Unmet Needs of Patients with Systemic Lupus Erythematosus

Sharon Danoff-Burg, PhD; Fred Friedberg, PhD

*The authors' goal was to assess unmet needs of patients with systemic lupus erythematosus (SLE). Participants (*N *= 112), who were recruited through the mailing list and support group meetings of a Lupus Alliance of America Affiliate, completed a survey based on prior research. All participants perceived at least 1 unmet need. The most frequently reported unmet needs were in the physical symptoms domain. Older patients were more likely than younger patients to have higher levels of unmet needs related to physical and psychological functioning. African American patients were more likely than white patients to have higher levels of unmet needs related to health services and information. Our findings document the high prevalence and variety of unmet needs among these patients, as well as variations among demographic groups. To address unmet needs of SLE patients, targeted referrals to patient educators, mental health professionals, and support organizations are important adjuncts to medical treatment.*

Index Terms*: needs assessment, patient satisfaction, systemic lupus erythematosus, unmet needs*

Qualitative studies have revealed that patients with chronic illnesses, including systemic lupus erythematosus (SLE), often report withholding the full range of their needs from health care providers.[1–3] Ascertaining the perceived needs of patients with SLE is important for multiple reasons. In a discussion of unmet health care needs in patients with rheumatoid arthritis (RA) and ankylosing spondylitis, 3 functions of needs assessment research were identified.[4] First, feedback from patients concerning the type and level of their unmet illness-related needs can be used to improve existing services and develop new interventions. Second, patients' responses can inform future research (eg, which questions are posed and which outcomes are prioritized). Third, patients increasingly have become involved in their disease management and medical decision making, which, in turn, may lead to enhanced psychological adjustment and improved outcomes.[5] Needs assessment research, therefore, may benefit patients directly by allowing them to consider not only their satisfaction level, but also their own role in influencing the content and the provision of their health care. Given the bidirectional nature of the patient-provider relationship and the complex nature of SLE, patients must be active participants in their health care.[6]

Needs assessment research is related to, but not synonymous with, patient satisfaction research. With regard to the latter, a survey of Swedish patients with SLE[7] indicated that the majority were dissatisfied with their health care and the level of understanding they received from physicians. However, needs assessment research may be more useful than patient satisfaction research in contributing to health care quality, because needs assessment research

---

***Dr Danoff-Burg** is with the Department of Psychology at the University at Albany, SUNY. **Dr Friedberg** is with the Department of Psychiatry and Behavioral Science, School of Medicine at Stony Brook University, SUNY.*

specifies the level and type of services desired and expected by patients.[8] In other words, assessment research is arguably more solution focused than quality of life research or patient satisfaction research.[9] A previous needs assessment of patients with SLE in Australia[8] found that 94% of participants had 1 or more unmet needs. The most prevalent unmet needs were related to physical symptoms, such as tiredness, pain, and sleeping problems. However, unmet psychosocial needs were also common. For example, 72% of participants reported the need for help related to (1) coping with fears of a disease flare and (2) frustration with not being able to do what they used to do.

A concerning finding of the needs assessment study conducted in Australia[8] was that the prevalence of unmet needs among patients with SLE was greater than the prevalence of unmet needs documented among other patient groups. Among the patients with SLE, 94% reported at least 1 unmet need, whereas among samples of patients with RA[10] or cancer,[11–12] a minority of participants reported unmet needs. However, comparisons among these various studies must be made with caution because of notable differences in methodology (eg, recruitment strategies, survey instruments).

The goal of the present study was to determine whether results similar to those of the needs assessment study conducted in Australia[8] would be obtained with a sample of patients with SLE in the United States. In addition to examining level and type of patient-reported unmet needs, we sought to identify correlates of unmet needs. Findings may have implications for the further study of disease variables and the development and delivery of medical, educational, and psychosocial services for individuals with SLE.

