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The JOURNAL OF FAMILY NURSING is a peer-reviewed journal publishing scholarly work on nursing research, practice, education, and policy issues related to families in health and illness. Appropriate articles of empirical and theoretical analysis on the subject of family health will also be considered for publication. Both family-as-context and family-as-unit are represented. The journal recognizes a strong mandate to represent cultural diversity and families across the life cycle and encourages interdisciplinary and collaborative perspectives as well as international contributions. Papers will be selected for their scientific merit and creative treatment of significant issues in the field.

One of the objectives of the journal is to establish a forum in which practitioners, educators, and researchers in various clinical specialties and settings can extend the lively debate and begin a more critical dialogue about the family in health and illness.

MANUSCRIPTS should be sent to Janice M. Bell, R.N., Ph.D., Editor, Journal of Family Nursing, Faculty of Nursing, University of Calgary, 2500 University Dr., NW, Calgary, Alberta, Canada T2N 1N4. Fax (403) 284-4803; e-mail jmbell@ucalgary.ca. Submit five copies of your 15-20 page manuscript, prepared according to the guidelines in the 4th edition of the Publication Manual of the American Psychological Association, entirely double-spaced, with all art camera ready. A copy of the final revised manuscript saved on an IBM-compatible disk should be included with the final revised hard copy. Submission to JFN implies that the manuscript has not been published elsewhere, nor is it under consideration by another journal.

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Telehealth: Connecting With Families to Promote Health and Healing

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Telehealth is defined as the provision of health care via telecommunications wherever individuals are geographically separated. In this literature review, we explore the role of telehealth in family care. Telehealth has not been fully examined for its potential to support health and healing in families. Moreover, technological innovation, such as telehealth, presents an opportunity to question concepts and approaches to family care.

Telehealth was introduced to current health care systems in the late 1950s with the initiation of two projects, distance transmission of X-ray images and the provision of live psychiatry counseling across 150 miles (Jutra, 1959; Wittson, Affleck, & Johnson, 1961). In the past decade, the flourishing of telecommunication technologies has
spawned numerous and diverse applications for telehealth. Increased use of telehealth technologies parallels the trends in health care systems toward early discharge and the closing of home health care agencies (Jenkins & White, 2001). Telehealth technology has potential to close the gap between the demand for and availability of home health care (Jenkins & White, 2001; Warner, 1997).

Now a major phenomenon, studies on telehealth technology are reported from around the world. Current literature addresses with whom and in what settings telehealth is used, issues related to feasibility and user satisfaction, benefits, inadequacies, and utility. In this article, a review of the literature alerts readers to the potential of this new technology to support family-centered care.

METHOD

This literature review was conducted using search terms in several databases. The databases included Medline, Cumulative Index to Nursing and Allied Health Literature, HealthStar, PubMed, Sociological Abstracts, PsycINFO, and Family Studies. Search terms were directed toward terms encompassing telehealth and care outside of the hospital (see Table 1). Articles were reviewed for content and methodology and were included for analysis if they described telehealth applications with families or in home settings and if they were case reports, retrospective studies, or prospective trials.

THE TECHNOLOGY

Telecommunications technology used in telehealth varies from the simple radio, telephone, or facsimile machine to the more advanced interactive video system, such as videoconferencing. There are two main forms of telehealth: store-and-forward and real-time interaction. Store-and-forward methods capture still images or information that can be retrieved for later viewing. E-mail represents a common example of store-and-forward, whereby the message is sent for later
review by the recipient; transmission, although rapid, does not need to be live or instantaneous. Similarly, images from radiology, pathology, or dermatology can be sent via a variety of telecommunications systems for review at a later time by a consultant. The other form of telehealth involves real-time interaction, sometimes called live interactive. In fact, telephone consultation, the most commonly used telehealth strategy, is an example of this. The addition of video images expands the range of information and allows participants to see body movements and facial expressions and to receive other data. Real-time interactive systems include videoconferencing, videophones, and specialized telehealth units that combine videoconferencing capability with medical peripheral devices, such as electronic stethoscopes, sphygmomanometers, or endoscopes. For both store-and-forward and real-time interaction, bandwidth is what determines the amount of data that can be sent via telecommunications networks, thus affecting data transmission and image quality.

**SETTINGS AND TARGET AUDIENCE**

The literature shows that telehealth is used across the life course, although many studies focus on pediatric or geriatric populations. Telehealth has applications across all health care disciplines. Telehealth has been extensively reviewed for its role in clinical care, education, and administration, in both acute and chronic conditions (Allen, 1995; Baer, Elford, & Cukor, 1997; Crump & Pfeil, 1995; Goldberg, 1996; Grigsby, 1995; Perednia, 1995). Already used widely for diagnosis and treatment, telehealth’s potential for health promotion is beginning to emerge (Hetherington, 1998). Other researchers have discussed the challenges posed by implementation, evaluation,
and research in telehealth (Bashshur, 1995; Jennett, Hall, Morin, & Watanabe, 1995; Yellowlees, 1997).

Telehealth has moved into the home and is just beginning to extend beyond individual patients to the family and caregivers. Situations where telehealth has been used with family member caregivers include cystic fibrosis (Adachi & Miyasaka, 1996) and dementia (Strawn, Hester, & Brown, 1998; Wright, Bennett, Gramling, & Daley, 1999).

**USER SATISFACTION**

Feasibility of and user satisfaction with telehealth technologies are reported from the perspective of health professionals and patients in diverse settings. At current state of the art, clinicians can be reassured that the technology is capable of delivering sufficiently rich information to support clinic judgments. Current technologies display and transmit high-quality images, sufficient for accurate diagnoses. The increasing reliability of the technology and clinician confidence have catalyzed its widespread implementation.

Across health care disciplines, health care professionals and patients/families are satisfied with telehealth services (Aarnio, Lamminen, Lepisto, & Alho, 1999; Blackmon, Kaak, & Ranseen, 1997; Brennan et al., 1999; Dick, Filler, & Pavan, 1999; Doolittle, Williams, et al., 1998; Doolittle, Yaezel, Otto, & Clemens, 1998; Huston & Burton, 1997; Loane, Corbett, Bloomer, & Eedy, 1998). These studies found that whereas concerns about respect for privacy, perceived specialist comfort, and patient’s own comfort level each independently affected participants’ satisfaction, the technical aspects of telehealth (i.e., image quality, technical interruptions) had no influence. Vesmariovich, Walker, Hauber, Temkin, and Burns (1999) postulated that patients’ satisfaction could be the result of being on their own “turf,” leading to greater personal empowerment and thus satisfaction. Furthermore, a high level of patient and family satisfaction may in fact be due to cost savings (i.e., travel time and money) rather than the telehealth technology itself. Studies noted that patients expressed their appreciation for the opportunity to have this service (Johnston, Wheeler, Deuser, & Sousa, 2000), would gladly participate in telehealth in the future (Wan, Gul, & Darzi, 1999), and would recommend its use to interested others (Aarnio et al., 1999). A minority of patients, however, felt that they would have preferred an in-person

Although most telehealth equipment functioned very well for clinical purposes, a number of studies report technical difficulties, with the majority of problems being image quality, transmission delays, or connection malfunctions (Aarnio et al., 1999; Allen et al., 1996; Mair, Wilkinson, Bonnar, Wootton, & Angus, 1999; Wan et al., 1999; Whitten, Collins, & Mair, 1998). However, some patients did not even notice when video screens “froze” but simply continued with their sessions (Cukor et al., 1998). Technical problems, such as poor images or sound delays, may be more of a problem for the telehealth provider than for the patient (Cunningham, Marshall, & Glazer, 1978). Nevertheless, the comfort level with telehealth among all participants is generally high (Dick et al., 1999; Johnston et al., 2000; Loane, Bloomer, et al., 1998; Pavan-Nickoloff & Sherrington, 1998; Sibson et al., 1999; Whitten et al., 1998).

**BENEFITS**

There are many benefits from telehealth use, particularly savings in cost, time, and travel. Telehealth is cost-effective, yet savings may not be initially realized because of high initial setup costs. Furthermore, the cost-effectiveness is threatened by lack of attention to implementation issues with health professional users (Doolittle, Williams, et al., 1998; Johnston et al., 2000). Nevertheless, with appropriate implementation, ongoing costs of telehealth visits do appear to be cheaper than in-person visits (Allen et al., 1996; Cheung et al., 1998; Dick et al., 1999; Mahmud & Lenz, 1995). When telehealth is working well, considerable time savings have also been noted, including a decrease in the number of in-person medical visits and shorter duration of appointments and throughput time (Brennan et al., 1999; Loane et al., 1999; Mahmud & Lenz, 1995).

Travel costs are dramatically reduced for patients when telehealth is offered either at their nearest health center or doctor’s office or is available in their own homes. Oakley and colleagues (2000) found that patients traveled an average of 271 kilometers to attend a conventional specialist clinic appointment, whereas telehealth patients only traveled an average of 12 kilometers to nearby health centers. Patient expenses include the financial costs of travel, accommodation, wage loss, mental or physical stress or pain, child care expenses, and time.
away from the family support system. Many families using telehealth expressed gratitude for these cost savings (Pavan-Nickoloff & Sherrington, 1998). Thus, telehealth holds promise for improving care delivery, particularly for families who are housebound, live in rural or remote communities, or with limited income.

TELEHEALTH, HOME CARE, AND FAMILY-CENTERED CARE

Telehealth technology has demonstrated user satisfaction and benefits in a variety of health care disciplines in diverse settings. Opportunities and issues for family-centered telehealth care emerge from a review of the literature on telehealth and home-based care and telehealth with caregivers and spouses.

Telehealth has been implemented in home settings primarily for discharge follow-up care and home care for those with chronic conditions. Successful uses of home-based telehealth include supporting the elderly, those suffering from acute conditions, those suffering from chronic illness/disability, and terminally ill patients (see Table 2). Telehealth plays a role in both facilitating hospital discharge and in providing direct home health care. The literature cited in Table 2 targets the patient as the focus of care. It must be noted, however, that home-based telehealth care often occurs within a family setting, suggesting the opportunity to expand from patient-centered care to family-centered care.

One study that focused on patient and spouse care suggested the opportunities for expansion to the family arena. Keeling and Dennison (1995) analyzed the content of telephone follow-up conversations between nurses and discharged myocardial infarction patients and their spouses. These researches uncovered five themes in their work: (a) difficulty accepting changed health status, (b) reports of attempts at risk factor reduction, (c) concern for financial difficulties, (d) dealing with uncertainty, and (e) expression of appreciation for the nurse-initiated telephone call.

There is a paucity of literature, however, describing support to the family as a unit. Although the literature reports home-based, patient-directed telehealth, most of it does not access family-level data. There are only a few articles directly addressing or including the family (see Table 3). Some of this work uses data obtained from family members in situations where the patients may not be able to answer for themselves. This type of reporting was done in studies of pediatrics (Dick
et al., 1999) and elders with dementia (Wright et al., 1999). The foci of these types of studies are telehealth technology and user satisfaction, data often acquired through questionnaires. Although this information is important to the development of telehealth applications, it does not address family health per se. It does suggest that there are opportunities within the setting of telehealth research to extend the inquiry into family.

The potential for telehealth to support families in unique ways is suggested by one case report of mothers of chronically ill children with cystic fibrosis who communicated via a video-based system. The videophone allowed the children to “meet,” the mothers to discuss their feelings, and one mother to demonstrate a new pulmonary physiotherapy to the other (Adachi & Miyasaka, 1996). The ability to transmit images facilitated emotional connections; for one woman, using a videophone meant “smiles of a mother of a child with the

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<th>Authors</th>
<th>Application</th>
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<tbody>
<tr>
<td>Allen, Roman, Cox, &amp; Cardwell, 1996</td>
<td>Home health care, medicine</td>
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<tr>
<td>Bostrom, Caldwell, McGuire, &amp; Everson, 1996</td>
<td>Hospital discharge, medicine-surgical</td>
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<td>Chewitt, Fallis, &amp; Suski, 1997</td>
<td>Hospital discharge, surgery</td>
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<td>Erkert, 1997</td>
<td>Home health care, geriatrics</td>
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<tr>
<td>Infante-Rivard, Krieger, Petitclerc, &amp; Baumgarten, 1988</td>
<td>Home health care, geriatrics</td>
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<tr>
<td>Johnston, Wheeler, Deuser, &amp; Sousa, 2000</td>
<td>Home health care, medicine</td>
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<tr>
<td>Keeling &amp; Dennison, 1995</td>
<td>Hospital discharge, cardiology</td>
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<tr>
<td>Mahmud &amp; Lenz, 1995</td>
<td>Home health care, medicine</td>
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<td>Mair, Wilkinson, Bonnar, Wootton, &amp; Angus, 1999</td>
<td>Home health care, medicine</td>
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<tr>
<td>Miyasaka, Suzuki, Sakai, &amp; Kondo, 1997</td>
<td>Home health care, pediatrics</td>
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<td>Nakamura, Takano, &amp; Akao, 1999</td>
<td>Home health care, geriatrics</td>
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<td>Phillips, Temkin, Vesmarovitch, &amp; Burns, 1998</td>
<td>Hospital discharge, rehabilitation</td>
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<tr>
<td>Phillips, Temkin, Vesmarovitch, Burns, &amp; Idleman, 1999</td>
<td>Hospital discharge, rehabilitation</td>
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<tr>
<td>Piette, Weinberger, &amp; McPhee, 2000</td>
<td>Home health care, medicine</td>
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<tr>
<td>Savage &amp; Grap, 1999</td>
<td>Hospital discharge, cardiac surgery</td>
</tr>
<tr>
<td>Vesmarovitch, Walker, Hauber, Temkin, &amp; Burns, 1999</td>
<td>Hospital discharge, rehabilitation</td>
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<td>Whitten, Collins, &amp; Mair, 1998</td>
<td>Hospital discharge, medicine</td>
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<tr>
<td>Wootton et al., 1998</td>
<td>Hospital discharge, medicine</td>
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same disease are more encouraging than any words.” In another study, Piecuch and colleagues (1983) connected mothers at home with their sick newborns at a neonatal intensive care unit. The analysis was limited to a case control study recording the number and duration of visitation calls to the intensive care unit, which was used to “quantify” contact between the mother and her sick newborn. Results indicated that the videophone mothers made a significantly larger number of calls to see their babies than did the telephone mothers, who could only ask about their babies’ conditions via telephone. This study captures linear data but suggests avenues for exploring the complexities of the interface between families, telehealth technology, health, and healing.

Turner (1996), in his work on health education posthospital discharge, included family members in the analysis, with more than one third of the sample consisting of carers or family members. In this study, nurses used a structured telephone contact system to provide support and reassurance to patients and families postdischarge. Strawn and colleagues (1998) used telehealth to reduce stress levels among family caregivers of dementia patients.

The overall lack of family-level data may reflect an assumption that because telehealth enables a link to the home, it will vicariously support other members of the family system beyond the patient; yet, this remains an unstated and untested hypothesis. Indeed, reviewing the literature on telehealth and families raises several questions. What counts as family-centered health care? Is the inclusion of one family member in telehealth adequate to qualify as family-centered care? Or rather, should telehealth with the patient or selected family members be categorized as home-based care, whereas family-centered care requires an approach that targets the whole family as a social unit in support of the health and healing of individual members? What opportunities to support health and healing are missing if telehealth

### Table 3: Telehealth With Caregivers, Parents, and Spouses

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<th>Authors</th>
<th>Setting</th>
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<tr>
<td>Adachi &amp; Miyasaka, 1996</td>
<td>Home health care, pediatrics</td>
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<tr>
<td>Blackmon, Kaak, &amp; Ranseen, 1997</td>
<td>Clinic, psychiatry</td>
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<tr>
<td>Dick, Filler, &amp; Pavan, 1999</td>
<td>Clinic, pediatrics</td>
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<tr>
<td>Strawn, Hester, &amp; Brown, 1998</td>
<td>Home health care, geriatrics, dementia</td>
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<tr>
<td>Turner, 1996</td>
<td>Hospital discharge, geriatrics</td>
</tr>
<tr>
<td>Wright, Bennett, Gramling, &amp; Daley, 1999</td>
<td>Home health care, geriatrics, dementia</td>
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professionals overlook family care? When providing family-centered telehealth care, how do health professionals ensure that the voices of all family members are part of the discussion between the health professional and the family?

The conclusion drawn from the literature is that there are many unaddressed questions in this aspect of family-centered care that, if addressed, have potential to strengthen and support family-centered practice. Heightened awareness among nurses and physicians who deliver family-centered care regarding emerging technologies may catalyze innovative approaches to family care. Thoughtful, evidence-based applications of telehealth technology conducted by family researchers, such as nurses, have potential to improve family-centered practice. Multidisciplinary or interdisciplinary evaluations of telehealth technology have potential to create the synergy and creativity necessary for developing family health promotion theories relevant to family-centered professional practice across disciplines. Yet, little evidence exists to support family-centered telehealth care, and no theories specifically address family-centered telehealth practice. This literature review points out the way in which an innovation, in this case telecommunications, provides an entrée for new avenues of inquiry into basic concepts relevant to practice within the field.

