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A Mixed Methods Exploration of Family Involvement in Medical Care for Older Adults with Serious Mental Illness

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Abstract

Objective—Many older persons with serious mental illness (SMI) suffer from high rates of comorbid medical conditions. Although families play a critical role in psychiatric illness management among adults with SMI, their contributions to improving health outcomes in this population has received little attention. This study explored family involvement in medical care for older adults with SMI.

Methods—This mixed methods study involved analysis of quantitative data collected from older adults with SMI and cardiovascular risk (n=28) participating in a pilot study of an intervention designed to improve patient-centered primary care augmented by qualitative interviews with their relatives (n=13) to explore family involvement in medical care.

Results—Approximately 89% of older adults with SMI reported family involvement in at least one aspect of their medical care (e.g., medication reminders, medical decision making). However, many family members reported that they were rarely involved in their relative's medical visits, and most did not perceive a need to be involved during routine care. Family members identified obesity as their relative's primary health concern and many wanted guidance from providers on effective strategies for supporting weight loss.

Conclusions—Although many family members did not perceive a need to be involved in their relative's routine medical visits, they expressed interest in talking with providers about how to help their relative change unhealthy behaviors. Educating patients, families, and providers about the potential benefits of family involvement in medical care, including routine medical visits for persons with SMI and cardiovascular health risk may promote patient-and family-centered collaboration in this high-risk population.

Keywords

families; older adults; medical care; serious mental illness

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INTRODUCTION

People with serious mental illness (SMI) have a life expectancy one to three decades shorter than the general population [1,2]. This health disparity is largely due to the elevated burden of cardiovascular risk factors, such as obesity, diabetes and metabolic syndrome in persons with SMI at nearly twice the rate of the general population [3,4]. Medical comorbidity in older adults with SMI is compounded by poor medical care, unhealthy behaviors (e.g., poor diet, lack of exercise, smoking), and non-adherence to treatment [5,6]. To decrease the high risk of mortality and morbidity in this population, healthcare providers need to help adults with SMI follow-through with medical recommendations and adopt preventive health behaviors. One key to improving health practices in older adults with SMI may be to enlist support from family members who can support health behavior change in the patient's natural environment.

There is growing recognition that families are important to the health and healthcare of older adults with complex care needs [7]. Family involvement has been identified as a key dimension of patient-centered care [8], and a major factor in chronic disease self-management [9]. Health-related caregiving, ranging from accompanying a relative on medical visits to supporting health behavior change is associated with better quality of healthcare and positive health outcomes [10,11]. Despite growing evidence of the benefits of health-related support from family members in the general population [12,13], family involvement in addressing the physical health of older adults with SMI has been largely unexplored.

To date, family interventions for people with SMI have primarily focused on teaching family members about mental illness and its treatment as well as reducing family stress and conflict [14], with little attention to the physical health needs of the individual with mental illness. However, older adults with SMI and their families may benefit from interventions that target both physical health and mental illness management. In a study of community dwelling older adults with SMI, two-thirds (67%) of participants reported at least monthly contact with a family member, and results indicated that living at home and more frequent family contact were associated with more severe medical conditions [15]. This suggests that family members may play a role in assisting older relatives with mental illness manage their medical conditions in community living.

Relatively little is known about family involvement in medical care and health-related support for older adults with SMI and cardiovascular health risk. This exploratory mixed methods study was conducted to provide useful information and rich insights that could inform future efforts to increase support for older adults with SMI and successfully engage family members in their healthcare in collaborative and meaningful ways.

METHODS

We conducted an exploratory mixed-methods study using baseline data from a pre-post pilot evaluation of a program designed to improve patient-centered primary care for older adults with SMI [16] augmented by qualitative interviews with a subset of participants' relatives

exploring family involvement in their medical care. Written informed consent for the study was obtained through procedures approved by the Committee for the Protection of Human Subjects at Dartmouth College and by the State of New Hampshire Institutional Review Board.

