

**Compliance : Effects of Stress and Social  
Support within a Hemodialysis Population  
and Research Portfolio**

Submitted in Partial Fulfilment of the  
Degree of Doctor of Clinical Psychology within the  
Faculty of Medicine, University of Glasgow.

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August 1995

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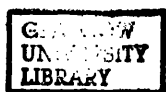
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## **Acknowledgements**

The author would like to give special thanks to all patients and staff in the Renal Unit at Stobhill Hospital; for the encouragement, help and support given during the course of the research study.

Thanks also to all members of the Department of Psychological Medicine for their advice and support over the last three years.

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# **LITERATURE REVIEW**

**Title : END-STAGE RENAL DISEASE (ESRD) - SOCIAL SUPPORT,  
STRESS AND COMPLIANCE : A REVIEW.**

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**Targeted Journal : Behavioral Medicine**

## **END STAGE RENAL DISEASE (ESRD) - SOCIAL SUPPORT, STRESS AND COMPLIANCE: A REVIEW**

### **Abstract**

This review sets out to consider selected literature in relation to End-Stage Renal Disease (ESRD) populations, specifically focusing on hemodialysis patients. The relationship between social support and outcome, with special consideration given to compliance, is outlined, and a theoretical model of support discussed. Compliance within hemodialysis populations is considered in detail and associated methodological problems highlighted. Studies evaluating the stress-buffering model of social support in relation to stress and compliance are outlined and implications for future research briefly highlighted.

**Key Words : Social Support, Stress Compliance, Hemodialysis.**



## **INTRODUCTION**

Available literature on the role that social support plays in effecting health and health-related behaviours is vast, with increasing numbers of papers published in this field every year.<sup>1</sup> The importance of social support is also reflected in the literature on chronic renal failure or End-Stage-Renal Disease (ESRD). Due to physical limitations, an arduous medical regime and continued disruption to daily functioning, ESRD, as a medical condition, is demanding for patients.<sup>2</sup>

## **SOCIAL SUPPORT & ESRD**

### *Definition & Measurement of Social Support*

Definitions of social support employed in ESRD studies are numerous. Burton et al.,<sup>3</sup> for instance, define social/emotional support as the information received by individuals that "they are loved and wanted, respected and valued and part of a context in which they can count on others should the need arise". As with any empirical investigation, operational definitions are necessary if the presence or effect of support on other variables is to be evaluated. Measures of support tend to reflect the definitions employed and consequently a wide range of instrumentation is available. Facets of support commonly assessed include eg. i) number/network of supports,<sup>4</sup> ii) relationship ie. friends, family, colleagues,<sup>5</sup> iii) frequency<sup>5</sup> and iv) type eg. global or health/task-specific.<sup>6,7</sup> Methodologically however, perhaps reflecting lack of clear definition in some cases, measures employed are often of poor reliability and validity, making interpretation of research data difficult. (See Winemiller et al.<sup>8</sup> for fuller discussion and review of measurement of social support).

### *The Relationship between Social Support & Outcome in ESRD*

Social support is an important variable in hemodialysis populations, which is perhaps best illustrated by the consistent relationship between support and outcome measures documented in the literature. ESRD outcome has been defined and measured in a variety of ways eg. adjustment, psychological distress, morbidity and mortality. Absence of a perceived social support system has been associated with poorer long-term adjustment in hemodialysis patients in that, for instance, social introversion, hypochondriacal behaviours and anxiety are less evident in those with more perceived support.<sup>3</sup> Similarly lower reported incidences of depression,<sup>9</sup> suicide,<sup>10,11</sup> and mortality rates<sup>12</sup> are associated with presence of support.

To summarise, there is evidence that presence or absence of support has important short and long-term effects on health and well-being in ESRD populations, with presence of support typically associated with better outcome. One model proposed to account for this relationship - the Stress Buffering model - will be outlined next, prior to discussion of specific mechanisms via which the effect may occur.

### **THE STRESS-BUFFERING MODEL OF SOCIAL SUPPORT**

The stress-buffering model of social support suggests that the beneficial effects documented are due to the tendency of support to 'buffer' an individual against the deleterious effects of stress. In this model, the effect of support is proposed to be most evident when individuals experience high levels of stress. As an alternative, the 'direct' or 'main effect' model suggests that support has a beneficial effect irrespective of the level of stress experienced by individuals.<sup>13</sup>

The majority of studies evaluating the stress-buffering hypothesis have tended to use general population samples. However, the model has also been

considered in relation to medical populations where illness-related chronic stress is often experienced (see Schwarzer & Leppin<sup>14</sup> for review).

Before the stress-buffering model can be evaluated appropriately it is essential that a relationship between social support and stress exists. Both Cohen & Wills<sup>13</sup> and Alloway & Bebbington<sup>15</sup> provide comprehensive reviews of the literature outlining, in detail, methodological characteristics required for fair evaluation of the model. Cohen & Wills<sup>13</sup> review both the stress-buffering and main-effect models of support, and consider social support measures in terms of a) whether a measure assesses support structure or function and b) the degree or specificity (vs. globality) of the scale. They conclude that studies employing measures assessing support functions which are related to elicited needs (ie. task-specific) are the most appropriate tests of the buffering model of support. In contrast, studies using global support measures best test the main-effect model.

### *The Proposed Buffering Mechanism*

The mechanisms via which social support may moderate stress and consequently affect physical disease have been reviewed.<sup>16</sup> It is suggested that support may operate by preventing or short-circuiting biological and behavioural responses to stress which adversely affect illness. Support may intervene "...between the potentially stressful event (or expectation of that event) and a stress reaction by attenuating or preventing a stress appraisal response...". Alternatively support may mediate "... between the experience of stress and the onset of pathological outcome by reducing or eliminating the affective reaction, by directly dampening physiologic processes, or by altering maladaptive behaviour responses...".<sup>16</sup> This latter group of responses would include behaviours typical of non-compliance with treatment regimens.

Compliance is especially important to consider in relation to ESRD populations since failure to comply with the dialysis regimen has detrimental effects on short- and long-term health.<sup>17</sup> An extensive literature exists on compliance in this population. However, there is a relative paucity of studies directly relating to the potential effect of stress and social support on compliance in this population, which is surprising given the proposed relationship between stress and health-related outcome documented for other medical populations.<sup>16</sup> Prior to evaluating existing literature, compliance in hemodialysis populations will be reviewed with particular emphasis given to methodological considerations.

## **COMPLIANCE & ESRD**

### *Definition*

Compliance has been defined as "...the extent to which an individual chooses behaviour that coincides with a clinical prescription".<sup>18</sup> In accordance with this, Cummings et al.<sup>19</sup> state that, conceptually, compliance includes two aspects ; medical recommendations and behavioural performance, with the latter evaluated in the light of the former. Much of the literature on compliance has concentrated on compliance with prescribed medications. In reviewing this, Morris & Schulz<sup>20</sup> conclude that "...there is very little consistent information available on compliance except that people do not take their medications as prescribed...". Problems with adopted methodology, design flaws and lack of conceptual rigour contribute to inconsistency.

For ESRD populations the recommended treatment regimen is particularly complex and required compliance-behaviour multi-faceted. Behaviours necessary for compliance include : frequent hospital visits (2 or 3 times a week), routine blood samples for biochemical assessment, restriction of fluid and dietary intake and

the taking of multiple-medications, vitamins and supplements. Consequently empirical assessment of compliance and operational definitions employed vary with the particular aspect of compliance studied.

### *Measurement of Compliance*

Measurement of compliance has been undertaken in three ways, using ; i) biochemical measures eg. inter-dialytic weight gain (IWG), serum potassium (serum K) and phosphorous ( $P0_4$ ) levels, ii) self-report measures and iii) staff/other ratings.

Biochemical measures are typically employed as the most objective way to assess compliance.<sup>21-23</sup> The specific biochemical measures employed reflect different aspects of compliance behaviours. Inter-dialytic weight gain (IWG) is used to assess compliance to recommended fluid-intake restrictions, serum potassium (serum K) level is a measure of dietary compliance, and serum phosphorous ( $P0_4$ ) levels indicate how well patients adhere to medication requirements. These biochemical markers, are in themselves however, only indirect measures of compliance behaviour since they may be influenced by factors unrelated to patient non-compliance eg. time when measurement was taken, physical characteristics of the individual,<sup>19</sup> natural recuperative processes,<sup>19</sup> differences in metabolism rates<sup>17</sup> and seasonal variation.<sup>24</sup>

Biochemical measures are predominantly employed as the most valid and reliable indicators of compliance, however, the criteria adopted to interpret obtained data are themselves vulnerable to presupposition and researcher bias. A range of methods have been used to distinguish compliant from non-compliant patients. Cut-off points have been specified, with compliance criteria determined in a number of ways eg. based on medical recommendation guidelines,<sup>23</sup> empirically for a particular patient group<sup>23</sup> or by consultant agreement.<sup>25</sup> Some authors have classified patient compliance into a number of levels eg. excellent to great abuse<sup>26</sup>,

<sup>27</sup> using a composite score of eg. serum K, IWG and blood urea nitrogen (BUN) to do this. Consequently wide variation in non-compliance rates are reported for this group eg. 20-78%<sup>28</sup>. Manley & Sweeney<sup>24</sup> suggest that, since it cannot convincingly been shown that there is a direct correlation between eg. fluid restriction and freedom from medical complications, adopting overly strict compliance criteria may be imposing additional and unnecessary burden on patients. In response to the difficulties inherent in adopting compliance criteria, Ferraro et al.<sup>29</sup> suggest that biochemical indices are used as continuous variables, with higher reported levels indicative of poorer compliance, recommendations which have been adopted in a number of studies.<sup>30</sup>

Self- and staff/other-report measures also serve as indirect measures of compliance for the reasons outlined above.<sup>19</sup> In addition however, they are altogether a more subjective means of assessing compliance and susceptible to individual biases eg. inaccurate recall, perceived social pressure to present as 'good'. Typically, as Wolcott et al.,<sup>31</sup> point out, the measures employed have tended to reflect global qualitative assessment eg. excellent to poor. Quantitative measures "How many days in the last month have you complied with you diet?" have rarely been used. The use of qualitative, rather than quantitative, measures in previous studies may go some way to explaining the minimal consistency reported for compliance on laboratory, self- and staff-report measures.<sup>19,21</sup>

Despite difficulties inherent in measurement of compliance a number of consistent findings are reported for hemodialysis patients. Typically patient's level of compliance is stable across time<sup>32</sup> with initial level of compliance established within the first 4-6 months.<sup>25, 26</sup> Differences exist in reported levels of compliance for separate components of the dialysis regimen ie. diet, fluid and medication.<sup>23</sup> Therefore, whilst compliance may be relatively stable across time, individuals may be complaint with some aspects of the regimen and not others.

To summarise, compliance is a multidimensional process,<sup>33</sup> which needs to be appropriately reflected in the range and type of assessment measures employed. Ideally biochemical and self/other-report indices of compliance should be utilised concurrently with, where possible, both qualitative and quantitative aspects assessed.

### *Variables Investigated in Relation to Compliance in ESRD*

Aside from methodological and definition considerations, a number of variables have been proposed as determinants of compliance in ESRD populations, including social support which is considered in more detail below. Sociodemographic variables studied include age,<sup>34, 35</sup> sex,<sup>32, 36</sup> education,<sup>37</sup> marital status,<sup>38</sup> and employment status.<sup>36</sup> Dialysis-related variables include time on dialysis<sup>38,39</sup> and transplant history.<sup>21</sup> Situational variables have included forgetting medication,<sup>40</sup> being away from home<sup>40</sup> and special meal preparation.<sup>21</sup> Psychological variables have included eg. locus of control,<sup>38,41</sup> depression,<sup>9</sup> denial,<sup>42</sup> health beliefs and values,<sup>21</sup> self- and other- expectations,<sup>41,43</sup> knowledge base,<sup>44,45</sup> feelings about illness,<sup>46</sup> personality factors,<sup>26</sup> and frustration tolerance.<sup>45</sup> Family and staff variables eg. impact of illness,<sup>21</sup> communication<sup>47</sup> and interactions<sup>48</sup> have also been considered. (For comprehensive reviews see<sup>18, 31, 40</sup>).

On the whole, evidence for the effect of these variables on compliance is equivocal which, at least in part, probably reflects lack of methodological consistency across studies. The relationship of social support to compliance in ESRD populations is next considered in detail.

## **SOCIAL SUPPORT AND COMPLIANCE IN ESRD**

Whilst there is a sizeable literature on compliance within ESRD populations, the relationship of social support to this has been studied relatively infrequently.

Evidence for a significant positive relationship between compliance and social support has been documented by some authors employing global measures of support. Sherwood<sup>50</sup> for instance, reported that compliance with the prescribed regimen was associated with a supportive and understanding family. Similarly, O'Brien<sup>43</sup> studied a group of patients over a 9 year period and reported that variation in level of support (assessed in terms of primary and secondary support systems eg. family and staff) was associated with differences in compliance on a self-report measure ie. those with more support reported better compliance. Christensen et al.,<sup>51</sup> similarly using a global measure of support, however, reported differential findings for different aspects of the dialysis regimen. Using IWG to assess compliance to fluid restrictions and serum K to measure dietary compliance, individuals holding perceptions of most supportive environments complied better with fluid restrictions. The relationship was not however, substantiated for dietary restrictions.

A number of studies employ measures of support specifically related to the ESRD regimen. Again findings are mixed. A positive relationship between family support and self-report (but not biochemical) measures of compliance has been found.<sup>38</sup> Similarly Boyer et al.<sup>52</sup> used a number of methods to assess ESRD-related support : self-, family- and staff- reports. Social support was significantly related to compliance indicated by serum potassium and phosphorous levels and blood urea nitrogen (BUN). However, prediction of compliance disappeared when demographic and situational variables were controlled for. In contrast, Cummings et al.<sup>21</sup> reported no relationship between biochemical indices of compliance and level of ESRD-related support. However, patients' perceptions that their illness



affected their family lives were found to be significantly related to the self-report measures of compliance. Individuals who perceived more interference to their family reported less compliance

One study using both global and specific indices of support reported differential relationships with self-reported compliance (assessed as a composite measure).<sup>7</sup> Support was divided into an 'Affection' factor - a measure of physical and verbal expressions of caring (global), and a 'Directive Guidance' factor - an indicator of task-related support eg. information and feedback relating to the regimen (specific). Compliance was only associated with presence of task-related support.

In addition to these studies, social support has been employed in interventions aimed at improving compliance.<sup>53</sup> Hegel et al.<sup>54</sup> found positive reinforcement and behavioural techniques were associated with long and short-term improvements in fluid compliance. Staff praise for compliance behaviours has also been associated with improved fluid compliance in case studies.<sup>55,56</sup> There are limitations in the interpretation of intervention studies however, due to the small sample sizes and simultaneous use of components.

To summarise, findings relating to social support and compliance in the ESRD literature are inconsistent with regard to differences in types of assessments and aspects of behaviour evaluated by compliance measures. There does however appear to be some evidence that presence of social support, using both global and task-specific measures, is associated with compliance, particularly for self-report measures. At present however, empirical data is limited and therefore difficulties in extrapolating from the reported findings persist.

## **SOCIAL SUPPORT AND COMPLIANCE IN RELATION TO THE BUFFERING HYPOTHESIS**

Despite the complex and arduous nature of the hemodialysis treatment regimen, there is a paucity of literature investigating the effect of stress in this population, particularly with regard to its effect on compliance.<sup>17</sup> This appears surprising given the proposed relationship between stress and health-related behaviours found in other medical populations (see Cohen<sup>16</sup>). Consequently, investigation of support has rarely been investigated in terms of its effect on compliance specifically within the context of the stress-buffering hypothesis. The model itself, has, however, been evaluated in relation to other outcome variables eg. depression,<sup>3,9,57</sup> anxiety,<sup>3,57</sup> social introversion<sup>3</sup> and self-deprecation.<sup>3</sup>

The author is aware of only two studies which directly set out to test the stress-buffering model of social support in terms of compliance-related outcome.<sup>17,51</sup> Again findings are equivocal. Christensen et al.<sup>51</sup> found that patients holding perceptions of a more supportive family environment, using the Family Environment Scale,<sup>58</sup> exhibit significantly more favourable adherence to fluid-intake, but not dietary, restrictions on biochemical measures of compliance. The effect of support on adherence was not however, moderated by stress (measured using the Sickness Impact Profile).<sup>59</sup> The results obtained support a main-effect model of social support. As a test of the stress-buffering model however, the study is open to criticism as the authors themselves highlight. The SIP, a measure of stress-related physical impairment, differs from measures typically used to test the buffering model ie. life events or daily hassles measures.

Hitchcock et al.'s study,<sup>17</sup> employed more conventional measures of stress ie. Schedule of Recent Events<sup>60</sup> and Weekly Stress Inventory.<sup>61</sup> Social support was assessed using the Social Support Questionnaire-Short Form<sup>62</sup> which has reported good validity and reliability. Biochemical measures ie. serum K and BUN

were assessed at two points; 2 weeks prior to and after assessment. Neither social support nor life events predicted compliance in this study. Minor stress was, however, predictive of change in dietary compliance. Since there was no interaction between social support and minor stress, the buffering hypothesis could not be tested. From the findings, the authors conclude that minor stress may affect the health of hemodialysis patients by affecting compliance behaviours. There was no evidence to support either a buffering or main-effect model of social support.

As tests of the buffering hypothesis the use of global, rather than task-specific, support measures, as Cohen & Wills<sup>13</sup> highlight, make it more probable that the non-significant findings reported in these two studies would be found. There has been no previous evaluation of the buffering model and compliance-related outcome using task-specific support measures. Future research would benefit from employing a number of support measures ie. global and specific to assess more effectively the buffering hypothesis. Furthermore, given the inconsistent relationship reported between different measures of compliance, multiple assessment methods ie. biochemical and self-report measures which assess quantitative aspects of compliance behaviour, should also be employed in order to facilitate comparison and consistency of data between studies.

## **CONCLUSIONS**

There is evidence that social support plays an important role in effecting health-related behaviours in medical populations by mediating stress-reponses. Despite this, studies investigating the relationship between support and compliance in ESRD populations are scarce. Available evidence does, however, provide some indication that support may be beneficial to compliance, though lack of consistency in definitions and measures utilised means that extrapolation from studies is problematic. It is suggested that future studies improve on these methodological

considerations, particularly in relation to the stress-buffering model of support, which has rarely been considered within this context.

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# **RESEARCH PROPOSAL**

**Title : COMPLIANCE : EFFECTS OF STRESS AND SOCIAL SUPPORT  
WITHIN A HEMODIALYSIS POPULATION.**

**Applicant : SUSAN RAMSAY, DEPARTMENT OF PSYCHOLOGICAL  
MEDICINE, UNIVERSITY OF GLASGOW**

## **RESEARCH PROPOSAL**

**Applicant : Susan Ramsay, Department of Psychological Medicine, University of Glasgow.**

**Supervisor : Christine Puckering.**

**Project Title : Compliance : Effects of Stress and Social Support within a Hemodialysis Population.**

### **SUMMARY**

The proposed study aims to investigate relationships between stress, social support and compliance in a group of hemodialysis patients attending the Renal Unit at Stobhill Hospital. It is intended that patients with End-Stage Renal Disease (ESRD), meeting exclusion criteria, will be interviewed whilst attending for routine treatment. Compliance will be assessed in terms of adherence to dietary, fluid and medication components of the dialysis regimen, using biochemical and self-report indices. Stress and social support variables will similarly be assessed using multiple measures to improve on methodological considerations of previous studies.

In particular the project aims to answer a number of questions which will ultimately determine overall rates of compliance within this population and identify individuals particularly at risk of poor compliance. It is expected that, in investigating the relationship between support and stress, the study will identify ways in which staff and family members in regular contact with patients can best support and encourage compliance to the dialysis regimen. Consequently, the detrimental short- and long-term effects on health, associated with non-compliance, may be avoided and unnecessary hospital admissions prevented.

## INTRODUCTION

Chronic renal failure, or End-Stage Renal Disease (ESRD), occurs when the kidneys lose the capacity to maintain the volume, composition and distribution of body fluids essential for physical well-being. Once this occurs, individuals must either receive a kidney transplant or begin dialysis, a lifelong maintenance therapy, to survive.

Increased mortality rates are reported for ESRD patients receiving hemodialysis therapy who are non-compliant with the recommended treatment regimen.<sup>1</sup> Generally compliance within this group is poor<sup>2</sup> with failure to follow prescribed dietary, fluid and medicinal routines resulting in short and long-term deterioration in health, and, for some, frequent hospital admissions. The regimen itself is complex, multifaceted and demanding. Additional limitations in physical functioning contribute to patients experiencing ESRD as a chronically stressful medical condition.<sup>3</sup> Despite this, there is a paucity of studies investigating the effect of stress within this population in general, and specifically in relation to compliance.

Compliance with the dialysis regimen has itself been investigated in relation to a number of background variables. Of particular interest is the finding that patients reporting presence of a supportive environment tend to comply better with aspects of the prescribed regimen.<sup>4</sup> Support may influence compliance by mediating stress responses, an hypothesis espoused by the Stress-Buffering model of social support.<sup>5</sup> Whilst there is evidence supporting this model within the general health literature,<sup>6</sup> the model and proposed mechanism have rarely been investigated within hemodialysis populations, despite obvious relevance to health-related outcomes.

The author is aware of only two studies evaluating the effects of stress and social support in relation to compliance.<sup>7,8</sup> Obtained results are mixed. Between the studies both social support and stress were shown to have significant but independent relationships with indices of compliance. Presence of support was

related to better adherence to fluid restrictions<sup>7</sup> and stress significantly predicted changes in dietary compliance, with greater degree of minor stress associated with poorer compliance.<sup>8</sup>

It has been proposed that support matching elicited needs ie. task-specific support is most appropriate for evaluations of the Stress-Buffering model.<sup>5</sup> Studies described above however, fail to employ such measures. Given the demanding and complex nature of the treatment regimen, social support may need to be more practically orientated in order to decrease perceived or actual stress associated with complying with the regimen. The present study aims to improve on previous research by employing a number of measures of social support, global and task-specific, with the aim of identifying specific types of support which appear to most consistently affect compliance, either independent of, or through an interaction with stress. In doing so it may be possible to suggest ways of improving compliance by advising others, ie. staff and family members, of the best ways to support and encourage compliance-related behaviour.

## **STUDY AIMS**

This study proposes to investigate the proposed Stress-Buffering model of social support in terms of effects on compliance-related outcome in a group of hemodialysis patients. In particular to answer the questions

- does social support have a beneficial effect on compliance to the dialysis regimen, ie. diet, fluid and medication components, irrespective of the level of stress patients report experiencing?
- if so, which aspects of support, global or task-specific, are most consistently associated with compliance?
- does stress affect compliance to components of the dialysis regimen?

- if so, which types of stress, ie. hemodialysis-related or life-events, affect compliance?
- what is the current level of compliance to dietary, fluid and medication recommendations, measured by self-report and biochemical indices, for this group as a whole?

## **PLAN OF INVESTIGATION**

### **Subjects**

It is intended that patients attending the Renal Unit at Stobhill Hospital for routine hemodialysis treatment will act as the subject population. It is estimated that approximately 70 participants will be available for interview once exclusion criteria have been employed. Patients with i) significant urinary output ie. daily urine output of 50cc or more, ii) a dialysis history of less than 4 months, iii) younger than 18 years of age, and iii) who exhibit difficulties in communication ie. poor command of English, will be excluded from the study.

### **Measures**

#### ***Support Measures***

##### ***Social Support Questionnaire (SSQ-Short Form)***<sup>9</sup>

Reviews suggest that the SSQ provides a valid and comprehensive assessment of support.<sup>10</sup> Two different aspects of support, ie. perceived number (SSQNo) and satisfaction (SSQSat), are assessed by this measure. Both indices, obtained from responses on 6 questions, will be utilised.

##### ***Dialysis Regimen Support Scale (DRSS)***

It is intended that this quantitative measure will assess frequency of task-specific support, ie. support theorised to be beneficial to complying with a dialysis regimen. The measure will be developed in the course of the study in consultation with

members of the Renal Unit team and clinical psychologists working in this area. Primarily the measure will be based on evidence from critical review of relevant literature. The measure will be piloted prior to inclusion in the main study.

### ***Stress Measures***

#### ***Life Experiences Survey***<sup>11</sup>

The Life Experiences Survey (LES) will be used to assess impact of life events on individuals for the previous year. It is traditionally employed as a measure of stress in evaluations of the buffering model.

#### ***Hemodialysis Stressor Scale***<sup>12</sup>

The Hemodialysis Stressor Scale (HSS) is a 29-item scale which measures the incidence and severity of hemodialysis-related stress. Evidence for reliability and validity are reported by the authors<sup>12</sup> and elsewhere.<sup>13</sup>

### ***Measures of Compliance***

#### ***Biochemical Measures***

Biochemical measures are typically employed as the most objective means of assessing compliance.<sup>14</sup> Compliance with fluid restrictions will be assessed using interdialytic weight gain (IWG). Dietary adherence will be measured via blood potassium levels (Serum K) and medication compliance via levels of serum phosphorous (PO<sub>4</sub>). To obtain a reliable estimate of compliance, biochemical data will be averaged over dialysis sessions for the three months preceding interview, with data collected from medical records following completion of all interviews.

#### ***Self-Reported Compliance Questionnaire (SRCQ)***

Self-reported compliance with regimen components will be assessed quantitatively. Participants will be required to indicate the total number of days on which they complied with dietary (SRCDiet), fluid (SRCFluid) and medication (SRCMed)



requirements for the previous week. Perceived difficulty with compliance will also be assessed, again, for individual components : SRDDiet, SRDFluid and SRDMed.

