

Feasibility Testing of the COPE Psycho-education and Emotion Support Intervention for Cancer Caregivers in India

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Abstract

The cumulative effect of the rapid scientific, industrial, and societal changes have made substantial improvements in life, longevity, and ease of living, the process has not been without its share of adverse consequences. Chronic illnesses and their psychosocial sequelae on the patient and family are at the forefront of these concerns. The current study aimed to examine if a tailored psycho-education and emotional support intervention module, titled COPE, developed in the United States of America, would be effective in improving the general health of cancer caregivers, using a single-subject design. Five distressed cancer caregivers were repeatedly assessed on their levels of general health, to establish baseline, intervention, and follow-up trends and these emerging trends were subjected to visual and statistical analysis using the 2 SD band method. The results indicated positive and consistent drops in psychological distress in three cases and qualitative data also supplemented these findings. These findings underscore the need to recognize and fulfil the unmet needs of information and support for cancer caregivers who are instrumental in the care their patients receive. It also sheds light on the forgotten single-case designs as a valuable alternative to the conventional RCT-based models for running interventions meaningfully for at-risk and inaccessible populations.

Keywords: Cancer caregiver, psychoeducation, COPE model, general health, emotional support, psychosocial oncology, prepared family caregiver model.

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Cancer caregiving is challenge that will confront an increasing number of people (Dsouza, Murthy, & Aras, 2013; Toree, Seigel, Ward, & Jemal, 2016). Although both positive and negative outcomes are inherent to the caregiving experience, one has to experience and work through the adverse demands of caregiving prior to actually experiencing the benefits. The linkage between cancer caregiving and adverse health effects, quality of life disruptions and socio-emotional toll are well documented (Bevans & Sternberg, 2012; Fletcher et al. 2012).

Zarit (1989), a pioneering researcher in this field, published a paper titled “Do we really need another stress and caregiving study?” in which he argued that research on caregiving had to be redirected toward identifying effective interventional strategies, rather than reinforcing the well-established notion that caregiving is inherently stressful. Since then, many intervention modalities have been developed like respite care (Carson et al., 2016), psychoeducation, counseling and supportive psychotherapy (Kissane & Bloch, 2002; Manne et al., 2005, McLean, & Nissim, 2007) and palliative care (Pasacreta & McCorkle, 2000; Wright et al., 2008).

Gathering information about a problem is the first step in resolving it. The same applies to cancer caregiving but adequate, accurate and understandable information is one of the most common unmet needs caregivers report (Glajchen, 2004). Psycho-education is an intervention that addresses this need. Research shows that caregivers benefit from psycho-education through increased levels of self-efficacy (Keefe et al., 2005). Badr, Smith, Goldstein, Gomez, and Redd (2015), Dockham, et al. (2015) and Holm et al. (2015) have successfully used psycho-education to promote better caregiving outcomes.

Partially related to the psycho-educational strategies is the approach of fostering active problem-focused coping among caregivers. The problem-solving approaches to caregiver interventions seek to restore the sense of self-efficacy that caregivers have by preparing them to cope in a certain way. The key tenets of problem-solving approaches are information gathering, active coping, generating

alternative solutions combined with an “I-Can” outlook. Problem-solving interventions have been used by Toseland, Blanchard and McCallion (1995) and by Houts, Nezu, Nezu, Bucher (1996).

In the current study, the COPE Model was examined as an intervention strategy for cancer caregivers. The COPE Model arose out of the broader Problem-Solving Therapy (PST) approach and aims at providing cancer caregivers with information and support such that they are able to orient themselves to the problem situation, understand the problem and various potential solutions and finally, apply and evaluate the efficacy of their solutions. Houts (1996) demonstrated the efficacy of the PST approach for patients and caregivers coping with cancer.