Study participants were adults with SMI age 50 and older with cardiovascular risk factors who were recruited for an intervention study through a state-funded community mental health center, a Federally Qualified Health Center, and two primary care practices in Manchester, New Hampshire. Chart reviews were conducted at the clinics and the community mental health center to identify patients who met the following criteria: (1) age 50 and older; (2) residing in the community; (3) a DSM-IV diagnosis of schizophrenia spectrum disorder, bipolar disorder, or major depression associated with a functional impairment of at least 12 months or longer; and (4) at least one major cardiovascular risk factor, defined as one or more of the following: heart disease, diabetes, impaired fasting glucose, hypertension, hyperlipidemia, current smoker, or overweight/obese (diagnosis or BMI>25). The identification of cardiovascular risk factors during chart reviews was based on ICD-9 codes for participants recruited through the health care clinics, and based on self-reported medical conditions and clinician rated Axis III diagnoses (general medication conditions) for participants recruited through the community mental health center. For the present study we used quantitative data collected from all 28 participants at baseline.

During the informed consent process, participants in the intervention study were told about a component of the study involving interviews with family members to explore the role they play in supporting participants' medical care, physical illness, and health behavior change. Participants in the intervention study were invited to refer a family member for a one-time interview. Family was defined as two people who are connected biologically or emotionally, recognizing that many older adults with SMI have significant long-term relationships with non-biological family members. Over half (57%) of participants referred at least one family member. Ten semi-structured interviews were conducted with 13 family members who provided informed consent for their involvement in the qualitative interviews.

Questionnaires and Other Information

Trained research interviewers conducted quantitative assessments that included demographic information, clinical characteristics, amount of family contact and family involvement in medical care. Quantitative data collection sessions for the intervention study lasted 90 minutes and participants were given \$25 dollars compensation for their time. All quantitative measurements used in this study were conducted at baseline, prior to participation in the intervention.

Information about the amount of family contact was obtained from the Family and Social Contact Questionnaire adapted from the Social Relationship Scale [17]. Respondents were asked whether they had any family members or close friends considered to be 'like family' whom they saw on a regular basis. If the respondent answered 'yes,' they were asked to report the frequency of face-to-face contact with the person whom they saw the most often on a Likert scale ranging from 1 (*daily contact*) to 5 (*once a year*), and to specify the nature of their relationship (e.g., spouse, brother, sibling, close friend).

Family involvement in medical care was assessed using the Medical Care Questionnaire (MCQ) [18]. The MCQ assesses the degree to which family members are involved in respondents' medical care and medical decision-making. Respondents were asked to indicate 'yes' or 'no' whether family members have regular involvement in their medical care in the following ways: (1) 'schedule doctor's appointments'; (2) 'go with you to doctor's appointments'; (3) 'pick-up prescriptions'; (4) 'help you to remember to take medication'; and (5) 'participate in making decisions about medical care'. We calculated the percentage of positive responses for each single item representing an aspect of family involvement in medical care.

Qualitative Interviews

The semi-structured interviews with participants' family members covered the domains of family involvement in aspects of medical care, including medical visits, and other health-related support for their relative (e.g., medication management, health behavior change). We used an interview topic guide that followed the 'funnel structure' described by Krueger [19]. Broad questions were asked at the beginning, with the interviewer gradually proceeding to more specific questions within each domain. Interviews lasted 60 to 90 minutes for which participants were compensated \$25. All interviews were audiotaped and transcribed verbatim.

Data Analysis

Analyses were conducted with two components of mixed methods designs: convergence and expansion [20]. Convergence involves the use of quantitative and qualitative methods to measure the same phenomena in order to compare the two sets of data and results. We compared the results of the quantitative data on family involvement in medical care collected from older adults with SMI to the results of the qualitative data from family members and assessed the nature and degree of convergence. In addition, we used the technique of expansion to further explore two questions that could not be addressed by the quantitative data: (1) Are family members satisfied with their level of involvement in their relative's medical care; (2) What, if any, other types of health-related support (beyond involvement in medical care) do family members provide to a relative with SMI and cardiovascular health risk?

