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◆ Editorial

The Research Time Line

Sitting in my garden looking at the late spring blossoms and thinking about this editorial, it occurred to me that it would be published in the winter, a full 6 months away. This time frame made me recall some issues about research and time that are often referred to in discussions with practitioners and bureaucrats. Both groups want answers quickly to implement change or help make decisions. Many times, these issues have fiscal ramifications, and the researcher who cannot provide immediate answers is perceived as blocking innovation. Nonresearchers do not always understand the difference between corporate or institutional goals and the generation of new knowledge for the discipline. Researchers and clinicians are not always in tune when expediency is the driving force.

The time frame most researchers know is generally slow and complex. This comes about because of the processes that have become embedded into scientific research as methods of ensuring standards are maintained and the research output is trustworthy. At the outset, the problem must be clearly identified, a formal proposal written that indicates where the problem fits with established knowledge and describes how the investigator plans to study the problem. This intellectual process is time-consuming and often has to fit in with other work activities. The proposal has to be submitted for funding, a process that can take many months before any answer is received from the funding agency. If not funded, the researcher has to decide whether further work should take place to comply with suggested changes or to give up the particular project. The review by experts appointed by the funding agency is considered an essential part of maintaining quality in research. At some time during this process, the research will also have to pass through ethic reviews, and depending on the institution or organization where the research will take place, more than

one committee may be involved.

Once the research is funded, subjects are obtained, data is collected and analyzed, resulting in findings generated. Depending on the study, this process may take a few months or even a few years and involve any number of persons, both researchers and subjects. One practicing nurse told me about being variously involved in problem development, finding subjects, and data collection for a number of different studies. She had changed units or left the institution before the research had reached the stage of writing the report so she never knew the results of the studies she had helped with. Her wish to have some results provided as the data gathering progressed also identified that there had been little information about the research protocol given to the unidentified helper. This made it difficult for the nurse to stay interested and involved in the research process.

By the time the final report of the research is written for the funding agency there may be a number of people who have been minimally involved in the research and have been forgotten as time passed. In addition to the final report, decisions have to be made as to where to publish articles about the study. Once an article is submitted to a journal, the process of review begins. For most research journals there is the peer-review process in which a panel of colleagues examines the article and makes judgments about standards of the research undertaken, quality of the material presented, and the overall level of scholarship demonstrated. Even with a turnaround time of a month to complete the review, the procedure takes time. The problems of work commitments and idiosyncratic postal services often mean a few months may pass before the editor is able to tell an author the dispensation of an article. With increasing use of e-mail, the length of time for this procedure is shrinking. There are journals where in-house editors do the reviews and articles are processed more expeditiously; nevertheless, there is a traditional scholarly status in publishing in a peer-reviewed journal even if there is a time delay.

The editor will reply to an author identifying the decision about an article and, if accepted, the revisions that are required. This is the time when the author will be told which issue of the journal the paper will appear in on condition that revisions are returned within a specified time period. It is also

the time when the author may hear that there is a backlog of accepted articles, meaning that there may be many months before the article will be published. Novice authors also do not realize that for many journals, the date required for inclusion in an issue may be months before the issue is circulated. For *Clinical Nursing Research*, it is 6 months from the time papers are sent to the publisher and the actual issue is printed and circulated.

From the time a research question is first conceived and the process begins until publication of the results in a journal, a number of years can pass. The checks and balances that have been instituted by the scientific community are placed at intervals throughout the research process but are not usually identified in any final written report. The delays are considered by researchers to be an inevitable part of ensuring quality in our research, but the actual time involved is rarely articulated. It does not help the nurse or the bureaucrat to be told the reasons for these procedures because they want immediate answers. They ask if there is any other way research can be conducted that would provide rapid results.

Let us consider how industry deals with research. Research is part of the developmental edge that industry maintains to keep ahead of competitors; thus, the liberal dissemination of research findings for others' use does not occur in the same way as a discipline's knowledge is built. In fact, there is industrial espionage in some cases where new knowledge might have an effect on the market. We are even suspicious of research that is done by a particular company because we are not sure of the quality control that might have been in place or the biases that could be introduced into the research design. Think of the comments made about research into smoking conducted by the cigarette manufacturers.

I can remember many years ago when I worked as a research assistant in a bureaucratic environment being asked to develop a questionnaire in 2 days for distribution the following week. I was told that I was a sufficient expert in the content area to develop the questions and it was not necessary to do any pretests on the wording. I went to the statistical group members who were going to do the analysis on the questionnaire to discuss how the responses were to be interpreted (I would no longer be around to help with the analysis when the

questionnaires were returned). They informed me that it was most unusual for this level of interaction to take place. I found out that they analyzed questionnaires on a regular basis without any input from the person who had developed the questions. Believe it or not, decisions were made on the basis of their interpretation of responses!

There is a place for the time-consuming method of research dissemination that is part of the scholarly development of knowledge. There may be new ways to speed up the process through the use of electronic media, but there should never be a dilution of quality and standards in exchange for speed. This is the reason that despite the length of the process, *Clinical Nursing Research* maintains its peer-review status.

—Patricia Hayes

Family caregiving within institutional settings is a neglected area of research. In an era of cost containment, more and more is being asked of families of institutionalized persons. This article presents the results of a study designed to investigate family caregiving following the admission of an elderly relative to a long-term care facility. Beginning with a brief summary of findings from previous research, the article reports on visiting and task performance by families within the long-term care facility. Continuing with descriptions of families' satisfaction with institutional care and their care-related learning needs, the article concludes with recommendations for policy and practice.

Family Caregiving in Long-Term Care Facilities

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Admission of an elderly relative to a long-term care facility involves integration into a new and frequently foreign social environment and requires the establishment of new and meaningful relationships. This is so not only for residents of the long-term care facility but also for members of their families. For many, family relationships continue, albeit in a different form and setting. In particular, caregiving relationships continue. Transition to institutional caregiving generally follows an

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extended period of caregiving at home for a relative who is severely and irreversibly impaired. Although relief from round-the-clock care is achieved, for many families, feelings of responsibility for care continue. Much of the research on family caregiving has focused on care in the home. Less is known about the experience of family members who continue to provide care following admission of an elderly relative to a long-term care facility.

PRESENT STATE OF KNOWLEDGE

Research findings belie the notion of family abandonment following admission to a long-term care facility. Visiting occurs regularly (Evans & Scullion, 2000; Friedmann, Montgomery, Rice, & Farrell, 1999; Keefe & Fancey, 1996; Ross, Rosenthal, & Dawson, 1998). Families' feelings of responsibility for residents' physical and emotional well-being continue, as does the provision of care by family members (Duncan & Morgan, 1994; Hopp, 1999; Keefe & Fancey, 2000; Ross, Rosenthal, & Dawson, 1997).

Questions, however, remain about the visiting experience. Although there is evidence that families visit often, little is known about what the visiting experience is like for family members. There are reports that feelings of guilt, sadness, and depression are associated with visiting (Ross et al., 1998) and that visiting can be depressing and demoralizing for families (Grau, Teresi, & Chandler, 1993; Perris, Kinney, & Osgrocki, 1991). Motivation for visiting may lie in a long tradition of duty and obligation, with resultant feelings of duty and obligation (Ross et al., 1998). Questions also remain about task performance. The provision of care by families in an institutional setting frequently goes beyond the traditional list of tasks typically explored in research studies. Task performance has been conceptualized in many ways, including preservative, preventive, anticipatory, supervisory, and instrumental care (Bowers, 1988); technical and nontechnical care (Dempsey & Pruchno, 1993); personal, instrumental, relational, recreational, and spiritual care (Ross et al., 1997); and direct and indirect care (Keefe & Fancey, 2000). Caregiving responsibilities, however, are much more complex than is evident from the visible tasks that families perform. Motivating factors and emotional

responses constitute an important dimension of task performance rarely inquired about by researchers (Ross et al., 1997).

The conceptualization of family caregiving is in its infancy. This is particularly so for family caregiving in institutional settings. Families have been referred to as resources to institutionalized persons (Buckwalter & Hall, 1987). These researchers stressed the need for families to share in the caregiving process on a regular basis. Families have also been characterized as strangers and interlopers to nursing homes (Gubrium, 1991). This is so even when they are there on a daily basis and for extended periods of time. This researcher described how families intrude into activities that otherwise have a social logic of their own. They take stock of things and inspect the environment for what seems right or does not seem right according to the sense of order that they bring with them. He also wrote about families as agents for residents. More recently, the formation of partnerships between families and staff members is advocated as a means of ensuring high-quality residential care (Penning & Keating, 2000).

Little, however, is known about whether family care substitutes for formal care or whether it complements or supplements the care provided by staff members. Complementary care refers to a division of labor, with families and staff members providing different kinds of care. Supplementary care refers to the care provided by one source being augmented by another. Whereas institutional care may seem in some ways to be the clearest example of the substitution of formal care for informal care, it is not clear that this was ever an accurate view given that no studies have directly tested this hypothesis (Penning & Keating, 2000). There are studies that suggest technical care is viewed as primarily the responsibility of staff members and nontechnical tasks the responsibility of family members (Bowers, 1988; Dempsey & Pruchno, 1993). Findings from these studies support the notion that family care is complementary to that of staff. More recent evidence, however, suggests that family care supplements the care provided by staff members, with family members involved in the provision of both technical and nontechnical care (Duncan & Morgan, 1994; Ross et al., 1997). In an era of increasing longevity coinciding with fiscal crises, expectations are moving toward increased family responsibility for caregiving. It is important to

learn more about the experience of family members who visit and provide care for seniors who reside in long-term care facilities.

PURPOSE AND OBJECTIVES

The purpose of this study was to investigate family caregiving in long-term care facilities. More specifically, the study sought to answer the following questions:

- How frequently do families visit following the admission of a relative to a long-term care facility?
- Why do families visit as they do?
- What care-related activities do families carry out for their institutionalized relative?
- What is their level of satisfaction with the formal care provided in long-term care facilities?
- What are their care-related learning needs and resources?

Finally, we wished to make recommendations about strategies to facilitate and support family involvement following the admission of an elderly relative to a long-term care facility.

METHODS

The study employed a descriptive exploratory design. The University of Ottawa Human Research Ethical Review Committee provided ethical clearance for the study. A purposive, two-stage procedure was used for data collection. A list of the 19 long-term care facilities providing care to seniors in the Ottawa-Carleton Region was generated, and 9 facilities were invited to participate in the study. Facilities were selected to represent provincial patterns of size, rural/urban location, language, and type of ownership. Facility staff members identified family members who were personally involved with their relative, and a random sample of 194 was invited to participate in the study. The number of participants invited from each long-term care facility was proportional to the number of seniors residing in the institution. Potential respondents received a letter from the facility explaining the purpose and objectives of the study, the study questionnaire, and a request

for their participation. They were asked to respond directly to the researchers to ensure confidentiality.

INSTRUMENTATION

Questionnaires employed both open-ended and fixed-choice questions to gather data about the characteristics of family members and their elderly relative, patterns of visiting, assistance provided during visiting, satisfaction with the quality of institutional care, and perceptions of their own care-related learning needs.

Visiting was measured by a fixed-choice question that asked about the frequency of visiting. This item was similar to that used to measure visiting in other studies (Keefe & Fancey, 1996; Ross et al., 1997). Responses were coded as every day, several times a week, once a week, two to three times a month, once a month, several times a year, and less than once a year. Respondents were asked to estimate the average length of their visits in minutes and why they visited as they did. Their reasons for visiting were coded according to emergent themes. Respondents were also asked how enjoyable they found their visits. Responses were coded *not enjoyable at all*, *fairly enjoyable*, *enjoyable*, and *very enjoyable*.

Task performance was assessed through a series of questions related to caregiving activities that were similar to those of other studies (Keefe & Fancey, 1996; Ross et al., 1997). Direct care activities involved hands-on care such as personal care (bathing, grooming, toileting, and feeding), providing specialized medical care (medications and wound care), accompanying relatives on outings, and doing laundry. Indirect care involved the organization, supervision, and monitoring of care. Such activities included arranging for appointments, transportation, and shopping and monitoring residents' health status and ongoing care. Respondents were asked whether they were currently performing each task. Items were scored as dichotomous variables with those carrying out the task being assigned a score of 1 and those not carrying out the task being assigned a score of 0. Respondents were also asked to identify the most and least pleasant activity in which they engaged during visiting.

Satisfaction with institutional care was measured by a series of questions inquiring about level of satisfaction with various

aspects of institutional care. These questions were modeled on the FAMCARE scale (Kristjanson, 1993) that was developed to measure family satisfaction with cancer care. Responses were coded as *very dissatisfied*, *dissatisfied*, *neutral*, *satisfied*, and *very satisfied*. The scale achieved an internal consistency estimate of 0.89. An open-ended question also asked respondents to identify the aspect of institutional care they valued most highly. Responses were coded according to emergent themes.

Learning needs, resources, and preferred strategies were assessed using questions modeled on a tool developed to assess the learning needs for frontline community care workers (Kelly, Minore, McDougall, & Sweet, 1995). Respondents were asked to identify the care-related skills they wished to learn more about to improve the quality of care they provided their relative. A series of 16 care-related activities were identified that included aspects of personal care, providing emotional support, acting as an advocate, managing pain and discomfort and behavioral problems, preventing falls, communicating with their relatives and health care providers, affecting change in the way that relatives were cared for, and managing their own personal stress. Respondents were also asked to identify the resources that were available for information about caring for their relative. Choices varied from previous knowledge and experience to human resources such as seniors, experienced family caregivers, friends, neighbors, physicians, and nurses to material resources such as books, pamphlets, and the popular press. Preferred learning strategies were assessed by a series of 12 questions asking respondents to identify their preferred method of learning. Responses included hearing from seniors themselves; discussing with experienced family members; talking with health care workers; listening to presentations by speakers; attending workshops, seminars, and conferences; engaging in small group learning; participating in demonstration sessions; and using telephone information lines, computer-assisted packages, and self-directed or independent learning activities. Responses to all these questions were coded as dichotomous variables.

SAMPLE CHARACTERISTICS

A total of 122 family members returned their questionnaires for a response rate of 62%. The vast majority (69%) of respon-

Table 1
Frequency of Visiting (N = 120)

	Spouses (n = 20)		Daughters (n = 46)		Sons (n = 29)		Others (n = 25)	
	n	%	n	%	n	%	n	%
Daily	5	25.0	3	6.0			1	4.0
Several times a week	12	60.0	22	47.7	15	51.7	8	32.0
Weekly	1	5.0	14	30.4	9	31.0	6	24.0
Several times a month	2	10.0	4	8.7	4	13.7	3	12.0
Monthly			3	6.5	1	3.5	7	28.0

dents were female. Most were daughters (40%) or sons (15%). Twenty percent were spouses, 14% were friends or others, and 9% were nieces or nephews. They were on average 61 years of age, ranging from 45 to 84. The majority (73%) were married with families of their own, and a minority (28%) were employed outside the home. Typically, their relative was female, 84 years of age on average, and physically frail with some degree of cognitive impairment. They had lived in the long-term care facility an average of 3.5 years, and their health had deteriorated since admission. An overall response rate of 62.8% was achieved.

FINDINGS

VISITING

Families visited frequently (see Table 1). Close to one half (48%) of family members visited several times a week. One quarter visited once a week, and the remainder was divided between those who visited daily (8%) and those who visited less than weekly (18%). There were no significant differences among respondents with respect to frequency of visiting.

Their visits ranged from a few minutes to several hours and averaged 110 minutes per visit. Whereas the majority believed that they were well prepared or fairly well prepared for visiting, a substantial proportion (35%) felt that they were not at all prepared for visiting. In large measure, they felt that they had surrendered care to the long term-care facility and were uncertain about how best to occupy their time while visiting. Their reasons for visiting related to the provision of instrumental and

expressive support and demonstrated the enduring nature of the emotional bond among family members and the strength of their feelings for each other. Visiting allowed for the continuation of family relationships; facilitated a sense of connectedness among the senior, family, and outside community; and provided the opportunity for ensuring a high quality of care. Less than half of the respondents (43%) rated their visits as enjoyable, and there were many verbatim comments suggesting that the term *enjoyment* did not really capture the nature of their visiting experience.

TASK PERFORMANCE OF FAMILIES

While visiting, family members provided both direct and indirect care. Direct care was defined as "providing care of a hands-on nature," specifically, assisting with bathing, grooming, toileting, mobility, eating, and other care of a personal nature. Indirect care was defined as "those activities related to the organization and management of care," such as the overseeing of care, communicating with staff members, attending meetings, and so on. The majority of care provided by family members was indirect in nature. A substantial minority (40%) viewed their primary responsibility as ensuring that the necessary care was provided for their relative. They observed the care that was provided by staff members and made suggestions about ways to more easily and effectively achieve the desired care outcomes. They acted as advocates, raising issues and intervening in situations when their relative was unable to do so. They also took care of appointments and provided outings such as going for drives, shopping, visiting home, and eating out in restaurants. One third of family members provided transportation as necessary and made efforts to personalize the environment with plants, books, pictures, and so on. Only one quarter (26%) engaged in personal care activities, such as helping with bathing and grooming, with another 20% doing laundry. The provision of specialized medical care was a category of task performance that emerged from an open-ended question. Close to one fifth of family members (19%) reported monitoring the health status of their relative, identifying potential problems such as urinary tract infections, and monitoring medication use. In addition, families performed the "little things" that staff members were unable to do that enhanced

Table 2
Satisfaction With Care

Dimensions of Care	Percentage of Respondents (<i>N</i> = 122)		
	Satisfied	Neutral	Dissatisfied
Medical services	80	15	5
Nursing services	78	14	8
Recreational services	72	21	7
Pastoral care services	70	22	8
Family conferences	70	19	11
Opportunities for involvement	70	12	18
Availability of information	68	18	14
Notification of changes in relative's health status	67	12	21
Opportunities for relative to interact socially	67	22	11
Meal preparation and services	67	28	5
Housekeeping and laundry services	62	20	18
Overall environmental atmosphere	60	22	8

the quality of life of their relative. These activities included making certain that birthdays and special occasions were celebrated, arranging for visits from friends and relatives, providing special foods, and running errands.

In response to an open-ended question asking about their most and least pleasant care-related activity, respondents reported discussing family activities, making sure residents were comfortable, and participating in social activities such as watching TV and going for walks as the most pleasant activities they engaged in while visiting. Their least pleasant activities were being ignored by staff members, hearing about pain, dealing with confusion, and having to say good-bye at the end of a visit.

SATISFACTION WITH CARE

The majority of family members were satisfied with the institutional care provided their relative (see Table 2). This was particularly so for medical and nursing services. Close to one third, however, found information sharing and communication about their relative's health status less than optimal. In addition, they were least satisfied with food, housekeeping, laundry

services, and the overall environmental atmosphere of the long-term care facilities.

In response to an open-ended question asking what they valued most highly about the care of their relative, there were many comments about the level of care that was provided in the long-term care facility that families could no longer provide at home. These comments suggested that respondents felt assured that their relative was now in a safe environment with round-the-clock supervision. There were also many comments about the importance of their relationships with staff members in ensuring a high quality of care for their relative.

