ABSTRACT

Purpose: Sleep is important in maintaining the body's circadian rhythm and in maintaining health. Aim was to investigate sleep and physical activity among people who have Inflammatory Arthritis and their engagement with Health Professionals.

Materials and Methods: Members from a national charitable organisation for patients with arthritis and a national rheumatology health professionals society were invited to participate in separate cross-sectional surveys hosted on SurveyMonkey(R)TM.

Results: Ninety (90) people responded and report an average of 5.7 (SD 1.46) hours sleep per night. A majority (61%) report their sleep quality as bad, with 31% taking medications at least once a week to help sleep. There was a statistically significant association between longer years with symptoms, taking medication at least once a week and limited in their activities, when rating their sleep quality as bad. Twenty eight (65%) health professional's responded with 53% discussing sleep with their patients.

Conclusions: People with inflammatory arthritis report low sleep with those having symptoms longer, taking medications regularly and having limitations with their activities, reporting poorer sleep quality. Only half of health professionals discuss sleep. More research is needed in investigating poor sleep quality, disturbances and physical activity in order to promote health and well-being in this population.

Key words: inflammatory arthritis; sleep; physical activity; exercise; health professional

INTRODUCTION

Inflammatory arthritis is a term used to describe a group of conditions which directly affect the immune system. They are classified as chronic and characterised by joint pain, joint swelling, and stiffness among other signs and symptoms [1]. They are also identified by sleep disturbances, reduced sleep quality, depression and decreased physical activity levels [2].

Regarding sleep quality and disturbances, a number of studies indicate that people with inflammatory arthritis report issues relating to their sleep, including sleep onset latency, total sleep time, sleep efficiency and wake after sleep [3, 4].

Sleep is an important component in quality of life therefore, sleep disturbances can have a detrimental impact on same. Poor sleep quality may contribute to the feelings of pain, fatigue and mental health which in turn may further deteriorate functional ability and reduced activity. Previous studies have shown joint pain and stiffness to be factors in sleep disturbances [5, 6] and in particular the length of morning stiffness affecting sleep quality [7, 8].

Physical activity and exercise have been well established as being important in preventing disease in both healthy and rheumatic disease populations [9, 10]. However, little is known regarding the impact this disease activity and poor sleep has in relation to exercise and sedentary behaviour, in people who have inflammatory arthritis. Poor sleep quality and disturbances are known to affect 40-70% of rheumatic patients [11] and while its' association with reduced quality of life has been reported, it's association with physical activity and exercise has not, even though sleep disturbances are significantly correlated with decreased functional ability and activity levels [12]. Indeed the intensity level of the activity in people with inflammatory arthritis may be of additional importance [13].

People with inflammatory arthritis's experience of their sleep and physical activity levels have yet to be fully explored or evaluated through exercise and in addition there is no information available regarding the engagement by health professional's when discussing sleep with this population. Thus, the aims of this study were to investigate sleep quality, disturbances and physical activity among people who have inflammatory arthritis, so that we can possibly understand more the potential for long-term changes in overall health status. The engagement by health professionals when discussing sleep may be of particular benefit in influencing the provision of educational and research opportunities in this area, which will ultimately help in improving overall patient care.

METHODOLOGY

Participants/Sample

Members from a national charitable organisation for patients with arthritis (Arthritis Ireland; AI), were invited to participate in a cross-sectional survey. A self-selected sample of convenience was used, with a broad inclusion criteria being utilised, with the aim of maximising recruitment and increase the generalisability of the findings. Members from a rheumatology health professionals society (Irish Rheumatology Health Professionals Society; IRHPS) (n=43) were invited to participate in a separate cross-sectional survey. This professional group was chosen, as membership either indicated a particular interest in Rheumatology or were more likely to be involved in the management of inflammatory arthritis. This group also provided a random sample of those working in public and private clinical settings, helping to improve the generalisability of the study. Cross-sectional questionnaires were chosen as it allowed for the collection of data from a wider range of participants.