SUMMARY

Telehealth, although gaining widespread attention recently, has been used for decades by health care providers in professional practice, especially in cases of geographic separation. With the advent of high-speed, high-capacity telecommunications networks, there is new interest in exploring telehealth’s potential to support professional practice, in rigorously studying its application and impact, and in using it as a vehicle to ask broader conceptual questions.

Telehealth can be used across health care disciplines and in innumerable health conditions. Its entrée into the home setting is only just being explored. Even this nascent literature exposes the conceptual blurring between health care brought into the home and health care brought to the family. Telehealth provides an opportunity to examine new ways of providing care and also to ask new questions about how and to whom care is provided. Researchers exploring telehealth’s potential have an opportunity to extend their inquiry much further into broader family health issues.
NOTE

1. Telehealth is the use of telecommunications technology to provide health care information, services, and education over distances. In the literature, there are many terms used synonymously such as telemedicine, teleconsultation, telenursing, or telerehabilitation. This review will simply use the term telehealth.

REFERENCES


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The 24-7-52 Job: Family Caregiving for Young Adults With Serious and Persistent Mental Illness

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Calvin College

Few of the studies focusing on family caregiving have dealt with families caring for a young adult member with a serious and persistent mental illness. This qualitative study expands our understanding of the caregiving processes in these families. The narrative responses of 76 family caregivers from National Alliance for the Mentally Ill chapters across the United States were analyzed using content analysis. Five caregiving processes were identified including monitoring, managing the illness, maintaining the home, supporting/encouraging, and socializing. Family caregivers cited a need for information about the illness and available resources with which to prepare themselves for their caregiving responsibilities. Multiple client outcomes were used by the caregivers to evaluate the effectiveness of their efforts. Comparisons are made between these results and the findings of empirical studies in the broader caregiving literature.

The National Institute of Mental Health (NIMH) (1994) has estimated that there are approximately 5 million Americans with serious and persistent mental illnesses (SPMIs). Between 40% and 60% of these persons either reside with or receive care from their families (Cook, Cohler, Pickett, & Beeler, 1997; NIMH, 1994). This is due to the fact

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that the SPMIs often follow an unpredictable course that includes relapses and frequent hospitalizations, and the current mental health care system has failed to adequately address the service needs of those challenged with these devastating illnesses. Thus, of necessity, a substantial number of family members have assumed the multifaceted role of caregiver to their loved ones who struggle with mental illnesses.

BACKGROUND

The caregiving experiences of families with an SPMI member have rarely been mentioned in the caregiving literature, and thus, this category of caregiver has essentially been ignored (Lefley, 1996). Many of the studies that do exist have focused primarily on the burden associated with the families’ caregiving responsibilities (Cook, Lefley, Pickett, & Cohler, 1994; Jones, Roth, & Jones, 1995; Reinhard, 1994; Ricard, Bonin, & Ezer, 1999). Therefore, little is known about the complexities of the caregiving processes in SPMI families.

Several researchers have expanded our understanding of the context of family caregiving processes. An early study by Chafetz and Barnes (1989) explored issues surrounding psychiatric caregiving by conducting focused interviews with 20 family caregivers recruited from community organizations and clinical services. This research documented problems associated with caregiving, issues related to protracted parenting, and critical sources of support for caregivers. Although these caregivers acknowledged the stressful nature of caregiving, a warmth and concern for their ill relatives were apparent and appeared to mitigate the aversive aspects of their responsibilities.

Tuck, du Mont, Evans, and Shupe (1997) continued this delineation of the context of caregiving processes by exploring the lived experiences of 9 parental caregivers of adult children with schizophrenia. Participants were obtained through referrals from mental health professionals and a National Alliance for the Mentally Ill (NAMI) chapter. The study revealed that a diagnosis of schizophrenia was viewed as a destructive force that interrupted and radically transformed the normative family life trajectory. The caregiving experience was described as a grief-filled one in which the imagined, idealized child was lost and the physically present child was transformed into a needy stranger.
Similarly, Mays and Lund (1999) explored the lived experiences of 10 male caregivers of severely mentally ill relatives, recruited from community mental health centers and a NAMI chapter, by using an informal interview guide that addressed psychosocial, physical, financial, and crisis-management categories. These researchers found themes of burden, commitment, and role affirmation. Relative to these themes, the caregivers experienced decreased levels of stress over time, a long-term commitment to the role based on duty and emotional attachment, and a sense of pride in accomplishment of their roles.

A few researchers have more explicitly explored the actual phenomenon of caregiving processes in SPMI families. An early study by Chesla (1989) explored the lived experience of schizophrenia as understood by the parents who care for these individuals. These parents were recruited from NAMI chapters. Chesla found evidence of four distinct illness models that characterized the parents’ personal understanding of the causes, nature, course, and appropriate treatment of schizophrenia. The models included the strong biologic, the rational control, the normalizing, and the survival-through-symptoms model. Not surprisingly, the caregiving processes that these parents engaged in were substantially shaped by the illness model that they held.

Rose (1998b) conducted an important qualitative study of family caregivers of persons with serious mental illnesses, recruited from two large urban hospitals, in an attempt to increase understanding of the meaning that they assigned to the caregiving experience. Rose’s findings indicated that “caregiving meant accepting a responsibility to influence the impact of the illness on the relatives’ lives” (p. 371). Furthermore, the meaning of caregiving revolved around three concerns. First, caregivers were concerned with finding the essence of the person obscured by the illness and thus worked toward not losing sight of the person beneath the illness. Second, the theme of finding a place for self in influencing the illness emerged and was related to caregivers’ attempts to develop routine responses to illness-related behaviors that would make the illness better. A final theme, helping the relative to move forward, involved focusing on the future by setting goals, sustaining hope, and stepping back.

Schene, van Wijngaarden, and Koeter (1998) also explored family caregiving processes for persons with schizophrenia. Their random sample of 480 caregivers was obtained from the Dutch family organization for persons with schizophrenia. Data were obtained via mailed
questionnaires, and principal component factor analysis was performed. Four caregiving domains were identified including tension, supervision, worrying, and urging. Tension referred to the strained interpersonal relationships between caregivers and their relatives, whereas worrying dealt with painful interpersonal cognitions about the clients’ safety, care, and health. Supervision, on the other hand, included the caregiver’s tasks of ensuring and guarding relative to issues of medication, dangerous behaviors, and rest. Finally, urging referred to activation and motivation of clients to engage in activities of daily living and other activities.

In the broader caregiving literature, an emphasis on family burden is also apparent (Cain & Newsome Wicks, 2000; Sisk, 2000). Several exceptions were noted where the emphasis was clearly placed on understanding family caregiving processes. For example, Bowers (1987) explored the caregiving of adult children for their aging parents and distinguished family caregiving activities by purpose rather than task. Five conceptually distinct categories of family caregiving, including anticipatory, preventative, supervisory, instrumental, and protective care, were identified.

Schumacher, Stewart, and Archbold (1998) spoke of the fact that the concept of “doing caregiving well” was just beginning to be explored in the nursing literature, and thus, there is a lack of clarity as to the meaning of this concept. In an effort to develop this concept, family caregiving for cancer patients was examined by interviewing the patients as well as their primary caregivers (Schumacher, 1996; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Using qualitative analysis, the concept was defined as the “ability to engage effectively and smoothly in nine core caregiving processes” (Schumacher et al., 2000, p. 199). These nine core caregiving processes included monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system (Schumacher et al., 2000).

Preparation for families assuming the caregiving role is an underexplored area in the caregiving literature as well. It appears as though many families are thrust into the role without the prerequisite information and training. Although some psychoeducational programs for SPMI families have been developed, tested, and found to produce positive outcomes (Dixon & Lehman, 1995), Lefley (1996) identified a “notable lack of information and help from the treatment system” (p. 7) for families dealing with behaviors associated with
serious mental illness. In the broader caregiving literature, preparation is a concern as well (Brereton, 1997; Levine, 1998). Specifically, caregivers for persons with a variety of chronic, physical illnesses spoke of feeling unprepared, both technically and emotionally, for their caregiving responsibilities (Levine, 1998). Some empirical work has been directed toward increasing the level of preparation for caregivers of older adults (Archbold et al., 1995).

When reviewing the empirical research related to family caregiving, it is important to make a distinction between family-related research and family research (Feetham, 1991). Family-related research derives data from individuals and explores relationships among family members, whereas family research focuses on the family unit as the entity of investigation (Feetham, 1991). Conceptualizations and definitions of family must correspond with the type of research being conducted (Feetham, 1991). Although some of the family caregiving research is explicit about the perspective taken and the definitions used, other studies are less clear.

Thus, the caregiving research is limited in terms of studies that clearly delineate the type of family research that is being conducted, those that explore family caregiving in families with SPMI members, and those that approach this phenomenon from a process orientation. Therefore, using a family-related approach where the parental care providers’ perspectives are captured, this study investigated the processes of family caregiving in SPMI families, including issues of preparation, quality of care, and professional understanding. Such an explicit focus on the actual caregiving processes in SPMI families has only been addressed in a select number of studies to date.

METHOD

This qualitative research was part of a larger, quantitative investigation examining factors contributing to family health in caregiving families. Simultaneous methodological triangulation (Morse & Field, 1995) was used to obtain a richer perspective on the interface between family caregiving processes and family health in families with a young adult member with an SPMI. This article focuses on a “question analysis” of the written responses of 76 caregivers for young adults with SPMIs to open-ended inquiries about their caregiving experiences (Morse & Field, 1995). Inclusion criteria required that the respondent be a parent and a caregiver for a young adult member
with a diagnosis of schizophrenia, bipolar disorder, or schizoaffective disorder. Participants were recruited from NAMI chapters throughout the United States. E-mail contact was made with the president of the NAMI chapter, and the president solicited volunteers from among group members. Questionnaire packets were either mailed directly to the participant or in bulk to the chapter president who distributed them. Packets included an informed consent form and a stamped, addressed envelop for return of the materials to the researcher.

Respondents were asked to provide narrative responses to four questions related to their caregiving experiences. The questions were as follows:

1. What is involved in caring for your relative who struggles with a mental illness?
2. What type of information did you need as you learned to care for your relative? Where did you find this information?
3. How do you know when you are doing a good job caring for your relative?
4. What do you wish mental health care professionals understood about the experience of caring for a relative with a mental illness?

Following receipt of the narrative data, participants’ responses were transcribed from the actual questionnaires and sorted by question. The question sort provided four a priori categories into which the family caregiving data were organized: processes, preparation, competence, and professional understanding.

At this point, Morse and Field (1995) suggested that a question analysis is similar to a content analysis. Therefore, all responses to a question were read in their entirety, treating each separate idea as a distinct data element. Preliminary themes were identified by reading each element in the context of the complete narrative. The process of identifying preliminary themes was facilitated by use of the Ethnograph V5.0.

In an attempt to enhance the trustworthiness (Lincoln & Guba, 1985) of the study, two procedures were used. First, an attempt was made to ensure neutrality (Lincoln & Guba, 1985) by circulating the elements and preliminary themes to the other members of the research team for evaluation of the fit between the element and the corresponding theme. In addition, the thematic label was evaluated to ensure clarity. Second, the preliminary themes were shared with two parents who functioned as family caregivers to a young adult
with an SPMI to determine the credibility (Lincoln & Guba, 1985) of the results.

Pertinent sample characteristics are listed in Table 1. The family caregivers were primarily female, middle-aged ($M = 55.80$ years, $SD = \pm 9.84$), and highly educated ($M = 15.63$ years of education, $SD = \pm 2.7$). The clients were young adults ($M = 29.76$, $SD = \pm 6.38$) and had been ill an average of 9.21 years ($SD = \pm 3.12$).

### RESULTS

The results will be presented in terms of the a priori categories that were used to obtain and analyze the data. Each category will be presented in terms of the themes derived from the content analysis.
Caregiving Processes

The content analysis revealed five major caregiving processes in operation in families with a relative with an SPMI. Caregivers were involved in monitoring, managing the illness, maintaining the home, supporting/encouraging, and socializing.

Family caregivers engaged in monitoring that can be understood as “making sure.” They monitored for medication compliance, presence of symptoms, and attendance at appointments, as shown in the following statement.

I have to make sure that he goes to all of his appointments and takes his medication as he is supposed to (time and dosage). I have to watch that the prescription doesn’t run out. I always observe his behavior to see if he is getting sicker.

Family caregivers took an active role in managing the illness as well. This aspect of caregiving encompassed the process of attending to those needs that were specifically related to the mental illness. The following statement illustrates how one family operationalized managing the illness.

I take him for lab work and attend appointments with him. . . . I call his case manager, doctors, and nurses to see that he’s getting good care. . . . I set up his medications. . . . There is a lot of paperwork that needs to be kept up with and I need to do that. . . . He has taken overdoses of aspirin so we have to keep everything locked up.

At times it was necessary to assist with personal care.

I have done everything from bathing her to deciding what she should wear. She can now do her hygiene most of the time.

The family caregivers also took an active role in maintaining the homes of their relatives struggling with mental illness. This was a multifaceted process that involved helping with routine household chores as well as providing critical support in the area of child care for dependent children of the ill young adult. This aspect of caregiving appeared to be operational whether the ill relative lived in the family home or outside.
She is often not capable of making a meal, cleaning the house, picking up after herself, buying groceries, or doing her laundry. . . . I help with managing finances—budgeting, paying bills and balancing the checkbook. . . . I often need to transport her because she doesn’t have a car.

We are regularly involved in caring for her children (our grandchildren). Sometimes we have responsibility for them for extended periods of time. We try to provide stability and consistency for them.

The families saw supporting/encouraging as an essential caregiving process. This component of the caregiving role was operationalized via telephone, e-mail, or face-to-face contact. All methods of contact were used to enhance and fortify the client.

I function as an overall support system . . . so I make sure to talk to him daily by phone. . . . I try to support and encourage him in his efforts to be self-sufficient. . . . I try to give positive feedback for the things he is able to do. . . . I’m there for him when he’s struggling. . . . I am available to him when he needs to talk.

The final caregiving theme was that of socializing. Socializing focused on the provision of social activities for the purpose of structuring time in a positive manner. This is seen in the following statements.

We try to spend as much time with him as possible—going to the movie theater, restaurants, etc.

We have family dinners and play ping-pong. . . . He goes out for coffee with his father.

We go for walks. . . . We try to keep him occupied so that he doesn’t smoke four packs a day or drink Coke so much.

Preparation for Caregiving

Families identified a need for an array of information to equip themselves for their role as caregivers. Much of the desired information pertained to the illness itself. For example, the need for specifics related to the diagnosis and prognosis was prevalent, as illustrated in the following statement.
We need information about the illness itself and what to expect next. What we have been told is just some general information and that it affects everyone differently so it’s just a guess as to what will happen next.

Predictably, the family caregivers also wished for information related to psychotropic medications.

We need an explanation of the medications. How long does it take for medication to start working? Does a relapse occur when the person is on medication? What are the side effects of medication? What do you do about non-compliance?

Information pertaining to the development of interventions for dealing with symptoms was also a need expressed by the families.

How do you deal with anger—like when he just went off on me? I don’t know what to do when he is silent, withdrawn, or has erratic behavior. How am I supposed to react when he has hallucinations, delusions, and paranoid ideas?

In addition to illness-related information, the family caregivers desired greater knowledge of the resources available to them and their ill relatives and how to access them.

We needed to know where to go and how to go about getting services such as support groups, therapy, public aid, SSI [supplemental security income], rehabilitation, and vocational training.

Finally, some family caregivers gave indication of the breadth of information that they needed, as shown in the following statement.

We needed to know EVERYTHING! We previously had no clue about schizophrenia.

Families employed multiple methods of obtaining the information that they deemed necessary. The most frequent source of information was family support groups or family educational programs conducted by NAMI. Families also did their own research using books, magazines, and newsletters as well as Internet sites. Mental health professionals were the final and least cited source of information.
Competence in Caregiving

When asked about competence in caregiving, families cited a variety of client indicators as outcome data. Many of these indicators related to a theme of client stability. Caregivers felt as though they were successful and effective in their caregiving role when the client demonstrated stability along several dimensions including medication compliance, independence, productivity, symptom control, communication with social network, and happiness. These aspects of stability are seen in the following statements.

Twenty-four hours passes and we don’t go to the hospital or the police don’t come here.

When he takes his meds.

When she lives on her own without any crises and her reliance on us decreases.

When he is in remission and can sometimes work or take classes.

He laughs, jokes, he’s happy! . . . When we can all sit and talk openly.

Some family caregivers spoke of their own internal cues that led them to believe that they were effective in their role as a caregiver.

We go by how we feel we’re doing . . . We are caring people and only doing good for him.

It was interesting to note that another prevalent theme relative to competence in caregiving was uncertainty. In spite of the significant commitment that caregivers made to their role and its accompanying responsibilities, they remained unclear about the effectiveness of their efforts.

I don’t know when I’m doing a good job. I take each day separately and hope that tomorrow won’t be the day that I’m dreading.

I’ve only felt I’m doing a good job for moments . . . especially early on.

Most of the time I don’t know if I’m doing a good job or not . . . I don’t really know that I make any impact at all . . . I just do the best I can.
Professional Understanding of the Caregiving Experience

Four major themes emerged relative to what family caregivers wished mental health professionals understood about their experiences. First, the families felt the need for greater understanding of the impact of the mental illness on the entire family unit. Some families spoke globally of the difficulties, as seen in the following segment.

