

Rewriting the Story of Mid- and Late-Life Family Caregiving: Applying a Narrative Identity Framework

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Abstract

Family caregivers of older people with health needs often provide long-term, intensive support. Caregivers are, in turn, shaped by these caregiving experiences. According to the *narrative identity* framework, self-narratives from lived experiences influence self-beliefs and behaviors. We assert that family caregiving experiences, filtered through individuals' memory systems as self-narratives, provide substantial scaffolding for navigating novel challenges in late life. Self-narratives from caregiving can guide positive self-beliefs and behaviors, leading to constructive health-focused outcomes, but they also have the potential to guide negative self-beliefs or behaviors, causing adverse consequences for navigating late-life health. We advocate for incorporating the narrative identity framework into existing caregiving stress models and for new programs of research that examine central mechanisms by which caregiving self-narratives guide self-beliefs and behavioral outcomes. To provide a foundation for this research, we outline 3 domains in which caregiving self-narratives may substantially influence health-related outcomes. This article concludes with recommendations for supporting family caregivers moving forward, highlighting *narrative therapy* interventions as innovative options for reducing the negative consequences of maladaptive caregiving self-narratives.

Keywords: Aging, Caregiver preparedness, Health planning, Reminiscence, Values clarification

Caregiving ... may well be one of the most important passages of your life. How you handle this crisis will shape how you feel about yourself and almost certainly change you in ways that follow you to the end of your days.

—Gail Sheeny, *Passages in Caregiving*

Family caregiving is a fundamental pillar of the care delivery system in the United States and beyond (Schulz et al., 2020). Recognizing the critical contributions of family caregivers, the bulk of research examines caregiving as a series of experiences spanning a care recipient's illness and end of life, with a focus on optimizing caregivers' contributions while minimizing the negative consequences of stress (Gaugler, 2022). We call for a complementary focus where we not only examine what caregivers contribute to care, but also what they may derive psychosocially from caregiving. In this Forum article, we provide a new direction for the study of family caregiving, extending existing stress-process models with a narrative identity framework. Using health-focused example domains, we describe how constructive self-narratives from caregiving may guide productive self-beliefs or behaviors, whereas non-

functional self-narratives may promote harmful self-beliefs or behaviors. We advocate for research that establishes attributes of self-narratives as mechanisms guiding self-beliefs and behaviors in caregivers, and we present illustrative, measurable mechanisms and outcomes. We conclude by encouraging the testing of narrative-based interventions to promote healthy aging outcomes in family caregivers.

As described by the National Alliance for Caregiving and the AARP (2020), most family caregivers are mid-life or older adults; the average age of America's family caregivers is around 50. Care of older family members (e.g., parents, spouses, siblings) experiencing chronic, progressive illness (e.g., cancer, heart failure, Alzheimer's disease) is increasingly common and relatively intense. As such, this article primarily addresses the experiences of middle-aged and older-adult caregivers who provide regular support to care recipients who are older family members or close others with chronic, progressive illnesses. We recognize that most caregiver-care recipient relationships involve some degree of mutuality, including bidirectional exchange of support (Park & Schumacher, 2014); we use the term "care recipient" throughout to refer to the individual in the dyad in need of consistent support to maintain health and functioning.

The Narrative Identity Framework: Overview and Application to Family Caregiving

Across adulthood, individuals construct a *narrative identity* (McAdams, 1993) comprising self-narratives that are woven together with self-characteristics (e.g., gender identity, cultural background), contextual, and social factors. They reflect what we feel our life has looked like in the past, what it is in the present, and what it could be in the future (Dunlop & Walker, 2013). Middle-aged and older adults draw on self-narratives to substantiate self-assessment (Sharma & Bluck, 2022) and maintain well-being (Mroz et al., 2022b). Narrative researchers describe a “directive function,” arguing that self-narratives direct our beliefs and behaviors (Bluck et al., 2019), helping us decide how to act in novel situations. This directive function is synergistic with Lazarus and Folkman’s (1984) model of stress and coping. Although challenging events can cause automatic emotional or behavioral responses, their impacts on psychological or behavioral outcomes over time are dictated by the ways the original events are appraised (i.e., a conscious process described by Lazarus and Folkman) or integrated (i.e., a process that involves conscious and unconscious weaving together of event details and other aspects of one’s narrative identity). Imagine, for example, a middle-aged man who previously became lost on a hike. While in an outdoor gear store, he remembers his feeling of panic and confusion as he decides to purchase a guidebook before his next hike. In many cases, self-narratives, as interpretations of our pasts, guide outcomes: a different man could recall a similar hiking experience as thrilling, rather than frightening, and decide there was no need to buy a guidebook for a next hike.

