Occupational Therapy Intervention on Sexual Dysfunction among Epilepsy Patients: A Pilot Study

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Introduction

Around 50 million people worldwide are estimated to have epilepsy, making it one of the most common neurological diseases globally [1]. It is characterised by a lasting predisposition to generate spontaneous epileptic seizures and has numerous neurobiological, cognitive, and psychosocial consequences [2]. Sexual dysfunction is more common among epilepsy patients as compared to the general population and is an important yet under-diagnosed co-morbidity. Sexual dysfunction is difficult to diagnose because of the taboo attached to it. The epilepsy patients are often not forthcoming with these complaints and at times think them to be unrelated to epilepsy [3].

The chronic antiepileptic drug (AED) use adds to the sexual and reproductive dysfunctions. The AEDs modulate the hypothalamo-pituitary-adrenal axis and may have direct inhibitory effects on sexual behaviour. The PWE receiving enzyme-inducing drugs like carbamazepine and phenytoin have a higher incidence of sexual dysfunction [4–7]. Additionally, the prevalence of psychiatric co-morbidities especially depression among people with epilepsy is more common which leads to poor quality of life and high suicidal rates among these patients [8,9].

Occupational therapists have long recognized sexuality as an area of occupation and a known activity of daily living (ADL). In fact, American Occupational Therapy Association (AOTA) endorses the belief that sexuality is a central characteristic and foundational factor for human QOL [10-12]. Despite this knowledge, occupational therapists continue to be reluctant to address sexuality with their disabled clients. Therapists have reported varying reasons for this inattention, including a lack of knowledge, decreased comfort, feelings of incompetency, perceived lack of treatment options, fear of offending the client, and time constraints [13,14]. Many previous studies have been conducted on the impact of sexual education modules on occupational therapy students and practicing occupational therapists, but the impact of sexuality interventions on clients in relation to quality of life, and the impact of societal stigmas on addressing sexuality in occupational therapy and other areas of health care is still an un-sailed domain in the field of occupational therapy. The high number of epilepsy patients in India and the lack of research from this region on sexual dysfunction and associated psychiatric co-morbidities in epilepsy patients lead to the present analysis. Hence, the primary purpose of this pilot study was to determine the effect of occupational therapy (OT) intervention in sexual dysfunction, anxiety and depression levels, and quality of life patients with epilepsy.

Methodology

After obtaining ethical approval, an interventional study was carried out at the OT outpatient department for duration of four months on idiopathic focal or generalized epilepsy adult patients in the age group of 18-45 years. Males or females with non-institutionalized idiopathic focal or generalized epilepsy, diagnosed with seizure disorder for not less than 1 year and on medications, with seizure duration of not more than 5 years, ambulatory and physically active, and Patients screened with Changes in Sexual Functioning Questionnaire (CSFQ) for sexual dysfunction were included in this pilot study. Whereas, patients with any acute and chronic illness including neurological disorders other than epilepsy, previous surgery, with use pacemakers, pregnancy, major congenital malformations, cancer were excluded from this pilot study.

Based on the inclusion and exclusion criteria a total of 15 epilepsy patients with sexual dysfunction were recruited and informed consent in written form was obtained from the patients after explanation of the intervention program. The outcome measures consisted of Changes in Sexual Functioning Questionnaire-Male or Female (CSFQ-M/F), Generalised Anxiety Disorder scale-7 (GAD-7), Patient Health Questionnaire-9 (PHQ-9) for depression and the Quality of Life in Epilepsy Inventory – 31 (QOLIE-31) questionnaire that was assessed at the baseline level (pre-intervention), at the end of the 8 weeks of the intervention, and at the end of the four months of the intervention.

