Coping Strategies and Psychosocial Functioning in Women with Newly Diagnosed Breast Cancer, and their Partners.

and Research Portfolio

Submitted in partial fulfilment of the degree of Doctor of Clinical Psychology within the faculty of Medicine, University of Glasgow.

Julie Dunan
August 1996.
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Many thanks to all those from the Department of Psychological Medicine who offered advice, comments, and encouragement. I am also very grateful to the staff and patients at the Western General without whom this research would not have been possible.

I would particularly like to thank C. M. and my ‘comrades in battle’ for distracting me from the task and providing me with an alternative form of ‘Beck’s therapy’!
Small Scale Service Evaluation Project

Changing Referral Patterns in a New Service for Adults with Learning Disabilities.

Submitted in the format of Health Bulletin.

(see appendix 1.1 for Notes for Contributors)
Changing Referral Patterns in a New Service
for Adults with Learning Disabilities.

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Abstract

This study provides a description of the referrals received by a new clinical psychology service for adults with learning disabilities. The change in referral pattern over the first six months of the service is monitored and urgent and routine referrals are compared and described. The professions referring to this service, waiting times, and numbers referred are discussed.

Throughout the EPPIC (Effective Purchasing and Providing in the Community)\(^1\) categories of 'reason for care' and 'care aim' are used. These categories are part of a new classification system which is to be used to construct care packages for clients receiving clinical psychology services. Their use with this population are discussed.

Objectives

I) The first objective of this study is to provide a description of the referrals made to a new clinical psychology service for adults with learning disabilities. This information is likely to be of benefit to those involved in service planning and development.

II) The second objective is to describe those cases which are perceived as urgent by referrers. This will be determined by comparing urgent and routine referrals. It is expected that those referrals made in anticipation of a new clinical psychology service would contain a higher proportion of urgent cases and this will also be assessed.
III) The final objective is to determine whether the recently developed EPPIC categories can be applied to clinical psychology interventions for adults with learning disabilities.

EPPIC categories are eventually to be used as a method of providing information to purchasers, referrers and clients regarding expected care. The minimum contract data set is to be used in constructing care packages and consists of ‘reasons for care’ (care descriptions) and ‘care aims’ (interventions). It is anticipated that clinical psychologists nationally will need to be familiar with the use of these EPPIC categories. It is therefore of interest to establish whether the categories available are useful and easily applied to psychological interventions with this client group.

**Design, Setting and Subjects**

A total of 62 cases referred to the Clinical Psychology Department were examined. The cases were selected from referrals made at three different time points. Group A consisted of 18 referrals made in anticipation of a clinical psychologist taking up post but before the service started. Group B consisted of 22 referrals made in the first three months of the service and group C consisted of 22 referrals made in the fifth and sixth months of the service.

All data were gathered from clinical psychology casenotes. The factors extracted from each were:

1. Date of birth
2. Sex
3. Waiting time (date of first appointment - date referral received)
4. Whether the referral was urgent or routine
5. Whether there was a referral letter or not
6. Source of referral
7. Reasons for referral
8. Care Descriptions
9. Care Aim

'Reasons for referral', 'care descriptions' and 'care aims' were coded using EPPIC criteria. It was expected that referrers and clinical psychologists may have differing opinions as to the reason for the client's care. The two opinions were therefore coded separately using EPPIC 'reasons for care' categories (appendix 1.2). 'Reasons for referral' were taken from the referral letter and reflect the view of the referrer. 'Care descriptions' were extracted from the clinical psychologist's letters and reports and therefore reflect the opinion of the clinical psychologist.

Information was also extracted from the psychologists' reports and letters to determine the 'care aims'. These were based on the EPPIC categories (appendix 1.3). In some cases multiple 'reasons for referral' and 'care descriptions' were extracted but in all cases only one 'care aim' was obtained.

The data was stored and analysed using SPSS for windows.

Results

In all cases, which have been seen, the information on sex, age and waiting time is complete (appendix 1.4). There is missing data in group A which is the result of six cases which were deferred and not seen. The sex ratio of the three groups is not significantly different (chi sq = 2.53, df= 2, p=.282). However, an analysis of variance indicates that
there is a significant difference in ages between the three groups ($F = 3.81, p = .028, df = 2$). Statistical analysis was not carried out to compare waiting times as the samples were skewed as the result of floor and ceiling effects (described below).

Twelve referrals, out of a total of 53 cases with a referral letter, were classified as urgent (appendix 1.5). There was a statistically significant difference in the proportion of urgent and routine cases in the three groups ($\chi^2 = 7.27, df = 2, p = .026$). The majority of urgent cases were to be found in group A (6) and constitute half of all referrals for which this information is available in this group. In group B there were fewer urgent referrals (4) and in group C there were the least (2).

Four referrals were made without referral letters. Two were in group A and two in group B. There were none in group C.

In group A there were three categories of referrer. In groups B and C there were seven and six respectively (table 1). The majority of referrals came from social workers. All missing information is in group A and is likely to be because of the deferred cases, as described above.

Twenty-two 'reason for care' categories, out of a possible seventy-one, were used to classify reasons for referral (table 2). In twenty cases this information is missing. The majority of these missing cases are in group A. 'Anti-social behaviour: challenging of people' is the most frequently used category (17). It is used in all groups. The next most commonly used category is that of 'carer management problem' (13) which is also found in all groups. All other categories were used on less than ten occasions.

Nineteen 'reason for care' categories, out of a possible seventy-one, were used to classify care descriptions (table 3). Significant numbers of cases, in all groups, have no
care descriptions recorded. In group C no care descriptions have been recorded for the majority (17) of cases. ‘Anti-social behaviour: challenging of people’ and ‘anxiety states’ are the most commonly used categories. They have been used eight times each.

Four ‘care aim’ categories, out of a possible eight, were used (table 4). Half (31) of the care aims are missing. The majority of cases with no care aim recorded are in group C (18). The pattern of care aims used seems to be different at the three time points but, because of the small numbers involved, no statistical tests were carried out and therefore there is no evidence of any significant difference between groups. ‘Assessment’ is the only care aim found in all three groups.

Comparison of urgent and routine cases indicated no significant age difference between the two groups ($t = 1.61$, $df = 44.8$, $p = .115$, two-tailed), no significant difference in sex ratio ($\chi^2 = 3.42$, $df = 1$, $p = .064$) and no significant difference in the length of waiting time ($t = .64$, $df = 44$, $p = .524$, two-tailed) (appendix 1.6). There were two urgent cases without a referral letter but all routine cases had a referral letter.

The range of referrers also appears to be different for urgent and routine referrals but because of low numbers no statistical tests were carried out (table 5). There are 17 routine referrals from nursing staff and seven from psychiatrists. Neither of these referrers requested any urgent referrals.

Each category of care aim is used infrequently because of the low number of subjects in this analysis (table 6). ‘Assessment’ is most frequently used routine care aim (10) but it is not used at all in urgent cases.

The most common ‘reason for referral’ categories used with routine referrals are ‘anti social behaviour: challenging of people’ (14) and ‘carer management problem’ (9).
These are also used in the urgent referrals. ‘Social adjustment / relationship’ appears to be a relatively common reason for referral in routine cases (8) but it is not used in urgent cases. There are eight other categories of reason for referral which are only used for routine cases and three which are only used for urgent cases. Each is however used only once or twice and no specific conclusions can be drawn (table 7).

Over half of the care descriptions (27 out of 53 cases) were missing. Two categories were used with urgent referrals but not the routine referrals and five were used with routine referrals but not urgent ones. Each was, however used only once or twice and therefore it is not possible to say that there are any significant differences (table 8).

Conclusion

1) Description of the referrals made to the service.

Results indicate that it was possible to provide a description of the referrals made to this new clinical psychology service for adults with learning disabilities. This may reflect the high standard of record keeping within the particular department.

The significant age difference in the three groups is likely to be accounted for by six referrals from one of the wards with elderly residents. These clients were being assessed for a move into the community and their ages will have skewed the age distribution of group C.

No statistical analysis was carried out to compare the waiting times of the three groups because it was believed that groups A and C were skewed. There is a ceiling effect in operation on the waiting time of group C. The time of writing was only two weeks after the end of the referral period and therefore it was not possible to have some of the longer
waiting times found in the other two groups. Five cases had also not been seen in group C and these cases would presumably be the ones waiting longest and would therefore be likely to increase the mean waiting time figure for this group. It is also possible, however, that the waiting times were shorter during this period as another clinical psychologist had taken up post and this would certainly have been expected to reduce waiting times. In group A there is a floor effect in operation with no clients being seen less than 17 days after referral. It would not have been possible for any referrals to have been seen during this time as there was no clinical psychologist in post when the referrals were originally made. It is recommended that the data collection be completed when all cases have been seen and also that a further sample is taken six months later. This would give a better account of the nature of changes in waiting time.

There were no referrals in group C without referral letters. By this time, the service would have been more established and the referral procedure within the department would be formalised. It is therefore possible that by this time no referrals were being accepted without letters.

The range of professions referring to the clinical psychology service appears to have been relatively restricted when waiting for the clinical psychologist to take up post. During this period the three joint community teams were actively solicited for priority referrals. It is possible that there is this a preponderance of social work referrals because most referrals from the joint community teams were administered by social workers. Clinical psychologists have long been viewed as playing an essential role in such teams. Not only would the teams have been more aware of the clinical psychologist coming into post but they should also have been aware of what role the clinical psychologist would have as part of the teams' resources. Therefore it is not surprising that at the earliest stage in
the development of this service that a majority of referrals appeared to be from this source. As the service developed more referrers would become aware of the availability of a clinical psychologist and therefore access this resource. It is also the case that there were fewer cases in group A and this may in itself be sufficient to account for the fewer sources of referral.

It was surprising to find how infrequently general practitioners were referring to this service giving the current fund holding ethos. However, in the region containing this service, all work is funded by the Health Board and general practitioners are not required to contract for learning disabilities services. It is expected that if general practitioners become responsible to contract for these services then this referral pattern may change.

In twenty cases the reason for referral was missing. Four of these were missing because there was no referral letter. In the other 16 this information was not contained in the referral letter. In some cases the referral letter was a covering letter and the psychologist would have received additional information either by telephone or other documentation. Since the majority of cases without a reason for referral are to be found in group A it is possible that there may have been a lot of such covering letters during this period. The fact that as the service has developed and there has been fewer letters with this information missing may indicate that the referral procedure has been improved.

Referral letters varied greatly in length and content. Some were very vague and included requests such as ‘management advice is sought’ without giving any hint of what was to be managed. It is possible that the quality of referral letter may have varied across referrers and across joint community teams (from whom the majority of referrals originated). If this study is continued and numbers increased then it may be possible to
identify sources of poor referral letters. It may then be possible to target these for advice on appropriate letter format.

Significant numbers of cases had no care descriptions or care aims. The majority of such missing data was in group C cases. This is likely to reflect the fact that at the time of writing these were only recently referred cases. The psychologists dealing with these cases may not have finished their assessments or written letters to referrers. Five cases in group C had not been seen.

Group B consisted of 22 referrals which were made in the first three months of this service. Approximately six months later there were 22 referrals made in only two months of service. Although with measures taken at only two time points it is impossible to say that this is a significant increase over this period, referral rate appears to be going up and this may reflect an increasing demand on the service. However, it is also possible that seasonal fluctuations may account for this difference. Nevertheless service planners should be aware of this observation and it is recommended that the referral rate should continue to be monitored.

With the small numbers available for this analysis it is difficult to draw firm conclusions about what referrers perceive to be the role of the psychologist. As the two most commonly identified reasons for referral are 'anti-social behaviour: challenging of people' and 'carer management problem' it is likely that these represent referrers perceptions of the main functions of clinical psychology services for people with learning disabilities. As the majority of EPPIC categories remain unused it is possible that there does exist a range of areas in which clinical psychologists have expertise yet referrers remain ignorant of. If this study was continued and the numbers increased it would be possible to confirm or reject such a hypothesis.
II) Perception of Urgency.

All referrals were recorded as routine unless referral letters specifically stated that they were ‘urgent’ or ‘top priority’. In some cases urgency may have been indicated by a telephone call or the clinical psychologist may have interpreted that the referral was urgent by the information provided in the referral letter even though the referrer has not explicitly specified this. Such cases would not show up in this analysis as urgent. This is likely to have lead to an underestimate rather than an overestimate of urgency.

As mentioned above, joint community teams were actively solicited for priority cases before the clinical psychologist took up post. Although the data does not distinguish between these priority cases and other urgent cases it is likely that many of the cases classified as urgent in group A were the cases requested in this manner. Such cases are likely to differ from the other cases labelled urgent in this study. They are likely to have been managed for some time by existing resources, for example, whereas other urgent cases may have been referred as crises developed.

In total there were 12 urgent cases and 41 routine cases. This study indicated that the majority of urgent cases were to be found in and indicates that referrers did initially refer a higher proportion of urgent referrals at the start of this service. This suggests that referrers are prepared to prioritise according to some perception of ‘urgency’.

There was a greater variety of referrers referring routine cases than referring urgent cases. As there were more routine cases this is not surprising. It is of interest to note that the highest number of routine referrals came from nurses (17) whereas no urgent referrals came from this source. Perhaps nursing staff are looking more for long term support and assessments rather than acute crisis intervention. Other agencies not
available round the clock may be more in need of clinical psychologists to respond to crisis situations.

There were no routine referrals without a referral letter but there were two urgent referrals without a letter. It is possible that in some particularly urgent cases there is no time to send a referral letter before action is required.

