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Psychological Intervention for Partners Post-Stroke: A Case study

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***Abstract***—*Background and aims*: Relationship breakdown is common when one partner lives with an acquired brain injury caused by issues like a stroke. Research has found that the perception of relationship satisfaction decreases following such an injury among non-injured partners. Non-injured partners also are found to experience caregiver stress/burden as they take on the role of a caregiver along with being a partner of the injured. Research has also found that perceptions of relationship continuity/ discontinuity (i.e. whether the relationship is experienced as similar or different to the pre-injury relationship) vary within caregiving partners, and that these perceptions have an impact on the psychological wellbeing of the caregiving partner and the quality of the relationship. However, there is a lack of available intervention strategies that can help those partners with both individual and relationship difficulties. The aim of this case study was to conduct a pilot test of an intervention aimed at exploring whether it is possible to support a partner to experience greater continuity within the relationship poststroke, and what benefits such a change might have. *Method:* A poststroke couple were provided with Integrated Behavioral Couples Therapy for 3-months. The intervention addressed goals identified by the couple and by the formulation of their individual and relationship difficulties, alongside the goal of promoting relationship continuity. Before and after measures were taken using a battery of six questionnaires to evaluate changes in perceptions of continuity, stress, and aspects of the relationship. *Results*: Both quantitative and qualitative data showed that relationship continuity was improved after the therapy, as were the measures of stress and other aspects of the relationship. The stress felt by the person with the acquired brain injury also showed some evidence of improvement. *Conclusions*: The study found that perceptions of relationship continuity can be improved by therapy, and that improving these might have a beneficial impact on the stress felt by the carer, their satisfaction with the relationship and overall levels of conflict and closeness within the relationship. The study suggested the value of further research on enhancing perceptions of continuity in the relationship after an acquired brain injury. The intervention is currently being further developed and evaluated.

*Keywords*— Acquired brain injury, stroke, couples’ therapy, relationship continuity.

# INTRODUCTION

L

ITERATURE shows that partners caring for an individual with an acquired brain injury (ABI) often suffer from burden and stress [1]. They also experience changes in their relationship with their injured spouses which often causes marital instability or even separation or divorce [2]. However, there are only a handful of studies that have worked with couples and their dyadic relationship following ABI and even fewer have been guided by theories about the specific impact of

ABI on the relationship. This paper describes a therapeutic intervention with one poststroke couple using the framework of Integrated Behavioral Therapy (IBCT) to promote continuity within the relationship alongside meeting the specific needs of the couple identified during the assessment

## Relationship Continuity/ Discontinuity

 One potentially important contributor to partner/ caregiver distress following ABI is the perception of relationship discontinuity (RD) [3]. The concept of relationship continuity/ discontinuity is an idea that developed in research on spouses providing care for people with dementia [4]. Although nearly all relationships are likely to change to some degree following ABI, it is whether the essence of the relationship survives the change that distinguishes experiences of continuity from discontinuity. There are five components of relationship continuity/ discontinuity which are viewed to be intimately connected [5]; *Relationship redefined* (whether the nature of the relationship is viewed as a continuation of the pre-morbid relationship or as radically changed and discontinuous); *same or different person* (whether the caregiving partner feels that the injured partner is essentially the same or has radically changed post-ABI); *same or different feelings* (whether the partner continues to feel the same love and affection for their injured partner or these feelings have been replaced with other feelings like emotional detachment); *couplehood* (whether the partner perceives that they are in a partnership with the injured partner or they perceives themselves in a individualistic way in the relationship); *loss* (whether or not the partner feels a sense of loss and grief for the pre-injury person and relationship). The concept of relationship continuity (RC) and some of its components have also been found in partner experiences following ABI.

## B. Integrated Behavioral Couples Therapy (IBCT)

 IBCT is an extension of traditional behavioral couple therapy, developed to increase engagement in couples’ therapy and promote behavior change and emotional acceptance [6][7]. The theory behind IBCT states that problems in relationships are caused due to challenging situations (external stressors) that trigger undesirable behaviors which, in turn, create and maintain difficulties [8]. Various treatment techniques are used within this framework. Since IBCT focuses on behavior and emotional reactions to behavior, it was appropriate to use it for the present case study since it was considered that the behavioral difficulties and the emotional reactions to them that the couple were facing, significantly contributed to relationship discontinuity following the stroke [9].