LEARNING NEEDS, RESOURCES, AND PREFERRED LEARNING STRATEGIES

The majority of care-related learning needs were affective and interactional in nature. Family members (61%) indicated an interest in learning to better provide emotional support. Their difficulties ranged from a father who rarely spoke to a mother who no longer recognized anyone to another mother who was disgruntled most of the time. They also felt the need to act as advocates but were unsure about how best to do this. One daughter described her fear of antagonizing the staff members and making matters worse for her mother. Another worried that her expectations were unrealistic given the realities of institutional life.

Family members reported dealing with disruptive behavior such as repetitive wandering, questioning, and confusion as problematic. Others (43%) were concerned about the number of falls their relative had experienced and ways of preventing these falls. In addition, learning to prevent and deal with their elderly relative's pain and knowing how to promote his or her emotional health were problematic for a substantial proportion of family members (40%). They also found understanding the long-term care system, managing their own personal stress, and working effectively with staff members difficult.

Other learning needs related to knowing when medical investigations of symptoms and treatment decision were appropriate. One woman described the uncertainty she experienced in deciding whether to agree to invasive cardiac testing for her 88-year-old mother who had been frail for years and was now very confused. A minority of family members (28%)

found assisting with mobility difficult. A daughter expressed frustration with the equipment used to transfer her father, which she felt was awkward and unsafe.

The majority of family members (80%) reported that their major source of learning derived from members of the staff. A substantial proportion (58%) also reported physicians as a learning resource, and 50% used books, newspaper articles, and magazines for assistance in learning to carry out new caregiving responsibilities. These related primarily to information about their relative's health status, medical treatment, and ways of negotiating the health care system. Their preferred learning strategies were interacting with staff members who had special expertise (90%), members of other families with similar problems (62%), and guest speakers (50%). Information sessions provided by long-term care facilities were not well attended. Only 50% reported attending any information sessions within the past year.

DISCUSSION

This study examined the involvement of families in the care of seniors following admission to a long-term care facility. Findings revealed that residents were not abandoned by their families, who remained involved and continued to participate in their care in a number of ways. Family members visited frequently. There were no significant differences among respondents with respect to visiting and task performance. They advocated for care, provided care, organized care, and managed care. These findings are congruent with those of other studies (Keefe & Fancey, 2000; Ross et al., 1997, 1998) that found the majority of family members continued to visit and provide care following admission of their relative to a long-term care facility.

Family caregivers were in large measure daughters or spouses who were acutely aware of the deteriorating health of their elderly relative. As in previous studies, family caregiving occurred within the context of visiting and long-term relationships. In addition, family caregivers had a long history of personal commitment and obligation (Aronson, 1991; Friedmann et al., 1999; Ross et al., 1997).

Visiting has been reported as both a task to be performed and the context for continuity of family relationships. In this study, although the majority of family members visited frequently, the majority did not enjoy visiting. This finding is congruent with the few other studies that have investigated visiting (Grau et al., 1993; Ross et al., 1998). Adjustment to the institutionalization of a relative is often difficult, with family members experiencing dissatisfaction with aspects of institutional care, feelings of guilt and sadness, and uncertainty about their role within the institution. It may be that the term *enjoy* is not an appropriate descriptor for visiting, failing to capture the nature of the experience. It may also be that the institutional setting is foreign, and families require assistance to learn how to best occupy their time and energy while visiting.

With respect to the provision of care, family members continued to assume responsibility for ensuring that their elderly relative received the care he or she needed. They were very watchful of both the resident and the staff members. The bulk of their care was indirect in nature and involved advocating for, organizing, managing, and supervising care. They also tried to ensure the emotional well-being of their relative. Such care can be viewed as nontechnical in nature in that it does not involve the hands-on care required for bathing, grooming, or manipulating technology. A minority, however, also performed the technical tasks associated with personal care. In addition, a minority reported carrying out activities related to the monitoring and assessment of their relative's health status, medical treatment, and medication use. These findings suggest that following institutionalization, although families transfer some responsibility for technical tasks to staff members (Bowers, 1988; Dempsey & Pruchno, 1993), they continue to provide assistance with both technical and nontechnical tasks (Keefe & Fancey, 2000; Ross et al., 1997). In this way, families collaborate with staff members in the provision of care. The nature of these relationships has been categorized as both supplementary (task sharing) and complementary (task segregation) (Penning & Keating, 2000).

In large measure, family members were satisfied with the institutional care their relative received, in particular, the medical and nursing services. However, they were less satisfied with the availability of information about the long-term care

system, notification about changes in relatives' health status, and the overall physical environment of the long-term care facility. Close to one third of respondents were also less than satisfied with food, housekeeping, and laundry services. These findings, although similar to other studies (Maas, Buckwalter, & Kelley, 1991), must be interpreted with caution. The questions were fairly general in nature and did not allow much room for elaboration. Responses may also have reflected a social desirability bias. It may be easier to be less satisfied with food and housekeeping services when compared with nursing and medical services. Nevertheless, as with other studies of long-term care facilities (Ross et al., 1997, 1998; Zinn, Lavizzo-Mourey, & Taylor, 1993), these data can be used to identify modifiable features of long-term care facilities that influence satisfaction with care. Policies and practices can then be altered to increase families' sense of satisfaction.

Although information sessions were provided periodically for families in all facilities, only a small proportion of family members actually attended. This finding is similar to that of other studies (Keefe & Fancey, 2000; Ross et al., 1997) reporting a low attendance at organized educational sessions for families. Family members, however, sought to learn from staff members and others how to best ensure the physical and emotional well-being of their relative. They also looked for assistance from staff members to learn to deal with the difficult behavior associated with cognitive impairment. Finally, they sought ways of discovering how to interact most effectively with staff members. An increased commitment on the part of long-term care facilities to family learning may go a long way toward increasing satisfaction with institutional aspects of care (Ross, Carswell, & Aminzadeh, 2001). Families are not always prepared for the arduousness of the care they provide following the institutionalization of their elderly relatives. They need support. Findings from this study provide direction for policy and practice.

RECOMMENDATIONS FOR POLICY AND PRACTICE

There is a need to broaden the conceptualization of family caregiving within institutional settings. The responsibilities for

care that family members assume are multidimensional in nature. They involve not only technical tasks related to personal care but also nontechnical activities associated with ensuring the physical and emotional well-being of elderly relatives. They also include activities of an advocacy, managerial, and supervisory nature. Administrators and staff members of long-term care facilities need to provide support for families' continued involvement with their elderly relative. This is not to suggest that increased responsibility for care should be placed on families but rather that they should be supported in the care they are willing and able to provide. Family care should be viewed as both complementary and supplementary to that provided by staff members and not a substitution for formal care. Strategies for supporting family care include the following.

Facilitating the visiting experience. Families frequently have ambiguous feelings about the admission of an elderly relative to a long-term care facility. On one hand, they are relieved that their relative will receive professional care; on the other hand, many feel that they have abandoned the relative to strangers. Visiting can be a difficult and demoralizing experience. Family members need to become familiar with the routines and practices of the organization. They need to get to know the staff members who will provide care for their relative. They need to understand their responsibilities in relation to those of the staff members. Long-term care facilities can help by developing policies and programs that make the visiting experience as pleasant and meaningful as possible. Social activities in which both the resident and family members can engage, such as listening to music, watching old movies, tending plants, sharing a cup of tea, or any other number of activities, can help to make the visiting experience comfortable and enriching for both families and residents.

Strengthening support for the provision of family care. Families need to be involved in care-related decision making as members of the multidisciplinary team. They are an important resource for both residents and staff members. They often have a long history of providing care for their elderly relative prior to admission, have biographical knowledge of the resident, and

can provide suggestions about effective ways of meeting their physical and emotional needs. It is also important for staff members to share information with family members about changes in residents' health status, including information about diagnoses, prognoses, treatment, and care options. Individual consultations and educational activities of a group nature that are targeted to the needs of family members will go a long way toward supporting the care they can provide. As care needs escalate, it is also important to ensure that family members do not feel overwhelmed or uncertain about their role in the provision of care. They may require assistance to meet the changing care requirements that evolve over time as a result of deteriorating health. Families make a substantial contribution to the quality of life of residents and therefore play an important role in supplementing care in long-term care facilities. They need support.

Creating a comfortable environment. Following admission, the long-term care facility becomes the resident's home. It needs to be as attractive and pleasant as possible and have meaning for the resident and family. Despite the fact that long-term care facilities are underresourced from a human and material perspective, the environment should be as pleasant, attractive, and comfortable as possible. Ensuring that the formal care is technically and interpersonally excellent will provide families with confidence that their relative is being well cared for. Providing space for private visits and places to go such as a snack bar, library, and chapel will allow for movement and variety within the institution. Ensuring meals that are nutritious, attractive, and offer choice; personalizing the environment with pictures, plants, reading material, and personal mementos; and creating opportunities for social interaction will help to generate a feeling of home for residents and families. Creating opportunities for involvement with staff members and other family members can help families experience a sense of community within the long-term care facility. Ensuring a supportive work environment for staff members that values the affective and interpersonal aspects of care will also serve to create a meaningful and comfortable environment for residents and families.

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Commentary

Commentary by Janice Penrod

Family caregiving after the placement of an older adult into long-term care is a phenomenon that is well-known to clinicians regardless of the type of health system in which they function. We all know of wives who visit daily around mealtimes regardless of the weather or other demands on their lives. We know of the children who dutifully visit at regular intervals, scanning their loved one and the immediate surroundings for changes during their rather brief visits. We know of the distant loved ones who arrive on holidays or special occasions in an attempt to maintain some connection to the older relative. These are, as these authors point out, acts of commitment to long-standing relationships; or taken one step further, they are acts of love that transcend systems of care and are applicable far beyond the constraints of the Canadian system of socialized medicine.

Despite our familiarity with these universal images of family caregiving after institutionalization, these authors cogently argue that we know little about what the visiting experience is like for family members. Observation of visible task performance provides a superficial glimpse of what is going on during these visits, but understanding these actions from the perspectives of the family members falls woefully short. Thus, this study opens investigation into the family members' perspectives of caring for a loved one who resides in a nursing home.

The study design provided access to a relatively large number of caregivers ($N = 122$) from nine different care facilities that represented a range of important facility characteristics (e.g., urban/rural setting, size, and type of ownership). The described sampling techniques are somewhat limited by the initial identification of potential participants by facility staff members. It would be interesting to know if any criteria for selection were provided to staff members to preclude biases toward maximizing the phenomenon of interest by recom-

mending only the most prominent family visitors, thus skewing the findings toward a certain type of family caregiver. Furthermore, it would be of interest to know more of the derived sampling frame from which a "random sample of 194" was then invited to participate. Although the implemented design strategies support the exploratory, descriptive purpose of the study, further clarification of sampling and selection would strengthen the study.

The authors' discussion of instrumentation indicates careful attention to their posed research questions. Aspects of visiting, task performance, satisfaction with institutional care, and learning needs were addressed methodically using both fixed-choice and open-ended question formats. Data were subsequently scored or coded into emergent themes, then analyzed to provide a descriptive level of findings. Although these techniques were appropriate for this study, a persistent question of change over time arose with each primary variable. The average length of institutionalization of the older adult was 3.5 years in this sample. Did the caregivers' perceptions of frequency, duration, and reasons for visiting change over this extended period of time? Did their views on task performance shift between direct and indirect care activities over this time? Did their satisfaction wax and wane with the older adults' changing care demands? And was there any evidence of more dynamic learning needs as the caregivers lived through the initial admission and orientation processes followed by the deteriorating health status of their loved ones?

Although beyond the scope of this study, these questions focusing on how the caregivers' views of caregiving postplacement dynamically change over time demand further attention. Pragmatically, clinicians sense subtle yet important changes in caregiving patterns over time. What meaning do these changes hold from a family perspective? How can we tailor interventions to support caregivers through this trajectory of continued commitment?

Dynamic change in caregiving patterns is a complex phenomenon, for as the clinicians alter treatment strategies to address changing health states in the older adult, new opportunities or challenges for caregivers arise. Although the caregivers may "surrender care" on one level, this study shows that

continued involvement marks caregiving after institutionalization. The power of the relationship forged between the experts and the families is highlighted by the finding that the vast majority of these caregivers reported that their major source of learning was from staff members (80%), and further, they preferred learning from staff members with expertise (90%). Couple this finding with Gubrium's (1991) well-known insights regarding families as interlopers and intruders, and a significant question arises: How can we harness the power of the provider-family caregiver relationship to positively influence the experience of continued caregiving postinstitutionalization?

Measuring the degree of enjoyment experienced during caregiver visits continues to be a striking contrast to what we know of this difficult life experience. Although some activities undertaken by caregivers may provide a degree of enjoyment, in itself, caregiving is a demanding and very often stressful undertaking. Ross, Rosenthal, and Dawson (1993) also indicated these concerns regarding the appropriateness of the concept of enjoyment in relation to caregiving.

In their discussion of findings, these authors cite the difficulties of adjustment into a new caregiving role postplacement and then echo an acknowledgement that *enjoyment* may not capture the nature of the experience. Considering that these caregivers have on average 3½ years of experience as caregivers of an institutionalized loved one, "adjustment to institutionalization" does not seem the most plausible reason underlying the lack of enjoyment of these activities. What, then, is the nature of caregiving from the families' perspectives? What concept more accurately captures this experience in a manner that enables measurement and targeted intervention? Again, investigation of the caregiving trajectory over time is indicated by these queries.

Recommendations for policy and practice are developed around the following three areas of concern that, again, transcend the boundaries of organized health care systems: facilitating the visiting experience, strengthening the support for the provision of family care, and creating a comfortable environment. Each area develops strategies that are plausible and perhaps familiar to geriatric clinicians. More important, however, this study reveals that transitioning into a caregiving role for an institutionalized loved one is not a short-term endeavor.

After more than 3 years in this role, these caregivers identified ongoing educational, informational, and personal needs. These findings support the notion that such transitions are blurred rather than crisp and require ongoing assessment and timely intervention along with programmatic strategies.

Given the insights provided by this study and integrated with earlier work, what have we learned of this experience? Earlier, Johnson (1990) described how daughters felt excluded from care decisions following placement of a parent and encouraged "greater involvement of nurses to facilitate family oriented care" (p. 10). In 1991, Dellasega admonished nurses to dismiss the assumption that caregiving activities and related stresses end with placement and called for interventions to help ease caregivers through difficult transitions in caring. Ross et al. (1993) reviewed selected literature related to caregiving (primarily from the 1970s through early 1990s) and revealed initial insights on relinquishing care, visiting, and continued involvement in task performance.

Such historical insights regarding issues surrounding this difficult transition in caregiving are not limited to the professional literature. In the lay literature, early handbooks for caregivers highlighted similar concerns, advocating that families explore and negotiate active roles in care after placement. In 1991, Karr addressed the family's role in nursing home care and summarized:

The custom of families being socialized to accept a peripheral role in institutional care is an unfortunate by-product of health care professionalism, which fails to consider the valuable role families can and do play in health care. Gradually that custom is changing, primarily as families recognize they must become an integral part of a team approach in the care of their institutionalized elder. (p. 15)

A decade later, this article contributes to our deeper understanding of caregiving postplacement. This is an important topic, one that will only increase in significance with the global implications of impending demographic trends. But the time has come to advance science beyond description of *what is* to begin exploring *what can be done* to maximize the potential contributions of caregivers while carefully attending to their needs.

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This study observed the public health nurse's and the patient's activity level during blood pressure measurement and the kind of nonpharmacological treatment that was given. Using the Nurse Practitioner Rating Form, three structured observations were made of 21 public health nurses at their offices at health care centers. The nurses were randomly selected from 22 health care centers in Southern Sweden. The public health nurses used nonpharmacological treatment at 18 out of 63 visits, mainly diet and physical activity. The nonpharmacological conversation had a psychosocial aspect at 15 observations. During the visits, most of the facts and advice concerned somatic aspects of health promotion. Almost all patients were asked about their medication. At more than half of the observations, the nurses and the patients met at the same medium or high communication level. The nurses need training and information about nonpharmacological treatment to practice health promotion in hypertension care.

Counseling Hypertensive Patients

An Observational Study of 21 Public Health Nurses

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This article presents what public health nurses discussed with patients at visits for blood pressure measurement and the activity level the nurses and patients had in their communication. The care provided by nurses of patients with moderately high blood pressure has been evaluated in a review by the Swedish Council on Technology Assessment in Health Care (1998). The nurses were described as team members and

leaders; they mostly measured the blood pressure, gave advice, informed and educated the patients about nonpharmacological treatment with a holistic and psychosocial approach, and acted as translators for the physician. The reviewed studies were mostly intervention studies measuring outcomes such as the level of blood pressure, weight, physical activity, compliance with medication, and follow-up visits when a nurse participated in hypertension care or managed the care on her own following a program. These studies did not describe what the nurses said or how the nurses actually talked to the patients or the communication and interaction between patient and nurse in conversation in daily work at ordinary clinics.

**BACKGROUND: NONPHARMACOLOGICAL
TREATMENT AND ECONOMY, SELF-CARE
ASPECTS, AND PSYCHOSOCIAL APPROACH**

Nonpharmacological treatment means educating the patient about the importance of stopping smoking, reducing alcohol intake, weight reduction, diet, physical activity, and stress management. Nonpharmacological treatment is the first choice of treatment for moderately high blood pressure (Swedish Council on Technology Assessment in Health Care, 1995). Stopping smoking is most important for reducing the risk of cardiovascular diseases. A high intake of alcohol can lead to high blood pressure. Increased physical activity can lower the blood pressure partly through the increased activity itself but also through loss of weight (de Simone, Mancini, Mainenti, Turco, & Ferrara, 1992; Kaplan, 1989; Laidlaw & Chockalingam, 1990). Stress can be experienced if the individual does not have the opportunity to exercise control over his or her life situation. The stress can lead to tension, which raises blood pressure and can increase the risk of cardiovascular diseases (Swedish Council on Technology Assessment in Health Care, 1997).

There is an economic benefit from hypertensive care nurses performing nonpharmacological treatment, as they have lower salaries than the physicians, and nonpharmacological treatment costs less than pharmacological treatment (Fuchs et al., 1993; Pheley et al., 1995). In Sweden, the cost of antihypertensive treatment was SEK 3,000/patient (\$500) in 1992, and

500,000 to 600,000 patients are treated in Sweden every year (Swedish Council on Technology Assessment in Health Care, 1995).

Self-care aspects. Counseling and education should aim to help people to help themselves. According to Tschudin (1995), the patient has responsibility for changes and the ability to solve problems. The public health nurse should take into account the patient's own ability when giving advice about diet and physical activity for self-care. Orem (1995) has in her theory a thesis that the human being is a social being. Everybody strives for self-care to support and take care of himself or herself and suffers if he or she cannot. The ability differs between different people depending on capacity and circumstances. If a self-care deficit occurs because of surrounding factors, there will be an imbalance between needs and ability. In the event of imbalance, the nurse uses a nursing system and organizes special professional caring activities to stimulate and strengthen the patient to take care of himself or herself.

