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Researching art therapy with people suffering from AIDS related dementia

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Introduction

The Human Immunodeficiency Virus (HIV) and the resulting condition known as Acquired Immunodeficiency Syndrome (AIDS) have brought together areas of experience which we in the western world consider to be taboo: death, sex, sexuality, disability and contagion. The dementia resulting from the activity of HIV upon the brain perhaps represents a final taboo—a loss of the sense of oneself. AIDS dementia is not an inevitable consequence of HIV infection. It occurs in about a quarter of all those who are HIV positive, but it is probably the most feared of all the conditions related to HIV. I worked as an art therapist for 9.5 years in a hospice that cared specifically for people with HIV and AIDS. This was a new field of practice for art therapy and one which I found challenging in a number of ways (Wood, 1990, 1998). However what I found most challenging was working with the patients who had HIV brain impairment or AIDS dementia who formed a small part of my caseload. This report describes an exploration of my practice with these patients. The exploration took the form of research, using qualitative analysis techniques that included case notes made by me after our sessions. The aim of the exploration was to make sense of these clinical encounters by arriving at a set of propositions about the nature of art therapy practice in this area.

This report begins with a survey of the literature on art therapy with people suffering from a variety of dementias, thus providing a context within which to understand the present study. The next section provides a detailed description of the methodology used and is followed by a section detailing the findings of the research. These findings are then discussed and propositions are made about the nature of the art therapy relationship with people who have AIDS dementia. Some areas are also suggested as worthy of further research.

Brain damage due to HIV

The focus of this study is on work done with people suffering the effects of brain damage due to HIV. Such damage produces impaired functioning in terms of the sufferer's personality, motor skills and cognition. Several terms are used to describe this condition: HIV-related cognitive impairment, HIV-related brain impairment and AIDS dementia. The impairment can be mild, moderate or severe in which case it is described as AIDS dementia. McKeogh (1995) points out that this illness can be hard to diagnose since its onset is often insidious. Typical difficulties presented by those with this condition are lack of motivation and concerns about personal affairs, reduced speech output, flat affect or unusual gregariousness, agitation, an inability to concentrate, a slowing of thought, absent-mindedness and memory difficulties (Kocsis, 1996). Loss of balance, leg weakness and organic psychoses are also common. Not everyone diagnosed with HIV or AIDS will go on to develop AIDS dementia, and various studies show that the percentage of people who do ranges from 7 to 28%. AIDS

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dementia affects adults and children, with individuals at both ends of the age spectrum suffering in greater numbers (Starace, Dijkgraaf, Houweling, Postma, & Tramaarin, 1998).

Art therapy and dementia

The literature on the use of art therapy with clients who have any form of dementia is relatively small, although growing in recent years (Byers, 1995, 1998; Couch, 1997; Harlan, 1990; Kahn-Denis, 1997; Kamar, 1997; Orr, 1997; Osler, 1988; Shore, 1997; Wald, 1983; Waller, 1999), and the literature detailing any work with HIV or AIDS dementia is even smaller (Bartholomew, 1998; Feldman, 1993; Wood, 1998). Much of the literature focuses on the benefits of art therapy, emphasising that it can enhance self-esteem and autonomy and that it can contribute to an improved quality of life. The significance of the non-verbal processes of art therapy for self-expression also features highly in the literature. Osler (1988) describes work with a man suffering from Alzheimer's disease where the effects of painting and drawing were reflected in the client's behaviour and state of mind. Osler reports that once engaged in the art making, his client displayed less anxiety and confusion, his concentration increased and he was able to work independently. A similar benefit is seen in the work described by Kamar (1997) who used a co-operative drawing technique to engage a reluctant observer of her art therapy group for people with Alzheimer's disease. Harlan (1990) describes art therapy as supporting the individual's sense of autonomy, counteracting isolation and losses, aiding communication and the release of emotion. In this respect she is echoing Wald (1983), who suggests that art therapy may help extend the life expectancy for someone with Alzheimer type dementia through the preservation of their self-respect and dignity. Couch (1997) similarly proposes that art therapy helps preserve the client's sense of self. Byers (1995) discusses the interest in art materials that her patients with severe memory loss show—not for mark making but for exploring in a manner akin to play. Byers (1995) sees the benefits of art therapy to this client group as an opportunity for them to become absorbed in themselves through handling the materials, with the presence of the therapist providing a validation and affirmation of the client's individuality. And, like other art therapists, she found that her clients' attention span increased and was more focused during this activity. Kahn-Denis (1997) who draws attention to the evocative nature of art media highlights the sensory benefits of art therapy. In an attempt to establish exactly how art therapy benefits people with dementia Sheppard (1998) and Waller

(1999) report a control study which used measures of objective evaluation to compare the use of art therapy for people with dementia against a similar unselected group of clients who engaged in social non-art based groups. The results showed that people with dementia do respond to art therapy and specifically that it is an effective means of addressing the depression associated with dementia.

