



Feasibility, utility and symptom impact of modified mindfulness training in sarcoidosis

To the Editor:

Sarcoidosis is a multisystem disorder characterised by noncaseating granulomatous inflammation of unknown aetiology. It may resolve spontaneously, but ~30% of patients have progressive disease with significant organ damage [1]. Although any organ is vulnerable, the lungs are frequently involved resulting in shortness of breath and dry cough. Fatigue is an overarching symptom in sarcoidosis, originating from multiple and combined causes of mental fatigue and physical fatigue [2]. This is also true of the psychosocial impact of sarcoidosis, which may include depression, anxiety, isolation and feelings of uncertainty. The prevalence of these factors remains high even for those who achieve clinical remission, resulting in psychological distress and reduced health status [3].

Health-related quality of life (HRQoL) and health status in sarcoidosis in those with multisystemic involvement, asthenia and arthralgia is reported to be poorer based on the World Health Organization Quality of Life Assessment Instrument-100 and several other generic measures of health status [4, 5]. Symptoms limit activity, impact social isolation, and exacerbate stress, anxiety and depression [6]. In countries where healthcare is privatised many patients with sarcoidosis are underinsured [7], creating additional health-related stresses. Pharmacological treatments for sarcoidosis may add to the physical and psychological burden, further impairing overall HRQoL [8, 9]. A multidisciplinary approach [10] that includes coping strategies and stress reduction may benefit those living with sarcoidosis [11, 12].

Mindfulness-based exercise interventions informed by t'ai chi have been used in cancer and demonstrate improved physical functioning, relief from treatment effects, increased HRQoL and improved memory and concentration [13–17]. Mindfulness-based exercise is also an effective therapy in patients with anxiety disorders and chronic fatigue [10]. Mindfulness-based exercise aims to reduce stress and tension to assist the practitioner to gain the serenity needed to achieve a state of mindfulness. Standard mindfulness training is comprised of at least eight 3-h sessions. This is not always feasible for chronically ill patients experiencing symptom-related functional limitation and who may also be managing debilitating symptoms in the context of a working life. Thus, we developed and have been teaching a modified version to people living with scleroderma, sarcoidosis and pulmonary fibrosis for several years. This has been positively evaluated from a patient satisfaction perspective. To formally describe our experience, we sought to measure the impact on a naïve group of people living with sarcoidosis. The delivery of a single point in time intervention was perceived to be the most feasible approach for this heterogeneous group.

The 45-min workshop engaged participants in a step-wise series of evidence-based foundational exercises in mindfulness techniques. Exercises ranged between 3 min and 15 min primarily focusing on body sensation and breath, with brief exposure to emotion and thought concepts. The format was intended to progressively build confidence and deepen acquaintance with mindfulness practices and breath management techniques. The session included a brief overview of the scientific evidence around mindfulness and its applications in healthcare both in terms of a treatment modality for patients and as a practice for health providers to improve provision of care and avoidance of burn-out.



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A modified mindfulness-based exercise intervention has beneficial impact on people living with sarcoidosis <http://ow.ly/XYTO30jtmms>

Cite this article as: Saketkoo LA, Karpinski A, Young J, *et al.* Feasibility, utility and symptom impact of modified mindfulness training in sarcoidosis. *ERJ Open Res* 2018; 4: 00085-2017 [<https://doi.org/10.1183/23120541.00085-2017>].

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26 participants (23 with sarcoidosis and three family members), previously unknown to the teacher (L.A. Saketkoo), consented to participate. The mindfulness training was delivered during their attendance at a sarcoidosis education day. Participants immediately completed anonymous pre- and post-mindfulness training evaluations in privacy. Evaluations contained six pre-/post-mindfulness questions pertaining to symptoms, four questions pertaining to psychological burden on a 0–10 Likert scale (higher scores = more severe symptoms) and three questions pertaining to degree of focus, well-being and motivation (higher scores = higher ability). All questions were time-referenced “now” for response. Dependent t-tests were used to compare the pre-/post-mindfulness items. The post-mindfulness evaluation also assessed participant perception of the workshop content itself (higher score = more positive feedback).

Analysis of the symptom scales (table 1) revealed statistically significant pre-/post-mindfulness decreases in all physical and psychological symptoms, and statistically significant improvements in pre-/post-mindfulness well-being ($p=0.003$) and motivation ($p=0.005$).

