

Experiences of living with persisting post-stroke dysphagia and of dysphagia management – a qualitative study

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ABSTRACT

Purpose: The aim of this study was to investigate people's experiences of living with dysphagia after stroke, and their experiences of dysphagia management.

Methods: The study design was qualitative, and an open-ended approach to data collection was used, with follow-up probing questions to gain more information as needed. Personal interviews were conducted with five persons who had persisting moderate to severe dysphagia after stroke, living in the south-west part of Sweden. The data were analysed with qualitative content analysis.

Results: When analysing the data, the following theme emerged; "Dysphagia impacts life situations negatively and requires individually adapted, long term support from skilled health care professionals". The theme consists of three categories: "Learning to manage dysphagia and its complications", "Professional support with dysphagia varies" and "Finding small moments of joy despite large restrictions in life situations".

Conclusions: Findings indicated that people with dysphagia experienced a lack of support from health care professionals. Better health care support following discharge from hospital is required to ensure an optimal quality of life. Actions to achieve this may include developing national guidelines for adequate dysphagia follow-up and establishing multidisciplinary dysphagia teams in hospitals and long-term care facilities.

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Introduction

Every year, 30,000 people are affected by stroke in Sweden (Stroke-Riksförbundet, 2017). Dysphagia (difficulty in swallowing) occurs in up to 78% of all people with stroke and greatly impacts their daily life (Arnold et al., 2016; Falsetti et al., 2009; Martino et al., 2005). For most people, the dysphagia resolves in a short period of time, but for some it becomes a permanent condition (Mann, Hankey, & Cameron, 1999). Speech and language pathologists (SLPs) in Sweden provide assessment and treatment for dysphagia but may be geographically far away from and offer differing amounts of support to people living with post-stroke dysphagia (Guldstrand, 2014; Sjögren, 2015). Since little is known about how people with dysphagia experience the dysphagia management received, further knowledge may help adapt and improve dysphagia management to better meet the needs of people with dysphagia.

Dysphagia

Dysphagia is the medical term for difficulty transporting saliva, food, drinks and/or medicine from the mouth to the stomach (Logemann, 1998). Swallowing is often

divided into three phases: the oral stage, which includes chewing and mixing with saliva to form a bolus, and moving the bolus backwards to the pharynx by the tongue; the pharyngeal stage, where the soft palate rises, the hyoid bone rises bringing the larynx up the epiglottis close, the base of the tongue contacts the pharyngeal wall, and the cricopharyngeal muscles relaxes; and the oesophageal stage, where the bolus moves through the oesophagus (Baijens et al., 2016). Dysphagia is caused by dysfunction or impairment in structures involved in any of these stages, and oropharyngeal dysphagia consists of the first two stages of swallowing (Baijens et al., 2016; Speyer, Baijens, Hejnen & Zwijnenberg, 2010). In this study, dysphagia is the term used for oropharyngeal dysphagia.

Symptoms of oropharyngeal dysphagia might include impaired bolus propulsion, delayed or absent pharyngeal swallow initiation, impaired pharyngeal peristalsis, impaired laryngeal elevation, coughing, nasopharyngeal regurgitation, impaired upper oesophageal sphincter opening, aspiration or penetration, and post-swallow residue (Baijens et al., 2016; Cook, 2009). If dysphagia is not appropriately managed, it can lead to pulmonary, nutritional and psychological consequences, such as aspiration

pneumonia, malnutrition, dehydration and depression (Cohen et al., 2016; Martino, Beaton, & Diamant, 2009; Smithard et al., 1996). People with dysphagia require a longer stay in the stroke unit and have increased healthcare costs; also, mortality and morbidity are higher than among patients without dysphagia (Arnold et al., 2016; Cohen et al., 2016; Smithard et al., 1996).