A patient-oriented approach more often leads to changed living habits (Arborelius, Krakau, & Bremberg, 1992). In Becker's health belief model, goal setting, decision making, and social learning are integrated. The individual makes his or her own decision as to perceived positive or negative aspects of his or her action and decides what is important for his or her own health (Polit & Hungler, 1999). The staff member can give support and help the patient by using biological markers (Arborelius, 1994). A certain lifestyle can be described on the personal level as an approach to life that shows the proper attitude to health, disease, work, spare time, food, and physical activity. Different personalities differ in their ability to be motivated to make lifestyle changes (Tamm, 1990).

Kjellgren, Ahlner, and Säljö (1995) studied patients' compliance with antihypertensive medication in a review. Traditionally, the patient is told by the physician to take a pill by one-way communication. If the patient is instead encouraged to take part in decisions, is well informed, and is prescribed medicine to be taken once a day, the compliance with treatment increases. Motivating the patient to treatment is a great part of the nurse's psychosocial work.

Psychosocial approach. In Sweden, most patients are told to go to their public health nurse at their local health care center when they want to check their blood pressure. The nurse should have a psychosocial and holistic approach to the patient's health and life situation. Motivating the patient is a great part of the psychosocial work. Counseling should be connected to the patient's social life to help the patient understand how different factors in the environment affect him or her and help him or her to handle the problems (Caraher, 1998). The holistic approach means seeing the patient in his or her social context. Approved codetermination for the patient is based on the staff member's knowledge of the patient's situation at home, a holistic approach, empathy, individually adjusted treatment, and the patient's participation in decision making and trust in the staff members (Toop, 1998).

The Swedish public health nurse's special area includes health promotion, including working for public health. The health-promoting work is health oriented to make people capable of improving and increasing their control over their health (Annand, 1992). At a health care center, the nurse can manage special surgeries for patients who want to stop smoking and for patients with diabetes, allergy, incontinence, and hypertension. The nurse can identify health risks in the patient's lifestyle and counsel and educate individually or in groups (Socialstyrelsens allmänna råd, 1995).

PURPOSE

Within the area of self-care, the public health nurse should counsel and educate the hypertensive patient about nonpharmacological treatment. It is not known how efficiently spread the knowledge of this treatment is among the nurses and how much of it is used. The purpose of this study was to observe what kind of nonpharmacological treatment was given by the nurses during visits for blood pressure measurement and to measure the nurse's and the patient's activity level using the Nurse Practitioner Rating Form (NPRF) instrument.

METHODS

STUDY POPULATION, NPRF INSTRUMENT: GENERAL DESCRIPTION, ACTIVITY AREA, CONTENT AREA, GLOBAL SCALE, AND VALIDITY AND RELIABILITY TESTING

Selection of study population. A district of Skåne County was selected. There are 22 health care centers employing 114 public health nurses. Nurses without special education for public health nurses and with less experience than 2 years were excluded. According to the local direction of levels of competence, 2 years' training is a minimum for being assessed as a competent public health nurse (Benner, 1984). The nurses at the first author's health care center were also excluded as they had been involved in the testing of the instrument. Of the remaining 99 nurses, 25 were randomly selected. Four nurses dropped out on account of not working with adult patients or of being on sick leave. The remaining 21 nurses had been working 15 to 40 years since their registration and 3 to 22 years as public health nurses since their special education.

The study was introduced to the nurses with a letter a month before they were contacted by phone to make an appointment. Informed written consent was obtained. When patients who were to have their blood pressure measured arrived at the clinic's open hour, the patients were asked if they approved of the observer's presence in the room, and none of them disapproved. All observations were carried out by one of the authors (ED), and during the open hour that day, a maximum of three observations were performed, mostly one or two. When the nurse left the room to let the patient rest, the author left too so as not to disturb the patient. The study forms a component part of the clinic's quality progress (Socialstyrelsens allmänna råd, 1996) and was conducted with permission from the head physician of the primary care area. Approval was obtained from the local ethics committee.

NPRF instrument, general description. A structured nonparticipating observation was used to investigate what kind of nonpharmacological treatment was given by the nurses and to measure the nurse's and the patient's activity level using the NPRF instrument (Prescott, Jacox, Collar, & Goodwin, 1981)

while the blood pressure was measured. The instrument contains the following three parts: activity area, content area, and global scale.

NPRF instrument, activity area. The first part, activity area, deals with the kind of tasks that are performed with registration every 30 seconds, including history, physical examination, treatment, advice and instructions, factual information, explanation, demonstration, consultation, out of room, and other. Any activity that was performed during a 30-second observation period was registered, even if the activity did not last for a whole 30 seconds. During one 30-second period there could be several activities going on that were registered. For example, conversation about treatment and facts could occur during application of the sphygmomanometer. *Out of room* refers to the time when the patient was left alone to rest before the measurement and *other* refers to silence or small talk.

NPRF instrument, content area. The second part, content area, deals with psychosocial and somatic aspects of the existing problem and of the health promotion in the conversation. Somatic aspects of existing problems could be a question of pharmacological discussions, visits to the physician, hospital visits, examinations the patient had undergone, and changes in the body as a consequence of high or low blood pressure. Psychosocial aspects mirrored the patient's emotional experience of, for instance, side effects of medicine, hospital visits, worries about taking care of relatives, and stress at work.

Somatic and psychosocial aspects of health promotion relate to when nonpharmacological treatment was mentioned or other problems were taken care of. *Somatic* aspects means a strict somatic approach in the conversation, whereas *psychosocial* aspects of health promotion means that the counseling was given with the aim of increasing the patient's understanding and motivating a lifestyle change. Other problems could include explaining the effects and side effects of drugs, the need for physician consultation, discussions about results of tests, or the physiology of blood pressure.

The nurses could not be asked whether the patient had received any nonpharmacological treatment before because there was usually no access to the patient's record in the exam-

ination room. At several offices, the nurses did not have the responsibility for certain patients or a specific catchment area. Instead, the nurses let the patients in one after another. This meant that some of the patients were new to the nurse, although the patient might have been to the office before.

NPRF instrument, global scale. The third part, global scale, is a scale from 1 to 7 where both the patient and the nurse are assessed as to their level of activity in the encounter. Level 2 (low) on the Nurse Practitioner Communication Scale was briefly defined as "Nurse does not attempt to identify client's feelings, has a disinterested manner, and does not individualize the approach." Level 4 (medium) was defined as "Nurse elicits concerns or feelings of client but does not explore these in depth, has a friendly and interested manner, and individualizes approach to client in some areas." Finally, Level 6 (high) was defined as "Nurse consistently explores client's feelings or concerns in depth; has a supportive, empathetic, and attentive manner; and individualizes approach to client in all areas."

The patient's communication activity at Level 2 (low) was defined as "Client cannot identify problems, is inattentive, and responds with 'I don't know' or with poorly thought out answers." Level 4 (medium) was defined as "Client gives appropriate responses to questions, is comfortable and cooperative during the visit, and identifies potential problems." Level 6 (high) was defined as "Client recognizes responsibility for own health care, appears spontaneous and positive, and is able to identify an approach to problems."

Validity and reliability testing. The authors of the NPRF instrument (Goodwin, Prescott, Jacox, & Collar, 1981) examined its reliability and validity. The authors said that when the instrument is used in its present form, close attention needs to be paid to the global scales during rater training, and interrater reliability must be determined prior to actual use. They also said that there is evidence for the validity of the observation form, especially the teaching-activity categories. The validity of the global scales is still unknown.

Three observations of each nurse were estimated after testing to be enough to cover the internal validity of the instrument in this study to capture the technique the nurse had for mea-

asuring blood pressure (Polit & Hungler, 1999). To control the reliability in the observation situation, the instrument was tested with parallel observations with another public health nurse at the workplace of one of the authors (ED). The instrument was found to be easy to fill in but required some practice to quickly define somatic and psychosocial aspects of problems and health promotion in the conversations.

STATISTICS

All statistical calculations were carried out with SPSS 7.0. Normal distribution was investigated for the quantitative variables. Hypothesis testing of nonnormally distributed variables was performed using a nonparametric method, the Mann-Whitney *U* test. Chi-square test was used when comparing qualitative variables. Calculating correlations was carried out using Spearman's rank test. The significance level was set at $p < .05$.

FINDINGS

TIME DISTRIBUTION, MEDICATION, CONVERSATION CONTENT, NONPHARMACOLOGICAL TREATMENT, AND COMMUNICATION ACTIVITY

Time distribution. A visit for blood pressure measurement to the public health nurse lasted on average 15.2 minutes ($SD = 6.5$), that is, 31 periods. Out of this time, measuring the blood pressure and taking the pulse lasted 6 periods. The rest of the time, the patient rested and talked to the nurse. The patients were interviewed for 1 to 23 periods ($MD = 7$) about their illness history (see Table 1). For 10 patients (16%), it was the first visit. Five (8%) of these patients were interviewed during 4 periods (95% CI = 5, 15), and the rest were interviewed during 8 to 23 periods. For patients on return visits ($n = 53$), the interview lasted for 6 periods (95% CI = 6, 8). There is no statistically significant association between longer interviews and patients' first visits (Mann-Whitney *U* test). Advice and facts occurred most often in the conversations and were mostly given during 1 to 5 periods. Explanations were used during 1 period at 15

Table 1
Activity Area: Number of 30-Second Periods That Were Consumed for History Taking, Advice, Facts, and Explanations in the Conversations

<i>n</i> of Periods	Time for History Taking <i>n</i> of Patients	Time for Advice <i>n</i> of Patients	Time for Facts <i>n</i> of Patients	Time for Explanation <i>n</i> of Patients
0	0	5	1	42
1	1	23	11	15
2	6	20	23	3
3	6	7	9	0
4 to 5	16	7	15	3
6 to 7	11	1	4	0
8 to 9	7	0	0	0
10 to 11	6	0	0	0
12 to 23	10	0	0	0
Total	63	63	63	63

NOTE: One or two activities could occur during the same period.

observations (24%) and not at all at 42 (67%) observations. No time was used for demonstration and consultation.

Medication. At 54 (86%) out of the 63 observations, the patients were asked if they were taking any medication. At new visits, 80% ($n = 8$) of the patients were asked this question, and at follow-up visits, it was put to 87% ($n = 46$). Fifty-seven percent ($n = 36$) answered that they were on antihypertensive medication, 33% ($n = 21$) were not medicated, and 1 patient said that she did not take the prescribed medicine.

Conversation content. All the conversations had a somatic approach to existing problems, with 68% ($n = 43$) of them lasting for two to nine periods (see Table 2). The conversations also covered a psychosocial aspect of existing problems during one period in 29% ($n = 18$) of the observations. In half of the cases, there was no psychosocial aspect. In 16 conversations (26%), there was a psychosocial angle on the problems for two to nine periods.

Nonpharmacological treatment. The nurses used nonpharmacological treatment at 18 observations (28%). These 18 blood pressure measurements were performed by 12 nurses. With some of these patients, the nurses discussed all

Table 2
 Content Area: Distribution of the 30-Second Periods Devoted to Somatic and Psychosocial Aspects of Existing Problems and Health Promotion

n of Periods	Existing Problems		Health Promotion	
	Somatic Aspects n of Patients	Psychosocial Aspects n of Patients	Somatic Aspects n of Patients	Psychosocial Aspects n of Patients
0	0	29	51	48
1	0	18	2	11
2	4	5	7	1
3	6	0	3	3
4 to 5	12	6	0	0
6 to 7	12	4	0	0
8 to 9	9	1	0	0
10 to 11	7	0	0	0
12 to 19	13	0	0	0
Total	63	63	63	63

NOTE: The somatic and psychosocial aspects could occur interchangeably with each other within a 30-second period.

parts of nonpharmacological treatment, but mostly they did not. The most common topics were discussions about diet and physical activity, and the least common topic was alcohol. Twelve patients (19%) were informed about somatic aspects and 15 (25%) patients about psychosocial aspects of the nonpharmacological treatment (Table 2). There is no significant statistical evidence that the longer the public health nurse had worked in primary care the more often she used nonpharmacological treatment (Mann-Whitney *U* test). Nonpharmacological treatment was used at 40% ($n = 4$) of the new visits and at 28% ($n = 14$) of the return visits, but there is no statistically significant evidence that it is used more often at new visits than at return visits (chi-square test). The more years the public health nurse had been working in primary care, the more likely she was to refer to psychosocial ($p = 0.024$) and somatic aspects ($p = 0.026$) of health promotion (Spearman's rank test). When asked, 97% ($n = 61$) of the nurses thought that the content of the visit was complete.

Communication activity. The nurses' communication activity on the global scale was estimated mostly at Levels 4 and 5 (see Table 3). The patient's communication activity was estimated

Table 3
Global Scale: Frequencies for the Activity Levels at Which the Nurses and Patients Met

Health Nurses' Communication Activity Level	Patients' Communication Activity Level							Total (Nurses)
	(Low)		(Medium)			(High)		
Activity Level	1	2	3	4	5	6	7	
1								
2 (low)								
3				1		1		2
4 (medium)				27	4	5		36
5				3	4	6		13
6 (high)				1	2	6		9
7						3		3
Total (patients)				32	10	21		63

NOTE: For example, in 27 observations, the nurse's and the patient's activity level met at 4, and in 5 observations, the nurse's activity level was at 4 and the patient's at 6.

mostly at Level 4. At one third of the observations, the patients were on Level 6. There is a correlation according to Spearman's test ($p < .01$) between the nurses' and the patients' communication activity. At 27 (43%) encounters out of 63, the nurse and patient met at Level 4, that is, the nurses were kind and interested and the patients responded by being relaxed and cooperative. At 16 (25%) observations, the patients' activity was on the higher level of 5 or 6 and the nurses at Level 3, 4, or 5. The nurses had a higher activity level (Level 5, 6, or 7) on 9 (14%) occasions, and the patient responded with a lower level of 4, 5, or 6.

DISCUSSION

According to the observations, history taking took less time at the patient's first visit than at return visits. The public health nurses used nonpharmacological treatment at only 18 (28%) out of 63 visits for blood pressure measurement. The nonpharmacological conversation had a psychosocial aspect at 15 (25%) observations. During the visits, most of the facts and advice concerned somatic aspects of health promotion. The more years the nurse had been working in primary care,

the more likely she was to use health promotion. Almost every patient was asked about his or her medication. During more than half of the observations, the nurses and the patients met at the same communication level.

When patients were asked if they were on medication, only one patient said he or she was not taking the prescribed medicine. Often patients exaggerate their compliance (Balzovjech & Hnilica, 1993; Kjellgren, 1998; Kjellgren et al., 1995; Kjellgren, Svensson, Ahlner, & Säljö, 1998), but we cannot know as the nurses did not ask whether the patient actually took their medicine. Johnson (1993) said in her observational study of nurse practitioners' work, "Much effort went into unraveling the mystery of the patient's medication regimen—what was ordered versus what was changed versus what the patient was really taking" (p. 155). It would have been easy to check this at the health care centers that had computerized records. This check would have been even more important as the physicians are known not to use nonpharmacological treatment to any great extent (Arborelius & Österberg, 1995; Kjellgren, 1998; Kjellgren et al., 1998; Wilhelmsen & Strasser, 1993).

The time consumed for history taking was not longer at the first visits, rather the reverse, which is remarkable as more questions would be expected because the nurse and patient had not met before. One interpretation of this finding is that the nurses are hesitant about being too intimate with the patient at their first meeting and wait until they get more acquainted.

Two thirds of the problem-oriented conversations were concentrated on somatic aspects, but the health promotion conversations were equally divided between somatic and psychosocial aspects. There was a significant association between the more years a public health nurse had been working and her likelihood of referring to psychosocial aspects of health promotion, which means a greater security and ability to initiate a discussion about problems or to listen to the patient talking about the subject. Johnson (1993) reported from a study that nurse practitioners individualized the approach to the patient and were skilled at developing an agreement with the patient based on experience, which gave assurance in the role as a nurse.

Arborelius et al. (1992) reported from interviews with general practitioners and public health nurses that these individuals

thought health promotion was important, but that they were doubtful and disappointed or just disappointed because they affected the patient's behavior so little. This attitude may possibly explain why so few of the nurses in this study used nonpharmacological treatment. On the other hand, if the nurses were educated in nonpharmacological treatment, there would be a greater chance for the patient to have that kind of treatment. The conversation would then, as individualized counseling, be naturally more psychosocial in orientation as this is the special area of the public health nurses. The nurses acted in good faith, as almost all of them stated the visit was complete.

At 17 observations, the nurses were assessed as being one step lower on the communication scale than the patients, and at 9 observations, the nurses were one step higher. Although the blood pressure measurement and the nonpharmacological treatment were discussed at the visits, it was not always necessary for the nurse to be engaged at Level 6 ("Nurse consistently explores client's feelings or concerns in depth; has a supportive, empathetic, and attentive manner; and individualizes approach to client in all areas") but sufficient to stay at the fourth level ("Nurse elicits concerns or feelings of client but does not explore these in depth, has a friendly and interested manner, and individualizes approach to client in some areas"). As the nurses did not use nonpharmacological treatment frequently, they could not attain Level 6 with an individualized approach in all areas. On the other hand, one third of the patients were interested and recognized their responsibility for their own health care, and they appeared spontaneous and positive. The engagement is, of course, based on the personality and ability of the nurses and patients to express themselves.

The use of alcohol was asked about at 2 observations, compared to diet, which was talked about at 10, and physical activity at 13 observations. There are apparently obstacles to talking about alcohol (Adelswärd & Sachs, 1996). Adelswärd and Sachs (1996) studied a nurse's conversation with 28 patients about the risks of cardiovascular diseases. They described how the nurse used herself as an instrument to talk to the patient about his or her risk behavior without letting the patient lose face. Although the message was presented indirectly, the patients understood it. In a similar study, Aminoff (1998) found

that the patients felt free to introduce many different subjects and to discuss the situation at home with the public health nurse. Creating a concord with patients is a female way of working, according to studies of nurses' work at their own clinics and teamwork with physicians (Swedish Council on Technology Assessment in Health Care, 1998). This approach increased the compliance with medication, counseling, and follow-up visits.

At some health care centers, the nurses did not have their own patients; instead, the nurses just called for the next patient when they were finished with one. In that way, the patient could be new to a nurse even if he or she had been to the office several times before. To increase continuity, the organization has to be changed. The patient has a good opportunity to get better information, be followed up on, and collaborate with the nurse if he or she sees the same nurse at every appointment. The nurse should be able to prepare the visit by reading the record, have a chance to get to know the patient, and complete and finish a conversation started at an earlier visit. That relationship with the patient is the base on which the nurse can achieve cooperation with the patients to make them active in their self-care (Orem, 1995).

