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Narcolepsy and disruption to social functioning

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Title Page

Narcolepsy and disruption to social functioning

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Abstract

This study sought to create an in depth understanding of the impact of living with narcolepsy (a disorder of excessive daytime sleepiness) through qualitative research. The study used an essentially phenomenological methodology. Twenty- seven participants (18 females, 9 males, Mean age = 54.30, range = 26-90 years) were recruited from medical files in Canada and the narcolepsy support group in Australia. Data were collected via an open-ended narrative inviting the informant to focus on the impact of the disorder and analysed thematically. The issue of *social context* emerged as a key theme in understanding perceptions of the impact of living with narcolepsy. A secondary theme was that narcolepsy was experienced as an *invisible illness*. Thus the impact of living with narcolepsy is embedded in the need to maintain acceptable social functioning (within family, friendship and work relationships) and, related to this, cognitive functioning. This is complicated by the often indistinguishable nature of the symptoms from behaviors that people without narcolepsy experience. Health professionals need to understand that narcolepsy differs from other illnesses in that its key impact is a disruption to normal social functioning.

Narcolepsy is a chronic neurological sleep disorder which is non-life threatening, non-degenerative and non-curable and affects approximately 1:1500 people in Caucasian populations (Siegel, 2000). The condition can be understood as a disruption of the sleep control mechanism resulting in a dysregulation of Rapid Eye Movement (REM) sleep. Excessive daytime sleepiness and sleep attacks generally precede the onset of other symptoms such as cataplexy (temporary loss of muscle tone), hypnagogic hallucinations and sleep paralysis. It is not unusual for symptoms to unexpectedly intrude into normal wakefulness in narcoleptic patients.

The onset of narcoleptic symptoms usually occurs between 15 and 30 years of age, however, the symptoms may be present and undiagnosed during childhood (Passouant & Billiard, 1976). Identification of the condition is often complicated by the fact that sleepiness may be the only presenting symptom for many years. Diagnosis can be a long and drawn out process involving numerous medical and psychological assessments and, in some cases, mistaken diagnoses (Douglas, Hays, Pazderka & Russell 1991, Bruck

and Broughton 2003). Both medical and behavioural measures are typically used to ameliorate the symptoms of the disorder. Amphetamine-like stimulants are often used to treat the excessive daytime sleepiness, and tricyclic antidepressant compounds may be used to treat the symptoms of abnormal REM sleep such as cataplexy, sleep paralysis and hypnagogic hallucinations. In regard to behavioural therapy, lifestyle changes such as planned naps, strategies to maintain emotional well-being, avoiding over-stimulation and eating light meals during the day, reportedly all assist in abating the intrusion of symptoms into daytime activities and help in maintaining alertness (Bruck & Broughton, 2001).

The success of these intervention strategies is variable and research findings indicate that the clinical symptoms of narcolepsy have a profound negative effect on the quality of life of those diagnosed as narcoleptic, engulfing most aspects of daily functioning. It seems that narcoleptic patients experience a higher rate of work, home and driving accidents, greater unemployment, lower job satisfaction and performance and lower educational outcomes than their non-narcoleptic counterparts (Broughton, Ghaneem, Hishikawa, Sugita *et al.*, 1983). It is not uncommon for people living with the disorder to be labeled as lazy or irresponsible in work and school settings or seen as emotionally unstable (Alaia, 1992; Douglas 1998; Kales, Soldatos, Bixler, Caldwell *et al.*, 1982). Issues regarding interpersonal relationships and psychological well-being in narcoleptic patients are also well documented with problem areas including sexual dysfunction, depression, low levels of self esteem, anxiety, social and emotional withdrawal, poor psychosocial adjustment and irritability (Broughton, 1992; Bruck, 2001; Cohen, Ferrans, & Smith, 1992).

According to the literature, the relatively low community profile of narcolepsy and the stigma attached to the diagnosis and the treatment (stimulants) contribute to the complexity of the impact of living with the disorder, often resulting in negative attitudes toward narcoleptic patients (Broughton, 1992; Cohen & Mudro, 1992). Furthermore, unlike other comparable illnesses, the incessant nature of the symptoms means that the patient seldom experiences respite.