Over half (10 out of 19) of routine care aims were for 'assessment' whereas there were no urgent referrals for this reason. Intuitively it makes sense that assessments are not typically urgent pieces of work. So few of the other care aims are used that it is not possible to draw further conclusions about their use.

There appear to be reasons for referral which are used in routine cases but not in urgent cases and vice versa. This was also found for care descriptions. If the numbers used were expanded it may be possible to say whether this indicates that particular categories are generally classified as urgent.

III) Use of EPPIC Categories

In all cases it was possible to extract EPPIC categories. Therefore it appears that they can be applied to interventions used with clients with learning disabilities. There were, however, some problems with their use.

One difficulty was found in extracting 'reasons for referral'. It was not always clear which EPPIC category was most appropriate. There were a number of cases of aggression, for example, for which it was not clear if 'anger' or 'anti-social behaviour: challenging of people' was the most appropriate category. There were similar problems in the use of 'care aim' categories. For example, there does not appear to be an appropriate category for working with individuals who have been abused. It is a concern
that when work does not fit easily into any particular care aim category that it may become undervalued or take second place to work which can be more easily classified using this system.

A further difficulty arose in cases where there were multiple ‘reasons for care’ and one care aim had to be selected which encompassed them all. Perhaps using separate care aims for each ‘reason for care’ may overcome this difficulty.

It was found that referrers perceptions of disabilities and psychologist’s perceptions after assessment were not usually the same. There were 23 cases which had complete information on the referrer’s ‘reason for referral’ and the psychologist’s ‘care description’. In only five cases were these the same. These five cases only used one ‘reason for care’ category. In an additional five cases, there was one ‘reason for care’ category used as both a ‘reason for referral’ and as a ‘care description’ but also additional ‘reason for care’ categories which were not common to both. As part of the role of the psychologist is to assess, it is not surprising that their perception of difficulties are different from the referrer’s perceptions which have not incorporated such assessments. The finding that there is a difference between referrer’s and psychologist’s reasons for care reinforces the need for comprehensive assessment as part of any care package. It is also not surprising that it is the simplest (in terms of number of categories used) cases in which the psychologists and referrers are in agreement on. It is likely, in these cases, that the client has one identifiable problem rather than a host of complex needs.

It is recommended that if the EPPIC system were to be widely used that workers would extract the categories for their own cases. Familiarity was reported to make the task easier and less time consuming. It would also be recommended that workers do this at
the time of writing the first letter to the referrer as this is when the information should be
at hand.

'Anti-social behaviour: challenging of people' and 'carer management problems' are the
most frequently used EPPIC 'reason for care' categories. These reasons for referral
appear to reflect the difficulties of staff, parents and carers in coping with the referred
individuals. Unfortunately, for people with learning disabilities, referrals are often
prompted not from the individual themselves but from other sources. It is possible that
the use of these reasons for referral reflect this.

There were a total of 71 EPPIC 'reason for care' categories. Of these, only 22 were
used. Half (4) 'care aim' categories were not used. As mentioned above, it is possible
that so many categories were not used because referrers may have been unaware or areas
of clinical psychologist's expertise. In this study there were not enough cases to use all
categories and care must be used in drawing conclusions about whether any specific
category would remain unused as the service expanded.

This study did not use a second rater so reliability of category use can not be calculated.
It is recommended that in future studies that two independent workers extract the EPPIC
categories and inter rater reliability is calculated. It is of importance to establish their
reliability before these categories go into widespread use.
Table 1: Source of referral

<table>
<thead>
<tr>
<th>Source of Referral</th>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
<th>All Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Work</td>
<td>9 (60%)</td>
<td>7 (31.8%)</td>
<td>5 (22.7%)</td>
<td>21 (35.6%)</td>
</tr>
<tr>
<td>Nursing</td>
<td>6 (27.3%)</td>
<td>12 (54.5%)</td>
<td>18 (30.5%)</td>
<td></td>
</tr>
<tr>
<td>Psychiatry</td>
<td>2 (13.3%)</td>
<td>5 (22.7%)</td>
<td>1 (4.5%)</td>
<td>8 (13.6%)</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>4 (26.7%)</td>
<td>1 (4.5%)</td>
<td></td>
<td>5 (8.5%)</td>
</tr>
<tr>
<td>Centre Manager</td>
<td></td>
<td>2 (9.1%)</td>
<td>2 (3.4%)</td>
<td></td>
</tr>
<tr>
<td>Dermatology</td>
<td>1 (4.5%)</td>
<td></td>
<td>1 (1.7%)</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>1 (4.5%)</td>
<td></td>
<td>1 (1.7%)</td>
<td></td>
</tr>
<tr>
<td>Speech Therapist</td>
<td>1 (4.5%)</td>
<td></td>
<td>1 (1.7%)</td>
<td></td>
</tr>
<tr>
<td>Hostel Manager</td>
<td></td>
<td>1 (4.5%)</td>
<td>1 (1.7%)</td>
<td></td>
</tr>
<tr>
<td>Head Teacher</td>
<td></td>
<td>1 (4.5%)</td>
<td>1 (1.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>total</strong></td>
<td>15 (3 missing)</td>
<td>22</td>
<td>22</td>
<td>59 (3 missing)</td>
</tr>
</tbody>
</table>
Table 2: Reasons for referral

<table>
<thead>
<tr>
<th>Reason for referral</th>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Agoraphobia</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>3. Antisocial behaviour: damaging to property</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>4. Antisocial behaviour: challenging of people</td>
<td></td>
<td></td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td>5. Anxiety states</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>7. Carer management problem</td>
<td></td>
<td>4</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>9. Depressed mood</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>12. Eating: not specified</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>17. Elimination: enuresis</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>20. Family relationship problems</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>27. Interpersonal skills deficit</td>
<td></td>
<td>2</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>28. Irritability</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>33. Obsessional compulsive behaviour</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>34. Other: mood disorder</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>37. Other; social adjustment relationship</td>
<td></td>
<td></td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>41. Peer relationship problem</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>43. Personality</td>
<td></td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>48. Self care problem</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>49. Self injury</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>52. Sexual variation</td>
<td></td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>60. Stress adjustment</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>65. Temper tantrums</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

| number of cases | 9     | 15    | 18    |
| number of categories per case | 1 - 5 | 1 - 2 | 1 - 3 |
| missing cases   | 9     | 7     | 4     |

22 EPPIC categories used
Table 3: Care Descriptions

<table>
<thead>
<tr>
<th>Category</th>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Agoraphobia</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>2. Anger</td>
<td>3</td>
<td>1</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>4. Antisocial behaviour: challenging of people</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>5. Anxiety states</td>
<td>3</td>
<td>5</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>7. Carer management problem</td>
<td>1</td>
<td>2</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>9. Depressed mood</td>
<td>1</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12. Eating: not specified</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>17. Elimination: enuresis</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>18. Epileptic behaviour</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>20. Family relationship problems</td>
<td></td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>23. Grief reaction</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>27. Interpersonal skills deficit</td>
<td></td>
<td>5</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>32. Obsessional ruminations</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>37. Other; social adjustment relationship</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>40. Parental management problems</td>
<td></td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>41. Peer relationship problem</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>49. Self injury</td>
<td>2</td>
<td>1</td>
<td></td>
<td>3</td>
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<tr>
<td>52. Sexual variation</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
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<tr>
<td>65. Temper tantrums</td>
<td>2</td>
<td></td>
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<td>2</td>
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<tr>
<td>Total number of cases</td>
<td>9</td>
<td>18</td>
<td>5</td>
<td>18</td>
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<td>1 - 2</td>
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<td>9</td>
<td>4</td>
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19 EPPIC categories used

Table 4: Care Aims

<table>
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<tr>
<th>Category</th>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
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<tr>
<td>Restoration</td>
<td>9 (88.9%)</td>
<td>2 (11.1%)</td>
<td></td>
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<tr>
<td>Assessment</td>
<td>1 (11.1%)</td>
<td>8 (44.4%)</td>
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<tr>
<td>Enabling</td>
<td>5 (27.8%)</td>
<td>2 (50%)</td>
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<tr>
<td>Problem Resolution</td>
<td>3 (16.6%)</td>
<td>1 (25%)</td>
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</tr>
<tr>
<td>Total</td>
<td>9 (9 missing)</td>
<td>18 (4 missing)</td>
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Table 5: Source of Referral for Urgent and Routine Cases

<table>
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<tr>
<th>Source of Referral</th>
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<tr>
<td>Nursing</td>
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<tr>
<td>Psychiatry</td>
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<td>General Practice</td>
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<td>Speech Therapist</td>
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<tr>
<td>Hostel Manager</td>
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<tr>
<td>Head Teacher</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Dermatologist</td>
<td>1</td>
<td></td>
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<td>Centre Manager</td>
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<td><strong>Total</strong></td>
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Table 6: Care aims of urgent and routine cases

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<tr>
<td>Restoration</td>
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<tr>
<td>Problem Resolution</td>
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<td><strong>Total</strong></td>
<td>8</td>
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Table 7: Reasons for Referral

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<tbody>
<tr>
<td>Agoraphobia</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Antisocial behaviour: damaging to property</td>
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<td>2</td>
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<tr>
<td>Antisocial behaviour: challenging of people</td>
<td>2</td>
<td>14</td>
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<td>Anxiety states</td>
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<td>Carer management problem</td>
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<td>9</td>
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<tr>
<td>Depressed mood</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Eating: not specified</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Elimination: enuresis</td>
<td></td>
<td>2</td>
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<tr>
<td>Family relationship problems</td>
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<tr>
<td>Intellectual / memory impairment</td>
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<td>Interpersonal skills deficit</td>
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<td>Irritability</td>
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<td>Obsessional compulsive behaviour</td>
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<tr>
<td>Other: mood disorder</td>
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<td>1</td>
</tr>
<tr>
<td>Other; social adjustment relationship</td>
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<td>8</td>
</tr>
<tr>
<td>Peer relationship problem</td>
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<td></td>
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<tr>
<td>Personality</td>
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<td>Self care problem</td>
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<td>Self injury</td>
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<tr>
<td>Sexual variation</td>
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<tr>
<td>Stress adjustment</td>
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<td>Temper tantrums</td>
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22 EPPIC categories used
Table 8: Care Descriptions

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<td></td>
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<tr>
<td>Anger</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Antisocial behaviour: challenging of people</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Anxiety states</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Carer management problem</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Depressed mood</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Elimination: enuresis</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Family relationship problems</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Grief reaction</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Interpersonal skills deficit</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Obsessional ruminations</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Other; social adjustment relationship</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Peer relationship problem</td>
<td></td>
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<tr>
<td>Self injury</td>
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<td>1</td>
</tr>
<tr>
<td>Sexual variation</td>
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<td>2</td>
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<tr>
<td>Temper tantrums</td>
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<tr>
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<td>8</td>
<td>18</td>
</tr>
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16 EPPIC categories used
References


Literature Review

Prepared for the *Journal of Psychosocial Oncology*

(see appendix 2.1, for Instructions for Authors)
Coping strategies used in the early stages of breast cancer: implications for the psychosocial functioning of women and their partners.

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Trainee Clinical Psychologist

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Abstract.

Diagnosis and treatment of breast cancer have been found to cause both psychological distress and impairment in social functioning. There is considerable interest in how women cope with this disease and in understanding the effects of adopting particular coping strategies. Studies are reviewed which have identified an association between particular strategies and measures of psychosocial functioning, during the early stages of breast cancer. Recent work has suggested that the coping of partners may be of relevance to the adjustment of the women. This area is therefore also reviewed. The implications of adopting particular coping strategies are discussed.
Introduction and outline of review

Each year in England and Wales approximately 20,000 women are newly diagnosed with breast cancer (Swerdlow & Santos Silva, 1993). In Scotland the figure is approaching 2,000 (Coleman et al., 1993). It is the most common cancer in adult women in Western countries. It has been estimated that one in twelve women will develop breast cancer some time in their life (Watson, 1991) and that the incidence is increasing (Coleman et al., 1993). There is therefore growing interest in how people cope with this disease and in understanding the implications of adopting particular coping strategies.

There is a large amount of literature on coping with breast cancer and it covers a number of areas. Coping strategies have been found to have a relationship with prognostic variables such as tumour development and life span after diagnosis (Derogatis et al., 1979; Greer et al., 1979; Pettingale et al., 1985). Coping strategies have also been related to quality of life measures (Heim, 1991). This review will, however, focus on those studies relating coping strategies to psychological and social functioning.

Diagnosis and treatment of breast cancer have been found to cause significant levels of psychological distress and also impairment in social functioning (Hughes, 1982; Morris et al., 1977). A number of factors have been associated with psychosocial functioning in this patient group. These include age (Vinokur et al., 1990), stage of disease (Gotay, 1984), and treatment (Munroe et al., 1989; Meyerowitz et al., 1983). Coping strategies are however of particular interest because coping is one of the few factors potentially amenable to change. It may therefore be possible to develop interventions based on developing or reducing particular coping strategies and thereby reduce the distress associated with this disease.
Significant levels of anxiety and depression have been reported in spouses as well as the breast cancer patients (Wellich et al., 1978; Baider & Kaplan de Nour, 1984; Northouse & Swain, 1987). It has been suggested that the coping of partners of breast cancer patients is related to not only their own psychosocial functioning but also that of the women with breast cancer (Hannum et al., 1991). This area will therefore also be covered in this review.

**Coping strategies**

Coping has been defined as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus & Folkman, 1984). Coping strategies are 'specific techniques used in adjusting to illness or other major stressor' (Lipowski, 1970). Folkman and Lazarus (1980) distinguish between emotion-focused and problem-focused coping. They define problem-focused coping as that which is directed at managing or altering the problem causing the distress and emotion-focused coping as that which is directed at regulating emotional response to the problem. It has been suggested that in some circumstances emotion-focused coping may be more adaptive and in other circumstances problem-focused coping may be more adaptive.

