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LISTEN TO ME! INVOLVING CHILDREN AND FAMILIES LIVING WITH CONGENITAL HEART DISEASE IN THE RESEARCH PROCESS

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ABSTRACT: Children and families affected by congenital heart disease have rarely had the opportunity to share their school experiences and recommendations, and be actively involved with research and the dissemination of research results. In June of 2003, however, families who had participated in a study on the quality of life and school experiences of individuals affected by congenital heart disease attended a research retreat and became active research participants. Outcomes of this participatory research project were positive as family members had the opportunity to network with similar others, share insights, and formulate recommendations to be used in a school handbook, and researchers were able to share research findings and gather additional information and recommendations. Consequently, a research retreat, when preceded by semi-formal interviews, appears to be an effective method for involving participants in the research process and contributing valuable knowledge to the development of educational theory and practice.

Key words: participatory action research, congenital heart disease, quality of life

INTRODUCTION

Participatory action research (PAR) is a powerful strategy in which participants are involved in the research process to advance science and practice (Whyte, 1991). Furthermore, PAR is a meaningful and respectful way of empowering participants and obtaining information regarding lived experiences (Gilgun, Daly, & Handel, 1992). This article describes how a team of researchers in Victoria, British Columbia used PAR to disseminate research findings with participants, gather new information, and therefore, involve participants in the research process.

CONTEXT

Congenital heart disease (CHD) is "[a]ny structural or functional heart disease that is present at birth, even if it is discovered much later" (Hoffman, 1990, p. 25) and is found in 8 of every 1000 live births (Saenz, Beebe, & Triplett, 1999). Although CHD is one of the most serious and pervasive chronic illnesses found in children, significant advances in diagnosis and medical technology have dramatically increased survival (Davis, Brown, & Bakeman, 1998), making CHD one of the most common childhood chronic illnesses (Tak & McCubbin, 2002).

An increase in the survival rate of children with CHD has led to a growing group of families that have unique challenges and needs (Tong & Sparacino, 1994) and must adapt to stressful and persistent medical conditions (Mescon & Honig, 1995). Because most teachers will work with a child who has a chronic illness (Frieman & Settel, 1994), teachers and school professionals must be prepared to meet the needs of the children and families who are affected by chronic illnesses such as CHD (Nevile & Roberts, 1999; Roberts, 2000; Roberts, Pettifor, Cairns, & DeMatteo, 2000). A need exists, therefore, to expand research and accurately identify the stressors chronically ill children experience and the interventions that will enable these children to function most efficiently (Spirito, Stark, Gil, & Tyc, 1995).

Given the aforementioned research need, the first author, in collaboration with the Department of Pediatrics at the Victoria General Hospital, implemented a study to better understand the school experiences of children and families affected by CHD. Semi-structured interviews were conducted with the parent(s) or guardian(s) of 29 school age children with CHD who resided on Vancouver Island and the Lower Mainland of British Columbia. When possible, the children with CHD were also interviewed. The interviews were conducted to identify the participants' perceptions of and experiences with school, and ascertain how families think schools can best support, accommodate, and prepare for students and families affected by CHD. Information provided by the participants indicated school professionals must be better educated about and prepared to meet the needs of children with CHD. Therefore, to provide educators with information about CHD and methods to improve the school experiences, the primary investigator decided to culminate the study with the publication of a school handbook. To increase the amount of information provided in the handbook and the contributions made by the participants, a research retreat, modeled after the HIV/AIDS study retreat (Roberts, DeMatteo, King, & Read, 2002) was planned for participants and their families. The goal of the research retreat was to enable the families to meet and share with others, share information about the study, and receive clarification, insights, and additional recommendations from participants for the handbook.

PROCEDURE

Invitations were sent to all of the participant families, and in June of 2003, 61 people gathered for the CHD research retreat in Victoria, British Columbia at a site specifically chosen for its relaxed atmosphere and ability to accommodate all who attended. Upon arrival, each family was given a folder containing an agenda for the day, a photo release form, and a retreat evaluation form, and invited to enjoy refreshments and mingle in a dining area. When everyone had gathered, the primary investigator gave a brief welcome and overview of the day's events. Following the welcome, the families and research team took part in an icebreaker activity that provided a fun time of interaction between people of all ages. The research team thought it was imperative that all family members had an enjoyable and memorable day, and were actively involved in learning about the study and contributing to the school handbook. Participants, therefore, were separated into a group of adults, youth (ages 12 to 17), and children (ages 2 to 11) and each group moved to its own room to participate in its own activities.