 The aim of the single case study was to explore whether it is possible to support a partner to experience greater continuity within the relationship, and what benefits such a change might have.

# Methodology

## Design

 This is a case study that compared pre- and post-intervention assessments.

## Participant characteristics

##  The participants were one heterosexual couple who were voluntarily recruited from the department of Neurosurgery, AMRI Hospitals, India. The husband (in his early 60s) had a stroke 9 months before the intervention. He was admitted to the hospital where he had a surgery for a subdural hemorrhage. Post-surgery he was found to have speech difficulty and movement issues. When the intervention was conducted, he was under regular medical supervision and was undergoing rehabilitation. At that time his arm movement had improved a little, but he was still unable to walk and was using a wheelchair. His speech difficulty had improved a little with rehabilitation, but he still had difficulties in functional aspects of communication such as initiating conversations. Fatigue was also an issue.

##  The wife (in her late 50s) was the main caregiver and was experiencing relationship difficulties and discontinuity (assessed quantitatively) following her husband’s stroke. The couple had been married for more than 35 years and have two sons. They live in a joint family with their elder son, daughter in law and grandchildren. The husband was a businessman but stopped working following the stroke. The wife was a homemaker but did often engage in helping her husband manage the finances of his business. The couple had not experienced any relationship difficulties prior to the stroke (assessed quantitatively).

##  Measures

## Birmingham Relationship Continuity Measure (BRCM)

BRCM is a validated 23-item questionnaire where participants are asked to express their view on changes in their partners and the relationship following ABI based on how things were before the injury and how things are at present [10]. The scale has a high internal consistency (Cronbach’s α= .963), high test-retest reliability (intra-class correlation= .960), high discriminatory power (delta= .963), and good concurrent validity. This scale was administered to the caregiving partner.

## Relationship Assessment Scale (RAS)

##  RAS is a brief measure of global relationship satisfaction [11]. It has good validity and good overall internal consistency, with an alpha of 0.85. A version of the RAS referring to the pre-injury relationship was used in the study as a screening tool. Since the BRCM assumes that the pre-injury relationship was at least satisfactory [5], the pre-injury RAS provided a check on whether this was the case. A post-injury version of the RAS, referring to satisfaction with the current relationship, was also administered pre- and post-intervention as an outcome measure to evaluate the effectiveness of the intervention.

## Dyadic Adjustment Scale (DAS)

 DAS is a self-report measure of relationship adjustment that measures four aspects of a relationship; dyadic satisfaction, dyadic cohesion, dyadic consensus, and affectional expression [12][13]. It has good validity and good overall internal consistency, with an alpha of .96. The scale was administered to the caregiving partner pre-and post-intervention.

*Caregiver Strain Index (CSI)*

CSI is a screening instrument used to measure stress and burden in the caregiver [14]. The scale has good validity and good reliability of 0.86. The scale was administered to the caregiving partner pre-and post-intervention.

*Depression Anxiety Stress Scale (DASS-21)*

 DASS-21 is a set of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress [15]. The depression scale has a reliability of 0.91, anxiety scale has a reliability of 0.81, and the stress scale has a reliability of 0.89. The scale was administered to both the caregiving partner and her husband, pre-and post-intervention.

*Session Evaluation Questionnaire (SEQ)*

 SEQ assess clients’ evaluations of therapeutic sessions and the impact it had on them [16]. The questionnaire has three sections, but just one section which had the following questions were used in the present study; 1) What was your favorite or the most useful part of the sessions? Why? 2) What was the worst or least useful part of the sessions? Why? 3) How much do you want to come back for future sessions? 4) How much did you like the sessions? 5) After completing the sessions, how stressed do you feel? 6) Please give us any other comments or suggestions that you have about how we can make future sessions better. The scale was administered to both the husband and wife after the therapeutic sessions, and the answers provided by the clients were used as qualitative evidence.