The NPRF was the only instrument to be found for observation of a nurse in primary care. The instrument has never been used in Sweden before. Courtney and Rice (1997) criticized it for being too limited and for not classifying important activities performed by a nurse practitioner. Activities such as verbal and nonverbal communication, interaction about self-care decisions, improving self-esteem, establishing contracts, and therapeutic decisions in interaction with the patient are not illuminated. Kasch and Knutson (1986) found that the instrument is useful for judging how the nurse spends time with the patient. They claimed that it is far too oriented to education and could not be used for evaluation of the nurse practitioner's communication skills. Because of these qualitative characteristics, the instrument was chosen for this study. The reliability of the observations could not be guaranteed. In observing the content of the conversations, an equal estimation was made to the best of the observer's ability. The nurses in the study had all been working as registered nurses for at least 15 years and were very experienced. There were no problems for the observer

to watch and listen to the nurse and patient from her position in the room. The nurses, although few, were randomly selected from a certain geographic area, but the area is both of rural and urban character. Both the long experience and the randomization of the nurses corroborate that the findings in this study show how a public health nurse typically acts during a consultation with a patient while measuring blood pressure.

The intention was to ask the nurses after the patient had left the room if nonpharmacological treatment was not mentioned because it had been mentioned at an earlier visit. This was, however, made impossible because of lack of time at the visiting hours, and the nurse did not always have access to the records in her examination room. It is unlikely that all nonpharmacological treatment could have been given before as the treatment was not given even at the first visits. Even if the nurses thought that the physician had taken care of that part, they should have followed up on the information. It is the nurse's task to coordinate and be an interpreter for the patient (Johnson, 1993; Statens Offentiiga Utredningar, 1996).

There is still insufficient knowledge about what kind of care and treatment the patients want to have. Kjellgren et al. (1998) found in interviews with hypertensive patients that they had a defective knowledge and understanding of their disease and treatment. To be engaged in his or her self-care, the patient must receive knowledge of and insight into the disease (Calnan, 1995; Henderson, 1966; Orem, 1995). The National Committee on Public Health in Sweden has decided in its national goals that health care and medical attendance should focus on disease prevention and health promotion (Statens Offentiiga Utredningar, 1998).

APPLICATION

To increase nurses' usage of nonpharmacological treatment and make it available for them, nurses have to be informed about the treatment. They also have to have education about how to give it to the patients to make use of their special psychosocial education and skill. When developing programs for hypertension care, it is important to point out that at the first visit there should be enough time reserved for a full history

taking, including previous diseases, medication, lifestyle, and so on. It would also improve the continuity if appointments were made for the following visits with the patient's own nurse instead of using the open visiting hours. Both the nurse and the patient would then experience less stress. Future studies are needed to assess different ways of motivating patients for lifestyle change and to explore which care and approach patients want themselves.

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Caregiving is both an art and a science; both knowledge and skills are necessary to improve the quality of care that professionals provide. Researchers are often limited in their assessment of skill performance due to inadequate and unrealistic measurement options. Simulation using standardized patients offers researchers an objective method to evaluate skill performance. This article describes the use of simulations by researchers in their quest to measure changes in violence prevention skills after an intervention program given to nurse assistants working in long-term care facilities.

Using Simulations and Standardized Patients in Intervention Research

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Epidemiological findings indicate that nurse assistants working in nursing homes experience frequent physical and emotional abuse by residents (Fitzwater & Gates, in press; Gates, Fitzwater, & Meyer, 1999; Lusk, 1992). According to data from the Bureau of Labor Statistics (1994, 1995), the nurse assistant working in a nursing home is the most frequently assaulted employee in the workplace. Although nursing home residents represent some of the most complicated and difficult

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patients, nurse assistants often receive minimal education and training regarding the care of such patients (Fitzwater & Gates, *in press*; Gates et al., 1999; Lusk, 1992).

Workplace violence can have serious effects on the employer, the employees, and the nursing home residents, including financial costs related to medical and psychological care, increased property damage, decreased productivity, litigation, increased workers' compensation, and personnel changes. Personnel changes commonly occur as a result of burnout and termination (Banaszak-Hall & Hines, 1996; Mesiro, Klopp, & Olson, 1998). Caregivers experiencing verbal or physical assault have short-term and long-term emotional reactions, including anger, sadness, frustration, anxiety, irritability, fear, apathy, self-blame, and helplessness (Gage & Kingdom, 1995; Gates et al., 1999; Lanza, 1985). A secondary effect is that nurse assistants who are not able to effectively cope with the daily emotional and physical stressors related to resident care are more prone to respond with aggressive and abusive response toward residents (Pillemer & Hudson, 1993; Pillemer & Moore, 1989). There is a reciprocal relationship between the violence that occurs against the caregiver and the violence that occurs against the resident (Pillemer & Moore, 1989). Either type of occurrence has the potential to cause the victim to retaliate, thus resulting in two victims of abuse.

There are approximately 1.8 million nursing home beds in 17,176 nursing home facilities in the United States (American Health Care Association, 1996). The number of nursing home patients is expected to increase dramatically in the near future (Sekscenski, 1990); thus, efforts are needed to improve the nursing home environment for both caregivers and residents. Although nurse assistants provide 70% to 90% of the health care in nursing homes, scant attention has been paid to the working environment of this occupational group (Wunderlich, Sloan, & Davis, 1996).

BACKGROUND

The investigators embarked on a research program to decrease the incidence of assaults against caregivers. Research methods were needed to measure the effectiveness of an educational intervention planned to increase the caregivers'

use of violence prevention skills. The investigators hypothesized that an increase in skills would result in a decrease in number of assaults. Prior violence intervention studies in nursing homes have primarily measured changes in knowledge, beliefs about safety, or self-efficacy (Cohen-Mansfield, Werner, Culpepper, & Barkley, 1997; Feldt & Ryden, 1992; Mentis & Ferrario, 1992). Although knowledge and self-efficacy often precede behavioral changes, the investigators did not consider them to be the strongest predictors for change in violence prevention skills. Because of confidentiality issues and logistics, it was not possible to videotape and evaluate nurse assistants interacting with actual residents being cared for in nursing homes. It was decided that the next best option for assessing changes in violence prevention skills was to assess the nurse assistants' use of violence prevention skills during a simulation exercise.

The purpose of this article is to describe the development and use of simulation exercises and standardized patients as an evaluation methodology for intervention research. Implications for practice will also be discussed.

SIMULATIONS AND STANDARDIZED PATIENTS

Because oral and written examinations do not reveal a caregiver's actual skills in providing care to patients, evaluators frequently seek alternative methods to judge clinical competency. Simulations provide researchers with a criterion-based method that provides an opportunity to evaluate clinical skills.

A simulation is a type of role-play when one of the participants is the standardized patient. Standardized patients can be real patients or actors who are hired and trained to simulate a scenario with a student or research subject. Simulation provides an opportunity to create a realistic environment without compromising a patient's confidentiality or safety. Although there is evidence of the use of simulations in the nursing literature (Arthur, 1999; Bramble, 1994; Foley, Nespoli, & Conde, 1997; McDowell, Nardini, Negley, & White, 1984), there is a greater abundance in the medical literature (Ainsworth et al., 1991; Barrows & Abrahamson, 1964; Barrows, Williams, & Moy, 1987; Carney, Dietrich, & Freeman, 1993; Harden & Gleeson, 1979; Johnson, Zerwic, & Theis, 1999; Mann et al., 1996; Quirk & Letendre, 1986; Sanson-Fisher & Poole, 1980). Much

of the literature describing simulations is focused on its usefulness in the teaching of skills rather than a measurement or evaluation strategy. Simulations with standardized patients provide educators with the opportunity to not only evaluate skill attainment but also review the performance with the student and provide immediate feedback and suggestions for improvement.

There are several advantages to using simulations with standardized patients as a measurement or evaluation strategy for research. Simulations offer a realistic opportunity for health care workers to demonstrate competency in using verbal and nonverbal caregiving skills. Studies indicate that performance with standardized patients during a simulation is similar if not identical to that with real patients (Barrows, 1971; Quirk & Letendre, 1986; Sanson-Fisher & Poole, 1980; Swarz & Collier, 1996; Tamblyn, Klass, Schnabl, & Kopelow, 1991). The simulation method provides this "real-life" opportunity while protecting patients' privacy and confidentiality. This is especially important when working with patients who are vulnerable due to such factors as age and mental capacity. Simulations with standardized patients can be done frequently without the concern of causing pain, fatigue, or distress that could occur with real patients. Evaluators are able to plan the scenario to capture precisely the presence or absence of caregiver skills deemed to be important to measure. In addition, when the simulation is used with a coordinating instrument listing the skills of interest, simulations can be more objective than other evaluations of skill performance. The consistency of performance by the standardized patient also provides comparison of students or subjects over time. When the simulations are videotaped, the evaluators have the opportunity to evaluate and obtain good interrater reliability in their evaluation of skills.

The disadvantages to using simulations and standardized patients include the cost and time necessary for the hiring, training, and use of standardized patients. The validity and reliability of this evaluation strategy rely on the ability of the actor to portray a patient in a realistic scenario and to do so consistently over time with many subjects. It is important to hire an actor or actress that is familiar with the clinical scenario and if possible has previous acting experience. In addi-

tion, it is imperative that training be extensive enough to cover a range of appropriate patient responses and behaviors that portray the potential scope of the scenario. This training usually includes several trial runs prior to the actual simulations. Another disadvantage may include the anxiety that occurs when persons are aware of their performance being watched or videotaped. Studies document that although students rate the simulation method as a positive experience, they may experience stress prior to the interaction (Tamblyn et al., 1991).

VIOLENCE PREVENTION CHECKLIST

Prior to development of the simulation, the authors needed to determine the violence prevention skills that were considered to be important to measure before and after an intervention program with nurse assistants working in long-term care. The development of the Violence Prevention Checklist (VPC) is described in detail in an earlier manuscript (Gates, Fitzwater, & Deets, 2001). Five items on the VPC were behaviors that nurse assistants should do to prevent residents from becoming aggressive. Seven items on the VPC were behaviors that the nurse assistants should do once he or she recognizes that a resident is becoming agitated or aggressive. After developing the VPC, gerontological experts participated in the determination of its content validity. After establishing content validity, 11 skill items remained on the VPC. The VPC is scored by simply adding up the number of skills performed correctly by the nurse assistants during a simulation exercise.

The researchers developed three videotaped simulations to use in assessing for interrater reliability of the VPC. The researchers wanted to determine if six trained raters would be able to identify the presence and absence of 11 violence prevention skills in three videotaped simulations. The raters were asked to determine whether they saw the nurse assistant actress perform each skill, marking a yes or no for each skill. Percentage of agreements for the 11 items on checklist ranged from 67% to 100%. After the evaluation of the VPC for validity and reliability, the VPC was ready to use in the simulations with the nurse assistants (Gold, Hadda, Taylor, Tideiksaar, & Mulvihill, 1995).

PROJECT SIMULATION

DEVELOPMENT OF THE SIMULATION

For the research project, one simple and short scenario was written based on the expertise of one of the authors who has 16 years of experience in nursing homes. The same scenario, which was used with all nurse assistants, depicts a nursing home resident in a situation commonly encountered with nurse assistants working in nursing homes. To increase the reality of the situation, the simulations take place in an actual resident's room in the nursing home where the nurse assistant is working.

The investigators created and wrote a script that provided the opportunity for each nurse assistant to perform or not perform each of the 11 skills listed on the Violence Prevention Checklist. In addition, the script contained instructions that the actress should take when the nurse assistants do not perform certain skills properly or at all. For example, if the nurse assistant approaches the actress (resident) from behind to give care, the actress is instructed to attempt to strike the nurse assistant. If the nurse assistant provides care in a rushed manner and does not allow the resident to assist in the care, the actress becomes aggressive. Several alternative scenarios were written into the script. The script is written so that each nurse assistant has opportunities during the simulation to prevent resident aggression and assault and perform all the skills on the VPC. Although the actress must be prepared to ad lib to some degree, it is important that the actress maintain consistency between participants (nursing assistants).

After writing the script, the investigators practiced the scenario and videotaped themselves, one acting as the resident and one as the nurse assistant. This experience gave the investigators the opportunity to feel what it might be like to participate in this simulation exercise and identify any questions, concerns, and feelings the participants might have. The videotape was also used to train the actress and to seek input from university experts in the field of radio and television on methods to obtain adequate videotaping results with limited funding. The experts suggested that a new microphone was needed because evaluation of the verbal communication was critical. It was decided that the videotaping process itself would not

require a professional because the biggest challenge was simply getting the camera situated in the patient room properly so that the nurse assistant's and patient's activities would be fully captured on videotape.

EVALUATING THE SIMULATION

A nurse with experience in psychiatric nursing was hired as the standardized actress in the simulations. Although this nurse did not have acting experience, it was decided that her personality and familiarity with the type of resident to be portrayed were important characteristics. The standardized patient (actress) was given the script and the sample videotape to review before meeting with the investigators to review and practice. Practice sessions occurred only a few days before the simulations were to take place so that the scenario would remain fresh to the actress. After practicing the scenario as written, along with several variations based on possible responses from the nurse assistants, the actress was deemed prepared.

An appointment was made with the director of nursing (DON) at a local nursing home to conduct simulations with 5 nurse assistants. The DON was asked to obtain an empty patient's room and ask for volunteers to participate in our project. The nurse assistants were told that their participation would take about 15 minutes during their workday and they would be videotaped during an interaction with a patient. The nurse assistants were also told they would be receiving a small monetary incentive for their participation. The investigators and the director of nursing predicted that it might be difficult to obtain volunteers because the participation included the videotaping. It was thought that being watched and videotaped might increase anxiety and fear related to the simulation experience. However, this was not the case; the DON reported that she quickly had 5 volunteers and could easily obtain more if needed.

The simulations took place in the afternoon in an empty patient's room with the actress sitting in a chair watching television. Also in the room were a bed, television, sink, towels, washcloths, and soap. Before each nurse assistant entered the room she was asked to sign a consent form and given the following written instructions: "You are to assist the patient in

getting ready for lunch. You are to help the resident change her soiled shirt and wash her face and hands.”

An investigator met with each nurse assistant on completion of the simulation to ask the following questions: Did the patient seem realistic to you? If not, why not? Is there anything that would make the patient more realistic? Did the scenario seem realistic to you? If not, why not? Is there anything that would make the scenario more realistic? How did you feel about participating in this exercise? Was your behavior with the resident typical of how you usually interact with residents? Is there anything we could do to lessen your anxiety about participation in this exercise?

RESULTS FROM THE EVALUATION

Five nurse assistants participated in the simulation, each one taking only about 5 minutes. All 5 nurse assistants stated that the scenario and patient were very realistic. All 5 nurse assistants stated the realism of the simulation could be improved by having the resident be more aggressive. All 5 nurse assistants stated that they were a bit apprehensive about participating in the simulation, and 4 stated that the camera made them nervous. Three of the nurse assistants stated that once they got involved in the simulation they forgot the camera. All the nurse assistants stated that their own behavior was typical of how they usually respond to residents. The nurse assistants said that there was not anything that could be done to decrease the anxiety as it is the “unknown factor” beforehand that raises the anxiety.

The videotapes were copied so that three investigators could watch the videotapes separately and score (rate) the nurse assistants' performances based on the 11 items on the original Violence Prevention Checklist (Gates et al., 2001). The interrater agreement on 9 of the 11 items was 100%. The following two items had poor interrater reliability: Item 2, approach the resident from the front versus the side or rear, and Item 5, give resident choices about activity. After discussing these two items, the following decisions were made. Item 2, approach resident from the front versus the side or rear, was a problem because the resident's room configuration did not

allow for this behavior to occur and be captured on video. Item 5, give resident choices about activity, had poor interrater reliability because there were several situations when the nurse assistants verbally gave the resident a choice but did not wait for the resident to voice their choice or did not honor the resident's choice. The checklist was revised by eliminating 2 as written and combining Items 2 and 4 with a new item, introduce self when in eyesight of resident. Item 5 was revised to give resident choices about activity, wait for resident's response, and follow up with choice.

Although the remaining items on the checklist had 100% interrater reliability, the investigators did add descriptors to Items 6, 7, 8, 9, and 10 for clarity. Item 6, give one-step instructions, was revised to give one-step instructions to resident for activities to assist in self-care. Item 7, keep resident's extremities in view at all times, was revised to position yourself so resident's extremities are in view while in hitting or kicking range, with no back to resident. Item 8, block assaultive attempts, was revised to block assault attempts properly with no sense of retaliation and no hitting, yelling, or scolding back. Item 9, back off when resident becomes aggressive, was revised to back off when resident demonstrates verbal or physical aggressiveness and gets out of range of extremities. Item 10, validate resident's emotional state, was revised to validate resident's emotional state when resident demonstrates emotions; this does not include reassurance.

A new Item 12, tell resident what you will do before doing it, was added to the Violence Prevention Checklist. The three investigators decided to add this item after they all commented that they saw the majority of nurse assistants telling the resident what they planned to do as they were actually doing it. For example, the nurse assistant was taking the resident's eye-glasses off as she said, "I am going to take your glasses off." Although this item was not on the original VPC, the investigators felt it was important to be included. All three investigators commented on how irritated they became as they watched the nurse assistants perform care in such manner; they agreed that this activity could increase a resident's frustration and lead to aggressive behaviors. The revised checklist is being used in the current research project.

DISCUSSION

Results from this project indicate that using simulations with standardized patients is an effective method for evaluating the performance of violence prevention skills. The information learned from the project was incorporated into the simulations currently being used as a measurement strategy for a large-scale educational intervention study. For example, the scenario was made simpler by asking the nurse assistants to "assist the resident to removed soiled shirt and replace it with a clean one." The part of the scenario that asks the nurse assistants to also assist the resident to wash her hands was eliminated. The investigators decided that a simpler scenario would provide the opportunity for the nurse assistants to demonstrate the use of all the skills on the Violence Prevention Checklist while decreasing the time and increasing the consistency of the scenario between nurse assistants. The actress would have less chance to change responses or actions between the subjects. Changes made to the Violence Prevention Checklist were described earlier in the Results section.

Although researchers often seek methods to observe and evaluate the performance of caregiving skills, they are often met with the issues of patient confidentiality and rights. Simulations with standardized patients provide an additional strategy for direct observation of skills. Simulations can be videotaped to allow the investigators to observe and evaluate the performances at a later time. This allows for additional time for viewing as well as the opportunity to assess the reliability on the part of the person (intrareliability) or persons (interreliability) rating the performances. There are disadvantages for using videotaping as part of the evaluation process. The nurse assistants in this research study found videotaping to be stressful yet did not believe that it changed their behavior. These comments support the literature findings that participants often become anxious when asked to participate in simulation exercises. In addition, videotaping requires additional personnel, equipment, and adequate room space.

There are other possibilities for evaluating performance without videotaping. Evaluators could either use a form or checklist during the simulation to note the performance of skills. The subject or student may become nervous as she

becomes acutely aware of the evaluation taking place. The evaluator could also elect to evaluate the performance immediately after the simulation. The reliability of this strategy is based on the evaluator having an excellent memory that does not vary from one subject to the next. With both of these methods, it becomes difficult if not impossible to determine reliability of the ratings.

