Journal of Religion and Health (2019) 58:2065–2085
https://doi.org/10.1007/s10943-019-00921-8

ORIGINAL PAPER

Feasibility and Acceptability of a Telephone-Based Chaplaincy Intervention to Decrease Parental Spiritual Struggle

John Betz[4] · Rhonda Szczesniak[1,2] · Katrina Lewis[3] · Teresa Pestian[3] · Amy Simpson Bennethum[4] · Judith McBride[4] · Daniel H. Grossoehme[1,3,4]

Published online: 4 October 2019

Abstract

Spiritual struggles (SSs) are distressing spiritual thoughts associated with poorer health outcomes. This study's purpose was to test feasibility, acceptability, and fidelity of an intervention to decrease SS of parents of children with CF. Parents screening positive for SS were enrolled and were randomized to intervention or attention-control condition. Intervention focused on intra-, inter-, and divine SS. Mixed linear modeling examined between-group differences. We present analyses of $N=23$, and participants all showed decreased levels of SS. Acceptability was high; feasibility was higher in the intervention arm. GuideSS_CF is acceptable and feasible and warrants development as a potentially efficacious intervention.

Keywords Chaplaincy · Intervention · Adolescent · Cystic fibrosis

✉ Daniel H. Grossoehme
violas9502@gmail.com

Amy Simpson Bennethum
dgrossoehme@akronchildrens.org

[1] Department of Pediatrics, University of Cincinnati, College of Medicine, Cincinnati, OH, USA

[2] Division of Biostatistics and Epidemiology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

[3] Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue MLC2021, Cincinnati, OH 45229, USA

[4] Department of Pastoral Care, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

Introduction

Spirituality, "a search for the sacred—elements of life that are seen as manifestations of the divine, transcendent or ultimate, either inside or outside of a specific religious context," (Exline et al. 2014; Quittner and Opipari 1994) is usually thought of as a positive force in people's lives, yet some aspects are associated with poorer health behaviors and outcomes. One such health behavior is people's adherence to prescribed therapies for self-management of their chronic diseases. Poor adherence to prescribed cystic fibrosis therapies exacerbates disease progression. We have shown that spiritual beliefs relate to adherence to cystic fibrosis (CF) therapies by both parents of children with CF (Grossoehme et al. 2015), by adolescents with CF (Grossoehme et al. 2016a), and adults with CF (Grossoehme et al. 2012b). Parents of children with CF who did not understand treatment adherence as a problem to be solved in collaboration with the divine were more likely to be in the least adherent group, which averaged 23% adherence to prescribed daily airway clearance treatments. Those reporting spiritual struggles were less adherent in completing their child's nebulized medications (Grossoehme et al. 2015). Higher levels of intention reported by adolescents with CF to complete their airway clearance treatments were predicted by lower spiritual struggle, as well as a greater engaged spirituality (Grossoehme et al. 2016a).

Spiritual struggles (SSs) "occur when some aspect of religious/spiritual (R/S) belief, practice or experience becomes a focus of negative thoughts or emotions, concern or conflict." (Exline et al. 2014) Spiritual struggles are the specific aspect of spirituality associated with poorer adherence by both parents and adolescents (Grossoehme et al. 2015, 2016a). Identifying persons with SS is a necessary task in order to triage the limited resource of chaplain availability (Fitchett et al. 2000). It is also important because SS is linked with poorer health behaviors, such as adherence to prescribed chronic disease treatment regimens (Dalmida et al. 2009; Grossoehme et al. 2015). Adherence to prescribed evidence-based therapies slows disease progression. SS is also related to poorer health outcomes (Jones et al. 2015; Kremer et al. 2015), including depression (Fitchett and Risk 2009; Thuné-Boyle et al. 2013). Screening for SS has been shown to be feasible in both clinical and telephone encounters (Fitchett and Risk 2009; Grossoehme and Fitchett 2013; Grossoehme et al. 2016b).

Telephone interventions conducted by a chaplain and which include spiritual constructs have been shown to be feasible and acceptable to adult caregivers of adult palliative care patients (Steinhauser et al. 2016). This caregiver outlook (CO) intervention sought to improve well-being by exploring role-related meaning among the caregivers. CO is an intervention delivered using three semi-structured telephone calls. This intervention significantly decreased SS scores after an 8-week follow-up (Cohen's $d = 0.75$). The present study adapted the framework of caregiver outlook. Outpatient CF clinic appointments typically include clinicians from as few as three or as many as nine disciplines and can last 2–4 h for a family. Increasing parent burden by adding an intervention to their clinic experience was not feasible. Preliminary data showing SS preceding depression, coupled with the telephone-based CO

reduction in SS, led to development of guidance through spiritual struggles in CF (GuideSS_CF).