Whilst acknowledging the benefits of previous studies in creating a solid foundation for understanding the disorder,

research to date has almost exclusively focussed on assessing the assumed deficits and effects of the symptoms of narcolepsy according to researcher-directed standardized criteria within quantitative research designs. Studies pertaining to the psychological and psychosocial effects of living with narcolepsy, exclusively based on qualitative data collection and analysis, have been rarely undertaken.

The current study aimed to contribute to the literature associated with the experience of living with narcolepsy by adding a personal, qualitative perspective. Phenomenological methodologies provided the latitude to explore issues which may otherwise be difficult to elicit. As a means of conveying the personal experiences of the informants from their perspective, in their own words, extracts from the informants' narratives are presented throughout the report.

The research question being studied was the impact of living with narcolepsy as perceived by the person with the disorder.

Method

The underlying theoretical perspective used in the study was phenomenological (Patton, 1990). However, the study drew on other theoretical constructs such as a naturalistic theme of inquiry (Gubrium & Holstein, 1997) and an interpretive research approach (Hones, 1998). Perceptions of the impact of living with narcolepsy were studied in a non-manipulative and non-controlling method with no preconceived constraints on what the outcomes of the research should be.

Data collection and analysis used a thematic analysis approach to derive patterns in informants' perceptions of the impact of living with narcolepsy (Miles & Huberman, 1984). No preliminary hypotheses were offered and data was analyzed continuously to identify common themes.

Participants and sampling

The data for the study were collected in both Canada and Australia. The Canadian sample consisted of 19 informants with narcolepsy. Participants were originally selected from medical files of 123 patients diagnosed with narcolepsy at the Sleep Disorders Clinic, Ottawa General Hospital. Selection was sequential alphabetically and based on availability. The Canadian group comprised: 13 females, 6 males, *M* age = 54.3 years, range = 26-72 years. In Australia the interview participants were recruited from an Australian narcoleptic support group, Narcolepsy and Overwhelming Daytime Sleep Society (NODSS). Details of eight potential participants living in Melbourne who were registered as 'willing to participate in research' were provided by the executive of NODSS. The Australian interview sample comprised 5 females, 3 males, *M* age = 61.2 years, range = 35-90 years. The overall combined sample thus consisted of 18 females, 9 males, *M* age = 54.3 years, range 26-90 years. The interviews in Canada were conducted by the second author (Bruck), while those in Australia were conducted by the first author (Culbertson). The Canadian interviews were

more lengthy than those in Australia and also contained open-ended questions about how the informants achieved control over sleepiness. This material has been published elsewhere (Bruck & Broughton, 2001).

Demographic details have been summarized into Table 1 to provide a broad outline of the distribution of some of the relevant characteristics of the sample. In categories such as age, marital status and years since diagnosis the distribution presents as generally skewed, reflecting an older sample. Sixty-eight percent of participants were aged > 50 years, 59% were married at time of the research and 48% had been diagnosed with narcolepsy for > 20 years. All participants were asked two questions which were quantified: (1) What do they perceive as their worst symptom?; and, (2) How would they rate the perceived impact of narcolepsy on the overall quality of their life? Results are shown in Table 1, showing a relatively even distribution across the symptoms of excessive daytime sleepiness, cataplexy and "other" symptoms and a mix of ratings of impact from "hardly at all" to "extremely".

Table 1: Characteristics of participants (*n*=27)

<i>Demography</i>	<i>No.</i>
Age (1 unknown)	
20-30	2
31-40	3
41-50	4
51- 70	14
70+	3
Martial status	
Married	16
Divorced	3
Widowed	3
Single/ never married	5
Years since symptoms diagnosed	
0-5	3
6-10	5
10-20	6
20+	13
Perceived worse symptom	
Excessive sleepiness	10
Cataplexy	8
Hypnagogic hallucination	1
Sleep paralysis	2
Other (concentration, depression, memory)	6
Perceived impact on overall quality of life	
Hardly at all	6
A little	7
Moderately	4
Quite a bit	4
Extremely	6

Procedure

Initial telephone contact was made to all the potential participants. Once verbal consent was obtained, a cover letter and a plain language statement were mailed to each of the participants, explaining the purpose and methodology of the study. All interviews in Canada occurred in a quiet room on University premises, while those in Australia took place in the homes of the informants. All the interviews were tape-recorded and transcribed by the interviewer word for word within 48 hours of conducting each interview.