The patients were treated with OT intervention for a period of 4 months. The intervention was given once in a week for four months and each session lasted for 30-45 minutes. The OT intervention included the following three major areas health promotion, remediation, and modification. Each of these methods were used at all levels of the intervention, as outlined by the EX-Permission, Limited Information, Specific Suggestions and Intensive Therapy model (Ex P-LI-SS-IT) [15,16]. Health promotion consists of stress-relieving activities, educational information in the form of handouts,

reference material in the form of print or electronic media, and support groups. Health remediation consists of restoring skills, such as range of motion, strength, endurance, effective communication, and social engagement, as part of meeting sexual needs. Modification consists of adapting or changing the environment or routine to allow for sexual activity. Following this the patients were given Jacobson's relaxation technique to reduce stress. Additionally, energy conservation techniques, and sexual positions for better participation and less energy expenditure was advised. The progression of individual patient was noted at the end of 8 weeks and 4 months duration by calculating the CSFQ, GAD, PHQ-9, and QOLIE-31 questionnaires and the changes observed were noted [16,17].

Descriptive statistics like frequency, percentage, mean, standard deviation and confidence interval were obtained to summarize the collected data. For normal data, within the same group comparison was done by repeated measures ANNOVA and between different groups comparison was done by unpaired t-test for non-normal data within the same group by Friedman test and between different groups comparison was done by applying Mann-Whitney U test. P-value less than or equal to 0.05 was considered as the level of significance.

Results

Overall 15 epilepsy patients were recruited for the present study. The patients were screened for changes in sexual functioning using CSFQ-Male/Female questionnaire, generalised anxiety disorder using GAD-7 questionnaire, depression using patient health questionnaire — 9 (PHQ-9), and quality of life in epilepsy patients using QOLIE-31 questionnaire during pre-interventional period, after 8 weeks of intervention, and at the end of the 4 months of intervention. The age distribution of the participants is demonstrated in Table 1

Age Range	Number of participants (%)			
18-25	7 (46.67%)			
26-35	5 (33.33%)			
36-45	3 (20%)			
Total	15 (100%)			

Table 1: Age-wise distribution of participants

The gender-wise distribution of participants is described in Table 2.

Gender	Number of participants (%)					
Male	10 (66.67%)					
Female	5 (33.33%)					
Total	15 (100.00%)					

Table 2: Gender-wise distribution of participants

The CSFQ scores of participants at the baseline level, at the end of 8 weeks, and at the end of 4 months is described in Table 3.

Changes in sexual functioning questionnaire (CSFQ)								
Mean ± SD	At baseline (pre- intervention)	At the end of 8 weeks	At the end of 4 months	One way ANOVA				
Males	31.08 ± 5.12	44.07± 4.29	51.02± 4.02	p-value=0.0031 (statistically significant)				
Females	32.62 ± 4.49	44.06± 4.13	65.00± 5.14	p-value=0.0044 (statistically significant)				
Total	32.13 ± 6.69	44.67 ± 5.69	64.80 ± 3.55	p-value=0.0032 (statistically significant)				

Table 3: Mean CSFQ scores of participants.

The GAD-7 scores of participants at the baseline level, at the end of 8 weeks, and at the end of 4 months is demonstrated in Table 4.

General anxiety disorder – 7 questionnaire (GAD-7)									
Mean ± SD	At ba	aseline	(pre-	At the end of 8	At the end of 4	One way ANOVA			
	intervention	on)		weeks	months				
	16.13 ± 2.01			9.53 ± 3.55	1.67 ± 1.11	p-value=0.048	(statistically		
						significant)	_		

Table 4: Mean GAD-7 scores of participants.

The PHQ – 9 scores of participants at the baseline level, at the end of 8 weeks, and at the end of 4 months is demonstrated in Table 5.

Depression using patient health questionnaire (PHQ-9)									
Mean	±	At baseline	(pre-	At the end of 8	At the end of 4	One way ANOVA			
SD		intervention)		weeks	months				
		10.87 ± 1.51		6.47 ± 1.88	1.33 ± 0.62	p-value=0.02	(statistically		
						significant)			

Table 5: Mean PHQ - 9 scores of participants.

