

Journal Article

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Wyatt, M and Liggett, S

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The potential of painting: unlocking Disenfranchised Grief for people living dementia

Susan Liggett & Megan Wyatt

Wrexham Glyndwr University

**Abstract**

As part of the “*Creative Well*” programme at a local health board, one of the authors qualitatively investigated how painting can access a means of communication for people living with Dementia. In a workshop setting within a gallery environment, participants living with dementia were facilitated on a one to one basis the opportunity to paint alongside the researcher.

During the workshops, a number of experiences were articulated. These included experiences of illness, crisis and loss. They were captured through observations, interviews, visual art and video to contribute to new understandings and models of engagement through art for people living with dementia and their carers.

Focusing on theory and practice in arts based research and the social sciences, this paper investigates the potential of painting to unlock experiences such as disenfranchised grief for people living with dementia. The conclusions of this paper do not measure how and if participants felt disenfranchised grief but rather provide an alternative to augment the body of knowledge surrounding how people living with dementia can communicate feelings of disenfranchised grief through painting.

*Keywords: dementia, painting, arts based research: materiality, disenfranchised grief,*

*Arts in Health*

## The potential of painting: Unlocking Disenfranchised Grief for people living Dementia

### **Introduction**

As part of a larger practice based PhD study into the communicative capacities of painting for people living with Dementia, a number of experiences were articulated and captured in innovative ways that contribute to new understandings and models of engagement through art for people living with dementia and their carers. Amongst the different experiences explored, were feelings of illness, crisis and loss through dementia, with anxiety and negative emotions being identified as key themes. This paper investigates the potential of painting to unlock experiences of crisis illness and loss, and in particular, disenfranchised grief for people living with dementia. Participant observations, interviews, visual art and video have been used in order to gain a deeper understanding of this topic.

Within the United Kingdom, dementia presents as a huge health care challenge with currently 850,000 people living with the disease in the UK (Alzheimer's Society, 2017). Without significant research and intervention, this will have doubled in the UK to one million by 2025 and by 2051 will have doubled again.(Alzheimer's Society, 2014). The term dementia is defined as a set of symptoms which cause a progressive decline in the brain and its capabilities, commonly causing problems with memory loss, mental agility and thinking speed (National Health Service, 2013). Dementia still remains a stigmatized condition due to the decline of mental capacity and the therefore loss in independence. The experience mostly affects people over the age 65 and this connotation with aging also exacerbates this social opinion (Cohen-Mansfield, Golander and Arnheim, 2000).

Diagnosis of dementia can have significant ‘*emotional, social, psychological and practical impact*’ with people often experiencing a sequence of losses (Alzheimer’s Society, 2018b). Many people living with dementia are aware of the changes that are taking place but may have difficulty in expressing this due to their ‘*memory loss, cognitive impairment and communication difficulties*’ (Irish Hospice Foundation, 2016). Due to this, it is often misconceived that that people living with dementia cannot experience or sustain grief due to this progressive decline in their memory and mental capacity. This societal misunderstanding of a person living with dementia’s experience of loss means that grief can often become disenfranchised. This can occur at any point of someone’s journey with dementia and often occurs on a daily basis. The different types of loss faced by somebody can also be simultaneous, accentuating this disenfranchisement (Irish Hospice Foundation, 2016).

### **Disenfranchised Grief and people living with Dementia**

Thompson and Doka (2017) identify disenfranchised grief as a sociological concept that arises as a result of social expectation. Their work has been influential in locating grief in broader theoretical applications which have been utilised in this study. Disenfranchised grief can be defined under three main headings. These are; grief that cannot be openly acknowledged, that is not socially sanctioned or grief that is not publicly mourned (Thompson, & Doka, 2017). Examples of disenfranchised grief can have different implications and various resonances in contrasting social circumstances (Thompson & Doka, 2017). Painting, and other art related approaches can enable contexts to be explored for those living with dementia.

#### *Grief that is not openly acknowledged.*

Grief that is not openly acknowledged relates to grief which has some level of secrecy or confidentiality aligned with it (Thompson & Doka, 2017). Receiving a dementia diagnosis

can result in a feeling of social dislocation. The person often enters a new lower status social group a process that is a function both of the condition itself and responses to it (Katsuno, 2005).

