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Information Sources of Self-Care Strategies for Persons Living with HIV

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Abstract

Objectives—A number of studies have been conducted to identify the self-care strategies that are used by persons living with chronic illnesses to manage their symptoms, but little work has been done to identify the primary information source for these self-care strategies.

Methods—We conducted an anonymous online survey with 1,373 persons living with HIV to identify the self-care strategies they use to manage 28 commonly experienced symptoms. Following their report of their symptoms and self-care strategies, we asked an open-ended question to identify where the participant obtained the information. We applied iterative content analysis of the narrative data and multi-nominal regression to identify which demographic factors were significantly related to each information source category.

Results—Respondents reported a total of 8,539 information sources for their self-care strategies categorized as follows: Common sense/Self-experience, Healthcare professional, Internet, Literature, Multiple Sources, Social Support, and TV ads.

Conclusions—We found that respondents without any college education were significantly more likely to report the use of the Internet as the information source for their self-care strategies. On the other hand, males as compared to females were significantly less likely to use the Internet and significantly more likely to use TV ads.

Keywords

Information Source; Self-care strategies; Online Survey; HIV

Author Contributions

Rebecca Schnall: Conception and design of the study, Interpretation of the data, drafting the manuscript

Jiafang Liu: Analysis and interpretation of the data, drafting the manuscript

Sarah Iribarren: Analysis and interpretation of the data, drafting the manuscript

All authors approved the final version to be published and agree to be accountable for all aspects of the work.

Conflict of Interest Form

The authors declare no competing interests.

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Introduction

Self-care can be broadly defined as activities an individual independently employs in order to promote health, prevent or detect disease, or manage an illness.(1, 2) Self-care is an important component of everyday life for those suffering from chronic illnesses,(3) including HIV.(4) Self-care can be particularly useful for managing the symptoms associated with chronic illnesses and has been shown to improve quality of life.(5) Since persons living with HIV (PLWH) are primarily cared for in ambulatory settings, self-care is a very important aspect of effective management of the illness.(6–8)

While a number of studies have investigated the self-care strategies used by PLWH to manage their illness,(9, 10) little work has been done to identify the primary information source for these self-care strategies. One study conducted by Fang-Yu Chou et al. (2004) identified categories of information sources in which individuals living with HIV/AIDS used to guide their self-care practices.(11) The largest source of information for self-care strategies was the individual himself or herself, followed by healthcare providers, then personal networks, and finally, the community. These findings have been observed by other researchers who have identified healthcare providers, personal networks, and the community as integral sources of information for PLWH.(12–14) Furthermore, evidence also suggests that many self-care strategies employed by PLWH are learned primarily through trial and error(15) and that individuals may use multiple sources of information to guide their self-care strategies.(16) Most of the earlier research regarding information sources was conducted nearly 15 years ago in an earlier age of the Internet and prior to the use of smartphones. This was also prior to the use of combined antiretroviral therapy (cART), when HIV was considered to be a death sentence.

There is congruence among researchers that healthcare providers give patients information regarding medication, while PLWH teach themselves mainly self-comforting strategies.(16, 17) There is also evidence which shows individuals often seek help from a network of referral systems, like family members and friends in addition to seeking the help of professionals.(18, 19) One major barrier that may prevent PLWH from finding resources for information is the stigma attached to the illness,(16, 20) making the Internet a common information source for them.

In general, the Internet has become a popular and useful source for obtaining health information.(21) It is estimated that approximately 60% of United States (US) adults regularly seek health information online.(22) In fact, researchers have found that websites and search engines are the first sources consulted when consumers seek health information. (23–25) Using the Internet for accessing health information may be particularly relevant for older adults or frail individuals who have limited physical ability to access healthcare services.(21)