Patients have been found to use a range of strategies in coping with breast cancer (Heim et al., 1993; Jarrett et al., 1992). Such strategies may change over time (Dunkel-Schetter et al., 1992) and as individuals enter different stages of the cancer (Heim et al., 1993). It may be the case that different strategies are effective at different stages in the disease. This review will, however, focus on the strategies used in the initial stages of dealing with this cancer (table 1).
Particular coping strategies are defined and measured differently by different researchers. The studies reviewed below will therefore reflect this. Emotion-focused strategies, to be discussed, include 'denial', 'avoidance', 'helpless-hopeless', and 'resignation-fatalism'. Problem-focused strategies, to be reviewed, include 'active coping', 'confronting' and 'seeking social support'.

Denial

The coping strategy of denial is perhaps the most widely investigated. As early as 1951, Shands et al., noted that denial is commonly used by breast cancer patients. High cancer specific denial has been associated with reduced post mastectomy distress in a study of 113 patients (Meyerowitz, 1983). Watson et al., (1984) also studied the effects of denial on women recovering from mastectomy. Their data, from 24 hospitalised patients, indicated that patients who denied the seriousness of a cancer diagnosis experienced significantly less mood disturbance than those who were more accepting of the diagnosis. These researchers concluded that, in the short term, denial of a cancer diagnosis is an effective means of dealing with the stress. However other researchers (Friedman et al., 1990) failed to find any relationship between denial and adjustment in breast cancer patients and yet another study has found that use of denial was positively related to distress both pre-surgery and a few days later (Carver et al., 1992). There is therefore some debate as to how adaptive this strategy is.

Avoidance

In some ways the strategy of avoidance is considered to be similar to that of denial. Unlike denial, however, an avoidant style of coping has typically been associated with poor adjustment. This was reported by Friedman et al., (1988) who carried out a study of 67 breast cancer patients between two and 255 months after surgery. In a replication
study (Friedman et al., 1990) of 49 women, this group again found that coping by avoidance was related to poor adjustment. Penman (1979) in her study of 27 post-mastectomy women found that women who were coping best used less avoidance behaviours than those whose coping was not rated so highly.

A prospective study has also been carried out (Stanton & Snider, 1993). Coping and mood were assessed in 117 women receiving a breast biopsy. They were assessed before the biopsy, after diagnosis and, for those who had surgery, after surgery. It was found that pre biopsy coping by avoidance was a particularly important predictor of high distress both post biopsy and post surgery. An avoidant style of coping would therefore appear to relate to and also predict distress.

Helpless-hopeless

Higher anxiety and depression scores have been associated with a helpless-hopeless response to diagnosis in a study of breast cancer and lymphoma patients (Burgess et al., 1988). Lampic et al., (1994) studied a broad range of cancers, 88 (45%) of whom had breast cancer. They found that high use of ‘helplessness-hopelessness’ was associated with low levels of psychosocial well-being.

Resignation-fatalism

Use of ‘resignation-fatalism’ has been associated with higher distress. This was reported in a study of 151 women with breast disease, 72 (48%) of whom had breast cancer (Heim, 1991).

Of the emotion-focused coping strategies reviewed ‘denial’ is the only one where there is any evidence that it is psychosocially adaptive and there is some debate about this. Coping which involves the strategies of ‘avoidance’, ‘helpless-hopeless’, and ‘resignation-fatalism’ are related to poor psychosocial adjustment.
Active

Active coping has been associated with better psychosocial adjustment (Friedman et al., 1988). This conclusion has been supported by Penman (1979). She looked at the coping of 27 post mastectomy patients and found that the women who were coping best used a greater range of tackling behaviours, exhibiting active engagement with issues raised by diagnosis and surgery.

Confronting

Lower psychological morbidity has been associated with a ‘positive/confronting’ response to diagnosis in a study of breast cancer and lymphoma patients (Burgess et al., 1988). Weisman and Worden (1976) also studied a mixed cancer population. 37 (31%) of their 120 newly diagnosed patients had breast cancer. Confrontation was associated with lower distress in this study also.

Seeking social support

Social support has been found to be related to psychological adjustment in women with breast cancer (Bloom & Speigel, 1984; Dunkel-Schetter, 1984; Taylor et al., 1986). It is therefore expected that ‘seeking social support’ would be an adaptive coping strategy. This view is supported by a recent prospective study which indicated that pre-biopsy coping through seeking social support proved beneficial in terms of adjustment after diagnosis (Stanton & Snider, 1993). Dunkel-Schetter et al., (1992) carried out a large study of 668 cancer patients, 42% of whom had breast cancer. They found few effects of having breast versus other types of cancer and concluded that coping through social support was associated with less emotional distress. Heim (1991) reports a relationship between social withdrawal and higher distress. It can therefore be concluded that
seeking social support is psychologically adaptive and withdrawing from it is maladaptive.

Current research on the use of problem-focused coping strategies indicates that they are adaptive in dealing with the early stages of breast cancer. It is therefore expected that women who confront and actively cope with their diagnosis and also seek social support may be better adjusted in terms of psychosocial factors.

**Partners**

Although there is no published research assessing coping in couples at the time initial breast cancer surgery there are two studies which suggest that the coping of one partner may influence the adjustment of the other. Hannum et al., (1991) carried out detailed interviews with 22 couples in which the wife had received her diagnosis nine to twelve months earlier. These subjects reported no more psychological symptoms than did men and women in the general population. Nevertheless, it was concluded that the husband’s coping behaviours and ratings of the relationship were the best predictors of the wife’s psychological distress, whereas the husband’s distress depended on a combination of his own and his wife’s coping behaviours.

Coping and psychological functioning of couples has also been studied during the treatment period. A retrospective study of 36 breast cancer patients and their husbands assessed their coping with a course of radiation therapy (Ptacek et al., 1994). Although, both husbands and wives used multiple methods of coping the coping strategies of each sex differed and were largely unrelated. The wives engaged in more extensive and varied coping whereas the husbands expended a greater percentage of their total coping effort in problem-focused coping. For both husbands and wives, greater relative use of seeking
support and less use of avoidance were associated with better mental health. Mental health was also associated with the use of problem-focused coping and negatively associated with the use of wishful thinking in wives. It was negatively associated with blaming oneself and wishful thinking in husbands.

They also reported that the wives self-reported coping related significantly to the mental health of their husbands. Wives who used less avoidance and wishful thinking, and more problem-focused coping had husbands reporting better mental health. However, the husbands self-reports of coping were not found to be related to the wives mental health. These studies therefore suggest that the coping of one partner may affect the adjustment of the other. This implies that an understanding of both the patient's and their partner's coping is important. It does, however, seem that different strategies are used by the men and the women. This may be because the situation is different for the men and women or because of more general sex differences in coping.

Research with couples also appears to suggest that problem-focused coping is more adaptive than emotion-focused strategies. It appears that when women use problem-focused coping during the treatment period that their husbands benefit. Ptacek et al., have suggested that this benefit may not be extended to women if their husbands use problem-focused coping strategies because the male situation is less amenable to problem-focused coping.
Conclusions

The most widely reported coping strategy is denial. This appears to be psychosocially adaptive in dealing with the initial treatment for breast cancer. Other emotion-focused coping strategies do not appear to be adaptive. Such strategies include; avoidance, 'helpless-hopeless', and 'resignation-fatalism'. In general problem-focused coping strategies seem to indicate better psychosocial functioning in this patient group. These include active strategies, confronting and seeking social support. At this stage it is not possible to determine the relative importance of particular strategies and more work needs to be done.

More prospective studies are particularly required. It is important to determine the nature of the association between coping and psychosocial adjustment. Perhaps coping strategies directly affect adjustment. It is also possible that psychosocial adjustment influences which coping strategies are used, or it is even possible that some third factor is predictive of both coping and adjustment. Resolving this issue has implications in terms of developing programmes aimed at reducing the distress of this patient group particularly if such programmes are to be based on developing new coping skills.

Recent studies have investigated the coping and psychosocial adjustment of couples. Work in this area is very limited but again suggests that problem-focused coping may be more adaptive than emotion-focused coping. It does, however, seem that men and women use different coping strategies. Further research is certainly required to determine the implications of these findings.
Table 1: Studies relating coping to psychosocial factors in breast cancer patients

<table>
<thead>
<tr>
<th>Authors</th>
<th>Subjects</th>
<th>Measures Used</th>
<th>Main findings</th>
</tr>
</thead>
</table>
| Burgess et al, 1988      | 178 newly diagnosed mixed breast cancer and lymphoma patients | 1. ratings of the cognitive response to diagnosis  
2. Wakefield Self Assessment Depression Inventory  
3. Trait Measure of the Spielberger State-Trait Anxiety Inventory  
4. Multidimensional Locus of Control | a) a positive / confronting response to diagnosis is associated with lower psychological morbidity  
b) higher anxiety and depression associated with a hopeless-helpless response to diagnosis |
| Carver et al, 1992       | preliminary analysis of breast cancer patients | 1. COPE  
2. Life Orientation Test | a) positive reframing, acceptance and the use of humour were all inversely related to self reports of distress both pre- and post-surgery  
b) denial and behavioural disengagement were positively related to distress both pre- and post-surgery  
c) acceptance pre-surgery predicted less distress post-surgery  
d) disengagement post-surgery predicted greater distress at the three month follow-up |
| Dunkel-Schetter et al, 1992 | 603 mixed cancer patients                      | 1. Ways of Coping Questionnaire (adapted)  
2. Profile of Mood States | a) coping through social support, focusing on the positive, and distancing was associated with less emotional distress  
b) using cognitive and behavioural escape-avoidance was associated with more emotional distress |
| Friedman et al, 1988 | 67 breast cancer patients | 1. Psychosocial Adjustment to Illness Scale - Self Report  
2. Buss-Durkee Hostility Scale  
3. Moos Coping Scale  
4. a 14 item cancer specific coping survey  
5. Oral Optimism Questionnaire  
6. Health Locus of Control Scale  
7. Hassles Scale | a) an avoidant style of coping was associated with poorer adjustment  
b) an active style of coping was associated with better adjustment |
| Friedman et al, 1990 | 49 breast cancer patients | 1. Moos Coping Scale  
2. Cancer Adjustment Survey  
3. Psychosocial Adjustment to Illness Scale- Self Report | a) fighting spirit was related to better psychosocial adjustment  
b) coping by avoidance was related to poorer adjustment  
c) denial was not related to any adjustment measures |
| Hannum et al, 1991 | 22 couples, women had breast cancer | 1. Marital and family questionnaire  
2. Marital Adjustment Test  
3. Family Cohesion and Adaptability Scales  
4. SCL-90-R  
5. Health Symptom Checklist (adapted)  
6. Friendship Scale  
7. Philosophies of Marriage Scale | a) the husbands’ coping behaviours and ratings of the relationship were the best predictors of the wives psychological distress  
b) the husband’s distress depended on a combination of his own and his wife’s coping behaviours |
| Heim, 1991 | 151 women with breast disease, 72 of whom had breast cancer | 1. Bernese Coping Modes  
2. a coping questionnaire (SVF)  
3. Sense of coherence questionnaire  
4. Social Adjustment Scale  
5. Emotional State Scale (B.f.-s)  
6. Compliance questionnaire (unpublished)  
7. Frieburger Anpassungsinventar | a) dissimulation and isolation-suppression relate to lower distress  
b) resignation-fatalism, social withdrawal, rumination and emotional release relate to higher distress  
c) the impact of coping varies with time |
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heim et al, 1993</td>
<td>74 breast cancer</td>
<td>1. Bernese Coping Modes</td>
<td>There is both variability and stability in coping over time and situation</td>
</tr>
<tr>
<td>Jarrett et al, 1992</td>
<td>49 women in remission following treatment for early breast cancer</td>
<td>1. Ways of Coping Questionnaire (adapted)  2. Faith Courtauld Schedule for coping with cancer (adapted)</td>
<td>The majority of patients use a wide variety of coping responses which challenges the notion of mutually exclusive coping styles.</td>
</tr>
<tr>
<td>Lampic et al, 1994</td>
<td>197 ambulatory mixed cancer patients</td>
<td>1. Mental Adjustment to Cancer Scale  2. Hospital Anxiety and Depression scale.  3. a measure of psychosocial well-being  4. an ad hoc measure of cancer related worry</td>
<td>a) high levels of anxious preoccupation and helplessness/ hopelessness were associated with low levels of psychosocial well-being, more situation specific anxiety and more cancer related worry.  b) high levels of fighting spirit and fatalistic coping were found to be associated with high psychosocial well-being and for fighting spirit also with less cancer related worry.  c) patients with a dismal prognosis were found to have higher levels of helplessness/hopelessness than patients with a more favourable prognosis.</td>
</tr>
<tr>
<td>Meyerowitz, 1983</td>
<td>113 post mastectomy patients</td>
<td>1. Multiple Affect Adjective Checklist  2. Physical discomfort inventory  3. activities survey  4. personal opinion survey  5. survey of concerns  6. Social environment scale</td>
<td>a) level of cancer specific denial was the variable most associated with post-mastectomy distress</td>
</tr>
<tr>
<td>Study</td>
<td>Sample Description</td>
<td>Methods</td>
<td>Findings</td>
</tr>
<tr>
<td>-------</td>
<td>--------------------</td>
<td>---------</td>
<td>----------</td>
</tr>
<tr>
<td>Penman, 1979</td>
<td>27 post mastectomy patients</td>
<td>1. an observer rated instrument to assess coping behaviour 2. rating of psychosocial function 3. Karnofsky Patient Performance Rating 4. Profile of Mood States</td>
<td>a) the women judged to be coping best used a greater variety of the confronting behaviours of the tackling mode b) the women judged to be coping best used less of the behaviours from the avoiding and capitulating modes</td>
</tr>
<tr>
<td>Ptacek et al, 1994</td>
<td>36 breast cancer patients and their husbands</td>
<td>1. Ways of Coping Checklist-Revised 2. Dyadic Adjustment Scale 3. Mental Health Inventory</td>
<td>a) wives engaged in more extensive and varied coping efforts than their husbands did b) the coping strategies which husbands and wives used were largely independent c) the coping of one spouse was related to the mental health and marital satisfaction of the other</td>
</tr>
<tr>
<td>Stanton &amp; Snider, 1993</td>
<td>117 women receiving a breast biopsy</td>
<td>1. a nine item scale to assess locus of control 2. Life Orientation Test 3. cognitive appraisal scales 4. Ways of Coping Questionnaire 5. Profile of Mood States</td>
<td>a) cognitive avoidance coping was a predictor of high distress and low vigour b) coping through seeking social support pre-biopsy proved beneficial after diagnosis</td>
</tr>
<tr>
<td>Watson et al, 1984</td>
<td>24 hospitalised post mastectomy patients</td>
<td>1. Spielberger State-Trait Anxiety Inventory 2. Profile of Mood States 3. denial was rated from tape recorded interviews</td>
<td>patients who denied the seriousness of a cancer diagnosis experienced significantly less mood disturbance than those who were more accepting of the implications of the diagnosis</td>
</tr>
<tr>
<td>Weisman &amp; Worden, 1976</td>
<td>120 newly diagnosed mixed cancer patients</td>
<td>1. Profile of Mood States</td>
<td>a) good copers (high resolution, low vulnerability) used confrontation, redefinition and compliance with authority</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Minnesota Multiphasic Personality Inventory</td>
<td>b) poor copers used suppression/passivity, stoic submission and a variety of tension reducing measures.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Thematic Apperception Test</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. COPE</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Resolution</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Inventory of Predominant Concerns</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Index of Vulnerability</td>
<td></td>
</tr>
</tbody>
</table>
References


