

Stress Process Model for Individuals With Dementia

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Purpose: Individuals with dementia (IWDs) face particular challenges in managing and coping with their illness. The experience of dementia may be affected by the etiology, stage, and severity of symptoms, preexisting and related chronic conditions, and available informal and formal supportive services. Although several studies have examined particular features of IWD's illness experience, few draw upon a conceptual model that outlines the global illness experience and the resulting stressors that commence with symptom onset, proliferate over time, and continue through the later stages of cognitive loss. Building on the work of Pearlin and colleagues (1990, *Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist*, 30, 583–594), this article proposes a stress process model (SPM) for IWDs that conceptualizes and examines the illness experience of IWDs. **Implications:** The proposed SPM for IWDs serves as a guide to (a) consider and understand the short- and long-term complexities of the illness experience for IWDs, (b) investigate specific hypotheses by outlining key stressors in the illness experience and by positing relationships among stressors and outcomes, and (c) help inform the development of interventions to prevent or reduce the negative stressors and

enhance the positive experiences of living with a dementing illness.

Key Words: *Dementia, Stress and coping, Theoretical model*

Over the past 20 years, a growing body of research has emerged which calls attention to the personhood of individuals with dementia (IWDs). Work by Downs (1997), Kitwood (1990), and Woods (2001) emphasizes that the experience for IWDs is a product of the individual's personality, biography, physical health, neurological impairment, and social psychology. Building from this and anecdotal evidence (McGowin, 1993), researchers and practitioners have advocated for maintaining the "individual" in "individual with dementia" (Cotrell & Schulz, 1993; Downs) and, in turn, are learning more about the unique factors and complex issues facing IWDs.

As part of the movement to focus on the individual, several lines of research have emerged, which investigate the multiple stressors associated with the experience of living with dementia. Drawing from a variety of perspectives and methodologies, these studies have investigated (a) the impact of psychosocial interventions on dementia symptoms (Camp, 1989; Judge, Camp, & Orsulic-Jeras, 2000) and (b) how IWDs make meaning of and cope with their illness (Clare, Goater, & Woods, 2006; Preston, Marshall, & Bucks, 2007). For example, a range of intervention programs have

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examined how to improve or ameliorate cognitive symptoms (Camp), facilitate engagement and independence (Josephsson, Baechman, Borell, & Nygard, 1995; Judge et al., 2000), manage difficult behaviors and symptoms (Beck et al., 2002; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001), and utilize informal and formal supportive services (Bass, Clark, Looman, McCarthy, & Eckert, 2003). Whether targeted directly at the IWD or indirectly through a family caregiver, these studies demonstrate that intervention programs can have a positive impact on a wide range of stressors associated with a dementing illness.

Although there is a growing emphasis on the personhood of IWDs, many studies to date have relied on caregiver or other proxy reports to understand the experiences of IWDs (e.g., Albert et al., 2001; Cotrell & Lein, 1993; Kerner, Patterson, Grant, & Kaplan, 1998). To gain a more subjective assessment of the experience of IWDs, researchers are increasingly including IWDs as active participants in the research process. These research studies have examined (a) the process by which IWDs make sense of their illness (Preston et al., 2007), (b) how IWDs manage their sense of self (Pearce, Clare, & Pistrang, 2002), and (c) the difficulties and coping strategies identified by IWDs (Clare, Roth, & Pratt, 2005; Clare et al., 2006). Additionally, research suggests that IWDs can consistently and accurately report information about their illness experience (Feinberg & Whitlatch, 2002; Squillace, Mahoney, Loughlin, Simon-Rusinowitz, & Desmond, 2002; Whitlatch, Feinberg, & Tucke, 2005). Self-reported information provides a qualitatively different source of data that are invaluable to understanding the experience of living with dementia. Likewise, informant-based and observational methods may be useful when IWDs are no longer able to communicate in the later stages of the illness or are unaware of their symptoms. In general, findings from IWD-focused studies underscore the importance of examining the range of biopsychosocial stressors associated with a dementing illness.

