

## CONCEPT ANALYSIS

## Perceived HIV symptom manageability: synthesis of a new use for a known concept

Katharina Fierz, Dunja Nicca &amp; Rebecca Spirig

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Correspondence to R. Spirig:  
e-mail: rebecca.spirig@usz.ch

Katharina Fierz MNS RN  
Scientific Collaborator  
Institute of Nursing Science, University of  
Basel, Switzerland, and  
Department of Nursing and Allied Health  
Professions, University Hospital Basel,  
Switzerland

Dunja Nicca PhD RN  
Scientific Officer  
Institute of Nursing Science, University of  
Basel, Switzerland, and  
Department of Infectious Diseases, Cantonal  
Hospital St. Gallen, Switzerland

Rebecca Spirig PhD RN  
Head of Department  
Institute of Nursing Science, University of  
Basel, Switzerland, and  
Center of Clinical Nursing Science,  
University Hospital Zurich, Switzerland

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**Abstract**

**Aim.** To report the synthesis of the concept of perceived symptom manageability.

**Background.** Common symptom assessment parameters fail to address concerns about the impact of symptoms on everyday life, overall functioning, or threats to individuals living with the human immunodeficiency virus. We claim that the concept of ‘perceived symptom manageability’ integrates these important dimensions of the patients’ experience of their symptoms.

**Data sources.** Online databases, thesauri, and dictionaries were accessed in January 2012. A free search was performed scanning the PubMed, CINAHL, and PsycINFO databases for entries from 2001–2011 using ‘manageability’ in the title or abstract as a search term.

**Design.** Text-based analysis.

**Review methods.** We followed the steps delineated by Walker and Avant for concept synthesis. Uses of the concept ‘manageability’ were identified and listed, meaningful usage clusters were generated, and a preliminary working definition was created.

**Results.** Social resources and individual interpretation were relevant in view of managing a difficult situation, thus positioning ‘manageability’ in a social and interpretational context that exceeded objective control. We preliminarily defined perceived symptom manageability as ‘the extent of the perceived ability to bring social and personal resources into play to successfully deal with or control symptoms, despite difficulties’.

**Conclusion.** We believe that our working definition represents a promising start to understand and address the manageability problems that individual patients face regarding particular symptoms and may serve as a basis to identify not only symptoms but also areas of intervention that are of most concern to individual patients.

**Keywords:** concept analysis, human immunodeficiency virus, manageability, nursing, symptoms

## Introduction

In countries where antiretroviral therapy is available and affordable, human immunodeficiency virus (HIV) is acknowledged as a long-term illness. As with many other chronically ill populations, persons living with human immunodeficiency virus (PLWH) can be challenged by a host of symptoms due to comorbidities, the illness itself, and the side effects of medications in the course of their illness trajectory. Identifying symptoms that need management from the patients' perspective is, thus, an integral part of clinical follow-up visits in any social or political context. In a research project conducted to better understand the mechanisms underlying the symptoms and medication management of PLWH (Nicca *et al.* 2011), we realized that the ability to manage symptoms in their daily routine is of great importance to this population and that this perceived manageability of symptoms is crucial to the overall experience of symptoms by PLWH. We also realized that the symptom experience parameters commonly used by providers to identify symptoms needing management, i.e. symptom frequency and severity/intensity, bother, or distress, failure to address the concerns of PLWH about integrating their symptoms into everyday life, and overall functioning (Willard 2006, Hobbs 2009). Disagreement on symptoms needing management may occur (Apollo *et al.* 2006, Edelman *et al.* 2010). Therefore, we postulate that the parameters used to identify symptoms needing management ought to incorporate the individual interpretation of PLWH related to their daily living with symptoms and propose 'perceived symptom manageability' to be such a term. To our knowledge, the term 'manageability' has not been described or used in the context of symptoms to date; therefore, an exploration and description of the concept are needed. Our aim was to explore 'perceived symptom manageability' and establish a working definition of this concept.

