

UC San Diego

UC San Diego Previously Published Works

Title

Is Religiosity Related to Attitudes Toward Clinical Trials Participation?

Permalink

<https://escholarship.org/uc/item/6sw9q97g>

Journal

Journal of Cancer Education, 30(2)

ISSN

0885-8195

Authors

Daverio-Zanetti, Svetlana

Schultz, Kathryn

del Campo, Miguel A Martin

et al.

Publication Date

2015-06-01

DOI

10.1007/s13187-014-0696-9

Peer reviewed

Is Religiosity Related to Attitudes Toward Clinical Trials Participation?

Svetlana Daverio-Zanetti · Kathryn Schultz ·
Miguel A. Martín del Campo · Vanessa Malcarne ·
Natasha Riley · Georgia Robins Sadler

Published online: 24 June 2014
© Springer Science+Business Media New York 2014

Abstract Research indicates that a low percentage of cancer patients enroll in cancer clinical trials. This is especially true among minority groups such as Hispanic Americans. Considering the importance of religion in the Hispanic American community, it is important to understand its relationship to perceptions of clinical trials. Five hundred and three Latina women completed the Barriers to Clinical Trials Participation Scale and the Duke University Religion Index. For the total sample, higher organizational and intrinsic religiosity was significantly associated with a perceived lack of community support for clinical trials participation. In subgroup analysis, the relationship between organizational religiosity and lack of support was stronger among Latinas who were Spanish language preferred and Latinas who were Catholic. Intrinsic religiosity was associated with mistrust among Spanish language-preferred Latinas, and both organizational and intrinsic religiosities were associated with a lack of familiarity with clinical trials among Christian (non-Catholic) Latinas. These results indicate that religious institutions that serve Latinas may be an effective venue for disseminating clinical trial education programs to improve attitudes toward clinical trials participation.

Keywords Clinical trials · Religiosity · Training · Cancer · Attitudes · Hispanic American · African American · Women

Introduction

Attracting volunteers to participate in research studies is a well-documented challenge for researchers [1, 2]. It has been a widely accepted estimate that, among all cancer patients, less than 5 % participate in a clinical trial. This underrepresentation is more severe among minority groups, effectively limiting the generalizations that can be drawn from research studies [3]. To address these problems, the National Institutes of Health Revitalization Act of 1993 was passed by the US Congress and signed into law. The act mandated the recruitment of women and minorities in clinical trials [4]. Also, the NCI initiated the Minority-Based Community Clinical Oncology Program, a research-based network connecting academic centers with community physicians, to promote the recruitment of ethnic minorities [5, 6].

In spite of these efforts, minority groups remain to be underrepresented in clinical trials. Thus, efforts have been made to identify the factors serving as barriers and facilitators of clinical trials participation for minority groups [7]. Among the barriers that have been identified are such things as ineffective communication, language barriers, family and friends' negative influences, stigma, and limited opportunities to learn about research studies seeking participants [8–11]. Other researches have identified facilitators of participation, including being able to speak with a nurse in one's preferred language, building a trusted relationship with the medical researchers, and face-to-face interactions with ethnically diverse staff [12, 13].

Hispanic Americans are one of the groups for whom underrepresentation in research studies is of great concern. Although it has been established that religion plays a central role

S. Daverio-Zanetti · K. Schultz · M. A. M. del Campo ·
V. Malcarne · G. R. Sadler
UCSD Moores Cancer Center, 3855 Health Sciences Drive, La Jolla,
CA 92093-0850, USA

V. Malcarne
San Diego State University, 6363 Alvarado Court, Suite 103, San
Diego, CA 92120-4913, USA

N. Riley
Vista Community Clinic, 1000 Vale Terrace Drive, Vista,
CA 92084-5218, USA

G. R. Sadler (✉)
Department of Surgery, University of California, San Diego, 9500
Gilman Drive, La Jolla, CA 92093-0850, USA
e-mail: gsadler@ucsd.edu

in the Hispanic community [14], it is unknown precisely what influence religiosity and one's religious community might have on informing and encouraging participation in clinical research. Professional and lay religious leaders may be open to collaborations with the medical community for interventions that will improve the health and well-being of their congregation. For example, a study with the Presbytery of San Diego and Imperial County found that spiritual leaders may be effective in informing their parishioners about the role and availability of clinical trials, at least when cancer is the concern [15]. Another study explored the role that religious organizations can play in disseminating cancer information among members of the Deaf community [16]. The current study investigated the relationship between religiosity and attitudes toward clinical trials among Latinas.

