The Impact of a Brief Psycho-educational Group intervention on Dementia Care givers : A Pilot Study

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Background

Introduction

The last decade has seen a growing interest and concern about dementia, as reported prevalence rates increase steadily (Knapp & Prina, 2007). In 2009 the then Secretary of State for Health, Alan Johnson, commented in Living well with dementia: A National Dementia Strategy (DH, 2009) “we all know someone who has been affected by dementia”.

Over half of those diagnosed with dementia (63.5%) remain in their own homes throughout their illness or disability, being cared for by a family member or informal unpaid carer.

There is a both a financial and psychological cost when undertaking a caring role which may include increased anxiety and depression. Supporting these carers is paramount in supporting the person with dementia.

Definition of “a carer”

A carer is defined as: “someone who looks after and supports a friend, relative or neighbour who could not manage without their help. This could be due to age, physical or mental illness or disability. It does not mean a professional care worker or personal assistant who gets paid for their work.” (www.direct.gov.uk/en/caringformonees)

Aims and Hypothesis

Aims

• to determine the effect of the group intervention upon the physical health and emotional wellbeing of carers.
• to determine any effects from the group intervention to their perceived carer burden.
• to evaluate the acceptability of the group intervention and any change or increased knowledge and understanding of dementia post intervention.

Hypothesis

Caregivers of people with dementia, who attend a brief psycho-educational support group will experience a change in physical health, emotional wellbeing and perceived carer burden.

Ethics Approval

Local Clinical Academic Group (Mental Health of Older Adults and Dementia) approval was received January 2012.

IRAS Project number 111699. REC reference 12/LO/1660. Approval was obtained from Fulham Ethics Committee, London on 9/11/2012.

The appropriate R & D committee agreed to sponsor the study with approval approved on 10/1/2013. R & D reference RAD2013/001.

Reference List


www.direct.gov.uk/en/caringformonees accessed on 28th June 2013

Acknowledgements

David Matthews, Noushig Nahabedian, Chris Ball and my family and friends

Method

Study Design

A quantitative, before/after study design was selected to determine the effect of the group intervention on a single group of participants.

Recruitment of participants

The participants of the study were carers of service users who were recently diagnosed with dementia according to ICD-10 (WHO, 1992)

Sample Size

The sample size for the study was determined by a powers calculation with the primary outcome measure being the General Health Questionnaire (Goldberg & Hillier, 1979). Using nQuery software the sample size required was 13 participants.

Outcome measures

Two validated questionnaires were used:-

• The General Health Questionnaire (GHQ) (Goldberg & Hillier, 1979). A score of greater than 5.5 was determined as the threshold to indicate ‘psychiatric caseness’
• The Zarit Burden Interview – 12 (Short version) (Bedard, 2001). A score of over 17 indicates high carer burden.

An intervention was formed to evaluate the ‘acceptability’ of the group intervention and any subjective change in ‘increased knowledge and understanding of dementia’.

Group Intervention

The group ran once a week for 2½ hours over 5 consecutive weeks. The group was split into 2 parts with a break in between. The first part of the group was psycho-educational and during the second part of the group the clients and carers met separately to discuss emotional issues associated with their roles.

Data Analysis

Non-parametric testing was employed as the spread of the data on the pre test indicated a large variance with a non-normal distribution of the data.

A Wilcoxon Signed Rank test was chosen with the probability value set at p = 0.05.

SPSS 20 was used to generate outcomes for analysis.

Conclusion

• Results of the study highlighted a difficulty in measuring a subjective subject such as carer burden and emotional wellbeing using solely a quantitative study design.
• There appeared to be an inconsistency between quantitative results and those from the evaluation form.
• An important issue arising from these findings appears to be the absence of an outcome measure for carer burden that encompasses all its multi-dimensional components.

As a pilot study, there has been much learnt to inform the development of a follow on study, especially with regards to the selection of appropriate outcome measures as being vital when undertaking quantitative analysis.

Study design also requires careful consideration for the future, the learning being that emotion may be difficult to measure quantitatively. A mixed methodological design would be most likely to capture change in all its complexity.