In acute care, the prevalence of dysphagia among people with stroke is reported to range between 20 and 78% (Arnold et al., 2016; Falsetti et al., 2009; Martino et al., 2005). Longer term, the prevalence of persisting dysphagia at six months post stroke varies from approximately 3% to 50%, depending on what methods have been used to detect dysphagia, either self-reported or by instrumental assessment (Mann et al., 1999; Nilsson, Ekberg, Olsson & Hindfeldt, 1998). Living with dysphagia post stroke may be challenging, but to date, knowledge regarding this and how people experience life with dysphagia is scarce.

Dysphagia and impact on life situations

Few qualitative studies have been published regarding experiences of living with post-stroke dysphagia (Carlsson, Ehrenberg, & Ehnfors, 2004; Jacobsson, Axelsson, Österlind, & Norberg, 2000; Medin, Larson, von Arbin, Wredling & Tham, 2010; Moloney & Walshe, 2018; Perry & McLaren, 2003). When studying people with persisting dysphagia, both Perry and McLaren (2003) and Carlsson et al. (2004) found that people aspired to “get back to normal”, either to as it was before the stroke or to find a “new normal”. Another way for the people to cope with dysphagia was to “get by”, accept their limitations and the need for modified consistencies such as thickened liquids or pureed food, and find strategies to maintain social functions or hide their difficulties when with others (Perry & McLaren, 2003). When studying experiences of the eating situation, not just swallowing, in people with dysphagia six months post stroke, Medin, Larsson, von Arbin, Wredling and Tham (2010) found that the participants expressed embarrassment about eating with unfamiliar people, thus making dinner parties or restaurant visits less appreciated.

In the study by Carlsson et al. (2004), participants reported that nursing staff lacked knowledge on how to help with dysphagia. Participants had to learn on their own how to manage their swallowing difficulties, what food and consistencies they could manage and how to position themselves when eating (Carlson et al., 2004). Medin et al. (2010) found that health care professionals need to have dialogue and discussion when meeting people with dysphagia, to adapt management of meal time situations to their individual needs. Several researchers have identified that people with dysphagia, who needed modified

consistencies such as thickened liquids or pureed food, felt that their quality of life was impacted negatively (Karlsson, 2007; McCurtin et al., 2018; Swan, Speyer, Heijnen, Wagg & Corbier, 2015).

Of the few qualitative studies published about living with dysphagia post stroke, all but one focused on the six months post-stroke period (Carlsson et al., 2004; Jacobsson et al., 2000; Medin et al., 2010; Moloney & Walshe, 2018; Perry & McLaren, 2003). Klinke, Wilson, Hafsteinsdóttir, and Jónsdóttir (2013) acknowledge that there is a gap in knowledge about long-term challenges when living with chronic dysphagia. Knowing that dysphagia affects quality of life and that people with dysphagia feel left on their own, it is important to further investigate their experiences to review and adapt interventions that will improve the benefit for future people with dysphagia.

SLPs and dysphagia management in Sweden

SLPs work predominantly with people with oropharyngeal dysphagia and work in various settings in the health care system. The Swedish National Guidelines (Socialstyrelsen, 2018) for stroke are very brief regarding dysphagia management. Evaluation of swallowing function in the acute care setting has the highest priority possible, and ongoing treatment and follow-up of swallowing function are placed in the third highest group of priorities. The guidelines do not specify the profession(s) responsible for evaluation, treatment or follow-up of swallowing function. SLPs should be a part of the stroke team, but guidelines do not specify to what extent. Furthermore, once a person is discharged from hospital in Sweden, there are no guidelines available regarding ongoing dysphagia follow-up and rehabilitation (Socialstyrelsen, 2018). In 2012, the European Society for Swallowing Disorders (ESSD) published position statements regarding screening, diagnosis and treatment of oropharyngeal dysphagia in people with stroke. This document recommended dysphagia reviews every two to three months during the first year post stroke, and thereafter every six months (ESSD, 2012). These guidelines have not yet been implemented in Sweden. In the study by Carlsson et al. (2004), participants found that SLPs had been helpful providing practical advice regarding the swallowing but that the adaptation of this advice to their own unique situation was needed. Furthermore, the access to SLPs varies greatly both within Sweden and even within specific counties (Guldstrand, 2014). In some areas, people with dysphagia must travel hundreds of kilometres to see an SLP; in other areas, the SLP travels to people's homes or nursing homes (Sjögren, 2015).