Online health information, such as personal care and illness prevention, can be particularly useful in helping those living with chronic illnesses maintain good physical, psychological, and social well-being.(26–28) Researchers have demonstrated that individuals use online health information to inform treatment decisions, self-care activities, and discussions with

health care providers,(24, 29).. For example, research on diabetes has shown that most people use their physician or other allopathic health provider as their primary source of information, followed by the media, friends and family, and common sense.(30) In another study of persons living with rheumatoid arthritis, patients employed self-care activities informed by advice from alternative health practitioners in addition to the information received from their physician,(31) yet little is known about the sources of information for self-care of illnesses among PLWH

This study presents an important contribution to the extant literature because there are only two other studies on information sources of self-care strategies for PLWH and both geographically and historically distinct from our current study. One of the studies was conducted in South Africa (32) and the other was conducted nearly 15 years ago prior to the widespread use of cART and before the Internet became a wide source of health information across diseases.(11) Our study adds to the current body of literature by focusing exclusively on the information sources for self-care among PLWH. The purpose of this paper is to identify the helpful information sources for self-care strategies and assess demographic differences in the types of information sources sought for these strategies.

Methods

We conducted an online survey from March to August 2016 with PLWH in the US. Study participants were recruited from BGCLive.com, POZ.com, CraigsList and Facebook.com through study banners on these sites. After participants clicked on the study banner, they were re-directed to a survey. The survey, built using Qualtrics, was used to collect demographic data (e.g., age, race/ethnicity, gender, education, household income), whether they had previously been diagnosed with AIDS, and data on symptom experience and their management. HIV infection is classified as AIDS when the immune system of a person infected with HIV becomes severely compromised, measured by a CD4+ T-lymphocyte count <200 Cells/ μ L and/or the person becomes ill with an opportunistic infection. (33) An AIDS diagnosis is not synonymous with an HIV diagnosis.

Participants were asked to report their frequency of experiencing 28 common symptoms (e.g., dry mouth, muscle aches and pains, depression) over the past 30 days, including severity and self-management strategies used to ameliorate the symptom, its helpfulness, and the source from where they obtained the idea to use the reported self-management strategy. Therefore, each participant could report experiencing up to 28 symptoms and provide, by free text, a unique source for each self-management strategy.

Participants then rated the helpfulness of the self-care strategy on a 5-point range of *not at all helpful* to *very helpful*. Using a similar approach as employed in a previous study exploring the information source for self-management strategies(6, 11), we included the following question in our survey with a free text answer box: “Where did you get the idea that this strategy might relieve your symptom?”. The purpose of this question was to understand where individuals seek information for self-care strategies (e.g., TV, online, friends, health care professionals) and which sources lead to more successful symptom relief (e.g., very helpful). Results from the symptom reporting and self-management strategies are

reported elsewhere.(34, 35) All study procedures and materials were approved by the lead investigator's Institutional Review Board.

To be eligible to participate in the study, individuals had to: report a diagnosis of HIV, be at least 18 years of age, provide informed consent, be living in the US, and able to read in English. A benefit of online research is the ability to reach large samples of geographically diverse and "hidden" populations quickly. However, there is the ever-increasing threat to valid data with fraudulent and inattentive respondents. We employed real-time quarantine measures to prevent fraudulent or inattentive participation, which in turn can reduce response bias and improve data quality.(36) These measures included failing trap questions (e.g., select number 4) and completing a recaptcha box. We removed survey responses with duplicate information. In addition, participants who completed the survey received no compensation so the chances of participating solely to gain incentive payments did not exist.

Category Development

Survey data were imported into Microsoft Word and NVivo for category/code development. Microsoft Excel was used to code the data once the coding scheme was developed. We developed a coding scheme of information sources using inductive category analysis of the narrative responses.(37, 38) We used an inductive approach to allow research findings to emerge from the frequent, dominant, or significant themes inherent in the raw data, without the restraints imposed by structured methodologies. The following procedures were used for inductive analysis of the data. *1. Preparation of raw data files:* Data were cleaned. *2. Close reading of text:* The raw text was read in detail to gain an understanding of the "themes" and details in the text. *3. Creation of categories:* The authors identified and defined categories or themes. *4. Overlapping coding and uncoded text:* Some of the text may not have been assigned to any category, as much of the text may not have been relevant to the research objectives. *5. Continuing revision and refinement of category system:* Within each category, the authors searched for subtopics, including contradictory points of view and insights and selected appropriate quotes that conveyed the themes.(38)

The final list of information source categories with examples is presented in Table 1. Codes of "Unsure" and "Not applicable" were combined because neither provided an information source.

