

Training for Caregivers and Compliance with Dysphagia Recommendations in a Tertiary Multiple Sclerosis Rehabilitation Center

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Background: Dysphagia is common in persons with multiple sclerosis (MS). Speech and language therapists give dysphagia recommendations to persons with MS and caregivers. Nonadherence to these recommendations can increase the risk of aspiration. We investigated current compliance with dysphagia recommendations among caregivers and kitchen staff and assessed improvement in compliance by increasing knowledge through tailored training.

Methods: An observational cohort study was conducted over 4 weeks during which the compliance of the caregivers and kitchen staff in a rehabilitation center was monitored. A questionnaire was used to assess reasons for noncompliance. A 2-hour training session was provided for all caregivers and kitchen staff to improve their knowledge and skills. The compliance rate was observed again 1 and 6 months after the training. Compliance was defined by whether recommendations were followed.

Results: Results showed a significant improvement after training for overall compliance by caregivers (from 58% to >81%, $P < .001$). This improvement was still observed 6 months later (80%). After training, significant differences were found in compliance with the following recommendations ($P \leq .001$): consistency of soup, consistency of liquids, food preparation, alertness, speed, amount, posture, and supervision. Recommendation for utensils did not improve ($P = .44$). Compliance with diet modifications made by the kitchen staff improved significantly (from 74% to >86%, $P = .002$), and even more during follow-up (to >95%, $P = .009$).

Conclusions: Dysphagia training tailored to the needs of caregivers to improve knowledge significantly improves compliance with dysphagia recommendations and the quality of care. *Int J MS Care.* 2021;23:223-228.

The incidence of dysphagia in people with multiple sclerosis (MS) has been estimated to be 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 persons with MS are important.⁴

Treatment of dysphagia needs a multidisciplinary approach.³⁻⁷ The speech and language therapist (SLT) plays an important role in diagnosis, treatment, and

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management of dysphagia. Treatments for dysphagia, advised by the SLT, may consist of compensatory strategies such as changes in head posture or diet modifications such as thickening liquids and consistency modifications on the one hand and exercises to strengthen muscles on the other hand.⁸ Caregivers play a crucial role in managing and preventing complications related to dysphagia by following the adaptations made by the SLT.^{4,9,10}

Both the patient's and the caregiver's noncompliance with dysphagia recommendations can have serious consequences and can increase the risk of penetration, aspiration, morbidity, and mortality.¹¹ Unfortunately, noncompliance by caregivers with the SLT recommendations is common in long-term care.^{4,10,11} Rates of compliance with the SLT's feeding recommendations among health care professionals did not exceed 50% to 57%.¹¹⁻¹³ Insufficient knowledge, lack of time, and the patient's resistance to the dysphagia recommendations were the main reasons for noncompliance.^{12,13}

Various studies have confirmed that training can significantly improve knowledge of dysphagia and compliance with dysphagia recommendations.^{4,10,14-19} Likewise, we have noticed in our center (National MS Center Melsbroek) a high incidence of caregiver noncompliance with the SLT's recommendations. No previous research was identified that investigated such compliance of caregivers working with persons with MS. For this reason, we decided to investigate and improve the compliance of caregivers working with persons with MS regarding dysphagia recommendations.

Methods

Study Design and Sample

An observational cohort study was used to examine compliance and reasons for noncompliance and the impact of training on the knowledge and attitudes of the caregivers and kitchen staff working in a rehabilitation center.

All caregivers (nurses and health care assistants) working with inpatients and kitchen staff were included from September 2018 to October 2019.

Procedure

Existing evidence and methods from previous similar studies were considered and served as an inspiration for the protocol of this study.^{10-13,20} The study was conducted in an MS rehabilitation center in Belgium and was led by an SLT working in the center. The study was approved by the ethics committee of the National MS Center, Melsbroek, Belgium (OG 033). Because the study was focused on improving quality of care among employees of the rehabilitation center, a waiver of consent was granted by the ethics committee. Before the start

of the project, the aims and methods were discussed with the management.

