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## Recovery from Schizophrenia: The Case of Mexican-origin Consumers and Family Caregivers

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### Abstract

This study examined the views about the future of persons with schizophrenia and their caregivers to understand what's at stake in engaging in recovery. The views of 60 Mexican-origin consumer-caregiver dyads were coded by three independent raters using a recovery literature-based coding system of recovery components: social relations, care-giving burden relief, independence, self-responsibility, and empowerment. General recovery expectations were also rated. Inter-rater reliability, component frequency, and congruence between the consumers and caregivers' expectations were statistically examined. Dominant recovery components for consumers and caregivers were independence (72.5%), general expectations for recovery (51%) and social relations (43%). Relatives differed in two important ways. Consumers held significantly greater expectations for independence ( $p < .01$ ) whereas caregivers focused more on general recovery ( $p < .001$ ). What matters for recovery for this sample of Mexican-origin consumers and caregivers differs. Addressing differences in views may facilitate person-centered treatment that considers the views of consumers and caregivers.

### Keywords

recovery; serious mental illness; Mexican-origin Latinos; consumers; family caregivers

National and international discourse have embraced recovery, or the idea that individuals with serious mental illness (SMI) and mental health disability can engage in a process of change and healing. Individuals with schizophrenia are thought to be able to carry out productive and satisfying lives to achieve full human potential while living with symptoms (SAMHSA, 2005). The notion of recovery now shapes the goals and guidelines for the provision of quality care for SMI (New Freedom Commission, 2003). A number of long-term outcome studies suggest that recovery is viable as between 25–45% of individuals with

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schizophrenia experienced significant improvement characterized by relatively independent role functioning (Silverstein and Bellack, 2008).

Effective recovery-oriented care is multifaceted and key practice characteristics have been distilled from the extensive and at times divergent literature designed to guide providers in the delivery of this type of care (Boutillier et al., 2011). Key to recovery-focused practice is providing individualized, person-centered care (Bellack, 2006), which supports recovery as defined by the individual in treatment (Boutillier et al., 2011). How an individual construes appropriate recovery-focused care to meet their unique needs, preferences, goals, and ambitions is thought to be shaped by their experiences.

A context-specific conceptualization of experience proposes that experience reflects the fluctuating or ebbing intersection of the human mind, body, and social world (Kleinman, 1995; Kleinman and Seeman, 2000). Practically speaking, the connection between mind, body, and social world is reflected in “what is at stake” or what matters for an individual in a local moral world. By learning what’s at stake or what deeply matters for individuals in the experience of illness and recovery-driven treatment, clinicians can obtain experience-based knowledge about the individual that can inform the design and delivery of person-centered care (Kleinman and Benson, 2006). Understanding what’s at stake may not be a straightforward process, as individuals may find it challenging to identify what’s at stake for them in pursuing recovery when presented with the explicit question. One avenue by which a clinician can access what matters as it relates to recovery is by understanding an individual’s expectations for the future.

Individualized recovery-based treatment may be especially needed for groups that are negatively impacted by mental health disparities. Spanish-speaking Latinos, particularly Mexican origin individuals, comprise such a group. In 2014, Mexican-origin Latinos in the U.S. made up 64% of the 55.3 million U.S. Latinos (Stepler and Brown, 2016). This group encounters significant disparities in care (U.S. Department of Health & Human Services, 2001), as Spanish-speaking Mexican-origin Latinos with various mental disorders are less likely to use mental health services than other ethnic/racial groups (Alegria et al., 2007). When they do access services, Mexican-origin Latinos and other minority groups also tend to receive poorer quality mental health care (U.S. Department of Health & Human Services, 2001). For instance, once registered as clients, Spanish-speaking consumers with schizophrenia are less likely than their English-speaking counterparts to receive case management services (Barrio et al., 2003). According to the Institute of Medicine (2001), one approach for reducing the gap in quality of care is to customize care according to an individual’s needs and values. Delivering person-centered recovery-focused care that is informed by a consumer’s current and experiential background has the potential to improve quality of care. This may, in turn, help to reduce Latino mental health disparities.

