A pilot study to validate modification of the Duke University Severity of Illness scale to measure a family’s burden of illness

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Background. Measurement of burden of illness is rarely undertaken in general practice, although a specific tool [Duke University Severity of Illness DUSOI scale] has been incorporated in the International Classification in Primary Care. This measures the burden of illness in an individual at a point in time. There has not been any measure of the burden of illness in families. Such an instrument would allow measurement of the impact of events on the health of families.

Objective. This pilot study aimed to modify the DUSOI to measure a family's burden of illness and to validate any changes.

Methods. The DUSOI was modified to measure the mean burden of illness in a family over a 1 year period. The changes were then subject to a validation process using convenient samples of patients from the author’s multidoctor practice in Australia. Reliability was examined by the test–re-test method. Inter-rater reliability could not be assessed. Responsiveness was measured by measuring changes in score in the years before and after four events: counselling for a minor mental health problem; referral to a psychiatrist; diagnosis and treatment of breast cancer; and the occurrence of an acute myocardial infarction.

Results. The modifications made to the DUSOI have not altered the face or content validity of the original instrument. Construct validity and test–re-test reliability were satisfactory. Inter-rater reliability was not tested, but the original single patient score showed levels lower than are desirable. Responsiveness varied significantly. Families where a member was referred to a psychiatrist showed a decrease in burden after referral, while families where a member suffered an infarct showed a large increase. The other family groups did not show any change.

Conclusion. A Family DUSOI will be of value in research when validated for individual conditions.

Keywords. Breast cancer, family health, health status indicators, mental disorders, myocardial infarction.

Introduction

The burden of illness in a family has been shown to vary with the presence of severe illness in one family member. This has been particularly well demonstrated in relation to severe mental illness and myocardial infarction.

There have been few studies in general practice that have examined health or health-seeking behaviour in distressed families. Sobieraj et al examined families of depressed patients using the Duke University Severity of Illness scale (DUSOI). The DUSOI measures the burden of illness (severity) in an individual at a point in time. Sobieraj et al. took the step of averaging the DUSOI score across family members and showed that for general practice depressed patients, the mean DUSOI in a family (with the patient excluded) was significantly higher in the affected group than in matched controls.

The DUSOI is a novel measure of severity designed for use in general/family practice where each illness is scored on four factors: (i) the symptoms experienced in the preceding week; (ii) the complications experienced in the preceding week; (iii) the prognosis, without treatment, over the next 6 months; and (iv) the treatability of the condition. Each factor is scored from 0 to 4 and the scores of each factor are added to give a score out of 16. Each score is then scaled to a
score between 0 and 100. The scores are then summed in a manner that emphasizes the more severe illnesses. This method of addition results in a score between 0 and 100, with higher scores indicating greater severity (or burden) of illness.

The DUSOI has been validated and its reliability demonstrated, and is now included in the International Classification in Primary Care (ICPC). This study aimed to develop the DUSOI to measure family burden of illness. If this was possible, then it could be used to examine a family’s response to illness and treatment.

For this study, a family was defined as a group of people, usually related, living in the same household. It did not include members of the family living in different sites, as it was impossible in this pilot study to ensure that details of all family members could be obtained. The author was aware that in the counselling group, there were significant others who had a significant role in the patients' care. Records of such patients were not kept at the practice where this study occurred. No attempt was made to define a caring role as these data were rarely included in the medical record.

Modifications of DUSOI

Sobieraj et al. used a mean of the family’s score at the time of diagnosis of depression. This, however, would miss any increase in consultations for minor or transient complaints. It was therefore decided to modify the DUSOI to measure family burden of illness over a period of time. The period of time had to be sufficient for an intervention or a disease to have an effect on the family. Experience suggests that after such an event, it would be at least 3 months before there would be a change in behaviour. Beyond 12 months, the effect of the family may be diluted by other events. Arbitrarily, it was decided to choose a year as the interval over which to measure.

In Australia, a person who visits a GP does so 6.5 times per year. The rate varies with age and gender. The DUSOI adds each additional disease or symptom as a smaller proportion of the overall score. Anything beyond three or four has minimal impact on the final score. It was therefore decided to conduct individual scoring over 3 month periods and to calculate a mean of four scores to arrive at a final score for the year. The 3 month period also enabled the modified DUSOI to measure any increase in consultations due to stress-related conditions.

For any given 1 year period, the method of scoring is as follows: (i) divide the year into 3 month periods; (ii) calculate each person’s score for all conditions seen in a 3 month period; (iii) calculate a mean for the family for each 3 month period; and (iv) calculate a family mean from the four scores calculated in (iii).

