

Peer supporter experiences of home visits for people with HIV infection

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Purpose: This study's purpose was to explore the experiences of peer supporters regarding their work in a home visit program for people with HIV infection.

Patients and methods: A qualitative descriptive study was conducted using focus groups. Participants were 12 HIV-positive peer supporters conducting home visits with people living with HIV/AIDS in South Korea. Thematic analysis was used to analyze the data.

Results: Six major themes emerged: feeling a sense of belonging; concern about financial support; facing HIV-related stigma and fear of disclosure; reaching out and acting as a bridge of hope; feeling burnout; and need for quality education. The study findings indicate that although peer supporters experience several positive aspects in the role, such as feelings of belonging, they also experience issues that make it difficult to be successful in the role, including the position's instability, work-related stress, and concerns about the quality of their continuing education.

Conclusion: The findings suggest that to maintain a stable and effective peer supporter program, such positions require financial support, training in how to prevent and manage stress associated with the role, and a well-developed program of education and training.

Keywords: human immunodeficiency virus, qualitative research, workplace experience

Introduction

It is important to reduce health disparities in people living with HIV/AIDS (PLWHA) and to improve quality of life (QOL), as many PLWHA have unmet support needs.¹⁻³ PLWHA are at a high risk for suicide ideation,⁴ depression,⁵⁻⁷ and loneliness,⁸ and are reluctant to disclose their HIV status because of HIV-related stigma.^{8,9} Depression and HIV-related stigma can compromise QOL, and the findings from previous studies suggest that social support may have a buffering effect on HIV-related stigma and depression.^{5,10,11} Despite growing interest in the use of peers to provide much needed social support, studies of HIV-positive peer supporters are limited in South Korea. Previous studies have explored the activities and experiences of peer roles such as peer educators and peer counselors,^{12,13} the experiences of males and females in peer counselor roles,^{14,15} and the effects of peer counseling interventions.^{16,17} Peer supporters can play many roles, including providing care and treatment, emotional support, and/or service referrals,^{12,13} as well as fostering hope.¹⁸ The findings from several studies indicate that the support from HIV-positive peers has positive effects on care compliance¹⁹⁻²¹ and behavioral change.^{16,18} Thus, peer support may be an important intervention strategy for improving QOL and health status for PLWHA.

Peer support may be a particularly effective intervention in situations where perceived HIV-related stigma may limit the support received by PLWHA, as fear of

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disclosure makes it difficult to access support from others and may also make others reluctant to provide needed care.²² To address such concerns, a government-funded home visiting program, which used HIV-positive peers to provide support to PLWHA, was implemented in the South Korean capital city in 2004. As of May 2014, eight trained HIV-positive volunteers worked as peer supporters, undertaking a monthly home visit program for socially and economically marginalized PLWHA. Peer supporters provided various support services based on PLWHA needs, such as delivering side dishes for daily meals, home cleaning, washing, accompanying patients to hospital, being a companion (listening to their stories), and making referrals to social services or community resources.

New beneficiaries of the peer supporters were selected twice per year from referrals from the infirmary, medical, or other institutions. Individuals with poor health or disabilities or who were older were given priority.

Limited research has focused on the role of the peer supporter, particularly in the context of HIV/AIDS, and even less research has focused on the perspective of the peer supporter in South Korea. Additionally, the peer supporter role and the experiences of the peer supporter may vary across context and culture. This study was conducted to explore the experiences of peer supporters in a home visit program for PLWHA in a city in South Korea.

Methods

Design and sampling

We conducted a qualitative descriptive study using a focus group method²³ to elicit descriptions of the experiences of peer supporters conducting home visits with PLWHA.

Peer supporters working for home visit programs to support PLWHA in the community in South Korea were invited to participate. Researchers contacted the coordinators of the peer supporter programs in the city, explained the study purpose, and arranged to meet with those willing to participate in the study. There were two types of peer supporter programs in the city: a government-funded program, which was the only one of its type in South Korea, and a non-funded program. Peer supporters from both types of programs were invited to participate, resulting in a sample of 12 peer supporters for the focus group interviews. Of the participants, six received government funding and six did not. Peer supporters without government funding did not receive special training. The peer supporters who received government funding received 40 hours of formal training relating to work ethics, role and attitude as a peer supporter, effective communication, privacy

protection, how to provide emotional and social support, and how to refer the client to other assistance if needed.