The QOLIE – 31 scores of participants at the baseline level, at the end of 8 weeks, and at the end of 4 months is demonstrated in Table 6.

Quality of life in epilepsy inventory – 31 questionnaire (QOLIE-31)									
Mean	\pm	At	baseline	(pre-	At the end of 8	At the end of 4	One way ANOVA		
SD		intervention)			weeks	months			
		27.62 ± 9.69			52.24 ± 10.64	68.04 ± 6.13	p-value=0.024	(statistically	
							significant)		

Table 6: Mean QOLIE - 31 scores of participants

Discussion

The present pilot study demonstrated the positive effect of occupational therapy intervention on sexual dysfunction, depression, anxiety, and quality of life in epilepsy patients. The occupational therapy intervention performed in the present pilot study involved three major areas health promotion, remediation, and modification which was in congruous with a previous study based on EX-Permission, Limited Information, Specific Suggestions and Intensive Therapy model (EX-P-LI-SS-IT) [18]. The Ex-PLISSIT model is an extension of the much-used PLISSIT model. The PLISSIT model was developed by Annon (1976) for use by practitioners in meeting the sexuality and sexual healthcare needs of patients [15].

The acronym PLISSIT signifies the four levels of intervention — Permission, Limited Information, Specific Suggestions, and Intensive Therapy. The Permission-giving stage that involves the assessment process which is the first step in addressing the patient's sexual health needs. Explicit Permission-giving during this assessment provides patients with the opportunity to voice their concerns about sexual health. Some opportunities for Permission-giving occur before any interaction between the patient and the healthcare professional. The waiting room and practice newsletter are ideal places to advertise the services available and to provide reassurance about confidentiality. Specific

reference to young people's right to confidentiality is crucial because teenagers may be reluctant to disclose information that they perceive would be shared with their parents. The practice leaflet and posters in waiting rooms are also a means of illustrating an inclusive, responsive environment where the diversity of patients' health needs is recognised [18].

The next stage involves Limited information stage in which information should be given about the impact of illness on sexuality and the effects of treatments on sexual function. Occupational therapists have an important role to play in clarifying misinformation, dispelling myths and giving factual information in a limited manner. This is followed by specific suggestion stage in which problem-solving approach is needed to address an individual's particular problem. The Specific Suggestions stage needs to address all aspects of sexuality and sexual health rather than only focusing on sexual behaviour. This stage is followed by Intensive therapy stage which is the most advanced stage of both the PLISSIT and Ex-PLISSIT models. While many therapists working in primary care have contraceptive expertise, few have sufficient training to provide Intensive Therapy in other areas of sexual health.

Unlike the PLISSIT model, the Ex-PLISSIT model incorporates reflection and review following all interventions. For effective review, the therapist needs

to seek the patient's perspective. Through reflection, any issues can be identified and addressed. This reflection can occur alone or with peers. Clinical supervision provides opportunities for the therapists to reflect on their practice, explore their feelings, challenge any assumptions and develop confidence [18]. Hence, in the present pilot study along with Ex-PLISSIT model intervention health promotion involving stress-relieving activities, educational information in the form of handouts, reference material in the form of print or electronic media, and support groups was performed. Health remediation consisting of restoring skills, such as range of motion, strength, endurance, effective communication, and social engagement, as part of meeting sexual needs was included. Modification consists of adapting or changing the environment or routine to allow for sexual activity was advised. Following this the patients were given Jacobson's relaxation technique to reduce stress. Additionally, energy conservation techniques, and sexual positions for better participation and less energy expenditure was advised. All the above mentioned intervention significantly improved sexual functioning in epilepsy patients which was observed from the increase in CSFQ scores that were monitored at the baseline (preintervention) level, at the end of eight weeks and at the end of the four months.

