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Sorting it out: Eliciting consumer priorities for recovery in supportive housing

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Abstract

Objective—This study aims to understand participant priorities in their personal recovery journey and their perspectives of recovery domains.

Methods—A card sort data gathering technique was employed to elicit priorities in recovery from consumers in supportive housing programs serving formerly homeless adults with severe mental illnesses in New York City. Participants (N=38) were asked to sort 12 cards printed with recovery domains in order of importance and describe the meaning attached to each domain.

Results—Mental health (95%), physical health (89%), and housing (92%) were the domains most frequently included and prioritized in the top three rankings. Family (76%) and partner (74%) were also frequently included and endorsed as most important second only to mental health. Housing was prioritized yet rated most important less often (58%). Work, school, hobbies, program, friends and neighborhood were less frequently endorsed. ‘Card sort talk’ revealed critical understanding of participants’ priorities and their reasons for endorsing other domains less frequently.

Conclusions—Most important to participants was regaining functional independence through improved mental and physical health and access to housing. With underlying principles of efficiency and empowerment, card sort is a promising engagement technique for providers to elicit consumer priorities in their own recovery.

Introduction

A mental health system predicated on mental health recovery values is an ethical (1–2) and policy mandate (3). Widespread endorsement of the mental health recovery movement owes

much to survivor/ex-patients whose first-person accounts attest to the importance of consumer-driven service provision (4–5). Person-centered services, a core principle of the Affordable Care Act (6), can be construed as consumer self-determination in mental health treatment decisions (7–8). Research suggests that this focus on consumer-driven care is related to improved clinical outcomes (9) and the process of consumer engagement can influence perceived choice in treatment decision-making (10).

Research on consumer preferences and priorities has focused primarily within treatment settings (11–12). Byrne & Morrison (13) examined consumer preferences in treatment objectives targeting particular psychiatric symptoms (e.g. paranoia). Findings suggest consumers wanted collaborative decision making and choice in treatment modalities. Rosenheck and colleagues (14) found that some psychiatric problems were of a higher priority than others among consumers (e.g. confusion). Other studies have compared consumer versus family member preferences for intensity of support services (15) as well as consumer preferences among housing options (16), decision-making practices (17), and their family's involvement in mental health services (18). Less articulated in the literature are consumers' priorities for their lives beyond psychiatric treatment, specifically those domains they find most important to their recovery.

Scholarship on conceptual dimensions of recovery contributes a framework for understanding clinical practice and research on consumer perspectives of recovery. Building on extant recovery definitions, Whitley and Drake (19) proposed a broad taxonomy of five recovery dimensions – clinical, existential, functional, social, and physical. Clinical recovery is centered on control of medical and psychiatric symptoms. Existential recovery encompasses more nebulous factors—such as hope and self-determination. Functional recovery refers to the ability to participate in the routines of daily life. Social recovery focuses on the establishment or development of fulfilling relationships with friends, family and community members. Physical recovery encompasses improvements in physical health, potentially associated with high incidence of comorbid medical issues. Leamy and colleagues (20) synthesized research on the recovery journey using the acronym CHIME to stand for Connectedness, Hope and optimism for the future, Identity, Meaning in life, and Empowerment. Additionally, Gordon and colleagues (21) employed a consumer-driven measure of the core dimensions of recovery resulting in five higher order dimensions including belonging and relating, being and doing, thinking and feeling, resources and satisfaction with services. Building on this scholarship, this study addresses the consumer priorities as they conceptualize mental health recovery more broadly defined. Specifically, we are interested in a subgroup of consumers in supportive housing who are among the most vulnerable.

Investigations of consumer-elicited recovery preferences have rarely included vulnerable groups such as formerly homeless adults with co-morbid mental and substance use disorders. For these individuals, cumulative life adversity may introduce a broader array of needs and concerns beyond those linked to serious mental illness (22). This study employed a card sort data gathering technique with formerly homeless adults with serious mental illness to elicit their priorities in pursuing a recovering life. Building on Whitley & Drake's

(19) taxonomy, the parameters of consumer preferences included multiple dimensions of recovery. Research questions to be answered included:

1. What are participants' priorities in their recovery?
2. What do these dimensions of recovery mean for participants with histories of homelessness and co-morbid substance abuse?

In addition to answering these questions, we report on use of this technique and implications for consumer-driven elicitation in mental health services.

Methods

Card Sort Data Gathering Technique

Ordinal card sorting is a popular tactile and visual data gathering method as it retains the capacity for theoretical grounding and facility with minimal cognitive and abstract reasoning requirements for participants (23–24). The card sort technique has a long history in anthropological field research where the focus was on eliciting participant perspectives (25). In mental health research, card sort techniques have been used to identify symptoms (26–28) and provider competencies (29). In ranking card sort techniques, participants are asked to order the phenomena by the intensity of their endorsement (30). Advantages of card sort methods are their economy and capacity for eliciting relationships among multi-dimensional mixtures of phenomena (31, 23–24).

