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Screening for Spiritual Struggle in an Adolescent Transgender Clinic: Feasibility and Acceptability

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Abstract

Spiritual struggles are associated with poorer health outcomes, including depression, which has higher prevalence among transgender individuals than the general population. This study's objective was to improve the quality of care in an outpatient transgender clinic by screening patients and caregivers for spiritual struggle and future intervention. The quality improvement questions addressed were whether screening for spiritual struggle was feasible and acceptable; and whether the sensitivity and specificity of the Rush Protocol were acceptable. Revision of the screening was based on cognitive interviews with the 115 adolescents and caregivers who were screened. Prevalence of spiritual struggle was 38–47%. Compared to the Negative R-COPE, the Rush Protocol screener had sensitivities of 44–80% and specificities of 60–74%. The Rush Protocol was acceptable to adolescents seen in a transgender clinic, caregivers, and clinic staff; was feasible to deliver during outpatient clinic visits, and offers a straightforward means of identifying transgender persons and caregivers experiencing spiritual struggle.

Keywords

spiritual struggle; screening method; transgender; adolescent; parent

INTRODUCTION

Background

Spiritual struggle is defined as the tensions that emerge when basic spiritual beliefs, practices, strivings are challenged or threatened (Oemig Dworsky et al., 2013). Spiritual struggle may be struggles with the Divine, between individuals (interpersonal) or within one's self (intrapersonal) (Pargament, 2007). Spiritual struggle has been described in the

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context of a variety of populations, primarily in health care (Cotton et al., 2013; Fitchett et al., 2004; Fitchett, & Risk, 2009; Fitchett, Winter-Pfändler, & Pargament, 2014). Whether spiritual struggle are against the Divine, inter- or intra- personal, the presence of spiritual struggle has been associated with poorer health outcomes including mental health such as depression (Fitchett, & Risk, 2009; McConnell et al., 2006). Spiritual and religious tensions indicative of spiritual struggle have been described in transgender population (Hernandez, Mahoney, & Pargament, 2014). Suicide rates among young transgender adults are significantly higher than the general population, with 22–43% having seriously considered suicide over the course of their lives, and 9–10% during the prior year (Bauer et al., 2015). Routine screening does not normally include screening for spiritual struggle.

Setting and Local Problem

Cincinnati Children's Hospital Medical Center is a 575-bed tertiary academic pediatric medical center. The Transgender clinic, which is part of the Division of Adolescent and Transition Medicine, follows approximately 160 children and youth between 8 and 18 years of age. Transgender Clinic is scheduled six times a month. The hospital has a strong commitment to QI, indicated by the mission statement, which reads, in part, "…deliver demonstrably superior patient outcomes and experiences, and discover and apply better ways to improve the health of children." QI efforts have a long history and include a Robert Wood Johnson Foundation grant, "Pursuing Perfection: Raising the Bar for Health Care Performance" in 2001. In the context of seeing patients and families in Transgender Clinic, the last author (LAC) perceived religious struggles after hearing transgender adolescent patients describe attempting to come out to their youth pastor and being dismissed from youth group, or receiving reparative therapy at a religiously-affiliated school. Parents have also made comments to the last author indicative of religious struggle, including a tearful mother who stated that she could not accept her child as transgender because it is against her religion; and a mother that said they would have to move out of a religiously conservative area because they would not be accepted in their congregation once it became known that the adolescent was transgender.

Intended Improvement

The specific aim of this study was to improve holistic care by developing a routine means of identifying persons with spiritual struggle for future intervention. The clinic's Medical Director, based on anecdotal evidence provided by transgender youth and parents about negative, inappropriate, or hurtful comments about spiritual experiences suggested the need for identifying persons with spiritual struggle.

Study Question

This study follows the SQUIRE Guidelines for reporting quality improvement work (Davidoff, Batalden, Stevens, Ogrinc, & Mooney, 2008; Davidoff, Batalden, Stevens, Ogrinc, & Walker, 2008). The primary improvement question was whether the Rush Protocol was feasible to use in clinic and acceptable to transgender youth, parents and staff. The secondary improvement question was whether sensitivity and specificity of the Rush Protocol were acceptable compared to an established scale not intended to be completed orally.