Ethical approval granted by the University of Limerick (UL) Faculty of Education and Health Sciences Research Ethics Committee (Approval number: 2015_09_02_EHS). Informed consent was implied if the participant continued with the survey, having initially read the information sheet. All procedures performed in studies involving human participants were in accordance with the ethical standards of the University and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Questionnaire

Following a review of the literature no validated tool was established to examine sleep and physical activity in people with inflammatory arthritis or the interaction by health professionals therefore, 2 questionnaires were developed (see Supplementary material). The people survey consisted of 20 questions, 19 of which were closed and 1 was open and the health professional's consisted of 17 questions, 15 closed and 2 were open. Questions were developed based on an extensive literature review of exercise and sleep. It is acknowledged that having a majority of questions being closed can create false opinions if there is not a sufficient range of alternative answers provided [14].

To ascertain face validity of the questionnaire, discussions were organised with three health professionals' i.e. Physiotherapist, Occupational Therapist and a Clinical Nurse Specialist to cover different groups. In addition interviews with four people with inflammatory arthritis i.e. two Rheumatoid Arthritis, one Ankylosing Spondylitis and one Psoriatic Arthritis took place to cover different disease spectra. These discussions took place in order to explore whether the constructs surveyed within each questionnaire reflected the aims under study (i.e. to identify missing or problematic questions/constructs). We therefore applied a purposive sampling method to reflect different diagnoses of arthritis, age and gender and subsequently the questionnaires were

adapted to improve their readability, validity and specificity. The final questionnaires were piloted with people with inflammatory arthritis and experts in this field to optimise content validity, thus ensuring questions were readable, relevant and representative of the study's aims, in addition to minimise the risk of missing data. One of the author's is an experienced researcher in this field (NK). Minor syntax changes to the original questionnaires were made and the question on physical activity was split into four to make it easier to read and answer.

The questionnaires were divided into three sections: (1) Demographics, (2) Sleep, and (3) Physical Activity. The sleep section was based on the Pittsburgh Sleep Quality Index (PSQI) and adapted to an Irish population. This Index is an outcome measure used to assess sleep quality and disturbances in adults in numerous populations, including inflammatory arthritis, over the preceding month [15] [16]. Reliability studies on the PSQI indicate Cronbach's alpha of between 0.77 and 0.83 [17, 18], indicating high internal consistency, with criterion validity and convergent validity with polysomnographic indices and sleep diaries [19]. To determine respondents own physical activity levels and to assess if they meet the public health protocols, a question based on the Short Questionnaire to Assess Health Enhancing Physical Activity (SQUASH) was asked [20]. This outcome measure contains 11 questions on physical activity related to commuting activities, leisure time and sports activities, household activities, and activity at work and school. It is a fairly reliable and reasonably valid questionnaire and is a very useful tool for the evaluation of health enhancing physical activity [21]. Reproducibility of the separate questions have a mean value of 0.75 (range: 0.44 - 0.96) [20].

Data Collection

Questionnaires were administered through SurveyMonkey(R)TM. This approach was chosen as the advantages of distributing a survey online include a broad geographic distribution, convenience to respondents and guaranteed respondent confidentiality [22]. Other advantages in using web-based questionnaires include ease of data collection and analysis [23].

The national charity agreed to act as gatekeeper and distributed the questionnaire via social networking e.g. facebook, twitter, to their members while, the health professionals society acted as gatekeeper for their survey. As advocated, to obtain the highest possible response rate three reminders were sent [24].

Data Analysis

The services of a statistician were used to advise on the analysis. Basic descriptive statistics for demographic questions were generated by SurveyMonkey(R)TM and transported into Microsoft Office Excel (2013) for further analysis. Closed questions using a Likert Scale were analysed using SurveyMonkey's(R)TM inbuilt statistical system. Data were missing from some questions, therefore each question has an absolute and relative response included (e.g. 90%; 81/90).

