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ORIGINAL RESEARCH

Social rehabilitation in long-term conditions: learning about the process

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Abstract

Aim. This paper is a report of a study of the process of social rehabilitation, and the analysis of the main elements and influencing factors which are important in the process.

Background. The process of social rehabilitation lacks conceptual and empirical understanding in Neurology because most rehabilitation programmes have focused on cognitive and physical recovery.

Methods. An action research project was undertaken in two neurological wards of a highly specialized hospital in Spain, and was completed in 2006. A social rehabilitation programme based on the assessment of social needs and individualized social education was planned with health professionals, and implemented and evaluated with patients and carers. Several instruments were used to explore how patients and carers perceived the process of social rehabilitation before and after the programme: semi-structured interviews, socio-demographic forms, field notes, participant observations, and scales of activities of daily living, social impairment and adjustment. Comparative content and statistical analyses were undertaken.

Findings. Social rehabilitation was identified as a dynamic process in which the environment, activities, social interaction, self-recognition and awareness of social problems, coping and satisfaction played an essential role. Some defining criteria for social rehabilitation related to patients' and carers' attitudes, behaviour and the external implications that the socialization process had for them.

Conclusion. This study shows the advantages of multidisciplinary work, and user and family involvement in social rehabilitation and provides in-depth knowledge about how patients and carers experience and could face barriers to develop a role in their family environment, social groups and society.

Keywords: healthcare domain, long-term conditions, nursing, social problem, social rehabilitation, socialization

Introduction

Up to one-third of people with long-term neurological diseases suffer psychological changes and social isolation due to changes in the body image and the incapacity to cope with them (Calne 2003, Halper 2007, Williamson *et al.* 2008). Social isolation is gaining importance at an international level due to the growing interest in reducing the length of hospital stays and maintaining patients at home (Burton & Gibbon 2005). This has a direct impact on families assuming

care at home whose needs for psychosocial support also increase, but are not met (Portillo *et al.* 2009). The ageing of populations in society and the consequent growth of long-term conditions and disability also contribute to the intensification of this social issue. Anticipating future psychosocial problems and detecting caregivers in need of social care are of great relevance for health disciplines because social isolation affects some mainstays of society, namely the family structure, relationships, organization and life (Lackey & Gates 2001, Halper 2007, Kalb 2007, Visser-Meily *et al.* 2008).

Background

Conceptualizing social rehabilitation

The process of social rehabilitation in long-term care is not clearly conceptualized in the literature (Vähäkangas *et al.* 2006). More attention is paid to quality of life (QoL) than to social life in degenerative conditions (McKeown *et al.* 2003, Sturm *et al.* 2004). Social rehabilitation has not been considered a final goal in these programmes, probably due to the scepticism about the practical effectiveness of long-term rehabilitation on degenerative and progressive conditions (Prvu Bettger & Stinenman 2007). However, most rehabilitation programmes dealing with QoL have also measured the indirect impact of the programmes on social life/isolation of patients and relatives. This is not sufficient to develop social rehabilitation conceptually, or to achieve positive outcomes in its implementation (Burton & Gibbon 2005, Louie *et al.* 2006). Consequently, this has led to a poor understanding of the process of social rehabilitation as many authors have conceptualized social life as an element of QoL and therefore conceptual and theoretical criteria of social rehabilitation (Trigg *et al.* 1999) are not clearly covered in the programmes (Mant *et al.* 2000, Patti *et al.* 2002, Trend *et al.* 2002, Wade *et al.* 2003, Fjaertoft *et al.* 2004, Aprile *et al.* 2008). When we talk about social rehabilitation, what do we mean? Very few attempts have been made to understand the main elements and factors that influence the process. Trigg *et al.* (1999) interviewed 30 stroke patients 6 months after discharge from a rehabilitation unit. They attempted to clarify the process of 'social reintegration' instead of 'social rehabilitation'. Reintegration to 'normal' patterns of life was described as 'an individual's ability to do what he or she wants or has to, to his/her own satisfaction' (Trigg *et al.* 1999, p. 342). According to the study by Trigg *et al.* (1999), three elements were relevant in the process: environment, activities and social interaction. In their study, patients experienced difficulties to develop 'leisure activities' and this decreased their satisfaction with life. 'Interaction' restriction was also experienced within home, and outside home. Lastly, according to Trigg *et al.* (1999), the 'environment' element referred to structural, architectural hazards and finances, which influence the potential for social reintegration.