Statistical Analysis

SAS 9.3 (SAS Institute, 2012) was used to conduct the quantitative analysis to assess differences in helpfulness of the information source for the self-care strategies and in information seeking behavior among demographic groups. The overall type error was set as 0.05 at two tail in the study. We deleted the following categories of information sources from our analysis because they were infrequently reported or not useful (e.g., rated as *not at all or a little useful*) information sources: Instruction (N =37), Alternative Healthcare Professional (N=15), Do Not Know/Not Applicable (N=2,621).

Self-care strategies are reported elsewhere(34) and were rated on a level of helpfulness on a scale of 0 (not at all helpful) – 4 (very helpful).. For this analysis, we dichotomized self-care strategies as helpful or not helpful at ameliorating the symptom. Following this analysis, we

used a multi-nominal regression model to assess whether there was a significant difference in helpfulness of the information source for the self-care strategies compared with common sense/self-experience. The effects of demographic and socioeconomic factors were controlled for in the model. The random effects of the symptom reports were also controlled for in the analysis.

We also sought to understand if there was a significant relationship between key demographic and socioeconomic factors, and information source rated as helpful by participants. Following this analysis, we conducted a bivariate analysis to identify which demographic factors were significantly related to each information source category, with common sense/self-experience as the reference group. The following factors were included in our final multi-nominal logistic regression model: race, age, education, income, gender, AIDS diagnosis, and sexuality. The continuous age variable was dichotomized as older adult (65 years old or above) vs. adult (18–65 years of age). Education was also dichotomized as some college education or above versus no college education. Transgender was removed from the final model due to the low frequency.

Results

Sample

A total of 1,373 PLWH from the US completed all survey questions and are the focus of this paper. Of the total participants, 957 reported their current gender identify as male and 385 as female, with the remaining participants reporting other or failing to reply to this question. Participants' ages ranged from 19 to 81 (Mean = 48.57, S.D. = 11.68). The majority of participants reported being White (n=849) followed by Black (n=412) and Hispanic (n=163). Further demographics of the study participants are included in Table 2.

Information Source

For each self-care strategy, respondents had the opportunity to report where they obtained the idea for the strategy. Participants reported a total of 8,539 ideas, operationalized as information sources in this manuscript, for their self-care strategies. This is the total number of information sources reported across all participants and symptoms, but this is not a unique number of sources. The 8,539 open-ended responses were then coded into the following 7 categories: Common sense/Self-experience, Healthcare professional, Internet, Literature, Multiple, Social Support, and TV ads. The information sources in order of frequency are listed in Table 2.

These 7 categories of information sources which were included in our final analysis were comprised of 5,235 information sources with 3,443 rated as being *at least somewhat helpful*. Table 3 presents the predictors of helpfulness of each information source as compared with common sense/self-experience.

Healthcare professionals were more likely to be rated as a helpful information source compared with common sense/self-experience (RRR: 1.38; 95% CI: 1.20–1.59). Multiple information sources were also more likely to be rated as helpful information sources compared with common sense/self-experience (RRR: 1.78; 95% CI: 1.30–2.43). There was

no significant difference between other information sources and common sense/self-experience.

In our final regression model (Table 4), we present who is more likely to use different information sources. We found no significant difference in income in our bivariate analysis; thus, it was removed from the final model. We found that those who reported being homosexual (RRR: 4.22; 95% CI: 2.04–8.74) or bisexual (RRR: 4.19; 95% CI: 1.98–8.89) as compared to heterosexual, or those without a college education (RRR: 2.38; 95% CI: 1.50–3.77) compared with those with some college education or higher, were significantly more likely to report the use of the Internet as the information source for their self-care strategies. On the other hand, males as compared to females were significantly less likely to use the Internet as an information source (RRR: 0.35; 95% CI: 0.18–0.70) and significantly more likely to use TV ads (RRR: 3.88; 95% CI: 1.09–13.77).