### ***Supplementary Measures***

Affective symptomatology and disease severity have been identified as potential confounding factors and therefore need to be assessed. Affective symptomatology will be measured using the Hospital Anxiety and Depression Scale.<sup>15</sup> Disease severity will be assessed using the End-Stage Renal Disease Severity Index (ESRD-SI).<sup>16</sup> This will be completed by two independent raters (qualified medical staff) to ensure reliability.

### **Design & Procedure**

Subjects will be approached whilst attending the Unit for routine hemodialysis. Participants will be given a brief resume of the purpose of the study and asked to give written consent to the effect that relevant biochemical data may be obtained from their medical files. Data will be collected via individual interview, with randomised presentation of questionnaires to control for potential order effects. All interviews will be conducted by the named proposer and subjects assured of the confidentiality of their responses.

It is proposed that a small pilot study will be undertaken to assess for any methodological difficulties and to evaluate administration of identified questionnaires prior to commencing the major project. 8 participants will act as the pilot group. Whilst this may be a small sample, the administrator will be present throughout all interviews and immediately aware of methodological difficulties arising. It is initially estimated that the time required for interviews will be approximately 45 minutes.

In order to evaluate the effect of social support on stress within the context of the stress-buffering model, it is necessary to compare groups with different levels of these attributes ie. with high and low levels of stress and support, and to assess for differences in compliance between these groups. Comparison groups will be obtained from within the total subject population. Responses on stress and social support measures will be categorised into groups, classified as high and low on these variables, consequently yielding a 2x2 (Stress X Social Support) matrix. Comparisons between these groups will then be made for compliance-related outcomes on self-report and biochemical indices of dietary, fluid and medication-related components. Relationship between compliance measures will be studied and level of compliance for the population obtained.

### **Setting**

Participants will be interviewed whilst undergoing dialysis in order to limit interference into their lives already dominated by ESRD.

### **Data Analysis**

Data will be stored and analysed using SPSS for Windows. Statistical procedures commonly employed to test the buffering hypothesis model of social support have been evaluated by Cohen & Wills.<sup>5</sup> 2-Way ANOVA's will be employed as the main statistical procedure to evaluate the effect of support on stress within the 2x2 matrix. This will be undertaken once appropriate exploratory analysis has been completed. In investigating potential relationships between measures of social support, stress and compliance, correlational methods, ie. Pearson's product-moment correlations, will be employed.

## **STUDY IMPLICATIONS**

The results of the study will allow identification of variables associated with compliance and non-compliance to components of the dialysis regimen for this group. Subsequently, service providers will be able to target interventions aimed at improving compliance towards high risk patient groups. In doing so, deterioration in health associated with non-compliance might be avoided, subsequently preventing unnecessary hospital admissions.

Identification of measures which best highlight at risk populations will be determined in the course of the study. If social support measures are differentially related to compliance then it will be possible to suggest ways of encouraging compliance within this group, particularly if task-related support is implicated. The information gathered may then be used to advise and educate staff and family members of the best way to support ESRD patients in order to improve compliance.

## **TIMESCALE**

It is intended that data collection will begin in July, 1994. Interviewing within the unit is estimated to take approximately 4 months, depending on number of consenting patients. Collation and analysis of data will follow. Research findings will be written-up in a format appropriate for submission to 'Behavioral Medicine' and completed by August, 1995. Feedback to the Unit will take place in September. All participants will receive an individual summary of the research findings.

## **ETHICAL APPROVAL**

Potential subjects will be approached whilst attending the Unit. Those willing will be required to complete a consent form to allow biochemical data to be gathered from their medical records. Given that individual informed consent is

implicit and measures used non-intrusive, ethical approval is judged to be unnecessary. The research proposal is supported and approved by Renal Consultants working within the Unit.

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# **RESEARCH PAPER**

**Title : COMPLIANCE : EFFECTS OF STRESS AND SOCIAL SUPPORT  
WITHIN A HEMODIALYSIS POPULATION.**

**Applicant : SUSAN RAMSAY, DEPARTMENT OF PSYCHOLOGICAL  
MEDICINE, UNIVERSITY OF GLASGOW**

**Targeted Journal : Behavioral Medicine**

## **COMPLIANCE : EFFECTS OF STRESS AND SOCIAL SUPPORT WITHIN A HEMODIALYSIS POPULATION**

### **Abstract**

The present study examined the effects of social support and stress in relation to compliance within a group of 70 End-Stage Renal Disease (ESRD) patients attending for hospital hemodialysis. Measures assessed i) global and regimen-related support, ii) stress related to life events and specific to hemodialysis, and iii) biochemical and self-reported compliance to dietary, fluid and medication recommendations. Higher levels of regimen-related support were associated with better compliance on biochemical indices ie. lower blood potassium and phosphorous levels. The relationship was not present for indices of fluid compliance however. No effect of stress on compliance was found. Overall, the results support a main-effect, rather than stress-buffering model of social support.

**Key Words : Social Support, Stress, Compliance, ESRD**

## INTRODUCTION

Increased morbidity and mortality rates are reported for End-Stage renal disease (ESRD) patients receiving hemodialysis therapy who are non-compliant with the recommended treatment regimen.<sup>1</sup> Treatment requires that patients follow a complex, multifaceted and demanding regimen which includes strict adherence to dietary, fluid and medicinal routines. Approximately one third of patients comply with fluid and dietary components of the regimen,<sup>2</sup> and similar figures are reported for compliance with medications in general.<sup>3</sup> Wide variation in compliance is evident however, with between 20-78% of patients rated as non-compliant.<sup>4</sup>

Social support is seen to have an important role in effecting health and health related behaviours in medical populations, with presence of support typically associated with better outcome.<sup>5</sup> This relationship is similarly reported for ESRD populations where lower rates of anxiety,<sup>6</sup> depression,<sup>7</sup> suicide<sup>8</sup> and mortality<sup>9</sup> are related to the presence of a supportive environment.

The relationship of social support to compliance in ESRD populations has been studied relatively infrequently. Available literature has however, been reviewed in detail elsewhere.<sup>10</sup> Generally, evidence appears inconsistent with respect to differences in both the type of measure (ie. biochemical or self report), and the facet of compliance-related behaviour (ie. diet, fluid or medication) assessed. Furthermore, differences in operational definitions, measures and facets of support utilised across studies, make interpretation of findings difficult. Difficulties further compounded by psychometric inadequacy of some social support measures.<sup>10</sup> Nonetheless, there is some evidence that presence of social support, using both global and task-specific measures, is associated with compliance in this group, particularly for self-report measures.<sup>11-14</sup>



In accounting for the relationship between social support and outcome, the Stress-Buffering model proposes that the beneficial effects of support are due to the tendency of support to 'buffer' an individual against the deleterious effects of stress. In this model, the effect of support is proposed to be most evident when individuals experience high levels of stress.<sup>15</sup> A variety of mechanisms have been proposed to account for the effect. Amongst these, support is hypothesised to mediate stress by altering maladaptive behavioural responses. Responses which include health-related practices and behaviours associated with non-compliance to treatment regimens.<sup>16</sup>

Despite the arduous medical regimen, physical limitations and interference with daily routines experienced by ESRD patients, there is a paucity of literature investigating the effect of stress in this population, particularly with regard to its effect on compliance. This appears surprising given the proposed relationship between stress and health-related behaviour found in other medical populations.<sup>16</sup> Consequently, investigation of support in relation to the stress-buffering model has rarely been investigated, though the model has itself been evaluated in relation to other outcome variables eg. depression,<sup>6</sup> anxiety<sup>17</sup>

The author is aware of only two previous studies which directly set out to test the stress-buffering model of support in relation to compliance<sup>17,18</sup>. In the latter study, lack of interaction between stress and support determined that the model could not be tested. However, minor stress, assessed using the Weekly Stress Inventory,<sup>19</sup> did predict change in dietary compliance. This relationship was not replicated for stress related to life events. In Christensen's study there was no effect of support on stress-related physical impairment. However, a main-effect for social support was reported, with higher levels of support associated with better compliance.

The present investigation was developed in order to examine the effects of social support on stress and compliance within a group of hemodialysis patients. Jung<sup>20</sup> found that compliance amongst a group of hypertensives was best predicted by health-specific, rather than global measures of social support. There is, at present, equivocal evidence for a relationship between regimen-related support and compliance within ESRD populations, dependent on the type of compliance measure utilised. No previous evaluations of the stress-buffering model have used task-specific support measures within this context.

The present study therefore aimed to assess the impact of a number of types of support (number, satisfaction and task-specific), and stress (hemodialysis-related and life events), on compliance within this group. In addition, given the reported variety in evidence associated with types of measures employed, the study also aimed to improve on previous research by utilising multiple assessment methods. Both biochemical and self-report indices of compliance were employed, with self-reported compliance assessed quantitatively.<sup>1</sup>

## **METHOD**

### **Subjects**

Patients were recruited from a hospital hemodialysis population during routine attendance for treatment. 70 participants were interviewed during dialysis to limit interference into their lives already dominated by ESRD. Exclusion criteria included i) significant urinary output ie. daily urine output of 50cc or more, ii) a dialysis history of less than 4 months, ii) younger than 18 years of age and iii) difficulty in communication ie. poor command of English. Table 1 summarises relevant demographic and clinical characteristics. The mean age of the group was 55.2 years.

## **Measures**

### ***Support Measures***

#### *Social Support Questionnaire (SSQ-Short Form)*<sup>21</sup>

This global measure assesses two different aspects of support i) perceived number (SSQNo) and ii) satisfaction (SSQSat). Both indices, obtained from responses on 6 questions, were utilised, with higher total scores indicative of more support. Reviews of the SSQ<sup>10,21</sup> suggest that it provides a valid and comprehensive assessment of support. Internal reliabilities for the short version of the SSQ are .93 and .90 for SSQSat and SSQNo respectively.

#### *Dialysis Regimen Support Scale (DRSS)* (See Appendix A for details of development)

This quantitative measure assesses frequency of task-specific, ie. regimen-related support. Respondents were required to rate on a 5 point Likert-like scale the frequency with which others engaged in behaviours theorised to be supportive to compliance with a dialysis regimen eg. 'How often do others prepare meals for you according to your diet?' 'How often do others remind you to take your medication?'. By 'Others', this referred to friends, family members or people specifically connected with treatment ie. renal unit staff. Responses on the 14 questions were summed to produce the total DRSS score. Possible total scores ranged from 0 - 56, with higher total scores indicative of more support.

### ***Stress Measures***

#### *Life Experiences Survey*<sup>22</sup>

In contrast to other measures of life events<sup>23</sup> the Life Experiences Survey (LES) requires that individual's make their own evaluations of the extent to which life events, occurring within the preceding 12 months, made either a positive

or negative impact on their lives at the time of occurrence. The total change score, obtained by totalling positive and negative subscores, was calculated for each participant. Higher scores are indicative of greater impact.

### *Hemodialysis Stressor Scale*<sup>25</sup>

There is a paucity of scales available to evaluate treatment- and health-related stress in ESRD populations. One exception is the Hemodialysis Stressor Scale. Ratings on this 29-item scale are based on the incidence and severity of stressors specifically associated with hemodialysis treatment. Higher total scores again reflect a greater degree of dialysis related stress. Evidence for reliability and validity are reported elsewhere.<sup>24,25</sup>

## *Measures of Compliance*

### *Biochemical Measures*

Biochemical measures are typically employed as the most objective means of assessing compliance.<sup>26</sup> Adherence to recommended fluid restrictions are commonly assessed using interdialytic weight gain (IWG), markers of dietary adherence are reflected in blood potassium levels (Serum K) and levels of phosphorous ( $\text{PO}_4$ ) employed as indicators of medication compliance.<sup>9</sup> To obtain a reliable estimate of compliance, biochemical data was averaged over dialysis sessions for the three months preceding interview. Data was collected from patient's medical records following completion of all interviews. Given the documented problems inherent in categorising biochemical markers, blood chemistry parameters were used as continuous, rather than categorical, variables.<sup>27</sup> Poorer compliance is indicated by higher scores on the three indices. Commonly, IWG of above 1.5kg, Serum K above 6.0mmol/l and  $\text{PO}_4$  above 2.0mmol/l are used as parameters to highlight problematic adherence.<sup>1</sup>

### *Self-Reported Compliance Questionnaire (SRCQ)*

Self-reported compliance with regimen components was assessed quantitatively. Participants were required to indicate the number of days on which they had complied with dietary (SRCDiet), fluid (SRCFluid), and medication (SRCMed) requirements in the previous week. Higher scores therefore indicate better compliance. Perceived difficulty with compliance was also assessed again, for individual components : SRDDiet, SRDFluid and SRDMed respectively. Difficulty ratings were made on 5 point Likert-like scales ranging from 1(Not at all difficult) to 5 (Impossible).

### *Supplementary Measures*

In order to control for potential confounding effects affective symptomatology and disease severity were also assessed. Affective symptomatology was measured using the Hospital Anxiety and Depression Scale.<sup>29</sup> Disease severity was measured by the End-Stage Renal Disease Severity Index (ESRD-SI).<sup>30</sup> Two independent raters completed this measure for each participant. Good inter-rater reliabilites were obtained ( $r = .95, p < .0005$ ) (See Appendix A, Figure 2). Based on these separate ratings, mean ESRD-SI scores were calculated for each participant, and used in all subsequent analysis.

## **RESULTS**

Based on median scores, responses on stress (HSS and LES) and social support measures (SSQNo and SSQSat) were categorised into high and low groupings. DRSS responses were similarly categorised utilising the presenting bimodal distribution (Appendix A, Fig.1).

Biochemical data ; IWG, Serum K and Serum  $PO_4$ , was summarised to obtain group means. These were 1.81kg, 5.01 mmol/l and 1.72 mmol/l

respectively. On SRC measures, total compliance, ie. 7 days, was reported by 30% of patients for fluid restrictions, 35.7% for dietary restrictions and 88% for prescribed medications. These figures increased to 37.1%, 52.8% and 90.0% respectively when compliance was determined as adherence to regimen recommendations on 6 days or more. Pearson product-moment correlations were employed to assess for relationship between measures (biochemical and self-reported) and components of compliance (fluid, food and medication). Table 2 shows the results presented as a correlation matrix. The significant relationships between measures support their use as valid indicators of compliance.

Relationship between reported difficulty and measures of compliance were also investigated using correlations. (Results are presented in Tables 2-4 of Appendix A). Modal difficulty ratings were : 4(Very Difficult) for fluid restrictions, 2(Mildly Difficulty) for dietary restrictions and 1(Not at All Difficult) for medication requirements of the regimen. Individuals found most difficulty complying with fluid restrictions.

Significant relationships between background variables and compliance were evident for only two measures : age and time on dialysis. These variables were subsequently controlled in later analysis. Using Pearson's product moment correlations, age correlated negatively with two of the three self-report measures : IWG ( $r = -.32, p < .01$ ) and  $P0_4$  ( $r = -.39, p < .005$ ). A positive relationship for age was also evident on SRC measures : SRCDiet ( $r = .46, p < .0005$ ), SRCFluid ( $r = .58, p < .0005$ ) and SRCMed ( $r = .43, p < .0005$ ). Both biochemical and self-report indices suggest that poorer compliance is associated with increased age. Length of time on dialysis also showed a significant relationship with Serum K levels ( $r = .25, p < .05$ ), with higher, and therefore poorer outcome on the Serum K marker associated with a longer dialysis history.

In terms of stress, total group scores on the LES showed no relationship with any measure of compliance (see Appendix A Figs. 3 & 4). HSS scores for the whole group were significantly related to SRCFluid ( $r = -.27, p < .05$ ) and approaching significance for SRCMed at the 10% level. In addition HSS was significantly associated with SRD scores : SRDDiet ( $r = .30, p < .05$ ), SRDFfluid ( $r = .25, p < .05$ ) and SRDMed ( $r = .21, p < .10$ ). Consequently, HSS, but not LES, scores were utilised to evaluate the buffering model of support.

2-Way ANOVA's were performed to assess for the effect of social support on hemodialysis related stress (HSS), using groups high and low in each attribute. Small sample sizes within some cells however, determined that the model could be evaluated only tentatively (See Appendix A, Figs. 5-7). Available results show main effects were evident for DRSS with biochemical indices of compliance: Serum K [ $F(1, 64) = 5.11, p < .05$ ] and  $PO_4$  [ $F(1, 62) = 4.41, p < .05$ ]. Where higher levels of regimen-related support were present, lower blood potassium and phosphorous levels were evident. These results suggest that better compliance with dietary and medicinal recommendations is associated with presence of higher levels of regimen-related support. Similarly, a main effect for SSQNo with SRCDiet was obtained [ $F(1, 68) = 7.78, p < .01$ ]. Patients in the high support group reported complying with their dietary requirements on a significantly greater number of days compared to those in the low support group. Relevant group means and standard deviations are shown in Table 3, with the effects depicted graphically in Figures 1-3.

## **DISCUSSION**

The present results suggest that social support is an important correlate of compliance for hemodialysis populations, affirming a main-effect, rather than stress-buffering, model of support. Presence of support was seen to have a salutary

effect on compliance independent of level of stress experienced since no interaction between stress and support was evident. Once the effects of age and time on dialysis had been controlled, individuals with more regimen-related support were seen to have lower blood potassium and phosphorous levels, and those typically describing a larger number of available supports, reported better compliance with dietary requirements.

The beneficial effect of support was not however, replicated for indices of fluid compliance. Prescribed fluid-restrictions are perhaps the most difficult aspect of the dialysis regimen to comply with,<sup>31</sup> and certainly, self-reported levels of compliance with individual regimen components within the present study support this. Reviews of the literature suggest that compliance is multi-determined,<sup>32</sup> and authors have suggested that other factors eg. personality characteristics, for instance, frustration tolerance and delay of gratification,<sup>31</sup> are particularly important as determinants of compliance to fluid-restrictions. Whilst presence of support may, of itself, be sufficient in encouraging dietary and medication adherence, it may be that other factors are more pertinent for compliance to fluid recommendations.

Alternatively, differences between biochemical markers ie. IWG, Serum K and  $PO_4$ , in terms of their reliabilities as indices of compliance, are also important to consider in this respect. Some authors suggest that whilst inter-dialytic weight, blood potassium and phosphorous levels are all physiological endpoints of compliance behaviours, and consequently susceptible to extraneous influences (see review),<sup>9</sup> IWG is a more direct reflection of the patient's own behaviour since the last dialysis session, and perhaps, therefore, more reliable as an index of compliance. In the light of this it may be argued that the main-effect of support found for dietary and medication recommendations is simply an artefact of the biochemical measures employed, (and certainly there is some overlap between serum K and  $PO_4$  as markers).<sup>14</sup> However, interventions manipulating regimen-



related support (similar to that assessed by the DRSS) provide some evidence that this is not the case, since fluid-compliance is seen to improve when higher levels of support are provided.<sup>33,34</sup>

In considering the utility of support measures in relation to compliance-related outcome, main-effects were evident on quantitative, but not qualitative, measures of support. The absence of a significant relationship between individual's satisfaction with support and compliance replicates other studies, utilising the SSQSat as the main index of support.<sup>18</sup> The current findings provide some support for the hypothesis that task-specific, rather than global aspects of support, are most consistently associated with improvements in compliance. As other authors suggest, regimen-related support does appear to meet patients' elicited needs most appropriately.<sup>15,20</sup>

Whilst generally, research findings suggest that presence of regimen-related support has a beneficial effect on compliance,<sup>9</sup> the documented findings are mixed with respect to the type of compliance indices utilised ie. biochemical or self-report. In the present study, the effect of regimen-related support on compliance was evident for biochemical (serum K and  $PO_4$ ), but not self-report, measures. Similar results have been documented elsewhere for a composite biochemical measure<sup>13</sup> and also when comparable data has been reported (though the effect of regimen-related support was not significant when demographic and situational variables were controlled in the latter study).

In terms of the other quantitative measure of support, the SSQNo., the network measure, results appear less convincing. The effect of this type of support was evident only with self-report measures, and then only for dietary compliance. Whilst significant relationships between biochemical and self-report indices exist, biochemical measures are perhaps the most salient and objective index of compliance since morbidity associated with poor compliance is most likely to be

reliably identified on these physiological indices. Given the significant relationships between biochemical indices and task-specific support reported, it appears that the DRSS may be a useful indicator of compliance-related support, at least for dietary and medication aspects of the regimen.

Within the present study no main-effect of hemodialysis-related stress on compliance was evident. However, it is perhaps premature to exclude stress as an important variable in determining compliance on this basis. Previous studies have documented a significant relationship between minor stress and changes in dietary compliance when more conventional measures eg. weekly stress inventory, have been employed to assess stress. Differences in measures utilised then, may account for the present findings. Certainly other authors using health-related measures have similarly failed to find significant effects.<sup>17</sup> It may be that minor stress unrelated to ESRD, interrupts typical daily routines, consequently interfering with patterns of behaviour necessary to ensure compliance to the hemodialysis regimen.

It is also interesting that stress associated with impact of life events did not correlate with any indices of compliance. This may, in part, be explained by lack of consistency between the time periods assessed by measures employed. Whilst life-events were assessed for the previous year, biochemical data was gathered over the preceding three months and self-report indicated compliance within the last seven days. The lack of a significant relationship between life events and compliance found in the present study does, however, replicate findings reported elsewhere,<sup>18</sup> although comparable methodological constraints were similarly identified.

Despite lack of main-effects for stress and compliance, the present study provides tentative evidence to suggest that stress may have a role to play in effecting compliance, such that future research evaluating the relationships between these variables appears warranted. The present results suggest a relationship

between hemodialysis-related stress and self-reported fluid compliance may exist, although the effect was not significant once demographic and clinical variables were controlled. Whilst overall sample size was relatively large for research within a hemodialysis populations,<sup>27</sup> small sample sizes for some aspects of the evaluation may, at least in part, account for these findings. It may be that stress is salient, particularly as a determinant of fluid-compliance, when short-term fluctuations in stress are considered. Previous research has not evaluated the relationship of fluid compliance to stress using measures sensitive to transient fluctuations in stress. Research evaluating this relationship in more detail is needed. Studies comparing a variety of types of stress eg. health-related, global, transient, stable, across regimen components, might provide insight into the most salient stressors affecting compliance to dietary, fluid and medication facets of the treatment regimen .

## **CONCLUSIONS**

The present study provides some support for a main effect model of social support in relation to dietary and medication compliance within an ESRD population. It may be suggested that absence of a similar relationship with indices of fluid compliance reflects either, inadequate assessment of relevant support or the fact that other variables are more important as determinants of fluid compliance. Stress may act as one such variable. A paucity of studies evaluating the effect of stress within this population however, means that interpretation of the present findings can only be somewhat tentative. Further research is necessary in order to ascertain which types of stress, if any, show consistent relationships with compliance to components of the dialysis regimen, so that, in turn, the most appropriate means of support can be identified, and provided by those in regular contact with ESRD patients.

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**Table 1 : Demographic and Clinical Characteristics of the Hemodialysis Population**

	<i>N</i>	<i>%</i>
<b>Sex</b>		
Male	49	70
Female	21	30
<b>Marital Status</b>		
Married	32	45.7
Single	18	25.7
Disrupted marriage	20	28.6
<b>Education</b>		
School Leaver	50	71.4
College	15	21.4
Graduate	4	5.7
Other	1	1.4
<b>Occupational Status</b>		
Unemployed (Medical)	19	27.1
Unemployed (Other)	3	4.3
Employed (Full-Time)	4	5.7
Employed (Part-Time)	4	5.7
Retired (Age)	20	28.6
Retired (Medical)	20	28.6
<b>Time on Dialysis</b>		
4-6 months	10	14.3
6-12 months	12	17.1
1-2 years	9	12.9
2-5 years	20	28.6
5-10 years	11	15.7
10-20 years	6	8.6
>20 years	2	2.9
<b>Diabetic Status</b>		
Diabetic	11	15.7
Non-diabetic	59	84.3
<b>Transplant History</b>		
Yes	53	75.7
No	14	20.0



**Table 2 : Correlation Matrix of Compliance Indices : Biochemical  
and Self-Report**

	IWG	SERUM K	P04	SRCDIET	SRCFLUID	SRCMED
<b>IWG</b>	1.0000 (69) P= .	.0213 (67) P= .864	.2811 (65) P= .023 *	-.1349 (69) P= .269	-.3428 (68) P= .004 **	.0173 (69) P= .888
<b>SERUMK</b>		1.0000 (68) P= .	.4005 (65) P= .001 **	-.0674 (68) P= .585	.0397 (67) P= .750	-.0835 (68) P= .498
<b>P04</b>			1.0000 (66) P= .	-.1777 (66) P= .153	-.3180 (65) P= .010 *	-.2955 (66) P= .016 *
<b>SRCDIET</b>				1.0000 (70) P= .	.4460 (69) P= .000 ***	.1855 (70) P= .124
<b>SRCFLUID</b>					1.0000 (69) P= .	.1863 (69) P= .125
<b>SRCMED</b>						1.0000 (70) P= .

IWG = Interdialytic Weight Gain, Serum K = Serum Potassium, P0<sub>4</sub> = Blood Phosphorous.

