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Evaluation of a nurse-led social rehabilitation programme for neurological patients and carers: An action research study

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Abstract

Background: Very few neurological rehabilitation programmes have successfully dealt with patients' and relatives' social needs. Furthermore, the nurses' contribution in those programmes is poor or unclear.
Objectives: To determine the rationale, effectiveness and adequacy of a nurse-led social rehabilitation programme implemented with neurological patients and their carers.
Design: In this action research study Hart and Bond's experimental and professionalizing typologies were applied through Lewinian cycles. A social rehabilitation programme was planned, based on the results of an in-depth baseline assessment of the context and individual needs. The programme focused on increasing the level of acceptance/adaptation of the disease through verbal and written education, easing the discharge planning, and offering social choices based on the social assessment of individual needs and possibilities at home.
Settings: Two neurological wards of a hospital in Spain.
Participants: The programme evaluation included 27 nurses, and two groups of patients and relatives (control group = 18 patients and 19 relatives, intervention group = 17 patients and 16 relatives).
Methods: The two groups of patients and relatives were compared before and after discharge to determine the effectiveness of the programme. Socio-demographic forms, semi-structured interviews, participant observations, and validated scales to measure activities of daily living and social life were used, and data were analysed using content (QSR Nudist Vivo, v.2.0) and statistical (SPSS v. 13.0) analyses.
Results: The new programme resulted in social care being integrated in daily practice and developed knowledge about social rehabilitation. This had a positive impact on nurses' attitudes. Patients and relatives had more realistic expectations and positive attitudes towards social life, and developed a wider variety of choices for social changes. Better adaptation, and more coping skills and satisfaction were achieved.
Conclusions: This rehabilitation programme was feasible and effective. Patients and relatives benefited from better understanding of the socialisation process, as a result of advancing nurses' knowledge, experience and role in psychosocial care.

Keywords: Action research; Advancement of nursing role; Evaluation; Social rehabilitation

What is already known about the topic?

- Very few neurological rehabilitation programmes have successfully dealt with the social needs of patients and relatives at acute and chronic stages.

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- Neurological rehabilitation programmes based on multifaceted educative packages and the assessment of clients' environmental, social and interactional needs achieve more positive social outcomes.
- Further work is needed with nurses to promote their contribution in the planning, implementation and evaluation of successful rehabilitation programmes in the neurology field.

What this paper adds

- Context related and individually planned educative packages are more applicable in nursing daily practice and promote the advancement of the nursing role in underdeveloped areas of practice like social rehabilitation.
- The nursing role in Social Rehabilitation can be promoted by increasing nurses' awareness of clients own needs and experiences, increasing the nursing educative interactions and gaining knowledge and experience through ''story telling''.
- Rehabilitation programmes which focus on the patients' and relatives' awareness and recognition of social needs, coping strategies, and social environment are more realistic and viable for the promotion of safe social rehabilitation.

1. Introduction and background

There is clear evidence that neurological patients and their carers experience changes holistically (Lackey and Gates, 2001; Smith et al., 2004), so both their physical and psychosocial wellbeing are considered of equal importance in western countries. Therefore, professional care is expected to deal with patients' and relatives' holistic needs, promote safe care and maintain their quality of life within acceptable limits (Boletín Oficial del Estado 39/2006, 2006).

However, rehabilitation programmes do not deal with these holistic needs at acute and chronic stages. Most programmes have focused on acute disorders rather than on degenerative conditions (Burton and Gibbon, 2006; Nir et al., 2004), and have mainly dealt with physical problems (Thompson and Playford, 2001; Patti et al., 2002; Calne, 2003). The acute exacerbation of any neurological disease during hospitalisation represents the unknown and therefore, re-orientation is required before discharge. Either acute or chronic patients and their relatives need to be prepared to adjust to the disease process, ''loss'' and ''change'', and to home care (Calne, 2003; Senosiáin-García and Narvaiza Solís, 2005; Mackenzie et al., 2004). Much of the research on these issues has focused on patients' and carers' perceptions of their adjustment needs with much less attention to how professionals view these and how an intervention could deal with them.

A literature review of the evidence on neurological rehabilitation programmes dealing with non-physical issues (Portillo Vega, 2006) showed that most programmes have aimed at promoting adjustment to the disease process, with very few programmes focusing on increasing social life, social problem solving skills or emotional wellbeing (Glass et al., 2000; Knapp et al., 2000; Ojeda del Pozo et al., 2000; Pacchetti et al., 2000; Grant et al., 2006). In these programmes an intervention which clearly aimed to improve patients' and carers' social life was developed and implemented and this was essential for their success. In contrast, other rehabilitation programmes which have focused on the early discharge and integration in the community have not always had a positive impact on social life (Askim et al., 2004; Corr et al., 2004; Fjaertoft et al., 2004).

Educative interventions also seem to have an important role in rehabilitation programmes. Some rehabilitation programmes incorporated an educational input into the intervention (Thomas and Sweetnam, 2002; Nir et al., 2004; Burton and Gibbon, 2006; Grant et al., 2006). In these studies the educational package helped to expand the professionals' role in underdeveloped practice issues, and to approach patients' and relatives' perceptions and attitudes. To achieve social rehabilitation (SR) the contents of educational packages have to be multifaceted and focused. In other words, educational programmes which deal with relevant issues such as self-care, resources, social contacts-activities, independence/disability, burden of care, adjustment, satisfaction, communication and behaviour, or family functioning had better results than those dealing with single but complex issues such as quality of life after discharge, physical rehabilitation and psychological status. These insights have not always been considered, with some rehabilitation programmes introducing and evaluating innovations in the professional practice, but not including any educational packages (Mayo et al., 2002; Gilbertson et al., 2000).

SR is a very subjective process, which depends on personal wishes, expectations and possibilities (Portillo Vega, 2006). Therefore, in the literature, programmes that considered some patients' or carers' personal circumstances in their educational package seemed most successful at improving social functioning. These personal circumstances were: environmental possibilities (Mayo et al., 2002); definition of functional and adjustment needs at acute and chronic stages (Trend et al., 2002; Askim et al., 2004); active involvement of the patient in the therapy (Walker et al., 1999); individualised follow up and social problem solving (Grant, 1999); individual information packs (Thomas and Sweetnam, 2002); and individual sessions on negative attitudes and dynamic involvement of patients (Ojeda del Pozo et al., 2000). Only one rehabilitation programme, which was based on the individual assessment of the social function (Wade et al., 2003) was not completely successful.

The importance of individualisation in the socialisation process was also underlined by Trigg et al. (1999, p. 342) who defined social reintegration as ''*an individual's ability to do what he or she wants or has to, to his/her own satisfaction*''. According to Trigg et al. (1999) three elements have to be considered in the process of social reintegration:

1. *Activities*,
2. *Social interaction* and
3. *Environment*.

Following more recent work, Portillo Vega (2006) added three more elements:

4. *Self-recognition and awareness* of the social/adjustment problems.
5. *Coping* with the social/adjustment problems and
6. *Satisfaction* with choices for social/adjustment problems.

These last elements are essential to achieve SR because social problems have to be prevented if possible, before social isolation occurs (social reintegration refers to a later stage of the process). Therefore, in this reported study the term SR was adequate to provide a more constructive perception of the process. Moreover, it is interesting to note that some of the reviewed programmes which considered some of these elements of SR (1, 2, 4, 5 and 6) seemed to achieve positive social outcomes more clearly (Trend et al., 2002; Corr et al., 2004; Burton and Gibbon, 2006) than others which did not (Thomas and Sweetnam, 2002; Boter, 2004).

Another important issue in the evidence of neurological rehabilitation programmes is the poor nursing contribution in the planning and coordination of rehabilitation programmes (Rawl et al., 1998; Forster et al., 1999; Boter, 2004; Nir et al., 2004; Burton and Gibbon, 2006). Among these studies, only Burton's and Gibbon's programme (2006) was successful and this supports the fact that further work with nurses is needed to explore, understand and develop their role in psychosocial rehabilitation to involve them in the coordination of programmes successfully.