Descriptive statistics were used to characterize the amount of family contact and family involvement in medical care. Statistical analyses were performed using SPSS software, version 18.0. A thematic analysis was used to analyze the qualitative transcripts, which consisted of examination of text by identifying and grouping themes, followed by coding, classifying, and developing categories [21]. We took a flexible approach to qualitative data analysis, combining both inductive and deductive reasoning in the analytic process. The analysis was in part guided by a predetermined framework based on the primary domains of family involvement in medical care used in the interview topic guide. We remained open to the possibility of discovering unanticipated nuances and themes in the data. The qualitative transcripts were coded by the primary author (KA) and a postdoctoral fellow (RP). Both coders independently examined the data before reviewing each other's coding scheme. After

discussion, the coders reached consensus on the prominence of themes within each domain listed in the results. Atlas.ti qualitative software was used for the qualitative data analysis.

RESULTS

The demographic and clinical characteristics of the sample of older adults with SMI are listed in Table 1. Almost two-thirds of participants (57%) reported at least monthly face-to-face contact with a family member. Among the family members interviewed in the present study, 53% were siblings, 23% were adult children, 14% were parents, and one was a significant other. Over three-quarters (76%) of family members were female.

Approximately 89% of older adults with SMI reported family involvement in at least one aspect of their medical care: 39% scheduling medical appointments; 68% go with them to medical appointments; 46% pick up prescription medication; 43% give reminders to take medications; 57% participate in making decisions about medical care. Among the 11% (n=3) of participants who reported no family involvement in any aspect of their medical care, one participant reported contact with a relative a couple times per week, while two participants reported contact with a relative once per week.

The first set of mixed methods findings focused on convergence. The results of the quantitative and qualitative data analysis are presented in Table 2. Converging the qualitative data with quantitative data yielded consistent findings with respect to family involvement in picking up participants' medications, giving reminders to take medications, scheduling medical appointments, and participating in medical care decision making. However, comparison of the two types of data revealed an important distinction between going to a relative's medical appointment and participating in a relative's medical visit. While many family members indicated that they went with a relative to medical appointments, they clarified that their primary role in going to appointments was to provide their relative with transportation and they rarely accompanied them into medical visits with providers and stayed in the waiting room while their relative saw a provider.

Our expansion analysis allowed us to further explore these findings, specifically whether family members were satisfied with their level of involvement in their relative's medical care and what, if any, other types of health-related support did family members provide to a relative with SMI and cardiovascular health risk. Most family member respondents indicated that they were satisfied with their level of involvement in their relative's medical care, indicating that they would attend a medical visit if their relative experienced a health crisis, otherwise they did not perceive a need to be involved in their routine medical visits.

As one respondent noted:

“There was concern when they thought my mother had COPD, and that's why she quit smoking because that was the ultimate scare for her. If something like that comes up, I would definitely want to meet with her medical doctors, but as long as things are going well and they're making recommendations for her to eat healthy, I think that communicating with her doctors isn't necessary at this time.”

Using expansion to explore family involvement in health related support beyond medical care revealed that the most common type of other support provided to a relative was helping them make positive health behavior changes (i.e., improve eating habits and increase physical activity). Despite having little or no communication with their relative's medical providers, family members recognized a critical need to address their relative's health behaviors that contributed to increased cardiovascular risk. The most common health concern identified for a relative was being overweight or obese, and family members often played an active role in helping a relative lose weight.

Several family members expressed a desire for more information from professionals about how to help their relative make healthy food choices, particularly because of their role in grocery shopping and/or cooking with their relative. As one respondent said:

“When I take her [mother] grocery shopping I'll try to get her to get the healthier things. She doesn't really pay attention to what she's picking up. I know she's met with a nutritionist because she'll tell us certain things about what the nutritionist recommended, but it would be nice to hear directly from a professional so that we can tailor her shopping around recommendations.”