Swedish and international stroke guidelines require that a dysphagia screen occurs before a person is allowed to eat or drink (ESSD, 2012; Socialstyrelsen, 2018). Following a positive screen, a more comprehensive dysphagia evaluation should

occur, consisting in a clinical swallow evaluation (Cohen et al., 2016; Speyer, 2013) and/or instrumental assessments such as modified barium swallow or fiberoptic endoscopic examination (Bours, Speyer, Lemmens, Limburg, & de Wit, 2009; Cohen et al., 2016; Speyer, 2013). The findings of the evaluation help form an intervention plan, which may consist of compensatory techniques and/or dysphagia rehabilitation. Compensatory techniques may include one or more of the following: postural techniques, swallowing manoeuvres, modifying food or drinks (Cohen et al., 2016; Speyer et al., 2010). Dysphagia rehabilitation may include: oral sensory stimulation, pharyngeal electric stimulation, neuromuscular electric stimulation, McNeill Dysphagia Therapy Program, oropharyngeal muscle training or manoeuvres, or expiratory muscle strength training (Clavé et al., 2006; Cohen et al., 2016; Crary, Carnaby, LaGorio, & Carvajal, 2012; Huckabee & Macrae, 2014; Speyer et al., 2010; Wheeler Hegland, Davenport, Brandimore, Singletary, & Troche, 2016).

Traditionally, dysphagia intervention in Sweden has consisted of compensatory techniques rather than dysphagia rehabilitation (Andersson, Dahlberg, Silfwerbrand, & Sjögren, 2017). In cases of severe dysphagia, non-oral feeding via nasogastric tube or percutaneous endoscopic gastrostomy (PEG) may be required (Arnold et al., 2016; Falsetti et al., 2009). Intervention that is offered to the individual person varies according to different oropharyngeal difficulties and SLP access/services.

Secondary to dysphagia and dysphagia management, a person's life situation is commonly affected in many ways, transiently and chronically. Since there are no national guidelines on follow-up and rehabilitation of dysphagia after being discharged, and since the access to SLPs varies, dysphagia management may differ greatly from hospital to hospital, people with dysphagia may not receive equal or evidence-based care. Little is known about how people's experiences change over time, and even less is known about their experiences of dysphagia management received from SLPs. Consequently, the aim of this study is to investigate the experiences of living with dysphagia, what impact dysphagia has had on people's life situations, and what type of dysphagia management has been offered people and their experiences of this. It is anticipated that these documented experiences can lead to improved follow-up and rehabilitation of future people with dysphagia.

Materials and methods

The study was approved by the ethical committee at the master programme for medical sciences at Lund University (VEN 89-16).

Participants

Purposeful sampling of potential participants occurred within the SLP stroke and dysphagia networks in the south-west part of Sweden. SLPs were asked to inform all potential participants, who met inclusion and exclusion criteria, about the study between June 2016 and March 2017, and potential participants' permissions were obtained prior to being contacted by a member of the research team. Criteria for inclusion were: at least six months of persisting dysphagia after stroke, with a Functional Oral Intake Scale (FOIS) < 5 (Crary, Carnaby Mann, & Groher, 2005) (Appendix 1) and being able to participate in an interview in Swedish without an interpreter. Criteria for exclusion were: severe aphasia as reflected by Reinvang Oral communication 3–4 (Reinvang & Engvik, 1980), dementia diagnosis, dysphagia caused by other conditions than stroke and/or previous treatment by the first author, J.H. SLPs provided the research team with contact details to six consenting participants, who were then contacted by phone or e-mail, received additional information about the study and the meaning of participation, and were asked to accept or decline participation in the study. One potential participant received information about the study but declined to participate because of difficulties communicating. Five participants were recruited in the study (Table I).

