

SELF-NEGLECT AMONG OLDER ADULTS: IS IT A 'LIFESTYLE' CHOICE?

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Learning Objectives

Upon completion of this workshop, participants will be able to:

- Understand the scope of the problem and identify risk factors that contribute to self-neglect among older adults
- Understand the theoretical perspectives that guided the study

Learning Objectives

- Understand the lived experiences of study participants
- Implications for social service delivery

Definitions of Self-Neglect

“...an adult’s inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including:

- a) obtaining essential food, clothing, shelter, and medical care;
- b) obtaining goods and services necessary to maintain physical health, mental health, emotional well-being, and general safety;
- C) managing one’s own financial affairs”

(Elder Justice Act, 2010, p. 785)

Significance of Self-Neglect

Self-neglect is a global public health and human rights issue that threatens older people's health and safety (Dong, 2017)

Significance of Self-Neglect

- The changing demographic trends in the U.S.:

It is projected that by the year 2030, one in five Americans will be 65 years and is projected to reach 23.5% (98 million) by 2060 (Colby & Ortman, 2014)

- Medical and scientific triumphs over infectious diseases and management of chronic conditions: increased longevity, multiple risk factors

The Scope of Self-Neglect

- Self-neglect among older adults is associated with higher rates of Emergency Department admission and higher rates of nursing home placement when compared to older adults without self-neglect

(Dong, 2017; Dong et al., 2013; Dong et al., 2012)

The Scope of Self-Neglect

- Self-neglect is associated with increased rate of hospitalization, increased morbidity and greater rate of 30-day hospital readmission among community dwelling older adults
(Dong, 2017; Dong & Simon, 2015; Dong et al, 2012)

The Scope of Self-Neglect

- Self-neglecting older adult more likely to have poor quality of life (Dong, 2017; Lachs et al., 1998; Zhao et al., 2017)
- Associated with high mortality rates among older adults reported to Adult Protective Services
(Dong & Simon, 2012; Reyes-Ortiz et al., 2014)

Prevalence of Self-Neglect

- Chicago Health and Aging Project (CHAP) study suggested that 1 out of 9 older adults experience some form of self-neglect in a community setting (Dong et al., 2012)

Prevalence of Self-Neglect

- A study within a cohort of 3,159 community-dwelling Chinese older adults in Chicago found that the overall prevalence of self-neglect was 29.11%, with 18.24% being categorized as mild and 10.8% as moderate to severe (Dong, 2014)

Prevalence of Self-Neglect

- Within a cohort of 4,627 older adults, the prevalence of self-neglect by race:

Black older adults (men 13.2%; women 10.9%)

White older adults (men 2.4%; women 2.6%)

5 domains assessed: personal hygiene, hoarding, house in need of repairs, unsanitary conditions & in adequate utilities

(Dong et al, 2012)

Prevalence of Self-Neglect

- For older adults with less than high school education within the same cohort (4,627), the prevalence of self-neglect was 14.7% in men and 10.9% in women.
- For older adults with annual income less than \$15,000, the prevalence of self-neglect was 21.7% in men and 15.3% in women

(Dong et al., 2012)

Risk Factors that Contribute to Self-Neglect

Empirical Research Findings:

- Executive function is important for planning, initiation, decision-making, organizing and carrying out tasks
- Executive dysfunction (difficulty problem-solving, managing finances, identifying dangerous situations, etc. (Dyer et al., 2007))

Risk Factors that Contribute to Self-Neglect

- Old age
- Living alone
- Untreated medical conditions
- Chronic medical conditions and non-compliance with medications
- Mental illness, Substance abuse/alcohol

Risk Factors that Contribute to Self-Neglect

- Depression, Dementia
- Inadequate social support
- Lower levels of education & economically disadvantaged
- History of trauma
- Severe disability, requiring assistance with ADLs & IADLs