## Background

As the collaboration between PLWH and healthcare providers has become a core issue in healthcare encounters and is particularly important in the field of HIV care (Fehr *et al.* 2005), we conducted a mixed methods research project (Nicca *et al.* 2011) in an effort to better understand the collaboration between providers and patients in view of medication and symptom management. We based our thinking on the Common Sense Model (CSM) of Leventhal *et al.* (1992) and specifically on its adaptation for PLWH suggested by Spirig *et al.* (2005), which provides an advanced framework for the care of PLWH. While conducting interviews for this project, we

discovered that PLWH are actively involved in designing and negotiating symptom management strategies; however, patients and healthcare providers do not always agree on the symptoms needing management (Apollo *et al.* 2006, Edelman *et al.* 2010). This divergence may impede effective illness management and diminish the quality of the healthcare encounter (Jackson & Kroenke 2001).

To understand potential sources of disagreement in view of the symptoms needing management, subjective illness theories such as the CSM (Leventhal *et al.* 1980, 1984) and specifically its adaptation by Spirig *et al.* (2005) are useful frameworks. These theories underscore the individuality inherent in the interpretation of an illness and its symptoms. In the CSM, Leventhal *et al.* (1980, 1984) state that first, internal and external stimuli generate an individual, cognitive representation of the problem and emotions. Emotions and representation are cues that lead to separate, yet intertwined, coping actions and the evaluation of outcomes in both dimensions, which feed back into representations and generate further emotions, finally representing a self-regulatory system. Both processing tracks, i.e. the emotional and the cognitive, are influenced by self and the social context. To understand the drivers of patient behaviour, it is crucial for healthcare providers to be aware of a patient's illness representation, which, in turn, shapes their actions to confront the illness and form the basis for outcome interpretation. Disagreements may occur within the attributes of illness representation, i.e. identity, time-line, consequences (physical, social, and economic), antecedent causes, and the potential for cure and/or control of a threat. Furthermore, according to the authors, diverging notions of problem space (i.e. the representation-coping-evaluation pathways), culturally diverging interpretations of the illness, or inconsistencies with an individual's personality may result in divergence between patients and providers regarding treatment. In fact, the lay interpretation of the cause, effect, and controllability of an illness or symptom determines how people react to the threat and cope with the unpleasant situation (Leventhal *et al.* 1992). As the self-regulatory system is coherent in itself and consistent for an individual patient, it is crucial that providers are aware that a patient's interpretations of their emotional and cognitive representation-coping-evaluation pathways (i.e. the patient's problem space) may differ from state-of-the art interpretations and cannot be altered without acknowledging its consistency for the patient.

For PLWH, social support has been established as being crucial to successful symptom and illness management (Spirig *et al.* 2005) and was integrated as a core determinant for successful symptom management by these authors into

the CSM. Furthermore, symptom manageability was introduced as a variable representing the cognitive and emotional evaluation of individual symptom management endeavours by addressing the overall success of these actions as perceived by the patient, which will, eventually, affect further actions, health-related quality of life, clinical parameters, and adherence.

We suggest that discrepancies between providers and PLWH about symptoms needing management occur due to their different perspectives when evaluating symptom management outcomes. PLWH and providers are both concerned about identifying those symptoms that need management and to initiate management actions and a reduction in symptom severity (intensity), and their frequency of occurrence is commonly interpreted as management success. However, this perspective fails to address the challenges posed by the symptoms (Hobbs 2009), which are subject to the patient's individual evaluation. In a recent study investigating adherence and attitudes towards haemodialysis in patients with end-stage renal disease, Karolich and Ford (2010) found that the subjective meaning attributed to the illness greatly influenced how patients understand and manage their chronic condition. Furthermore, there is evidence that interventions based on a patient's illness representation can successfully promote their well-being (Hill *et al.* 2007) and adherence to medication (Phillips *et al.* 2012). Integrating a concept that addresses a patient's lived experience of managing their symptom(s) in addition to 'objective' criteria to identify symptoms needing management may contribute to mutual understanding and improved satisfaction with the health-care encounter (Jackson & Kroenke 2001). On the basis of our clinical observation that PLWH often use 'manageable' when describing their symptoms, we considered 'perceived symptom manageability' as a concept that expands the focus of symptom assessment from mere symptom expression to a comprehensive understanding of the problem space perceived by PLWH, as depicted by Spirig *et al.* (2005).

## Data sources

If a concept is already used, but not described in a specific area or context, concept synthesis is deemed especially useful (Walker & Avant 2005). By exploring broadly as many current uses of a concept as possible, summarizing core aspects of the concept and translating it to a new area of use may add a new perspective to this specific area. According to these authors, concept synthesis

precedes the well-known approach of concept analysis, which is used if a concept is common knowledge, has been used in different areas in many situations, became blurred, or needs sharpening. Concept synthesis also complements the process of concept derivation, where a concept is transferred from one domain to another where it has not yet been used (e.g. from industry to nursing). To expand and target the use of 'manageability' to HIV symptoms and to preliminarily define 'perceived symptom manageability', we employed concept synthesis as described by Walker and Avant (2005).