Major Research Project Proposal
Applicants.

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Title.

Coping strategies and psychosocial adjustment in breast cancer patients and their partners.

Summary

This study aims to investigate the coping strategies used by breast cancer patients and their partners. The relationship between these strategies and psychosocial functioning will be measured by questionnaire. The questionnaires to be used are the COPE (Carver et al., 1989), the Psychosocial Adjustment to Illness Scale - Self-Report (Derogatis & Derogatis, 1990), and the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983). These three questionnaires will be administered pre-surgery and at three months post-surgery to forty patients and their partners. The women will all be inpatients at the Western Infirmary awaiting surgery for newly diagnosed breast cancer.
Introduction

Each year in the United Kingdom 24,500 women are newly diagnosed with breast cancer and 15,000 die from this disease (CRC, 1988). In western countries breast cancer has been identified as the most common cancer in women and it has been estimated that one in twelve women will develop this disorder and the prevalence is increasing. Much of the research in psycho-oncology has focused on this particular malignancy and there is growing interest in understanding the psychological consequences of this cancer and how people cope.

Some researchers have attempted to identify the relationship between coping strategies and physical measures such as tumour development and life span after diagnosis Greer et al., (1979). Other researchers (Heim, 1991) have looked at the relationship between coping strategies and various quality of life measures. However, a number of coping strategies have been identified which are related to psychosocial adjustment (Dunan, 1996) and this will be the focus of this study.

Coping has been defined as, ‘constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus & Folkman, 1984). Social adjustment refers to how well the individual is performing in his or her everyday role. Psychological functioning, in this study, refers to levels of anxiety and depression.

At present there is little work which looks at the coping strategies of partners as well as of the patients. It has been reported that partners experience similar levels of distress to the patients (Baider & De-Nour, 1984; Northouse & Swain, 1987). It is therefore important to also investigate how they cope. Ptacek et al., (1994) carried out one of the
few pieces of research in this area. This was a retrospective study of 36 breast cancer patients and their husbands and subjects were asked how they coped up to three years after a course of radiotherapy.

It would be possible to measure coping at a variety of different time points in this disease but this study will focus on the early stages. This is for two reasons. Firstly, it has been reported that the preoperative period is the most stressful (Stolar, 1982). Maguire (1981) found that 77% of spouses whose wives had a mastectomy reported that they had experienced moderate or marked degrees of distress in the period between hospital admission and surgery. Secondly, investigating this time period would also serve to bridge the gap left by the Ptacek et al., study reported above.

It has been reported that coping strategies change with time (Heim et al., 1987). Because coping strategies may change as individuals adapt to the diagnosis and treatment and move away from the original shock it was felt necessary to repeat the measures at a second time point. Therefore the measures are to be repeated three months after surgery.

**Aims**

This piece of research aims to answer four questions. It is anticipated that it will be the first study measuring the coping strategies used by both breast cancer patients and their partners at the time of surgery. Therefore the first research question is:

1. What coping strategies are used by breast cancer patients and their spouses when faced with surgery?
It is expected that the coping strategies used will change with time. The pattern of this change will be investigated. Therefore the second question is:

2. Do coping strategies change following surgery?

It is known that there is a relationship between the psychosocial adjustment between patients and partners but little is known however about the relationship between patients and their partner’s coping strategies. Therefore the third research question is:

3. Do patients and their partners make similar use of coping strategies?

It is hoped to build on existing findings and investigate further the relationship between coping strategies and psychosocial functioning in breast cancer patients and their partners. Therefore the fourth question is:

4. Is there a relationship between particular coping strategies and psychosocial functioning in breast cancer patients and their partners?

**Subjects.**

The study group will comprise all heterosexual couples, where the woman is undergoing surgery for newly diagnosed breast cancer at the Western Infirmary in Glasgow.

Couples will be excluded if they have been together less than six months or if either is unwilling or unable to give informed consent. There are no age restrictions but women will be excluded if they have previously had surgery for breast cancer.

It is aimed to recruit forty couples.
Measures.

A) The COPE

The COPE is a multidimensional coping inventory developed by Carver et al., (1989). It has two forms a) dispositional b) situational. In this study the situational version will be used because interest lies with the subject's response to cancer.

The COPE assesses a wide range of coping techniques and incorporates 13 distinct scales. These are:

1. Active coping
2. Planning
3. Seeking instrumental social support
4. Seeking emotional social support
5. Suppression of competing activities
6. Turning to religion
7. Positive reinterpretation and growth
8. Restraint coping
9. Acceptance
10. Focus on and venting of emotions
11. Denial
12. Mental Disengagement
13. Behavioural disengagement
B) Psychosocial Adjustment to Illness Scale - Self Report (PAIS-SR).

The PAIS-SR incorporates both psychological and social adjustment to illness (Derogatis & Derogatis, 1990). It provides scores for the seven domains of:

1. Health environment
2. Vocational environment
3. Domestic environment
4. Sexual relations
5. Family relationships
6. Social environment
7. Psychological distress.

The scale can be used to provide a measure of general adjustment as well as information about adjustment in specific areas. It has been used in previous breast cancer trials.

C) The Hospital Anxiety and Depression scale (HAD).

The HAD (Zigmond, & Snaith, 1983) was developed specifically to detect anxiety and depression in medical patients and excludes somatic symptoms with the exception of one item ('I feel as if I am slowed down'). This scale has been validated on a cancer patient sample (Razavi et al, 1989).

Total time to complete these three questionnaires is thirty minutes.
Design and Procedure.

Suitable patients will be identified after each ward round. All women who do not meet the exclusion criteria would be asked to participate. They would also be asked if they would be willing for their partners to take part.

All subjects will be asked to sign a consent form before completing the questionnaires. The set of three should take no more than thirty minutes to fill in.

Type of surgery and grade of cancer would be recorded. The numbers of couples either unwilling or unable to take part would also be noted.

At three months post surgery the second set of questionnaires would either be handed out at a follow up appointment or sent by post. Stamped addressed envelopes would be included for replies. Subjects may also be followed up by phone or letter to increase the return rate.

Setting and equipment

All subjects would be approached in the Breast Care Unit of the Western Infirmary in Glasgow. The first batch of questionnaires would be completed at this site and the second batch would be completed in the individuals' own homes.
Data analysis

Data will be stored and analysed using SPSS (Statistical Package for Social Scientists). The cases will be recorded using a numerical code and the list of patient names will be destroyed once the data has been gathered. It will therefore not be possible to identify any subject using the details available on the computer and this will ensure complete confidentiality.

Statistical analysis is likely to consist mainly of correlations and descriptive statistics.

Purpose

The purpose of this research is to elucidate whether there is a relationship between coping strategies and psychosocial functioning. If this relationship is established then it would be possible to target appropriate psychological interventions at those individuals identified to be vulnerable. Such interventions would include developing more adaptive coping strategies.

Time scales

Recruitment is proposed to start in September 1995 and it is anticipated that it will be complete by March 1996.

Ethical approval

Ethical approval has been obtained.
References.


Main Project Paper

Prepared for submission to The Journal of Psychosocial Oncology

(see appendix 4.1 for Instructions for Authors).

Julie Dunan, MA, MSc

Trainee Clinical Psychologist

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Abstract.

This study investigated the relationship between five coping strategies and measures of adjustment in women with recently diagnosed breast cancer and their partners. Questionnaires were administered both pre-surgery and three months post-surgery and results indicated that both sexes used a broad range of coping strategies that were typical of a population coping with a situational stressor. There was no evidence that use of these strategies changed significantly over the first three months or of any association in their use between partners.

Male psychosocial adjustment was not associated with either male or female coping at either time point. However pre-surgery female psychosocial adjustment was associated with both male and female coping. At this time point, female use of 'acceptance' was negatively associated with anxiety and male use of 'active coping' was positively associated with female psychosocial adjustment. It was concluded that it is psychosocially adaptive for the women if the couple use passive forms of coping pre-surgery.

The men made significantly less use of 'seeking emotional social support' than the women and it is believed that this reflects a general sex difference in the use of this strategy. However, as their use of this strategy pre-surgery was significantly associated with their anxiety scores at three months, it may be that not using it is adaptive for men when faced with their partner's breast cancer.

It was found that the more anxious women made more use of the seeking social support strategies than the less anxious women. This finding is the inverse of previously reported associations and is discussed.
Introduction.

Breast cancer is the most common cancer in women in western countries and it has been estimated that one in twelve women will develop breast cancer at some point in their lives (Watson, 1991). This is a disease which causes significant levels of distress to both the women (Hughes, 1982; Morris et al., 1977) and their partners (Wellich et al., 1978; Baider & Kaplan De-Nour, 1984; Northouse & Swain, 1987). It is therefore of interest to establish how people cope and whether coping strategies are related to psychosocial functioning.

Coping strategies are ‘specific techniques used in adjusting to illness or other major stressor’ (Lipowski, 1970). Psychosocial functioning incorporates both psychological and social functioning. Psychological functioning, in this research, refers to levels of anxiety and depression. Social functioning refers to how well the individual is fulfilling his or her roles in the particular sociocultural environment.

A number of coping strategies have been identified which are believed to have a relationship with psychosocial adjustment. ‘Active coping’ (Friedman et al., 1988), ‘seeking social support’ (Dunkel-Schetter et al, 1992) and ‘acceptance’ (Carver et al, 1992) have been associated with a better adjustment to breast cancer and will be included in this study.

The coping strategy of denial is perhaps the most widely investigated. Some researchers have concluded that it is a useful coping strategy in dealing with the initial impact of breast cancer (Meyerowitz, 1983; Watson et al., 1984). Some have not found any association (Friedman et al., 1990) and yet others have concluded that use of denial was positively related to distress (Carver et al., 1992). It therefore remains to be established
whether denial is an adaptive strategy to adopt when faced with breast cancer and for this reason this strategy will also be incorporated in this study.

Recent work has begun to look at the coping of both the patients and their partners and whether the coping of one is related to the psychosocial adjustment of the other (Hannum et al., 1991; Ptacek, Ptacek & Dodge, 1994). It is believed that the current research should fill a gap in the literature, in that it will be the first study to measure the coping strategies used by both breast cancer patients and their partners at the time of surgery.

Eighty-three percent of breast cancer patients and fifty percent of their husbands report that the diagnostic phase prior to surgery is the most stressful (Northouse, 1989). It is proposed to administer the first set of measures prior to surgery to assess the coping strategies used at this difficult time. It is expected that adjustment will change with time, but it is not known if coping will, therefore measures will be repeated at a later date.

This study therefore aims to address the following four questions:

1. Which of the coping strategies of interest are used by breast cancer patients and their spouses when faced with surgery?

2. Is there a change in the use of these coping strategies following surgery?

3. Do patients and their partners make similar use of these five coping strategies?

4. What is the relationship between these particular coping strategies and psychosocial functioning in breast cancer patients and their partners?
Methods.

Couples were recruited from the Breast Care Unit at the Western Infirmary in Glasgow. All women undergoing surgery for newly diagnosed breast cancer who did not meet the exclusion criteria were approached. Women were excluded if they had a previous diagnosis of cancer. Couples were excluded if they had been together less than six months. Subjects were required to sign a consent form and were excluded if they were either unwilling or unable to give informed consent.