Despite promising advances in research, few studies draw upon a comprehensive theoretical model that outlines the illness experience as it unfolds over time and the multifaceted relationships among stressors associated with living with dementia. Without a well-defined model, we are left with a limited understanding of the illness experience and the complex associations among stressors that accompany illness-related changes. A theoretically

based comprehensive model would provide the foundation from which researchers and practitioners could describe and systematically investigate from the onset through the later stages of the illness: (a) the conception, proliferation, and interaction of stressors and outcomes experienced by IWDs, (b) the process by which IWDs manage and cope with their illness experience, and (c) the areas of stress amenable to targeted intervention protocols. This article proposes a conceptual model for studying the illness experience of IWDs from early to later stages. The model draws upon the conceptualization of the stress process of family caregivers (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990) and the subsequent application of the stress process to the experience of IWDs (Menne, Judge, & Whitlatch, 2009; Menne & Whitlatch, 2007). The application of the stress process to the experience of IWDs used multivariate ordinary least squares regression analysis (Menne et al., 2009) and hierarchical multiple regression analysis (Menne & Whitlatch) to examine how specific domains of the adapted stress process model (SPM) were related to one another and predicted key outcomes.

Stress Process Model for IWDs

The SPM has been widely used in research examining stress and coping for family caregivers of IWDs (Aneshensel et al., 1995; Gaugler et al., 2000; Pearlin et al., 1990). The proposed adaptation of the SPM (heretofore referred to as the stress process model for individuals with dementia [SPM for IWDs]) focuses solely on the stress and well-being of IWDs (see Figure 1). For this model, stressors refer to the negative symptoms of a dementing illness and the resulting strains and psychosocial effects. The domains of the SPM for IWDs represent broad theoretical concepts: (a) Background and Context Characteristics, (b) Objective and Subjective Primary Stressors, (c) Role and Intrapsychic Secondary Strains, (d) Internal and External Mediators, and (e) Outcomes of Well-being.

The SPM for IWDs is a framework for understanding the illness experience from onset to the later stages for IWDs. As such, it is important to take into account IWD's cognitive impairment and level of awareness of their own cognitive processes (e.g., meta-cognition, anosognosia) in discussing the objective and subjective aspects of their illness. Consequently, in the end stages of dementia or when IWDs are not able to communicate

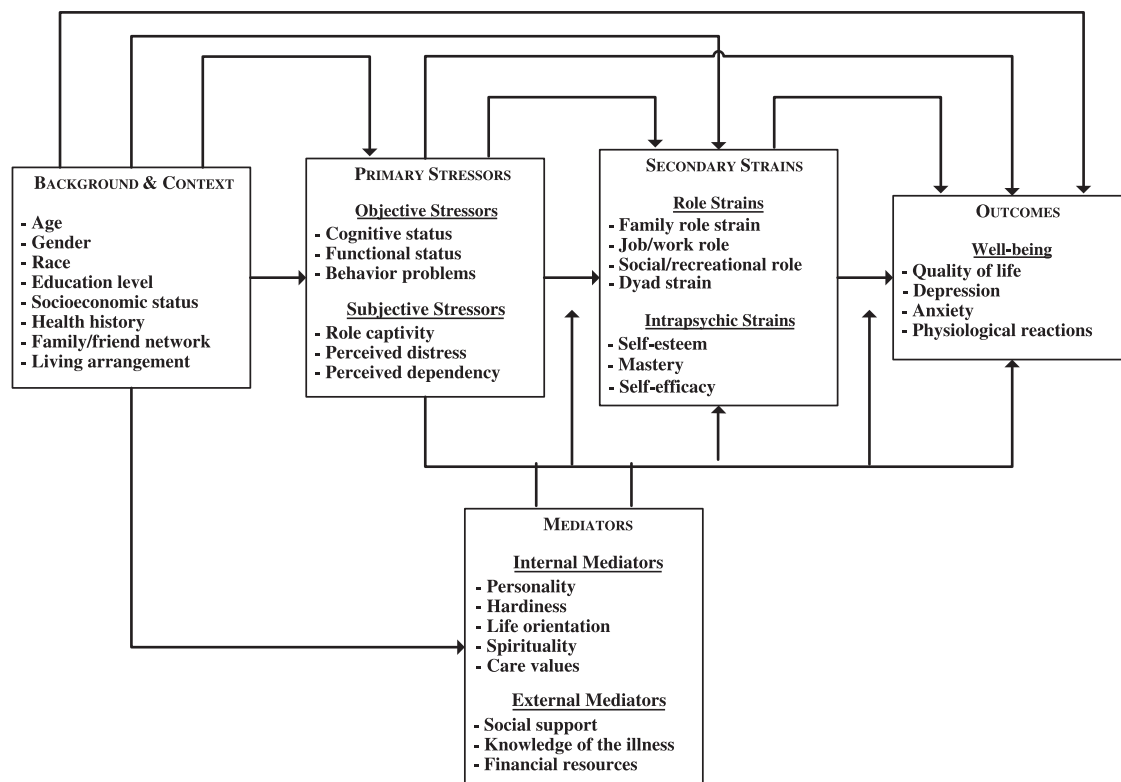


Figure 1. Stress process model for individuals with dementia.

