

Significante verbetering van de naleving van het slikadvies in een tertiair MS revalidatiecentrum

(Significant improvement of compliance with dysphagia recommendations in a tertiary MS rehabilitation center)

Masterproef voorgedragen tot het behalen van de graad van Master in het management en het beleid van de gezondheidszorg

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Preface

This is the master's thesis "Significant improvement of compliance with dysphagia recommendations in a tertiary MS rehabilitation center." The research was conducted at the National MS Center in Melsbroek. It was written in the context of my graduation from the Master in policy and management in health care at the university of Leuven. I have noticed in our center that care takers often don't adhere to the dysphagia recommendations made by the SLT. Therefore I decided to investigate and improve compliance of care takers with the dysphagia recommendations. During the investigation, the complexity of the process became clear. This project took but also gave me a lot of energy. After a year of hard work, we achieved good results as a center.

I would like to take the opportunity to thank a number of people because without them this would never have been the end result. In the first place, my thanks go to my supervisor Kris Vanhaecht and co-supervisor Ann Goeleven for the support, both in terms of process and in terms of content.

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I wish you much reading pleasure

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Dutch abstract

Achtergrond: Dysfagie komt frequent voor bij personen met MS. Zorgverleners zijn verantwoordelijk voor het opvolgen van het slikadvies dat gegeven wordt door de logopedist. Als de zorgverleners de aanbevelingen niet opvolgen, kan dit leiden tot een verhoogd risico op aspiratie.

Doel: In deze studie onderzocht men in welke mate het slikadvies van de logopedisten opgevolgd werd door zorgverleners. Tevens werd geprobeerd om het opvolgen van het slikadvies te verbeteren door de kennis bij zorgverleners te verhogen aan de hand van een opleiding.

Methode: Een observationele studie werd gedaan om te kijken of de aanbevelingen van de logopedist met betrekking tot het slikadvies gevolgd werden door zorgverleners. Er werd een vragenlijst gegeven aan het verzorgend personeel om te peilen naar de kennis en attitude omtrent slikstoornissen en om andere redenen voor het niet opvolgen te achterhalen. Er werd een opleiding georganiseerd gebaseerd op de bevindingen uit de observaties en vragenlijsten. Na de interventie werden opnieuw observaties gedaan om de interventie te evalueren.

Resultaten: De resultaten toonden een significante verbetering voor het naleven van de aanbevelingen van de logopedist (58%-81%, p<0,001). Er werden significante verschillen gevonden voor volgende aanbevelingen: consistentie van soep (36%-84%, p<0,001), consistentie van vloeistoffen (51%-84%, p<0,001), voorbereiding van de maaltijd (70%-83%, p<0.01), alertheid (44%-74%, p<0.001), tempo (87%-97%, p<0.001), hoeveelheid (59%-88%, p<0.001), houding (64%-87%, p<0,001) en supervisie (28%-48%, p<0,001). Het gebruik van het juiste hulpmiddel verbeterde niet (72%-69%, p = 0.44). Men zag een verbetering voor het opvolgen van de aanbevelingen van de logopedist voor alle verpleegafdelingen. Ook de menuaanpassingen die gedaan werden door de keuken verbeterden significant (74%-86%, p<0.01).

Conclusie: Een trainingsprogramma om de kennis bij de zorgverleners te verhogen, bleek effectief voor het verbeteren van de naleving van het slikadvies.

Relevantie voor de praktijk: Ook in ons centrum merken we dat zorgverleners het slikadvies niet altijd opvolgen. Dit kan leiden tot een verhoogd risico op aspiratie voor de patiënt. Daarom hebben we besloten het nalevingsniveau van onze aanbevelingen te onderzoeken en te verbeteren.

English abstract

Background: Dysphagia is common in persons with Multiple Sclerosis. The speech and language therapist (SLT) gives dysphagia recommendations to the patient and his care takers. These recommendations need to be applied by care takers. Not following these recommendations can increase the risk of aspiration in patients with dysphagia.

Objective: To investigate compliance with dysphagia recommendations among care takers and to improve compliance by increasing the knowledge of care takers through tailored training.

Methods: An observational study was used to examine the compliance and reasons for non-compliance of the care takers working in a rehabilitation center. A questionnaire was used to assess knowledge, attitudes and other reasons for noncompliance. Based on the gaps defined by the observations and questionnaires, a training session was developed. The same observations and questionnaires were repeated after the intervention.

Results: Results showed a significant improvement for overall compliance by care takers (58%-81%, p<0.001). Significant differences were found in compliance with the following recommendations: consistency of soup (36%-84%, p<0.001), consistency of fluids (51%-84%, p<0.001), food preparation (70%-83%, p<0.01), alertness (44%-74%, p<0.001), speed (87%-97%, p<0.001), amount (59%-88%, p<0.001), posture (64%-87%, p<0.001), supervision (28%-48%, p<0.001). Recommendation for utensils did not improve (72%-69%, p=0.44). Improvement in compliance was demonstrated in all nursing units. Also compliance for diet modifications improved significantly (74%-86%, p<0.01).

