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Abstract

For persons living with HIV, effective symptom management is crucial for good health outcomes and usually involves close support persons. The collaboration of persons living with HIV and their close support persons in the process of symptom management, including symptom experience reports, was investigated using an exploratory mixed methods design. Integration of methods included hypothesis generation from participants' narratives. Results revealed that collaboration is constituted by distinct but integrative positions of manager and partner that are reflected in diverse themes of symptom management and confirmed in quantitatively assessed symptom reports. Divergent qualitative and quantitative findings highlighted problems in neurocognitive symptom communication. Symptom management processes should be supported by better integrating the close support persons into clinical service, and further research on neurocognitive symptom experience is needed.

Keywords

symptom management, symptom experience, mixed methods research, HIV/AIDS, collaboration

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Despite significantly improved survival prospects due to long-term antiretroviral therapy, many persons living with HIV (PLWH) continue to experience a wide range of symptoms related to the disease as well as comorbidities, opportunistic infections, and medication side effects (Harding, Molloy, Easterbrook, Frame, & Higginson, 2006; Karus et al., 2005; Silverberg et al., 2004; Sterne et al., 2005). Effective symptom management is essential for these patients. It usually involves collaborating with others, in particular close support persons (CSPs), as patients' chronic condition is primarily managed in the home setting with hospital care services provided in outpatient settings. Symptom management is important since a high number of symptoms have been shown to negatively affect health-related quality of life and antiretroviral treatment adherence (Ammassari et al., 2001; Lorenz, Cunningham, Spritzer, & Hays, 2006; Rivero-Mendez, Portillo, Solis-Baez, Wantland, & Holzemer, 2009). A high level of antiretroviral treatment adherence is important as even small irregularities can lead to insufficient plasma drug levels, which increases the risk of drug-resistant mutations, cross-resistance, and ultimately, ineffectiveness of the medications used for treatment (Harrigan et al., 2005). Despite this, PLWH make daily adherence decisions based on their symptom management (Wilson, Hutchinson, & Holzemer, 2002).

Symptom management is complex for PLWH. It encompasses day-to-day decisions about dealing with symptoms, such as when to contact a health care provider, whether to alter exercise or diet, and when to take certain medications or perhaps not take them at all (Gifford & Sengupta, 1999). These processes are likely to be influenced by the social contexts in which they take place. PLWH are part of diverse families, partnerships, and friendships. These diverse relations can be influenced by the continuing social stigmatization of the condition and those affected by it.

A qualitative investigation undertaken in Switzerland revealed that only a small subgroup of family members was willing to assume caregiving tasks for PLWH. They performed these tasks privately to prevent being rejected or judged by others (Spirig, 2002). Nevertheless, the presence of at least one close and informed support person seemed to be important for the health of PLWH. A prospective cohort study demonstrated that stable partnerships were associated with slower rates of disease progression in PLWH receiving antiretroviral therapy (Young et al., 2004). Other investigations found that for PLWH, high levels of social support were associated with fewer depressive symptoms and enhanced treatment adherence (DiMatteo, 2004; Ingram, Jones, Fass, Neidig, & Song, 1999). In sum, research clearly demonstrates the importance of relationships with CSPs to promote health for the PLWH. Yet the collaborative process between PLWH and CSPs for symptom management remains unclear. A better understanding of PLWH and CSPs' symptom management collaboration is needed if health care providers are to guide tailored symptom management interventions.

The first step in the process of symptom management is the symptom experience of the PLWH. This process involves a cognitive component, where the frequency and severity of a symptom is recognized, and an emotional component, where the distress caused by the symptom is felt (Spirig, Moody, Battagay, & De Geest, 2005). The negative influence of high symptom frequency, severity, and high distress levels on health outcomes such as adherence and quality of life has been documented (Reynolds et al., 2009; Spirig et al., 2005). Taking the PLWH symptom experience as the starting point for symptom management, it would seem that concordance between symptom reports by PLWH and CSPs is crucial if they are to collaborate in the symptom management process. Insufficiently managed symptoms have been shown to cause distress not only for patients with chronic conditions but also for their CSPs. Furthermore, such distress seems to hinder effective symptom communication between the two people (Lobchuk & Degner, 2002). To our knowledge, concordance in symptom experience has not been investigated in the HIV population. In cancer patients, Kurtz, Kurtz, Given, and Given (1996) found a high

agreement of 71% in symptom reports between patients and their CSPs. However, in a more recent study of cancer patients and their CSPs, agreement levels for single symptoms were diverse and ranged from poor to excellent with a general trend for CSPs to overestimate symptom experience (McPherson, Wilson, Lobchuk, & Brajtman, 2008). An understanding of the concordance or discordance in the perception of symptoms between PLWH and their CSPs and the role this plays in the overall symptom management process is important for health care providers. For example, they might need to educate patients and support persons about symptom communication or educate support persons in symptom distress presentation in order to improve health outcomes for PLWH.

The purpose of this mixed methods research study was therefore to explore the collaboration between PLWH and their CSPs within the process of symptom management, including the concordance of symptom reports of the two people.

The first phase of the study involved a qualitative exploration of how PLWH and their CSPs experienced collaboration on symptom management. In the second phase, based on participant's narratives analyzed in the first (qualitative) phase, we constructed hypotheses for a quantitative exploration about concordance of symptom reports. The three hypotheses were as follows:

Hypothesis 1: PLWH will report more symptoms than their CSPs.

Hypothesis 2: There are specific neurocognitive symptoms that are more often reported by CSPs.

Hypothesis 3: When symptoms are reported as very distressing by PLWH, symptom reports by PLWH and CSPs do not differ.

