Exploring Personal Medicine as Part of Self-Directed Care: Expanding Perspectives on Medical Necessity

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Objective: Self-directed care (SDC) offers flexibility in and control over mental health services. This study examined the types of goods and services that individuals with serious mental illness request in an SDC intervention.

Methods: Data were from a randomized controlled trial that enrolled adult participants receiving Medicaid-reimbursed services, with two years of expenditures at the 50%-90% level of all Medicaid enrollees in the county and no hospitalizations within six months of the study. Data were analyzed for 60 participants randomly assigned to an SDC intervention, who were allowed to make requests for and purchase nontraditional goods and services through a noncapitated fund. Requests were coded by using the section on activities and participation of the World Health Organization's International Classification of Function, Disability, and Health (ICF) model. Descriptive statistics are presented for the categories of requests made by participants.

Results: The 60 participants made a total of 507 requests, representing 621 ICF codes. Requests ranged from 0 to 37 requests per person, with a mean of 8.45 requests. The average time to first request was 95.5 days. Most codes were in the area of self-care (19%) and general tasks and demands (19%). Among the 52 participants who made requests, the mean was 11.94 requests, which addressed an average of 5.60 unique needs.

Conclusions: Individuals with serious mental illness identified personal-medicine strategies to address needs that are currently unmet by traditional mental health services. Selfdirected care may be a service delivery option that allows consumers to access their own personal medicine and better address their needs.

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Self-directed care (SDC) offers individuals increased decision making and flexibility in the types and amounts of services received to address mental health needs (1). Promising SDC outcomes in mental health services have been reported in Florida (1), and recent guidance has been offered on standards for including SDC as part of home- and community-based long-term services related to Section 2402(a) of the Affordable Care Act (2). SDC allows for maximum personalization of services by enabling individuals to identify and select the services they believe will facilitate their mental health and wellness goals.

SDC goes beyond "person-centered planning," in which treatment decisions are often made by the provider in collaboration with the consumer, by placing consumers in control of treatment decisions and offering nontraditional opportunities to improve mental health. These choices are their own "personal medicine" (3). Personal medicine includes strategies to reduce stress and increase engagement in meaningful activities (3). The ability to adhere to personal medicine contributes to increased self-esteem and a reduction in traditional psychiatric symptoms, such as symptoms of depression and positive and negative symptoms (3). Personal medicine may include not only medications, psychiatry visits, and case management supports but also workouts at a gym, yoga classes, and employment, in which case a car repair or a new set of clothes may be necessary for successful engagement. Engagement in meaningful activities (for example, yoga) and personally valued roles (for example, work) has frequently been cited as an important element in recovery (4-8).

Personal medicine that enhances engagement in meaningful activities is also consistent with the International Classification of Functioning, Disability and Health (ICF) model (9), which views health in three domains: body function and structure, activities, and participation. Body function and structure encompass areas typically addressed through traditional medicine (for example, symptoms, cognitive functions, and structures of the nervous system), activities address the individual's ability to perform a specific task (for example, grooming and dressing), and participation focuses on levels of engagement in community life. These domains are viewed as interactive and as indicators of health.

The implementation of an SDC program in Delaware County, Pennsylvania, provided a unique opportunity to examine what consumers request—either directly as personal medicine or as goods and services that facilitate personal medicine—to enhance mental health and wellness beyond traditional "in-plan" services. Unlike other studies that simply examined consumer perspectives on quality of care (10), an examination of SDC "requests" allowed us to examine the nontraditional goods and services that consumers seek when given the opportunity and the extent to which these requests vary across individuals. In doing so, we can better understand consumers' personal medicine and its requisite facilitators and design services to better fit consumers' needs. Therefore, the purpose of this study was to answer the following research questions. To what extent do individuals with serious mental illness have unmet needs outside traditional, reimbursable services? What percentage of individuals request nontraditional goods or services when given the opportunity, and how long does it take for them to initiate the request? What community participation needs are addressed by the purchase of nontraditional goods or services, and to what extent do these needs vary within and across individuals?

