

## Financial Capacity in Persons with Schizophrenia and Serious Mental Illness: Clinical and Research Ethics Aspects

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**In contrast with issues of consent capacity, financial capacity has received surprisingly little clinical or ethical attention in the psychiatric literature. Issues of financial capacity emerge frequently regarding clients with serious mental illness (SMI), and their resolution has practical and ethical significance for clients, their families, and mental health professionals. These issues include whether a client has sufficient financial skills and judgment to live independently, whether a client requires a representative payee, and what goals for community reintegration should be established with a client. Similar to informed consent, issues of financial capacity raise ethical challenges for clinicians, caseworkers, and agencies. The present article addresses clinical and research ethics questions related to financial capacity in clients with schizophrenia and SMI. Clinical questions concern evaluation of financial capacity in clients with SMI, whether to seek assignment of a mandatory representative payee, whether to leverage treatment compliance through a representative payee arrangement, and whether a mental health professional should also serve as a client's representative payee. The research ethics question addresses implications of providing financial compensation for research participation to individuals with SMI and limited financial capacity and means. The ultimate goal of this article is to focus clinical and ethical attention on a neglected decisional capacity in SMI that is of fundamental importance for clients, families, clinicians, and researchers.**

*Key words:* financial capacity/ethics/schizophrenia/SMI/representative payee

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### Introduction

Serious mental illnesses (SMI) such as schizophrenia and bipolar disorder can often significantly impair the cognitive abilities and decisional capacities of affected individuals.<sup>1–4</sup> For example, there is increasing recognition that individuals with SMI may have impaired capacity to provide informed consent to treatment or to research participation.<sup>3,5–7</sup> In its report entitled *Research Involving Persons with Mental Disorders That May Affect Decision-Making Capacity*, the National Bioethics Advisory Commission focused attention on, and made substantive recommendations regarding, informed consent procedures in research with persons with mental disorders such as schizophrenia and dementia.<sup>8</sup> Significant questions have been raised concerning the ethics of “challenge” and “wash-out” study designs in psychopharmacological trials on clients with SMI.<sup>9</sup> As a result, considerable attention in research ethics has been devoted in recent years to issues of treatment consent capacity and research consent capacity in individuals with schizophrenia and other severe psychiatric disorders.<sup>9–13</sup> The current special issue of *Schizophrenia Bulletin* is a testament to the topicality and importance of issues of informed and proxy consent in this population.

In contrast, the psychiatric literature has devoted relatively little attention to other important decisional capacities. In particular, financial capacity—the capacity of a patient to manage his or her own money and financial affairs—has received very little attention. This is surprising insofar as financial capacity implicates core issues of personal autonomy in adults.<sup>14,15</sup> Financial capacity is critical to, and is possibly the single best litmus for, the ability to function independently in the community.<sup>16</sup> Issues of financial capacity emerge frequently regarding clients with SMI, and their resolution has practical and ethical significance for clients, their families, and mental health professionals. Such issues include whether a client has sufficient financial skills and judgment to live in an independent versus a dependent setting (e.g., apartment versus boarding house or group home), whether a client requires a representative payee to handle monthly expenses, and what goals for community reintegration should be established with a client.

In this article we address clinical and ethical aspects of financial capacity in persons with schizophrenia and SMI. We begin by positing the importance of financial capacity as a decisional capacity in the area of SMI. We then briefly discuss the limited literature on financial capacity in SMI. Drawing upon theoretical work our group has conducted in the area of aging and dementia, we next discuss financial capacity as a general construct, and describe a general conceptual model for adults. We then offer a revised conceptual model of financial capacity that addresses specific financial needs and concerns of clients with SMI. These individuals often have a limited financial skill set, and specialized financial needs, as compared with normal adult peers. Finally, we focus on clinical and research ethics concerns that relate to financial capacity in clients with schizophrenia and SMI. We address four clinical ethics issues: the challenge of clinical assessment of financial capacity, decisions to assign representative payees, the use of representative payees to leverage clients' treatment compliance, and the practice of mental health workers serving as representative payees. We also address one key research ethics issue: monetary compensation in research studies involving individuals with schizophrenia and SMI and the potential for coercion, exploitation, and/or disruption of clinical and financial status.

The ultimate goal of this article is to focus clinical and research ethics attention on a neglected decisional capacity in schizophrenia and SMI that is of fundamental importance for clients, families, and clinicians.

