

The impact of Disorders of Consciousness on the occupational life of family members

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Abstract

The impact of Vegetative State (VS) and Minimally Conscious States (MCS) on an individual is devastating. VS may be transitional towards recovery, but may be permanent if still present at 12 months. For the purposes of this study the collective term of '*Disorders of Consciousness*' (DOC) was used to include both of these diagnoses. Although devastating for the individual the nature of these conditions and their unpredictability also has a profound effect on the family.

Research exists to demonstrate the factors that impact on families, but the evidence fails to explore how this affects the daily life, occupations and the future. This study aimed to explore the impact on the family member and the changes that occur in the individuals' occupation (i.e. any activity that has intrinsic or extrinsic meaning). Six participants (spouses, partners or parents) were recruited to the study.

Mixed methods were adopted to meet the requirements of the research and participants. The design was a longitudinal embedded case study. Data was collected at 6 and 12 months post-injury, using time diaries, a follow-up questionnaire and finally semi structured interviews.

At six months post-injury the greatest amount of carers' time was allocated to occupations involving the person in DOC, less time was allocated to social and leisure activities. Participants had difficulty viewing the future, lacked the desire or capacity to engage in previously enjoyed activities and lived a day to day existence. They also reported stress or health impacts as a consequence. At twelve months those impacts were still evident observable changes had occurred, albeit to differing degrees. Participants began to view the future, although life plans were still limited. The transition to a balanced occupational activity is very slow and the transition process appears to require a number of catalysts to change. A conceptual framework for a return to balance is provided, and guidance on advice from family members to families in a similar situation are given.

Introduction

Disorders of Consciousness (DOC) is a collective term for individuals who have sustained a profound brain injury resulting in a change in the levels of consciousness. Vegetative state (VS) and minimally conscious state (MCS) are two diagnoses which come within the categorisation of DOC.

An individual in VS is not aware of themselves or their environment, defined criteria include a **disturbed** sleep-wake cycle, roving eye movements and reflexive movements (RCP 2013, Jennett 2002). Minimally conscious state (MCS) became recognised as a syndrome in its own right as a result of a greater understanding of the parameters of consciousness of the vegetative state patient (Giacino et al. 1997). The Royal College of Physicians (RCP) guidelines 2013 identifies the criteria for MCS to include minimal but evident response to the environment or self, which may be inconsistent.

Clinical diagnosis is based upon careful assessment of the individual's behavioural responses to external stimuli, to ascertain **their** awareness of self and the environment (Royal College of Physicians 2013). The recognition that emergence **to consciousness** may occur over a longer time period is reflected in guidelines (RCP 2013) which recommend that a 'permanent vegetative state' diagnosis can only be made 6 months following non-traumatic injury and 12 months following traumatic injury.

The impact of a person in a DOC on the family member, **particularly during such a lengthy period of time before diagnosis of permanency**, may lead to a rollercoaster of emotions and responses which may change over time. Understanding the impact on family members daily life would contribute to greater understanding and support being provided at the appropriate time. Accordingly, this paper presents an empirical study that explored the impacts on a family member's occupation and the transitions that occur during the 12-month period following diagnosis either of VS or MCS, referred to collectively here as disorder of consciousness (DOC).

Background

Responses of family members to brain injury have been suggested to resemble responses seen in bereavement (Man 2002; Chiambretto 2001) but with DOC's **reference to loss is** an emotional paradox where the family member **is** mourning, but the relative **is** still with them (Chiambretto et al 2001).

The ability to cope with the experience of traumatic brain injury varies considerably between individuals (Man 2002). Families experience a re-organisation and distribution of roles, but coping strategies may be adversely affected by the financial situation, personal strengths of family members, and cultural influences (Kosciulek & Lustig 1999, Man 2002).