A thread which runs through the literature but which has received little exploration (with the exception of Byers, 1995, 1998; Feldman, 1993) concerns the patient–therapist relationship. Both Kamar (1997) and Osler (1988) point to the importance of the client's relationship with the therapist. They found that their respective clients would only engage in the art activities while in the presence of the therapist, declining to work if another caregiver provided similar materials (although in Kamar's (1997) paper she describes enabling the client's wife to use the drawing activity at home with the same result of calming the client when he was agitated). Shore (1997) pays attention to the mutuality between therapist and client:

Art therapy afforded him [the client with Alzheimer's Disease] the opportunity to tap into his ability to express appreciation regarding his sense of inter relatedness in a tangible and descriptive manner. Within the safety of the therapeutic relationship, he manifested a sense of mutuality. (p. 174)

Correspondingly, the limited literature on art therapy with people who have AIDS dementia focuses on the value of the non-verbal processes of art therapy (Bartholomew, 1998; Wood, 1998). Feldman (1993) discusses the impact that working with such a distressing condition has on the therapist, and recognises the ways in which she was moved to deny the realities of her client's deterioration. The therapeutic relationship is an important part of any work with clients but certainly a crucial one to explore when the client is facing death. Skaife (1993) suggests that much may be gained in work with clients facing physical and terminal illness when the nuances of the relationship are explored.

Thus, the literature indicates that art therapy can counter the effects of dementia by providing a means of expression and sensory experience which increases the individual's sense of autonomy, self-esteem and reduces their sense of isolation and depression. It suggests that art therapy may aid and even increase the sufferer's concentration, and their capacity for communication. The influence of the patients' relationship with their therapists to the outcome of therapy is an area that is beginning to receive some attention in the literature. It is the nature of the art therapy relationship that is the focus for the present study.

Methodology

The purpose of this study is to explore the relationship between myself as the art therapist, the patient with AIDS dementia or brain impairment and the art materials. The context for these therapeutic encounters with patients was a specialist HIV/AIDS hospice. One aim of this research is to propose some principles of art therapy practice with people who have AIDS related dementia based on this exploration. In referring to my interactions with patients I use the term “therapeutic encounter” because it more clearly conveys a sense of the unpredictable nature of a unique meeting, rather than the term “art therapy session” which has certain expectations to it. The present study also aims to grasp something of the way in which I (as the therapist) came to understand and construct such encounters.

Establishing a way to explore what actually occurs between the art therapist, art materials and patient is a difficult business. Direct observation is fraught with problems particularly around gaining the patient’s consent, and for people with memory problems who are also physically unwell, it could be perceived as quite intrusive. Looking at accounts of therapy seemed more appropriate, although gaining the patients’ view (through questionnaires or interviews) would again be extremely difficult or impossible due to their condition. There are very few art therapists working in the area of HIV/AIDS and although interviewing may have yielded some interesting insights, my own clinical records seemed to be the most fruitful source of data available for this study.

Record keeping is an important part of the clinician’s role at the hospice where I worked. There are multidisciplinary (MD) notes written on paper in the patient’s files and the patient has access to these. There are MD records held on computer which all disciplines contribute to, there are departmental notes from each department (art therapy is part of the Counselling and Social Care Department), and then there are my own notes. Hence my notes were a part of all records maintained on a patient. The purpose of my records was to capture the thoughts, concerns or important facts that occurred during the course of my encounters with patients. They provided me with a link between sessions and a way of putting to rest, work with one patient before embarking on work with another. They also documented the sessions in a way that could be discussed with my clinical supervisor. The notes sometimes contained something of my dilemmas and struggles. As archival data these notes provided snapshots of the practice I wished to investigate.

My first step was to define the period of time from which the notes would be selected.

A 7-year period (1989–1996) was chosen for several reasons. Firstly, this was the maximum time I had been working at the hospice when I began to write my research proposal (in 1996) and I wanted to ensure data drawn from as large a pool as possible. Secondly in 1996, the hospital was in the process of establishing a new unit specifically for people with AIDS dementia thereby formalising an approach to the care of these patients. Research using records of work undertaken after this point would introduce another influence—that of a change in the clinical context of care. My research project occurred on the cusp of this transition and it seemed an ideal opportunity for me to explore art therapy encounters that had occurred under one regime in order to make recommendations for the way art therapy might operate under another. On a personal level, working with patients with cognitive impairments had been an unsettling experience for me: the work was characterised by ragged boundaries, with several attempts to start sessions, little engagement with the art materials and then sudden endings. I had been left with very ambivalent feelings about the value of art therapy to these patients. Thus, this research project also provided me with an objective way to clarify and resolve some difficult clinical experiences.

The methodology I decided to use was Grounded Theory developed by Glaser and Strauss (1967) and later by Strauss and Corbin (1998). It was chosen because it provided a clear way of exploring social interactions through text/archival material in a manner that is sympathetic to the nature of the therapeutic encounter itself. This methodology recognises the interplay between researchers and their data, while encouraging each researcher to approach the data without pre-defined expectations. Instead a sensitive unpacking of the data yields a wealth of information about the area in question, in the same way in which the therapist’s sensitive questions and reflections enables a patient to lead the therapist to the “truth” of their situation.