SIGNS THE ELDERLY ARE NEGLECTING THEIR CARE

SIGNS THE ELDERLY CAN NOT CARE FOR THEMSELVES

**HOARDING--UNABLE TO CLEAN THEIR HOUSE OR KEEP THINGS NEARBY
BECAUSE THEY CAN NOT GET UP TO PERFORM ACTIVITIES**

**MEDICAL CARE--FAILURE TO TAKE THEIR MEDICATION OR REFUSAL
TO SEEK MEDICAL CARE FOR A SERIOUS ILLNESS**

**MEAL PREPARATION--UNABLE PREPARE HEALTHY MEALS
AND WHEN THEY TRY TO THEY MAY LEAVE THE STOVE ON**

**POOR HYGIENE--NOT TAKING SHOWERS, WEARING DIRTY CLOTHES
NOT WEARING APPROPRIATE CLOTHES FOR THE WEATHER**

**DEHYDRATION--THE ELDERLY FORGET TO DRINK AND HAVE
LOST THEIR THIRST SENSATION AND CAN GET CONFUSED**

Assessment

- Assess to determine risk of harm
- Assess to determine capacity for decision-making

Ethical Considerations

- Professionals confront a variety of scenarios when working with older adults who self-neglect
- Elements of self-determination, personal independence, lifestyle choices
- Laws and regulations of states statutes that protect adults come together. These complexities often require the proverbial wisdom of Solomon

(Simmons & O'Brien, 1999, p. 34)

Ethical Consideration

- Competence is a legal determination of mental capacity. Legal standards for evaluating capacity are generally based on the older adults/clients/patients ability to:
- Understand relevant information about presenting circumstances and proposed treatment
- Appreciate the nature of presenting circumstances, including underlying values and potential consequences
- Reason about the potential risks and benefits

(Baruth & Lapid, 2017)

Lived Experiences of Older Adults Who were Identified as Self-Neglecting

- *Understanding Self-Neglect from the Older Person's Perspective* was a qualitative study conducted in 2007

There were 4 Research Questions:

- What were the lived experiences of the older adults identified as self-neglectful?
- What were the salient issues in the lives of those older persons identified as self-neglectful?

Lived Experiences of Older Adults Who were Identified as Self-Neglectful

Research Questions Cont'd:

- How did the study participants experience self-neglect?
- What were the meanings of those experiences to the study participants?

Interview Guide for the Study

- As you go through your day in providing for yourself necessities like food, clothing, housing, medical care, general safety etc., which of these areas do you feel you need help with?
- Given the areas you have described as needing help with, have you always had problems in these areas? What do you think has changed to make the problem more difficult for you to manage now than before?

Interview Guide

- Some people might see your having unmet needs in these areas like not making necessary repairs on the house, not having enough food in the house, not having a well maintained house, etc., in a sense as some sort of not taking care of yourself the way you should. What would you say to some one who might say something like that to you?

Lived Experiences of Older Adults Who were Identified as Self-Neglecting

- Participants were from APS and home health; had multiple unmet needs as defined by APS as “self-neglect” and had willingness to participate
- The older adults volunteered to participate and met criteria for inclusion in the study
- Sample size (n-12), 2 male and 10 female
- Ranged in age from 73-94, with average age of 81

Sample Risk Factors/Signs for Study Participants						
Names	Difficulty managing finances	Falls	Chronic medical conditions	Feelings of vulnerability	Difficulty with ADL/IADL	Complaints of physical weakness
Ms. Summers		X	X		X	X
Ms. Knight		X	X	X	X	X
Ms. Lane	X		X		X	X
Ms. Clay		X	X	X	X	X
Ms. Lamb		X	X		X	X
Mr. Movva		X	X		X	X
Ms. Waters	X		X	X	X	X
Mr. Wells			X		X	
Ms. Peoples			X		X	X
Ms. Gardner			X		X	
Ms. Roebuck			X		X	X
Ms. Flowers	X		X		X	

Lived Experiences of Older Adults Who were Identified as Self-Neglecting

Marital status:

- Married-2 Single -1 widowed-5 divorced 4
- Educational attainment varied from four year college education to fourth grade
- Living arrangements: 8 lived alone, with five living in apartments and three living in their homes; 4 participants lived with others in apartments or homes

Lived Experiences of Older Adults Who were Identified as self-Neglecting

- The incomes among APS participants ranged from \$569-\$2,495, and their average income was about \$1,516
- Monthly incomes of participants in home health care ranged from \$523 to \$1,666, and their average income was \$1,050

Theoretical Perspectives that Guided the Study

- Three theoretical perspectives:
 1. Compliance Theory
 2. Ecological Theory
 3. Symbolic Interactionism

Theoretical Perspectives that Guided the Study

- Compliance-the extent to which a patient engages in behaviors consistent with clinical instructions (Dracup & Melesis, 1982)
- Self-neglect and non-compliance have similar concepts as both refer to client's lack of participation in prescribed regimen
(Reed & Leonard, 1989)
- In self-neglect, “refusal of services” is more commonly used than non-compliance

Theoretical Perspectives that Guided the Study

- Ecological theory-focuses on interactions and the goodness of fit between individuals within their environments
- Where the environment cannot accommodate the changing needs of the older adult, a poor fit will result (Germain & Gitterman, 1996; Gitterman & Germain, 2008)

Theoretical Perspectives that Guided the Study

Symbolic Interactionism:

- Major social psychological perspective associated with George Herbert Mead & Herbert Blumer (in Patton, 2002)
- Focused on the subjective meaning of human behavior on how older persons in the study perceived their circumstances

Data Collection & Research Instrument

- Semi-structured one time face-to-face interviews, researcher observations, and field notes
- Multiple case study design
- Interview was audio-taped, transcribed verbatim and analyzed

Research Findings

- Although the Kutame study was conducted in 2007, however, it was an important study and the second known to interview older adults about their experiences with self-neglectful. The first known study was Bozinovski (1995; 2000). Since 2007, other researchers (Day, 2012; Lien et al., 2016) have conducted similar studies and found common themes as in the previous two studies

Findings From The Study

Ten themes emerged from the analyzed data:

1. Experience of living with a medical/health condition
2. Perception of health and medical care seeking behavior
3. Sense of mistrust
4. Difficulty with activities of daily living/instrumental activities of daily living
5. Lack of adequate resources/services

Findings From The Study

Themes cont'd:

- 6. Pride in self-sufficiency
- 7. Good and helpful to others
- 8. Unfulfilled dreams
- 9. Connectedness to places and things
- 10. God, prayer, and coping mechanisms

Narratives From The Themes

- Experience of living with a medical/health condition

Mr. Movva commented on his experience with arthritis:

...then my hand be tired and weak and everything drop. Everything I take in my hand, I get in my hand, it fell out of my hand. I can hardly hold a glass of water, you know. I have to hold it with both of my hands.

Narratives From The Themes

- Perception of health & medical care seeking behavior:

Ms. Gardner had this to say about her health seeking behavior-

“...It’s not necessary to see a doctor every year. Medicare doesn’t pay for all that stuff any how so why bother if you don’t have to? ... What the heck?...Never went to doctors ...never went to see doctors unless I was pregnant and that was it.”

Narratives From The Themes

- Mistrust of healthcare professionals included skepticism about prescribed medications, recommended medical regimen, and subtheme that focused on relationships with friends and family. Many participants also felt vulnerable and tried to protect themselves and maintain control in their lives

Narratives From The Themes

Sense of mistrust cont'd:

Mr. Movva shared he was previously receiving physical and other therapies, however, had stopped because he questioned whether the therapy was helping:

...They come out here whole year taking therapy...therapy don't do nothing either and the people say, I don't want to do therapy. I want to do therapy but they ain't going to help...

Narratives From The Themes

■ Difficulty with ADL/IADL Cont'd:

Ms. Clay described having difficulty with combing her hair.