Man (2002) found that family members initially sought assistance outside (e.g. from professionals and other families) in the acute stages as a result of the uncertainty of the diagnosis. The most frequently identified issues of concern were having less time for self, poor sleep patterns and anxiety (Marsh et al 1998). Chiambretto et al (2001) identified that caring occupied an average of 3.25h/day over 5 days and more than 70% felt that they had a restricted life that provided little opportunity for social and leisure activity. Social isolation then becomes likely (Kolakowsky et al 2001; March et al 1998 Jacinta et al 1996). Issues such as uncertainty about the future, lack of information, planning and control also have adverse effects on family members (Brown & McCormick 1998, March, Kersel and Havill 1998, Man 2002), factors that are likely to disrupt the family system and upset the homeostasis of the family (Verhaeghe et al 2005). A failure to restore the equilibrium can cause the family system to become 'stuck' resulting in crisis and unsatisfactory relationships within the family unit (Cope & Wolfan 1994; Chiambretto 2001). **Understanding the underlying processes that could prevent being 'stuck', or recovery from it, is therefore important. However, the** impact for families on routines, occupations and function is not an area that has been fully explored.

Theoretical concepts

As a concept, occupation has multiple dimensions. Occupations are culturally shared (Nelson 1988), have individual meaning, are self initiated (Yerxa 1998) and require active participation (Gray 1997). Occupations are also set within a temporal framework (Chrisiansen & Baum 2005, Hocking 2000) that exists within an individual's life story (Mattingly 1998) and as such are changeable with life events, such as those experienced by individuals with a relative in a Disorder of consciousness (DOC).

Occupations have a purpose (Jarman 2005) they actively engage the individual, are usually meaningful to the person and involve a process with an outcome (Schkade and Schultz 2003). The relevance of occupations is embedded within and evolve from social cultural influence (Hocking 2000), occupations are gained through personal choice, with some occupations being more highly accepted by society, and some being affected by gender Jarman (2005). However, Harvey and Pentland (2004) assert that despite these influences on occupation, that occupation will lack personal meaning unless it is contextualised. Therefore, there is a need to understand occupational experience through the analysis of daily human engagement (Jarman 2005) recognising a need to participate in occupation (Wilcock 1993, Fidler & Fidler 1978) and balance daily activities. Occupations are observable as a pattern of behaviour and often have responsibility or duty attached (Pentland and Harvey 2005) which may be established by choice or obligation (Farnworth 1999).

It is a combination of occupation and occupational roles that contribute to a person's identity. The carer role holds a new set of expectations, demands and occupations, which are perhaps less about choice (Polgar & Landry 2005) and more about circumstances, potentially causing role or identity conflict. Role loss can occur when an individual is prevented from participating in their chosen occupations which can impact on that person's life and view of themselves. Mattingly (1998) considers the occupational narrative as a change in events brings a change in meaning, it alters the present and future. By having a sense of occupation over time there is both meaning and a framework which provides direction.

Change or disruption occurring to an individual's occupation **ordinarily** leads to occupational adaptation to accommodate the change (Krammer et al 2003, Clark 2000). Ability to adapt is affected by previous experience of occupational adaptation and mastery in evaluating the occupational response needed (Krammer et al 2003). **In the present study to** consider the impact of having someone in a DOC on the family member's occupation then initially the relationship of the **central tenets** could be seen as primarily having a sequential impact i.e. Person in DOC **(1) impacts on** family member **(2), which impacts on (3) occupation**

1. DOC

The family member may respond to this diagnostic uncertainty and medical instability through emotion, coping mechanisms and health changes. Initially the DOC condition could become the driver to the responses from the family member and also be the catalyst to changes in the family and daily life. At what point the condition is accommodated through adaptation within daily life and no longer facilitating immediate changes and responses from the family member is not evident in current literature.

2. Family member

The family member is an occupational being and a significant relative of someone in a DOC. The family systems theory (Rosenthal & Young 1988) would suggest that changes in that unit from one person will have an influence on the remaining members of the family.