Regarding perceptions of the workshop itself, mean \pm SD values indicated participants perceived high benefit (7.54 \pm 1.88), ease of daily incorporation (7.84 \pm 1.72), a high likelihood to seek out similar experiences (7.24 \pm 1.99), recommend mindfulness training to others with sarcoidosis (7.81 \pm 2.19) and incorporate mindfulness training into daily routines (7.76 \pm 1.92).

Further the method of evaluation demonstrated an internal consistency reliability for all item scores at pre-mindfulness (Cronbach's $\alpha=0.839$)/post-mindfulness ($\alpha=0.843$) were high (range: 0–100), as was the test-retest reliability ($r=0.761$; $p<0.001$). The total psychological scales for pre-/post-mindfulness reliabilities were also high ($\alpha=0.944$ and 0.95) and test-retest was modest ($r=0.701$; $p<0.001$), which is encouraging for this instrument as a measure in future evaluations of mindfulness training in disease groups.

Our study has some limitations. Participants who attended were a self-selecting sample possibly representing a more highly motivated population. Although attendees had no prior exposure to mindfulness interventions we did not categorise the prior level of knowledge and/or experiences of other of complementary approaches to health management. The receptiveness of our patient group may have

TABLE 1 Concept items with response scales and statistical results

	Response scale	Pre-mindfulness mean \pm SD	Post-mindfulness mean \pm SD	p-value
Physical items	0–10 (None at all to worst possible)			
Shortness of breath?		2.77 \pm 2.46	1.83 \pm 2.06	0.002
Coughing?		1.56 \pm 2.38	0.78 \pm 1.57	NS
Body pain?		4.08 \pm 2.87	3.27 \pm 2.73	NS
Headache?		2.44 \pm 2.86	1.43 \pm 2.19	0.009
Fatigue?		5.62 \pm 2.73	3.57 \pm 2.79	<0.001
Nausea?		1.42 \pm 2.52	0.48 \pm 1.04	0.041
Psychological items	0–10 (None at all to worst possible)			
Feelings of stress?		4.08 \pm 2.99	2.43 \pm 2.66	0.012
Anxiety?		3.96 \pm 2.89	2.17 \pm 2.31	0.002
Feel worried?		4.27 \pm 2.92	2.30 \pm 2.18	0.001
Depressed?		3.77 \pm 3.02	2.13 \pm 2.36	0.003
Additional items				
Ability to focus?	0–10 (Not able at all to excellent focus)	3.69 \pm 2.34	3.48 \pm 2.48	NS
Overall sense of well-being?	0–10 (Extremely poor to excellent well-being)	4.58 \pm 2.16	3.30 \pm 1.92	<0.01
Feel sense of motivation?	0–10 (Not at all to excellent motivation)	3.80 \pm 2.36	2.82 \pm 2.15	<0.01
Workshop				
How beneficial?	0–10 (Not at all to extremely beneficial)		7.54 \pm 1.88	
How likely to recommend to others with sarcoidosis?	0–10 (Not at all likely to extremely likely)		7.81 \pm 2.19	
How easy to incorporate into daily life?	0–10 (Not at all easy to extremely easy)		7.84 \pm 1.72	
How likely to seek similar experiences?	0–10 (Not at all likely to extremely likely)		7.24 \pm 1.99	
How likely to introduce into daily routine?	0–10 (Not at all likely to extremely likely)		7.76 \pm 1.92	

NS: nonsignificant.

been positively skewed. Participants were offered one workshop at a single point in time. Thus, comparative data to assess benefit against a traditional programme of eight 3-h sessions is not possible, nor were data demonstrating durability over time collected.

In conclusion, this study is the first to show that a modified 45-min mindfulness training workshop had immediately measurable benefit and was perceived as a feasible, acceptable and beneficial introduction to routine daily life by people living with sarcoidosis and their caregivers. This model is cost-effective and sustainable as a one-off intervention. However, further studies with a robust patient-centred end-point model are needed. Longitudinal assessment of adherence to mindfulness practices, its impacts, perceived benefit and utility will need to be demonstrated before mindfulness practices are endorsed by health service commissioners and providers.

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Received: July 18 2017 | Accepted after revision: March 17 2018

Conflict of interest: None declared.

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