It (mental illness) has a devastating effect on the whole family. . . . It can destroy the family.

Others were more specific about the areas of impact.

Everything is disrupted in an ordinary life. This includes daily schedules especially sleeping, work, family relationships, health of family, friendships, even neighborhoods.

The second theme pertained to the desire for professionals to understand the caregivers’ need to be included in the treatment planning process. Some family caregivers expressed this in terms of their right to inclusion.

Families are frequently the primary care provider and therefore have a place at the table in all decision making. . . . We are as much a part of the process as the client. This is a family disease like other chronic illness.

Others spoke of the benefits that could be derived from greater inclusion.

We can supply essential information, often not available otherwise, on our relative’s condition.

The third theme that emerged relative to the family caregivers’ wish for understanding related to the amount of time that they devote to their caregiving responsibilities.

The family works 24 hours a day, 7 days a week, 52 weeks a year. We don’t work an 8-hour shift and then go home—away from the client. We are always “on call.”

Finally, the families sought understanding of the primary emotion associated with the caregiving role.
The overarching thing associated with these responsibilities and activities is frustration. We experience frustration at all levels...frustration with the illness, the symptoms, our daughter, the system.

DISCUSSION

Similarities to previous work were documented in this study of families with a member with an SPMI. First, and perhaps most important, caregivers for persons with SPMI described purposeful processes of caregiving rather than a set of specific tasks. Several of these processes could be linked to previous empirical findings. Monitoring, as it was described in this study, appears to be analogous to the supervision of persons with mental illnesses by their caregivers described in Schene et al.’s (1998) work as well as the monitoring described by Schumacher et al. (2000) by caregivers for their loved ones with cancer. The overall process of managing the illness may be regarded as the mental health equivalent of providing hands-on care (Schumacher et al., 2000) or instrumental caregiving (Bowers, 1987). In addition, the component of managing the illness in which caregivers ensure adequate care is similar to Schumacher et al.’s (2000) negotiating the system. Furthermore, supporting/encouraging may parallel Bowers’s (1987) protective care where the focus was on safeguarding the self-esteem of the care recipient.

The most unique caregiving process identified in this study, as compared to the existing family caregiving literature, was that of socializing. The focus on structuring time in a constructive manner via social activities is, no doubt, specifically related to the nature of mental illness. The negative symptoms of schizophrenia (Stuart & Laraia, 2001) involve difficulties engaging in goal-directed behavior as well as difficulties maintaining social contacts.

The caregiving families in this study outlined extensive needs for information with which to prepare themselves for their caregiving role with a loved one with an SPMI. This desire for information has been cited previously in the SPMI literature (Ip & Mackenzie, 1998; Rose, 1997, 1998a), and three of the four topics (illness information, interventions for dealing with symptoms, and identification of resources) identified by the respondents in this study have been previously set forth as essential for caregivers of persons struggling with mental illness (Rose, 1998b; Winefield & Harvey, 1994). Interestingly, the families in the current study tended to obtain necessary informa-
tion from caregiving peers and independent research more frequently than from mental health care professionals. This coincides with Lefley’s (1996) observation that the treatment system has had limited involvement in the provision of information and assistance to SPMI families. It will be important for mental health care professionals to take an active role in delineating and providing the specific type of information that will be most useful to families caring for a mentally ill member.

This desire for information is operational in the broader caregiving arena as well. Schumacher et al. (2000) identified accessing resources as one of the caregiving processes that families used when caring for a loved one with cancer. Accessing resources included “obtaining what was needed to provide care, including information . . . help from community agencies . . . ” (p. 198).

When asked about competence in caregiving, the families identified an array of client indicators or outcomes that they used to evaluate their efforts. This paralleled the work of Schumacher et al. (2000), who labeled caregiving as effective “when it led to the best possible outcomes of care” (p. 199). The theme of uncertainty about effectiveness of caregiving efforts coincides with the work of Mishel (1990), who spoke of the continual uncertainty associated with chronic illness. Such uncertainty may suggest a role for mental health professionals. Mishel suggested that nurses assist chronically ill clients in developing a probabilistic worldview where uncertainty is seen as natural and can be used as a positive force in one’s life. Other empirical studies have shown that the uncertainty associated with chronic illness can be effectively reduced by means of nursing interventions (Ritz et al., 2000; Santacroce, 2000).

The caregiving families wished for mental health professionals to enhance their recognition of several issues. They spoke eloquently and consistently of the tremendous impact on the family, the associated frustration, and the time commitment that a mental illness exacts from the family unit. Although this has been previously outlined in the literature (Cook et al., 1994; Jones et al., 1995; Ricard et al., 1999; Tuck et al., 1997), positive aspects of caregiving, not noted in this study, have also been documented (Chafetz & Barnes, 1989; Mays & Lund, 1999). It is possible that the specific questions asked or the manner in which they were posed may have contributed to the limited variability evident in the responses. Caregivers were not explicitly asked about the rewarding aspects of their caregiving experiences and may have been less likely to write about a related but unsolicited...
topic than to weave it into discussion in a focus group or interview. The families in this study also desired involvement in the treatment planning of their ill relatives, which is analogous to the previously documented call for affirmation, respect, and recognition of the significance of their role (Levine, 1998; Rose, 1997, 1998a).

The limitations of this study can be found in several areas. First of all, the respondents were members of NAMI family support groups, and, as such, they may differ in significant ways from the larger population of family caregivers for SPMI clients. They have explicitly sought out the resources offered by NAMI, which might indicate that they are either greatly affected by the illness or highly invested in advocating for the mentally ill. Furthermore, the caregivers were predominately mothers of the clients. There has been a call for broadening the understanding of caregiving experiences with SPMI clients by giving more attention to the experiences of male caregivers (Mays & Lund, 1999). Another limitation lies in the actual method of data collection. Soliciting handwritten responses to structured questions may result in somewhat truncated data and does not allow for interaction between the researcher and informant for the purpose of clarification and accurate interpretation.

CONCLUSION

A look at the caregiving processes of SPMI families allows us to expand our understanding of the uniqueness of this group of informal caregivers. In addition, such research enables us to identify commonalities in caregiving processes between client populations and, in so doing, allows us to move logically toward consolidation of the existing empirical findings. Such consolidation can strengthen the foundation for future intervention studies with family caregivers.

REFERENCES


Mary Molewyk Doornbos, Ph.D., R.N., is a professor of nursing in the Department of Nursing at Calvin College in Grand Rapids, Michigan. Her research continues to focus on family caregiving in the families of persons with serious and persistent mental illnesses as well as on interventions that would support these caregivers. Dr. Doornbos’s recent publications include “The Problems and Coping Methods of Caregivers of Young Adults With Mental Illness” (1997) in *Journal of Psychosocial Nursing* and “The Strengths of Families Coping With Serious Mental Illness” (1996) in *Archives of Psychiatric Nursing*.
Family Functioning and Motivation for Childbearing Among HIV-Infected Women at Increased Risk for Pregnancy

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This study examined family composition and functioning in a cohort of HIV-infected women of reproductive age living in the southern United States. Participants were predominately single (82.2%), African American women (86.7%) with annual incomes of less than $10,000 (65.5%), with a mean age of 31.2 years. Using the Family Apgar Scale as a measure of perceived family functioning, women reported that their families functioned moderately well. Multiple regression analysis showed that level of education, life satisfaction, and coping through avoidance and coping by seeking social support were positively associated with family functioning. In contrast, a history of interpersonal verbal violence and a history of drug use were negatively associated with family functioning. These six factors accounted for 26% of the variance. Study findings support the need for comprehensive nursing interventions that include addressing family issues if HIV-infected women are to be provided quality care.

HIV/AIDS is increasing rapidly among women of reproductive age (Centers for Disease Control and Prevention [CDC], 2000; Klirsfeld,
The increase in cases of HIV/AIDS has been particularly dramatic among African American women living in the southern United States (CDC, 2000; Rosenberg & Biggar, 1998). For women of childbearing age, a diagnosis of HIV infection not only represents a potential loss of health to a life threatening disease, but it may also alter their most intimate family and partner relationships. Furthermore, because HIV infection can be perinatally transmitted to a baby, a diagnosis of HIV disease may be an important factor in women’s decisions to become pregnant and deliver a baby. Motivation for childbearing for women with HIV/AIDS is complex and can be influenced by intense emotional factors, powerful family influences, and social pressures that are often culturally based (Miller, 1994, 1995).

Despite the potential of transmitting HIV infection to a baby, research has shown that an HIV-seropositive status is not the decisive factor in a woman’s decision to have a baby (Ahluwalia, DeVellis, & Thomas, 1998; Murphy, Mann, Keefe, & Rotheram-Borus, 1998; Sowell & Misener, 1997). Many women who are HIV infected continue to be motivated to have a baby even after their HIV diagnosis. In previous research examining HIV-infected women’s motivation for childbearing, a woman’s significant other (husbands and sex partners) and other family members have been identified as important in decisions related to childbearing. In fact, in a study of motivation for childbearing by Sowell, Phillips, and Misener (1999), more than one half of the women stated that having a baby would give them someone to love. Furthermore, women in that study identified the desire of a husband or partner as an important motivation for wanting a baby, and they reported that if they became sick or died, their family members would provide their babies with a good home (Sowell, Phillips, et al., 1999). That finding suggests the importance of family in women’s lives and in their decisions to have a baby. For women who lacked the support of their family of origin or who felt rejected by their family, the desire for a loving family relationship motivated them to want to start a family of their own.

Family, as the basic unit of society, provides the framework in which individuals conduct their life activities such as establishing a sense of well-being and responding to stressors such as illness (Hawley & DeHaan, 1996; Walsh, 1996). For women with HIV/AIDS,
family and family functioning might be expected to be paramount in how they respond to HIV/AIDS, including their motivation for childbearing. However, little is known concerning families and family functioning of HIV-infected women. Although HIV serostatus has been shown not to be the deciding factor in HIV-infected women’s reproductive decision making (Ahluwalia et al., 1998; Sowell & Misener, 1997), it is unclear what effects family functioning exerts on HIV-infected women’s motivation to have a baby. Therefore, the purpose of this study was to describe HIV-infected women’s families and family functioning. In addition, the study sought to examine factors associated with positive family functioning and to test the relationship of family functioning and motivation for childbearing in these women.

BACKGROUND

Although the rate of persons progressing to AIDS in recent years has slowed, largely due to better treatment of HIV infection, the prevalence of AIDS continues to rise with approximately 320,000 persons living with AIDS at the end of 1999 (CDC, 2000). In addition, the annual rate of new HIV infections in the United States remains stable at approximately 40,000 new infections (CDC, 1998). Rising numbers of new HIV/AIDS cases are most often associated with drug use and heterosexual transmission, with these new cases occurring in both rural and urban settings. Women represent one of the fastest growing groups being diagnosed with HIV/AIDS. Over the past decade, the proportion of AIDS cases in adult and adolescent females of reproductive age (ages 13 to 49) has tripled (CDC, 2000). By June 2000, approximately 150,000 women between the ages of 13 and 49 had been reported as having HIV/AIDS. This number is acknowledged as being a significant undercount of women in light of the fact that only 36 states in the United States have confidential reporting of HIV infection.

African American women and their children represent a disproportionate number of cases of HIV/AIDS. Whereas African American women represent 13% of the U.S. population (Altman, 1999), they account for more than one half (57%) of women diagnosed with AIDS (CDC, 2000). This trend in cases of African American women continues to escalate, with 63% of the cases diagnosed in women between July 1999 and June 2000 being among African American women.
Likewise, 66% of pediatric AIDS cases diagnosed between July 1999 and June 2000 were among African American children. In addition, the number of HIV/AIDS cases has increased dramatically in the past decade in rural areas, especially in the southern region of the United States (CDC, 2000; Fordyce, Thomas, & Shum, 1997).

Women at the highest risk for HIV infection are more likely to be of reproductive age, live in poverty, and be associated with substance use activities—either using drugs or having a partner who uses drugs (CDC, 2000; Zierler, Witbeck, & Mayer, 1996). Often, HIV-infected women are caregivers for other family members with AIDS and/or single heads of households with dependent children (Persson, 1994; Sabo & Carwein, 1994; Sowell, Seals, et al., 1997). Already, these women are likely to be stigmatized due to race, poverty, and/or association with drug use. Women who are involved in drug use may be particularly isolated from caring relationships and be consumed by shame and disconnectedness (Kasl, 1990). A diagnosis of HIV infection can intensify this stigma and lead to rejection by family and friends. McCain and Gramling (1992) acknowledged that persons living with AIDS may suffer more stigmatization than any other group.

In fact, Herek and Capitanio (1993) have called AIDS an epidemic of stigma that can alter relationships with others. Stigma can emanate from family, friends, lovers, employers, and health care professionals, altering the stigmatized individual’s ability to obtain needed emotional and tangible support, as well as undermining their ability to receive quality health care and maintain a sense of well-being (Leenerts, 1998; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Furthermore, women may retreat from family and social networks to conceal their HIV infection to protect their families and significant others from the stigma of their illness (Sowell, Lowenstein, et al., 1997).

Despite advances in treatment that can decrease perinatal transmission of HIV (Connor et al., 1994), the potential for such transmission can further stigmatize or act as a barrier to social support and health care services for HIV-infected women who desire to have a baby. Yet, women’s views of family and the importance of motherhood are often culturally based (Hogan & Kitagawa, 1985). In many women at risk for HIV infection, motherhood and having a baby are a primary source of self-expression as well as a sign of adulthood and independence (Bowser, 1992; Kurth, 1993). For these women, motiva-
tion for having a baby can be based in strong emotional factors and cultural beliefs.

Many rural, southern African American women have strong ties to their extended families. This extended family is often important in providing support in coping with adverse situations and solving life problems. In addition, family members can be an important source of advice in making important decisions such as seeking health care or having a baby (Gutman, 1976; Lock, 1990). However, HIV/AIDS is a severe distressor that can affect the well-being of the individual and the family (Demi, Bakeman, Sowell, Moneyham, & Seals, 1997; Fleishman & Fogel, 1994). Although Cox and Davis (1999) proposed that there is limited empirical research examining family problem solving, there has been considerable emphasis placed on the importance of problem solving within the context of family functioning. Demi, Moneyham, Sowell, and Cohen (1997) found that seeking/social support was the most frequently identified coping strategy in a sample of 264 HIV-infected women in Georgia. Family and significant others were an important source of such support with many women seeking love, caring, and a feeling of emotional closeness from those important to them.

A large body of research suggests that social support benefits individual and family well-being and enhances coping in stressful situations (Dyson, 1997; Hadadian, 1994; Trivette & Dunst, 1992). For women with HIV/AIDS, obtaining support from family is dependent on their ability to be accepted within the family after disclosure of their HIV infection. It may be important to recognize that for women with HIV/AIDS, family members and other social networks may not be perceived as helpful but rather as a source of physical and emotional abuse. A large number of research studies have shown that women of reproductive age, especially those who become pregnant, can be at risk for intimate partner or family violence (Coker, Smith, McKeown, & King, 2000; O’Campo, Gielen, Faden, & Kass, 1995). Sowell, Seals, Moneyham, Guillory, and Mizuno (1999) reported that in a cohort of predominately poor, African American women with HIV/AIDS, violence was found to be higher than in other populations. The violence reported in their population was primarily at the hands of family including intimate partners and friends. In addition, Rothenberg and Paskey (1995) found that HIV-infected women often report fear of physical violence, emotional abuse, and abandonment related to disclosure of their HIV-seropositive status. This increased risk of violence and abandonment may be the result of dysfunctional
family relationships, the marginalized lives poor women have been forced to lead, or their association with drug use (He, McCoy, Stevens, & Stark, 1998). No matter the reason, those types of life circumstances decrease quality of life by denying women a safe environment where they can talk about their experiences and seek social support without fear of rejection or negative responses by family and others (Campbell, 1990; Nokes, 1995; Ward, 1993).

For the growing number of HIV-infected women living in the southern United States, there is limited knowledge concerning their families and living situations. These women potentially face the conflict of valuing strong ties to family while fearing rejection due to their HIV infection and HIV risk behaviors. This conflict may be stressful for women who more than ever need the advice and support of family to cope with HIV/AIDS. This study seeks to provide an initial understanding of the characteristics of HIV-infected women’s families, women’s perceptions of the functioning of their families, and how, if at all, these perceptions were related to their motivation for childbearing.

METHOD

The data reported in this study were collected in the first of four interviews conducted in a 3-year longitudinal study examining reproductive decision making and factors influencing decisions to take AZT in a group of HIV-infected women at increased risk of pregnancy. The sample for the longitudinal study consisted of 322 women who were recruited from 12 health clinics and community-based organizations (CBOs) serving persons with HIV/AIDS in Georgia, North Carolina, and South Carolina. These clinics and CBOs provide a wide range of health care and social services including antibody testing, primary health care, case management, and support groups. The recruitment of potential participants from these three southern states was particularly appropriate due to the growing number of women of reproductive age being diagnosed with HIV infection in this geographic region of the United States. For the period from July 1998 to June 1999, South Carolina ranked 5th, Georgia 9th, and North Carolina 16th in the number of new cases of AIDS in the United States.
Women participating in the study were of reproductive age and sexually active by self-report. Prior to the study, a series of focus groups was conducted with HIV-infected women of reproductive age in Georgia and South Carolina who were drawn from the same population as the sample for this study. Based on input provided by women participating in these focus groups, study methods were established, study variables were determined, and measures of study variables were refined or developed to assure validity, cultural appropriateness, and relevance of the instruments. When possible, input from the women was directly followed and the women’s actual words were used in developing or refining study measures. Therefore, the study methods and data collection measures used in the study were designed specifically for use in this population to increase the meaningfulness of the results.