To address this deficit, an action research (AR) project was carried out in two neurological wards of a highly specialised hospital in northern Spain, in which a nurse-led SR programme for neurological patients and their carers was planned, implemented and evaluated. The study was completed in 2006.

2. Objectives

The purpose of this paper is:

1. To briefly explain the study design and intervention (the SR programme).
2. To present the findings of the evaluation element of the study showing:
   - How nurses' daily work in social care positively evolved after the implementation of the SR programme.
   - How neurological patients and relatives who benefited from the SR programme improved their social life and perceptions towards the process of SR in comparison with those who did not benefit.

3. Method

3.1. Study design

This was a cyclical AR project (Lewin, 1946) which applied the experimental and professionalizing typologies of Hart and Bond (1995). Using this methodology a researcher from the university actively worked with nurses from two nursing wards to develop the research design, plan and implement the SR programme (intervention), and carry out the evaluation.

The information provided in the following sections is represented in Fig. 1, which shows the cycles, stages, participants and activities of the AR study and intervention.

3.2. Participants

There were three groups of participants in this project: nurses, and neurological patients and relatives. They were recruited from two neurological wards of a highly specialised hospital in northern Spain. Ethical approval was obtained from the ethics committee of the hospital and consent forms were signed by all participants.

3.2.1. Nurses

All nurses ($n = 37$) working permanently in the wards were included as participants. Nurses had a mean age of 32.08 years, with a mean of 8.14 years of professional experience with neurological patients. They were actively involved in the research process and in the planning, implementation and evaluation of the SR programme (intervention). Therefore, they were not only informants but also co-researchers on occasions and change agents, which encouraged a positive attitude towards the study.

3.2.2. Patients and relatives

Two groups of neurological patients (with diseases such as stroke, Parkinson' disease (PD), and multiple sclerosis (MS)) and their relatives were recruited through convenience sampling (Bowling, 2002) and participated in the study, if they met the inclusion criteria (Portillo Vega, 2006) for the baseline-control and intervention groups. The inclusion criteria mainly related to the diagnosis, the absence of communication disorders, being cared for by a relative, the access to the place of residence, speaking Spanish language and being hospitalised at least for 4 days (Portillo Vega, 2006). For simplicity, the ‘‘baseline-control group'' has been named ‘‘group 1'' and the ‘‘intervention group'' has been named ‘‘group 2''.

Group 1 of neurological patients and their relatives ($n = 22/22$) was recruited during hospitalisation. Group 1 left the hospital by the time the SR programme had been completely planned, and no new nursing social care happened with them. Group 2 of patients ($n = 18$) and relatives

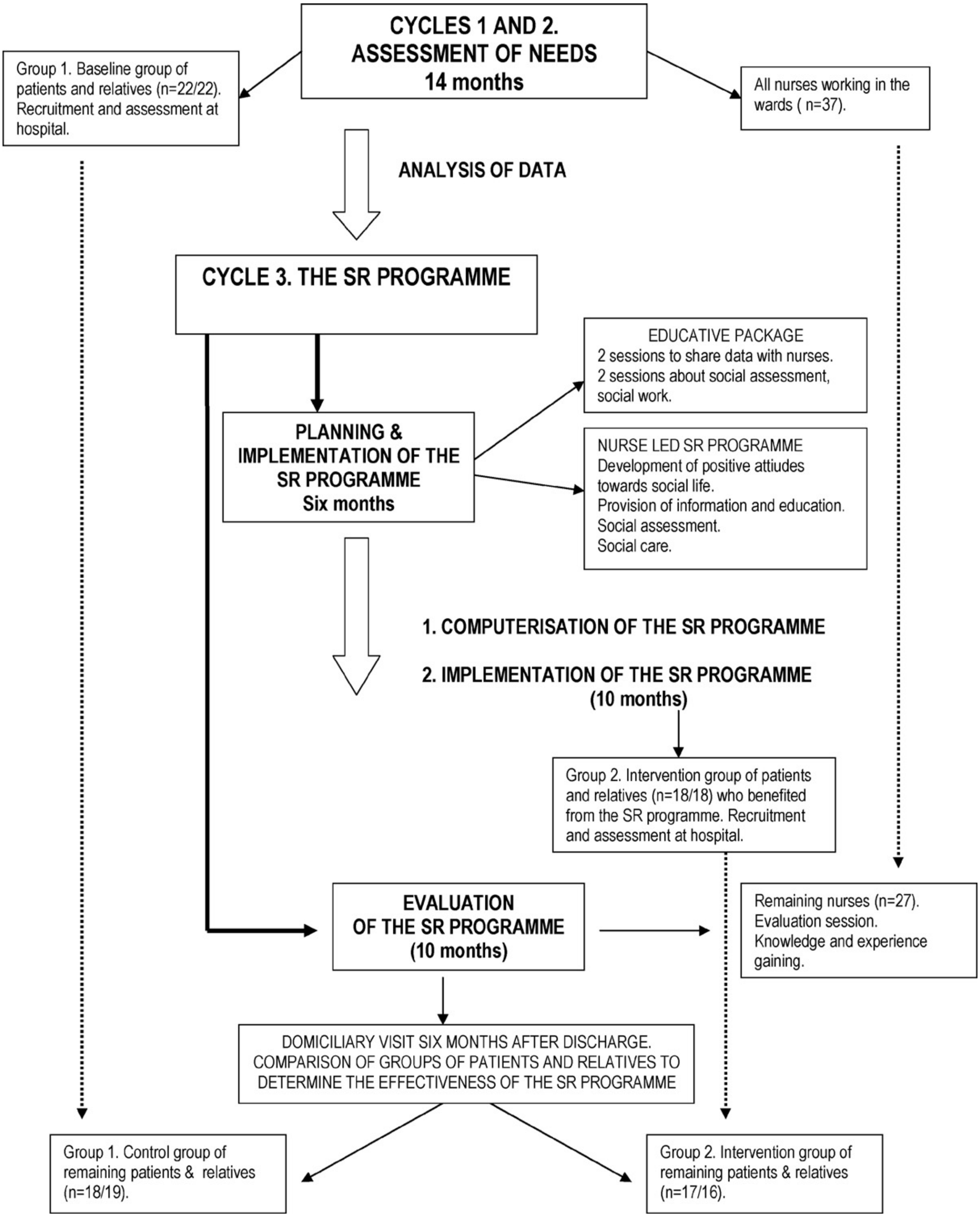

Fig. 1. Project design and stages.

($n = 18$) was recruited after this point during their hospitalisation and benefited from the programme described below.

Groups 1 and 2 of patients and relatives were assessed with the same initial instruments and the same analysis to ensure both groups of patients and relatives had comparable status and perceptions of needs at hospital. The main socio-demographic characteristics, sample sizes and scores obtained in the Barthel Index of activities of daily living (ADLs) (Wade and Langton Hewer, 1987) of both groups of patients and relatives are summarised in Table 1. No significant differences regarding age and gender of both groups were found. According to the Barthel Index of ADLs, the median level of disability of both groups of patients at hospital was moderate but slightly higher in group 2. Most carers were the spouses of the patients in both groups (72.7 and 72.2%, respectively) (see Table 1).

3.3. Intervention. The SR programme

As shown in Fig. 1, before the intervention or SR programme was planned and implemented, there was a baseline stage which lasted 14 months when the needs of participants regarding social care and SR were defined. After this stage, during 6 months all this information was triangulated to design the intervention, summarised in Table 2.