METHODS

The study was reviewed, approved, and conducted in accordance with the Committee on Research Involving Human Subjects of Stony Brook University. Letters inviting patients diagnosed with SLE to volunteer in a research study were sent to the mailing list of the Lupus Alliance of America, Long Island/Queens Affiliate, in New York State. The membership of the organization is drawn from multiple sources, including newspaper advertisements, public service announcements, local physician referrals, and the organization's Web site (Joann Quinn, personal communication, March 12, 2008). No single primary recruitment source was identified.

Patients were invited to complete an anonymous survey designed to ascertain service needs of people with SLE. To maintain the anonymity of patients' responses, informed consent was indicated by survey completion rather than by signature. It was estimated that completion of the survey would take no more than 20–25 minutes.

Packets containing a cover letter, questionnaire, and return envelope were mailed to 960 addresses. Approximately half of the return envelopes included paid postage, but returned surveys were not more likely to have come from the subset of respondents that received stamped envelopes, χ^2 (1, $N = 88$) = 0.409, $p = .552$. From the 960 packets mailed, 102 completed questionnaires were returned (11%). In addition, 20 surveys were distributed at Lupus Alliance of America, Long Island/Queens Affiliate, support group meetings, 10 of which (50%) were completed and returned. These procedures yielded a final sample of 112 respondents. We were unable to examine potential differences between responders and nonresponders because surveys were completed anonymously in order to promote participation and protect privacy.

Reflecting the greater prevalence of SLE among women,[12] 95% of respondents were female. The average age was 50.1 years (*SD* = 13.5 years). The average respondent was 31.0 years old (*SD* = 14.0 years) when she developed symptoms of SLE and 38.2 years old (*SD* = 13.4 years) when she received the diagnosis. One-fifth of participants had a college degree, and 37.5% reported 1 or more years of postcollege education. One-quarter of participants were currently working full time, 28.6% were working part time, 22.4% were on disability pension, 14.3% had retired, 5.4% were on unemployment, and 3.6% were students. With regard to marital status, 61% were married or living with a partner, 13% were divorced or separated, 6% were widowed, and the remainder never married. Participants reported the following racial backgrounds: white, 75.9%; Asian/Pacific Islander, 2.7%; African American, 11.6%; Hispanic, 5.4%; Native American, 1.8%; and multiracial, 2.7%.

The 75-item questionnaire was a slightly modified version of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ). The psychometric properties of the SLENQ have been documented.[8] Using a 5-point scale (1 = *not applicable*, 2 = *already satisfied*, 3 = *low need*, 4 = *moderate need*, 5 = *high need*), respondents indicated their level of need for help during the past 6 months with various issues within the following domains: physical symptoms, activities of daily living, psychological/existential, social support, health services, health information, and employment/financial. To reduce patient burden, 22 items were dropped from the original SLENQ that we judged to be redundant or less relevant to American patients in contrast to the Australian sample of patients with SLE.

RESULTS

All participants perceived at least 1 unmet need. Of all possible unmet needs, tiredness had the highest prevalence, with 90.2% of participants endorsing some need for help. At the other end of the spectrum, speaking problems and concerns about gaining employment had the lowest prevalence, with 19.6% of participants endorsing some need for help in each of these areas. Following a method used in prior research,[8] we categorized items into 7 content domains: physical, daily living, psychological/existential, social support, health services, health information, and employment/financial. Table 1 displays the percentage of participants who reported *no need* (rating 1 or 2 on the 5-point scale), *some need* (rating > 2 on the 5-point scale), or *moderate to high need* (4 or 5 on the 5-point scale), within each domain. Table 2 shows these percentages for all items.

