Narratives of Self-Neglect: Patterns of Traumatic Personal Experiences and Maladaptive Behaviors in Cognitively Intact Older Adults

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OBJECTIVES: To identify patterns of personal experience or behavior in self-neglect by exploring narratives of cognitively intact older adults.

DESIGN: Descriptive study involving semistructured interviews and unstructured narratives.

SETTING: A parent study of self-neglect characteristics.

PARTICIPANTS: Cognitively intact, self-neglecting older adults referred from 11 community-based senior services agencies (N = 69).

MEASUREMENTS: Interviews included a comprehensive psychiatric assessment using the Structured Clinical Interview for *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, Axis-I and II Disorders and an unstructured interview that allowed subjects to describe important elements of their life stories. Content analysis was used to identify personal experiences and behavior patterns in each subject's narrative.

RESULTS: Four types of traumatic personal experiences (psychologically traumatic loss, separation or abandonment (29%); violent victimization, physical trauma, or sexual abuse (19%); exposure to war or political violence (9%); prolonged mourning (7%)) and five behavior patterns (significant financial instability (23%), severe lifelong mental illness (16%), mistrust of people or paranoia (13%), distrust and avoidance of the medical establishment (13%), substance abuse or dependence (13%)) were identified in the life stories.

CONCLUSION: Patterns of traumatic personal experiences and maladaptive behaviors that self-neglecters frequently report were identified. Experiences, perceptions, and behaviors developed over a lifetime may contribute to elder self-neglect. Further exploration and better understanding of these patterns may identify potential risk factors and areas for future targeted screening, intervention, and prevention. **J Am Geriatr Soc 2016.**

Key words: self-neglect; elder abuse; traumatic life events

Self-neglect is the most frequent form of elder mistreatment that adult protective services (APS) agencies investigate.[1,2] Elder self-neglect is defined as inability to meet self-care needs for physical, emotional, and social well-being.[3] Self-neglecters may be found in dangerous environments because of inattention to home safety. Malnutrition, dehydration, and uncontrolled medical illness due to refusal of care may compromise their health. These self-neglecting behaviors lead to greater emergency department use,[4] nursing home placement,[5] and mortality.[6] Despite its public health importance, the etiology of self-neglect is poorly understood, and few effective interventions exist.[7] Given the trends for growth in the geriatric population, a deeper understanding of elder self-neglect is urgently needed.

Self-neglect is currently thought to be a geriatric syndrome, resulting from interactions between poor social support, functional disability, chronic medical conditions, psychiatric illness, and mild cognitive impairment.[8–10] Research has also suggested that an individual's social, cultural, and environmental circumstances over the course of a lifetime may affect self-neglecting behaviors.[10] This qualitative research aimed to improve understanding of older adults with different types of self-neglecting behavior by providing a unique, experiential perspective of self-neglecters. Previous qualitative research has been limited to small samples[11–13] and second-hand accounts,[14] with a dearth of self-reported, comprehensive narratives in this population. The aim of this qualitative study was to identify frequently reported themes in the personal narratives of a large sample of community-dwelling, cognitively intact, self-neglecting older adults.

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METHODS

Overview

Data initially gathered for a larger parent case–control study of community-dwelling, cognitively intact adults with and without self-neglecting behavior were qualitatively analyzed. The purpose of the parent study was to identify characteristics that differentiate self-neglecting from non-self-neglecting older adults. Subjects were enrolled in the parent study from 2008 to 2010. Potential subjects were referred from case managers and social workers at 11 community-based senior services agencies in the New York metropolitan area. These agencies were asked to refer clients aged 65 and older who lived in the community, were English or Spanish speaking, and were not cognitively impaired. Before enrollment, the research team screened each subject using the Mini-Mental State Examination with a threshold score of 25. Subjects were informed that the purpose of the study was to learn about challenges in self-care faced by older adults and received up to $40 for participating in the study. Self-neglecters were identified using criteria that the research team developed based on systematic review of the literature and an expert panel including a geriatric psychiatrist (RA) and geriatrician (ML) verified. These criteria for self-neglect included exhibiting inattention to personal hygiene, inattention to living environment, refusal of some or all indicated services, or self-endangerment through the manifestation of unsafe behaviors. Only subjects determined to be self-neglecters according to these criteria were included in the present qualitative analysis. All subjects were interviewed in their own homes or at a senior center of choice. The Weill Cornell Medical College institutional review board approved this study.