Baseline observations were conducted to determine whether kitchen staff and caregivers were following the SLT's recommendations. A questionnaire was distributed to assess knowledge, attitudes, and other reasons for noncompliance. Based on the gaps defined by the observations and questionnaires, a training session for the caregivers and kitchen staff was provided to improve their knowledge and skills. The same observations were repeated after the intervention and 6 months later. An overview of the project can be found in Figure S1, which is published in the online version of this article at ijmsc.org.

Assessment

To determine whether kitchen staff and caregivers were following the SLT's recommendations, checklists were used during the observations. The checklists consisted of individual swallowing recommendations taken from the patient file and were marked according to adherence to the recommendations. 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. Checklists were organized into the following sections: consistency of fluids, consistency of soup, preparation of food by the caregivers (cutting crusts from bread, making bread pudding, cutting meat into smaller pieces), dietary modifications made by kitchen staff (does the patient get food as requested according to the dysphagia recommendations, eg, extra sauce, mixed food), general recommendations (eg, advice on alertness, posture, amounts to be given, speed), level of supervision required, and assistive devices (eg, adapted cups, straws, shortened straws). The severity of the patient's dysphagia (mild, moderate, severe) was subjectively determined by the treating SLT based on the adaptations needed and the risk of aspiration.

Observations of dietary modifications were conducted during 4 weeks in September 2018 by two SLTs. The mealtime observations were performed by a student during 4 weeks in October 2018, at lunchtime and during the evening meal on every nursing unit. Observations were conducted in the dining room or in the patient's room. The student was well trained and informed before starting the observations. During March 2019 (posttraining) and October 2019 (follow-up), menu and mealtime observations were performed again using the same method as before the training. Before the observations, caregivers were verbally informed that the aim of the project was to investigate the obstacles that caregivers come across when following the SLT's recommendations and what support they require from the SLT.

The 21-item Mealtime and Dysphagia Questionnaire (MDQ) from Colodny¹¹ was translated into Dutch. Colodny¹¹ describes the questionnaire as a reliable tool to assess reasons for noncompliance. The questionnaire consists of 21 questions clustered in three factors: hassle (the added work that the recommendations require), knowledge of

dysphagia, and degree to which caregivers disagree with the recommendations made by the SLT. All items are scored on a 5-point scale (higher scores indicating more hassle, less knowledge, and more disagreement). By summing the scores on the statements and dividing by the number of statements, a mean score is computed. This allows comparisons to be made about the impact of each factor on noncompliance.¹¹

To gain more information, demographic data from the caregivers and four additional questions were included based on the literature and relevance for the study.^{10,13} This amended questionnaire highlighted the problems that caregivers face when caring for patients with dysphagia, expectations from the SLT, the desired knowledge about dysphagia, and what could be improved concerning communication of the dysphagia recommendations. This questionnaire was distributed to all caregivers in the center working with inpatients and was completed anonymously. Completed questionnaires were collected in boxes located on every nursing unit. Questionnaires with 10% or more of the questions unanswered were excluded from the analysis. The questionnaire took 10 minutes to complete and was distributed in November 2018 (baseline) and again in March 2019 (posttraining).

A meeting was set up with a focus group composed of eight patients to determine the information that was required for patients to be able to follow any dysphagia recommendations. During this meeting, the SLT interviewed the members of the focus group about their barriers to following the SLT's recommendations.

Intervention

All caregivers, kitchen staff, and dietitians were scheduled to attend an obligatory group training in February 2019. The session started with a presentation of the results of the questionnaires and observations at baseline, followed by theoretical and practical parts, 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 persons with MS were presented. The symptoms of dysphagia and how to manage them were also discussed. In the practical session, caregivers observed a demonstration of fluid thickening. They could also experience how it feels to be fed by others and what the impact is of different postures, safe feeding techniques, different consistencies, and utensils. The training sessions were given by two experienced SLTs and lasted for 2 hours. At the end of the training, the caregivers received a questionnaire to provide feedback about the training and to determine the three most important things they had learned during the training.