Establishing a representative sample of patients with HIV/AIDS dementia was my second task, and this proved to be less clear-cut than I had expected. There were 28 patients that had either been referred to art therapy or with whom I had worked whose behaviour and cognitive functioning suggested deterioration indicative of HIV-related brain impairment. However, they did not all have an official diagnosis. I therefore decided to exclude any patient who did not have a diagnosis of HIV-related brain impairment or AIDS dementia when first referred for art therapy. This yielded 24 cases. This research project was part of my MA and as such the time available to conduct it and the format for its presentation were determined by academic requirements. Consequently, the sample

Table 1
Research sample

Case pseudonyms	Year seen	Gender	Age in years	Number of sessions
Arthur	1989	Male	45	5
Bert	1990	Male	31	2
Cole	1993	Male	37	4
Dorothy	1994	Female	34	11
Eleanor	1996	Female	40	3

of 24 cases had to be reduced to produce data of a size manageable within the prescribed academic framework. I wanted however to ensure that the variability inherent in these 24 differing encounters was still represented in the smaller sample. Personal details about the patient such as gender and age were factors to be considered. The number of sessions received by each patient was indicative of other factors such as length of admission, patients' health and interest in art therapy. The development of my skills with the accumulation of experience was also an aspect of the encounter to be explored. To achieve a smaller sample I decided to choose one patient from each of the years under consideration and decided that each patient selected should have had a different number of art therapy sessions to reflect the variables of health, admission length and interest. Consequently, the following patients were chosen (Table 1).

There were no records found for patients with AIDS dementia or HIV-related brain impairment referred for art therapy during 1991 and only one patient who received art therapy in 1992 with this condition. However, another art therapist who was my temporary replacement when I was on maternity leave saw him. I discounted these records on the grounds that my analysis of them would be different to that of my own notes in terms of the reflexivity I would be bringing to their interpretation. In addition, it could be argued that the other art therapist's reasons for writing his notes differed from my own reasons for note keeping in one important respect—not only were his notes to aid his own thinking and memory of the sessions but they were also his accounts to me of what had occurred during my absence. The therapeutic encounters explored in this research took place within a particular context—hospice care. Although not directly referred to in the analysis of the data all encounters between myself and the patients were the result of a referral to art therapy.

The sample of five patients provided me with 25 records of case notes. The quality of these case notes varied in length from two sides of a page to no more than one paragraph. The next stage of my research process was to subject the most densely recorded cases to a very detailed exploration through the pro-

cess of microanalysis described by [Strauss and Corbin \(1998\)](#). This involved an examination, questioning and interpretation of the words and phrases used in my case notes. [Garfinkel's \(1967\)](#) writings on how social activities are described and accounted for by their participants also informed my analysis. I observed the descriptions of events I had chosen to record, and also noted the absence of certain aspects that could have been recorded but were not. In addition, the type of language (words and phrases) used in the case notes was explored. These strands of thinking generated questions that enabled me to engage with the text of my case notes.

Through "mining" the data as [Strauss and Corbin \(1998\)](#) recommend, questions about conditions of the encounter and the substance of what took place guided my reading of the notes, e.g., how long was the session? Where was it held? How does the therapist engage the patient, and what is the patient doing with their body that might aid or hinder this? What does the patient want from the therapist? In answering these questions concepts began to form. I used these emerging concepts to generate more questions, which I then applied again to my case notes. These questions and concepts helped me explore the remaining case notes, and by comparing these I was able to establish the characteristics of the concepts being formed. Originally, I found 19 ideas which upon further analysis (through the procedures of coding) clustered together to form discrete categories. After thinking about the phenomena referred to in these categories, and through re-examining my case notes again several categories were amalgamated until I was left with six categories (to be described further in the next section).

Findings

In this section, I will describe the six categories that emerged from the analysis of my case notes which illuminate the key issues in art therapy with patients with AIDS dementia. These are:

1. Starting.
2. The impact of the patient's health.
3. Channels of communication.
4. Developing the therapeutic encounter.
5. Ending sessions/terminating the art therapy work.
6. Ideas or thoughts guiding the therapist.

In so far as these categories elucidate the meeting of therapist and patient they also describe the movement into and out of the therapeutic encounter. These findings give a sense of the process as well as the conditions needed for the therapeutic encounter to occur.

Extracts from my research notes have been included where appropriate to illustrate the development of the categories from the data.

Starting

There were several aspects to beginning a session with a patient. Whether or not the session would start was dependent on its location, with the deciding factor being how comfortable or familiar the patient felt in the space. On one occasion this was reversed so that it was my sense of comfort, particularly a sense of safety, which decided the location. Getting started was also dependent on a third party—the patient’s nurse—to provide a link or bridge to the therapy. This was either as an escort to the art therapy room, or as a chaperone throughout the meeting, or simply through passing on information about the patient by completing my referral form. The encounter generally started with an introduction to me and to the art materials with an invitation from me to handle or use them. Although logically getting started should mean the first meeting with the patient, the memory loss which is part of AIDS dementia meant that for some patients a subsequent session was the “first time” therefore, this category also relates to beginning each session or meeting.

The impact of the patient’s health

Understandably, this is a crucial element of work in the area of HIV/AIDS dementia and I found that it had a significant impact on the therapeutic encounter in three ways.

Firstly, their impairment and overall health determined the level at which the patient was able to respond to me and to the materials. The consequence of this can be seen in adjustments I made to the boundaries of the session and in my style of working with the patient. For example, I saw patients in their own rooms if they were too ill to get out of bed; the time allocated for session was shortened if the patient was too tired or unwell. When I worked with patients in their own rooms I brought art materials with me which were ready to handle without much preparation on the patient’s part. Thus, the patient’s condition determined the nature of my responses and the encounter between us.

Secondly, changes in the patient’s health altered the therapy. Improvements in health were reflected in the interactions between the patient and myself and in their use of the materials. It is difficult to ascertain from the records how much art therapy was responsible for any of the improvements seen. Other factors such as changes in medication, a settling-in of the patient into the ward environment and their increasing

familiarity with the clinicians, including the art therapist, all played their part, and were indicated in my case notes. Both Arthur and Dorothy serve as examples of this. Arthur’s improved mood, due to changes in his medication, led him to accept a session and to use the materials where he had previously refused. In Dorothy’s case, the change was considerable, for in one session she decided to draw the view from her window. Dorothy’s work was very different to anything she had produced previously; it was a realistic pencil drawing and was the last piece of artwork that she made with me. I wrote in my case notes “[She] seems like a different person.”

