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Use of telephone- and internet-based support to elicit and address financial abuse and mismanagement in dementia: Experiences from the Care Ecosystem study

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Abstract

Background—Financial mismanagement and abuse in dementia have serious consequences for patients and their families. Vulnerability to these outcomes reflects both patient and contextual factors.

Objective—Our study aimed to assess how multidisciplinary care coordination programs assist families in addressing psychosocial vulnerabilities and accessing needed resources.

Methods—Our study was embedded in a clinical trial of the Care Ecosystem, a telephone- and internet-based supportive care intervention for patients with dementia and caregivers. This program is built around the role of the Care Team Navigator (CTN), an unlicensed dementia care guide who serves as the patient and caregiver's primary point of contact, screening for common problems and providing support.

We conducted a qualitative analysis of case summaries from a subset of 19 patient/caregiver dyads identified as having increased risk for financial mismanagement and abuse, to examine how Care Ecosystem staff identified vulnerabilities and provided support to patients and families.

Results—CTNs elicited patient and caregiver needs using templated conversations to address common financial and legal planning issues in dementia. Sources of financial vulnerability included changes in patients' behavior, caregiver burden, intrafamily tension, and confusion about resources to facilitate end-of-life planning. The Care Ecosystem staff's rapport with their dyads

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CONFLICT OF INTEREST

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helped them address these issues by providing emotional support, information on how to access financial, medical, and legal resources, and improving intra-familial communication.

Conclusion—The Care Ecosystem offers a scalable way to address vulnerabilities to financial mismanagement and abuse in patients and caregivers through coordinated care by unlicensed care guides supported by a multidisciplinary team.

Keywords

Dementia; care navigation; financial management; caregivers

INTRODUCTION

For people with dementia, financial losses due either to mismanagement or abuse by others can have devastating consequences for their future ability to access care and for their families' financial stability. There is growing recognition of the problem of financial abuse of older adults (affecting both those with dementia and those who are cognitively healthy); large-scale studies suggest a roughly 5% prevalence of financial fraud or exploitation in older adults [1–3], although comparisons across these studies is limited by methodological heterogeneity [4]. These are likely to be underestimates as financial abuse is often unreported or even unrecognized. Individuals with dementia are the subgroup at greatest risk [5].

Though financial abuse and mismanagement are recognized as significant problems in dementia, these problems are not addressed by existing systems for providing support to people with dementia and their families. For example, while physicians and other clinicians have experience with functional impairment in dementia, they often lack practical expertise with relevant community resources as well as the time to explore the financial and family circumstances that may contribute to individual patients' vulnerability or inform solutions [6]. Banks, credit card companies, and other financial institutions are sometimes able to identify and block suspicious transactions, but lack specific dementia expertise and are poorly positioned to address problematic relationships or broader patterns of behavior [7]. Professional financial advisors are not economically accessible to most people with dementia, often lack specialized training in anticipating typical problems in dementia, and unfortunately have sometimes been themselves responsible for abuse of older adults [8]. Legal counseling is often not sought until after substantial harm has been incurred and is burdened by silos between domains of need (e.g., estate/life planning, housing advocacy, long term care, elder abuse) that are intertwined. While cost is assumed to be the primary barrier to legal services, individuals' inability to self-diagnose the need for legal help is the most commonly-found barrier [9].

Novel, scalable models are needed for eliciting and characterizing sources of financial vulnerability in dementia and for providing assistance to people with dementia and their families. The Care Ecosystem is a telephone- and web-based support intervention designed for people (care recipients) with dementia and their caregivers, recently shown to improve care recipient, caregiver, and health system outcomes in a large single-blind randomized controlled trial [10]. The primary point of contact for care recipients and caregivers is the

"Care Team Navigator" (CTN), an unlicensed and trained dementia care guide supervised by a clinical team, providing longitudinal telephone- and internet-based support for medical and psychosocial problems commonly encountered in dementia. Using a mixed-methods approach in the initial cohort of care recipient/caregiver dyads enrolled in the intervention group, we assessed sources of financial vulnerability in people with dementia as well as experiences from this program in eliciting and addressing such vulnerability.

METHODS

Description of the Care Ecosystem program

The Care Ecosystem program is a telephone- and internet-based supportive care intervention for people with dementia and their caregivers, who are enrolled as dyads. Each dyad is assigned a Care Team Navigator (CTN), an unlicensed but trained dementia care guide who serves as the dyad's primary point of contact, screening for common problems and providing support as well as standardized education. In the original Care Ecosystem randomized trial, CTNs were trained by a multidisciplinary team including a lawyer specializing in elder law and were supervised by a nurse, social worker, and pharmacist, with the ability to triage complex issues to this supervising multidisciplinary team. Given their specialized roles, CTNs are able to follow care recipient/caregiver dyads over the course of months or years, developing a deeper understanding of the dyad's unique psychosocial situation over a longitudinal time frame. In the original randomized trial,[9] the Care Ecosystem intervention improved quality of life for people with dementia, reduced their visits to the emergency department, and decreased caregiver depression and burden.