Data collection

Once consented, participant interviews were conducted at a time and place as suggested by each participant. One interview took place at a hospital, and the remaining four were performed in the home of each participant. At the time of each interview, all participants again received both oral and written information about the study, including their right to withdraw their participation at any point without consequences. Written consent was obtained from all participants.

During the interviews, an open-ended approach to data collection was used, with follow-up probing questions to gain more information as needed. The participants were asked to share their experiences,

Table I. Participants included in the study.

Participant	Gender	Age	Years since stroke	Location of stroke	Communication
1	Male	95	10	Unknown	Independent
2	Male	68	7	Unknown	Speech + written support
3	Male	70	2	Brainstem	Assistance from wife
4	Male	76	2	Right hemisphere	Assistance from wife
5	Male	54	3	Brainstem	Assistance from daughter

based on their own, unique perspective (Hsieh & Shannon, 2005). No pre-set questions were used during the interviews, but participants were asked to share their experiences about topics relevant to the aim of this study. This included details such as their current swallowing difficulties, how their swallowing difficulties had changed over time, how these difficulties affected their quality of life and what management had been offered by SLPs and other health care professionals. Follow-up questions were made based on the information obtained during each interview, and therefore differed between the interviews. Towards the end of each interview, a short summary was made by the interviewer, and participants were able to correct misunderstandings or add additional information. Interviews lasted between 14 and 32 minutes. All the interviews were audio-recorded with a smartphone and transcribed verbatim by the first author shortly after each interview. To maintain confidentiality for the participants, each participant's audio-recording and transcript were de-identified and labelled with a code (1–5), and only the first author (J.H.) had knowledge of which participant had which code.

Data analysis

Data were analysed after all interviews had been completed using qualitative content analysis, following the steps described by Graneheim and Lundman (2003) and Lundman and Hällgren Graneheim (2012). Qualitative content analysis is one of many methods used to analyse text data and focuses on providing knowledge and understanding of a certain phenomenon (Hsieh & Shannon, 2005). One definition of qualitative content analysis is “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p. 1278). All data obtained from the interviews were accounted for in the analysis. All interviews were initially reviewed to get an overall picture, and the authors, aware of the risk of bias, strived to consider the perspective of people with

dysphagia when searching for meaning and essence during data analysis. Meaning units were identified based on the aim of the study. The meaning units were then condensed and each labelled with a code, before creating sub-categories and categories based on the codes, in accordance with the steps described in the literature (Graneheim & Lundman, 2003; Lundman & Hällgren Graneheim, 2012). Finally, a theme, based on the content of the categories, emerged (Table II). The content of the interviews was analysed on a manifest (visible) level as well as on a latent (underlying) level. The third author (S.K.) independently reviewed the interviews and discussed the codes with the first author in development of the sub-categories, categories and theme, until consensus was reached.

Results

Participants shared their experiences on how they managed dysphagia and consequences of dysphagia, how swallowing function had changed over time, dysphagia management and their experiences of it, how to keep training, challenges in daily life caused by dysphagia and ways to maintain or enhance quality of life. When analysing the data, the following theme emerged: “Dysphagia impacts life situations negatively and requires individually adapted, long-term support from skilled health care professionals”. The theme consists of three categories and 11 sub-categories (Table III).

Learning to manage dysphagia and its complications

Modifying food and fluids based on swallowing function

When learning how to manage dysphagia, participants reported different ways of facilitating eating and drinking, ranging from modified consistencies of food and fluids to implementing swallowing manoeuvres and sitting positions. Even situations not involving eating or drinking required strategies, for example, choosing a seat near the door at concerts,

Table II. Examples of the data analysis.

Meaning unit	Condensed meaning unit	Codes	Sub-categories	Category	Theme
When I was in the hospital, the SLP came twice a week and once a week, and they stimulated with electrodes, but not now	In the hospital, I had contact with the SLP once or twice a week, but not any more	Frequent help in the hospital but not later	Lack of follow-up	Professional support with dysphagia	Dysphagia impacts life situations negatively and requires individually adapted, long term support from skilled health care professionals
I didn't get any support from SLPs with this, only with my speech	SLP only supported with speech, not swallowing	More focus on speech than swallowing	Support may be variably adapted to the person's needs	Varies	

Table III. Sub-categories, categories and theme.

