



**PERCEPTIONS OF BENEFICIARIES WITH MENTAL ILLNESS AND FAMILY
REPRESENTATIVE PAYEES REGARDING SATISFACTION AND CHALLENGES**

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Abstract

This paper examines family representative payeeship provided to adults with mental illness. In-depth interviews were conducted with five beneficiaries with mental illness who have a family representative payee and seven family representative payees for this population. The qualitative descriptive method and thematic analysis were employed to examine satisfaction with, and conflict experienced in, family representative payeeship.

The paper found that:

- Most participants described having a high level of satisfaction with representative payeeship.
- Most participants identified benefits of family vs. organizational representative payees being easier access to, and greater trust and closeness with, family representative payees.
- Some beneficiaries said one drawback of family vs. organizational representative payees is that family members may try to influence more of their decisions than would organizational representative payees.
- Most family representative payees provided assistance to beneficiaries beyond managing their money; some participants worried about the burden experienced by family representative payees.
- Considerable variation was described in how informed beneficiaries are of their finances and in their level of involvement in making financial decisions.
- Beneficiaries reported that not being involved in financial decision-making detracted from their satisfaction.
- Participants (beneficiaries and representative payees) who reported beneficiaries were less involved in making financial decisions tended to experience more financial arguments.
- Some beneficiaries believed family representative payees were less skilled and/or knowledgeable than organizational representative payees about the rules and limits of representative payeeship; they suggested that family representative payees receive more education and training from the Social Security Administration (SSA).

- A couple of beneficiaries reported misuse of funds by representative payees. They wanted alternatives to formally filing a complaint to help resolve issues of misuse and financial disagreements, with one suggestion being to offer mediation.

The policy implications of the findings are:

- SSA may want to consider making additional efforts to educate and train family representative payees on financial matters and the rules and limits of representative payeeship.
- It may be helpful for SSA to further promote engaging in supported decision-making among family representative payees and beneficiaries; increasing the involvement of beneficiaries in financial decision-making may prevent conflicts and enhance satisfaction for both parties.
- SSA may want to consider alternative means of recourse for beneficiaries perceiving misuse of their funds or experiencing frequent financial disagreements.

Context

The Social Security Administration (SSA) provides benefits to more than 69 million adults and children through Old-Age and Survivors Insurance (OASI) and Supplemental Security Income (SSI). In December 2018, 2.7 million adults with schizophrenia, other psychotic disorders, or mood disorders received OASI and/or SSI benefits, with considerably more adults receiving benefits for other developmental/mental disorders (SSA, 2018). When beneficiaries are unable to manage their finances, the SSA appoints a legal representative payee.

Representative payees directly receive beneficiaries' benefits and are tasked with managing these benefits in a manner that ensures beneficiaries' basic needs are met. Approximately 5.6 percent of all adult beneficiaries have representative payees. Beneficiaries with disabilities, however, are much more likely to have representative payees, and 26 percent of adult beneficiaries with schizophrenia, other psychotic disorders, or mood disorders – approximately 700,000 adults – have a representative payee (SSA, 2018). Organizations can act as representative payees. However, 70 percent of all representative payees for adult beneficiaries are family members (SSA, 2018), and the SSA most favors family members for appointment as representative payees for adult beneficiaries. Having a representative payee has been found to be associated with many desirable outcomes for persons with mental illness, including increased ability to meet basic needs and participation in substance abuse and mental health treatment, as well as decreased rates of hospitalization and homelessness (for overviews see Kinsky et al., 2019; National Academies of Sciences, Engineering, and Medicine, 2016). Although inconsistent, some evidence even suggests that payeeship may result in decreased substance use by persons with mental illness (Kinsky et al., 2019).

Likely reflecting these benefits, most beneficiaries with mental illness report being satisfied with their representative payee arrangement. In the earliest examination of satisfaction among recipients with mental illness, Dixon et al. (1999) found the average participant receiving assertive community treatment to nearly be “somewhat satisfied” with their representative payee arrangement. Rosen et al. (2001) reported 86 percent of those receiving representative payeeship from a community mental health center were pleased with the ways in which their money was managed. Shortly thereafter, Rosen et al. (2003) found the average veteran psychiatrically hospitalized to “somewhat agree” with being pleased with how their representative payee manages their money and later reported that the average client of a community mental health

center endorsed “somewhat agree” to the statement “I am satisfied with my payee” (2005). Elbogen et al. (2007) reported that 56 percent of consumers with mental illness were extremely satisfied with how they and their representative payee worked together. Most recently, Labrum et al. (under review) report that among 60 beneficiaries with mental illness, 65 percent reported being “somewhat satisfied” or “very satisfied” with having a representative payee.

