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Abstract

The aim of this study was to explore the social networks of older adults living with HIV. Interviews were conducted with nine individuals aged 50 or older living with HIV in Helsinki, Finland. Analysis of transcripts was analysed by inductive qualitative content analysis. Results indicated that these participants' networks tended to be large, including those both aware and unaware of the participants' health status. Analysis identified three main themes: large multifaceted social networks, importance of a support group and downsizing of social networks. Support received appeared to be of great importance in coping with their health condition, especially since the time of diagnosis. Friends and family were the primary source of informal support. The majority of participants relied mostly on friends, some of whom were HIV-positive. Formal support came primarily from the HIV organisation's support group. In this study group, non-disclosure did not impact participants' well-being. In years to come, social networks of older adults living with HIV may shrink due to personal reasons other than HIV-disclosure. What is of primary importance is that health-care professionals become knowledgeable about psychosocial issues of older adults living with HIV, identifying latent problems and developing adequate interventions in the early stages of the disease; this would help prevent social isolation and foster successful ageing with HIV.

Keywords: HIV; older adults; social networks; social support.

Introduction

The importance of the social network and the support it provides for individuals' well-being and quality of life (QoL) has been widely reported in the HIV literature (Bekele et al., 2013; Chesney, Chambers, Taylor, & Johnson, 2003; Mavandadi, Zanjani, Ten Have, & Oslin, 2009), although less frequently among those with HIV who are aged 50 and older (Emlet, Fredriksen-Goldsen, & Kim, 2013). As this segment of the HIV population is steadily growing worldwide and is an emergent issue in Finland (National Institute for Health and Welfare [THL], 2015), acknowledging the importance of social networks in the older population may provide a good baseline for health and social care interventions aimed at promoting healthy ageing with HIV.

Ageing has been related to declines in social-network size, diversity of relationships, and interaction in both the general and HIV population (Cornwell, 2011; Emlet, 2006; Marcum, 2012). Among people living with HIV/AIDS (PLWHA), these changes may lead to increased risk for social isolation (Emlet, 2006; Schrimshaw & Siegel, 2003), psychological distress (Mavandadi et al., 2009; Sun, Zhang, & Fu, 2007), poor adherence to HIV treatment (Battaglioli-DeNero, 2007), and impaired QoL (Burgoyne & Renwick, 2004; Lan et al., 2015). Malfunctioning social networks also lead to individuals' increased vulnerability to loneliness, affect individuals' well-being (Karpiak, Shippy, & Cantor, 2006), and may aggravate their susceptibility to depression (High et al., 2012).

To our knowledge, no evidence-based information is available for this segment of the ageing Finnish HIV population; making this study is therefore the first attempt to explore the impact of social support networks on PLWHA aged 50 years and older.

Methods

Participants

Participants were recruited from an HIV support group located in Helsinki, Finland. After giving his permission to conduct the study, the support group leader contacted group members by phone and asked about their willingness to participate in the interviews. All the voluntary participants were informed about the study purpose by the researcher and the support group leader. After providing informed consent, those fulfilling inclusion criteria (HIV-positive, aged ≥ 50) were enrolled. Ethical consent for the study was granted by the support group leader.

The sample comprised nine Finnish participants: seven men and two women aged 51 to 73 (Mean = 60.6). Three participants were infected with HIV at 50 or older. Number of years living with HIV ranged from 4 to 24 (Mean = 11.1). Eight participants were asymptomatic, one was in the AIDS phase. Homosexual contact the most common route of HIV transmission ($n = 5$). Most participants had divorced ($n = 5$) for reasons other than HIV (Table 1).

[Insert_Table_1]

Data collection

Data collection involved audio-recorded thematic interviews conducted by the first author (registered nurse) between June and July 2011. This study had no interview guide. At the beginning of the interviews participants answered one question: “Could you please describe your social networks and possible social support you have received up until now?”. Additional specifying questions were posed by the interviewer during the interview. Seven interviews were conducted on the support group premises, one at the university library, and one at the interviewer’s home. The duration of the interviews ranged from 30 to 90 minutes.

Method of analysis

Each interview in Finnish, was transcribed *verbatim*. Written transcripts were reviewed by the first author who replayed the recordings to detect inaccuracies and familiarise himself with their content. The interviews were analysed in the Finnish language. Extracts cited here were translated into English. Only the first author was aware of participants’ identities; hence interviewee anonymity was secure throughout the entire study.

During analysis, all statements (words and sentences) related to each other were marked with different colours. A detailed analysis of the data, including data reduction (coding), grouping (categorization) and abstraction of ideas and concepts underwent inductive qualitative content analysis (Kylmä et al., 2008). Because social networks of older PLWHA have never been explored in Finland, the use of inductive content analysis as a method of analysis proved to be adequate method (Elo & Kyngäs, 2008).

