. Within these collages and

prose poems the dualities of being *over* and *under protected* came to the fore, and Susan's need to find a *balance* between a desire for protection but also freedom.

During the photo-elicitation sessions, Susan said that as a child she was in a 'catch 22' situation with regards education and learning, with her father enraged if Susan showed signs of being an academic or 'too clever', and equally enraged if she was 'below average' in her school work. Susan said she had to hide her reading of academic and literary works from him, and could still 'taste the tears' and feel the anticipated fear of his fury if he found out. During our co-designing of Susan's *Catch 22* portrait-sculpture (see Figure 89) we initially had the idea of depicting Susan as a child walking across a tight rope, however we also felt that there needed to be 'books' involved. We also reintroduced the pins used in *Pin Hole Camera* (see Figure 45) as a symbol for pain and discomfort.



Figure 89. *Catch 22* by Susan Carr (co-designed by Susan)

Statement of Emergent Knowing: Catch 22

A small faceless child attempts to 'balance the books', afraid to move, a heavy load on her young head, one slip and she is impaled on spikes of steel. And yet the child cannot help but fall?

Statement of Emergent Learning: Catch 22

Susan is caught in a catch 22 situation, whereby she can only be acceptable to her father by denying herself. Susan's academic self is hidden to keep the peace. As her Father's daughter, Susan is not allowed to fail but also not allowed to be too clever. She must therefore maintain a perfect balance or face the fearful storm of tears and shame. As her Mother's daughter, Susan also hides her true self and colludes with her mother to maintain the façade of the idealized daughter, encouraged to placate her father to avoid both being caught in the storm of his anger.

This portrait sculpture demonstrated my mirroring and attunement of Susan's childhood distress, showing how impossible the task of 'keeping the peace' or 'balancing the books' was for such a small vulnerable child. As the project progressed the idea of 'balance' within the collages became something Susan focused on, making sure that there were an equal number of both positive and negative collages. We subsequently co-designed a portrait-sculpture that served to 'balance' the negatives in *Catch 22*, this was *The Cupboard of Imagination and Dreams* (Figure 90). The 'portrait' aspect is represented by a small child standing on a swing on the lower drawer:



Susan said:
When I was a child
My parents had a locked cupboard
with a glass front full of classic
books.
One day I discovered where the
key was hidden.
From that day on, I surreptitiously
'stole' the key and read all the
books one by one,
Risking my father's wrath
I discovered a world of freedom
and adventure
in my cupboard of imagination
and dreams.

Figure 90. *The Cupboard of Imagination and Dreams* by Susan Carr (co-designed by Susan)

Statement of Emergent Knowing: Cupboard of Imagination and Dreams

In the cupboard of imagination and dreams is a world where it is ok to take risks and explore, a land free from guilt and anger, a land where you can be yourself or an 'other', a land of magic, mystery and intrigue, a land without limits.

Statement of Emergent Learning: Cupboard of Imagination and Dreams

Susan gains integrity in her love of learning. The cost of this is her idealised innocent self, which slips from the pedestal with each deception. Susan gains knowledge of the world and learns she must hide her deception and evolving self. Through this deception Susan also comes to know her shadow self.

Susan 'slipped' a little from the idealised child pedestal with each deception, the portrait therefore holding dualities of truth and deception, and hope and fear. Susan reflects how the portraits helped her to find 'balance' in the collages and through this process find a coherent sense of self-identity:

SC: I suppose there's this idea that traumatic memories are perhaps ... that they're stored in a part of the brain that is non-verbal ... it's about images.

S: You probably do store it in images yes.

SC: So it's probably difficult to talk about these things and you need a visual metaphor to describe some of these feelings?

S: It's certainly helped to bring up the positive parts of my childhood as well, because I probably would have ... if somebody had put me on the spot and asked me about childhood, I probably would have remembered a lot of bad things, but not *how* they were bad, what made them so upsetting for me. I probably wouldn't have been able to consciously explore what it was about the things that I hated. And then, also to *counterbalance* them with things that were *positive*, more than I had thought would be there. *And I quite like this idea of me still being me despite everything.* [...] So yes, I think it's been something that would have been a lot more difficult to achieve, with simply talking sessions.

SC= Susan (ATR) Artist-Researcher & S = Susan (PR) Patient-Researcher (EPI 19/10/2012)

It is therefore *through* the *images* and the reflective space created, that Susan finds a new understanding of herself (O'Neill 2008; Lett 1998), suggesting that through the mirroring and attunement inherent within them, a personal recognition of 'me still being me despite everything' is found.

The dualities of idealisation and vilification, of power and helplessness, of fear and courage, as well as her father's patriarchal views about femininity and education were all depicted within Susan's *Being Pandora* portrait:



Figure 91. *Being Pandora* (after Rossetti, 1828-82) by Susan Carr (co-designed by PR Susan)

Statement of Intention: Being Pandora

Susan said I love the pastel painting of Pandora by 'Rossetti', which is in Buscot House, I cannot go and see it now as it is unreachable to me being upstairs and there is no lift.

Statement of Emergent Knowing:

Mysterious, mythical girl/woman is cast in the role of beautiful femme fatal, betrayed by her curiosity, she is blamed for releasing all ills into the world, yet she is also bountiful all giver, peace maker and holder of hope and grace.

Statement of Emergent Learning:

Idealised uncapturable Susan, falls victim to her curiosity and opens the box, resulting in a loss of innocence, She remains a romanticised, beautiful, 'all-giver', holder of hope and grace.

Statement of Reflexive Resonance:

I have been to Buscot house many times to see Rossetti's version of this painting, and never tire of its powerful sense of mysterious haunting womanhood holding burdensome secrets and power.

This encapsulates the conflict of holding idealisation and vilification, but adds *aesthetic resonance* to mitigate this and leaves Susan literally 'holding hope' within the box. The idea of 'the box' is also revisited within this portrait – but this time Susan is outside it, and left within the box is 'hope'.

In Paul's portrait *Broken Lungs* the focus is on the dualities of inner and outer realities. Paul describes his intuitive 'drawing towards' Frida Kahlo's *Broken Column* self-portrait when he saw it for the first time in the PRA:

S: So how did you find the collaborative process, that is ... where we looked through the book of images ... you chose the Frida Kahlo one and we talked about the American Gothic one, thinking of ideas ...

P: I suppose we chose that [indicating *English Gothic* portrait] because it was more into my sort of life ... that's why I chose them ... to see them now is very good actually.

S: They reflected ... they obviously resonated with something ...

P: Yeah, well ... you could understand what she [Frida Kahlo in *Broken Column*] was going through, yeah I found them quite good actually, those paintings.

S: Yes, because if you have an illness that's invisible ...

P: Yeah ... like you could tell that she was in pain and all that ...

S= Susan, (ATR) Artist-Researcher & P = Paul (PR) Patient-Researcher. (EPI 03/06/2013).

Images are able to convey physical pain in a way that is *inexpressible* in any other form (Toombs 1990: 235; Padfield 2003), and Paul recognises this when he says 'you could tell that she was in pain'. Paul is therefore choosing to reveal his inner pain and suffering through the portrait, and through this aligning his inner and outer landscapes or realities. This was highlighted within the knowing and learning essence statements:

Statement of Emergent Knowing: Broken Lungs.

You stand in naked isolation, chest ripped open, revealing your pierced lungs, a window onto invisible suffering, stripped back, laid bare, revealing your pain in a barren landscape. Is there anybody there ... to see?

Statement of Emergent Learning: Broken Lungs.

Portraying his body unbounded Paul connects his inner and outer realities ... it is hard to look at ... but even harder to be ... Paul. Holding his breath he opens himself to hope, that by some stroke of luck someone may reach out and switch his faulty heart and lungs for some that work ... allowing him to breathe ... and love ... life ... once more ...

Exposing the outside flesh and the inside organs of the body, Paul reveals his 'inner-self', within this portrait. It is a brave and risky thing for him to do. If the cut-open chest is not enough to indicate Paul's suffering, the nails driven into his flesh and lungs serve as emphasis. The portrait reveals how Paul's feeding tube punctures his

abdomen wall and snakes its way up inside him to find his stomach. The ‘unboundedness’ (Lawton 1998: 127) of the body evokes a sense of shock, as viewing the interior of our bodies is something that modern physicians normally protect us from (Sawday 1996 [1995]: 12). The ‘unbounded body’ refers to a body where the skin has been broken, allowing bodily fluids to escape (Lawton 1998: 127). As Anzieu says ‘bodily containment seems related to our sense of identity and self containment’ (1989: 98-108), however within invisible illnesses the perfection and seamlessness of intact skin, as the ultimate container of a person, may contrast sharply with a person’s inner reality (*ibid.*). By portraying himself with an ‘unbounded body’ Paul reverses reality to acknowledge the ‘unboundedness’ of his inner self, and a recognition of his *being-towards-death*.

As mentioned in chapter 5 Paul talks about feeling trapped within his own body, therefore portraying himself with an unbounded body may also have been a way to express his hopes of *escape*. Luzzatto (2005: 164) talks about how in art therapy groups with cancer patients ‘some patients may need to make images clearly focused on ‘the negative’ such as: anger, fear and death, as a form of catharsis. Although this portrait clearly contains painful and cathartic content, in the EPI I suggested to Paul that the *Broken Lungs* portrait may also be a *hopeful* painting, if he is able to gain enough weight, a way of visibly rehearsing the possibility of a heart lungs transplant:

S: Do you think it [Broken Lungs portrait] is a hopeful portrait as well though ... because there is this sense that you might have a heart-lung transplant ...

P: Well there is that in it ... because there I am open ... you can reach out and take them out and put some new one’s in ... as such ... [laughs]

S= Susan, (ATR) Artist-Researcher & P = Paul (PR) Patient-Researcher. (EPI 03/06/2013).

For Paul, even the background reflects his feelings of *unboundedness*. The barren landscape in which Paul stands is a replica of the background from Kahlo’s *Broken Column* painting, and a barren landscape as a metaphor in paintings is indicative of feelings of depression, a lack of nourishment and social interaction (Thorne 2011: 24), all characteristics of Paul’s lived experience. The significance of the landscape in this portrait is not lost on Paul as he equates it to a war zone:

P: That one [indicating Broken Lungs portrait] it *looks like I am in one of those landscapes with bomb holes ...*

S= Susan, (ATR) Artist-Researcher & P = Paul (PR) Patient-Researcher. (EPI 03/06/2013).

Through the portrait *Broken Lungs* Paul literally ‘lets us in’ to his interior world of pain and suffering, uncharacteristically letting down his guard, and demonstrating vividly his vulnerability. By portraying himself with an open ‘unbounded body’ (Lawton 1998: 127), Paul reverses reality to reveal the *unboundedness* of his inner self, and his closeness to death, acknowledging that he may suffer acute respiratory failure at any time, as such this portrait portrayed dualities of fear and courage. The combining of the PRs ‘inner’ and ‘outer’ landscapes in one image then allows for feelings of *integration* and *identity coherence* to develop (Ulman 1980: 6). This was also a portrait that Paul needed others to see, perhaps as a way to help them understand the gravity of his illness and to demonstrate his need for love and acceptance and his connection to all humanity:

S: Yes ... *get to the essence of the person ...*

P: *Deep underneath what you are asking ... there is a heart as such.*

S: Yes ... *I can see it ... [laughs]*

P: Yeah [laughs]... in that one ... [indicating Broken Lung painting]

S: *We found it somewhere in there ... [laughs]*

P: Yeah ... *well you know what I am saying ...*

S: *I know what you are saying ...*

S= Susan, (ATR) Artist-Researcher & P = Paul (PR) Patient-Researcher. (EPI 03/06/2013).

In this exchange Paul indicates his awareness of how much I *know* him, so much so that he assumes I can ‘read between the lines’ of his attempts to explain his feelings and I reflect that when I say ‘*I know what you are saying ...*’. I remember this as a poignant emotion filled moment within the EPI, filled with I-thou (Buber 2004) recognition and intersubjective *knowing*.

In this section I have described the way portraits are able to hold dualities such as hope and despair in all its myriad forms, that these were ‘given’ to me to hold and contain within the portraits. In her three portraits Rose explores *being seen* and

unseen, as well as *imprisonment* and *freedom* and I am unable to close the door on the cage, as this seems to be a metaphor for hope. For Susan the portrait objects allowed her to see the impossible task she was given as a child, trying to ‘balance the books’ and keep the peace, and recognising the dualities of being *under* and *over* protected. In *Being Pandora* good and evil, power and helplessness are explored and Susan is left holding *hope* in the box. In *Broken Lungs* Paul explores the dualities of *inside* and *outside* realities, and literally opens up and lets us in to his inner world of pain and suffering. I suggest that the development of an intersubjective symbolic capability with the PRs was crucial to this process, enabling them to unravel the layers of meaning within the portraits, developing a stronger sense of self-identity coherence through increased self-knowledge and understanding.