In some cases, family members expressed uncertainty or a lack of confidence about what to say when it comes to supporting their relative's healthy eating and exercise behaviors. One respondent described her frustration that her adult son who lives with her does not respond positively to her efforts to encourage healthy eating at home. She said:

“I always have apples, oranges, and bananas available for him. I don't know what else I can do. If somebody could tell me how to encourage him in a more persuasive way to drink more water and eat more fruits and vegetables that would be helpful. He knows the things that he needs to do, but I don't know why he doesn't follow through with them.”

DISCUSSION

Our quantitative and qualitative findings suggest that family members of older adults with cardiovascular health risk were involved in facilitating instrumental aspects of their medical care (e.g., picking-up medications, transportation) and supporting their efforts to change health behaviors. However, qualitative interviews with a subset of family members revealed that they rarely accompanied a relative during routine medical visits and did not perceive a need to do so. Obesity was identified by family members as their primary health concern for their relatives, and many expressed a desire for guidance from providers on effective strategies for facilitating weight loss. These findings provide preliminary evidence that family members frequently provide support for health behavior changes in an older relative with SMI and cardiovascular risk, and may benefit from additional collaboration with healthcare providers in fostering such change.

The lack of family involvement in medical visits for older adults with SMI in this study is in contrast to estimates that nearly forty percent of older adults in the general population are accompanied by a family member on medical visits, typically by a spouse or adult child [11], with usually the same family member participating in subsequent visits [22]. In these

studies, not only are family members present during routine medical visits, but they are actively involved in communicating with providers and exchanging health-related information [11], such as providing information to the doctor, asking questions, and explaining the doctor's instructions to the patient [11,23,24]. Older adults who are accompanied on medical visits are more likely to report that they understood the medical issue addressed during the visit and feel more confident that they will be able to carry out treatment recommendations than older adults who attend visits alone [23].

Our qualitative data indicated that family members of older adults with SMI did not perceive a need to attend their relative's medical visits unless a major health problem arose, despite the fact that all of the older adults in our sample had a known cardiovascular health risk (e.g., hypertension, diabetes, smoker, obesity). Involving family members of older adults with cardiovascular health conditions in their medical encounters only in response to urgent medical issues is contrary to patient-and family-centered care in which ongoing partnerships among patients, families, and healthcare providers are established in order to address prevention as well as the management of chronic illness [25,26].

Families of adults with SMI are rarely engaged in their relative's mental health treatment [27,28], despite studies showing that families desire more education about mental illness [29] and that the majority of consumers prefer family involvement in some aspect of their mental healthcare [30]. It has been well established that collaboration between families and mental health professionals improves long-term mental health outcomes of persons with SMI and has a positive impact on family member well-being [31-33]. As a result of limited past experiences being involved in the mental health system, family members of older adults with SMI may not expect to collaborate with their relative's healthcare providers despite their involvement in informal health-related caregiving.

Given estimates that adults with SMI have obesity rates that are nearly twice that of the general population [3], it is not surprising that family members identified obesity as a major health concern. Research on the general population shows that mobilizing support from family and friends can enhance the effectiveness of interventions addressing obesity [34-36]. Many of the family members we interviewed supported their relative's weight loss efforts with little guidance from providers. They helped their relatives decide which foods to buy, how physical activities fit into the family schedule, and provided emotional support for health behavior change. Patients, families, and providers may benefit from working collaboratively in routine medical visits where they can discuss weight reduction and management strategies in this high-risk population.

Involving family members in medical visits is perhaps an opportunity to leverage community-based supports for health behavior change. However, the values and preferences of adults with SMI should be explored as a first step in designing treatment protocols that incorporate families in medical care for this population. Understanding patient preferences, values, and experiences is an essential component of patient-centered outcomes research and can help guide healthcare decision-making between patients, families, and providers [37]. Further research is needed to understand whether and to what extent older adults with SMI

want family members present during medical visits when health behavior change goals are discussed with providers.