The planned intervention consisted of three main groups of activities, whose implementation lasted 10 months:

1. Educative input for nurses which involved action on attitudes, knowledge, experience, skills and role regarding social care and SR. This part of the intervention consisted of four sessions taking place with nurses. The first two sessions were essential to actively involve nurses in the planning of the activities of the SR programme and increase their awareness and knowledge about the social problem. The other two sessions were more educative and focused on social assessment and social work to provide nurses with knowledge and skills to assess and deal with the social problem.
2. Computerised package. The main nursing educative input for patients and relatives of the SR programme was recorded in a checklist form in a computer programme, which nurses used for daily care. The main activities introduced in the programme were: social assessment, family assessment, a reminder for the provision of the leaflets and brochures, the evaluation of the understanding of the information and education provided, and key aspects of the social education and home care. This was time-scaled so that nurses could plan, validate and record

Table 1
Demographic data and scores in ADLs for groups 1 and 2 (patients/relatives).

Variables	Patients	*p*-Value	Relatives	*p*-Value
Recruitment at hospital (ADLs and demographic data)				
Age	Group 1: 67 (57.5, 73)^{a} Group 2: 61 (47.7, 68)^{a}	0.11*	Group 1: 56 (42.5, 70.2)^{b} Group 2: 55.5 (33.75, 66)^{b}	0.35*
Gender	Group 1: male, 13 (59.1%); female, 9 (40.9%)^{a} Group 2: male, 13 (59.1%); female, 9 (40.9%)^{a}	0.74**	Group 1: male, 7 (31.8%); female, 15 (68.2)^{b} Group 2: male, 7 (31.8%); female, 15 (68.2)^{b}	0.61***
10-Barthel Index of ADLs	Group 1: 12; (6, 17.75)^{a} Group 2: 14; (7.5, 17)^{a}	0.99*	–^{b}	–
Patients' disease	Group 1: stroke, 10 (45.5%); PD, 10 (45.5%); MS, 2 (9.1%)^{a} Group 2: stroke, 4 (22.2%); PD, 7 (38.9%); MS, 7 (38.9)^{a}	0.08**	–^{b}	–
Domiciliary visit (ADLs)				
General Rivermead Scale of ADLs	Group 1: 66.50; (40, 90)^{c} Group 2: 69; (54, 88)^{c}	0.88*	–	–
Rivermead self-care	Group 1: 38; (19.75, 48)^{c} Group 2: 38; (28, 48)^{c}	0.76*	–	–
Rivermead housework I	Group 1: 19; (9, 25.50)^{c} Group 2: 21; (12, 26)^{c}	0.78*	–	–
Rivermead housework II	Group 1: 12; (6, 18)^{c} Group 2: 10; (6, 15.50)^{c}	0.48*	–	–

Age, 10-Barthel Index and Rivermead Scale of ADLs values: median and interquartile range (IQR): Percentile 25/75 (P25, P75).

[a] Group 1: $n = 22$, group 2: $n = 18$.

[b] Group 1: $n = 22$, group 2: $n = 18$.

[c] Group 1: $n = 18$, group 2: $n = 17$.

[*] *U* Mann–Whitney test.

[**] Contingency, χ^2-test.

[***] Contingency, χ^2-test (mid-*p*, Abramson and Gahlinger, 2001) used due to low expected frequencies.

Table 2
The rationale of the SR programme.

Educative input for nurses

Action on attitudes & knowledge (two sessions)

Rationale

Sharing baseline findings from the assessment stage (cycles 1 and 2).

Promotion of positive attitudes towards SR showing evidence of the need for social care.

Active involvement of nurses in the planning of the SR programme.

Session 1

Lack of knowledge about non-physical care had to be approached.

Nurses' self-confidence and responsibility for social care had to be enhanced.

Need to deal with nurses' feelings of intrusion on patients' and relatives' social life.

Session 2

Need to include carers in the nursing care planning. Taking into account patients' and relatives' wishes and needs in the planning of the programme.

Need to make nurses aware of patients' and relatives' wishes and need to be socially cared for.

Action on experience, skills & role (two sessions)

Rationale

Gaining knowledge and skills about social assessments and provision of social choices and advice.

Integration of social assessment in daily routines and practice.

More involvement of patients and carers in decision-making.

More knowledge about social advice, networks and resources in the community.

More cooperation between tertiary and primary levels of care. Associations as an key source of social support and information.

Development and transmission of the nursing role in SR.

Session 3: social assessment

A mental health nurse expert in psychosocial assessments prepared and led the session.

A first draft of a social assessment form was developed and discussed, and also reviewed by nurses and the manager of a different ward. Issues related to the implementation of social assessments and clients' response were covered. The social assessments focused on family environment and social life pre/post disease.

Session 4: social work and networking

Cooperation with a social worker and nurses of a community health centre. Contacts were made with health professionals of Primary Care, associations of patients and relatives, the department of Social Welfare-Security and the social services department. Information available in the wards.

Education focused on all the social procedures and services, and social activities available for patients and relatives in the community. Handout with relevant information given.

Computerised package

The SR package followed this time-scale during hospitalisation and included:

Admission. Planning of the package.

Day 2. Social assessment (continuous updating).

Day 3. Family assessment (continuous updating).

Day 3. Leaflets and brochures had to be handed out and explained.

Day 4. Checking understanding of leaflets and brochures.

Up to discharge. Education about social resources, centres and home care. Evaluation of clients' response to education.

Individualised educative input for patients and carers

Attitudes towards social life

Development and rationale: Discussion of experienced social changes, expectations and feelings. Development of positive attitudes. Promotion of acceptance and adaptation to the disease and changes, and involvement of relatives. Providing emotional support.

Provision of information and education

Development: The researchers and nurses designed three leaflets and three self-help brochures (stroke, PD, and MS). The first draft was reviewed by a nursing specialist and consultants.

Contents: Disease, treatment, care, architectural hazards and home adaptation, post-discharge services and support, social life, and key telephone numbers and addresses of associations and social services. Available in www.cun.es and www.viatusalud.com.

Rationale: Nursing role in education had to be more noticeable. No sound written information was provided in the wards before.

Social assessment and care

Development and rationale: Presenting nurses as a reliable source of social care. Patients and relatives becoming aware of own social limitations and possibilities. Setting social choices in collaboration with nurses.
Follow up of patients' and carers' in the community, and promotion of the use of social services and resources.

information about the activities of the SR programme when a neurological patient was admitted.

3. Educative input for patients and carers implemented by nurses. Nurses collaborated in the design of a social assessment form, and three leaflets and three self-help brochures (stroke, PD, and MS). These were used with patients and carers. After assessing social needs, nurses, patients and carers together planned social choices for social life in the community to promote patients' and relatives' social interactions. Social care and education focused on the promotion of positive attitudes, acceptance and adaptation of the disease, and satisfaction of patients and relatives with social life in/outdoors. Further guidelines about social procedures, services, and resources were also provided.

3.4. Evaluation (10 months)

The effectiveness of the SR programme was evaluated with nurses (comparing before and after implementing the SR programme), and with patients and relatives (comparing groups 1 and 2 before and after discharge). Although evaluation in AR is normally a dynamic and continuous process, three main data collection points can be identified at this stage:

1. *Participant observations*: (Gold, 1958) and field notes (Polit-O'Hara and Hungler, 1997) were carried out at the beginning of the study before the planning of the intervention and while the intervention took place for comparison purposes. The main researcher formed part of the observed picture, making direct contact with participants, the routines of the wards and the studied phenomenon. Therefore, the role as observer was not concealed. The practices to be observed were selected through event sampling with the event being defined as "*every interaction between the nurses under study, and neurological patients and relatives during the observational period(s)*".

   Before planning the intervention, 70 interactions were observed (66 h and 10 min in early shifts, and 68 h and 30 min in late shifts). During the intervention 108 interactions were observed (161 h and 42 min in early shifts when most activities planned for the SR programme took place, and 39 h and 30 min in late shifts).

   Before the intervention was planned, the observation instrument contained structured, semi-structured and unstructured items to record more general aspects of nursing care which could be used in the design of the SR programme. During evaluation, the instrument was more structured to register whether nurses undertook the activities of the SR programme with group 2 of patients and relatives with or without difficulties.
2. *Nurses. A final evaluation session and semi-structured interviews*. Twenty-seven of the 37 nurses who initially participated in the study were still working in the wards and collaborated in the evaluation of the programme during the implementation and evaluation of the intervention.