6.4 Portraits of transformation: attaching *aesthetic resonance*

I define *aesthetic resonance* as a process of adding beauty, complexity and coherence through many layered meanings within the portraits, which may be achieved through the use of metaphor and symbolism within the mirroring and attunement process, thereby adding to or changing meanings. This project has shown that within the revisioning process the PRs needed to recapture and make sense of themselves as valuable and beautiful, as Broyard (1992: 134) says ‘with the tubes and the weight loss, *I have to recapture myself and my beauty*. I have to *reinvent* myself’ (Broyard 1992: 134). My interpretation of ‘beauty’ is similar to that found in Japanese *Wabi Sabi*, which is described as ‘a beauty of things imperfect, impermanent, and incomplete’ (Koren 1998: 7). I suggest that attaching *aesthetic resonance* or ‘beauty’ to portraits and collages dealing with difficult feelings and events, whilst not taking away their painful significance, lends them a sense of ‘hope’ mitigating against the sense of despair felt in LT&CIs. As art therapist Lachman-Chapin (1983: 21) says of response art she made for an art therapy client, ‘where Bob saw beauty in my work – it may represent something of my ideals, spirit, and hope’. Beauty is also described as a ‘universal need of human beings’, which ‘brings consolation in sorrow and affirmation in joy’, showing human life to be ‘worthwhile’ (Scruton 2012). There is also a sense of meaning in aesthetics, adding ‘coherence’ to something discordant. As Dissanayake says:

Another way of looking at it is to recognize that meaning is aesthetic. Ordinary day-to-day life is formless, incoherent. When shaped and embellished or transformed as in ritual or play or art it takes on a greater or more significant reality so that when we find something to have coherence it seems to be 'aesthetic'. When we feel something to be aesthetic we recognize that it is coherent (1980: 404).

In Susan's *Saying Goodbye to the Sea* portrait (see Figure 92 below), metaphor and symbolism are utilized to mirror the disturbed feelings she felt as a child.



Figure 92. *Saying Goodbye to the Sea* by Susan Carr (co-designed by Susan)

Statement of Intention: Saying Goodbye to the Sea

Susan said "Paint me as a child stood saying goodbye to the sea, I would stand there and pretend to be *Boudicca*". Susan chose the Pre-Raphaelites, Joseph Wright and the painting 'Morning' by the Newlyn School as stylistic references for the portrait.

In the visual analysis of this painting I identified these self-identity titles:

Wild-Boudicca-Child
Mermaid-Uncapturable-Child
Idealised-Conforming-Child

Statement of Emergent Knowing: Saying Goodbye to the Sea

I stand strong and defiant facing the waves, shouldering the storm, safe inside my imagination. I long to stay by the sea, but must retain my idealized self through obedience and hide my true powerful self.

Statement of Emergent Learning: Saying Goodbye to the Sea

Susan fears returning to her childhood home, where her father's rage is uncontrolled. Staying by the sea would mean that the 'holiday spirit' continues, and the strangle hold on the doll's neck could be released.

By attaching 'beauty' as a metaphor for recovery and self-reclamation to this portrait, Susan is able to *revision* her remembrance of this difficult time, capturing again a sense of 'balance' and holding the dualities of hope and despair and enabling a sense of *aesthetic resonance* and coherence.

SC: You're changing that remembrance... [indicating *Saying Goodbye to the Sea*]

S: Yes, definitely. I get all good feelings of this, you know. The sadness of saying goodbye to the sea is balanced by being there in the first place, you know, to be there and to be protected but to be protected in a nice way, have things made for you and all the love that's implied in that.

SC= Susan (AR) Artist-Researcher & S = Susan (PR) Patient-Researcher (EPI 19/10/2012)

Rediscovering her lost child-self through the portraits and finding beauty within them was also important for Norma, as she possessed no photographs of herself as a baby or young child, saying that this part of her life was missing, and that any photographs she'd had were either lost or destroyed in a fire. The portraits of herself as a child may then equate to a *repossession* of her past child-self. Seymour (2002) suggests that 'by repossessing the past a person may abandon or rework an earlier life script: the 'cleaned slate' may enable the person to reconstitute him or herself in a more purposeful manner' (Seymour 2002: 239). Certainly these portraits became significant in their ability to change meaning and add coherence through attaching *aesthetic resonance*. This is indicated in Norma's portrait of herself as a child, entitled *Lost*:



Figure 93. *Lost* by Susan Carr (co-designed by Norma)

You have seen this one [*Lost* portrait] before haven't you? ...

N: *Oh, it looks beautiful, looks lovely.*

S: *Nice isn't it.*

N: *Very sad, lost little girl. It's lovely.*

S= Susan, (ATR) Artist/Therapist/Researcher N=Norma (PR) Patient/Researcher
(EPI: 26/09/2012)

Norma's first reaction to seeing the *Lost* portrait of herself as a child was to exclaim how 'beautiful' it is, how it 'looks lovely', that even though it is of a 'very sad, lost little girl' – it is still 'lovely'. This demonstrates how the meaning of the image is subtly changed, not in a way that romanticises illness or loss, as Norma still recognises herself as a 'sad lost little girl', but through validating the experience in a symbolic concrete form, to which aesthetic *resonance* and coherence can be added without losing the meaning behind the image.

This therefore added a sense of coherence to these difficult childhood memories, again a way of holding both 'hope and despair', something also evident within Norma's *A Fish Out of Water* portrait (see Figure 94 below).

Statement of Intention: A Fish Out of Water

Norma said paint me as a child growing up in the back streets of Aberdeen.

This brief statement of intention perhaps reflected Norma's own lack of knowledge about her early years, and I reflected on how to progress with the portrait in the ADS:

ADS: Norma		1/09/2012 9:15
Title	Created	
	<i>I know Norma enjoys metaphor and symbolism within NAI artwork which she has shown to me, so I will try to use this within the portrait. I want to somehow get a sense of Norma's early abandonment and disorientation, whilst also a sense of reconciliation and hope, perhaps of Norma 'finding' herself. Perhaps incorporating a bear in the portrait?</i>	



Norma said ...
I was a tomboy when I
was a child
I would go out to play
and kick off my shoes
and socks
Returning home with
black feet –
My Mother said I
should be
A member of the black
foot tribe –
Now I am ... North
Bear ...

Figure 94. *Fish Out of Water* by Susan Carr

Norma's difficult early life is represented in the yellow/greenish sky and the large puddles symbolising a 'storm', which has passed. The houses and the back ally within which Norma stands are 'empty' and lifeless, the walls are high and the windows are 'blank', the 'gates' have no handles, and no smoke billows from the chimneys, all of which speaks of Norma's early abandonment and lack of a secure attachment. The dualities held within the symbolism of the objects held by the two Normas have also become evident since completing the portrait, with the 'fish out of water' again making an appearance. A 'fish out of water' is a metaphor for an 'unhomelike-being-in-the world' (Svenaesus 2011), also, although the fish held by Norma is 'out of the water' the fish reflected in the puddle is 'in the water' and this reflection also becomes the shape of a bear, North Bear, Norma's Native American Indian identity.

Statement of Emergent Knowing: Fish Out of Water

Lost in the back streets of Aberdeen, searching for her true identity, a child stands, clinging to life, fighting for breath, transfixed by her own reflection.

Statement of Emergent Learning: Fish Out of Water

Norma demonstrates her strength through stories of survival against the odds and reflects upon what might have been and might still be ...

Statement of Reflexive Resonance: Fish Out of Water

I have on many occasions felt as though I was 'a fish out of water,' with a real sense of unhomelike-being-in-the-world, as I was brought up in Gibraltar where there were two dominant communities the locals and the military, I was therefore unable to fit in with my English 'military' friends, or my local Gibraltarian friends.

I was aware when painting this portrait that despite showing all the above, I wanted to add aesthetic resonance, not only by making the painting 'beautiful' but by making it complex, with multi-layered meanings and riddles, something I knew Norma enjoyed.

In order for a sense of surprised recognition and for the symbolism and metaphor to work for Norma, I refrained from telling her what I had planned. Norma therefore really enjoyed the sense of personal discovery when looking at the portrait for the first time, and discovering the 'bear' hidden within the portrait:

N: There he is! [indicating the 'bear' in the puddle] **S: Yes, there he is indeed, I didn't want to make him immediately obvious.** N: You haven't! That is brilliant. **S: So that's the reflection.** N: He's standing there with his hands out, like they do when they're up on their hind legs. **S: Yes, and it's strange because that fish is out of the water, and that fish is in the water isn't it because it's in the puddle.** N: *And that's where Norma found North Bear!* [...] *That's beautiful!* It's really nice, so unusual. And it is very much like the backstreets of Aberdeen.

S= Susan, (ATR) Artist/Researcher N= Norma (PR) Patient/Researcher (EPI: 26/09/2012)

Norma recognises the aesthetic, metaphoric attunement and coherence within the portrait when she says 'that is brilliant ... that's beautiful!'

The ability of this portrait to capture Norma's: past and present, inner and outer, early and whole life experiences (characterized by the search for her self-identity) within one portrait, enabled a process of re-discovery, as she says ... 'that's where Norma found North Bear!' This portrait therefore becomes for Norma a 'point of reference' within the uncertain landscape of her previous life and the ongoing uncertainty of her

illness, something that exemplifies and yet *re-visions* these experiences through *aesthetic resonance* enabling more positive memories and connections to develop, capturing the essence of Norma, or at least the essence of Norma's early way-of-being-in-the-world experience.

Within this section I have outlined a process of *aesthetic resonance*, adding meaning, complexity and coherence within the portraits, enabling PRs to recapture a sense of themselves as valuable and beautiful. Susan and Norma were able to redefine childhood experiences and reclaim their child-selves, recognising the difficulties they faced, and enjoying the layered meanings and complexity.

6.5 Summary

In this chapter I have described the PRs lived experience of portraits as visual channels of *mirroring and attunement*, and that through this process PRs become aware of previously unknown and 'untold' aspects of self-identity, sharing stories of self-identity that they had *never told anyone else before*. The portraits therefore became a unique way of being known, both to themselves and others. I have described the *intra-subjective* validation of self-identity that the portraits provided for the PRs through viewing portraits and collages that *PRs needed to see*, as well as the *intersubjective* validation provided by portraits they needed *others* to see. This is based on a view that portraits as objects can be active *participants* in the world, able to influence and change peoples' views and society. I have explained how Paul found a renewed sense of *agency* and liberation from his agoraphobic fears, enabling him to revisit for a final time a place he 'loved' and where he was *known*. Through viewing *The Two Normas* portrait Norma is able to *see the difference* between two important aspects of her self-identity and realise for the first time how they support each other.

I also described a process of *aesthetic resonance*, through adding meaning, complexity and coherence to the portraits, enabling PRs to recapture a sense of themselves as *valuable and beautiful*. Susan and Norma were able to redefine childhood experiences and reclaim their child-selves, recognising the difficulties they faced, enjoying the layered meanings and complexity added to the portraits. I have explained the ability of portraits to hold dualities such as *hope* and *despair* and how these were 'given' to me to 'hold' and 'contain' within

the portraits. In *Being Pandora* good and evil, power and helplessness are explored and Susan is left holding *hope* in the box. In *Broken Lungs* Paul explores the dualities of *inside* and *outside* realities, and literally opens up and lets us in to his inner world of pain and suffering. I explained my belief that the development of an *intersubjective symbolic capability* with the PRs was crucial to this process, enabling them to unravelling the layers of meaning within the portraits, increase self-knowledge and sense of self-identity coherence.

7.0 Chapter 7. Drawing Conclusions: Portraits as unique ways of knowing and being known.

I begin this chapter with a summary of the thesis, followed by an evaluation of the findings and the major themes identified within the analysis. I then revisit the research questions, aims and objectives, and offer descriptions of the PRs lived experience of the intervention to show how these questions have been answered and the original contributions to knowledge suggested by this. I look at the implications for future research and offer a final reflection on my experience of the project as a whole and on *portrait therapy* as a unique way of knowing the self and being known.

