

Unspoken Depths: Dramatherapy and Dementia

*A Heuristic Exploration of a Dramatherapist's Experience of Working with a
Group of Older Adults with Dementia*

By Nicky Morris

Abstract

In the dual role of therapist and researcher, working in an NHS Day Hospital with a small group of clients with moderate dementia, my question was simple, yet perplexing: What could I learn from the paradox between the joyful energy of my Dramatherapy group and the intense sadness and confusion that seemed to exist on the periphery? A qualitative, heuristic approach was the most appropriate in respect of ethics and practicality. By using vignettes - in which client names were changed - as opposed to detailed case studies, I required neither written nor ongoing verbal consent - though spoke informally about it with my clients and their carers throughout the process. I followed the six stages of heuristic research described by Clark Moustakas and gathered data using the tools and techniques recommended (1990): I created a personal log book and collated my official session notes on twenty clients seen between January and October 2009.

Through the analysis of data, key themes arose: Fear and Stigma, Anger, and Self-Identity. This article may be most relevant to those working creatively with this client group, who find themselves confronted by a paradox of emotions, forced to confront personal fears and limitations. Whilst the need for further research is evident, my small and subjective study meets the minimal requirements of BADth's EPB/PBE guidelines (Ditty Dokter and Linda Winn, 2009) and could compliment larger-scale studies using both quantitative and qualitative methods.

Key Words

Dementia, Dramatherapy, Heuristic, Qualitative, Fear, Stigma, Anger & Self-Identity

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Introduction: Rationale and Setting

This article summarises a qualitative, heuristic research project completed for a Dramatherapy MA (upgrade) in July 2010. Choosing this model, I immersed myself into the dual role of therapist and researcher with a small group of clients with moderate dementia. My question was simple, yet perplexing: What could I learn from the paradox between the joyful energy of my Dramatherapy group and the intense sadness and confusion that seemed to exist on the periphery?

I have worked with adults over the age of sixty-five with organic problems and co-morbid symptoms for the past four years, within a Day Hospital attached to an NHS Mental Health Trust. My facilitation style is humanistic and person-centred, a helpful balance within a medical setting and a multi-disciplinary team. Whilst my clients laugh, sing, share stories, words and gestures, the conflicting reality is that their brain cells are slowly dying and their futures bleak. Working with them can then be both rewarding and distressing. The depths I sought to unearth stood between these opposing poles and the research marked a step towards deepening my understanding of dementia and the potential for Dramatherapy in this field.

It has been estimated that 750,000 people in the UK currently have dementia, a number now predicted to reach over a million by 2021 (Alzheimers Society, 2011). Recommended by the Department of Health (DH) Dramatherapy is a therapeutic activity with the potential to promote "...good-quality social environment and the possibility for self-expression" (2009:58).

Ethics

Ethics are complex regarding clients with dementia, who will at some stage be identified as lacking the capacity to make an informed decision. Regarding research, BADth advise one to seek clarification regarding organic brain injury, including dementia (2005:Consent). Within the Mental Capacity Act 2005, it states that research based upon clinical practice requires written consent from both clients and their primary carers - to remain an ongoing aspect of the process (UK Parliament). Repeatedly raising the issue of consent with dementia clients could be distressing however, as the majority have severely impaired short-term memory. Whilst it may be possible to obtain prior consent, it might be unethical to retain it. I needed a method therefore that would allow me to use my clinical practice both ethically and effectively. After considering several options, I decided to take a heuristic approach, which appeared to be the most appropriate in respect of ethics and practicality. Rather than writing detailed case studies, I would focus on my internal process and highlight case vignettes, in which client names would be changed. This would require neither written nor ongoing verbal consent.

Methodology

Following a University seminar on research techniques, I explored the heuristic approach, wherein one moves into the dual role of therapist and researcher. Clark Moustakas describes it as a demanding journey of self-dialogue and analysis (1990:14) and I discovered that it was a method that could ethically incorporate my work, whilst complementing the analytical and reflective processes I practice. Tom Kitwood suggests that one can only develop a genuine understanding of dementia through an embodied experience (1997:79) - in other words, by spending time with those directly affected by it. Similarly, Heuristic enquiry requires personal experience of one's research subject.