Black participants were significantly more likely to use social support as compared to other racial groups (RRR: 1.82; 95% CI: 1.27–2.59). Older persons (RRR: 1.48; 95% CI: 1.04–2.10), compared to younger persons, and persons who had an AIDS diagnosis (RRR: 1.47; 95% CI: 1.26–1.73) compared to those who did not have an AIDS diagnosis were more likely to rely on a healthcare provider. Homosexual participants (RRR: 2.78; 95% CI: 1.30–5.94) compared to heterosexual participants, and older participants (RRR: 2.38; 95% CI: 1.31–4.33) compared to younger participants, were more likely to use multiple information sources.

Discussion

Given the importance of self-care for PLWH and the host of symptoms experienced by people affected by the illness, we sought to identify the self-care strategies used by PLWH and the most helpful information sources for those strategies. There are a number of self-management programs for those living with chronic illnesses, including HIV;(39) yet there is a dearth of literature on the information source for the development of these programs and strategies. This study aimed to identify the helpful information sources for self-care strategies and assess demographic differences in the types of information sources sought for these strategies.

Researchers have suggested that seeking health information through the Internet leads to greater knowledge acquisition, more active participation in health decisions, and more robust patient–provider discussions without displacing healthcare professionals.(23, 40–42) Despite the widespread use of the Internet for seeking health information, in our study the Internet was not significantly more helpful than using common sense/personal experience as an information source. This finding is interesting given that so many consumers use the Internet to seek health information. This finding may be supported by studies in which researchers identified drawbacks to online health information, including the challenge of identifying trustworthy sources, the high volume of information, and the tendency of some individuals to self-diagnose without consulting a healthcare provider.(43–45) Our findings suggest that one’s own experiences continues to be a more helpful information source for self-care for

PLWH. Another important finding is that there were significant demographic differences in the use of the Internet as compared to other information sources.

When assessing by demographic characteristics, we did identify higher use of the Internet as an information source. Homosexuals, bisexuals, and participants with a higher level of education were more likely to use the Internet as an information source for their self-care activities. This is congruent with past findings that suggest sexual minorities are more likely to report using the Internet for seeking health information.(46, 47) Older adults (65 years and older) and those with an AIDS diagnosis were more likely to seek self-care strategies from healthcare providers. Past research has shown that older adults are more willing to defer to the expertise of their own healthcare provider and report less searching for their own information.(45) Some of the demographic differences may be explained by older adults' difficulty with navigating Internet tools in the context of online diagnosis,(48) making them less likely to seek health information online if they have had negative experiences using the Internet for this purpose.(21) Older adults were also more likely to rely on multiple sources of information which may be the result of having lived longer with the disease and therefore being more likely to combine a number of useful strategies. Another possibility is that older adults, including PLWH, are more likely to suffer from co-morbid conditions (49, 50) and are therefore more likely to use multiple sources of information to target multiple conditions.

We noted gender differences in health information sources; men are more likely to use TV ads as an information source(51) and less likely to use the Internet than women. In a study of the general population of Finnish adults, women reported receiving far more informal health-related information from close family members, other kin, and friends/workmates than men did.(52) In a US study, 72% of women sought health information online versus 51% of men.(53) Finally, we noted racial differences with Blacks significantly more likely to rely on social support for healthcare information to self-manage symptoms than any other information source. This may be because African Americans are less likely to trust their healthcare providers when compared to other racial groups.(54, 55)

Limitations

One of the limitations of this study is our inability to differentiate between actively seeking information (e.g., going online and looking for specific information) and being exposed to information incidentally (e.g., watching a TV ad). Related to this limitation is that if a respondent got the idea during an active search of information, it suggests that s/he already thinks that source of information is helpful, making the follow-up question about the helpfulness of the information source less relevant. Second, our study was conducted online and thus our sample is likely more representative of those who use the Internet. Nonetheless, we found important demographic differences suggesting that even though those who complete an online-only survey may be higher Internet users, they were still more likely to use non-Internet sources to inform their self-care practices. Finally, our study sample was largely male and homosexual; however, this is representative of the HIV epidemic in the US.

