Benefits of personalised nurse counselling in neurological patients

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Abstract
Objective: To assess an educational counselling intervention, based on personalised nurse counselling (NC) in neurological patients [with a diagnosis of epilepsy, myasthenia gravis, multiple sclerosis, cerebrovascular disease, spinal cord injury, and aneurysms].
Method: A total of 171 patients were included and sequentially randomised into two arms and followed-up for one year: NC (n = 100), and controls (n = 71) who were given conventional inpatient care. The independence level was evaluated (Barthel Index), as well as the treatment adherence (Morisky Green Scale), both included in the Marjory Gordon Functional Health Pattern Assessment guidelines. ANCOVA and logistic regression were used (OR; 95% CI), and the size of effect (sef) was calculated.
Results: The NC group had a higher score of treatment adherence (sef, 74%) and independence (sef, 23%); engaged in recreational activities (OR = 6.0; 95% CI; 1.27–4.72), productive activities (OR = 4.0; 95% CI; 2.19–8.9), recognition of warning signs and symptoms (OR = 9.5; 95% CI; 4.63–21.5), received timely rehabilitation (OR = 13.37; 95% CI; 4.56–86.82), and had less urination problems (OR = 3.8; 95% CI; 1.89–7.8).
Conclusions: NC shows outstanding benefits for the patients' health, of treatment adherence, and independence, and enables the patient to return to work and to carry out other daily activities.
Discussion: We agree with other authors in that it is essential to provide personalised health education to patients with neurological disease and their families.

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Introduction

Neurological diseases have enormous physical, mental and social impact due to the extensive control that the nerve structures exercise over feelings, locomotion, cognition and vegetative activities, among other functions.\(^1\),\(^2\)

There are studies in the area of neurology that support the effectiveness of educational intervention for adults with epilepsy,\(^3\),\(^4\) multiple sclerosis\(^5\) and cerebral vascular disease (or stroke).\(^6\) All patients should receive education on the issues common to neurological disorders, such as: identifying the warning signs and symptoms of their disease,\(^7\)\(^-\)\(^9\) adherence to treatment, timely physical rehabilitation, and achieving partial or total independence for activities of daily living.

In a study performed in Navarra, Portillo\(^5\)\(^-\)\(^6\) intervention plan included people with neurological conditions such as stroke, Parkinson’s disease and multiple sclerosis. The intervention in this study was based on the fact that neurological diseases are associated with short and long term physical, emotional and social changes that affect both the sufferer and their caregivers. However, the effects of this type of intervention were not conclusive\(^11\) because specific scales with long-term follow-up were not applied, specifically in the area of specialist nursing assessment.

Therefore, it was essential to put personalised nurse counselling (NC) to the test, in offering information and specialist, organised care for all patients and their families\(^12\) towards improving domiciliary care and preventing complications. The experience of NC in Mexico’s Hospital General was systematically assessed in pregnant women\(^13\) and people with COPD,\(^14\) studies of people with allergic rhinitis, high blood pressure and kidney damage are in the process of publication, therefore there is a need to establish nurse counselling for neurological patients.\(^1\),\(^15\)

NC as an educational health tool used for people with neurological disorders requires attentive and genuine listening, that enables the patient and their family to express their concerns in a warm and professional atmosphere to provide them support in their disease process and reinforce areas of opportunity by identifying, through human contact, any warning signs and symptoms, drug and non-drug treatment adherence, timely physical rehabilitation and, as an ultimate goal, achieve partial or total independence according to their state of health.

This study arose from a situational diagnosis of neurological patients and its results enabled the design of a nursing intervention plan. The objective of the study was to evaluate the results of the NC-based intervention aimed at neurological patients in Mexico’s Hospital General. This assessment covered early physical rehabilitation, timely identification of warning signs and symptoms of the disease, adherence to treatment and the patient’s capacity for independent living. The initial design covered achieving tangible benefits such as: fewer pressure ulcers, fewer nutritional problems due to poor diet (anaemia, malnutrition or obesity), less depression, better emotional support, adherence to treatment, partial or total independence, integration in productive activities and identifying warning signs and symptoms of their disease. However it was not possible to study all these variables, therefore we stress the importance of analysing the patients’ adherence and independence rates.
Method