(e.g., aphasia) and/or discuss their illness (e.g., denial, anosognosia), gathering information from additional sources (i.e., medical records, observation, family members, primary caregiver, and/or nursing assistants) may be necessary to understand IWDs' illness experiences.

The main postulate of the model is that "primary stressors," which are characteristics of IWDs' impairment and symptoms of dementia, have an impact on "secondary strains," which, in turn, can have direct and indirect effects on "outcomes of well-being." Similar to Pearlin and colleagues (1990) original SPM, the SPM for IWDs includes "internal and external mediators," which may buffer the relationships among primary stressors, secondary strains, and outcomes of well-being. The SPM for IWDs also provides a framework for including interventions as internal and external mediators that may offset the negative effects of the stress process while enhancing the IWD's care situation. For example, an intervention targeted at enhancing communication between an IWD and his or her caregiver could lead to decreased relationship strain (i.e., secondary strain) experienced by the IWD and improved quality of life (i.e., outcome of well-being). In the following pages, we describe each domain of the SPM for IWDs, including the constructs that characterize each domain and,

where applicable, examples of potential measures that correspond to each construct. Proposed measures reflect a variety of data collection methods that include self-report, direct assessment, observation, adapted versions of caregiver measures, and proxy reports. Utilizing a multi-method approach is essential as it enables researchers and clinicians to gather information regardless of IWDs' level of impairment and stage of illness. For example, in the early stages, self-report measures would be useful in capturing the illness experience of IWDs, whereas in the later stages of the illness, observational and informant-based measures would be more appropriate. Whether using the model in the early or later stages, the SPM for IWDs provides a comprehensive framework for examining the stress process of IWDs.

Background and Context Characteristics

The SPM for IWDs accounts for each individual's life circumstance in the form of background and context characteristics. These characteristics are lifelong attributes of the individual that may impact the illness experience (e.g., gender, race), whereas at the same time, these characteristics describe the individual's current environment and circumstances in which the illness is being experienced

(e.g., health history, living arrangement, family and/or friend network). Prior research has found racial disparities in the trajectory of cognitive impairment (Sloan & Wang, 2005), which may result in different illness experiences for IWDs (Shaw & Krause, 2001). Physical and mental health history can differentially affect the illness experience of older adults coping with multiple chronic illnesses (Kahana, et al., 2004). For example, persons with diabetes or individuals with long-standing mental health conditions who then develop dementia will face different challenges as they cope with these comorbid conditions, such as managing complex medication schedules. Background and context, therefore, provide an understanding for the fixed and dynamic characteristics that individuals bring to their experience of living with dementia and provide a larger backdrop for understanding the stress process.

Objective and Subjective Primary Stressors

The SPM for IWDs focuses on the stressors that emerge solely from the experience of living with dementia. These are the experiences and related reactions that threaten, thwart, or encumber individuals (Pearlin et al., 1990). These stressors account for the amount and type of impairment experienced by an individual (i.e., objective) and the potential distress that results (i.e., subjective). Objective primary stressors are the type and severity of primary dementia symptoms, including etiology, cognitive impairment (e.g., short-term memory, language, executive functioning), functional ability (e.g., household tasks, bathing, grooming), and behavioral issues (e.g., appetite, sleep–wake cycle, agitation). Objective primary stressors are the starting point for the stress process, the point from which the entire process unfolds (Aneshensel et al., 1995). For example, research suggests that IWDs with greater functional impairment report lower levels of quality of life (Logsdon, Gibbons, McCurry, & Teri, 2002), which reflects the link between an objective primary stressor and an outcome of well-being. These objective primary stressors can be measured using standardized assessments of an individual's cognitive and functional status, such as the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) for cognitive status and the Direct Assessment of Functional Status (Lowenstein & Bates, 1992) for functional status. Behavioral symptoms of dementia are typically measured using proxy

reports from informal or formal caregivers. However, many of these instruments could be modified and adapted as self-report measures, thereby enabling IWDs to discuss changes in their behavior (e.g., appetite, sleep–wake cycle, agitation). The Revised Memory Behavior Problems Checklist (Teri et al., 1992) could be adapted for use by IWDs as a self-report measure for assessing memory and behavioral concerns. For example, IWDs could respond to questions that have either dichotomous (*yes* or *no*) or Likert response categories (i.e., *once in a while* to *all of the time*) which assess the occurrence over the past week of a variety of memory and behavioral challenges (e.g., trouble remembering recent events).

