Symptom manageability in Swiss HIV-infected patients

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Abstract

Background: Managing symptoms in daily life is a challenging problem for people living with HIV. As traditional parameters used to identify symptoms needing management do not integrate aspects of daily living with symptoms, we introduced 'perceived symptom manageability' to fill this gap.

Aim: The aim of this study was to quantitatively explore 'perceived symptom manageability' in a sample of 268 persons living with HIV.

Methods: Secondary analysis of existing cross-sectional data. Social support, gender, age, depressive and anxiety symptoms were bivariately and multivariately analyzed and related to symptom experience and manageability as measured by the HIV Symptom Assessment Scale and the HIV Symptom Manageability Scale.

Results: Least manageable symptoms were hair loss, vomiting and insomnia. Multivariately, age (β = −.11; p = .024), symptom distress (β = −.62; p < .001) and total anxiety and depressive symptoms (β = −.18; p = .003) were statistically significant correlates of symptom manageability.

Conclusions: Although a promising concept to identify symptoms needing management, further research employing primary data is recommended.

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1. Introduction

Despite improvements in antiretroviral therapy and access to care in developed countries, Persons Living With the Human Immunodeficiency Virus (PLWH) may experience a host of disturbing symptoms (Nicca, 2009) across their illness trajectory. As it is for other patients with chronic illnesses, managing symptoms and integrating them in daily living remain a major portion of illness management for PLWH. Although a great share of the illness management is performed by patients outside the health care setting, health care providers represent important collaborators for PLWH in identifying and negotiating symptoms needing management, as well as initiating appropriate management strategies (Bodenheimer, 2003). It is widely accepted that an individual's symptom experience, an amalgamation of emotional and cognitive components, should serve as the basis for determining symptom management needs. However, the traditional parameters representing symptom experience may not adequately identify symptoms needing management in persons living with a chronic illness. More specifically, symptom severity, frequency, and associated distress (Leventhal, Diefenbach, & Leventhal, 1992; Portenoy, 1994; Spirig, Moody, Battegay, & De Geest, 2005) do not take into account the context of living with symptoms and managing them in every-day life. Therefore, we propose that the introduction of a concept representing the patients' perspective on symptoms needing management is timely and necessary.

Based on the clinical observation that PLWH often use 'not manageable' when describing symptoms interfering with their lives and that these symptoms may or may not be severe, frequently occurring, or even distressing, we hypothesized that 'perceived symptom manageability' holds promise to expand the current focus on symptom experience assessment by providing a comprehensive understanding of symptom management as perceived by PLWH. In an

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endeavour to explore 'perceived symptom manageability', our research team chose to follow the procedural steps of concept synthesis (Walker & Avant, 2005), which encompasses the definition of a theoretical definition, its empirical verification and modification, and the development of defining attributes of the concept. Employing a mixed methods triangulation design (Creswell & Plano Clark, 2007) seemed appropriate to follow these steps. The development of a working definition of the concept (Fierz, Nicca, & Spirig, 2012), and the verification/modification using qualitative data are described elsewhere (Fierz, Nicca, Martin, Frei, & Spirig, submitted). In the current study, our aim was to quantitatively explore and verify 'perceived symptom manageability' and position the concept within a theoretical framework.

2. Background

2.1. The Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV)

The Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV) was presented in 2005 by Spirig et al. (Spirig et al., 2005) and represents the conceptual framework for our exploration. According to this model, symptom management in PLWH comprises a system of distinct and intertwined personal, symptom-related, social, contextual, and behavioral factors, as shown in Fig. 1 and acknowledges the profoundly individual nature of perception. We consider perceived symptom manageability to represent the patients' view on the symptom management concept, and integrate the elements outlined by Spirig et al. in their conceptualization of symptom management in PLWH.

2.2. Perceived symptom manageability

Based on findings of the first procedural steps of concept synthesis, i.e., development of a theoretical definition and its first empirical verification (Fierz et al., 2012) (Fierz, Nicca, Martin, Frei, & Spirig, submitted), we assume that 'perceived symptom manageability' embodies a different and more comprehensive view on symptoms needing management than traditionally used parameters by incorporating the patients' perspectives on a daily living with symptoms. Furthermore, we assumed that the model presented above represents this comprehensiveness in a sufficiently apt way to serve as the basis to explore our concept. Thus, we hypothesized that the elements representing symptom management in the model are also represented in 'perceived symptom manageability'. In order to verify 'perceived symptom manageability' quantitatively, we, therefore, explored the concept within the context of variables presented by the model.