7.1 Summary of Thesis

In the introduction I discussed the key theories and concepts used within this project. I argued that self-identities are ‘multiple’ and ‘flexible’, and that self-identity disruption caused by LT&CIs often negatively affects the whole body/life/world of a person. This can cause feelings of ‘unhomelike-being-in-the world’ as described by Svenaeus (2011), a sudden awareness of Heidegger’s (1962) ‘being-towards-death’, and of being thrown into an unknown and uncomfortable ‘liminal’ (Turner 1969) ‘world of illness’ (Radley 2009). I described the development of ideas for self-identity revisioning through portraiture, identifying this as intrinsically relational, adapting Wright’s (2009) thesis of ‘mirroring and attunement’ and Kramer’s (1971) ‘third hand’ art therapy model. I also discussed some of the stigmatising cultural constructs that people with LT&CIs face on a daily basis, as well as the problem of *depersonalised care* within the health service (Reeve *et al.* 2011).

There is a shift of focus within this project from a reliance on biography (Bury 1982, Williams 1984, Frank 1997; Riessman 1990) as a way to ‘reconstruct’ self-identity, to one focused on the primacy of perception and the embodiment of all experience (Merleau-Ponty 2002 [1945]), demonstrating that in portraits people can be seen as whole ‘embodied’ persons, and not just ‘stories’. I described how the visual nature of painted portraits engage with our human need to present ourselves visually to others and the ability of portraits to depict ambiguity, emotion and tacit knowledge through metaphor and symbolism. I suggested that the idea of *redemption* or *repair* was not the focus of this intervention; rather the focus was on *transformation* through the

revisoning process (Carr 2014). I introduced the idea that through the portraits PRs find new ways of *seeing* and *relating* to their self-identities, which can produce new ways of *knowing*.

I also reviewed the literature pertinent to this project, focusing on the interdisciplinary boundary crossings, discussing the literature around portraiture, illness and art therapy, and how they correlate or deviate from the ideas supporting the *revisoning* of self-identities in this project. I found two studies featuring the work of portrait artist Mark Gilbert; these studies demonstrated the potential therapeutic value of portraiture and the ability of portraiture to portray 'identity formation' (Aita *et al.* 2010). Due to the paucity of research studies in the field I widened my literature search to include artists (non-research) who paint portraits of people living with LT&CIs, focussing on how portraiture can celebrate *changed* self-identity: help people find 'beauty' and self-acceptance within illness (Rosselli 2009; Grice 2009a); enable 'a graceful death' and give voice to their personal 'truths' (Antonia Rolls (2013, 2014a, 2014b). I also examined the work of artists who use photographic portraiture, or 'phototherapy' (Spence 1986; Martin 2009) to: explore and depict the self as subject/object: the impact of illness and the medicalisation of their bodies on their self-identity; and also the impact of aging (Hogan & Warren 2013), demonstrating how portraits can unlock hidden pain and feelings, and transform them into something tangible, beautiful, confrontational and meaningful.

In chapter three I described the practical and ethical issues surrounding painting portraits *for* PRs, as well as the diverse methods of data generation used within the five phases of the project. I emphasised the importance of PRs being recognised as co-researchers and experts on their self-identity, retaining autonomy over the design of the portraits and control over how they were represented within them. The development of the phenomenological analysis was achieved through the adaption of *reflexive-relational* (Finlay 2011) and *experiential* (Lett 1998) methods, into something I have called *arts-based life/world phenomenological analysis*. This adaptation enabled the data generated by this study to be used to explicate the lived experience of the PRs, incorporating both *transcendental* and *hermeneutic* phenomenological approaches.

To enable the analysis of verbal data within the EPIs I adapted the *voice centred relational analysis* methods used by Balan (2005), Gilligan *et al.* (2003), and Mauthner & Doucet (1998), which enabled PRs voices of identity to be identified and used within the discussion. Finally I outlined my rationale for a multiple-case study design and how this fits within a phenomenological study. These case-studies were then discussed with the PRs for their final adjustments and approval, ensuring that the descriptions and negotiated interpretations employed accurately reflected their lived experience of the intervention. I also described how this study correlates with Finlay's (2011) four 'Rs' of 'good' phenomenological research, i.e. rigorous, resonant, reflective and relevant.

The phenomenological approach honoured the PRs embodied lived experience and facilitated hearing their voices. One of the strengths of the phenomenological approach was the direct use of PRs own words within the analysis and the finding of overlapping and congruent themes within the PRs EPI accounts, and in the case-studies the themes discovered were underpinned by the PRs own verbatim abstract from the EPIs. The EPIs were designed to be flexible, giving PRs ample opportunity to give full answers and to ask their own questions. In the next section I will discuss the findings from the three analysis chapters.

7.2 Findings

Art, it is said, is not a mirror, but a hammer: it does not reflect, it shapes.
(Trotsky [1924] 2005: 120)

Trotsky's quote (above) describes succinctly one of the central findings of this research project. When I began the project it was with the belief that portraiture had the potential to act as an attuning 'mirror' for the PRs to see themselves in more clearly, a way to *re-vision* and *remember* their sense of self-identity. However, the findings suggest that portraiture is more effective than simply *reflecting* self-identities implies, there is *power* in portraiture, and it does *shape* people. The ability of portraiture to transform paint and canvas into a powerful and meaningful representation of a person is arguably the emotive power that enabled PRs to *re-shape* their disrupted self-identities.

The initial elicitation phase of the project was a process of unravelling and revealing the many layers of self-identity evident within the PRs stories. These stories were generally episodic and fragmented, they did not necessarily begin their life story at the 'beginning' and end at the 'present', they sprang out of the button & Lego tasks and photographs of events which were turning points in their lives. One of the most important aspects of this process, was to find and recognise these turning points, and these were depicted within the portraits as moments of *becoming* (e.g. as in Rose's *The Poppy Field* portrait (Figure 62, p177) and Norma's *Fish Out of Water* portrait (Figure 94, p227). This helped PRs to *re-member* their creative child-selves and the adaptive strengths they possessed.

In the following sections I will consider the significance of the findings as clustered under the three master themes found in the analysis.

7.2.1 Themes from the analysis

Within the analysis three master themes emerged, under which further subordinate themes were clustered. These were identified in the Matrix of Themes table (see Figure 27 p117) and are outlined below.

7.2.2 Master Theme 1: Increasing the PRs lived experience of their *creative capacity to adapt to illness*.

Within the analysis I found evidence to support the view that *portrait therapy* (Carr 2014) increases a person's *creative capacity* (Reeve et al. 2010), which enables them to *adapt to illness*. I see this as a process of *empowerment* and *growth*, offering the potential for ongoing adjustment to self-identity as the PRs LT&CI progresses. This finding correlates with Aita *et al.*'s (2010: 10) study, suggesting that an ongoing process of adaption was conveyed within the portraits from their project.

I described how Hilary found an increased capacity for *imaginative thinking*, finding relief and comfort in a portrait she designed showing herself, finally and eternally *Held by an Angel*. I identified *humour* as an *adaptive* process facilitated and developed within this project, helping PRs to manage their experience of 'liminality' (Turner 1995; Sibbett 2005:

12-37) and ‘unhomelike-being-in-the-world’ (Svenaeus 2011). Humour also enabled PRs to ask the metaphorical question ‘*do you get it?*’ and therefore ‘*do you get me?*’, highlighting the importance of humour as a function of *being known*. Hilary and Peter demonstrated the value of the portraits by asking for copies of their portraits to ‘keep with them at all times’. Norma used the project to ‘find’ and grieve for her abandoned baby-self, as well as her own lost babies, bringing her past into the present to be engaged with in the ritualised practices of the Native American Indian smudging ceremony.

Mourning losses was a key adaptive process facilitated by this intervention, and PRs used the portraits as *externalising objects*, capable of *containing* and *holding* hidden pain and suffering, enabling both *emotional connection* and *distancing* to take place, and new meanings to be developed. Through engagement in creative and adaptive *rituals*, Norma and Peter described how the portraits enabled experiences of *closure* regarding important bereavements and losses within their lives. This project also increased the PRs feelings of control and autonomy, and the rediscovery of adaptive strategies used in their pre-illness lives, resulting in increased adaption through self-care and agency.

The data derived from descriptions of the PRs lived experience of this intervention and negotiated interpretation of meanings, seems to indicate that *portrait therapy* enabled the PRs to increase their creative capacity to adapt to illness, and as such begins to answer the call by Reeve *et al.* (2010) for the development of such interventions.

7.2.3 Master Theme 2: Portraits Making Meaning: increasing the lived experience of *homelike-being-in-the-world* and *ontological security*.

A sense of ‘home-like-being-in-the-world’ (Svenaeus 2011) is often lost when people are plunged into ‘liminal space’ (Turner 1995; Sibbett 2005: 12-37) or the ‘world of illness’ (Radley 2009) following the diagnosis of a LT&CI. The visual and verbal data has shown that the PRs used the portraits and portrait-sculptures in ritualistic and sacralizing ways, enabling feelings of *ontological security* and *homelike-being-in-the-world*, characterised by a sense of belonging. All the PRs to some extent utilized this project to connect to something or someone they felt a sense of *belonging* to and as

such the portraits acted as bridges to significant others and ways to connect to humanity as a whole. Paul found a sense of homelike-being-in-the-world in his *At Home* portrait (see Figure 75, p199), which also enabled him to develop an increase in agency and self-care (Carr 2014). All the PRs said they gained an increased sense of a *worthwhile* and *valuable self/life*, with their portraits becoming a focus and channel for 'love', enabling PRs and myself to express 'love' for the portraits without this being misconstrued.

This process of *re-membering* and *belonging* engendered feelings of *continuity* within the PRs, linking and integrating aspects of their *past, present* and *future* self-identities. Susan found a sense of connection with her deceased mother in *The Paper Dress* portrait-sculpture and a sense of continuity of being within her four portraits. Despite the gap of nearly 70 years, Bill's WWII experiences depicted within the portraits, collages and prose poems, revealed *everything he needed to tell me* about his self-identity and how it had been *formed, broken* and *reformed*. Rose celebrated her sense of belonging and connection to Freddie Mercury in her portrait *Bohemian Rhapsody*, someone she recognises as a fellow inhabitant of *liminal* space.

The evidence suggests that *portrait therapy* enabled the PRs to develop their personal search for spiritual meaning through a process of 'making special' (Dissanayake 1988) and this correlates with Aita *et al.*'s (2010) study where exhibition viewers noted that the portraits portrayed evidence of a search for meaning. The PRs also expressed an experience of portraits as *legacy* and as an important part of their *future* self-identity, thereby equating to a sense of *immortalisation* or *cheating death*. The portraits capture *time* within the layers of paint applied and this, combined with the ATRs *positive focused attention*, resulted in feelings of *being-held-in-mind* and the formation of *positive memories*.

The evidence found within the PRs lived experience therefore supports the view that *portrait therapy* enables an increase in: meaning making, ontological security, and the lived experience of *homelike-being-in-the-world*, all of which may contribute to a stronger, more coherent sense of self-identity.

7.2.4 Master Theme 3: Mirroring and Attunement through Portraiture: Intersubjective and Symbolic ways of *knowing, being and relating.*

The data provided by the analysis suggests that portraits created by ‘third hand’ methods are effective visual channels for *mirroring and attunement*. Through this process PRs became aware of previously *unknown* and *untold* aspects of self-identity, sharing stories of self-identity they had *never told anyone else before*, which correlates with findings from the Saving Faces project carried out by Mark Gilbert (Farrand 2000).

The evidence suggests that the portraits enabled mirroring and attunement that was both an *intra*-subjective validation of self-identity for the PRs through viewing portraits and collages that *they needed to see themselves*, as well as an *inter*-subjective validation provided by portraits they needed *others* to see. This is based on the view that portraits as subject-objects can be seen as active *participants* in the world, able to bear witness to the PRs physical presence and subjectivity, and as such able to influence and change the views of people and society. I have explained how Paul found a renewed sense of *agency* and liberation from his fear of leaving the house, enabling him to revisit, for a final time, a place which he ‘loved’ and where he was *known*. Through viewing *The Two Normas* portrait Norma was able to *see the difference* between two important aspects of her self-identity and realise for the first time how they support each other.

Mirroring and attunement included a process of *aesthetic resonance*, which equated to my intuitive additions of ‘beauty’, symbolic meaning and complexity, resulting in an overall sense of *coherence* within the portraits. This process enabled PRs to recapture a sense of their own significance and themselves as *valuable* and *worthwhile*. Susan and Norma were able to redefine childhood experiences and reclaim their child-selves, enjoying the layered meanings and complexity added to the portraits. The development of an *intersubjective symbolic capability* with the PRs was crucial to this process, enabling PRs to unravel layers of meaning within the portraits. The portraits mirrored the PRs as ‘whole people’, which correlates with Aita *et al.*’s findings (2010: 5), and the recognition of the embodiment of all experience.

