

# Self-Determination and Choice in Mental Health: Qualitative Insights From a Study of Self-Directed Care

Elizabeth C. Thomas, Ph.D., Yaara Zisman-Ilani, M.A., Ph.D., Mark S. Salzer, Ph.D.

**Objective:** Although quantitative research has begun to establish an evidence base for self-directed care (SDC) in mental health, less is known about how people with serious mental illness experience this care, especially in relation to having choices and making decisions. The purpose of this qualitative study was to examine the extent to which people with serious mental illness experienced a greater degree of choice as a result of their participation in an SDC intervention and how their experience of having choices was related to the fulfillment of three psychological needs (competence, autonomy, and relatedness) identified by self-determination theory.

**Methods:** Participants included 45 adults with serious mental illness who participated in an SDC intervention. Participants were administered open-ended questions to capture their subjective experiences of the intervention after two years of participation. Responses were quantified to examine the extent to which participants experienced

greater choice in selecting goods and services for meeting recovery goals. The authors used the constant comparison method, guided by self-determination theory, to independently code statements from participants who indicated they had experienced greater choice. The authors then discussed the statements to achieve consensus in coding.

**Results:** The majority of participants indicated they had experienced greater choice as a result of the intervention. Themes of competence, autonomy, and relatedness were well represented within participants' responses about their experience of increased choice.

**Conclusions:** SDC interventions that address competence, autonomy, and relatedness needs can facilitate decision making by people with serious mental illness as they work to achieve their recovery goals.

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Self-directed care (SDC), which has emerged as a promising model for organizing and financing mental health services, is congruent with recovery-oriented and person-centered care (1–3). Under this model, people with mental health conditions have the opportunity to select goods and services to support them in achieving their recovery goals, typically with assistance from a support broker or consultant and the availability of funds for making purchases (4). SDC aims to promote empowerment and self-determination, giving people with mental illness greater choice and control over traditional and nontraditional services and sources of support (5) to help them live full and satisfying lives (6).

People with mental health conditions, especially serious mental illness, consistently express a desire for greater involvement in making decisions about their care (7). Consequently, advocates of recovery-oriented and person-centered services have encouraged the use of approaches such as shared decision making (8). Shared decision making has become a dominant approach in medical decision making and has become increasingly popular in mental health care (9–18). Compared with more traditional, paternalistic

approaches to medical decision making (19), shared decision making emphasizes the equal contribution of patients and clinicians (20, 21). Still, shared decision making assumes that clinicians are an essential part of the decision-making

## HIGHLIGHTS

- The majority of adults with serious mental illness who participated in a self-directed care (SDC) intervention indicated they had experienced greater choice as a result of their participation.
- The participants' experience of choice was related to fulfillment of three psychological needs (competence, autonomy, and relatedness) identified by self-determination theory.
- The findings reported here not only suggest ways in which SDC may facilitate choice, but also illustrate how other interventions to empower people with serious mental illness to make decisions about their care can do so through addressing these three psychological needs.

process (20). Smith and Williams (22) have suggested a spectrum of practices to support person-centered care and recovery. Accordingly, shared decision making supports person-centered care, but SDC gives people with mental health conditions ultimate decision-making authority. This self-determinism is seen as closely aligning with the founding principles of psychiatric rehabilitation (23) and is an important yet understudied outcome in intervention research pertinent to serious mental illness.

While quantitative research has begun to establish an evidence base for SDC (3, 24), a recent learning exchange identified a need for qualitative research to further elucidate the value of self-direction from the perspective of key stakeholders (4). To date, qualitative studies have examined participants' and caregivers' views regarding the impact of SDC on recovery (25, 26), quality of life (27), and health and well-being (28). To our knowledge, only one qualitative study (29) has highlighted facilitators of or barriers to enabling patient choice and power (e.g., attitudes and values toward SDC and SDC participants and power relations and orientations among participants, service providers, and local authorities). Because the Hamilton et al. study (29) focused primarily on impediments to choice and power, in our study we aimed to further clarify how SDC may facilitate choice as seen by people with serious mental illness participating in an SDC intervention. Such knowledge is needed to further improve the capacity of SDC and related approaches to maximize empowerment and self-determination among people with serious mental illness.