### **Financial Capacity in Schizophrenia and SMI**

As discussed above, issues of informed consent have received predominant attention to date in the psychiatric ethics and capacity literature. As a result, important gaps in our knowledge of decisional capacities in schizophrenia continue to exist. Of particular importance in this regard is financial capacity. Financial capacity is a fundamental instrumental activity of daily life that comprises a wide range of knowledge and judgment skills.<sup>15,17</sup> As mentioned above, financial capacity is critical to and is often a litmus for independent functioning in the community,<sup>16</sup> and it implicates core issues of personal autonomy in adults.<sup>14,15</sup> By clinical report, financial capacity is commonly impaired in persons with SMI and is an ongoing and challenging issue for clinicians.<sup>18</sup> Many, but certainly not all, persons with schizophrenia never acquire basic financial skills and experiences, due to onset of their illness in early adulthood, the adverse developmental effects of positive and negative symptoms, and the unfortunate impact upon neurocognition seen in the disease.<sup>2</sup>

The consequences of these impairments in financial capacity are often devastating. Problems of malnutrition, homelessness, and even premature death have been at-

tributed to clients' inability or unwillingness to use funds to provide for basic needs.<sup>18</sup> As a result of drug abuse and dependence, many clients cyclically dissipate governmental and other financial resources intended to support themselves and family members.<sup>18-20</sup> One study found that cocaine-abusing persons with schizophrenia spent nearly half of their total income on illegal drugs, and that psychiatric symptoms and hospital admissions were phase-linked with receipt of monthly disability checks.<sup>20</sup> Such chronic misuse of funds has led to calls over the past decade for more effective money management approaches in this population, such as mandatory representative payees.<sup>19,21,22</sup>

Problems with financial capacity in schizophrenia also impact family members and relationships. Money mismanagement by persons with schizophrenia is a key concern of family members,<sup>23</sup> and the issue of control over funds can often become a battleground involving clients, families, and government agencies.<sup>18</sup> For all these reasons, financial capacity is often a central issue in the assessment, treatment, and rehabilitation of clients with schizophrenia and SMI.

### **Existing Research on Financial Capacity in Schizophrenia**

Despite its importance, very little research exists concerning financial skills in schizophrenia and SMI. As trenchantly noted by Frank and Degan, "the literature of law and psychiatry is unaccountably mute on the subject of patients' competence to handle money."<sup>18</sup> Our own review of the psychiatric literature has revealed no conceptual models, no dedicated assessment instruments, and very little empirical data. Two relatively recent studies have examined a few financial abilities as part of an overall effort to assess a wide range of functional abilities in middle-aged and older individuals with schizophrenia.<sup>4,24</sup> Using global measures of everyday function, these studies demonstrated impairments in some discrete financial skills, such as counting change and paying bills.<sup>24</sup>

However, the above studies were not specific to financial capacity and thus offer only an initial glimpse into this construct as it operates in schizophrenia and SMI. In addition, these studies lacked a conceptual model of financial capacity relevant to schizophrenia and SMI, and did not sample specific skills and judgment abilities essential to characterizing financial capacity in this population. As discussed further below, such SMI-specific financial abilities would include simple money skills, basic conceptual knowledge of money, carrying out simple cash transactions, understanding and completing money orders or checks, understanding representative payees, judgment in selecting representative payees, and being able to budget monies from a fixed income source (e.g., from a government entitlement check).<sup>25</sup>

**Table 1.** General conceptual model of financial capacity: 18 tasks, 9 domains, and overall capacity

	Task Description	Difficulty
<i>Domain 1 Basic Monetary Skills</i>		
Task 1a Naming coins/currency	Identify specific coins and currency	Simple
Task 1b Coin/currency relationships	Indicate relative monetary values of coins/currency	Simple
Task 1c Counting coins/currency	Accurately count groups of coins and currency	Simple
<i>Domain 2 Financial Conceptual Knowledge</i>		
Task 2a Define financial concepts	Define a variety of simple financial concepts	Complex
Task 2b Apply financial concepts	Practical application/computation using concepts	Complex
<i>Domain 3 Cash Transactions</i>		
Task 3a 1-item grocery purchase	Enter into simulated 1-item transaction; verify change	Simple
Task 3b 3-item grocery purchase	Enter into simulated 3-item transaction; verify change	Complex
Task 3c Change/vending machine	Obtain change for vending-machine use; verify change	Complex
Task 3d Tipping	Understand tipping convention; calculate/identify tips	Complex
<i>Domain 4 Checkbook Management</i>		
Task 4a Understand checkbook	Identify and explain parts of check and check register	Simple
Task 4b Use checkbook/register	Enter into simulated transaction; pay by check	Complex
<i>Domain 5 Bank Statement Management</i>		
Task 5a Understand bank statement	Identify and explain parts of a bank statement	Complex
Task 5b Use bank statement	Identify specific transactions on bank statement	Complex
<i>Domain 6 Financial Judgment</i>		
Task 6a Detect mail fraud risk	Detect and explain risks in mail fraud solicitation	Simple
Task 6c Detect telephone fraud risk	Detect and explain risks in telephone fraud solicitation	Simple
<i>Domain 7 Bill Payment</i>		
Task 7a Understand bills	Explain meaning and purpose of bills	Simple
Task 7b Prioritize bills	Identify bills; identify overdue utility bill	Simple
Task 7c Prepare bills for mailing	Prepare simulated bills, checks, envelopes for mailing	Complex
<i>Domain 8 Knowledge of Assets/Estate</i>		
	Indicate knowledge of asset ownership, estate arrangements	Simple
<i>Domain 9 Investment Decision-Making</i>		
	Understand investment options; determine returns; make decision	Complex
<i>Overall Financial Capacity</i>		
	Overall functioning across tasks and domains	Complex

