# Lupus patient education: an examination of approaches

Lupus is a chronic disease that requires an interdisciplinary treatment management approach to facilitate optimal outcomes. One key component believed critical to overall treatment management is the inclusion of educational programs to improve patient knowledge. It is unclear which educational programs are most effective in improving patient knowledge of lupus and, ultimately, long-term outcomes. The purpose of this review is to examine the current literature related to educational programs for patients with lupus.

KEYWORDS: disease information group sessions internet lupus patient education patient management psychoeducation review

Systemic lupus erythematosus (lupus) is a chronic, inflammatory autoimmune disease with an estimated prevalence in the USA of 100–150 cases per 100,000 [1]. Lupus is known as the 'great imitator' because of the multidimensional manifestation of joints, internal organs and skin that are commonly confused with other disorders [101]. Lupus occurs most frequently among women of childbearing age [2], and disproportionately affects ethnic minorities who also experience more severe consequences of the disease [3,4].

The financial burden of lupus is substantial in the USA, with annual direct medical care costs exceeding US\$207 million or approximately US\$13,305 per patient [5].

Individuals with lupus seek treatment from a variety of health professionals in attempts to alleviate the acute and chronic symptoms of the disease and manage the disease progression. Many patients frequently experience fatigue, arthritis, rashes, organ failure and decreased quality of life despite treatment. Among the many consequences are unpredictable disease flare-ups that can alter common daily activities.

Patient education is a component of disease management plans and includes general information, treatment strategies and decision-making resources to benefit an individual's quality of life [6-8]. Lorig defined patient education as "any set of planned educational activities to improve patient health behaviors and/or health status" [6]. Thus, to facilitate maximum coping strategies and overall disease management, patients, their support system and healthcare providers may consider collaborative approaches to patient education because of its therapeutic value [9]. Healthcare providers typically offer patients printed information (i.e., fact sheets, information on medical societies or resources) intended to serve as requisite patient education

regarding their disease and disease progression at each stage of their treatment. However, these 'patient education' approaches are broad in scope with limited emphasis on disease prevention, health promotion and health education. The American College of Rheumatology online patient information for lupus focuses on tips for living with lupus (see [102] for detailed descriptions). Yet educational strategies could also instruct patients to address lifestyle risk factors, medication adherence and potential side effects, and immunization.

Approaches to patient education for patients with lupus vary in terms of intervention type, mode of administration, number of educational sessions and duration of intervention, facilitator type and outcome measures. As such, it is unclear which approaches are most commonly used, patient friendly or endorsed by patients and those mostly likely to effectively improve the systemic clinical manifestations of lupus [10]. The purpose of this review is to examine what current literature presents on patient educational approaches for patients with lupus.

## Methods

#### Literature search

To complete this review, we used a modified version of the Cochrane Collaboration Strategy for systematic reviews. We searched three computerized databases (Medline, CINAHL and PsycINFO) from 1966 to November 2011 based on the Cochrane Collaboration search strategy. The MESH terms used for the review were 'patient education', 'lupus', 'lupus erythematosus' and 'systemic lupus'. The non-MESH terms were 'patient education' and 'lupus'. We also searched Google Scholar and performed hand searches of references of identified papers. Finally, we completed hand searches of journals likely to publish manuscripts related to lupus

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patient education to identify full-length articles, abstracts, editorials, letters or other texts [11]. For this review, the inclusion criteria included studies with adult participants ( $\geq$ 18 years of age), written in English and patient education interventions.

For this review, we included papers with mixed populations (i.e., other chronic diseases); however, we only report data from participants with lupus. All reports of patient education intervention studies (structured instruction, informational material and psycho-education) were eligible for inclusion. Study titles and abstracts were reviewed and the full articles were retrieved for all articles that included patient education. Disagreements regarding inclusion of studies were resolved through discussion and consensus. Data extraction was completed with an adapted version of the Effective Practice and Organisation of Care Data Collection Checklist [103]. The checklist guided reviewers with the identification of relevant information or data included for analysis.