Methodology and Methods

A mixed methods design featuring a combination of qualitative and quantitative approaches was chosen to expand existing knowledge about how PLWH and their CSPs collaborate on the management of symptoms. More specifically, an exploratory design was used with a greater emphasis on the qualitative investigation (Creswell & Plano Clark, 2007). Although data were collected concurrently, data analysis was performed sequentially. The data were collected concurrently because this study, a dissertation project, was part of a larger investigation (Spirig, 2002). Within the frame of the larger study, data collection decisions had been made for quantitative data, by the time the dissertation project started. Data analysis, however, was performed sequentially, starting with a qualitative phase designed to explore the phenomena of collaboration in symptom management. The data gathered during this phase were used to form hypotheses which were then tested with the quantitative data (Figure 1). The quantitative follow-up study was used to complement and extend the qualitative findings.

From a methodological point of view, the study was guided by dialectical pragmatism (Teddlie & Tashakkori, 2009). This position assumes that to explain the complexity of an increasingly pluralistic society, of which the heterogeneous HIV population is a good example, qualitative and quantitative approaches both can be viewed as equally relevant and valid ways of exploring specific questions (Tashakkori & Teddlie, 2003). Dialectical pragmatism involves considering opposite viewpoints and interacting with the tension caused by their juxtaposition to develop a synthesis of the research results (Tashakkori & Teddlie, 2003).

To better meet the demands of a dialectical approach, the study was conducted by a team of researchers, all with basic training in qualitative and quantitative methods and with complementary expertise in qualitative (DN, RS), quantitative (KF, KM), and mixed methods (MBH) research.

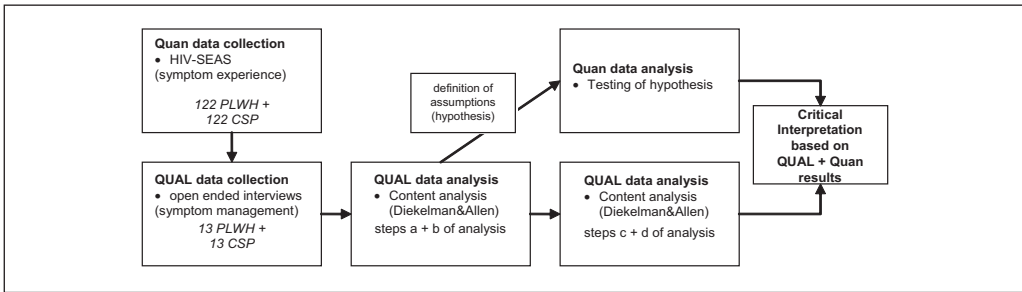


Figure 1. Overview of the exploratory design

Note: HIV-SEAS = HIV Symptom Experience Assessment Scale; PLWH = person living with HIV; CSP = close support person.

Setting and Sample

This study, undertaken within the framework of the larger investigation, was implemented in collaboration with the Swiss HIV Cohort Study (SHCS). The SHCS is an ongoing multicenter research project currently following approximately 7,417 PLWH every 6 months. The study reported in this article was implemented in four of the seven SHCS centers. All relevant ethics committees granted approval.

PLWH and their CSPs were consecutively recruited for this study at medical appointments. To be eligible for study participation, PLWH had to be on antiretroviral therapy, 18 years and older, able to read and speak German, and able to participate together with a CSP. A CSP was defined as an individual who by birth, marriage, friendship, or declared commitment shared deep and personal connections with the PLWH and provided various types of support in times of need (Levine, 1990). PLWH decided whether or not they had someone who met this definition. With the consent of the PLWH, their CSP was then contacted and asked to participate in the study. This resulted in a sample of 122 PLWH and their 122 CSPs. From this larger sample, a smaller sample of 13 PLWH and 13 CSPs was purposefully selected for qualitative interviews. The qualitative study sample was therefore a subsample of the quantitative sample. The selection of participants for qualitative interviews was performed to achieve maximum variation according to centers of care, means of HIV acquisition in PLWH, gender of PLWH, and diversity in the types of relationships with their CSPs.

Data Collection and Measurement

Collection of quantitative and qualitative data occurred concurrently and independently of each other.

Participants who consented to this study were given a set of structured study questionnaires, which they completed and returned by mail. PLWH and CSPs were asked to fill in the questionnaires individually, without discussing them with each other. However, no further safeguards to ensure that they were not sharing information were implemented. Demographic data and health information were assessed with the SHCS Questionnaire for PLWH and CSPs, including age, gender, education, ethnicity, and HIV status for all participants and transmission group, CD4 cell count, and HIV-1 RNA for PLWH only. The HIV Symptom Experience Assessment Scale (HIV-SEAS) was used to assess occurrence and distress of symptoms. The instrument consists of 73 items (symptoms) to be rated across three dimensions: frequency and severity (representing symptom occurrence) and distress. PLWH filled in the questionnaire for

themselves, whereas their CSPs rated the symptom experiences of the PLWH from their perspective. Participants were asked to indicate if a symptom had occurred during the past week (yes/no). If it had occurred, they were asked to rate how often it had occurred on a 4-point Likert-type scale (1 = rarely, 2 = occasionally, 3 = frequently, 4 = almost constantly), how severe it usually was (1 = slight, 2 = moderate, 3 = severe, 4 = very severe), and how much it distressed or bothered the PLWH (0 = not at all, 1 = a little bit, 2 = quite a bit, 3 = very much). The HIV Symptom Experience Assessment Scale was developed and tested within the larger study (Vincenzi, Moody, & Spirig, 2009).

For this study, qualitative interviews took place in the participants' homes or in a private room of the HIV outpatient clinic, according to preference. The PLWH and CSPs were interviewed separately. An interview guide suggesting open-ended questions was used to facilitate a dialogue on the participants' perspectives of symptom management and their collaboration. Interviews lasted between 50 and 90 minutes. They were recorded and later transcribed verbatim. To ensure confidentiality, any names that were used were changed.

Data Analysis

The mixed methods analysis was done in a sequential but integrated fashion with periodic exchange between the preliminary results of the two parts of the study.