Narratives have been used across many disciplines to understand the impacts of events on self-belief and behavioral outcomes. As one example, when individuals are reminded of their own or others’ mortality (e.g., through a terminal diagnosis or the death of a loved one), terror management theory suggests that they are compelled to cope either by avoiding reflecting on these experiences or by reinforcing a sense of coherence, meaning in life, and connection to others (Maxfield et al., 2014). Recognizing that avoidance is often maladaptive, grief researchers have turned to develop resources for supporting adults to construct adaptive, directive self-narratives following death-salient events. For example, making meaning through loss self-narratives is known as an essential mechanism of grief adjustment (Neimeyer et al., 2006) and is the center of many grief interventions for the bereaved (Lichtenthal et al., 2019). Narrative-based interventions support those who, for example, are anticipating the loss of a care recipient (She et al., 2021), recently acted as a surrogate for a care recipient in the intensive care unit (Schenker et al., 2015), or are seriously ill and approaching death (Bluck et al., 2022).

Self-Direction From Caregiving Experiences: The Subjectivity and Salience of Narratives

Because of its intensity, family caregiving is historically depicted as burdensome or harmful (Noonan & Tennstedt, 1997; Zarit et al., 1980). For example, in introducing the stress–process model of family caregiving, Pearlin and colleagues (1990) describe caregiving as “potentially a fertile ground for persistent stress” due to the often drastic restructuring of an established relationship and reshaping of caregivers’ lives (Pearlin et al., 1990, p. 583). Recently, some have

called for a paradigm shift (Pruchno & Gitlin, 2012), urging researchers to consider caregiving as a dynamic life experience (Marino et al., 2017) through, for example, defining and measuring positive aspects of caregiving in tandem with stressors (Zarit, 2012) and describing ways that caregiving can positively influence caregiver well-being across time (Roth et al., 2015). We argue that all perspectives can and should coexist; indeed, Pearlin and colleagues acknowledge the potential for caregiving experiences to be enriching, yet these authors are clear that enrichment through caregiving is not guaranteed. We believe the narrative identity framework can bridge these perspectives: Reflection on self-narratives is likely an essential mechanism by which objective caregiving experiences positively influence self-belief and behavioral outcomes for some, but not all, caregivers. Self-narratives from caregiving serve as powerful guides for positive and negative outcomes due to both their *subjectivity* and *salience*.

First, self-narratives reflect versions of ourselves in earlier life scenes, and are thus inherently subjective. Our flexible memory systems afford us the ability to define ourselves and our worldviews by interpreting our lived experiences. Because of this, caregivers can walk away from similar events with different interpretations to personify or preserve their identities in novel situations (Hayes et al., 2009). For example, two caregivers can each recall the first time their care recipient experienced a fall. Semantic details (e.g., setting, time of day) and automatic, in-the-moment thoughts can be similar across experiences. Yet, on recall, one caregiver might focus on their own quick-thinking and the gratitude conveyed by their care recipient, whereas the other might emphasize the suddenness of the fall and their disturbance at recognizing their care recipient’s frailty.

Next, emotionally laden self-narratives are salient in our memory systems. Insights and meanings are often extracted from salient (e.g., joyful, frustrating, poignant) caregiving moments and used to structure caregivers’ beliefs and values (Cherry et al., 2019; Lloyd et al., 2016; Shim et al., 2013), which can, in turn, compel actions across novel or familiar situations. For example, a former caregiver may recall the tranquility and respite afforded to themselves and their care recipient after incorporating home hospice care for the last months of their care recipients’ life. This vivid self-narrative may nullify previous stigmas or socially influenced views (e.g., that hospice is indicative of “giving up” on one’s care recipient) and may motivate early incorporation of hospice in future relevant situations.

