

SESSION 8C INTERNATIONAL PERSPECTIVES ON CARE MANAGEMENT

C71 PREDICTORS OF SOCIAL SERVICES INPUT AMONGST PEOPLE WITH ALS/MND

O'BRIEN M¹, WHITEHEAD B^{1,2}, MITCHELL D², MURPHY P¹, CALLAGHER P², JACK B¹

¹Edge Hill University, Lancashire, United Kingdom, ²Lancashire Teaching Hospitals NHS Foundation Trust, Preston, United Kingdom

E-mail address for correspondence: obrienm@edgehill.ac.uk

Keywords: care, social services, predictive factors

Background: A descriptive audit of the key characteristics of the MND population in a large UK specialist MND clinic was undertaken in 2008 as part of a larger study exploring the personal experience of living with MND. The audit revealed that a significant number of patients and carers were not accessing external caring support provided by local social services, despite increased levels of disability (1).

Objectives: The aims of this study were to document changes in the key characteristics over a 12 month period in an attempt to identify factors predictive of uptake of social services care.

Methods: A comprehensive case note review of patients was undertaken at 2 time points, T1 (March 2008) and T2 (March 2009). Statistical analysis was aided by SPSS version 16.0.

Results: The sample had a mean age of 64.4 years (SD = 11.7 years), with a mean onset age of 59.1 years (SD = 12.6 years). Age at T1 and duration of the illness were both significantly correlated with ALS Health Severity Scale (ALSHSS) ratings. Only 27.1% of the sample were in receipt of local authority care at T1, with this rising to 37.7% of the surviving sample at T2. The presence or absence of local authority care at T1 was taken as a dependent variable in a logistic regression analysis employing onset age, time from diagnosis to T1, and ALSFRS scores as a predictive model. The model was highly predictive of the dependent variable, with each unit rise in ALSFRS scores being related to an 8.1% decrease in the odds of receiving local authority care at T1.

A separate logistic regression showed that forced vital capacity (% of predicted) at T1, and the time from disease onset to T1, were both positively predictive of being alive at T2. In particular, each unit increase in vital capacity at T1 was related to a 4% increase in the odds of being alive at T2.

Conclusions: This study has provided detailed information regarding the level of uptake of care services over a one year period for the current MND population followed up by a specialist UK MND clinic. It confirms previous findings of relatively poor uptake of care services by people with MND which may be predicted by taking into account age at onset, disease duration and ALSFRS scores. Additionally, there is confirmation of the role of forced vital capacity as a predictor of survival.

Reference:

1. O'Brien M., Whitehead B., Mitchell D. *et al.* ALS 2008, 9; Supp 1, 147

C72 A CARING APPROACH TO ALS CARE

GOLDMAN B¹, HARTMANN S², WEBER M¹

¹Neuromuscular Disease Unit Kantonsspital, St. Gallen, Switzerland, ²Palliative Care Unit Kantonsspital, St. Gallen, Switzerland

E-mail address for correspondence: bea.goldman@kssg.ch

Keywords: patient instruction, home care, quality of life

Background: Good patient care for ALS sufferers is a prerequisite for maintaining their quality of life. Knowledge about the disease and patient care is therefore essential for both patients and their caregivers. The patients' and caregivers' thirst for information was immense and could not be fulfilled in an adequate way during the regular outpatient consultations. To address this need, we designed a special training programme for ALS patients, caregivers and health-care professionals.

Objectives: The aim was to enhance patients' and caregivers' knowledge about the disease and patient care and to enable adequate care for a tetraplegic person in a home setting.

Methods: We therefore offered five theme-based afternoons, each was a module lasting five hours. These took place in comfortable surroundings and included presentations from experts, question and answer sessions, practical group exercises under supervision and ample time to exchange experiences. The themes of the modules were "mobility", "breathing", "nutrition", "homecare" and "last phase". The ALS Care Training Programme is based on the adult education concept consisting of information, practical experiences with supervised training and the exchange of experiences. The programme was mainly designed for patients (P) and caregivers (CG) but health care professionals (HC) could also participate. A booklet for everyone to take home was handed out at each module.

Questionnaires with a self-rating scale of 0 to 5 (0 = no knowledge, 5 = best knowledge) were given out before and after each training session addressing the major goals of each theme.

Results: A total of 42 patients, 52 Caregivers and 21 healthcare professionals participated during the years 2005, 2006 and 2008. A total of 532 questionnaires were completed. Improvement of knowledge was noted for all themes. Average scores increased for mobility from 2.3 to 3.7 (P); 1.9 to 3.2 (CG); 3.5 to 4.0 (HC), for breathing from 2.5 to 4.3 (P); 2.3 to 4.1 (CG); 3.7 to 4.7 (HC), for nutrition from 3.1 to 4.5 (P); 2.8 to 4.5 (CG), for homecare from 2.9 to 4.3 (P); 2.4 to 3.9 (CG) and "last phase" from 2.1 to 4.3 (P); 2.3 to 4.3 (CG); 3.4 to 4.7 (HC). All improvements were highly significant ($p < 0.01$; paired t-test).

