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

Cynthia Lien, MD¹, Tony Rosen, MD, MPH², Elizabeth M. Bloemen, MPH^{1,2}, Robert C. Abrams, MD³, Maria Pavlou, MD⁴, and Mark S. Lachs, MD, MPH¹

¹Division of Geriatrics and Palliative Care, Weill Cornell Medical College, New York, NY

²Division of Emergency Medicine, Weill Cornell Medical College, New York, NY

³Department of Psychiatry, Weill Cornell Medical College, New York, NY

⁴Mercy Clinic Geriatrics, St. Louis, MO

Abstract

Corresponding author: Cynthia Lien, MD, 525 East 68th Street, New York, NY 10065, 212-746-1596 (phone), 212-746-4888 (fax), cyl9013@med.cornell.edu. Alternate corresponding author: Mark S. Lachs MD MPH, 525 East 68th Street, Box 39, New York, NY 10065, 212-746-7000 (phone), 212-746-8207 (fax), mslachs@med.cornell.edu.

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Employment or Affiliation		X		X		X		X		X		X
Grants/Funds		X		X		X		X		X		X
Honoraria		X		X		X		X		X		X
Speaker Forum		X		X		X		X		X		X
Consultant		X		X		X		X		X		X
Stocks		X		X		X		X		X		X
Royalties		X		X		X		X		X		X
Expert Testimony		X		X		X		X		X		X
Board Member		X		X		X		X		X		X
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* Authors can be listed by abbreviations of their names.

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Background/Objectives—Self-neglect is a complex, poorly understood public health problem associated with high morbidity and mortality. Previous qualitative research is limited to small samples and second-hand accounts, with a dearth of self-reported, comprehensive narratives in the geriatric population. Our goal was to identify patterns of personal experience or behavior in self-neglect by exploring narratives of cognitively intact older adults.

Design/Setting/Participants—We used qualitative data from a larger parent study of self-neglect characteristics. For our analysis, we evaluated interviews with 69 cognitively intact, self-neglecting older adults referred from 11 community-based senior services agencies.

Measurements—Interviews included a comprehensive psychiatric assessment using the Structured Clinical Interview for DSM-IV Axis-I and II Disorders (SCID-I and II), and an unstructured interview that allowed subjects to describe important elements of their life stories. We used content analysis to identify key personal experiences and behavior patterns within each subject's narrative.

Results—We identified 4 traumatic personal experiences and 5 behavior patterns in the life stories. Traumatic personal experiences included: 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%). Maladaptive behavior patterns included: 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%).

Conclusion—Patterns of traumatic personal experiences and maladaptive behaviors frequently reported among self-neglecters were identified. Experiences, perceptions, and behaviors developed over a lifetime may contribute to elder self-neglect. Further exploration and improved understanding of these patterns may identify potential risk factors and areas for future targeted screening, intervention, and prevention.

Keywords

self-neglect; elder abuse; traumatic life events

Introduction

Self-neglect is the most frequent form of elder mistreatment investigated by adult protective services (APS) agencies.^{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. Their health may be compromised by malnutrition, dehydration, and uncontrolled medical illness due to refusal of care. These self-neglecting behaviors lead to increased emergency department use,⁴ nursing home placement,⁵ and mortality.⁶ Despite its public health importance, the etiology of self-neglect remains 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 impact self-neglecting behaviors.¹⁰ This qualitative research aims 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 is 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 is to identify frequently reported themes in the personal narratives of a large sample of community-dwelling, cognitively intact, self-neglecting older adults.

Methods

Overview

In this study, we qualitatively analyzed data initially gathered for a larger parent case-control study of community-dwelling, cognitively intact adults with and without self-neglecting behavior. The purpose of the parent study was to identify characteristics that differentiate self-neglecting and non-self-neglecting older adults. Subjects were enrolled into the parent study from 2008–2010. 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 who lived in the community, were English or Spanish speaking, and were not cognitively impaired. Before enrollment, each subject was screened by the research team using the Mini-Mental Status Exam 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 among the subjects were identified using criteria developed by the research team based on systematic review of the literature and verified by an expert panel including a geriatric psychiatrist (RA) and geriatrician (ML). These criteria for self-neglect included exhibiting 1 of: 1) inattention to personal hygiene, 2) inattention to living environment, 3) refusal of some or all indicated services, or 4) self-endangerment through the manifestation of unsafe behaviors. Only subjects determined to be self-neglecters by these criteria were included in the present qualitative analysis. All subjects were interviewed in their own homes or at a senior center of choice. This study was approved by the Weill Cornell Medical College Institutional Review Board.

Subject Interviews/Data Collection

In the parent study, each subject was evaluated in-person over 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 DSM-IV (SCID-I and SCID-II), a standardized, semi-structured interview designed to identify current and lifetime DSM-IV Axis I and II diagnoses. 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. Here we report a qualitative analysis of SCID-I, SCID-II and all unstructured narrative field notes of self-neglect subjects.

