
Research and Applications

A qualitative analysis of communication workflows between adult day service centers and primary care providers

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ABSTRACT

Objectives: Our study documented communication workflows across adult day care centers (ADCs) and primary care providers (PCPs) around complex needs of persons living with dementia (PLWD). We also identified barriers and facilitators to productive communication in clinical decision support and clinical information systems.

Materials and Methods: We conducted 6 focus groups with ADC staff ($N=33$) and individual semistructured interviews with PCPs ($N=22$) in California. The eHealth Enhanced Chronic Care Model was used to frame the directed qualitative content analysis.

Results: Our results captured cumbersome and ineffective workflows currently used to exchange information across PCPs and ADCs. Stakeholders characterized current communication as (1) infrequent, (2) delayed, (3) incomplete, (4) unreliable, (5) irrelevant, and (6) generic. Conversely, communication that was bidirectional, relevant, succinct, and interdisciplinary was needed to elevate the standard of care for PLWD.

Discussion and Conclusion: ADCs possess a wealth of information that can support clinical decision-making across community-based providers involved in the care of PLWD, especially PCPs. However, effective information exchange is mired by complicated workflows that rely on antiquated technologies (eg, facsimile) and standard templates. Current information exchange largely focuses on satisfying regulatory guidelines rather than supporting clinical decision-making. Integrating community-based services into the health care continuum is a necessary step in elevating the standard of care for PLWD. In the absence of interoperable electronic health records, which may not be financially viable for ADCs, other options, such as mobile health, should be explored to facilitate productive information exchange of personalized relevant information.

Key words: adult day services, primary health care, health communication, dementia, electronic health records

INTRODUCTION

Every day in the United States, 4600 adult day care centers (ADCs) provide health and social services to nearly 150 000 persons living with dementia (PLWD),¹ all of whom are at high risk of avoidable emergency department visits and hospitalizations. ADCs are nonres-

idential, community-based facilities that support the health and social needs of adults in a professionally staffed group setting.^{2,3} Participants attend ADCs anywhere from 4 to 8 h a day, as many as 5 times per week. ADC staff, who often consist of highly trained registered nurses and clinical social workers, are well-positioned to

reduce avoidable health care utilization, including unnecessary emergency department visits and hospitalizations among PLWD.^{4,5} PLWD, who frequently cannot recognize or communicate changes in their health independently,⁶ often rely on interdisciplinary ADC staff to recognize and address their unmet needs. Staff can use serial observations of participants' health and functional status to identify emergent clinical problems before complications arise.

However, the ADCs' ability to communicate these changes to health care providers and serve as a source of early intervention is always a challenge in terms of reliance on antiquated methods of communication and underestimation of ADCs to operate seamlessly within the health care continuum.⁷ For example, the National Study of Long-Term Care Providers, conducted by the Centers for Disease Control, found that 92% of ADCs lack interoperable electronic health record (EHR) systems, making it challenging to seamlessly exchange information with outside health care providers.⁸ Prior research has identified lack of effective communication between ADC providers and primary care providers (PCPs) as one of the reasons for increased emergency department visits and hospitalizations among their clients.⁷ A recent comparative effectiveness review by the Agency for Healthcare Research and Quality found that models emphasizing collaborative care were the only care interventions for PLWD with sufficient evidence to support their use.⁹ Therefore, the purpose of this paper is to lay the groundwork for future interventions to strengthen communication between ADCs and PCPs to support integrated, collaborative care and decrease avoidable acute care utilization, particularly among PLWD. We specifically sought out perspectives of multiple key stakeholders to (1) map and describe characteristics of clinical information exchange between ADCs and PCPs and (2) elucidate on attributes of communication that are needed to facilitate clinical decision-making for providers caring for PLWD.

THEORETICAL FRAMEWORK

The eHealth Enhanced Chronic Care Model (eCCM) served as the guiding framework for this study.¹⁰ The eCCM expands on Wagner's original Chronic Care Model,¹¹ which focuses on a well-informed patient collaborating with a prepared, proactive, and professional interdisciplinary team to align treatment goals across settings. The eCCM strengthens Wagner's model by incorporating electronic health components to facilitate improved exchange of clinical information between communities and health systems. The eCCM promotes a feedback loop between patients and interdisciplinary providers through productive interactions that are supported by information technology, and continuity of care is improved, thereby supporting better health outcomes. The eCCM consists of 5 components that drive productive communication across health care settings: *patient self-management support*, *health system structure*, *clinical decision support*, *delivery system design*, and *clinical information systems*.¹⁰ For the purposes of this qualitative paper, we focus specifically on the role of *clinical information systems* (how patient data are managed and exchanged) and *clinical decision support* (offering providers patient-specific information that enhances their health and health care) in fostering productive communication between ADCs and PCPs around the needs of PLWD.