Conclusions: Training to improve knowledge and tailored to the needs of care takers significantly improves compliance with dysphagia recommendations and improves the quality of care.

Relevance to clinical practice: We have noticed in our center that care takers often don't adhere to the dysphagia recommendations made by the SLT which can increase the risk of aspiration. We therefore decided to determine and improve compliance of care takers with the SLT's recommendations.

Key words: compliance, dysphagia, dysphagia recommendations, nurses, multiple sclerosis

Introduction

Background

Depending on the type of assessment, the incidence of dysphagia in persons with Multiple Sclerosis (pwMS) has been estimated at 33% to 43%.^{1,2} Dysphagia can result in a reduced quality of life, malnutrition, dehydration, aspiration pneumonia and an increased risk of death.^{1–4}

To avoid these complications, early diagnosis and treatment of dysphagia in pwMS are important.⁴

Treatments for dysphagia, advised by the speech and language therapist (SLT), may consist of thickening liquids, consistency modifications, changes in head posture to prevent aspiration and exercises to strengthen muscles.⁵ Adaptations of the menu and reductions in bolus volume significantly decreases the risk of penetration and aspiration. Videofluoroscopic studies found that the prevalence of penetrations and aspirations can be reduced by thickening liquids.⁶ Proper positioning at mealtimes is furthermore important to prevent aspiration.^{4,6,7}

According to Langmore et al. (1998) patients who are dependent for feeding, are at higher risk for aspiration of larger quantities of liquids and/or food. This increases the risk of aspiration pneumonia by a factor of 20.8

Both the patient's and the care taker's noncompliance with dysphagia recommendations can have serious consequences and can increase the risk for penetration, aspiration, morbidity and mortality. 9-11 Other persons and factors can have an influence on patient's compliance to dysphagia recommendations. 10 In the study of Rosenvinge and Starke (2005) care takers were trained and patient compliance to dysphagia recommendations was observed. Compliance with recommendations for thickening liquids, amounts given and safe swallow guidelines improved after training. 12

Treatment of dysphagia needs a multidisciplinary approach.^{3,4,6,7,13} The SLT plays an important role in diagnosis, treatment and management of individuals with dysphagia. Although SLT's often recommend modifications and safe swallowing guidelines to the patient himself, implementation of these recommendations is often the responsibility of the care takers.^{11,14} They execute the dysphagia recommendations which contributes to the overall quality of compliance.¹⁵

Care takers therefore play a crucial role in identifying, managing and preventing complications related to dysphagia. A,16,17 However, a lack of knowledge of dysphagia can have serious consequences. Noncompliance by care takers with the SLT recommendations is unfortunately common in long-term care. Colodny (2001) found that health care professionals were compliant less than 50% of the time with SLT's feeding recommendations for dysphagia patients. A lack of knowledge, disagreement with the SLT recommendations and increased workload due to following the recommendations were three reasons for noncompliance with dysphagia recommendations. SLT recommendations can be time-consuming.

Tan et al. (2018) showed that care takers followed prescribed dysphagia management only in 57% of the time. ¹⁸ Insufficient knowledge, a lack of time and the patient's resistance to the dysphagia recommendations were the biggest reasons for noncompliance. Balancing the patient's preferences and preventing aspiration can be a struggle for care takers. ^{18,19} Rosenvinge and Starke (2005) found

that the compliance to dysphagia recommendations was 52%. Noncompliance was in their study related to a lack of knowledge. 12

Despite the advantages, 75% of the patients themselves are reluctant to make modifications to the diet.²⁰

It is the responsibility of the SLT to coach family and care takers in following the recommendations. ^{4,21} SLT's need to take the following into account: which recommendations are needed, who will carry them out and what is their knowledge. Not considering these factors can ultimately lead to noncompliance. ²²

Various studies have confirmed that training can significantly improve knowledge of dysphagia and improve compliance with dysphagia recommendations.^{4,17,22–27} According to Tan et al. (2018), a training session of 1 hour was sufficient to improve the knowledge and skills of care takers.¹⁹

Likewise, we have noticed in our center a high incidence of noncompliance by care takers with SLT recommendations. We therefore decided to investigate and to improve compliance of care takers with the SLT's recommendations.

Objectives

- 1) Determine the compliance of care takers in a MS rehabilitation center to dysphagia recommendations made by the SLT.
- 2) Improve compliance to the dysphagia recommendations through tailored training and education.

Methodology

Study design: an observational study was used to examine the compliance and reasons for noncompliance and the impact of training on the knowledge and attitude of the care takers working in a rehabilitation center.

Prior to the study, literature was reviewed to provide a good basis for the intervention. Existing evidence and methodology from previous, similar studies was taken into account and has served as an inspiration for this study. 11,12,17-19,21

Before the start of the study, ethical approval was received. The project was led by a SLT in a MS rehabilitation center in Belgium. Prior to the start of the project, the aims and methods were discussed with the managers.

