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ChILD Family Education

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The Children's Interstitial Lung Disease (chILD) Foundation and chILD Research Cooperative identified a need for accurate and understandable chILD-related information for families. As a result, collaboration with the University of Alabama at Birmingham (UAB) Pediatric Pulmonary Center (PPC) produced "Get Up And Go With chILD!," a comprehensive, chILD-specific family education resource. Families and clinicians from multiple backgrounds and perspectives submitted content suggestions and copies of currently used family education and health management materials. Families provided information about the helpful and unhelpful information they had received in the past, the information they wished they had received, and their educational preferences. The resultant booklet is comprehensive, containing the education topics identified as critical for inclusion by families and clinicians, and is written at a seventh grade reading level. Available both in print and online, the online version contains live links to interactive Web sites, support groups, teaching videos, and downloadable forms and tools. If health education is to be understandable, useable, efficient, cost-effective, and of superior quality, if it is to improve people's lives by facilitating a change in their attitudes, beliefs, knowledge, skill levels, and behavior, an interdisciplinary, family-centered approach is crucial. This is resource intensive, but the initial costs of producing materials in this manner far outweigh the potential costs of poorly developed and delivered health education. Through an iterative, well-coordinated, collaborative process between families and clinicians from a variety of backgrounds and perspectives, "Get Up And Go With chILD!" exemplified this approach.

Introduction

A few years ago, with the support of a National Institutes of Health (NIH) R13 Conference for Pediatric Interstitial Lung Disease and in conjunction with a NIH Rare Lung Diseases Consortium Conference, specialists interested in Children's Interstitial Lung Disease (chILD) and families of affected children met and formed the chILD Foundation and the chILD Research Cooperative. One of the major needs identified by these 2 groups was for accurate and understandable information for families. Many families reported having little or no information about chILD, both at the time of and following diagnosis.

The chILD Foundation is a 501(c)3 charitable organization dedicated to provide support, education, and hope to families affected with a pediatric interstitial lung disease and to advocate and raise funds for scientific research. The foundation hosts an annual meeting of families and physicians and maintains a Web site at www.childfoundation.us, which provides links to educational materials, support groups, and other family-related materials.

The University of Alabama at Birmingham (UAB) Pediatric Pulmonary Center (PPC) is 1 of 7 PPCs across the nation funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration in the Department of Health and Human Services. As the UAB PPC (www.health.uab.edu/ppc) has expertise in the development and dissemination of family education materials regarding the care of children and youth with chronic lung conditions, a collaboration between the UAB PPC, chILD Foundation, and chILD Research Cooperative was initiated to address the perceived need.

Understanding the educational needs of families and children with chILD is critical to providing comprehensive care, yet the full spectrum of needs is not always appreciated.

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"Get Up And Go With chILD!," and the process undertaken to produce the material, provides important information for primary care and specialty physicians, health care team members, and families.

Methods and Materials

Initially, the plan was to develop the comprehensive chILD education materials from a previously published family education resource on bronchopulmonary dysplasia, which is available at http://main.uab.edu/ppc/show.asp?durki=68262. However, it soon became clear that diagnosing and managing chILD presents its own set of unique challenges, requiring the creation of chILD-specific materials. In keeping with the "nothing about me without me" principle of family-centered care, families and clinicians from multiple backgrounds and perspectives were asked to submit their content suggestions. Families responded to the questions: (1) What especially helpful or unhelpful information have you received and (2) What information do you wish you had received, and when and how would you have liked to receive it? Over a period of several months, the UAB PPC collected pictures, anecdotes, and copies of currently used family education and health management materials for inclusion. Both families and clinicians alike had multiple opportunities to participate in the editing of several drafts of the material. The resulting booklet, written at a seventh grade reading level, is primarily housed and distributed online (www.childfoundation.us/images/Get_Up_And_Go_With_chILD_-_Jan_2009.pdf), ensuring a document that is dynamic and responsive to changes in medical care and technology, although hard copies are available. Additionally, the online document contains live links to interactive Web sites, support groups, teaching videos, and downloadable forms and tools.

Results

Throughout the development process, several education topics were identified as critical for inclusion by families and clinicians:

Because the workup for chILD can be long and confusing, families identified a critical need for early education regarding the definition of chILD (including its various forms), the symptoms of chILD, and the various testing procedures involved in the diagnostic process, even before being formally diagnosed with chILD.