The first meeting took place on the day of admission to hospital which was also the day prior to surgery. If the woman was willing to participate, the study was explained and a short five minute interview took place to gather demographic details. The women consented to their partner’s participation before partners were approached. All subjects were asked to complete a set of questionnaires on the day prior to surgery. The interviewer returned to the ward to pick up the questionnaires. Some of the men were not returning to the hospital and posted their questionnaires in.

Type of surgery, treatment and grade of cancer were recorded post-surgery.

At ten weeks post-surgery the second set of questionnaires were sent by post. Stamped addressed envelopes were included for their return. All follow-up questionnaires were returned within two weeks which was twelve weeks post surgery.
Subjects.

Sixty-three suitable women were identified. One was not available to be contacted. Ten women either did not wish to take part or did not want their husbands to do so. There were therefore fifty-two women who agreed to participate and of these questionnaires were returned for twenty-seven couples (43% of the original sample). It is not known why twenty-five couples did not return sets of questionnaires.

All women filled in the first set of questionnaires on the day prior to surgery. It was not always possible to get the men to do this and the majority of men were approached an average of 2.7 days later. This ranged from nine men who completed the questionnaires on the same day as the women to one man who filled his in twenty days later.

The age of the women in this study ranged from 35 to 73 years with a mean of 55.6 years (SD = 8.06) and all couples had been together at least ten years (see appendix 4.3 for demographic details). The grades of their cancers were taken from the medical notes and are shown in table 1. (see appendix 4.4 for treatment).

Twenty-one couples (77.7%) completed and returned the follow-up questionnaires.

Table 1. Grade of Cancer

<table>
<thead>
<tr>
<th>Grade of Cancer</th>
<th>Number of Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>ductal carcinoma <em>in situ</em></td>
<td>4</td>
</tr>
<tr>
<td>grade I</td>
<td>12</td>
</tr>
<tr>
<td>grade II</td>
<td>5</td>
</tr>
<tr>
<td>grade III</td>
<td>5</td>
</tr>
<tr>
<td>grade IV</td>
<td>0</td>
</tr>
<tr>
<td>total</td>
<td>26 (1 case missing)</td>
</tr>
</tbody>
</table>
Measures.

Three questionnaires were used. These were the COPE (Carver et al., 1989), the Psychosocial Adjustment to Illness Scale - Self Report (PAIS -SR) (Derogatis & Derogatis, 1990) and the Hospital Anxiety and Depression scale (HAD) (Zigmond & Snaith, 1983). All were self-administered (see appendix 4.2 for descriptions and scoring).

Results.

HAD scores are shown in table 2. As only one woman and two men scored above the cut-off (above ten) for clinically significant symptoms of depression pre-surgery, HAD depression scores were not incorporated in any further analysis.

<table>
<thead>
<tr>
<th></th>
<th>HAD Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td>Sex</td>
</tr>
<tr>
<td>anxiety</td>
<td>initial</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>follow-up</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>depression</td>
<td>initial</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>follow-up</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PAIS-SR T scores were constructed using mixed cancer patient norms (Derogatis 1983, cited in Derogatis & Derogatis, 1990) (appendix 4.5). Pre-surgery the ‘domestic environment’ T score was greater than one standard deviation below the mean for both sexes but the T scores of the other domains were all within one standard deviation of the mean. At follow-up all T scores were within one standard deviation of the group mean. It was not possible to compare adjustment scores to that of the general population as no norms were available. It was concluded that the psychosocial adjustment of this breast...
cancer group and their partners is typical of that of a mixed cancer population. The one exception was that of the domestic environment which appears to indicate that pre-surgery breast cancer has little impact on this area of functioning. (see appendix 4.6 for discussion of HAD and PAIS scores)

It was of interest to establish whether these levels of psychosocial functioning may be attributable to the age group of this population. Therefore the psychosocial factors which were to be used in the analysis (HAD anxiety and total PAIS-SR) were correlated with age. Anxiety scores were not found to correlate with the age of the women \( r = -0.330, p = 0.099 \) but total PAIS-SR scores did \( r = -0.462, p = 0.015 \).

The COPE has been standardised on a student population and the means and standard deviations for each of the individual coping scales of the situational version have been published (Carver et al 1989). These were compared with those obtained in this study (table 3).

### Table 3. Coping Strategies.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Time</th>
<th>Sex</th>
<th>N</th>
<th>Mean</th>
<th>Std Dev</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>Initial</td>
<td>F</td>
<td>24</td>
<td>13.29</td>
<td>2.49</td>
<td>7 - 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>23</td>
<td>12.57</td>
<td>3.34</td>
<td>4 - 16</td>
</tr>
<tr>
<td></td>
<td>Follow-up</td>
<td>F</td>
<td>20</td>
<td>13.90</td>
<td>2.25</td>
<td>10 - 19</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>20</td>
<td>13.55</td>
<td>3.03</td>
<td>4 - 16</td>
</tr>
<tr>
<td>Denial</td>
<td>Initial</td>
<td>F</td>
<td>24</td>
<td>6.21</td>
<td>2.45</td>
<td>4 - 12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>23</td>
<td>5.22</td>
<td>1.65</td>
<td>4 - 10</td>
</tr>
<tr>
<td></td>
<td>Follow-up</td>
<td>F</td>
<td>20</td>
<td>5.45</td>
<td>1.54</td>
<td>4 - 10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>20</td>
<td>5.20</td>
<td>1.96</td>
<td>4 - 12</td>
</tr>
<tr>
<td>Seeking Emotional</td>
<td>Initial</td>
<td>F</td>
<td>24</td>
<td>11.75</td>
<td>3.43</td>
<td>4 - 16</td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
<td>M</td>
<td>23</td>
<td>6.57</td>
<td>2.37</td>
<td>4 - 15</td>
</tr>
<tr>
<td></td>
<td>Follow-up</td>
<td>F</td>
<td>20</td>
<td>10.50</td>
<td>3.19</td>
<td>6 - 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>20</td>
<td>7.65</td>
<td>3.12</td>
<td>4 - 16</td>
</tr>
<tr>
<td>Active Coping</td>
<td>Initial</td>
<td>F</td>
<td>24</td>
<td>12.46</td>
<td>2.02</td>
<td>6 - 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>23</td>
<td>10.35</td>
<td>2.89</td>
<td>4 - 16</td>
</tr>
<tr>
<td></td>
<td>Follow-up</td>
<td>F</td>
<td>20</td>
<td>11.05</td>
<td>2.91</td>
<td>6 - 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>20</td>
<td>10.40</td>
<td>3.12</td>
<td>4 - 16</td>
</tr>
<tr>
<td>Seeking Instrumental</td>
<td>Initial</td>
<td>F</td>
<td>24</td>
<td>11.75</td>
<td>3.90</td>
<td>5 - 16</td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
<td>M</td>
<td>23</td>
<td>6.96</td>
<td>2.77</td>
<td>4 - 15</td>
</tr>
<tr>
<td></td>
<td>Follow-up</td>
<td>F</td>
<td>20</td>
<td>9.45</td>
<td>3.89</td>
<td>4 - 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>20</td>
<td>8.20</td>
<td>3.25</td>
<td>4 - 16</td>
</tr>
</tbody>
</table>

The first research question was: **Which of the coping strategies of interest are used by breast cancer patients and their spouses when faced with surgery?**

As can be seen from table 3, pre-surgery the mean scores for all coping strategies were within one standard deviation of the published means for the women. For the men there was one exception. Their use of ‘seeking emotional social support’ was greater than one standard deviation below. A paired t-test was carried out \( t_{[20]} = 5.93, p = .000, \) two-tailed) which confirmed that pre-surgery the men made significantly less use than the women of this coping strategy. It was therefore concluded that the women made significant use of all five strategies but the men only made significant use of four.

The second research question was: **Is there a change in the use of the coping strategies following surgery?**

Three months post-surgery the pattern of strategy use appeared to have changed little. The women continued to use all five strategies within one standard deviation of the mean of the standardised population. The men continued to used four within one standard deviation of the mean and their use of ‘seeking emotional social support’ was once again more than one standard deviation below. As it was not believed that the use of particular coping strategies changed significantly with time, further analysis was not carried out.

The third question to be answered was: **Do patients and their partners make similar use of the five coping strategies?**

Correlations were carried out on the use of the five strategies between the sexes to establish whether there was any relationship between patients’ and partners’ use (appendix 4.7). No significant correlations were found. It was concluded that, although
both the men and women use coping strategies that are typical of a population facing a situational stressor, there was no evidence of any relationship in the use of particular coping strategies between partners.

The final research question was: **What is the relationship between these particular coping strategies and psychosocial functioning in breast cancer patients and their partners?**

In order to answer this question a number of correlations were carried out between the five coping strategies of interest and HAD anxiety and PAIS-SR raw total. The PAIS-SR raw total was constructed excluding the work domain because of inconsistencies in scoring (see appendix 4.2). As the PAIS-SR included questions designed to measure anxiety, the effect of HAD anxiety was partialled out in correlations with PAIS-SR scores. Because of the number of correlations a probability level of 0.01 was required for significance.

The first correlations were carried out between the coping strategies and adjustment measures for each sex at each time point (appendix 4.8). Only one strategy was significantly associated pre-surgery. Female use of 'acceptance' was negatively correlated with HAD anxiety ($r = -0.586, p = .003$). Post-surgery there were no significant correlations.

The second part of this analysis was whether the coping strategies of one sex were related to the adjustment of the other (appendix 4.9). Female coping and male adjustment were not correlated at either time point in this study. However, male 'active coping' and female PAIS-SR scores were correlated pre-surgery ($r = 0.654, p = .002$). At follow-up there were no significant associations.
It is of interest to establish whether coping is related to later adjustment.

Initial use of coping strategies was therefore correlated with the adjustment scores at three months. Female use of the five strategies was not associated with either their later psychosocial adjustment or the later adjustment of the men (appendix 4.10). However, male use of ‘seeking emotional social support’ was significantly correlated with later male HAD anxiety ($r = .673, p = .002$). No male strategies were significantly associated with later female adjustment scores.

The final part of this research question aimed to identify whether the most poorly adjusted coped differently. At initial assessment the scores of a large proportion of the women on the HAD indicated clinically significant anxiety. There was a significant difference in the PAIS-SR scores of the two groups with the least anxious being better adjusted ($t [24] = 2.86, p = .005$, one-tailed) (appendix 4.11). It was decided to test whether there were any significant differences between the lower anxiety / lower PAIS-SR and the higher anxiety / higher PAIS-SR women in terms of use of coping strategies. Observation of the data (table 4) appeared to indicate that both seeking social support strategies were used more by the group with the higher HAD anxiety scores. No differences were suspected for the other three strategies. T-tests were therefore carried out on these two strategies. Results indicated that the more anxious group made significantly more use of both of the seeking social support strategies (table 5).
Table 4. Coping Strategies

<table>
<thead>
<tr>
<th>Coping Strategy</th>
<th>Anxiety</th>
<th>N</th>
<th>Mean</th>
<th>Std Dev</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>low</td>
<td>8</td>
<td>14.25</td>
<td>1.83</td>
<td>11-16</td>
</tr>
<tr>
<td></td>
<td>high</td>
<td>15</td>
<td>12.60</td>
<td>2.64</td>
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Table 5. T-Tests

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<tr>
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<td>21</td>
<td>2.44</td>
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* p< .05 (two-tailed significance)

Discussion.

The results reported above were found for a group whose psychosocial adjustment to illness appeared to be typical of a population coping with cancer and for whom increased age was associated with better psychosocial adjustment to this illness. However, a large proportion of subjects did not report any significant symptoms of anxiety or depression and results may therefore not generalise to populations with higher levels of psychological distress.

Use of Coping Strategies.

It was found that the women and men used a range of coping strategies in dealing with the initial impact of breast cancer and surgery. This is in keeping with other work in this area (Heim et al, 1993; Jarrett et al, 1992). Three months post-surgery there was no significant change in their use of coping strategies. At this second time point there would have been different difficulties to face and these coping strategies appear to be
ones that are used in response to a variety of life stresses. Therefore this study finds that,
although the men and women use a range of coping strategies, there is no evidence of
any particular strategies being activated by the demands of initial surgery for breast
cancer.

There was no relationship detected between the sexes in their use of coping strategies
and it was therefore concluded that patients and their partners do not make similar use of
coping strategies. This is in keeping with the work of Ptacek, Ptacek and Dodge (1994)
who assessed 36 couples coping with treatment for breast cancer and found that the
coping strategies of each sex were largely unrelated.

The men made significantly less use of 'seeking emotional social support' than the
women at both time points. However, men make less use of seeking social support than
women in situations where both sexes face an identical stressor (Ptacek et al, 1992;
Ptacek, Smith & Dodge, 1994). It was concluded that this finding was the result
of general sex differences in coping rather than a feature of coping with breast
cancer.

**Coping Strategies and Psychosocial Adjustment.**

Although the strategy of 'denial' is perhaps the most widely reported in the literature,
this was the only coping strategy in the present study for which there were no significant
findings. This lack of association is in accordance with Friedman et al., (1988). Although
it may be that there is no relationship between denial and adjustment it is also possible
that there is a non-linear relationship. This might explain the seemingly contradictory
findings of previous researchers and also explain why no association was picked up in
this study which tested mainly for linear correlations. However, this possibility requires further investigation.

Hannum et al., (1991) found that the adjustment of women with breast cancer related more to the coping behaviours of the spouse rather than to their own. They also found that the adjustment of the men was a combination of both their own and their wives coping behaviours. The present study differed from that reported above in that male adjustment was not associated with either male or female coping at either time point. However, female adjustment was associated with both male and female coping. Female use of ‘acceptance’ was negatively associated with HAD anxiety and male use of ‘active coping’ was positively associated with female PAIS-SR scores. This was found pre-surgery only.

