

Let's Talk About Sexual Intimacy in Persons With Amyotrophic Lateral Sclerosis and Their Partners

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PURPOSE: Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease. The symptoms of ALS have been found to play a role in limiting sexual intimacy among persons with ALS (PALS) and their partners. Sexual intimacy as an Activity of Daily Living (ADL) has been recognized as an important element of everyday life and well-being of individuals, no matter the present illness. There is a need for occupational therapists to discuss the impact of ALS on sexual intimacy to provide holistic care. The objective of this study was to explore concerns and experiences among PALS and their partners related to sexual intimacy and learn from them what would be the most effective method to address the issues they face related to sexual intimacy.

DESIGN: This study was designed with a mixed methods approach to fully capture the experiences of PALS and their partners with qualitative and quantitative data. Participants were recruited within a multidisciplinary ALS clinic with inclusion criteria of PALS diagnosed no less than 6 months prior to participation and partners of these individuals. Anyone under the age of 18 was excluded.

METHOD: 42 surveys were distributed and included both quantitative and qualitative questions addressing topics such as: importance of sexual intimacy to quality of life, assistance required to participate in sexual intimacy, safety concerns, and preferred timing and method of discussing/receiving information from health care professionals. Surveys were disseminated via email using REDCap as well as on paper via USPS mailing services. Responses were received then analyzed and interpreted via REDCap with qualitative data coded by the research team.

RESULTS: 27 participants responded to the survey out of 42 sent. One hundred percent of the participants that responded to the survey stated they had never been asked about sexual intimacy by any health care provider. 92% of respondents agreed ALS had affected their ability to express sexual intimacy. 48% of participants preferred use of an online video series to address concerns regarding sexual intimacy and ALS. Additionally, coded qualitative data themes included ways in which sexual intimacy should be addressed in the clinic, the ways in which ALS affected ability to express sexual intimacy, assistance provided or devices used while engaging in sexual intimacy, ALS's effect on communicating wants/needs regarding sexual intimacy, and experienced concerns for safety.

CONCLUSION: The findings greatly illustrated the difficulties and concerns experienced with sexual intimacy among PALS and their partners as well as the lack of discussion regarding these concerns. Occupational therapists must take action in providing the opportunity for PALS and their partners to express their concerns with sexual intimacy to provide them with the proper educational materials, potential adaptations, and holistic care.

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