

Self-care practices in Italian people with HIV

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Abstract

The aim of our study was to measure self-care levels among people living with HIV. A cross-sectional study was conducted in Northern Italy between February and June 2019. Self-care behaviours were measured using the Self-Care of Chronic Illness Inventory and a sample of 108 individuals was enrolled. Adequate levels of self-care maintenance and monitoring (mean score ≥ 70) were implemented by only 24.8% and 36.2% of the sample, respectively. Self-care management was the least implemented dimension of self-care (mean score = 48.13 standard deviation ± 17.80). Higher self-care was observed in newly-diagnosed individuals, whereas self-care confidence was higher in those with an older diagnosis, suggesting a trend of self-care through time. Our study revealed that self-care is poor in Italian people with HIV, and its level seems to decrease as the condition progresses. Further studies should be conducted to identify determinants of poor self-care, thus allowing for a better understanding of self-care in people with HIV.

Introduction

Advances in care over the last 30 years have helped transform the acquisition of HIV into a chronic [1], manageable condition for many people, improving long-term outcomes for people living with HIV/AIDS [2]. Despite the gradual decline in AIDS-related mortality [3], HIV continues to be a major global public health issue; according to latest available data, 37.9 million people were living with HIV in 2018 and almost 2 million people are diagnosed with HIV annually, with higher incidence among those aged 25–29 years [4,5].

There is growing recognition of the need for people with chronic diseases to take responsibility for their health and to be actively involved in self-care practices [6]. Self-care is defined as a decision-making process that influences actions that maintain physiologic stability (self-care maintenance), facilitate the perception of symptoms (self-care monitoring) and actively direct the management of those symptoms when they occur (self-care management) [7]. Self-care is strongly affected by the confidence that one has in the ability to perform an action and to persist in performing that action despite barriers (self-care confidence) [8]. Research findings highlight that self-care is related to better quality of life (QoL) and decreased mortality and hospitalisation rates [9,10]. Specifically, evidence shows that self-care behaviour in people with HIV can help prevent HIV transmission and adverse effects of antiretroviral therapy (ART), while also improving mental health [11,12].

Self-care maintenance practices mainly include the adoption of a healthy lifestyle, such as sufficient sleep, balanced diet, weight control, smoking cessation, physical activity and adherence to treatment [13]. Specific behaviour for people with HIV may also involve practicing safer sex to reduce the risk of

transmission. Although there is no direct method for people with HIV to self-monitor their physical status, effective early recognition and self-management of HIV-related symptoms is an important component of HIV self-care. Self-care practices are also an efficient strategy to manage adverse effects of ART, such as gastrointestinal symptoms, mood changes and sleep disorders [14].

In this scenario, nursing can play a vital role in enhancing education for people with HIV, increasing their understanding of HIV as a chronic disease in which self-care practices can improve quality of life, hence leading to better health outcomes [15]. Addressing complex challenges (e.g. medication adherence, prevention of transmission) that chronically-ill patients face and deal with is essential to identify potential barriers to self-care [16]. However, people with HIV experience unique psychosocial and behavioural conflicts (e.g. stigma, criminalisation of HIV exposure) connected to the condition and its negative social connotation that could interfere with their involvement in self-care [17]. Several studies found that chronically-ill patients show low levels of self-care ability in recognising and managing their symptoms [18–20]; however, no studies have been conducted on people living with HIV in Italy.

Materials and methods

Aim

The aim of this study was to assess self-care behaviours of people living with HIV.

Study design and setting

We conducted a cross-sectional study involving people with HIV who visited four different outpatient clinics

and associations in Northern Italy between February and June 2019. Selection criteria for participants were as follows: (a) living with HIV or AIDS diagnosis; (b) aged ≥ 18 years; (c) agreement to sign a consent form for participation; and (d) ability to read and respond in Italian.

Data collection instruments and process

After fully understanding the study purpose and the rights and responsibilities of participants, the staff at the HIV clinics and associations approached eligible participants and written informed consent was obtained. The consent information included details about the study aim, the confidentiality and anonymity of patient information, and the voluntary nature of participation.