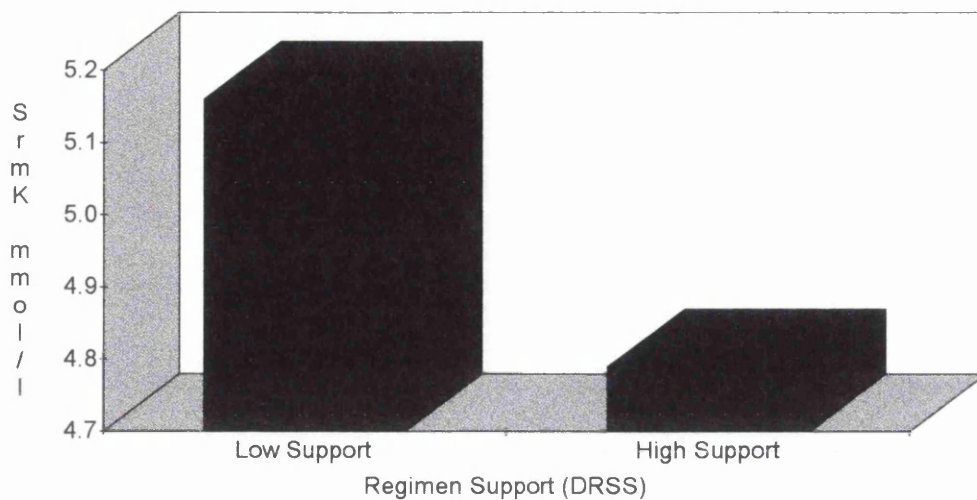
SRC<sub>D</sub>iet = Self-Reported Compliance with Dietary Recommendations; SRC<sub>F</sub>luid = Self-Reported Compliance with Fluid Recommendations; SRC<sub>M</sub>ed = Self-Reported Compliance with Medication Recommendations.

\* p<0.05;    \*\* p<0.01;    \*\*\* p<0.005

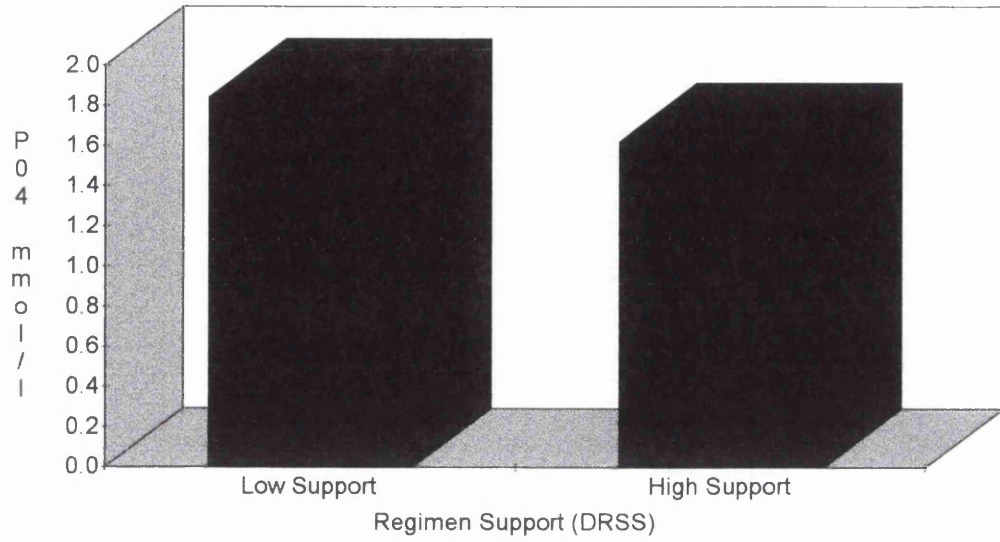
**Table 3 : Cell Means and Standard Deviations For Social Support  
and Indices of Compliance**

COMPLIANCE MEASURES		SUPPORT MEASURES					
		DRSS		SSQNo.		SSQSat.	
		Low	High	Low	High	Low	High
<i>IWG</i>	Mean	1.77	1.84	2.17	1.79	1.91	1.64
	Std. Dev	0.63	0.53	0.34	0.61	0.6	0.55
<i>Serum K</i>	Mean	5.16	4.79	4.56	5.05	5.07	4.97
	Std. Dev.	0.57	0.66	0.58	0.61	0.58	0.68
<i>P04</i>	Mean	1.84	1.61	1.79	1.74	1.85	1.59
	Std. Dev.	0.48	0.32	0.30	0.46	0.51	0.31
<i>SRCFluid</i>	Mean	4.00	3.74	2.00	4.09	3.82	4.21
	Std. Dev.	2.69	3.02	3.46	2.76	2.72	2.97
<i>SRCDiet</i>	Mean	4.34	5.13	1.33	4.83	4.51	4.86
	Std.Dev.	2.72	2.28	2.31	2.51	2.70	2.49
<i>SRCMed</i>	Mean	6.52	6.70	7.00	6.58	6.46	6.76
	Std. Dev.	1.44	1.11	0.00	1.34	1.52	0.99

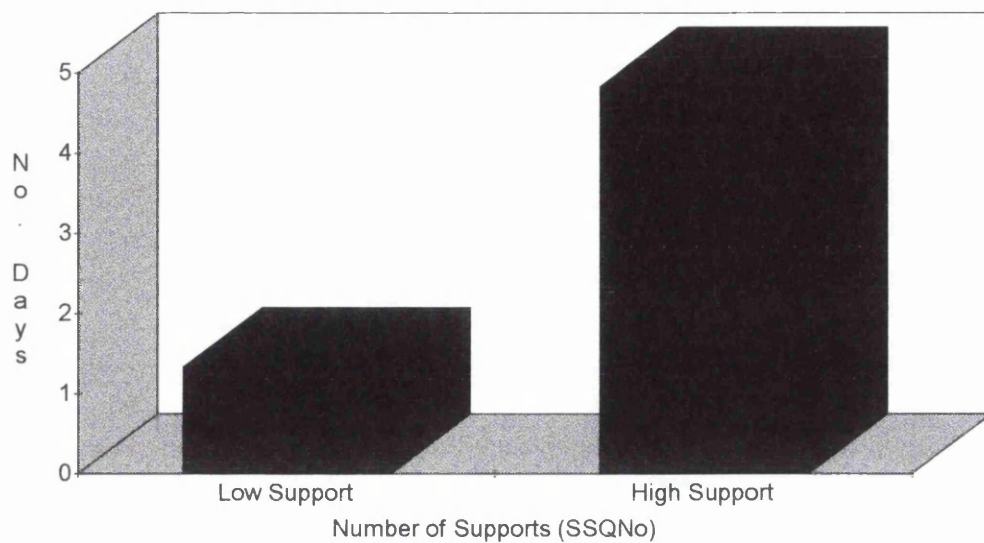
**Figure 1 : Effect of Regimen Support on Index of Compliance with Diet (Serum K)**



**Figure 2 : Effect of Regimen Support on Index of Compliance with Medication (P0<sub>4</sub>)**



**Figure 3 : Effect of No. of Supports on Self-Report of Compliance  
with Diet  
(SRCDiet)**



# **CLINICAL CASE RESEARCH STUDY**

**Title : DO SERVICES REALLY MEET PRESENTING NEEDS? CASE REPORT OF AN INDIVIDUAL WITH SCHIZOPHRENIA REFERRED TO LEARNING DISABILITY SERVICES.**

**Running Head : SERVICE PROVISION**

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**Targeted Journal : Journal of Mental Health**

## **DO SERVICES REALLY MEET PRESENTING NEEDS? CASE REPORT OF AN INDIVIDUAL WITH SCHIZOPHRENIA REFERRED TO LEARNING DISABILITY SERVICES.**

### **Abstract**

This paper considers the current use of diagnostic decisions in determining responsibility of service provision for individual patients. For the majority of cases primary diagnosis determines which sector of the mental health services provide care. In some cases however, needs of the individuals are not being met using this method and the case study presented, of a woman with deficits in learning, illustrates one such case. With increasing emphasis on consumer-led services within the NHS, the question of how best to meet the needs of the individual should be addressed. It is suggested that, to do so, a more flexible approach needs to be adopted by service providers to ensure individuals have access to local services which best meet their *presenting* needs.

## INTRODUCTION

Within NHS Mental Health Services, provision of resources is principally determined by the primary diagnosis. For the majority of cases establishing responsibility for provision of care is a relatively simple process relying on this diagnostic process. At times however, patients present with symptomatology which can be accounted for by a number of conditions with differing aetiologies, ie. organically or functionally determined. In psychiatric populations this can be particularly problematic since patients often have disrupted communication, distortions of reality and/or attention difficulties which make it difficult to attain a coherent and reliable history. Whilst there have been advances in classification systems such as DSM-III-R, as Kay (1989) points out with regard to psychiatric populations, the diagnostic process still relies primarily on "subjective clinical judgements".

Difficulties with differential diagnosis are well illustrated by some cases of learning disability and psychiatric disorder, especially where chronic psychotic patients present primarily with residual, negative symptomatology. Both populations share common presenting features. These are seen as poor intellectual functioning, lack of or deficits in social skills, and failures in adaptive functioning.

AAMR (1992) define Learning Disabilities as

"substantial limitations in present functioning. It is characterised by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental Retardation manifests before age 18."



Whilst definitively, Learning Disability manifests before the age of 18, this is not necessarily the case with psychotic disorders. Early failure in cognitive development however, can also be present in chronic schizophrenic populations (Kay, Opler, & Fiszbein, 1986). Reliance on onset of difficulties therefore does not always help to determine the aetiology of the presenting disorder.

The case study below illustrates the importance of the differential diagnosis process in determining the source of service provision for individuals who present with specific mental health problems. It also raises questions about relying on this process alone in determining responsibility for service provision, and further highlights the issue of best meeting individuals needs within current NHS internal markets.

### **Referral**

Mary, a 31 year old woman, was referred to the Clinical Psychology Department (Learning Disabilities) via psychiatric services. An assessment was requested to determine whether the patient, who had a long history of schizophrenic illness, would be more appropriately treated by Learning Disability Services. It was stated that the difficulty experienced by the two local psychiatric day units she attended was that..."due to Mary's learning disabilities and low level of functioning there is little more to offer her from psychiatric facilities." A referral had already been made to the local day care centre for people with Learning Disabilities and Mary was on the waiting list to attend this facility.

### **Assessment Aims**

From the referral a clear history of schizophrenic illness was presented. However, also evident was the perception of some kind of learning disability. Two competing hypotheses existed as to the aetiology of the disability : i) it had arisen as

a consequence of the chronic illness, ie. residual, negative symptoms or ii) it reflected a pre-existing learning disability. Of further significance was the obvious problems that the psychiatric services had in meeting the needs of the referred individual.

The assessment set out to answer a number of questions, thereby determining : i) the nature and extent of presenting problems, ii) whether or not the patient could be classified as learning disabled using AAMR's definition (1992) and if so, to identify the aetiology of the disability ie. pre-existing developmental learning disability or negative, residual symptoms of chronic illness and iii) current level of functioning (to highlight areas of need for future intervention and act as a baseline data). On the basis of this information, the assessment would be used to answer the question - which service would best suit the patient's presenting needs?

## **METHOD**

A variety of assessment methods were employed to obtain the necessary information and data. Description of the nature and extent of problems was obtained from clinical interviews with patient, staff and family members, observation and psychiatric notes. To establish a picture of pre-morbid functioning, a full history (developmental, medical, education/occupational and social) and formal psychometric testing of pre-morbid intellectual functioning (National Adult Reading Test, Nelson et al.1982) were used. In differentiating between the possible aetiologies of the presenting problem, assessment of current cognitive functioning was also therefore necessary. Given that the patient presented with communication deficits, a non-verbal measure was employed (Coloured Progressive Matrices, Raven, 1962). To assess functional skills, and thereby highlight areas of need, two formal measures were used to provide a comprehensive picture of functioning

across a number of setting i) Basic Social Knowledge Test (BSKT) (Paton,1981) a measure of basic academic cognitive skills, and ii) Adaptive Behaviour Scale : Residential and Community 2 (ABS:RC2)(Nihara et al. 1992) - a measure of coping skills necessary for independence and community living.

### **Presenting Problem and History**

Mary had been attending her main day placement for one year. Her initial referral to the unit had been opposed at the time, as it was felt the unit had little to offer her. The unit itself served as a resource for people with psychiatric problems, living in the community, who were independent enough to travel to the unit unaccompanied and who possessed independent living skills. Mary did not meet these specifications and needed to be accompanied when travelling. Staff were further concerned that the level of supervision provided within the unit was inadequate given Mary's level of dependence.

Staff reported Mary had made no progress since she began attending the unit. They noted a slight deterioration in functioning, specifically in communication and social interactions. Mary was very withdrawn, preferring to sit for the majority of the time in the TV room by herself. There were difficulties engaging Mary in any form of activity, and, in group situations, she was passive and uncommunicative. Excessive prompting was needed to get Mary to respond.

Mary displayed some behaviours which were viewed as disruptive in groups settings and distressing for other clients. The behaviours were in response to i) infrequent auditory hallucinations, and ii) demands eg. involvement in tasks, which were more frequent. There were some stereotypical behaviours and some self - injurious behaviours eg. digging her nails into her palms and excessive scratching.

## **Psychiatric History**

Mary first became involved with the psychiatric services at the age of 20, when she was diagnosed as suffering from schizophrenia, with a somewhat atypical presentation. EEG measurement 4 years later showed considerable abnormality supporting this diagnosis. Two acute episodes precipitated short in-patient admissions but Mary was treated mainly on an out-patient basis. A 6 month in-patient admission to the Rehabilitation Unit had taken place 2 years prior to referral. There was reported minimal improvement in her daily living skills over this period and because of this Mary was discharged from the unit. Following this Mary began attending the day unit regularly, which led to the referral.

## **Educational & Occupational History**

Mary attended local mainstream schools leaving at 16 without qualifications. Her parents report that in relation to academic work Mary "was never bright". There was however, no special educational input received. After leaving school Mary went on various YOP schemes, following which she was employed in a book binders for three years. Mary stopped working prior to her initial admission, and subsequently only worked occasionally in her father's business on administrative tasks.

## **Pre-Morbid Personality**

In terms of social relationships Mary was described as a quiet girl whilst at school, establishing only a few friendships. Parental descriptions suggest Mary had always been somewhat immature for her age, though reportedly she handled stress well prior to initial admission. Her parents reported noticing a gradual deterioration in overall functioning, particularly within the last four years.

## **Medical History**

There were no complications during pregnancy or birth. Mary was tested for the presence of hormone deficiency at age 8, although no treatment was

required for this. There were no other significant medical problems, and no mention made of delayed development in any relevant areas. Hearing and sight had recently been tested, no problems were highlighted. Current medication: Perphenazine 12mgs and Kemadrin 5mgs daily.

### **Clinical Presentation**

Mary presented as a very withdrawn woman, with limited communication skills; she responded using one or two word phrases and did not initiate any conversation. Mary frequently responded to questions saying 'aye' even though this was inappropriate. Her eye contact was poor, though on occasion, particularly when she appeared to fully comprehend tasks required of her and was able to complete the task, her eye contact was appropriate and in addition she smiled. Otherwise Mary's affect was flat. At times she giggled to herself, but otherwise appeared to concentrate on the tasks.

### **RESULTS**

Results of individual tests are summarised below.

#### **Coloured Progressive Matrices (CPM).**

Every effort was made ie. through verbal, non-verbal/pictorial and repeated presentation, to convey the purpose of the task to Mary. However, responses reflected that Mary was unable to comprehend the concept and the task was therefore discontinued. This response may reflect difficulties in comprehending complex instructions and/or in attending to relevant stimuli.

#### **Basic Social Knowledge Test (BSKT).**

The total score obtained on the BSKT was 6 (maximum score =20). The overall pattern of results obtained provides a description of Mary's basic academic cognitive skills summarised below. *Orientation.* Mary was oriented in place, but

not in time. Knowledge of her age, birthdate and weekdays, though not of months, indicated presence of intact long-term memory functioning. *Memory functioning.* Obtained scores indicated poor ST memory functioning. Given the psychiatric history, this score may have reflected deficits in attending to relevant target stimuli at initial presentation. Staff reports suggested that, given enough prompting, Mary was able to recall recent information eg. what she had been involved in earlier that day. *Literacy.* Mary was able to read, though this was slow with omission of small words, eg. "me, and, of". Her comprehension of text was poor, which may again have reflected attention deficits, poor short term memory functioning, or the length of time taken to read the target passages. Mary was able to write only basic information. *Verbal Fluency.* Obtained scores reflected the limited communication Mary exhibited throughout testing, and on a daily basis. Occasionally spontaneous and fluent speech occurred, usually in response to music or during hallucinations. *Coin Recognition and Money Use.* Mary displayed poor knowledge of coins and numbers. Staff reports however, suggested that Mary did have some skills in using money which was more evident in natural settings eg. being able to pay for simple items in cafes. *Colour Discrimination* There were no problems on colour discrimination tasks.

**Adaptive Behaviour Scale : Residential and Community 2 (RSC:2).**

*Independent Functioning and Domestic Activity.* Mary was able to perform basic daily living skills eg eating, washing, personal hygiene routines, on the whole independently, although occasionally required prompting. With household tasks constant prompting was necessary. In terms of community independence, supervision was necessary for Mary at all times. *Responsibility.* Mary was given few general responsibilities by staff and parents alike. She was, however capable of looking after her own belongings. She attended the formal assessment sessions clutching her bag and gloves, but needed to be prompted to put them down.

*Socialisation.* Mary demonstrating little evidence of co-operation, consideration, or awareness of others. Whilst she did recognise individuals eg. family members and staff, her interactions with others were passive in both individual and group situations. *Self Direction.* Mary scored poorly. She showed little initiative, requiring constant prompting to engage in, and complete activities, and was described as passive. Staff reported that Mary was able to attend to a specified task for short periods of time (approximately 15 minutes) but required prompting to do so.

### **National Adult Reading Test (NART)**

A predicted Full Scale IQ score of 103 was obtained and suggested a level of pre-morbid functioning in the average classification.

### **Case Formulation**

Mary presented as a withdrawn woman, with poor communication and social skills. Reports suggested that there had been a gradual deterioration in cognitive and social functioning, with onset dated to around the age of 20. Prior to this it appears from her history (educational, occupational, and medical/developmental) that, although not academically focused, cognitive/intellectual functioning was reportedly normal. It is possible that deterioration may have begun earlier, given Mary's failure to achieve academically, however her parents explain this failure as lack of interest, rather than ability. No other evidence was available to support cognitive deterioration prior to 18. Results of the NART were indicative of pre-morbid intellectual functioning within the average range, and pre-morbid social functioning enabled her to secure employment and friendships appropriate for her age. Available evidence was therefore insufficient to allow a firm diagnosis of learning disability to be made. It appeared

that, at least in part, noted deterioration reflected residual symptoms of schizophrenia.

## **DISCUSSION**

Presenting symptomatology appeared from the assessments undertaken, best attributed to the onset and progression of schizophrenia, which was not superimposed on specific developmental disability prior to the age of 18. Whilst generally it is recommended that parental reports should not be relied upon to establish pre-morbid levels of functioning since they may be biased by inaccurate recall and personalised interpretations and therefore unreliable (Kay, 1989), in this case, it appeared that the results of the NART concurred with parental reports of average pre-morbid intellectual functioning, and therefore allowed exclusion of a pre-morbid learning disability diagnosis to be made with a greater degree of confidence.

The available evidence therefore supported existing allocation of service provision in that responsibility of care lay within the remit of local psychiatric service. Despite this, Mary's needs were clearly not being met by these services, and her presentation very much resembled the profile of an individual with a learning disability, fulfilling the majority of the AAMR's criteria.

Prior to discussing the implications for services highlighted by this case, one methodological issue must be raised : that is reliance on the NART to establish pre-morbid level of intellectual functioning. Whilst Crawford (1992) suggests that the NART is a valid means of estimating pre-morbid intelligence in schizophrenic populations, and, certainly it has been employed in other studies eg. Frith et al, (1991), Jones & Rodgers (1993) caution against extrapolating from scores obtained to stating pre-morbid IQ's. They suggest that the considered explanations of poor performance on this measure are not comprehensive, and that other factors, such as



severity and age of onset of schizophrenia, may affect reading scores differentially. If this is the case, then the validity of using the NART to estimating pre-morbid intellectual functioning in schizophrenic populations is questionable. Having said this however, as Jones & Rodgers (1993) themselves conclude, the NART "...does provide a more accurate assessment of pre-morbid functioning than can be obtained by many tests...".

Feedback of information, in this case, led to traditional processing of service allocation, in that responsibility of care *was* determined by primary diagnosis ie. schizophrenia, despite presenting needs not being met. The Learning Disability service's decision not to provide care based on this diagnostic criteria appeared relatively straightforward. This is not always the case however, particularly where patients have dual diagnosis (Reiss, Levitan & McNally, 1982). In more complex cases placement of the individual may be determined idiosyncratically, relying more on, for instance, the local availability of resources, than on the presenting needs of the patients.

It appears then that, at least in some cases, presenting needs of individuals may not be best met by the services designated as having a remit for care, where reliance on primary diagnosis determines this decision initially. The case presented highlights the deficiencies in local day care provision for individuals with chronic psychiatric problems and resulting poor adaptive functioning, cognitive problems and communication difficulties.

With the increasing emphasis on consumer led services within the NHS, the question of how best to meet the needs of these individual needs to be addressed. One potential solution already exists in the form of learning disability services, where professionals are highly trained in providing necessary input and support to individuals with deficits in learning ; deficits markedly evident in this subgroup of chronic psychiatric patients. Furthermore, given the high incidence of psychiatric

problems in the learning disabled population (Reid, 1976), and the expertise already developed by professionals working with this population, the input required for patients like Mary would not differ significantly from that already provided to individuals in learning disability services with dual diagnoses. An alternative solution would be to develop specific services for individuals with both psychiatric problems and learning difficulties, where remit for care depends not on the primary diagnosis being organic/genetic in aetiology, but on the presenting problem ie. general deficits in learning. If this were to be the case certainly a subgroup of individuals with head injuries could also potentially qualify and benefit from such services.

It may be argued therefore that, as highlighted by this case, the use of primary diagnosis alone to determine remit for service provision is not always the most appropriate, nor does it always ensure that the needs of individuals are best met. There is a need for service providers to adopt a more flexible approach when assessing the appropriateness of providing care to individuals. More attention should be given to the presenting needs of the individual at referral and the capacity of the service to meet these if the NHS is to fulfil its consumer-oriented policies. Gaps in service provision need to be addressed so that all individuals have access to local services which best meet their *presenting* needs.

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# **CLINICAL CASE RESEARCH STUDY**

**Title : RECURRENT ABDOMINAL PAIN IN CHILDREN : A  
TREATMENT CASE STUDY.**

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**Targeted Journal : Clinical Child Psychology and Psychiatry**

## **RECURRENT ABDOMINAL PAIN IN CHILDREN : A TREATMENT CASE STUDY**

### **Abstract**

The paper presents a single case study of the treatment of recurrent abdominal pains in a 12 year old boy. Somatic presentation was associated with ongoing parental conflict which was not directly amenable to intervention. Parental management reinforced the behaviour, school avoidance associated with separation anxiety and dysthymia were also present. Difficulties engaging the family in therapy determined that a brief education/behavioural management approach was utilised along with individual cognitive-behavioural therapy. Progress was evaluated using a single subject design. Results supported an improvement in targeted behaviours, and though follow-up was of minimal duration, these were maintained at initial 6 week follow-up. The results suggested that the combined intervention package was an effective means of treating recurrent abdominal pains.

**Key Words : Abdominal Pain, Children, Family, Intervention.**

## INTRODUCTION

In reviewing the literature on childhood somatoform disorders, Shapiro & Rosenfield (1987) point out that, in comparison to the literature on adult disorder 'little is known about the natural history and age-related changes of the same condition in childhood', and available literature is meagre. Somatoform disorders in children, like adults, are characterised by presentation of somatic symptoms, eg. stomach-aches, headaches, motor and sensory disturbances, which cannot be explained by organic pathology. Shapiro & Rosenfield suggest that these disorders exist on a clinical spectrum, ranging from transitory reactions to early manifestations of disorders that become defined only during adulthood.

Incidence of childhood somatoform disorders presenting in general medical populations is low (0.08 - 0.25%), though higher in psychiatric populations (3 - 24%), depending on the type of service and diagnostic criteria used (see Shapiro & Rosenfield, 1987). In contrast, somatoform *symptoms* are quite prevalent. Recurrent abdominal pains, are particularly common and estimated to affect between 10-15% of children with an organic cause diagnosed in less than 7% of cases (Apley, 1975). Certain psychological childhood disorders are also typified by somatic symptomatology eg. separation-anxiety disorder (Livingston et al., 1988), panic disorder and school refusal (Last, 1991). In addition, discrete somatic symptoms have been associated with specific disorders. Abdominal pains are particularly common in separation-anxiety disorder (Livingston et al. 1988). These unexplained pains are experienced by both the child and family as distressing (Walker & Greene, 1989) and there is often uncertainty in parents of how to manage pain reports. It is not surprising that childhood somatoform disorders often present along with anxiety and depressive disorders (Shapiro & Rosenfield, 1987),

which can either be the result or cause of the symptoms. Prolonged absences from school are a similar feature (Garralda, 1989).

Onset of somatoform symptoms is commonly associated with major stress eg. loss, family change, divorce (Shapiro & Rosenfield, 1989), minor stress or normal developmental change, eg. onset of puberty or may follow actual physical illness (Carek & Santos, 1984). Family factors associated with recurrent abdominal pain (RAP) were reviewed by Sines (1987) and include; extreme life changes, recent loss of a relationship with a friend or family member, a family history of somatic complaints, overprotective or domineering parent(s) and marital or family conflict.

In general, it has been suggested that children with somatoform disorders have difficulties expressing their emotions (eg. Loeff 1970), though empirical data is lacking. Families of these children themselves have difficulties communicating (Maloney, 1980). It is suggested that discussion of physical symptoms becomes the acceptable means of expression within families. Certainly there are more models of illness and family dysfunction found in these families (Siegel & Barthel, 1986), and evidence suggests that reports of pain are reinforced by parental behaviours (Sanders et al. 1989).