The SLT had a meeting with the head of the kitchen staff and the two dietitians. During this meeting she discussed the results of the observations of the menu and explained the importance of following the dietary recommendations. For 4 weeks, the SLTs went into the kitchen to check the adapted menus for the right consistency and to give feedback.

Statistical Analysis

Data were analyzed using a statistical software package (SPSS Statistics for Windows, version 26.0; IBM Corp). Differences in distribution in compliance between test moments and between subgroups were calculated using the χ^2 test. A $P < .05$ was considered statistically significant. Normal distributions of MDQ scores were evaluated using visual inspection of histograms and the Shapiro-Wilk test. All MDQ scores were normally distributed, and, therefore, one-way analysis of variance was used to analyze differences.

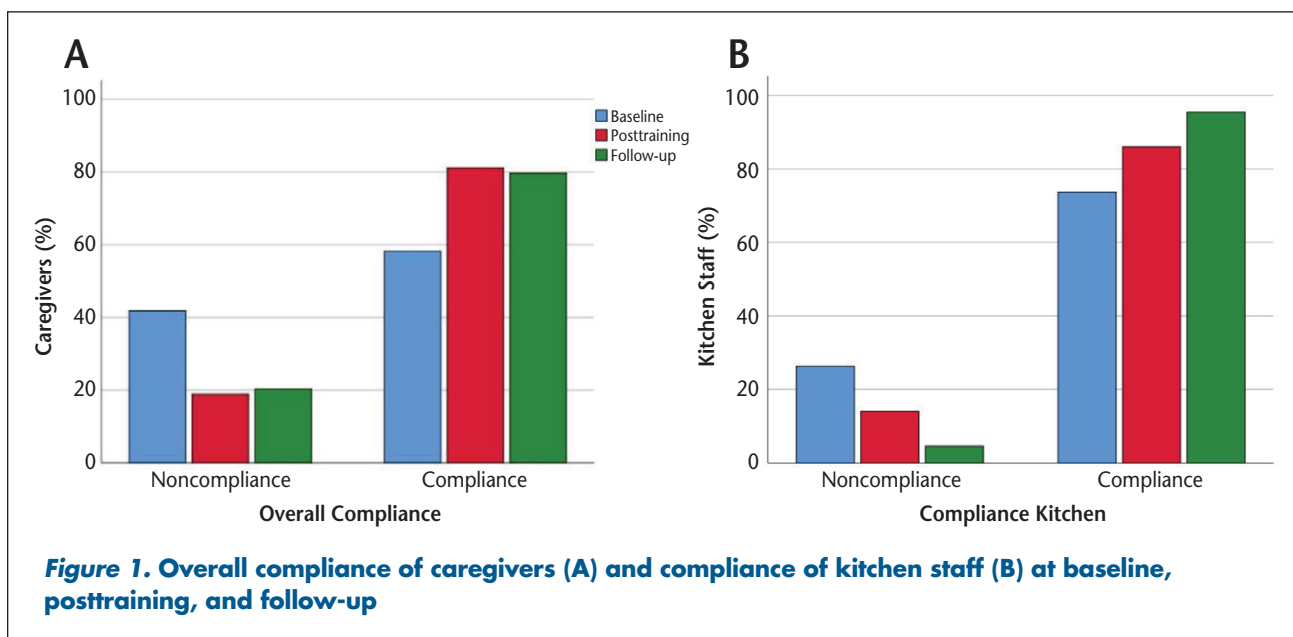
Results

At baseline, modified diets were often not applied (compliance, 74%). The food provided was too dry, which made it more difficult to swallow, was not sufficiently mixed, or was not of the right consistency as requested by the SLT. After the training, in 86% of the cases the food prepared in the kitchen was deemed appropriate ($P = .002$). At follow-up (6 months later), the compliance rate was 95%, which is a significant increase compared with posttraining ($P = .009$) (Figure 1B and Table S1).

For mealtime observations compliance differed according to the type of guideline. An overview of compliance of caregivers with different recommendations for the different audits is given in Table S1. Overall compliance improved from 58% at baseline to 81% after training ($P < .001$). This improvement was sustained 6 months later (80%) (Figure 1A). Significant improvement in compliance was found for all recommendations except for utensils. Compliance for utensils decreased across the three audits. Improvement in compliance was demonstrated for all nursing units. Compliance improved for observations at lunchtime and in the evening from baseline to posttraining. This did not change for follow-up.

