

Critical Review:

The effects of aphasia on sexuality and intimacy within a spousal relationship

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This critical review examines the current evidence regarding aphasia and its effects on sexuality and intimacy within spousal relationships. Research designs included qualitative studies, survey studies, and a case study. Overall, there is weak to suggestive evidence supporting that aphasia has a negative impact on the sexuality and intimacy of people with aphasia (PWA) and their spouses.

Introduction

Sex is a fundamental human behaviour, but beyond this it is also an important aspect in the quality of life of adults. Engaging in sex for pleasure, having a sexual identity, and creating intimacy are common themes of importance for adults within relationships (Freak-Poli, Licher, Ryan, Ikram, & Tiemeier, 2018). To fulfill these qualities within relationships, the need for strong and open communication is very important. In general, for many people and cultures, the topics of sexuality and intimacy are still quite taboo in nature, therefore making these topics more challenging than others to discuss openly; these topics of discussion become even more challenging when one partner has a communication disorder.

Aphasia is an acquired language disorder caused by damage to the language centers of the brain, most often from stroke (Dickey et al., 2010). There are different types of aphasia, such as Broca's and Wernicke's, which are acquired. Aphasia can sometimes also present in a progressive form, as Primary Progressive Aphasia (PPA). Aphasia is a debilitating condition that over one-third of stroke victims in Ontario will experience (Dickey et al., 2010). In addition to those affected by aphasia, these stroke survivors might also experience other complications of brain injury such as fatigue, weakness, and depression. Acquiring a communication disorder, such as aphasia, can make communicating even the most basic wants, needs, thoughts, feelings, opinions, and emotions extremely difficult (ASHA, 1993). Aphasia is associated with difficulty finding words, and understanding language. These communication breakdowns are often provoked when the person with aphasia is feeling emotional, as might be the case when trying to discuss sex or verbally create intimacy with a spouse. Likewise, due to the dyadic nature of communication, spouses may also face challenges surrounding sexuality and intimacy when communicating with a partner with aphasia.

Therefore, coping with aphasia could negatively impact spousal communication about sex and intimacy. With the constraints of aphasia imposed upon a couple, the frequency and quality of communication needed to support the couple's pre-stroke sexuality and intimacy may be impacted. Among dealing with the many other after-effects of stroke, aphasia may pose an added element of difficulty on the sexuality and intimacy of a couple.

By conducting this critical analysis to identify the effects of aphasia on sex and intimacy, it could then, in theory, be used in consideration within assessment, intervention, counseling, and education of aphasic speech-language pathology (SLP) clients. Clinicians may feel better equipped and more inclined to address this issue clinically if there was better understanding of the impacts of aphasia on sexuality. In related research, healthcare professionals report a lack of education is a barrier to addressing sexuality and intimacy with clients and spouses (McLaughlin & Cregan, 2005; Richards, Dean, Burgess, & Caird, 2016). By understanding how aphasia affects sexual and intimate communication, SLPs could make it a more prominent consideration within client care, which may subsequently work to improve the life participation of clients and further satisfy their quality of life within the WHO-ICF Model.

Currently, there is little research explicitly focused on the effects of aphasia on sexuality and intimacy. Adequate research exploring the effects of stroke on sexuality and intimacy exists but routinely excludes people with aphasia (PWA) due to the added challenges of their language disability on data collection (McGrath, Lever, McCluskey, & Power, 2019; Thompson, & Ryan, 2009; Yilmaz, Gumus, & Yilmaz, 2015). Overall, the literature agrees stroke negatively impacts sexuality and intimacy in spousal relationships (Kniepmann & Kerr, 2018; McGrath et al., 2019; Rosenbaum, Vadas & Kalichman, 2014). The results of such studies may or may not apply to those with aphasia and their partners. Relatedly, aphasia may or may not pose its own unique effect on

sexuality and intimacy. Therefore, it is now crucial to look deeper into the available literature specifically focused on aphasia to determine if this has its own exclusive effect on sexuality and intimacy.

Objectives

The primary objectives of this paper are to explore and critically evaluate the present literature to identify the specific impacts aphasia may have on sexuality and intimacy in spousal relationships.

Methods

Search Strategy: Three computerized databases, PubMed, PsychINFO, and CINAHL were searched using the following search terms and strategies:

(("communication disorder" OR "aphasia" OR "speech disorder" OR "language disorder") AND ("sexuality" OR "intimacy" OR "sexual behaviour" OR "sexual behavior" OR "intimate relationship"))).

The search was limited to articles written in English. In the interest of being thorough, the references cited by each collected work were reviewed for additional relevant studies.

