

**PERCEIVED SYMPTOM MANAGEABILITY –  
SYNTHESIS OF A NEW USE OF A KNOWN CONCEPT BASED ON  
A SAMPLE OF HIV OUTPATIENTS**

**Inauguraldissertation**

zur Erlangung der Würde eines Doktors der Pflegewissenschaft

vorgelegt der Medizinischen Fakultät der Universität Basel

von

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von Männedorf / ZH

Basel, 2012



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Basel, October 2012

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## MY ACKNOWLEDGEMENTS

My deepest gratitude goes to my advisor, **Prof. Rebecca Spirig**, who introduced me to the world of qualitative research and supported my creative analytical thinking. Prof. Spirig also accompanied and supported my scientific work throughout the whole process.

I also wish to express special thanks to the other members of my PhD committee, who have all given close support and guidance throughout the dissertation process, enabling my learning and progress. I greatly appreciated **Prof. Manuel Battegay's**, quick and substantial feedback and his continuous structural guidance throughout the process of my PhD studies. I want to thank **Prof. Jill Bennett**, of the Oregon Health and Science University, who critically supervised some of my work until her withdrawal from the committee due to a burdensome illness experience. My great appreciation goes to **Prof. Sandra Engberg** of the University of Pittsburgh, who agreed to replace Prof. Bennett in the committee and further supported my critical and scientific thinking by devoting time and energy to my work. Prof. Engberg specifically provided expert advice to the development of the quantitative part of my study. I especially would like to thank **Prof. Kim Moody** of the University of Southern Maine, for her cheerful and motivating mentorship throughout the process, and made possible the excellent opportunity of personal mentoring in Portland, Maine, during my PhD education. Many thanks also to **Prof. Mary-Beth Happ**, whose broad experience in Mixed Method research was an invaluable source of inspiration and learning for me. Prof. Happ has been an appreciated mentor in the writing phase of the concept analysis paper. I further gratefully thank **Prof. Langewitz** for his effort as external evaluator of this thesis.

I especially wish to thank **Prof. Sabina De Geest**, head of the Institute of Nursing Science, University of Basel, who introduced me to the world of research, accompanied and supported my scientific development and work for many years and provided a rich scientific environment, allowing constant learning opportunities and inspiration from her network of renown international researchers. I also want to thank her for chairing the defense colloquium as representative and chair of the Medical Faculty's PhD Commission (University of Basel).

I wish to express my deepest gratitude to **Dr. Dunja Nicca**, **Jacqueline Martin** and **Dr. Irena Anna Frei** who have been most supportive colleagues for many years. They were always reliable discussion partners providing inspiring contributions regarding qualitative data analysis and a wide range of questions that arose throughout my study process and contributed substantially, as co-authors, to the improvement of my dissertation project.

Many thanks also go to the following persons, all of whom contributed substantially to this dissertation project:

- **Sabine Bigler** who was an appreciated colleague throughout the SOLEXA project. She contributed substantially to the project by conducting interviews, collecting, managing and analyzing data, writing reports and added many constructive and critical inputs in research meetings.
- **Christine Vincenzi**, who was a much-valued colleague contributing substantially to the SOLEXA project and the validity analyses of the HIV-SEAS. Furthermore, for many years at the Department of Clinical Nursing Science, she always was a reliable discussion partner providing helpful structure and linearity to my circular thinking.
- **The study nurses and physicians at the SHCS centers in Basel, Bern, St. Gallen and Zürich**, who were involved in recruitment and follow-up of participants and therefore supported the research process substantially.
- **All participants** in the qualitative interviews, who shared their stories with my colleagues and me. Specific thanks go to two persons who agreed to discuss, negotiate and validate my qualitative findings.

I specifically would like to thank **Leslie Nicholl**, for her careful editing of my manuscripts. Working with Leslie improved my writing and English language skills considerably.

I am also extremely grateful to the **Nora van Meeuwen Haefliger Foundation** for their grant support.



Finally, my profound personal thanks go to my beloved partner, **Baptist Thurnherr**, for his ongoing commitment and support throughout this project, and to my colleagues at the INS and the Department of Clinical Nursing Science, who encouraged my work and provided me with many pleasant diversions to replenish my energy.

Katharina Fierz 2012



## EXECUTIVE SUMMARY

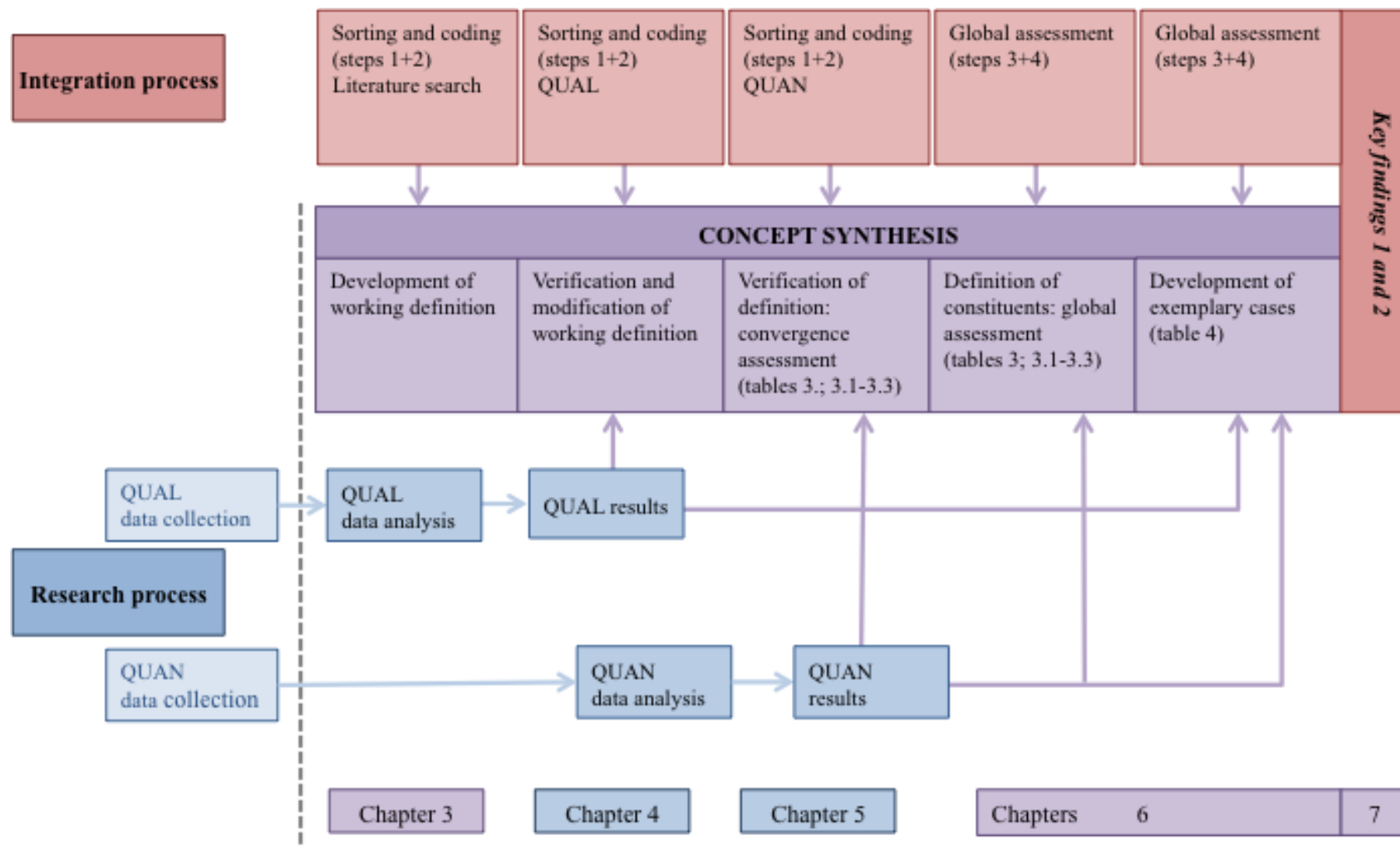
Despite tremendous and ongoing advances in treatment, HIV remains a global health problem. Although for some regions, in which Anti Retroviral Therapy (ART) coverage is low, access to ART for all in need is focused <sup>1</sup>, problems in countries that have ART coverage of nearly 100% and sustained low morbidity and mortality due to HIV/AIDS <sup>2,3</sup> pertain largely to the consequences of lifelong treatment, adherence, and maintaining quality of life. Persons living with HIV (PLWH) on ART, despite continually improving treatment options with a relatively low side effects profile, are challenged with numerous and often fluctuating and debilitating symptoms due to the illness itself, comorbidities and medication side effects <sup>4</sup>. Health-care providers are important collaborators in facilitating effective symptom management support to keep limitations on productivity, social engagement, and well-being <sup>5,6</sup> as low as possible <sup>7,8</sup>. Moreover, since an ongoing rigorously designed intervention trial substantiates evidence that ART can prevent the sexual transmission of HIV <sup>9</sup>, health care providers are more than ever asked to support patients' efforts to achieve and maintain adherence in order to ensure ART effectiveness and viral suppression. Caring for PLWH, therefore, involves assisting patients in adhering to their medication regimen despite intrusive and non-treatable side effects. Engaging in quality of life issues comes to the fore. Due to the individual interpretation and perception of symptoms <sup>10</sup> and their link to the efforts patients living with a chronic illness must make on an everyday basis in order to live as normal a life as possible <sup>11,12</sup>, identifying symptoms that need management, however, is challenging. Comparing traditionally used "objective" measures, i.e. symptom severity or frequency, with concerns of patients in terms of self-management in daily life <sup>13</sup>, makes clear that traditionally employed parameters may not be those of most concern to patients and that the patients' perspective on consequences of a symptom for daily life may be neglected. As in clinical encounters, patients often describe their life with symptoms using sentences like "I can't manage symptom x or y anymore," or "well, yes, symptoms are well manageable," thus directly referring to their ability to influence the impact of the symptoms on their life, we suggest "perceived symptom manageability" as an apt concept for describing PLWHs' lived experience with symptoms and also as a potential means of identifying symptoms that need attention. Our assumptions require verifica-

tion, however, before the concept can be recommended for use in clinical practice. The aim of this PhD project was thus to explore the concept and its potential for identifying symptoms that need management.

As the concept (manageability) is well-known, but has not yet been used in relation to symptoms, the procedural steps of concept synthesis <sup>14</sup> were used to transfer the concept from its current use (“manageability”) to a use with symptoms (“perceived symptom manageability”) and to define attributes of the concept. To follow the steps of concept synthesis, a mixed method triangulation design <sup>15</sup> seemed appropriate. Qualitative and quantitative analyses were conducted independently and systematically combined at the interpretation phases of the concept synthesis. Conclusions as to the concept’s constituents and its usefulness in identifying symptoms that need management were then drawn (see diagram next page) based on these results.

The PhD project was conducted within the scope of a larger, multi-center mixed methods study exploring symptom experience of PLWH, **The Symptoms and other Life Experiences and Adherence (SO-LEXA)** study, which was conducted by our team from 2003 to 2006. For the PhD project, we thus partly drew on existing data taken from the overarching study. The patients we recruited for the studies were all undergoing treatment at one of the four centers of the Swiss HIV Cohort Study (SHCS) (Basel, Bern, Zürich, and St. Gallen).

Diagram 1. The combined integration and research process



Concept synthesis is deemed especially useful in the case of concepts that have already been used, but have not yet been described in a specific area or context<sup>14</sup>. By broadly exploring as many current uses of the concept as possible, summarizing core aspects of the concept, and applying it to perceived symptoms, a new area of use was added and a new perspective was explored<sup>16</sup>. Study 1 comprises these first steps of the concept synthesis process<sup>14</sup> and reports the transfer of “manageability” to “perceived symptom manageability” on the basis of data drawn in January 2012 from online databases, thesauruses, and dictionaries. We found that “manageability” referred to managing a difficult situation and that social resources as well as individual interpretation were relevant in this regard, thus positioning “manageability” in a social and interpretational context that exceeded objective control. We thus 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.” By transferring the concept to symptoms, 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.

In the second study, we further followed the concept synthesis procedure aiming at the empirical verification of the formerly developed working definition of “perceived symptom manageability.” Drawing from existing SOLEXA data, we conducted a secondary analysis of interviews with 13 HIV long-term survivors using conventional content analysis<sup>17</sup>. This step enabled us to modify and refine the definition by integrating key components of the concept according to the lived experience of people with HIV, which we were able to capture employing a qualitative approach. More specifically, we found that a symptom was perceived as manageable if it was reconcilable with professional, social, and personal activities. Contributory factors were keeping interference endurable, being embedded in an accessible supportive network of professionals and laypersons, and being placid in the view of HIV.

We integrated these findings into the theoretical working definition of perceived symptom manageability for long-term HIV survivors, and, thus, transferred the concept’s use from generic to specific: “Perceived symptom manageability relates to the extent of the perceived ability to secure information,

and emotional and instrumental support as well as to apply tailored symptom management strategies to keep a symptom's interference with the social, professional, and personal realms at an acceptable level.”

Study 3 encompasses the quantitative exploration of the perceived manageability of 61 symptoms in a sample of 268 persons living with HIV and the further verification of the concept by positioning it within the conceptual framework of symptom management in persons living with HIV as suggested by Spirig et al. <sup>10</sup>. In this secondary data analysis employing data collected for the cross-sectional mixed-method SOLEXA project, perceived manageability of symptoms was identified. Social support, gender, age, depressive and anxiety symptoms, traditional symptom experience parameters, and symptom manageability as measured by the HIV Symptom assessment scale and the HIV Symptom manageability scale were explored bivariate and multivariate.

The least manageable symptoms were hair loss, vomiting, insomnia, weight gain in the stomach area, decreased ability to withstand psychological strain, anxiousness, skinny arms and legs, depressed mood, and fatigue. Multivariate, age (Beta=-0.11; p=.024), symptom distress (Beta=-.62; P<.001) and total anxiety and depressive symptoms (Beta=-.18; p=.003) were statistically significant correlates of perceived symptom manageability.

### **Integration of findings from studies 1-3**

If using a triangulation design, i.e., conducting quantitative and qualitative analytical steps independently, the combination of findings is recommended to take place at the interpretation phase of the study <sup>15</sup>. The integration findings from studies 1-3, we employed the systematic steps recommended by Farmer et al. <sup>18</sup>, who suggest, first, to develop a “triangulation protocol” in which the distinct steps of integration are described <sup>18,19</sup>. Coding, sorting, and listing findings on one page in order to enable a comprehensive assessment of divergence, concordance, or silence between themes from different methods and studies are the recommended steps. To list uses from our studies, we used convergence coding matrices <sup>19</sup>, which enabled the global assessment of concept constituents and of patients' appraisal of symptom manageability in terms of symptoms mentioned in qualitative interviews. From this step, our key findings emerged.

## **Key findings**

Key Finding 1 refers to the global assessment of antecedents, attributes, and consequences of perceived symptom manageability, which revealed that the concept's constituents mainly refer to normalization, i.e. a person's efforts to live as normally as possible despite the chronic illness<sup>11</sup>. Normalizing is especially difficult if symptoms are fluctuating, regimens are changing; social interactions and roles endangered, or the trajectory of the illness is perceived as fatal<sup>11</sup>. For PLWH, who must live with many untreatable and potentially intrusive symptoms the success of normalization efforts can, therefore, not only depend on medical symptom control but also on the extent of how successful they are to keep the intrusiveness by the illness and symptoms tolerable. Perceived symptom manageability, thus, refers to the perceived ability to lead a normal life despite potentially intrusive symptoms.

Key Finding 2 relates to the symptoms mentioned in qualitative interviews and the concordance assessment of symptom appraisals in qualitative interviews and quantitative survey data. Poorly manageable symptoms mainly belong to three clusters of symptoms, namely mood and mind-related symptoms, symptoms related to energy and recreation, and physical changes. These symptoms were identified concordantly among the least manageable symptoms by the two approaches. Although associated with negative health outcomes, many of these symptoms are under-recognized and under-treated<sup>20,21</sup>. Overall, we conclude that the concept can be used to recognize symptoms that impede normalization, and that symptoms relating to mood and mind, energy and recreation, and physical changes need attention due to their potential to negatively impact daily life and consequently adherence and quality of life.

## **Final reflection: Limitations and recommendations**

While there are indications that "perceived symptom manageability" may be a promising concept for identifying symptoms that need management by identifying the patients' perspective on a life with symptoms in a chronic phase of HIV, evidence is far from conclusive. Based mainly on secondary data use, further testing the concept using primary data is recommended.



Emerging evidence that addressing the emotional situation of patients not only increases satisfaction with the health care experience, but may also facilitates adherence <sup>22</sup> and reduces perceived symptom burden <sup>23,24</sup>, however, advocates the use of the concept in clinical encounters. Self-management support must integrate the various ways in which persons with chronic illnesses manage their own bodies, experiences, and health choices <sup>25</sup>; addressing the tensions related to sustaining a coherent identity, having valued social roles, and leading a normal life may create context-specific opportunities to support patients and facilitate self-management <sup>26</sup>.

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# **GLOSSARY**

## **Abbreviation**

HIV	Human Immunodeficiency Virus
cART	combined Anti Retroviral Therapy
PLWH	Persons Living With HIV

# CHAPTER 1

## INTRODUCTION

## BACKGROUND

Despite tremendous and ongoing advances in treatment, HIV remains a global health problem. Although the number of new infections decreased from 3.1 million (Confidence Interval (CI): 2.9 million–3.4 million) in 1999 to 2.6 million (CI: 2.3–2.8 million) in 2009 and AIDS-related deaths decreased from 2.1 million CI: 1.9–2.3 million) in 2004 to 1.8 million (CI: 1.6–2.1 million) in 2009, the total number of people living with HIV rose from approximately 26.2 million (CI: 24.6–27.8 million) in 1999 to 33.3 million (CI: 31.4–35.3 million) in 2009 <sup>1</sup>. There was great improvement with regard to ART coverage and accessibility throughout low-income and middle-income countries, as, for instance, 5,254,000 people were receiving antiretroviral therapy at the end of 2009, which corresponds to an increase of over 1.2 million people from December 2008; representing a 30% rise from a year earlier and a thirteenfold increase over six years. There are still differences between resource-limited and resource-affluent settings in view of accessibility to ART, however; in North Africa and the Middle East, for example, only 11% of persons in need of ART in 2009 were able to access these medications <sup>2</sup>.

Whereas the global aim to “achieve universal access to HIV prevention, diagnosis, treatment, care and support” <sup>3 (p 3)</sup> guides interventions in all areas as a response to HIV and AIDS, depending on a setting's needs and available resources, health care priorities are different <sup>4</sup>. In high-income countries, individualized and highly targeted interventions delivered in specialized settings prevail, whereas in resource-limited settings, a programmatic public health approach is widely employed that provides standardized monitoring and a limited number of regimens to as many people as possible in order to ensure universal access to treatment. While for those having access, virological outcomes seem to be similar for both approaches <sup>5</sup>, ART coverage is still low in resource-limited areas, and the primary effort goes toward increasing the accessibility and availability of ART. In the western and central parts of Europe, ART coverage lies between 90-100% <sup>6</sup>. As a result, morbidity and mortality due to HIV/AIDS have decreased dramatically over the last decades <sup>7</sup> and the initial drop in these parameters since the introduction of ART has been sustained <sup>6</sup>.

These achievements, however, come at a cost: PLWH on ART, despite continually improving treatment options with a relatively low side effects profile, are challenged with numerous and often fluctuating

tuating and debilitating symptoms due to the illness itself, comorbidities, and medication side effects. Health-care providers play a key role in facilitating effective symptom management to minimize negative effects on productivity, social engagement, and wellbeing<sup>8 9</sup> as low as possible<sup>10,11</sup>. Moreover, since an ongoing rigorous intervention trial substantiates evidence that ART can prevent the sexual transmission of HIV<sup>12</sup>, health care providers are more than ever asked to support patients' efforts to achieve and maintain adherence in order to ensure ART effectiveness and viral suppression. Caring for PLWH, therefore, involves assisting patients in adhering to their medication regimen despite intrusive and non-treatable side effects, and providing symptom management support for these symptoms comes to the fore. Identifying symptoms that need management, however, is challenging, and due to the individual interpretation and perception of symptoms<sup>13</sup> and their link to the efforts patients living with a chronic illness must make on an everyday basis in order to live as normal a life as possible<sup>14,15</sup>. Although traditional "objective" measures to identify symptoms that need management i.e., symptom severity or frequency, are important parameters, they are not necessarily of primary concern to PLWHs when it comes to successfully managing everyday life despite having less treatable symptoms. Effective symptom management support, therefore, ideally starts with the identification of symptoms that need management from the patient's view, thereby integrating the patient's concerns.

In the paragraphs that follow, we discuss the situation of PLWH living in Switzerland and the rationale behind taking a broader perspective than traditional symptom experience dimensions when striving to identify symptoms that need management. We also propose a new approach to this challenge.

### **Patients living with HIV in Switzerland**

In Switzerland, according to a 2011 estimation issued by the Federal Office of Public Health (FOPH)<sup>16</sup> between 19,000 and 26,000 persons are currently living with HIV, and AIDS accounted for less than 100 deaths in 2009, as opposed to more than 600 in 1995<sup>17</sup>. In fact, due to nearly area-wide coverage, the life expectancy of persons living with HIV (PLWH) on cART rose from 36.1 to 49.4 years<sup>18</sup> and as such approaches normalcy. Consequently, PLWH must nowadays cope with issues related to living with a chronic illness<sup>14</sup>(pp. 10). PLWH have the option to receive state-of-the-art care and treatment either at one of the

seven centers enrolled in the Swiss HIV Cohort Study (SHCS), an ongoing multi-center cohort study project that was established in 1988 and is focused on patient oriented HIV research, or through a private care provider. Health care and treatment costs are reimbursed by health insurances independent from the provider. Highly tailored symptom management and chronic illness care interventions are available in many of these settings.