Design and sample studied

A controlled clinical study was designed comprising 200 patients, 100 controls and 100 allocated NC. Before the intervention started, an informed consent letter, approved by the ethics committee, was sent to the participants explaining that there was a likelihood of being assigned to either of the 2 groups and what their participation would involve. They were assigned a number according to a one-to-one distribution table (systematic random allocation) to complete a balanced sample according to the diagnoses: aneurysm, multiple sclerosis, myasthenia gravis, epilepsy, cerebral vascular disease and spinal cord injury (Fig. 1). Although the intervention assigned could not be blinded, prediction of the continuing sequence of disease was unlikely, and only one of the researchers (VC) was responsible for these sequences for each disease separately.

Adherence to treatment, independence, identification of warning signs and symptoms for prompt recognition of any complications, physical rehabilitation, recreational (leisure) and productive (employment) activities, and the presence of urinary tract infection were studied in both groups. At the end of the study the sample comprised 171 patients (NC n = 100 and control n = 71).

Selection criteria

Patients over the age of 18 were included, with the above-mentioned neurological diagnoses and who also had a primary caregiver, attended as outpatients.

Patients with any disorder that affected their cognitive ability such as: deafness, impaired memory or behavioural disorders were excluded. These were not very restrictive criteria and therefore the external validity of the study was maintained.

Instruments and measurements performed

We made a situational diagnosis in which we interviewed 30 patients with different neurological diseases, if they had any difficulty in talking, we interviewed family members. This diagnosis enabled us to define the priorities (hierarchy) of the educational intervention. From these interviews, five nurses, expert in caring for neurological patients, designed 7 instruments: an assessment guide and 6 questionnaires on knowledge covering care of the patient at home, one per disease (each had 10 questions with 4 multiple choice options, which included “I don’t know” as an option), since there were no specific questionnaires for each disease process. It was also necessary to adapt the questionnaires to the
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The patient’s identified care needs, internal consistency measured by Cronbach’s alpha coefficient was greater than 0.74.

The assessment guide is based on Marjory Gordon’s 11 functional health pattern assessment guidelines. These guidelines included the Morisky Green scale (treatment adherence) and the Barthel Index (independence) modified by Sha et al., with 10 activities and 5 score levels. The assessment guide was applied to 18 patients to evaluate the quality of the questions; some shortcomings were detected and therefore adjustment was needed in a further 2 pilot tests. The usefulness of this instrument was confirmed when a third test was applied to 12 patients, from which the final version was obtained. We should clarify that none of the patients who took part in the pilot tests were included in the study. The expert nurses and the researchers formed work groups to analyse the responses and their usefulness for the patients’ education plan according to their disease.

**Personalised nurse counselling educational intervention plan**

The educational intervention was based on the nursing assessment with Marjory Gordon’s 11 functional health pattern assessment guidelines: (1) health perception and management (including Morisky Green to measure adherence to medication); (2) nutritional metabolic (skin characteristics, weight and height, type of diet); (3) elimination (micturition and evacuation); (4) activity exercise (sufficient strength, exercise and regularity, physical rehabilitation, including Barthel Index to measure independence); (5) sleep rest (identifying whether there is any change, a determining factor for complications in the neurological patient); (6) cognitive-perceptual (existence and control of pain); (7) self perception/self concept (body changes and coping, how they feel about their disease); (8) role relationship (who is there for support, family problems, problems relating to others, whether they feel part of their community); (9) sexuality reproductive (contraception method, problems or changes in sexual relationships and whether they have already told the specialist this); (10) coping-stress tolerance (whether there has been anything that has lead to an emotional crisis, how emotional problems are solved, having somebody close to discuss problems with); and (11) value-belief pattern (religion, does religion deter from completing any treatment or personal health recommend). A further data collection instrument was applied, the knowledge card for each disease, which enabled the patients’ and their families’ needs for guidance on self care to be identified before and after the intervention.