Spotlight on Self-Narratives: What We Know, and Where to Go

Colloquially, caregiving self-narratives are described as catalysts for self-beliefs and behaviors across late life. Authors of memoirs such as journalist Gail Sheehy (*Passages in Caregiving*) and physician Arthur Kleinman (*The Soul of Care*) describe the ubiquity of caregiving and the influence that caregiving self-narratives can have as we age. For example, Kleinman (p. 4) writes, “Care can offer wisdom for the art of living. Understanding the meanings that arise from the practical work of care may ... strengthen us to face other tests that life brings.” Other authors, such as social worker Joyce Beckett (*Lifting Our Voices: The Journeys into Family Caregiving of Professional Social Workers*), offer essay compilations that detail the duality of working professionally in

a human services role while engaging in family caregiving. Contributors to Beckett's compilation, a majority Black-and African American-identifying group, describe how self-narratives provide insights for compassionate professional and personal care that cannot be taught academically. Still, the impact of self-narratives from family caregiving has scarcely received focused research attention. Here, we lay the groundwork for examining associations between narrative mechanisms, quantified through *narrative analysis*, and outcomes: We describe narrative attributes that are likely mechanisms of self-beliefs and behaviors and key health-related domains from which to test outcomes.

Measurement of Narrative Mechanisms

The narrative identity framework encourages measuring and testing of narrative variables (e.g., those obtained through narrative analysis; Adler et al., 2017) as incrementally valid predictors of belief and behavior outcomes. There are dozens of defined narrative attributes that can be examined through narrative analysis and applied to caregiver's self-narratives. Interestingly, narrative attributes described across several qualitative caregiver studies are reflected in the "big three" attributes described by narrative researchers as impactful to well-being across adulthood (McLean et al., 2020; Stern et al., 1999). This synergy suggests these three types of attributes are promising first targets for investigation.

We describe these three attributes using terms from the narrative literature: motivational themes, autobiographical reasoning, and structure, which are further detailed elsewhere (McLean et al., 2020). First, motivational themes capture narratives' orientations toward innate human qualities, such as emphasis on mastery and personal ability (i.e., *agency*) or interpersonal connections (i.e., *communion*; McAdams, 2003). Themes like agency and communion echo caregiver's descriptions of sense of belonging and self-confidence in caregiving narratives (Lloyd et al., 2016; Singh, 2022). The second, autobiographical reasoning, involves making sense of lived experiences by forging connections or new understandings while narrating events. Caregivers' narratives can include reference to this sense-making process: Caregivers have been described as making meaning of their experiences by, for example, rectifying expectations and outcomes about events through articulating moral or practical explanations (Ayres, 2000; Shim et al., 2013). Finally, narrative structure involves the ways narratives are built and organized. This attribute includes aspects like coherence of narrative or inclusion of elaborations that convey a fuller picture of the lived experiences. Autobiographical reasoning and narrative structure are often described as interrelated narrative attributes, such that narratives that "make better sense" (i.e., are better structured) involve "sense-making processes" (i.e., demonstration of autographical reasoning). This is illustrated in research on caregivers' narratives, where narratives that are less coherent (structure) are described as conveying randomness of the lived experience, indicating the lack of meaning made (autobiographical reasoning; Stern et al., 1999). Researchers can examine narrative attributes based on their conceptual fit with target caregiver outcomes. Below we present three possible domains of caregiver outcomes.

Three Domains of Outcomes

In middle age and older adulthood, shrinking time horizons (Giasson et al., 2019) and changing social roles (Gryzman &

Dimakis, 2018) shift life priorities toward the maintenance of health and support of loved ones (Magnaye et al., 2020). The domains we present were chosen because they relate to priorities in the promotion of own and others' health in late life. The first two describe personal health-related behaviors. The third describes self-beliefs in the context of future family caregiving. We assert that recalled caregiving experiences can, depending on the individual, either promote or hinder constructive outcomes within these domains.

Domain one: personal health planning

Across mid- and late life, adults are encouraged to incorporate health planning practices into their everyday lives to improve and maintain their personal health. Despite this, middle-aged and older adults inconsistently engage in health planning. Barriers, including lack of clarity about planning options (Bechthold et al., 2022) and limited motivation (Sokas et al., 2021), impede health planning in late life. Family caregiving has been considered an opportunity to act as an "under-study for one's own performance"; supporting a close other through illness can demonstrate to the caregiver what can go right, and wrong, as health considerations change (Hogstel et al., 2005).

Self-narratives from caregiving may dictate a range of measurable health planning outcomes, including articulation of health priorities, compliance with preventative recommendations, and health-related self-efficacy. For example, self-narratives that emphasize care recipients' control over their own health (i.e., *agency*) or connections between preventative activities and delay of illness onset (i.e., autobiographical reasoning) may promote constructive health planning outcomes in the caregiver to the extent that they guide navigation of care planning options or renew caregiver's intentions to take care of their health. Caregiving narratives may also have the opposite effect. For example, narratives that emphasize the failings of the health system, inevitability of a care recipient's decline despite health planning, or randomness of health events may foster ongoing worry, feelings of uncertainty, and/or health complaints without health-promoting behavior change.