Methods

This study was conducted via a community-campus partnership among the Vista Community Clinic, San Diego State University, and the University of California, San Diego. The data used for this analysis were gathered as part of a cross-sectional study to confirm or establish the psychometric properties of psychosocial instruments for use with Hispanic American community women. None of the instruments required a reading level beyond the eighth grade. Because the study was conducted in Southern California, the Hispanic American women in the sample were mostly of Mexican descent.

The self-report instruments that were used in the analysis reported in this paper were the Duke University Religion Index (DUREL) [17] and the Barriers to Clinical Trials Participation (BCTP) Scale [18, 19]. They were administered in Spanish or English according to each participant's expressed language preference.

Participants

Women were eligible to participate if they self-identified as Hispanic American and were at least 18 years old. The sample of 503 Latina women ranged in age from 18 to 80 ($M=38$, $SD=13$). Half took the survey in English (252) and half in Spanish (251). Options for religious preference were Catholic (69.8 %), Christian (17.1 %), Jewish (.7 %), Buddhist (.7 %), other (2.2 %), and none (9.5 %). Over half (52.7 %) were married. The education range was 42.8 % with less than a high school graduation, 18.9 % with a high school diploma, 7.7 % with at least some college, and the remainder with a college degree or higher. About 54.3 % indicated that they were employed for wages, 23.3 % were homemakers, and the rest of the participants reported they were either unemployed, retired, or students.

Participant Recruitment

Participant recruitment was accomplished through the distribution of institutional review board (IRB)-approved flyers in Spanish and English, face-to-face interactions, and word-of-mouth at diverse community venues throughout San Diego County. This included the following: civic and social venues, health clinics, churches, community organizations, health fairs, neighborhood businesses, schools, clubs, stores, and restaurants. A concerted effort was made to employ participant recruitment strategies that would be likely to reach women with and without prior research experience to assure accrual of a sample that was representative of the population of HA women in the region. Participants received \$20 as a "thank you" for their participation.

Consenting, Accrual, and Data Collection Process

Bilingual IRB-certified research assistants of the community partner were trained by the campus partners in the optimal conduct of the informed consenting process using the language preferred by the participant. The research assistants were all required to pass UCSD's in-depth IRB certification examination before consenting participants. The research assistants were also trained by the campus partners in the standardized process of administering the packet of psychosocial instruments.

Survey instruments were administered at community sites and private homes, either individually or in small groups. Participants required between 1 and 2 hours to complete the packet of psychosocial instruments. If participants were bilingual, they were encouraged to select the language in which they preferred "to argue," as a consistent means to determine their dominant language. Potential participants were told that the completion of the surveys would require a reading level of eighth grade. If a person was unsure but thought their reading level was adequate, they were told to try completing the surveys with the assurance that, if they were too difficult, they could stop at any point. This occurred in less than 1 % of the sample. The incentive was given to any participant who attempted in good faith to complete the surveys, regardless of how much of the surveys they completed.

