

The Illness Demands of Diabetes on Couples in Botswana

Motshedisi B. Sabone, RN, PhD

University of Botswana

This report is part of a larger study that investigated the relationships between illness demands, marital support, and psychological adjustment in the context of diabetes mellitus in rural and urban middle-aged marital couples in Botswana. Ninety-six persons experiencing diabetes and 87 of their spouses participated in the study. This report is based on data from 87 diabetic patients and their spouses. Data were collected through face-to-face interviews. Patients and their spouses were interviewed separately. Three open-ended questions elicited participants' personal experiences of illness demands. The couple participants reported many challenging illness experiences associated with the illness and contextual factors that influenced their perception about the burden of illness and reported that the illness experienced was often a growth-enhancing and maturing process.

Keywords: chronic illness; marital couple; diabetes; family; patients and spouses; Botswana families; illness demands

Background

Lifestyle changes such as poor physical activity and increased consumption of a diet high in fats and refined carbohydrates have contributed to increased prevalence of chronic noncommunicable diseases (Walker, Walker, & Adam, 2003). As a result, individuals and families are increasingly challenged by the demands of lifestyle changes required for the management of such diseases (Chelsa et al., 2003; Miller & Brown, 2005; Newman, Steed, & Mulligan, 2004; Trief, Ploutz-Snyder, Britton, & Weinstock, 2004).

Author's Note: This study was jointly funded by the University of Botswana, Sigma Theta Tau International, and the Case Western Reserve University Alumni Association. Address all correspondence to Motshedisi B. Sabone, RN, PhD, School of Nursing, University of Botswana, P.O. Box UB 70318, Gaborone, Botswana, Africa; e-mail: sabonemb@mopipi.ub.bw.

The construct illness demands or demands of illness has its roots in the theories of stress, coping, and adaptation and was empirically derived from studies of families coping with chronic illness (Haberman, Woods, & Packard, 1990; Packard, Haberman, Woods, & Yates, 1991; Woods, Haberman, & Packard, 1993). Woods et al. (1993) defined *illness demands* as "illness related thoughts and events that individuals and families experience in response to health problems such as chronic illness" (p. 11), and they argued that illness demands can be appraised as either hardships or stressors or as growth-enhancing opportunities.

Packard et al. (1991) collapsed demands of illness into three broad categories of (a) direct effects of the disease, (b) personal disruptions caused by the illness, and (c) environmental transactions necessitated by the illness. In the case of marital partners, demands of illness have been reported by both patients and spouses (Loveys & Klaich, 1991). In their study of patients with Type 2 diabetes and their marital partners, Miller and Brown (2005) reported that couples' adaptation to a diabetic diet followed different patterns. Some couples adopted a teamwork approach, whereas other couples adopted an enmeshed pattern whereby one spouse took responsibility for the diet while the other was dependent. These patterns changed over time; couples who had initially adopted the teamwork approach to diet management changed to spouses being functionally separate (Miller & Brown, 2005). Chelsa et al. (2003) studied baseline family characteristics among Latino and European diabetes patients and their partners. They found that family functioning was important in managing aspects such as diet, exercise, blood glucose monitoring, and management of medications. There were observed similarities and differences across the two ethnic groups. These findings underscore the importance of incorporating the spouse both in the management of illness and in research about the illness experience. The findings also point to the need for cultural sensitivity in research and practice.

Demands of illness have been found to be dynamic, varying with the phase of the illness and the diagnostic category. As much as illness demands are often associated with negative feelings, such as fear, sadness, and anger, they are also associated with positive experiences, such as reaching out, showing empathy, easing the misery of other people, and acquiring new knowledge in the process of adjusting to life with the illness (Loveys & Klaich, 1991). Kumar, Shah, and Chandra (2006) found that the response to the demands of illness included denial, substance abuse, and distraction. Illness demands have been shown to have gender implications in that women reported conflicting demands from family and employment that

interfered with their participation in a rehabilitation program (Hamberg, Johansson, Lindgren, & Westman, 1997).

In Botswana, diabetes and cardiovascular diseases have been identified as emerging chronic diseases that are a result of a shift from agrarian to industrial life (Ministry of Finance and Development Planning, 1997). Because little is known about the couple's experience of chronic illness in Botswana, a study was conducted to investigate the relationships between illness demands, marital support, and psychological adjustment in the context of diabetes mellitus in rural and urban middle-aged marital couples in Botswana. This research report focuses on the couple's experience of illness demands of diabetes. Although some illness demands may be universal across cultures, ethnicity, culture, and gender influence how illness is experienced and how people respond to it. As Botswana strives to improve the social conditions of every citizen in the midst of rapid urbanization, more needs to be known about the demands that chronic illnesses such as diabetes impose on couples.