Somatoform disorders then, are seen to reflect a psychological response to stress or conflict, in that the conversion reaction mitigates the child's pain and anxiety. Somatic presentation may be an acceptable means of expression and communication and learnt via social modelling. Primary gain and/or the avoidance of the noxious or stressful stimuli may result from the somatic complaints (Maloney, 1980, Volkmar et al., 1984), and through this is reinforced.

Treatment of recurrent pain is often managed by primary care physicians, with simple reassurance that the pains will remit spontaneously and that the children will "grow out of them" (see Sanders et al. 1994). However simple reassurance may

be insufficient and children may have undergone numerous physical investigations and hospital admissions before referral to psychiatric/psychological services. The use of cognitive-behavioural techniques in treating a number of childhood disorders is increasing eg. depression (Reynolds, 1984), anxiety (Kendall, 1992) and cognitive therapy, particularly for older children is similarly indicated (see Hackman, 1993, for review).

In terms of recurrent abdominal pain (RAP), controlled studies of psychological interventions are scarce, with a few notable exceptions eg. Sanders et al. (1989, 1994). Coping skills training (Linton, 1986) and dietary and behavioural interventions have been reported effective in uncontrolled case reports (eg. Finney et al. 1989). Given the influence of family factors, Sanders et al. (1994) developed a cognitive-behavioural intervention for the family, which focused on teaching children coping skills and creating a supportive family environment. Family CBT proved more effective in i) eliminating RAP reports, ii) decreasing interference of pain in activities, iii) lowering relapse rates at 6 and 12 month follow-up, than standard paediatric care (SPC). Parents in the CBT group were also more satisfied with treatment.

Where ongoing family stress is obviously present and perceived as of aetiological significance, what should the treatment of choice be in such cases? The case study below outlines intervention with a boy presenting with RAP. Ongoing marital conflict was viewed by the family themselves as the causal factor in presentation of pain however the parents were reluctant to address their relationship problem directly. Previous inconsistent attendance at therapy indicated family involvement may be problematic. The study aimed to evaluate the effectiveness of a brief family intervention ie. education in behavioural management techniques and individually focused cognitive-behavioural therapy.



## **METHOD**

### **Referral**

Paul, was referred to the local Child & Family Clinic said to be suffering from recurrent abdominal pain, with a seven year history. A number of hospital admissions had occurred, however medical investigation had excluded an organic cause. Prior to his most recent admission Paul had missed several months of schooling and had managed only half a day's attendance in the previous term. Referral followed discharge from hospital. Case history was reported by Paul and his parents during initial interview, from school and hospital reports.

### **Presenting Problem**

Paul, who presented as a mature boy of 12, was the eldest of three children. He complained of abdominal pains on an intermittent basis which resulted in absence from school. Pain reports were triggered by parental conflict, which Paul felt responsible for. There had been violence in the marital relationship in the past, though not recently. However Paul believed this was because his presence prevented "things getting out of hand". When conflict was apparent Paul complained of pain and was reluctant to go to school. His mother reinforced the behaviour and encouraged him to stay at home. There was a two year history of dysthymic symptoms, with reports of subjective feelings of sadness, frequent crying, tiredness, poor sleep and appetite.

### **History of Presenting Problem**

Paul was first admitted to hospital with abdominal pains at the age of six and numerous admissions had occurred in the following years. Onset of the problem began one year after reported marital conflict. Previous hospital admissions had resulted in increased contact between his parents on occasions when

they had been separated. Focus on somatic complaints had therefore been reinforced in the past.

### **Family Situation, Marital Relationship and Parental Characteristics**

Conflict between his parents was apparent at interview, Paul became distressed. Paul's parents did show concern for their son, but this was primarily in an instrumental, rather than openly affectionate manner. Discussion confirmed that emotions were difficult to deal with and express directly in the family, although anger was one emotion which was. Expression of anger however was not tolerated when displayed by Paul.

Mr & Mrs D's (Paul's parents) relationship had been unstable for 8 years. Mr D frequently left home, and on return always kept his clothes packed in a bag ready to leave at any time. Many of their arguments centred around money and Mr D gambled. They also disagreed on managing and disciplining their children. In terms of parenting styles, Mr D was "too strict" and described difficulties controlling his temper. Mrs D, reportedly compensated by being "soft and overprotective". She was particularly inconsistent in managing her children and appeared overinvolved with her son. Mrs D related to Paul, as an adult, particularly when he complained of pain.

### **School**

Paul had missed substantial amounts of schooling and because of this was failing to achieve his real potential. There were no behavioural problems, indeed Paul was described as a 'model' pupil. Social functioning was affected. Paul had few friends at school. He had been being bullied in primary school, which he blamed himself for.

### **Personal History**

Paul spent time at home in solitary pursuits, reading and drawing. He had a close relationship with one friend from school, and his maternal grandparents.

## Measures

A number of measures were employed ;

a) *Target Behaviours* - frequency of i) pain reports, ii) school attendance were recorded (Figure 1).

b) *Ratings of Parental Behaviour* "Strictness Ratings - Actual & Ideal". Paul made spontaneous graphs of discipline/strictness within the home, at the beginning and end of intervention (Figure 2).

c) *Cognitions* eg. Feelings of Responsibility (Pie Charts). Paul made pie charts to illustrate his feelings of responsibility for conflict in the family, at two points across the intervention (Figures 3 & 4).

d) *Child Depression Inventory (CDI)*. To determine the presence and severity of depressive symptomatology. This measure is used solely as a screening, not a diagnostic, instrument. T-scores above 65 indicate the need for service provision (Figure 5).

e) *Play/Drawings*. Drawings were used during initial assessment and throughout intervention (See Appendix C).

## Treatment Intervention

On the basis of assessment a number of goals were set, as follows, i) reduce reports of pain, ii) improve and optimise school attendance ie. attending 5 days per week, and thereby decrease separation anxiety, iii) teach behavioural management techniques to parents to improve consistency iv) teach individual behavioural and cognitive techniques to facilitate appropriate coping with parental conflict and alter dysfunctional cognitions eg responsibility for conflict v) decrease dysthymic symptoms. Treatment was weekly with follow-up at 6 weeks. Two family appointments were held, at the beginning and end of treatment. The majority of treatment was individual sessions, Mrs D attended two additional sessions for

education in specific behavioural management techniques. Mr D was reluctant to attend.

### *Brief Family Intervention - Education and Behavioural Management*

Basic information regarding Paul's pain presentation, (aetiology and maintaining factors) was given in the initial interview to both parents. Appropriate behavioural management techniques were also reinforced, eg. ignoring pain itself, but encouraging appropriate discussion of anxieties/worries. Paul was to be sent to school on these occasions, thereby ending the inappropriate reinforcement of avoidance behaviour. Behavioural management techniques eg. limit setting, consistency (Douglas, 1989) were discussed with Mrs D in a second session to target the reported inconsistent management. A homework task involving appropriate management of Paul was explicitly set targeting this area, and reviewed in the following session.

### *Behavioural Techniques*

"Action Plans", ie. plans outlining ways of dealing with parental conflict eg. going out to visit his grandmother, were also set up with Paul. These served two functions i) exposure to feared situation ie. separation and ii) support. Use of cognitive strategies whilst away from home were encouraged to counteract anxious thoughts.

### *Cognitive Restructuring*

Cognitive therapy techniques, modified for use with older children and adolescents, have been effective in treatment of anxiety and depressive disorders (Hackman, 1993). Given Paul's presentation and age, these techniques were introduced and used to address the cognitive distortions identified and associated with the presenting problems. Positive self-statements, and challenging techniques using pictorial modes of presentation were employed. Homework tasks were assigned to allow Paul to practice these between sessions.

### *Support and Emotional Expression*

Ventilation of feelings related to his home and family circumstances was encouraged during sessions. Techniques were also suggested whereby Paul could express anger, towards his father in particular, without undue repercussions to himself. Paul adopted a 'coded' behaviour which he alone knew the meaning of. When angry at his father Paul would clench his fists behind his back and give him a 'cold stare'. Supports outwith the family for further ventilation of feelings were also identified.

In addition social supports were identified in Mrs D's existing environment. The aim of this was to allow appropriate discussion of ongoing difficulties ie. marital conflict, within her own peer group. In doing so this diverted inappropriate attention and involvement in parental conflict away from Paul and allowed exposure and facilitation of appropriate separation.

### *Play/Drawings*

Axeline (1969) suggests the use of play in therapy as a means of facilitating communication and emotional expression. Paul discussed his own feelings in an adult/mature manner, which was reinforced by his parents. In general his parents tended to communicate with him as an adult. Paul described being unhappy that they did this. Play was therefore incorporated, along with drawings, to free him from this pressure to interact as an adult. Drawings are included to illustrate i) feelings at assessment (Paul drew spontaneously, choosing to leave 2 of his 3 drawings) and ii) expression of emotions during intervention (See Appendix C).

### *Relapse Prevention*

A review of techniques found to be useful during intervention were highlighted, and written down in an 'Action Plan' for/by Paul. Potential times of future relapse were also identified for the family and coping techniques identified.

## RESULTS

The results were analysed in terms of the targeted problems.

### *Pain Reports and School Attendance*

Figure 1 depicts pain reports and school attendance across the intervention period and follow-up. Following interview school attendance was optimal. There was an increase in pain reports initially though this behaviour decreased rapidly. Paul was sent to school despite reported pain, indicating an immediate change in parental behaviour. Follow-up at 6 weeks shows change in behaviour was maintained.

### *Parental Management of Behaviour*

In addition to improved management of pain reports, further change in parental/maternal behaviour also occurred. Successful completion of a behavioural task eg. ensuring Paul was in bed by a specified time, by Mrs D had a number of significant and interesting results. Maternal behaviour changed positively. Paul reported consistency in his mother's behaviour toward him. Figure 2 depicts his spontaneous ratings of parental 'strictness' before (Actual and Ideal) and after intervention. There was an increase in maternal 'strictness', (ie. limit setting). There was evidence of generalisation, Mrs D implemented a similar routine with her 3 year old, which was successful. She further reported applying appropriate management techniques with her two daughters consistently. Further benefits occurred in that Mrs D described obtaining more time to herself, consequently feeling more relaxed and therefore more able to be consistent in her parenting style.

'Strictness' ratings also highlight a change in Mr D's behaviour, though he had not been involved directly. At the final family interview Mr S supported the appropriate changes in his wife's behaviour, commenting further that as a result he felt less need to be strict with his children. In addition both Mr and Mrs S reported

a slight decrease in the number of arguments they had, particularly over issues relating to the children

#### *Coping with Parental Conflict ; Behaviour and Cognitions*

Paul confirmed a change in his own behaviour during conflict, as did his parents. His distress was openly discussed with his mother. Paul left the house during parental conflict. Over the intervention period, reports of subjective anxiety on separation decreased. Paul utilised challenging techniques to help him cope with his anxiety. Change in dysfunctional cognitions, eg. responsibility for parental conflict is illustrated in Figures 3 & 4. This shows a decrease in self-attribution of responsibility for conflict across the intervention period.

#### *Dysthymia*

Figure 5 depicts CDI scores at initial assessment and end of intervention. At assessment, score on the Negative Mood subscale was over the cut-off screening score of  $t = 65$ , by end of intervention this had decreased to within normal range. Self-report supported a decrease in dysthymic symptoms, with improved sleep, appetite, and mood.

In summary, outcome measures show a significant reduction in pain reports, school non-attendance, anxious and depressive symptomatology. Furthermore appropriate means of expressing distress were being utilised. Separation had occurred, with Mrs S using appropriate supports to discuss her own difficulties. In addition she was employing appropriate child management techniques consistently within the family. There was also a change in Mr S's parenting style and a slight decrease in marital conflict.

## **DISCUSSION**

The intervention outlined here was developed specifically according to the presenting problems and needs of the individual. Family factors and characteristics

influenced the type of approach utilised. The ongoing marital conflict was not amenable to direct intervention, but was of clear aetiological significance in terms of the presenting problem, intervention therefore had to be directed towards the child, who needed to develop sufficient skills to enable him to cope with the enduring stress. Problems engaging the father in therapy also meant that change in management of the children, became the responsibility of the mother, despite the identified problem in paternal management. The intervention package was therefore multifaceted and, whilst improvements in targeted behaviour were evident, it is impossible to identify directly which components were responsible for the success of the intervention since the design was a simple AB kind, components of treatment being undertaken simultaneously. Change in both parental management and individual coping were obvious however and maintained at follow-up. From a systems perspective, it is interesting that change in paternal behaviour did occur, and was linked specifically to change in maternal behaviour, with an additional reported improvement in the enduring family stressor ie marital conflict.

## **CONCLUSION**

This single case study supports the use of a brief family education/behavioural management approach combined with individual cognitive-behavioural therapy for recurrent abdominal pain in children. Given the reported familial factors which may contribute to the presenting problem there is evidence that this approach is useful, at least where there is ongoing family conflict. Further controlled studies are needed however to thoroughly evaluate the intervention package.



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**Figure 1. Pain Reports and School Attendance**

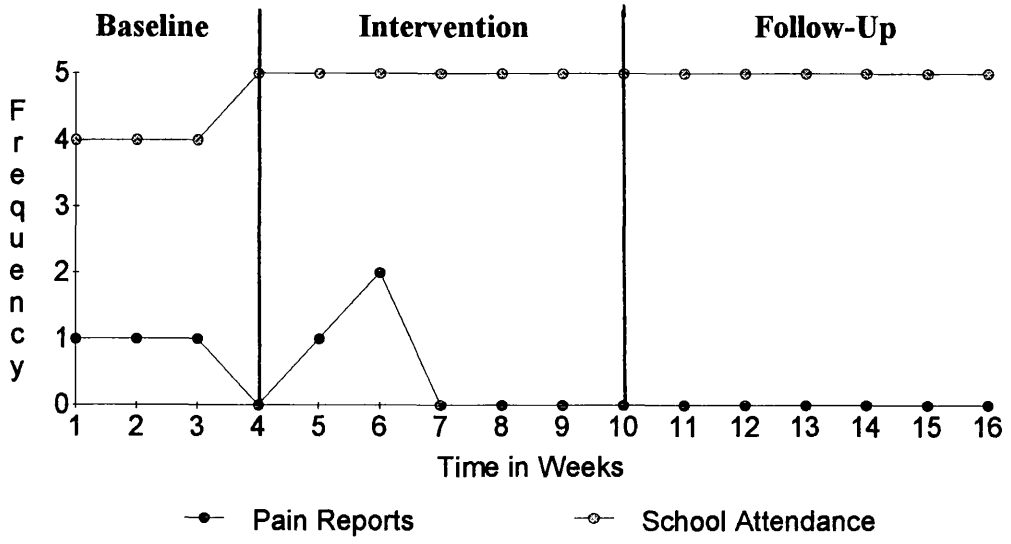
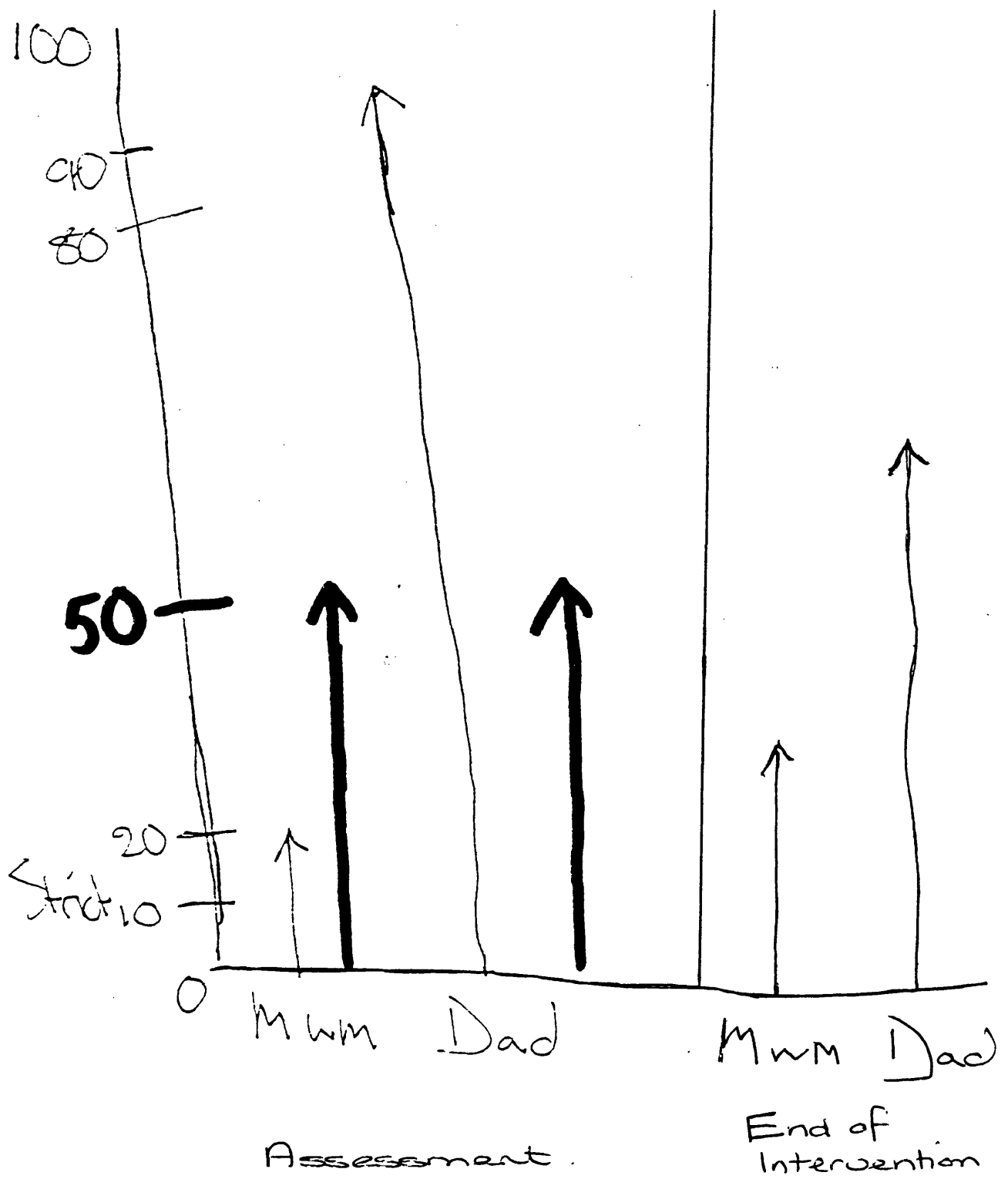


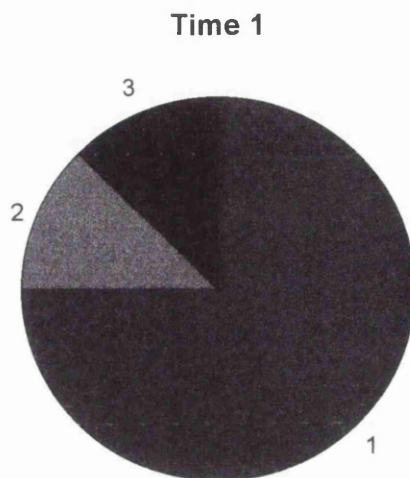
FIG 2: 'STRICTNESS' RATINGS: ACTUAL AND IDEAL CHANGE ACROSS TIME



Key

- 'Actual Strictness'
- 'Ideal Strictness'

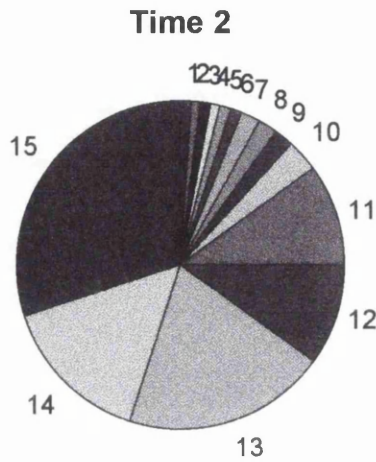
**Cognitions : Feelings of Responsibility for Parental Conflict :**  
**Figure 3. Attributed Reasons for Parental Conflict - Time 1**



**Key - Cognitions**

- 1 Self**
- 2 Oldest sister**
- 3 Youngest sister**

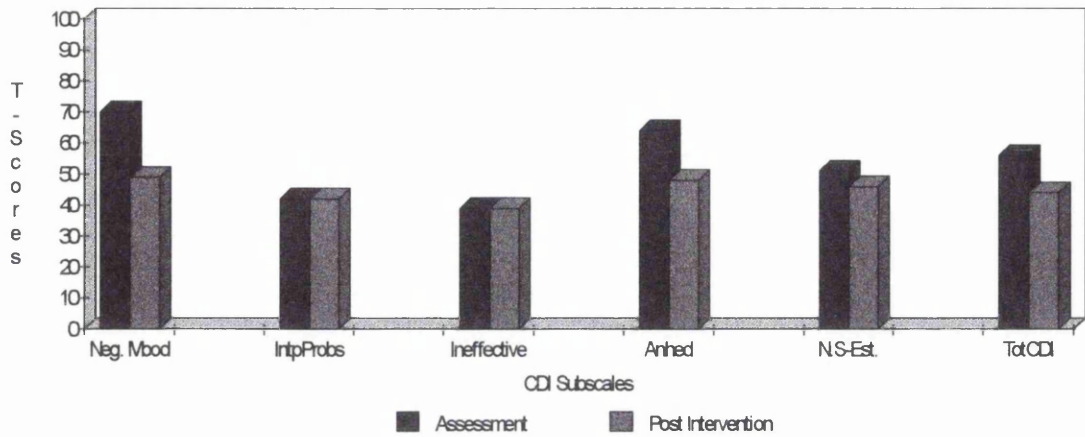
**Cognitions : Feelings of Responsibility for Parental Conflict :  
 Figure 4. Attributed Reasons for Parental Conflict - Time 2**



**Key - Cognitions**

- |  |                                     |
|--|-------------------------------------|
| 1 Bored                                    | 9 Having to do things don't want to |
| 2 Bad day                                  | 10 Things feeling unfair            |
| 3 For the sake of it                       | 11 Not wanting to be beaten         |
| 4 Lack of sleep                            | 12 Disliking each other             |
| 5 Other things going wrong                 | 13 Lack of compromise               |
| 6 Feeling miserable                        | 14 Earlier arguments unresolved     |
| 7 Getting on each others nerves            | 15 Different opinions/wants/wishes  |
| 8 Taking out their feelings on each others |                                     |

**Figure 5. CDI Scores : Across Intervention Period**



**Key - CDI**

**Neg. Mood - Negative Mood**  
**Int.Probs. - Interpersonal Problems**  
**Ineffective - Ineffectiveness**

**Anhed. - Anhedonia**  
**N.S-Est. - Negative Self-Esteem**  
**Tot.CDI - Total CDI Score**



# **CLINICAL CASE RESEARCH STUDY**

**Title : MASKED BEREAVEMENT PRESENTING AS DYSPHONIA.**

**Running Head : MASKED BEREAVEMENT**

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**Targeted Journal : Behavioural and Cognitive Psychotherapy: Brief Clinical  
Reports**

## **MASKED BEREAVEMENT PRESENTING AS DYSPHONIA**

### **Summary**

This single case study outlines treatment of a woman presenting with functional dysphonia. Grief therapy was effective in alleviating dysphonic presentation within two sessions. Brief anxiety management techniques were also taught, with response prevention in mind, to increase subjective coping in future stress situations. The case highlights the need for assessment to include routine questioning on significant losses.

## **Introduction**

The term 'functional dysphonia' covers a wide range of voice disorders, characterised by difficulty in voice production ie. quality, volume, consistency, or pitch, which cannot be explained by neurological or structural lesions. It is proposed that disruption to the voice represents a conversion disorder. Changes in vocal functioning in dysphonia are suggested to represent the expression of psychic conflict or need, wherein the conversion acts as a defence against expression of unacceptable feelings (Matas, 1991). Functional dysphonia itself has been associated with a number of factors including; anxiety, lack of assertiveness, social anxiety and conflict over speaking out. Deficits in support networks and difficult personal relationships are also seen to exist, and conversion may be triggered by life events (see House & Andrews, 1988). Delay between triggering factors and symptom presentation in these types of disorders however make it difficult for patients to make relevant connections themselves (Kinzl et al., 1988)

Masked or repressed grief frequently presents with conversion symptoms, with presentation in some cases, resembling the dead person in a certain way. Loss in bereavement is associated with feelings of isolation and loneliness and it is seen that anxiety and depressive disorders may result (Parkes, 1985). Where the loss is of a significant other eg. spouse, who acted as the major confidant and support, feelings of isolation and loneliness may be particularly severe (Worden, 1993). With few or insufficient opportunities to talk about the loved one it is perhaps not surprising that this behaviour can of itself become a way of coping, with abnormal grief subsequently presenting in these terms ie. as dysphonia. Conversion disorders are particularly likely to occur where there has been a family or previous history of difficulties accepting and expressing emotions.

## **Case History**

Emily, a 54 year old woman, was referred to a clinical psychologist for relaxation training related to stress at work. Somatic symptoms of anxiety were present eg. palpitations, chest tightness. Particularly problematic was that Emily lost the use of her voice at times, which made her job difficult; she was a nursery school teacher. Emily's voice would lose volume and become very faint. It was at times difficult to hear her during interview, because of this. Lack of assertiveness appeared to contribute to stress at work. There had been no previous psychological/psychiatric history or reported difficulties prior to onset. Anxiety symptoms were associated with an exacerbation of pressure at work in recent months, vocal difficulties however had a 2 year history. There were no objective, additional stressors or change in her work. Clinical interview however revealed that Emily had become a grandmother around the time of dysphonic onset, and because of increased demands on her son's time, was seeing less of him than previously. Emily had close relationships with both her two sons, but felt increasingly lonely since the birth. At the same time disagreement within the family meant that her sons were not talking to each other, a situation she felt responsible for.

