BSc in Psychology

Department of Psychology

Quality of life and mental health of people with narcolepsy in Iceland

Foreword

Submitted in partial fulfillment of the requirements of the BSc Psychology degree, Reykjavík University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.

This thesis was completed in the Fall of 2021 and may therefore have been significantly impacted by the COVID-19 pandemic. The thesis and its findings should be viewed in light of that.

Abstract

Narcolepsy is a chronic neurological sleep disorder, most commonly characterized by excessive daytime sleepiness (EDS) and cataplexy. The symptoms of narcolepsy can be very disabling and can cause genuine disruptions in daily activities. Research has reported that individuals with narcolepsy suffer from increased symptoms of anxiety and depression as well as lower quality of life. The aim of this study was to explore the quality of life and mental health of individuals with narcolepsy in Iceland. DASS was used to measure symptoms of depression, anxiety and stress, the QoLS to assess perceived quality of life and the ESS to measure sleepiness. All participants answered an online questionnaire. Participants consisted of 79 individuals in total, of which 22 (28.6%) were diagnosed with narcolepsy and 54 (70.1%) were not. Women were in majority (73.3%) and the most frequent age range was 18 – 29 (41.3%). Results showed significant difference between groups. Total scores from Epworth sleepiness scale amongst narcoleptics and quality of life, depression, anxiety, and stress had no significant difference.

Keywords: Narcolepsy, quality of life, anxiety, depression, treatment.

Útdráttur

Drómasýki er ólæknandi taugasjúkdómur sem einkennist mest af yfirþyrmandi dagsyfju og slekjuköstum. Einkenni drómasýki geta verið afar hamlandi og valdið verulegum truflunum á daglegum athöfnum. Erlendar rannsóknir hafa sýnt fram á að einstaklingar með drómasýki séu í áhættuhópi fyrir að finna fyrir einkennum kvíða og þunglyndis og upplifa einnig minni lífsgæði. Markmið þessarar rannsóknar var að kanna lífsgæði og andlega heilsu einstaklinga með drómasýki á Íslandi. DASS var notaður til þess að mæla einkenni þunglyndis, kvíða og streitu, QoLS var notaður til þess að meta lífsgæði og ESS til að meta syfju. Allir þátttakendur svöruðu vefkönnun. Þátttakendur voru 76 talsins, þar af 22 (28,6%) með drómasýki en 54 (70,1%) ekki með drómasýki. Konur voru í meirihluta (73,3%) og algengasta aldurbilið var 18 – 29 (41,3%). Niðurstöður sýndu marktækan mun á milli hópa. Engin marktæk fylgni fannst á heildarstigum Epworth sleepiness skalanum meðal drómasýkis sjúklinga og lífsgæðum, þunglyndi, kvíða og stressi.

Lykilorð: Drómasýki, lífsgæði, kvíði, þunglyndi, meðferðir.

Quality of life and mental health of people with narcolepsy in Iceland

Narcolepsy is a chronic neurological sleep disorder characterized by two predominant symptoms, excessive daytime sleepiness (EDS) and cataplexy (Daniels et al., 2001). EDS is defined as the inability to stay awake and alert during the day and is usually the most disabling symptom of narcolepsy (Zhang & Han, 2017). Cataplexy is described as sudden episodes of partial or complete paralysis of the voluntary muscles, usually triggered by strong emotions such as laughter (Wada et al., 2019). Other symptoms of narcolepsy are sleep paralysis, hypnagogic hallucinations, sleep attacks and insufficient night sleep (Raggi et al., 2019). Sleep paralysis is described as a temporary generalized inability to move or speak during the transition between wakefulness and sleep (Mamelak, 2009). Hypnagogic hallucinations are abnormal sensory perceptions that occur during the transition between wakefulness and sleep and can be, just like sleep paralysis, a very unpleasant experience (D'Agostino & Limosani, 2016). Sleep attacks are irresistible, often brief, episodes of sleep where individual may suddenly fall asleep in any circumstances (Murray & Foley, 1974). Insufficient night sleep is associated with fragmented and disturbed sleep. Patients often report poor quality of sleep and have more body movements and awakenings during their sleep (Antelmi et al., 2020; Dauvilliers et al., 2017).