METHODS

Procedures

Data were from a randomized controlled trial examining the effectiveness of SDC on psychosocial outcomes in a non-acute group of individuals with serious mental illness receiving relatively intensive treatment supports. Inclusion criteria were as follows: age 18–65; receiving Medicaid-reimbursed services in Delaware County, Pennsylvania, for either a schizophrenia spectrum disorder, major depression, or bipolar disorder; two-years of Medicaid expenditures at the 50%–90% level of all recipients in the county; two or fewer inpatient hospitalizations of at least ten days in the two years preceding the study; and no hospitalization within six months before entering the study. The study targeted consumers who were stable with the services they received and who could take full advantage of SDC.

After the study received approval from the Temple University Institutional Review Board, a total of 744 individuals were identified as eligible. Recruitment occurred from January 2010 to March 2011. Researchers phoned eligible individuals to explain the study. Staff scheduled a meeting with interested individuals to review the consent form and complete a baseline interview. Of the 744 eligible individuals, 515 were reached. Of these, 35 could not consent, 182 were uninterested, 168 were interested but never enrolled, and ten were deemed ineligible at a later date. Included in the final sample were 120 participants who were randomly assigned to either the services as usual (N=60) or SDC (N=60). The study reported here analyzed data from the SDC group.

Individuals assigned to SDC were given the opportunity to meet with a recovery coach trained as a certified peer specialist. The coach worked with individuals to develop recovery goals and identify desires to engage in meaningful social roles; reviewed current services, utilization patterns, and service costs; and discussed the extent to which participants felt services were facilitating movement toward recovery goals, whether they wanted to keep using or reduce services, and what other goods or services might help them achieve their recovery goals.

The coach worked with the individual to link requests for desired nontraditional goods or services (that is, "outof-plan" items) to their recovery plan with a justification from the consumer's perspective and to submit the request and estimated cost to the SDC program director for approval. The request was routed to the Medicaid managed behavioral health care organization, which assessed it for medical necessity (defined as assisting the individual "to achieve or maintain maximum functional capacity" [11]) and approved or denied the request. Approval never took longer than one week and typically occurred in 24 to 48 hours. No requests were denied. Following approval, consumers received access to Freedom Funds, a noncapitated, essentially cash fund, through a debit card to purchase the nontraditional goods or services. Coaches were trained to support the individual to acquire the goods or services and helped monitor purchases.

Data

Justifications associated with each request were categorized by using ICF codes from the following chapters of the section on activities and participation (9): general tasks; selfcare; domestic life; mobility; community, social, and civic life; and major life areas (Table 1). Coders used all information from the justification to generate a primary code. A request that facilitated more than one area of participation received a second code. For example, a dually coded item was a request for a monthly transportation pass. In the justification, the participant identified the need for greater mobility and the need to find gainful employment. Therefore, this request addressed two participation needs: using public transportation (D4702) and acquiring a job (D8450). Two research staff independently coded the data. They agreed on 271 of 507 requests (53%). When discrepancies arose, a third coder independently rated requests. When agreement between the third coder and one of the previous coders occurred, this code was used. Two additional coders were included to discuss the relatively few requests (<10%) in which agreement could not be reached, and a final code was assigned by consensus.

Analysis

Descriptive statistics are presented on the categories in which requests were made and the diversity of requests within and between participants.

RESULTS

Sample

Among the 60 SDC participants, 43 (72%) were females and 17 (28%) males, with a mean \pm SD age of 44.9 \pm 10.5. Most

participants identified as white (N=27, 45%) or black (N=27, 45%), five (8%) identified as Hispanic, and six (10%) identified as another race (some participants identified as more than one race; percentages are greater than 100%). Most (N=34, 57%) were single and never married, and 19 (32%) reported having a significant other. Twenty-eight (47%) had more than a high school education, 19 (32%) had no higher than a high school education, and 12 (20%) had less than a high school education. Twenty-five participants (42%) had major depression, 19 (32%) had bipolar disorder, and 16 (27%) had a schizophrenia spectrum disorder.