Social rehabilitation has to be considered a subjective and dynamic process that can start at any point between hospitalization and community care as it is reflected in this definition of the term: 'Social Rehabilitation is the process through which a person becomes aware of his/her own social limitations and consequently, develops activities to cope with and enjoy social life situations in familiar and/or other environments' (Portillo Vega 2006, p. 286).

Other previous attempts have been made to understand the social rehabilitation process after traumatic brain injury from a practical perspective (Tate *et al.* 2003), also highlighting key elements in the process like occupational activities, interpersonal relationships, contextual factors and independent living skills. The line between social integration and isolation is narrow and therefore social needs have to be identified and dealt with at early stages of the disease to achieve any success before the problem becomes entrenched.

Response to social needs

The professional response to social needs in terms of social rehabilitation programmes or knowledge development still remains poor. Drawing on a literature review (2000-present) of issues related to social rehabilitation (Portillo Vega 2006), Figure 1 shows some key aspects about social rehabilitation, which have not been developed or need further research and analysis. We carried out a content analysis on evidence related to the topic, and generated an initial picture (shown in Figure 1) of what a social rehabilitation programme could conceptually and practically include.

The process of socializing varies over time, including healthy stages and relapses either in acute or long-term conditions; therefore, both types of patients and relatives face an exacerbation of the social needs when they are hospitalized (Figure 1, boxes A and B). At this stage, the assessment of social needs and social care is essential.

The proposed intervention is a rehabilitation programme applicable to hospital or community contexts, but in this study, it was implemented before discharge and evaluated in the community (Figure 1, boxes C and C1). At this stage, through the rehabilitation programme, we promoted more active collaboration between patients, relatives and professionals in decision-making and self-management of patients' and carers' social problems. Consequently, social skills should be defined and developed during stages A to C1, so that social rehabilitation can happen in stage D (see Figure 1). The end of

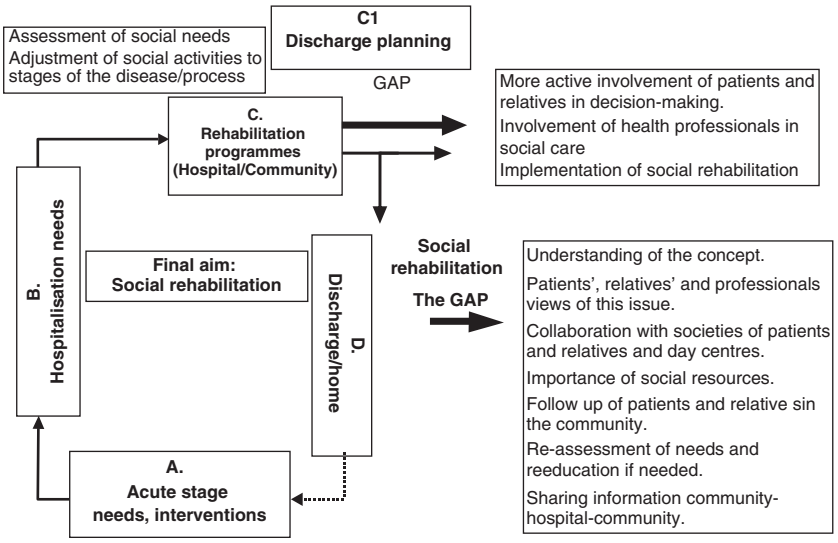

Figure 1 Analysis of the literature: care process and social rehabilitation.

the process (Figure 1, box D) is when patients, relatives and professionals have a complete view of the process of social rehabilitation. Factors and resources which influence the process are also identified, and re-planning of solutions and choices can take place. This last stage may not end the process, because an acute exacerbation, complication or relapse of the disease will create a need for the process to be repeated until normalization is achieved again.

In the literature, the main approach to rehabilitation in acute and long-term conditions has been physical and cognitive functions (Nieuwboer *et al.* 2001, Gage & Storey 2004, Booth *et al.* 2005) to achieve short-term effects. Twenty-three papers were reviewed and more information is available in Portillo Vega (2006), Portillo *et al.* 2009). A few rehabilitation programmes have dealt with non-physical aspects through multidisciplinary team work due to the complexity of issues like social life, social problems, QoL or satisfaction, which claim a multidimensional strategy of change. However, teams need to have clearly delineated roles and specialization to maximize outcomes (Minden *et al.* 2008) and this is not always achieved in these programmes. Most programmes did not include individually tailored interventions as they were mainly implemented through randomized controlled trials.

