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Symptom Management in HIV/AIDS

Advancing the Conceptualization

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For people living with HIV, symptoms related to the disease, comorbidities, and treatment side effects make symptom management essential. Poorly managed symptoms result in reduced medication adherence, disease progression, and lower quality of life. The Self-regulatory HIV/AIDS Symptom Management Model is a conceptual model that describes how persons living with HIV/AIDS manage their symptoms. The model links symptom experience, symptom management, social support, adherence, and health-related quality of life. It can assist nurses, through a multidimensional approach to illness management, to enhance symptom assessment, better understand factors influencing symptom experience, and to improve symptom management among people living with HIV/AIDS. **Key words:** *chronic disease/therapy*, *disease management*, *HIV infection*, *models*, *nursing research*, *quality of life*, *symptom experience/occurrence/management*

HIV/AIDS has been a major worldwide health problem for more than 20 years. International advances in HIV research and treatment have increased survival and lengthened the chronic stage of the illness. The Swiss HIV Cohort Study ($N = 5156$) documented this trend as early as 1996, with an increase in the survival ratio from 19% in 1991 to 62%.[1] Despite further improvements in survival, people living with HIV are confronted with persistent symptoms resulting from the HIV infection, medication side effects, comorbidities, and associated opportunistic diseases.[2,3]

Potent antiretroviral therapy (ART), introduced in the mid-1990s, currently entails triple combination therapy, including nucleoside/nucleotide reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, protease inhibitors, and entry inhibitors. In Western countries, ART has become the standard of care for HIV disease because it is the most effective means to achieve maximal viral suppression. However, for effective virological suppression, ART requires nearly perfect adherence and is associated with a variety of disturbing side effects, partly resulting in additional comorbidities.[2]

Medication adherence rates of HIV-infected individuals are similar to rates among people living with other chronic diseases, falling between 20% and 50%.[4] The consequences of nonadherence are higher in patients with HIV, because when adherence is below 95%, resistant strains of the virus tend to develop

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and the disease progresses.[5] Adhering to the HIV therapeutic regimen is complex. A person may need to take up to 10 pills daily, some of which must be taken with meals while others require an empty stomach. Some pills can be taken together at the same time while others must be spaced several hours apart. These medications produce side effects, ranging from mild to severe. Side effects and HIV disease symptoms overlap to create a complex clinical situation that affects symptom management and adherence behaviors. For example, diarrhea is an unpleasant side effect that requires quick access to a toilet. If a person knows that she or he will be in an environment without such access, she or he may postpone or skip the medication to avoid an embarrassing situation.

Thus, in HIV practice and clinical research, understanding a patient's symptom experience has major relevance for disease outcomes. However, research on symptoms and symptom management since the advent of ART and other more recent therapeutic combinations is limited. Recent medication combinations have changed prognosis, side effects, and comorbidities, thus changing patients' perceived symptom experiences. For instance, while there are reports of significantly improved psychosocial symptoms (eg, depression symptomatology) in patients receiving newer therapies,[6] various challenging symptoms arise from alterations in glucose and lipid metabolism, such as abnormal body fat distribution.[7] Further development of knowledge regarding current symptoms experienced by people living with HIV is needed to achieve evidence-based symptom management.

Studies have indicated that several key factors are related to symptoms and adherence to HIV medication regimens; however, few models exist to guide nurses and clinical researchers in understanding how HIV-infected individuals experience and manage their symptoms and how that influences adherence patterns. The Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV) offers a comprehensive symptom management framework. The model links the key concepts of symptom experience, social support, and other influencing factors (ie, demographic and cultural factors) with symptom management and medication adherence to explain HIV clinical outcomes and health-related quality of life (HRQOL).

