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Identifying Palliative Care Needs Among Older Adults in Nonclinical Settings

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Abstract

Though palliative care is appropriate for patients with serious illness at any stage of the illness and treatment process, the vast majority of palliative care is currently delivered in inpatient medical settings in the past month of life during an acute hospitalization. Palliative care can have maximal benefit to patients when it is integrated earlier in the illness trajectory. One possible way to increase earlier palliative care use is to screen for unmet palliative care needs in community settings. The goal of this study was to assess the rates of unmet palliative care needs in older adults who attend New York City–based senior centers. The results of this study revealed that 28.8% of participants screened positive for unmet palliative care needs. Lower education and living alone were predictors of positive palliative care screens, but age, gender, marital status, and race were not. This study determined that the rate of unmet palliative care needs in community-based older adults who attend senior center events was high and that living arrangement and education level are both correlates of unmet palliative care needs. Screening for unmet palliative care needs in community settings is a promising approach for moving palliative care upstream to patients who could benefit from the additional supportive services prior to an acute hospitalization.

Keywords

palliative care; community; screening; palliative care screening; senior centers; community-based palliative care

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Declaration of Conflicting Interests

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Introduction

Palliative care focuses on improving quality of life in patients with advanced illness and their family members. Patients who receive palliative care experience improved quality of life,^{1–5} fewer depressive symptoms,^{1,3,5} decreased emergency room visits and hospital admissions,^{6–8} as well as higher levels of satisfaction with care.⁴ Despite these documented positive associations with palliative care, many individuals who could benefit from palliative care never see a palliative care provider.⁹ Currently, the vast majority of palliative care is delivered in the inpatient medical setting during an acute hospitalization,¹⁰ but palliative care is appropriate at any stage of serious illness and can be most beneficial when integrated early in a patient's illness trajectory.^{1,11–13} The number of older adults living with serious illness is expected to increase rapidly as the population ages,¹⁴ and palliative care teams will need to find additional ways to reach patients with high multidomain symptom burden who could benefit from palliative care.

One way to increase the reach of palliative care is to screen for palliative care needs in nonclinical settings, such as senior centers, case management agencies, and congregate housing facilities. In 2012, approximately 13 million older adults (ages 60 years and above) received services from community-based supports and organizations.¹⁵ Screens implemented in community-based organizations could reach large numbers of older adults from diverse backgrounds and theoretically increase access to palliative care services providing that screen-positive adults are referred to outpatient-based palliative care programs.

In order to identify individuals with unmet palliative care needs in the community, appropriate screening measures would have to be utilized. We developed a new screening tool using a community-based participatory research approach that is intended to be used in nonclinical settings.¹⁶ Prior screening tools for unmet palliative care needs have primarily focused on inpatient populations, patients with cancer, and patients who are nearing the end of life^{17,18} and thus are not appropriate for community-based populations who are likely earlier in the illness trajectory. The new tool is composed of 3 specific domains: symptom burden, emotional concerns, and goals of care (Table 1). A preliminary study recently demonstrated that the newly developed tool can be feasibly implemented in senior centers to screen for unmet palliative care needs in community-dwelling older adults.¹⁶

The goal of this study was to assess the rates of unmet palliative care needs in older adults attending several New York City–based senior centers. We hypothesized that administering the palliative care screening tool in New York City–based senior centers would successfully identify individuals with unmet palliative care needs. We further hypothesized that positive screens would be more prevalent among participants with demographic factors associated with higher unmet palliative care needs and more barriers to receiving a palliative care referral. For example, older adults,^{19–25} ethnic minorities,^{15,25,26} men,^{21,22} unmarried or widowed adults,¹⁹ and adults without home caregivers²¹ are all less likely to receive palliative care services despite, in many cases, having high needs.

Methods

Sample

The current study was conducted as part of the TRIO for Successful Aging (TRIO) Program, a partnership between the Institute of Geriatric Psychiatry in the Department of Psychiatry and the Division of Geriatrics and Palliative Medicine, both located at Weill Cornell Medicine, and the New York City Department for the Aging.²⁷ TRIO integrates the importance of medical and social aspects of chronic illnesses into mental health service delivery in New York City–based senior center settings. Designed using an innovative service delivery model, that is, a combination of innovative outreach and case identification, TRIO brings mental health services to community-based settings.²⁸ TRIO staff host a variety of engagement activities (eg, lectures, discussion groups) to promote mental health awareness and healthy aging in participating senior centers. As part of the service delivery model, multifaceted needs assessments are conducted with consenting older adults who attend the engagement activities.