Despite the aforementioned benefits and relatively high levels of satisfaction among beneficiaries, representative payeeship provided to persons with mental illness is not without concern (Kinsky et al., 2019; National Academies of Sciences, Engineering, and Medicine, 2016). Many beneficiaries are involuntarily appointed a representative payee, with some beneficiaries continuing to perceive that they do not need a representative payee. Additionally, evidence consistently indicates that a sizable minority of representative payees enact various forms of financial leverage, which has been defined as “a representative payee’s use of control over an individual’s funds to encourage, incentivize, or otherwise coerce certain behaviors” (Kinsky et al., 2019, p. 724). Although there is likely considerable variation across subgroups of recipients with mental illness (Appelbaum & Redlich, 2006), evidence suggests that as many as 30 percent to 40 percent of representative payee recipients with mental illness perceive experiencing financial leverage (Angell et al., 2007; Elbogen, Swanson, and Swartz, 2003). Consequently, a primary concern raised regarding representative payeeship is that it may be perceived by beneficiaries as coercive and a threat to their autonomy. Perceiving such a threat to their autonomy may lead beneficiaries to feeling stigmatized and disempowered and experiencing anxiety and self-doubt (National Academies of Sciences, Engineering, and Medicine, 2016).

Another primary concern raised regarding representative payeeship is that it may lead to conflicts between beneficiaries and representative payees and may otherwise damage their relationships with each other. Conflict between case managers and persons with mental illness has been documented to be more common when representative payeeship is present (Angell et al., 2007; Dixon et al., 1999). Regarding representative payeeship provided by family members, 36 percent of recipients with mental illness and half of representative payees have reported that representative payeeship leads to family conflict and arguments “often” or “always” (Elbogen et al., 2007). Most recently, Labrum et al. (under review) report that one-third of beneficiaries with

mental illness endorsed “sometimes” or more often in response to the question “How often have you had conflict or arguments with your representative payee because of how s/he handles your money?”. Even more concerning, the risks of violence (Elbogen et al., 2005; Labrum & Solomon, 2016) and theft (Labrum, 2017) against family members increase when persons with mental illness have a relative serving as their representative payee.

Available evidence suggests that satisfaction with representative payeeship is negatively related to beneficiaries perceiving the use of financial leverage and conflicts with representative payees (Elbogen et al., 2007; Labrum et al., under review). Most studies conducted on the topic of representative payeeship for persons with mental illness pertain to representative payeeship provided by professionals; however, available evidence indicates that compared to representative payeeship provided by professionals, these concerns likely pertain at least as much to representative payeeship provided by family members. For example, as previously described, evidence indicates that half of family representative payees report that providing representative payeeship to beneficiaries with mental illness leads to conflict and arguments “often” or “always”, with 36 percent of beneficiaries reporting the same (Elbogen et al., 2007). Additionally, it has been found that the likelihood of physical violence (Elbogen et al., 2005; Labrum & Solomon, 2016) and theft (Labrum, 2017) by persons with mental illness toward family members is at least two-fold when family representative payeeship is present. There is also tentative evidence that family representative payees may be slightly more likely than their professional counterparts to exercise financial leverage (Labrum et al., under review), perhaps because they have more interactions with beneficiaries and/or are concerned about a larger range of beneficiaries’ behaviors (e.g., acting in accordance with household rules). Relatedly, family representative payees likely experience challenges not experienced by professional representative payees, such as also providing beneficiaries with financial aid (utilizing the payees’ own money) and general caregiving (Labrum, 2018). Notably, despite the importance of services provided by family representative payees, research has largely failed to examine family members’ satisfaction with being representative payees.

Research Questions

Utilizing a qualitative design, this study seeks to examine the following research questions, from the perceptions of beneficiaries with mental illness who currently have family representative payees and family representative payees for beneficiaries with mental illness:

- 1) What are the benefits of family members being representative payees as opposed to organizations/professionals?
- 2) What are the drawbacks of family members being representative payees as opposed to organizations/professionals?
- 3) What explanations do parties provide as to why they are as satisfied with their involvement in representative payeeship as they are?
- 4) What explanations do parties describe as to why they are not more satisfied with their involvement in representative payeeship?
- 5) What recommendations do parties make for how the Social Security Administration can improve satisfaction with family representative payeeship?
- 6) What do parties believe lead to or cause conflict/arguments between beneficiaries and representative payees?
- 7) What recommendations do parties make for how the Social Security Administration can help prevent conflict/arguments?