METHODS

Overview and sampling

In this qualitative descriptive study, we used interdisciplinary focus groups with multidisciplinary ADC staff and in-depth semistruc-

tured interviews with PCPs to achieve our study purpose. We specifically used purposive sampling to recruit 2 categories of stakeholders—ADC staff members and PCPs. Having 2 separate formats for the 2 stakeholder categories boosted study participation, as ADC staff operated on similar schedules, whereas PCPs tended to have varying availability. Purposive sampling, followed by snowball sampling, was used to recruit a robust and diverse multistakeholder sample that represented the range of professionals in ADCs (eg, social workers, nurses, therapists) and a variety of primary care practice setting (eg, home-based, academic medical center, federally qualified health center). Our purposive approach was carried out with the help of 2 California-based community partners, a primary care physician and an ADC executive, who helped disseminate information about the study to ADCs and primary care networks across the state. We specifically asked them to help identify (1) PCPs who are actively engaged in clinical practice, regardless of years of experience or practice setting, and (2) ADC staff members whose job responsibilities involve interactions with PLWD (eg, registered nurses, social workers and program directors). The parameters for sample size are consistent with Guest et al^{12,13} who suggests that major themes are generally established after 12 interviews and 3–6 focus groups in relatively homogeneous groups.

Data collection

Our on-the-ground partners sent out electronic mail describing the study to their wide-ranging professional networks, which spanned the state of California. A member of the research team followed up by reaching out to these contacts, initially by email and then by phone, to schedule a video interview (PCPs) or focus group (ADC staff) via Zoom. Participants often referred colleagues to participate in the study, enabling snowball sampling. Study participants provided consent electronically and were asked to complete a brief demographic survey prior to interview/focus group that also captured current modes and frequency of health care communication. All participants received a \$200 gift card for their participation.

ADC staff members participated in a 90-min recorded focus group, and PCPs participated in a single 30- to 45-min recorded interview, all of which were conducted by the principal investigator (PI). A full interview guide can be found in [Supplementary Appendix 1](#). Sample interview and focus questions included the following:

- How would you characterize your communication with ADCs/PCPs?
- What are the biggest barriers you face to communicating and exchanging clinical information?
- What information do you think would help you meet the needs of PLWD?

During interviews and focus groups, the PI (TS) continuously reviewed interview notes, supporting a reflexive process that allowed for the flexibility of emerging new questions. To ensure methodological rigor, a detailed audit trail was developed to document the rationale for methodological changes using notes during the interview and analysis process¹⁴ such as when a unique follow-up question was posed to a specific participant based on his/her previous response. All study procedures were approved by the Institutional Review Board at the PI's home institution.

Data analysis

Interviews were recorded and professionally transcribed. Transcripts were reviewed for accuracy by the PI and deidentified by a research

assistant before sharing with team members. Qualitative data were analyzed using directed content analysis.¹⁵ The research team (TS, JB, and JZ) generated a codebook a priori based on the eCCM as a coding scheme for all transcripts. Any texts that could not be categorized within the codebook were discussed with the research team to determine if a new category or code needed to be defined or aligned with an existing category or code. The codebook was continuously updated accordingly to reflect an iterative process. Two coders (JB and JZ) coded independently in Dedoose, a web-based platform for qualitative and mixed-method coding, and met regularly to review coding and resolve any disagreements. To ensure the reliability and consistency of coding, a subset (20%) of transcripts were analyzed by a third independent coder. Any unresolved disagreements, as well as potential new categories or codes, were addressed in team meetings with the PI. Themes were identified by consistently comparing codes across categories. Saturation occurred when no new themes emerged. The research team members regularly debriefed to discuss and validate results of the analysis.