Sampling

The 38 consumer-participants were part of the New York Recovery Study (NYRS), a longitudinal qualitative study of a purposive sample of consumers entering two supportive housing programs serving homeless adults with severe mental illness meeting the inclusion criteria of serious mental illness and co-occurring substance abuse histories (details on NYRS methods can be found in Author, (22)). This sample represents all study participants still enrolled at the final (18-month) interview of the NYRS. Participants were primarily male (82%) and African American (82%), with at least some high school education (74%). On average, participants were 42 years old ($SD= 10.83$) with 6.9 years of homelessness in their lifetime (34% less than 1 year, 42% 1–3 years, 24% more than 3 years).

Data Collection

During their final interview, participants engaged in the card sort exercise. Informed by previous research in recovery as well as findings from the previous waves of data collection, 12 recovery domains were each printed on a separate 5×8 laminated card. Organized into categories, these included social (friends, family, partner), clinical (physical health, mental health, substance use), functional (work, school, meaningful activities, their current housing). Domains added to fit the circumstances of this population included their current program and their residential neighborhood.

Participants were asked to sort and rank the 12 cards in order of importance to their well-being and to leave out any that were not important to their well-being. Our use of the term 'well-being' was a proxy for 'recovery' since the latter term was not likely to be known (or

to be confused with substance abuse recovery). Participants were also asked to ‘think aloud’ and describe their reasoning behind the rank ordering as well as why some domains were omitted (32). Questions included, “Can you tell me about these topics and why you put them in this order? What makes this [name of domain] important? What made you leave these cards out?” Participants had the opportunity to add any domains not included but did not volunteer any new information that could be categorized as a new domain. The 18-month interviews were conducted from April, 2013 to July, 2014 and were audio-recorded and transcribed verbatim. Transcripts were entered into Atlas.ti for retrieval and analysis. All protocols were approved by the university human subjects committee.

Data Analysis

Descriptive statistics were calculated for frequency of each domain ranked as most important, each domain in the top three, and domains were endorsed versus omitted. Domains selected as the top three most important were included for improved reliability as an analytic strategy (31). Based upon this identification of priorities, the first and second author independently read the transcripts to identify salient quotes that reflected participants’ perspectives on what mattered in their lives and why. Transcripts were reviewed for their responses to each domain (why included or omitted, why ranked, etc.). During the independent reviews of these transcripts, memo-ing (33) was used to identify common themes in the responses as well as representative quotes. As a next step, the co-authors met to discuss their choice of themes and quotes and to reach consensus. When discrepancies occurred, they jointly re-reviewed the transcripts to ensure meanings were consistent with the rankings from the card sort.

Results

Setting Priorities: Most Frequently Endorsed Recovery Domains

Table 1 presents the frequency of participant rankings for domains as a first priority, domains ranked in the top three, and those endorsed as important at all. Mental health (95%), physical health (89%), and housing (92%) were the domains most frequently included and prioritized in the top three rankings. Family (76%) and partner (74%) were also frequently included and more often selected as most important second only to mental health. While housing was rated first less frequently, it ranked in the top three most important domains more frequently than any other domain (58%).

Mental health was ranked most important by the largest proportion of participants—one fourth--and one-half included it in their top three priorities (see Table 1). From the interviews, mental health was expressed as foundational to participants’ ability to engage in daily life. One stated, “mental health, to me, is the cornerstone. ... Can I get up today and function or do I just feel like getting up and then looking out the window and going back to lay down” (ID#226). Stress can inhibit participation in desired activities. One participant shared, “It’s not complicated. ...I’m stressin’ 24/7. I ain’t begin to use my mind yet” (ID#231) and another said, “My mental health comes first because when I hear voices I can’t function” (ID#201).

The overwhelming majority of participants (92 %) endorsed housing as important to their well-being, saying housing was important, “because you need a foundation to live” (ID#246). Participants with independent housing acknowledged the role it played in their recovery. “Having a roof over my head of my own has been one of the biggest helps in me achieving any of my success in any aspect of my life over the last few years” (ID#223). When asked how housing contributed to well-being, another shared, “You have to have peace of mind, and to have contentment so that’d be the housing situation” (ID#226). Given the lengths of homelessness found in the study sample, the primacy of the importance of housing is not surprising.