To better understand the conditions that may facilitate choice in the context of SDC, we used self-determination theory (SDT) (30) as a guiding framework. Specifically, we considered how participants' experiences of choice may be related to three innate psychological needs identified by SDT—competence, autonomy, and relatedness. Competence refers to a feeling of efficacy or capability in attaining desired outcomes, which may be enhanced by helping people access the skills and tools needed to pursue recovery goals. Autonomy is defined by a having a sense of choice and control. Mental health service providers can support autonomy by offering individuals choices and minimizing the degree to which they feel pressured to choose specific options or restricted in their choice of options. Relatedness, operationalized as a feeling of being connected to and understood by others, may be facilitated by a therapeutic relationship in which warmth and empathy are conveyed consistently and unconditionally (31). According to SDT, within interpersonal contexts (e.g., mental health interventions and services), fulfillment of each of these needs is a necessary condition for goal pursuit and attainment (32). Thus addressing these needs may play a central role in facilitating choices that people with serious mental illness make as they use SDC to work toward achieving their goals.

The purpose of this study was to address two questions about the experience of choice during an SDC intervention: To what extent do people with serious mental illness

experience greater choice as a result of the intervention, and Does qualitative analysis of statements about choice, elicited through minimally structured open-ended questions, identify competence, autonomy, and relatedness as being connected to increased choice?

## METHODS

### Sample

Qualitative data were collected as part of a randomized controlled trial of SDC for people with serious mental illness. Inclusion criteria were age 18–65 years; receiving Medicaid-reimbursable services in Delaware County, Pennsylvania; diagnosis of schizophrenia spectrum, major depression, or bipolar disorder; cost profile within the 50%–90% band of all Medicaid recipients in the county; no more than two inpatient hospitalizations of 10 days per stay over a 2-year period prior to study entry; no hospitalization in the 6 months preceding study entry; and ability to understand SDC requirements and express interest in working with a recovery coach. These criteria were used to select participants who were relatively stable with their current services and who could take full advantage of the intervention.

### Intervention

The SDC intervention was manualized and included the assistance of a trained and certified peer specialist (i.e., recovery coach) and availability of cash funds (i.e., Freedom Funds) that participants could use to purchase nontraditional goods and services. Examples of nontraditional goods and services included gym memberships, household furnishings, and driving lessons and/or test fees (5). Participants could continue to access previously received services. An initial appointment with the recovery coach was scheduled within a week of assignment to the intervention group. The recovery coach helped participants develop recovery goals and make decisions about how to use services and support to attain them, submitted Freedom Fund requests to the Medicaid managed care organization, and assisted participants with making and monitoring purchases once their requests were approved. Participants determined the frequency and number of meetings with the recovery coach, but monthly meetings were recommended.

### Procedure

The study was approved by the institutional review board of the researchers' academic institution. Recruitment took place from January 2010 to March 2011. A total of 744 individuals met eligibility criteria on the basis of county records. Researchers contacted eligible individuals to explain the study and assess interest in participation. Of those eligible, 120 were enrolled after receiving a thorough description of study procedures and providing written informed consent. Reasons for nonenrollment included the following: not able to be reached (N=229), not able to provide informed consent (N=35), not interested in the study (N=182), interested but

not enrolled (N=168), and found to be ineligible (N=10). Of those enrolled, 60 were randomly assigned to receive SDC and 60 were assigned to services as usual. This study used data only from the SDC group. Of the 60 randomly assigned to receive SDC, qualitative data were available from 45 participants. Reasons for missing data included loss to follow-up (N=11), deceased (N=2), and individual did not participate in SDC (N=2).

### Measures

Participants receiving SDC were asked open-ended questions by a research assistant to capture their experiences with the intervention after 2 years of participation. For example, participants were asked, “Do you feel like you have more choices about the services you receive for your mental health problems? If yes, why? If no, why?” We did not specifically ask participants about competence, autonomy, or relatedness, thus enabling us to assess the degree to which content related to these needs arose spontaneously in the participants’ discussions of their experience of choice. Responses to open-ended questions were audio-recorded, anonymized, and transcribed verbatim.