Correlates of Unmet Needs

To identify demographic correlates of unmet needs, we again followed a method used previously,[8] dichotomizing levels of unmet need into *no or low unmet needs* (all items within a domain rated as 1 = *not applicable*, 2 = *already satisfied*, or 3 = *low need*) and *higher unmet needs* (1 or more items within a domain rated either 4 = *moderate need* or 5 = *high need*). We then conducted a stepwise logistic regression analysis for each of the 7 content domains, with the level of unmet need as the dichotomous dependent variable and demographic variables (ie, age, sex, marital status, racial group, employment status, education) as predictors. Disease-related variables (ie, type of medication, age when symptoms emerged, age at diagnosis) were not included because preliminary analyses revealed these to be unrelated to levels of unmet need.

Domains of Need

Physical Domain

As seen in Table 1, the greatest area of unmet need was related to physical symptoms. Ninety-eight percent of respondents reported at least 1 unmet need in the physical domain, and 92% of respondents perceived a moderate to high level of unmet need within this domain. As seen in Table 2, the items endorsed most frequently were as follows: needing help with tiredness (90.2%), pain (80.4%), not sleeping well (75.0%), and feeling worse after physical activity (70.5%). Need for help with physical symptoms such as dry mouth, headaches, and skin rashes was endorsed by approximately half the sample, but the proportion of the sample experiencing these needs at the level of moderate to high was closer to one-third (see Table 2).

Stepwise logistic regression examining demographic correlates of patients' levels of unmet needs revealed that only age was significant. Increasing age was associated with greater unmet needs related to physical symptoms (odds ratio [OR] = 0.933, confidence interval [CI] = 0.878–0.991).

Daily Living Domain

Ninety percent of participants reported at least some need within the daily living domain, and slightly over two-thirds reported a moderate to high level of need (see Table 1). With regard to these activities of daily living, 67.0–72.3% of respondents reported some unmet needs for help regarding eye sensitivity to bright light, avoiding sun exposure, and coping with hot or cold temperatures; however, only 38.4–45.5%

TABLE 1. Percentage of Participants Reporting No Need, Some Need, and Moderate to High Need in Each Domain

	Level of need (%)		
Domain	None	Some	Moderate to high
Physical	1.8	98.2	92.0
Daily living	9.8	90.2	76.8
Psychological/existential	8.9	91.1	77.7
Social support	21.4	78.6	62.5
Health services	22.3	77.7	57.1
Health information	25.9	74.1	49.1
Employment/financial	21.4	61.6	43.7

Note. Participants ($N = 112$) reported level of need using a 5-point scale (1 = *not applicable*, 2 = *already satisfied*, 3 = *low need*, 4 = *moderate need*, 5 = *high need*). Participants who rated 1 or 2 on the 5-point scale were grouped as *no need*, those who rated > 2 on the 5-point scale were grouped as *some need*, and those who rated 4 or 5 on the 5-point scale were grouped as *moderate to high need*.

TABLE 2. Percentage of Participants Reporting No Need, Some Need, and Moderate to High Need for Each Item, by Domain

	Level of need (%)		
Domain	None	Some	Moderate to high
Physical			
Tiredness	10	90	67
Dealing with pain	20	80	61
Not sleeping well	25	75	52
Digestive problems	40	60	38
Nausea and/or vomiting	66	34	20
Dry mouth	39	61	30
Mouth ulcers	57	43	19
Maintaining dental health	59	41	27
Headaches	45	55	34
Shortness of breath	44	56	32
Feeling worse after physical activity	29	71	48
Urinary frequency or difficulty	53	47	30
Skin rashes	44	56	32
Daily living			
Writing problems	75	25	11
Speaking problems	80	20	6
Reading difficulties	77	23	5
Difficulty thinking clearly	49	51	21
Eyes being sensitive to bright light	29	71	38
Coping with the heat	30	70	46
Coping with the cold	33	67	43
Avoiding sun exposure	28	72	41
Shopping	54	46	28
Difficulty with driving	70	30	12
Psychological/existential			
Feeling down or depressed	29	71	43
Feeling angry about having SLE	51	49	29
Feeling uncertain about the future	32	68	44
Dealing with anxiety or stress	21	79	52
Anxiety about treatment	40	60	36
Concerns about changes in your appearance	35	65	40
Not being able to do the things you used to do	23	77	57
Fears about the SLE getting worse again	20	80	62
Fears about physical disability	26	74	50
Feeling like a failure as a wife/husband/parent	49	51	31
Feeling isolated and/or lonely	43	57	28
Finding meaning in this experience of having SLE	61	39	25
Setting new priorities	48	52	27
Social support			
Maintaining relationships with family members	60	40	23
Obtaining greater physical and emotional support from your partner/children	56	44	28
Concerns about the ability of those close to you to cope with your different level of functioning	43	57	32
Changes in your sexual relationships	56	44	32
Coping with changes in other people's attitudes and behavior toward you	45	55	36
Maintaining relationships with friends	52	48	31
Ability to participate in social activities	40	60	43