The research question that addressed the qualitative aspect of the study was, "What does living with diabetes mean to persons with diabetes and their spouses?"

Method

In the larger study, a cross-sectional exploratory design with convenience sampling was used to investigate the relationships between illness demands, marital support, and psychological adjustment to chronic illness in rural and urban female and male diabetic patients and their spouses. This report focuses on the three open-ended questions used to capture the expression of the respondents' experiences of the illness of diabetes in their own words.

Sample

Couples were recruited from the outpatient departments of local hospitals of rural and urban communities in Botswana. The inclusion criteria consisted of men and women (a) with a diagnosis of diabetes mellitus of at least 1 year in duration, (b) between the ages of 30 and 65, and (c) who have spouses or partners to whom they were married or with whom they lived with for at least 1 year. Individuals whose spouse also had diabetes or any other illness that caused significant limitation in daily function or impaired judgment, including psychiatric illness, were excluded. In total, 87 patients and their spouses provided data for this report. All (87) patients were experiencing diabetes and gender break down was 39 females and 48 males.

Data Collection

Following collection of the quantitative data related to the larger study, the couple was invited to respond to the three open-ended questions through a face-to-face interview in the couple's own home. Data collection took place in 2001 during a 6-week period. Patients and spouses were interviewed separately. No audio recording was done; answers to the questions were collected through careful note taking by the author. The literature guided the construction of the three open-ended questions, covering the negative or the most difficult illness experiences, the positive experiences, and the strategies that the participants in the study reported they were using to cope with the illness experience. The three open-ended questions included the following: (a) What is the hardest thing about living with diabetes? (b) What is positive about living with diabetes? and (c) What advice would you give to a person or family who has just been diagnosed with diabetes?

Informed consent was obtained from husbands and wives separately. The study was approved by the Institutional Review Board of Case Western Reserve University, where the author was a doctoral student, and the research and ethics review committees of Botswana, where the study participants were recruited.

Data Analysis

Thematic analysis was used to analyze each participant's responses to each of the open-ended questions. Initially, the data from patients and spouses were analyzed separately. At the second level of analysis, responses from the couple were analyzed for congruency between the patient and the spouse. For example, responses from patients and spouses were cross-checked by pairing the participants' identifying codes by couple; for instance, spouse response coded as Number 23 was compared with patient response coded as Number 23. Each question was analyzed individually, using sentences as units of analysis. Codes were developed and condensed into categories. By carefully examining categories thus developed, conceptual linkages were used to further condense the categories into more abstract and parsimonious themes. A count of participants endorsing each theme was done, and counts were then expressed as percentages of the total number of participants (Polit & Hungler, 1993). Patterning of themes was also noted (Polit & Hungler) so as to identify any theme variation by demographic variables. Finally, themes were integrated into a conceptually coherent conclusion regarding the views of the participants in relation to each question posed.

Table 1
Frequency Distribution for Personal Characteristics
of the Sample (Couples)

Variable	Couples (<i>N</i> = 87)	
	Frequency	%
Residence		
Rural	46	52.9
Urban	41	47.1
Gender		
Males	87	50
Females	87	50
Marital status		
Married	80	92.0
Living together	7	8.0

Findings

Sample Demographic Characteristics

Eighty-seven (87) couples completed the interviews. Rural residents composed 52.9% of the sample, whereas urban residents comprised 47.1% of the sample.

The classification of the participants' towns of residence was according to the Botswana town and village profile, which classifies a settlement as urban if it has a population threshold of 5,000 people and at least 75% of the economically active population is engaged in nonagricultural activities. However, Botswana is experiencing rapid urbanization, which makes accurate classification difficult especially in rural villages surrounding the capital city, such as the ones used in this study. Details of the demographic characteristics of the sample are presented in Tables 1 and 2.

