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ARTICLE

'Finishing that plate of food …' The role of the nurse caring for the patient with dysphagia

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Objective: Dysphagia is a 'hidden' disorder that can present with a range of consequences including fatality. It is important for intervention to be timeous and adopt a team approach, with each professional displaying understanding of both dysphagia and each other's roles. The nurse is at the epicentre of service provision in hospitals and is ideally positioned to collaborate with the speech-language therapist to manage dysphagia. The state of collaboration, however, is not ideal. Reasons perpetuating this need, to be understood to facilitate improved care by nurses for patients with dysphagia.
Design: The aim of the study was to describe the caseload of dysphagia patients seen by nurses, their experiences caring for patients with dysphagia, and nurses' views on inter-professional training.
Setting: A qualitative, exploratory study was conducted with nurses working at two government hospitals in Johannesburg, South Africa.
Subjects: An open-ended semi-structured interview was conducted with nine nurses working with adult patients. Descriptive and inductive thematic analysis was used, comparisons were made between the responses, and data were categorised according to emerging themes.
Results: Results confirmed that while experience improved care, gaps in dysphagia knowledge, inexperience and contextual challenges adversely impacted efficiency of dysphagia care. Inter-professional training and recognition of nurse intervention positively impacted on interactions with dysphagia.
Conclusion: Nurses have a central role in dysphagia care in acute settings. The study confirmed that multidisciplinary management, inter-professional training and inter-professional relations contribute to overall improved service delivery in dysphagia in acute settings, with nurses at the epicentre.

Keywords dysphagia, dysphagia care, nurse, speech therapist, acute, training, multidisciplinary, education

Background

Dysphagia is a 'hidden' disorder that, if not efficiently and effectively managed, could present with food aversion, malnutrition, dehydration, aspiration pneumonia or death. Therefore, timeous intervention and team understanding of dysphagia is an advantage. While international studies have interrogated the role of the nurse in various aspects of dysphagia, such as screening, implementation of feeding strategies and reinforcement of speech language pathologist (SLP) recommendations for feeding,[1,2] similar studies in developing contexts such as South Africa are lacking. In developing contexts specifically, there is a need for the speech-language therapist (SLT) to identify and intervene earlier with patients who have dysphagia, to prevent comorbidities, complications, increased medical expenses and increased length of hospital admission. However, the question of how remains.[3,4] The nurse at the epicentre of service provision at hospitals, either as part of routine care or during medication dispensing, is the first professional to observe and identify eating and/or drinking difficulties, i.e. dysphagia in a patient, hence may be ideally positioned to fulfil this role via collaborations with the SLT and dietitian.

Nurses assist patients with eating,[5] but their role within the eating routine is not clearly delineated and defined, leaving health professionals, as well as nurses themselves, unclear about 'professional boundaries', roles and responsibilities. The training received by nurses in South Africa specific to dysphagia precipitates this lack of clarity. This results in conflict and misunderstanding of how, when and to what extent the nurse fits into the team managing the patient with dysphagia.

Methodology

This study aimed to determine the level of understanding about dysphagia by nurses who worked at two government hospitals in Johannesburg. The study looked specifically at the type of dysphagia cases seen in the wards, how nurses perceived their role with these patients and, based on this, aimed to determine the need for information provision and inter-professional training in dysphagia. A qualitative, exploratory research design was used. Convenience sampling was used to recruit nine participants. The participants were nurses working within general medical adult wards. An open-ended semi-structured interview was used to gather data. The interviews were conducted by the researcher, a qualified SLT with experience as a clinician in dysphagia and with experience as an academic and researcher in mixed-methods and qualitative research methodology. Ethical approval to proceed with the study was obtained from the University of the Witwatersrand Human Research and Ethics Committee (Medical) (Protocol Number M110536) and all ethical considerations pertinent to the study were adhered to. A pilot study confirmed reliability and validity of the questions. Descriptive and inductive thematic analysis was used. Participants had to be employed within the nursing sphere, working with adult patients in either general medical, ENT or neurological wards. Nurses working in intensive care, critical care and trauma units were excluded, due to the specialised training needed to work in these wards. Each interview was conducted

in an unoccupied room within the ward that was available at the time, and was set up with two chairs and a table. Privacy to ensure confidentiality was maintained. The interview was semi-structured and questions covered the following aspects:

- the frequency and regularity of caring for patients with dysphagia;
- a description of caseload with special attention to patients with dysphagia, and what the most common types of difficulties related to dysphagia were encountered;
- general understanding and knowledge of dysphagia and, linked to this perception, attitude and confidence managing patients with dysphagia;
- views on further training in dysphagia;
- views on inter-professional training.

