



Published in final edited form as:

J Health Care Chaplain. 2013 ; 19(1): 22–32. doi:10.1080/08854726.2013.761007.

Use and Sanctification of Complementary and Alternative Medicine by Parents of Children with Cystic Fibrosis

Daniel H. Grosseohme, DMin¹, Sian Cotton, PhD², and Gary McPhail, MD³

¹Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio

²Department of Family and Community Medicine, University of Cincinnati College of Medicine, Cincinnati, Ohio

³Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio

Abstract

Complementary and alternative medicine (CAM) use, including spiritual modalities, is common in pediatric chronic diseases. However, few users discuss CAM treatments with their child's physician. Semi-structured interviews of 25 parents of children who have cystic fibrosis (CF) were completed. Primary themes were identified by thematic analyses. Most parents (19/25) used at least one CAM modality with their child. Only two reported discussing CAM use with their child's pulmonologist. Most reported prayer as helpful (81%) and multi-faceted, including individual and group prayer; using aromatherapy or scented candles as an adjunct for relaxation; and the child's sleeping with a blessed prayer. Parents ascribed sacred significance to natural oral supplements. CAM use is relevant to the majority of participating parents of children under age 13 with CF. Chaplains can play a significant role by reframing prayer's integration into chronic disease care, co-creating rituals with pediatric patients, and mediating conversations between parents and providers.

Keywords

complementary medicine; cystic fibrosis; parent; prayer; chaplain

INTRODUCTION

Complementary and alternative medicine (CAM) is widely and increasingly used among both children and adults in the United States (Barnes, Powell-Griner, McFann, & Nahin, 2004). CAM, defined as a collection of health-related behaviors and practices outside of conventional medicine, encompasses the use of natural products (e.g., herbs, supplements), mind-body therapies (e.g., meditation, deep-breathing), manipulative and body-based practices (e.g., chiropractic, massage), and other health approaches (e.g., traditional Chinese medicine, homeopathy) (NCCAM, 2012). As recently as 2004, NCCAM reported that three of the five most frequently used CAM modalities by American adults were prayer, with up to 43% of adults using a form of prayer (NCCAM, 2004). Recent estimates of CAM use indicate that approximately 38% of healthy adults and 12% of healthy children report using some form of CAM in the past year; with CAM use being often higher among illness populations (Barnes, Bloom, & Nahin, 2008). Indeed, adolescents with chronic illnesses are more likely to use CAM as compared to their healthy peers, with prevalence rates over three

times higher in this population (McCann & Newell, 2006). For example, up to 89% of parents reported using CAM to manage their child's asthma (Braganza, Ozuah, & Sharif, 2003), and 84% of children with cancer reported using some form of CAM for health promotion (Kelly et al., 2000). CAM use is rarely reported to or asked about by physicians (Shelley, Sussman, Williams, Segal, & Crabtree, 2009; Tanase & Zanni, 2008).

Cystic fibrosis (CF) is the most common genetic disorder among Caucasians, with a US incidence of 1:4000 live births; the median life expectancy in the US is approximately 38 years (Marshall & Hazle, 2009; Wilfond & Taussig, 1999). CF affects multiple organ systems, including pulmonary, gastrointestinal, endocrine and reproductive. Daily treatments are not preventive, but are aimed at slowing disease progression, and they are burdensome; including twice-daily airway clearance, and may also include nebulized medications, replacement enzymes and insulin.

A handful of studies have documented CAM use among children and adults with CF. In one of the first large studies in CF, researchers asked 402 patients and families of patients from infancy to 45 years of age (mean age, 17.5 years, median 18 years) about their CAM use, including religious practices (e.g., group prayer), physical practices (e.g., chiropractic), folk remedies (e.g., nutritional supplements), and other modalities (e.g., acupuncture). Sixty-six percent of patients reported using some form of CAM, with the most commonly used modality being group prayer (48%), followed by chiropractic (14%), nutrition (11%), and meditation (5%) (Stern, Canda, & Doershuk, 1992). Most (70 – 94%) reported perceived health benefits associated with CAM (e.g., reduced symptoms, greater emotional comfort), particularly group prayer, and no patients reported adverse effects (Stern, et al., 1992). In a study including children with CF, Tanase and Zanni reported that 73% of patients (mean age 11.1 years SD 6.8 years) used at least one CAM modality, and the most frequently used modality was prayer (42%); 77% reported that CAM was useful (Tanase & Zanni, 2008).

