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Refining a Taxonomy of Goals for Older Adults With Functional Limitations and Their Caregivers to Inform Care Planning

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Abstract

Purpose: The purpose of the study is to capture goals expressed by older adults with functional limitations and their caregivers. **Methods:** Through focus groups and interviews, 76 older adults with ≥ 1 activity of daily living limitation and 28 family/friend caregivers were asked about what mattered most to them and their goals for care. Transcripts were coded using an existing taxonomy. Goals that did not fit the taxonomy were assigned new codes. **Results:** We identified more than 50 goals in eight domains. Domains included (a) Medical Care; (b) Quality of Life: Physical; (c) Quality of Life: Social and Emotional; (d) Access to Services and Supports; (e) Caregiver Needs and Concerns; (f) End of Life; (g) Independence; and (h) Acceptable Housing. **Conclusion:** While there is overlap between identified goals and the existing taxonomy, new goals emerged. The goal domains identified could serve as a framework to improve and measure the quality of goal-oriented care for older adults with complex needs.

Keywords

older adults, caregivers, goal-oriented care, goal taxonomy, qualitative

Introduction

Older adults with functional limitations (defined as experiencing difficulties with activities of daily living) are a complex population with high rates of health care utilization and multimorbidity (Dunlop et al., 2002; Ryan et al., 2015). National survey data estimate that half of adults older than 65 years report difficulty with or receiving help with household activities, mobility, or self-care (Riffin et al., 2017). Despite representing a substantial subset of the older adult population, clinical practice guidelines primarily focus on a single disease rather than functional limitation, and clinical trials underrepresent older adults with multimorbidity and disability (Fabbri et al., 2012; Freedman & Spillman, 2014; Jindai et al., 2016; Quiñones et al., 2016). The causes and nature of functional limitations in older adults are heterogeneous, resulting in individualized health-related concerns, experiences, and goals for care that may not align with single-disease guideline-based care (Bayliss et al., 2014; Fried et al., 2011; Montori et al., 2013). This standard practice of addressing disease conditions instead of functional limitations for older adults can result in misguided care (Wenger et al., 2003). For example, treating an individual with a diuretic medication for heart failure without consideration of mobility limitations could lead to increased susceptibility to urinary incontinence and falls.

Due to the heterogeneity of this population, providers must tailor care to the individual. Consequently, the American Geriatric Society's *Guiding Principles for the Care of Older Adults with Multimorbidity* and *Person-Centered Care: A Definition and Essential Elements* recommend that patient preferences and goals should guide care (American Geriatrics Society Expert Panel on the Care of Older Adults With Multimorbidity, 2012; The American Geriatrics Society Expert Panel on Person-Centered Care, 2016). Others have recommended that patient-defined goals should be used to assess health outcomes for this population, rather than

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focusing on disease-specific outcomes, such as meeting blood pressure or glycosylated hemoglobin targets (Reuben & Tinetti, 2012; Tinetti et al., 2016).

Goal setting is critical to creating tailored goal-based treatment and care plans that address what matters most to older adults with functional limitations (Rowe et al., 2016; Schulman-Green et al., 2006). The importance of goal setting for geriatric populations has been observed in rehabilitation settings (Hurn et al., 2006; Leach et al., 2010) and for conditions such as diabetes (Chin et al., 2008; Morrow et al., 2008), dementia (Bogardus et al., 1998; Jennings et al., 2017), and other chronic conditions and multimorbidity (Kuluski et al., 2013; Street et al., 2007; Vermunt et al., 2017).

Clinician researchers have developed goal taxonomies to aid in goal setting (Bogardus et al., 1998; Jennings et al., 2017; Naik et al., 2016). A goal taxonomy that demonstrates the scope and breadth of goals expressed by older adults with functional limitations could serve both clinical and measurement purposes, including (a) use in clinical practice to initiate goal-setting discussions and develop person-centered care plans, and (b) use as a framework for measuring whether care received meets individual goals, thus closing a critical gap in quality of care measurement for older adults with complex care needs.