Comparisons were made between the responses from the different participants, and the responses were subsequently categorised according to emerging themes. To ensure trustworthiness of data, the researcher made use of within and between-nurse comparisons, i.e. within the same ward in one hospital, between wards in the same hospital, and then across the same type of ward between the two hospitals.

Results

The participants were nurses of different designations, from enrolled nursing assistants to qualified nurses. Similarly, their experience varied, ranging from 1 to 15 years. As noted, nurses from wards seeing patients with dysphagia were recruited, with nurses working in ICU, critical care and trauma units excluded because of any specialised training pertaining to swallowing that they may have received.

Description of patients with dysphagia seen in the wards

Patients presented with dysphagia due to stroke, oral lesions, oral candida and lip carcinomas secondary to HIV, advanced age and traumatic brain injury, which were reported to be the most common associated medical conditions. Of these, stroke was most frequently aligned with dysphagia. Participants were able to identify overt symptomatology such as choking and coughing, though subtle presentations of oropharyngeal difficulties were not known:

> 'Yes, we see lots of patients with strokes, severe ones, and more often than not, they can't eat and they choke when they drink water.'

> 'Of the patients with strokes, we just help them to eat and get the food in as best we can, not really with their swallow. As long as at least half the plate is finished.'

Participants also aligned lowered immune function and HIV with swallowing difficulty. Explicit lesions such as trauma, cancer or sores in the mouth and throat area were identified by the participants as the easiest reasons to predict a swallowing difficulty. The more visible the sign, the more painful and/or difficult the swallow. A majority of the participants ($n = 8$) felt that HIV as opposed to stroke resulted in a more painful and difficult swallow.

> 'Patients with HIV/AIDs experience pain when they swallow – they have many sores. So you just know that this patient is not going to be able to eat or drink. At least with a stroke, the patient can sometimes have something, but a sore on the lip or tongue, no, no, no, no way.'

Based on the above quotes, when comparing a patient with a stroke and a patient with sores, there seemed to be poor differentiation between painful swallowing, i.e. odynophagia, and impaired swallowing, i.e. dysphagia. While participants were alert to signs of distress from the patient, they did not mention silent aspiration or food residue after a meal, which was likely to cause more harm.

With older patients, confusion and refusal of food due to ageing and possible decreased cognitive acuity, i.e. presbyphagia, as opposed to aspects of difficulty with the actual swallowing mechanism, i.e. dysphagia, were not differentiated nor considered to coexist:

> 'Very sick geriatrics, they refuse to eat or drink anything, and then what do you do? I sometimes force them, or bribe them. I tell them that if they eat they can go home, but it doesn't always work. These patients I don't think they really have a problem, they are just old and tired.'

> 'Oh no – the old ones who are confused, they are very frustrating to work with. They are old so you have to respect them, but then they just don't want to listen. I just have to give up. They refuse.'

Thus, understanding the difference between presbyphagia and dysphagia did not come across clearly from the participants, suggesting the need for additional information.

Nurse perceptions of patients with dysphagia

A majority of participants reported feeling 'disturbed' by patients presenting with swallowing impairments. Feelings conveying agitation, irritation, apathy and trauma were expressed, as nurses reported feeling helpless in their attempts to assist and feed patients with dysphagia who were either not cooperative or not fully oriented to their surroundings. Nurses felt responsible for dealing with the emotional trauma and frequently the death of patients with dysphagia. In isolation these aspects, they noted, were not remarkable but, coupled with long working shifts, insufficient staff, equipment malfunction, general ward shortages, personal difficulties and insecurities, negative feelings towards patients and their jobs transpired.

A minority of nurses ($n = 3$) expressed confidence and empowerment when working with patients with dysphagia. The responses from these three nurses suggested that the more confident they were, the less disturbed or apathetic they felt working with dysphagia. These three nurses each had between 8 and 15 years of experience respectively. Furthermore, these nurses very likely, given their years of experience, were able to provide more detailed information and more accurate descriptions of the swallowing and swallowing difficulty experienced by patients. Overall, however, the majority of participants felt that they were not sufficiently prepared at an undergraduate level to identify, intervene or refer patients presenting with a swallowing impairment.

Disturbance

Disturbance, frustration and irritation were felt due to the time-consuming nature of dysphagia care, which resulted in nurses

having insufficient time to complete other duties and routines that they felt were more important:

> 'It is irritating – I feel like I need to beg them to eat just so that I can give them their medication.'

> 'I know that it's hard for them and it's hard to be hungry all the time, but sometimes I think they are not even trying. I mean really, what is so difficult about eating?'