Themes From Diabetic Participants and Their Spouses

Participants experienced the illness both as couples and as individuals, and the individual experience was related to each person's relationship with and perceptions of the illness. A synopsis of the participants' responses to the three qualitative questions yielded three central themes: (a) living with diabetes was challenging, especially during the first few years of the illness;

Table 2
Frequency Distribution for Personal Characteristics of the Sample
(Patients and Spouses Treated Separately)

Variable	Patients (<i>N</i> = 87)		Spouses (<i>N</i> = 87)	
	Frequencies	%	Frequencies	%
Employment status				
Full-time employed	49	56.3	40	46.0
Part-time employed	1	1.1	1	1.1
Short-term employed	–	–	2	2.3
Self-employed	31	35.6	33	37.9
Retired	6	6.9	9	10.3
Unemployed	–	–	2	2.3
Education				
Never attended school	10	11.5	7	8.0
Literacy to primary	33	37.9	39	44.8
Secondary school	22	25.3	24	27.6
Postsecondary degree	18	20.7	13	14.9
First degree and above	4	4.6	4	4.6
Monthly income				
Under U\$80	23	26.4	23	26.4
U\$81 to U\$200	18	20.7	15	17.2
U\$201 to U\$600	19	21.8	24	27.6
U\$601 to U\$1,000	16	18.4	13	14.9
U\$1,001 to U\$1,400	8	9.2	8	9.2
U\$1,401 to U\$1,800	1	1.1	2	3.3
U\$1,801 and higher	2	2.3	2	2.3
Occupation				
Higher executives	1	1.1	3	3.4
Managerial	22	26.4	15	17.2
Skilled workers	11	12.6	10	11.5
Semiskilled nonmanual	9	10.3	11	12.6
Unskilled manual	5	5.7	10	11.5
Semiskilled manual	35	40.2	34	39.1
Nonmarital support resource reported				
Children	49	56.3	45	51.7
Relatives	35	40.2	60	69
Friends	20	23	16	18.4
Extended family	82	94.3	67	77.0
Coworkers	4	4.6	3	3.4
Church	6	6.9	3	3.4
Others	2	2.3	2	2.3

Table 3
Percentages of Participants Expressing Negative Experiences: Patients Spouses

Subthemes	Frequency	%	Frequency	%
The diagnosis of diabetes itself	14	16.1	31	35.6
Coping with symptoms	22	25.3	20	23
Lifestyle change	10	11.5	7	8
Multiple losses	4	4.6	10	11.5
Lack of support	11	12.6	3	3.4
Patient factors	—	—	8	9.2

Note: Each subtheme is expressed as a percentage of all patients or spouses interviewed, as one participant could express more than one subtheme.

Table 4
Percentages of Participants Expressing Positive Experiences: Patients Spouses

Subthemes	Frequency	%	Frequency	%
Social support	64	73.6	26	30
Learning and maturing opportunity	16	18.4	4	4.6
Closer family relationships	4	4.6	4	4.6
Being able to live a normal life	12	13.8	22	25.3
Families' acceptance of the illness	—	—	8	9.2
Patient being a wonderful patient	—	—	24	27.6

Note: Each subtheme is expressed as a percentage of all patients or spouses interviewed, as one participant could express more than one subtheme.

(b) certain conditions influenced the participants' perception about the burden created by the illness (contextual factors in the illness experience); and (c) the illness experience was often a growth-enhancing or maturing process. These three themes will be further elaborated below. Participants also offered several strategies for living well with diabetes, which will also be summarized. The incidence of subthemes, which emerged from each of the responses to the three questions, is summarized in Tables 3, 4, and 5. Because responses from one participant could cut across themes and subthemes, such as one expressing both the positive and the negative experiences of diabetes, themes and subthemes are reported as a percentage of all patients or spouses interviewed.

Table 5
Percentages of Participants Suggesting Ways
to Living Well With Diabetes: Patients Spouses

Subthemes	Frequency	%	Frequency	%
Adherence to treatment regimen	63	72.4	54	62
Adopting a positive attitude	18	20.7	10	11.5
Attention to the patient's emotions	20	23	28	32.2
Seeking out and providing support	5	5.7	22	25.3
Learning more about the illness	9	10.3	—	—

Note: Each subtheme is expressed as a percentage of all patients or spouses interviewed, as one participant could express more than one subtheme.

The Challenges of Diabetes

Challenges of the illness that the couple participants reported included: (a) perceived symptom experience, (b) lifestyle change, (c) multiple losses, and (d) sexuality issues. The challenges are presented in Table 3, and they are elaborated in the discussion that follows.