**General Conceptual Model of Financial Capacity**

Our group has previously explored the construct of financial capacity as it pertains to normal community-dwelling adults, and in particular older adults.<sup>15,26</sup> Financial capacity is a knowledge structure involving a broad range of conceptual, procedural, and judgment abilities.<sup>15,17</sup> Our general conceptual model views financial capacity at three levels: specific financial abilities (tasks); broad areas of financial activity relevant to independent functioning (domains); and overall financial capacity (global). Development of this model is discussed in detail in several reports.<sup>15,17,27</sup> A schematic of the general model is presented in Table 1.

*Domain Level (Financial Activities)*

We have conceptualized financial capacity as a series of discrete, clinically relevant domains of activity rather than as a unitary construct.<sup>15</sup> Examples of domains include basic money skills (e.g., naming and counting change/currency); conducting cash transactions (grocery store purchases, vending-machine usage, tipping); and checkbook management (understanding/using a checkbook/register). A domain-based approach approximates

the multidimensionality of financial capacity, and is consistent with the legal doctrine of limited financial competency that recognizes that an impaired individual may have preserved as well as impaired financial skills, and may still be able to carry out some financial activities.<sup>28</sup>

In developing a working model, we first identified domains of everyday financial activity.<sup>15</sup> Inclusion criteria for domains were (1) theoretical relevance to independent functioning of community-dwelling older adults; (2) clinical relevance to healthcare professionals who treat older adults and evaluate financial capacity; and (3) general relevance to state statutory criteria for financial competency. Based on these criteria, we have currently identified nine domains of financial activity for the general model: 1-Basic Monetary Skills; 2-Conceptual Knowledge; 3-Cash Transactions; 4-Checkbook Management; 5-Bank Statement Management; 6-Financial Judgment; 7-Bill Payment; 8-Knowledge of Personal Assets/Estate Arrangements; and 9-Investment Decision Making (see Table 1).

*Task Level (Financial Abilities)*

In addition to activity domains, our model identifies specific financial abilities or tasks.<sup>15</sup> Tasks reflect basic

financial skills that comprise domain-level activities. For example, the domain of “financial conceptual knowledge” draws upon specific abilities such as *understanding* concepts such as loan or savings, and also pragmatically *applying* such concepts in everyday life—e.g., selecting interest rates, identifying a medical deductible, or making simple tax computations. The domain of financial judgment might consist of tasks related to detection/awareness of financial fraud. Tasks thus represent abilities that are constituent to broader, clinically relevant domains of financial activity. We identified quantifiable behavioral tasks specific to each domain. Inclusion criteria for financial tasks were (1) theoretical relevance to a particular domain; (2) practicality of implementation within a laboratory setting;<sup>29</sup> and (3) varying task difficulty levels (*simple* or *complex*) that might be differentially sensitive to dementia stage. Financial tasks were identified in part from a review of existing functional instruments with financial items.<sup>29,30</sup> At present we have identified 18 specific financial tasks organized by domain and proposed difficulty level.

#### *Global Level (Overall Financial Capacity)*

Our model now also conceptualizes financial capacity at the global level.<sup>27</sup> Capacity is ultimately a categorical judgment made by a human decision-maker.<sup>28,31</sup> Most clinical competency evaluations of financial capacity require an overall judgment. Thus global financial capacity represents overall functioning across the model’s financial domains and tasks.

#### *Summary*

The above conceptual model represents an initial effort to describe financial skills and activities relevant to normal community-dwelling older adults. The model presupposes normal acquisition and use of a wide range of financial skills during an individual’s lifetime, which may then show decline as a result of age-related cognitive disorders. As such, this general model has only limited application to individuals with schizophrenia and SMI. As mentioned, persons with SMI have frequently experienced a range of psychiatric symptoms such as psychosis and severe mood disorders as young adults, along with persisting neuropsychological impairments and other residual symptoms as they age.<sup>2,32,33</sup> As a result, these individuals have experienced developmental delays and even arrest that in many cases have interfered with, or prevented, acquisition of everyday financial skills and judgment. In addition, due to their psychosocial circumstances and socio-economic status (SES), clients with SMI often have unique financial issues and concerns that distinguish them from typical adults in the community. For this reason, meaningful examination of financial capacity in clients with schizo-

phrenia and SMI requires development of a revised conceptual model specific to this patient group.

