

Critical Review:

What are the characteristics of caregiver burden that affect caregiver well-being (e.g., mental health, stress, quality of life, etc.) in individuals providing support to adults with dysphagia?

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The present study critically evaluates research on the presence and characteristics of caregiver burden associated with caregivers of care recipients with dysphagia. Included is a critical review of six articles pertaining to various studies and systematic reviews related to this topic. Overall, the results of this review suggest that dysphagia symptoms are associated with increased emotional burden, physical burden and anxiety levels in care givers. Furthermore, this study suggests that dysphagia may be an independent predictor of caregiver burden. Future research should be conducted in order to further explore this topic and facilitate implementation of interventions to improve the quality of life for caregivers of this population.

Introduction

Dysphagia is a swallowing impairment involving any difficulty with moving ingested material (food and liquid) and/or secretions from the mouth to the stomach, resulting in an increased risk for nutritional (malnutrition, dehydration) and/or respiratory outcomes (penetration, aspiration, choking). Swallowing impairments can impact individuals at any age and result from a variety of sources including congenital anomalies, structural change, and/or medical conditions. Some common illnesses and diseases associated with dysphagia are stroke, dementia, head and neck cancer, amyotrophic lateral sclerosis, and brain injury (Namasivayam-MacDonald & Shune, 2020). The outcomes of dysphagia can also reach beyond health measures, negatively impacting an individual's social participation, quality of life, and increased feelings of anxiety and depression (Namasivayam-MacDonald & Shune, 2018). These outcomes not only affect the individuals with dysphagia, but also their families and friends, and especially those who act as their caregivers.

Caregiver burden is a term that encompasses the overall stresses that individuals feel when caring for family members or friends (also referred to as informal caregiving), and these stresses stem from the needs and demands of the person with a medical/neurological condition (Namasivayam-MacDonald & Shune, 2020). Across the spectrum of medical diseases and illnesses, the burden of care placed on informal caregivers is largely overlooked and under-researched, contributing to decreased health, chronic stress, and feelings of depression and anxiety. Caregiver burden has been investigated at length in various populations (e.g., stroke, neurodegenerative diseases), but the unique

aspects of caregiver burden in dysphagia have not been studied until recent years.

The existing literature has shown that illnesses and disorders associated with dysphagia change the daily living and mealtime habits of patients, meaning they change the daily lives of caregivers as well (Arslan, Demir, & Karaduman, 2017). Caregivers experience decreased interaction during mealtimes which can result in less social participation with family members, and discourage caregivers and patients with dysphagia from eating meals outside of their home. Caregivers often become responsible for dysphagia care because they receive the training for diet and fluid modifications, proper positioning, and strategy implementation (Arslan et al., 2017). Namasivayam-MacDonald and Shune (2018) found that the need for feeding tubes and their associated risks and maintenance in dysphagia patients was significantly associated with caregiver burden. Individuals providing care also take on the increased financial, emotional, psychological, and time commitment demands for dysphagia-specific needs (Arslan et al., 2017; Howells, Cornwell, Ward, & Kuipers, 2020; Namasivayam-MacDonald & Shune, 2020). Another unique aspect reported was the lack of social supports in the form of support groups for caregivers of those with dysphagia (Namasivayam-MacDonald & Shune, 2020; Shune & Namasivayam-MacDonald, 2020).

Namasivayam-MacDonald & Shune (2020) provided a comprehensive review of the existing literature on dysphagia-related caregiver burden, but the authors acknowledged that there has been less focus on this clinical population compared to other groups, and no standardized assessment tools have been developed to study caregiver burden specific to dysphagia. The

aim of this paper is to critically appraise the current literature to identify the characteristics of caregiver burden that affect caregiver well-being (e.g., mental health, stress, quality of life, etc.) in individuals providing support to adults with dysphagia.

