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## Journal

Brain Injury, 2(2)

## **ISSN**

0269-9052

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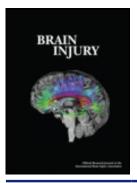
# **Publication Date**

1988

## DOI

10.3109/02699058809150938

Peer reviewed



# **Brain Injury**



ISSN: 0269-9052 (Print) 1362-301X (Online) Journal homepage: http://www.tandfonline.com/loi/ibij20

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To cite this article: Susan Quine, John P. Pierce & David M. Lyle (1988) Relatives as lay-therapists for the severely head-injured, Brain Injury, 2:2, 139-149, DOI: 10.3109/02699058809150938

To link to this article: <a href="https://doi.org/10.3109/02699058809150938">https://doi.org/10.3109/02699058809150938</a>

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# Relatives as lay-therapists for the severely head-injured

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Although the need for an integrated approach to the management of the head-injured patient has been recognized, and the concept of incorporating the family in the rehabilitation treatment programme suggested, there is minimal documentation of how the services of family members can be utilized to optimal effect. At a large university teaching hospital in Sydney, Australia, an early intensive rehabilitation programme was pretested on 37 patients during 1984–85. The pretest was to identify the extent to which relatives could contribute input as lay-therapists to such a programme. The findings indicate that relatives can make a major time commitment to providing therapy, but that to avoid harm to both patients and relatives certain safeguards need to be enforced. These experiences and resultant recommendations may have a bearing on the organization of rehabilitation programmes for other categories of patient.

#### Introduction

It is well documented that head injury can result in a variety of physical, cognitive and behavioural deficits [1, 2]. In most instances the injury is not serious and deficits are short-lived, although subtle changes may persist [3–5]. However, in a significant number of cases injury is severe and major residual deficits result. Up to one in eight severely head-injured patients remain in coma for more than two weeks, and of these two-thirds have an unsatisfactory outcome, either dying or remaining severely disabled and unable to care for themselves [6, 7].

There are few guidelines available to direct doctors, therapists and relatives in treating the severely head-injured patient, particularly during the unconcious phase [8]. However, a belief in the efficacy of early treatment persists, and is deeply rooted in the rehabilitation literature [9–12]. Data from a small number of studies are supportive of the benefits of early intensive rehabilitation for such patients [13, 14], and intensive treatment schedules, containing cognitive and physical strategies, have been devised [15–18].

The provision of this rehabilitation is generally carried out by a team of allied health workers in the areas of mobility, personal care, communication skills, social interaction, employment and leisure activities [17]. The involvement of relatives as part of the team has been encouraged in some quarters [8, 13, 16], but ways of optimizing their contribution have not been systematically studied.

The use of relatives to provide general supportive care for patients with a wide variety of conditions (acute, chronic, terminal) has been documented in the literature, but their use as lay-therapists has received scant attention. Where documented it mainly refers to assisting with one specific therapy, such as speech [19, 20].

For the brain-injured patient two studies have reported the use of lay-therapists in the treatment team. LeWinn [13] used relatives in the coma arousal team working in a hospital setting. He recommended that the team should consist of four members: a physician, a registered nurse, a physical therapist and a member of the patient's family. Cole, Cope and Cervelli [21] reported the use of recruited volunteers (rather than relatives) as lay-therapists,

to provide outpatient rehabilitation to patients who were no longer in coma. The team consisted of one full-time paid professional and a variable number of volunteers who received in-service training. Neither study reports the number of hours lay-therapists can provide, the duration over which they can maintain this input, or the factors associated with variation in their input.

The study described in this paper is the first to quantify the input lay-personnel can make to providing therapy.

#### Background

#### The programme

An early intensive rehabilitation programme making use of therapeutic inputs specifically designed for the unconscious and confused patient was set up to include the involvement of the patient's relatives as lay-therapists in the rehabilitation process. Patients who had been in coma for more than 2 weeks were considered for the treatment, which was commenced after the patient was transferred from the intensive care unit to a high-dependency ward.

The treatment team consisted of a supervising doctor, specially trained nurses (employed to provide some therapy and to train and supervise the patients' relatives and friends in providing therapy), and the patients' relatives and friends. All nursing care was provided by general nursing staff with relatives recruited solely to act as lay-therapists. There were also team social workers employed to monitor relatives' involvement. In addition, conventional rehabilitation treatment was provided by hospital staff from the departments of physiotherapy, occupational therapy and speech pathology.

