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Planning and Decision Making for Care Transitions

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Abstract

The need to plan for future health care and residential adjustments increases with age, growing frailty, and restrictions in coverage of long-term care and will continue to grow with population aging. Older adults' lack of financial preparation for health care costs, insufficient knowledge about available options, and inadequate communication about care-related values has become an increasing public health challenge. This chapter describes a model of Preparation for Future Care (PFC), which encompasses different levels and domains of planning. Research about the extent to which planning is helpful in navigating care transitions is reviewed, and barriers and facilitators of planning including individual, familial, cultural, and national long-term care policy factors are discussed. Planning in the context of dementia and practical approaches that can be taken to enhance PFC is addressed, as well as recommendations for future research in the area of planning and decision making in the context of care transitions.

INTRODUCTION

As populations age worldwide, the need to plan for future health care and residential adjustments will continue to grow. Of the world's population in 2004, 98.3 million (14.3%) were severely or moderately disabled and 46% of adults older than 60 years had a disability (Mathers, Fat, Boerma, & World Health Organization, 2008). Thirty-eight percent of American older adults report some kind of impairment, including physical, cognitive, and sensory disabilities (U.S. Department of Health and Human Services, 2009). Conservative estimates project that men and women, at age 65, will experience an average of 1.6 years and 2.6 years, respectively, of cognitive or physical impairment (Murtaugh, Spillman, & Wang, 2011; Murtaugh, Spillman, & Warshawsky, 2001). The average total time an older adult spends in long-term care, including nursing homes, assisted-living facilities, or receiving formal and informal inhome care services, is 3 years (Kemper, Komisar, & Alecxih, 2005). Thus, future care needs and transitions can be anticipated because of common disease trajectories (Lynn, 2005).

More than half of older Americans are worried that they would not be able to pay for their future health care needs in the event of a serious illness (Robert Wood Johnson Foundation, 2009). Regarding long-term care needs, this concern is likely to be further magnified. Although preparing for future stressors and negative events leads to better coping (Aspinwall, 1997; Bode, de Ridder, & Bensing, 2006; Ouwehand, de Ridder, & Bensing, 2007) and lower levels of depression and anxiety (Sörensen, Mak, Chapman, Duberstein, & Lyness, in press), surprisingly few older adults engage in care planning behaviors. Lack of financial preparation for health care costs, insufficient knowledge about available options,

and incomplete clarity about personal care-related values has become an increasing challenge for older adults, their families, and public health practitioners.

In this chapter, we describe a model of preparation for future care (PFC), which encompasses different levels and domains of care planning for older adults. We review what is known to date about the extent to which planning is helpful in navigating care transitions. Then we discuss known barriers and facilitators of planning, including individual, familial, cultural, and national long-term care policy factors. We also discuss planning in the context of dementia. Finally, we discuss practical approaches that can be taken to enhance PFC and make recommendations for future research in the area of planning and decision making in the context of care transitions.

WHAT IS PREPARATION FOR FUTURE CARE?

Broadly, PFC is an information-seeking and decision-making framework aimed at maintaining quality of life. It is a dynamic process that must adapt to different levels of need and changing circumstances associated with different life stages. It includes both planning for the inability to perform only a few instrumental activities of living (“I can’t see the buttons on my stove to cook”), potential disability (“I can’t walk independently”), and for choices around treatment of terminal illnesses, palliative care, and resuscitation (“I don’t want to be in pain,” “I don’t want a feeding tube,” “If my heart stops, don’t bring me back”). This latter type of planning, called *advance care planning*, also encompasses the designation of a health care proxy, completion of a living will, and, in some states, the completion of a Physician’s Orders for Life-Sustaining Treatment form. Although these are important aspects of future planning, which have received broad recognition as an important part of late-life care (Bomba, Doniger, & Vermilyea, 2004; Camhi et al., 2009; Clements, 2009; Golden, Corvea, Dang, Llorente, & Silverman, 2009; Lawrence, 2009), this chapter focuses on late-life care planning for a time of increasing disability or frailty that often accompanies aging.

PFC occurs when an individual, couple, or family considers the possibility that frailty or disability might be a future health state. This awareness may initiate the exploration of choices addressing those health states and choices about preferences regarding care personnel, care contexts, and how and when to make transitions into those contexts. Ultimately, the process of PFC should culminate with concrete actions that reflect those preferences and decisions. Thus, PFC is a type of health-promotion activity that combines thoughts and behavior (Kulys & Tobin, 1980; Sörensen & Pinquart, 2000a; Sörensen & Pinquart, 2001a).

Theories of reasoned action and planned behavior (Fishbein, 2008), and planning in everyday situations (Berg, Strough, Calderone, Meegan, & Sansone, 1997; Hayes-Roth & Hayes-Roth, 1979; Rebok, 1989; Scholnick & Friedman, 1993; Smith, 1999), and their translation into retirement planning (Noone, Stephens, & Alpass, 2010) explain the cognitive processes involved in planning for the future. These theoretical approaches largely agree that the steps in planning include increasing awareness of the need to plan, gathering information about the present situation, determining future goal states, comparing various

options for reaching these goals, choosing specific plans, implementing these plans, and evaluating their effectiveness.