Methods

This study was approved by the institutional review board at the University of Pittsburgh. This study conducted qualitative analysis of in-depth individual interviews of five beneficiaries who reported having a mental illness and currently having a family member acting as their representative payee and seven persons who reported being family representative payees for this population. All participants were adults. Participant recruitment occurred primarily through Pitt+Me, an institutional research participant registry. Pitt+Me's primary objective is to identify and recruit University of Pittsburgh Medical Center (UPMC) patients of all ages from every UPMC point-of-service location (approximately 6 million outpatient visits and 388,000 inpatient admissions), as well as community member volunteers who may be eligible to participate in University of Pittsburgh research studies. The UPMC is one of the largest providers of mental health and psychiatric services in the country. Currently, the Pitt+Me Registry has more than

245,000 enrolled participants interested in learning more about research, with more than 19,000 adult participants diagnosed with schizophrenia, schizoaffective, bipolar, or major depressive disorder. Additionally, one participant was recruited through referral from mental health treatment agencies affiliated with UPMC.

Participants completed one in-depth interview, conducted over the telephone. Participants were informed that interviews would not last longer than 90 minutes; most lasted 60 minutes or less. Participants received a \$40 e-gift card as compensation for their time. Interviews were semi-structured, balancing the need for standardized data collection with the flexibility of following participants' responses (Streubert & Carpenter, 2011). All interviews were conducted by the principal investigator. The interview guides are provided in the appendix. Interviews were audio recorded and transcribed verbatim, with the accuracy of transcripts verified. The study employed a qualitative descriptive design (Sandelowski, 2010). Thematic analysis (Vaismoradi, et al., 2013) was conducted regarding the verbatim interview transcripts. In an effort to achieve immersion, all recordings were listened to twice prior to performing coding (Hsieh, & Shannon, 2005).

Results

Benefits of Family vs. Organizational Representative Payeeship

Most participants reported that a main benefit of having family members serve as representative payees as opposed to organizations/professionals is that there is considerable trust and/or closeness between beneficiaries and family members.

- Beneficiary: "We're really close. I trust her. I trusted her to become my payee and have my best interests at heart."
- Beneficiary: "I think she gives me emotional support that I might not get with a stranger because of the fact that we are close. So much close. And I lean on her whenever I'm going through hard times, hard situations. She gives me emotional support. She understands me better. So I feel like she's – I cannot say that I would prefer a stranger over her."
- RP: "I like that a family member can do things like these for family. It seems like it makes them feel more comfortable. The other person it seems like it makes them feel more comfortable with family doing it for them."

- RP: “Trust is a key point.”
- RP: “I think it's a lot better that I'm the payee because I think my mother feels more like I care and that we wouldn't just leave her at the mercy of a stranger.”

Another benefit described by participants is that it is easier to access family representative payees than organizational representative payees.

- Beneficiary: “Oh, well, it's easier access [to] my money. She just lives upstairs. She will pay my bills and do all that. If I need money, I just got to ask her for it. It's just really convenient... if I need something, I can just walk upstairs and talk to her about it as opposed to having an agency where I got to make sure somebody's in there.”
- Beneficiary: “I see her every day, talk to her every day. I have a very good relationship with her.”

A beneficiary who had previously had an organizational representative payee reported:

- “It's nice because I can get a hold of her [family representative payee] at any time. It was difficult communicating with the people at the agency. They were really overworked. They had way too many clients for the number of people that worked there, and so it was hard to get a hold of anyone. It was hard to make requests.”

One beneficiary reported that family representative payees followed fewer “rules” than organizational payees and were more person-centered.

- Beneficiary: “And they [organizational representative payees] said no a lot more than my mom does.”

Relatedly, one representative payee reported that a drawback to having a family member serving as a representative payee is that beneficiaries may think they will be less inclined to follow the rules.

- RP: “They feel like because you're a family member, that you're just going to just, "Oh, yeah, I got this. I ain't got to worry about no professional." But no, it still works the same way.”

Drawbacks of Family vs. Organizational Representative Payeeship

Most representative payees described that they provide considerable support and care to beneficiaries beyond managing their money and a couple reported spending their own money to help pay beneficiaries' bills.

- RP: "You definitely want to make sure that if you're someone's payee, you would want to make sure that you take care of their whole well-being."

Similarly, most beneficiaries reported that their representative payees provided them with emotional support and helped them with tasks unrelated to their finances (child care, college work, attending somatic and mental health treatment etc.).

- Beneficiary: "She gives me a home, somewhere to live. She provides me everything I need. And she cares for me. I think she really likes me. She cares for me, provides for me."

Relatedly, some representative payees and beneficiaries reported that a drawback to family members being representative payees is the burden it added to their lives, which could be exacerbated by how tight the budget was. Representative payees described that they had to deny requests for money made by the beneficiary due to inadequate funds. Even when this did not create conflict or arguments, having to do so detracted from their satisfaction.