*Grief that is not socially sanctioned.*

The second element of disenfranchised grief comprises grief that is not socially sanctioned. This can be due to social disapproval or a feeling of cultural rules being broken (Thompson.& Doka, 2017). Stigmatisation for people living with dementia is prevalent with people often feeling lonely and isolated. The cognitive degenerative nature of dementia means people living with it can experience behavioural or psychological symptoms. This can lead to a worry about the response from others and society, meaning that people living with dementia can often feel like they are being hidden. (Kuriakose cited in (Batsch and Mittelman, 2012).The stigma associated with dementia can affect the persons willingness to pursue a diagnosis, request support or participate in research once diagnosed (Burgener and Berger, 2008)(Milne, 2010) (Garand et al 2009 cited in Swaffer, 2014).

*Grief that is not publicly mourned.*

For people living with dementia and their carers, it can often be very difficult to publicly grieve the changes that are taking place. People often feel a sense of loss when diagnosed with dementia and this is accompanied by an uncertainty and obscurity about how the disease will progress and the impact this will have on the individual (Alzheimer's Society Canada, 2013). It can also be very difficult for people living with dementia to publicly mourn a loss or death of somebody.

*'Self-stigmatization, a process whereby stigma is absorbed by the individual, also plays a role. It encourages people with dementia to remain invisible and withdraw from social contact'* (Milne, 2010: 228)

### **Using art as a research tool**

There is a substantial body of knowledge about arts based research. Knowles and Cole (2008) provide an overview of how such research provides possibilities that arise through the use of a mixed method approach using both arts based practice and social science methods. There has been less of a focus within existing research in developing conceptual and theoretical frameworks for understanding the processes through which the arts may exert their benefits (Stickley *et al.*, 2017). Research needs to address not only causal relationships but investigate a deeper understanding of 'how' arts practices function to promote wellbeing. The specific subject domains of 'arts' and 'health' do not exist as concrete entities, but are shifting, amorphous and contested, subject to competing knowledge claims (Broderick, 2011). Wider academic engagement across discipline boundaries are needed to create a creative conversation between the place, sites and spaces in which arts in health possibilities can critique medicalised models of health care (Stewart cited in Stickley, 2017).

This research adopted a practice led approach with the authors as practicing artists not art therapists. Painting was specifically chosen for this study as *'it is an original psychic act which is derived from a person's own individuality, experiences and ideas'* (Kuspit, 2000: 3). There is abundant art therapy literature that supports the use of painting to enable the healing and renewal of the imagination and illnesses associated with the loss of soul (Mcniff, 1992). Art activities such as painting which have a kinaesthetic element allow for a *'rhythm, action, movement and the release of energy'* to be undertaken by the creator. (Hinz, 2009:42). The use

of a paintbrush by participants removes any use of a mediator which in turn increases the sensory quality of the experience and therefore the ability to express experiences (Hinz, 2009).

Art based research can be defined as the:

*‘systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies’ (Mcniff, 2008:29) .*

As such, arts based research allows for unexpected outcomes (Till, Mottram and Rust, 2005), and can be used to capture new perspectives and emotions, something which would otherwise go unknown (Eisner, 2008). Meaning emanates through the creative process’ ability to provide an outlet for the artists own expression (Mcniff, 2008). As Eisner (2008:12) states:

*‘If the arts are about anything, they are about emotion, and emotion has to do with the ways in which we feel. Becoming aware of our capacity to feel is a way of discovering our humanity. Art helps us connect with personal, subjective emotions, and through such a process, it enables us to discover our own interior landscape. Not an unimportant achievement’*

The intervention described in this paper was not funded, allowing for the focus to be specifically on the intrinsic value of paint or the activity of painting as a medium to aid communication rather than on supporting assumptions around its benefits.



## Methods

### *Research Overview*

As part of a “*Creative Well*” programme provided through the North Wales Health Board, we qualitatively investigated how painting can access a means of communication for people living with dementia. In a workshop setting within a gallery environment, one of the authors worked on a one to one basis with participants, facilitating the opportunity to paint alongside her whilst she made her paintings. The intervention was not therapeutic in its aims, but part of a programme called *Lost in Art*, organised by a rural crafts centre, which provides enjoyment and friendship for people living with dementia and their carers.