Our research team developed an assessment tool for PFC that conceptually mirrors these steps in subscales (Sörensen & Pinquart, 2001a). In our model, *Awareness of future care needs* assesses older adults' consciousness of the risks for disability and need for future assistance (e.g., "Talking to other people has made me think about whether I might need help or care in the future"). *Gathering Information* focuses on assessing the current situation, possible future goal states, and options for reaching these goals (e.g., "I have been following the public discussion in the media to learn more about care options"). *Decision Making* involves weighing different options and gaining clarity about one's preferences such as whether inhome care is preferable to assisted living and why (e.g., "I have compared different options of obtaining help or care in the future and have decided which would work for me and which would not"). The *Concrete Planning* scale assesses timely care plan initiation and communication of care preferences to relatives (e.g., "I have identified how I want to be cared for and taken concrete steps to ensure that those options are available"). Because some individuals simply eschew thoughts about future care altogether, we also include a measure on *Avoidance*, which assesses the tendency to shun thoughts of future frailty (e.g., "I try not to think about things like future loss of independence").

Figure 6.1 depicts a hypothesized progression of PFC processes. However, one cannot assume that every individual follows these planning or problem-solving steps exactly, or even makes rational or mindful decisions (Langer, 1994; Lovallo & Kahneman, 2003). People may commit to a particular alternative for nonrational reasons and then stop considering other possibilities (Langer, 1994). Some individuals prefer to choose the first available option when they are under stress, or they may rely on others to make decisions for them (Janis & Mann, 1977). Such "nonrational" approaches to planning may be caused by emotional distress, such as anxiety and depression, that obstructs effective problem solving (Wetherell, Reynolds, Gatz, & Pedersen, 2002). For example, older primary care patients with more depression symptoms report less information gathering even after controlling for personality traits (Sörensen, Duberstein, Chapman, Lyness, & Pinquart, 2008).

An ordered decision-making process as depicted in Figure 6.1, however, is more likely to lead to informed and values-based decisions that fit the individual's true preferences (O'Connor et al., 2009). Nevertheless, most plans must be modified regarding changing realities such as unexpected loss of informal helpers, changes in health status, or newly available assisted living options (Pinquart & Sörensen, 2002).

Many older adults underestimate their future care needs—57% of older adults say they rarely or never think about their future care needs (Walz & Mitchell, 2007), only 15% of older adults report having a concrete plan for their care, 55% state they have no plans at all, and 31% report having general preferences, with no clear idea of how to implement them (Sörensen & Pinquart, 2001b). Because planning can enhance access to choices, help individuals gain control over their environment, aid in maintaining health-related quality of life, and prevent disease progression, the aforementioned statistics suggest that one public

health strategy in aging services may be to help older adults overcome their reluctance to engage in care planning, a preventive health behavior.

ADVANTAGES AND DISADVANTAGES OF PREPARATION FOR FUTURE CARE

Our theory of PFC is informed by the concept of proactive coping (Aspinwall & Taylor, 1997), which suggests that preparation for future stressors, by mobilizing resources and considering responses in advance, may help individuals cope with age-related stressors and improve well-being (Aspinwall, 2005). Despite evidence in favor of preparing for future stressors (Aspinwall, 2005; Berg et al., 1997), it can be unpleasant and anxiety-provoking to think about future vulnerability (Pinquart & Sörensen, 2002; Sörensen & Pinquart, 2000b). Qualitative studies on older adults' subjective evaluation of PFC suggest that they see both advantages and disadvantages to future planning. Some state an unwillingness to contemplate potential future illness and disability (Black & Reynolds, 2008; Carrese, Mullaney, Faden, & Finucane, 2002). Others engage in what might be termed *unrealistic optimism* (Walz & Mitchell, 2007; Weinstein, 1987). Participants in a cross-national study (Pinquart & Sörensen, 2002) stated that thinking about future frailty would reduce their present psychological well-being. In addition, they stated that uncertain contextual factors may render specific plans irrelevant in the future. For example, the lack of predictability of specific future care needs, the constant change in health care systems, and the potential loss of informal support from kin in poor health (e.g., older spouses) are uncertainties that contribute to older adults' avoidance of future planning, especially for relatively healthy individuals (Pinquart & Sörensen, 2002).

However, the perceived drawbacks of planning can be addressed by effective planning strategies that take into account potential changes in environments and resources, or are updatable as circumstances change. Older adults state that taking charge of their lives could ease the burden of insecurity for the future, and that planning for future care needs may benefit potential helpers (e.g., by reducing the burden on a frail spouse or an adult child). Finally, PFC is seen as a way to cope with current health challenges. For example, moving to a continuing care facility would not only address existing minor care needs, but also ensure additional assistance with increasing frailty (Pinquart & Sörensen, 2002).

Quantitative studies, although still rare, have also linked PFC with various positive outcomes. Regarding general planning (e.g., "I like to plan for the future"), evidence suggests that older adults who plan report greater life satisfaction at follow-up (Prenda & Lachman, 2001). Furthermore, future-oriented thinking enhances subsequent health-promotion behaviors, such as exercise (Kahana, Kahana, & Zhang, 2005). Prospective research shows that older adults with greater awareness of their long-term care preferences tend to have better subjective well-being after residential transitions (Ball et al., 2005). A 2-year longitudinal study of older primary care patients showed that those who had made more concrete plans at intake were less likely to meet criteria for a depression diagnosis at follow-up (Sörensen et al., in press). They also had lower anxiety-severity scores (Sörensen et al., in press). Patients who had avoided thinking about future care needs had greater depression

symptom severity at follow-up (Sörensen et al., in press). However, the mechanisms underlying the effect of planning on later health outcomes are less clear.