Sample

The sample for this report consisted of 275 women enrolled in the larger longitudinal study (N = 322) who responded to at least 80% of the items on the scales measuring the variables of interest in this analysis. Women were included in the larger study if they (a) verified HIV-seropositive status, (b) were 17 to 48 years of age, (c) were at risk for becoming pregnant (i.e., sexually active, no indwelling contraceptive device [e.g., IUD], or not sterilized), (d) were not currently pregnant, (e) had no evidence of dementia, and (f) were English speaking.

Demographically, the sample was predominantly single (82.2%), African American (86.7%) women with annual incomes less than $10,000 (65.5%). The women ranged from 17 to 49 years of age with a mean age of 31.2 years. A majority (67.1%) of the women had completed high school with almost a third (29.7%) of them having some college or being college graduates. The largest number of women (61.1%) reported their current illness status as asymptomatic HIV disease. Approximately 40% of the women had been pregnant since becoming HIV infected. However, only 15 HIV-infected children were reported among all participants. Greater than a third (37%) of the women reported they wanted to have another baby even though they were HIV infected. Table 1 provides a more detailed overview of sociodemographic characteristics of the participants.
Table 1: Selected Characteristics of the Sample (N = 275)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Race</td>
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<tr>
<td>African American</td>
<td>222</td>
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<tr>
<td>Other</td>
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</tr>
<tr>
<td>Age (years)</td>
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<tr>
<td>15-27</td>
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<tr>
<td>28-32</td>
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<td>33-39</td>
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<tr>
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<tr>
<td>Partnered</td>
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</tr>
<tr>
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</tr>
<tr>
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<td>High school</td>
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</tr>
<tr>
<td>Some college</td>
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<td>College graduate</td>
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<tr>
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<td>2.5</td>
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<td>Annual household income</td>
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<td></td>
</tr>
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<tr>
<td>&gt; $10,000</td>
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<td>35.3</td>
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<tr>
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</tr>
<tr>
<td>Unemployment benefits</td>
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<td>AFDC</td>
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<td>Symptomatic</td>
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<td>25.5</td>
</tr>
<tr>
<td>AIDS</td>
<td>37</td>
<td>13.5</td>
</tr>
</tbody>
</table>
Procedure

At each data collection site, female research assistants recruited all women who potentially met study criteria. Potential participants were provided with an overview of the study and the requirements for participation. For women who expressed interest in the study, informed consent was obtained, and a brief screening questionnaire was used to ensure that women met the study inclusion criteria. Data were collected using a structured questionnaire that was read to the participants. Research assistants recorded women’s responses verbatim on the questionnaire. Data collection interviews were conducted at one of the cooperating clinics or CBOs or at another mutually agreed upon site that provided both privacy and comfort for the participants. Women were paid $40.00 at the end of the interview to reimburse them for their time and contributions to the study.

Instruments

Sociodemographic characteristics. Demographic and selected social characteristics of participants were measured using a questionnaire designed specifically for the study. Participants were asked to provide standard demographic data including their age, race, education,
partnership status, religious preference, personal employment status, employment status of others living in the household, and income. Also, participants were asked their total number of children, number of pregnancies and children since being diagnosed with HIV infection, and number of children who were HIV infected. In addition, participants were asked to report their own HIV status (asymptomatic HIV, symptomatic HIV, or AIDS) and if any family members or friends were HIV infected or had died as a result of AIDS. Stage of illness was confirmed using reported CD4 cell counts and symptoms reported in other parts of the survey questionnaire. AIDS classification was a CD4 cell count below 200 cells per mm$^3$ (CDC, 1992). Furthermore, women were asked to indicate how helpful specific groups of family members were in providing tangible support (i.e., money, transportation, baby-sitting or child care, preparing meals, or helping with housework) and emotional support (i.e., love, comfort, and affection) since they had been diagnosed with HIV/AIDS.

*Family Apgar Scale (FAS).* Perceived family functioning was measured with the FAS. Smilkstein’s (1978, 1981; Smilkstein, Ashworth, & Montana, 1982) five-item scale measures satisfaction with family functioning. The concepts of adaptation, partnership, growth, affection, and resolve are measured on a 3-point ordinal scale. The FAS has been correlated with previously validated instruments, with the Pless-Satterwhite Family Index ($r = .80$), and with estimates of family functioning made by psychotherapists ($r = .64$), suggesting the validity of the FAS. For this study, the scale was revised to a 4-point scale ranging from *always* (4) to *hardly ever* (1) to make it consistent with other study measures. A higher score indicates better family functioning.

*Desire to have a baby.* Desire to have a baby was measured with a single item that asked women if they wanted another baby. Responses for the item were no = 1, unsure = 2, and yes = 3. Desire to have a baby in this study was operationalized as an internal emotional force, whereas motivation for childbearing was operationalized as a variety of internal and external factors that influence a woman’s motivation to have a child. Desire to have a baby and motivation for childbearing showed only a moderate degree of correlation ($r = .28$, $p = .00$).

*Motivation for childbearing.* Motivation for childbearing was measured using a 13-item scale developed in the formative phase of the
larger longitudinal study using information obtained in focus groups with HIV-infected women, supporting the validity of this scale (Sowell, Phillips, et al., 1999). Participants were instructed to indicate on a 4-point ordinal scale (strongly agree to strongly disagree) how closely they agreed with a series of statements concerning their potential motivation for having a baby. Scale items included statements such as, “A baby would be a positive influence in my life right now” and “My husband or partner wants a baby.” A higher score indicates a greater motivation to have a baby.

Experience of violence. O’Campo and colleagues (1995) described three types of violence: (a) incidences of psychological violence such as being yelled at, humiliated, or made to feel worthless; (b) physical violence such as being punched or kicked, tied up, or threatened with a weapon; and (c) sexual violence such as being forced to have sex or perform sexual acts against the woman’s will. The eight-item scale used by Sowell, Seals, and colleagues (1999) was developed to measure these types of violence after diagnosis of HIV. In their study, the researchers reported a reliability coefficient of .74 for the subscale to measure physical violence and .82 for the subscale to measure emotional violence. The reliability coefficient for sexual violence was not reported. The items were modified and refined by women participating in a focus group study (Sowell & Misener, 1997) to help ensure face validity and cultural appropriateness. Each item was scored on a 4-point scale measuring the frequency of violence from never (1) to more than five times (4). Summation of the two items related to verbal abuse yielded a total verbal violence score after HIV diagnosis. Likewise, three items related to physical violence and three items related to sexual violence were summed to provide a physical violence and sexual violence score.

Drug history. History of drug use was measured by nine items asking if the woman had used drugs, ranging from tobacco and alcohol to marijuana, cocaine, heroin, or other substances. Women were asked if they had ever used these drugs and if they had used these drugs in the past 30 days. Responses to “ever used” and “used in the past 30 days” were combined to measure drug history. A higher score indicates that the woman had a history of greater use.

Coping. Coping was measured using a 54-item scale developed and tested in a population of HIV-infected women in a 3-year longitudinal
study of the effect of HIV on women and their families (Demi, Moneyham, et al., 1997; Moneyham et al., 1998). Methods of coping measured by the scale included (a) avoidance coping, (b) seeking social support, (c) using spiritual activities, (d) managing the illness, and (e) focusing on others. Participants indicated on a 4-point response scale (never, rarely, often, and always) how frequently in the past 3 months they used specific approaches or ways to cope with having HIV infection.

**Life satisfaction.** The 28-item Life Satisfaction Scale measures on a 10-step Cantril’s Ladder (Cantril, 1965) where the participant is at present, was 1 year ago, will be 1 year from now, and would be if she were not HIV positive. The domains of (a) physical health, (b) relationship with family and friends, (c) mental health or emotional state, (d) financial state (money situation), (e) spiritual well-being, (f) peace of mind, and (g) overall satisfaction with life are measured. The participants were asked to mark where on the ladder they are for each domain and for each time. A higher score indicates a greater life satisfaction.

Table 2 lists the instruments used in this study. In addition, it provides the number of items, potential and actual range, mean, standard deviation, and reliabilities for each instrument used in these analyses.

**Data Analysis**

The sample and selected family characteristics were described using frequencies and percentages. Bivariate correlations were performed among selected variables that have been suggested by the literature as potentially influencing family functioning and motivation for childbearing. First, variables that showed statistically significant relationships at the \( p = .05 \) level with family functioning were entered into a multiple regression model (history of drug use, history of verbal violence, education, avoidance coping, coping by seeking social support, coping by managing the illness, coping by focusing on others, coping by positive thinking, coping by information seeking, life satisfaction, and motivation for childbearing). Next, variables that were significantly related to motivation for childbearing (family functioning; avoidance coping; coping by seeking social support, by focusing on others, and by positive thinking; life satisfaction; age; and desire to have a baby) were tested using a second multiple regression model.
RESULTS

The women in this study reported a moderate level of family functioning. The mean score for family functioning was 13.4 (SD = 5.1) out of a possible maximum score of 20. The most frequent family unit consisted of a single woman living alone (20%) or with dependent children (38.9%) in an apartment (40.7%). One hundred forty-four (68.2% of women with children) had dependent children living at home, whereas 67 women (31.8%) reported having dependent children living with friends or relatives. Only 49 women (17.7%) were living with a husband or male partner. Of those women reporting having male partners either living with them or separately from them, 99 (15%) women reported that their partners were also HIV infected, resulting in a need for women in some cases to give care to their partners. Consequently, 168 (68.6%) of the women reported being the major wage earners in the household. Husbands or partners were identified as the major wage earners by only 12.3% of the women. Thirty-seven women (15.1%) reported that a parent or other family member was the major wage earner in their households. In addition, 143 women reported having had a family member or close friend die with AIDS, and 99 women reported currently having a family member with HIV/
AIDS. As shown in Table 3, women reported that they received the greatest tangible support such as money, transportation, child care, and help with housework from their mothers and children, respectively. Likewise, it shows that the women identified their mothers as providing them with the greatest level of emotional support. The second largest number of women indicated that they obtained the greatest level of emotional support from their husbands or partners.

When examining all types of violence (verbal, physical, and sexual), it was shown that 100% of the women had experienced some type of violence both before and after HIV diagnosis. In examining physical and sexual violence only, it was found that 68% of the women reported having experienced physical and/or sexual violence at some point in their lives. Before HIV diagnosis, 65% of the women had experienced physical and/or sexual violence compared to 33% of the women who had experienced such violence after their HIV diagnosis. Physical and sexual violence before HIV diagnosis was significantly related to physical and sexual violence after HIV diagnosis ($p = 0.47$, $p = .0001$).

One hundred participants (36.6%) reported they had used alcohol or drugs in the past 30 days, suggesting current usage. Of those women reporting current alcohol/drug use in the past 30 days,
89 women (89%) reported using alcohol, whereas 44 women (44%) had used marijuana and 17 (17%) had used cocaine.

To examine factors associated with positive family functioning, bivariate correlations were performed among selected sociodemographic variables and family functioning using Pearson’s $r$ (see Table 4). Variables that were significantly positively related to family functioning at the $p = .05$ level of significance were education, seeking social support, managing the illness, positive thinking, focusing on others, information seeking, and life satisfaction. Variables that were significantly negatively related to family functioning were history of drug use, history of verbal violence, and avoidance coping. These variables were entered into a linear multiple regression model with family functioning as the dependent variable. Variables that retained significant relationships with family functioning were history of drug use, history of verbal violence since diagnosis, education, life satisfaction, avoidance coping, and coping by seeking social support (see Figure 1 for beta weights and $p$ values).

Pearson’s correlations were used to examine the relationships between family functioning and motivation for childbearing. A statistically significant relationship was found between family functioning and motivation for childbearing ($r = .12, p = .04$). To further determine factors influencing motivation for childbearing, bivariate correlations were performed between the sociodemographic factors and motivation for childbearing. Variables that were significantly positively related to motivation for childbearing were family functioning, desire to have a baby, avoidance coping, seeking social support, focusing on others, positive thinking, information seeking, and life satisfaction. The only variable that was significantly negatively related to motivation for childbearing was age (see Table 4). These variables were entered into a linear multiple regression model using motivation for childbearing as the dependent variable. Variables that retained significance with motivation for childbearing were age and desire to have a baby (see Figure 2 for beta weights and $p$ values).

**DISCUSSION**

Several limitations exist in this research. The participants in this study were predominantly African American women living in Georgia, North Carolina, and South Carolina who were currently receiving medical and/or social services. In addition, self-reports of family
Table 4: Bivariate Correlations of Study Variables

<table>
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<tr>
<th>1</th>
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<th>4</th>
<th>5</th>
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<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Family functioning</td>
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<tr>
<td>2. History of drug use</td>
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<td>4. Education</td>
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<td>—</td>
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<td></td>
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<tr>
<td>5. Coping: avoidance</td>
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<td>7. Coping: spiritual activities</td>
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<td>8. Coping: managing the illness</td>
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<td>9. Coping: focusing on others</td>
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<td>.19, .00</td>
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<td>15. Motivation for childbearing</td>
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<tr>
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<td>.02, .81</td>
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<td>−.02, .75</td>
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<td>.03, .67</td>
<td>−.01, .83</td>
<td>.04, .56</td>
<td>−.04, .51</td>
<td>−.13, .03</td>
<td>−.04, .51</td>
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</table>
Figure 1: Regression Model of Family Functioning
Note: $\beta = (p < .05)$

Figure 2: Regression Model of Motivation for Childbearing
Note: $\beta = (p < .05)$
structure and functioning were limited to those characterized by HIV-infected women living in the southeastern United States. Participants may not be representative of women who are not currently receiving health care or social services or who reside in other geographic regions of the United States; therefore, the findings of this study should be generalized with caution. Despite these limitations, the findings of this study provide important insights that can assist in understanding family functioning in a population in which infection is growing exponentially.

Consistent with previous reports of the demographic characteristics of women with HIV/AIDS (CDC, 2000; Zierler et al., 2000), the women in this study were predominantly poor, single African Americans with dependent children living in both urban and rural areas. The majority of the women had completed high school, and a number of them had attended college. Because many women of reproductive age are diagnosed with HIV infection during prenatal care, it was not surprising that approximately 40% of the women had been pregnant since HIV diagnosis. More important, 37% of the women reported wanting another baby, whereas an additional 24.5% were unsure or potentially desired to have a baby. These findings suggest the importance of health care professionals working with HIV-infected women assessing women’s desire for another baby, as well as providing women with factual information concerning perinatal transmission and the need to be closely monitored if becoming pregnant. Nurses who have frequent contact with HIV-infected women may have a unique opportunity to assess women’s motivation for childbearing and provide necessary health education concerning HIV infection and pregnancy that allows women to make informed decisions related to having a baby.

In examining women’s family and living situations, it was found that most of the women headed their households and lived alone or with dependent children. Only 18% of the women lived with husbands or partners. Even when living with a partner, more than one third of the women with husbands or partners continued to be the primary family wage earners. A possible explanation for this finding is that of women with husbands or partners (either living with them or living separately), 15% stated their husbands or partners also had HIV/AIDS, requiring them to provide some level of care for the partner. This statistic is consistent with the findings of Hackl, Somlai, Kelly, and Kalichman (1997) who reported, in their study of women with HIV/AIDS, that often women are the caregivers for their hus-
bands and sex partners from whom they became infected. Although women in this study were adults, 15% of the women reported they lived at home with their parents who provided for the household. In further examining the families of women, it was clear that women and their families had been touched by HIV/AIDS. More than 50% of the women reported having a family member or friend die of AIDS. Furthermore, 35% of the women said they currently had another family member with HIV/AIDS. These findings support the dramatic effect HIV/AIDS is having on families and communities of color. HIV/AIDS is often another devastating problem that families and communities already experiencing high levels of poverty, substance use, and violence have to face (Zierler et al., 2000). Nursing interventions designed to support women with HIV/AIDS will need to be comprehensive and consider the family context in which women live. To provide care and support for women, there will often be a need to assess the family unit in which they live and provide/obtain services for other members of the family.

Even though many of the women do not currently live in traditional families, most come from a cultural background and/or geographic region where family ties are strong. To better explain who the women’s families were, we examined who provided them with emotional and tangible support. As might be expected, for these women, mothers were a primary source of both emotional and tangible support. Interestingly, second only to mothers, husbands and partners were reported as a primary source of emotional support, although they were not a primary source of tangible support. The level of tangible support the children provided to the women in this study and to their families underscores the central role children play in the lives of HIV-infected women. It has not been unusual in our previous research for women to identify their children as their major support and only family.

To examine family functioning, we used the FAS. Although this scale is short and only has one item to measure each of the five constructs of adaptation, partnership, growth, affection, and resolve, it has been found to be a reliable and internally consistent measure of family functioning that is easy to administer in traditional and non-traditional families (Smilkstein et al., 1982). Considering that women were most often living alone and without partners, they reported an unexpectedly high level of family functioning. The high evaluation of their family functioning may be based on their ability to gain adequate emotional and tangible support from their mothers, children,
and partners, or it may be partially a result of their frame of reference about how a family should function. Such expectations of family functioning may be based on their previous experiences and observations within their communities.

