


A randomised controlled trial of benefit finding in caregivers: The Building Resources in Caregivers Study Protocol

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Abstract

Caregivers may engage in benefit finding, that is, an increase in perceived positive growth, as a cognitive strategy for coping with stress. The Building Resources in Caregivers study will compare effects of a brief benefit finding writing intervention with a control intervention. Caregivers of people with mental and physical disabilities will be randomised into either a benefit-writing group or a neutral writing group. Caregivers will complete measures relating to themselves and care-recipients (e.g. sociodemographics and illness type) and psychometric measures of benefit finding, distress and quality of life at three time points. Additionally, qualitative commentary on participation experiences will be gathered.

Keywords

Benefit finding, caregiver, expressive writing, intervention, randomised control trial

Introduction

Levels of distress in family carers of individuals with disabilities can be high (Gallagher and Whiteley, 2013; Pinquart and Sörensen, 2003; Vitaliano et al., 2003), and this has been associated with increased morbidity and mortality (Schulz and Beach, 1999). Furthermore, the potentially harmful effect of life distress as experienced by caregivers of functionally dependent persons is exacerbated by the long-term nature of care recipient needs and behavioural symptoms (e.g. Gallagher et al., 2009; Vitaliano et al., 2003). In fact, alongside this, and given the large number of caregivers in national populations (Ireland, 278,000; United Kingdom, 6.5 million; United States, 67.5 million), caregiver health has now been argued to be a public health concern (Talley and Crews, 2007). However, not all caregivers succumb to poor health (Vedhara et al., 2002), some cope extremely well with the demands of caregiving. For example, a population-based study from the United States found decreased mortality in caregivers who spent more time caregiving (Brown et al., 2009), implying a paradox in the literature. Moreover, alongside the stress of caring, caregivers also report uplifts and rewards, and a review of the literature on these aspects revealed a health-promoting

effect in caregivers (Pinquart and Sörensen, 2003). Additionally, studies have recently found that caregivers who perceived more benefit finding (BF), that is, an increase in perceived positive growth in areas of relationships, gratefulness, spirituality and meaning making, had increased social support which in turn predicted higher quality of life (QoL; Brand et al., 2014). Similar findings have been reported elsewhere (Cassidy, 2013; Kim et al., 2007; Pakenham, 2005; Samios et al., 2011), attesting to the positive contribution BF has for caregiver health.

Caregivers may engage in BF as a cognitive strategy for coping with stress (Brand et al., 2014). As part of that cognitive strategy, those who engage in BF transform their view of themselves, others and their place in the world to produce

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a positive psychological change after a traumatic event through a process of cognitive restructuring (Cheng et al., 2014; Tedeschi and Calhoun, 2004). Thus, increasing BF through intervention may be one way to improve coping mechanisms in caregivers and to build resources to deal with the challenges of caring. Indeed, harnessing the power of BF through intervention may be a key way of helping caregivers deal with the unpleasant nature of caring. Although the body of evidence attesting to the negative effects of caring cannot be ignored, equally one cannot ignore these positive findings and the potential of BF as an intervention strategy for caregivers has just being harnessed with positive results (Cheng et al., 2014).

Caregivers who participated in an 8-week BF intervention were found to have lower depression scores relative to a control group immediately after the intervention (Cheng et al., 2014); whether these reductions were maintained over time is not yet known. As well as the lack of maintenance data, it is not known whether improvements in BF were evident, which was due to lack of measurement of the construct. As such, it is difficult to know whether BF was driving the observed effects. Moreover, previous cognitive restructuring interventions with caregivers' reasons suggest that providing too many restructuring techniques may hinder caregivers to integrate and apply all those learned simultaneously in their daily lives (Lavoie et al., 2005), implying that simple and brief techniques may have more utility. Similarly, given that caregivers are notoriously difficult to recruit for interventions, primarily due to time and respite constraints (Pasacreta and McCorkle, 1999) and lack of transport (Areán and Gallagher-Thompson, 1996), it was hardly surprising that only 25 caregivers were recruited in total which impacts on the generalisability of the study. Other barriers to recruitment include inaccessibility to the research site and mistrust of researchers (Dowling and Wiener, 1997; Gallagher-Thompson et al., 2003; Lampley-Dallas, 2002; Moreno-John et al., 2004). Thus, considering the limitations of earlier studies and the constraints and barriers in conducting face-to-face interventions, in addition to the considerable costs involved, a solution which can circumvent some of these obstacles is using an online environment to deliver a brief and simple writing intervention.