The Care Ecosystem model is organized into several modules that cover core aspects of dementia care and management. These modules address prescription medications, behavior management strategies, caregiver support, and decision-making (including medical, legal and financial decisions). In the Decisions Module, CTNs are provided with standardized training, protocols, and referral materials for identifying and responding to common financial and legal needs and vulnerabilities arising in dementia. These include: the need to appoint legally-recognized financial caregivers, anticipate and plan for the costs of long term care, guard against elder abuse and exploitation, and make other legal plans for end of life, such as wills or trusts.

Study design

We conducted a mixed methods study, using a survey to characterize care recipients' engagement in financial decision-making. We then identified care recipients at risk of financial abuse or mismanagement using criteria described below and performed an in-depth qualitative chart review of 15 high-risk dyads to further characterize (1) individual sources of financial vulnerability to abuse or mismanagement as elicited by CTNs, and (2) strategies used by CTNs to address such vulnerability, as well as barriers encountered (see Figure 2).

Participants

We administered a financial activities survey to the first 97 dyads who were randomly assigned to the intervention group in the Care Ecosystem clinical trial. As described in

previous work on the broader trial,[9] care recipient inclusion criteria were pragmatic and directed at a population that would be encountered in usual care: a dementia diagnosis by a treating clinician; age older than 45 years; enrollment in, or eligibility for enrollment in, Medicare or Medicaid; residence in California, Nebraska, or Iowa; the presence of an identified caregiver who agreed to co-enroll; fluency of both the person with dementia (care recipient) and caregiver in English, Spanish, or Cantonese. Dyads in which the care recipient was living in a nursing home at the time of screening were excluded; those who subsequently entered nursing home residence remained in the trial.

Quantitative Methods - Survey

The survey asked (1) whether, prior to disease onset people with dementia had made their own purchases, paid household bills by themselves, or prepared taxes or other important documents by themselves; (2) if so, whether they had performed any of these activities in the preceding year; and (3) if so, whether they had made financial errors (see Appendix). Financial errors were defined as making mistakes in managing money or property. Demographic information including care recipients' disease stage, educational attainment, household size, and income levels were obtained from baseline data collected from dyads at the time of enrollment. Among care recipients who had performed the financial activities in question prior to disease onset, we tested the association between continued financial activities in the preceding year and care recipient educational attainment, as well as the association between continued financial activities in the preceding year and household size, using Fisher's exact test.

Qualitative Methods - Case review

Of the 97 dyads who completed the questionnaire, we identified 15 dyads who reported one or more of the following responses that indicated high vulnerability to financial abuse and mismanagement: (1) care recipients with moderate or advanced stages of dementia who continued to make financial decisions; (2) care recipients who had made a financial error in the past year. Demographics for these 15 dyads, as compared to the original 97 dyads are included in Table 1. Comprehensive case descriptions were created for each of these 15 dyads by the second author (JH) utilizing data from case notes and call summaries logged by CTNs in the course of their work, with additional details obtained in interviews with the CTN assigned to each dyad. These case descriptions were uploaded into the software application Atlas.ti and independently coded by the first author (MM) and senior author (WC). Coders analyzed the cases for topics pertaining to vulnerability to financial mismanagement (i.e., errors made in managing money by care recipients or those acting on their behalf) and financial abuse (i.e., exploitation of care recipients' cognitive decline for financial gain, whether by relatives or strangers). Throughout the coding process the coders met to compare their codes and code definitions. The coding structure was organized into the following overarching domains with themes and sub-themes within each domain: (1) individual sources of financial vulnerability identified by Care Ecosystem staff and (2) how this informed tailored support to care recipients and caregivers. Any discrepancies in coding were discussed and resolved. Two cases were chosen to illustrate how multiple sources of financial vulnerability to mismanagement and abuse compound the deleterious effects on the care recipient and their families.

RESULTS

Quantitative

In the initial cohort of 97 dyads, among care recipients with mild disease, 26 of 43 (60%) who had made purchases before disease onset continued to do so in the previous year, while 15/33 (45%) continued to pay bills and 5/21 (24%) continued to prepare taxes. One person with moderate disease continued to pay bills and prepare taxes, suggesting high financial vulnerability (Figure 3a) Care recipients who had completed a college degree were more likely to continue to make purchases ($p = 0.032$) and to pay bills ($p = 0.015$) (Figure 3b). Contrary to our initial expectation, living alone was not associated with continued financial activities (Figure 3c). Out of 35 still participating in financial activities in the preceding year, 11 made financial errors.

Qualitative case review

We found that Care Team Navigators, trained and supervised by a multidisciplinary team that included elder law expertise in the context of a phone- and web-based intervention, were able to elicit sources of financial vulnerability and utilize care protocols to identify tailored interventions to address this vulnerability. Key themes are articulated below, with two exemplary cases presented in Table 3.