Two instruments were used for data collection in this study:

- *Socio-demographic and clinical characteristics questionnaire.* Demographic characteristics (e.g. gender, age, education level, employment, marital status) and medical data (e.g. HIV transmission, year of HIV diagnosis, stage of infection, adherence to ART, CD4 T cell count, comorbid health conditions) were obtained by self-report.
- *Self-care of Chronic Illness Inventory (SC-CII).* Self-care was assessed using the Italian version of the SC-CII, a self-reported generic tool developed and validated by Riegel *et al.* in 2018 to measure self-care in patients affected by chronic conditions [21]. The instrument consists of 30 items distributed in four subscales: self-care maintenance (8 items), self-care monitoring (5 items), self-care management (7 items), and self-care confidence (10 items). Individual items are rated on a 5-point Likert scale, from 1 (never/not likely/not confident) to 5 (always/very likely/very confident). Each of the three scales is scored separately and standardised 0–100. Higher scores reflect greater self-care and scores ≥ 70 points for each subscale indicate appropriate self-care.

Data analysis

Data were preliminarily checked for possible missing information, erroneous entries or outliers through the frequency distribution analysis. Descriptive statistics were used to analyse the demographical characteristics of the overall sample and the scores obtained in each subscale of the SC-CII: mean \pm standard deviation (M \pm SD) for continuous variables, and frequencies and percentages for categorical variables. A comparison of self-care maintenance, monitoring, management and confidence was performed stratifying the sample by years since HIV diagnosis and independent t-tests and chi-squared tests were employed to analyse sample characteristics and self-care subdomains in the 'adequate self-care' and 'inadequate self-care' groups. All analyses were conducted using SPSS version 22.0.

Ethical considerations

This research was conducted according to the principles of the Declaration of Helsinki and international ethical standards and guidelines were followed. Patients

Table 1: Socio-demographic characteristics of the sample (N = 108)

Characteristic	n (%) [*]
Age, mean (SD)	46.5 (11.6)
Sex	
Male	76 (70.4)
Female	32 (29.6)
HIV transmission	
Heterosexual transmission	34 (31.8)
Men who have sex with men (MSM)	48 (44.9)
Injection drug user (IDU)	16 (15)
Blood/blood products	7 (6.5)
Unknown	2 (1.9)
Stage of condition	
Clinical latency	91 (87.5)
AIDS	13 (12.5)
Presence of comorbidities	
Yes	37 (34.6)
No	70 (65.4)

^{*}Unless stated otherwise. SD: standard deviation; MSM: men who have sex with men; IDU: injecting drug users. Missing and non-responses are not included in table subsection totals.

were informed about the study aim, its design and the confidentiality and anonymity of data collected. Written consent was obtained from all participants.

Results

Participant characteristics

A total of 108 individuals were enrolled in this study. Table 1 shows the socio-demographic and clinical characteristics of the participants. Most participants were male (70.4%), with a mean age of 46.5 ± 11.6 years, ranging 25–72 years. Unprotected sexual behaviour was the most frequent cause of HIV transmission (76.7%) and 87.5% of participants were in the asymptomatic stage of the condition. The mean duration of the condition was 12.2 ± 11.4 years, and 34.6% ($n = 37$) of participants reported the presence of comorbidities, such as osteoporosis ($n = 15$), hypertension ($n = 8$), diabetes ($n = 3$), and hepatitis C ($n = 3$).

Self-care behaviour

Table 2 shows descriptive statistics of the SC-CII. Analyses of the SC-CII revealed that self-care monitoring was the most implemented dimension of self-care, as it obtained the highest mean score (M = 60.14 ± 23.19) and was adequate (mean score ≥ 70) in 36.2% ($n = 38$) of participants (Table 3). Self-care confidence had a mean score of 58.57 ± 29.09 and was adequate in 42.9% ($n = 45$) of the sample. Only 24.8% ($n = 26$) of participants implemented adequate levels of self-care maintenance (M = 53.43 ± 21.99). Self-care management was studied among those who had experienced symptoms of HIV acquisition ($n = 41$) and obtained

the lowest mean score ($M = 48.13 \pm 17.80$). Among those who reported symptoms, 92.7% were not able to manage them appropriately. According to these results our study revealed inappropriate self-care behaviours across all dimensions of self-care as none of the subscales obtained an adequate mean score of ≥ 70 .