Another gap in the literature is that many rehabilitation programmes have measured social life as an outcome when no specific social needs interventions or assessments have been introduced (Patti *et al.* 2002, Trend *et al.* 2002, Wade *et al.* 2003, Corr *et al.* 2004, Fjaertoft *et al.* 2004, Burton & Gibbon 2005, Aprile *et al.* 2008). In contrast, including these interventions has ensured success in other studies (Ojeda del Pozo *et al.* 2000, Pacchetti *et al.* 2000, Hartman-Maeir *et al.* 2007, Jeong & Kim 2007, Portillo *et al.* 2009).

Although a great effort has been made in the literature to present the evaluation of rehabilitation programmes, as for social life, QoL, leisure activities, life satisfaction, coping skills or family functioning, it remains unclear:

- how the process of rehabilitation is perceived by patients and relatives and
- what are the conceptual mainstays of the programmes.

These are needed for the body of knowledge about social rehabilitation in healthcare domains and to provide the basis for developing future social rehabilitation programmes.

The study

Aim

The aim of this paper is to clarify the process of social rehabilitation, and analyse the main elements and influencing factors which are important in the process as they emerged from the results.

Design

This paper constitutes the conceptual backbone of a complex and multidimensional action research project that was undertaken in two neurological wards of a highly specialized hospital in Spain and was completed in 2006.

The professionalizing and experimental typologies of Hart and Bond (1995) were applied, and three cycles with stages of assessment, planning, action and evaluation (Lewin 1946, Portillo *et al.* 2009) were completed. Multiple triangulation also took place.

Sample/participants

A convenience sampling strategy was followed to recruit participants. During the first and second cycles, a first baseline group of stroke, Parkinson's disease (PD) and multiple sclerosis (MS) patients (n = 22) and their relatives (n = 22) were accessed at hospital. During the third cycle, a second intervention group of patients (n = 18) and relatives (n = 18) was also recruited.

Data collection

Planning and implementing the social rehabilitation programme

At the end of the two-first cycles, the planning of the social rehabilitation programme took place, considering data of this AR project, the experiences of participants (Rolfe 1998) and some of the contents of previous rehabilitation programmes.

Details of the contents of the programme, evaluation of the programme and change process have been published before (Portillo 2009, Portillo *et al.* 2009). In summary, the mainstays of the social rehabilitation programme focused on attitudes towards social life, information and education through leaflets and brochures, social assessments, conjoint planning of social care and choices for social life. Everything was registered in a computer programme.

During cycle 3, the social rehabilitation programme was implemented. The intervention group of patients and relatives benefited from the programme. The baseline group left the hospital by the time the social rehabilitation programme had been completely planned, and no new social care happened with them. Beforehand, assessment with semi-structured interviews, socio-demographic forms and 10-Barthel Index of activities of daily living (ADLs-only with patients) (Wade & Langton Hewer 1987) took place with patients and carers of the baseline and intervention groups to compare their baseline status. At assessment, the defined problems and needs regarding social rehabilitation were explored and analysed in depth.

Evaluation of the social rehabilitation programme with patients and carers

Evaluation took place at patients' home 6 months after discharge to compare the social life of both groups, evaluate the effectiveness of the social rehabilitation programme, and explore the perceptions of patients and relatives about the social rehabilitation process this time at the community. Semi-structured interviews, the Rivermead Scale of ADLs (only with patients) (Lincoln & Edmans 1990), the Modified Self-report Measure of Social Adjustment (SAS-M) (Cooper *et al.* 1982) and the Reintegration to Normal Living Index (RNL) (Wood-Dauphinee *et al.* 1988) were used.

Ethical considerations

Ethical procedures were carried out with all participants and approval from the Ethics Committee of the hospital was obtained beforehand.

Data analysis

Content analysis of qualitative data (Miles & Huberman 1994) was carried out using NVivo (v.2.0; QSR International PTY LTD, Doncaster, Victoria, Australia). Descriptive and comparative statistical tests (SPSS 15.0; SPSS Inc., Chicago, IL, USA) were used to analyse quantitative data from ADLs and social life scales. More concretely, the *Wilcoxon signed rank test* was run to compare data from the Likert scales and qualitative, ordinal and not normally distributed numerical data between pairs (patients vs. relatives) in each group. A *Contingency test* was used to compare qualitative variables of baseline and intervention groups (χ^2). If there were low expected frequencies, the *Mid-P value* of an 'Exact-p' programme was applied (Abramson & Gahlinger 2001). Significance level was established at 0·05.

Validity and reliability

The multiple triangulation design increased the validity of data ensuring confirmation and completeness of data (Jick 1979). Furthermore, criteria of rigour of qualitative and quantitative research and action research designs were followed (Guba & Lincoln 1981, 1989, Waterman 1998). The internal consistency and reliability Cronbach's coefficient of the scales has been presented before (Cooper *et al.* 1982, Wood-Dauphinee *et al.* 1988, Lincoln & Edmans 1990). The *reverse translation process* technique was applied to all scales, which had to be used in Spanish for data collection (Chang *et al.* 1999).