2.3. Aims of the study

The aims of the study were to relate perceived symptom manageability to traditionally used symptom experience parameters, and to bivariately and multivariately explore correlates of 'perceived symptom manageability' employing parameters of symptom management designated in the presented model.

3. Methods

3.1. Study design

The reported study is a secondary analysis of cross-sectional data collected for a mixed-method project investigating symptom experience and the collaboration between health care providers, PLWH and their primary support persons regarding symptom and medication management (further referred to as the primary study) (Nicca, Fierz, Happ, Moody, & Spirig, 2012).

3.2. Sample and setting

Due to the secondary data use, most sample and setting information of the primary study also apply to the reported study. In the primary study, a convenience sample was used. Patients were recruited between June 2004 and November 2005 at the four outpatient clinics in the German-speaking part of Switzerland.
(Basel, Berne, Zurich and St. Gallen) that participate in the Swiss HIV Cohort Study (SHCS). The SHCS is a large prospective cohort study with continuing enrollment of HIV-infected individuals aged 16 years or older. Patients were eligible to participate in the primary study if they were HIV-infected and on antiretroviral therapy (ART), over 18 years of age, and German speaking. Local and community ethical committee approvals were obtained for each of the study locations. Participants completed a survey packet and were asked to return the questionnaires within 2 weeks in pre-addressed and pre-stamped envelopes. To assist participants, the research team provided a hotline during office hours. If the questionnaires were not returned in a timely manner, participants were reminded twice by a research assistant or by a study nurse. The first reminder occurred after 2–3 weeks, the second after 4–6 weeks. Research assistants checked survey forms for missing data upon receipt. If there were missing or equivocal values, participants were contacted by telephone by either a research assistant or the study nurse for clarification. For the reported study, participants were excluded from the analysis if they did not report at least one symptom or if they provided no information on perceived manageability of reported symptoms.

3.3. Variables and measurements

Symptom experience (severity, frequency, distress) and manageability ratings, socio-demographic and clinical variables, anxiety and depressive symptomatology, and social support were abstracted from the primary database and were measured in the following way. The symptom experience for 82 HIV-specific symptoms was measured by the HIV Symptom Assessment Scale (HIV-SEAS) (Vincenzi, Moody, & Spirig, 2009), which combined the symptom list from the ‘Symptom Check-List for HIV (SSC-HIVrev)’ (Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001) with the scaling of experience-related characteristics used in the ‘Memorial Symptom Assessment Scale (MSAS)’ (Portenoy, 1994). Characteristics of each symptom perceived during the prior week were measured by asking patients ‘how severe was the symptom usually?’ (four-point Likert-type scale from 1 = slight to 4 = very severe), ‘how often did it occur?’ (four-point Likert-type scale from 1 = rarely to 4 = almost constantly), and ‘how distressing was the symptom?’, which describes the distress or bothersomeness associated with a given symptom (four-point Likert-type scale from 0 = not at all to 3 = very much). Both underlying instruments, the SSC-HIVrev and the MSAS, are often used and widely validated with PLWH. Validity evidence based on test content, scaling dimensions, and response process were established for the combined questionnaire (American Educational Research Association, American Psychological Association,, & Education, N. C. o. M. i, 1999; Vincenzi et al., 2009). The perceived ability to manage specific symptoms was assessed by The Symptom Manageability Scale (HIV-SMS). The question ‘how manageable was this symptom for you?’ was integrated in the HIV-SEAS as the last question asked for each reported symptom and was answered using a six-point Likert-type scale answering options (1 = very poorly to 6 = very well).

Depressive and anxiety symptoms were measured by the German version of the Hospital Anxiety and Depression Scale (HADS) (Bjelland, Dahl, Haug, & Neckelmann, 2002; Herrmann, Buss, & Snaith, 1995; Zigmont & Snaith, 1983). The HADS is a self-report scale consisting of 14 items in two subscales and was designed as a non-diagnostic screening tool for use in non-psychiatric clinical settings. Seven items measure anxiety symptoms (e.g., anxiousness or fearfulness) and seven items assess depressive symptomatology (e.g., depressed or sad mood, decreased interest in almost all activities). Items are rated from 0 (not at all/hardly at all) to 3 (most of the time, very definitely). Item scores of the anxiety and depression subscales are summarized, resulting in total scores from 0 to 21. A cut-off of 8 or more has been recommended as a positive screening test for both scales, with sensitivities of 0.90 and 0.83, and specificities of 0.78 and 0.79, respectively. For the German version (HADS-D), Cronbach’s alpha was 0.80 for the anxiety scale and 0.81 for the depression scale and test-retest reliabilities were 0.84 and 0.85, respectively.