Selection Criteria: Articles were selected based on their focus on the effects on sexuality and/or intimacy of stroke and at minimum, had people with aphasia and/or their spouses as a subset of the participants. Due to the small number of results, studies included were permitted to focus on either PWA and/or their spouses. Articles mentioning children or sexual deviance following stroke were excluded as it is beyond the scope of this research question and critical review.

Data Collection: Results of the literature reviewed yielded 5 studies with non-experimental research designs, two qualitative research studies, two survey studies, and one case study. In part, these studies were critiqued with reference to levels of evidence as defined in Archibald (2009).

Results

Qualitative Studies

Although qualitative research designs are rated as a lower level of evidence (IV), they are most appropriate when the research objectives are explorative in nature. Due to the scarce literature on aphasia and sexuality and intimacy it is acceptable that studies in this area be explorative and allow for

flexibility as unknown themes, effects, and relationships emerge as research is conducted. Qualitative research is best suited to analyze human behaviour and experience, as it works to uncover the complexities of the current inquiry. Interpretation and generalization of results must be made with caution due to small sample sizes, the potential for subjective interpretations, and the effect of the researcher(s) involved on data collection.

Bouchard-Lamothe et al. (1999) conducted an explorative study using focus groups and a nominal group technique to uncover the perceptions of physicians, adolescents, and spouses on the effects of aphasia on communication and their compensatory strategies. Although the study was not specifically designed to investigate sexuality and intimacy, results of the study revealed spouses of PWA felt a lack of intimacy, affiliation, and support due to the aphasia. Many of the spouses reported the frequency and quality of deep and intimate conversations diminished due to post-stroke aphasia.

The design of the study was suitable for the exploratory nature of the question posed. Methods of data collection and analysis were appropriate for the study design and had descriptive clarity, supporting adequate audibility. The study lacks details pertaining to procedural rigour; the location and setting of the focus groups, details of the facilitator, description of the recruitment process, and inclusion/exclusion criteria were left unreported. In addition, no potential biases were identified, impacting the overall trustworthiness of this research study.

Overall, this study provides equivocal evidence regarding the impact of aphasia on sexuality and intimacy.

Lemieux, Cohen-Schneider, and Holzapfel (2001) conducted one-on-one interviews including a structured verbal questionnaire with aphasic individuals and their spouses to determine the specific effects of aphasia on sexuality (n = 6 couples). Participants were recruited from an aphasia centre with existing and appropriate testing to identify the aphasia on file. A trained speech-language pathologist completed the interviews either in home or at an aphasia centre using appropriate conversational strategies and materials. Couples were interviewed both together and individually. Additionally, the spouses of PWA completed an open-ended written questionnaire. Results of the study revealed that although the importance of sex had not changed post-stroke, the frequency of, and desire for sex decreased. All couples reported aphasia

negatively impacted sexuality and most couples reported that they thought improved communication would improve sexuality. None of the couples had sexuality addressed by a healthcare professional during the rehabilitation process.

The study design and interview methods were appropriate for the research question and population. Reportedly, the use of structured interview questions helped to ensure credibility. Rationale for the study, inclusion criteria, recruitment process, and structure of the interview process were clear and concise. Furthermore, credibility was further ensured by reviewing gathered data with spouses before ending the interview. It was unclear why persons with aphasia were not involved in this process. As well, the analytic approach to determining themes arising from the data was not described in detail. The authors also note that a number of potential participants declined to participate in the study raising potential for bias or limited generalizability.

Overall, this study provides suggestive evidence that sexuality and intimacy are negatively impacted in aphasia. Also relevant was the finding that this issue was not addressed during routine health care for the individuals with aphasia.

Case Study Designs

Case studies can be beneficial when research is focused on uncovering rich insights from specific circumstances. They are considered a weak level of evidence (IV) due to their inability to be replicated or generalized. The power of a case study may lie in its ability to give a holistic perspective of a phenomenon and generate hypotheses or further research avenues.

Pozzebon, Douglas, and Ames (2017) conducted a case study to explore the lived experiences and impact on the relationship of a spouse who cared for her husband with semantic variant primary progressive aphasia (svPPA). A 2-hour in-depth interview was conducted in the participant's home. The interviewer asked only broad and open-ended questions and only spoke to seek clarification. The interview was audio recorded and transcribed verbatim. Five themes emerged following analysis of the data. Within those themes, reportedly, the impacts of svPPA lead to the cessation of sexual intimacy, physical contact, and reciprocity in emotional conversation.

The researchers acknowledge the intrinsic limitations of case study research, a 2-hour limit to the data collection, and the retrospective nature of the topic. Although not described in detail, a six-phase thematic

analysis with an audit trail and memo-writing was completed, and credibility, originality, and usefulness were considered. As well, verbatim quotes were included in the report, which helped to support that the data was analyzed effectively.