The analysis demonstrated that portraits have the ability to ‘hold’ and ‘contain’ dualities such as *hope* and *despair*, mitigating feelings of *cognitive dissonance* (Festinger 1962). In *Being Pandora* (see Figure 91, p219) good and evil, power and helplessness are explored and Susan is left holding *hope* within the ‘box’. In *Broken Lungs* Paul explores the dualities of *inside* and *outside* realities, and literally ‘opens up’ and ‘lets us in’ to his inner world of pain and suffering. Aita *et al.*’s study noted that exhibition attendees recognised the presence of ‘hope’ and yet also the centrality of ‘mortality’ within the portraits (2010: 5), suggesting a correlation with the findings of this project regarding the holding of dualities.

Mirroring and attunement through portraiture allows a different way of seeing and *knowing* a person, through the sustained positive focussed attention and empathic listening required to accurately re-present the PRs vision of themselves. I suggest that opportunities for this kind of *empathic listening* have diminished in a health service stretched beyond capacity, with low staffing levels in the National Health Service impacting negatively on patient care (Kalisch *et al.* 2011). The fundamental requirement for *holistic* care is one that third hand art therapy interventions such as *portrait therapy* may provide.

Although this study did not specifically aim to find generalisations within the PRs accounts with the particular focus being on individual self-identity, common themes were identified. I do however acknowledge that a different art therapist undertaking *portrait therapy* with the same group of PRs may have produced different, but no less valid results, due to the personalised ‘attuning’ aspect of this particular intervention. I will now consider how the data from the analysis answers the research questions.

7.3 Answering the research questions

In chapter one I outlined how patients living with LT&CIs often describe a disruption to their sense of self-identity, saying things like ‘I don’t know who I am anymore’ and ‘I’m not the same person I was before I was ill’, suggesting the need for the development of an intervention focused on self-identity reconstruction and revisioning. A literature review highlighted calls for research in this area (Reeve *et al.* 2010; Hubbard *et al.* 2010; Wood *et al.* 2011; Waller & Sibbett 2005). These

factors, combined with the idea of using portraiture as a ‘third hand’ art therapy intervention, gave rise to the primary research question:

What role does portraiture play in enabling people living with life threatening and chronic illnesses (LT&CIs), who experience illness as a disruption to their self-identity, to develop a stronger more coherent sense of self-identity and increase their quality of life?

This question was then broken down into further subordinate questions, I have sought to answer these questions through the description of the PRs lived experiences of this intervention, the analysis of the portraits and verbatim extracts from the EPIs within the case-studies. The involvement of the PRs in the negotiation of meanings and interpretations within the case-studies was a central feature of this process.

7.3.1 What are the PRs lived experiences of *portraiture* as a ‘third hand’ art therapy intervention?

The evidence provided by this study has demonstrated the effectiveness of *portrait therapy* with this group of patients as a ‘third hand’ art therapy intervention within a palliative care setting. This shift in focus brings the art therapist’s *artistic practice* back into the profession of *art* therapy and I suggest enables a more fulfilling role, one where art therapists harness the power of creativity, not only within their clients, but also within themselves (Rogers 2002). This also serves as a way to mitigate embodied countertransference and in effect equates to *taking our own medicine*. This approach also enables an *inclusive* and *flexible* way of working, where patients who are unwilling or unable to create their own artwork can be included, giving a sense of control and hope back to people who’s lives have become characterized by feelings of helplessness and hopelessness. *Portrait therapy* also offers ‘the opportunity to reintroduce the creative, imaginative process of co-designing and viewing self-referential images into what would otherwise be *artistically barren* art therapy encounters’ (Carr 2014: 54).

By stepping out of the shadows and painting portraits of patients, the art therapist’s artistic identity becomes visible and we have to own our part in *creating experience* and *creating meaning with* our clients. Therapeutic relationships are different in third

hand collaborative encounters and require the development of *I-thou relationships* (Buber 2004 [1937]), which means relinquishing our status as ‘expert’. Kramer claims that third hand interventions are ‘gifts to the client, with no strings attached’ (2006: 25), highlighting our need to remember that we are there to channel the PRs ideas through the artwork created, rather than our own.

As an intervention for vulnerable people there are important reasons why *portrait therapy* should be an *art therapy* intervention carried out by a trained art therapist (with skills in portraiture and ‘third hand’ interventions) rather than a portrait artist. As this study, the Saving Faces (Farrand 2000) project and Portraits of Care study (Aita *et al.* 2010) have shown, there seems to be an interesting *portrait effect* in that having a portrait painted often enables people to open up to the artist and tell them stories of self-identity they had *told no one else before*. It is important therefore, when working with vulnerable people, to know how to witness, contain and perhaps transform this knowledge. Secondly, as Kramer pointed out, third hand techniques require the therapist to suppress their own ‘pictorial ideas or preferences’ (Kramer 1986: 71), which it seems Gilbert (in the aforementioned studies) did not do. Instead Gilbert utilised his own artistic style for all participants, which begs the question as to whether the participant was *there for the artist to paint*, rather than the artist being there to *paint for the participant*? Perhaps Aita *et al.*’s (2010) reticence in calling the process ‘therapeutic’ reflects this different positioning. As well as working on a creative level, art therapists are trained to understand the ‘interpersonal dynamics’ (Wood 2005: 84) that exist between the art therapist and patient, the need to develop a therapeutic relationship with secure boundaries, and are required to undergo regular clinical supervision to ensure their own and the patients’ safety. Artists may not have access to this kind of learning or support, and may not understand the ethical issues regarding confidentiality and its limits.

If as art therapists we are to produce our *own kind of evidence* (Gilroy 1996: 55), we ourselves need to be involved in the finding of it and the explaining of it, and third hand interventions offer just such an opportunity. Pink (2009) suggests that researchers should engage in the activities and environments that they wish to learn about – and to do this we need *insider knowledge*. This will not be gained simply by

observing the behaviour of others, but by stepping out of the shadows and making border crossings into unknown landscapes (McNiff 1992). This involves *giving time* and working collaboratively with our clients, *to enable them to tell us what they need, what works and why*.

Importantly the findings from this study support the claim made by Kramer (1971: 40) that creating portraits of clients has the ability to ‘reassure them and strengthen their feelings of identity’ (ibid.). It also corroborates the claims made by Moon (2002: 214), that creating portraits of clients is one of the most direct ways that art therapists can ‘witness’ their clients, to promote feelings of being acknowledged rather than judged, and to ‘take time to notice and at some level, to care’ (Moon 2002: 215).

7.3.2 What role does *mirroring and attunement*, reflected within the portraits play in the process of *revisioning self-identities*?

The evidence within the analysis indicates the efficacy of *portrait therapy* as a mirroring and attuning device, enabling PRs to see images of themselves that *they* needed to see and also that they needed *others* to see. Mirroring and attunement included processes of *empathic listening*, *aesthetic resonance* and the *holding of dualities*, such as hope and despair. The presence of the (m)other, e.g. the ATR, is essential to this process, offering the vital ‘relational’ aspect of mirroring and attunement *through* the portraits.

Throughout this thesis I have suggested that the portraits enable embodied intersubjective ways of *knowing*, *being* and *relating* to the self and others, and mirroring and attunement has been an important part of this process, a way to reflect back to PRs attuned aspects of their self-identity. This involved selecting PRs self-identity stories that resonated with me, and adding my own aesthetic attunement, enabling the PRs to gain new insights and new ways of *knowing* the self. This process was also collaborative, with the PRs adding their own mirroring and attunement to the portraits through their intuitive co-designing of *that which they needed to see*, underlining the need to rebuild their relationships with themselves.

Mirroring and attunement through the portraits enabled a sense of *being known* which is I suggest unique to portraiture and encapsulates the ‘work’ that the portraits do and are still able to do after a person dies. As Rose says in her EPI (22-03-2011), the portraits testify to each person being a *somebody*... rather than a ‘nobody’, reflecting how Rose ‘found’ her ‘self’ and her own sense of meaning again.

There is no escaping the fact that *healthcare* (and increasingly *palliative care*) is being increasingly *standardised* and risks being turned into a business, losing the individualised ‘care’ which should be an intrinsic requirement (Rastegar 2004) and was the founding ethos of the hospice movement (Saunders 1975). As Kinsella (2006: 25) points out, there needs to be a recognition of the *harm* that can be done by healthcare professionals who do not recognise their own power to ‘affirm or demean’ the self-identities of patients within the medical or clinical encounter. Voices of people living with LT&CIs are rarely heard and through the medicalisation process they often become invisible and inaudible to others and also themselves. Human beings are relational creatures who need others to mirror and attune their sense of self-identity, this takes time and requires the *positive focused attention* implicated within mirroring and attunement.

7.3.3 What role do portraits play in enabling meaning making and the exploration of existential questions around ‘being-towards-death’?

The question of meaning in one’s life can be linked to how ‘worthwhile’ or ‘substantial’ it has been as opposed to ‘empty and trivial’ (Taylor 1989: 42). However the data generated by this study indicates that the fear of loss of meaning is also linked to: a fear of anonymity, of no longer ‘being known,’ a fear of lost relationships and existential loneliness. It is therefore the *meaning* in relationships, the *meaning* in presence which characterizes a sense of ontological security or homelikeness when faced with *being-towards-death*.

I had thought that PRs would use the project to explore their own deaths and wondered if I may have colluded in the *denial* of death (Hardy 2005: 190) within the portraits when only a few of the PRs explored their own death explicitly. Paul in Broken Lungs (see Figure 82, p209) and Hilary in *Held by an Angel* (see Figure 30,

p123) were perhaps the only PRs to explore their impending death overtly, although even these were ambiguous in meaning. The paradox of death is that we cannot know our own death, it is only through the death of others that we learn about it (Heidegger 1962), and this is how it manifests in the portraits, with the death of others explored in many of the portraits (and consequently the relational identities lost through bereavement). As such, mourning, loss and facing existential uncertainty was an invisible thread that ran through all the portraits, adding a tangible recognition of the finiteness of human existence and a search for meaning that lends life an authenticity. The act of portrayal and the illusion of life within portraiture at once proclaim a person's existence, whilst also recognising its potential as a legacy, highlighting the body's frailty and the inescapable reality of human mortality. Therefore portraits allow the 'assembling' of oneself 'in the consciousness of a disassembling life' (Pointon 2013: 229-31).

This project gave rise to a recognition of unresolved grief and loss, underlining the need for bereavement and grief work for patients, including rituals and relational work. The revisioning process enabled the explication of and grieving for, losses of self-identity and the attachment of aesthetic resonance with the potential to transform those losses through meaning making. The data from this project suggests that mourning the loss of others through portraiture is a unique way to learn about *being-towards-death*, about how to come to terms with one's own death as part of the human condition (Kubler Ross 1975), and ultimately how to be remembered, or remember the self.

7.3.4 What are the PRs experiences of the collaborative nature of this project?

This study brings into focus the necessity of a collaborative therapeutic and research process as evidenced by recent experience-based co-design (EBCD) practices (e.g. Springham & Woods 2014). The co-designing and interpretation of the portraits within this project offers an intersubjective and collaborative way of working, and directing the art therapist helps clients retain their own 'expert' status within third hand interventions, going some way towards equalising the power structures in art therapy. As Kapitan (2010a: 2) says 'reflexive examination of the power structures in research will yield greater complexity and richness in how art therapy knowledge is

constructed and difference is theorized.’ It also seems that by directing the art therapists ‘third hand’ PRs are able to find their own ways of healing, using the portraits as a way to highlight that which needed attention in their lives, to open the psychological ‘wounds’, to clean them out, and find ‘closure’. I also believe that working with patients to design the protocol for this study resulted in an intervention aimed at specifically identified needs, i.e. self-identity disruption. This was underlined by the zero drop out rate within the study and the enthusiasm with which it was undertaken by the PRs.

This project offers further evidence of the importance of using a collaborative approach to art therapy research design, application and evaluation. It is also a *non-pathologising, non-stigmatising* approach, liberating the patient from a focus on illness to a focus on their subjective experience of self-identity.

When asked how she found the collaborative design process PR Susan said:

That was probably the most important part of it. [...] I think it is good, because [...] you have ideas triggered by things I said. I like the way it develops, it’s more kind of organic development [...], because everything else to do with the illness is rigid, “*you* take this medicine” or “*you* have this treatment”. It’s very prescriptive, whereas something grows out of this in a much better way. I feel really comfortable about saying what I like or what I feel could be different (EPI 18-10-2012).

When I asked Hilary how she found the collaborative design process she was able to acknowledge that although she found it ‘difficult’, by working together the ideas began to flow and the portraits ‘evolved’, she said:

That was probably more difficult because my mind goes blank when I am asked anything like that. But with your encouragement I was able to pick things out and then after a while ... ‘ooh yes I have got something else ... yes ... I will just go and get that for you!’ So it just sort of evolved didn’t it (EPI 20-02-2012).

