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1 **Title**

2 **Structured nursing educational programs improve quality of life outcomes in patients**
3 **with Cushing's Syndrome**

4
5 **Authors**

6 Sofia Llahana, RGN, INP, MSc, DNSc

7 Consultant Nurse in Endocrinology, UCLH, London, UK

8 Clinical Academic Fellow, Centre for Behavioral Medicine, UCL, London, UK

9

10 Nicola Thomas RGN, BSc (Hons), MA, PhD (Professional Practice)

11 Associate Professor in Kidney Care

12 School of Health and Social Care, London South Bank University, London, UK

13

14 **Address for correspondence**

15 Department of Diabetes & Endocrinology

16 University College London Hospitals (UCLH) NHS Foundation Trust

17 3rd Floor Central Wing

18 250 Euston Road

19 London NW1 2PG

20 UK

21

22 Email: sofia.llahana@uclh.nhs.uk

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25 Patients with Cushing's syndrome report impaired quality of life (QoL) even after
26 biochemical cure and have worse QoL outcomes compared to patients with other pituitary
27 adenomas [1]. A variety of physical, neuropsychosomatic, psychological and

28 sociodemographic factors have been found to influence QoL parameters in patients with
29 Cushing's syndrome [1, 2]. A systematic review by Andela *et al* found that 6 out of the 8
30 studies involving patients with Cushing's syndrome showed a positive effect on QoL
31 following surgical or pharmaceutical interventions [1].

32 Despite the well documented impaired QoL in patients with Cushing's syndrome, the
33 prospective randomized study by Martinez-Momblan *et al* [3], discussed in this issue, is the
34 first to provide evidence of the positive effect of an educational intervention program on

1 patients' QoL outcomes, physical activity, healthy lifestyle habits, sleep patterns and
2 reduction in pain levels. Moreover, patients with Cushing's syndrome in this study
3 maintained improvements in QoL at 9 months post educational intervention [3].
4 Nursing educational programs which involved patients with Cushing's syndrome have been
5 documented since the early 1960's but focused mainly on the management of glucocorticoid
6 treatment and prevention of adrenal crisis. Kathleen Shea and colleagues developed a
7 structured educational program which also included a teaching guide for nurses to "...prepare
8 the patient to live intelligently with his regimen of hormonal replacement therapy in both
9 normal and emergency situations" (p. 82) [4].
10 A more recent study found that a nursing educational program delivered over a 3-hour group
11 meeting (N = 246; 71% secondary adrenal insufficiency) showed significant improvement (p
12 < 0.05) at 6 months post intervention in patients' self-management skills to prevent adrenal
13 crisis [5].
14 Improved self-management skills for glucocorticoid replacement forms a cornerstone in the
15 care of patients with Cushing's syndrome who develop adrenal insufficiency and the above
16 studies emphasize the importance of patient education [4, 5]. However, these interventions
17 have a narrow focus and unlike the Martinez-Momblan *et al* study [3], they do not take into
18 consideration the patient's holistic self-management needs and QoL parameters.
19 Despite advantages of group educational programs and evidence from Martinez-Momblan *et*
20 *al* [3] in improving QoL, one should not assume that this approach is suitable for all patients
21 with Cushing's syndrome.
22 Geographical dispersion, time/date restrictions when educational programs are delivered,
23 literacy levels and patients' comfort levels of learning and interacting within a group may
24 often influence non-attendance. Response rates of 49% (N = 61) [3] and 61% (N = 246) [5]
25 were achieved and it would have been useful for these studies to have explored why patients
26 declined participation in the educational program.
27 We know that patients' ability to retain information following educational interventions
28 diminishes over time [6] and it is therefore crucial to provide "real time" access to
29 information and continuous reinforcement of existing knowledge.
30 Moreover, patients' readiness and motivation can influence the outcome of educational
31 programs on improving QoL parameters. A strength in Martinez-Momblan's *et al* study
32 regarding QoL outcomes was that patients with Cushing's syndrome entered the program
33 with strong motivation to complete all education sessions and to improve their health [3],
34 although one may also view this as limitation as it can skew the results.

1 Martinez-Momblan *et al* found lower number of unscheduled visits and acute hospital
2 admissions for patients in the intervention group compared to patients in the control group.
3 More importantly, patients in the intervention group reported reduction in unscheduled visit
4 and acute hospital admissions post educational program compared to baseline [3]. This has
5 important implications in justifying health resources required to deliver intense educational
6 programs which can lead to improved QoL outcomes for our patients and lower cost for
7 health services in the long run.

8 A lack of reliable biochemical parameters to assess changes in QoL outcomes for patients
9 with Cushing's syndrome in remission and with hypopituitarism is a limitation compared to
10 other long term conditions. This is reflected in a study involving 102 patients with treated
11 Cushing's syndrome where 92% were biochemically cured but only 80.4% felt they had
12 achieved remission and continued to report impaired QoL [2].

13 However, there are validated questionnaires such as the CushingQoL [7] that can detect
14 improvement or deterioration in QoL and it is crucial that these are adopted in clinical
15 practice to evaluate outcomes of any educational programs.

16 Martinez-Momblan *et al* [3] provide the first piece in the puzzle of research evidence
17 supporting the need for nurse-led multidisciplinary educational programs in Cushing's
18 syndrome. However, there is urgency for further research to develop effective intervention
19 programs which can improve QoL outcomes for patients with Cushing's syndrome and other
20 pituitary conditions.

21 Educational interventions often lack theoretical underpinning which makes it difficult to
22 generalize findings and adopt their study design to other settings. A recent systematic review
23 into effective teaching strategies for patients with a variety of conditions, found that there
24 were challenges in evaluating the success of specific methods of delivery: details of the
25 educational intervention are not fully reported, and more importantly outcome measures are
26 not clearly articulated [8].

27 It is therefore important to adopt a clear theoretical framework which can guide robust
28 research methodology and explain the likely influences of educational interventions on QoL
29 outcomes. These programs should not only aim to improve patient's knowledge and self-
30 management skills but should also adopt psychosocial approaches to address patient
31 motivation, beliefs and illness perceptions [9].

32 Tiemensma *et al* found that patients with Cushing's syndrome in remission report more
33 negative illness perceptions compared to patients with other chronic conditions and these
34 were strongly related to impaired QoL [10].

1 As Friedman *et al*'s systematic review suggested, specific individualized education should be
2 provided to patients rather than general information about their condition [8]. Education
3 should be structured (an ad hoc random question and answer sessions are not effective),
4 sessions should involve a variety of teaching strategies, and education for minority groups
5 should be culturally sensitive [8]. We need to be creative and eHealth educational programs
6 may present many opportunities to provide patients with “real time” structured education to
7 complement face-to-face care away from the traditional hospital setting.

8

9 **Conflict of interest**

- 10 • S. Llahana has received unrestricted educational grants from Sandoz UK and
11 lecture/consultancy fees from Shire and MerckSerono.
- 12 • N. Thomas has no conflict of interest.

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