#### Results

The search strategies used initially yielded 102 studies. Of those 102 studies, the titles and abstracts of 26 studies appeared to meet the inclusion criteria and the full article was retrieved to assess topic relevance. We excluded 14 of the initial 26 articles because they were not patient education intervention studies. Below we report a summary of the 12 studies included in this review (TABLE 1). Seven studies reported patient educational approaches designed to improve knowledge related to the disease or disease symptomology via various education modes. For example, Braden and colleagues examined learned responses to chronic illness in 291 patients with lupus [12]. Study participants attended a series of seven weekly 2.5-h self-management classes designed for groups of eight to 18 adults. Course activities emphasized problem solving, cognitive reframing and promoting belief in self. Exercise and relaxation were also incorporated into the program. The training sessions resulted in significant changes (p < 0.01) in learned responses over time. Decreases in uncertainty and depression and increases in enabling skill, self-efficacy and self-worth facilitated change.

Konttinen and colleagues examined patient knowledge about lupus after reading a patient guide [13]. The comprehensive guide was written and edited by the study authors and was 45 pages in length. Ninety patient members of the Finnish Lupus Society participated in the program and decreases in incorrect answers were observed after reading that patient guide. Prior educational attainment appeared to influence prereading scores but not postreading scores.

Young and colleagues developed a patientoriented internet administered educational program to provide lupus information [14]. Five hundred and ten participants accessed the website and 59% accessed the website on at least a monthly basis. In total, 56% found the diseaserelated information at an appropriate level; however, 37% found the information too basic. The website was believed to have a positive effect on disease knowledge for individuals who accessed the website.

Sohng examined the effects of a lupus selfmanagement course on fatigue, coping skills, self-efficacy, depression, pain and disease activity in 21 Korean patients [15]. The group-based self-management course consisted of six weekly 2 h sessions of ten to 15 adults while the control group did not receive an intervention. Course activities emphasized pharmacological therapy, symptom management, exercise, interpersonal relationships, coping with flares, healthy lifestyles and management of lupus related health problems. Compared to the control group (20 participants), those receiving the self-management course demonstrated improvements in fatigue, coping skills, self-efficacy and depression. The course was believed to be effective in community-based settings.

Karlson and colleagues conducted a randomized controlled trial of a theory based intervention to improve patient self-efficacy and partner support in 122 patients with lupus [16]. Patients in the experimental group received an intervention designed to improve self-efficacy, couples communication about lupus, social support and problem solving using mixed educational modes. The intervention consisted of a 1-h session with a nurse educator followed by monthly telephone counseling sessions over 6 months. Following the completion of the 6 months of counseling sessions, improvements were noted in couples' communication and problem-focused coping. At 12 months, improvements were noted in social support, self-efficacy, couples' communication and reports of fatigue were decreased.

Harrison *et al.* designed a psychoeducational group intervention that included functional strategy training and psychosocial support for adults with lupus and cognitive dysfunction [17]. The program was based on the multicontext approach that is based on the theory that

Study (year)	Study design	۲	Age, mean (years) <sup>†</sup>	Female %	Completers, n (%)	No. of sessions <sup>†</sup>	Program duration (weeks)	Intervention type	Education mode	Program facilitator	Ref.
Braden (1991)	Descriptive	291	46	96	201 (69)	7	7	SH	ט	HP, LL	[12]
Dobkin <i>et al.</i> (2002) and Edworthy <i>et al.</i> (2003)	RCT and secondary analysis	133	43	100	124 (93)	12	12	PsycT	U	с	[20,21]
Harrison <i>et al.</i> (2005)	Prepost	17	46	100	17 (100)	Ø	œ	PE	U	OT	[17]
Haupt <i>et al.</i> (2005)	Descriptive	38	42	91	34 (89)	18	24	PE, PsycT	U	Ps, R	[19]
Karlson <i>et al.</i> (2004)	RCT	150	43	98	122 (81)	1 + 5	25	PE	F, T	Z	[16]
Konttinen <i>et al.</i> (1991)	Prepost	66	37	92	66 (100)	Distributed guide	8–10	Info	$\geq$	NA	[13]
Miljeteig and Graue (2009)	Mixed methods	13	35	100	13 (100)	2	$\overline{\nabla}$	Info	F, G	ЧЬ	[18]
Pai (2010)	Prepost	63	NR	NR	63 (100)	2	₩ V	Info	F, W	Z	[23]
Shah <i>et al.</i> (2000)	Descriptive	4	50	100	4 (100)	9	9	BT, C	G, T, V, W	Di, FE	[22]
Sohng (2003)	Prepost	56	33	NR	41 (73)	9	9	SM	ט	N, RA	[15]
Young <i>et al.</i> (2002)	Descriptive	510	NR	88	510 (100)	Website	24 months	Info	_	NR	[14]
<sup>†</sup> Number of sessions: BT: Behavioral treatm LL: Lay leader; N: Nur.	1 + 5 = 1 h session + i ent; C: Counseling; Di se; NA: Not applicable	five tele Dietic: Dietic	ephone counseling ian; F: Individual fa Number; NR: Not n	calls. ce-to-face contac eported; OT: Occu	t; FE: Female experime pational therapist: PE	enter; G: Group sess : Psychoeducation:	sions; HP: Health profession Ps: Psvchotherapist: PsvcT: I	al; 1: Internet-delive <sup>2</sup> sychotherapeutic: ,	ered information; R: Rheumatologis	Info: Information or t: RA: Research assi	ıly; stants;