Family inclusion in treatment has also been identified as a key element of comprehensive recovery-oriented care (Glynn et al., 2006). Families are widely recognized as a primary source of care for consumers with schizophrenia. Although an estimated 40% of individuals with schizophrenia in the US reside with relatives (WHO, 2001), between 70 and 90 % of Latino consumers with schizophrenia and other serious mental illnesses have been estimated

to live with relatives (Guarnaccia, 1998; Kopelowicz, 1998; Ramirez Garcia et al., 2004). Moreover, most Latinos with schizophrenia go on to live with their relatives long-term after the onset of the illness (Guarnaccia and Parra, 1996). Understanding what matters to consumers and their families in pursuing treatment and recovery and developing shared views about what matters for treatment planning, may help facilitate adjustment on the part of both the consumer and caregiver.

The recovery literature to date offers guidance on what's at stake for consumers (Bellack, 2006) in engaging in recovery. However, it offers much less guidance on what's at stake for consumers' families in engaging in the recovery and treatment processes. To our knowledge, the existing literature does not provide insight into what matters to Mexican-origin consumers and families. Efforts to understand the meaning of recovery for people from ethnic/racial minority communities have highlighted the limited availability of data on the perspectives of these groups. Our understanding of core recovery components primarily stems from the perspectives of consumers from ethnic/racial majority groups in high-income countries (Leamy et al., 2011). Available data suggests that the experience of identifying with an ethnic/racial minority group may have noteworthy implications for the meaning of recovery (Leamy et al., 2011).

Key recovery components identified to date include social relationships, which involves obtaining support from others and developing valued social roles (Cooke, 1997; Davidson et al., 2006); independence (Bellack, 2006), which can be facilitated by developing new skills and engaging in daily activities and routines (Leamy et al., 2011); and self-responsibility, which involves the consumer taking responsibility for and becoming an active participant in their care (Davidson, 1997; Deegan, 1996). Another element is empowerment, which involves the consumer being encouraged and supported to recognize and exercise their strengths and their ability to gain skill (Davidson et al., 2006), effect change in their life, and identify and pursue their self-defined life goals (Leamy et al., 2011). Empowerment also involves helping the consumer nurture and maintain hope for a fulfilling life (Hall and Purdy, 2000). The extent to which these factors are important for a consumer's recovery will depend on the consumers' unique needs, preferences, and experiences. Indeed, there are various pathways to recovery (SAMHSA, 2005).

With regard to families' perspectives on the essential factors for consumers' recovery, Kopelowicz and Liberman (2001) found that three-fourths of relatives, along with consumers, mental health professionals, and paraprofessionals, endorsed living independently and two-thirds endorsed engagement in social/recreational activities, school, and work as key to recovery. Relief of the caregiving burden may be, from caregivers' perspectives, a key recovery element. Proposed as a criterion to evaluate the clinical effectiveness of treatments (Nasrallah et al., 2005), caregiving burden relief has been thought to be an important component of recovery from the clinician and researcher viewpoint as well (Bellack, 2006). Caregivers and consumers alike may consider this element to be essential for recovery given that reducing burden is consistent with processes that are core to recovery for some consumers. Consumers may conceivably expect that by increasing independence and self-responsibility, they may achieve decreased reliance and burden on their caregivers. Recovery elements are elaborated in Table 1.

Given the limited data on the recovery elements that might be useful to consider in engaging in person-centered care with Mexican-origin individuals, we assessed what's at stake for recovery for Mexican-origin consumers and their primary family caregivers. We did this by assessing their expectations for the consumer's future. We also examined the congruence between consumers' and caregivers' expectations for recovery given that consistency (or lack thereof) between both parties may have implications for the course of recovery-driven care. Our overall aim is to advance an understanding of both consumers' and family caregivers' recovery expectancies with an eye towards how best to integrate family members in the recovery process. Consumers and caregivers' brief verbal responses were quantified in order to make appropriate and full use of the concise interview data.

## Methods

The study was part of a larger project that examined family factors and schizophrenia and was approved by the institutional review board of the University of California, Los Angeles. Study methods most pertinent to the current study are reported below; an elaboration on methods are available in Breitborde et al. (2010) and Aguilera et al. (2010).

