Barriers to Treatment Seeking in Primary Insomnia in the United Kingdom: A Cross-Sectional Perspective

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Study Objectives: To examine the most commonly perceived barriers to treatment seeking among individuals in the United Kingdom diagnosed with primary insomnia. Although there are effective treatments, the rate of insomnia in the United Kingdom is 22%, which is substantially higher than in other parts of Europe and in the United States.

Design: Cross-sectional.

Setting: Treatment and research clinic at a university department of psychiatry.

Participants: Fifty-six women and 29 men who met Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-TR criteria for primary insomnia who had (n = 48) or had not (n = 37) sought treatment.

Interventions: N/A.

Measurements and Results: Endorsement of reasons for not seeking treatment on the Barriers to Treatment Questionnaire. The most commonly endorsed reasons for not seeking treatment were the perception of insomnia as benign, trivial, or a problem that one should be able to cope with alone. Other commonly endorsed barriers to treatment related to lack of awareness of treatment options and to perception of the available treatment options as ineffective and unattractive.

Conclusions: Given the chronicity and serious adverse consequences of insomnia, this study suggests that programs of public health awareness designed to reduce the perception of insomnia as trivial and to increase awareness of the effective treatments available may be important for reducing the prevalence of insomnia in the United Kingdom.

Keywords: Insomnia, treatment, public health

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INTRODUCTION

Despite the existence of effective treatments for insomnia (e.g., see Morin et al.4), the prevalence of severe insomnia is estimated at 22% in the United Kingdom.5 This rate is substantially higher than in other parts of Europe (estimated at 4%-9%; see Chevalier et al6 and Nutt and Wilson7) and than in the United States (estimated at 10%8). Although it is possible that this apparently higher rate may be due to differences in definitions and assessment procedures across studies, it is also possible that the difference can be attributed to "a very marked bias in the United Kingdom against the treatment of insomnia."8,9 The goal of the present study was to begin the process of filling a gap in knowledge; namely, what are the barriers to seeking treatment among individuals with insomnia in the United Kingdom that might contribute to the higher prevalence? Barriers to treating insomnia exist from the perspective of both the clinician and the patient. The present study focused on the patient’s perspective.

This study had 2 specific aims: to index the sources from which treatment had been sought and to determine the most common barriers to treatment seeking in individuals suffering from primary insomnia. On the basis of the previous research largely conducted in North American, it was hypothesized that the barriers would include (1) perception of insomnia as benign, trivial, or a problem one should be able to cope with alone;4 (2) lack of awareness of available treatment options;5 (3) perception of available treatment options as ineffective;6 (4) perception of available treatment options as unattractive;4 and (5) personal constraints on treatment seeking.7 Although not yet examined in the insomnia literature, (6) stigma surrounding psychological difficulties8 may well also be a barrier to treatment seeking. This study is novel because it is the first to investigate treatment-seeking behavior among patients with insomnia in the United Kingdom—an important public health issue given the high rates observed.

METHODS

Participants

Eighty-five people who met strict diagnostic criteria for primary insomnia were recruited from 1 of 2 sources. Thirty were treatment-seeking individuals who were assessed at an insomnia treatment clinic, and 55 were individuals who responded to advertisements inviting people to participate in sleep research. Because 18 of these 55 had sought treatment in the past, the Treatment Group comprised 48 individuals who had sought treatment and the No-Treatment Group comprised 37 participants who had never sought treatment.

During the period in which we recruited patients for this study from the insomnia clinic, 176 potential participants were screened over the telephone. Participants were excluded because they were outside the 18- to 65-year-old age range for this study (n = 24), insomnia was not the primary concern (n = 29), they had another psychological or medical difficulty that was primary (n = 14) or a suspected or confirmed sleep disorder was present (n = 7), English was not the primary language (n = 3), or the person was unable or unwilling to participate in the detailed psychological assessment (n = 69). After the exclusion of 146 respondents, 30 attended the clinic and completed the psychological assessment.
of which the current study was 1 part.