Sources of financial vulnerability—We identified several themes related to sources of financial vulnerability to mismanagement and abuse. These sources included care recipient cognitive and behavioral factors as well as caregiver/family factors. In addition, related financial stressors were identified in many cases, which were not always direct sources of financial vulnerability to mismanagement and abuse, but that many families found psychologically overwhelming and impeded more comprehensive consideration of financial plans and future needs. These included concerns related to affording long-term care, preserving the household/family's assets, and qualifying for public benefit programs. (Table 2):

Care recipient cognitive/behavioral factors

Care recipients' memory and other cognitive deficits, and associated lack of insight about these deficits, were specifically linked to financial errors and/or vulnerability to mismanagement and abuse in many of the case summaries. For example, some care recipients forgot they had already paid a bill, so they paid it again. Some care recipients who still had access to their finances exhibited heightened impulsivity and new spending patterns, sometimes accruing excessive debts in the process. Several of the case summaries included documentation of unsubstantiated beliefs and actions directed at family members (such as accusations or hiding money). A few care recipients were excessively trusting with strangers, giving money away, or confiding details about their financial situation that could invite exploitation. While many cases focused on changes in cognition and behavior due to illness, others documented that financial vulnerabilities reflected premorbid personality tendencies, potentially exacerbated in the setting of dementia.

Caregiver/family factors

In addition to care recipient vulnerability factors, CTNs also elicited sources of vulnerability to mismanagement and abuse related to caregiver characteristics and family dynamics. These dynamics were characterized in cases that included documentation of significant conflicts between the primary caregiver and other family members regarding the disposition of care recipients' assets. Some family members had to learn to assume new roles and responsibilities as care recipients declined, and one spouse was found to herself have cognitive deficits requiring accommodations in the care recipient's care plan, indicating a high risk for financial mismanagement. High caregiver burden was a common theme identified in many of the cases, which might have impacted the caregivers' ability to manage the household's finances and/or address instances of financial abuse or mismanagement. In some cases, while planning documents such as durable powers of attorney for finances had been appropriately completed, caregivers still needed referral for guidance on interpreting or revising these documents.

Related financial stressors

Costs of care were cited as a key caregiver concern, both in terms of the ability to pay for the care recipient's own care needs, and the desire to preserve assets for a surviving spouse or other relatives. These concerns contributed to the significant caregiver burden we identified in the cases, as caregivers were navigating complicated legal and estate planning while simultaneously caring for the care recipient. As a result, many cases involved CTNs working with caregivers to address such concerns by applying for supplemental respite grants or providing resources and referrals to understand Medicaid eligibility.

CTN approaches to address vulnerability—Given the heterogeneous sources of financial vulnerability elicited by CTNs, CTN approaches to address financial vulnerability were necessarily individualized, often unfolding across multiple telephone calls and amidst other acute behavioral, medical, and pharmacological issues requiring attention. CTNs utilized a structured screening tool for identifying legal and financial needs and utilized protocols for addressing those needs through referrals and educational materials. We identified the following themes as ways in which CTNs addressed dyads' financial vulnerability to mismanagement and abuse: by building rapport, facilitating access to external resources, and improving communication among families.

Building rapport through addressing immediate felt concerns

In many cases care recipients and caregivers did not regard financial vulnerability as a problem, either because they were more focused on immediate behavioral, medical, and pharmacological issues or because they were too burdened to take the active steps necessary to formulate or implement advance financial plans. Also, as part of a telephone support intervention, CTNs could not implement strategies *for* caregivers, but rather worked by advising caregivers who themselves had to put plans into action. As a CTN said in a follow-up interview regarding Case 1 (case summary in Table 3), "Giving [the caregiver] ideas and strategies to deal with it… [she] did not end up doing this. We provide ideas, but [she] is responsible for what happens." When building rapport with dyads in such pre-contemplative

and contemplative stages of decision-making, CTNs worked with them to resolve what they perceived as the most pressing problems, with the aim of mitigating burden and empowering dyads to assume the task of addressing financial vulnerability. As noted in one call log regarding Case 2 (Table 3), “Referred to CANHR [California Advocates for Nursing Home Reform] (however, no steps have been taken by [caregiver] to consult with lawyer due to stress level).” In this case the response was not to insist on legal consultation, but instead to work with the caregiver regarding other care needs (the care recipient’s urinary incontinence and irritability) before returning to legal and financial planning.

Facilitating access to other medical, legal, and financial resources

We found that care provision and support for patients with dementia and their caregivers involves an often-confusing patchwork of programs across various local and state programs, nonprofit agencies, and community organizations. Care Ecosystem did not directly provide needed medical, legal, and financial services (given their role, CTNs specifically cautioned dyads that they could not give legal or financial advice), but CTNs were able to guide caregivers through the process of identifying needed resources and applying for them. Several cases (including Case 2, Table 3) included caregiver questions about Medicaid and Medicaid spend-down, for which caregivers used pre-curated handouts developed by local legal aid agencies to address those questions and referrals to local agencies. In four cases, CTNs documented caregiver resistance to or discomfort with seeking legal representation and responded by addressing misconceptions and seeking resources for lower-cost aid, although in some cases this proved challenging (Case 2, Table 3). Three cases involved providing information and assistance on applying for respite grants for in-home care.

