



Patient Perception, Preference and Participation

How a cancer education group serves the underserved: 'Family' ties and battling cancer

Daniel Dohan^{a,*}, Robertina Szolarova^b, Blue Walcer^c^a Philip R. Lee Institute for Health Policy Studies, UC San Francisco, San Francisco, USA^b Hospice By The Bay, San Francisco, USA^c Department of Education and Training, San Francisco General Hospital, San Francisco, USA

ARTICLE INFO

Article history:

Received 26 January 2011

Received in revised form 27 July 2011

Accepted 28 August 2011

Keywords:

Cancer

Underserved

Health education

Poverty

Qualitative research

ABSTRACT

Objective: Socially disadvantaged cancer patients have unmet educational needs, but we know little about how educational groups might help. This exploratory study examines how a group education program met underserved patients' needs.

Methods: We examined a program for US patients in a safety-net hospital that featured English and Spanish language groups. We collected data from 54 group sessions over 28 months, including information on participant demographics, attendance, and satisfaction. Qualitative field notes collected by trained observers were analyzed via a grounded-theory approach to examine group dynamics.

Results: Participants were underserved, had diverse disease sites and race/ethnicity, and reported that groups met their needs. Emergent analysis identified two themes related to group dynamics. First, members identified with each other as a fictive family, although the meaning of "family" differed in the groups. Second, groups focused on battling cancer not adjusting to life as a survivor—a focus that impaired participants' ability to discuss coping strategies for managing negative feelings.

Conclusion: Fictive 'family' engages participants. The emphasis on 'family' and resistance to coping strategies may reflect participants' social disadvantages.

Practice implications: Groups for the underserved should strive to create a 'family' and may have difficulty helping participants cope with their illness.

© 2011 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

Cancer education groups seek to improve the quality of life of cancer patients, caregivers, and survivors through knowledge and support. Participating in a group can create a feeling of support [1] and provide unique kinds of support that differ from that provided by spouses, friends, or family [2].

Within a given community, individuals with a greater need for a group support may self-select to participate [3]. Studies have generally not examined those cancer patients who are, arguably, most in need of support—patients who are medically underserved due to lack of health insurance or other access barriers, patients who are socially, economically or educationally disadvantaged, and patients from cultural or linguistic minority groups [4–7]. These patients, who we refer to as disadvantaged or vulnerable,

may have lower levels of health literacy and less access to diverse sources of information and thus might benefit from participation in a group but do not have the opportunity to do so [8,9]. Disadvantaged patients may also experience social isolation and could benefit from group companionship [10]. It is not clear why disadvantaged individuals are not well-represented in the literature on cancer groups. One possibility is that while mainstream groups serving more-advantaged patients are plentiful, those with underserved patients fail to thrive [5,7,11].

This paper uses qualitative research to examine how a cancer education and support program for disadvantaged patients operates and succeeds. The program has enrolled a diverse and disadvantaged patient population for five years. We describe the group's history, organization, and curriculum to share a model that has engaged patients who may not generally seek out a group experience. We explore how the program engages participants and provides a meaningful experience for them by examining group dynamics and culture. We discuss these findings in the context of cancer and health disparities in the contemporary United States and consider implications for efforts to engage socially disadvantaged and diverse cancer patients.

* Corresponding author at: Philip R. Lee Institute for Health Policy Studies, University of California San Francisco, 3333 California St. Suite 265, San Francisco, CA 94118, USA. Tel.: +1 415 476 0751; fax: +1 415 476 0705.

E-mail address: daniel.dohan@ucsf.edu (D. Dohan).

2. Methods

2.1. Setting

We worked with the HELP (Health and Education for Low-Income Patients) program based at County Hospital (CH), a safety-net hospital located in Northern California (HELP, CH, and other proper names are pseudonyms). CH is part of the metropolitan area's public health care network, which serves uninsured and indigent patients. CH coordinates all oncology services, so patients come to CH from throughout the network for treatment. Patients have MediCal insurance (a Medicaid program for low-income individuals) or are uninsured. Table 1 shows that cancer patients come from many ethnic/racial backgrounds; no ethno-racial group has a majority.

The metro area includes resources for cancer patients' education and support, but a needs assessment in 2001 showed that CH patients found these resources inaccessible due to cost, transportation, and lack of language and cultural tailoring. HELP began in 2002 to meet these needs by providing culturally and linguistically appropriate educational and psychosocial support for CH cancer patients at a convenient time and place and at no cost. HELP began with English and Spanish-language groups in 2002 and expanded to include Chinese in 2006.