While prior studies have outlined goals that are important to older adults in condition-specific populations, little research has been done to understand the goals of older adults with functional limitations, and we found no existing taxonomy specifically addressing this population. A taxonomy that is not disease-specific would be applicable to older adults with multiple morbidities or functional impairment. As a starting point, we chose to build upon a goal taxonomy developed by Jennings et al. (2017) for older adults with dementia and their caregivers. We chose this taxonomy as a starting point because many older adults with dementia also have functional limitations. Jennings et al. (2017) elicited personalized health goals from individuals with early-stage dementia and caregivers of persons with all stages of dementia in a qualitative study. Using focus groups, their study generated a goal taxonomy of patient and caregiver goals for dementia care that included 41 unique goals across five domains: (a) Medical care and end-of-life care; (b) Quality of life: physical; (c) Quality of life: social and emotional; (d) Accessing services and supports; and (e) Caregiver support. The researchers found that most goals were not focused on medical care; rather, they broadly covered a range of health-related aspects of living, such as “Continue to work or volunteer” and “Have more free time for caregiver.” They suggested that many of the goals could apply to individuals without dementia, but the dementia-specific context of some goals limited generalizability to the broader population of older adults with functional limitations (e.g., *Increase community awareness and education about dementia*).

The purpose of this study was to build on the Jennings et al. (2017) study to characterize the values and goals of older adults with functional limitations. Beginning with goals identified in Jennings et al. (2017), we used focus groups and interviews of patients and caregivers to gain insight into what is important to older adults aged 65 years or older living with at least one functional limitation and their family or friend caregivers. With the methods of Jennings et al. (2017) as the basis for our study, we refined and expanded their findings in this population.

Method

Study Design, Setting, and Participants

We conducted a qualitative study from March to May 2016 to explore goals of older adults with functional limitations as well as the goals of their family and friend caregivers. The Chesapeake Institutional Review Board (Columbia, MD) approved this study (Protocol No. Pro00016259).

We recruited a convenience sample of participants from six health care organizations (two Medicare managed care plans with complex case management programs, one Medicare accountable care organization with a complex case management practice, one geriatric outpatient practice, and two home-based primary care practices) in four states, representing urban and suburban regions in the West, Midwest, and Southwest United States (see Table 1). Health care providers and other staff in the participating organizations recruited participants they deemed to be cognitively and physically capable of participating. The original study population was limited to English-speaking participants, age 65 years and older with a need for assistance in one or more activity of daily living (i.e., walking, bathing, dressing, transferring, eating, or toileting). During data collection, age criteria were expanded to include 13 participants between the ages of 53 and 65 years who were recruited by the organizations because their conditions did not differ substantially from the 65+ study participants. Caregivers of eligible participants were invited to be interviewed. Where possible, we interviewed caregivers (including spouses) separately, but some caregivers were present for patient interviews at the patient's request.

The study sample included 104 participants. We conducted six focus groups using a semi-structured interview guide with 53 older adults and 23 individual interviews for a total sample of 76 older adults. All participants resided in the community or in assisted living facilities. We conducted four focus groups with 26 caregivers and two individual interviews for a total sample of 28 caregivers. Participants provided written informed consent to participate in this study.

Data Collection and Analyses

The semi-structured interview guide was derived from the focus group guide developed by Jennings et al. (2017). The

Table 1. Participating Sites.

Location	Population	Type of organization	Program description	Payer type	Number of focus groups & interview conducted at the site
Wisconsin	Urban	Case management program as part of Medicare-Medicaid Dual Eligible Special Needs Plan	Health plan employed care managers provide home-based assessment and work with networked providers to coordinate care for at-risk older and disabled adults.	Medicare Advantage and Medicaid	2 Focus Groups 3 Interviews
Michigan	Suburban	Transitional-care case management program as part of Medicare Advantage Plan	Health plan employed registered nurse care managers work on site at skilled nursing facility to facilitate transition to community for older adults.	Medicare Advantage	2 Focus Groups 5 Interviews
California	Urban	ACO case management program	ACO employed care managers work with primary care practice and ACO-affiliated specialists to coordinate care.	Medicare Shared Saving ACO	1 Focus Group 5 Interviews
California	Urban	Geriatric home-based primary care	Practice employed physician and nurse practitioner provide primary care in the home.	Medicare fee-for-service	2 Focus Groups 4 Interviews
Michigan	Suburban	Geriatric home-based primary care	Physician and registered nurse provide primary care in the home. Home care and hospice provider offices are co-located.	Medicare fee-for-service and Medicaid	2 Focus Groups 5 Interviews
Texas	Urban	Geriatric home-based primary care	Physician and registered nurse provide primary care in the home. Home care and hospice provider offices are co-located.	Medicare fee-for-service and Medicaid	1 Focus Group 3 Interviews

Note. ACO = accountable care organization.

same guide was used for both interviews and focus groups. Interviews and focus groups started with open-ended questions about what goals were important to participants followed by prompts about the importance of goals within specific domains identified in the original Jennings guide: (a) medical, (b) social, (c) functional, (d) spiritual, and (e) end of life. The goals were not limited to a specific time-frame for achievement (e.g., 2 weeks, 3 months, 1 year).

