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In the Realm of Haunting Ghosts: Denying the Existence of Substance Abuse in Medicare Home Health

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ABSTRACT

Purpose: There is extensive literature on the significance of substance use, misuse, and abuse among the elderly in the United States. A literature review indicates no studies on the nature, significance, or impacts of the lack of substance use and abuse coverage in Medicare home health.

Method: The current study is an initial, exploratory study to address the literature gap, based on interviews of a convenience sample of 37 home care nurses between January 2013 and May 2014 in the New York City metropolitan area.

Results: Nurses believe substance use and abuse occurs frequently among Medicare home health patients; substance use and abuse is not assessed and treated professionally in Medicare home health; the lack of coverage in Medicare home health results in exacerbation of existing patient physical and mental health conditions, which, in turn, worsen substance use and abuse conditions; the homebound requirement and lack of coverage of transportation and personal care assistants limits home care patients ability to obtain outpatient substance use and abuse treatment; and lack of home-based assessment and treatment contributes to increased home care readmissions, re-hospitalizations, and increased caregiver burden.

Discussion: The new PDGM system, which begins January 2020, provides an ideal opportunity for representatives of the home care, social work, and substance use professional associations to assert the need to change coverage and reimbursement requirements to allow for a more evidence-based approach to assess and treat Medicare home health patients with substance use challenges.



KEYWORDS

Medicare; nurses; home health; substance use; substance abuse

Purpose

Establishing context

Substance use, misuse, and abuse has been documented as a major national problem, accentuated recently by what is commonly referred to as the opioid epidemic (United States Department of Health and Human Services, Office of the Surgeon General, 2016, 2018). The Substance Abuse and Mental Health Services Administration (SAMHSA) has reported in 2013 that 9.4% (or 24.6 million) of Americans aged 12 or older had used an illicit drug in the past month, an increase over 8.3% in 2002 (National Institute on Drug Abuse, 2015).

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According to the United States Department of Health & Human Services [(USDHHS), 2016], over 175 million persons aged 12 and older (65.7%) reported alcohol use in the past year; more than 36 million (13.5%) reported using marijuana in the past year; 12.5 million reported misusing prescription pain relievers; and over 300,000 reported using heroin in the past year. Almost 8 percent of the population met diagnostic criteria for a substance use disorder (SUD) for alcohol or illicit drugs, and 1 percent met diagnostic criteria for both an alcohol and illicit drug use disorder. USDHHS (2016) further reports that while 20.8 million people (7.8 percent of the population) met the diagnostic criteria for a substance use disorder in 2015, only 2.2 million individuals (10.4 percent) received any type of treatment and only 63.7 percent of those treated received treatment in specialty substance use disorder program.

USDHHS (2018, p. 5) defines substance misuse as, “The use of any substance in a manner, situation, amount, or frequency that can cause harm to users or to those around them.” USDHHS (2018, p. 5) indicates substance use disorder “Occurs when the recurrent use of alcohol and/or drugs causes clinically and functionally significant impairment, such as health problems, disability, and failure to meet major responsibilities at work, school, or home. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5, a diagnosis of substance use disorder is based on evidence of impaired control, social impairment, risky use, and pharmacological criteria.” However, while individuals with substance use disorders have elevated rates of substance misuse, such as related health and social problems and costs, many people who misuse substances do not meet the diagnostic criteria for a substance use disorder (USDHHS, 2016).

Alcohol misuse, illicit drug use, misuse of medications, and substance use disorders have significant adverse consequences for individuals and society. In the United States alone they result in an estimated \$400 billion in lost workplace productivity (USDHHS, 2016). Worldwide, the global burden of disability attributable to substance misuse problems and disorders, mainly due to lost ability to work and years of life lost to premature mortality, is significant. A 2010 international study (Whiteford et al., 2013) found that mental and substance use disorders were the leading causes of years lived with disability worldwide, largely because these problems begin for many individuals early in their lives and can continue, particularly if untreated, for long periods into old age.