Data Analysis

For this analysis, we examined data from 69 subjects. Two additional subjects did not complete the second interview and were excluded from our qualitative analysis. The interview responses and narrative notes were transcribed, reviewed, coded, and analyzed iteratively by three authors (CL, TR, EB), a geriatrics fellow, a geriatric emergency physician, and a public health gerontologist. We identified themes frequently reported by subjects using content analysis.¹⁵ In lieu of having coders working independently and calculating kappa based on coders' consistency, we used a consensus approach based upon the group interactive analysis component of Borkan's "immersion/crystallization" method.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, we calculated the percentage of respondents that made statements corresponding to each identified theme. Using this process, we developed consensus around 4 traumatic personal experiences and 5 maladaptive behavior patterns.

Results

Characteristics of Subjects

The self-neglect subjects evaluated were predominantly female (70%) and non-Hispanic white (74%). Most lived alone (83%); 43% had never married, 22% were widowed, and 22% were divorced. 72% exhibited self-endangerment through unsafe behavior, 65% exhibited inattention to environmental hygiene, 49% exhibited inattention to personal hygiene, and 45% had refusal of some or all indicated services. (Details in Table 1).

Themes Identified

We identified 9 frequently reported themes in two domains: traumatic personal experiences and maladaptive behavior patterns. Among traumatic personal experiences, we identified four themes: 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%) (Illustrative notes in Table 2). Among maladaptive behavior patterns, we identified five themes: 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%) (Illustrative notes in 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. Our 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 significantly impact all age groups.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 following 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 low 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, post-traumatic stress disorder (PTSD) and panic disorder.¹⁷ Acquired vulnerabilities in the aftermath of traumatic loss such as maladaptive coping strategies and psychiatric illness²⁰ 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 for severe mood disorders and behavioral disturbances in adolescence and adulthood.^{21,22} Interpersonal trauma occurring in late life may also predispose to behavioral disturbances. Among elderly adults referred to APS agencies for self-neglect, 28% of subjects had previously been victims of other forms of elder mistreatment.²³ Elderly women who reported cumulative experiences of interpersonal violence over a life time 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 for 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, depression, and poor life satisfaction compared to non-displaced counterparts, even sixty years later.²⁶ Among trauma-exposed refugees, losses of family members, abuse, and the lack of social support following 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 represent an important trigger to 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 impact of such losses can be profound, yet no studies to date 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 underutilization of health care services,²⁹ suggesting diminished capacity for self-care in the aftermath of loss.

Patterns of Behavior

Financial instability—Self-neglecters in our study reported long-term, burdensome financial difficulties. Older adults with low income levels have been shown to have higher rates of self-neglect.⁹ Our findings are consistent with prior reports of significant financial difficulties among self-neglecters in the setting of unstable employment, substance use, mood disorders, and challenges navigating personal finances.^{11,12} Although some of our subjects reported financial hardship, with incomes at or below 150% of the federal poverty level at the time of the study, socioeconomic status among self-neglecting older adults is widely variable.³⁰ It is also likely that many of our 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 impact 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-neglecters⁸ 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 surrounding 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 only be recognized as a component of self-neglect 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. Among community-dwelling self-neglect subjects, alcohol-related problems are commonly reported.⁸ Both 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 our knowledge, this is the largest sample of self-neglecting older adults qualitatively analyzed and provides a unique, experiential perspective of elder self-neglect. Themes of traumatic life events in both childhood and adulthood and maladaptive behaviors emerged. Our analysis supports existing research on the contribution of social, cultural, and environmental factors to self-neglecting behaviors¹⁰ and offers insight into vulnerabilities developed over a lifetime. Potential populations identified for targeted intervention include geriatric victims of even remote interpersonal violence or traumatic loss, trauma-exposed populations in the aftermath of war, victims of complicated bereavement, substance abuse, financial insecurity, and psychiatric illness. Further understanding of the impact of traumatic personal experiences and maladaptive behaviors may inform elder self-neglect prevention, screening, and intervention efforts.

Limitations

Our 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. Our work relies 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 our sample. Nevertheless, exploring the subjective experiences of self-neglecting older adults contributes to the conceptual understanding of this phenomenon. Our conclusions do not rely on event accuracy, but on the emotional and experiential aspects that have influenced subsequent behavior in old age. Also, our 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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Table 1
Demographic Characteristics (n=69)

Variable	Subgroup	n	%
Age (years)	65-74	27	(39)
	75-84	20	(29)
	85-94	21	(30)
	95	1	(0)
Sex	Female	48	(70)
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 (%yes)	20	(29)
	Primary Care	60	(87)
	Use assist device	45	(65)
Substance Use	Current Smoking	16	(23)
	Current Alcohol Use	27	(39)

Table 2
Personal Experiences Commonly Reported by Cognitively Intact Self-Neglectors (n=69)

	n	% of subjects	illustrative field notes of personal experiences described by subjects
Victim of psychologically traumatic loss, separation or abandonment	20	29	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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 Reported by Cognitively Intact Self-Neglectors (n=69)

	n	% of subjects	illustrative field notes of personal experiences described by subjects
Significant financial instability	16	23	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Spends too much money on alcohol...almost evicted for failure to pay rent Started drinking in 40's...'I know I had a problem'...long battle Abused alcohol...dependent on crack...realized it was leading him to financial ruin