Data analysis was also carried out using the Statistical Package for Social Sciences for Windows Version 22 to allow for further statistical analysis. Tests for normality were conducted and non-parametric tests were utilised throughout. Specifically when investigating variables surrounding differences in sleep and years with symptoms; taking sleep medication; limited with activities; years qualified as a health professional; years working with people with IA and health professional, Mann-Whitney U and Chi-

square/Fisher's Exact (FET) tests were used depending on the nature of the data i.e. continuous or categorical. Level of significance was set at $p<0.05$.

Data from open-ended questions were evaluated using conventional content analysis. These responses were short and often consisted of a word or one line, therefore Microsoft Office Excel (2013) was used to store and organise the data rather than more specialist software like NVivo. Analysis was carried out in six steps as described by Hsieh and Shannon [25].

RESULTS

Respondents – People with Inflammatory Arthritis

A total of 90 people with inflammatory arthritis responded to their survey, with socio-demographic profiles provided in table 1.

The majority of respondents were female at 77% (69/90), which is slightly higher than the 75% reported by the American college of Rheumatology [26]. Rheumatoid Arthritis (RA) was diagnosed in 62% (56/90) of cases with respondents reporting an average of 10 years (SD 7.9) since first diagnosis. Respondents over 35 years of age (83.3%, 75/90) made up the majority of respondents with the age group 35-44 representing 37% of those who responded (33/90). Regarding their working situation, a third were in full-time employment (30/90), with over half having a third-level qualification (48/90).

A total of 56% (50/90) reported having arm pain in the previous week, with 86% (77/90) limited with moderate activities.

Sleep

Respondents reported a mean of 5.7 (SD 1.46) hours sleep per night. A total of 75% (61/81) stated their sleep quality as fairly bad/very bad, during the past month, while 31% had to take medications at least once a week to help with their sleep, over the previous month. Full details available in table 2.

A large majority report 'pain' (95%), 'waking up in the middle of the night or early morning' (97%) and 'cannot get to sleep within 30 minutes' (91%) as disturbances, see table 3.

A chi-square test of independence was performed to examine differences in sleep quality across longer years with symptoms (95% CI: 8.42, 11.76), taking sleep medication at least once a week, and limited in their activities. There was a statistically significant difference in sleep quality across longer years with symptoms $X^2_{(1)\ (N=81)} = 10.04$, $p = .004$, taking sleep medication at least once a week, $X^2_{(1)\ (N=81)} = 8.326$, $p = .004$ and limited in their activities, $X^2_{(1)\ (N=81)} = 10.38$, $p = .001$.

Physical Activity

A total of 72% believe it is important to measure physical activity. When using the Short Questionnaire to Assess Health Enhancing Physical Activity, patients' physical activity levels were 1,210 minutes per week. Those with less than 1,210 minutes of physical activity per week, 73% reported their sleep quality as fairly bad/very bad with 65% receiving more than the reported 5.7 average hours sleep per night.

Cluster analysis

A two-step cluster analysis was performed on the data to identify individuals with similar activity levels. A Wards hierarchical approach was used first and 3 clusters were chosen based on the dendrogram plot. A k-means cluster analysis was then applied to the data to verify the optimal 3 cluster-solution. Group 2 had the highest physical activity, whereas group 3 had very low levels of physical activity.

The sleeping patterns were then analysed across these three groups. The most active group with 4.27 hrs of activity had the longest sleeping time 7.65 hrs (SD 0.25), while the group with the lowest physical activity levels with 0.87 hrs had the shortest sleeping time 4.55 hrs (SD 1.15). Full details available in table 4.

Respondents – Health Professionals in Rheumatology

A total of 65% (28/43) of health professionals responded to their survey and socio-demographic profiles are provided in table 5.

The majority of respondents were female at 86% (24/28). Results found the mean number of years qualified to be 16.93 (SD 6.82), mean number of years working in Rheumatology to be 10.07 (SD 4.04) with 40% of respondents reporting at least half of their patient workload coming from people who have inflammatory arthritis

Regarding their place of work, most respondents had some involvement with a Hospital setting, either part or full time (85.7%), with primary care making up 28.5%.