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basic cognitive strategies, such as the use of mnemonics, can be learned and generalized across day-to-day situations. The program consisted of eight weekly 2-h sessions. Seventeen women with lupus who completed the program had improvements in metamemory, specifically memory self-efficacy (the belief that one can use their memory effectively), which has been associated with cognitive performance and quality of life. The authors noted 100% retention of participants during the program administration, suggesting that patients with lupus can be willing and capable of completing the program.

Miljeteig and Graue evaluated a patient educational program in 13 adults with lupus to determine the impact on quality of life, pain, fatigue and physical wellbeing mixed educational modes [18]. The aims of the program were: first, to educate patients about the disease and treatments approaches to improve daily living; second, to provide information about multidisciplinary treatment teams and how patients can participate; and third, to learn disease management strategies to achieve better physical and psychosocial health. Patients reported satisfaction with the program's organizational structure; however, standardized scores on the SF-36 general health and mental health subscales demonstrated statistically insignificant increases, while no increases were noted on measures of pain, fatigue and physical wellbeing.

Three studies used psychotherapeutic approaches designed to improve psychological symptoms of lupus. For instance, Haupt and colleagues evaluated a novel psychological intervention designed to improve coping in patients in lupus [19]. Participants completed 18 educational sessions that emphasized disease-related information including lupus specific programs. Sessions were administered to groups of eight patients over 6 months. Participants demonstrated improvements (reductions) in depression, anxiety and overall mental burden.

Dobkin *et al.* evaluated a 12-week randomized clinical trial of psychotherapy intervention intended to reduce psychological distress, medical symptoms of lupus and improve quality of life [20]. The intervention sessions (four to eight patients, variations by site) focused on emotional and social support, as well as copingskills training; however, there were no statistical or clinical improvements reported for any of the eight clinical outcomes up to 12 months postintervention compared with usual care.

Edworthy and colleagues conducted secondary analyses of the brief supportive-expressive group psychotherapy intervention described by Dobkin *et al.* with particular interest in whether the group therapy would reduce illness intrusiveness [20,21]. Findings suggest that the 12-week psychotherapy intervention significantly reduced overall illness intrusiveness (F = 5.282; p = 0.012) because of intimacy (F = 5.057; p = 0.013, subscale) and relationships, and personal development (F = 2.34; p = 0.065, subscale) up to 12 months postintervention.

Two mixed educational mode studies reported patient educational programs designed to improve disease-related risk factor control and a disease-specific therapy (steroid pulse therapy). First, Shah et al. developed and evaluated the acceptability of intensive ethnic specific cholesterol lowering diet program for patients with lupus [22]. The program had a behavioral component that included culturally sensitive menus to facilitate changes in dietary behavior to reduce cardiovascular risk. The program consisted of 2-3-h weekly sessions followed by telephone contact every 2 weeks for 6 weeks. The primary author, a nutritionist and a bilingual research assistant, administered the program. Participants included two African-American and two Mexican-American women. The program received high ratings among the participants as it was found to be informative, easily understood, ethnically sensitive and included useful behavioral strategies. Significant reductions were observed in low-density lipoprotein (LDL) and body weight following completion of the program.

Second, Pai and colleagues examined the effect of instruction on patient knowledge in patients receiving steroid pulse therapy for the treatment of autoimmune disease [23]. Sixty three lupus patients on pulse steroid therapy received nursing instruction and their knowledge regarding steroid pulse therapy was significantly higher following the instruction. The study concluded that lupus treatment-specific education is needed for many patients and will ultimately positively influence overall outcomes.