In the study, *host verification/participant validation* (Guba & Lincoln 1981) took place since data were checked with some interviewees to find out if they meant what was recorded. To increase objectivity, data from interviews were analysed simultaneously by two researchers who achieved high concordance (Sandelowski 1986).

Findings

Social rehabilitation: a dynamic process

This paper focuses on understanding how patients and carers perceived and experienced the social rehabilitation process at

the last stage (evaluation) of this project. Some data from the comparison of both groups of patients and carers collected through the measuring scales and semi-structured interviews are provided to back up results and statements. Baseline characteristics of the baseline and intervention groups of patients and relatives were shown to be homogeneous (Portillo *et al*. 2009).

Study data and the research process showed that social rehabilitation occurred along a continuum. It started from the professional assessment of the social status and patients' and carers' recognition of social needs. However, social rehabilitation became more meaningful in the clients' more familiar environment. To complete the existing evidence on the term of social reintegration/rehabilitation results have been structured as follows: (i) defining criteria that could indicate when social rehabilitation takes or does not take place, and (ii) influencing elements that are important throughout the process. Furthermore, the analysis and comparison in two cases are presented as an example, to show how these criteria and elements are interrelated in the process of social rehabilitation in this study.

Defining criteria

For social rehabilitation to take place, several criteria had to be met. These criteria have been grouped under three main chronologically ordered themes: (i) internal criteria, (ii) active behaviour criteria and (iii) external implications of the social rehabilitation process.

Internal criteria

Internal criteria referred to those internal psychological and cognitive processes patients and carers had to experience to develop positive attitudes towards social life. Therefore, to socialize at first instance, patients and carers had to

- accept themselves, and adjust to their physical and non/physical disabilities,
- determine the cause of the social problems and
- separate social life from the caring-disability situation.

The following statements show participants who met or did not meet these criteria:

P8MSG2 (met): 'Yeah, I go out…but I take the wheelchair with me in case I get tired. I am scared of falling but I know I need social life to feel better'.

P1STG1 (unmet): 'My social life will change because I won't go to some places in case something happens to me. I don't want to get worse'.

Active behaviour criteria

The theme 'active behaviour criteria' underlined that patients and carers had to develop certain behaviours to promote social activities. This normally took place after the internal process of social rehabilitation had happened and was directly related to the effort patients and carers made to socialize and enjoy or benefit from social life. To achieve this, patients and relatives had to

- maintain a healthy social relationship between them at first because the caring situation and bilateral dependence could prevent them from having other relationships or social activities,
- plan and implement social choices which were as satisfactory as the substituted activities or had a positive impact on social life,
- agree that the carer could deal with the social issue when the patient wished but could not and
- enjoy leisure activities in-outdoors.

The following statements show participants who met or did not meet these criteria:

R8PDG2 (met): 'I am doing something…John (the patient) has gone to play Bingo five times in the last month. He asks me to take him there. I have found somebody to look after the kids so that we can go and enjoy'.

P1STG1 (unmet): 'Well…I have tried…I want to do what I used to but I can't. I only want to recover my previous life'.

External implications of social rehabilitation

By external implications of the social rehabilitation process, we meant that patients and carers made other people aware of the activities they were engaged in, and their evolving social activities had a clear orientation to others. For this to happen, criteria 1 and 2 had to be met and additionally, patients and carers had to

- develop a role which satisfied their needs and the society's,
- implement a new functional role to mitigate the change and
- demonstrate and transmit the active behaviour criteria in society.

The following statements show participants who met or did not meet these criteria:

P14PDG2 (met): 'I go out…I need to look after me and have my own space…if not…I go to the gym two days a week, I meet my friends for coffee…once I have given him his tablets, I go for a walk…uhm…I must say that sometimes my son watches him out when I am away…and then I feel calm'.

R6STG1 (unmet): 'This (emotional change and the patient's disease) has affected me a lot, more than I thought. I am on a treatment and seeing a psychiatrist. I don't want to see anybody not even going shopping'.

When patients and relatives met the social rehabilitation criteria, this also showed in scores obtained in the social life scales (Table 1). Generally, in both groups, relatives had better scores in most subscales of the SAS-M and in the RNL

scale than patients because carers faced fewer barriers for social activities.