Experiencing the symptoms of the disease. The symptoms of diabetes were a source of concern for both patients and spouses. Fatigue was the most common disturbing symptom and was particularly disturbing because the participants felt helpless about its management. Irritability, fatigue, and sexuality problems were common causes of tension in husband–wife relationships. The problem of frequent diarrhea was reported as limiting the patient's socializing activities with others. Other disturbing symptoms were weight loss and frequent infections. Of the commonly known complications of diabetes, loss of vision was reported as the most disturbing for the participants.

Physical symptoms were more often reported as challenging by the patients than by their spouses. This seemed to be because the patients were the ones who had to deal with the symptoms of diabetes so intimately. However, symptoms such as hot and cold spells were experienced by both patients and their spouses. Body aches and pains were often aggravated by the activities of daily living, which may help explain why females, who more often have many more daily physical responsibilities and errands than males, reported more physical symptoms.

Many participants reported feeling reassured that the illness was well controlled and that the patient was adhering to the management regimen.

Others, and especially spouses, described how the possibility of the diabetes “silently” developing complications made them worry about the potentially worrisome underlying causes for symptoms such as fatigue. One particularly feared complication of diabetes reported by participants was the loss of sight, which, as they reasoned, could make it difficult for the patient to accurately comprehend support from others.

Lifestyle change. Many participants described having to modify aspects of their lifestyle because of the illness. The common lifestyle changes involved diet and sexual activity. Participants found it challenging to balance their dietary needs with those of other family members. Lifestyle change and decreased life enjoyment were particularly emphasized by male patients and less frequently by these patients’ wives. One female spouse said, “I worry about how my husband feels about the changed lifestyle, I feel for him.” Lifestyle change was reported to be the hardest thing for patients to endure. A few male patients reported that having diabetes was difficult because they had excellent appetites that were hard to control.

Other accounts related to lifestyle change included the need for adjustments related to social activities and employment. For example, for many male patients, spending time with friends was missed. The need to withdraw from drinking alcohol for some of these participants often meant also withdrawing from social networks. One male patient said:

You cannot hang out with friends any more, you actually become a loner. You isolate yourself because you do not want to frustrate them, or they desert you when they realize that you are no longer the friend that they used to know.

Patients reported higher illness demands related to social relationships than their spouses. However, spouses described often feeling constrained from socializing with others on their own for fear of leaving the patient alone and in case of a medical emergency. Examples of changes that involved work life included moving from one department to another, taking on less strenuous assignments, and reducing job-related traveling, which are related to lack of energy for doing the work. In a few instances, patients reported that their supervisors had refused to take their illness into consideration in doing job assignments. For the spouses, the illness demands required them to take time off at times to attend to patients’ medical needs.

Multiple losses. Living with diabetes was reported to be associated with a variety of losses, especially for patients. The most common loss reported

was the loss of the ability to “provide” adequately for self and family. Reported financial strain was usually related to the dietary demands of diabetes. Other losses reported by participants included “the ability to do for self” (particularly for male patients who were farmers), sexual prowess, friendships, and the ability to express affection through “doing for spouse” (particularly for female patients). One female patient reported that, because of her illness, employed home helpers had taken over doing activities, such as cooking and laundry, that she used to do. Doing things for each other as a couple was taken as an expression of love and was enjoyed by both the giver and the recipient of the actions.

Sexuality issues. Sexuality was a major issue for men and women alike. Seventy-eight percent of male patients and 75% of female patients reported a change (that is, reduced frequency, diminished enjoyment of sexual intercourse) in their sexual lives because of their illness. For women patients, reduced enjoyment and decreased frequency of sex was as a result of loss of interest and the increased frequency of vaginal rashes. Women rarely described these changes as being due to fatigue. For one patient and his spouse, however, the decreased frequency of sexual activity was seen as a normal process of becoming older, or “go gola” in Setswana terms. Overall, in this study, if there was any diabetes-related friction described between husband and wife, it was likely to be about issues related to their sexual relationship.

Contextual Factors Influencing the Experience of Illness Burden

Contextual factors that participants believed had influenced their illness burden were (a) spousal support, (b) health care professional support, and (c) other circumstances surrounding the diagnosis (i.e., age of couple’s children at time of diagnosis, the degree of fear and intensity of presenting symptoms around time of diagnosis; e.g., gangrene, excessive weight loss, excessive sweating, abnormal/disturbed, urination, palpitations).

Contextual factors that acted as modifiers of shock and disbelief at the time of diagnosis were past experience with diabetes, prior knowledge about diabetes, childbearing situation, children’s schooling situation, and passage of time.

