

The Effects of Loneliness and Internalized Stigma on Perceived Social Support in People with AIDS: A Cross-Sectional Study

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Abstract

A cross-sectional study examined social support, loneliness, internalized stigma, the effects of loneliness and internalized stigma on perceived social support in 140 Greek adults with AIDS. The Medical Outcomes Study Social Support Scale, UCLA Loneliness Scale, and Internalized AIDS-Related Stigma were administered. Significant associations: between social support, social loneliness, psychological loneliness, isolation, and Aids Related Stigma. Psychological loneliness and isolation had the strongest effect on social support. Efforts reducing them may positively affect social support.

Keywords: AIDS, Greece, internalized stigma, loneliness, social support

1. Introduction

According to the United Nations Programme on HIV/AIDS nearly 21 million patients are now on antiretroviral treatment, boosting their life expectancy (United Nations Programme on HIV/AIDS [UNAIDS, 2017]; World Health Organization: Data and statistics), by mid-2017, while in 2016 1.0 million AIDS-related deaths were recorded (UNAIDS, 2017). In Greece, by nearly the end of 2017, 16,527 cases of HIV infection have been registered, 4,083 were AIDS cases and 9,500 were receiving antiretroviral therapy, while there were 2,746 deaths. New HIV diagnoses per 100,000 for the same time period have been reduced compared to previous years (Hellenic Center for Disease Control & Prevention [HCDCP, 2017]).

Nowadays, AIDS, is considered a chronic and in many cases manageable disease (Mills et al., 2011), consisting of physical-psychosocial problems (Mo & Coulson, 2013), and an increased need for social support (Ware, Wyatt, & Tugenberg, 2006). Nevertheless, many people complain about unfulfilled needs, and inadequate social support (Heckman, 2003). HIV/AIDS continues to unequally affect stigmatized populations (eg, homosexuals and those who inject drugs).

In Greece, since the 1990s, HIV/AIDS units have been operating within the national health system departments for the treatment of both HIV carriers and patients with AIDS. There are 17 HIV units operating and staffed by medical doctors, clinicians, nurses and administrative staff. Over the last 5 years there has been a reduction of HIV/AIDS new cases, reflecting the duplication of the outset of antiretroviral therapy (HCDCEP E-bulletin).

People with AIDS satisfied with the actual support received, have less psychological distress, and higher self-esteem (Van Dam et al., 2005). It can be assessed both as the perceived assistance available, but also, as the actual support received. Social support includes: professional, peers, and family members (Orrick, Worrall, Morris, & Wang, 2011), while the types of social support are: emotional, instrumental, information/education, and appraisal (Li, Sung-Jae, Panithee, Chuleeporn, & Rotheram-Borus, 2009).

Additionally, people with AIDS often face stigma, prejudice, and discrimination, affecting access to testing, care, treatment (Mahajan et al., 2008), adherence (Groves, Golub, Parsons, Brennan, & Karpiak, 2010), and access to social support systems (Baker, 1999) due to concealment of their seropositivity, fear of rejection, disease progression, and side-effects (Bogart et al., 2007). Earnshaw and Chaudior (2009) suggested that stigma includes enacted, anticipated, and internalized stigma. In particular, internalized stigma (assessed in the present study) has been argued that makes them feel shame, and guilt as they are worried about spreading infection to others (Lee, Kochman, & Sikkema, 2002), thus feeling that they deserve received misbehavior. Despite progress in clinical care, stigma negative influences quality of life, while associated with loneliness (Herrmann et al., 2013).

It is a common psychological symptom of people with AIDS (Nokes & Kendrew, 2001), affecting their everyday life, in that they expect and fear negative interactions, often recall negative social information, thus, resulting in withdrawal (Cacioppo, Hawkley, Norman, & Berntson, 2011).

Although there are studies on the relationships between loneliness, isolation and social support (Acton, 2011; Coyle & Dugan, 2012; Kuper, Marmot, & Hemingway, 2002; Nicole et al., 2016; Udell et al., 2012), there are no studies addressing the possible effect of loneliness and internalized stigma on perceived social support in patient population, especially in people with AIDS.

In spite of great advances in the application of available resources for AIDS, perceptive of stigma, loneliness-isolation, and low social support still persist, while data in Greek patients is insufficient. The hypothesis under study is that loneliness and internalized stigma effect perceived social support in this population.