The SSMM-HIV (Fig 1) is derived from the widely used self-regulation theory of Leventhal and colleagues[8] and a critical literature review. This expanded model integrates other models that also partly incorporate Leventhal's model.[8–12] For instance, Reynolds and colleagues introduced a self-regulatory adherence model in HIV that helps clinicians offer effective adherence support to patients.[11] The SSMM-HIV differs from these previous models by supporting a broader perspective and, congruent with Leventhal et al, focuses on the individual's perception of illness based on one's specific symptom and other life experiences. A major addition in the SSMM-HIV, different from the other conceptualizations in the literature, is the modeling of social support and symptom experience as separate but interrelated concepts that influence symptom management, adherence patterns, and health-related outcomes. The inclusion of social support as a key concept is one of the important contributions of the SSMM-HIV over other existing HIV symptom management models.[10,12,13]

OVERVIEW OF THE SSMM-HIV

The SSMM-HIV is a recursive model linking the concepts of symptom experience, social support, symptom management, and adherence to the medication regimen, to objective clinical outcomes, and the more subjective HRQOL outcomes. In the SSMM-HIV, symptom experience is related to the way a person views her or his illness, referred to here, similar to that in Leventhal and colleagues, as the illness representation.[8,14] This understanding consists of 2 interconnected processes, a cognitive and an emotional

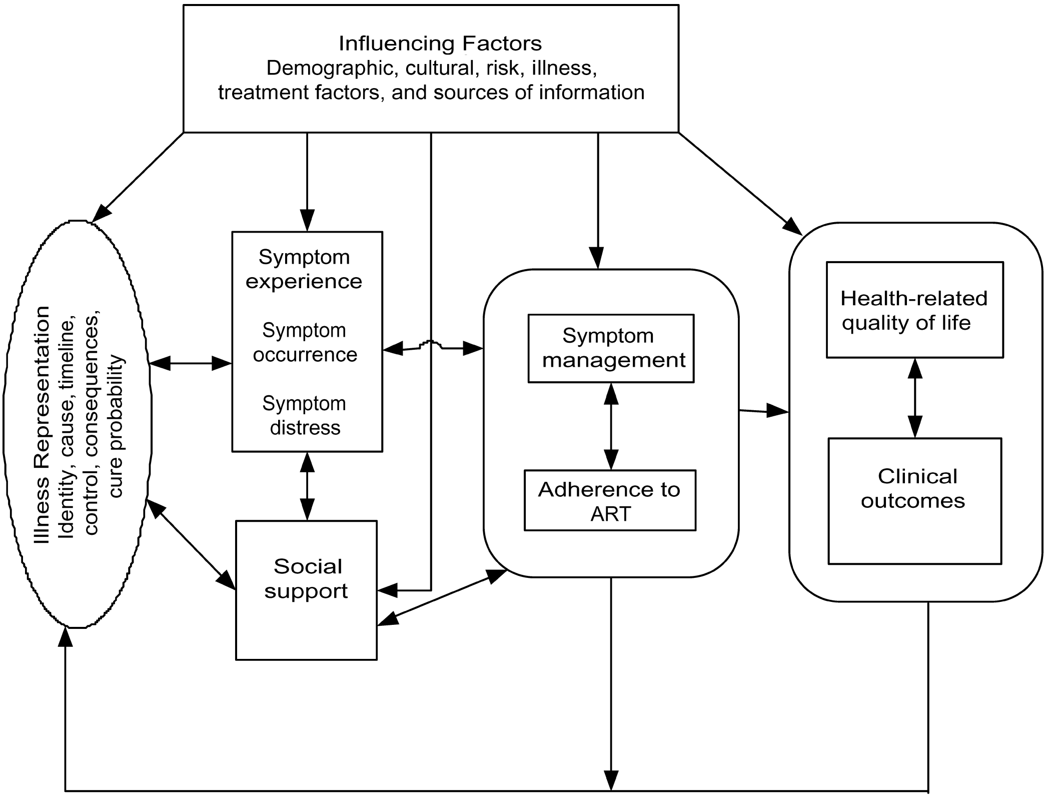

Figure 1. Self-regulatory HIV/AIDS Symptom Management Model (SSMM-HIV).

pathway that result in a patient's symptom experience. Consequently, the SSMM-HIV puts symptom experience in the center and focuses on its relationship to symptom management and adherence to ART. A patient's symptom experience is affected by a number of factors such as age, gender, race, ethnicity, religion, and culture; illness factors such as health status and health-related behaviors; treatment factors; and sources of information such as the media and the Internet.