## CHRONIC CARE MANAGEMENT

A fundamental change has occurred with regard to health care needs and the delivery system over the last 20 years. As a result of the demographic and lifestyle changes as well as medical improvements, health care systems are challenged by an increasing number of patients of older age and patients with chronic conditions<sup>19</sup>. The publications "*Innovative Care for Chronic Conditions (ICCC) – building blocks for action*" by the WHO<sup>19</sup> and the "*Chronic Care Model (CCM)*" by Wagner et al (2001) both propose a restructuring of the health care environment in response to the increasing number of patients suffering from chronic conditions<sup>20-22</sup>. In the WHO publication, the authors point out that improved, comprehensive, and sustainable care for the chronically ill relies on an orchestrated interplay of political leaders and policy makers, health care organizations and the community systems, and the people involved in managing the chronic condition and the interaction between them. Prepared, informed, and motivated health care teams, patients and families, and community supporters interact in a productive and targeted manner in order to systematically cover important health care elements, such as managing medication and symptoms. The continuity and reliability of relationships and the taking into account of the patients' values and needs are particularly important components of productive interaction<sup>22</sup>.

In many settings, consequently, the perspective of care changed from a provider-focused to a patient-focused care paradigm. This perspective reinforces collaboration and mutual understanding, which seeks to integrate the patient's perspective when tailoring interventions for chronic illness management<sup>20,23,24</sup>. The chronic illness management approach has become a core element in providing supportive care to people living with HIV (PLWH), who, due to highly developed medical therapeutic possibilities, are rather living with a chronic condition than an acute illness.



As a consequence of this change, symptom management actions have changed from those focusing palliation and symptom alleviation to actions relating to living with a chronic condition. The principle of care-giving shifted from the health care provider to the patient<sup>25</sup>; correspondingly, the role of the health care providers changed from one who knows and directs to facilitator and skilled companion supporting a PLWH who lives independently, and health care providers may invent, adjust or negotiate symptom management strategies used by PLWH in order to improve quality of life and health outcomes<sup>26</sup>. Despite the potential to reduce mortality and morbidity and thus increase the quality of life, many patients receiving ART are challenged by symptoms due to medication side effects, comorbidities, and the illness itself, and the identification of symptoms that need management is an important topic in health care encounters. The first step towards providing tailored and patient-focused symptom management support, and not merely "applying" management strategies for a provider-defined symptom to the patient<sup>27</sup> is the identification of symptoms that potentially need management from the patient's perspective. The following paragraph highlights the living context of PLWH, and the approaches employed to integrate the patient's perspective to identify symptoms that need management.

### **Symptom self-management in HIV**

Symptom management is an individual and dynamic task, and due to the symptoms' influence on and interference with everyday routines, symptom management is often difficult for PLWHs, their families, and health care providers. Living with HIV demands the watchful observation of fairly unpredictable variables and the integration of changes into daily living in order to maintain physical and mental well-being<sup>28,29</sup>. Depending on the predictability and expression of symptoms due to medication side effects, the condition itself, and comorbidities<sup>9,30</sup>, maintaining quality of life or working capacity may require day-to-day decisions<sup>31</sup> in view of symptom management choices. Being confronted with managing their illness while continuing with their lives demands specific skills and tasks from PLWH and their families, enabling the skillful handling of every-day challenges in various domains<sup>32</sup>.

Self-management is widely understood as the day-to-day actions that patients living with a chronic condition must take in order to minimize the negative consequences of their condition. Self-management

actions generally aim at increasing overall well-being, maintaining a given level of health, or slowing down decline<sup>33,34</sup>. Corbin and Strauss<sup>35</sup> identified three basic areas of self-management, namely medical management, role management and emotional management, in which patients are challenged across a range of chronic conditions<sup>33</sup>. Emotional management, for instance, included coping with unpleasant emotions commonly associated with suffering from a chronic illness trajectory, such as fear, anger, or frustration. Medication and role management included, for example, adhering to a specifically defined diet or medication regimen, and adapting or altering old life roles and creating new ones according to the condition's requirements. Nicca, in her dissertation study<sup>32</sup> further refined and expanded these areas to eight areas specific for PLWH, who, due to the transmission pathway, treatment side effects and stigmatization of HIV, face the additional challenge of managing transmission, disclosure, substance abuse, lifestyle, and perhaps most importantly, medication<sup>32</sup>. From a medical perspective, medication and symptom control have first priority; for a patient, however, other self-management areas may temporarily be more important. Moreover, despite their distinct nature, areas of self-management are mutually influential. Management of a perceived symptom may thus be temporarily intertwined with disclosure or uncertainty in view of HIV and progression. Ideally, supporting patients in managing their own symptoms thus involves assessing all self-management areas.

Health care needs of PLWH are increasingly recognized as those of other populations with chronic conditions, and self-management dimensions seem to be similar across different chronic conditions. In a recent review, Swendeman, Ingram & Rotheram-Borus identified three broad categories for self-management that are common across chronic diseases, highlighting elements within these categories that are specific to living with HIV/AIDS<sup>36</sup>. Identified shared categories were physical health, psychological functioning, and social relationship, in accordance with the three management areas identified by Lorig & Holman (2003) mentioned above: namely, medical management (relating to physical health), emotional management (relating to psychological functioning), and role management (corresponding to social relationship). Categories of symptom management that are specific to living with HIV were, among others, maintaining and strengthening the immune system and focusing on activities that reduce stress. In the domain of psychological functioning, the authors emphasize what a challenge it is for the PLWH to build up self-efficacy and a sense of control regarding the uncertainty inherent to the HIV trajectory, which

seems to be an ongoing concern despite good medical control of the virus<sup>34,37</sup>. Managing transmission and disclosure represent further HIV-specific areas for self-management<sup>38,39</sup>.

Interventions targeting better symptom management in populations living with HIV have been investigated in relation to symptom control/alleviation, those investigating adherence, and those related to a life with symptoms and the illness. In studies targeting single symptoms, symptom management interventions were successfully employed to decrease symptoms of depression<sup>40</sup> or diarrhea<sup>41</sup>. The use of a symptom management manual including self-care strategies for 21 common symptoms, for instance, resulted in a successful reduction of symptom frequency and intensity in the intervention group as compared to the control group ( $t=2.36$ ,  $P=0.018$ )<sup>42</sup>. The use of a symptom management intervention program comprising group teaching followed by telephone counseling was related to increased adherence and improved quality of life<sup>43,44</sup>, as well as increased self-care abilities in view of managing symptoms. In a randomized clinical trial by Webel et al.<sup>45</sup>, although a peer-based self-care intervention using a HIV self-care manual was not successful in view of adherence or intensity of perceived symptoms, the intervention seemed to have a positive effect on "HIV Mastery" ( $\chi^2(2)=25.08$ ;  $p<0.005$ ) and "Disclosure Worries" ( $\chi^2(2)=24.67$ ;  $p<0.005$ ). In a pilot intervention promoting self-management skills targeting the transition to work and work-life balance<sup>46</sup>, participants' perceived ability to work and balance health, work and daily life increased immediately after the intervention; there was a sustained negative impact of perceived symptoms on work performance at follow-up, however. A population-specific and culturally sensitive intervention targeting emotional distress of African American mothers<sup>47</sup> was successfully tested and women in the intervention group reported feeling less stigmatized and improved physical function after six home visits by nurses. In addition to provider-offered strategies, it seems that to successfully master their life with symptoms, patients employ a variety of self-management strategies originating from diverse sources<sup>48</sup>. The use of conventional and complementary treatments, self-comforting, or spiritual care was common, and strategies were self-invented or learned from people in the social network. Self-management strategies used by patients are often symptom-specific<sup>49-51</sup>. For instance, for peripheral neuropathy, patients employed strategies involving their social network or used complementary medicine or consumed substances such as nicotine, alcohol, or street drugs. For depressive symptoms, which are frequently under-identified and under-treated, six self-care categories were discovered in a study of 1217

PLWH from Colombia (44%), Norway (66%), Puerto Rico (57%), Taiwan (35%), and the USA (56%): "complementary therapies, talking to others, distraction techniques, physical activity, medications, and denial/avoidant coping," where the most commonly employed strategies varied by country <sup>49</sup>. For another group of symptoms that seems to be under-recognized <sup>52</sup> and difficult to control conventionally, namely, cognitive symptoms, PLWH also employ unconventional strategies to keep symptoms tolerable. Patients frequently reported using methamphetamine and diverse substances <sup>53,54</sup> to alleviate depressive symptoms, fatigue and neuropathic symptoms, as well as using marijuana, illicit drugs, and/or heavy alcohol intake and smoking to control fatigue and/or confusion/distress <sup>55</sup>. These findings indicate the importance of increasing recognition of these symptoms in order to arrive at other solutions for self-management.

Recent publications add to the evidence that bring into play the patients' perception of symptoms as the basis for communication between health care providers and patients, which contributes to mutual understanding and productive interactions. Nader et al. <sup>56</sup> tested the use of a new decision support tool to improve the recognition of symptoms that need management and reduce the patients' burden in view of symptom assessment. Patients were asked to indicate the most bothersome symptoms within a list of 20 symptoms validated by PLWH and found that mutual understanding and satisfaction of providers and PLWH increased by using this tablet-PC based symptom list. In another publication, a questionnaire integrating aspects important for the management of HIV and related symptoms was administered, i.e., health-related quality of life, satisfaction, tolerability, and adherence were assessed and results show that such a tool may be a novel approach to therapeutic management of PLWH <sup>57</sup>.

As above findings suggest, assessments solely focusing symptom expression seem to miss the aspect of symptom self-management in daily life, especially of emotional symptoms and those difficult to control with medications. Employing, first, an idiom incorporating an individual's lived experience, and, second, a patient-defined list of symptoms would additionally integrate the individual perspective of the person concerned <sup>58,59</sup>.

In summary, symptom self-management enhancing programs for PLWH provide a fragmented view on the life with the illness and associated symptoms. Although there is increasing evidence that symptom self-management and interventions focusing self-management support can not only be seen as a summary

for strategies aiming at symptom alleviation or total symptom control, but rather as a broad view on symptoms encompassing the various aspects of the work required in view of living with a chronic condition, there is no concept capturing patients' perspective on how they self-manage symptoms and master their daily routine with symptoms.

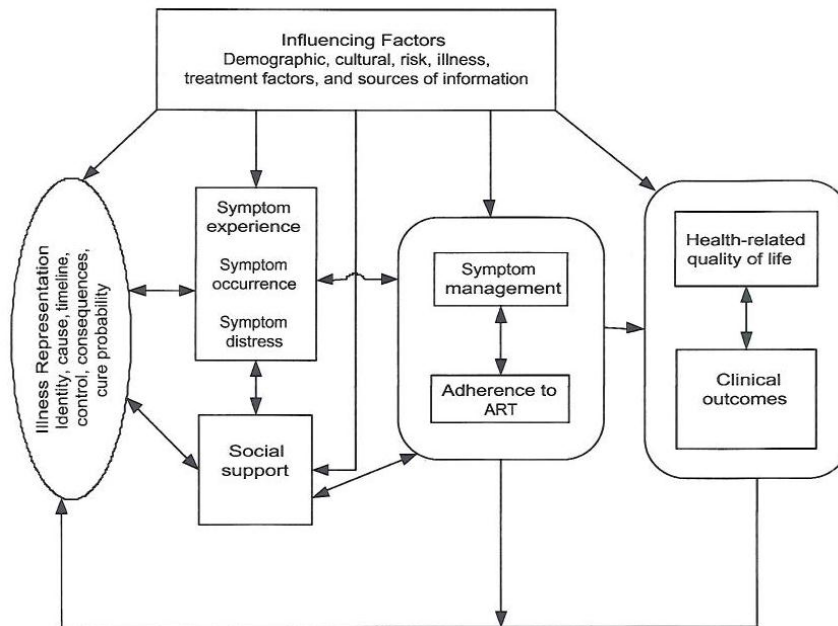
### **The Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV) <sup>13</sup>**

Subjective illness theories such as the Common sense Theory by Leventhal et al.<sup>60</sup> are useful frameworks for understanding the elements contributing to the patients' interpretation of symptoms and the importance of the individual perception in relation to subsequent behavior.

In an attempt to advance the conceptual foundation of care for people living with HIV, Spirig et al. applied in 2005 Leventhal et al.'s theory to symptom management in the context of HIV and developed on the basis of a critical literature review the Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV). This model links symptom experience, social support, adherence, and symptom management to clinical and individual outcomes, and, as such, accounts for the specific conditions of living with HIV <sup>61</sup>. In the above framework, symptoms are defined as the "patient's responses to the changes in their biopsychosocial functioning and cognition" (Spirig et al, p.337). In order to understand the individual reactions to symptoms and mechanisms for symptom management choices, diverse internal and external factors need to be considered (see model below). Above all, a symptom is always perceived and evaluated individually. Based on an individual's illness representation, the intrapersonal basis on which symptoms are perceived, an individual ascribes identity, cause, timeline, control, consequences and cure probability to a symptom. External factors, i.e., social support and the wholeness of a person's context, may also shape symptom perception. Once a symptom is noticed, symptom experience may be described as a function of symptom severity/intensity, symptom frequency, and associated distress. After having evaluated the symptom, strategies to face it are assessed. The term "symptom management" refers to how a patient makes decisions relating to symptom management actions, e.g., adherence decisions or seeking information. Outcomes may be measured as individually perceived quality of life, or assessed in terms of clinical indicators. Illness representation, influencing factors, social support, symptom experience, symptom management (representing the actual strategies used), and adherence are all contributing to outcomes. It is important to note that Sprig's model

is recursive and the elements mutually influential, which means that the linearity suggested in our above description is to be seen as an auxiliary construction to better understand the complexity of the entire symptom management task.

**Diagram 1. Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV) by Spirig et al. (2005); used with permission: Wolters Kluwer Health.**



In summary, in the symptom management model described above, a patient's symptom perception precedes symptom experience, which constitutes the foundation on which uptake and choice of symptom management strategies is based. A patient's individual symptom perception and interpretation, thus, determines the symptoms that need management; it also illustrates that symptom management activities taken up by a person are driven by the individual and context. The model also illustrates that symptom experience – defined as symptom severity, frequency, and associated distress – only represents one specific aspect contributing to symptom management in the daily life of PLWH.

## CONCEPTS EMPLOYED TO IDENTIFY SYMPTOMS THAT NEED MANAGEMENT

In order to identify symptoms that need management, a measure accounting for the change of HIV from an acute to a chronic illness is key. Such a measure should, ideally, not only assess symptom ex-

pression but also dimensions of daily living with symptoms from the patient's perspective. Traditionally, symptoms that need management are identified by asking patients about their symptom experience. Although a patient's symptom experience is an individually shaped concept and embraces cognitive and emotional dimensions, however, it does not account for the daily challenges encountered when living with HIV<sup>32</sup>. When confronted with a symptom, PLWH are concerned about controlling medical parameters and symptom expression, may experience symptom distress, *and at the same time*, are concerned about the impact on their everyday life, overall functioning or threats to their individual identity<sup>62</sup>. A concept used in times of the chronic illness care paradigm, therefore, not only needs to allow for symptoms important for immediate and long-term health maintenance but also must consider the patient's perspective by integrating symptoms and dimensions that are potentially relevant to PLWHs' individual quality of life and well-being.

## Symptom experience

*Symptom experience* is defined as the "subjective experience reflecting changes in the biopsychosocial functioning, sensations, or cognition of an individual" <sup>63</sup>. Traditionally measured dimensions of symptom experience, based on the Common Sense model by Leventhal et al. (1992), refer to symptom severity/intensity and symptom frequency as the cognitive elements, and symptom distress as the emotional component of symptom experience <sup>13,60</sup> and are explained in the next paragraph, followed by an exploration of instruments currently used to assess symptom experience and/or symptom distress.

*Symptom severity* denotes the perceived seriousness of a symptom. In the literature, intensity has been a term used synonymously with seriousness. There is some evidence suggesting that symptom severity/intensity inversely negatively correlates with quality of life dimensions <sup>64,65</sup> and adherence <sup>66,67</sup>.

*Symptom frequency* refers to how many times a specific symptom was experienced during a given time. From the literature on HIV, it appears to be the least studied dimension of symptom experience. Only one study was found reporting the relationship between symptom frequency and adherence. This study found that very frequently occurring symptoms was a barrier to adherence <sup>67</sup>. Frequency and intensity of HIV-related symptoms were found to be strongly positively correlated <sup>68</sup>.

### Instruments used to assess symptom experience

Instruments purporting to measure symptom experience often do not integrate the emotional component, and although individual symptom experience is widely acknowledged as the basis to identify symptoms that need management, there is a great diversity of tools used to assess PLWHs' symptom experience. These tools comprise diverse and varying amounts of symptoms, often compiled on the basis of symptoms prevalent before the wide distribution of ART. Most instruments lack adaptation to currently experienced symptoms based on a patient-reported symptom pool. Symptoms that need management from a patient's individual perspective might, thus, not be identified <sup>69,70</sup>. Moreover, instruments include varying symptom experience parameters in diverse combinations, i.e., symptom severity/intensity, and/or frequency, and/or distress/bother, however, these typically employed measures to query PLWH about their symptom experience are reductions of the concept of symptom management <sup>71</sup> and disregard other elements important to



lead a normal life with a chronic illness. This deficiency is passed on into clinical practice, and might be one reason why PLWHs' symptom experience does often not concur with the health care provider's assessment of the situation <sup>52,72,73</sup>.

Most often and internationally used instruments are the Memorial Symptom Assessment Scale in its full length and as short form (MSAS/MSAS-SF <sup>74,75</sup> and the Sign and Symptom Checklist for HIV patients, revised (SSC-HIVrev <sup>76</sup>). The SSC-HIVrev is a comprehensive list of 72 signs and symptoms that could be experienced by PLWH complemented by a Likert-type scale asking about perceived symptom intensity. The authors differentiate between signs, which describe individually perceived changes in functioning, and symptoms, under which all changes perceptible by others are subsumed. Signs are not necessarily perceptible by others, whereas symptoms are. The SSC-HIVrev is often complemented by a question relating to overall symptom distress as perceived by the patient. The MSAS (36 symptoms, frequency, severity, distress), and its short form, the MSAS-SF (36 symptoms, only frequency and distress of symptoms), was originally designed for patients with cancer. The MSAS-SF has first been used and validated in a HIV-positive sample in 1999<sup>77</sup> and has been used to assess HIV-related symptoms since. In addition to the symptoms, this instrument encompasses the differentiated assessment of severity, frequency, and associated distress of each of the symptoms. No differentiation is made between signs and symptoms. Other symptom lists include symptoms as condensed from printed evidence <sup>78</sup>, or physical assessment by a physician <sup>79</sup>. Some symptom lists used before cART, e.g., the 14-item scale of signs and symptoms commonly associated with HIV illness <sup>80</sup>, or the symptom inventory by Cleary et al (1993) <sup>81</sup>, were also used after the life-saving changes in medical treatment <sup>64,82</sup>. Justice et al. <sup>83</sup> developed a 20-item symptom index from existing knowledge on symptom frequency and bothersomeness.

### **Evidence: symptom experience**

Symptom experience was mainly reported in relation to different domains of quality of life and adherence to medical treatment. Both outcomes, quality of life in its diverse dimensions and adherence to medical treatment, were better with less <sup>9,77,79,84-96</sup>, less severe <sup>65-67,90,97</sup>, and less distressing or bothersome <sup>77,90,93,94,98-100</sup> symptoms as perceived by the patients. Evans et al (1998) found a negative correlation of symptom experience and life satisfaction <sup>101</sup>. The experience of more <sup>102</sup> and more severe <sup>103</sup> symptoms, or

body image changes due to lipodystrophy was related to increased emotional distress and bother<sup>104</sup>. Women and IV substance users seemed to report more and more severe symptoms than men or non-users<sup>105,106</sup>. A further area of interest relating to symptom experience is the interplay between patients and providers relating to perceived symptoms: providers and patients seem to focus on different symptoms<sup>73,107</sup>. The positive effect of patient-provider concordance in view of symptoms on adherence and overall functioning was reported recently<sup>108</sup>. Collaboratively reaching clarity on symptom definition and symptom weight<sup>109</sup> in addition to laboratory parameters<sup>70,82</sup> seems a promising way to improve concordance and achieve satisfactory patient-provider encounters. Moreover, considering the (sometimes diffuse) impact of living with HIV and symptoms on daily routine or social interactions<sup>81,110,111</sup> was recommended in order to properly assist PLWH.

While, for instance, some symptoms and symptom parameters that are important for health care providers may have a limited immediate impact on patients' daily lives<sup>112</sup>, others, such as appearance-related symptoms<sup>113</sup>, fatigue and sleep disorders<sup>114</sup>, can severely interfere with the patient's every-day functioning and overall quality of life<sup>115</sup>. Finding a common basis on which symptoms that need management are identified, i.e., what constitutes symptom experience, could have an impact on diverse outcomes, as symptom experience has been linked to adherence<sup>89</sup>, quality of life<sup>111</sup>, and disease progression<sup>116,117</sup> in PLWH.

