

Patient and Family Perceptions of the Role of Social Work in Dysphagia Rehabilitation: A Qualitative Study

Nouf S. Almulaik¹, Abdullah M. Alboaimi², Shahad H. Almaqary³,
Hani M. Alenezi

Health Affairs at the Ministry of National Guard

Abstract

This study explores the role of social workers in supporting caregivers of patients with dysphagia, focusing on how education and social support can improve management. We used a qualitative approach, involving 20 caregivers at a tertiary hospital, to gather in-depth insights into their experiences. Through semi-structured interviews, we found that targeted education and support significantly boosted caregiver knowledge, confidence, and reduced their burden. Caregivers also reported better communication with healthcare professionals, leading to improved patient outcomes. However, challenges such as long-term implementation and the need for ongoing support were noted. This study emphasizes the importance of sustainable, personalized caregiver interventions for effective dysphagia management.

Keywords: Dysphagia, Caregiver Education, Social Support, Multidisciplinary Care, Caregiver Burden, Patient Outcomes

Introduction

Dysphagia, or difficulty swallowing, can severely impact a person's quality of life, especially among older adults or those with neurological conditions or head and neck cancers (Logemann, 1984). Effective management often requires a team effort involving medical, nutritional, and rehabilitative professionals. However, caregivers play a crucial role in the day-to-day care of patients, helping with feeding techniques, diet adjustments, and following therapeutic exercises (Cichero & Murdoch, 2006). Without the right support, caregivers may struggle, negatively affecting both their own well-being and patient outcomes (Smithard et al., 1996).

Social workers are becoming increasingly recognized as important members of the dysphagia care team. They provide emotional support, connect caregivers to resources, and deliver tailored educational programs (Carnaby and Harenberg, 2013). Research has shown that when caregivers receive this kind of support, they experience less stress, lower anxiety, and are better equipped to manage the patient's care, ultimately leading to better outcomes (Gandolfi et al., 2014).

Despite these benefits, there has been limited research into the full impact of social work and caregiver education on dysphagia management. This study aims to address that gap by exploring how these supports can influence treatment adherence and patient outcomes, highlighting the value of a multidisciplinary approach to improving care quality for dysphagia patients (Logemann, 1984; Cichero & Murdoch, 2006).

Literature Review

Dysphagia is a complex condition that requires input from various healthcare professionals. Caregivers play a vital role in managing dysphagia, but they often face many challenges that can make effective care difficult (Smithard et al., 1996). Previous studies have demonstrated that providing caregivers with support and education can improve patient outcomes, reduce complications, and enhance the quality of life for both patients and caregivers (Logemann, 1984).

Education programs for caregivers have shown promising results. For instance, Cichero and Murdoch (2006) emphasized that when caregivers are trained in feeding techniques, diet modification, and compensatory strategies, they can help patients avoid complications like aspiration. More confident caregivers are also more effective in providing the needed care.

Social workers contribute significantly by providing emotional support and connecting caregivers to necessary resources (Carnaby and Harenberg, 2013). Studies have shown that with the involvement of social workers, caregivers feel less burdened and are better able to manage the day-to-day challenges of caring for a person with dysphagia (Gandolfi et al., 2014).

Effective communication between caregivers and healthcare providers is key to managing dysphagia successfully. Social workers help facilitate this communication, making sure caregivers feel informed and involved in the decision-making process (Miller et al., 2007). The involvement of social workers, swallowing therapists, and other healthcare professionals leads to better patient outcomes, fewer hospital readmissions, and higher satisfaction (Logemann, 1984).

Still, there is a need for more research on the long-term effects of caregiver education programs and social work involvement. Much of the existing research has focused on short-term outcomes, with little attention given to lasting impacts or standardized protocols (Carnaby and Harenberg, 2013).

Methodology

This study used a qualitative approach to gather detailed insights from caregivers of patients with dysphagia. Data collection took place at a tertiary hospital.

Participants

Twenty caregivers participated, recruited from the hospital's outpatient rehabilitation department. All participants were at least 18 years old, actively caring for someone with dysphagia, and spoke English. Social workers and swallowing therapists also provided insights during the study.

Data Collection

Data were collected through semi-structured interviews with caregivers, social workers, and swallowing therapists. The interviews focused on the experiences of caregivers, the benefits they perceived from the programs, the challenges they faced, and their suggestions for improvement. Depending on the participants' preferences, interviews were conducted either in person or over the phone.