Objectives

With the growing population of aging persons in the world, there's an increased reliance on informal caregivers to meet the needs of older adults with chronic health conditions (Shune & Namasivayam-MacDonald, 2020). There has been literature produced with regards to caregiver burden found in caregivers of individuals with chronic health conditions such as dementia. However, there has been less clinical and research focus on caregivers of individuals with dysphagia. The majority of published literature related to dysphagia in older adults focuses primarily on care recipients, with limited attention provided to the needs of the family (Shune & Namasivayam-MacDonald, 2020). Upon doing some research on caregiver burden, we saw this discrepancy in the databases with less research available to describe the burden that caregivers of individuals with dysphagia face. For this reason, we chose to focus our project on completing a review and summarizing the results of the limited data available on this topic. The aim of this paper is to provide a comprehensive review of the existing literature to guide clinicians on the best way to support primary caregivers of our patients with dysphagia.

Methods

Search Strategy

Articles related to the topic of interest were discovered using the following search databases: PubMed, Google Scholar, and Western Libraries. The following search terms were used: (dysphagia) OR (swallowing difficulties) OR (feeding difficulties) AND (caregiver burden) OR (carer burden). Reference lists of previously selected articles were reviewed to obtain further relevant articles.

Selection Criteria

Studies selected for inclusion in this critical review were required to investigate caregiver burden and care recipients with dysphagia.

Data Collection

Results from the literature yielded six articles congruent with the previously mentioned search strategy and selection criteria. Two of these studies involved a

survey research design (Arslan et al., 2017; Shune & Namasivayam-Macdonald, 2020), one study involved a qualitative research design (Howells et al., 2020), one paper involved a systematic review (Namasivayam-Macdonald & Shune, 2018), one study involved a literature review (Shune & Namasivayam-Macdonald, 2020), and the last study involved a non-randomized between groups clinical trial (Namasivayam-Macdonald & Shune, 2020).

Results

Arslan, Demir, & Karaduman (2017) conducted survey research to investigate anxiety in caregivers of neurological patients with dysphagia and the link between their anxiety level and patient related factors. 103 patient and caregiver dyads were included who were over 18 years of age, had a dysphagia diagnosis for over one month, and scored a 3 or higher on the Eating Assessment Tool 10 (EAT-10, a screener used to determine the symptoms and severity of dysphagia). The authors collected patient demographic information for diagnosis, age, gender, height, weight, types of feeding, the level of dependency in eating and drinking, dysphagia duration, and history of previous dysphagia treatment, Turkish EAT-10 (T-EAT-10) for oropharyngeal dysphagia, penetration aspiration scale (PAS). Arslan et al. (2017) collected caregiver demographic information along with their anxiety level using the State-Trait Anxiety Inventory (STAI). The control group for this study were 30 dyads of caregivers and neurological patients without dysphagia.

Their analyses revealed that caregivers of patients with dysphagia scored higher on the STAI than caregivers of patients without dysphagia, therefore, had higher levels of anxiety. However, the only significant correlation between anxiety in caregivers and patient-related factors was with history of previous dysphagia treatment. Arslan et al. (2017) theorized that caregivers of neurological patients with dysphagia may experience additional caregiver burden due to a greater monetary need required for care, leading to higher levels of anxiety. The authors of this study used reliable and valid measurement tools to determine inclusion criteria and anxiety levels in their sample. The sample size was a representative group with a wide variety of dysphagia severities. Their findings indicate that caregivers of neurological patients with dysphagia experience a higher level of anxiety than caregivers of those without dysphagia, meaning that clinicians need to offer the support to match those increased needs. This study provides compelling evidence with regards to emotional and physical burden existing in caregivers of individuals with dysphagia.

This qualitative study (Howells, Cornwell, Ward, & Kuipers, 2020) used individual, semi-structured interviews to examine the perspective of caregivers who were supporting a person with dysphagia across various etiologies (e.g., stroke, Parkinson's disease, etc.). They asked questions to explore the impact of dysphagia on the lives of primary caregivers. Howells, Cornwell, Ward, and Kuipers (2020) used convenience sampling methods through government health services and a private practice clinic for SLP services. They included participants who were older than 18 years old, the primary caregiver for someone who received a diagnosis of dysphagia in adulthood, had sufficient English language skills, and had the cognitive ability to participate in the interviews. The study was comprised of 15 participants (13 females, two males) between the ages of 30-91 years old ($M = 72.7$) who were providing care for 14 unique individuals with dysphagia. All the caregivers were a partner, child, or friend who was living with the person with dysphagia. Each interview was recorded for verbatim transcription and they concluded the interviews when they determined that data saturation had been reached (when no new information was gained from the interviews).