From a global view, most patients and relatives had mild-to-moderate social impairment (RNL scale). Likewise, most patients and relatives had moderate to good social adjustment (SAS-M). There were no significant differences between the level of social impairment between patients and relatives. As shown in Table 1, there were only significant differences in the subscale 'Family unit' between patients and relatives of the baseline ($P = 0{\cdot}004$) and intervention ($P = 0{\cdot}01$) groups. In this subscale, patients obtained better scores because many relatives had very poor and poor social adjustment when most patients had at least moderate social adjustment.

Regarding *housework* in both groups, most relatives had good social adjustment when most patients had moderate-good social adjustment. There were important differences in *housework,* between patients and relatives of the intervention group.

Both groups obtained similar scores in some subscales, so the social rehabilitation programme did not seem to have any effect on *housework*, *extended family*, *marital* and *parental role* (only relatives of the intervention group obtained better scores in this subscale ($P = 0{\cdot}08$) when comparing with relatives of the baseline group). These subscales measured aspects of social life which were easier to achieve for patients and carers or were not the main focus of the social rehabilitation programme.

Patients and relatives who benefited from the social rehabilitation programme also met the last set of the social rehabilitation criteria (external implications of the social rehabilitation process) and seemed to have better social adjustment (SAS-M) in areas such as work outside home, social life and leisure activities, and also better RNL than patients and relatives of the baseline group. These subscales and the RNL scale registered the integration of all the elements and social rehabilitation criteria. This improvement was notable for patients of the intervention group in the *RNL* scores ($P = 0{\cdot}08$) when compared with patients of the baseline group. There was a significant and positive correlation between the subscale Social and Leisure Activities and the RNL scale (patients: Spearman's $\rho = 0{\cdot}63$; $P = 0{\cdot}009$; relatives: Spearman's $\rho = 0{\cdot}50$; $P = 0{\cdot}04$). Other statistical results of the evaluation of the programme have been published before (Portillo *et al.* 2009).

Elements of the social rehabilitation process

The definition of social reintegration given by Trigg *et al.* (1999) referred to 'normal living' rather than 'reintegration after social change'. Furthermore, their definition does not seem to involve clearly 'interaction' and 'dynamism' when these need to be present in most defining criteria for social rehabilitation.

As Trigg *et al.* (1999) stated there are three elements involved in social rehabilitation that have also emerged in this paper: environment, activities and social interaction. According to the emerging data of this present study, these elements encapsulate the following issues:

- *Environment*: aspects of structural/family safety and resources.
- *Activities*: in-outdoor choices and functional role.
- *Social interaction*: role, safety in society, new culture of life and healthy caring relationship.

Other elements could be deduced from the defining criteria for social rehabilitation presented in this paper, which complete Trigg *et al.*'s analysis of the process.

- *Self-recognition and awareness*: determining causes of change and needs, level of dependence–independence and disability vs. social life.
- *Coping*: attitudes, acceptance-adjustment and possibilities.
- *Satisfaction*: realistic expectations and wishes met, and joy in social life.

Analysis of two cases

Two cases have been selected as exemplars, to illustrate the conceptual analysis of the process of social rehabilitation. These represented one dyad from the baseline group and one from the intervention group. In these cases, the presence or absence of the defining criteria and elements of social rehabilitation will be analysed for the achievement of social rehabilitation.

Baseline situation

Patient 1 (P1, baseline group) and patient 2 (P2, intervention group) were male and 70 and 64 respectively, and had long-progression PD and had undergone surgery during the admission period in which they were accessed. Their carers were their spouses and were 69 and 62 respectively. Patient's Barthel Index Scores at hospital were 16 and 8 respectively. Therefore, P2 was severely disabled and P1 was mildly disabled. Scores of 20 indicate complete autonomy.

In both cases, in the interviews patients were emotionally labile, and had negative attitudes towards social life, and a 'sick relationship' (Kralik *et al.* 2006) with the carer because patients were very demanding and carers overprotective (bilateral dependence).