The COPE model derives its name from the four elements that comprise this approach, namely, *creativity, optimism, problem-solving and expert information*. It basically involves coaching caregivers on what each of these components imply, encouraging them to apply their knowledge to real caregiving problems with the help of a standard psychoeducational resource. The COPE module also contextualizes caregiving by helping caregivers understand what the needs of caregiving are. Various aspects of the healthcare systems (coordination of care, insurance), cancer treatment (surgery, radiotherapy, targeted therapy) and difficult situations (end-of-life care, discussing cancer with children) are detailed in this resource. A sample session protocol is presented in the following table.

Table 1: Sample session protocol for the psycho-education offered through the COPE module

Plan
Explain the agenda to the caregiver
Introduce the COPE principles
Identify specific and real problem, the first priority symptom
Review COPE principles relative to the first priority symptom

Create a plan of action for the first priority symptom through discussion and with the help
of the Home Care Guide

Review the plan, encouraging the caregiver to use it

Identify the second priority problem and encourage the caregiver to review the same from
the Home Care Guide

Schedule the next intervention visit

McMillan, et al., (2006). Intervention training module of the Caregiver Intervention
Research Project, University of South Florida.

It is important to place on record that in the original attempt to use the COPE by McMillan and colleagues (2006), the COPE intervention and the emotional support were administered independently (although they are a part of the manual) as the aim of that research effort was compare the feasibility of psycho-education through the COPE module without incorporating elements of emotional support. Emotional support was designed as a competing intervention strategy to the COPE module in that study. In the current study, however, the researcher primarily aimed at alleviating caregiver distress and for this purpose, emotional support seemed to be an essential aspect. Additionally, incorporating the emotional support condition was beneficial in generating a sense of rapport or connection with the intervention participants who may have otherwise dropped out. A schema for the same is provided in the following table.

Table 2: Schema of the Emotional Support condition

Themes	Elements of Active Listening
History of caregiver’s relationship with the patient	Body language and eye contact
Caregiver’s feelings about providing care	Focusing and attending
Caregiver’s feelings about how caregiving is affecting other aspects of their life	Empathic responses
Caregiver’s reactions and feelings about witnessing the suffering of the patient	Rephrasing and reflection

Caregiver's feelings of grief and loss**Probing****Summing up**

McMillan, et al., (2006). Intervention training module of the Caregiver Intervention Research Project, University of South Florida.

The COPE model has been effective in improving caregiver quality of life, specifically through reduced caregiver burden related to caregiver tasks and symptom management in a randomized controlled study of 354 caregivers (Bahrami, & Farzi, 2014; McMillan et al., 2006).

The current study examined whether the COPE model would have similar feasibility outcomes in the Indian setting as well. For this purpose, it was used with permission from the original authors.

Method

Research Question

Does the COPE psycho-education and emotional support intervention have a significant impact on the general health of family caregivers of cancer patients?

Objectives

To evaluate the feasibility of the COPE psycho-education and emotional support intervention in improving the general health of family caregivers of cancer patients.

Hypothesis

There will be a difference in the general health of the family caregivers at the end of the COPE psycho-education and emotional support intervention.

Design

The current study was conducted in two phases: survey and intervention. A fairly representative survey of the family caregivers of cancer patients was an essential first step to understand the cancer

caregiving experience. This helped tailor the intervention to the needs that emerged as being important both in theory and in the field. In the current paper, the focus is on the intervention which was run using a single subject design.

Sample

Inclusion criteria

- A. The family caregiver had to be the family member most closely involved in the care of the patient.
- B. The minimum duration of caregiving had to be three months for a significant perception of caregiver burden to emerge.

Exclusion criteria

- A. Family caregivers of cancer patients who were in remission were excluded as the lack of active treatment translated into fewer and less intense caregiving duties.
- B. Family caregivers with a previous history of psychopathology or major health conditions were excluded.

Design

The ABA design comes under the broad category of single-subject designs (SSD) or single-case designs (SCD) where A denotes baseline, B indicates intervention and A represents a withdrawal or reversal of the intervention. Although not as popular as randomized controlled trials, these designs are used quite often (Segool, Brinkman, & Carlson, 2007). They involve an in-depth analysis of a few cases, rather than the formulation of group-level comparisons to establish experimental effect. An idiographic approach characterized by fewer participants, intensive data collection, case-based analysis and highly accurate analysis of intervention effects are some features of this design.