Congruent with Leventhal's cognitive and emotional processes described above, the SSMM-HIV introduces symptom experience as consisting of 2 different, albeit linked concepts: symptom occurrence and symptom distress. Symptom occurrence largely reflects the cognitive pathway of illness representation and is conceived along the dimensions of frequency, severity, and duration of symptoms. Symptom distress reflects the emotional pathway and refers to the mental anguish or suffering caused by the symptom. Importantly, patients' symptom experiences serve as guides to action and thus determine their health behaviors in terms of how they manage their symptoms and their adherence to ART. Symptom experiences interact with symptom management and adherence to determine a patient's HRQOL and clinical outcomes. The model illustrates how a patient's symptom management influences and is also influenced by adherence to ART and how they together affect HRQOL, virological outcome, and ultimately mortality in the HIV population.

The model of Leventhal and colleagues views social support as a factor influencing people's illness representation and coping.[8,14] The SSMM-HIV, however, proposes social support as an essential factor related to symptom management and adherence. Thus, social support is a major concept in the model. Here it refers to the various resources provided by one's interpersonal ties, such as relatives and friends. These social support sources influence the illness representation and subsequently influence the patient's symptom experience, symptom management, and adherence. Within the SSMM-HIV, social support is seen to play an important role in influencing many outcomes, both directly and indirectly.

As in the model of Leventhal et al,[8] the concept of self-regulation is also important in the SSMM-HIV. The information feedback loop continuously creates a dynamic interplay among all the SSMM-HIV concepts. Within this model, patients have self-regulation mechanisms that provide potential for behavior change. Outcomes can influence the information processed by the patient, possibly influencing a patient's illness representation, symptom experience, symptom management, adherence to ART, and future outcomes.

MAJOR CONCEPTS OF THE SSMM-HIV

Influencing factors

Influencing factors, although not a central focus in the SSMM-HIV, shape illness representations, symptom experiences, symptom management, adherence to ART, and clinical outcomes, including HRQOL. There are a number of influencing factors, such as demographic characteristics and culture, illness factors such as health status and health-related behaviors, and treatment factors, as well as sources of information such as the media and the Internet. These factors have a variety of influences on the central concepts in the model. For example, demographic characteristics such as age, gender, race, and level of formal education have been associated with differences in symptom experience. In one study,[15] middle-aged and older persons with HIV had higher levels of physical impairment than their younger counterparts. Also, female gender was more strongly associated with signs and symptoms affecting physical functioning than was male gender. Persons with HIV who had lower levels of formal education reported higher levels of role limitation and physical constraints related to symptoms.[15]

Illness factors include the stage of HIV disease, co-occurring diseases such as hepatitis C infection, depression, or addictive disorders involving alcohol or injecting drugs. These illness factors may influence the meaning or threats associated with the HIV illness, thus affecting the overall illness representation. Symptom experience may be affected by stage of HIV disease, with occurrences of multiple symptoms and increasing severity of symptoms. Addiction to injected drugs may influence symptom experience through the altered state of consciousness caused by the injection drug effects. Addiction may also influence symptom management and adherence: people in recovery from addictions may be averse to taking prescribed injection medications for HIV treatment as a result of their past addictive behaviors. Research has shown that depression, substance use, stage of disease, and risk behaviors were related to symptom number and bothersomeness.[16]

Treatment factors refer to the quality of patient-provider relationship, aspects of treatment options and the complexity of the ART regimen, as well as the convenience of accessing appointments. These factors are emerging as important correlates to ART adherence patterns and have been a focus of models specific to ART adherence behaviors.[11] In the SSMM-HIV, treatment factors are important through their proposed relationships to symptom experience, symptom management and ART adherence, and ultimately clinical outcomes, including HRQOL. These factors are currently being studied as important variables for intervention by healthcare providers to increase ART adherence rates with the goal of repressing resistant strains of HIV.[11,17]