Table 1 Levels of social adjustment and impairment in the SAS-M and RNL

Social life scales	Total minimum to maximum punctuation and meaning (Likert scale)	Baseline group results analyses (paired samples), *n* (%)			Intervention group results analyses (paired samples), *n* (%)			Baseline vs. intervention analyses (independent samples), *P* value	
		Results patients (*n* = 22)	Results relatives (*n* = 22)	*P* value (2-tailed)	Results patients (*n* = 18)	Results relatives (*n* = 18)	*P* value (2-tailed)	Patients	Relatives
Subscale 1 of SAS-M: Work outside home	6–11 Very poor social adjustment	0	0	0·32†,‡	0	0	1·000†	0·46§,‡	0·12§
	12–17 Poor social adjustment	0	0		0	0			
	18–23 Moderate social adjustment	2 (66·7)	2 (25·0)		1 (16·7)	9 (90·0)			
	24–29 Good social adjustment	1 (33·3)	6 (75·0)		4 (66·7)	1 (10·0)			
	30 The best social adjustment	0	0		1 (16·7)	0			
Subscale 2 of SAS-M: Housework	6–11 Very poor social adjustment	0	0	0·53†	0	0	0·06†	0·40§	0·64§
	12–17 Poor social adjustment	0	0		0	0			
	18–23 Moderate social adjustment	3 (23·1)	2 (10·5)		7 (43·8)	1 (6·3)			
	24–29 Good social adjustment	8 (61·5)	14 (73·7)		6 (37·5)	14 (87·5)			
	30 The best social adjustment	2 (15·4)	3 (15·8)		3 (18·8)	1 (6·3)			
Subscale 3 of SAS-M: Social and leisure activities	9–17 Very poor social adjustment	0	0	0·74†	0	0	0·13†	0·41§	0·23§
	18–26 Poor social adjustment	2 (12·5)	1 (5·30)		0	0			
	27–35 Moderate social adjustment	8 (50·0)	11 (57·9)		10 (62·5)	6 (37·5)			
	36–44 Good social adjustment	6 (37·5)	7 (36·8)		5 (31·3)	9 (56·3)			
	45 The best social adjustment	0	0		1 (6·3)	1 (6·3)			
Subscale 4 of SAS-M: Extended family	7–13 Very poor social adjustment	0	0	0·08†	0	0	0·13†	0·92§	0·64§
	14–20 Poor social adjustment	1 (6·30)	0		0	0			
	21–27 Moderate social adjustment	9 (56·3)	6 (31·6)		9 (56·3)	4 (25·0)			
	28–34 Good social adjustment	5 (31·3)	13 (68·4)		6 (37·5)	11 (68·8)			
	35 The best social adjustment	1 (6·30)	0		1 (6·30)	1 (6·30)			
Subscale 5 of SAS-M: Marital	10–19 Very poor social adjustment	0	1 (6·30)	1·000†	1 (7·70)	0	0·21†	0·62§	0·66§
	20–29 Poor social adjustment	7 (53·8)	5 (31·3)		4 (30·8)	3 (21·4)			
	30–39 Moderate social adjustment	4 (30·8)	7 (43·8)		5 (38·5)	6 (42·9)			
	40–49 Good social adjustment	2 (15·4)	3 (18·8)		3 (23·1)	5 (35·7)			
	50 The best social adjustment	0	0		0	0			
Subscale 6 of SAS-M: Parental	4–7 Very poor social adjustment	0	0	0·76†	0	0	0·23†	0·73§	0·08§
	8–11 Poor social adjustment	3 (35·0)	0		1 (9·10)	0			
	12–15 Moderate social adjustment	2 (16·7)	4 (30·8)		2 (18·2)	0			
	16–19 Good social adjustment	3 (25·0)	5 (38·3)		5 (45·5)	9 (75·0)			
	20 The best social adjustment	4 (33·3)	4 (30·8)		3 (27·3)	3 (25·0)			
Subscale 7 of SAS-M: Family unit	3–5 Very poor social adjustment	1 (7·7)	0	**0·004**†	0	1 (7·70)	**0·01**†	0·25§	0·80§
	6–8 Poor social adjustment	0	7 (41·2)		1 (7·1)	4 (30·8)			
	9–11 Moderate social adjustment	1 (7·7)	6 (35·3)		5 (35·7)	5 (38·5)			
	12–14 Good social adjustment	4 (30·8)	4 (23·5)		3 (21·4)	3 (23·1)			

Table 1 (*Continued*)

Social life scales	Total minimum to maximum punctuation and meaning (Likert scale)	Baseline group results analyses (paired samples), *n* (%)			Intervention group results analyses (paired samples), *n* (%)			Baseline vs. intervention analyses (independent samples), *P* value	
		Results patients (*n* = 22)	Results relatives (*n* = 22)	*P* value (2-tailed)	Results patients (*n* = 18)	Results relatives (*n* = 18)	*P* value (2-tailed)	Patients	Relatives
RNL scale	15 The best social adjustment	7 (53·8)	0	5 (35·7)	0				
	< 60 Severe social impairment	7 (46·8)	3 (15·8)	0·10†	1 (60·3)	0	0·56†	0·08§	0·16§
	60–98 Mild to moderate social impairment	9 (56·3)	16 (84·2)		13 (81·3)	16 (100)			
	99 No social impairment	0	0		2 (12·5)	0			

†Wilcoxon signed rank tests to compare related samples (patients vs. carers in each group).
§Test of contingency χ^2 to compare independent groups (baseline vs. intervention group), more concretely Mid-*P* value (Exact test) used in all cases due to low expected frequencies as indicated in the cells (Abramson and Gahlinger (2001).
‡Not considered due to too small sample size.
Bold values indicate significance level established at 0·05.