Using the theme of perceptions of living with narcolepsy as a basis for investigation, the interview was designed to encourage participants to reflect on living with the disorder in terms of perceived impact. In order to explore issues within the identified theme, open-ended questions were put and the informant was encouraged to “tell their story” in terms of the impact of the disorder on their life. As several themes began to consistently merge during data collection, a few more probing questions about “impact” were incorporated into subsequent interviews to ensure that all relevant information was collected.

The duration of the interviews ranged from 1 to 3 hours depending on the informant’s desire to continue. As data analysis progressed, four follow-up telephone interviews were made to clarify or expand upon some equivocal or incomplete data.

Talking at length and in-depth about the effects of narcolepsy on their lives often evoked an emotional response from the informants, and at times reopened painful memories. Therefore, at the termination of each interview, the informant was given time to debrief and was reminded of the offer in the plain language statement to follow up any disturbing issues with the researchers or other professionals. (No such follow up was required.)

This study was approved by the Victoria University Human Ethics Committee and the Ottawa Hospital Ethics Committee.

Data analysis

Manual line by line microanalysis of the interview data was conducted. Key words and preliminary common themes and groupings were written next to each point in each transcript and these were then grouped according to emergent key themes. To facilitate this process, the data were organized into a checklist matrix to provide a visual display (Miles & Huberman, 1984).

Trustworthiness

A variety of strategies were employed to enhance the validity of the study. Firstly, audio-tapes of the interviews provided a concrete reference to the original source to verify any potential discrepancies. Interviews were transcribed word for word immediately after each interview by the interviewer. Moreover, some triangulation of data sources and triangulation of multiple analysts (Patton, 1990) occurred to strengthen findings. For example, data were

obtained from two different sources with different researchers conducting the interviews in each location and emerging themes were followed up during the interview process to check the consistency of responses. Interpretations were discussed among the researchers to gain a different perspective and to examine rival explanations. Narratives and detailed descriptions of perceptions of living with narcolepsy were included in the report to maximize accuracy and to minimize the possibility of distortion resulting from researcher bias in the data. Sample limitations were considered to shed additional light on the validity of emerging themes and helped qualify the degree to which general themes could be established.

Results and Discussion

Analysis of informant’s responses reflected an apparent struggle in identifying impressions of the ‘impact’ of narcolepsy *per se*. The perceived impact of living with narcolepsy generally manifested itself within a social framework enmeshed in experiences of social interactions. The issue of **social context** therefore emerged as a key theme in understanding perceptions of the impact of living with narcolepsy. More in-depth thematic analysis of the data collected identified that the theme of social context embodied a secondary theme that narcolepsy is experienced as an **invisible illness**. Findings indicate that the invisibility of narcolepsy in terms of public understanding and acceptance of the symptoms contribute to problematic personal well-being and functioning.

The following sections relate to each theme in turn. To help convey the essence of the perceptions of the impact of living with narcolepsy, and to reflect as closely as possible the informants’ own world, direct quotes and narratives of experience are incorporated in the interpretations of data.

Social Context

...the hardest part is fitting in with the rest of the world...

Findings from this project suggest that perceptions of the impact of living with narcolepsy vary according to personal constructions of the symptoms within a social context, rather than the effects of symptoms themselves. Factors such as perceptions of the strength of relationships, how the informants and their loved ones coped emotionally and psychologically with the clinical symptoms and the importance placed on maintaining control in front of others all contributed to determining the impact of living with the disorder.

This desire for controlling the symptoms of narcolepsy in public emerged as an important issue. Informants were often reluctant to let their guard down, and tended to avoid situations that may place them in a vulnerable position. Strategies such as eating a light meal, and taking a nap before going out and controlling laughter and emotions in public were employed to alleviate potential embarrassment

(see also Bruck & Broughton, 2001). Many participants had experienced negative consequences of the symptoms being played out in public in the past, and were cautious of repeat situations.

...if you want to survive you don't tell people any more than they need to know... sometimes it causes problems... I do hide a great deal.

Not surprisingly, within their social context interpersonal relationships were absolutely critical and are discussed here in sections dealing with family, friends and work colleagues. In addition, the importance of optimizing cognitive functioning was also highlighted.