A strength of the collaborative methods and the small sample size used within this

study was also the ability to effect an in-depth study of the PRs lived experience and the negotiating of meanings and interpretations with the PRs. Together the PRs and I created a ‘third space’ within the portraits, one in which *relational meaning* was developed, something necessary for self-identity construction and revisioning.

7.4 Original Contributions to Clinical Theory Development

My aims in relation to theory building within art therapy and palliative care, relate specifically to the development of *portrait therapy*, extending and combining the art therapy models of ‘mirroring and attunement’ (Wright 2009), the art therapist’s ‘third hand’ (Kramer 1971), and Carel’s philosophical theories on ‘health within illness’ (Carel 2009). In this project I extend the boundaries of Wright’s theory to include portraits painted for others, as a way to enable PRs to achieve a stronger, more coherent sense of self-identity. The evidence from this study suggests that the portrait does become for the PR a surrogate for the ‘good enough’ (m)other, which holds, resonates, reflects and validates their sense of self-identity through suffusing the portraits with the PRs inner feeling states or significant forms. These can then be looked at, recognised, adjusted and assimilated by the PR. I have called this the ‘revisioning process’ of *portrait therapy*.

The importance of Edith Kramer’s ‘third hand’ theory was that it gave me as the ATR ‘permission’ to develop an intervention that focussed on the ‘art object’ as the healing form rather than the art making ‘process’. This allowed the mirroring and attunement to take place, through reflecting back to the PRs significant resonant forms within the portraits, therefore the ‘process’ of art making was used in a different way. (I have outlined the benefits of creating the portraits *for* the patients within thesis sections 4.3.3:p126; 5.4:p178; 6.2:p205). This reversal enabled the analysis to be focussed almost entirely on the healing qualities of the art objects, i.e. the significant resonant forms within the portraits. Ultimately Kramer believed the aim of art therapy was to create aesthetically coherent ‘formed expressions’, and the evidence suggests that this was enabled through Portrait Therapy, despite the lack of PR engagement in the physical art making process.

This project builds on Carel's (2008) thesis and adds to knowledge in the field of medical humanities, in that it offers further evidence to support the idea that people living with LT&CIs experience illness primarily as a disruption to the lived body, but also as a disruption to their sense of self-identity. Further research into self-identity disruption as part of the lived experience of illness would add to knowledge in this field.

This study necessitated questioning the taken-for-granted normalised assumptions within art therapy regarding:

- Who makes the artwork in art therapy?
- The universal requirement for confidentiality irrespective of context?
- The *dys*-engagement with aesthetics as a healing force?

I will explore these questions and the implications suggested by this project in the following sections.

7.4.1 Who makes the artwork in Art Therapy?

As outlined in chapter one the expectation common to most art therapy models that patients will create the artwork within art therapy and talk about this within the sessions has its 'limitations' (Maclagan 2011: 8), particularly in palliative care where patients are often too unwell, fatigued, disabled, or for any other reason unwilling or unable to make art. This means that many patients who might benefit from art therapy self-exclude, and for those who attend and make no art, the session becomes reliant on 'talking therapy', which while beneficial in its own way is not the point of *art* therapy and does not harness the power of creative processes to transform meanings and experience.

The data from this project suggests that in palliative care, the making of art by an art therapist *for* patients, including portraits, collages and prose poems, is a useful and healing way of working. However when art therapists make images *for* patients/clients, they make themselves vulnerable and risk making mistakes. In a sense they also enter a borderland 'liminal' space filled with creative potential, engaging with patients through collaboratively creating meaning and aesthetic resonance. I suggest that *portrait therapy* benefits from being a *third hand* encounter

and that this is part of its efficacy. Self-portraits created by patients would have excluded the important aspects of *mirroring and attunement, empathic focussed attention, aesthetic resonance* and *being held in mind*, and was quickly ruled out by the patient focus group when designing the study.

7.4.2 The universal requirement for confidentiality irrespective of context.

This project has shown that in certain circumstances, particularly when validating self-identity, confidentiality may be inappropriate or even counter productive. All the PRs in this study indicated that they wanted their portraits to be shown in publications and exhibitions and yet art therapists are often reticent about asking patients permission to display their artwork.

Anonymising the portraits would have defeated the object of the intervention and yet in the National Health Service Confidentiality Policy (April 2013) it states in point 4.1.3 that ‘Person-identifiable information, wherever possible, must be anonymised by removing as many identifiers as possible whilst not unduly compromising the utility of the data’. To anonymise a portrait would have meant blanking out PRs faces meaning they could never bear witness to the presence or self-identity of the patients. Whilst PRs all signed consent forms for these images to be shown, many clients never get the option for their work to be shown, or used within research.

Whilst confidentiality has been put in place for good reasons to safeguard and protect patients’ privacy, its blanket use seems to suggest that patients are *unable to make their own decisions* around confidentiality. This assumption seems to infringe the Mental Capacity Act (2005), which states in section 1.3 that ‘A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’ and in section 1.2 that ‘A person must be assumed to have capacity unless it is established that he lacks capacity’. My contention is that decision are often made by art therapists *for* patients, without recognising the patients’ rights to choose for themselves.

It is important to remember that a blanket confidentiality policy also serves to keep those who are ill separate and hidden and to silence their voices. Radley (2009)

suggests that the ‘acceptability’ of representations of illness, are often ‘[...] a useful measure of where matters concerning illness (and the sick as a group) stand in the scale of public concern’ (ibid: 17). Ultimately it seems just as important to be aware of a patient’s right to be seen and heard, to reciprocate, and most importantly to support them in their right to decide for themselves.

7.4.3 The *dys*-engagement with aesthetics as a healing force?

Whilst I do not argue against a focus on pain and suffering within the many approaches to art therapy, the results from this study correlate with McNiff’s (2004: 60) suggestion that ignoring the power of aesthetics to transform ugliness and pain, may impose limits on the potential of art created within art therapy to heal in diverse ways. I therefore agree with Knill’s (1995) proposal for an ‘aesthetic response’ within art therapy and the integration of the cathartic with the aesthetic, something which is evident within the *aesthetic resonance* added to the portraits and equates to holding dualities such as ‘beauty’ and ‘suffering’ within the one image.

The attachment of empathically attuned *aesthetic resonance* to PRs images of self-identity is a key element of this project, and a powerful healing force. As Wilkinson & Gioia (2013: 8) say ‘Capitalizing on such “signature strengths” as creativity, playfulness, appreciation of beauty, and other elements of positive art therapy might inspire transformation of our practices and communities, not only to cope with stressors but also to attend to, appreciate, and attain the best in life’.

7.5 Original contributions to knowledge

In chapter one I identified three main original contributions to knowledge within this project. These contributions have been covered during the proceeding points, however I offer some further points here:

- This project offers evidence to support the efficacy of *portrait therapy* as a ‘third hand’ art therapy intervention, aimed at strengthening self-identity and developing a lived experience of self-identity coherence in those living with LT&CIs.

Identifying self-identity coherence as an important component of ‘health within illness’ (Carel 2008) could have far reaching implications for the way people are treated at end of life especially within the National Health Service, with the importance of ‘being known’ a fundamental characteristic. As Norma said in her EPI, it is imperative to remember that patients are also people ...

that they’re human, that they’re not just a number, or a name. There is actually someone inside that person ... because if you don’t know what people are and what they’ve done, *you know nothing about them* (Norma EPI 26-09-2012).

- The contribution to knowledge provided by this study within the field of palliative care is the description of a new intervention and protocol, designed to improve the quality of life of people who experience LT&CIs as a disruption to their self-identity.
- This project also offers further evidence to support the use of a phenomenological approach to research and analysis within illness and art therapy research, and the detailed description of the protocol for the *reflexive-relational life/world phenomenological analysis*.

These contributions to knowledge suggest that as a meaning-making practice within palliative care, *portrait therapy* has a lot to offer in its ability to support individual eclectic spiritual beliefs, as well as enabling an amelioration of existential anxiety and meaninglessness. Through creating portraits and portrait-sculptures, and bringing them into being in the present, patients can use these in a ritualized way to develop meaning and a lived experience of healing can occur.

This project contributes to the Dying Matters Coalition’s aim to make ‘living and dying well’ possible for more people. This involves changing attitudes within society to one in which death, dying and bereavement are seen and accepted as natural aspects of human life. This change could potentially have a positive impact on the range of support services offered to patients and their carers, and would mean that many more people are able to achieve a more peaceful, dignified and meaningful end of life.

This project also offers a contribution to research about painted portraiture as a depiction of self-identity and healing, detailing how people facing the end of their lives and the deterioration of the body wish to be portrayed, as well as to further understanding about the complex relationship between a portrait artist and their sitters. This project suggests that mourning the loss of others through portraiture is a unique way of learning about being-towards-death, underlining the need for bereavement and grief work for patients facing death.

7.6 A Final Reflection on Portrait Therapy: *Knowing the self through being known*

The findings from this study suggest that *portrait therapy* is an embodied way of knowing the self and of paying *focused empathic attention*, offering a unique way of accounting for the body and the physical presence of a person. Instead of ‘losing’ anything through the adoption of ‘third hand’ art therapy techniques, empathic attunement and aesthetic resonance is gained. The body becomes newly visible in a way that is not possible in narrative, acknowledging its importance as humanity’s only way of experiencing the world and being experienced. The portraits reflect, through the eyes and hands of the ATR messages of: companioning, witness, presence and the holding in mind of the person portrayed.

From the evidence generated by this study I contend that the feeling of *knowing the self* is intrinsically linked to *being known*, therefore PRs have a need to *be known* in order to *know themselves*. This relational view of self-knowledge highlights the requirement to ‘understand identity not as a fixed, natural state of being, but as a process of *becoming*’ (Kinnvall 2004: 747-8 [my emphasis]) and the portraits I suggest act like *bridges* or conduits, where *knowing* is offered *through being known* both by the ATR and by others through the viewing of the portraits. This may indicate that the negative impact of isolation and loneliness upon the body and the immune system (Jaremka *et al.* 2012) is linked to being *unknown* by others, but also the self.

The evidence suggests that there is a fundamental need or urgency to know the self or *be known* when one is faced with impending death and that the portraits enable this by *being the bridges between* and therefore providing the *difference* between:

Seeing and *being seen*
Recognising and *being recognised*
Knowing and *being known*

As bridges, linking these opposing concepts, portraits become *a unique way of knowing the self*, therefore the above equation can be developed into:

Seeing *through* being seen
Recognising *through* being recognised and
Knowing *through* being known

As Carel (2004: 230) says: ‘meaning is not generated by the speaker, rather it is located intersubjectively, somewhere between the reception of the listener and the intention of the speaker. If there is no one to receive my speech I become mute. I cannot speak or make sense at all, not even to myself’. Radley (2009: 90) believed that the act of making testimony was the key to healing, saying:

For people who have undergone extreme suffering, testifying in this way – by means of speech, text or paint – is not a distillation of knowledge but knowing oneself again only through making testimony (Radley 2009: 90).

However this study suggests that it is knowing the self *through being known*, which is key. This is subtly different in that it requires a *reflected* testimony, an *attuned knowing* by a ‘third person’, that of the ‘(m)other’ or ATR. This has important implications for healthcare professionals who do not ‘know’ their patients – for the widespread prescription of antidepressants for patients at end of life (Grau 2006) who experience LT&CIs as a disruption to their self-identity. This project has highlighted the need for those living with LT&CIs to express who they are/were within an empathic relationship, and particularly older adults who may expressed a *different* self-identity to the one they are currently ‘living’. Being known for ‘who’ they are, not ‘what’ society perceives them to be, with all the stigma and judgement implied in that. The findings seem to suggest that being plunged into the liminal space of LT&CIs ‘requires’ a creative solution, or a creative, collaborative and flexible kind of

knowing to ameliorate *suffering*, something that is ‘central to the experience of illness’ (Kleinman 1988: 30).

Portraits as empathic attunement therefore have the power to ‘call us into relationship’ (Gablik 1991: 114) and to establish feelings of connection and understanding between others and ourselves. All of which adds support to the concept of portraiture as a therapeutic intervention, enabling self-identity coherence and increased quality of life, within which PRs were able to resolve their own unique pain, something which required a unique way of *being known*.

7.7 Limitations to the study and implications for future research and art therapy training.

7.7.1 Limitations to the study

The participant sample

The participants in this study were all white British citizens, which reflected the demographic of the day hospice, however this lack of ethnic diversity does limit the findings and it would have been helpful to include people from other ethnic backgrounds had that been possible. The PRs were however from different social and economic backgrounds, offering more of a diversity of lived experience. There are perceived restrictions to working with some ethnic groups, particularly people of the Muslim faith, who may not wish to have their image captured within a portrait, however I think that the co-designing of the portraits would enable this issue to be overcome through producing non-figurative ‘portraits’ or portrait ‘objects’ such as Susan’s ‘Cupboard of Imagination and Dreams’ (Figure 90 p217). Further research of portrait therapy with people from other ethnic backgrounds would therefore build on the results from this study.

