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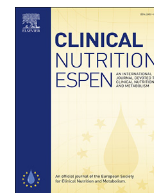
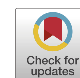


Short Communication

Identifying patients with benign chronic intestinal failure on home parenteral nutrition in whom a psychological support intervention may improve quality of life



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SUMMARY

Rationale: Home parenteral nutrition (HPN) is the ultimate treatment for patients who suffering from chronic intestinal failure (CIF). We tested the feasibility and effects of Mindfulness Based Cognitive Therapy (MBCT) in patients on HPN. Because of the high dropout rate, however, we were next urged to develop and test a web-based coaching program (web-based MBCT). The aim of the present study was to compare the effects of MBCT with this web-based MBCT.
Methods: A quasi-experimental pilot study was conducted in a tertiary referral center for CIF in the Netherlands to evaluate the feasibility of both a MBCT and the internet-based MBCT intervention. In 2016 we included 17 patients in the MBCT group. These patients followed MBCT training. End of 2016 an internet-based online MBCT program was constructed for which we invited 14 patients and their caregivers.
Results: In the MBCT 5 out of 17 patients (29%) completed their therapy. Patients attributed positive effects to their acquired mindfulness skills and reported a better QoL. In the internet-based mindfulness therapy group 2 out of 14 patients (14%) fulfilled the training sessions. Also, six caregivers started the training in this latter group and one caregiver fulfilled the training.
Conclusion: The study suggests that both MBCT and the internet-based MBCT are no feasible strategies to decrease disease burden and improve QoL for CIF patients and their caregivers due to the intensity of these programs on one side and the experienced physical limitations on the other. The patients who fulfilled the program were positive and use MBCT in daily practice.
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1. Introduction

Home parenteral nutrition (HPN) is a life-saving therapy for patients suffering from intestinal failure (IF). Intravenous supplementation of nutrients and fluids is required to maintain or improve health and/or growth [1]. In long-term IF patients parenteral nutrition is administered in the home setting (HPN). Relatives frequently participate as caregivers in this situation. As such, HPN is never a 'single event' in patients' lives, but it has an inevitable impact on their lifestyle.

Few studies show the range of problems that HPN patients experience [1]. Psychosocial problems, depression, social impairment and fatigue and previously experienced venous access complications have been strongly associated with a lower Qol [1,2]. One of the main obstacles reported is the lack of knowledge of coping and social skills and techniques that help to improve patients'Qol [1]. Mindfulness Based Cognitive Therapy (MBCT) has shown the potential to improve Qol in other clinical settings [3]. Earlier studies have also shown that web-based mindfulness interventions appear to be an acceptable and valid alternative to existing MBCT treatments with great satisfaction and acceptance for the training [4–6].

Standard 8-week MBCT programs require time for group meetings (24–30 h) under guidance of an instructor, daily exercises (45–60 min) and a full day's silent meditation. Despite the lack of contact with an instructor and fellow participants in mindfulness-

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based interventions online, the results have been shown to be comparable to MBCT interventions [6]. This notion provides preliminary evidence for the effectiveness of internet-based mindfulness treatment compared to MBCT.

In this paper, we examine the feasibility of MBCT as a means to modulate and improve the coping strategy of HPN patients. Yet, due to the high drop-out rate during the MBCT sessions we were urged to develop a web-based Mindfulness program and compared this program with MBCT in our CIF patients on HPN and their caregivers.

2. Methods

2.1. The MBCT program

The structure of our MBCT training was based on the original program as developed by Kabat-Zinn [7] which comprises: 1) 8 sessions of 2,5 h each, 2) a silent day and 3) daily home practice homework of 45 min a day. Each participant received a CD-set to guide home practice and a workbook with information of each session. During MBCT a range of formal and informal exercises were exercised. The patients were invited to do these exercises within the supposed limits of their personal abilities. After the session we planned interviews with the patients who fulfilled the whole training.

