

Predicting Long-Term Care: Determinants of Probability

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Abstract

Determinants and variables which impact probability for long-term care are reviewed to help understand the high-risk populations and plan accordingly. The challenges and barriers to adequately planning for future needs remain consistently dependent upon the personal characteristics of an individual, including socio-demographic factors and behaviors such as smoking. Research of multiple sources and data was completed to help identify high-risk groups as well as variables that impact the probability of the need for long-term care services and supports. Knowledge of predictors can help guide future research efforts, allocate funding and help improve quality of care.

The functional status of an individual is a strong predictor of multiple health outcomes including mortality (Murphy and Cicilline, 1999). Professionals working in the long-term care industry continue to warn of the need to engage and prepare individuals and families by discussing important topics early and developing an aging life care plan. Aging demographics, along with the number of individuals living with one or more chronic health conditions into old age, place a demand on communities and individuals to be better prepared. Unfortunately, there has not been broad support by the general population to self-prepare. Many of the challenges revolve around the financial ability to pay for long-term care as many Americans do not adequately prepare for their own potential needs, often outliving their assets or relying heavily on public assistance.

Perhaps this comes from the general uncertainty that may exist of whether an individual is truly going to need help. Determining this probability is often difficult, reliant on a multitude of variables and dependent upon the characteristics of each situation. Stakeholders, such as insurers and healthcare organizations, rely on evidenced-based practice to understand what their beneficiaries will need. Strategizing for proper allocation of funds requires an understanding of the situation and developing a care plan, or road map, for life long needs.

Long-term care is often misunderstood. Society tends to identify long-term care with the frail, elderly person who is confined to a nursing home. However, baby boomers, due to their large cohort, are the highest risk for disability and need for long-term care (Knickman & Snell, 2002). The United States Department of Health and Human Services refers to long-term care as a range of services and supports to help individuals over a long period of time, which most often

involves assistance with basic personal tasks of everyday life (Favreault & Dey, 2016). Identification of daily living needs is essential to long-term care planning. The civilian population spent an average of 9.59 hours per day performing personal care activities, such as bathing, dressing, and health related self-care, and over two hours per day preparing meals and eating (United States Department of Labor, 2018).

Daily Living Needs

Daily personal care tasks are referred to as activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Areas of focus related to personal upkeep include meal preparation, nursing and personal care, home maintenance, financial and medication management and supervision for safety (Graf, 2013). All tasks related to personal upkeep are important and integral to a plan for optimal wellness. Any decline in an area of function should be given proper attention for mitigation. Proper nutrition, for example, is achieved through proper meal planning, including shopping for needed items, and meal preparation. If one area fails or is difficult to achieve, the result may be poor nutrition, which has the potential to jeopardize any care plan. Likewise, the administration of a medication regimen is often an overlooked required task of daily life. Medication reconciliation, the process of reviewing the medication list and comparing to the prescribed orders and instructions, is intended to avoid harm due to errors in dosing or timing and help prevent adverse reactions and was recognized by the Joint Commission as a National Patient Safety Goal in 2005 (Barnsteiner, 2008).

It is important to consider all tasks individually and develop a person-centered approach for meeting the needs when an individual is not able. Having a better understanding of the typical frequency of occurrence and timeframe for completion of daily tasks helps one plan for care, with the understanding that the timeframe for task completion is dependent upon the individual environment and personal attributes. It is important to consider all sequential or necessary skills required for completing combined ADLs and make the most appropriate plan for assistance, if necessary. If an individual is unable to complete a functional task of daily living independently, for whatever reason, they would likely benefit from the use of long-term care services and supports, whether paid or informal, depending on the given situation.

Table 1 outlines functional tasks, a combined list of ADLs and IADLs, required to maintain personal care and manage personal affairs for a healthy adult. This table was developed based upon the authors experience in planning care for individuals in their home and reviewing levels of care in facilities. The Human unencumbered Minimum Anticipated Need (HuMAN) estimate is based on a normal healthy aging adult, who is not burdened by disease or disability. It is the lowest expectation to effectively maintain and manage personal affairs and health on a daily or routine basis. The minimum anticipated need will vary, depending on the personcentered care plan, personal characteristics and impacting variables. It is a baseline for a projection of needs for the minimum number of occurrences which should be planned for on a weekly basis, at the most basic level, and help guide planning and identification of funding sources to meet those needs. It is intended to be a guide for professionals charged with assessing the need for assistance. Each task in Table 1 is further expanded to include the additional skills required to complete each activity.