Howells et al. (2020) conducted a thematic analysis on the data using a semantic approach to identify themes that were common between the participants' interviews. They found that present in all caregivers was the theme that "you do whatever it takes", and this theme influenced the three common sub-themes identified in the interviews: being a caregiver, support networks, and the practicalities of living with dysphagia. Being a caregiver was characterized by the complexity of care needed, especially when the person's needs included communication support, their own individual factors which impacted their ability to provide care, understanding how dysphagia had changed the individual's life, and their own feelings of frustration, stress, and embarrassment. The caregivers in this study indicated that having family and friends as their own support network was very important and helpful, and all participants expressed how much they valued SLP support and advice for dysphagia as well as communication needs. The caregivers felt that supporting mealtimes, especially when eating out of the home, required a lot of supports and strategies, which lead to a decrease in eating meals away from home. The researchers concluded that there was a strong sense that these caregivers would "do whatever it takes" to ensure that they provided the best care, but it was crucial to have their own support networks and SLP support in the process.

One limitation of this study was the convenience sampling method used in participant selection - this may not have provided the most representative group as the sample. Moreover, the caregivers interviewed were mostly females who were over the age of 65 and retired. The individuals with dysphagia only showed a mild severity, indicated by the minor changes in their diet and fluid modifications, so this study did not capture the experience of those caring for a person with severe dysphagia. These results should be interpreted with caution, however, the information gathered from these interviews is valuable in guiding clinical practice. These findings indicate that SLPs must account for the practical and psychosocial needs of caregivers of individuals with dysphagia, as well as realize the importance of supporting them not only with dysphagia needs, but also with their communication deficits. This study provides somewhat suggestive evidence with regards to emotional and physical burden existing in caregivers of individuals with dysphagia.

Namasivayam-MacDonald & Shune (2018) produced a systematic review which synthesized results of published literature related to caregiver burden in caregivers of community-dwelling older adults with dysphagia. This systematic review was guided by methods from the Cochrane group. A comprehensive literature search was conducted by a librarian and the electronic databases were listed in the systematic review article. References listed and citing literature was cross-checked to ensure that only relevant articles with published abstracts were considered. The methodological quality of the accepted studies was assessed using critical appraisal tools from the Joanna Briggs Institute and chosen based on the type of study. The initial search yielded 2331 articles published through April 2018. However, through review and exclusion criteria, the final inclusion list was narrowed down to 4 articles - two of the articles were cross-section studies, one was a qualitative study, and one was a cohort study.

The results of this systematic review concluded that, overall, increased caregiver burden was associated with the presence of dysphagia in care recipients across all four studies. Worsening feeding-related behaviours over time were associated with increased burden. The use of feeding tubes was more frequently associated with "heavy burden". Dysphagia and the necessity for feeding tubes were also associated with increased emotional and psychological caregiver burden related to balancing risks associated with choking, allowing care recipients to eat desired foods, nutritional intake concerns, and the grieving and acceptance processes related to tube use. A strength of

this study is that it included more diverse populations across studies. Another strength is that limitations were acknowledged by the authors. Additionally, the systematic review included more than one article, thus, increasing the evidence available for our critical review. Limitations included that the articles were a result of a comprehensive search strategy using specific keywords and medical subject headings. The results may also have been limited by the inclusion criteria. Additionally, only 50% of articles were reviewed in duplicate during their data extraction process. Based on our observations, additional factors existed that could contribute to the evidence based on our critical review. This systematic review included care recipients post stroke and individuals with neurodegenerative diseases as care recipients across studies. It may be questionable as to whether the conclusions are specific to these populations, as this paper is looking for caregiver burden across the general population with dysphagia. Additionally, while the presence of increased burden was concluded, dysphagia-related burden was not the primary focus of the literature analyzed. Therefore, the exact nature of the burden and underlying contributors were not delineated and the present paper seeks to review literature on dysphagia-related caregiver burden. Finally, the majority of caregivers across the four studies were spouses, with one study recruiting mainly caregivers that were children.