Following a staged model for developing behavioral trials (Rounsaville et al. 2001), Stage 1 (pilot) tasks are to demonstrate that an intervention can feasibly be delivered with fidelity and that it is acceptable to parents of children with CF. The objective of this study was to document intervention fidelity, acceptability, and feasibility of GuideSS_CF in this population. To attain the objective of this aim, we will test the working hypotheses that GuideSS_CF will be feasible to deliver with at least 85% fidelity and be acceptable to parents and chaplains. This hypothesis will be tested by using a single site, two-arm trial with participants with spiritual struggle allocated by randomization to receive GuideSS_CF or an attention-control (AC) intervention with pre- and post-follow-up measures for 6 months. The two specific aims to be tested were, first, to document the intervention fidelity, acceptability, and feasibility of GuideSS_CF trial and second, to model changes in SS (operationalized as negative spiritual coping), spiritual coping, depressive symptoms, and adherence to airway clearance over time. We postulated, based on our experience, that GuideSS_CF would be feasible to deliver with at least 85% fidelity and be acceptable to parents; and, based on our preliminary data, our working hypothesis was that GuideSS_CF would decrease SS.

Methods

Participants

This study was carried out in the CF Center at a 575-bed academic pediatric medical center in the Midwestern USA and was approved by the institutional review board. Persons were eligible if they were legal guardians over age 18 years of a child between 0 and 17 years old diagnosed with CF, whose English was sufficient enough to participate in the study, and screened positive for spiritual struggle using the negative subscale of the Brief RCOPE (see below for additional detail) (Pargament et al. 2000). All eligible persons were notified by a letter from the CF Center Director to inform them of their eligibility and which provided a phone number if they desired no further study contact, or if they wished to inquire further or enroll at that time.

Procedures

Eligible persons were approached at their child's subsequent outpatient clinic appointment or during their child's inpatient admission. After completing the informed consent process, participants were screened using the negative subscale of the Brief RCOPE. Since the primarily outcomes of the study were feasibility and acceptability, rather than intervention efficacy, persons who screened positive, whether mild or moderate/severe spiritual struggle was indicated, were offered the opportunity to enroll in the study. Participants were randomized to intervention or control condition using an online random number generator. Participants completed

measures (described below) at enrollment (baseline, T0) and at 1- and 3-month post-intervention (T1 and T2, respectively).

Intervention Condition

Assignment of one of the two chaplains as the interventionist was randomly chosen for the first intervention participant, and then alternating assignments between the chaplains. The intervention consisted of three semi-structured telephone conversations with one of the two chaplain interventionists. GuideSS_CF retained CO's overall structure for out-of-clinic delivery, by the PI and two CF parents in consultation with CO's developer, Karen Steinhauser. A review of the theoretical and empirical literature on SS suggested that a semi-structured session be devoted to each of three types of SS defined by McConnell and colleagues: *intra*personal, *inter*personal, and divine struggles (McConnell et al. 2006). Other spiritual constructs such as imbuing the body of one's child with sacred significance (Mahoney et al. 2005) which play a role in parental CF treatment behavior (Grossoehme et al. 2015) were also integrated. The intervention was developed to be acceptable to persons with a monotheistic background, which encompasses the majority of persons in the USA and Europe and matching our Center's demographic of approximately 48% Christian, 40% "spiritual but not religious," 6% atheist/agnostic, 3% Muslim, 2% Latter-day Saints, and 1% Jewish (Murray-Swank and Pargament 2005). While "God" language was retained for ease of understanding, the interventionist established at the first call how the participant understood and named the sacred and used that language throughout the intervention. Following the structure of the CO intervention, the chaplain interventionist conducted three scheduled 45–60 min calls spaced approximately 2 weeks apart to allow participants to reflect on session content and develop questions. The intervention (treatment) manual is included in Table 1.

Control Condition

The choice of control group requires balancing several considerations: It should be sufficiently meaningful to aid recruitment and overcome resistance to treatment allocation, be ethically justifiable and enhance validity by controlling for nonspecific factors, and alternative explanations for the intervention's effect. We attempted to address these issues by using a control group that included (a) CF-related education, including setting routines for meals and treatments; cleaning and maintaining respiratory equipment; and a review of current medical regimen and (b) equivalent time and social contact. These elements were intended to minimize potential threats to internal validity posed by differences in intervention delivery mode; the social contact afforded by the conversation; or a control condition that might influence the outcome variables. This control condition was previously used as control condition with CF parents in another, unrelated, telephone-based trial (Powers et al. 2015).

Table 1 GuideSS_CF intervention guide

Domain	Question	Probe	Toolbox
Intervention Call #1			
Introduction	Hello again, I'm *N.*, from the GuideSS Study. We scheduled today as a time to talk. Our time together will take approximately 30 min to an hour. Is this still a good time? As I mentioned when we set up today's time, I would like to speak with you and learn about what's been spiritually challenging for you as a parent of a child with cystic fibrosis. As a reminder, I will be talking with you 3 times over the next month. Each session will take 30–60 min. Today is the first of those three sessions. I am a healthcare chaplain on the research team. As a healthcare chaplain, I am trained to focus on what is important to you. I have questions to guide our conversation, but please know that as I ask the questions, I do not have any expectations about your beliefs or how you should answer any question. There are no right or wrong answers, there is no better or worse set of beliefs. Rather, this time is about you and what you have found challenging. I am here to listen and help you tell your story as well as offer some suggestions. You certainly do have to answer any question you don't want to, and you have the right to stop the conversation at any time. With your permission, I will be recording our conversations. This will help us recall exactly what you said so that we may understand more about what is spiritually challenging and how parents have worked to lessen those challenges. Recording the conversation also helps me so that I can learn how to do my job better making these calls. To ensure that our conversations will be kept confidential, we will transcribe the conversation into a Word document and at that time, your name removed	(If yes, proceed. If no, schedule another time)	