## Participants

Participants were recruited at two local outpatient mental health centers in Southern California from 2004 to 2007. Potential participants were referred by mental health providers, who obtained consumer consent to be contacted by study investigators. Consumers were eligible for the study if they had a research-based diagnosis of schizophrenia or schizoaffective disorder and had frequent communication with a caregiver who was willing to participate in the study. Moreover, consumers and caregivers met study criteria if they were of Mexican origin, ages 18–65, did not evidence organic impairment or mental retardation, and had the ability to provide informed consent. For the larger project, data were collected from 60 Mexican-origin consumer-caregiver dyads. All dyads participated in the baseline interviews during which expectations for recovery were assessed. Table 2 presents demographic characteristics for the sample by type of participant. Caregivers were comprised of 33 mothers, 7 sisters, 6 wives/girlfriends, 6 fathers, 3 husbands, 3 daughters, 1 brother, and 1 son.

## Procedure

Eligible and consented participants completed comprehensive assessments at baseline and approximately 9 months post-baseline for the larger study at a clinic or the consumer's home. At each data collection time point, participants completed a variety of measures, including a semi-structured interview of the caregiver to assess for EE and its subconstructs in the context of discussing the development of the illness and the consumer's daily life in the last 3 months, and measures of acculturation, enculturation, symptomatology, health status, and consumer relapse. At the end of the semi-structured interview component of the assessment, each participant was asked to share his or her expectations for the consumer's future to identify what's at stake for consumers and their family caregivers. Consumers were asked, "In thinking about the future, what do you most want for yourself?" Key relatives were asked, "In thinking about the future, what do you most want for your relative?" In

general, the assessor did not utilize sub-probes following the presentation of these questions to further clarify the content provided by the participant.

Expectations for the future were assessed because the research team was interested in learning about what mattered most for each relative in thinking about the consumer given their own lived cultural experiences. An anthropological perspective is that individual experience is affected by the unfolding of a multitude of events, including but not limited to political, economic, interpersonal, psychological, and biological ones. These events comprise culture and give rise to its heterogeneous and continuously changing nature (Kleinman and Benson, 2006). Directly asking an individual what's at stake has been conceptualized as a "mini-ethnography" that enables the ethnographer (researcher or clinician) to gain insight into what a person stands to gain or lose in the context of any given experience (e.g., that of their own illness and treatment, or that of their relative's) as shaped by their lived and cultural experiences (Kleinman and Benson, 2006). Rather than ask directly, "What's at stake?" or "What matters most?," we chose to probe participants' perspectives by using an open-ended prompt that could be answered with ease and that explicitly elicited views on what mattered deeply to the respondent in relation to the consumer ("...what do you *most* want..."). Given that what matters is reflected in an individual's everyday views and actions, any responses provided by the participant was considered to reflect what's at stake for the interviewee. This includes a response to the probe on expectations. Use of the "what's at stake" approach has been proposed for and adopted in considering culture in relation to concepts and phenomena examined within the mental health, illness, and treatment arena (e.g., Jenkins and Carpenter-Song, 2005; Lakes et al., 2006; Lopez, 1997).

A specific goal was to better understand the meaning of recovery for Mexican-descent families through responses to the question on expectations. The probe was expected to produce material of relevance to recovery from SMI given that it was presented in the context of discussing at length both the consumer's illness and their daily life and was focused on the future. Recovery is seen as a process that is temporally situated in the near and distant future. The expectation probe was deemed preferable to using a direct probe about recovery because the former did not presuppose that recovery and aspects of it were salient for the participant. Use of this probe is consistent with approaches used in other studies to understand the meaning of recovery. For instance, Jenkins and Carpenter-Song (2005) adopted an open-ended interview that included questions on consumer's expectations for recovery. In their study on the recovery of African Americans with SMI, Armour et al. (2009) posed questions that are future-oriented, one of which assessed expectations for the future ("What are your life aspirations?").

For the current study, only responses on expectations for the consumer's future were used. Responses were written down verbatim or tape-recorded and later transcribed. The content produced by the probe and later coded for this study was characterized by brief responses ranging from 1–2 sentences to 1–2 full paragraphs. Interviews were conducted by the larger study's principal investigator (third author), doctoral students in psychology, and undergraduate research assistants. Interviewers were trained by the study's principal investigator and were fluently bilingual in English and Spanish. Consumers and their

caregivers were interviewed separately in their primary language and were compensated for their participation.