Subject Interviews and Data Collection

In the parent study, each subject was evaluated in person in two separate encounters. During the first encounter, subjects were interviewed to collect demographic information and to administer a battery of standardized instruments to test general health, functional ability, gait, mobility, vision, nutritional status, social networks, health-related quality of life, and psychosocial well-being. The second interview consisted of the Structured Clinical Interview for *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV), a standardized, semistructured interview designed to identify current and lifetime DSM-IV Axis I and II diagnoses (SCID-I and SCID-II). The interviewers also asked the subjects to describe important elements of their life stories and collected field notes from these personal narratives. Subjects were not specifically prompted to discuss traumatic events. A qualitative analysis of SCID-I, SCID-II, and all unstructured narrative field notes of self-neglect subjects are reported.

Data Analysis

Data from 69 subjects were examined for this analysis. Two additional subjects did not complete the second interview and were excluded from the qualitative analysis. Three authors, a geriatrics fellow (CL), a geriatric emergency physician (TR), and a public health gerontologist (EB), transcribed, reviewed, coded, and iteratively analyzed the interview responses and narrative notes. Themes that subjects frequently reported were identified using content analysis.[15] In lieu of having coders working independently and calculating kappa based on coders' consistency, a consensus approach based upon the group interactive analysis component of Borkan's immersion and crystallization method was used.[16] In this process, each rater identified frequently occurring themes by organizing and corroborating them with other members of the team. After coding was complete, the percentage of respondents that made statements corresponding to each identified theme was calculated. Using this process, consensus was developed around four types of traumatic personal experiences and five maladaptive behavior patterns.

RESULTS

Subject Characteristics

Seventy percent of the self-neglect subjects evaluated were female, and 74% were non-Hispanic white. Eighty-three percent lived alone; 43% had never married, 22% were widowed, and 22% were divorced. Seventy-two percent exhibited self-endangerment through unsafe behavior, 65% exhibited inattention to environmental hygiene, 49% exhibited inattention to personal hygiene, and 45% had refused some or all indicated services (Table 1).

Table 1. Demographic Characteristics (n = 69)

Variable	n (%)
Age	
65–74	27 (39)
75–84	20 (29)
85–94	21 (30)
≥95	1 (0)
Female	48 (70)
Race and ethnicity	
Hispanic-white	11 (16)
Non-Hispanic white	51 (74)
African American	16 (23)
Asian	1 (0)
Marital status	
Married	6 (9)
Widowed	15 (22)
Divorced	15 (22)
Separated	2 (3)
Never married	30 (43)
Self-neglect recruitment criteria	
Inattention to hygiene	34 (49)
Inattention to environment	45 (65)
Refusal of services	31 (45)
Endangerment of self	50 (72)
Monthly income ≤150% poverty level	28 (41)
Other social variables	
Living alone	57 (83)
Home attendant	20 (29)
Primary care	60 (87)
Use assist device	45 (65)
Substance use	
Current smoking	16 (23)
Current alcohol use	27 (39)

Themes Identified

Nine frequently reported themes were identified in two domains: traumatic personal experiences and maladaptive behavior patterns. Of traumatic personal experiences, four themes were identified: psychologically traumatic loss, separation, or abandonment (29%); violent victimization, physical trauma, or sexual abuse (19%); exposure to war or political violence (9%); and prolonged mourning (7%) (Table 2). Of maladaptive behavior patterns, five themes were identified: significant financial instability (23%), severe lifelong mental illness (16%), mistrust of people or paranoia (13%), distrust and avoidance of the medical establishment (13%), and substance abuse or dependence (13%) (Table 3).

DISCUSSION

Patterns of Personal Experience

Traumatic Loss, Separation, and Abandonment

Personal experiences of psychologically traumatic loss, separation, and abandonment were frequently identified as important life events. They included unexpected losses or separation from an attachment figure at various ages in the context of forced displacement, accident, homicide, or suicide. These findings are consistent with prior qualitative studies of elder self-neglect that have emphasized cumulative losses, betrayals, neglect, and abandonment over a lifetime.[12,13] Unexpected or traumatic death of a loved one has been shown to affect all age groups significantly.[17] Traumatic parental death in early life leaves individuals more vulnerable to psychiatric illness and substance abuse than parental death from other causes.[18] Maladjustment after parental death during childhood, including development of poor self-esteem and insecure attachment styles, has been shown to contribute to unstable relationships, poor social support, and lack of resilience to external stressors in adulthood.[19] In adulthood, unexpected death of a loved one has been linked to the development of major depression, alcohol or substance abuse, posttraumatic stress disorder (PTSD), and panic disorder.[17] Acquired vulnerabilities in the aftermath of traumatic loss such as maladaptive coping strategies and psychiatric illness[20] may contribute to the development of elder self-neglect.