The main components of CSFQ-M/F involve sexual desire, sexual pleasure, sexual arousal, and sexual orgasm. Previous studies found that in women with epilepsy, all the four types of sexual dysfunctions are present. However, majority of women have dysfunctions in the domains of sexual desire (hyposexuality) and sexual arousal, while orgasmic and pain-related sexual problems are less frequent. Whereas, males usually have sexual dysfunction related to physical response which mainly includes erectile dysfunction and premature ejaculation [19-23]. One of the reason behind sexual dysfunction involves usage of chronic antiepileptic drug (AED)[4,6,7,24]. It is proposed that epileptiform discharges propagating through amygdalo-hypothalamic pathways can interfere with pulsatile secretion of gonodatrophic hormones and dopamine. This in turn causes hypogonadism, hyperprolactinemia, and sexual dysfunction [3,25,26].

Furthermore, epilepsy is also known to be associated with various psychiatric co-morbidities such as depression and anxiety as stated in previous studies [3]. Similarly, a study that was done by Souza et al. also points to an association between sexual dysfunction, depression and anxiety [27] and therefore, all epilepsy patients should be screened for associated psychiatric co-morbidity [28]. However, to combat anxiety and depression in epilepsy patients and to enhance quality of life the present pilot study was perfomed to determine the effect of OT intervention on these parameters which resulted into reduced anxiety and depression levels as reported by reduction in scores on GAD-7 and PHO-9

questionnaires. OT aims to help people overcome the effects of disability through practical support to improve performance and satisfaction in activities of daily living which include physical rehabilitation through guided activity practise, practical management of pain and fatigue, support to address mental health problems and support to reduce dependency and optimise independence [29].

Epilepsy affects all domains of daily living but, it is usually associated with impairment of quality of life (QOL). The opportunity to self-express is crucial for maintaining mental health. Therefore, many nonpharmaceutical interventions have been utilized to relieve psychiatric symptoms, such as fear, anxiety, and depression in persons with epilepsy. A previous study aimed to investigate the effect of the OT program with drama activities (ODTA) on the QOL of patients with epilepsy. The outcome measure involved was Quality of Life in Epilepsy Inventory (OOLIE-31) mean scores. The study concluded that the importance of providing an ODTA program in patients with epilepsy and proposes its broader combined application as a complementary intervention in such patients [30]. Similarly in the present pilot study QOL of the patients improved significantly (p-value = 0.024) following the OT intervention.

Occupational Therapist have been using the PLISSIT Model and Occupational Adaptation Model as a facilitation tool in order to increase healthcare professionals' ability and likelihood to address sexuality and sexual activity on a regular basis with clients [15,18]. In contrast to this, the OT practitioners face certain barriers in addressing sexuality and intimacy with clients that includes attitudes and bias toward sexuality and disability, cultural/religious barriers, fear of offending the client, therapist perceived lack of knowledge, and therapist discomfort. In order to address these barriers, educational opportunities should be available to OT practitioners. While AOTA offers a continuing education (CE) article on sexuality, AOTA does not have an online CE course available. This course aims to provide continuing education opportunities for OT practitioners about sexuality and intimacy, increase OT practitioner's knowledge and confidence to advocate for clients, and promote occupational justice by addressing occupations that are important to the populations that they serve and prevent further occupational injustice in the area of sexuality and intimacy [12,18,31].

Conclusion

Interplay of multiple causes including direct effects of epilepsy, effects of AEDs, and psychosocial factors contributes to sexual dysfunction in epilepsy patients. The present pilot study highlighted the positive impact of OT intervention in improving sexual functioning which was measured with CSFQ, reducing depression and anxiety levels that was observed on GAD-7 and

PHQ-9 scales, and enhancing quality of life in epilepsy patients which was reported through QOLIE-31 questionnaire. In summary, occupational therapy is recognised as part of multidisciplinary intervention but there is a limited evidence base therefore more future studies focussing on effects of occupational therapy related to various conditions needs to be carried out. Hence, the findings of this pilot study suggests that the impact of OT intervention on sexual dysfunction in epilepsy patients can be studied in more diverse and larger populations.

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