Table 2 continues

TABLE 2. (continued)

Domain	Level of need (%) None	Some	Moderate to high
Health services			
Insufficient time to discuss problems when seeing a general or specialist medical practitioner	55	45	20
Getting adequate information from medical staff about side effects of treatment	56	44	18
Having 1 health care professional to talk to about your whole situation	55	45	26
Health care staff acknowledge and show sensitivity to your feelings and emotional needs	58	42	21
Knowing when to see your doctor with changes in symptoms	62	38	16
Guidance on the amount of exercise, activity, and rest required during different phases of flare or remission	50	50	22
Having the opportunity to talk with someone who understands and has had similar experiences	44	56	27
Obtaining support for exploring the use of complementary/alternative health therapies	53	47	30
Health information			
Obtaining enough current information on SLE and how it particularly affects you	54	46	22
Being given written information about the important aspects of your care	52	48	21
Information about things you can do to help yourself stay as well as possible	45	55	29
Having access to books, videos, cassettes and other resources about SLE	62	38	21
Having access to telephone support and an SLE advisory service	62	38	20
Counseling services for yourself, family, or friends	54	46	21
Being informed about relaxation, meditation, or stress control classes	50	50	24
Employment/financial			
Concerns about gaining employment	80	20	15
Maintaining a satisfactory performance in your job because of changes in health	62	38	23
Meeting basic living expenses	53	47	32
Coping with extra costs involved in managing your condition	47	53	30

Note: SLE = systemic lupus erythematosus. Participants (*N* = 112) reported level of need using a 5-point scale (1 = *not applicable*, 2 = *already satisfied*, 3 = *low need*, 4 = *moderate need*, 5 = *high need*). Participants who rated 1 or 2 on the 5-point scale were grouped as *no need*, those who rated > 2 on the 5-point scale were grouped as *some need*, and those who rated 4 or 5 on the 5-point scale were grouped as *moderate to high need*.

respondents reported that these needs were moderate to high. As shown in Table 2, other activities within this domain, such as reading, speaking, writing, driving, and shopping were less often cited as a source of unmet needs.

With regard to demographic correlates, the odds of having a higher level of unmet needs increased with age (OR = 0.956, CI = 0.918–0.996). In addition, patients who were employed full time had a lower level of unmet needs within this domain (OR = 6.150, CI = 2.034–18.589).

Psychological/Existential Domain

Just as the vast majority of respondents reported unmet needs related to physical functioning, the vast majority of respondents (91.1%) acknowledged at least some unmet psychological or existential needs. A somewhat smaller proportion of the sample (77.7%) felt that these unmet needs were at a moderate to high level. For example, 80.4% of participants had some level of need for help dealing with fears about SLE getting worse, with 61.6% reporting that this was a moderate to high unmet need. Similarly, 78.6% had some level of need for help dealing with anxiety or stress, and 70.5% had some level of need for help dealing with feeling down or depressed; 51.8% and 42.0% of individuals, respectively, reported a moderate to high level of need for help with these psychological concerns. Sixty-five percent of the sample reported some need for help dealing with concerns about changes in appearance, and 40.2% viewed this need to be at a moderate to high level. About half of respondents reported some level of need with regard to feeling like a failure as a spouse or parent, and 30.4% reported that the level of need for help with this issue was moderate to high. A need for help with setting new priorities was endorsed by about half the sample, and 25.9% described the level of this unmet need as moderate to high. Additional existential and psychological needs are presented in Table 2.