Professional intervention

P1: As part of the baseline group, no new social care happened with P1 and his carer. However, during the assessment, the main researcher and the practitioners from the wards realized there were some problems in the relationship between patient and carer, which needed reorientation. This was approached after the study finished.

The patient overestimated the severity of his status and therefore going to Associations of patients could help him to meet other patients in worse situations and encourage him. Some work was also needed with the carer because she did not motivate, but forced the patient to socialize and help with housework. Meeting other carers could be helpful to learn negotiation skills and manage reluctant patients. Although the new intervention was not implemented with this dyad, resolutions to change were made.

P2: This patient and his carer were in the intervention group so new social care was implemented. A social assessment of P2 and his carer was carried out. P2 had hobbies, which were hindered by the presence of important architectural hazards at home. This topic was reviewed in the leaflets and brochures we developed in the wards and handed to P2. The importance of avoiding hazards for social life was explained. The patient was encouraged to develop his hobbies (green gardening) and it was important to insist on safety issues. Another point was the need to gain independence for both the patient and the carer. Concretely, the carer was also encouraged to leave the patient alone and to start determining a realistic level of risk for the patient.

Outcome – The domiciliary visit

Six months after discharge, P1 and P2 had achieved physical improvements after the surgery. However, their Rivermead Scale scores showed that P1 had 69 points so he was almost independent and only needed some instructions to develop ADLs. P2 had 54 points and was dependent.

During the visit, P1 still experienced the social problems identified in the hospital such as the lack of mobility and awareness, poor encouragement from the carer, safety problems and negative relationships with the carer. P2 benefited from our programme and more social reintegration was achieved in relation to the encouragement of independence, realistic responsibilities, safety and positive desire for social life in both the patient and the carer.

Social rehabilitation: defining criteria and elements

The analysis of both cases illustrates what has been presented in this paper regarding social rehabilitation, elements and criteria, and backs up the empirical data obtained from the two groups of patients and relatives.

Table 2 Outline of criteria and elements in the social rehabilitation process

Defining criteria for social rehabilitation	Hint	Dynamic elements in social rehabilitation
Inner criteria	Acceptance and adjustment	Self-recognition and awareness
	Definition of causes	
	Avoiding low self-esteem due to disability	Environment
Active behaviour criteria	Healthy social relationship patient-carer	Environment
	Avoiding bilateral dependence	Activities
	Planning and implementing satisfactory social choices	Social interaction
	Taking over responsibility over social activities	Coping
	Enjoying leisure activities in-outdoors	Satisfaction
External implications of the social rehabilitation process	Social needs at user and society levels are satisfied	Activities
	New functional role	Social interaction
	Satisfaction and new role are shown in society	Coping
		Satisfaction

P2 and his carer determined the cause of social problems and tackled it. Their relationship improved by avoiding bilateral dependence. Indoor/outdoor leisure activities happened and were satisfactory. In addition, the carer was actively involved in negotiating with the patient. This had direct repercussions on the carers' social life.

Regarding the elements of social rehabilitation, P2 and his carer improved the environment, developed new activities/choices and roles, interacted, self-recognized what they had to change, coped with the situation and consequently, they felt satisfied.

P1 did not achieve this improvement, perhaps, because of the failure to promote emotional safety feelings in the patient and the lack of professional support. For this case (P1), we propose interventions focusing on the carer's behaviour and empathy towards the patient could have helped, along with self-recognition of the poor relationship between the patient and carer and the lack of the latter's involvement in social rehabilitation. In this case, the physical environment was safe, but the interaction and social choices failed, leading to poor coping and satisfaction in the development of social and functional roles.

This paper has shown the relevance of some criteria and elements in the process of social rehabilitation in the implementation of a social rehabilitation programme. Table 2 includes the outline of these elements and criteria which seemed relevant in this study at individual and group levels.

Discussion

Study strengths and limitations

One of the main strengths of this study is the usefulness of the action research method to introduce change in practice and involve professionals, patients and carers. This had a positive impact on participants and enabled new clarity about the concept of social rehabilitation. The multiple triangulation design increased the validity and reliability of the qualitative and quantitative approaches.