Illness representation

On the basis of Leventhal et al,[8] the SSMM-HIV proposes that people try to understand their illness by developing an inner model: the illness representation. Illness representation includes the synthesis of information gathered from previous experience, social communication and cultural background, significant others and healthcare authorities, and the individual's present perception of the illness.[8] The cultural background and pictures about HIV/AIDS that are inherent in the social environment of people particularly influence their inner model. For instance, HIV/AIDS is a stigmatized illness and people living with the illness report feeling socially devalued.[18] This affects the illness representation and depends on factors such as the identity and cause of the illness, its consequences, timeline, and the patient's level of control over the illness or cure probability.[14] These emotional and cognitive factors are important. Because HIV/AIDS is characterized by a variety of disturbing symptoms such as diarrhea, fatigue, and depression, and these symptoms vary in their degree of control, duration, and effects, symptoms play a key role in a patient's illness representation. Once a patient perceives a symptom, that symptom will be interpreted on the basis of the illness representation.[9,14] This representation is not static; it changes in response to new illness experiences or information by media, families, friends, or healthcare providers.[8]

Symptom experience

Symptom experience is how patients perceive their illnesses. It refers to patients' responses to the changes in their biopsychosocial functioning and cognition.[12,19] The SSMM-HIV proposes that this symptom experience can be viewed as a function of *symptom occurrence* and *symptom distress*. Symptom occurrence is the presence of symptoms and processes from a cognitive perspective, while symptom distress encompasses emotions associated with the occurrence of symptoms. It appears that the emotional toll from symptoms may be more important to a patient's well-being than the actual frequency and duration of symptoms. Empirical evidence from other chronic patient populations demonstrates that of the 2 components, symptom distress was the stronger correlate of nonadherence with medication regimens and poorer HRQOL.[20] This implies that emotions may play a stronger role in the relationship of symptom experience to adherence in HIV. Despite this observation, researchers focusing on symptom experience in HIV/AIDS have often limited their scope to the study of symptom occurrence,[21,22] leaving the more important aspect of symptom experience, that is, symptom distress, unexplored.

Symptom occurrence

Symptom occurrence refers to the perceived frequency, severity, intensity, or duration of symptoms. Patients typically experience multiple signs and symptoms. Mathews and colleagues[16] found that only 9.1% of the population ($N = 4042$) reported being free of HIV-related signs and symptoms during a 6-month period. Reports of symptom occurrence typically focus on the frequency of symptoms. After initiating ART, fatigue (60% to 80%) and diarrhea (40% to 75%) were the symptoms most frequently reported. The dimensions of severity and duration of symptoms have been less well studied. Moreover, there are problems with the measurement of symptom occurrence in HIV. Many of these studies rely on symptom scales derived from oncology research[23] and only a few address HIV-specific symptomatology such as lipodystrophy and gender-specific concerns such as gynecological symptoms.[16,21] This heterogeneity in symptom scales makes comparison among studies difficult.

Symptom distress

As discussed previously, symptom distress prevails as the most relevant factor in chronically ill patients' symptom experiences because research indicates a stronger relationship with nonadherence and poor HRQOL than does the mere presence and severity of symptoms.[20] Unfortunately, symptom distress has not been studied extensively in the HIV/AIDS population. In one descriptive study, Vogl and colleagues[23] reported that 20% of the patients (*N* = 504) experienced each of 28 measured signs and symptoms as highly distressing. These findings show that HIV patients experienced greater levels of symptom distress than in previously reported distress scores of cancer patients. In a multistage national probability sample of adults with HIV infection receiving medical care at eligible sites in the United States, Mathews et al[16] assessed symptom distress in terms of bothersomeness of signs and symptoms in persons living with HIV (*N* = 4042). The proportion of patients who identified individual signs and symptoms as most bothersome ranged from 37% for white patches in the mouth to 67% for severe headache.