2.2. Internet-based MBCT

In 2016 an internet-based online MBCT program was developed by the Mindfulness Academy in Nijmegen using video interviews with two patients of the MBCT group who fulfilled the whole training. The structure of Internet-based MBCT is based on the original program but the content differs. Participants in the Interned-based MBCT start with a group session of 4 h for patient and caregiver to explain and train the practice exercises. Also sessions 5 and 9 was a group session of 4 h. For the sessions 2 till 4 and 6 till 8 they log in on a secured personal webpage where the content relevant to that week's session can be downloaded. Participants are asked to read the information and do the mindfulness exercises and write down their experiences in their personal log. They are encouraged to corresponded with their personal teacher about their practice experiences via a secure, integrated mailing system. The teacher replies to this log on a predetermined day of the week and guides the participants through the curriculum.

3. Results

3.1. MBCT

Of All patients with CIF in Nijmegen (n = 175) 17 patients started the Mindfulness program with a mean age of 54 years (9 female) of whom 8 suffered from a gastrointestinal motility disorder.

3.2. Feasibility and acceptability

Five patients (29%) completed the 8 week training. One patient did not start MBCT training because of an acute illness and one patient dropped out of the training program because this was experienced as being too intense. After the first training day, one patient decided to stop, as it was ‘not the right moment’ due to mental issues. After the fourth training day, a third patient also stopped due to hospital admission. Furthermore, 4 patients only attended the training days once or twice because of acute illness. Five patients participated in interviewing by the psychologist from the Mindfulness center.

3.3. Qualitative evaluation

Patients mentioned that both the duration and frequency of the training were too intense because of their physical symptoms (mainly fatigue). All participants reported that they sensed a positive feeling of support by their mindfulness trainer, felt very positive about participating in a group, which was experienced as an open and safe environment. Also, they felt connected with and supported by the other group members. They also mentioned that they learned from others. The written material and CD's from the Mindfulness Centre were considered useful. Participants mentioned that it was difficult to practice at home on a daily basis because of fatigue and hospital admission. Some of the quotations: “The body scan” helps to relax whereby I get peace in my life.“; “The seated mediation “helps to free me from suffering.“, “The awareness of breath meditation “I can do every ware”; .“Duration and logistics of the Mindfulness course program should be adapted.”

3.4. Internet-based MBCT

14 patients participated in the internet based mindfulness training with a mean age of 56 years (6 Female). The majority of patients were diagnosed with gastro intestinal dysmotility (8 patients).

3.5. Feasibility and acceptability

Four patients (28%) did not start the internet-based MBCT training because of an acute illness. One patient started later on in the training program because of hospital admission. The online sessions was difficult to complete because of fatigue and non-wellbeing. Two patients (14%) participated in all sessions.

3.6. Qualitative evaluation

Patients mentioned that the duration and frequency of the group sessions at the mindfulness center was doable, but the duration (4 h in the morning) was a problem because of their physical symptoms. All participants felt supported by their mindfulness trainer. The flyer and CD's were considered useful, the internet-based application was clear and helpful but some patients found it difficult to login on the web-based program with a code and login name. It was difficult to practice at home on a daily basis because of fatigue and hospital admission. Patients felt very positive about participating in a group, which felt as an open and safe environment. They felt connected with and supported by the group members. They also mentioned that they learned from others and they learned much from the personal interviews in the web-based sessions. The tools, struggles and suggestions they gave were very useful and supported the patients to go on. Some of the quotations: “The body scan” helps to relax whereby I get peace in my life.“; “The seated mediation “helps to free me from suffering.“, “The awareness of breath meditation “I can do everywhere”; .“Duration and logistics of the Mindfulness course program should be adapted.”