Russo, Denious, Keita, and Koss (1997) have found that women who experience domestic violence have lower self-esteem and withdraw from their support systems, including family. Unsurprisingly, in our study, a history of verbal violence since HIV diagnosis was negatively associated with family functioning. This finding underscores the importance of verbal abuse on a woman’s perception of how well her family functions. Likewise, drug use is associated with lower self-esteem and withdrawal from support systems (Hicks, 1984). In fact, it may be that drug use actually is a more significant factor in deteriorating family and intimate relationships than HIV infection. It was not surprising that a history of verbal violence and drug use was negatively related to family functioning or that coping by seeking social support and life satisfaction were positively related to family functioning. The significant negative relationship between drug history, verbal violence, and family functioning found in this study supports the need for nurses to focus on family interventions that address drug use and abuse. Even when women report not living in a traditional family unit, there remains a need to consider the family unit as the women define it in efforts to provide health care and social services. It may be necessary for nurses and social service providers to develop partnerships that can assist women in leaving violent or abusive living situations in order for them to address issues with drugs and maintain their health (Moser, Sowell, & Phillips, 2001).

In looking at the various approaches to coping that an individual may use, coping by avoidance, seeking social support, managing the illness, focusing on others, positive thinking, focusing on the present, and information seeking were significantly related to family functioning. However, only avoidance coping and coping by seeking social support retained significance in the regression model. According to Demi, Moneyham, and colleagues (1997), avoidance coping consists of five strategies to avoid mentally dealing with HIV disease. Avoidance coping can range from passive avoidance (keeping busy) to active avoidance (avoiding all thoughts and reminders of HIV disease). This fact underscores the importance of coping strategies and social support in dealing with stressful situations such as HIV/AIDS (Leserman et al., 2000), especially social support within the context of the family. Interestingly, education was a factor that influenced family
functioning. The fact that the women in this study had a relatively high level of education may have contributed to the family functioning that was reported. Education was also significantly positively related to family functioning even though family income was not related to family functioning. This finding suggests a lack of relationship between education and income in this population.

In the initial examination of the relationship between family functioning and motivation for childbearing, a significant relationship between these two factors was found. This finding suggests the potential importance of family in reproductive decision making. However, when factors related to motivation for childbearing were examined in the regression model, family functioning was not retained. Only age and the woman’s desire to have a baby retained significance. Younger women who had not started a family were more motivated to have a child, underscoring the importance they placed on motherhood (Sowell, Phillips, et al., 1999). Likewise, the relationship between desire and motivation to have a baby suggests the importance of complex emotional factors that influence motivation for childbearing. Further research needs to be conducted to identify emotional, social, and cultural factors that significantly influence an HIV-infected woman’s desire to have a baby. Within clinical settings, these findings support that simply asking a woman if she desires to have another baby may provide a simple way of assessing her motivation for childbearing and her likelihood of becoming pregnant. In addition, this preliminary research suggests that additional research is needed to understand and predict how HIV/AIDS families function. With more in-depth study of these issues, a more complete and complex model of family functioning can be built. However, this work has implications for family nursing practice. The findings of this study underscore the need for interventions designed to strengthen family functioning in HIV-infected women. Interventions for strengthening family functioning include comprehensive family assessments and the development of family-focused health care interventions, linking women and their family members to community resources, and providing mental health services for women and family members that deal with substance abuse counseling and treatment, as well as assistance in coping with HIV/AIDS. The findings of the current study support that the provision of quality health care to women with HIV infection will be most successful if provided in the context of and considering the women’s defined family unit or structure.


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Kenneth D. Phillips, Ph.D., R.N., associate professor, College of Nursing, University of South Carolina, has worked with HIV-infected persons for more than 15 years. His areas of research interest are psychoneuroimmunology, complementary and integrative therapies, and sleep and immunity in HIV disease. His most recent publications include (with R. L. Sowell, Rush, & C. Murdaugh) “Psychosocial and Physiologic Correlates of Perceived Health Among HIV-Infected Women” (2001) in Southern Online Journal of Nursing Research, (with R. L. Sowell, Misener, & Tavakoli) “Levels of Hope in HIV-Infected African-American Women of Reproductive Age” (2000) in Clinical Excellence for Nurse Practitioners.

Carolyn Murdaugh, Ph.D., R.N., F.A.A.N., is professor and associate dean of research, College of Nursing, University of South Carolina. In addition to her research role, her personal research interests are quality of life in chronic illness and family and individual adjustment in chronic illness. Her most recent publications include (with Russell & R. L. Sowell) “Using Focus Groups to Develop a Culturally
Interaction Between Family Members and Health Care Providers in an Acute Care Setting in Finland

Päivi Åstedt-Kurki, R.N., Ph.D.  
Eija Paavilainen, R.N., Ph.D.  
Tarja Tammentie, R.N., M.N.Sc.  
Marita Paunonen-Ilmonen, R.N., Ph.D., M.Ed.  
University of Tampere

The purpose of the study was to ascertain health care providers’ perspectives about interaction with patients’ family members. Data were collected by questionnaire from health care providers who worked in a Finnish acute care hospital (N = 320). The response rate was 51%. The hospital staff perceived the interaction with the patient’s family to be important. Family members were primarily seen as informants of the patient’s condition and family situation, and the interaction was marked by dissemination of information. The support provided by family members to the patient was also seen as important. The interaction with hospital staff was mainly initiated by a family member. Further research should explore family members’ perceptions of the interaction with health care providers to enable comparisons between perceptions. Application of qualitative study methods would also deepen the existing knowledge of the family–health care provider interaction.

The focus of nursing has traditionally been on the individual, although the patient remains a member of his or her family and social

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setting when he or she falls ill and is hospitalized. A family member’s illness influences the whole family and affects all the family members in one way or another (Friedemann, 1995; Friedman, 1998; Wright & Leahey, 2000). Because the family members are individuals, they differ in their experiences and responses to a significant other’s illness (Cray, 1989). Patients and their families may find the hospital setting alien and frightening (Sharp, 1990), and, especially in the case of an acutely ill patient, family members may experience strong fear, which is alleviated by realistic information from nurses and health professionals and the chance to participate in the patient’s care. A family member’s illness may induce stress in the other family members, and this, in turn, often complicates their capacity to absorb information. Family members’ stress also has an effect on the patient, affecting their ability to support the patient. Even if the family functions well, a family member’s sudden illness may render the family temporarily incapacitated (O’Keeffe & Gilliss, 1988).

Interaction between patients, their families, and nurses is one of the cornerstones of nursing. It is important for family members to be able to trust the professionals caring for their loved ones and to be treated individually and humanely (Potinkara & Paunonen, 1996). The family members of a surgical patient are particularly frightened because an illness requiring surgical treatment is often acute in nature, perhaps an accident, and for many people, surgery in itself presents a frightening event.

**PURPOSE OF THE STUDY**

The purpose of this study was to ascertain health care professionals’ understanding of the importance of interaction with the patients’ family members, the frequency and nature of the interaction, and the factors that promote or complicate family-provider interaction in an acute care setting. Interaction, in this study, is seen as an umbrella concept that encompasses personal discussions, written and oral information, and nonverbal communication. Interaction refers to target-oriented cooperation (King, 1981), presence, and involvement in a relationship (Paterson & Zderad, 1976). Health care provider–family interaction aims to promote family well-being (Wright & Leahey, 1999). In a mutual and equal relationship, both parties are experts. The family is an expert on their own life and with respect to their experiential knowledge of the illness. The health care providers, on the
other hand, are experts at understanding the illness experience because of their education and practice experience (Jokinen, 1999). Good interaction involves comprehensive attention to the patient, which also includes the attention paid to the patient’s family in terms of disseminating information and answering questions (Åstedt-Kurki, Paunonen, & Lehti, 1997; Poutala, 1998).

**REVIEW OF THE LITERATURE**

Several nursing studies have been published on nurse-family relationships (Åstedt-Kurki et al., 1997; Bruce & Ritchie, 1997; Chesla, 1996; Jantunen, 1991; Kirschbaum & Knafl, 1996; Robinson, 1996). Dixon (1996) presented a historical overview of the research literature on parent and nurse interaction. The common themes in the studies reviewed were trust, information gathering, participation in care, and decision making. In the past, family members expected to trust professionals; today, trust is viewed as something that is established across a series of interactions. There has been increased emphasis on collaboration and shared decision making between families and professionals.

Earlier research in Finnish hospitals has focused on family members’ need for information and on the significance of information giving (Åstedt-Kurki et al., 1997; Jantunen, 1991). Characteristics of a good nurse-family relationship and factors complicating interaction have been identified. These studies indicated that families need information and that they sometimes had difficulty locating staff members to be able to discuss the patient’s condition. Significant others usually initiated the interaction, and very little information was given spontaneously. There was no peaceful place for discussions available on the hospital units, and hence, the discussions were mainly carried out in corridors or patient rooms. Significant others needed information about the patient’s illness rather than that associated with the hospital unit’s routines and organization. Bruce and Ritchie’s (1997) study revealed that nurses regarded sharing information with families as important but that there was a great difference between the nurses’ actual practice and their perceptions of practice.

The need for information has been shown to be the primary concern for the patient’s family members (Moser, Dracup, & Marsden, 1993). Significant others need honest, reliable, and relevant information about their loved ones’ illnesses. Families have expressed a wish
to be able to talk with the attending physician or nurse at least once in 24 hours, which is not, however, always possible. Nurses and doctors blame their busy work schedules for not having time for the patients’ family members. However, continuity of care is important to patients and their families (Johnson et al., 1998; Wright & Leahey, 1999).

Healthcare professionals are expected to be active and assertive in supporting family members in illness situations. Mutual participation is of importance (Ástedt-Kurki et al., 1997; Henson, 1997; Paavilainen & Ástedt-Kurki, 1997). A positive attitude toward provider-family interaction enhances the interaction (Jantunen, 1991). The health professionals are expected to recognize the value of the family in the patient’s care (Chesla, 1996). One component of a positive attitude is to enable visits to the patient within the visiting hours (Hickey & Lewandowski, 1988). The patient’s family members report appreciation of the health professionals’ interpersonal skills even more than their professional skills (Johnson et al., 1998).

It has been found that provider-family interaction is complicated by busy work schedules, lack of time, and negative attitudes (Chesla, 1996; Hupcey, 1998; Jantunen, 1991). For example, long waiting times and scarce information and guidance impeded the creation of a good interactive relationship (Poutala, 1998). Treating patients like objects and avoidance of direct discussion and eye contact also hampered the establishment of positive interactions. Overemphasis on efficiency manifests itself in haste, excessive concentration on procedures, and ignoring the family’s wishes, thus preventing the creation of a positive relationship between staff and family members (Hupcey, 1998). Healthcare professionals may engage in power games and tend to control interactive situations (Hewison, 1995). Hickey and Lewandowski (1988) found health professionals often perceive their skills to be inadequate when it comes to meeting the emotional needs of families. The patient’s family members may also complicate the creation of a good relationship by covering up matters, concealing relevant information, intervening in the patient’s care in an exaggerated manner, withdrawing from interaction, or showing a lack of confidence in the patient’s care (Hupcey, 1998). According to Bruce and Ritchie (1997), the nurses sensed a lack of accountability and support from other health professionals to incorporate family-centered ideas like sharing information and collaboration with families into everyday practice.
RESEARCH QUESTIONS

1. How important is the interaction with patients’ family members considered by health professionals?
2. How frequently do the health care providers in acute care settings have interactions with patients’ family members, and what is the nature of the interaction?
3. What factors promote and what factors complicate interaction between the patients’ family members and health care professionals?

METHOD

Data for this descriptive survey were collected on five surgical units and in one emergency unit of a university hospital in southern Finland.

Sample

The sample comprised all of the hospital staff on five adult surgical units, a pediatric surgical unit, and an emergency unit (N = 320). The mean age of the hospital staff was 42 years (range 23-59). Women constituted 81% of the respondents. The majority of respondents (81%) were nurses with a variety of educational and practice backgrounds. The respondents were experienced, with 73% indicating they had worked more than 10 years. The mean of the participants’ work experience in health care was 18 years, ranging from 2 to 36 years. More than half (64%) of the respondents worked on an adult surgical unit. Demographic characteristics of the respondents are displayed in Table I.

Data Collection

Data were gathered using a questionnaire constructed from the literature (Åstedt-Kurki et al., 1997; Åstedt-Kurki, Lehti, Paunonen, & Paavilainen, 1999; Friedemann, 1995; Häggman-Laitila & Åstedt-Kurki, 1995; Sharp, 1990; Walters, 1995). The instrument has been used with health care professionals working in acute care settings (neurological, pulmonary, and gastroenterological hospital units) (Åstedt-Kurki, Paavilainen, Tammentie, & Paunonen-Ilmonen, in press). On the basis of pilot testing, two questions were added to the
Table 1: Demographic Characteristics of Respondents (n = 165)

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</table>

Note: Mean age of respondents was 42 years; age range was 23 to 59 years. Mean of work experience in health care was 18 years; the range was 2 to 36 years. Mean of work experience on current unit was 11 years; the range was 0 to 35 years.
instrument and some questions were reworded. The questionnaire contained both open-ended and structured questions. There were eight questions about staff-family interaction, eight questions about personal discussion with family members, four questions about telephone discussions, four questions about written instructions to patients’ families, and four questions about factors that promote and complicate interaction. Demographic data were also collected about the respondents’ age, marital status, education, work experience, and professional title.

Nurses from the hospital units in the sample acted as contact persons in the distribution of the questionnaires. Respondents returned the questionnaire in a closed envelope to the researchers using internal mail. The response rate was 51% (n = 165).

Ethical Considerations

Permission for the study was obtained from the surgical clinic’s management team. Participation in the study was voluntary. The questionnaires were kept in a locked room and were only accessible by the investigators of this study. The findings are being reported in a group form, which makes it impossible to identify individual respondents. The questionnaire was anonymous and did not contain any information by which the respondent could be identified.

Data Analysis

The data were analyzed using SPSS statistical software and were described using frequencies, percentages, cross-tabulations, and chi-square test values. The open-ended questions were analyzed using content analysis and noting the frequency of themes that emerged from the responses (Miles & Huberman, 1994).

RESULTS

Nature of the Family–Health Care Provider Interaction

Hospital staff reported that interactions with family members primarily occurred by telephone (49% of respondents), by personal discussion (48%), and by written material (1%). Two thirds of providers (67%) rated the interaction with family members as “very important.”
Beliefs about the importance of successful dissemination of information, holistic patient care, appreciation of the effects of the illness on the whole family, and successful care postdischarge were identified. One third of providers (29%) rated interaction with family members as “fairly important.” In addition to the reasons cited above, they explained their views by the fact that patients mainly attended to their own affairs. Only a few hospital staff believed interaction with family members was “unimportant,” claiming that the patient, not the family, is the primary target of care (see Table 2).

Hospital staff on the pediatric unit reported knowing interaction with family members as very important more often than did the hospital staff on the adult surgical units and in the emergency unit (p < .05). Female respondents reported family interaction as important

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
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<td>Importance of interaction</td>
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<td>Successful dissemination of information</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Holistic patient care</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Effects of illness on entire family</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Successful aftercare</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Fairly important</td>
<td>48</td>
<td>29</td>
</tr>
<tr>
<td>Patients mainly attend to their own affairs</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Successful dissemination of information</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Successful continued care</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Improved holistic care</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Fairly unimportant</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Primary target of care is patient</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Importance of knowing the family member</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td>33</td>
<td>20</td>
</tr>
<tr>
<td>Successful dissemination of information</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Holistic care</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Successful aftercare</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Fairly important</td>
<td>92</td>
<td>56</td>
</tr>
<tr>
<td>Holistic and family-centered care</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Successful dissemination of information</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Successful aftercare</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Fairly unimportant</td>
<td>32</td>
<td>19</td>
</tr>
<tr>
<td>Treatment periods are short</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Patient is primary target of care</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Unimportant</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
more often than did the male respondents; however, the difference was not statistically significant.

Hospital staff on the pediatric unit deemed knowing the family members very important more often than hospital staff on the adult surgical units or in the emergency unit ($p < .01$). The length of employment also had an effect on opinions about the importance of knowing the patient’s family members. Hospital staff with more work experience reported knowing family members important more than those with a shorter work experience ($p < .01$). Differences were found between nurses and doctors, with nurses more often rating the importance of knowing the family members ($p < .05$). Women were more likely than men to perceive knowing the patient’s family members as important ($p < .01$).

**Quality and Frequency of Interaction**

The majority of hospital staff (86%) reported that their unit had adopted the model of primary nursing. About one fifth (18%) reported that family members’ visits to the patients were restricted. The hospital units in this study had no official visiting hours, but nurses were sometimes forced to restrict the family members’ presence. The restrictions occurred most frequently in the emergency unit ($p < .01$). Reasons given for restricting family members were respect for patients’ privacy (17 respondents), lack of space (14 respondents), procedures that were best performed without the presence of family members (10 respondents), and concern about the negative effect of excessive number of visitors (6 respondents). Reasons given for not restricting visiting hours included unwillingness to limit family members’ visits to the hospital, believing patients need their significant others (32 respondents), operating guidelines set by the hospital (10 respondents), and a belief that unrestricted visiting hours enable significant others’ involvement in the patients’ care (5 respondents).