The authors realize that the usefulness of the information obtained from the simulations is dependent on the raters' ability to accurately identify the performance of skills by the nurse assistants while viewing the videotapes. For the investigators' current study, the effectiveness of a violence prevention program is being determined by the performance of nurse assistants before and after the intervention. To increase the interrater reliability of the scores, raters need to be accurate and consistent in their judgments of whether the nurse assistants performed each skill. Training is essential for those persons who view and score (rate) the nurse assistants' performance on the videotapes. The training needs to review content related to the scenario as well as each skill listed on the VPC. In addition, the raters need to have several opportunities to practice using the checklist while watching several live or videotaped simulations of the identical scenario. The raters are considered prepared to rate the study videotapes after they reach a minimum of 90% interrater agreement on each item on the VPC during training. In addition, once raters are trained and begin to evaluate the study videotapes, the interrater agreement is checked routinely after 10 simulations. If high interrater agreement is found to be lacking for one or more items (skills) on the VPC, retraining is done until satisfactory agreement is obtained.

The costs associated with the simulation with standardized patients method needs to be considered before adopting its use. In addition to the researcher's time, personnel costs include the following: training of the actor, training of the raters, the actor's time during the simulations, and the person doing the videotaping. A person is needed to schedule and oversee the simulations. Costs for equipment include those for the camera and microphone, videotapes, and participant incentives, if desired. The cost to the nursing home associated with the caregiver's time off the floor is minimal because their par-

ticipation took only approximately 5 minutes and the simulations took place at the worksite.

CLINICAL APPLICATION

The Violence Prevention Checklist can be used both as a teaching tool and as an instrument to measure skills. Simulation using standardized patients offers an effective method to those educators and researchers seeking to observe and evaluate caregiving skills. This method is also useful when evaluation is needed to assess for efficacy of an intervention aimed at students or staff members in an educational setting. In addition, this method provides educators with an opportunity to view the videotapes with the caregiver to critique skill performance and provide helpful tips for improvement. Watching one provide care can be a powerful motivation for behavioral change.

SUMMARY

Although performance on pencil-and-paper tests can assess for a change in knowledge, such evaluation is not helpful in assessing a change in skill performance. Simulation using standardized patients offers an effective method to those researchers and educators seeking to observe and evaluate caregiving skills. This method is particularly useful when evaluation is needed to assess for efficacy of an intervention aimed at caregivers. However, this strategy requires sufficient time and resources to plan, conduct, and evaluate the simulations in a valid and reliable manner.

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This study investigated the effects of selected variables on quality of life (QOL) in persons living with HIV. Eighty-one HIV-positive adults completed a demographic questionnaire, the Sickness Impact Profile, the Center for Epidemiologic Studies Depression Scale, and a fatigue visual analog scale. Blood samples were collected for CD4+, CD8+, and CD16+ lymphocyte numbers. Based on an expanded psychoneuroimmunology model, hierarchical multiple regression analysis was used to determine the extent to which four blocks of variables predicted variance in quality of life. These included sociodemographics, depression, immune status, and fatigue. Findings revealed that work status, depression, and fatigue predicted 58% of the variance in QOL in persons with HIV. Findings support the need for routine assessment and management of depression and fatigue in persons living with HIV.

Quality of Life in Persons Living With HIV

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According to the Joint United Nations Programme on HIV/AIDS, estimates indicate that as of the end of 2000, 36.1 million persons worldwide were living with HIV/AIDS, and 21.8 million had died of the disease (Centers for Disease Control, 2001). Recent pharmacological advances and the use of highly active antiretroviral therapy have increased the life expectancy of those living with HIV (Collier et al., 1996). Thus, for many, infection with HIV has become a chronic illness, with a progressive increase in the incidence and severity of physical and psychological symptoms. The numerous side effects of combination drug therapy coupled with symptoms of the disease can reduce an individual's quality of life (Dykeman, Wallace, Ferrell, Jasek, & Tortorice, 1996; Williams, 1997). Although HIV has been compared to other long-term chronic diseases,

when compared to matched groups with other chronic medical conditions, quality of life (QOL) in persons living with HIV is significantly lower (Wachtel et al., 1992; Wu et al., 1991). It has also been suggested that there is much work to be done to understand differences in QOL related to age, socioeconomic status, and other demographic variables (Clancy & Eisenberg, 1997). It is clear that persons living with HIV disease are subjected to multiple biopsychosocial stressors, all of which can influence the quality of their lives. A psychoneuroimmunology (PNI) theoretical framework that provides a model for understanding the complex biopsychosocial relationships that affect health outcomes and quality of life guided the research reported here. Correlates of QOL were examined, and the degree to which selected sociodemographic characteristics and psychological and clinical indicators predicted QOL in persons with HIV disease was explored. It was hypothesized that QOL would differ by stage of disease. In the instrument used in this study to measure QOL, higher scores indicate poorer QOL; therefore, positive associations were hypothesized between QOL and age, non-White race, less than full-time work status, depression, fatigue, and disease stage. Negative associations were hypothesized between QOL and years of education, income, CD4+ and CD16+ lymphocyte numbers, and CD4+/CD8+ ratio. Based on the PNI model that guided the study, it was hypothesized that a combination of depression, immune status (CD4+ and CD16+ lymphocyte number and CD4+/CD8+ ratio), and fatigue would explain a significant amount of the variance in QOL after controlling for sociodemographic factors.

CONCEPTUAL FRAMEWORK

The psychoneuroimmunology paradigm that guided this study provides a multidimensional model of mind-body relationships. This model posits that psychosocial factors, via neural and endocrine mediators, can affect immunological outcomes and ultimately influence health. Bidirectional communication occurs through direct innervation of lymphoid tissue and the release of biochemical mediators by both immune and neural cells (Pert, Dreher, & Ruff, 1998). The

model typically is used to describe the effects of psychological stressors as immune moderators that ultimately affect physical health status. Immune outcomes, such as changes in lymphocyte numbers or reactivation of latent herpesvirus, and health outcomes, such as incidence of upper respiratory infections, are frequently the indicators used to elucidate PNI relationships (Cohen, Doyle, & Skoner, 1999; Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1998; Glaser et al., 1999). Increased recognition of the necessity to include quality of life as an outcome indicator in clinical populations guided the development of a broader conceptualization of PNI in the current study (Clancy & Eisenberg, 1997). The PNI model was expanded to include QOL, a subjective multidimensional indicator of health, as the endpoint. Thus, the model used here posits that depression can moderate immunity (CD4+, CD8+, and CD16+ lymphocyte numbers). Immune changes in turn influence fatigue and, ultimately, quality of life.

QUALITY OF LIFE

Differences in the conceptualization of quality of life can be divided into two broad categories. The first uses a satisfaction model based on generic measures of well-being and life satisfaction in multiple domains, with most unrelated to health. The second category includes health-related quality of life and is based on measures of sickness impact, the burden associated with illness (Gladis, Gosch, Dishuk, & Crits-Christoph, 1999). In this study, quality of life is conceptualized as health-related quality of life and does not include indicators of life satisfaction or well-being. This conceptualization of the construct was based on that suggested by Holzemer and Wilson (1995) for persons living with HIV. Quality of life in this study was viewed as a subjective construct that includes the dimensions of physiological and psychosocial health. Based on associations described in the literature, hypothesized predictors of QOL included sociodemographic indicators (age, race, gender, education, income, and work status), depression, fatigue, and immune status.

Three stages of disease relevant to HIV infection are early-stage or asymptomatic disease, midstage or symptomatic dis-

ease, and late-stage disease or AIDS. Several descriptive studies explored the effects of disease stage on QOL in persons with HIV. In some studies, those with early-stage disease scored higher on overall quality of life than those with midstage disease or AIDS, with significant relationships observed between QOL and illness stage (Ganz, Schag, Kahn, Petersen, & Hirji, 1993; Lubeck & Fries, 1992; Mellors, Riley, & Erlen, 1997; Nunes, Raymond, Nicholas, Leuner, & Webster, 1995; Revicki, Wu, & Murray, 1995). Other researchers reported no difference in QOL scores by disease stage (Griffin, Rabkin, Remien, & Williams, 1998; Keithley, Zeller, Szeluga, & Urbanski, 1992; Nokes, Wheeler, & Kendrew, 1994). Ragsdale and Morrow (1990) reported the poorest QOL scores for those with midstage disease. This was observed for total QOL scores as well as the physical and psychosocial dimensions of QOL. In a longitudinal study, Lubeck and Fries (1992) found that baseline mental health scores were equally poor across disease stages. Ganz et al. (1993) also reported similar frequencies for psychological distress across disease stages. The QOL dimension of sleep/rest varied by HIV status in two studies, with poorer sleep in persons at later disease stage compared to those at earlier stages (Moeller et al., 1991) and in persons in early-stage disease compared to HIV-negative subjects (Norman et al., 1992). These findings suggest declines in sleep and rest with disease progression. Taken together, these findings indicate that the effect of disease stage on QOL in persons with HIV remains unclear. In addition, they suggest that the psychological effects of HIV occur early in infection and continue throughout the course of disease. Multiple factors beyond disease stage apparently influence both the physical and psychological dimensions of QOL.

Early studies of persons with HIV showed a positive relationship between higher levels of physical function and self-reported quality of life (Cleary et al., 1993; Wu et al., 1991). In drug trials, measures of QOL detected treatment effects at an earlier time point than clinical indicators (Wu et al., 1990). Several variables associated in the literature with quality of life in persons with HIV will be discussed according to the conceptual framework of the study. Relationships posited in the PNI model will also be reviewed.

PREDICTORS OF QOL

Sociodemographics

Several sociodemographic characteristics have been associated with QOL in persons with HIV. These include age, gender, race, education, income, employment status, and type of insurance. In a two-group comparison, Cunningham, Bozzette, Hays, Kanouse, and Shapiro (1995) reported poorer QOL in all dimensions for subjects who were older, non-White, had lower incomes, and were on public insurance. Wachtel et al. (1992) reported poorer physical QOL and role function in subjects who were older. Women also had poorer psychological QOL, Whites had lower QOL in the area of physical function, and lower educational level was associated with poorer QOL in all domains. Employment status and income were significant predictors of psychosocial needs in HIV-positive samples (Berk & Nanda, 1997; Swindells et al., 1999). In a sample of 202 women, those who were older, unemployed, or former injecting drug users had poorer health-related QOL (Smith et al., 1996). In the present study, relationships between these sociodemographic factors and QOL and the degree to which they explain the variance in QOL were explored.

A number of studies also examined disease-related predictors of QOL in persons with HIV. Ganz et al. (1993) found that a combination of variables including disease stage, age, CD4+ lymphocyte count, work status, income, use of pain medication, and presence of Kaposi's sarcoma accounted for 35% of the variance in total QOL. In the Wachtel et al. (1992) study, predictors including age, gender, race, intravenous drug use, education, neurologic and constitutional symptoms, and presence of pneumocystis carinii pneumonia and/or Kaposi's sarcoma accounted for 26% to 40% of the variance in QOL. When neurological symptoms (difficulty remembering, seizure, limb weakness, or numbness) and constitutional symptoms (fever, chills, sweats, weight loss, dyspnea, and diarrhea) were not included in regression models, only 2% to 10% of the variance in total QOL was explained by the models. These findings suggested that physical symptoms were the strongest predictors of QOL, however, neither Ganz et al. (1993) nor Wachtel et al. (1992) included psychological variables in their models.

Depression

The incidence of depression in persons with HIV disease appears to vary by gender and risk group. Depression occurred in 30% of women (Swartz, Markowitz, & Sewell, 1998), 21% to 58% of men who have sex with men (Lyketsos et al., 1993; Mayne, Vittinghoff, Chesney, Barrett, & Coates, 1996), and 30% of a primarily male sample (Perry, Fishman, Jacobsberg, & Frances, 1992). Depression has also been reported in 33% of injecting drug users of both genders (Rabkin et al., 1997).

Depression was strongly associated with psychosocial quality of life in HIV-positive samples (O'Dell, Meighen, & Riggs, 1996; Walker, McGown, Jantos, & Anson, 1997). In one study that included indicators of both psychological and physiological health, Cleary et al. (1993) reported that general health perception and mental health score together explained 27% of the variance in life satisfaction in an HIV-positive sample.

Immune and endocrine dysregulation caused by psychological states such as depression have been documented in patients with cancer, patients with major depression and anxiety disorders, and community dwellers older than 70 years of age (Allen-Mersh, Glover, Fordy, Henderson, & Davies, 1998; Castilla-Cortazar, Castilla, & Gurpegui, 1998; Dentino et al., 1999). A recent meta-analysis and a review of depression and immunity supported an association between depression and reduced lymphocyte proliferation in response to mitogens and reductions in lymphocyte populations and in natural killer (NK) cell activity (Herbert & Cohen, 1993; Irwin, 1999). Among persons with HIV, equivocal results have been reported. Some studies reported lower CD4+ lymphocyte counts and rapid declines in this marker among depressed subjects (Burack et al., 1993; Kemeny et al., 1994; Lyketsos et al., 1993). Other studies reported higher depression scores in those who would be expected to have better immune function. For example, depression scores were higher among those who were at risk but seronegative compared to those with midstage HIV disease (Ostrow et al., 1989). Depression scores were also higher in those with midstage disease compared to those with AIDS (Ragsdale & Morrow, 1990). Some researchers reported no relationship between depression and disease stage, disease progression, or immunity (Perdices, Dunbar, Grunseit, Hall, &

Cooper, 1992; Rabkin et al., 1991; Vedhara, Schifitto, & McDermott, 1999; Walker et al., 1997). The relationship between depression and immunity in persons with HIV disease remains unclear and was further explored in the current study. The amount of variance in quality of life predicted by depression was also examined.

Immunity

Clinical indicators have also been shown to correlate with QOL in persons living with HIV. CD4+ lymphocyte counts, viral burden, and clinical endpoints were significant predictors of health-related quality of life in persons living with HIV disease (Chan & Revicki, 1998; Ganz et al., 1993; Weinfurt, Willke, Glick, Freimuth, & Schulman, 2000).

The following three markers of immune status were measured in this study: CD4+ and CD16+ lymphocyte number and CD4+/CD8+ lymphocyte ratio. The primary physiological response to infection with HIV is suppression of cellular immunity, particularly progressive loss and functional impairment of CD4+ lymphocytes and an inverted CD4+/CD8+ ratio. The CD4+ lymphocyte count is a surrogate marker of HIV disease progression. The relative proportion of CD8+ lymphocytes to CD4+ lymphocytes, the CD4+/CD8+ ratio, is another important marker of immunity in this clinical population.

The CD16+ lymphocyte, or natural killer cell, is responsible for non-major-histocompatibility complex (non-MHC) restricted recognition and destruction of virally infected cells and tumor cells. Natural killer cell activity is reduced in persons with HIV disease, and those who progress rapidly to AIDS have lower NK cell numbers than those with slower disease progression (Bruunsgaard, Pedersen, Skinhoj, & Pedersen, 1997; Vulcano, Galassi, Felippo, Vernava, & Olabuenaga, 1999).

Fatigue

Similar to depression, fatigue is a frequent and severe symptom in persons across all stages of HIV disease (Darko, McCutchan, Kripke, Gillin, & Golshan, 1992; Friedland, Renwick, & McColl, 1996; Longo, Spross, & Locke, 1990; Lyketsos et al., 1993; Tross & Hirsch, 1988). It has been estimated that

fatigue occurs in 20% to 60% of persons with HIV (Barroso, 1999) and in up to 85% of those with AIDS (Vogl et al., 1999).

Reported relationships between physical and psychological quality of life and fatigue in HIV-positive individuals are inconsistent. Breitbart, McDonald, Rosenfeld, Monkman, and Passik (1998) found that fatigue was significantly and negatively related to health-related quality of life in a sample of 427 persons with AIDS. And, fatigue was reported to be the strongest predictor of both psychological and functional health (Cleary et al., 1993). Walker et al. (1997) observed no significant relationships between fatigue and either functional status or psychological well-being in a sample of 61 men living with HIV. Lovejoy, Paul, Freeman, and Christianson (1991) reported that symptom distress was positively and significantly related to indicators of both psychological and physical QOL and to fatigue.

Psychological distress and fatigue covaried significantly and positively in several studies of persons with HIV/AIDS (Breitbart et al., 1998; Burack et al., 1993; Walker et al., 1997). Fatigue was significantly and negatively related to immune status (Darko et al., 1992; Walker et al., 1997). Treatments that increased CD4+ numbers in this population resulted in improvement in symptoms of fatigue. In the present study, relationships among sociodemographic variables, depression, immunity, and fatigue were explored. The degree to which each of these variables predicted quality of life was examined.

METHOD

DESIGN AND SAMPLE

A cross-sectional design was used in this descriptive, correlational study. A convenience sample of 81 HIV-positive adults was recruited over 6 months from the outpatient clinic of a large university hospital. Disease stage was determined by Centers for Disease Control (1992) classification criteria. Twenty-seven participants had early-stage HIV disease, 27 were at midstage, and 27 had AIDS. Eligible participants were able to understand and communicate in English and were not partici-

pating in research protocols. Data for this study were collected at the time of recruitment but prior to subjects' participation in an intervention study (Eller, 1999).

MEASURES

A sociodemographic questionnaire included questions regarding gender, age, race, education, income, work status, and months since diagnosis. Categorical variables included gender (male = 1, female = 2), race (White = 1, non-White = 2), education (less than high school through graduate school, values 1 through 6, respectively), and work status (working full-time = 1, working part-time = 2, not working = 3).

The Sickness Impact Profile (SIP) was used to measure quality of life (Bergner, Bobbit, Carter, & Gilson, 1981). The SIP consists of 136 items divided into 12 subscales that measure changes in behavior related to sickness. The subject checks off phrases that describe current health-related state in each category. The 12 subscales include sleep and rest, emotional behavior, body care and movement, home management, mobility, social interaction, ambulation, alertness behavior, communication, work, recreation and pastime, and eating. Scale values are assigned to each item, and the score is calculated as the sum total of checked items. Higher scores indicate poorer quality of life. A global QOL score is the sum of all 12 categories. Two dimension scores may also be calculated. The psychosocial dimension is the sum of scale values for the emotional behavior, social interaction, alertness behavior, and communication categories. The physical dimension is the sum of the body care and movement, mobility, and ambulation categories. The SIP can be interviewer administered or self-administered and requires 20 to 30 minutes for completion. The Cronbach's alpha reliability coefficient for the total scale in this sample was .90. Reliabilities for the psychosocial and physical dimensions were .82 and .77, respectively. Reliabilities were similar to those reported by Ragsdale and Morrow (1990) for this instrument in an HIV-positive population.