Improving communication among families

In many cases, addressing financial vulnerability was complicated by family challenges in communicating with patients or with one another. Financial matters were particularly sensitive topics, and for some patients, discussions about financial management elicited agitation, hostility, or suspicion. Some caregivers benefited from resources about how to communicate with patients who have dementia, such as by simplifying messages or avoiding unnecessary contradiction. In other families (see also Table 2, “Intrafamilial conflict”) disagreements about financial management or the future disposition of patients’ assets were also sources of tension. CTNs drew on their longitudinal relationships with caregivers and understanding of family dynamics to identify specific family resources that could help address these tensions (Case 1, Table 3).

DISCUSSION

In the initial cohort of care recipient/caregiver dyads randomized to the Care Ecosystem intervention group, we have characterized sources of financial vulnerability as well as strategies used for eliciting and addressing such vulnerability within a telephone-based supportive care intervention. Our quantitative findings indicate a gradual restriction of financial activities with illness progression, though concerningly, some patients continued to manage money in moderate stages of illness. Educational attainment was associated with continued financial activities while, contrary to our initial expectations, living alone was

not associated with continued financial activities. However, an inclusion criterion for the broader study was co-enrollment with a caregiver closely involved in the patient's care, so these findings may not be representative of a broader population including people with dementia who have more limited social contacts. Our quantitative findings add to a sparse literature on the extent to which individuals with dementia continue to engage in financial management, which creates opportunities for financial mismanagement and exploitation. Earlier work has shown that people with dementia overestimate their ability to manage their finances [11, 12], and so may be inclined to continue such management after receiving a dementia diagnosis. Another study addressing household divisions of responsibilities found that when the primary financial decision-maker in a household experiences cognitive decline, household financial responsibilities are often only transferred to a cognitively intact spouse well after difficulties in money management have emerged [13].

Our qualitative findings reveal the capabilities and constraints of telephone-based support provided by CTNs, which may generalize to other interventions that expand the dementia workforce by using unlicensed personnel that are trained by a multidisciplinary team including elder law expertise and supervised by a clinical team. CTNs were able to elicit individually-specific sources of financial vulnerability including care recipient behavioral/cognitive deficits, caregiver/family factors, and psychosocial concerns. CTNs were not able to directly intervene to resolve most financial issues and could not give financial or legal advice but were able to build rapport to empower caregivers to address sources of financial vulnerability, facilitate access to other community resources, and support family communication.

There is consensus in the literature that novel, interdisciplinary, and scalable interventions are needed to address financial vulnerability, particularly for those with dementia [6, 14–17]. It may be particularly important to focus on unpaid family caregivers, as these individuals bear many of the financial burdens of dementia care [18, 19] and are often uniquely positioned to assist people with dementia and to implement strategies for addressing vulnerability [20]. In one report, Shrestha and colleagues have presented findings from the Partners in Dementia Care program, a telephone-based care coordination and support service intervention for veterans with similarities to Care Ecosystem [21]. This was a principally quantitative study of 93 patient-caregiver dyads, tabulating self-reported legal and financial needs from an initial screening questionnaire and reviewing case files to categorize the interventions implemented. These authors documented a high rate (54.8%) of reported need for legal and financial services and classified responses related to: legal services (e.g., education or referral), nonhealth-related financial benefits (mostly related to Veterans Affairs programs), health-related financial benefits (such as VA and Medicare), financial management and planning, and financial support (including direct referral to community services). Our study adds to this evidence base in several ways. Enrollment in Care Ecosystem is not restricted to those eligible for veterans' benefits, and this study demonstrates how telephone- and internet-based support from unlicensed dementia care guides can help care recipients and caregivers to navigate a more heterogeneous set of community resources. Our qualitative review of case records also reveals how CTNs were able to elicit individual sources of financial vulnerability, as well as strategies used and barriers encountered in addressing such vulnerability.

In a large randomized controlled trial, Care Ecosystem has been shown to improve care recipient, caregiver, and health system outcomes [10]; the initial trial was conducted in California, Nebraska and Iowa, and implementation projects are currently also underway in Minnesota, Colorado, and Louisiana. In addition to the Partners in Dementia Care program [22], the design of Care Ecosystem was informed by other dementia care programs such as the UCLA Alzheimer's and Dementia Care Program [23] and the Indiana University Aging Brain Care Program [24]. These varied programs indicate broad interest among health systems and funding agencies in innovative approaches to extend the dementia care workforce and provide interdisciplinary support, including psychosocial support, to people with dementia and their families. Our findings may inform the design of future approaches to addressing financial vulnerability as well as related legal and social needs.