### Data Analysis

To address research question 1, the number and proportion of “yes” versus “no” responses to the question “Do you feel like you have more choices about the services you receive for your mental health problems?” was calculated.

To address research question 2, an integrated approach was used, enabling both inductive (i.e., data-driven) coding of participants’ responses as well as a deductive (i.e., theory-driven) framework to organize the codes (33). The first author (E.C.T.) read open-ended responses from participants who indicated they had experienced greater choice because of the intervention, making notes about participants’ experiences of choice to facilitate development of an initial draft of coding categories. These categories were reviewed by the two other authors (Y.Z.-I. and M.S.S.) and revised accordingly. Using the constant comparison method (34) and the preliminary coding guide, the first author and a research assistant independently coded responses to open-ended questions; differences in coding were discussed between them to reach consensus, which was achieved through iterative refinement of the coding guide. The final coding of open-ended responses was double-checked by the authors for accuracy after finalization of the guide. Then, guided by SDT, the interrelationships between codes were discussed among the authors to finalize grouping into themes and subthemes. Data analysis was performed with NVivo 12 Plus (QSR International).

## RESULTS

### Participant Characteristics

As shown in Table 1, most participants were middle-aged, single women. The majority identified as white or black.

**TABLE 1. Baseline demographic characteristics of 45 participants in a study of self-determination and choice among individuals with serious mental illness**

Variable	N	%
Gender		
Men	13	29
Women	32	71
Race-ethnicity <sup>a</sup>		
White	22	49
Black	19	42
Latino	3	7
Native American	2	4
Asian	1	2
Other	3	7
Education (years)		
<12	7	15
12 or GED	17	38
>12	21	47
Marital status		
Single	22	49
Married	3	7
Significant other, but not married	13	29
Age (M±SD)	45.48±10.80	
Diagnosis <sup>b</sup>		
Major depressive disorder	19	42
Bipolar disorder	11	24
Schizoaffective disorder	9	20
Schizophrenia	5	11
Mood disorder not otherwise specified	1	2

<sup>a</sup> Ethnic categories are not mutually exclusive.

<sup>b</sup> Diagnoses were determined according to participants’ self-report.

Slightly less than half had completed some postsecondary education. Most had affective disorder diagnoses; a smaller percentage had schizophrenia or schizoaffective disorder diagnoses.

### Greater Choice in Services

Most participants receiving the SDC intervention (N=37; 82%) indicated they experienced greater choice in services and support because of the intervention. A minority reported that they did not experience greater choice for the following reasons: could access the same sources of support and services without SDC (N=1); did not take advantage of SDC (N=1); ideas did not move forward into action (N=1); did not have enough money to access desired services and support (N=1); not offered choices (N=1); intervention was not beneficial (N=1); and no reason or unclear response given (N=2).

### Themes of Competence, Autonomy, and Relatedness

Competence, autonomy, and relatedness themes were well represented within participants’ responses about their experience of increased choice. A minority of statements could not be categorized according to these themes and were coded as miscellaneous support. Some participants made statements that were categorized according to multiple themes or subthemes. Themes, subthemes, and example quotations are provided in Table 2 and are expanded on below.

