Circumventing Burnout in AIDS Care

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Previous studies have determined that health care providers who specialize in AIDS care are particularly susceptible to work-related stress and resulting burnout. This qualitative study derived themes from interviews with three occupational therapists in order to examine these findings. Ultimately, stress and burnout were not dominant themes in the interviews. Instead, the prominent themes were loss; death and dying; boundaries, connecting, and empathy; education; and coping strategies. An accepting attitude toward diversity coupled with the use of both individual and institutional stress management techniques modulated stress and prevented burnout among the study participants.

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"AIDS evokes powerful emotions with significant consequences" (Peloquin, 1990, p. 271). In fact, no other recent medical condition has been infused with so much meaning or challenged the medical establishment as much as has AIDS (Peloquin, 1990). These meanings have led to the development of individual, institutional, and sociocultural factors that are stressful to health care providers who treat patients with AIDS (Cooke, 1992; Frierson & Lippman, 1987; Gala, Pergami, & Invernizzi, 1993; Hurley, Grossman, & McGriff, 1990; Piemme & Bolle, 1990; Shubin, 1989). Individual factors contributing to stress among AIDS caregivers include, but are not limited to, fear of contagion of an incurable condition, negative or punishing attitudes toward persons with AIDS, feelings of professional incompeptency, issues surrounding death and dying, and grief overload (Baker & Seager, 1991; Cooke, 1992; Ferrari, McCown, & Pantano, 1993; Gala et al., 1993; Shubin, 1989; Siminoff, Erlen, & Lidz, 1991; Wade & Simon, 1993). Institutional factors may include inadequate resources and staffing, institutional bureaucracy, communication problems, lack of control, and case overload (Macks & Abrams, 1992). Sociocultural factors include social stigmatization and lack of peer, familial, and community support because of persistent negative attitudes toward high-risk groups (Frierson & Lippman, 1987; Gala et al., 1993; Hurley et al., 1990).

Health care providers consider treating persons with AIDS to be a considerable source of stress (Bernstein, Rabkin, & Wolland, 1990; Gala et al., 1993; Peloquin, 1990; Siminoff et al., 1991). If not properly managed and ameliorated, this stress may lead to burnout syndrome (Cooke, 1992; Ferrari et al., 1993; Gala et al., 1993; Macks & Abrams, 1992). Although there is no consensus regarding its definition, it is agreed that burnout syndrome has negative implications for individual health care workers, institutions, and the client population being served (Cooke, 1992; Macks & Abrams, 1992; Wade & Simon, 1993).

The majority of previous studies have measured stress, as manifested by perceived stress, anxiety, and fear, through surveys (Atchison, Beard, & Lester, 1990; Baker & Seager, 1991; Falk-Kessler, Barnowski, & Salvant, 1994; Ferrari et al., 1993; Frierson & Lippman, 1987; Vincent & Schkade, 1990). Several authors have advocated the use of individual methods to manage work-related stress (Cooke, 1992; Ferrari et al., 1993; Frierson & Lippman, 1987; Gala et al., 1993; Lego, 1994; Piemme & Bolle, 1990; Shubin, 1989; Wade & Simon, 1993). Others have advocated institutional intervention for prevention of burnout syndrome (Cooke, 1992; Gala et al.,
Occupational therapists in two western cities were asked to nominate other occupational therapists who worked in HIV and AIDS care as prospective study participants. Because burnout tends to occur after a period of 1 year (Gala et al., 1993), inclusion criteria communicated to the nominating therapists were working full time in an HIV-AIDS unit for at least 1 year and within 6 months before the study. The search for prospective participants who met the inclusion criteria proved more difficult than anticipated because of the limited number of occupational therapists who work full time in AIDS care. Five therapists met these criteria. When contacted by phone, all five agreed to participate; however, only three were available for interviews within the time frame established for data collection. Although this number represents few participants, phenomenological studies, also called qualitative or ethnographic studies, often use a limited number of participants (Schmid, 1981) because data gathering can be “time consuming and restricts attention to a small number of cases” (McClintock, Brannon, & Maynard-Moody, 1983, p. 154). These three participants came from two settings in two western cities: a specialized psychiatric unit, whose focus was gay and lesbian clients and clients with HIV-infection, and an AIDS adult day health program.

Participant 1 was a 31-year-old Caucasian lesbian woman from Samoa on a leave of absence from her job site because she had begun graduate course work. Her intention was to leave occupational therapy to begin a new career. Nonetheless, she had remained active in disseminating information about gay and lesbian issues as well as AIDS issues. She had been a registered occupational therapist for 8 years and had specialized in AIDS care for 5 years.