Social support

The structure and characteristics of social networks and social support derived from social networks are increasingly recognized as significant factors in a patient's health and well-being. Social support refers to the various resources provided by one's interpersonal ties in terms of emotional, appraisive, informational, instrumental, and financial support.[24]

Reports from studies of patients living with chronic illnesses show that the availability of social support from a social network, especially a primary support person, is an important determinant of health and well-being. In a large epidemiological study with chronically ill persons (*N* = 10,630), Turner and Marino[25] described a stable relationship with another person as the minimum social network condition needed for experiencing social support. Married people and people in stable partnerships reported significantly more support and lower mortality than their unmarried counterparts. A diversity of family and social network constellations are seen in many individuals with HIV/AIDS.[26] To acknowledge this, within the SSMM-HIV, primary support persons are defined as "individuals who by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need."[27(p36)]

In a study of 11 HIV-family networks, the presence and support of a close and stable person was found to be essential for the general well-being of HIV-infected persons.[28] Similarly, a longitudinal descriptive study using the data of the Swiss HIV Cohort Study (*N* = 5350) demonstrated that the presence of a stable partnership was a significant predictor of slower progression of disease.[29]

Social support and symptom experience

Within the SSMM-HIV, social networks and social support influence the way patients develop and adapt to their symptom experience. For instance, higher levels of social support in HIV-infected persons have been found to be associated with fewer depressive signs and symptoms, fewer unhealthy coping styles, and improved HRQOL. Studies have shown a relationship between poor social support and physiological outcomes, such as a more rapid decline in CD4 cell count, progression to AIDS, and death.[30] However, other studies have not confirmed these findings.[31] The mechanism by which social support works to improve illness conditions is not well established. Social support may directly impact psychological and physiological outcomes or it may work indirectly as a mediator. In a cross-sectional descriptive survey with 101 HIV-infected women, Bova[32] reported that appraisal of illness mediated the effect of social support on adjustment and symptom experience. These findings clearly indicate the important role that social support plays in the symptom management process.

Social support and symptom management

The role of support persons in symptom management is consistent involvement in patients' everyday lives. This includes instrumental support such as cleaning the house and preparing special meals. Emotional support encompasses listening, discussing, and advising. While support persons identify symptom management as one of their major concerns in caring for an ill family member at home,[33] in patients with HIV, there is scant information about how support persons engage in the symptom management process. Very little is known about how they assess a patient's symptoms or how their assessment matches the patient's own symptom assessment. In other chronic illness populations, concordance of patient and family caregivers regarding symptom experience varies, with primary support persons reporting fewer symptoms than patients. In a descriptive study with cancer patients ($N = 207$), the overall accuracy of caregivers' reports of symptom occurrence was approximately 71%.[34] If these results pertain to people with HIV, it underscores the importance of working collaboratively with family/friends of persons living with HIV who are involved in their care so that they are more aware of the patient's symptom management needs.

The SSMM-HIV depicts social support and symptom management as central and suggests involving both patients and support persons in active interactions to achieve good patient outcomes.

Symptom management

Symptom management refers to how the person with HIV makes day-to-day decisions regarding aspects of symptom management, such as when to contact the healthcare provider, when or when not to take certain medications, and whether or not to alter exercise or diet.[35] The patient is central to symptom management because she or he is the one who experiences symptoms related to HIV and ART. A patient's active self-management of symptoms involves both monitoring and managing symptoms. Few studies have been published describing how persons living with HIV develop symptom management skills. A qualitative evaluation of participants ($N = 24$) in a self-management health education program found that after having attended 7 sessions, their active participation in symptom management improved. The skills acquired in the program included monitoring and more actively taking care of oneself.[35]

Most studies have been limited to how persons living with HIV/AIDS manage single specific symptoms such as diarrhea, fatigue, depression, or pain. This single-symptom focus does not address the reality of the majority of persons living with HIV who experience several symptoms and continuously strive to manage multiple competing needs. Studies are needed that investigate the effect of self-management strategies on the entire array of symptoms.