Our concept synthesis is based on online data sources. The steps to perform concept synthesis, as described by Walker and Avant (2005) and how the steps were followed, are summarized in Table 1. As a first step in concept synthesis and to achieve familiarity with the topic, Walker and Avant (2005) suggest the use of all possible sources of information to detect as many current uses of the concept as possible. Our sources were PubMed, CINAHL, PsycINFO (entries within the last 10 years (2001–2011), 'manageability' in the title or abstract); the Google search engine (entries within 24 months; search term 'manageability' in the title), and online versions of dictionaries and thesauri which were scanned using the search terms 'to manage', 'manageability', 'ability', and 'manageable' (Table 1). To allow a broad perspective on concept use, the search was not limited to any area of use.

In a second step, we listed the uses of 'manageability', 'to manage', and 'manageable' as retrieved from online thesauri and dictionaries. Similar uses were grouped and same uses were discarded. Abstracts retrieved from online databases (PubMed, CINAHL, and PsycINFO) were scanned for the use of 'manageability' and emerging groups of uses were compared with the categories identified in online thesauri and dictionaries and assigned accordingly. Abstracts were then scanned in each semantic group and included in our synthesis if the use of 'manageability' provided information on the meaning of the concept from a person's/patient's perspective, if the use of the concept was either related to health or a condition or was transferable to the health context. The meaning of manageability was summarized in each group of uses.

To extend the information on the uses of the concept to non-scientific sources, the Google search engine was employed and citations were scanned for additional uses of the concept. In the next step, we combined the core information from summarized evidence and a working definition of the use of the concept with symptoms was created.

**Table 1** Steps of the concept synthesis.

Steps described by Walker and Avant (2005)	Data source	Action	Process
Step 1: achieve familiarity with the topic; identify current uses of the concept	Online versions of thesauri and dictionaries PubMed, Cinahl and PsycINFO Google search engine	Search term: 'to manage', 'manageability', 'ability', and 'manageable' Search term: 'manageability' [Title and Abstract] Search term: 'manageability'	Results of step 1 inform step 2
Step 2: list and combine uses of the concept	Results from step 1: abstracts and definitions	Clustering of uses listed in dictionaries and thesaurus; reviewing abstracts, listing of uses of manageability in abstracts and clustering of abstracts presenting similar uses	Results of step 2 inform the definition of the new use
Steps 3a and 3b: definition of the new use	Reduced uses (results from step 2)	Summarizing meaning of manageability within semantic clusters; transfer of uses to symptoms and creation of the preliminary working definition	

## Results

### Steps 1 and 2: Achieve familiarity with the topic and identify current uses of the concept; list the uses and combine them into meaningful clusters

#### *Online versions of English dictionaries and a thesaurus*

We accessed four different online dictionaries and one thesaurus: Wiktionary (<http://en.wiktionary.org/wiki/Manage>, <http://en.wiktionary.org/wiki/manageability>), Merriam-Webster Online Dictionary (<http://www.merriam-webster.com/dictionary>), Merriam-Webster Online Thesaurus (<http://www.merriam-webster.com/thesaurus>), Oxford English Dictionary (<http://www.oed.com>), and Houghton-Mifflin Online Dictionary (<http://ahdictionary.com/word/search.html>): All electronic sources were accessed on 2 January 2012. 'Manageability' was referred to as 'the quality or condition of being manageable' (<http://www.oed.com>) and not further discussed in any of the sources as a noun. Therefore, we performed all further steps using the descriptions of 'to manage', mainly described as a transitive verb with some intransitive uses (Table 2). Uses were summarized into four broad semantic categories: 'to act as a manager', 'to control the movements or actions of something (tool)', 'to exert one's authority: control someone (animal or human)', and 'to succeed in accomplishing or achieving, especially with difficulty' (Table 2). As the

only source to do so, the Oxford English Dictionary listed the specific use of 'to manage' in the healthcare setting as follows: 'to control or relieve (a disease or disorder); to look after (a patient, case, or client) as appropriate. Also especially in later use: to provide or coordinate (a suitable course of action for the care of such a person)' (<http://www.oed.com>).