Qualitative analysis. We began by analyzing qualitative data, using the following steps of the dialectical and critical content analysis suggested by Diekmann and Allen (1989). These were (a) developing an overall understanding of the texts, (b) defining categories for each interview, (c) developing relational themes (themes that cut across all texts), and (d) building constitutive patterns (patterns present in all documents expressing the relationships of the relational themes). Atlas software was used to support this process (Atlas.ti 5.2 Scientific Software Development, Berlin, Germany). Final descriptions of results were translated into English.

Mixed methods integration by hypothesis generation. After the first three steps of the qualitative analysis (Steps a, b, and c above) were completed, the preliminary results were discussed by the research team. Based on three themes that cut across all narratives, tentative hypotheses for the quantitative analysis were built and tested.

Quantitative analysis. Descriptive data were calculated for demographic variables as follows: medians for nonnormally distributed interval data and frequencies for categorical and nominal data. To test the differences in the numbers of reported symptoms between PLWH and CSPs (Hypothesis 1), the Wilcoxon signed rank test was used. To explore discordant and concordant symptom reports (Hypotheses 2 and 3, respectively), the McNemar paired samples test was used. To account for multiple testing, q values were calculated as suggested by Benjamini and Hochberg (1995), that is, the expected number of Type 1 errors was kept below 5%. The adapted p values were denoted as q values. Symptom distress across the PLWH sample was defined by averaging individual symptom distress ratings. The presence of the 20 most "distressing" recorded symptoms by PLWH was compared against those given by CSPs. All analyses were performed using SPSS® Version 16.0 (SPSS Inc., Chicago, IL).

Mixed methods integration by data interpretation. The final steps of the qualitative analysis (Steps c and d) were conducted concurrently with the quantitative analysis. Thus, preliminary quantitative outcomes influenced the qualitative data analysis. In particular, after knowing the outcome of the rejection of the two hypotheses, the relational themes (analysis Step c) were reevaluated for their consistency before constitutive patterns were built. Moreover, the quantitative analysis was performed separately for the 17 dyads where both participants lived with HIV to explore differences with dyads where only one person lived with HIV. After

finalization of qualitative and quantitative analyses, data combination occurred at the level of data interpretation that is outlined in the Discussion section.

After completion of data analysis, anonymous data were stored in a double-locked data storage room where they will be kept for 10 years and then destroyed.

Results

At medical consultation, 220 PLWH agreed to participate. Subsequently, 34 of their CSPs did not agree to participate. Of the remaining 186 dyads, 64 were lost to follow-up, mainly because of unreturned questionnaires of one person. The final sample consisted of 122 PLWH and their 122 CSPs.

Description of Sample and Participants

The characteristics of the overall sample (CSPs and PLWH) are shown in Table 1. On average the sample was middle-aged with almost no age differences between PLWH and CSPs. Participants were predominantly White Swiss men, with males accounting for 75% of PLWH and 59% of CSPs. Importantly, 17 of the 122 CSPs were living with HIV themselves. Whereas the majority of the PLWH mostly only had a basic education, many CSPs had a higher level of education: 20% of PLWH and 40% of CSP had a bachelor's degree or higher. The median plasma CD4 cell count for the PLWH was 455 cells/mm³ (interquartile range = 294-590) and the majority (90%) had plasma HIV-1 RNA <400 copies/mL.

The qualitative sample derived from the larger sample consisted of 26 participants: 13 PLWH and their 13 CSPs. Compared with the larger sample, there were no major differences in age, CD4 cell count, HIV-1 RNA copies/mL, or median of prevalent symptoms. The group of PLWH consisted of eight males and five females, four of whom had a history of intravenous drug use. Their CSPs were made up of 10 males and 3 females; of this group, 1 male was living with HIV himself. All the PLWH had been living with HIV for many years and their narratives revealed a broad range of experiences in managing their symptoms. Their living circumstances in rural and urban areas of Switzerland were diverse: Some lived in homosexual or heterosexual partnerships, others in families with children, others by themselves in close contact with friends and family members. Reflecting this diversity, the CSPs consisted of partners, close friends, brothers, or sisters. All the CSPs had had a close relationship with the PLWH for more than 2 years. The broad experiences of participants of collaboratively managing symptoms are described below.

Collaboration on Symptom Management

Narratives revealed that even small changes in the symptom experience of PLWH could severely affect their daily lives. To handle these changes, both PLWH and CSPs reported actively participating in the symptom management process. Constitutive across all interviews were the two distinct positions of the two players. PLWH seemed to be the managers who were taking a clear leadership role, whereas their CSPs appeared to be their companions who supported them in specific areas of symptom management. The positions of *being a manager* and *being a companion* were closely connected, which is portrayed by the theme *keeping in touch*. Two other themes, *putting symptoms into place* and *working things out*, each with diverse subthemes, further reveal the collaboration in symptom management as Figure 2 shows.

Being a Manager. Interviews showed that PLWH made a clear decision to not only manage their symptoms but also their entire chronic condition. The feeling of having a grip on HIV rather

Table 1. Characteristics of Participating PLWH and CSPs and Nonparticipating PLWH

Variable	PLWH	CSP	PLWH Lost to Follow-Up
Total (N)	122	122	64
Male gender (%)	75.4	59.2	84.4
Age in years; median (IQR)	44.5 (40-51)	45 (39-55)	43.0 (39-48)
Highest completed educational degree (%)			
No completed school or educational degree	1.6	0.8	4.7
Mandatory schooling (9 years)	11.5	11.6	9.4
Completed apprenticeship	63.1	43.8	54.7
Bachelor's degree/higher professional education	9.9	15.7	7.8
Graduate degree	10.7	24.0	15.6
No information/other	3.3	4.1	7.8
Swiss nationality (%)	92.6	87.3	No information
White ethnicity (%)	97.5	95.9	No information
Transmission group (%)			
MSM ¹	50.8		42.2
MSF/FSM ²	27.0		26.6
IV drug use	8.2		18.8
Other	14.0		12.5
AIDS (%)	27.0		29.7
CD4 cell count in mmol/L; median (IQR)	454.5 (305.5-630.0)		369.5 (299.3-634.5)
HIV-1 RNA in copies/mL (%)			
<50	77.9		67.2
50-399	13.1		17.2
≥400	9.0		15.6

Note: IQR = Interquartile range; PLWH = persons living with HIV; CSP = close support person.