Sub-categories	Categories	Theme
Modifying food and fluids based on swallowing function Personal characteristics facilitating the new situation Bodily complications because of dysphagia Experiences of improved swallowing function Lack of follow-up Support may be variably adapted to the persons' needs To continue swallowing training on you own Challenge eating away from home Unpredictable symptoms give limitations in social life Appreciation of food, fluids and activities Keeping up hope for improved swallowing function	Learning to manage dysphagia and its complications Professional support with dysphagia varies Finding small moments of joy despite large restrictions in life situations	Dysphagia impacts life situations negatively and requires individually adapted, long-term support from skilled health care professionals

in case coughing/choking on saliva occurred. Some of these dysphagia-management strategies were suggested by SLPs; others evolved and were developed by the participants themselves.

At the kitchen table at home I've got a bucket to spit in, in case I can't swallow. (P1)

I got the advice to swallow golf balls, swallow as if I had a golf ball, and that helped. (P4)

Personal characteristics facilitating the new situation

Besides finding strategies to facilitate eating and drinking, all participants described personal characteristics as being important when managing dysphagia. Being stubborn or having patience had helped getting used to the new life situation.

I am old and stubborn, and I try to get by on my own. (P1)

Bodily complications because of dysphagia

Because of their dysphagia, the participants had experienced various bodily complications, such as weight loss, taste change and meals taking longer time. Restaurant visits were less and less joyful post stroke because of this. Complications from the PEG or saliva management also had a negative impact on their life situation.

I felt like I was drowning and then they went down and looked ... and it was lots of enteral nutrition in the lung. (P3)

It's difficult with all the saliva when I'm talking. (P3)

I lost almost 20 kilograms while I was in the hospital. (P2)

Experiences of improved swallowing function

For those participants who had experienced improved swallowing function, this had meant that they now required less food and fluids consistency modification, or even that the PEG could be removed. Improved swallowing function had to some extent decreased the impact on life situation.

In the beginning it was miserable. I had a nasogastric tube. I don't know for how long but it was for several months. (P4)

Professional support with dysphagia varies

Lack of follow-up

Immediately after the stroke, all participants found that SLPs at the hospitals were involved in evaluating the swallowing function and sometimes commenced swallow training of swallowing function. However, after being discharged, participants reported a lack of continuity in SLP contact. Post-discharge appointments with SLPs were few and mostly focused on evaluation rather than training. Despite this, participant experiences were that SLPs were the only profession providing post-stroke dysphagia support. It was reported that doctors and nurses changed too frequently or had too little knowledge about dysphagia to be able to give proper support. When the participants felt that health care professionals listened to their experiences, or when the support correlated with their needs, satisfaction was expressed.

When I was at the hospital the SLP came twice a week, once a week and then they used electrodes, but nothing now. (P5)

If I'm honest, it's not much they (the district nurses) have been able to help with. (P1)

They (the doctors and nurses) have been very good so there is nothing to complain about. (P3)

Support may be variably adapted to the persons' needs

The experience of the participants were that SLP appointments focused on dysphagia investigation and evaluation rather than training, or on speech and/or language instead of swallowing, creating a discrepancy between what they desired and what they received. During evaluations, participants felt that SLPs were sometimes inattentive to descriptions of what consistencies or amounts of fluid usually worked at home and performed an evaluation only based on a pre-set protocol. This made the

participants feel that the evaluation was of no use, since it did not correspond with the consistencies or amounts they usually drank. At other times, when SLP contact ended, participants wished to continue for a longer time, feeling that they had been discharged too soon. It was reported that home services sometimes provided help with training after stroke, but the focus was on training the legs, and no help was provided training the swallowing function.