#### *Literature search PubMed (National Library of Medicine), CINAHL, and PsycINFO*

The literature search of PubMed, CINAHL, and PsycINFO was performed for the years 2001–2011 with 'manageability' in the title or abstract. A total of 320 abstracts were listed, of which 86 were identified as duplicates and were discarded, resulting in 234 abstracts for closer inspection. Six citations were additionally discarded because 'manageability' was not in their title or abstract. Finally, 228 abstracts were checked for the use of the term 'manageability' and clustered according to the use of this term. Table 2 provides an overview on the combined uses of the concept in dictionaries and the assignment of abstracts retrieved from PubMed, CINAHL, and PsycINFO.

#### *Open internet search using the Google search engine*

The Google search returned 777 links when 'manageability' was entered. These were compatible with the already discovered uses and no new uses were detected.

**Table 2** Step 2: Listing and combining the uses of the concept in dictionaries, assignment of clustered abstracts, and articles integrated in synthesis.

Intransitive uses	Categories of 'manageability' use listed in dictionaries	Search results: clustered abstracts (number of abstracts)	Articles integrated in the working definition, reporting perceived manageability
To direct affairs or interests, be in charge of (manage a company)*, †	'Act as manager'	IT and e-learning (9) Project (5)	–
To look after and make decisions about* Also: to handle or direct with a degree of skill§ To conduct, carry on, supervise, control‡, **, *		Processes, non-medical (5) Services (11) Hair (8) Risk (12)	Eklof (2002), Peters-Guarin <i>et al.</i> (2012), Sanne (2008), Stave <i>et al.</i> (2006) Arapakis <i>et al.</i> (2005), Bergk <i>et al.</i> (2004), Perlioli <i>et al.</i> (2009)
To handle, wield (a tool, weapon)*		Medical processes (24)	–
To direct or control the use of, handle (a machine tool)†		Occupational demands (8)	–
To control the movements or actions of (something) (=control)‡	To control the movements or actions of something (tool);	Material for clinical use (10) Medical device (7)	–
To handle, wield, or make use of**			–
To make submissive to one's authority, discipline, or persuasion†	To exert one's authority: control someone (animal or human)	Trait in children (9) Prisoners (3) Workers (1) Disabled persons (1) Horses (5) Other (2)	–
To control the behaviour of (a child or animal)†, **, *			–
To train or direct**			–
To handle or control (a situation or job)*	To succeed in accomplishing or achieving, especially with difficulty	Condition, situation, illness (29) SOC (75)	Johansson <i>et al.</i> (2007), Karolich and Ford (2010), Olsson Orzanne <i>et al.</i> (2012), Power <i>et al.</i> (2010), Sunvisson and Ekman (2001), Wiklund (2008) <i>Structure</i> : Bernabe <i>et al.</i> (2009), Bengtsson-Tops <i>et al.</i> (2005), Zimprich <i>et al.</i> (2006), Flensburg-Madsen <i>et al.</i> (2005, 2006)
To succeed in doing, accomplishing, or achieving something, especially with difficulty; contrive or arrange‡, †			<i>Patients with specific conditions</i> : Jensen (2001), Malterud and Hollnagel (2004), Nyman <i>et al.</i> (2012), Strang and Strang (2001)
To deal or cope with (something) usually skilfully or efficiently (managed the crisis)‡, **, *			Antonovsky (1987); Kennedy <i>et al.</i> (2009); Vincenzi <i>et al.</i> (2009); Reece <i>et al.</i> (2010), Hollub <i>et al.</i> (2011)
With infinitive: to be successful or skilful enough to do something, usually with difficulty or in the face of adversity**		Use in scale (4)	
<i>Intransitive uses</i>	Total	228	

**Table 2** (Continued).

Intransitive uses	Categories of 'manageability' use listed in dictionaries	Search results: clustered abstracts (number of abstracts)	Articles integrated in the working definition, reporting perceived manageability
To meet one's day-to-day needs* To be able to live or to do what is needed by using what you have even though you do not have much <sup>†</sup> To cope or get by; to contrive to get on with something which is barely adequate** To succeed (despite difficulties) in accomplishing a task**	Intransitive use To continue to <i>get along</i> , carry on	There were no intransitive uses in the cited abstracts	
<p>*Wiktionary.  <sup>†</sup>Houghton-Mifflin Online Dictionary.  <sup>‡</sup>Merriam-Webster Online Thesaurus.  <sup>§</sup>Merriam-Webster's Learner's Dictionary.  <sup>¶</sup>Merriam-Webster Online Dictionary.  **Oxford English Dictionary.</p>			

**Step 3a: Review and summarize the uses**

The uses of 'manageability' in the abstracts basically represented the substantiated transitive uses of 'to manage' listed in the online thesaurus and dictionaries and 'manageability' as part of the sense of coherence (SOC) (Table 2).