Conversely, the decline in the patient’s health led to a limiting of the therapeutic encounter; their engagement with me or with the art materials became minimal, and sessions terminated. The following memo is taken from research notes in which I refer to myself in the third person to differentiate between my role as researcher and myself as the object of research (as the therapist).

Memo: Arthur—termination of therapy.

The question that comes to mind is how much the therapist’s countertransference/difficulties with facing physical deterioration influences the termination of treatment. It is not recorded in any way. Certainly in notes she acknowledges “soreness on his face is very marked,” and that Arthur “looked unwell.” A question must be asked about the absence of further notes. My memory is that Arthur did not want to see me and went into a decline, and that a point was reached beyond which a forced contact on my part would have felt invasive.

This extract points to the third area of impact, which is my countertransference response to the patients’ health and their physical presentation in the sessions. I have already mentioned the way in which I adapted my interventions to accommodate the patient’s level of functioning. However, the impact went beyond practical/technical considerations making an impression on my feelings about our meetings. This sub-category was highlighted in the analysis through a notable absence in the case notes as much as by what I had recorded. Although I had not written much on this aspect I found that in reading through even quite scrappy notes memories were evoked including feelings of impotence, vulnerability and sadness. One finding therefore of this research is that the impression of these encounters is still with me. On another level my case notes showed that, although not working in an overtly psychodynamic way, I used my countertransference to the patients at the time to plan subsequent sessions, e.g., where work with the patient had evoked a sense of threat.

Channels of communication

I eventually decided upon the name for this category after much wrangling with the data (or perhaps more truthfully the research methodology). The process of classifying, comparing and coding gave me several discrete “meaning units” (McLeod, 1997, p. 94) which eventually seemed to group together around concepts of the patient’s use of their body, their use of the art materials and their use of words. Also my words and actions appeared as a corollary to those of the patient’s. At first I saw these as separate categories, but in separating them I felt that the unity of the phenomenon being explored was lost. I decided that they were sub-categories joined by the fact that they could all be described as channels of communication. Through these channels both patient and therapist could be regarded as trying to communicate. This seemed to make more sense and conveyed something of their didactic nature.

The body

I had noted patients’ unusual or bizarre presentations of their body. Eleanor paced continually; Bert chewed coins while we talked. My first meeting with Arthur led me to record his coughing and nose blowing as occurring for “quite long periods of time” as though he had contravened some acceptable length of time for such activities. These behaviours presented a barrier to communication, while at the same time providing a strong communication of the patients’ isolation and the distress caused by their condition.

Art materials

The concept of the patient’s use of their body leads naturally onto their use of the art materials with which they engaged physically. The data showed several instances where body sensations or concerns about the body were communicated through the use of art media. An example taken from my case notes:

Dorothy used platercine—made a piece—started flat with little pieces which she named—“boot,” “cat,” “dog,” “French loaf” (which she marked with her nail), “carrot,” “Bugs Bunny.” Then her working of the platercine got cruder and more aggressive. She tore and twisted and talked of twisting—being churned up—being/feeling cheated at work.

In a later session Dorothy talks about her doll (present in her room) having its fingers eaten off (my observation showed them to be intact). Dorothy then bites her own nails and firmly places a piece of nail in the platercine structure.

Alternatively patients refused to use the materials. This lack of engagement is itself a communication

and gives rise to thoughts about the patient’s fear of exposure through making marks or their inability to comprehend the task. My presentation of the materials was designed to stimulate interest and exploration, without the making of marks being the only option. In the early days, I presented ready-made images (magazine photographs mounted on sugar paper) to provide a focus for discussion. It seemed I was motivated to try a variety of tools to establish communication with the patient.

Words

When patients did speak much of what they said was characterised by confabulation, with the patient weaving the objects of their surroundings into a story which conveyed their own personal meanings, like Dorothy and her doll. Sometimes a sense of isolation, or fear came through. Often the desire to connect with another person seemed to compel the interaction. Sometimes patients’ words were straightforward and insightful responses to something I had said; sometimes they were bizarre or aggressive or sexual; sometimes words were never used.

My interventions

My interventions can be interpreted in many ways, however their inclusion in this category emphasises them as channels of communication. The overwhelming characteristic of my interventions that emerged was their flexibility. I seemed prepared to try anything. I paced with Eleanor and set up art materials in patients’ bedrooms. I viewed tapestries and showed magazine photographs. My case notes give an indication of my insecurity about such flexible practice, but also a belief that once a channel of communication had been established the processes of art therapy would take over. My style included an acknowledgement with the patient of their difficulties and a desire not to patronise. My responses to the patients showed ways of connecting with them that involved adapting the structure of sessions and commenting on here-and-now situations.

The following extract from my notes shows an example of my intervention and something of the process of connection, disconnection and reconnection that characterised the developing relationship. Arthur’s initial disinterest in my art materials was followed by a willingness to look through some magazine photographs that I had mounted on sugar paper. He expressed an opinion about each picture and then his thoughts wandered.