CAM use in CF has also been examined via small-scale intervention studies of persons from ten to 44 years of age (Belsky & Khanna, 1994; Delk, Gevirtz, Hicks, Carden, & Rucker, 1994; Lin & Ly, 2005). Belsky and Khanna tested the effects of self-hypnosis compared to a control group using a sample of twelve pediatric patients with CF, aged 7–18 years. Significant improvement in the experimental group was found for locus of control, health locus of control, and self-concept. Improvement in trait anxiety (but not state anxiety) was also noted. The experimental group also demonstrated significantly higher peak expiratory flow immediately after the intervention. Delk and colleagues tested the treatment effect of biofeedback-assisted breathing retraining compared to biofeedback-assisted relaxation training using matched pairs of 26 persons with CF, aged 10–41 years. The experimental group showed a significantly higher improvement in pulmonary function (measured by forced expiratory volume over one second) than the control group. Lin and Ly provided acupuncture as an intervention for pain experienced by persons with CF in a sample of 23 persons, aged 12–44 years. Reported levels of pain decreased significantly in the experimental group and the mean duration of the treatment effect was three days.

The aim of the present study was to understand parents' perspectives on the use of various CAM modalities with their children to assist with their children's CF. Although previous studies have documented the incidence of CAM use, there is little qualitative information available concerning what motivated parents to use or not use CAM, or about the meaning of using CAM. We anticipated that parents would discuss CAM use with the interviewer; and report that spiritual CAM modalities, such as prayer, would have been commonly employed.

Methods

This study was approved by the institution's IRB and occurred in the context of a larger study of treatment adherence, which included telephone interviews with n=25 parents of children aged three months to thirteen years who have CF. Telephone interviews are preferred to in-person methods, which may yield less data (Jaya, Hindin, & Ahmed, 2008), and when there is the potential to provide socially correct responses to questions (Midanik, Greenfield, & Rogers, 2001). Using a list of CAM modalities adapted from the work of Stern and colleagues (Stern, et al., 1992), parents were asked (1) if they had used each modality on their child specifically related to the child's CF and, (2) if they had, whether or not the child experienced it as helpful, and; (3) if they had used a CAM modality, whether or not they had informed their child's pulmonologist that they were using each modality. In an effort to normalize potential hesitancy to discuss CAM use, the questions were prefaced by the interviewer's statement that, "We know that sometimes parents have increasingly been using what are sometimes called complementary or alternative medicine methods. These can include many different kinds of treatments, and they are generally not what your child's pulmonologist prescribes. I'd like to read you a list of treatments which some people have tried, and I'd like to know if you have ever had your child use this for their CF symptoms." The interviews were conducted by the first author, digitally recorded, transcribed and accuracy verified. Analysis proceeded by counting positive responses to each of the questions in the transcripts. Explanatory comments made by participants about CAM use were collated, and thematic analysis was used to identify significant themes.

Results

A total of 25 parents were interviewed (n=17 female), and 24 responded to questions about CAM use with their child. Demographic and clinical data about the participants and their children are presented in Table 1. Table 2 presents the frequency of use for various CAM modalities, parent-reported efficacy, and whether or not they discussed their CAM use with the child's pulmonologist. Prayer was the most commonly used CAM modality, reported by 21 of 24 parents. Two other spiritual modalities also were reported by two parents (healing touch and meditation). Most of the parents who reported using prayer for their child's CF also reported that they believed it helped (17/21 parents). Only two of the 21 parents who reported using prayer indicated that they had discussed this with their child's pulmonologist. The only other CAM modality reportedly discussed with their child's pulmonologist was the use by one family of aromatherapy (scented candles) for relaxation in conjunction with prayer.