RESULTS

Between May and July 2021, we conducted 6 focus groups with ADC staff ($N = 33$) and 22 one-on-one interviews with PCPs. Tables 1 and 2 present participants' demographic information and survey responses around their communication methods. The average size of ADC focus groups was 5.5. ADC staff members represent a range of disciplines and were highly experienced in the ADC setting; over half (51.5%) had more than 10 years of experience. The vast majority (70%) of ADC participants were nurses, social workers, or activity directors. Approximately 30% of participants did not interact with PCPs, and among those that did, they most frequently utilized phone calls (37.0%) or fax (28.3%) to communicate. PCPs most commonly were physicians and specialized in internal medicine (27.3%) and geriatrics (36.4%). Slightly less than half (45.4%) had more than 10 years of clinical practice experience. In addition, they most frequently selected phone calls (40.9%) and direct messaging in EHR systems (27.3%) as their preferred methods of communicating with ADCs.

As previously indicated, an overarching component of the eCCM is effective information exchange between community resources (eg, ADCs) and health systems (eg, primary care) that supports a prepared practice team who can then interact with an informed patient. The qualitative results are categorized within 2 eCCM domains most pertinent to information exchange between ADCs and PCPs—clinical information systems and clinical decision support. In part 1, we describe and depict (Figure 1) the current system of *clinical information exchange* within and across ADCs and PCP offices when there is an acute concern regarding a PLWD's health. We then present stakeholders' characterizations of current clinical information exchange systems between ADCs and PCPs. Finally, we present characteristics of effective communication workflows, according to stakeholders, that would support *clinical decision-making* and enable a prepared, proactive, interdisciplinary team to align treatment goals across settings.

Systems of clinical information exchange

Figure 1 depicts the typical flow of information exchange across ADCs and PCPs around the care of PLWD, based on study participants' descriptions. It also depicts internal communication workflows within both ADCs and PCPs.

Internal ADC communication workflow

Within the ADC, a team-based approach is used by staff to identify and assess changes or concerns in participants' health status. These mechanisms include regular updates in multidisciplinary morning meetings, monitoring and alerts from program staff members (eg, bus drivers, activity directors), and then follow-up and assessment of all concerns by clinical staff members (eg, registered nurses, social workers, and therapists). As summarized by one ADC staff member, "the full team is communicating with each other in order for us to see the whole of the participant. When we see something that we need to communicate with the family, with the doctor, we need to bring it up."

A common example, paraphrased, is when an activity therapist identifies emotional and behavioral issues in a PLWD (eg, increased agitation) during daily activities. The therapist alerts the ADC nurse, who conducts an assessment to obtain further information. The nurse may then contact the informal caregivers for further information (ie, is anything different at home?) or guidance for follow-up with the PCP office. In certain cases, potentially serious problems (eg, blood pressure reading outside parameters, signs and symptoms of a urinary tract infection) would be reported directly to the PLWD's PCP office by phone or facsimile. During actual emergencies (eg, PLWD falls in ADC or exhibits signs and symptoms of a stroke), 9-1-1 would be called, and the informal caregiver would subsequently be alerted.

Internal communication workflow within the PCP office

Although there tended to be slight variations, the typical PCP office generally had a multistep process for receiving, processing, and responding to concerns from external sources (patients, caregivers, and ADCs). Initial phone calls were commonly received by a central call center outside the physical PCP office. Depending on the nature of the concern, the caller would either be directed to call 9-1-1 (eg, for chest pain) or be delivered by the call center to either clinical staff (eg, triage nurse) or nonclinical office staff (eg, administrative assistant). Depending on the nature of the request and the staff's availability, the message in the EHR system would remain in a queue for hours to days, potentially delaying necessary care, or be directed to the provider in a timely manner. Most direct communication with patients, families, and outside agencies was done by the nursing staff in the PCP office. One physician assistant summarized this process as follows:

They (outside agencies or families) leave the message. They (call center) say there should be a response in 4 hours... If you have an 8-hour clinic day, you're getting a call after your last patient leaves, which is 5:15. Then, you take care of some other stuff, maybe it's-if they call at 10:00, it could be 5:30 by the time they get a call. By then, of course, the lab's closed.