**Coding system**—A codebook was designed to acquire an understanding of broad, explicit, and concrete aspects of recovery. The recovery literature guided the development of codes reflecting the following expectation categories: independence, social relations, care-giving burden relief, self-responsibility, and empowerment. The definition of recovery is still developing (e.g., Silverstein and Bellack, 2008). These categories represent some of the key themes that were derived from the literature. A final category was added to identify nonspecific expectations for the consumer to engage in or achieve recovery, but not within any specific domain. We referred to this as recovery. The recovery theme was identified through an initial thematic analysis of a subset of 20 cases intended to inform the development of the codebook. Code saturation, or the point at which no additional themes or issues are identified and the codebook stabilizes (Hennink et al., 2017), was achieved by the 20<sup>th</sup> case. Methodological research indicates that code saturation can be achieved after nine interviews, consistent with prior literature. This “rule of thumb” is recommended for a study aiming to outline broad thematic issues (Hennink et al., 2017).

Sub-categories were used to delineate each major recovery code to be used in the analysis. Sub-themes encompassed different aspects of the a major theme reflected in the literature. For instance, sub-categories for independence included expectations for structured activity and expectations for financial well-being. Table 1 presents the category descriptions and definitional expectations that comprise each broad category and define coding boundaries.

**Coding procedure**—Participants’ statements about expectations for the future were coded by three raters, namely the first and third authors, and an undergraduate research assistant who had little knowledge of this field. Rater 1 coded all available data and Raters 2 and 3 coded 46% and 54% of the data, respectively. Together Raters 1 and 2 coded 45% of consumers’ responses and 47% of caregivers’ responses; Raters 1 and 3 coded the remaining responses. During coding sessions, raters coded a participant response independently and then came together to compare ratings for the response. If raters disagreed, they discussed their rationale for applying a code and then reached a consensus on the categories reflected in the response. Otherwise, they proceeded to code the next set of participant responses. Discussions during coding sessions served as continuous training, helped maintain raters’ level of skill in applying a coding system (Kobak et al., 2007), and guarded against rater drift (Mulsant et al., 2002). The raters did not code narrative content that did not fit with themes delineated a priori.

**Inter-rater agreement**—Fleiss’s (1981) criteria were used to evaluate inter-rater agreement. Raters 1 and 2 achieved high agreement on independence ( $\kappa = .87$ ), social relations ( $\kappa = .89$ ), empowerment ( $\kappa = .76$ ), and recovery ( $\kappa = .85$ ) and fair to good agreement on care-giving burden relief ( $\kappa = .66$ ) and self-responsibility ( $\kappa = .55$ ). Raters 1 and 3 achieved high agreement on independence ( $\kappa = .97$ ), social relations ( $\kappa = .85$ ), and recovery ( $\kappa = .87$ ); fair to good agreement on self-responsibility ( $\kappa = .73$ ) and empowerment ( $\kappa = .69$ ); and poor agreement on care-giving burden relief ( $\kappa = -.02$ ). Care-giving burden relief was dropped from the analyses given poor agreement and occurrence in two of the

sixty cases, indicating the limited relevance of the category in relation to the experiences of the Mexican-American families sampled.

**Data analyses**—Quantified consumer and caregiver expectations for recovery were compared using McNemar’s tests. This analytic plan was adopted over a more in-depth qualitative analytic approach as it made appropriate use of the brief response data.

## Results

In thinking about the future, most participants desired greater independence for the consumer (consumer 86.7%, caregiver 58.3%) and the fewest participants referred to self-responsibility (consumer 1.7%, caregiver 13.3%). Most consumers looked forward to greater independence. This expectation was reflected in statements such as, “[I want to] get an apartment of my own someday...” and, “[I want to] have the American Dream...have a job, ...house, bills...” Almost half of consumers desired to develop or maintain meaningful relationships with others, an expectation that is reflected in statements such as, “[I] would love to have a wife,” and, “[I want to] be a parent, get married.” Nearly one-third of consumers expressed a broad expectation for recovery, which was reflected in statements such as, “[I want to] live like an everyday normal person.” Consumers occasionally indicated a desire for empowerment, such as “[I want] to be more confident...” The expectation for self-responsibility was endorsed only once, and is reflected in the statement, “[I want to] maintain...good hygiene..., fitness, exercise, nutrition...”