However, participants noted that the type of housing mattered. Those residing in transitional congregate housing contended that having their own place was necessary for their well-being. One stated, “I need to get a life! ... I need some space. ...I moved on from shelter to shelter, foster home to foster home, prison to prison....I need to live independently.” (ID#231). Another transitional housing resident shared, “the most important thing to me is getting my own [permanent] apartment. Once I get there, I really put a rock down, stable foundation where I could build. Right now, I can’t build ‘cause I’m standing on sand” (ID#233).

Physical health was considered important by 89%, “health is everything. If you don’t have your health, it doesn’t matter, you can’t do anything else” (ID#223). Physical health was also considered a domain where everyone is equally vulnerable. “... physical health is the most important thing ... more important than money, any relationships or anything. ..your body is a temple of God.” (ID#205). The primacy of physical health represented independence in addition to survival. “Physical health is important to me because I don’t want to become disabled to where I need people to do things for me” (ID#224).

One-fifth of participants ranked family first and 37% ranked it among their top three priorities. Participants interpreted family as important for instrumental and emotional support. For some, it is “the foundation” (ID#231) and relatives were viewed as assisting with money or shelter “family was always there for me from day one” (ID#234). Others emphasized love and connection, “Your loved ones are the people who care about you and that you care about them. That’s important to me” (ID#251). For others, family ties were burdens they could not bear. “... my kids, like I’m not going to forget about them. They should’ve been my first priority, but they can’t be first.” (ID#246). Relatives also could be demanding and stressful. “I like my family from a distance.” Another participant had no contact with his family. “I’m not strong enough to deal with my family right now, in my recovery. So I got to let them go. It’s been holding me back” (ID#213).

Partner was ranked in the top three domains for 29% of participants. The majority included partner as important (74%) even though only 7 of the 38 had a partner at the time. One participant stated “Maybe a girlfriend is nice, you know. She can talk to me...on top of what my doctor talks to me about it. She can understand” (ID#216). Another stated, “somebody to ...hang out with. To share with, to get out my own head, you know?” (ID#251). For most, speaking about a partner highlighted something they were missing, “Somebody I want back in my life” (ID#222). Participants for whom a partner was not important (26 %) explained

that they did not want a relationship that drained already limited resources or had other negative connotations. As one man stated, “seriously, girlfriends cost money” (ID#226).

Less Frequently Endorsed Recovery Domains

Domains not included or endorsed less frequently—work, school and hobbies--were often part of a life phase already completed. Some participants considered returning to work or school in the future while others felt such opportunities were in the past. “School means a lot. You know I wish I would have finished it, ... But I didn’t you know, so, that’s that.” (ID#232). Another participant stated, “I don’t work no more. I’m too old for that...” (ID#235).

Hobbies were considered less important than working. “I’m trying to find a job. Hobbies, that’s for kids” (ID#204). Another stated, “Hobbies. Yeah, that dead last.” (ID#238). One participant noted this as a problem. “Well, I have two hobbies now, playing bass [guitar] and bicycle riding ... I don’t have a bass right now and I don’t have a bike.” (ID#225). For others, hobbies “help you relax the mind ... You know I function a little more better” (ID#235).

While neighborhood was prioritized below others, it was endorsed by 74% as important. As one participant noted, “The neighborhood is very important. You could be on one of those blocks that the police is going to stop you every day or there’s a shooting--the block is very important” (ID#213). Another noted, “I hate to have to know that when I go outside I have to duck and roll so neighborhood is very important” (ID#226). Others were less concerned. “Neighborhood, well, I keep to myself, I don’t try to get into too many people business” (ID#206). In their neighborhood, participants were primarily concerned with safety from crime and police intrusion and the potential negative repercussions of personal relationships with neighbors.

As shown in Table 1, substance use was least likely to be endorsed as important (47 percent). Although all participants had histories of substance abuse by virtue of the study’s inclusion criteria, the majority viewed this to be behind them albeit a threat to their future, “Housing or friends or partner or whatever, I don’t have any of that stuff if I’m using” (ID#251). Another noted, “I don’t use or nothing like that. It’s still a factor I got to deal with” (ID#227).

Participant’s current housing and service program was not ranked highly. Some described their program as helping them ‘maintain,’ but others had negative views. As one man noted, programs “are helpful because we get things off of our chest, but...it’s the least important thing to me..., my programs be treating me like garbage, and I haven’t graduated yet” (ID#233).

Participants ranked friends as important less often because of strained or lost relationships. One said, “I put friends last because I don’t have any” (ID#225). Another talked about all of the friends he had lost over the years. “Everybody on the block I lived on, I outlived them all. I’m serious. Even the people that used to tell my mother, your son is so bad, someone is going to wind up killing him one day...I don’t know what it is. I don’t know if I’m blessed

or being punished” (ID#213). Others ranked having friends, as something to work on after they found stability. “Friends come after that, ‘cause if I don’t take care of myself ... I’m not worth anything to friends and they’re not worth anything to me” (ID#223). A participant on parole stated, “Not right now, moved from jail to parole. You can’t have friends, no...friends will tear you down” (ID#220).