Participants were required to complete numerous tasks in a day. With regard to their role in ensuring that the patient ate, they felt that the patient could display more effort to try and eat, as they felt that this was an easy activity/routine for the patient. By displaying more effort, it would inadvertently ease their role (i.e. the nurses'), hence the participants were disturbed when this was not seen as they also realised the implications of nutrition and recovery:

> 'It's painful, I have to ensure they get their nutrients so can take their medicine so can be discharged from the hospital.'

> 'It's very difficult, I can't give them their meds [medication] because they don't eat, Therefore, [they] cannot improve.'

Apathy

Although in the minority, a few nurses were apathetic about work and some about working with patients with dysphagia:

> 'I don't feel like anything. What is the point, I just have to do my work.'

> 'Dysphagia and patients who can't swallow is not a major issue. I've seen so much worse. You just handle it and do what you can.'

> 'My job is to make sure that the patient finishes that plate of food. How that happens – I don't have time or energy to think about it – as long as it is all gone … .'

It was clear that the participants worked under less than ideal conditions that required them to prioritise where and how they focused their energy so as to cope emotionally and psychologically. Ultimately, aspects that the SLT considered important were not regarded as equally so by the nurse. Lack of acknowledgement and support from management structures contributed to participants feeling that they were in a hopeless situation. They did not envisage change to work circumstances, additional support from management or even acknowledgement from management for their contribution to patient care.

Confidence

The confidence of a minority of nurses when working with patients who have dysphagia was attributed to the intermittent recognition of their role with the patient by medical or allied health professionals. They believed that their skills and understanding of swallowing and swallowing difficulty improved over time. Acknowledgement from peers and managers impacted positively on their service delivery, culminating in positive feelings of autonomy and recognition:

> 'It's good to be told thank you by the physio or speechie [SLT] – it makes me feel better, like I know what I am doing and makes we want to work with the patient again … .'

In contrast, the nurses who held less positive views about working with patients with swallowing difficulties felt disempowered, disrespected and were generally more despondent about the efficiency of the services they delivered to these patients:

> 'I don't know much about swallowing problems or what to do. When the therapist doesn't explain what she wants you to do or not do with the patient slowly and properly, but talks quickly and then leaves, then I get confused and I'm not sure. I don't know if I will ever know enough about swallowing to help the patients the best I can … .'

Nurses' perceptions of their role with the patient with dysphagia

Five themes emerged: responsibility for adequate nutrition, making referrals, oral care, aspects related to medication provision, and training needs. The participants understood the importance of their role in ensuring that the patient met their nutritional requirements whether orally, or via enteral means. Some participants acknowledged that they did not think about how the food went down, as long as the plate of food was eaten.

Nutrition

All participants concurred that ensuring nutritional intake was their primary role with patients who had difficulty eating. Only three of the nine participants were aware of the need to implement modifications to ensure safety when the patient was fed either orally or via enteral means:

> 'I always get the patient to sit upright and I've learnt not to push the patient too much, otherwise she/he will vomit.'

> 'I have been told to always feed the patient slowly otherwise the patient can vomit or choke on the food.'

> 'The speech therapist told me to avoid giving liquids with a syringe, otherwise the patient can choke. So I only use a syringe if I am desperate but I watch the patient to see if he's struggling'

> 'The one thing I know is that the patient's head must be raised even if they are on the NGT [nasogastric tube]. So I try to always do that although it is sometimes difficult when there aren't enough pillows.'

In contrast to the above, there were some participants who believed in 'getting the food into the patient by whatever means necessary'. These participants expressed anguish and frustration with patients who have dysphagia.

Referrals

Seven participants agreed that their role included making referrals for patients when necessary. Referrals were made for the very frail, medically weak patients and those not fully oriented to their surroundings and so not eating. Not all participants agreed that the SLT was the first point of referral. Five participants identified this as being the dietitian. Some confusion

about the difference in the role of both these professionals was noted:

> 'I only refer to the dietitian. I didn't know that speech was involved.'

> 'I actually don't know what the speech therapist does. Do they work with these patients who cannot eat or drink?'

Some participants were not aware of the role of the SLT in terms of swallowing. This was flagged as an area that would benefit from information sharing.

Oral hygiene

The participants did not voluntarily identify their role in oral care. This aspect was probed by the researcher. Some participants ($n = 2$) subsequently confirmed that they were involved in this routine, but none of the participants were able to identify the importance of oral care in preventing aspiration for the patient with dysphagia. This was therefore identified as an area that would benefit from additional information.