Focus groups and interviews were conducted either in participating organization's conference rooms or in the participant's home. Staff on the research team trained in qualitative methods conducted interviews and moderated focus groups. At least two staff members participated in all focus groups and interviews. Interviews lasted approximately 60 min. Focus groups with older adults had an average of eight participants, and focus groups with caregivers had an average of six participants. All focus groups lasted approximately 90 min. Interviews and focus groups were digitally recorded and transcribed verbatim by a professional transcriptionist.

The Phase 1 coding template used the Jennings et al. (2017) taxonomy as the coding structure, and additional codes were allowed in Phase 2 coding. Transcripts were independently coded line-by-line by one investigator (C.A.C.). The Phase 1 coding template used the Jennings et al. (2017) taxonomy as the coding structure and categorized those goals that fit within the existing taxonomy as "original" (i.e., they were included among those reported by Jennings et al., 2017). Goals or areas of importance identified by study participants that did not fall within the original Jennings et al. (2017) coding template were initially coded as "Other." In addition to directly stated goals (e.g., "My goal is to quit smoking"), any statement of a desirable or undesirable outcome or process (e.g., "I am afraid of falling") was defined as a goal. Phase 1 coding was reviewed by

the research team. Coding was facilitated by NVivo 11 Pro software, a qualitative data organization and management software.

Phase 2 coding included review of the "Other" code and identification of new goals using an inductive coding approach (Saldaña, 2009). New goals were considered for the taxonomy if voiced by more than one participant. One investigator (C.A.C.) conducted the secondary analysis, and the research team reviewed the analysis. New goals were reviewed for frequency and, if distinct from original goals, were categorized as "new." Some goals overlapped those of Jennings, but were not identical, and required a revision of the original goal. These goals were categorized as "adapted." New goals, domain structure, and salient passages were discussed among the research team, and any differences were addressed through group consensus. Once team consensus was reached, goals were classified within the Jennings domain structure and new domains identified to accommodate additional goals. The investigator (C.A.C.) updated codes as discussed, and the final structure of goals and domains was reviewed by the research team.

Results

Participant Characteristics

The mean age of older adult participants was 74 years, range 53 to 89 and older; 78% were female; 64% were White; and 29% were African American. The caregiver participants were 81% female; 62% White; and 23% African American. Of the older adult and caregiver samples, 3% and 19% were Hispanic or Latino, respectively. Demographic data were available for 92% of participants. Participant age above 89 years was not collected to protect personal health information.

Participant Identified Goals and Domains

Participants identified 52 discrete goals across eight domains: (a) Medical Care; (b) Quality of Life: Physical; (c) Quality of Life: Social and Emotional; (d) Access to Services and Supports; (e) Caregiver Needs and Concerns; (f) End of Life; (g) Independence; and (h) Acceptable Housing (see Table 2). Some discrete goals (e.g., medication management) were further divided into subgoals as patients and caregivers identified specific goals within the context of a broader goal. For example, under the broader goal of *medication management*, some individuals expressed goals related to *avoiding side effects* while others expressed goals around *reducing the number of prescribed medications*. While most of the goals identified by participants fit within the Jennings et al. (2017) taxonomy, several new topics were identified. These included new goals (e.g., “Manage caregiver role and expectations”) and domains (e.g., Independence, Acceptable Housing). Based on our findings, we divided the original domain, “Medical care and end-of-life care,” into two domains (Table 2).

Goal Domains

Medical care. The *Medical Care* domain includes goals related to health care received or desired and to experiences with providers and the health care system.

Many older adults expressed a desire for appropriate medical care, including appropriate level of care intensity, provider type, visit frequency, and setting. They also expressed a fear of receiving burdensome care, such as unnecessary hospitalization.

Older adults identified goals related to medication management, including eliminating or reducing side effects, reducing the number of medications taken, and understanding the purpose of each prescribed medication.

Many participants also repeatedly articulated goals concerning provider–patient interaction, often focused on communication and collaboration. Specifically, participants expressed the desire to “have providers who work with me/us” when older adults and their caregivers described how providers did not consider their wishes. Participants also emphasized the importance of being understood. They expressed “being heard and listened to” as a desire to have more input into care decisions.

Participants described negative experiences when navigating the health care system, such as difficulties managing multiple providers, medical resources, and finances. These experiences were associated with a participant’s goal to gain confidence in managing her or his health care.

Quality of Life: Physical

The *Quality of Life: Physical* domain encompasses goals related to managing physical symptoms or conditions and improving or maintaining the ability to participate in physical activities.