Spousal support. Issues surrounded the future of couples’ marriages and relationships after the diagnosis of diabetes and contributed to illness burden. An example of a question that was asked was, “Is my spouse going to

accept me with this illness?" Indeed, there were two instances when partners had left the relationship, seemingly because of the impact of the illness. In the households of three male and three female patients, partners were continuing to live in the same physical space but reported that they were no longer emotionally or functionally there for one another.

Participants reported strains in family relations, which were not always diabetes related. Lack of family support was reported by 13% of patients, especially females. Some female patients reported that their husbands were not helping them financially, nor were they helping to provide care during their hospitalizations. One female patient described that her husband made critical comments that contributed to an exacerbation of her illness. Another patient reported that her husband believed that she was "acting sick" as a way to manipulate him. Lack of spousal support described by male patients concerned failure of the spouse to serve the right food at the right time and to provide constant company as well as finding alternative persons to fulfill sex needs or incorrectly ascribing the husband's reduced sexual interest to having alternative sexual partners.

Many spouses and a few patients reported that people with diabetes tend to be moody, short tempered, and emotionally over-sensitive, all of which present a challenge to communication between the spouse and the patient, in general, and specifically in terms of discussing issues related to treatment regimen. Such participants were grateful though that the health care providers had informed them about the possibility of the patient being emotional as a result of the illness. Some had devised some strategies of dealing with the patients' emotional irritability, such as withdrawing when the conversation became difficult, taking the blame to make the patient feel good, or postponing the discussion to a later time.

Although participants generally did not blame anyone for the illness, they would often reflect back on the history of their life and ask why they had endured so much suffering. For instance, as one male patient described, "I never knew my mother. I was orphaned. Now I have diabetes and I cannot enjoy life to its fullest. Why should life be so rough on me?" Some female spouses reported thinking about lifestyle choices, such as drinking, and wondering if that might have caused their husband's diabetes.

Uncertainties about the relationship between diabetes and AIDS contributed to illness burden. Participants questioned whether diabetes was somehow AIDS related and whether it was communicable. It appeared that the relationship between diabetes and male sexuality, and the fact that males tended not to be open about their sexual problems, made their wives suspect that there might be a relationship between AIDS and diabetes. One

spouse reported that she was abstaining from sex with her husband for fear that his diabetes might be AIDS related.

Patients and spouses provided accounts of the various coping strategies that they had used in dealing with illness burden, especially in the early period following diagnosis transitioning from the phase of diagnosis and their initial reactions to illness toward a stage of adaptation. Some participants reported that they went from one healer to another looking for a cure. Some described using prayer as another strategy. The most commonly used coping approach was making comparisons. Participants were reassured by seeing people who had been living "normal lives" with diabetes. Making comparisons helped them believe that they could also live for a long time, if they followed the diabetes self-care regimen. Seeing people who were very sick and/or who had lost limbs because of the illness helped participants realize that their situation was "not that bad" and encouraged them to keep up their lifestyles.

Health care professional support. Oftentimes, the attitudes of health care professionals added to the stress of the diagnosis and illness burden. Participants reported that one of the most difficult experiences in living with diabetes was around relationships with health care professionals. Several patients and spouses talked about how patients had gone to the health clinic several times because of diabetes symptoms and that they had been ignored. They described that even when they had asked to be tested for diabetes, they had been ignored. Some patients felt that health care professionals had preconceived notions about symptoms being related to AIDS. One woman reported that she had stopped going for medical evaluations because she did not want to be subjected to impersonal treatment by doctors and nurses. She used these words to describe her experience: "They force pills into me without explaining anything to me." What she wanted was a dialogue with a health care professional, feedback on her blood sugar results, and an explanation about medications. Another participant described the health care system as uncaring.

The participants reported that if they complained of health problems other than diabetes, they were usually ignored. If they felt unwell and went to the hospital before their scheduled date, they were returned or if they were attended to, it was done with an attitude of "after all you shouldn't be taking my time." One was more likely to be a victim of the uncaring attitude of health care professionals if they were ignorant and if they were not assertive than when the reverse was true.