The early intensive rehabilitation treatment covered stimulation of all senses. The main objective was to apply intensive stimuli to patients in order to bring them out of coma quicker, and once out of coma to continue application of stimuli to orient them as soon as possible.

The programme was individualized for each patient. For the unconscious patient multisensory stimulation was given by treatment team staff and relatives using similar equipment to that described by LeWinn [13]. In addition, relatives administered passive limb therapy. For the conscious but confused patient relatives were encouraged to aid in the orientation process and to assist overcome cognitive, linguistic and motor disabilities. Relatives also assisted the patient's posture and movements by performing active as well as passive limb exercises. The programme was not continued for the orientated patient, who either returned home, or was transferred to the rehabilitation centre for conventional therapy.

#### Rationale for using relatives

The programme strongly emphasized relatives' involvement in providing treatment, and it was suggested that family members (and significant others such as friends) should be available to provide up to 8 hours of treatment a day. The major premise for involving relatives was that, on account of the bonding which exists within a family, they would be more likely to motivate the patient and elicit desired responses than hospital staff unknown to the patient prior to the injury [8, 16]. It was also suggested that the relatives' awareness and familiarity with the patient's pre-injury response patterns would enable them to interpret the patient's needs and responses quicker. These responses could then be verified by appropriate trained staff. Another reason was that relatives, unlike staff, would provide a source of continuity of care which might increase the effectiveness of the programme.

Apart from the assumed effectiveness of relatives in providing treatment there was also a strong financial incentive. The therapy required is labour-intensive and therefore expensive if provided by remunerated staff [8]. It was envisaged that the use of relatives as laytherapists would greatly reduce staffing costs.

This study examines the feasibility of using relatives as lay-therapists in a general hospital. In particular it identifies the amount of time and therapy relatives are able to provide and the factors associated with variations in their input.

#### Methods

Subjects

Both patients and their relatives were studied. Eligible patients were those in coma, admitted to a major university teaching hospital in Sydney, Australia, between January 1984 and September 1985, who were unable to obey a command 2 weeks after hospitalization. The relatives of such patients were approached and asked to become lay-therapists in the research study. Thirty-seven of the 38 families approached agreed to participate, indicating the willingness of relatives to contribute to therapy, and become part of the treatment team.

From figure 1 it can be seen that on admission to hospital 16 of these 37 patients had Glasgow Coma Scale scores [22] of 3 or 4, whilst 21 had scores of 5 to 7. At this time pupils were fixed and dilated in six cases, bilaterally reactive in 27 cases and unilaterally reactive in four cases. Thirty-one patients were victims of non-missile head trauma, four of cerebral anoxia and two of viral encephalitis. All 37 patients were unable to obey a command at the time of family recruitment to the programme; a mean of 4 weeks after hospitalization.

Patients ranged in age from 1 to 75 years, with the majority (24, or 65 per cent) being older than 18 years on admission. They were predominantly male; being 23 (62 per cent) males and 14 (38 per cent) females. Twelve patients were married; 10 of these had dependent children. In most instances parents of unmarried patients had other relatives to care for, either other children and/or ageing parents.

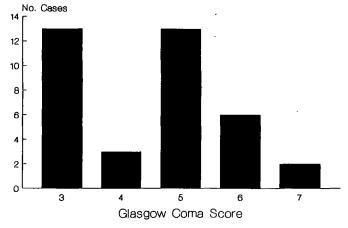


Figure 1. Glasgow Coma Scale score on admission for 37 study patients.

#### Research instruments and other data sources

Date of commencement and length of time on the early intensive stimulation programme were recorded on the patient's medical record. General observations on input by relatives for all patients were obtained from treatment team staff, general nursing staff and team social workers. For some patients a weekly timesheet was used to record the total amount of time spent with the patient; the proportion of this time actually spent providing treatment; the time of day; and the identity of the lay-therapist. Data obtained from this source were used to validate the general observations recorded.

Data on the number and characteristics of relatives providing therapy at commencement of the programme were obtained from information recorded at the initial interview with relatives conducted by the team social workers [23]. Data on variation in the number and characteristics of lay-therapists over time, together with reasons to account for variation in input, were obtained through the frequent in-depth interviews conducted by the team social workers. Corroborative information was obtained from reports by other staff members in the weekly treatment team meetings (patients' relatives were not included in these meetings).