Interpersonal Trauma

Experiences of interpersonal trauma perpetrated by family members, spouses, parental figures, and other close acquaintances emerged from the narratives. Subjects described violence, physical trauma, or sexual abuse at multiple stages in life. Interpersonal trauma in childhood including physical abuse, sexual abuse, and neglect have been shown to increase risks of severe mood disorders and behavioral disturbances in adolescence and adulthood.[21,22] Interpersonal trauma occurring in late life may also predispose to behavioral disturbances. Of elderly adults referred to APS agencies for self-neglect, 28% had previously been victims of other forms of elder mistreatment.[23] Elderly women who reported cumulative experiences of

Table 2. Personal Experiences That Cognitively Intact Self-Neglectors Commonly Reported (N = 69)

Experience	n (%)	Illustrative Field Notes of Experiences That Subjects Described
Victim of psychologically traumatic loss, separation, or abandonment	20 (29)	Mother left [subject] when [subject] was a child...felt angry and abandoned Got pregnant...was 16...2 weeks before giving birth, found her mother dead...was very depressed Lost her husband and son to unexpected heart attacks within 2 years... was very depressed since Mother was murdered in her home...died next day
Victim of violence, physical trauma, or sexual abuse	13 (19)	Survivor of incest by older brother...boyfriend verbally abused her...low self-esteem, victimized Raped at age 6...incident caused complications late in life...[husband] cut her face with a knife...[he] tried to poison her Foster parents beat her a lot...another foster family "starved her"...father sexually abused her Had a very abusive 16-year relationship with man...would stop this man from beating the children, and take on beating herself Was raped by a boyfriend when she was 19 and still thinks about it often Had an abusive relationship with her second husband...threatened to kill her and abused her
Exposure to war or political violence	6 (9)	Lost all of her family [in Holocaust]...instantly weepy when mentioning this Family was taken on a train to Auschwitz...he could see the gas chambers...lost his family Was in Vietnam for 2 years as a Green Beret...saw many men die...feelings of guilt Drafted during Korean War...was in therapy after war, now getting counseling
Prolonged mourning	5 (7)	Lost parents when she was young, both died same year...in her 20s...realized she was still grieving...5 years after death Started to get depressed after parents passed away, over 20 years ago...has not recovered Husband and sister deaths were great issues for her, though they died years ago Lost husband and son...within 2 years of each other...was very depressed after that Son died of AIDS 4 years ago...has been depressed since he died

Table 3. Behavior Patterns Commonly That Cognitively Intact Self-Neglectors Reported (n = 69)

Pattern	n (%)	Illustrative Field Notes of Experiences That Subjects Described
Significant financial instability	16 (23)	Owes money, can't afford meds. . .spends a lot of time worrying about financial situation. . .avoiding phone calls Struggles to pay fees on apartment. . .worries about financial situation. . .obsessed with making money Admits to buying things she cannot afford. . .over 20 credit cards with $40,000 on each one. . .very concerned about finances Had to sell [life insurance] for money. . .feeling depressed because paying bills is hard
Severe lifelong mental illness	11 (16)	Long history of depression since early teens. . .three suicide attempts, currently on disability for depression Schizophrenic. . .hospitalized several times. . .often had to take leave from work for being "sick" Got laid off most jobs because. . .problems with depression and is bipolar. . .always in therapy Suffered from panic attacks since age 6. . .also suffered from depression since then
Mistrust of people or paranoia	9 (13)	Mistrust of people from young age. . ..at 8 years, felt betrayed and didn't trust people after that People were really out to get him and wanted to ruin him. . .people have tried to kill him. . .scared Doesn't like to leave apartment. . .someone will come in. . .apartment broken into many times
Distrust and avoidance of the medical establishment	9 (13)	Afraid of being hospitalized. . .they would kill her Says doctors just like to write prescriptions. . .does not trust them. . .mother died of complications of mouth cancer so afraid to see the dentist Was sent to hospital. . .3 months there were the worst 3 months of her life She will not take any meds. . .when doctor prescribes [medications] tends not to go back to the doctor, believes that it poisons her
Substance abuse or dependence	9 (13)	Spends too much money on alcohol. . .almost evicted for failure to pay rent Started drinking in 40s. . ."I know I had a problem". . .long battle Abused alcohol. . .dependent on crack. . .realized it was leading him to financial ruin

interpersonal violence over a lifetime reported feelings of social and emotional isolation, neglect and abandonment, low self-worth, and loneliness.[24] Trauma of victimization at various ages may heighten the risk of elder mistreatment and self-neglect.

Exposure to War or Political Violence

Subjects described separation, displacement, and traumatic experiences in the context of war and political violence. Exposure to war and forceful displacement in early life may contribute to late-life maladaptive behavior and mental illness. Older adults displaced from their home country during World War II have reported greater frequency of traumatic events,[25] poor resilience, greater anxiety and depression, and poorer life satisfaction than their nondisplaced counterparts, even 60 years later.[26] In trauma-exposed refugees, losses of family members, abuse, and lack of social support after displacement have been associated with PTSD and prolonged grief disorder (PGD),[27] a bereavement-related entity associated with adverse mental health outcomes including depression, PTSD, and anxiety.[28] Late-life consequences of war-related trauma and displacement may be an important trigger of the onset of self-neglect.