Hospital staff (67%) reported the most common way they used to contact the patient’s family members was to ask the patient to name his or her contact person. One quarter of respondents (26%) felt that afternoon was the best time for discussions with family members because the daily duties had mostly been done and the afternoon was the most peaceful time on the hospital unit (see Table 3); 14% felt that evening was the best time because, in their opinion, it was the most peaceful time on the unit. Nearly one third of respondents (29%) reported that any time of day was convenient for them. This was
Table 3: Time, Frequency, Duration, and Place of Interaction and Person Initiating Interaction (n = 165)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Best time for discussion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Before noon</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Noon</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Afternoon</td>
<td>42</td>
<td>26</td>
</tr>
<tr>
<td>Evening</td>
<td>23</td>
<td>14</td>
</tr>
<tr>
<td>Any time</td>
<td>47</td>
<td>29</td>
</tr>
<tr>
<td>Missing data</td>
<td>42</td>
<td>24</td>
</tr>
<tr>
<td>Actual time of discussion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Noon</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Afternoon</td>
<td>40</td>
<td>24</td>
</tr>
<tr>
<td>Evening</td>
<td>52</td>
<td>32</td>
</tr>
<tr>
<td>Missing data</td>
<td>64</td>
<td>38</td>
</tr>
<tr>
<td>Frequency of discussions (times per week)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-6</td>
<td>23</td>
<td>14</td>
</tr>
<tr>
<td>3-4</td>
<td>27</td>
<td>16</td>
</tr>
<tr>
<td>1 or 2</td>
<td>56</td>
<td>34</td>
</tr>
<tr>
<td>Less frequently</td>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>Missing data</td>
<td>46</td>
<td>28</td>
</tr>
<tr>
<td>Duration of discussions (minutes)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5</td>
<td>33</td>
<td>20</td>
</tr>
<tr>
<td>5-15</td>
<td>124</td>
<td>75</td>
</tr>
<tr>
<td>16-30</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Place for discussion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s room</td>
<td>86</td>
<td>52</td>
</tr>
<tr>
<td>Unit office</td>
<td>35</td>
<td>21</td>
</tr>
<tr>
<td>Corridor</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Separate room</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Some other place</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Missing data</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Person initiating discussion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family member</td>
<td>96</td>
<td>58</td>
</tr>
<tr>
<td>Respondent</td>
<td>48</td>
<td>29</td>
</tr>
<tr>
<td>Patient</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Another staff member</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Somebody else</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Missing data</td>
<td>7</td>
<td>4</td>
</tr>
</tbody>
</table>

explained by a belief that the hospital unit has an obligation to the needs of patients and their family members (18 respondents) and to honor family members’ irregular working hours (13 respondents).
However, when asked when family member discussions actually occurred, one third of respondents (32%) interacted with family members in the evenings and one quarter (24%) in the afternoon because these were the times when the family members mainly visited the patients.

In terms of the frequency of family member discussions, about one third of hospital staff (30%) reported they met with family members several times a week (see Table 3). The hospital staff of the pediatric units talked with family members more frequently than those on adult surgical units or in the emergency unit ($p < .01$); nurses reported more discussions with family members than doctors ($p < .01$), and women had more discussions with family members than men ($p < .01$). The majority of respondents (75%) reported that the discussions with family members usually lasted 5 to 15 minutes.

The most common location for family member discussions was the patient’s room and the unit office (see Table 3). About half of the hospital staff (54%) were satisfied with the place they used, whereas 41% were dissatisfied with it. Those who felt that a patient room was a good place for discussion explained this as valuing the patient’s presence and involvement (27 respondents) and that it was therefore the most natural place for discussions. The reported disadvantages of using a patient room was that it lacked intimacy (24 respondents) and was busy. Those with busy work schedules spoke in favor of using the unit office for discussions but acknowledged the disadvantage was that it was usually crowded. Using the hospital corridor for family discussions was identified as “natural” but lacked privacy.

More than half of the hospital staff (58%) reported talking to family members in response to the family’s initiative, with only one third (29%) initiating the discussion with family members (see Table 3). The staff of the pediatric unit initiated discussions with the families most often, whereas on the adult surgical units, family members initiated the discussions with hospital staff ($p < .01$). More than half (60%) of the hospital staff reported that the patient was often present during those discussions, and two thirds (66%) felt that the patient should be present during the discussion. The rationale offered was that the discussion is about the patient’s affairs and therefore the patient should be present to participate in the discussion.

The majority of hospital staff (80%) reported they had contact with family members by telephone, and one third (33%) reported telephoning the family several times a week. However, most of the hospital staff (76%) felt that interaction was easier in person on the hospital
The majority of providers (67%) distributed written instructions to patients’ families. Seventy responses indicated that the most important information needed by family members is about the patient’s discharge care and instructions on home care. Thirty five responses indicated the most important information was who to contact in case of emergency. Hospital staff reported that family members also needed information about the patient’s disease and its prognosis (22 respondents) and about various support services (6 respondents). Half of the providers (54%) responded they always discussed written instructions with family members because they wanted to ensure that family members understood the instructions given (21 respondents) and this provided the family members with the opportunity to ask specific questions and hear the rationale for the instructions (24 respondents). One fifth of respondents (20%) reported they discussed written instructions occasionally with family members, usually when the patient had difficulty understanding them (6 respondents) or if the family members happened to be present when instructions were being discussed with the patient (4 respondents).

Factors Promoting and Complicating Interaction

Approximately two thirds of the hospital staff (60%) reported that interaction with the patient’s family members was easy, whereas 10% felt it was difficult. A large number of respondents failed to answer this question about factors that promote or complicate interaction with families. Those who rated the interaction as easy explained this was related to their interpersonal skills and work experience (33 respondents) and by the fact that the patient’s family members were interested in the patient’s affairs. Those who felt that the interaction with family members was difficult explained this was related to the seriousness of the patient’s illness (23 respondents) and the families’ negative attitudes (18 respondents). In addition to this, 4 respondents felt that the hospital unit’s busy work schedule interfered with interaction of the patient’s family.

The majority of hospital staff agreed that the their own behavior, their own openness, and their own friendliness facilitated interaction with family members (see Table 4). One quarter of respondents (26%) disagreed with the statement that a family member’s appreciation for staff facilitates interaction. Respondents reported two other factors
that facilitated interaction with family members: the use of a primary nursing model and the patient’s desire to have family discussions.

The majority of hospital staff (91%) agreed that their busy schedules complicated interaction with family members (see Table 5). Respondents reported that the family members’ shyness in approaching the staff complicated interaction more than the staff’s shyness. More than half of the respondents (65%) reported that shift work complicated interaction with families, and 63% reported that the lack of a suitable place for discussion also complicated discussions with family members. Almost 40% of respondents felt that the seriousness of the patient’s illness hampered interaction with family members.

**DISCUSSION**

The majority of health professionals participating in this study considered interaction with the patients’ family members important. This supports the findings of Bruce and Ritchie (1997) who also found that nurses value sharing information with families. Knowing the family members was also seen as relatively important. These findings are consistent with those by Ponkala, Suominen, and Leino-Kilpi

### Table 4: Factors Promoting Interaction (n = 165)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interaction is facilitated by the fact that the staff offer the opportunity for discussions.</td>
<td>158</td>
<td>96</td>
</tr>
<tr>
<td>Interest shown by family members facilitates interaction.</td>
<td>162</td>
<td>98</td>
</tr>
<tr>
<td>On the unit, friendly attitudes toward family members facilitate interaction.</td>
<td>159</td>
<td>96</td>
</tr>
<tr>
<td>A family member’s appreciation for staff facilitates interaction.</td>
<td>119</td>
<td>72</td>
</tr>
<tr>
<td>Primary nursing facilitates interaction.</td>
<td>153</td>
<td>93</td>
</tr>
<tr>
<td>Attention to significant others as unit policy facilitates interaction.</td>
<td>157</td>
<td>95</td>
</tr>
<tr>
<td>The patient’s wish to have discussions facilitates interaction.</td>
<td>154</td>
<td>94</td>
</tr>
<tr>
<td>The staff’s openness facilitates interaction.</td>
<td>157</td>
<td>96</td>
</tr>
</tbody>
</table>
However, it is still uncertain whether patients, their family members, and health care providers see the interaction in a similar way, especially when research has shown that family members do not necessarily perceive health care provider support as sufficient (Eriksson, 1996; Reardon, 1995).

Liberal visiting policies have been recognized since the 1970s as an important aspect of family-centered care (Dixon, 1996). The Finnish hospital in this study had no official visiting hours, but the hospital staff reported restricting family members’ visits from time to time because of lack of space, because a procedure was being performed on the patient, or to safeguard the patient’s privacy. Family members were asked to step out of the patient’s room for a moment, or they were taken to the waiting room, which indicates that hospital facilities, in part, complicate the implementation of family-centered care. The hospital staff believed that family members’ visits to the patient were important, and only infrequently were family members regarded as complicating the work of the hospital staff. Family members were primarily seen as informants of the patient’s health and family situation; dissemination of information became emphasized in the interaction. The patient’s family was regarded as “context, not as unit,” which shifts the primary focus from the family to the individual patient (Wright & Leahey, 1990).

### Table 5: Factors Complicating Interaction (n = 165)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Agree</th>
<th></th>
<th></th>
<th>Disagree</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>The staff’s busy work schedule complicates staff-family interaction.</td>
<td>10</td>
<td>91</td>
<td>10</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>The family member’s shyness of approaching the staff complicates interaction.</td>
<td>150</td>
<td>78</td>
<td>31</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>The staff’s shyness of approaching complicates interaction.</td>
<td>97</td>
<td>59</td>
<td>62</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Staff’s poor accessibility complicates interaction.</td>
<td>116</td>
<td>70</td>
<td>43</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Shift work complicates interaction.</td>
<td>107</td>
<td>65</td>
<td>53</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>The involvement of family members complicates working.</td>
<td>56</td>
<td>34</td>
<td>104</td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>The lack of suitable places for discussion complicates interaction.</td>
<td>103</td>
<td>63</td>
<td>57</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>The patient’s serious illness complicates interaction.</td>
<td>64</td>
<td>39</td>
<td>95</td>
<td>58</td>
<td></td>
</tr>
</tbody>
</table>
Discussions with family members usually took place in the afternoon or evening because these were the times when families visited the patients. This timing was primarily related to the family members’ work schedules but also related to the fact that family members were not aware of the fact that the hospital had removed all restrictions on visiting hours. Some hospital staff suspected that family members still adhered to the earlier scheme where visiting hours were restricted. It can be asked why the hospital staff failed to clarify the unrestricted visiting hours if they assumed that family members were unaware of the new hospital policy.

The hospital staff described the afternoon as being the best time for family members to visit, when the daily duties had mainly been done and the opportunity for interaction was best. This would suggest that at least some hospital staff had the idea that the “more important duties” had to be taken care of before meeting with families. However, one third of staff reported that any time was convenient for interaction with family members. It is possible that the staff’s attitude toward the patient’s family varies and is dependent on who happens to be present, which has also been shown by other studies (Bruce & Ritchie, 1997).

Nurses talked with family members more frequently than doctors, which may be because nurses are more accessible on the hospital units than doctors. The family discussions mainly took place in patient rooms or in the unit office. On the surgical units, family members usually initiated the discussion with hospital staff. This finding is consistent with the results reported by Jantunen (1991) and Åstedt-Kurki and colleagues (1997). Greater value on having a mutual and equal relationship with families would require greater willingness on the part of hospital staff to initiate discussions with family members. The pediatric unit professionals were most active in initiating discussions with families. Pediatric units differ from adult units in that families consider their presence to be important to their children’s well-being and treatment and are more frequently visible and present in hospital units.

The majority of hospital staff reported that the patient’s presence during family discussions was important. Discussions mainly concerned the patient’s health status, and it was reported as desirable to have the patient present. None of the hospital staff reported that the discussions concerned the family members’ own condition or coping.
Hence, the providers saw the patient as the primary unit of care, and the discussions with family members mainly concerned the patient’s health and treatment issues.

The hospital staff maintained active contact with the patient’s family members by telephone, but personal discussions on the hospital unit were considered easiest. The providers distributed a great deal of written material and discussed this with family members to make sure that the family understood the instructions. The hospital staff reported that family members needed information about the patient’s discharge care, contact information about the hospital, and information about the patient’s disease and prognosis. Other research (Johnson et al., 1998; Moser et al., 1993) found the need for relevant and reliable information about the patient as the most urgent need of family members. Previous research (Eriksson, 1996; Jantunen, 1991) has also shown that significant others need illness-related information rather than that related to the hospital unit’s routines and organization.

The majority of hospital staff reported that interaction with the patient’s family members was easy. The fact that the staff offered an opportunity for discussion and had a friendly and open attitude toward family members was seen as facilitating interaction. Another study by Jantunen (1991) also found these factors to promote interaction. Interaction with family members is complicated by the providers’ busy work schedule, family members’ shyness in approaching the providers, and the providers’ poor accessibility, a feature also pointed out by Jantunen (1991).

Limitations of the Study

The instrument used in this study was constructed from literature and was pilot tested earlier on the medical units of the same hospital. Despite pretesting, a relatively large proportion of respondents failed to respond to some questions, which would suggest that these questions were perceived to be irrelevant, these question were not understood, or that the response options were considered inadequate. The weakness of a self-report instrument is that the response options are preset. The results give a general description of interaction between health care providers and family members as recalled by the respondent. Qualitative and observational methods could yield deeper experiential knowledge. The sample for this study was small and the
response rate was rather low, so the results cannot be generalized beyond the study sample.

**IMPLICATIONS FOR FAMILY NURSING PRACTICE AND FUTURE RESEARCH**

Hospital staff perceived interaction with the patient’s family members to be important. Nursing staff usually interact with family members while they visit the patient on the unit, but lack of space on the hospital units and shortage of staff restrict interaction. On the other hand, interaction is largely about attitudes, and Wright and Leahey (1999) argued persuasively that successful interaction can come about despite a lack of space and time. These findings suggest that education for nurses and other hospital staff should focus on attitudes and specific skills for successful family-provider relationships.

Further research that explores the professionals’ and family members’ perceptions of the family-provider relationship would enable comparisons between the professionals’ and families’ views across a variety of settings. More work is required on instrument development for exploring the nature of provider-family relationships. Qualitative methods would deepen the knowledge of this important interaction. More conceptualization and theory development of family-provider interaction are also still needed.

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Åstedt-Kurki et al. / Family and Health Care


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Conversations of Spirituality: Spirituality in Family Systems Nursing—Making the Case With Four Clinical Vignettes

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Nursing has a history of acknowledging the spiritual as a taken-for-granted dimension in health and illness. However, nurses and other health professionals have struggled to find meaningful ways to attend to the spiritual in practice. This article explores the notion that to inquire about spirituality is not neutral and not inquiring is also not neutral. In addition, four clinical vignettes are presented that illustrate ways of opening space to the spiritual in family systems nursing, within the framework of the Illness Beliefs Model. These include opening space for the following: the gift of listening, curiosity and surprise, inviting reflections, and the invocation of metaphor. This article also addresses how some constraining beliefs of the clinician can actually inhibit or close the door to possible exploration of spiritual experience.

As a clinician with many years’ experience in family systems nursing and a strong commitment to the spiritual and religious dimensions of life and care, I (first author, Deborah L. McLeod) was surprised by a conversation I recently had with a client. Lisa is a young woman with whom I had consulted for several sessions around issues...
related to childhood trauma and recent suicidal gestures. She was strongly linked to a supportive faith community and considered her relationship with God to be deeply meaningful. I was moved by her descriptions of “pure worship” that she encountered in her flute playing; thrilled when she discovered her “calling” to return to school and leave a dead-end job in which she had the sense of marking time; and laughed with her as she invoked images of “WWJD” (“What Would Jesus Do”) by touching her pen on which these initials were inscribed when she became angry. The images invoked were of Jesus turning those with whom Lisa was angry into a pillar of salt or sending locusts or other plagues—the resulting laughter released the grip of rage and allowed Lisa to put things more into perspective (I had in fact added the locusts to the picture and my own laughter as we talked about the ways Lisa had discovered to keep rage from taking over). I had, in short, believed myself to be open to every aspect of Lisa’s faith and the way it enriched her life, explicitly inviting conversations about her spirituality and related religious beliefs and themes (many of which I shared). So, I was surprised by the following conversation near the end of our fourth session. I explained to Lisa that I was working on a paper about spiritual and religious beliefs in therapy and asked if I could talk with her about her experience of the spiritual in our work together. She agreed and the following is part of our conversation.

Deborah McLeod (DM): I’m curious Lisa—have you been able to talk about your religious and spiritual beliefs as much as you would like to here?

Lisa: I think I’ve been a bit guarded.

DM: Oh [pause]. Is there anything that I could do to make it more comfortable for you—would it be helpful if you could talk more comfortably about your beliefs?

Lisa: Yeah it would.

DM: And what would need to happen in order for you to be more comfortable do you think?

Lisa: Just this.

DM: You mean this conversation?

