NIH Public Access

Author Manuscript

Psychiatr Serv. Author manuscript; available in PMC 2013 June 09.

Published in final edited form as:

Psychiatr Serv. 2009 October ; 60(10): 1383–1385. doi:10.1176/appi.ps.60.10.1383.

Preferences for Psychiatric Advance Directives among Latinos: How do Clients, Family Members and Clinicians View Advance Care Planning for Mental Health?

Richard A. Van Dorn, Ph.D., **Jeffrey W. Swanson, Ph.D.**, and **Marvin S. Swartz, M.D.**
Department of Psychiatry and Behavioral Sciences, Duke University Medical Center

Abstract

Objective—Psychiatric advance directives allow individuals to plan for future mental health treatment. Little is known about how minority groups, particularly Latinos, view these legal mechanisms. This paper examines demand for, and attitudes towards psychiatric advance directives among Latinos with mental illness (N=85), their family members (N=25) and their clinicians (N=30).

Method—All participants completed a one-time interview.

Results—Participants showed substantial interest in completing psychiatric advance directives, specifically in involving family or other surrogates in their preparation and execution. There were few between-group differences in attitudes towards psychiatric advance directives. These findings are compared to prior research on psychiatric advance directives.

Conclusions—Psychiatric advance directives provide an acceptable way to increase culturally appropriate services and family involvement for Latinos with mental illness. Psychiatric advance directive-interventions should capitalize on the centrality of the family in Latino culture, which could provide an opportunity to reduce mental health crises in this population.

Keywords

Psychiatric Advance Directives; Preferences; Latinos; Stakeholders; Culture

Psychiatric advance directives allow persons with mental illness to declare preferences for future treatment through an advance instruction and/or a health care agent. Initial outcomes are promising (1-5). However, the role of psychiatric advance directives in the cross-cultural context of mental health services has not been examined. These documents may play an important role for Latino individuals in US mental health care settings.

Psychiatric advance directives may represent an opportunity to align culturally appropriate services with treatment needs in Latino populations. However, no research has examined the acceptability of these documents by Latino mental health stakeholders. This study assessed demand, interest, and attitudes towards psychiatric advance directives for clients, families and clinicians.

Methods

This study includes data from 85 Latino adults with mental illness, 25 family members and 30 clinicians. Data were collected between December 2007 and June 2008. Inclusion criteria

Disclosures: None for any author

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

for clients were: Latino ethnicity; age 18+ years; diagnosis of schizophrenia or mood disorder; and lifetime psychiatric hospitalization. Clients were randomly selected from management information system data from one of South Florida's largest treatment providers. Eighty-five of 100 clients that met study criteria consented to participate. Consenters and refusers did not differ by sex, age, or diagnosis.

Family members were eligible if they had a relative who met the above criteria. Twenty of the twenty-five family members (80%) were related to a client participating in the study. Eligibility criteria for clinicians included: treating 10 or more severely mentally ill individuals in the past year; and having Latinos constitute at least 50% of their caseload. Graduate-level research assistants administered a structured interview using instruments from a recent study (3).

The interview assessed indirectly the association between "culture" and interest in psychiatric advance directives. Participants were told that culture represented unique or special factors--such as language, beliefs, attitudes, and behaviors--common to members of one ethnic group or another (6). Interviewers provided three examples: (a) use of the term *ataque de nervios* to describe mental health problems; (b) reticence to disclose personal information for fear of shaming family; and (c) use of culturally-specific treatments--*curanderismo* or *remedies*--for mental health problems.

All measures were translated to Spanish and back to English. Ninety percent of interviews were completed in Spanish. Participants were paid $25. The protocol was approved by Florida International University's IRB.

Results

The clients' mean age was 53.4±13.01 years and fifty-six (66%) were women. Sixty-eight clients (80%) were from Cuba, 9 (10%) were from Puerto Rico, and the remainder were from Colombia, Nicaragua or the Dominican Republic. Twenty-eight clients (33%) had a chart diagnosis of schizophrenia while the remaining had major depression or bipolar disorder. The sample both thought that they did not speak English well (4.26±1.33) nor were they comfortable speaking English (4.23±1.35). Both factors ranged from one to five.

The mean age of family members was 56.4±16.73 years and 17 (69%) were women. Fifteen (60%) were parents, 5 (20%) were adult children, 4 (16%) were spouses and 1 (4%) was a sibling. The mean age for clinicians was 41.19±10.64 years, 22 (73%) were women and 20 (67%) were Latino. Twenty clinicians (66%) held a Master's degree; the remaining ten were evenly divided between those with an M.D. and those with a Bachelor's degree.