It was planned for the NC group to be given individual talks on the following subjects: taking medication, identifying warning signs and symptoms, mobilisation (to prevent pressure ulcers), physical rehabilitation, nutrition (to prevent anaemia, malnutrition and obesity), micturition and evacuation (to improve elimination conditions), motivation towards independence depending on the patients’ state of health and integration into productive activity. They were also given educational material according to their disease such as: facial exercises, diet specific to their disease, mental agility magazines, stress balls and puzzles.

Telephone follow-up took place when necessary, there were open appointments and patients were able to consult by phone with any concerns at any time they needed.

The data collection instruments were applied to both groups. The educational intervention plan and medical consultation were only given to the NC group; for this group there were nurse researchers who devoted their professional time to personalised health. The control group had scheduled consultations with their treating physicians. For this group, educational care as outpatients generally involved any concerns regarding their care being dealt with by doctors and nurses with a considerable care load.

Both groups were followed up on set dates by telephone, at 6 months and one year from the beginning of the intervention, in order to record any progress and to address concerns.

**Statistical analysis**

The data are expressed as means and standard deviation (SD) or absolute and relative frequencies, according to how the variable was measured. The Student’s t-test or Chi-squared test was used for comparing the distribution of the demographic and diagnostic variables depending on the measurement size of the variable. Logistical regression adjusted by sex and age was used to calculate the odds ratio (OR) and 95% confidence interval. In addition, we used an analysis of covariance (ANCOVA) to adjust the marginal means according to sex and age. The differences between neurological diagnoses were compared by simple contrast. By codifying the diagnoses in this way it was possible to obtain estimations for each of the diagnoses by ordinary least squares and calculate the marginal averages adjusted and contrasted per intervention group. The standard error was calculated for each of these marginal means, while the contrasts between the intervention groups were calculated with the least-square distances test, those that showed a p value lower than 0.05 were considered significant. The ANCOVA analysis enabled us to maintained the power of the sample and avoid making an analysis of subgroups. The size of effect calculated by ANCOVA is termed f and corresponds to d-Cohen thus: $f^2 = d$. The effects are shown as d-Cohen, since it is a more understandable way of expressing the size of effect. In this case, a d-Cohen explains to us how much the dependent variable changes (in standard units multiplied by 100) with the presence of the intervention and compared to the control group.

The sample studied included all patients that attended the neurology department during the recruitment period. The sample size was not estimated a priori because it was not known beforehand whether the patients would agree to participate in this type of study or the distribution of the neurological diseases (this is why systematic allocation was used). The a posteriori analysis demonstrated that statistical power was achieved with the sample obtained and it was feasible to contrast patients that were assigned to the educational intervention group and the control group.

IBM SPSS Statistics for Windows, Version 22.0. Released 2013. Armonk, NY: IBM Corp was used to analyse the data.
Table 1  Baseline characteristic of the groups under comparison.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Control No. = 71</th>
<th>NC No. = 100</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (M/F)  n (%)</td>
<td>33 (46)/38 (54)</td>
<td>28 (28)/72 (72)</td>
<td>0.013</td>
</tr>
<tr>
<td>Age* (years) mean (SD)</td>
<td>38 (17.6)</td>
<td>40 (19.5)</td>
<td>0.433</td>
</tr>
<tr>
<td>Diagnoses: n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>8 (11)</td>
<td>18 (18)</td>
<td></td>
</tr>
<tr>
<td>Cerebral vascular disease</td>
<td>9 (13)</td>
<td>22 (22)</td>
<td></td>
</tr>
<tr>
<td>Aneurysm</td>
<td>5 (7)</td>
<td>6 (6)</td>
<td>0.001</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>35 (49)</td>
<td>39 (39)</td>
<td></td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>8 (11)</td>
<td>8 (8)</td>
<td></td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td>6 (8)</td>
<td>7 (7)</td>
<td></td>
</tr>
</tbody>
</table>

NC: nurse counselling; M/F: male/female.

* For age corresponding to mean (standard deviation), the Student’s t-test was used for contrast, the Chi-squared test for the remaining variables.

Ethical considerations

This study was approved by the institutional committees of the Directorate of Research Methodology and Ethics of Mexico’s Hospital General. The informed consent letter conformed to the General Health Law in the field of research in Mexico (DIC/09/403/03/122).