This result indicates that passive forms of coping by the couple are adaptive for the women. It may be that pre-surgery active forms of coping are not beneficial because there is little that either the women or the men can do. This explanation is in accordance with the work of Carver et al., (1992) who found that use of acceptance was related to absence of distress both pre-surgery and at assessment between seven and ten days later. However, this result appears to contrast with the results of Friedman et al., (1988) who found that active coping was associated with better adjustment. Friedman et al., looked retrospectively at the coping of women between 2 and 255 months after initial surgery for breast cancer and it may be that an active style of coping becomes adaptive with time as individuals are faced with challenges to which an active response is required. It is therefore recommended that couples, in which the women is facing breast cancer surgery, should be encouraged to use coping strategies which are accepting and discouraged from using those which are active. This is only appropriate in the early
stages of hospitalisation and surgery. Passive forms of coping are not recommended for long term use.

No coping strategies were correlated with later female adjustment. This appears to indicate that it is not possible to make predictions concerning later female adjustment on the basis of their use of the five coping strategies selected. The only coping strategy associated with later male adjustment was initial male use of 'seeking emotional social support'. This group of males typically made little use of 'seeking emotional social support' and the majority were not anxious. It may be that not using this strategy is adaptive for them or it may be that this is a spurious finding partly attributable to low scores on both the measure of anxiety and strategy use. Further work therefore needs to be done to establish whether this is a genuine finding and whether it is also found in anxious men.

Seeking social support was related to adjustment in the women. Pre-surgery, the more poorly adjusted used both of the seeking social support strategies more. This finding is in contrast with Dunkel-Schetter et al., (1992) who found that for a mixed cancer group of 603 patients that coping through social support was associated with less emotional distress. However, many of the mixed cancer group completed questionnaires several years after diagnosis with 28% having had their diagnosis over five years. This is in contrast with the present study in which the comparison between the better adjusted and poorer adjusted was made pre-surgery. It may be that use of seeking social support leads to a reduction in distress but also that the more anxious make more use of it initially. Alternatively, it could be that the implications for breast cancer patients are different than those for patients with other cancers. A larger study which followed up
the effects of seeking social support over time is required to further investigate the nature of this relationship.

No attempt was made in this study to control for pre-surgery variables. A number of factors could potentially contribute to anxiety levels. These include time from initial consultation to surgery, amount of information, quality of relationship with spouse and significant additional stressors. Each is worthy of study.

In addition it is to be expected that the grade of cancer and additional treatments would also contribute to outcome. Although this information has been included it was not the focus of this study and larger numbers would be required to analyse these variables.

It is likely that part of the lack of results concerning male anxiety reflects the low level of anxiety in this group. More work is certainly required in this area and it may be that a larger study is required to analyse the effects of coping on male adjustment.
References.


Single Case Study.

Cognitive-Behaviour Therapy for Post Traumatic Stress Disorder
resulting from Multiple Trauma.

prepared for British Journal of Medical Psychology

(see Appendix 5.1 for Notes for Contributors)
Cognitive-Behaviour Therapy for Post Traumatic Stress Disorder resulting from Multiple Trauma. A Case Study

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Cognitive-Behaviour Therapy for Post Traumatic Stress Disorder resulting from Multiple Trauma. A Case Study.

A case is presented of a woman who developed the symptoms of Post Traumatic Stress Disorder (PTSD), after two separate and different traumatic incidents. Mrs A. developed PTSD after an armed robbery in which she was threatened with a knife. She was still experiencing PTSD symptoms when she was in a car accident. The second trauma did not merely reactivate or exacerbate the existing disorder but caused the development of a new set of PTSD symptoms. This case was successfully treated using a combination of cognitive-behavioural techniques.

It has long been recognised that exposure to traumatic events can lead to a range of distressing psychological symptoms. However, it was not until 1980 that Post Traumatic Stress Disorder (PTSD) was given recognition as a diagnostic category with its inclusion in the Diagnostic and Statistical Manual of Mental Disorders, third edition, (DSM III) (American Psychiatric Association, 1980). The criteria for diagnosis has since been modified with its inclusion in DSM III-R (American Psychiatric Association, 1987) and then again for its inclusion in DSM IV (American Psychiatric Association, 1994).

Estimated lifetime prevalence of PTSD is 0.5% in males and 1.3% in females (Helzer et al., 1987).

Stressors sufficient to cause PTSD are not rare events. Breslau and colleagues (1991) found that 39% of a community sample of young adults had been exposed to a traumatic event sufficient to qualify as a stressor according to DSM III-R criteria. Of those exposed, 23% went on to develop PTSD. Since exposure to traumatic events is a
frequent occurrence and a significant proportion of those exposed go onto develop PTSD, it is to be expected that significant numbers of individuals will develop PTSD resulting from multiple traumas.

There has been some research looking at the incidence of PTSD in populations at greater risk for exposure to traumatic events. The police are such a population. 50% of San Diego police officers exposed to a restaurant massacre developed PTSD. The prevalence in the police department as a whole was 26% (McCafferty et al., 1992). In a study of 224 mental health staff, Caldwell (1992) found that 62% had experienced an incident involving serious threat to life or physical safety or had witnessed a serious injury or death. Ten percent met criteria for PTSD. Perhaps the most studied at risk population is that of Vietnam veterans. Life time prevalence amongst US veterans has been estimated as 30.9% for men and 26.9% for women (Kulka et al., 1990).

Studies of such at risk populations typically examine individuals who are exposed to one type or class of traumatic incident. A case will be presented in which a traumatic event caused the development of PTSD symptoms in an individual with pre-existing PTSD. It is shown that such a case can be successfully treated with a combination of cognitive and behavioural techniques.

Case Report

History

Mrs A, a twenty-eight year old married woman, was referred for treatment of PTSD.

Previous psychiatric history consisted of postnatal depression, after the birth of her only child, four years earlier. She had been treated with medication by her GP.
The first traumatic incident took place seventeen months prior to being seen for treatment. Mrs A. was held up at knifepoint in the building society where she worked. A man held her by her hair, he had a knife at her throat and was demanding money from the other staff. Mrs A felt that her life was in danger. She developed PTSD symptoms which included flashbacks to the incident and avoidance of things associated with it. She threw out the clothes she had been wearing and took different routes to work. Mrs A. also became irritable, anxious, tearful and could not concentrate. She experienced panic attacks and was finding sleeping very difficult. She withdrew from her friends, family, and colleagues.

Nine months later Mrs A experienced a second traumatic event. She was run over while crossing the road. She was thrown into the air, hit the car cracking the windscreen and fractured a vertebra. She was in hospital overnight and off work for six weeks. She developed further PTSD symptoms. When near roads she reported feeling as though she was being thrown into the air and she had nightmares about being run over. She would avoid crossing the road and driving.

Six months later, Mrs A was in another car accident. A car ran into the vehicle Mrs A was travelling in. Everyone involved was taken to hospital. Mrs A was not physically injured but another passenger required stitches for cuts to the face where she had been hit with broken glass. Mrs A said that she was very distressed in the hospital. This incident further exacerbated her symptoms. She felt withdrawn for many days afterwards and her panic attacks increased.
Symptoms and Diagnosis.

Clinical assessment revealed that Mrs A had developed PTSD. This diagnosis requires that the individual experiences three categories of symptom. These are intrusive imagery, behavioural avoidance and disordered arousal.

Mrs A experienced different intrusive imagery after each of the first two traumatic incidents. After the first, she had flashbacks to being threatened with a knife. After the second, she would re-experience the feeling of being thrown into the air and had nightmares about being run over. Mrs A avoided anything which reminded her of the day she was threatened with a knife. She had thrown out the clothes she was wearing that day and also avoided the route she had taken to work. After being knocked down the number of things she avoided increased. They included crossing the road, driving and being in cars. Mrs A experienced a number of symptoms of disordered arousal. these included; sleeping difficulties, irritability, difficulty concentrating and an exaggerated startle response.

In addition, Mrs A. had symptoms of panic disorder. These included; dizziness, heart pounding, hands trembling, sweating, indigestion, tingling and face flushing. Panic symptoms were within the context of PTSD and therefore she did not meet DSM IV criteria for an additional diagnosis of Panic Disorder.

Mrs M also had some depressive symptoms. These included low mood, sleeping difficulties and impaired concentration. However, she did not fulfil DSM IV criteria for a depressive disorder at the time of initial assessment.

There was no history of drug or alcohol abuse.
At the time of assessment Mrs M’s psychological symptoms were having a significant effect on her level of functioning. She was avoiding people, not answering the phone, and had stopped socialising. She felt unable to drive and was not working.

Formulation of Mrs A’s difficulties indicated that she had developed PTSD as a result of being held up at knifepoint at her work. A second traumatic incident, consisting of being run over, caused her to develop further PTSD symptoms. Another car accident, six months after the first, further exacerbated her symptoms.

Mrs A. had been depressed after the birth of her child four years previously and may well have been predisposed to developing PTSD. She also suffered from endometriosis and had significant financial difficulties. These additional factors may have increased her vulnerability.

**Method**

*Treatment*

Treatment consisted of five sessions using cognitive-behavioural techniques. These took place over a period of four months. Five other sessions were cancelled.

Foa *et al.*, (1995) conclude that both exposure and anxiety management techniques are effective in reducing PTSD symptomatology. These were the main focus of intervention with this woman. In addition, thought stopping (Salkovskis & Kirk, 1989) and distraction techniques (Fennel, 1989) were used.

Controlled breathing (Clark *et al.*, 1985) and progressive relaxation (Wolpe & Lazarus) are commonly used anxiety management techniques. As Mrs A had a number of panic symptoms it was felt that controlled breathing was particularly suitable for this woman.
She had previous experience in the use of relaxation techniques. This was reviewed and incorporated in treatment.

Two exposure hierarchies were constructed. The first contained things which had been avoided as the result of the assault and the second things which had been avoided as the result of the car accident. Mrs A had avoided the route she had previously taken to work. Retracing this route was one of her first exposure tasks. Initially she completed this task accompanied and later she made the journey alone. Mrs A had avoided driving since she had been run over. Exposure to driving was also carried out. The first task consisted of sitting in the driving seat of the car. Such tasks were carefully graduated and Mrs A progressed to driving in a car park and then on the road.

Thought-stopping and distraction techniques were used to control flashbacks. Although thought-stopping is a technique traditionally used with obsessive-compulsive patients (Salkovskis & Kirk, 1989) it was used with considerable effect with Mrs A. She described her intrusive images as a video tape that would replay at points throughout the day. This technique therefore fitted well with her conceptualisation of the images. Mrs A would try not to think about what had happened. Distraction techniques were developed. These focused on the use of pleasant memories and Mrs A was asked think of memories that were personally relevant.

**Results**

*Outcome of Treatment*

Despite only attending half of the sessions offered there was a significant reduction in symptoms. Mrs A rarely experienced flashbacks or nightmares. She could cross roads and no longer re-experienced the feeling of being thrown into the air. She did not avoid,
the route she had previously taken to work, crossing the road or driving the car. She no longer experienced panic attacks. Her sleeping and concentration had markedly improved.

The reduction in symptoms had led to an improvement in social functioning. Mrs A. had restarted up her own business and was now answering the phone and contacting customers. She was also socialising more. This was generally with her family but she had also planned a short holiday. She was no longer avoiding people and had even arranged to appear on a television programme.

Beck’s Anxiety Inventory (BAI) (Beck et al., 1988) and Horowitz’s Impact of Events Scale (IES) (Horowitz et al., 1979) were administered at the beginning and end of treatment. The IES contains two subscales measuring the PTSD symptoms of ‘intrusion’ and ‘avoidance’. Results are shown in figures 1 and 2.

**Discussion**

Cognitive behavioural techniques have been used effectively to treat PTSD in populations likely to have been exposed to multiple traumas. Keane et al., (1989) demonstrate, for example, that Vietnam veterans can be successfully treated with a combination of relaxation and flooding. Case studies have also been presented in which the multiple traumas have been documented and treated successfully. McCaffrey and Fairbank (1985), for example, demonstrate that PTSD resulting from multiple car accidents can be successfully treated using exposure and anxiety management techniques. It is believed that the present study is the first to demonstrate the effectiveness of cognitive behavioural techniques in treating PTSD resulting from multiple but different traumas.
Figure 1. Horowitz Impact of Events Scale.
Figure 2. Beck Anxiety Inventory.
References


Single Case Study.

Psychometric assessment of a man with Down’s Syndrome with marked behavioural changes.

prepared for Journal of Intellectual Disability Research,

(see appendix 6.1 for Information for Contributors)
Case Report

Psychometric assessment of a man with Down's Syndrome with marked behavioural changes: an outline of the issues.

Running title: Assessment of Behavioural Change.

Key words: Down's syndrome, Alzheimer's disease, depression, assessment, psychometric, behavioural disorder.

Julie Dunan

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Abstract
A case is presented of a forty-one year old man with Down’s syndrome who demonstrated marked behavioural changes. Differential diagnoses are considered and discussed. These include, dementia, depression and the development of a behavioural disorder. An understanding of the issues raised is essential for anyone working with adults with Down’s syndrome.

Introduction
Mr B, a forty-one year old man with Down’s syndrome, was referred for assessment because of changes in his behaviour. He had outbursts of aggression towards himself and others, would steal and destroy possessions and withdrew from previously enjoyed activities. At times he appeared to be confused and a decline in his level of skills was reported.