- Beneficiary: "I worry that it stresses her out more than she needs to be stressed out. I think it stresses her out because I don't get that much money, I mean, after my premium comes out, it's like [redacted] month, which isn't a whole lot. It doesn't go very far, especially with everything as expensive as it is. And my boyfriend works. He has some health problems, and he's off work every so often for weeks at a time. And she worries, and I don't like that she worries about my finances. It was better when she didn't know how much I made. I could pretend that everything was better than it was. I think she wonders how I subsist on the weekly amount of money that I get when my boyfriend isn't working... she gives me money sometimes that she can't afford to give me. And I know she can't afford to give it to me."
- RP: "I feel like this is a burden for me."

A couple representative payees reported that they found the paperwork requirements to be an inconvenience. A couple beneficiaries reported that family members may not be as knowledgeable or capable in certain areas as professionals. One beneficiary who previously had an organizational representative payee reported:

- Beneficiary: “The one thing I can say that's good about the payee programs, though, is they do all the paperwork for you. And my [family RP] has a hard time with that. So I end up having to do a lot of the paperwork for the extra help programs for your Medicare Part B premiums and your prescription drug stuff. I end up having to do all of that, that kind of stuff because she has a hard time figuring out how to do that stuff. So that's the one thing I can say that was better about them [organizational payee] is that I never had to worry about filling out any paperwork with them.”

Another beneficiary described that her family member has historically been a capable representative payee. However, she considers this family member to currently be less capable than an organizational representative payee would be due to cognitive issues experienced as a result of a medical condition.

- Beneficiary: “Well, I think just mainly the fact that she's not paying things as good as she would had she not had the [medical condition]. Some things I'm afraid that she's not even paying at all. And the fact that I don't know, the fact that I don't know what's going on is even worse. So those are the negative parts of it.”

Another drawback reported by some beneficiaries is that family members may be less “objective” than organizational payees and may try to influence more of their decisions than would organizational representative payees.

- Beneficiary: “Mothers do know their kids best rather than somebody who's a stranger. But the problem is that because she knows these things and because she thinks she knows best and, well, I can put the money wherever I think I should do it and pay her own bills or pay my student loans when I need haircuts and things like that. I haven't had a haircut in two years. She just doesn't care....if I were to have a court-appointed one [an organizational payee], he probably would be more likely to follow the law and the rules because it comes from more of an objective view rather than a subjective view coming

from a mom who thinks she knows best and then she's going to talk to dad and what do you think and what do I think...she's my mom, and she thinks she can control me as a child because she always has. So she thinks she knows what's best.”

- Beneficiary: “She can sometimes be a little – like when I moved, she was very involved in where I was moving to, to the point where it was a little irritating. If it's within my budget, I want to move where I want to move to. I don't really want someone telling me, "Oh, you shouldn't stay at this apartment. You should stay at this other apartment." If I like a particular apartment, I want to stay there. I had to fight with her to get to stay at this apartment I'm in now. And I love this apartment. It's beautiful. I really don't know what her problem with it was. But I think she had a little bit of a control thing sometimes.”

Some representative payees described that they do try to influence beneficiaries' behaviors in a range of areas, usually in pursuit of what they consider to be the beneficiaries' best interest.

- RP: “Like I'm almost finger wagging, telling her, "You can't do this. You can't have your hair like this." But I told her, I said it's for her own good. I wouldn't dare let her get a hairstyle that wasn't age-appropriate nor wear something that was not age-appropriate.”

One representative payee reported worrying she would be held responsible if the beneficiary was unwell.

- RP: “And I try to make sure that he doesn't disobey what the doctors say because they're the ones who initially got him approved. And if he doesn't make it to his appointment or if he drinks too much alcohol or anything like that, he uses drugs or anything like that that he could be cut off from his Social Security or he could get really sick of what I was trying to say. He can get really sick. He's like a diabetic, so he doesn't need to drink alcohol.... It feels like I can get in trouble from Adult Protective Services or anybody like that. If I don't supervise his money well, then they can come in and say that I abused him or anything like that. Somebody's always watching; so I would like to say that I definitely make sure that he has groceries, he has his rent paid, and that he doesn't partake in drinking way too much alcohol or going on binges or drinking too much or that he

doesn't fall into the wrong crowd and also that he doesn't eat the wrong food because he can get to eat too much sugar.”

Finally, a couple beneficiaries reported that they are hesitant to be assertive with their family representative payees about their concerns or file a complaint with the SSA because “we’re family.” These beneficiaries described that they would be more inclined to be assertive or file an official complaint if their representative payees were an organization.