4. Discussion

Poor quality of life is reported in association with the burden, anxiety and depression related to HPN support and should be prioritized for psychological support because of this increased risk and the impact of CIF for the individual [8]. To our knowledge such trainings has not been assessed in the setting of CIF before. This report presents the results of our attempts to integrate mindfulness training in HPN support in the major tertiary referral center for CIF in the Netherlands. More specifically we tested Mindfulness Based

Cognitive Therapy and the internet-based MBCT in patients and (if available) their caregivers.

Our most important findings are that both treatment by MBCT and the internet-based form of MBCT proved not feasible for patients with CIF and their caregivers, mainly due to experienced fatigue and physical lack in wellbeing with repeated acute hospital admissions. This is exemplified by the finding that the majority of patients did not even complete their training. This experience differs significantly from findings in other patient populations and therefore seems specific for this patient population [9,10]. Consequently, the question also remains to what extent (and if so, what) further adaptations to these programs would be helpful to justify their implementation in HPN care.

Especially in light of the lower energy level of CIF patients, providing internet-based mindfulness without a need to plan and undertake travels might well hold promise by increasing the accessibility to this form of therapy. The web-based MBCT for CIF patients was tailored for this group by its construction that was based on interviews with those patients who participated in the MBCT. In this way, their experiences with Mindfulness, struggles and the tools they used during the sessions could specifically be integrated into these web-based sessions. As such, the patients who took part in the web-based MBCT were very positively impressed about the quality of these online sessions.

We hope that the experiences described will aid in the further development of tools to provide more helpful psychosocial support for this very delicate patient population.

Declaration of competing interest

The authors report no conflicts of interest.

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Judith Beurskens: design study, practical performance, preparation manuscript.

Getty Huisman de Waal: critical review manuscript.

References

[1] Beurskens-Meijerink J, Huisman-de Waal G, Wanten G. Evaluation of quality of life and caregiver burden in home parenteral nutrition patients: a cross sectional study. Clinical Nutrition ESPEN; 2020.

[2] Huisman - de Waal Getty, Versleijen Michelle, van Achterberg Theo, Jansen Jan B, Sauerwein Hans, Wanten Geert. Psychosocial complaints are associated with venous access-device related complications in patients on home parenteral nutrition. JPEN - J Parenter Enter Nutr 2011;35(5):588–95.

[3] Schoultz Mariyana, Atherton Lian M, Hubbard Gill, Angus J.M. Watson. The use of mindfulness-based cognitive therapy for improving quality of life for inflammatory bowel disease patients: study protocol for a pilot randomised controlled trial with embedded process evaluation. Trials 2013;14:431.

[4] Boettcher Johanna, Astrom Victor, Pahlsson Daniel, Schenstrom Ola, Andersson Gerhard, Calbring Pel. Internet-based mindfulness treatment for anxiety disorders: a randomized controlled trial. Behav Ther 2014;45(2):241–53.

[5] Gluck TM, Maercker A. A randomized controlled pilot study of a brief web-based mindfulness training. BMC Psychiatr 2011;11:175.

[6] Krusche Adele, Cyhlarova Eva, Williams J Mark G. Mindfulness online: a preliminary evaluation of the feasibility of a web-based mindfulness course and the impact on stress. BMJ Open 2012;2(3).

[7] Paulson Steve, Davidson Richard, Jha Amishi, Kabat-Zinn Jon. Becoming conscious: the science of mindfulness. Ann N Y Acad Sci 2013;1303:87–104.

[8] Aaronson Neil K, Muller Martin, Cohen Peter DA, Sprangers Mirjam AG, te Velde Adrienne, Verrips Erik. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol 1998;51(11):1055–68.

[9] Huisman - de Waal Getty, Schoonhoven Lisette, Jansen Jan, Wanten Geert, van Achetrberg Theo. The impact of home parenteral nutrition on daily life-a review. Clin Nutr 2007;26(3):275–88.

[10] Piet J, Wurtzen H, Zachariae R. The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: a systematic review and meta-analysis. J Consult Clin Psychol 2012;80(6):1007–20.