As was found in the physical and daily living domains, a higher level of unmet needs in this domain was associated with increasing age (OR = 0.965, CI = 0.932– 1.000).

Social Support Domain

With regard to the social support domain, 78.6% of respondents had some unmet needs, with 62.5% of respondents reporting need at the moderate to high level. The most commonly endorsed social support items were needing help with the ability to participate in social activities (59.8% with some need, 42.9% with moderate to high need) and concerns about the ability of close others to help the patient cope with his or her different level of functioning (57.1% with some need, 32.1% with moderate to high need). Some level of unmet need related to maintaining relationships with friends and family members was noted by 48.2% and 40.2% of respondents, respectively. Need for help regarding changes in sexual relationships was reported by 43.8% of the sample, with 32.1% of patients rating this need at the moderate to high level. No significant demographic correlates were identified within this domain. See Table 2 for additional information about the social support domain.

Health Services Domain

In the health services domain, 77.7% of respondents had some unmet needs, with 57.1% of respondents reporting need at the moderate to high level. Endorsed items ranged from 38.4% (needing assistance with knowing when to see the doctor when changes in symptoms occur) to 56.3% (needing assistance with finding the opportunity to talk with someone who understands and has had similar experiences). Items rated at the moderate to high level of need ranged from 17.9% (getting adequate information from medical staff about treatment side effects) to 29.5% (obtaining support for exploring the use of complementary/alternative health therapies). Forty-five percent of participants reported unmet needs regarding continuity of care and the amount of time spent with medical practitioners (see Table 2 for additional details concerning these items and other items within the health services domain).

Analysis of demographic correlates of the levels of unmet need indicated that only racial group was significant. White patients had the lowest level of unmet needs in this domain compared to African American patients (OR = 0.266, CI = 0.069–1.023). For example, of the 13 African American patients in the sample, 11 had *higher unmet needs*. In contrast, of the 85 white patients in the sample, 42 had *higher unmet needs* and 43 had *no or low unmet needs*.

Health Information Domain

As seen in Table 1, the percentages of participants reporting some need (74.1%) and moderate to high need (49.1%) in this domain were slightly lower than the comparable percentages in the health services domain. In the health information domain, levels of unmet needs ranged from 38.4% (having access to books, videos, cassettes, and other resources about SLE; having access to telephone support and advisory services) to 55.4% (having information about things one can do to help stay as well as possible). Unmet health information needs were rated by 19.6–28.6% of respondents as moderate to high. For example, 21.4% of patients reported a moderate to high level of need for written information about important aspects of their care. Other health information items are shown in Table 2.

As in the health services domain, the only significant demographic correlate within the health information domain was racial group. All but 1 of the African American patients had "higher unmet needs," whereas white patients were more likely to have "no or low unmet needs" (OR = 0.525, CI = 0.167–1.647).

Employment/Financial Domain

Unmet needs related to employment and finances were the least common relative to the other domains studied. Nonetheless, 61.6% of respondents had at least 1 unmet need in the area, and 43.7% of respondents indicated moderate to high need in the area. The most frequently noted concerns were (1) needing help coping with extra costs involved in managing SLE (52.7% with some need, 30.4% with moderate to high need) and (2) meeting basic living expenses (47.3% with some need, 32.1% with moderate to high need). In addition, as shown in Table 2, 19.6% reported a need for help with concerns about gaining employment, and 37.5% reported a need for help with maintaining a satisfactory job performance because of changes in health.

Not surprisingly, patients with full-time employment were less likely to have higher levels of unmet needs in this domain (OR = 3.000, CI = 1.153–7.807).