Emotional and instrumental support provided by the social network was measured using the Norbeck’s Social Support Questionnaire (NSSQ) (Norbeck, Lindsey, & Carrié, 1983). The nine-item questionnaire measures three major components of social support—functional aspects, network and loss. For the purpose of this study, only subscale scores for functional aspects (affirmative, affective, and instrumental support) were used. Subscores are calculated on the basis of a list of network members, initially provided by the participants. Six questions, two for each subscale, are rated using a five-point rating scale (0 = not at all to 4 = very much). Subscale scores are calculated by summing up ratings of network members on the subscale questions. The scale has been translated into German by our team following the adapted Brislin protocol including forward- and backward translation and content validation by experts. Furthermore, the three-dimensional structure suggested by Gigliotti et al. (affirmation, affect, and aid) has been confirmed and will be utilized in this study (Gigliotti, 2002).

3.4. Data analysis

Data analysis was performed in three steps. First, descriptive statistics were generated for demographic, behavioral, psychosocial variables as well as the average perceived symptom manageability across perceived symptoms and the prevalence of symptoms across the study sample. Total number of symptoms perceived by each participant was also calculated. Symptoms experienced by fewer than 10% of the participants and gender-specific symptoms were excluded from the analysis.

Second, we explored the associations between overall symptom severity, frequency or distress and manageability at the symptom level. At the symptom level, the respective ratings of each symptom were averaged across all participants who reported experiencing the symptom. At the patient level, we averaged the ratings across all symptoms reported by each patient. Nonparametric and parametric methods were used as appropriate, depending on variable measurement level and data distribution.

In a third step, bivariate and multivariate analysis was performed using average perceived symptom manageability as the outcome

<table>
<thead>
<tr>
<th>Table 1 Overall sample characteristics and psychosocial parameters of PLWH.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
</tr>
<tr>
<td>---------------------------------</td>
</tr>
<tr>
<td>Total – n</td>
</tr>
<tr>
<td>Male gender - %</td>
</tr>
<tr>
<td>Age – median (IQR)</td>
</tr>
<tr>
<td>Swiss nationality – %</td>
</tr>
<tr>
<td>White ethnicity – %</td>
</tr>
<tr>
<td>AIDS – %</td>
</tr>
<tr>
<td>CD 4 cell count (mmol/L) – median (IQR)</td>
</tr>
<tr>
<td>HIV-1 RNA (copies/ml) – %</td>
</tr>
<tr>
<td>&lt;50</td>
</tr>
<tr>
<td>50–600</td>
</tr>
<tr>
<td>&gt;600</td>
</tr>
<tr>
<td>Depressive symptomsa – no symptoms – %</td>
</tr>
<tr>
<td>Anxietyb – no symptoms – %</td>
</tr>
<tr>
<td>Social support (n = 255)</td>
</tr>
<tr>
<td>Affirmationc – median (IQR)</td>
</tr>
<tr>
<td>Aaide – median (IQR)</td>
</tr>
</tbody>
</table>

* Measured by the Hospital Anxiety and Depression Scale (HADS) (score min–score max both scales 0–21; 0–7 = no symptoms, 8–10 = mild symptoms, 11–14 = moderate symptoms, 15–21 = severe symptoms).

* Measured by the Norbeck Social Support Questionnaire (NSSQ), affirmation/affect/aid subscale.
variable. Correlates potentially influencing the perception of symptom manageability (influencing factors from the Spirig model) (Spirig et al., 2005), were gender, age, stable partnership, highest educational degree, number of symptoms, depressive and anxiety symptoms, as well as symptom experience and social support. Using average manageability ratings at the patient level, bivariate correlations were conducted to examine the relationships between symptom manageability and psychosocial and demographic variables. (i.e., Spearman correlation for non-normally distributed continuous data and ordinal data, point-biserial correlations between continuous and dichotomous variables and Pearson correlation for normally distributed, continuous data).