In addition to societal costs, research studies indicate substance misuse can have many health and personal consequences for individuals (USDHHS, 2016). The direct effects depend on the specific substances used, how much and how often they are used, how they are taken (e.g., orally vs. injected), and other factors. Acute effects often range from changes in mood and basic body functions, such as heart rate or blood pressure, to overdose and death. Alcohol misuse and drug use can also have long-term effects on physical and mental health and can lead to substance use disorders. Drug use is associated with chronic pain conditions and cardiovascular and cardiopulmonary diseases. Alcohol misuse is associated with liver and pancreatic diseases, hypertension, reproductive system disorders, trauma, stroke, and a variety of cancers, including cancer of the oral cavity, esophagus, larynx, pharynx, liver, colon, and rectum. Substance misuse also can affect nutrition and sleep and increase the risk for trauma, violence, injury, and contraction of communicable diseases, such as HIV/AIDS and Hepatitis C.

Within the United States population specifically, the elderly are acknowledged as a sub-population increasingly vulnerable to substance use, misuse, and abuse issues. One study

noted that data indicates “substance use among older adults has been under-identified for decades” and that “SUD rates among people older than 50 years are projected to increase from about 2.8 million in 2006 to 5.7 million in 2020.” (Kuerbis, Sacco, Blazer, & Moore, 2014, p. 1). Other researchers have supported these concerns and have additionally a concern specifically for abuse of opioids and other prescription drugs, noting that “... as the ‘baby boom’ cohort ages, it appears likely that the proportion of older adults using these drugs and experiencing substance abuse associated problems will also increase.” (Kalapatapu & Sullivan, 2010, p. 3).

Medicare beneficiaries appear particularly vulnerable to substance abuse use, misuse and SUD, given that an estimated 95% of all Americans aged 65 years and older are Medicare beneficiaries (Mather, et al, 2015). However, SAMHSA reported that in 2016 Medicare represented only the fourth largest payer for treatment of persons with mental and/or substance use disorders (M/SUDs), or only 13% of all national health spending on M/SUDs (SAMHSA, 2019a). SAMHSA does not report SUD only data separate from the M/SUD data.

In 2018, there were approximately 5.1 million Medicare beneficiaries served under Medicare home health, or about 10% of all Medicare beneficiaries (Centers for Medicare & Medicaid Services, 2019a) CMS data appears to indicate limited focus on substance use, misuse, and SUD in the Medicare home health program. For example, using CMS data, Avalere Health (2018) found no SUD, substance use, substance misuse, mental health, or M/SUD diagnosis among the top twenty primary International Classification of Diseases, Version 10 (ICD-10) diagnosis, which represented 58% of all 2017 Medicare home health claims. Ironically, mental health is a significant issue for Medicare beneficiaries with CMS reporting in 2015 44% of all Medicare home health beneficiaries had a severe mental illness (SMI), which is defined “as having depression or other mental disorder including bipolar disorder, schizophrenia, and other psychoses.” (Avalere Health, 2018, p. 28) The SMI data is limited because it only includes severe mental illness and because CMS data does not even capture data on substance use, misuse, or SUD, either in the aggregate or by type of substance; not even as a subset of its data on mental health conditions (Avalere Health, 2018).

Background

The limited insight from government data on the prevalence and coverage of substance misuse, use and SUD in Medicare home health prompted a literature review on studies of the topic.

The literature review used Cinahl, PubMed, Medline, Cochrane Library, Campbell Collaboration, PsycINFO, Sociological Abstracts, and Social Science Abstracts databases with an search period of January 1, 1965 through September 30, 2012 followed by an updated search after the study was conducted covering October 1, 2012 through June 30, 2019. Multiple keywords were used in the search: substance use and home care; substance abuse and home care; opioid use and home care; home care nursing; Medicare home health nursing; psycho-social care and Medicare home health; and substance use and abuse and the elderly. The searches yielded multiple studies on home health and home health nursing and generally on substance use and abuse among the elderly but no studies specifically on prevalence, coverage, or consequences of substance use or abuse in the Medicare home health setting.

The present study is the result of the gap in the existing literature regarding the topic. The article presents the results of an exploratory research study of 37 home care nurses in

the New York City metropolitan area between January 2013 and May 2014. The study used interviews to probe nurses' perceptions of the nature and extent of substance use and abuse prevalence and coverage in Medicare home health and the impact on patients, caregivers, and Medicare.