**TABLE 2. Themes and subthemes related to participants' experience of choice in self-directed care (SDC)<sup>a</sup>**

Theme and subtheme	Description	Example
<b>Competence</b>		
Access to financial resources (cash funds)	Participants expressed that because of the availability of cash funds as part of the SDC intervention, they had the means to access more goods/services to achieve desired goals.	"I now crochet. I never would have had the money to buy materials before."
Access to nontraditional goods or services	Participants said that they had the ability to access options other than those traditionally offered because of the intervention.	"I can think outside the box in regard to what will make me more independent."
Knowledge and information	Participants described learning more about goods/services available or being provided with information in order to make decisions about or access goods/services.	"They gave me a list of places to go for activities and volunteering."
<b>Autonomy</b>		
Offered choices	Participants said that they had more choices because they were offered choices.	"Unlike the traditional care I used to receive, they actually offered things to me even if I didn't take it."
Opportunities for autonomous decision making	Participants indicated that they had the ability to make choices by themselves for themselves.	"I have a say in what I want to do in terms of services."
<b>Relatedness</b>		
Emotional support	Participants said that the recovery coach empathized, listened, or accompanied them to an activity in order to provide moral support.	"I have a person to talk to"; "I go to meetings with the recovery coach. I'm too scared doing this on my own."
Peer support	Participants commented about how they had greater choice because of the unique benefits of working with a recovery coach with lived experience of a mental health condition.	"[Recovery coach] knew a lot more resources than someone who wasn't in recovery."
Miscellaneous support	Participants described being supported to make choices, but did not specify how.	"They gave me support in ways other places didn't."

<sup>a</sup> Themes in this table were generated from participants who responded "yes" to the question, "Do you feel like you have more choices about the services you receive for your mental health problems?"

**Competence.** Fourteen participants described factors that made them feel capable of achieving desired recovery outcomes. Two participants indicated that the ability to follow through on choices was made possible through access to financial resources, namely the cash funds provided as part of SDC. Similarly, participants (N=4) described having an ability to choose and access nontraditional goods and services in support of their recovery goals (e.g., "[I had the] ability to take classes and go on trips that weren't available to me before the program"). Finally, nine participants experienced competence through a growth in knowledge about their options or about how to access or use services. As one participant stated, "I found there are a lot of agencies and things available, and I've learned how to benefit and take advantage of all of them."

**Autonomy.** Seventeen participants provided statements consistent with the theme of autonomy. Many (N=10) expressed that they experienced greater choice simply because they were offered options. Some felt that they had "more options" because of their participation in SDC. Others commented on how the recovery coach made them aware of their options. Another group (N=10) described having opportunities for autonomous decision making. These participants felt that they were in control of making choices for themselves (e.g., "I can choose what I want to do" [emphasis

added by authors], "not them making the choice for me," and "I'm in control of the treatment I want—have a choice").

**Relatedness.** Seven participants indicated that relatedness was involved in their experience of greater choice. Two participants provided examples of how the recovery coach provided emotional support. Having a person "to talk to" and to "go to meetings with" were viewed as being important facilitators of choice. Five others noted that they experienced greater choice because of having a recovery coach who had lived experience with a mental health condition. One participant stated that the recovery coach shared information about his or her personal experiences with medications, which then had an impact on the participant's choice about his or her own medication. Other participants felt that because the recovery coach had lived experience, he or she was more familiar with the available options than someone who was not in recovery and thus was able to offer them more options. Another participant said it was helpful to "know that there are others with the same problem [who are] coping with it."

**Miscellaneous support.** Nine participants made reference to what we coded as miscellaneous support. "More of a connection to services," "more support," "explaining [things] to me in a way so I can make my own decision," and "another

opinion” were all examples of statements coded as relating to miscellaneous support.

## DISCUSSION

This study corroborates and extends findings from other research demonstrating a positive relationship between participation in SDC and outcomes related to having greater choice and control in the selection of services for supporting recovery goals (3, 29). The majority of participants reported experiencing greater choice as a result of participation in SDC. This study also contributes to the small qualitative literature on SDC, increasing understanding of how SDC facilitates choice from the perspective of people with serious mental illness. Finally, while previous research has used SDT to explain clinical outcomes (e.g., treatment engagement, quality of life) among people with serious mental illness (35, 36), to our knowledge, this is the first study to apply this framework to the experience of choice in this population. Participants’ statements indeed reflected how competence, autonomy, and relatedness were connected to their experience of increased choice and indicated specific ways in which SDC addressed these needs.

