



HHS Public Access

Author manuscript

J Health Care Chaplain. Author manuscript; available in PMC 2016 January 01.

Published in final edited form as:

J Health Care Chaplain. 2015 ; 21(2): 76–90. doi:10.1080/08854726.2015.1015365.

Testing the Feasibility and Acceptability of a Chaplaincy Intervention to Improving Treatment Attitudes and Self-Efficacy of Adolescents With Cystic Fibrosis: A Pilot Study

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Abstract

Religious factors are known to contribute to treatment adherence in different patient populations, and religious coping has been found to be particularly important to adolescents dealing with chronic diseases. Adherence to prescribed treatments slows disease progression and contributes to desirable outcomes in most patients, and, therefore, adherence-promoting interventions provided by chaplains could be beneficial to various patient populations. The current article describes a pilot study to test the feasibility of a theoretically and empirically based chaplain intervention to promote treatment adherence for adolescents with CF. Cognitive interviews were conducted 24 with adolescents with CF, and content analysis was used to identify themes, which informed revision of the intervention protocol. The authors thought that presenting the methods and results of this pilot study would be helpful for chaplains who want to conduct intervention research. The results indicated that the proposed intervention was acceptable and feasible to deliver in hard copy or an electronic platform.

Keywords

adherence; adolescents; cystic fibrosis; research social network; spirituality

Religious factors are known to contribute to treatment adherence in different patient populations, such as patients with HIV (Parsons, Cruise, Davenport, & Jones, 2006),

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congestive heart failure (Park, Moehl, Fenster, Suresh, & Bliss, 2008), and hypertension (Lewis, 2011). Numerous studies have shown that adolescents' religious and spiritual beliefs are important to them (Cotton, Zebracki, Rosenthal, Tsevat, & Drotar, 2006), and that these beliefs are used to cope with chronic diseases and their treatments (Benore, Pargament, & Pendleton, 2008; Cotton et al., 2009; Cotton, Grossoehme, Bignall, & Weekes-Kanu, 2014; Ragsdale, Hegner, Mueller, & Davies, 2014). Beliefs are associated with pro-healthy behaviors, including exerting a protective effect against substance use (Ritt-Olson et al., 2004), physical activity (Rachele, Cuddihy, Washington, & McPhail, 2014) and treatment adherence (Grossoehme, Szczesniak, Dodd, Dimitriou, & Seid, 2013).

Cystic fibrosis (CF) is the most common genetic disease among Caucasians, and research has found that genetic mutations lead to mucous buildup in the lungs, causing pulmonary infections, and poorer lung function. The daily treatment burden for CF is complex and time-consuming, typically consisting of twice-daily airway clearance therapy, nebulized medications, and may include pancreatic enzyme replacement with all meals and snacks, and insulin if diabetic. Although adherence to treatment is the only means of slowing disease progression, adherence to treatment is poor among adolescents, with adherence rates vary between 36 and 90% (Modi et al., 2006).

A study of teens found that religion is associated with better CF treatment adherence (Grossoehme, Szczesniak, Dodd, et al., 2013). For example, lower levels of negative religious coping and higher regard for the sacred qualities of the body both were associated with higher airway clearance treatment utility. Therefore, it seems reasonable that pro-adherence interventions should include religious interventions, and that the interventions should be delivered by chaplains. The present article describes a study to test the feasibility of such a chaplain intervention.

Theoretical Background

Behavioral Model

Fishbein and Ajzen (2010) published the “theory of reasoned action” (TRA), which demonstrated that a person's behavior follows from their intention to behave in a certain way (Fishbein & Ajzen, 2010). The adherence intention of individuals is determined by three factors: their attitudes regarding the behavior, their perception of normative expectations for them to behave that way, and their perception that they have the ability to control their behavior. The TRA model has been used extensively to predict health-related behaviors (see Figure 1), including CF (Grossoehme, Opipari-Arrigan, VanDyke, Thurmond, & Seid, 2012).