   A final session took place with nurses and focused on: the nurses' opinion about the study, the application, development and progress of the study, nurses' response to and development of social care, and findings from the evaluation of the effectiveness of the programme. Furthermore, at the same moment semi-structured interviews with nurses were used to evaluate if there had been improvements in knowledge, attitudes, experience, skills and role in social care and SR.
3. *Patients and relatives. A domiciliary visit to both groups 6 months after discharge*. The main researcher visited patients and relatives of both groups at home 6 months after their discharge and evaluated the impact that the SR programme had had on patients' and relatives' social life. Several instruments were used:
   a. Semi-structured interviews.
   b. The Rivermead Scale of ADLs (only with patients) (Lincoln and Edmans, 1990); and
   c. Social life scales:
      - The Modified Self-report Measure of Social Adjustment (SAS-M) (Cooper et al., 1982).
      - The Reintegration to Normal Living Index (RNL) (Wood-Dauphinee et al., 1988).

The Rivermead Scale of ADLs was used at this stage because it allowed assessment of a wider range of ADLs than the 10-Barthel Index of ADLs at home after determining the progression of the autonomy of the patient. Not all patients and relatives could fill in all the subscales of the SAS-M because some items were not applicable to their personal situation, this scale was broken down in its seven subscales for the presentation of results. In order to clarify this, the number of participants who provided information for each subscale and scale will be provided.

As the scales selected for this study had been obtained in English, it was necessary to translate them into a Spanish version. The *reverse translation process* technique was applied to ensure continued validity of the measures (Bowling, 2002). For this process, a bilingual interpreter and a sociologist were required. Furthermore, a bilingual interpreter cooperated in ensuring the adequate translation of the quotes from Spanish to English.

Content analysis (Miles and Huberman, 1994) of qualitative data was carried out using N-Vivo v.2.0. Descriptive and comparative statistical tests (SPSS v.13.0) were used to analyse quantitative data from observations, and ADLs and social life scales. Significance level was established at 0.05. The specific statistical tests which have been used are listed under each results table.

4. Findings

In this section findings from the evaluation of the SR programme are presented. The integration of the SR programme in nursing daily routines, the improvement of nursing practice in social care and its positive impact on patients' and relatives' social life are described.

4.1. Observations data. The integration of the SR programme in nursing daily routines

Observational data showed how social care and the SR programme were integrated in nursing daily care. Table 3 includes observational data registered before and after the planning and introduction of the SR programme in the wards. The frequencies obtained at assessment and evaluation and the most significant differences are described.

The number of interactions between nurses, and patients or relatives which involve social care significantly increased after the programme (2.9% vs. 33.3%; $p < 0.001$). Furthermore, nurses focused their care less on the patient and more on patients and carers as a pair (15.7% vs. 35.2%; $p = 0.01$).

A total of 35 and 50 interactions were educative/informative at assessment and evaluation, respectively. These showed a significant increase in the nurses' initiative in the

Table 3
Contingency, χ^2-test results from observations (assessment–evaluation).

Variables	Assessment ($N = 70$)	Evaluation ($N = 108$)	p-Value
Type of care ($n = 70$, 108)			
Physical	57 (81.4%)	76 (70.4%)	0.10*
Cognitive	12 (17.1%)	17 (15.7%)	0.80*
Emotional	27 (38.6%)	51 (47.2%)	0.26*
Social	2 (2.9%)	36 (33.3%)	<**0.001***
Spiritual	0 (0%)	2 (1.9%)	0.52*
Other	13 (18.6%)	27 (25%)	n/a
Who was cared for? ($n = 70$, 108)			**0.01***
Patient	54 (77.1%)	62 (57.4%)	
Relative	5 (7.1%)	8 (7.4%)	
Both	11 (15.7%)	38 (35.2%)	
Informative/educative interactions by nurses ($n = 70$, 108)			0.08*
Yes	22 (31.4%)	48 (44.4%)	
No (it could then be by doctors)	48 (68.6%)	60 (55.6%)	
Contents of informative/educative interactions ($n = 35$, 50)			
Lay participation in care	2 (5.7%)	5 (10.0%)	0.44**
Rehabilitation	1 (2.9%)	2 (4.0%)	0.78*
Social rehabilitation programme (other health professionals and centres, home services and structure, social services and resources, leisure activities)	1 (2.9%)	31 (62.0%)	<**0.001***
Disease/treatment/physical aspects	27 (77.1%)	29 (58.0%)	0.07*
Discharge planning, transport	3 (8.6%)	1 (2.0%)	0.23**
Budget	1 (2.9%)	0 (0.0%)	0.20**
Who had the initiative? ($n = 35$, 50)			
Nurse	14 (40.0%)	32 (64.0%)	**0.05***
Patient	0 (0.0%)	2 (4.0%)	0.34**
Relative	5 (14.3%)	3 (6.0%)	0.20**
Doctor	14 (40.0%)	2 (4.0%)	<**0.001***
More than one?	2 (5.7%)	11 (22.0%)	**0.04***
Who was informed? ($n = 35$, 50)			0.79*
Patient	7 (20.0%)	13 (26.0%)	
Relative	13 (37.1%)	16 (32.0%)	
Both	15 (42.9%)	21 (42.0%)	
Informative/educative resources? ($n = 35$, 50)			<**0.001****
No resources (oral)	31 (88.6%)	33 (66.0%)	
Leaflets and brochures	0 (0.0%)	15 (30.0%)	
Internet	1 (2.9%)	0 (0.0%)	
Other documentation (nursing/medical reports, phone/address)	3 (8.6%)	2 (4.0%)	
Was a social assessment taking place? ($N = 78$, 108)	n/a		n/a
Yes		26 (24.1%)	
No		82 (75.9%)	
Problems during social assessment? ($n =$ –, 26)	n/a		n/a
Yes		15 (57.7%)	
No		11 (42.3%)	
Type of problem during social assessments ($n =$ –, 15)	n/a		n/a
Nurse lacks skills		9 (60.0%)	
Difficult communication or contact with patient/carer		1 (6.7%)	

Table 3 (*Continued*)

Variables	Assessment ($N = 70$)	Evaluation ($N = 108$)	p-Value
Somebody annoyed during assessments		1 (6.7%)	
Social assessment interrupted		1 (6.7%)	
Inadequate environment		2 (13.3%)	
Poor participation of patient/carer		2 (13.3%)	
Poor participation of nurse		2 (13.3%)	
Lack of time		1 (6.7%)	
Difficulties to answer questions		1 (6.7%)	
Reasons researcher participation in interactions ($n = 29, 56$)			
Not related to study, help required	27 (93.1%)	25 (44.6%)	**<0.001****
Related to the study. Role modelling	2 (6.9%)	26 (46.4%)	
Safety of patient and relative at risk, bad practice	0 (0.0%)	4 (7.1%)	
Extreme situations in which the researcher's help is required	0 (0.0%)	1 (1.8%)	

Significance level was established at 0.05.

* Contingency, χ^2-test.

** Contingency, χ^2-test (mid-*p*, Abramson and Gahlinger, 2001) used due to low expected frequencies.

educative process (40.0% vs. 64.0%; $p = 0.05$). This could be related to the use of the leaflets and self-help brochures developed for the SR programme, which was also registered during observations (0% vs. 30% for use of written resources during education, $p < 0.001$).

Social assessments were also carried out as planned in 24.1% of the interactions of nurses with neurological patients and their relatives during the evaluation. The inclusion of social assessments in daily care also led to a significant increase of educative interactions whose contents focused on issues such as home services, leisure activities, resources and day centres (2.9% vs. 62.0%; $p < 0.001$).