The cause of narcolepsy is not completely known, but it is associated with the loss of hypocretin producing neurons in the lateral hypothalamus, that is considered the cause of an auto-immune response (Schinkelshoek et al., 2020). Hypocretin has been proved to play a major role in controlling the interplay between REM sleep and wakefulness (Majid & Hirshkowitz, 2010). According to Kim et al. (2021), narcolepsy can also be due to head trauma, tumors and even stroke. Narcolepsy is rare, said to affect roughly 0,025% to 0,05% of the general population (Plazzi et al., 2018) or 1 out of 2,000 people worldwide (Bhattarai & Sumerall, 2017). The prevalence of narcolepsy is very similar among men and women,

with prevalence rates consistent across the globe. Typical onset is during teenage years or young adulthood (Flores et al., 2016).

The results from a research study on the impact of narcolepsy on health-related quality of life (HRQoL) (Tadrous et al., 2021) revealed that people with narcolepsy experience considerably lower health-related quality of life when compared with the general population. The most noticeably affected domains of the HRQoL were physical role limitations, social functioning, and emotional role limitations. A cross-sectional study on Chinese narcoleptics and health-related quality of life showed similar results (Li et al., 2021). The severity of narcolepsy symptoms could disrupt daily activities and self-care, as well as increase pain, discomfort, anxiety and depression. Narcolepsy has a substantial impact on patients and their families in various ways (Dodel et al., 2007). It may interfere with education and career and other social functions. Narcolepsy has been associated with negative effect on work performance and productivity as well as increased unemployment and early retirement (Flores et al., 2016). Another research connected narcolepsy, poor quality of life and increased risk of developing depression (Daniels et al., 2001). Ultimately does narcolepsy affect all different domains and dimensions of HRQoL to different degrees. (David et al., 2012; Flores et al., 2016; Ong et al., 2021).

Depression is very common and serious psychiatric disorder in narcolepsy patients (Alasim et al., 2020; Maski et al., 2017) and have numerous studies presented relationship between disturbed sleep and depression (Mamelak, 2009). Depression is defined as a type of mental disorder that inflict serious hardship and strain on individuals and families. Depression has been reported to be linked to approximately 50% of suicides (He et al., 2021). The results of numerous studies have suggested higher prevalence of depression or symptoms of depression among narcoleptic patients compared to the general population (Li et al., 2021; Reynolds et al., 1983). Past studies using self-reported questionnaires, for example the Beck

Depression Inventory (BD), have reported that 45.1-56.9% of patients with narcolepsy experience depression (Daniels et al., 2001; Dauvilliers et al., 2009; Lee et al., 2017). A research study on the prevalence and relationship between anxiety, mood disorders and narcolepsy showed that anxiety, more than depression, was significantly more rampant in patients with narcolepsy (Fortuyn et al., 2010). Many narcolepsy patients reported high levels of anxiety that impair their daily function and activities.

In line with previous studies, Feketeova et al. (2020) found that patients with narcolepsy, compared with controls, showed double excess prevalence in mental disorders, especially anxiety and depression. The high rate of mental diseases as a comorbidity is a continuous finding in patients with narcolepsy.

Despite appropriate treatment, narcolepsy has an immense psychosocial impact and negatively effects quality of life (Alasim et al., 2020). Research study on the association between narcolepsy treatment and depressive symptoms and suicidal thoughts in narcoleptic adults revealed striking but not surprising results (Barateau et al., 2020). Untreated narcolepsy patients were more depressed and experienced more frequent suicidal thoughts than treated patients. According to Figorilli et al., (2021) does treatment positively impact the patients quality of life, lowering depressive symptoms and overall relieving the burden of the disease.

In reference to previous research, having narcolepsy seems to be associated with lower quality of life, as well as increased possibility of other mental health issues such as anxiety and depression. The aim is to study quality of life and mental health of people with narcolepsy in Iceland compared to the general population. Research among Icelandic narcolepsy patients is seriously lacking, as this is the first of its kind.