- Beneficiary: “She doesn't like that I buy cigarettes. I do buy cigarettes. I was clean and sober for many, many years, and I relapsed on coffee and cigarettes, and she's very upset. So she feels like, "No. I'm not paying for this, and I'm not paying for that." I said, "Oh, my goodness." And in some ways, I'm just like, "You have to. You have to be doing this." "No, I'm not," she says. And what are you supposed to tell your own mom? Your mom takes care of you, you know what I mean? And you can't talk back to her because it's your mom. I was raised not to talk back. I was raised in a generation where we listened....”

Supporters of Satisfaction with Family Representative Payeeship

Participants were asked to rate how satisfied they are with representative payeeship “on a scale of 0-10, with 0 being not at all satisfied, and 10 being the most satisfied”. Ratings provided by representative payees were 6, 8, 8, 9, 10, 10, and 10. Ratings provided by beneficiaries were 3, 8, 9, 9, and 10.

Most family representative payees reported that they receive satisfaction from knowing they are helping their relatives.

- RP: “I like that I can help a family – I can help a family member, even though it can be difficult at times.”
- RP: “So I'm helping him accomplish some of the goals that he set forth.”
- RP: “I feel good helping my uncle.”

Some beneficiaries saw having a representative payee as being beneficial in managing their money and reported that it supported their financial stability.

- Beneficiary: “It's like having an accountant for free. [laughter] You know what I mean? They pay my bills for me and they keep track of what's left over and tell me what I have.

And we say this much of what's left over is going in savings and this is how much is left. And then you divide it by the number of weeks and the month, and that's how much you get. And it's pretty straightforward. And it's basically like having an accountant and you don't have to worry about paying your bills. It's done for you. And you never have to worry about being impulsive and going on a shopping spree and not having your rent paid.”

Beneficiaries who described being involved in making financial decisions and being able to access their money reported that these were reasons they were satisfied with having a payee.

- Beneficiary: “She gives me my money when I ask for it.”
- Beneficiary: “And I feel like I have a little more autonomy with her because she pretty much lets me decide what to spend the money on and then she just does it for me. But luckily, I mean, within limits. She's like I have to make sure my bills are paid. "You have to have your rent paid." I have to pay my rent. I have to pay my utilities. But after that, whatever Wi-Fi plan I want to go with, I go with. Whatever phone service I want to go with, I can go with. Whatever's leftover with the money, I can pretty much make my own choices, and she will go with it. So I like that about her. There's a lot of flexibility with her.”

Detractors of Satisfaction with Family Representative Payeeship

Some beneficiaries reported that having a representative payee limits their autonomy. They described that in asking their payee for money they usually need to explain what they want the money for, which can feel like a violation of their privacy.

- Beneficiary: “I don’t feel as independent.”
- Beneficiary: “Well, I mean it's just a matter of having someone else control your money. It's very annoying. You don't have your own mind...”
- Beneficiary: “I worked my whole life, and it's not very easy for me not to control where I can go and what I can pay for.”
- Beneficiary: “She wants to know what I want to use the money for. She doesn't just give me the money. She really wants me to explain what I want it for. Sometimes I feel that she doesn't give me my own space to do my own thing. But she's so much

overprotective. And she gives me the money only after I've explained what I want to use it for... I think she's overprotective. And I feel like she still sees me like a child.”

One participant reported that losing privacy to a family representative payees is more uncomfortable than losing it to an organizational RP.

- Beneficiary: “Sometimes I don't like her knowing everything about my finances. I guess it's almost a little intrusive having someone, even if it's a family member. I grew up being taught that your finances are very personal. You don't talk about your finances with people. That's your own business, and you keep it to yourself. So it's weird to me to have someone, even my mom, know all of my financial business like that. So, it's kind of intrusive in a way, and it's not her fault. It's not like I'm mad at her about it. I'm just kind of – I feel like the whole thing is just intrusive. It's a little more intrusive to me having a family member do it, I guess, than having a paid person do it because maybe because I know I'm close with the person doing it now.”

Of the five beneficiaries, two reported they were adequately involved in making financial decisions. Among the three who perceived not being adequately involved, they all reported that this detracted from their satisfaction.

- Beneficiary: “Well, it'd be nice to know what I make. It'd be nice to know what I owe. And maybe I could try to help out with kind of divvying it out for myself.”
- Beneficiary: “sometimes I feel like she doesn't involve me in creating the budget. And she does things her own way. Sometimes she's dictating how we live... So we don't sit down together to create a budget, but she asks me what I want...”

Relatedly, said beneficiaries reported they would be more satisfied if they were more involved in making financial decisions.