### **Symptom distress**

*Symptom distress* is defined as the lived experience associated with mental and social suffering as a result of symptoms and refers to the emotional aspect of symptom experience. As conceptualized by Ridner<sup>118</sup>, symptom distress delineates the unique discomfort or emotional state experienced by an individual in response to symptom occurrence or symptom management which results in harm to the person, either temporary or permanent. Due to the diversity of concept uses, the authors suggested to use "psychological distress" instead of distress only, describing "patient discomfort related to symptoms"<sup>118</sup>. Distress seems to be used by nurses rather in the sense of bothersomeness, as is described in her conceptualization article. Some authors explicitly use bothersomeness associated with symptoms<sup>83,90,106</sup>.

### **Instruments used to assess symptom distress**

In the scientific literature referring to symptom distress, the concept is operationalized in various ways and its use is manifold. Two main sets of used measurement tools can be roughly distinguished:

- Distress is assessed as one dimension of symptom experience, as, e.g., in the MSAS / MSAS-SF <sup>75</sup>. Each of perceived symptoms is assessed in view of its severity/frequency/associated distress. Distress is not further operationalized.
- Distress is used as a correlate of symptom experience, and differentiated by assessing symptoms of depression, anxiety, or psychopathology representing distress (e.g., <sup>119-121</sup>. For instance, the Symptom Check List SCL90-R <sup>122</sup>, and its short form, the Brief symptom inventory (BSI) <sup>119</sup> are often employed in symptom distress research, either to assess symptoms of distress in their own right or for correlations with, e.g., total number of symptoms. Both are tools to assess psychological distress by self-report and build upon 53 questions physical and psychological symptoms grouped in 9 primary symptom dimensions as sources of psychological distress: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. In addition, both, the SCL90-R and the BSI provide three summary scores for distress ("global indices"), namely the General Severity Index (GSI), the Positive Symptom Distress Index (PSDI), and the Positive Symptom Total (PST). The global indices are frequently used as representation of the subjectively perceived burden by (physical and psychological) symptoms of distress.

As symptom manageability refers to the individually perceived symptom, it rather depicts symptom-associated bother than psychopathology. We, therefore, focus on the first set of symptom distress measures. Although symptom distress is often used in direct relation to symptoms, its operationalization remains a challenge; and many authors do not provide a semantic definition of "symptom distress."

In the used tools to assess distress due to symptoms, "symptom distress" is either incorporated as one of several dimensions representing symptom experience, or specifically assessed by employing a list of varying symptoms. Each of perceived symptoms is rated in terms of symptom experience dimensions, or

distress only. For instance, in the MSAS, to each symptom denoted as present during the prior week patients are asked to specify distress in addition to symptom severity and/or frequency. Most tools allow a distress summary score.

Some questionnaires use a slightly different wording by assessing "bother" or "bothersomeness" (see the table "Instruments used to measure symptom experience"), thus focusing the PLWH's unique experience in terms of emotional burden due to symptoms. Mathews et al. (2000) and Crystal et al. (2000), for instance, both assess the bothersomeness of 14 HIV-related symptoms<sup>90,106,107</sup>; Justice (1999) and Justice & Holmes (2001)<sup>83,107</sup> employ a list of 20 symptoms and includes 'bother' in addition to frequency of symptoms. Duran et al. (2001) and Carrieri et al (2003) use a tool that assesses the presence and distress of symptoms compiled on the basis of the various short-term side effects described in the literature<sup>78,88</sup>.

### **Evidence: symptom distress**

Symptom distress was found to be related to diverse outcomes, such as lower quality of life<sup>98,123-129</sup>, adherence<sup>108,130-133</sup> or daily variations in mood<sup>134</sup>.

Self-management strategies to alleviate perceived symptoms include, for example, spiritual activity<sup>135</sup> distraction, or acupuncture<sup>136</sup>. As spiritual activities increased, quality of life increased, distress of HIV-related stressors (functional impairment, work impairment, HIV-related symptoms) decreased.

Distress or bother due to symptoms seems to be specific to population and illness. Symptom distress scales were invented for specific populations in specific situations, for example, the distress scale for cancer patients<sup>137,138</sup> or the physical symptom distress scale by Chiou (1998)<sup>139</sup>, designed for patients with end-stage renal disease. Symptom bother, however, only in parts seems to be relating to ethnicity: in a recent publication, Regnault et al. provided evidence for the cross-cultural validity of the ACTG symptom distress module, a list of 20 symptoms including a measure for symptom-associated bothersomeness of each perceived symptom<sup>83,140</sup>. Differential item functioning (DIF) was analyzed using logistic regression analysis and revealed statistically significant differences (0.001 threshold) between ethnic groups for only four symptoms, namely fatigue, headaches, fever, and anxiety. Bother due to headaches, for instance, was significantly higher for Bantu patients than it was for the other ethnic groups, and fatigue

seemed to be more bothersome for English – speaking patients using the occidental-English version of the questionnaire than it was for patients responding to the Bantu, American Spanish and African Indo-European versions of the questionnaire.

*Bothersomeness* of symptoms refers to the worry, disturbance, or trouble related to a symptom as expressed by those concerned. Bothersome symptoms were found to relate to quality of life<sup>90,93,94,98</sup> and adherence<sup>100</sup>. *Bothersomeness* integrates the patients' individual perspective and denotes an emotion due to symptoms. Although a useful concept, is not systematically employed to identify symptoms that need management.

## SUMMARY

In sum, symptom management issues are regularly discussed in medical follow-up appointments, however, despite the integration of patients' perspectives in symptom management negotiations, traditionally used measures (i.e., symptom severity and frequency) to identify symptoms that need management do not seem to capture the patient's needs and, consequently, patients' expectations are frequently unmet<sup>141</sup>. Although symptom frequency, symptom severity, and associated distress or bother are considered core indicators of the patient's individual experience of perceived symptoms<sup>13,60,75,142,143</sup>, they do not truly capture the wholeness of PLWHs' lived experience associated with symptoms in the chronic phase of the HIV trajectory. Therefore, they only allow the identification of a limited number of symptoms that need management due to symptom expression and associated distress. Moreover, symptom lists that were invented before cART was widely available may not have been adapted to new symptom profiles, and are of limited value to capture symptoms of concern to patients in a chronic phase. Subjective illness theories, such as the Common sense Theory by Leventhal et al. (1992) support the assumption that objective measures may be of limited importance to patients, as illness perception is greatly determined by individual concepts and interpretations. Patients, according to this model, base the assessment of symptoms that need management not only on symptom expression, but rather on a combination of their own interpretation of perceived symptoms, illness representation (e.g., cause, time-line, control), personal (such as demographic and cultural) factors, and social support. Moreover, these factors are mutually influential and individually

weighted. Symptom severity or frequency, thus, may or may not be the most important aspects when patients express concern about a symptom. Moreover, to our knowledge, there is no instrument or concept currently used which integrates dimensions of daily living with HIV to identify symptoms that need management in the chronic phase of HIV. The most promising approach to caring for patients with chronic diseases is to approach the illness as a collaborative endeavor, acknowledging the patient as an expert of his condition, living context, and emotional situation. Health care providers and patients not only exchange information but also are partners for negotiating approaches to symptom self-management in every-day life. Comparing the parameters used to identify symptoms that need management and those important for patient self-management in daily life, it becomes clear that the patient perspective on consequences of a symptom for daily life are often neglected.

In order to assess a patient's unique and individual perception of symptoms that need management, and in the future, the success of symptom management interventions, we therefore propose to use a measure representing this individuality and uniqueness. As in clinical encounters, patients often describe their life with symptoms using sentences like "I can't manage symptom x or y anymore", or "well, yes, symptoms are well manageable," thus directly referring to their ability to influence the impact of the symptoms on their life, we suggest "perceived symptom manageability" to meet this condition: the patient is the only person who is able to assess the perceived manageability of a symptom in the context of his or her lived experience.

## **CHAPTER 2**

# **AIMS AND METHODS OF THE RESEARCH PROGRAM**

## AIMS OF THE PROJECT

The changes asked from the health care system to care for a growing number of people with chronic illnesses, among which are PLWH, also call for a new interpretation of symptoms that need management and might warrant the adaption of instruments to the new paradigm. We propose "perceived symptom manageability" as a concept holding promise to provide common ground for identifying and negotiating symptoms that need management by its broad perspective on a life with symptoms. Before it can be presented to clinical practice and research as a useful concept, however, its in-depth exploration is warranted. Therefore, the aims of this dissertation study were to develop a theoretical definition of the concept, and explore its constituents. Moreover, the association with symptom experience parameters commonly used to identify symptoms that need management and the relation of relating concepts as depicted in a theoretical framework is explored.

## DETAILED RESEARCH QUESTIONS

In order to achieve these aims, we followed the procedural steps of concept synthesis <sup>144</sup> using a mixed method approach to answer the following research questions:

- How can "perceived symptom manageability" be preliminarily defined and
- What elements are important for PLWH regarding perceived symptom manageability?
- What are the most/least manageable symptoms in the sample and how does "manageability" relate to known symptom experience parameters and influencing factors proposed in the model presented by Spirig et al. (2005)?

## METHODS OF THE PROJECT

*Design.* The research project presented in this thesis was designed and proposed as a descriptive exploratory cross-sectional investigation, using existing data of a larger, multi-center project exploring symptom experience of PLWH. Our study team conducted the **Symptoms and other Life Experiences and Adherence (SOLEXA)** from 2003 to 2006 <sup>145</sup>. The SOLEXA study integrates relationships between symptom experience, symptom manageability, adherence, health-related quality of life, and disease pro-



gression from the patients and their close support persons' perspective. The SOLEXA study was established in close collaboration with four of the seven centers enrolled in the Swiss HIV Cohort Study (SHCS), an ongoing multi-center cohort study project established in 1988 and focusing on patient oriented HIV research. In order to allocate resources in a focused manner, questionnaires were solely translated into German, with the consequence, that the investigation only was possible in centers where the prevailing language was German, i.e., Zürich, Basel, Berne, and St. Gallen.

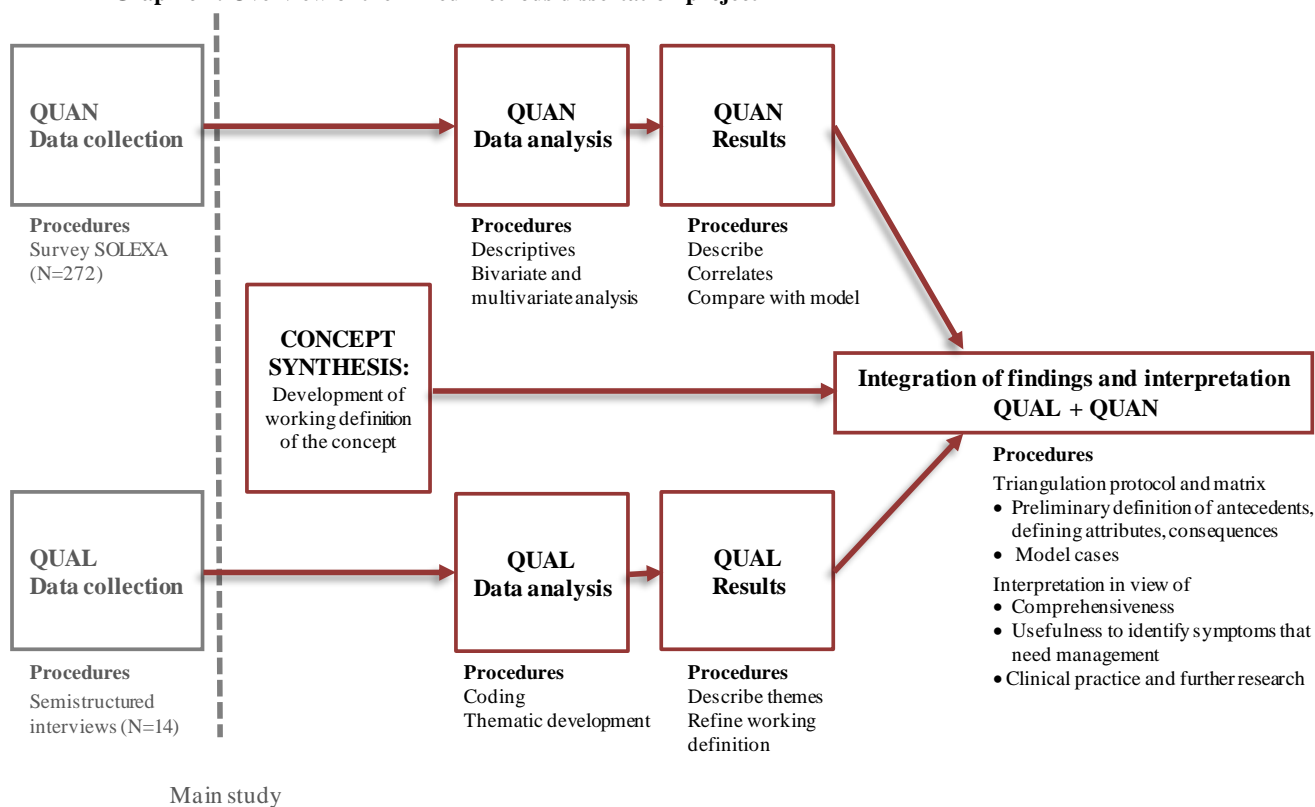
**Methodology and procedure.** For the PhD project, as for the main study, a mixed methods triangulation design <sup>146</sup> (see figure below) was used to follow the procedural steps of concept synthesis <sup>144</sup>. More specifically, based on a wide variety of uses of the concept, a working definition was elaborated. To verify and modify the definition and to further elaborate the concept's constituents, qualitative, and quantitative methods were used. All steps were taken purposefully to develop the concept's constituents and definition. Philosophically, thus, our guiding worldview was pragmatism: qualitative and quantitative approaches were used with the focus on our overall aim, rather than on the methods <sup>147</sup>. Using qualitative as well as quantitative techniques to collect and analyze data, the often limited view of a single approach was diminished by facilitating a more comprehensive view and increasing understanding the “perceived symptom manageability” concept from different, yet complementary perspectives. Using a triangulation design, which requires convergence of qualitative and quantitative results, allowed us to bring together the strengths of both methods <sup>148</sup>, that is, large sample size, generalization (“outside view”), detailed description, and in depth exploration (“inside view”), taking advantage of the complementarity of the qualitative and the quantitative perspective <sup>149</sup>. To allow transparency in view of the processes used to combine findings from the different analyses and methods (integration), we developed triangulation protocols depicting the steps taken <sup>150</sup>. A first protocol sheds light on the integration process in view of modifying and verifying the definition of the concept; a second protocol was elaborated to compare and contrast symptoms mentioned in qualitative interviews and manageability of these symptoms as explored in the quantitative analysis. Using multiple methods helped to achieve a valid, although preliminary, conceptual definition of perceived symptom manageability, because it allowed us to complement quantitative findings with meaning and, thus, enhance the interpretability of quantitative study results by allowing insight into a

patient's qualitative perception of symptom manageability. Moreover, it assisted the recognition of main findings discussed in [Chapter 7](#).

The research project was conducted in four phases, the first and third of which comprised separate, independent analyses. More specifically, in phase 1, a new use of the known concept “manageability” was defined and a working definition of “perceived symptom manageability” was suggested. Analysis 1 synthesizes the broad range of uses of manageability” and interprets the concept in view of symptoms. Based on a broad literature search, a concept synthesis was conducted and a working definition of the specific use “perceived symptom manageability” was developed, following the first procedural steps of a concept synthesis according to Walker and Avant <sup>144</sup> (analysis 1, concept synthesis).

In a second phase, the qualitative analysis of narrative interview data allowed insight into elements of “perceived symptom manageability” from the patients' perspective. Dimensions rendering a symptom more or less manageable were identified. Analysis 2 addresses the issue of perceived manageability dimensions as used by patients: By listening to patients, the concept “perceived manageability” was identified as potentially promising to identify symptoms that need management from the patients' perspective, and from narrative interviews, elements contributing to symptom manageability were inductively explored <sup>151</sup>. Furthermore, the preliminary working definition from analysis 1 was refined.

In a third phase, the concept was explored in relation to a theoretical model of symptom management in persons living with HIV<sup>13</sup>; and analysis 3 addresses this relation by employing bivariate and multivariate analysis. The integration of findings, the fourth phase, is described in [Chapter 6](#).

**Graphic 1: Overview of the mixed methods dissertation project**

Legend: QUAN = quantitative part of the study    QUAL = qualitative part of the study

This thesis is divided into seven chapters. Chapter 1 provides a literature-based rationale for the introduction of an integrative measure to identify symptoms that need management based on PLWHs' living context and health care premises. Chapter 2 describes the aims of the research program. The next three chapters incorporate the publications. Chapter 3 presents the synthesis of “perceived symptom manageability,” the description of a new use of the well-known “manageability” concept, titled “I can't manage symptoms anymore” - Perceived symptom manageability, the synthesis of a new use of a known concept. This article appeared in the *Journal of Advanced Nursing*. Chapter 4 features ““You need to manage, you know:” Long-term HIV survivors' perception of symptom manageability: The integration of lived experience into a theoretically developed concept.” This article summarizes the results of the qualitative exploration of 13 qualitative interviews and has been submitted to *The Scandinavian Journal of Caring Sciences*. Chapter 5 presents the publication “Symptom manageability in Swiss HIV-infected Patients.” This article focuses on the quantitative exploration of “perceived symptom manageability” in relation to parameters suggested by Spirig et al. (2005) in their theoretical model of symptom management in people living with HIV. In Chapter 6, findings of the three analyses are discussed as one entity, and Chapter 7 contains the discussion of key findings. Finally, suggestions for further research and clinical implementations are provided.

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## CHAPTER 3

### **PERCEIVED HIV SYMPTOM MANAGEABILITY: SYNTHESIS OF A NEW USE FOR A KNOWN CONCEPT**

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## ABSTRACT

**Aim:** This paper is a report of 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.

**Review methods:** We followed the steps delineated by Walker and Avant for concept synthesis. Uses of the concept ‘manageability’ were identified, 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 not only identify symptoms but also areas of intervention that are of most concern to individual patients.



## SUMMARY STATEMENT

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.

## INTRODUCTION

In countries where antiretroviral therapy is available and affordable, human immunodeficiency virus (HIV) is acknowledged as a chronic 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<sup>1</sup>, we realised 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 realised 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<sup>2,3</sup>. Disagreement on symptoms needing management may occur<sup>4,5</sup>. 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

Since the collaboration between PLWH and healthcare providers has become a core issue in health care encounters and is particularly important in the field of HIV care<sup>6</sup>, we conducted a mixed methods research project<sup>1</sup> 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.*<sup>7</sup> and specifically on its adaptation for PLWH suggested by Spirig *et al.*<sup>8</sup>, 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<sup>4,5</sup>. This divergence may impede effective illness management and diminish the quality of the health care encounter<sup>9</sup>.

To understand potential sources of disagreement in view of the symptoms needing management, subjective illness theories such as the CSM<sup>10,11</sup> and specifically its adaptation by Spirig *et al.*<sup>8</sup>, are useful frameworks. These theories underscore the individuality inherent in the interpretation of an illness and its symptoms. In the CSM, Leventhal *et al.*<sup>10,11</sup> 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 health care 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<sup>7</sup>. 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<sup>8</sup> 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, impact 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 of 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<sup>2</sup>, 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 *et al.*<sup>12</sup> 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<sup>13</sup> and adherence to medication<sup>14</sup>. 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<sup>9</sup>. 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.*<sup>8</sup>.

## DATA SOURCES

If a concept is already used, but not described in a specific area or context, concept synthesis is deemed especially useful<sup>15</sup>. By exploring broadly as many current uses of a concept as possible, summarising 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 <sup>15</sup>.

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 summarised in Table 1.

As a first step in concept synthesis and to achieve familiarity with the topic, Walker and Avant <sup>15</sup> 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.

**Table 1. Steps of the Concept Synthesis**

Steps described by Walker and Avant <sup>15</sup>	Data source	Action	Process
<b>Step 1:</b> achieve familiarity with the topic; identify current uses of the concept	Online versions of thesauri and dictionaries	Search term: ‘to manage’, ‘manageability’, ‘ability’ and ‘manageable’	
	PubMed, Cinahl and PsycINFO	Search term: ‘manageability [Title and Abstract]’	
	Google search engine	Search term: ‘manageability’	Results of step 1 inform step 2
<b>Step 2:</b> 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
<b>Steps 3a and 3b:</b> definition of the new use	Reduced uses (results from step 2)	Summarising meaning of manageability within semantic clusters; transfer of uses to symptoms and creation of the preliminary working definition	

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 ‘managea-

bility' 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 summarised 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 summarised evidence and a working definition of the use of the concept with symptoms was created.

## 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 4 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 summarised into 4 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 health

care 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 334 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.

### **Step 3a: Review and summarise 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 health care 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<sup>16,17</sup>. The following paragraphs provide a summary of concept uses in semantic clusters.