Lisa: Yes. You see part of my self is really God centered. It’s not just my voice that is here, because in Christianity we believe that the Holy Spirit
is here and a lot of what I present as my self is actually God’s voice telling me, “whoa—think about this.”

DM: So how would it be helpful for us to talk more about God’s voice in your life?

Lisa: Just because I want to acknowledge His presence in my life—His guidance.

DM: And it would be helpful to you to be able to acknowledge Him more fully?

Lisa: It helps me for one thing to connect more with Him—to be able to not be so afraid. We all have our own clichéd thought of what God is. This way it makes Him more accessible—He IS part of my life—He is a positive force in my life.

DM: Are you saying it would strengthen your relationship with God to have conversations about God even more a part of our work together? [Lisa nods yes.] I’m curious, in our work together so far, have you talked as much about your spiritual beliefs as you thought you would?

Lisa: I’ve talked more than I thought I would.

DM: And how do you explain that?

Lisa: I just felt comfortable enough to share it. Like when I was rejoicing that I had found my calling, it was received with, “Wow that’s wonderful!”

DM: Oh. OK—so the fact that I was excited for you helped. I’m curious about how you understand that you thought you would talk less about God here than you actually did?

Lisa: Well I guess, whenever you think about therapy, you think therapy is about me and my spiritual life is over here [spreading her two hands apart]. And here I’m learning that they’re both together—like my spiritual life is not a separate entity from me. You know it’s part of me—it’s what guides my goals, guides my dreams, guides my behavior—just bringing those two together [joins her two hands together with fingers intertwined].

DM: And that’s been helpful?

Lisa: Yes—absolutely.

Although interest in spiritual and religious aspects of family work has mushroomed over the past decade (Griffith, 1995; Walsh, 1999; Wright, Watson, & Bell, 1996), spurred on perhaps by the interest in other aspects of diversity, such as race, ethnicity, gender, and socio-
economic status (Adams, 1995; Bergin, 1991; Boyd-Franklin & Lockwood, 1999; Lax, 1999; Lukoff, Lu, & Turner, 1992; Stewart & Gale, 1994; White & Tapping, 1990), my conversation with Lisa convinced me once again that as health professionals, we need to find more active ways of opening space to spirituality in our practices. A family’s spiritual/religious orientation is as important a consideration in our work with them as are other aspects of diversity, reflecting powerful ways of understanding, making meaning, or being in the world. In the context of working with families experiencing serious illness, “the experience of suffering from illness becomes transposed to one of spirituality as family members try to make meaning out of their suffering” (Wright, 1999, p. 62). Yet, too often we do not make explicit our openness to having conversations about spiritual or religious experience. To be open, as I believed I was with Lisa, even asking about the meaning of her faith and involvement with her church community, is not sufficient. We (health care professionals) too often have inadvertently, or at times with intention, participated in a form of “professional oppression” (Griffith, 1995; Weingarten, 1992) with regard to spiritual and religious diversity. In relation to gender, Johnella Bird (2000) offered that to inquire is not neutral and to not inquire is also not neutral. Neutrality sometimes is taken to mean remaining silent on an issue. Such silence on the part of professionals may equate to rejection for families, marginalizing and silencing conversations that families may find healing. As health professionals, we need new understandings of how we wittingly and unwittingly oppress by sealing off our practices to the spiritual as well as how we might open space for spirituality in our practices. This article explores a variety of ways that space is opened to spirituality in a particular advanced clinical practice in family systems nursing at the Family Nursing Unit (FNU), University of Calgary. The guiding model for family systems nursing at the FNU is the Illness Beliefs Model (Wright et al., 1996).

THE ILLNESS BELIEFS MODEL

The Illness Beliefs Model (Wright et al., 1996) rests on the assumption of the biopsychosocial and spiritual nature of human beings. Illness beliefs (including religious and spiritual beliefs) are understood to be at “the heart of the matter” in the suffering as well as the healing that families experience in the face of illness. A belief is understood to
be a persisting set of premises about what is taken to be true. Among
our most strongly held beliefs are those that are spiritual and religious
in nature. These are especially forged in community with others such
as families and faith communities. Walsh (1999) offers,

Faith is inherently relational. . . . the most fundamental convictions
about life are shaped in care-giving relationships. Caring bonds with
partners, family members, and close friends nourish spiritual well-
being; in turn spirituality deepens and expands our connections with
others. It can be a spiritual experience to share physical and emotional
intimacy, to give birth, to care for a frail elder, to befriend strangers, or
to receive the loving kindness of others. (p. 22)

Although spirituality has been intertwined with nursing practices
throughout history, and nursing has maintained a taken-for-granted
acknowledgment of the importance of spiritual concerns in practice,
understanding the meaning of spirituality and the nature of nursing
practices in this domain has been elusive (Cusveller, 1998; Martzolf &
Mickley, 1998; Reed, 1992).

SPIRITUALITY IN NURSING PRACTICE

There seems to be consensus within nursing that spirituality is part
of the focus of nursing; however, there remains confusion about the
meaning of spirituality in our practices (Cusveller, 1998; Martzolf &
Mickley, 1998; Oldnall, 1995). Much effort has been expended in the
past decade in defining and conceptualizing spirituality (e.g., Burk-
hardt, 1989, 1994; Emblen, 1992; McSherry & Draper, 1998; Reed,
1992). For example, Emblen (1992) surveyed more than 30 years of the
nursing literature to distinguish the concept of religion from that of
spirituality by using concept analysis procedures. The following nine
words appeared in defining spirituality: personal, life, principle, anima-
tor, being, God, quality, relationship, and transcendent. Six words were
associated with religion: systems, beliefs, organized, person, worship, and
practices. In analyzing the concept of spirituality emerging in nursing
literature, Martzolf and Mickley (1998) identified the following attrib-
utes of spirituality: meaning, value, transcendence, connecting, and
becoming. Although much work has been done, there has been rela-
tively little clarity on the topic of spirituality, limiting direction for
both researchers and practitioners (Cusveller, 1998; Martsolf & Mickley, 1998; McSherry & Draper, 1998).

Bradshaw (1994) argued that attempts to define spirituality may result in fragmentation and loss of meaning as ideas are taken, piece-meal, out of context. Efforts to define and conceptualize to measure have been guided largely by the tenets of empirical science, contributing knowledge about the spiritual that largely rests on the position of subject and object. Rather than define and conceptualize spirituality, some authors have attempted to describe the meaning of spirituality by the way it invites us to live. Using a “theoretical-phenomenological” approach, Elkins and his colleagues (Elkins, Edstrom, Hughes, Leaf, & Saunders, 1988) described nine major components of spirituality (see Table 1). No one interpretation of spirituality may capture the meaning for all, with every interpretation necessarily opening space for some understanding while simultaneously closing down the possibility of other understandings. However, many of the definitions identified above and others point to aspects of spirituality that include connection with oneself, others, and a transcendent meaning that provides meaning and purpose in one’s life.

<table>
<thead>
<tr>
<th>Table 1: Dimensions of Spirituality</th>
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<td>A way of being and experience that is embodied in:</td>
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<td>1. A transcendent dimension, a belief in “something more,” ranging from a belief in a personal God to a belief in a greater self.</td>
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<td>2. A sense of meaning in life that values a quest for meaning and is confident that one’s life has purpose.</td>
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<tr>
<td>3. A mission in life, a sense of purpose, vocation, a “call,” a “destiny.”</td>
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<td>4. The sacredness of life. Life is not separated into the secular and the sacred but rather all of life is experienced as sacred and with reverence.</td>
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<tr>
<td>5. Ultimate satisfaction in spiritual values not material objects.</td>
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<td>6. Altruism: Spiritual awareness moves people to respond to the needs of others.</td>
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<td>7. Idealism that sees the potential of people, society, and the planet. It includes a commitment to the betterment of the world through prayer, meditation, acts of charity, or acts of social activism.</td>
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<tr>
<td>8. Realism that acknowledges the tragic realities of human existence, such as suffering, and increases commitment to make a difference.</td>
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<tr>
<td>9. Fruits of spirituality: Spiritual beliefs, attitudes, and activities bear fruit in compassion, courage, joy and positively influence one’s relationships with other people, nature, self, and the transcendent reality.</td>
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WHY INCLUDE SPIRITUALITY?

The Illness Beliefs Model (Wright et al., 1996) offers that the focus of nursing is the alleviation and healing of suffering. Wright (1997) further argues that

Discourse of suffering frequently opens up a discourse of spirituality. Suffering invites us into the spiritual domain. A shift to and emphasis on spirituality is frequently the most profound response to suffering from illness. If nurses are to be helpful we must acknowledge that suffering and, often, the senselessness of it are ultimately spiritual issues (R. B. Patterson, 1994). The influence of family members' religious and spiritual beliefs on their illness experience has been one of the most neglected areas in family work. (p. 5)

The neglect of spirituality as an explicit focus in practice is not unique to nursing but has been identified in a number of health professions, including medicine (Benson, 1996; Dossey, 1993; Kristeller, Zumbrun, & Schilling, 1999; Larson, 1993; Levin, 1994; Mathews, Larson, & Barry, 1993), psychology (Bergin, 1991; Moore, 1992; Richards & Bergin, 1997), and family therapy (D. A. Anderson & Worthen, 1997; Becvar, 1996; Chubb, Gutsche, & Efron, 1994; Griffith, 1995; Prest & Keller, 1993; Stewart & Gale, 1994; Walsh, 1999). Such neglect is gradually diminishing as society and the health professions are gradually becoming sensitive to diversity in all its aspects. Substantial bodies of literature are accumulating that attest to the importance of spiritual and religious beliefs to health and illness (e.g., Benson, 1996; Dossey, 1993; Gartner, 1996; Koenig, 1995; Mathews et al., 1993; Mickley, Carson, & Soeken, 1995; Weaver, Flannelly, Flannelly, Koenig, & Larson, 1998). As might be expected, there is a substantial body of nursing literature in the context of life-threatening illness that reveals a positive relationship between spiritual and religious variables and a wide variety of health-related outcomes. Recent studies examine the associations between a religious or spiritual variable and the following outcome variables: feelings of health and well-being (Fehring, Miller, & Shaw, 1997; Fryback & Reinert, 1999; Kurtz, Wyatt, & Kurtz, 1995), coping (Dein & Stygall, 1997; Feher & Maly, 1999; Fredette, 1995; Jenkins & Pargament, 1995), quality of life (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Ferrell et al., 1996; Gioiella, Berkman, & Robinson, 1998; Wyatt & Freidman, 1996), meaning and hope (Ballard, Green, McCaa, & Logsdon, 1997; Feher & Maly, 1999;
Fryback & Reinert, 1999), social support (Feher & Maly, 1999), and demands of illness (Fernsler, Klemm, & Miller, 1999).

This body of literature is not without difficulties. Most of the studies cited above are correlational in design, limiting the conclusions one might draw. Spiritual and religious variables for the most part are operationally defined and measured using existing instruments with reasonable psychometric properties, but many of the instruments have been criticized for not being culturally relevant (Mytko & Knight, 1999). However, the preponderance of research interpreted within the empirical tradition overwhelmingly demonstrates the relevance of spiritual and religious dimensions of life for health and well-being. In addition, there are accumulating numbers of studies guided by qualitative approaches that also support the importance of spirituality in health and as a resource in illness and healing (e.g., Burkhardt, 1991; Chiu, 2000; Dunbar, Mueller, Medina, & Wolf, 1998; Humphreys, Lee, Neylan, & Marmar, 1999; Learn, 1993; Smucker, 1993).

Survey findings in Canada highlight the importance of religious and spiritual beliefs to Canadians, with approximately three quarters of the population professing Christian beliefs and association with a Christian denomination (MacLeans magazine survey, 1993, cited in Swenson, 1999) and between 73% to 93% of the population professing a belief in God (depending on the region of the country) (Bibby, 1987). Surveys have identified that up to 40% of individuals would consider it very important for their physicians to address spiritual issues with them if they were seriously ill (H. Gallup, 1997), and up to 77% of inpatients in another study wanted their physicians or counselors to address their spiritual needs (King & Bushwick, 1994). Moadel and colleagues (1999), in a sample of 248 ethnically diverse people living with cancer, identified a variety of spiritual/existential needs. Patients indicated they wanted help with overcoming their fears (51%), finding hope (42%), finding meaning in life (28%), and finding spiritual resources (39%) or someone to talk with about finding peace of mind (43%), the meaning of life (28%), and dying and death (25%). In another Gallup poll (G. Gallup, 1996), 66% of respondents stated that in a counseling situation they would prefer their caregivers to represent spiritual values and beliefs, and more than 81% would prefer a caregiver who enabled them to integrate their values and belief system into the counseling process. Griffith (1995) reported that clients “want to reflect on spiritual experiences in therapy, and . . . feel fragmented by attempting to delegate psychological, relational issues to
conversations with their therapist and spiritual issues to conversations with their priest, rabbi, or pastor” (p. 124). These findings provide some indication of how important these issues might be to families experiencing serious illness.

SPIRITUALITY IN FAMILY SYSTEMS NURSING

In the context of clinical work with families at the FNU, University of Calgary, spirituality emerges in practice in a variety of ways. A clinical nursing team of faculty and graduate students collaborates and consults with families experiencing serious illness. The focus of the advanced practice nursing that is taught at this outpatient clinic is the alleviation and healing of suffering, including physical, emotional, and/or spiritual suffering.

Spirituality and religion are understood to be distinct from one another, though not necessarily disconnected one from the other. Within this practice, spirituality is embodied in taken-for-granted ways of being in the world and is consistent with the dimensions identified by Elkins and colleagues (1988). The etymological roots of spirit include the Latin, meaning soul, courage, vigor, and breath and the Hebrew ruach and the Greek pneuma, both of which also point to breath, or breath of life (Barnhart, 1988). Religion is understood to refer to an organized, institutionalized belief system that includes shared values and beliefs and involvement in a faith community (Wright et al., 1996). Some understand the relationship between spirituality and religion as being very separate; others see the connection more as praxis, transforming experience to a way of living life. Capra and Steiendl-Rast (1991) suggested,

You can have spirituality without religion, but you cannot have religion, authentic religion, without spirituality... So the priority belongs... to spirituality as experience, a direct knowledge of the absolute Spirit in the here and now, and as praxis, a knowledge that transforms the way I live out my life in this world... Institutionalization is one of the consequences when an original spiritual experience is transformed into a religion... religion brings out the intellectual dimension of spirituality, when it seeks to understand and express the original experience in words and concepts; and then it brings out the social dimension, when it makes the experience a principle of life and action for community. (pp. 12-13)
The etymological roots of religion mean “connection” (Capra & Stindl-Rast, 1991) and in the Native American tradition are loosely translated as meaning “the way you live” (Spretnak, 1991). At the same time, the limitations of these descriptions are acknowledged. Although the intent is to be inclusive, not all will feel included by these descriptions. Some might prefer to think in terms of existential, moral, or ethical meaning. Some understand their spirituality to be unrelated to any religion, and some that are religious do not relate particularly to spiritual experiences. In our attempts to interpret these ideas for the sake of illustration and some understanding, we necessarily limit other understandings. As Max Jacobs, a French, Jewish-Christian mystic noted, “You must live things, not define them” (cited in H. Anderson, 1999, p. 157).

Therapeutic conversations that evolve within the clinician/family relationship provide a frame for healing and embody the spiritual. It is hoped that through the following illustrations of living and breathing spirituality in the midst of therapeutic conversations, new understandings may emerge to guide clinical nursing practices. The following case vignettes from the FNU illustrate the opening of therapeutic conversations to spirituality. Doors through which spirituality is received in the therapeutic process include the gift of listening, curiosity and surprise, reflection, and the invocation of metaphor. Constraining beliefs that may limit a clinician’s sensitivity to the spiritual in therapeutic conversations are also discussed.

CASE VIGNETTES

Vignette 1: Opening Space for the Gift of Listening

The gift is to the giver, and comes back most to him—it cannot fail.
—Walt Whitman (1881, p. 188)

In circling twice in this way the gift itself increases from bread to the water of life, from carnal food to spiritual food.
—Hyde (1979, p. 11)

The Campbell family was referred to the FNU for help in coping with the aftermath of leukemia and a stroke that the father, Mr. Campbell, had experienced as a result of the chemotherapy treatments. Mrs. Campbell’s concern for her husband and his associated depression
precipitated her call to the FNU. During the second interview, the conversation turned to Mr. Campbell’s “difficulty accepting” the way his life had been changed. As Mr. Campbell spoke of his struggle, the team noticed that whenever Mr. Campbell wept in the session or spoke of his anguish, his wife tried to cheer him by expressing her beliefs that he was “on a different path now; God has something different for you; God didn’t bring you back for no reason.” Following a phone-in from the faculty supervisor commenting on this emerging pattern, the clinician joined with Mrs. Campbell and suggested they both sit quietly and hear all that Mr. Campbell had to say. What followed was a full 5 minutes in which Mr. Campbell, haltingly at first, then with more fluidity and anguish, expressed some of the pain he was experiencing in relation to the losses he had suffered.