Heuristic Research

Gary Ansdell and Mercédès Pavlicevic suggest that the dual role may provoke conflicting priorities, as well as each having the potential to enhance the other (2001:103). Moustakas takes this further, suggesting the emergence of both professional and personal enlightenment, expanding one's knowledge and understanding by focusing on personal process (1990:13). Ansdell and Pavlicevic advise one to work openly with subjectivity, whilst trying to control the purely personal (2001:138). I endeavoured to follow their advice, using the core processes of heuristics: Self Dialogue, Tacit Knowing, Intuition, Indwelling, Focussing, Inner Attention and an Internal Frame of Reference (Moustakas, 1990:15-27).

My Heuristic Design:

My aim was to illuminate, then analyse the unspoken depths within my group. By using vignettes, in which client names were changed, as opposed to detailed case studies, I required neither written nor ongoing verbal consent - though spoke informally about it with my clients and their carers throughout the process. I gathered data using the tools recommended by Moustakas (1990): I created a personal log book including self-dialogue, informal interviews, relevant dreams and my response to televised documentaries. I also wrote self-reflective poetry, which seemed to compliment both the heuristic method and the existential nature of my research. Carl Leggo describes the significance of poetry within social science research, suggesting that it seeks truth without demanding answers "...uniting the heart, mind, imagination, body and spirit." (2008:167)

I collated the official notes I had written on RiO (the Mental Health NHS Trusts computerised client data-base) describing the experience of twenty individuals who attended my group between January and October 2009. Moustakas advises that one should remain free of time constraints (1990:14) so with a deadline, I was aware that my research may only touch the surface of the phenomenon. I was guided by the six phases of heuristics: Initial Engagement, Immersion, Incubation, Illumination,

Explication and Creative Synthesis (Moustakas, 1990) and broadened my research through reviewing relevant literature.

The Six Phases of Heuristic Research

My focus was the weekly Dramatherapy group I facilitate for older adults with moderate dementia and co-morbid symptoms, in a Day Hospital attached to an NHS Mental Health Trust (Section 1). Individuals are typically referred for a ten to sixteen week assessment period. I will present my findings through the six heuristic phases:

Initial Engagement:

To discover "...an intense interest or a passionate concern that calls out to the researcher and that holds important social meanings as well as personal compelling implications" (Sandy Sela-Smith, 2002:64). I had worked with the chosen client group for three years, and in reflection could see that the experience had stirred existential questions, deep emotions and internal conflicts. When first sharing my ideas with fellow students, I began to cry and felt nauseous. It was this raw, unconscious emotion that I wanted to understand.

Immersion:

One lives the question "...consciously and unconsciously, in waking state, while sleeping, and in dream states" (Sela-Smith, 2002:65). I was able to focus more deeply on my clients - reflecting at length on our time together and how it impacted upon me on different levels. It also led me to look more closely at the possible benefits of the group and I became increasingly aware of emerging themes such as 'fear' and a 'struggle with identity'. In parallel, I became more fearful about growing old and developing dementia - having several nightmares in which I lost my memory and identity. I explored these fears through a personal dialogue and in reflection it seemed there were two conflicting parts of me - one hopeful, the other frightened. This split was also evident amongst my

patients, indicating counter- transference. I wrote a poem at this time, which captured the spirit of a few of them, together with their contrasting emotions, personalities, circumstances and symptoms:

Timeless

*A man and his violin play together again
And a lady sings whilst dancing through time.
A German song, remembered and shared
A duet is born, as their voices combine*

*There's a frightened wife, on the edge of a chair
Confused, paranoid, too much to bear.
Her grip on reality is ebbing away,
She's too young to be here and cannot stay.*

*A lady from Jamaica speaks lovingly of mangoes
And a man from Kenya shares a passion for pineapples
Memories are stirred, shared and respected,
Individuals are safe, free and protected*

Within the Dramatherapy group, I have witnessed clients recover memories and develop confidence. In between opening and closing rituals, I use percussive improvisation, character work, games, guided journeys and stories. One of the most inspiring moments occurred when I played a piece of music – a combination of classical, opera and drumming – and encouraged gentle movement. Mrs Del spontaneously began to sing in German, in rhythm and tune with the music. A few minutes later, Mr Len began to mime playing the violin and duetted with her. They were both new to the group and it was moving to witness. They were carefree and happy, yet lost in time.