Table 1 (continued)

Domain	Question	Probe	Toolbox
	Do you have any questions before we begin?	If "yes," answer questions if able; or refer to PI for a response If "no," proceed	
	I'd like to use language to talk about the Sacred in ways that are familiar to you. By what name do you refer to the Sacred?	Probe for God, Lord, Jesus, Christ, Allah, the goddess, etc. Use that name throughout intervention in lieu of "God" as appropriate	
	In this study, we are talking with parents who have experienced some type of spiritual or religious struggle. We know that people who have spiritual or religious struggles also tend to have a higher chance of having symptoms of depression later, and parents who have depression usually find it even more difficult to make sure their child's CF treatments get done each day. We think that if we can help people have fewer spiritual or religious struggles, we can lower the chance they will have depressive symptoms later on, and that they will be more likely to complete all of their child's CF treatments. Today, we'll focus on struggles that you experience in your own mind or heart, perhaps questioning beliefs you may have grown up with. Spiritual struggles tend to be difficulties we have with other people over spiritual issues, and that's what we'll focus in our next call. In the third and last call, we'll focus on struggles you have with God or your Higher Power		
	Do you have any questions before we continue?	If "yes," answer questions if able; or refer to PI for a response If "no," proceed	
Intrapersonal struggles	Some struggles are "intrapersonal"—they are all challenges that we wrestle over within ourselves		

Table 1 (continued)

Domain	Question	Probe	Toolbox
	If you can think back to before _____ was born, can you tell me what you were expecting or hoping for with this birth and child?	Probe for follow-up if you hear any unmet expectations or loss of hope	
	What was it like for you when you learned _____ has CF?	Listen for story Probe: Where was God in this for you? Probe: Where was God absent for you?	
	Taking care of a child with CF takes a lot of time, and energy: Where do you get the strength to get through everything?	If faith/God/spiritual beliefs are not named, probe for any role of spirituality in coping If faith/God/spirituality is named, probe for a time whether there was ever a time that was not the case and how it changed	
	How much control do you think you have over _____'s CF—both the disease and the daily treatments and nutrition guidelines?	Probe for how stressful it is (or is not) to complete daily treatments and follow nutrition guidelines	
	When it comes to solving problems or dealing with a stressor, people view how they work with God differently. When you think of taking care of your child's CF, and completing the daily treatments and nutrition recommendations, do you see yourself more Working with God as a partner, OR Doing everything you can leaving the rest up to God, OR Trying to accomplish everything required without God's help?	If coping style is Active Surrender or Self- directed, probe for willingness to discuss alternatives (e.g., Collaborative)	Affirm Collaborative spiritual coping as an effective means for things which are under the person's control (e.g., completing airway clearance treatments) Active Surrender spiritual coping most effective for situations that are beyond a person's control (e.g., disease progression) and less useful for situations within one's control. Consider reading and discussing the "Serenity Prayer" as means of active surrender Self-directed spiritual coping has been associated with poorer mental health outcomes among persons with CF Affirm use as effective for things that are under one's control

Table 1 (continued)

Domain	Question	Probe	Toolbox
	If you think about _____'s body, can you think of three words that you would use to describe it? Some parents see a large difference between what is physical and what is not. If I ask you to think about _____'s spirit—can you think of three words that describe their spirit—or are they the same words as describe their body?	Probe for: 1. Ways the word relates to child's body; 2. are there three spiritual words that you think might describe it also? (if needed, add, some people have said things like miraculous, a gift, a free spirit, beautiful) Probe for extent to which spirit is affected or unaffected by CF	
Conclusion	This is the end of our first phone conversation. We've covered a lot of topics today. How are you feeling? Thank you very much for talking with me. I look forward to our next call, when we will talk more about spiritual struggles that involve other people. Good-bye	If anxiety, discomfort, anger, seem high, de-escalate and refer to PI or others if needed. Offer other external supports as indicated	
Intervention call #2			
Review of last call	Hello! This is *N.* from the GuideSS Study calling for our second conversation. Is this still a good time for you? Last call we focused on struggles that happened mostly inside your own heart and mind. You specifically mentioned, [summarize in 1–3 sentences]. I'm wondering if anything more has occurred to you since we spoke last?	If "yes" probe for story and meaning	
	This call we will focus mostly on struggles that happen between people—perhaps members of the family, or between you and friends, or with social or other groups including a congregation if you belong to one Do you have any questions before we begin?	If "yes" respond to question if able or refer to PI for resolution	

Table 1 (continued)