Coded Requests

The 60 SDC participants made a total of 507 participation requests, ranging from 0 to 37 requests per person, with a mean of 8.5 ± 7.4 requests per person. Eight (13%) of the 60 participants made no requests for nontraditional goods or services. The time required to make the first request ranged from 14 to 331 days, with a mean of 95.5 ± 88.0 days.

Table 1 presents descriptions of the codes and the number and percentage of requests in each category for the entire sample and by diagnosis. Of the 507 requests made by the 60 participants, 114 targeted participation in at least two areas, resulting in a total of 621 coded requests (393 single-coded requests plus 228 dually coded requests). Requests were evenly distributed across the primary ICF chapters (Table 1): general tasks and demands (19%); self-care (19%); domestic life (18%); mobility (16%); community, social, and civic life (15%); and major life areas (13%). The most frequently identified individual codes were managing diet and fitness (9%), using public transportation (9%), handling stress (7%), looking after one's health (6%), and acquisition of a place to live (6%). Examples of requests and justifications for these codes are presented in Table 2.

Different needs were identified across diagnostic groups. Individuals with a schizophrenia spectrum disorder made a total of 124 requests. Needs in self-care were most frequently identified (33%). The top three individual codes for individuals with a schizophrenia spectrum disorder were managing diet and fitness (21%), acquiring a job (10%), and using public transportation (7%). Examples, respectively, included workout shoes, a printer and ink for résumés, and a transportation pass. Participants with major depression made 289 requests. Eighty (28%) of their requests were in the area of general tasks and demands, and 21% were in the area of domestic life. The top three individual codes for those with major depression were using public transportation (12%), maintaining one's health (9%), and handling stress (9%). Examples of requests, respectively, included a public transportation pass, a therapy copay, and money to pay the electric bill. Individuals with bipolar disorder made 208 requests, and most needs were identified in the area of general tasks and demands (27%). The top three individual codes for individuals with bipolar disorder were using private motorized transportation (9%), handling stress (7%), and managing diet and fitness (7%). Examples of requests,

respectively, included a driving test fee, a divorce fee, and a gym membership.

Among the 52 participants who made requests, the mean per person was 11.9 ± 8.1 requests, which addressed a mean of 5.6 ± 3.3 unique needs (that is, different codes). On average, needs were identified in 3.6 ± 1.6 domains. Nearly 75% of the participants (N=38) identified needs in at least three domains. Only six participants (12%) made requests coded into a single category.

DISCUSSION

These data suggest that when given the opportunity, the overwhelming majority of individuals with serious mental illness are able to identify a number of goods or services not traditionally available through Medicaid that would facilitate their mental health. Moreover, the breadth of requests across domains and individuals appears to reflect the diversity of needs that can be addressed through innovative service delivery models, such as SDC, to maximize the ability to provide truly individualized care.

Individuals with serious mental illness clearly have unmet needs, but their identification of those needs may take a significant amount of time. Participants took an average of 95 days to initiate their first request. A possible explanation is that consumers commonly play a passive role in treatment decisions (12). SDC represents a major shift in how services are delivered and requires that consumers play more active roles. Consumers may need time to adapt to the promotion of autonomy and ability to self-direct service decisions. Another possible explanation is that study enrollment coincided with the start of SDC implementation, and the program was not mature; however, recruitment occurred over a two-year period, so any such effect should have diminished.