Participants in the current study consisted of adults aged 60 years and above receiving services at 1 of 5 senior centers located in Brooklyn and Staten Island, New York. TRIO staff asked older adults attending the center-based events whether they would be willing to participate in a needs assessment. The palliative care screening tool was administered as part of a broader needs assessment that included questions about elder abuse, functional impairment, and mental health care, among other domains and took approximately 40 minutes to administer. Assessments were conducted in English, Cantonese, or Spanish when appropriate and when multilingual staff were available. The needs assessment underwent back-translation procedures to ensure content was identical in English, Cantonese, and Spanish. Any older adult who screened positive on the palliative care screening tool was offered a palliative care referral to a local outpatient palliative care clinic. Participation was voluntary, and participants received a tote bag as a token of appreciation.

The local institutional review board approved the project and all participants provided oral consent.

Measures

Demographic data (ie, age, gender, marital status, education level, senior center location, and living status) were collected at the time of the assessment. Medical comorbidity data were also collected using a 22-item medical condition checklist.²⁹ A comorbidity sum score was calculated, with 1 point attributed to each item on the checklist; possible sum scores ranged from 0 to 22, with higher scores reflecting a greater number of medical conditions.

The recently developed 22-item palliative care screening tool was also administered.¹⁶ For each item, the participant was asked whether he or she experienced a given concern “never,” “sometimes,” or “all the time.” The 22 items are divided into 3 domains: physical symptoms, emotional concerns, and goals of care (Table 1). Participants screened positive if they reported experiencing 2 or more items within a domain “all the time” in at least 2 domains. For example, if a patient experienced 2 or more physical symptoms and 2 or more

emotional concerns all of the time, they were considered to have screened positive for unmet palliative care needs.

Analysis

Means (M) and standard deviations (SD) were computed to characterize the sample. χ^2 tests were conducted to assess for differences in screening outcome (positive vs negative) for categorical variables (gender, education level, living situation, marital status, and race), and t tests were used for to determine whether age or number of medical comorbidities varied between those who screened positive versus negative. SPSS version 24 was used to perform all statistical analyses.

Results

Over the 18-month recruitment period (July 2016 to December 2017), 240 individuals provided oral consent to complete a needs assessment, and 219 (91.3%) completed the palliative care screener. Demographic characteristics of the sample are shown in Table 2.

Screening Tool Results

Of the 219 participants, 63 (28.8%) screened positive on the palliative care screening tool (ie, endorsed experiencing at least 2 symptoms “all of the time” in at least 2 domains). Across the 3 palliative care domains on the screening tool, participants screened positive most frequently for unmet needs in goals of care ($n = 166$, 75.1%) followed by physical concerns ($n = 59$, 25.7%) and emotional concerns ($n = 50$, 21.8%). Figure 1 shows the breakdown of total positive screens by domain. For example, 5 participants endorsed having emotional concerns but did not screen positive on either goals of care or physical concerns while 15 participants screened positive for both emotional concerns and goals of care concerns.

Predictors of Positive Screen

The following variables were examined as possible predictors of a positive palliative care screen: age, race/ethnicity, gender, marital status, education level, living situation, and the number of medical comorbidities (Table 2). Age, gender, marital status, and race were not associated with screen positives; however, education, the number of medical comorbidities, and living arrangement were significantly associated with a screen-positive result. Those with lower education were significantly more likely to screen positive for unmet palliative care needs, $\chi^2 (2, n = 182) = 6.8 (P < .05)$. The percentage of positive palliative care screens in individuals with less than a high school education was 52% compared with 25% and 28% for those with a high school education or college and graduate school education, respectively. Regarding living arrangements, the percentage of positive screens among individuals living alone was 37% compared to 24% for those who did not live alone, $\chi^2 (2, n = 196) 4.0 (P < .05)$.

Finally, there was a significant difference in the number of medical comorbidities in those who screened positive for palliative care needs compared to those who screened negative ($M = 4.89 [SD = 2.64]$ and $M = 3.96 [SD = 2.64]$, respectively; $t[178] = 2.05, P < .04$).

Discussion

This study sought to examine the rates and predictors of unmet palliative care needs in an urban community-based sample using a newly developed palliative care needs screening tool.¹⁶ Our results demonstrated that over one-quarter of seniors who attend community-based senior centers in New York City screen positive for unmet palliative care needs and would therefore likely benefit from receiving palliative services. Given the high rates of individuals in the community who may benefit from palliative care, more outpatient palliative care services are warranted, and community-based agencies, such as senior centers, represent feasible locations to screen for unmet palliative care needs in the community.

This study identified several predictors of positive palliative care screens in community settings. Having less education, higher rates of medical comorbidities and living alone were associated with screening positive for unmet palliative care needs. Lower education is associated with lower socioeconomic status and reduced access to health care, as well as lower health literacy and limited knowledge of end-of-life care.³⁰ Given the many additional barriers to quality health care that adults with limited education face, it is unsurprising that lower education was associated with more unmet palliative care needs. Appropriate informational resources about palliative care, such as educational pamphlets and videos, must be developed to reach individuals with high palliative care needs and low education. Furthermore, prior research has highlighted that people are generally unaware of or misinformed about palliative care,^{31,32} which may serve as a key barrier to accessing the service. Fortunately, preliminary studies suggest that brief videos and informational pamphlets are successful methods for improving peoples' knowledge of palliative care services,³³ but more research is needed to elucidate the role knowledge of palliative services has in increasing access to palliative care.