Finally, 21 articles corresponded to the inclusion criteria for the concept synthesis and represented a patient/person experience in the healthcare setting or experiences that were transferable to this setting. Four articles referred to the use of the concept as part of a scale. Only one study group included PLWH (Reece *et al.* 2010, Hollub *et al.* 2011). The following paragraphs provide a summary of concept uses in semantic clusters.

*To act as a manager*

From two subgroups of this cluster, i.e. risk management and management of medical processes, we extracted qualitative information that could be transferable to our envisioned use of 'manageability'.

*Risk management:* The authors investigating the risk-taking behaviour of fishermen (Eklof 2002) and farmers (Stave *et al.* 2006) found that the interviewees engaged in preventive actions (safety work) if they perceived the manageability of a risk as low. The finding was that the interviewees generally underestimated the risk or overestimated their ability to manage such a threat. After group interventions, both groups perceived risks as less manageable. In another qualitative study, communities in the Philippines were questioned about their perception of flood hazards. Communities perceived the manageability of a flood hazard in relation to the community's capacity and available coping mechanisms (Peters-Guarin *et al.* 2012). In a study on the risk-taking behaviour of railway workers, Sanne (2008) found that risk-taking was not only related to the workers' appraisal of risk manageability but also their duty to provide a functioning railway to the public.

Manageability in medical processes comprised user-friendliness, as viewed by the researchers, such as non-invasive, frameless, and self-adhesive for an X-ray surgery procedure (Arapakis *et al.* 2005). Bergk *et al.* (2004) found, in a quantitative study, that the frequency and severity of drug interactions may not be adequate dimensions to assess the potential risk/harm. The authors state that measuring potential outcomes irrespective of their manageability may overestimate the risk arising from drug interactions.

In sum, manageability of a risk or threat, as applied to studies of fishermen, railway workers, and farmers, was the perceived ability to deal or cope with a difficult situation. However, the concept was connected to influencing factors

such as personal values and social desirability. Moreover, solely weighting the quantifiable expression of an occurrence may underestimate the role of manageability. Procedure manageability was used in the sense of user-friendliness as viewed by non-patients. The semantic clusters 'to control the movements or actions of something (tool)' and 'to exert one's authority: control someone (animal or human)' did not provide relevant information for our purpose.

*To succeed in accomplishing or achieving, especially with difficulty*

Under this group of concept uses we assigned articles that were related to dealing with an illness, condition, or difficult situation. For patients living with amyotrophic lateral sclerosis, the constant fluctuation between opportunities and limitations in an individual's abilities made managing the life situation challenging and difficult (Olsson Ozanne *et al.* 2012). Creating a new frame of reference for interpreting life facilitated the manageability of the illness and for these patients comprised developing one's own strategies to accept the situation, living in the present and the felt presence and assistance from a supportive network and authorities. For people living with a substance use disorder, manageability of their situation was supported by experiencing coherence in their life, confirmation and acceptance, and gaining a sense of community and attachment (Wiklund 2008). Connectedness and interactions with a social network were also fundamental for patients with myocardial infarction to manage their situation (Johansson *et al.* 2007). Being part of a social context and meeting adequate physical challenges were important factors supporting the perceived manageability of the illness situation in patients with Parkinson's disease (Sunvisson & Ekman 2001).

In sum, perceiving symptoms may be experienced as challenging and the main factors supporting the perceived manageability of the situation were connectedness, functional relationships, and interaction with the social environment. Furthermore, the ability to constantly develop strategies to adapt to the fluctuating and unpredictable physical and mental changes due to a long-term illness emphasized the volatility and difficulty of the situation.