During the period in which we recruited patients for this study from advertising, 215 potential participants were screened over the telephone. Participants were excluded because they were outside the 18-to 65-year-old age range for this study (n = 12), did not meet full diagnostic criteria for insomnia (n = 57), had another psychological or medical difficulty that was primary (n = 11) or a suspected or confirmed sleep disorder was present (n = 1), English was not the primary language (n = 3), or the person was unable or unwilling to participate in the detailed psychological assessment (n = 76). After the exclusion of 160 respondents, 55 attended the clinic and completed the psychological assessment, of which the current study was 1 part.

**Materials**

**Insomnia Diagnostic Interview**

The Insomnia Diagnostic Interview is a clinician-administered structured interview that assesses for the presence of each of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-TR\(^6\) criteria for primary insomnia including that (a) the predominant complaint is a difficulty initiating or maintaining sleep or non-restorative sleep for at least 1 month (Cluster A); (b) the complaint causes distress or impairment (Cluster B); (c) the insomnia does not occur exclusively as a result of another sleep disorder (Cluster C); (d) the insomnia does not occur exclusively as a result of another mental disorder (Cluster D); and (e) the insomnia is not due to the effects of a substance or illness (Cluster E). In addition to endorsing each of the criteria, the participant must have experienced the problems on at least 3 nights per week for at least 1 month. In a sample of 55 individuals with insomnia, the Insomnia Diagnostic Interview showed high internal consistency (\(\alpha = .87\)), sensitivity (92%), and specificity (89%). The test-retest reliability of the Insomnia Diagnostic Interview has been evaluated on 62 individuals with a re-administration interval of 1 to 2 weeks. The results indicated strong test-retest reliability (\(r = .90\) and good diagnostic agreement for the presence (90%) and absence (92%) of insomnia.

**Barriers to Treatment Questionnaire**

Designed specifically for this study, this questionnaire is comprised of 3 sections: A, demographic information; B, treatment-seeking behavior (whether the respondent has ever sought treatment for their insomnia and, if so, from which of a list of sources they have sought it); and C, reasons for delays in seeking insomnia treatment. Section C is comprised of 26 statements. These were derived from 2 sources: a comprehensive review of the existing literature on barriers to treatment seeking and informal consultation with insomnia sufferers (n = 7). The statements could be categorized within the 6 conceptual categories that formed the basis of the hypotheses to be tested: (i) perception of insomnia as benign, trivial, or something one should be able to cope with alone (items 5, 8, 11, 16, 19, 24 in the Table), (ii) lack of awareness of the available treatment options (items 1, 3, 6, 7, 13), (iii) perception of the available treatment options as ineffective (items 4, 9, 12), (iv) perception of the available treatment options as unattractive (items 2, 20, 21), (v) personal constraints on seeking treatment (items 10, 14, 15, 22, 23, 25, 26), and (vi) stigma surrounding insomnia (items 17 and 18). The respondent was asked to rate whether they disagree strongly (score 1), disagree (score 2), don’t know (score 3), agree (score 4), or agree strongly (score 5) with each statement. Finally, participants were asked for other reasons for a delay in seeking treatment for insomnia and were given 2 lines to respond.

**PROCEDURE**

Prior to the commencement of the study, ethics approval was received. For each participant, after written informed consent was given, the Insomnia Diagnostic Interview was administered. The participants then completed the Barriers to Treatment Questionnaire. The interview was administered by a registered clinical psychologist or an experienced graduate student.

**RESULTS**

**Participant Characteristics**

The age of the respondents was 31.7 ± 13.9 years (mean ± SD) (range 18-61 years). Sixty five percent of participants were women, and 35% were men. The No-Treatment Group was significantly younger (24.1 ± 8.5 years) than the Treatment Group (37.8 ± 14.4 years)(\(t_{9} = 5.1, p < .001\)). The 2 groups did not differ on sex (No-Treatment Group = 16 men, 21 women; Treatment Group = 13 men, 34 women); \(\chi^2 (1) = 2.4, NS\). The Treatment Group had suffered from insomnia for significantly longer (13.1 ± 13.0 years) than the No-Treatment Group (5.7 ± 8.2 years)(\(t_{9} = 3.2, p < .01\)).