In contrast, lack of planning for age-related health decline may increase the risk of residential or care arrangements that are incongruent to the patient's values and preferences (Liu, Chia, & Olin, 1999; Monagle, 2002). Inappropriate home-based care, for example when living quarters are inadequately adapted for vision loss or mobility problems, may lead to falls and emergency room visits (Biderman, Cwikel, Fried, & Galinsky, 2002; Long, King, & Coughlin, 2005; Monagle, 2002); unnecessary nursing home admission may be related to incident depression (Hoover et al., 2010), a known risk factor for disability, and premature death (Wulsin, Vaillant, & Wells, 1999). Depression and anxiety may also be a consequence of poor or insufficient planning (Sörensen et al., in press).

In addition to advantages linked to maximizing older adults' quality of care and reducing personal stress, planning for long-term care also has implications for relatives. For example, effective PFC is a likely stress buffer for care-givers when they are more clearly informed of their family member's wishes and needs. Furthermore, PFC may have financial implications for older adults and their families. Individual finances will be under increasing strain as baby boomers transition to more precarious health states, and the responsibilities of family caregivers and their associated physical, emotional, and opportunity costs grow (Sörensen & Conwell, 2011). The cost of assisted living and other long-term care and residential facilities may exceed the financial ability of many families, especially when these costs appear unexpectedly. The accessibility of long-term care insurance remains limited because of high premiums and the prospective approach necessary to make long-term care insurance a worthwhile investment. In some cases, having long-term care insurance may not be enough to cover medical emergencies, and these "medical expenditure shocks" can rapidly deplete financial resources of older adults and their children (Brown & Finkelstein, 2009). For this reason, preparation for care needs to include financial planning.

In large part because of the aging of the population, long-term care expenditures are projected to triple over the next few decades, posing a serious public policy concern. At the societal level, the financial consequences of planning (or lack thereof) stem, in part, from excessive use of federal or state funds to cover growing long-term care costs; middle-class older persons interested in ensuring their children's inheritance rely on Medicaid to cover the bulk of their care. Thus, although long-term care is being planned for by some, widespread reliance on Medicaid may burden the system. PFC does not protect against this type of planning. Establishing flexible long-term care financing systems, as in several European countries (Albert & Freedman, 2010; Wiener et al., 2007), may enhance the usefulness of PFC for protecting government financial interests.

BARRIERS AND FACILITATORS TO PREPARATION FOR FUTURE CARE

Barriers and facilitators to PFC may occur at all levels and are conceptualized in the context of the integrated model of behavioral prediction (IMBP), a health promotion model based on the combination of the theories of reasoned action and planned behavior (Ajzen & Albarracin, 2007; Fishbein, 2008). The IMBP, as depicted in Figure 6.2, states that behavior

—in this case engaging in PFC-related thoughts and actions (or alternatively, the avoidance of PFC)—is preceded by the intention to do so. Having appropriate intentions, however, does not guarantee the enactment of PFC because individuals may lack the skills and abilities to plan (because of cognitive deficits, lack of education, or lack of financial means with which to plan). Individuals may also encounter other environmental barriers such as no available aging services in their region, no available caregivers, or no acceptable residential care. Effectively translating intention into action, thus, requires sufficient internal and external resources.

Intentions are directly affected by subjective social norms relating to the importance and effectiveness of PFC, individual beliefs and attitudes toward future care need and future care planning, personality, decision-making styles, selective information processing, and self-efficacy beliefs defined as the conviction that one can effectively perform the planning activity. In addition, socioeconomic status, available community resources (e.g., inhome care and assisted living facilities), and awareness of those resources play a role in affecting intentions.

Subjective Norms: Cultural and Familial

Experienced social pressure follows from familial, cultural, or national norms regarding whether one should engage in PFC. For example, unspoken or explicit family expectations and role descriptions for family caregiving may affect the extent to which an individual engages or does not engage in PFC. Although such expectations can be specific to a particular familial system or culture (Delgadillo, Sörensen, & Costner, 2004; Spitze & Ward, 2000), many such expectations are caused by cultural views of eldercare. Culturally-based kinscripts about family caregiving responsibilities, views of the caregiving role, and preferences for informal versus formal support have been documented in African American (Burton & Stack, 1993; Dilworth-Anderson et al., 2005), Chinese (Cheung, Kwan, & Ng, 2006), Asian American (Pinquart & Sörensen, 2005), and Latino families (Delgadillo et al., 2004), and may play an important role in determining the extent to which the individual older adult considers future care needs. However, race differences in PFC actually favor Blacks (Hirsch, Sörensen, & Lyness, 2010; Pinquart, Sörensen, & Davey, 2003); this may be caused by greater perceived caregiver availability among African Americans, particularly among extended family members (Roth, Haley, Wadley, Clay, & Howard, 2007), or higher rates of community-level disease burden (Diez-Roux et al., 1997; Gary et al., 2008), which may sensitize African Americans to expect and plan for future care.

Culturally-based views of eldercare often translate into individually measurable filial obligation beliefs, which motivate many families to expect and provide family care (Bromley & Blieszner, 1997; Burr & Mutchler, 1999; de Valk & Schans, 2008; Dilworth-Anderson et al., 2005; Dilworth-Anderson, Goodwin, & Williams, 2004; Groger & Mayberry, 2001; Hsueh, Hu, & Clarke-Ekong, 2008; Lee, Peek, & Coward, 1998). When filial expectations are high, older adults may falsely assume that their family caregivers are aware of their needs, translating into inappropriate planning. This may partially explain a finding in a cross-national study that showed that high filial norms are related to lower life satisfaction among older persons (Lowenstein, Katz, & Gur-Yaish, 2007). Conversely, older

adults may feel obliged to plan because they do not want to burden their adult children with care decisions and responsibilities. Although filial obligation has been studied extensively, to date, subjective norms to engage in planning for family or nonfamily care have not been measured.