2. Methods

A cross-sectional design study was conducted in the Red Cross General Hospital "Special Infection Unit" in Athens, Greece, between December 2013 to August 2014. The study's inclusion criteria were: patients with AIDS, fluency in Greek language, while the exclusion criterion was <18 years old. From the 600 patients treated in the Unit, the study sample consisted of 154 consecutive and eligible people with AIDS treated in the Unit. Fourteen patients (9.09%) refused to participate, so the final sample consisted of 140 (90.90%) patients; 121 (86.4%) were males, and the majority (69%) was in the age group of 20-69 years old, single (61.4%), living alone (53.6%), and with high school education (40.7%). No missing data were reported. Participants were informed of the study's nature and signed a written informed consent. The instruments: Medical Outcomes Study Social Support Survey, UCLA Loneliness Scale (Version 3), and Aids Related Stigma were completed, in the presence of a psychotherapist, who also recorded disease status, treatment and socio demographic characteristics (table 1). If needed, patients received additional information and/or clarifications. The hospital's ethics committee approved the study, conducted according to Declaration of Helsinki Principles and to guidelines for Good Clinical Practice.

Table 1 Demographic Characteristics

		N	%
Gender	male	121	86.4
	female	19	13.6
Relation	Single	86	61.4
	relation	54	38.6
Education	Junior High School	19	13.6
	High School	57	40.7
	University	44	31.4
	MSc-Phd	20	14.3
Occupation	Retired	22	15.7
	Freelance	19	13.6
	Civil servant-Private official	54	38.6
	Unemployed	45	32.1
Income	<500 €	45	32.1
	500-1.500 €	83	59.3
	>1.500 €	12	8.6
Country of Origin	Greece	126	90.0
	Other	14	10.0
Age: mean±Sd (min-max)	43.10±11.96 (20-69)	20	69
HIV duration: mean±Sd (min-max)	9.00±7.26 (1-28)	1	28
Treatment duration:median(min-max)	4.00 (0-26)	1	28

2.1 Measures

The Medical Outcomes Study Social Support Survey (MOS) is a self- administered, 19 items unidimensional, social support inventory, a five-point Likert scale (Hays, Sherbourne, & Mazel, 1995). It consists of four functional support scales and an overall functional support index (Sherbourne, 1991). In the current study the Greek version of MOS (cronbach alpha= .97) was used (Parpa et al., 2016).

The UCLA Loneliness Scale (Version 3) is a 20-item scale measuring the subjective feeling of loneliness (Russel, 1996). For each question, there is a 4 – point scale, while scores range from 20- 80. It is a unidimensional, valid and reliable instrument ($\alpha = .89$ to $.97$ and $r = .73$). The Greek version of UCLA Loneliness scale was utilized (Pikea, Parpa, Tsilika, Galanos, & Mystakidou, 2016). It consists three factors: *social loneliness* (items 2, 3, 4, 7, 8, 11, 12, 14, 18), *psychological loneliness* (items 13, 15, 16, 19, 20), and *isolation* (items 1, 5, 6, 9, 10). The Internalized AIDS-Related Stigma Scale contains six-items. It represents self-effacing sentiments and adverse perspectives of people with HIV/AIDS. Each item has a yes/no response, summing up to a total score. The scale is internally consistent (overall α coefficient=0.75) and time stable ($r=0.53$) (Kalichman et al., 2009).

2.2 Translation

By using the “forward-backward” procedure the Internalized AIDS-Related Stigma Scale was translated from English to Greek. Then, two independent translators translated it to Greek, while another two translated it back to English. The final step was the matching of these translations.

3. Statistical analyses

Data was expressed as *mean±S.D* for quantitative variables, and as percentages for qualitative variables. The *Kolmogorov—Smirnov test* was utilized for normality analysis of the quantitative variables. Bivariate analyses were carried out by the Student t-test, one-way ANOVA and Pearson’s correlation coefficients, to assess the relation among MOS total score and the quantitative, qualitative demographic and clinical attributes. All demographic, clinical variables and questionnaires’ total scores were presented (p -value<.2) in bivariate analyses were incorporated in multiple linear regression, using the stepwise method to emerge at the final model and opt the most significant factors associated with MOS. All assumptions of linear regression analysis were examined. All tests were two-sided, while a p -value of <.05 was used for statistical significance. Analyses were conducted using the SPSS vr 17.00 statistical package.

3.1 Results

3.1.1 Descriptive

The *mean* (\pm *sd*) of MOS scale, UCLA scales, as well as MOS-total are presented in table 2. The average total score on MOS-total was 3.46 ± 1.09 (range: 1.05-5.00) and for Aids-Related Stigma was 2.74 ± 1.47 (range: 0-6). All UCLA scales mean scores were relatively high (table 2).