Generally, conducting research online saves time by making research instruments and content available instantly, saves money in terms of space/travel and other additional costs associated with the employment of those involved in the face-to-face administration of the project (Kazdin and Rabbitt, 2013). Apropos of all the preceding benefits of conducting online research, there is another even more relevant reason for applying an online approach to conducting this research with caregivers. Due to the nature of caregiving, a lack of time for oneself is a re-occurring theme within caregiving narratives and is also identified as a reason for increased burden on caregivers (Zarit et al., 1980), as contributing to an inability to meet their own personal needs

(Grant and Davis, 1997). Hence, E-health also has the potential to remove the time and space barrier between caregivers and therapists.

Importantly, caregivers will take part in this study on an individual basis and this Internet-based model of delivering the study intervention adheres to research recommendations made by Sørensen et al. (2002) who established that interventions aimed at individual caregivers were more effective in improving caregiver well-being than group interventions. Moreover, we have preliminary data employing a randomised control trial (RCT) methodology to deliver a brief 2-week Internet-based writing intervention to improve social well-being (O'Connell et al., 2015) which would be ideally suited to caregivers who are constrained by both time and geography. Thus, feasibility to deliver interventions of this type over the Internet is already established. Furthermore, Grant and DePew (1999) recommend developing relationships with the key individuals in referring agencies, including healthcare providers and their key personnel in order to aid with recruitment and help retain study participants. Maintaining collaborative relationships with healthcare providers through presentations and feedback about interventions may foster important referral sources (Areán and Gallagher-Thompson, 1996). Accordingly, this study will recruit caregivers through the online social networks operated by the two largest caregiver non-governmental organisations (NGOs) in Ireland: Care Alliance Ireland and the Carers Association.

Thus, the primary aim of this Building Resources in Caregivers (BRiC) intervention is to test the methodology and feasibility of a brief 2-week Internet-based BF writing intervention to increase BF with a secondary aim of improving their overall QoL and psychological health. We will also seek to ascertain the feasibility of delivering this type of writing intervention via an Internet-based model.

Methods

Study design

This will be a double-blind, randomised controlled parallel group trial design, with three measurement periods (T1 – baseline, T2 – immediately after intervention and T3 – 3 months later). The between groups will be (a) the intervention group and (b) the control group (see below for details). The trial will be conducted in accordance with the CONSORT guidelines (Turner et al., 2012) with an equal 1:1 allocation ratio. The primary outcome will be BF (Antoni et al., 2001) and secondary outcomes the Caregiver Quality of Life (QoL; Joseph et al., 2012) and Hospital and Depression Scale (HADS; Zigmond and Snaith, 1983). Ethics for this project has been approved by the universities Institutional Review Board (no: 2014_12_26_EHS).

Parallel to the RCT, a brief qualitative component will be undertaken along with intervention difficulty and acceptability ratings. In this qualitative study, participants will be asked

to write comments about the effects of the intervention and aspects of the intervention method (see below for details). Observations drawn from the qualitative part of the study will be used to consider the feasibility aspects of the study.