All patients who had dysphagia recommendations at the time of the study were included (26 patients at baseline, 28 at posttraining, and 21 during follow-up). There was a significant difference ($P < .001$) in the three audits regarding the proportion of the patient's severity of dysphagia, the distribution of patients, and the number of observations. These differences were due to discharges over the study period. No relationship was found between guideline application and severity of dysphagia. For all degrees of dysphagia severity, guidelines have been improved ($P < .001$). The degree of improvement was the same for all degrees of dysphagia severity.

The response rate for the questionnaires was 67% (62 of 92) at baseline and 70% (64 of 92) after training.



Nine questionnaires were excluded because respondents did not attend training (seven of 92) or because of incomplete response (>10% of questions unanswered; two of 92). The distribution of respondents at baseline and after training did not differ statistically significantly.

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

Preintervention and postintervention MDQ scores did not differ significantly (hassle $P = .450$, knowledge $P = .067$, disagreement $P = .156$) (Table 1).

Table 1. Mealtime and Dysphagia Questionnaire subscores

Subscale and audit	Participants, No.	Subscore, mean \pm SD	P value
Hassle			.450
Baseline	60	2.2268 \pm 0.63852	
Posttraining	56	2.3118 \pm 0.56352	
Total	116	2.2678 \pm 0.60238	
Knowledge			.067
Baseline	60	2.2458 \pm 0.54168	
Posttraining	56	2.0558 \pm 0.56554	
Total	116	2.1541 \pm 0.55910	
Disagreement			.156
Baseline	60	2.0833 \pm 0.50829	
Posttraining	56	2.2125 \pm 0.46322	
Total	116	2.1457 \pm 0.48926	

The training was well attended (86 of 92 caregivers [93%]). Six persons could not follow the training due to illness. Two dietitians and all the kitchen staff (10 of 10) involved in preparing the adapted menus attended the training.

During the training session, caregivers mentioned several problems that they faced, and solutions were suggested. These suggestions were discussed with the head of nursing and were put into practice (Table S2). At the end of the training, caregivers were asked to provide feedback about the training: 85 of 86 (99%) found the training useful, 83 of 86 (97%) found the demonstration of the preparation of different thickened fluids useful, and 74 of 86 (86%) thought that the training would change their way of feeding patients with dysphagia, and they found it useful to know how it feels to be fed by others. The most important learning points that were mentioned most often were the following: how to thicken liquids the right way, the impact of a good posture of the patient, the importance taking enough time to feed the patients, and the need for patients' concentration while eating.

Patients from the focus group mentioned that it would be easier to follow the recommendations if the visual attractiveness of the food would increase. They mentioned that it is important to understand the impact of menu adaptations on their quality of life and that it takes time to adapt to the recommendations. A good explanation by the SLT is necessary to stress the importance of the given recommendations.

Discussion

A quality improvement study of caregiver and kitchen staff compliance with dysphagia recommendations in an MS rehabilitation center was conducted. There was a significant improvement in compliance with recommendations after a single training session based on direct observations and caregiver input.

At baseline, in 74% of the cases, food distributed by the kitchen was appropriate, but compliance increased to 86% after training. After providing specific feedback to kitchen staff, a further improvement to 95% was observed.

Results of the observations during mealtime showed poor compliance at baseline (58%). This is comparable with the overall level of compliance found in similar studies with other patient groups from Tan et al¹³ (57%) and Rosenvinge and Stark (52%).¹² In the latter study,¹² compliance for thickening fluids was 48%. Likewise, in the present study, the thickening of fluids was considered a problem (36% compliance for soup and 51% for fluids before training). Compliance for supervision was only 28% in the present study compared with 35% in the study by 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. Caregivers may also be preoccupied with helping dependent patients and, therefore, not be able to supervise other patients. This was also mentioned in the study by Crawford et al²⁰ as a reason for noncompliance.