The project consisted of 3 steps. An overview of the project can be found in Figure 1: Overview of the project

T Pre-training

- observations of the

- observations of care takers during mealtimes
- questionnaire
- information patient group

Intervention

- meeting with

- training care takers and kitchen staff
- reference nurse and nutrition group

Post-training

 $\frac{\square}{\Omega}$ - observations of the

- observations of care takers during mealtimes
- questionnaire

Figure 1: Overview of the project

Step1: Pre-training

The pre-training period consisted of four parts: observations of the menu, observing care takers during mealtimes, a questionnaire for the care takers and information gathered from a patient group.

Observations:

Menu and mealtime observations were conducted before training to determine whether kitchen staff and care takers were following the SLT's recommendations. All inpatients with dysphagia who had dysphagia recommendations made by the SLT, were included. Checklists were employed. The checklists consist of individual recommendations taken from the dysphagia guidelines and were split into the following sections:

- Consistency of fluids
- Consistency of soup
- Preparation of food by the care takers (cutting crusts from the bread, making bread pudding, cut meat into smaller pieces)
- Dietary modifications made by kitchen staff (does the patient get food as requested according to the dysphagia recommendations, e.g. extra sauce, mixed food,...)
- General recommendations: (e.g. advice on alertness, posture, amounts to be given, speed)
- The level of supervision required
- Assistant devices (e.g. adapted cups, straws, shortened straws)

Observations of dietary modifications were conducted during 4 weeks in September 2018 by two SLT's. The mealtime observations were carried out by a student during 4 weeks in October 2018. Observations were conducted at lunchtime and during the evening meal. The student was well-trained and informed before she started the observations.

Before the observations, care takers were verbally informed that the aim of the project was to investigate what obstacles care takers come across when following SLT recommendations and which support they require from the SLT.

Checklists were marked according to adherence of recommendation. If the recommendation was followed, value 1 was assigned, if not value 0. Only the recommendations that were applicable during the observations, were scored. Overall compliance and compliance per guideline were calculated by adding the values and dividing by the number of observations. The severity of the patient's dysphagia was subjectively determined by the treating SLT based on the adaptations needed and the risk of aspiration.

Questionnaire:

A literature search for validated questionnaires in Dutch was conducted, however, no validated tool that evaluated the knowledge of dysphagia and attitude of care takers was found. For this reason the validated 21 item Mealtime and Dysphagia Questionnaire (MQD) from Colodny (2001) was translated into Dutch. Colodny describes the questionnaire as a reliable tool to assess reasons for noncompliance. Reliability nor validity was however evaluated in the translated version. The questionnaire consists of 21 questions clustered in three factors (appendix 1). Factor 1 contains 8 statements that refer to the added work that the recommendations require (1, 3, 7, 8, 9, 11, 18 and 19). Factor 2 contains 8 items to assess the knowledge of dysphagia (2, 4, 5, 6, 10, 12, 13 and 16). Factor 3 indicates the degree to which care takers disagree with the recommendations made by the SLT (14, 15, 17 20 and 21). All items are scored on a 5 point scale (1=strongly disagree, 2=somewhat disagree, 3=neither agree nor disagree, 4= somewhat agree, 5=strongly agree). By summing the scores on the statements and dividing by the number of statements, a mean score is computed. This allows to make comparisons about the impact of each factor on noncompliance. 11

To gain more information, we added extra questions in the Dutch version based on the literature and what was relevant for the study. ^{17,19} A pilot version of the questionnaire was discussed by 5 SLT's. To prevent bias, each SLT first evaluated the questionnaire separately. Following discussion, alterations were made. This amended questionnaire consisted of demographic data and 4 extra questions: what are the problems care takers face when caring for patients with dysphagia, what do they expect from the SLT, what would they like to know about dysphagia, and what could be improved concerning the communication of the dysphagia recommendations. All respondents completed the instrument anonymously. After completion the questionnaires were collected in a box, located on every nursing unit.

Before distribution, the questionnaire was first completed by 1 nurse and 3 health care assistants, who worked in the same center, but with ambulatory patients, for ease of use and understanding difficulties. It took 10 minutes to complete the questionnaire. The questionnaire was also checked by the managers. The questionnaires were distributed in November 2018.

<u>Information from the patient</u>

A meeting was set up with a focus group comprised of 8 patients, in order to determine the information that was required for them to be able to follow any dysphagia recommendations.

Step 2: Intervention

Training:

All care takers, kitchen staff and dieticians were scheduled to follow a training in February 2019. The session started with a presentation of the results of the questionnaires and observations, followed by a theoretical and a practical part, based on the gaps identified by the observations and questionnaires. Results were discussed interactively.