Conclusion: To the best of our knowledge, this is the first systematic ALS Care Training Programme to have been reported. This project shows that systematic ALS Care Training is a particularly effective and appropriate way of transferring knowledge to improve confidence in care management of patients and their caregivers. It could be an inspiration for others. We would like to thank for their support: Fresenius Kabi, Switzerland, Aventis Sanofi, Switzerland, patients' sponsoring and since 2008 by the Swiss Muscle Society.

C73 ALS OUTREACH SERVICES

CHAM E, POIRIER B

Vancouver Coastal Health, ALS Centre, Vancouver, British Columbia, Canada

E-mail address for correspondence: brigitte.poirier@vch.ca

Keywords: client satisfaction, education, outreach

Background: The Vancouver Coastal Health ALS Centre is British Columbia (BC)'s trans-disciplinary team providing services to people with Amyotrophic Lateral Sclerosis (ALS) from time of referral to end of life. The team is composed of clinicians in Neurology, Dietetics, Nursing, Occupational Therapy, Physiotherapy, Social Work and Speech-Language Pathology and offers outpatient diagnostic, assessment, intervention, consultation, outreach and educational services in partnership with other community organizations throughout the province. With the support of the ALS Society of BC, the ALS Centre developed a Mobile Outreach Clinic to better serve ALS clients, families and local service providers. This started as a pilot project and is now a permanent service offered by the ALS Centre. Approximately four clinics per year are offered to different regions of the province. Education sessions to local service providers were later added to the mobile clinic schedule to meet the learning needs of the community.

Objectives: 1) To evaluate the effectiveness of the Mobile Outreach Clinic and Education sessions offered to local communities. 2) To evaluate satisfaction levels of clients, families and local health care providers with the Mobile Clinic and Education session outreach model.

Methods: Satisfaction questionnaires including 5 items on a 5-point Likert scale and open-ended questions were distributed to clients seen during Mobile Clinics and to health care providers who attended the education sessions. Complete data were obtained from 34 clients and 55 health care providers. Results were collated and analyzed with descriptive statistics (crosstab and bar graphs) using statistical software (SPSS V15).

Results: ALS clients, their family and the local health care providers all seem to be highly satisfied by the outreach services they received from ALS Centre.

Discussion: The high level of satisfaction of the ALS clients and their local health care providers illustrates the relevance of outreach services, in particular the mobile clinics and the education of local professionals about the management of ALS symptoms. As a result, those services have now been established as part of the permanent service provision offered by the ALS Centre.

Conclusions: The mobile outreach clinic project demonstrated high satisfaction from clients living in various regions of the province of British Columbia. The local health care providers involved with ALS clients expressed high satisfaction about education provided by the ALS Centre. However, this model of service provision does not serve some of the ALS clients living away from major urban centres: for example, clients living in facilities or home bound with limited transportation options. Future options to consider may include: home visits to facilities and client homes in rural areas, extending mobile clinic operating hours, and videoconference education sessions.

C74 OUTCOMES USING AN ON-LINE PRE-CLINIC ASSESSMENT TOOL

KITTRELL P, JACKSON C

University of Texas Health Science Center at San Antonio, San Antonio, TX, United States

E-mail address for correspondence: kittrellp@uthscsa.edu

Keywords: pre-clinic assessment, communication, satisfaction

Background: Multidisciplinary ALS clinics use pre-clinic assessments to gather information before the patient is seen by each team member. Typically, these are sent by mail or completed over the telephone. Telephoning patients can be time consuming and, over time, disease progression can impact the patient's ability to communicate verbally.

Objectives: To develop an on-line survey that can be completed by the patient prior to their multidisciplinary visit. Secondary objectives were: to improve efficiency in obtaining information; to provide current information to the team members so that they can be prepared with equipment, teaching tools, information etc. to meet the needs of our patients; to prioritize the issues to be addressed by the team and to streamline the clinic process.

Method: Using Survey Monkey[®], a survey was developed by polling the team members for questions and concerns covered during the clinic visit. The survey included questions regarding change in medical status, medications, swallowing, nutrition, breathing, speech, mobility, medical equipment and family concerns (disability, wills, power of attorney). Patients were sent the survey link by email one week before their visit. Patients without email were called and the survey was completed by one of the team members. The survey link also served as a reminder of the upcoming visit. Patients with incomplete surveys were contacted to determine if a phone interview was needed. Surveys went to a secure server monitored by one of the clinic RNs. Identified concerns or questions needing immediate attention were addressed as indicated. Two days before clinic, responses were forwarded to all team members. Following the clinic visit, a questionnaire was sent to the patients who completed the on-line survey, asking for feedback on the process and suggestions for improvement. Revisions were incorporated into the survey.

Results: All patients but two (2) who attended the clinic between December 2008 and April 2009 completed the survey either by email (78%) or with a team member via telephone (20%). Of the 67% of patients who completed the follow up survey, 78% perceived their quality of care at clinic was improved by completing the pre-clinic survey and 52% perceived their visit took less time and clinic flow was improved. A follow up survey with team members indicated they felt more prepared to answer questions and provide appropriate interventions. Loan Bank equipment utilization was improved with less need for home delivery, impacting time and travel costs. Time spent by team members on the telephone (pre and post clinic) was cut by more than 50%.