COMMENT

The present research brings to light the high prevalence of unmet needs among many people with SLE. Over

90% of respondents reported some need for help with physical concerns, activities of daily living, and psychological issues. These findings are consonant with previous research documenting impaired health-related quality of life in patients with SLE.[13] Despite the apparent need for help with multiple illness-related problems, no generally accepted self-management program is available for SLE. However, randomized controlled trials provide evidence that some of these problems can be ameliorated with cognitive-behavioral interventions without adverse effect. For instance, psychoeducation[14] and graded aerobic exercise[15] have been shown to be useful in the management of fatigue.

Our findings parallel those of the needs assessment study conducted in Australia.[8] In that sample, as in ours, unmet needs were greater in the physical and psychological domains than in the economic, social, and informational domains, and help with tiredness was the most frequently cited need. Although longitudinal studies[16–17] have documented that fatigue among patients with SLE often remits without intervention, from the patient perspective, it appears that targeting fatigue is a priority. This makes sense, given the impact of fatigue on multiple important aspects of functioning, from work status[18] to sexuality.[19] To intervene most effectively, clinicians must attempt to determine whether fatigue stems from daytime sleepiness, primary sleep disorders, or depression.[20]

Stress, anxiety, and depression often accompany SLE,[6] and unmet needs related to these psychological sequelae can be interpreted in reference to patients' perceptions of their health care. A qualitative study of patients with SLE in the United Kingdom[3] illustrated the connection of unmet needs related to psychosocial well-being to unmet needs related to health services and health information. Participants revealed in interviews that they did not know which health care providers could help them with psychosocial needs. Moreover, they did not believe that health care professionals fully understood the psychosocial impact of SLE or that health care professionals were providing enough information in this domain.

For patients with SLE, the perception of not having their experience understood by others may lead to social isolation and otherwise negatively affect personal and professional interactions.[21] In the current sample, unmet needs related to social support were of less concern than unmet needs related to physical well-being. This may be explained in part by the fact that participants were recruited through a lupus support organization. Nonetheless, many participants reported a desire for assistance with interpersonal difficulties; for example, nearly half of participants (48.2%) reported some level of unmet needs related to maintaining relationships with friends.

Limitations

The present investigation was limited by a relatively small sample whose diagnoses were not corroborated for this study and whose characteristics cannot be assumed to be similar to those of patients with SLE who reside in other parts of the United States or in other countries. Moreover, this convenience sample yielded results that may not generalize to participants who are unaffiliated with lupus support organizations. In particular, ethnic minorities are probably underrepresented in our sample.[22] Within our sample, African American patients had relatively high levels of unmet needs in the domains of health services and health information. Similar surveys should be conducted with larger samples likely to be more representative of the population of persons with SLE.

The low response rate (11%) in this study requires comment as well. Although the anonymity of respondents precluded follow-up inquiries, we can address, to some extent, the possible reasons for nonreturned questionnaires. First, an estimated 2% of surveys were returned because of an incorrect address. In addition, an interview with the executive director of the Lupus Alliance of America, Long Island/Queens Affiliate (Joann Quinn, personal communication, March 12, 2008), suggested that lupus patients in her support organization were more likely to be nonresponders to questionnaires during symptom flares, on the basis of her experience conducting previous needs surveys of the membership (with estimated response rates of 20%). Similarly, examples in published surveys of chronic illness groups with widespread symptomatology[23–24] have found that interviewed nonresponders were more likely to report more frequent pain and greater use of health care.

Another potential reason expressed by the organization's director for the nonreturn of the lupus needs survey was the perception that many patients did not want to be reminded of their illness, either because they were feeling well at the time or because they became ill relatively recently. These issues may reflect, in part, different forms of illness coping, such as denial and disengagement,[25] or perhaps a "crisis" stage of adjustment[26] during which attempts to nullify or quickly cure the illness become a paramount motivation.