Self-care behaviour stratified by years since diagnosis

Following the stratification of the sample by years since diagnosis, it was found that those with a more recent diagnosis (group A) had higher mean scores in the self-care maintenance, monitoring and management subscales (Table 4). However, their self-care confidence levels were found to be the lowest ($M = 38.0 \pm 20.73$). On the contrary, those who have been living with HIV for a longer period of time (group C) had the highest level of self-care confidence ($M = 76.15 \pm 20.98$) but implemented inappropriate self-care behaviours (mean score < 70 in the maintenance, monitoring and management subscales).

Table 2: Descriptive statistics of the Self-care of Chronic Illness Inventory (SC-CII)

Domain	Mean score (SD)	P-value
Self-care maintenance	53.43 (21.99)	<0.005
Self-care monitoring	60.14 (23.19)	
Self-care management	48.13 (17.80)	
Self-care confidence	58.57 (29.09)	

SD: standard deviation.

Discussion

To the best of the authors' knowledge, this study provides the first quantitative description of self-care behaviour among people living with HIV. The results of this study contain innovative aspects that could stimulate interest in exploring this topic. In fact, the strategic role of self-care in treatment and cure of patients with chronic illnesses, such as diabetes and heart failure patients [22] is recognised by the entire scientific community. However, there is a lack of knowledge regarding self-care behaviour of people with HIV; the implications of the current research gap in HIV self-care care might have an impact on the optimal management of HIV.

According to our findings, people living with HIV in Italy mainly perform suboptimal self-care behaviours (mean score < 70), with low scores especially in the self-care maintenance and management dimensions. These collected data translate into a situation where people with HIV are unaware of their physical status and the need for self-care. Furthermore, the majority of those who experience symptoms related to HIV are not able to manage them, possibly leading to worse health outcomes. These findings are consistent with other studies involving chronically-ill patients in which self-care was poor [18–20].

Ever since the identification of HIV and the first cases of AIDS, having HIV has significantly evolved, not only in terms of therapeutic approach, but also as a social and epidemiological issue, as it is now considered a chronic condition [1]. Considering the different attitudes of modern society towards HIV [17], we deemed it appropriate to stratify the sample into three categories (A, B and C) according to years since diagnosis, since

Table 3: Self-care domains stratified by adequate (≥ 70) or inadequate (< 70) mean scores

Score	Self-care maintenance, n (%)	Self-care monitoring, n (%)	Self-care management, n (%)	Self-care confidence, n (%)	P-value
Adequate (≥ 70)	26 (24.8)	38 (36.2)	3 (7.3)	45 (42.9)	<0.005
Inadequate (< 70)	79 (75.2)	67 (63.8)	38 (92.7)	60 (57.1)	

Table 4: Descriptive statistics of the study sample stratified by years since diagnosis

Domain	Group A (0–3 years)		Group B (4–20 years)		Group C (≥ 20 years)		P-value
	Mean	(SD)	Mean	(SD)	Mean	(SD)	
Self-care maintenance	71.87	(14.78)	45.45	(17.42)	34.37	(12.36)	<0.005
Self-care monitoring	72.00	(19.64)	51.15	(21.78)	53.80	(22.23)	
Self-care management	62.50	(9.39)	42.16	(15.27)	44.22	(16.45)	
Self-care confidence	38.00	(20.73)	67.63	(28.63)	76.15	(20.98)	

SD: standard deviation.

participants may have a different approach to self-care in relation to the experiences they have had during their lifetime. In so doing, we found that self-care levels seem to decrease as the condition progresses. In contrast, self-care confidence appears to increase in time, although it is not reflected in self-care practices, as patients with newer HIV diagnosis show adequate self-care behaviour despite their low self-care confidence, whereas patients with an older HIV diagnosis have high self-care confidence but implement poor self-care practices. Such contradictory dynamics of poor self-care behaviour and higher self-care confidence have been observed in other studies regarding patients with heart failure and other chronic conditions [23,24].