Instruments

The DUREL measures three aspects of religiosity: organizational, non-organizational, and intrinsic. The DUREL includes five questions that are answered on a six-point scale (from 6 = never to 1 = more than once per week for the first two questions and from 1 = definitely true of me to 6 = definitely *not* true for the last three questions). These items were reversely coded before the analysis, such that higher scores reflected greater religiosity. The first two questions

are single items measuring organizational and non-organizational religiosity, respectively. Organizational religiosity measures how often individuals attend church or religious meetings, while non-organizational religiosity measures how often individuals engage in private religious practices outside of institutions. Intrinsic religiosity is measured using the average of the three items asking the extent to which an individual incorporates religion in their daily life. Reliability analyses yielded a Cronbach's alpha of .77 for the DUREL and .81 for the intrinsic religiosity subscale. No alphas were calculated for organizational or non-organizational religiosity because they are single-item scales. The DUREL has previously been published in both English and Spanish.

The BCTP Scale is a 19-item survey that assesses factors that might negatively influence person's attitudes toward clinical trials participation. This instrument was developed and validated on a community sample of African American men and women with similar education levels to those of this study's Hispanic American participants [18, 19]. The BCTP Scale was developed in English and translated into Spanish by this research team using the gold standard of forward and back translation with reconciliation. At the top of the survey document, there is a brief description of what is meant by the term "clinical trials" in order to provide all participants with a standardized minimum basic knowledge of clinical trials. Responses are recorded using a five-point Likert scale (1 = strongly disagree to 5 = strongly agree) and yield a mean score for each of the four subscales representing perceived barriers to participation in clinical trials. The four subscales are as follows: lack of personal benefits (e.g., "There's nothing in clinical trials for me"; $\alpha=.60$), lack of community support (e.g., "People I know have told me not to be in clinical trials"; $\alpha=.59$), mistrust (e.g., "I worry that they are not telling me everything I need to know"; $\alpha=.74$), and lack of familiarity (e.g., "It costs too much money to be in a clinical trial"; $\alpha=.78$). Higher scores reflect more perceived barriers. The total scale yielded a Cronbach's alpha of .89.

Results

Table 1 displays the mean and standard deviations for the subscales of the DUREL and BCTP Scale. Bivariate zero-order correlations were calculated among the DUREL and BCTP scales for the total sample as well as for language-preferred and religious affiliation (Catholic/non-Catholic Christian) subgroups (see Table 2). For the total sample, organizational and intrinsic religiosities were both significantly positively correlated with lack of community support. This indicates that those who attend religious meetings more frequently, or who are more intrinsically religious, perceive their community as being less supportive of participation in clinical

Table 1 DUREL and BCTP scale means and standard deviations

| | Mean (SD) |
|---|--------------|
| Duke University Religion Index Scale | |
| Organizational religiosity | 3.97 (1.53) |
| Non-organizational religiosity | 3.32 (1.80) |
| Intrinsic religiosity | 12.46 (2.80) |
| Barriers to Clinical Trials Participation Scale | |
| Lack of personal benefits | 9.01 (2.93) |
| Lack of community support | 6.23 (2.37) |
| Mistrust | 15.34 (4.52) |
| Lack of familiarity with clinical trials | 14.37 (4.32) |

trials. There were no other significant correlations of DUREL to BCTP scales for the total sample.

Language Preference When correlations were calculated separately for the English and Spanish language-preferred subgroups, organizational religiosity was significantly positively associated with lack of community support for women with Spanish language preference, but not for women with English language preference. For women with Spanish language preference, intrinsic religiosity was significantly positively associated with mistrust. There were no significant correlations of DUREL to BCTP scales for women with English language preference.

Religious Affiliation Among the women who identified themselves as Catholic, a significant positive correlation was found between organizational religiosity and lack of community support. Among those who identified as non-Catholic Christian, both organizational and intrinsic religiosities were significantly positively correlated with lack of familiarity. Other religious affiliations were not included in the analysis due to the small size of these groups in the sample.