#### **Preliminary Conceptual Model of Financial Capacity in Persons with Schizophrenia and SMI**

Our research group has recently modified and elaborated on the existing conceptual model of financial capacity to apply to persons with schizophrenia and SMI. A number of basic assumptions informed our modification of the model. First, we posited that a majority of individuals with schizophrenia and SMI would be of low SES and would be dependent on entitlement programs for support, in particular Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). We note that a smaller number of individuals with personal or family financial support or Veterans Administration Benefits and SMI may enjoy higher income levels than SSDI and SSI beneficiaries. Statistical data from 2003 indicate that more than 2.6 million individuals in the US between age 18 and 65 currently receive SSDI or SSI as a result of psychiatric disability.<sup>34</sup> In addition, we assumed that a significant proportion of individuals with psychiatric disability have a representative payee or other proxy managing their funds. As of 2003, it was estimated that as many as 800,000 psychiatric patients receiving Social Security disability were assigned a representative payee.<sup>34</sup> A third assumption informing the revised model was that substance use would be a critical variable affecting financial capacity in this population. As noted by Rosen and Rosenheck, “a large amount of money is a well-recognized trigger for substance abuse relapse.”<sup>35</sup> The literature has demonstrated a clear temporal connection between receipt of government entitlement checks and substance abuse relapse, psychotic symptoms, and hospitalization.<sup>20</sup> Thus any model of financial capacity in the SMI population needs to take into account the effects of substance abuse/dependence on financial judgment and capacity.

Based on these working assumptions, and in consultation with psychiatrists, psychologists, nurses, social workers, and case managers in the Department of Psychiatry and Behavioral Neurobiology, Public Division, at the University of Alabama at Birmingham (UAB), we identified financial skills and issues relevant to individuals of low SES with schizophrenia and SMI. A schematic of the revised model is set forth below in Table 2.

As can be seen, the SMI model shares with the general model (see Table 1) certain core domains, such as basic money skills, cash transactions, and bill payment, although the domain items in the SMI model tend to test more elementary abilities. Additions distinct to the SMI model include domains related to use of money orders, budgeting expenses on a fixed monthly income, and understanding and selecting representative payees. In addition, we have included a domain inquiring about

**Table 2.** Conceptual model of financial capacity for individuals with schizophrenia and SMI

	Item Description
<i>Domain 1 Basic Money Skills</i>	
1. Define concept	Define simple concept of money
2. Naming coins/currency	Identify specific coins/currency
3. Coin/currency relationships	Identify relative worth of coins/currency
4. Counting coins/currency	Accurately count coins/currency
<i>Domain 2 Cash Transactions</i>	
1. Identify cost	Identify cost of single item from price tag
2. Purchase item	Use coins/currency to make purchase
3. Sales tax	Explain additional charge
<i>Domain 3 Using Money Orders or Checkbook/Register</i>	
1. Understand instrument	Define money order or checkbook/register
2. Use instrument in transaction	Simulated transaction; pay by money order or check
<i>Domain 4 Bill Payment</i>	
1. Understand bills	Define bill
2. Identify bill amount	Identify money owed on bill
3. Inquiry regarding bill	Explain how to inquire concerning a bill
4. Unpaid bills	Explain consequences of unpaid bills
<i>Domain 5 Budgeting</i>	
1. Understand budget	Define budget
2. Develop monthly budget	Budget expenses using monthly entitlement check
3. Judgment in budgeting	Explain budget choices
<i>Domain 6 Representative Payees</i>	
1. Understand representative payee	Define representative payee
2. Positive and negative aspects	Explain good and bad aspects of representative payee
3. Judgment in selecting rep payee	Decision-making vignette
<i>Domain 7 Prior History with Money</i>	
1. Current financial arrangements/activities	Informational questions
2. Prior money problems	Informational questions
3. Areas of desired financial assistance	Self-identified areas of skill weakness
<i>Overall Financial Capacity</i>	
1. Capacity to manage financial affairs	Assessor judgment
2. Strengths and weaknesses	Assessor judgment
3. Supervision needed?	Assessor judgment

a patient’s prior history with money, including prior problems related to substance abuse. Such information may be as relevant as direct performance data in assessing a patient’s financial capacity, need for financial supervision, and appropriate community placement.

The preliminary model above represents a first step in identifying and measuring constructs of importance to understanding the financial needs and world of people with schizophrenia and SMI. As discussed, the model is predicated on assumptions that most individuals with schizophrenia and SMI will be of low SES, will receive income through a government entitlement program (usually SSI or SSDI), will have a limited repertoire of basic financial skills, and in many cases will have financial decision-making delegated to a representative payee or a guardian/conservator. Another explicit aspect of the model is the likelihood that many clients’ financial skills and decision-making will also be adversely affected by substance use.<sup>34</sup> This model provides a backdrop for the section below that discusses specific clinical and re-

search ethics issues related to financial capacity in individuals with schizophrenia and SMI.