Methods

Validity, reliability and responsiveness were examined using four convenient groups of 20 families. The four groups consisted of families where a member had (1) undergone counselling by the author for a mental health problem; (2) been referred to a psychiatrist for the treatment of a mental health problem; (3) been diagnosed with breast cancer; or (4) suffered an acute myocardial infarction (AMI).

Validity was examined by comparing the modification of DUSOI with the original version and by comparing the results of group 2 in the year prior to referral with the technique used by Sobieraj et al. Group 2 was chosen as it was the nearest to the Sobieraj et al. patients. There were no possible comparators for the other groups. Inter-rater reliability was not tested directly, but was examined from the standpoint of the original DUSOI. Test–re-test reliability was tested on group 1 (the first five patients). This ensured that there was 18 months between test and re-test and would provide 40 scores (of 3 month family scores) for comparison. As the process was well standardized, it was felt this should be sufficient to ensure the author was consistent across time.

In order to examine the responsiveness of the instrument, each group of families was scored for the year before and the year after the occurrence of the event outlined above.

Group 1 families were taken from a personal list of patients who received family therapy-based counselling from the author. Patients were randomly selected from this group if they received counselling as the only form of treatment and the case records contained all members of the family. Scores were generated for the years prior to and after the commencement of counselling.

Group 2 families were selected by examination of randomly selected case notes until 20 families were found with complete records and a member had been referred to a psychiatrist. If any member of the family had received counselling from the author, they were excluded.

Group 3 families were selected by a computer database search for ICPC code for breast cancer. Records were searched from youngest to oldest, to maximize the chances of finding family groups, to select complete family records. Group 4 families were selected in the same manner as group 3, except the code for myocardial infarction was used. Analysis of the relationship between patient age and Family DUSOI score did not show a significant correlation (data not reported).

Using the data generated in the study by Sobieraj et al., calculations indicated that 10 families would produce a power of 0.8 to detect a difference in the years before and after when using a before and after study and $\alpha = 0.05$. Because of the different method in this study, 20 families in each group were chosen.
The Human Research Ethics Committee of the University of Adelaide approved the study. All patients and families came from the author’s multidoctor practice in a middle-class suburb of an Australian city. All analyses were carried out using Statistical Package for Social Sciences (Windows Version 9).

Validity
As indicated above, the DUSOI has undergone an extensive validation and the modification used in this study has not materially altered the structure of the instrument. As such, face and content validity are unchanged. There is no standard instrument against which the Family DUSOI could be measured. A comparison was made with the method of Sobieraj et al.

The scores of the two methods for the 20 families in group 2 are shown in Table 1. Correlation (Spearman’s rho) is 0.785, which is significant (two-tailed) at the \( P = 0.001 \) level. This is greater than the level (0.75) recommended by Fleiss\(^7\) as indicating excellent agreement. This result indicates that the Family DUSOI produces similar results to the Sobieraj DUSOI, which previously has been shown to be an effective measure.

The validity of the Family DUSOI has not been altered by the changes from the original instrument.

Reliability
Inter-rater reliability was not assessed directly in this study as only one recorder was used. However, it is unlikely that the changes have altered the inter-rater reliability of the DUSOI. Previous studies have revealed that inter-rater class correlation coefficients are less than ideal, with figures ranging from 0.43\(^8\) to 0.85\(^4\). Most studies are below the 0.75 recommended by Fleiss\(^7\) as indicating excellent agreement. This result indicates that the Family DUSOI produces similar results to the Sobieraj DUSOI, which previously has been shown to be an effective measure.

The reliability of the Family DUSOI has not been altered by the changes from the original instrument.

Responsiveness
Group 1 patients consisted of a mix of conditions, but primarily adjustment disorders (65%). Group 2 patients were also mixed, but 50% suffered from depression. The two groups were different in severity of the mental illness, with group 2 being generally more severe. In these two groups, scores were expected to decrease after the commencement of treatment.

Groups 3 and 4 were homogenous to diagnosis, and scores were expected to increase in the year following the onset of the disease.

In all cases, the families were scored with the patient excluded. Data were analysed using one sample \( t \)-test for normally distributed data and Wilcoxon for non-parametric data.

Table 3 shows the results. The data from the breast cancer and AMI groups had several outliers (as detected by box and whisper plots) which were reviewed and found to be extreme variations in response of a family member. The results are reported with the outliers included and excluded. As seen in Table 3, inclusion and exclusion of the outliers did not alter the significance of the results.