For the intervention, five cancer caregivers scoring high on psychological distress as assessed by the GHQ were selected.

Procedure

The study began with obtaining permissions for data collection at various cancer hospitals in Bangalore. A preliminary survey was conducted to assess common caregiving outcomes in light of their demographic and situational correlates. The selected participants were recruited after providing them with some insight into the study, obtaining informed consent, and clarifying any queries the participants had. Following this, nine weekly assessments were made split in three phases: baseline, intervention, and follow up. At the end of the last baseline assessment, the intervention sessions began.

Tools. The following tools were used in the current study.

A socio-demographic questionnaire (constructed by the researcher) and a psychosocial assessment sheet (Family Caregiver Alliance, 2003) were used.

General Health Questionnaire, GHQ (12-item version). The General Health Questionnaire was first developed by Goldberg and Hillier (1978) as a tool to screen individuals for potential psychological morbidity. The version of the GHQ used in the current study was developed by the authors in 1988 and comprises of 12 items of the original 60 items. The tool essentially records self-reported ratings for a particular set of symptoms that either indicate a) inability to function normally or b) the emergence of new distressing behaviors and thoughts. The provided ratings are scored on a four-point scale (0-1-2-3) with the Likert scoring approach being used. The tool has been used widely in research involving general and clinical populations and has a good degree of reliability as demonstrated by the internal consistency coefficients that range between 0.77 and 0.93. In the current study, the GHQ was estimated

to have a reliability of .83. The tool has also been shown to have good content and construct validity; the degree of psychiatric disturbance in patients is frequently reflected in their GHQ scores.

Analysis

Visual analysis (with interrater validation) and statistical analysis using Shewart's two standard-deviation confidence band was undertaken. Additionally, effect sizes were computed for the standardized mean difference and converted to 'r' values to control for autocorrelation.

Results and Discussion

The aim of the current study was to examine the feasibility of a standard psycho-education and emotional support intervention module in the Indian setting. For this purpose, five participants scoring high on the GHQ were selected. Specific details for each of the five participants are provided in the table below.

Table 3: Socio-demographic profile of intervention participants

	Case 1	Case 2	Case 3	Case 4	Case 5
Age	37	26	35	52	41
Gender	Male	Female	Female	Female	Female
Education	Graduation	Graduation	Graduation	Graduation	Postgraduate
Occupation	Self-employed	Trainee Doctor	Corporate	Homemaker	Doctor
SES	Middle	Middle	Middle	Middle	Middle
Marital Status	Married	Single	Married	Married	Married