“...I have trouble combing my hair. Getting my arms up in the air, you know. Sometimes I have to take one hand that push my arm up like this to get to combmy hair. I got awful bad up here, my shoulders here... my back and my legs give way on me if I do something I know that I'm not supposed to do....”

Narratives From The Themes

Difficulty with ADL/IADL Cont'd:

Most participants talked about their eating habits and food preferences, in various forms. One participant said she could have Meals on Wheels, but added, “I don’t care for their food. Some participants shared they were eating once a day because they felt no hunger. One participant said she would go all day until evening before feeling hungry when she would “open up some real good can soup...or cook potatoes, or somethings that’s quick, to get done. Something’s that you put in the microwave and cook” (Kutame, 2007)

Narratives From The Themes

Difficulty with ADL/IADL Cont'd:

Multiple factors affected participants' decisions about diet and nutrition.

Some had denture problems. Others lacked an appetite, perhaps because of psychological and/or emotional reasons as in the situation of one participant who had lost significant amount of weight, which she attributed to the change in her appetite, not feeling hungry and not having a good appetite. This participant was facing foreclosure on her home.

Narratives From The Themes

- Lack of adequate social resources/services:

This theme focused on participants' inadequate resources and lack of services to help them maintain their support system and to pay for heat to keep the homes warm, their prescription medications, and home repairs.

Ms. Clay was on the energy assistance program, but claimed that the program hardly helped her. She also wanted a haircut, but she was to pay the \$7.00 it would cost to have this done.

Narratives From The Themes

- Lack of adequate resources/services

Ms. Clay's hair cut situation cont'd:

“....generally I like to get me a haircut I can't afford so I don't get a haircut. My daughter once in a while before she took sick, now she cut my hair, but she's sick herself so I don't ask her to do it no more...she had her hair cut two weeks ago and she told me that it cost her like \$7.00 for a haircut....and she say I 'll take you up there and have you get a haircut. She said she 'll pay for it, I said no, you'll need it; you have trouble of your own...”

Narratives From The Themes

- Difficulty with activities of daily living/instrumental activities of daily living:

Participants struggled to complete ADL/IADL. Below, Ms. Lamb described her difficulties completing chores.

“It’s depressing, it’s depressing, because I can’t. I want to do and I can’t, that’s the thing. I sit here and see the dirt and the mess. I would like to jump up and do it but I can’t... The sores on my feet are stopping me. The sores on my feet are stopping me...”

Narratives From The Themes

Lack of adequate resources/services cont'd:

- In the study, five women were widows, and two had multiple marriages. One widowed participant expressed bitterness at the extra-marital affairs her husband had prior to his illness and death, the majority of the widows shared they had experienced good marriages, but their circumstances at the time of the study were due in part to their husbands' death

Narratives From The Themes

- Lack of adequate resources/services cont'd:

Some of the widowed participants missed their husbands' physical presence, but also confronted reduced social and economic resources and lifestyle changes. Some had to relocate; these were major challenges that they had to face alone for the first time in their lives

Narratives From The Themes

■ Pride in self-Sufficiency:

Sometimes it is difficult for professionals and service providers to understand why some seniors who need services are reluctant to ask for help and hesitantly accept assistance. One reason for their resistance is due to their sense of pride. Under this theme, there were three major issues: (1) values learned from their parents such as you “don’t be scared and don’t go out and beg”; (2) doing a good job and maintaining self-sufficiency; and (3) avoiding assistance from agencies and service organizations

Narratives From The Themes

- Pride in self-sufficiency Cont'd:

Ms. Lane shared values she learned from her mother:

...That's the way my mother brought me up, don't go out there and beg. You don't beg for nothing unless you really down and out..."

Narratives From The Themes

- Pride in self-sufficiency cont'd:

Ms. Peoples talked about pride in her work:

When I go to the VA Hospital and the Department of Justice, I don't think there is any place in the United States that they did not send me to talk. I have speeches down there included and I have letters from doctors and judges where they congratulated me on my speaking, how well I conduct the task..."