Caregiver as an intermediary between ADCs and PCPs

Both ADC staff members and PCPs confirmed the central role and responsibility of informal caregivers in serving as intermediaries between ADCs and PCPs. ADCs largely relied on informal caregivers to alert them of any changes in the PCPs' care plan, as well as any clinical or functional changes they noted at home. During the COVID-19 pandemic, ADC nurses followed up with caregivers weekly, asking them to report vital signs (eg, blood pressure readings) and other clinical observations. In ordinary times, caregivers are tasked with relaying any assessments or observations from the ADCs to the PCPs. They are also tasked with summoning responses

Table 1. Demographic characteristics of participants from ADCs (N=33)

Characteristics	No. (%)
Age (years)	
<30	1 (3.0)
30–39	6 (18.2)
40–49	9 (27.3)
50–60	7 (21.2)
≥60	8 (24.2)
Prefer not to answer	2 (6.1)
Race	
White	22 (66.7)
Black or African	5 (15.6)
Asian	5 (15.6)
Prefer not to answer	1 (3.1)
Ethnicity	
Non-Hispanic	25 (75.8)
Hispanic	8 (24.2)
Gender	33
Female	32 (97.0)
Male	1 (3.0)
Years of experiences	
<1	1 (3.0)
1–4	8 (24.2)
5–10	7 (21.1)
11–20	13 (39.4)
>20	4 (12.1)
Current role in center	
Nurse (RN, LPN)	8 (24.2)
Social Worker	5 (15.2)
Occupational Therapist	3 (9.1)
Therapy Aide	1 (3.0)
Program Director	6 (18.2)
Activity Director/Assistant/Coordinator	10 (30.3)
Frequency of direct interaction with PCP	
Biweekly	4 (12.1)
Monthly	6 (18.2)
Bi-monthly	1 (3.0)
Every 6 months	6 (18.2)
Annually	2 (6.1)
Do not interact	10 (30.3)
Prefer not answer	4 (12.1)
Current methods to communicate concerns from clients with dementia with PCP (Multiple choice)	46
Phone call	17 (37.0)
Fax	13 (28.3)
Direct messaging in her	3 (6.5)
Email	2 (4.4)
Text message	1 (2.2)
Letter	3 (6.5)
Do not interact	3 (6.5)
Prefer not answer	4 (8.7)

Abbreviations: ADC: adult day care center; LPN: license practice nurse; PCP: primary care provider; RN: registered nurse.

when the PCP does not respond directly to the ADC's request, such as in this case, where a nurse stated the following:

Sometimes, faxing, we don't get a response. That happens a lot of time. That's why, sometimes, we have to involve the family to help us get the point across to the doctor and get the paper back. Basically, we need their help to get what we need to provide the services for the participant.

PCPs similarly relied on informal caregivers to serve as historians for the PLWD and to implement plans of care. One PCP reported that she “trained” informal caregivers to come to visits prepared to answer the PCP's questions. Others contact the informal caregiver prior to the office visit to discuss any of their concerns so as not to do so in front of the PLWD during the visit. In the absence of a reliable caregiver, one PCP stated that the office visit with PLWD is “purely social.”

Characterization of information exchange between ADCs and PCPs

In Table 3, we summarize the perception of current communication between ADCs and PCPs. In general, both groups agreed that communication is infrequent, delayed, incomplete, unreliable, and often consists of irrelevant information. ADCs reported having to “figure out ourselves” and “hound” primary care offices to get timely information. When ADCs received responses from PCPs, forms were incomplete and requested information was missing. Both ADCs and PCPs questioned the accuracy of information exchanged. PCPs, for example, did not trust the accuracy of blood pressure readings in the ADCs, and ADC staff did not feel PCPs had accurate or complete “problem lists” for the PLWD. Both ADC staff and PCPs attributed the overwhelming amount of irrelevant, and sometimes inaccurate, information exchanged to overreliance on standardized templates. PCPs, for example, reported that the generic documents ADCs faxed them to comply with regulatory guidelines were often “20 pages long,” did not contain “anything really about the patient,” and “really [didn't give]. . .any information.” PCPs reported that they often did not read lengthy documents prior to signing, because most of the information was extraneous and/or irrelevant, which one PCP dubbed “information bloat.”

Clinical decision support

Perceived attributes of productive communication that facilitate clinical decision-making

Through our analysis, we were able to identify aspects of communication that ADC staff and PCPs perceived as productive and positive. Productive communication was *bidirectional*—in which both PCPs and ADCs were providing, receiving, and responding to communications from one another. Any information exchanged was *relevant* to a specific change in condition, or, at a minimum, was new and additive to the PLWD's care plan. It was important for new information to be summarized in the form of a *succinct* narrative. Finally, PCPs valued the *interdisciplinary* perspectives ADC staff offered and saw them as essential effective care planning. Attributes of productive communication are defined in Table 4.