*Use of 'manageability' as part of questionnaires*

There were 4 questionnaires distinctly employing the concept: The Orientation to Life Questionnaire (Antonovsky 1987), The Perceived Manageability Scale (PMnac) (Kennedy *et al.* 2009), the Multi-factor Attitude Towards Conditions Scale (MFACS) (Reece *et al.* 2010, Hollub *et al.*

2011), and the HIV-Symptom Manageability Scale (HIV-SMS) (Vincenzi *et al.* 2009).

The Orientation to Life Questionnaire was developed to measure the sense of coherence, which represents an individual's global attitude towards life and basically describes what keeps people healthy in a hostile environment. The SOC encompasses three explanatory concepts: making sense of what is going on (meaningfulness), understanding (comprehensibility), and manageability, which is defined as 'the extent to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one' (Antonovsky 1987, p. 17). This global definition of manageability refers to life in general and remains abstract. In the questionnaire, manageability was operationalized as the perceived ability to trust in oneself, trust in others, and act and control or overcome an unpleasant situation. The Orientation to Life Questionnaire has been employed and evaluated in diverse healthcare contexts and countries for many years (Abu-Shakra *et al.* 2006, Nabi *et al.* 2008, Wiesmann & Hannich 2011). Validity evidence in terms of the structure of the questionnaire, however, is inconclusive. The 3-factor structure, as suggested by Antonovsky, has been examined by numerous authors: in the Finnish general population, a 1-factor solution seemed the most adequate (Bernabe *et al.* 2009), whereas in patients with schizophrenia, a 4-factor solution emerged (Bengtsson-Tops *et al.* 2005). Zimprich *et al.* (2006) explored 1107 Swiss students, for which a 2-factor solution was found, combining 'manageability' and 'comprehensibility'. While the construct 'sense of coherence' and the three components of comprehensibility, manageability, and meaningfulness are well accepted, the operationalization of the construct has been criticized and an adaptation of scale items was suggested (Flensburg-Madsen *et al.* 2005, 2006).

*Perceived manageability in the SOC.* Patients with chronic fatigue syndrome described their lives as increasingly chaotic, with lower manageability, comprehensibility, or meaningfulness scores than persons diagnosed with other enduring illnesses (Jensen 2001). Patients newly diagnosed with a brain tumour reported that they achieved manageability by actively seeking social support and information. Despite their insecure situation, these patients constructed comprehensibility mainly by their own theories and thoughts (Strang & Strang 2001). Feeling part of the care process and having personal and social resources at one's disposal facilitated coping with health problems among patients attending a general practice or persons with substance use disorder (Malterud & Hollnagel 2004, Nyman

*et al.* 2012). In sum, although the kind of support may differ between populations, creating a new frame of reference to interpret life, the experience of coherence in life, and being embedded in a community were elements contributing to the perception of manageability for all groups. *The PMnac* was developed by Kennedy *et al.* (2009) and based on Antonovsky's concept to assess the manageability of spinal cord injury, emphasizing (successful) control as the core dimension of manageability.

*The HIV-SMS* (Vincenzi *et al.* 2009) encompasses a list of 82 HIV-specific symptoms, medication side effects, and non-specific symptoms that occur frequently in PLWH. To assess their perceived ability to manage a specific symptom, the participants were asked to rate their perception of symptom manageability for each symptom that occurred during the prior week on a Likert-type scale that provided options from 1 'very poorly'–6 'very well'. However, there was no information on the definition of perceived symptom manageability used in the scale. The scale was piloted a few years ago and preliminary validity evidence on the response process and test content was established, and the generation of further validity evidence is underway.

The MFACS (Reece *et al.* 2010, Hollub *et al.* 2011) was developed to fill a gap in previous research on condom use, which had been conducted for specific contexts or outcomes, e.g. preventing a pregnancy or the transmission of a disease. The MFACS specifically measures condom use. It encompasses 3 dimensions and covers cognitive and emotional aspects: perceived effectiveness, affective issues, and manageability. Condom manageability not only refers to the actual handling of condoms but also addresses less clearly defined issues such as dealing with embarrassment and being a difficult topic between sex partners.

### Step 3b: Creation of the working definition

The group of uses listed in dictionaries and the thesaurus, 'achievement of something despite difficulties' or 'coming to terms/dealing successfully with difficult situations' where a focused, skilfully performed activity with the ultimate goal of success was described, allowed the application of the concept to symptoms. Symptom manageability, thus, could then be summarized as 'the ability to successfully handle or deal with symptoms with a degree of skill'.

