Journal of Human Sciences and Extension

Manuscript 1476

# Cost of Care Conversations: Perspectives from Rural Health Care Providers and Older Adult Patients

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*Older adults often struggle with health care costs. Cost of care (CoC) conversations are conversations between health care providers and patients to discuss direct and indirect costs associated with health care. These conversations have been found to increase patient compliance, but patients and health care providers often do not have these discussions. This article describes a project to provide Extension education to encourage CoC conversations for older adults and health care providers in rural counties in a southern state. To inform educational material development, 125 older adults and 51 health care providers completed surveys about their cost-related barriers to health care, attitudes and frequency of CoC conversations, and preferred educational methods. Older adults reported that they were most comfortable discussing health care costs with physicians and pharmacists but that health care providers rarely initiated these conversations. Health care providers indicated that they were comfortable talking about health care costs with patients and reported that they often initiate these conversations. Both older adults and health care providers indicated fact sheets as a top educational method. This project demonstrates how Extension educators can partner with health care providers to educate older adults about communicating cost-related challenges and needs.*

*Keywords*: cost of care conversations, older adults, health care providers, health care costs

## Introduction

Health care costs remain top of mind for consumers in the United States (Perez et al., 2019). Nearly one in three individuals in the US report struggling to pay health care bills (Richman &

Brodie, 2014). These struggles can sometimes lead to catastrophic financial consequences such as damaged credit and personal bankruptcies (Cook et al., 2010). Southern states lead the country in medical debt, with nearly 24% of all residents in this region reporting such debt as well as having the largest average amounts of past-due medical debt (Kluender et al., 2021).

Today, patients are responsible for an increasingly larger portion of out-of-pocket expenses (Sloan & Ubel, 2019). High-deductible health care plans are more common (Brick et al., 2019). Furthermore, projections indicate that patients will have increased costs related to prescription drugs and treatments for older adults, such as home health care (Keehan et al., 2017). Higher out-of-pocket costs and more expensive interventions have created a burden for consumers who must balance health care costs and their ability to provide for other necessities of daily living like food, clothing, and basic household items.

Cost discussions between health care providers and patients can help mediate the financial challenges patients face while improving health care decision-making (Henrikson et al., 2019). Referred to in the literature as cost of care (CoC) conversations, these discussions between health care providers and patients hold a promise for helping consumers make informed choices about health care interventions and health outcomes. Additionally, CoC conversations have been linked to higher compliance and stronger relationships between patients and health care providers. In their study of 912 patients with diabetes recruited from five Veteran Affairs health systems, Piette and colleagues (2005) found that trusting relationships between physician and patient were critical in moderating the impact of costs on patients' adherence to medical therapies. In their study of 677 outpatient appointments for breast cancer management, Hunter and colleagues (2017) found oncologists and patients were willing to engage in cost conversations. The conversations were often initiated by the health care provider and lasted a median duration of 33 seconds. Furthermore, over a third of the conversations focused on strategies to reduce patient costs for treatment.

Despite evidence pointing to the positive effects of CoC conversations, patients and health care providers struggle to incorporate CoC conversations into practice systematically. Due to a lack of knowledge and training, many physicians do not feel well-equipped to discuss costs with their patients. A study of 167 oncologists revealed that over half (58%) sometimes or rarely discussed treatment with patients (Schrag & Hanger, 2007). Thirty-one percent reported a high degree of discomfort discussing patient costs. According to work from the Robert Wood Johnson Foundation's Cost Conversation Projects, health care providers report difficulty identifying patients in financial distress, lack of understanding of local resources which can support patients, and are often unable to estimate costs of treatment plans (Dine et al., 2019). On the other hand, patients are hesitant to initiate CoC conversations. They fear that doing so would be perceived as inappropriate, a challenge to the provider-patient relationship, and an unwise use of valuable provider-patient time (Erwin et al., 2018). In their study on patients' knowledge of office copayments, Benedetti and colleagues (2008) found less than 5% of survey respondents actually

discussed health care costs with their provider. Additionally, almost 80% (79%) felt their health care provider could not help with cost issues. Over half (51%) believed it was not appropriate to discuss costs with health care providers. These challenges create a dichotomy in which patients want to have CoC conversations yet are waiting for their providers to initiate the conversations, while providers, in turn, believe such conversations can be beneficial but are reluctant to initiate the discussions.