Incubation:

During this period, I felt a mixture of anxiety and relief. It was time to retreat from the intense focus I had devoted to the world of dementia and realised that I was unconsciously resisting the move. Moustakas suggests that the tacit dimension may reach its full potential within this stage (1990:28) and at the heart of heuristic discovery lies "...the power of revelation in tacit knowing" (1990:20).

Illumination:

"It may take place in a single moment, or it may take place in waves of awareness over time" (Sela-Smith, 2002:67). During this phase, whilst compiling and reflecting upon my data, I became increasingly aware of a deep, unconscious sense of fear. It contrasted vividly with my initial optimism. I wrote poetry and self-reflective dialogue to develop my thinking and came to identify three central themes: Fear and Stigma, Anger and Self-Identity.

Fear and Stigma: The Silent Scream

The first step is to talk openly about dementia because it's a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name. Once we have recognised the demon, without secrecy or shame, we can find its weaknesses.

(Terry Pratchett 2008: X)

I have come to understand that my group is a space in which an often unknown, otherwise inconceivable truth can be explored, whilst remaining anonymous. There is a professional divide on the question of whether or not individuals with dementia should be told their diagnosis, as revealed by R. Cheston, J. Jones & K. Gillard (2003:452) and mirrored by Pratchett (2008). I have witnessed this divide within my own work place. Cheston, Jones & Gillard describe the need for more psychotherapy and counselling groups to help those with dementia to make sense of their lives

(2003:452). Dramatherapy accounts describing Developmental Transformation work (a method developed by David Read Johnson, 1991) also focus on addressing existential needs.

The word 'dementia' was voiced by a client of mine during a Dramatherapy session for the first time recently, in response to her concern for another client's state of mind. This was a rare moment, as whilst clients often acknowledge having memory problems, they do not use the word 'dementia'. (Log, 05.09.09)

Dementia gradually takes hold of people, suffocating their abilities, personality and memories. This is a terrifying concept and fear itself has become an essential component of my research. The following thoughts were recorded in my personal research log:

I am now in touch with the fear attached to the diagnosis of dementia. It seems to exist on a cultural and personal level... stirred even by close friends and family. Dramatherapy can perhaps work with this often unconscious fear, by offering unconditional positive regard, respect, acceptance and encouragement. (Log, August 2009)

At times, my fear has transformed into self doubt and I have questioned whether Dramatherapy and I are inadequate for the client group:

I often think about Mrs Tricia. There is something so incredibly sad about her. I want to draw her, to capture the feelings she evokes in me. My pastels and pad have been out for weeks untouched. Why? What am I afraid of? Am I scared about this research? Is it worthwhile? Can I do it? Can I do it justice? Mrs Tricia is my youngest client and the most severely demented. She is so lost and desperate. I want to help her. She is at the brink of losing herself. (Log, 20.05.09)

Through my desire to know if my fears were unique or common within my team, I arranged an informal group discussion, during which spontaneous feelings were shared and recorded (07.09.09). It became clear that I was not alone in my thinking and that 'fear' was a key theme to consider when working with dementia clients. Prior to death, those affected may lose their minds completely, which adds to the depth of fear attached to the diagnosis. Stigma is another component. People are often afraid of what they do not understand and this frequently leads to misconception, prejudice and fear.

Strong feelings may be provoked within those working with individuals with dementia. These need to be understood at a conscious level, in order to prevent them from having a negative impact upon the work. Madeline Andersen–Warren (1999) advises that before working creatively with older people, one first needs to understand and challenge one's perception of older people, old age and death. (Log, 17.09.09)

Anger: Hidden and Exposed

Each week I reassure my clients that the group is a safe and confidential space in which they can express their emotions. For many, anger is one such emotion and in some cases the reason for their referral. Within the group, I have witnessed such anger appear to ease and disperse. The fear, sadness and stigma previously described, link closely to anger. I will present this through reflecting upon my formal RiO notes and informal Log, regarding two clients, in the form of vignettes:

Vignette 1

Mrs Runa was referred to us for aggressive behaviour at home. Her carer was struggling to cope. Her anger seemed to be directly related to her dementia and was regularly projected onto staff and clients in the Day Hospital. Mrs Runa was a highly independent, strong willed woman. She could not understand or accept the care that she felt was being thrust upon her.