Parents' discussion of the use of prayer referred to both individual prayer as well as group intercessory prayer. Parents who used prayer attributed a very positive meaning to the effect of prayer. The father of three year-old girl said, "I think it has a very big impact on her health. I think it helps a lot with her sickness and helps with her being...knowing that somebody is looking over her." He continued, "She had a prayer cloth that was... prayed over... all the way to West Virginia and Tennessee and she slept with it next to her bed ever since she was diagnosed ..." The mother of 11 year-old girl said, "My whole church was praying and fasting for her the day of her surgery and it turned out the *alcaligenes* was gone." The mother of two year-old girl, talking about the power of prayer to influence God said, "No, I feel He hears what He needs to hear and He does what He can do and then it's all up to us..."

Another spiritual CAM modality, healing touch was discussed by one parent, who attributed empirical evidence of weight gain, improved breathing and lack of infections to this modality. This mother of two year-old boy said, "We have someone...doing healing touch

on him. And I have proven results that it has been helpful...consistent weight gain the next couple of days after she leaves and...better breathing, no infections.” The father of a three year-old boy referred to his son having been “anointed with oil as a baby and he had hands laid on him for healing.”

The mother of four year-old girl commented, “If it’s natural, God-created, those things, it’s completely with in my understanding that they could be helpful just because of God’s creation.” This was a novel finding: to hear sacred significance and meaning attached to herbal supplements, because they are natural products from the world created by God and pronounced as “good.” Annette Mahoney has introduced the term “sanctification” to refer to any aspect of life (a role or an object) which has divine significance (Mahoney et al., 1999). Sanctifying CAM modalities gives them a meaning which makes them superior to manufactured or artificial means for this mother and others who believe similarly. This mother continued, “So if I had the money, I would definitely research it myself and we would be on supplements absolutely... We already do Boost but that’s man-made, I kind of want something organic...” The only barrier this mother identified to using herbal supplements was limited financial resources.

The parents in this sample sometimes combined modalities (prayer and aromatherapy). The father of ten year-old girl said, “There was some different certain candles and incense that we tried to just kind of help her relax. She used that conjunction with prayer...it really helps to, just relax and just open your mind and heart and soul.” The mother of a four year-old girl used a therapeutic activity (horse therapy) to augment her child’s normal airway clearance as prescribed by her pulmonologist: “My goal was when she ran with the horse to help her cough naturally and spit.” Only a small minority of parents reported discussing their CAM use with their child’s pulmonologist. One mother of a 15 month-old boy said, “Usually, when I go to the doctor’s I don’t talk too much religion.”

Most of the CAM modalities reported by parents were used with their child at home. The notable exception to this was massage, which is a service available to children and youth who are inpatients and provided by the hospital’s Holistic Health staff. With one exception, the parents who indicated that they used this modality with their children referred to requesting this service during periods when their child was an inpatient. The parent of a three year-old boy, referring to this inpatient service, commented that, “I wish there were more alternative therapies provided before or after clinic and not just for when he’s admitted.”

Not all parents in the sample reported using CAM modalities. The responses of those who did not use CAM fell into five categories. First, parents relied on trusted “medical” treatments rather than “holistic” therapies which may not have demonstrated efficacy. The mother of a 20 month-old girl stated “We only use anything that was given to us by the doctors. I don’t believe in holistic healing and things...I guess ‘cause I work in the medical field.” Second, the parent considered the child too young for certain CAM modalities, as in the case of a two year-old boy’s mother who said, “He’s too young for chiropractic, but as soon as he gets older we are going to.” Third, parents cited a lack of money to afford CAM modalities, exemplified by this mother of four year-old girl who said, “So if I had the money, I would definitely ...I’ve thought about it, but... it does, you know, cost an extra dollar.” Fourth, the mother of a two year-old was unable to access CAM modalities despite an interest in them (“I would like to try acupuncture, but I don’t know where to find an acupuncturist.”); and finally, parents would not use CAM modalities because of direct conflict with child’s health conditions (“Not with him...no, I’m too afraid to use herbal supplements”).

Discussion

We present narrative descriptions of the use of CAM modalities by parents of children with CF. As anticipated, parents readily disclosed their CAM use and discussed its meaning in this study. The majority of parents in this sample reported using at least one CAM modality on their child to address aspects of their child's CF. Consistent with other studies, the most commonly employed modality was prayer. Most parents who reported using a CAM modality with their child also reported that the child found it beneficial. While dissimilar in design to the intervention studies cited in the introduction, our findings that participants reported CAM use being experienced by their child as beneficial is consistent with the findings from those intervention studies. Very few parents discussed their CAM use with their child's pulmonologist. Various reasons were given by those parents who had not used any CAM modality, including child's age, access, cost, conflict with other health issues, and the expectation that a modality such as prayer would not be a topic of conversation at a medical appointment. The lack of reporting CAM use by participants in this study is similar to that reported by Shelley and colleagues (Shelley, et al., 2009).