Sleep

A total of 53% (15/28) of health professionals discuss how many hours sleep their patients receive per night. Through an open question, 46% (13/28) of respondents mentioned fatigue as their main reason for when enquiring, followed by pain with 14% (4/28).

Table 6 outlines sleep disturbances mentioned by their patients. A total of 100% of those surveyed stated that their patients mentioned 'pain' and 'waking up in the middle of the night or early morning' as disturbances, while 67% reported 'taken prescribed or over the counter medication', to help with their sleep.

A chi-square test of independence was performed to examine differences when discussing sleep across longer years qualified (95% CI: 14.24, 19.62), more years working with people with inflammatory arthritis (95% CI: 8.47, 11.67) and health profession. There were no statistical differences when discussing sleep across longer years qualified $X^2_{(1)(N=28)} = 15.75$, $p = .075$, more years working with people with inflammatory arthritis $X^2_{(1)(N=28)} = 8.25$, $p = .089$, or health profession $X^2_{(1)(N=28)} = 10.04$, $p = .102$.

Physical Activity

A total of 100% (28/28) of health professionals believe it is important to measure physical activity. When using the Short Questionnaire to Assess Health Enhancing Physical Activity, respondents' physical activity levels were 2,248 minutes per week. Those with less than 2,248 minutes of physical activity, 78% don't discuss sleep with their patients. There was a statistically significant association between those who were more physically active and discussing nightly sleep with their patients $X^2_{(1)(N=28)} = 6.39$, $p = .004$.

DISCUSSION

This report is one of the first to collate responses from both patients and health professionals on sleep and physical activity. Sleep deprivation and poor sleep quality may have a profound impact on health, well-being and the ability to be physically active. The National Sleep Foundation, based in the United States, discuss the appropriate sleep duration for adults/older adults on a spectrum between 7 to 9 hours [27]. From our survey people with inflammatory arthritis report an average of 5.7 (SD1.46) hours sleep per night, which falls far below this 'sleep needs spectrum'. This is concerning as individuals who have reduced levels of sleep have been associated with decreased quality of life, physical function and increases in morbidity [28].

Sleep has an important role to play in our immune system and is important in the restoration and maintenance of homeostasis [29]. Sleep disorders may trigger immune system abnormalities inducing autoantibody production, which may lead to the development of autoimmune disease such as systemic lupus erythematosus, scleroderma or rheumatoid arthritis [29]. Pharmacologic interventions have improved the management of inflammatory arthritis however, physical activity and exercise remain an important part of overall treatment [30]. The literature provides evidence for a positive immune response for exercise in chronic diseases [31, 32] however, studies are required to specifically investigate exercise's effect on sleep and therefore, the most effective exercise prescription in terms of the Frequency, Intensity, Time and Type principle, the ideal approach to exercise delivery and indeed how compliance can be promoted.

Sleep is an important component of quality of life, in addition sleep disturbances affect quality of life in people with inflammatory arthritis [33]. With a large majority of our respondents reporting their sleep quality as fairly bad/very bad and a third having to take

medications to help with their sleep, this will have an adverse effect on their ability to be physically active. It is interesting to note that those having symptoms longer, taking medications regularly and having limitations with their activities, report poorer sleep quality. Poor sleep quality and disturbances may contribute to feelings of pain and mood disturbances, which may further deteriorate quality of life [2] therefore, our participants could be putting themselves into a situation where theirs is more adversely affected.

Participants from our study show that, although reporting low levels of physical activity, they are meeting the American College of Sports Medicines' guidelines on being physically active. However, what is most interesting is that those participants who were more active had the longest sleeping time, while those with the lowest activity levels had the shortest sleeping time. This further indicates more studies are required to specifically investigate physical activity levels and exercise's effect on sleep. Our data also support the results of a recent systematic review on exercise and sleep in rheumatoid arthritis (RA), in which the authors indicate there is some indication that exercise may have positive benefits on sleep in people who have RA however, further studies are required [34].

