The Advanced Nursing Practice Team as a Model for HIV/AIDS Caregiving in Switzerland

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To offer advanced nursing care for people living with HIV, a participatory action research project was initiated that enabled constant learning and change at the levels of (a) the culture and organization of an outpatient department, (b) clinical leadership and interdisciplinary collaboration, and (c) development of new services. In this project, the development of the Advanced Nursing Practice (ANP) Team not only affected the practice of individual nurses with advanced degrees but also created a team of nurses educated at different levels. Through a systematic process, the nurses on the team became more educated and refined their clinical expertise. An essential aspect of the ANP Team was the specialization of each nurse in a self-selected topic within HIV/AIDS care. As members of the ANP Team, the nurses offer state-of-the-art nursing care including patient assessment, medication management and adherence support, symptom management, health maintenance and prevention, and family support for persons living with HIV.

Key words: advanced nursing practice, HIV/AIDS, action research

Patients with chronic illness require nursing care that is advanced and specialized. Persons living with HIV have frequent health care visits and need the services of well-educated and skilled nurses. Nurses provide assessment and ongoing follow-up, give support during diagnostic evaluation, and offer education and consultation about medications. In addition, they develop and manage complex treatment plans, provide symptom management, make necessary referrals, and maintain open communication between all members of the health care team, including patients and families.

Traditionally, this care would be provided by nurse practitioners, advanced practice nurses, or clinical nurse specialists who are master’s-prepared professionals (Davis, 1999; Irwin, 1998; Nokes, 2000). In fact, higher education is absolutely necessary as preparation for a nurse practitioner or clinical nurse spe-

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cialist role that includes advanced assessment of patients as well as management of the complex health needs in HIV-infected people. The HIV Outpatient Department at the University Hospital in Basel, Switzerland, however, has a team of nurses with a skill mix that is the result of different educational backgrounds, including advanced practice nurse, clinical nurse specialist, and generalist registered nurses. This team provides nursing services and care to persons living with HIV and their families. The nursing team originally consisted of three diploma-prepared nurses and one nursing assistant. During the past 3 years, the nurses pursued a variety of educational programs that helped them to refine their expertise. Now, they are an Advanced Nursing Practice (ANP) Team. The team is one of the results of an ongoing participatory action research process that sought to enhance nursing care at the clinic. The ANP Team offers a coordinated range of skills, expertise, and clinical experience in a setting of interdisciplinary support. The ANP Team approach is powerful, with highly skilled nursing care being provided for patients and their families.

This article introduces ANP as a team approach. The action research project through which ANP as a team approach was developed and established will be described, educational and research activities of the team will be outlined, and some of the new services that are offered today will be introduced.

HIV/AIDS Care in Basel, Switzerland, and the Need for ANP

In Switzerland, as in other Western countries, HIV/AIDS is considered a chronic illness. Today, approximately 25,000 to 30,000 Swiss people live with HIV/AIDS (Bundesamt für Gesundheit BAG, 2003). Antiretroviral therapy is their standard therapy. Advanced drug therapies have resulted in a longer duration of the chronic stage. The Swiss HIV Cohort Study ($N = 5,156$) documented this trend, with a reduction in the mortality ratio from 19% in 1991 to 62% in 1996 (Egger et al., 1997). Yet treatment advances have raised new concerns and identified needs that are inadequately addressed by current health care programs. In addition, because HIV is being recognized as a chronic disease, the effort of researchers, health care providers, and politicians is not as coordinated as it was in the early days of the epidemic when HIV was acutely lethal.