¹Male having Sex with Male

²Male having Sex with Female / Female having Sex with Male

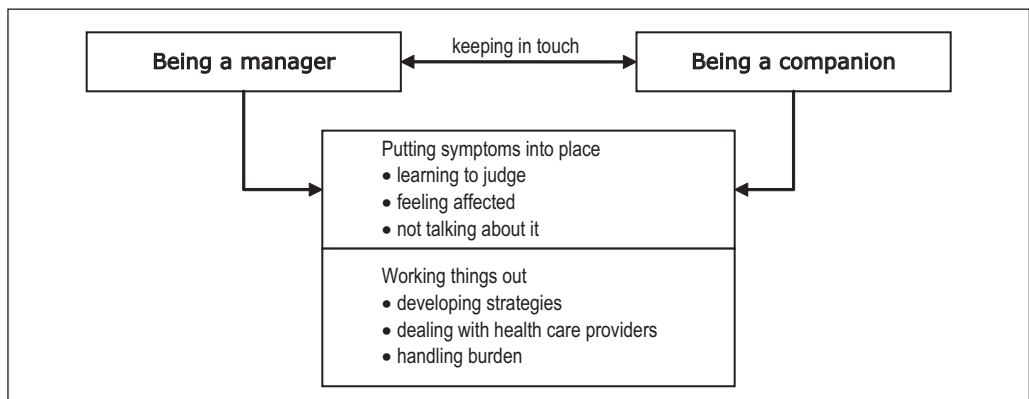


Figure 2. Constitutive pattern of collaboration in symptom management

than being controlled by it seemed to be most important for them. Their narratives revealed broad medical knowledge and expertise related to their own health and well-being. PLWH seemed to purposefully integrate the expertise of health care providers and CSPs in their management. A female participant shared an experience:

The virus is not a problem, it is quiet. My lab parameters are fine and I don't have any problems with my meds. I am so picky; I always take them every morning in the same order. But the fatigue is something I have to get a grip on again. I really have to discuss it with my doc next week.

Being a Companion. CSPs emphasized a strong commitment to stay in the relationship despite HIV. With a strong focus on illness management for the PLWH, CSPs talked about finding their responsibilities in the process according to their own resources. For instance, CSPs described supporting medication management, general health behaviors such as exercise and nutrition, and symptom management. A CSP reported the following example of responsibility for symptom management:

Well, if he has a cold or any kind of infection, I feel a little responsible to evaluate if it's necessary for him to see his doc. You know, since I kind of have a professional background.

Keeping in Touch. Despite a broad diversity in lifestyles, participants highlighted the importance of close and ongoing contact with one another. PLWH wanted to know about the well-being of their CSPs and whether they felt burdened by anything. This seemed important since partners struggling with their own difficulties could make the PLWH feel like they were losing their grip on HIV. They mentioned that CSPs made it possible for them to live meaningfully and actively manage their condition. In addition, CSPs wanted to know about the well-being of the PLWH in order to better understand behaviors and provide adequate support. Knowing about the health status of PLWH seemed to help them overcome fears of losing their loved ones. Ongoing exchanges about clinic visits, medication scheduling, or symptoms were integrated into daily routines. Nevertheless both parties reported taking special efforts to enable exchanges, illustrated through the example of a male CSP:

I drive her to the clinic, because I think it's easier for her and on the way back we have time to talk, you know we drive for more than an hour and that's time to talk about it.

Participants also revealed that exchanges had to be carefully balanced in order not to overburden each other. For many of them, other discussion partners were rare or not available, since they carefully balanced their need to talk with others against possible negative consequences of HIV status disclosure.

Putting Symptoms Into Place. Participants explained the importance of watching out for new or changing symptoms and putting them into a known frame of reference. PLWH revealed a constant monitoring of their own state of health and occurring symptoms, whereas their CSPs did not seem to observe the situation constantly. However, they were attentive and listened to PLWH in their daily exchanges. The following three subthemes—*learning to judge*, *feeling affected*, and *not talking about it*—explore this process further.

Learning to judge. Participants described a learning process, which made it easier for them to put symptoms into a known frame of reference. The PLWH explained how they improved their knowledge about possible treatment side effects and HIV-related symptoms, and how they learned to interpret their lab parameters and to be sensitive to small body reactions. They learned from their own experiences and from health care providers. Health care providers were described as important partners, especially at the beginning. A male PLWH said,

Nowadays I take symptoms in a more relaxed way, if I have a rash or something like that, I recognize it but I am not scared anymore. In the beginning I went to see the doc immediately in order to get decision making support. Today I tell the doc to wait with examinations. I just know it could be this or that, I wait and I realize if it's something more serious. In such a case I don't put it off for long.

There was more variation among the CSPs' stories. Some explained that knowing about possible symptoms and side effects helped them overcome fears. They mostly learned about HIV from PLWH or from the media. Others favored a kind of "naive" view on symptoms. They explained that they did not want to learn anything about HIV since it helped them interpret symptoms on an everyday level. They experienced this as complementary to PLWH symptom interpretation. Another group of CSPs had some sort of professional background that they used for basic knowledge. They mentioned how they expanded their knowledge through professional online searches or by asking colleagues. This group most often expressed fear of a misjudgment related to symptoms. One CSP revealed,

In the case of infections, I feel responsible to help him to evaluate if he has to see the physician. But it is difficult sometimes, since I don't want to blame myself for waiting too long or giving the wrong advice.