Table 1: Functional Tasks of Daily Living

Combined Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

Task/Activity	Associated skills	Human unencumbered Minimum Anticipated Need (HuMAN)
Bathing	Recognizing need to bathe Obtaining supplies Entry/Exit into bathroom Adjusting water temperature Rinsing & drying body parts	2-3 times weekly
Dressing	Understanding environmental needs & choosing appropriate clothing Putting on/taking off clothing Recognizing need to change or adjust clothing Managing zippers, buttons, snaps	2-3 times daily
Toileting	Recognizing need to use bathroom Getting to/from commode Personal care/cleanliness Clothing adjustment Disposal of soiled items	Multiple times daily On demand/anytime
Transferring	Recognizing need to move body Identification of next step or next location Use of assistive devices Body adjustment & stabilization	Multiple times daily On demand/anytime
Mobility	Recognizing need to move location Use of assistive devices Body positioning Spatial organization and mapping	Multiple times daily On demand/anytime
Eating	Recognizing need or desire to eat Choosing and planning food Preparing food Clean up Awareness of concerns due to appetite, swallowing difficulty or other	Multiple times daily
Medications	Obtaining medications from pharmacy Utilizing current list of meds Identifying pills, reading labels Storage and location of meds Understanding reason for taking Side effects to watch for & what to do Administering meds and tracking compliance	Daily to multiple times daily
Meal preparation	Planning for meal Obtaining ingredients Use of proper cookware including stove, refrigerator or microwave Proper food storage or disposal	3 times daily
Shopping	Planning for items Getting to store Purchasing items/handling money Delivery & proper storage of items	Weekly
Finances Bill Paying	Review of financial statements, bills Understanding bills Recall or awareness of financial status Check writing or fund transfer Recording payments/balances Applications and security Organization & filing	1-2 times weekly
Transportation	Planning transportation Understanding directions Maintaining & operating vehicle Finding alternative transportation as needed	1-2 times weekly
Social Participation Home Exercise Recreation	Initiating & planning for activity Understanding available activities Recognizing value Getting to/from or setting up for activity Attending activity	3-5 times weekly
Housekeeping Home Maintenance	Recognizing need for upkeep Planning for tasks needing accomplished Obtaining supplies and equipment Performing tasks while maintaining safety	Weekly

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Normal Aging & Predictor Variables

Normal physiological changes occur within the aging body. Every system of our body is affected by the degenerative process of aging. On the outside, it is clear how aging takes its toll. For example, in the skin, the largest organ of the body, wrinkles appear due loss of collagen and loosening of the skin. On the inside, we might only notice a problem with symptoms that signal our brains that something is not right, such as with joint pain or stiffness. The rapidity to which someone ages will depend on heredity traits, environment, congenital conditions, disease or disability, accidents, injuries and trauma. The normal, healthy aging adult 65-year-old female can expect to live until age 86 and a 45-year-old today is expected to live an additional 38 years (Social Security Administration, 2018). As individuals age, there is a likelihood they will require assistance with ADLs, but it is difficult to predict when and how much assistance they will require. It is important to recognize being an older adult by itself does not guarantee or predict the need for long-term care supports and services.

Determinants & Variables: Predictors of Need

Determining the likelihood of the need for long-term care supports and services is based on a comprehensive assessment, data analysis and research. Some of the factors which contribute to a rise in probability for long-term care supports and services include social demographics, chronic disease, cognitive impairment, and health care utilization. These factors are further impacted by variables that are highly individualized and require a person-centered approach for complete understanding. These include: Poly-pharmacy, or multiple medications, and medication side effects, history of falls, incontinence, mental stability, concerning behaviors, pain, sensory impairment, use of assistive mobility device or loss of limb function.