Social Norms, Public Policy, and Individual Action

In the past, care planning has not been publicly emphasized—and few older adults know how to go about it. A study commissioned by the GE Center for Financial Learning showed that only 7% of baby boomers had an “adequate” plan in place (Senior Citizens Information and News, 2001). Similarly, a survey of 983 American adults conducted by The Prudential Insurance Company found that 71% worry about needing long-term care, but 63% of respondents are unsure how they will afford the appropriate services (The Prudential Insurance Company of America, 2010).

Because of the increasing relevance of PFC, there have been some large-scale efforts to encourage more long-term care planning. “Own your future” was a recent six-state campaign to influence social pressure to plan and consider long-term care insurance and order a long-term care planning kit (Administration on Aging, 2009; Long Term Care Group, Inc., LifePlans, & McCay, 2006). The project involved state-based direct mail campaigns supported by each participating state’s governor, targeting households with members between the ages of 45 and 70 years. Campaign materials included a long-term care planning kit and state-specific information and resources. The point of this campaign was to change the social views on planning for future care; however, the effectiveness of these programs has been modest with regard to ordering the planning kit and obtaining long-term care insurance.

Public policies such as state-sponsored long-term planning campaigns often reflect larger cultural orientations regarding collectivism versus individualism. These, in turn, also influence individual beliefs about the necessity and usefulness of planning and concrete planning actions (Pinquart et al., 2003; Sörensen & Pinquart, 2000a). National long-term care policies differ in the extent to which they support and/or expect families to provide all, partial, or no care. For example, Germany’s more collectivistic national long-term care insurance policy provides funds to older adults to be used for formal or informal caregiving. In contrast, the individualistic approach to formal care in the United States relies heavily on family caregiving or on long-term care insurance policies, which are only accessible to individuals with sufficient wealth. For those with very limited income, long-term care is reliably covered by Medicaid, but immense stress is placed on individuals in the middle-income bracket. The result has been that individuals transfer their wealth and spend down their resources to be eligible for Medicaid, thus escalating Medicaid expenditures not originally designed for such a large population. Policies influence individual actions, which in turn influence the use of government resources.

A report on California’s Medi-Cal program suggests that elastic Medicaid eligibility rules “desensitize the public to long-term care risks and costs, resulting in a false sense of security and entitlement” (Moses, 2011, p. 9), and leading to a discussion about whether long-term care is a social “right,” or rather a personal responsibility that requires planning, saving,

investing, and insuring oneself (Moses, 2011). In response to similar trends in Hong Kong, some authors have advocated promoting filial piety as a way to minimize reliance on government support in eldercare (Cheung et al., 2006), thus applying cultural and social pressure for more family-based care planning. Based on the effect that national policies may have on the social norms for care planning, coordinating policy and media efforts with a clear agenda would at least clarify the need for effective PFC.

An important point to highlight is that the desired norms for planning promoted by programs and policies are primarily aimed at financial coverage of planning, not values clarification, and selection of preferences (R. A. Kane, 2001; R. L. Kane & R. A. Kane, 2001). This approach misses one of the main activating and motivating factors for PFC, which is to maintain current quality of life despite any health decrements. Without being able to communicate what constitutes quality of life for a particular individual (e.g., access to social contact vs. high levels of privacy; remaining in familiar surroundings vs. continued intellectual and social stimulation) and without assurance that one's values will guide care decisions, the acquisition of long-term care insurance may not have much relevance to middle-aged and older adults. Thus, guaranteed care without a focus on care values may not suffice to maintain quality of life for older adults. Not much social encouragement exists, however, for older adults to clarify the type of care they prefer and why.

Socioeconomic Factors

Perceived and internalized social norms are often considered the result of contextual factors. Another contextual factor is the socioeconomic position of the older adult. Income and education are associated with more preparatory behaviors (Black & Reynolds, 2008) and can offset the impact of age-related health vulnerabilities. For example, for German older adults with higher socioeconomic status, ADL deficits are related to more PFC (Sörensen & Pinquart, 2001b). In general, lack of financial and educational resources appears to play a major role in why individuals hesitate to plan because they lack awareness of options or the financial capability to afford them. The American Association of Retired Persons (AARP) reports that only a small minority of older adults understand how long-term care is covered financially (Matzek & Stum, 2010). Individuals with lower incomes, who are married, and without living children know even less about long-term care options and financing (Matzek & Stum, 2010). Furthermore, the private market for long-term care insurance is not very well developed in the United States, leaving many long-term care expenditures uncovered and excluding many individuals who cannot afford high premiums (Brown & Finkelstein, 2009). Older adults often desire to plan but feel unable to do so because available options are too costly. These situations are not ideal but some choose to move forward by making very general plans with the potential for future adjustments, if needed, or by developing several alternative plans for different possible future situations (Pinquart & Sörensen, 2002).

Attitudes and Beliefs

Attitudes relevant to PFC include the belief that care planning is useful and the expectation that care is likely. Older adults do not find planning useful and some expect to pass away without needing long-term care. These beliefs are clearly predictive of planning behaviors such as gathering information and concrete planning from the theoretical model of PFC

(Figure 6.1; Sörensen & Pinquart, 2000a). Attitudes are also a function of additional underlying external factors (Figure 6.2). These include beliefs about the outcomes of planning. “The more one believes that performing the behavior ... will lead to ‘good’ outcomes and prevent ‘bad’ outcomes, the more favorable one’s attitude toward performing the behavior will be” (Fishbein, 2008, p. 839). Translating this to the case of PFC, the attitude that “planning for *my own* future care is useful” follows from more general beliefs (“planning for care can prevent negative outcomes for older adults”). It should be noted that general beliefs about care planning may be influenced by life experience or social norms. In a cross-national study, for example, individuals who reached adulthood during regimes that left little room for personal choice and planning, such as older adults in East Germany, reported lower levels of the belief that planning for care is useful (Pinquart & Sörensen, 2002; Sörensen & Pinquart, 2000b).