### *Ethics*

Ethical permission for the research was granted through approval from Wrexham Glyndwr University Research Ethics Committee. All participants had early to mid-stage dementia and had sufficient mental capacity, meaning that they agreed to participate through signing informed consent forms. For the purpose of anonymity, pseudonyms have been used throughout this study.

### *Participants*

Permission to participate in the project and thus access participants was gained via a local arts development officer. Four female and four male participants all living with dementia and their family/main carers were recruited through the *Lost in Art* scheme. *Lost in Art* provides weekly art workshops for people living with dementia and their main carers who live in a rural county in North Wales. This meant that a diagnosis of dementia had already been established and all participants lived in a local area. All participants were over the age of sixty-five. As the

focus of this research was on the communicative capacities of painting for people living with dementia, other detailed demographic information was not specifically sought at the outset of this study.

### *Data Collection*

Each participant and their carer attended a one hour one to one creative workshop with one of the authors at their local craft centre. Participants and their carers were provided with a selection of different coloured acrylic paints, paintbrushes and canvas boards and were asked to paint whatever they wanted while they sat next to the researcher, who then painted alongside them.

A loose semi-structured interview guide was utilised during the workshops to gain a more of an in depth understanding of the creative painting process for participants. Interviews covered broad themes such as mark making, colour and relation of painting to memory. It was also important to understand that participants had varying levels of verbal communication and care needs, so the conversation and needs were adapted for each session. This was done through simplifying how questions were asked if needed, using reminiscence to help ease participants and redirecting conversation to help lessen or avoid participants anxieties (Beuscher and Grando, 2011).

This person centred approach where a person's care is based around their 'interests, abilities, history and personality' is highlighted by the Alzheimer's Society (Alzheimer's Society, 2018a) through the acknowledgement of it being a mechanism of managing psychological or behavioural difficulties.

Participant observation (Kawulich, 2005) was also used to gain a deeper understanding of the experiences and creative process of all participants. Each workshop was video recorded

which allowed re-examination of the participant's behaviour, painterly process and speech. Observations were also recorded through field notes throughout each hour workshop. Semi-structured interview and video recordings were transcribed along with a corresponding step by step description of observations made.

Resulting data consisted of paintings from participants, field notes from observations within the workshop and video recordings within the workshops which documented semi-structured interviews with corresponding written observations.

### *Analysis*

A qualitative thematic analysis approach (Braun and Clarke, 2012) was used to identify themes and patterns from this data for people living with dementia and the capabilities of the engagement with paint to provide a communicative capacity. To ensure a rigorous and transparent approach, data was transcribed and then coded line by line (Neal, 2016) using the qualitative analysis tool NVivo. Semi structured interview data was transcribed along with corresponding written up observations gained through the video recordings. These were analysed through NVivo. Final paintings were not analysed through Nvivo as the focus of the research is on the process of creating the paintings not the final output of the finished work itself.

Emergent inductive themes were developed from these, one of which was the emotions that participants faced during the art workshop. After data had been coded, thematic charts were created to visually simplify, highlight and visualise relationships between themes (Ritchie and Lewis, 2014). This allowed for a '*systematic*' and '*comprehensive*' exploration of '*similarities*' between different themes and topics and between the different participants involved.

## Findings

Four out of the eight examples were specifically chosen from the sample of eight for this paper as they most consistently presented relevant considerations. Carers paintings were not analysed as the focus of the research was to provide an in depth focus on the grief associated with dementia.

Each participant's final painting can be seen below:



Figure 1. James (May 2017)



Figure 2. Poppy (May 2017)



Figure 3. Flossy (May 2017)



Figure 4. Rose (May 2017)

Analysis suggests that all four participants felt some form of either grief that is not openly not acknowledged, grief that is not socially sanctioned or grief that is not publicly mourned. This was embodied in exhibited negative emotions of: anxiety, frustration, crying and an awareness of their own difficulties. It is important to note that this analysis did not

establish measures of how and if participants felt disenfranchised grief but rather provided alternative perspectives and adds to the body of knowledge into how people living with dementia can communicate feelings of disenfranchised grief through painting.