Discussion

The consistent association between participation in organized religion and the perception that one's community does not support participation in clinical trials held true overall for the sample of Latinas and, particularly, for those participants who reported Spanish language preference or a Catholic religious affiliation. In general, participants who reported higher organizational religiosity (attending more services and events at a religious institution) also reported higher community barriers (believing that their community disapproves of clinical trials). For the non-Catholic Christian participants, both organizational and intrinsic religiosities were associated with less familiarity with clinical trials. Although the reasons and causal

Table 2 Correlations between types of religiosity and personal characteristics

| BCTP subscales | Organizational religiosity | Non-organizational religiosity | Intrinsic religiosity |
|---------------------------------|----------------------------|--------------------------------|-----------------------|
| Personal benefits | .034 | .023 | .024 |
| Community | .118** | .002 | .099* |
| Mistrust | .044 | .052 | .066 |
| Lack of familiarity | .060 | .012 | .036 |
| Language | | | |
| Spanish (personal benefits) | .049 | .055 | .098 |
| English (personal benefits) | .028 | .029 | .099 |
| Spanish (community) | .133* | .008 | .101 |
| English (community) | .108 | .001 | .117 |
| Spanish (mistrust) | .075 | .079 | .130* |
| English (mistrust) | .014 | .026 | .013 |
| Spanish (lack of familiarity) | .080 | .013 | .059 |
| English (lack of familiarity) | .045 | .005 | .038 |
| Religious preference | | | |
| Christian (personal benefits) | .095 | .062 | .160 |
| Catholic (personal benefits) | .035 | .045 | .003 |
| Christian (community) | .023 | .018 | .083 |
| Catholic (community) | .145* | .021 | .085 |
| Christian (mistrust) | .155 | .082 | .140 |
| Catholic (mistrust) | .031 | .059 | .095 |
| Christian (lack of familiarity) | .216* | .130 | .199* |
| Catholic (lack of familiarity) | .018 | .060 | .002 |

* $p < .05$; ** $p < .01$

directions for these associations cannot be discerned from the present study, the findings suggest that religious institutions serving Latinas may have the potential to serve as an effective venue from which to reach individuals who are currently underrepresented in cancer clinical trials.

Religious institutions have proven to be effective venues for health promotion efforts [20, 21] because they are recognized as a trusted source of information. Campuses could develop community partnerships with religious organizations serving the Hispanic community with the goal of raising clinical trials literacy levels and promoting awareness of opportunities to participate in health-related research studies. Earlier research with religious leaders of Presbyterian churches and Deaf ministries demonstrated that they were willing to receive training on clinical trial education and act as a source of information for their congregations and the community at large [16]. For example, clinical trial education programs could take place as part of community gatherings organized by religious leaders or when privately ministering to a person coping with an illness. Such efforts could serve to increase familiarity with clinical trials via education, while simultaneously reducing perceptions of lack of community support through the demonstration of religious support for clinical trials participation.

For Spanish language-preferred participants only, there was a significant correlation between religion and attitudes toward clinical trials, suggesting that institutions with large numbers of Spanish language-preferred members might gain a particular benefit from clinical trial education programs. Such programs would be an effective way of overcoming language barriers and communication difficulties, which have been identified among the reasons that minority groups choose not to participate in clinical trials. These programs may help to reduce individuals' misunderstandings related to clinical trials and may help to increase their perceptions that clinical trials participation can be a part of their culture and that their participation can be beneficial for their community.

This study had several limitations. The sample was comprised entirely of Latina women and did not include Latino men, limiting the generalizability of the study. Further, the study was conducted in Southern California; thus, the vast majority of the Latinas were of Mexican descent, further limiting generalizability. The data were cross-sectional, thus precluding inferences about causality, and only self-report questionnaires were administered. Another limitation of this study was the omission of a question that inquired about prior experience/participation in research studies. The opportunity to analyze the data set with that additional information might have generated other important insights.

Despite these limitations, the findings suggest directions for further investigation. Future research could further examine the role of religious organizations and religiosity in research participation, while simultaneously considering religious institutions and settings as an avenue for promoting health research. Whether or not religiosity is associated with barriers to clinical trials participation in the same manner for men as for women could also be explored. Religious institution-based interventions to promote clinical trials participation, such as that tested by the Presbytery of San Diego and Imperial County regarding clinical trials, could also be developed and evaluated.