Based on these presented factors, overall, this study presents suggestive evidence of increased caregiver burden in caregivers of community-dwelling older adults with dysphagia. This study brings to attention the need for valid and reliable tools to measure both the severity of caregiver burden and swallowing function in order to understand how swallowing impairments can contribute to caregiver burden. This may also help develop evidence-based interventions to support caregivers, which would in turn reduce levels of burden when caring for older adults with or without dysphagia. Exploring successful interventions for caregivers and care recipients may have the potential to improve the quality of life for both individuals.

Namasivayam-MacDonald & Shune (2020) explored the type and severity of caregiver burden experienced by adults caring for community-dwelling older parents reporting symptoms of dysphagia. Additionally, they looked at whether the presence of self-reported dysphagia symptoms are an independent predictor of emotional, physical, and/or financial burden for adult child caregivers. The study was completed by extracting data on 895 dyads from Round 1 of the National Health and Aging Trends Study (NHATS) and its companion study, the National Study of Caregiving (NSOC), collected in 2011. One hundred

and eighty-two of those eight hundred and ninety-five individuals were caregivers of recipients with swallowing difficulties. All the individuals were adult child caregivers, and the majority were female and/or Caucasian. Exclusion criteria was noted. During the NSOC, caregivers were asked about perceived difficulty of caregiving, restrictions on social and economic participation, how often they helped their parents, how often they argued with their parents, how many hours per day they spent helping their parents, and other things related to their caregiving role and personal life. They were also asked questions related to appreciation and if they were lonely and depressed. In order to determine type and severity of burden, caregivers were asked about financial, emotional, and physical difficulties related to caregiving and to rate the amount of difficulty on a Likert scale.

Through binary logistic regression analyses, this study concluded that this group of caregivers suffer from both emotional and physical burden, but not as much financial burden, in the presence of a care recipient with swallowing difficulties. Forty percent or more of these caregivers reported moderate to severe physical and/or emotional burden. Therefore, swallowing difficulties reported by a parent is a significant independent predictor of increased physical and emotional burden in the caregivers. Additionally, caregivers of parents with swallowing difficulties were increasingly more likely to report feeling lonely than caregivers of parents who did not report any swallowing impairments. A strength of this study is the large sample size that allows it to be further generalized. However, there were also limitations to this study, some of which were acknowledged by the authors. The study used a self-reported question on swallowing difficulties as the measure of "swallowing status". Thus, we do not know how severe the swallowing difficulties were and whether more or less severe cases would increase or decrease the burden explained by this study. The study also used cross-sectional data, which limits the ability to determine a causal relationship. In addition, the majority of caregivers were female. This means that the data presented may not apply to male caregivers. Information on caregiver race and/or ethnicity and co-residence was not included in the analyses. However, the acknowledgment of these limitations by the authors acts as an additional strength to the study.

Overall, due to the strengths and limitations mentioned, this study is suggestive of the presence of self-reported dysphagia symptoms being an independent predictor of emotional and physical burden for adult child caregivers. This study brings to light the importance of increased education for caregivers and

attending to swallowing status or identifying swallowing impairments early on.