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

Transitive uses	Categories of 'manageability' use listed in dictionaries	Search results: clustered abstracts (number of abstracts)	Articles integrated in the working definition, reporting perceived manageability
<p>To direct affairs or interests, be in charge of (manage a company)<sup>1,2</sup></p> <p>To look after and make decisions about<sup>3</sup>. Also: to handle or direct with a degree of skill<sup>4</sup></p> <p>To conduct, carry on, supervise, control<sup>3,6</sup></p>	<p>'Act as manager'</p>	<p>IT and e-learning (9)    Services (11)</p> <p>Project (5)                Hair (8)</p> <p>Processes, non-medical (5)</p>	-
		Risk (12)	Eklof 2002, Peters-Guarin et al. 2012, Sanne 2008, Stave et al. 2006
		Medical processes (24)	Arapakis et al. 2005, Bergk et al. 2004, Perioli et al. 2009
		Occupational demands (8)	-
<p>To handle, wield (a tool, weapon)<sup>1</sup></p> <p>To direct or control the use of, handle (a machine tool)<sup>2</sup></p> <p>To control the movements or actions of (something) (= control)<sup>5</sup></p> <p>To handle, wield, or make use of<sup>6</sup></p>	<p>To control the movements or actions of something (tool);</p>	<p>Material for clinical use (10)</p> <p>Medical device (7)</p>	- -
<p>To make submissive to one's authority, discipline, or persuasion<sup>2</sup></p> <p>To control the behaviour of (a child or animal)<sup>2,6</sup></p> <p>To train or direct<sup>6</sup></p>	<p>To exert one's authority: control someone (animal or human)</p>	<p>Trait in children (9)    Disabled persons (1)</p> <p>Prisoners (3)            Horses (5)</p> <p>Workers (1)             Other (2)</p>	-
<p>To handle or control (a situation or job)<sup>1</sup></p> <p>To succeed in doing, accomplishing, or achieving something, especially with difficulty; contrive or arrange<sup>2,5</sup></p> <p>To deal or cope with (something) usually skilfully or efficiently (managed the crisis)<sup>3,6</sup></p> <p>With infinitive: to be successful or skilful enough to do something, usually with difficulty or in the face of adversity<sup>6</sup></p>	<p>To succeed in accomplishing or achieving, especially with difficulty</p>	<p>Condition, situation, illness (29)</p>	Johansson et al. 2007, Karolich & Ford 2010, Olsson Ozanne et al. 2011, Power et al. 2010, Sunvisson & Ekman 2001, Wiklund 2008
		SOC (75)	Structure: Bernabe et al. 2009, Bengtsson-Tops et al. 2005, Zimprich et al. 2006, Flensburg-Madsen et al. 2005, 2006 Patients with specific conditions: Jensen 2001, Malterud & Hollnagel 2004, Nyman et al. 2011, Strang & Strang 2001
		Use in scale (4)	Antonovsky 1987; Kennedy et al. 2009; Vinenzi et al. 2009; Reece et al. 2010, Hollub et al. 2011.
	<b>Total</b>	<b>228</b>	
<b>Intransitive uses</b>			
<p>To meet one's day-to-day needs<sup>3</sup></p> <p>To be able to live or to do what is needed by using what you have even though you do not have much<sup>5</sup></p> <p>To cope or get by; to contrive to get on with something which is barely adequate<sup>6</sup></p> <p>To succeed (despite difficulties) in accomplishing a task<sup>6</sup></p>	<p>Intransitive use</p> <p>To continue to <i>get along</i>; carry on</p>	<p>There were no intransitive uses in the cited abstracts</p>	

<sup>1</sup>Wiktionary; <sup>2</sup>Houghton-Mifflin Online Dictionary; <sup>3</sup>Merriam-Webster Online Thesaurus; <sup>4</sup>Merriam-Webster's Learner's Dictionary; <sup>5</sup>Merriam-Webster Online Dictionary; <sup>6</sup>Oxford English Dictionary



### **‘To act as a manager’**

From 2 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<sup>18</sup> and farmers<sup>19</sup> and 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<sup>20</sup>. In a study on the risk-taking behaviour of railway workers, Sanne *et al.*<sup>21</sup> 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<sup>22</sup>. Bergk *et al.*<sup>23</sup> 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 <sup>24</sup>. 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, as well as gaining a sense of community and attachment <sup>25</sup>. Connectedness and interactions with a social network were also fundamental for patients with myocardial infarction to manage their situation <sup>26</sup>. 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 <sup>27</sup>.

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 chronic illness emphasised 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 <sup>28</sup>, The Perceived Manageability Scale (PMnac) <sup>29</sup>, the Multi-factor Attitude Towards Condoms Scale (MFACS) <sup>16,17</sup> and the HIV-Symptom Manageability Scale (HIV-SMS) <sup>30</sup>.

*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 3 explanatory concepts: making sense of what is going on (meaningfulness), understanding (comprehensibility) and manageability, which is defined as ‘the ex-

tent 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 operationalised 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<sup>31-33</sup>. 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<sup>34</sup>; while in patients with schizophrenia, a 4-factor solution emerged<sup>35</sup>. Zimprich *et al.*<sup>36</sup> explored 1107 Swiss students, for which a 2-factor solution was found, combining 'manageability' and 'comprehensibility'. While the construct 'sense of coherence' and the 3 components of comprehensibility, manageability and meaningfulness are well accepted, the operationalisation of the construct has been criticised and an adaptation of scale items was suggested<sup>37,38</sup>.

*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 chronic illnesses<sup>39</sup>. 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<sup>40</sup>. 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<sup>41,42</sup>. 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.*<sup>29</sup> and based on Antonovsky's concept to assess the manageability of spinal cord injury, emphasising (successful) control as the core dimension of manageability.

*The HIV-SMS*<sup>30</sup> 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, to 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, the generation of further validity evidence is underway.

The MFACS<sup>16,17</sup> 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 summarised 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 emphasised 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 reference 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<sup>29</sup> and the importance of emotions and cognition<sup>16,17</sup>. The generic and abstract formulation of Antonovsky's<sup>28</sup> definition of manageability presented above allows the concept to be concretised 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 conceptualised by Spirig *et al.*<sup>8</sup>.

We undertook this concept synthesis because we realised 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 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<sup>43</sup>, 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<sup>44</sup>. 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<sup>45,46</sup> 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, 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<sup>47,48</sup>. 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.*<sup>8</sup> and Leventhal *et al.*<sup>7</sup> 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<sup>47,48</sup> or as difficult to deal with<sup>45,46</sup>, 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<sup>25-27</sup> and thus verifies the framework suggested by Spirig *et al.*<sup>8</sup>. Healthcare providers, among others, represent an important source of information and support for PLWH<sup>49</sup>. 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 health care 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<sup>48,50</sup>. Moreover, studies in HIV populations have shown that a positive appraisal of illness-related phenomena supports living successfully with this chronic condition<sup>51,52</sup>. 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<sup>22,53</sup> 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 chronic illness management, perceived control moderated the improvement of self-efficacy<sup>54</sup>, whereas a perceived lack of control was associated with decreased quality of life<sup>55</sup>, self-care behaviour<sup>56</sup>, medication adherence<sup>57</sup> and increased distress<sup>58</sup>.

## 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 2 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.

*Acknowledgements to Mary Beth Happ, PhD, RN, FAAN, for ongoing consultation and editorial assistance; Manuel Battegay, MD, and Jacqueline Martin, MNS, for thoughtful reviews and valuable input; Professors Kimberly Moody, PhD, RN, and Sandra Engberg, PhD, RN, FAAN, for process supervision and continuing feedback.*

*No conflict of interest has been declared by the authors.*

*This work was supported by unrestricted educational grants from Nora van Meeuwen - Haefliger Stiftung, Glaxo-SmithKline AG, Merck Sharp & Dohme-Chibret, Roche Pharma AG, Bristol-Myers Squibb GmbH, Boehringer Ingelheim, the Swiss National Science Foundation Grant Nr 3346-100884, and Swiss National Science Foundation Grant Nr 33CSCO-108787, which supported the Swiss HIV Cohort Study.*



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## CHAPTER 4

# **“YOU NEED TO MANAGE, YOU KNOW”: LONG-TERM HIV SURVIVORS' PERCEPTION OF SYMPTOM MANAGEABILITY: THE INTEGRATION OF LIVED EXPERIENCE INTO A THEORETICALLY DEVELOPED CONCEPT**

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## ABSTRACT

**Rationale:** For people living with HIV, commonly used parameters for identifying symptoms needing attention cover symptom severity, frequency, and distress. These parameters, however, do not integrate the challenges of symptom management in daily living. This study posited that a broader perspective is needed to identify symptoms needing management. Therefore, we introduced the concept ‘perceived symptom manageability’ and developed a working definition of this concept.

**Aims and objectives:** The aim of the study was to verify the working definition and identify the components of the aforementioned concept as expressed by patients.

**Design and justification:** A secondary analysis of interviews with 13 HIV long-term survivors using conventional content analysis was conducted. Employing a qualitative approach, we captured the lived experience of people with HIV by incorporating individual and dynamic facets of that experience.

**Ethical issues and approval:** All participants provided written informed consent to primary and secondary uses of narratives and ethical committees approved the study from which data were taken. Confidentiality was guaranteed.

**Results:** A symptom was perceived as manageable if it was reconcilable with professional, social, and personal activities. Contributory factors were keeping interference endurable, being embedded in an accessible supportive network of professionals and laypersons, and being placid in the view of HIV.

**Study limitations:** The limitation was that our analysis was based on an already existing pool of interviews, which could not be expanded.

**Conclusions:** With ‘perceived symptom manageability’, we present a novel approach for clinicians to identify symptoms needing awareness. Using an inductive approach, we gained detailed and specific information on patients’ lived experience, enabling patient-centred and individualized care. Asking patients about symptom manageability expands the currently employed parameters used to identify symptoms needing management and acknowledges the challenges of living with this chronic illness, notwithstanding good medical treatment.

## INTRODUCTION

Despite tremendous advances in medication therapy, people living with human immunodeficiency virus (PLWH; HIV) can be confronted with numerous symptoms, from comorbidities, the illness itself, and treatment side effects<sup>1</sup>. For PLWH, symptom management is a daily task, and the identification of symptoms needing management is an important issue in patient/provider encounters. However, parameters commonly used to identify symptoms needing attention, that is, symptom severity/ intensity, frequency, and distress, provide a limited perspective on the daily challenges posed by symptoms. We presumed that to fully understand and identify the symptoms needing attention from the patients' perspective, a more comprehensive approach is needed. Thus, we suggested the concept of 'perceived symptom manageability'.

'Perceived symptom manageability' represents patients' view on symptom management. To grasp patients' perception of illness, a subjective illness theory such as the Common Sense Model (CSM) by Leventhal et al.<sup>2,3</sup> is a useful framework. The model's adaptation for PLWH by Spirig et al., the Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV)<sup>4</sup>, is especially helpful.

The SSMM-HIV, like the CSM, is a recursive model, meaning that the patient's evaluation of the intervention outcome feeds back onto their interpretation of the targeted symptom. The model consists of various elements, namely illness representation (referring to identity, cause, timeline, control, consequences, and cure probability of an illness), symptom experience (comprising symptom severity, frequency, and distress), social support, symptom management activities, adherence, and influencing factors such as demographic and cultural influences, or sources of information. Successful symptom management might increase quality of life and influence clinical outcomes favourably. The CSM and the SSMM-HIV underscore the intrinsically individual interpretation of an illness and its symptoms and the recursive nature of the management process. As with the CSM, the SSMM-HIV is coherent within itself and consistent for individual patients<sup>4,5</sup>. The ongoing and challenging work involved in integrating the known and new symptoms of a chronic illness into daily routine<sup>6</sup>, coping with the dynamic nature of some symptoms<sup>7</sup>, and the evaluation of successful symptom management is thus subject to individual interpretation and the interplay between the elements identified in the SSMM-HIV. Therefore, identifying



symptoms needing management requires a wider perspective than that of the parameters commonly used to identify symptoms needing attention, that is, symptom severity/ intensity, frequency, and distress.

In an endeavour to establish ‘perceived symptom manageability’, our research team recently conducted a literary-based synthesis of the concept <sup>8</sup> and presented the following working definition: “The extent of the perceived ability to bring social and personal resources into play to successfully deal with/control symptoms despite difficulties.” (authors, available online). In the current study, we sought to verify and further develop this working definition by inductively exploring components of the concept as identified by PLWH. We deemed the inductive approach as fitting our intention, because (a) we could only assume what might be important for PLWH and (b) existing evidence did not provide sufficient support for interpretation of the concept in its new area of use. We therefore analysed existing narrative interviews with the goal of describing PLWH’s perception of living and dealing with their symptoms.

## METHODS

**Design.** We based this exploratory, descriptive, and qualitative study on 13 existing open-ended interviews that had been conducted in a study on medication and symptom management (authors, in press). To conduct this secondary analysis, we used a conventional content analysis approach <sup>9</sup>. We deemed that the nature of the research question regarding patients’ descriptions of the important aspects of managing symptoms was appropriate for qualitative inquiry. Content analysis can be employed to structure a text along predefined categories or develop categories inductively <sup>9</sup>. Using conventional content analysis inductively, with emerging categories, we were able to capture the lived experience of PLWH by incorporating the individual and dynamic facets of that experience <sup>9,10</sup>. The focus of the content analytical approach lies on the systematic analysis of symbols, which are the basis of meaning in any form of communication <sup>9</sup>. Yet, the approach does not limit text exploration to obvious and visible content and allows the emergence of latent meaning. Consequently, a certain extent of interpretation cannot be avoided <sup>11</sup>. To preclude unrestricted interpretation, we used a systematic and specific analytical process, following explicitly described rules <sup>9,12</sup>.



**Context, Setting, and Data.** Approximately 70% of the PLWH living in Switzerland participate in the Swiss HIV Cohort Study, an ongoing multicentre research project established in 1988, taking place at seven outpatient clinics of Swiss hospitals (Zürich, Basel, Berne, Geneva, Lausanne, Lugano, and St. Gallen) (<http://www.shcs.ch>). In Switzerland, health insurance is compulsory for all persons living in the country. Most health expenses, including treatment and care costs within the SHCS, are covered by a basic insurance package and can be reimbursed. The interviews employed for this secondary analysis were conducted in 2005 in four sites of the Swiss HIV Cohort Study (Zurich, Berne, Basel, St. Gallen), within the scope of a larger mixed-methods study, which was concerned with symptom experience and management of PLWH, their close support persons, and health care providers and comprised quantitative descriptive/correlational and qualitative/hermeneutical components (authors, in press). For primary data collection, PLWH were contacted twice, first by physicians, and subsequently by study nurses, and asked if they would be willing to participate in the quantitative survey as well as in the qualitative enquiry. Of those who consented to both, interviewees were chosen purposely on the basis of gender, age, and transmission group, as appropriate for the hermeneutical approach chosen for primary analysis. Primary data collection integrated the quantitative data of 268 PLWH cared for at the four aforementioned HIV outpatient centres, and the qualitative data of 13 PLWH.

Semi-structured interviews were conducted by three Master's prepared nurses with extensive interview training, under close supervision of an experienced qualitative researcher. Interviews were conducted either at the hospital in a separate room or at the PLWH's home, as preferred by the participant. The interviews, all of which were between 45 and 75 minutes long, were audiotaped, transcribed verbatim, and stored as .rtf files.

**Ethical considerations.** Patients providing written informed consent for the quantitative component of the primary study were also asked to participate in the interviews of the qualitative component. Those who consented to the interviews were asked for permission to use their interviews for further analysis. All interviewees agreed to the further use of interview data. Local and regional ethical review boards of all participating hospitals approved the study protocol.

**Sample description.** Interview partners were diverse with regard to age (nine participants were between 40 and 50 years old, and four were younger than 40 years), origin (rural (6)/urban (7)), homo (6)/heterosexual (4)/no (3) partnership, and living situation (with children (2)/single or partnership without children (11)). The group of PLWH consisted of eight men and five women. Four participants had a history of intravenous drug use. Interview data revealed that 7 of the 13 PLWH had been living with HIV for more than 10 years, and the narratives presented rich data regarding their experiences in managing symptoms. Compared to the 255 remaining PLWH in the primary sample from which these 13 PLWH were drawn, no major differences in age, CD4 cell count, HIV-1 RNA copies/mL, or median of prevalent symptoms were identified.

**Interviews.** The patients were asked an opening question about their symptom experience in general and how they manage. The interviewers were trained to elicit information on the following topics: symptom management, medication management, types of symptoms to be managed, collaboration with care providers, close support persons, and others in view of symptom and medication management and how PLWH would describe collaboration with these individuals.

**Data Analysis.** For this secondary analysis, the transcribed content of the interviews was transferred to a Microsoft Excel (Microsoft, Inc., Redmond, WA, United States) file to facilitate the coding process. We analyzed data in accordance with the content analysis method described by Mayring<sup>9</sup> as follows:

1. While reading the interview transcript, passages containing information on living with symptoms, management of symptoms, and symptom self-management strategies, as well as context and outcome, were identified, extracted from the transcripts, and paraphrased. More specifically, content not relating to the above topics was deleted and the content was abstracted by rephrasing the text on a non-personal level. Grammatical short forms of paraphrases were created.
2. Aspects of symptom manageability emerging from the paraphrases were identified and paraphrases were reworded (generalized) on a shared level of abstraction, thus forming descriptive codes.

3. Repetitive descriptive codes (generalizations) with equal content were merged. Merged codes were further condensed into larger categories defined by theoretical similarities among codes. Interviews were continuously cross-monitored to ensure consistency of codes and categories with the original text.
4. Categories were used to identify shared themes (latent content) among the study participants; themes were compared and visualized in a preliminary diagram, which was submitted to rigorous examination by two qualitative researchers with expertise in content analysis and then to a peer review by experts in qualitative methods other than content analysis, as well as two PLWH not participating in the interviews who had acquired HIV before highly active antiretroviral therapy (HAART) was introduced. The feedback from these people was integrated in the description of the findings, and changes were crosschecked by in-depth comparison with the original interview texts until agreement among the researchers was achieved.

The entire analysis process was closely supervised by two researchers experienced in the care of PLWH, as well as in content analysis. All interviews were conducted in German. The cultural and linguistic adequacy of translated quotes was checked by a professional translator.

## RESULTS

Overall, a symptom was perceived as manageable if it was reconcilable with professional, social, and personal activities. Contributory factors were keeping interference endurable, being embedded in an accessible supportive network of professionals and laypersons, and being placid in the view of HIV.

### **Keeping interference endurable**

*Familiarity* with a symptom enabled PLWH to choose management strategies through which symptom interference with daily life could be kept at an endurable level. Knowing a symptom's origin seemed of utmost importance, and a symptom with a non-identifiable cause could trigger a feeling of insecurity, as a woman with severe back pain of unknown origin stated:

*However, it is very bad if one has something, like pain, and no one knows what to do or has an explanation for it. This has been very bad indeed, and this has also been the only time that I have started studying medical books and checking the Internet a hundred times a day, just to see what can be done and what could be the cause. [E]*

In our sample of 13 PLWH, familiarity with a symptom was achieved by acquiring information and knowledge about the symptom's origin, course, and predictability. Health care providers, books, and the Internet were mentioned as important sources of information.

Apart from knowing the origin of a symptom, its predictability was an important aspect of manageability. As one patient explained, learning about one's bowel activity allowed anticipatory behaviour such as getting up early for proper toileting or using pads to prevent embarrassing situations with diarrhoea. [A, M] Unexpectedly occurring symptoms such as sudden vomiting remained overwhelming and cumbersome, as the following statement by a woman illustrates. *“Yes, there are things which are really frightening—for example, every time I am at a congress, I have massive problems at the buffet and often vomit without warning, suddenly, unpredictably.” [E]*

In cases of multiple symptoms, management strategies do not seem easily available, and keeping up a daily routine seems difficult and wearisome. The challenge in such cases is keeping several symptoms in balance, and ensuring their joint interference is acceptable, as the following quote by a woman, who works full-time in a team, illustrates:

*Keeping up performance if I feel blue is really exhausting and uses up all my energy. Tiredness, sleeping problems, and mood swings are very bothersome; this needs to change. If those sleeping problems could be reduced or resolved, and possibly the mood swings improved, then another equilibrium would develop, even if symptoms did not disappear entirely. [C]*

**Knowing and using effective management strategies.** The ability to maintain tolerability of a symptom's interferences with workplace, individual, or social scopes of action contributed substantially to symptom manageability. One element was the knowledge and employment of effective management strategies. A middle-aged man, for instance, explained that a symptom for which cure or treatment was

readily available and easily applicable would not interfere with any of these areas, and management strategies could easily be integrated into the daily routine. Two male participants pointed out, *“Using a special soap or cream for dry skin...this is easily integrated into everyday life, and no big thing, because it creates no limitations.”* [D] Although the example describes total symptom control, PLWH did not primarily expect symptoms to disappear entirely and limitations not exceeding a certain extent were accepted. For instance, in case of hastened physical exhaustion, reducing workout time to ensure that one's physical capacities were not overstretched was an accepted limitation. [N] The perceived physical, social, or mental limitations that substantially interfered with a person's activities because of the severity or frequency of a symptom, the unpredictable and sudden occurrence, and the uncontrollable effects of a symptom, however, were perceived as unacceptable and not well manageable. Memory problems, which interfered with individual plans, or sickness and migraine, which interfered seriously with work capacity, were two examples, illustrated by the following two quotes from a 43-year old woman and from a man working in a highly demanding position.