Illness Experience as a Learning and Maturing Opportunity

The illness experience was reported to have cultivated a sense of maturity and personal capacity for the participants in a number of ways. Fourteen percent of patients reported that they had adopted healthier lifestyles and that they were coaching their family members to do likewise. Five percent of spouses reported increased knowledge about health matters such as what diabetes is, how to manage it, the role of emotions in physical health, the value of regular medical exams and leading healthy lifestyles, and the important role that the health care system was playing in their care. As a result of the diabetes diagnosis, 4% of patients reported increased self-control, tolerance, and problem-solving abilities. For female patients, increased personal capacity was felt even more if the woman's spouse was unsupportive. This is because for such women, adapting to the illness of diabetes on their own helped them realize that they had the capability to be independent.

Four male patients and their spouses reported that the illness had brought them closer together, because the husbands had more time at home. One female spouse reported that she was even enjoying more respect from her mother-in-law. A male patient said "the diagnosis of diabetes was like a wake-up call for me. I began to think more about my family. I now spend more time with my wife and children."

The participants were asked what advice they would give to other individuals or families who were diagnosed with diabetes. Respondents observed that even though diabetes cannot be cured, one could lead a relatively normal life with it. Reported ways to leading a positive life with diabetes included (a) adhering to the treatment regimen, (b) adopting a positive attitude, (c) taking care of emotional health, (d) seeking out and providing support, and (e) learning more about diabetes. Ways to living positively with diabetes are presented in Table 5.

Adherence to treatment regimen. Adherence to the treatment regimen was reported by 68% of patients and 62% of spouses as the hallmark of a long and quality life with diabetes. The regimen included attention toward such areas as diet, medications, alcohol consumption, medical visits, and blood glucose monitoring. One way for patients to avoid temptation to deviate from the prescribed regimen was to be selective about his or her company and to spend time with people who were likely to encourage healthy behaviors.

Adopting a positive attitude. Twenty-three percent of patients and 12% of spouses believed that one has to understand that diabetes can be controlled and that having diabetes is not the end of one's life. A positive

attitude also meant acceptance of the illness and integrating it in one's daily existence. One spouse observed that the patients themselves need to accept and be comfortable with their own selves before they could expect other people to accept them.

Attention to emotional health. For patients, attention to emotional health had to do with having patience and tolerance as well as being a good communicator. Open communication on the part of the patient was said to encourage others to also communicate openly with the patient and, ultimately, to help the patient accept their illness. Keeping active, as opposed to playing the "sick role," as well as making prayer a habit were also reported to be good strategies for living well with diabetes. For spouses, attention to the patient's emotional health meant being open with them about issues pertaining to the illness and exercising tactfulness, calmness, patience, and tolerance when communicating with him or her. One spouse talked about emotional maturity on the part of the spouse. Spouses needed to take some time to know the patient and his or her moods, to avoid becoming emotionally overinvolved, to do their best to attend to the patient's needs, and to learn from day-to-day experiences. One spouse observed that there is a place for being firm in encouraging the patient's adherence to the treatment regimen. Twenty-two percent of patients and 32% of spouses talked about attention to the patient's emotional health. None of the respondents mentioned attention to the spouse's emotional health. Urban residents more often talked about the emotional care than rural ones.

Seeking out and providing support. Patients conveyed that a person with diabetes should know that a spouse can be their Number 1 support resource and that such support should be sought. To foster the support of the spouse, patients recommended getting spouses involved through attending medical reviews, for example, so that they get to understand more about the illness and its treatment. Study participants advised that spouses could support patients by adopting a healthy lifestyle and leading by example, having realistic expectations for the patient to change their lifestyle, accompanying patients to medical appointments, encouraging regimen adherence, and providing positive reinforcement. Five percent of patients and spouses talked about the importance of support.

Learning more about diabetes. Taking time to learn more about diabetes was also mentioned by 11 % of patients as a means toward living positively with diabetes. Participants described that one has to understand that diabetes will change a family's life.

Discussion

The demands of illness were particularly hard at the initial stage, when patients had just been diagnosed. Because the mean duration of the illness for the sample was 7 years, the majority of the participants had become more comfortable with the illness at the time of the study. Packard et al. (1991) also observed that illness demands are most felt during the early stages of the illness. The participants believed that prior knowledge about diabetes could have made their coping easier. Both patients and their spouses reported having many questions and concerns. Concerns went beyond the patient to the entire family and covered the challenge of a lifetime illness, the possibility of death, and the impact that the illness might have on the marital relationship.