A large number of requests facilitated engagement in activities commonly emphasized in the mental health system, including diet and fitness, transportation, handling stress, and maintaining health. The most frequently identified need was in the area of diet and fitness. High rates of obesity (13), sedentary behavior (13-17), and poor nutrition (18) among individuals with serious mental illness are well documented. Research has drawn attention to the needs of community mental health centers to support the general medical health needs of consumers (19). In addition to primary care, mental health agencies may offer lifestyle interventions focused on agency-based activities (for example, exercise groups and nutrition groups). However, participants in this study requested items that facilitated independent engagement in healthy lifestyles (for example, gym memberships). The desire for these types of goods or services suggests that the current offerings from mental health agencies are inadequate to meet consumer needs.

Equally important were participation needs in the area of using public transportation, which accounted for 9% of overall requests. Research has often cited the impact of transportation barriers among individuals with serious

TABLE 1. ICF codes assigned to requests for nontraditional goods and services made by 52 participants in a self-directed care program, overall and by diagnostic group^a

program, overall and by diagnostic group ^a				-				
	Requests							
	Total (N=621)		Bipolar disorder (N=208)		Major depression (N=289)		Schizophrenia spectrum disorder (N=124)	
ICF chapter, definition, and codes	N	%	N	%	N	%	N	%
General tasks and demands: goods or services that facilitate actions associated with carrying out single or multiple tasks; organizing one's routine; managing stress								
2301 Managing daily routine 2400 Handling responsibilities	20 19	3 3	7 14	3 7	13 4	5 1	0 1	_ 1
2401 Handling stress	43	7	15	7	25	9	3	2
2402 Handling crises	2	<1	0	_	13	5	2	2
2403 Handling depression	24	4	10	5	24	8	1	1
2404 Handling anxiety	12	2	10	5	1	<1	1	1
Total	120	19	56	27	80	28	8	7
Mobility: goods or services that facilitate one's ability to change location either through human-powered or motorized transportation 4500 Walking	1	<1	0	_	1	<1	0	
4701 Using private motorized transportation (driving, rides with others)	33	5	18	9	8	3	7	6
4702 Using public transportation (bus, taxi, etc.)	57	9	13	6	35	12	9	7
4000 Movement, other	9	2	0	_	4	1	5	4
Total	100	16	31	15	48	16	21	17
Self-care: goods or services that facilitate one's ability to care for self through grooming, fitness, attending doctor appointments, or generally looking after one's health								
5200 Caring for body parts (grooming, including hair appointments)	4	1	1	1	1	1	2	2
5400 Dressing	9	2	3	1	2	1	4	3
5500 Eating	6	1	4	2	2	1	0	_
5701 Managing diet and fitness	58 38	9	15 4	7 2	17 26	6 9	26 8	21 7
5702 Maintaining and looking after one's health (includes doctor appointments, immunizations, and examinations)	30	0	4	2	20	9	0	/
5980 Self-care, other (rest and sleep)	2	<1	0	_	2	1	0	_
Total	117	19	27	13	50	18	40	33
Domestic life: goods or services that facilitate one's ability to carry out domestic tasks required in day-to-day living, including acquiring and maintaining a place to live, acquiring and preparing food, cleaning, caring for household objects, and caring for others								
6100 Acquisition of a place to live (includes renting, purchasing, and furnishing living quarters and paying for necessary utilities)	37	6	8	4	22	8	7	6
6200 Acquisition of goods and services (shopping, etc.)	24	4	9	4	10	4	5	4
6300 Preparation of meals (includes purchase of meal preparation items)	4	1	1	1	3	1	0	_
6500 Caring for household objects (plants, clothing, etc.)	1	<1	0	_	1	<1	0	_
6501 Maintaining dwelling and furnishings 6503 Maintaining vehicles	31 15	5 2	7 10	3 5	20 3	7 1	4 2	3 2
6600 Assisting others (includes caring for pets)	13	<1	10	1	0	_	0	_
Total	113	18	36	18	59	21	18	15
Major life area: goods or services that facilitate the involvement in tasks or actions required to participate in education, work or employment, or volunteering								
8100 Informal education	3	1	0	_	2	1	1	1
8200 School education (formal)	6	1	6	3	0	_	0	_
8250 Vocational education	2	<1	0	_	2	1	0	_
8300 Higher education	12	2	5	2	3	1	4	3
8450 Acquiring a job (applying for a job, interviewing, and résumé development) 8451 Maintaining a job	36 8	6	11 5	5	13	5	12	10
8451 Maintaining a job 8550 Nonremunerative employment	10	2	0	2	3 4	1 1	0 6	_ 5
Total	77	13	27	12	27	10	23	19
								continued