### Discussion

In this review, we examined the current literature related to educational programs for patients with lupus. Indicative of the systemic nature of lupus, the majority of the trials included multiple outcome measures. After all, the potential for patients with lupus to experience cognitive dysfunction may impair the ability for an educational intervention to work effectively; therefore, the focus of this review is on the

Table 2. Outo	omes and measures of the	lupus patient education trials included in the review.	
Study (year)	Outcomes	Measures	Ref.
Braden (1991)	Severity of illness (SI) Limitations (L) Uncertainty (U) Depression (D) Enabling skills (ES) Self-efficacy (SE) Self-worth (SW) Life quality (LQ) SLE knowledge (SLEK) Rest, relaxation, heat, and exercise range (RRHER) Rest, relaxation, heat, and exercise number (RRHEN)	Study-specific VAS <sup>†</sup> , three formatted items Study-specific single item Study-specific VAS <sup>†</sup> , three formatted items Study-specific VAS <sup>†</sup> , four formatted items Six items drawn from Rosenbaum's 36-item Self-Control Schedule (SCS) Study-specific VAS <sup>†</sup> , single formatted item Study-specific VAS <sup>†</sup> , ten formatted items Three items drawn from Campbell Inventory of Well-Being (IWB) Seven study-specific multiple-choice items Various types of pain management and self-strengthening activities during 1 week Total number of times that various types of pain management and self-strengthening activities during 1 week	[12]
Dobkin <i>et al.</i> (2002) and Edworthy <i>et al.</i> (2003)	Psychological distress <sup>‡</sup> Health-related quality of life Disease activity <sup>‡</sup> SLE disease damage <sup>‡</sup> Health service utilization and productivity Social support Coping style Stress Illness intrusiveness <sup>§</sup>	The Symptom Checklist 90 – Revised (SCL-90-R) The SF-36 The Systemic Lupus Activity Measure Revised (SLAM-R); the Systemic Lupus Disease Activity Index (SLEDAI) The Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) Modified version of the economic portion of the Stanford Health Assessment Questionnaire (HAQ) Shortened version of the Social Support Questionnaire (SSQ6) Coping Inventory for Stressful Situations (CISS) Revised version of the Hassles Scale The Illness Intrusiveness Rating Scale (IIRS)	[20,21]
Harrison <i>et al.</i> (2005)	Depression Social support SLE disease damage Cognition Self-perception to perform everyday activities	The Beck Depression Inventory The Medical Outcomes Study – Social Support Survey The Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) Metamemory in Adulthood Questionnaire (MAI); the Memory Functioning Questionnaire (MFQ); the California Verbal Learning Test The Cognitive Symptoms Inventory	[17]
Haupt <i>et al.</i> (2005)	Symptoms General health Anxiety and depression Lupus activity Control convictions Coping Self-acceptance Everyday life SLE disease damage	The Symptom Checklist 90 – Revised (SCL-90-R) The SF-36 The Hospital Anxiety and Depression Scale (HADS-D), German version European Consensus Lupus Activity Measurement The Questionnaire for Registration of Control Convictions Relating to Illness and Health (KKG) Freiburg Questionnaire on Coping with Illness (FKV; abbreviated form/ self-rating [FKV-LIS-SE]) Self-Acceptance Registration Scale (SESA) Everyday Life Questionnaire (FAL; abbreviated form) The Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI)	[19]
Karlson <i>et al.</i> (2004)	General health status Disease activity, self-reported Disease activity, physician-rated Self-efficacy Social support Problems-solving Satisfaction with medical care Prescribed medical treatment compliance	Medical Outcomes Study SF-36 Systemic Lupus Activity Questionnaire (SLAQ) Systemic Lupus Activity Measure (SLAM) The Arthritis Self-Efficacy Scale (SE Arthritis) Not available Assessment of Daily Experiences (ADE) Medical Interview Satisfaction Scale Not available	[16]
<sup>†</sup> VAS, 100 mm hor <sup>‡</sup> Used by Dobkin et <sup>§</sup> Used only by Edw SE-36: ShortEorm	izontal. t al. (2002) and Edworthy et al. (2003). /orthy et al. (2003). 36: SLF: Systemic lunus erythematosus: V	/A.S. Visual analogue scale	