**Ethical and Research Aspects of Financial Capacity in Schizophrenia and SMI**

Schizophrenia and SMI are conditions that impair cognition, emotional functioning, and decisional capacity, often on an intermittent or fluctuating basis, and that adversely impact an individual’s capacity to live in the community. Clinicians treating clients with SMI face a wide range of ethical issues that are framed broadly within the context of two core ethical principles: *beneficence* (protecting the client’s best interests) and *autonomy* (respecting the client’s right to self-determination).<sup>36-38</sup> Ethical issues in psychiatry that continue to receive attention include decisions regarding involuntary hospitalization, capacity to consent to or refuse medical (psychiatric) treatment, confidentiality, and capacity to participate in experimental research and clinical trials.<sup>39</sup>

What is less appreciated is that impairment of financial capacity in this patient group also raises a number of clinical and research ethics issues. Clinical issues include the following:

- How does a clinician objectively determine whether a client with schizophrenia or SMI has financial capacity?
- Should a mandatory representative payee (RP) be assigned to manage a client's funds and ensure payment of monthly living expenses?
- Should RP be used as a form of leverage to ensure a client's treatment participation and compliance?
- Should a treating mental health professional also serve as the client's RP?

A research ethics issue raised is the following:

- Can monetary compensation for research participation act as a coercive or exploitative influence upon individuals with SMI and limited financial capacity?

Each of these ethical issues is addressed below.

*1. How does a clinician assess whether a client with schizophrenia or SMI has financial capacity?* Loss of financial decision-making ability and control over one's funds represents a major restriction of personal autonomy.<sup>14,15</sup> Accordingly, clinical decisions concerning an individual's financial capacity have important ethical implications, and must be predicated on objective assessments of financial skills relevant to that individual's everyday functioning. While not a legal judgment, the clinician's findings have adjudicative significance, as they are accepted by clients and family members, and usually result in actual restrictions on autonomy.<sup>26</sup>

From a research standpoint, financial capacity has only recently begun to receive attention as a measurable construct and as a specific topic of empirical clinical research.<sup>17,40</sup> Most of this work has been carried out in dementia populations.<sup>15,17,26</sup> As noted, there has been a striking lack of research attention paid to financial capacity in the field of psychiatry. At the present time there are no conceptual models or assessment instruments specific to financial capacity in psychiatric populations.

In everyday practice, however, clinicians and caseworkers in Community Mental Health Centers (CMHCs) must regularly evaluate financial skills in clients with schizophrenia and SMI. Such evaluations are unstructured and informal, and are primarily linked to decisions concerning placement, community reintegration, and the need for representative payees.<sup>37</sup> Little is currently known about clinician practice patterns in this area, or about the criteria or factors clinicians use to make decisions about clients' financial capacity. However, some

glimpses into clinician behavior are available. Luchins and colleagues used chart reviews to identify criteria used by mental health professionals for assigning representative payees to clients.<sup>37,41</sup> In order of importance, these criteria were co-morbid substance abuse or dependence (48% of cases), history of homelessness (33%), frequent hospitalizations (32%), lack of financial skills (29%), danger in one's own residence (22%), long-term hospitalizations (21%), and need for treatment motivation (18%).<sup>37,41</sup> In a recent census survey of over 100 CMHCs, the same group found that clinicians' criteria for appointing representative payees included poor financial skills (89%), insufficient rent money (52%), homelessness (33%), and frequent (37%) or long-term (30%) hospitalization.<sup>42</sup>

Findings from these two studies suggest that distinct from financial knowledge or skills per se, a client's psychosocial and treatment history are key factors that influence clinician judgments of a client's financial capacity and need for financial supervision. The findings also suggest that it is not simply a client's financial performance skills (counting coins/currency, handling cash transactions, writing money orders, etc.) but rather his or her financial judgment and capacity to act over time in his or her best financial self-interest that may predominantly influence these clinician capacity judgments.

Although interesting and suggestive, the above findings do not themselves provide a satisfactory basis for guiding clinician decisions regarding financial capacity in individual cases. Currently, clinical assessment of financial capacity in schizophrenia and SMI remains a poorly understood, largely unstructured, and idiosyncratic enterprise that arguably suboptimally serves clients and their families, and may also adversely impact client autonomy. It is clear that more systematic research is needed to develop the conceptual models, assessment instruments, and empirical normative data necessary to objectively ground such assessments. Such a body of knowledge has clearly advanced psychiatric research and practice in the area of informed consent to treatment and research.<sup>1,6,10,43-46</sup>

*2. Should a client be assigned a mandatory representative payee (RP)?* A second ethical issue involves decisions to assign RPs for clients with schizophrenia and SMI.<sup>35</sup> Representative payeeship "is a form of money management designed for individuals who, because of physical or mental disability, are unable to manage their benefit checks in a way that ensures that their basic living needs are met."<sup>47</sup> Both the Social Security Administration (SSA) and the Veterans Administration (VA) are empowered to mandatorily assign RPs to assist individuals with disabilities in managing their money. It is notable that such mandatory assignments, which occur without client consent and which are clear deprivations of liberty, do not require a legal process or judicial finding of legal