Self-Expression

All behavior (such as treatment routines) has meaning, meanings are expressed as narratives and can induce behavior (White & Epston, 1990). Some behaviors are stressful (e.g., adherence to treatment), and the ability to problem-solve is reduced under stress (Ames et al., 2007). Writing interventions have been found to be a useful way to reduce stress by allowing individuals to express their own narratives and reframe narratives to gain mastery over their meaning, which can lead to greater self-efficacy.

Writing interventions have been found to be associated with health outcomes, including: the number of health care visits (Campbell & Pennebaker, 2003; Creswell et al., 2007); the success of smoking cessation programs (Ames et al., 2007); decreased viral load in persons with HIV (Petrie, Fontanilla, Thomas, Booth, & Pennebaker, 2004); perceived stress and depressive symptoms (Danoff-Burg, Mosher, Seawell, & Agee, 2010), and anxiety and depression (Graf, Gaudiano, & Geller, 2008).

Writing in response to prompts is developmentally appropriate; adolescents will understand the same prompt in different ways (concrete, pre-abstract, abstract thinking). These prompts are written at a 5th-grade level. The prompts were dictated by significant findings in a previous study (Grossoehme, Szczesniak, Dodd, et al., 2013).

Religious Constructs Relating to Adherence

Mahoney, who described the spiritual construct of “sanctification” in which a role (e.g., parenting) or a behavior (adherence) is imbued with spiritual significance, demonstrated that sanctification is associated with pro-healthy behaviors (Mahoney, 2005; Mahoney et al., 1999). Body sanctification has two related sub-constructs: Manifestation of God in the body, which taps into religious constructs (e.g., “My body is created in God's image”); and Sacred Qualities of the body, which taps spiritual constructs not associated with a monotheistic deity (e.g., agreement with the extent to which one sees their body as “blessed” or “miraculous.”). Sanctification has been related to treatment adherence in CF by both parents and adolescents (Grossoehme et al., 2012; Grossoehme, Szczesniak, Dimitriou, et al., 2013; Grossoehme, Szczesniak, Dodd, et al., 2013; Grossoehme, VanDyke, & Seid, 2008). Many studies have reported that negative spiritual coping, (often measured by the Brief R-COPE) (Pargament, Koenig, & Perez, 2000), is associated with poor physical and mental health. Among parents of children with CF, negative spiritual coping has been associated with poorer adherence (Grossoehme, Szczesniak, Dimitriou, et al., 2013) and an increasing decline in pulmonary function among adolescents who have CF (Grossoehme, Szczesniak, McPhail, & Seid, 2013). Therefore, body sanctification and negative spiritual coping were integrated into writing prompts described in the following sections.

Methods

Participants

The CF Center at that medical center provides care for approximately 280 children and youth with CF, a total of 91 of whom were eligible to participate in this study based on their age (11–19 years old), having a confirmed CF diagnosis, and having no cognitive impairments that would limit their ability to participate in the interview. A list of eligible adolescents was obtained from the CF Center's database and they were approached by study staff at an outpatient clinic appointment or during an inpatient admission. At that time, the study was described in detail, questions were answered, and a time was scheduled to obtain written informed consent along with completion of the interview if the adolescent chose to participate. The parent or legal guardian completed the informed consent process prior to the study, while the adolescent completed an assent document. Participants who were 18 or 19 years old at enrollment completed the informed consent process. The study was approved by

the institutional review board at the 525-bed academic pediatric medical center where the study was carried out.

Procedure

A semi-structured cognitive interview guide was developed for this study, during which the participants were shown the instructions and each prompt of the intervention one at a time. The interview guide is presented in the Appendix. For each item, the participant was asked to describe in their own words what was being asked, and whether or not any of the wording was unclear. If the wording was considered unclear, the participant was invited to suggest an alternative wording that was clearer to them. Verbal probing was used to elicit their understanding of the intent of the question. The final questions in the interview explored feasibility and acceptability of the intervention. All interviews were audio recorded and transcribed for analysis.

Analysis

Participant responses were coded for gender and age, and content analysis was used to identify themes in the responses. Descriptive statistics were obtained using SPSS 21.0 for acceptability and feasibility items which generated a numerical response.