Participant 2 was a 31-year-old Pacific Islander who identified herself as heterosexual. She was married and had a child. She had been a registered occupational therapist for 8 years and had specialized in AIDS care for 3.5 years.

Participant 3 was 35 years old and described herself as a “white girl.” She had been a registered occupational therapist for 2 years and had worked at an AIDS adult day health program for 14 months. She indicated that she would like to present AIDS-related material at occupational therapy national conferences.

Data Collection and Analysis

Data were collected through individual interviews that followed a semistructured format. They primarily evolved from general descriptive questions that were based on the participants’ responses (Spradley, 1979). In this way, participants controlled what themes and issues were discussed and explored. The initial interview, which lasted about 1 hr, was initiated with a single grand-tour question (Spradley, 1979): “Tell me about the issues you face as a consequence of treating patients with HIV and AIDS.” The interviews also incorporated predetermined questions specifically dealing with self-reported stress levels, size of caseload, and personal and institutional methods of coping with work-related stress. These questions, however, merely resulted in a redundancy of data because the participants had addressed most of them during discussion of general themes. Follow-up interviews were conducted with two participants for elaboration and clarification, and each lasted approximately .5 hr. All interviews were audiotaped and transcribed verbatim.

Data also were collected by observing two participants in their work settings to determine how they functioned within their natural environment (Portney & Watkins, 1993). The researcher recorded these observations in a journal along with field notes of responses to interviews and her thoughts, feelings, and behavior in relation to the interviews, observations, and analyses.

Analysis was conducted through multiple readings of the transcribed interviews and field notes. Triangulation
of data collected from the field notes and audiotapes as well as peer examination (Krefting, 1991) were used to establish the truth value of emergent themes and the credibility of the findings. Peer examination involved having an experienced qualitative researcher read the interview transcripts and identify emergent themes. The findings of the reviewer matched those of the author. Interpretations of emergent themes from in-depth interviews, participant observation, and field notes were cross-checked and validated to ensure trustworthiness of the findings.

**Themes**

Notably, the participants used very similar expressions in describing their experiences. The prevalent themes were loss; death and dying; boundaries, connecting, and empathy; education; and coping strategies. Although all of these issues are interrelated, they will be presented in separate theme areas to facilitate simplicity and clarity of discussion.

**Loss**

All participants indicated that the worst aspect of AIDS care was loss. Indeed, they were more affected by the social losses—loss of support networks, such as friends and partners, to AIDS; social isolation; and alteration of roles—and functional losses experienced by their clients than by, in many instances, the actual death of the clients. For example: “The loss and pain, and not so much in terms of people dying, but people losing function, people seeing their roles and everything go.” The persistent functional decline and cumulative social losses persons with AIDS experience were readily apparent to and greatly affected the participants.

Over time, the participants, as members of the therapeutic “community” in which loss was pervasive, began to experience a similar sense of cumulative loss, as did their clients. Ultimately, this shared sense of loss fostered understanding and an empathic response:

I just think about a lot of the gay men who talk about most of their friends being dead, and most of us don’t experience that; most of us haven’t had our peer groups dying off. But there’s a way that that is an adopted place for us in AIDS care because all of a sudden, we are in the same position as those earlier generations of gay men who have lost... their close friends... There is something very profound about making sense of that kind of loss.

Because of the sometimes lengthy period during which occupational therapy intervention is provided to persons with AIDS, the participants described watching their clients’ progressive physical and cognitive losses secondary to HIV and AIDS. This challenged the participants’ concepts and measurements of treatment success. One participant stated:

I think also there’s a piece about having to... keep redefining success in what I do because it’s not that this person lives longer, it’s not that they recovered a certain function and went on to have satisfaction in that area. Sometimes the people I put the most energy into are people who are closer to end stages of life. So maybe it’s an extra week at home, a day that they were able to walk, or respite for their caregiver. But it’s different markers for success.

The participant then described how she coped with the decline of clients:

...my defense mechanism is that I know they have AIDS. So there’s... some emotional, not a distancing, but... the expectation that [decline] can happen... that I am seeing them toward the end of their life... so that when they start declining, I feel it, but here is almost like, “Well, I knew that was going to happen.”

**Death and Dying**

Although the participants were affected by the deaths of all their clients, certain deaths affected them more than others. Two participants described how the death of an individual client would initiate a sense of collective mourning for all those who had died within a certain period. One of these participants described the experience as “piles and piles of poignant moments that just start building up over time.” Conversely, the remaining participant reported being affected by each death as it occurred. One participant who had specialized in AIDS care for 3.5 years, discussed being less affected by the deaths of clients than she once had been:

You get a little bit more used to people dying when you have large numbers of people dying... In the month of October of 1995, we had 14 people die... I don’t want to say we get immune to it, but it becomes more of a daily factor... a more frequent occurrence.