During the course of discussion, the interviewer enquired about bereavements. Emily became tearful and distressed. Her husband had died 8 years previously and her mother 2 years later. Interview revealed that Emily had coped with these bereavements using avoidance strategies. She kept herself constantly busy and avoided spending time alone relaxing, a pattern of behaviour which continued to the time of presentation. Feelings of loneliness and loss of perceived support within the last two years had exacerbated Emily's feelings of isolation.

Presentation suggested that the process of grieving had been insufficiently worked through. It was hypothesised that the dysphonic presentation was a masked bereavement reaction, rather than a simple anxiety state, wherein change in

available and regular support had exacerbated feelings of loss relating to the two significant deaths, leaving Emily feeling vulnerable and unable to cope. There was no reinforcement obtained from the environment by dysphonic presentation, but rather it appeared that vocal difficulties were conversion symptoms which allowed unresolved grief to be kept from Emily's awareness.

Following initial assessment, two sessions of grief therapy were undertaken. Feedback of formulation was an important initial step given that, in accordance with the nature of conversion disorders, Emily was unaware of the connection between her symptoms and the nature of the underlying difficulties. Emily was able to acknowledge the intense feelings of grief she still experienced when reminded of her husband and mother, the latter in particular. She cried throughout the session following this. Therapy then focused on helping Emily accept both the negative and positive emotions she experienced in relation to these individuals. She had had good relationships with both. During this work it became evident that Emily's expectations of coping in relation to work and in her role as a mother, were unrealistic and contributed to the stress and anxiety she reported. She tended to perceive her own mother as "perfect", - a woman who coped admirably with all life events without difficulty. Emily compared herself against this ideal image, a standard which she consequently failed to live up to. Cognitive challenging techniques were employed to help modify this image and allow more realistic expectations of her own coping and ability. During this Emily remembered that her mother, following her own mother's death, experienced vocal difficulties. She, however, had experienced complete vocal loss ie. aphonia. This helped Emily accept her mother had experienced difficulties coping at times. In relation to her husband, Emily repeatedly described him as, "never a great talker" and identified that he, like her own father, had difficulties expressing emotions, particularly with his sons. This, she felt, had lead to difficult relations between them.

Following grief therapy dysphonia resolved. In the absence of more objective measurement of dysphonia eg. laryngoscope examination, retrospective analysis of clinical case notes was undertaken as a means of evaluating treatment effects. Analysis revealed that dysphonia had been rated as 'severe', 'moderate' and 'absent' for sessions 1-3 respectively. There was no evidence of dysphonic presentation after session 3. Emily reported that colleagues had also noted the change in her voice around that time. They had commented on her accent which they had previously been unaware of. In addition Emily reported increased confidence and assertiveness at work, and she had begun to delegate tasks appropriately to junior staff members without feeling guilty. Consequently Emily felt more confident and able to cope within her work situation. In decreasing subjective loneliness, it had been suggested that Emily discuss her feelings of loss within her own family, particularly with her sister, with whom she had a close relationship. Having done so, Emily felt more supported and able to express herself within this context. She also described improved relationships with her two sons after discussing her feelings openly with them. They commented on the change themselves.

In addition to the cognitive challenging, other anxiety management techniques ie. basic education, relaxation exercises were taught to alleviate residual anxiety, increase perceived control over anxious symptomatology, and thereby act as a means of response prevention for future times of stress. Change in affective symptomatology, measured on the Hospital Anxiety & Depression Scale (HAD) (Zigmond & Snaith, 1983), across the intervention period is illustrated in Figure 1. Results indicate that a decrease in anxious and depressive symptomatology had occurred prior to introduction of specific anxiety management techniques (session 4). Reported improvement in dysphonia, anxiety, assertiveness and feelings of loneliness were maintained at 6 week follow-up.

## Discussion

In alleviating subjective feelings of stress at work, anxiety management, rather than grief therapy, could have been undertaken initially, however, it seems unlikely that this approach would have been as effective in resolving the presenting dysphonia. Whilst absence of a suitable time period between grief therapy and introduction of anxiety management techniques makes it impossible to assess the contribution of individual treatment components, available evidence does lend support to the hypothesis that, for Emily, dysphonia represented a masked bereavement reaction rather than a simple anxiety state.

Firstly, there is evidence from clinical presentation; eg. absence of dysphonia following grief therapy and subjective reports of subsequent vocal change by both Emily and colleagues. Secondly, in concordance with relevant literature, there is evidence that characteristics associated with conversion disorders of the dysphonic type were present; eg. lack of assertiveness, change in perceived support network, stressful life events (death of husband and mother) and disagreement within the family. A family history of inhibited emotional expression both in the family-of-origin and the marital relationship also made it more likely that conversion symptoms would present in this way. Finally, evidence based on interpretation of relevant clinical information supports a grief reaction; dysphonic presentation appears to resemble aspects of the dead individuals; eg. Emily's own mother's history of aphonia (which was triggered by a similar loss), and the phrase she repeatedly used to describe her husband "never a great talker". In interpreting this latter evidence it may be that the conflict between Emily's sons, where the process of communication *itself* was once more disrupted, acted as the final significant trigger which precipitated use of vocal and, therein, expressive difficulties as a defence, at a time when additional loss of support occurred.

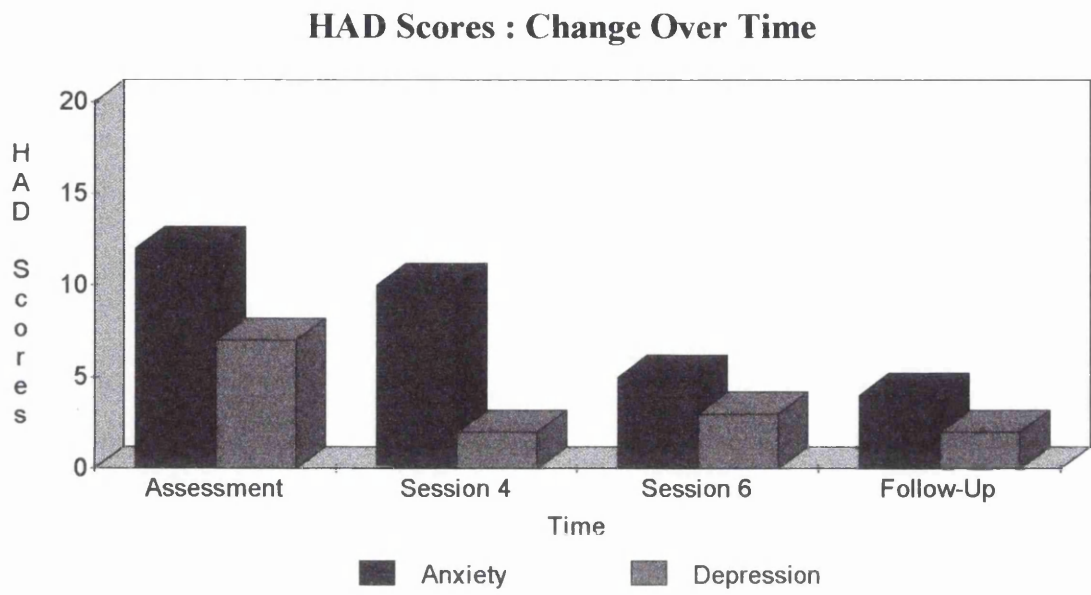
This case illustrates presentation of dysphonia as a masked grief reaction. It highlights the importance of thorough initial assessment including routine questioning of experienced losses, which in this case revealed the underlying problem. Without grief therapy, it does seem likely that some improvement in somatic symptoms would have occurred following anxiety management though whether dysphonia would have resolved remains unanswered. It seems unlikely.

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**Figure 1. HAD Scores : Change over Intervention Period.**



# **SERVICE EVALUATION PROJECT**

**Title : QUALITY OF LIFE WITHIN A RESIDENTIAL SETTING FOR  
INDIVIDUALS WITH LEARNING DISABILITIES.**

**Author : SUSAN RAMSAY, DEPARTMENT OF PSYCHOLOGICAL  
MEDICINE, UNIVERSITY OF GLASGOW.**

**Targeted Journal : Forum**

# **QUALITY OF LIFE WITHIN A RESIDENTIAL SETTING FOR INDIVIDUALS WITH LEARNING DISABILITIES**

**SUSAN RAMSAY, Department of Psychological Medicine,  
University of Glasgow**

## **Introduction**

As Goode (1990), points out, there has been an increasing interest in the concept of quality of life in recent years, and it has been demonstrated that social environments have a considerable impact on an individuals way of life (Edgerton, 1975). This growing interest is also increasingly reflected in the human services sector (Schalock et al. 1989).

In line with the principles of normalisation (Wolfensberger, 1983), recent legislation emphasises the need to provide services, including residential placements, to people with learning disabilities in the community. The Kings Fund Centre has been increasingly influential in the planning and development of community placements for people with learning disabilities, which is highlighted by the 'An Ordinary Life' (Kings Fund Centre, 1980). Emerson and Pretty (1987) highlighted that one of the fundamental objectives of these facilities is to 'enhance the quality of life experiences of those whose status has been significantly devalued'. With this recognised necessity of providing a good quality of life to people with learning disabilities (Landesman, 1986), there has been a corresponding interest in using quality of life as an outcome measure in the evaluation of service provision to this

population (Quellette-Kuntz, 1990). However, to date the views of the learning disabled have largely been overlooked, and this groups satisfaction with their quality of life has rarely been assessed (Heal and Harner, 1992).

### *What is meant by Quality of Life?*

A number of social, environmental factors have been used to indicate quality of life. These have included for instance, environmental conditions eg. health, housing, friendship, leisure, which can be objectively measured. Psychological indicators however tend to be more subjective. Schalock et al. (1989) suggest that the greater the satisfaction with these social factors the greater personal well-being and life satisfaction individuals will report. In considering an individuals quality of life both social and psychological factors need to be assessed (Campbell et al. 1976).

The study aimed to evaluate, in terms of objective and subjective measures of quality of life, the service provided to a group of people with learning disabilities currently living within a hospital, habilitation setting, prior to their move to community living. Specifically, the study aimed to determine the extent to which a group of individuals living within the habilitation area of a traditional hospital setting (Bungalows, RSNH) were satisfied with their quality of life. Information gathered would also be used as baseline data since reassessment, following move to the community, was planned.

### *Residential Setting*

The group selected for community placement were all living in the habilitation area within the grounds of a large hospital for people with learning disabilities. The 'Bungalows' are small houses for groups of up to 8 people, supervised by staff 24 hours a day.

## **Method**

### *Selection*

Fifteen individuals had been proposed, by a multidisciplinary team, as suitable candidates for resettlement in the community. Selection was based on a number of criterion: including groups of two or three individuals who were living together successfully, and who, it was believed, would continue to enjoy living together in the community. Selection was also influenced by regional funding policy.

### *Interviews*

All fifteen candidates were assessed by one member of the Psychology Department. An initial meeting took place with the candidates where a brief discussion of the purpose of the interview followed. All candidates agreed to take part in the study. Confidentiality of information was assured. It was also emphasised that there would be no change to the participants present living circumstances as a result of the interview. Assessment of each individual took place in their own homes, which is the preferred setting (Faire, 1985), and one in which the individual is most likely to be relaxed (Atkinson, 1988). Assessment took place over a number of sessions and was conducted as an interview. The average number of sessions for interview was 3. The time taken to complete assessment with each individual was, on average, two hours.

### *Assessments*

The range of assessments administered to each individual were as follows. Assessments 3-6 were given to respondents in a random order to control for order effects

1) THE BRITISH PICTURE VOCABULARY SCALE-Short Form (Dunn et al.,1982)

There is a non-verbal test, which measures individuals' level of comprehension. It was administered first in the series of assessments, to give the assessor a general indication of the interviewee's level of understanding.

2) 39 STEPS CHECKLIST (Gunzberg, 1973)

This simple checklist is designed to indicate the extent to which the home situation approximates to a normalised, rather than an institutionalised, living environment. The presence or absence of 39 key features of both physical environment and the daily routines of living, are assessed.

3) QUALITY OF LIFE INDEX (Schalock et al. 1989)

This measure was devised specifically for use with a learning disabled population. It is a 28 item scale devised to assess objectively quality of life, which is defined in terms of the three subscales; i) Environmental Control, ii) Community Involvement and iii) Social Relations. A measure of the overall QOL (Total Quality of Life Index) is obtained from these subscales.

4) LIFESTYLE SATISFACTION SCALE (Heal and Harner, 1993)

Satisfaction with current lifestyle is measured by this scale. Individuals are required to answer questions relating to their satisfaction with i) home and community, ii) friends, free time, leisure and recreation and iii) employment. The assessor is required to rate the strength of response on a 5 point scale which ranges from overwhelmingly favourable (assertive, affirmative, enthusiastic) to overwhelmingly negative (vigorous, unqualified, negative). Again a measure of overall satisfaction with present quality of life is obtained (Total Lifestyle Satisfaction). The scale also incorporates a measure of acquiescence which gives an indication of the degree to which an individual exhibits the tendency to say 'yes' to questions posed by the examiner.

#### 5) SLAPS (Simon, 1992)

This measure provides a further indication of quality of life. It has been devised from four indices of subjective quality of life measure and is based on self report of i) satisfaction with a variety of living situation components, ii) loneliness, iii) positive or negative affect derived from bi-polar adjective questions eg. happy - sad, and iv) perceived stress.

#### 6) SELF ESTEEM

This is a measure which is currently being developed and evaluated by the Psychology Department. Individuals are asked 16 questions which assess the current perception they hold of themselves and their abilities. Individuals are asked to select one of four faces (Very Happy to Very Unhappy) to describe how they feel about themselves in relation to specific questions. Each of the four faces has a standard point value. A total score, indicating level of self esteem, is obtained for each individual.

### **Results**

Of the fifteen residents involved in this evaluation, 3 were female, giving a male : female ratio of 3:1. Ages ranged from 28 to 72 years. The mean age was 50.9 years.

#### *39 Steps Checklist*

Results on the 39 Steps environmental measure suggests that, from a possible score of 39 (indicative of a 'homely' environment), the Bungalows score of 33 compares favourably with that obtained by the traditional hospital based ward (RSNH), which was 11. The Bungalows score is suggestive of a 'normalised' environment, providing some evidence that the aims of the Bungalows, as a habilitation service stressing independence and individual choice, are being met.

### *Quality of Life Index*

Table 1 shows the means and the range of scores obtained on the Quality of Life Index. The possible range of scores for the Total QOL Index is from 28 (low quality of life), to 84 (high quality of life).

The data obtained during the development of this scale provide information on a group of individuals with a learning disability living in the community in the USA. Because of the disparity between the type of group used in this development of the scale and that used in this project, comparison can only be performed at a descriptive level.

It appears that, in comparison with a similar group of individuals receiving Level 5 support in the community (supervision, training, assistance and support on a 24 hour basis), the mean QOL Index compares favourably. This result suggests that the group studied here report a better quality of life than a similar group living in the community, in the USA on this objective measure. Lack of vocational activity was apparent for the majority of this group, and contributed to lowering the overall group mean.

### *Lifestyle Satisfaction Scale*

Table 2 shows the group's mean and standard deviation scores on the Lifestyle Satisfaction Scale. In terms of the Total Lifestyle Satisfaction score there is a significant difference between the obtained results and the published norms, (obtained from a community sample) indicating that the group here are significantly less satisfied with their quality of life. However, as the authors point out slightly lower scores are to be expected in the group studied here ie. living within a more



restrictive home setting which is hospital based, and again lack of vocational activity lowered mean scores.

Further caution is required in evaluating these results, as high acquiescence scores, which differ significantly from the published norm, were obtained, and indicate a greater tendency in this group to acquiesce on this measure. Correlations between this and other measure of lifestyle satisfaction were also found to be surprisingly low suggesting that either the results are of dubious validity, or that this measure reflects some quite different aspect of satisfaction with lifestyle.

### *SLAPS*

Table 3 shows group mean scores and percentiles on this subjective measure. On both the Loneliness and Perceived Stress subscales higher percentile scores indicate a more negative outcome - ie. perceptions of greater loneliness and perceived stress. The results indicate this group report satisfaction with their lifestyle at the 38th percentile in comparison to a similar group of individuals. In choice of bi-polar adjectives this group scores at the 45th percentile.

### *Self Esteem*

Possible scores on this measure range from 9 (low self-esteem) to 36 (high self-esteem). The obtained range of results was from 10 to 36, with a mean Self-Esteem score of 27.57, suggesting a moderately high level of self-esteem exists across the group.

Correlations performed highlight significant relationships between specific aspects of quality of life (subscales of the SLAPS measure) and more global measures (Total QOL Index). Scores on the Loneliness subscale were found to have

significant negative relationship with the Total QOL Index ( $r = -0.74$ ,  $p < 0.05$ ), suggesting that perceptions of loneliness are associated with an overall poorer quality of life on this measure.

A significant negative relationship was also found between Loneliness and Total Self-Esteem scores ( $r = 0.57$ ,  $p < 0.05$ ). Whilst this result should be viewed tentatively given that the Self-Esteem measure is being piloted, it appears that higher scores of reported loneliness are associated with an overall lower self-esteem score. Scores on the SLAPS Stress subscale and Total Self-Esteem measure, were also negatively correlated, ( $r = -0.76$ ,  $p < 0.05$ ), suggesting that higher levels of stress are associated with lower self-esteem scores.

Further correlations revealed a significant positive relationship between the Total QOL Index and the Total Self-Esteem score, ( $r = 0.69$ ,  $p < 0.05$ ). The relationship found suggests that a better reported quality of life is associated with a more positive score on the self-esteem measure.

## **Discussion**

The results of the 39 Steps Checklist suggests that a favourable 'home' environment has been created for this group of individuals. As a habilitation environment, and transitional link between hospital and community living, it appears to encompass many essential features of a 'normal' home environment, which promotes independence and choice, two of the major aims of the service. Certainly informal observation of environmental features, living routines and staff behaviour and attitudes towards the residents support this view.

Data obtained on the more objective measurement of quality of life, QOL Index, suggests that the group selected received a service providing them with positive experiences in terms of i) environmental control, ii) social relationships and iii) community involvement, although the latter is restricted by lack of vocational activity for the majority of the group. More subjective measurement, obtained in terms of residents own opinions on the SLAPS measure, suggests that they are less satisfied with their lifestyles than objective measures of quality of life alone (QOL Index) would suggest. The group did report comparatively high levels of stress and loneliness, which were associated with lower scores on the QOL Index. Perceptions of loneliness and stress would certainly contribute to less lifestyle satisfaction.

It is interesting to note that the preliminary data obtained on the measure of self-esteem imply an association between self-esteem and objective measures of quality of life ie. community involvement, social relationships and environmental control. This suggests that these factors are important in contributing to a person's view of themselves. Lower self-esteem ratings were also associated with increased reports of stress and loneliness.

The evaluation undertaken is the initial stage in evaluating services provided to this group of individuals prior to their discharge from hospital to community living. The results obtained are to be used as a baseline data against which this planned move and change of service can be evaluated. Follow-up and re-assessment 6 months post discharge is planned. In addition current areas of need were highlighted ie. vocational activity for this group as a whole. It is recommended that the service addresses this lack of vocational activity. Exploration of available employment opportunities, involvement in college courses and structures community activities or day centre placements should be undertaken.

## **Conclusion**

Overall it appears that the habilitation area provides residents with access to a 'normalised' home environment. In addition social factors which form the objective measure of quality of life are well developed in this setting, and associated with improved self-esteem. However, lack of vocational activity was a problem for this group. Subjective measurement suggests that loneliness and stress contributed to lowering individuals own perceptions of satisfaction with their lifestyles, which in turn were associated with lower self-esteem. Involvement in regular structured vocational activity in the community is recommended to help reduce perceptions of loneliness and improve self-esteem.

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**Table 1 : Group Mean and Range of Scores on Quality of Life Index**

SCALE	MEAN	RANGE		NORM MEAN
		Min.	Max.	
Total Quality of Life Index	58.07	52	64	44
- Environmental	30.33	26	35	
- Community Involvement	10.4	8	15	
- Social Relations	17.33	14	21	

**Table 2 : Lifestyle Satisfaction Scale Scores : Group Mean and Standard Deviations**

SCALE	OBTAINED SCORE		NORMS	
	MEAN	S.D.	MEAN	S.D.
Total Lifestyle Satisfaction	-11.33	14.81	6.5	15.9
- Community	2.8	5.6	5.8	5.2
- Recreation	-11.73	10.47	-4.2	11.4
- Job	-2.4	8.91	4.9	3
- Acquiescence	12.13	5.95	4.3	3.4

**Table 3 : Group Mean Scores on the SLAPS Measures**

SCALE	MEAN	PERCENTILES	NORMS
- Lifestyle Satisfaction	8.98	38.5	9.28
- Loneliness	29.3	80.2	26.01
- Affect	13.35	45.6	13.11
- Perceived Stress	1.67	67.5	1.66

# **APPENDICES**

## **APPENDIX A**



## SCOPE

*Behavioral Medicine* is an interdisciplinary journal of research and practice that deals with psychosocial influences on health and behavior and the implications and applications of research findings in this field. It publishes original controlled research studies, both experimental and clinical; evaluation studies; occasional review articles; case reports; and book reviews.

In addition to the studies described above, the journal seeks three-part, coordinated submissions on a theme topic that deal in depth with (1) a review of the literature on a health problem that can be treated through the use of sound psychological or behavioral interventions; (2) the evidence from clinical field trials and applied research for the usefulness of the behavioral intervention; (3) an analysis of the policy implications of the therapy and means of introducing it into mainstream health practices. Wherever possible, the economic impact of new or evolving therapies should be included in the discussion.

Those who are interested in submitting such a three-article series should work directly with the executive editors of *Behavioral Medicine*, providing a detailed outline of their proposal; the names and qualifications of participating authors; and an estimate of the time frame for completion. Proposals should be submitted to the managing editor, *Behavioral Medicine*, Heldref Publications, 1319 Eighteenth Street, NW, Washington, DC 20036-1802 (202-296-6267, X-214; fax: 202-296-5149).

## SUBMISSION REQUIREMENTS

1. Send three copies of manuscripts to Managing Editor, *Behavioral Medicine*, Heldref Publications, 1319 18th St NW, Washington, DC 20036-1802. Pre-

ferred length is 15-20 pages, including references, tables, and figures.

2. Include an abstract of no more than 150 words and 3 to 5 index terms. The article title should be short, specific, and clear; text in research submissions should be divided into sections headed Method, Results, and Discussion.

3. List authors' names, academic degrees, affiliations, current positions, telephone, fax or electronic mail numbers, and address on a separate page; indicate who is to serve as corresponding author.

4. Include a separate letter stating that the manuscript has not been submitted simultaneously to any other publication.

5. Double space manuscripts in all parts, including references, tables, figures, and notes. Use 1-inch margins and leave right margin unjustified. Please do not use elaborate typographic effects.

6. Type tables on a separate sheet of paper; use them sparingly as a nonredundant enhancement of the text. Send figures in camera-ready form.

7. Follow the *American Medical Association Manual of Style*, 8th edition, Baltimore: Williams & Wilkins; 1989, in matters of medical and scientific usage and reference format.

8. Include written permission from publishers and authors to reproduce or adapt previously published tables or figures.

9. Await acceptance before sending disks; details about appropriate word-processing programs for Heldref Publications will be sent at that time.

10. Indicate approval by the institutional review board for all studies involving human subjects; describe how subjects gave informed consent.

## EDITORIAL PROCESS

Authors are responsible for the accuracy of all material submitted. Before submit-

ting a manuscript, authors should proof-read carefully, double-checking all statistics, numbers, symbols, references, and tables.

Manuscripts are usually blind reviewed by at least two consulting editors and an executive editor. When reviews have been completed (after about 4 months), the managing editor will notify the corresponding author of the editors' decision to accept, reject, or ask for revision of the manuscript. Review comments will be forwarded to the authors; rejected manuscripts will not normally be reconsidered.

Accepted manuscripts are published within 6 months to 1 year of acceptance. Each author receives 2 complimentary copies of the journal issue in which the article appears. Additional copies and reprints are available to authors at a reduced price.

## REFERENCES

Limit references to those cited in the text. They should be numbered with superscripts in order of appearance. *Behavioral Medicine* does not use the author-date system of references. Abbreviations of journal names should conform to those used in *Index Medicus*. Common forms are as follows:

### Journal Article

1. Beecher HK. Ethics and clinical research. *N Engl J Med*. 1966;274:1354-1360.

### Book

2. Pearson K. *The Grammar of Science*. 2nd ed. London, England: Adam and Charles Black; 1900.

### Article in Book

3. Lambrinos J, Papadakis PJ. The analysis of risks, costs, and benefits in critical care. In: Fein LA, Strosberg MA, eds. *Managing the Critical Care Unit*. Rockville, MD: Aspen Systems; 1987: 358-370.

## RENAL UNIT PROJECT

We are undertaking a small study within the Renal Unit and would appreciate it if you would be willing to participate. It will probably take about 45 minutes of your time.

The study is aimed at finding out how hemodialysis affects different people. For some, treatment might be very stressful, whilst for others this might not be the case. We are interested in finding out what people find difficult or easy about the treatment they receive.

Beginning dialysis usually means that peoples' lives change. We are interested in how people cope with these changes, particularly how people on dialysis manage the changes in their diet and fluid intake.

If you agree to take part you will be asked to fill in some questionnaires and answer a few questions.

**Your answers will be anonymous and all information will be treated in the strictest confidence. No other members of the Renal Unit will have access to your individual answers.**

We would also appreciate it if we could use some basic information which is in your medical notes. We need your permission to use this information and would therefore appreciate it if you could sign the consent form below.