This study was designed to assess three hypotheses. First, it was hypothesized that people with narcolepsy have less quality of life than the general population. Second hypothesis was

that people with narcolepsy have more symptoms of depression, anxiety and stress compared to the general population. Lastly, the third hypothesis assumes that narcoleptics who experience more excessive daytime sleepiness have worse quality of life and experience more symptoms of depression, anxiety, and stress.

Method

Participants

Participants were enlisted by random sample from Facebook, with a direct link to the questionnaire online. A total of 76 individuals participated, of which were 55 (73.3%) female and 20 (26.7%) were male. One participant did not give up their gender. All participants were 18 years or older, and the age span was from 18 years of age and up to 60 years old or older, with the most common age group being 18 – 29 (41.3%). The most common educational level was bachelor's degree (34.2%), and the most common employment status being employed (46%). Of all the participants in the study, 22 (28.6%) were diagnosed with narcolepsy and of these individuals were 21 (95.4%) that are currently taking medications for their symptoms. The inclusion criteria were to be 18 years or older, but participants were not required to have narcolepsy, as the aim of the study was to compare people with narcolepsy with the general population.

Measures

All participants were administered the same survey with all the questions in the same order. The participants had unlimited time to answer the questions. The first part of the survey consisted of demographics, with six questions about their gender, age, highest degree of education, employment, if the individual had been diagnosed with narcolepsy and if the individual took any medication for the symptoms of narcolepsy.

The second part of the survey was seeking answers about symptoms of stress, anxiety, depression, quality of life and sleepiness. Three different self-reported measurement scales were applied.

Depression, anxiety, and stress. To measure symptoms of depression, anxiety and stress, the self-reporting Depression Anxiety Stress Scales (e. DASS) was used. The scale consists of 42 questions divided into three subscales that each consist of seven affirmations where individuals match how much each affirmation apply to themselves when looking back at their feelings and behavior the last week. For example, not being able to feel any positive feeling at all, getting upset rather easily or not feeling worthy as a person. The total score for the depression subscale can range from 0 – 42, were the score of 28 or more can be interpreted as extremely severe. The total score for the anxiety subscale can range from 0 – 42, with 20 or more being interpreted as extremely severe. The stress subscale has total scores ranging from 0 – 42 and scoring 34 and more can be interpreted as extremely severe. According to Basha & Kaya, (2016) the scale has a good reliability and high consistency. In addition, the scale has shown good reliability in Icelandic version (Björgvin Ingimarsson, 2010), that was translated by Pétur Tyrfingsson in 2005. The inner reliability was for each subscale was high, with Cronbach's α =.96 for depression, α = .91 for anxiety and α = .93 for stress.

Quality of Life. To measure quality of life among the participants of the study, The Quality-of-Life Scale (e. QoLS) was used. The QoLS includes 16 questions that measure physical and psychological well-being, independence, social connections, personal maturity and the individual's well-being in the society. For example, how happy or unhappy the participant is with their financial status, personal understanding of self or relationships with friends. Scores can range from 16 to 112, with the indication that higher scores represent

higher quality of life. Previous studies have shown the scale to be a valid and reliable instrument for measuring quality of life and can be used with confidence in chronic illness groups (Burckhardt & Anderson, 2003). The Icelandic version of the scale was translated by Pétur Tyrfingsson in 2005. The inner reliability was high, with Cronbach's $\alpha = .92$.

Sleepiness. To measure sleepiness, The Epworth Sleepiness Scale (ESS) was used. The scale measures daytime sleepiness and how likely or not likely the individual is to doze off in common activities. The participant rates their chances to doze off or fall asleep in eight different situations on a four-point scale and each situation receives a score of zero to three. For example, how likely the participant is to fall asleep or doze off while watching the TV, lying down in the afternoon, or sitting and talking to someone. The total scores can vary from 0 – 24, with 16 – 24 interpreted as severe excessive daytime sleepiness. The scale is considered the best available tool for evaluate perception of sleepiness (Doneh, 2015) and a simple, yet reliable method for measuring daytime sleepiness (Johns, 1992). The inner reliability was high with Cronbach's $\alpha = .90$.