These findings seem to suggest a potential relationship between HIV self-care and time since diagnosis, or more in general, an evolution of self-care in time. Several quantitative studies have stratified a recruited sample according to years since diagnosis and shown its association with health-related quality of life [25,26], in fact, lower anxiety and depression, and higher quality of life was found in those living with HIV for a longer period of time. However, the relation between health-related quality of life, anxiety/depression and HIV self-care has not yet been extensively studied in HIV self-care.

This study has some strengths and limitations. Major strengths of our study include the pioneering description of self-care levels among people with HIV, the multicentric design adopted and the outpatient setting from which participants were recruited. The cross-sectional nature of our study, however, limits the understanding of the directionality or stability of self-care over time; longitudinal studies are needed to confirm the influence of time on self-care behaviour. Moreover, participants were recruited from one geographic location (Northern Italy) using convenience sampling, so the sample may not be representative of the general HIV population; therefore, caution should be used in generalising our findings. Furthermore, the SC-CII is a self-reported generic tool that might not meet the specific needs of people living with HIV; this limitation may also be seen as a strength, as it allows a comparison between HIV self-care and other chronic conditions.

Conclusion

This study has shown that self-care is poor in Italian people with HIV. Enhancing patients' willingness to adopt self-care practices should become one of the main goals in HIV nursing. Our study sets the foundations for future research about self-care in HIV. Further studies are recommended to have a better understanding of the relationship between self-care and modifiable (e.g. quality of life, health literacy, mental health) and non-modifiable factors (e.g. age, gender, social status). Stigma, low social support, quality of life, anxiety and depression have been described as major issues in HIV care [17,27,28]; however, their impact on self-care practices among people with HIV is still unknown.

Addressing such issues could lead to the development of tailored educational interventions to improve self-care, hence improving health outcomes. Moreover, research aimed at identifying sociodemographic and clinical determinants of self-care might be helpful to find those at risk of poor self-care [7]. In this context, gender differences in self-care is a growing area of interest and many studies have focused on describing how gender is related to self-care in populations with chronic conditions [18,20,29,30].

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Conflict of interest

The authors declare no conflicts of interests.

References

1. Deeks SG, Lewin SR, Havlir D V. The end of AIDS: HIV infection as a chronic disease. *Lancet* 2013; **382(9903)**: 1525–1533.
2. Beaudin CL, Chambré SM. HIV/AIDS as a chronic disease: emergence from the plague model. *Am Behav Sci* 1996; **39(60)**: 684–706.
3. Mahy M, Marsh K, Sabin K et al. HIV estimates through 2018: data for decision-making. *AIDS* 2019; **3(Supple 3)**: S203–S211.
4. Dailey A, Gant Z, Johnson S, et al. *HIV Surveillance Report 2018 (updated)*. Atlanta, US: Centers for disease control, 2018. Available at: www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2018-updated-vol-31.pdf (accessed July 2020).
5. Istituto Superiore di Sanità. *Update of new HIV infection diagnosis and AIDS cases in Italy as at December 31, 2018*. Volume 32, 2019. Available at: http://old.iss.it/binary/publ/cont/AGGIORNAMENTO_HIV_2018.pdf (accessed July 2020).
6. Vellone E, Chung ML, Alvaro R et al. The influence of mutuality on self-care in heart failure patients and caregivers: a dyadic analysis. *J Fam Nurs* 2018; **24(4)**: 563–84.
7. Riegel B, Jaarsma T, Strömberg A. A middle-range theory of self-care of chronic illness. *ANS Adv Nurs Sci* 2012; **35(3)**: 194–204.
8. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. *J Cardiovasc Nurs* 2008; **2(3)**: 190–196.
9. Grady KL. Self-care and quality of life outcomes in heart failure patients. *J Cardiovasc Nurs* 2008; **2(3)**: 285–292.
10. Lin K, Yang X, Yin G, Lin S. Diabetes self-care activities and health-related quality-of-life of individuals with type 1 diabetes mellitus in Shantou, China. *J Int Med Res* 2016; **44**: 147–156.
11. Oskouie F, Kashefi F, Rafii F, Gouya MM. Barriers to self-care in women of reproductive age with HIV/AIDS in Iran: a qualitative study. *Pan Afr Med J* 2017; **28**: 231.
12. Gielen A, McDonnell K, Wu A et al. Quality of life among women living with HIV: the importance violence, social support, and self care behaviors. *Soc Sci Med* 2001; **52(2)**: 315–322.
13. Swendeman D, Ingram BL, Rotheram-Borus MJ. Common elements in self- management of HIV and other