As shown in Table 1, in 2008, HELP was providing educational and support services for nearly 200 cancer patients at CH. In terms of race and ethnicity, HELP participants resembled the cancer patient population at CH with Asians somewhat over-represented in HELP and Whites somewhat under-represented.

HELP held three series each year (spring, summer, and fall) that each included 8–12 sessions. Sessions meet for 2 h each week and include dinner. Most sessions focus on cancer or self-care, e.g. "What's New in Cancer Therapy," "Symptom Management," "Eating Well, Healing Well," and "Healing Moves." Guest speakers include health professionals (from medicine, psychology, complementary and alternative medicine, palliative care, and nutrition) and educators (in dance, massage, social work, bereavement, and clergy). Each series starts with an Orientation session and ends with a Wrap-up/Evaluation/Graduation at which participants provide detailed written and verbal feedback on sessions and speakers.

All sessions are facilitated by a professional health educator (this paper's third author facilitates the English-language sessions), whose training and experience includes an MPH in community health education and experience leading and developing cancer health education curricula for low-income patients. The facilitator starts each session by reviewing a large poster-board listing the HELP ground rules, which include starting and stopping on time, listening respectfully to others, no "sidebar" conversations, and self-monitoring so all members have the chance to speak. The facilitator then goes around the room and encourages each participant to check-in. During check-in, participants typically talk about news from their week or their health, and the facilitator often draws generalizable health education messages. The facilitator then turns the session over to the guest speaker, who presents his or her material, and then facilitates a question and answer with the speaker. Each session ends with the facilitator moderating a check-out during which participants say what they will take away from the day's session, and all members complete a brief written evaluation.

Table 1
Characteristics of cancer patients at CH and HELP, 2008.

	White	Black	Asian	Latino	Other	<i>n</i>
CH cancer patients	32%	26%	20%	16%	6%	466
HELP participants	20%	22%	31%	22%	5%	190

Local university students in medicine, nursing, and public health co-facilitate HELP sessions. Co-facilitators set up the room where HELP takes place and assist with participants' transportation needs. Co-facilitators undergo a 4 h training prior to the start of each semester, and their work is monitored and supervised by the facilitator during HELP sessions.

2.2. Procedures

In addition to providing logistical support for HELP, co-facilitators gather qualitative data using participant-observation methods. Prior to the start of each HELP session, the first author, a PhD trained ethnographer with extensive experience conducting research with HELP and teaching qualitative research methods, trains all co-facilitators in how to take field notes using a structured form to ensure comparable data from all sessions. The form includes close-ended fields (number and gender of participants, session topic, guest speaker, learning objectives) and five open-ended questions that are completed by the co-facilitator based on their interpretation of group interactions:

1. What types of questions are participants asking?
2. Comments other than questions—how else are people engaged? What are people talking about? Are they interacting with each other, with the speaker?
3. What did we learn today? (be specific).
4. Checkout: were the objectives for the session accomplished? Was this session helpful?
5. Additional comments/problems/issues/suggestions that arose today.

As is commonplace when recording fieldnotes [12], co-facilitators take brief notes during the HELP session and then expand these in to full field notes after the session has ended. The facilitator and lead author review these notes and provide feedback. For this analysis, we used co-facilitator field notes from HELP sessions that took place from September 2005 to February 2008. We include notes from the English and Spanish sessions only as Chinese HELP did not begin until 2006.

To analyze the notes, we reviewed and organized the notes by session, language, speaker, and topic. We analyzed qualitative data for themes. In addition, we reviewed notes to discern the level of engagement of the participants, as captured by the questions and comments made by participants, and observations made by recorders. A score was then assigned to each session where a level of engagement could be determined: 3 for a high level of engagement, 2 for moderate level, and 1 for low level. Our research protocols were approved by appropriate IRB.

For qualitative data analysis, we focused on co-facilitators' responses to the five open-ended fields on the data collection form. Following procedures similar to those of grounded theory research [13], the first and second authors read through the field notes, made notations about issues they interpreted as relevant to group dynamics and culture, and discussed and reviewed their interpretations. This process proceeded iteratively, with multiple readings and discussions of field notes, until consensus was achieved about emergent themes. Then, the second author developed a preliminary coding scheme based on these emergent themes. Coding—the process of systematically labeling raw qualitative data according to a set of pre-defined themes—facilitates retrieval and analysis, and projects often develop a unique coding scheme [14]. Over the course of several meetings, the first and second authors reviewed and finalized the coding scheme and discussed and resolved discrepancies in how the scheme had been applied to the raw data. Finally, we reviewed the scheme and coded data with the third author. While we did not

Download English Version:

<https://daneshyari.com/en/article/3814476>

Download Persian Version:

<https://daneshyari.com/article/3814476>

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