---

### CONSENT FORM

I \_\_\_\_\_ give my permission for relevant information from my medical notes to be used in this study. I understand that this information, and all information obtained in the process of this study, will be treated in the strictest confidence.

Signature \_\_\_\_\_ Date \_\_\_\_\_

## INFORMATION

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

1) I.D. \_\_\_\_\_ [ ]

2) D.O.B. \_\_\_\_/\_\_\_\_/\_\_\_\_ AGE IN YEARS [ ]

3) SEX        Male  
              Female [ ]

4) MARITAL STATUS  
      Married/Living with Partner  
      Single  
      Disrupted Marriage (div/sep/wid.) [ ]

5) NUMBER IN HOUSEHOLD [ ]

6) EDUCATION  
      School Leaver  
      College  
      Graduate/Professional  
      Other (Specify) \_\_\_\_\_ [ ]

7) OCCUPATIONAL STATUS  
      Unemployed (Medical)  
      Unemployed (Other)  
      Employed (Full-Time)  
      Employed (Part-Time)  
      Student (Full-Time)  
      Student (Part-Time)  
      Retired  
      Retired (Medical)  
      Other (Specify) \_\_\_\_\_ [ ]

- 8) **TIME ON DIALYSIS** Starting Date \_\_\_\_/\_\_\_\_/\_\_\_\_
- 0 - 6 months
  - 6 - 12 months
  - 1 - 2 years
  - 2 - 5 years
  - 6 - 10 years
  - 11 - 20 years
  - > 20 years [ ]
- 9) **DIABETIC STATUS**
- Non-Diabetic
  - Diabetic [ ]
- 10) **TRANSPLANT HISTORY**
- No Transplant
  - Transplant [ ]
- 11) **No. of FAILED TRANSPLANTS : If Applicable** [ ]
- 12) **MEMBER OF SUPPORT GROUP**
- Yes
  - No [ ]
- 13) **SPECIFY GROUP/S : If Applicable**
- Kidney Association Support Group [ ]
  - Other Local Specialist Group [ ]
  - National Association [ ]
  - Other (Specify) \_\_\_\_\_ [ ]
- 14) **INVOLVEMENT - TYPE (Tick as many as apply) : If Applicable**
- Receive information eg. newsletters etc. [ ]
  - Telephone contact eg. helpline [ ]
  - Home-visits [ ]
  - Drop-In facility [ ]
  - Group meetings eg. discussions, social events etc. [ ]
  - Other (Specify) \_\_\_\_\_ [ ]

**15) INVOLVEMENT - FREQUENCY OF CONTACT : If Applicable**

**Exact Contact \_\_\_\_\_**

**Once a fortnight or more**

**Once a month**

**Once every 2 months**

**Once every 3 months**

**Once every 6 months**

**Once a year**

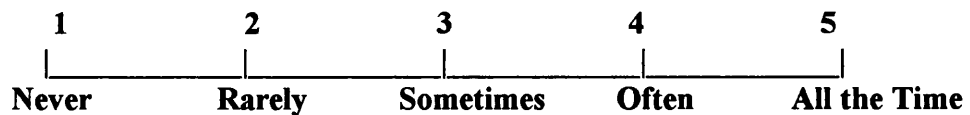
**[ ]**

## DIALYSIS-REGIMEN SUPPORT SCALE (DRSS)

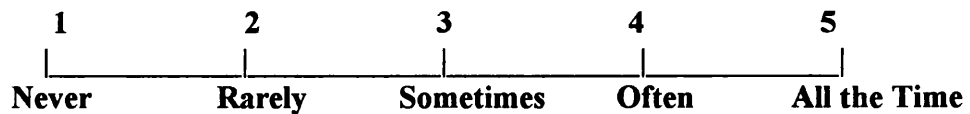
The questions below ask about how 'others' react to different aspects of your dialysis regime, particularly those aspects to do with your diet and fluid restrictions. By 'others', this can mean anyone you are close to or see on a regular basis, eg. friends and family, or who are specifically connected with your treatment ie. any of the Renal Unit staff.

For each question circle the number which best describes how often others react in the manner described.

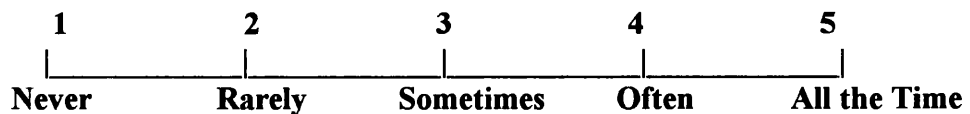
1. Others tell me I'm doing well/praise me when I manage to follow my diet.



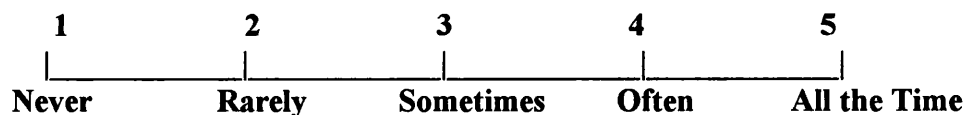
2. Others encourage me to stick to my diet.



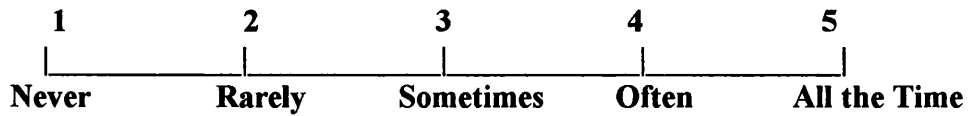
3. Others will try to take my mind off things when I want to eat the wrong foods.



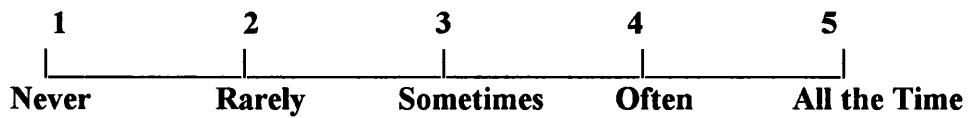
4. If I have difficulty understanding what I should and should not eat, others will try to explain things to help me understand.



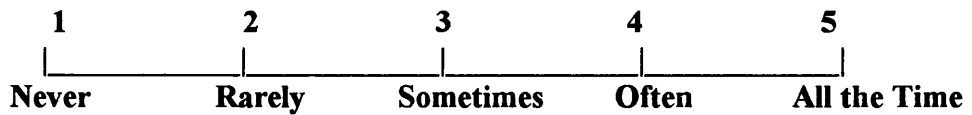
**5. Others remind me to eat the right types of foods.**



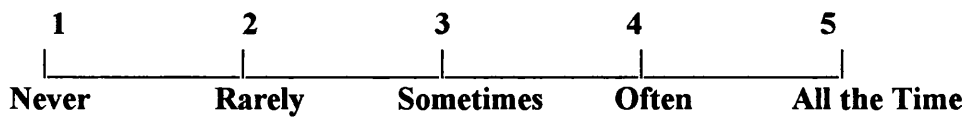
**6. Others encourage me to drink only the amount I have been advised.**



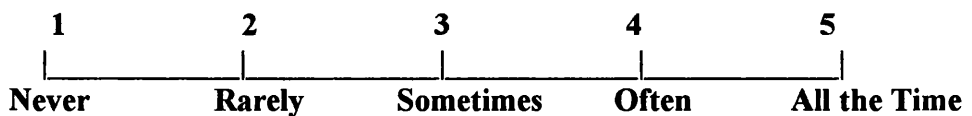
**7. Others will try to take my mind off things when I want to drink more than I should.**



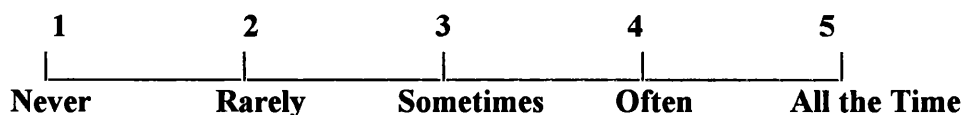
**8. Others remind me not to drink more than I have been advised.**



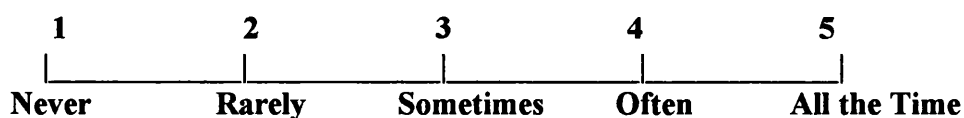
**9. Others tell me I'm doing well/praise me when I manage not to drink more than I should.**



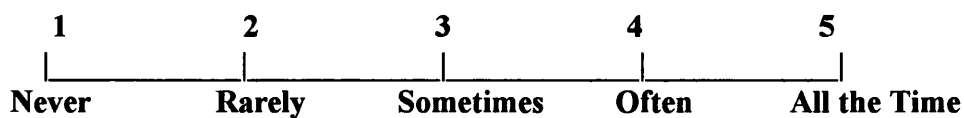
**10. Others remind me to take all of my medications.**



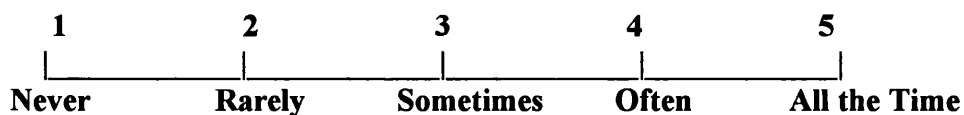
**11. If others are preparing food for me they make it according to my diet.**



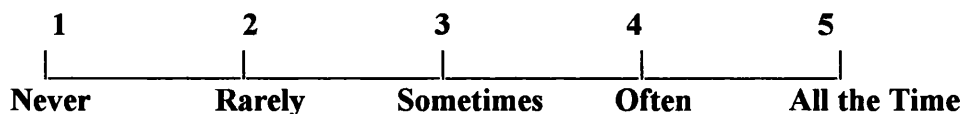
**12. If I am eating with others they plan their meals to fit in with my diet.**



**13. Others tell me to follow the advice of the renal unit team.**



**14. Others tell me I should follow the advice of the renal unit team ie. following my diet and fluid restrictions and taking my medication, since it will be helpful to my long-term health.**





## SELF-REPORT COMPLIANCE-QUESTIONNAIRE (SRCQ)

It is often difficult for people on dialysis to stick to the advise given by the medical team. For the questions below please answer as accurately as you can.

Please remember all your answers are anonymous.

1. In your opinion, how many days in the last week (7 days) have you stuck to your diet?

\_\_\_\_\_ days.

2. In general, how difficult do you find sticking to your diet?

1	2	3	4	5
----- ----- ----- -----				
Not At All	Mildly	Fairly	Very	Impossible
Difficult	Difficult	Difficult	Difficult	

3. Listed below are some times when you might find it particularly difficult to stick to your diet. Please tick the one(s) which best describe when you find it most difficulty to do this.

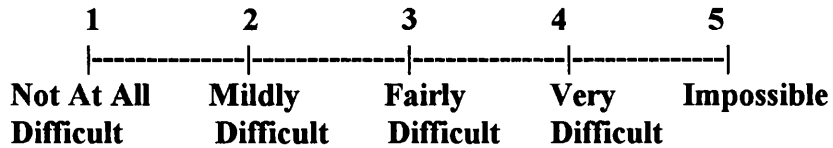
When I'm

.... by myself	<input type="checkbox"/>
.... with others	<input type="checkbox"/>
.... at home	<input type="checkbox"/>
.... outside	<input type="checkbox"/>
.... feeling in a bad mood eg.unhappy/worried/frustrated etc.	<input type="checkbox"/>
.... feeling in a good mood eg. happy, excited, content etc.	<input type="checkbox"/>
.... feeling particularly unwell	<input type="checkbox"/>
.... in social situations	<input type="checkbox"/>
.... bored	<input type="checkbox"/>
.... other (please specify) _____	<input type="checkbox"/>

4. In your opinion, how many days in the last week (7 days) have you managed to drink only the amount of fluid recommended by the Renal Unit Team?

\_\_\_\_\_ days.

**5. In general, how difficult do you find sticking to your recommended fluid allowance?**



**6. Listed below are some times when you might find it particularly difficult to restrict the amount of fluid you drink. Please tick the one(s) which best describe when you find it most difficulty to do this.**

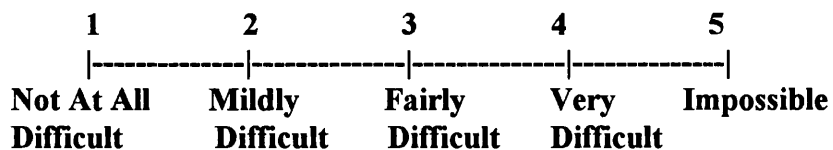
**When I'm**

- |   |                          |
|---|--------------------------|
| .... by myself  | <input type="checkbox"/> |
| .... with others  | <input type="checkbox"/> |
| .... at home  | <input type="checkbox"/> |
| .... outside  | <input type="checkbox"/> |
| .... feeling in a bad mood eg.unhappy/worried/frustrated etc. | <input type="checkbox"/> |
| .... feeling in a good mood eg. happy, excited, content etc.  | <input type="checkbox"/> |
| .... feeling particularly unwell                              | <input type="checkbox"/> |
| .... in social situations                                     | <input type="checkbox"/> |
| .... bored  | <input type="checkbox"/> |
| .... other (please specify) _____                             | <input type="checkbox"/> |

**7. In your opinion, how many days in the last week (7 days) have you taken all the medications you are prescribed?**

\_\_\_\_\_ days.

**8. In general, how difficult do you find taking all your prescribed medications?**



**9. Listed below are some times when you might find it particularly difficult to take all your medications. Please tick the one(s) which best describe when you find it most difficulty to do this.**

**When I'm**

- .... **thirsty**
- .... **feeling in a bad mood eg.unhappy/worried/frustrated etc.**
- .... **feeling in a good mood eg. happy, excited, content etc.**
- .... **feeling particularly unwell**
- .... **other (please specify) \_\_\_\_\_**

## **Supplementary Information**

### **The Dialysis Regimen Support Scale**

**Table 1 : Correlation Matrix of Support Measures**

**Figure 1. Distribution of DRSS Score**

**Figure 2. Scatterplot of ESRD-SI Ratings**

**Table 2 : Correlation Matrix of Biochemical Indices of Compliance & Reported Difficulty Coping**

**Table 3 : Correlation Matrix of Self-Report Indices of Compliance & Reported Difficulty Coping**

**Table 4 : Correlation Matrix for Self-Reported Difficulty with Compliance across Components**

**Figure 3. Scatterplot of LES & Biochemical Indices**

**Figure 4. Scatterplot of LES & Self-Report Compliance Indices**

**Figure 5. Scatterplot of HSS & DRSS Groups**

**Figure 6. Scatterplot of HSS & SSQNo Groups**

**Figure 7. Scatterplot of HSS & SSQSat Groups**

## **The Dialysis Regimen Support Scale (DRSS)**

This measure was developed specifically for use in the presented research study. Literature on social support was reviewed in detail for the purposes of the study, with relevant and selective summaries of this presented in detail elsewhere (See Review)<sup>9</sup>. During this process, the author critically evaluated social support measures within the health-related literature, particularly measures assessing behaviours theorised to be supportive to health-related practices and compliance. In addition, relevant literature reporting outcome from empirical investigations and intervention studies on compliance and ESRD were included. In essence relevant literature, by authorities working within the field, was reviewed and used as the basis for scale components. Content validity was empirically supported since the items were acceptable based on a critical review of studies by noted authorities in dialysis and psychologists in the field.

Following this initial phase, the protocol was critically reviewed by clinical psychologists working within the area, and commented on by members of the Renal Unit team (ie. consultant, dietician and research nurse). Minor modifications were made, eg. elimination of superfluous questions, vocabulary changed, prior to piloting with a small sample of ESRD patients. There were no difficulties highlighted during this pilot. The questionnaire itself was reportedly easy to understand and complete.

Table 1 shows correlations between the DRSS and other measures of social support utilised in the present research. The DRSS is seen to show a significant and positive relationship with other support measures, in particular the satisfaction index (SSQSat) of the Social Support Questionnaire-Short Form,<sup>21</sup>( $r = .28, p < .05$ ). The SSQ is reported to have good validity and reliability.

From the total population sample, exploratory data analysis revealed a bimodal distribution of scores on the DRSS measure (see Figure 1). Further analysis could not account for the distribution in terms of any identifiable background variable assessed during the course of the study.

**Table 1 : Correlation Matrix of Support Measures**

	DRSS	SSQNO	SSQSAT
DRSS	1.0000 (67) P= .	-.1401 (66) P= .262	.2783 (66) P= .024 *
SSQNO	-.1401 (66) P= .262	1.0000 (68) P= .	.2265 (67) P= .065
SSQSAT	.2783 (66) P= .024	.2265 (67) P= .065	1.0000 (68) P= .

**DRSS = Dialysis Regimen Support Scale; SSQNO = Social Support Questionnaire - No. of Support Index; SSQSAT = Social Support Questionnaire - Satisfaction Index.**

**\* p<0.05**

Figure 1. Distribution of DRSS Scores

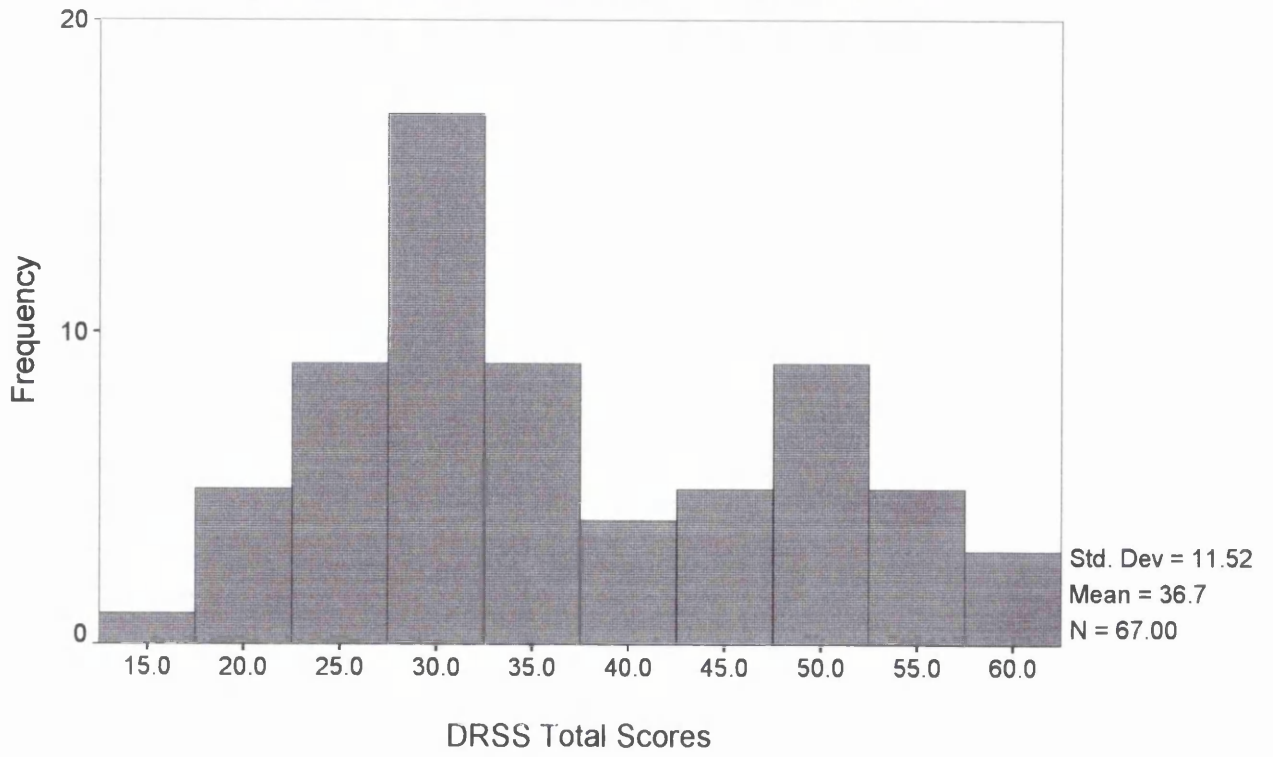
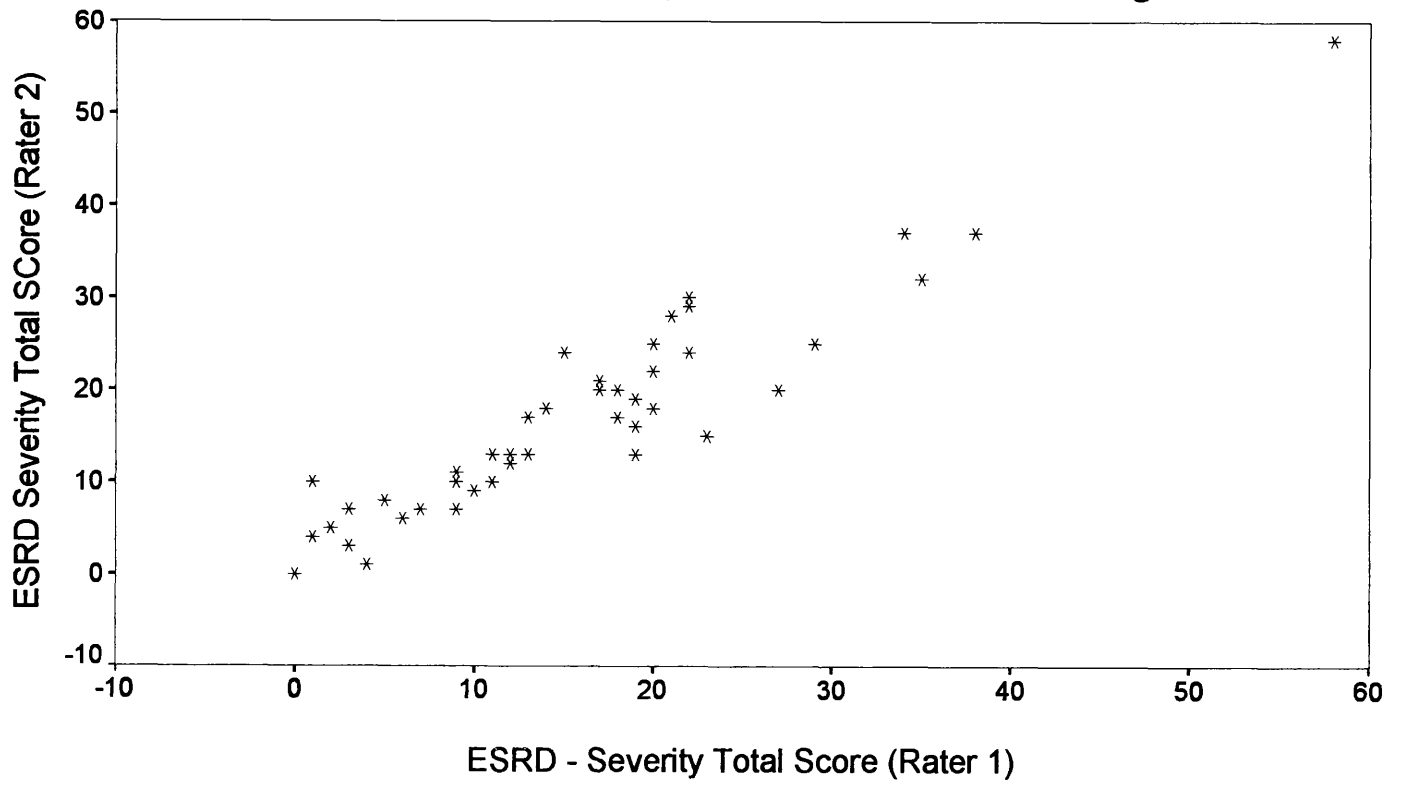




Figure 2. Scatterplot of ESRD-SI Ratings



**Table 2 : Correlation Matrix of Biochemical Indices of Compliance  
& Reported Difficulty Complying**

SRDDDIET	SERUMK -.1024 (67) P= .410	IWG .1805 (68) P= .141	P04 .1827 (65) P= .145
SRDFLUID	.0851 (65) P= .500	.3510 (66) P= .004 ***	.2202 (63) P= .083 *
SRDMED	.3244 (67) P= .007 **	.0753 (68) P= .542	.3530 (65) P= .004 ***

IWG = Interdialytic Weight Gain, Serum K = Serum Potassium, P0<sub>4</sub> = Blood Phosphorous.

SRDDiet = Self-Reported Difficulty Complying with Dietary Recommendations; SRDFluid = Self-Reported Difficulty Complying with Fluid Recommendations; SRDMed = Self-Reported Difficulty Compliance with Medication Recommendations.

\* p<0.10    \*\* p<0.01    \*\*\* p<0.005

**Table 3 : Correlation Matrix of Self-Report Indices of Compliance  
& Reported Difficulty Complying**

	<b>SRCDIET</b>	<b>SRCFLUID</b>	<b>SRCMED</b>
<b>SRDDIET</b>	<b>-.4619</b> <b>(69)</b> <b>P= .000</b> <b>***</b>	<b>-.3460</b> <b>(68)</b> <b>P= .004</b> <b>**</b>	<b>-.1366</b> <b>(69)</b> <b>P= .263</b>
<b>SRDFUID</b>	<b>-.2295</b> <b>(67)</b> <b>P= .062</b>	<b>-.6471</b> <b>(67)</b> <b>P= .000</b> <b>***</b>	<b>-.2479</b> <b>(67)</b> <b>P= .043</b> <b>*</b>
<b>SRDMED</b>	<b>-.2879</b> <b>(69)</b> <b>P= .016</b> <b>*</b>	<b>-.2804</b> <b>(68)</b> <b>P= .021</b> <b>*</b>	<b>-.5541</b> <b>(69)</b> <b>P= .000</b> <b>***</b>

**SRC**Diet = Self-Reported Compliance with Dietary Recommendations; **SRC**Fluid = Self-Reported Compliance with Fluid Recommendations; **SRC**Med = Self-Reported Compliance with Medication Recommendations.