Conclusion

This study provides insights into the information sources for self-care strategies for PLWH in the US. There has been little prior research in this area which makes the findings of this work particularly important. Despite the stigmatization of HIV and the widespread use and accessibility of the Internet, healthcare professionals, social support, and TV ads remain widely used information sources for self-care for PLWH. We also noted important demographic differences between racial, gender, and sexual minority groups in their use of information sources for informing their choice of self-care strategies. Future development of informatics strategies for PLWH should pay particular attention to these significant differences between demographic groups.

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Highlights

- This study provides insights into the information sources for self-care strategies for persons living with HIV.
- Despite the stigmatization of HIV and the widespread use and accessibility of the Internet, healthcare professionals, social support and TV ads remain widely used information sources for self-care for persons living with HIV.
- There are demographic differences between racial, gender and sexual minority groups in their use of information sources for informing their choice of self-care strategies.

Summary Points

- Health care professionals were more likely to be rated as a helpful information source compared with common sense/self-experience
- Multiple information sources were also more likely to be rated as helpful information source compared with common sense/self-experience
- Homosexuals and bisexuals as compared to heterosexual, or those without a college education compared with those with some college education or higher were significantly more likely to report the use of the Internet as the information source for their self-care strategies
- Males as compared to females were significantly less likely to use the Internet as an information source and significantly more likely to use TV ads as an information source.
- Black participants were significantly more likely to use social support as compared to other racial groups.

Table 1

Information Source Categories and Examples

Information Source	Examples
1) Common Sense/Self- Experience	I came up with it myself, trial and error, past experiences
2) Alternative Healthcare Professional	natural healers, acupuncturist
3) Instruction	formal/informal training, education
4) Internet	Internet search, online
5) Literature	self-help books, magazine articles
6) Multiple Sources (e.g., more than 2 distinct categories)	Comments from others, reading material
7) Social Support	Family, friends, church, social network
8) TV ads	TV, commercials
9) Unsure	Don't know, don't remember
10) No Action	Did not do anything, just put up it
11) Not applicable	phlegm makes me gag, nothing has worked

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Table 2

Characteristics of Study Sample (N=1373)

Characteristics	N	%
Gender		
Female	385	28.39
Genderqueer	4	0.29
Male	957	70.58
Transgender Female/Transwoman/MTF	8	0.59
Transgender Male/Transman/FTM	2	0.15
Race *		
White/Caucasian	849	61.84
Black/African American	412	30.01
Other	132	9.61
Ethnicity		
Non-Hispanic	1181	87.87
Hispanic	163	12.13
Sex orientation		
Homosexual	816	60.18
Heterosexual	399	29.42
Bisexual	141	10.4
Education (Highest Level Completed)		
None/Prefer Not to Answer	4	.29
Elementary School	2	0.15
Some High School	51	3.79
High School Graduate/Got GED	137	10.19
Associate's Degree/Technical Degree	190	14.14
Some College	406	30.21
College Graduate (4 years)	292	21.73
Professional or Graduate Degree	262	19.49
Annual household income		
\$10,000–\$19,999	272	20.37
\$100,000–\$149,999	74	5.54
\$150,000 or more	26	1.95
\$20,000–\$39,999	299	22.4
\$40,000–\$59,999	162	12.13
\$60,000–\$79,999	125	9.36
\$80,000–\$99,999	61	4.57
Don't know	13	0.97
Less than \$10,000	234	17.53

Characteristics	N	%
Prefer not to answer	69	5.17
Age (years) mean(SD)	48.57	11.68
AIDS		
No	821	63.15
Yes	479	36.85
Information Source**		
Do not know/Not applicable	2621	30.69
Common Sense/Self-experience	2237	26.20
Health care professional	2014	23.59
No Action	631	7.39
Social support	305	3.57
Multiple	250	2.93
Internet	196	2.30
Literature	146	1.71
TV ads	87	1.02
Instruction	37	0.43
Alternative health care professional	15	0.18