CoC conversations between patients and providers are even more crucial in older adults, who often utilize the health care system at higher levels than younger people. Even though the older adult population is predominantly insured by Medicare, out-of-pocket costs are still a concern, particularly among low-income residents. According to Cubanski and colleagues (2019), older adults with traditional Medicare coverage spent an average of $5,460 out of their own pocket for health care; these costs represent up to 16% of their income. Moreover, older adults in the South spent more than their counterparts in the Northeast and West. Finally, women, people in older age groups, those in poor health, and with multiple chronic conditions spend more as well.

Older adults residing in rural areas face their own unique needs when compared to their urban or suburban counterparts (Kaye & Long, 2021). Rural areas have higher concentrations of older adults than urban areas. Around 19% of rural populations are 65 years or older compared to 15% in urban areas (Cromartie, 2021). Older adults in rural communities tend to be poorer, have complex health conditions with multiple comorbidities, often lack access to essential services such as transportation, and are more food insecure (Pooler et al., 2017). Rural older adults are challenged to navigate a health care landscape characterized by diminished access, hospital closures, and a lack of health care resources (Pender et al., 2019).

**Study Objectives**

The main objectives of this study were to identify facilitators and barriers for CoC conversations among rural older adult patients and health care providers with the purpose to use this information to guide the development and implementation of patient and provider training related to increasing CoC conversations.

The results discussed here are part of a larger United States Department of Agriculture Rural Health and Safety Education grant-funded project to utilize Extension educators as catalysts for promoting CoC conversations between older adults and health care providers in rural communities. Formative research was conducted at the start of the project to collect input from health care providers and older adults in the Appalachian region with the purpose to inform the development of CoC educational resources that would resonate with both rural health care providers and patients. This article describes the process and outcomes of this formative research. Following a description of the methods, key findings from the research are presented. These findings and the implications they hold for Extension's work in health education and Extension's engagement with health care providers conclude the article.

## Methods

This cross-sectional survey study assessed facilitators and barriers to CoC conversations in five rural counties in Tennessee. Institutional Review Board (IRB) approval was received for this study as an expedited approval from the University of Tennessee IRB-20-06058-XP.

### Participants

Convenience samples of both health care providers and older adults were recruited to participate in this study. The research team asked Extension Agents in five targeted counties to recruit at least 10 rural health care providers. To get information from a variety of health care providers about CoC, the research team had a broad definition of health care providers that included physicians, nurses, physician assistants, and nurse assistants, as well as pharmacists and office staff who worked in health care facilities.

Extension Agents in targeted counties also were instructed to recruit at least 25 older adults to take the patient surveys. Older adults were defined as adults ages 55 and older. These older adults tended to be participants in existing Extension programs that the agent was delivering in the community.

### Measures

Two surveys were created for this study: one for health care providers and one for older adults who are referred to as patients. The surveys were reviewed and edited by four expert health care providers and pilot-tested with 25 older adult patients. Feedback from both groups was incorporated into the final versions of the surveys.

#### *Patient Surveys*

**Costs as a barrier to health care.** Cost-related barriers to health care were assessed with questions that identified barriers as well as frequency or how often costs prevented health care. Barriers were identified using a question that listed seven potential cost-related barriers to health care: "What costs make it difficult for you to receive medical care?" Patients could select all applicable costs that make it difficult for them to receive medical care, with an additional option to write in any barriers not included in the list. This list included indirect costs of health care like transportation, childcare, and elder care as well as health care costs related to insurance such as deductibles and copays. The frequency measure included four questions where patients reported how often they were unable to go to a health care provider, follow recommended treatment, fill prescriptions, and follow health care advice using a 5-point Likert scale (1 = *never* to 5 = *always*).

**Cost of care conversations.** Assessment of CoC conversations included questions related to frequency, level of comfort, barriers to CoC, and educational methods to help facilitate

CoC. For frequency, patients answered three questions related to how often they discussed health care costs with doctors, nurses or office staff, and pharmacists. An additional question asked how often health care providers discussed CoC before visits. All four questions used a 5-point Likert scale (1 = *never* to 5 = *always*). Level of comfort was assessed using one question: "Who would you feel comfortable talking about medical costs with?" Patients could select all applicable options from a list of seven health care professionals, such as physicians, nurses, nurse practitioners, pharmacists, and office staff, with an option to write in any health care professional who was not included on the list. Barriers to CoC conversations were measured using one question: "What makes it hard to talk with health care providers about medical costs?" Patients could select all applicable barriers from a list of five that included lack of time, not sure who to discuss costs with, and worried that they might not receive medical care, with a write-in option for additional barriers. Preferred learning methods to facilitate CoC conversations were assessed using one question: "How would you like to learn about how to talk with health care providers about medical costs?" Patients could select all applicable learning methods from a list of six that included educational programs, Facebook posts, one-on-one discussions with health care providers, videos, and brochures, with a write-in option to include additional learning methods.