Method

The study used a grounded theory approach (Corbin & Strauss, 2007). Grounded theory is the research methodology of choice because it was developed for interpreting qualitative data in the absence of a preexisting theory. In the present study, the existing literature does not provide insight into how home care nurses perceive the coverage of SDOH and the impact on patients, caregivers, and payers, including Medicare. Data were collected through interviews of 37 home care nurses, selected from the New York City metropolitan area between January 2013 and May 2014. Participants were selected using a snowball convenience sampling technique, whereby home care industry professionals known to the author identified potential interviewees. In-person interviews were conducted at locations convenient to participants and off-site from where they worked. An interview guide was used to help standardize the data collection, and all participants were assured of anonymity and confidentiality through an informed consent form they signed. Qualitative analysis began shortly after the initial data were collected and resulted in additional questions and probes that were applied to subsequent interviews, in an ongoing iterative process. Analysis followed the grounded theory three-stage coding of interview data: open, axial, and selective coding.

Open coding was used to fracture the data to “identify some categories, their properties, and dimensional locations”. (Corbin & Strauss, 2007, p. 97) The coding and classification generated a list of 268 codes. Code and category labels were created, systematically sorted, compared, and contrasted until they were complete, with no new codes or categories produced and all data accounted for. Through axial coding, multiple phenomena were identified from the connected categories and subcategories. These phenomena included the Medicare decision-making framework, home care nurse perceptions of substance use and abuse, home care nurse perceptions of ability to address substance use and abuse in care planning and delivery, and home care nurse perceptions of impacts of ignoring substance use and abuse issues. Finally, using selective coding, a “story line” was identified and a “story” written that integrated the axial coding phenomena (Corbin & Strauss, 2007). The story that emerged was the influence of Medicare home health's lack of coverage of substance use and abuse on patients, caregivers, and payers.

In keeping with the grounded theory approach, the data analysis and interpretation were facilitated by analytical and self-reflective memo writing, which helped move empirical data to a conceptual level; expanded and refined the data and codes; developed core categories and interrelationships; and integrated the experiences, interactions, and processes embodied in the data. (Corbin & Strauss, 2007) All initial abstraction, analysis, and interpretation were done by the author of this article. After the initial process, all abstraction, analysis, and interpretations were reviewed by two additional experienced qualitative researchers. Any differences were discussed by the two external reviewers and the author to reach final decisions used for the study results. All analyses were done using ATLAS.ti software.

Table 1. Nurse participant demographic characteristics.

| Characteristic | Number | Percent |
|----------------------------|--------|---------|
| Gender | | |
| Male | 2 | 5% |
| Female | 35 | 95% |
| Race/Ethnicity | | |
| Caucasian, Non-Hispanic | 30 | 81% |
| Hispanic | 3 | 8% |
| African American | 2 | 5% |
| Asian American | 1 | 3% |
| Other | 1 | 3% |
| Age Range | | |
| >55 | 2 | 5% |
| 45–55 | 28 | 76% |
| 36–44 | 4 | 11% |
| 25–35 | 3 | 8% |
| Years as a Home Care Nurse | | |
| >10 | 3 | 8% |
| 6–10 | 28 | 76% |
| 1–5 | 5 | 13% |
| <1 | 1 | 3% |
| Average Patient Caseload | | |
| 26–30 | 1 | 3% |
| 20–25 | 32 | 86% |
| <20 | 4 | 11% |

Study participants

Limited demographic data was collected from study participants using a short survey. The results appear in Table 1. Overall the nurses were 45–55 years old (76%); female (95%); had 6–10 years of home care experience (76%); and had an average caseload of 20–25 patients (86%). Statistical analysis of the demographic variables' impact on study outcomes was not done due to the qualitative nature of the study.

Results

Five themes emerged from the interviews, which are detailed below with supporting quotes.