4.2. Nurses' patients' and relatives data. The improvement of nursing practice in social care

4.2.1. Gaining knowledge and experience

Most nurses (26/27) said that they had learnt how to include social care in their daily activities in order to promote community reintegration before discharge. Only four out of 27 nurses said that they had not developed any further knowledge and experience in social care. Nurses said that the educational programme had helped them to change their attitudes towards neurological care. For example, 26 out of 27 nurses said that after the educative package was implemented they had learnt what social changes these diseases caused; others (16/27) said that they were aware of the aftermath of these diseases and could plan their care consequently. Finally, 7 out of 27 nurses said that after the programme they involved the family more in decision making.

Twenty-three nurses said that they had gained experience in social care as a result of this project. More concretely, they listed the activities they had developed to promote SR. These consisted of providing emotional support, orientating for home care, coordinating other services, and assessing social life and changes, daily life, occupation, coping skills and management at home. Nurses also said they had given choices and advice about alcohol intake, the use of facilities, diet and leisure activities, and had provided oral and written information and education for life and care at home. Supporting this, data from patients and relatives of group 2 (30/32) reflected that nursing social care did take place and focused on the activities mentioned above.

However, 11 nurses were convinced that they still needed to improve social care. Twenty nurses said that they had informed more about social aspects, held more conversations which covered sensitive and private issues with patients and relatives, and that written resources had enriched information and eased the educational process in both acute and chronic situations.

N12: "At some point leaflets can be helpful. I prefer standing in front of the patient and family with the leaflets in my hand, like I already have something to give them rather than saying: "yeah, somebody will inform you" Now we can check directly how the family responds. . ."

The increase in the use of written information was also noticed when comparing the perceptions about information of both groups of patients and relatives. Patients and relatives in group 1 said that they had not received nursing information at hospital and after discharge, but most patients and relatives of group 2 (30/32) did not share this perception. Generally, the leaflets, brochures, and list of telephone contacts and addresses that were handed out were highly valued as illustrated in this quote:

P6MSG2: "Do you see those leaflets? I brought them for my visits so that my family and friends can read about MS. . . . . . I think that it was probably after you and Susanne (a nurse of the ward) interviewed me. You helped me, intentionally or not you did it. I realised that it could be interesting to clarify many things my loved ones don't know."

At the beginning of the project nurses felt that they needed further understanding of the individuals' social problems to deal with them and provide adequate advice guidelines (27/27). That was the reason why the social assessment was introduced as a key intervention of the SR programme. Generally, nurses (22/27) positively valued the social assessment because they could get closer to clients and improve relationships, could find out what patients and relatives wanted or needed, and the assessment also had a positive effect on clients because they had to face their situation by stating their needs. Most nurses felt that their knowledge had increased especially due to the social assessments and the communication with clients.

N22: "I think that we have learnt a lot from the assessments... ... Also they (patients/relatives) can get it off their chest. Sometimes, a patient has some helpful ideas and shares them with me, maybe I could transmit these ideas to other patients with similar problems..."

4.2.2. Development of the nursing role in social care

There was a change regarding the nursing role in SR. Most nurses (26/27) had taken their responsibility for social care and started to intervene. Nurses felt like leaders in social care during hospitalisation and felt responsible for social care. They negatively criticised other colleagues who could forget doing some of the activities of the SR programme.

N5: "We have assessed patients and relatives, we have informed them and explained solutions, I think that we have been responsible for this... more than before of course."

The development of the nurses' role in SR was also seen when comparing the perceptions of both groups of patients and carers. Patients and relatives of group 1 did not perceive nursing activities at this level but they wanted professional advice on social life and ADLs since they believed this was the professionals' responsibility. This completely differed from the evaluation data of group 2 in which patients and relatives felt socially cared for (30/32). Concretely, 16 patients and 15 relatives of group 2 stated that nurses, doctors or other professionals had guided them and had been responsible for supporting them at this level. For example, patients (5/16) said that they were helped to deal with tiredness in social life, do some sports (4/16), plan social choices, organize leisure activities and ADLs to save energy, and keep hobbies (9/16). Relatives also added that they have been encouraged to promote self-care (5/15), not to lose control (2/15) and to deal with changes in the patient's behaviour (3/15). Other choices focused on hobbies and spare time (5/15).

R16MSG2: "My father and I felt safer after this hospitalisation, I felt more supported and not alone facing the problem like before. Even more, the nurse and doctor from the outpatient consultation have called us to find out how we are"

4.3. Patients' and relatives' data. The improvement of social life

4.3.1. The domiciliary visit 6 months after discharge

Evaluation took place with groups 1 and 2 of patients and relatives at home to determine the success of the programme. At the time of the domiciliary visit some patients and relatives did not continue participating in the study. In group 1, one patient died and three patients and relatives withdrew, and in group 2 one patient and two relatives withdrew. Therefore, a total of 18 and 17 patients and 19 and 16 relatives of groups 1 and 2 respectively still participated in the study.

Six months after discharge, according to the Rivermead Scale of ADLs, the median level of impairment (ADLs) of both groups of patients was moderate to mild (Table 1) and no significant differences were found between groups.

In the following sections the positive impact of the SR programme on patients' and relatives' social life will be described by comparing baseline and evaluation data from both groups of patients and relatives.

4.3.2. Expectations of social life

The main difference between groups 1 and 2 of patients and relatives was that group 2 seemed better able to accept the changes they experienced as a result of their illness, and had more positive attitudes and realistic expectations. This helped them to adapt indoor and outdoor social life to these changes when necessary.

In hospital both groups of patients and relatives complained about the social changes they experienced and these were similar. However, there were differences in how both groups faced these changes. Twelve patients and 11 relatives of group 1 realised that their expectations for social life before discharge were unreal, and that social life was worse than or as bad as social life before the last hospitalisation. For example, three patients expected to go back to work and this did not happen as they said because of the slow recovery.

P6STG1: "Expectations?......what I have noticed is that while one is in the hospital ambit, one feels so protected... things are perfect, I mean, I thought:" I get out of here and in a week time I am on again...". It is not like that. It is dismay, the severe reality. I have not achieved either the rhythm or the results I had proposed to myself......I wanted to change my lifestyle but the problem is still here."

Participants in group 1 had negative attitudes towards social life and that resulted in "no SR" because only three patients of this group felt motivated and tried to be occupied in different ways.

However, after the nursing SR programme was implemented, patients and relatives in group 2 had more realistic expectations of social life than those in group 1, as it was perceived during interviews. At the domiciliary visit with group 2, three patients and six relatives had met their expectations of social life and seven patients and nine relatives had even exceeded them. Only two patients and one relative of group 2 felt that emotional distress, disability and the lack of family understanding had frustrated their positive outlook. Therefore, having positive attitudes, and emotional and family support played an important role in the social adaptation of patients and relatives of group 2 (19/36).

4.3.3. The achievement of SR

The SR programme had a positive effect on the patients' and relatives' expectations and acceptance of the disease, which was important to achieve SR.

Patients and relatives in group 1 could not always meet the objectives they wanted for their social life. The activities that were easier for group 1 to carry on were: increasing the number of home visits of relatives or friends, listening to the radio, reading the newspaper and cooking. This did not satisfy their social needs because 13 patients and 17 relatives of group 1 still wanted to find choices for social life changes.

Data from patients and relatives in group 2 showed that although they experienced social changes (28/33), they were more optimistic and realistic about social changes and social choices. For example, they said that they had gone back to their hobbies, had joined a sport club, had felt relaxed, had travelled, and according to them, their quality of life and independence had increased. In other words, they had taken back their past leisure activities, had found choices or had positive attitudes/wishes towards social life.