Results

Participants demographics

A total of 15 participants agreed to participate in the study, however 2 failed to complete the course. Statistical information was therefore taken from the 13 participants.

The Effect of the Intervention

Results of GHQ

<table>
<thead>
<tr>
<th>N</th>
<th>Mean</th>
<th>Std Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHQ pre</td>
<td>13</td>
<td>10.19</td>
<td>10.00</td>
<td>15.00</td>
</tr>
<tr>
<td>GHQ post</td>
<td>13</td>
<td>9.19</td>
<td>8.00</td>
<td>13.00</td>
</tr>
</tbody>
</table>

Pre and post intervention GHQ scores were identical at 2.77 however the SD increased from 3.00 on pre score testing to 3.75 on post score testing. This indicates that despite the overall mean outcomes remaining the same, suggesting no overall change on GHQ, the spread of the data or variance increased.

A Wilcoxon Signed Rank Test revealed there was no statistically significant change identified on GHQ scores following the group intervention, z = -211 p = .833. As the z score was based on outcomes from non-parametric testing no further analysis was undertaken.

Pre intervention 23% of participants reached the threshold for ‘psychiatric casesness’ (when the threshold is set at GHQ score of 5) and post intervention 15% people remained within the threshold with 8% improved and 8% newly met the criteria.

The data shows no statistically significant change on the GHQ when employing the Wilcoxon Signed Rank test. The null hypothesis was therefore accepted.

Results of Zarit Burden Interview – short version

<table>
<thead>
<tr>
<th>N</th>
<th>Mean</th>
<th>Std Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zarit pre</td>
<td>13</td>
<td>13.6923</td>
<td>8.53017</td>
<td>1.93</td>
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<tr>
<td>Zarit post</td>
<td>13</td>
<td>13.6923</td>
<td>11.2675</td>
<td>2.93</td>
</tr>
</tbody>
</table>

The Zarit Burden Interview – short version mean score increased from pre score result of 16.39 to 13.92 on post score results. This change suggests an increase in perceived carer burden. The SD also increased from pre score results of 9.53 to 11.28 post intervention suggesting there was also an increase in variance.

A Wilcoxon Signed Rank test showed no statistically significant change in Zarit Burden Interview – short version scores following the group intervention z = .596 p = .551.

The data shows no statistically significant change on the ZBI when employing the Wilcoxon Signed Rank test. The null hypothesis was therefore accepted.

Caregivers of people with dementia, who attend a brief psycho-educational support group will experience no change in perceived carer burden, physical health and emotional wellbeing

Results from Evaluation Form

Acceptability of the group

On reviewing the evaluation form 100% of participants found the group helpful. Comments were made on how participants may have felt differently since attending the group shown below:

Comments from participants regarding ‘Feeling differently’:
1. I have learnt a lot. It has helped me to accept the diagnosis
2. I have an understanding of the problems I face and that others face the same
3. I realise how ‘normal’ the condition is
4. I am more aware of the many ways that help can be given
5. I am more able to deal with problems
6. It has been good to participate and hear how others cope
7. I know where to go for help in the future
8. I am aware of what’s ahead and feel more able to cope

Increased knowledge and understanding of dementia

Results from the evaluation form indicated that 85% of participants had acquired an increase in knowledge and understanding of dementia. Comments were made as such:-

Comments from participants regarding ‘Increased knowledge and understanding of dementia’:
1. I have understood what dementia is and how to overcome problems
2. I have improved understanding
3. Listening to the stories helped
4. I have a better understanding of my understanding
5. I feel particularly interested to meet someone who had dementia for over 5 years
6. I understand that dementia journey is different for all. I have learnt to adapt to changing circumstances
7. I found listening to other people and putting ideas into practice helped me understand more
8. I have learnt to be more patient

Results from the study highlighted a difficulty in measuring a subjective subject such as carer burden and emotional wellbeing using solely a quantitative study design.

There appeared to be an inconsistency between quantitative results and those from the evaluation form.

An important issue arising from these findings appears to be the absence of an outcome measure for carer burden that encompasses all its multi-dimensional components.