Information Selectivity

Older adults remember positive features of selected options better than negative features (Mather & Carstensen, 2005), and pay more attention to positive versus negative information (Carstensen, 2006), with the goal of optimizing emotional experience and well-being (Blanchard-Fields, Jahnke, & Camp, 1995). Furthermore, older adults tend to avoid making decisions or seek less information than younger adults when making a decision (Mather, 2006). Engaging in behaviors that promote or protect health, however, requires an awareness of the risks for disease-related disability (Kleindorfer et al., 2009; Slovic, Finucane, Peters, & MacGregor, 2004; Wang et al., 2009). Realistic consideration of the chances of frailty or dependence is often unpleasant for older adults (Pinquart & Sörensen, 2002; Sörensen & Pinquart, 2000b) who tend to use more affective information to estimate the risks and benefits in decisions (Finucane, 2008). Therefore, because the feelings evoked by considering nursing home care, for example, are often negative, older adults tend to overestimate the risks (to well-being) of thinking about such care and underestimate its benefits; thus, they may attend more to information that contradicts their potential need for nursing home care, or they may avoid care decisions altogether.

Given that information seeking and decision making are core components of PFC, these findings would suggest that increasing age might hinder effective care planning. However, the immediacy of health threats and diminishing everyday abilities may overcome these barriers in older adults. Individuals are more likely to attend to and seek information about threats that are more salient. The salience is often determined by temporal proximity of the threat or by the amount of control that can be exerted over it (Ouwehand, de Ridder, & Bensing, 2008; e.g., being able to avoid loss of mobility through physical therapy vs. coping with a degenerative disease). In addition, because health maintenance is the foundation for pursuing other goals such as social relationships, it receives the most proactive attention among middle-aged and older adults (Ouwehand, de Ridder, & Bensing, 2006). In some contexts, increasing age may be associated with an increase in pressure to consider and plan for changing health-related needs, leading to positive associations of age and PFC (Sörensen & Pinquart, 2000a). These counterbalancing forces may explain the inconsistencies in the literature regarding the relationship of age to PFC.

Self-Efficacy, Problem-Solving Skills, and Personality

The belief that one is able to make effective plans, or planning self-efficacy, is important for PFC because people with greater self-efficacy respond to stress with better problem-solving strategies (Li & Yang, 2009). When potentially stressful situations seem more manageable, the likelihood of proactive coping is greater (Ouwehand et al., 2006). In pilot research, individuals with good problem-solving skills were more likely to consider and address potential future problems (Point Du Jour & Sörensen, 2009). In the context of problem-solving training, they learned how to reformulate previously vague goals into clearer, more specific goals that are realistically achievable through concrete behavior. For example, being able to break down the goal of “I want to stay independent” into “I want to live in my own house, regardless of my limitations, and obtain quality in-home care when I need it” allowed participants to gather pertinent information about inhome care options. In the face of low self-efficacy, the energy expended to make decisions can be less worthwhile for some older adults who would rather entrust family members with that responsibility (Funk, 2004).

Engagement in PFC may also be enhanced by more rational problem-solving styles and inhibited by dependent and avoidant decision styles (Sörensen & Pinquart, 2001a). These could be reflections of personality traits that may be more or less conducive to planning. In a study of primary care patients, higher neuroticism, openness, and agreeableness were associated with greater awareness of care needs; higher openness was also associated with more gathering information and less avoidance (Sörensen et al., 2008). Whether or not these relationships are further moderated by specific attitudes, measured skills or subjective norms has not been assessed.

Variation Across Behaviors

It is important to note that some health behaviors are driven more by attitudes or resources, whereas others are influenced mainly by normative factors, which in turn are related to cultural context (Fishbein, 2008). For example, buying long-term care insurance may not only be driven in large degree by positive attitudes and perceived control, but also financial resources, whereas normative pressure is a much less significant predictor. In contrast, normative pressure may be a stronger predictor of saving money “for a rainy day.”

PREPARATION FOR FUTURE CARE IN THE CONTEXT OF DEMENTIA

Unlike preparing for future care among older adults with other leading causes of illness and death in later life, those with dementia present a special set of circumstances to consider. Cognitive impairment limits a person’s ability to be actively involved in planning for care and the related transitions of care, especially as dementia severity worsens. The importance of addressing these issues is growing worldwide.

There are an estimated 35.6 million cases of dementia worldwide, a figure expected to double every 20 years (Ferri et al., 2009), and 5.4 million Americans are currently living with Alzheimer’s disease (Alzheimer’s Association, 2011). Care planning in the face of these statistics is increasingly relevant, although the current health care system in the United States does not sufficiently meet the needs of older adults with cognitive impairment (Naylor et al., 2007). Patients with cognitive impairment and their caregivers report that

managing transitions of care has raised three key areas of concern: working with multiple providers to manage care, illness management, and psychosocial support and coping (Naylor, Stephens, Bowles, & Bixby, 2005).