At the HIV Outpatient Department at the university hospital in Basel, approximately 570 patients are seen each year for primary care. The department offers services to patients and conducts and participates in local, national, and international studies. However, comprehensive nursing care and psychosocial and support services were lacking. For example, HIV-infected patients struggle with a host of signs and symptoms resulting from the infection itself, associated infections, and side effects from medication (Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001; Justice, Rabeneck, Hays, Wu, & Bozzette, 1999; Vogl et al., 1999). Signs and symptoms, though less frequent than during the pre-antiretroviral therapy era, still lack satisfactory management and continue to be a significant problem. At the HIV Outpatient Department, the researchers found that health care providers did not always systematically assess signs and symptoms. For instance, no validated instruments were used for assessment purposes. In addition, the literature finds that adherence is imperative to guarantee effectiveness of antiretroviral therapy in HIV-infected patients (Carpenter et al., 2000; Paterson et al., 2000). The prevalence of nonadherence to combination antiretroviral therapy, however, is estimated to be as high as 54% (d’Armanio Monforte et al., 1998; d’Armanio Monforte et al., 1999; Roca, Gomez, & Arnedo, 2000; Walsh, Dalton, & Gazzard, 1998). Also, patients struggled with the complexity of their medication regimen and medication adherence, but adherence counseling was rarely offered. Further, earlier research shows that availability of social support from a social network—in particular, a close family caregiver—is an important determinant of disease stabilization for HIV-infected people (Spirig, 2002). Yet at the HIV Outpatient Department, services for affected families, partners, and/or friends were not provided.

Current literature shows that components such as self-management support and decision support—but more important, active patient and family that interact with a proactive practice team—improve the management of chronic illnesses (Bodenheimer, Wagner, &
Grumbach, 2002; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The services at the HIV Outpatient Department needed to be tailored in that direction. It was clear that changes were necessary to provide high-quality nursing care in this ambulatory setting.

**Participatory Action Research**

At the beginning of 2001, collaborators from the HIV Outpatient Department, University Hospital, Basel, and the Institute of Nursing Science, University of Basel, initiated a joint project with the goal to offer competent and effective long-term nursing care to patients and families. Supervisors and clinic physicians were supportive of the project from the beginning because it focused on improving HIV/AIDS care.

The project, aimed at practice development, is seen as a continuous process of improvement toward increased effectiveness in patient-centered care. This is brought about by helping health care teams to develop their knowledge and skills and to transform the culture and context of care. It is enabled and supported by facilitators committed to systematic and continuous processes of emancipatory change that reflect the perspectives of service users (McCormack & Garbett, 2000).

**The Participatory Action Research Processes**

To implement and evaluate practice development, participatory action research was used. Participatory action research is an ongoing process that involves all participants in a circular dynamic surrounding planning, acting, observing, evaluating, and reflecting (Lewin, 1946). It generates knowledge about systems while at the same time attempting to promote social and organizational change (Titchen & Binnie, 1994). It results in facilitated change and helps practitioners research their own practice. Stakeholders are included in the process to identify specific outcomes and to generate and test theory (Titchen & Binnie, 1993). The dynamic methodology involves educational methods and diverse qualitative and quantitative research methods for evaluation.

**The Consultant Practitioner**

The action research project was developed and implemented by a doctorally prepared nurse with expertise in HIV/AIDS who served as principal investigator (PI). A graduate nursing student assisted her and gradually became a member of the nursing team during the course of the project. Both served as facilitators in the project. The PI’s role as both project leader and consultant practitioner included enabling the team to achieve a patient-centered, evidence-based, and effective workplace culture. She was also a direct-care provider in the HIV Outpatient Department.

Conceptually, the consultant practitioners used emancipatory and transformational leadership processes. The use of emancipatory processes has been alluded to in facilitating enlightenment and empowerment (Manley, 2000a, 2000b). At the HIV Outpatient Department, these processes included reflection on patient cases in the team, self-reflection of the individual nurses, and using different learning strategies, such as presenting personal actions and receiving feedback from the group members. Transformational leadership processes facilitate participation, involvement, and the development of a shared vision and positive change. Transformational leaders enable others through supporting them to take on challenges and developing ownership to change (Manley, 2000a, 2000b).

At the HIV Outpatient Department, it was the PI’s specialization in HIV/AIDS care that allowed implementation of new knowledge into practice. The consultant practitioners strove toward a transformational culture with high-quality patient and family services and workplace effectiveness; toward empowering staff to enable empowered patients/families and to challenge themselves, others, and the system; and toward practice development, a continuous process of improvement aimed at increasing effectiveness in patient-centered care (Manley, 2000a, 2000b).