Older adults endorsed goals about managing physical symptoms of illness, including pain, sleep, and bodily functions (e.g., incontinence). Maintaining comfort while managing physical symptoms or a chronic health condition was also a common theme. Participants differentiated between managing physical symptoms and managing health conditions, such as diabetes.

Older adults expressed a desire to improve their confidence in managing their chronic conditions on their own or with assistance from family members.

In addition to managing symptoms and chronic conditions, older adults and caregivers also emphasized the importance of maintaining or improving health and quality of life. Even when asked to expand, older adults would describe the goal broadly, wanting to either “stay where I’m at” or “get back to where I was”:

My goals are to stay healthy. (Older adult)

My goal . . . I’m going to get my health back together. (Older adult)

Other physical quality of life goals included maintaining adequate nutrition, quitting smoking, walking or other exercise, and maintaining a healthy weight. Related to physical safety, some older adults expressed the desire to avoid falling and the fear of falling when alone and without assistance.

Quality of Life: Social and Emotional

The *Quality of Life: Social and Emotional* domain addresses goals related to managing mental health symptoms or participating in activities that impact emotional aspects of quality of life.

Participants expressed a diversity of social and emotional quality of life goals across different topics.

Quality of life goals focused on maintaining a fulfilled life as an older adult. Older adults expressed the desire to work, volunteer, and participate in recreational activities ranging from painting to preparing family dinners. Several expressed a desire to continue educational studies, including technology training. Participants also wanted to travel, attend specific life events, or have everyday outings.

Coupled with their desire to maintain a full life while aging was a fear of becoming overwhelmed by the impact of disability and aging. Both patients and caregivers expressed the desire to maintain dignity in older age:

Regarding some of the goals we have as a family, to maintain his dignity as he progresses . . . (Caregiver)

Religious and spiritual goals were common. Older adults described a sense of purpose when fulfilling their religious or spiritual needs, even if they were not able to attend religious services.

Table 2. Goals Identified by Older Adults and Caregivers and the Relationship to the Jennings et al. (2017) Goal Taxonomy.

Domain	Goal	Status	Sample quote
Medical Care	Receive needed medical care	Original	"So my basic goal about it would have to be to get my knees done. And like they said, it would help with my back and it would help with my legs"
	Do not receive burdensome medical care	Original	"I don't want anything else in life to hinder me from being me again. And I feel that hand surgery, knee surgery, hip surgery will hinder me."
	Stay out of the hospital	Original	"It took five years for me to heal. So, decrease hospitalization."
	Manage medications	Adapted	"I take a lot of pills. I take seven pills in the morning, and then in the evening, two more, and sometimes during the day, they give me a pill."
	• Do not take medications with side effects	Original	"They throw a pill at it. Then, the pills make me sick, but then they give me pills every time"
	• Understand why I am taking my medications	New	"I've been prescribed four different kinds of pain pills or headache pills . . . even though it's the same, they both have different names, but it's the same product. Why do I have to take the same thing double when that's like overdosing?"
	• Reduce the number of medications I am taking	New	"I don't want to go out like that—just a pill head. I want to start eliminating, since I'm doing good mentally."
	Improve communication with providers	Adapted	"The goal was for them to sit up and give me an answer."
	• Have providers who understand my/our cultural background and speak primary language	Original	"No Greek-speaking psychologist or behavioral therapist, no Greek-speaking support groups. What I've gathered, again from my professional experience and from attending these kinds of events myself, I share with my mom, but it's not the same."
	• Have providers who work with me/us	Original	"It's almost like they're working against you and not understanding what your goal is to get to. Or they don't seem to care."
Quality of Life: Physical	• Be heard and listened to	New	"My goal was to get heard, to make my voice heard."
	Improve confidence with navigating the healthcare system	New	"My biggest fear is not getting good healthcare, not having responses to my questions and requests about health situations."
	Maintain adequate nutrition	Original	"I hate to look at myself in the mirror, because I am so thin, and I don't eat enough . . . I don't have the appetite that I used to have."
	Be physically safe	Original	"That's one of my primary concerns . . . the safety when I have to do things by myself."
	Be physically active	Original	"My goal is to sit up and continue to do what I've been doing, the exercising."
	Manage physical symptoms	Adapted	"I go to dialysis three times a week and usually I'm so tired that I sit home the next day recovering and sleeping. That's about it."
	• Get adequate sleep at night	Original	"I just can't sleep and can't do nothing."
	• Control pain	Original	"I want to be as pain free as possible."
	• Control bodily functions	New	"Am I limited if . . . I have to go to the bathroom because I'm leaky?"
	• Maintain comfort	New	"We would like to keep him comfortable . . . as comfortable as possible."
Manage health conditions	New	"My goal was my sugars have been out of control."	
• Improve confidence with managing health conditions	New	"My husband was a doctor, so . . . when I had the floaters, I immediately read everything about the floaters."	
Improve or maintain health	New	"My goal is like everyone else: to get my health in better shape."	
Quit smoking	New	"One of the biggest ones I set is to quit smoking."	
Maintain a healthy weight	New	"Right now, I would like to lose weight—that's number one for me"	