Methods & Analysis

A possible limitation to the method of painted portraiture employed within this study is the need for the art therapist to be a competent portrait artist. However, it is a requirement for art therapy training that prospective art therapists either have an art degree or can prove (through a portfolio) that they are practicing artists. Most art degrees have life drawing components, therefore this limitation may not be a problem,

or may indicate a need to develop a specialist module on portraiture within art therapy training. It may also be possible to create portraits which do not require competent portraiture skills, such as the creation of portrait sculptures or the use of stylised portraits such as those of David Edwards (see chapter 2. Fig.6). However I would suggest that through doing the project and painting many portraits art therapists would *become* proficient portrait artists.

Another limitation may be the amount of time required to paint the portraits and make the collages and prose poems away from the clients. This however need not be onerous, as it was possible to produce some of the portraits within an hour, however I do think that time needs to be taken and the amount of time given to producing the portraits is not lost on the PRs and becomes part of the time + attention = memories equation. I do however feel that the time spent working on portraits away from the clients is not just of benefit to the client, but also of benefit to the art therapist, both by mitigating against embodied counter-transference, and reducing stress through developing the art therapists artistic practice. This finding would benefit from further study, as it may have mental and physical health implications for practicing art therapists who *do not* continue to create art after qualifying.

A limitation to the study is the possibility of ATR bias as the data generated from the semi-structured EPIs was inevitably co-constructed intersubjectively (Mishler 1986) between the PRs and the ATR, which may question the validity of the PRs answers. However, the questions were only a starting point in the discussion and PRs were invited to elaborate on their answers enabling them to identify specific examples that answered the question. The EPIs were all audio-recorded and transcribed verbatim. PRs were given the opportunity to read and adjust the transcripts and the ATRs questions and responses were not deleted from the transcripts enabling *transparency* (Hiles 2008). Also the EPIs were only part of the multiple and rigorous methods used for data collection and analysis, therefore *triangulation* of findings was possible (Roulston 2010: 205).

7.7.2 Implications for Future Research

In the EPIs I asked PRs if they thought that the intervention would help other people living with similar illnesses. All the PRs expressed the view that it would be helpful,

with some adding that it may also help people with other issues such as depression. Additional research evaluating the effectiveness of *portrait therapy* with people who experience *trauma* as a disruption to their self-identity (e.g. combat stress or posttraumatic stress syndrome), would build upon the results from this and Aita *et al.*'s study, adding to knowledge in this area. As would the research of *portrait therapy* as a third hand art therapy intervention for children, teenagers and people from other ethnic groups facing LT&CIs.

The findings within this study correlate with Aita *et al.*'s, where they reiterate 'the importance of recognising the identity of the person even when both the patient and those around (him) are overshadowed by the medical condition' (2010: 10). This has important implications for the training of health-care professionals in ways that affirm and support the fragile self-identities of their patients, something I believe is central to *holistic* care and the empowerment of the individual.

Recognising the shortcomings of our culture and our health service, is an important function of culturally aware art therapists, and if we do not question or critique cultural constructs, then we collude with that culture (Moon 2014), with the stigmatisation of illness and the denial of death, and fail to recognise the needs of individuals facing LT&CIs.

This study has highlighted the need for increased awareness by healthcare professionals regarding the power they possess through their actions, words or interventions, to either validate or demean the self-identities of their patients/clients. Also this project suggests that recognising and reaffirming positive past, present and future self-identities, particularly for older adults, should be considered a vital aspect of their psychological and emotional support. This challenges the widespread prescription of antidepressants for people who are living with identities disrupted by illness or who are essentially lonely or *unknown* (Hansen *et al.* 2007).

The portraits within this project are socially responsive artworks (Hocoy 2007) in that they highlight a need and point out the current lack of time and opportunity, for self-identity validation and mirroring and attunement within relationships between health

care providers and patients. I suggest that ‘third hand’ interventions such as *portrait therapy* have the potential to offer real benefits to patients, at a time when they feel the medical profession has ‘given up on them’, an intervention with the potential to offer amelioration of suffering and increased quality of life.

7.7.3 Implications for Art Therapy Training

This project has implications for the training of art therapy students, and I suggest theoretical and experiential training for first year students could include ‘third hand’ and ‘mirroring and attuning’ techniques e.g. creating collage and prose poems as ‘response art’ initially for other students and subsequently for their clients within palliative care placement settings. Students could also practice the button and Lego emotional distancing techniques with other students in experiential training sessions, before using them with their clients at their placements. This project also highlights the importance of art therapy students’ creative art practice with a particular emphasis on continued professional development in the area of portraiture. Life drawing/portrait sessions could become part of the curriculum, as well as developing their creative art practice to include an awareness of aesthetic resonance. Art therapy students in their final year could use the portrait therapy protocol as experiential work with other students, and art therapy students with placements within *palliative care* could then use the portrait therapy protocol to work (under supervision) with patients. Whilst portrait therapy may be beneficial to other client groups who experience trauma as a disruption to their self-identity, further research is needed before training can be suggested for portrait therapy with other client groups.

Training in the Arts-Based Life/World Phenomenological Analysis protocol would enable trainee art therapists to evaluate the patients’ experience of portrait therapy, thus preparing them for ongoing research and evaluation of patients’ lived experience of art therapy interventions once they are qualified. Similarly training in the Voice Centred Interpersonal Analysis would give them a tool to use when evaluating recordings of patients’ lived experience of art therapy interventions.

7.8 *Afterward: Reflecting on experience*

Accompanying Rose, Hilary, Peter, Bill, Susan, Norma and Paul on their journey of self discovery and reflection has been a humbling and extraordinary privilege, and yet with each completion I felt a sense of guilt, that I was free to continue with my life, whereas they were left to continue alone in their liminal world of illness. However our time together left a trail of collaboration and creativity evident in the portraits, collages and prose poems, acting as a lasting reminder of this journey and as points of reference for the PRs in the uncertain landscape that lies ahead for each of them.

I had anticipated that some of the PRs might die during the initial stages of this project leaving unfinished portraits, however fortunately this did not happen and I was able to complete the project with all 7 PRs. Sadly in the past months since the collaborative work ended five of the PRs have died. Working in palliative care there is an expectation that patients will die, and yet each death came as a shock and left me questioning whether I had done *enough* to help them. Thinking about this I was reminded again of Winnicott's 'good enough (m)other' and also the sense that death always leaves unfinished business. Each loss inevitably affects who I am, through the loss of a relational sense of self-identity, unique to each PR and myself.

Within the portraits something tangible remains of the subjectivity of the person portrayed, providing evidence of their personal significance and the sacredness of human life. Through this project and enabling PRs to find their voices, I also found my own voice, as I started to speak and show this work to the world. As such the project has also been about my own identity, about reconciling the *artist, therapist* and *researcher* within me into a coherent whole.

I have attended each PRs funeral and created a final creative acknowledgement of our collaborative relationship (see Figure 95, *RIP Peter*), both ritualistic practices that enable the creating of a *farewell gesture* important for closure. As Wood (2005) says: 'the process of building up and letting go of relationships is intrinsic to working in cancer care, and in the end we must be satisfied with this ...' (*ibid*: 97).




Figure 95. *RIP Peter*

There is however comfort in the portraits that remain, – a visual testimony which still ‘have their work to do’ ... enabling something new to be discovered, as meanings continue to emerge, develop and re-vision identities. As Patricia Benner says, supporting people facing death requires:

[...] the art of holding open a life so that social death does not occur before physical death; so that leave-taking rituals and the human task of facing death are possible. These are the fragile goods that require connection and discernment (2003: 135).

Appendix 1: NRES Letter of Ethical Approval.



National Research Ethics Service

South West 2 Research Ethics Committee
Royal Devon & Exeter Hospital (Heavitree)
Room TH5
Gladstone Road
Exeter
Devon
EX1 2ED

Telephone: 01392 405272
Fax: 01392 405270
Email: Southwest.REC@nhs.net
www.nres.npsa.nhs.uk

07 October 2010

Ms Susan Carr, Art Therapist
Prospect Hospice
Moormead Road
Wroughton
Swindon
SN25 1PN

Dear Ms Carr

Study Title: Re-constructing identities disrupted by Life Threatening or Chronic Illness through the creation of collaborative Narrative Portraits.

REC reference number: 10/H0206/50

Protocol number: 1 dated 24 July 2010

Thank you for your letter of 23 September 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

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

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV		26 July 2010
Protocol	1	24 July 2010
CV for supervisor		26 June 2010
REC application	3.0	26 July 2010
Covering Letter		26 July 2010
Covering Letter		23 September 2010
Letter of invitation to participant	1	24 July 2010
Participant Information Sheet	2	22 September 2010
Response to Request for Further Information		23 September 2010
Participant Consent Form: Informed Consent Form	2	21 September 2010
Participant Consent Form: Permission for exhibition and publication of voice recording	1	24 July 2010
Participant Consent Form: Permission for use of Participant's first name accompany exhibition and publication of portrait and voice recordings	1	24 July 2010
Evidence of insurance or indemnity		01 February 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views



known please use the feedback form available on the website.

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

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0206/50

Please quote this number on all correspondence

Yours sincerely

**Mr Richard Ashby
Chair**

Email: Southwest.REC@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL- AR2 for other studies]

Copy to: Ms Debbie Ho

Appendix 2: Letter of Invitation to Participants

(Hospice Headed note paper)

Date:

Dear

This letter is to invite you to take part in an Arts Based PhD Research Project which is being carried out by Susie Carr within the Prospect Day Hospice, and validated by Loughborough University.

Attached is an information sheet which tells you all about the project, as well as an informed consent form which you would be required to sign should you wish to be included in the project. Please read these carefully and discuss them with your family if appropriate. If you require further information, please ask a member of staff about it next time you attend the Day Hospice, or you can telephone us on 01793 813355.

Please remember you are under no obligation to take part in this project and need not reply to this letter.

If you decide you would like to be involved in the project please tell a member of staff at your next visit to the Day Hospice and arrangements will be made for you to discuss the project further with Susie Carr.

Many thanks.

Yours sincerely

Jaqui Maggs
Carepoint Prospect Day Services Team Leader



Appendix 3: Letter of Invitation to Participants



Resolving Disrupted Identities: where portraiture meets therapy in life threatening and chronic illness.

Participant Information Sheet

Version 3. 20/05/2013

Main Investigator : Ms Susan Carr

Contact Details : Prospect Hospice, Moormead Road, Wroughton, Swindon, Wiltshire, SN4 9BY. Tel. 01793 813355.

Loughborough University, School of Art & Design

Epinal Way, Loughborough, Leicestershire, United Kingdom, LE11 3TU.

Tel : 01509 228901.

Supervisor : Mr Alastair Adams

Contact Details : Loughborough University, School of Art & Design

Epinal Way, Loughborough, Leicestershire, United Kingdom, LE11 3TU.

Tel: 01509 228932.

Supervisor : Professor Sarah Pink

Contact Details : Loughborough University, Loughborough,

Leicestershire, LE11 3TU. Tel.: 01509 223356.

This study has been reviewed by the South West 2 Research Ethics Committee, and the Prospect Hospice Research and Ethics Committee.

What is the purpose of the study?

This study offers the opportunity for you to work with a portrait artist, who will help you co-design a portrait of yourself and then paint it for you, and finally ask you to talk about the work.

The information collected in this project will contribute to a growing body of knowledge about the lived experience of people who have serious illnesses and will help health professionals and other academic scholars in their attempts to develop supportive therapies.

Who is doing this research and why?

This research is part of a Loughborough University PhD Student project, to be carried out by Prospect Art Therapist Susie Carr. The data will be part of the artist/researcher's PhD thesis which will be held by Loughborough University.

Do I need to be good at art to take part in this project?

No! Artistic skills are not necessary! The artist/researcher will work as your 'third hand' to create the portrait. All you need is a willingness to work with her to look at different ways of portraying your sense of self and identity in the form of a portrait.

Are there any exclusion criteria?

Yes. Participants must be over 18 years of age at the commencement of the project and attend the Prospect Day Hospice services. Participants must not be involved in any other research project during their involvement in the project.

Once I take part, can I change my mind?