According to the PFC model, being aware of one's future needs is an essential part of successful care planning. People with dementia may have more difficulty with care planning because of deficits in memory, executive function, sensorimotor function, problem solving, and judgment (Alzheimer's Association, 2010, 2011). By definition, executive functioning includes planning and monitoring (Mack & Patterson, 1995), and deficits in this area disrupt goal formation, establishing plans, and plan implementation (Lezak, 1995), consequently making it difficult for persons living with dementia to accurately assess their own care needs and initiate care plans or discussions. Level of insight also depends on the type of dementia. For example, individuals with Alzheimer's disease typically retain insight longer than those with frontotemporal dementia (Salmon et al., 2008), although insight generally worsens as dementia severity increases (Graham, Kunik, Doody, & Snow, 2005). These limitations may restrict the level of involvement for people with dementia to a more reactive than proactive orientation.

In contrast to these rather sobering facts, research in the area of self-reported well-being shows that people with mild-to-moderate dementia provide reliable feedback when evaluating their "living situation," using the quality of life in Alzheimer's disease scale (Logsdon & Albert, 1999; Logsdon, Gibbons, McCurry, & Teri, 1999, 2002), suggesting the potential for active involvement in finalizing housing decisions or evaluating living situations after a transition. Research on possible selves in Alzheimer's disease (Cotrell & Hooker, 2005; Frazier, Cotrell, & Hooker, 2003) has found that people with mild-to-moderate dementia are able to verbalize "hoped for" and "feared" selves, indicative of social or health-related goals or preferences. Even when language abilities are compromised in the later stages of dementia, observational reports of well-being by trained staff (Lawton, Van Haitsma, & Klapper, 1996; Lawton, Van Haitsma, Perkinson, & Ruckdeschel, 1999) provide reliable feedback that could be used to inform care decisions.

Despite greater difficulty with planning for the older adult with dementia, PFC can be a critical aspect of effective dementia care, in the realm of both physical and mental/emotional needs of the patient. The Alzheimer's Association reported that people with dementia are more likely to require health care and long-term care services, accumulating costs that are on average three times more than those of nondemented counterparts (Alzheimer's Association, 2011). People with dementia are more likely to need assistance with activities of daily living (ADLs) such as getting dressed, bathing, or dealing with incontinence, all of which increase their chances of institutionalization (Alzheimer's Association, 2010). Although transitioning to nursing home care may be planned in some cases, a significant proportion of people with dementia are institutionalized, following acute care hospitalization (Cohen & Pushkar, 1999). In addition to the financial strain of long-term care, which eclipses other disease-related costs, relocation is one of the key transitions in the progression of dementia (Gaugler, Pearlin, Leitsch, & Davey, 2001) and may be difficult both for the person with dementia and their caregiver (Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Kelsey, Laditka, & Laditka, 2010).

In addition to health-related needs, people with dementia require meaningful activity to maintain their quality of life. With the progression of dementia, individuals are at risk for social isolation (Korczyn & Davidson, 1999; Miranda-Castillo, Woods, & Orrell, 2010). Thus, a good plan might include attending an adult day center with socially and cognitively stimulating activities (e.g., reminiscence, art, music), or other goal-driven activities that enhance feelings of purposefulness (Mak, 2011). In fact, adult day services have positive effects on patient and caregiver well-being (Gaugler & Zarit, 2001; Schmitt, Sands, Weiss, Dowling, & Covinsky, 2010). Thus, becoming aware of additional needs unique to dementia may provide families with a greater overall understanding of types of services they might need; help them identify caregivers, both informal and formal; and also estimate long-term cost.

How dementia is handled in the family context is also an important determinant of effective planning. Despite deficits in general planning abilities and awareness, people with dementia may still participate in care planning, given adequate verbal abilities. For example, in semi-structured interviews, people with mild-to-moderate dementia (Mini-Mental State Examination [MMSE] scores of 13–27) were able to make health care choices (Horton-Deutsch, Twigg, & Evans, 2007). In this study, participants integrated themes of “reliance on family,” “safety,” “resources,” “sense of normalcy,” and “function” among others to explain the logic of their decisions. Menne, Tucke, Whitlatch, and Feinberg (2008) reported that people with mild-to-moderate dementia (MMSE scores of 13–26), on average, were “fairly involved” in everyday decision-making tasks regarding housing, activity, finances, and medical care. In another study, people with mild-to-moderate dementia consistently reported their desire to not burden others and their preferences related to care assistance across 2 years (Piiparinen, True, & Whitlatch, 2008). Despite evidence that decision-making involvement is possible, people with dementia are often excluded from making decisions, potentially dampening their quality of life (Menne, Judge, & Whitlatch, 2009; Menne & Whitlatch, 2007). Choosing to be less involved with planning is sometimes the preference of the person with dementia (Funk, 2004; Whitlatch & Menne, 2009), but involvement of the care recipient does not necessarily correlate with dementia severity (Menne et al., 2008; Menne & Whitlatch, 2007). Instead, it varies with care recipient’s decision-making interest and the recognition of this interest by the caregiver (Whitlatch & Menne, 2009).

As dementia caregivers become increasingly involved in care recipient decision making, the nature of decision making changes for both the caregiver and the care recipient. In the early stages of the disease, when caregiver decision making and supervisory tasks increase (Adams, 2006), communication with the care recipient is typically preserved, which buffers caregiver burden (Savundranayagam, Hummert, & Montgomery, 2005). The notion of getting help is not pressing because the care demands still seem manageable. This is a good time for caregivers to learn about the disease, its treatment, care options, and other financial or legal matters (Carpenter et al., 2007).