TABLE 1, continued

	Requests								
Total (N=621				rder	der depression		Schizophrenia spectrum disorder (N=124)		
ICF chapter, definition, and codes	N	%	N	%	N	%	N	%	
Community, social, and civic life: goods or services that facilitate activities and tasks that occur in social and community life									
9100 Informal associations (groups and clubs based on similar interest, such as gardening, sports, and nature)	1	<1	1	1	0	_	0	_	
9102 Ceremonies	1	<1	1	1	0	_	0	_	
9200 Play (games and play, both structured and unstructured)	2	<1	2	1	0	_	0	_	
9201 Sports (includes participation in or watching formal and informal sports, including practice and exercise)	9	2	3	1	0	_	6	5	
9202 Arts and culture (includes creating and observing art, theater, music, and culture)	15	2	2	1	13	5	0	_	
9203 Crafts (engaging in handiwork)	3	1	1	1	1	<1	1	1	
9204 Hobbies	1	<1	1	1	0	_	0	_	
9205 Socializing (informal gatherings with others)	24	4	8	4	13	5	3	2	
9208 Recreation and leisure, other specified (includes entertainment, such as listening to music, watching television, reading, and purchasing cable)	26	4	11	5	12	4	3	2	
9210 Recreation and leisure, other specified (thinking and contemplation)	1	<1	0	_	1	<1	0	_	
9300 Organized religion	8	1	1	1	6	2	1	1	
9301 Spirituality	3	1	0	_	3	1	0	_	
Total	94	15	31	17	49	17	14	11	

^a ICF, International Classification of Function, Disability, and Health. Percentages may not sum to 100 because of rounding.

mental illness (19-21). Specifically, the inability to access transportation has a negative impact on social connectedness (20), participation in exercise interventions (19), and employment (21). This study provides additional evidence that consumers experience limited transportation as a barrier to participation and a barrier to their personal medicine.

Participants made requests that fell into six broad categories. However, fewer than 10% of requests across all participants were categorized within unique codes, and some needs were identified by only a few individuals-for example, arts and culture (2%), higher education (2%), and informal education (<1%). These requests indicate that individuals with serious mental illness have extremely diverse interests and needs that mental health services can never fully address if consumers are not given the opportunity to self-direct care. Furthermore, consumers may have common needs, as represented by the broader ICF chapter codes, but diverse and unique ideas as to how to best address those needs.

Reed and colleagues (22) provided case examples of how the ICF model can be used to improve treatment planning for individuals with serious mental illness. Although individuals may have the same clinical diagnosis, their environmental barriers and facilitators, as well as their functional capacities, contribute differently to their engagement in meaningful roles. Reed and colleagues argued that the uniqueness between individuals is better captured by a biopsychosocial model, rather than by a traditional medical model. In addition, research has documented difficulties experienced by individuals with serious mental illness across activities and participation categories of the ICF model (23).

This study found unique differences in needs on the basis of diagnosis. Participants with a diagnosis of a schizophrenia spectrum disorder more frequently requested items to support fitness, whereas those with bipolar disorder and major depression were more likely to request items to help manage stress. The most common requests within diagnoses were consistent with the ICF diagnostic core sets. Handling stress has been identified as an area of functioning with which individuals with bipolar disorder (24) and major depression (25) may struggle. Maintaining health is identified in the schizophrenia core set (26).