We are unaware of previous reports describing the "sanctification" of CAM modalities--imbuing CAM treatments with a spiritual significance because they were natural substances or processes which came from God's creation and therefore were "good." Sanctification as a construct has previously been described in the sanctification of marriage, parenting and care of the body (Mahoney et al., 2005; Mahoney, et al., 1999; Murray-Swank, Mahoney, & Pargament, 2006). Previous studies that explored the role of sanctification found relationships with behavior; for example, pro-healthy behaviors (exercise, healthy eating, lower alcohol/substance use) associated with sanctification of the body (Mahoney, et al., 2005). The results of the present study suggest a broadened understanding of this construct so that not only roles but physical parts of the world may be sanctified and may relate to health behaviors. Implications for a chaplain's potential role in patients with chronic disease who may use herbal supplements are discussed.

Limitations

This study has the limitations of sample size; limitations inherent in convenience samples; and the limitations of potential recall bias. Nonetheless, this study contributes to the understanding of the role of prayer and other spiritual CAM modalities among parents of children with CF. The data support previous findings of the importance of CAM for these patients and their families, and suggest the importance of the role of chaplains to assess prayer efficacy, explicitly inquire about CAM use, and when indicated, serve as a mediator between members of the health care delivery team and the patient/parent/family member to resolve potential conflicts.

These preliminary findings suggest two future directions for research about CAM use in pediatric chronic disease. First, chaplains may consider the inclusion of case-based descriptions of their work as communication facilitators between clinicians and patients/parents, as well as rich case studies of the use of prayer in pediatric chronic illness. George Fitchett has encouraged clinical chaplains to develop a case-study literature as a necessary first step in developing an evidence-base for the profession (Fitchett, 2011). Second, the importance of patient reported outcomes, such as quality of life data, is gaining prominence in contemporary health care. Since parents often believe that CAM modalities are beneficial to their child's quality of life, and some of these modalities have spiritual significance, prospective studies exploring how spiritual CAM modalities improve patient reported outcomes could be undertaken.

Implications for chaplains

These findings present clinical chaplains with three opportunities. The first is reframing “prayer.” Children’s different stages of spiritual development mean that they may have different ways of praying than adults. The parents in the present study described what might be considered “ritualized” forms of prayer that were helpful or meaningful to their children. Rituals are most appropriate for children whose thinking is typified by Piaget’s preoperational stage, usually between ages two and seven years of age. However, under stress (such as hospitalization or chronic illness), children and adolescents of any age may temporarily regress to this stage (Imber-Black, Roberts, & Whiting, 2003). One parent described the child’s use of a cloth that had been prayed over and blessed for that child’s use and healing by faith communities, and which that child used in bed like a comfort object. The second was the use of candles in conjunction with prayer or meditation to aid in relaxation. Ritual objects symbolize the power they represent: they have the power to make God present to the child and be vehicles of healing. Chaplains may affirm the use of, or offer to help families develop, ritual ways to pray. This may also serve to invite patients and families to understand their own prayer for healing as their collaboration with the professional health care delivery team for wholeness, health, or healing, rather than an isolated activity in which they engage.

The second opportunity emphasizes the chaplains’ role as communication facilitator with two opportunities for this. The first is between clinician and patient/parent about CAM use in general and about spiritual CAM modalities (prayer, healing touch, and meditation) in particular. It is possible that some persons might reject using manufactured or synthetic treatments in favor of naturally-occurring, “sanctified” substances. While some CAM modalities have little risk or cost (prayer costs only time), some CAM modalities do have risk, including side effects and drug interactions. An example is the potential use of St. Johns Wort, which interferes with a drug used for some children with CF such that the child does not receive the full benefit from the prescribed drug. Without an open dialogue with parents and patients about CAM modalities, potentially unsafe CAM therapies might be used which result in poorer patient outcomes. Chaplains are potentially key mediators to assist with such discussions. Another facilitation opportunity is based upon the work of Curlin and colleagues, who reported that physicians with higher levels of increased spirituality and religiosity had greater willingness to integrate CAM into a treatment program (Curlin et al., 2009). With knowledge about the physician colleagues’ spirituality, chaplains may be a “bridge” connecting a parent using, or contemplating using CAM, with a physician who may be more open to it than the parent realizes. In fact, persons may want their (western) medical providers to refer them to appropriate CAM practitioners (Ben-Arye et al., 2009).