R17PDG2: "I think that now I am more independent to go out… for example … if I want to go to the hairdresser's or to a place where husbands don't usually go… I don't have to take him (the patient) with me… Previously, he (the patient) did not like coming and then I stopped going to these places…"

This seemed to have a positive effect on their socialisation process because many patients and relatives (24/33) of this group had met the social choices which they planned with nurses' support, or had planned new social choices after discharge on their own. This quote illustrates the search for choices:

P9STG2: "I have been quite busy… and I used to get bored at home sometimes… Ah, you know? I have bought two parakeets to keep me company. I might teach them how to speak [laughs] I probably needed somebody to wake me up and take me out from my own isolation…"

Some examples of these choices are grouped under the two next titles "*Met social choices*" referring to social activities planned with nurses during hospitalisation that group 2 of patients and carers complied with more easily, and "*New social choices*" referring to other social activities group 2 of patients and carers planned after discharge without nurses' support:

1. Met social choices
    - *Indoor entertainment*: preparing dinner for friends, receiving visits of friends reading, crocheting, watching TV.
    - *Family relationships*: looking after grandsons.
    - *Group socialisation*: meeting friends in a bar, non-alcoholic drinks, going to the cinema.
    - *Social life outdoors*: going to restaurants, going shopping.
    - *Care management*: planning care breaks, family support and paid carer.
    - *Sports*: saving energy, cycling, walking.
2. New social choices
    - *Indoor entertainment*: sleeping, listening to music, buying parakeets, praying, renting movies.
    - *Family relationships*: more social life with spouse.
    - *Social life outdoors*: growing a vegetable garden, travelling, going to street markets.
    - *Sports*: spa, going to the swimming pool and mountain, basketball.
    - *Activities planned for the patient*: retiring to accompany the patient, growing plants with the patient.
    - *Work choices*: starting work after discharge, working at home, professional retraining courses.

SR took place for these 24 patients and relatives of group 2 who maintained a positive and active attitude towards social life. The positive effect of the SR programme on the social life of group 2 was also shown by comparing the scores obtained in the social life scales (SAS-M and RNL) by both groups (Table 4). This table presents results from the comparison of the scores of pairs (patients vs. carers) of each group, and from the comparison of the scores of patients and carers of both groups (group 1 vs. group 2). Significant results are presented in bold.

In most subscales of the SAS-M and in the RNL scale relatives had better scores than patients in both groups and this confirms how receptive carers seemed to be towards socialisation. Moreover, relatives had significantly better scores in the RNL scale than patients in group 1 ($p = 0.04$). In groups 1 and 2, patients obtained more positive scores than relatives in the subscale number 7 of the SAS-M.

From a global view of the scales scores of both groups, the median level of all patients' and relatives' social impairment (RNL scale) was mild to moderate. Likewise, the median level of all patients' and relatives' social adjustment (SAS-M scale) was moderate to good varying in some subscales of the SAS-M.

Results from the comparison of both groups in Table 4 show that patients and relatives of group 2 seemed to have better social adjustment (SAS-M) in areas such as work outside home, social life and leisure activities, relations with extended family and marital life, and also better RNL than patients and relatives of group 1. This improvement was notable for patients in group 2 in the RNL scores ($p = 0.08$),

Table 4
Social life scales scores for patients and relatives of the groups 1 and 2, and comparison.

Social life scales	Group 1			Group 2			*p*-Value group 1 vs. group 2	
	Results patients	Results relatives	*p*-Value (two-tailed)	Results patients	Results relatives	*p*-Value (two-tailed)	Patients	Relatives
SAS-M Subscale 1. Work outside home.	20; (19, –) (*n* = 3)[a]	26.5; (23.75, 28) (*n* = 8)	0.18[*,a]	26; (24.5, 28.5) (*n* = 6)	28; (28, 29) (*n* = 10)	0.20[*]	0.26[**,a]	**0.03**[**]
SAS-M Subscale 2. Housework.	27; (23.5, 28) (*n* = 13)	27; (25, 29) (*n* = 19)	0.59[*]	25.5; (22, 28) (*n* = 16)	27; (25, 29) (*n* = 16)	0.06[*]	0.56[**]	0.83[**]
SAS-M Subscale 3. Social and leisure activities.	33.5; (31.25, 36.75) (*n* = 16)	34; (32, 36) (*n* = 19)	0.78[*]	33.5; (32.2, 38) (*n* = 16)	37; (35, 38) (*n* = 16)	0.16[*]	0.47[**]	**0.04**[**]
SAS-M Subscale 4. Extended family.	27; (23.7, 30) (*n* = 16)	28; (27, 30) (*n* = 19)	0.36[*]	27; (26, 29.7) (*n* = 16)	29.5; (27.2, 32.7) (*n* = 16)	0.15[*]	0.67[**]	0.30[**]
SAS-M Subscale 5. Marital.	29; (24, 36) (*n* = 13)	34; (26.7, 37.5) (*n* = 16)	0.95[*]	33; (26.5, 40.5) (*n* = 13)	35.5; (29.2, 41.7) (*n* = 14)	0.27[*]	0.48[**]	0.26[**]
SAS-M Subscale 6. Parental.	17.5; (12.5, 20) (*n* = 12)	19; (14.5, 20) (*n* = 13)	0.76[*]	17; (15, 20) (*n* = 11)	18; (16, 19.7) (*n* = 12)	0.28[*]	0.83[**]	0.85[**]
SAS-M Subscale 7. Family unit.	15; (13, 15) (*n* = 13)	11; (11, 14) (*n* = 17)	0.15[*]	13; (11, 15) (*n* = 14)	12; (11, 14.5) (*n* = 13)	0.97[*]	0.22[**]	0.80[**]
RNL.	61.3; (51.8, 76.5) (*n* = 16)	73.6; (69.5, 80.2) (*n* = 19)	**0.04**[*]	75; (69.9, 85.9) (*n* = 16)	80.7 (75.1, 88.9) (*n* = 16)	0.16[*]	0.08[**]	**0.01**[**]

SAS-M and RNL values: median; IQR (P25, P75).

[a] Not considered due to too small sample size.

[*] Wilcoxon signed rank test (comparison of related samples in each group).

[**] *U* Mann–Whitney test (comparison of baseline and intervention groups).

and significant for relatives in group 2 in areas such as work ($p = 0.03$), and social life and leisure activities ($p = 0.04$) of the SAS-M. The increase of socialisation (RNL) was also significant for relatives in group 2 compared with relatives in group 1 ($p = 0.01$).

5. Discussion

The design and contents, and the results from the evaluation of the effectiveness of a nurse-led SR programme implemented with neurological patients and their carers have been presented in this paper. Two perspectives of this evaluation have been considered: firstly, the impact of the programme on the nurses' daily practice (integration of the programme in daily routines, and the improvement of nursing social care), and secondly, the improvement of patients' and relatives' social life, which was its most important contribution. Data from scales, interviews, observations and field notes obtained from all sources supported the effectiveness of the programme.

The change in nursing practice was achieved because nurses modified their attitudes towards social care and acquired responsibility for SR. Initially, nurses were reluctant and denied their responsibility especially due to the fact that SR seemed more feasible in the community context (Mackenzie et al., 1998). The increase of knowledge and experience was important in enabling the nurses to become more proactive dealing with social problems. This change of attitudes and the development of knowledge and experience were consequences of the educative package included in the programme. First of all, this package was designed according to the individual needs of patients and relatives. This was very enriching for nurses who could perceive what patients and relatives needed and wished, and consequently, could increase the quality of care provided. The educational package was context related and realistic, and this eased its integration in daily practice because nurses committed with its contents. This supports the fact that rehabilitation programmes which include individualised educational packages are more feasible (Forster et al., 2001; Trend et al., 2002; Burton and Gibbon, 2006).

A lack of successful nurse-led rehabilitation programmes in literature (Burton and Gibbon, 2006), meant that nurses in this project needed to advance their role in social care. Using a computer programme to record nursing social care was very helpful to integrate new care and the change of practice in the wards. Furthermore, the communication and transmission of information between different health professionals and levels of care improved because every professional in charge of those patients had access to that information. Moreover, other disciplines cooperated in the planning of the programme. The need for a multidisciplinary approach of SR was also highlighted by Long et al. (2002).

The provision of social choices after the individual assessment of social needs was the most original aspect of this programme, since most previous neurological rehabilitation programmes have not included it as a key intervention. This had a positive impact on the nurses' assumption of the new role and understanding of social issues in daily care as they gained knowledge and experience from the patients' and relatives' own experiences (Kralik et al., 2006).