To explore the correlation of manageability with influencing factors on a multivariate level, averaged manageability ratings on the patient level were used as response variable and all influencing factors identified from the model were used as potential predictors. All variables were entered in an initial model. Then, as indicated by collinearity statistics, variables were removed one by one or collapsed as appropriate. All statistical analyses were performed using SPSS (Version 20, IBM SSPS Inc., Chicago, IL, USA). For each test, the level of significance was set at alpha = 0.05.

4. Results

Seven hundred forty-four patients on ART, participating in the SHCS, and >18 years old were invited to participate in the primary study. Among those who declined to receive study information (n = 274), the main reason was a lack of time. Of the 382 PLWH who were eligible and agreed to participate, 107 did not return the questionnaires and were classified as non-responders, two participants withdrew their previously signed informed consent, and one participant was excluded from analysis due to 60% missing data, resulting in a final sample of 272 participants (36.6% of invited patients and 71.2% of those who declined to receive study information (n=20; 7.4%), resulting in a reduction of missing data on symptom experience to less than 1%. For our analysis, three (1.1%) participants who did not report any of the 82 symptoms and one participant who did not provide information on manageability were excluded, yielding a total of n = 268 PLWH.

The sample consisted largely of white Swiss middle-aged males with basic schooling (i.e., 9 years of mandatory school and, generally, 3 years of profession-specific apprenticeship) (see Table 1). One third of participants had at least one AIDS-defining medical condition but few had viral loads of more than 400 HIV-1 RNA copies per milliliter. The most probable mode of viral transmission was men having sex with men.

Twenty-one percent (n = 56) of our study participants had mild to severe depressive symptomatology and 31% (n = 83) had significant anxiety symptomatology. The median number of symptoms experienced by participants during the past week was 16.5 (IQR: 9–25.75, range: 1–46). One patient reported having 46 symptoms during the prior week.

After excluding the nine gender-specific symptoms, the prevalence of symptoms across participants ranged from 61.8% (n = 168) for fear/worries to 1.1% (n = 3) for nipple discharge. Twelve symptoms reported by fewer than 10% (n = 27) of participants were excluded.

The 10 most prevalent, severe, frequently occurring, distressing, and least manageable symptoms are summarized in Table 2. Within symptoms, manageability scores were strongly and negatively correlated with distress scores (Spearman’s rho = −.753) and were nearly uncorrelated with symptom severity and frequency ratings (n.s.).

Bivariately, anxiety (Spearman’s rho = −.389) and depressive symptomatology (Spearman’s rho = −.287) and total number of perceived symptoms (Spearman’s rho = −.367) correlated with symptom manageability (p < .001). None of the social support dimensions (aid, affect, affirmation), nor any of the demographic (age, gender) or psychosocial (stable partnership, educational degree) variables were significantly related to symptom manageability.

Collinearity diagnosis prompted us to collapse the anxiety and depressive symptomatology subscale scores into a HADS total score.

Table 2

<table>
<thead>
<tr>
<th>Most prevalent (%)</th>
<th>Most severe</th>
<th>Most frequent</th>
<th>Most distressing</th>
<th>Least manageable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear/worries (61.8%)</td>
<td>Sensitivity to insect bites</td>
<td>Dry skin</td>
<td>Headaches</td>
<td>Hair loss</td>
</tr>
<tr>
<td>Fatigue (53.3%)</td>
<td>Insomnia/can’t sleep</td>
<td>Thrust</td>
<td>Caries/brittles teeth</td>
<td>Vomiting</td>
</tr>
<tr>
<td>Dry skin (52.2%)</td>
<td>Vivid dreams</td>
<td>Insomnia/can’t sleep</td>
<td>Insomnia/can’t sleep</td>
<td>Insomnia/can’t sleep</td>
</tr>
<tr>
<td>Weakness (50%)</td>
<td>Fatigue</td>
<td>Gas/bloating</td>
<td>Heartburn</td>
<td>Weight gain in stomach area</td>
</tr>
<tr>
<td>Diarrhea (47%)</td>
<td>Thrust</td>
<td>Vivid dreams</td>
<td>Increased sensitivity</td>
<td>Decreased ability to withstand psychological strain</td>
</tr>
<tr>
<td>Depressed mood (46%)</td>
<td>Lack of appetite</td>
<td>Lack of appetite</td>
<td>Fatigue</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Gas/bloating (45%)</td>
<td>Diarrhea</td>
<td>Constipation</td>
<td>Anxiously</td>
<td>Vomiting</td>
</tr>
<tr>
<td>Vivid dreams (44%)</td>
<td>Insomnia/can’t sleep</td>
<td>Increased appetite</td>
<td>Fear/worries</td>
<td>Fear/worries</td>
</tr>
<tr>
<td>Difficulty concentrating (43%)</td>
<td>Numbness/tingling in legs, feet and toes</td>
<td>Diarrhea</td>
<td>Nausea</td>
<td>Desire</td>
</tr>
</tbody>
</table>