One explanation of such changes is that they are indicative of the onset of dementia. An association between Down’s syndrome and dementia was first noted over a century ago (Fraser & Mitchell, 1876). The incidence of Alzheimer’s disease in the population with Down’s syndrome is significantly higher than both that of the general population (Ellis et al. 1974) and the population with learning disabilities (Collacott et al. 1992).

A second explanation is that these changes are indicative of a depressive disorder. Attention has been drawn to the under-diagnosis of depression in this population and the mistaken attribution of treatable symptoms to senility (Harper & Wardworth, 1990). Adults with Down’s syndrome are more prone to develop depressive illnesses than other adults with a learning disability (11.4% of those with Down’s syndrome and 4.3% of those with another learning disability) (Collacott et al. 1992).
It is also possible that Mr B developed a specific behavioural disorder. Day and Jancar (1994) report that behaviour disorders account for between a third and a half of all psychiatric disorders in individuals with learning disabilities. Newly arising behavioural problems in adulthood are not uncommon (James, 1986).

Methods

Case report

Mr B is a forty-one year old man with Down’s syndrome. He lived in a long stay learning disabilities hospital from the age of four until the age of thirty-nine. Eighteen months prior to referral, he moved to a four bedded house in the community. His days in this house were very structured and residents were responsible for many domestic and self care tasks. Mr B had initially settled well into this accommodation. He carried out household duties well and took a pride in his clothes and personal appearance. Nine months prior to referral Mr B’s behaviour began to cause problems both at his home and at the day centre which he attended. A range of uncharacteristic behaviours were reported. Aggressive outbursts had been directed both at staff and other residents. He would spit, shout, swear, slap, kick and throw furniture. He would also hurt himself. This included biting and punching himself and picking his gums until they bled. A number of unusual behaviours occurred. Mr B had eaten raw food, taken other people’s possessions, destroyed his own possessions, danced naked in his room and hidden in the house. In addition, a deterioration in Mr B’s general skills including speech and writing had been noted by staff. He was also withdrawing from activities and there had been episodes of incontinence and confusion. Mr B was admitted to hospital as a result.
In hospital there were few problems and his general skills and personal hygiene were good. He went on visits to his day centre and home but there were still difficulties in these environments. Mr B was unwilling to take part in activities, many of which he previously enjoyed. On one overnight pass home he was found wandering outside in his pyjamas.

Referral to clinical psychology was made for assessment, specifically to determine if such changes were indicative of a dementing disorder. The assessment took place in the hospital environment although information obtained from other sources was considered. Three assessment measures were used. These were, 'An Assessment for People who are Thought to be showing Signs of Dementia' (Cheseldine, 1987), the 'Dementia Rating Scale' (Mattis, 1988) and the Communication Assessment Profile (CASP) (Van Der Gaag, 1988). These measures were selected on the basis of being suitable for this client’s ability level and on providing information of relevance to the assessment request. None of these measures had been used previously with this man which made it difficult to determine whether there had been a deterioration in functioning. However, it was intended that this assessment could provide a baseline measure for the comparison of future assessments and thereby make it easier to answer this question if it was asked again in the future.

Results

I) An Assessment for People who are Thought to be showing Signs of Dementia.

1. Orientation

Mr B appeared to be geographically oriented. He did not get lost in familiar environments. He knew where his room, the toilet and the kitchen were. He was able to
find things around the ward and knew where things were kept in the kitchen cupboards. As this was Mr B’s first stay in the hospital and he had only been in the ward a couple of weeks, this also demonstrates that Mr B was capable of new learning.

Mr B also seemed to be oriented in time. He indicated by his behaviour that he recognised differences between days of the week. He expected to go to church on Sundays, for example. However, if asked what the day of the week was he would nearly always say that it was Monday. He appeared to have learned that ‘Monday’ was the answer to such a question. This response did not indicate disorientation. It is a learned response that shows a lack of understanding of the concept. Mr B also used learned ‘answers’ to other questions. Therefore there was no evidence that Mr B was disorientated in either time or place.

2. Memory

Mr B seemed to have some problems with memory tasks. One task required Mr B to remember a number of objects placed on a table. He was only able to tell which object was missing if he had actually watched it being removed. He was unable to do this task correctly even with only three objects. A second task required Mr B to remember a list of words. He could only remember three out of a list of five items. Of the three items that were retained all were recalled twenty minutes later. He had, however, also added extra items to the list. Mr B could not repeat a short sentence or even a couple of words. Individuals with Down’s syndrome are poorer on sentence imitation tasks than others with learning disabilities (Marcell et al. 1995). Therefore such results are not necessarily indicative of a deterioration in memory function.
Mr B was able to retain two component instructions. He could count to ten and recite the days of the week. He could also remember new names and recall what he had been doing a short while earlier. In general he was able to recall well learned information. Mr B’s attention was often poor, he was not always interested in the tasks and did not always appear to understand what was asked of him. These factors make it difficult to establish to what extent poor performance on memory tasks indicate genuine memory problems.

3. Sequencing skills

Mr B could competently use sequencing skills in well learned tasks. This was revealed in making cups of tea, drying dishes and tidying around the kitchen. He performed such tasks proficiently, appeared confident in his abilities and had the steps of these tasks in the right order.

4. Language

Mr B’s speech was at times difficult to comprehend. He did however use non verbal communication, such as looking away when he was unwilling to do something. He was also able to use makaton signs. Mr B did not use complex sentences.

Mr B was more likely to say ‘yes’ or agree than say ‘no’ or disagree. For example, if he was asked if an object was big he would agree. He would also agree if asked if it was small. Acquiescence (the disposition to answer ‘yes’ regardless of the question asked) is a commonly observed response bias which has been found to be exaggerated in individuals with a learning disability (Heal & Sigelman, 1995). In response to choice questions Mr B typically repeated back the last option and did not appear to consider the alternatives at all. This was also found when asking Mr B why he had done certain behaviours and whether anything was making him unhappy. His pattern of responses
indicates comprehension difficulties. Receptive language skills have been found to deteriorate with age whereas expressive language skills do not (Carter-Young & Kramer, 1991; Cooper & Collacott, 1995). It may be that Mr B's relatively good expressive skills were masking a deterioration in comprehension.

5. Fine motor co-ordination

Mr B has broad hands and this therefore causes difficulty with tasks requiring fine motor co-ordination. He would often spill things for example when pouring tea. He was able to tie his shoelaces but was slow.

6. Behavioural change

Many uncharacteristic behaviours had been reported from staff. These included.

i) spitting, shouting and swearing

ii) slapping, kicking and throwing furniture

iii) taking other people's possessions

iv) head butting other people

v) biting and punching himself

vi) picking his gums until they bled

vii) destroying his clothes and other possessions

viii) overeating and even eating raw food

ix) demanding food and drink

x) dancing naked in his room

xi) hiding in wardrobes and behind his bed

xii) incontinence and confusion

xiii) withdrawing from activities
These behaviours were rare as an inpatient but staff at his home and day centre reported numerous incidents. None were witnessed during the assessment which took place in the hospital although Mr B was at times inattentive and uncooperative.

Urinary incontinence was reported in both hospital and home environments. Hospital staff attributed this to the diuretics which he was taking.

II) Dementia Rating Scale

1. **Attention**

Mr B could only remember a sequence of two digits (or three words). He could perform single commands but if two or more commands were linked together he had some difficulty. He could imitate single actions but not a string of different ones. Such findings indicated that Mr B had a very limited attention span.

2. **Verbal Initiation and Perseveration**

Mr B managed the verbal initiation tasks. He could name items that would be found in a supermarket, for example. He was, however, unable to do the verbal perseveration tasks. These required Mr B to repeat the same letter.

3. **Construction**

Mr B had difficulty with construction tasks. He could not copy simple designs.

4. **Conceptualisation**

Mr B could not use concepts to distinguish in what way objects were alike or unlike. He could not identify that two things were alike because they were both food, for example.

5. **Memory**

Mr B’s visual memory was better than his verbal memory. He could recognise abstract designs he had seen a few moments earlier but he could not remember or recognise words. This is perhaps not surprising as he did not appear to be able to read or write.
III) The CASP

1. Event Knowledge

Mr B could count coins but did not know their worth. Reports from 1992 indicate that previously he had this skill and this may therefore reflect a deterioration. He knew where he was and where he lived.

2. Vocabulary

Mr B performed well on naming tasks and had a reasonable vocabulary. He was capable of using simple sentences to communicate.

3. Comprehension

Mr B had the ability to understand certain attributes of objects. Examples that he was able to understand include; under, over, following and giving.

Discussion

The results of this assessment are discussed in terms of each of the three identified differential diagnoses.

Dementia

It has long been known that there is a high incidence of Alzheimer’s disease in the population of people with Down’s syndrome (Ellis et al. 1974). However, although the neuropathological changes characteristic of Alzheimer’s disease have been reported as present in all individuals with Down’s syndrome over the age of 35 years (Dalton & Wisniewski, 1990), not all develop dementia. (Wisniewski and Rabe (1986) estimated that between 15 and 30 % develop dementia). The average age of onset of dementia has
been estimated as 54 years with an average duration from dementia to death of 4.6 years (Lai & Williams, 1989).

Although not all individuals with Down’s syndrome develop dementia, a significant deterioration in cognitive function has been reported in older individuals with Down’s syndrome (Zigman et al. 1987; Thase et al. 1984; Johanson et al. 1991). A decline in adaptive function has also been documented (Collacott, 1992; Zigman et al. 1987). It has been speculated that this age-related deterioration is an artefact of the histories of the different age cohorts assessed or that it is due to increased sensory impairment in elderly individuals. Roeden and Zitman (1995) specifically attempted to control for these factors yet still detected deterioration across a broad range of cognitive skills.

Longitudinal analysis has also indicated a pattern of decline in self-help skills in individuals with Down’s syndrome older than 40 (Rasmussen & Sobsey, 1994).

Cognitive deficits include: a higher prevalence of recent memory loss, and deterioration in orientation and attention with increasing age (Wisniewski et al. 1978). Johanson et al. (1991) reported a particular decline in visuospatial skills, memory and orientation.

Although adolescents with Down’s syndrome are found to be particularly poor at tasks requiring the phonological coding of words (Varnhagen et al. 1987) this ability declines in those over 40 (Das & Mishra, 1995). Receptive language skills have been found to deteriorate with age whereas expressive language skills do not (Carter-Young & Kramer, 1991; Cooper & Collacott, 1995).

Deterioration in adaptive behaviour has been measured by the Adaptive Behaviour Scale and reached statistical significance in most domains in the cohort aged 50-59 and in all domains in those aged 60 and over. (Collacott, 1992).
The results of Mr B's assessment indicate that he may have been experiencing the gradual onset of these age related deficits. His expressive skills appeared to be better than his receptive skills. His performance on tasks of memory was poor and may have indicated some memory loss. His attention was very poor. There was however no evidence of orientation difficulties or adaptive skill loss (although this had been suggested by other workers).

**Depression**

Atypical symptoms, such as increased behaviour problems have been associated with a diagnosis of major depression in adults with learning disabilities (Meins, 1995). However, there is often difficulty in making the diagnosis of depression as many of the symptoms are similar to those of early dementia and individuals have been mistakenly diagnosed with dementia when they are in fact depressed. Warren *et al.*, (1989) identified five individuals with Down's syndrome who had been mistakenly diagnosed as suffering from dementia. Diagnosis of depression was confirmed by response to ECT. Warren *et al.*, suggest that affective disorder should be considered in the differential diagnosis of apparent dementia in individuals with Down's syndrome.

Mr B was put on antidepressants while in hospital and the psychiatrist responsible for his care believed that he responded well.

**Behavioural Disorder**

It is also possible that Mr B developed a specific behavioural disorder. Individuals with poor verbal skills may use a change in behaviour as a means of expression. Health problems are relatively common in individuals with Down’s syndrome and Mr B could be using his behaviour as a way of telling his carers that he is in pain or discomfort. Higher rates of osteoporosis, epilepsy, motor handicaps and non-specific lung disease have been
reported with advancing age in individuals with Down's syndrome over age 40 as compared with a matched group of adults with learning disabilities (Haveman et al. 1989). Of individuals with Down’s syndrome over 50 years of age, 79% had hearing loss and 82% had a visual impairment. Thyroid deficiencies are also relatively common (Roeden & Zitman, 1995) and can cause apathy and lethargy in later life.

Mr B’s hearing and thyroid functioning were checked and both found to be satisfactory. However the high incidence of other physical illness in older adults with Down’s syndrome suggests that further assessment of physical health is required to rule out this as a cause of his behaviour change.

Mr B’s behaviour did not cause so many problems when he became an inpatient in a hospital environment. It therefore seems likely that environmental factors are at least contributing to his difficulties. Mr B moved accommodation eighteen months prior to referral and changed the day centre which he was attending nine months prior to referral. This coincided with the start in uncharacteristic behaviour in this man. Ghaziuddin (1989) suggested that increased life events in the twelve months leading up to referral of patients to the psychiatrist predicted increased behavioural problems in the mildly mentally handicapped. Mr B may have been missing something from his previous environment or unhappy about something in his new environment and trying to express this. It is possible, for example, that there are less incidents in the hospital environment because there is less pressure put on Mr B to perform tasks and he is free to withdraw when he feels like it.
In conclusion, it remains possible that Mr B could be experiencing the early stages of a dementing disorder. He could also have a depressive disorder or a behavioural disorder. Such cases highlight the importance of ongoing assessment.