Domain	Question	Probe	Toolbox
Interpersonal struggles	Some parents have told us about being afraid for their child to be around other groups of people, for fear of catching bacteria or viruses. Is that something that has happened with you?	If "yes," invite story. Probe: has it affected going to your congregation? (may say "We have had some parents tell us that they take turns going at different hours, or that they go early and wipe down the seats with sani-wipes" Probe: has this changed your ideas about the congregation members, or God? (if yes, probe for meaning)	Limited problem-solving related to decreased congregational participation due to infection control concerns May mention research finding that parents of children with CF reported higher congregational support than parents of children without a chronic disease, and pose the question of how they might be a resource to other congregants about how to provide spiritual/emotional support (move from care-receiver to "coach")
	Have you ever felt like people treated you or _____ differently because of their CF?	If "yes" probe for story Probe: Some parents have told us how it makes them feel when people look at them while their child is coughing Probe: do you feel that there is any stigma that goes with having a child who has CF? If "yes" probe for story and meaning	
	Some parents have felt abandoned by people or groups they were close to, or who didn't act the way they were expected to. Has anything like this happened to you?	If "yes" probe for story and meaning	
Conclusion	This is the end of our second phone conversation. We've covered a lot of topics today. How are you feeling? Thank you very much for talking with me. I look forward to our next call, when we will talk more about spiritual struggles that involve other people. Good-bye	If anxiety, discomfort, anger, seem high, de-escalate and refer to PI or others if needed. Offer other external supports as indicated	
Intervention call #3			

Table 1 (continued)

Domain	Question	Probe	Toolbox
Review of last call	Hello! This is *N.* from the GuideSS Study calling for our third conversation. Is this still a good time for you? Last call we focused on struggles that happened mostly between you and other people. You specifically mentioned, [summarize in 1–3 sentences]. I'm wondering if anything more has occurred to you since we spoke last?	If "yes" probe for story and meaning	
	This call we will focus mostly on struggles that happen between you and God or your Higher Power Do you have any questions before we begin?	If "yes" respond to question if able or refer to PI for resolution	
Divine struggles	What are you dreams and goals for _____?	Probe: what would you like to see her/him doing in 5 years? 10 years? 15 years? Probe: what do you see as obstacles or barriers for _____ reaching those goals?	Limited problem-solving of barriers (if extended, refer to CF psychosocial team)
	Different faith groups have different levels of tolerance for questioning what one believes, or even for questioning God Can you tell me a little about your way of believing and how you feel to question faith?	If there is little freedom to question, probe: What have you seen happen when you don't tell someone you're angry with them? What do you suppose would happen if you were to question your faith or God? Or, what is the risk of questioning?	Some Christians may have greater tolerance for asking questions of "Jesus" rather than "God." Draw parallels of relationship between human and Divine, explore how they deal with anger in human relationships Draw parallels of human development: just as our bodies and minds are different as adults than as children, so our spirit develops and so old ways of believing sometimes do not help us anymore, or don't explain the world to us anymore. Having a child with CF is a significant life event, and it's not surprising that the way we think about God might change Normalize reactions of "I thought God would help me" (and similar) as signs of normal growth and help participant articulate new ideas

Table 1 (continued)

Domain	Question	Probe	Toolbox
	Has your experience of parenting a child with CF led you to re-think your ideas about who God is or how God acts or how God feels about you?	Where do you see God in your life now? Where is God absent in your life now? Probe for why and how the shift in beliefs occurred (process > content)	Help articulate places, activities, relationships that are special, meaningful, or help people feel connected inside themselves?
	Many parents have described hearing or saying statements like "God doesn't give you more than you can handle." Have you heard or said things like this?	What does that statement mean? What do you hear (trite, unhelpful, comforting, empowering)? Do you know where it comes from? If appropriate, may add, "some parents turn the words around so that it comes out, "Since God gave me this, God must think I can handle it." for them it becomes a statement that gives them the power to do all the CF treatments and parenting that they have to do. May probe for other ordinary theologies or "God talk"	In what ways does "God talk" preserve the myth that God is, despite appearances to the contrary, still in control? Probe for alternative control myths and or willingness to reframe control myths differently
	Since newborn genetic screening began, most parents had no idea they were carriers for the CF gene until their child was born. Many of them have used the word "devastated" to describe how they felt back then. Some of them felt… Angry at God Punished by God Does this describe how you felt then or how you feel now?	If yes, probe for: 1. Meaning and story 2. Is it allowable to be angry at God? Resent God for punishing you, etc.? 3. If there was a shift in belief, how did that shift happen?	May remind participants of passages from Scriptures in which people expressed anger towards God May suggest writing a letter to God expressing feelings. Note that written expression of prayers has been shown to improve mood
	Some parents have said that their child's CF is the work of the devil? Is that something that you have thought or struggled with?	If "yes" probe for story and meaning Probe for participant's experience of God and how this belief matches the God they believe in	How do you "fight back" against the devil? What do you need to succeed in doing this? Engage in limited problem-solving, e.g., does participant pray; presence of significant others praying also; use of congregation, if any: engage community to end isolation