Death was identified as part of “a life cycle” and “a spiritual issue” and required “quiet time to reflect” for “making sense of it.” The participants described the importance of acknowledging the death of clients by talking to colleagues, both informally and in support groups, and by attending facility-sponsored memorial services.

**Boundaries, Connecting, and Empathy**

Each participant described “connecting” with some clients more than others. Although the participants believed that developing connections with clients was not exclusive to AIDS care, they indicated that certain aspects of the specialty area promoted the establishment of connections. These aspects included getting to know and working with clients in a holistic manner over several months, interacting with clients within the therapeutic community, and working with clients with a wide variety of needs who have been, in many instances, socially isolated:

For so many people, this is the only sense of community and home that they have ever experienced in their lives. They have been rejected a lot, so they take us on as their family of choice; they depend on...
AIDS education. Instead, the participants strongly advocated the need for AIDS-related education to address negative attitudes toward persons with AIDS that they were able to incorporate into their practice. In all instances, the participants described sharing their feelings about the work. Similarly, one of the participants, as a member of the gay and lesbian community, spoke of feeling “more empathy” and “commonality” toward her clients. In all instances, the participants described sharing a sense of understanding, an empathic sense with those with AIDS that they were able to incorporate into their work.

Education

The need for AIDS-related education to address negative attitudes toward persons with AIDS was readily acknowledged. Although universal precautions (e.g., washing hands before and after client contact, donning surgical gloves to avoid contact with body fluids) were mentioned, they were not identified as the most important aspect of AIDS education. Instead, the participants strongly advocated intensified educational efforts in the areas of cultural awareness, homophobia, and acceptance of differences:

I think we need to address [negative attitudes] not so much with knowledge about [HIV] transmission because I don’t think it’s a rational fear. I think a lot of the negative attitudes are more based on morality rather than fear of infection. And we need to approach it from a sort of cultural perspective. Part of that is looking at that notion of other and that notion of different and how difference is devalued in our culture. Being HIV positive is a devalued difference in our culture.

The participants advocated introducing diversity issues into the occupational therapy curriculum and identified a need for students to initiate learning and understanding through direct interaction with others. They indicated that this interaction could be facilitated through volunteer and observation opportunities.

The participants reported varying degrees of self-involvement in the AIDS education arena. One participant, who was active in her facility’s AIDS task force, among other things, described how her involvement in AIDS education functions as a “coping skill”: “Disseminating information is . . . a way to have control in a situation in which there’s not a lot of control. . . . Conferences and research and writing, those are other ways, I think, that I cope.”

Coping Strategies

Myriad individual and institutional strategies to cope with AIDS and work-related stressors were identified and discussed (see Appendix). Individual methods that all three participants used included talking to others, exercise, and having a life outside of work. Institutional programs included staff support groups, retreats, memorial services, and ample time off. Each participant indicated that the collaborative efforts between self and facility were successful in facilitating appropriate coping. Nonetheless, although the participants reported using the institutionally bolstered programs available to them, they emphasized individual coping methods.

Having “informal discussions” with colleagues was identified as an invaluable coping method: “It’s sort of intense kind of work, and you build relationships with the people you work with.” These informal relationships were described as “a safe place to talk about how somebody’s loss felt and to talk about some of the harder things about the work.” Further, a universal point of discussion was the sense that persons outside of the therapeutic community “don’t understand” the issues the participants faced and coped with. This reinforced the participants’ reliance on the informal relationships formed with colleagues.

Most interestingly, work-related stress was not a dominant topic in the interviews. In fact, participants did
not mention the word burnout without prompting from the researcher. The participants did not speak about work in terms of stress. Instead, they spoke of the “intensity” and “challenge” of the work. Although intense and challenging issues such as death, dying, and loss were identified, none of the participants indicated that the issues were unmanageable or negatively affected their ability to continue to specialize in AIDS care.

The participants were asked why stress and burnout did not factor into the interviews as much as previous studies would have suggested. One stated:

Maybe we are more aware of...activity configuration: work, play, self-care...We may be more balanced...I think [occupational therapy practitioners] might just be better at coping, too...Maybe we know more coping skills...It also may be that people don’t feel safe to say that (they are stressed or burned out). I mean, burnout has a pretty negative connotation.