Yes! You can withdraw at any time, for any reason and you will not be asked to explain your reasons for withdrawing. After you have read this information and asked any questions you may have we will ask you to sign an Informed Consent Form, however if at any time, before, during or after the sessions you wish to withdraw from the study please just contact Susie Carr, or a member of the Day Hospice Team.

Will I be required to attend any sessions and where will these be?

You will be required to attend two interviews and between three and five portrait sessions/sittings.

All portrait sessions and interviews will take place either at the Prospect Hospice in Wroughton, during your normal attendance at the Day Hospice, or if preferred in your own home.

How long will it take?

Your involvement in the project will be for approximately 7 weeks, with one session per week. If you miss a week it will not mean that you lose your appointment, it will just be put back a week.

The time requirement for the interviews and portrait sessions is flexible, with each session lasting approximately between 15 and 50 minutes, depending upon your other commitments on the day and how you are feeling.

Is there anything I need to do before the sessions?

If appropriate you could talk to your family about the project and discuss any images or photographs, which may be used in your portrait. It may be useful to keep a diary in which you can note down thoughts and feelings you may have about the project during the week, and then bring it to the next session.

Is there anything I need to bring with me?

It would be helpful if you could bring some photographs of yourself to talk about at the first portrait sitting, ideally these would be:-

1. Photographs of yourself as a child and growing up.
2. Photographs of yourself before you were diagnosed with your current illness and which you feel reflect a feeling of health and wellbeing.
3. Photographs of yourself after your diagnosis, which you feel reflect feelings related to your illness.
4. Any other photographs which you feel show key moments in your life.

During the project you may be asked to bring in objects or photographs which have a particular meaning for you, and which you may like to be included in your portrait.

What type of clothing should I wear?

Please wear comfortable clothing for your portrait sessions/sittings, however it is also important to consider the clothes you would like to be wearing in your portrait.

Who should I return the consent form to?

The consent form should be returned to Susan Carr or any member of the Day Hospice Staff. You will be given a copy of the signed consent form and a copy of the participant information sheet for you to keep.

What will I be asked to do?

At the initial interview you will be invited to take part in a short, easy, creative task, called the Button Identity Task, which involves selecting buttons that represent aspects of your identity and to talk about why you chose them. With your permission the creative task may be photographed or videoed and this session and all subsequent sessions will be recorded. This is to enable the artist/researcher to reflect on the narrative or stories told within the session and any themes which emerge. You will also be asked to think up a pseudonym, (a made up name) for your portrait to be exhibited under or you can choose to use your own first name.

At the first portrait sitting you will be invited to take part in a short creative task called 'photo elicitation' which involves talking about the photographs you have brought in and which one's best represent your sense of self or identity.

At the second portrait sitting you will be invited to take part in another short easy creative task, called 'Lego Serious Play.' This involves making a model out of Lego, which represents your identity. Help will be given with this task if you have difficulty using your hands. You will be asked to talk briefly about what you have made. This task may be videoed or photographed with your permission. The artist researcher may make some quick reference sketches of you or take some reference photographs of you, provided you give permission for this.

At the third, fourth and fifth portrait sessions, the artist/researcher will discuss different ideas with you for the portrait and show you sketches she has made. This will be an opportunity to modify the portrait and to talk about the process of designing it.

At the final interview you will be asked to complete the Button Identity Task again. You will also be asked to discuss what you feel about the completed portrait and how you have found the experience. You will also be asked to sign a permission form, enabling the artist/researcher to use a specific section of your voice recording to accompany your portrait when it is exhibited, this is so that viewers of the exhibition can listen to your actual voice as they view your portrait.

At the end and during the project the portraits and voice recordings may be exhibited in a suitable location and may also be included in educational publications. You and your family will be sent invitations to attend the exhibition of portraits and voice recordings and also informed of any inclusion in publications.

Will my GP be informed about my participation in the Project?

Yes, a letter will be sent to your GP outlining your participation in the project.

What personal information will be required from me?

No additional personal information will be required from you, other than that already available to the principal researcher in her capacity as an Art Therapist at the Prospect Hospice. You will however be asked to talk about how your illness has affected your sense of self and identity, and about your experiences of being painted.

Are there any risks in participating?

There are no known risks involved in participating, however talking about how illness has affected your sense of self and identity may bring up feelings of grief, loss and anger. If you wish to talk further about any topics or themes which are raised within the interviews or portrait sessions, appropriate confidential appointments with hospice staff can be made for you or you can telephone the Prospect Hospice to talk to staff at any time of the day or night on their 24 hour telephone line, Tel: 01793 813355.

Will my taking part in this study be kept confidential?

Yes, no one will be informed that you are taking part in this project, except for the Prospect Hospice Day Services Team.

All voice recordings and any other data concerning you, will be held on the Prospect Hospice computer system, with access only by Susan Carr with a user name and password. All data will be recorded anonymously unless you have specifically asked for your name to be credited to your portrait and voice recording. No other person will have access to this data.

All data collected for this project will be destroyed in accordance with the Data Protection Act 10 years following the successful completion of Susan Carr's PhD Thesis, except for the portraits (which remain the property of Susan Carr) and agreed voice recordings, which may continue to be exhibited following the completion of the project.

If I withdraw from the study can I ask for all data referring to me to be destroyed?

Yes, if you withdraw from the project you can ask for all data referring to yourself to be destroyed and this will be done for you, unless the final results have already been published and cannot be retrieved.

What will happen to the results of the study?

The results of the study will be written up as case-studies which will be used in the thesis for Susan Carr's PhD Project. The portraits and voice recordings may be exhibited in an exhibition and may also be published in academic journals or books, for educational purposes. A copy of Susan Carr's PhD Thesis will be held by Loughborough University and the Prospect Hospice. The portraits will not be offered for sale to the general public at any time, but may be bequeathed to a museum/art gallery after the project is completed.

What do I get for participating?

A copy of your portrait, printed on canvas or board will be made available to you or your family if required.

I have some more questions who should I contact?

Please contact the Chief Investigator Susan Carr or a member of the Day Care Services Team at the Prospect Hospice.

What if I am not happy with how the research was conducted?

If you feel unhappy with the way this research project has been conducted, please contact Loughborough University 'Whistle Blowing' site which is available online at

[http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing\(2\).htm](http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm).

You can also contact Debbie Ho, Patient Services Director, Prospect Hospice, Wroughton, Swindon, SN4 9BY. Tel. 01793 816138.

For out of hours help and advice if you are feeling distress about any aspect of this project, or your illness, please contact the Prospect Hospice on their 24 hour telephone line on Tel: 01793 813355.

*Thank you very much for taking the time
to read this form and for considering
taking part in this study.*

Appendix 4: Participant Informed Consent Form



Resolving Disrupted Identities: where portraiture meets therapy in life threatening and chronic illness.

INFORMED CONSENT FORM (Version 2: 21/09/2010) (to be completed after Participant Information Sheet has been read)

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the National Research Ethics Service Committee and by the Prospect Hospice Research Committee.

Please initial the box for each statement you agree with.

- I have read and understood the information sheet and this consent form.
- I have had an opportunity to ask questions about my participation.
- I understand that I am under no obligation to take part in the study.
- I understand that I have the right to withdraw from this study at any stage and for any reason, and that I will not be required to explain my reasons for withdrawing.
- I understand that all the information I provide will be treated in strict confidence and will be anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others.
- I agree to assign copyright of all copies of photographs used within the collaborative portraits to Susan Carr.

- I understand that voice recordings will be made of interviews and portrait sittings and may be exhibited anonymously in conjunction with the finished portrait, within exhibitions and as typed transcripts in educational publications, e.g. within the PhD Thesis of Susan Carr.
- I understand that I can choose to remain anonymous and not have my name mentioned in relation to my images or voice recordings, or any other data collected during this study.
- I understand that my portrait, photographs and verbal data collected during the course of this study may continue to be used in the study, exhibited and published, to further research and education into resolving disrupted identities, even after my death.
- I understand that portraits painted or drawn of myself will remain the property of the Susan Carr, although a copy printed on canvas or board will be made available to myself or my relatives should I/they like to have one.

I agree to participate in this study.

Your name _____

Your signature _____

Signature of
investigator _____

Date _____

Appendix 5: Letter to PRs GP's informing them of their participation in the project.

(Hospice Headed note paper)

Date:

Dear

NHS Reference No:

This letter is to inform you that your patient, has volunteered to be a participant in an Arts based Research project, which is being carried out at the Prospect Hospice over the next two years.

I have enclosed the Participant Information Sheet, given to patients participating, for your information.

If you have any queries about participation, or would like more information about the project, please contact me at the Prospect Hospice on Tel: 01793 813355.

Yours sincerely

Susie Carr
Art Therapist
Prospect Hospice



Appendix 6: Permission to use voice recording Form



'Resolving Disrupted Identities: where portraiture meets therapy in life threatening and chronic illness.'

**Permission for exhibition and publication of Voice Recording.
(Version 1. 01/12/2010)**

I give permission for my voice recording, as transcribed below, to be exhibited in conjunction with my portrait, in exhibitions and publications, for educational purposes.

“Transcript of voice recording”.

Your name

Your signature

Signature of investigator

Date

Appendix 7: Permission to use Participant's first name Form



Resolving Disrupted Identities: where portraiture meets therapy in life threatening and chronic illness.

Permission to use real first name

Version 1. 10/09/2011

I agree to the use of my real first name (or a pseudonym) in conjunction with any photographs, paintings, collage, poems or literature, in any publication or exhibition (for educational purposes).

Name to be known as

Your name

Your signature

Signature of investigator

Date

Appendix 8: Art Therapy Practitioner Insurance (including research) renewed yearly.

howden

Evidence of Professional Civil Liability Insurance

for members of British Association of Art Therapists

Name of Policyholder:	Ms Susan Carr		
Customer Reference:	HP8503		
Policy Period:	From: 01 February 2010	To: 31 January 2011	
Indemnity Limit:	£3,000,000		
Professional Services:	Art Therapy		

Including, where applicable, the provision of supervision and training in these activities.

Cover is provided by Dual Corporate Risks Limited acting for Arch Insurance Company (Europe) Limited under a Binding Authority Master Policy Number AB087130W 02.

This Policy covers (subject to its terms and conditions) any civil liability arising from the professional services shown. It is, effectively, a combination of Professional Indemnity and Public Liability insurance. The indemnity limit applies to each and every claim.


Claims made basis
All protection provided by this policy ceases when the policy lapses (i.e. you do not pay the renewal premium) or if it is cancelled for any other reason.

The insurance can only respond to a claim if the policy is in force at the time a claim is made against you, irrespective of the date when the events giving rise to the claim are alleged to have occurred.


You must tell us immediately (and in any event within the policy period) if you become aware of any claim or circumstances that might give rise to a claim being made against you, and bear these points in mind before allowing your policy to lapse.

IMPORTANT
The insurance can only respond to a claim if the policy is in force at the time a claim is made against you. Therefore, you must immediately contact Howden on 0113 251 5011 with details of any circumstances that you think may result in a claim being made against you.

LEGAL ADVICE HELPLINE
Cover includes a 24 hour legal helpline which provides extensive advice across a broad range of both business and personal legal issues.
To Contact the helpline call 0870 1648 208 quoting reference HL/7/36

 **Howden Professionals**
1200 Century Way Thorpe Park Leeds LS15 8ZA Tel: +44 (0)113 251 5011 Fax: +44 (0)113 251 5100
Email: enquiries@howdenpro.com Web: www.howdenpro.com

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Appendix 9: Semi-structured End of Project Interview Questions

1. How have you found the experience of being painted and having paintings made of you?
2. How did you find the collaborative process?
3. Did you find out some more things about your self? Can you give any examples?
4. Did it help you find different parts of yourself and identity that you had perhaps lost or didn't know existed? Can you give any examples.
5. Would you have liked to have been involved with the actual making/painting of the portrait?
6. How do you feel about the fact that these portraits will go into an exhibition and be seen by lots of people?
7. Is that an important aspect of the project for you?
8. Is it important to you that your contribution to this project might help other people in a similar situation to you?
9. How did you find my visits to your home?
10. How did you find telling your story to me and my interpretation of that into a painting?
11. Did that help you feel heard?
12. How do you feel about my input in your paintings. The interpretations I have made?
13. Has this project helped give you a stronger sense of your self and your identity? Can you give an example?
14. Has this project helped you make meaning of your life? Or find a new meaning? Can you give any examples.
15. Do you have any ideas of how I could improve this project?
16. Do you feel that this kind of project would benefit other people who have a similar illness or issues to you?
17. How have your family reacted to the paintings and collages we have created?
18. Has this project made you feel exploited in any way?
19. Would you like your real first name or a pseudonym attached to your painting when it is exhibited or printed?
20. Are you happy for your diagnosis to be mentioned in literature accompanying your portraits?
21. Do you have any questions or comments of your own?