The proper management of chILD demands an interdisciplinary, family-centered approach. Families need information about the various types of clinicians and caregivers most likely to be involved in their child's care. Families need to understand the roles of physicians (both generalists and subspecialists), nurses, respiratory therapists, speech language pathologists, dietitians, social workers, physical therapists, and occupational therapists, just to name a few. From the beginning, families need skills to navigate the health care system and communicate important information to the appropriate clinician so they can be effective advocates for themselves and their children.

Each patient with chILD has unique medical needs and often has concurrent diagnoses that affect care. Families require education about how to provide medications and therapies for each diagnosis, including the use of various outpatient, inpatient, and home care therapies specific to each need. Early on, intensive education must be provided to ensure that the home environment contains the necessary equipment and supplies along with the training to provide specialized care for a wide range of chILD-associated medical needs. Each educational topic has its own set of skills and knowledge areas to be addressed, its own partner group, its own monitoring methods, and its own equipment, which requires procurement, maintenance, cleaning, and periodic replacement. Each child's needs are different and, even within the same child, these needs can be quite dynamic. Education efforts, therefore, must be ongoing and responsive to the changing family and patient landscape.

Some topics are common among families. Most families dealing with chILD must address growth and nutrition issues that evolve over time, so targeted nutrition information and a good relationship with a dietitian knowledgeable in the care of children with chronic lung diseases are invaluable. All families require information on emergency and disaster preparedness, traveling with children and medical supplies, and general information about health maintenance and disease prevention for themselves and their children. A basic understanding of their role in medical research, assisting in fund-raising for research and advocacy efforts, and helping to raise awareness and educate others is also important.

Some families require education related to topics not necessarily pertinent to other families dealing with chILD. These topics include sibling care, school success, transplantation, transitioning from pediatric to adult care, and dealing with the loss of a child and other stressors associated with long-term, special health care needs. Social workers are uniquely trained to assist with these and many other issues and are often familiar with local and state resources available to assist families with the medical care, equipment, and financial concerns that accompany chronic disease.

Obviously, this is a tremendous amount of potentially new information for any family to digest and use. Educational efforts should be focused on helping families to best organize and use the available information to their advantage. The inclusion of a glossary can be quite helpful, though this often elevates the reading level of the final document and can contain multiple cross references. For online versions, hyperlinks to other definitions within the glossary can be included, which can ease navigation within the document and support learning. Including a "Helpful Links" and "References" section in written materials can also support learning by helping families identify trusted sources for more detailed information on the topics most pertinent to their needs. Furthermore, having examples of various checklists, supply sheets, schedules, care plans, and health records can go a long way in enabling families to take charge of their children's care and communicate effectively with other team members.

Discussion

Clearly, the production of quality education materials is resource intensive, especially if the assumed definition of "quality" includes the concept of interdisciplinary, family-centered teamwork among people with a variety of backgrounds and perspectives sharing common goals and responsibility for goal attainment.[1,2] Interdisciplinary, family-centered teams are actively interdependent, with an established means of ongoing communication among all members to facilitate all aspects of planning, delivering, and evaluating health education materials.[1–3] This process can be time-consuming and can result in differences of opinion and conflict, which can be uncomfortable but which is also necessary and desirable to provide unique insights, innovation, and creative problem-solving, ultimately resulting in a superior product.[4] The initial costs of producing education materials in this manner far outweigh the potential costs of poorly developed and delivered health education.[2] It is in this rich environment, where multiple people are allowed to focus on their particular area of expertise, that the varied challenges, needs, and cultural backgrounds of children with chILD can be most effectively, efficiently, and comprehensively addressed.[1] Just as complex medical care requires the coordination of multiple services, the creation of comprehensive, population-based health education materials that emphasize health promotion and disease prevention also require well-coordinated collaboration.[1,5,6]