Feeling affected. All participants described many similar stories about the course of certain symptoms. PLWH talked about the most difficult symptoms, which could not be sufficiently managed over time and caused uncertainty, fear, and loss of morale. CSPs discussed how they recognized the suffering of PLWH and expressed empathy and understanding. They stated that they were not as affected by the symptom as the PLWH were and did not feel stressed or bothered by the problem itself. In spite of this, they felt bothered by symptoms that influenced their relationship and common activities. One CSP said,

I got the impression that his meds make him incredibly tired and this really troubles me. If we watch a movie together or we want to discuss something, after ten minutes he starts snoring, this really gets on my nerves. I really do not know if it is connected to the medications, the illness, or whether it would have been like this anyway.

His partner with HIV explained,

The fatigue got worse and worse. In our relationship this was a huge disturbing factor, since my partner just can't handle it. I still work full time, but in the evenings I let go and then I fall asleep when I sit down. For him it's very negative; for me it's more positive.

Not talking about it. Participants explained that symptoms which the PLWH felt that they had a grip on were almost never discussed in daily life. Yet there also appeared to be reasons for not talking about new symptoms or old ones which were still distressing. Some PLWH reported dealing with all their symptoms on their own or including health care providers as primary discussion partners. Other PLWH explained that they tried to not overburden their CSPs by carefully balancing discussions about distressing symptoms. They also withheld symptoms if the CSP seemed to be very fearful. One person living with HIV explained,

There are certain things I don't tell him. If I have headaches again, I don't tell him, because otherwise he concludes it's something because of the illness.

CSPs mentioned situations where they felt that the PLWH were suffering from symptoms but did not talk about them. This seemed to cause feelings of powerlessness for some of them. CSPs also revealed that they sometimes observed symptoms that they did not share with the PLWH. They mentioned symptoms such as memory loss and concentration problems, which, they assumed, might be very stressful for the PLWH. One CSP reported,

Well, sometimes I realize that she stops in the middle of a sentence and then starts talking again about something else. She has these gaps and she doesn't realize it. But I've never discussed it with her. I think it would be very distressing for her.

Working Things Out. Participants described how they worked out strategies with the aim of curing symptoms or integrating them into daily life and reducing stress. Sometimes symptoms could be dealt with quickly and easily. In such cases the PLWH dealt with the symptoms on their own and they did not appear as major issues in the corresponding CSP narratives.

The situation was, however, different in the case of distressing symptoms. Here, both PLWH and CSPs described how they each had to handle their emotions and how they sometimes worked out strategies either collaboratively or on their own. This process is further described by the following subthemes: *developing strategies*, *dealing with health care providers*, and *handling burden*.

Developing strategies. Participants revealed that very individualized strategies had to be worked out to manage distressing symptoms of PLWH efficiently. PLWH reported a process of testing different ways to deal with symptoms in which they integrated recommendations from health care providers, friends, and peers as well as from diverse media sources such as the Internet. One female PLWH explained,

I have this diarrhea and the doc gave me Imodium (loperamide). But over time I learned to better manage it. I used Bioflorin which rebuilds the intestinal mucosa. It works for me now. I have also tried managing (the diarrhea) with food. For a while I ate bananas.

There were varying accounts of the collaboration between PLWH and CSPs. Some CSPs reported being actively integrated in the testing of different ways to manage symptoms. Others said that they mainly listened to the stories of PLWH and encouraged them to reflect on their symptoms. They also brought their own suggestions into these discussions. Some CSPs mentioned that they were not integrated into the development of strategies. In situations where PLWH were struggling with management, CSPs often seemed to experience a sense of being excluded. As one male CSP revealed,

I would like to be more involved with his problem solving, since it's difficult for him. I still have resources and would be able to mobilize strengths to support him, in order to make him feel better and make both of us feel better.

Dealing with health care providers. Participants' narratives revealed health care providers to be important partners for working out symptom management strategies. PLWH emphasized the importance of a close participative relationship with health care providers. They actively asked questions and developed strategies collaboratively. Yet providers were not always experienced as helpful partners. The PLWH talked about providers who did not seem to listen and appeared to push their own agenda. If PLWH experienced such behaviors while struggling with symptoms, they expressed feelings of insecurity, distress, and desperation. A male PLWH reported,

All went well for years. I had the impression they [physicians] appreciated how well I managed besides a full time job. Now I have this fatigue and everything has changed. I sometimes think my lab results are still too good to be taken seriously. My last physician for example, in every consultation he told me that he wants to take me off the antibiotics and have me go back to work. He really scared me, I almost panicked. I always wanted to work, that's not it, but now I think they don't take my problems seriously.

Their CSPs did not appear to be directly involved in the collaboration with health care providers even though some had accompanied the PLWH on clinical visits. Nevertheless, CSPs reported discussing clinical consultations regularly with PLWH. Accordingly they provided emotional or decision-making support and sometimes encouraged the PLWH to contact a health care provider. Knowing about a positive PLWH-provider relationship seemed to relieve their own fears and sense of burden. As one male CSP put it,

I'm not stressed, I know she goes to see her doc every three months and also goes there in between if necessary. If something comes up, I just tell her to call the doc and ask him if it's something normal or not.

Handling burden. Difficulties in the management of symptoms over time were shown to cause stress and be a burden for participants. PLWH emphasized that their CSPs were important partners to share feelings of fear, sadness, and desperation related to unsuccessful symptom management. At the same time they revealed how they had to focus strongly on their own needs. Even though they sometimes talked about feeling guilty toward their CSPs, they described this process as important in stabilizing their situation and recovering their strength. A male PLWH explained,

They [friends] have to accept it. I sometimes tell my partner that I can't go out that day, I don't feel well and I just can't. For me, rest is most important, and over the years I have arranged my life according to the rest I need, it works out that way.