Data collection

Three focus groups were conducted over a 3-month period in 2014, each with two to six participants. The focus groups were conducted in a private room at a site with convenient participant access. Each focus group session lasted 1–2 hours. The sessions were audiotaped with participants' permission and transcribed verbatim.

The following topics guided the focus groups: 1) participants' experiences with their role; 2) benefits and difficulties experienced in work activities; 3) satisfaction with their position and working conditions; and 4) barriers for peer supporters working for home visit programs. A focus group interview guide was formulated and evaluated by qualitative research experts for its appropriateness. Sociodemographic data were collected including sex, age, years since HIV diagnosis, education, and duration working as a peer supporter.

Data analysis

The focus group transcripts were analyzed through manual open coding, using the process of thematic analysis, whereby two investigators independently coded each transcript, then compared the codes to establish interrater reliability; when discrepancies in coding occurred, the investigators discussed and resolved these by consensus. The sociodemographic data were also analyzed descriptively.

Ethical considerations

The study was approved by the Institutional Review Board (SMUIRB-2013-6) of Sangmyung University, Cheonan-si, South Korea. Written informed consent was obtained for each participant prior to participation in a focus group. The investigator emphasized the voluntary nature of participation and their right to withdraw from the study at any time. The study purpose was explained, as well as all procedures that would be used in data collection, including efforts to protect participants' identities.

Results

Study population characteristics

The sample ranged in age from 34 to 70 years (mean [M]=46.67 years; standard deviation [SD] =10.76). The six volunteer peer supporters ranged in age from 36 to 70 years (M=53.0 years; SD =11.59), and the six funded peer supporters ranged in age from 34 to 45 years

($M=40.3$ years; $SD=4.89$). All were male and had been HIV-positive for between 4 and 14 years ($M=8$ years; $SD=3.13$). Most participants had education beyond high school (83.3% of the total sample; 66.7% of the volunteer peer supporters; 100% of funded peer supporters). The duration as a peer supporter ranged from 3 months to 7 years ($M=36.50$ months; $SD=28.74$).

The analysis of focus group interview data revealed five major themes: 1) feeling a sense of belonging; 2) concern about financial support; 3) facing HIV-related stigma and fear of disclosure; 4) reaching out and acting as a bridge of hope; 5) feeling burnout; and 6) need for quality education. Each of the major themes is described in the following sections.

Main themes

Theme 1: feeling a sense of belonging

Participants considered their position as a peer supporter positively; they perceived that working as a peer supporter meant they were connected and accepted by other peer supporters and they felt they have a place where they belong and people who care about them. They appreciated the opportunity to interact with other peer supporters, discuss their common interests, and share their experiences with the group. For example, one participant stated, "Working as a peer supporter, it helps me psychologically and physically a lot. Above all, I feel a sense of belonging. That's why I am continuously working."

Theme 2: concern about financial support

Participants expressed concerns and dissatisfaction with the level of government financial support. They worried about the possibility of no funding and possible cessation of work. For example, one participant stated, "Somehow I worry about the discontinuity of this program." In a similar vein, another participant stated, "I wonder whether this program can be continued again next year. Each year, we have to write a proposal to get funded and the budget has been cut back gradually." Another stated, "We could not think about the long-term plan without knowing how long this program will be supported or last."

Peer supporters working without funding wished for government financial support for the peer supporter program to help minimize disparities. For example, one participant stated:

We [peer supporters working without funding] visit someone intermittently rather than regular home visiting, especially when they are sick. With government funding, it will

be possible to visit the people who are marginalized and need social support and promote their quality of life.

Theme 3: facing HIV-related stigma and fear of disclosure

Most participants expressed difficulties visiting the homes of HIV-positive patients which they attributed to stigma associated with HIV disease that is held by many people in the community. One participant described it as follows: "The hardest thing during the work is people's negative perceptions of HIV-positive people." Stigma may be directed toward the peer supporter because of the association with HIV-infected individuals for whom they provide support and because the peer supporters are also HIV-positive. The peer supporters expressed concern that their HIV status could be disclosed to the community in the process of undertaking their role. Peer supporters reported that they disclosed their HIV-positive status to the patients they visited, but were reluctant to disclose themselves to neighbors for fear of stigmatization. To prevent disclosure of their HIV status, peer supporters described their efforts to keep their HIV status confidential by not disclosing the reason for their visits. Participants described it this way: "It is difficult to answer when someone asks where we are from and why we are visiting that person" and "Sometimes, we make up a story, such as we came from church, rather than telling the truth of why we visited in order not to be disclosed."