Despite the multiple communication challenges between ADCs and PCPs, there was near universal agreement between both stakeholders that improved communication was essential to improving the standard of care for PLWD. For example, one ADC staff member said, “everything is about communication and understanding. As long as we have those 2 things, then we can make our services much more effective.” A PCP went further to say,

I really wish we had those kinds of [productive] communications because there's so much rich data that they give me, and it helps me stratify my patients with dementia and slot people in earlier.

DISCUSSION

In this paper, we specifically sought out perspectives of key stakeholders to (1) map and describe characteristics of existing communi-

Table 2. Demographic characteristics of PCPs (N=22)

Characteristics	No. (%)
Age (years)	
<30	1 (4.5)
30–39	8 (36.4)
40–49	5 (22.7)
50–59	7 (31.8)
≥60	1 (4.5)
Race	
White	15 (68.2)
Black or African	0 (0.0)
Asian	7 (31.8)
Ethnicity	
Non-Hispanic	22 (100.0)
Hispanic	0 (0.0)
Gender	
Female	19 (86.4)
Male	3 (13.6)
Years of experiences	
<1	2 (9.1)
1–4	2 (9.1)
5–10	8 (36.4)
11–20	5 (22.7)
>20	5 (22.7)
Types of primary care settings	
Internal Medicine	6 (27.3)
Geriatrics	8 (36.4)
Family Medicine	3 (13.6)
Adult Primary Care Nurse Practitioner	3 (13.6)
Family Nurse Practitioner	1 (4.6)
Physician Assistant	1 (4.6)
Percent of patient population aged ≥65 years	
10%–24%	1 (4.6)
25%–49%	6 (27.3)
50%–74%	1 (4.6)
>75%	14 (63.6)
Percent of patient population with Alzheimer or related dementia	
<2%	2 (9.1)
2–5%	4 (18.2)
5–10%	4 (18.2)
>10%	12 (54.6)
Number of patients currently receiving services in ADC	
<5	6 (27.3)
5–9	6 (27.3)
10–20	5 (22.7)
>20	1 (4.6)
Do not know	3 (13.6)
Prefer not to answer	1 (4.6)
Frequency of direct interaction with ADC	
Biweekly	0 (0.0)
Monthly	4 (18.2)
Bi-monthly	3 (13.6)
Every 6 months	7 (31.8)
Annually	3 (13.6)
Do not interact	4 (18.2)
Prefer not answer	1 (4.6)
Preferred methods of receiving communication from ADC regarding concerns from clients with dementia	
Phone call	9 (40.9)
Direct messaging in her	6 (27.3)

(continued)

Table 2. continued

Characteristics	No. (%)
Fax	4 (18.2)
Email	2 (9.1)
Text message	0 (0.0)
Letter	0 (0.0)
Prefer not answer	1 (4.6)

Abbreviations: ADC: adult day care center; LPN: license practice nurse; PCP: primary care provider; RN: registered nurse.

cation workflows between ADCs and PCPs and (2) elucidate attributes of communication that are needed to facilitate clinical decision support for the care of PLWD. The eCCM,¹⁰ which focuses on a well-informed patient collaborating with a prepared, proactive, and professional interdisciplinary team to align treatment goals across settings, served as the study's framework and guided the directed content analysis. The study sample reflected an interdisciplinary group with significant professional experience in both primary care and adult day services. Based on the results of the directed content analysis, we identified a complex and cumbersome communication workflow across these community-based settings, which limits direct communication between providers through multiple layers in the workflow, requires informal caregivers to serve as intermediaries, and relies heavily on antiquated methods of communication, all contributing to delayed and fragmented care for PLWD.