- Beneficiary: “Well, I think to get a little bit more of my needs met like the haircuts, the clothes, maybe a few extra things per month to – maybe if I could buy pop or something, that kind of thing...I definitely would like to be more in charge of it.”
- Beneficiary: “Also, [RP] trust me more, understand that I am an adult, and also let me pay my own bills. Let me handle my own – yeah, pay my bills and make my own plans, get myself on a vacation on my own or trip.”

Conflict between Beneficiaries and Representative Payees

Most beneficiaries reported that at some point they had experienced financial arguments with their family representative payees, with a couple reporting that they regularly had such arguments. Arguments centered around how beneficiaries' money was spent; the beneficiaries who reported being the least involved in making financial decisions reported having the most arguments with their family representative payees. One participant reported that she and her representative payee consistently disagree about how her funds should be prioritized and argue "every day".

- Beneficiary: "Yes, me and my mom have a lot of conflicts regarding what the money should be used for and how should we spend it and why aren't you giving me this and why aren't you giving me that? And we literally have been doing that for 13 years. It's been really, really hard... just trying to get her to pay for something that I want, like a haircut, she'll say, "Oh, you don't need it," and then she'll make an appointment for me that I can't afford... It's hard for me to get toiletries and all this stuff. And she just keeps controlling this and controlling that...It's every day. Every day. She's got something to say about, "You've got to pay this dental bill... Well, you have to make sure you pay for it, or I'm going to take your [beneficiary's monthly allowance] and pay for it myself." I said, "Well, I need that...So we definitely argue a lot. It literally is just that. Right now, that's all we do."

Most representative payees also reported that financial arguments had occurred, with some reporting that they occur regularly.

- RP: "I can honestly say that [financial arguments] happens – I'd say every month, maybe a few times of the month."

Among beneficiaries and representative payees, when financial arguments occurred, they deteriorated satisfaction and strained the relationship. One representative payee reported that she discontinued being a representative payee for a different family member due to the regularity of arguments.

- RP: "I think the relationship somehow is not as open as it was before. And this mostly has happened maybe due to continuous conflicts between me and mom. So the

interaction I think is not as good as it was before.... So once I enter into a conflict with my mom and a very serious conflict, I sometimes tend to avoid being close, and maybe somebody else will come and be there for a few days.”

- RP: “I don't like when she gets mad at me...[the arguments] make you feel like you don't want to do it [be a RP] no more.”

Representative payees reported considerable variation in the degree to which beneficiaries were involved in budgeting their money. A couple representative payees reported never having had financial arguments with beneficiaries. These representative payees described beneficiaries as being highly involved in making financial decisions and in being aware of financial matters, with beneficiaries regularly accessing online banking. Most representative payees reported that a way of resolving or preventing arguments was to comply with requests for funds, when possible.

- RP: “So early planning, sometimes we use it to resolve the dispute.”

When arguments were resolved in the beneficiary’s favor, beneficiaries reported that this primarily occurred through being persistent in addressing their concerns. Relatedly, some representative payees reported a stressor was beneficiaries being persistent in their requests.

- RP: “I would just say it was kind of bad because she was the type of person that would try to hunt you down. Like, "I need my money”.”

Recommendations for SSA to Improve Satisfaction and Decrease Conflict

Some beneficiaries reported believing the SSA should provide more education to representative payees.

- Beneficiary: “I think they'd probably have to maybe, and I hate to do this to my mom, but kind of have to explain to her the rules as far as what you can do and what you can't do. And I was reading on the Social Security website that – what was I going to say? That she's supposed to be saving what I don't use. So it's just a matter of maybe telling her facts like that and telling her what she's actually supposed to be doing because we really didn't have – she didn't have that type of information. She didn't have that type of what do you call it? She didn't have that much information as far as what she's supposed to do,

put aside this much money, and this has to be paid before that and only pay this much and stuff like that, so Yeah.”

Two beneficiaries reported being unsatisfied with how their money was spent and believing that their representative payees used their money to pay for the representative payee’s own needs. They knew they could file a complaint and described they were not interested in doing so because the payee is a family member. A related suggestion they made for improving satisfaction is the SSA providing more oversight of how funds are spent, which they believed would help prevent misuse.

- Beneficiary: “They need to hold them [family RP] responsible for whatever they do with the money. And make sure that the needs of the patient or the victim has everything they want or has the best so that the payee doesn't spend all the money on their own issues and leave the things that they should have done for someone like me undone.”

A couple beneficiaries also reported desiring alternatives to formally filing a complaint to help resolve issues of misuse and disagreements about how money is spent. Relatedly, beneficiaries suggested that mediators could be helpful in resolving disagreements about how money is spent.