During the theoretical training the normal swallow and swallowing problems that can occur with pwMS were presented. Also the symptoms of dysphagia and how to manage them, were discussed. In the practical session, care takers observed a demonstration of fluid thickening. They could also experience what it meant to be fed by others and the impact of different postures, safe feeding techniques, different consistencies and utensils. All sessions were held in a room on the same site as the rehabilitation center. They were given by 2 experienced SLT's. Each session lasted 2 hours. At the end of the training, the care takers received a questionnaire to ask for feedback about the training and to determine the three most important things they had learned during the training.

Meeting with kitchen staff:

The SLT had a meeting with the head of the kitchen staff and the two dieticians. During this meeting she discussed the results of the observations of the menu and explained the importance of following the dietary recommendations. During a period of 4 weeks in March, SLT's went to the kitchen to check the adapted menus for the right consistency and to give feedback. The kitchen staff and the two dieticians also followed the same training session as the care takers.

Reference nurse and nutrion group

A nutrition group already existed in the MS rehabilitation center, however SLT was up till now not involved. As part of the intervention program, one SLT became member of that group. This group meets every month, during which the members discuss meal related topics as well as dysphagia issues. The project was presented by the SLT. She suggested it would be interesting to have a reference nurse on each unit. In the study of Werner (2005) it seemed valuable to have a reference nurse. The role of the reference nurse could be to support the recommendations and to coordinate information about the patient's dysphagia. He or she can have a potential impact on reduction of dysphagia-related complications. Each person of the nutrition group was asked if he or she was interested in swallowing and if he or she would like to take the role of reference nurse. Everyone answered this question positively. It was agreed that if a patient received dysphagia recommendations, SLT would explain these in detail to the reference nurse. The reference nurse was also asked to coordinate the agreements that were made after the training.

Step 3: Post-training

During March 2019 a menu and mealtime observation was carried out again using the same method as before the training.

The translated version of the MQD from Colodny¹¹ was distributed again in March 2019.

Results

Data were analyzed using the statistical software package MATLAB version R2016a. Chi square test was applied to analyze the difference in compliance and overall compliance before and after training. P-values ≤ .05 were considered as statistically significant.

Menu observations:

Before the training, modified diets were often not applied. The food provided was too dry which made it more difficult to swallow, the food was not sufficiently mixed or was not of the right consistency as requested by the SLT. After the training, in 86% of the cases food prepared in the kitchen was deemed appropriate (p<0.01) (Table 1).

Table 1: Overall compliance for dietary modifications made by kitchen staff before and after training

Group	Chi2	p-value	Compliance before training	Compliance after training	Risk Ratio (CI 95%)	Risk Difference (CI 95%)
Kitchen staff	10.1	< 0.01	73.7%	86.0%	1.17 ± 0.12	+12.3 ± 7.7

Mealtime observations

Before training 436 observations of patients (26 patients with dysphagia) who had dysphagia recommendations were included and 454 observations (28 patients with dysphagia) after training. There was a significant difference before and after training in the distribution of patients and the number of observations due to discharges. During the observations, there were no patients with dysphagia recommendations at nursing unit 2. Compliance differed according to the type of guideline. An overview of compliance of care takers for different recommendations before and after training can be found in Table 2.

Before training, the following matters were observed: no thickener was used, patients were given bread instead of semi-solid food, meat was not finely chopped, crusts were not cut from the bread, noisy environment which made that the patient was easily distracted, patients watching television while eating, patients indicating that they were not ready for another bite while the next bite was already given, amounts were too big, patients not positioned straight enough, care takers giving food or drinks while standing so the patient had to bring his head in extension, no supervision when needed, no straw or no shortened straw when indicated, ...

No relation was found between guideline application and severity of dysphagia. For all degrees of dysphagia severity, guidelines have been improved (p<0,001). The degree of improvement was the same for all degrees of dysphagia severity.

Results showed a significant improvement for overall compliance from 58% before training to 81% after training (p<0.001). Significant improvement in compliance was found with the following recommendations: consistency of soup (36%-84%, p<0.001), consistency of fluids (51%-84%, p<0.001), preparation of food (70%-83%, p<0.01), alertness (44%-74%, p<0.001), speed (87%-97%, p<0.001), amount (59%-88%, p<0.001), posture (64%-87%, p<0.001) and supervision (28%-48%, p<0.001). Recommendations for utensils did not improve (72%-69%, p=0.44). Improvement in

compliance was demonstrated for all nursing units (Table 3). Compliance improved for observations at noon (61%-84%, p<0.001) and in the evening (54%-78%, p<0.001) (Table 4).