Results

The nature of the participants' social networks was related to their openness to their significant others, although total concealment of one's HIV diagnosis did not impede any participants' social interaction and social relationships. As one participant said: "...it didn't affect [social interaction with others] at all because outside of this group [people who know about his disease] I'm healthy..." (Man #5).

The three main categories in the participants' narratives identified were: multifaceted social networks, importance of support, and downsizing of social networks. A summary of the main themes and subthemes, along with illustrative quotes, is presented in Table 2.

[Insert_Table_2]

Multifaceted social networks

Most participants portrayed their social networks as good, strong, and large, associated with their active participation in social life. After being diagnosed with HIV, some reported making new acquaintances from net chat rooms. The Internet was thus useful as an informal support channel and as a source of further knowledge regarding others' experiences in growing older with HIV.

The importance of support

Descriptions of social support from different kinds of social networks were essential for psychosocial well-being and coping. Informal support was linked with emotional support, essentially offered by family members and friends to whom the participants had disclosed their HIV status. Such support was of primary importance, especially after diagnosis. As to formal support, information regarding HIV came from specialised health institutions. Aid from the HIV support group was also of great importance identity construction as an HIV-positive or as a gay man. Support from others attending the group enabled them to share life experiences, resulting in a source of optimism regarding one's future as an ageing individual with HIV.

Interestingly, two participants said that they had never needed any kind of support from any source for their HIV positivity. The way these participants faced HIV influenced their way of living with the disease positively.

Downsizing of social networks

For some of the participants, downsizing of social networks led to depression and shock. Some expressed the importance of quality over quantity of their social networks. For two, HIV had played a role in the reduction of their social networks, by causing self-breakdown from social life or withdrawal from leisure activities.

Discussion

In this first study examining the social networks of HIV older adults in Finland, participants portrayed their social-relationship networks as multifaceted and composed of several groups of people from whom they obtain support whenever needed, but they valued more the quality than the quantity of support. Among these groups, some were of people to whom they had not disclosed their disease and from whom they received support as a “healthy individual”. Both types of support combined contribute to life satisfaction and psychological well-being, giving a sense of belonging to a normal population regardless of health status.

Contrary to the suggestion that older PLWHA face increased risk of isolation (Shippy & Karpiak, 2005), loneliness (Emler, 2006; Karpiak et al., 2006) and lack of appropriate support (Schrimshaw & Siegel, 2003), we found that the social networks of participants to be large, strong, and supportive, consistent with findings for the general population (Smith et al., 2015). After being infected, they established new acquaintanceships and adopted new ways of viewing life. Friends and family were the primary sources of informal and emotional support, with both rated as equally important. Moreover, the formal support offered by the support group and the reciprocity of the relationships within the group proved highly important, particularly in construction, reconstruction, and strengthening of their self-identity (as HIV-positive and ageing individuals). For these patients, belonging to a support group offered an opportunity to share lived experiences with others regarding the disease and its inherent social issues. As seen in younger individuals with HIV (Bolding, Davis, Hart, Sherr, & Elford, 2005), for older PLWHA, the internet has also become newly relevant in their social lives for sharing experiences or meeting new partners.

Most participants also indicate receiving support from people unaware of their HIV status. This support did not change over time and was considered important. This was evidently a strategy of the participants for living as “normally” as possible and as a process of coping with HIV. These

findings are in line with the socio-gerontological continuity theory, according to which, individuals tend to maintain as much as possible their habitual life practices and social relationships in the face of life-changing events (Atchley, 1989).

Limitations of the study include the participant's recruitment from a limited geographical area of Finland, the small sample size and sample homogeneity. Because of sample size, it is possible therefore that content saturation might not be achieved. Further exploration of these themes will be valuable. Additionally, women's and heterosexual men's lives differ from those of homosexual men, and the latter who formed the majority of our sample. Studies with larger and more heterogeneous samples are thus warranted. Although all interviewees participated voluntarily, they were all recruited from a support group, which may have introduced some bias. Those older PLHWA who experience their disease in a more negative way were not represented. The transferability of these findings is thus context-bound.

Despite these limitations, this study provides a first insight into life experiences of older PLWHA in Finland and can offer useful information to health care institutions in developing age-appropriate health and social care interventions that meet the unique needs of older PLWHA, particularly those related to sexuality and close relationships, management of antiretroviral treatment, as well as of other medical comorbidities that are more frequent in this age-group (Mahy, Autenrieth, Stanecki, & Wynd, 2014).