When it all started—when I realized that something was wrong with me—I had memory problems and couldn't learn anymore; this I found extremely difficult. This was frightening—I wanted to make up for the college diploma and go to university and then I couldn't remember what I had read—one thing was, okay, I am too ill to study—the other thing was that I couldn't use my brain anymore. [B]

It happens that I cheerfully get up in the morning, go to work, and suddenly I feel sick and bad. This sickness might disappear after a while, but sometimes, a migraine develops, and I have great difficulties in concentrating, which can be dangerous in my job. [N]

Some participants pointed that visible symptoms were specifically difficult for them to manage because of the social and personal consequences, as one participant commented about fat redistribution: *“Exactly—the fat redistribution is somehow closer, because it is something everybody immediately recognizes and associates with HIV, isn't it? It always comes first; then, afterward, it defines the whole life.”* [B] And as a mother of two children commented: *“...Well, it has been very difficult for me, it is as simple as that. I had many problems with fat redistribution—this has been the worst thing for me and it is very distressing. (...) I think things are more difficult to handle if they are visible.”* [H]

## Supportive network

Interviewees pointed toward the importance of cultivating and securing a functioning supportive structure, which included health care providers as well as laypersons. Providers were primarily responsible for health-related information and symptom alleviation, and laypersons mainly provided quick and non-bureaucratic instrumental support if needed and both were mentioned in the context of emotional support. Ideally, people in the supportive network were accessible in times of need and informed about HIV—they did not ask ‘unnecessary questions’ (one patient) and did not need many explanations in case of emergency. Appreciation for immediate access to health care providers in specialized facilities in case of an unknown symptom was emphasized by one man with the words: *“It was very important for me and provided a sense of security, because I always knew I could go to the hospital—day and night.”* [G]

The following words of a young man might serve as an example for concrete support provided by laypersons: *“On some days, I already have a stomach ache when I wake up—real aches—so badly that I can’t work. Then, to keep the farm running, my wife or my father need to step in.”* [L] A woman in her late 40s conveyed how important laypersons were in case of emergencies for her: *“Then, if certain symptoms occur, it is very important that you can ask someone like neighbours to give you a ride to the hospital.”* [E]

Medical doctors were not only described as sources of information but also as important sources of emotional support by accepting a patient’s request for affirmation, as the following statement by a 40-year old man illustrates: *“Well, for me, it is very helpful (...) if the docs take it seriously, you know”* [B] or *“...If I would like to have, for instance, a lung screen, they [the doctors] are willing to refer me to specialists, if this is important for me”* [H] and *“It would be nice if the doctors accepted that although my lab parameters are excellent, there can still be problems with symptoms.”* [N] The recommendations of a health care provider relating to one man’s lifestyle, however, were sensed as intrusive and unwelcome, and were described as follows: *“Then the doctor said ‘you need to quit cigarettes’, ‘you need to lose weight’, and ‘actually, vegetarian food would be good for you’. This, I found, was too much—these are personal issues. I then asked to change doctors.”* [E]

## Placidity in the view of HIV

Symptom manageability, to a certain extent, also seemed to be influenced by individual attitude toward the illness. When asked about symptom manageability, PLWH responded with a varying extent of urgency when explaining the importance of acquiring information, support, and clarity about the symptom. Some participants, for instance, insisted on immediate support from their resources, whereas others displayed placidity handling symptoms. One or the other was expressed in all narratives, and some participants stated that a change from the urgency to explain and control a symptom to a more placid approach was possible over time. One participant who had been HIV positive for 25 years and had taken medication since 1990 explained:

*By and by, I became expert in dealing with HIV—for example, I judged things differently than the doctors, which for them certain occurrences would be new and sometimes frightening, but are incidents which belong to my everyday life. Then, I sometimes ask the doctor to be patient and to wait and see. [D]*

Although the urgency might decrease over time, it remains part of the experience, as the following quote from an interview with a woman in her early 50s illustrates:

*The difference is, you know, that nowadays, slowly but steadily, it is recognized that a positive test result does not represent a death sentence anymore—also I know. But somewhere, deep inside, there is this feeling that I am living on a razor edge and that there will be the onset of the disease—there is just no guarantee that there will be NO onset. One little piece [of the illness] is not controllable—it might be very small, but it is there. It is there. [C]*

One of the two PLWH contacted for feedback on preliminary results had been living with HIV for more than 20 years and summarized the two faces of living with HIV:

*Well, now I am without fear or anxiety, even placid—for me, it has been the decision to trust in the medical system. I remember other times, when fear was my daily company. I still recognize this fear when I am talking with people who are newly diagnosed, who need explanations for everything. I can also imagine that fear and uncertainty would return if, for example, I learned that my medication would not work anymore because of the development of resistances. [X]*

## DISCUSSION

### Summary of aim and concept components

The current study was conducted to validate, expand, and refine the theoretically developed working definition of perceived symptom manageability by inductively exploring the components of the concept as identified by PLWH. Employing conventional content analysis, we identified three main components contributing to the perceived manageability of a symptom, which, overall, was described as the ability to reconcile a symptom with everyday life. A symptom was perceived as manageable if PLWH were able to keep its interferences with daily activities at an acceptable level and if PLWH were embedded and secured in a supportive network. Furthermore, we found that interviewees approached their health situation with an attitude between placidity and urgency, which was also reflected in PLWH's approach to symptoms.

Our components 'keeping symptom interference with everyday living at an acceptable level' and 'being embedded and secured in a supportive network' confirm recently published findings from a qualitative study in women with chronic pain<sup>13</sup> contributing to well-being, which, eventually, may also be a result of good symptom manageability. Specific to our population was the dynamic nature and unpredictability of some symptoms, demanding a high flexibility of the PLWH and the supportive network, which is similar to findings from other studies<sup>7,14</sup>. Moreover, excluding the limitations and emotional consequences linked to living with a chronic illness when identifying symptoms needing management only partly reflects these patients' experiences, as has already been discussed in studies by other authors<sup>15,16</sup>. Although symptom severity and frequency are important elements of manageability assessment in PLWH's perception, exclusively concentrating on them represents a limited perspective on PLWHs' lived experience. Fatigue, mood swings, cognitive impairment, unexpected occurring symptoms, and changes of appearance caused substantial limitations of a person's scope of action and were especially burdensome. Unfortunately, for these symptoms, only limited treatment options are available, and the elaboration of individualized management strategies is especially important to enhance perceived symptom manageability<sup>17</sup>. Furthermore, because HIV stigmatization remains widespread<sup>18</sup>, the potential for unwanted disclosure and the perceived reduction in a person's worth because of the visible symptoms of their HIV are issues which still need to be addressed.



Receiving various types of support from a defined network of laypersons and professionals was the second component of 'perceived symptom manageability' identified in our analysis and was essential to PLWH perceiving symptoms as manageable. The kind of support received comprised affective, affirmative, and instrumental elements, and concurred with social support as defined by Kahn and Antonucci<sup>19</sup>(p.267). PLWH assigned health knowledge primarily to professional care persons and expected information from them, whereas instrumental support was ascribed to laypersons. Affirmation, defined as support through agreement with what people do or say, and affect, comprising love, admiration, or respect<sup>19</sup>, was received from both groups. Laypersons offered affirmation by knowing what was needed, accepting sudden needs, and not asking questions. The disappointment apparent in some PLWH's accounts where affirmation was not received from providers if they, for instance, were perceived as not listening to PLWH, or not accepting the existence of a PLWH's problem, points toward the significance of emotional support from health care providers.

The third component of perceived symptom manageability refers to placidity in the view of living with HIV. Very similarly, the quest for harmony has been identified in patients living with other chronic illnesses<sup>20</sup>. Despite constantly developing treatment<sup>20</sup> options, the vulnerability because of the vagueness and, to a certain extent, uncertainty of the HIV illness trajectory<sup>21</sup>, might not entirely be eradicated. Although in the course of increasing experience with HIV, PLWH might gain confidence and the uncertainty of the HIV illness trajectory will be reduced<sup>21-23</sup>, the perceived stability of the living situation seems fragile and only relative.

### **Adaptation of the working definition**

Our findings contribute to the refinement of the theoretically developed working definition in several ways. Our initial definition, "The extent of the perceived ability to bring social and personal resources into play to successfully deal with/control symptoms despite difficulties" reflects the individual skills necessary to manage symptoms and involves the social network as an important resource important for symptom manageability. Although it integrates the notion of symptom control and mentions the difficulties with which people must cope it remains on an abstract level. Our analysis revealed that symptom control was not neces-

sarily total medical control and symptom disappearance, but rather developing familiarity with the symptom by knowing its origin and engaging in behaviour that develops coherent management strategies. Management success, then, was evaluated in terms of PLWH's ability to keep the interference of a symptom with their scope of action in the social, professional, and personal realms at an acceptable level. The *ability to bring social and personal resources into play* can be differentiated as the necessity to secure a flexible and accessible supportive network, providing emotional and instrumental support and information, and the skilled development and employment of management strategies by the PLWH.

On the basis of our findings, we therefore suggest adapting the theoretical working definition of perceived symptom manageability for long-term HIV survivors as follows: "Perceived symptom manageability relates to the extent of the perceived ability to secure information, and emotional and instrumental support as well as to apply tailored symptom management strategies to keep a symptom's interference with the social, professional, and personal realms at an acceptable level."

### **Strengths and limitations**

A major strength of our study relates to using an inductive approach to gain detailed and specific information, enabling truly patient-centred and individualized care. Acknowledging the facets of lived experience and integrating them into a theoretically deducted concept increases its credibility, significance, and validity for the target patient population and health care providers. Moreover, by integrating patient perspectives, the boundaries of provider-defined parameters commonly used to identify symptoms needing management interventions might be traversed and enlarged.

The limitations primarily referred to the fact that the analysis was based on an existing pool of interviews, which could not be expanded. However, we were able to verify the results with two PLWH who had not previously participated in the interviews. Nevertheless, more in-depth information is needed on all components, such as determination of the relative importance of each of the components within the HIV trajectory.

Although interviewees are comparable regarding CD4 counts and RNA to the sample from which they were chosen, they represent only a specific group of PLWH; most participants have been living with the illness for many years, all were under close medical supervision employing the latest evidence on the

illness and medical treatment options and were in relatively stable health. The findings of qualitative analyses are always context-driven, so our findings might be different in people newly diagnosed with HIV, in an acute state of illness, or with poorer treatment, as might be the case for PLWH living in resource-poor settings. Therefore, although it uses an in-depth approach, our analysis is based on a small and specific sample of PLWH, providing only a first insight into the topic.

## CONCLUSION

With 'perceived symptom manageability', we have presented a novel approach for clinicians to identify symptoms needing awareness. In drawing attention to patients' lived experience and asking them about symptom manageability, we have expanded the currently employed parameters used to identify symptoms needing management and have acknowledged PLWH's emotional burden of living with a chronic illness despite good medical treatment. Health care providers hold a special role—not only are they a source of information, but the fact that they represent a valuable source of affirmation and, thus, emotional support is also equally important. Integrating the potential for emotional support into symptom management negotiations might contribute to more mutual understanding and increased satisfaction with the encounter.

Further research is needed to test the usefulness of the concept in daily practice and its relation to relevant outcomes. Moreover, to further verify the concept within the broader PLWH population, additional qualitative research is needed to provide information on such notions as the relative weight of concept components across the entire illness trajectory.

*The authors thank all people living with HIV who contributed their time to being interviewed. This acknowledgment includes the two people who helped to verify our results. The authors also thank Sabine Bigler and Christine Vincenzi for providing rich and meaningful interview data, as well as Elisabeth Spichiger and the participants of the doctoral seminar at the Institute of Nursing Science at the University of Basel, for their careful review and comments at an early stage of the analysis and the manuscript. Thanks are also extended to Leslie H. Nicoll for her careful review and editing of the manuscript and Manuela Oswald for a professional translator's check of the cultural and linguistic adequacy of quotes.*

*The authors disclose receipt of the following financial support for the research and authorship of this article: Unrestricted educational grants from Nora van Meeuwen-Haefliger Stiftung, Glaxo-SmithKline AG, Merck Sharp & Dohme-Chibret, Roche Pharma AG, Bristol-Myers Squibb GmbH, Boehringer Ingelheim, the Swiss National Science Foundation [grant numbers 3346-100884, 33CSCO-108787, the latter supporting the Swiss HIV Cohort Study].*

*The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.*

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## **CHAPTER 5**

### **SYMPTOM MANAGEABILITY IN SWISS HIV-INFECTED PATIENTS**

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*Submitted to: Applied Nursing Research ANR*

## 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:** 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 analysed 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 (Beta=-0.11; p=.024), symptom distress (Beta=-.62; P<.001) and total anxiety and depressive symptoms (Beta=-.18; p=.003) were statistically significant correlates of the concept.

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



## INTRODUCTION

Despite improvements in antiretroviral therapy and access to care in developed countries, persons living with HIV (PLWH) may experience a host of disturbing symptoms<sup>1</sup> across their illness trajectory. As for other patients with chronic illnesses, managing symptoms and integrating them in daily living remains a major portion of illness management also 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<sup>2</sup>. 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<sup>3-5</sup> 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.

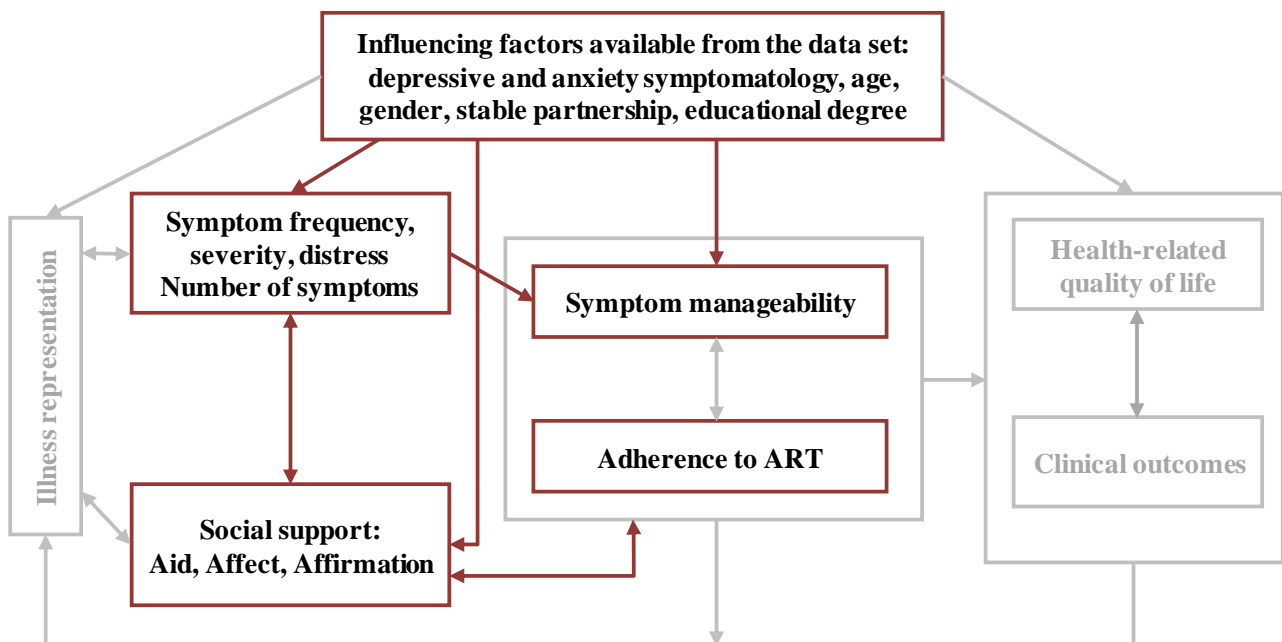
Based on the clinical observation that PLWH often use 'not manageable' when describing symptoms interfering with their lives and that these symptoms may or may not be severe, frequently occurring, or even distressing, we hypothesized that 'perceived symptom manageability' holds promise to expand the current focus on symptom experience assessment by providing a comprehensive understanding of symptom management as perceived by PLWH. In an endeavour to explore 'perceived symptom manageability', our research team chose to follow the procedural steps of concept synthesis<sup>6</sup>, 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<sup>7</sup> seemed appropriate to follow these steps. The development of a working definition of the concept<sup>8</sup>, and the verification / modification using qualitative data<sup>9</sup> is described elsewhere. In the current study, our aim was to quantitatively explore and verify 'perceived symptom manageability' and position the concept within a theoretical framework.

## BACKGROUND

### 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.<sup>5</sup> 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 figure 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.

Figure 1. Model (Spirig et al, 2005) adapted to our analysis of proposed parameters contributing to symptom manageability



### 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,<sup>8,9</sup> 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. Further-

more, 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.

### **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.

## **METHODS**

**Study design.** The current study is a secondary analysis of cross-sectional data collected for a mixed-method project investigating symptom experience in PLWH<sup>10</sup>.

**Sample and setting.** In the parent 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 Gall) 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 parent 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 two 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 this study, participants were excluded from the analysis if they did not report at least one symptom.

**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)<sup>11</sup>, which combined the symptom list from the ‘Symptom Check-List for HIV (SSC-HIVrev)’<sup>12</sup> with the scaling of experience-related characteristics used in the ‘Memorial Symptom Assessment Scale (MSAS)’<sup>4</sup>. These instruments are often used and widely validated with PLWH. The symptom list was tested for comprehensibility and the adequacy of the symptoms by asking PLWH and HIV-specialized health-care providers and was adapted as described elsewhere<sup>11</sup>. Validity evidence based on test content, scaling dimensions, and response process were established for the combined questionnaire<sup>11,13</sup>.

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 6-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)*<sup>14-16</sup>. *The HADS* was designed for use in non-psychiatric clinical settings and assesses anxiety and depression symptomatology. In the current study, for both subscales, scores  $\geq 8$  indicated significant symptomatology.

Emotional and instrumental support provided by the social network was measured using the *Norbeck’s Social Support Questionnaire (NSSQ)*<sup>17</sup>. The 9-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 5 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 3-dimensional structure suggested by Gigliotti et al. (affirmation, affect, and aid) has been confirmed and will be utilized in this study<sup>18</sup>.

**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 variable. Correlates potentially influencing the perception of symptom manageability (influencing factors from the Spirig model)<sup>5</sup>, 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  $\alpha=0.05$ .

## 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 (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 participants who signed the informed consent). One hundred fifty-five ( $n=155$ , 57%) patients were contacted to obtain missing data or to clarify responses ( $n=20$ ), resulting in a reduction of missing data on symptom experience to less than 1%. For our analysis, 3 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 ml. The most probable mode of viral transmission was men having sex with men.

**Table 1. Overall sample characteristics and psychosocial parameters of PLWH**

Variable	Sample
Total – n	268
Male gender - %	78.3
Age – median (IQR)	44 (39 - 51)
Swiss nationality - %	81.3
White ethnicity - %	95.6
AIDS - %	32.7
CD 4 cell count (mmol/L) - median (IQR)	420 (295 - 589)
HIV-1 RNA (copies/ml) - %	
<50	79.4
50 – 399	9.6
≥400	9.6
Depressive symptoms <sup>b</sup> – no symptoms- %	79.1
Anxiety <sup>b</sup> - no symptoms - %	69.4
Social support (N=255)	
Affirmation <sup>c</sup> – median (IQR)	61 (35-90)
Affect <sup>c</sup> – median (IQR)	58 (32-88)
Aid <sup>c</sup> – median (IQR)	48 (29-70)
IQR = interquartile range	

<sup>a</sup> MSM: males having sex with males; MSF/FSM: males / females having sex with females/males

<sup>b</sup> 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)

<sup>c</sup> measured by the Norbeck Social Support Questionnaire (NSSQ), affirmation / affect / aid subscale

Twenty-one percent (21%) of our study participants had mild to severe depressive symptomatology and 31% 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 9 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% of participants were excluded.

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.).

**Table 2. 10 most prevalent, severe, frequently occurring, distressing, and least manageable symptoms**

Most Prevalent (%)	Most Severe	Most Frequent	Most Distressing	Least Manageable
Fear / worries (61.8%)	Sensitivity to insect bites	Dry skin	Headaches	Hair loss
Fatigue (53.3%)	Insomnia/can't sleep	Thirst	Caries/brittle teeth	Vomiting
Dry skin (52.2%)	Vivid dreams	Insomnia/can't sleep	Insomnia/can't sleep	Insomnia/can't sleep
Weakness (50%)	Fatigue	Gas/bloating	Heartburn	Weight gain in stomach area
Diarrhea (47%)	Thirst	Vivid dreams	Increased sensitivity to insect bites	Decreased ability to withstand psychological strain
Depressed mood (46%)	Lack of appetite	Lack of appetite	Fatigue	Anxiousness
Gas/bloating (45%)	Diarrhea	Fatigue	Anxiousness	Skinny arms and legs
Vivid dreams (44%)	Constipation	Dry mouth	Vomiting	Depressed mood
Difficulty concentrating (43%)	Increased appetite	Fear/worries	Fear/worries	Fatigue
Insomnia/can't sleep (42%)	Numbness/tingling in legs, feet and toes	Diarrhea	Nausea	Caries/brittle teeth

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) was significantly related to symptom manageability.

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



Table 3. Multiple regression analysis for mean symptom manageability on patient level

Model	95.0% confidence interval for B					
	B (SE)	Beta	T	p	lower	upper
(constant)	6.063 (.276)		21.960	.000	5.519	6.607
<b>Age</b>	<b>-.008 (.004)*</b>	<b>-.109</b>	<b>-2.271</b>	<b>.024</b>	<b>-.016</b>	<b>-.001</b>
Stable partnership	.020 (.051)	.019	.401	.689	-.079	.120
Gender	.159 (.094)	.082	1.688	.093	-.027	.345
<b>Symptom distress</b>	<b>-.753 (.070)</b>	<b>-.624</b>	<b>-10.789</b>	<b>.000</b>	<b>-.890</b>	<b>-.616</b>
Highest completed educational degree	-.042 (.029)	-.071	-1.442	.151	-.099	.015
<b>HADS total score</b>	<b>-.020 (.007)</b>	<b>-.182</b>	<b>-3.000</b>	<b>.003</b>	<b>-.033</b>	<b>-.007</b>
Total functional support score	.000 (.000)	.057	1.133	.258	.000	.001
Number of reported symptoms	.000 (.004)	.006	.110	.912	-.008	.009

## 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 ten 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<sup>19</sup>. Because stigmatization due to HIV is still widespread<sup>7</sup>, 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<sup>20</sup>. Thus traditionally used parameters, indeed, may only elucidate a limited segment of symptoms needing management and miss symptoms with wider-ranging impacts<sup>21</sup>.