Interpersonal relationships

Many of the informants described the impact of living with narcolepsy within a family context. Consistent with previous research (e.g., Bruck, 2001), there was a recognition that the symptoms of narcolepsy contributed to family problems. Lack of empathy, social support and understanding of the implications of narcolepsy from other family members often emerged. For example, one man noted that his wife,

... never accepted that it was there, and she never realized what the issues are, she was never aware of the sort of struggle I was having...

Another informant said of her husband, (with reference to cataplexy):

...31 years and he still hasn't got it straight, he will walk in and give me a surprise and walk off and I'm standing there grabbing hold of something and he has walked off. He never even thinks to look.

Despite acknowledgment of the problems concerning the impact of narcolepsy on family relationships, outcomes were not always seen as negative. Often practical solutions were sought and difficulties were overcome.

It probably forced me to talk to them more. They've understood it. We've talked about a lot of things that we may not have if I hadn't have had it. I've been forced to talk to them.

Non-intimate or friendship-based relationships frequently emerged as very relevant in perceptions of the impact of narcolepsy. Friends were often viewed as mainstays in the informants' lives providing an independent sounding board and at times keeping the informant grounded in reality.

I have a good friend... one person that really understands.

According to one informant:

With friends it doesn't bother me any more (falling asleep) we might even laugh about it. In a situation with strangers around I am so on edge that I will fall asleep . I get really nervous that I will go to sleep, really nervous... I am so afraid to fall asleep.

Similar to findings of social isolation reported by others (e.g., Ferrans, Cohen, & Smith 1992), informants generally felt that when faced with the possibility of falling asleep in public the option of staying home in a safe comfortable environment was often far more appealing. They spoke of declining invitations because of bad experiences in the past and uncertainty about how they were going to be. Dinner invitations were the most dreaded within the sample group. The following sentiments expressed by the one informant, encapsulate the feelings of many:

It's very, very difficult. People invite me out for meals occasionally... It's just awful... They always get a nice warm room ready, they always get you a big meal... and it's just so conducive to go to sleep. Its so embarrassing... and that dreadful feeling of trying to stay awake, 'Oh I mustn't go to sleep, I must try and stay awake, I must listen to what they're saying, I must talk to them and be sociable; and all the time I'm dropping off. It's just awful.

Current findings supported earlier research regarding interpersonal problems at work. Bosses and colleagues would misinterpret sleepiness as laziness and boredom, and taking medication at work sometimes caused concerns. Many of the informants felt that the situation was made worse by a lack of understanding of the disorder. Issues of discrimination, intolerance of the symptoms and negative attitudes of co-workers, as reviewed by Douglas (1998), were also apparent in the experiences of the informants.

...certainly I would never have been employed if I told them that I had narcolepsy. I had made up my mind that I was going to be very open about this. I realized pretty rapidly that wasn't going to be very sensible.

Strategies such as taking work home, sleeping in the toilets and disguising naps were employed to overcome some workplace problems. Most of the informants felt that although issues of concentration and sleepiness limited their capacity to function efficiently, they could be improved in a more flexible work environment.

I wouldn't have been able to work if I hadn't worked with people I knew pretty well, who were prepared to compensate for me napping. There were other ways I could compensate with things for them... it has never been an uneven relationship.

Despite the difficulties experienced, many of the informants worked or had worked in paid or voluntary positions. Work was sometimes highlighted as critical in normalizing life and maintaining contact with the greater world.

I think it would be harder for me to maintain a sense of well-being if I wasn't working... working, I feel, is my one contact with normal.

Cognitive symptoms

Concentration and short term memory problems are often regarded as secondary to the primary symptoms of narcolepsy. However, this study found, as has been documented quantitatively (Hood & Bruck, 1997; 2002), that for many narcoleptics satisfactory cognitive functioning can be difficult and is a major concern.

I wouldn't want my mind to stop, that's very important to me. More important than the physical thing, I really want to be mentally acute.

In conjunction with the desire to be 'mentally acute', the informants' responses suggested that concentration is a critical component with respect to adequate social functioning. Many of the informants grounded their issues about poor concentration and difficulties in short-term memory in terms of conversations with others. The following extract illustrates some of the frustrations of concentration and memory impairments faced by the informants:

You get half way through a sentence and you can't think of the word, then you remember the word but you realize that you've forgotten what the sentence was.