(continued)

Table 2. (continued)

Domain	Goal	Status	Sample quote
Quality of Life: Social and Emotional	Socialize with friends and family	Original	"I have my church family, and I have friends at the food pantry . . . just to keep socializing with them instead of sitting in the house"
	Maintain relationship with spouse or partner	Original	"But those were my goals in life, to continue with a happy family life with my kids and this lady"
	Continue to work or volunteer	Original	"I want to function as an adult and as to the extent I still can as a lawyer"
	Do recreational activities	Original	"I was in the choir in church and I didn't look at the director and they stopped and I kept going and they said, 'Oh!' I need singing lessons. So that's my short term goal to improve my voice."
	Keep mind stimulated/be alert	Original	"I mean, for me, alertness is a big issue. I shared with you already my concern that I might zone out in the car."
	Manage behavioral symptoms of dementia	Original	"The biggest problem is the other caregivers—it's like they don't want to go in. You know, because sometimes my mother is mean . . . I just don't know what to do."
	Maintain positive affect	Adapted	"To give more love to people, to love myself and just do the best I can in life and enjoy it"
	• Manage depression	Original	"I don't want anything else in my life to hinder me from being me again. And I feel that . . . surgery will hinder me. It will put me back into a depression of helplessness. And I don't ever, every want to go there again."
	• Maintain positive outlook	New	"The goal is to get out, to stay away from the negative . . . try to do positive stuff."
	• Practice religion and spirituality	New	"I'm not actively churchy, but I do pray a lot, and I do think I have a close relationship with the Lord"
Access to Services and Supports	Continue educational studies	New	"Before I leave this world, I would like to get my high school diploma."
	Use or receive assistance with using technology	New	"Being in the hospital wasn't a problem?" "No, my children brought me the computer."
	Continue to care for my pets	New	"I have three dogs and three cats at home. So I'm not going anywhere."
	Maintain dignity	New	"Regarding some goals, we have as a family, to maintain his dignity as he progresses"
	Go on a trip or outing (not related to medical care)	New	"My favorite day is Tuesday because we go to Walmart . . . like a normal person."
	Feel financial resources are not a barrier to care; find assistance with managing finances	Original	"The one thing I really want to focus on . . . is trying to find out how I can help with medications. And because even though you're paying out to Medicare, you're paying out to [health plan], you still end up having to pay out a terrible amount"
	Have adequate caregivers	Original	"You never get the same person twice. You have to train them all the time."
	Have legal and financial affairs in order	Adapted	"I keep track of my bank, I do my taxes, I look at investments . . . my children take care of nothing at all"
	Find or use community resources	Adapted	"We be trying to get the van to pick him up and get him to church on time. That's a goal that he needs"
	Have access to durable medical equipment	New	"Three steps. I need a ramp for three steps . . . I'm just trying to make you understand where I feel like I'm stuck."

(continued)

Table 2. (continued)