High frequency of substance use, abuse, and SUD: “they are like ghosts haunting us”

- (1) “It is as common as diabetes, wound care, COPD (Chronic Obstructive Pulmonary Disease), and heart disease, but you’d never know it based on what we do.” All nurses interviewed (100%) agreed there is a high frequency of substance use, misuse, and SUD among their patients:

It hangs over us all the time; that is these patients with big-time substance [abuse and misuse] problems. We can’t do anything about it. Medicare won’t let us treat it. We know it’s there. It’s almost like a ghost haunting us, hanging over us while we try to ignore it and treat what we are paid for like healing wounds, diabetes, heart and respiratory conditions mainly (Nurse LM)

- (2) I have been doing home care for about 15 years. Substance [use, misuse, abuse] are as common as wound care and diabetes, which most of our patients have. Some [patients]

are okay and it is simply medication management to deal with. Most are on multiple meds. But I'd say 70% of our patients have serious drug abuse issues. (Nurse TD)

- (3) "You are asking about substance abuse? It is our most consistent issue across all our patients. We never code it as a diagnosis. Most of our patients have diabetes, hypertension, COPD, wound care or some orthopedic follow-up as their primary diagnosis, but they all have a substance abuse or misuse issue, regardless of their primary diagnosis." (Nurse PS)
- (4) "Well definitely if you count alcohol abuse, I'd say 90% of our patients have a substance abuse issue and that is not counting their caregivers, who we can't treat anyway." (Nurse SH)

Failure to professionally assess and treat substance use issues

- (1) "The patient's substance use behaviors simply are not assessed and rarely treated by a professional who knows the condition." Nurses were concerned that neither Medicare nor their agencies require assessment and treatment of SUD and other substance issues, let alone mandating evidence-based assessment measures and treatments. Ninety-five percent of nurses interviewed believed there was no professional assessment or treatment of substance use, misuse, or abuse:
It is pretty ridiculous. The [substance] abuse issues are there, often all over the [medical] record, but we can't professionally assess or treat it. I know there are approved [evidence-based] interventions and assessment tools, but we don't do it. Why? Well, it's not required on the OASIS [Outcome and Assessment Information Set] and, I guess, it's considered a chronic condition, which we don't deal with. We focus on acute episodes, even if it is for a chronic condition. You know drug abuse is considered chronic so you need to get into an outpatient recovery program or therapy or something. Medicare won't pay for it at home. It makes no sense to me. (Nurse TJ)
- (2) We have absolutely not professional protocol for assessing substance use and no coverage of the professional treatments. (Nurse GD)
- (3) Medicare is so out of it. Here we have all these patients on meds and many on opioids for pain and we can't treat them for misuse or abuse. Don't they know there is an opioid epidemic? It's all over the news. More interventions like naloxone are being offered if you are outpatient or on the street, but what about people who are at home, homebound like our patients? Do they think they are immune from opioid addiction? (Nurse SC)

Lack of coverage of substance misuse and SUD exacerbates physical health, mental health, and substance use issues

- (1) "I'd say it's circular. We do not assess or treat substance issues which usually complicate most conditions like diabetes, depression, wound care. That then makes the substance issues worse." All nurses (100%) agreed that the inability to cover substance abuse issues contributed to exacerbation of existing physical and mental health conditions:
A typical scenario is a patient comes in diabetes or a cardiac problem or both. We focus on immediate, short-term treatment of the condition in front of us, the primary diagnosis, like diabetes or a heart problem. That's it. But we have so many that are alcoholics or near-alcoholics or loaded with opioids to deal with

pain that our nursing care for the diabetes or cardiac condition doesn't take hold. The drug problem limits their compliance with our care plan, including medication compliance, diet and exercise. (Nurse SF)

- (2) Here's an example. I had a patient who had limited mobility due to heart and respiratory problems. They also had diabetes. A lot of our patients have multiple conditions. So, of course, they were depressed. We assessed that using the PHQ-9 on the OASIS, but we saw it on our first visit and the caregiver told us. Well, what do you do when you are that state? A lot of people drink and pop pills which then makes everything worse. That is what this patient did. (Nurse RA)

Inability to provide transportation and personal care assistants limits patients ability to get outpatient substance treatment services: "it's a downright shame"

- (1) Most nurses (95%) expressed frustration with their inability to facilitate patients obtaining substance misuse and SUD in Medicare-covered outpatient settings:

"The closest place to get [substance use and SUD] help without being hospitalized is an outpatient clinic. These people [the home care patients] have a hard time getting there. They are homebound. They have to be to be eligible [for Medicare home health], but we provide no care at home and no assistance to get the outpatient care." (Nurse TL)
- (2) "So, yes, we have a lot of patients with drug issues. Some are just from all the meds they take for their illnesses. Others have a long-time alcohol or other drug addiction, or both. And, guess what, they are homebound. That is a requirement for Medicare home health [eligibility]. So they need considerable help to get out of the home to shop for groceries, clothes, see their doctor, socialize ... everything. We can't treat the drug issues. Medicare won't cover it at home. So they need to go to an outpatient program or therapist. But many [of our patients] are so homebound with limited mobility that they need transportation and an aide or PCA (Personal Care Assistant) to get them there. Most can't pay for that and Medicare won't either." (Nurse ED)

Failure to address substance use issues contribute to home care readmissions, re-hospitalizations, and caregiver burden: "it's your worst nightmare"

CMS does not measure or track re-admissions to home care, let alone by reason. However, nurses indicated failure to acknowledge, assess, and treat SUD and related substance issues results in a continual stream of home care re-admissions, re-hospitalizations, and increased caregiver burden. All nurses (100%) believed the inability to assess and treat substance misuse issues, including SUD, contributes to home care readmissions, re-hospitalizations, and increased caregiver burden:

- (1) We have so many patients we readmit. A lot come back in 30–60 days after discharge. Why do they come back? Well a lot has to do with the fact the post-discharge care is up o them at home. If they have a caregiver, that might help, but a lot of the caregivers are on the edge themselves. It is not unusual for the caregiver and the patient to have a drug problem on top of mobility issues, so compliance is non-existent. I had an elderly patient, I think he was about 84 or so. His caregiver was his son who was living with him because he [the son] was a drug

addict and had no job. He lived off the patient's social security and savings. Is it any wonder the patient deteriorated at home and was re-admitted. He got so bad that after a couple admissions with us we had to discharge him to the hospital. (Nurse MDR)

- (2) My husband has his own business. I tell him about how these patients are constantly recycled. I tell him how we can't treat mental health or drug issues even though most patients have them. I tell him how it aggravates caregivers; burns them out not to have that kind of help. He tells me "That's no way to run a business. It must be costing the government a lot of money." He's right. It does. We don't do the right thing as nurses because Medicare limits us. That hurts the patients and increases costs. It really is not the way to run a business and it's not the way to care for people." (Nurse TD)
- (3) We are nurses. We know that if you have a drug issue it will affect your physical and mental health and we know that some of these [patient physical] health issues can lead to substance abuse or make existing drug issues worse. We learn the in nursing school and in in-services. But Medicare doesn't let us address these issues in our care plan. So we watch things get worse. We discharge patients and they come back. Often it's because we can't treat the drug issue and it becomes worse. So we readmit, then discharge, often to a hospital, and then re-admit. It wears on us, the patients, the caregivers and has to cost Medicare more than if they simply let us do interventions [for substance misuse and abuse] at home. (Nurse WD)

Limitations

The study was a qualitative, exploratory study. As such it does not address causality and has several limitations including: small sample size; lack of random sampling for sample selection; and lack of a randomized controlled trial experimental design to test specific interventions against a control group.

Discussion

Despite its limitations, the study does begin to address a gap in the literature and policy by exploring nurse perceptions of the prevalence and impact of lack of assessment, coverage, and treatment of substance use and abuse on Medicare home health patients and their caregivers. The study supports other studies on the current and projected increase of substance use and SUD among the elderly (Kalapatapu & Sullivan, 2010; Kuerbis et al., 2014; Mather, Jacobsen, & Pollard, 2015), adding qualitative insight to its occurrence in the Medicare home health setting. The story told in the nurse interviews also identifies some specific areas for potential policy reform to benefit patients, home health professionals, and the Medicare program. The initiation of the new Medicare Home Health Patient-Driven Groupings Model (PDGM) in 2020 provides a timely opportunity for such reforms (Abt Associates & Centers for Medicare & Medicaid Services, 2019).