Caregivers emphasized a different set of expectations. Most caregivers expressed a broad desire for their relative’s recovery (70%). For instance, they made statements such as, “[Quiero] que sea una persona normal” [(I want her to) be a normal person], and “[Quiero] que salga adelante” [(I want him) to get ahead]. Over half of caregivers wanted their relative to achieve greater independence. Examples of their statements included, “...hopefully he can work and...do for himself,” and, “[I hope] for his independence...when he feels right... that he would move [out].” Over one-third of caregivers looked for their relative to develop or keep personal relationships, reflected in statements such as, “[Yo quisiera] que encontrara una muchacha que lo aceptara como es” [(I would like him) to find a girl that will accept him as he is], and, “[I want him] to find a friend that is a real good friend, not just an acquaintance.” Few caregivers stated a desire for their relative to engage in self-responsibility, such as, “...if he needs help, [I want him] to get help to better himself.” They also infrequently expressed empowerment expectations such as, “...lo que más quiero es que ella, ella realice sus, sus, sus metas” [What I want most is that she meet her goals]. (See Table 3 for frequency of endorsement of type of recovery by consumer and caregiver.)

McNemar’s tests indicated that consumers were more likely than caregivers to hold expectations for independence ( $p = .002$ ). However, caregivers more often stated broad and nonspecific expectations for recovery ( $p < .001$ ). Caregivers also endorsed more expectations regarding self-responsibility ( $p = .02$ ). Consumers and caregivers referred to social relationship and empowerment expectations to a comparable extent.

## Discussion

Mexican-origin individuals with SMI and their caregivers differentially endorsed recovery themes. On the one hand, many more consumers referred to expectations for independence compared to their caregivers. Instances of independence included participating in meaningful activity (e.g., paid or volunteer work), achieving financial well-being, and meeting responsibilities. On the other hand, caregivers were more likely than consumers to endorse expectations for general recovery that reflected a desire for the consumer to get well without specifying the nature of the improvement. In fact, the greatest difference between consumers and caregivers was observed in the frequency with which they voiced general expectations for recovery. The main difference is that consumers primarily desire independence in specific domains of their lives whereas caregivers primarily want their loved ones to get well. Although generally endorsed infrequently, caregivers were also more likely to expect the consumer to take greater responsibility for their care compared to consumers. There were no group differences regarding establishing meaningful social connectedness or empowerment.

The very limited endorsement of caregiver burden relief, particularly by family caregivers, was surprising given that burden is related to poor outcomes for Mexican-descent caregivers of individuals with schizophrenia. Family caregivers who report high levels of caregiver burden experience greater depressive symptoms (Magaña et al., 2008) and worse health outcomes over a one-year period (Breitborde et al., 2009). Given these findings, one would anticipate caregivers to expect a relief in burden. Despite the apparent impact of burden on caregivers' lives, mitigating caregiver burden may not be at stake or salient for respondents when considered alongside other factors. Another possible explanation for the scant endorsement of burden expectation is that caregivers may perceive an obligation to care for their relative (Barrio and Dixon, 2012) and may therefore be disinclined from endorsing expectation for reductions in burden or improvements in life circumstances (e.g., reduced leisure time) that predict burden.

Experiences situated in distinct sociocultural contexts likely play an important role in the observed consumer-caregiver differences in what is at stake for recovery. Consumers are primarily men who, as a group, were approaching 40 years of age after 15 years of mental illness and over 60 percent were single. As noted in their responses, most wanted to have as full and independent lives as possible that include relationships, jobs, and fending for themselves. One consumer stated, “[Mi] meta de largo plazo es estudiar computación... hacer mi vida para mí mismo...tener una pareja...buscar trabajo” [(My) long-term goal is to study computing...make my life for myself...have a partner...look for work]. Another consumer said, “[Quiero] tener un buen trabajo, es lo primordial. [Quiero] encontrar un pareja para ayudarme a no recaer de nuevo” [(I want) to have a job, that is essential. (I want) to find a partner to help me not relapse again]. In contrast, their caregivers, who were primarily mothers, had witnessed the harmful effects of serious mental illness on their loved ones and primarily wanted them to be well, absent of the illness. One caregiver stated, “[Quiero] que se sienta lo mejor posible, básicamente...que...[él] pudiera llevar una vida los más normal posible” [I want him] to feel the best that he can, basically...that... (he) could lead as normal a life as possible]. Accomplishing independent life goals is important for



caregivers as well, just not as much as it is for consumers. The different vantage points and experiences of the consumers and caregivers in living with illness and its effects provide a compelling explanation for the differences in recovery expectations.