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure depression (Radloff, 1977). This is a 20-item scale with a 4-point response format for each item. Participants respond to the frequency with which they experi-

enced symptoms during the past week, with responses ranging from less than 1 day to 5 to 7 days. Scores of 16 or higher out of a possible 60 points indicate depressed mood. The Cronbach's alpha reliability coefficient for the scale was .92 in this sample.

Immune measures included the numbers of CD4+ lymphocytes/mm³, CD8+ lymphocytes/mm³, and CD16+ lymphocytes/mm³ as measured by direct single- or dual-color immunofluorescence, with whole blood lysis followed by flow cytometry. Mouse monoclonal antibodies specific for the three markers were used to determine the percentage of positively stained cells for each cell surface antigen from a count of 5,000 cells. Estimates of absolute lymphocyte numbers were calculated from the complete blood count and differential. Quality control for accuracy and precision of analyses included parallel analysis of normal adult controls with each subject sample. In addition, analyses of three blinded observations of a single blood sample were conducted during each month of the study. Findings of no significant difference supported the accuracy of analyses.

A single-item Fatigue Visual Analog Scale was used to measure fatigue. The scale was a 100-mm scale with anchors at each end indicating extremes of fatigue. Anchors were *not at all fatigued* and *most fatigued I ever felt*. Subjects were asked to indicate the amount of fatigue experienced during the past week by marking a point on the line. Test-retest reliability in this study, conducted on 85% of participants, was .70.

DATA ANALYSIS

SPSS-PC version 8.0 was used to conduct analyses. Dependent measures were tested for and met the appropriate statistical assumptions. Multivariate linear regression models were built to assess the degree to which sociodemographic, clinical, and subjective symptom variables predicted total QOL. Order of entry was based on a PNI model and included sociodemographic variables (age, gender, race, educational level, income, and work status), depression, immune markers (CD4+ and CD16+ lymphocyte numbers and CD4+/CD8+ lymphocyte ratio), and fatigue.

RESULTS

DESCRIPTIVE STATISTICS

Mean age of study participants was 35.6 years (range = 20 to 76 years). The majority was male (89%) and White (60%), with a minimum of high school education (90%). Fifty-seven percent of the sample worked full time, and median income was \$10,000/year.

Participants across the HIV spectrum differed significantly on total QOL, physical QOL, and psychosocial QOL as well as on all QOL subscales, depression, and fatigue (see Table 1).

There was a downward linear trend in physical QOL (higher scores on the SIP) across disease stage, with poorest physical QOL in persons with AIDS. However, total QOL and psychosocial QOL were worse (higher SIP scores) in participants with midstage disease compared to those with AIDS. Symptoms of depression and fatigue were also worse in subjects with midstage disease compared to those with AIDS. Based on these observed trends, post hoc analyses were conducted to compare subjects with midstage disease and AIDS. Differences were not significant for total QOL ($t = .57, p = .27$), physical QOL ($t = -.73, p = .23$), and fatigue ($t = .97, p = .17$). Significant differences were found between these two groups for psychosocial QOL ($t = 1.77, p = .04$) and depression ($t = 2.06, p = .02$). Among those participants with CES-D scores of 16 or higher, 10 had early-stage disease (CES-D range = 19 to 40), 20 had midstage disease (CES-D range = 16 to 49), and 15 had AIDS (CES-D range = 18 to 40).

CORRELATIONAL ANALYSES

Significant negative correlations were observed between QOL scores and two sociodemographic variables, education ($r = -.20, p < .05$) and income ($r = -.37, p < .01$), with the strongest association observed for income. Two clinical variables, CD4+ lymphocyte number ($r = -.23, p < .05$) and CD4+/CD8+ lymphocyte ratio ($r = -.25, p < .05$), were moderately correlated with QOL scores. Significant positive relationships were observed between QOL scores and less than full-time work status ($r = .55, p < .01$), disease stage ($r = .37, p < .01$), depression ($r = .63,$

Table 1
Means, Standard Deviations, and F Values for Main Effect of Disease Stage on Total Quality of Life (QOL), Physical and Psychosocial Dimensions of QOL, and Subscales of QOL, Depression, and Fatigue

	Early Stage (n = 27)		Midstage (n = 27)		AIDS (n = 27)		F	p
	M	SD	M	SD	M	SD		
Sickness Impact Profile (SIP) dimension								
Total QOL	85.5	101.0	213.3	149.0	193.2	107.9	8.68	< .000
Physiological QOL	10.9	19.0	33.4	34.7	40.2	33.6	7.05	.002
Psychosocial QOL	43.0	50.9	112.0	77.9	78.1	61.5	7.75	.001
SIP subscale								
Sleep and rest	8.5	11.4	21.4	17.3	18.9	14.6	5.90	.004
Emotional behavior	11.6	14.2	25.4	18.6	17.3	16.3	4.83	.011
Body care/movement	5.2	10.1	15.9	18.9	18.7	19.9	4.77	.011
Home management	4.3	8.7	10.9	12.0	15.8	14.0	6.47	.003
Mobility	2.5	5.4	9.9	13.0	9.7	9.8	4.88	.010
Social interaction	17.3	20.0	49.4	33.8	37.1	31.7	8.24	.001
Ambulation	3.2	7.1	7.7	7.7	11.9	10.4	7.01	.002
Alertness								
behavior	13.4	19.2	31.0	26.4	18.1	16.1	5.12	.008
Communication	0.8	2.2	6.2	9.3	5.7	8.9	4.30	.017
Work	10.9	16.1	18.6	16.5	24.6	14.8	5.06	.009
Recreation/pastime	6.3	7.9	12.2	8.7	12.4	8.1	4.78	.011
Eating	1.5	3.1	4.8	5.0	3.1	4.5	4.06	.021
Depression	15.6	13.0	25.5	11.9	19.1	10.9	4.71	.012
Fatigue	32.4	29.4	55.4	28.5	49.0	27.7	4.99	.009

$p < .01$), and fatigue ($r = .62$, $p < .01$). Age, non-White race, and CD16+ lymphocyte count were associated with QOL scores in the hypothesized direction but were not significant (see Table 2).

MULTIPLE REGRESSION ANALYSES

In Block 1, six sociodemographic variables were entered into the model in stepwise fashion. One variable, work status, entered the equation, accounting for 28% of the variance in total QOL. In the second block, depression was entered into the

Table 2
Means, Standard Deviations, and Bivariate Correlations Between Variables in Analysis (N = 81)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	M	SD
1. Age		-.27*	-.14	.02	.02	.10	.19	-.18	.14	-.27*	.05	.06	-.01	35.6 yrs	8.7 yrs
2. Gender			.30**	-.03	-.25*	.19	.07	.10	-.00	.18	.02	-.05	.08		
3. Race				-.17	-.33**	.18	.03	-.03	.04	-.05	.06	.09	.14		
4. Education					.34**	-.33**	-.11	-.001	.18	-.08	-.04	-.12	-.20*		
5. Income						-.57**	-.37**	.07	.05	.09	-.13	-.23*	-.37**	\$15,342	\$16,908
6. Work status							.38**	-.26*	-.22	-.23	.31**	-.29**	.55**		
7. Depression								.01	.02	-.01	.50**	.16	.63**	20	12.5
8. CD4+ number									.38**	.84**	-.24*	-.55**	-.23*	259	226
9. CD16+ (natural killer cell) number										.18	-.17	-.13	-.05	119	103
10. CD4+/CD8+ ratio											-.15	-.45**	-.25*	.44	.91
11. Fatigue												.23*	.62**	46	30
12. Stage of disease													.37**		
13. Quality of life														164	132

* $p < .05$; ** $p < .01$ (two-tailed).

model and accounted for an additional 18% of the explained variance in total QOL. In the third block, three clinical indicators (CD4+ T-lymphocyte count, CD4+/CD8+ lymphocyte ratio, and CD16+ lymphocyte count) were entered into the regression. None of these immune variables entered the equation. In Block 4, fatigue was entered and accounted for an additional 10% of the variance in total QOL. In total, three predictor variables, work status, depression, and fatigue, explained 58% of the variance in total QOL, $F(11, 69) = 11.07, p < .000$. Beta weights indicated that fatigue was the best predictor of QOL, followed by work status and depression (see Table 3).

DISCUSSION

Based on a PNI framework, this study investigated relationships among sociodemographic variables, depression, immunity, and fatigue and the degree to which they predicted quality of life in persons living with HIV disease. As hypothesized, persons across the HIV spectrum differed significantly on the psychosocial and physical dimensions of QOL and on total QOL. It was also observed, however, that psychosocial QOL was significantly poorer in persons with midstage HIV disease when compared to persons with AIDS. In addition, although depressed mood was present in both groups, those at midstage had significantly higher scores for depression than those with AIDS. The literature to date reports better QOL in those with early-stage disease compared to midstage or AIDS (Ganz et al., 1993; Lubeck & Fries, 1992; Mellors et al., 1997; Moeller et al., 1991; Norman et al., 1992; Nunes et al., 1995; Wu et al., 1991). Ragsdale and Morrow (1990) reported poorer QOL in persons with midstage disease compared to those with AIDS, however, observed differences were not significant. The observation in the present study that the effect of HIV disease on psychosocial QOL and depression was greatest among persons with midstage disease suggests that factors other than clinical status influence psychological outcomes. These may include greater uncertainty and hopelessness and less control at this stage of illness (Kelly & Murphy, 1992; Miller & Riccio, 1990).

A number of sociodemographic variables, clinical indicators, and subjective symptoms have all been shown to be related to QOL in persons with HIV. In this study, work status, income,

Table 3
Hierarchical Regression: Demographics, Depression, Immunity, and Fatigue as Predictors of Total Quality of Life

Predictors	R ²	Adjusted R ²	R ² Change	Beta	F
Block 1	.33	.28	—		6.07**
Age				.05	
Gender				-.10	
Race				.12	
Education				-.04	
Income				.03	
Work status				.47***	
Block 2	.50	.46	.18		10.77***
Age				-.13	
Gender				-.11	
Race				.09	
Education				-.00	
Income				.04	
Work status				.44***	
Depression				.46***	
Block 3	.54	.48	.04		8.31***
Age				-.17	
Gender				-.08	
Race				.07	
Education				-.05	
Income				.05	
Work status				.41***	
Depression				.47***	
CD4+ lymphocyte number				-.17	
CD4+/CD8+ lymphocyte ratio				-.05	
CD16+ lymphocyte number				.12	
Block 4	.64	.58	.10		11.07***
Age				-.16	
Gender				-.06	
Race				.04	
Education				-.08	
Income				.01	
Work status				.33**	
Depression				.30**	
CD4+ lymphocyte number				-.03	
CD4+/CD8+ lymphocyte ratio				-.14	
CD16+ lymphocyte number				.13	
Fatigue				.38***	

p* < .01; *p* < .001.

and education were the sociodemographic variables significantly related to QOL. Respondents who were not working and those with lower incomes or education reported poorer QOL. Two clinical variables, CD4+ lymphocyte number and CD4+/CD8+ lymphocyte ratio, were moderately and negatively related to QOL scores, linking better immune status with higher QOL. Strong and significant relationships were observed between QOL and subjective measures of depression and fatigue. Both symptoms were positively related to QOL scores, indicating poorer QOL with higher levels of either symptom.

In regression analyses, work status, depression, and fatigue were significant predictors of QOL, explaining 58% of the variance. Work status alone explained 28% of the variance in QOL. Work status may be a surrogate for other symptoms or disease indicators not measured in the current study. It may explain the effects on QOL of the multiple losses related to unemployment. These can include loss of income, health insurance, coworker and supervisor social support, and self-esteem (Ezzy, de Visser, & Bartos, 1999; Kass, Munoz, Chen, Zucconi, & Bing, 1994; Muntaner & Schoenbach, 1994; Theodossiou, 1998).

CD4+ lymphocyte count, the clinical indicator typically used to assess treatment efficacy, was not predictive of QOL. It may be that the enumerative measures of immunity used in this study are less sensitive to psychosocial factors than indicators of functional immunity (Kiecolt-Glaser & Glaser, 1992). Future studies should incorporate both functional and enumerative indicators of immune status.

CLINICAL IMPLICATIONS

Better treatments that prolong life for persons living with HIV beg the question of how to assess and improve the quality of those lives. In an early study in an HIV-positive population, researchers found that QOL was an early indicator of treatment benefits (Wu et al., 1990). Therefore, disease management should also include attention to quality of life as a measure of the efficacy of medical treatments and nursing interventions.

In this study, the usual clinical indicators did not predict a substantial portion of the variance in QOL. Meanwhile, work status, depression, and fatigue were significant predictors of QOL. Therefore, assessment of these three variables and management of depression and fatigue in persons with HIV disease should be prime considerations in the nursing care of this population. Clinicians should routinely conduct brief, serial assessments that include work status and measures of depression and fatigue that can provide critical information indicating trends in the patient's QOL. The use of the CES-D and a visual analog scale for fatigue, as used in this study, could be completed during a routine visit by the patient in 5 minutes or less. It has been reported that psychological—not physiological—symptoms were the primary causes of unemployment in persons with HIV/AIDS (Ezzy et al., 1999; Vitry-Henry, Penalba, Beguinot, & Deschamps, 1999). Early diagnosis and treatment of depression may prevent unemployment and maintain quality of life in this population. Mayne et al. (1996) reported a strong positive relationship between depression and mortality in a study of 402 HIV-positive men. This relationship was independent of physiological and clinical indicators of disease progression and lends support to the notion that adequate management of depression may impact not only QOL but also survival in this population.

Findings that persons with midstage HIV disease have the poorest psychosocial QOL and greater severity of depressive symptoms have additional implications for both nursing assessment and nursing care. The degree of depression observed in the present study strengthens the argument for routine assessment and targeted interventions to reduce psychosocial symptoms in persons with midstage disease or AIDS. Mean scores for both groups were well above 16 on the CES-D, indicating the presence of depressive symptomatology.

Additional studies are needed to provide knowledge that can inform clinical practice in the care of persons with HIV. One of the limitations of the present study is the small number of women in the sample. Future studies should describe predictors of QOL in women living with HIV. Interventions to reduce symptoms that impact QOL should be developed and tested across HIV-positive subpopulations.

One potential avenue of research is the development and testing of cognitive-behavioral interventions that could improve QOL by reducing symptoms. Studies of multiple combinations of cognitive-behavioral interventions in HIV-positive populations have supported their positive effects on several outcomes, including distress, anxiety, depression, fatigue, pain, headache, nausea, insomnia, and multiple immune measures (Antoni et al., 1991; Auerbach, Olesson, & Solomon, 1992; Eller, 1995; Mulder et al., 1995). Further research is needed to determine effective nursing interventions for management of specific symptoms to improve the QOL of persons living with HIV.

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This descriptive, correlational study surveyed 79 pierced and/or tattooed participants to determine reasons why people pierce and tattoo their bodies and to assess participants' knowledge of health risks involved in body alteration procedures. Participants queried represented a wide age range—between 19 and 55. Results showed that participants perceived few health risks involving piercing and tattooing and desired additional piercings and/or tattoos. Individual expression was an important body alteration motivation for both piercing and tattooing. These findings underscore the importance of health care professionals' maintaining nonjudgmental attitudes about those who alter their bodies, thereby facilitating important health education concerning related health risks. Suggestions for nursing applications are discussed.

Body Piercing and Tattooing Perspectives

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The practices of body piercing and tattooing reflect changing societal mores and are sometimes seen as behavior bordering on the fringes of proper conduct in the United States. If nurses do not understand the motivations of those with pierced and/or tattooed bodies, then they may be less likely to engage in therapeutic relationships with those patients. Knowing the patient is becoming an increasingly important concept in contemporary health care and is seen as essential to the development of full quality health care (Whittemore, 2000).

BODY PIERCING AND TATTOOING: INCREASING UNDERSTANDING

Tattooing and body piercing, ancient traditions of body alteration, have experienced major resurgence in popularity in the United States. Body piercing and tattooing, now considered to be mainstream activities (Lemonick, 1999), are no longer confined to prison populations, sailors, and gang members. Persons with tattoos and piercings now include adolescents (Armstrong & McConnell, 1994; Armstrong & Murphy, 1997; Farrow, Schwartz, & Vanderleeux, 1991), career women (Armstrong, 1991), and college students (Greif, Hewitt, & Armstrong, 1999). A growing base of research regarding the age and gender of people obtaining tattooing and body piercing (Armstrong, 1991; Armstrong & McConnell, 1994; Armstrong & Murphy, 1997; Houghton, Durkin, Parry, Turbett, & Odgers, 1996) indicates that males and females of various ages are modifying their bodies.

This fast-paced trend has resulted in a chasm between the health community and the public at large regarding body modification health risks (Balakrishnan & Papini, 1991; Budd, 1996; Farrow et al., 1991) and generally appears in the form of regulation versus unregulation. Because of possible adverse reactions to the increasingly large variety of pigments being used in the tattoo process as well as infections that occur from tattooing, the U.S. Food and Drug Administration (FDA) (2000) warned consumers to use caution when obtaining tattoos. The agency refrained, however, from regulating tattoo inks or the pigments used in these inks (Anderson, 1992; Larkin, 1993; FDA, 2000). State health boards also do not regulate tattoo pigments. In addition, sterilization of instruments and studio inspection are largely unregulated in tattoo/piercing studios (Anderson, 1992), leaving consumers generally to monitor safety precautions. Because tattoo/piercing practices are governed by local laws and local jurisdictions, some consumers may enter a tattoo/piercing studio with the perception that it is regulated and not realize that the extent of regulation depends on the location of the studio. Inconsistent regulation as well as inconsistent enforcement of existing regulations can provide a mixed public health message (Armstrong & Fell, 2000; Greif et al., 1999).

TATTOO AND BODY PIERCING PROCEDURES

The operational definition of tattooing is the injection of pigment particles underneath the epidermis that remains in the dermis to create a decorative design. Tattoos can be applied by professionals, amateurs, or self. Tattoo professionals inject tattoo pigments, which are usually metallic salts (Korn, 1996), into the dermis at a depth of 1 to 2 millimeters (Sperry, 1992) and at a rate of 50 to 3,000 times per minutes with an electrically powered, vibrating instrument (Freyenberger, 1998). Amateurs apply tattoos by using objects such as pens, pencils, knives, needles, or straight pins and inject substances such as India ink, carbon, charcoal, or mascara (Armstrong, 1995, 1997).

Body piercing, for the purpose of this study, is a piercing of any part of the body, with the exclusion of single ear piercing, by professionals or amateurs. A body part pierced with a hollow needle is accessorized by inserting body jewelry in the hole. There are many different types of body piercing jewelry, including barbell studs, rings, or clamps (Vale & Juno, 1989). They range from short barbells for the tongue to ampallangs (usually metal bars held in place with metal discs) placed through the head of the penis. In addition, there are rings or studs for the navel, rings for the labia, and various other adornments for both the male and female genital areas.

Although the earlobe and ear cartilage are believed to be the most frequently pierced sites, piercings can also appear on the eyebrow, lip, nose, tongue, nipple, navel, and assorted genital sites (Freyenberger, 1998). Healing time varies according to site and may range from 6 to 8 weeks for the ears, eyebrows, nose, lips, and tongue to 8 to 38 weeks for the navel, nipple, and genitals (Armstrong, Ekmark, & Brooks, 1995).