3. Occupation

Occupational choice or restriction of choice influences the individual's participation and engagement and the creation of preferred identity for the family member. It would be expected that over time the sustained nature of the experience would facilitate some form of adaptation. Potentially there could

be influences on occupational adaptation, though as yet these are unknown with families undergoing this particular experience.

Aims

The aim of this study was to apply a longitudinal design to explore the process of occupational adaptation within a group of primary caregivers. To achieve this data were collected from family members at 6 and 12-months post injury in accordance with the timelines for potential diagnosis of permanent VS (RCP 2013).

Methods

The nature and rarity of this condition and limited evidence in relation to the impact on the family's occupation influenced the methodology and research design. A pragmatic viewpoint was adopted as the focus of this research is set within the family members experience (Robson 2002). With the specific needs of the family members being at the forefront of the design flexibility is required to accommodate the participants pressure and stressful situation, particularly in the initial stages of the research, and at the same time accommodate time restraints and the impact of the person in DOC. A pleuristic approach of mixed methods facilitated the research phenomena to be viewed from both a qualitative and quantitative perspective, and enabled corroboration (Greene & Caracelli 1989) of data and exploration of underlying concepts that may not be identified by one method (Greene & Caracelli 1989).

As this research is exploring new and complex phenomena small numbers were anticipated and a multiple case study design was used (Yin 2003), providing the opportunity to confirm and extend theory in a relatively rare situation. This design enables exploration through one or more cases within predetermined boundaries (Yin 2003); the relationship of the participants, the time post injury, the context and occupational life.

Three methods were used to collect data;

1. **Time diary** - used as a means to record activity data (Harvey 1999). A 24h diary was distributed to participants who were asked to record activities undertaken in given time intervals. Diaries were recorded for 2 days to increase reliability (Sanik 1983). Closed time intervals of 30 minutes enabled quick completion by participants.
2. **Questionnaire** – A questionnaire was designed to support and extend observations from the diary entries by exploring views and use of time. The tool was piloted and distributed to

participants following completion and return of the time diaries. The tool is shown in Figure 1.

3. **Qualitative interviews** - 1-hour duration conducted after the diaries and questionnaire. Semi structured interviews were the prime focus of the data collection enabling use of questions built on existing theory, and related to that person's experience and data identified in the questionnaire. This use of multiple methods facilitated both methodological and data triangulation.

Insert Figure 1

Participants

All families were invited from a specialised brain injury unit who met the inclusion criteria. This purposive sampling strategy was the most appropriate due to the limited numbers of people with DOC (Tashakkori & Teddlie 2003). Recruitment took place over an 18-month period in order to recruit 6 participants (see Tables 1 and 2). Seven possible family members were identified, but one declined to be involved. Inclusion criteria were that the relative with brain Injury must be between 18 and 60 years of age, and must be 6-9 months post injury. The individual with the brain injury also should not have a drug related injury.

Insert Tables 1& 2

Ethics

Ethical approval was gained for this study from the UK national research ethics service.

Insert table 3

Data analysis

Data was collected case by case, analysis was carried out on individual cases and then a cross case analysis was completed. Quantitative data from the diaries and questionnaire were entered into an SPSS database (Statistical Package for Social Sciences; Version 15) and analysed descriptively due to the very small number of participants. Areas of change between 6 & 12-month data were identified. Qualitative data from the interviews were analysed using Burnards (1994) analysis with influences from Miles and Hubermans (1994) coding patterns, which aided the longitudinal aspect of the design. Note were made following each interview and manuscripts were completed from the audio recordings. Transcripts were read and themes identified followed by categories and open coding. Peer

checking was completed to verify categories. Two participants agreed to check their quotations against the categories.

Findings

Findings are reported here as (1) Occupational activity, and (2) catalysts for change.

1. Occupational activities.

The time diaries and questionnaire looked at the participant's view of changes that had occurred (increase, decrease or no change) in categories of occupations, post injury. For all working participants (n=5), work had decreased. Perceptions of engagement with leisure activity had decreased for all except one participant, who had just retired. Self-care activities remained the same for the adults over 35 (n=4), but decreased for those under 35 (n=2).