CSPs seemed sometimes torn between arguing with the PLWH about their own needs and being understanding toward PLWH. Because of the restrictive disclosure of HIV status, other support persons were limited. CSPs who seemed to cope well with the burden reported escaping briefly, doing recreational things on their own, and organizing their needs around those of the PLWH. A male CSP reported,

There are situations that are how they are, one has to accept it. And I've now learned to organize my free time (space) according to her symptoms and not the other way around. We just have to be at home by 3 p.m., in order for her to relax; otherwise the evening is a mess.

Concordance in Symptom Experience Reports

Participants' narratives provided an in-depth insight into their collaborative management of symptoms. Based on those insights we further explored their concordance in symptom experience reports. Three hypotheses were drawn from participants' narratives and tested in the larger sample of 122 dyads as described below.

The first hypothesis was that the PLWH reported more symptoms than their CSPs did. It was based on the observation that CSPs use of language often reflected some insecurity about the symptom reports, for example, "I think he had diarrhea at that time." In contrast, PLWH reported very clearly about symptoms. Additionally, the minority of CSPs explicitly mentioned symptom

management as an area in which they engaged; most of them supported their counterparts' medication management or general health behaviors.

The results with regard to symptom reports supported the hypothesis; there were statistically significant differences in symptom reports over the past week, with PLWH and CSPs reporting a median of 16 ($Q_1 = 9$; $Q_3 = 24$) and 12 ($Q_1 = 5$; $Q_3 = 17$) symptoms, respectively ($p < .001$).

The second hypothesis was that there were some symptoms more often reported by CSPs than by PLWH. CSPs' stories revealed that they did not talk to the PLWH about certain symptoms such as memory loss or forgetfulness in order not to hurt or offend them. We therefore expected CSPs to report more often on at least some of the neurocognitive symptoms assessed. Results revealed significant differences in symptom reports for 16 out of 73 assessed symptoms as shown in Table 2. However, all 16 symptoms were reported more often by the PLWH. PLWH also reported significantly more often on the following neurocognitive symptoms, which we had expected to be reported more often by CSP: difficulty concentrating, memory loss, and forgetfulness. In contrast, symptom reports of the 17 CSPs living with HIV themselves and their PLWH revealed no significant differences regarding the sum or type of reported symptoms.

The third hypothesis was that there was no discordance between CSPs and PLWH for symptoms reported as being very stressful by PLWH. When participants talked about their most distressing stories, dyads often used almost the same wording. From the 73 assessed symptoms, 55 were reported as being "distressing" by PLWH, with average distress levels ranging from 1.52 to 2.95 on a scale of 1 to 3. The 20 most distressing symptoms as rated by PLWH are shown in Figure 3. Of these 20 symptoms, there was discordance among the reports on 4 of the symptoms, which were also most often named by PLWH: memory loss, being anxious, forgetfulness, and feeling a restriction in the chest (symptoms shown in Table 2).

Discussion

The mixed methods approach used in this study allowed exploration in a field where limited research had been conducted. Previous qualitative and quantitative studies focused on overlapping but not entirely similar concepts such as symptom management and symptom experience. The results of the qualitative analysis (first phase of the study) provided broad insights into a collaborative process of managing symptoms. Based on this knowledge, hypotheses were then formulated that were quantitatively tested in the larger sample (including participants from the qualitative sample). This iterative process of developing hypotheses based on participants' narratives helped build well-informed propositions despite the paucity of research in the field. It also helped focus the quantitative investigation on very specific issues grounded in the participants' reported experiences that seemed relevant for further investigation. However, a limitation of this study was the concurrent data collection that restricted the development of the hypothesis to the data that were available for testing. Although both the qualitative and quantitative investigation provided interesting results, it was particularly the inference between both approaches that provided new insights that will be further discussed.

Consistent with earlier research, our results highlight a complex process of managing symptoms in everyday life and shed light on PLWH taking a clear position to actively manage such challenges (Thorne, Paterson, & Russell, 2003; Wilson et al., 2002). Compared with these earlier investigations, this study highlights symptom management as a collaborative task between PLWH and CSPs with a clear leadership role of the PLWH. So far, involvement of CSPs into symptom management has mostly been described as "informal caregiving" with support flowing in a unidirectional manner from caregiver to care recipient (Pinquart & Sorensen, 2007). A few qualitative studies have added the relational and often reciprocal dynamics of informal caregiving (Bunting, 2001; McGraw & Walker, 2004). Lingler, Sherwood, Crighton, Song, and Happ (2008)

Table 2. Concordance/Discordance of Reports of PLWH and Their CSPs on the Presence of Symptoms