In the Dramatherapy group, she was invited to engage at her own pace, without pressure or expectation. During the first few weeks, she was disruptive within sessions, restless and agitated. She gradually became calmer as the weeks progressed, opening up and communicating with others. At the end of session eight, when the group made wishes, she wished that her husband could be alive again. She then appeared uncomfortable when another client became tearful and hugged her. Mrs Runa told the group she had many emotions, which she kept inside because she had to. She appeared to be scared and angry about what was happening to her and this needed to be expressed and respected. Her demeanour shifted positively during her twelve week admission.

Vignette 2

During her admission, Mrs Tricia (section 4.4.a) was both my youngest client and the one suffering with the most severe cognitive decline. Overwhelmed by fear and anger, she believed that her husband had changed since she had been unwell and was mistreating her. As part of a multi-disciplinary-team, I sometimes support the patients in between sessions, during lunch and tea time. Within these moments, Mrs Tricia spoke to me of her desire to hurt her husband and her belief that she would be better off dead. Within the sessions, she was often frustrated and confused, unable to follow simple instructions, yet keen to help the other clients, who she saw as vulnerable elders. During session five, Mrs Tricia told the group that she did not know whether to "laugh, cry or disappear". Able to express her distressing feelings safely was a valuable process, though unfortunately due to the severity of her dementia and the speed of her decline, she became increasingly paranoid and with her husband and the team, agreed on an early discharge. Mrs Tricia was both terrified and angry. She could not understand or accept what was happening to her. I met her again a year later. She was an inpatient on the acute mental health ward for older adults attached to the Day Hospital. She was totally lost, unaware of who or where she was. She smiled and chatted continuously, her coping method for a terrifying situation.

Self-Identity: Liberation in the Chasm

Whilst exploring the subject of fear and anger, I became aware of a contrasting theme: The struggle to hold on to one's identity and the opportunity to redefine oneself in the Dramatherapy group. Within my group, I have witnessed individuals achieve a sense of liberation. I will present this through reflecting on the formal RiO notes and informal personal notes I wrote about three clients, in the form of vignettes:

Vignette 1

Mrs Rose was an introverted, anxious woman, who gradually gained confidence during her ten weeks at the Day Hospital. Her husband informed us that her mood also improved at home. During the first six weeks in the group, Mrs Rose appeared very anxious. She held on to her bag and would not take her coat off. She liked to speak first, though never knew what to say, often repeating the words of others. During her fourth session, she admitted to the group that she was finding life difficult and felt anxious all the time. After sharing this, she appeared more relaxed. She was smiling and described the experience as "wonderful". At week eight, Mrs Rose took her coat off and put her bag down. Over the next couple of weeks, she smiled often and particularly enjoyed percussive improvisation. She spoke of having been a violinist and said that she enjoyed our sessions because they helped her to relax and to be herself.

Vignette 2

Mr Nimble, one of our youngest clients, was referred because he had become aggressive at home. He was living with his only daughter, having lost his wife to cancer several years earlier. Their relationship was strained and she was struggling to cope. Mr Nimble had worked until recently as a gardener. His anger seemed to have evolved through frustration and loneliness, rather than as a direct physiological effect of his dementia. His ten-week attendance at the Day Hospital helped to improve both his temperament and the relationship with his daughter. For several weeks Mr Nimble seemed to be over-animated and in his eagerness to become friends with everyone, at times

appeared intimidating. At week seven, Mr Nimble engaged fully and for the first time in the group, spoke freely and emotionally about his late wife. His demeanour clearly shifted and on his tenth and final session, he described his experience of Dramatherapy and the Day Hospital as very positive.