Our study has several limitations. A primary limitation is that cases were selected for this study based on a screening questionnaire administered to an initial cohort of 97 dyads, rather than the full set of 512 dyads randomized to the Care Ecosystem intervention arm. The broader study had an "agile" care model design [25], and the initial screening questionnaire was phased out of the intervention arm after this initial cohort as CTN feedback indicated that the questionnaire did not guide management. Thus, the sample size for our quantitative findings is limited. Our qualitative findings depend upon the CTNs' interviewing with dyads and of their documentation in case logs; so, for instance, our findings in Table 2 should not be interpreted as characterizing the *actual* prevalence of individual sources of financial vulnerability, but instead as characterizing types of vulnerability that a program with this design is able to elicit. Furthermore, while enrollment criteria for the broader randomized trial were broad and pragmatic, as noted above the enrollment of participants as dyads excluded some people with dementia who are more isolated; also, dyads willing to enroll in a randomized trial with a non-intervention control arm may have been less burdened overall than dyads unwilling to enroll in research, potentially limiting the generalizability of our findings. Another limitation is that while we included dyads for review in which caregivers reported past financial errors, we also included dyads for review in which caregivers did not report such errors but did report continued financial activities in more advanced stages of dementia. This telephone- and internet-based support system is delivered through dementia caregivers, and all changes in the care recipient's environment depend (as they do in most clinical care settings) on the caregiver for implementation. The highest risk people with dementia are those without caregivers, or those with caregivers who are unaware of or unable to intervene on their financial activities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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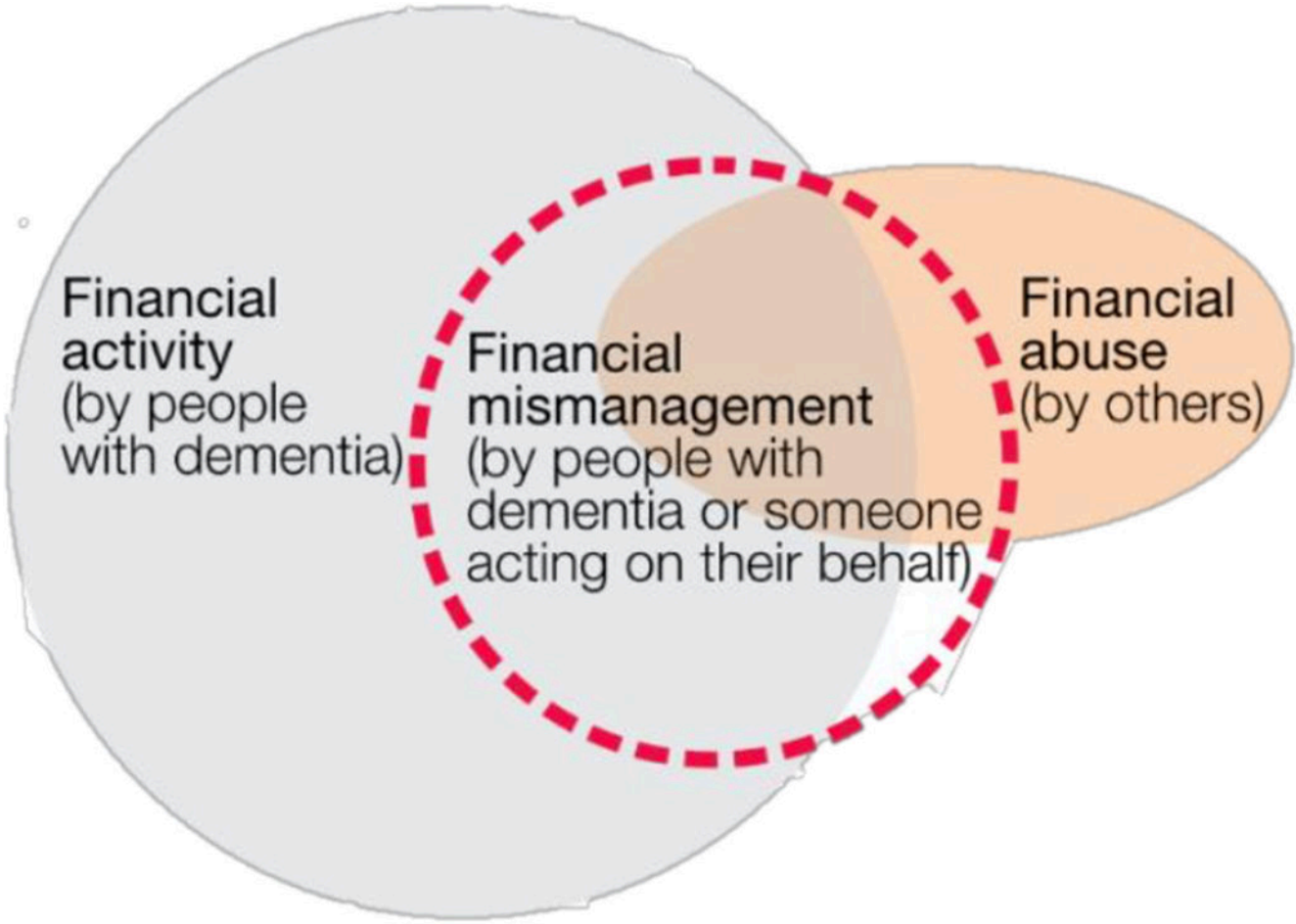

Figure 1:

Conceptual model of relationships among financial activity, mismanagement and abuse in dementia.