An invisible illness

...(it's) frustrating that you don't see it. I know that people don't believe me. I would expect them not to believe; it's too bizarre.

Social context dominated informants' interpretations of the extent to which narcolepsy impacted on their lives. However, a secondary theme, at times enmeshed in the social, emerged as relevant to well-being and functioning. This was the notion that perceptions of the impact were

often rooted in the social and individual obscurity of the disorder.

I know there are other illnesses that are so much more grave and life threatening than mine, but in many of these, the public knowledge is so much better; understanding and acceptance are there...

The similarity of some of the symptoms of narcolepsy to normal things others have caused some dilemmas. Issues such as reactions of others to the symptoms, the role of information and support groups and implications of being able to positively identify the disorder, surfaced as determinants in the life impact of the symptoms of narcolepsy. This is similar to issues of questionable legitimacy identified in chronic fatigue syndrome (Harley, 2001).

Other people's perceptions

Consistent with earlier findings (Goswami, 1998), the current study identified other people's perceptions of the disorder as influential in personal constructions of the impact of narcolepsy. Many of the informants felt that the degree to which the symptoms of narcolepsy limited their lives was often underestimated by others. According to one informant:

A few times in the summer I put the lawn mower in the car, drove to a friend's and mowed their lawn and then came back. Major accomplishment for me. No one else thinks it is, but it is really major for me.

The inability of others to comprehend the extent to which the symptoms were debilitating was commonly discussed by the informants. This was compounded by the frustration of others dismissing the symptoms of narcolepsy as more or less common to all people. The ensuing comment reflects a universal theme amongst the sample group.

You get half way through a sentence and you don't know how you're going to end it. People don't want you to feel bad and they tend to go, 'Oh I'm like that too'. But they're not like it to the extent that we are.

Feelings of despondency and bitterness toward others were also echoed in the dialogues of some of the respondents. The perceptions and reactions of others clearly contributed to overall feelings of emotional wellness.

...It's a bit useless trying to explain because they don't hear you or want to hear you, they think you're making a fuss about nothing actually.

Ambiguity of attribution

A number of informants noted that they had trouble knowing whether their behaviour arose from narcolepsy or were a part of their own character or personality.

I guess that it's been a part of me for so long, I don't know if it is me or if it is the narcolepsy.

Such ambiguity of attribution was sometimes seen as potentially problematic as it could increase their guilt about their 'lazy behaviours'.

Information/support groups

Interest in support groups was mixed. Some informants viewed a support group as a means of social support, to meet with others with similar issues. In several cases the relief of meeting another person with narcolepsy after enduring many years of feeling isolated and lonely was overwhelming.

...I was the first narcoleptic that she'd spoken to and she was the first one I'd spoken to, I spent 2/3 of a day with her and I didn't want to leave.

The importance of meeting others experiencing similar symptoms was commonly conveyed as normalizing the disorder as informants had typically endured a long process of diagnosis, and as the symptoms are ambiguous in nature. Two informants describe how they perceived support groups:

Very wonderful to know I am normal for what I am and so is the other person.

And,

Everyone needs to know it could be worse, stops the woe is me feeling.

For others, support groups were seen as a combination of anecdotal information, such as advice on 'how to cope with the symptoms' and a shoulder to cry on:

I would like to have a support system, somewhere I could go and talk and cry about it if I want to. This is a crappy life, I can't work, our social life has disappeared, I'm black and blue from falling.

Others saw support groups as a resource for information. Many people found the literature a source of comfort and saw no benefit in meeting others with narcolepsy. It was not unusual for people holding this view to actively avoid such contact and deem it as depressing. The dichotomy of expectations of the role of support groups caused tension for some within the self-help group.

We originally achieved great success, but as with any self-help group, once the 'sufferers' have their questions and qualms satisfied you usually never hear from them again.

Comparisons to other illnesses

Despite identifying a diversity of issues concerning the negative effects of living with narcolepsy, informants generally conveyed a surprisingly positive attitude toward their disorder when making comparisons with other illnesses. The physical debilitating and life threatening aspects of other disorders were largely viewed as much more restricting than the symptoms of narcolepsy. It was generally accepted amongst the group that other illnesses were potentially much more severe, and that 'there are a lot of worse things out there'.