Domain two: end-of-life values clarification

Adults are also encouraged to consider values for end of life prior to or early in the course of illness to increase the likelihood of a value-concordant death. Values contemplation, recording (Gillick, 2004), and discussion (Sudore et al., 2008), as well as preparing to make in-the-moment decisions during acute health events (Sudore & Fried, 2010), are all considered to promote a value-aligned end of life. Knowledge about and actions toward values clarification remain variable (Born et al., 2004; Kozlov et al., 2018).

Narratives constructed following care recipients' deaths may shape caregivers' own end-of-life values. For example, witnessing the suffering of a close other when providing end-of-life care can lead to intense personal distress (Schulz et al., 2017). This distress may detract from values clarification predominantly for individuals who interpret suffering as inevitable or random through self-narratives, thus forming incorrect assumptions about the benefits of or options for care planning. In other cases, exposure to the death of others is associated with shifts in values for one's own end-of-life medical care (Fried et al., 2006) and can demonstrate to caregivers the utility of advance care planning materials (e.g., living wills; Noh et al., 2020), motivate end-of-life family conversations

(Siconolfi et al., 2021), and strengthen one's ability to navigate end-of-life values clarification (McMahan et al., 2013). Here too, attributes of self-narratives, such as agency in surrogate decision-making, may dictate whether loss experiences lead to these values-clarification activities.

Domain three: future caregiver preparedness

Caregiver preparedness describes the extent that caregivers feel self-efficacious in their caregiving abilities. High caregiver preparedness is essential to the navigation of the caregiving role, with impacts on outcomes for care recipients (Grant et al., 2013; Pucciarelli et al., 2022) and caregivers themselves (Archbold et al., 1990; Petruzzo et al., 2019; Sterling et al., 2022). As life spans and illness trajectories are extended due to medical advancements, family caregivers are commonly providing care to multiple close others across mid- and late life. For example, over one third of those who act as family caregivers once do so a second time (Fast et al., 2021). This reliance will grow as the availability of family caregivers declines (Gaugler, 2021).

Examination of links between self-narratives from past caregiving experiences and future preparedness will reveal circumstances where self-narratives can threaten one's sense of preparedness. Studying links between past caregiving self-narratives and outcome measures of caregiver preparedness lays a foundation for shifting to prevention (i.e., minimizing the harm of caregiving for those with low preparedness) rather than intervention (i.e., addressing harmful situations after they have begun) in caregiving support strategies. To do this, we must first develop novel measures of caregiver preparedness tailored to disease-specific caregiver populations (Mroz et al., 2022a). Other outcomes (e.g., caregiver mastery, care recipient institutionalization) may also be influenced by self-narratives from former care roles. Concordance between circumstances surrounding previous caregiving roles (e.g., sense of communion in self-narratives from prior caregiving experiences) and novel care roles (e.g., relationship closeness with a new care recipient) may dictate the degree to which self-narratives have effects on outcomes.

Exploring Caregiving Self-Narratives: Individual and Group Differences

Life-story researchers posit that one's narrative identity is constructed from a blend of self-narratives, personal characteristics, and ecological contexts (Bluck et al., 2019). Research that adapts a narrative identity framework should attend to the variation in caregiver characteristics and ecological contexts. For example, we recognize that the parameters outlined at the outset of this article (i.e., a focus on middle-aged and older adults caring for older adults with chronic, progressive illnesses) include millions of family caregivers, each with unique circumstances driven by a combination of factors such as their care recipients' illness, available resources and competing role demands, family relations, geographical location and proximity to care recipient, and length of care provision. We are not suggesting that research on caregiving self-narratives should involve nonspecific samples of caregivers. Rather, we advocate for research that examines narrative attributes and outcomes within specific, intentionally chosen subpopulations of caregivers.

In addition, the American aging population is increasingly diverse (Torres-Gil & Demko, 2019), but research on aging in the United States has been slow to respond to this diversity.