Study (year)	Outcomes	Measures	Ref.
Konttinen <i>et al.</i> (1991)	SLE knowledge	Comprehensive SLE guidebook (Finnish)	[13]
Pai <i>et al.</i> (2010)	Need for nursing instructions Knowledge Symptom distress	Study specific 45-item questionnaire Study specific 20-item questionnaire Symptom Distress Scale-Chinese Modified Form (SD-SCMF)	[23]
Shah <i>et al.</i> (2000)	Diet counseling questionnaire Food intake Lipid and lipoproteins Physical activity Reading ability Cognitive status	Study specific five-item questionnaire Computrition computerized database of the National Research Council's nutrient content of foods (Computrition Inc., Chatsworth, CA, USA) Blood samples Verbal 7-day recall Rapid Estimate of Adult Literacy in Medicine screening tool Mini-Mental State questionnaire	[22]
Sohng (2003)	Fatigue Coping skills level Self-efficacy Depression Pain	Multidimensional Assessment of Fatigue scale Ten-items (numerical scale 1–10, 1 = 'not true about me' and 10 = 'true about me' Seven-items (numerical scale 1–10, 1 = 'very uncertain and 10 = 'very certain' Beck Depression Inventory Study-specific VAS (10-cm, 0–10; higher score > pain)	[15]
Young <i>et al.</i> (2002)	Not applicable	Not applicable	[14]
<sup>†</sup> VAS, 100 mm hori <sup>‡</sup> Used by Dobkin (2 §Lised only by Edwi	zontal. 1002) and Edworthy (2003). 10rthy (2003)		

#### Table 2. Outcomes and measures of the lupus patient education trials included in the review (cont.)

SF-36: ShortForm 36; SLE: Systemic lupus erythematosus; VAS: Visual analogue scale.

approaches used and the primary outcomes in each case (TABLES 1 & 2). Patient educational programs are key components of patient management strategies and improved quality of life for adults with chronic diseases [24]. Lupus is a very complex chronic disease and improved outcomes are facilitated by interdisciplinary treatment approaches as well as increasing self-efficacy and disease-related knowledge among patients [16,25].

Unfortunately, our review suggests that lupus-related patient educational programs vary greatly in their design and goals; thus, the results have been quite mixed. Similarly, there does not appear to be any consistency in the focus, theoretical basis and mode of administration or justification for the approach to outcome measurement among studies that are reported in the current literature. Notwithstanding the aforementioned confounding factors, the current evidence suggests that patients with lupus received minimal-to-moderate benefit from the group-based, psychoeducational and psychotherapeutic patient education programs presented [16,17,19,21]. Specifically, cognitive, psychological, support and coping outcomes - the nonmedical factors - were improved more often than lupus disease damage or activity. Among those that do report successful outcomes, many are limited by very small sample sizes and nonstandardized outcome measures for lupus. Another major issue is the cost frequently associated with educational programs, whether provided individually or in a group. In this case, only one of 12 trials included in this review, Dobkin et al., conducted a randomized clinical trial with 133 subjects for 12 weeks, and a year-long follow-up reported that no clinically or statistically meaningful differences in health services utilization (cost proxy) were noted for the participants with lupus for this intervention [20]. There is limited published data on the cost of lupus patient education; however, there is value in an economic evaluation when deciding to complement standard care or traditional patient education with psychotherapy or cognitive-behavioral therapy when they add no therapeutic benefit [26]. Likewise, Lorig and colleagues presented evidence that supports the importance of conducting a cost analysis on patient education programs for arthritis [27]. Therefore, studies of cost and cost-effectiveness of such approaches are urgently needed because this gap makes judicious, evidence-based decision-making problematic.

A number of questions remain regarding educational approaches for patients with lupus. The research designs of the trials included in the current review ranged from descriptive informational studies [14] to a randomized clinical trial [20]; however, the most rigorously designed study offered no adjunctive benefits for Canadian women with lupus. In addition, the results of the patient education review limit its generalizability, and because of the diverse social, cultural and geographic differences of the patients with lupus, the programs must be designed to meet the needs of the target population [10,24]. Now, what is the optimal mode of administration? Do patients gain information that is more beneficial from trained professionals or well-designed self-administered programs? Similarly, given the significant increase in technology, what technological advances could enhance currently available approaches? A second issue relates to what specific information is key and most relevant to patients with lupus. Should patient educational programs emphasize disease-specific knowledge, general disease symptomology, self-efficacy, depression and other mental health symptoms, self-management, or all of the aforementioned issues? Likewise, it is unclear which elements are most salient in lupus patient educational programs and most likely to facilitate positive outcomes.