METHODS

Ethical Issues

Ethical approval is not required by our institution for quality improvement efforts. Nonetheless, certain ethical safeguards were followed. These include: a study staff member approached adolescent patients and parents in clinic and explained that an ongoing effort was underway to improve the clinic's ability to provide comprehensive care. One aspect of that effort was to learn the extent of spiritual struggles people have. If they were willing, they would be asked to complete a screening form (and after the first iteration, an additional questionnaire). In the subsequent iterations, participants were told that based on their responses, a chaplain may contact them by telephone to follow up on their responses. They were told that if they did not want to participate in this effort, it would not affect their care in any way and that only deidentified data would be stored and no links to identifiable persons would be retained.

Planning the Interventions

A clinical research staff member approached each adolescent patient and their caregivers during a routine transgender clinic outpatient appointment. The research staff member informed them that the clinic was attempting to improve by determining whether it was possible to identify the extent to which spiritual struggles were an issue for those coming to clinic because there had been suggestions of this in the past. Adolescent patients and their caregivers were then invited to complete the screener in a paper format.

Any process to screen for spiritual risk had to meet certain pre-established conditions. These were: (1) screening process had to be acceptable to adolescents, caregivers and staff; (2) feasible for clinic staff to do in course of other duties; (3) screening could not significantly disrupt or alter clinic flow; and (4) ideally should use orally administered screening. Consultation between the clinic director and principal investigator led to the initial use of the Rush protocol. A study staff member would approach adolescent clinic patients and their caregivers in clinic, explain the project and invite their participation. The Rush screening questions would be provided in a paper format to participants rather than be orally administered. The reasons for this were (a) empirical data of clinic director was that adolescents and caregivers frequently had different expressions concerning religious beliefs; (b) the need to minimally disrupt clinic flow meant that people had to be approached simultaneously because (c) participants may not feel comfortable expressing divergent or unacceptable beliefs in front of other family members (Midanik, Greenfield, & Rogers, 2001). The goal of the first iteration was to test whether this was unfeasible to further test in clinic and initially quantify the potential prevalence of spiritual struggle. Assuming it was feasible to carry this iteration out in clinic, it was initially decided that future iterations would focus on improving the process of delivering the screener, measuring the utility of the screener by calculating its sensitivity and specificity, and quantifying acceptability to adolescents, caregivers and staff.

Planning the Study of the Intervention

An observational study design was chosen to obtain cross-sectional data on feasibility and acceptability from patients, caregivers and staff. Feasibility would be assessed among patients and caregivers as having at least 85% of persons approached complete the screener. Feasibility among staff was assessed by feedback from two nurses, social worker and clinic director that clinic flow was not disrupted and screener completion did not add significantly to time in clinic. Acceptability would be assessed among patients and caregivers as no more than 15% refusal to complete the screener after learning of its topic. Acceptability among clinic staff would be assessed by staff self-report that they were comfortable asking screener questions as part of their clinical role. In addition, prevalence, sensitivity and specificity of Rush screener would be calculated and used to determine if the screener was a feasible means to identify persons with spiritual struggle. The initial goals for feasibility were that a prevalence consistent with previously published values (7–50%) were found, and values for sensitivity of 0.6 and specificity of 0.75 would be calculated.

Brief cognitive interviews were conducted by study staff with adolescents and caregivers following completion of the screener. Persons were asked if the instructions and the wording of each item was clear. They were also asked what changes might be made to make the screener more understandable. These changes were then discussed among the three authors and implemented in the next iteration.

The most significant anticipated threat to internal validity was selection bias. The goal that no more than 15% of persons approached would refuse to complete the screener was chosen to counteract selection bias and assure internal validity. It was assumed that the screener itself might evolve during this process; therefore, beginning with second iteration, the negative subscale of the Brief R-COPE was used as comparison for external validity (Grossoehme, & Fitchett, 2013). Cronbach’s alpha for the Brief R-COPE (patients) was 0.81.