### *Health Care Provider Surveys*

**Costs as a barrier to health care.** Assessment of cost-related barriers included four questions where health care providers were asked to rate the different financial stressors facing their patients on a 5-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). Financial stressors included financial burdens related to costs of medical treatment, such as copays and prescriptions, as well as costs related to health promotion and prevention, such as eating healthier and being more physically active.

**Cost of care conversations.** Assessment of CoC conversations included questions related to frequency, level of comfort, barriers to talking with health care providers about CoC, and preferred tools to facilitate CoC conversations. The frequency of CoC was assessed using one question: "How frequently do you discuss costs of treatment with patients?" This question used a 5-point Likert scale (1 = *never* to 5 = *always*). Level of comfort discussing CoC was assessed using four questions that included discussing costs related to health care treatment, prescriptions, and health care promotion and prevention, such as eating healthy and being physically active. These questions used a 5-point Likert scale (1 = *very uncomfortable* to 5 = *very comfortable*). Barriers to CoC conversations were assessed using one question: "What barriers prevent you from engaging in cost-of-care conversations with your patients?" Health care providers could select all applicable barriers from a list of 10, such as lack of time, lack of knowledge about costs, and lack of comfort, with a write-in option for additional barriers. Preference related to tools to facilitate CoC conversations was assessed using one item: "What tools would you like to facilitate cost-of-care conversations?" Health care providers could select

all applicable tools from a list of three tools that included online trainings, consultations, and fact sheets, with a write-in option for additional tools.

### Statistical Analyses

All items were examined through frequencies and descriptive statistics using SPSS 28.0.

## Results

### Patient Surveys

From the five counties, 125 patients completed the surveys (Table 1). Almost all of the respondents identified as white (94%), and over half (62%) were women. The mean age was 66 years, ranging from 34 to 96 years. The median educational level was some college, and the median household income was between $25,001 to $50,000 annually. Over half of respondents were on Medicare (51.3%), with 38.5% being on employer insurance and 3.4% on Medicaid. The number of health care visits annually ranged from none to 30, with a mean of almost 6 (5.85) visits.

***Table 1. Demographic Characteristics of Patient Survey Respondents***

| Characteristic | *n* | Percentage |
|---|---|---|
| Gender | | |
| Male | 48 | 38.4 |
| Female | 77 | 61.6 |
| Age in years | | |
| Under 50 | 7 | 5.0 |
| 50 – 59 | 31 | 24.8 |
| 60 – 69 | 39 | 31.2 |
| 70 – 79 | 25 | 20.0 |
| 80 – 89 | 14 | 11.2 |
| 90 and older | 2 | 1.6 |
| Missing | 7 | 5.6 |
| Race/ethnicity | | |
| White | 117 | 93.6 |
| Other | 5 | 4.0 |
| Missing | 3 | 2.4 |
| Educational Level | | |
| High school or less | 4 | 3.2 |
| High school graduate/GED | 40 | 32.0 |
| Some college | 27 | 21.6 |
| Bachelor’s degree | 24 | 19.2 |
| Master’s degree or higher | 14 | 11.2 |
| Missing | 16 | 12.8 |

| Characteristic | *n* | Percentage |
|---|---|---|
| Annual household income | | |
| Less than $10,000 | 11 | 8.8 |
| $10,001 - $15,000 | 17 | 13.6 |
| $15,001 - $20,000 | 13 | 10.4 |
| $20,001 – 25,000 | 11 | 8.8 |
| $25,001 - $50,000 | 21 | 16.8 |
| $50,001 - $100,000 | 27 | 21.6 |
| More than $100,000 | 4 | 3.2 |
| Missing | 21 | 16.8 |

### *Costs as Barriers to Health Care*

The top three cost-related barriers to health care identified by patients were associated with insurance costs, with half of respondents (50.2%) selecting insurance deductibles, 30.4% selecting insurance copays, and 20.8% selecting the overall cost of insurance. Few patients indicated that costs prevented them from following through with medical appointments and purchasing prescriptions, with slightly more patients reporting that costs were a barrier to following health care advice related to healthy eating and exercising (Table 2).