Uses of the concept identified in empirical evidence across diverse populations emphasized the importance of connectedness with a supportive network as a resource to deal with a condition or a difficult situation. Moreover, the evidence supported the individuality of the frame of refer-

ence providing the basis to evaluate the manageability of a situation and the notion that personal strategies to meet a constantly changing condition influenced its perceived manageability.

The inspection of questionnaires using the concept accentuates the relevance of 'being in control' of a condition or illness situation (Kennedy *et al.* 2009) and the importance of emotions and cognition (Reece *et al.* 2010, Hollub *et al.* 2011). The generic and abstract formulation of Antonovsky's (1987) definition of manageability presented above allows the concept to be concretized for its use with symptoms. Therefore, 'the extent to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one' (Antonovsky 1987, p. 17), served as the basis for our working definition. The uses of the concept in diverse realms revealed that the activation of social and personal resources contributed substantially to the perceived manageability of a complex situation. By integrating these aspects, our working definition of 'perceived HIV symptom manageability' unfolds as follows. The extent of the perceived ability to bring social and personal resources into play to successfully deal with/control symptoms, despite difficulties.

### Discussion

There are limitations to the present study. In the almost complete absence of evidence relating to 'manageability' in PLWH, the transfer of 'manageability' to symptoms perceived by PLWH was based on evidence from other chronically ill populations, even from areas that were not related to symptoms or illnesses. Moreover, aspects contributing to the manageability of a challenging situation were investigated in relation to illnesses, but not to symptoms. Thus, its adaptation to symptoms involves a certain degree of insecurity and interpretation. The working definition is preliminary and needs further exploration. As it was developed theoretically, it may be incomplete; therefore, the interpretation of the concept by PLWH and the verification of the definition relating to symptoms in this population are important next steps. Further work needs to be done to relate the value and position of perceived symptom manageability in the broader conceptual model, integrating contextual and outcome variables such as quality of life, adherence, and social support, as conceptualized by Spirig *et al.* (2005).

We undertook this concept synthesis because we realized that the concerns of PLWH in view of living with symptoms go beyond alleviation and that commonly used parameters to measure management success do not sufficiently capture the

### What is already known about this topic

- Persons living with the human immunodeficiency virus (HIV) can be confronted with burdensome symptoms due to the illness itself, medication side effects, and co-morbid conditions.
- Symptoms needing management in persons living with HIV are identified using parameters exploring the expression of symptoms, e.g. frequency, severity/intensity, and bother/distress.
- Although patients often use the expression ‘I manage well (not well)’ when asked about their life with symptoms, the concept of ‘perceived symptom manageability’ has not yet been explored.

### What this paper adds

- The concept of ‘manageability’ has been used generically and specifically, but not with regard to symptoms; however, manageability is a concept that can be used with symptoms.
- Manageability of health challenges is consistently associated with the availability of a supportive social environment and the use of personal resources.
- A working definition of ‘perceived symptom manageability’, based on an open internet search and concept synthesis, i.e. the extent of the perceived ability to bring social and personal resources into play to successfully deal with/control symptoms, despite difficulties.

### Implications for practice and/or policy

- ‘Perceived symptom manageability’ represents a promising complement to the parameters commonly used to identify symptoms needing management, but should not be used without inquiring the patients’ interpretation of the concept.
- Further research exploring attributes of perceived symptom manageability from the patients’ perspective is needed to substantiate or refine the working definition.
- Inquiring the patients’ perception of symptom manageability may elicit concerns not captured by commonly used parameters assessing symptom severity (intensity) and frequency and facilitate satisfactory and more effective patient–provider interactions.

patients’ perspective in view of integrating symptoms into a daily routine and maintaining a normal life. Our working definition of ‘perceived symptom manageability’ clearly