##  Procedure

 Clinical collaborators at the AMRI hospital assessed the eligibility of the clients they had at the time based on the study’s inclusion and exclusion criteria and the client’s physical and cognitive status. After careful consideration, one couple was identified. After they provided consent, the researcher met the couple and conducted the pre-intervention quantitative assessments, followed by a semi-structured interview to gain a greater understanding of their pre- and post-ABI relationship. The RAS pre-injury score suggested that the wife was generally satisfied with the pre-injury relationship (raw score 31) while the RAS post-injury score suggested relationship dissatisfaction (Table I). Following 12 therapy sessions, another assessment session was conducted.

## Ethical considerations

 Ethical approval was given by the University of Birmingham School of Psychology Human Research Ethics Committee, and by the AMRI Hospital.

# PARTICIPANT/ RELATIONSHIP HISTORY

 The couple went through an arranged marriage when they were both relatively young. Their relationship began to develop more strongly after the wedding as they started getting to know more about each other. Both the partners talked about having a peaceful married life pre-stroke. They stated that they always enjoyed each other’s company as they had similar needs and hobbies.

 From both partners’ perspective, their relationship has changed post-stroke in many of the important aspects that previously defined them as a couple. According to the husband, the wife had developed irritability. She would get angry very quickly. They also were not able to do many things they enjoyed doing in the past, due to his physical restrictions and her time constraints.

 According to the wife, she had added responsibility following the stroke that has affected her both psychologically and physically. Her routine had drastically changed and besides doing her usual household chores she now had the added responsibility of taking care of her husband’s daily activities. She talked about having less time for herself, had noticed increased anger more than love towards her husband. However, her anger and frustration often made her feel guilty since she felt she was not as supportive as she should be towards him. She also felt the transition to her new role was made more difficult by the changes in her husband. She stated that she had noticed a fundamental change in her husband’s personality. For example, she felt he did not converse properly anymore and did not share his feelings with her. This made it more difficult for her to understand his needs. She felt the relationship had become less of a partnership, less like a spousal relationship and more like a caregiver-care recipient relationship.

# CASE CONCEPTUALISATION

 The conceptualization of the relationship difficulties of the couple was based on the IBCT approach [17]. The stroke functioned as an external stressor. Lack of knowledge regarding the effects was causing individual and relationship difficulties. The wife was unable to understand the causes of those difficulties, especially certain aspects of his communication difficulties and fatigue, which made her attribute it to ‘laziness’. This led to frustration and outbursts of anger. These outbursts, in turn, made the husband interact less, leading to reduced communication and failing to express his feelings to his wife. The couple also failed to understand each other’s perspectives. Their negative emotions regarding the sudden change in their lives hindered emotional sensitivity towards each other, and this was compounded by a failure to express their feelings clearly to one another. For example, the husband did not realize that the wife’s sudden anger issues were due to the frustrations created by his lack of communication; and she did not understand that his lack of communication was due to his anxiety about causing her extra stress or provoking her anger. The sense of couplehood had disintegrated in their current relationship. They no longer did things together that used to define them as a couple and made them happy, like praying together.

#  INTERVENTION

 The therapeutic intervention consisted of 12 sessions, one session per week, where each session lasted for approximately two hours. The intervention was based on the individual and relationship difficulties that were highlighted in the case formulation, on the therapeutic aims expressed by the couple, and on the aim of promoting perceptions of continuity. The goals were not exclusively focused on promoting continuity; it was considered essential that the work addressed the needs of the couple, and not just the needs of the research. Continuity was also promoted by the therapist explicitly highlighting to the couple similarities and continuities between the pre-stroke and current situation when opportunities arose in the course of the therapy.

