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Occupational Therapy's Role in Addressing Sex and Intimacy for Individuals with Progressive Neuromuscular Disorders

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Occupational Therapy's Role in Addressing Sex and Intimacy for Individuals with Progressive Neuromuscular Disorders

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BACKGROUND

Various occupational performance disruptions in intimacy and sexual participation occur in individuals with progressive neuromuscular disorders (PND); specifically, Parkinson's disease (PD), Multiple Sclerosis (MS), Huntington's Disease (HD), and Amyotrophic Lateral Sclerosis (ALS) and their partners (Mayers & Heller, 2003; Poletti et al., 2019; Verschuren et al., 2010). These changes in functional motor skills and psychosocial domains often have a negative impact on their personal relationships; specifically, sexual activity and intimacy (Verschuren et al., 2010). Occupational therapy (OT) practitioners are equipped with unique knowledge of analysis of activities, performance skills, and client factors related to sex and intimacy, but professionals often exclude sexuality from everyday practice (Mc Grath & Sakellariou, 2015). There is a large body of evidence linking sexuality and intimacy to quality of life and well-being (Diamond & Huebner, 2012; Poletti et al., 2018). In order to properly address sexual concerns an online survey was conducted for people with PND and their partners to gain insight into their lived experience.

PURPOSE

Examine the lived experience of individuals with progressive neuromuscular disorders (PND) and their partners in order to create a program that addresses occupational deficits in intimacy and sexual participation.

METHODS

Design

- Mixed-methods (Likert scale and open-ended questions)

Recruitment

- Posting on social media groups serving the target population
- Virtual support groups

Survey

- Demographics, relationships, intimacy, perceptions of effects of diagnosis, suggestions for future programming

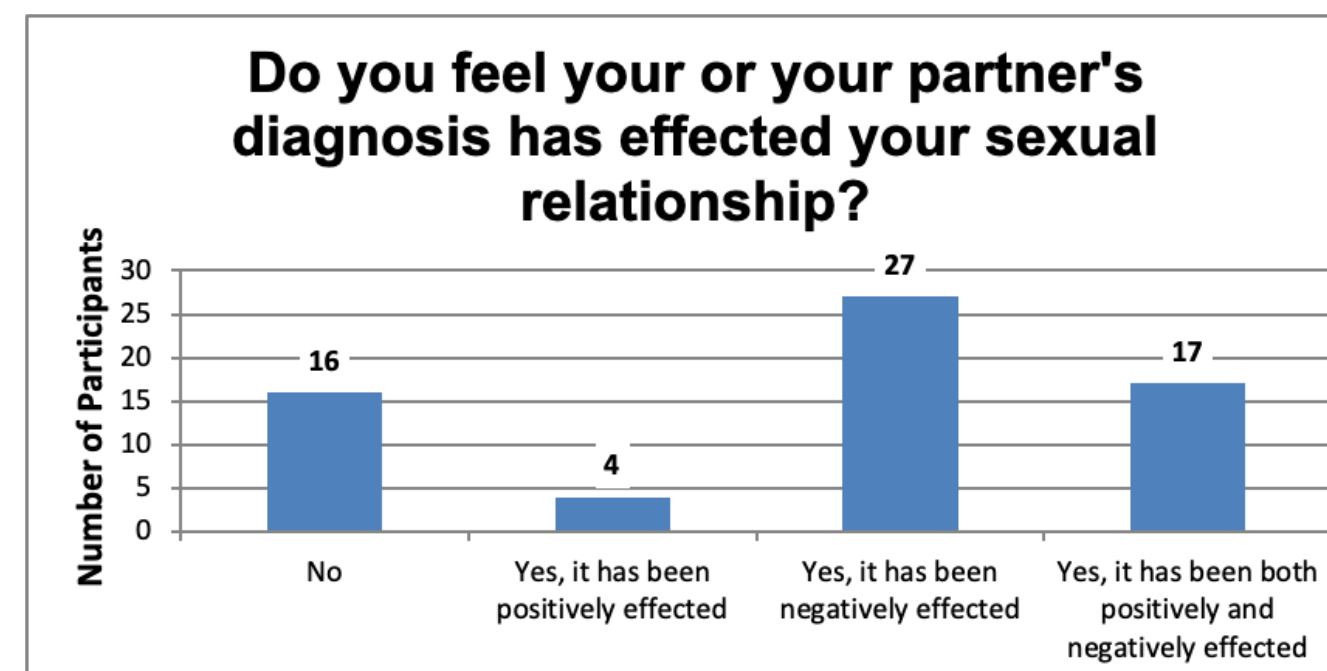
Sample

- 64 individuals with PND (Age > 18)
- PD (N=26), MS (N=14), HD (N=11), ALS (N=13)