Conclusions: On-line pre-clinic assessment surveys can be a beneficial tool to help multidisciplinary teams prepare for and respond to patient needs.

C75 ENHANCING SPEECH DURING BIPAP USE

CHUA S, KRUCHTEN P, EISEN A

*University of British Columbia, Vancouver, BC, Canada**E-mail address for correspondence: eisen@interchange.ubc.ca**Keywords: BiPAP, speech, quality of life*

Background: The efficacy and benefit of BiPAP use in amyotrophic lateral sclerosis (ALS) is well established with daily utilization varying from several hours to 24 hours depending on disease progression and stage. Problems associated with BiPAP use include dry mouth, abrasion from the mask and claustrophobia. These can be dealt with relatively easily. A more major problem is its interference with speech caused by muffling of vocalization by the BiPAP mask and the associated airflow noise. For patients using BiPAP several hours a day this problem greatly limits their communication.

Objectives: To improve speech when using Bi-level Positive Airway Pressure (BiPAP).

Methods: To overcome muffled speech due to BiPAP use a small electret microphone was suspended near the top of the mask away from the direct path of the rushing air. The sound output was filtered and amplified by software on a digital signal processing board that computes an average of the noise during non-speech activity and then removes it from subsequent sound frames. Residual noise in a sound frame is then further attenuated based on information provided by an algorithm that examines adjacent sound frames.

Results: During preliminary testing, it was found that the airflow noise was removed almost entirely with very little residual noise from the sound signal and after amplification, allowing listeners to hear a BiPAP user's voice very clearly. Occasionally nasal bridge prominence caused the microphone to be flush against the skin and speech capture was impossible. Placing the microphone nearer the mouth overcame this problem but the airflow noise increased significantly affecting the performance of the noise filtering. Possible solutions involve finding an alternative optimal placement in the mask or designing a microphone housing that would help shield the microphone from noise. Sometimes reverberations in the mask resulted in a "radio-like" speech; a possible solution to this would be use of multiple microphones.

Discussion and Conclusions: The prototype developed allows significant improvement in speech whilst using a BiPAP. We believe that this is the first attempt to solve the problem of audible speech whilst using a BiPAP. Several modifications are being tested to improve the aesthetics and other aspects of the present prototype and we are presently evaluating its use in a larger cohort of ALS patients.

C76 THE SURVEY REPORT OF THE ALS PHYSICIANS IN JAPANOGINO M¹, OGINO Y^{1,2}, HAMADA J¹*¹Kitasato University, Department of Neurology, Sagamihara, Kanagawa, Japan, ²Toshiba Linkan Hospital, Sagamihara, Kanagawa, Japan**E-mail address for correspondence: mieko@kitasato-u.ac.jp**Keywords: palliative care, withdrawal of permanent ventilation, questionnaire*

In March 2009 we sent out a questionnaire to the 4,500 Board Certified Membership of the Japanese Society of Neurology to ask 30 questions about their clinical experiences, practice and thoughts in connection with palliative care at the terminal stage and patients' rights, especially about the withdrawal of permanent ventilation. This is the very first of this kind of comprehensive survey in Japan to cover the exclusive population of ALS physicians. By the end of April, 1,470 anonymous responses (33%) had been returned. To date, 700 responses have been analyzed.

The purpose of the survey is to grasp what is happening to the physician's side of the Japanese ALS community where the high rate of ventilated ALS patients and the low rate of morphine prescription for ALS patients have often been pointed out.

As for the palliative care practice, 21% of the respondents prescribe morphine, which shows a drastic increase from the 14% in the 2007 survey. However, 72% of them had less than 5 patients. 50% of them studied and trained themselves when they began prescribing morphine. It illustrates that most of the neurologists are not well experienced with morphine, and that they are isolated in their practice. This may be explained by the fact that the Japanese national medical insurance does not pay for long acting morphine administered to ALS patients. However, 45% of the respondents answer that they would prescribe morphine whether or not the national insurance pays. This implies that the physicians' perspective about morphine prescription in the clinical setting is changing. On the other hand, approximately 30% of the respondents identify morphine prescription with euthanasia.

As for the withdrawal of permanent ventilation, which is not legal in Japan, 21% of the respondents were asked by their patients to turn off the ventilation, and 6% of them agreed and accommodated the patient's wish. 77% of them declined and explained they were not allowed to do so. 18% of them declined and explained they were not supposed to do so. While 23% of the respondents believe that no discussion of whether the withdrawal right is permitted or not should be promoted, 46% believe that such rights should be granted if the decision made by the patient and/or his/her family members can explicitly be recognized. The results illustrate that the physicians are also divided.

It is worth noting that 20% of the respondents commented on their own, aside from answering the questionnaire, to share their thoughts. It may be the time to lay the foundation for the Japanese ALS physicians to discuss openly and candidly together to deal with the wants and wishes of their patients.