Results

A total of 24 adolescents (50% female) ages 11–19 years (median age 14 years) with mild CF disease completed cognitive interviews for this study. In general, 11- and 12-year old female participants and males across the age range found the initial wording of the instructions and some of the prompts to be less clear than the 13–19 year old females. The main reasons given for perceived lack of clarity were the use of vague terms (e.g., “electronic device” rather than “cell phone”) and the order in which information was presented. For example, the instructions initially stated that persons using the intervention would have 2 weeks to complete six responses. Participant feedback was that the instructions easier to understand if they were given the task (respond to each of the six prompts) before being given the timeframe (over the next 2 weeks).

Participants found having a choice of prompts (an emotional and a future-oriented) to be helpful, and were evenly divided on which option they would select. Comments included, “... some people don't know what my life is about with CF so I like to tell people what CF is ... a lot of people worry ‘cause they don't know what I go through” and “...sometimes you don't want to talk about really emotional things that have happened.” The third prompt presented a list of words taken from the Body Sanctification Scale and asked for a response. A few of the words were difficult for some to understand (e.g., spirit-filled); however, the decision was made not to change them since they came from a validated instrument. Participants who described themselves as not religious were not offended by the questions and indicated that they would still respond to them. One 15-year old male said, “...I have people who are religious and I think their religion has affected how they act towards me, they pray for me and I know they've definitely gone out of their way to do things for me ...I wouldn't do it for my own reactions but others' ...” Several commented that the prompts

allowed them to, "...think about how blessed your body is and how it comes with CF" (14-year old female) and, "you should be blessed that you have CF" (13-year old male). In the fourth prompt, the initial excerpt from Psalm 139:12–15, which was taken from the Book of Common Prayer (Book of Common Prayer, 1979) was found to be difficult to understand by some participants. In the revised intervention (available upon request from the corresponding author), the quotation has been replaced by an excerpt from *The Message* as being a more readily understandable translation (Peterson, 2005). The fifth prompt (attitude toward the value of the daily treatment regimen) led to several comments that participants preferred the emotionally-oriented prompt because, "you can tell people what it's like to have CF and what I feel like to get treatment...I like sharing what it's like and what CF means..." (14-year old female). One 15-year old male participant thought that both the emotional- and future-oriented prompts were clear, and rephrased the future-oriented prompt as, "It's asking with your CF how you're going to control it so that you do what you want." This restatement of the prompt was integrated into the revised intervention presented below. The sixth prompt (negative religious coping) did not deter non-religious participants. One 16-year old female said, "I'm not religious but I feel that'd be easier to answer (the emotionally-oriented prompt about feeling punished by God) 'cause at some point of my life I feel like I have thought about that in relation to having CF, but the second one is more straight forwardly religious." Males felt the final prompts were understandable and were willing to answer them. One male encouraged a revision (which was adopted) to the future-oriented option so that it focused on being "an adult male" (rather than an adult male with CF) as, "...there's more to me than just the disease." Two participants expressed some discomfort over thinking about the future in these terms, and the possibility of being infertile (a common co-morbidity for males with CF). However, as one 15-year old male said, "I think you did a really good job of not directly asking how do you feel about not being able to have children... I think it's fine how it is." Female participants also suggested revision of the final prompt so that they could respond as an adult women and not defined by the disease ("... I don't want to be seen as just a girl with CF, I want to be seen as just a regular girl"; age 12 years).

During the cognitive interviews, participants had to be refocused to responding to the interviewer's prompt rather than attempting to respond to the intervention's prompt; their eagerness to answer the question was taken to be a sign of the intervention's acceptability to the participants. The participants indicated that they would be willing to participate in using the intervention in the future, with a mean score of 7.6 (SD 1.9) on a scale of 1–10. When asked which discipline was most appropriate to introduce them to the intervention in the outpatient clinic, the most common response was their pulmonologist (8/24; 33%). Explanatory comments related to this were, "... because she's the reason I'm alive. I owe a lot to that woman so anything she says is law" (15-year old male) and "... because CF kids have been with the pulmonologist forever so they'd be more comfortable with them". Although only one adolescent indicated that they would like to learn of this intervention from the chaplain, 15 of 24 (63%) indicated that anyone from chaplaincy, social work, psychology or their pulmonologist would be acceptable. Adolescents strongly preferred writing in response to the prompts ($n = 21$) rather than a video response ($n = 3$). Their preference was to type responses to the prompts online, through a secure, internet platform

