

TOPLINE ANALYSIS OF FOCUS GROUPS FOR AIDS CAREGIVERS

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Introduction

Two focus groups were conducted in Kansas City, Missouri among individuals who are caregivers to those with AIDS. The groups were conducted on March 23, 1998. Approximately two-thirds of the respondents were professional caregivers and the rest were volunteers, one was a parent.

Findings

1. Although there were a wide variety of care giving roles represented (counselors, case workers, hospital workers, direct caregivers) serving a diversity of environments (i.e., hospitals, churches, non-profit agencies, prisons), participants all shared very similar feelings, opinions and perspectives about their experiences.

Probably *the* most prevalent and powerful theme which emerged from these groups was the fact that these caregivers perceive that their experiences encompass both very positive and uplifting feelings as well as very negative/stressful feelings.

It is important to these caregivers that others understand that the joy and sense of accomplishment is just as prevalent and powerful as the frustration and grief. Most of these caregivers do not want their experiences to be perceived as all pain and loss and, in fact, many report that they receive more back than they give.

Despite their strong desire to emphasize the sense of connectiveness, purpose and even fun they sometimes experience; the frustrations, anger and isolations were obviously a very strong element in the caregiver's experience. It is these more negative feelings which often resulted in 'burnout'. Several of these caregivers had in fact recently experienced significant burnout and had changed jobs or responsibilities in order to overcome personal problems resulting from the stress of dealing with the AIDS issue.

2. The consistent feelings which these caregivers expressed can be categorized as follows.

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<ul style="list-style-type: none"> • Sense of <i>honor and privilege</i> that they are involved in life and death struggle with others and that individuals with AIDS 'let them in' their lives. • A sense of strong <i>emotional connection</i> with clients, patients, friends with AIDS. • A renewed sense of joy in life itself and its <i>simple pleasures</i> – often directly related to the AIDS patient's approach to dealing with their disease. 	<ul style="list-style-type: none"> • A feeling of being alone with their pain and stress – <i>isolation</i>. • Often an <i>ongoing anger</i> at hospitals, services organization, laws/government and often the families of individuals with AIDS ... that they perceive are not doing enough or doing the right things to assist those with AIDS. • A feeling of <i>helplessness and impotence</i> was prevalent among these caregivers; a sense that they cannot do enough to fix problems, whether it be with obtaining the right medication, providing ongoing day-to-day assistance or helping them receive the services that they need. • Virtually all of these caregivers felt <i>overwhelmed and pressured</i> with the sheer amount of tasks that needed to be completed and the belief that they were the only one available to help or the only one aware of the need. • The sense of <i>sadness and loss</i> which comes from the death of individuals they are working with is an ongoing struggle for many.

4. The loneliness, helplessness, sense of pressure and anger was evident throughout these discussions ... discharging of emotions were common in these groups. It is imperative to note that ***all of these caregivers*** perceive themselves as emotionally strong individuals who can take a lot of pressure; these individuals are reluctant to appear weak or vulnerable. This reluctance to admit pain and the need for help is a significant barrier to obtaining assistance and support. Understanding their struggles in more depth is imperative if an effective program is to be developed.

◆ ***Loneliness*** – this loneliness was the result of a combination of factors:

- A belief that they had to keep up an image – a stoicism in order to appear professional and efficient.
- A belief that most others in society simply do not understand the struggles and needs of this group of individuals – and that their efforts are often misunderstood and not respected.
- Not wanting to personally appear weak or to make others feel sorry for them, particularly when individuals with AIDS are exhibiting such bravery/courage.

◆ ***Anger*** – The ongoing anger which these individuals consistently experience was quite evident. This anger is often not channeled and they generally feel very constrained in voicing their anger.

- ◆ **Helplessness** – Virtually all of these respondents felt extremely helpless relative to being able to meet the often overwhelming needs of individuals with AIDS. They were constantly in touch with their own personal limitations in getting the services, medications, assistance, support that these AIDS individuals need. This helplessness was particularly difficult because these respondents see themselves as efficient, effective and strong individuals.
- ◆ **Overwhelmed** – The sense of being overwhelmed is directly correlated to helplessness; this is always more to be done than they can accomplish; they also feel pressured and have a belief that they are the only ones that see the needs and thus it is incumbent upon them to satisfy all of them.
- ◆ **Sadness** – Most of these individuals indicated they experienced bouts of sadness, particularly at the loss of someone they worked closely with; a few individuals though mentioned they had chronic sadness when dealing with this disease and all of its many manifestations.

5. Despite the very obvious need that these caregivers have for emotional relief – companionship/camaraderie and honest dialog – there were clear barriers to receiving such support and help.

- Do not want to feel vulnerable and have their professional image tarnished.
- Do not want to reveal even to themselves their intense feelings – afraid that they will breakdown or not be able to continue the work.
- Often perceive that their needs are much less compared to those who actually have AIDS – feel embarrassed or ashamed at needing support or help.
- Are simply not aware of a safe, comfortable environment where they could ascertain help.

6. It became obvious that virtually none of these caregivers had a safe, comfortable place to go to address their frustrations, sadness, helplessness and anger. The only two individuals who seemed to have sufficient support was a person who also had AIDS and went to an AIDS support group and another woman who was part of a group from church who provided assistance to one individual. The rest of these professionals, as well as volunteers, often felt extremely isolated and indicated they had very few options.

Although several of the professional caregivers did mention that some of the organizations provided workshops or seminars, they were adamant about the fact that they generally did not feel comfortable being totally candid ... they were generally more politically oriented and were not focused on meeting the individual emotional needs of the caregivers.