**SRD**Diet = Self-Reported Difficulty Complying with Dietary Recommendations; **SRD**Fluid = Self-Reported Difficulty Complying with Fluid Recommendations; **SRD**Med = Self-Reported Difficulty Compliance with Medication Recommendations.

**\*** p<0.05    **\*\*** p<0.01    **\*\*\*** p<0.005

**Table 4 : Correlation Matrix for Self-Reported Difficulty with  
Compliance across Components**

	<b>SRDDIET</b>	<b>SRDFLUID</b>	<b>SRDMED</b>
<b>SRDDIET</b>	<b>1.0000</b> <b>(69)</b> <b>P= .</b>	<b>.3930</b> <b>(67)</b> <b>P= .001</b> <b>**</b>	<b>.1718</b> <b>(69)</b> <b>P= .158</b>
<b>SRDFLUID</b>	<b>.3930</b> <b>(67)</b> <b>P= .001</b> <b>**</b>	<b>1.0000</b> <b>(67)</b> <b>P= .</b>	<b>.2820</b> <b>(67)</b> <b>P= .021</b> <b>*</b>
<b>SRDMED</b>	<b>.1718</b> <b>(69)</b> <b>P= .158</b>	<b>.2820</b> <b>(67)</b> <b>P= .021</b> <b>*</b>	<b>1.0000</b> <b>(69)</b> <b>P= .</b>

**SRDDiet = Self-Reported Difficulty Complying with Dietary Recommendations; SRDFluid = Self-Reported Difficulty Complying with Fluid Recommendations; SRDMed = Self-Reported Difficulty Complying with Medication Recommendations.**

**\* p<0.05    \*\* p<0.005**

Figure 3. Scatterplot of LES & Biochemical Indices

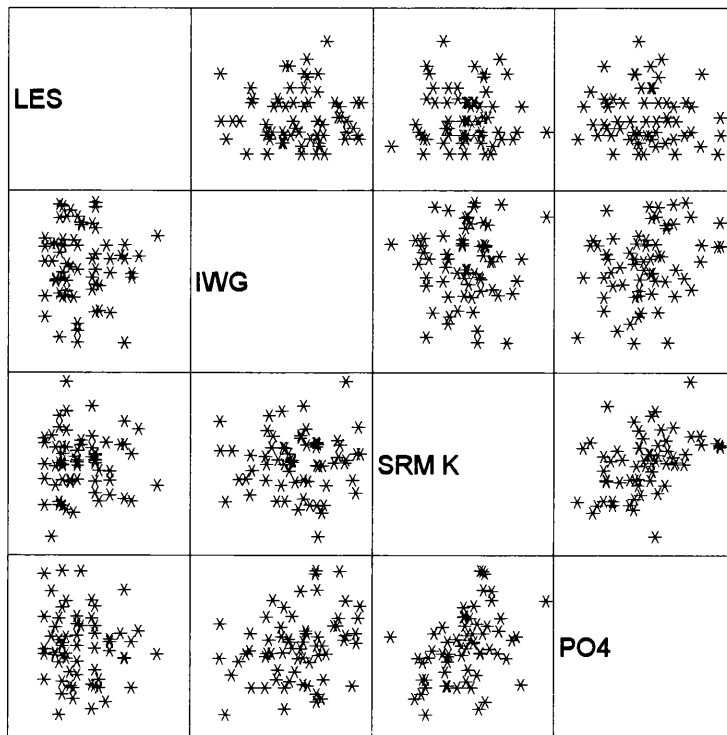


Figure 4. Scatterplot of LES & Self-Report Compliance Indices

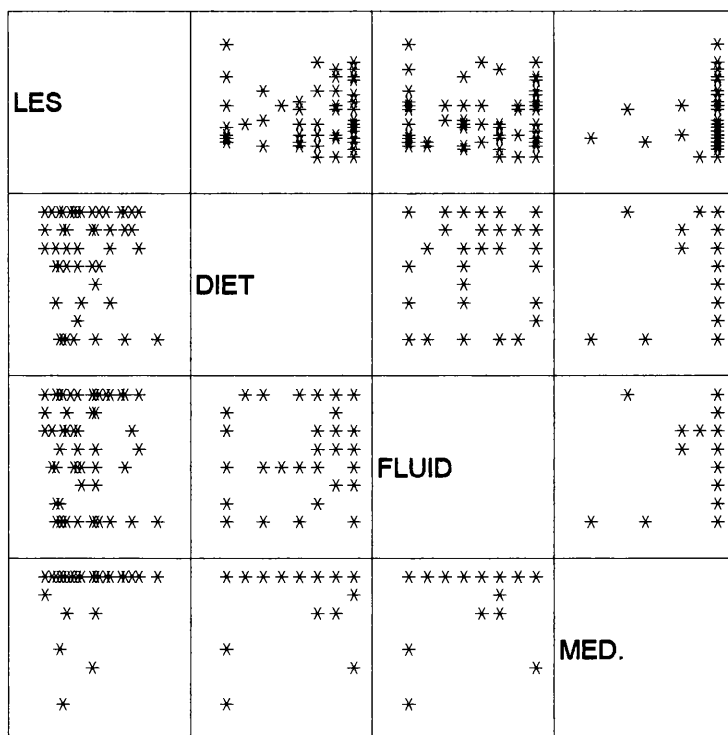


Figure 5. Scatterplot of HSS & DRSS Groups

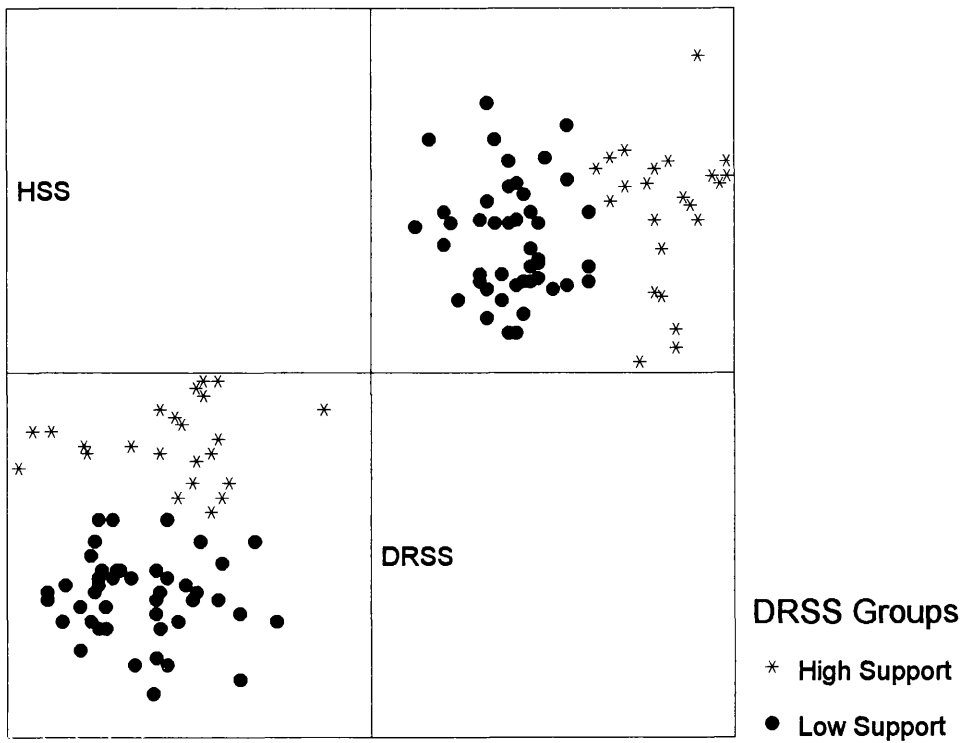


Figure 6. Scatterplot of HSS & SSQNo Groups

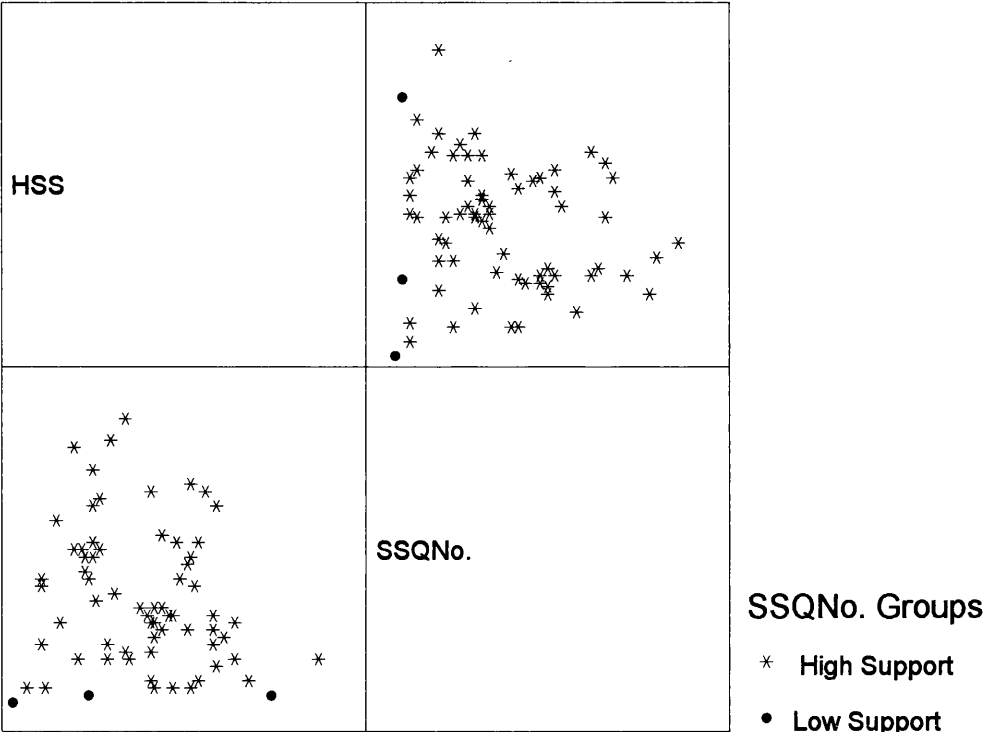
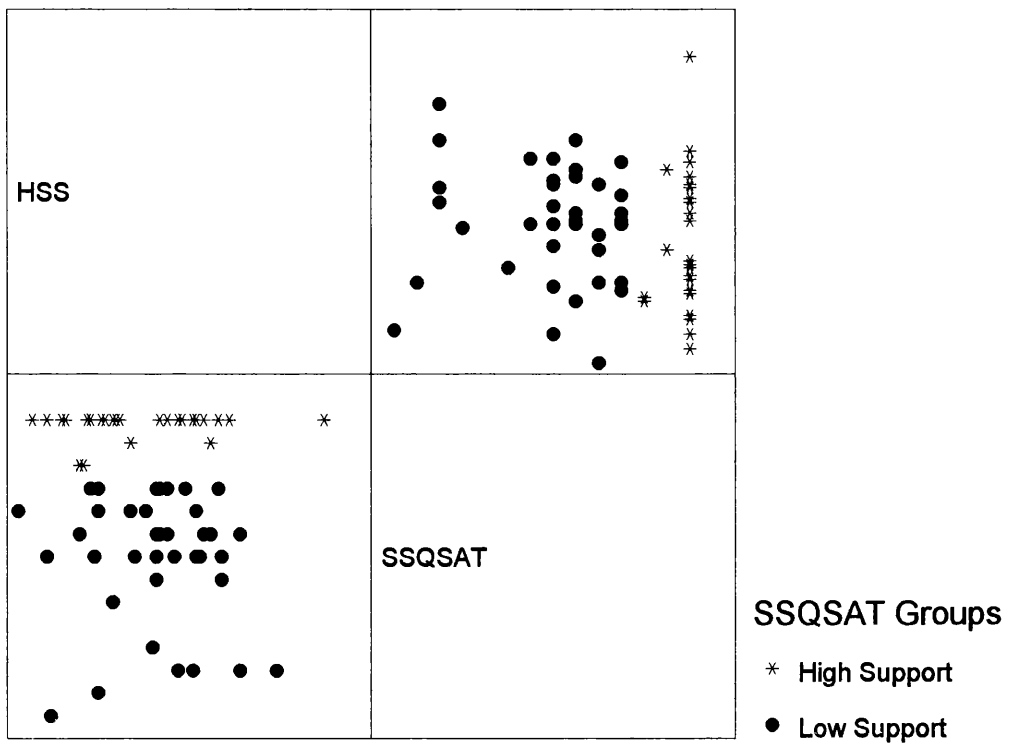




Figure 7. Scatterplot of HSS & SSQSat Groups



## **APPENDIX B**

## Notes for Contributors

The *Journal of Mental Health* welcomes original communications and articles which have relevance to the field of mental health. Papers are accepted on the understanding that they are subject to editorial revision and that their contents have not been published elsewhere.

Manuscripts should be sent to the Executive Editor, Ian Hughes, Department of Clinical Psychology, Whitchurch Hospital, Cardiff, CF4 7XB, United Kingdom.

To expedite assessment, 3 complete copies of each manuscript should be submitted. They should be typed on one side of the paper, double spaced, with ample margins of at least 25mm. The first sheet should include the full title of the paper, a short title not exceeding 45 characters (for a running title at the head of each page), names of authors and the address where the work was carried out. All pages should be numbered. Each article should be accompanied by a summary of not more than 150 words, typed on a separate sheet. The full postal address of the author who will check proofs and receive correspondence and offprints should also be included. Footnotes should be avoided where possible.

In order to improve accuracy and cut down the publishing lag authors are requested, if possible, to also submit their manuscripts on disc. Preferably this should be in Microsoft Word for an Apple Macintosh (3.5" disc). Alternatively, the following IBM compatible packages can be accepted: Microsoft Word; Displaywrite; Multimate; Samna Word; Wang PC; Word Perfect; Word Star; Word Star 2000; Volkswriter.

References should be submitted in the Harvard system. References should be indicated in the typescript by giving the author's name, with the year of publication in parenthesis, eg Smith (1989); or - if there are more than 3 authors - Smith et al (1989). If several papers from the same author/s and from the same year are cited, (a), (b), (c), etc should be put after the year of publication.

The references should be listed in full at the end of the paper, on a separate sheet. They will take the following standard forms:

Hodgson, R.J. & Rollnick, S. (1989). *More Fun, Less Stress: how to survive in research*. In: Parry, G. & Watts, F. (Eds) *A Handbook of Skills and Methods in Mental Health Research*. London, Lawrence Erlbaum.

Powell, T.J. & Enright, S.J. (1990). *Anxiety and Stress Management*. London, Routledge.

Rachman, S., Cobb, J., Grey, S.J., McDonald, B., Mawson, D., Sartory, G. & Stern, R. (1979). The behavioural treatment of obsessive-compulsive disorders, with and without clomipramine. *Behaviour Research and Therapy*, 17, 467-478.

Title of journal should not be abbreviated. Unnecessary references should be avoided.

Clear, graphical and tabular presentation is strongly encouraged.

Illustrations should not be inserted in the text. Each should be provided separately, and numbered on the back with Figure numbers, title of paper, and name of author/s. Illustrations should be prepared about twice their final size. Three copies of all figures must be submitted. All photographs, graphs and diagrams should be referred to as Figures and should be numbered consecutively in the text in arabic numerals (eg Fig 3). The approximate position of each illustration should be indicated in the text. A list of captions for the Figures should be submitted on a separate sheet and should make possible interpretation - without reference to the text. Captions should include keys to symbols.

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Proofs are supplied for checking and making essential corrections, not for general revision or alteration. Proofs should be corrected and returned to the publisher within 3 days of receipt.

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## **APPENDIX C**

# Clinical Child Psychology and Psychiatry

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Editor Dr Bryan Lask

Department of Psychological Medicine, Great Ormond Street Hospital for Children, Great Ormond Street, London WC1N 3JH, UK  
Tel: +44 (0)171 829 8679 Fax: +44 (0)171 829 8657

## INSTRUCTIONS TO AUTHORS

To ensure rapid and efficient processing of your contribution it would be most helpful if you could take careful note of the following information:-

Articles submitted for publication must be typed in double spacing throughout, on one side only of white A4 paper, with generous left and right-hand margins. There is no absolute limit on length, but 7500 words, including footnotes and references, is a useful target. An abstract of up to 150 words should precede the main text, accompanied by up to five key words.

Titles and section headings should be clear and brief. Lengthy quotations (exceeding 40 words) should be displayed, indented, in the text. British or American spellings may be used. British spellings should use the "z" spelling in those words where it has generally replaced the "s", eg organize. Indicate italic type by underlining, and use single quotation marks. Dates should be in the form "9 May 1994". Take out points in USA and other such abbreviations and do not use points after Dr, Mr, Mrs, etc. When referring to pagination and dates use the smallest number of numerals possible (eg 10-19, 42-5, 1961-4, 1978-85).

Tables and figures should have short, descriptive titles. All footnotes to tables and their source(s) should be typed below the

tables. Column heading should clearly define the data presented. Camera-ready artwork for all figures must be supplied. Artwork intended for same-size use should have a maximum size of 170:100mm (page depth: page width); oversized artwork should be prepared in the same proportion.

Essential notes should be indicated by superscript numbers in the text and collected on a single page at the end of the text. References cited in the text should read thus: Brown (1990: 63-4), Brown and Smith (1985, 1990). Use "et al" when citing a work by more than two authors, eg Brown et al (1991). The letters a, b, c, etc, should be used to distinguish citations of different works by the same author in the same year, eg Brown (1975a, b) All references cited in the text should be listed alphabetically and presented in full after the notes, using the following style:

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Books: Nelson, Richard R and Winter, Sidney G (1982). An Evolutionary Theory of Economic Change. Cambridge, MA: Harvard University Press.

Articles in Books: Sable, Charles F (1992). 'Studied Trust:

Building New Forms of Co-operation in a Volatile Economy',  
in Frank Pyke and Werner Sengenberger (eds) Industrial  
Districts and Local Economic Regeneration, pp.215-50. Geneva:  
International Institute for Labour Studies.

Unpublished works: Pearce, David G (1987). 'Renegotiation-proof  
Equilibria: Collective Rationality and Inter-temporal  
Cooperation', Mimeo, Yale University.

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## **Supplementary Information**

### **Drawings from Initial Assessment Session**

**Protective Mother Bird & Tiger**

**Bags Packed**

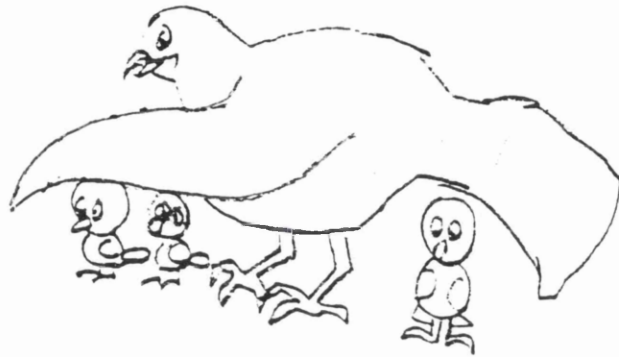
### **Drawings from Intervention Sessions**

**Angry Feelings**

**Family Showing Anger**

**Anger Towards Mother**

**Anger Towards Father**



"Protective Mother Bird."

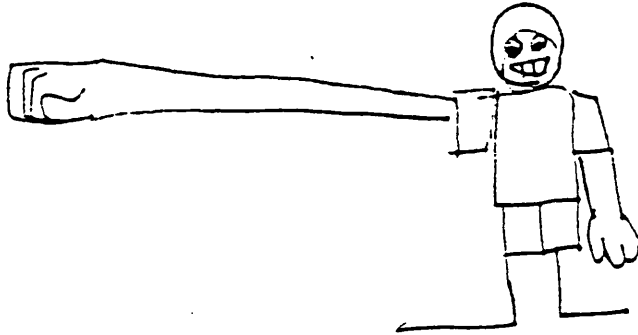
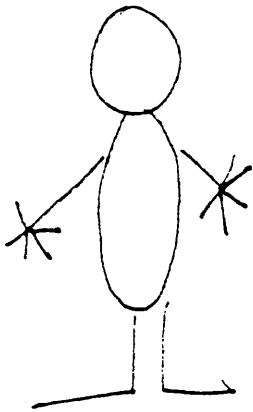


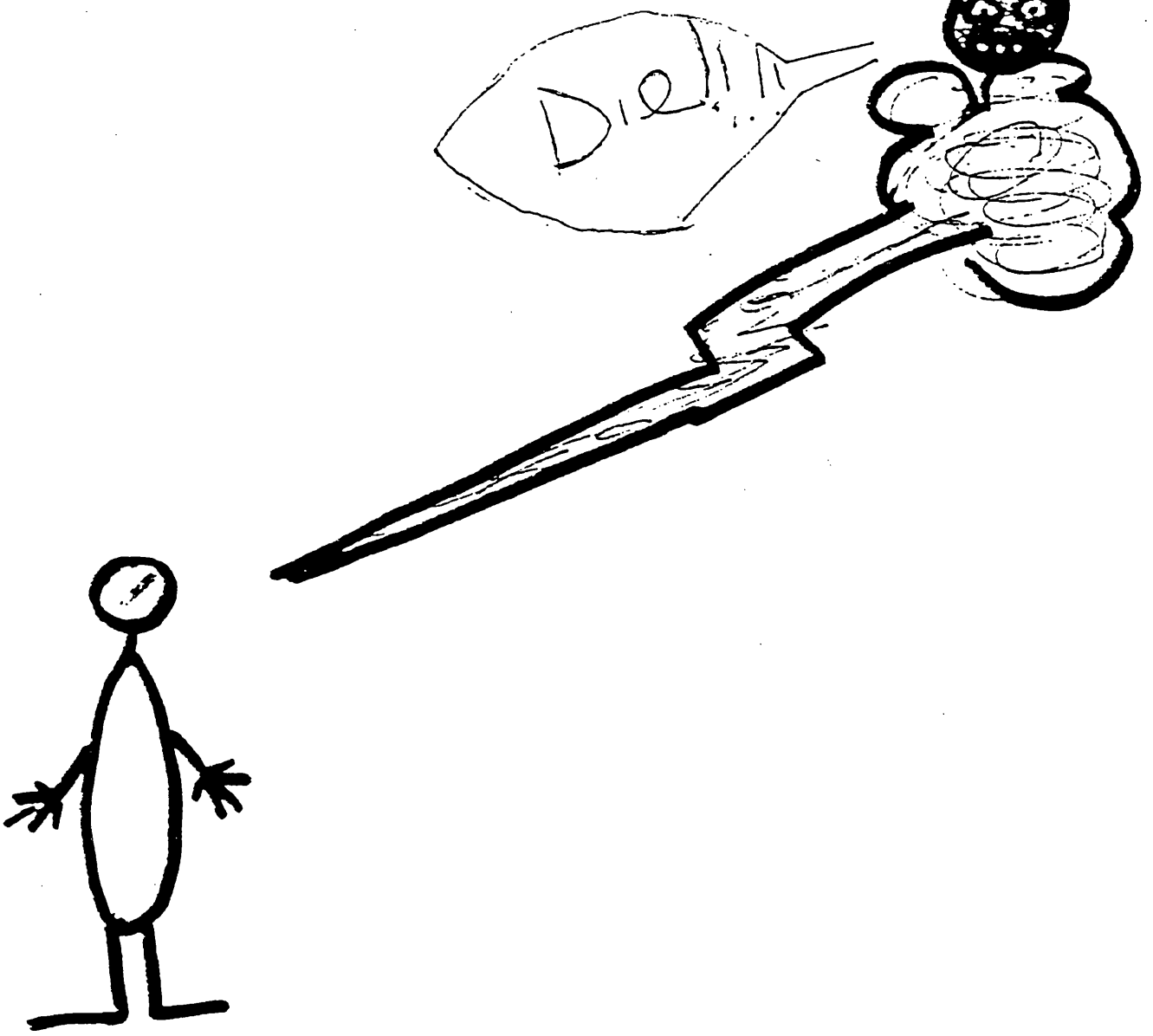
"Tiger"











## **APPENDIX D**



## Instructions to Authors

1. **Submission.** Articles written in English and not submitted for publication elsewhere, should be sent to Paul Salkovskis, Editor, *Behavioural and Cognitive Psychotherapy*, Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford OX3 7JX, UK.

2. **Manuscript preparation.** Four complete copies of the manuscript must be submitted. Original figures should be supplied at the time of submission. Articles must be typed double-spaced throughout on standard sized paper (preferably A4) allowing wide margins all round. Where unpublished material, e.g. behaviour rating scales, therapy manuals, etc. is referred to in an article, copies should be submitted to facilitate review.

Manuscripts will be sent out for review exactly as submitted. Authors who want a blind review should mark two copies of their article "review copy" omitting from these copies details of authorship.

*Abbreviations* where used must be standard. The Système International (SI) should be used for all units; where metric units are used the SI equivalent must also be given. Probability values and power statistics should be given with statistic values and degrees of freedom [e.g.  $F(1,34) = 123.07, P < 0.001$ ], but such information may be included in tables rather than the main text.

*Spelling* must be consistent within an article, either using British usage (*The Shorter Oxford English Dictionary*), or American usage (*Webster's New Collegiate Dictionary*). However, spelling in the list of references must be literal to each original publication.

Details of style not specified here may be determined by reference to the *Publication Manual of the American Psychological Association* or the style manual of the British Psychological Society.

Articles should conform to the following scheme:

(a) *Title page.* The title should phrase concisely the major issues. Author(s) to be given with departmental affiliations and addresses, grouped appropriately. A running head of no more than 40 characters should be indicated.

