

Sleepless nights, sleepless days: The invisible journey of narcolepsy and its impact on the family

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INTRODUCTION

Narcolepsy is this entity that is driving us in a car and we have no idea where we're going. It's in complete control and you're never going to like this driver. But every now and then it might take you somewhere kind of even funny and interesting." This quote is taken from an interview with a parent who has a child diagnosed with narcolepsy. This statement poignantly captures the reality that while families experience pain from having very little sense of control of this incurable condition, they also discover new ways of being resilient that they otherwise would not have known. A common source of pain for families affected by narcolepsy are the misperceptions about the condition. People often assume narcolepsy is a sleep disorder that causes spontaneous sleep at any given time. However, with the proliferation of the narcolepsy diagnosis following the H1N1 epidemic in 2010, an increase in medical and clinical research has provided more insight into the condition as an autoimmune disease. This poster presents the most pronounced themes in the qualitative results of a mixed method study examining the impact of narcolepsy on the family.

METHODS

This project utilized a mixed methods approach to explore the psychosocial impacts of narcolepsy on relationships, particular within the family and in regards to the family's engagement in social support. Participants were recruited from Wake Up Narcolepsy, a non-profit organization that raises awareness, advocates for research, and provides support for families coping with narcolepsy. Participants were adults (18+) who have a diagnosis of narcolepsy or are an immediate family member of a person diagnosed with narcolepsy. Data was collected across two phases, 1) survey (n = 26) and 2) semi-structured interviews (n = 5). Survey participants indicated dissatisfaction in the couple relationship, as well as challenges in affective involvement, affective responsiveness, and problem solving in regards to family functioning. These results guided the semi-structured interviews exploring how family members describe the impacts of narcolepsy on family relationships, particularly in regards to the parent-child relationship and the intimate partner relationship.

WHERE DO WE GO FROM HERE?

Clinical Implications

Participants overwhelmingly reported the importance of advocating for themselves and the power of medical and mental health professionals that listened to their lived experience of illness. Practitioners who maintained a biopsychosocial approach and expressed curiosity were described as the most effective.

Research Recommendations

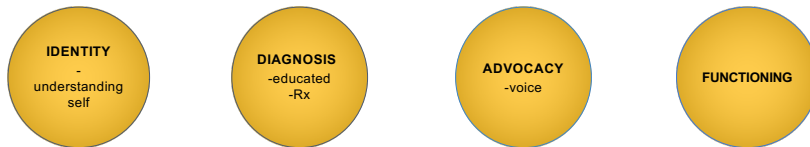
Researchers experienced recruitment challenges and low participation rates due to the demanding schedules, medication regimens, unpredictable side effects, and lack of support that families coping with narcolepsy face each day. Future research should focus on service delivery, aiming to provide and evaluate resources for families.

ACKNOWLEDGEMENTS

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THEMES AND PARTICIPANT QUOTES

AGENCY



RESILIENCY
meaning-making

LOSSES

COMMUNION



"we just try to not give narcolepsy as much power, I guess" never- you don't ever get a respite from it."

"though he doesn't totally remember what he was like before narcolepsy, he knows what he's like now"

"learning the symptoms of narcolepsy, um and learning about the hallucinations and sleep paralysis and, cataplexy and, you know, things like that... helped me to figure out what my body was doing, what was going on with me."

"It's always there. It

"When we talk about narcolepsy as a family it's usually, um, I don't know just kinda in the day-to-day stuff, you know. Um, if we're talking about medication or we're talking about school or we're talking about friends or you know it seems to come up quite a bit."