The sample assessed at the insomnia clinic (n = 30) was also significantly younger (44.63 ± 11.90 years) than the sample who responded to advertisements (n = 55) 24.76 ± 9.45 years) (\(t_{9} = 8.41, p < .001\)). These 2 groups did not differ on sex (insomnia clinic sample = 10 men, 30 women; advertisement sample = 19 men, 36 women) (\(\chi^2 (1) = 0.99, NS\). The insomnia clinic group had suffered from insomnia for significantly longer (18.86 ± 13.27 years) than the advertisement group (5.79 ± 7.55 years) (\(t_{9} = 5.66, p < .001\)).

**Sources of Insomnia Treatment**

Those who had sought treatment were most likely to have consulted their general practitioner (41.2%; n = 35) or their pharmacist (16.5%; n = 14). Other professionals who had been consulted were a counselor (10.6%), herbalist (8.2%), acupuncturist (8.2%), psychologist (7.1%), hypnotist (4.7%), psychiatrist (3.5%), or nurse (3.5%).

**Reasons for Not Seeking Treatment**

For Section B of the Barriers to Treatment Questionnaire, if participants circled either that they agreed strongly or agreed with a statement, they were scored as endorsing that statement. As evident in the Table, the 5 most commonly endorsed reasons for not seeking treatment were “I thought the difficulty with sleep was an expected response to a life situation,” “I thought it was something I should be strong enough to handle myself,” “I didn’t recognize the difficulty with sleep was an illness,” “I have developed my own treatments/ways of coping,” and “I thought the problem would get better by itself.” These 5 items all fall into the first of

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*Data were not available for 3 participants for duration of insomnia.*
The first aim was to index the sources from which treatment
had been sought. The most common sources of treatment were
the general practitioner (41.2%; n = 35) and pharmacist (16.5%; n
= 14). Few participants had sought treatment from a psychologist
(7.1%; n = 6). Given that patients prefer psychological treatment,
relative to pharmacologic treatment,4 that randomized controlled
trials have indicated the effects of psychological treatments to be
more durable—relative to pharmacologic treatment,1 and that
psychologists are the professionals most likely to have the skills
to deliver psychological treatments, it is surprising that so few
treatment seekers had consulted a psychologist. Because general
practitioners and pharmacists are the first point of consultation
for many patients with insomnia, and because the median time
formally allocated to medical student teaching in the United
Kingdom on sleep is as low as 5 minutes overall,10 these findings
suggest that a priority for the education of these professional
groups is to increase future training in sleep disorders.

Our second aim was to identify the most common barriers to
treatment seeking among patients. Of the 5 conceptual categories
investigated, the most commonly perceived barrier to treatment
was the perception that insomnia was benign, trivial, or a problem
one should be able to cope with alone. This pattern of findings
held whether the data were analyzed for the entire sample, just the Treatment Group, or just the No Treatment Group.

As evident in the bottom half of Table 1, the mean percentage
of endorsements for conceptual category i (perception of insomnia
as benign, trivial, or something one should be able to cope with
alone) was highest, followed by categories ii (lack of awareness
of the available treatment options), iii (perception of the available
treatment options as ineffective), iv (perception of the available
treatment options as unattractive), v (stigma surrounding insom-
ния), and vi (personal constraints on seeking treatment), respec-
tively. Participants did not volunteer any additional reasons that
could not be subsumed within 1 of these 6 categories. Individuals
endorsed a mean of 7.8 reasons for not seeking treatment.