From the quantitative point of view, the sample size of patients and carers was small, but the positive results pointed to the need to replicate this study and programme with larger samples. For the AR design, the sample sizes were appropriate. Efforts were made to ensure saturation of qualitative data, the diversity of the sample and confirmation of results. Another evaluation point (after 6 first months) could also complete the picture of the social rehabilitation process.

This study has attempted to clarify the process of social rehabilitation, and to provide a more comprehensive view of the process from conceptual and practical perspectives. The process of social rehabilitation was of great relevance for patients with long-term conditions and also for families, leading to the conclusion that social activities are a family and society matter. Furthermore, families were regarded as receivers of services as well as caregivers. Carers benefited from the programme and were also considered key elements in the social rehabilitation process to encourage patients in the relation with others, and also in the promotion of self-care and own social life.

Consequently, as stated in the social rehabilitation criteria, the process of social rehabilitation could be better understood if the bilateral relationship of dependence between patients and relatives is taken into account (Secrest & Zeller 2007). This relationship can be influenced by the body and mind changes (Calne 2003) that patients and carers experience, leading them to a new life culture surrounded by 'any type of disability' that may emotionally and socially 'paralyse' them. Therefore, the first step

What is already known about this topic

- The process of social rehabilitation in long-term care is not clearly conceptualized in the literature, and this limits the development of the nursing role in social care and the implementation of social rehabilitation programmes.
- The professional response to social needs in terms of social rehabilitation programmes or knowledge development still remains poor because most programmes have measured quality of life in general, rather than social life in particular as an outcome.

What this paper adds

- To make social rehabilitation operational in a programme, three main criteria have to be met: internal criteria, active behaviour criteria and external implications of social rehabilitation.
- Social rehabilitation has to be approached as a dynamic and changeable long-term process in which some elements play an essential role: environment, activities, social interaction, self-recognition and awareness, coping and satisfaction.

Implications for practice and/or policy

- Nurses could play a role as coordinators of other disciplines in the process of social rehabilitation at hospital and community levels.
- Patients and carers could benefit from a more active social life if most social rehabilitation elements are approached by clinical nurses at hospital and community levels from a collaborative perspective.

towards social rehabilitation is also to promote positive attitudes and emotional wellbeing.

The practical contents and activities of the social rehabilitation programme in this study were essential to settle the process of social rehabilitation from hospitalization and achieve success. The literature highlights the importance of the assessment of the impact of the disease and adjustment, as these are key elements for transition at any stage (Smith *et al.* 2004, Kralik *et al.* 2006).

Special emphasis was given to the provision of social choices and promotion of coping strategies after the assessment of social needs to achieve social rehabilitation. This was not normally undertaken in previous programmes, which were not individually tailored, although poor coping strategies of relatives of patients often led to worse QoL (Visser-Meily *et al.* 2008). Other key strategies were: the identification of social needs, the awareness of health professionals of such needs through the assessment and the provision of social choices according to personal preferences and possibilities. Consequently, patients and carers felt listened to and empowered to tackle their social life problem, and therefore, felt experts in the process.

To understand social rehabilitation, it is essential to see the process from patients' and families' perspectives at different stages. This supports the assumption that social needs evolve through the caring process, but exist from early stages of a disease and also during hospitalization (McKeown *et al.* 2003, Tate *et al.* 2003). This needs to be considered to ensure a safe transition to home after acute exacerbations of the disease and enhance the discharge planning. In conclusion, it is important to highlight that this process of social rehabilitation is a process of transition with dynamic elements (Tate *et al.* 2003, Kralik *et al.* 2006). Both transition/adjustment and social rehabilitation processes bear certain resemblance to each other, with regard to the need for the awareness of changes, the search for the inner reorientation of self, the assumption of new roles and responsibilities, and the positive influence of family support.

Conclusions

The conceptual analysis of the social rehabilitation process was successfully applied to practice because it emerged from empirical contextual data. There are international implications of this study as there were no similar models of social rehabilitation to base this study on, and its development was informed by the related literature and emerging data. The practical and theoretical contents of this social rehabilitation programme can be a reference for future international research programmes, as key aspects that need to be covered in any social rehabilitation programme have been highlighted. Understanding the process of social rehabilitation also has direct implications for practice as the process of re-integration in the community could be safer if practitioners know the main aspects that have to be approached, reducing in this way, re-admissions and improving self-management.

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Conflict of interest

None.

Author contributions

MCP and SC were responsible for the study conception and design, performed the data analysis, were responsible for the drafting of the manuscript, made critical revisions to the paper for important intellectual content and obtained funding. MCP performed the data collection. SC supervised the study.

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