Overall, this study provides somewhat suggestive evidence regarding the impact of aphasia on sexuality and intimacy.

Non-Experimental Survey Research

Non-experimental survey research is rated as a lower level of evidence (IV). Survey research can provide objective information about the beliefs, attitudes, and behaviours of people that are sampled. Although surveys appear as an efficient way to collect and analyze data, the power of their results is highly dependent on questionnaire design, piloting strategies, sample selection, administration considerations, and data cleaning and analysis. In the understudied topic of sexuality and intimacy, survey research can help to provide information on the experiences of a larger population of people with aphasia.

Korpelainen, Nieminen, and Myllylä (1999) conducted a non-experimental survey study to investigate the effects of stroke on sexual function of stroke survivors and their spouses. Stroke patients (n=192) and spouses (n=94) recruited through a hospital rehabilitation program completed a study-designed questionnaire, as well as published questionnaires of geriatric depression and stroke disability. Results of the study revealed marked decreases in sexual activity following stroke, which was most significantly and highly correlated with "disability to discuss sexuality with spouse". Satisfaction with sexual life also considerably decreased following stroke for both partners, which again was most significantly and highly correlated with an "inability to discuss sexuality".

A survey study was appropriate to answer the research question and to reach a large sample size. The statistical analysis applied was appropriate. The reliability and validity of the study is uncertain. Reportedly, PWA were included in the study and appropriate accommodations were made for their participation. Details regarding the PWA in the sample or how they were identified were not provided, nor were results specific to this subgroup provided. A major limitation to this study was the exclusion of severely aphasic individuals (n = 6), which negatively impacts the representativeness of this subgroup in this study. The highest correlated effect on sexuality post-stroke was "dis/inability to

discuss sexuality” but how this item was interpreted by aphasic and non-aphasic individuals could have differed greatly. Furthermore, the study questionnaire was not described in detail, raising questions regarding validity. Lastly, findings may have limited generalizability because all participants were recruited from hospital rehabilitation programs.

Overall, this study provides somewhat suggestive evidence regarding the impact of aphasia on sexuality and intimacy.

Williams and Freer (1989) conducted a non-experimental survey study to explore the effects of aphasia on marital satisfaction. Spouses of PWA (n = 16) were grouped in accordance to partner’s aphasia severity and completed a ‘knowledge of aphasia’ questionnaire as well as a published questionnaire of marital satisfaction focused on components of emotional support (intimacy), lifestyle, and the sexual relationship. The marital satisfaction questionnaire was completed twice to compare pre/post stroke perceptions. Results of the study revealed no significant relationships between aphasia severity and knowledge of aphasia on components of marital satisfaction. However, marital satisfaction, in all its components, was negatively impacted following the onset of post-stroke aphasia.

Overall, the study presents with acceptable reliability and validity. Both questionnaires reportedly have adequate reliability, validity, and control for potential biases and social desirability. The appropriate statistical analyses were applied to the data. The authors discussed the limitations of the small sample size and a potential selection bias, as only couples considered “emotionally stable” were referred to the study. It is unclear why the authors chose not to report on the three individual components that account for marital satisfaction.

Overall, this study provides suggestive evidence regarding the impact of aphasia on sexuality and intimacy.

Discussion

In summary, the results of the five reviewed studies provide equivocal to suggestive evidence in regard to the effects of aphasia on sexuality and intimacy in spousal relationships. Although weaker levels of evidence, the research agrees that aphasia negatively impacts sex and intimacy within the spousal relationship in various ways. Specifically, it was found that across the reviewed research negative

effects included decreases in feelings of intimacy, frequency of sexual interaction, and satisfaction with sex life. It was interesting to note that studies involving only spouses of PWA had specific results pertaining to a perceived loss of intimacy with their partners. However, the findings of this review should be approached with caution due to the inherent limitations of each study. Many of the studies are dated beyond this decade and only involved small, non-diverse samples. As well, many of the studies lacked detail in their audibility, analytical rigour, and failed to report potential biases. In conclusion, the findings from this critical analysis should be given some consideration when working with those affected by aphasia. Findings should also be used to inspire future research. Future studies should include larger and more representative samples. Further research should look to include PWA outside of spousal relationships and those who identify within minority groups in regard to sexuality and intimacy. Relatedly, a detailed look into how aphasia and its consequent communication breakdowns interact with decreases in spousal sexuality and intimacy would help guide interventions.

Clinical Implications

The more high-quality research that exists on this topic will lead to better-informed clinicians. SLPs should understand how aphasia might affect sexuality and intimacy and consider addressing it with their clients if they feel it is appropriate. By beginning the discussion with clients, it may lead to better quality of life outcomes and assist in part to clients getting back to their pre-stroke life participation.

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