The relatively small sample size and breadth of data are limitations of this study. We conducted qualitative interviews with a subset of participants' family members and therefore, caution is needed in interpreting the study results related to family involvement in medical visits. Although the study sample represented older adults with serious mental illness and cardiovascular risk, participants were all white. Hence, the results do not necessarily generalize to an ethnically diverse sample. While building upon an existing pilot study limited the extent to which we were able to collect additional data (for example, qualitative interviews with older adult participants), our mixed methods approach yielded several important new insights into the role of families in medical care for an older relative with SMI. The overall sample size (n=41) is consistent with exploratory qualitative methods [38] and the intent and scope of a pilot study aimed achieving preliminary descriptive findings [39].

CONCLUSIONS

From the perspective of both patients and family members, family members of older adults with SMI played an active role in supporting various aspects of their relative's medical care, including medication reminders and decision-making. However, family members reported that they rarely accompanied their relative on medical visits or communicated with their medical providers. Family members did not perceive a need to attend their relative's routine medical visits, although they expressed interest in talking with providers about how to help their relative change unhealthy behaviors. Health behavior change represents a potentially promising opportunity to engage family members of older adults with SMI in routine medical visits where they can collaborate with providers to help reduce the high cardiovascular risk experienced by this population.

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Table 1

Sample Characteristics of Older Adults with Serious Mental Illness

Characteristic	Total Sample (N = 28)	
	<i>n</i>	%
Age (<i>M</i> ± <i>SD</i>)	59.4 ± 8.3	
Gender		
Male	13	46
Female	15	54
Ethnicity		
White	28	100
Non-white	0	0
Marital Status		
Currently married	5	18
Divorced/widowed	19	68
Never married	4	14
Education		
Completed high school	24	86
Did not complete high school	4	14
Residential Status		
Independent	22	78
Living with family members	1	4
Supervised/supported housing	5	18
Diagnosis		
Schizophrenia/schizoaffective	15	54
Psychosis NOS	5	18
Mood disorder	8	28
Cardiovascular Risk Factor		
Myocardial infarction	3	10
Hypertension	17	61
Diabetes	13	46
Smoker	12	43

Note: Cardiovascular risk factor categories are not mutually exclusive

Table 2**Mixed Methods Results Exploring Convergence of Quantitative and Qualitative Data**

Method:	Quantitative (n=28)	Qualitative (n=10)
Question:	<i>Do family members pick up prescriptions for their relatives?</i>	
Answer:	Yes: Forty-six percent of older adults with SMI reported that a family member picked up prescriptions for them	Yes: Many of the family members interviewed reported that they regularly picked up prescriptions for their relative
Question:	<i>Do family members give their relatives reminders to take medications?</i>	
Answer:	Yes: Forty-three percent of participants reported that a family member reminded them to take medications	Yes: Some family members reported that they gave their relative reminders to take prescription medications
Question:	<i>Do family members schedule medical appointments for their relatives?</i>	
Answer:	Yes: Thirty-nine percent of participants reported that a family member scheduled their medical appointments	Yes: Some family members scheduled medical appointments for their relative
Question:	<i>Do family members go with a relative to their medical appointments?</i>	
Answer:	Yes: Sixty-eight percent of participants reported that a family member went with them to medical appointments	Yes: Many family members reported that they went with a relative to their medical appointments No: Family members clarified that while they often took their relative to medical appointments, they stayed in the waiting room while he/she saw the doctor
Question:	<i>Do family members participate in making decisions about a relative's medical care?</i>	
Answer:	Yes: Fifty-seven percent of participants reported that a family member participated in making decisions about their medical care	Yes: Many family members indicated that they helped their relative make decisions about their medical care on topics ranging from medication to major surgery