HEALTH RISKS

There are multiple serious health risks associated with nonsterile tattooing practices, including the blood-borne infectious diseases of HIV (FDA, 1995), syphilis (Christensen, Miller, Patsdaughter, & Dowd, 2000), hepatitis B virus (Long & Rickman, 1994; Tope, 1995), hepatitis D virus (Tope, 1995), and hepatitis C (Ko, Ho, Chiang, Chang, & Chang, 1992). In

addition, there are increased risks of hematoma formation and neuroma (Wright, 1995).

HIV has been associated with only two nonconclusive tattooing cases. Although not directly associated with HIV, HIV risk is present in the tattooing process because blood can be transmitted (FDA, 1995; Long & Rickman, 1994).

Less serious infections associated with tattoos are generally superficial pyoderms (Long & Rickman, 1994). Local infections can become systemic if healing does not proceed well (McCance & Huether, 1998). Because bacteria can enter the skin at any break, there are several hazards associated with piercing, including staphylococci and streptococci (Tweeten & Rickman, 1998). Viral infections such as warts have also been documented (Long & Rickman, 1994).

Skin reactions to tattoo pigments include photosensitivity to cadmium (yellow dye) (Armstrong, 1991; Goldstein, 1967) and hypersensitivity to cinnabar (red pigment) (Armstrong, 1991; Armstrong & McConnell, 1994). There is potential for allergic reactions as well as infection and metal toxicity from exposure to other substances in tattoo pigments such as aluminum, titanium, iron, cobalt, selenium, chromium, zinc, or copper (Tope, 1995).

Metals typically used in body piercing include noncorrosive metals such as surgical stainless steel, niobium, or titanium. Sterling-silver, gold-plated, and gold-filled jewelry are not used for fresh piercings because of the risk of allergic reactions. Some individuals form allergic reactions to even nonreactive metals, however, such as niobium (Miller, 1997).

Other problems include keloid scars and abscesses. Keloid scars can be treated with a laser, whereas abscesses are best treated with a topical or systemic antibiotic so that surface and deep healing can occur (Armstrong, 1998). In addition, scar tissue resulting from piercing the areola can constrict a duct during lactation (Tweeten & Rickman, 1998).

There are particular risks associated with oral piercings, such as dental fractures (Botchway & Kuc, 1998) and speech impediment (Reichl & Dailey, 1996). Aspiration is also considered a risk because those with mouth piercings may play with the jewelry, thereby dislodging it (Reichl & Dailey, 1996).

PIERCING/TATTOO REMOVAL

Piercing is not generally considered a permanent procedure because holes close after jewelry is removed. Some individuals allow piercings to close on the recommendation of their health providers due to problems with the piercings such as abscesses and scar formation (Christensen et al., 2000; Tweeten & Rickman, 1998).

There are numerous accounts of those who desire to have their tattoos removed (Balakrishnan & Papini, 1991; Hall-Smith & Bennett, 1991). Tattooed individuals seek to remove their tattoos for various reasons, including to improve self-image (Armstrong, Stuppy, Gabriel, & Anderson, 1996), correct immature judgment and/or an amateurish tattoo (Balakrishnan & Papini, 1991), get out of a gang (Freyenberger, 1998), and move on from a failed relationship (Korn, 1996).

In the event individuals decide to eliminate a tattoo, there are procedures available for the removal of some tattoos. Most can be removed to some extent with standard laser treatment (Kilmer, Lee, Grevelink, Flotte, & Anderson, 1993; Taylor et al., 1990). Other forms of tattoo removal include dermabrasion, salabrasion, chemical cauterants, surgical resection (Korn, 1996; Sperry, 1992), excision, infrared coagulation, grafting, and cryosurgery (Wright, 1995). Some tattoos are particularly resistant to eradication, however, such as those with green and yellow dyes (Armstrong et al., 1996) and in some cases black dyes (Korn, 1996). Double tattoos (i.e., tattoos overlaid with second tattoos) are also difficult to remove and appear to be associated with an increased risk of scarring (Alora, Arndt, & Taylor, 2000).

MOTIVATORS

Increased popularity of tattooing and body piercing combined with potential health risks underscore the need for examination of motivations related to body-altering techniques. It is important to realize that if programs are to succeed at educating the public about body modification health risks, attention must be directed toward both acknowledgment of the popularity of the movement and the public's perceptions of health risks involved in body-altering procedures (Fried, 1983).

In addition, consciousness of demographics, such as age, gender, and ethnic background, as they relate to body alteration decisions can assist health practitioners in understanding the scope of patients' health risks.

A few common themes for modifying bodies in the West include image management (Langford, 1996; Miller, 1997), sexual expression/sexual enhancement (Fried, 1983; Langford, 1996; Malloy, 1989; Steward, 1990; Vale & Juno, 1989; Wright, 1995), and individuation (Armstrong, 1991, 1995, 1996; Vale & Juno, 1989). Reasons for body alteration are elusive, however; for example, one tattoo practitioner and historian noted, "A tattoo is never just what the appearance is, anyway. . . . Tattoos are indicators, or little vents to [the owner's] psyche" (Hardy, 1989, p. 60).

The body can be considered a metaphor of political and social order (MacRae, 1975; Turner, 1991). The skin can designate one's social status, ideas of beauty, and at times, psychic conflict. Changes in the fabric of the skin can reflect a multiplicity of images designed to weave mystery, beauty, sexual fulfillment, and inner sanctum into one's internal and external image. The outer body image reflects the management of impressions as well as personal control of the body within society (Featherstone, 1991). As expressed by Cazazza (1989), "If you don't have any identity, you try to re-create your life in such a way that you think you have some. How do you do that? Tattoo some weird design on your stomach" (p. 128). Control of appearance is often a reflection of the establishment of identity within culturally defined standards (McKinley, 1999).

Body alteration also often reflects individuals' expression of the changing mores of sexuality (Vale & Juno, 1989). Sexuality is one way in which a person may define herself or himself within an impersonalized society (Petras, 1978). Individuals can express personal control by acknowledging their own sensuality within the current social structure and may do so by sexual modification of the body. For instance, by modifying genitalia, individuals can experience as well as control private sensations within cultural restraints (Vale & Juno, 1989).

For health professionals, knowing the pierced/tattooed patient involves understanding motivations for piercing and tattooing, learning about associated health risks, and grasping

an idea of the type of people who pierce and/or tattoo their bodies. The current research purposes were threefold. First, we sought to explore the reasons for body piercing and tattooing. Although a few studies have addressed motivations for tattooing (Armstrong et al., 1996; Farrow et al., 1991) and body piercing (Armstrong, 1996; Vale & Juno, 1989), motivation needs to be further explored to gain further understanding of the reasons for the rising trend in body alteration. Because health risks regarding piercing and tattooing are plentiful, our second goal was to discern participants' awareness of health risks involved in body-altering processes. Third, we wanted to examine how body-piercing and tattooing behavior varied according to such factors as age, gender, and ethnic background. Because piercings and tattoos are becoming increasingly mainstream, we hypothesized that for this study's sample there would be no relationships between (a) age and number of piercings and tattoos, (b) gender and number of piercings and tattoos, and (c) ethnic background and number of piercings and tattoos.

METHOD

This was a descriptive correlational study primarily designed to gather information and discern relationships, if any, between selected variables.

PARTICIPANTS

A total of 81 participants were recruited through tattoo and body art parlors in Florida and Louisiana by employees of the facilities between October 1998 and February 1999. Two of the participants omitted all survey responses other than demographic information and were excluded. Data, then, from a total of 79 participants were included in the analyses. The sociodemographic characteristics of the study population include age (mean = 25; range = 19 to 55), employment status (79% employed), ethnicity (81% Caucasian), gender (57% female), marital status (70% single), sexual orientation (75% heterosexual), and educational level (63% college educated).

SURVEY INSTRUMENT

The Body Art Survey, a self-report questionnaire, was developed by the investigators. Items intended to assess participants' encounters and personal observations with piercings and tattoos were based on a review of the literature, interviews with piercing and tattoo artists, and investigators' clinical experience. Face and content validity were established by consulting with three body art/tattoo artists, a physician, a nurse, and a counselor. Seventeen body-piercing questions and 18 tattoo items were developed, and the instrument was separated into two sections. An additional eight items were used to assess demographics, including participants' race, gender, age, employment status, marital status, sexual orientation, educational level, and place of residence. Items were in a varied format, including Likert style, multiple choice, and open ended.

In the body-piercing section of the survey form, participants were asked their number of piercings, age of first piercing, and anatomic locations of piercings. They were also asked who performed the procedure, the location of the procedure, and type of object used in the procedure. Participants' perception of safety regarding previously obtained piercing was assessed by three questions (e.g., "How safe would you consider the procedure of body piercing that you obtained?"). Three items assessed participants' possible exposure to health risks with the procedure of body piercing (e.g., "In your opinion, how clean was the facility where you first obtained body piercing?"). To evaluate participants' motivations for piercing, 11 choices were presented, including a write-in *other* option. Satisfaction with piercing was assessed by Likert-type queries and an open-ended question (e.g., "How is it [the piercing] helpful to you?").

In the tattoo section of the survey form, questions paralleled the questions in the first section with the exception of tattoo-related queries replacing body-piercing questions. There was one additional question wherein participants indicated in a yes/no format whether the tattoo instrument was sterilized.

Prior to the main analyses, the survey instrument was checked for internal consistency as a measure of its reliability. Cronbach's alpha for the entire measure was .71. Reliability analyses revealed the body-piercing portion of the survey to

have internal consistency, with $\alpha = .70$ for the body-piercing survey items and $\alpha = .72$ for the tattoo items. Two raters coded responses to the open-ended questions. Interrater reliability was established by computing Cohen's kappa coefficient for each case. The average kappa coefficient for the four recoded cases was .85.

PROCEDURE

Approval was obtained from the University of South Alabama's Institutional Review Board. After discussing confidentiality requirements with participating body art/tattoo studio owners, surveys were mailed to Orlando, Florida, to two body art/tattoo parlors and hand delivered to body art/tattoo parlors in New Orleans, Louisiana, and Mobile, Alabama. Those 19 years and older seeking tattoos and/or body piercing at the studios were recruited by studio employees. Study eligibility was further defined on the survey form by defining *tattoo* as a permanent mark or design rather than a temporary decal. *Body piercing* was referred to as a hole placed anywhere in the body other than one-hole ear piercing. Participants were notified of their right to refuse to participate. Individuals who were both pierced and tattooed were asked to complete the demographic portion of the instrument and the following two sections on body piercing and tattooing. Pierced individuals were asked to respond to demographic queries and questions in the piercing section only. Tattooed individuals without piercings were requested to respond to demographic questions and the tattoo portion of the survey form. Instrument completion took about 10 to 15 minutes.

All responses were anonymous and returned by mail in sealed packets to the researchers. Two hundred surveys were distributed, 50 to each of four locations, including The Hole Experience in Orlando, Florida, Body Graphics in Orlando, Florida, Rings of Desire in New Orleans, Louisiana, and L.A. Body Art in Mobile, Alabama. Body Graphics in Orlando, Florida, went out of business, and L.A. Body Art declined to participate. Of the two participating sites, we received responses from 81 people, a response rate of 81%.

STATISTICAL METHODS

Data were analyzed with the SPSS statistical package for Windows 6.1 (Norusis, 1993). Characteristics for both body-piercing and tattoo populations were summarized using frequency distributions. Pearson correlation coefficients were then computed to assess the relationships among age, gender, and ethnic background in number of both piercings and tattoos.

RESULTS

The first purpose of our study was to investigate motivations for body piercing and tattooing. In the subjects who had their bodies pierced, the most important reasons for body piercing were individual expression (62%) and art (43%). Less important reasons included perception of sexiness, celebration, beauty, mystical or religious symbol, control, friends have it, symbol for group membership, fashion statement, and symbol of commitment to romantic relationship. A large percentage of those tattooed reported that they were motivated to receive tattoos because of individual expression (40%) and art (23%). Other reasons reported included group membership, mystical/religious experience, celebration, perception of sexiness, friends have it, symbol of commitment to romantic relationship, control, beauty, and fashion statement.

Our second purpose was to assess participants' perception of health risks related to their body piercing and/or tattooing. Regarding piercing, 88% of participants believed their piercing procedures to be safe. The remaining 12% reported a concern with piercing safety. Of those tattooed, the majority (73%) perceived that procedures used to tattoo them were safe. Twenty-two percent expressed concern with the safety of tattooing procedures, whereas 5% were not sure of the safety risks.

Finally, we hypothesized that age, gender, and ethnic background would not be associated with number of body piercings and/or tattoos. As expected, gender and race were not associated with number of body piercings. Regarding tattooing and contrary to our expectation, age was positively associated with

number of tattoos ($p < .01$). That is, increases in age resulted in increases in the number of tattoos for each individual. Gender and ethnic background were not associated with number of tattoos, as anticipated.

PIERCED PARTICIPANTS

Of the 79 subjects, 77 had body piercing. The mean age of the respondents was 25 years (range = 19 to 55), and mean age of first piercing was 18 years (range = 1 to 39). Sixty-five percent of those pierced had some college education; 6% stated that they had either received a graduate degree or had received some graduate education. Seventy-eight percent indicated that they were employed. The majority (80%) were Caucasian, most (72%) were single, and a little more than half (58%) were female. Seventy-three percent reported that they were heterosexual, 20% stated that they were homosexual, and 7% indicated that they were bisexual.

The two most important reasons for choosing the person who performed the piercing were recommendation and safety (81%). Among the more frequent of other miscellaneous responses were best price and friendly atmosphere. The majority (74%) of those pierced were performed by a professional artist, 9% by a friend or family member, 7% by another amateur, 5% by self, 1% by a physician, and 3% by unidentified persons.

Among the most popular body-piercing sites reported were multiple ear holes (74%), tongue (61%), nipple (58%), navel (41%), nose (33%), and genital area (28%). Other areas mentioned were the upper lip, lip, eyebrow, tragus (cartilage in front of ear opening), and various facial areas. Nine individuals with nipple and/or genital piercings listed sexual stimulation/gratification as reasons they enjoy these piercings (e.g., "Much more physical stimulation during sexual activity, wider foreplay possibilities, multiple orgasms").

TATTOOED PARTICIPANTS

More than half of the study subjects (52%) were tattooed prior to data collection. The tattooed individuals had a mean age of 27 (range = 19 to 55). The mean age of their first tattoo was 21 (range = 14 to 40). A majority (64%) had some college education; most (74%) were employed. Eighty-two percent

were Caucasian, more than half (55%) were male, 54% were single, and 88% were heterosexual. The majority (52%) had multiple tattoos. Forty-eight percent had four or more tattoos.

Among the tattooed subjects, almost all (98%) reported that they believed they were tattooed in a clean facility. The majority (93%) reported that the tattoo instrument had been sterilized. Most subjects (81%) demonstrated an awareness of the difficulty of tattoo removal. There were 11 (25%) respondents who indicated that they did not like something about their tattoos. Three (7%) previously tattooed participants reported that they intended to have one or more tattoos removed.

The most important reasons listed for choosing the person who performed the tattoo were recommendation and safety, respectively. Other reasons included friendly atmosphere and convenient location. Of those tattooed, the most popular sites were the back (55%), shoulder (43%), leg (40%), arm (38%), and ankle (21%). Other frequently tattooed sites included the chest/breast area (19%), stomach (17%), and buttock (10%). Less prevalent sites included the wrist, side, neck, inner lower lip, knuckles, elbow, and thigh.

DISCUSSION

We found evidence that those pierced and tattooed enjoy their body modifications. Most intend to obtain more piercings and/or tattoos. The majority of people in this study were employed, Caucasian, and heterosexual. More than half were female, single, and college educated. This study's results supported Korn's (1996) premise that females are increasingly being tattooed as well as Armstrong's (1991) findings that pierced individuals include career women. In addition, these results respond to Greif et al.'s (1999) question of whether women might be more interested in body art than men. It could be speculated that more studies of females desiring piercing and tattooing might yield increasingly stronger piercing and tattooing trends among career women, particularly Caucasians.

Self-image as reflected in sexual expression through body alteration appears to be an upcoming trend in North American society. Because individual expression, art, perception of sexiness, celebration, and beauty were listed as the top five motiva-

tions for piercing and tattooing, it is reasonable to surmise that individuals use these procedures, particularly piercing, to embellish their appearance, express their sexuality, and enhance their sexual functioning. For instance, an explanation given by some participants in relation to reasons given for genital/nipple piercings was increased sexual arousal. More than half of the pierced females had nipple piercings, and more than one fourth had genital piercings, with many of them listing sexual gratification as a reason for the procedures.

It is likely that health professionals will see more instances of piercings and tattoos in intimate locations. Because motivations for body alteration appear to be related in most instances to self-image and require sensitivity of health professionals as they come upon these body alterations, it is important for future research to explore the nature and scope of this alternative form of sexual expression, particularly for women.

Health risks as related to body piercing and tattooing were not seen as a threat to most participants. The majority of respondents reported that they believed they were pierced and/or tattooed in a safe, clean environment. Those tattooed, however, reported less assurance with safety than did pierced participants. Perhaps the perceived safety risk is greater with tattooed individuals because tattooed persons are subject to being tattooed with unregulated pigments as well as unregulated instrument sterilization methods, whereas pierced individuals may be only exposed to unregulated instrument sterilization.

A wide variety of people now pierce and tattoo their bodies. It was expected and found through our results that gender and ethnic background were not related to number of body piercings and/or tattoos. Contrary to our expectations, we found that age was positively related to the number of tattoos; that is, older individuals were more likely to have more tattoos. This seems reasonable because older people have had more time to accumulate tattoos. It is important to recognize that although adolescents are increasingly becoming tattooed (Armstrong, 1995; Armstrong & McConnell, 1994; Armstrong & Murphy, 1997), the tattooing trend continues to be strong with middle-aged adult populations as well.

Inconsistent with Korn's (1996) statement that individuals often regret their tattoos, most participants in this study indi-

cated that they were satisfied with preexisting tattoos and desired more. It is likely that this is not representative of all of those tattooed, however, because the participants in this study were those indicating a new or continued interest in body art just by their inclusion in the study. No information was obtained on the span of time from first tattooing/piercing.

There are inherent limitations to this study, such as response errors as related to possible nonattitudes or willful lying. Because this is a correlational study, only inferences may be drawn rather than conclusions concerning behavior.

Results cannot be generalized beyond the restricted target population. Participants were those who entered body art/tattoo parlors and requested body alteration. Therefore, those who were approached by studio employees and who agreed to respond may have self-selected themselves. Additional research is needed to verify the representativeness of the sample in this study.

Further research efforts could also be targeted toward discovering length of time individuals spend in deciding whether to have their bodies pierced or tattooed. Such information could be helpful in targeting health risk education regarding piercing and tattooing.