Medication

Provision of medication centred on two aspects: inability to provide medication when the patient had not eaten (i.e. on an empty stomach), or alternative means of medication provision when the patient was unable to cope orally. The participants also commented on patients' stress and their anxiety, trauma and resentment associated with them having to take tablets orally. Given their role in medication provision, nurses felt significant responsibility in ensuring medication intake, especially with patients who had a swallowing difficulty. The participants were unfortunately not forthcoming about how they succeeded in getting patients to swallow their medication when the patient was unable to eat.

Training needs

All participants expressed good inter-professional relations between themselves and allied health professionals. The majority felt that this enhanced multidisciplinary patient management and holistic patient care, and promoted inter-professional respect amongst the health professionals:

> 'We have a great team here. We meet every Tuesday, all the different allieds, to discuss and refer patients correctly. There is mutual respect among each other; if someone is not there, we will catch them up on what was discussed. We all work closely together.'

Despite the positive feedback on the question of whether the participants felt that they worked within a team approach, responses were accepted with caution. Earlier responses had suggested that there was minimal one-on-one inter-professional discussion on patients, explanation of recommendations by the SLT to the nurse, and implementation of strategies when assisting a patient with a swallowing impairment. The participants did, however, note that additional training and information exchange would improve relations and communication between SLTs and nurses, ultimately improving knowledge transfer and improving patient care:

> 'I think if we [nurses and speechies] speak to each other more, we can learn from each other, we can see each other's point of view, we can learn from each other's experience and then we nurse the patient more holistically. It doesn't make a difference if we all complain and never do anything to improve our situation.'

Discussion

Similar to the current study, others[6,7] have noted that dysphagia was a frequent symptom of stroke. As noted from the results, knowledge regarding dysphagia symptomatology, presentation of dysphagia and management was poor. Consequently, improving nurses' understanding and knowledge regarding these aspects specifically is documented to have proven benefits in terms of patient prognosis and length of hospitalisation.[8,9] Given the status of knowledge about dysphagia it was understandable that only the more overt symptomatology was noticed by nurses. Buchholz[10] agreed that often dysphagia of neurogenic cause may have insidious symptoms, making identification of impairment that much more difficult. Positively though, as supported by the literature,[11] knowledge from both life interactions and clinical interactions builds over time and as with the participants in this study, informs clinical practice in a positive beneficial way. More concerning was nurses with limited knowledge who found feeding time-consuming and additional stress. Researchers[9,12] have cautioned concerning the dangers of this for dysphagia intervention. This highlights the importance of changing attitudes by way of information sharing or training programmes for dysphagia, as this could positively impact on compliance and foster more favourable attitudes during mealtimes. However, given the conditions of work for nurses, such as increased workloads, the timing and format of training needs to be thoughtfully interrogated, so as not to worsen feelings of burnout.[7,13] Continued commitment to work needs to be reinforced and supported to alleviate feelings such as apathy. Another aspect that was neglected but is critical when working with patients who have dysphagia is that of oral care. Previous studies[14,15] have noted that water intake in the presence of good oral care contributes to decreased aspiration pneumonia.

The comments from the participants illustrate that recognition, acknowledgement and communication were essential in fostering feelings of confidence, motivation and overall work commitment.[16,17] Inter-professional relationships and those between nurses and direct managers were noteworthy factors that influenced nurse interactions when nursing patients such as those presenting with dysphagia. Participants reported feeling either increased levels of stress and frustration or a more positive commitment to persevere, depending on the nature of the relationship and interaction with peers.

Conclusion

Nurses are acknowledged as the most relevant and essential health professionals for the patient during a period of hospitalisation.[7,18] They have a significant role in ensuring that the patient eats his/her plate of food, swallows the prescribed tablets and drinks adequate amounts of water, whilst the nurse must also provide necessary emotional and informational support as and when required by the patient.[19,20] In a clinical context, assumptions are inadvertently made by health professionals concerning nurses' knowledge about dysphagia. This study confirmed that not all nurses are confident or equipped to work with dysphagia. Younger and recently qualified nurses lacked experiential insight and did not feel that their training prepared them adequately to care for a patient with a swallowing impairment. Unless they worked as a team with the SLT, knowledge about dysphagia, its consequences and possible strategies that may be useful at mealtimes were not

learned. Greater opportunities for information exchange, enhanced inter-professional relations and improved team working were identified as avenues to improve intervention with dysphagia. The current study provides valuable insights into how nurses care for patients with dysphagia and their perspectives on what was lacking and what was needed for service delivery to improve. Despite the small sample size, which is acknowledged as a limitation, the depth of information obtained was constructive.

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