incompetency. For example, the SSA uses the following general criterion for representative payee assignment: “[when] the interest of the individual under this title would be served thereby, regardless of the legal competency of the individual.”<sup>48</sup> This is arguably an exceedingly broad criterion for mandatory decisions to remove a client’s control over his or her funds. More specifically, SSA will require an RP if they “determine that the beneficiary is not able to manage or direct the management of benefit payments in his or her own interest.”<sup>47</sup> Stated criteria for such decisions include medical evidence, the client’s living situation, the client’s current ability to handle money, and the client’s living needs and whether they are being met.<sup>47</sup> Little additional guidance is provided, and decisions to seek RP rely in large part on clinical judgment.<sup>47</sup> The Veterans Benefit Administration division of the VA offers much more extensive benefits and a separate and more involved procedure for addressing payeeship issues that will not be detailed here (see [www.vba.va.gov](http://www.vba.va.gov)).

There appear to be only modest procedural safeguards to the Social Security Administration representative payee process. The decision to assign a client to RP is the result of an administrative rather than a legal process, and the client is not by right represented by counsel. The amount of clinical input into such an RP decision varies and can be minimal in some cases. In addition, clients themselves do not determine who will be assigned as the RP, although clients are permitted to indicate their preference and their input is considered.<sup>47</sup> (This caution is indicated, as clients with SMI may not exercise good judgment in their personal selection of an appropriate RP.) Clients are entitled to appeal a representative payee decision, or choice of RP, to an administrative law judge.<sup>47,48</sup> There is also an established mechanism for reporting abuse or fraud by RPs to the Social Security Administration.<sup>49</sup>

RPs have demonstrated a range of benefits for individuals with mental disabilities.<sup>47</sup> The RP arrangement ensures that a client’s basic living needs are met on a monthly basis (e.g., rent, bills, food, medication). This promotes client stability and community tenure,<sup>47</sup> and leads to a series of important additional secondary benefits. These include reduced mental-health and physical symptomatology, reduced inpatient and emergency hospitalizations, increased housing retention and reduced homelessness, reduced substance abuse, increased treatment compliance, improved quality of life, reduced victimization related to money, and increased use of community services.<sup>47,50,51</sup>

Assignment of an RP is also a less restrictive option compared with other mandated treatments, such as outpatient treatment or inpatient hospitalization:

The threat to the client for non-compliance with his or her payee, and the payoff for complying with the

payee’s wishes, are both small in relation to the costs and benefits associated with the choice between mandated outpatient treatment and inpatient hospitalization or jail. The threat to the client is to lose control of benefit money, while the payoff is to have this same money used to ensure the client’s basic living needs. From a purely financial perspective, the primary mechanism of RP is the payee’s use of a beneficiary’s funds to pay rent and other essential expenses—none of which is negotiable or dependent on client behavior.<sup>37</sup>

In summary, recommending that a client receive a mandatory RP is an ethically complex decision. On the one hand, mandatory RP involves a clear loss of client autonomy. However well-intentioned an RP arrangement may be, clients lose control over their benefit monies. Clients may view the compulsory spending of their benefit money on rent, medication, and other necessities as a violation of their autonomy.<sup>37</sup> Clients may claim that it should be their right to decide not to pay rent, even if the consequence of their decision is to live on the streets or in a shelter.<sup>37</sup> In addition, once an RP is established, it may be very difficult for the client subsequently to regain control over his or her benefit check. Finally, it is always possible that the RP arrangement will be abused by the assigned payee, either through coercive measures on the client or by outright fraud (e.g., self-enrichment).

On the other hand, RPs have a very good track record in effecting individual, social, and financially desirable outcomes among individuals with SMI. RPs appear to facilitate stable access to shelter, food, clothing, and transportation among many individuals with SMI. There are a range of positive secondary outcomes, which include reduced inpatient and emergency hospitalization, increased treatment compliance, and increased use of community services. In particular, RP may be an effective solution to the problem of substance-abusing clients who misspend their benefit checks at the beginning of the month for drugs and alcohol,<sup>20</sup> with associated subsequent problems of homelessness, victimization, and psychiatric readmission.

In the authors’ personal view, mandatory RP may be clinically desirable in many cases. However, given the deprivation of liberty involved and its limited procedural safeguards, RP is a decision that should be made carefully, based on a thorough knowledge of the client, his or her behaviors, and his or her financial abilities.

3. *Should an RP be used to leverage a client’s treatment participation and compliance?* A third ethical issue relates to use of the RP arrangement to leverage client treatment participation and compliance. By its nature, the RP arrangement permits assigned payees some latitude or leverage with respect to influencing client behavior. Although a majority of the benefit check will be spent on necessities

and is therefore not “contingent,” RP allocation to clients of “personal allowance” or discretionary monies from the benefit check can be made contingent on behavior and is often used to leverage treatment compliance.<sup>37</sup> Receipt of discretionary funds has been linked to adherence to treatment goals such as substance use, medication use, and treatment program attendance. While the amount of monies are generally small (less than \$100 per month),<sup>37</sup> they assume substantial significance for clients with schizophrenia and SMI who wish to make some personal purchases and decisions of their own.<sup>34</sup>

The ethical issue presented is thus how conservatively or liberally a payee should interpret his or her role with respect to the RP arrangement. A conservative approach involves payment for necessities of shelter, food, and transportation, with leverage used “simply to deter gross mismanagement of their clients’ benefit payments.”<sup>47</sup> This approach emphasizes client autonomy within the RP arrangement. A more proactive approach involves using the RP arrangement to achieve treatment and behavioral goals beyond that of securing core necessities. This approach emphasizes professional beneficence in the RP arrangement, at the expense of client autonomy.