All 6 participants reported a balance of activity (work vs leisure vs self care) prior to the family members' injury. At 6 months' post-injury 3 stated there was no longer a balance in activities and 3 were not sure. The 12 months' findings identified a failure to return to reported pre-injury activity status, but indicated a change in balance had taken place. All participant's identified the issue of time spent with the brain injured person, and the resultant impact of this on their activities and lifestyle.

Health was stated by four participants to have been affected. The two participant who did not feel health was affected still indicated an impact on stress levels "*feel more stressed and anxious, but no illness to speak of*" (participant 2). For the participants the impact of caring on their health had altered between 6 and 12 months with health becoming more of an issue.

Time spent in occupations with or for the person in DOC decreases time in other occupations with social and leisure activities having less time than visiting, work and self-care. The greatest proportion of time spent in active occupation was during a week day (WD) focussing on work and time spent with brain injured family member (8.5 h, 34%, in total). At a weekend (WE) the largest amount of time was still spent with the brain injured family member but had decreased (to 5h, 21%).

Five themes were identified from the interviews.

Theme 1. Impact on emotional/health

The emotional load in the initial stages had an impact on family carer's occupation which resulted in reducing or ceasing certain occupational activity:

'The despair ...I couldn't think about anything. I couldn't even read. ... I didn't want to do anything. I didn't want to eat, I didn't want to socialise...'
(Participant 4)

All participants identified an emotional impact presented in differing forms such as irritability, 'easily upset' (participant 3), anger (participant 1), low mood (participant 5) and frustration (participant 2). The emotional element was very present and the power of the emotion returned with the medical instability of their relative.

Four participants had seen a change in their own health status through the return of eczema, loss of sleep and general tiredness. One participant had also experienced an extreme behavioural response to the situation (pulling out hair) and also low mood. For those participants with children all illustrated examples of the impact on the children regardless of age. These varied from being 'more emotional' (participant 3) to behavioural changes.

As identified by the diaries, at 12-months health changes were still an issue for the participants, along with stress and tiredness. Participant 4 identified that they even felt worse at this later stage.

Theme 2. Change- occupation, role and environment

'my whole pattern has changed...I have changed my life completely.'
(Participant 6)

Change was an underlying theme throughout the interviews. Specific occupations are adjusted to accommodate the new focus of time and activity e.g. altering the working day (participant 2, 4 & 6). For most of the participants their role was now to provide stimulation and advocacy. Occupational adaptation at twelve months was not a natural progression for all participants, nor was it simply a move back to previous occupations.

The point at which advice to take time for themselves was acted upon varied and appeared to be dependent upon a number of factors which are identified later (**see 2; below**) as catalysts to change. It was also important that the participant had identified the need themselves and had the motivation to pursue change.

'If having time on your own or time to do something you enjoy is important to you and you can put out of your head the distress and anxiety then it's worth making time for it.' participant 4

When the participants reached the point where other occupations were reintroduced into their routines there was a conscious selection of occupations which avoided possible emotional links to the relative with the brain injury, for example not going to certain restaurants or bars, avoiding holiday destinations or familiar places. Occupational choices were made in new areas of activity (e.g. running or voluntary work) or previous activities which only involved the participant and were considered 'emotionally safe':

'Yes, but there are places I can't go because I know that x would want to be there too and that upsets me, but I can do things for myself that are nothing to do with anyone else... therefore it was my time.' (Participant 4)

Two participants had not reached the point of reintroducing occupations due to the catalyst of change not being in place.

By twelve months all of the participants had noticed changes in the condition of their relative. All stated the importance of the relative's apparent ease, happiness or contentment; despite their level of cognitive function.

'Tuesday we went to see him and he looked absolutely fantastic. Very calm and making a bit of eye contact.' (Participant 5)

Theme 3. Use of time

One strong theme **in the first six months** was the lack of opportunity or inclination for time for self and a need to live day-to-day.