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Table 1
Demographic characteristics of participants

	<i>n (%)</i>
Sex	
Male	7 (77.8)
Female	2 (22.2)
Age	
50-55	1 (11.1)
56-61	5 (55.6)
62-67	1 (11.1)
>67	2 (22.2)
Marital status	
Divorced	5 (55.6)
Single	2 (22.2)
Widow(er)	2 (22.2)
Education	
Elementary school	2 (22.2)
Middle school	1 (11.1)
Higher school examination/degree	2 (22.2)
College degree	2 (22.2)
Polytechnic or university degree	2 (22.2)
Mode of transmission	
Homosexual	5 (55.6)
Heterosexual	4 (44.4)

Table 2

Summary of themes, subthemes and illustrative quotes of the interviews

Themes	Subtheme	Illustrative quotes
Multifaceted social networks	Strong friendship circle	“...I have a very good and big friendship circle...men and women constitute my social network...I have friends everywhere. I rode motorcycles as a hobby, from it I have a lot of friends...then I have long-term friends from my school years that I have known since my childhood...” (Woman #2).
	Net chat rooms	“...I have sought this kind of connections...fate comrades...mostly I’m interested to know how those who have been infected longer than me, well what has happened in their life...well, a kind of curiosity and at the same time what the future might be for me as I age...I never have met anybody, we just chat and exchange opinions...” (Man #7). “...today I am going to meet one guy...it is a gay chat-room. I have been there since last winter and from it I have met one guy a couple of weeks ago, we have chatted...” (Man #2).
	Meeting new people	“...I have been in some international HIV conferences...I have met really fantastic people...” (Woman #2) . “...along with my organizational participation I have gathered a lot of friends and very fast...very nice people, cheerful people...” (Man #3).
The importance of support	Emotional support from friends	“...in the beginning he [a friend] helped me ...especially emotionally...for sure the shock [after HIV diagnosis] would be longer if I hadn’t had him...otherwise I would deal with the situation alone. I had this kind of emotional-support person who helped me...I passed rather quickly over the shock because of the support I got...” (Man #7).
	Family support	“...one of my sister’s sons knows about me...he works in health care and has worked with HIV patients...he was really a big, if not, the biggest support...My aunt, she looks after me...last Christmas took me to Romania... quite often I’m in contact with my cousins, sister and brother, with my brother every day...” (Woman #2).
	Support from health	“...when I got to hospital...my knowledge about the disease was very poor...from there I got a lot of

- professionals information...It was a big help...it calmed me down and gave a sense of good feelings...” (Man #7)
 “...I have not sought any kind of emotional support from health professionals...Mostly I sought information...” (Man #6).
- HIV support group “...for me it was very nice...I noted that it was a nice experience, some take pills from their bags and took them. Well it was a kind of free feeling; you can somehow behave freely here. Ah now it is my pills time and someone take the pills out from the bag. Well, it is a kind of feeling...we are in this situation, it was really nice...” (Woman #1)
 “...here [support group] I can be myself as a gay and as HIV-positive; I do not need to assume any role...I found myself through the support group...The best support I ever got was from it...Here is the only place where I dare to be myself, dare to cry and smile, dare to speak about...The emptiness that I had has been filled by the support group. I got everything from here; when we speak about a big issue such as HIV/AIDS back in 98 when knowledge about the disease and its treatment was under development and rather poor, it was very important to sit nearby HIV-positive persons and listen to their life stories and how was their health at the moment, how the medicines were working or not working.” (Man #2).
 “...I really feel at home here [in the support group]. I don’t need to be afraid of anything...we are in the same boat...When I went there [to HIV support group]... a couple of years ago, one guy said that he has been HIV-positive for nine years and he doesn’t have anything yet [HIV-related symptoms], it was quite nice feeling...and I thought that can happen to me also.” (Man #5).
- No need of support “...Well, I never needed [support]. Because of my HIV infection I never needed any kind of support...no I never needed it because I didn’t see it as something special... It is one among other diseases”. (Woman #1).
 ”I didn’t need any kind of support, I reacted... well let’s organise life and live according to it [HIV]... it is a treatable disease, same as other diseases... does it really matter if you have diabetes or HIV... it is the same, do I have HIV or other disease; I had cancer before, the same way I faced HIV...” (Man #3).

Downsize of social network	Death	“...she [mother] died of surgical complications. It was a new crisis and a new shock that led [me] to a bad depression which lasted for two years. Then one year after my mother’s death, my father died. Then one year after my father’s death, my grandson died. Well it was a really bad five years.” (Man #2).
	Normal friendship circle reduction due to others reasons than HIV diagnosis disclosure	“...I used to have plenty of friends before; friends and friends more fellows I think; this circle with time has squeezed into a small group of good-hearted friends...” (Woman #2) “...I have a group of friends with whom I seldom keep contact....However I have actively been in contact with those who are important for me.” (Man #1).
	Self-breakdown from social life	“...the working environment was my social network. My hobbies, my work ended at the same time. When my work ended, then ended my social life. Well I broke intentionally with everything...” (Man #2). “...I have been for about 15 years very active in all kinds of organisations...when I got Infected I left everything...I was 10 years without any kind of organisational affiliations...” (Man #1).