Symptom (in Order of Appearance in Questionnaire)	Appraisal of Symptom by PLWH and CSPs (N = 122)		McNemar (Paired Test)		
	Yes by PLWH (n)	Yes by CSPs (n)	χ^2	p Value (Two-Tailed)	H ₀ = 1 (q Value)
Muscle cramps	18	6		.023 ^a	.088
Weakness	23	13	2.25	.134 ^b	.245
Painful joints	16	17	0.01	1.000	1.000
Fatigue	24	9	5.94	.015	.064
Muscle aches	16	7		.093 ^a	.200
Fever	6	10		.454 ^a	.603
Chills	11	15	0.35	.556 ^b	.712
Flushing	19	18	0.00	1.000 ^b	1.000
Night sweats	20	11	2.07	.151	.262
Day sweats	12	3		.035 ^a	.116
Sensitivity to insect bites	7	5		.774 ^a	.869
Increased sensitivity to hematoma	3	5		.727 ^a	.842
Weight gain	12	9		.664 ^a	.822
Weight loss	8	14		.286 ^a	.426
Weight gain in stomach area	19	21	0.025	.874 ^b	.967
Hump on back of neck/shoulders	2	4		.687 ^a	.836
Skinny arms and legs	13	5		.096 ^a	.200
Swollen feet/legs	8	3		.227 ^a	.365
Prominent leg veins	17	7		.064 ^a	.146
Fear/worries	30	12	6.88	.009^b	.041
Anxious	31	12	7.54	.006^b	.037
Decreased ability to withstand psychological distress	26	13	3.69	.055 ^b	.146
Depressed mood	23	11	3.56	.059 ^b	.146
Dizziness	25	7	9.03	.003^b	.024
Seizures/tremors	4	3		1.000 ^a	1.000
Difficulty concentrating	35	9	14.21	2.00 × 10^{-4b}	.003
Memory loss	21	6	7.26	.007^b	.039
Forgetfulness	27	10	6.92	.009^b	.041
Insomnia/cannot sleep	21	10	3.23	.072 ^b	.159
Vivid dreams	21	13	1.44	.230 ^b	.365
Headaches	19	13	0.78	.377 ^b	.540
Nose bleeds	8	4		.388 ^a	.545
Dry mouth	24	11	4.11	.043 ^b	.121
Mouth ulcers	14	6		.115 ^a	.221
White patches in mouth	3	1		.625 ^a	.787
Sore, bleeding gums	21	4		0.001^a	.009
Blood in spittle/sputum	3	0		.250 ^a	.388
Caries/brittle teeth	15	5		.041 ^a	.120
Swollen glands	14	6		.115 ^a	.221
Sore throat/painful swallowing	14	5		.064 ^a	.146
Tingling in head area	14	1		.001^a	.009
Blurred vision	22	3		2.00 × 10^{-4a}	.003
Shortness of breath at rest	6	5		1.000 ^a	1.000

(continued)

Table 2. (continued)

Symptom (in Order of Appearance in Questionnaire)	Appraisal of Symptom by PLWH and CSPs (N = 122)		McNemar (Paired Test)		H ₀ = 1 (q Value)
	Yes by PLWH (n)	Yes by CSPs (n)	χ ²	p Value (Two-Tailed)	
Shortness of breath with activity	17	6		.035 ^a	.116
Coughing	20	13	1.09	.296 ^b	.432
Heart racing	13	3		.021 ^a	.085
Chest pain	7	2		.180 ^a	.306
Feeling of restriction in chest	18	4		.004^a	.029
Heartburn	20	11	2.07	.151 ^b	.262
Abdominal pain	16	11	0.59	.441 ^b	.596
Lack of appetite	12	12		1.000 ^a	1.000
Increased appetite	9	5		.424 ^a	.584
Thirst	16	9		.230 ^a	.365
Nausea	14	5		.064 ^a	.146
Vomiting	6	4		.754 ^a	.860
Gas/bloating	28	13	4.78	.029 ^b	.106
Constipation	11	3		.057 ^a	.146
Diarrhea	23	10	4.36	.037 ^b	.117
Rectal itching	22	0		1.00 × 10^{-7a}	.000
Rectal bleeding	10	2		0.039 ^a	.119
Numbness/tingling in arms, hands, fingers	18	1		8.00 × 10^{-5a}	.003
Numbness/tingling in legs, feet, toes	23	3	13.89	2.00 × 10^{-4b}	.003
Dry skin	25	8	7.76	.005^b	.033
Itchy skin	20	10	2.70	.100 ^b	.203
Reddening skin	10	11		1.000 ^a	.000
Increased rashes	14	10		.541 ^a	.705
Hair loss	9	4		.267 ^a	.406
Splitting finger nails	15	1		.001^a	.009
Change in body hair	5	3		.727 ^a	.842
Nipple discharge	2	1		1.000 ^a	.000
Breast pain/breast changes	7	1		.700 ^a	.838
Sores or lumps on genitals	4	0		.125 ^a	.234
Burning with urination	8	0		.008^a	.041

Note: PLWH = persons living with HIV; CSP = close support person.

a. Exact significance, two-tailed; binomial distribution. b. Asymptotic significance, two-tailed; continuity corrected. Bold: significantly discordant symptom reports.

recently pointed out the shortcoming of those perspectives: On the basis of three case examples, they highlighted the diversity in caregiving relationships and the need for a broader understanding of informal caregiving to yield findings and develop interventions that carry greater clinical relevance. The different but connected positions of the PLWH and CSPs, with the clear leadership of the PLWH in symptom management and strong partnerships between both people, adds an

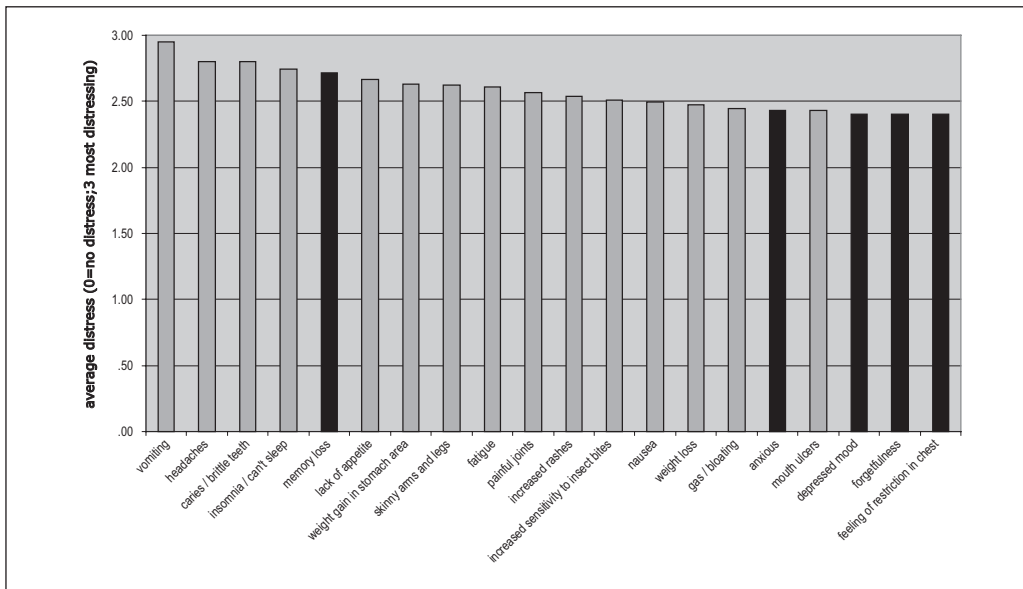


Figure 3. The 20 most distressing symptoms for persons living with HIV (PLWH)