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<sup>22,23</sup>. As people continue to age with HIV, they are also confronted with comorbidities due to living longer<sup>24</sup>, and managing symptoms may be more difficult, as suggested by our result.

Given evidence<sup>25,26</sup> and the findings of our qualitative analysis that social support is a core variable in managing HIV, it was surprising this study did not find a relationship between social support and symptom manageability was surprising. 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.

The high correlation between symptom distress and manageability was consistent across all analyses, and remains a matter of further research. Clinically, questioning patients about distressing symptoms may be as suitable to identify symptoms needing management as asking patients about symptom manageability. No matter which parameter is used, the individual interpretation of the situation warrants further exploration and negotiation between PLWH and provider.

### **Limitations of the study**

Comparing descriptive parameters displayed in table I 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.

Our analysis was based on an existing data set and the assumption that perceived manageability represents a patient's view of symptom management as conceptualized in a model. The qualitative analysis, however, elicited factors contributing to perceived manageability, which could not be quantitatively explored due to the limitations of data available for inclusion in the current study. Moreover, qualitative findings are always context-driven; therefore, findings from a small sample of PLWH who have been living with HIV for many years may not be transferrable to a bigger sample of PLWH with different or shorter experiences with their condition.

### **Implications for further research**

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.

## CONCLUSION

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.

*Acknowledgements to: Tracy Glass, PhD, Christine Vincenzi, MNS; Susanne Stölzl, RN; Pietro Vernazza, MD; Anna Christen, RN; Hansjakob Furrer, MD; Susan Hochstrasser, RN; Rainer Weber, MD.*

*This work was supported by: unrestricted educational grants from Nora van Meeuwen - Haefliger Stiftung, Glaxo-SmithKline AG, Merck Sharp & Dohme-Chibret, Roche Pharma AG, Bristol-Myers Squibb GmbH, Boehringer Ingelheim, the Swiss National Science Foundation Grant Nr 3346-100884 and by the Swiss National Science Foundation Grant Nr 33CSCO-108787 which supported the Swiss HIV Cohort Study.*

*The authors declare no conflicts of interest*

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## **CHAPTER 6**

# **SYNTHESIS: INTEGRATION OF FINDINGS**

## SYNTHESIS: INTEGRATION OF FINDINGS

We proposed that the parameters traditionally used to identify symptoms that need management do not sufficiently embody PLWHs' concerns regarding living with this chronic condition, which may result in under-recognition of bothersome symptoms. We therefore introduced "perceived symptom manageability" as a concept, which we suggest incorporating the patients' perspective on daily living with symptoms and that could be useful for clinical use to identify symptoms that need management. Moreover, using this concept may provide common ground for providers and patients to negotiate symptoms that need management and apt management strategies.

Before the concept can be recommended for use in clinical practice, however, our assumptions must be verified. Since the concept has not yet been used in relation to symptoms, a concept synthesis<sup>1</sup> seemed appropriate and allowed us to explore the suitability of the concept for our purpose, to transfer the concept from its current use to the new use and specify its use with symptoms, and to verify our assumption that the concept can be used to identify symptoms that need management. Following the procedural steps of concept synthesis proposed by Walker and Avant<sup>1</sup>, a mixed methods design seemed appropriate. More specifically, we first developed a working definition of the concept by integrating as many uses of the concept as possible based on an open search of the Internet employing various data sources ([Chapter 3](#)). Second, we analyzed qualitative interviews ([Chapter 4](#)) using conventional content analysis to explore shared themes relating to the concept among a sample of 13 PLWH ([Chapter 4](#)), and third, we conducted an analysis of quantitative survey data to explore the conceptual context of perceived symptom manageability ([Chapter 5](#)). As the overarching study of our project (SOLEXA) provided a rich database of qualitative and quantitative data matching our topic, we decided to take advantage of existing data. Two of our three analyses drew from this data pool, and one analysis was based on additionally collected data. In mixed methods research, one of the most important steps is the combination of data, which eventually is the heart of the added value by this method. This step, however, should not be left to intuition. Although the concept synthesis procedure provides an overarching structure to combine data, the data combination process is not explicitly described in the literature; we therefore employed sources from mixed methods research to inform our integration steps. Data can be combined at various stages of the research process<sup>2</sup>.



As our data were generated using different methods and were independently analyzed, the recommendation is that the integration takes place in the interpretation phase<sup>3</sup>. This corresponds with our methodological approach, in which findings from each source and method are not used in a competitive but rather in a complementary manner and contribute to a more comprehensive picture of the concept than each perspective alone would have allowed, thus serving an overarching aim and resulting in an integrative description of results. Within the concept synthesis steps<sup>1</sup>, our data combination pursued three goals (see Diagram 1): to verify and modify the working definition resulting from step 1 of the concept synthesis procedure; to develop constituents of the concept; and to create exemplary cases of symptoms. Verification and modification occurred at two points: first, at the integration of qualitative findings into the working definition and thus ensuring the integration of the patient perspective; and, second, at the incorporation of quantitative findings into the modified definition. The identification of constituents took the form of a further integrative step, providing a comprehensive view on components embraced by the concept (global assessment, [Table 3](#)). In a fourth step, quantitative and qualitative appraisals of symptom manageability were combined and both convergent and divergent assessments of symptoms were used to create model cases and a borderline case. To enable maximum transparency in terms of the combination of findings from different data sources or methods, Farmer et al.<sup>4</sup> recommend a triangulation protocol containing a set of six distinct steps, which highlight the steps taken at the integration phase of a project<sup>3,4</sup>. Although presented for qualitative data, the steps briefly described in the next paragraph also apply to integrating findings from different methods, and were guiding our integration process.

In a first step, findings from the different sources that address the research question are coded and categorized according to meaningful topics in view of the research question in a way that enables comparison (sorting).

The second step refers to the identification of themes from each data source of method, and convergence in view of the research question. Sorting and coding of data relating to our concept was integrative to the development of the working definition and the qualitative verification. Coding and sorting using quantitative data was inherent to the method; the choice of data relating to the concept was based on the conceptual framework by Spirig et al.<sup>5</sup>, which provided a comprehensive description of symptom management in HIV. This framework was also used to guide the sorting procedure for the overall integration of findings resulting in the global assessment of findings, described in further detail below and representing the core of this chapter. The "convergence coding scheme" provides an apt structure for assessing agreement (agreement between findings), partial agreement, silence (only one method provides themes), and dissonance (contradicting results) between data sources in view of the research question.

The third step focuses on the global assessment of the overall convergence of the findings based on the convergence coding scheme. In our study, constituents were thematically grouped along concept antecedents, defining attributes, and consequences derived from Spirig et al.'s framework, and the global assessment of overall findings comprised the overarching description of concept constituents.

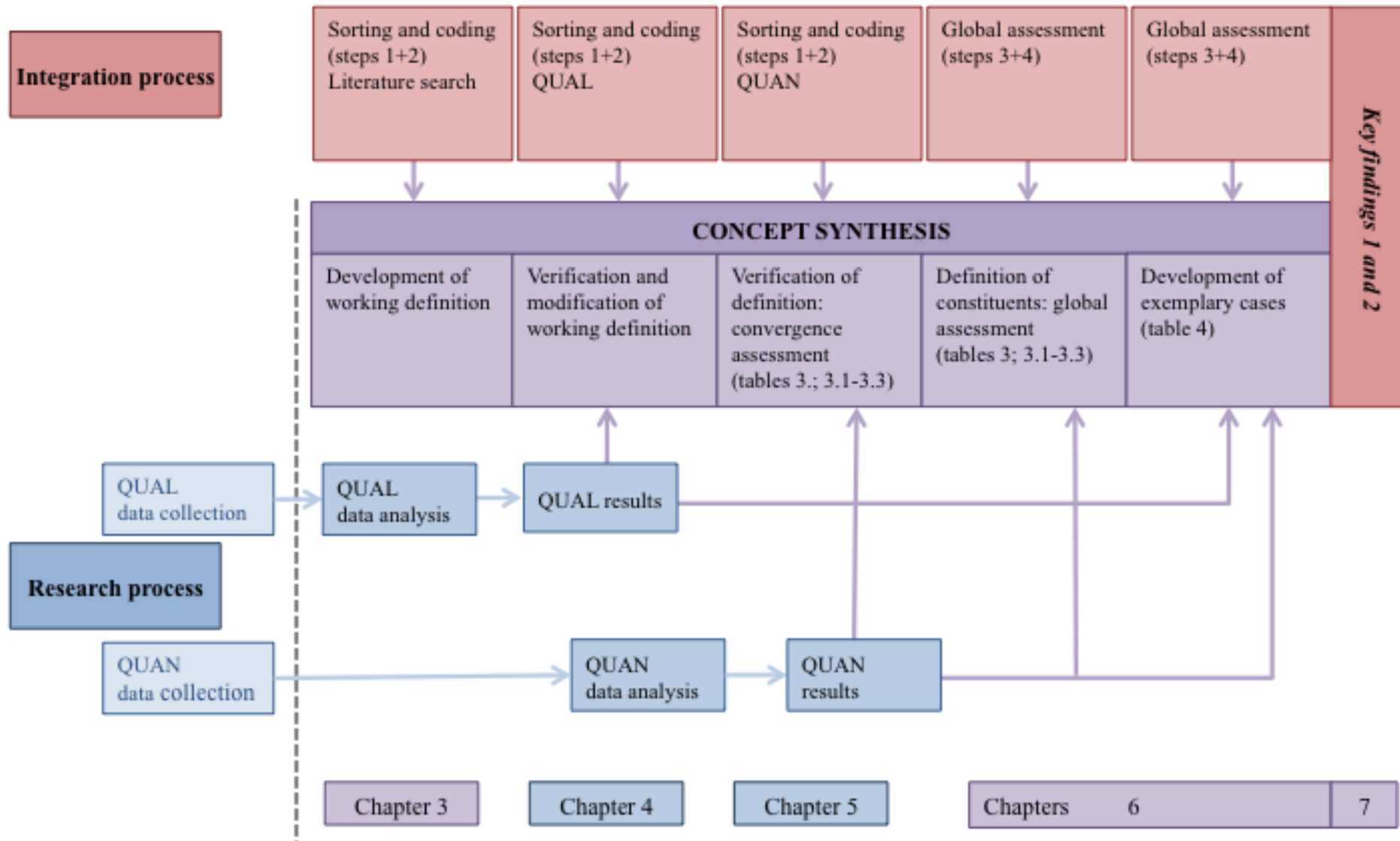
The fourth step that the authors recommend is completeness assessment. This refers to the completeness of the different sources in terms of the topic of interest and the completeness of the entire set of findings. During this process, for instance, differences in scope and/or coverage are identified. Researcher comparison (step 5) and feedback (step 6) denote the reflection and review of integrated findings by fellow researchers and stakeholders. Researcher comparison was provided by co-authors contributing to the analytical steps; and feedback was provided by all co-authors of the particular articles presented in chapters three, four, and five.

Developing and following a triangulation protocol, therefore, guides the integration process by describing the different steps taken, and the convergence coding matrix represents a key element in the triangulation protocol by summarizing core findings from the analyses in a matrix structure and enabling a comprehensive picture and analysis of data from different sources. Our integration process was determined by the procedural steps of concept synthesis as the overarching methodology (Walker and Avant)<sup>1</sup>, as follows.

First, we searched different sources to identify as many uses of the concept as possible. Second, uses were sorted, clustered, and overarching themes identified, which were condensed to a working definition ([Chapter 3](#)). Empirical verification and modification of the concept is the next step. To integrate the concerned persons' lived experience, we conducted a content analysis of semi-structured interviews and refined the definition according to the emerging themes, resulting in a first empirically supported definition of the concept. For this developmental step, findings of the two analyses were integrated following the triangulation protocol represented in [table 1](#). To further verify the concept and to determine its relation to existing theory and related concepts, we conducted bivariate and multivariate analyses ([Chapter 5](#)) of survey data generated on the basis of a conceptual framework on symptom management <sup>5</sup>, which integrates various influencing factors and correlates of perceived symptom manageability. The framework, therefore, offered an apt basis for coding findings as antecedents, attributes, and consequences of the concept (see [table 3](#)).

In a final step, convergence coding matrices for antecedents, attributes, and consequences of the concept are created (see [tables 3.1-3.3](#)). The following diagram and tables highlight the process how we combined findings from the three analyses in several distinct steps and developed main findings as discussed below.

Diagram 1. The combined integration and research process



## Triangulation Protocols

**Table 1. Triangulation protocol of qualitative concept verification and modification**

Integration 1: Refining the working definition by integrating qualitative findings	Activity	Result
<i>Summary of as many uses of the concept as possible</i>		<i>Working definition: Perceived symptom manageability denotes "the extent of the perceived ability to bring social and personal resources into play to successfully deal with/control symptoms, despite difficulties"</i>
Step 1: Sorting	Key themes that emerged from the qualitative analysis and those emerging from the first concept synthesis steps were listed.	
Step 2: Convergence coding	Because qualitative analysis was used to fill the theoretically developed definition with meaning, inductively developed themes (for details, please refer to <a href="#">Chapter 4</a> ) were used to complement and refine the formerly created working definition of the concept in an explanatory manner.	
Step 3: Convergence assessment	<p><i>Dealing with/controlling</i> symptom denotes rather achieving familiarity with the symptom by knowing its origin and engaging coherent management strategies than total medical control and symptom disappearance</p> <p><i>Success</i> was evaluated in terms of PLWH's ability to keep the interference of a symptom with the scope of action in the social, professional, and personal realms at an acceptable level.</p> <p>The <i>ability to bring social and personal resources into play</i> can be differentiated as the necessity to secure a flexible and accessible supportive network, providing emotional and instrumental support and information, and the skilled development and employment of management strategies by the PLWH.<sup>6</sup></p> <p>The working definition was adapted and a preliminary definition of the concept was created.</p>	<i>Refined definition:</i> "Perceived symptom manageability relates to the extent of the perceived ability to secure <i>information</i> , and emotional and instrumental support as well as to apply tailored symptom management strategies to keep a symptom's interference with the social, professional, and personal realms at an acceptable level." <sup>6</sup>
Step 4: Completeness assessment	In view of qualitative data and data from Internet sources	
Step 5: Researcher comparison and feedback	The adapted definition has been critically reflected and approved by all co-authors	

**Table 2. Triangulation protocol describing the development of concept constituents using findings from qualitative and quantitative analyses**

<b>Integration 2: Verification of the theoretical definition</b>	
Step 1: Sorting	<p>Components of the theoretical definition and results from the qualitative and the quantitative analyses were coded as "<i>antecedents</i>" (referring to elements that affect perceived symptom manageability); "<i>defining attributes</i>" referring to factors common to all integrated uses of a concept. "<i>Consequences</i>" refer to elements potentially affected by the concept. Antecedents and consequences were defined based on the SSMM-HIV <sup>5</sup>.</p>
Step 2: Convergence coding	<p>Convergence coding matrices were used <sup>3,4</sup></p> <ul style="list-style-type: none"> <li>- To compare and reflect findings from the quantitative and the qualitative analysis see <a href="#">table 3</a> and explore whether findings from the quantitative exploration confirm the theoretical definition of the concept</li> <li>- To analyze the convergence of quantitative and qualitative findings relating to the concept constituents antecedents, defining attributes, and consequences (tables <a href="#">3.1-3.3</a>)</li> <li>- To construct model cases by combined analysis of symptoms mentioned in qualitative interviews and were rated in the quantitative survey, as well as by the differentiated listing of symptom-related antecedents and consequences of manageability (<a href="#">table 4</a>)</li> </ul>
Step 3: Convergence assessment	<p>Convergence codings were applied in terms of agreement, partial agreement, silence, and dissonance in view of concept antecedents, defining attributes, and consequences To provide a comprehensive understanding of integrated elements, the structure of concept analysis was employed (see below, tables <a href="#">3, 3.1-3.3</a>)</p>
Step 4: Completeness assessment	In terms of data from quantitative survey and global assessment
Step 5: Researcher comparison and feedback	The representation and findings were reflected and approved by the PhD mentor (RS)

## Convergence Coding Matrices and Global Assessment

Table 3. Global assessment: Convergence coding matrix, integrating findings on the research questions

Study	Data used	Identified antecedents <sup>1</sup>	Identified defining attributes	Identified consequences <sup>1</sup>
Concept synthesis	Definition: "Perceived symptom manageability relates to the extent of the perceived ability to secure information, and emotional and instrumental support as well as to apply tailored symptom management strategies to keep a symptom's interference with the social, professional, and personal realms at an acceptable level."	A symptom's interference with social, professional, personal realms	Secure information, emotional and instrumental support as well as to apply tailored symptom management strategies	The perceived ability to keep interference at an acceptable level
Qualitative exploration	Shared themes contributing to perceived symptom manageability across interviewees (nr of persons who mentioned topic, N=13)	<b>Available symptom self-management strategies (13)</b>	Targeting symptoms (13)	Interference with every-day life is tolerable in terms of (13) <ul style="list-style-type: none"> <li>• Lifestyle (7)</li> <li>• Disclosure (7)</li> <li>• Role performance (5)</li> </ul>
		<u>Symptom-related: severity, frequency (10), only implicitly</u> <u>Symptom predictability (4)</u> <u>Symptom visibility (3)</u>	Resource utilization: symptom control: treatment (13) Self-management strategies (12)	
		<i>Accessible and available information (10)</i>	Resource utilization: information (10)	
		Accessible and available supportive network (12)	Resource utilization: aid, affirmation, affect (9)	
		<b><i>Illness uncertainty (12)</i></b>		Individually perceived ability to keep interference tolerable (13)
Quantitative exploration	Variables statistically significantly associated with "symptom manageability"	<u>Symptom – related: symptom distress</u> <i>Personal:</i> <i>Depressive and anxiety symptomatology (HADS)</i> <i>age</i>	Focus on perceived symptoms	Degree of manageability of perceived symptoms

<sup>1</sup> as conceptualized in the SSMM-HIV <sup>5</sup>: *influencing factors; illness representation; symptom-related; social support; **bold: additional components***

The above components of the convergence coding matrix are transferred to three separate matrices illustrating concept constituents, thus enabling a slightly different picture of integrated findings. Agreement, partial agreement, silence, and dissonance in view of the research question are discussed below.

In the following tables, constituents appear in **blue type** when the source is the **concept definition** <sup>6,7</sup>, in **green type** when the source analysis is the **qualitative exploration** <sup>6</sup>, and in **red type** when the source analysis is **quantitative** <sup>8</sup>.

Findings from the concept definition emerged from a search of the literature, compiling various uses of the concept and the qualitative exploration; findings from the qualitative analysis were generated inductively, and findings of the quantitative analysis evolved from a multivariable analysis, in which age, stable partnership, gender, symptom distress, highest completed educational degree, HADS total score, total functional support score, and number of perceived symptoms were integrated as potential correlates of perceived symptom manageability.

**Table 3.1. Antecedents – convergence coding matrix**

Concept	Qualitative analysis	Quantitative analysis
<ul style="list-style-type: none"> <li>A symptom's interference with social, professional, personal realms</li> </ul>	<ul style="list-style-type: none"> <li>(Symptom severity, frequency)</li> <li>Symptom predictability</li> <li>Symptom visibility</li> </ul>	<ul style="list-style-type: none"> <li>Symptom distress</li> <li>Symptom severity</li> <li>(Symptom frequency)</li> </ul>
	<ul style="list-style-type: none"> <li>Illness uncertainty</li> </ul>	<ul style="list-style-type: none"> <li>Age</li> <li>Depressive and anxiety symptomatology (HADS)</li> </ul>
	<ul style="list-style-type: none"> <li>Availability and accessibility of symptom self-management strategies</li> </ul>	Silence
	<ul style="list-style-type: none"> <li>Availability and accessibility of information</li> </ul>	Silence
	<ul style="list-style-type: none"> <li>Accessible and available supportive network</li> </ul>	<i>Silence (!)</i>

### **Agreement, partial agreement, silence, and dissonance in view of antecedents**

The above table makes it clear that there is almost no agreement between findings in view of antecedents. There was partial agreement that interference related to symptom expression; the expression itself, however, was different between the qualitative and the quantitative findings.



Partial agreement also can be interpreted in terms of the existence of factors that influence perception, and that these are negative emotions. Availability and accessibility of various resources (own strategies, information, social support) was found in the qualitative results, but not in the quantitative findings. This kind of convergence is called silence.

**Table 3.2. Defining attributes – convergence coding matrix**

Concept	Qualitative analysis	Quantitative analysis
<ul style="list-style-type: none"> <li>Secure information, emotional and instrumental support as well as to apply tailored symptom management strategies</li> </ul>	<ul style="list-style-type: none"> <li>Targeting symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Focus on perceived symptoms</li> </ul>
	<ul style="list-style-type: none"> <li>Resource utilization: Self-management strategies</li> </ul>	Silence
	<ul style="list-style-type: none"> <li>Resource utilization: information, symptom control options</li> </ul>	Silence
	<ul style="list-style-type: none"> <li>Resource utilization: aid, affirmation, affect</li> </ul>	<i>Silence(!)</i>

### Agreement, partial agreement, silence, and dissonance in view of defining attributes

Also in view of defining attributes, agreement between qualitative and quantitative results was scarce. Agreement was on the fact that the targets of manageability were symptoms.