Card Sort Experiences

While some study participants needed assurance that the card sort technique was not a psychological or intelligence test, most reacted positively to the experience and adapted readily to using it. Participants generally took charge of the cards to indicate their priorities and engaged quickly in self-reflection about their sorting activities. Though not intended as a form of intervention, many participants appreciated how the card sort component helped them to reflect upon and process priorities in their recovery. One participant stated, “...you could sort out in your mind the things you need to do, and, from that exercise right there, it showed, you have to get your priorities in order” (ID#202). This stood in contrast to the other forms of data collection in the study that used open-ended responses to direct elicitation. During their prior study interviews, participants spoke in depth about many of the domains listed in the card sort technique but they were not asked to rank or prioritize this information in a concise way.

Discussion and Conclusions

The card sort technique proved to be an efficient and engaging means of gaining insight into consumer priorities in their personal recovery journey. Consistently important to participants was regaining functional independence through improved mental and physical health and access to housing. Rated less important were life achievements that were perceived as too difficult to attain (school, work), in the past (substance use), or potentially problematic (family, friends, partner and neighborhood).

The narratives that accompanied card sorting proved to be critical to understanding participants’ meaning. We note that mental health was rated number one most often, yet its meaning to participants was less about symptom reduction than about their ability to participate in daily life. Similarly, ratings of family, friends and partner were made with ambivalence, i.e., wanting such relationships but cautious about their potential for trouble. This finding has clear implications for practitioners who prioritize family and social support in recovery. Previous research demonstrating the importance of family relationships among persons with schizophrenia (34–35) should be juxtaposed with research showing severely depleted social networks in this highly disadvantaged population due to premature mortality, imprisonment and estrangement (36). Thus, participants’ endorsement of the importance of family and friends is a priority but one that is not easily achieved. The somewhat older age of our study sample points to the need to pay heed to stages of life development in promoting recovery, e.g., how to restore or move past ‘lost opportunities’ for schooling and job training associated with younger adult years.

Taken together, the rankings and ‘card sort talk’ point to needs specific to this population, e.g., housing. They also provide insight into the complexities of recovery amidst multiple

inter-related problems that extend well beyond serious mental illness—poor health, unemployment and a lack of meaningful activities, substance abuse recovery and depleted social networks. If mental health recovery is approached too narrowly, service providers risk overlooking these complex problems and miss an opportunity to engage with consumers in supportive housing in a more collaborative manner.

Rank ordering recovery domains and eliciting participants' opinions while doing so is a promising technique for service providers to help consumers in supportive housing programs to identify their priorities. While a somewhat different set of domains might be used than was relevant for our study sample, the underlying principles of efficiency and empowerment render card sorting a valuable tool for person-centered decision-making (37–38). The card sort offers assistance in generating consumer-driven goals that grow from reflection on their personal priorities. As services shift to recovery-oriented practice integration, this card sort exercise engages consumers living in supportive housing, forefronts their choices for their lives and provides a concrete set of prompts while affording the freedom to attribute personal meaning to multiple recovery domains (39).

Strengths and Limitations

We note that this report was focused on a specific study population—consumers who had histories of homelessness, were predominantly nonwhite and living in supportive housing. Nevertheless, we believe that these demographic parameters apply to many consumers and supportive housing programs in large cities in the U.S. Future research on the priorities of consumers living in supportive housing and housing quality are needed in the wake of recent national initiatives to integrate service systems and promote 'housing first', or immediate access to housing and services (40). Finally, we acknowledge that this card sort technique was deployed at the end of a longitudinal study. As a result, we cannot attest to its efficacy or optimal timing of administration in real-world practice, only to its potential.

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Table 1

Participant Card Sort Rankings

Domains	Participants who ranked as first priority		Participants who ranked in top 3 priorities		Participants who included in ranked priorities	
	N	%	N	%	N	%
Mental Health	9	24	19	50	36	95
Family	8	21	14	37	29	76
Physical Health	5	13	15	39	34	89
Partner	5	13	11	29	28	74
Housing	4	11	22	58	35	92
Program	2	5	7	18	23	61
Neighborhood	2	5	6	16	28	74
Substance Use	2	5	5	13	18	47
Hobbies	1	1	1	3	28	74
Friends	0	0	6	16	28	74
Work	0	0	7	18	23	61
School	0	0	2	5	22	58