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The Arts in Psychotherapy 29 (2002) 207–219

THE  
ARTS<sup>IN</sup>  
PSYCHOTHERAPY

# 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.

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