Other factors which appeared likely to be associated with variation in relatives' input were time post-injury, and the patient's progress and prognosis. Such information was extracted from the following: the patient's medical record, medical reports given in treatment team meetings, and from relatives' perceptions of the patient's progress and prognosis recorded by the team social workers and other team staff members.

#### The findings

Time

How much time/therapy did relatives provide?

In assessing the ability of relatives to provide therapy two measures of time are considered. One measure is 'length of time on the programme'. From figure 2 it is evident that this varied widely, from 2 to 32 weeks, indicating that for some relatives their commitment was short, whereas for others it extended over a lengthy period depending on the patient's condition.

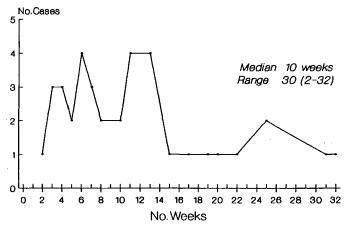


Figure 2. Distribution of cases by length of time on programme.

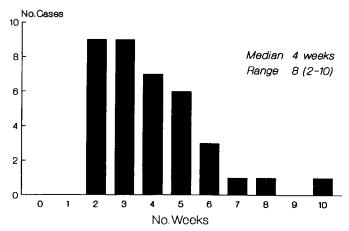


Figure 3. Distribution of cases by length of time before programme commenced (median 4 weeks; range 8 weeks (2–10)).

Using this measure of time alone may be misleading, because relatives had already spent time visiting the patient in hospital prior to commencement on the programme. Consequently this period was also taken into consideration when assessing relatives' total time commitment. It is referred to in the text as 'length of time post-injury', and ranged from 6 to 36 weeks. From figure 3 it can be seen that length of time before the programme commenced varied widely, from 2 to 10 weeks, dependent on clinical and organizational factors.

There are two main facets in assessing relatives' usefulness as part of the treatment team. One is identifying the actual amount of time they can make available: the other is monitoring how this time is utilized. The findings indicate that for the first few weeks on the programme (up to 6 weeks post-injury) it was generally feasible for relatives to be available to provide the required input of 8 hours per day. However, it became increasingly difficult to maintain this number of hours, so that typically by 3 months post-injury relatives were available for only 4 hours per day. From the timesheets and observations it was evident that of the time relatives made available not all was spent providing treatment. Active participation in providing therapy varied from 6 or 7 out of the 8 hours initially made available, to 2 or 3 out of the 4 hours at 3 months post-injury. It should be noted that these are general trends only. In a couple of instances the input of lay-therapists did not decrease appreciably, whereas in others it decreased markedly.

#### Variation

What factors were associated with variation in input? Several factors were considered:

(1) Number of lay-therapists. In general the more lay-therapists, the easier it is to achieve the required input; however, in some instances this merely indicated that the responsibility was shared rather than that a higher level of input was achieved. From table 1 it can be seen that the number of lay-therapists available per patient at commencement of the programme ranged from one to four, with a median of two. Even at commencement of the programme a number of patients (27 per cent) were dependent on input from one lay-therapist.

Table 1. Number of lay-therapists on commencement of program	Table 1.	mmencement of programme.
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	Cases		Lay-therapists	
No. lay-therapists per case	No.	Percentage	No.	Percentage
1	10	27.0	10	12.8
2	16	43-2	32	41.0
3	8	21.6	24	30.8
4	3	8-1	12	15.4
Total	37	100-0	78	100-0

The number of lay-therapists decreased over time. As patients entered and left the programme at different times the following comparison has been standardized on time post-injury. Almost half of the patients (18) were no longer on the programme 3 months post-injury, and consequently the comparison over time is based on the remaining patients (19). (An examination of the initial number of lay-therapists for these 19 patients indicates that the distribution of lay-therapists was similar to that for the other 18 patients.)

The initial distribution for these 19 patients is shown in figure 4 charted alongside the distribution at 3 months post-injury. It can be seen that by this period there is a marked increase in reliance on one lay-therapist, with an accompanying decrease in patients having two or three lay-therapists, and no patient having four lay-therapists. Team social workers found that families tended to exhaust their manpower resources early in the programme, being unaware of the duration of their involvement. There were therefore few or no backup resource persons to replace relatives who had to return to their other commitments.