Procedure

The study was conducted with an online survey using the website Questionpro, which was available for voluntary participants for three weeks. The survey was published and advertised on several different Facebook groups, one of the groups being a closed group for people with narcolepsy. Additionally, the survey was advertised in a newsletter for members in Lokbrá, an association for people with narcolepsy. To advertise the questionnaire for possible participants for the control group, the survey was published on the researchers personal Facebook page. The data was collected by the website Questionpro and then transferred to the Statistical Package for the Social Sciences software (SPSS).

Immediately upon opening the survey link, before participants could start answering the survey questions, an information letter appeared. The information letter had detailed

information about the study, what was being researched and a statement that announced participants that by answering the questions in the survey was equivalent to informed consent. It was informed to the participant that if at any time for any reason, they could be withdrawn from the study without any explanation. The participants were informed that no payment was offered for participating in the study. For ethical reasons, the participants were also informed that the researchers considered there not being a risk involved in participation in the study, however, the questionnaire included questions about a disease, depression, anxiety, and stress that could trigger some undesirable emotions. For all that, if the questions evoked distress or undesirable emotions, the participants could contact a psychologist for one personal consultation appointment for free. All information needed to contact the provided psychologist was included. All data was considered confidential and could not be tracked back to the individual participants. Permission for the study was secured from the National Bioethics Committee in Iceland (VSNb2021100007/03.01).

Research design and data analysis

The independent variable of the study was having narcolepsy and the dependent variables of the study were quality of life and mental health. The experimental group were the group of individuals that had been diagnosed with narcolepsy and the group that had not been diagnosed with narcolepsy served as a control group. The study was a between group study and aimed to compare the mental health and quality of life of the two groups.

For data analysis, the Statistical Package for the Social Sciences (SPSS) software was used with the significance level of $p < 0.05$. The comparison of the variables,

To determine if there was a significant difference in total scores and to compare means on DASS subscales, depression, anxiety, and stress, between both narcoleptics and control groups, a t-test was conducted. Furthermore, to compare means and determine if there was a significant difference between the two groups in total scores on the variables quality of life

and excessive daytime sleepiness (EDS), an independent sample t-test was conducted. To examine the connection between having narcolepsy, severe excessive daytime sleepiness and quality of life, depression, anxiety and stress, an independent sample t-test was conducted. The narcolepsy group was divided into two groups, based on total scores on the Epworth sleepiness scale.

Results

The participants consisted of 76 individuals, of which 22 (28.6%) were diagnosed with narcolepsy, 54 (70.1%) were individuals that had not been diagnosed with narcolepsy and one person did not want to answer the survey question. Females were in majority in both groups. There were 16 (72.7%) females in the narcolepsy group and 6 (27.2%) were male. In the control group were 38 (74.5%) female participants and 13 (25.4%) were male. Among both groups, was 18 – 29 the most frequent age range, with 8 (26.6%) narcoleptic participants and 22 (73.3%) without narcolepsy. The most frequent educational level for both groups was a bachelor's degree, consisting of 8 (32%) narcoleptics and 17 (68%) without narcolepsy. The most common employment status amongst narcoleptics was unemployment, with total of 9 (42.8%) narcoleptic participants. However, amongst the control group, the most common employment status was being employed, with 26 (49%) participants

Demographics characteristics of the participants diagnosed with narcolepsy or not, is shown in table 1.

Table 1.

Demographics of participants with narcolepsy and without.