The major challenge that the participants were faced with at the time of the study was lifestyle modification to accommodate diabetes. They had to cope with a diet that was often unpalatable and that some families could hardly afford. Many were missing their usual routines and social support. Many of the lifestyle change illness demands reported in this study have also been reported in similar studies (Hagedoorn et al., 2006; Mann & Dieppe, 2006; Sandberg, 2006; Stodberg, Sunvisson, & Ahlstrom, 2006).

Another major challenging area was that of sexuality, specifically the frequency and quality of sex between the marital partner. Issues addressed by study participants regarding sexual relationships with their spouse have been reported in similar studies. Campbell, Redelman, Borkman, McLay, and Chisholm (2002) reported decreased libido, slow sexual arousal, decreased lubrication, and painful sexual intercourse among women with diabetes. However, women in this study did not report vaginal dryness. The pain that they associated with sexual intercourse was attributed to frequent vaginal rashes. Decreased sexual desire was also reported by women with diabetes in another study (Schreiner-Engel, Schiavi, Vietorisz, & Smith, 1987).

Gender had an influence in the experience of illness demands. It was hard for female patients to imagine their death when their children were still young. Self-care and regimen adherence were challenging for male patients, who missed such lifestyles as hanging out in bars and enjoying the company of fellow men. DesRosier, Catanzaro, and Piller (1992) and Hamberg et al. (1997) also observed that assigned gender roles were determining the nature of illness demands that men and women were experiencing. Sandberg (2006) also found gender differences in spousal support related to diet and treatment regimen.

Whereas the spouse's illness challenged the otherwise emotionally distant females to reconsider their marital obligation of being a Number 1 support resource to their husbands, that did not happen with male spouses. Hoskins et al. (1996) also found that the illness did not restore the relationship when

the patient was a female. Problems related to sexuality were harder for males than for females. Erectile dysfunctions related to the illness were like a blow to the inner core of male patients' manhood and were difficult to communicate to spouses.

For couples with reported friction in the spousal relationship, the wife would be willing to participate in the study and the husband would be reluctant to participate or would refuse altogether. The wife took it as an opportunity to have the couple's problems addressed, whereas the husband looked at it as an attempt to investigate his alleged misdeeds. Because entry into a household was through the patient, troubled families with male patients were not usually recruited, and those with female patients often had only the wife participating in the study. Therefore, the sample in this study may have been biased toward couples with relatively stable relationships. In their study with couples coping with rheumatoid arthritis, Mann and Dieppe (2006) also reported bias in favor of selecting couples with healthier relationships over those with conflictual relationships. (In this study, the spousal relationship was assessed in the quantitative portion of the study, not reported here.)

Whereas there were many negative experiences that patients and spouses endured, the illness experience was also perceived as a growth-enhancing opportunity for patients and spouses, leading to increased capacity for problem solving and coping with adversities. Participants believed that the hallmark of quality life with diabetes was to adhere to the treatment regimen. Also important was to protect and take care of the patient's emotions. Other coping strategies used were making comparisons and adopting a positive attitude to life in general.

Contrary to studies by Loveys and Klaich (1991) as well as Kumar et al. (2006), this study did not uncover any direct concerns by patients or their spouses regarding issues of employability and health insurance coverage. The difference in the findings may be related to the fact that Botswana is characterized by a low rate of job change and a relatively inexpensive health care.

Professional support is considered important and relevant in studying the demands of the illness on couples for several reasons: A patient who feels unsupported by the health care system may have a negative attitude toward the illness, and that may affect his or her illness-related interaction with the marital partner. Professional support to the patients includes helping them in developing skills for bringing the family on board in the management of the illness. When it is available, professional support hopefully extends to the family, especially the marital partner, so that the family members feel

recognized and accommodated in the illness management and so that they have an opportunity to learn more about the illness and give the patient the necessary support. Couples wanted collaborative partnerships with health care providers and that was not always forthcoming. Hoskins et al. (1996) have argued that support from health care professionals enhances a more positive perception of global health status, which in turn influences trust and confidence in the treatment process.

The desire for and appreciation of support from health care providers by persons with diabetes and their partners have been reported in prior studies. In their study with women with breast cancer and their partners, Fielding and Lam (2006) also found that marital partners' wished they could have more information about the illness. Similarly, Stodberg et al. (2006) found that significant others of persons with diabetes reported a yearning for involvement in the illness management and support from the health care staff. Golin, Dimatteo, Duan, Leake, and Gelberg (2002) also reported that patients with diabetes were happier if they were involved in decision making related to their care than when they were not.