Theme 4: reaching out and acting as a bridge of hope

Peer supporters reported that they visited all beneficiaries monthly and provided extra visits for people who needed additional home help services. For patients who had no family, they would also make visits when the patient was hospitalized. The peer supporters felt that they provided practical help to people with HIV by sharing their own experiences living with HIV disease. One participant described it this way:

I know their status and how far they came based on my experiences. I tell them it is a hard time, but I encourage them to be patient because it [taking medications and emotion] will be much better than [it is] now after several months. I share how I have coped with the difficulties of HIV disease and medical treatment and provide anticipatory guidance and support they need.

Peer supporters also perceived other major aspects of their role to be monitoring patients for any difficulties they

might be experiencing and referring them to the appropriate clinicians or social services as needed. One participant stated, “We visit someone who is sick when we get a call for help and we bring him to the hospital if necessary” and “There are people who have been diagnosed with HIV and do not know the social service system at all. We inform them about the social services they are entitled to and refer them to social workers when needed.”

Some peer supporters noted that they had been beneficiaries of the program and that it was very helpful for them, especially when newly diagnosed, because of the enormous changes required. They also noted that the support they received was important to their progress in living successfully with the disease and their eventual role as a peer supporter. One participant described it this way:

Support from the home visit service was not enough, but it was great help for me, especially when I was cut off from my family and society and sick. I felt embraced by peer supporters. It helped me to cope with difficulties, to regain my health including emotional stability, and to transform myself as a peer supporter.

Theme 5: feeling burnout

Participants said they felt stress and burnout while working as a peer supporter, and felt they needed support of their own. When informing someone that they would no longer receive peer support because of the tight budget, they felt distressed because they felt they were letting the patients down. Participants also identified uncivil behavior from patients as a source of stress and burnout. One participant described the uncivil behavior this way:

We had to put up with the uncivil attitude of the patients, otherwise we will fall apart, especially when the patients treat us like ‘we know all about you and you are just same.’ We are mentally tired because we listen to them and cannot fight back even though they pour their anger out onto us and we have to bear them.

Despite the identified stress and burnout associated with the peer supporter role, participants were reluctant to use workplace counseling because of the difficulty discussing their concerns with someone they perceived as a coworker. They also perceived that such counseling was ineffective: “I have never seen anybody who was satisfied with it [workplace counseling] for the last 3 or 4 years and I do not want to use it either.” While they expressed a preference for counseling outside the

workplace setting, which they saw as being more confidential, they were not able to use such services because they would have to pay for this counseling out-of-pocket. Participants reported using other strategies to manage their work-related stress, such as talking with friends or participating in activities that diverted their attention from the distress (eg, Internet shopping, exercising, drinking, or socializing at a café). Despite the role of stress as described by the participants, it was not identified as a primary reason for leaving the position. Major reasons identified for quitting the peer supporter position included personality clashes between a peer supporter and the patients to whom they had been assigned or dissatisfaction with the nature of the work. One participant noted, “It is too bad wasting the skills and know-how of trained supporters.” Another participant noted that the turnover rate was highest in the first 3 months of the position.

Theme 6: need for quality education

Most participants wanted to learn more so they could be more effective in their role of peer supporter. Several participants expressed concern about the gap between what they wanted to know and the education and training being provided. Participants were critical of the continuing education provided, which they described as “textbook knowledge”. Instead, they wanted education and training that focused on practical knowledge that would support and improve their performance in the peer supporter role.

Participants who had participated multiple times in the continuing education offered saw it as being unsatisfactory: “I had education, but the contents were not practical and were boring due to the stereotyped education”; “I did not feel I was having specialized education or training”; and “It was not very helpful because the educational materials were not targeting us specifically and educated us as if we were home helpers who care for general patients.” Participants stated that education from experts currently involved in HIV-related education, research, or activities would be more helpful than education from individuals who were not. They also wanted to learn more about basic health monitoring, including how to check blood glucose and blood pressure levels: “It will be very helpful for someone who really needs it because some of them are not checking blood glucose regularly and are in a chronic health condition.”