		Narcolepsy	Control Group
		n %	n %
Gender			
	Male	6 (27.3%)	13 (25.5%)
	Female	16 (72.7%)	38 (74.5%)
	Total	22 (30.1%)	51 (69.9%)
Age			
	18 – 29	8 (36.4%)	22 (43.1%)
	30 – 39	5 (22.7%)	7 (13.7%)
	40 – 49	5 (22.7%)	1 (2.0%)
	50 – 59	2 (9.1%)	14 (27.5%)
	60 +	2 (9.1%)	7 (13.7%)
	Total	22 (30.1%)	51 (69.9%)
Education			
	Elementary	3 (13,6%)	4 (7,7%)
	Collage	7 (31,8%)	13 (25,0%)
	Trade school	3 (13,6%)	6 (11,5%)
	BSc/Bsa	8 (36,4%)	17 (32,7%)
	MS/MA/MBA/PhD	1 (4,5%)	12 (23,1%)
	Total	22 (29,7%)	52 (70,3%)
Employment			
	Employed	7 (33,3%)	26 (49,1%)
	Employed/Part-time student	3 (14,3%)	2 (3,8%)
	Student	1 (4,8%)	5 (9,4%)
	Student/Part-time	1 (4,8%)	12 (22,6%)

	employment		
	Unemployed	9 (42,9%)	8 (15,1%)
	Total	21 (28,4%)	53 (71,6%)

The first hypothesis was that narcoleptics have worse quality of life than the general population and to test if there was a significant difference between both groups, narcoleptics and control group, an independent t-test was conducted. The Independent t-test displayed that participants with narcolepsy differed significantly from the control group and had higher total scores on all subscales of DASS. On average, narcoleptic participants experienced more depression (M = 29.23, SD = 13.43) than the control group (M = 19.64, SD = 6.65). This difference was significant (p = < .001) according to the two-tailed probability. Likewise, the narcoleptic participants scored higher in anxiety subscale (M = 23.60, SD = 9.62) when compared to the control group (M = 18.26, SD = 5.07). The difference was significant (p = .003), and the null hypothesis can therefore be rejected. As for the stress subscale, narcoleptics scored more on average (M = 26.23, SD = *11.17),* than the control group (M = 21.32, SD = 6.52) and the difference was significant according to the two-tailed probability (see table 2).

Table 2.

T-test results for both groups

		N	*M*	*SD*	*t*	*p*
Depression	Narcolepsy	21	29.23	13.43	4.03	<.001
	Control group	50	19.60	6.65		
Anxiety	Narcolepsy	20	23.60	9.62	3.02	.003
	Control group	50	18.26	5.07		

Stress	Narcolepsy	21	26.23	11.17	2.35	.024
	Control group	49	21.32	6.52		
QoL	Narcolepsy	21	55.33	17.90	4.54	<.001
	Control group	51	37.72	13.56		
EDS	Narcolepsy	22	26.04	3.57	9.95	<.001
	Control group	53	15.84	4.20		

The means from the Quality-of-Life Scale differed significantly between the two groups (p =.001). Correspondingly, the means from the Epworth sleepiness scale for excessive daytime sleepiness (EDS), had also a significant difference between the two groups (p = <.001).

To test the connection between excessive daytime sleepiness and quality of life, independent sample t-test was conducted. Participants were divided into two groups, using the median split approach. The participants that scored 26 or less on the Epworth sleepiness scale, were placed in the low group, and the participants that scored 27 or higher, were placed in the high group. The findings revealed that there was no significant difference in quality of life for the participants in the high (N = 13, M = 55.07, SD =18.42) group and low (N = 8, M = 55.75, SD = 18.27) group (t (19) = 0.08, p =.936).

Additionally, an independent sample t-test was conducted to test the connection between excessive daytime sleepiness and depression, anxiety, and stress. The same two groups of high, and low were used. The t-test revealed no significant difference in depression (t(19) = -0.39, p =.701), anxiety (t(18) = -1.45, p =.163) or stress (t(19) = -1.13, p =.272). See table 3.

Table 3.