The use of resources was only mentioned in qualitative findings, and silence in quantitative findings.

**Table 3.3. Consequences – convergence coding matrix**

Concept	Qualitative analysis	Quantitative analysis
<ul style="list-style-type: none"> <li>The perceived ability to keep interference at an acceptable level</li> </ul>	<ul style="list-style-type: none"> <li>Interference with every-day life in terms of               <ul style="list-style-type: none"> <li>Lifestyle</li> <li>disclosure</li> <li>role performance</li> </ul> </li> <li>Individually perceived ability to keep interference tolerable</li> </ul>	Silence  <ul style="list-style-type: none"> <li>Degree of manageability of perceived symptoms</li> </ul>

### **Agreement, partial agreement, silence, and dissonance in view of consequences**

Agreement was found between concept definition and qualitative analysis, and partial agreement with quantitative findings. The convergence between quantitative and qualitative findings was silent in view of dimensions of interference with every-day life.

In fact, it is to consider that the consecutive display rather serves the delineation of antecedents, attributes, and consequences of the concept than represents a reality. As described in the model purported by Spirig et al.<sup>5</sup>, all related elements are mutually influential. Symptom distress, which we position as a consequence, can be a substantial contributor to the development of depression<sup>9</sup> if manageability is not possible and a symptom affects every-day life. Perceived symptom manageability shapes disclosure, lifestyle changes, life roles, and distress due to symptoms influencing further outcomes such as quality of life and adherence; and these consequences may also feed back into factors listed as antecedents.

### **Completeness assessment**

As a structure to reflect the completeness of data, we employed the six-step approach by Moffatt et al.<sup>10</sup>, which is recommended if there is silence or dissonance between findings to interrogate the datasets. First, the authors suggest comparing data sets in view of differences and further endorse to treat data sets as fundamentally different and therefore, results as complementary. As further steps, the authors suggest exploring the methodological rigor of each study and data set comparability, further data collection, intervention evaluation (if applicable), and exploration if outcomes of integrated studies match.

*Comparison of data sets.* In our case, the concept synthesis definition to be verified was, in parts, already modified using data from the qualitative analysis. The convergence between these two data sets relating to antecedents, defining attributes, and consequences, therefore, is not surprising. Quantitative and qualitative data sets, however, were generated by two fundamentally different analysis approaches, each answering a slightly different, yet complementary research question. It is, therefore, sensible to treat data as complementary and not as one cross-validating the other.

The *methodological rigor* of each study seems adequate, within the limitations given by the secondary data analysis for both, the qualitative and the quantitative analysis.

*Comparability of data sets.* Comparability of data sets was limited. Again, limitations were mainly rooted in the secondary analysis, where data were given and could not be altered. *Match of outcomes of quantitative and qualitative analyses.* As analyses were planned parallel, constituents of the concept, which were explored within the qualitative analysis could only be integrated in the quantitative exploration within narrow confines.

Overall, due to the different methods employed and the slightly differing research questions as well as the limitations based on the secondary character of qualitative and quantitative data, the low degree of agreement between findings is not unexpected. However, the silence in view of social support is surprising, as social support was mentioned in almost every source used for the concept synthesis and identified as a major contributor to perceived symptom manageability in qualitative interviews. The collaboration of PLWH and support persons, to whom the HIV status was disclosed, was described as intimate and for many interviewees almost self-evident<sup>11</sup>. This fact may have contributed to the answers provided to social support questions in the survey questionnaire, where social support is questioned in a distanced way and related to the entire social network, and the non-significance detected in the quantitative analysis.

Overall, the concept encompasses situation-related as well as emotional and cognitive elements, as proposed, and seems comprehensive in view of its ability to detect symptoms that need management from diverse reasons, although this conclusion is preliminary and needs further testing and verification.

### **The construction of model cases and a borderline case based on constituents**

As the last step in concept synthesis, model cases for good and poor manageability and a borderline case were constructed. In order to construct model cases of poorly or well manageable symptoms, symptoms mentioned in the qualitative analysis were listed and coded using manageability appraisals from qualitative as well as rank orders from the quantitative analysis, as shown in the following table.

Table 4.: Convergence coding matrix and global assessment of symptom appraisals

Symptom	Rank order Manageability (61 symptoms; N=268) <sup>1</sup>	Combined appraisal <sup>2</sup> (convergence coding)	Antecedents Symptom expression: Among 10 most severe/frequent/distressing: yes/no (ranks) <sup>3</sup>	unpredictable/visible/treatable	Consequences Interference with: Lifestyle (L) Disclosure (D) Role performance (Rp) <sup>5</sup>
vomiting	1	1/-	Yes (D) <sup>4</sup> (25/45/8)	Yes/yes/(no)	L, Rp
hair loss	2	1/-	No (44/n.a./38)	No/yes/(no)	(L)
insomnia/can't sleep	3	1/-	Yes (S,F,D) (2/3/2)	Yes/no/yes	L, Rp
weight gain in stomach	4	1/-	No (46/n.a./25)	- /yes/(no)	D
skinny arms and legs	7	1/-	No (24/n.a./32)	- /yes/(no)	D
depressed mood	8	1/-	No (40/38/13)	(yes)/(yes)/(yes)	L, Rp
fatigue	9	1/-	Yes (S,F,D) (4/7/6)	Yes/(yes)/(yes)	L, (D), Rp
caries/brittle teeth	10	1/-	Yes (S, D) (10/n.a./3)	-/yes/yes	?
fear/worries	12	2/-	Yes (F,D) (14/9/9)	Yes/(no)/(yes)	L, Rp
memory loss	14	2/-	No (60/37/20)	(yes)/no/no	L, Rp
weakness	15	2/-	No (27/11/15)	Yes/yes/(no)	L, Rp
headaches	16	3/+	Yes (D) (19/40/1)	Yes/no/yes	L, Rp
difficulty concentrating	17	3/-	No (41/29/2)9	Yes/no/(no)	L, Rp
forgetfulness	26	3/-	No (57/36/3)3	Yes/no/(no)	L, Rp
weight loss	28	3/-	No (39/n.a./47)	- /yes/(yes)	(D)
diarrhea	38	3/+/-	Yes (S, F) (7/10/21)	(Yes)/(yes)/(yes)	L, Rp
weight gain	39	3/-	No (53/n.a./56)	- /yes/(yes)	(D)
dry skin	58	3/+	Yes (F) (17/1/50)	No/no/yes	-

<sup>1</sup> manageability ratings were between 3.5 (hair loss) and 4.6 (very poorly manageable = 1; poorly = 2; somewhat poorly = 3; somewhat well = 4; well = 5; very well = 6).

<sup>2</sup> Quantitative study: among the 10 (15) least manageable symptoms = 1 (2); later = 3; Qualitative study: poorly/well manageable (-/+ symptom groups: physical; body changes; mood and mind; energy and recreation

<sup>3</sup> rank symptom expression: 1=most severe/1=most frequent/1= most distressing

<sup>4</sup> (S, F, D): among ten most severe (S), frequently occurring (F), distressing (D) symptoms, as identified in the quantitative survey

<sup>5</sup> as appraised by interviewees

Although many symptoms assessed in the quantitative exploration were not mentioned in qualitative interviews, the majority of those explicitly mentioned were considered poorly manageable. Overall, there was an interesting concordance of qualitative and quantitative findings. More specifically, fifteen of 18 symptoms mentioned in qualitative interviews were also rated as poorly manageable, and eleven of them ranged among the 15 least manageable symptoms as quantitatively explored. The 15 symptoms appraised as poorly manageable by interview participants were rated between "somewhat poorly" to "somewhat well" manageable across the entire sample and can be roughly assigned to 3 groups, namely *body changes*, such as weight gain in stomach area, or hair loss; symptoms referring to *mood and mind*

*changes*, such as forgetfulness or depressed mood, symptoms relating to *energy and recreation*, such as fatigue, weakness, or insomnia. Physical symptoms, such as diarrhea (if predictable) or dry skin, were considered as well manageable by interviewees and quantitatively rated as "somewhat well" to "well" manageable. The table also substantiates that relying on one of the traditionally used parameters may not be meaningful in terms of manageability of a symptom in daily living, and symptoms ranging among the 15 least manageable symptoms did not necessarily range among least severe, frequent, or distressing symptoms. Dry skin, vomiting, and headaches are such examples: dry skin was rated as the most frequently occurring symptom, but appraised as very well manageable quantitatively and in qualitative interviews; vomiting was not among the ten least severe, frequently occurring or distressing symptom and was the least manageable symptom when not predictable; and headaches appeared as the most distressing symptom, but was rated as rather well manageable. Weight gain in stomach area, on the other side, was not ranging among the 10 most severe or distressing symptoms, but was rated as not well manageable due to its relation to HIV and its potential to unwantedly disclose someone's HIV status.

In sum, it seems that traditionally used parameters were more meaningful if used in combination with additionally identified antecedents (predictability, visibility, treatability) or consequences as identified in the convergence coding matrices. What applied to almost all these symptoms was that they were appraised as intrusive on one or more of the domains of daily living by interviewees. Based on the above table, the construction of model cases of poor or good manageability and a borderline case in terms of symptoms was attempted:

Construction of a **model case of good symptom manageability**: dry skin was mentioned as well manageable in qualitative interviews as well as rated in the same way in quantitative exploration.

Mr. X, middle-aged, mentioned that this symptom was no problem, because he knew that it was due to ART (origin, predictability), and although occurring almost constantly and was rather severe, he perceived it as easy to treat by using a special soap and lotion (treatability). The symptom could not unequivocally be attributed to HIV and was not visible. There was no need for further information or support, Mr. X. has got a specific lotion from his health care provider. As Mr. X. has been living well with HIV, has built up trust in his medications and laboratory parameters. He said he was a positive-thinking person,

and there was no influencing factor impeding good manageability (age, uncertainty, depressive/anxiety symptomatology). The symptom caused no burden for Mr. X and did not interfere with any of his social, work (100%) or personal domains.

Construction of a **model case of poor manageability**: Mr. Y, who is now in his late fifties, sometimes suffers from fatigue in the morning and thus has difficulty getting up and going to work in time. Colleagues, who are annoyed because he often turns up late at work, no longer invite him to join them for post-work social activities. What no one knew was that he had problems with resistant strains a few years ago and suggested changing ART because a friend had told him that the medications might be causing his problem and found corresponding information in an Internet blog. However, his provider was in a hurry and only hastily and negatively responded to Mr. Y's request, by saying there is no certainty about the origin of his fatigue, and medication changes would not give any guarantee to reduce his symptom. Anyway, he should rather agree to use antidepressants. Mr. Y was taking ART reluctantly, he thought they were poisonous and was not able to build up trust in chemicals. He observes anxiously any physical changes, expecting further signs of resistances and illness progression. As a consequence, Mr. Y only leaves his home to see the doctors or to work, does not talk to people and fears disclosure due to physical changes. Only his partner knows about his HIV status.

Borderline case: diarrhea may be seen as borderline case – a symptom that does not fit the concept and was described as rather unmanageable despite its predictability, or due to its unpredictability. In both cases, after employing intrusive management strategies, the symptom became manageable: in the first case, integrating life changes (getting up 1.5 hours earlier in order to do proper toileting), and in the second case, using pads and mapping public toilets rendered the symptom more manageable.

In sum, constructing model and borderline cases underscores the importance to complement the traditionally used parameters (symptom severity, frequency, or distress) by components relating to the daily living with symptoms and thus integrate a key concern of patients.

## **CHAPTER 7**

### **REVIEW OF KEY FINDINGS**

## REVIEW OF KEY FINDINGS

With our mixed methods study, we explored "perceived symptom manageability," representing a new use of a known concept. By systematically combining findings from three analyses, we achieved a comprehensive representation of the concept. First, the theoretical definition extracted from current uses of the concept and the qualitative analysis enabled the conclusion to be made that the concept represents an individual view on a potentially difficult situation and components, which moderated the extent of difficulty. With the first integrative step, which combined the condensed uses of the concept with empirical data taken from interviews with patients, we succeeded in refining the theoretically developed working definition and transferring the concept to its intended new use. By integrating qualitative findings related to the concept, the modified definition of "perceived symptom manageability" represents the patients' perspective on components of the concept. The second integration step facilitated the quantitative verification of the concept definition and its constituents, as well as embedding "perceived symptom manageability" in the wider context of a theoretical framework. This step resulted in a comprehensive representation of the concept and its constituents (global assessment, chapter 6, [table 3](#)), from which [Key Finding 1](#) was derived. While our process ensured the integration of patient concerns into the new use of the concept, [Key Finding 1](#) illustrates in what way concept components refer to PLWHs' daily living with symptoms. In the last integrative step, the patients' quantitative assessments and qualitative appraisals of symptoms mentioned in the qualitative interviews were combined (chapter 6, [table 4](#)) and allowed the exploration of the concepts' potential to identify symptoms that need management, which is the subject of [Key Finding 2](#).

### KEY FINDING 1

#### COMPONENTS OF THE CONCEPT ALLUDE TO NORMALIZING WITH SYMPTOMS

The listing of findings as antecedents, attributes and consequences of perceived manageability offers an interesting summary of its constituents, which clearly relate to normalization as part of chronic illness management. In fact, we can say that the concept represents a person's perceived ability to use



resources within the struggle to achieve normalcy in view of potentially intrusive symptoms. We identified perceived manageability of a symptom as the ability to keep the interference of a symptom with everyday life tolerable. Moreover, most constituents of "perceived manageability" can be linked to normalizing, which is a core concern of persons living with chronic conditions<sup>12</sup>. Normalizing refers to the efforts of persons living with a chronic illness to live their life "as normally as possible despite the symptoms and the disease" and is especially difficult if symptoms are fluctuating, regimens are changing; social interactions and roles endangered, or the trajectory of the illness is perceived as fatal<sup>12</sup>. For PLWH, who must live with many untreatable and potentially intrusive symptoms the success of normalization efforts can thus depend not on medical symptom control alone, but rather on the extent to which they succeed in keeping the intrusiveness of the illness and symptoms at a tolerable level. Perceived symptom manageability, thus, refers to the perceived ability to lead a normal life despite potentially intrusive symptoms. To substantiate the link between concept constituents and normalizing, and thus our hypothesis that "perceived symptom manageability" integrates PLWHs' key concerns in terms of living with symptoms, we discuss antecedents, attributes, and consequences of the concept in the context of normalization.

*Antecedents* of the concept are elements that affect perceived symptom manageability. Symptom control and expression, supportive network, and further influencing factors (as suggested in the framework presented by Spirig et al.<sup>5</sup>) were identified as such elements.

*Cognitive parameters* of symptom experience traditionally used to identify symptoms that need management, symptom severity and symptom frequency, were only implicitly mentioned by PLWH as relating to symptom manageability, but were substantially and negatively correlated with manageability in our quantitative analysis, pointing to the integration of these parameters in the concept.

Symptom control and expression, especially *visibility and predictability* of symptoms seems especially forceful in view of symptom manageability referring to the fact that concealing symptoms is one way of keeping symptom intrusiveness on the social context controllable and ensure normalization in view of social relationships. Bodily changes, such as fat redistribution or extreme hair loss, were explicitly perceived as causing intolerable interference with everyday life in our qualitative analysis. Unpredictability in view of social consequences of a symptom may be related to fear of stigmatization<sup>13</sup> or social isolation. Since stigmatization due to HIV is still a reality<sup>14</sup>, visible symptoms may impede normalization by being related to unwanted disclosure and potentially negative reactions by the social context.

Manageability of HIV symptoms seems, to a certain extent, to be related to the unpredictability that results from the individual, social, and illness-related consequences of these symptoms<sup>15</sup>. Disruptions in daily living as a consequence of medication side effects did increase ambivalence and uncertainty in view of treatment<sup>16</sup>. The sudden and unpredictable appearance of a symptom further demands day-to-day decisions in view of medication adherence choices<sup>17</sup>, self-care<sup>18</sup>, or symptom and impairment management<sup>19</sup>, thus impeding a normal daily routine. Living with "good and bad days"<sup>20</sup> relates, in parts, to the appearance and expression of symptoms, which might also be unforeseeable, and requires a great flexibility and adaptability on the patient's side and from the *supportive network*. A reliable and accessible supportive network providing aid, affirmation and affective support if needed is innately connected with normalization success, especially if symptoms are fluctuating, such as fatigue or sudden vomiting. The unpredictability of fluctuating symptoms requests permanent alertness and the ability to adapt from both, the person and the person's supportive network. Moreover, in order to avoid non-productive interactions, PLWH withdrew from non-supportive relationships<sup>21</sup> which rather increased a feeling of uncertainty than providing a safe and understanding environment. Reinforcing productive social relationships, therefore, seems a comprehensible intervention to support PLWH, and responding to the PLWHs' request to provide certainty, there-

fore, represents an important task for health care providers in order to keep the patient/provider interaction fruitful and productive and enabling normalization support.

*Depressive and anxiety* symptomatology is a well-known factor to negatively influence overall perception, <sup>22,23</sup>. As both were identified as correlates of perceived symptom manageability in our quantitative analysis, and frequently were mentioned in the interviews as relating to symptom manageability, we suggest both as antecedents, influencing the perception of symptom manageability. Recent findings support the notion that a negative mood state is unfavorably related to health-related quality of life, and that interventions should not only target physical but also the emotional well-being of PLWH <sup>24</sup>.

Because we suggest that traditionally used parameters to identify symptoms that need management do not sufficiently consider the emotional burden of living with symptoms, the finding that "*illness uncertainty*" substantially seemed to be an antecedent of perceived symptom manageability was interesting. While attempting normalization, being reminded that medications can only retard decline may have deleterious effects on the interpretation of symptoms and their manageability in different patient populations <sup>25-28</sup>.

Also in PLWH, uncertainty continues to be part of the HIV trajectory and changes its form across the trajectory despite the life-saving effect of cART <sup>15,29</sup>. Higher levels of uncertainty were related to increased mood disturbance and lower levels of overall quality of life <sup>30</sup> in a sample of PLWH, thus also potentially influencing the perception of symptom manageability. In the report of a qualitative investigation, participants described uncertainty as a fluctuating, episodic experience, relating to unforeseeable stages of feeling well or ill and disabled. Illness uncertainty, therefore, seems to affect normalization endeavors, and certainty in terms of living with HIV and symptoms may be a condition to perceive normalization feasible. There is evidence that individual psychotherapy <sup>30</sup>, cognitive behavioral therapy <sup>31</sup>, or stress management training <sup>32</sup> was effective to reduce uncertainty in PLWH.

Table 3.2 in chapter 6 shows integrated *defining attributes*. As we defined the use of the concept, it is comprehensible that symptoms were the target of manageability efforts. Core attributes of the theoretical definition and its refinement were relating to the ability of resource utilization: using self-management and management strategies, including control options, employing a supportive network <sup>11</sup> or accessing sources of information. Skilled use of resources was the core attribute of the concept and facilitated normalization.

For instance, to many patients, the use of complementary and alternative medicine was of substantial importance to manage symptoms, emotions, and stigma<sup>33</sup>; but many more resources were employed to live a normal life despite symptoms<sup>34</sup>.

*Consequences* pertain to elements affected by the concept. Interference with everyday life, especially in terms of lifestyle, disclosure, role performance, and symptom distress, which also correspond to self-management dimensions identified by Nicca<sup>35,36</sup>, were derived from the antecedents, and constitute the obstacles to normalization if a symptom is not well manageable. Depending on the extent of symptom manageability, these dimensions are influenced positively or negatively and impede or facilitate normalization.

On *the* grounds of these reflections we summarize that traditionally used parameters, emotional elements, the individual contribution to living with symptoms, and self-management domains specifically important for PLWH in view of symptoms<sup>36</sup> need be included into efforts to support PLWHs' strive for normalization within a chronic illness trajectory. Perceived symptom manageability, indeed, seems to capture a broad range of components meaningful to the situation of a PLWH and his or her ability to engage in living a normal life with the illness. Traditionally used parameters to identify symptoms that need management do only capture a small, countable entity in this regard. Perceived symptom manageability, therefore, denotes the perceived ability to normalize in the midst of intrusive symptoms by engaging personal and social resources.

## **KEY FINDING 2**

### **THE CONCEPT HAS THE POTENTIAL TO IDENTIFY SYMPTOMS THAT NEED MANAGEMENT**

In [table 4](#) in chapter 6, symptoms with poor manageability were identified; first, by interviewees, and, secondly, by analyzing survey data. The majority of the symptoms appraised as poorly manageable ranged among the 15 least manageable symptoms as assessed in the survey. Roughly, poorly manageable symptoms can be summarized as mood and mind-related symptoms, symptoms related to energy and recreation, and physical changes, which were identified concordantly as belonging to the least manageable

symptoms by two different approaches. Interestingly, although associated with negative health outcomes, many of the symptoms appraised as poorly manageable are often under-recognized and under-treated<sup>37,38</sup>.