***Table 2. Frequency of Costs Preventing Health Care for Patients***

| In the last year, how often were you not able to do the following due to the cost? | *N* | Percentage reporting often or always (*n*) |
|---|---|---|
| Go to a health care provider | 123 | 7.2% (9) |
| Fill a prescription | 118 | 10.4% (13) |
| Follow the recommended treatment (like buy a knee brace, OTC medications, or bandages) | 119 | 13.6% (17) |
| Follow the advice of your health care provider (like healthy eating, fitness, etc.) | 122 | 14.4% (18) |

### *Cost of Care Conversations*

Over half of respondents (59.2%) reported that health care providers rarely or never initiated CoC. Most patients reported that they would prefer to discuss CoC with physicians (71.2%) and pharmacists (60.0%). Similarly, patients reported that they had more frequent CoC conversations with pharmacists (2.41) compared to physicians (2.09). About one-quarter of patients indicated that they did not initiate CoC conversations because of limited time, they had not thought about having these conversations, they were not sure who to talk to about costs, and they were not sure how to start the conversation (Table 3).

***Table 3. Barriers for CoC Conversations Identified by Patients***

| What makes it hard to talk to medical providers about health care costs? | Percentage (Number) |
|---|---|
| Not sure who to talk to about costs of care | 27.2% (34) |
| Not enough time | 26.4% (33) |
| Not sure how to start the conversation | 24.8% (31) |
| I never thought to talk about costs with my health care provider. | 24.0% (30) |
| Worried that I might not receive care | 9.6% (12) |
| Not comfortable talking about medical costs | 6.4% (8) |

Most respondents (67.2%) selected having one-on-one conversations with health care providers as the top way they would want to learn about CoC conversations, followed by written brochures (42.4%).

## Health Care Provider Surveys

From the five counties, 51 health care providers completed surveys. Most respondents were women (83%) and were white (86%). Nurses represented the largest number of health care providers, completing 24 surveys or almost half (47%) of the responses. Far fewer responses were received from health care provider office staff (6 responses), pharmacists (4 responses), nurse practitioners (3 responses), and nurse assistants (2 responses). Only one survey was received from a physician. Other responders included a first responder, an executive director of health care services, a health educator, a home health provider, and a medical biller.

### *Costs as a Barrier to Health Care*

Health care providers were aware that many of their patients faced different types of financial barriers to health care. They also reported high levels of comfort about discussing these costs with their patients (Table 4).

***Table 4. Barriers and Level of Comfort Discussing Barriers with Patients***

| | Barrier to care for patients[i] | | Comfortable discussing with patients[ii] | |
|---|---|---|---|---|
| **Issue** | **N** | **Mean (SD)** | **N** | **Mean (SD)** |
| Cost of health care treatments | 50 | 4.54 (.71) | 47 | 4.15 (.96) |
| Cost of health care visits (copays, deductibles, etc.) | 51 | 4.49 (.73) | 47 | 4.15 (.91) |
| Cost of medications and prescriptions | 51 | 4.47 (.76) | 47 | 4.17 (.94) |
| Cost of health promotion and prevention (such as eating healthier foods, participating in physical activity, etc.) | 51 | 4.29 (.90) | 46 | 4.00 (.99) |

[i]Response scale ranged from 1 to 5 with 1 = *strongly disagree* to 5 = *strongly agree*.

[ii]Response scale ranged from 1 to 5 with 1 = *not comfortable at all* to 5 = *very comfortable*.

### *Cost of Care Conversations*

A majority of respondents (65%) indicated that they often or always initiated CoC conversations with their patients. Health care providers indicated that the top selected barriers related to CoC were not being able to provide adequate solutions to patients' concerns and lack of knowledge about different costs (Table 5).

***Table 5. Barriers to Initiating CoC Conversations with Patients***

| What barriers prevent you from engaging in CoC conversations with your patients? | Percentage (Number) |
|---|---|
| Not able to provide adequate solutions | 54.9% (28) |
| Lack of knowledge about the costs of treatment | 45.0% (23) |
| I am concerned that I will give out incorrect information. | 39.2% (20) |
| Lack of knowledge about insurance | 37.3% (19) |
| Lack of knowledge about the costs of medication | 37.3% (19) |
| Lack of knowledge about the cost of the health care visit | 31.4% (16) |
| Lack of time | 29.4% (15) |
| I do not feel that these conversations are my responsibility. | 15.7% (8) |
| I am concerned that my patients will not be receptive. | 10.0% (5) |
| I am not sure how to start the conversation. | 3.9% (2) |

Most health care providers (83.4%) selected fact sheets with information as the preferred tool to help facilitate CoC conversations. Over a quarter (25.2%) preferred online trainings.

