

BOUND BY BOUNDARIES:

The Informal/Formal Care Divide in the HIV/AIDS Field

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Introduction

Networks of HIV/AIDS support vary dramatically depending on the population in question. For some populations, the families and friends take on the brunt of this work. For some of the highly stigmatized individuals in Winnipeg and Regina there is a much heavier reliance on the formal care systems — doctors, nurses, therapists, outreach workers, etc. While the formal systems take this on during the course of their work, they are not necessarily prepared for the impact of this demand, or for the complications that come when clients shift from needing professional support and care to needing more interpersonal and “informal” care. Where do the boundaries sit?



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Methods

As part of a broader study on the social support networks of people living with HIV or AIDS, we conducted in-depth interviews with 17 service providers (14 from Winnipeg and 3 from Regina) from five agencies. The interviewees included 1 front line support staff, 1 board member, 5 medical staff, and 10 social service staff members (outreach workers, social workers, etc). The content analysis of the interviews identified the issue of professional boundaries as a central theme.

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Findings

The analysis suggested some level of tension in relation to the interpersonal boundaries between formal caregivers and clients. This emerged primarily in relation to the creation and maintenance of boundaries as the following comments suggest.

“You do cross a boundary somewhere when they rely on you more than they would their own family members.”

“...I know there are some of my clients that have identified me as their friend. I think I would too probably identify them as a friend in a sense.”

“Some think I’m like their auntie, some like a big sister, some like their mom from hell when they get the mom look. Some see me as a friend. A part of the family, or very, very intimate and special to them.”

“In this job you have to know your boundaries and you’re always crossing and making mistakes and going back and going, okay, how do I change this for next time?”

“I make up my own rules that protect me; that’s it.”

Particular difficulty was experienced in how these boundaries fit with the expectations and responsibilities of the workplace.

“I often find some of those policies are contradictory, like in our theories and practice of work that we are trained to do, you’re first, you’re told to help others, that you’re there to help them, but they put policies in place, and rules in place where they inhibit you... from helping.”

Conclusions

The findings suggested that the issue of boundaries needs to be pro-actively addressed by service organizations within a comprehension of its inherent tensions and complexities. Most service providers felt that their organizations could do more to support them better. Among the suggestions were the following: staff retreats; debriefing sessions; better communication; more recognition that staff is knowledgeable; more team work across areas; more understanding of the effects of violence, death and other vicarious trauma on the staff.