IMPLICATIONS FOR PRACTICE

Because both body piercings and tattoos are seen by many to be part of their identity, it is important for nurses to respect individuals' body modification as an inherent part of the person. Perceiving that people generally maintain condemnatory attitudes toward body modification, pierced and tattooed individuals may not feel comfortable in disclosing a health problem wherein the piercing and/or tattoo might be displayed. It is important to encourage patients to disclose their tattooing and/or piercing history so that risks may be identified.

The majority of participants in this study perceived no health risks related to body piercing and tattooing. Health risks, however, are inherent in many of the procedures and range from rather serious blood-borne diseases to minor irritations. Health education, then, may pose a challenging task for nurses and may best be considered as both preventive and ter-

tiary care. Nurses can provide education about body piercing and tattooing in secondary and college settings as well as in general medical practices via brochures, presentations, and confidential counseling. One preventive education measure to be considered might include body alteration brochures in health offices that address relevant health issues and corresponding appropriate treatment for common problems related to body art. For those who then identify themselves as considering body piercing and/or tattoos, nurses could offer personal counseling to include relevant educational health care components about appropriate care and risk factors for body piercings and tattoos. Nurses can also encourage individuals to obtain procedures only in those locations that recognize universal precautions against infection. Tertiary care could include education about wound care and systemic infection. In addition, Korn (1996) suggested encouraging individuals to keep a record of the color name and pigment of the tattoo obtained in case they would like it later removed. To assist practitioners in patient advocacy, there are various educational resources regarding body art available.¹

In summary, this investigation describes survey findings on body piercing and tattooing. The number of body piercings and tattoos were not related to gender or ethnic background of the participants. Age, however, was related to number of tattoos, with older individuals more likely to have more tattoos. Overall, participants expressed satisfaction with their piercings and tattoos, and most indicated that they would acquire additional body alteration procedures. Management of self-image was a primary motivator for body alterations. More than half of the pierced females had nipple piercings, and more than one fourth had genital piercings, with some offering comments linking these piercings to sexual expression and/or sexual stimulation. Findings from this study help demystify body piercing and tattooing, thereby assisting health practitioners in offering appropriate preventative and tertiary educational interventions for those considering these procedures.

NOTE

1. Body art educational resources are available. A tattoo video for health education can be obtained from the Texas Tech University Health Sciences Cen-

ter of Nursing (FAX: 806-743-1622). A standardized body art regulations promotional code, *Model Body Art Code*, is available by contacting the National Environmental Health Association (303-756-9090).

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This study examined the clinical usefulness of the Short-Form McGill Pain Questionnaire (SF-MPQ). Thirty postoperative patients were asked to describe their postoperative pain and were then administered the SF-MPQ. Eighteen (60%) used exact SF-MPQ sensory or affective words or synonyms to describe their postoperative pain during the interview. These results provide further evidence of the clinical relevance of the SF-MPQ sensory and affective scales. Pain descriptions by patients that go beyond pain intensity descriptions may communicate more precise information about the pain and lead to more effective pain interventions. Patients with difficulty describing their pain might be assisted by using the SF-MPQ.

Adult Patients' Postoperative Pain Descriptions and Responses to the Short-Form McGill Pain Questionnaire

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The subjective nature of pain makes effective pain communication by people in pain an essential component of competent pain management. The 0-to-10 pain intensity rating scale has been commonly used to assist adult patients to describe their pain. Restricting patients to the intensity dimension of their pain could omit valuable information about the pain that might lead to more effective pain treatment. Sensory and affective descriptions of pain by patients might provide additional information about the etiology of the pain, thus expediting more specific pain interventions. For example, postoperative

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patients describing their pain as throbbing might indicate deeper sources for their pain, whereas patients describing their pain as sharp might indicate more peripheral pain sources (Fortin, Schwartz-Barcott, & Rossi, 1992). A narcotic analgesic would be the medication of choice for the former and a nonsteroidal antiinflammatory drug the medication of choice for the latter. Nurses need ways to encourage patients to describe relevant dimensions of their pain. The purpose of this study was to examine the usefulness of the Short-Form McGill Pain Questionnaire (SF-MPQ) in helping people communicate their pain by comparing patients' unassisted pain descriptions with their subsequent responses to the sensory and affective scales of the SF-MPQ.

SF-MPQ PSYCHOMETRICS

The SF-MPQ was developed by Melzack (1987) and derived from the McGill Pain Questionnaire (MPQ) (Melzack, 1975). The main component of the SF-MPQ consists of 15 descriptors (11 sensory, 4 affective) that are rated on an intensity scale as 0 = *none*, 1 = *mild*, 2 = *moderate*, or 3 = *severe*. Three pain scores are derived from the sum of the intensity rank values of the words chosen for sensory, affective, and total descriptors. The SF-MPQ may be administered in situations that require more rapid acquisition of data than the standard MPQ.

Concurrent validity of the SF-MPQ with the long form of the McGill Pain Questionnaire (Melzack, 1975) has been supported by significant correlations for people with postsurgical pain ($r = .77$), labor pain ($r = .81$), musculoskeletal pain ($r = .70$) (Melzack, 1987), and cancer pain ($r = .77$ to $.88$) (Dudgeon, Raubertas, & Rosenthal, 1993). The SF-MPQ detected significantly less pain for postoperative patients following pain interventions with standard doses of analgesics, women given blocks for their labor pain, people treated with TENS for their musculoskeletal pain (Melzack, 1987), patients treated with Gabapentin for their postherpetic neuralgia (Rowbotham, Harden, Stacey, Bernstein, & Magnus-Miller, 1998), and people treated with Gabapentin for their diabetic peripheral neuropathy (Backonja et al., 1998). These pain intervention studies support the ability of the SF-MPQ to differentiate pain outcomes for patients across a wide variety of clinical contexts.

Zalon (1999) examined the internal consistency of the SF-MPQ with postoperative patients and found adequate reliability for sensory but not for affective dimensions of pain when recalled for the past 24 hours, $\alpha = .81$ and $\alpha = .63$, respectively. Internal consistency for sensory and affective dimensions of present pain was inadequate at $\alpha = .64$ and $\alpha = .41$, respectively. The total SF-MPQ pain score, the sum of the sensory and affective scores, was adequate with $\alpha = .85$ for past 24-hour pain and $\alpha = .72$ for present pain. Zalon suggested that pain recalled for a 24-hour period might be more likely to capture the multidimensional nature of the pain. Present pain may be more likely to be affected by factors such as present activity, time since last analgesic, and other pain treatment factors and thus subject to more variability.

Patients tend to select the SF-MPQ affective descriptors less frequently than the sensory descriptors (Fortin et al., 1992; Giuffre, Ascii, Arnstein, & Wilkinson, 1991; Zalon, 1999). Several postoperative patients in Zalon's (1999) study mentioned that they tried not to let the pain impact their mood. This might explain the less frequent selection of affective pain descriptors. Williams, Davies, and Chadury (2000) found that chronic pain patients responding to visual analogue pain scales and numerical rating scales for pain often spontaneously relabeled the scale end points using factors of function, affect, or their usual pain as more relevant descriptors. Williams et al. suggested that pain measures that allow patients to address the affective dimension of their pain might be helpful.

COMMUNICATING PAIN

Patients' response to pain measures may be affected by the demand effect of the health care provider assessing the pain as well as by the use of pain descriptors unfamiliar to the patients (Williams et al., 2000). Both of these factors further underscore the importance of effective communication by both the health care provider and the patient experiencing pain. Health care providers who take the time to assess sensory or affective dimensions of pain could still end up with inaccurate pain responses from patients if they suggest pain descriptors instead of allowing patients to describe the pain in their own words. Patients with English as a second language might have difficulty understanding the meaning of the pain descriptors

used in a pain measure such as the SF-MPQ. In both cases, more accurate communication of pain by patients might lead to better pain relief for patients.

Communication accommodation theory (CAT) provided the theoretical background for the present study. CAT (Giles, 1973) addresses motivations and behaviors of people as they adjust their communication in response to others (Fox & Giles, 1993). Attuning strategies were added to CAT by Coupland, Coupland, Giles, and Henwood (1988) and include strategies that can be used to assist with more effective communication. An important aspect of effective pain communication involves understanding and using terminology common to health care professionals (health care jargon). Interpretability strategies, the attuning strategy relevant for the current study, include the use of common terminology. Encouraging people to describe their pain more completely by using other pain dimensions in addition to the intensity dimension might assist health care providers to respond with more effective pain interventions. The present study explored the use of the SF-MPQ as a potential aide for pain communication with postoperative adults.

METHOD

DESIGN

A descriptive design was used. This study was a secondary analysis of a survey study that examined how postoperative adults communicate their pain to their health care providers (McDonald, McNulty, Erickson, & Weiskopf, 2000).

SAMPLE

The purposive sample of 30 adults consisted of 10 White, 10 Black, and 10 Latino individuals, with five women and five men in each group, who were recently discharged from four different hospitals located in the Northeastern United States. Sample eligibility criteria included being a recent postoperative inpatient, having experienced at least moderate physical pain during at least one point in their postoperative hospital stay (rated as a 4 or greater on a 1 to 10 scale, with 1 = *no pain* and 10 = *the*

worst pain possible), being between the ages of 18 and 64, having no terminal diagnosis, and having no history of substance abuse. Few patients turned down the opportunity to participate in the study, and even fewer were ineligible because they had experienced only mild postoperative pain. Relatively few Black and Latino postoperative patients were available to recruit for the study.

The participants represented 15 surgical procedures. The procedures ranged from a bilateral breast reduction to coronary artery bypass graft surgery. The most common surgical procedures included cholecystectomy ($n = 5$) and laminectomy ($n = 6$).

The majority ($n = 24$; 80%) had a high school education or greater. Most participants spoke English ($n = 28$). Two Spanish-speaking-only participants were interviewed with the assistance of an interpreter. Six participants described Spanish as their primary language, and a seventh described Spanish and English as his primary language. The mean participant age was 40.3 years ($SD = 13.49$), with a range of 18 to 63 years.

PROCEDURE

Participants were interviewed in their homes after hospital discharge by either the first author or a trained research assistant and doctoral student. Participants were interviewed from 1 to 14 days after discharge ($M = 5.6$; $SD = 2.95$), with a median and mode of 5.5 and 7 days, respectively. Prior to administering the SF-MPQ, participants were interviewed for approximately 30 minutes. All interviews were audiotaped. The interview questions were developed by the first author and included the question examined in the present study, "Tell me about the physical pain that you had during your recent hospital stay."

The procedure for preparation and content analysis of the audiotaped interviews involved four components. All transcripts were checked for accuracy and corrected by either the authors or another doctorally prepared nurse. Using content analysis methods based on Holsti (1969) and Weber (1990), the first author established a priori criteria for the content analysis. The a priori criteria for the pain description data involved identifying any words or phrases used by participants to describe their postoperative pain during their recent hospital

stay. Four raters (including the two authors) independently read the transcripts and identified pain descriptions used by the participants. Any disagreements in the descriptions were resolved by discussion.

For the present study, the second author examined the specific pain descriptions. These descriptions were broken into two categories, actual words from the SF-MPQ and synonyms of words from the SF-MPQ. Synonyms were identified if they were listed in either *Roget's 21st Century Thesaurus* (The Princeton Language Institute, 1999) or *Webster's New World Dictionary* (Neufeldt, 1988) as synonyms for pain descriptors from the SF-MPQ. The computed SF-MPQ scores (sensory, affective, and overall) were compared to previous SF-MPQ scores obtained by Melzack (1987) for three kinds of pain.

RESULTS

Eighteen (60%) people used either actual SF-MPQ sensory or affective words or synonyms to describe their postoperative pain. Thirteen (43%) used either an actual sensory word (23%) or a synonym (20%) from the SF-MPQ. Actual sensory words used from the SF-MPQ included *shooting*, *sharp*, *throbbing*, *cramping*, *heavy*, and *burning*. Sensory synonyms included *sore*, *pulling*, and *pressure*. Four people used the word *sore*.

No one used any actual affective words from the SF-MPQ, however, 8 people (27%) used synonyms. Two people used two affective descriptors each to describe their postoperative pain, *killing/unbelievable* and *intolerable/suffering*. The other affective synonyms included *excruciating*, *overpowering*, *screaming*, *incredible*, *unpleasant*, and *annoying*. No one used the same affective descriptors. Three people (10%) used combinations of affective and sensory SF-MPQ words or synonyms, *shooting/overpowering*, *heavy/incredible*, and *sore/killing/unbelievable*.

The sensory, affective, and overall SF-MPQ scores from the present study were compared to English and French Canadian postoperative, labor, and musculoskeletal pain patients from the Montreal General Hospital as described by Melzack (1987). Pain scores from the Canadian patients prior to pain treatment were compared with pain scores from patients in the current study. Table 1 compares the pain score across the two studies.

Table 1
 Comparison Across Studies of Short-Form McGill Pain Questionnaire (SF-MPQ)
 Means and Standard Deviations

SF-MPQ	Present Study (n = 30)		English Canadian Postoperative (n = 27)		French Canadian Postoperative (n = 13)		Labor (n = 20)		Musculo- skeletal (n = 10)	
	M	SD	M	SD	M	SD	M	SD	M	SD
Sensory	11.0	6.5	11.7	7.2	11.5	7.7	13.4	7.8	11.1	8.7
Affective	3.6	2.9	3.7	3.5	3.9	3.0	3.9	3.9	4.6	3.7
Overall	14.6	9.1	15.4	9.6	15.5	10.3	17.2	11.0	15.7	11.9

NOTE: This table is adapted from Melzack (1987).

DISCUSSION

The majority of the postoperative adults in the present study spontaneously described their pain using exact words or synonyms from the SF-MPQ. Evidence that people with postoperative pain continue to spontaneously use words or synonyms from the SF-MPQ more than 10 years after development of the instrument supports the continued relevance of the SF-MPQ. This finding relates well with previous research with patients experiencing postoperative pain. A significant portion of patients, 30% or greater, in these previous studies selected many of the same words from the SF-MPQ that patients in the present study spontaneously used when describing their postoperative pain. The commonly selected words that overlap with the present study include *throbbing* (Fortin et al., 1992; Giuffre et al., 1991; Taenzer, Melzack, & Jeans, 1986; Zalon, 1999), *sharp*, *tender* (Fortin et al., 1992; Taenzer et al., 1986; Zalon, 1999), *stabbing* (Fortin et al., 1992; Taenzer et al., 1986), *aching* (Giuffre et al., 1991; Zalon, 1999), *cramping* (Fortin et al., 1992), *heavy* (Giuffre et al., 1991), and *tiring-exhausting* (Zalon, 1999). Patients describing their myocardial infarction pain also used the words *heaviness* and *burning* (Jairath, 1999). Together, these findings point toward some common words that assist patients in describing their pain.

Only 23% of the postoperative adults in the present study used exact words from the SF-MPQ, and all were sensory words. This may be a result of the brevity of the instrument,

which includes only 11 sensory words and 4 affective words. The availability of fewer words makes exact word matches less likely. When encouraging people to communicate their pain, use of words with similar meanings might be as likely to convey important characteristics about the pain as exact words. The difference between exact words and synonyms for pain might therefore be negligible in clinical practice.

Similar to the previous postoperative pain studies (Fortin et al., 1992; Giuffre et al., 1991; Zalon, 1999), postoperative adults in the present study used sensory words more frequently than affective words to describe their pain. Brevity of the affective portion of the SF-MPQ may partially explain the infrequent word choice as well as the previous point made by Zalon (1999) that some patients might choose to downplay the affective dimension of their pain. Reasons why people do not use affective descriptors warrant further study because conflicting results appear in the literature (Williams et al., 2000; Zalon, 1999).

The pattern of sensory, affective, and total pain scores from the SF-MPQ was most similar to the two other postoperative pain groups and least similar to the labor pain group described by Melzack (1987). Comparisons were made with published findings rather than the actual raw data from these four groups, so the statistical significance of these similarities and differences could not be tested. The mean sensory, affective, and total pain scores were lower for postoperative patients in the present study. The standard deviations were also lower, suggesting less variability.

The greater than 10 years between the present study and the comparison studies suggest that the pain scores for the present study should have been even lower. Advances in pain management information and treatments and the wide dissemination of the Agency for Health Care Policy and Research postoperative pain guidelines (Acute Pain Management Panel, 1992) might be expected to result in even greater decrements for the present postoperative pain scores. Reasons for this lack of differentiation across time might be related to several factors. The sample sizes for all five studies were small, ranging from 10 for the musculoskeletal study to 30 for the present study. The small samples might not accurately reflect the pain experiences of those populations. Recall of average postopera-

tive pain approximately 1 week after hospital discharge might have been inflated. Some evidence exists that recall for average pain remains fairly accurate over a 1-week period, however. Bolton (1999) found an intraclass correlation coefficient of .82 between actual daily pain ratings and recall of average pain over the past week by back pain patients. Recall ability may differ, however, between postoperative patients and chronic back pain patients. The similarity in scores might also be the result of a general lack of use by health care providers of the pain management advances or ineffective pain communication by patients or providers that interferes with more effective pain relief for patients.

Jairath (1999) suggested that health care providers might not always possess the communication skills needed to assist patients to clearly describe their pain. Findings from the present study suggest that health care providers should first give the patient the opportunity to describe their pain using their own words. Patients' spontaneous descriptions, unhampered by any demand effect (Williams et al., 2000), might provide the most accurate information about the pain and expedite the most appropriate pain treatment. When pain descriptions prove difficult for the patient, the SF-MPQ might offer the health care provider a way to share with the patient some common pain descriptions used by postoperative patients without introducing a demand effect by suggesting one or two specific words that might be favored by the provider. In effect, use of the SF-MPQ might provide patients with some common pain management jargon.

Teaching patients to describe their pain in their own words might help nurses and other health care providers to more fully understand the person's pain experience. Nurses hearing patients describe their pain with a word such as *screaming* might be even more responsive to decreasing the pain and even more proactive in seeking ways to prevent such pain from recurring. Allowing patients to share their pain descriptions might also decrease some of the distress caused when patients silently worry about what the pain might represent (i.e., internal tearing of sutures). Nurses can respond to words such as *tearing* with reassurance about the intactness of the sutures and the importance of adequate analgesia to avoid such sensations.

Effective pain communication between postoperative adults and their health care providers establishes the basis for effective pain relief. Jairath (1999) made a compelling point about the importance of timely, clear pain communication when experiencing myocardial infarctions. Although postoperative pain does not have the same physiological consequences that pain from an evolving myocardial infarction does, the potential for life-threatening consequences does exist. Postoperative patients generally experience more pain with movement and activities. Patients who experience moderate to severe pain often respond by curtailing their movement. Decreased movement contributes to hypostatic pneumonia and deep venous thrombosis, with possible pulmonary emboli. Both complications can be life threatening. The importance of assisting patients to communicate their pain therefore remains critical. Use of the SF-MPQ has the potential to improve communication between patients and health care providers by encouraging patients' pain descriptions, thus promoting more effective pain management for patients.

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