Both ADC staff and PCPs agreed on the incredible importance of effective communication across community-based settings, as well as changes that could be made to existing workflows to foster communication and promote collaboration between these providers. These areas of consensus provide a critical foundation for future intervention design around improving communication and strengthening collaboration between ADCs and PCPs—something that is fundamental to highly effective care of PLWD.¹⁶ Because effective communication is a precondition for any collaborative care model, it represents a logical “jumping-off point” for exploring strategies that improve care continuity in the community, optimize care quality and efficiency, and expand support for people with Alzheimer's disease and their families—all of which are components of the National Plan for Alzheimer's Disease.^{17,18}

Our findings reinforce the vital, but commonly overlooked, role ADCs play in caring for PLWD. ADCs have clinical staff who are trained to provide comprehensive health services—about 62% of centers have a registered nurse and 40% employ a social worker.⁵ Staffed with experienced multidisciplinary professionals, ADCs possess rich information about the health and social needs of PLWD based on in-depth observations and interactions. Ruggiano et al⁷ noted that licensed ADC staff spend a significant amount of time with clients and collect a wealth of information on their health and social needs that can also inform clinical decision-making by PCPs and others involved in their care.

However, ADCs lack ways to summarize and share this information. We found that most of the information exchanged between PCPs and ADCs is done purely to comply with regulatory requirements rather than providing clinical decision support across care teams. PCPs in our study were overwhelmed by forms and regulatory documents, and they reported that they could not easily focus on key information from ADCs requests. This is unsurprising given the substantial baseline number of inbox type messages PCPs receive, which has risen even further during the COVID-19 pan-

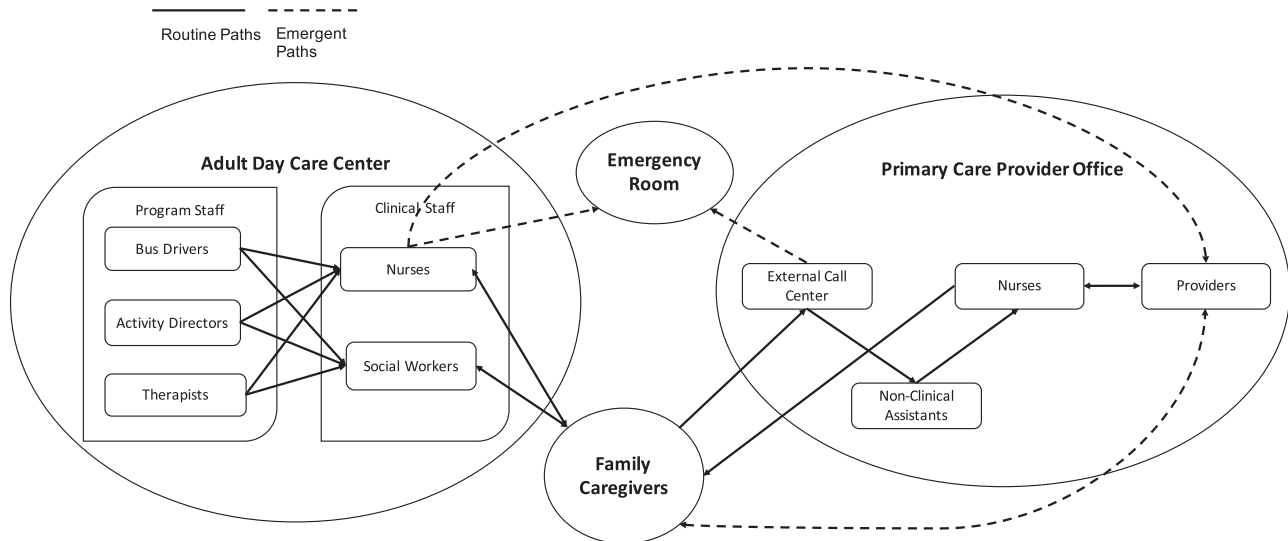


Figure 1. Typical flow of information exchange across ADCs and PCPs around the care of PLWD. *Abbreviations:* ADC: adult day care center; PCP: primary care provider; PLWD: persons living with dementia.

demic.¹⁹ This frequently led to incomplete responses to requests from ADCs. Other research in home and community-based services validates this. Several studies have found that a majority of PCPs reported that they only rarely or occasionally carefully read care order forms from home health services, creating potential patient safety issues.^{20–22} While prototypes have been developed to assist home health and PCPs interface electronically and enhance patient safety, they have not been implemented in practice.²³ Moreover, almost 40% of home health nurses report never or rarely being able to reach a physician, and these nurses were 3.66 more times likely to send patients to the emergency department.²⁴