chronic illnesses: an integrative framework. *AIDS Care* 2009; **21(10)**: 1321–1334.

14. Schiller DS. Identification, management, and prevention of adverse effects associated with highly active antiretroviral therapy. *Am J Heal Pharm* 2004; **61(23)**: 2507–2522.

15. Chou F-Y, Holzemer WL. Linking HIV/AIDS clients' self-care with outcomes. *J Assoc Nurses AIDS Care* 2004; **15(4)**: 58–67.

16. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Educ Couns* 2005; **57(3)**: 300–307.

17. Chenard C. The impact of stigma on the self-care behaviors of hiv-positive gay men striving for normalcy. *J Assoc Nurses AIDS Care* 2007; **18(3)**: 23–32.

18. Dellafiore F, Arrigoni C, Pittella F et al. Paradox of self-care gender differences among Italian patients with chronic heart failure: Findings from a real-world cross-sectional study. *BMJ Open* 2018; **8(9)**: e021966.

19. da Conceição AP, dos Santos MA, dos Santos B, da Cruz D de ALM. Self-care in heart failure patients. *Rev Lat Am Enfermagem* 2015; **23(4)**: 578–586.

20. Heo S, Moser DK, Lennie TA et al. Gender differences in and factors related to self-care behaviors: a cross-sectional, correlational study of patients with heart failure. *Int J Nurs Stud* 2008; **45(12)**: 1807–1815.

21. Riegel B, Barbaranelli C, Sethares KA et al. Development and initial testing of the self-care of chronic illness inventory. *J Adv Nurs* 2018; **74(10)**: 2465–76.

22. Dellafiore F, Borella A, Magon A et al. Descriptive pilot study on self-care and daily living activities in Italian patients with heart failure: What are the criticalities? *Ric e Prat* 2018; **34(1)**: 6–16.

23. Dellafiore F, Baroni I, Conte G et al. The psychological aspects of the assistance to patients with heart failure. Which impact on self-care behaviours? *Ric e Prat* 2019; **35**: 150–8.

24. Graven LJ, Grant JS, Vance DE et al. Factors associated with depressive symptoms in patients with heart failure. *Home Health Nurse* 2014; **32(9)**: 550–555.

25. Oliveira FBM, Moura MEB, De Araújo TME, Andrade EMLR. Quality of life and associated factors in people living with HIV/AIDS. *ACTA Paul Enferm* 2015; **28(6)**: 510–516.

26. Miners A, Phillips A, Kreif N et al. Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population. *Lancet* 2014; **1(1)**: e32–40.

27. Fife BL, Wright ER. The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav* 2000; **41(1)**: 50.

28. Basu S, Chwastiak LA, Bruce RD. Clinical management of depression and anxiety in HIV-infected adults. *AIDS* 2005; **19(18)**: 2057–2067.

29. Caruso R, Arrigoni C, Magon A et al. Health determinants in Italian type 2 diabetes mellitus (T2DM) patients: a critical gender differences Analysis. *J Res Gend Stud* 2017; **7(2)**: 93.

30. Dellafiore F, Conte G, Baroni I et al. Gender differences in heart failure self-care behaviors: do we know enough? *Minerva Med* 2018; **109**: 1–3.

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