'I work, I see X I go home, I sleep' (Participant 2)

At 12-months arrangements became 'practical rather than emotional' (Participant 4) as new routines and activities developed. The consuming nature of the situation for some had lessened:

'...because undoubtedly it is a grieving process because you have lost virtually all of who you knew.... I think to start with it's all you can think about and then it becomes less and less.' (Participant 3)

By having more time and space and not having to react to emergency situations the outlook of the participants began to move from the previous day to day perspective.

'I don't look too far ahead actually; I take it year by year.' (Participant 3)

One participant still did not wish to consider or discuss the future and was still coping on a more limited view of time.

Theme 4 Coping

The participant's strategy at the first interview focussed on the physical need of being close which can be seen in the pattern of visiting.

'When he was in a semi conscious state I always thought he would wake up while I wasn't there and I didn't want not to be there.' (Participant 4).

Being there appeared to be a way of coping with the situation. Change of occupations at twelve months that no longer focus to such an extent on the relative with the brain injury brings about a sense of normality and balance which is summed up by Participant 3:

' the big change is it's not so much of one's subconscious attention, everybody focussed on X and it's more widely spread now which is healthier.'

With this realisation, changes began to be seen within the occupational lives of the participant resulting in a change of visiting patterns **observed** for all participants. The tension between commitments outside of the hospital and to the brain injured person became a slightly uncomfortable compromise for **those** who were able to justify their decisions in visiting less often, but felt a sense of guilt and loss due to the change in activity and routine.

Theme 5. The future

'We didn't have much idea. No one ever said he might not come out of it, or wasn't going to come out of it, it was a terrible waiting time'. (Participant 4)

The future was a difficult aspect for the participants to consider at 6-months, **and one participant felt unable to discuss it**. The difficulty in focussing on the future was, for some, embedded in the medical instability of the first few weeks and months, which had led the families to contemplate issues of survival and intervention.

At over 12-months post-injury the families had gained a sense of medical stability and comprehension of the longevity of the condition. Things were becoming more stable and expectations of recovery readjusted;

‘A year ago he was going to come home ...I don’t think he will ever come home now, I totally did at the start of it.’ (Participant 1)

Despite the multitude of issues for the participants they were able to begin to reflect on their experiences to identify aspects that enabled them to cope (see advice for others).

2. Catalysts for change

Change was an underlying theme throughout the interviews, in the medical condition, prognosis, environment, visiting patterns routines and occupation. For some it is a gradual awareness of the need to alter their lives and adapt to the long term nature of the situation **while** for others it is more of an active adjustment to their lives. What became evident across the sources of data, **and especially in the interviews**, was that there were catalysts which brought about an actual change or consideration of the potential future change. **These appear to be key for transition of the participants into a more balanced occupational status, and are summarised in Table 3.**

Insert table 3

Discussion

The aim of this study was to identify processes of adaptation for carers of relatives with a DOC, over the period of 6-12months after traumatic injury. The intention was to seek to understand the changes that promote adaptation. It was recognised that there first needed to be the desire to change occupations and also there were factors that needed to be in place in order to facilitate (catalysts) change. It was medical stability that was highlighted by the participants as being of importance in their own rehabilitation. The emotional wellbeing of the participants therefore seemed to echo the medical stability of the relative. This combination of medical stability and move to permanent placement appeared to act as a catalyst to occupational changes. The decrease in occupational focus on the relative provided an opportunity to introduce occupations back into the participant’s lifestyle, but the choices of occupations had neutrality about them. Participants had sought occupations devoid of an emotional link to their relative and this also included the context/environment in which the occupation would be executed. **In so doing, their experiences followed a hierarchical process towards a balanced occupational status (Figure 2).**

Insert Figure 2 here

Figure 3 expands on this model to provides a conceptual collation of the main findings in order to represent the experience of the participants over this time period and suggest the relationships between them. There are five strands (a-e below) to this diagram which will be briefly discussed.