Table 1 (continued)

Domain	Question	Probe	Toolbox
	Some parents have pleaded with God "to make things turn out okay" is that something you do?	If "yes" probe for story and meaning. Probe for how much control they feel they have over their child's CF	Pleading may be a very good form of spiritual coping when the situation is beyond one's control. To the extent that CF is in their control, other forms of spiritual coping may be better. Probe for use of, or willingness to discuss Collaborative, Active Surrender, or Self-directed forms of spiritual coping
Conclusion	We have covered a lot of ground today, and in our last two conversations. Before we bring this to a close, do you have any questions?	If "yes" respond as able or refer to PI for resolution	
	Some of the topics for today might have been difficult to think about or talk about. Can you tell me what you're feeling right now?	Probe for feeling words: glad, mad, sad, or scared. Respond as appropriate to particularly strong emotions	
	Thank you very, very much for talking with me today and for participating in the trial of these phone conversations with parents. We deeply appreciate your time and your honesty. Thank you		

Measures

Spiritual Struggle and Spiritual Coping

The Brief RCOPE (Pargament et al. 2000) was used to quantify spiritual coping. The Brief RCOPE is a well-established measure with good psychometric properties that has been used with validity in other studies with parents of children with CF (Grossoehme et al. 2012a; Grossoehme et al. 2015). Responses are scored on a Likert-style scale from 0 to 3 for responses ranging from using a particular coping style "never" to "a great deal." The negative subscale was used both to screen for spiritual struggle to determine eligibility, and as a secondary outcome variable. We followed Fitchett et al. (2014) in classifying a participant as screening positive for SS if they answered any of the negative spiritual coping items with a value of 1 or higher.

Depressive Symptoms

The CES-D (Radloff 1977) was used to quantify depressive symptoms. This scale has 20 items, scored 0–3, indicating the extent to which the respondent has experienced a symptom in the past week. Example items include, "I felt that everything I did was an effort" and "I enjoyed life."

Feasibility and Acceptability

The feasibility of GuideSS_CF was defined as the ratio of attempted to completed study calls. GuideSS_CF's acceptability to both participants and the chaplain interventionists was important. Acceptability was measured as the ratio of eligible persons approached to those enrolled. Data relating to GuideSS_CF's acceptability to chaplain interventionists were obtained by cognitive interviews at the end of the study.

Fidelity

Study calls were recorded by study staff. Fidelity was assessed by randomly auditing 50% of the transcribed intervention calls using the intervention manual as a checklist of interventionist behaviors to be demonstrated. Study staff scored each question as "asked" or "not asked," and fidelity was calculated as the percentage of scripted questions actually asked.

Adherence

Adherence to prescribed AC and pulmozyme therapies was calculated as the ratio of completed treatments to prescribed. The number of prescribed treatments was obtained by chart review for each participant's child. The number of completed treatments was obtained using the Daily Phone Diary (DPD) (Quittner and Opipari 1994). The DPD uses a cued recall system which leads participants through naming

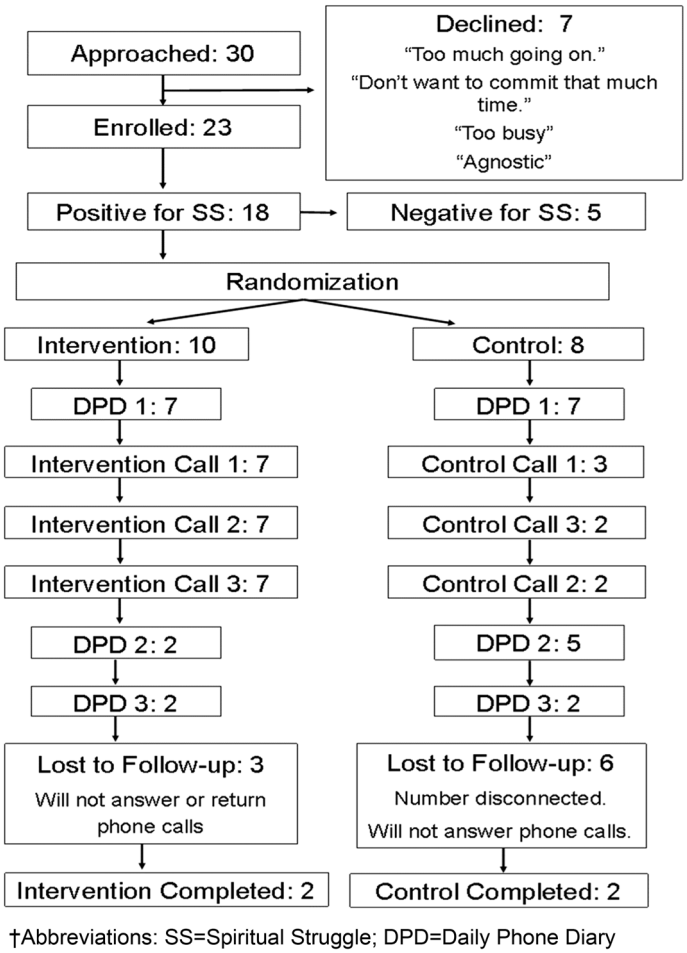

Fig. 1 Enrollment and study process flow sheet. *SS* spiritual struggle and *DPD* Daily Phone Diary