Narratives from the Themes

■ Pride in self-sufficiency Cont'd:

Participants' sense of pride is significant to understanding self-neglect, and Mr. Wells also shared his feelings about this.

“...I never missed a day's work. When I worked I never missed any day's work and I never collect from the government when you got laid off. Yeah, as long as you can make it I guess I don't want to beg anybody for money...”

Narratives From The Themes

- Good and helpful to others:

Another important theme that emerged from this study was that participants perceived themselves as good and helpful to family, friends, and others who were in need. Mr. Wells commented that he bought a lot for his mother when he was younger:

“When I was young I used to buy my mom a lot of stuff. I used to you know, go to the store and what she likes, I used to bring stuff like that. You can tell a person how they take care of their parents...”

Narratives From The Themes

- Good and helpful to others Cont'd:

Ms. Knight shared her perspective on this theme:

“...I made it. Was back in the sixties before I got married and I had, I made good money for those days, hundred and fifty a week....I helped my mother pay the mortgage on our new house that we bought...”

Narratives From The Themes

■ Unfulfilled Dreams:

Most participants experienced unfulfilled dreams, though they varied in their descriptions. For the most part, the participants' dreams varied from wishes about getting a good education to working a well-paid employment to having a baby

Narratives From The Themes

Unfulfilled Dreams Cont'd:

Mr. Wells described a job he worked at when he was younger and how he made little money:

He shared that when he was younger he had three jobs: ...“tree trimmer...sanitation and I worked at a hospital... a custodian... at that time we didn't make a lot of money, you know, custodian, very little money and when you don't have an education...”

Narratives From The Themes

■ Unfulfilled Dreams Cont'd:

Ms. Summer shared her experience of lack of opportunity for formal education.

“I just wish that I could have went to school and ...I would have a better...have had a better job. I would have made more money...I always wanted to be a nurse...I wanted that job but I couldn't do it because I didn't have an education...”

Narratives From The Themes

■ Unfulfilled Dreams Cont'd:

Ms. Summer also described how she wanted to have a baby but she never got pregnant.

“...never had no children and I always want them so bad, never got pregnant, ...I always wanted a baby. I wanted to rock a baby, but never have them...”

Narratives From The Themes

- Connectedness to places and things:

Participants' connectedness to their environments emerged as another major theme in this study. Some of the participants wanted to remain in environments where they had always resided even when their safety and well-being were at risk

Narratives From The Themes

- Connectedness to places and things cont'd:

Here was what Ms. Waters shared about her house:

“...I’m not gonna give up my house as long as I don’t have to. I’m not gonna do it because that is my house. I have lived in that house for fifty years, can you see where that’s home? Fifty years, my animals here, why should somebody take me out of my own house?...”

Narratives From The Themes

- Connectedness to places and things cont'd:

Here was how Ms. Summer shared her thoughts on this theme.

“...I just do the best I can and I will make it...I will keep on trying, trying to do cause I'll never gonna, never, never. I may have to do it but I don't never want to go to a nursing home, no...”

Narratives From The Themes

- Connectedness to places and things cont'd:

Ms. Summer was asked what it was about nursing homes that she didn't like, here was how she responded:

“...The way the people treat the people there. What they tell me about what they do and then they don't know like the people soon they go to the nursing home they gone that quick...But it just seem like something about it, people don't live long when they go there, we already old when we go there so you can't look for nothing else...”

Narratives From The Themes

- Connectedness to places and things cont'd:

Ms. Waters had many objects in her house that looked as if it had never been cleaned, though she had the city cleaned her house the year prior to the study. The condition of the house was deplorable. The pets were scratching a lot and the it smelled. In efforts to understand how she experienced her situation, the researcher listened as she talked about what happened at the time of the house cleaning

Narratives From The Themes

- Connectedness to places and things cont'd:

Below are some important points Ms. Waters shared about the house cleaning the previous year:

“...I had real nice radio, VCR, all of them, I had everything...I had stopped working, saved up money and I made up my mind that I was gonna get things that I wanted I never had in my childhood...There's a lot of nice things in there that real nice people had given to me over the years, it's all gone. It's all gone...”