... he misheard me several times and made oblique associations to my comments. He said that he wasn’t well in response to mishearing me. I said maybe I didn’t speak clearly enough. He said that the

problem was him—he was going mad. We go on to talk about what he means by “mad” (from author’s case notes).

The moment in which we both acknowledged our lack of connection (mishearing/being misheard) a connection was established and a moment of insight followed which deepened the connection between us. With a change in medication Arthur’s mood and sociability improved beyond recognition and this first session with me was completely forgotten. However, a relationship did develop with me viewing his embroideries and artwork from his past. He subsequently borrowed some art materials from me and eventually had an art therapy session in which he raised his concerns about his health and uncertain future. The familiarity important to developing a relationship evidently paying off.

Developing the therapeutic encounter—making relationships

There is a clear recognition throughout the case notes and from the analysis that this was a key element in my work with these patients. The cumulative result of each encounter seemed to aid familiarity and ease with the work, which enhanced patients’ use of art therapy. The notes indicate the variety of ways in which I was prepared to make some connection with the patient. For example the records in 1989 give the impression that I regarded the relationship with Arthur as moving in and out of art therapy. When Arthur wanted to discuss his art, but clearly stated that he did not want art therapy, I took the time to talk with him and to look at his recently rediscovered portfolio of pictures made when he was in prison. The use of the word “chat” in one recording implies that my focus was on developing the relationship rather than encouraging him to use art. Work with Eleanor in 1996, shows a very tentative approach to developing a relationship which unfortunately ended abruptly when she suddenly became ill. The balance between the art therapy relationship “proper” (a dynamic interplay of patient, their artwork and therapist) and simple human contact is one that was constantly being tested in my relationships with these patients. It was a point of professional vulnerability for me, as the following extract from my analysis shows:

Memo: developing relationships

Session 27/10 appears to be one in which no art was made, rather the patient talked. I have noted “counselling?” which I understand as a question of whether Dorothy should be referred to the counsellors. I have also noted the subject of Dorothy’s talking as two-fold: “wants company” and “wants to talk about dying.” It’s difficult to know if the latter

is Dorothy’s way of gaining the former. From earlier case notes Dorothy does seem concerned with the “being here” existential issues. I have also noted that she feels comfortable with me (this is our 8th session) as though our relationship is providing a safe context in which she can talk about dying. In reply to the question of counselling I have written “me to continue,” it did not seem right to introduce another professional.

Ending sessions/terminating the art therapy work

The termination of each session and the eventual cessation of the work with the patient were two aspects of this category to emerge. The recognition of the emotional impact of endings each week and the power of boundaries to evoke deep felt anxieties was recognised by me in the case notes in relation mainly to patients. For example, Dorothy would become upset when I brought our sessions to a close each week. She found it hard to believe we would meet again the following week, either because she saw herself leaving the hospital before then due to improvements in her health, or because she may die. Exactly who brought the encounter to a close for that week appeared to vary, sometimes there was an already established time limit (30 min or 1 h) on other occasions the patient brought the meeting to a close, giving their poor health as the reason.

Ideas or thoughts guiding the therapist

As stated in the introduction to this report my capacity to think about my therapeutic encounters with patients was, and continues to be, in part aided by the process of writing my case notes. What I chose to record and what I chose to omit give some indication of my approach to the work and the assumptions that guided my interventions. Such ideas form the final category of my findings. The most significant idea running through the records, which has been highlighted already in the other categories, is that I believed that art therapy must involve a relationship with art materials and that my task was to bring about such a relationship. The underlying assumption is that something beneficial would occur in the patient once a connection with the art materials had been established. When this was compromised in some way I was anxious and insecure about my practice and felt my identity as an art therapist was threatened. References in my case notes to a worry about being patronising reflects an assumption on my part that however impaired the patient was, I believed that they still retained some capacity for insight and would know if I treated them with any less respect than other adults. In some ways, this ties in with another idea that was implied in my notes; that through the art work I could

glimpse something of the patient's fundamental personality, and their way of being in the world. This encouraged me to find out about the patient's life before their dementia. Also there is little in my notes about the specifics of the patient's impairment. It is as though I was trying to focus on the person beyond and before the impairment with a hope that art therapy could provide some continuity or reclamation, if only for a moment. There seems some evidence for this view in my analysis of Dorothy's case notes where I link her frequent representation of food with the knowledge of her pre-HIV diagnosis of an eating disorder and substance abuse, perhaps to the exclusion of the orality that may have been stimulated by the plastercine she so often used or the regression inherent in her condition.

There is evidence that I used the patients' own responses to me to find a point of connection, especially if these responses contained a glimmer of an interest in "art." However my concern about moving away from orthodox art therapy practice (as I had defined it after years of working in a psychodynamic way in mental health) and the concomitant loss of professional identity was indicated by my keeping the focus in the encounters on art, however interested or disinterested the patient was in "art therapy."

This category also demonstrates my willingness to try a variety of ways of connecting with patients. For example, using the sound of my voice (in talking) as an attempt to provide a sense of holding reminiscent of music therapy when it seemed the patient may not even understand what I was saying.

There is evidence from the case notes that I was prepared to adapt my usual boundaries. I accepted a chaperone on one occasion and engaged in informal contacts with patients in order to increase their familiarity with me, something I would never do with other patient groups. The importance of teamwork, and especially of my colleagues' support, featured in my notes. For example, when I felt threatened or concerned about my safety (Bert's bizarre behaviour and aggressive manner) I alerted the wider staff team and tried to remove any ambiguity about our contact, such as meeting in a neutral space rather than his bedroom.