all activities during the previous 24 h which lasted more than 5 min, theoretically blinding them to the behavior of interest. Two DPD calls were scheduled to occur over a 2-week period following enrollment (and prior to receiving either the intervention or control calls) and two DPD calls at 1, 3, and 6 months after the final study call. The DPD has been used extensively with parents of children with CF (Grossoehme et al. 2015; Modi et al. 2006; Modi and Quittner 2006) as well as in other populations (Modi 2009; Wiener et al. 2004). The DPD has demonstrated psychometrics including reliability (Quittner et al. 1998; Quittner and Opipari 1994) and has shown convergent validity with electronic measures (Modi et al. 2006).

Table 2 Summaries of secondary outcomes over follow-up

Measure	Baseline			T1 (1-month post-intervention)			T2 (3-month post-intervention)		
	All	Intervention	Control	All	Intervention	Control	All	Intervention	Control
Positive spiritual coping									
M (*SD*)	12.3 (5.7)	11.6 (4.9)	12.9 (6.3)	10.3 (6.6)	9.2 (5.4)	13.0 (11.3)	12.3 (5.5)	15.0 (N/A)	11.0 (7.1)
Mdn (range)	14.0 (0–21)	11.5 (0–17)	14.0 (1–21)	11.0 (0–21)	11 (0–14)	13.0 (5–21)	15.0 (6–16)	15.0 (15)	11.0 (6–16)
Negative spiritual coping									
M (*SD*)	6.9 (6.2)	8.0 (4.9)	6.0 (7.0)	1.9 (2.0)	1.0 (1.4)	4.0 (1.4)	4.0 (5.4)	1.5 (0.7)	6.5 (7.8)
Mdn (range)	5.0 (0–17)	6.0 (3–17)	2.0 (0–17)	2.0 (0–5)	0 (0–3)	4.0 (3–5)	1.5 (1–12)	1.5 (1–2)	6.5 (1–12)
Depressive symptoms									
M (*SD*)	25.7 (12.8)	15.2 (9.9)	30.1 (9.2)	14.1 (8.9)	14.2 (9.9)	11.5 (7.8)	13 (7.5)	6 (0)	16.5 (6.4)
Mdn (range)	25 (5–53)	14 (6–29)	30.5 (20–42)	14 (6–29)	14 (6–29)	11.5 (6–17)	12 (6–21)	6 (0)	16.5 (12–21)
Adherence to prescribed airway clearance									
M (*SD*)	0.45 (0.32)	0.33 (0.3)	0.75 (0.00)	0.56 (0.44)	0.53 (0.30)	0.63 (0.88)	0.25 (0.50)	0.0 (0.0)	0.5 (0.71)
Mdn (range)	0.5 (0–1)	0.25 (0–1)	0.75 (1)	0.50 (0–1.25)	0.50 (0.17–1)	0.63 (0–1.25)	0.0 (0–1)	0.0 (0)	0.5 (0–1)
Adherence to prescribed medication (dornase alfa)									
M (*SD*)	0.07 (0.12)	0.10 (0.14)	0.00 (0.0)	0.25 (0.56)	0.35 (0.65)	0.0 (0)	0.33 (0.58)		0.5 (0.71)
Mdn (range)	0.0 (0–0.25)	0.0 (0–0.25)	0.0 (0)	0.0 (0–1.5)	0.0 (0–1.5)	0.0 (0)	0.0 (0–1.0)		0.5 (0–1)
Body mass index percentile									
M (*SD*)	44.5 (27.8)	44.2 (32.3)	45.5 (13.4)	47.6 (26.1)	53.2 (29.4)	33.5 (9.2)	40.0 (N/A)		40 (N/A)
Mdn (range)	43.5 (1–92)	43.5 (1–92)	45.5 (36–55)	51.0 (10–92)	51.0 (10–92)	33.5 (27–40)	40.0 (40.0)		40 (40)

Data are summarized as mean and standard deviation, labeled *M* and *SD*, and median and range, labeled Mdn and range. Measures were summarized over baseline, 1 month later at timepoint 1 (T1) and 3 months after at timepoint 2 (T2)

Table 3 Estimated intervention effects on secondary outcomes

				Estimate	*SE*	Significance (*p*)
Positive spiritual coping	12.9	0.97	< 0.001	12.9	0.96	< 0.001
Negative spiritual coping	3.73	0.62	0.008	3.73	0.62	0.008
Depressive symptoms	20.3	2.74	< 0.001	23.3	2.74	< 0.001
Adherence (airway clearance)	0.50	0.09	0.005	0.48	0.11	0.022

Each estimate and standard error (*SE*) represents effect of intervention averaged over time