They didn't train the swallowing; they only evaluated. (P2)

They [the home service] are helping me with the leg, but no one does anything about swallowing function. (P4)

To continue swallowing training on your own

Feeling left on their own after being discharged from SLP, participants expressed a lack of knowledge on how to continue training on their own. Participants reported that they would have liked to continue, but they did not know how to. They were also curious as to whether there were any new methods of training swallowing function that they did not know about.

I think I have sufficient knowledge to keep training the speech, but I have no knowledge on how to train the swallowing function. (P4)

What you really wonder is: What research is available? What do you do about it [dysphagia]? (P3)

Finding small moments of joy despite large restrictions in life situations

Challenges eating away from home

Dysphagia had a negative impact on the participants' life situation, for example, not being able to eat and/or drink as before, having to abstain from things they previously enjoyed, or not being able to eat or drink when they were hungry or thirsty. They expressed that travels and eating at restaurants did not bring the same joy as it used to do. Eating away from home was difficult when they needed a modified diet or when they needed to be able to spit out food when it was impossible to swallow. Participants also found that it was important to plan ahead and bring what they need, but difficulties arose in some countries where it was not possible to bring certain products for alternative nutrition.

At hotels, they couldn't always get a blender for us, and we didn't have any enteral nutrition with us; we weren't allowed to, so we had to mix food on our own. (P5)

It requires some planning always bringing some thickener with you. (P4)

Unpredictable symptoms give limitations in social life

Participants had found that dysphagia might be unpredictable, which made it hard to know if they were going to be able to swallow or not. This might cause distress at social events such as weddings or funerals, so some participants reported avoiding certain social situations.

It is hard not being able to swallow when you are thirsty, and you long for something. (P3)

I have brothers and sisters at the café, and I sometimes avoid it. I avoid it because it feels unpleasant. (P1)

Appreciation of food, fluids and activities

Although the dysphagia had made a negative impact on life situation, the participants also described what they did to increase their quality of life. Sometimes they chose to eat or drink something special because it tasted good, even though they knew it might be difficult.

A couple of days ago I had fried a pork chop, and I pushed it all in and it went alright. (P1)

Sometimes I take a small grog, whisky and coke. (P2)

Another way to maintain quality of life, expressed by the participants, was to continue with activities that did not include eating or drinking, such as concerts or theatre. Having a supportive spouse also had a positive impact, making it possible to continue participating in activities outside the house.

Two weeks ago, that Sunday, you went to two concerts. (P3)

Because I have my wife at home, quality of life is not affected. (P4)

Keeping up hope for improved swallowing function

Despite having lived with dysphagia between 2 and 10 years, and experiencing little or no improvement, the participants still hoped for improved swallowing function and being able to eat or drink as before the stroke. "Keeping up hope" was described as necessary; otherwise life would be meaningless. They also hoped for spontaneous recovery or new methods of training available in the future, which might help them to improve.

I want to be able to take a swig again; it's not the same with small sips. (P2)

The nerves grow but they grow slowly, and if you're lucky they may suddenly get in contact again. (P3)

Discussion

Discussion of the results

Findings from this study suggest that dysphagia follow-up seems to be insufficient and not adapted to individual needs. The results in this study showed that the participants felt that support focused on speech and/or language instead of on swallowing and on evaluation rather than training, and that health care professionals in general had insufficient knowledge of dysphagia. The findings of this study are similar both to those of the studies conducted in the early 2000s (Carlsson et al., 2004; Jacobsson et al., 2000; Perry & McLaren, 2003) and to more recent research (Moloney & Walshe, 2018), indicating that dysphagia management still is not adequately adapted to the needs of people with dysphagia.