Visual Analysis

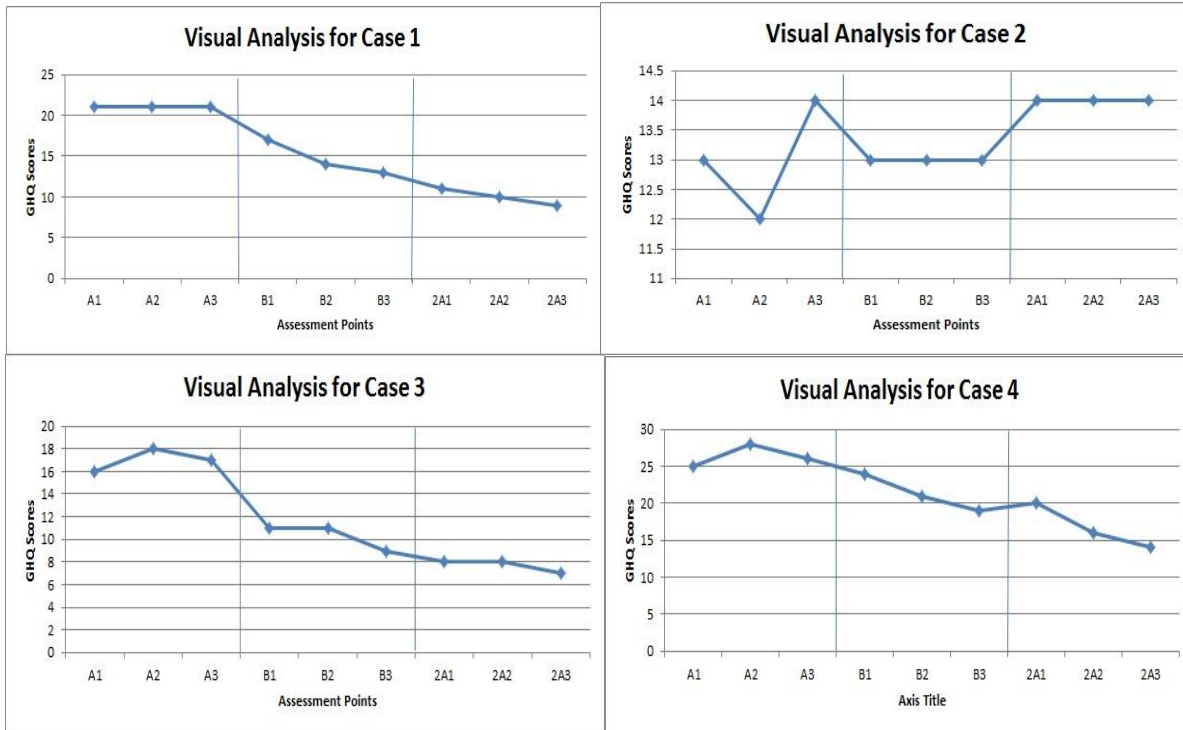


Figure 1: Composite image of line graphs showing scores on GHQ across the three phases of the intervention for visual inspection

Visual analysis or visual inspection is the conventional mode of analysis for data from single-subject designs. Visual analysis is defined as "reaching a judgment about the reliability or consistency of intervention effects by visually examining graphed data by Kazdin (1982) and assesses the data set for three vital criteria: level, trend, variability along with certain additional parameters like overlap, immediacy of effect and consistency of patterns. In the current study, the trajectory taken by the GHQ scores were analyzed against these parameters by both the researcher and an independent statistical expert from Indian Statistical Institute, Bangalore. The ratings reflected a consensus with regard to the major parameters of level, trend, variability, immediacy, and non-overlap in three out of the four cases. Case 2 did not fulfill these criteria and was held back from any further analysis. While many studies

consider visual analysis adequate for single subject designs, the contemporary trend has been to substantiate visual analysis with statistical analysis.