Note: Black bars indicate discordant reports of symptom presence by PLWH and close support person (CSP).

additional dimension to the debate; however, to our knowledge, prior discussions have not taken account of this perspective. This seems especially important in the field of HIV/AIDS, where most publications on informal caregiving described situations before highly active antiretroviral treatments became well established and helped reduce morbidity. In those early studies, the importance of nonstigmatizing and reciprocal caring partnerships was emphasized, yet the active leadership of the PLWH in the management process was not described (Brown & Powell-Cope, 1991; Powell-Cope, 1996; Spirig, 1999).

In accordance with previous studies, PLWH experienced a comparatively high number of symptoms. For example, this study revealed an average of 16 symptoms per person during the previous week, whereas an earlier study for the same time period found an average of 14 symptoms for PLWH also on antiretroviral therapy (Harding et al., 2006). In contrast to a recent investigation of cancer patients and their CSPs, where a small to moderate trend for CSPs to overestimate symptoms was described (McPherson et al., 2008), CSPs in this study reported on significantly less symptoms than the PLWH. Not one single symptom was reported more often by CSPs. This might be explained by the different positions of PLWH and CSPs in the management process, with the PLWH taking overall responsibility and integrating their CSPs into different aspects of symptom management. The different positions in the management process could also be influenced by health care systems that strongly focus on the individual and do not routinely integrate CSPs into their services.

Of greatest interest, however, were the somewhat divergent findings of the qualitative and quantitative approaches. The subtheme *not talking about it* illustrated that participants withheld symptoms to protect each other. CSPs in particular mentioned diverse neurocognitive problems that they recognized but did not want to talk about with the PLWH in order not to hurt them. This led to the hypothesis that some specific neurocognitive symptoms were reported more often by CSPs. Interestingly, this could not be substantiated. Symptoms such as “difficulty concentrating,”

“memory loss,” and “forgetfulness” were reported discordantly but in contrast to our expectations, were more often named by PLWH. In dyads, in which both the PLWH and CSPs lived with HIV ($n = 17$), however, an additional analysis showed no discordance in any symptom reports. This should be further analyzed in a larger sample and with mixed methods approaches. It is important to know how PLWH who experience neurocognitive symptoms perceive and deal with those symptoms especially if, as this analysis suggests, they may be managing the symptoms on their own.

On a methodological level both approaches were used to expand and not to cross-validate findings. Therefore, such discrepancies in findings were not totally unexpected and are recognized by diverse researchers, to enable discussion and debate (Moffatt, White, Mackintosh, & Howel, 2006; Pluye, Grad, Levine, & Nicolau, 2009; Slonim-Nevo & Nevo, 2009). For example, it can be assumed that the neurocognitive symptom complex would not have been focused so strongly with either method alone. In the qualitative exploration, those symptoms were included in the subtheme “not talking about” next to many other themes and subthemes. In the quantitative symptom assessment and comparison of reports, they belonged to a larger group of symptoms that were reported discordantly. It was finally the combination of results that initiated a discussion and highlighted the need for further investigation in this area. So far, we can only conclude that CSPs, as described in the qualitative part, and PLWH, as described in the quantitative part of the study, are well aware of diverse neurocognitive symptoms. Results further point toward some difficulties in symptom communication, in particular in HIV-serostatus-diverse dyads. A context-specific explanation for not communicating specific symptoms might be that in our society, cognitive impairments are highly stigmatized, especially in a middle-aged population as were the participants in this study. Goffman (1963) explained stigma as an attribute that is deeply discrediting and separates people with an undesired differentness from others. To protect themselves from shame and social rejection, affected persons continuously struggle with the decision of whether or not to talk about their stigmatizing attributes (Bairan et al., 2007). Even though the PLWH in this study had disclosed a stigmatized attribute such as their HIV infection to their CSPs, it could be the case that they still struggled to talk about possible neurocognitive problems. The qualitative results clearly revealed such difficulties in communication for the CSPs.

During the past few years, neurocognitive deficits in PLWH have received growing attention. However, the discourse has remained mostly on an epidemiological and biomedical level, describing the aging HIV population and neurocognitive deficits, including the influence of antiretroviral therapy and associations of biological processes such as chronic infections (Robertson et al., 2007; Sacktor, 2002). Health care providers should broaden this discussion and include patient perspectives to provide everyday symptom management support for PLWH and their CSPs. This seems highly important since it has been shown that neurocognitive deficits in PLWH influence activities of daily living and work performance (Albert et al., 1995; Benedict, Mezhir, Walsh, & Hewitt, 2000).

Overall, the exploratory mixed methods approach moved the two described phenomena of symptom experience and symptom management, which have often been treated as distinct in prior research, closer together. This provides new insights into the collaboration between PLWH and CSPs on both tasks, driven by the active leadership position of PLWH and the companionship (support) of CSPs. Using hypothesis generation from participants' narratives as an approach to integration of methods, revealed important divergent findings. They highlighted previously undescribed problems in the communication of neurocognitive symptom experience between PLWH and CSPs. Therefore, the collaboration and, in particular, communication about neurocognitive symptoms should be better understood by further research and be clinically supported by health care providers to improve health outcomes and well-being for PLWH. This

will require a family- or dyad-oriented counseling approach with the integration of CSPs into some of the clinical services.

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