For many people with dementia, continued financial activities are central to their self-conceptions and sense of independence but can expose them to risk of financial mismanagement; finances can also be mismanaged by well-intentioned people acting on their behalf. Financial abuse takes different forms. Some perpetrators of financial abuse take advantage of cognitive deficits of people with dementia to lead them to act contrary to their own interests, so these are also instances of financial mismanagement. Other perpetrators capitalize on situational rather than cognitive vulnerabilities—e.g., by coercing dependent people with dementia into signing documents or acting without their knowledge in violating a fiduciary duty—so these cases of financial abuse do not represent financial mismanagement.

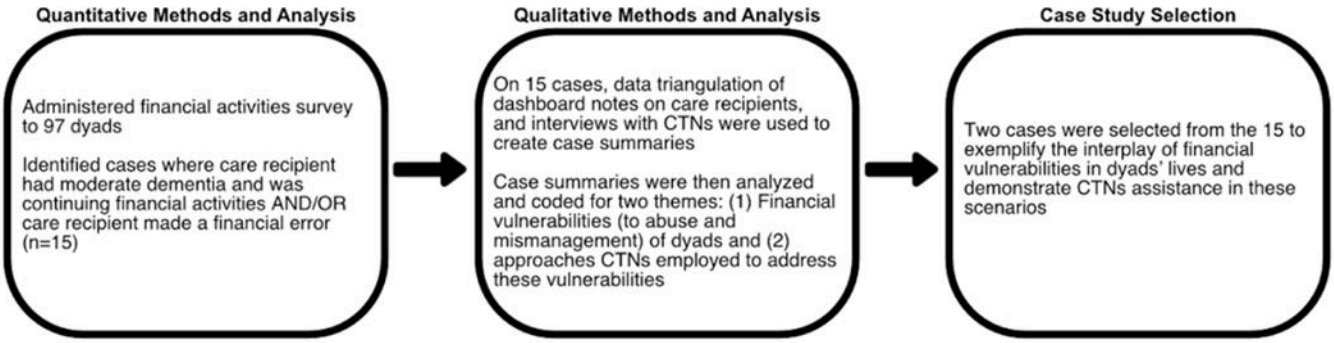

Figure 2:
Flow chart for quantitative and qualitative methods and analysis

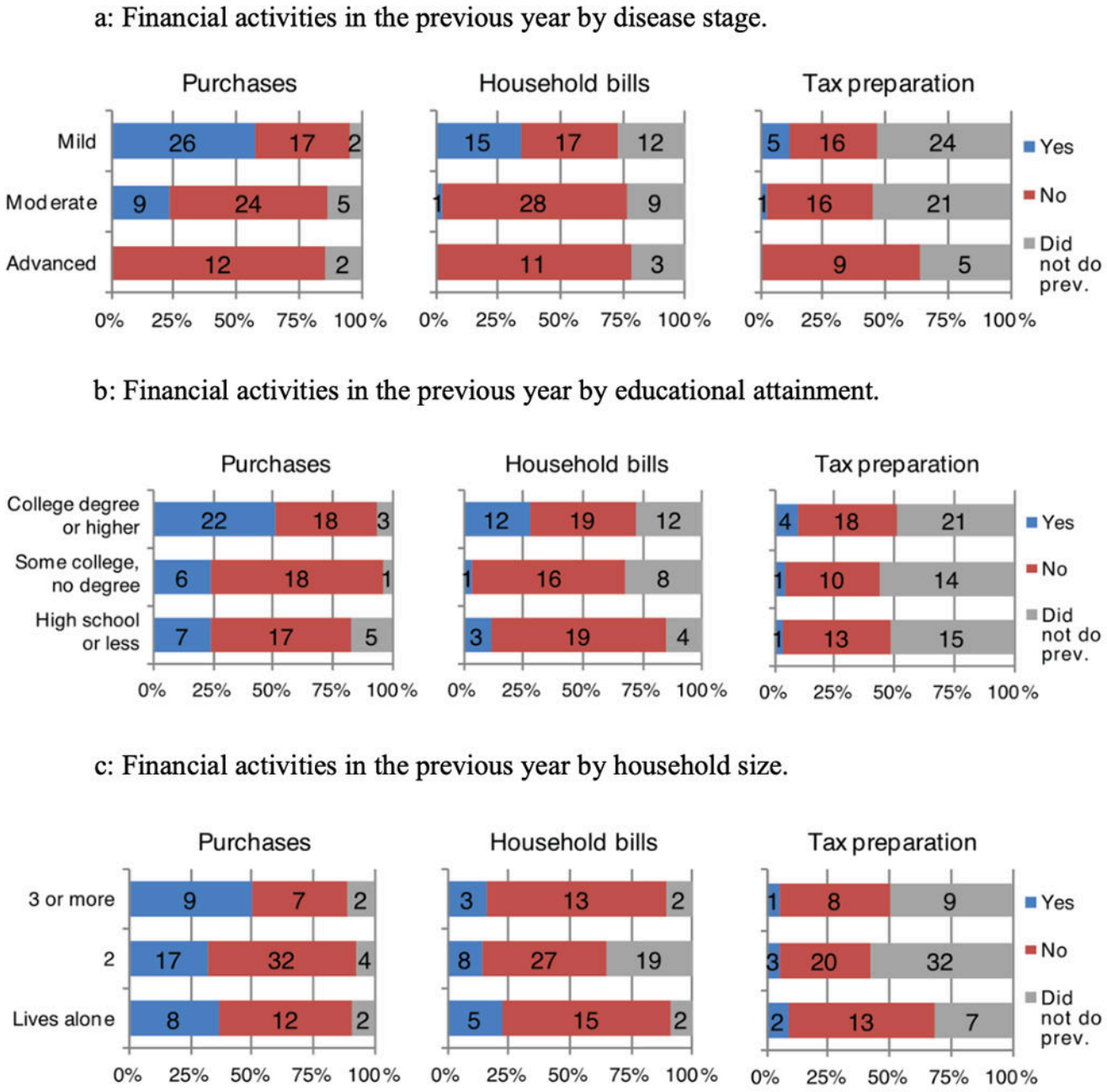

Figure 3.

Gray bars indicate care recipients who had not participated in the financial activity prior to disease onset.

Table 1:

Care recipient/dyad characteristics (n=97; 15)