Statistical Analysis

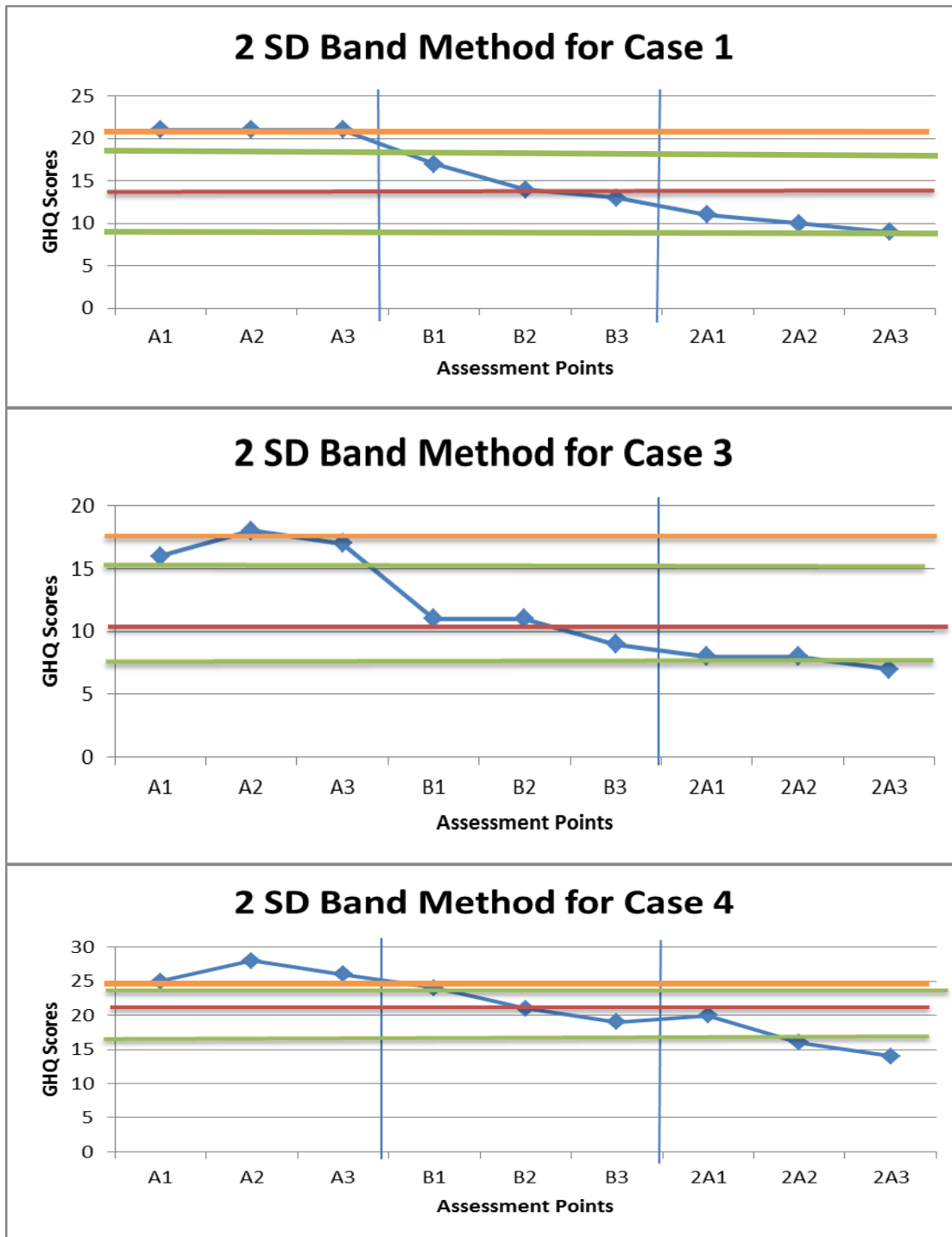


Figure 2: Composite image of mean GHQ scores from baseline and intervention with their corresponding lower two-standard deviation cut-offs

In the current study, the experimental effect was estimated through the two-standard deviation-band method, a variant that is considered suitable for shorter data series (Manolov & Solanas, 2008; Perdices & Tate, 2009s). Although the sample size for the current study was small, making it difficult to compute statistical estimates of experimental effect, the study maintained the recommended minimum of three assessments per phase – a criterion used in research involving limited sample availability (Lojovich, 2014). In Shewart's two-standard deviation band method, a significant change is recorded when two successive observations in the next phase fall beyond the two standard-deviation confidence band – an occurrence with a probability of less of than 5 in 100 by chance (Janosky, Leininger, Hoerger, & Libkuman, 2009; Portney & Watkins, 2009). This was noted in each of the three cases and provided evidence of intervention impact.

In the image, the data points on or below the two standard-deviation band (the lowest line, in green) indicate consistent statistically significant departures from the mean. Since they are noted across the three cases, it serves to validate the hypotheses that there will be a significant difference in scores on the GHQ following the COPE psychoeducation and emotional support intervention.

Information (Adams, Boulton, & Watson, 2009) and support (Bee, Barnes, & Luker, 2009) are two of the most key requirements faced by cancer caregivers. The access to the valid medical information cannot be taken for granted. For instance, the fourth caregiver in the study confused chemotherapy with some form of “gas” being used for her daughter's treatment. Most caregivers asked for more information during the intervention, had specific queries, and wanted to feel more equipped to

deal with their patient's requirements. The researcher addressed these queries and that probably served to create some sense of self-efficacy that mitigated some part of the distress, in turn.