Subjective primary stressors are the psychological and emotional consequences experienced by the IWD as a result of the cognitive, functional, and behavioral aspects of the dementia. These stressors can have both indirect and direct effects on subsequent secondary strains and outcomes of well-being. Differentiating between objective and subjective primary stressors is important for understanding how an IWD's perception and appraisal may change over time and thus impact other domains in the SPM for IWDs. For example, IWDs who have the identical cognitive and functional profiles may react differently to these impairments resulting in varying levels of subjective distress (i.e., subjective primary stressor). Distinguishing between objective and subjective stressors also applies to illness-related changes in an IWD's behaviors and emotions. An IWD experiencing more episodes of agitation (i.e., objective primary stressor) may perceive and appraise this as very distressing (i.e., subjective primary stressor), whereas an IWD experiencing changes in his or her sleep–wake cycle (i.e., objective primary stressor) may not perceive or appraise this as distressing (i.e., subjective primary stressor). By distinguishing between objective and subjective stressors, we gain a better understanding of how IWDs perceive changes in their own behaviors and emotions and how these changes contribute to the stress process.

Measures that assess an individual's subjective perception of the illness include the psychological and emotional distress experienced due to one's memory loss and ability to manage personal and instrumental activities of daily living (Bass, McClendon, Deimling, & Mukherjee, 1994; Golden, Teresi, & Gurland, 1984). Another strategy for gaining information about the illness experience of IWDs is to adapt measures typically used with

caregivers. Examples of adapted measures include a version of Pearlin and colleagues' (1990) role captivity scale that assesses an IWD's feeling of isolation and being trapped as a result of their dementia symptoms (Judge, 2008) and a scale that assesses the physical and emotional health strain that results from living with dementia (adapted from Bass, Noelker, & Rechlin, 1996).

Role and Intrapsychic Secondary Strains

The stress process is driven by the primary stressors of the illness, which, in turn, lead to additional sources of stress in the form of secondary strains. These secondary strains are not secondary in importance (Pearlin et al., 1990) but are considered secondary because they occur as a direct result of living with dementia. Secondary strains include the life roles that are affected by living with dementia. These roles can include family roles, professional or work roles, and social or recreational roles. IWDs may even experience strains in their role and relationship with their caregiver (Lyons, Zarit, Sayer, & Whitlatch, 2002). Secondary role strains can be assessed by measures of family conflict (Aneshensel et al., 1995; Semple, 1992) and the dyad's relationship (Sebern & Whitlatch, 2007).

Secondary strains also manifest in the internal self-perceptions and feelings (i.e., intrapsychic), which result from living with dementia, such as self-esteem, mastery and gain, loss of self, and self-efficacy. As described by Pearlin and colleagues (1990), intrapsychic strains can be further conceptualized as global or situational (this level of detail is not depicted in Figure 1). Global strains reflect internal characteristics of individuals that are relatively permanent and durable, such as self-esteem (Rosenberg, 1965) and mastery (Pearlin & Schooler, 1978). Conversely, situational intrapsychic strains are less enduring and vary depending on the context of a person's experience, such as self-efficacy for maintaining activities or relationships (e.g., self-care tasks, social activities, personal relationships).

Internal and External Mediators

Mediators "govern (or mediate) the effects of stressors on stress outcomes" (Pearlin, 1989, pp. 249–250) and are coping mechanisms that play a significant role in how IWDs manage the illness experience. Mediators vary in intensity, account for potential coping mechanisms that can have an