Table 2: Compliance of care takers for different recommendations before and after training

Type of recommendation	Chi2	p-value	Compliance before training	Compliance after training	Risk Ratio (CI 95%)	Risk Difference (CI 95%)
Consistency Soup	24.0	< 0.001	35.6%	84.3%	2.37 ± 1.00	+48.8 ± 17.2
Consistency Liquids	40.0	< 0.001	51.2%	84.3%	1.64 ± 0.27	+33.0 ± 9.6
Preparation of food	9.1	< 0.01	70.7%	83.0%	1.17 ± 0.13	+12.3 ± 8.0
Alertness	71.7	< 0.001	44.3%	73.7%	1.66 ± 0.21	+29.4 ± 6.5
Speed	11.6	< 0.001	87.0%	96.7%	1.11 ± 0.07	+9.7 ± 5.3
Amount	42.9	< 0.001	58.8%	88.4%	1.50 ± 0.19	+29.6 ± 8.3
Posture	56.5	< 0.001	64.2%	86.7%	1.35 ± 0.11	+22.5 ± 5.7
Supervision	24.0	< 0.001	28.2%	58.8%	2.08 ± 0.60	+30.6 ± 12.2
Utensils	0.6	= 0.44	72.1%	68.9%	0.95 ± 0.11	-3.3 ± 8.3
Overall compliance	245.3	< 0.001	58.2%	81.1%	1.39 ± 0.06	22.9 ± 2.8

Table 3: Overall compliance regarding the different nursing units before and after training

Nursing unit	Chi2	p-value	Compliance before training	Compliance after training	Risk Ratio (CI 95%)	Risk Difference (CI 95%)
Unit 1	65.3	< 0.001	52.0%	79.3%	1.53 ± 0.15	+27.3 ± 6.1
Unit 2	/	/	/	/	/	/
Unit 3	59.2	< 0.001	62.0%	77.8%	1.25 ± 0.07	+15.8 ± 3.9
Unit 4	121.3	< 0.001	50.0%	96.3%	1.93 ± 0.24	+46.3 ± 6.6
Unit 5	19.4	< 0.001	66.0%	82.0%	1.24 ± 0.13	+16.0 ± 7.5

Table 4: Overall compliance for observations at noon and in the evening before and after training

Moment of observation	Chi2	p-value	Compliance before training	after (CL 95%)		Risk Difference (CI 95%)
At noon	142.7	< 0.001	61.0%	83.6%	1.37 ± 0.07	+22.6 ± 3.5
Evening	112.8	< 0.001	53.7%	78.1%	1.45 ± 0.11	+24.4 ± 4.4

Questionnaire:

The questionnaire was distributed to all care takers in the center working with inpatients. Before training the response rate was 67% (62/92) and 70% (64/92) after training. Before training, 2 questionnaires were excluded from the study because respondents indicated that they had no contact with patients during the mealtime (were not allowed to help the patient while drinking/eating). 7 questionnaires were excluded because training was not attended by respondents (5/92) or incomplete response (i.e; > 10% of questions blank, 2/92). The final sample before training consisted of 60 questionnaires and 57 after training. Questionnaires were anonymous. The distribution of respondents before and after training did not differ significantly (Table 5).

Before training 69% of the respondents reported they did follow a training about dysphagia in the past. However, 66% indicated that they were not satisfied with their knowledge regarding swallowing difficulties. 64% indicated that they had problems concerning the communication of the dysphagia recommendations.

Table 5: Distribution	lage and v	ears of experience	of care	takers for Mo	OD before and	after training
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Variable	average before (CI 95%)	average after (CI 95%)	p-value	t stat
Age	39.5 ± 3.4	44.0 ± 3.6	= 0.07	-1.805
Experience	15.3 ± 3.5	18.7 ± 3.7	= 0.19	-1.323

Before training the most frequently reported problems care takers faced when caring for patients with dysphagia, were the following: it is difficult to position the patient in a good way, it is time-consuming, patients refuse mixed food or thickened liquids and patients are easily distracted while eating. As a response to the question on additional information needed on dysphagia, care takers stated they are in need of a yearly education program. Concerning improvement of the communication of the dysphagia recommendations, they reported that it would be nice if the dysphagia recommendations were written immediately in the nursing file. The SLT should give information about the dysphagia recommendations once a week during a briefing and it would be interesting to have information about the thickening of fluids on a document in the patient's room. For the last question (what support do you expect from the SLT?) they mentioned that the SLT should observe during the entire mealtime, observe the patient sooner when he is hospitalized, help care takers during different mealtimes, spend more time at the nursing unit, coach care takers and give feedback about what they do wrong.

Results of the MQD:

Based on the change in the average, no significant difference can be detected for the different MQD subscores (two sample t test). Based on the change in order (median), a significant difference can be detected for the different MQD subscores (Wilcoxon ranksum test). As a result of the intervention, the distribution of the hassle score has shifted to higher scores (increase in workload). The distribution of the knowledge scores has shifted to lower scores (increase in knowledge). The distribution of the disagreement score has shifted to lower scores (decrease of the disagreement) (Table 6).

Table 6: Median scores on MOD subscores

Variable	median before	median after	p-value	eta2
MQD Hassle Score	10.0 (7.0 - 12.0)	11.0 (7.3 - 13.8)	< 0.001	0.140
MQD Knowledge Score	10.0 (6.0 - 13.0)	8.0 (4.0 - 11.8)	< 0.001	0.311
MQD Disagreement Score	6.0 (4.0 - 7.0)	6.0 (4.3 - 8.0)	< 0.001	0.122

Training:

93% (86/92) of the care takers attended the training. 6 persons could not follow the training due to illness. The two dieticians and all kitchen staff (10/10) involved in preparing adapted menus attended the training.