*Grief that is not openly acknowledged within context of dementia*

Grief that is not openly acknowledged relates to grief which has some level of secrecy or confidentiality attached to it. Receiving a dementia diagnosis can result in a feeling of social dislocation due to the nature of responses to the condition and the nature of the condition itself (Katsuno, 2005). Findings from the workshops suggested that all four participants felt some level of grief that was not openly acknowledged.

James found it difficult to communicate on entering the room. Once his wife left he immediately began to cry. When asked if he was ok, James said he could no longer do anything for himself anymore and that he had to rely on his wife for everything. He expressed his frustrations, saying with a sense of loss that he had once been very independent and had a good career. He spoke of how this independence had been taken away from him and that his complete reliance on his wife was something he found upsetting.

Once James was seated, the researcher displayed a range of paintbrushes and asked if he would like one. When engaged in the activity of painting James's strong emotions subsided and it was observed that James was immersed in the process of painting for the majority of the one hour's workshop. James was making up the imagery of a small man like figure in the corner of his canvas through applying repetitive delicate marks of different coloured paint. Mid way through the art workshop, James' wife commented on his painting saying:

*'he recited a poem this morning that he remembered, I don't know if that's because of it. He said about a friend of his and somebody did this verse or something*

*and what did you say, and blue legs was it and you know somebody said with black teeth and blue legs. He's done his with blue legs now'.*

James did not verbally respond to this statement, however he then began to speak of his memories of old school friends and walking to school in the morning. It was observed that James was very animated and appeared happy whilst speaking about this.

The evidence here implies that James felt dislocated socially in the workshop setting but the painting activity enabled these strong feelings to subside. It can be suggested that the painting workshop gave James the opportunity to express the grief associated with the loss of independence.

At the beginning of the session, Poppy's speech was very fast and rambling and was largely incoherent. For the parts of Poppy's speech which were coherent, she was talking about how she had been asked to take part in a questionnaire the previous day and she was concerned that she hadn't been able to think of the right answers. It was observed that this made her very anxious, something which may be an example of Poppy feeling socially dislocated.

At the beginning of each of their workshops, Flossy appeared anxious and Rose was fed up. Flossy repeatedly asked whilst exhaling, what she was supposed to be doing. The researcher asked her if she would like to choose a brush and flossy chose a medium sized one and after a few minutes began to paint. Once Flossy engaged in painting, she became immersed in the process and it was observed that her anxieties lessened from what they had been at the beginning. Neither Flossy, or Rose initially verbally commented on their emotions, something which may show that they could not openly acknowledge their feelings or felt some level of secrecy towards them.

Initial resistance to working in an unfamiliar workshop setting was combatted by participants being asked to paint alongside the researcher and acting spontaneously when painting. The presence of the artist researcher as witness helped restore confidence and placed them in a more relaxed frame of mind, opening them up to the creativity within them.

*Grief that is not socially sanctioned within the context of dementia*

Findings from this study also suggests that the participants experienced the second element of Disenfranchised Grief (Thompson, N & Doka, 2017). Something which is prevalent for people living with Dementia is the feeling of being stigmatised with anxieties relating to their own behaviour and the responses of this from others (Kuriakose cited in Batsch and Mittelman, 2012).

All the participants communicated negative emotional feelings at the start of the painting workshop and throughout the session with three out of the four participants showing negative expressions towards their painting.

At the beginning of the session Poppy chose a brush and then stated '*my pictures are no good*'. She then went on to say that she was '*hopeless*' and that '*every time I do it, it comes to a blob*' whilst tapping her head and appearing frustrated. Flossy also stated '*I don't know what I'm ending up with I don't know what I'm doing*' and Rose said '*I'm not a talented painter you see*'.

The above observations could indicate that the participants were worried what others would think of their paintings, trying to hide symptoms in a new setting and withdrawing into themselves. It is important to note however that people without dementia may also be critical of their own abilities.

Poppy and Flossy also both questioned the purpose of the session. with Flossy repeatedly asking questions throughout the workshop such as *'are you not going to give us anything to paint, is it just out of your head'* and *'what do you reckon I'm painting here'*. This may indicate a lack of confidence and anxiety surrounding their own abilities and purpose within the workshop. When reassured by the researcher or their carer however, they engaged in the process of painting.