There is little evaluation of the therapeutic encounters with patients in my notes. Using my case notes to record an evaluation of the work with patients or to describe the termination of the therapy was not a matter of course. There may be several reasons for this such as the inclusion of this material in the wider hospital notes, or it may point to a difficulty on my part about drawing the work to a close. This needs further research. The absence of this material is interesting and will be discussed in the next section.

Discussion

The aim of this research was to explore the therapeutic encounter that results from a meeting between the art therapist, the art materials and a patient with HIV/AIDS dementia. From such an exploration I hoped to be able to propose some principles for art therapy practice; by constructing a framework for understanding what had occurred in the past I hoped to arrive at a set of ideas which may be a helpful reference point for future work. The eventual aim of the grounded theory approach is to generate a theory about the basic social process at work in the phenomenon being studied. The categories that I have identified in my analysis point to one overarching idea—that of "connection." By connection I mean the moment where communication takes place between therapist and patient and something is understood, and insight or a sense of relief transpires. In arriving at the idea of connection I became aware of its converse—isolation, and it is here that I shall begin.

Isolation

Isolation is a multi-faceted issue that affects the individual with AIDS dementia, their loved ones and the professionals who care for them. [Rosner David and Sageman \(1987\)](#), in their explanation of the use of art therapy for people with AIDS suggest that such individuals have an existing experience of isolation. They do not expand on this but I take it to mean that since most people with the HIV virus in Europe and America come from sections of the population which are marginalised from mainstream society for reasons of sexual orientation and illegal drug misuse, that this is the cause of their isolation. People from the African continent who are HIV positive in England (whether they have come here as asylum seekers or students) will also experience a degree of isolation. [Joffe \(1997\)](#) in her account of the representations of AIDS in both lay and Western scientific communities describes the way in which AIDS is constructed as "other," belonging to groups outside the norm, thereby diminishing the perceived threat of the condition on the individual members of the mainstream culture. The secrecy surrounding a diagnosis of HIV inevitably leads to isolation and the process of illness can compound this further.

Not stated in my case notes but certainly available to me from the hospital records was the fact that three of my five sample cases came from cultures that were not British. These patients were, for differing reasons, isolated from their homelands. Dorothy's presentation and reason for referral was her distress at being alone, resulting in extreme attention seeking behaviour. In Eleanor's case her symptoms included

the loss of language, social skills and continual pacing. Harlan (1990) suggests that the therapist thinks about the meaning that lays behind a patient's behaviour. In particular, she suggests that the wandering common to dementia may be the patient's way of searching for something they feel has been lost. This concept of isolation fits the patients described in this study. I would therefore suggest that overcoming a sense of isolation might motivate the patient to enter a therapeutic encounter with the art therapist. Aldridge (1993), in discussing the benefits of the creative art therapies for people with AIDS, points to the increasing isolation felt by these individuals. He highlights that a consequence of being HIV positive is that opportunities for intimacy in relationships become increasingly limited, and suggests that art, music and drama therapies can offer the possibility for intimacy within a creative relationship.

The loss of their usual communication skills as a consequence of HIV activity in the brain is surely a very isolating experience and one that not only causes frustration and distress in the sufferer but also in the caregiver. None of the patients studied here initially requested art therapy. It was suggested by my colleagues, usually the nurses, that art therapy might be able to help with their patients' communication and expressive difficulties. The staff team's sense of isolation in the face of such a condition must also be recognised as a motivating force either towards or away from connecting with their patients. Feldman (1993), an expressive therapist, writes of her desire to deny her AIDS dementia patient's sense of isolation, and describes her need to give him gifts as a denial of his eventual death.

Professional isolation is something that must be considered as a motivational factor on my part as a therapist in entering the therapeutic encounter. Art therapy was a new addition to the large MD team in 1989 and one that still needed to demonstrate its value in the subsequent years, especially when funding was being cut. In agreeing to assess a patient with AIDS dementia (which is how the first meeting was always characterised) I was ensuring a connection with colleagues that would mitigate my isolation and ensure a higher profile for art therapy.

Thus, isolation is a factor in terms of the patient's illness, society's response to it, and their cultural origins; it is also a factor in terms of staff members' reactions to this particular patient group and their responses to one another.

Connection

From this research I would suggest that achieving a meaningful connection with a patient is the aim of the art therapist, in both her relationship with the

patient and in the art making. For the patient connection provides an increased sense of continuity of their experience, and may mean that they are able to mobilise a more functioning part of their personality. I would like to propose that the relationship between therapist and patient provides a context in which to view and experience the multiplicity of connections that are possible in the therapeutic encounter.

My willingness to find a way of connecting with patients has already been described as a striking feature of the data. I chose a location in which to meet which was familiar to the patient in order not to exacerbate further their sense of disorientation and isolation. I used magazine photographs as the focus for discussion; I responded to invitations to look through Arthur's portfolio of artwork that he had made while in prison; I paced with Eleanor, and sat and watched her pace. In reading through the literature this adaptability is not unusual. Harlan (1990) describes needing to be more active with Alzheimer patients than she had expected. Connell (1992) although working with people who have cancer, explored the difficulties of using art therapy within the limits of a patient's declining health. She writes of the therapist's role as one of supporting the patient to discover their creativity; she finds many ways of making a link with the patient, following up on their personal interests. Byers (1995) describes taking the art materials to her patients when they are unable to come to the art therapy room. Kamar (1997) has a strong reaction to her patients with dementia, which she describes as a desire to break through the barrier of the disease. This results in her struggling to make what becomes a significant connection with a patient through co-operative drawing. Feldman (1993) suggests that the task of a therapist with patients who have AIDS dementia is to develop ways of promoting interpersonal communications and connections.