Narratives From The Themes

- God, prayer, and coping mechanisms

Spirituality came through as a significant theme for almost all of the participants.

Here was what Ms. Lamb shared about her spiritual beliefs:

“I believe in God, in prayer, that’s the one thing that will take us through. The good Lord won’t give you any more chores any more than you can bear.”

Narratives From The Themes

- God, prayer, and coping mechanisms cont'd:

When Ms. Peoples was asked what kept her going, she said:

“...And what keeps me going is God. I guess who else keep me going at ninety-four...? Who else will keep us going but God, I don't think there's a man on earth who will keep us cause doctors can't keep us here when we get sick. There are times when they cannot help us, when they can not save us, and I say that's our time to go...”

Narratives From The Themes

- God, prayer, and coping mechanisms cont'd:

Ms. Lane also believed that God kept her going:

“...I know that much is nobody else keeping me going but God. I believe Him because he can turn off my windpipe in a hurry and I will be lying out there gasping and then let me go, keep on going. He’s the only one that is in my corner, keeping me from one day to another and I am blessed for what little I got...”

Limitations of the study

- The qualitative nature of this study poses limitations on its findings, however, remain significant and add to our understanding of the perspectives of older adults identified as self-neglectful

Unmet Needs & Service Refusal

- There is evidence that unmet needs are at the core of self-neglect (Longres, 1994; Rathbone-McCuan, 1992). However, service delivery professionals also know that service refusal is a hallmark of self-neglecting older adults

Factors/Characteristics that Contribute of Self-neglect

- The following factors & characteristics have been found to contribute to service refusal: **older persons near death, despairing older adults, older adults despaired due to depression or anger, those who deny the existence of a problem or had disabilities, mistrusting older persons** (Dubin et al., 1988), **pride** (Dubin et al., 1988; Kutame, 2007), **shame** (Kutame 2007), **fear, embarrassment, and lack of understanding** (Ramsey-Klawnsnik, 2006)

A Call to Action

- Given the severe consequences of refusal of needed services, social workers/service providers must develop effective intervention strategies that older adults with multiple risk factors will accept

Best Practice Intervention Guidelines

- No Cookie Cutter intervention strategy
- Go slowly to establish rapport, with the goal of reducing isolation (Dayton, 2006)
- Recognize and respect the strong drive for independence and continuity (Dayton, 2006)

Best Practice Intervention Guidelines

- Be creative to make a connection to the client's sense of self and dignity, knowing the usual approaches may not work (Dayton, 2006)
- Geared efforts toward risk reduction, resolving the immediate crisis, and establish long-term stability (Ramsey-Klawnsnik, 2006)

Intervention: Best Practice Guidelines

- The older person's perspective, coping strategies, and underlying factors that lead to the behavior must be incorporated into working with them (Day, 2012, Kutame, 2007; Mixson, 1991)
- Explore alternatives, fear of change may be an issue so explaining that there are alternative ways forward may encourage the person to engage

Intervention: Best Practice Guidelines

- Maintain patience when working with self-neglecting older persons because months or years may pass before they might accept help (Clark, 1975)
- Create a collaborative interdisciplinary team approach

(Dayton, 2006; Dyer & Goins, 2000)

Summary & Conclusion

- No two self-neglecting older adults are the same, though there may be some common patterns
- The older adults who participated in this study did not identify as self-neglecting
- Most of them believe they do their “best to care” for themselves, though their best might not be enough

(Kutame, 2007)

Summary & Conclusion

- In caring for themselves, they “let other things go” (Kutame 2007)
- Underneath their traumatic experiences some of them will say that they are good people
- We must see the humanity in them and act compassionately