Participants

Inclusion criteria will be primary caregivers in the Republic of Ireland aged over 18 years currently providing care to one or more persons. Those excluded from the proposed study will be professional caregivers such as those who are in the employment of institutions of care or home care provision companies. Caregivers will be recruited through our NGO collaborators (Care Alliance and Carer's Association) who have an extensive network of carer groups nationally. We have worked in partnership with these groups previously (Brand et al., 2014). The study will be advertised on their respective websites and appear on Twitter feeds whereby caregivers can contact the principal investigator directly to receive the study information sheet, seek clarity and have the opportunity to ask questions. As in our previous study (Brand et al., 2014), we will include all caregivers, as we have found no differences on psychosocial outcomes in those caring for physical or mental health disabilities. Moreover, this all-inclusive approach allows for comparisons to be made regarding efficacy and whether the intervention is appropriate for all caregiver groups.

Sample size calculation

The null hypothesis of this between-subjects RCT is that there are no significant differences in well-being in caregivers who write their thoughts and feelings in a diary about the benefits of caregiving and those caregivers who write about topics unrelated to their caregiving activities. Based on previous research (Cheng et al., 2014), a power calculation with a medium effect size of $F = .25$, $p < .05$ and power of .8, the total sample size required is 86, with 43 in each trial arm (calculated with G*Power Version 3.9). Participant demographic information will be gathered at the beginning of the T1 data collection process which should, according to Bosnjak and Tuten (2001) minimise the dropout rate to approximately 10.5 per cent. Therefore, a sample size of 96 caregivers will be recruited to provide data for the final analysis.

Recruitment

Caregivers will be recruited using social media and via the e-mail communications platforms used by Care Alliance and The Carer's Association. On the respective caregiver websites, potential participants will be invited to read a short description of the study on the organisation home pages. Should they wish to obtain further information, they will be directed to a link bringing them to a web page where they can read more detailed information about the study.

Once they are satisfied that they have read sufficient information about the study, they will be directed to a link on the consent page which they can click should they wish to participate. The consent forms and questionnaires will be delivered over the Internet through QuestBack™ software.

Intervention

The proposed intervention will be based on and informed by prior work in the BF interventions literature (Cheng et al., 2014; Henry et al., 2010) which found that cognitive approaches that focussed on increasing BF among caregivers had superior results in reducing depression over psychoeducational approaches attempting to achieve the same goal. Caregivers will be instructed to write about their thoughts and feelings in a diary/personal notebook focussing on the benefits of caring, to consider improved social relationships, the appreciation of life and loved ones, and think about the positive consequences with respect to these. To better meet the needs of the caregivers in our study (e.g. time pressures, sensitivity), we will not ask diaries to be returned. While we acknowledge that this may be a limitation, if participants do not engage, then our results should reflect this and our fidelity assessment may provide more information if this is the case. These activities will be done three times a week for 2 weeks. The control group will be asked to write about the weather that day for the same number of days.

The intervention group writing instruction will read as follows:

Writing is a great way to reflect on your life in general and on the roles we have in life, helping to look back and focus on the good things in our lives. These things can be big and small. For the next two weeks, three times a week on the days of your choosing we encourage you to really let go, explore your innermost thoughts and feelings about the benefits of providing care to your loved one and write these thoughts down. Examples could include writing about becoming closer to your loved one, focussing on the things your loved one is able to do rather than what they cannot do, no matter how big or small this is, feeling needed, more empathetic, accepting, compassionate, new relationships with others, your loved one or family members; perhaps seeing your life in a different way - more positive. It could also be about you and how satisfied you are as a carer moving forward and learning how your priorities have changed. These are just examples, but you may have other benefits that you would like to talk about regarding your caring role, no matter how big or small they may be. Although when you write the sentences they can be as long or as short as you like but try and aim for about 3 or 4 sentences at least.

The control group writing instruction will read as follows:

Writing is a good way of getting us to reflect a bit better and it may help improve our well-being. For the next two weeks, on just six days of your choice (3 days each week), write in a

copybook or a personal diary, a number of things about the weather on each day. Although when you write the sentences they can be as long or as short as you like but try and aim for about 3 or 4 sentences at least.