When not getting adequate support, participants in this study found it hard to learn how to manage dysphagia in all aspects of life. Little or no support was offered from doctors or nurses, leaving SLPs as the only health care professionals involved in dysphagia management. Similar results were found in the study by Carlsson et al. (2004), in that participants felt that doctors and nurses lacked competence in dysphagia, and SLPs generally provided most of the advice. Kelly, D'Cruz, and Wright (2009) used a focus group of various health care professionals dealing with people with dysphagia and their medicines, and found that the wide spectrum of difficulties among people with dysphagia required very good knowledge both about the individual person's dysphagia and about the formulations of certain medicines. Another study showed that when health care professionals did not have adequate dysphagia knowledge, a risk for oral medication difficulties was identified (Kelly, D'Cruz, & Wright, 2010). Awareness about dysphagia and dysphagia management needs to increase among health care professionals and in society overall (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002). By increasing awareness of dysphagia among health care professionals, a more person-centred, evidence-based and high-quality dysphagia management might be possible (Moloney & Walshe, 2018). Ideally, there would be multidisciplinary dysphagia teams in hospitals and long-term facilities taking care of these people, as proposed by the European Society for Swallowing Disorders (ESSD, 2012). Kelly et al. (2009) also emphasises the need for close interprofessional communication when prescribing medicines to people with dysphagia. The variation in access to SLPs (Guldstrand, 2014) and the lack of national guidelines on follow-up of dysphagia (Socialstyrelsen, 2018) lead to insufficient support. To better meet the needs of people with dysphagia, clinical national guidelines for dysphagia would be necessary.

Another finding in this study was that dysphagia management by SLPs ceased too early, leaving the participants to learn how to manage dysphagia in daily life on their own. Advice regarding modified consistencies or swallowing techniques were given to the participants at the hospital, but when discharged they had to find out on their own how to adjust the advice to their unique situation. They had created different strategies to facilitate their daily life, such as always having a bucket to spit in when eating at home or taking small sips instead of a gulp/swig. Similar findings were expressed in the study by Carlsson et al. (2004), in that SLPs had been helpful with general advice but not with individual adjustment of the advice. When studying people who received PEG because of stroke-related dysphagia, James, Kapur, and Hawthorne (1998) found that 41 participants had recovered their swallowing, 20 could have their PEG removed within six months, and 19 could have their PEG removed after six months had passed. They also found that only 44% of those receiving PEG had had a swallowing assessment after PEG insertion (James et al., 1998). This suggests that there is a need for ongoing follow-up of swallowing function, since recovery can occur more than six months post stroke.

When studying the social and psychological burden of living with dysphagia, Ekberg et al. (2002) found that 32% of people with dysphagia had received professional dysphagia treatment, but 61% of the people believed dysphagia was untreatable. The participants in this study expressed a lack of knowledge on how to keep training on their own, after the SLP management had been completed/ceased, but they still believed dysphagia was treatable. SLP intervention may consist of a variety of compensatory techniques and a range of rehabilitation options (Clavé et al., 2006; Cohen et al., 2016; Crary et al., 2012; Huckabee & Macrae, 2014; Speyer et al., 2010; Wheeler Hegland et al., 2016), but according to the experience of the participants of this study, a further explanation and ongoing follow-up are needed to assist with continuing training on their own. Furthermore, a shift in perspectives is needed regarding dysphagia intervention in Sweden, moving from compensatory techniques to dysphagia rehabilitation, to better meet persons' needs (Andersson et al., 2017). Exploring this topic further would give a deeper understanding of the needs of people with dysphagia and how health care professionals can best meet these needs, thus taking a more person-centred approach to care.

Living with dysphagia often has a negative impact on life situations. In this study, the participants acknowledged that travelling and maintaining social relations were more difficult than before. Because of dysphagia, travelling had become more challenging, and they sometimes avoided social gatherings such as weddings or funerals, which is similar to the findings of Medin et al. (2010) and Moloney and Walshe (2018). The participants

of this study also had found strategies to facilitate participation in activities, such as choosing seats at concerts to facilitate getting out easily, or getting help from their spouse to be able to participate in social gatherings. These strategies were similar to those identified by Perry and McLaren (2003), where participants found strategies to maintain a social life and hide their difficulties among others.

Several authors have found that people who need to modify consistencies of foods and fluids experience a negative quality-of-life impact (Karlsson, 2007; McCurtin et al., 2018; Swan et al., 2015). The participants in this study expressed the same experiences, for example, that modified consistencies made it possible for them to eat and drink, but they were not able to eat or drink as they did before or that they had to abstain from certain things. Despite all the negative impacts in life situations, the participants in this study also found ways of enhancing their quality of life, either by activities that did not include eating or drinking or by eating or drinking certain things, even though it was difficult.