In comparison to this single assessment report, prospective studies would shed light on how unmet needs develop and change over time in relation to other variables. For example, a longitudinal study of adults using mental health services provided preliminary evidence for a causal relationship between higher levels of unmet need and lower levels of quality of life.[27] Prospective studies would be particularly interesting in light of the fact that within our sample, increasing age was indicative of higher levels of unmet needs related to patients' physical symptoms, activities of daily living, and psychological functioning. Despite the significance of age within this sample, the variables of age at which symptoms first developed and age at diagnosis were unrelated to levels of unmet need.

In conclusion, despite the aforementioned limitations, the present findings document the variety and high prevalence of perceived unmet needs among many patients with SLE. The needs of patients with complex chronic illnesses such as SLE often remain unvoiced to health care providers but must be understood if optimal health care services are to be designed and implemented.[1–3] Although the argument could be made that patients' expectations of health care are too high,[28] we argue that researchers must continue to investigate biomedical and behavioral interventions to improve patients' health and quality of life. At the same time, the demographic differences observed in the present data suggest that more must be done to identify and eliminate structural barriers (eg, limits on health plan benefits and provider choice, the availability of transportation to services) that may limit access to high-quality care and affect outcomes among subgroups of patients with fewer resources.[10] The results of our study require replication but suggest that older patients may be more likely than younger patients to require assistance with needs related to physical and psychological functioning, whereas African American patients may have greater unmet needs than white patients in the areas of health services and health information.

In regards to practice implications, referrals to professionals with expertise in patient education and psychological intervention, as well as referrals to organizations that provide support and information to persons with chronic illness, are an important supplement to the medical treatment of SLE. Finally, patients themselves must communicate with their health care providers about perceived unmet needs, and health care providers must attend to the needs and priorities of individual patients.[4] The ability of the patient to communicate unmet needs in both the physical and psychosocial domains can be facilitated by practitioners who are willing to inquire about them with sensitivity.

ACKNOWLEDGEMENT

This research was supported by NIH grant MH01961-02 to Dr Fred Friedberg. We are grateful to the staff and members of the Lupus Alliance of America, Long Island/Queens Affiliate, for their generous assistance with this project.

NOTE

For comments and further information, address correspondence to Dr Sharon Danoff-Burg, Department of Psychology, University at Albany, 1400 Washington Avenue, Albany, NY 12222, USA (e-mail: sdb@albany.edu).

REFERENCES

1. Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. *BMJ.* 2000;320:1246–1250.
2. Hale ED, Treharne GJ, Norton Y, et al. "Concealing the evidence": the importance of appearance concerns for patients with systemic lupus erythematosus. *Lupus.* 2006;15:532–540.
3. Hale ED, Treharne GJ, Lyons AC, et al. "Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Ann Rheum Dis.* 2006;65:585–599.
4. Kjeken I, Dagfinrud H, Mowinckel P, Uhlig T, Kvien TK, Finset A. Rheumatology care: involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis Rheum.* 2006;55:394–401.
5. Cahill J. Patient participation: a review of the literature. *J Clin Nurs.* 1998;7:119–128.
6. Seawell AH, Danoff-Burg S. Psychosocial research on systemic lupus erythematosus: a literature review. *Lupus.* 2004;13:891–899.
7. Archenholtz B, Burckhardt CS, Segesten K. Quality of life of women with systemic lupus erythematosus or rheumatoid arthritis: domains of importance and dissatisfaction. *Qual Life Res.* 1999;8:411–416.
8. Moses N, Wiggers J, Nicholas C, Cockburn J. Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. *Patient Educ Counsel.* 2005;57:30–38.
9. Thewes B, Butow P, Girgis A, Pendlebury S. Assessment of unmet needs among survivors of breast cancer. *J Psychosoc Oncol.* 2004;22:51–73.
10. Jacobi CE, Rupp I, Boshuizen HC, Triemstra M, Dinant HJ, Van Den Bos GAM. Unmet demands for health care among patients with rheumatoid arthritis: indications for underuse? *Arthritis Rheum.* 2004;51:440–446.
11. Siegel K, Raveis VH, Houts P, Mor V. Caregiver burden and unmet patient needs. *Cancer.* 1991;68:1131–1140.
12. Hampton T. Researchers probe lupus causes, treatments. *JAMA.* 2007;297:141–142.
13. McElhone K, Abbott J, Teh L-S. A review of health related quality of life in systemic lupus erythematosus. *Lupus.* 2006;15:633–643.
14. Karlson EW, Liang MH, Eaton H, et al. A randomized controlled trial of a psychoeducational intervention to improve outcomes in systemic lupus erythematosus. *Arthritis Rheum.* 2004;50:1832–1841.
15. Tench CM, McCarthy J, McCurdie I, White PD, D'Cruz DP. Fatigue in systemic lupus erythematosus: a randomized controlled trial of exercise. *BMJ.* 2003;314:1647–1652.
16. Dobkin PL, Da Costa D, Fortin PR, et al. Living with lupus: a prospective pan-Canadian study. *J Rheumatol.* 2001;28:2442–2448.