Table 3

<table>
<thead>
<tr>
<th>Model</th>
<th>B (SE)</th>
<th>Beta</th>
<th>T</th>
<th>p</th>
<th>95.0% confidence interval for B</th>
</tr>
</thead>
<tbody>
<tr>
<td>(constant)</td>
<td>6.063 (0.276)</td>
<td>21.960</td>
<td>.000</td>
<td>5.519</td>
<td>6.607</td>
</tr>
<tr>
<td>Age</td>
<td>−.008 (0.004)*</td>
<td>−.109</td>
<td>−2.271</td>
<td>.024</td>
<td>−.016</td>
</tr>
<tr>
<td>Stable partnership</td>
<td>0.020 (0.051)</td>
<td>0.019</td>
<td>0.401</td>
<td>.689</td>
<td>−.079</td>
</tr>
<tr>
<td>Gender</td>
<td>0.159 (0.094)</td>
<td>0.082</td>
<td>1.688</td>
<td>.093</td>
<td>−.027</td>
</tr>
<tr>
<td>Symptom distress</td>
<td>−.753 (0.070)</td>
<td>−.624</td>
<td>−10.789</td>
<td>.000</td>
<td>−.890</td>
</tr>
<tr>
<td>Highest completed educational degree</td>
<td>−.042 (0.029)</td>
<td>−.071</td>
<td>−1.442</td>
<td>.151</td>
<td>−.099</td>
</tr>
<tr>
<td>HADS total score</td>
<td>−.020 (0.007)</td>
<td>−.182</td>
<td>−3.000</td>
<td>.003</td>
<td>−.033</td>
</tr>
<tr>
<td>Total functional support score</td>
<td>0.000 (0.000)</td>
<td>0.113</td>
<td>.912</td>
<td>.358</td>
<td>0.000</td>
</tr>
<tr>
<td>Number of reported symptoms</td>
<td>0.000 (0.004)</td>
<td>0.067</td>
<td>.110</td>
<td>.921</td>
<td>−.008</td>
</tr>
</tbody>
</table>
and aid, affirmation and affect into a ‘total functional support’ score. Multivariately, we found that age, gender, depression/anxiety symptomatology and symptom distress were significant correlates of symptom manageability (see Table 3).

4. Discussion

We conducted a secondary analysis of data from PLWH collected in four Swiss-German centers of the Swiss HIV Cohort Study in 2004/2005 with the goal to expand the findings from a theoretical definition and its qualitative verification recently conducted by our team and to further verify the theoretically developed concept definition. Moreover, to our knowledge, this is the first quantitative study in this population exploring perceived symptom manageability in the wider context of a theoretical model and compare traditionally employed parameters to identify symptoms needing management with symptom manageability.

The comparison of most distressing, severe and prevalent symptoms with the least manageable symptoms revealed that these dimensions seem to capture different aspects of a symptom. For instance, insomnia, fatigue and depressed mood, among the 10 most prevalent, and vomiting, anxious, and fatigue, among the most distressing symptoms, were also found among the 10 least manageable symptoms. Physical changes, however, such as skinny arms and legs and weight gain in stomach area, did not fall high into the other dimensions and were found only among the least manageable symptoms and known to cause substantial distress (Nokes et al., 2007). Because stigmatization due to HIV is still widespread (Whetten, Reif, Whetten, & Murphy-McMillan, 2008), the potential for unwanted disclosure in case of visible symptoms is an issue, which needs to be addressed. Although these symptoms are difficult to control from a medical perspective, supporting patients to gain a sense of symptom manageability is of utmost importance to enhance overall well-being (Lyons, Pitts, Grierson, Thorpe, & Power, 2010). Thus traditionally used parameters, indeed, may only elucidate a limited segment of symptoms needing management and miss symptoms with wider-ranging impacts (Hobbs, 2009).