The participants in this study stressed how important it was keeping up hopes of improvement, otherwise life would be meaningless. This differs from findings from a previous study, whose participants expressed hopelessness (Jacobsson et al., 2000). For health care professionals, this knowledge might help in understanding the importance for people to find or continue with activities that have a positive impact on life situations.

Although this study focuses on the experiences of a small group of people living with dysphagia in Sweden, findings are similar to those of the European Burden of Stroke project, in that ongoing, long-term support is lacking, access to rehabilitation therapy must be improved, and guidelines lack information about follow-up after discharge (Stroke Alliance For Europe [SAFE], 2017). However, as reported by the UK's National Stroke Audit in 2017, even though there are guidelines, there might be a lack of adherence owing to inadequate use of resources or a lack of funding (Sentinel Stroke National Audit Programme [SSNAP], 2017).

Methodological considerations

The participants of this study have been living with dysphagia for between 2 and 10 years, thus giving them a broad experience of how it affects their daily life. Severity of dysphagia varies, which means they have different experiences of the impact it has made on their lives. Different levels and amount of support offered might also impact their experiences.

To strengthen the methodology of this study, female participants would have been desirable, but no females with dysphagia meeting the study criteria

were available for inclusion. Since women traditionally do more meal preparation in the home, it would have been interesting to have their opinions of the impact of stroke and dysphagia on their lives, particularly if a change in roles and meal preparation occurred within their daily life. Other considerations to strengthen this study would have been to have a greater variation of participant geographical location, and to interview people from different health care regions/counties. The participants in this study, however, have all been treated at different hospitals in Region Västra Götaland, which means they have experienced different health care settings and follow-up.

Interviewing participants with various communication difficulties occasionally made it difficult to explore topics in depth. Furthermore, when participants struggled with saliva or forming the words, most answers were then quite short. Open-ended questions often were more difficult for the participants to answer than closed questions. These influences may have affected the results of this study, if the participants had not been able to adequately describe their experiences. In three of the interviews, a close relative participated, partially or through the whole interview. Positive aspects of this were (a) getting deeper into the topics, as the close relative sometimes remembered more details and could remind the participant of this, and (b) that information could be clarified when the participant had problems communicating. Complications of having a close relative present during the interview, however, might be that this then inhibited the participant from fully describing some information. Interviews with couples as participants could be of interest, providing information on being directly and indirectly affected by dysphagia, and the impact it has had on their life together.

Given that symptoms and interventions of oropharyngeal dysphagia often are similar in other neurological populations (Logemann, 1998), the findings of this study and dysphagia impact on daily life might be applicable to people in other neurological disease groups.

The analysis has primarily been conducted by the first author (J.H.), with support from the second (L.B.) and third (S.K.) author. If the analysis had been provided jointly in all steps, other interpretations might have been made.

Conclusion

The findings from this study indicated that people with dysphagia experienced a lack of support from health care professionals. They felt left on their own and were required to adapt strategies on their own, without support or guidance. Better health care support following discharge from hospital is required to ensure improved health outcomes and patient quality of life.

Recommendations to achieve this include developing national guidelines for adequate dysphagia follow-up and establishing multidisciplinary dysphagia teams in hospitals, long-term care facilities and the community.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Appendix 1. FOIS ITEMS (Crary et al., 2005)

- Level 1: Nothing by mouth.
- Level 2: Tube-dependent with minimal attempts of food or liquid.
- Level 3: Tube-dependent with consistent oral intake of food or liquid.
- Level 4: Total oral diet of a single consistency.
- Level 5: Total oral diet with multiple consistencies, but requiring special preparation or compensations.
- Level 6: Total oral diet with multiple consistencies without special preparation, but with specific food limitations.
- Level 7: Total oral diet with no restrictions.