* Participant can select multiple races

** Participants can report multiple symptoms and thus multiple information sources

Table 3

Multi-nominal logistic regression assessing the helpfulness of each information source compared with common sense/self-experience* (N=5235 information sources)

Effect	Information Source	Relative Risk Ratio(RRR)	95% CI of RRR		p-value
			Lower Bound	Upper Bound	
Helpful	Health care professional	1.382	1.204	1.587	<.0001**
Helpful	Internet	1.092	0.798	1.496	0.582
Helpful	Literature	0.857	0.600	1.224	0.395
Helpful	Multiple	1.775	1.296	2.430	<.0001**
Helpful	Social support	1.059	0.813	1.380	0.671
Helpful	TV ads	0.908	0.582	1.416	0.669

* effects of age, gender, sex orientation, AIDS status, annual income, education level, as well as random effects of symptom are controlled in the model.

** significant at 0.05 level.

Relative risk ratio of predictors on proportion of each information source compared with common sense or personal experience* (N=3443 information source rated as helpful by patients)

Table 4

Effect	Information Source	Relative Risk Ratio(RRR)	95% CI of RRR		p-value
			Lower Bound	Upper Bound	
Male	Health care professional	0.745	0.535	1.037	0.081
	Internet	0.351	0.176	0.703	0.0032**
	Literature	0.469	0.183	1.200	0.114
	Multiple	0.662	0.320	1.369	0.266
	Social support	1.016	0.520	1.987	0.962
	TV ads	3.882	1.094	13.771	0.0358**
Homosexual	Health care professional	1.056	0.754	1.479	0.751
	Internet	4.217	2.035	8.738	0.0001**
	Literature	1.953	0.744	5.132	0.174
	Multiple	2.779	1.301	5.938	0.0084**
	Social support	1.403	0.717	2.746	0.323
	TV ads	0.656	0.206	2.087	0.475
Bisexual	Health care professional	0.889	0.615	1.286	0.534
	Internet	4.190	1.976	8.885	0.0002**
	Literature	1.434	0.513	4.003	0.492
	Multiple	2.113	0.960	4.653	0.063
	Social support	0.916	0.418	2.009	0.826
	TV ads	0.571	0.141	2.319	0.434
Black	Health care professional	0.906	0.745	1.102	0.323
	Internet	1.026	0.648	1.623	0.913
	Literature	1.293	0.764	2.190	0.338
	Multiple	0.960	0.632	1.457	0.847
	Social support	1.816	1.274	2.589	0.001**
	TV ads	0.681	0.308	1.507	0.343

Effect	Information Source	Relative Risk Ratio(RRR)	95% CI of RRR		p-value
			Lower Bound	Upper Bound	
Age=> 65	Health care professional	1.480	1.042	2.104	0.0288**
	Internet	1.358	0.593	3.112	0.469
	Literature	1.677	0.691	4.072	0.253
	Multiple	2.382	1.311	4.327	0.0044**
	Social support	0.540	0.192	1.523	0.244
	TV ads	0.742	0.174	3.167	0.687
Previous AIDS diagnosis	Health care professional	1.474	1.256	1.729	<.0001**
	Internet	0.577	0.384	0.867	0.0082**
	Literature	1.120	0.705	1.778	0.632
	Multiple	1.035	0.748	1.433	0.835
	Social support	0.892	0.646	1.232	0.488
	TV ads	0.610	0.339	1.098	0.099
Less than a college degree	Health care professional	1.070	0.853	1.343	0.557
	Internet	2.379	1.501	3.769	0.0002**
	Literature	1.098	0.581	2.076	0.773
	Multiple	1.106	0.677	1.807	0.687
	Social support	1.524	0.997	2.330	0.052
	TV ads	0.813	0.316	2.091	0.668

* Results are from multi-nominal logistic regression model with random effect of symptoms.

** Significant at 0.05 level.