In later stages of the disease, decision making may become the sole responsibility of the caregiver (Livingston et al., 2010; Silveira, Kim, & Langa, 2010). Caregivers typically make decisions based either on what they predict the care recipient would do, or what is in the best interest of the care recipient. The decision to institutionalize a care recipient is typically a

“last resort” (Ryan, 2002) and often causes feelings of guilt, sadness, anxiety, fear, loss of control, and general distress for the caregiver (Ryan, 2002; Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006).

CONCLUSIONS AND IMPLICATIONS

Decision making about transitions in care is enacted by individuals and their families in the context of differing needs and abilities, family subcultures, community resources, cultural expectations, and state or national policies. These may directly or indirectly influence older adults’ normative beliefs, outcome evaluations, and self-efficacy beliefs about PFC, leading to greater or lesser intentions for the enactment of PFC. We have seen that PFC can be very useful in the context of care transitions. However, both attitudinal and environmental barriers to PFC are strong, and it is necessary to identify those that are modifiable and amenable to intervention. Bypassing clear identification of relevant barriers to PFC may jeopardize the effectiveness of an intervention. For example, the Administration on Aging’s campaign, offering a long-term care planning kit, generated a response rate of less than 8% (Administration on Aging, 2009; Long Term Care Group, Inc., LifePlans, & McCay, 2006), and a free long-term care consultation had poor attendance (McGrew, 2006). In both cases, the intervention failed to address the appropriate barrier to planning, which resulted in relatively low turnout. Based on the current research on barriers to care planning, it is feasible to design and test interventions that target specific barriers, although further work is necessary to fully understand how to assist older adults to engage in care planning.

Practical Approaches to Enhancing Preparation for Future Care

Failure to prepare for future care is a potential risk marker for depression and anxiety, unnecessary hospitalization, and inadequate care. Human service professionals must recognize that PFC is multifaceted both in its structure and in its effects on mental health. Given the potential negative outcomes associated with the lack of care planning, it is necessary to activate older adults to make future care decisions and take concrete steps toward implementing them, even before long-term benefits of PFC emerge.

Several tools may be useful in this context. First, there are two short forms of the original PFC assessment instrument (Sörensen et al., 2011) that can help detect planning processes not yet attempted, without creating excessive burden for the client, patient, or research participant. Identifying where older adults fall on the continuum of PFC would allow for individualized interventions that target the specific barriers that are preventing them from progressing toward more advanced planning behaviors.

In addition, proposed guidelines for caseworkers to incorporate PFC concepts in the context of an individual interview are available (Pinquart, Sörensen, & Peak, 2004). After assessing an individual’s current level of PFC, for example, they may focus on identifying and overcoming potential barriers to planning, such as financial limitations, or lack of family support. They can then identify life goals, values, and care preferences; provide information about care options; and help structure the decision-making process (e.g., by generating and evaluating more than one solution or option). Finally, case workers could encourage the selection or serious consideration of the most feasible options, help the older adults identify

ways to make the plan work by recommending available personal and community resources, and evaluate whether the plan is effective (Pinquart et al., 2004).

To enhance PFC among older adults not receiving case management, we have developed a *preventive problem-solving training* (PPST) intervention, based on the original problem-solving therapy (PST) model (Areán et al., 2010; Mynors-Wallis, 1996; Mynors-Wallis, Gath, Lloyd-Thomas, & Tomlinson, 1995; Nezu & Perri, 1989). We are currently applying this training with older adults who have macular degeneration, a progressive eye condition that leads to increasing disability over time (Gottlieb, 2002; Rovner & Casten, 2002), and serious consequences for older adults' quality of life (Pinquart & Pfeiffer, 2011).

PPST takes into account that many older adults may have ceased using active problem-solving skills, especially ones involving brainstorming and generating a range of solutions. Our intervention first addresses participants' current problems. The training builds confidence in the notion that problems are a normal part of living and that they can be, at least, partially addressed through identifying clear behavioral goals and solutions. In addition to altering participants' attitudes about problems, the training enhances their problem-solving skills. Participants receive "homework" that requires them to take a concrete, or behavioral, step toward a chosen solution to the problem. This training is conducted for 4 weeks. Subsequently, the participants apply those skills to potential future problems for another 4 weeks (e.g., having sufficient privacy, not knowing where to live when vision is more impaired, not being able to get to where they want), which they have identified as most pressing or worrisome. We have demonstrated that 8 weeks of PPST was associated with increased problem-solving orientation and decision making about future care needs and decreases in avoidance of future care thoughts (Point Du Jour & Sörensen, 2009; Sörensen, Hegel, et al., 2008). These data provide evidence for the potential malleability of PFC.

Other programs have been developed to address future planning. A program named "In Anticipation of the Golden Years," based on the proactive coping model, relies on group meetings to enhance proactive competencies and improve participants' proactive orientation and behavior (Bode et al., 2006; Bode, de Ridder, Kuijer, & Bensing, 2007). Another intervention uses an individual, web-based, long-term care decisions tool that separates decision making into two steps: one for determining the best-suited type of long-term care for the individual and another to determine which potential providers of the desired services are best able to meet the individual's needs and preferences (Kane, Boston, & Chilvers, 2007). These approaches could be incorporated into existing employer-sponsored retirement preparation programs (Bayer, Bernheim, & Scholz, 2009) to attract a broader potential audience that needs to consider long-term care decisions and engage in PFC. Unfortunately, although boosting current problem-solving skills through these programs may enhance older adults' ability to consider future problems rationally and with less anxiety, it is often difficult to convince them of the necessity of this activity unless they are in a situation where future disability and need for assistance are unavoidable.