Appendix 10: Portrait Reference Album List

Portrait Reference Album (90 portraits/portrait objects dating from 1661-2010)

Title	Artist & Date
<i>Young Woman Holding a Black Cat</i>	Gwen John, 1920-5
<i>Constellation</i>	Mika Koto, 2004
<i>Rest</i>	Edwin Harris, 1855-1906
<i>Cupid Delivering Psyche</i>	Edward Burne-Jones, 1871
<i>Fibre Portrait</i>	Jill Parry, 2009
<i>Arctic Hare Skullcap</i>	Katherine Coe, 2009
<i>Distill</i>	Sarah Clement, 2010
<i>Twins Border</i>	Sarah Clement, 2010
<i>Pillar of Salt (Lot's Wife)</i>	Sam Webber, 2008
<i>The Return Home</i>	Roselina Hung, 2007
<i>Self-Portrait (The Past Five Years)</i>	Roselina Hung, 2006
<i>Mom & Dad I</i>	Roselina Hung, 2008
<i>The Order of Release</i>	Sir John Everett Millais, 1853
<i>Mariana</i>	Sir John Everett Millais, 1851
<i>The Blind Girl</i>	Sir John Everett Millais, 1856
<i>Young Girl</i>	Sir John Everett Millais, 1852
<i>Self-Portrait</i>	David Caldwell, 2009
<i>John</i>	Benjamin Cohen, 2008
<i>Brian</i>	Benjamin Cohen, 2008
<i>Liam</i>	Elizabeth Payton, 1996
<i>Zandvoort Fisher Girl</i>	Elizabeth Adela Forbes, 1912
<i>Glauke: Pensive</i>	Edwin Longsdon Long, 1833
<i>April Love</i>	Arthur Huges, 1856
<i>Self Portrait</i>	Rembrandt, 1661
<i>Self-Portrait (1914)</i>	Sir Stanley Spencer, 1914
<i>Portrait Presume de son geolier</i>	Jacques-Louis David c1820
<i>Self-Portrait</i>	Eugene Delacroix c1818
<i>The English Boy</i>	Ford Madox Brown, 1860
<i>Girl Before the Mirror</i>	Pablo Picasso, 1932
<i>The Weeping Woman</i>	Pablo Picasso, 1937
<i>Emilie Flöge</i>	Gustav Klimt, 1902
<i>Three Ages of Women</i>	Gustav Klimt, 1905
<i>Endangered Species IV</i>	Paul W Ruiz, 2008
<i>Saltimbanque II</i>	Paul W Ruiz, 2008
<i>Child Portrait</i>	Gee Vaucher, 2010
<i>Self Portrait Sketch</i>	Paul S Brown, 2005
<i>Girl Reading</i>	Charles Edward Perugini, 1878
<i>Carnation, Lily, Lily, Rose</i>	John Singer Sargent 1886
<i>Jacques Barenthon</i>	John Singer Sargent, 1883
<i>Ena and Betty Wertheimer</i>	John Singer Sargent, 1901
<i>William Butler Yates (drawing)</i>	John Singer Sargent, 1908
<i>Andromeda: Grand Hôtel de l'Observatoire</i>	Joseph Cornell, 1954
<i>Circe Invidiosa</i>	John W Waterhouse, 1892

Title	Artist & Date
Garton Orme at the Spinnet	Jonathan Richardson the elder, 1707
<i>Broken Column</i>	Frida Kahlo, 1944
<i>Tree of Hope Keep Strong</i>	Frida Kahlo, 1946
<i>The Two Fridas</i>	Frida Kahlo, 1939
<i>My Body is No Longer a Temple</i>	Hollis Sigler, 1995
<i>Out of this World</i>	John D Edwards, 2008
<i>Carry me this way</i>	Michele Angelo Petrone, 1996
<i>Portrait on Violin</i>	P J Crook, 2010
<i>Drip portrait</i>	Indigo (contemporary street art)
<i>Dame Judi Dench</i>	Alessandro Raho, 2004
<i>Mike's Brother (Sir Paul McCartney)</i>	Sam Walsh, 1964
<i>Nighthawks</i>	Edward Hopper, 1942
<i>American Gothic</i>	Grant Wood, 1930
<i>The Drifter</i>	Jack Vettriano, 1994
<i>Mo Mowlam</i>	John Keane, 2001
<i>Alfred Tennyson</i>	Samuel Laurence & Sir Edward Coley Burne-Jones, 1840
<i>Sir Ian McKellen</i>	Clive Smith, 2002
<i>Self-Portrait</i>	Lucian Freud, 1963
<i>Lady Emma Hamilton as Calypso</i>	George Romney, 1792
<i>Self-portrait</i>	Sir Joshua Reynolds, 1780
<i>Womans Head (Collage)</i>	Meriel Potts, 2011
<i>A Wood Nymph</i>	Robert Poetzelberger, 1886
<i>Isabel 1 & 2</i>	Loretta Lux, 2009
<i>The Drummer</i>	Loretta Lux, 2004
<i>Self-Portrait</i>	Vincent van Gogh 1889
<i>A Mermaid</i>	John W Waterhouse, 1900
<i>Girl in the Window</i>	Peter Matthews, 2009
<i>Man at the Bar</i>	Fabian Perez
<i>Pandora's Box</i>	Dante Gabriel Rossetti, 1869
<i>Self Portrait (with hardware)</i>	Zac Freeman, 2010
<i>Assemblage 1</i>	John Whipple, 2009
<i>A School Girl</i>	Sir George Clausen, 1891
<i>A Village Maiden</i>	Sir George Clausen, 1892
<i>The Stone Pickers</i>	Sir George Clausen,
<i>Phonebook Paper Dress</i>	Jolis Paons, 2009
<i>Peace (Paper Couture)</i>	Lia Griffith, 2010
<i>Esmé Robbe</i>	George Henry Boughton, 1897
<i>Never Morning Wore to Evening</i>	Walter Langley, 1894
<i>Cherish</i>	Susan Cutts, 2011
<i>Footsteps Past & Present</i>	Susan Cutts, 2008
<i>Lullaby</i>	Susan Cutts, 2004
<i>Irren-Anstalt Band-Hain</i>	Adolf Wölfli, 1910
<i>Blood Man</i>	Howard Terpning, 1988
<i>Child of the Earth</i>	Virgil Stephens, 2008
<i>On the Beach</i>	Arthur Rackham, 1910
<i>Amelia</i>	Sascalìa, 2009

Tuba K.
Dead Man Walking (Philip Ledbury)

Mark Gilbert, 2000
David Fisher, 2009

Appendix 11: Permission to use images of other artist's work.

1. Email from MAP Foundation Re: 'Carry Me This Way' by Michele Angelo Petrone.

Dear Susan

Thank you for getting in touch. Normally we charge for a license for use of Michele's images but because you will be using it for your Thesis we can waive the fee. Please make sure that the image is fully attributed. I attach the image for you.

With best wishes

Trisha Stone

Development Co-ordinator, Michele Angelo Petrone Foundation

2. Email from Hollis Sigler's Representative Re: 'My Body is No Longer a Temple' by Hollis Sigler.

Susan,

You may go ahead and use her images for your work. I am her executor and I know she would be pleased.

I would love hear about it when you finish it.

Best wishes,

Patricia Locke

3. Email from Mark Gilbert Re: 'Robin & Mardi' and 'Barry C' by Mark Gilbert.

Dear Susan,

Thank you for your message. I too am working on my PhD dissertation here in the US.

What is your dissertation on?

I am happy for you to use the images and will send you the correct accreditation later today.

Best wishes

Mark

4. Email from Heath Rosselli Re: 'Evelyn'

Hi Susan,

Great to hear from you again - yes, indeed you may use the image of Evelyn. Do you have it or would you like me to send it across? It is good to hear you are reaching the end of your PhD at last - what a relief that will be! I would love to see some of your portraits too, if you are able to show via email or something like that?

With warmest wishes,

Heath Rosselli

5. Email from John D Edwards Re: 'Out of This World'

That's fine Susan, I'd be interested to hear how it all goes.

Good luck! JD

6. Email from Brenda Fisher, wife of the late David Fisher Re: 'Dead Man Walking: Portrait of Philip Ledbury'

Dear Susan,

I remember you writing to David, this is his Wife Brenda here now.

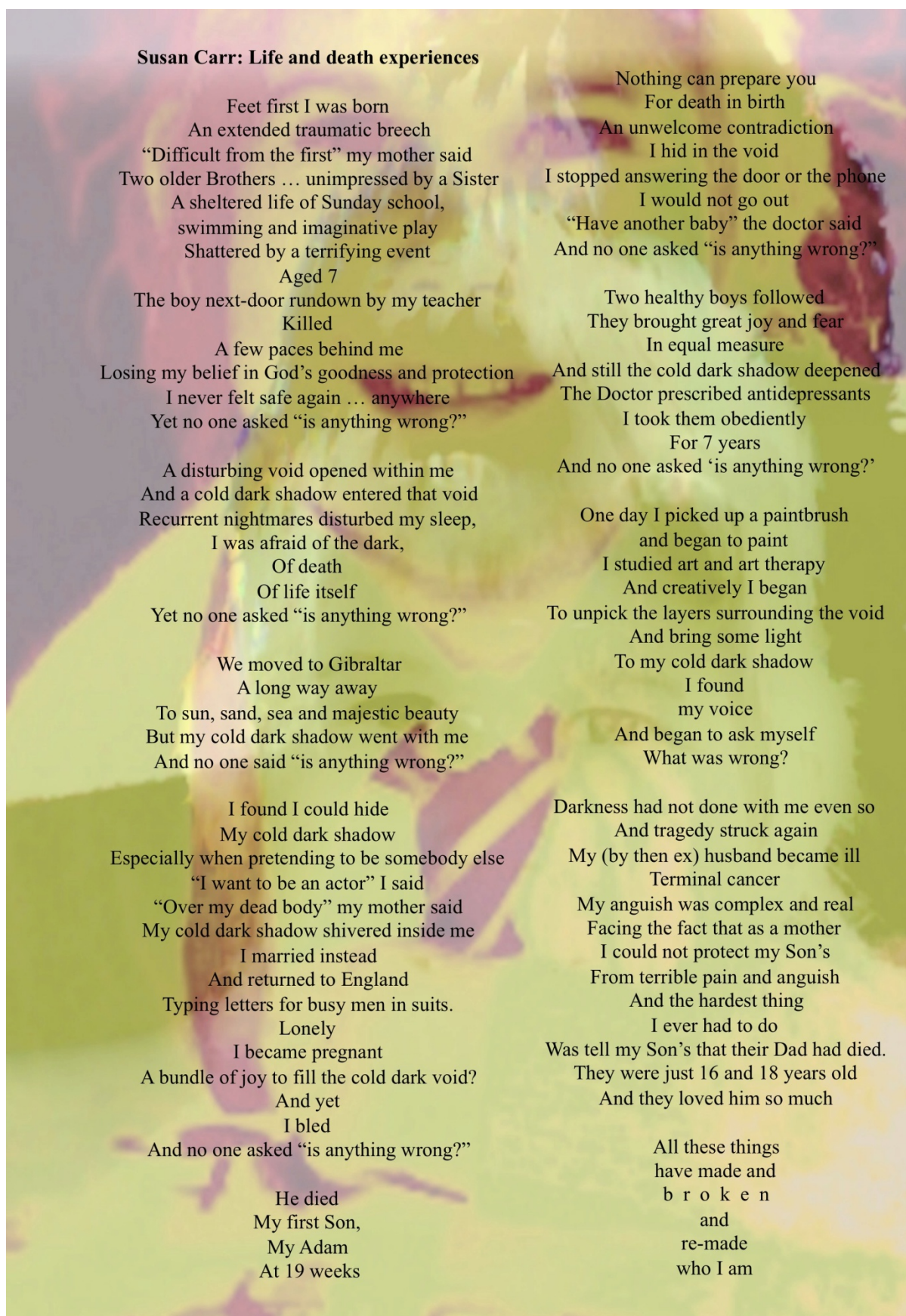
David passed away 21st, March 2013. after nearly four years of having Cancer, he had nine operations, and fought it with great honour, but I am afraid to say it took over in the end. Of course you can use the picture in question. I hope it all goes well, and please let me know if I can see the exhibition anywhere. Best Wishes Brenda Fisher.

7. Email from Antonia Rolls Re: 'Steve' and 'Julia'

I hope this is helpful, let me know if you need anything more. I will attach some photos of the paintings I have mentioned now, and hope that all goes well for your PhD. With very best wishes,

Antonia

Appendix 12: Susan Carr, reflexive and reflective statement



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