Domain	Goal	Status	Sample quote
Caregiver Needs and Concerns	Control caregiver frustration and manage stress	Original	"When it's your own family because there's so much history there, there's a lot of frustration involved in that too."
	Receive caregiver support	Original	"You know, I say . . . just pray to God. Just let them come and feel with me, so that at least I can feel a little relief."
	Have more free time for caregiver	Original	"But they say, you don't have a life of your own. You never go anywhere. You never go on vacation. I haven't been on vacation since 2003."
	Minimize family conflict	Original	"But I want to take on more hours but I'm kind of scared. Because then we start fighting, and I try not to fight with her."
	Maintain caregiver health	Original	"I just pray to God every single day. Just give me good health so that I can continue giving good care for my father."
	Feel confident in managing health problems	Original	"Sometimes seems like I've got about five things on my mind at once. And I end up forgetting things."
	Manage caregiver role and expectations	New	"It's such a fine line of being a caregiver, when to help, when not to help, when to feel useful, when to not feel you're the martyr"
	Improve confidence with navigating the healthcare system	New	"I'm considered difficult because I go through practitioners very quickly . . . in order to be successful, they need to be really versed in Alzheimer's, dementia, or cognitive"
	Die peacefully	Original	"You now, all my life, ever since I remember, I'm always sick . . . they might as well let me go, you know?"
	Live as long as possible	Original	"My goals are just to be here as long as I can."
Independence	Not be a burden on family	Original	"Because you want to help yourself. You want to be able to do for yourself. You don't really want to depend on nobody doing it for you."
	Respected for my end-of-life preferences	New	"I think we both have agreed that, as long as our mind would be functional, we would like them to do, you know, to try to resuscitate us if we stop breathing."
	Continue to drive or use transportation	Original	"I met my goal of driving. That would've been one of my concerns."
	Manage household activities and self-care	Adapted	ADAPTED BY NCQA RESEARCH TEAM
	Do household activities and self-care	Original	"I just want to be able to do housework and yardwork."
	Be in charge of household activities	Original	"The thing I miss the most about being able to walk is yardwork . . . so I hire everything done."
	Receive assistance with household activities and self-care	New	"I have someone helping me clean and cook four hours a week and that's enough for me."
	Regain or maintain independence	New	"I don't use a cane. I have a scooter, but I don't use it. I used it one time, and that was it. I don't want to be dependent on them, you know to get around."
	Move to a more supportive setting	Original	"But when I get so I can't do that no more, I want to be put in a nursing home."
	Find acceptable long-term care	Original	"My father was a full care patient in a skilled nursing facility . . . our goals weren't being met there."
Acceptable Housing	Continue to live at home	Original	"I want to stay at home as long as I can bathe myself and get up and walk."
	Return to home setting	New	"My goal is to just go home and get myself together"
	Avoid staying in a nursing home	New	"I don't want to go to a nursing home. And that's probably what's going to have to happen."

Note. Original = Original goal, unchanged from Jennings et al. (2017); Adapted = Adapted goal, addition to wording/splitting in the Jennings et al. (2017); New = New goal, added to Jennings et al. (2017).

While older adults and their caregivers described specific goals related to overcoming depressive symptoms, participants also emphasized the need to maintain a positive outlook on life. These subgoals were grouped under the larger category of maintaining a positive affect.

Older adults expressed the desire to keep their mind stimulated and alert. Caregivers also expressed goals related to managing behavioral symptoms of dementia.

Goals that centered on interaction with others involved the desire to remain close to family and friends. Some older adults wanted to maintain or improve relationships with others, including family members, friends, and romantic partners. Other participants expressed the desire to continue caring for pets.

Access to Services and Supports

The *Access to Services and Supports* domain includes goals focused on the ability to access, afford, and utilize appropriate health care services and equipment.

Fears and barriers drove access to services and supports goals. Participants feared that they would lack the financial resources to pay for needed care. They described financial worries ranging from medical (e.g., copays for visits with specialists, the cost of necessary medications) to nonmedical expenses (e.g., paying for groceries). Financial concerns were sometimes paired with legal concerns. A few older adults described fears that their affairs would not be in order before they die.

Other fears included a lack of access to adequately trained paid caregivers and community resources. In addition to access, caregivers noted that the person might refuse available resources. One caregiver said,

She has a Lifeline thing now. And she didn't want that in the beginning . . . Before she [said], "I don't need that, I don't want that."

Several older adults also expressed the need for durable medical equipment, such as continuous positive airway pressure (CPAP) machines, wheelchairs, and ramps. They described their struggles to obtain this equipment.

Caregiver Needs and Concerns

The *Caregiver Needs and Concerns* domain encompasses goals both expressed by and for caregivers.

Caregivers shared many goals expressed by the older adults whom they cared for, but they also articulated goals specific to caregiving.

Many caregivers struggled with their role and found it challenging to navigate the expectations of being a caregiver. Expectations of caregiving were not always clear and managing the role of caregiver was not easy. One caregiver found it difficult to know when to help and when not to help. Another caregiver described the challenge of balancing his role as a caregiver against his own needs:

There was a friend of mine . . . who was aware of some horrible things I was going through . . . He picked me up and threw me to the mirror. He goes, "Look, who do you see? That's the person you need to look after and take care of."

Caregivers expressed the desire to improve their confidence with caregiving, making a distinction between confidence in managing health problems for the person they care for and confidence in navigating the health care system.