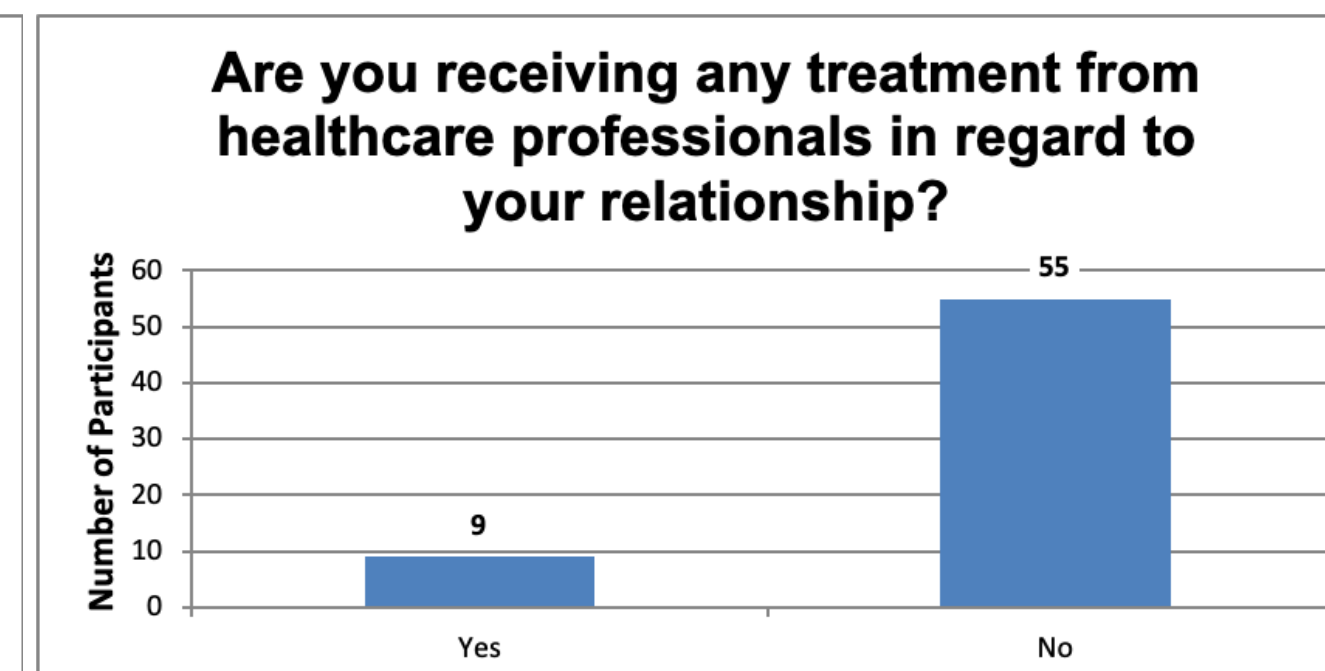
RESULTS

Research question: What are the perceived impacts, barriers, and supports of PND on intimacy and sexual activity in individuals with PND and their partners?