Upon gathering, the adults heard an overview of the research study by the primary investigator. Using lay-person language, the investigator discussed CHD and related literature, and the study's purpose, research questions, methodology, analysis procedure, and findings. Parents then had the opportunity to ask questions specific to the study and its findings. The afternoon activities began with a presentation from a pediatric cardiologist. To enhance understanding about CHD and medical advances, this research team member reviewed and discussed the spectrum and severity of congenital heart defects, changes and advances in surgical and non-surgical management, and issues related to long term outcome. In a discussion period that followed, parents raised concerns about the lack of strategies that enable their adolescent children to assume ownership of their cardiac diagnosis, and explored issues such as the paucity of studies that have examined physical function and cognitive and emotional development.

Adult participants were then separated into three parent focus groups. Led by a research team member, each focus groups discussed and developed recommendations to be included in the school handbook. Each group was asked to examine and prioritize the recommendations that had been raised in the study's interviews (and were provided to them on a sheet of paper), and discuss and record new or omitted recommendations. In the focus groups, parents shared stories, ideas, and perspectives, and came up with several new and helpful recommendations such as incorporating a flexible studies program that would allow children to make up work without penalty if they miss school because of illness or surgery, and ensuring school professionals are educated about the day-to-day "ups and downs" and long-term physical, emotional, intellectual, and social wellbeing of children with CHD.

Throughout the day, the children participated in many activities that were informative and developmentally appropriate. To educate the children about the study, a research team member shared what she had learned by interviewing the participant children. Specifically, the researcher discussed what it is like to have CHD, and what the children's teachers, family, and friends will learn because of their participation. To involve the children in the handbook, each child drew a picture that illustrated what it is like to have CHD or be the sibling of someone with CHD. The children were told their pictures would be displayed for their parents later in the day, in future presentations, and in the upcoming school handbook. Many poignant pictures of hearts, hospitals, homes, and families were drawn by all of the children. In the afternoon, the children spent time making mementos such as heart picture frames, and playing group games. All activities appeared to be a source of enjoyment for the children, and were essential to and successful in enabling the children to meet and interact with others "just like them".

The first youth activity was a presentation delivered by one of the research team members. This presentation was adapted from the primary investigator's presentation and was intended to inform the youth about how their input from the family interviews had been interpreted and used by the researchers. The youth were encouraged to ask questions, and effort was made to ensure they understood and were in agreement with the findings of the study. Like the children, the youth produced drawings, poems, or prose to be included in the school handbook. A few excerpts from the poems were, "I feel good most of the time! But sometimes I get worried & a little bit scared", and, I feel "locked up" with "nowhere to run or hide". The afternoon began with age-appropriate and fun ice-breaking and problem-solving activities, bead-bracelet making, and a scavenger hunt. These activities gave the youth a chance to get to know each other, and talk about common experiences at school and on sports teams. The final activity for the youth and several of the older children was writing the dedication for the school handbook. With the assistance of research team members, small groups of the youth and children shared and generated ideas about what they wanted the dedication to say and which people they wanted to thank. After a time of brainstorming, each group's ideas were merged by a research team member to create the final book dedication.

Throughout the day, there were several important and special activities that made the retreat more enjoyable, comfortable, and memorable. For instance, a buffet style lunch provided an opportunity to share and relax with other families and the research team, and towards the end of the lunch hour, families had the opportunity to enjoy interactive singing with a children's entertainer. Additionally, the day concluded with a presentation of the handbook dedication and the children's and youth's drawings and poems. Many of the parents were noticeably touched by the drawings and poems and requested copies for themselves. Also, throughout the day, a research team member took digital photographs of the children and youth. After the retreat, these photos were printed and sent to the participants in thank you cards, and displayed on a poster about the retreat.

OUTCOMES

The research team was delighted with the outcome of the retreat as its goals were met. That is, the CHD retreat was successful in bringing participants together to enable them to network with others, learn about the study, and provide valuable information for the school handbook. Furthermore, feedback regarding the organization of the retreat, relevancy and interest of the presentations, and variety and enjoyment of the activities was very positive. Highlights for the participants included the study and medical presentations, and having the opportunity to meet and share stories and ideas with similar families. Suggestions for future retreats included adding psychological and educational input from different professionals, providing more time for the parent focus groups, and including school representatives so they can witness the concerns of parents and children.

CONCLUSION

The study of children and families requires methods or approaches tailored to suit the complexity of family phenomena (Gilgun, Dal, & Handel, 1992). A research retreat such as the one previously described is a positive and powerful research strategy as it empowers participants by enabling them to contribute to educational knowledge and practice. By bringing research participants together, retreats enable researchers to share research findings with the individuals who gave of their time to share their stories, perceptions, and recommendations. Furthermore, research retreats enable participants to feel more informed, valued, and respected as they are given the opportunity to discuss and share experiences with each other and academic and medical professionals. Although the participants were not involved in the entirety of the research design, the CHD retreat exemplifies the benefits of PAR and provides a valuable example of how researchers can involve participants in the research process and development of educational theory and practice.

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