The development and use of written information facilitated nurses' educative role as they felt more confident and had more initiative during the information and education process. The professional and clients' view of the advantages of the use of leaflets completes the evidence of the literature which has normally highlighted the benefits of written information for patients and carers (Grant, 1999; Mant et al., 2000; Thomas and Sweetnam, 2002).

As for the impact of the SR programme on patients' and relatives' social life, all interventions of the programme seemed to be beneficial. This programme covered the defining elements of SR stated by Trigg et al. (1999) and Portillo Vega (2006), and this made the programme operational.

It is important to underline that there were no pre-existing models of rehabilitation programmes which clearly promoted SR upon which to base this study. Therefore, its development was informed by a content analysis of the related literature and baseline data from this study. Although some patients had long-term conditions, this programme of SR seemed to be appropriate and have contributed to the previous related literatures (Trend et al., 2002; Wade et al., 2003). The key strategy of this programme was the professional work done with/on patients' and relatives' attitudes towards social life. This has also been successful in previous studies (Ojeda del Pozo et al., 2000; Pacchetti et al., 2000) and indicates that the first step for SR is to promote social attitudes, realistic expectations, acceptance and emotional wellbeing.

Consequently, this programme was effective because its interventions promoted the increase of awareness and recognition of social needs through the assessment, helped to cope with social problems through social education and information, and considered the patients' and carers' past, present and future activities and their home social environment. This made this programme more individualised, realistic and viable.

The programme had a positive impact for patients and relatives not only changing their attitudes and perceptions about the nursing role in social care and education but also achieving social interaction and satisfaction.

The SR programme seemed effective and its effectiveness was not influenced by differences in patients' level of impairment in ADLs as shown in Table 1. Despite both groups having the same level of dependence, group 2 of patients and relatives developed more social life. The social life scales supported the fact that patients and relatives of group 2 complied with the social choices planned at hospital and also had the initiative to think of new choices after discharge. This clearly increased their capacity of adaptation and socialisation, and consequently, their level of satisfaction.

This study has also provided further understanding of the socialisation process of carers who have become the target population of many health projects and research (Boletín Oficial del Estado 39/2006, 2006). In particular, the intervention seemed to be more effective for relatives than for patients because relatives found it easier to put social choices into action: patients – as reflected in interviews – faced more barriers. Patients seemed to spend more time at home with sons and daughters than relatives in their group, which could explain that they obtained slightly better scores in the subscale 7 of the SAS-M (*family unit*).

There are also some remaining challenges regarding the implementation and evaluation of the programme which will need reconsideration in future studies. These are:

1. Time restraints and the increase of workload which could be considered in the distribution of tasks in the wards, and recorded for their inclusion in the total nursing workload by the organization.
2. The continuity of social care in the community, the coordination of services, the transmission of information, the provision of further training for nurses, and the follow up of patients and carers could be ensured by identifying some people responsible for social care in the different settings. For example, this advanced role in social care could be undertaken by a nurse and a social worker in hospitals; and other nurses, general practitioners and social workers in the community. And finally, to ensure the success of these psychosocial interventions nurses could be provided with continuous updating or educative packages to deal with psychosocial issues.
3. The long-term impact that this type of programme could have on other health outcomes and resource utilisation in hospital and community facilities could be measured in future studies.

5.1. Strengths and limitations of the study

This study presented a complex design in which multiple quantitative and qualitative instruments of data collection were triangulated, which compensated for the limitations of the different approaches in each element of the research. This enhanced validity and reliability as confirmation of findings were revealed, and further understanding of SR emerged (Jick, 1979; Mitchell, 1986; Norman, 1994).

The completion of three cycles in this AR (Fig. 1) made the final evaluation stage more coherent and rigorous because decisions could be revised according to emerging evaluation results, and the planning and execution of the programme was based on an intensive study of the context and relationships of participants and researchers (Sandelowski, 1986).

With regard to the quantitative side of this AR study the sample size of patients and relatives was small, thus, this could be seen as a starting point which needs to be replicated with a larger sample in a future study. However, if we look at the qualitative aspect of the study, the sample size seemed adequate because information was rich, saturated and sufficient to develop an effective SR programme. This programme could be applicable to other wards due to the diversity of the sample in terms of level of disability, speech problems, disease and population definition. This diversity also provided the short and long-term view of the social problem, which was essential to develop a multifaceted SR programme.

Another aspect of the method which could be modified in a future project is the follow up period (6 months) as this project has not considered the impact on outcomes in the further long term.

6. Conclusions

This SR programme has advanced the nursing role and knowledge in social care, increasing experience and integrating social care into wards daily routines. The most important contribution of this study is the social benefit it had for neurological patients and carers. This programme could be considered a starting point and further research is needed to implement SR in other contexts and with other type of long-term patients and at earlier stages of the disease to deal with social problems before they become entrenched.

Contributions

Study design: Mari Carmen Portillo, Sarah Cowley; data collection: Mari Carmen Portillo; data analysis: Mari Carmen Portillo, Sarah Cowley and manuscript preparation: Mari Carmen Portillo, Silvia Corchon, Olga Lopez-Dicastillo, Sarah Cowley.

Conflicts of interest

Research funding was obtained from the Department of Health of the Government of Navarre. Financial support was also provided by the School of Nursing of the University of Navarre (the researchers' employer). This funding and financial support were obtained more than three years ago. Therefore, potential biases have disappeared.

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Ethical approval[1]

Ms PURIFICATION DE CASTRO LORENZO, doctor of Medicine, secretary of the Ethical Committee of Inves-

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[1] Translation of the original statement.

tigation of the Clinic of the University of Navarra's Faculty of Medicine.

CERTIFIES: that, in the session held on the 10th of October, 2002, the Committee examined the ethical aspects of the changes made to the protocol previously presented by Ms Maria Carmen Portillo Vega, which is now titled:

''Social rehabilitation in a Nurse unit: A Study of Investigation in Action with nurses, neurological patients and their lay carers''.

After evaluating the reasons that drive the investigator to include patients with other neurological pathologies, the Committee decided to accept the changes.

For the record, the Committee issues the present certificate in Pamplona, on the 14th of October, 2002.

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References

Abramson, J.H., Gahlinger, P.M., 2001. Computer Programmes for Epidemiologists: PEPI Version 4.0. Sagebrush Press, Salt Lake City.

Askim, T., Tohweder, G., Lydersen, S., Indredavik, B., 2004. Evaluation of an extended stroke unit service with early supported discharge for patients living in a rural community. A randomized controlled trial. Clinical Rehabilitation 18, 238–248.

Boletín Oficial del Estado, 2006. Ley 39/2006 de 14 de diciembre, de Promoción de la autonomía personal y atención a las personas en situación de dependencia. BOE, p. 299.

Boter, H., 2004. Multicenter Randomised Controlled Trial of an Outreach Nursing support program for recently discharged stroke patients. Stroke 35, 2867–2872.

Bowling, A., 2002. Research Methods in Health. Investigating Health and Health Services, 2nd edition. Open University Press, Berkshire, UK.

Burton, C., Gibbon, B., 2006. Expanding the role of the stroke nurse: a pragmatic clinical trial. Journal of Advanced Nursing 52 (6), 640–650.

Calne, S.M., 2003. The psychosocial impact of late-stage Parkinson's disease. Journal of Neuroscience Nursing 35 (6), 306–313.

Cooper, P., Osborn, M., Gath, D., Feggetter, G., 1982. Evaluation of a modified self-report measure of social adjustment. British Journal of Psychiatry 141, 68–75.

Corr, S., Phillips, C.J., Walker, M., 2004. Evaluation of a pilot service designed to provide support following stroke: a randomised cross-over design study. Clinical Rehabilitation 18, 69–75.

Fjaertoft, H., Indredavik, B., Johnsen, R., Lydersen, S., 2004. Acute stroke unit care combined with early supported discharge. Long-term effects on quality of life. A Randomised controlled trial. Clinical Rehabilitation 18, 580–586.