Conclusion

This study suggests that religiosity interacts with Hispanic American women's orientation to clinical trials, and this is especially true for Latinas with Spanish language preference and for Latinas who are Catholic. Thus, there may be valuable opportunities for collaborations between religious organizations and clinical trials educators who are concerned with increasing the accrual of Hispanic American women to clinical trials.

Acknowledgments This study was funded by the California Breast Cancer Research Program grants 13AB-3500 and 14BB-2601, along with support from National Cancer Institute grants R25CA130869, NIH U56 CA92079/U56 CA92081, and U54 CA132379/U54 CA132384.

References

- Gul R, Ali P (2010) Clinical trials: the challenge of recruitment and retention of participants. *J Clin Nurs* 19(1–2):227–233
- Durant RW et al (2014) Perspectives on barriers and facilitators to minority recruitment for clinical trials among cancer center leaders, investigators, research staff, and referring clinicians: enhancing minority participation in clinical trials (EMPaCT). *Cancer* 120:1097–1105
- Geller SE et al (2011) Inclusion, analysis, and reporting of sex and race/ethnicity in clinical trials: have we made progress? *J Women's Health* 20(3):315–320
- Freedman LS et al (1995) Inclusion of women and minorities in clinical trials and the NIH Revitalization Act of 1993—the perspective of NIH clinical trialists—response. *Control Clin Trials* 16(5): 310–312
- McCaskill-Stevens W et al (2005) Increasing minority participation in cancer clinical trials: the minority-based community clinical oncology program experience. *J Clin Oncol* 23(22):5247–5254
- Kaluzny A et al (1993) Assuring access to state-of-the-art care for U.S. minority populations: the first 2 years of the minority-based community clinical oncology program. *J Natl Cancer Inst* 85(23): 1945–1950
- George S, Duran N, Norris K (2014) A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health* 104(2):e16–e31
- Evans K, Lewis M, Hudson S (2012) The role of health literacy on African American and Hispanic/Latino perspectives on cancer clinical trials. *J Cancer Educ* 27(2):299–305
- Byrne MM et al (2014) Participation in cancer clinical trials: why are patients not participating? *Med Decis Mak* 34(1):116–126
- Virani S et al (2011) Barriers to recruitment of rural patients in cancer clinical trials. *J Oncol Pract* 7(3):172–177
- Albrecht TL et al (2008) Influence of clinical communication on patients' decision making on participation in clinical trials. *J Clin Oncol* 26(16):2666–2673
- Dunlop AL et al (2011) Preconsent education about research processes improved African Americans' willingness to participate in clinical research. *J Clin Epidemiol* 64(8):872–877
- Ibrahim S and Sidani S (2013) Strategies to recruit minority persons: a systematic review. *J Immigrant Minority Health*, p 1–7
- Suro R et al. (2007) Changing faiths: Latinos and the transformation of American religion. *PHC*
- Sadler GR et al (2001) Cancer education for clergy and lay church leaders. *J Cancer Educ* 16(3):146–149
- Sadler GR et al (2012) Health promotion via deaf-friendly ministries. *J Cancer Educ* 27(4):606–611
- Koenig HG, Büssing A (2010) The Duke University Religion Index (DUREL): a five-item measure for use in epidemiological studies. *Religions* 1(1):78–85
- Blue, R., et al. (2008) Gender differences in African Americans: barriers to clinical trials participation. In *Association for Women in Psychology*. San Diego.
- Malcarne V et al. (2008) Translating and validating instruments for diverse communities: the Barriers to Clinical Trials Participation Scale. American Association of Cancer Education. Clearwater Beach, FL.
- DeHaven MJ et al (2004) Health programs in faith-based organizations: are they effective? *Am J Public Health* 94(6):1030–1036
- Asomugha CN, Derose KP, Lurie N (2011) Faith-based organizations, science, and the pursuit of health. *J Health Care Poor Underserved* 22(1):50–55