During the training session the care takers mentioned that it was time consuming to feed patients, they did not always know how much thickener to use, they did not have time to look up the amount of thickener in the patients file, thickener is not always available (when pharmacy is closed), it is not easy to thicken larger amounts of fluids, patients refuse to eat mixed food or to thicken their liquids, mixed food is not attractive to eat, adapted cups are not available at the unit and patients want to talk during mealtime. During the discussion the following solutions were suggested: write the right amount of thickener on the patient's box with thickener, it would be interesting to have a number of measuring cups and a whisk at the nursing unit so that a bottle of half a liter can be thickened more easily, provide some adapted cups for patients with dysphagia at the nursing unit and thickener is available in the emergency locker of the pharmacy. These suggestions were discussed with the head of nursing and were put into practice. At the end of the training, care takers were asked to provide feedback about the training: 99% (85/86) found the training useful, 97% (83/86) found the demonstration of the preparation of different thickened fluids useful, 86% (74/86) thought that the training would change their way of feeding patients with dysphagia, they found it useful to know what it means to be fed by others. The most important learning points that were mentioned were most often the following: how to thicken liquids the right way, a good posture of the patient is important, it is important to take time to feed the patients and it is important for the patient to concentrate while eating.

<u>Information from the patient</u>

Patients mentioned it would be easier to follow the recommendations if food would look more attractive, because you eat with your eyes. They also said that it is important to understand the impact on their quality of life and that it takes time to adapt to the recommendations. A good explanation by the SLT why it is important to follow these recommendations is necessary.

Discussion

This study assessed care takers' compliance with dysphagia recommendations in a MS rehabilitation center and the impact of training.

Before training, in 26% of the cases, food distributed by the kitchen was inappropriate but noncompliance decreased to 14% after training. This demonstrated the importance to include kitchen staff in any training about dysphagia. Training for kitchen staff and giving feedback by

checking the food for the right consistency during 4 weeks improved compliance. Furthermore, it became clear by thoroughly evaluating food and it's consistency that in many cases the food was not sufficiently mixed and was too grainy. This seemed to be due to a lack of good equipment. Buying a new blixer could solve this problem.

Results of the observations during mealtime showed poor compliance. The overall level of compliance for care takers with SLT's recommendations before training was only 58%. This is comparable to the overall level of compliance found in similar studies from Tan et al. (2018) (57%) and Rosenvinge and Stark (2005) (52%). ^{12,18} In the study of Rosenvinge and Stark compliance for thickening fluids was 48%. ¹² Likewise in our study the thickening of fluids was considered as a problem (36% compliance for soup and 51% for fluids before training). Compliance for supervision was only 28% in our study in comparison to 35% in the study of Rosenvinge and Stark. ¹² Some patients want to eat in their room where supervision is not always possible due to insufficient staff to provide one on one supervision. Care takers may also be preoccupied with helping dependent patients and therefore not be able to supervise other patients. This was also mentioned in the study of Crawford et al. (2007) as a reason for noncompliance. ²¹

After the training, overall compliance improved from 58% to 81%. Compliance improved significantly across all units. There was improvement in compliance for all recommendations except for utensils. For patients who need to thicken their liquids and drink with a straw, sucking up their thickened liquid by using a straw can be exhausting. For this reason, it is often recommended to shorten the straw. If the recommendation was to shorten a straw, we saw that often a regular straw was given but not a shortened straw. Providing shorter straws on the nursing unit can improve compliance for this recommendation. The provision of the amount of thickener to use on the patient's box with thickener was a simple, very low-cost measure. Providing the tools to thicken the liquids removed some of the potential error of not thickening the liquids, reducing the risk of aspiration.

After the training care takers mentioned it was confronting to experience the impact of bad posture, giving food or drinks too quickly,... and they would change their way of giving food and drinks to the patient in the future. Consistent with findings in the literature, this study confirms that education is an important tool to improve compliance with dysphagia recommendations. ^{11,12,21,24} Because of the increased risk of aspiration by not following dysphagia recommendations, good communication and continuous coaching of care takers by the SLT are important. Management agreed to organize a three yearly training session to update the care taker's knowledge about dysphagia. In the future we can also start with e-learning for new staff. The study of llot et al. (2013) showed that blended e-learning is a cost-effective way to improve knowledge about dysphagia. ¹⁷

No relation was found between guideline application and severity of dysphagia. For all degrees of dysphagia severity, guidelines have been improved. The degree of improvement was the same for all degrees of dysphagia severity.