A major challenge in enhancing effective planning for and navigating of care transitions is, therefore, to learn at which point older adults are most receptive to receiving information

about future care needs and beginning the planning process. Without any intervention, an older adult's tendency to plan for the future may grow minimally across time (Mak & Sörensen, 2011). In our current research, individuals with progressive vision loss are often quite receptive to ideas about PFC because they can anticipate loss of independence. Similarly, a newly published program using PFC principles and measures to support planning in people who have recently taken on the caregiver role (Ducharme et al., 2011) is perhaps effective, in part, because it is well-matched in timing to the transition.

Recommendations for Planning in Dementia

In 2011, the financial costs of caring for those with Alzheimer's disease will total an estimated \$183 billion (Alzheimer's Association, 2011), not including the human and opportunity costs of burnout, physical overexertion, and emotional stress among caregivers. With the annual number of new dementia cases expected to double by 2050, the importance of planning and decision making for maintaining a good quality of life, both for those with the disease and their caregivers, is becoming ever more pressing. As mentioned earlier, cognitive impairment can be a serious barrier to effective planning, but it does not preclude identification of preferences and finding good long-term care solutions.

Thus far, there are no established guidelines for determining the decisional capacity of a person with dementia. Some have recommended that the planning process should be tailored to the specific decisions to be made (Whitlatch & Menne, 2009). Gauging decision-making abilities solely based on cognitive testing may not be reliable because decisions are not always rational and may depend on other factors such as emotions or quality of life (Braun, Gurrera, Karel, Armesto, & Moye, 2009). Alternatively, a semistructured approach to assessing decisional capacity based on probing for understanding and reasoning behind choices (Lai et al., 2008; Lai & Karlawish, 2007) may be a fruitful way of gauging decisional capacity for specific issues. In addition to decisional capacity, Naik, Dyer, Kunik, and McCullough (2009) recommend that executive capacity, or the ability to comply with medical treatment plans, is considered in care planning to identify areas in which the person with dementia might need assistance.

Planning for future care would be most effective when dementia severity is mild to increase the chances for good communication of preferences for care from the person with dementia to the caregiver. A good place to start is to keep the person with dementia involved with everyday decision making. Greater involvement of care recipients in decision making is associated with greater quality of life in the care recipients and caregivers, in addition to less depression and negative relationship strain for caregivers (Menne et al., 2008). To assess what types of care plans their family members with dementia might want, families should have detailed discussions about care preferences, housing preferences, and advance directives. Although concrete plans may be hard to establish because of the uncertainty surrounding when a person with dementia will experience significant cognitive or functional impairment, planning discussions may promote awareness of needs through the understanding of care recipients' preferences by their caregivers. Effective communication of these preferences will be especially useful in the case of surrogate decision making. The recommendation for surrogate decision making is to use "substituted judgment" or deciding

as the care recipient would decide, whenever possible, before resorting to decisions based on the best interest of the care recipient (Buchanan & Brock, 1990).

Understanding care preferences of the person with dementia would also provide a basis for families to gather the appropriate information about potential future care needs such as in-home services, assisted living facilities, or nursing homes to make tentative choices and plan for cost. Consulting a doctor or health care professional may aid resolution of decisional conflicts (Allen, Allen, Hilgeman, & DeCoster, 2008), and lessen the psychological distress associated with the decision to institutionalize (Reed & Morgan, 1999). For both the caregiver and the care recipient, joining a support group may alleviate psychological distress associated with caregiving or coping with dementia, respectively. A support group is a good place to find information about care services, hear about other people's experiences, and learn how to make informed decisions and concrete plans. Care planning may involve the needs and preferences of entire families. Emphasis, however, should be placed on the needs and preferences of the main caregiver and care recipient because of the highly interdependent nature of the relationship (Whitlatch & Menne, 2009).

FUTURE DIRECTIONS

Although evidence now exists that PFC is protective regarding subsequent depression, randomized controlled trials with longitudinal assessments will need to ascertain whether early coaching in future care planning can prevent loss of functioning over time, as well as reduce the incidence of depression specifically after residential transitions. Future studies should identify combinations of health conditions associated with greater probability for changes in health status to identify groups at greatest need for planning (Lafortune, Béland, Bergman, & Ankri, 2009). Other important topics of future inquiry include identifying the ideal timing of PFC initiation—whether it should occur at a particular age, or when early changes in health and disability surface—and how often plans should be reevaluated and updated, similar to the recommendations for advance care planning.

To develop better interventions, studies should aim for a better understanding of how the individual components of PFC contribute and interact in preventing distress and facilitating positive adjustment. Also, further studies should explore whether stronger action planning steps, or training in use of life span control strategies, would be as helpful in activating older adults to engage in PFC because they are for precipitating exercise (Ziegelmann & Lippke, 2007) and other health behaviors. Additional research should focus on different domains of long-term care planning (e.g., health, financial, living situation, social needs; Friedemann, Newman, Seff, & Dunlop, 2004) and planning in various geographic and cultural settings.

In summary, the latter third of life encompasses many transitions based on changing health and functional needs. Older adults, who are aware of the potential changes that lie ahead, what realistic options they have for coping with them, and how to go about identifying and communicating their preferences may increase the chances of successfully navigating through potentially difficult life transitions.

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FIGURE 6.1.
Theoretical model of preparation for future care.
Note. LTC = long-term care.

FIGURE 6.2.

Preparation for future care as explained by the integrated model of behavioral prediction.

Note. LTCI = long-term care insurance; PFC = preparation for future care.