DISCUSSION

The first aim was to index the sources from which treatment
options were sought for insomnia. Despite the high percentage
of respondents who are aware of insomnia treatment options
(91.9%, n = 79), endorsement of treatment options was low,
with a mean of 3.2 reasons endorsed. Endorsements were most
likely to occur for pharmacological treatments (mean 2.33)
and psychological treatments (mean 1.02), with a modest-
ly larger endorsement for over-the-counter treatments
(mean 0.78). Low endorsement of psychological treatment
options could be explained by the fact that many of the
participants were unaware of psychological treatment options
(a mean of 6.6 reasons endorsed). Low endorsement of
pharmacological treatments could be explained by the fact
that many participants were unaware of the availability of
pharmacological treatments. Low endorsement of over-the-
counter treatments could be explained by the fact that many
participants were unaware of the availability of over-the-
counter treatments.

Table 1—Individuals Who Endorsed Reasons for Not Seeking Treatment and Endorsements per Item in Each Conceptual Category

<table>
<thead>
<tr>
<th>Reason for Not Seeking Treatment</th>
<th>All participants (N = 85)</th>
<th>Treatment Group (n = 48)</th>
<th>No-treatment Group (n = 37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I spoke to my local GP about my sleep but he/she wasn’t able to help</td>
<td>17.3</td>
<td>29.2</td>
<td>2.9</td>
</tr>
<tr>
<td>I thought sleeping pills were the only treatment and I didn’t want to take medication</td>
<td>51.9</td>
<td>42.3</td>
<td>63.8</td>
</tr>
<tr>
<td>I thought that being a poor sleeper was something that couldn’t be changed, that it is just part of who I am</td>
<td>54.8</td>
<td>46.8</td>
<td>64.9</td>
</tr>
<tr>
<td>I tried treatment before but it didn’t work</td>
<td>25.3</td>
<td>40.9</td>
<td>5.7</td>
</tr>
<tr>
<td>I have developed my own treatments/ways of coping</td>
<td>62.7</td>
<td>54.4</td>
<td>73.0</td>
</tr>
<tr>
<td>My poor sleep is just a fact of life, I can’t change it</td>
<td>41.7</td>
<td>44.7</td>
<td>37.8</td>
</tr>
<tr>
<td>I have talked to my doctor about my sleep problem but he/she did not seem to think anything could be done about it</td>
<td>22.1</td>
<td>34.9</td>
<td>5.9</td>
</tr>
<tr>
<td>I thought the difficulty with sleep was an expected response to a life situation</td>
<td>68.7</td>
<td>63.0</td>
<td>75.6</td>
</tr>
<tr>
<td>I didn’t believe treatment would help</td>
<td>23.2</td>
<td>13.3</td>
<td>35.1</td>
</tr>
<tr>
<td>I couldn’t afford it financially</td>
<td>17.3</td>
<td>18.2</td>
<td>16.2</td>
</tr>
<tr>
<td>I didn’t recognize the difficulty with sleep was an illness</td>
<td>66.3</td>
<td>54.6</td>
<td>80.5</td>
</tr>
<tr>
<td>I didn’t think anyone could help</td>
<td>44.4</td>
<td>40.9</td>
<td>48.6</td>
</tr>
<tr>
<td>I didn’t know where to go for help</td>
<td>51.9</td>
<td>50.0</td>
<td>54.0</td>
</tr>
<tr>
<td>I didn’t have any way to get to treatment</td>
<td>16.1</td>
<td>15.9</td>
<td>16.2</td>
</tr>
<tr>
<td>I didn’t have time to go for treatment</td>
<td>35.4</td>
<td>31.1</td>
<td>40.5</td>
</tr>
<tr>
<td>I thought the problem would get better by itself</td>
<td>62.2</td>
<td>51.1</td>
<td>75.7</td>
</tr>
<tr>
<td>I was too embarrassed to discuss it with anyone</td>
<td>11.0</td>
<td>13.3</td>
<td>8.1</td>
</tr>
<tr>
<td>I was afraid of what my boss, friends, family, or others would think if I went for treatment</td>
<td>22.2</td>
<td>27.2</td>
<td>16.2</td>
</tr>
<tr>
<td>I thought it was something I should be strong enough to handle myself</td>
<td>67.5</td>
<td>58.7</td>
<td>78.4</td>
</tr>
<tr>
<td>I was afraid the treatment would be unpleasant</td>
<td>8.6</td>
<td>11.4</td>
<td>5.4</td>
</tr>
<tr>
<td>I hate answering personal questions</td>
<td>19.8</td>
<td>15.9</td>
<td>24.3</td>
</tr>
<tr>
<td>The times treatment was offered were inconvenient</td>
<td>5.2</td>
<td>9.6</td>
<td>0.0</td>
</tr>
<tr>
<td>A member of my family objected</td>
<td>1.3</td>
<td>0.0</td>
<td>2.8</td>
</tr>
<tr>
<td>My family thought I should go, but I didn’t think it was necessary</td>
<td>12.7</td>
<td>15.9</td>
<td>8.6</td>
</tr>
<tr>
<td>I can’t speak English very well</td>
<td>2.6</td>
<td>0.0</td>
<td>5.6</td>
</tr>
<tr>
<td>I couldn’t get childcare</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Conceptual Category