Results of the multivariate analysis showed that our findings partially confirm the model underlying the analysis. Of the influencing factors analyzed, the correlation with symptom manageability could be substantiated for age, depressive and anxiety symptomatology, and symptom-associated distress; the latter two being well known correlates of HIV (Eller et al., 2010; Lee et al., 2009). As people continue to age with HIV, they are also confronted with comorbidities due to living longer (Lyons et al., 2010), and managing symptoms may be more difficult, as suggested by our result.

Given evidence (Chesney, Chambers, Taylor, & Johnson, 2003) and the findings of our qualitative analysis that social support is a core variable in managing HIV, it was surprising that this study did not find a relationship between social support and symptom manageability. One explanation could be a measurement issue. First, in the primary study the NSSQ questionnaire was utilized to measure social support in relation to overall illness management, not symptom management. Although symptom management is an integral part of illness management, the score may only partly reflect the role that a social network plays relative to symptom management. Second, the NSSQ targets dimensions of social support across the entire network. Specific types of support assigned to specific groups within a person’s supportive network as outlined in our qualitative exploration [i.e., instrumental support (aid) and affect to lay persons, affirmation to lay persons and health care providers] were omitted in this quantitative exploration. Moreover, the provision of information, which was also perceived as support and asked from health care professionals, was not included in any of the questions in the NSSQ. Therefore, the questionnaire may be too general and blur these specific types of support. A more differentiated analysis of types of support by laypersons and professionals on the network list in the questionnaire might provide different results. Third, the sample we analyzed in the qualitative exploration might have been very specific, and the results, as always in qualitative analyses of this type, are context-driven and do not necessarily apply to the entire sample used in the quantitative analysis.

5. Limitations of the study

Comparing descriptive parameters displayed in Table 1 might point towards a possible sampling bias due to the inclusion criteria, which stipulated the ability to read or speak German. Persons with good knowledge of the German language tend to have been born in a German speaking country or have been living in Switzerland for many years, tend to be integrated into the working process, and generally understand and follow instructions well. Therefore, neither the limited racial/ethnic diversity, nor good disease control is unexpected. The differences found preclude generalization of our results to the entire cohort.

A further limitation of our study was the secondary character of our data. Our analysis was based on a theoretical conceptual model assuming that ‘perceived manageability’ represents a patient’s view of symptom management and an existing data set created on the basis of this model before the qualitative concept verification analysis was conducted. Therefore, instruments used to measure correlates of the concept may capture different aspects than were revealed through our qualitative exploration, leading to unexpectedly negative findings.

6. Implications for further research

Based on existing evidence we recommend that health care providers should not only assess symptoms indicating medical complications but also the patients’ symptom experience. Although needing further exploration, our concept provides an interesting starting point to initiate a conversation on symptoms needing attention by directing the clinical attention from symptoms themselves to their every-day manageability as perceived by patients. For clinicians, the question of perceived manageability, after assessment of symptoms, might be an easy and straightforward way to talk about and support symptom management and reduce symptom-related distress relating to living with symptoms. For symptom management programs, this concept should be taken into consideration and be tested in terms of its usefulness to identify symptom management domains specific to PLWH.

7. Conclusions

In order to better understand the patients’ concerns in view of symptoms needing management, an effort should be made to further develop a measure based on qualitative findings from a primary investigation targeting symptom manageability. Moreover, in order to verify the value of the concept, the concordance and differences between symptom-associated distress or bother and manageability should be further investigated. The relative importance of the dimensions identified in the qualitative analysis may be temporal in nature, and the sensitivity of aspects of perceived symptom manageability to changing symptom profiles should be examined prospectively in future studies.

Although our findings reveal that the concept ‘perceived symptom manageability’ holds promise as a valuable alternative to commonly used parameters to identify symptoms needing management, evidence is far from conclusive. Moreover, due to the similarity of symptom distress and our concept, it is likely that they capture similar
aspects. Given the evidence that manageability decreases with an increasing number of symptoms and the finding that most severe or prevalent symptoms are not necessarily the least manageable, symptom lists based on the most prevalent or most severe symptoms might not reflect a PLWH’s reality symptomwise, and might not capture less prevalent/severe symptoms related to low manageability in every-day life, and, eventually, quality of life.

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References