We thus conclude that using the concept would enable the recognition of symptoms which need to be addressed due to their potential to impede normalization, and, therefore, considerably reduce emotional burden for patients. Emerging evidence that addressing the emotional situation of patients not only increases satisfaction with the health care encounter, but may facilitate adherence<sup>39</sup> and reduce perceived symptom burden<sup>40,41</sup> advocates the use of the concept in clinical encounters: The substantial negative correlation of perceived symptom manageability with symptom distress in our quantitative analysis highlights the emotional burden in case of symptoms impeding normalization due to their potential to interfere with a daily routine if treatment is not possible or difficult, as is often the case with symptoms related to mood and mind-related, energy and recreation, and physical changes. While mood- and mind-related symptoms and those referring to energy and recreation were interfering with leading a normal and productive life, physically visible symptoms were difficult to manage because of their unpredictable consequences in a wider social context. Despite the medically dominated public discourse, the emotional burden and management of the on-going adaptational and integrational work of those affected<sup>42</sup> and the importance of emotional support must not be underestimated. Kendall et al.<sup>43</sup> raise a critical voice addressing the current patient self-management discourse. They highlight that self-management support by practitioners frequently overlooks the various ways in which persons with chronic illnesses manage their own body, experiences and health choices, by merely providing information and skills to (technically) manage the illness or symptom. Addressing and negotiating the tensions relating to the maintenance of a coherent identity, valued social roles and leading a normal life and ambiguous symptom management experiences in clinical encounters may establish context-specific opportunities to support patients and facilitate self-management<sup>44</sup>.

Employing a concept identifying mood and mind-related symptoms as well as those related to energy and recreation is important because these symptoms were not only burdensome for patients and their families but also found to be an important reason for non-adherence in PLWH: "forgetting pills" was the most common reason for not taking medications, and daytime sleepiness and sleep problems may result in "sleeping through" dose time<sup>45</sup>. Sleep problems may also contribute to more symptom burden and reduced

quality of life: of 290 adults, for instance, only 30% reported no sleep problems, and those reporting sleep problems, also reported significantly more anxiety symptoms and morning fatigue than good sleepers<sup>46</sup>. Addressing the manageability of sleeping problems and worries, and initiate management strategies if manageability was poor, may, thus, contribute to better health outcomes in terms of symptom burden, quality of life and adherence. The individual strategies employed to enable a PLWH to live with fatigue, for instance use of illicit substances<sup>47,48</sup>, underscore the importance of having an eye on these individually bothersome symptoms even though they are not immediately health-threatening.

Changes affecting body image, especially facial atrophy, are recognized as HIV-related stigmatizing conditions and the impact on quality of life seems obvious. However, although measuring the patients' perception of the impact of lipodystrophy on quality of life is difficult due to a lack of appropriate instruments and no standardized definition of the bodily changes<sup>49</sup>, receiving professional help, satisfaction with health care, and employing proactive coping strategies (all  $p < .05$ ) were factors moderating the negative effect of stigma due to physical changes on adherence<sup>39</sup>.

The substantial correlation of our concept with symptom distress may raise the question of a conceptual overlap and needs to be further investigated. Clarifying if the invention of a new concept, indeed, is sensible, or if, for instance, bothersomeness or any measure integrating the emotional dimension of symptoms would also be a promising starting point to identify symptoms that need management is reasonable. Recently published findings based on a reduced list of symptoms integrating symptom-specific questions on bothersomeness, for instance, show promising results. Using a tablet PC presenting a list of symptoms and a symptom algorithm prior to the health care visit substantially increased the mutual understanding between health care provider and patient regarding symptoms<sup>50</sup>. Employing a questionnaire which integrates the patients' illness representation<sup>51</sup>, satisfaction and tolerability<sup>52</sup>, or a palliative care paradigm<sup>53</sup>, also show that including the patients' perspective contributes to better outcomes. For instance, Harding and colleagues (2005) found that following a palliative care approach yields better patient outcomes with regard to the perception of pain and symptom control, anxiety symptomatology, spiritual wellbeing, and understanding. The perception of being in control of HIV significantly predicted a PLWH's engagement in self-care activities: Engagement with provider, physical condition, and the illness representation domains of timeline, control, and identity were significantly associated with

self-care effectiveness<sup>51</sup>. Based on a recent study investigating physicians' communication and its effect on adherence, the authors concluded that using Leventhal's model as the foundation of communication resulted in better adherence ratings than the use of communication skills alone<sup>54</sup>. The above endeavors, however, lack the inclusive and comprehensive perspective, which underlies our concept.

Apart from the underlying perspective, practicability of such a measure is important. Assessing each patient using a list with all possible symptoms and symptom dimensions is, reasonably, not feasible. The use of an interactive, web-based tool to self-assess symptoms that need management, as suggested by Wantland, seems promising<sup>55</sup>. This tool promotes, first, the targeted identification of individually bothering symptoms before the planned visit. The symptoms identified then are used as the basis for the negotiation of apt and individual management strategies. Although in this brief report on a pilot test several questions still needed clarification, such a tool, in which symptom manageability is rated, would potentially facilitate the targeted discussion of symptom management strategies based on symptoms identified by patients. Identifying symptoms that need discussion by using a tablet PC before seeing a nurse or a doctor might, moreover, be one way of saving time and increase the productivity of the PLWH-health care provider encounter.

In sum, despite other encouraging initiatives published lately, due to its comprehensibility in view of aspects potentially bothering for PLWH, perceived symptom manageability may represent a promising new approach to identify symptoms that need management.





## CHAPTER 8

# FINAL REFLECTION AND REVIEW OF METHODS

## FINAL REFLECTION AND REVIEW OF METHODS

The study was designed and proposed as a descriptive exploratory cross-sectional investigation, using existing data. A mixed methods triangulation design<sup>2</sup> was used. Creating a triangulation protocol clarified the stages and procedures of integrating findings from methodologically different sources, and the overarching structure of concept synthesis proved to be useful to guide this process. The pragmatic approach allowed us to use the data as complementary rather than competing, and despite the fundamentally different data, a comprehensive picture of the concept was achieved.

In our original analysis plan, we proposed to test the mediatory effect of manageability, shaping the pathway between symptom experience and quality of life. Using path analytical techniques (structural equation modeling), the hypothesized mediating effect between symptom experience and outcome measure was not confirmed. This result was substantiated by conducting a parallel analysis employing the correlational procedure suggested by Baron & Kenny<sup>56</sup> for mediator testing. We, therefore, did not further pursue the mediatory hypothesis and concentrated on the concept exploration using concept synthesis and the analysis of empirical data to verify the theoretical definition of the concept.

The major limitation of the study was the use of existing data, collected for an overarching mixed method research project investigating symptom experience (SOLEXA). Although the overarching topic is very close to ours, the secondary use of empirical data did not permit, for instance, further questioning of PLWH when specific questions arose during the qualitative analysis, or participant checking. To partly make up for this shortcoming, we invited two additional PLWH for the critical evaluation of a preliminary visual representation of the main themes. Furthermore, our quantitative analysis was restricted to variables in the existing data set, therefore, interesting aspects, for instance, illness uncertainty or coping styles could not be integrated in the multivariate analysis. Therefore, although our findings seem comprehensive and contribute to the symptom management discourse, due to the secondary character or empirical data, our findings must be taxed as preliminary and need further verification and validation.

A second shortcoming of the study is the limited generalizability of results due to the high attrition rate ([Chapter 5](#)) and the inclusion criteria, as our sample was predominantly Swiss and successfully treated with ART. Furthermore, for qualitative interviews, participants were purposefully chosen as dyads with a

close support person for the main analysis, which restricts the results of this analysis to PLWH in a close relationship. Moreover, although the most important validity evidence for an index was established, the publication of an article establishing evidence based on internal structure of the symptom list to investigate symptom prevalence, severity, frequency, distress and manageability is still pending<sup>57-59</sup>.

Although at the time when the study was planned, guidelines to develop patient reported outcomes (PRO)<sup>60</sup> have not yet been published, "perceived symptom manageability," in our opinion, represents a concept which has been identified by patients and integrates aspects important to them. There is an increasing understanding that user involvement is a prerequisite for successful chronic illness management<sup>61-63</sup> and the identification of symptoms that need management, as the first step for the successful negotiation of interventions and management strategies, therefore, needs to truly integrate the patients' perspective. Perceived symptom manageability, therefore, can be seen as a sound basis to develop a patient reported outcome instrument as defined by the Food and Drug Administration (patient-reported outcomes, PRO)<sup>60,64</sup>.

## IMPLICATIONS FOR FUTURE RESEARCH AND CLINICAL PRACTICE

### Future research

Since our findings are based on secondary analyses of empirical data, we recommend further qualitative and quantitative studies providing primary data to substantiate the concept. Moreover, our interviewees were in a relatively stable condition and have been living with HIV and cART for years. Future research should be targeted at the applicability of our concept for PLWHs in more acute phases of the illness, for instance, immediately or shortly after testing positive or PLWH living in less resource-affluent countries than Switzerland.

*Quantitative research:* The strong negative correlation between symptom manageability and symptom distress allows the hypothesis that these concepts represent opposite sides of a coin. As our design does not allow establishing causal relationships, longitudinal research needs to be conducted to clarify the relation. Testing a meditational effect of symptom manageability on the correlation of symptom expression parameters, such as symptom severity, predictability, visibility, and symptom distress would be another

option for further investigation. As the equilibrium between overall functional ability and symptom alleviation has also been identified as element of quality of life, future research should be targeted at relating perceived symptom manageability to quality of life. Our finding that certainty/uncertainty in view of living with HIV seems to play a key role in the perception of symptom manageability and some evidence that uncertainty can be changed by targeted interventions could show a way to an intervention study aiming at increasing perceived symptom manageability by reducing illness uncertainty.

*Qualitative research:* We identified the patients' interpretation of "perceived symptom manageability," but the PLWHs' interpretation of "distress" is still unclear and needs clarification<sup>65</sup>. Generating qualitative data on the patients' definition of symptom distress, and then comparing the patients' interpretation of the concepts could be one way of doing so. Both pathways could refine our understanding of the concept and if "perceived symptom manageability" is going to expand, complement, or replace any of the currently used concepts.

*Instrument development:* Developing a concise instrument for use in practice settings could be an aim for further research. Our integration findings provide excellent groundwork to develop an instrument based on a concept and constituents important to patients. Further exploring concept attributes, antecedents, and consequences may serve as a starting point, informing more rigorous instrument development and psychometric testing. Furthermore, using a tablet PC presenting a comprehensive list of symptoms and their manageability to be filled in beforehand could be an interesting starting point to think about longitudinal study designs, for instance, an intervention study targeting the increased productivity and satisfaction with the PLWH-health care provider encounter or adherence.

### **Implications for clinical practice**

In clinical practice, symptoms that need management are frequently identified on the basis of cognitive aspects of symptom experience, i.e., symptom severity and/or frequency, and treatment necessity is concluded from these dimensions. Living with symptoms in every-day life, however, is often accompanied by emotional and practical burden relating to normalization which is not yet routinely integrated in the identification of symptoms that need management. The integration of findings from our analyses revealed defining attributes, antecedents and consequences of "perceived symptom

manageability," which all present areas for intervention for health care providers. Basically, we found that "perceived symptom manageability" is a useful concept for identifying symptoms that need management because it provides a wider perspective on a life with symptoms than traditionally used parameters.

For instance, understanding and acknowledging a PLWHs' need for affirmation by acknowledging the emotional burden especially if medical control of the symptom is not possible, but also the uncertainty and worries that may go with any symptom despite treatment options, may increase satisfaction of the encounter on both sides. Addressing potential concerns relating to a variety of topics relating to daily living with fluctuating and partly debilitating symptoms, facilitating self-efficacy, supporting self-management tasks and skills, providing affirmation and acknowledging emotional burden as legitimate reason to treat/negotiate a symptom are further recommendations to enhance normalization.

## CONCLUSION

Symptom experience assessment and the identification of symptoms that need management currently mainly rely on parameters describing symptom expression. Important elements of the lived experience of living with a chronic illness, and associated emotional burden, however, are frequently neglected. Our findings bring forth first evidence that perceived symptom manageability is a concept that holds promise to enable mutual understanding between health care providers and patients by embracing not only cognitive but also emotional aspects of living with symptoms and integrates the challenges pertaining to the daily living with a chronic condition. Most importantly, by assessing "perceived symptom manageability" to identify symptoms that need management, health care providers acknowledge the existence of illness uncertainty and emotional burden despite good medical treatment and prevailing logic reasoning as rationale for symptom management interventions.

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# CURRICULUM VITAE

## CURRICULUM VITAE

### PERSONAL DATA

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### EDUCATION

#### Graduate

2008-present	<b>PHD DEGREE IN NURSING SCIENCE</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland
2006-2008	<b>DIPLOMA OF ADVANCED STUDIES (DAS) IN APPLIED STATISTICS</b> University of Berne Switzerland
2001-2003	<b>MASTER'S DEGREE IN NURSING SCIENCE</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland

#### Undergraduate

2000-2001	<b>BACHELOR OF SCIENCE IN NURSING</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland
1992-1996	<b>REGISTERED NURSE IN PSYCHIATRIC AND MENTAL HEALTH NURSING</b> School of psychiatric and mental health nursing, psychiatry University Hospital Zürich, Switzerland
1980	<b>MATURA</b> Freies Gymnasium Zürich, Switzerland

## APPOINTMENTS AND POSITIONS

### Academic

7.2012- present	<b>ASSISTANT</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland
2006-6.2012	<b>SCIENTIFIC COLLABORATOR</b> University Hospital Basel, Department Clinical Nursing Science (from 2012: Department for practice developmet)
2008-2012	<b>LECTURER, MODERATOR</b>
2008-2012	<b>LECTURER</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland
2004-2006	<b>RESEARCH ASSISTANT</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland
2003-2006	<b>LECTURER</b> Institute of Nursing Science, Faculty of Medicine, University of Basel, Switzerland

### Non-academic

2005- present	<b>MODERATOR</b> Diasan GmbH  Licensure
1996	<b>NURSING LICENSE SWITZERLAND / PSYCHIATRIC AND MENTAL HEALTH NURSING (Diploma level 2)</b>

## MEMBERSHIP IN PROFESSIONAL AND SCIENTIFIC SOCIETIES

	Swiss Association of Nursing Science (VFP) Professional Association for Graduated Nurses Member of the interest group Psychiatric and Mental Health Nursing
1992 - present	Swiss Nurses' Association (SBK)

## RESEARCH GRANT

**Fierz, Katharina.** Perceived symptom manageability – synthesis of a new use of a known concept based on a sample of HIV outpatients. A Mixed Methods Study. 2008-2012; **Nora Van Meeuwen Haefliger Stiftung:** unrestricted educational grant CHF 30.000

## PUBLICATIONS

### Peer reviewed journals

Spirig R, **Fierz K**, Hasemann W, Vincenzi C. Assessments als Grundlage für eine evidenzbasierte Pflege (Editorial). *Pflege* 2007; 20:182-184.

**Fierz K**, Steiger J, Denhaerynck K, Dobbels F, Bock A, & **De Geest S**. Prevalence, severity and correlates of alcohol use in adult renal transplant recipients. *Clinical Transplantation* 2006; 20(2): 171-178.

Voggensperger J, **Fierz K** & Spirig R. An evidence-based guideline to support HIV/AIDS patients with alcohol problems. *Pflege* 2006; 19(4): 223-33. German.

Martin JS, Frei IA, Suter-Hofmann F, **Fierz K**, Schubert M, Spirig R. Evaluation der Pflege- und Führungskompetenz – eine Ausgangslage für die weitere Praxisentwicklung. *Pflege: die wissenschaftliche Zeitschrift für Pflegeberufe* 2010; 23(3): 191-203. DOI 10.1024/1012-5302/a00039.

**Fierz K**. ‚Evaluiert doch einfach‘ einmal...die Kunst, eine gute (Evaluations)Frage zu stellen (Editorial). *Pflege* 2010; 23(5): 295-298. German.

Nicca D, **Fierz K**, Happ MB, Moody K, Spirig R. Symptom management in HIV/AIDS: A mixed methods approach to describe collaboration and concordance between persons living with HIV and their close support persons. *Journal of Mixed Methods Research* 2012; 6: 217-235. DOI: 10.1177/1558689811421773.

Vincenzi CB, **Fierz K**, Moody KA, Glass T, Nicca D, Spirig R. Development and testing of a comprehensive HIV-Symptom Experience Assessment Scale. *Submitted to: Journal of Applied Nursing Research*

**Fierz K**, Engberg S, Nicca D, Moody K, Glass T, Battegay M, Spirig R. Symptom experience assessment in Swiss HIV-infected Patients. *Submitted to JAIDS and AIDS Behav (both rejected); currently under revision. Submitted to Advanced Nursing Research.*

**Fierz K**, Nicca D, Spirig R. Perceived HIV symptom manageability: Synthesis of a new use for a known concept. *Journal of Advanced Nursing* 2012; online first July 2012. doi: 10.1111/j.1365-2648.2012.06068.x.

**Fierz K**, Nicca D, Martin JS, Frei, IAF, Spirig R. ‘You need to manage, you know’: Long-term HIV survivors’ perception of symptom manageability: The integration of lived experience into a theoretically developed concept. *Submitted to: Scandinavian Journal of Caring Sciences*

## Other journals

- Fierz K**, Lindpaintner L, Müller-Fröhlich C, Schäfer-Keller P, De Geest S. Das Institut für Pflegewissenschaft hat im Herbst 2004 erstmals zwei Weiterbildungskurse für Pflegende angeboten: "Assessment bei Herzpatienten" und "Kompetenz durch Evidenz". *Gazetta USB* 2005;2:8-9
- Rüeger-Schaad E, **Fierz K**, Egger B, Zogg K, Spirig R. Ambulante Wundsprechstunde mit Entwicklungspotenzial. *Krankenpflege – Soins infirmiers – Cure infirmieristiche* 2009; 102(7): 18-19.

## Book Chapters

- Spirig R & **Fierz K**. (2010). In einem Journal veröffentlichen. In: E.M.Panfil (Ed.), *Wissenschaftliches Arbeiten in der Pflege* (pp. 325-335). Bern: Huber.
- Nicca D & **Fierz K**. Chronisches Krankheitsmanagement mit einem Palliative Care Ansatz für Menschen mit HIV. In: C. Knipping (Ed.), *Lehrbuch Palliative Care (revision in progress)*. Bern: Huber.

## PRESENTATIONS

### International

- Fierz K**, Moody K, Bategay M, Spirig R. Does a primary support person make a difference? Symptom experience in HIV-infected individuals. 13th Research Conference of the Workgroup of European Nurse Researchers (WENR), Vienna, Austria, September 2-5, 2008.

### National

- Fierz K**, Voggensperger J, Spirig R. Problematischer Alkoholkonsum? Eine evidenzbasierte Richtlinie zur Beratung von Menschen mit HIV/AIDS. Kongress für Angewandte Pflegeforschung, Bern, Switzerland, June 3 & 4, 2005.
- Fierz K**. Motivierende Gesprächsführung; workshop. 2nd Swiss HIV Nurses Congress, Herzogenbuchsee, Bern, Switzerland, November 11, 2004.
- Fierz K**. Motivierende Gesprächsführung – eine Pflegeintervention für Patientinnen und Patienten mit Dualdiagnose? PES-Tagung, Zürich, Switzerland, October 14/15, 2004.
- Fierz K**, Steiger J, Denhaerynck K, Dobbels F, Bock A, De Geest S. Alkoholkonsum nach Nierentransplantation - Vorkommen, Ausmass und Korrelate. Präsentation der Masterarbeiten, Aarau, Switzerland, September 1st, 2004.
- Fierz K**. Wissenschaftliches Fehlverhalten / scientific misconduct. Schaufenster (oral presentation) Jubiläums-Kongress SBK, Luzern, 26.-28. Mai 2010.

## Keynote presentations

**Fierz K.** Symptomerfahrung von HIV Patienten und ihren Angehörigen. Advanced Training Day for Swiss HIV Nurses, Bern, Switzerland, November 14, 2008.

## Posters

Spirig R, Moody K, Battegay M, **Fierz K**, Nicca D, Vincenzi C, De Geest, S. Patients' Symptom Distress and Symptom Manageability in the Presence/Absence of a Primary Support Person when treated with ART. 11<sup>th</sup> European AIDS Conference/EACS, Madrid, 24-26 October, 2007. Number P9.8/01.

**Fierz K**, Steiger J, Denhaerynck K, Dobbels F, Bock A, De Geest S. Alkoholkonsum nach Nierentransplantation - Vorkommen, Ausmass und Korrelate. 35. Kongress der Gesellschaft für Nephrologie, Basel, 18-21 September 2004. Number P03.16

**Fierz K**, Moody K, Nicca D, Glass T, Battegay M, Spirig R. Der kleine Unterschied - Symptomerfahrung bei HIV-positiven Personen mit oder ohne Bezugsperson. 1. Deutsch-Österreichisch-Schweizerischer AIDS-Kongress (SÖDAK 2009) in St. Gallen, Schweiz, 24.-27. Juni 2009. Abstract-nr. A-173-0005-00325.

**Fierz K**, Ullmann-Bremi A. Evaluation von Praxisprojekten: Richtige Frage = Aussagekräftige Ergebnisse!. Jubiläums-Kongress SBK, Luzern, 26.-28. Mai 2010. Poster-nr. 16.

Helberg, D. **Fierz K**, Frei IAF. Evaluation einer Rolle. SBK-Kongress Interlaken 9-11 Mai 2012.

Gisin M, Bühler B, **Fierz K**. Akupunktur auf der Geburtsabteilung der Universitäts-Frauenklinik, Universitätsspital Basel; SBK-Kongress Interlaken 9-11 Mai 2012

## TEACHING ACTIVITIES

### Master of Nursing Science, University of Basel, Courses taught

2012 - present	Quantitative Research: Proposal Writing seminar Co-teacher, student advisor
2012- present	Quantitative Research: Master's seminar Co-teacher, student advisor
2008 - present	Lecture: scientific misconduct

### Bachelor of Nursing Science, University of Basel, Courses taught

2008 - present	Lecture: scientific misconduct
2003 – 2006; 2010- present	Chair and moderator of action learning sets
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