Social demographic factors which increase need for long-term support include low education level, childhood health problems, and a lack of social relationships which may contribute to a cognitive decline (Knickman & Snell, 2002). Those living in poverty are more likely to either have unmet, or under met needs (Alecxi and Kennell, 1994). While social demographics alone do not significantly raise the probability of need for long-term care, when they appear alongside chronic illness or disability, the chance of requiring care assistance rises drastically.

A chronic health condition may increase the likelihood of requiring long-term care. The progressive nature of the disease course, the number of co-occurring conditions, the severity of symptoms and effective management each impact this need. Those with chronic illness are more likely to be on multiple medications, creating a risk for unmanaged or unrecognized side effects, geriatric syndrome, morbidity and death (Abdulraheem, 2013). People with multimorbidity, or two or more chronic health conditions, are expected to live 81% of their remaining years of life with disability,

approximately five years (Rizzuto, Melis, Angleman, Oui & Marengoni, 2017). A large portion of elderly, chronically ill individuals have significant functional impairments and substantial symptoms which make it difficult to manage their care needs and access medical care (Wajnberg, Ornstein, Zhang, Smith, and Soriano, 2013).

Those with cognitive impairments such as with Alzheimer's Disease or other forms of dementia, will require assistance at the highest level at an earlier onset than those with multiple chronic conditions and no cognitive impairment. This typically results from an inability to perform sequential tasks, behaviors such as wandering or agitation, or not being able to recognize a potential threat to safety. It is important for individuals and families with a current diagnosis of dementia, or those at risk, to plan for the almost certain need for assistance as the disease progresses.

Chronic health conditions involving functional loss of a limb or dependency on mobility devices will raise the probability for life-long needs. Normal aging related conditions will be aggravated by such conditions, making it difficult for the individual to be independent with all combined ADLs. As people age, they may experience more problems with balance, coordination, and strength which can have a negative effect on mobility, creating a reliance on wheeled devices, such as a wheelchair, further increasing concern for injury and other adverse outcomes (Gavin-Dreschnack, Volicer, and Morris, 2010).

Identifying individuals with prior health care utilization helps to identify and understand those at risk. In this sense, health care utilization refers to hospitalizations and emergency department visits. The term "health care utilization" is misleading, built on the assumption that exposure to health care might focus greater attention on maintaining wellness or catching problems before they unravel. For individuals with multiple morbidities, difficult symptoms or frailty, and especially those with cognitive impairment, hospitalizations or emergency department visits pose a real threat. Care fragmentation due to multiple physician involvement and difficulty with communication can lead to medication errors and deficiencies in care delivery. These individuals often experience additional care transitions, increasing the risk of errors or accidental omissions, potentially resulting in re-admission, placement in a long-term care facility, or even death (Mondor, et.al., 2017). Many programs across the nation are directed at improving transitions and employing professionals or volunteers to intervene. In 2012, United States, the highest healthcare users were responsible for 50% of healthcare costs, a mean cost per person of more than \$43,000 annually (Siekman and Hilger, 2018).

Limitations

Projecting care needs is a dynamic process, dependent on the individual situation. There are several limitations to projecting care needs with absolute certainty. Sometimes, a

disease course changes or health improves, making predictions less accurate. In most circumstances, a projection of need is based on a probability of greater than 50%, or likelihood the individual will require help, and is an estimate of needs, dependent on many circumstances. Understanding usage of long-term care supports and services requires a complex process of review and reporting. This has been limited to relatively smaller cohorts of Medicare populations and may not be fully applicable within the life care plan process. Freedman and Spillman (2014) analyzed the 2011 National Health and Aging Trends Study to find nearly one half of older adults had difficulty or received help in the last month with daily activities. However, this panel study was limited to 8,000 Medicare enrollees, offering only a small perspective of needs amongst the over 48 million Medicare enrollees in 2011 (Centers for Medicare & Medicaid Services, 2018). Care guidelines may be limited in helping to understand a disease and its anticipated progression and targeted treatment, for the purpose of preparing for eventual needs.