Our findings also highlight the role of the informal caregiver in serving as an intermediary and broker of information across community health settings. Similar to another study of informal caregivers,²² ADCs and PCPs expected informal caregivers to take primary responsibility for tracking medical information and coordinating care across facilities. Although engaged informal caregivers are often willing to fulfill these communication responsibilities, they may lack the time, resources, and health education needed to do so.^{25,26} Moreover, the complexity of facilitating indirect communication between ADCs and PCPs creates a potential risk of missing important medical information. Therefore, a pattern of open and direct communication across all team members (care partner, ADC staff, PCP) is essential to the foundation for a successful collaborative care model.¹⁶

To our knowledge, our study is the first to document communication workflows between ADCs and PCPs. We were able to identify facilitators that stakeholders universally agree could contribute to effective communication. First, a conceptual shift is needed: PCPs and ADCs must move away from exchanging information solely to comply with regulatory guidelines. Instead, the community-based care team needs to be reimaged to include the informal caregiver and ADC staff, in addition to the PCPs. All members of the team must be provided with tools to organize and share information and the Centers for Medicare and Medicaid Services and individual states should develop reimbursement and regulatory structures that prioritize this cross-team communication. Second, when information is exchanged, it must be in a format that captures the providers' clinical assessment succinctly so

that it can be used to support clinical decision-making by both the ADC and PCP without adding to existing burden. The SBAR method,^{27,28} highlighted as a key communication model by the Agency for Healthcare Research and Quality, was commonly cited by both ADC staff and PCPs as an effective method of exchanging information when a new clinical problem arises. This streamlined format limits inclusion of extraneous details.

Furthermore, information and communication technologies (ICTs)—such as EHR systems or mobile health technologies—have been found to promote the secure and effective exchange of communication across health care settings.²⁹ In our study, ADC nurses were given “proxy” access by patients to access their patient portals within the PCP's EHR. This was an effective method for the ADC nurse to get a summary of the PCP visit online but limited their ability to enter their own information or observations into the record. Although the high cost of interoperable EHRs might not be financially viable for ADCs, mobile health, which is ubiquitous, should be explored as a means of facilitating direct communication across all members of the care team. Mobile health is being used for patient communication, monitoring, chronic disease management, and improving access to health services for underserved populations.³⁰ In fact, a new rule issued by the Office of the National Coordinator for Health Information Technology will require patients to be able to access and control information from their medical record using the smartphone application of their choice by 2022.³¹

Although this study is the first to explore communication workflows between PCPs and ADCs, there are limitations that must be considered. Our sample was limited to a single state. The manner in which ADCs are regulated is state-specific; thus, communication patterns may reflect state-based regulations and not be widely generalizable. However, our findings were generally consistent with other studies of communication patterns among community-based providers, such as home care providers. In addition, our analysis did not include the perspectives of informal caregivers, despite them being brokers of communication. Future studies should explore how best to incorporate them within the care team and strengthen their perspectives when developing person- and family-centered aged care models.

Table 3. Characterization of information exchange between ADCs and PCPs

Characterization	Description	ADC perspective	PCP perspective
Infrequent	Limited communication and feedback from the other	ADC-EDAY: “We often ask and don’t get a response, so we just figure it out ourselves.”	PCP-NK (<i>family medicine physician</i>): “. . . it’s heartbreaking. I don’t remember the last time an adult daycare provider or anybody actually reached out to me or actually had a conversation with somebody-like it was initiated from them to me. It’s super fragmented, and I think we’re very siloed. . .”
Delayed	Lack of timely response to clinical concern	ADC-SC: “My experience, when I was trying to get a health record from them, I would have to be communicating, hounding them daily, calling them. Where’s this health record? Where is it?”	PCP-JG (<i>geriatric nurse practitioner</i>): “Sometimes you don’t actually get the fax, or by the time you get the fax it’s 2 to 3 days late. . .”
Incomplete	Communications that are missing required information, such as clear directives and useful information	ADC-EDAY: “We ask for direction. How would you like us to manage this? What shall we do if somebody’s blood glucose is over 400? How would you like us to handle this? Sometimes, we get responses, and sometimes, we don’t.”	PCP-MG (<i>geriatrician</i>): “I feel like, a lot of times, they just send over a med list that’s not right, and I don’t have time to read it, and you just send it back.”
Unreliable	Communication that contains potential inaccuracies	ADC-ACA: “. . . they should at least have a basic knowledge of medication management and treatment for people with dementia and not just assume it’s old age. . . when the person had fallen, they were incontinent, they were having a syncopal episode. ‘Oh, it’s just because they’re old. . .’”	PCP-ET (<i>family medicine physician</i>): “I think they were taking some blood pressures and stuff for a while. . . Then they would get down to the clinic, and the blood pressure would be totally different, so I wasn’t sure if it was the wrong size cuff. . .”
Irrelevant	Contents of communication are dense and lengthy with information that does not inform clinical decision support	ADC-CIA: “They give us 20-page history of their patient and that’s not what we’re asking. This is what we’re asking: Can you please fill out this 2-page form for us so we know what is currently going on with your patient?”	PCP-JM (<i>geriatric nurse practitioner</i>): “. . . but you rarely ever get information like, ‘Hey, I just wanted to let you know that your patient is just not—they used to participate, but now they’re not really,’ or just something that can indicate to me that there’s maybe a change or something that was going on.”
Generic	Overreliance on lengthy standardized templates that do not reflect clinician’s assessment	—	PCP-RR (<i>primary care physician</i>): “. . . the problem with the Electronic Health Record is that it takes away the useful communication. People cut and paste. . . I think without the interpersonal connection; all of these texts are a pain in the neck.”