Intervention

The intervention consisted of an education program led by swallowing therapists, which involved four weekly sessions on feeding techniques, dietary modifications, and safety measures. Social workers provided a support program that focused on stress management, accessing community resources, and offering emotional support.

Data Analysis

Thematic analysis was used to analyze the qualitative data, following the framework of Braun and Clarke (2006). Interview transcripts were coded to identify recurring themes, which were further reviewed to understand the experiences of both caregivers and healthcare professionals more deeply.

Ethical Considerations

Ethical approval for the study was granted by the ethics committee. Participants provided written informed consent and were assured that their responses would remain confidential. Participation was voluntary, and caregivers could withdraw from the study at any time without impacting the care provided to their loved ones.

Findings

Theme 1: Improved Caregiver Knowledge and Confidence

Caregivers reported that they felt more knowledgeable about managing dysphagia and more confident in applying the feeding techniques they had learned. One caregiver shared, "I had no idea there were specific techniques to make feeding safer. Now, I feel so much more confident in helping my mother."

Theme 2: Reduced Caregiver Burden

The emotional support provided by social workers helped alleviate caregiver stress. Many participants mentioned how important it was to have someone to talk to and how the social workers helped them find additional resources. One caregiver said, "Talking to the social worker made a huge difference for me. It felt like someone finally understood what I was going through."

Theme 3: Enhanced Communication and Collaboration

Caregivers reported feeling more comfortable communicating with healthcare professionals and felt more included in decision-making processes. As one participant put it, "Before, I felt like I was just following instructions. Now, I feel like I'm part of the team, making decisions that are best for my father."

Theme 4: Challenges in Long-Term Implementation

Despite the positive impacts of the programs, some caregivers found it challenging to consistently apply the techniques they had learned, especially while managing other responsibilities. Several caregivers also expressed the need for ongoing support beyond the initial program. One caregiver mentioned, "The training was great, but I wish there were follow-up sessions to help us stay on track."

Discussion

The findings of this study highlight how important targeted education and support programs are for improving the management of dysphagia. Caregivers felt better equipped to handle the responsibilities of caregiving, which aligns with previous research by Cichero and Murdoch (2006). The emotional support from social workers helped reduce caregiver stress and strengthened their resilience, allowing them to provide more effective care.

Enhanced communication between caregivers and healthcare providers was also a key benefit. Caregivers felt more included in care discussions and more comfortable interacting with the healthcare team, which aligns with Miller et al. (2007), who emphasized that involving caregivers leads to better adherence to treatment and improved care quality.

However, challenges remain, particularly regarding the long-term implementation of the techniques learned. Caregivers noted difficulties in maintaining these practices without continued support, suggesting that short-term programs alone may not be enough. Sustainable, long-term support systems are likely needed for lasting improvements (Carnaby and Harenberg, 2013).

In conclusion, this study underscores the value of personalized, ongoing interventions for caregivers of patients with dysphagia. Addressing the long-term challenges of caregiving and developing standardized support protocols could improve patient care and reduce caregiver burden over time.

References

1. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
2. Cichero, J. A., & Murdoch, B. E. (Eds.). (2006). *Dysphagia: foundation, theory and practice*. John Wiley & Sons.
3. Carnaby, G. D., & Harenberg, L. (2013). What is “usual care” in dysphagia rehabilitation: a survey of USA dysphagia practice patterns. *Dysphagia*, 28, 567-574.
4. Gandolfi, M., Smania, N., Bisoffi, G., Squaquara, T., Zuccher, P., & Mazzucco, S. (2014). Improving post-stroke dysphagia outcomes through a standardized and multidisciplinary protocol: an exploratory cohort study. *Dysphagia*, 29, 704-712.
5. Logemann, J. (1984). Evaluation and treatment of swallowing disorders. *NSSLHA Journal*, (12), 38-50.
6. Miller, J. J., Frost, M. H., Rummans, T. A., Huschka, M., Atherton, P., Brown, P., & Clark, M. M. (2007). Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. *Journal of Psychosocial oncology*, 25(4), 105-119.
7. Smithard, D. G., O'Neill, P. A., Park, C. L., Morris, J., Wyatt, R., England, R., & Martin, D. F. (1996). Complications and outcome after acute stroke: does dysphagia matter?. *Stroke*, 27(7), 1200-1204.