Frustration was common among caregivers. They described the need to manage stress and the desire to have more free time for themselves. Family conflict was also a concern, and caregivers described conflicts stemming from unclear roles, the expectations of primary versus secondary caregivers, inconsistent priorities between the older adult and their family members, and health conditions with challenging behaviors like dementia. One caregiver described attempts to avoid family conflict:

It's hard because sometimes I feel like I have [to] . . . make her do things. I've sort of backed off. I mean, she's supposed to do all these exercises and . . . she just doesn't do them, so I've started making her walk . . . So we have arguments about that kind of stuff. I try to come up with ways to get her to do stuff without arguing.

The need for caregiver support, both caregiving support for the older adult and support for the caregiver, was a common theme. This need for support was often expressed with a concern about the caregiver's health. For example, some caregivers feared that they would get sick or become unable to care for the older adult.

End of Life

The *End of Life* domain addresses all goals related to end-of-life care and desires.

When discussing the end of their lives, some older adults said they wanted to "die peacefully," but that included a range of end-of-life care preferences. Some expressed a desire for limited intervention, while others emphasized a desire for any measures that might extend life (e.g., "live as long as possible"). Both older adults and caregivers focused on respect for the stated preferences of the older adult. Older adults were concerned about whether providers and family members would respect their wishes.

A commonly expressed end-of-life theme from older adults was the fear of becoming a burden on family or others at the end of life and after their death.

Independence

The *Independence* domain addresses goals that center on living one's life independently without help or assistance from others.

Older adults articulated the desire to retain or regain independence in daily life. Independence included participating in activities such as physical activity, self-care, and traveling. The goal, "Regain or maintain independence" was broadly construed because the meaning of independence was personal:

I think I can get back to where I could just do these things on my own and take care of myself. (Older adult)

I can go to the library . . . these things do not mean much to my daughter . . . My independence is not her goal. (Older adult)

[My goal is] that I'm able to function independently with the least care . . . that I can take care of myself, basically. (Older adult)

The desire to continue to drive or use transportation was classified under the Independence domain. Some older adults expressed frustration or concern about needing to rely on family members, friends, or transportation services to leave home for pleasure or necessity.

Older adults also discussed household and self-care management as important to independence. Some expressed a desire to maintain their independence, including self-management and household activities. Those who required assistance with these activities wanted to guide how paid or unpaid caregivers provided personal care or household help.

Acceptable Housing

The *Acceptable Housing* domain includes goals related to individuals' place of residence.

Choice of residence was important to both older adults and caregivers. Older adults emphasized the desire to stay in their home, and caregivers emphasized the desire to have the person continue to live at home for as long as possible. Home was defined individually, which included living alone or with a caregiver in the older adult's residence, in a family member's home, or in an assisted living facility or nursing home. A number of people stated some variant on:

I want to stay at home as long as I can. (Older adult)

Participants expressed a fear of moving to a nursing home, but they drew a distinction between that and other types of supportive settings, which they viewed as appropriate when necessary.

The goals expressed by older adults and their caregivers span a wide range of domains and often are not associated with a specific clinical condition.

Discussion

We found that older adults with one or more functional limitations and their caregivers articulated a range of goals that mattered to them. We identified more than 50 goals and

categorized them into eight domains building on the Jennings et al. (2017) framework. These findings support the original study and expand upon those findings by building a more expansive taxonomy. This more expansive taxonomy is a tool that providers can use with a broader older adult population with functional limitations, with and without cognitive impairment.

Our expansion of the Jennings et al. (2017) domains based on input from older persons with functional impairment and their family or friend caregivers captures more types of goals and may be applicable to more people for whom goal achievement is an important outcome. Because dementia is a progressive disorder, returning to a previous state or maintaining a current state may not be as common as it is for individuals with functional limitations. Among the population targeted by this study, there is a greater possibility of returning to a previous or maintaining a current health status. Thus, goals such as independence, housing, or improving health would be more likely among populations defined by functional impairment rather than dementia.

Implications

Our findings have important implications for the care of older adults with functional limitations.

Older adults with functional limitations and their caregivers were clearly able to describe goals for themselves and the individuals they care for, but these goals are not captured well in traditional measures of health outcomes and care quality (Reuben & Tinetti, 2012). Some participant goals aligned with commonly measured clinical outcomes used by health care providers, researchers, health systems, and policy makers to define "success" (e.g., "maintaining a healthy weight," measured by body mass index). Most goals, however, differed from these traditional clinical and health-related quality-of-life outcomes. For example, reducing burdensome medical care and living in preferred housing are not common outcomes measured in the U.S. health care system. Other individual, idiosyncratic goals, such as maintaining independence in traveling to the library, are not easily captured by existing person-reported outcome measures. These findings may help to inform a framework for assessing outcomes in older adults with functional limitations that are meaningful to the individuals.