**Analysis of Nursing Care: Beginning the Journey**

The first step in the project included analysis of current nursing care delivery at the HIV Outpatient Department. Because the PI had already conducted
research in the areas of illness experiences as well as caring experiences of people living with HIV/AIDS and family caregivers (Spirig, 1999, 2001, 2002), in this study, the analysis of nursing care focused on the perspective of the health care providers. This was accomplished through group discussion, observation, and interviews with nurses and physicians. The analysis revealed the following: (a) nursing practice in the clinic was mostly based on tradition and experience, (b) no conceptual framework was used to guide practice, and (c) a traditional division of labor between physicians and nurses existed. For instance, the nurses mostly followed physicians’ orders and did not think of themselves as being in a position to offer independent services or to successfully use their nursing skills. The nurses’ caregiving was provided in an unsystematic and coincidental way. In addition, most of the state-of-the-art literature was neither known nor taken into account in planning and delivering care. The analysis clearly showed the need for improvements in nursing care.

Developing a New Model for Care

The nursing team critically discussed the analysis of care and decided to choose ANP as the basis of their professional identity and work. The first step was to develop a conceptual definition of ANP for people with HIV/AIDS. For the authors, ANP is oriented toward individuals, families, and groups with care provided according to state-of-the-art knowledge. Research results are put into practice, and nursing services are systematically developed and evaluated (Hamric, Spross, & Hanson, 2000). Attention to caring, evidence, patient preferences, and clinical expertise serve as a basis for a professional identity (Spirig, Petry, Kesselring, & De Geest, 2001). Competencies such as research skills, collaboration, consultancy, leadership, and ethical decision making are also essential (Hamric et al., 2000).

The nurses’ vision was to build a competent and highly skilled nursing care delivery team that provided advanced nursing care. With this model in mind, the nurses started to develop their clinical knowledge and skills by attending continuing education programs to obtain specialist or public health certificates. Ongoing reflection on patient and family situations helped to bridge their experience with the theory they learned in their courses.

The nursing team decided on actions in the following areas:

- Understanding the culture and organization of ANP in the outpatient department;
- Developing clinical leadership and interdisciplinary collaboration; and
- Implementing and evaluating new nursing services.

Culture and Organization of ANP in the Outpatient Department

Patient Centeredness

Essential for the nursing team was that all services placed patients and families at the center of attention. Patients and family members are seen as collaborative partners in care (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Gallant, Beaulieu, & Carnevale, 2002; Powell-Cope, 1994; Spirig, 1999). More specific, patients and families are viewed as experts in their own lives, and the services at the HIV Outpatient Department had to strive toward expert patients and families working collaboratively together with health care providers who are experts about the disease. Working collaboratively means patients/families and health care providers make every effort toward sharing expertise and negotiating care.

Learning to Work Professionally

Professional competence is dependent on learning how to learn, particularly in a changing environment where what is required today is different than what is required tomorrow. Step by step, the nurses started to integrate newly acquired knowledge into practice. This happened through the continuous reflection on patient and family cases. Learning from practice through reflection is an important mechanism for maintaining and acquiring competency and also
patient/family-centered approaches. Helping practitioners to learn and become self-sufficient in their own problem solving is a core purpose of action research (Titchen, 2000).

**Shaping the Work Environment**

Shaping the work environment was another key issue. The nurses needed a forum to discuss how the department should be organized and to scrutinize their routines. New structures were created such as establishing educational and reflective meetings as well as organizational and interdisciplinary meetings. This organizational framework allows time for patient care, clinic management, and ongoing education and time to further develop services.

**Clinical Leadership and Interdisciplinary Collaboration**

**Clinical Leadership**

An important decision in creating the ANP Team was that each nurse would enhance overall knowledge about HIV and in addition, develop in-depth knowledge and clinical expertise in a subarea relevant to HIV/AIDS care. Areas selected included medication management, symptom management with a focus on fatigue, and health promotion and maintenance. This specialization allowed a thorough study and reflection on the state-of-the-art literature and the development of new skills and practice protocols. In the future, it will allow each nurse to become a clinical leader in this specific subarea. Moreover, the individual nurse’s knowledge and skills are continuously shared with the other nurses and allow a variety of expertise within a team.

**Interdisciplinary Collaboration**

To promote and support interdisciplinary collaboration and to receive the necessary support for such a project, nursing managers, physicians, and other collaborators were regularly invited to informational/discussion meetings about the ongoing project. In these meetings, content-oriented and organizational questions were discussed and decisions were made by the group. Because of this collaboration and the appreciation by administration of the value in this new model, it was even possible to increase the percentage of nursing staff at the HIV Outpatient Department. As time went by, the physicians became collaborators in subprojects such as comprehensive HIV assessment.