After the training, caregivers stated that it was eye opening to experience the impact of bad posture, or giving food or drinks too quickly, and expressed a willingness to change their way of giving food and drinks to patients in the future. Indeed, overall compliance improved from 58% to 81%. Compliance improved significantly across all units. These results remained during follow-up, 6 months later (80%). There was improvement in compliance for all recommendations except for utensils. Compliance for utensils even decreased across the three audits. The provision of the amount of thickener to use on the patient's container with thickener was a simple, very low-cost measure. Providing the tools to thicken the liquids may have facilitated the (correct) use of thickener, reducing the risk of aspiration and improving compliance to 88% during follow-up.

Consistent with findings in the literature, this study confirms that education is an important tool to improve

compliance with dysphagia recommendations.^{11,12,16,20} Due to the increased risk of aspiration when not following dysphagia recommendations, good communication and continuous coaching of caregivers by the SLT is important. The hospital management team agreed to organize a training session every 3 years to update the caregivers' knowledge about dysphagia. Also, in the future, e-learning for new staff can be used. The study by Ilott et al¹⁰ showed that the combination of blended e-learning and traditional methods is a cost-effective way to improve knowledge about dysphagia.

Despite the advantages, many patients and caregivers are reluctant to modify their diet and to thicken their liquids. During our training, caregivers mentioned that a lot of patients refuse mixed food or thickened liquids. However, this can have an effect on compliance of the caregivers. Whether patients refuse their modifications was not included in the study. Caregivers 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 because this can improve food intake and quality of life for patients. Also, patient education is important to stress the importance of the adaptations and to help patients to accept the recommendations.

During the training sessions, caregivers asked for more support from the SLT, such as SLTs spending more time at the nursing unit, SLTs observing during the entire mealtime, SLTs giving feedback about what

PRACTICE POINTS

- In an MS rehabilitation hospital, food preparation and feeding recommendations issued by speech and language therapists for patients with dysphagia were not always followed.
- Insufficient knowledge, lack of time, and the patient's resistance to the recommendations were cited by caregivers as the main reasons for noncompliance.
- Training sessions for caregivers and kitchen staff were followed by improved compliance with dysphagia recommendations, and the improvement was sustained 6 months later.
- Patients in a focus group stated that making food look more attractive and appetizing would make it easier for them to follow dysphagia recommendations.

they do wrong and more coaching of the caregivers, and reporting SLT's recommendations immediately in the nursing file. The caregivers stating that the SLT should help during mealtime may indicate that the recommendations create additional workload. The suggestions were partly incorporated into local SLT practice. For practical reasons, it was not possible to write the swallowing recommendations immediately in the nursing file.

A literature search for validated questionnaires in Dutch was conducted; however, no validated tool that evaluated the dysphagia knowledge and attitudes of caregivers was found. For this reason, the MDQ was translated into Dutch. Neither reliability nor validity was, however, evaluated in the translated version. Colodny¹¹ describes the MDQ as a reliable tool to assess reasons for noncompliance. No difference was found in knowledge, hassle, or disagreement despite verbal feedback that caregivers found the training beneficial. The MDQ may not be the best tool to assess changes in knowledge, hassle, and disagreement. Although no significant difference was found, there was a trend in the decrease of knowledge as a barrier (from 2.25 to 2.06).

There are some limitations to this study. Caregivers knew that they were being observed, which may have biased the results. However, this was the case in all three audits. Observations were made by a trained student who did not benefit from the project. Therefore, observation bias was minimized. Observations before and after training were performed by a different student, but the interrater reliability of observations was not determined. We did not include a control group, which may have decreased the methodological quality; however, using a control group in the same hospital can give some contamination effect. Therefore, future research may include comparison with a control group in a similar setting in another hospital.

In conclusion, dysphagia training tailored to the needs of caregivers to improve knowledge significantly improves compliance with dysphagia recommendations and the quality of care. The relationship between compliance with the SLT's recommendations and aspiration pneumonia in patients was not examined in this study. This could be an interesting subject for future research. □

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