During the training sessions care takers asked for more support from the SLT, such as SLT's spending more time at the nursing unit, SLT's observing during the entire mealtime, SLT's giving feedback about what they do wrong and more coaching of the care takers and reporting SLT's recommendations immediately in the nursing file. The fact that they indicated that the SLT should help during mealtime may suggest excessive work pressure. The suggestions were partly incorporated into local SLT practice. Nevertheless, a number of suggestions (recommendations in the

nursing file and helping during mealtime) were not implemented because they are part of a larger problem in the center. The need for more and better communication and collaboration between therapists and the care takers is a big issue in the center. A large project to improve communication and collaboration, also involving IT has been set up in 2018 across the hospital and is still running.

The commencement of the nutrition group makes it possible to discuss problems more easily and to follow up problems faster.

Colodny (2001) suggests to compute the mean scores for MQD subscores. ¹¹ By computing the mean scores no difference was found in knowledge, hassle or disagreement. Therefore, distribution was also considered. The distribution of the knowledge scores on the MQD has shifted to lower scores (increase in knowledge) which confirms that knowledge has improved due to training. The distribution of the hassle score has shifted to higher scores (increase in workload). An increase in workload may be due to the fact that care takers apply more guidelines and take more time to feed the patient which may increase workload.

Care takers knew they were being observed. This may have biased the results. However this was the case in both audits. Observations were made by a trained student who did not benefit from the project. Therefore bias was minimized. Observations before and after training were done by a different student. The student's inter-rater reliability was not determined. This can be included in a future study.

Despite the advantages, many patients and care takers are reluctant to modify their diet and to thicken their liquids. Our training, care takers mentioned that a lot of patients refuse mixed food or thickened liquids. Whether patients refused their modifications was not included in the study. However this can have an impact on compliance of the care takers. Care takers and patients expressed their frustration about the appearance of food being brought from the kitchen. Modified meals should be made more visibly appealing to the patients. This can improve food intake and quality of life for patients.

A significant improvement one month after the training was found. It will be interesting to study the sustainability of the learning effect six months later. The relation between compliance with SLT's recommendations and aspiration pneumonia in patients was not examined in this study. This can be an interesting subject for future research.

References

- 1. Alali, D., Ballard, K. & Bogaardt, H. Treatment Effects for Dysphagia in Adults with Multiple Sclerosis: A Systematic Review. *Dysphagia* **31**, 610–618 (2016).
- 2. Guan, X.L., Wang, H., Huang, H.S., & Meng, L. Prevalence of dysphagia in multiple sclerosis: a systematic review and meta-analysis. *Neurol. Sci.* **36**, 671–681 (2015).
- 3. Pasquinelli, S. & Solaro, C. Nutritional assessment and malnutrition in multiple sclerosis. *Neurol. Sci.* **29**, 367–369 (2008).
- 4. Werner, H. The benefits of the dysphagia clinical nurse specialist role. *J. Neurosci. Nurs.* **37,** 212–215 (2005).
- 5. Lancaster, J. Dysphagia its nature, assessment and management. *British Journal of Community Nursing* **20**. (2015).
- 6. Clavé, P. *et al.* The effect of bolus viscosity on swallowing function in neurogenic dysphagia. *Aliment. Pharmacol. Ther.* **24,** 1385–1394 (2006).
- 7. Aoki, S. *et al.* The multidisciplinary swallowing team approach decreases pneumonia onset in acute stroke patients. *PLoS One* **11**, 1–9 (2016).
- 8. Langmore, S. E. *et al.* Predictors of aspiration pneumonia: How important is dysphagia? *Dysphagia* **13**, 69–81 (1998).
- 9. Low, J., Wyles, C., Wilkinson, T. & Sainsbury, R. The Effect of Compliance on Clinical Outcomes for Patients with Dysphagia on Videofluroscopy. *Dysphagia* **127**, 123–127 (2001).
- 10. Krekeler, B. N., Broadfoot, C. K., Johnson, S., Connor, N. P. & Rogus-pulia, N. Patient Adherence to Dysphagia Recommendations: A Systematic Review. *Dysphagia* **33**, 173–184 (2018).
- 11. Colodny, N. Construction and validation of the mealtime and dysphagia questionnaire: An instrument designed to assess nursing staff reasons for noncompliance with SLP dysphagia and feeding recommendations. *Dysphagia* **16**, 263–271 (2001).
- 12. Rosenvinge, K. S. & Starke, I. D. Improving care for patients with dysphagia. *Age aging* **34**, 587–593 (2005).
- 13. Leslie, P., Carding, P. N. & Wilson, J. A. Clinical review Investigation and management of chronic dysphagia. *J. Clin. Nurs.* **23**, 1354–1364 (2013).
- 14. Palmer, J. L. & Metheny, N. A. How to try this: Preventing aspiration in older adults with dysphagia. *Am. J. Nurs.* **108**, 40–48 (2008).
- 15. Zolnierek, K. B. . & Dimatteo, M. R. Physician Communication and Patient Adherence to Treatment. *Med. Care* **47**, 826–834 (2009).
- 16. Hines, S. *et al.* Identification and nursing management of dysphagia in individuals with acute neurological impairment (update). *Int. J. Evid. Based. Healthc.* **9,** 148–150 (2011).
- 17. Ilott, I. *et al.* Evaluating a novel approach to enhancing dysphagia management: Workplace-based, blended e-learning. *J. Clin. Nurs.* **23**, 1354–1364 (2013).
- 18. Tan , L. et al. Honey I Fed my patients! An improvement project to improve compliance to dysphagia measures. *Dover Park Hosp.* (2018).