Results

Table 1 describes the distribution of the patients’ general characteristics according to the study groups. Two hundred patients were included in the study, 100 in each group; however, some did not continue to the end of the study. Therefore, 171 of the patients were followed-up, 100 from the NC group and 71 from the control group, with an average age of 39 years (SD: 19 years) and 110 women (64.3%).

The marginal mean (calculated as ordinary least squares) of the Morisky Green scale (adherence to treatment) the Barthel Index (independence) in the NC group showed an effect of size (d-Cohen) of 108% in the Morisky Green calculation and 27.3% Barthel, compared to the control group.

The detail of each of the differences between the control and NC groups according to the patients’ neurological disease measured using the Morisky Green and Barthel scales are shown in Figs. 2 and 3.

The logistic regression model (Table 2) assessed modifiable risk factors, the NC group showed a favourable odds ratio for physical rehabilitation (OR = 13.37; 95% CI: 4.56–86.82), identifying warning signs and symptoms (OR = 9.5; 95% CI: 4.63–21.5), recreational activities (OR = 6; 95% CI: 1.27–4.72), productive activities (OR = 4; 95% CI: 2.19–8.9) and urinary tract infections (OR = 3.9; 95% CI: 1.89–7.8), compared to the control group.

Discussion

This study shows that NC-based education has a clinically relevant effect on treatment adherence, patient independence and physical rehabilitation. These 3 effects were modified by the patient’s baseline disease, in this case the groups that best responded to NC were, epilepsy, multiple sclerosis and cerebral vascular disease.

Figure 2  Barthel Index score, independence achieved by patients at the end of their follow-up. Means adjusted by sex and age (ANCOVA). The bars represent the standard error. Aneu: aneurysm; MS: multiple sclerosis; Epi: epilepsy; CVD: cerebral vascular disease; SCI: spinal cord injury; MG: myasthenia gravis. *p < 0.05.

Portillo analysed 3 diseases.10 By contrast, our team of researchers evaluated the educational intervention in 6 groups of patients with different neurological diseases. This study was undertaken in one of the largest hospitals of Latin America, where we had limitations in terms of materials and personnel numbers. We consider that the method we used gives support to the external validity, and therefore we consider that a basic nursing activity is to educate neurological patients and their families about their specific treatment, domiciliary care and timely physical rehabilitation.21,22 The opportunity cost when nurses are referred to for professional counselling (rather than care of hospitalised patients) results in social and clinical benefits for these patients.

The NC detected the need to start or continue with physical rehabilitation in order to reduce sequelae and disability, with a view to improving health conditions. The patients and their families were made able to identify the warning signs and symptoms of their particular disease, attend a surgery promptly and avoid complications.
Patients with a spinal injury below C5 suffer late complications such as urinary tract infections. From the outcomes achieved in this study, the patients with NC did not experience problems in the functional health pattern of elimination, and were 24 times more likely not to suffer a urinary tract infection compared to the control group.

Studies on multiple sclerosis highlight the importance of communication as an important requirement in patients’ prognosis. In this regard, the nurse counsellors prepared the patients to learn to live with their disease, by attentive listening and seeking to accompany them in the process of their health condition.

Considering behaviour in general, we observed that the patients in the NC group were 6 times more likely to undertake a recreational activity and 4 times more likely to enter the labour market, which coincides with Portillo’s study. This outcome is relevant, because the capacity of neurological patients is underestimated, and it is often their families that believe that they have lost all ability. This is when the majority of patients become isolated, become unproductive, and tend to feel dissatisfied with life.

Physical rehabilitation was 13 times greater in the NC group than the control group. We consider that this was down to NC recommending, motivating and monitoring timely physical rehabilitation, although this also depended on the patient’s state of health on discharge from hospital.

It is recommended that the 2 tools, the Barthel Index and Morisky Green scale should be used clinically because they are usefully implemented in neurological departments and should be extended to other clinical areas to assess processes in which there is NC intervention. A further research study should be considered to measure the effect of self-care at home over more than one year in order to continue with the prevention of complications.

The few studies in the literature on neurological patients have essentially been qualitative and with insufficient statistical description. Portillo’s study enabled us to include such a description in our discussion because it gives percentages and quantitative characteristics. In our case study the outcomes are shown as quantitatively as possible to enable future researches to make comparisons with them.