 The first goal of the intervention was to increase the couple’s understanding of the effects of ABI. An educational session was provided to give the couple an overview of the emotional, cognitive and behavioral changes that follow after an ABI, and how spousal relationships can be affected by those changes. The session had an important impact in helping the couple, especially the wife, become aware that certain difficulties like communication and fatigue were a part of the stroke. It was intended that the session would promote a sense of continuity by giving the wife an understanding of these issues as symptoms of the stroke rather than representing a fundamental change in his identity as a person (i.e. promoting *same person* component of RC). Explanations in terms of the husband’s pre-stroke personality interacting with the symptoms of the stroke may have been particularly effective in promoting the sense of *same person* and the same relationship. For example, the wife came to see her husband’s lack of communication as being driven, in part, by his desire not to add to burden and distress by raising more problems and difficulties. This desire was highly consistent with her perception that, pre-stroke, he was strongly driven by a desire to protect her from upset and distress.

 Related to the aim of improving the couple’s understanding of the symptoms of ABI, another goal focused on increasing their empathic understanding of each other’s situation. The therapist aimed to facilitate the expression of soft emotions towards one another like compassion and sadness, instead of the hard emotions like anger that characterized much of their current interaction [17]. Examples of the expression of these soft emotions include:

 *It makes me sad seeing him like this…I am scared about what will we do if he does not recover. (Wife)*

 *I feel that I have brought this hard time on my family and my wife. She has all these responsibilities now, and I am unable to help her even if I want to do so... She has become this angry person she was not before. (Husband)*

 [It should be noted that all quotes in the paper are from the therapist’s written records of the sessions. They are not verbatim transcriptions.]

 The mutual expression of soft emotions was intended to enhance the experience of *empathic joining*, a key component of IBCT [17][6]. It was also intended to promote continuity. Sharing prosocial compassionate emotions may have helped the couple appreciate that they were in the experience together (promoting the *couplehood* component of RC). Empathy for the other’s situation may also promote feelings of closeness (promoting the *same feelings* component of RC). Understanding the positive and caring feelings behind some of her husband’s behaviors and feelings may also have helped the wife see him more in the context of the loving person she knew him to be before the stroke (promoting the *same person* component of RC).

 Another goal was to improve the communication between the couple. There was a repetitive dysfunctional cycle of communication that led the wife to interact with the husband anxiously and angrily. This led the husband to withdraw from the wife to avoid such interaction. Using role playing sessions, the couple were encouraged to engage in more rewarding patterns of communication [17]. Before the stroke, the couple used to have a regular conversation especially during or after dinner about the day’s events. Following the stroke, they stopped this practice. They were given the task of starting this up again. As well as promoting better communication, the aim was to restore a previous pattern of communication to help them feel connected again with their life before ABI (promoting the *same relationship* component of RC).

 *Yes, he has started talking comparatively more than he used to before we started the sessions... At least now I do not have to ask him something several times to get a nod. He now responds to my question like a normal human being! (Wife)*

 Another important intervention goal was to develop the husband’s ability to participate in daily activities effectively; thereby reducing his dependency on his wife and alleviating some of the burden she felt. Much of this work focused on helping them develop more effective ways of managing the fatigue that was a significant cause of his reduced activity. A graded approach was taken involving a steady increase in the number of daily activity goals set for the husband. Over the course of the intervention, the husband’s tiredness reduced, and he started feeling more involved and less dependent. It is possible that seeing her husband more active and engaged may have helped the wife see him as closer to his old self (promoting the *same person* component of RC). The reduced dependency on herself may also have helped her feel that the relationship was more similar to what it had been before the stroke and less characterized by the giving and receiving of care (promoting the *same relationship* component of RC). Many of the daily activity goals also involved the couple working together on a task, rather than the husband passively receiving help. This co-operation may also have fostered a sense of togetherness (promoting the *couplehood* component of RC).

 One aspect of IBCT involves the couple identifying behaviors towards one another which are perceived as positive and desirable by the other partner, so that the frequency of such behaviors can be increased. These behaviors are, in turn, expected to improve the positive feelings the couple have for each other. In the present case, before the stroke, whenever one person was busy with other work, the other took the initiative to get some household chores done. This made them feel that the other cared for them. However, following the stroke, this pattern of interaction had disappeared because the husband had become so dependent and inactive. The intervention involved encouraging the husband to carry out housework that the husband could manage within his physical limitations. This was set within the context of alleviating some of the burden on his wife and conceptualized as a way of showing that he cared for his wife.