The practice of identifying what's at stake to gain an understanding of what's important to consider in providing person-centered care given individual current and historical experience may contribute to delivering culturally-informed care (Kleinman and Benson, 2006; Lakes et al., 2006; Lopez, 1997). The notion of what's at stake in people's daily lives is at the heart of an anthropologically-grounded conception of experience that should be of paramount concern to a culturally-sensitive provider (Kleinman and Benson, 2006). Knowledge of what matters most to a client can shape the development of a culturally-informed case conceptualization given that identifying what matters allows a clinician to account for the influence of culture on a client's behavior, views, and daily life (Lakes et al., 2006). For instance, a clinician might learn that a client really cares to be a contributing member of his family and community and that he has made unsuccessful attempts at regularly meeting responsibilities at home and volunteering. Operating from an anthropological framework, a clinician would surmise that the consumer's desire to contribute to his family and community is an important cultural view to consider in collaboratively selecting treatment targets. For a client such as this, culturally-informed goals could include scheduling and structuring activities to meet responsibilities at home and identify volunteer opportunities in the consumer's community. Since "what's at stake" is grounded in the everyday lives of every person, identifying what matters allows a clinician to understand and consider the influence of culture on any client. This strategy is particularly useful when striving to provide the highest quality culturally-sensitive care to individuals affected by mental health disparities, such as Mexican-origin Latinos.

The value of utilizing information on what matters to design culturally-sensitive person-centered care, rather than knowledge of broad cultural characteristics, is suggested by findings on consumer-caregiver differences on expectations for consumer self-responsibility for their mental health care. Consumers and caregivers are of Mexican origin, but consumers are more acculturated to the dominant culture in the U.S. than their caregivers. English is the dominant language for over 60% of the consumers whereas Spanish is the dominant language for over 60% of the caregivers. Given their greater acculturation to the U.S., greater endorsement of expectations for independence, and a positive relationship between acculturation and the EuroAmerican cultural value of individualism (Olson et al., 2013), one might have expected consumers to endorse self-responsibility more than their family caregiver; the opposite was observed. Only one consumer endorsed self-responsibility as a recovery expectation and a greater number (albeit only 8) of caregivers endorsed self-responsibility. While consumers' and caregivers' cultural characteristics, such as acculturation level, may have informed their expectations for recovery, we suggest that their distinct lived experiences or unique local social worlds likely gave shape to what mattered more in thinking about the consumer's future.

## Implications

We encourage practitioners to assess what is at stake for the individual and their caregiver to provide high-quality, person-centered, and culturally-sensitive care when working with consumers and families engaged in recovery. A useful strategy for accessing what matters to consumers and caregivers is to assess and understand expectations for the future as it relates to recovery. Given the results of this study, a provider could directly assess whether the specific recovery themes examined and highly endorsed by the Mexican-origin families sampled – namely, independence, social relations, and recovery – are endorsed by each relative involved in treatment. Learning from both relatives that what’s at stake for recovery is, for instance, improved social connections would suggest that the work of therapy for the particular family might need to be focused on helping the consumer enrich their social relationships. It would also suggest the need to draw a connection between “front-line” indicated treatment and what’s at stake for the family. In the case of serious mental illness, in which antipsychotic medication is a major cornerstone of recommended treatment (Kopelowicz et al., 2012), a provider should draw the connection between good adherence and experiencing psychiatric stability that can help enhance existing social connections and establish new relationships.

The provider should also examine the extent to which the consumer and caregiver’s views on recovery align. This study’s findings suggest the need to assess differences along the theme of independence and the endorsement of broad, unspecific wishes for improvement when working with Mexican-origin families. A provider should know of relatives’ endorsement of incongruent recovery expectations. Divergent views on the importance of attaining greater independence, for example, could lead to distinct and conflicting priorities for treatment. On the one hand, a consumer for whom independence is at stake might identify gaining paid employment as a primary treatment goal. On the other hand, the caregiver from whom self-responsibility is at stake might prioritize good medication use as the most important goal. Failing to attend to recovery expectation differences could negatively impact treatment outcomes. If the treatment plan was designed to address what matters to the consumer but not the caregiver, the caregiver may perceive that the treatment does not align with their goals and caregiver engagement and retention in treatment may be threatened. Broaching the topic of recovery expectations affords providers and families an opportunity to discuss differences and arrive at shared views on recovery and engaging in it, and may reduce conflict and increase agreement that facilitates the work of treatment.

