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PARTICIPANT'S EXPERIENCES OF TAKING MELATONIN FOR THE TREATMENT OF NOCTURIA IN MS: QUALITATIVE FINDINGS FROM A DOUBLE BLIND RCT

Hypothesis / aims of study

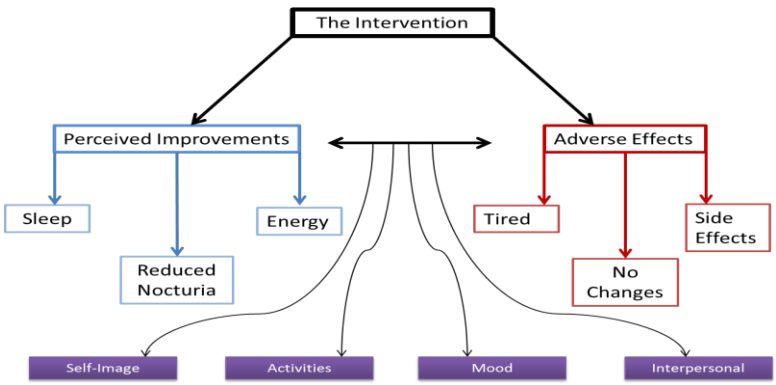
Multiple Sclerosis (MS) is a chronic neurological disorder caused by eventual neurodegeneration within the central nervous system resulting in impaired physical, cognitive and psychological functioning. It is often progressive and can result in many unpredictable symptoms, all of which can have a detrimental effect on quality of life(1). Commonly, people with MS will report a number of lower urinary tract symptoms (LUTS) including nocturia (1). This is defined by the International Continence Society (ICS) as the need to 'wake at night one or more times to void' (2). Previously, clinical trials have sought to understand the causes of nocturia and have found an association between melatonin secretion and nocturia (3). However, to date, no qualitative studies have been conducted which explore the experience of taking melatonin for the treatment of nocturia within the context of a clinical trial. This study specifically aimed to explore perceptions of this intervention on nocturia and associated quality of life impact from the patients' perspective.

Study design, materials and methods

This qualitative exploration was embedded within a double blind, placebo controlled, randomised trial which explored the effectiveness of melatonin for the treatment of nocturia in MS. During the trial, participants were invited to take part in five study visits to monitor progress and were interviewed by a qualitative researcher following their final study visit. Semi-structured, face to face interviews were conducted among 17 consenting participants with progressive MS and were facilitated by a semi-structured topic guide. The sample consisted of ten female participants and seven males with an age range of 39 to 67 (mean 58 year). Interviews took between 20 and 40 minutes to complete and where possible, the partners of participants were also involved within these discussions. Data was audio recorded and transcribed verbatim. Transcripts were then coded using NVivo 10 and analysed using a thematic analysis.

Results

Data revealed a number of significant themes that were grouped and divided into two key categories 'perceived improvements' and 'adverse effects' which captured participants' experiences of taking melatonin and a placebo for the treatment of nocturia. All themes were believed to have a significant effect on various aspects of their quality of life.



Quotes detailing perceived improvements

- 'It's having more energy the following day and having a better life really… I think that's what it is really just giving me a better standard of life'
- 'To go from getting up twice every night to only getting once in the last week is significant progress'
- 'My sleep was a lot better… so it's the quality of sleep is a lot better and because the quality of sleep's a lot better I feel a lot better I've got more energy I just felt great'

Quotes detailing adverse effects

- 'I could have been on the placebo both times really yeah I didn't notice enough to go wow that's made a difference'
- 'You were getting up with a very thick head and quite grumpy and it would take you a long time to come round'
- 'An hour or so after I'd fallen asleep I would have a dream. They weren't unpleasant, they weren't nightmares they were just a bit whacky'

Interpretation of results

This qualitative exploration revealed that some participants perceived the intervention to be beneficial as they described positive changes to their nocturia, sleep quality, and energy levels. This was found to have a substantial effect on their quality of life as individuals noted that their psychological and cognitive functioning had improved, as did their ability to fully engage with their daily lives. However, for other participants, some negative experiences were reported including a range of side effects such as headaches and vivid dreams. Furthermore, some noted that this intervention was largely ineffective as they reported a distinct

lack of change to their condition. Finally, the presence of excessive drowsiness and tiredness during the day meant that participants were reluctant to view the trial as a success even when occurrence of nocturia had reduced.

Concluding message

Some participants taking melatonin for the treatment of nocturia reported a perceived reduction in nocturnal voiding, resulting in better sleep which improved their daily quality of life. However, for others, drowsiness resulted in enhanced feelings of MS-related fatigue, making their daily lives much more challenging. These qualitative findings will ultimately support the quantifiable trial data and enable more accurate counselling for future recipients of this treatment for nocturia.

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Disclosures

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