I think I'm very lucky, if the worse thing that's going to happen to me is I'm just going to fall asleep, it's not too bad after all is it?

The implications of a label

The benefits of having a name, or a label, for the combination of narcolepsy symptoms was viewed in different ways by different informants. For some of the participants having a label provided a framework to live and work within; it validated behavior and feelings.

It was having a name, parameters and boundaries. Something had almost legitimized all that laziness, not working... not only was it justifying things to other people but even to yourself.

For other informants, however, labeling the disorder was perceived as having unwelcome stereotypes projected upon them. Thus the notion of being labeled was conceived as interfering with one's privacy and positive self identity, and as contributing to negative perceptions of the disorder. This view is consistent with the findings that control in front of others, and other people's perceptions, emerged as factors determining the impact of living with narcolepsy.

It makes it more of a fact, that others treat it that way, it just reinforces the fact that it's not the way everybody is. You try to keep yourself even with everyone else, although in my mind I knew I wasn't but you try to keep up. Its kind of personal too, its my business.

Further considerations

As the sample was skewed toward narcoleptic people aged over 50 years (68%), with confirmation of diagnosis for more than 20 years (48%), the findings presented here may not be generalisable to younger people with narcolepsy.

Interestingly, in spite of the dominance of social context as a key theme in the assessment of the impact of narcolepsy, the two youngest informants (both younger than 30 years old) emphasized different aspects when asked about the impact of the disorder. Rather than being entrenched in the social implications, the impact of narcolepsy was viewed as an annoying (and possibly even temporary) aberration. In both these cases, the individuals perceived narcolepsy as remote from themselves, something to be overcome and managed successfully. One comment was:

I want to have a life, I want to have respect and do something for myself. I'm sick, OK I understand that, but this is not a disease I can't manage. I could have a very well oriented career with this disease and be able to be successful...

It is hypothesized that the disorder does also have a major effect on their social functioning, but that in such younger people this is considered to be secondary to the anxiety they have over the potential impact of narcolepsy on their career goals and overall life prospects. Evidence from previous research (using the Canadian participants in this sample, see Bruck & Broughton, 2001) indicates that the passage of time since diagnosis is a significant factor in coming to terms with the limitations imposed by the disorder and understandably, determining how best to achieve some control over symptoms. It is known that younger narcoleptics report more work adjustment problems than older people with the disorder (Bruck, 2001), and that the reported impact of some symptoms of narcolepsy reduces with time (Bruck & Costa, 2004). Further research should focus more sharply on this younger group to qualitatively document the key difficulties that the disorder presents to them.

The interviews suggested that there was a great deal of variability across the informants in "how bad" the disorder was to live with, and this is supported by the spread of evaluations of narcolepsy's impact on the quality of life, shown in Table 1. What the key variables were in determining how a person rated the overall impact of narcolepsy (e.g., symptom severity, personality, emotional resilience, social support, age) is a complex question but one worthy of further research.

Conclusion and Implications

The current study highlights several key issues in a new way. The use of an open-ended interview style permitted the informants latitude to explore issues of their choice within the life impact framework, and an opportunity to convey these within a lived context. As a consequence of this process, an emphasis on describing the impact of living with narcolepsy within a social context emerged. Although some of the life effects identified in this study are documented elsewhere, variables measured quantitatively are often

viewed independently of context and differences in the importance of different variables may not be clear.

The key theme of social context implies that the direct impact of the symptoms is a consequence of how the disorder is perceived or constructed within the patient's own world. Thus the impact of living with narcolepsy is often embedded in maintaining acceptable social functioning (within family, friendship and work relationships), and this is further complicated by the invisible nature of some of the symptoms.

The findings carry significant practical implications for health professionals. A key point is that narcolepsy differs from many other illnesses in terms of its disruption to normal social functioning. In order to understand some of the stresses facing people with narcolepsy, it is important to look at the disorder's impact on social interactions within the process of counselling.

Due to the under-representation of young and/or recently diagnosed participants in the current study, it is suggested that a project employing a similar qualitative approach, but with a focus on a younger sample, be conducted to gain a greater understanding of the impact of the disorder for people still coming to terms with narcolepsy and making the necessary lifestyle adjustments.

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