Prolonged Mourning

Subjects frequently referred to the death of a spouse or child in adulthood as a significant life event, with yearning or grief persisting for many years. The psychological effect of such losses can be profound, yet no studies have explored the relationship between bereavement and self-neglect. A subset of bereaved individuals may develop PGD, characterized by distrust and detachment from others, yearning for and avoidance of reminders of the deceased, a sense of emptiness, or lack of meaning in life. Traumatic grief is associated with underuse of healthcare services,[29] suggesting diminished capacity for self-care in the aftermath of loss.

Patterns of Behavior

Financial Instability

Self-neglecters reported long-term burdensome financial difficulties. Older adults with low income levels have been shown to have higher rates of self-neglect.[9] The current study findings are consistent with prior reports of significant financial difficulties of self-neglecters in the setting of unstable employment, substance use, mood disorders, and challenges navigating personal finances.[11,12] Although some subjects reported financial hardship, with incomes at or below 150% of the federal poverty level at the time of the study, socioeconomic status of self-neglecting older adults is widely variable.[30] It is also likely that many of the self-neglecting subjects had significant incomes. That even financially secure subjects emphasize burdensome financial difficulties when recounting their life experiences suggests that the perception of financial instability rather than instability itself may be an important contributor to self-neglect.

Lifelong Mental Illness

Subjects frequently described the effect of psychiatric illness in their lives, including depression, anxiety, schizophrenia, and bipolar disorder. Many reported recurrent psychiatric hospitalizations and suicide attempts. This finding supports previous research suggesting that mental disorders are common in community-dwelling self-neglecters[8] and increases risk of self-neglect.[10]

Mistrust of People or Paranoia

Subjects described lifelong mistrust and avoidance of family, friends, neighbors, and other people in the community. Previous qualitative studies of self-neglecters have also highlighted pervasive mistrust and estrangement and alienation from family and friends.[13] Socially isolative behavior may be recognized as a component of self-neglect only when the subject becomes functionally dependent as an older adult. Thus, age-related frailty may be a "catalyst," causing a shift such that isolating behaviors increase risk of self-harm.[12]

Distrust and Avoidance of the Medical Establishment

Avoidance of doctors and hospitals was a recurrent theme among study subjects, often in the context of negative prior experiences. Refusal of medical intervention and social services is a feature of self-neglect frequently described in the literature.[11,13] Fear of institutionalization may drive older adults to remain in self-endangering situations.

Substance Abuse or Dependence

Substance abuse, particularly alcoholism, was frequently described in the narratives. Alcohol-related problems are commonly reported in community-dwelling self-neglecters.[8] Alcoholism and illicit drug use may lead to financial instability, eviction, unemployment, and other psychosocial factors contributing to poor self-care and breakdown of social support networks among self-neglecters.[11]

CONCLUSIONS

To the knowledge of the authors, this is the largest sample of self-neglecting older adults that has been qualitatively analyzed, and it provides a unique, experiential perspective of elder self-neglect. Themes of traumatic life events in childhood and adulthood and maladaptive behaviors emerged. The analysis supports existing research on the contribution of social, cultural, and environmental factors to self-neglecting behaviors[10] and offers insight into vulnerabilities developed over a lifetime. Potential populations identified for targeted intervention include older adults who have experienced even remote interpersonal violence or traumatic loss; trauma-exposed populations in the aftermath of war; and individuals who have experienced complicated bereavement, substance abuse, financial insecurity, and psychiatric illness. Further understanding of the effect of traumatic personal experiences and maladaptive behaviors may inform elder self-neglect prevention, screening, and intervention efforts.

LIMITATIONS

This research has several limitations. Findings from cases of self-neglect from a single U.S. metropolitan area identified by senior service organizations may not be generalizable. This work relied on analysis of self-reported, unstructured field notes that were not initially gathered for this study. Another limitation is the unique sampling of self-neglecters who agreed to participate, were cognitively intact, and had connected with community services. Given the recruitment challenges of extreme self-neglecters, who often avoid contact with the healthcare system, the most-severe cases of self-neglect may not be represented in the sample. Nevertheless, exploring the subjective experiences of self-neglecting older adults contributes to the conceptual understanding of this phenomenon. The conclusions rely not on event accuracy but on the emotional and experiential aspects that have influenced subsequent behavior in old age. Also, the analysis did not include a comparison group of non-self-neglecting subjects. It is possible that older adults who do not exhibit self-neglect may report similar experiences and behaviors. Self-neglecters and non-self-neglecters may emphasize different experiences or differ in their resilience and coping abilities in the aftermath of traumatic experiences and external stressors. Further exploration of these differences is an important next step in self-neglect research.

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