Living alone was also associated with higher rates of unmet palliative care needs. Older adults who live alone may experience more psychological distress than those who live with a partner or spouse, which could contribute to or exacerbate mental health problems and other difficulties related to end-of-life planning.^{34–36} Given the results of this study, older adults who live alone may be good targets for more rigorous screening and assessment for unmet palliative care needs.

Similarly, individuals who screened positive for unmet palliative care needs had more medical comorbidities, on average, than individuals who screened negative. This aligned with our hypothesis, as medical illnesses are associated with increased physical symptom burden. Given that physical symptomatology is a domain on the palliative care screening tool, we expected individuals with positive screens to have more medical illnesses.

Though age, gender, race, and marital status were hypothesized to be predictors of positive palliative care screens, our study failed to confirm these anticipated relationships. As adults age, they tend to have more medical comorbidities,³⁷ which could contribute to screening positive on palliative care needs assessments. However, all adults in this study were older individuals who were able to attend activities at a senior center, which implies a reasonable

level of health and functional status. Age by itself was therefore not a predictor; however, the number of medical conditions was significantly predictive of positive palliative care screens. In populations that are more heterogeneous in regard to age, it may make sense to include age as a possible predictor of unmet palliative care needs, but results from our study suggest that age is not predictive of unmet palliative care needs in a population of adults older than 60 years who are attending senior centers.

Our results did not confirm the previous literature that suggested that men, racial minorities, and unmarried individuals are more likely to have palliative care needs. Perhaps, receiving services at senior centers mitigates the isolation and lack of emotional support associated with these variables, as senior center programs have been shown to improve both physical and emotional health.³⁸

Our study has several limitations. Our sample was likely subject to selection bias as participants were individuals who attended activities promoting health and wellness. These participants were likely more open to talking about health or may have more health concerns than the average older adult. Additionally, our study was limited to 5 senior centers in 2 boroughs of New York City, so our findings may not be generalizable to the broader older adult population nor nonurban-dwelling older adults. Another limitation is that we did not collect data on whether participants who screened positive and received a palliative care referral followed through with the referral. Further studies looking at the follow-through rate of palliative care referrals following a positive screen are warranted to determine the effectiveness of screening for unmet palliative care needs and referring for appropriate services. Lastly, we had incomplete or missing data for 40 participants. We handled missing data by not analyzing cases that were missing variables of interest in each analysis. Sample sizes for each analysis are reported in Table 2.

Conclusions

Identifying individuals with unmet palliative care needs in a nonclinical setting is feasible; however, challenges related to how best to address unmet needs in the community remain. For example, there are limited resources available for out-patient palliative care despite the growing palliative care needs of community-based older. Given the success of identifying palliative care needs through collaboration with preexisting programs in the aging services network, there may be value in exploring the possibility of partnerships between aging services and clinical palliative care providers to deliver palliative services to community-based adults. Screening for and delivering palliative care to community-based older adults in settings that they already frequent, such as senior centers, have the potential to remove many of the obstacles older adults face in accessing health care, including issues of mobility and disability.^{39,40}