indirect or direct impact on other domains of the stress process, and are extremely important for understanding how interventions can enhance IWDs' illness experience. Two types of mediators are identified for the SPM for IWDs: internal and external. Internal mediators originate from within an individual, are enduring individual characteristics that reflect lifelong patterns of coping and adaptation, and can help explain how individuals approach challenges (McCrae & Costa, 1986; Taylor & Chatters, 1988). Examples of internal mediators include personality, resilience, and life orientation. Although some IWDs may experience illness-related changes in their personality, we have included "personality characteristics" as an internal mediator as it has been shown to be an integral component of coping, especially for individuals with chronic illnesses (Taylor, 2009). Examples of measures of personality characteristics include the subscales "conscientiousness" and "neuroticism" of the NEO Personality Inventory (Costa & McCrae, 1992) and 'sense of control' (Lachman & Weaver, 1998). Spirituality is considered an internal mediator based on evidence that individuals may call upon spiritual resources to manage the stressful experience of chronic illness (Daaleman, Cobb, & Frey, 2001). The importance that individuals place on care-related values, such as maintaining independence and not being a burden (Feinberg & Whitlatch, 2002; Whitlatch et al., 2005, 2009), is also considered an internal mediator. These "care values" span topics related to autonomy, safety, and social interactions. By understanding and respecting the care values of IWDs, we expect to have a positive impact on the illness experience. External mediators are coping resources that stem from a person's environment and therefore do not originate from within the individual. Examples of external resources include the amount and types of available informal and formal support, knowledge about the illness, and financial assets. For example, IWDs' utilization of available informal and formal social supports may strengthen their ability to manage functional losses (i.e., primary stressors) and relationships (i.e., secondary strains) and the subsequent effects on outcomes of well-being.

Outcomes of Well-being

The conceptualization of the SPM for IWDs provides for a broad array of outcomes related to well-being (e.g., quality of life, depression). Outcomes of well-being are the net result of the

complex interaction among the SPM domains (i.e., background and context, primary stressors, secondary strains, and mediators) and are indicators of an IWD's overall emotional, psychological, and physical well-being. For example, the SPM for IWDs could be used to illustrate how symptoms of depression may be affected by a combination of an IWD's cognitive and functional impairments (i.e., objective primary stressors), perceived distress (i.e., subjective primary stressor), and dyadic relationship strain (i.e., role secondary strain). This example highlights (a) the interaction among multiple stressors, (b) how stressors jointly affect well-being outcomes, and (c) how the SPM for IWDs provides a systematic method and context for examining complex associations. In addition to depression (Radloff, 1977), other measurable outcomes of well-being include anxiety (Zung, 1971), quality of life (Logsdon, Gibbons, McCurry, & Teri, 2002), and physiological reactions to stress (de Vugt et al, 2005).

Using the SPM for IWDs in Research and Interventions

The proposed SPM for IWDs serves as a useful heuristic for understanding the illness experience of IWDs. This model can be used for (a) developing and evaluating interventions designed to ameliorate stress and (b) testing specific research hypotheses. To date, few research studies and intervention protocols have drawn upon the SPM for IWDs as a theoretical base, although exceptions exist. Our research team has used the model to examine (a) the relationship among an IWD's background characteristics and the dyadic relationship strain (i.e., intrapsychic strain) experienced by IWDs and their caregivers (Menne, Johnson, & Whitlatch, 2008) and (b) the domains and specific constructs of the stress process that influence the quality of life of IWDs (Menne et al., 2009). These examples reflect the utility and application of the proposed model for gaining a more in-depth understanding of the stress process within the context of living with dementia.

Two unique intervention studies have drawn on the SPM for IWDs for developing protocols and for testing the effects of the interventions for IWDs. The first intervention, *Acquiring New Skills While Enhancing Remaining Strengths* (ANSWERS; Judge, Yarry, & Orsulic-Jeras, 2009; Yarry, Judge, & Orsulic-Jeras, in press), investigated the effects of a six-session cognitive rehabilitation and educa-

tional program for IWDs and their family caregivers. These caregiving dyads were taught a core set of skills related to effective communication, managing memory, staying active, and recognizing emotions and behaviors. Findings indicated that IWDs and their family caregivers found the ANSWERS program highly acceptable and feasible (Judge et al., 2009). Compared with control group participants, IWDs who participated in ANSWERS reported less distress in managing personal activities of daily living (i.e., subjective primary stressor), decreased relationship strain with their primary caregiver (i.e., role strain), and fewer symptoms of anxiety (i.e., well-being outcome; Judge, 2008).

A second intervention that fits within the proposed model is the *Early Diagnosis Dyadic Intervention* (EDDI; Whitlatch, Judge, Zarit, & Femia, 2006), which provided information and techniques for alleviating stress associated with dementia for both care partners. Trained clinicians worked with the IWD and family caregiver to help them understand dementia; discuss their preferences for care; and resolve conflicts about autonomy, social interactions, and quality of care. Clinicians worked to enhance everyday decision making for both care partners. These strategies were designed to reduce negative outcomes (e.g., depression and negative mood) and enhance positive outcomes (e.g., quality of life). Preliminary findings suggest that the EDDI program is acceptable and feasible (Whitlatch et al., 2006) and leads to positive outcomes for both care partners (Whitlatch, 2007). The ANSWERS and EDDI interventions illustrate how the SPM for IWDs can guide the development of strategies to ameliorate the negative effects of living with the early to moderate symptoms of dementia.