Procedure

After providing informed consent, caregivers will be randomly allocated using the random allocation feature of survey QuestBack™ software to the intervention or control condition. Baseline measures will be completed at T1, for example, demographics, care recipients details, and primary and secondary outcome measures; after the 2-week writing stage is complete, participants will be sent an e-mail with a link to complete the post-intervention (T2), and 3-month follow-up (T3) assessment, with outcomes as previously administered at baseline.

Fidelity, implementation and adherence

The writing instructions are a core component of the proposed intervention. In order to ensure as high a level of adherence to fidelity criteria associated with the main outcome measure (BF) as possible, the writing instructions for both the control and intervention groups have been constructed in such a way as to induce an equal chance of perceiving benefit. Additionally, to assess the level of expectation across both groups of perceiving benefit, prior to random allocation, all participants will be asked to answer the following question ‘*How well do you expect to feel after taking part in the writing activities?*’ on a Likert-type scale ranging from 1 (*Not at all*) to 6 (*Very well*). We would expect that both groups have a similar level of expectation to benefit from the writing exercise. Moreover, to assess participant’s difficulty and acceptability of the writing exercise at T2, participants will be asked a series of questions rated on 6-point Likert-type response scales. For example, How difficult did you find the writing activities to do, 1 (*not at all difficult*) to 6 (*very difficult*); How disruptive of your time did you find the writing activities, 1 (*not at all disruptive*) to 6 (*very disruptive*); How acceptable was it for you to writing activities for you, 1 (*not at all acceptable*) to 6 (*very acceptable*); and How likely would you recommend this type of writing activity to other carers, 1 (*not at all likely*) to 6 (*very likely*). Furthermore, to improve adherence, caregivers will receive an e-mail prompt each week to remind them to write in their diaries. Finally, we will also include a free form text box where caregivers can respond freely to the question ‘If there is anything that we may have forgotten to ask about your experiences of writing then feel free to write in the space provided’.

Measures

Caregiver and care-recipients’ sociodemographics including age, gender, socioeconomic indices and health-related

variables such as illness types, time and hours spent caring will be captured by questions created in-house.

Primary outcome

All measures of BF will be obtained using the 17-item Benefit Finding Scale (BFS) (Antoni et al., 2001). The BFS was originally developed by Behr et al. (1992) as the Positive Contributions Scale (PCS), which they used to assess the perceptions of parents of children with special needs with ‘Being a parent of a child with special needs’ used as the introductory preamble. Examples of items include ‘Has led me to be more accepting of things’ and ‘Has helped me to take things as they come’. Participants will be asked to indicate, using a five-point Likert-type scale ranging from (1) ‘not at all’ to (5) ‘extremely’, the extent to which each item has applied to them. The total score of the scale can range from 17 to 85, where higher values indicate a higher degree of BF. The scale has been in various populations and has found to have excellent reliability (Cronbach’s $\alpha = .91$; Kim et al., 2007; Urcuyo et al., 2005). We use an adapted version here replacing ‘parent’ with ‘caregiver’, and in order to capture change in BF, we replaced the baseline stem to read ‘Being a parent of a child with special needs’ with ‘As a caregiver, I feel that’ instead of ‘Since becoming a caregiver’. We also altered the wording of each item to reflect current feelings (e.g. ‘I am more accepting of things’ ‘I take things as they come’) so that we could capture change following the intervention. For T2 and T3 follow-up measures of BF, the stem will be changed to ‘After taking part in this writing exercise how much have the following changed for you? As a caregiver, I feel that ...’ with the same 17 original items used.

Secondary outcomes

Caregiver QoL. Caregiver QoL will be measured using the 40-item Adult Carer Quality of Life Questionnaire (AC-QoL; Joseph et al., 2012). The AC-QoL measures QoL in eight separate domains: support for caring, caring choice, caring stress, money matters, personal growth, sense of value, ability to care and carer satisfaction. Participants will be asked to indicate the frequency that they feel or experience different aspects of the caregiving role on a 4-point Likert-type scale ranging from 0 (never) to 3 (always). AC-QoL scores can be calculated for a total QoL using the entire set of items (range 0–120) or for each of the subscales individually (range 0–15) with higher scores indicating higher perceived QoL on that subscale. This scale has also been shown to have excellent consistency reliability (Cronbach’s $\alpha = .94$) with subscales ranging from .78 to .89 (Joseph et al., 2012).