The third opportunity for chaplains is to mediate communication between persons with chronic illness and faith communities. Some of the parents in this study sanctified CAM modalities and gave sacred significance to “natural” substances over commercial pharmaceuticals. Chaplains are uniquely positioned to bring congregations, CAM practitioners, and the traditional, western-style health care community together. Such a gathering would provide opportunities for representatives from different backgrounds to hear the theological basis for CAM and its importance to many families; the effectiveness CAM modalities have and do not have; and to about the importance of evidence-based therapies’ in physical or mental health.

Acknowledgments

This study was partially funded by NIH/NICHD grants K23 HD062642 (PI: Grossoehme) and K23 HD052639 (PI: Cotton), and the Division of Pulmonary Medicine, Cincinnati Children’s Hospital Medical Center (Raouf Amin,

MD, Director). The authors gratefully acknowledge the critical review of this manuscript by Sue Jelinek, BCC, Staff Chaplain II (Cincinnati Children's Hospital Medical Center) and medical writer J. Denise Wetzel (Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center).

References

- Barnes PM, Bloom B, Nahin RL. Complementary and alternative medicine use among adults and children: United States, 2007. *National Health Statistics Reports*. 2008; 12
- Barnes PM, Powell-Griner E, McFann K, Nahin RL. Complementary and alternative medicine use among adults: United States, 2002. *Seminars in Integrative Medicine*. 2004; 2(2):54–71.
- Belsky J, Khanna P. The effects of self-hypnosis for children with cystic fibrosis: a pilot study. *American Journal of Clinical Hypnosis*. 1994; 36(4):282–292. [PubMed: 8203356]
- Ben-Arye E, Karkabi K, Karkabi S, Keshet Y, Haddad M, Frenke M. Attitudes of Arab and Jewish patients toward integration of complementary medicine in primary care clinics in Israel: a cross-cultural study. *Social Science and Medicine*. 2009; 68(1):177–182. [PubMed: 18992983]
- Braganza S, Ozuah PO, Sharif I. The use of complementary therapies in inner-city asthmatic children. *Journal of Asthma*. 2003; 40(7):823–824. [PubMed: 14626339]
- Curlin FA, Rasinski KA, Kaptchuk TJ, Emanuel EJ, Miller FG, C TJ. Religion, clinicians, and the integration of complementary and alternative medicines. *Journal of Alternative and Complementary Medicine*. 2009; 15(9):987–994.
- Delk KK, Gevirtz R, Hicks DA, Carden F, Rucker R. The effects of biofeedback assisted breathing retraining on lung functions in patients with cystic fibrosis. *Chest*. 1994; 105:23–28. [PubMed: 8275737]
- Fitchett G. Making our case(s). *Journal of Health Care Chaplaincy*. 2011; 17:3–18. [PubMed: 21534063]
- Imber-Black, E.; Roberts, J.; Whiting, RA. *Rituals in families and family therapy*. New York, NY: W.W. Norton & Company; 2003.
- Jaya J, Hindin MJ, Ahmed S. Differences in young people's reports of sexual behaviors according to interview methodology: a randomized trial in India. *Am J Public Health*. 2008; 98(1):169–174. [PubMed: 18160677]
- Kelly KM, Jacobson JS, Kennedy DD, Braudt SM, Mallick M, Weiner M. Use of unconventional therapies by children with cancer at an urban medical center. *Journal of Pediatric Hematology/Oncology*. 2000; 22(5):412–416. [PubMed: 11037851]
- Lin Y-C, Ly H. Acupuncture pain management for patients with cystic fibrosis: a pilot study. *American Journal of Chinese Medicine*. 2005; 33(1):151–156. [PubMed: 15844843]
- Mahoney A, Carels RA, Pargament KI, Wachholtz A, Leeper LE, Kaplar M, Frutchey R. The Sanctification of the Body and Behavioral Health Patterns of College Students. *International Journal for the Psychology of Religion*. 2005; 15(3):221–238.
- Mahoney A, Pargament KI, Jewell T, Swank AB, Scott E, Emery E, Rye M. Marriage and the spiritual realm: The role of proximal and distal religious constructs in marital functioning. *Journal of Family Psychology*. 1999; 13(3):321–338.
- Marshall, B.; Hazle, L. *Patient registry annual data report 2008*. Bethesda, MD: Cystic Fibrosis Foundation Patient Registry; 2009.
- McCann LJ, Newell SJ. Survey of paediatric complementary and alternative medicine use in health and chronic illness. *Arch Dis Child*. 2006; 91:173–174. [PubMed: 16428365]
- Midanik LT, Greenfield TK, Rogers JD. Reports of alcohol-related harm: telephone versus face-to-face interviews. *J Stud Alcohol*. 2001; 62(1):74–78. [PubMed: 11271967]
- Murray-Swank A, Mahoney A, Pargament KI. Sanctification of parenting: Links to corporal punishment and parental warmth among biblically conservative and liberal mothers. *International Journal for the Psychology of Religion*. 2006; 16(4):271–287.
- NCCAM. NIH News. Rockville, MD: National Center for Complementary and Alternative Medicine; 2004. More than one-third of U.S. adults use complementary and alternative medicine, according to new government survey.