At the end of the session however, Flossy stated *'I think it's magic'* when referring to her painting, something which can suggest that that she felt a certain sense of achievement whilst Poppy said *'The only thing you get out' of this is a laugh isn't it'* and Rose looked at her painting and said *'wow wow'* all of which can indicate that they had enjoyed the workshop. Our lives are improved by having a network of social connections for example art groups, clubs and associations which are of benefit in times of need (Thompson, N & Doka, 2017).

#### *Grief that is not publicly mourned in the context of dementia*

All four participants felt some form of the third element of disenfranchised grief –grief that is not publicly mourned. People living with dementia can feel a sense of loss due to the degenerative and uncertain nature of their condition (Alzheimer's Society Canada, 2013). All four of the participants verbally acknowledged their own difficulties whether physical or mental and it was observed that whilst speaking about these difficulties, participants appeared either sad, anxious or frustrated by them. As indicated earlier James cried at the beginning of the session and spoke about his loss of independence, suggesting that he felt saddened by this. Whilst Poppy was painting she said *'the stuff is here but it goes in the wrong place all the time with me'* whilst tapping her head and looking frustrated. Flossy did not verbally acknowledge any difficulty but appeared confused and said *'I don't know what I'm doing'*. It was observed



that Flossy appeared frustrated when saying this and was exhaling, suggesting that she was aware of this difficulty but unable or reluctant to articulate it. Rose also stated that she had experienced a bad night and had been up a lot but that her painting was cheering her up.

Flossy's anxieties were lessened when painting as it was observed her facial expression no longer appeared anxious and she had stopped asking what she should be doing. She appeared very immersed in this process.

### **The Immersive Experience of Painting and Dementia**

All four of the participants engaged in the process of painting and it was observed that at some points in the workshop, they all appeared immersed. Although their mood and behaviour fluctuated throughout the session, it was noted that their negative emotions were not as profound at the end as they were at the beginning.

McNiff (2008: 32) states:

*'I give examples of how the arts help us improve the way we interact with others by learning how to let go of negative attitudes and excessive needs for control, learning how to foster more open and original ways of perceiving situations and problems, gaining new insights and sensitivities toward others, learning how the slipstream of group expression can carry us to places where we cannot go alone, learning how to create supportive environments that inspire creative thought, and realizing that nothing happens in creative expression unless we show up and start working on a project, even with little sense of where we might ultimately go with it'.*

The work of a number of authors who have published work in the field of 'material thinking'; (Tonkinwise, 2008), (Carter, 2005) and (Bolt and Bolt, 2006) may help with the understanding of 'how' communication of disenfranchised grief can be facilitated through the

process of painting for those living with dementia. Tonkinwise (2008) raises the question of how is it possible to project ourselves, our thoughts and feelings into an inanimate matter? Painting knowledge and understanding is personal, local and distinct from knowledge that is communicable and sharable. The sharing of this embodied, or *emplaced*, *tacit knowledge of our being-there-making in the world is at the heart of material thinking* (Tonkinwise, 2008). This is potentially the route to understanding ‘*how*’ painting can enable communication for people living with dementia.

Painting encourages a dialogue that can have therapeutic effects for people living with dementia allowing access to an expression of grief through activities that focus on the present. The lives of people living with dementia can be improved through engagement in art activities with their focus on growth, humour, and emotional connection rather than memory (Basting, 2009).

### **Implications for Practice**

An Arts Council Wales (ACW) survey mapping the arts in health provision across revealed the need to strengthen the evidence base stating that, ‘*if we don’t we risk not being able to confidently demonstrate the impact the arts engagements are having on people’s health and well-being*’. (ACW, 2018: 91)

The Dementia and Imagination Arts and Humanities Research Council (AHRC) funded project has had significant impact in North Wales through journal papers, booklets and guides for artists and clinicians working in the field (Dementia and Imagination, 2017). This paper builds upon good practice established by this research and demonstrates on a small scale ‘*how*’ being immersed in painting can access disenfranchised grief for four people living with dementia; contributing to evidence of the positive benefits of Arts in Health more generally. In

October 2017 the Arts Council Wales signed a three year Memorandum of Understanding with Public Health Wales and the Welsh Local Government Association to advance work around Arts and Health and to promote the benefits to the public and policy makers in Wales (NHS Confederation 2017). The painting intervention in this paper has forged friendships with those living with dementia and their carers, created partnerships between local galleries, local authority arts officers, the local health board and the University who are now working collaboratively establish funding for further research projects.