This study increases our understanding of what is important for recovery according to family caregivers. The recovery literature to date is largely grounded in the perspectives of consumers, or individuals with SMI, and offers very little knowledge about the perspectives of family caregivers regarding consumer recovery. Another important contribution is that the study expands the recovery literature to include the point of view of ethnic minority consumers and families who are poorly represented in the literature (Leamy et al., 2011). We examined the generality of findings obtained with samples of ethnic/racial majority groups to a U.S. ethnic/racial minority sample (Sue, 1999). Our results suggest that most of the themes in the extant literature on personal recovery align with what’s at stake for many of the U.S. Mexican-origin consumers and families sampled. To our knowledge, this is the only

study to examine the perspectives of Mexican-origin consumers and their caregivers on what matters for consumers' personal recovery from SMI, and to do so by directly analyzing relatives' brief narratives.

This paper also expands the focus on recovery within the schizophrenia management and family caregiving literatures centered on Latinos by proposing an approach to engaging in recovery-focused care with members of this group. Most of the literature does not explicitly discuss recovery or how recovery-oriented care may be provided. The illness management literature focuses on effective and culturally sensitive treatments that produce positive outcomes for Latinos, including skills training that incorporates the family as learning coaches (Kopelowicz et al., 2003) and family psychoeducation (Kopelowicz et al., 2012) to improve medication adherence. (See also Lopez et al., 2002.) Recommendations for how to implement effective treatment content while engaging in recovery-focused care processes are needed. In discussing how to best support family caregivers and consumers' treatment, Barrio and Dixon (2012) provide guidelines for engaging in recovery-grounded clinical interactions with Latino and other ethnic minority consumers and families. Recovery oriented patient-family centered care involves the provider, consumer, and family being engaged in a shared-decision making process that involves sharing knowledge and information, such as about each actor's cultural and mental health beliefs, to arrive at common ground on aspects of treatment. Our recommendations to providers are consistent with Barrio and Dixon's (2012) recommendations for recovery-oriented care. Understanding and considering families' expectations for recovery is one way to access consumer and caregivers' cultural beliefs, which can be incorporated into a shared-decision making process to arrive at collaborative treatment decisions.

A limitation of this study was the use of brief participant responses on expectations for the consumer's future. Application of the coding system to elaborated participant responses may have led to greater depth and breadth of knowledge about what matters to Mexican-origin consumers and their caregivers as it relates to recovery. Future study should be conducted with more extensive data per case as this may allow a more nuanced understanding of what matters to participants in thinking about the consumers' recovery. In addition, future studies should examine consumer and caregiver factors associated with specific expectations for recovery, or what matters in engaging in the recovery process.

## Conclusion

What was at stake for recovery differed among Mexican-origin consumers and caregivers, as reflected in expectations for recovery shared in thinking about the consumer's future. Independence mattered more to consumers than to caregivers. Caregivers were more likely than consumers to make general expectations for the consumers' improvement without specifying the nature of the improvement they wished to observe. What matters given people's local social world should be considered in entering recovery-oriented treatment relationships with consumers and their families and developing treatment plans. After assessing family members' perspectives, providers can help consumers and caregivers develop a shared view of what matters in pursuing recovery to guide the collaborative work of treatment.

