

Creating Avenues for Parent Partnership (CAPP): An intervention for parents of children with epilepsy and learning problems

Janice M. Buelow ^{a,*}, Cynthia S. Johnson ^b, Susan M. Perkins ^b, Joan K. Austin ^c, David W. Dunn ^d

^a 1111 Middle Drive, NU 413, Indiana University School of Nursing, Indianapolis, IN 46202, USA

^b Indiana University School of Medicine, Department of Biostatistics, Indianapolis, IN, USA

^c Indiana University School of Nursing, Indianapolis, IN, USA

^d Indiana University School of Medicine, Department of Psychiatry, Indianapolis, IN, USA

ARTICLE INFO

Article history:

Received 4 October 2012

Revised 11 December 2012

Accepted 12 December 2012

Available online 1 February 2013

Keywords:

Pediatric epilepsy

Family intervention

Behavioral intervention

Problem solving

Psychosocial care needs

Pediatric comorbidity

Developmental disability

ABSTRACT

Caregivers of children with both epilepsy and learning problems need assistance to manage their child's complex medical and mental health problems. We tested the cognitive behavioral intervention "Creating Avenues for Parent Partnership" (CAPP) which was designed to help caregivers develop knowledge as well as the confidence and skills to manage their child's condition. The CAPP intervention consisted of a one-day cognitive behavioral program and three follow-up group sessions. The sample comprised 31 primary caregivers. Caregivers reported that the program was useful (mean = 3.66 on a 4-point scale), acceptable (mean = 4.28 on a 5-point scale), and "pretty easy" (mean = 1.97 on a 4-point scale). Effect sizes were small to medium in paired *t* tests (comparison of intervention to control) and paired analysis of key variables in the pre- and post-tests. The CAPP program shows promise in helping caregivers build skills to manage their child's condition.

© 2013 Elsevier Inc. All rights reserved.

1. Introduction

Epilepsy, the most common serious neurological condition in childhood, is often associated with significant learning problems (SLP) [1]. Moreover, children with both epilepsy and SLP have high rates of behavioral problems [2–4]. Although caregivers of children with these multiple conditions report high rates of stress [5,6] and need assistance to manage their children's complex problems, typically, they have received little attention from health care providers and from the research community. Our research team found that caregivers need skills to build effective partnerships with both health care providers and school personnel who are involved in the management of their children's complex needs. These skills include identifying goals and creating action plans to meet the goals [7].

From preliminary work, we determined that, although caregivers could talk generally about their concerns, they had difficulty articulating specific problems and setting achievable goals to address these problems [8]. Caregivers with good self-esteem, high levels of mastery, active participation in decision-making, and a sense of belonging to the community have been found to be empowered or better able to advocate for their child with a disability [1,9]. Preconditions for

empowerment include a strong bond with the child, reasonable quest for information, critical reflection, and ability to take charge (advocating and establishing partnerships). When caregivers have these skills, they tend to have knowledge about their child and their child's condition, competence to care for their child, and confidence in communicating what is best for their child [9].

Although currently no published interventions exist for families of children with both epilepsy and SLP, interventions developed to aid caregivers of children with either epilepsy or intellectual disability have been shown to be effective in lowering caregiver stress [7,10–12]. Interventions that provided information to caregivers of children with epilepsy helped them make better decisions about their children's health care through a better understanding of epilepsy [8,13]. Improving both problem-solving and goal-setting skills also has reduced caregiver stress [14,15]. Other family intervention studies have focused on giving caregivers the confidence to address their children's specific problems [16,17]. Our research team originally developed "creating avenues for parent advocacy" (CAPA) to meet these needs. The intervention for this study was revised from the original CAPA program and driven by Buelow's work [18], Bandura's theory of self-efficacy [19], intervention literature [7,11,16,17,20–22], and interviews with caregivers [8,23]. Creating Avenues for Parent Partnership (CAPP) is the first intervention to specifically address the problems of caregivers of children with both epilepsy and significant learning problems.

* Corresponding author. Fax: +1 317 278 1856.

E-mail address: jbuelow@iupui.edu (J.M. Buelow).

The central aims of this report are to describe the CAPP intervention and to report the findings of this pilot study. Pilot studies serve to explore sampling issues and intervention delivery and to estimate effect sizes and intervention efficacy [24]. In this study, we discuss these issues in relation to the CAPP program.

2. Methods

2.1. Study design

The study was a randomized controlled trial using a wait list control group. Wait list control groups serve as a control group in the first round of analysis because they have not yet had the intervention. After all data are collected (baseline, immediately following the intervention, and 3 months after the intervention), the control group receives the intervention. This methodology is useful in small studies as it encourages participation because all participants, both intervention and control groups, receive the intervention. Further, it allows for a larger pool of persons receiving the intervention, making it possible to do pre- and post-testing with the entire sample.