Conclusions

Improved diagnostic techniques have led to an increase in the number of individuals who are being diagnosed with dementia early in the disease process. In addition, significant medical advances are helping individuals live longer with their symptoms. As a result, IWDs are seeking assistance earlier in the disease process making it imperative that practitioners and researchers understand the stressors and care needs of IWDs at all stages of the illness. To date, the literature has identified important aspects of the dementia experience (Downs, 1997; Kitwood, 1990). However, there lacks a

comprehensive theoretical model focused on the experience of living with dementia. The proposed SPM for IWDs extends prior research with family caregivers to the illness experience of IWDs.

Rather than examining a single stressor in isolation, the SPM for IWDs is a guide for studying the myriad paths through which primary stressors, secondary strains, and mediators can have an influence on well-being outcomes and provides an overarching context for more fully examining and understanding the illness experience of IWDs. The model can be used to examine the effect of background and context characteristics on stressors and the manner in which stressors change over time as the illness progresses or as a result of a targeted intervention. Practitioners who work with IWDs may find the model as a useful heuristic for conceptualizing the illness experience, developing treatment goals, and adapting therapeutic techniques. For example, practitioners who understand the role of context characteristics (e.g., living arrangement, health history) can modify treatment goals for IWDs who live alone and/or who are managing other complex illnesses.

It is expected that the SPM for IWDs will continue to be a “work in progress” as new research and practices involving IWDs evolve. Thus, we do not suggest that the SPM for IWDs is exhaustive in its current form but rather a starting point to promote discussion, debate, and theoretical discourse. Moreover, we do not suggest that living with dementia is solely a linear experience. Rather, our model can be used to shape complex longitudinal analyses that account for the recursive, reciprocal, and interaction effects among the model components.

In turn, we hope that with further refinement, the SPM for IWDs will address important yet understudied areas of research. Measures adapted from the caregiving literature (e.g., perceived distress, symptoms of depression and anxiety) have demonstrated good reliability and validity when used to examine the illness experience of IWDs (Clark, Bass, Looman, McCarthy, & Eckert, 2004; Judge, 2008). Future research is needed to confirm the reliability and validity of these adapted measures as well as to develop additional measures that assess the illness experience. Therefore, developing measures that appropriately and adequately represent the domains of the SPM for IWDs is a critical step in further understanding the illness experience of IWDs. Empirical inquiry is needed to determine which methods are best suited for collecting information about IWDs’

illness experience. For example, research can help to establish benchmarks for when IWDs are no longer able to provide reliable self-report information about the objective aspects (e.g., cognitive and functional status) and the subjective experience (e.g., emotional distress, loss of self) of their illness. In addition, data collection procedures need to accommodate the cognitive difficulties experienced by IWDs. Specific strategies for developing understandable and user-friendly questions and response categories include: simplified language, dichotomous response categories, choice cards with large font sizes on high-contrast backgrounds, and short breaks to decrease the likelihood of fatigue.

Finally, although we present this conceptual model with the intention of providing a structure for researchers and practitioners to study the illness experience of IWDs, we also hope this framework, in a more simplified form, can help families and IWDs to understand the changing circumstances of their lives. Likewise, although the experience of living with dementia is distinctly affected by unique aspects of the illness (e.g., changes in memory, personality, behavior), the constructs of the model are applicable to the experiences of individuals living with chronic or terminal nondementia conditions (e.g., multiple sclerosis, AIDS, rheumatoid arthritis). For example, the severity of symptoms and resulting distress (i.e., primary stressors) associated with many progressive chronic conditions may negatively effect one’s relationships and sense of self (i.e., secondary strains) while also compromising quality of life (i.e., outcomes of well-being).

Our past work (Judge et al., 2009; Menne et al., 2008; Whitlatch et al., 2006) suggests that the model has utility in both research and practice settings, including interventions with IWDs and their family caregivers. Yet, as with the original SPM presented by Pearlin and colleagues (1990), our adapted version for IWDs is best viewed as “something to be built upon rather than something to be followed or perpetuated” (p. 591). We have much to learn from IWDs about their experiences living with dementia and hope this model can provide the structure for systematically investigating and supporting this experience.

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