Shune & Namasivayam-MacDonald (2020) conducted a literature review and summarized the findings to better capture caregiver burden that is specific to dysphagia and how clinicians can use this knowledge to guide more targeted intervention, maximize health, and increase quality of life in caregivers. The authors stated that there are a limited number of studies which focus solely on caregiver burden related to dysphagia, but the studies that have been conducted produced similar results. Shune & Namasivayam-MacDonald (2020) found that third-party disability - limitations of activity and participation due to their family member's/friend's disability - was common among caregivers of those with dysphagia. More specifically, family members saw changes in their daily and mealtime routines, experienced increased levels of negative emotions (distress, fear, frustration, sadness, and isolation), lost social connections, and had a decreased quality of life or satisfaction with life. The researchers found that across studies, specific to this population, dysphagia was found to be an independent predictor of caregiver burden. A lack of education surrounding dysphagia, how to provide the best care, and being unprepared for the severity and longevity of dysphagia also contributed to the feelings of third-party disability and increased caregiver burden. These authors found that support groups were beneficial for those providing care to individuals with dysphagia because they offer a social network and promote information sharing. However, more research needs to be completed to determine if this can significantly decrease caregiver burden.

Overall, the researchers stressed that when treating dysphagia, clinicians must remember the widespread impact the disorder has on caregivers. Family members and friends must feel supported when they are providing care, and organizing support groups for families and delivering thorough education and training may lessen the impact of caregiver burden on these individuals. Clinicians must remember to tailor their services to ensure quality of life not only for the patient, but for their caregivers as well, as studies have shown that dysphagia can have a unique impact on their lives. These findings present real, tangible guides for ways that clinicians can shape their future practice, but they were derived from a limited pool of research studies due to the lack of coverage in the literature. The authors provided a great summary of the existing literature, pointing out the limitations where they saw them, and controlled for differing variables when comparing results, which is a strength of their paper. This study provides highly suggestive evidence with

regards to emotional and physical burden existing in caregivers of individuals with dysphagia.

Shune & Namasivayam-MacDonald (2020) conducted a cross-sectional study through survey research to explore dysphagia's independent role in increasing the likelihood of burden in caregivers of older adults, in addition to the type and extent of caregiver burden. Data included in the study was extracted from the National Health and Aging Trends Study and its companion study, the National Study of Caregiving. Through this data, they explored whether swallowing status was an independent predictor of financial, emotional, and/or physical burden, when controlling for other factors known to contribute to caregiver burden. Of the 422 care recipients included, 17% self-reported swallowing difficulties, 14% reported difficulty eating by themselves, and 16% who received help eating. The researchers found that dysphagia was only associated with emotional burden, when controlling for other factors known to influence caregiver burden. Of the spouses caring for partners with dysphagia who reported emotional burden, almost 70% rated the burden as moderate to severe. These caregivers often reported feeling depressed, with over half having felt depressed or hopeless at least several days in the month prior to being interviewed. The emotional burden found in this study is consistent with the anxiety, sadness, and isolation previously noted in caregivers of individuals with head and neck cancer, stroke, and other neurological diseases who experience dysphagia. In addition, third-party disability may also negatively influence the health and well-being of the care recipient with dysphagia.

Overall, the researcher contributed to the importance of not only looking at how care recipient variables influence the caregiver and how caregiver variables influence the care recipient, but also looking at how the health of the dyad is influenced by these variables and changes over time. Future research should further explore the relationship between caregiver, care recipient, and dyadic health in the presence of dysphagia in order to identify potential moderators of this relationship and what to target in therapeutic intervention. Limitations acknowledged by authors included relying on a single question for determining dysphagia status and the presence or absence of burden. An additional limitation acknowledged was that race and ethnicity data were not known for caregivers, but are known to influence the caregiving experience. The authors had great descriptions of their source material and appropriate statistical analysis were conducted. The authors also did a good job in breaking down "burden" into specific parts to help explain how it can affect a caregiver's life and aid clinicians in identifying what

kind of support to provide. This study provides highly suggestive evidence with regards to emotional burden existing the caregivers of individuals with dysphagia.