The third and final issue relates to conceptual frameworks that guide patient education programs and outcome measures. A number of conceptual frameworks guided the studies reported in this review and the outcome measures were highly variable and emphasized a long list of potential outcomes (mental health, psychosocial and so on). Moreover, it is unclear which outcome measures are most likely to correlate with patient-reported functional improvements. In addition, it is difficult to know which educational modes result in the most cost-effective and measurable outcomes. Further trials are needed to progress the science beyond updates toward investigations that assess the effectiveness of lupus patient education programs with outcomes that improve quality of life, health status and participation in life roles. Educational programs that account for patients' attitudes,

#### **Executive summary**

#### Background

- Patient education is a component of disease management plans and ranges from general information to treatment strategies and decision-making resources to benefit an individual's quality of life.
- Approaches to patient education for patients with lupus vary in terms of intervention type, mode of administration, number of educational sessions and duration of intervention, facilitator type and outcome measures.

#### Methods

A computerized search of three databases (Medline, CINAHL and PsycINFO) from 1966 to November 2011, Google Scholar and hand searches of references of identified papers, as well as hand searches of journals likely to publish manuscripts related to lupus patient education, were performed. The search terms included 'patient education', 'lupus', 'lupus erythematosus' and 'systemic lupus'.

#### Results

- Initially, 102 articles were identified, with 26 screened for full-text review and 12 included in the current review.
- Seven studies reported patient educational approaches designed to improve knowledge related to the disease or disease symptomology via various education modes.
- Three studies used psychotherapeutic approaches designed to improve psychological symptoms of lupus.
- Two mixed educational mode studies reported patient educational programs designed to improve the disease-related risk factor control and a disease-specific therapy (steroid pulse therapy).
- Patients with lupus received minimal-to-moderate benefit from the group-based, psychoeducational and psychotherapeutic patient education programs presented.
- Cognitive, psychological, support and coping outcomes, the nonmedical factors, were improved more often than lupus disease damage or activity.
- There are limited data on cost of lupus patient education.
- There is, however, value in an economic evaluation when deciding to complement standard care or traditional patient education with psychotherapy or cognitive-behavioral therapy when they add no therapeutic benefit.

#### Discussion

- The current review examined educational programs for patients with lupus.
- Given the systemic nature of lupus, the majority of the trials included multiple outcome measures.
- The focus of this review is on the approaches used and the primary outcomes.
- A number of questions remain regarding educational approaches for patients with lupus, including best mode of administration, use of professionals versus self-administration, use of technology, content and the most applicable conceptual framework to guide the intervention and outcomes selection.
- Patient education interventions are a key component of patient management programs and lupus-specific patient educational programs are needed to ensure that the most effective programs exist and are available for patients with lupus.

beliefs, culture and perspectives (interpretative structures) acknowledge the patient/layperson as an expert that may contribute valuable information to the healthcare and research communities' agendas [24]. Methodological issues to consider for future studies include participatory action designs that integrate patients, healthcare professionals and researchers with designing and implementing tailored patient education programs to ameliorate disparities. Overall, the next steps for research on lupus patient education should consider adequately powered studies with statistically as well as clinically meaningful significant effect sizes for the development of interventions that produce long-term outcomes. Similarly, patient education should incorporate social media; determine the timeline for intervention implementation and establish consensus for nonpharmacological quality indicators and/or outcomes, as well as measures that eventually result in clinical improvements.

In summary, lupus is an oftentimes devastating and debilitating condition. If the goal of lupus interventions is to promote effective and meaningful therapeutic clinical interactions between patients with lupus, healthcare providers and the healthcare system, then the development of comprehensive disease management programs is warranted to improve patient quality of life as the current findings suggest opportunities and challenges. Patient education interventions are a key component of patient management programs [24] and lupus-specific patient educational programs are needed to ensure that the most effective programs exist and are available for patients with lupus.

#### **Future perspective**

Patient education is a typical part of standard care; however, the content, format, frequency and method of dissemination vary. For patients with lupus, limited research has been conducted on patient education. As a critical component of patient management, the development of model lupus-specific patient education studies will facilitate future studies and lupus outcomes.

The complex manifestation of lupus and its comorbid consequences may contribute to both the limited and mixed results of current lupus patient education. Thus, additional investigations of multifaceted, nonpharmacological lupus patient education are needed to manage lupus effectively and improve patients' quality of life.

#### Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

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