(2) Characteristics of lay-therapists. The characteristics of the lay-therapists were investigated as they may be associated with varying ability to provide input. On commencement of therapy lay-therapists came from a wide variety of relationships with the patient (see table 2). Parents were the main lay-therapists (56 per cent), which largely reflects the young age group of these patients. Nearly two-thirds of all lay-therapists were female (63 per cent),

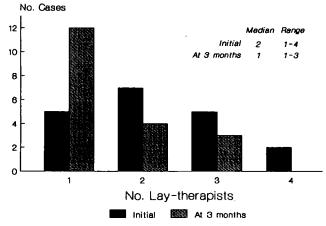


Figure 4. Distribution of lay-therapists on commencement of programme and after 3 months post-injury (n=19).

Relationship	Male	Female	Total	Percentage
Spouse	4	9*	13	16.7
Parent	17	27	44	56∙4
Grandparent	0	2	2	2.6
Sibling	4	5	9	11.5
Child	1	1	2	2.6
Fiancée	2	3	5	6.4
Friend	1	2	3	3.8
Total	29	49	78	100.0

Table 2. Characteristics of lay-therapists.

indicating the dependence on mothers and wives. Although the services of friends were encouraged it can be seen that numerically their contribution was negligible.

As noted earlier there was an overall decrease in the number of lay-therapists over time post-injury; however, this was not equally distributed. Whereas the number of mothers and wives giving therapy remained similar across time, the number of fathers and all other categories decreased. To a large extent this reflects the differing ability of males and females to be available to provide input, with males often finding it economically essential to return to their employment. This trend was discernible during the first 3 months post-injury, but was particularly evident after this period. Thus the contribution which male lay-therapists make is primarily in the early stages of the programme and in general they encounter major problems in providing treatment over an extended period. (The dependence on close female relatives to provide care continued when patients returned home, and is supported by the findings of other studies [24, 25].)

There were also gender differences in time of day when treatment was provided. Relatives were allowed 24-hour access to patients, to enable them to meet the daily therapy goal. As time on the programme increased most of the therapy provided by males was given in the evenings and weekends. These were times when supervision by trained staff was not available, and hence the quality of relatives' input could not be assessed. It also raised concerns over possible injury to the patient which might occur in the absence of supervision.

Other characteristics which may affect ability to act as lay-therapists were considered. These included the existence and strength of family and community support systems, together with situational factors such as proximity of residence to the hospital and availability of transport [23]. Team social workers reported that such factors were indeed an advantage. Impediments to involvement were poor health, work and family commitments. Age in itself did not appear to be a restricting factor, although elderly relatives were more easily fatigued. Financial difficulties were not a major constraining factor in this study, as financial assistance was made available if needed.

Although the factors listed above were considered, the findings of the in-depth inverviews held by the team social workers clearly indicate that the most critical factor associated with the extent and continuation of relatives' input was a conviction that the programme would have positive results. This is illustrated by the fact that where distance of hospital from home restricted ease of access motivation was so great that in a few instances relatives sold, or left, their homes to be closer to the hospital and thereby facilitate input. This suggests that the most crucial factor is attitudinal rather than situational.

<sup>\*</sup> Includes one de facto.

Table 3. Relationship between patients' progress and duration of relatives' involvement.

		No. of weeks before programme commenced	No. of weeks on the programme	Total no. of weeks post-injury in hospital	
Patients' progress (weeks before out of coma)	No. of cases	Mean (range)	Mean (range)	Mean (range)	
Fast	9	3.0	6.5	9.5	
(up to 4 weeks) Moderate	9	(2–5) 4·1	(3–13) 7·3	(6–14) 11·4	
(5 up to 7 weeks)	9	(2–6)	(4–13)	(8–18)	
Slow	7	`4.6	18·7 ´	23.3	
(8 or more weeks)		(2–10)	(10–32)	(13–36)	
Minimal*	12	4.2	13-2	17.3	
(did not emerge from com2)		(2–8)	(2–31)	(6–34)	

<sup>\*</sup> The ranges for the Minimal group are wide and the means lower than those for cases whose progress was slow. This is because the Minimal group includes four patients who died after only a short period on the programme.