Measures

Rush Screener for spiritual struggle.—A protocol to screen persons for spiritual struggle was developed by Jay Risk and George Fitchett (Fitchett, & Risk, 2009). This screener (hereafter known as the Rush Protocol, or RP) was intended to be used by health care staff other than chaplains in order to identify persons with whom a chaplain should follow-up to conduct a more complete spiritual assessment. The RP is intended to identify as “positive” for potential spiritual struggle persons for whom faith is important yet is not providing them currently with strength or comfort, as well as those for whom spiritual beliefs are not important currently but had been in the past. They reported a prevalence of 7% for spiritual struggle. This screener has also been used in the context of a telephone interview with parents of children with cystic fibrosis, a life-shortening disease); an incidence of 18% was reported, and compared to the Brief R-COPE, performed with 29% sensitivity and 87% specificity (Grossoehme, & Fitchett, 2013). Sensitivity is a measure of a tool’s ability to correctly identify those who are positive for a characteristic; specificity is a measure of a tool’s ability to correctly identify as negative persons without the characteristic.

Brief R-COPE.—The negative religious coping subscale of the Brief R-COPE (Pargament, Koenig, & Perez, 2000) was used as the reference guide for sensitivity and specificity testing of the Rush Screener. This subscale is composed of seven items (for example, “Decided the Devil made this happen”) to which respondents indicate their frequency of using each of the coping styles in a 4-item Likert-style response format ranging from “Did not use” (0) to “A great deal” (3). Cronbach’s alpha for this subscale was 0.82.

Analysis

The implementation of the screener’s use was assessed using mixed methods. Quantitative methods were used to assess feasibility, and acceptability to patients and caregivers, as well as the outcome measures. Qualitative methods were used to assess acceptability to staff. The cutoff values chosen as initial goals were: (1) the cutoff value to judge feasibility would be at least 85% of patients and caregivers would be approached and complete screening; (2) the cutoff value to judge acceptability would be at least 85% would agree to complete the screening process. It was expected that the prevalence of spiritual struggle as determined by screener would fall in anticipated range of 7–50%. Cutoff values for the sensitivity and specificity of a meaningful screener would be 0.6 or higher, using the Negative R-COPE (Pargament, Koenig, & Perez, 2000) to validate the Rush screener. Ideally the sensitivity and specificity cutoffs would be 0.8 or higher; however, for the exploratory nature of this study focusing on feasibility and acceptability, lower values were judged to be acceptable. Research study staff were trained by investigators on the administration of Rush screener, data collection, confidentiality and privacy.

All analyses were carried out using SPSS 21.0. Descriptive statistics were calculated for spiritual struggle using criteria for Rush screener (Fitchett, & Risk, 2009) and for Negative R-COPE. The anticipated prevalence of spiritual struggle led to categorizing responses as indicative of struggle in two ways, following the example of Fitchett and colleagues (Fitchett, et al., 2004) . An individual was categorized as having “moderate-severe” religious struggle if any response was 2 or 3; and categorized as having “religious struggle, including mild” for any response of 1, 2 or 3 to an item. Sensitivity and specificity were calculated for Rush screener (Gordis, 2009). Cognitive interview comments were recorded on paper and reviewed after each iteration by two authors and coded using content analysis. As a pilot feasibility and acceptability study, the enrollment of a minimum sample size to ensure adequate power for inferential analysis was not necessary. The goal of each iteration was to improve acceptability, sensitivity and specificity of the screener, while recognizing that some revisions may unintentionally cause the reverse to occur.

RESULTS

Acceptability

A total of 115 persons completed the screener (98% of those approached); 63 were adolescent patients. Demographic, screener and Brief R-COPE results are presented in Table 1 below. One caregiver declined due to time constraints and one patient refused, citing a difference in beliefs. This participation rate suggests that screening for spiritual struggle in the transgender clinic was acceptable to both adolescent transgender patients and their

caregivers. Approaching patients and caregivers to complete the spiritual struggle screening process as part of clinic quality improvement was acceptable to the two clinic staff who made the approaches. Cognitive interview data from clinic staff demonstrated that the use of the screener had no adverse effect on clinical care delivery. One commented, “Spirituality is part of what we do. We’re supposed to be asking these questions.” Inclusion of spirituality was regarded by clinic staff as an enhancement of the care delivery process.