Another participant explained:

I think part of it is also...people think of [AIDS] as, “It’s a bunch of gay people, a bunch of IV drug users.” And so I think that part of the perception of the work [as stressful] is based on some of those stereotypes...Possibly, there is so much fear around the disease...When I worked in pediatrics, there were times when I would go home and say, “God, this seems so unfair. These totally sweet little kiddos who are not even getting a chance to have a normal life.”...[Yet] you don’t hear people talking about a high level of stress and burnout in pediatrics.

Discussion

Although the physical and cognitive decline of clients with AIDS affects the health care providers working with them, witnessing the substantial cumulative role and social network losses these clients experience is particularly problematic for the occupational therapy practitioner. This is likely because occupational therapy practitioners are concerned with the overall quality of life, functional capacities, and emotional well-being of clients rather than their physical and cognitive condition alone.

As evidenced by the participants’ coping strategies, this study has illustrated the effectiveness of collaborative efforts between individuals and institutions in managing work-related stress among occupational therapists who specialize in AIDS care. In fact, among the study participants, stress and burnout were not as prevalent or as severe as has been indicated in previous studies on AIDS care (Baker & Seager, 1991; Cooke, 1992; Frierson & Lippman, 1987; Gala et al., 1993; Piemme & Bolle, 1990; Shubin, 1989; Wade & Simon, 1993). Although stressors were identified and discussed, none of the participants indicated that the stressors were unmanageable or threatened their ability to continue to function in their professional capacities over time. Clearly, the use of both individual and institutional coping methods is essential in modulating the intensity and challenge of the work, preventing burnout, and maintaining the emotional and psychological well-being of practitioners. Although institutional support is important, development and use of individual coping methods is vital, according to the study participants.

The participants expressed a personal investment in and dedication to AIDS care. This may have resulted in an increased tolerance for the emotional demands of the work. In addition, because of their dedication, the participants may have been particularly motivated to develop and use individual coping strategies to maintain their professional competency and effectiveness.

Wade and Simon (1993) indicated that survival bonding among AIDS care specialists occurred in the early phase of the AIDS epidemic, before implementation of institutional stress management strategies. However, the participants in the current study continued to obtain informal support through bonding with colleagues, despite the fact that formal, institutionally bolstered support programs were in place. According to the participants, the formation of informal support networks was a naturally occurring coping mechanism used by AIDS care providers who shared a similar sense of intensity and challenge around work. Reliance on these informal relationships was reinforced by the universally maintained perception that persons who were not AIDS care providers did not understand the issues they faced.

Previous studies have indicated that irrational fear of contagion and negative reactions to stigmatized groups, such as gay men and persons who use IV drugs, were a major source of stress for health care workers (Baker & Seager, 1991; Cooke, 1992; Frierson & Lippman, 1987; Gala et al., 1993; Shubin, 1989; Wade & Simon, 1993). Although the participants acknowledged that such fears and biases exist, they indicated that they neither shared nor experience them as stressful. The participants’ lack of bias was likely the result of their direct contact and interaction with, or being a member of, stigmatized groups associated with AIDS before working in AIDS care. One participant identified herself as a lesbian woman having a relative who is HIV positive; another spoke of being influenced by two friends, gay men with AIDS, to specialize in AIDS care. This direct contact and interaction fostered positive attitudes, understanding, and an empathic response toward persons with AIDS.

Indeed, because of an empathic sense, the participants connected with clients. According to Peloquin (1995), empathy requires a disposition that is “congruently rational and emotional, an act of analytical observation balanced against one of holistic synthesis. Occupational therapy practitioners who would be empathic must reflect the duality of thinking and feeling in their disposition,
presence, and actions” (pp. 27–28). This statement helps to explain the conflict between the tendency to connect with clients and the need to maintain boundaries that the participants spoke of. Although establishing a connection is a natural result of an emotional response toward a person, professional boundaries must be maintained to ensure continued rational analysis of the client’s treatment and, in the case of persons with AIDS, decline. On the basis of this study’s findings, a connecting–boundaries dichotomy is, apparently, unavoidable for occupational therapists who specialize in AIDS care. Coexistence of professional demeanor and emotional responses is inevitable. An acceptance of “the duality of reasoning and feeling” (Peloquin, 1995, p. 25) was evidenced by the participants.