Additionally, many previous psychoeducation intervention modules have been tested on a standalone basis. In the current study, the combination of psychoeducation and emotional support modules together proved to be fruitful. Revenson (1990) proposed four dimensions of socio-cultural, interpersonal, situational, and temporal factors to enhance ecological validity when studying illness and illness-related process. Bearing this approach in mind, the researcher chose to keep the intervention more wholesome (overall focus on the caregiver too, rather than information on the patient alone) and perhaps that led to a greater perception of benefit.

For some caregivers, the emotional support module became an important way to explore their worries and concerns that were not processed previously. The male caregiver (case 1), in fact, stated that he began to see himself as a caregiver only during the course of the intervention. This aligns well with the contemporary understanding of coping which has moved away from seeing active and avoidant coping processes as mutually exclusive and favoring the former over the latter (Aldwin, 2004; Lazarus, 1993). Chronic challenges like caregiving requires deeper levels of emotion-focused coping.

Since caregiving is deeply personal and enduring demand, merely visualizing it as a medical management or care coordination process keeps caregivers away from being in touch with the emotional upheavals of the process. These aspects stay unacknowledged and unprocessed in most part, with the focus being the patient, but continue to register effects in the mood and functional impairments of caregivers – which gets registered well in the GHQ. The cathartic space of this intervention probably helped caregivers process and reframe these emotional aspects. Reframing is linked to lower caregiver strain as it helps caregivers process and adapt to illness-related realities and challenges (Redinbaugh, Baum, Tarbell, & Arnold, 2003).

Effect size estimates

The 'd' values from the standardized mean difference approach were inflated due to autocorrelation and were converted to 'r' values; they were .94 and .80 for cases 3 and 4, respectively. This reflects a high level of experimental effect (Rosenthal & Rosnow, 1984). Due lack of any variability in the baseline scores in case 1, no effect size could be computed for that dataset.

Insights from Qualitative Analysis

Qualitative data was collected using a psychosocial assessment format from the Family Caregiver Alliance (FCA, 2006). Contextualizing each participant's response against their thoughts, feeling, and resources about coping with caregiving provided valuable insights about the pattern of response to intervention. In the first case, the client was operating from a primarily problem-focused approach, ignoring his emotions and challenges related to the caregiver role and the emotional support leg of the intervention helped him clarify that.

In the third and fourth cases, psycho-education restored caregiver self-efficacy and emotional support gave them an important opportunity to discuss key concerns, like spirituality, fear of recurrence, agony at the spectator role that caregiving involves. In contrast, cases 2 and 5 involved caregivers who were medical professionals; while the former participated in the study for its full duration, one can perceive a haphazard response pattern.

The fifth caregiver never submitted her second assessment and discontinued. It could be that the psychoeducation part of intervention did not hold as much interest to a trained medical professional.

The findings of the study, though supported by analysis and qualitative data, are of limited generalizability owing to the sample size. This is despite the fact that the study does meet the guidelines for SCDs that have been provided by experts in terms of the What Works Clearinghouse (Kratochwill et

al., 2010). Since the COPE model is a Western import, it may not be sufficiently tailored to the socio-cultural mindset of Indian caregivers.

Conclusions and Implications

Psycho-education and emotion support through the COPE module did reduce psychological distress in cancer caregivers.

The study strongly recommends that more rigorous efficacy testing of this module be undertaken for this population as well as for patients and families dealing with other chronic illnesses. The study also recommends sensitization of the medical fraternity to the unmet need and challenges of caregivers and encourages to see caregivers as stakeholders in patient care, rather than as “attenders” as they are often called.

Caregivers are often the “invisible” patients in a cancer wards. This implies that the needs of cancer caregivers could be more layered and complex than contemporary research can explain. Qualitative explorations of cancer caregiving experiences can help us understand the finer points and uniqueness of unmet needs of this population so the interventions ahead are more tailored to their lived experiences.

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