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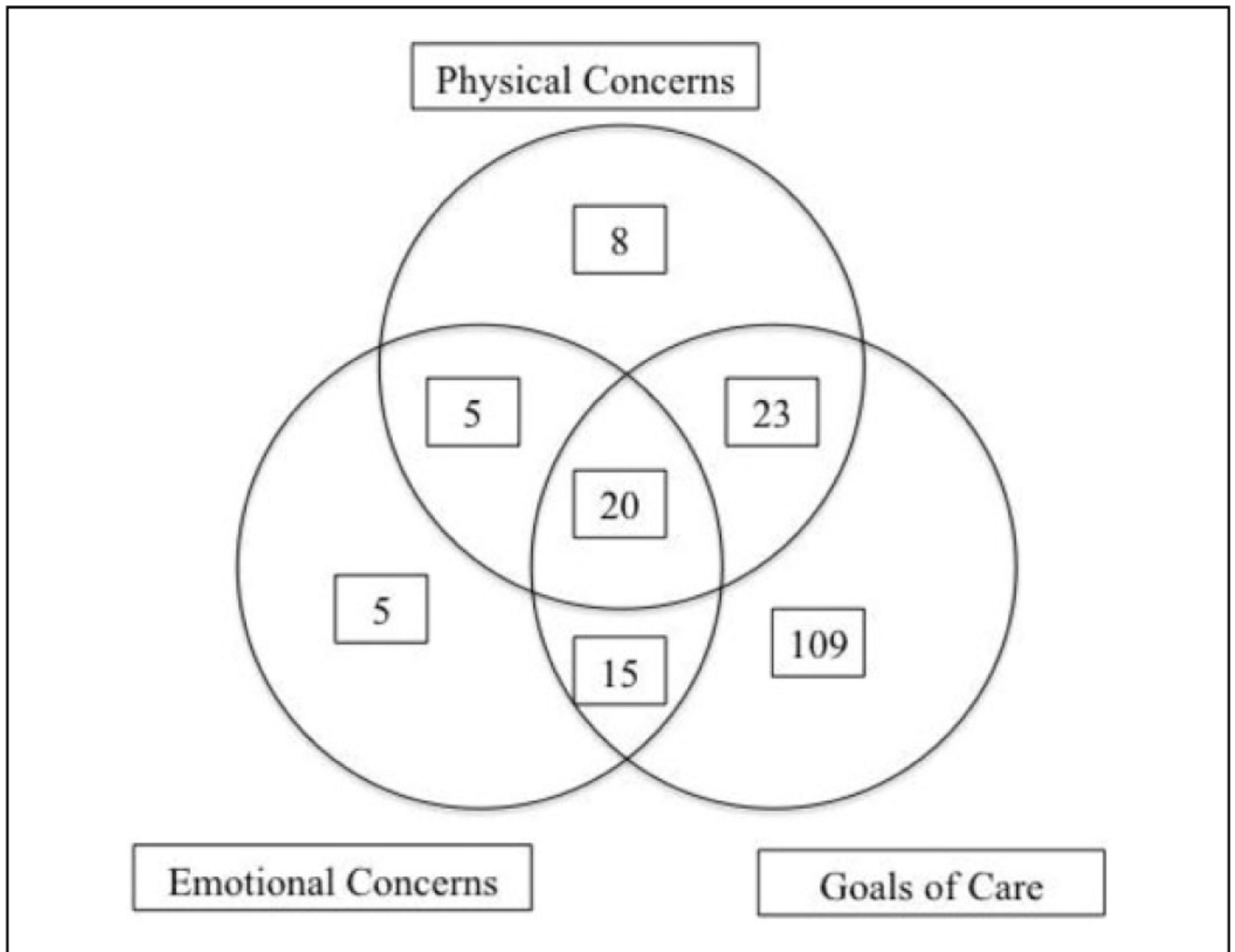


Figure 1.
Breakdown of positive screens by domain.

Table 1.Items in the Community-Based Palliative Care Screening Tool.¹⁶

Physical symptoms
Feeling tired or fatigued
Low energy
Difficulty sleeping (sleeping too much or can't sleep)
Pain or physical discomfort
Difficulty standing or walking
Shortness of breath
Emotional concerns
Feeling nervous, anxious, or on edge
Not being able to stop or control worrying
Having little interest or pleasure in usual activities
Feeling down, depressed, or hopeless
Feeling overwhelmed about any medical treatment
Feeling a loss of meaning or purpose in your life at the moment
Worried about being dependent, or a burden on friends or family
Feeling like there is no one in your life whom you can talk to
Having conflicts with friends or family
Goals of care
Feeling confused about your medical care
Feeling uncomfortable asking questions about your care
Feeling like you want more support with your medical care
Feeling like you need access to more medical providers
Feeling like you need more information about available providers
Have you given thought to how you want to be cared for when your illness(es) advance?
Have you talked with anyone about how you want to be cared for?
Do you have a document that indicates what your wishes are and who will make decisions for you?
Do you have a Health Care Proxy? Have you completed a Living Will?

Table 2.

Demographics and Associations With Screening Positive on Palliative Care Screen.

	n (%) / M (SD)	Percentage of Category With Positive Screen	P Value
Age (n = 237)	75.01 (9.14)	NA	NS
Gender (n = 237)			
Male	69 (29.1)	22.6	NS
Female	168 (70.9)	31.2	
Race (n = 230)			
White	124 (51.7)	30.9	NS
Nonwhite	106 (46.1)	25.7	
Education (n = 200)			
<High school	27 (11.3)	52.1	.03
High school	74 (30.8)	24.6	
College +	99 (41.3)	28.3	
Marital status (n = 218)			
Married	63 (28.4)	26.3	
Divorced	74 (30.8)	35.9	
Single	42 (17.5)	28.1	
Widowed	34 (14.2)	25.4	
Other	6 (2.5)	5.3	NS
Living arrangement (n = 217)			
Alone	101 (46.5)	36.7	
Not alone	116 (53.5)	23.6	.046
Medical comorbidities (n = 215)	4.2 (2.7)	NA	.04

Abbreviations: M, mean; NA, not applicable; NS, nonsignificant; SD, standard deviation.

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