A myriad of personality traits exist which may create problems with recognition of need or engagement in the planning process. These traits may include subtle behaviors, opinions, faith and values which can complicate or impede the ability to understand, accept and plan for eventual care. Another limitation with long-term care planning pertains to the workforce. No matter how well a plan is made, the reliability of projections can become undermined when there are insufficient supports and services. The United States is currently facing a geriatric workforce shortage, raising the risk for individuals to have unmet needs. This creates a false sense of decreased need or demand for services, especially in underserved areas where individuals are often isolated.

It is important for stakeholders to identify solutions to meet the needs of individuals in the community, especially those at risk, and recognize the need for early care planning. The burden on public benefits, health care entities, and stakeholders may be reduced if greater emphasis is placed on early care planning and individual preparedness. Knickman and Snell (2002) provide optimistic predictions for reduction in long-term care needs and decreased disability in aging populations, attributable to advances in medicine, better prevention, pharmaceuticals, and surgical treatments, such as joint replacements. Targeted treatment and prevention may help reduce the onset of disease or deterioration.

Implications for Life Care Planning

Care planning and care management can be effective mechanisms to help reduce the risk of adverse outcomes and improve quality of life. Care managers can provide oversight of the care plan, helping to identify necessary changes and implementing strategies for optimizing one's situation. There needs to be better understanding of the utilization of long-term care supports and services, especially in the community. Life care plans are often created for cases involving

catastrophic injury or those requiring complex future medical care. A framework for performing follow-up and review of the implementation of the life care plan would help to understand how the projections and recommendations were used and what may have impacted them.

Continued research and scientific exploration allows for improved targeting of treatment and adoption of preventive measures for the highest risk populations. For example, the correlation between head injuries and risk for development of cognitive problems later in life is concerning for the population of survivors of such injuries, many whom have gone on to lead meaningful and productive lives. Fazzini (2016) explored the association between traumatic brain injury (TBI) and the risk of dementia, reporting evidence to suggest a significant risk for development of cognitive impairment following TBI, increasing with advancing age, and primarily the result of abnormal tau protein deposition and neurodegeneration. Understanding the pathological mechanisms by which TBI leads to dementia may help target treatment early in the recovery process and potentially delay or mitigate the progression altogether.

Engaging individuals in their own health affairs can be encouraged across all health settings, with specialized training to help clinicians to improve outcomes. Patient engagement is seen as an effective way to improve quality and lower costs in health care but is challenged by several limitations, including inattentiveness, inertia and other behaviors (Nease, Frazee, Zarin, and Miller, 2013). Nease et al. (2013) recommends using strategies to allow individuals to make one-time decisions and encouraging pre-commitment. Pre-commitment requires individuals to understand and place value on events which may take place in the future and to plan accordingly. However, it is not human nature to focus on future events. It is more typical to wait until something presents itself with no other option and then deciding to act. Unfortunately, with many healthcare decisions, waiting until it is necessary may erode the person-centered approach and force important decisions to be made by others or individuals under duress.

It is important for health care organizations to have an established protocol for initiating the complex and personal discussions related to advance care planning, especially with high-risk individuals. Understanding determinants for elevated risk for long-term care helps clinicians assist the individuals they serve by improving early and informed decision making through education and guidance. Due to limitations in resources, clinicians may improve efficiency and potentially be more effective by recognizing and targeting interventions at high-risk groups or individuals. Preventive or restorative measures can be implemented to help reduce the social burden of disease or disability and targeted engagement of high-risk populations can improve livelihoods.

Conclusion

Projecting care needs requires a collaborative process, relying upon the medical opinions of physicians and other health care team members, while utilizing guidelines for care, identifying recommendations for optimal wellness, considering the normal aging physiologic process, and adopting a person-centered approach. In some cases, it is easy for a physician to predict the eventual or life-long needs for someone with certain conditions, such as with a progressive disease or current disability already requiring assistance. However, in many cases it may be difficult to understand if the individual will or will not require care assistance as they age. A person-centered approach focusing on the current functional ability of the individual, while taking into consideration key determinants of risk and impacting variables, helps prepare for current and future care needs.

Case managers, social workers, life care planners and rehabilitative consultants strive to identify and predict care needs for those living with chronic health conditions or disability. Through the development of care plans, stakeholders can adequately prepare and educate all parties and necessary funds can be allocated to meet those anticipated needs.

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