Analysis

Analysis of cognitive interviews was done by thematic analysis. Descriptive statistics were calculated for all scale variables from questionnaire data. Linear mixed models were used to evaluate differences between the intervention and control groups over time with respect to positive spiritual coping, negative spiritual coping (which was used to operationalize SS), depressive symptoms, and adherence to prescribed airway clearance treatments for CF. The model included a random intercept to account for within-patient correlation from repeated measurements over time; the interaction between group and time was evaluated to examine differences in mean trajectory per group. Efficacy was estimated using two established analytic approaches (Ellenberg 1996). Patients with all available data (regardless of protocol compliance) were used to estimate effects. Given the size of the sample which completed at least one post-intervention questionnaire and DPD set ("as treated"), an intent-to-treat analysis was also conducted to minimize bias due to missing data and to gain additional precision for estimating effect sizes. SPSS version 23 was used for the analyses (IBM SPSS Statistics for Windows 2015).

Results

A total of 30 eligible parents were approached; 23 enrolled (77% enrollment rate) and were screened for SS. Of those who were screened, 18 (78%) were positive (78% female) and continued participation (see Fig. 1). Descriptive statistics are shown in Table 2. The mean (*SD*) duration of intervention calls was 37.8 (17.1) minutes and for control calls was 29.9 (5.8) minutes, and this difference was statistically significant ($t = 8.73$; $df = 1$; $p = 0.02$).

Interventionist fidelity was 95%. GuideSS_CF's feasibility, defined as the ratio of attempted to completed calls, was considered to be good, with a mean number of 1.7 calls required to complete one intervention call and 2.7 calls required to complete one control call. Reasons for not answering scheduled calls included participant illness and death in the family, in addition to call attempts that simply went unanswered. Feasibility for the chaplains' availability to make the selected call was very good. Only one call was rescheduled due to an emergent event in the chaplain's clinical area occurring at the time of the scheduled intervention call. GuideSS_CF

was acceptable to participants; 100% of those who began the intervention calls completed all three calls. However, some participants expressed mild surprise that they screened positive for SS. GuideSS_CF was highly acceptable to the chaplain interventionists. One statement from the post-intervention cognitive interviews was, "Doing the intervention calls has been one of my favorite activities these past few months. Thanks for the opportunity!"

The control calls were shorter in duration than intervention calls. There was notable attrition (63%) after enrollment and prior to completing the first control call. These factors suggest that the control calls were not acceptable to the participants assigned to the control condition. The mean number of attempted telephone calls required to complete the first intervention call was 5.7; for the second control call, one attempt was required to complete the call, and for the third control call, two attempts were required to complete the call. The number of attempts required to complete the first control call suggests that telephone contact may not be a feasible method to reach some participants. Fidelity to the control call script was 100%.

The secondary aim of the study was to test for between-group differences on the outcome variables. The results of linear mixed modeling, for both as treated and intent to treat, are shown in Table 3. Based on exploratory analysis, there was higher variation in negative spiritual coping values at the baseline timepoint. From T1 to T2, the intervention group tended to maintain lower negative spiritual coping scores, on average, over follow-up; however, persons in the control condition appeared to increase negative spiritual coping scores over follow-up as well as exhibit increased variability. There were no significant interactions between treatment arm and time. There were no statistically significant interaction effects between time and treatment arm (control or intervention). The potential effect size from baseline to T1 was large (Cohen's $d=4.04$; $r=0.89$) and from baseline to T2 (Cohen's $d=4.04$; $r=0.9$). The level of depressive symptoms also decreased in both groups and was below the usual cutoff value for clinically significant symptoms (16). The use of positive spiritual coping increased from baseline to the second post-intervention timepoint in the intervention group. Adherence to daily airway clearance improved in both groups.

Post-study cognitive interviews with chaplain interventionists also identified potential areas for revision prior to subsequent trials. For example, interventionists discussed including an incentive for participants following each phone call to improve participation rates, and they also recommended shortening the length of time between intervention calls to improve study adherence. While study staff concluded that three intervention phone calls were a sufficient amount, phone calls were interruptions in the participants' environments. To combat this, revisions would include either an in-person interview, use of the telehealth center, or Skype calls without using video. During some phone calls, participants stated information that brought up safety concerns. For instance, one participant mentioned coping with alcoholism and prior suicidal ideation. Other participants noted that they were having trouble completing some prescribed treatments. Revisions of this study should also include a safety plan to successfully work with these disclosures. A safety plan was in place prior to study start to combat current feelings of suicidal and/or self-injurious ideation. Chaplain interventionists suggested broadening the safety plan on subsequent trials to include disclosures around unhealthy alcohol or other substance

abuse. This safety plan may involve the patient's medical team or a staff psychologist or social worker if necessary.