Forster, A., Dowswell, G., Young, J., Sheard, J., Wright, P., Bagley, P., 1999. Effects of a physiotherapist-led stroke training programme for nurses. Age Ageing 28, 567–574.

Forster, A., Smith, J., Young, J., Knapp, P., House, A., Wright, J., 2001. Information provision for stroke patients and their caregivers. The Cochrane Database of Systematic Reviews 3 (Art. No. CD001919). doi:10.1002/14651858.CD.001919.

Gilbertson, L., Langhorne, P., Walker, A., Allen, A., Murray, G.D., 2000. Domiciliary occupational therapy for patients with stroke discharged from hospital: randomised controlled trial. British Medical Journal 320 (March 4), 603–606.

Glass, T.A., Dym, B., Greenberg, S., Rintell, D., Roesch, C., Berkman, L.F., 2000. Psychosocial intervention in stroke: Families in recovery from stroke trial (FIRST). American Journal of Orthopsychiatry 70 (2), 169–181.

Gold, R.L., 1958. Roles in sociological field observations. Social Forces 36 (3), 217–223.

Grant, J.S., 1999. Social problem-solving partnerships with family caregivers. Rehabilitation Nursing 24, 254–260.

Grant, J.S., Elliott, T.R., Weaver, M., Glandon, G.L., Raper, J.L., Giger, J.N., 2006. Social support, social problem-solving abilities, and adjustment of family caregivers of stroke survivors. Archives of Physical Medicine Rehabilitation 87, 343–350.

Hart, E., Bond, M., 1995. Action Research for Health and Social Care. A Guide to Practice. Open University Press, Buckingham.

Jick, T.D., 1979. Mixing qualitative and quantitative methods: triangulation in action. Administration Science Quarterly 24, 602–611.

Knapp, P., Young, J., House, A., Forster, A., 2000. Non-drug strategies to resolve psychosocial difficulties after stroke. Age Ageing 29, 23–30.

Kralik, D., Visentin, K., van Loon, A., 2006. Transition: a literature review. Journal of Advanced Nursing 55 (3), 320–329.

Lackey, N., Gates, M.F., 2001. Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. Journal of Advanced Nursing 34, 320–328.

Lewin, K., 1946. Action research and minority problems. Journal of Social Issues 2 (4), 34–46.

Lincoln, N.B., Edmans, J.A., 1990. A re-validation of the Rivermead ADL Scale for elderly patients with stroke. Age Ageing 19, 19–24.

Long, A.F., Kneafsey, R., Ryan, J., Berry, J., 2002. The role of the nurse within the multi-professional rehabilitation team. Journal of Advanced Nursing 37 (1), 70–78.

Mackenzie, A.E., Holroyd, E.E., Lui, M.H.L., 1998. Community nurses' assessment of the needs of Hong Kong family carers who are looking after stroke patients. International Journal of Nursing Studies 35, 132–140.

Mackenzie, A.E., Lee, D.T.F., Ross, F.M., 2004. The context, measures and outcomes of psychosocial care interventions in long-term health care for older people. International Journal of Nursing Practice 10, 39–44.

Mant, J., Carter, J., Wade, D.T., Winner, S., 2000. Family support for stroke: a randomised controlled trial. The Lancet 356 (September 2), 808–813.

Mayo, N., Wood-Dauphinee, S., Cote, R., Gayton, D., Carlton, J., Buttery, J., Tamblyn, R., 2002. There's no place like home. An evaluation of early supported discharge for stroke. Stroke 31, 1016–1023.

Miles, M.B., Huberman, A.M., 1994. Qualitative Data Analysis an Expanded Sourcebook, 2nd edn. Sage Publications, London.

Mitchell, E.S., 1986. Multiple triangulation: a methodology for nursing science. Advances in Nursing Science 8, 18–26.

Nir, Z., Zolotogorsky, Z., Sugarman, H., 2004. Structured nursing intervention versus routine rehabilitation after stroke. American Journal of Physical and Medicine Rehabilitation 83, 522–529.

Norman, I.J., 1994. Towards an Understanding of the Quality of Nursing Care: An Evaluation of Assessment Instruments [Doctoral Thesis]. King's College Department of Nursing and Midwifery Studies, London.

Ojeda del Pozo, N., Ezquerra-Iribarren, J.A., Urruticoechea-Sarriegui, I., Quemada-Ubis, J.I., Muñoz-Céspedes, J.M., 2000. Entrenamiento en habilidades sociales en pacientes con daño cerebral adquirido. Revista de Neurología 30 (8), 783–787.

Pacchetti, C., Mancini, F., Aglieri, R., Fundarò, C., Martignoni, E., Nappi, G., 2000. Active music therapy in Parkinson's disease: an integrative method for motor and emotional rehabilitation. Psychosomatic Medicine 62, 386–393.

Patti, F., Ciancio, M.R., Reggio, E., Lopes, R., Cacopardo, M., Reggio, A., 2002. The impact of outpatient rehabilitation on quality of life in multiple sclerosis. Journal of Neurology 249, 1027–1033.

Polit-O'Hara, D., Hungler, B.P., 1997. Métodos de observación. In: Polit-O'Hara, D., Hungler, B.P. (Eds.), Essentials of Nursing Research: Methods, Appraisals and Utilization. 4th edition. Lippincott-Raven, PA, Philadelphia, pp. 307–326.

Portillo Vega, M.C., 2006. Social Rehabilitation from a Hospital Ward: An Action Research Study With Nurses, Neurological Patients and their Carers [Doctoral Thesis]. King's College Department of Nursing and Midwifery Studies, London.

Rawl, S., Easton, K.L., Kwiatkowski, S., Zemen, D., Burczyk, B., 1998. Effectiveness of a nurse-managed follow-up program for rehabilitation patients after discharge. Rehabilitation Nursing 23, 204–209.

Sandelowski, M., 1986. The problem of rigor in qualitative research. Advances in Nursing Science 8 (3), 27–37.

Senosiáin-García, J.M., Narvaiza Solís, M.J., 2005. Enfermos de Parkinson. ¿Qué conocen y qué quieren conocer? Revista ROL Enfermería 28 (2), 122–130.

Smith, L., Lawrence, M., Kerr, S.M., Langhorne, P., Lees, K.R., 2004. Informal carers' experience of caring for stroke survivors. Journal of Advanced Nursing 46, 235–244.

Thomas, S., Sweetnam, C., 2002. Parkinson's disease. Caring for the carers. Primary Health Care 12, 27–31.

Thompson, A.J., Playford, E.D., 2001. Rehabilitation for patients with Parkinson's disease. Lancet 357 (10), 410–411.

Trend, P., Kaye, J., Gage, H., Owen, C., Wade, D., 2002. Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers. Clinical Rehabilitation 16, 717–725.

Trigg, R., Wood, V.A., Langton Hewer, R., 1999. Social reintegration after stroke: the first stages in the development of the Subjective Index of Physical and Social Outcome (SIPSO). Clinical Rehabilitation 13, 341–353.

Wade, D., Gage, H., Owen, C., Trend, P., Grossmith, C., Kaye, J., 2003. Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. Journal of Neurology and Neurosurgery Psychiatry 74, 158–162.

Wade, D.T., Langton Hewer, R., 1987. Functional abilities after stroke: measurement, natural history and prognosis. Journal of Neurological and Neurosurgical Psychiatry 50, 177–182.

Walker, M., Gladman, J.R.F., Lincoln, N.B., Siemonsma, P., Whiteley, T., 1999. Occupational therapy for stroke patients not admitted to hospital: a randomised controlled trial. Lancet 354, 278–280.

Wood-Dauphinee, S.L., Opzoomer, A., Williams, J.I., Marchand, B., Spitzer, W.O., 1988. Assessment of global function: the reintegration to normal living index. Archives of Physical and Medicine Rehabilitation 69 (August), 583–590.