A recent study examined consumer views of representative payee use of disability funds to leverage treatment adherence.<sup>34</sup> A majority of consumers interviewed (65%) did not view withholding benefit monies as a useful method to improve treatment adherence. Consumers were more likely to view such leveraged arrangements as coercive when they felt their own views and concerns were not being respected or considered by the payee. Interestingly, consumers who were least likely to endorse the value of leveraged treatment were those with at least a high school education and who had reported abusing substances in the past month.<sup>34</sup>

As in all ethical issues of this type, there is not a clear, right answer to the issue of leveraging treatment in a particular case. Perhaps the best guide to action is the observation of Luchins and colleagues: “A good payee retains a balance between professional beneficence and respect for the client’s autonomy.”<sup>47</sup> Elbogen and colleagues have expressed a similar view: “Leverage of disability funds will likely have an optimal effect if combined with efforts to enhance a sense of self-determination.”<sup>34</sup>

*4. Should a treating mental health professional serve as a client’s RP?* A fourth ethical issue concerns whether a treating clinician or caseworker should also serve as a client’s RP. Under SSA regulations, RPs can include, in addition to family members, a client’s case manager, therapist, an agency auditor, or the mental health agency itself.<sup>37</sup> The appointment of a case manager as RP, particularly when the payee arrangement is used to leverage treatment compliance, can adversely impact the therapeutic relationship.<sup>37</sup> Such a dual relationship juxtaposes the typical advocacy and support roles of the caseworker

with a coercive, parental type of role with respect to controlling funds and spending. This role conflict can understandably create caseworker-client tensions, and one study reported that mentally ill clients verbally abused nearly half (44%) of RP caseworkers over management of funds.<sup>25,37</sup> The literature provides little information on the topic of psychotherapists acting as representative payees. The traditional position has been that psychotherapists assiduously avoid dual relationships of any sort.<sup>52</sup> Certainly the RP relationship would be viewed as an unacceptable dual relationship in most psychotherapy settings.

However, for caseworkers and case managers, there is literature support for such a dual role. In a study of potential negative effects on the therapeutic alliance, only 21% of case managers believed that serving as RP disrupted the therapeutic relationship, and only 20% of clients affirmed the statement “I can’t talk to my therapist about my feelings because he or she controls my funds.”<sup>25,37</sup> The same study found that client satisfaction with their caseworker RP was low initially but increased steadily over time, with 66% of clients being satisfied with the arrangement at the time of the study.<sup>25,37</sup> The study concluded that an RP arrangement implemented by the caseworker does not seriously affect the therapeutic (caseworker/case manager) relationship.

A review of the literature suggests that caseworker and agency implementation of RP arrangements for clients is a common practice. If a dual role is undertaken, the caseworker must take care that the coercive aspects of the RP arrangement do not undermine client trust or the advocacy and support aspects of the caseworker role. As discussed above, it is unlikely that a professional psychotherapist working with a client with SMI could ethically also act as the client’s RP.

*5. Can monetary compensation for research participation exert a coercive, exploitative, and/or disruptive influence upon individuals with SMI and limited financial capacity?* The impact of mental disabilities such as dementia, developmental disabilities, and mental illness upon decisional capacity has been recognized as an important ethical consideration in research participation and informed consent. Dresser (1996) has observed that US regulatory policy does not answer many of the ethical issues raised in these decisionally impaired populations, leaving it to institutional review boards (IRBs) and investigators to determine their own guidelines.<sup>8</sup> Dresser has strongly encouraged the limited inclusion of decisionally impaired persons in research, as well as the inclusion of advocacy groups, mental health consumers, and other stakeholders, in better defining ethical parameters for research participation.<sup>53</sup> However, the role of financial capacity and the influence of monetary compensation have typically not been examined in detail in such discussions.