i. Perception of insomnia as benign, trivial, or something one should be able to cope with alone
   | 56.7 (48.2) | 49.6 (23.8) | 65.3 (24.2) |
ii. Lack of awareness of the available treatment options                                    | 37.6 (32.0) | 41.1 (19.7) | 33.1 (12.3) |
iii. Perception of the available treatment options as ineffective                           | 31.0 (26.4) | 31.7 (15.2) | 29.8 (11.0) |
iv. Perception of the available treatment options as unattractive                            | 26.8 (22.8) | 23.2 (11.1) | 31.2 (11.5) |
v. Personal constraints on seeking treatment                                                  | 11.1 (9.4)  | 10.7 (5.1)  | 11.6 (4.3)  |
vi. Stigma surrounding insomnia                                                               | 16.6 (14.1) | 20.3 (9.7)  | 12.2 (4.5)  |

The data for reasons for not seeking treatment are presented as percentages. The data in the conceptual categories are percentages (standard deviations).
was participants’ perception of insomnia as benign, trivial, or a problem one should be able to cope with alone. This finding is consistent with, and extends, previous research from the United States. Participants’ poor understanding of the treatment options and their perception of the treatment options as ineffective and unattractive also highlight the applicability of previous findings to the United Kingdom. A novel finding was that the participants in this study endorsed a mean of almost 8 reasons for not seeking treatment. This suggests that barriers to treatment are multifactorial. In addition, through investigating treatment barriers, this study provides us with clues as to motivators to seeking treatment. The fact that both the Treatment Group and the No-Treatment Group endorsed the same barriers to treatment, combined with the greater age and insomnia duration of the Treatment Group, suggests that a key motivator to seeking treatment may simply be having suffered from insomnia for a long time.

The conclusions we can draw are limited by the small sample; by the use of a new measure without preestablished psychometric properties; and, because the sample was relatively young and without comorbidity, there is also a concern about the representativeness of the sample and generalizability of the results. In particular, it will be important for future research to check whether these findings replicate in other insomnia samples, such as older adults and those with comorbid insomnia. With these limitations as caveats, the preliminary conclusions to be drawn from this study are that the perception of insomnia as benign, trivial, or a problem one should be able to cope with alone may be the most common barrier to treatment seeking among sufferers in the United Kingdom. Given the serious adverse consequences of insomnia, public health awareness campaigns designed to reduce these misperceptions and to provide information about the effective available treatments may be a crucial step toward reducing the prevalence of insomnia in the United Kingdom. Future research in this domain, across cultures and countries, is likely to be fruitful and should include psychometric validation of the Barriers to Treatment Questionnaire, as well as the inclusion of measures of possible moderators of treatment seeking, such as insomnia severity, self-medication with alcohol, over-the-counter medications, or herbal or dietary products.

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REFERENCES