T-test results on connection between EDS and DASS for narcoleptics

	EDS	*N*	*M*	*SD*	*t*	*p*
Depression	Low	9	27.88	12.70	-.39	.701
	High	12	30.25	14.42		
Anxiety	Low	8	19.87	2.79	-.1.45	.163
	High	12	26.08	11.75		
Stress	Low	8	22.75	6.08	-.1.13	.272
	High	13	28.38	13.16		

Discussion

This study examined the quality of life and mental health of individuals with narcolepsy in Iceland compared to the general public. This was the first study of this kind on Icelandic subjects. The results of the study were comparable with previous research on the matter (Li et al., 2021; Tadrous et al., 2021), therefore confirmed previous findings. First it was hypothesized that narcoleptics have less quality of life when compared with the control group. The results supported the hypothesis and the difference between the two groups was significant therefore equivalent with David et al., (2012) and Flores et al., (2016) findings.

The second hypothesis was that narcoleptics experience more symptoms of depression, anxiety, and stress than the general population. The hypothesis was supported in view of there being a significant difference between narcoleptics and control group for depression (p = <.001), anxiety (p = .003) and stress (p = .024). These findings are supported

by Li et al., (2021) study on prevalence of depression in patients with narcolepsy and Feketeova et al, (2021) findings on narcolepsy comorbidities.

Last hypothesis was that narcoleptics that experience more excessive daytime sleepiness have worse quality of life, depression, anxiety, and stress than those who experience less. There was no significant difference between quality of life and high or low excessive daytime sleepiness among narcolepsy patients (p = .936), which is different from the findings of Zhang & Han (2017) when examining excessive daytime sleepiness in narcolepsy patients. Likewise, there was no significant difference between depression (p =.701), anxiety (p =.163) and stress (p = .272) in both high and low excessive daytime sleepiness among narcoleptics.

The correlation between narcoleptics, taking medication for their symptoms and quality of life was explored. However, data revealed that all but one narcoleptic participant were taking medication, therefore no further data analysis were made on that matter.

There were a several limitations to the study. The sample size was much smaller than it was expected, with only 76 participants, therefore hard to generalize the results. The narcolepsy patient group was considerably smaller than the control group, which possibly can be explained due to small number of diagnosed narcoleptics in Iceland. Additionally, the sample size might have been bigger if there would have been more time for participants to enter the study, but the questionnaire was open for four weeks. Another possible limitation is the timing of the study. Due to COVID-19 and a busy holiday season, there might be an explanation to the small sample size.

Narcolepsy is a serious and debilitating disorder that can affect one's life tremendously. There has been an increased number of reported cases of narcolepsy in Iceland in the last ten years, as reported by European Centre for Disease Prevention (ECDC).

It is unquestionably important to research this matter for scientific benefits and to evoke interest to future research. The benefits of this study would be first and foremost raising awareness on the disease and its burden and increase knowledge on Icelandic narcolepsy patients. Hopefully, the research will be useful to professionals, helping them to understand the disease and how to manage it, as well as helping individuals with narcolepsy and their families. As for today, there are unbelievably few physicians in Iceland that have enough knowledge of the disease to provide suitable treatment.

As the results of this study revealed, narcolepsy has negative effects on quality of life and mental health and therefore important for both patients and their family to recognize these effects. Narcolepsy is a very misunderstood disease, which makes it hard to deal with and thus difficult for family and friends to understand.

Considering the importance of expanding knowledge among Icelandic specialists and physicians, further research is necessary. Future research could focus on a bigger sample size, more detailed and precise method, and procedure. Furthermore, future research could examine the association between other comorbidities and narcolepsy, the effects of narcolepsy treatment, such as different medication, has on quality of life and mental health. Treatment options for narcolepsy are few, but most narcoleptics need to take various medications every day to function and some even must schedule naps throughout the day. Future research could examine the effects of narcolepsy in academic environment, social life, and close relationships.

In conclusion, the findings of this study revealed that narcolepsy patients in Iceland do experience worse quality of life and have greater symptoms of depression, anxiety, and stress than the general public. As well as experiencing considerably more of excessive daytime sleepiness, as could be expected, than the general public. Narcoleptics that experienced more excessive daytime sleepiness and could seemingly fall asleep in various

daily activities, appeared to not experience worse quality of life than the narcoleptics that experienced less.

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