Vignette 3

Mrs Dutch had a brief, though liberating Dramatherapy journey. Whilst struggling to cope with life-changing symptoms, she fought to hold on to her identity and to adapt to her altering self. Mrs Dutch responded with ease to the creative process, always participating fully and showing support to others. During her third session, she described deep sadness at her recent discovery that as well as being unable to organise her thoughts, she could no longer write properly. She added that English had been central to her academic and professional life. Mrs Dutch was tearful, though said it was relieving to share her feelings with the group. In her fourth session, she said she felt "safe and free" in the Dramatherapy group. She added that whilst she loved her husband very much, at home she felt she had to behave in a certain way, as he seemed to be waiting to see what she was going to do wrong next. Mrs Dutch said that she felt no judgement in the Dramatherapy space and "I have the freedom to be myself".

Unlike the majority of my clients, Mrs Dutch had not yet reached the moderate stage of dementia. She was therefore able to express herself more confidently than most. She was also both academically and emotionally intelligent, having previously worked as both a teacher and preacher. Each person with dementia responds uniquely to their illness, due to life experience, personality and a variety of both physiological and co-morbid symptoms. They will likewise respond individually to Dramatherapy.

Explication:

During this stage, I stepped back from the process in order to review my discoveries objectively. As Sela-Smith suggests, one must examine the material that lies within the depths of the tacit dimension whilst continuing to use the techniques employed during immersion (2002:68). Together with the themes of 'Fear and Stigma', 'Anger' and 'Self-Identity', a triple metaphor emerged as a symbolic way in which to view the three stages of dementia - mild, moderate and severe - and the individuals within them: *On the edge of the Chasm* is mild, *Falling through the Chasm* is moderate and *Re-emergence* is severe. I chose the word 'chasm' to symbolise dementia. Inspired by a painting titled 'Chasm' by Ralph White (2008) I explored the idea that one could perhaps re-emerge through the chasm of dementia.



Ralph suggests that inspiration and possibility may lie within a chasm - where we may fall towards our authentic soul and abandon our past inhibitions. Understandably, people fear the prospect of falling into the chasm of dementia. If we were able to view the chasm from a different perspective however, perhaps the terror could lessen for those who receive the diagnosis.

Moving Towards a Creative Synthesis:

Within this stage, I expressed my thoughts and feelings through free-flowing poetry, combining my words and reflections with those of my clients. Writing poetry enabled me to move beyond the constraints of formal language "...to create, to know, to engage creatively and imaginatively with experience" (Leggo, 2008:165). I began to see my Dramatherapy group as a 'chasm' that could hold both chaos and joy, fear and hope.

Conclusion: Implications for further Research and Practice

Relevant Literature:

Conscious of both the strengths and weaknesses of following a heuristic course, I understood the need for my discoveries to be grounded and accessible to others. I therefore spent considerable time linking my research to relevant literature. The core themes revealed within my data analysis were: Fear and Stigma, Anger and Self-Identity. Within the articles available I recognised these themes together with similar questions and discoveries: The depths of the relationship between client and therapist (Anita Gorst, 2007) the therapist's struggle to contain the chaotic inner world of the clients (Alix Harrow, 2005) the question of whether Dramatherapy can genuinely help people with dementia (Mechaeil, Graybow and Cobham, 2009) the existential needs of both client and therapist (A. Grunberg-Smith, 2000 and Emily Parkinson, 2008) and the potential for Dramatherapy to promote self-identity in dementia clients (Anne Davis-Basting, 2001).

In 2009, Adrian Burton wrote an article focusing on the lack of research supporting the effectiveness of using the Arts Therapies with dementia sufferers. He explains that whilst a literature search will reveal many accounts offering observational and anecdotal evidence, only a few describe controlled quantitative trials. I feel inclined to agree with Roger Grainger however that a combination of approaches will produce the most informed results (1999). Quantitative methods require tight procedures, large numbers of participants and an extensive time frame, to establish credible evidence through facts and figures. In contrast, qualitative methods offer flexibility and a closer connection to human experience. They aim to explore human processes, illuminate meaning and deepen understanding (Grainger, 1999). Following psychotherapy research into working with dementia clients, Cheston, Jones and Gillard claim that whilst large scale quantitative randomised control trials are effective, they will be enhanced by detailed qualitative investigations (2003:460). My small and subjective research study meets the minimal requirements outlined within BADth's EPB/PBE guidelines (Ditty Dokter and Linda Winn, 2009) and will hopefully complement larger scale quantitative studies.