### **Limitations of study and potential for future research**

Within this research study there are evident limitations. Firstly, all participants who were accessed already attended a two-hour workshop art workshop every week and had been involved in creative activities. This therefore excluded people living with dementia who had no experience of taking part in a creative class. It is possible that this skewed the findings and that another sample of people would not show such an engagement with the painting. The ability to verbally communicate was varied for each participant meaning that data from semi-structured interviews was varied and dependent on each participant. However, the methodology used was able to at least partly capture the painting experience for all participants.

The nature of dementia is extremely unpredictable and somebody's behaviour and cognitive abilities can fluctuate throughout the day. Therefore, it needs to be noted for the purpose of this research that the findings capture the feelings and experiences of the participants at the particular time of the workshop. It cannot be assumed that all participants would experience the same things at a different point in time. It is also important to understand that many people living with dementia are living with a co-morbidity (Alzheimer's Society,

2015). Again this can complicate behaviours and cognitive abilities for participants and cause a decline in their daily functioning (Scrutton and Brancattie, 2016)

It was noted within this research that all participants' anxiety decreased throughout the session. Specific instances were recorded where anxiety lessened once painting, which suggests that there was a relationship between the two. However, there is ambiguity about whether the act of painting led to a lessening in anxiety or whether it was the adjustment of having spent time in a new place. In addition, many people lack confidence in their creative ability and this is not just an issue for people with dementia. This study provides a very person centred approach into investigating how people living with dementia experience and communicate through painting. Although this study only involves eight participants (on a certain day at a certain time), it could be repeated with more participants from different contexts to further explore the communicative and experiential qualities of painting.

The work produced at the workshops by the participants and the researcher is to be exhibited in a public space in 2018. Audiences can engage with the artworks to help understand the dementia condition through a carefully curated show with accompanying literature that aims to de-stigmatise. This professional context for the artwork produced by those with dementia being shown alongside professional artists elevates the status of the artwork. A similar initiative was the successful exhibition *Beyond Dementia* at the Whitworth Gallery, Manchester 2017 (Whitworth, 2017). This exhibition explored the lived experience of dementia through looking beyond the negatives and highlighting the positives of the condition through engaging those living with dementia in practical workshop activities similar to that led by the researcher here. Museums and galleries are increasingly becoming socially engaged spaces that tackle human challenges with public audiences.

## **Conclusion**

Research shows that people with dementia still maintain a '*rich inner life*' (Johnson, 2016). It is also evident however, from the findings of this project, that participants in the study felt the varying negative emotions. Engagement in the creative process can help develop knowledge and understanding about how these feelings represent the processes of loss and grief; and can through facilitating provision of an outlet that can explore '*how*' the loss effects an individual through recognition of that loss and grief as it is encountered. It can also help with developing appropriate responses for both those living with dementia and their carers as they create artworks together. This research contributes to new ways of communicating with people living with dementia. Sharing and exhibiting the artwork can help de-stigmatise dementia and raise awareness and public understanding of the condition to combat isolation and give validation to the grief experienced by those living with dementia and their carers.

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### **Author Biographies**

**Susan Liggett** is Reader in Fine Art at Wrexham Glyndŵr University and Research Centre Head for the School of Creative Arts. Her primary research interests are in the field of arts in health and her work as a practicing artist includes painting, fine art film and collaborative research projects resulting in her artwork and writings being exhibited and published in a variety of interdisciplinary contexts. She has a PhD from the University of Wales, a Post Graduate Diploma in Painting (MA) from The Royal Academy Schools, and a BA (Hons) in Fine Art from Nottingham Trent University.

**Megan Wyatt** is a practising artist and currently undertaking a PhD at Wrexham Glyndŵr University. The focus of her study is on tacit knowledge and materiality within painting as an immersive experience for people living with Dementia. In her research she creates a meaningful dialogue between herself as an artists and people living with Dementia in a gallery setting in North Wales. She has an MA in Art Practice from Wrexham Glyndŵr University a BA(hons) in Fine Art from the University of Chester.