Results of this assessment do however suggest that although Mr B may have experienced some cognitive deterioration this is not out with what would be expected of an ageing man with Down’s syndrome. There is therefore no evidence that he will necessarily develop a dementing disorder. In such cases further psychometric testing should be carried out at intervals to monitor change. This may also be combined with computer-assisted tomography (CT) scans. Schapiro et al., (1992) conclude that CT scanning can be used to distinguish dementia from the lesser cognitive decline seen in older adults with Down’s syndrome.

The possibility that Mr B has a depressive disorder should not be ruled out at this stage. His symptoms and response to antidepressants should continue to be monitored.

Behavioural disorders are not uncommon in adults with a learning disability. Mr B’s behaviour will need to be monitored when he returns to his home and day centre and a behavioural analysis may be required to identify triggers to his outbursts.
References.


Cheseldine S. (1987) *An assessment for People who are Thought to be Showing Signs of Dementia.* (unpublished).


Single Case Study.

Behaviour Therapy for Hypochondriasis.

prepared for Behavioural Psychotherapy

(see appendix 7.1 for Instructions to Authors).
Case Report

Behaviour Therapy for Hypochondriasis.

Running Head: Behaviour Therapy for Hypochondriasis.

Julie Dunan

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A case is presented of behavioural treatment for hypochondriasis. Treatment was given in two blocks. The first block consisted of anxiety management techniques which incorporated progressive muscular relaxation and controlled breathing. The second block consisted of exposure and response prevention which involved exposure to anxiety provoking stimuli and the prevention of reassurance seeking. Results suggest that there was no significant improvement in symptoms after the first block of treatment but considerable improvement after the second block. These findings are discussed.

Introduction.

The essential feature of hypochondriasis is a preoccupation with fears of having or the idea that one has a serious disease based on a misinterpretation of one or more bodily signs or symptoms. This fear persists despite medical reassurance (American Psychiatric Association, 1994). The six-month prevalence of DSM III-R hypochondriasis has been estimated as between 4.2% and 6.3% of those attending a general medical clinic (Barsky, Wyshak, Klerman and Latham, 1990) and it is believed that such patients make a significant contribution to medical outpatient referrals (Van Hemert, Hengeveld, Bolk, Rooijmans and Vanderbrouke, 1993; Barsky, Coeytaux, Sarnie and Cleary, 1993). Hypochondriasis is believed to be more common among patients with medically ill-explained or unexplained symptoms. Van Hemert et al. (1993) found that the prevalence of psychiatric disorders was 15% for patients with a medical explanation for their presenting symptoms, 41% for patients with ill-explained or unexplained symptoms and
hypochondriasis or somatization disorder were found in approximately 40% of the patients with psychiatric disorders.

Hypochondriasis has been conceptualised from a behavioural perspective (Warwick and Salkovskis, 1989). It is assumed that anxiety has become conditioned to stimuli associated with illnesses and for the hypochondriacal patient such stimuli are primarily internal bodily sensations. Like obsessional patients, the hypochondriacal patient resorts to behaviours designed to neutralise the anxiety. Reassurance seeking is used as a form of avoidant behaviour and Warwick and Salkovskis (1985) have suggested that it may be fundamental in the maintenance of this disorder. Reassurance seeking can take many forms such as asking friends and family, seeking medical opinions and repeatedly checking the body for symptoms or signs of illness. Such behaviours can reduce anxiety in the short term but serve to increase preoccupation with physical illness in the long term (Salkovskis and Warwick, 1986).

Recently successful treatment of hypochondriasis has been reported which incorporated exposure and response prevention. A study incorporating two single case experiments indicated that treatment designed to eliminate reassurance seeking is effective (Salkovskis and Warwick, 1986). The treatment programme incorporated fully exposing the two patients to their feared stimuli and allowing anxiety to reduce without any reassurance seeking. A pilot study of 17 cases has indicated that exposure to illness cues and prevention of reassurance produced rapid improvement in both health anxiety and social functioning in patients with illness phobia and hypochondriasis (Warwick and Marks, 1988). A cross-over design of six patients receiving cognitive-behaviour therapy indicated that both exposure in vivo with response prevention and cognitive therapy may be useful in the treatment of hypochondriasis (Visser and Bouman, 1992).
The results of the later study appeared to indicate that the behavioural therapy accounted for improvement more often than did the cognitive sessions.

The present case study is of a woman with a diagnosis of hypochondriasis. She was given two blocks of behavioural treatment. The first consisted of anxiety management techniques and the second of exposure and response prevention. The efficacy of both are discussed.

**Method.**

_Case History_

Mrs C was a married woman, aged 37. She had two children. She had not worked since the birth of her daughter eight years previously.

Mrs C reported that the first time she had ever felt terrified was when she was fifteen and had been at home alone with her father when he had a heart attack. She first became concerned about her health when she was pregnant with her second child. She had been rather depressed after the birth of her first child and was still finding him difficult to cope with when she was pregnant for the second time. A routine check-up indicated that her heart was beating rather fast. She had further tests which indicated that she had an irregular heart beat. She was on propanalol for this at the time of referral. She said that it was after these tests that she became very concerned that something was wrong with her heart.

In the year prior to referral there had been a number of medical stresses in Mrs C's life. Her husband had been rushed to hospital in an emergency as the result of a stomach ulcer. A neighbour who suffered from palpitations and who was of a similar age had died in her sleep and another neighbour had died of lung cancer. At the time of her first
appointment Mrs C’s father, who had a number of health problems, had been taken into hospital. It seemed that these stresses had exacerbated her symptoms and precipitated the referral.

Although Mrs C was in general very concerned about her own health and that of her family she was particularly concerned that she had heart disease and cancer. She reported being very aware of her heart beat and would regularly take her pulse. She also regularly checked her body for any signs or symptoms of cancer. At the time of treatment she was very concerned that weight and hair loss indicated cancer. She was worried that if she went on holiday it would be too late for chemotherapy to be effective by the time she came back. Mrs C. felt that she was going to die quite soon and was certain that there was something wrong with her that the doctors had missed. Fava, Grandi, Saviotti and Conti (1990) reported on a series of six case studies and found that both thanatophobia (fear of impending death) and disease phobia (a fear that one has a severe illness despite evidence to the contrary) characterised hypochondriacs.

Mrs C had a number of reassurance seeking behaviours. In addition to seeking reassurance from friends and family, she numerous GP appointments and specialist referrals. She was also considering using private health care so that she could see other doctors. Mrs C had a number of medical text books and would frequently refer to them. She had also recently attended a first aid course.

Mrs C stated in the first session that she did not think however that she was a hypochondriac and that she believed that there was something medically wrong with her. She was however pleased to see a clinical psychologist because she felt that she was rather anxious.
Mrs C. met DSM IV (American Psychiatric Association, 1994) diagnostic criteria for hypochondriasis. In addition, she had a number of symptoms of anxiety. She described palpitations, light-headedness and occasionally took panic attacks. These symptoms were all within the context of her health fears and did not warrant the separate diagnosis of an anxiety disorder. She also experienced some low mood but did not meet criteria for a depressive disorder.

_Treatment._

**Session 1**

The first session was used primarily for assessment, the results of which have been described above.

**Sessions 2-6.**

Anxiety symptoms are a common feature of the psychopathology of hypochondriasis (Kellner, Abbott, Winslow and Pathak, 1989) and Mrs C reported a number of these. Salkovskis (1989) has suggested that anxiety management techniques should be applied in the treatment of somatic patients for the management of stress and anxiety. Mrs C was instructed in controlled breathing (Clark, Salkovskis, and Chaukley, 1985) and progressive muscular relaxation (Wolpe and Lazarus, 1966) and was to practice both daily. In addition, pleasurable activities were scheduled. This was firstly to distract Mrs C from spending large periods of time ruminating about health related issues but also had the added benefit of increasing her engagement in enjoyable activities. During this block of treatment although Mrs C. was asked about reassurance seeking no attempt was made to reduce this.
Sessions 7-11.

The role of reassurance seeking in maintaining anxiety was discussed. Mrs C was asked to record how often she used each of eight types of reassurance seeking techniques and how long she spent. For the second week in this block of treatment she was asked to pick one of these to resist. Mrs C picked ‘asking another person about health related issues’. This meant that she was not to ask anyone about a health related issue with the exception of her husband and mother. For the third week Mrs C. was to stop examining her body and for the fourth week she was to stop taking her pulse.

Record of the time spent in reassurance seeking and the number of days per week on which she performed each behaviour are given in tables 1 and 2.

During the second block of treatment although Mrs C still used the techniques learned in the first block these were not discussed or set as homework tasks.

Measures.

The Beck Anxiety Inventory (BAI) (Beck, Epstein, Brown and Steer, 1988) was administered pre-treatment (during session 1), after the block of anxiety management (end of session 6) and after the block of exposure treatment (end of session 11). The Beck Depression Inventory (BDI) (Beck, Rush, Shaw and Emery, 1979) was administered at only the second and third time points.

Results.

No significant reduction in anxiety symptoms, expressed health concerns or reassurance seeking was detected as a result of the five sessions of anxiety management techniques. However after four sessions of reducing reassurance seeking there was a significant reduction in each of these. In terms of anxiety symptoms there was a reported reduction
in the severity of anxious fears, palpitations, dizziness and indigestion. Mrs C reported
that in the week preceding her last appointment that she had not had any episodes of
feeling panicky and had even felt able to relax. She also reported that her mood and her
appetite had improved and she had regained weight which she was very pleased about.
Each week Mrs C had managed to successfully reduce the number of days on which she
was performing the particular reassurance behaviour which she had been set as a task to
reduce. With the exception of taking her pulse she was also able to reduce the total
time spent as well. Mrs C described taking her pulse as the most frequent of the
behaviours and the one that was hardest to stop. In the week which reducing it was set
as a task Mrs C reported that most days she had managed to cut down the number of
occasions however she had one particularly bad day which accounted for most of the
occasions of that week.

The measures used verified the clinical opinion that there had been a reduction in
symptoms. (figure 1 and table 3).
Table 1. Time (minutes) spent in reassurance seeking activities per week.

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Session 8 Baseline</th>
<th>Session 9</th>
<th>Session 10</th>
<th>Session 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consulting Medical Text Book</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Asking Husband about a Health Issue</td>
<td>13</td>
<td>10</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Phoning the Doctor</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Asking mother about a Health Issue</td>
<td>10</td>
<td>5</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>Taking Pulse</td>
<td>34</td>
<td>10</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Examining Body</td>
<td>20</td>
<td>7</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Asking Another Person about a Health Issue</td>
<td>110</td>
<td>35</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Attending a Medical Appointment</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Checking health of family member</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2. Number of days per week on which behaviour was carried out.

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Session 8 Baseline</th>
<th>Session 9</th>
<th>Session 10</th>
<th>Session 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consulting Medical Text Book</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
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<tr>
<td>Asking Husband about a Health Issue</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Phoning the Doctor</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Asking mother about a Health Issue</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Taking Pulse</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Examining Body</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Asking Another Person about a Health Issue</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Attending a Medical Appointment</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Checking health of family member</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Figure 1.  BDI and BAI Scores.

Table 3.  BAI and BDI Scores.

<table>
<thead>
<tr>
<th></th>
<th>session 1</th>
<th>session 6</th>
<th>session 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>B A I.</td>
<td>28</td>
<td>26</td>
<td>5</td>
</tr>
<tr>
<td>B.D.I</td>
<td>not administered</td>
<td>24</td>
<td>2</td>
</tr>
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</table>
Discussion.

Clinical assessment and questionnaire measures indicated that treatment which incorporated exposure and response prevention was effective in reducing psychological symptoms in a woman with hypochondriasis. This is in keeping with other studies (Salkovskis & Warwick, 1986; Warwick & Marks, 1988; Visser & Bouman, 1992). Although recommended by Salkovskis (1989), there was no evidence that anxiety management techniques were effective in this case.

It remains possible, however, that the effects were in some way cumulative and improvement was the result of the combination of techniques. It is likely, for example, that Mrs C was making use of both relaxation and controlled breathing to cope with her anxiety resulting from resisting the reassurance seeking behaviours. A cross-over study with more subjects is therefore required before these results could be generalised.

Of note is the fact that anxiety symptoms (which were secondary to hypochondriasis) were reduced by preventing reassurance seeking. In terms of the model outlined by Warwick and Salkovskis' (1989), in which it was assumed that anxiety has become conditioned to stimuli associated with illnesses, this finding implies that this patient habituated to the anxiety provoking stimuli which therefore lead to the reduction in anxiety.

Perhaps the fact that anxiety did not reduce as a result of anxiety management techniques verifies the secondary nature of anxiety symptoms in this patient. It may be that in cases where an anxiety disorder was primary to fears about health or in cases where there is an additional anxiety disorder then the anxiety symptoms would have been more amenable to such interventions. This points to the importance of correct diagnosis in such patients particularly considering that the majority of patients with
hypochondriasis also meet criteria for an additional disorder (Barsky, Wyshak and Klerman, 1992; Noyes et al., 1994). These comments are speculative and further research in this area is warranted if treatment packages are to be offered that best match individual patients needs.

Mrs C reported that her reassurance seeking behaviours had previously been much higher than that recorded as the baseline. These activities had taken up significant parts of the day. She said that she could spend half an hour a day checking her pulse and did not feel that she could leave the house unless she had phoned her mother. When her husband came in from work she always had to ask him about her health and this had been putting a strain on their relationship. It may be the case that Mrs C’s reassurance seeking behaviours had reduced as the result of the first block of treatment and it is recommended that clinicians carrying out similar studies should establish a baseline of these behaviours prior to any intervention.

It is also recommended that future researchers use questionnaires designed to specifically monitor symptoms of hypochondriasis as the questionnaires given to Mrs C did not serve this function.
References.