Providing "quality" health care education also requires the specialized ability to address varying levels of literacy and health literacy. In the United States, 17%–27% of the adult population cannot read and understand very basic written materials. An additional 22%–33% can read a little, but not well enough to fill out an application, read a food label, or read a simple story to a child. On average, Americans have about 12.5 years of education, but the average reading level for adult Americans is actually somewhere around the 8th or 9th grade with people in Medicaid programs and those 65 and older substantially lower. Between 1992 and 2003, the National Adult Literacy Survey (NALS) reported stable American literacy levels, with around 50% of all adults surveyed either illiterate or possessing either basic or below basic literacy levels.[7,8] Because of the associated shame, the vast majority of people with low literacy skills will not disclose their difficulties, so asking about literacy, regardless of how compassionately the question is posed, is not likely to produce much reliable information. It has been suggested that clinicians use universal precautions for health literacy because literacy skills may not indicate health literacy.[8,9] People with high literacy skills may still have low health literacy skills because health literacy is dynamic and affected by a wide variety of intellectual, emotional, and physical factors.[10] Low literacy and low health literacy are common and strongly linked to poor knowledge of disease condition and improper use of medications and therapies, resulting in increased emergency room use, increased hospitalization rates, delayed hospital discharge, increased morbidity and mortality, and an estimated cost of between $50 and $73 billion per year to the U.S. health care system.[8,9,11–16]

Effective disease management requires a multifaceted approach that includes effective medical treatment, appropriate environmental measures, individualized pharmacotherapy, and patient education.[17] A clinician providing unclear family education provides poor quality care. According to the Joint Commission and the National Committee for Quality Assurance, failure to provide understandable information to patients may be a negative factor in the accreditation status of a health care organization. A clinician's communication style and attitude are major factors in nearly 75% of malpractice suits and if a physician fails to fully disclose risks and benefits in general terms or ascertain patient understanding of signed documents, he or she could be held legally liable. Unfortunately, traditional patient education relies heavily on printed materials that are often written at a reading level too high for low-literate patients to read and comprehend essential points.[11,13,18,19] To provide efficient, cost-effective, quality health education and to improve people's lives by facilitating a change in their attitudes, beliefs, knowledge, skill levels, and behavior, the issues of low literacy and health literacy must be strategically addressed. "Get Up And Go With chILD!," though comprehensive in nature, is written at a seventh grade level.

A final draft of the completed booklet, upon review, garnered consistently positive remarks. The most common comment was regret that an educational resource such as this had not been available to the family reviewers when their own children were diagnosed with chILD. This was visibly apparent when a draft of the booklet was met with an emotional response at the 2008 annual chILD Foundation conference.

Through an iterative, well-coordinated, collaborative process between families and clinicians from a variety of backgrounds and perspectives, "Get Up And Go With chILD!" was completed in 2008 to address each of the general topic areas described earlier. Prior to general distribution, a philosophical discussion took place. Was it best to distribute a comprehensive but potentially overwhelming tool or to break the existing tool into a chILD 101-type of booklet for families and a more advanced chILD booklet for families and clinicians? There was concern that families of newly diagnosed children may find it undesirable and even disturbing to read about transplantation or coping with loss, when those topics may never be pertinent to their child's treatment. It was determined that it is desirable not only to have the comprehensive resource available for downloading in its entirety but also to link the booklet's various sections to different tabs, enabling people to selectively download only those sections that are most pertinent to their situation or that they are most interested in reviewing. Immediately following this decision, hard copies of the booklet and links to the online version posted on the chILD Foundation Web site were widely distributed to families of children with chILD and pediatric pulmonary practices. Subscribers to the pedlung listserv were e-mailed information about the booklet and a link to the online version, as well.

The effort to have the book translated into Spanish began in the spring of 2009 with the help of a physician in Argentina and a physician in the United States. There exists the possibility of translating it into several other languages as well, including Danish, French, and Japanese.

The chILD Foundation desires their Web site to serve as a repository for education materials and research findings, as well as a meeting place, of sorts, for family and clinician networking. The Foundation is committed to developing materials for distribution to families and clinicians including a regular newsletter, family education materials, and clinician education materials specific to each of the known chILD diagnoses. The Foundation is also committed to producing materials and programs for continuing education credit for clinicians. Long-term plans include the formation of a teen/young adult support group, the support of the new patient registry, and the compilation of contact information for physicians knowledgeable about chILD, social workers, patient advocates, and chILD-support programs by locality and/or state in an effort to develop a national chILD family support network. The new Rare Pediatric Lung Disease Patient Registry will contain a corresponding patient portal that will feature "Get Up And Go With chILD!" along with disease-specific resources, ongoing discussion topics, and disease-specific forums. The chILD Foundation has a long-term commitment to family–clinician collaboration and family and clinician education. The creation and distribution of "Get Up And Go With chILD!" was simply among the first of many goals and collaborations to be realized.

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Author Disclosure Statement

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