	All dyads (97)	Selected dyads (15)
Care recipient age, mean ± SD	74.5 ± 15.6	76.5 ± 8.7
Female, n (%)	58 (60)	7 (47)
Dementia stage, n (%)		
Mild	45 (46)	7 (47)
Moderate	38 (39)	8 (53)
Advanced	14 (14)	0
State of residence, n (%)		
California	32 (33)	6 (40)
Iowa	3 (3)	1 (7)
Nebraska	62 (64)	8 (53)
Yearly household income, n (%)		
<10K	1 (1)	0
10K-14	7 (7)	0
15K-24	6 (6)	0
25K-49	26 (27)	2 (13)
50K-99	32 (33)	7 (47)
100K-149	10 (10)	2 (13)
150K-199	4 (4)	0
200K +	3 (3)	0
I don’t Know	7 (7)	2 (13)
NA	1 (1)	2 (13)
Household size, n (%)		
Care recipient lives alone	22 (23)	0
2	55 (57)	6 (40)
3	14 (14)	6 (40)
4	2 (2)	0
5	2 (2)	1 (7)
NA	2 (2)	2 (13)
Ethnicity, n (%)		
Hispanic	2 (2)	1 (7)
Non-Hispanic	95 (98)	14 (93)
Race, n (%)		
Asian-American	4 (4)	1 (7)
Black	6 (6)	4 (27)
White	81 (84)	10 (67)
Two or more races	1 (1)	0
NA	5 (5)	0

	All dyads (97)	Selected dyads (15)
Educational attainment		
<8th grade	1 (1)	0
9th-12th grade	3 (3)	1 (7)
High school graduate	25 (26)	3 (20)
Some college/trade	25 (26)	4 (26)
Bachelor's	17 (18)	1 (7)
Postgraduate	26 (27)	6 (40)

Table 2:

Sources of financial vulnerability to mismanagement and abuse (quotations from CTN case logs)