Adherence to Antiretroviral Therapy

Adherence is understood as the extent to which a patient's behavior, such as taking medications or following a diet, corresponds with the agreed recommendations that were collaboratively developed with the healthcare provider.[4] Strict adherence to medication regimens is especially important in HIV. Empirical evidence has demonstrated the negative impact of poor adherence to ART on virus replication, CD4 cell count, and virus mutations producing drug-resistant strains.[36,37] Increasing rates of unprotected sex, a phenomenon called barebacking, make it even more important that viral loads be kept at the lowest level possible so that the likelihood for viral transmission is reduced.[38] Poor adherence is associated with an increase in morbidity, mortality, and healthcare utilization.[37] In the SSMM-HIV, adherence to ART is imperative to symptom management.

In persons living with HIV, the prevalence of nonadherence to ART ranges from 0% to 54%,[39,40] depending on the case-finding methods, operational definitions, and measurement methods used. Adherence is influenced by multiple factors, including the complexity of the regimen, frequency and severity of drug side effects, and tolerability of symptoms.[4,41,42]

Adherence to ART and symptom experience

Adherence to ART is related to the symptom experience in multiple ways. For example, the occurrence of certain symptoms such as nausea, diarrhea, anxiety, depression, confusion, and abnormal fat distribution were significantly associated with poor adherence to ART in several studies.[2,13,41,42] The relationship between symptom distress and poor adherence, however, has not been well studied in HIV. In one descriptive study ($N = 133$), patients with higher levels of symptom distress were less adherent to ART.[35] Although relationships were reported, these studies did not provide information about the exact mechanisms involved. These findings were further supported by Fogarty and colleagues,[17] who found that medication side effects were strongly associated with decreased adherence. Research on other chronic illness populations has indicated that a patient's appraisal of symptom distress is associated with adverse events, which in turn triggers nonadherence.[8]

The SSMM-HIV provides a framework for analyzing the mechanisms of how side effects, associated symptoms, and a patient's previous experience of other symptoms influence patient medication-taking behaviors. Distressing signs and symptoms such as fatigue or diarrhea have a negative impact on HRQOL. For example, patients may decide to adjust their medication regimen or omit a prescribed medication in an effort to control negative symptoms. This was substantiated with a grounded theory study investigating how people ($N = 66$) manage their HIV-related symptoms, medication side effects, and treatment adherence choices.[43] The study results demonstrated that people decided to adhere day-to-day and dose-by-dose, which was influenced by symptom experience and medication side effects. These daily dose-by-dose adherence choices were an important factor in peoples' adherence behavior.[43]

Outcomes

In the SSMM-HIV, outcomes are based on a synthesis stemming from influencing factors, illness representation, symptom experience, symptom management strategies, and available social support. Outcomes are experienced by the patients as her or his current health status (eg, HRQOL) or include the more objective clinical outcomes as virological and immunological status and mortality.

Health-related quality of life

The World Health Organization's definition of health as "a state of complete physical, mental, and social well-being and not merely absence of disease or infirmity" was used as starting point for the definition of HRQOL in the SSMM-HIV.[44] Health-related quality of life describes the subjective appraisal of one's current life by assessing the domains of physical, mental/cognitive, and social functioning. It is HRQOL that is traditionally measured in clinical trials and medical research to evaluate the benefit-burden ratio of new healthcare and treatment modalities. What is of core importance in health-related research is whether or not treatment results in improved conditions for people. Thus, although the HRQOL has been widely studied, due to the complexities and varieties of individual influences determining what constitutes "improved conditions" for people, there is still a lack of understanding about what contributes to positive and negative levels of HRQOL and how these processes work. Thus, it remains an important concept for further study.

According to the SSMM-HIV, HRQOL is viewed as an outcome describing a person's subjective appraisal of her or his current health-related status. A randomized clinical trial[45] ($N = 296$) and 2 exploratory studies[41,46] ($N = 50$ and $N = 118$) found that patients with more signs and symptoms scored lower in HRQOL dimensions. Symptom experiences therefore affect patients' HRQOL, with higher symptom levels having a negative effect. In addition to the number of symptoms, the frequency of symptoms also had a significant adverse effect on HRQOL outcomes. High symptom levels were also related to a faster progression of AIDS, leading to lower HRQOL.[15]

Referring to the SSMM-HIV, not only does symptom experience affect HRQOL, but HRQOL provides feedback and affects awareness of symptoms, symptom experience, symptom management, adherence, and eventually disease outcomes. For example, a patient who attributes symptom distress to effects of medications may turn to nonadherence as a means to enhance immediate factors related to HRQOL.[37] More studies are needed, however, that contribute to a better understanding of how HRQOL is related to symptom management and medication adherence.