The discussion so far has presented the movement from the therapist (armed with art materials and all the right conditions) towards the patient with the aim of making a connection. However, it must also be recognised that there can be a resistance within the therapist to making such a move.

Byers (1998) in her discussion on art therapy with the cognitively impaired elderly patient argues the clinical importance of the therapist acknowledging her negative feelings. She found that by attending to her own countertransference she was able to engage more empathetically with her patients. In an earlier paper Byers (1995) identifies the difference in ages and therefore life-stages, between a young therapist and an elderly person with dementia as one reason why therapists find it difficult to connect. Shore (1997) also draws attention to the effects of this age difference, but found that it helped rather than

hindered her work. However working with AIDS dementia patients is unlike other areas of dementia for it is more likely that the therapist and patient are of similar ages; in fact in my sample all the patients were of a similar age to me, apart from Arthur who was only 16 years older. Thus, the resistance to connect with those who have HIV/AIDS can lie instead with an over-identification causing the therapist to withdraw on some level. This may in part account for the tailing off of my involvement with Dorothy, and my acceptance of the end to our work when the nursing staff told me that she wanted to spend all her time with her family. With hindsight a final session to conclude our work together would have been appropriate, and yet since I had not suggested this at the time I wonder if my withdrawal was the easier option for me. Another reason for this was the fact that in our final sessions Dorothy stopped using the art materials. The non-use of the art materials was an important area to come out of the research. The analysis has highlighted my belief that art therapy must involve the use of the art materials, and it also drew attention to my insecurity when this did not happen. Such a belief meant that I worked hard to create the conditions which would enable the patient to use the materials. The example of my work with Arthur shows that location and familiarity can be important precursors to art making. In addition, the recognition of the impact of the patient's variable health on their involvement in art making enabled me to contain my anxiety about "proper" practice. In other words as my experience accumulated I became less worried if a patient did not use the art materials. However, art and art making always remained a feature of my interactions with patients.

It has been suggested in the literature, and very tentatively by the findings of the present study, that the art materials may themselves aid an individual's memory of sessions and give a sense of continuity of experience from week to week. This was the case for Osler's patient (Osler, 1988) who, when shown his previous art work, remembered it and displayed as a consequence a change in mood which Osler describes as tranquil. Dorothy is an example from this study where, despite her poor memory, she was able to recognise from week to week the plastercine that she enjoyed using.

The work described in the literature on art therapy and dementia also suggests that the use of art materials can enable the patient to connect with something of him or herself which lies beyond their cognitive impairment. Kahn-Denis (1997) writes:

In most cases . . . the art releases feelings unexpectedly and gives the witness (the art therapist) a means to cut through an ambiguous communication sys-

tem and see the person without layers of confused thought. (p. 198)

Thus, the connection lies in enabling a reconnection of the patient to a more functioning part of himself or herself. Harlan describes it as follows:

[Her intention was] to offer the individual the opportunity to identify with his or her former, high-functioning self in the hope that keeping an image of that self alive would help preserve it as long as possible. (Harlan, 1990, p. 103)

The proposition that art making demonstrates that a reconnection with or limited restoration of the dementia sufferer's personality is an idea not without controversy. The non-verbal nature of art activity makes any explanation of the artwork in words a translation in which some of the meaning is lost. When art making is undertaken by a person whose condition prevents insightful or coherent discussion any understanding of the resultant art work and its capacity to reflect the artist/patient's personality must inevitably be an interpretation on the viewer's (therapist's) part. This is seen clearly in the debate around the last paintings of the abstract expressionist Willem de Kooning who developed Alzheimer's disease in later life. Espinel (1996) suggests that de Kooning's art demonstrates the power of art making to heal, and he wonders at the power of creativity to adapt to the assaults of age and disease. However, it has been argued that de Kooning's late paintings were no more than an expression of his dementia—a symptom—rather than a sign of recovery. Gibson (1996) and Meulenberg (1996) suggest that without an ability to convey conscious intentions in his painting, de Kooning's paintings should not be considered as art. Gibson (1996), rather arrogantly I feel, dismisses any benefit in painting for people who have dementia. Whether or not art making does represent some reconnection with the self can only be determined by those who knew the patient/artist before their impairment. The process of witnessing the art making and attending to the feelings evoked in the art therapist by the patient/artist and their activity can provide a context of meaning in which the art work can be interpreted. Although this is an interpretation it is, I would suggest, preferable to dismissing art making as non-communicative.

The possibility that there can be time for a relationship to develop between therapist and patient before the onset of dementia is another aspect of working with people with HIV/AIDS that sets it apart from the other dementias (where patients come into contact with the art therapist once their dementia has occurred). If we accept the previous argument that if the therapist is able to know something of the person

prior to their cognitive impairment, then they are in a good position to determine what is being lost and what remains of their patient's personality. Aldridge (1993) endorses this by suggesting that the involvement of the arts therapist with patients should come early on after a diagnosis of HIV so that there is enough time for a stable long-term relationship to develop. The patients excluded from the present study (because I began working with them before their brain impairment developed) would be good subjects for another exploration of this aspect of the work.