Some days I just feel—[sighing deeply]—well it’s really hard; it’s really hard accepting the way things are. I tell myself that I should—that I should be thankful that I am alive—that these things have happened to me—and I’ve got to accept them, but I just can’t do things like I used to. I trip over things; I understand that my brain doesn’t work the way it used to [pause, sighing]. I sit on my balcony and I see people walking and riding, walking their dogs without looking like a gimp, and I am a gimp [weeping]. I don’t know what I am going to do—I think a lot about that. I can’t take each day as it comes, and I live life being thankful that I—you know—I didn’t die. I have my wife here with me and—but so much is unknown. I know this sounds silly because there’s always the unknown, but at least my wife knows she’s going to work . . . You—you come here and talk to us . . . You’ve got some kind of schedule to your life—like my doctor said she’d die to have 2 weeks off. I don’t know what my future’s going to hold, and I think a lot about that. Maybe I shouldn’t—I don’t know [sighing]. If I could do something beneficial—you know I don’t want to spend my time getting up, making the bed, doing the laundry; it’s not like I mind doing that, it’s not like I hate it, but there’s got to be something more [pause, weeping]. And it’s going to take time, well I know its going to take time [deep sighing]—am I making any sense?

“The inviting, listening to, and witnessing of illness stories provides a powerful validation of a profound human experience. . . . [Within these stories a] domain of spirituality is encountered” (Wright, 1999, pp. 67, 75). Listening to such stories is profoundly difficult work in which both clinician and family struggle with ultimate meaning and purpose and the unknown. The gift of listening in the
face of such suffering is given with anguish also. To think of what one might “do” or how one might “intervene” in such encounters is to diminish the profound nature of the topic. “When listening becomes a task, instead of a gift, then stories are not witnessed and honored but rather become ‘clinical material,’ demanding manipulation and change.” (Frank, 1998, p. 199). To offer “deep listening” (Stein, 1998, p. 213) or “empathic witnessing” (Kleinman, 1988, p. 10) allows a story to be told that cannot be told unless someone listens (Frank, 1998). “Meaning of life” questions demand the gift of such listening. Telling stories of suffering and spiritual searching helps us to make meaning in the midst of chaos. Telling such stories uncovers the meaning that people attach to their suffering for both listener and speaker. Yet, the listening called for in such places with families demands that we hold the belief that the story (and the teller) needs no change (Frank, 1998).

Listening as an act of the spirit acknowledges the need for mutuality in the encounter with spiritual questions. The clinician does not listen to “intervene,” nor does he or she invite family members to listen from such a place, but rather to honor the mysteries of life that illness often brings. In the context of family work, the nurse creates space for the telling and witnessing of stories (Wright, 1999). For Mr. and Mrs. Campbell, the story of suffering opened the spiritual domain in which her beliefs (“you are on a different path”) silenced his anguish (“I can’t accept this—there has to be more”). Although this “meaning of life” story was anguished and difficult to listen to, the telling of it was accompanied by deep sighs—a letting go of something that had been held for too long. When the family and the clinician could reflect on their witness of this story, Mrs. Campbell was able to comment on her fears of depression and suicide, both of which had touched their family in significant ways in the past. Acknowledging that a story is a child of a relationship (Stein, 1998), not a thing to be manipulated, invites the clinician and family members to a reflection on the meaning of life for all of us, a position in which the family and clinician both may experience spiritual connection and mystery. In Mr. Campbell’s story are heard the many discourses that have silenced him with “you need to accept,” as well as the release of anguish in the sighs as he speaks of those things he cannot accept. When families can provide the gift of listening to each other, the gift cannot fail to come back as the possibilities are opened up for new meanings to emerge in their own time.
Vignette 2: Curiosity and an Openness to Surprise

Knowing how to act “is a dance … a conversation between what is said and what could be, an openness to passionate sorrow and surprise, a play between understanding and perception.”

—Phelan (in press)

Within the Illness Beliefs Model, maintaining curiosity and explicitly inquiring about religious and spiritual beliefs provide openings for spirituality in therapeutic work with families. Such inquiry emerges out of therapeutic conversations as the clinician listens for cues in the language or themes the family offers in their stories. Part of a respectful and culturally sensitive practice is curiosity and maintaining the mind of a beginner (Epstein, 1995). A lapse in curiosity often precedes the closing down of conversations about spiritual experiences and beliefs. As the clinician embraces the mind of a beginner, the family is invited to teach the clinician about their beliefs, faith, or spiritual experiences. Curiosity is sometimes more difficult to maintain when the clinician shares the same faith, as we may be inclined to make more assumptions. Holding the belief that each family (and individuals within the family) makes sense of their spirituality in varying ways and, that in a very real way, no two people share exactly the same spiritual understandings (even within the same faith community) may help the clinician maintain curiosity. Although conversations are not aimless, there is a sense that when curiosity and openness to learning from families are high, that one is conducted by the topic as much as one is the conductor. In such conversations we do not talk at cross-purposes, seeking to understand so that we can make predictions (in which the clinician is distanced and “objective”). Nor do we seek to understand the meaning that relates to me (a social conversation). We listen, rather, with the other for the way in which what the other is saying is “right” (Gadamer, 1989). We seek to understand what the topic (spirituality) might have to say to all of us, clinician and family together. Out of such hermeneutic listening new understanding and possibilities for healing may emerge.

In a therapeutic conversation with a man living with multiple sclerosis, the clinician’s curiosity helped to maintain an openness to the spiritual in the conversation as the client, Brian, described his spiritual experiences at the funeral of his brother. The clinician remained curious about the ideas Brian had, the language he used, the meanings he drew from these experiences, and the relationship between his
beliefs and his suffering related to feelings of guilt about the last conversation he had with his brother. The following conversation picks up as Brian is describing his experience of his brother’s presence at the funeral home and, later, the funeral.

Brian: There’s something else out there—it’s not ghosts but—your spirit is made out of an energy; you can’t destroy energy so where does it go?

Clinician (C): What do you think?

Brian: I—there’s something else out there—whether it be another plane, whether it be, something—I don’t know—but there’s something else out there.

C: Because what did you experience that convinced you of that?

Brian: Well, try a 5 or 6 hour conversation with my [dead] brother that night—and it wasn’t just me. My wife had it too. [Brian goes on to describe the sense of his brother’s presence that came and went during this time.]

C: So have you found it a comforting experience or disturbing?

Brian: It made it easier to deal with.

C: It did? In what way?

Brian went on to describe the comfort he gained from the sense of his brother’s presence and the way he became convinced through this that his brother’s death was not a suicide but an accident.

A belief about change reflected in the Illness Beliefs Model is that change must be languaged to be real. “Like other ‘realities’, change is brought forth through the distinguishing of it” (Wright et al., 1996, p. 92). “The act of indicating any being, object, thing or unity involves making an act of distinction which distinguishes what has been indicated as separate from its background” (Maturana & Varela, 1992, p. 40). Change is brought forward and solidified through the therapeutic conversations that evolve between the clinician and the family. Spiritual meanings emerge and evolve in the context of conversations that are characterized by curiosity and mutuality. Maintaining a curious openness to the spiritual seemed important to Brian in easing the suffering that he was experiencing at the loss of his brother. The clinician’s willingness to adopt the mind of a beginner (Epstein, 1995) and be taught by the client’s experience maintains an openness to the expression of the spiritual in human experience.
Vignette 3: Inviting Reflection on Spiritual/Religious Beliefs

In family work, sometimes the more difficult encounter for clinicians is with families who hold strong religious views (Prest & Keller, 1993; Stewart & Gale, 1994). The assumption that religious beliefs are rigid and unlikely to change closes down conversations and goes against the call for deep, hermeneutic listening that stories of spiritual quest, strength, and meaning demand. The more conservative religions seem particularly vulnerable to monolithic stereotypes (Stewart & Gale, 1994). Many of us do not reflect deeply on the religious beliefs, stories, and teachings of our faith traditions until confronted with a question. Often, such teachings have a taken-for-grantedness that does not invite questioning. Within a given faith community, however, there is often (if not always) more than one way to understand a given idea, belief, or scripture. One might even argue that with reflection, no one understands such teachings in exactly the same way. New understandings often do evolve in the midst of the questions that we have not yet confronted, individually, as a family, or even as a faith community.

The Walsh family presented at the FNU with questions about how to manage the serious illnesses of their son, Brad, who was 10 years old and the father, Jeff, who was 49. Brad had been diagnosed with a serious brain tumor shortly after birth. The tumor had caused significant developmental delays, and the family believed he would not live beyond his adolescence. In addition, Jeff had recently been diagnosed with a degenerative brain disease. The family also expected that Jeff’s life would be shortened, though they were uncertain by how much. Their presenting concern was Brad’s behavior that his mother, Susan, described as “out of control” at times, with temper tantrums, screaming, and demanding behavior. The neurologist had told Brad’s parents that his tumor likely would affect his behavior and that at times Brad would have difficulty controlling his impulses and emotions. The family described themselves as conservative Christians. Part of Susan’s suffering was the conflict she experienced about how to discipline Brad. Her Christian beliefs supported the idea that discipline was the responsibility of all godly, loving, and responsible parents. Godly parents discipline their children—to spare the rod would mean spoiling the child and would negatively affect Susan’s relationship with God, to whom she felt accountable. Susan was also experiencing criticism from her parents and friends who admonished her to discipline Brad and correct his behavior.
As is a common practice in the FNU, a reflecting team (Wright et al., 1996) offered their thoughts to the family toward the end of a session. One idea that was offered the family was the notion that the word *rod* in the original Hebrew could also be translated “shepherd’s hook” and that a shepherd’s hook is used for shaping and guiding the path of lost sheep. Perhaps one way to understand their work as Christian parents might be to think of guiding this little boy as a form of discipline. For the family, this notion was very powerful and invited them to think of discipline in a different, gentler way by offering a possible alternative understanding of Scripture. Such an offering invited new possibilities for this family as they reflected on the enactment of their faith in their parental role. Maturana and Varela (1992) offered the notion that

reflection is a process of knowing how we know. It is an act of turning back upon ourselves. It is the only chance we have to discover our blindness and to recognize that the certainties and knowledge of others are, respectively, as overwhelming and tenuous as our own. (p. 24)

Invitations to a reflection emerge out of therapeutic conversations. In working with religious families, maintaining deep listening, curiosity, and a position of listening for what the other is saying that might be right facilitates open, reflexive conversations. Believing that one’s understanding of his or her faith evolves and deepens over time may invite the clinician to ask questions silently or out loud and may allow new understandings to emerge. Questions such as, “How else might this be understood?” and “How do others in your faith community understand this?” can be helpful in the invitation to reflection.

Vignette 4: The Invocation of Metaphor

Religious meaning and experience are carried in the metaphors of rituals, stories, songs, and symbols of a faith. The invocation of metaphor in clinical work with families is an open door to the spiritual and often emerges in conversations about meaningful experiences, stories, or scriptures. The word *invoke* means to call on or to summon into presence (Barnhart, 1988). Such metaphors embody the divine in the midst of our work with families. The spiritual is invited to be present to families as they share the stories of their faith. As we listen, we par-
the singer is not conveying “information” in any ordinary sense of a “pipeline transfer” of data from singer to listener. Basically the singer is remembering in a curiously public way—remembering not a memorized text, for there is no such thing—nor any verbatim succession of words, but the themes and formulae that he has heard other singers sing. He remembers these always differently, as rhapsodized or stitched together in his own way on this particular occasion for this particular audience. The song is an interaction between him, his audience, and his memories of songs sung. (pp. 17-18)

For many families, the telling of faith stories through therapeutic conversations, even though they may rest at times on “memorized text,” is often told “as stitched together . . . on this particular occasion for this particular audience,” for the experience of stories depends on the particularities of this time and this place. The telling of such stories can be profoundly healing of spirit.

The Lange family attended the FNU following the death of first their brother and then, a year later, the death of their father/husband. The family was involved with their religious community and considered their faith important to them. In the second session, the clinician explored their religious beliefs, and these beliefs are expressed through stories of faith. As the clinician listened, there was a sense for the observer that the family as a whole was strengthened by listening to the son speak of his own faith and their faith as a family. This was witnessed in the side comments of his sister and the nods, tears, and smiles of his mother as she listened. There is a sense, too, of an invocation of spirit carried in the stories and a renewing of faith as the stories are told in this place and time and to these particular witnesses.

Clinician (C): The first time we met we talked some about the events at your church and the way you felt betrayed. At times of loss, families sometimes find that they really start to question their faith; I’m wondering—has your spirituality—your beliefs in God brought you comfort or brought you pain?

Son: It’s kept us sane!

Mother: Yes—I would say that’s really been the anchor of my soul.

Son: What we experienced in the church before, it was like a precursor of now . . .
Daughter: It was a foreshadowing of death.

Son: And we experienced it; I believe we experienced it and we took it very hard and we took it in different ways and it reaffirmed everything that we were taught since we were little—so it made it [our faith] stronger... that has been the only thing that has been able to keep us sane—because it’s true—if I didn’t have the things, the simple things that I know in my heart, I know to be true, I wouldn’t have a hope in the world. I would be lost. It would be like walking around with a toque on my head; [with my faith] I can still see a trail—it’s a little obstructed but I can still see some light.

C: If you were to offer some advice to other families going through this—to make their pain less—what would you say?

Son: You can’t make the pain less. You just have to remember the things that you know in your heart to be true. And for me the things that I know in my heart to be true are that I’m only passing through. I was able to have a relationship with two people; there’s a verse in the bible—“He who has started a good work in you will be faithful to complete it”—it goes on to talk about how it may not be in our frame of time, it may not be when we want it to happen, we will know though; it’s just a matter of on whose time frame. My hope now is in my family and in my beliefs.

C: Can you tell me what those beliefs are—what you believe in?

Son: [Speaks at some length of God as comforter and of His unconditional love.] For me, that’s what I’ve been raised with since I was little—and my experiences since through my life have reaffirmed that—it’s a reality I live with.

C: Those sound like very comforting beliefs.

The telling of these stories, coming as they do after the loss of two members of this family, invokes new and comforting images and meanings for this particular time. Told as they are in the midst of family who are both speakers and witnesses invites a healing, a reaffirmation of faith, that for this family seemed powerfully healing.

CONSTRaining BELIEFS

A variety of beliefs may constrain spirituality in our nursing practices. Some health professionals feel unprepared to deal with spiritual themes and issues in their practices and may not themselves have
considered such topics important in their own lives. A lack of personal reflection and education specifically on spirituality in practice may contribute to this discomfort and the constraining belief that “I don’t have the expertise or previous experience” to address spiritual issues. If we believe that conversations are coevolved with families (Wright et al., 1996) and that the clinician can learn from families about their particular spiritual experiences and beliefs, the belief that the clinician must have expertise is challenged. A colleague offered the notion that because she had absolutely no family experience herself in religion or spirituality, she particularly felt unable to incorporate spirituality into her practices. As she stated, “I simply have no questions that might open up conversation.” This is more about a lapse in curiosity than about a lack of expertise. Clinicians who want to develop their practices in this area may benefit from reading about spirituality and different faiths (J. Patterson, Hayworth, Turner, & Raskin, 2000), with the understandings gained perhaps contributing to increased curiosity and exploration with families.

Clinicians sometimes believe that inquiry about spirituality can be dangerous, intrusive, or disrespectful. Some may even believe such topics are not relevant to our practices. Clearly, the research and survey findings cited previously reflect the importance of these topics to health and illness and the interest of many people in having their spiritual experiences and beliefs respected through inclusion in their health care. Provision of culturally respectful care requires that we become open to the spiritual in our practice, not simply by “being” open but by finding ways to explicitly include spirituality in our practices.

Finally, clinicians are sometimes constrained by their beliefs that they “know” what the family believes when they name their religion (or denomination). Such stereotyping always closes down conversations and possibilities for healing whether the stereotypes are about ethnicity, race, class, or religion. “A generic approach to ‘religious’ clients will not do, any more than a generic approach to ‘ethnic’ clients or ‘middle-class’ clients will do. What religious clients believe is more important than the mere fact that they believe” (Stewart & Gale, 1994, p. 17). Challenging such constraining beliefs often occurs through learning from families who hold a variety of spiritual or religious beliefs or through conversations with colleagues who hold different beliefs (or the same beliefs differently!).
PRAXIS OF SPIRITUALLY SENSITIVE PRACTICE

The power of narrative to nurture and heal, to repair a spirit in disarray, rests on two things: the skillful invocation of unimpeachable sources and a listener’s knowledge that no hypocrisy or subterfuge is involved. —Lopez (1989, p. 19)

It is neither neutral to inquire nor neutral to not inquire about spirituality in our work with families. Both may be considered political acts. Either could invite oppression—the former potentially through the imposition of certainty; the latter through marginalization and oppression by silence (Griffith, 1995). We, as nurses, cannot be neutral in our work with families, for we cannot not hold the beliefs that we do. However, we can be thoughtful about the ways in which our beliefs are at play in our practices. Most important, we are ethically bound to respect the family’s beliefs as central to the therapeutic process. Holding the family’s beliefs as central requires that I, as a nurse, continually evaluate how my own spiritual and religious beliefs, or lack of belief, might be at play in the things that I choose to inquire about, those that I attend to, those that I choose to ignore. We are obliged to be aware of what we are potentially opening up, closing down, and imposing. We continually do all of these in our conversations with people, but to do so with a lack of awareness may constitute culturally disrespectful practices. The clinical vignettes highlighted in this article illuminate some possible ways of embracing the spiritual in our work with families.

NOTE

1. Pseudonyms have been used to protect the anonymity of the families.

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