Two versions of scoring the negative subscale of the Brief RCOPE have been proposed when using it to screen for spiritual struggle. The broader criteria were used for this study. Use of the narrower criteria may be helpful to increase the likelihood of enrolling only those whose screening results are true positives. Disclosure of a participant's actual responses to RCOPE items to the interventionist is suggested as a revision to enable personalization of the intervention. Domains addressing potential tension between the Christian belief in the body as created well by God, and the reality of living with a genetic, life-shortening disease, were difficult for some parents to understand and respond to. The interview guide may not have adequately addressed these items. Finally, delivery of the intervention by telehealth rather than telephone was raised. Telehealth delivery could be an improvement when hearing only a disembodied voice and allow for universal communication. There is evidence suggesting that telephone conversations are preferable when the topic is sensitive and the participant may feel pressure to provide socially desirable responses.

Discussion

We present the results showing the feasibility and acceptability of a chaplain-delivered intervention delivered via semi-structured telephone calls in a sample of parents of children who have CF. Although chaplaincy intervention by telephone is novel, our results suggest it is both feasible and acceptable to carry out while retaining ongoing inpatient chaplaincy care demands. Our results suggest a large effect size for decreasing spiritual struggle 6-month post-intervention may be obtained using this intervention. Addressing parental SS is important in pediatrics because their SSs are associated with their adherence to their child's chronic disease treatments, which are the only means of slowing disease progression.

The acceptability and feasibility of chaplain intervention delivered by telephone suggest potential new avenues for intervention design and prototyping. Parents and legal guardians of pediatric patients may be unavailable to meet with a chaplain due to their lack of available time away from work due or due to the chaplain's working hours. Outpatient clinics, where children with chronic disease receive most of their care, are not feasible places to deliver a multi-session chaplain intervention. A telephone-based intervention such as GuideSS_CF may be a viable model for further development. Both parent participants and chaplains found the intervention acceptable. The lack of conflicts between scheduled telephone calls, and spontaneous or emergent needs on the chaplains' inpatient units, was an important factor in both feasibility and acceptability for the chaplain interventionists.

Our results include effect size estimation and precision analyses for four outcome variables, in order to plan sample size for an adequately powered clinical trial. Although findings are preliminary with regard to efficacy, we found large overall variability at the baseline timepoint. During the remainder of follow-up, persons in the control condition exhibited higher variability, while intervention participants had steadier profiles with regard to negative spiritual coping. It is

possible that application of this particular intervention stabilizes the extent of spiritual struggle when operationalized as negative spiritual coping. Additional testing is needed to confirm these observations. The potentially large effect size and relatively small precision to be expected from delivering GuideSS_CF suggest that the next step of testing its efficacy is warranted. An efficacy trial's goal is to determine whether there is any benefit to receiving the intervention under controlled, ideal conditions; the effectiveness of an intervention, which is a subsequent step, determines whether there is any benefit to receiving the intervention under real-world conditions. At this stage, it is not possible to say whether GuideSS_CF is efficacious, much less whether it is effective. That said, our study establishes that it is feasible to deliver and acceptable to participants and chaplains, and there was a large effect size in decreased SS among the intervention group. GuideSS_CF is a potentially efficacious intervention and may develop into a revised version that would be an appropriate stewardship of the chaplain's time.

Areas for revision prior to subsequent trials should also include adolescents. Typically, patients with CF begin their own treatments during early adolescence and some parents had difficulty answering some questions. Participants of the revised study would include parents of CF patients ages younger than 13 and adolescents diagnosed with CF ages 14–18. The inclusion of these criteria would add a third arm to the study. Participants would be randomized into three arms instead of two and included in the attention-control arm, the intervention with a chaplain arm, or the added arm of intervention with a social worker. With these revisions, it will be easier to schedule phone calls, and the data will show SS and coping in adolescents as well as their parents and provide a better understanding about SS and treatment adherence in families experiencing CF.

This study has the following limitations. All persons who were enrolled in the intervention arm completed the three intervention calls. However, only 20% of those enrolled in the intervention arm participated in the study through the final Daily Phone Diary phone call. The intervention completion rate is indicative of acceptability; the full participation of all enrollees through the final Daily Phone Diary call suggests potential issues with feasibility and/or acceptability of the study design. These should be addressed in future efforts to replicate or extend this study. The control calls were unacceptable to some participants leading to attrition. Although the primary outcomes in this study were feasibility and acceptability, a more psychological control condition would also have permitted a more robust comparison between the two groups. Future revisions should include more acceptable content for the control condition; providing incentives for both control and intervention groups might improve this as well. The sample of participants came from a single CF Center and may not be generalizable across the country, particularly to regions with a relatively low level of spirituality or religiosity. Nonetheless, meaningful conclusions can be drawn. Chaplaincy intervention for SS is acceptable to both parents and chaplains. Telephone delivery of a 3-session semi-structured intervention is feasible and does not conflict with chaplains' traditional effort on an inpatient unit. Chaplains can follow a semi-structured interview guide with high fidelity while retaining the flexibility of using their skills to ask additional probing questions. GuideSS_CF is a potentially

efficacious intervention to decrease parental spiritual struggles. Future research should test the efficacy of a revised version of GuideSS_CF based upon findings from this study.

Acknowledgements The authors gratefully acknowledge the partial funding from the institution's Research Innovation and Progress Award, the Division of Pulmonary Medicine and the Department of Pastoral Care.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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