- Beneficiary: “Just someone that informally comes and listens to me, listen to my complaint, and explain to my [RP], or ask my [RP], listen to my complaint informally.”
- Beneficiary: “Just a little bit more of maybe we could get some kind of mediator and [family member other than representative payee] or somebody to come in and kind of figure out what we're going to spend on what. So that's what I wish would change about the situation.”
- Beneficiary: “I think there maybe should be some sort of system set in place where a person who has a payee can contest the decision made by the payee and possibly go through a mediation process.”

Connected to this, one representative payee reported that one way to resolve financial disagreements between her and the beneficiary was to have an additional family member talk to them.

- RP: “So I try to involve my older brother.”

A couple beneficiaries reported that when they voice concerns about how their money is spent to their representative payees, their concerns are dismissed as being symptoms of their mental illness. For this reason, one beneficiary believed a mediator could be helpful.

- Beneficiary: “Maybe she was just a little bit more lenient if I was informed and just a little bit more of my involvement and hearing me. And because I'm mentally ill, she can always use that as some kind of a thing where you're not able to handle it. You're not mentally equipped to handle it. I'm still a person, you know? Still a person, and I used to work. So I know what I, you know what I mean? I used to work. So I know what I'm doing. I just happen to hear a little bit still. And I get manic. I know I get manic, and I talk too much. You're getting manic, you're getting manic. And you can't spend this money because of your manic depression and your bipolar. And so that's what I wish would happen, just involved.”

Another beneficiary similarly reported that when she presents complaints to her representative payee, she is told that she is unwell.

- Beneficiary: “It's like she doesn't want to get into an argument with me about the money. So if I try to push it, she would just shut me down and tells me that, "You are not okay." She thinks I don't have to say anything. The only time that I say a word to her is when I'm not okay.”

Some participants reported their satisfaction would increase if the beneficiaries' Social Security benefits increased. One beneficiary reported her representative payee likely would grant more of her requests for money if her disability benefits were greater. Similarly, a couple representative payees reported it would be easier to manage their relative's finances and “make ends meet”, if benefits were greater.

Conclusion

This study examined family representative payeeship provided to adults with mental illness by conducting in-depth interviews with five beneficiaries with mental illness who have a family representative payee and seven family representative payees for this population. The results offered insight into the level of satisfaction with this arrangement and suggestions for improvement.

Most participants described having a high level of satisfaction with representative payeeship. Some beneficiaries said that a drawback of family vs. organizational representative payees is that family members may try to influence more of their decisions than would organizational representative payees. Considerable variation was described in how informed beneficiaries are of their finances and in their level of involvement in making financial decisions. Beneficiaries reported that not being involved in financial decision-making detracted from their satisfaction. Some beneficiaries believed family representative payees were less skilled or knowledgeable than organizational representative payees about the rules and limits of representative payeeship; they suggested that family representative payees receive more education and training from the Social Security Administration. A couple of beneficiaries reported misuse of funds by representative payees and wanted alternatives to formally filing a complaint – such as mediation – to help resolve issues of misuse and financial disagreements.

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Appendix

Interview Guide for Representative Payees

Date:

Interviewer:

Interviewee first name:

Thank you for taking time to speak with me. I would like to hear about your experiences serving as the payee for your family member. It is not uncommon for a family member to serve as a payee for someone with a mental illness. With this research project, I am trying to understand what makes the experience positive and what causes strain or conflict in that relationship. I appreciate your willingness to share your experiences with us. If there are any questions you prefer not to answer, you are free to say “pass” and move to the next question. You may also stop the interview at any time.

Remind about using first names only.

- 1) You are the payee for someone. How are you related to that person? Possible probes:
 - a. Do you live together?
 - b. How often do you communicate with each other?
 - c. How long have you been _____’s payee?
- 2) Given that your [the relationship] has been assessed as needing a payee, how do you feel about being assigned as the payee for your [the relationship]? Probe:
 - a. What do you think about being the payee for your [the relationship], rather than having a stranger who is a payee for many other people be assigned to your [the relationship]?
- 3) I’d like to ask you about all the things you like and the things you don’t like about being the payee for your [the relationship]. Let’s start out with the good things. What do you like about being the payee for your [the relationship]? Probe:
 - a. What are the good things about you being the payee for your [the relationship]?
 - b. Imagine that a stranger was your [the relationship]’s payee rather than you, what is better about you being the payee rather than a stranger?
- 4) Now I’d like to ask about the bad things. What do you not like about being the payee for your [the relationship]? Probe:
 - a. What are the things about being the payee for your [the relationship] that you don’t like?
 - b. Imagine that a stranger was your [the relationship]’s payee rather than you, what would be better about a stranger being the payee for your [the relationship] rather than you?