2.2. The CAPP intervention program

The CAPP program, consisting of knowledge-building and skill-building components as well as mastery experiences, was designed to improve caregiver skills and confidence to develop effective partnerships with their child's health care providers and school personnel. It consisted of a one-day program that lasted approximately 6 h and three follow-up monthly group sessions, each lasting about 2 h. The one-day program incorporated informational presentations in three modules. A question/answer period followed each module that also included open discussion, problem identification, and problem solving. Discussion of mastery experiences occurred during follow-up sessions. Caregivers brainstormed together to identify problems and then recorded their action plans (problem, goals, and interventions) in the "Action Plan Notebook." Their homework was to enact at least one of their action plans prior to each of the three follow-up sessions, which were designed to reinforce training and provide opportunity for experiencing mastery experiences. Specifically, the follow-up sessions allowed for continuous appraisal of activities, interaction with an expert caregiver, and time to discuss successes and failures and to encourage one another. The sessions were specifically designed for caregivers to work on each of the partnership activities (information notebook, partnership with health care provider, and partnership with school personnel). To ensure consistency in delivery, author JMB conducted the one-day intervention program and the follow-up sessions.

Each participant received a notebook that included the three informational modules. *Module 1* was designed to introduce epilepsy-specific information and to help caregivers begin to collect information to build an information booklet about their child and their child's disorders. *Module 2* introduced the idea of building a partnership with the health care provider. It discussed needs and concerns in dealing with health care professions (HCP) as well as effective communication techniques. This module also introduced the idea of developing written and attainable goals based on the identification of problems. *Module 3* was designed to help caregivers develop a partnership with school professionals. In this module, we discussed caregiver and student rights, constraints experienced by school systems, and effective ways to communicate with school personnel.

2.3. Intervention delivery

After obtaining institutional review board approval, caregivers were recruited and randomized to either an intervention or wait list control group. Randomization occurred prior to baseline data

collection because caregivers needed to know which group they would be attending to make arrangements for their child.

2.3.1. Data collection

Data were collected at five time points. Data collection (DC) 1 represented baseline data which were collected from all participants (intervention and wait list control groups) prior to the first intervention. Data collection 2 occurred immediately after the one-day program for both the intervention and control groups. Data collection 3 occurred after the last follow-up group (3 months after the one-day program) for both the intervention and control groups. Data collections 2 and 3 represented measures of comparison between the intervention and control groups. Data collected at time points 4 and 5 were measures of the wait list control group only, which occurred after they had received the intervention. Those data were used for pre- and post-intervention comparisons (Fig. 1).

During the course of the study, the CAPP intervention (one-day program and three follow-up sessions) was offered on three separate occasions. The first included the caregivers randomized to the intervention group. The second program was conducted for those who had originally been randomized to the wait list control group; however, because recruitment was slower than expected, we recruited caregivers in a second wave and randomized them to the intervention and wait list control groups. Thus, the second offering, which was identical to the first program offering, was offered to the initially recruited wait list control group as well as the second wave of caregivers randomized to the intervention group. The final program included the second wave of caregivers who had been randomized to the wait list control group. Data were collected as described above for both waves of recruitment.

2.4. Inclusion and exclusion criteria

Caregivers were recruited if they had a child who (a) was between the ages of 7 and 16 years; (b) had a diagnosis of epilepsy (two seizures within the last year and taking at least one anticonvulsant medication); (c) had either been diagnosed with mild intellectual disability or had a serious learning problem (i.e., at least two grades behind same-aged peers in school or was in a special education placement); and (d) could read and speak English. We selected this age range because by the age of seven years, school problems in most children with both epilepsy and SLP would have been diagnosed. We did not exclude caregivers if their child had another comorbid chronic disorder such as cerebral palsy or deafness; caregivers were excluded, however, if their child had a terminal condition.

2.5. Instrumentation

Feasibility and usability of the CAPP intervention were measured by the Ease of Use Scale and by a subscale of the Parent Report of Psychosocial Care Scale. Using a four-point Likert-type scale, caregivers rated their perceptions of the usefulness (*not at all useful to very*

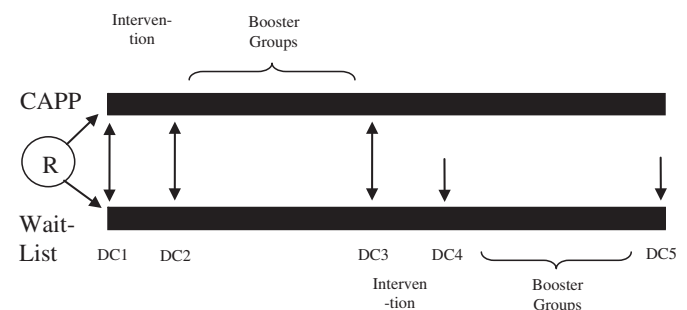


Fig. 1. Data collection time points for the intervention and wait list control groups.

Download English Version:

<https://daneshyari.com/en/article/6013171>

Download Persian Version:

<https://daneshyari.com/article/6013171>

[Daneshyari.com](https://daneshyari.com)