Theme	Excerpts
Physical symptoms impacting sexual activity <ul style="list-style-type: none"> Sensorimotor symptoms Erectile dysfunction and vaginal dryness 	<ul style="list-style-type: none"> "The fatigue is crippling at some points" "Vaginal dryness that causes unbearable pain, so NO intercourse"
Relationship with emotions <ul style="list-style-type: none"> Open up Shut down Stress (Disease, lifestyle) 	<ul style="list-style-type: none"> "Open conversations were super bad. Like depressing. No connection. No deep check ins...I wished he dug deeper but never did. And I was hurting too much to open up.. as it turns out so was he and he thought talking about it would make it worse because then we would feel sad and cry... but actually I wanted him too. I wanted to know his world was rocked like mine. That he's understood the severity of it all. That he was processing it. "Negative" emotions aren't bad, they're just hard but they're necessary for coping and grieving and moving forward."
Connectedness <ul style="list-style-type: none"> Replacement for a sexual relationship Enhancement for a sexual relationship Partner's role (supportive vs unsupportive) 	<ul style="list-style-type: none"> "Facts being, sometimes, you accept things as they are and go forward, doing without some things in order to obtain other forms of closeness. Sexual expression can be in many other forms besides intercourse...Having a relationship that depends on sex is not a truly lasting concept. Sex is not love. Love does not mean sex. They are completely separate beings..." "My partners are all supportive and make me feel wanted and accepted. They see I'm still a sexual person despite my diagnosis"
Supporting actions <ul style="list-style-type: none"> Empowered self-concept Changing what the sex looks like Biopsychosocial supports 	<ul style="list-style-type: none"> "This diagnosis doesn't mean you are broken in any way." "Due to the decline in my physical capabilities, we are limited in how we can physically pleasure each other. We find ways, however, to continue to have sexual relations" "Orgasms encourage me to keep living"



Conversion of participant number to percentages:
No (25%), Positive effect (6%), Negative effect (42%), both positive and negative (27%)



Conversion of participant number to percentages:
Yes (14%), No (86%)

CONCLUSION

This study aimed to identify what are the perceived impacts, supports, and barriers of individuals with PND regarding sex and intimacy. The findings from this study support an increased role for OT practitioners in the domain of sexuality. Occupational therapists can facilitate meaningful participation in sexual occupations for these individuals by addressing: their unique physical barriers through positioning and adaptations, providing stress management strategies for both internal and external stressors, and facilitating positive communication between individuals with PND and their partners.

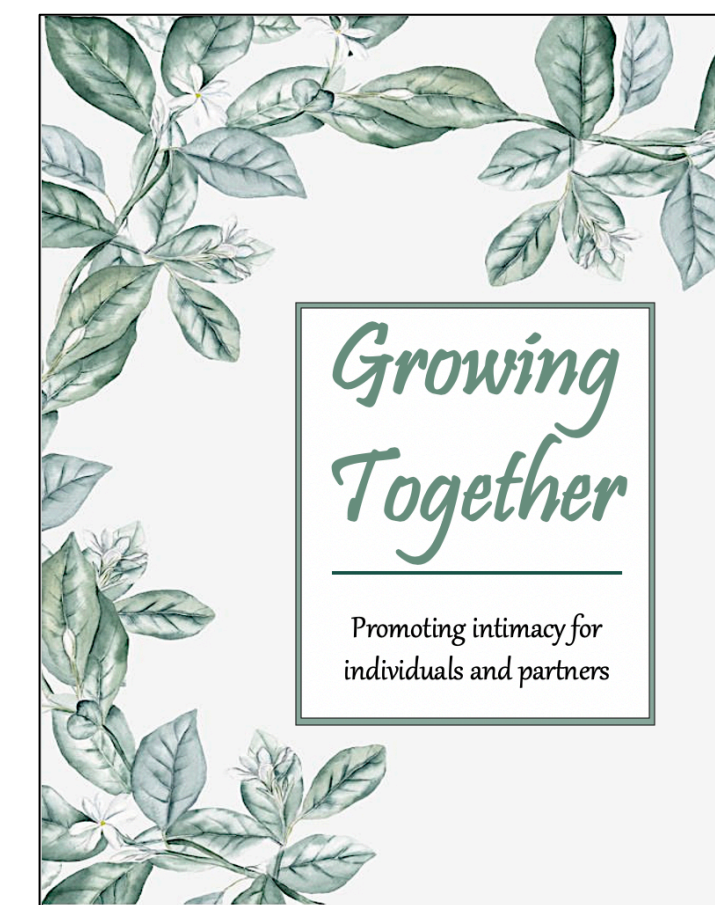
ENVISIONED NEXT STEPS

Program

Future plans include creating a resource for individuals with PND and their partners based on the research results. This will likely be in the form of a workbook that can be used by these individuals or in tandem with an occupational therapy professional.

Advocacy

Interventions and education related to sex and intimacy is lacking within the OT profession. An important future step is to continue advocacy efforts through student lectures, continuing education courses, and various publications.



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