A key barrier to implementing SDC may be differing interpretations of medical necessity (27). SDC allows participants to use funds to purchase nontraditional goods or services that they consider medically necessary. For example, in regard to the definition of medical necessity used in the Pennsylvania Public Welfare program, this study provided important justification for nontraditional goods or services to "assist the individual to achieve or maintain maximum functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age (11)." Use of codes from the ICF model indicated that the needs for participation in community life identified in this study are consistent with activities that most adults engage in during their lifetime (9). Providers often target increased capacity through skill development interventions but do not address the financial barriers that affect participation. Functional capacity, however, does not always lead to independent participation (28). Services that do not address barriers to participation point to a major gap in the ability of the current system to achieve increased rates of participation in community life, a

TABLE 2. Examples of most frequent requests made by 52 participants in a self-directed care program, by diagnostic group

Diagnosis and code	Request	Identified major life goal
Schizophrenia spectrum disorder		
5701 Managing diet and fitness	Workout shoes	Improving my physical well-being
8450 Acquiring a job	Printer and ink	I need a printer and copier ink for my job search to copy résumés and work-related identification.
4702 Using public transportation	Transportation pass	Tokens for bus rides to and from drug and alcohol groups 3 times a week. I need this to stay clean from drugs. Paying for transportation is a barrier.
4701 Using a private motorized vehicle	Driving lessons	Learn to drive. It will improve my lifestyle to get a better job. I will be able to take my child to where ever I want to.
Bipolar disorder		
4701 Using a private motorized vehicle	Driving test fee	Go to driving school to learn how to drive and be more independent
2401 Handling stress	Divorce fee	Enhancing my relationship
5701 Managing diet and fitness	Gym membership	To become more fit and healthy
2400 Handling responsibilities	Pay rent	Living responsibly, drug free, paying bills, and being happy
Major depression		
4702 Using public transportation	Monthly transportation pass	Becoming more independent
5702 Maintaining and looking after one's health	Therapy copay	Maintain and control my mental health
2401 Handling stress	Pay electric bill	Reduce financial stress
2403 Handling depression	Household furnishings	To feel like my home is a positive space

central aspect of health as indicated by the ICF model. Innovative approaches, such as SDC, may lessen this gap and facilitate greater community inclusion.

Previous research indicates that even when individuals with serious mental illness have geographic access to community-based resources (29), they still may not participate at desired levels (30). Providing the financial support to access resources may help bridge the gap between proximal access and full participation. This study demonstrates that individuals with serious mental illness have the capacity to identify their needs to enable their own participation in community life.

The study had some limitations. First, the self-directed care program was new to study participants, and the program took a while to mature. Therefore, although the represented requests were diverse, they may not fully represent participants' needs; participants with greater program familiarity might have requested different goods or services. In addition, the coding of needs relied on the best interpretation of participants' justification of their request. The amount of detail that participants provided about their requests varied, which could have affected how items were coded. Also, male participants were underrepresented; more than 70% of the participants were women. Finally, the study focused only on needs identified by participants and personal strategies to address those needs, not the effectiveness of this approach in achieving traditional outcomes.

CONCLUSIONS

Community participation is critical to the health and well-being of individuals with serious mental illness (4–7,31). These individuals are interested in goods and services beyond

those traditionally offered by community mental health centers and have insight into what would best support their recovery. Placing individuals at the center of services facilitates the development of self-directed goals and identification of the personal medicine necessary to enhance their own mental health. Medical necessity is the primary criterion for determining reimbursement and has been discussed as going beyond eliminating illness or reducing symptoms to include improvements and maintenance in functioning and avoidance of functional deterioration (32).

Common views of medical necessity result in funding for interventions that directly focus on eliminating illness or reducing symptoms, with the expectation that these changes ultimately lead to engagement in meaningful roles. However, there is little evidence that such engagement occurs (33). Mental health policy should consider strategies to broaden interpretations of medical necessity to allow individuals to direct services and personally navigate the barriers that prevent full engagement in life. Research should explore the health benefits of SDC and how independent access to goods and services affects community participation.

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