**Development and Evaluation of New Nursing Services**

Throughout the action research process, several new approaches were identified as crucial in HIV/AIDS nursing management and have subsequently been established and evaluated. These are presented in Table 1.

**Nursing Assessment of Patients**

Based on review of current research and practice experience, an evidence-based assessment guide was developed. It included physical, psychosocial, and behavioral aspects via a translated and validated symptom list (Holzemer et al., 2001), a checklist about medication management and adherence, and open-ended questions about the daily management of the illness by the patient and his or her involved family. With this instrument, patient problems can be assessed regularly, and if necessary, interventions such as further information, education, or counseling can be offered.

The introduction of this nursing assessment made overlaps and gaps of the prior medical and nursing assessment obvious. The nurses realized that synergies were not exploited and information not always exchanged appropriately among health care providers.
Together with the physicians, an evaluation study is being conducted to analyze the information gathered during the first health assessment and physical examination of patients.

**Medication Management**

If adherence problems are identified, counseling is now offered by the nurse with the goal to help the patient improve medication adherence. The nurse begins by systematically assessing the problems a patient may have related to following the medication regimen. By understanding when problems arise, the cultural background of the patient, and aspects within the patient’s daily life that affect medication-taking behaviors, appropriate interventions can be designed and implemented. Depending on the factors influencing adherence, the nurse may simplify and further explain the medication regimen and continue to discuss side effects. For the researchers’ patients, open communication about the difficulties in following the regimen, working together to organize daily schedules, or helping to establish habits such as regularly checking their supply of medication have all been shown to be effective. Family members are invited to adherence consultations, as it has been shown that patients with a good social support system are more likely to adhere to their regimen (Demas, Schoenbaum, Wills, Doll, & Klein, 1995; Eldred, Wu, Chaisson, & Moore, 1998; Gifford et al., 2000; Roberts, 2000; Singh et al., 1999).

**Symptom Management**

HIV-infected patients experience multiple physical and psychological symptoms at the same time. In one survey, the mean number of symptoms was 16.7 (Vogl et al., 1999), although this has been dropping with newer medication combinations. The most frequently reported symptom is fatigue, followed by worry, sadness, and pain (Anastasi & Capili, 2001; Holzemer et al., 2001; Justice et al., 1999; Mathews et al., 2000; Vogl et al., 1999). Symptom assessment is of growing importance in HIV practice and clinical research because limitations resulting from symptoms affect a patient’s functional status, perceived quality of life, adherence to medication, and progression to AIDS.

There is evidence that providers tend to underestimate the frequency and distress associated with symptoms, especially those that may not be readily observable such as fatigue, sadness, and depression (Justice, Chang, Rabeneck, & Zackin, 2001; Reilly, Holzemer, Henry, Slaughter, & Portillo, 1997). In the HIV Outpatient Department, the nurses assess symptoms with a translated, validated symptom list (Holzemer et al., 2001). The ANP Team works collaboratively with physicians in the treatment of many symptoms but offers independent (nursing) symptom management for fatigue, diarrhea, sleep problems, pain, and nausea. In addition, the ANP Team and researchers are implementing an interdisciplinary symptom management study that will involve patients and families. This study will enable the building of interventions on local data and the offering of more comprehensive services.

**Health Promotion and Prevention**

Two practice programs regarding health promotion and prevention were developed to address the needs of the HIV-population: smoking cessation and safer sex.

Because many patients expressed the desire to quit smoking, an evidence-based smoking cessation program was established. The program is based on two intervention strategies that have been evaluated as most effective in the state-of-the-art literature: nicotine substitution and counseling (Fiore, 2000; Rice & Stead, 2001; Zhu, Melcer, Sun, Rosbrook, & Pierce, 2000). Three different interventions are offered: general smoking information, a short intervention, and a long-term intervention (Voggensperger, Nicca, Battegay, Zellweger, & Spirig, 2003). Initial outcome data regarding effectiveness will soon be available.