to be developed by the medical center's bioinformatics staff. Nearly all of the adolescents ($n = 20$) had access to a mobile phone (their own or their parents') and internet access ($n = 19$), which makes delivery of the intervention feasible. Alternatively, simple composition books could be provided and collected during outpatient clinic or study appointments. All participants said they would be most likely to participate in such an intervention if it could be done from home, and that they were most likely to respond to such prompts either "after school" or "in the evening." Given the choice of participating in such an intervention during an inpatient stay, most had no preference compared to participating from home. Two specifically stated they would prefer not to do it during an inpatient admission (e.g., "... inpatient is focused on me getting better"; 14-year old female). Taken together, these results support the acceptability and feasibility of this intervention for 11–19 year old adolescents with CF.

Discussion

The results of only a limited number of chaplaincy interventions have been published (Bay, Beckman, Trippi, Gunderman, & Terry, 2008; Iler, Obenshain, & Camac, 2001) and these articles did not detail how the intervention nor were developed. This article presents the steps undertaken to describe the theoretical basis, acceptability and feasibility of an intervention prototype as a model, which are two of the key steps outlined by Rounsaville and colleagues (Rounsaville, Carroll, & Onken, 2001) for the process of developing behavioral interventions.

Once an intervention prototype has been developed by chaplains, this study shows how cognitive interviews may be used to learn about its acceptability. The sample may be a convenient sample with a relatively small number of participants. The interview guide shows how the participants were asked about each aspect of the intervention prototype. This leads to revisions so that the intervention does what the chaplain-designer wants it to do, and to be readily understandable to the intended participant. An example is the revision which utilized a more understandable translation of Psalm 139. Stratifying participant responses by age and gender allowed the developers to see that the initial wording was difficult for younger participants to understand. The developers chose to revise the wording; an alternative would be to revise the intended age range for future use. The feasibility of an intervention may be tested by determining what factors would allow the intervention actually to be delivered. In this example, it was necessary to know if adolescents had access to a computer, tablet or smartphone. Information about acceptability was gained by inquiring about factors affecting participants' willingness to use the intervention. In this study, participants were directly asked how interested they would be; they were also asked if it would be more acceptable to respond to prompts using hard copy composition books, or uploading responses via electronic means.

Chaplains tacitly have underlying reasons (theories) for doing what they do clinically. A few published case studies have begun to explicitly articulate their theoretical foundations (Nolan, in press; Risk, 2013). Intervention design begins by setting down the theory by which the chaplain thinks that doing X , the result will be Y . Information gained from the cognitive interviews can be compared to the theoretical background. This could lead to a

revision of the intervention if feedback does not contradict the theory. Data contrary to the theoretical model may lead to the revision of the theory itself. The present study has two underlying theories, one of human behavior and one of self-expression. This allowed the developers to pinpoint a behavioral “target” (attitudes toward CF treatments) and a means of modifying it (through self-expression). At some level, by specifying a priori the theoretical basis for a chaplain to intervene with an adolescent, the actual intervention virtually suggested itself.

The results suggest that the intervention is acceptable to 11–19 year old adolescents with CF, is feasible to deliver and led to revision of the intervention prompts. The overwhelming preference for writing responses rather than a video-based response was surprising. The personal nature of the prompts and responses is such that online or social media options may be perceived as not sufficiently private.

This study, like all studies, has certain limitations. In the present study these include use of a convenience sample, which limits the generalizability of the results. Moreover, the sample was mainly composed of adolescents with mild disease and it is unclear how acceptable or feasible the intervention would be for adolescents with moderate or severe disease. The next step for the revised intervention is to complete the tasks in Stages 1b and II (efficacy testing) (Rounsaville et al., 2001). Pilot-testing this intervention with adolescents who have other chronic diseases requiring daily treatments (e.g., HIV, epilepsy, or asthma) would be helpful.