Self-Identity:

This is crucial to consider. As dementia progresses, individuals move towards a cognitive death that precedes their final, physical demise. They face "...the death of a sense of identity, life roles and autonomy" (Holly Queen-Dougherty, 2001:21). Hatfield & McClune explain that whilst one must consider the impact of neurological damage, to define individuals by their impairments removes "...myriad possibilities for growth and healing" (2001:107). Dramatherapy allows individuals to play many parts and to express themselves freely, without judgement. Mirroring Grotowski's rehearsal process, each client is offered "...a terrain of discoveries, about himself, his possibilities, his chances to transcend his limits" (1995:118).

I tend to focus on the positive within my Dramatherapy group, celebrating what remains of each person, rather than mourning what is lost. This is mirrored by Davis-Basting, who developed a story-telling method in the US to use with dementia clients. She explains that "...rather than focusing on who people with Alzheimer's disease *were*, we are interested in who they *are now*, complete with missing words, repeated sounds, and hazy memories" (2001:80).

Metamorphosis:

At the start of my research journey, influenced by the ideas of poet John Killick, I was keen to explore the idea of dementia as a death of one self, allowing for the birth of another. I would now describe this transition as a metamorphosis, during which one moves uniquely through three stages of transformation. These represent the three phases of dementia described as mild, moderate and severe - also symbolised through the triple metaphor (section 4.5). The image of the 'chasm' (section 4.5) helped me to understand the paradox of emotions experienced in the Dramatherapy group by both clients and therapist. It may then be helpful for others to consider when working creatively in this field - as whilst doing so we may also be forced to confront our own fears and limitations. Through understanding these processes, I believe we will be able to work with more sincerity and more effectively with dementia clients. This is perhaps the area within which my piece of research has the most relevance.

The Invisible Fiend:

Dianne Waller (2002) begins her book about progressive illness with a verse from Samuel Taylor Coleridge's "The Rime of the Ancient Mariner" (1798). When first reading it, I was struck by its meaning in relation to the unspoken depths I had endeavoured to explore:

Like one, that on a lonesome road
Doth walk in fear and dread,
And having once turned round walks on
And turns no more his head;
Because he knows a frightful fiend
Doth close behind him tread

Thus revealed is the invisible fiend who lurks on the edge of my Dramatherapy group. In this case, the unnamed illness with which my clients struggle. Some are aware of it, some may never have been told, others simply cannot remember. What I have come to understand, is that it lingers in the shadows, no matter how much laughter or relief is generated. One may call it a fiend, or perhaps a chasm. More simply, it is dementia, complex and progressive, a relentless illness that plays a third role – invisible, often silent - in the therapeutic relationship.

Creative Synthesis: Unspoken Depths

I will conclude this article in a way that remains true to the heuristic path. After writing many poems during the process, the final one became my creative synthesis, embodying "...an inclusive expression of the essences of what has been investigated" (Sela-Smith, 2002:68). It is a poem that reveals the reality I have come to understand of the therapeutic relationship between myself and the clients with whom I have worked:

Unspoken Depths

*Between you and I there exists a void,
A wall of shadow, neither of us able to climb.
We are as close as can be, yet so far apart,
Our faces pressed up to the dank and the dark.*

*So painful is this, that we dance away,
Into songs and memories from better days.
I face you knowing what you often do not,
That you are dying within and the battle is lost.*

*Drifting ever further from the self you once knew,
Falling into the chasm, I try to join you,
I witness freely, yet unable to move,
I am futile, hopeless, unscathed, not bruised*

*Why does life do such terrible things?
Drowning now, with the pull of this disease
I can offer an anchor, a ship and a song,
I can see you and listen, shine a torch through the fog.*

*You may be battered, dishevelled and lost
But you are alive, with spirit and trust
I respect you all who have worked so hard,
To live your lives and become who you are.*

*I am scared of the future, the chasm out there
And when I am you, I hope someone will care.*

By Nicky Morris, 2010

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