**Family Assessment and Interventions**

Illness management is increasingly occurring in home settings with diverse members of families providing support and care to the infected person (Brown, 1997; Powell-Cope, 1996; Spirig, 2002). The authors’ qualitative research shows that the presence and support of a close and stable person are essential for the general well-being of HIV-infected persons (Spirig, 1999). Similarly, a longitudinal descriptive study using 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 (Young, De Geest, Spirig, Flepp, Rickenbach, & Furrer, 2004). HIV family caregivers report multiple sources of stress with regard to symptom management and the complexities of the medication regimen, stigmatization, and social isolation (Brown, 1997; Powell-Cope, 1996; Spirig, 2002). They also deal with their own health issues. From professionals, HIV family caregivers mostly need emotional and informational support (Levine, 1990; Powell-Cope, 1995; Ward & Brown, 1994).

In addition to inviting family members to all services, families that express a need for further support are seen by the PI, who has expertise in family care. With a translated family assessment instrument (Wright & Leahy, 2000), family problems are assessed and interventions are offered. Most family interventions focus on information, self-management, and decision-making support.

Building the ANP Team was and is a constant and ongoing effort and continues to be a priority. Through coordination and orchestration of a range of knowledge and skills, expertise, and clinical experience, the ANP Team is increasingly able to offer high-quality care to patients and families. Teamwork allows the coordination of inputs and the sharing of skills and experience in solving the complex clinical problems involved in helping individuals and families live with HIV.

**Conclusion**

Participatory action research processes have enabled nurses at the HIV Outpatient Department in Basel, Switzerland, to build an effective ANP Team, to broaden their knowledge, to develop new skills, and to acquire new roles. This project was possible because every individual considered how and where she or he could make a contribution. The common goal that provided direction was to offer patient/family-centered, competent care. Today, as a team, these nurses offer HIV-specific ANP. Because ANP traditionally has been seen as a role, the ANP Team approach has provided a new perspective for proactive practice and allowed each individual nurse to become knowledgeable in a subtopic of HIV/AIDS. The ANP Team approach helped to integrate nurses educated at different levels. It has allowed expertise and growth and always builds on the orchestrated effort of a team, which can be seen as an enhancement of the current care delivery model with its focus on individuality.

The collaborative framework building on effective teamwork is key and requires responsibility, leadership, and communication. In the future, the ANP Team at the HIV Outpatient Department may even evolve to a new format by initiating interdisciplinary teamwork. In interdisciplinary teams, the different professions agree on goals and coordinate their services toward excellence in treatment and care.

The researchers do not have sufficient outcome data to make effectiveness claims, but their experience attests to the success of the model. In the future, it is hoped that outcome results of the different practice and research programs will provide insights about the degree to which the ANP Team approach is successful by measuring the impact of these updated nursing services on patients and families.

Despite all the successes, there were also some challenges that emerged throughout the project. For instance, with the implementation of new services, there were at times too many initiatives that needed the attention of the nurses. This resulted in many hours of extra work and demanded endurance. Another example was that the nurses, in some cases, underestimated the force of long-lived habits: for example, who sees patients first, or work relationships with physicians and other health care providers. For some programs, it needed an orchestrated strategy and many interdisciplinary discussions to achieve the goal. Overall, the support of supervisors and the interdisciplinary team came through, especially when the increased clinical expertise of the nurses and the success of the services became obvious.

At this juncture (based on the first 30 months of action research processes) increased clinical expertise of individual nurses has been experienced and resulted in the establishment of new patient care services. Individual nurses have specialized in specific aspects of HIV/AIDS care, such as medication or symptom management, and are beginning to demonstrate their expertise. The authors have also experienced an improved work environment. In evaluation interviews, the nurses reported that their work environment has become more interesting, challenging, and supportive.
One of the nurses mentioned that the project has been instrumental in preventing her from leaving the hospital. Improved interdisciplinary collaboration has also been experienced. Today, nurses, physicians, and other health care providers all contribute from their perspective and area of expertise to improving patient management. Collaboration with health care workers across institutional boundaries is perceived as a necessity to achieving good patient outcomes. Finally, action research methodology to develop the ANP Team has been an effective instrument for improving patient services. The authors anticipate that it will help to assure continuous proactive quality management from within the team.

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