Discussion
This pilot study has indicated that a DUSOI modified to measure the burden of illness in a family is sometimes capable of detecting changes in the level of distress in families. For mental health problems severe enough to require referral to a psychiatrist, the burden of illness in the family decreased after such referral. The occurrence of an AMI led to a significant increase in the burden of illness in a family.

Minor mental health problems that responded to counselling did not have any measurable effect on the burden of illness in the family, and the diagnosis and treatment of an incidence of breast cancer did not change the explicit burden of illness in the rest of the family.

It would seem that the brief episodes of adjustment disorder were of insufficient impact to affect the family. In the breast cancer families, the lack of response is supported by the literature\(^9\). A subsequent analysis (not shown here) indicated that there was a reduction in consultations for symptoms (as compared with diagnosable conditions) in family members during the year after the occurrence of breast cancer in a family.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Comparison of Family DUSOI with Sobieraj DUSOI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
</tr>
<tr>
<td>Family DUSOI</td>
<td>20.2</td>
</tr>
<tr>
<td>Sobieraj DUSOI</td>
<td>15.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Test–re-test scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
</tr>
<tr>
<td>Quarterly scores: initial</td>
<td>17.1</td>
</tr>
<tr>
<td>Quarterly scores: re-test</td>
<td>16.5</td>
</tr>
</tbody>
</table>
The validity of the Family DUSOI is unchanged from that of the original instrument. The major limitation is that neither instrument measures those conditions not reported to the practitioner nor written on the medical record. While test–re-test reliability in this study was sound, previous studies have raised concerns about inter-rater reliability.

This study used a before and after method which is a very powerful method of detecting change. For between-group comparisons, a much larger number of patients would be required. Using the figures from the AMI group, in order for this instrument to have a statistical power of at least 0.8 at the \( \alpha = 0.05 \) level would require \( \sim 300 \) families in each group.

The DUSOI modified to measure the burden of illness in a family over a 1 year period is capable of detecting differences in burden for treatment of moderate to severe mental illness and the occurrence of an AMI. For reasons outside the control of the instrument, it is incapable of detecting change for the treatment of minor mental illness and the diagnosis and treatment of breast cancer. Studies exploring differences between families experiencing different illnesses would require large numbers of families to have sufficient power to detect any changes.

From a clinical point of view, the study indicates that practitioners should be aware of the increased burden of illness in families after the occurrence of an AMI in a family member. Whether intervening in the family after such an event will be of value is yet to be tested. The lack of change suggests that husbands or partners of women who develop breast cancer may need assistance in coming to terms with their wife’s illness. Whether they would accept such intervention is another question.

The study is a pilot and is limited by the small sample size and the restriction to one practice in urban Australia. As such it is not generalizable to other communities and cultures.

In summary, the Family DUSOI is a valid and reliable instrument that has potential for use in other studies, but will only be able to be used after piloting for specific diagnoses. Raters will need to be trained and steps taken to minimize inter-rater differences. An exploration of the impact of chronic disease on the family using a multicentre study will further define this instrument.

**Table 3  Responsiveness data**

<table>
<thead>
<tr>
<th>Group</th>
<th>n(^b)</th>
<th>Year prior</th>
<th>Year after</th>
<th>Difference (95% CI)</th>
<th>Test statistic</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselling, all families, means</td>
<td>20</td>
<td>16.06</td>
<td>16.31</td>
<td>0.25 (−2.2 to 3.4)</td>
<td>( \text{t-test df = 19, } t = 0.162 )</td>
<td>0.873</td>
</tr>
<tr>
<td>Psychological referral, all families, means</td>
<td>20</td>
<td>21.63</td>
<td>17.76</td>
<td>−3.88 (−6.72 to −1.04)</td>
<td>( \text{t-test df = 19, } t = −2.860 )</td>
<td>0.010</td>
</tr>
<tr>
<td>Breast cancer, all families, means</td>
<td>20</td>
<td>11.45</td>
<td>11.75</td>
<td>Wilcoxon ( Z = −0.454 )</td>
<td></td>
<td>0.650</td>
</tr>
<tr>
<td>AMI, no outliers, means</td>
<td>19</td>
<td>19.06</td>
<td>24.14</td>
<td>5.08 (0.62 to 9.55)</td>
<td>( \text{t-test df = 18, } t = 2.399 )</td>
<td>0.028</td>
</tr>
</tbody>
</table>

\( ^b \) \( n = \) number of families.

**References**