Contrary to the home health nurse interviews and studies on substance abuse among the elderly, Medicare does not publicly report on SUD or substance abuse among home health beneficiaries. For example there was no substance use code listed among the top 20

Primary International Classification of Diseases, Version 10 (ICD-10) Diagnoses for All Home Health Claims (Avalere Health, 2018). These top twenty diagnoses represented 58% of all claims. In addition, neither SUD nor substance abuse are listed in Medicare's reporting on severe mental illness (Avalere Health, 2018). Medicare does not report such data because it fails to capture the data. The OASIS currently has no section requiring nurses to assess, or otherwise measure, the existence of substance abuse or risk level for abuse at either admission, recertification, or discharge (Centers for Medicare and Medicaid Services, 2019c). This contrasts with Medicare requiring nurses complete the PHQ-2, an evidence-based depression scale (Kroenke, Spitzer & Williams, 2003), on the OASIS. The result is Medicare publicly reporting data that indicates 44% of all Medicare home health beneficiaries in 2015 had a severe mental illness (SMI) and 94% of those with an SMI had depression (Avalere Health, 2018). A remedy for the lack of home health beneficiary substance abuse data would be for CMS to add a mandated, evidence-based substance use assessment section to the current OASIS with a requirement that patients scoring as having SUD or a specified significant risk of abuse level must receive treatment. SAMHSA has developed multiple evidence-based assessment tools which are used in inpatient and outpatient programs which Medicare could adopt to systematically measure and report on substance abuse in home health (SAMHSA, 2019b).

However, improved assessment and reporting requirements do not guarantee that patients assessed or at risk of substance abuse will receive treatment. Medicare currently covers mental health and substance abuse services in inpatient, outpatient and partial hospitalization programs but not in home health (Center for Medicare Advocacy, 2019b; Centers for Medicare and Medicaid Services, 2019b). The only exception is the possible use of a psychiatric nurse in Medicare home health which "would only be considered medically reasonable and necessary if the evidence demonstrates that the patient is in danger to self or others" (Center for Medicare Advocacy, 2019a) and assuming a psychiatric nurse is available. To ensure professional treatment of home health patients assessed with or at-risk of substance abuse, Medicare would have to mandate that patients receive treatment and modify coverage and reimbursement rules to include such treatments. SAMHSA has developed multiple evidence-based treatments which are used in inpatient and outpatient programs which Medicare could adopt to systematically measure and report on substance abuse in home health (SAMHSA, 2019b). Expansion of the current Medicare home health social work benefit might be the most feasible avenue to provide such care. Currently the home health social work benefit is limited to only a few individual psycho-social therapy visits, no family therapy and no group therapy (Cabin, 2019b; Centers for Medicare and Medicaid Services, 2019b). Payment for such services would need to be accommodated within the new PDGM system or as a specified, separately reimbursement add-on payment. The covered mandated treatments also would enable Medicare to track progress of patients and possibly include such data in its home health quality improvement reporting (Centers for Medicare and Medicaid Services, 2019a).

In addition to reforms creating meaningful assessment and treatment of Medicare home health patients with substance use issues at home, Medicare could also facilitate homebound Medicare patients' ability to receive outpatient substance abuse services. This could be done by Medicare covering costs of transportation and accompanying personal care assistants to facilitate homebound Medicare home health patient access to covered outpatient substance abuse services. The PDGM system would require a coverage and payment change to facilitate

such services. However, Congress and CMS already have set a precedent for coverage of such services through Medicare Advantage plans (Cabin, 2019a).

These reforms seem reasonable for Congress and CMS consideration given the current and projected data on SUD and substance abuse among the elderly. They also seem reasonable because both Congress and CMS have recently recognized the relevance of social determinants of health and have begun efforts to cover transportation, personal care assistants, and other social needs services to improve patient outcomes and reduce Medicare costs (Cabin, 2019b).

Conclusion

The existence of the new PDGM system creates an opportunity to make changes. PDGM begins January 2020 and no doubt will be subject to review and potential adjustments once there is operational feedback. This would provide an ideal opportunity for representatives of the home care, social work, and substance use professional associations to assert the need to change coverage and reimbursement requirements to allow for a more evidence-based approach to assess and treat Medicare home health patients with substance use challenges.

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