- 19. Tan, L., Gan, G., Hum, A. & Lee, A. A Stepwise, Mixed-Method Study Approach to Identify the Barriers to Dysphagia Care in Hospice Care Nurses. *J. Hosp. Palliat. Nurs.* **20**, 88–94 (2018).
- 20. Macqueen, C. E., Taubert, S., Hons, D. C., Stevens, S. & Frost, G. S. Which Commercial Thickening Agent Do Patients Prefer? *Dysphagia* **18**, 46–52 (2003).
- 21. Crawford, H., Leslie, Æ. P. & Drinnan, Æ. M. J. Compliance with Dysphagia Recommendations by Carers of Adults with Intellectual Impairment. *Dysphagia* **22**, 326–334 (2007).
- 22. Smith-Tamaray, M., Wilson, L. & McAllister, L. Factors affecting dysphagia management and compliance with recommendations in non-metropolitan healthcare settings. *Speech Lang. Pathol.* **13**, 268–279 (2011).
- 23. Colodny, N. Dysphagic independent feeders' justifications for noncompliance with recommendations by a speech-language pathologist. *Am. J. Speech-Language Pathol.* **14,** 61–70 (2005).
- 24. Chadwick, D. D., Jolliffe, J. & Goldbart, J. Adherence to Eating and Drinking Guidelines for Adults With Intellectual Disabilities and Dysphagia. *Am. J. Ment. Retard.* **108**, 202–211 (2003).
- 25. Harper, J. Emergency Nurses' Knowledge of Evidence-Based Ischemic Stroke Care: A Pilot Study. *J. Emerg. Nurs.* **33,** 202–207 (2007).
- 26. Cichero, J. A. Y., Heaton, S. & Bassett, L. Triaging dysphagia: nurse screening for dysphagia in an acute hospital. *J. Clin. Nurs.* **18**, 1649–1659 (2009).
- 27. Chadwick, D. D. & Goldbart, J. Carer knowledge of dysphagia management strategies. *Int. J. Lang. Commun. Disord.* **37**, 345–357 (2002).

Appendix 1

Mealtime and dysphagia Questionnaire from ${\sf Colodny}^{\sf 11}$

<u>Directions</u>: The following statements describe perceptions and opinions on mealtime and swallowing issues in the <u>elderly</u>. Please indicate how you feel about each statement by circling the number of the answer the most reflects your feelings using the coding system below. There are no right or wrong answers.

Stron	ngly Disagree	Somewhat Disagree 2	Neither Agree nor Disagree 3	Somewhat Agree	Stron	gly 5	Ag	ree
1.	It takes too l	ong to thicken liquids. ((H)		1 2	3	4	5
2.	I'm not sure	how much thickener to	use. (K)		1 2	3	4	5
3.	I don't use th	I don't use thickener because the residents don't want it. (H)						
4.	Residents don't drink as much when they are on thickened liquids. (K)							5
5.	I am not sure which residents are on thickened liquids. (K)							5
6.	The meal tic liquids.(K)	ket does not always ider	ntify which residents ar	e on thickened	1 2	3	4	5
7.	They don't s	They don't send up enough thickener on the meal truck. (H)						
8.	Sometimes I forget to use thickener. (H)						4	5
9.	The resident	s occasionally drink the	ir liquids before I get a	chance to thicken them.	1 2	3	4	5
10.	I'm not sure why some of the residents are on thickened liquids. (K)					3	4	5
11.	I don't thicken liquids because I have too much to do. (H)					3	4	5
12.	No one show	ved me how to thicken the	he liquids. (K)		1 2	3	4	5
13.	I am never s	ure if residents are still o	on thickened liquids. (I	()	1 2	3	4	5
14.	Residents do	not need thickened liqu	iids. (D)		1 2	3	4	5
15.	Thickened li	quids improve the reside	ents' swallowing functi	on. (D-R)	1 2	3	4	5
16.		e which specific feeding is given slowly). (K)	techniques to use (e.g.	, double swallow and	1 2	3	4	5
17.	I don't have SLP. (D)	time to follow through	on swallowing recomm	endations given by the	1 2	3	4	5
18.	I don't have	time to sit when I am fe	eding. (H)		1 2	3	4	5
19.	It is difficult	to position residents ap	propriately during mea	ltimes. (H)	1 2	3	4	5
20.	It is not nece and sips. (D	essary to give the resider	nts small amounts and v	vait between mouthfuls	1 2	3	4	5
21.	I don't unde	rstand why specific feed	ing techniques were re	commended by the SLP.	1 2	3	4	5