	Care recipient cognitive and behavioral factors
Memory/ cognitive deficits and associated lack of insight	• "Money mistakes due to trouble with his memory and bad planning/organizing--patient paid a dentist upfront but paid too much for the bill." • "Caregiver also mentioned arguing with his father about the fact that he would not be getting a W2 one year – he kept thinking he worked and was missing a W2 and was 'adamant' even though caregiver insisted that there wasn't one and one wouldn't be coming." • "Caregiver reported that patient loses his credit card every 4-6 months… Patient 'still in denial' that he has any issues."
Impulsivity and new spending	• "Patient has been buying and taking expensive supplements to improve memory without telling the caregiver." • "Buys new shirts and will get rid of other shirts, will still use other older shirts (impulse buying)." • "Caregiver stated that patient has become more impulsive, and gets very excited about purchasing certain items – will get upset when she is told she doesn't need it, and caregiver will attempt to reason with patient about why the item isn't needed." • "Then right when the disease started, [the patient] started buying all sorts of things on his credit cards – clothes, jewelry, etc.… About a year ago [the patient] made another big purchase but since then he hasn't bought anything on his own. He doesn't think he purchased it, he thinks someone else gave it to him."
Suspicion	• "Son found out that patient wasn't writing the check--he thought he was mailing to federal IRS but was state [tax board] instead, so son took the checkbook away…. Patient yelling at son, calling him a thief -- 'Where's the checkbook?!' Patient was then hiding 10 checkbooks, accused [spouse] of being involved, saying that he wanted a divorce."
Premorbid personality traits	• "[Caregiver] states that dementia has accentuated his pre-existing behavioral tendencies, such as: agitation, need to be in control, etc." • "Caregiver reported that the patient is very stubborn, and has always been."
	Caregiver/family factors
Intrafamilial conflict	• "Family disagreement: when patient was first diagnosed, his family was arguing over bills, and family members have also criticized what caregiver has or hasn't done. Caregiver stated that there 'could be arguments in the future in regard to property that is in [the patient's] name.'"
Changing family roles	• "Caregiver mentioned that the patient and his spouse are working on filling pillboxes together and that [the spouse] is learning how to handle personal finances and taking on a new role in that sense, e.g. groceries, utilities, etc." • "Caregiver reported that she felt 'nervous' about taking over the financial matters in paying his bills while he lives in the nursing home."
Caregiver health needs	• "Sounds like [the patient's spouse] had also been taking her medications incorrectly and may have some cognitive deficits of her own." Later: "[The patient's spouse] had health issues of her own and was moved to a nursing home/rehab facility, while patient lives at home by himself – subsequently realized that patient is not capable of caring for himself and that, if this were to happen again, patient will need to go somewhere for care."
Lack of knowledge or comfort in accessing resources	• "[The caregiver] mentioned that patient's income is not enough to sustain her in a decent nursing home, and understands they need to find alternatives but doesn't know how." • "Trying to get an elder lawyer… hard to convince them that lawyers are what they need for finances." • "It appears that dyad's attorney and financial professional have already accounted for anticipated needs, but [caregiver] remains with questions around how to pay for future care and what the language in the legal documents means." • "Caregiver had financial concerns, specifically about whether or not his insurance covers respite care or in-home health care."
	Related financial stressors
Concerns about future care costs	• "Caregiver mentioned during decision making 5 call that she is specifically worried about protecting the family assets. She is concerned that if the pt. has to go into a nursing home or long-term care facility, that she would have to apply for Medicaid and go through Medicaid Spend Down. Caregiver is hoping to still protect the family resources so that her daughters can inherit some of the funds etc. and said that she does not want to 'lose the family farm so to speak'. The caregiver also mentioned that she does have a piece of land as well and does not want to lose this." • "[the patient's spouse] is concerned about planning for his future as he is sure how long [the patient] will live to require this level of care so financially planning for his own future is difficult."
Eligibility for assistance	• " She is concerned that if the pt. has to go into a nursing home or long-term care facility, that she would have to apply for Medicaid and go through Medicaid Spend Down." • " SW spoke with caregiver regarding issues surrounding affording respite care for spouse – discussed respite grants as an option for CG, who was enthusiastic about this opportunity."

Table 3:

Illustrative cases of CTN approaches to address vulnerability (abstracted from case logs and CTN interviews regarding cases)

Case 1 The care recipient was a bilingual retired professional with Alzheimer's disease. His enrolled caregiver was his wife, a younger woman who was principally Cantonese-speaking and had low health and financial literacy. Prior to enrollment in Care Ecosystem, his course was marked by familial conflicts influenced by educational disparities between him and his wife. He had been accustomed to managing all financial matters and would not entrust her with authority, despite his own errors such as unpaid bills incurring late fees, errors in tax preparation, and several payments for services that were unnecessary or never rendered. In Care Ecosystem, their bilingual CTN attempted to assist the wife in the complex process of taking responsibility for family financial management but found it difficult to ascertain details from her and noted that her implementation of these strategies was inconsistent. Her assumption of legal authority was also complicated by conflicts with other members of the care recipien's family. The CTN spoke with other family members to resolve tensions and improve communication, identifying another family member with legal training who could facilitate help for them. This family member agreed to assist in educating the wife about relevant resources and in facilitating communication between her and the rest of the care recipient's family.
Case 2 The care recipient was a retired salesman with mixed vascular dementia and Alzheimer's disease. He had previously been the sole financial decision-maker in the household and would become hostile if this was questioned. He had always been proud, controlling and somewhat irritable, tendencies that his wife perceived as exacerbated in dementia. He had poor insight and would express delusions about where missing items had gone. Prior to enrollment in Care Ecosystem, the care recipient had filed for bankruptcy, likely due to financial mismanagement in earlier stages of illness. While he was dependent upon his wife for meal preparation and medication management, they had separate bank accounts and she had no ability to monitor his financial activities. She knew that he had missed some payments and feared he would default on his bankruptcy plan, endangering their joint assets. Given his paranoia, suspicion, and anger, early calls with their CTN focused more on issues of immediate behavioral management rather than longer-range planning. After establishing trust by addressing immediate felt needs, their CTN was able to broach the topic of establishing financial powers. The wife was unsure of herself and encountered barriers to access. Many legal aid services would not take on cases involving older adults with questionable financial capacity, and as a middle income household they had difficulties in paying out of pocket. Eventually, the wife was able to establish herself as the care recipient's financial agent and slowly began to exercise oversight over his accounts.