Termination

The end stage of our therapeutic endeavour is that the patient will die (Aldridge, 1993, p. 285).

This is the sharp reality that hangs over all work with those who have a life-threatening or terminal illness. The inevitable outcome of the therapeutic encounter is separation and loss.

The strength of the connection with patients can be felt when disconnection occurs.

One significant issue that has been raised by this study is the lack of notes on this aspect of my casework. In most cases deterioration in the patient's health precipitated the end. The fragility of the framework for the therapeutic encounter is always an acknowledged difficulty in work with patient who have a terminal illness for this reason (Pratt & Wood, 1998), and so perhaps there was no need to record what I always knew would be inevitable. However, the gradual tailing off in my note taking for each case could be seen to reflect my own gradual disengagement in preparation for the end. The fluctuation in health, which is so often a part of terminal illness, must account for my ambivalence to close the work. For example, in Eleanor's case I had hoped she would resume her contact with me once her condition stabilised. From my analysis of my notes I discerned a tone of simple acceptance in some of the records which left me wondering how much of a relief I had felt when the encounters terminated. If this was an element of my feelings about the work it can also give some indication of the difficulties that must be overcome within the therapist in order for her to stay connected in her encounters with the patients. This point is reminiscent of Byers' (1998) idea of blockages in the therapist and patient relationship.

Issues of endings in therapy when the client is dying have been discussed by Lee (1996) and Schaverien (1998). Both writers describe the profound effect that their encounters with their clients have had upon them. I share this experience. The fact that I have been motivated to write about encounters that took place between 3 and 10 years ago and the finding that strong memories of these encounters

were evoked easily by my case notes, indicate something of the impression left on me by the work. Like Lee, the process of this research and of writing it down has enabled me to make sense of and move on from some distressing encounters with people of my generation who were not only losing their physical attractiveness, employment, relationships but were losing the memory of who they had been and how they connected to others.

How I dealt with ending with patients at the time is only hinted at in my case notes. Perhaps I had no need to record endings since these would have been explored in other places such as through talking informally with colleagues and more formally with my supervisor. And yet, the absence of this material in the notes raises questions about the impact upon me of the accumulation of distressing experience. In developing my categories "impact on therapist of patient's appearance," which later became a sub-category of "impact of patient's health," I noted the following:

Is there a link between the paucity of recorded observations and the development of practice? Has the therapist become blind to certain data due to familiarity and a need no longer to ponder or think about certain things?

I now believe that rather than becoming "blind" or no longer needing to think, that I was avoiding thinking because of the extremely distressing nature of the work. This is an area that merits further research, for the well-being of both staff and patients.

Conclusion

The particular difficulties experienced by people with AIDS dementia means that social interactions are awkward and opportunities for self-expression are limited. Likewise, there are difficulties for carers, both lay and professional, such as feelings of profound helplessness and sadness in the face of the patient's physical, social and cognitive losses. These feelings are also compounded by the fact that, until recently when the use of new drugs has introduced an element of reversibility (Lodge, Tanner, & McKeogh, 1998; Ward, 1998), death usually came within 6 months of a diagnosis of AIDS dementia. My contact with such patients over a 7-year period left me with a confusing picture of what I had offered and what art therapy could provide and became the subject for this study. In contrast to much of the art therapy literature on working with people who have dementia it was the brief relationship between myself as therapist, the patient and the art materials—described here as the therapeutic encounter—that was the focus of my research. What has emerged is the hypothesis that

establishing a connection between patient and therapist was the thrust of the therapeutic encounters, and that creating conditions which maximise this connection was an essential part of my practice. Much of my early confusion about the use and value of art therapy for this patient group was clarified in the process of this study, and it enabled me to recognise the confusion as a response to the very challenging needs of these patients. Firstly, the research shows that I needed to be flexible and able to adapt my boundaries to accommodate patients' particular difficulties. Secondly, that I had to recognise and deal with my own anxiety when faced with patients who did not appear to be able or willing to use the art materials, and finally that investing emotional energy in relationships which are quickly disrupted by illness and death does take its toll. My research shows that the familiarity of the location and the therapist to the patient are important factors to consider when embarking upon work with this patient group. It also highlights how the variabilities of the patient's health influence the clinical work and have an impact upon the therapist. The research has also raised questions about the role and function of the art therapist's note taking. This is an area that would benefit from more research and one which could provide interesting insights into how therapists understand and construct their encounters with patients. I had hoped, from this research, to propose some principles for art therapy practice with people who have AIDS dementia. What I have found is that beyond being prepared to take a flexible and patient focused approach to the work, there is very little difference in the principles of practice with this and other patient groups. The main difference lies in the time frame, which is extremely fragile with patients who are terminally ill. A resistance within the therapist to engage with the patient is perhaps the most important principle to recognise, for once the therapeutic encounter begins the therapist must mobilise her thinking and skill as she would for any patient. In developing the concept of connection I have found it helpful in understanding my work with other types of patients, such as nursery children. It may well be that this concept is descriptive of other areas of art therapy practice beyond HIV/AIDS dementia.

In conclusion, I have argued that a sense of isolation within both the patient and the therapist can be a motivating force towards a therapeutic encounter. I have proposed that the idea of a connection between the therapist and patient in therapy is a profound experience that goes beyond language, and should be considered as the substance and goal of the therapeutic encounter. I have also drawn attention to the impact upon the therapist of working with people who have a terminal illness.

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