- 5) When you think about problems or disagreements you've had with your [the relationship], what are those problems or disagreements generally about?
 - a. How often do those problems or disagreements happen?
 - b. How do you resolve those problems or disagreements?
 - c. How does being the payee for your [the relationship] complicate those problems or disagreements?

- 6) [If the participant has not described how budgeting typically occurs] Will you talk with me about how a budget is usually created?
 - a. What is the beneficiary's involvement in budgeting/deciding how their money is spent?

- 7) Since you became the payee for your [the relationship], how has your relationship changed?
 - a. Do you get along better, worse, or about the same?
 - i. If different: What made it better/worse?
 - b. Do you talk about money more, less, or about the same?
 - c. How do you feel about talking to your [the relationship] about money?
 - d. How much time do you spend together? [probe: outside of managing money]
 - e. Does your [the relationship] provide help or support to you? Tell me about it.
 - f. Do you help your [the relationship] other ways than managing their money?

- 8) If you had to rate how satisfied you are with being the payee for your [the relationship] on a scale of 0-10, with 0 being not at all satisfied, and 10 being the most satisfied, how would you rate how satisfied you are?
 - a. What would it take for you to say [1 number higher]?
 - b. What would your [the relationship] have to do so that you would rate your satisfaction as a [1 number higher] rather than a [the number they said].

- 9) What could the Social Security Administration do differently to improve how satisfied you are with being the payee for your [the relationship]?

- 10) What could the Social Security Administration do differently to prevent problems/arguments between you and your [the relationship]?

- 11) Would you prefer a gift card to Amazon or to Walmart?

Interview Guide for Beneficiaries

Date:

Interviewer:

Interviewee first name:

Thank you for taking time to speak with me. I would like to hear about your experiences with having a family member serve as your payee. It is not uncommon for a family member to serve as a payee for someone with a mental illness. With this research project, I am trying to understand what makes the experience positive and what causes strain or conflict in that relationship. I appreciate your willingness to share your experiences with me. If there are any questions you prefer not to answer, you are free to say “pass” and move to the next question. You may also stop the interview at any time.

Remind about using first names only.

- 1) How are you related to your payee? Possible probes:
 - a. Do you live together?
 - b. How often do you communicate with each other?
 - c. How long has ----- been your payee?
- 2) How do you feel about having a payee?
- 3) Given that you have a payee, how do you feel about having your [the relationship] be your payee? Probe:
 - a. What do you think about your [the relationship] being your payee, rather than a stranger who is a payee for other people?
- 4) I'd like to ask you about all the things you like and the things you don't like about having your [the relationship] be your payee. Let's start out with the good things. What do you like about having your [the relationship] be your payee? Probe:
 - a. What does your [the relationship] do as your payee that you like?
 - b. Imagine that a stranger was your payee rather than your [the relationship], what does your [the relationship] do better than a stranger?
- 5) Now I'd like to ask about the bad things. What do you not like about having your [the relationship] be your payee? Probe:
 - a. What does your [the relationship] do as your payee that you don't like?
 - b. Imagine that a stranger was your payee rather than your [the relationship], what would a stranger do better than your [the relationship]?
- 6) When you think about problems or disagreements you've had with your [the relationship], what are those problems or disagreements generally about?
 - a. How often do those problems or disagreements happen?
 - b. How do you resolve those problems or disagreements?

- c. How does having your [the relationship] as a payee complicate those problems or disagreements?
- 7) [If the participant has not described how budgeting typically occurs] Will you talk with me about how a budget is usually created?
- a. What is your involvement in budgeting/deciding how your money is spent?
- 8) Since your [the relationship] became your payee, how has your relationship changed?
- a. Do you get along better, worse, or about the same?
 - i. If different: What made is better/worse?
 - b. Do you talk about money more, less, or about the same?
 - c. How do you feel about talking to your [the relationship] about money?
 - d. How much time do you spend together? [probe: outside of managing money]
 - e. Do you provide help or support to your [the relationship]? Tell me about it.
 - f. Does your [the relationship] help you in other ways than managing your money?
- 9) If you had to rate how satisfied you are with having your [the relationship] as your payee on a scale of 0-10, with 0 being not at all satisfied, and 10 being the most satisfied, how would you rate how satisfied you are?
- a. What would it take for you to say [1 number higher]?
 - b. What would your [the relationship] have to do so that you would rate your satisfaction as a [1 number higher] rather than a [the number they said].
- 10) What could the Social Security Administration do differently to improve how satisfied you are with your [the relationship] being your payee?
- 11) What could the Social Security Administration do differently to prevent problems between you and your [the relationship]?
- 12) Would you prefer a gift card to Amazon or to Walmart?

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