 The intervention may have helped the wife to perceive continuity by providing evidence that her husband’s positive feelings towards her (like love and care), which was a major part of their pre-stroke relationship, were still there (promoting the *same relationship* component of RC). Perceiving these feelings again in him may have facilitated a reciprocation of those feelings (promoting the *same feelings* component of RC). These behaviors may also have strengthened the feeling of working together again (*couplehood*) and helped her feel that their current life together was closer to what their pre-stroke life was like (*same relationship*).

 *I now feel closer to him and feel more love for him than ever. My feelings for him, of course, have not changed which is why I still keep trying every day to help him out and it is the same for him. (Wife)*

 Another important goal was to help the couple re-establish valued shared activities. The couple were encouraged to think about things they did together before the stroke which created happiness and defined them as married partners. They were then encouraged to re-engage with those activities that were possible taking into account the physical and cognitive limitations of the husband, using a graded approach. These included activities such as taking evening tea together and praying together. These may have reduced the wife’s perception of discontinuity by rekindling the positive feelings she had towards her husband, enhancing the sense of togetherness, reducing the feelings of difference about his identity when she saw him doing these old familiar activities together, and making it feel like a more normal relationship between spouses.

 The intervention also focused on other therapeutic goals that are not described in detail here because they were less directed towards the promotion of continuity. They included work on the couple’s problem-solving abilities, helping the husband re-engage in valued roles and activities (not involving his wife), helping the couple come to terms with the likelihood that there would be some permanent physical disability, promoting the wife’s self-care strategies, and increasing their tolerance of annoying behaviors.

# TREATMENT EFFECTS

 Pre- and post-intervention quantitative assessment (Table I) was conducted. Pre-intervention scores suggested a high degree of perceived discontinuity on the part of the wife (BRCM), dissatisfaction with the relationship (RAS), and a poorly functioning relationship and impairment in dyadic cohesion, dyadic consensus, and affectional expression (DAS). The CSI score suggested that the wife experienced a high degree of burden. The DASS-21 scale scores suggested that neither the wife nor husband had clinical levels of depression or anxiety. However, the stress scale suggested that the wife and husband were undergoing a moderate and mild level of stress, respectively.

 Post-intervention quantitative assessment was conducted at the end of the therapy. The scores showed that the wife experienced more continuity in the relationship, was more satisfied, reported the relationship to be functioning more effectively. She also reported less stress, as did her husband (Fig 1). Application of the Reliable Change Index (RCI) [18][19] showed that these changes were statistically reliable. Table II shows the actual difference in pre- and post-intervention scores, with regards to their standard error, along with the difference required to conclude that there is a statistical reliable difference, which was calculated based on the two RCI formulas [18][19]. The depression and anxiety scores from the DASS-21 were not assessed since both the partners obtained low scores on these subscales and these scores showed no change post-intervention (Table I). However, the stress scores for DASS-21 were assessed for both the partners as both had a moderate/mild level of stress in the pre-intervention phase (Table I). The RCI showed a decrease in stress for both the partners providing evidence that the intervention had a significant effect on reducing their stress level (Table II).

*Qualitative Feedback*

 Findings from the quantitative measures were supported by qualitative comments made by the couple in the SEQ that indicated less stress, more continuity in the relationship and a better relationship generally. Components of the feedback suggesting an improvement in continuity are in bold.