- NCCAM. [Retrieved 28 May 2012] What is complementary and alternative medicine?. 2012 Feb 6. 2012, 2012, from <http://nccam.nih.gov/health/whatiscam>
- Shelley BM, Sussman AL, Williams RC, Segal AR, Crabtree BF. 'They don't ask me so I don't tell them': patient-clinician communication about traditional, complementary and alternative medicine. *Ann Fam Med*. 2009; 7:139–114. [PubMed: 19273869]
- Stern RC, Canda ER, Doershuk CF. Use of non-medical treatments by cystic fibrosis patients. *Journal of Adolescent Health*. 1992; 13(7):612–615. [PubMed: 1420216]
- Tanase A, Zanni R. The use of complementary and alternative medicine among pediatric cystic fibrosis patients. *Journal of Alternative and Complementary Medicine*. 2008; 14(10):1271–1273.
- Wilfond, BS.; Taussig, LM. Cystic fibrosis: general overview. In: Taussig, LM.; Landau, LI., editors. *Pediatric Respiratory Medicine*. St. Louis: Mosby; 1999. p. 982-990.

Table 1

Demographic characteristics of sample

Parents		n (%)	Mean (SD)
Gender	Female	17 (68)	
Ethnicity	Caucasian (non-Hispanic)	23 (92)	
	African-American	2 (8)	
Age (years)	18–25	1 (4.5)	
	26–30	4 (18.2)	
	31–35	10 (45.5)	
	36–40	3 (13.6)	
	41–45	3 (13.6)	
	46 and older	1 (4.5)	
Religious Affiliation	Christian	18 (72)	
	None/Other	6 (24)	
	Jewish	1 (4.5)	
Children			
Gender	Female	14 (56)	
Age (years)			6.5 (4.4)
Pulmonary exacerbations (in prior 12 mos)			0.92 (1.3)

Table 2

CAM use by parents for their children with CF

CAM modality	Ever used modality with child for child's CF n(%)	Modality experienced by child as helpful n(%)	Informed child's pulmonologist of CAM use n(%)
Prayer	21 (84)	17 (81)	2 (8)
Healing touch (Reiki)	4 (19)	1 (25)	0 (0)
Meditation	2 (10)	0 (0)	0 (0)
Massage	7 (33)	4 (57)	0 (0)
Aromatherapy	1 (5)	1 (100)	0 (0)
Chiropractic	1 (5)	0 (0)	0 (0)
Horse therapy	1 (5)	0 (0)	0 (0)
Yoga	1 (5)	0(0)	0 (0)
Herbal supplements	0 (0)	0 (0)	0 (0)
Acupuncture	0 (0)	0 (0)	0 (0)