Participants noted that the most valuable education/training was gained from observing more experienced peer supporters making home visits. Participants described it this way: “They guide us on how to handle or manage the

situation” and “We gradually make up the weak points by confronting challenges or problems while working.”

Discussion

Peer supporters noted a lack of stable financial support and a work environment that does not value the peer supporter role. This is in line with a previous study’s findings that indicated the challenges to the peer counseling role when there was insufficient financial and organizational support,²⁰ and with another study of HIV-infected lay peer educators, which found that they felt undervalued.¹⁴ Such findings indicate that the impact of the peer role is limited if the barriers created by insufficient funding and lack of supportive environments are not addressed. Thus, efforts are needed to increase financial support for the role and create work environments in which peer supporters feel valued for their contributions.

Stigma was a major barrier to participants’ work; they expressed difficulty working because their patients feared their HIV status would be evident to their neighbors because of the peer supporter home visits. Such concerns forced peer supporters to use extra effort to ensure the community did not know the nature of their home visits. This finding reinforces the impact of HIV-related stigma on the lives of PLWHA and the work of peer supporters, and how such stigma impacts the QOL and care of affected individuals. Efforts are still needed to overcome HIV-related stigma, which remains prevalent worldwide; indeed, despite a decline in stigma over the years, such attitudes persist in South Korea.²² In particular, Hong Kong Chinese adults believed PLWHA to be promiscuous.²⁴ As HIV-infected individuals anticipate that they will be affected by HIV-related stigma,²⁵ a common response of HIV-infected individuals is to avoid disclosure of their HIV status for fear of discrimination.²⁶ The findings of the present study support this. However, evidence indicates that HIV-related stigma can be lessened through comprehensive community interventions – consisting of workshops for PLWHA and people living nearby, namely partners, children, close family members, close friends, spiritual leaders, and community members – such as those implemented in South Africa.²⁷

Working in the HIV/AIDS field as a caregiver requires patience and puts enormous emotional strain on a person. In this study, most participants reported work-related stress and burnout. This is a serious health risk and may hinder program efficacy,²⁸ leading to high turnover that can negatively affect the quality of care. Work-related burnout is increasingly common among health care workers^{27,29,30} and informal

caregivers providing care for PLWHA.³¹ Role transition often leads to stress from workload demands and clients’ negative comments.³² Studies have shown that a lack of positive organizational culture, including teamwork,³³ negatively affects role stress and burnout, whereas social support positively affects the managing of burnout.²⁰ Therefore, assisting peer supporters to both prevent and recover from burnout is critical to help them work in good conditions.

Participants were dissatisfied with the ongoing education and training they received, stating that much of the training was redundant and did not encompass the more practical education that they wanted on how to effectively undertake the peer supporter role. Tobias et al¹³ suggest addressing gaps in knowledge through continuing education rather than assuming knowledge is sufficient once people start working.¹³ Thus, education should be provided in accordance with their unmet needs and should be comprehensive in order for them to have sufficient knowledge and skills to accomplish their work. Although education and training is expensive and time-consuming, it is essential in the retention of peer supporters who have been trained and are experienced.

Qualitative methods are used first and foremost to explore phenomena about which little is known to increase depth of understanding. Thus, the goal of sampling is not generalization, but rather selection of individuals with firsthand experience of the phenomena under study. To further knowledge about the peer supporter role, this study should be replicated with different populations in different settings, as differences may exist in different groups. Additionally, the perspectives of patients who received the services of peer supporters were not explored. To comprehensively understand the peer supporter program, studies on the positive impact that peers can have on the QOL of people with HIV, and the perspectives of the service’s beneficiaries, are needed.

Conclusion

The findings of this study suggest that for peer supporters to work continuously and with satisfaction, a positive work environment in which they feel secure, supported, respected, and valued is needed. Also, educational needs should be explored and tailored in advance to meet peer supporters’ individual needs. Furthermore, helping them to manage their work-related stress or burnout should be a priority. If peer supporters are provided with additional support themselves, this may not only increase the quality of care provided to people with HIV/AIDS, but empower peer supporters as well.

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Author contributions

All authors contributed to the study design, data analysis, interpretation of the study findings, and drafting and revising of the paper. All authors reviewed and approved the final manuscript prior to submission and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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