Nine clients (11%) had previously expressed future treatment preferences. Five told a family member while the others told a friend. Seventy-one clients (84%) wanted to complete a psychiatric advance directive. Among those, 45 (63%) wanted both an advance instruction and health care agent; twenty (28%) wanted only a health care agent, and six (8%) wanted only an advance instruction.

Though only three family members had prior knowledge of psychiatric advance directives, 24 family members (96%) endorsed them. Similarly, 28 clinicians (93%) endorsed psychiatric advance directives, yet only three had a client with one.

Table 1 presents between-group comparisons. Clinicians were less likely to believe that psychiatric advance directives would help people stay well. Clients were less likely to think they should consult their clinician about what to write in the psychiatric advance directive.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Finally, clinicians were more likely than clients to think that psychiatric advance directives could be used to convey culturally-specific information.

Clients ranked seven factors for importance (range 1-8). Doctor-recommended treatment (*prescriptive* function) was most important (7.84±2.34). This was followed by: having a family member or friend *support* them when completing a directive (7.53±2.47); *surrogate* decision-making (7.34±2.72); avoiding unwanted treatment (*proscriptive* function) (6.09±3.09); changing one's mind when ill (*irrevocability*) (6.09±3.09); not letting family or friends know about treatment (*confidentiality*) (3.56±2.81); and involving one's *religious leader* (3.23±2.92).

Fourteen (16%) clients did not want to complete a psychiatric advance directive. The principal reason cited by 12 (86%) of those clients was not knowing what to include. The documents were viewed as to cumbersome by 11 (79%) of the clients. Not thinking advance instructions will make a difference was a concern for 10 clients (71%). Nine clients (64%) cited not liking to sign legal documents. Seven clients (50%) reported not understanding psychiatric advance directives, six (43%) indicated not having anyone to trust, including three clients (21%) that reported not having a doctor to trust.

Discussion

Empirical information has been lacking about whether psychiatric advance directives, despite their promise and potential importance, are acceptable and desired by Latinos with mental health problems. These new data show strong support for psychiatric advance directives in Latino mental health stakeholder groups. Psychiatric advance directives may compliment Latino culture by reinforcing the centrality of families by allowing for client-family collaboration in completing these documents or allowing for surrogate decision-making during crises. In prior research, 180 of 1,001 (18%) participants in a mainly African American and White sample wanted to complete only an advance instruction (7), which can limit the role of surrogates. In these data, six clients (8%) preferred a stand-alone advance instruction; however, 65 clients (92%) wanted a health care agent.

Preferences for psychiatric advance directives have also been examined (8). The strongest preference in both this and a prior study was for the prescriptive function of these documents. In the current research there was more emphasis on surrogate decision-making and less on proscriptive decisions. Participants in both studies viewed irrevocability as less important. The remaining factors were unique to this study and thus cannot be placed in the context of prior research.

Psychiatric advance directives may also address treatment barriers for Latinos. Across the three stakeholder groups, 125 participants (89%) thought that bilingual documents would improve communication between families and clinicians. Clinicians also endorsed psychiatric advance directives at a rate higher than has been found in prior research (9). Additionally, 28 (93%) clinicians thought that psychiatric advance directives could convey cultural preferences.

Social anthropologists have defined *culture* broadly as a group's shared patterns of thinking, feeling, believing, relating, and communicating—as well as the symbols and actions that link these elements together into "webs of significance" (10). From this theoretical perspective, systems of meaning may collide and break down when Spanish-speaking individuals from Latin America seek mental health care and encounter English-speaking clinicians in conventional care settings in the US. In such cases, psychiatric advance directives may play a role in "translating"—symbolically and literally—the Latino patient's past experiences, current understandings, and future preferences for treatment.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

While psychiatric advance directives may play a role in cross-cultural mental health care, culture also plays a role in the directives. First, these documents are vehicles for communication, which is intrinsic to culture. Second, subjective information conveyed in the directives is suspended in cultural beliefs about mental illness, its causes, and what should be done about it. Third, authorization of surrogate decision-makers is intertwined with social and familial relationships that are part of the web of culture. Fourth, the directive itself may acquire symbolic meaning to the individual in ways that are shaped by culture, and by the felt need for empowerment in persons who are culturally marginalized.

While this was the first study to examine these issues with Latinos, there are limitations. The samples were small, which limits multivariable analyses. The majority of participants were Cuban. More research should be conducted with other Latino groups, which would allow for an understanding of intra-ethnic differences. The clients in this study were in treatment. It is possible that Latinos not in treatment would have viewed psychiatric advance directives more negatively.

Rather than directly assessing participants' cultural views of psychiatric advance directives, we gave examples of culturally-specific concepts and views of mental health and treatment, and assessed whether such factors were associated with participants' desire for psychiatric advance directives. Future research should further explore cultural characteristics that may affect Latinos' actual use of these legal documents.