Discussion

The following critical analysis sought to determine the characteristics or effects of caregiver burden on caregiver well-being in individuals providing support and care to adults with dysphagia. Six articles were identified for inclusion in this review. Of these articles reviewed, one provided somewhat suggestive evidence (Howells et al., 2020), two provided suggestive evidence (Namasivayam-MacDonald & Shune, 2018; Namasivayam-MacDonald & Shune, 2018), two provided highly suggestive evidence (Shune & Namasivayam-MacDonald, 2020; Shune & Namasivayam-MacDonald, 2020), and one provided compelling evidence (Arslan et al., 2017). Accordingly, the studies provide a suggestive to highly suggestive evidence base for the presence of caregiver burden in caregivers of individuals with dysphagia. The characteristics of caregiver burden found across studies included increased emotional burden, physical burden, and anxiety levels. Additionally, this review provided highly suggestive evidence of dysphagia being an independent predictor of caregiver burden.

This critical review allowed us to examine more recently published articles and contribute to the growing body of literature related to dysphagia and caregiver burden. Our paper provided an overall summary of the characteristics of caregiver burden associated with dysphagia symptoms based on these articles. In contrast to the limitations, the studies provided strengths that lead to an overall rating of suggestive to highly suggestive evidence base. These strengths included large sample sizes, well-explained statistical analyses and operational definitions, audio-recorded interviews for verbatim transcriptions, and acknowledged limitations.

Limitations were not consistent across studies for the majority of factors. However, the authors of each of the articles acknowledged the limitations. These included self-reported questions for swallowing difficulties, the use of secondary data, non-dysphagia specific data, and using restricted or specific populations with dysphagia studies. A limitation that stood out when conducting our research was the minimal amount of literature available for our research question. The number of articles we could include in our search was limited by this factor. Additionally, four out of the six articles we selected had the same authors. This may have led to potential biases in the way the information was presented. Further research should be

conducted in the future to gain a better idea of the effect of caregiver burden with regards to confirmed dysphagia in care recipients.

While the studies all targeted similar questions, their approaches varied in factors such as sample size, data collection, outcome measures, search criteria, dysphagia identification, care recipient population, and caregiver populations. Although the variety in approaches allowed authors to obtain diverse data on the presence of caregiver burden, Namasivayam-MacDonald & Shune (2018) displayed a good argument. They stated that future research should focus on the standardization of both measurement instruments and terminology, as their review displayed that several operational definitions and tools are being used to diagnose dysphagia and caregiver burden. Studies need to utilize more standardized, valid, and reliable tools in order to better understand the severity of caregiver burden in the presence of defined dysphagia. This would help prevent limitations in studies that we discussed, such as self-reports of dysphagia or indefinite questions to determine the presence of caregiver burden. In turn, this would strengthen the evidence base provided by the studies. As past papers have shown, dysphagia does not exist within an isolated individual only. Rather it may yield psychological strain on the entire family or caregiving unit. For this reason, we must recognize and address the caregiver burden as related to dysphagia in order to improve both caregiver and care recipient outcomes.

Conclusion

Overall, the six articles reviewed in this paper provided a suggestive to highly suggestive evidence base for the presence of caregiver burden in caregivers of individuals with dysphagia. The authors discussed used various study designs and methodologies to investigate the presence of caregiver burden in caregivers of individuals with dysphagia. The characteristics of caregiver burden found across studies included increased emotional burden, physical burden, and anxiety levels. Specific to the dysphagia population, caregiver burden included loss of social connections due to decreased participation in meals outside of the home, increased responsibility for diet and fluid modifications and feeding tube care/maintenance, and increased financial, emotional, psychological, and time commitment demands for dysphagia-specific needs. These factors can contribute to higher levels of anxiety in caregivers of patients with dysphagia compared to caregivers of patients without dysphagia. This review also provided highly suggestive evidence of dysphagia being an independent predictor of caregiver burden.

Clinical Implications

Across the studies discussed in this paper, a few commonalities in the caregiver experience were found that should be incorporated into service delivery. Clinicians should ensure that we are providing enough support and knowledge to caregivers so that they feel supported as well as equipped to handle dysphagia-specific care. Caregivers who viewed SLPs as a source for support felt better about their own abilities as a caregiver. Clinicians should also advocate for the formation of support groups for caregivers, which would also provide the chance to bring back the social connections that can be lost as a result of dysphagia and feedings needs.

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