Feasibility

The 115 persons approached were 84% of the persons who attended transgender clinic on the days when screening took place. In the first four iterations, the approach was made by a clinical research coordinator, and for the fifth iteration, the approach was made by two clinic staff. This result suggests that screening for spiritual struggle is feasible in the context of an outpatient clinic setting. Follow-up by telephone or email with persons who screen positive for spiritual struggle on the Rush Protocol has met with limited success. Permission must first be obtained from the legal guardian before contact is made with patients under age 18 years. This adds a step in the process and presents a potential barrier. The chaplain who contacted parents experienced some resistance from parents whose concern seems to have been to protect their child from further judgmental, condemning or otherwise inappropriate comments by clergy. Two or more telephone calls were needed to make contact with persons and actual contact was never made with some either by phone or email. While it appears feasible to screen for spiritual struggle in an outpatient clinic on at least an annual basis, follow-up outside of the clinic setting has been less than feasible.

Outcomes

One third of transgender adolescents screened positive for spiritual struggle using the Rush Protocol; using the Negative R-COPE, one third screened positive using the moderate-severe scoring and one half allowing for mild spiritual struggle. Caregivers had a higher prevalence than adolescents of positive screenings for spiritual struggle using the Rush Protocol (47%), and lower prevalence than adolescents using the Negative R-COPE (17% for moderate-severe spiritual struggle and 33% including mild spiritual struggle).

The sensitivity and specificity of the Rush Protocol in this sample was below 0.85. It was most sensitive (correctly identifying persons with spiritual struggle) among caregivers who scored in the moderate-severe range on the Negative R-COPE. For both patients and caregivers, it had better sensitivity when it was compared to the Negative R-COPE using the moderate-severe scoring criteria. It generally had increased specificity when compared to the more stringent scoring criteria for spiritual struggle using the Negative R-COPE, although the values were poor.

The initial version of the screener presented the Rush Protocol screening questions with checkboxes for each response option on one page. The evolution of the screener’s use was based on cognitive interview data obtained by study staff from patients and caregivers. This iteration filled the printed page and may have appeared daunting to some. This led to the second iteration in which the initial question, “Is spirituality or religion important to you as you think about your transgender issues?” was followed by a “flowchart” with a “yes”

option leading to the follow-up question, “How much strength or comfort do you get from your religion/spirituality right now?” and the “no” option leading to the follow-up question, “Has there been a time when religion/spirituality was important to you?” and directed the respondent to the reverse side to complete the Negative Brief R-COPE items. Feedback suggested the Rush Protocol items were clear. Study staff considered the potential ethical issue of identifying persons by screening who may have been experiencing spiritual struggle and not following up to offer care. This concern led to the third iteration, in which a statement was added which read, “Depending on your responses to these items, a member of the health care team who specializes in helping people talk about these things—called a chaplain—may be contacting you. You do not have to speak with them at that time if you do not wish to do so. If you would like to make sure that a chaplain contacts you, please mark the box below as well as provide a phone number and/or email address.” Participant comments about not being able to discuss these issues opening in their congregation led to the fourth iteration, which added questions about congregational support in a flowchart format beginning with, “Do you attend a congregation?” and having a positive flow to the question, “Do you feel you have love and support at your congregation” and a negative flow to the question, “Is this related to transgender issues?” Clinic staff approached patients and caregivers with this iteration to completing the screening process. While no cognitive interview feedback suggested a lack of clarity with this iteration, approximately 10% of the Rush Protocol screening pages were returned with responses in both the “yes” and “no” arms of the flowchart. This suggests that simply presenting two options without the instruction to choose only one is not enough to ensure that all screeners are completed correctly. In these cases, the completed screeners were counted as positive because the respondents indicated “none at all” in response to the question about the degree of strength and comfort from their beliefs and “yes” to the question that there had been a time (in the past) when their beliefs were important to them.

As noted above, the screener process as evolved had the benefit of identifying persons who might benefit from a chaplaincy intervention and who would otherwise had such needs unrecognized. An additional benefit accrued to clinic staff who believed it important to include spiritual issues in routine clinical care. No evidence of harm, problems or failures was noted.