Our results suggest that competence may be addressed in part through provision of instrumental support, such as financial resources and facilitated access to desired services and supports. Although financial support would presumably be helpful to most people, it may especially be important for people with serious mental illnesses, who disproportionately experience financial concerns (37), economic and health disparities (38–40), and consequently, poor access to mental health care (41). Previous studies of SDC demonstrate that personal budgets are often used to meet basic needs (5, 6, 26, 42), which are seen as prerequisite to making decisions about and pursuing recovery goals (26). Therefore, the use of special funds as part of SDC not only provides the means to make necessary purchases but also empowers people to consider higher-order needs and desires by enhancing feelings of capability to achieve desired outcomes.

Competence also may be promoted by empowering people through information about their options for mental health services and community-based support. The participants’ perception that information facilitates choice is in accord with discussions within the treatment decision-making literature. Addressing information needs is imperative to facilitating decisions about treatment options (43) and is a standard component of decision support tools (44, 45). A recent systematic review on barriers to and facilitators of treatment decision-making capacity among individuals with psychosis found that capacity was significantly improved among individuals who received information repeatedly and in a simplified manner (46). Similar findings were reported in a study that included individuals with bipolar disorder (47). Taken together, results from this study and other research suggest that mental health providers can enhance competence, and thereby facilitate self-determined choice,

by providing information about options in a way that is clear, memorable, and easy to understand.

Autonomy may be enhanced by offering people options about their services and support and giving them opportunities to make decisions for themselves. Although research has suggested that the involvement of people with mental health conditions in making decisions about their care is an ethical imperative that improves treatment adherence and health outcomes (48), many mental health providers remain concerned about impaired decision-making capacity (49–51) and so are less likely to share treatment options and decisions with their clients. Yet, autonomy is a basic psychological need (30), that, according to our qualitative investigation, is highly valued by individuals with serious mental illness. A number of strategies, such as patient and provider education, use of decision support tools, and supported decision-making approaches, may be used to mitigate barriers to the involvement of people with mental illness in making treatment decisions (52, 53).

Finally, relatedness may be affected by the working relationship between the recovery coach and the individual participating in SDC. Participants appreciated having someone to talk to about their experiences and recovery goals and someone who would accompany them to community spaces. They directly connected these relational elements of SDC to their experience of choice, further supporting the social process that is often involved in decision making about mental health services (54). Further, the results of this study suggest that SDC may confer additional benefits when delivered by a peer. Participants felt that because the recovery coach also had lived experience with a mental health condition, he or she was able to provide them with practical information that assisted with decision making, expanded the options available to them, and connected with them in a way that supported their self-determination. These findings are consistent with research demonstrating a positive relationship between participation in peer-delivered interventions and self-determination (55) and involvement in decision making (56, 57).

A few limitations of this study merit discussion. First, we did not collect qualitative data through in-depth interviews but via brief, open-ended questions related to different aspects of the SDC intervention. It is possible that we did not adequately capture the range of individuals’ viewpoints, ideas, and experiences. Second, we were unable to conduct member checking to ensure that we accurately recorded what participants reported. Thus the comprehensiveness and validity of current findings should be assessed in future research. Third, while obtaining qualitative data on SDC from the perspective of key stakeholders is considered a strength, the subjective nature of the data precluded our ability to distinguish between actual versus perceived competency, autonomy, and relatedness. Simply perceiving that these needs have been met may facilitate choice; this is an inquiry for further study. Finally, participants assigned to the control condition were not asked open-ended questions



about choice. Future research could examine and compare the degree to which competence, autonomy, and relatedness themes emerge and are related to the experience of choice in the context of other care models or within other patient populations (e.g., those with physical illnesses or diverse demographic or clinical characteristics).

## CONCLUSIONS

SDC is an approach that is person-centered and facilitates empowerment and self-determination. This study suggests ways in which SDC may facilitate choice. In addition, it also illustrates how other interventions that seek to empower people with serious mental illnesses to make decisions about their care can do so through addressing the three psychological needs identified by SDT—competence, autonomy, and relatedness.

## AUTHOR AND ARTICLE INFORMATION

College of Public Health, Temple University, Philadelphia. Send correspondence to Dr. Thomas (tug66715@temple.edu).

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