Implications for Family Nursing Practice

A thorough family assessment must be done upon diagnosis of diabetes, as it was apparent that some families were not in a position to provide supportive care to patients because of the quality of the existing family relationships. One participant succinctly justified the need for assessment of families in these words: "There is a lot that goes on in patients' lives." Such assessment needs to be repeated at intervals because life patterns of families change over time. A study related to diabetic families has revealed that families' response to the illness are diverse and heterogeneous—hence the need for a thorough assessment of each affected family (Mann & Dieppe, 2006).

There was a disturbing theme about the uncaring attitudes of health care providers. Participants told stories about how their initial diabetes symptoms had been minimized, how they had been ridiculed, and how their concerns had been ignored. Although the fact that health professionals are experts in the field cannot be disputed, it is equally hard to dispute the fact that individuals and families are experts in symptom experience. There is, therefore, a need for increased sensitivity to emerging chronic illnesses such as diabetes on the part of health care professionals because prompt response to problems can be both life and cost saving. The purpose of the health system is certainly defeated if the attitudes of professionals can deter clients from seeking care, as some incidents reported in this study suggest. Health professionals need to

be encouraged by the trust that clients put in them, as was reported in this study, and do their best within the resource constraints.

The yearning for information on diabetes reported by participants in this study is an indication for a need for public education about the emerging non-communicable diseases, and the media need to increase their role in that regard. It was unfortunate that participants in this study only came to know about diabetes through experiencing it. Clients need education that will help clear up misconceptions about emerging health problems such as diabetes and AIDS.

There is a need for community health workers who can visit patients in their own homes to assess their physical and social living circumstances and to provide education and counseling according to an individual client's needs. As findings of prior studies have indicated, the patient load at the hospital setting can hardly allow for a meaningful professional-patient interaction (Onen, 1999; Petlo, 1996). As such, work-related stress may be contributing to the uncaring attitudes of health care professionals reported in this study.

Diet, which may be considered the cornerstone of diabetes treatment, was reported to be too expensive for some families. Although families may be encouraged to help themselves and not to rely on government for everything, assessing families at the point of diagnosis may help identify those who need to be assisted in some way. The home interview was an eye opener about the poverty that exists in some households in Botswana.

Reaching out to others was not a usual coping strategy for participants in this study. However, it is a strategy that has been used in Botswana and elsewhere in the case of HIV/AIDS, whereby ill people ease their misery through easing that of others. This can be done through the media, whereby people with diabetes are invited as guests on special television or radio programs. Patients can also speak at conferences and workshops to provide a client voice in the scientific and academic discussions.

Implications for Future Research

Spouses in this study believed that patient's behavior, such as doing for self when one can, having a positive attitude, being open to suggestions, and being open with illness-related problems, counted as "support" provided by the patient. A more exploratory study is needed to generate more items for measuring the spouse's experience of support. The concept of respect, which was mentioned by two male spouses, may be an important element in supportive interactions in Botswana couples and may need further investigation.

Conclusion

In conclusion, findings of this study show that the experience of chronic illnesses such as diabetes puts demands on both patient and spouse. Illness demands are particularly challenging during the initial phase of the illness following diagnosis and appear to lessen as couples adapt to the illness. However, there is a positive side of the illness experience. There is a great deal of learning that takes place during the illness experience, including realization of one's personal and couple resourcefulness. Support, whether it is from health professionals or between spouses themselves, is an important resource for couples experiencing diabetes.

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Motshedisi B. Sabone, PhD, RN, is currently a senior lecturer at the University of Botswana School of Nursing and a coordinator for the Nursing Graduate Program. Her research focuses on family psychosocial health, and her clinical interests include the health promotion aspects of psychiatric care. She also conducts research and publishes in the area of HIV/AIDS. Her recent publications include "Using Qualitative Methods in Course Evaluation: A Case Study from Botswana," in *Nurse Educator* (Vol. 31, No. 6, 275-280; with Brown, Sebege, Ntsayagae, Mogobe, Sabone, & Seboni, 2006); "The Perceptions on the Use of the Nursing Process in 4 African Countries," in *Africa Journal of Nursing & Midwifery* (Vol. 6, No. 1, 67-77; with Irinoya, Kamanzi, Uys, Ofi, & Cassimje, 2005); and "Research Integrity and Misconduct: Clarification of the Concepts," in *Curationis* (Vol. 9, 40-45; with Khanyile, Duma, Fakude, Daniels, Mbombo, & Sabone, 2006).