Psychological distress. The Hospital and Anxiety Depression Scale (HADS; Zigmond and Snaith, 1983) will be measured as a covariate and secondary outcome of psychological

distress. The HADS is a brief self-report measure that was specifically designed to screen for distinct dimensions of anxiety and depression in non-psychiatric hospital departments. The severity of anxiety and depression are assessed using two subscales, each one consisting of seven items that are rated on a 4-point Likert-type scale ranging from 0 to 3. Corresponding answers differ depending on the stem question for each item statement. For example, Item 2 reads ‘I still enjoy the things I used to enjoy’: with answers ranging from 0 (*Definitely as much*) to 3 (*Most of the time*). Previous caregiver research has also used the HADS to investigate the effect of a family meeting intervention on depression among family caregivers of people experiencing dementia (Joling et al., 2012) and parental caregivers (Gallagher et al., 2008) and the associations between caregiver characteristics and caregiver burden, perceived health and mood status (Martinez-Martin et al., 2008). The psychometric properties of the HADS have been tested for validity and reliability in a caregiver sample by Gough and Hudson (2009) and demonstrated a high level of internal consistency ($\alpha = .89$).

Statistical analysis

All analysis will be executed using SPSS Statistics 21™ software package. Prior to formal statistical analysis, suitable descriptive statistics will be presented describing the baseline characteristics of the sample. Bivariate associations between the variables of interest will be conducted using correlation analyses. Tests of baseline homogeneity between the two treatment groups and attrition bias will be examined using independent samples *t*-tests and chi-square analysis. These will also be employed to check for successful randomisation. Preliminary inspections to ensure all distributional assumptions are met for the formal analysis will be conducted. All tests of significance will be two sided, with $\alpha = .05$ as criterion for statistical significance, or if the 95 per cent confidence interval does not contain zero. Throughout partial eta squared (η_p^2), Cohen’s *d* and R^2 will be reported as measures of effect size, depending on the analysis. To test the effectiveness of the intervention versus the active control on the primary outcomes BF, and secondary outcomes QoL, anxiety and depression, across each follow-up, mixed between–within analyses of variance will be conducted using complete cases only. Additional post-hoc analysis will be conducted on significant findings. Furthermore, as attrition rates in previous studies of this nature are high, a sensitivity analysis will be conducted using multilevel linear mixed modelling, where an intention-to-treat analysis strategy will be employed if there is a high level of missing data due to dropout. This will include all available data, and maximum likelihood estimations will be implemented to handle missing data. Furthermore, based on the findings in the above mixed between–within analyses of variance, and to further investigate the relationship between the intervention and outcomes, post-hoc

mediation analysis will be conducted using the *PROCESS* macro for SPSS (Hayes, 2013). Finally, measures of central tendency and dispersion will be used to understand the usability and feasibility data.

Discussion

This RCT will examine the effectiveness of a brief BF writing exercise, versus an active control exercise among caregivers. This BRiC intervention addresses limitations of previous BF interventions and other caregiver interventions highlighted in the literature to date. BRiC takes into account the need for brevity and the time constraints of caregivers combined with an evidence-based writing exercise activity, employing a mixed-methods approach and a long-term follow-up period. In order to systematically examine the intervention effects on caregiver well-being, BRiC will include an array of outcome measures including BF, distress and QoL as well as manipulation checks, that is, intervention expectancy and feasibility. Additionally, BRiC will build on the earlier BF research (Brand et al., 2014; Pakenham, 2005) by harnessing the power of BF to improve caregiver health outcomes. To this end, BRiC will serve to inform future directions of research and clinical practice with regard to brief psychosocial interventions for caregivers.

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Declaration of conflicting interests

The authors declare that they have no competing interests.

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