Insert Figure 3

a) Disorders of Consciousness

The individual in a DOC is pivotal to the experience of the carer and the research has shown that the changes that occur within that individual have a direct influence not only on health and stress of the family member, but also their daily lives and occupation. At the six month point the situation has dominated day to day life of the family member as routines adjust and increased time is focussed on the person in a DOC. Occupation and roles are prioritised for the person in DOC.

After 6-months the person in DOC has become more medically stable, there begins to be more trust in the service provision, which may be due to greater understanding of the process or perhaps greater security felt as a result of medical stability. At 12-months the prognosis and rate of recovery become clearer to the family and the team. The participants are also making changes, but the person in DOC is still influencing occupational choice and environment as the direct links to pre-injury occupational relationships are avoided.

b) Occupational change/ lifestyle

As a result of a relative in a DOC there is greater time allocated to that person. At 6-months there has evolved an 'occupational squeeze', i.e. new occupational roles and occupations related to the person in DOC necessitating an adjustment in pre-existing occupations. The choice of occupation becomes reduced as does the occupational potential i.e. the fulfilment of meaningful occupation, in relation to the future. This results in a loss of existing occupational narrative (Mattingly 1998). Between 6 and 12-months changes start to occur, occupations begin to adapt to new contexts and environments.

c) Occupational balance

Occupational balance changed in comparison to pre injury perceptions. By 12-months participants were moving towards a balanced occupational lifestyle or recognising the need to achieve greater balance.

d) Changes for self

As noted, occupational roles initially changed to roles involving the person in DOC. At 12-months the participants were beginning to seek greater time for self. Changes in visiting and therefore time use enabled a refocus or adaptation of occupations that reflected meaning and identity of the family member.

e) Catalysts to changes

Catalysts to change appeared to develop after the 6 months and along with observed changes in the person in DOC had the greatest impact on the participant being able to re-align occupations that create a greater balance and sense of self. This finding illustrates the significant influence that the situation of the relative in DOC has on the occupation and lifestyle of the family member, as well as the potential to adapt occupations for the future.

Relevance to practice

Insert table 4

As far as we are aware this is the first qualitative evaluation of the experiences of carers of relatives who have suffered a traumatic brain injury. In understanding better the transitions that occur over 12months post-traumatic injury, and the catalysts that promote transition, this study proposes professional guidance and advice offered to carers of relatives in DOC (Table 4).

In the interviews it was highlighted that several participants had been advised to do more activities for themselves and spend less time on the unit. However, looking at the catalysts that bring about change it could be argued that the family member may not be ready to pursue different occupations and so to seek a sense of 'normality' i.e. doing things for yourself in a potentially 'abnormal experience' is possibly unachievable. However, if the changes are facilitated e.g. engendering trust, then emphasising slowly changing routines and providing advice on the types of occupation, such as new activities without prior links to their relative, may enable more successful changes to be made.

Summary and conclusions

This study applied a mixed methods approach to identify the impact that caring for a relative with a traumatic brain injury can have on the carers' occupational status, and the process of adaptation over a period of 12 months post-injury. At 12-months post injury there remained a significant impact of on the participant's daily life and occupations. Although two participants felt their lifestyle had returned to that of pre-morbid status the remaining four still identified a continued lifestyle change. The commitment to caring for the person with the brain injury still had an impact on their health and wellbeing. Stress was a consistent factor although health issues varied for the participants and their families. However, there were signs that in some cases participants had adjusted their expectations of outcome, although this still remained an area of uncertainty particularly for those whose relative was still showing signs of recovery. Indeed, medical stability and a growing trust in service provision, appear to be key catalysts of change that enable carers to begin to re-establish occupational balance in their lives. This paper presents a conceptual framework that emphasises the relationships between various factors but what is evident is that restoring occupational balance is a slow process. Guidance to practitioners is offered.