 *Last week we had a religious festival, and so we decided to organize a small prayer session at our house. We hoped to pray that this positive change we are experiencing after the stroke and all the difficulties lasts forever and God bestows his blessings on our family...* ***We felt like a family again.*** *We both organized the prayer session on our own just like we used to do earlier.* ***I think it helped us re-connect again as a married couple.*** *(Wife)*

 *We progressed from feeling anxious to being excited to come to the sessions. Every time we came with so many things. We always wanted to share and change. Moreover, especially when he started going back to work and when we organized the prayer at home, we felt it was an achievement and motivation to come back for the sessions.* ***The best part is how the sessions helped us to do things together and share our responsibilities as much as we can.*** *It gave us the strength to* ***share our emotions with each other*** *that we had not done in months. It helped us feel connected again. It* ***changed the present us and our* *relationship to what it was before the stroke to some extent****. (Wife)*

 *Honestly, there are still daily life things that are stressful as they were even before the stroke. However, we now realize that that basic level of stress is inevitable in anyone’s life. However, we were experiencing unwanted stress due to the changes we have experienced since the stroke, and that has reduced after completing the session. Instead, we feel we are a little more confident now than stressed to handle our present situation. (Wife)*

 *I have seen a lot of changes in her after we started this therapy. She was so aggressive in the beginning, but now she reacts normally to conversations like she used to. It seems like she does not feel much stressed as she was experiencing and that makes me happy to see her happy! (Husband)*

TABLE I

COMPARISION OF PRE- AND POST-INTERVENTION QUANTITATIVE MEASURE

|  |  |  |
| --- | --- | --- |
| Measures | Pre-Intervention Scores (Interpretation) | Post-Intervention Scores (Interpretation) |

|  |  |  |
| --- | --- | --- |
| BRCM | 42  | 94  |
| RAS Post-Injury | 19  | 31  |
| DAS | 27  | 118  |
| CSI | 12  | 5  |
| Depression (Wife/ Caregiver) | 5 (Normal) | 2 (Normal) |
| Anxiety (Wife/Caregiver) | 0 (Normal) | 0 (Normal) |
| Stress (Wife/Caregiver) | 21 (Moderate) | 9 (Normal) |
| Depression (Husband/Caregiver) | 6 (Normal) | 6 (Normal) |
| Anxiety (Husband/Caregiver) | 0 (Normal) | 0 (Normal) |
| Stress (Husband/Caregiver) | 16 (Mild) | 1 (Normal) |

|  |  |  |
| --- | --- | --- |
|  |  |  |

TABLE II

RELIABLE DIFFERENCE BETWEEN PRE- AND POST-INTERVENTION SCORES BASED ON RELIABILITY CHANGE INDEX (RCI)

|  |  |  |
| --- | --- | --- |
| Measures | Actual Difference (Required Difference) (Jacobson & Truax, 1992) | Actual Difference (Required Difference) (Maassen, 2004) |

|  |  |  |
| --- | --- | --- |
| BRCM | 11.399 (8.942)  | 14.428 (7.064) |
| RAS Post-Injury | 34.384 (0.684) | 22.222 (1.058) |
| DAS | 17.491 (11.094)  | 21.864 (8.875) |
| CSI | 16.820 (2.564)  | 11.23 (3.838) |
| Stress (Wife/Caregiver) | 5.213 (4.512) | 3.930 (5.986) |
| Stress (Husband/Caregiver) | 6.516 (4.512) | 4.912 (5.986) |

|  |  |  |
| --- | --- | --- |
|  |  |  |

Fig. 1 Pre- and post-intervention quantitative measures assessing the impact of the intervention on the relationship and individual stress

# DISCUSSION

The study aimed to explore the possibility that perceptions of continuity can be improved by therapy, and that improving these might have a beneficial impact on the relationship and on the psychological wellbeing of the couple. The study provided some encouraging evidence that both these aims can be achieved. Further developing and evaluating this continuity-focused intervention merits further investigation.

*Limitations of the study*

 Because of the study design issues, it is not possible to conclude that the improvements were due to the intervention. Care should also be taken in generalizing the findings: The husband’s cognitive impairments were only moderate, and the study was conducted in India. Furthermore, the intervention in this study involved many components, some of which were not directly relevant to promoting continuity. Even for those components that were directly relevant, it was not always easy to distinguish them from components that might be included in other kinds of couple intervention that are not focused on promoting continuity. The study findings may provide the basis for developing a more distinct continuity-focused therapy in the future.

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