17. Dobkin, PL, Da Costa D, Joseph L, et al. Counterbalancing patient demands with evidence: results from a pan-Canadian randomized clinical trial of brief supportive-expressive group psychotherapy for women with systemic lupus erythematosus. *Ann Behav Med.* 2002;24:88–99.
18. Utset TO, Fink J, Doninger NA. Prevalence of neurocognitive dysfunction and other clinical manifestations in disabled patients with systemic lupus erythematosus. *J Rheumatol.* 2006;33:531–538.
19. Seawell AH, Danoff-Burg S. Body image and sexuality in women with and without systemic lupus erythematosus. *Sex Roles.* 2005;53:865–876.
20. Iaboni A, Ibanez D, Gladman DD, Urowitz MB, Moldofsky H. Fatigue in systemic lupus erythematosus: contributions of disordered sleep, sleepiness, and depression. *J Rheumatol.* 2006;33:2453–2457.
21. Danoff-Burg S, Revenson TA. Psychosocial aspects of the rheumatic diseases. In: Paget SA, Gibofsky A, Beary JF, Sculco TP, eds. *Manual of Rheumatology and Outpatient Orthopedic Disorders: Diagnosis and Therapy.* 5th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2005: 70–79.
22. McAlindon T. Update on the epidemiology of systemic lupus erythematosus: new spins on old ideas. *Curr Opin Rheumatol.* 2000;12:104–112.
23. Rupp I, Triemstra M, Boshuizen HC, et al. Selection bias due to non-response in a health survey among patients with rheumatoid arthritis. *Eur J Public Health.* 2002; 12:131–135.
24. Ronmark E, Lundqvist A, Lundback B, Nystrom L. Non-responders to a postal questionnaire on respiratory symptoms and diseases. *Eur J Epidemiol* 1999;15:293-299.
25. Livneh H, Lott SM, Antonak RF. Patterns of psychosocial adaptation to chronic illness and disability: a cluster analytic approach. *Psychol Health Med.* 2004;9:411–430.
26. Fennell PA. A four-phase approach to understanding chronic fatigue syndrome. In: Jason LA, Fennell PA, Taylor RR, eds. *Handbook of Chronic Fatigue Syndrome*. Hoboken, NJ: Wiley; 2003:155–175.
27. Slade M, Leese M, Cahill S, Thornicroft G, Kuipers E. Patient-rated mental health needs and quality of life improvement. *Br J Psychiatry.* 2005;187:256–261.
28. Alarcon GS, McGwin G Jr, Uribe A, et al. Systemic lupus erythematosus in a multiethnic lupus cohort (LUMINA). XVII. Predictors of self-reported health-related quality of life early in the disease course. *Arthritis Care Res.* 2004;51:465–474.