exceeds symptom management, which represents a provider view (Kendall *et al.* 2011), by focusing on symptom control as measured by the severity and frequency of symptoms. ‘Deal with’, as formulated in our working definition, explicitly integrates the possibility not only to be ‘in control of symptoms but also to negotiate, handle, cope with, or learn to live with symptoms. PLWH often perceive symptoms as fluctuating and unpredictable, creating difficult situations that require a high degree of flexibility from PLWH and their network (Wilson *et al.* 2002). The working definition of perceived symptom manageability addresses this aspect by incorporating the degree to which an individual perceives that they have symptom management strategies at their disposal and the skills to use them to live at ease with their symptoms. Perceived symptom manageability may be especially important for symptoms that often involve a person’s environment or threaten personal integrity. For instance, fatigue or vomiting (Chubineh & McGowan 2008, Jong *et al.* 2010) may impede social contacts or working capacity. Some patients manage well, some do not, often unrelated to the severity or frequency of symptoms. Also for skinny arms and legs, both symptoms attributable to HIV treatment, and the individual perception of manageability is only partly related to severity or frequency. Dealing with these symptoms may be challenging because of the stigma attached to HIV and the threat to individual integrity inherent in unwanted disclosure (Power *et al.* 2003, Reynolds *et al.* 2006). Assessing the ability of a PLWH to manage these symptoms may elucidate symptom-related areas for intervention that complement symptom alleviation as measured by severity or frequency.

We claim that ‘manageability’ can be defined for symptoms, integrates the subjective evaluation of emotional and cognitive processes in the face of symptoms, as depicted by Spirig *et al.* (2005) and Leventhal *et al.* (1992), and that it can be a useful concept to identify symptoms needing management as perceived by PLWH. The use of the concept in questionnaires targeting different populations, as well as the different semantic usages identified in our database search, provide evidence for the flexibility of the concept and that its use with symptoms lies within the scope of the concept. Although the concept is not yet used with PLWH, there is some evidence that PLWH interpret some HIV symptoms as threats (Power *et al.* 2003, Reynolds *et al.* 2006) or as difficult to deal with (Chubineh & McGowan 2008, Jong *et al.* 2010), which may impede symptom manageability. Therefore, we claim that the concept can also be used with PLWH to identify symptoms needing management and negotiate strategies, which increase their perceived ability to manage symptoms.

The importance of a supportive network is evident in the descriptions of manageability (Sunvisson & Ekman 2001, Johansson *et al.* 2007, Wiklund 2008) and thus verifies the framework suggested by Spirig *et al.* (2005). Healthcare providers, among others, represent an important source of information and support for PLWH (Holzemer 2002). Understanding the patient's interpretation of a symptom by addressing its manageability in daily life – the aspect of dealing/living with symptoms of the working definition – may create an environment where healthcare providers and PLWH can establish a true collaboration. Addressing and discussing patient worries seemed to facilitate successfully dealing with a symptom, even if there were limited treatment options (Jenkin *et al.* 2006, Reynolds *et al.* 2006). Moreover, studies in HIV populations have shown that a positive appraisal of illness-related phenomena supports living successfully with this chronic condition (Bova 2001, Fleishman *et al.* 2003). However, it is important to note that merely using 'manageability' will not make the difference and the interpretation of the concept by providers may still be different from its use by patients (Arapakis *et al.* 2005, Perioli *et al.* 2009) and needs exploration. The manageability of treatable or untreatable and visible or invisible symptoms would be an interesting area for future research using the concept.

Emerging evidence that the perception of control and the ability to deal with symptoms might be relevant to several outcome measures, e.g. the quality of life or adherence, points to the importance of our concept for future research, and patient care. In previous studies of long-term illness management, perceived control moderated the improvement of self-efficacy (Jerant *et al.* 2008), whereas a perceived lack of control was associated with decreased quality of life (Sarna *et al.* 1999), self-care behaviour (Lovejoy *et al.* 1991), medication adherence (Evans *et al.* 2000), and increased distress (Pergami *et al.* 1993).

## Conclusion

The concept synthesis procedure guided our process to explore the concept of 'manageability' and translate its generic use to a symptom-specific use. Our working definition of perceived symptom manageability combines symptom control with two dimensions relating to the continuing challenge of living with HIV symptoms: (1) the availability of social resources; and (2) the notion of successfully dealing with and, thus, integrating emotional and cognitive aspects. Integrating perceived manageability into symptom assessment in addition to using objective measures focusing on physiological state represents, in our opinion, is an interesting approach for negotiating symptoms that need management in PLWH

and identifying new, patient-defined areas for intervention. While further research is needed, our working definition is a promising starting point in developing a measure that might help to improve the care of PLWH.

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## Conflict of interest

No conflict of interest has been declared by the authors.

## Author contributions

All authors meet at least one of the following criteria (recommended by the ICMJE: [http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)) and have agreed on the final version:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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