(3) Motivation and the patient's condition. It was noted earlier that not all the time made available by relatives to provide therapy was used for this purpose. A small, but consistent, proportion of the time was lost due to organizational factors, external to the relatives, relating to hospital routine, such as the time spent awaiting the completion of routine care provided by hospital medical, paramedical and nursing staff. (There were also a few instances when relatives were not permitted to provide therapy as the patient had to be barrier-nursed.)

There were other factors, associated with the relatives' personal, physical and mental state, which affected their ability to actively provide therapy. That is, relatives spent time with the patient, but did not provide the treatment, preferring to sit passively at the bedside. Reference to patients' progress reports indicated that this was more likely to occur when relatives had been working on the programme for several weeks with minimal results. Team social workers reported that at such times relatives' motivation to provide active input was reduced. In general, even when patients showed improvements, relatives tended to become progressively physically and mentally exhausted, which reduced their active participation in providing therapy.

A patient's progress was categorized as fast, moderate or slow, based on time taken for the patient to emerge from coma. From table 3 it can be seen that for those patients in the 'fast' progress category the mean number of weeks of relatives' involvement in hospital was 9.5. For the 'moderate' progress category it was 11.4 weeks and for the 'slow' progress category 23.3 weeks. Thus time available for relatives' involvement is twice as long for patients whose progress is 'slow' compared to those whose progress is 'fast' or 'moderate'.

It has been shown that a family's capacity to provide input reduces over time. In addition, team social workers have recorded that there is reduced motivation to provide active input over time due to relatives' perception of the patient's poor condition and unfavourable chances of recovery. These factors account for the reduction in the number of hours and of active input to therapy over time.

Cost

No systematic study was undertaken to compare the cost of using relatives versus trained staff; nevertheless, certain points can be made. Given the variation in relatives' input in time and effort—and the irregular timing of this input—relatives, unlike trained staff, cannot be relied on to provide a set amount of treatment on a regular basis. If the level of input is to be maintained then trained staff would need to be rostered to handle unexpected contingencies in relatives' input. To ensure safety to patients relatives would need to be restricted in the activities they can perform, which would reduce their replacement value compared with trained staff. The professional staff investment required to train and supervise relatives in order to maintain high standards would diminish the saving from using relatives rather than trained staff. Given these limitations the use of lay-therapists would not appear to result in major cost saving, but would reduce the overall costs.

#### Discussion and recommendations

Despite falling short of the goal of 8 hours of therapy a day, the findings indicate that relatives can provide a major time commitment over a sustained period. Two or 3 hours a day is a fairly realistic expectation of family input. However, due to employment and family commitments, and the increasing problem of mental and physical exhaustion, relatives cannot be expected to act as lay-therapists over an indefinite period.

Female relatives, who usually had other family responsibilities, increasingly shouldered the burden of providing therapy. This suggests that families should not be expected to make an unconditional commitment to providing therapy. A patient's progress and family's response to involvement should be assessed at a time agreed on prior to commencement on the programme (at least by 3 months post-injury, if not sooner) so that the programme is not prolonged unduly.

Relatives did provide somewhat greater continuity of input than individual trained staff, but their input varied in amount of time and active participation over the treatment period. This suggests that relatives should not be expected to provide a consistent level of input.

In most cases the assumption that relatives would be more likely to detect changes in the patient earlier than trained staff was borne out. To some extent this may be attributed to the greater willingness of relatives to perceive the desired improvement, compared with the objective medical approach of trained staff not recording changes until they are clear and repeated. This suggests that relatives should not be relied on to objectively record responses.

The provision of therapy by relatives during periods when supervision was either unavailable or inadequate raised concerns about possible injury to patients, particularly from limb exercises. This suggests that relatives should be given more training, and/or organizational changes should be effected so that supervisory staff are available whenever relatives have access to patients. The provision of such training and staff would reduce the financial benefits of using relatives.

#### Conclusion

The findings of this study indicate that it is feasible to employ relatives as lay-therapists, particularly if the above recommendations are followed. Over a short period relatives provide a willing and available source of labour which can be tapped. However, the sole or major responsibility for providing therapy should not rest with them, as they do not possess adequate stamina, training or objectivity.

It has not been established whether the use of lay-therapists is more effective than using trained staff only. Furthermore, although there is a cost saving from the use of relatives rather than trained staff, this saving is not as great as was initially envisaged, and would reduce further if the recommendation made above was implemented.

The value of using relatives as lay-therapists lies chiefly in providing a highly motivated adjunct to the ministrations of professional staff.

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