Abbreviations: ADC: adult day care center; PCP: primary care provider.

CONCLUSION

Strong collaborations across community-based providers are vital in establishing care continuity for PLWD; effective communication is foundational in building and sustaining these collaborations. Currently, communication across ADCs and PCPs is infrequent, incomplete, irrelevant, often delayed, and generic, rather than patient-

specific. Clinical information systems commonly used by ADCs and PCPs, such as phone calls and facsimiles, are antiquated. It is vital that ADCs, PCPs, and caregivers be better resourced to communicate effectively. To limit avoidable health care utilization in PLWD, who might not be able to advocate for themselves, communication must be timely, relevant, focused on clinical decision support, and

Table 4. Perceived attributes of productive communication between ADCs and PCPs that support clinical decision-making

Characterization	Description	Example
Bidirectional	Interactive exchanges in which both parties are providing and responding to information	<i>ADC-BV</i> : “Personally, I think the healthcare providers who are very responsive, so if they’re the ones who return your phone calls, who return your faxes or read your requests or who leave you messages, who sound like they’re concerned about what’s going on with their clients. . .”
Relevant	Streamlined information pertaining to the patient that supports clinical decision-making	<i>PCP-AO</i> : “I think if there’s any worry that somebody’s decompensating or deteriorating or some chronic condition doesn’t seem to be under control or is getting worse, then I’d like to be contacted, and then certainly for any new acute complaints, I would wanna be contacted.”
Succinct	Brief, as opposed to cumbersome, documentation without extraneous detail	<i>PCP-HK</i> : “From the clinical people, I always like a SBAR (Situation-Background-Assessment-Recommendation) report. I think that’s a good way, with basics being a set of vital signs in their nursing assessment.”
Interdisciplinary	Drawing on information from all individuals involved in the care of the PLWD	<i>PCP-ET</i> : “My dream is, in primary care, is like, you have your panel. You’re working with all these teams in all these different places, and you could have some sort of multidisciplinary regular kind of contact. . . I think that would be useful. . . You just take a step back and can review the different domains of that person’s life and get an overall picture. . .”

Abbreviations: ADC: adult day care center; PCP: primary care provider; PLWD: persons living with dementia.

inclusive of the perspectives of PCPs, ADCs, and caregivers. Interventions that leverage ICTs and incorporate communication/reporting strategies, such as SBAR, could have potential in integrating the care provided to PLWD in ADCs and should be the basis for future study.

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AUTHOR CONTRIBUTIONS

JZ: Literature review, qualitative coding, data analysis and interpretation, writing and revising; JB: Data collecting, qualitative coding, writing and revising; AB and BW: Conceptualized study design, provided detailed review, critical and comprehensive revisions to final manuscript; TS: PI, study design, data collecting, literature review, data analysis and interpretation, writing and revising.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

CONFLICTS OF INTEREST STATEMENT

All co-authors declared no financial interests or connections, direct or indirect, or other situations that might raise the question of bias in this work.

DATA AVAILABILITY

Data are available on request. The data underlying this article will be shared on reasonable request to the corresponding author.

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