Advice and education is an important component in the management of inflammatory arthritis, with the engagement by health professionals being key in translating same. A 2011 found that 99% of Dutch physiotherapists provided advice on activity levels [35] and in a 2005 study 42% of people with arthritis had received advice from health care professionals [36]. Available research with regards to rheumatologists and clinical nurse specialists shows some interesting comparisons, with Iversen et al (1999) showing American rheumatologists' advice varied depending on their attitudes and beliefs [37]. Regarding the advice provided to patients on sleep and physical activity, there is no information available in the literature on whether health professionals engage their

inflammatory arthritis patients in discussing sleep. Our survey shows just only half of health professionals discuss how many hours sleep their patients get per night. Interestingly patients mentioned ‘pain’ and ‘waking up in the middle of the night or early morning’ as the top two sleep disturbances when their health professional engaged with them, which is similar to the self-report from their own survey. Due to the importance of receiving sufficient sleep and its’ effect on quality of life, there is a need to develop education and training for health professionals in the importance of enquiring from their patients sleep quality and disturbances and ultimately the potential impact it has on their physical activity levels.

Physical activity has been well established to be important in preventing disease however, despite its known benefits certain inflammatory arthritis patients are still physically inactive [38]. While a large majority of our respondents believe it is important to measure physical activity (75%), when using the Short Questionnaire to Assess Health Enhancing Physical Activity (SQUASH) , their average levels were a low 1,210 minutes per week, compared to other surveys from their healthy counterparts [35, 39]. Looking at those with less than this, nearly three-quarters reported their sleep quality as fairly bad/very bad however, nearly two-thirds reported receiving more than the reported 5.7 average hours sleep per night.

Regarding health professionals, it is interesting to note that there was a statistically significance with those reporting above average activity levels at 2,248 minutes per week and discussing sleep with their patients. Looking at the literature regarding physical activity and sleep in other populations, it has been noted that those who are more physically active achieve more and better sleep quality [40], [41]. It might be fair to conclude that health professionals are more cognisant of the importance in receiving a good nights’ sleep. As exercise prescription is a core skill for some health professionals

[42], it should be an important role in educating patients in the benefit of increasing their activity levels and its resultant effect on sleep.

Limitations

There are a number of limitations that need to be considered when interpreting the results of this survey.

Firstly, the study had a cross-sectional design therefore, conclusions on causal relationships cannot be drawn. This could have been helped by a follow up over time to allow for firmer conclusions about causality.

Secondly, the questionnaire was based on self-report through social networking, which may have attracted socially desired answers. This is an inherent limitation in most surveys and while it was ensured the data collection was anonymous, self-reports are never free from bias [43].

Thirdly, what constitutes an acceptable response rate for surveys has been debated [44]. The use of social networking to gather the responses from people with inflammatory arthritis could have biased the results and it is possible that the 65% (28/42) of health professionals who responded to the survey were different from those that did not, which may have resulted in selection bias.

Despite these limitations, this study is a novel contribution to the rehabilitation literature and provides insight into sleep and physical activity in people with inflammatory arthritis and their engagement with health professionals in rheumatology, from both public and private institutions.

CONCLUSIONS

As far as we are aware, this is the first study to jointly examine Sleep and Physical activity among people with inflammatory arthritis and the current practice of Health Professional's in their engagement with this population.

People with Inflammatory Arthritis fall far below the 'sleep needs spectrum' with those having symptoms longer, taking medications regularly and having limitations with their activities, reporting poorer sleep quality. In addition those participants who are more active have the longest sleeping time, while those with the lowest activity levels had the shortest sleeping time.

Only half of health professionals discuss sleep with their patients with fatigue as the main reason when enquiring. Those more physically active discuss sleep more with their patients. Therefore, there is a need to develop education and training for health professionals to deal with the lack of knowledge in the promotion of physical activity and its effect on sleep.

More research is needed with regards to investigating poor sleep quality and disturbances in order to promote health and well-being in people with Inflammatory Arthritis. In addition the effects of physical activity interventions on poor sleep needs to be examined to show if it is a positive non-pharmacological treatment approach for the management of poor sleep in patients with Inflammatory arthritis.

Conflict of Interest

All authors declare no conflicts of interest

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