Most goals addressed nondisease-specific outcomes as opposed to common medical goals, which often address an intermediate clinical outcome (e.g., controlling HbA1c). For example, participants emphasized the importance of performing household chores, traveling, and continuing with hobbies. Achievement of these goals spans outcomes and conditions but can be facilitated by achievement of intermediate clinical outcomes (i.e., controlling diabetes to maintain independence). Focusing care in the context of goals that matter to the individual (e.g., maintaining independence) may be more meaningful than solely focusing care on intermediate clinical outcomes (e.g., controlling

HbA1c). Working toward an outcome that the individual thinks is an appropriate measure of success allows for collaborative clinical decisions and reduces the use of interventions or care that do not align with the priorities of both parties.

In their care of patients, clinicians could use a goal inventory to initiate a discussion of what goals and outcomes are most important to the patient and caregiver and how care should be structured. Proactively eliciting what is important to older persons with functional impairment provides health care providers insight into crafting a more personalized care plan, which has been shown to improve quality of care (Edwards et al., 2017). For example, an individual may express the goal of reading a book every week. The care plan for this individual could include a visit to the ophthalmologist for a vision test and possibly new corrective eyewear and/or referral to transportation services for travel to and from the local library. It may include intermediate clinical measures, such as standing or walking long enough to get to the library and find a book on the shelves. The achievement of the individual's goal (e.g., reading a book every week) provides opportunities for both caregivers and providers to offer health care and supports that are directly tied to individuals and their personal preferences.

Articulating patient-driven, specific, and measurable goals can also inform a new approach to targeting health outcomes for both individual and population measurement. Our research suggests that measures focused on quality of life and life satisfaction have a place for use in the clinical setting. Targeted goals that allow for measurable achievement could be used by clinicians to assess whether a treatment or care plan is influencing progress toward the patient's goal. At a systems-level, targeted goals can inform population health and provide insight into the success of health care models. By focusing on goals that matter to the patient and capturing the outcome of those goals, we can gain a better understanding of whether care is helping to achieve outcomes important to patients and their families.

Limitations

Our study has several limitations that must be considered. Both the older adult and caregiver samples were predominantly female. While expected, given the populations sampled, this limitation highlights an area for future research into the goals of older adult males and male caregivers. We recruited individuals who were able to travel for a focus group or an interview or could participate in an interview in their home. These participants were likely to be less impaired than those who cannot travel or are too impaired to engage in an interview. Caregivers had to find someone to replace them while attending the focus group. We did not ask about the health status of the older adults or caregivers. Due to the use of focus groups, other limitations included the inability to review individual differences in types of goals and to link individual goals to patient characteristics. Although beyond the scope of this study, research to further the taxonomy

could include isolating and then comparing goals from individuals and their spouses and/or caregivers.

Also, due to the selective nature of a convenience sample, generalizability is limited. However, this sampling strategy was chosen to ensure both participant availability and willingness, as well as an adequate ability to communicate (Palinkas et al., 2015; Spradley, 1979). All study participants were English speakers, which limits the generalizations made to other non-English-speaking populations. Information pertaining to participants' diagnoses and functional status was not obtained, which also limits the generalizability of our findings.

Despite these limitations, the study draws from four large health organizations across the United States that support care for community-dwelling adults, which represent settings similar to where much of the U.S. older adult population receives care.

Conclusion

This qualitative study developed a taxonomy of goals important to older adults with functional limitations and their family and friend caregivers. Many of the goals were not disease-specific but focused on care needs that spanned conditions as well as broader aspects of quality of life. This taxonomy can serve as a tool in clinical practice to understand what matters most to older adults and their caregivers, providing an opportunity for person-stated goals to complement more traditional clinical outcomes. We recommend future research on the value of using the goal taxonomy in clinical practice and quality measurement. An individualized approach to care provision that focuses on what matters most to the patient may be better suited for this population than care plans that focus on achievement of intermediate clinical outcomes. Quality measurement in this population should likewise follow by focusing on achievement of individualized goals rather than clinical outcomes. This goal inventory could be a tool to help shape quality measures of the future.

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Human and Animal Rights

All procedures performed in this study involving human participants were in accordance with the ethical standards of the Chesapeake Institutional Review Board (Columbia, MD) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Chesapeake Institutional Review Board (Columbia, MD) approved this study (Protocol Number: Pro00016259).

Informed Consent

Informed consent was obtained from all individual participants included in the study.

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