## Discussion

This study provides insight into the issues related to CoC conversations among rural health care providers and patients. In this study, most providers felt comfortable and indicated that they initiated CoC with their patients. These findings do not support previous studies that found providers often have difficulty initiating CoC conversations with their patients (Alexander et al., 2004; Erwin et al., 2019; Schrag et al., 2007).

Health care providers in this study were concerned that they did not have enough knowledge or resources to address the financial burdens facing their patients adequately. These findings are consistent with previous research that has shown health care providers have some degree of comfort with CoC conversations, but often providers do not know the cost of prescribed treatments (Bethke et al., 2020).

Given the fast pace of electronic media and access to the internet, it was surprising to learn that most health care providers preferred a written fact sheet to assist with CoC conversations. In contrast, patients wanted to learn about CoC conversations from their health care providers directly, followed by written materials. Research on patient education has suggested that

providers need to match the preferred learning style of their patients to explore both high-tech and low-tech education options (Bukstein, 2016).

## Limitations

There were some limitations to this study. These were convenience samples of older adults and health care providers with the purpose of informing the development of cost-of-care educational materials. Therefore, it is not possible to generalize results to the entire population of older adults and health care providers in rural Appalachian communities. The sample of older adults identified almost exclusively as white which reflects the racial demographics for these communities but limits the findings for diverse groups. Additionally, the largest group of respondents to the health care provider survey was nurses; therefore, we cannot generalize these findings to all health care providers' preferences and opinions.

## Implications for Extension

Extension's contribution to rural health and well-being was acknowledged internally as early as the 1970s (Konyha, 1975; Wang, 1974; Yep, 1975). While some programs connecting Extension with the healthcare delivery system have experienced success (Tiret et al., 2019), Extension has continued to experience difficulty obtaining recognition in the health care and public health sectors (Buys & Rennekamp, 2020; Halpert & Sharp, 1991; Khan et al., 2020). Calls for Extension linkages with clinical partners have cited the value for improved health outcomes, particularly for rural audiences where access to health care is often limited (Bigbee et al., 2009; Dwyer et al., 2017; Grumbach & Mold, 2009). The role of health professionals and clinical and community preventive services was noted in Cooperative Extension's National Framework for Health and Wellness, a tool guiding Extension efforts to systematically address health at multiple levels (Braun et al., 2014). Health services are a component of the updated framework, Cooperative Extension's National Framework for Healthy Equity and Well-Being (Burton et al., 2021). Findings reported here highlight an area for strengthened linkages between community-based Extension outreach and the health care sector to educate and support patients and potentially improve health outcomes. Barriers to CoC conversations identified for both patients and providers clearly highlight areas for Extension intervention and point to potential expansion of partnership with the health care sector.

Published literature describing Extension collaborations with the health care sector is few but cites the importance of Extension working with healthcare professionals on health issues and the growing recognition that these collaborations need to expand (Koukel et al., 2018; Remley et al., 2018). Published studies describing Extension collaboration with community health nurses and academic nursing programs leveraged Extension primarily for research activities, such as participant recruitment and data collection, or as an internship site for students in health fields, not as a partner in providing community education (Condo & Martin, 2002; Gray, 1990; Hall et al., 2005). These types of joint activities, while valuable, overlook a key strength of Extension to

educate and engage communities. The study reported here required a lens shift to view Extension educational programs through a complementary clinical-community context. Findings are informative for program development with an aim for mutual benefit.

Nearly half of health care provider respondents for survey findings reported here were nurses. Extension partnerships with this group of health care professionals could be a path forward for other health care/Extension partnerships. This includes the need for models connecting primary care to community-based education provided through Extension. One successful example is fruit and vegetable prescription programs, where physicians prescribe produce for patients and collaborate with Extension to provide nutrition education to encourage increased consumption (Tiret et al., 2019). Scaling up successful programs, as well as encouraging and strengthening collaborations between Extension and healthcare professionals, provides continued opportunities toro improve healthcare outcomes for communities.

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## Acknowledgments

This work is supported by the Rural Health and Safety Education Competitive Grants Program grant no. 2020-46100-32838 from the USDA National Institute of Food and Agriculture. The authors want to acknowledge the assistance of the Extension Family and Consumer Science agents in the five counties and the health care providers and community members who assisted with this project.