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**Table 1**

Expectations for recovery category descriptions and definitional expectations

| Category                 | Description   | Definition  |
|--------------------------|---|---|
| Independence             | Expectation for consumer to function independently in various spheres of life   | <ul style="list-style-type: none"> <li>• Achieve independence</li> <li>• Fulfill everyday responsibilities</li> <li>• Achieve financial well-being</li> <li>• Participate in meaningful activity (e.g., employment, volunteering)</li> </ul>  |
| Social relations         | Expectation for consumer to establish and maintain meaningful social relationships  | <ul style="list-style-type: none"> <li>• Engage in social activities</li> <li>• Engage in romantic relationships</li> <li>• Form a family</li> <li>• Live with loved ones</li> <li>• Fulfill family roles and obligations</li> </ul>  |
| Caregiving burden relief | Expectation for consumer to relieve the caregiving burden placed on the caregiver   | <ul style="list-style-type: none"> <li>• Reduce burden</li> <li>• Eliminate burden</li> </ul>   |
| Self-responsibility      | Expectation for the consumer to become self-responsible or continue to engage in self-responsibility  | <ul style="list-style-type: none"> <li>• Accept diagnosis/condition</li> <li>• Seek support through mental health system (e.g., vocational counseling, peer support)</li> <li>• Engage in illness management (e.g., comply with medication, commit to professional relationships, follow up on referrals)</li> <li>• Engage in maintaining health and well-being</li> </ul> |
| Empowerment              | Expectation for consumer to develop and maintain belief that recovery is possible, or behave in ways that reflect belief in the possibility of recovery | <ul style="list-style-type: none"> <li>• Have hope for an improved life</li> <li>• Believe in self-efficacy, such as in pursuing goals</li> <li>• Have high self-esteem</li> <li>• Attitudinally resisting the (psychological and emotional) effects of the disorder</li> <li>• Establish and pursue personal goals</li> </ul>  |
| Recovery                 | Non-specific expectation for consumer to engage in or achieve recovery  | <ul style="list-style-type: none"> <li>• Live a normal life or be a normal person</li> <li>• Improve generally or experience improvement in the condition</li> <li>• Be well or experience well-being</li> <li>• “Que siga adelante” <sup>a</sup>: “Press on” or “forge ahead”</li> <li>• “Que salga adelante” <sup>a</sup>: “Get ahead” or “flourish”</li> </ul>           |

<sup>a</sup>Idiomatic expression used by Spanish-speakers

**Table 2**

## Consumer and Caregiver Demographic Characteristics

|   | Consumers<br>( <i>n</i> = 60) | Caregivers<br>( <i>n</i> = 60) |
|---|-------------------------------|--------------------------------|
| Male: <i>n</i> (%)                          | 40 (66.67)                    | 11 (18.33)                     |
| Age: <i>M</i> ( <i>SD</i> )                 | 39.40 (11.15)                 | 55.12 (16.76)                  |
| Born in U.S.: <i>n</i> (%)                  | 33 (55.00)                    | 11 (29.73) <sup>a</sup>        |
| English primary language: <i>n</i> (%)      | 38 (63.33)                    | 22 (36.67)                     |
| Marital status                              |                               |                                |
| Single: <i>n</i> (%)                        | 37 (61.67)                    | 5 (8.30)                       |
| Married or cohabitating: <i>n</i> (%)       | 13 (21.67)                    | 34 (56.67)                     |
| Widowed or divorced/separated: <i>n</i> (%) | 10 (16.67)                    | 16 (26.67)                     |
| Education (years): <i>M</i> ( <i>SD</i> )   | 10.38 (3.54)                  | 7.96 (4.42)                    |
| Years since onset: <i>M</i> ( <i>SD</i> )   | 15.20 (8.90)                  |                                |

<sup>a</sup>Birthplace data is available for a subset of caregivers (*n* = 37)

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**Table 3**  
Frequency and Comparison of Consumers' and Caregivers' Expectations for Recovery

|                     | Consumers |      | Caregivers |      | Combined |      | $\chi^2(1)$ | <i>p</i> |
|---------------------|-----------|------|------------|------|----------|------|-------------|----------|
|                     | <i>n</i>  | %    | <i>n</i>   | %    | <i>N</i> | %    |             |          |
| Independence        | 52        | 86.7 | 35         | 58.3 | 87       | 72.5 | 9.48        | <.01     |
| Recovery            | 19        | 31.7 | 42         | 70.0 | 61       | 50.8 | 14.67       | <.001    |
| Social relations    | 29        | 48.3 | 23         | 38.3 | 52       | 43.3 | 0.83        | .36      |
| Empowerment         | 12        | 20.0 | 7          | 11.7 | 19       | 15.8 | 0.84        | .36      |
| Self-responsibility | 1         | 1.7  | 8          | 13.3 | 9        | 7.5  | 5.14        | .02      |