DISCUSSION

The need for chaplains to screen for spiritual struggle in order to identify persons at risk for poorer health outcomes has been described (Fitchett, et al., 2004; Fitchett, & Risk, 2009; King, Fitchett, & Berry, 2013). This QI project demonstrated that administration of the Rush Protocol for spiritual struggle is acceptable to adolescents seen in transgender clinic; to caregivers; and to clinic staff nurses. It also demonstrated that the screener is feasible to deliver in paper version by both non-clinic staff and for clinic staff to integrate into routine duties. The feasibility of chaplain follow-up by telephone or email was not demonstrated. The prevalence of spiritual struggle among the participants was high. Given the association of spiritual struggle with depression (Pirutinsky et al., 2011), and depression with suicide ideation and gesture in the transgender population (Bauer, et al., 2015), this is a significant issue for health care chaplains’ attention. Bauer and colleagues include religious/spiritual

factors in their model of intervenable, modifiable constructs related to suicide among persons who are transgender. Spiritual struggle has been shown to be modifiable by several interventions (Oemig Dworsky, et al., 2013; Piderman, 2015; Tarakeshwar, Pearce, & Sikkema, 2005). Chaplains are the ideal clinical health professional to address spiritual struggle in this population. The Rush Protocol appears to offer a relatively simple, acceptable and feasible means to identify adolescents presenting at transgender clinic, and their caregivers, with spiritual struggle.

Compared to other studies of the prevalence of spiritual struggle (Fitchett, & Risk, 2009; King, Fitchett, & Berry, 2013), the prevalence of spiritual struggle in this population was within the range reported in other populations, although it was relatively high. The feasibility and acceptability of implementing the Rush Screener into routine clinic flow were acceptable. Fitchett and Risk reported screening 79% of admitted patients, which is less than was achieved in an outpatient clinic setting in this study. One important difference to note is that in the present study, completion rates of the screener did not decrease when responsibility for it was taken over by clinic staff from a specially detailed study staff. While this high rate of completion was sustained over a four-month period, the ability for clinic staff to maintain it for extended periods is unknown. Sensitivity and specificity have previously been calculated for the Rush Protocol when used with parents of children who have cystic fibrosis (sensitivity = 29%; specificity = 87%) (Grossoehme, & Fitchett, 2013). The sensitivity and specificity rates in this study, while within the acceptable range predefined for a quality improvement study, are nevertheless relatively low for clinical utility. The results from this study, coupled with those reported by Grossoehme and Fitchett, suggest that the Rush Protocol may benefit from revision to improve its sensitivity and specificity.

This study had the following limitations. While the refusal rate to participate in the screening process was very low, the sample is a convenient sample and is susceptible to selection bias. While spiritual struggle is commonly operationalized using the negative subscale of the Brief R-COPE, this tool may introduce some imprecision in measurement. Spiritual struggle has been described as having three types—struggles with the Divine, struggles within one's own self, and struggles with other people (Oemig Dworsky, et al., 2013). The Brief R-COPE focuses primarily on Divine, and to a lesser extent intrapersonal, forms of spiritual struggle and does not include interpersonal. To the extent that transgendered persons experience spiritual struggle as a result of negative experiences in congregations or other social settings, the use of the Brief R-COPE may actually underestimate the prevalence of spiritual struggle in this population. While the Transgender Clinic setting may be experienced as open and welcoming, it is situated in a religiously conservative part of the US, which may contribute both to the prevalence of spiritual struggle as well as minimize people's willingness to examine and possibly reframe spiritual or religious beliefs. Nonetheless, the results from this quality improvement study suggest an acceptable, feasible means of identifying persons with spiritual struggle who can be referred for a more complete religious or spiritual assessment by a chaplain, and when indicated, an intervention by a chaplain. Future iterations may also include asking teens and caregivers if they would like to meet with the chaplain during their next transgender clinic appointment; and differentiating between congregational support and support from clergy.

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Table 1

Demographic and spiritual struggle data for patients and caregivers

			N (%)	M (SD)	Median (range)
Gender	Patient (presented as female to male)		27 (48)		
	Caregiver		28 (52)		
Age	Patient			16.8 (3.5)	17 (15)
Spiritual Struggle	Rush Screener Protocol	Patient	13 (38)		
		Caregiver	14 (47)		
	Negative R-COPE (including mild)	Patient (n=31)	18 (53)		
		Caregiver (n=29)	10 (33)		
	Negative R-COPE (moderate-severe)	Patient	11 (32)		
		Caregiver	5 (17)		

Table 2

Sensitivity and specificity of Rush Protocol screener compared to negative Brief R-COPE

	Compared to Mild spiritual struggle R-COPE		Compared to Moderate-severe spiritual struggle R-COPE	
	Sensitivity	**Specificity**	**Sensitivity**	**Specificity**
Patient	0.44	0.69	0.63	0.74
Caregiver	0.58	0.65	0.80	0.60