Acknowledgments

The authors acknowledge with appreciation the adolescents who participated in this study, the contributions of McKenzie Roedig and Sofia Newaz who performed data entry and assisted with data collection for this study, Diana Turov for her graphic design work, and medical writer J. Denise Wetzel for editing the manuscript.

Funding: Ms. Cheng's effort was funded by NIH/NHLBI grant 1T35HL113229-01 (PI: Hardie). Additional funding was also obtained through a Place Outcomes Research Award (PI: Grosseohme) from the James M. Anderson Center for Health Systems Excellence, and the Division of Pulmonary Medicine.

Appendix

Cognitive Interview Guide Used to Elicit Acceptability and Feasibility Data

| Domain | Question | Probe |
|--------------|--|---|
| Introduction | Thank you very much for participating in this interview. The purpose of this study is to understand if the questions we want to ask in a future study are relevant and/or important to adolescents, like you. We want to know what you think the question is asking as well if there different words we could use to make it clearer. Finally, we want to describe a future study to you, and ask you about ways to make it easier for adolescents, like yourself, to participate. These questions were created based on a previous study done here with people your age. These are the topics which seemed to help those adolescents get more of their airway clearance or nebulized medication treatments done every day. Before we get started, I want to let you know that you can stop this interview at any time and you can ask me questions at any time. | If anything is unclear, provide alternative wording to clarify for participant. Respond to all questions if able; otherwise refer them to the PI for follow-up. |

| Domain | Question | Probe |
|---------------|---|---|
| | What questions do you have for me before we begin? | |
| Feasibility | <p>Here are a set of instructions we would be giving for a future study. Please read them, and then tell me in your own words what you think they are telling you to do. Here is the first pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> <p>Here is the second pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> <p>Here is the third pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> <p>Here is the fourth pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> <p>Here is the fifth pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> <p>Here is the sixth pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> <p>Here is the seventh pair of questions we would be asking in a future study. Please read them, and then tell me in your own words what you think they are telling you to do.</p> <p>What would be your emotional response to these questions, such as you would be motivated to answer both/either? Unaffected by both/either? Or would you skip both/either?</p> | <p>Show “Instructions” from Draft Intervention Prompts.</p> <p>Show “Introduction-Icebreaker” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand?</p> <p>What other words can we use to make the questions easier to understand or read?</p> <p>Show “Network Centralization” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand? What other words can we use to make the questions easier to understand or read?</p> <p>Show “Sanctification” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand?</p> <p>What other words can we use to make the questions easier to understand or read?</p> <p>Show “Sanctification II” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand?</p> <p>What other words can we use to make the questions easier to understand or read?</p> <p>Show “Treatment Attitude” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand?</p> <p>What other words can we use to make the questions easier to understand or read?</p> <p>Show “Negative Spiritual Coping” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand?</p> <p>What other words can we use to make the questions easier to understand or read?</p> <p>Show “Gender” questions from Draft Intervention Prompts.</p> <p>Are the questions clear and easy to understand?</p> <p>What other words can we use to make the questions easier to understand or read?</p> |
| Acceptability | <p>In the future, when we are ready to offer this intervention to teenagers, who do you think the best person would be to describe it to teenagers—Your doctor (pulmonologist—someone like Dr. A., Dr. B., or Dr. C)?</p> <p>A psychologist (someone like Dr. D. who helps people talk about feelings)?</p> <p>A chaplain (someone like Chaplain E, who talks with people about spiritual and religious questions)?</p> <p>A social worker (someone like Ms. F or Ms. G who talks about feelings, coping and resources)?</p> | <p>Even if this isn't your idea of the best person to introduce this to you, would be okay if they did?</p> <p>Even if this isn't your idea of the best person to introduce this to you, would be okay if they did?</p> <p>Even if this isn't your idea of the best person to introduce this to you, would be okay if they did?</p> <p>Even if this isn't your idea of the best person to introduce this to you, would be okay if they did?</p> <p>Even if this isn't your idea of the best person to introduce this to you, would be okay if they did?</p> |