Conclusions

There has been little research into how ethnic minorities view psychiatric advance directives. This study shows high interest and demand for psychiatric advance directives among Latino mental health stakeholder groups. Latinos' interest in these documents relates strongly to their desire to involve surrogate decision makers in mental health care decisions. Latinos may also wish to use psychiatric advance directives to express culturally-specific understandings and treatment preferences.

References

1. Elbogen EB, Swanson JW, Appelbaum P, et al. Competency to complete psychiatric advance directives: Effects of facilitated decision making. Law and Human Behavior. 2007; 31:275–289. [PubMed: 17294136]
2. Elbogen EB, Swanson JW, Swartz MS, et al. Effectively implementing psychiatric advance directives to promote self-determination of treatment among people with mental illness. Psychology, Public Policy, and Law. In-press.
3. Swanson JW, Swartz MS, Elbogen EB, et al. Facilitated psychiatric advance directives: A randomized trial of an intervention to foster advance treatment planning among persons with severe mental illness. American Journal of Psychiatry. 2006; 163:1943–1951. [PubMed: 17074946]
4. Swanson JW, Swartz MS, Elbogen EB, et al. Psychiatric advance directives and reduction of coercive crisis interventions. Journal of Mental Health. 2008; 17:255–267. [PubMed: 20221301]
5. Van Dorn RA, Swanson JW, MS S, et al. Reducing barriers to completing psychiatric advance directives. Administration and Policy in Mental Health and Mental Health Services Research. 2008; 35:440–448. [PubMed: 18633699]
6. Alegria M, Takeuchi D, Canino G, et al. Considering context, place and culture: the National Latino and Asian American Study. International Journal of Methods in Psychiatric Research. 2004; 13:208–220. [PubMed: 15719529]
7. Swanson JW, Swartz MS, Ferron J, et al. Psychiatric advance directives among public mental health consumers in five U.S. cities: Prevalence, demand, and correlates. Journal of the American Academy of Psychiatry and Law. 2006; 34:43–57.

8. Swartz MS, Swanson JW, Van Dorn RA, et al. Preferences for psychiatric advance directives: Results from a randomized trial of facilitation of psychiatric advance directives. International Journal of Forensic Mental Health. 2006; 5:67–81.
9. Elbogen EB, Swartz MS, Van Dorn RA, et al. Clinician decision-making and attitudes on implementing psychiatric advance directives. Psychiatric Services. 2006; 57:350–355. [PubMed: 16524992]
10. Geertz, C. The Interpretation of Cultures. New York: Basic Books; 1973.

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

NIH-PA Author Manuscript NIH-PA Author Manuscript NIH-PA Author Manuscript

Table 1

Between-group comparisons of attitudes towards psychiatric advance directives in three Latino stakeholder groups

	Client (N=85)		Family (N=25)		Clinician (N=30)	
	n	**%**	**n**	**%**	**n**	**%**
Psychiatric advance directives will help people stay well	72	85[a]	22	88[a]	20	67[b]
Writing down advance instructions will probably not do any good[1]	52	61	11	44	21	70
Doctors and hospitals should pay a legal penalty if they fail to follow a patient's advance instruction	54	64	18	72	16	53
People with mental health problems should…						
write down what kind of medicine/treatment they want	64	75	21	84	25	83
choose someone they trust to make decisions for them if they become very ill	79	93	24	96	28	93
talk to their doctor or therapist about what to write down	60	71[a]	24	96[b]	28	93[a,b]
always be allowed to change their mind--even when they are ill--about treatment	30	35	8	32	9	30
People with mental health problems should write down advance instructions for treatment because, otherwise they might be put in a hospital	57	67	18	72	17	57
otherwise they might go without treatment that they need in order to get well	55	65	15	60	24	80
an advance instruction will give them more control over their own lives	65	76	20	80	26	87
Thinking specifically about Latinos with mental illness…						
creating psychiatric advance directivs in both English and Spanish will facilitate the effective exchange of information	75	88	23	92	27	90
psychiatric advance directives could be used to convey relevant cultural factors	55	65[a]	18	72[a,b]	28	93[b]
psychiatric advance directives could be used to help family members better communicate with clinicians	69	81	24	96	29	97
psychiatric advance directives could be used to help family members better comprehend client's needs	71	84	22	88	28	93

Note : Percentages represent "Strongly Agree" and "Agree" (other responses were "Neutral" and "Strongly Disagree" and "Disagree". Unique superscripts indicate significant between-group chi-square differences ($p < 0.05$).

[1] Percentage refers to those that "Strongly Disagree" or "Disagree" with statement