Monetary payment is recognized as an influence upon the assessment of research risk by research participants. Healthy subjects have been shown to be more willing to participate in biomedical research, regardless of risk levels, when higher levels of payment are offered.<sup>54</sup> (At the same time, the authors noted that increased compensation levels did not appear to blind subjects to the risks of a study.) Grady has observed that payment can unduly influence research participation, obscure risks, impair judgment, and encourage misrepresentation by study participants.<sup>55</sup> The lack of widespread use of written policies regarding payment to research subjects, the lack of model practices for research payments to cognitively impaired subjects, and the use of “rules of thumb” in their stead are recognized as critical ethical considerations in human subjects research.<sup>56</sup>

In this regard, little attention has been paid to ethical issues surrounding compensation to research participants with schizophrenia and other SMI. As noted above, monetary payments have been shown to influence risk estimation and participation in biomedical research by healthy subjects.<sup>54</sup> What is the possible effect of such payments on research participants with SMI—individuals of low SES and frequently limited financial capacity? On the one hand, there is a problem of potential coercion. A monetary payment of \$50 may represent a full month’s personal spending money for the person with SMI, but only a modest recompense for his or her typical adult counterpart. The payment may thus be disproportionately attractive to the person with SMI, and as a result he or she may be prone to assume disproportionately higher, and possibly unacceptable, levels of research risk.

On the other hand, there is a problem of potential exploitation. A person with SMI and impaired decisional capacity may underestimate the financial value of his or her own time and participation. They may agree to participate in demanding, long-term research trials with little or no compensation. Members of the National Alliance for the Mentally Ill (NAMI) have complained about family members being recruited for psychopharmacological clinical trials and offered no monetary payment at all (personal communication to RS, co-author). While NAMI does address research issues in its official public policy platform,<sup>57</sup> it does not specifically address financial concerns of participants or family members.

It is the important responsibility of local IRBs, and of investigators, to develop policies regarding research compensation that balance the importance of conducting biomedical research with the task of ensuring that decisionally impaired participants are fairly compensated for their time and effort, and are not unfairly induced to participate. In addition, other protections are possible. For example, for those clients with an RP, should the RP be routinely involved (assuming the client’s consent) in the informed consent and enrollment phases of a research study?

A related ethical consideration is the *clinical impact* of serial research monetary payments to individuals with schizophrenia and SMI. As described above, many persons with SMI are prone to substance abuse disorders, and there exists a strong temporal relationship between the arrival of monthly disability checks and other external payments, and substance-abuse binges or relapses, with subsequent exacerbations of psychiatric symptoms and related hospitalizations.<sup>20</sup> Similarly, participation in some trials may give rise to cumulative annual compensation in amounts that produce tax consequences or a negative impact upon SSDI or SSI eligibility. These considerations are not intended to discourage research with patients with SMI—this is of fundamental importance—but rather to sensitize investigators and coordinators to these issues in this population.

In conclusion, ethical concern for persons with schizophrenia and SMI implies that, as a part of the broader discussion of research ethics, the financial means and capacity of these individuals receive attention. First, issues of possible financial coercion and exploitation related to monetary compensation need to be considered in conducting research with this population. Just compensation that is potentially neither coercive nor exploitative must be considered with care. Second, when a potential research participant is known to have an RP, the RP might be engaged at appropriate moments in the recruitment process. This can benefit the client and ultimately the investigative research team as well. Monetary compensation may have a unique clinical and financial impact in the SMI population related to possible substance-abuse patterns, tax consequences, and benefit eligibility criteria.

## Summary

This article has addressed clinical and ethical aspects of financial capacity in clients with schizophrenia and SMI. Despite its relevance to personal autonomy and independent functioning, financial capacity has received surprisingly little research attention in the psychiatric and mental health literature. Issues of financial capacity emerge frequently regarding clients with SMI, and their resolution has practical and ethical significance for clients, their families, and mental health professionals. These issues include whether a client has sufficient financial skills and judgment to live independently, whether a client requires a representative payee, and what goals for community reintegration should be established with a client.

Similar to informed consent, issues of financial capacity raise ethical challenges for clinicians, caseworkers, and agencies. The present article has addressed five ethical questions related to financial capacity in clients with schizophrenia and SMI. These questions concern clinical evaluation of financial capacity in persons with SMI,

whether to seek assignment of a mandatory representative payee, whether to leverage treatment compliance through a representative payee arrangement, whether a mental health professional should also serve as a client's representative payee, and whether monetary compensation for research participation can potentially exert a coercive, exploitative, or disruptive effect on persons with SMI.

The ultimate goal of this article has been to focus clinical and ethical attention on a neglected decisional capacity in SMI that is of fundamental importance for clients, families, clinicians, and researchers. The authors hope that this article will help stimulate interest and further research regarding financial capacity in psychiatric populations.

### Acknowledgments

This study was supported by research grants (NIH, NIA 1 R01 AG021927 (Marson, PI), NIH NIMH 1R01 MH55247 (Marson, PI)), an Alzheimer's Disease Research Center grant (NIH, NIA 1P50 AG16582-01) (Marson, PI), and the Alzheimer's Disease Cooperative Study (NIH, NIA U01 AG 10483-12) (Thal, PI).

The authors express appreciation to Sara Krzywanski, MS, and Katherine Belue of the UAB Department of Neurology, and Adreinne Thompson, MSW, and other members of the UAB Department of Psychiatry and Behavioral Neurobiology, for their assistance with conceptual modeling of financial capacity in SMI.

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