| Domain | Question | Probe |
|------------|---|---|
| | <p>Or is it not important to you who offers and explains this intervention to you for the first time?</p> <p>In the future study we would like to ask these questions, that you just looked over, by either a cellular phone or online using the internet. However, we need to know if most adolescents have access to either of these in order for the study to work.</p> <p>We would like to ask people your age to respond to these questions in a future study.</p> <p>So, do you have a cell phone that receives text messages that you can use every day, if you were in the study?</p> <p>Would you have internet access for at least 30 minutes every day, if you were in the study?</p> <p>If you were going to respond to them, would you prefer to respond by: Writing in a notebook that ONLY the study staff would look at, after the study was over?</p> <p>Typing in an online website in which ONLY the study staff could see your answers?</p> <p>Making a video on an electronic device (such as a smartphone, iPad, etc.) where you give your responses by capturing it on a video, in which ONLY study staff would see the video?</p> <p>What time of day do you think you would most likely answer these questions?</p> <p>Where do you think you would most likely have the time to answer these questions?</p> <p>On a scale of 0-10, with 0 being not at all interested and 10 being interested, can you tell me how interested you would be in participating in a future study like this if we are able to do it?</p> <p>What do you think about the length of the whole set of questions?</p> | <p>If the participant states they have access to the internet follow up by asking where they have access to the internet.</p> <p>Are there other ways you would rather respond to these questions?</p> <p>Before school, after school, at night, on the weekends, etc.?</p> <p>Or would you prefer to answer these questions only while your inpatient?</p> <p>Would it be at home? At school? Some other location?</p> <p>If <5, ask, What would have to happen for you to change your mind and rank your interest between 6 and 10?</p> <p>Is it too long, long but bearable, reasonable in length, or should be longer?</p> |
| Conclusion | <p>What else do you think would help us run this study in the future?</p> <p>What questions do you have for me before we stop?</p> <p>Okay, now that we are done I just wanted to say thank you very much for answering my questions and telling us what you think!</p> | |

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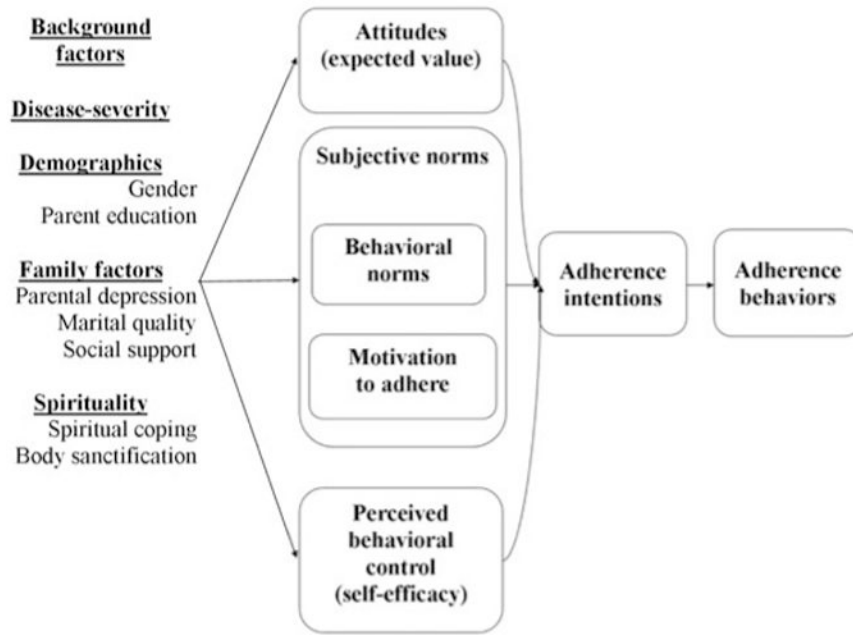


Figure 1.
Theory of reasoned action (adapted from Fishbein & Ajzen, 2010).