One of the advantages of the study was the systematic sequential allocation. A block allocation would have been very difficult since some of these neurological diseases are very rare. It is unlikely for a homogeneous sample of patients with these disorders to be obtained and therefore

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (%)</th>
<th>OR (95% CI)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely physical rehabilitation</td>
<td>Control (n = 71)</td>
<td>CE (n = 100)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 (7)</td>
<td>39 (39)</td>
<td>13.374.56 - 86.82</td>
</tr>
<tr>
<td>Identification of warning signs and symptoms of the disease</td>
<td>21 (30)</td>
<td>79 (79)</td>
<td>9.5 4.63 - 21.5</td>
</tr>
<tr>
<td>Recreational activity</td>
<td>24 (34)</td>
<td>73 (73)</td>
<td>6.0 1.27 - 4.72</td>
</tr>
<tr>
<td>Productive activities</td>
<td>24 (34)</td>
<td>47 (47)</td>
<td>4.0 2.19 - 8.9</td>
</tr>
<tr>
<td>With no urinary tract infection</td>
<td>58 (82)</td>
<td>88 (88)</td>
<td>3.8 1.89 - 7.8</td>
</tr>
</tbody>
</table>

Age and sex were used as adjustment variables.
NC: personalised nurse counselling; CI: confidence interval; OR: linear regression.

Figure 3 Morisky scale score, drug treatment adherence achieve by patients at the end of their follow-up. Means adjusted by sex and age (ANCOVA). The bars represent the standard error. Aneu: aneurysm; CVD: cerebral vascular disease, MS: multiple sclerosis; Epi: epilepsy; SCI: spinal cord injury; MG: myasthenia gravis. *p < 0.05.

We agree with other authors that the NC programme should consider the physical condition of patients with cerebral vascular disease and advise as to how they should undertake their daily activities. Likewise, the support of the family is essential in the physical rehabilitation of these patients.

Saunders et al., in a Cochrane review, demonstrated that it is not possible to recommend a specific type of intervention for the care of adults with epilepsy. Other authors have only measured the improvement in patients’ knowledge of this disease, but have not examined the clinical and social relevance or the behavioural changes of subjects receiving an educational intervention. We managed to demonstrate that the NC group developed recreational activities and even integration into employment activities, depending on their neurological limitations. In addition, the Barthel Index score showed that patients were better able to undertake daily activities. This seems to be associated with the efforts of the nurse counsellors in convincing patients of their self-sufficiency according to their health conditions.
an expected limitation of this study is the unequal distribution of the baseline characteristics of the groups. An effect associated with this problem is the difficulty in obtaining reliable body measurements for patients with sequelae making them wheelchair bound. Another aspect was the incidence of pressure ulcers or anaemia, which only occurred in one patient, and therefore inferences cannot be drawn with such a very small sample size. Another limitation of the study was the psychological aspect, since attending the psychologist was voluntary and most of the patients did not opt for this therapy.

It is clear that neurological disorders have a different impact on each person. The impact can be emotional, affect their family, relationships or individual situation, or affect them economically, productively and professionally, etc.

The nurse counsellor has to take care to detect what is currently affecting and interesting the patient and their family and thus empower them to self care within their capabilities. This might explain why patients undergoing NC decided to continue follow-up far more than the control group, where some patients dropped out.

Therefore, tools such as the assessment guidelines based on Marjory Gordon’s 11 functional health patterns, that include the Barthel Index and the Morisky Green scale, are essential to enable monitoring of patients’ self perception/self image with their disease, their progress in productive and recreational activities, and drug and non-drug treatment adherence. This type of assessment is essential because it results in the safety of care of people with neurological damage.

Conclusion

This study shows that NC-based intervention achieves important results such as: better treatment adherence, timely physical rehabilitation, identifying the warning signs and symptoms of each diagnosis, reducing complications such as urinary tract infections, preserving or increasing independence in line with the specific disease, and therefore bettering patients’ social and employment integration.

Conflict of interest

The authors have no conflict of interests to declare.

Acknowledgements

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