Table 2 Questionnaires' Descriptive Statistics

	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>
Social Loneliness	20.08	6.01	9.00	35.00
Psychological Loneliness	10.66	3.69	5.00	20.00
Isolation	9.24	3.01	5.00	16.00
Aids Related Stigma total	2.74	1.47	0.00	6.00
MOS Scale	3.46	1.09	1.05	5.00

3.1.2 Univariate Analyses

MOS total had a highly negative correlation with *social loneliness* ($r=-.524$, $p<0.005$), *psychological loneliness* ($r=-.671$, $p<.005$), *isolation* ($r=-.357$, $p<.005$), and *Aids-related stigma* ($r=-.217$, $p<.05$) (table not shown). However, there were no statistically significant associations between MOS total and the assessed qualitative variables (table not shown).

3.1.3 Multivariate analyses

Multiple regression analysis (stepwise model) examined the contribution of demographic and clinical variables as well as loneliness and stigma to participants' perceived social support. Examination of the strongest contributors to social support showed increased values of *psychological loneliness* (*Beta coefficient* \pm *SE*: $-.167\pm.24$; $p<.0005$), *isolation* (*Beta coefficient* \pm *SE*: $-.030\pm.015$; $p=.042$) and *age* (*Beta coefficient* \pm *SE*: $-.010\pm.006$; $p=.077$ marginally) were associated with lower values of perceived social support (table 3).

Table 3 Multiple Regression Analysis of MOS Scale (Stepwise Method)

	<i>Beta coefficient</i>	<i>SE</i>	<i>p</i>
Constant	6.288	.354	<.001
Psychological Loneliness	-.167	.024	<.001
Isolation	-.030	.015	.042
Age	-.010	.006	.077

4. Discussion

By the end of October 2014 (the present study period concluded in August 2014), the total number of registered HIV infections in Greece was 14,288 (82.3% men). Of these, 3638 had been diagnosed with AIDS. Approximately 6850 HIV-infected people are receiving antiretroviral treatment. The cumulative number of deaths was 2471. HIV reports during the first 10 months of 2014 are less than the same period in 2011–2013. Between Jan–Oct 2013, the number of HIV reports was 7.2 per 100,000 population while in 2014, the reporting rate dropped to 5.9. The newly reported HIV diagnoses in 2014 were 654 (86.1% males).

Although social support has a moderating effect on stressful life events (Komatsu et al. 2010), perceived social support appears as the most important as it advances self-esteem, resulting in a positive outcome in psychological health (Li, Sung-Jae, Panithee, Chuleeporn, & Rotheram-Borus, 2009). For people with AIDS social relationships might be limited resulting in loneliness and isolation (Perlman & Peplau, 1981), while most are, in some extent, stigmatized (Brouard & Wills).

The study assesses, for the first time, the effects of loneliness and internalized stigma in their perception of social support. Consistent with previous studies, perceived social support had a significant correlation with loneliness (Sun et al., 2009). Loneliness may restrict people's capacity or obtain to social relationship. Thus, if they are better supported, their negative psychosocial repercussions might be blocked or diminished. Perceived social support also had a statistically significant correlation with "internalized stigma".

This relationship has been acknowledged by other researchers (Kalichman et al., 2009), suggesting that diminished social support is linked to increased internalized stigma in people with AIDS. Accordingly, Li et al. (2009) reported that lower social support was significantly associated with higher stigma.

More importantly, multivariate analysis showed that psychological loneliness and isolation emerged as having a significant and independent effect on perceived social support. Higher rates of psychological loneliness and isolation might place people with AIDS at increased risk for poor social support. Interestingly, although social loneliness and internalized stigma had also strong bivariate correlations with social support, multiple regression analyses showed that they were not critical and decisive in predicting social support.

Age had a slight (trend) effect, which is consistent with existing research arguing that, whereas older individuals count on family members throughout illness, older AIDS individuals face several obstacles experiencing emotional and instrumental social support, while individuals aged 50 years and older are more socially isolated (Cantor & Brennan, 2000).

The potency of the study comprises the use of a large indicative sample from a unique and important population, and the absence of missing data. On the other hand, a restriction is that it is difficult to speculate from a cross-sectional study.

The present results highlight the importance of focusing counseling to reduce psychological loneliness and isolation to improve social support among people with AIDS. Moreover, by addressing them (i.e. loneliness and social isolation) through counseling may have an important role and benefits for the delivery of more tailored interventions for people with AIDS.

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