Jackson (1995) postulated that a lesbian, gay, or bisexual orientation “may serve as a symbolic theme that contributes to personal identity and bears upon daily occupations” (p. 677). Consequently, as sexual orientation may influence the meaning assigned to occupations, acknowledgment and acceptance of sexual orientation may be instrumental to the therapeutic process (Jackson, 1995). This premise has been realized by the two facilities from which the study participants were drawn. That is, as part of the therapeutic process, the facilities have established environments that are accepting of the sexual orientation of their clients: “For so many people, this is an environment, both for staff as well as clients, that they can be who they are. People can be open about their… sexual orientation, which can be emotionally very freeing.” Taking into consideration the social losses and isolation persons with AIDS face, the facilities have promoted a sense of community, family, and safety for their clients. For example, one facility provides dining and community outings for clients in order to diminish social isolation and promote positive occupations. These “environmental opportunities” (Jackson, 1995, p. 678) provide for mutual support, companionship, and acceptance. The meaning clients ascribe to their lives, occupations, and situations are acknowledged and accepted in order to facilitate the therapeutic process.

Implications for Practice and Directions for Future Research

As stated earlier, the majority of previous studies of the stressors of AIDS care have measured stress, as manifested by perceived stress, anxiety, and fear, through surveys. Although surveys may be useful in determining the incidence of perceived stress and burnout, they do not allow for personal narrative regarding the causes of stress in AIDS care, personal reactions to the stress, or individual coping strategies. In this way, surveys may restrict discussion of the many complex, personal issues related to treating clients with HIV and AIDS. According to Portney and Watkins (1993), “The qualitative approach emphasizes an understanding of human experience, exploring the nature of people’s transaction with themselves, others, and their surroundings” (p. 239). Because of the emotional impact of AIDS, it is important to understand the experience of occupational therapists who treat persons with AIDS. This phenomenological investigation revealed that AIDS care is not perceived as stressful so much as “intense” (provided greater understanding of the coping mechanisms that occupational therapists who specialize in AIDS care use) and illustrated the effectiveness of a collaborative effort between individual and institution in coping with the stressors of AIDS.

All three participants stated that many of the issues they face are not exclusive to AIDS care. Similarities between treating persons with AIDS and other high-need populations, such as persons with traumatic brain injury, spinal cord injury, cancer, and other terminal conditions, were identified. Therefore, a similar study methodology could be used to facilitate an understanding of the emotional impact among therapists who treat these populations. Such studies could help to determine whether institutional and individual coping methods for stress currently used in AIDS care could be appropriately applied to facilitate coping among therapists working with other populations.

The need for increased AIDS education among occupational therapists and students has been well documented (Atchison et al., 1990; Falk-Kessler et al., 1994; Hansen, 1990; Vincent & Schkade, 1990). Advocated educational efforts have focused on HIV transmission and ameliorating negative attitudes toward high-risk groups. However, specific recommendations for obtaining these educational goals have not been provided. Therefore, it is recommended that occupational therapy schools intensify educational efforts in the area of cultural diversity, homophobia, and the acceptance of differences. Diversity issues could be thoroughly incorporated into curricula. Most importantly, schools could encourage student participation in community-based AIDS programs. If this is not possible, persons with AIDS from the community could be invited to speak on campus to occupational therapy students. Either scenario would provide students an opportunity to interact directly with persons with AIDS. Direct interaction is an effective way to ameliorate fears and negative attitudes and to facilitate understanding and acceptance of differences, thus fostering an empathic response.

Current occupational therapy practitioners need to be aware of and sensitive to how sexual orientation serves as a symbolic theme that contributes to personal identity and influences choice of daily occupations (Jackson, 1995).
Acceptance of sexual orientation and resulting choice of occupations is instrumental for the success of the therapeutic process. Furthermore, practitioners should understand how the cumulative losses and social isolation associated with AIDS may affect clients with AIDS.

The demographics of AIDS are changing. According to Pizzi (1993), “The epidemiologic data show that women are the fastest growing group of people with AIDS in the United States” (p. 724). Just as the participants’ facilities have adopted and adapted programs to meet the unique needs of gay men with HIV, AIDS, and chemical dependency issues, these facilities should also be able to adapt to the special needs of women with HIV and AIDS. Facilities and individual therapists should be responsive to the changing demographics of AIDS. ▲

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Appendix
Individual and Institutional Coping Methods Used by Study Participants

Individual
- Acknowledging emotions
- Attending AIDS conferences
- Denial
- Establishing boundaries
- Exercise (walking, racquetball, yoga, etc.)
- Expectation of client decline
- Frequent vacations and travel
- Humor
- Informal friendships with colleagues
- Life away from work and work–play balance
- Massage
- Meditation
- Philosophical outlook
- Psychotherapy
- Research and writing
- Spirituality
- Talking to others and colleagues
- Time to reflect

Institutional
- Ample time off
- Contact with other AIDS agencies
- Flexible schedule
- Monthly memorial service
- Monthly unit support group
- Multidisciplinary team approach
- Staff meetings
- Weekly facility-wide support group
- Weekly supervision meeting
- Yearly retreats

References


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