(b) *Summary.* This should summarize the article in no more than 200 words.

(c) *Text.* This should begin with an introduction, succinctly introducing the point of the paper to those interested in the general area of the journal. *Attention should be paid to the Editorial Statement which appears in the January and July issues at the back of the Journal.* References within the text should be given in the form Jones and Smith (1973). When there are three or up to and including five authors the first citation should include all authors; subsequent citations should be given as Williams *et al.* (1973). Authors with the same surname should be distinguished by their initials. The approximate positions of tables and figures should be indicated in the text. Footnotes should be avoided where possible.

(d) *Reference note(s).* A list of all cited unpublished or limited circulation material, numbered in order of appearance in the text, giving as much information as possible about extant manuscripts.

(e) *References.* All citations in the text should be listed in strict alphabetical order according to surnames. Multiple references to the same author(s) should be listed chronologically, using a, b, etc., for entries within the same year. Formats for journal articles, books and chapters should follow these examples:

BECKER, M. R. and GREEN, L. W. (1975). A family approach to compliance with medical treatment: A selective review of the literature. *International Journal of Health Education* 18, 173-182.

THORP, R. G. and WETZEL, R. J. (1969). *Behaviour Modification in the Natural Environment*. New York: Academic Press.

ROSKIES, E. and LAZARUS, R. S. (1980). Coping theory and the teaching of coping skills. In P. O. Davidson and S. M. Davidson (Eds). *Behavioural Medicine: Changing Health Lifestyles*. New York: Brunner/Mazel.

(f) *Footnotes.* The first, and preferably only, footnote will appear at the foot of the first page of each article, and subsequently may acknowledge previous unpublished presentation (e.g. dissertation, meeting paper) financial support, scholarly or technical assistance, or a change in affiliation. Its concluding (or only) paragraph must be the name and full mailing address of the author to whom reprint requests or other inquiries should be sent.

(g) *Tables.* Tables should be numbered and given explanatory titles.

(h) *Figure captions.* Numbered captions should be typed on a separate page.

(i) *Figures.* Original drawings or prints must be submitted for each line or half-tone illustration. Figures should be clearly labelled and be camera-ready wherever possible.

3. **Proofs, Reprints and Copyright.** Proofs of accepted articles will be sent to authors for the correction of printers' errors; author's alterations may be charged. Authors submitting a manuscript do so on the understanding that if it is accepted for publication exclusive copyright of the paper shall be assigned to the Association. In consideration of the assignment of copyright, 25 copies of each paper will be supplied. Further reprints may be ordered at extra cost; the reprint order form will be sent with the proofs. The publishers will not put any limitation on the personal freedom of the author to use material contained in the paper in other works.

## Behavioural and Cognitive Psychotherapy: Editorial Statement

*Behavioural and Cognitive Psychotherapy* is an international multidisciplinary journal for the publication of original research, of an experimental or clinical nature, that contributes to the theory, practice and evolution of behaviour therapy. As such, the scope of the journal is very broad, and articles relevant to most areas of human behaviour and human experience, which would be of interest to members of the helping and teaching professions, will be considered for publication.

As an applied science, the concepts, methodology and techniques of behavioural psychotherapy continue to change. The journal seeks to reflect and to influence those changes.

While the emphasis is placed on empirical research, articles concerned with important theoretical and methodological issues as well as evaluative reviews of the behavioural literature are also published. In addition, given the emphasis on behaviour therapy on the experimental investigation of the single case, the Clinical Section of the journal publishes case studies using single case experimental designs. For the majority of designs this should include a baseline period with repeated measures; in all instances the nature of the quantitative data and the intervention must be clearly specified. Exceptionally, the journal will consider case studies where, although the interventions have not been experimentally evaluated, the treatment approach and/or problem dealt with is considered to be of particular importance *and* clear indicators of change are provided. Other types of case report can be submitted for the Brief Clinical Reports section (see below).

The following types of articles are suitable for *Behavioural and Cognitive Psychotherapy*:

1. Reports of original research employing experimental and correlational methods and using within or between subject designs.
2. Review or discussion articles which are based on empirical data and which have important new theoretical, conceptual or applied implications.
3. Brief reports and systematic investigations in single cases employing innovative techniques and/or approaches.

Articles should concern original material which is neither published nor under consideration for publication elsewhere.

### Accelerated Publication Section

In order to respond to rapid development in the field, the journal includes an accelerated publication section. Articles accepted in this section will appear in the first possible issue of the journal, usually 3–6 months from receipt by the editors.

The accelerated publication section is intended to accommodate a small number of important papers. Such papers will include major new findings for which rapid dissemination would be of considerable benefit and impact. For example: reports of the results of important new clinical trials; innovative experimental results with major implications for theory and practice; other work of unusually high calibre.

Authors wishing to submit manuscripts for the accelerated publication section *must* briefly indicate in a covering letter (i) their reasons for requesting accelerated publication; (ii) that the material is original and has not been published or is not currently under consideration for publication elsewhere, (iii) that in the event of acceptance, the authors agree to the assignment of all copyrights to the manuscript in all forms and media to the British Association for Behavioural and Cognitive Psychotherapies. Authors should also indicate whether they wish the manuscript to be transferred to the normal (non-accelerated) review process if rejected for either of the stages of accelerated review outlined below. When submitting, the envelope should be clearly marked **ACCELERATED REVIEW**.

Accelerated review will proceed in two stages:

1. In the first stage, an editor and a reviewer will decide whether, in principle, the study merits accelerated publication. Authors will be informed within 14 days of receipt if this stage is *not* passed, and the manuscript will be withdrawn at that stage or continue in the normal (non-accelerated) review track, depending on the preference specified by the author(s).
2. Once passed in principle, the paper will then be subject to review by the same reviewers as in stage 1 using normal criteria. At the end of this stage, manuscripts will be either accepted (with or without minor alterations) or rejected for accelerated publication. Acceptance will depend on unanimity between the reviewer and editor. If accelerated publication is ruled out at this stage, a manuscript will revert to normal review if this option has been indicated by the author(s), otherwise it will simply be returned.

In order to maximize the speed at which accelerated review proceeds, details of decisions on accelerated publication will be restricted to whether the manuscript has been accepted or not. Where applicable, minor alterations requested should be returned to the editors within three days of receipt. If a manuscript is transferred to the non-accelerated review track, the normal journal conventions regarding review decisions will be adhered to. The entire accelerated review process from receipt to final decisions should take an *average* of 2 weeks.

### Brief Clinical Reports

Material suitable for this section includes unusual case reports, accounts of potentially important techniques, phenomena or observations; for example, descriptions of previously unreported techniques, outlines of available treatment manuals, descriptions of innovative variations of existing procedures, details of self-help or training packages, accounts of the application of existing techniques in novel settings and so on. The brief clinical reports section is intended to *extend* the scope of the clinical section. Submissions for this section should be *no longer than five typescript, double spaced pages*, and should include no more than six references. However, the author/s *must* also include with the submission copies of an extended report which contains fuller clinical details. There are no restrictions on the size or format of this backup document. This may, for instance, be a treatment manual or a fully detailed case report, therapy transcript and so on. As both the report and the extended document will be sent for review, the usual number of copies are required. If a submission is accepted for publication as a Brief Clinical Report, the author/s must be prepared to send the fuller document to those requesting it, free of charge or at a price agreed with the editor to reflect the cost of materials involved.

# **CASE REPORT**

**MASKED BEREAVEMENT PRESENTING AS DYSPHONIA  
SUPPLEMENTARY INFORMATION**

## **MASKED BEREAVEMENT PRESENTING AS DYSPHONIA**

### **REFERRAL**

Emily, a 54 year old woman, was referred to the psychology department by her G.P., for relaxation training related to stress at work. She worked as a nursery school teacher. Initial interview took place two months after referral in February.

### **PRESENTING PROBLEM**

Emily presented as a pleasant, mature woman, who was tearful throughout interview. She spoke very quietly and at times it was difficult to hear her. Emily described "being unable to cope with life in general", in particular, there were difficulties at work. Due to staff shortages, forthcoming external assessment, and subsequent demands on time, there were ongoing pressures at work which Emily felt unable to deal with. In general she felt "inadequate and past doing the job". She had difficulty delegating tasks and being assertive, and felt guilty asking colleagues to help. This was a requirement of her job as a supervisor. Emily also felt under constant pressure at home, and described feeling guilty if she sat down to relax during the day. Somatic symptoms of anxiety eg. breathlessness, chest tightness, palpitations, were experienced on occasion. Her main physical complaint however related to her voice, which would lose volume, and become very faint when she spoke. Occasionally she lost her voice altogether and no sound would be projected. She described heightened subjective awareness of her throat and constant thirst. There was no pain. Loss of voice recently had been triggered by tiredness, stress at work, and reported low mood. Vocal difficulties were experienced as extremely distressing. Emily also described feeling 'depressed' and was tearful much of the time. Delayed sleep onset occurred due to reported worry about work.

Exacerbation of pressure at work in recent months, had lead to G.P. consultation and referral, however vocal difficulties had begun two years previously. There were no additional stressors in her work at that time, although a number of changes in her home life had occurred. Her two adult sons had a disagreement and did not speak to each other for approximately one year. Emily felt responsible for the situation. Around that time her grandson was also born. Due to demands on his time, Emily had less contact with her oldest son following the birth. Since then she had felt increasingly isolated and lonely. Emily coped with feelings of loneliness and inadequacy at work by avoidance, she described keeping herself busy to avoid letting herself "sit and mope about how miserable I feel".

### **Significant Background Relating to Presenting Problem**

There had been a number of significant deaths in recent years. Emily's husband died 8 years previously and her mother 2 years later. Both deaths occurred around Easter. Emily had a particularly close relationship with her mother, who had been a great support to her when her husband died. She had moved very soon after her husband's death. Following both bereavements Emily returned to work almost immediately, and described coping by "keeping myself busy", a pattern of behaviour which continued to the present day. Emily had not spent any significant time alone since her mother's death, that is up until two years ago, when the difficulties and changes in her own family situation arose. Distress was apparent when Emily discussed her bereavements.

## **HISTORY**

### **Medical**

A medical cause for the reported vocal difficulties had been excluded, although susceptibility to throat infections had been present since childhood.

### **Psychological/Psychiatric**

There was no previous history of psychological/psychiatric problems, or past family history. Her brother was, however, experiencing similar subjective stress at work.

### **Personal History**

Emily was the middle child, with one sister and one brother. She was born and brought up in England, living with her family until she married at the age of 22 when she moved to Scotland with her husband. Emily described a happy childhood, though related it had been difficult to express opinions and emotions within the family. Emily met her prospective husband when she was 19 and married 3 years later. She described him as "never a great talker". They had two sons. In terms of relationships, Emily had made and maintained lasting friendships, though described herself as rather shy. She had experienced a number of deaths ; her father died in April, 1977, her husband in 1987 and her mother in 1989.

### **Educational/Occupational History**

Emily attended local primary and secondary schools. On leaving school she worked as a clerical officer. She left one job aged 17, because of sexual advances made by a fellow employee at the time. The difficulties were not addressed directly and she had left without explanation. Following the birth of her two sons, she returned to work in various clerical jobs prior to training as a nursery nurse, aged 32. She had been in her current post for 10 years.

### **Pre-Morbid Personality**

Prior to onset of difficulties Emily described herself as "fairly easy going", enjoying others company and her involvement in hobbies.

## **CURRENT CIRCUMSTANCES**

Emily lived alone. She was in a relationship of three years, her partner was himself a widower. Emily maintained regular telephone contact with both her brother and sister, who still lived in England. One neighbour was a great source of support for her. Emily had attended and benefited from yoga classes. She had a number of outside interests eg. church activities, and hobbies eg. reading, decorating.

## **ASSESSMENT MEASURES**

### **1) Clinical Interview and Observation**

### **2) Self Report Measures**

- Hospital Anxiety and Depression Scale (HAD) Zigmond & Snaith (1983).  
This measure of anxious and depressive symptomatology was administered at 4 points : Initial interview, Sessions 4, 6, and 7 (Follow-Up).

## **FORMULATION**

Emily experienced dysphonia (a conversion syndrome) with a two year history. Anxiety symptoms and low mood were present with a more recent onset of 4 months triggered by stress at work. Current vocal attrition was triggered by stress, tiredness and low mood, and whilst problems at work had exacerbated this, original onset of vocal problems occurred two years previously. Onset at that time had been associated with change in family contact and relationship difficulties, and subsequent feelings of isolation and loneliness. Two significant deaths had occurred and it appeared that the process of grieving had been insufficiently worked through, with avoidance used as a means to cope. Dysphonia appeared to be a masked grief reaction, triggered by feelings of loneliness, following family conflict and loss of perceived support. Lack of assertiveness was also problematic, both at work and



within the family, and contributed to stress. A family history of difficulties dealing with and expressing emotions, appeared to contribute to current presentation of problems. Presentation occurred around the anniversary of the bereavements.

### **TREATMENT AIMS AND RATIONALE**

Formulation identified a number of treatment aims ; i) resolution of unresolved grief, ii) reduction in subjective feelings of loneliness and isolation, iii) reduction in vocal attrition and somatic symptoms of anxiety and v) increased assertiveness.

Worden (1993) points out that for individuals who do not allow themselves to experience grief directly, masked or repressed grief may present as physical symptoms, psychosomatic complaints or aberrant or maladaptive behaviour. Presentation may resemble the dead person in some way. In general terms conversion disorders are explained by one of two mechanisms, whereby the person obtains i) primary gain by keeping an internal conflict or need out of awareness or ii) secondary gain, by avoidance of a noxious activity and support obtained from the environment. Symptoms are not intentionally produced (DSM-IV). For Emily it appeared that presenting dysphonia represented a conversion disorder, reinforced by primary gain. Emily was unaware of her unresolved grief, and avoidance had kept these feelings from being fully experienced. Linking and identifying the underlying grief was therefore essential as a starting point in therapy. Utilising techniques suggested by Worden (1993), the planned purpose of grief therapy was to "resolve the conflicts of separation and facilitate completion of the necessary tasks of grieving". Feelings of loneliness and isolation are common following bereavements (Parkes, 1985). These were experienced by Emily as anxiety provoking, she used avoidance to cope. Exposure, without avoidance, to decrease

this anxiety was planned. In addition techniques suggested by Rokach (1990), eg. reframing the experience of time alone were to be introduced. Evaluation was planned to assess for presence of anxiety on completion of grief therapy. Anxiety management techniques (Clark, 1992) were to be utilised if necessary. Assertiveness was identified as problematic, and contributed to stress, addressing this using techniques outlined by Dickson (1992) was planned.

## **TREATMENT**

Appointments were scheduled initially every week and thereafter fortnightly. There were 7 sessions in all, including follow-up at 6 weeks. Homework tasks were set and reviewed. Full initial assessment took one and a half sessions.

### **Grief (Sessions 2 and 3)**

Grief therapy began with feedback of formulation that presenting dysphonia and difficulties experienced were possibly grief related. Emily was able to acknowledge her unresolved grief. The two bereavements were explored separately. Her mother's death was most distressing, possibly since she herself had acted as Emily's major support at the time of her husband's death. Using Worden's tasks of grief, Emily had accepting the reality of the death's but without the accompanying affective response. Therapy therefore focused on Emily's acceptance and experience of both positive and negative emotions in relation to her mother and husband. During discussion Emily became aware that her mother, following her own mother's death, experienced vocal difficulties, though her reaction had been complete vocal loss ie. aphonia.

### **Loneliness**

In targeting the reported loneliness, a number of techniques were used. To reduce anxiety associated with feelings of loneliness a graded hierarchy was

completed over one week, whereby Emily spent increasing periods of time by herself, not engaged in any other activity. Loneliness for Emily was not related to a small number of social contacts or lack of activities, but rather feelings of isolation in the loss and emotions she experienced, Emily was therefore encouraged to discuss her feelings within her own family networks.

### **Anxiety (Session 4-6)**

Anxiety management techniques were taught, covering the 3 systems approach. This consisted of basic education, relaxation exercises and cognitive challenging. Emily's expectations of coping in relation to work and her role as mother, were identified as unrealistic. Discussion of her mother revealed that Emily compared herself against an ideal which she consequently failed to live up. Modifying this ideal view of her mother was a central part of therapy.

### **Assertiveness**

Emily spontaneously reported increased confidence and assertiveness in work and at home following grief work. Formal assertiveness training was therefore judged to be unnecessary. Reports of assertiveness between sessions were however reinforced. In addition encouragement was given to continue assertiveness tasks and to evaluate their effectiveness.

## **TREATMENT OUTCOME**

Following initial assessment and bereavement work, by Session 4 a number of changes were reported. Dysphonia was no longer present, (following Session 3) and improvements in voice quality eg. volume, had been remarked upon by colleagues. There were spontaneous reports of increased assertiveness at work, Emily was beginning to delegate tasks to more junior colleagues, without feelings of guilt, and reported more confidence in doing so. Emily reported increasing

confidence and assertiveness across the intervention period, which continued to follow-up.

Subjective reports of loneliness and reported anxiety in spending time alone decreased rapidly following grief work and exposure. Emily reported being more at ease in her own company and able to relax when alone at home. By Session 4 Emily had begun to discuss her feelings of loss and loneliness within her family, particularly with her sister, which helped her feel less isolated.

Change in anxious symptomatology and improvement in subjective experience of depression was also evident on assessment measures. Whilst HAD depression score had never reached caseness levels, there is evidence of a decrease in obtained scores by assessment point 2 (Session 4) as illustrated in Figure 1. Prior to introduction of specific anxiety management techniques reported anxiety decreased to borderline level (10). Assessment at Session 6 shows anxiety within normal range. Improvements in anxiety and reported subjective depression were maintained at follow-up.

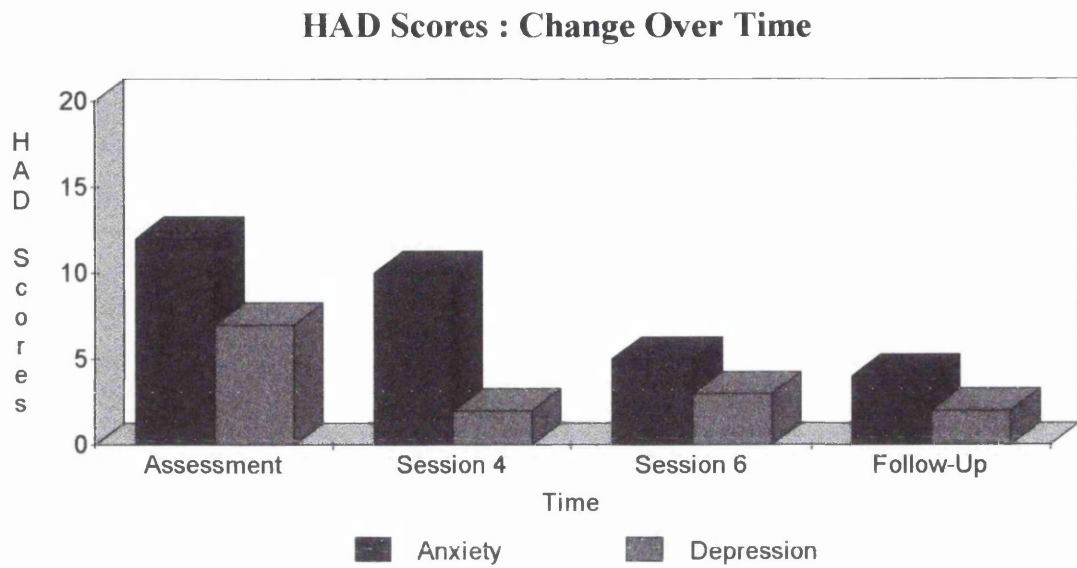
## **SUMMARY**

Dysphonia, anxiety and low mood decreased across the intervention period. Emily was increasingly assertive at work, and reported having more confidence in her ability to cope with demands and stress in this situation. She held more realistic expectations of herself. Whilst there had not been any objective increase in number of social contacts, Emily reported a decrease in feelings of loneliness, and was more at ease in her own company. She had gained support from her own family in dealing with her losses and felt more able to express her feelings openly with them. Overall, she reported less anxiety in expressing her opinions, and was generally feeling more confident in herself.

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**Figure 1. HAD Scores : Change over Intervention Period.**



## **APPENDIX E**

# CLINICAL PSYCHOLOGY FORUM

**Clinical Psychology Forum** is produced by the Division of Clinical Psychology of The British Psychological Society. It is edited by Steve Baldwin, Lorraine Bell, Jonathan Calder, Lesley Cohen, Simon Gelsthorpe, Laura Golding, Craig Newnes, Mark Rapley and Arlene Vetere, and circulated to all members of the Division monthly. It is designed to serve as a discussion forum for any issues of relevance to clinical psychologists. The editorial collective welcomes brief articles, reports of events, correspondence, book reviews and announcements.

## ■ Notes for contributors

Articles of 1000-2000 words are welcomed. Shorter articles can be published sooner. Please check any references. Send two copies of your contribution, typed and double spaced. Contributors are asked to keep tables to a minimum; use text where possible.

News of Branches and Special Groups is especially welcome.

Language: contributors are asked to use language which is psychologically descriptive rather than medical and to avoid using devaluing terminology; i.e. avoid clustering terminology like "the elderly" or medical jargon like "schizophrenic".

Articles submitted to **Forum** will be sent to members of the Editorial Collective for refereeing. They will then communicate directly with authors.

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■ **Clinical Psychology Forum** is published monthly and is dispatched from the printers on the penultimate Thursday of the month prior to the month of publication.



# **SLAPS MEASURE**

**E. Simon  
Bradley Hospital  
Providence  
RI  
1991**

# Life Satisfaction Scale

Score total number of satisfaction items only. Discourage use of middle position if possible. Ask: Are you satisfied or neutral or not satisfied with:

- |   | Sat. | Neut. | Not Sat. |
|---|------|-------|----------|
| 1. The place where I live.                    |      |       |          |
| 2. The people I live with.                    |      |       |          |
| 3. The staff at the place where I live.       |      |       |          |
| 4. My job.                                    |      |       |          |
| 5. My salary.                                 |      |       |          |
| 6. My boss.                                   |      |       |          |
| 7. My friends.                                |      |       |          |
| 8. My neighborhood.                           |      |       |          |
| 9. My family.                                 |      |       |          |
| 10. My freedom to do the things I want to do. |      |       |          |
| 11. My Social Life.                           |      |       |          |

Total Score:     /11

# Loneliness Scale

	YES	ST	NO
1. Is it easy for you to make friends here at _____?	1	2	3
2. Do you like to look at magazines?	1	2	3
3. Do you have people to talk to here at _____?	1	2	3
4. Are you good at living with other people here at ___?	1	2	3
5. Do you watch TV a lot?	1	2	3
6. Is it hard for you to make friends here at _____?	3	2	1
7. Do you like living here?	1	2	3
8. Do you have a lot of friends here at _____?	1	2	3
9. Do you feel alone here at _____?	3	2	1
10. Can you find a friend when you need one here?	1	2	3
11. Is it hard to get people to like you?	3	2	1
12. Do you like to cook?	1	2	3
13. Do you like music?	1	2	3
14. Do you feel left out of things here at _____?	3	2	1
15. Are there people you can go to when you need help here at _____?	1	2	3
16. Do you like to draw and paint?	1	2	3
17. Are you lonely here?	3	2	1
18. Do the people here at _____ like you?	1	2	3
19. Do you enjoy playing card games?	1	2	3

Total Score: \_\_\_\_\_

(Modified from Chadsey-Rusch et al. 1992)

# AFFECT SCALE

Tell me how you feel about your life here and the things that you do.

Discourage use of middle position.

Score only starred (positive ) items.

Pleasant\* .....Middle.....Unpleasant  
Boring.....Middle.....Interesting\*  
Enjoyable\* .....Middle.....Miserable  
Sad.....Middle.....Happy\*  
Rewarding\* .....Middle.....Frustrating  
Good\* .....Middle.....Bad  
Easy\* .....Middle.....Hard  
Like\* .....Middle.....Dislike  
Love\* .....Middle.....Hate  
Alone.....Middle.....Together\*  
Ashamed.....Middle.....Proud\*  
Warm\* .....Middle.....Cold  
Sweet\* .....Middle.....Sour  
Hard.....Middle.....Soft\*  
Accepted\* .....Middle.....Rejected  
Pain.....Middle.....Pleasure\*  
Sunny\* .....Middle.....Rainy  
Dead.....Middle.....Alive\*

Total Score:        /18

# Stress Scale

How do you feel most of the time?

Discourage use of middle category. Score only starred items.

Calm.....Middle.....Tense\*

Worried\*.....Middle.....Relaxed

Peaceful.....Middle.....Pressured\*

Calm.....Middle.....Upset\*

In Trouble\*.....Middle.....Not In Trouble

Calm.....Middle.....Scared\*

Rushed\*.....Middle.....Not Rushed

Total Score      / 7

# **SELF-ESTEEM QUESTIONNAIRE**

**(FOR PEOPLE WITH LEARNING DISABILITIES)**

**I am going to ask you some questions about how you feel about yourself. Listen to the questions then point to the face that describes you. There are no right or wrong answers.**

*(For scoring purposes: 4= happy face; 1 = sad face)*

- |  |          |          |          |          |
|--|----------|----------|----------|----------|
| <b>1) How much do you like yourself?</b>                                   | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>2) How pleased do you feel with yourself?</b>                           | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>3) How equal ("as good as") do you feel compared with other people?</b> | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>4) How useful do you think you are?</b>                                 | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>5) How well can you do things compared with other people?</b>           | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>6) How well do you think you do things?</b>                             | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>7) Do you think you're OK most of the time?</b>                         | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>8) How useless ("waste of time") do you think your life is?</b>         | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |
| <b>9) How good do you look compared with other people?</b>                 | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> |