Studies to date are often not representative of existing diversity, including diversity in cultural identification, family structures, and community customs (Butler et al., 2020). As a result, our understanding of family caregiving in late life is built upon primarily homogeneous (e.g., White, affluent, urban, and female) study samples. Recently, gerontologists have called for attention to the lived experiences of diverse groups of caregivers (Bonds Johnson et al., 2021; Dilworth-Anderson et al., 2020). A narrative identity framework approach must be coupled with strategies for diverse participant sampling to scaffold robust programs of research in this arena.

Rewriting the Study of Caregiving: Narrative-Based Interventions

Seminal caregiving research advocates for going beyond merely characterizing objective conditions that can cause or alleviate stress for the caregiver by instead charting *how* these conditions manifest and lead to impacts over time (Pearlin et al., 1990). This article extends this classic research by highlighting the construction and internalization of self-narratives from caregiving as one central process by which objective conditions impact caregivers. By embracing a narrative framework to explain central mechanisms that drive caregiving stress processes, we can begin to map links between objective experiences from caregiving, self-narrative mechanisms, and self-belief and behavioral outcomes. Ultimately, this framework extends existing stress models by emphasizing that outcomes are dynamic: because self-narratives begin construction during an event, are shaped over time (Ayres, 2000), and are continuously malleable, the extent of positive or negative impacts of self-narratives is dependent, in part, on coping across time. This highlights opportunities for developing resources for those who are struggling with distressing self-narratives from caregiving.

We assert that coping can be promoted through narrative-based interventions, such as those scaffolded by tenets of narrative therapy. Narrative therapy techniques facilitate the detection of constructive plotlines in one's personal memories and recasting of difficult narratives (Hitchcock et al., 2017). Techniques overlap with theoretically central narrative mechanisms (e.g., motivational themes, autobiographical reasoning). Chiefly, they guide individuals to develop storylines from lived experiences that emphasize competency while embracing objective realities. Narrative therapeutic approaches join other popular and well-evidenced psychotherapeutic approaches (e.g., cognitive behavioral therapy, CBT; rational-emotive behavioral therapy, REBT) as important resources for addressing psychological needs (da Silva et al., 2017; Lopes et al., 2014).

Narrative-based interventions are distinct from other psychotherapeutic interventions in ways that may uniquely fit caregivers' needs. CBT and REBT approaches target automatic or irrational thoughts. For example, CBT is grounded in modernism, which operates on the notion of a discoverable, objective truth (Hammack, 2003; Proctor, 2008). CBT interventions guide individuals to see through irrational thoughts (e.g., *my loved one would have been better off dead than cared for by me*) to uncover more productive truths. Narrative therapy, in contrast, is based on social constructivism, the concept that there is no objective truth and that humans are guided by their own interpretations of the world (White & Epston, 1990). Narrative therapeutic approaches are thus particularly useful in contexts where individuals describe truths as obscure or

unfavorable. As such, they are ideal for family caregivers, who often experience objectively difficult events (e.g., changes in care recipients' appearance or personality, surrogate decision-making; Matta, 2021). Further, narrative therapy is grounded in assumptions that the caregiver is the expert of their own narrative, and that they are directed by this narrative (e.g., *when my loved one was in a coma, the doctors asked me questions about what to do to care for him. I didn't have the answers and I felt like a failure. My loved one would have been better off dead than cared for by me*). Narrative therapeutic approaches guide individuals to adapt and concentrate on storylines that promote a sense of competency within challenging circumstances (e.g., *I remember many times when I was able to provide the care my loved one needed, and I think about these times when I think about my caregiving competency*) without attempting to reconstruct difficult objective truths.

Narrative therapeutic techniques have already been leveraged to support satisfaction in caregiver-care recipient relationships (Hawkins et al., 2019) and address caregiver grief adjustment (Chan et al., 2013). Narrative-based approaches are also emerging as promising interventions for caregivers and former caregivers (Ngazimbi et al., 2008). For example, Petrovic and colleagues (2022) recently established the feasibility of an intervention that draws on a "transformative storytelling technique" to support caregivers' well-being, broadly defined. Yu and colleagues (2020) are currently conducting a large trial comparing a 14-week course of group-based narrative therapy for individuals providing care for a person living with dementia, compared to dementia education control condition, testing changes in psychological outcomes. Application of narrative-based interventions to address self-belief and behavioral outcomes in caregivers is a promising next step. Development and refinement of narrative-based interventions have the potential to boost the potential for caregiving experiences to drive positive self-beliefs and behaviors across late life.

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Conflict of Interest

None declared.

Data Availability

This article does not report data and therefore the pre-registration and data availability requirements are not applicable.

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