Clinical outcomes

Patients' symptom experiences and symptom management are strongly related to HIV-disease progression and clinical factors. Surrogate markers such as HIV-1 RNA viral loads and $CD4^+$ lymphocytes have been found to correlate with therapeutic success or failure and are used to identify disease control or progression.[47] For instance, the prevalence of individual signs and symptoms increased with viral load and declining $CD4^+$ lymphocyte count.[48] According to the SSMM-HIV model, clinical outcomes are affected by and also affect symptom experience, symptom management, and adherence to ART treatment. This bidirectional relationship is substantiated by reports that at earlier asymptomatic stages of the illness, patients' levels of anxiety and depression were similar to those of the general population.[22] At later more symptomatic stages, however, patients were significantly more depressed and anxious[6,22] with rates of depression twice as high as the general population. Furthermore, since patients are required to take multiple antiviral medications for prolonged periods of time, adverse drug-related signs and symptoms such as diarrhea and nausea also increase as the disease progresses.[33]

IMPLICATIONS FOR CLINICAL PRACTICE AND RESEARCH

For nurses, the SSMM-HIV offers multiple entries into the system to assess and assist patients to become aware of their illness representation, to better manage their symptoms and disease experiences and ultimately, to improve HRQOL. When caring for an HIV-infected patient suffering from fatigue or pain, for instance, the nurse can use the SSMM-HIV to be more aware of the links between the symptom experience and management, social support, adherence, and HRQOL. The nurse can bring together patients and primary support persons and assess their symptom management needs. Nurses may educate patients and their support persons about how to monitor symptoms and identify changes in daily-life routines needed to decrease symptoms and increase adherence. In the process of symptom management for instance, it is imperative that nurses thoroughly assess symptom distress in patients, as it is this emotional component that appears to be a stronger correlate of poor adherence with medication regimens and poorer quality of life. In the role of advanced practice, HIV nurses with prescriptive authority may adjust ART prescriptions to simplify dosing schedules or to increase symptom management. Furthermore, they may work toward improving the patient-provider relationship to improve symptom management and increase the likelihood of their patients' achieving the goal of near-perfect adherence to their ART regimens.

For researchers, the SSMM-HIV guides inquiry at the level of the individual and social system. It also links symptom experience and management to adherence and HRQOL, other main aspects in the management of HIV. Since extant research has not thoroughly addressed the contribution of social support to symptom management, research questions at the social level are essential to understand symptom management in HIV/AIDS.[20] For example, a recent study of symptoms and adverse effects of ART reported that coping moderated the relationship between nausea and nonadherence.[49] These findings stimulate further research to explore how coping skills as a component of symptom management relate to levels of social support and adherence. Researchers may use the SSMM-HIV as an organizing framework from which they can study key variables and their interrelationships. Outcomes need to be evaluated that emerge from the symptom experience, symptom management, adherence, social support, and HRQOL perspectives to further test the conceptual framework.

It is not well understood how primary support persons help persons living with HIV in their symptom management process and what both parties need from healthcare providers to successfully manage HIV/AIDS-related symptoms at home. All clinicians, including nurses, need to focus on building the relationship with both patient and primary support person(s). The SSMM-HIV emphasizes effective collaboration among patients, support persons, and clinicians as crucial for symptom assessment and effective symptom management because they are inextricably interrelated.

CONCLUSION

Knowledge generated from this critical review of literature enhances our understanding of symptom management in HIV/AIDS. Clinicians and researchers must reshape symptom management programs to address individual HIV patients and their support persons. Especially important is that nurses and researchers work together to better understand patients' social systems, symptom experiences, adherence levels to therapeutic regimens, and overall quality of life.

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